THE ROLE OF PARENTING VARIABLES AND HEALTH-RELATED QUALITY OF LIFE IN PEDIATRIC CANCER

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CHAPTER I

INTRODUCTION

Approximately one out of every 300 children will develop cancer by the age of 20 (Ries, Percy, & Bunin, 1999), and where cancer was once a death sentence, the current five-year survival rate of pediatric cancer is 80% (American Cancer Society, 2008a). This increasing survival rate has led to a shift in psychosocial research, such that broad adjustment outcomes of both children and their parents have become a focus. Indeed, the cancer experience can impact multiple domains of a child's life, including physical, emotional, and social functioning. Though the literature suggests that most pediatric cancer patients cope well with their disease and do not evidence poor adjustment (see Kazak, 1994; Kazak & Barakat, 1997; Kupst, Natta, & Richardson, 1995; Mackie, Hill, Kondryn, & McNally, 2000; Madan-Swain, Brown, Sexson, & Baldwin, 1994; Simms, Kazak, Golomb, Goldwein, & Bunin, 2002; Patenaude & Kupst, 2005), approximately 25-30% of them will evidence difficulties in personal, family, and social domains (e.g., Friedman, & Meadows, 2002; Patenaude & Kupst, 2005; Vannatta & Gerhardt, 2003). Thus, research has turned to identifying factors that predict which children will fare well, and which children will exhibit poor adjustment (e.g., Fuemmeler, Mullins, & Marx, 2001; Kazak, 2005).

The relationship between discrete parenting variables and child adjustment across a range of chronic illnesses has increasingly gained attention in pediatric psychology research (Cote, Mullins, Hartman, Hoff, Balderson, Chaney et al., 2003). The transactional stress and coping model suggests that parent adjustment and child adjustment are reciprocal, and as such, parents who exhibit appropriate adjustment will have children who are well adjusted, and vice versa. The robust transactional relationship between parent and child adjustment to chronic illness (Thompson & Gustafson, 1996) suggests that even discrete parenting variables have the ability to influence child adjustment outcomes. Thus, in order to identify which children are at risk for poor adjustment to their illness, the examination of these discrete parenting variables is critical.

The current study sought to build upon existing literature by investigating the transactional relationship between three discrete parenting variables, namely parental overprotection, perceived child vulnerability, and parenting stress, and the child's health-related quality of life as a broad adjustment outcome. The study was guided by two specific aims:

Aim 1. To examine parent-proxy report of health-related quality of life in pediatric cancer.

Aim 2. To assess the relationship between parenting variables, including parental overprotection, perceived child vulnerability, and parenting stress, and parent-proxy report of health-related quality of life in pediatric cancer.

With regard to Aim 1, it was hypothesized that parental socioeconomic status would be positively related to health-related quality of life for their children. It was also

hypothesized that married parents would report higher health-related quality of life for their children than lone parents would report for their children.

With regard to Aim 2, it was hypothesized that parental overprotection would be negatively related to health-related quality of life in children with cancer. It was also hypothesized that perceived child vulnerability would be negatively related to health-related quality of life in children with cancer and that parenting stress would be negatively related to health-related quality of life in children with cancer.

In addition to the two specific aims of the current study, a research question was also addressed. Parent marital status was be examined to determine if single parents differ from married parents on reported levels of parental overprotection, perceived child vulnerability, and parenting stress.

CHAPTER II

REVIEW OF LITERATURE

Chapter Overview

The subsequent chapter is a review of the extant literature relevant to the proposed project. This review is divided into six major sections. The first section will focus on a description of pediatric cancer and will include a discussion of issues related to incidence, prevalence, and mortality rates, etiology, classification, and treatment. The second section includes an overview of adjustment outcomes of children with pediatric cancer with an emphasis on psychosocial outcomes and the relationship between parent and child adjustment to chronic illness. The third section is a brief discussion of the transactional stress and coping model and a review of the relevant literature as it relates to pediatric cancer. The fourth section provides an overview of the construct of health-related quality of life in addition to a review of relevant literature. The next section provides a brief discussion of socioeconomic status and single parent status as they relate to adjustment outcomes in childhood chronic illness. Finally, the chapter will conclude with a discussion of the constructs of parental overprotection, perceived child vulnerability, and the relationship between these two variables, as well as a discussion of parenting stress as a discrete parenting capacity variable.

Pediatric Cancer: Description of the Disease

Incidence, Prevalence, and Mortality

In the United States, pediatric malignancies are the leading cause of death by illness among children under the age of 15 (Vannatta & Gerhardt, 2003; ACS, 2008a). Further, cancer is second to accidents as the leading cause of death in children (ACS, 2008a). Approximately one out of every 300 children will develop cancer by the age of 20 (Ries, et al., 1999), and in 2008 alone, 10,720 new cases of cancer were expected to be diagnosed in children under 15 years old (ACS, 2008a). In addition, approximately 2,500 children and adolescents die of cancer each year, making cancer the most common cause of disease-related mortality for children 1 to 19 years of age (Ries et al., 1999). Notably, one-third of these deaths are due to one specific type of cancer, that being leukemia (ACS, 2008a).

Pediatric cancer incidence rates have slowly increased since 1975 but have recently begun to level off (Ries et al., 1999). The incidence rates for various pediatric cancers vary significantly by age, gender, and race. Overall, incidence rates are higher for males than for females; however, gender differences do vary by disease type and age. Additionally, children up to 5 years old and adolescents have much higher pediatric cancer incidence rates than children 5-14 years old. Again, these age groups vary by the site and histology of disease common for that age group. For example, the most common diagnosis for children up to 14 years old is leukemia, and it accounts for 32.6% of all childhood cancer (Ries et al., 1999; ACS, 2008a). On the other hand, the most common diagnosis for children 15-19 years old is lymphoma, which accounts for approximately one-quarter of adolescent cancer (Ries et al., 1999). Where the annual incidence rate of cancer in Caucasian children is 12 per 100,000, the rate is 9 per 100,000 in African-

American children. Further, leukemia is twice as common in Caucasian children as in African-American children, and Ewing's sarcoma is very rare in African-American children (Cecalupo, 1994).

Even though incidence rates of pediatric cancer have increased since the 1970s, over the same time period, mortality rates for pediatric cancer have declined by almost 50% (ACS, 2008a; Ries et al., 1999). Currently, the five-year survival rate of pediatric cancer is 80%, although survival rates vary considerably by disease subtype (ACS, 2008a). It is now estimated that there are more than 270,000 childhood cancer survivors living in the United States (Oeffinger, Mertens, Sklar, Kawashima, Hudson, Meadows, et al., 2006). Notably, survival rates for total childhood cancer are likely to have improved since the mid-1970s due to the substantial improvements in treatment regimens (Ries et al., 1999) and a high proportion of participation in clinical trials (ACS, 2008a). Despite the improvements to current cancer treatment protocols, they remain intense and often combine chemotherapy, radiation, and surgery. Additionally, these regimens can have short- and long-term effects on cognitive, social, emotional, and behavioral functioning, as well as quality of life of survivors of childhood cancer (Vannatta & Gerhardt, 2003).

Etiology of Pediatric Cancer

The term cancer describes uncontrolled, abnormal cell growth which occurs when a cell's genetic instructions allow proliferation of cells without normal control mechanisms (Li & Wendt, 1998). The exact etiology of most pediatric cancer is unknown. However, pediatric cancer is believed to have a multifactorial etiology in which not all children with the same type of cancer will have developed it for the same reason (Ries et al., 1999). Further, it is believed that pediatric malignancies are produced

by a complex interaction of many factors and that no single factor determines whether or not a child will develop cancer (Ries et al., 1999). Even though most adult cancers are thought to be caused by environmental factors, childhood cancer is likely due to genetic, chromosomal, developmental, immune, or viral factors (Cecalupo, 1994; Ries et al., 1999).

Classification

Childhood cancer is a spectrum of malignancies which vary by histology, site of origin, race, sex, and age (Ries et al., 1999). Most adult cancer groupings are classified by the site of cancer, but pediatric cancer is classified by histologic type (Ries et al., 1999; Steliarova-Foucher, Stiller, Lacour, & Kaatsch, 2005). Pediatric cancer classification has been standardized by the International Classification of Childhood Cancer (ICCC-3), which allows for international epidemiological comparison (Steliarova-Foucher et al., 2005). The ICCC-3 is based on the International Classification of Diseases for Oncology (ICD-O) and categorizes childhood cancer into three hierarchal levels of classification. The main classification table of the ICCC-3 contains level 1, which is comprised of the 12 main diagnostic groups and level 2, which is comprised of the 47 diagnostic subgroups. Level 3 is the extended, optional, classification, where selected diagnostic subgroups are further differentiated. An illustration of the ICCC-3 is included in Appendix A. According to the ICCC-3 classification, the most common types of pediatric cancer are leukemia (32.6% of all childhood cancer), brain and CNS cancer (21.1%), lymphoma (non-Hodgkin 4.2%, Hodgkin 3.7%), and neuroblastoma (6.7%; ACS, 2008a).

Cancer Treatment

Childhood cancers are generally more responsive to treatment than adult cancer (Vannatta & Gerhardt, 2003) and can be treated with chemotherapy, radiation therapy, surgery, bone marrow transplantation, or a combination of these therapies (American Cancer Society, 2008b; Vannatta & Gerhardt, 2003). The type and combination of treatment chosen is based upon several factors, including the stage and type of the cancer being targeted.

Chemotherapy is a systematic treatment which uses a chemical agent to destroy cancer cells by interfering with the ability of the cancer cells to divide and reproduce (Brown, 2006). Childhood malignancies generally respond well to chemotherapy because these types of cancers grow quickly (ACS, 2008b). Chemotherapy drugs are administered for a number of specific therapeutic reasons, including: 1) to treat cancers that have a known positive response to chemotherapy; 2) to shrink tumors for easier and safer removal by surgery; 3) to enhance the effectiveness of other treatments, such as radiation therapy; 4) in higher dosages, to overcome the resistance of cancer cells; and 5) to control the cancer and enhance the patient's quality of life (curesearch.org, 2008). Intravenous and oral administration are the most common ways of giving chemotherapy to children, but it may also be administered by injection into the spinal canal, muscle, the abdominal cavity, or a body cavity, or subcutaneously (Brown, 2006). Notably, many of the chemotherapy drugs used to treat childhood cancer lead to significant short- and long-term problems. Short-term side effects include hair loss, nausea and vomiting, fatigue, anemia, increased risk of infection, changes in cognition and memory, and other physical problems. Long-term side effects of chemotherapy include permanent organ damage and delayed development (Brown, 2006).

Another common treatment for pediatric cancer is radiation therapy. This treatment modality utilizes high energy x-rays to damage and destroy cancer cells. Radiation is typically administered externally in treatment of pediatric cancer, and treatments are typically given five days a week for several weeks (ACS, 2008b). During treatment, radiation can damage normal healthy cells causing side effects, including fatigue, loss of appetite, and skin irritation (Brown, 2006). Long-term side effects include problems with growth and hormone production as well as cognitive problems such as memory loss (ACS, 2008b). Due to the late-effects of radiation therapy, doctors have begun using gamma knife radiosurgery and conformal radiation therapy, which deliver localized radiation to the tumor and minimize the irradiation to the normal tissue surrounding it (Eder, Leber, Eustacchio, & Pendl, 2001; Kirsch & Tarbell, 2004).

Surgery is an effective treatment option for children with solid tumors. Primary surgery is conducted in order to remove all or a large portion of a tumor at the time of diagnosis. If the tumor is too large or cannot be removed safely in its current state, the surgery is conducted after chemotherapy or radiation treatment has been administered to shrink the tumor. A "second look" surgery is conducted after chemotherapy or radiation to remove the remaining tumor or to determine if the treatments have successfully removed the entire tumor. Surgery can also be conducted to aid in a patient's care by inserting supportive care instruments such as catheters and gastronomy tubes (curesearch.org, 2008). Even though there have been recent advances in surgery for pediatric cancer, surgery alone is rarely a sufficient treatment (Brown, 2006).

Bone marrow transplantation (BMT) is a fourth type of treatment used to combat pediatric cancer. These treatments are typically used to treat children whose cancer has

not responded to chemotherapy or whose cancer has relapsed (curesearch.org, 2008). BMTs are most frequently used to treat children with leukemia because the bone marrow is the source of the cancer in this subtype of the disease. In a BMT, very high doses of chemotherapy and/or radiation are administered in order to permanently damage the bone marrow. The child is then given new bone marrow intravenously (Brown, 2006). This marrow may come from the patient while in remission (autologous) or may be from a healthy matched donor (allogenic; Brown, 2006; curesearch.org, 2008). One major concern with BMTs is that they put patients at very high risk of infection by destroying the white blood cells in their bone marrow. Another concern is that the patient may develop graft-versus-host disease in which the patient's body identifies the newly donated bone marrow as foreign and rejects it (Brown, 2006).

Physical and Psychosocial Outcomes of Children and Adolescents with Pediatric Cancer

Over the past two decades, substantial improvements have been made in both treatments and survival rates of many types of cancer. Currently, five-year survival rates have soared to 80% for all childhood cancer and even up to 95% for specific subtypes (ACS, 2008a). Further, approximately one out of every 900 individuals in the United States between the age of 15 and 45 is a survivor of childhood cancer (Robison, Mertens, Boice, Breslow, Donaldson, Green, et al., 2002). As a result, childhood cancer is being recognized as a chronic illness rather than a terminal one (Kazak & Nachman, 1991), and researchers are seeking to identify the short- and long-term physical and psychosocial outcomes of the disease and its treatment. When assessed using broadband measures of adjustment and psychopathology, the extant literature suggests that a majority of childhood cancer survivors exhibit emotional, behavioral, and psychosocial functioning

similar to that of healthy peers as well as healthy siblings (e.g., Patenaude & Kupst, 2005; Noll, Bukowski, Davies, Koontz, & Kulkarni, 1993; Noll, Bukowski, Rogosch, LeRoy, & Kulkarni, 1990; Noll, Gartstein, Vannatta, Correll, Bukowski, & Davies, 1999; Kupst et al., 1995). Despite this, a subset of pediatric cancer survivors will experience significant depression, anxiety, and posttraumatic stress, which may require intervention (Chen, Craske, Katz, Schwartz, & Zeltzer, 2000; Engstrom, Strohl, Rose, Lewandowski, & Stefanek, 1999; Hockenberry, Hinds, Barrera, Bryant, Adams-McNeill, Hooke, et al., 2003; Taieb, Moro, Baubet, Revah-Lévy, & Flament, 2003; Cadman, Boyle, Szatmari, & Offord, 1987; Koocher, O'Malley, Gogan, & Foster, 1980).

Short- and Long-term Consequences

Undergoing treatment for cancer may put children at an increased risk for medical problems later in life. Specifically, childhood cancer survivors are at risk for recurrence, and it has been estimated that 3-12% of survivors will develop a secondary cancer within 20 years of their initial diagnosis (Vannatta & Gerhardt, 2003). Children who have completed cancer treatment are also at an increased risk for other health problems, including endocrine and thyroid complications (e.g., obesity, growth problems, and reproductive difficulties), and cardiac, pulmonary, gastrointestinal, renal/urological, dental, and ocular problems (Vannatta & Gerhardt, 2003). Additionally, approximately one-third of childhood cancer survivors suffer from functional limitations including decreased stamina. Neurocognitive late effects are also seen in children who have undergone treatment for cancer, specifically those being treated for brain tumors or receiving radiation therapy (Askins & Moore, 2008). Children may experience a decrease in attention, executive functioning, processing speed, working memory, and

memory, which contribute to declines in both intellectual and academic functioning. Further, the impact of these physical and cognitive limitations often does not become evident until months or years post treatment.

A retrospective national cohort study called the Childhood Cancer Survivor Study (CCSS) was initiated in 1994 to examine the late effects of childhood cancer. The CCSS has provided important data on the health, quality of life, and psychological adjustment of childhood cancer survivors (Robison, et al., 2002). In one study examining this data, Hudson and colleagues (2003) found that survivors of pediatric cancer were more likely to report poor general and mental health, activity limitations, and functional impairment than their healthy siblings (Hudson, Mertens, Yasui, Hobbie, Chen, Gurney et al., 2003). In another study, Zebrack and colleagues (2002) also compared childhood cancer survivors to their healthy siblings, and they found that survivors were 1.6 to 1.7 times more likely to report symptoms of depression and somatic distress (Zebrack, Zeltzer, Whitton, Mertens, Odom, Berkow et al., 2002). Notably, this study also found that socioeconomic variables, including annual household income and level of educational attainment, as well as a disease variable, intensity of chemotherapy, predicted both depression and somatic distress (Zebrack et al., 2002).

Using the CCSS data, Robison and colleagues (2002) identified several long-term adverse outcomes in survivors of pediatric cancer, including secondary malignancies, organ dysfunction, impaired growth and development, decreased fertility, impaired intellectual functioning, difficulties obtaining employment and health insurance, and overall reduced quality of life. More recently, Oeffinger and colleagues assessed the incidence rates of chronic health conditions in survivors of pediatric cancer (Oeffinger et

al., 2006). Compared to healthy siblings, survivors were 3.3 times more likely to have a chronic health condition and 8.2 times more likely to have a severe or life-threatening medical condition. Further, their results indicate that during the 25 years after their cancer diagnosis, 66.8% of survivors had a chronic health condition, 33.1% of which were severe, disabling, life-threatening, or fatal. The researchers concluded that the incidence of chronic conditions in survivors of pediatric cancer increases over time and does not appear to plateau (Oeffinger et al., 2006).

Psychosocial Outcomes among Children with Pediatric Cancer

The existing literature on psychosocial outcomes among children with various chronic illnesses suggests that these children are at risk for psychosocial maladjustment secondary to their illness (e.g., Lavigne & Faier-Routman, 1992). Specifically, early work suggested that childhood cancer survivors were at an increased risk for poor psychosocial outcomes. A study by Koocher and O'Malley (1981) suggests that 47% of survivors experience adjustment problems, and Chang and colleagues (1987) reported that 33% of the childhood cancer survivors in their study evidenced clinically significant levels of emotional difficulty. Another study by Koocher and colleagues (1980) found that pediatric cancer survivors reported experiencing residual psychosocial sequelae, including anxiety, depression, and low self-esteem, and that those children with poor psychosocial adjustment had poorer social and self-help skills. The authors hypothesized that an interruption in normal developmental tasks due to a combination of cancer treatment and parental overprotection may have contributed to these psychosocial sequelae. These findings should, however, be put in the context of the time frame such

studies were conducted, when treatment regimens were more intense and morbidity and mortality rates higher.

Many researchers choose to take an adaptive perspective on chronic illness and emphasize the extent to which children with chronic illnesses are indistinguishable or better adjusted than healthy children (Eiser, 1998). Many studies examining childhood cancer survivors have shown that survivors often exhibit adaptation that is similar to normative groups, peers, siblings, and healthy comparison groups (Kupst et al., 1995). In a review of literature on the psychological adjustment of childhood cancer survivors, Kazak (1994) concluded that most survivors of childhood cancer function well psychologically and do not evidence significant emotional problems in terms of traditionally defined psychopathology. Therefore, the research suggests that the majority of pediatric cancer survivors adjust well to the stress of their disease and its treatment (Marsland, Ewing, & Thompson, 2006).

Longitudinal studies of children with cancer have shown that children in the early stages of cancer treatment experience higher levels of distress than healthy children (e.g., Sawyer, Antoniou, Nguyen, Toogood, Rice, & Baghurst, 1995; Sawyer, Antoniou, Toogood, & Rice, 1997; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000). However, these studies also suggest that the emotional difficulties children experience soon after diagnosis are short-lived and that, by one year post-diagnosis, most children function at similar levels to healthy children.

Many studies exploring the adjustment of pediatric cancer patients and survivors report adequate overall functioning (e.g., Kaplan, Busner, Weinhold, & Lenon, 1986; Spirito, Stark, Cobiella, Drigan, Androkites, & Hewett, 1990; Kupst et al., 1995). In a

study by Kaplan and colleagues (1986), pediatric oncology patients reported low levels of depressive symptoms. Specifically, the authors found that, at three time points post-diagnosis, the Beck Depression Inventory (BDI) scores of the adolescent sample did not differ from those of a comparison sample drawn from the general population. Further, the Children's Depression Inventory (CDI) scores of their childhood sample were significantly lower than those from the general population.

In a later study, Spirito and colleagues (1990) assessed childhood survivors of cancer who underwent treatment when they were two to five years old. They found few differences between the cancer survivors and healthy controls on broad self-report measures of competency. In addition, teacher ratings indicated that cancer survivors were more interested in school and less likely to argue or be teased than their healthy peers. Teacher ratings also indicated that only a small number of the survivors had problems in social and academic areas, whereas approximately half of the healthy children had at least one social or academic problem. Despite this, teacher ratings also indicated that the pediatric cancer survivors played less with children their own age than the controls, and there was also a trend for them to spend more time alone, even though they did not desire being alone more than the control children (Spirito et al., 1990).

Adjustment Problems in Subgroups of Children with Cancer

Recent reviews of the literature on the psychological consequences of childhood cancer suggest that it is not inevitable that these children fare poorly; however, subsets of children evidence significant adjustment problems (Eiser, 1998). When examining difficulties specific to the cancer experience, results indicate that a clinically significant minority of survivors (25-33%) develop psychosocial problems during and after cancer

treatment. Further, individual, diagnostic, and treatment factors may cause subgroups of children to be at an increased risk for short- and long-term consequences (Vannatta & Gerhardt, 2003).

Children with brain tumors and those who experience insult to their central nervous system (CNS) as a result of cancer, or as a consequence of the treatment for cancer, have been shown to be at higher risk for adverse psychosocial outcomes (e.g., Mulhern, 1994). Children with CNS cancers are at risk for neurocognitive difficulties as well as for reductions in full-scale IQ, memory, attention, and academic functioning. These problems are considered to be late effects of the cancer treatment and tend to emerge several years after treatment has completed. Additionally, several researchers have found parent reports of both internalizing and externalizing problems in children with CNS cancers (e.g., Carlson-Green, Morris, & Krawiecki, 1995; Carpentieri, Mulhern, Douglas, & Fairclough, 1993). When considering children with brain tumors, the literature is mixed. Some studies report that these children have difficulties with regard to internalizing and externalizing problems while other studies have found no difference between these children and those with non-CNS cancers (Fuemmeler, Elkin, & Mullins, 2002).

In addition to neurocognitive difficulties, children with CNS cancers also appear to be at a greater risk for social difficulties and problems with peer relationships (Fuemmeler et al., 2002; Vannatta & Gerhardt, 2003). Children with CNS cancers have been shown to exhibit diminished involvement in social activities, diminished friendships, and social isolation (Radcliffe, Bennett, Kazak, Foley, & Phillips, 1996; Vannatta, Garstein, Short, & Noll, 1998). A review by Fuemmeler and colleagues found

that children who survive brain tumors are at risk for deficits in social competency and are more likely to be viewed by teachers and peers as less socially involved than children with other health conditions (Fuemmeler et al., 2002). Further, a longitudinal study of social and behavioral functioning among children with brain tumors found that parents rated their children below average on social competence at two time points (Kullgren, Morris, Morris, & Krawiecki, 2003). It may be that children with CNS cancers are likely to have greater social deficits than children with non-CNS cancer as well as those with other chronic health conditions.

Parent Adjustment to Chronic Illness

Family contextual variables have gained increased attention in research on child adjustment to chronic illness (e.g., Thompson & Gustafson, 1996). The transactional model suggests that parent adjustment and child adjustment influence each other in a reciprocal fashion. Thus, parents who are able to adjust well to their child's diagnosis will have children who are also well adjusted, and vice versa. Correspondingly, if children or their parents are not coping well with their illness, this may negatively affect the other's adjustment. Further, parent factors, such as concerns about child health, may lead parents to restrict their child's involvement in school and social activities. Research has demonstrated that children whose parents perceive them as more vulnerable report more generalized social distress as well as distress in response to novel social situations (Anthony, Gil, & Schanberg, 2003). The transactional relationship between parent and child adjustment outcomes in childhood chronic illness is supported by a substantial body of literature (Chaney, Mullins, Frank, Peterson, Mace, Kashani, et al., 1997; Eaton, Mengel, Mengel, Larson, Campbell, & Montague, 1992; Livneh & Antonak, 1997;

Mullins, Chaney, Hartman, Olson, Youll, Reyes, & Blackett, 1995; Thompson & Gustafson, 1996; Thompson, Gustafson, & Bonner, 2002).

Much of the early work on parent-child adjustment to chronic illness examined the relationship between parental global mood states and child behaviors and child global mood states. Specifically, Thompson, Gil, Burback, Keith, and Kinney (1993a) found that maternal anxiety accounted for a significant portion of the variance in internalizing and externalizing problems in children with sickle cell disease. Similarly, Mullins and colleagues (1995) found that maternal depression was significantly related to child depression in children with Type I diabetes (DM1) and that maternal depression was also significantly related to child state anxiety in children with cystic fibrosis (CF).

Within the last decade, research on parent-child adjustment to chronic illness has moved away from broad measures of parent adjustment to focus on more discrete parenting variables. For example, Holmbeck and colleagues (2002) found that higher levels of parental overprotective behavior were significantly related to less autonomy as well as more externalizing behavior problems in children with spina bifida. In addition to discrete parental behaviors, parental beliefs about their child's vulnerability have also been examined. Specifically, heightened levels of perceived child vulnerability in parents of adolescents with DM1 were significantly related to increased illness uncertainty (Mullins et al., 2007). A similar relationship was also found between perceived child vulnerability in parents of children with cancer and internalizing problems in those children (Colletti, Wolfe-Christensen, Carpentier, Page, McNall-Knapp, Meyer, et al., 2008).

Specifically regarding the adjustment of children with cancer, Kupst and colleagues (1995) conducted a longitudinal study to investigate coping in families of survivors of leukemia. The adjustment of survivors and their parents was assessed by self-ratings and physician ratings, and they found that both the survivors and their parents were rated as coping well at both six and 10 years post-treatment. Notably, support of family, quality of the parents' marriage, coping of other family members, open communication in the family, and lack of other concurrent stressors seemed to contribute to successful adaptation at six years post-treatment. However, the most significant predictor of survivors' adaptation at 10 years post-treatment was their mother's coping and adjustment. These results suggest that the mothers' coping behaviors may have served as a model for their children to learn how to adjust to their illness.

More recently, Robinson and colleagues (2007) compared the relationship between parent and child distress in families of pediatric cancer patients to that of families of healthy classmates (Robinson, Gerhardt, Vannatta, & Noll, 2007). Their results revealed that parents' distress was significantly related to the parents' report of the child's internalizing symptoms. Conversely, parental distress was not related to the child's report of internalizing symptoms.

Collectively, these studies demonstrate that parental adjustment to childhood chronic illness influences the child's adjustment. Instead of examining parental global mood states, future studies should examine discrete aspects of parenting a child with a chronic illness, including parental behaviors and beliefs about their child's illness. To set the stage for the current thesis project, the subsequent section will discuss a specific

model of child and parent adjustment to chronic illness, namely the transactional stress and coping model.

Transactional Stress and Coping Model

Most theoretical models of adjustment to childhood chronic illness recognize the salience of parent and family influences (e.g., Thompson, Gil, Burbach, Keith & Kinney, 1993b; Thompson & Gustafson, 1996). The transactional stress and coping model, perhaps the pre-eminent model of adjustment to pediatric health problems, conceptualizes chronic illness as a stressor to which children and families must adapt (Thompson et al., 1993b; Thompson & Gustafson, 1996). The model is set within Bronfenbrenner's ecological-systems theory (Bronfenbrenner, 1977) and is depicted in Figure 1. Adjustment to an illness is believed to be mediated by transactions between illness parameters, including type and severity of illness, and demographic parameters, including gender, age, and socioeconomic status (Hocking & Lochman, 2005). The model's primary focus, however, is on family processes, including parent and child adaptational processes (Thompson & Gustafson, 1996; Hocking & Lochman, 2005). A series of studies conducted by Thompson and colleagues provide evidence for the role of the transactional stress and coping model in the parent-child adjustment outcome relationship (Thompson et al., 1992; Thompson et al., 1993b). Further, numerous studies in pediatric psychology literature have utilized this model as a framework. A complete review of this literature is beyond the scope of this study; however, a brief summary of this work with an emphasis on pediatric cancer will follow.

Figure 1. Transactional stress and coping model

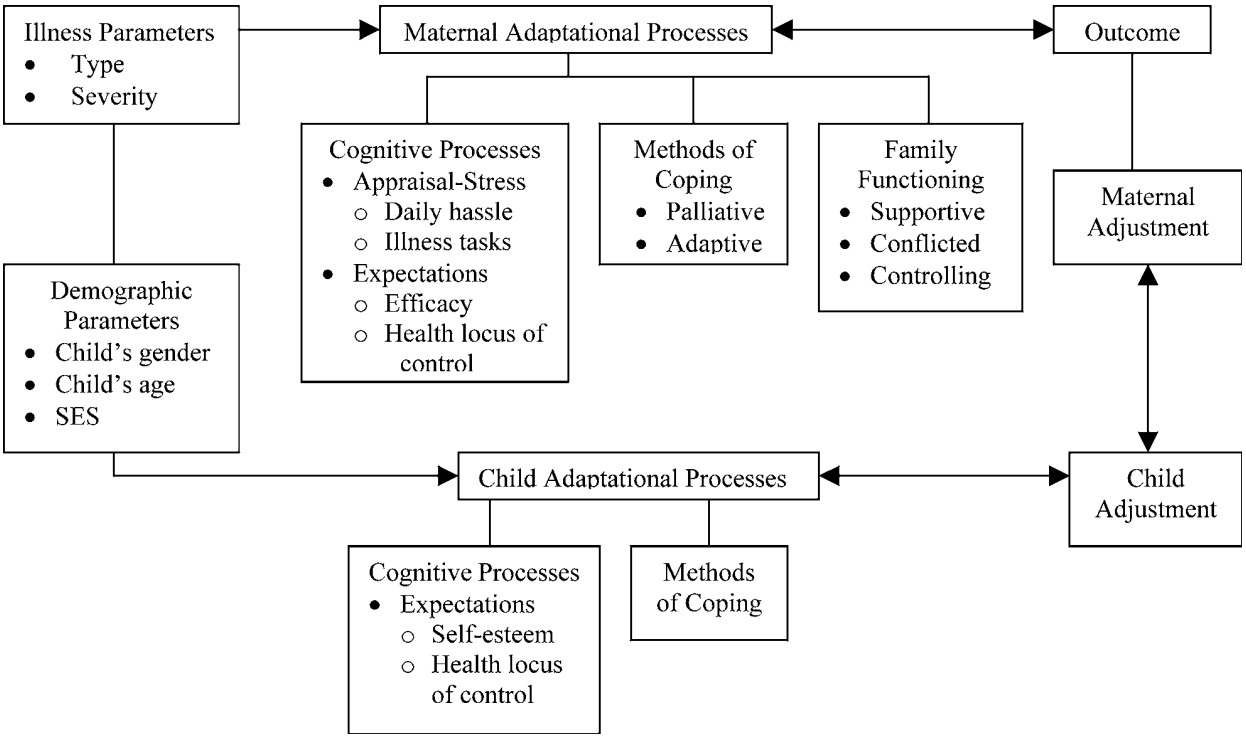

Figure 1. Transactional stress and coping model of adjustment to a chronic illness. From Thompson, Gustafson, George, and Spock (1994).

A growing body of literature has provided additional support for the parent-child adjustment outcome relationship in the context of pediatric cancer. Research has shown that maternal adjustment is one of the strongest predictors of coping and adjustment in children and adolescents with cancer (Carlson-Green et al., 1995; Kupst et al., 1995; Sawyer, Streiner, Antoniou, Toogood, & Rice, 1998; Trask, Paterson, Trask, Bares, Birt, & Maan, 2003). For example, as part of a longitudinal study of family coping with pediatric leukemia, Kupst and colleagues (1995) examined the relationship between maternal coping and child adjustment. They found that long-term child adjustment was positively associated with maternal coping both in the short- and long-term. Moreover,

maternal coping was identified as the single most important predictor of child adjustment. In a prospective study, Sawyer, Streiner, Antoniou, Toogood, and Rice (1998) examined the relationship between parent adjustment and child adjustment during the period immediately following a child's diagnosis with cancer and two years after the diagnosis. They found that maternal adjustment during the period immediately after the child's cancer diagnosis was significantly associated with the child's psychological adjustment two years after diagnosis.

The findings described above provide support for the transactional nature of parent and child adjustment to pediatric cancer. Indeed, they suggest that parent and child adjustment are interrelated and influence each other in a reciprocal fashion (Mullins, Fuemmeler, Hoff, Chaney, Van Pelt, & Ewing, 2004). The remainder of this chapter will focus on health-related quality of life as a specific measure of adjustment to chronic childhood illness, two social-ecological factors, namely socioeconomic status and single parent status, and three discrete parenting variables, specifically parental overprotection, perceived child vulnerability, and parenting stress, which have been shown to significantly affect parental adjustment, but have yet to be studied with regard to their impact on child adjustment as indicated by health-related quality of life.

Health-Related Quality of Life

With improvements in treatment and increasing survival rates of pediatric cancer, the focus of psychosocial research has shifted from palliative care to adjustment outcomes of these children and families. In the last several decades, quality of life (QOL) has become a critical construct in pediatric oncology research (Levi, 2006). A definition of QOL is based upon how an individual perceives their position in life in

relation to their culture's goals, standards, and concerns, and it encompasses physical, emotional, and social domains (WHO, 1993). Health-related quality of life (HRQOL) is an expansion of this construct, which refers to the impact of an illness or injury, medical treatment, or health care policy on one's QOL. It includes domains of physical, psychological, and social functioning as well as other functioning which may be affected by illness (Levi & Drotar, 1998; Levi, 2006).

In pediatric chronic illness, measures of HRQOL provide a comprehensive assessment of a child's response to medical treatment, disease course, and adjustment outcomes (Drotar, 1998). This definition is consistent with Bronfenbrenner's social ecology model in which biological, psychological, social, familial, community, and spiritual domains influence a child's functioning (Bronfenbrenner, 1979; Levi, 2006). Notably, HRQOL is a construct and, therefore, has no physical or temporal basis; however, it aims to capture the real-life experience of a child with a chronic illness (Wallander, Schmitt, & Koot, 2001; Levi, 2006). Research in this area has received criticism because quality is a subjective, individual, and fluid construct, therefore, making HRQOL difficult to operationally define. Additionally, criticism has been received because the development of definitions and measures of HRQOL has not been based upon a theoretical framework (Drotar & Levi, 1998; Levi, 2006). Given this, it is important to note that there are limitations in the ability to quantify HRQOL.

There are three principles to consider when examining child HRQOL: 1) child HRQOL is individual and unique and is influenced by both past and present lifestyle in addition to hope, expectations, and goals; 2) child HRQOL involves multiple domains; and 3) definitions and assessments of child HRQOL can comprise both objective and

subjective aspects of each of these domains (Eiser & Morse, 2001; Levi, 2006). Those domains which are most frequently used to assess pediatric HRQOL are physical health, psychological functioning, social functioning, cognitive functioning, and treatment-related impact.

Because there is variability in the domains considered to constitute HRQOL, variability is also seen in the definitions and approaches to measuring and assessing pediatric HRQOL. The two general types of HRQOL measures included are those that are considered generic, which assess a range of domains of QOL, and those that are specific, which assess those domains specific to a particular disease group or population (Spieth & Harris, 1996). The generic measures aim to assess a broad range of domains, including functional status, morbidity, social functioning, psychological functioning, and family functioning (Levi, 2006). Some generic measures of HRQOL focus on functional status and the impact that illness has on a child's ability to function in multiple domains. One example of this is the Play Performance Scale for Children (Lansky, List, Lansky, Ritter-Sterr, & Miller, 1987), which was specifically developed to measure HRQOL in children with cancer by measuring functional changes through assessing play activities. Other generic measures of HRQOL assess for comprehensive health status and can be used with both healthy and ill child populations, thereby allowing for comparison between children with and without a chronic illness. These measures generally provide a total score as well as a score for each domain being assessed. An example of this type of measure is the Children's Health Questionnaire (CHQ; Landgraf, Abetz, & Ware, 1996), which assesses across 14 domains and has equivalent parent, child, and adolescent forms.

Preference and utility measures are another type of generic measure of HRQOL which examine children's satisfaction with or preference for their health state across multiple domains. The Health Utilities Index System Mark 3 (HUI3; Feeny, Furlong, & Barr, 1998) is a utility-based measure, which assesses a child's preference across seven domains of functioning, and these preferences are rated on a continuum and combined into a total score. Another approach to HRQOL generic measurement is a qualitative and phenomenological approach, which uses open-ended or semi-structured interviews to assess a child's illness experience (Levi, 2006).

Specific measures of HRQOL include both disease-specific approaches and what can be termed modular measures. Disease-specific measures are used to determine HRQOL which is particular to a child's disease and treatment. Unlike generic measures, disease-specific measures cannot be used to compare children with that disease to healthy children or children with other chronic illnesses (Levi, 2006). The Pediatric Oncology Quality of Life Scale (Goodwin, Boggs, & Graham-Pole, 1994) is one example of a disease-specific measure of HRQOL for pediatric cancer. Modular HRQOL measures combine the generic and disease-specific scales and often include both core questions that are relevant to all children as well as disease-specific modules (Nathan, Furlong, & Barr, 2004). These measures aim to obtain the most comprehensive assessment of HRQOL. The most widely used modular scale for children with cancer is the Pediatric Quality of Life Inventory (PedsQL), which includes specific modules for cancer and fatigue as well as for specific age groups of children (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002).

A child's stage of development is especially important to consider when assessing HRQOL. Not only is a child's ability to read, comprehend, and self-reflect dependent upon developmental stage, but the impact of the disease may also vary due to the child's developmental stage (Levi, 2006). For example, a young child who misses preschool for treatments will not perceive the same impact on his QOL as a teenager who must miss days of high school and after-school activities for treatments. Additionally, the salience of the impact of an illness on children will depend upon development and will differentially affect their assessment of their HRQOL (Levi, 2006). For example, when considering HRQOL in pediatric cancer, infertility as a late-effect of treatment is likely to be more salient in the mind of teenagers or young adults than for young children who are likely to face infertility.

Another consideration in assessing HRQOL in childhood chronic illness, specifically cancer, is that the children, their parents, and their health care providers may experience a response shift (Levi, 2006). This concept refers to a change in one's internal values, perception of HRQOL, and expectations due to treatment for an illness (Sprangers, 2002). In accommodating and integrating an illness and its treatment into one's life, his/her value and perception of QOL may change even though there are no actual corresponding changes in functioning. Response shifts may be seen as a source of bias in measuring HRQOL; however, they are significant when considering how an individual perceives HRQOL.

Parent versus Child Report of Child Health-Related Quality of Life

Because children are often unable to report on their HRQOL due to inability to read or self-reflect, cognitive impairment, or impaired health status, measures of HRQOL

often include reports from other informants. Parents, specifically mothers, often provide these proxy reports of their child's HRQOL and are believed to be able to provide a reliable and valid report (Levi, 2006). However, parents and children have unique perspectives on the illness experience and parents have been found to report poorer functioning and greater disease impact than their children (e.g., Canning, 1994; Levi & Drotar, 1999; Parsons, Barlow, Levy, Supran, & Kaplan, 1999; Sawyer, Antoniou, Toogood, & Rice, 1999; Vance, Morse, Jenney, & Eiser, 2001). Levi and Drotar (1999) examined the difference in the degree of discrepancy between parent- and child-report in pediatric cancer patients and matched control parents and children. It was found that the discrepancy between parents and their children with cancer was significantly larger than the discrepancy between parents and their healthy children, such that parents of children with cancer rated their children as having poorer HRQOL than the children rated themselves.

Conversely, several studies have found parent and child report of HRQOL to be consistent in pediatric cancer samples (Russell, Hudson, Long, & Phipps, 2006; Roddenberry & Renk, 2008). Russell and colleagues (2006) assessed HRQOL in a heterogeneous sample of children with cancer and a sample of healthy children. Their results indicate that parents of children with cancer underestimate their children's HRQOL; however, the discrepancy was not significant for children on treatment across any of the 10 domains of functioning and only two of 10 differences were significant for those children currently off treatment. On the other hand, Russell and colleagues found that parents of healthy children tend to overestimate their children's HRQOL, and statistically significant discrepancies were found on eight of the 10 domains. Moreover,

research suggests that consistency of ratings may be better for particular domains of functioning. Eiser and Morse (2001) examined the agreement between parent proxy-report and child self-report of HRQOL. Overall, they found good agreement between parent and child report of physical activity, functioning, and symptom domains; however, there was poor agreement between parent and child report of emotional and social HRQOL domains.

Varni, Limbers, and Burwinkle (2007) conducted a review of pediatric oncology self-report of HRQOL. They concluded that efforts should be made to include both parent proxy-report and pediatric patients' self-report whenever the child is willing and able to provide their perspective. However, if the child is too young, too cognitively impaired, or too ill or fatigued to complete the measure, parent proxy-report alone is recommended. Notably, it is often the parents' perceptions of their child's HRQOL which influence health care utilization (Campo, Comer, Jansen-McWilliams, Gardner, & Kelleher, 2002; Janicke, Finney, & Riley, 2001; Varni & Setoguchi, 1992); therefore, parent report of a child's HRQOL can play an integral role in health care utilization and quality of care. In sum, these findings indicate that there is overlap in parent and child ratings of HRQOL; however, these ratings are not interchangeable. Parents and children have different perspectives on the cancer experience and both perspectives are valuable (Levi, 2006).

Health-Related Quality of Life in Pediatric Cancer

Findings of research on pediatric cancer indicate several factors which may affect HRQOL in the population including disease type, age, type of treatment, and treatment status. Similar to the findings of psychosocial outcomes in children with cancer (e.g.,

Fuemmeler et al., 2002), children on treatment for brain tumors have poorer overall HRQOL than healthy peers and children on treatment for other types of cancer (Armstrong, Tolendano, Miloslavich, Lackman-Zeman, Levy, Gay, et al., 1999; Meeske, Katz, Palmer, Burwinkle, & Varni, 2004). Once children have completed treatment, this difference persists in that children who have been treated for brain tumors and their proxies report poorer HRQOL than healthy peers, siblings, and those with non-CNS cancers (e.g., Eiser, Greco, Vance, Horne, & Glaser, 2004; Eiser, Vance, Horne, Glaser, & Galvin, 2003; Langeveld, Stam, Grootenhuis, & Last, 2002). Also consistent with psychosocial outcomes, young children have been found to fare better than adolescents. Particularly, HRQOL was found to be higher in preschool-aged children than other age groups while adolescents were found to have the poorest HRQOL (Barrera, Wayland, D'Agostino, Gibson, Weksberg, & Malkin, 2003; Phipps, Dunavant, Garvie, Lensing, & Rai, 2002).

The type of treatment which the child is undergoing may also affect the parent's and child's report of HRQOL. Phipps and colleagues (2002) found that children undergoing a bone marrow transplant (BMT) had lower parent and child ratings of the child's HRQOL. Further, those children with lower socioeconomic status had lower HRQOL ratings during BMT than children from higher socioeconomic backgrounds (Phipps et al., 2002). HRQOL may also change when a child goes off treatment. Several studies have found that those children who have been off active treatment for a year or longer have higher HRQOL (e.g., Meeske et al., 2004; Sawyer et al., 1999; Varni et al., 2002).

Parent Factors and Health-Related Quality of Life

Having a child with cancer is a traumatic and life-altering experience for parents (Fuemmeler et al., 2001; Goldbeck, 2001). The daily challenges, anxiety, and response shifts experienced by parents are likely to have an effect on the child's HRQOL as well as how the parents report on the child's HRQOL (Levi, 2006). Several studies have suggested that parental distress may affect parents' perceptions of their child's health and well-being (Berg-Nielsen, Vika, & Dahl, 2003; De Los Reyes & Kazdin, 2004; Richters, 1992).

Vance and colleagues (2001) found that those parents of children with Acute Lymphoblastic Leukemia (ALL) who reported lower HRQOL in their children also reported more illness-related stressors and higher perceived child vulnerability. Kazak and Barakat (1997) examined how parenting stress and parent report of child's HRQOL can affect post-treatment adjustment outcomes for both parents and children with cancer. Their results indicate that parental perceptions of the child's adjustment, as measured by parent-reported HRQOL, are a better predictor of long-term family adjustment than the immediate concerns of treatment. Further, research by Sawyer and colleagues suggests that the greatest impact on the HRQOL of a child with cancer is the parent's QOL (Sawyer et al., 1999). Parents are profoundly affected by their child's diagnosis, treatment, and prognosis, and this may, in turn, affect their perceptions of their child's functioning (Thomasgard & Metz, 1995).

For the purposes of this study, child adjustment to pediatric cancer was assessed through parent ratings of HRQOL as measured by the PedsQL. The following is a discussion of the relevant predictor variables which were considered in the current study. These variables were examined to determine their relationship to adjustment in a

pediatric cancer sample and include: socioeconomic status, single parent status, parental overprotection, perceived child vulnerability, and parenting stress.

Social-Ecological Factors Related to Child Adjustment to Chronic Illness

Bronfenbrenner's social ecology model explains that a child's environment, including biological, psychological, social, familial, community, and spiritual domains, influence his/her development and current functioning (Bronfenbrenner, 1979). With that in mind, the subsequent sections provide a brief discussion of two factors, namely socioeconomic status and single parent status, within a child's environment which were examined in the current study.

Socioeconomic Status

In mental health literature, lower socioeconomic status (SES) has consistently been shown to be associated with poorer psychological adjustment (Thompson & Gustafson, 1996). Unfortunately, the findings on the role of SES in child adjustment have been mixed, perhaps due to the variability in how SES is measured (Thompson & Gustafson, 1996). Therefore, it is unclear which aspects of a child's SES affect his/her adjustment to a chronic illness or how these aspects interact with processes of adaptation as well as other predictors of adjustment.

Several studies have shown lower SES to be related to poorer adjustment in both children with a chronic illness and their parents and siblings. Research conducted by Kupst and Schulman (1988) suggests that caregivers of children with chronic illnesses have poorer adjustment to their child's illness when they are under financial stress. Notably, research has also shown that caring for a child with a chronic illness can exacerbate a family's financial burden due to health care costs, medical equipment, travel

expenses, and time off from work (Winthrop, Brasel, Stahovic, Paulson, Schneeberger, & Kuhn, 2005; Jacobs & McDermott, 1989). Further, in a study of children with cancer who were undergoing a bone marrow transplant (BMT), it was found that children with lower SES had lower HRQOL ratings than children from higher socioeconomic backgrounds (Phipps et al., 2002). Zebrack and colleagues (2004) conducted a study of long-term psychological outcomes of survivors of childhood cancer and their siblings. They found higher levels of distress to be related to lower SES in survivors and their siblings.

Single Parent Status

Over the past several decades, the proportion of children in two-parent families has decreased from 85% to 69%, meaning that approximately three out of 10 children today live in single-parent homes (Brown, Wiener, Kupst, Brennan, Behrman, Compas, et al., 2008). Often, the child's mother acts as the head of the household in these single-parent homes. As discussed previously, parents of children with a chronic illness struggle to adapt and are often subject to distress. This struggle is likely to be more intense for single parents who must carry the burden alone (Brown et al., 2008). Specifically, single mothers of children with cancer appear to be at a greater risk for increased depression and anxiety. Dolgin and colleagues (2007) conducted a longitudinal study of mothers of children newly diagnosed with cancer. Their results indicate that single mothers had moderately high levels of distress which remained stable up to six months post diagnosis. Further, research conducted by Hong and White-Means (1993) and Landgraf and Abetz (1998) suggests that maternal reports of a child's physical and mental health status are influenced by marital status. Specifically, Landgraf and Abetz

(1998) found that, among parents of healthy children, single parents rated their children's general health, behavior, and self-esteem lower and worried more about their children than married parents.

Single parents are likely to have a greater financial burden as well as have less social support than married parents. Notably, the financial resources available to these single parents are 55% of those of two-parent families (Thomas & Sawhill, 2005). Where 4.9% of all married couples are at or below the poverty level, 28.3% of all female-headed households are seen as living in poverty (U.S. Census Bureau, 2008). To further complicate this situation, chronic illnesses, especially cancer, often lead to deterioration of finances or loss of a job (Montgomery, Oliver, Reisner, & Fallat, 2002).

Research has indicated that a mother's adjustment to her child's chronic illness is related to the availability of family and social support (Wallander, Varni, Babani, DeHaan, Wilcox, & Banis, 1989; Wallander, Varni, Babani, Banis, & Wilcox, 1989). Unfortunately, due to the nature of lone parenting, single parents are likely to have fewer family and social supports to help them to carry the burden of supporting a child with a chronic illness (Brown et al., 2008). As previously noted in the discussion of the transactional stress and coping model, child and parental adaptation to chronic illness is reciprocal, such that a mother's adjustment to the illness will impact the child's adjustment and vice versa. Therefore, it may follow that children of single parents will have poorer adjustment outcomes than those children with married parents.

Parent and Family Variables Related to Child Adjustment to Chronic Illness

As evidenced in the preceding reviews of the extant literature, most of the studies examining parent and child adjustment to childhood chronic illness have focused on the

relationship of global parent and child adjustment and mood states and have not attempted to identify more specific parenting behaviors or perceptions that may influence child adjustment. Discrete parenting variables, which assess parents' behaviors and beliefs, should also be considered to impact the child's adjustment. The relevant parenting variables that have been examined in the present study are described in the subsequent sections and include the concepts of parental overprotection, perceived child vulnerability, and parenting stress.

Parental Overprotection

Parental overprotection, a construct originally conceptualized by Levy (1931), has been associated with adjustment outcomes in children with chronic illnesses. It has been defined as overindulgent, oversolicitous, overprotective, and overanxious parenting (Levy, 1931; Parker, 1981; Parker, 1983). An overprotective parent is often described as one who is highly supervising, highly controlling, has difficulties with separation from the child, and discourages independent behavior (Thomasgard & Metz, 1999). Retrospective studies of overprotection in adolescent and adult psychiatric populations suggest that children raised in an overprotective environment may be at an increased risk for anxiety, depression, and problems with socialization later in life (e.g., Parker, 1983).

Sameroff and Emde (1992) considered parental overprotection to be a disorder within the parent-child relationship, which occurs when the separation-individuation process, which is a normative developmental process within the relationship, is excessively or persistently restricted. When examined within the context of childhood illness, they found that once a child had recovered from the illness, some parents were unable to allow their child to regain his or her autonomy and retained an overprotective

attitude toward their child, even long after the child had recovered from the illness (Sameroff & Emde, 1992).

To an extent, a certain level of vigilance and protectiveness are appropriate in the context of caring for a child with a chronic illness. Mullins and colleagues (2004) suggest that parents of children with Type 1 Diabetes (DM1) must take considerable control over their child's health and health care behaviors, such as administering the child's insulin. Similarly, parents of children with Juvenile Rheumatoid Arthritis (JRA) must monitor their child's pain, diet, exercise, sleep, activities, and medications much more closely than is typical for the child's developmental stage (Powers, Dahlquist, Thompson, & Warren 2003). Thomasgard and Metz (1993) suggest that when caring for a child who has a medical condition, the parent's perception that the child is vulnerable due to the illness is likely to lead to overprotective parenting in the form of overindulgence. Thus, illness demands may lead parents to take on more indulgent, protective, controlling, or intrusive care-giving roles. Despite this knowledge, the literature remains ambiguous regarding at what point these protective behaviors become maladaptive and lead to negative adjustment outcomes in children.

Several studies have examined overprotective parenting of children with chronic illnesses. Parker and Lipscombe (1979) used the Parental Bonding Instrument (PBI) to measure parental overprotection in children with asthma and their healthy siblings (Parker, Tupling, & Brown, 1979). Their results indicated that parents were more overprotective of their children with asthma than their siblings, suggesting that parents may be selectively overprotective of a child with a chronic illness and that overprotection may indeed be a consequence the child's health status.

Researchers have also examined parental overprotection in several other illness groups. Mattson (1972) found psychosocial maladjustment in children with hemophilia to be related to maternal overprotection, independent of the measure of maladjustment being examined. Similarly, Spock and Stedman (1966) and Tropauer and colleagues (1970) found behaviorally maladjusted children with cystic fibrosis (CF) to be overprotected by their parents.

Cappelli and colleagues (1989) also conducted a study which compared parental overprotection exhibited by parents of children with CF to that of parents of healthy children. Even though the degree of parental overprotection was not different for healthy children and those with CF, the relationship between parental overprotection and the child's age, gender, and psychosocial functioning differed between the groups. Specifically, female children with CF were significantly more likely to be overprotected as were 10-12 year old children with CF. Further, for children with CF, excessive parental overprotection was associated with increased behavior problems, whereas increased behavior problems in the healthy children were related to maternal neglect or lack of parental control (i.e., allowance of excessive autonomy and independence). These results suggest behavioral problems are related to differential levels of parental control in healthy children and those with CF (Cappelli, McGrath, & MacDonald, 1989).

Recently, several other studies have suggested that parents of a child with a chronic illness are more likely to exhibit overprotective behavior than parents of healthy children. Holmbeck and colleagues (2002) conducted a study using both parent-report data and observational methods to test parental overprotection in adolescents with spina bifida. Their results suggest that adolescents with spina bifida are more overprotected by

their parents than healthy peers; however, a significant portion of the association between health status and overprotection was mediated by the child's cognitive ability. Further, their results revealed that the parents in both groups who were more overprotective were less likely to grant autonomy to their children, which lends support to the belief that excessive parental overprotection hinders the normal development of early adolescent autonomy (Holmbeck et al., 2002).

Powers and colleagues (2003) examined overprotection among mothers of children with severe JRA and found that they were more directive, controlling, and evaluative than mothers of children with mild arthritis as well as mothers of healthy children (Powers et al., 2003). The authors hypothesized that this directive behavior may be a result of mothers of children with severe arthritis feeling that their children need more help with their daily activities than healthy children.

Reports by health care professionals have also suggested that parents of children with chronic illnesses are more overprotective than parents of healthy children. A study by Noll, McKellop, and Vannatta (1998) revealed that health care professionals working with children with sickle cell disease (SCD) perceived the children's parents to be more overprotective and worried than parents of healthy children. The health care professionals also reported that these parents were less effective with discipline than parents of healthy children. Davis and colleagues (2001) conducted a similar study in which they compared health care professionals' perceptions of parents of children with cancer with their perceptions of parents of children without a chronic illness (Davis, Delamater, Shaw, La Greca, Eidson, & Perez-Rodriquez, 2001). Health care professionals reported significant differences between parents of children with cancer and those with healthy children in

overprotection, discipline, and worry about the child. When parent reports were examined, it was found that parents of children with cancer reported greater worry about their child's health than parents of healthy children, and mothers of children with cancer were more likely to indicate that they worried they were over-involved. Collectively, these findings suggest that parents of children with a chronic illness may exhibit more overprotective, controlling, and directive behavior than parents of healthy children.

Parents of children with a chronic illness, such as cancer, may be overprotective because they perceive their child to be vulnerable due to their medical condition, or because these parents are attempting to exert control over a complex and unpredictable medical situation (Holmbeck et al., 2002). Regardless of the cause, overprotective parenting can be problematic because it does not allow the child to participate in age-appropriate, independent activities and may promote excessive dependency in the child (Powers et al., 2003). Additionally, overprotective parenting may limit the child's interactions with peers, such that the child does not develop appropriate interpersonal skills or gain confidence in socializing with peers.

Perceived Child Vulnerability

Perceived child vulnerability is another parenting capacity construct that has been demonstrated to relate to child adjustment outcomes. Green and Solnit (1964) first discussed perceived child vulnerability in the context of the parental processes surrounding a child's recovery from a life-threatening illness (Thomasgard & Metz, 1999). Perceived child vulnerability has been conceptualized in the literature more recently as *anxious cognitions* by parents about their child's health or their child's susceptibility to illness or injury (Anthony et al., 2003; Forsyth, Horwitz, Leventhal,

Burger, & Leaf, 1996). Whereas parental overprotection refers to a pattern of parental *behaviors* intended to promote the safety and security of the child, perceived child vulnerability refers to parental *attitudes* or *beliefs*. Even though the literature has often used the two terms interchangeably, perceived child vulnerability and parental overprotection represent two distinct clinical phenomena (Thomasgard & Metz, 1997; see discussion below). Child vulnerability has been the subject of a number of investigations, and they are summarized below.

Perceived child vulnerability and related cognitions have been used to explain health care use and utilization patterns (Bush & Iannotti, 1990). Specifically, increased health care utilization has been linked to children whose parents report worrying more about their child's susceptibility to illness (Fiegelman, Duggan, & Bazell, 1990; Maiman, Becker, & Katlic, 1986). Further, Forsyth et al. (1996) found that perceived child vulnerability predicted future use of health care services and that those children perceived to be vulnerable had a significantly greater total number of medical visits in one year than children not perceived as vulnerable. In another study, parents of children with asthma who perceived their children as vulnerable were found to be more likely to take their children to physicians for acute asthma care and to keep them home from school than those who did not perceive their children as vulnerable (Spurrier, Sawyer, Staugas, Martin, Kennedy, & Streiner, 2000).

Notably, parents' perceptions that their children are vulnerable are often accurate. Anthony et al. (2003) found that children, whose physicians and parents rated their disease as more severe, were also more likely to be perceived as vulnerable by their parents. Despite this result, only small to medium correlations were found between

disease severity and parent ratings of perceived child vulnerability, which suggests that some parents may perceive their child as more susceptible to health problems than is appropriate, as indicated by the child's disease severity. Although it may be adaptive for parents of children with a chronic illness to be vigilant of their child's health (e.g., for illness management and adherence), *excessive* amounts of vigilance and perceptions of vulnerability by parents may lead to negative psychological and social outcomes (Mullins et al., 2004; Thomasgard & Metz, 1996; Thomasgard & Metz, 1998; Anthony et al., 2003).

Mullins and colleagues (2004) found that perceived child vulnerability was independently associated with increased levels of depressive symptoms in 8-12 year old children with DM1. Given this finding, they hypothesized that the potential for serious, life-threatening complications associated with DM1 may be related to a heightened sense by parents that these children are vulnerable. Further, this perceived vulnerability may be communicated to the child transactionally such that the child exhibits poor adjustment outcomes as well.

The Relationship between Parental Overprotection and Perceived Child Vulnerability

Even though the literature has often used the two terms interchangeably, parental overprotection and perceived child vulnerability represent two distinct clinical phenomena (Thomasgard, Shonkoff, Metz, & Edelbrock, 1995b; Thomasgard & Metz, 1997). Where parental overprotection refers to a specific pattern of parental *behaviors* through which the parent intends to promote the safety and security of their child, perceived child vulnerability refers to parental *attitudes or beliefs* that a child is vulnerable to illness or is likely to die prematurely.

Thomasgard and colleagues demonstrated, through a series of empirical investigations, that correlations between parental overprotection and perceived child vulnerability are significant, though relatively small. Specifically, Thomasgard and colleagues (1995b) found that 20% of those children perceived to be vulnerable were also overprotected. In another study, they found that 35% of children who were perceived as vulnerable by their parents were also overprotected (Thomasgard & Metz, 1997). These results suggest that not all parents who worry excessively about their child being physically vulnerable behave in an overprotective manner toward their children.

Heightened levels of perceived child vulnerability to illness are not necessarily associated with the separation difficulties, excessive control, and interference with emerging independence that are evident in parental overprotection (Thomasgard & Metz, 1995b). In a study investigating the stability over time of and overlap of parental overprotection and perceived child vulnerability, Thomasgard and Metz (1996) found that parental overprotective behaviors and perceived child vulnerability were stable across a two-year time span. Thirty-one percent of parents who perceived their child as highly vulnerable yet reported low overprotective behaviors continued to perceive their child as highly vulnerable while still reporting low overprotection two years later. Additionally, 37% of parents who reported high overprotective behaviors and low perceived child vulnerability continued to report high overprotective behaviors and low vulnerability after two years. They also found that 20% of parents who perceived their child as vulnerable but reported low overprotective behaviors at time one subsequently reported both high vulnerability and high overprotective behaviors two years. These results indicate that a clinically significant minority of parents who initially perceive their

children as vulnerable may become overprotective at a later time point (Thomasgard & Metz, 1996).

To further differentiate parental overprotection and perceived child vulnerability, the antecedents, concurrent correlates, and consequences of each will be examined. The antecedents of parental overprotection have often been related to the parents' own childhood experiences rather than being reflective of the child's physical health (Parker & Lipscombe, 1981; Parker, 1981; Parker, 1983). Both parental anxiety (Parker & Lipscombe, 1981) and the parent having been raised in an overprotective family (Thomasgard & Metz, 1993) are risk factors for overprotection. Studies have also shown parental overprotection to be related to such antecedents as single parent status, lower socioeconomic status, less parental education, younger parent age, and younger child age (Parker & Libscombe, 1981; Thomasgard, Metz, Edelbrock, & Shonkoff, 1995a; Thomasgard & Metz, 1997; Thomasgard, 1998).

Thomasgard and colleagues (1995a) found a negative relationship between parental overprotection and child age such that overprotection declined as the child aged from two to five years. This relationship follows normative developmental processes as a child's independence and autonomy increases during that time. Another study found that parents with only one child exhibited more overprotection than those with multiple children. The authors suggest that this difference may be due to parental attention being given to only one child instead of being distributed across multiple children (Thomasgard & Metz, 1997). Finally, Thomasgard and Metz (1997) suggest that the association between less parental education and greater parental overprotective behavior may be due

to a lack of knowledge regarding the child's capabilities or may be due to the confound of living in an unsafe environment.

Regarding the consequences of parental overprotection, research indicates that children who have been overprotected are at risk for less behavioral autonomy as well as for both internalizing and externalizing behavior problems, including depression and oppositional behavior (Holmbeck et al., 2002). Additionally, retrospective studies of adults who have been overprotected suggest that children are at risk for dysthymia, anxiety disorders, and difficulties with interpersonal relationships in adulthood (Thomasgard, 1998).

On the other hand, studies of perceived child vulnerability's antecedents, concurrent correlates, and consequences have suggested relationships between perceived child vulnerability and low socioeconomic status, less parental education, a history of maternal infertility, being first born, frequent health care utilization, and previous life-threatening illness of the child (Thomasgard & Metz, 1997). Family socioeconomic status and parental education have been found to be negatively correlated with perceived child vulnerability such that lower socioeconomic status and lower parental education are related to higher perceived child vulnerability (Thomasgard & Metz, 1997). Additionally, similar to children who are overprotected by their parents, first-born children are perceived as more vulnerable than non-first born children. Research also suggests that children who are perceived as vulnerable by their parents are more likely than children who are overprotected to have a history of previous life-threatening illness or injury or a chronic medical condition (Thomasgard et al., 1995b; Thomasgard & Metz, 1997). Thomasgard (1998) found five factors related to child health to be significantly

associated with perceived child vulnerability: 1) parent report of the presence of a medical condition in the child; 2) parent report of the child having had a previous life-threatening illness or injury; 3) parent report of problems or complications during pregnancy, labor, and/or delivery of the child; 4) the child having been born prematurely; and 5) the child having been at the doctor's office for a sick visit.

Children perceived as vulnerable by their parents have been shown to participate in significantly fewer activities and have lower school and total competence scores compared with children not perceived to be vulnerable (Thomasgard & Metz, 1996). Psychosomatic illness, aggressive behavior, and school underachievement have also been found to be negative outcomes of a child being perceived as vulnerable (Thomasgard & Metz, 1997). A prospective study conducted by Thomasgard and Metz (1996) found significant associations between parental perceptions of child vulnerability and aggression and somatization in boys as well as symptoms of social withdrawal, anxiety, and depression in girls (Thomasgard & Metz, 1996). Further, in a more recent study, after controlling for child age and disease severity, increased parental perceptions of child vulnerability were found to be related to increased social anxiety in children (Anthony et al., 2003).

To summarize, the extant literature examining parental overprotection and perceived child vulnerability indicates that these concepts have distinct etiologies, concurrent correlates, and child outcomes, and therefore, suggests that they are separate clinical phenomena that may require unique clinical interventions (e.g., Parker & Lipscombe, 1981; Thomasgard & Metz, 1995; Thomasgard & Metz, 1996; Thomasgard & Metz, 1997). Further, some researchers have conceptualized parental overprotection as

a consequence or behavior exhibited due to perceiving the child as vulnerable, such that a subset of those parents who perceive their children as vulnerable may consequently become overprotective. Similarly, parental cognitions about their child's vulnerability may lead to unsuccessful parenting behaviors, such as overprotection, which may, in turn, lead to poor child adjustment outcomes (Anthony et al., 2003).

Parenting Stress

Parenting stress is a multidimensional construct that encompasses the parents' perception of their own characteristics, the characteristics of their child, and situational events (Abidin, 1990). This type of stress is based upon the parent-child relationship and arises when the parent's expectations about the resources necessary to meet the demands of parenting do not match the resources available to the parent (Deater-Deckard, 2004). Numerous studies have investigated the construct of parenting stress in non-chronically ill populations, and a thorough review of that literature is beyond the scope of this thesis. However, findings from studies of children with CF and SCD suggest that there is a significant relationship between parental distress, parenting stress, and parenting styles, and child cognitive and social development (Livneh & Antonak, 1997). Although the literature recognizes parenting stress as a common problem for parents of children with chronic illnesses (Kazak & Barakat, 1997; Streisand, Braniecki, Tercyak, & Kazak, 2001; Thompson & Gustafson, 1996), few studies have examined the discrete impact of parenting stress on adjustment outcomes in children with chronic illnesses.

Chalfin and colleagues (2002) examined parenting stress in a sample of caregivers of children with HIV. Their results showed that biological mothers reported clinically significant levels of parenting stress, while foster mothers' ratings fell within the normal

range. Additionally, biological mothers reported significantly more anxiety and depression than the foster mothers. The authors suggested that these differences were likely to be due to demographic variables, including caregiver age and monthly income, which may have served to protect the foster mothers. However, because these demographic variables were not significantly correlated with outcome measures, the authors did not control for this effect. Specifically, the results indicated that the foster mothers were significantly older than the biological mothers and had significantly more financial resources and social support. These findings suggest that demographic variables including parental age, income, and social support can affect levels of parenting stress in caregivers of children with chronic illnesses (Chalfin, Grus, & Tomaszeski, 2002).

In order to determine if illness characteristics affect levels of parenting stress, Hung and colleagues (2004) compared parents of children with a physical disability to parents of children with cancer. Parents of children with cancer were found to exhibit significantly higher levels of parenting stress than those parenting children with a physical disability. Specifically, the two groups differed significantly on all three subscales of the Parenting Stress Index as well as on the total parenting stress score. Despite this, no significant relationships were found between the levels of parenting stress and demographic variables including child's age, mother's age, and mother's education. The researchers suggest that the increased levels of parenting stress in parents of children with cancer may be due to the unpredictable nature of the disease.

Kazak and Barakat (1997) conducted a longitudinal study of the relationship between parenting stress, quality of life, and long-term adjustment in children with leukemia and their parents. For both mothers and fathers, the authors found that higher

levels of parenting stress while the child was undergoing treatment were significantly related to higher levels of parental anxiety after treatment. Accordingly, the researchers suggest that parents should be examined early in their child's treatment for high levels of parenting stress as this may be a risk factor for poor long-term adjustment for both parents and their children.

Mullins and colleagues (2007) conducted a recent study on the relationship between discrete parenting variables (i.e., parental overprotection, perceived child vulnerability, and parenting stress) and illness uncertainty in children with DM1. Their results revealed that both perceived child vulnerability and parenting stress were related to the child's illness uncertainty. Further, for children, their level of uncertainty was related to parenting stress, whereas adolescents' uncertainty was related to perceived vulnerability. These findings point to parenting stress differentially affecting child adjustment based upon the child's developmental level (Mullins, Wolfe-Christensen, Pai, Carpentier, Gillaspy, Cheek, et al., 2007).

Colletti et al. (2008) extended these findings by examining the relationship between discrete parenting variables and child adjustment outcomes (i.e., emotional, behavioral, social) in parents of children with cancer. Although perceived child vulnerability was found to be a significant predictor of child emotional adjustment, parenting stress was revealed to be a more consistent predictor of child emotional, behavioral, and social adjustment. Specifically, parenting stress was positively related to internalizing and externalizing problems and negatively related to prosocial behaviors in children with cancer. These results indicate that parenting stress is likely to have a transactional influence on child adjustment outcomes.

In order to assess the indirect relationship between parenting stress and child adjustment outcomes, Mullins and colleagues (2004) examined parenting stress as a moderator of the relationship between discrete parenting variables and child depression in mothers of children with DM1. Although perceived child vulnerability and parenting stress were both independently associated with child depression, parenting stress also moderated the relationship between perceived vulnerability and child depression, such that the relationship was intensified by higher parenting stress.

Even though few studies have examined the relationship between parenting stress and adjustment outcomes in children with chronic illnesses, each of the studies cited have shown that parents of children with chronic illnesses experience heightened levels of parenting stress. Further, these studies suggest that these heightened levels of parenting stress are associated with poor child adjustment outcomes such as psychological distress, depression, and illness uncertainty. These studies have also shown that parenting stress can be differentially affected by a number of demographic variables and even by the type of childhood chronic illness.

Chapter Summary

In summary, approximately one out of every 300 children will develop cancer by the age of 20 (Ries et al., 1999). Whereas cancer was once a death sentence, the current five-year survival rate of pediatric cancer is 80%, and thus, pediatric cancer is now characterized as a chronic health condition (ACS, 2008a). Following the cancer diagnosis, both children and parents must attempt to adjust. Where a child's life is greatly affected across multiple domains, parents are faced with the sudden onset of a new care-giving role. A parent's ability to adjust to this new role significantly impacts

the adjustment of their child. However, it is still unknown how specific socioecological and discrete parenting variables contribute to health-related quality of life in these children.

CHAPTER III

THE PRESENT STUDY

The preceding literature review provides evidence that children with cancer are at risk for a number of poor outcomes, including late effects of treatment, psychological adjustment problems, and overall lower quality of life. These poor adjustment outcomes have also been linked to the family's socioeconomic status, the parent's marital status, and several discrete parenting variables, including parental overprotection, perceived child vulnerability, and parenting stress. The transactional nature of adjustment to chronic illness also suggests that child adjustment is closely related to the parent's adjustment. Thus, parents who exhibit more overprotective behaviors, who perceive their child as more vulnerable, and who experience greater stress within the parent-child relationship will have children who will exhibit poorer adjustment.

Although parental overprotection, perceived child vulnerability, and parenting stress have been previously independently examined in the pediatric cancer population, to our knowledge, no studies have examined their relationships to broad child adjustment outcomes as assessed through disease-specific health-related quality of life. Further, specific demographic variables, including socioeconomic status and single parent status, have not been assessed in relation to these discrete parenting variables and health-related

quality of life in the pediatric cancer population. Thus, the current study sought to expand upon the extant literature.

The present study was guided by the following aims:

Aim 1. To examine parent-proxy report of health-related quality of life in pediatric cancer.

Hypothesis 1. It was hypothesized that parental socioeconomic status would be positively related to health-related quality of life for their children.

Hypothesis 2. It was hypothesized that married parents would report higher health-related quality of life for their children than lone parents would report for their children.

Aim 2. To assess the relationship between parenting variables, including parental overprotection, perceived child vulnerability, and parenting stress, and parent-proxy report of health-related quality of life in pediatric cancer.

Hypothesis 3. It was hypothesized that parental overprotection would be negatively related to health-related quality of life in their children with cancer.

Hypothesis 4. It was hypothesized that perceived child vulnerability would be negatively related to health-related quality of life in children with cancer.

Hypothesis 5. It was hypothesized that parenting stress would be negatively related to health-related quality of life in children with cancer.

The additional research question addressed in the present study was as follows:

Research Question 1. Do single parents differ from married parents on reported levels of parental overprotection, perceived child vulnerability, and parenting stress?

In order to test these hypotheses and explore the additional research question, de-identified, archival data from parents of children who were currently on treatment for pediatric cancer at the Jimmy Everest Cancer for Childhood Cancer and Bleeding Disorders (JEC) at the University of Oklahoma Health Sciences Center were examined. All participants completed a demographic form in addition to measures of parental overprotection, perceived child vulnerability, parenting stress, and health-related quality of life. A detailed explanation of the current study's sample, measures, and procedure can be found in the next chapter.

CHAPTER IV

METHODS

Participants

Participants for the current study were a part of a larger sample of children with pediatric cancer and their parents.

The current sample consisted of 89 parents (71 mothers, 14 fathers, 3 grandparents, and 1 unknown) of children (38 female and 51 male) between the ages of 2 and 16 years old (M = 6.50, SD = 3.07), who were diagnosed with pediatric cancer. Specifically, 57 of the children (64%) had been diagnosed with leukemia or lymphoma, 21 (23.6%) were diagnosed with a solid tumor, and 11 (12.4%) had been diagnosed with a brain tumor. The children's age at diagnosis ranged from 1 to 16 years old (M = 5.66, SD = 3.15), and the duration of their illness, which was calculated by subtracting the date of diagnosis from the date of participation in the study, ranged from 1 to 66 months (M = 10.88, SD = 14.35).

The parent participants were 20 to 51 years old (M = 34.03, SD = 7.06) and had a mean educational attainment of 13.73 years (*range:* 8 – 19). With regard to race and ethnicity, 80.9% of the sample self-identified as Caucasian, 4.5% as African American, 5.6% as Hispanic, 5.6% as Native American, 1.1% as Asian, and 2.2% as "other". The majority of parents (69.6%) reported being married, 22.5% reported being a single parent

or never married, and 7.9% identified as “other”. Additionally, 27% of the sample reported an annual family income of less than $20,000, 25.9% reported an income between $20,000 and $40,000, 15.3% of the sample reported an income between $40,000 and $60,000, and the remaining 31.8% reported an annual income of more than $60,000. The demographic makeup of the participant sample is consistent with that of the geographic region in which the study was conducted.

Families were included into the current study if they met the following criteria: 1) the child was between the ages of two and 18 years old; 2) the child was receiving treatment for pediatric cancer at the time of participation in the study; 3) the parent spoke English as his/her primary language; and 4) a parent completed the relevant psychosocial and demographic measures. Exclusion criteria included: 1) the child with cancer was experiencing an imminent medical crisis necessitating significant medical intervention; 2) the child with cancer was determined to be in the terminal phase and/or was receiving palliative care; 3) the parent was currently being treated for a serious psychiatric disorder or evidenced mental retardation; and 4) the child with cancer evidenced mental retardation or a significant developmental delay.

Measures

Demographic Form. Participants completed a brief demographic questionnaire to collect data regarding the child’s gender, current age, the ages and occupations of the child’s parents, parent marital status, and annual household income. A copy of the form is available in Appendix B.

Medical Chart Review. A medical chart review was conducted by a trained graduate research assistant to obtain information regarding the child’s diagnosis, date of

diagnosis, and treatment protocol (i.e., length of treatment, type and dosage of medication, radiation dosage). A copy of the form is available in Appendix B.

Pediatric Quality of Life Inventory 3.0 Cancer Module. Parent report of child health-related quality of life (HRQOL) was assessed using the Pediatric Quality of Life Inventory 3.0 Cancer Module (PedsQL). The PedsQL is a modular measure of HRQOL for assessment of children and adolescents ages two to 18 years old (Varni et al., 2002). The 27-item cancer module is specifically designed to measure HRQOL in a pediatric cancer population. The measure consists of eight scales: pain and hurt, nausea, procedural anxiety, treatment anxiety, worry, cognitive problems, perceived physical appearance, and communication. Respondents are asked to consider each problem over the previous one month, and responses are provided on a five-point Likert scale from 0 ("never") to 4 ("almost always"). Items include statement such as: "In the past one month, how much of a problem has your child had with . . . becoming nauseated during medical treatments" and ". . . worrying that the cancer will reoccur or relapse". Higher scores on the PedsQL indicate better HRQOL. Previous studies have demonstrated moderate to high internal reliability coefficients (.81-.93) for parent-proxy report of the eight individual scales for all age ranges (Varni et al., 2002). The internal reliability coefficient for the current sample was high (.86-.96) for each age range for the parent-proxy report measure.

Parent Protection Scale. Parental overprotection was assessed using the Parent Protection Scale (PPS; Thomasgard et al., 1995a). A copy of the scale is available in Appendix B. The PPS, a 25-item self-report measure, examines several dimensions of overprotective parenting behaviors. Parents are asked to rate the extent to which each statement is descriptive of their behavior with their child on a four-point scale ranging

from 0 (“never”) to 3 (“always”). Items include: “I comfort my child immediately when he/she cries” and “I let my child make his/her own decisions.” A higher total score indicates a higher level of protective parenting behaviors. Previous normative studies on the PPS have demonstrated moderate to high internal reliability (.73) and high test-retest reliability (.86; Thomasgard et al., 1995a). However, the internal reliability coefficient for the current sample was low (.51) compared to previous studies. Research has recommended that a score of 39 be used to indicate clinical levels of overprotection, corresponding to one standard deviation above the mean (Thomasgard & Metz, 1997). In previous research, the PPS has been successfully used to measure protective parenting behaviors in a pediatric diabetes population (Mullins et al., 2004).

Child Vulnerability Scale. The Child Vulnerability Scale (CVS) was used to measure parental perceptions of child vulnerability (Forsyth et al., 1996). A copy of the scale is available in Appendix B. On eight self-report items, parent respondents are asked to rate the extent to which they perceive their child as vulnerable on a four-point scale ranging from 0 (“definitely false”) to 3 (“definitely true”). Items include: “In general my child seems less healthy than other children” and “I get concerned about the circles under my child’s eyes.” Higher total scores on the CVS indicate greater perceived child vulnerability. Previous studies using the CVS have demonstrated moderate to high internal reliability coefficients (.74; Forsyth et al., 1996) and high test-retest reliability (.84; Thomasgard et al., 1995b). The internal reliability coefficient for the current sample was moderate to high (.76). The developers of this measure derived the clinical cutoff score from a prediction model discriminating children who were either medically vulnerable or whose parent had significant concerns that the child might die from a given

condition. Using this model, they recommended that a cutoff score of 10 be used to reflect clinical levels of perceived child vulnerability (Forsyth et al., 1996).

Parenting Stress Index/Short Form. The amount of stress present in the parent-child relationship was assessed using the Parenting Stress Index/Short Form (PSI/SF; Abidin, 1990). The PSI/SF is a 36-item instrument which asks parents to rate the extent to which each statement is descriptive of their relationship with their child on a five-point scale ranging from 1 ("strongly agree") to 5 ("strongly disagree"). Items include: "I feel trapped by my responsibilities as a parent" and "My child makes more demands on me than most children." The PSI/SF yields three subscale scores (i.e., stress attributable to the parent's personal distress, distress related to the child, and relational distress between the parent and child) as well as a total stress score, and higher scores indicated higher levels of parenting stress. In the current study, the total score will be utilized as the measure of parenting stress. The PSI/SF is highly correlated with the full-length PSI instrument (r = .94), and the two-week test-retest reliability of the PSI with the PSI/SF is also very high (.95; Abidin, 1990). The validity of the PSI and PSI/SF has been established in a range of populations, including parents of children with chronic illnesses (Carson & Schauer, 1992; Wysocki, Huxtable, Linscheid, & Wayne, 1989; Mullins et al., 2004). The internal consistency for the current sample was high (.92).

Procedure

Participants for the current study were recruited from the Jimmy Everest Cancer for Childhood Cancer and Bleeding Disorders (JEC) at the University of Oklahoma Health Sciences Center. Potential participants were identified from the JEC's outpatient clinic schedule, and the attending physician was then consulted to assess the family's

eligibility for the study. The parents were recruited in the clinic waiting room by a graduate research assistant trained in the process of informed consent and HIPAA research guidelines, and the process conformed to standards of the OUHSC and OSU Institutional Review Boards (IRB). When the study was described to parent participants, they were informed that consent to participate was completely voluntary and would in no way influence their child's medical treatment. The participants were presented with the measures to complete while they were waiting and were given the opportunity to complete the measures in a private room in the clinic to ensure confidentiality. Each parent was compensated with a $20.00 gift card upon completion of the measures. Of the 104 parents who were approached for participation in the larger study, 104 parents consented to participate, and 85.6% (n = 89) completed the study. The remaining 15 participants did not complete the relevant measures, even after receiving reminders in the clinic.

Once the measures were collected from the participants, the data was entered into SPSS using a de-identified subject number for analysis, and a review of the patient's medical chart was conducted by a graduate research assistant to obtain the relevant medical data, as described above. All raw data was identified by a subject number and was stored in a locked filing cabinet in the research office. Additionally, consent forms, HIPAA privacy forms, and demographic forms were removed from the rest of the raw data and stored separately to ensure confidentiality of the participants.

CHAPTER V

RESULTS

Preliminary Analyses

First, descriptive statistics were calculated for all of the variables of interest (see Appendix C: Table 1). Next, a series of bivariate correlations was conducted to determine if any of the demographic variables (i.e., child age, child gender, parent age, parent education, and annual family income) or illness parameters [i.e., age at diagnosis, illness duration, disease group (Central Nervous System vs. non-Central Nervous System)] were related to the outcome variable, specifically health-related quality of life. No demographic variables or illness parameters were found to significantly correlate with parent-proxy report of child health-related quality of life (see Appendix C: Tables 2 and 3).

The sample was also examined to determine the percentage of parents who reported scores within the clinically significant range on each of the measures. Using Thomasgard and Metz's (1997) recommended cutoff score of 39 or greater, 14 (15.91%) parents met criteria for clinical levels of overprotective behavior. Twenty-two (25.29%) parents met clinical criteria for perceiving their child as highly vulnerable, using the recommended cutoff score of 10 (Forsyth et al., 1996). Additionally, using the

recommended cutoff score of 90 (Abdin, 1990), 15 (17.05%) parents fell in the clinically significant range for parenting stress. Varni and colleagues (2007) recommend the cutoff score for the PedsQL be set at one standard deviation below the mean. Using this score, 16 (17.98%) parents reported clinically significant levels of poor disease-specific quality of life for their children.

To determine whether the parent participants (i.e., mothers, fathers, custodial grandparents) differed on the outcome variable, health-related quality of life, a one-way ANOVA was conducted. Results revealed no significant differences between the groups, $p > .05$. As such, all caregivers were included in the initial set of analyses. To determine whether single parent participants (i.e., mothers, fathers, custodial grandparents) differed on health-related quality of life, a one-way ANOVA was conducted. Results of this analysis also revealed no significant differences between the groups, $p > .05$. Thus, all single caregiver participants were included in the initial set of analyses. To determine whether married parent participants (i.e., mothers, fathers, custodial grandparents) differed on health-related quality of life, another one-way ANOVA was conducted. Results of this analysis also revealed no significant differences between the groups, $p > .05$. Thus, all married caregiver participants were included in the initial set of analyses.

To determine whether there was a significant relationship between the outcome variable, parent-proxy report of child health-related quality of life, and the predictor variables, annual family income, single parent status, parental overprotection, perceived child vulnerability, and parenting stress, a series of bivariate correlations was conducted. Results revealed that annual family income was significantly related to single parent status such that single parents have lower annual family income, and higher income was

found to be related to lower parental overprotection and perceived child vulnerability. Single parent status was negatively related to parental overprotection and child vulnerability such that single parents reported higher levels of each. Parental overprotection was related to both child vulnerability and parenting stress such that higher overprotection was related to higher vulnerability and parenting stress. Child vulnerability was found to be significantly positively related to parenting stress such that higher vulnerability was related to higher parenting stress (See Table 4).

Primary Analyses

First, collinearity statistics were conducted for all primary analyses. These results revealed that multicollinearity was not a concern in any of the analyses. To address Aim 1 and to test the hypothesis that parental socioeconomic status would be positively related to parent-proxy report of health-related quality of life for their children, a hierarchical regression was conducted. Although no illness and demographic covariates were identified by significant correlations in the preliminary analyses, child age and gender were selected as covariates in accordance with Thompson and Gustafson's transactional stress and coping model (1996). These covariates were entered on Step 1, and annual family income was entered on Step 2 as a measure of the family's socioeconomic status. The PedsQL Total score served as the dependent variable. After entering these theoretically important demographic variables, analyses revealed that annual family income was a significant predictor of parent-proxy reported child HRQOL, $\beta = .210$, $t(81) = 1.957$, $p = .054$, indicating that there is a relationship between socioeconomic status and child HRQOL, such that higher annual family income is related to higher parent-proxy report of HRQOL (see Table 5).

To test the hypothesis that married parents would report higher levels of child health-related quality of life than single parents, an independent *t*-test was conducted. The Total score of the PedsQL was examined. No significant difference was found between single parents and married parents on report of child health-related quality of life, $p > .05$.

In order to address Aim 2 and test the hypothesis that parental overprotection would be negatively related to health-related quality of life in their children with cancer, a hierarchical regression was conducted. Although no illness and demographic covariates were identified by significant correlations in the preliminary analyses, child age and gender as well as annual family income were selected as covariates in accordance with Thompson and Gustafson (1996), and were entered on Step 1, and the Parent Protection Scale Total score was entered on Step 2 as a measure of parental overprotection. The PedsQL Total score served as the dependent variable. Annual family income emerged as a significant predictor of child HRQOL on Step 1, $\beta = .210$, $t(81) = 1.957$, $p = .054$. In addition, parental overprotection was found to be significantly related to child HRQOL, $\beta = -.283$, $t(80) = -2.428$, $p = .017$, indicating that higher parental overprotection was related to lower parent-proxy report of child HRQOL (see Table 6).

To address the hypothesis that perceived child vulnerability would be negatively related to health-related quality of life in their children with cancer, a hierarchical regression was conducted. Again, child age and gender as well as annual family income were selected as covariates in accordance with Thompson and Gustafson (1996), and were entered on Step 1, and the Child Vulnerability Scale Total score was entered on Step 2 as a measure of perceived child vulnerability. The PedsQL Total score served as the dependent variable. After controlling for these theoretically important demographic

variables, perceived child vulnerability was found to be significantly related to child HRQOL, β = -.413, $t(78) = -3.788$, $p < .001$, indicating that higher perceived child vulnerability was related to lower parent-proxy report of child HRQOL (see Table 7).

The hypothesis that parenting stress would be negatively related to health-related quality of life in children with cancer was tested by conducting another hierarchical regression. As before, child age and gender as well as annual family income were selected as covariates and were entered on Step 1, and the Parenting Stress Index Total score was entered on Step 2 as a measure of parenting stress. The PedsQL Total score served as the dependent variable. After controlling for these theoretically important demographic variables, parenting stress was found to be significantly related to child HRQOL, β = -.348, $t(79) = -3.241$, $p = .002$, indicating that higher parenting stress was related to lower parent-proxy report of child HRQOL (see Table 8).

An additional hierarchical regression was conducted in order to examine the combined effect of the three parenting capacity variables on parent-proxy report of child HRQOL. Child age and gender as well as annual family income were again selected as covariates, and were entered on Step 1, and the Parent Protection Scale Total score, Child Vulnerability Scale Total score, and Parenting Stress Index Total score were entered simultaneously on Step 2. The PedsQL Total score served as the dependent variable. After controlling for these variables, child age, perceived child vulnerability, and parenting stress were found to be significantly related to child HRQOL, β = -.225, $t(75) = -2.059$, $p = .043$; β = -.271, $t(75) = -2.227$, $p = .029$; β = -.226, $t(75) = -2.035$, $p = .045$, respectively. Thus, lower HRQOL was associated with having older children and with higher levels of perceived vulnerability and higher parenting (see Table 9).

Research Question 1 was addressed by conducting a series of independent *t*-tests comparing the mean levels of parental overprotection, perceived child vulnerability, and parenting stress in married versus single parents. The Parent Protection Scale Total score, Child Vulnerability Scale Total score, and Parenting Stress Index Total score served as the dependent variables. Parenting stress was not found to differ significantly between married and single parents, $p > .05$. However, parental overprotection was found to be significantly related to parental marital status, $t(86) = 2.379$, $p = .020$, such that single parents reported higher levels of overprotection than married parents. Perceived child vulnerability was also significantly related to parent marital status, $t(85) = 2.384$, $p = .019$, such that single parents reported higher levels of child vulnerability than married parents.

Exploratory Analyses

The results of previous studies of parents of children with pediatric cancer have demonstrated differential psychological adjustment outcomes for mothers and fathers (Kazak, Barakat, Meeske, 1997; Pai, Drotar, Zebracki, Moore, & Youngstrom 2006; Pai, Greenley, Lewankdowski, Drotar, Youngstrom, & Peterson, 2007). Even though preliminary analyses did not indicate significant differences between the type of caregiver (i.e., mothers, fathers, grandparents) on levels of child health-related quality of life, it may be that this nonsignificant result is due to a small sample size, and therefore, low statistical power to detect significant group differences. Thus, in order to reduce the variability due to the type of caregiver, exploratory analyses were conducted using a mothers-only sample and all other caregivers were excluded from the analyses.

Preliminary Analyses for Mothers Only

First, descriptive statistics were calculated for all of the variables of interest (See Appendix C: Table 9). Next, a series of bivariate correlations was conducted to determine if any of the demographic variables (i.e., child age, child gender, parent age, parent education, and annual family income) or illness parameters [i.e., age at diagnosis, illness duration, disease group (Central Nervous System vs. non-Central Nervous System)] were related to the outcome variable, health-related quality of life. With regard to the demographic variables, results revealed that higher annual family income was significantly correlated with higher parent-proxy report of child health-related quality of life (see Table 10). No illness parameters were found to significantly correlate with parent-proxy report of child health-related quality of life (see Table 11).

The mothers-only sample was also examined to determine the percentage of mothers who reported scores within the clinically significant range on each of the measures. Using Thomasgard and Metz's (1997) recommended cutoff score of 39 or greater, 10 (14.08%) mothers met criteria for clinical levels of overprotective behavior. Eighteen (25.71%) mothers met clinical criteria for perceiving their child as highly vulnerable, using the recommended cutoff score of 10 (Forsyth et al., 1996). Additionally, using the recommended cutoff score of 90 (Abdin, 1990), 13 (18.57%) mothers fell in the clinically significant range for parenting stress. Varni and colleagues (2007) recommend the cutoff score for the PedsQL be set at one standard deviation below the mean. Using this score, 12 (16.9%) mothers reported clinically significant levels of poor disease-specific quality of life for their children.

To determine whether there was a significant relationship between the outcome variable, parent-proxy report of child health-related quality of life, and the predictor

variables, annual family income, single parent status, parental overprotection, perceived child vulnerability, and parenting stress, for the mothers-only sample, a series of bivariate correlations was conducted. Results revealed that annual family income was found to be significantly related to single parent status such that single mothers have lower annual family income, and higher income was found to be related to lower parental overprotection and perceived child vulnerability. Single parent status was negatively related to parental overprotection such that single mothers reported higher levels of overprotection. Parental overprotection was related to both child vulnerability and parenting stress such that higher overprotection was related to higher vulnerability and parenting stress. Child vulnerability was found to be significantly positively related to parenting stress such that higher vulnerability was related to higher parenting stress (See Table 13).

Primary Analyses for Mothers Only

To test the hypothesis that married mothers would report higher levels of child health-related quality of life than single mothers, an independent *t*-test was conducted. The Total score of the PedsQL was examined. No significant difference was found between single mothers and married mothers on report of child health-related quality of life, $p > .05$.

Research Question 1 was addressed by conducting an independent *t*-test comparing the mean levels of parental overprotection, perceived child vulnerability, and parenting stress in married and single mothers. The Parent Protection Scale Total score, Child Vulnerability Scale Total score, and Parenting Stress Index Total score served as the dependent variables. Parenting stress was not found to differ significantly between

married and single mothers, $p > .05$. Parental overprotection was found to be significantly related to mothers' marital status, $t(69) = 2.490$, $p = .015$, such that single mothers reported higher levels of overprotection than married mothers. Perceived child vulnerability was not significantly related to mothers' marital status; however, there was a trend toward significance, $t(68) = 1.695$, $p = .095$, such that single mothers reported higher levels of child vulnerability than married mothers.

CHAPTER IV

DISCUSSION

The purpose of the current study was to examine parent-proxy report of health-related quality of life in pediatric cancer. Specifically, the current study first sought to determine the relationship between parent-proxy report of health-related quality of life and socioecological variables, namely parental socioeconomic status and parental marital status. Second, the relationship between parenting capacity variables, including parental overprotection, perceived child vulnerability, and parenting stress, and parent-proxy report of health-related quality of life in pediatric cancer was assessed. The present study was guided by five hypotheses and one research question.

The first hypothesis stated that parental socioeconomic status would be positively related to health-related quality of life of children with cancer. The hypothesis was supported, with annual family income significantly related to parent-proxy report of child health-related quality of life after controlling for child age and gender. These results suggest that children from families of higher socioeconomic status evidence higher health-related quality of life; while conversely, children with cancer whose families are of lower socioeconomic status may be at risk for poorer disease-specific health-related quality of life. Although the specific linkage between income and HRQOL cannot be discerned directly from these results, it may be that lower quality of life is due to the

family being under multiple significant stressors (i.e., the cancer experience itself and significant financial stress) to which they must struggle to cope. These results are consistent with findings other studies of health-related quality of life in children with cancer. For example, Phipps and colleagues (2002) found that for children with cancer who were undergoing a bone marrow transplant, poor child-reported health-related quality of life was related to lower socioeconomic status. Notably, these children may also be at risk for poor adjustment into survivorship (Zebrack et al., 2004); therefore, it will be important to continue to monitor the impact of lower SES on children with cancer and their families throughout the course of the disease and into survivorship.

The second hypothesis stated that married parents would report higher health-related quality of life for their children than single parents would report for their children. The results did not support the hypothesis, and significant differences were not found between married and single parents. The analyses were also conducted on a mothers-only sample. Again, no significant difference was found between the parent-proxy report of child health-related quality of life of married mothers and single mothers. These results suggest that parental marital status may not be salient enough in parents' perceptions of their children's adjustment to have an effect on the child's disease-specific quality of life. These results stand in contrast to Landgraf and Abetz (1998) who found that single parents of healthy children rated their children's general health, behavior, and self-esteem lower and worried more about their children than married parents.

The third, fourth, and fifth hypotheses stated that parental overprotection, perceived child vulnerability, and parenting stress, respectively, would be negatively related to parent-proxy report of health-related quality of life in children with cancer.

These hypotheses were supported, as results of the analyses indicate that after controlling for theoretically important demographic variables, there is a significant negative relationship between each of the discrete parenting variables and child health-related quality of life, such that higher levels of each of the parenting variables was related to lower child health-related quality of life. Notably, after controlling for theoretically important demographic variables, the combined effect of the three discrete parenting variables on child health-related quality of life was also found to be significant such that older child age and greater perceived child vulnerability and parenting stress again emerged as significant predictors of poor parent-proxy reported child health-related quality of life. These results underscore the salience of these parenting capacity variables in their relationship to quality of life.

The precise linkage between these three parenting capacity measures and lower quality of life is uncertain, and a number of mechanisms may be operating. First, children who are evidencing lower quality of life as a function of their cancer experience may elicit particular parenting approaches. It may be that children with cancer who are evidencing poorer quality of life place greater demands on their caregivers, both physically and emotionally, which in turn leads to greater stress within the parent-child relationship. Parents of children who are evidencing poorer health-related quality of life may also perceive their children as more vulnerable, which may lead them to be more overprotective of their children. Conversely, it may be that parents who are under significant stress and perceive their child as highly vulnerable may view their child's quality of life as being poorer. Unfortunately, the lack of child-reported quality of life in this study precludes examination of this possibility. Future research would do well to

include child-reported quality of life in order to better determine the nature of this relationship.

Overall, these results support the transactional relationship between parent and child adjustment to pediatric cancer. Specifically, they indicate that protective behaviors, perceptions of vulnerability, and parenting stress are negatively related disease-specific health-related quality of life in children with cancer. The results of the current study are also consistent with those of other recent studies on overprotection, perceived vulnerability, and parenting stress. Holmbeck and colleagues (2002) demonstrated a relationship between parental overprotection and maladaptive adjustment outcomes, including internalizing and externalizing behaviors, in children with spina bifida. This result, combined with that of the current study, suggests that parental overprotection is related to both broad and discrete adjustment outcomes in children with a pediatric illness. The current results are also consistent with the literature on perceived child vulnerability, health care utilization, and health-related quality of life. Previous research indicates that both parents' perceptions of poor health-related quality of life for their children and greater perceived child vulnerability are related to more frequent health care utilization (Vance et al., 2001; Campo et al., 2002; Janicke et al., 2001; Varni & Setoguchi, 1992; Bush & Iannotti, 1990). All of the children in the current study are on active treatment for cancer, which entails attendance at frequent clinic appointments as well as in-patient hospitalizations. Therefore, it would follow that these children are experiencing frequent health care use, and their parents perceive them as more vulnerable as well as having a poorer quality of life. A recent study on parenting stress reveals consistent findings in a sample of children undergoing stem cell transplantations and their

parents (Vrijmoet-Wiersma, Kolk, Grootenhuis, Spek, van Klink, & Egeler, 2009). The authors indicate that poor parent-proxy report of health-related quality of life was significantly related to greater parenting stress in their sample. These combined results indicate that parents of children with cancer who are experiencing higher parenting stress report poorer quality of life for their children.

The result that older child age emerged as a significant predictor of poor health-related quality of life is also consistent with the literature. Levi (2006) explains that the child's developmental stage is important when measuring the impact of their disease on their health-related quality of life. The disease is likely to be a greater hindrance to the quality of life of older children, and the impact of the disease is likely to be more salient to older children than younger children.

Finally, the research question investigated whether single parents differed from married parents on reported levels of each of the discrete parenting variables, parental overprotection, perceived child vulnerability, and parenting stress. Results indicate that married and single parents did not differ on levels of parenting stress. However, single parents were shown to report significantly higher levels of parental overprotection and perceived child vulnerability than married parents. These analyses were also conducted on a mothers-only sample. Again, mothers were not found to differ on reported levels of parenting stress, but single mothers did report higher levels of parental overprotection than married mothers, and there was a trend toward significance such that single mothers reported higher levels of perceived child vulnerability than married mothers. These results are consistent with Brown and colleagues (2008) who suggest that the struggle of caring for a child with a chronic illness is more intense for single parents who must carry

the burden alone. Specifically, the results of the current study suggest that married and single parents are experiencing similar levels of stress within the parent-child relationship; however, single parents believe their children are more vulnerable and are protecting their children more than married parents. Although speculative, this difference may be due to single parents having less social support than married parents, leading them to turn to maladaptive coping mechanisms. Such results are also consistent with Wallander and colleagues (1989), whose research found that mothers with less social support have poorer adjustment to their child's illness.

Strengths and Limitations

Several strengths of the current study should be highlighted. First, the current study is, to our knowledge, the first to examine the relationship between these discrete parenting variables and parent-proxy report of health-related quality of life in a pediatric cancer population. Second, the hypotheses examined in the current study were set in the context of the transactional stress and coping model of adjustment to pediatric illness and thus was theory driven. Third, this study utilized a relatively large sample size within the context of pediatric cancer research, where studies with smaller samples sizes are often examined. Additionally, the current study utilized a disease-specific measure of health-related quality of life. Consequently, this study was able to examine aspects of the child's disease and treatment that are unique to the pediatric cancer experience.

In addition to the preceding strengths, several limitations to the current study should also be acknowledged. First, the cross-sectional nature of the current study prevents identification of causal relationships between the variables of interest. It may be that greater parental overprotection, perceived child vulnerability, and parenting stress

result in poorer health-related quality of life in pediatric cancer, but it is equally likely that poorer health-related quality of life in children with cancer leads to greater parental overprotection, perceived child vulnerability, and parenting stress. Second, parent proxy- and self-report measures were used in the current study, and thus, the results may reflect shared method variance. Third, the current sample included a wide age range of children and adolescents, which necessitated the utilization of several versions of the measure of health-related quality of life. Although the different versions are assumed to measure the same constructs across age groups, it is quite possible that some differences exist.

Future Directions

Overall, the current study has demonstrated significant relationships between parenting capacity variables and socioeconomic status and parent-proxy report of child health-related quality of life. Future studies should continue to examine each of these relationships in larger, more diverse samples and examine families impacted by other pediatric illnesses. Specifically, future research should continue to investigate the relationship between these parenting capacity variables and child health-related quality of life in pediatric illness populations. It is important to examine this relationship longitudinally in order to determine if the relationship between discrete parenting variables and child adjustment persists throughout the course of the disease as well as into survivorship. Additionally, parent adjustment should be examined both discretely and broadly in future studies in order to decrease the effects of shared method variance. Shared method variance may also be decreased in future research by including ratings from teachers, siblings, multiple parents, and health care professionals as well as by conducting behavioral observations of the family. Future studies should also continue to

examine adjustment differences between married and single parents of children with pediatric illnesses. No significant relationship was found between single parent status and parent-proxy report of health-related quality of life. It is possible that this non-significant finding is attributable to a small sample size and thus low power to detect differences between the groups. A larger sample size as well as controlling for other demographic variables would be advantageous in this line of research in order to increase statistical power.

Conclusions and Implications for Practice

The current study provides additional support for the transactional relationship between discrete parenting variables and child adjustment to pediatric cancer. Specifically, significant relationships were found between family socioeconomic status, parental overprotection, perceived child vulnerability, and parenting stress and parent-proxy report of child health-related quality of life. The evident contributions of socioeconomic status, parental overprotection, perceptions of vulnerability, and parenting stress to child disease-specific health-related quality of life may warrant assessment of these variables in parents of children who have been recently diagnosed with cancer. Parents who are deemed at risk may benefit from referrals to psychologists and other mental health professionals for interventions to address overprotective behaviors, increased perceptions of vulnerability, and increased levels of stress in the parent-child relationship. The family's socioeconomic status could further exacerbate the cancer experience by contributing additional stress to the family; therefore, families of lower socioeconomic status should be identified as at risk for poor adjustment outcomes. As a

result, interventions designed specifically for families of lower socioeconomic status may also be warranted.

REFERENCES

Abidin, R.R. (1990). *Parenting Stress Index.* Odessa, FL: Psychological Assessment Resources.

American Cancer Society. (2008a). *Cancer facts & figures 2008*. Retrieved November 18, 2008, from: http://www.cancer.org/downloads/STT/2008CAFFfinalsecured.pdf.

American Cancer Society. (2008b). *Patients, family, & friends*. Retrieved November 18, 2008, from: http://www.cancer.org.

Anthony, K. K., Gil, K. M., & Schanberg, L. E. (2003). Brief report: Parental perceptions of child vulnerability in children with chronic illness. *Journal of Pediatric Psychology*, *28*, 185-190.

Armstrong, F.D., Tolendano, S.R., Miloslavich, K., Lackman-Zeman, L., Levy, J.D., Gay, C.L., et al. (1999). The Miami Pediatric Quality of Life Questionnaire: Parent scale. *International Journal of Cancer, Suppl. 12*, 11-17.

Askins, M.A., & Moore, B.D. (2008). Preventing neurocognitive late effects in childhood cancer survivors. *Journal of Child Neurology, 23*, 1160-1171.

Barrera, M., Wayland, L.A., D'Agostino, N.M., Gibson, J., Weksberg, R., & Malkin, D. (2003). Developmental differences in psychological adjustment and health-related quality of life in pediatric cancer patients. *Children's Health Care, 32*, 215-232.

Berg-Nielsen, T.S., Vika, A., & Dahl, A.A. (2003). When adolescents disagree with their mothers: CBCL-YSR discrepancies related to maternal depression and adolescent self-esteem. *Child: Care, Health & Development, 29*, 207-213.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist, 32,* 513-531.

Bronfenbrenner, U. (1979). *The ecology of human development*. Boston: Harvard University Press.

Brown, R.T. (2006). *Comprehensive handbook of childhood cancer and sickle cell disease: A biospsychosocial approach.* New York: Oxford University Press.

Brown, R.T., Wiener, L., Kupst, M.J., Brennan, T., Behrman, R., Compas, B.E., et al. (2008). Single parents of children with chronic illness: An understudied phenomenon. *Journal of Pediatric Psychology, 33,* 408-421.

Bush, P. J., & Iannotti, R., J. (1990). A children's health belief model. *Medical Care, 28,* 69-86.

Cadman, D., Boyle, M., Szatmari, P., & Offord, D. R. (1987). Chronic illness, disability, and mental and social well-being: Findings of the Ontario Child Health Study. *Pediatrics, 79,* 805-813.

Campo, J.V., Comer, D.M., Jansen-McWilliams, L., Gardner, W., & Kelleher, K.J. (2002). Recurrent pain, emotional distress, and health service use in childhood. *Pediatrics, 141,* 76-83.

Canning, E.H. (1994). Mental disorders in chronically ill children: Case identification and parent-child discrepancy. *Psychosomatic Medicine, 56,* 104-108.

Cappelli, M., McGrath, P. J., & MacDonald, N. E. (1989). Parental care and overprotection of children with cystic fibrosis. *British Journal of Medical Psychology, 62,* 281-289.

Carlson-Green, B., Morris, R. D., & Krawiecki, N. (1995). Family and illness predictors of outcome in pediatric brain tumors. *Journal of Pediatric Psychology, 20,* 769-784.

Carpentieri, S. C., Mulhern, R. K., & Douglas, S. (1993). Behavioral resiliency among children surviving brain tumors: A longitudinal study. *Journal of Clinical Child Psychology, 22,* 236-246.

Carson, D. K., & Schauer, R. W. (1992). Mothers of children with asthma: Perceptions of parenting stress and the mother-child relationship. *Psychological Reports, 71,* 1139-1148.

Cecalupo, A. (1994). Childhood cancers: Medical issues. In R. A. Olsen, L. L. Mullins, & J. B. Gillman (Eds.), *The sourcebook of pediatric psychology* (pp. 90-97). Needham Heights, MA: Allyn & Bacon.

Chalfin, S. R., Grus, C. L., & Tomaszeski, L. (2002). Caregivers's stress secondary to raising young children with HIV infection: A preliminary investigation. *Journal of Clinical Psychology in Medical Settings, 9,* 211-218.

Chaney, J. M., Mullins, L. L., Frank, R. G., Peterson, L., Mace, L. D., Kashani, J. K., & Goldstein, D. L. (1997). Transactional patterns of child, mother, and father adjustment in insulin-dependent diabetes mellitus: A prospective study. *Journal of Pediatric Psychology, 22,* 229-244.

Chang, P., Nesbit, M. E., Youngren, N. (1987). Personality characteristics and psychosocial adjustment of long-term survivors of childhood cancer. *Journal of Psychosocial Oncology, 5,* 43-58.

Chen, E., Craske, M.G., Katz, E.R., Schwartz, E., & Zaeltzer, L.K. (2000). Pain-sensitive

temperament: Does it predict procedural distress and response to psychological treatment among children with cancer? *Journal of Pediatric Psychology, 25*, 269-278.

Colletti, C.J.M, Wolfe-Christensen, C., Carpentier, M.Y., Page, M.C., McNall-Knapp, R.Y., Meyer, W.H., Chaney, J.M., & Mullins, L.L. (2008) The relationship of parental overprotection, perceived vulnerability, and parenting stress to behavioral, emotional, and social adjustment in children with cancer. *Pediatric Blood & Cancer, 51*, 269-274.

Cote, M.R., Mullins, L.L., Hartman, V.L., Hoff, A., Balderson, B.H.K., Chaney, J.M., et al. (2003). Psychosocial correlates of health care utilization for children and adolescents with Type I diabetes. *Children's Health Care, 32*, 1-16.

Curesearch.org. (2008). *Cancer information*. Retrieved November 18, 2008, from: http://www.curesearch.org/for_patients/newlydiagnosed.

Davis, C.L., Delamater, A. M., Shaw, K. H., La Greca, A. M., Eidson, M.S., Perez-Rodriquez, J. E., et al. (2001). Parenting styles, regimen adherence, and glycemic control in 4- to 10-year-old children with diabetes. *Journal of Pediatric Psychology, 26*, 123-129.

Deater-Deckard, K. (2004). *Parenting stress*. New Haven: Yale University Press.

De Los Reyes, A., & Kazdin, A.E. (2004). Measuring informant discrepancies in clinical child research. *Psychological Assessment, 16*, 330-334.

Dolgin, M., Phipps, S., Fairclough, D., Sahler, O.J., Askins, M., Noll, R., et al. (2007). Trajectories of adjustment in mothers of children with newly diagnosed cancer: A natural history investigation. *Journal of Pediatric Psychology, 32*, 771-782.

Drotar, D. (1998). Preface. In D. Drotar (Ed.). *Measuring health-related quality of life in children and adolescents: Implications for research and practice* (pp. 3-24). Mahwah, NJ: Erlbaum.

Eaton, W. W., Mengel, M., Mengel, L., Larson, D., Campbell, R., & Montague, R. B. (1992). Psychosocial and psychopathologic influences on management and control of insulin-dependent diabetes. *International Journal of Psychiatry in Medicine, 22,* 105-117.

Eder, H.G., Leber, K.A., Eustacchio, S., & Pendl, G. (2001). The role of gamma knife radiosurgery in children. *Childs Nervous System, 17,* 341-347.

Eiser, C. (1998). Practitioner review: Long-term consequences of childhood cancer. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 39,* 621-633.

Eiser, C., Greco, V., Vance, Y.H., Horne, B., & Glaser, A. (2004). Perceived discrepancies and their resolution: Quality of life in survivors of childhood cancer. *Psychology and Health, 19,* 15-28.

Eiser, C., & Morse, R. (2001). A review of measures of quality of life for children with chronic illness. *Archives of Disease in Childhood, 84,* 205-211.

Eiser, C., Vance, Y.H., Horne, B., Glaser, A., & Galvin, H. (2003). The value of the PedsQL in assessing quality of life in survivors of childhood cancer. *Child: Care, Health and Development, 29,* 95-102.

Engstrom, C.A., Strohl, R.A., Rose, L., Lewandowski, L., & Stefanek, M.E. (1999). Sleep alterations in cancer patients. *Cancer Nursing, 22,* 143-148.

Feeny, D., Furlong, W., & Barr, R.D. (1998). Multiattribute approach to the assessment of health-related quality of life: Health Utilities Index. *Medical Pediatric Oncology, Suppl. 1*, 54-59.

Fiegelman, S., Duggan, A. K., & Bazell, C. M. (1990). Correlates of emergency room utilization in the first year of life. *Clinical Pediatrics*, *29*, 698-705.

Forsyth, B., Horwitz, S., Leventhal, J., Burger, J., & Leaf, P. (1996). The child vulnerability scale: An instrument to measure parental perceptions of child vulnerability. *Journal of Pediatric Psychology*, *21*, 89-101.

Friedman, D. L., & Meadows, A. T. (2002). Late effects of childhood cancer therapy. *Pediatric Clinics of North America, 49,* 1083-1106.

Fuemmeler, B. F., Elkin, T. D., & Mullins, L. L. (2002). Survivors of childhood brain tumors: Behavioral, emotional, and social adjustment. *Clinical Psychology Review*, *22*, 547-585.

Fuemmeler, B. F., Mullins, L. L., & Marx, B. P. (2001). Posttraumatic stress and general distress among parents of children surviving a brain tumor. *Children's Health Care, 30*, 169-182.

Goldbeck, L. (2001). Parental coping with the diagnosis of childhood cancer: Gender effects, dissimilarity within couples, and quality of life. *Psycho-oncology, 10,* 325-335.

Goodwin, D., Boggs, S., & Graham-Pole, J. (1994). Development and validation of the Pedatric Oncology Quality of Life Scale. *Psychological Assessment, 6,* 321-328.

Green, M., & Solnit, A. J. (1964). Reactions to the threatened loss of a child: A vulnerable child syndrome. *Pediatrics*, *34*, 58-66.

Hockenberry, M.J., Hinds, P.S., Barrera, P., Bryant, R., Adams-McNeill, J., Hooke, C., et al. (2003). Three instruments to assess fatigue in children with cancer: The child, parent and staff perspectives. *Journal of Pain and Symptom Management, 25,* 319-328.

Hocking, M.C., & Lochman, J.E. (2005). Applying the transactional stress and coping model to sickle cell disorder and insulin-dependent diabetes mellitus: Identifying psychosocial variables related to adjustment and intervention. *Clinical Child Family Psychology Review, 8,* 221-246.

Holmbeck, G. N., Johnson, S. Z., Wills, K. E., McKernon, W., Rose, B., Erklin, S., & Kemper, T. (2002). Observed and perceived parental overprotection in relation to psychosocial adjustment in preadolescents with a physical disability: The mediational role of behavioral autonomy. *Journal of Consulting and Clinical Psychology, 70,* 96-110.

Hong, G., & White-Means, S.I. (1993). Do working mothers have healthy children? *Journal of Family and Economic Issues, 14,* 163-186.

Hudson, M. M., Mertens, A. C., Yasui, Y., Hobbie, W., Chen, H., Gurney, J. G., et al. (2003). Health status of adult long-term survivors of childhood cancer: A report from the childhood cancer survivor study. *Journal of the American Medical Association, 290,* 1583-1592.

Hung, J. W., Wu, Y., & Yeh, C. (2004). Comparing stress levels of parents of children with cancer and parents of children with physical disabilities. *Psycho-Oncology, 13,* 898-903.

Jacobs, P., & McDermott, S. (1989). Family caregiver costs of chronically ill and handicapped children: Method and literature review. *Public Health Reports, 104,* 158-163.

Janicke, D.M., Finney, J.W., & Riley, A.W. (2001). Children's health care use: A prospective investigation of factors related to care-seeking. *Medical Care, 39,* 990-1001.

Kaplan, S. L., Busner, J., Weinhold, C., Lenon, P. (1986). Depressive symptoms in children and adolescents with cancer: A longitudinal study. *Journal of the American Academy of Child and Adolescent Psychiatry, 26,* 782-787.

Kazak, A. E. (1994). Implications of survival: Pediatric oncology patients and their families. In D. J. Bearison & R. K. Mulhern (Eds.) *Pediatric psycho-oncology: Psychological perspectives on children with cancer.* (pp. 171 – 192). New York, NY: Oxford University Press.

Kazak, A. E. (2005). Evidence-based interventions for survivors of childhood cancer and their families. *Journal of Pediatric Psychology, 30,* 29-39.

Kazak, A. E., & Barakat, L. P. (1997). Brief report: Parenting stress and quality of life during treatment for childhood leukemia predicts child and parent adjustment after treatment ends. *Journal of Pediatric Psychology, 22,* 749-758.

Kazak, A. E., Barakat, L. P., Meeske, K. (1997). Posttraumatic stress, family functioning, and social support in survivors of childhood leukemia and their mothers and fathers. *Journal of Consulting and Clinical Psychology, 65,* 120-129.

Kazak, A. E., & Nachman, G. S. (1991). Family research on childhood chronic illness: Pediatric oncology as an example. *Journal of Family Psychology, 4,* 462-483.

Kirsch, D.G., & Tarbell, N.J. (2004). Conformal radiation therapy for childhood CNS tumors. *The Oncologist, 9*, 442-450.

Koocher, G. P., & O'Malley, J. E. (1981). *The Damocles Syndrome: Psychological consequences of surviving childhood cancer*. New York, NY: McGraw-Hill.

Koocher, G. P., O'Malley, J. E., Gogan, J., & Foster, D. (1980). Psychological adjustment among pediatric cancer survivors. *Journal of Child Psychology and Psychiatry, 21*, 163-173.

Kullgren, K., Morris, R. D., Morris, M. K., & Krawiecki, N. (2003). Risk factors associated with long-term social and behavioral problems among children with brain tumors. *Journal of Psychosocial Oncology, 21*, 73-87.

Kupst, M. J., Natta, M. B., & Richardson, C. C. (1995). Family coping with pediatric leukemia: Ten years after treatment. *Journal of Pediatric Psychology, 20,* 601-617.

Kupst, M.J., & Schulman, J.L. (1988). Long-term coping with pediatric leukemia: A six-year follow-up study. *Journal of Pediatric Psychology, 13*, 7-23.

Landgraf, J.M., & Abetz, L. (1998). Influences of sociodemographic characteristics on parental reports of children's physical and psychological well-being: Early experiences with the Child Health Questionnaire. In D. Drotar (Ed.). *Measuring health-related quality of life in children and adolescents: Implications for research and practice* (pp. 105-126). Mahwah, NJ: Erlbaum.

Landgraf, J.M., Abetz, L., & Ware, J.E. (1996). *The Child Health Questionnaire (CHQ): A user's manual*. Boston: Health Institute.

Langeveld, N.E., Stam, H., Grootenhuis, M.A., & Last, B.F. (2002). Quality of life in young adult survivors of childhood cancer. *Support Care Cancer, 10*, 579-600.

Lansky, S.B., List, M.A., Lansky, L.L., Ritter-Sterr, C., & Miller, D. (1987). The measurement of performance in childhood cancer patients. *Cancer, 60,* 1651-1656.

Lavigne, J. V., & Faier-Routman, J. (1992). Psychological adjustment to pediatric physical disorders: A meta-analytic review. *Journal of Pediatric Psychology, 17,* 133-157.

Levi, R. B. (2006). Quality of life in childhood cancer: Meaning, methods, and missing pieces. In Brown, R.T. (Ed.), *Comprehensive handbook of childhood cancer and sickle cell disease: A biospsychosocial approach* (pp. 170-188). New York: Oxford University Press.

Levi, R.B., & Drotar, D. (1998). Critical issues and needs in health-related quality of life assessment of children and adolescents with chronic health conditions. In D. Drotar (Ed.). *Measuring health-related quality of life in children and adolescents: Implications for research and practice* (pp. 3-24). Mahwah, NJ: Erlbaum.

Levi, R.B., & Drotar, D. (1999). Health-related quality of life in childhood cancer: Discrepancy in parent-child reports. *International Journal of Cancer, Suppl. 12,* 58-64.

Levy, D. (1931). Maternal overprotection and rejection. *Archives of Neurology and Psychiatry, 25,* 886-889.

Li, C., & Wendt, R.N. (1998). Cancer (childhood). In L.A. Phelps (Ed.), *Health-related disorders in children and adolescents: A guidebook for understanding and educating* (pp. 114-120). Washington, DC: American Psychological Association.

Livneh, H., & Antonak, R. F. (1997). *Psychosocial adaptation to chronic illness and disability.* Gaithersberg, MD: Aspen Publishers, Inc.

Mackie, E., Hill, J., Kondryn, H., & McNally, R. (2000). Adult psychosocial outcomes in long-term survivors of acute lymphoblastic leukemia and Wilms' tumour: A controlled study. *Lancet. 355,* 1310-1314.

Madan-Swain, A., Brown, R. T., Sexson, S. B., & Baldwin, K. (1994). Adolescent cancer survivors: Psychosocial and familial adaptation. *Psychosomatics: Journal of Consultation Liaison Psychiatry, 35,* 453-459.

Marsland, A.L., Ewing, L.J., & Thompson, A. (2006). Psychological and social effects of surviving childhood cancer. In R.T. Brown (Ed.), *Comprehensive handbook of childhood cancer and sickle cell disease: A biopsychosocial approach* (pp. 237-261).

Mattson, A. (1972). Long-term physical illness in childhood: A challenge to psychosocial adaptation. *Pediatrics, 50,* 801-811.

Meeske, K., Katz, E.R., Palmer, S.N., Burwinkle, T., & Varni, J.W. (2004). Parent proxy-reported health-related quality of life and fatigue in pediatric patients diagnosed with brain tumors and acute lymphoblastic leukemia. *Cancer, 101,* 2116-2125.

Montgomery, V., Oliver, R., Reisner, A., & Fallat, M. (2002). The effect of severe traumatic brain injury on the family. *The Journal of Trauma Injury, Infection, and Critical Care, 52,* 1121-1124.

Mulhern, R. K. (1994). Neuropsychological late effects. In D. Bearison & R.K. Mulhern (Eds.), *Pediatric psychooncology* (pp. 99-121). New York: Oxford University Press.

Mullins, L. L., Chaney, J. M., Hartman, V. L., Olson, R. A., Youll, L. K., Reyes, S., & Blackett, P. (1995). Child and maternal adaptation to cystic fibrosis and insulin-

dependent diabetes mellitus: Differential patterns across disease states. *Journal of Pediatric Psychology, 20,* 173-186.

Mullins, L. L., Fuemmeler, B. F., Hoff, A., Chaney, J. M., Van Pelt, J., & Ewing, C. A. (2004). The relationship of parental overprotection and perceived child vulnerability to depressive symptomatology in children with type 1 diabetes mellitus: The moderating influence of parenting stress. *Children's Health Care, 33,* 21-34.

Mullins, L.L., Wolfe-Christensen, C., Pai, A.L., Carpentier, M.Y., Gillaspy, S., Cheek, J., et al. (2007). The relationship of parental overprotection, perceived child vulnerability, and parenting stress to uncertainty in youth with chronic illness. *Journal of Pediatric Psychology, 32,* 973-982.

Nathan, P.C., Furlong, W., & Barr, R.D. (2004). Challenges to the measurement of health-related quality of life in children receiving cancer therapy. *Pediatric Blood Cancer, 43,* 215-223.

Noll, R. B., Bukowski, W. M., Davies, W. H., Koontz, K., & Kulkarni, R. (1993). Adjustment in the peer system of adolescents with cancer: A two-year study. *Journal of Pediatric Psychology, 18,* 351-364.

Noll, R.B., Bukowski, W.M., Rogosch, F.A., LeRoy, S., & Kulkarni, R. (1990). Social interactions between children with cancer and their peers: Teacher ratings. *Journal of Pediatric Psychology, 15,* 43-56.

Noll, R.B., Gartstein, M.A., Vannatta, K., Correll, J., Bukowski, W.M., & Davies, W.H. (1999). Social, emotional, and behavioural functioning of children with cancer. *Pediatrics, 103,* 71-78.

Noll, R. B., McKellop, J. M., & Vannatta, K. (1998). Child-rearing practices of primary caregivers of children with sickle cell disease: The perspective of professionals and caregivers. *Journal of Pediatric Psychology, 23,* 131-140.

Oeffinger, K.C., Mertens, A.C., Sklar, C.A., Kawashima, T., Hudson, M.M., Meadows, A.T., et al. (2006). Chronic health conditions in adult survivors of childhood cancer. *New England Journal of Medicine, 355,* 1572-1582.

Pai, A.L.H., Drotar, D., Zebracki, K., Moore, M., & Youngstrom, E. (2006). A meta-analysis of the effects of psychological interventions in pediatric oncology on outcomes of psychological distress and adjustment. *Journal of Pediatric Psychology, 31,* 978-988.

Pai, A.L.H., Greenley, R.N., Lewankdowski, A., Drotar, D., Youngstrom, E., Peterson, C.C. (2007). A meta-analytic review of the influence of pediatric cancer on parent and family functioning. *Journal of Family Psychology, 21,* 407-415.

Parker, G. (1981). Parental representations of patients with anxiety neurosis. *Acta Psychiatrica Scandinavica, 63,* 33-36.

Parker, G. (1983). *Parental overprotection: A risk factor in psychosocial development*. New York, NY: Grune & Stratton, Inc.

Parker, G., & Lipscombe, P. (1979). Parental overprotection and asthma. *Journal of Psychosomatic Research, 23,* 295-299.

Parker, G., Tupling, H., & Brown, L.B.A. (1979). Parental Bonding Instrument. *British Journal of Medical Psychology, 52,* 1-10.

Parsons, S.K., Barlow, S.E., Levy, S.L., Supran, S.E., & Kaplan, S.H. (1999). Health related quality of life in pediatric bone marrow transplant survivors: According to whom? *International Journal of Cancer, Suppl. 12*, 46-51.

Patenaude, A. F., & Kupst, M. J. (2005). Psychosocial functioning in pediatric cancer. *Journal of Pediatric Psychology, 30*, 9-28.

Phipps, S., Dunavant, M., Garvie, P.A., Lensing, S., & Rai, S.N. (2002). Acute health-related quality of life in children undergoing stem cell transplant: I. Descriptive outcomes. *Bone Marrow Transplant, 29*, 425-434.

Powers, T. G., Dahlquist, L. M., Thompson, S. M., & Warren, R. (2003). Interactions between children with juvenile rheumatoid arthritis and their mothers. *Journal of Pediatric Psychology, 28*, 213-221.

Radcliffe, J., Bennett, D., Kazak, A. E., Foley, B., & Phillips, P.C. (1996). Adjustment in childhood brain tumor survival: Child, mother, and teacher report. *Journal of Pediatric Psychology, 21*, 529-539.

Richters, J.E. (1992). Depressed mothers as informants about their children: A critical review of the evidence for distortion. *Psychological Bulletin, 112*, 485-499.

Ries, L. A. G., Percy, C. L., & Bunin, G. R. (1999). Introduction. In L. A. G. Ries, M. A. Smith, J. C. Gurney, M. Linet, T. Tamra, J. L. Young, & G. R. Bunin (Eds.), *Cancer incidence and survival among children and adolescents: United States SEER Program 1975-1995* (pp. 1-15). Bethesda, MD: National Cancer Institute.

Robison, L.L., Mertens, A.C., Boice, J.D., Breslow, N.E., Donaldson, S.S., Green, D.M. et al. (2002). Study design and cohort characteristics of the childhood cancer

survivor study: A multi-institutional collaborative project. *Medical & Pediatric Oncology, 38,* 229-239.

Robinson, K.E., Gerhardt, C.A., Vannatta, K., & Noll, R. (2007). Parent and family factors associated with child adjustment to pediatric cancer. *Journal of Pediatric Psychology, 32,* 400-410.

Roddenberry, A., & Renk, K. (2008). Quality of life in pediatric cancer patients: The relationships among parents' characteristics, children's characteristics, and informant concordance. *Journal of Child and Family Studies, 17,* 402-426.

Russell, K.M.W., Hudson, M., Long, A., & Phipps, S. (2006). Assessment of health-related quality of life in children with cancer: Consistency and agreement between parent and child reports. *Cancer, 106,* 2267-2274.

Sameroff, A. J., & Emde, R. N. (1992). *Relationship disturbances in early childhood: A developmental approach.* New York, NY: Basic Books, Inc.

Sawyer, M. G., Antoniou, G., Nguyen, A. M., Toogood, I., Rice, M., & Baghurst, P. (1995). A prospective study of the psychological adjustment of children with cancer. *Journal of Pediatric Hematology and Oncology, 17,* 39-45.

Sawyer, M., Antoniou, G., Toogood, I., & Rice, M. (1997). Childhood cancer: A two-year prospective study of the psychological adjustment of children and parents. *Journal of the American Academy of Child & Adolescent Psychiatry, 36,* 1736-1743.

Sawyer, M., Antoniou, G., Toogood, I., Rice, M., & Baghurst, P. (2000). Childhood cancer: A 4-year prospective study of the psychological adjustment of children and parents. *Journal of Pediatric Hematology and Oncology, 22,* 214-220.

Sawyer, M., Streiner, D. L., Antoniou, G., Toogood, I., & Rice, M. (1998). Influence of parental and family adjustment on the later psychological adjustment of children treated for cancer. *Journal of the American Academy of Child and Adolescent Psychiatry, 37*, 815-822.

Sawyer, M., Antoniou, G., Toogood, I., & Rice, M. (1999). A comparison of parent and adolescent reports describing the health-related quality of life of adolescents treated for cancer. *International Journal of Cancer, Suppl. 12*, 39-45.

Simms, S., Kazak, A. E., Golomb, V., Goldwein, J., & Bunin, N. (2002). Cognitive, behavioral, and social outcomes in survivors of childhood stem cell transplantation. *Journal of Pediatric Hematology & Oncology, 24,* 115-119.

Spieth, L.E., & Harris, C.V. (1996). Assessment of health-related quality of life in children and adolescents: An integrative review. *Journal of Pediatric Psychology, 21*, 175-193.

Spirito, A., Stark, L. J., Cobiella, C., Drigan, R., Androkites, A., & Hewett, K. (1990). Social adjustment of children successfully treated for cancer. *Journal of Pediatric Psychology, 15*, 359-371.

Spock, A., & Stedman, D. J. (1966). Psychological characteristics of children with cystic fibrosis. *Medical Journal, 27*, 426-428.

Sprangers, M.A. (2002). Quality of life assessment in oncology. Achievements and challenges. *Acta Oncologica, 41*, 229-237.

Spurrier, N. J., Sawyer, M. G., Staugas, R., Martin, A. J., Kennedy, D., & Streiner, D. L. (2000). Association between parental perception of children's vulnerability to illness and management of children's asthma. *Pediatric Pulmonology, 29*, 88-93.

Steliarova-Foucher, E., Stiller, C., Lacour, B., & Kaatsch, P. (2005). International Classification of Childhood Cancer. *Cancer, 103,* 1457-1467.

Streisand, R., Braniecki, S., Tercyak, K.P., & Kazak, A.E. (2001). Childhood illness-related parenting stress: The pediatric inventory for parents. *Journal of Pediatric Psychology, 26,* 155-162.

Taieb, O., Moro, M.R., Baubet, T., Revan-Lévy, A., & Flament, M.F. (2003). Posttraumatic stress symptoms after childhood cancer. *European Child and Adolescent Psychiatry, 12,* 255-264.

Thomas, A., & Sawhill, I. (2005). For love and money? The impact of family structure on family income. *The Future of Children, 15,* 57-74.

Thomasgard, M. (1998). Parental perceptions of child vulnerability, overprotection, and parental psychological characteristics. *Child Psychiatry and Human Development, 28,* 223-240.

Thomasgard, M., & Metz, W. (1993). Parental overprotection revisited. *Child Psychiatry and Human Development, 24,* 67-79.

Thomasgard, M., & Metz, W.P. (1995). The vulnerable child syndrome revisited. *Journal of Developmental and Behavioral Pediatrics, 16,* 47-53.

Thomasgard, M., & Metz, W.P. (1996). The 2-year stability of parental perceptions of child vulnerability and parental overprotection. *Journal of Developmental & Behavioral Pediatrics, 17,* 222-228.

Thomasgard, M. & Metz, W.P. (1997). Parental overprotection and its relation to perceived child vulnerability. *American Journal of Orthopsychiatry, 67,* 330-335.

Thomasgard, M., & Metz, W.P. (1999). Parent-child relationship disorders: What do the child vulnerability scale and the parent protection scale measure? *Clinical Pediatrics, 38,* 347-356.

Thomasgard, M., Metz, W.P, Edelbrock, C., & Shonkoff, J.P. (1995a). Parent-child relationship disorders. Part I. Parental overprotection and the development of the Parent Protection Scale. *Journal of Developmental and Behavioral Pediatrics, 16,* 244-250.

Thomasgard, M., Shonkoff, J.P., Metz, W.P., & Edelbrock, C. (1995b). Parent-child relationship disorders. Part II. The vulnerable child syndrome and its relation to parental overprotection. *Journal of Developmental and Behavioral Pediatrics, 16,* 251-256.

Thompson, R. J., Gil, K. M., Burback, D. J., Keith, B. R., & Kinney, T. R. (1993a). The role of child and maternal processes in the psychological adjustment of children with sickle cell disease. *Journal of Consulting and Clinical Psychology, 61,* 468-474.

Thompson, R. J., Gil, K., Burbach, D., Keith, B., & Kinney, T. (1993b). Psychological adjustment of mothers of children and adolescents with sickle cell disease: The role of stress, coping methods, and family functioning. *Journal of Pediatric Psychology, 18,* 549-559.

Thompson, R. J., & Gustafson, K. E. (1996). *Adaptation to chronic childhood illness.* Washington, DC: American Psychological Association.

Thompson, R. J., Gustafson, K. E., & Bonner, M. J. (2002). Neurocognitive development of young children with sickle cell disease through three years of age. *Journal of*

Pediatric Psychology, 27, 235-244.

Thompson, R. J., Gustafson, K. E., George, L.K., & Spock, A. (1994). Change over a 12-month period in the psychological adjustment of children and adolescents with cystic fibrosis. *Journal of Pediatric Psychology, 19,* 189-203.

Thompson, R. J., Gustafson, K. E., Hamlett, K. W., & Spock, A. (1992). Psychological adjustment of children with cystic fibrosis: The role of child cognitive processes and maternal adjustment. *Journal of Pediatric Psychology, 17,* 741-755.

Trask, P.C., Paterson, A.G., Trask, C.L., Bares, C.B., Birt, J., & Maan, C. (2003). Parent and adolescent adjustment to pediatric cancer: Associations with coping, social support, and family function. *Journal of Pediatric Oncology Nursing, 20,* 36-47.

Tropauer, A., Franz, M. N., & Dilgard, V. W. (1970). Psychological aspects of the care of children with cystic fibrosis. *American Journal of Diseases of Children, 119,* 424-432.

U.S. Census Bureau. (2008). *Income, poverty, and health insurance coverage in the United States: 2007*. Retrieved on November 18, 2008, from: http://www.census.gov/prod/2008pubs/p60-235.pdf

Vance, Y.H., Morse, R.C., Jenney, M.E., & Eiser, C. (2001). Issues in measuring quality of life in childhood cancer: Measures, proxies, and parental mental health. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 42,* 661-667.

Vannatta, K., Garstein, M. A., Short, A., & Noll, R. B. (1998). A controlled study of peer relationships of children surviving brain tumors: Teacher, peer, and self ratings. *Journal of Pediatric Psychology, 23,* 279-287.

Vannatta, K., & Gerhardt, C. A. (2003). Pediatric oncology: Psychosocial outcomes for children and families. In M. C. Roberts (Ed.) *Handbook of pediatric psychology (3rd Ed.).* (pp. 342-357). New York: Guilford Press.

Varni, J.W., Burwinkle, T.M., Katz, E.R., Meeske, K., & Dickinson, P. (2002). The PedsQL in pediatric cancer: Reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales, Multidimensional Fatigue Scale, and Cancer Module. *Cancer, 94*, 2090-2106.

Varni, J.W., Limbers, C., & Burwinkle, T.M. (2007). Literature review: Health-related quality of life measurement in pediatric oncology: Hearing the voices of the children. *Journal of Pediatric Psychology, 32,* 1151-1163.

Varni, J.W., & Setoguchi, Y. (1992). Screening for behavioral and emotional problems in children and adolescents with congenital or acquired limb deficiencies. *American Journal of Diseases of Children, 146,* 103-107.

Vrijmoet-Wiersma, C.M., Kolk, A.M., Grootenhuis, M.A., Spek, E.M., van Klink, J.M., Egeler, R.M., et al. (2009). Child and parental adaptation to pediatric stem cell transplantation. *Supportive Care in Cancer, 17,* 707-714.

Wallander, J.L., Schmitt, M., & Koot, H.M. (2001). Quality of life measurement in children and adolescents: Issues, instruments, and applications. *Journal of Clinical Psychology, 57,* 571-585.

Wallander, J.L., Varni, J.W., Babani, L., DeHaan, C.B., Wilcox, K.T., & Banis, H.T. (1989). The social environment and the adaptation of mothers of physically handicapped children. *Journal of Pediatric Psychology, 14,* 371-387.

Wallander, J.L., Varni, J.W., Babani, L., Banis, H.T., & Wilcox, K.T. (1989). Family resources as resistance factors for psychological maladjustment in chronically ill and handicapped children. *Journal of Pediatric Psychology, 14,* 157-173.

Winthrop, A.L., Brasel, K.J., Stahovic, L., Paulson, J., Schneeberger, B., & Kuhn, E.M. (2005). Quality of life and functional outcome after pediatric trauma. *Journal of Trauma, 58,* 468-473.

World Health Organization: Division of Mental Health. (1993). *WHO-QOL Study protocol: The development of the World Health Organization quality of life assessment instrument*. Geneva, Switzerland: Author.

Wysocki, T., Huxtable, K., Linscheid, T.R., & Wayne, W. (1989). Adjustment to diabetes mellitus in preschoolers and their mothers. *Diabetes Care, 12,* 524-529.

Zebrack, B. J., Zeltzer, L. K., Whitton, J., Mertens, A. C., Odom, L., Berkow, R., et al. (2002). Psychological outcomes in long-term survivors of childhood leukemia, Hodgkin's disease, and Non-Hodgkin's lymphoma: A report from the childhood cancer survivor study. *Pediatrics, 110,* 42-52.

Zebrack, B.J., Gurney, J.G., Oeffinger, K., Whitton, J., Packer, R.J., Mertens, A., et al., (2004). Psychological outcomes in long-term survivors of childhood brain cancer: A report from the childhood cancer survivor study. *Journal of Clinical Oncology, 22,* 999-1006.

APPENDICES

Appendix A

INTERNATIONAL CLASSIFICATION OF CHILDHOOD CANCER, THIRD EDITION

International Classification of Childhood Cancer, Third Edition

I. Leukemias, myeloproliferative diseases, and myelodysplastic diseases
   a. Lymphoid leukemias
   b. Acute myeloid leukemias
   c. Chronic myeloproliferative dieases
   d. Myelodysplastic syndrome and other myeloproliferative diseases
   e. Unspecified and other specified leukemias

II. Lymphomas and reticuloendothelial neoplasms
   a. Hodgkin lymphomas
   b. Non-Hodgkin lymphomas (except Burkitt lymphoma)
   c. Burkitt lymphoma
   d. Miscellaneous lymphoreticular neoplasms
   e. Unspecified lymphomas

III. CNS and miscellaneous intracranial and intraspinal neoplasms
   a. Ependymomas and choroids plexus tumor
   b. Astrocytomas
   c. Intracranial and intraspinal embryonal tumors
   d. Other gliomas
   e. Other specified intracranial and intraspinal neoplasms
   f. Unspecified intracranial and intraspinal neoplasms

IV. Neuroblastoma and other peripheral nervous cell tumors
   a. Neuroblastoma and ganglioneuroblastoma
   b. Other peripheral nervous cell tumors

V. Retinoblastoma

VI. Renal tumors
   a. Nephroblastoma and other nonepithelial renal tumors
   b. Renal carcinomas
   c. Unspecified malignant renal tumors

VII. Hepatic tumors
   a. Hepatoblastoma
   b. Hepatic carcinomas
   c. Unspecified malignant hepatic tumors

VIII. Malignant bone tumors
   a. Osteosarcomas
   b. Chondrosarcomas
   c. Ewing tumor and related sarcomas of bone
   d. Other specified malignant bone tumors

e. Unspecified malignant bone tumors

IX. Soft tissue and other extraosseous sarcomas
   a. Rhabdomyosarcomas
   b. Fibrosarcomas, peripheral nerve sheath tumors, and other fibrous neoplasms
   c. Kaposi sarcoma
   d. Other specified soft tissue sarcomas
   e. Unspecified soft tissue sarcomas

X. Germ cell tumors, trophoblastic tumors, and neoplasms of gonads
   a. Intracranial and intraspinal germ cell tumors
   b. Malignant extracranial and extragonadal germ cell tumors
   c. Malignant gonadal germ cell tumors
   d. Gonadal carcinomas
   e. Other and unspecified malignant gonadal tumors

XI. Other malignant epithelial neoplasms and malignant melanomas
   a. Adrenocortical carcinomas
   b. Thyroid carcinomas
   c. Nasopharyngeal carcinomas
   d. Malignant melanomas
   e. Skin carcinomas
   f. Other and unspecified carcinomas

XII. Other and unspecified malignant neoplasms
   a. Other specified malignant tumors
   b. Other unspecified malignant tumors

CNS; central nervous system.

Appendix B

MEASURES

Demographic Form

Medical Chart Review

Parent Protection Scale/Child Vulnerability Scale

DEMOGRAPHIC INFORMATION

Subject Number: _____

Today's Date: _____

Child's Name: _____ Child's Gender: _____
Mother's Name: _____
Father's Name: _____

Name of person filling out this form and relationship to child (e.g., mother):
_____

Who currently lives in the household with you and your child? Please note their relationship to the child and age (e.g., brother- 15 months, stepparent-36 years old).

Name	Relation to child	Age
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

What is your age? _____ What was *your age* when your child was diagnosed? _____

What is your spouse's age? _____ What was *your spouse's age* when your child was diagnosed? _____

What is your child's age? _____ What was *your child's age* when he/she was diagnosed? _____

What grade is your child in? _____

What is your race?

Caucasian	African American	Hispanic	Native American	Asian	Other
1	2	3	4	5	6

Parent's Marital Status:

Married	Single Parent	Remarried	Never Married	Other
1	2	3	4	5

Parent's Highest Level of Education: Mother _____ Father _____

Parents' Occupations: Mother _____ Father _____

Please indicate your annual total family income: *(This information will be held strictly confidential).*

_____ 0-4,999 _____ 30,000-39,999
_____ 5,000-9,999 _____ 40,000-49,999

_____ 10,000-14,999
_____ 15,000-19,999
_____ 20,000-29,999
_____ 50,000-59,999
_____ 60,000 or greater

FORM FOR MEDICAL CHART REVIEW

Subject Number: _____

Child's Diagnosis: _____

Date of Diagnosis: _____

Current Date: _____

Date off Treatment: _____

Medical Interventions Received:
(Please check whether received and indicate number of times received)

Procedure	**Received (check to indicate)**	**Approx. Number of Times**
Surgery		
Biopsy		
Shunts		
Radiation		
Chemotherapy		
Bone Marrow Transplant		
Spinal Tap		
Bone Marrow Aspiration		
Other (describe)		
Other (describe)		
Other (describe)		

Complications Secondary to Diagnosis and/or Treatment:
_____
_____

PPS/CVS
Thomasgard, Shonkoff, Metz, & Edelbrock

Please read each statement carefully and determine the extent to which the statement is descriptive of you behavior with your child.

Never (0) Sometimes (1) Most of the time (2) Always (3)

1. I blame myself when my child gets hurt	0 1 2 3
2. I comfort my child immediately when he/she cries	0 1 2 3
3. I encourage my child to depend on me	0 1 2 3
4. I have difficulty separating from my child	0 1 2 3
5. I trust my child on his/her own	0 1 2 3
6. I let my child make his/her own decisions	0 1 2 3
7. I have difficulty leaving my child with a babysitter	0 1 2 3
8. I decide when my child eats	0 1 2 3
9. I use baby words when I talk to my child	0 1 2 3
10. I urge my child to try new things	0 1 2 3
11. I determine who my child will play with	0 1 2 3
12. I keep a close watch on my child	0 1 2 3
13. I feed my child even if he/she can do it alone	0 1 2 3
14. I feel comfortable leaving my child with other people	0 1 2 3
15. I protect my child from criticism	0 1 2 3
16. I let my child choose what he/she wears	0 1 2 3
17. I make my child go to sleep at a set time	0 1 2 3

Never (0) Sometimes (1) Most of the time (2) Always (3)

18. I go to my child if he/she cries during the night	0 1 2 3
19. I encourage my child to play with other children	0 1 2 3
20. I give my child attention when he/she clings to me	0 1 2 3
21. I decide what my child eats	0 1 2 3
22. I dress my child even if he/she can do it alone	0 1 2 3
23. I decide when my child goes to the bathroom	0 1 2 3
24. I know exactly what my child is doing	0 1 2 3
25. I allow my child to do things on his/her own	0 1 2 3

---

1. I general my child seems less healthy than other children	0 1 2 3
2. I often think about calling the doctor about my child	0 1 2 3
3. When there is something going around, my child usually catches it	0 1 2 3
4. I sometimes get concerned that my child doesn't look as healthy as s/he should	0 1 2 3
5. I often have to keep my child indoors because of health reasons	0 1 2 3
6. My child gets more colds than other children I know	0 1 2 3
7. I get concerned about circles under my child's eyes	0 1 2 3
8. I often check on my child at night to make sure s/he is okay	0 1 2 3

Appendix C

TABLES AND FIGURES

Table 1. Descriptive Statistics for Study Variables

	Possible Range	Observed Range	*M* (*SD*)
Parental Overprotection	0-75	17-49	32.4 (6.52)
Perceived Child Vulnerability	0-24	0-18	7.06 (3.63)
Parenting Stress	36-180	38-124	71.14 (18.51)
Health-Related Quality of Life	0 – 100	23.08-99.04	67.77 (17.12)

Table 2. Zero-Order Correlations for Demographic Variables and Health-Related Quality of Life

	1	2	3	4	5	6
1. Child Sex		.28**	.18	.06	-.03	-.06
2. Child Age			.50**	.06	.02	-.13
3. Parent Age				.16	.16	-.02
4. Parent Education					.48**	.14
5. Annual Family Income						.21
6. Health-Related Quality of Life						

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

Table 3. Zero-Order Correlations for Illness Characteristics and Health-Related Quality of Life

	1	2	3	4
1. Duration of Illness		.26*	-.21	.03
2. CNS Involvement			-.04	.04
3.Child Age at Diagnosis				-.14
4. Health-Related Quality of Life				

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

Table 4. Zero-Order Correlations for Variables of Interest

	1	2	3	4	5
1. Annual Family Income		.55***	-.36**	-.38***	-.20
2. Single Parent Status			-.25*	-.25*	-.06
3.Parent Protection Scale				.45***	.27*
4. Child Vulnerability Scale					.40***
5. Parenting Stress Index					

** $p < .05$. ** $p < .01$. *** $p < .001$.*

Table 5. Hierarchical Regression for Socioeconomic Status on Health-Related Quality of Life

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Child Age	-.132	-1.159	.020	.020	.834
	Child Gender	-.024	-.212			
2	Child Age	-.138	-1.230	.044	.064	3.828*
	Child Gender	-.017	-.151			
	Annual Family Income	.210	1.957*			

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

Table 6. Hierarchical Regression for Parental Overprotection on Health-Related Quality of Life

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Child Age	-.138	-1.230	.064	.064	1.851
	Child Gender	-.017	-.151			
	Annual Family Income	.210	1.957*			
2	Child Age	-.208	-1.848	.064	.128	5.896*
	Child Gender	-.019	-.175			
	Annual Family Income	.109	.968			
	Parent Protection Scale	-.283	-2.428*			

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

Table 7. Hierarchical Regression for Perceived Child Vulnerability on Health-Related Quality of Life

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Child Age	-.132	-1.164	.063	.063	1.763
	Child Gender	-.038	-.339			
	Annual Family Income	.204	1.874			
2	Child Age	-.151	-1.438	.146	.208	14.350***
	Child Gender	-.038	-.359			
	Annual Family Income	.048	.442			
	Child Vulnerability Scale	-.413	-3.788***			

** p < .05. ** p < .01. *** p < .001.*

Table 8. Hierarchical Regression for Parenting Stress on Health-Related Quality of Life

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Child Age	-.149	-1.310	.062	.062	1.757
	Child Gender	-.007	-.062			
	Annual Family Income	.197	1.818			
2	Child Age	-.197	-1.820	.110	.172	10.503**
	Child Gender	-.055	-.510			
	Annual Family Income	.126	1.201			
	Parenting Stress Index	-.348	-3.241**			

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

Table 9. Hierarchical Regression for Parenting Capacity Variables on Health-Related Quality of Life

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Child Age	-.143	-1.246	.060	.060	1.659
	Child Gender	-.028	-.246			
	Annual Family Income	.190	1.735			
2	Child Age	-.225	-2.059*	.200	.260	6.765***
	Child Gender	-.057	-.546			
	Annual Family Income	-.010	-.086			
	Parent Protection Scale	-.152	-1.263			
	Child Vulnerability Scale	-.271	-2.227*			
	Parenting Stress Index	-.226	-2.035*			

** p < .05. ** p < .01. *** p < .001.*

Table 10. Descriptive Statistics for Study Variables for Mothers-Only Sample

	Possible Range	Observed Range	*M* (*SD*)
Parental Overprotection	0-75	17-49	32.4 (6.63)
Perceived Child Vulnerability	0-24	0-18	7.04 (3.71)
Parenting Stress	36-180	38-124	70.77 (19.15)
Health-Related Quality of Life	0 – 100	23.08-99.04	68.36 (16.77)

Table 11. Zero-Order Correlations for Demographic Variables and Health-Related Quality of Life for Mothers-Only Sample

	1	2	3	4	5	6
1. Child Sex		.28*	.19	-.001	-.08	-.07
2. Child Age			.52**	.07	-.04	-.16
3. Mother's Age				.24*	.18	.03
4. Mother's Education					.50**	.12
5. Annual Family Income						.27*
6. Health-Related Quality of Life						

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

Table 12. Zero-Order Correlations for Illness Characteristics and Health-Related Quality of Life for Mothers-Only Sample

	1	2	3	4
1. Duration of Illness		.29*	-.17	.09
2. CNS Involvement			-.04	.04
3.Child Age at Diagnosis				-.20
4. Health-Related Quality of Life				

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

Table 13. Zero-Order Correlations for Variables of Interest for Mothers-Only Sample

	1	2	3	4	5
1. Annual Family Income		.54***	-.36**	-.33**	-.21
2. Single Parent Status			-.29*	-.20	-.01
3.Parent Protection Scale				.46***	.25*
4. Child Vulnerability Scale					.38**
5. Parenting Stress Index					

** p < .05. ** p < .01. *** p < .001.*

VITA

Stephanie E. Hullmann

Candidate for the Degree of

Master of Science

Thesis: THE ROLE OF PARENTING VARIABLES AND HEALTH-RELATED QUALITY OF LIFE IN PEDIATRIC CANCER

Major Field: Psychology

Biographical:

Personal Data: Born in Reading, Pennsylvania in 1983; Parents: Dennis B. Hullmann, P.E., and Karen M. Kochan, M.A.

Education: Graduated from Owen J. Roberts High School, Pottstown, Pennsylvania in 2002; Received Bachelor of Arts degree in Psychology and Biology from Bucknell University, Lewisburg, Pennsylvania in May 2006; Completed the requirements for the Master of Science degree with a major in Psychology at Oklahoma State University in July 2009.

Experience: Graduate Research Assistant to Larry L. Mullins, Ph.D., Pediatric Health Psychology Lab, Department of Psychology, Oklahoma State University, August 2008-present; Clinical practicum experience through the Oklahoma State University Psychological Services Center (PSC), August 2008-present; Instructor of laboratory component of Experimental Methods in Psychology, August 2008-May 2009.

Professional Memberships: American Psychological Association, Student Affiliate, Division 54 (Pediatric Psychology)

Name: Stephanie E. Hullmann Date of Degree: July, 2009

Institution: Oklahoma State University Location: Stillwater, Oklahoma

Title of Study: THE ROLE OF PARENTING VARIABLES AND HEALTH-RELATED QUALITY OF LIFE IN PEDIATRIC CANCER

Pages in Study: 121 Candidate for the Degree of Master of Science

Major Field: Psychology

Scope and Method of Study: The purpose of the current study was to assess the relationship between parenting capacity variables, namely parental overprotection, perceived child vulnerability, and parenting stress, and socioecological factors, including family socioeconomic status and parental marital status, and parent-proxy report of child health-related quality of life. Participants were 89 parents of children, ages two to 16 (M = 6.5 years, 57% male, 80.9% Caucasian), who were diagnosed with pediatric cancer. Parent participants completed a demographic form, the parent-proxy report of the Pediatric Quality of Life Inventory 3.0 Cancer Module (PedsQL), Parent Protection Scale (PPS), Child Vulnerability Scale (CVS), and Parenting Stress Index/Short Form (PSI/SF). A medical chart review was also conducted. Participants were recruited while attending outpatient appointments at the cancer center of a midwestern children's hospital.

Findings and Conclusions: After controlling for theoretically important demographic factors, results revealed that parent-proxy report of health-related quality of life was negatively related to family socioeconomic status, parental overprotection, perceived child vulnerability, and parenting stress. No significant relationship was found between parent marital status and health-related quality of life. However, older child age also emerged as a significant predictor of poor child health-related quality of life. Overall, these results support the transactional relationship between parent and child adjustment to pediatric cancer. The evident contributions of socioeconomic status, parental overprotection, perceptions of vulnerability, and parenting stress to child disease-specific health-related quality of life may warrant assessment of these variables in parents of children who have been recently diagnosed with cancer.

ADVISER'S APPROVAL: Larry L. Mullins, Ph.D.