THE RELATIONSHIP OF PARENTAL OVERPROTECTION, CHILD

VULNERABILITY, AND PARENTING STRESS TO EMOTIONAL,

BEHAVIORAL, AND SOCIAL ADJUSTMENT IN

CHILDREN DIAGNOSED WITH CANCER

By

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I can only hope to accomplish all that you have and to be as passionate about my work and as compassionate toward the people I serve as you are. I could not have asked for more kind, caring, loving, and supportive parents, and I hope to live my life with the same integrity and enthusiasm that you have.

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CHAPTER I

INTRODUCTION

Although childhood cancer is relatively rare, it is the chief cause of death by

illness in children between the ages of one and 14 (American Cancer Society, 2005).

Each year in the United States, approximately 12,400 children and adolescents younger

than 20 years of age are diagnosed with cancer (Reis, Percey, & Bunin, 1999), and one in

every 330 children develops cancer before age 19 (Ross, Severson, Pollack, & Robinson,

1996). Substantial progress has been made in recent decades in treatments and cure rates

for many types of cancer. As a result of these advancements, many childhood cancers

that were once considered fatal are now curable. Researchers have responded by

increasing their efforts to identify the short and long-term physical and psychosocial

outcomes of the disease and its treatment (e.g., Eiser, 1998).

Current literature examining psychosocial outcomes among children with a

chronic illness suggests that these children are at risk for psychosocial maladjustment

secondary to their illness (e.g., Lavigne & Faier-Routman, 1992). Psychosocial

adjustment problems secondary to chronic illness have been shown to occur in children

with various types of chronic illness, including asthma, cystic fibrosis, diabetes, sickle-

cell disease, spina bifida, and cancer (Thompson & Gustafson, 1996). Longitudinal

studies have demonstrated that children in the early stages of cancer treatment experience

increased levels of distress compared with healthy comparison children (e.g., Sawyer,

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Antoniou, Nguyen, Toogood, Rice, & Baghurst, 1995; Sawyer, Antoniou, Toogood, & Rice, 1997; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000). These studies have also suggested that the initial emotional difficulties children experience following diagnosis are relatively short-lived, and the extant literature suggests that most children function similarly to comparison children by one year post-diagnosis. Indeed, many studies examining child and adolescent cancer patients and survivors of cancer report adequate overall functioning (e.g., Kaplan, Busner, Weinhold, & Lenon, 1986; Spirito, Stark, Cobiella, Drigan, Androkites, & Hewett, 1990; Kupst, Natta, & Richardson, 1995).

Most recent reviews of literature examining the psychological consequences of childhood cancer conclude that although survivors do not inevitably fare badly, subgroups show significant problems with adjustment (Eiser, 1998). When compared to a healthy sample, survivors as a group are generally reported to function within normal limits. However, more detailed analyses focusing on specific, cancer-related variables suggest that a clinically significant minority of survivors (estimates range from 25-33%) develop psychosocial problems, including emotional, behavioral, social, and school adjustment problems, during and after treatment (Eiser, 1998). Thus, recent research has turned to identifying specific variables that predict adjustment outcomes, including parent and family variables.

Most theoretical models of adjustment to childhood illness recognize the salience of parent and family influences (e.g., Thompson, Gil, Burbach, Keith & Kinney, 1993b; Thompson & Gustafson, 1996). Parent and family variables are especially important in light of the fact that cancer imposes dependency at a time when children and adolescents are beginning to assert their independence (Harbeck-Weber & Conaway, 1994).

Problems can arise when parents react to their child's cancer diagnosis by becoming overly protective or involved in the management of their child's life at the same time that their child is seeking independence (Harbeck-Weber & Conaway, 1994).

Only recently have researchers begun to identify specific parent variables that can predict adjustment outcomes of children with chronic illnesses (Pless, 1984). Included among these variables are parental overprotection, perceived child vulnerability, and parenting stress. Parental overprotection refers to a specific pattern of parent *behaviors* intended to promote the safety and security of the child. In the scenario of a child who has a medical condition, the stage is set for overprotective parenting as the parent attempts to gain control over a stressful situation (Thomasgard and Metz, 1993). Recent research (e.g., Holmbeck, Johnson, Wills, McKernon, Rose, & Erklin, 2002; Powers, Dahlquist, Thompson, & Warren, 2003) suggests that parents of children with a chronic illness indeed manifest more overprotective, controlling, and directive behavior than parents of children without a chronic illness.

Perceived child vulnerability refers to parental *attitudes* or *beliefs* about the vulnerability of their child due to chronic illness or injury. Though less researched than the parental overprotection construct, perceived child vulnerability and related cognitions have been used to explain health care use (Bush & Iannotti, 1990). Increased health care use has been reported for children whose parents report worrying more about their child's susceptibility to illness (Fiegelman, Duggan, & Bazell, 1990; Maiman, Becker, & Katlic, 1986), and initial findings have indicated that perceived child vulnerability may predict future use of healthcare services (Forsyth, Horwitz, Leventhal, Burger, & Leaf, 1996). In addition, a recent study found that children with Type 1 diabetes mellitus (DM1)

whose mothers perceived them as vulnerable were more likely to experience depressive symptoms (Mullins, Fuemmeler, Hoff, Chaney, Van Pelt, & Ewing, 2004).

In addition to parental overprotection and perceived child vulnerability, the stress of caring for a child with chronic illness is another factor that has been associated with child distress. Findings from studies with chronically ill populations, including cystic fibrosis and sickle cell disease, suggest that there is an association between parental distress, parenting stress, parenting styles, and child cognitive and social development (Livneh & Antonak, 1997). It remains unclear exactly how the increased parenting stress associated with childhood chronic illness might influence overprotection and perceived child vulnerability, although arguably, higher levels of parenting stress may serve to either mediate or moderate the relationship between perceived vulnerability and overprotection (Mullins et al., 2004).

Prior to initiating the current study, only one study had systematically examined the relationships of parental overprotection, perceived vulnerability, and parenting stress to psychological functioning in children with a chronic illness (Mullins et al., 2004), and no study had examined these relationships in children with cancer. This study attempted to fill these gaps in the literature by examining the relationships among parental overprotection, perceived child vulnerability, and parenting stress among parents of children with cancer, and the relationships of these specific parent variables to child emotional, behavioral, and social functioning. It was expected that parental overprotection, perceived child vulnerability, and parenting stress would all be significantly and directly associated with child emotional, behavioral, and social functioning. In addition, parenting stress was expected to moderate the relationships

between parental overprotection and child emotional, behavioral, and social functioning, and between perceived child vulnerability and child emotional, behavioral, and social functioning, such that these relationships would be strengthened under conditions of heightened parenting stress.

CHAPTER II

LITERATURE REVIEW

Cancer: Description of the Disease

Incidence, Prevalence, and Mortality Rates

Childhood cancer is relatively rare, but is the chief cause of death by illness in children between the ages of one and 14 (American Cancer Society, 2005). Each year in the United States, approximately 12,400 children and adolescents younger than 20 years of age are diagnosed with cancer (Reis, Percey, & Bunin, 1999), and one in every 330 children develops cancer before age 19 (Ross, Severson, Pollack, & Robinson, 1996). In addition, approximately 2,300 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 (Reis et al., 1999). For children between the ages of 1 and 19, cancer ranked fourth as a cause of death behind unintentional injuries (12,447), homicides (4,306), and suicides (2,227) in 1999 (Reis et al., 1999).

Notably, incidence rates for some forms of childhood cancer have increased since the mid-1970s. The annual incidence of cancer for adolescents increased from 183.0 per million in the time period from 1975-79 to 203.8 per million in the time period from 1990-95. By comparison, the incidence of cancer for children younger than 15 years of age increased from 124.3 per million in 1975-79 to 139.9 per million in 1990-95 (Reis et al., 1999).

Although cancer incidence rates have increased in the last 30 years, mortality rates have declined dramatically in that same time period for most childhood cancers. Advances in treatment over the past 30 years have improved the 5-year survival rate to almost 75% (Reis et al., 1999). Overall survival rates increased from 69% to 77% from the time period from 1975-84 to the time period from 1985-94. In addition, for some cancer types (Hodgkin's disease, germ cell tumors, thyroid carcinoma, and melanoma), five-year survival rates were 90% or better for the time period from 1985-1994 (Reis et al., 1999).

Incidence and mortality estimates for 2005 indicate that approximately 9,510 cancer diagnoses and 1,585 deaths due to cancer are expected for children ages one to fourteen. Approximately one-third of these deaths are expected to be in children diagnosed with leukemia (American Cancer Society, 2005). Fortunately, although children typically have more advanced disease at diagnosis than adults, childhood cancers are more responsive to therapy (Vannatta & Gerhardt, 2003). The increase in childhood cancer survivor rates in recent years is primarily attributed to improvements in chemotherapy regimens. Despite the improvements that have been made to current treatment protocols, however, these regimens continue to be intense, often combining surgery, radiation, and chemotherapy, all of which can have short- and long-term effects on cognitive, social, emotional, and behavioral functioning, as well as overall quality of life for childhood cancer survivors (Vannatta & Gerhardt, 2003).

Cancer Etiology

Although the etiology of childhood cancer remains relatively unknown, it is generally thought to be caused by a complex interaction of environmental and genetic

factors (American Cancer Society, 2005). Some of these factors include genetic predisposition, chromosomal aberration, developmental abnormalities, and viral infections, and epidemiological data indicates that there is a strong association of childhood cancer with single gene traits and familial heritability (Cecalupo, 1994).

Cancer develops as a result of excessive growth of abnormal cells in the body (American Cancer Society, 2005). Normal (i.e., non-cancerous) cells in the body grow, divide, and die in an orderly fashion. Because cancer cells continue to grow and divide but do not die, they are different from normal cells. Instead of dying, they outlive normal cells and continue to form new abnormal cells. Cells in the body become abnormal, or cancerous, because of damage to DNA (American Cancer Society, 2005). Most of the time, when DNA becomes damaged, the body is able to repair it. In cancer cells, the damaged DNA is not repaired. People can inherit damaged DNA, which accounts for inherited cancers. However, it is thought that DNA can also become damaged through exposure to harmful substances in the environment, including chemical and radiation exposure (American Cancer Society, 2005).

Types of Cancer

The most common childhood cancers include acute leukemias (including both acute lymphoblastic and nonlymphoblastic leukemias), brain tumors, lymphomas (including both Hodgkin's disease and non-Hodgkin's lymphoma), neuroblastomas, soft tissue sarcomas, Wilm's tumors, and bone tumors (Cecalupo, 1994). The single most common childhood cancer is leukemia, accounting for approximately 30% of all cancer cases in children between the ages of one and 14 (American Cancer Society, 2005). The leukemias are a heterogeneous group of hematologic neoplasms that are characterized by

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an unregulated proliferation and accumulation of white blood cells and are capable of infiltrating all organs and tissues. Acute leukemias are broadly classified as lymphoblastic or nonlymphoblastic, with 80% of acute leukemias qualifying as the lymphoblastic type (Cecalupo, 1994).

Primary brain tumors are the second most common form of childhood cancer and account for approximately 20% of the malignancies diagnosed in children each year in the United States. Several different types of childhood brain tumors exist, each requiring special management. Medulloblastoma, cerebellar astrocytomas, and brainstem gliomas are the three most common types of childhood brain tumor, accounting for approximately 85% of tumors (Cecalupo, 1994).

Lymphomas, including both Hodgkin's and non-Hodgkin's types, are the third most common type of pediatric malignancy. Lymphomas are neoplasms of a wide range of cell types that affect the immune system. Hodgkin's disease is a disorder of unknown etiology that affects lymphoid tissue. The non-Hodgkin's lymphomas are a heterogeneous group of malignancies of the lymphoreticular system that include all malignant lymphomas not classified as Hodgkin's lymphomas (Cecalupo, 1994).

Some of the less common childhood cancers include neuroblastomas, soft tissue sarcomas, Wilm's tumor, and bone tumors. Neuroblastomas are highly malignant tumors comprised of sympathetic neuroblasts that account for 7% to 10% of childhood cancers. Fifty percent of neuroblastomas are diagnosed during the first two years of life, and over-two thirds are diagnosed before age five. The etiology of neuroblastomas is unknown (Cecalupo, 1994). Soft tissue sarcomas account for approximately 6% of childhood cancer diagnoses in the United States each year. The presentation of soft tissue sarcomas

is commonly a painless, steadily growing mass in the head and neck region. Wilm's tumor is an embryonal neoplasm of the kidney and is the second most common intra-abdominal pediatric malignancy. Finally, bone tumors are relatively uncommon malignancies in children. The two most common bone tumors are osteosarcoma and Ewing's sarcoma; both are neoplasms that arise in the bone (Cecalupo, 1994).

Cancer Treatments

Treatment regimens for childhood cancer typically involve chemotherapy, radiation therapy, surgery, or a combination of these therapies (American Cancer Society, 2005). Chemotherapy is a systemic treatment that involves the use of chemicals to destroy the cancer cells that are present in the body. More than 100 drugs are currently used in chemotherapy, either alone or in combination with other drugs or treatments, and many more chemotherapy drugs are expected to become available. The goals of treatment with chemotherapy are typically to: 1) cure the cancer, meaning that the tumor or cancer disappears and does not return; 2) control the cancer, or stop it from growing and spreading, in order to extend life and provide the best quality of life; and 3) relieve symptoms caused by the cancer, and thereby improve the child's quality of life. Although chemotherapy is administered to kill cancer cells, it also can damage normal cells. Damage to normal cells is thought to account for many of the side effects of chemotherapy, which include nausea and vomiting, appetite and weight loss, fatigue, changes in thinking and memory, and other physical problems. Long-term side effects of chemotherapy include permanent organ damage, delayed development, and increased risk of developing a second cancer (American Cancer Society, 2005).

Radiation therapy is another common form of treatment for childhood cancers. It involves the use of photons and other ions (e.g., x-rays) to destroy or damage cancer cells by altering their genetic code. Radiation may be used in early stage cancers to cure or control the disease. It can also be used before surgery to shrink tumors or after surgery to prevent the cancer from returning. Radiation may also be used to treat symptoms such as pain caused by cancers that have spread from their original site. As with chemotherapy, radiation therapy attacks reproducing cancer cells, but it can also affect reproducing cells of normal tissues, causing side-effects such as fatigue, mouth sores, and extreme dryness of the skin. More long-term effects of radiation therapy often include problems with growth and hormone production, learning problems, and memory loss (American Cancer Society, 2005).

Surgery is a third treatment option for children with solid tumors. Curative surgery is the removal of a tumor when it appears to be confined to one area. Surgery is performed when there is hope of taking out all of the cancer, and it is considered a primary treatment for solid tumor cancers. It may be used alone or with chemotherapy or radiation therapy, both of which can be given before or after the surgery has been performed (American Cancer Society, 2005).

Outcomes among Children and Adolescents with Cancer

Substantial progress has been made in recent decades in treatments and cure rates for many types of cancer. Many childhood cancers that were once considered fatal are now curable. As a result, childhood cancer has become more of a chronic illness than a terminal one (Kazak & Nachman, 1991), and researchers are increasing their efforts to

identify the short and long-term physical and psychosocial outcomes of the disease and its treatment.

Short- and Long-Term Consequences of Cancer

Children who have completed treatment are at increased risk for medical difficulties later in life. Survivors of pediatric malignancies remain at risk for recurrence, and 3-12% of survivors develop a secondary cancer within 20 years of their initial diagnosis (Vannatta & Gerhardt, 2003). Children who have completed treatment are also at increased risk for physical limitations and health problems, including endocrine and thyroid complications, (e.g., growth problems, obesity, and reproductive difficulties), and cardiac, pulmonary, renal/urological, gastrointestinal, ocular, and dental problems (Vannatta & Gerhardt, 2003). In addition, functional limitations, such as decreased stamina, have been noted in one-third of childhood cancer survivors. Often, the full impact of physical limitations does not become apparent until months or years after treatment.

Data from the Childhood Cancer Survivor Study (CCSS), a retrospective national cohort study initiated in 1994 to explore the late effects of childhood cancer, has provided important information about quality of life and psychological distress outcomes of childhood cancer survivors (Robison, Mertens, Boice, Breslow, Donaldson, Green, et al., 2002). Hudson and colleagues (2003) used the CCSS data to compare the health status of childhood cancer survivors to that of their siblings (Hudson, Mertens, Yasui, Hobbie, Chen, Gurney, et al., 2003). They found that the survivors were more likely to report poor general and mental health, activity limitations, and functional impairment (Hudson et al., 2003). In another study, Zebrack and colleagues (2002) found that childhood

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cancer survivors were 1.6 to 1.7 times more likely to report symptoms of depression and

somatic distress than their healthy siblings (Zebrack, Zeltzer, Whitton, Mertens, Odom,

Berkow, et al., 2002). Importantly, in this study, socioeconomic variables such as

household income and level of educational attainment, as well as intensity of

chemotherapy, were found to help predict both depression and somatic distress (Zebrack

et al., 2002).

Psychosocial Outcomes among Children with a Chronic Illness

The general literature examining psychosocial outcomes among children with a

chronic illness suggests that these children are at risk for psychosocial maladjustment

secondary to their illness (e.g., Lavigne & Faier-Routman, 1992). Several early

epidemiological studies suggested that children with chronic illness were at increased risk

for adjustment problems in three specific areas: 1) behavioral and emotional adjustment

and self-esteem; 2) social adjustment and peer relationships; and 3) school adjustment

and academic performance (e.g., Cadman, Boyle, Szatmari, & Offord, 1987; Pless &

Roghmann, 1971). Results of these epidemiological studies have consistently shown that

a higher proportion of children with chronic illness experience adjustment problems than

their healthy counterparts. For example, results of the Ontario Child Health Study

revealed that the percentages of children with at least one psychiatric disorder were 31%

for children with chronic illness and disability, 22% for children with chronic illness

without disability, and 14% for healthy children (Cadman et al., 1987).

Psychosocial adjustment problems secondary to chronic illness have also been

shown to occur in children with specific types of chronic illness, including asthma, cystic

fibrosis, diabetes, sickle-cell disease, spina bifida, and cancer (Thompson & Gustafson,

1996). Children with asthma have been found to exhibit increased internalizing and externalizing behavior problems, and poorer overall adjustment than control children (e.g., Kashani, Konig, Sheppard, Wilfley, & Morris, 1988). Similarly, results from a series of studies examining adjustment problems among children with cystic fibrosis suggest that these children are at increased risk for internalizing problems, particularly anxiety-based problems, either alone or in combination with externalizing problems (Thompson, Hodges, & Hamlett, 1990; Thompson, Gustafson, Hamlett, & Spock, 1992; Thompson, Gustafson, Gil, Godfrey, & Murphy, 1998). Children with sickle cell disease have also been reported to experience psychological adjustment problems, particularly internalizing problems (Thompson, Gil, Burback, Keith, & Kinney, 1993a). Finally, children with arthritis also appear to have adjustment difficulties. Results from a recent meta-analysis revealed that children and adolescents with chronic arthritis were at increased risk for developing overall adjustment problems and internalizing problems when compared to healthy controls (LeBovidge, Lavigne, Donenberg, & Miller, 2003). Notably, these children were not found to be at risk for developing externalizing problems or problems with self-esteem or self-concept.

Psychosocial Outcomes among Children with Cancer

Early work assessing psychological consequences of cancer suggested that survivors were at increased risk for poor psychosocial outcomes. Koocher and colleagues (1980) found that children who had survived cancer reported experiencing residual psychosocial sequelae, including depression, anxiety, and low self-esteem. In addition, they found that children whose psychosocial adjustment was poor had less effective socialization and self-help skills. They hypothesized that the interruption of

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normal developmental tasks by the cancer treatment experience and by parental overprotection may have contributed to these psychosocial sequelae. In a similar study, Koocher and O'Malley (1981) found that 47% of survivors reported experiencing adjustment problems. Chang and colleagues (1987) reported similar numbers, indicating that 33% of the survivors in their study evidenced clinical levels of emotional difficulty.

Researchers who take an adaptive or coping perspective on chronic illness tend to emphasize the extent to which individuals with chronic illness are indistinguishable from the general population or, in some cases, better adjusted (Eiser, 1998). Many studies of long-term survivors of childhood cancer have demonstrated that survivors often exhibit adaptation that is comparable to normative groups, peers, siblings, and comparison groups (Kupst et al., 1995). Kazak (1994) concluded after reviewing the literature in the area, that most long-term survivors of childhood cancer function relatively well psychologically and do not have significant emotional problems. Empirical data gathered since the review has supported this conclusion (Kupst et al., 1995).

Longitudinal studies have demonstrated that children in the early stages of cancer treatment experience increased levels of distress compared with healthy comparison children (e.g., Sawyer, Antoniou, Nguyen, Toogood, Rice, & Baghurst, 1995; Sawyer, Antoniou, Toogood, & Rice, 1997; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000). These studies have also suggested that the initial emotional difficulties children experience following diagnosis are relatively short-lived, and the extant literature suggests that most children function similarly to comparison children by one year post-diagnosis.

Indeed, many studies examining child and adolescent cancer patients and survivors of cancer report adequate overall functioning (e.g., Kaplan, Busner, Weinhold, & Lenon, 1986; Spirito et al., 1990; Kupst et al., 1995). For example, Kaplan and colleagues (1986) found relatively low levels of depressive symptoms among child and adolescent oncology patients. They found that the Beck Depression Inventory (BDI) scores of their adolescent sample at three time points post-diagnosis did not differ from the BDI scores of a comparison sample drawn from the general population. Furthermore, they found that the Children's Depression Inventory (CDI) scores of the childhood sample were significantly lower than those of a general childhood sample.

Spirito and colleagues (1990) later examined a group of cancer survivors between the ages of five and 12 who had been successfully treated for cancer when they were between the ages of two and five. They found that the cancer patients reported greater feelings of isolation than the comparison children. More specifically, they found that the cancer survivors played less with children their own age, and there was a trend for the cancer survivors to spend more time alone than other children their age. However, few other differences were noted between the two groups. For example, they found few differences between the cancer survivors and healthy controls on broad self-report measures of competency. In addition, the teachers of cancer survivors rated them as more interested in school and less likely to argue or get teased than healthy children. The teachers also reported that only a small percentage of the survivors had problems in social and academic areas, whereas approximately half of the healthy control children had some social or academic problem. It is important to note, however, that the children who had been treated for cancer played less with children their own age than the controls, and

there was a trend for them to spend more time alone, despite the fact that they did not report wanting to be alone more than the control children (Spirito et al., 1990).

Kupst and colleagues (1995) conducted a longitudinal study of coping in families of long-term child survivors of leukemia and found that both the survivors and their parents were perceived as coping well both 6 and 10 years post-treatment. Self-ratings of adjustment were high, as were ratings of adjustment by project staff. The factors that seemed to contribute to successful adaptation at 6 years post-treatment included support of family, quality of the parents' marriage, coping of other family members, open communication in the family, and lack of other concurrent stressors. The most significant predictors of survivors' adaptation at 10 years post-treatment were coping and adjustment of the mother, suggesting that children may learn how to cope with stress from mothers' modeling of positive or negative coping behaviors.

Adjustment Problems in Subgroups of Children with Cancer

Most recent reviews of literature examining the psychological consequences of childhood cancer conclude that although survivors do not inevitably fare badly, subgroups show significant problems with adjustment (Eiser, 1998). In other words, when compared to a normal sample, survivors are generally reported to function within normal limits. However, more detailed analyses focusing on specific cancer-related difficulties suggest that a clinically significant minority of survivors (estimates range from 25-33%) develop psychosocial problems during and after treatment.

For example, subgroups of children may be at increased risk for short and long-term consequences as a function of specific individual, diagnostic, or treatment factors (Vannatta & Gerhardt, 2003). This appears to be particularly true for children with brain

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tumors and other cancers that primarily affect the central nervous system (CNS). Children with CNS cancers are particularly at risk for neurocognitive difficulties, and there is considerable evidence suggesting that children treated for CNS cancers are at risk for decreases in full-scale IQ, memory, attention, and academic functioning. These problems tend to emerge years after children have been treated and, as a result, are considered late effects of treatment. Elevations in parent reports of both internalizing and externalizing problems in children with CNS cancers have been found by several researchers (e.g., Carlson-Green, Morris, & Krawiecki, 1995; Carpentieri, Mulhern, & Douglas, 1993). Among children with brain tumors, which affect the CNS, the literature is mixed with regard to internalizing and externalizing problems, with some studies reporting children to have problems in these areas and some reporting no differences between children with CNS and non-CNS cancers (Fuemmeler, Elkin, & Mullins, 2002).

Children with CNS malignancies also appear to be particularly at risk for difficulties with social functioning and peer relationships (Fuemmeler et al., 2002; Vannatta & Gerhardt, 2003). Research among children with CNS cancers has demonstrated outcomes such as diminished involvement in social activities, social isolation, and diminished friendships (Radcliffe, Bennett, Kazak, Foley, & Phillips, 1996; Vannatta, Garstein, Short, & Noll, 1998). A review of the literature on the psychological adjustment and quality of life of children who survive brain tumors found that these children are at risk for social competency deficits and are more likely than children with other health conditions to be viewed by teachers and peers as being less socially involved with other children (Fuemmeler et al., 2002). Similarly, in a longitudinal investigation of social and behavioral functioning among children with brain tumors, parents rated their

children lower than average on a measure of social competence at two time points (Kullgren, Morris, Morris, & Krawiecki, 2003). These findings suggest that children with CNS cancers have greater social deficits than children with other types of chronic health conditions, including non-CNS cancers.

Social and Developmental Outcomes of Children with Cancer

According to Vannatta and Gerhardt (2003), a reliance on deficits-based measures (e.g., internalizing and externalizing problems) has generally led to a neglect of more subtle aspects of cancer survivorship, such as attaining normal developmental goals and life achievements. They argue that to fully understand survivorship, a shift from the use of measures of psychopathology to the use of more subtle measures of developmental and social outcomes is important. Researchers have only recently begun to examine the impact of the cancer experience and cancer treatment on such outcomes areas as identity and self-concept development (e.g., Madan-Swain, Brown, & Foster, 2000), and peer and romantic relationships (e.g., Noll, LeRoy, Bukowski, Rogosch, & Kulkarni, 1991).

One outcome area that has been of interest to researchers more recently is the formation and maintenance of peer relations (Eiser, 1998). Children with chronic illnesses often miss school due to illness-related complications, medication side effects, and hospitalizations (Gil, Porter, & Ready, 2000). Although many children with chronic illnesses are well adjustment socially, others may become depressed or anxious, or develop problems with peer relationships (Noll et al., 1991). Further, parent factors, such as concerns about child health, may lead parents to restrict their child's involvement in school and social activities. Indeed, research has demonstrated that children whose

parents perceive them as more vulnerable report more generalized social distress and distress in response to novel social situations (Anthony, Gil, & Schanberg, 2003).

In one school-based study, Noll and colleagues (1993) found that children with cancer were rated by teachers as being less sociable and less likely to be a classroom leader, as well as more socially isolated and withdrawn than their healthy counterparts (Noll, Bukowski, Davies, Koontz, & Kulkarni, 1993). In a similar study by Noll and colleagues (1991), peer report data indicated that children with cancer were more likely to be perceived by their peers as socially isolated compared to their healthy classmates. However, in this same study, no significant differences were found between the children with cancer and the comparison children in the areas of popularity, number of mutual friends, loneliness, self-worth, depression, and self-concept (Noll et al., 1991).

Regardless of whether one takes an adaptive- or deficits-based stance with regard to the psychosocial outcomes of having cancer, the disease and its treatment appear to disrupt normal child and adolescent development and behavior in a variety of ways (Harbeck-Weber & Conaway, 1994). Cancer imposes dependency at a time when children and adolescents are beginning to assert their independence, and parents may have difficulty setting realistic behavioral expectations for their child or being consistent with discipline. Problems can arise when parents react to their child's cancer diagnosis by becoming overprotective or overinvolved in the management of their child's life at the same time that their child is seeking independence. Overprotection and/or indulgence by parents may lead children to feel that they are different from siblings and peers, contribute to behavioral problems, or limit the growth of autonomy (Harbeck-Weber & Conaway, 1994).

In summary, children and adolescents with cancer appear to adjust relatively well as a group to their diagnosis and treatment. However, a consistent subset of these children appear to be at risk for a range of emotional, behavioral, social, and school adjustment problems. In the section to follow, the current body of literature on parent and family variables related to child adjustment to chronic illness will be discussed.

Parent and Family Variables Related to Child Adjustment to Chronic Illness

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 conceptualizes chronic illness as a stressor to which children and families must adapt (Thompson et al., 1993b; Thompson & Gustafson, 1996). Included in the model are illness parameters, including type and severity of illness, and demographic parameters, including gender, age, and socioeconomic status. The model's primary focus, however, is on family processes, including parent-child processes, which are hypothesized to mediate the illness-outcome relationship (Thompson & Gustafson, 1996).

In a series of studies, Thompson and colleagues provided support for the role of the transactional stress and coping model in the parent-child adjustment outcome relationship (Thompson, Gustafson, Hamlett, & Spock, 1992; Thompson et al., 1993b). For example, Thompson and colleagues (1993b) assessed the utility of the stress and coping model in delineating the maternal and child processes associated with child psychological adjustment. They found that mothers who reported behavior problems in their children had significantly higher levels of anxiety and depression compared with children whose mothers did not report behavior problems. More specifically, after

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controlling for illness and demographic parameters, parental anxiety accounted for 16% and 33%, respectively, of the variance in mother-reported internalizing and externalizing behavior problems.

A growing body of literature has provided additional support for the parent-child adjustment outcome relationship in the context of childhood chronic illness. For example, as part of a longitudinal study of family coping with pediatric leukemia, Kupst and colleagues (1995) examined the relationship between mother coping and child adjustment. They found that child adjustment in the long term was positively associated with maternal coping in the short- and long-term. Moreover, maternal coping was identified as the single most important factor in child adjustment. Chaney and colleagues (1997) also examined the parent-child adjustment outcome relationship (Chaney, Mullins, Frank, Peterson, Mace, & Kashani, 1997). They examined the transactional patterns of child, mother, and father adjustment in a sample of children and adolescents with Type 1 diabetes mellitus (DM1) and found that increased feelings of distress by fathers contributed to poorer subsequent child adjustment, even after controlling for demographic and disease parameters including age, gender, socioeconomic status, and illness duration.

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 was diagnosed was significantly associated with the child's psychological adjustment two years after the diagnosis. Notably, the adjustment of fathers and the

family as a whole had a more limited impact on the later psychological adjustment of the child (Sawyer et al., 1998).

The findings described above provide support for the transactional nature of parent and child adjustment to childhood chronic illness. Indeed, they suggest that parent and child adjustment are interrelated and influence each other in a reciprocal fashion (Mullins et al., 2004). However, 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 psychological adjustment. The parenting variables that have been studied to date are described in the next section.

Parental Overprotection and Related Constructs

Only recently have researchers begun to identify specific parent variables that can predict adjustment outcomes of children with chronic illnesses (Pless, 1984). Some of the variables that have been identified to date are maternal intrusiveness, miscarried helping, parental psychological control, and parental overprotection. These variables are described below.

Maternal Intrusiveness and Miscarried Helping

Maternal intrusiveness in infancy has been found to influence the adaptation of healthy children (i.e., children without a chronic illness) in their early school years. Results from a longitudinal study demonstrated that intrusive styles of caregiving during infancy were associated with negative outcomes when the children were in the first and second grades (Egeland, Pianta, & O'Brien, 1993). In this study, those children whose mothers were judged to be intrusive during an observation of feeding and play

interactions with their baby at 6 months of age were doing more poorly academically, socially, emotionally, and behaviorally in the first and second grades compared to children of mothers who were not identified as intrusive. These findings held even after controlling for the effects of maternal IQ, stressful life events experienced by the family, and maternal affective behavior observed in the 6-month feeding situation. These results suggest that maternal intrusiveness early on may lead to child maladaptation later in life.

A related concept to maternal intrusiveness is that of miscarried helping. Anderson and Coyne (1991) described the interactive process of miscarried helping as one in which parents' well-meant helping behaviors can undermine the adaptive illness-related behaviors they are attempting to foster in their child. During this process, the child's self-efficacy and motivation to take care of him or herself are replaced by a need to preserve individual autonomy in the face of intrusive parental helping. According to this perspective, parents of children with chronic illness may interfere with their child's own problem-solving attempts or performance on tasks that are instrumental to his or her illness, and as a result may inadvertently lead their child to feel incompetent, resentful, or lacking in autonomy (Anderson & Coyne, 1993).

Inevitably, there is ambiguity and potential conflict between the need to foster independence and self-efficacy in children with chronic illness and the need to protect these children from harm and unnecessary suffering related to their illness. Similarly, there are tradeoffs between parents handling situations in ways that ensure their child's health, and their provision of opportunities for their child to develop autonomy in the face of possible failure and medical risk related to their illness. Over time, too much parental

involvement in the helping process may lead to over-involvement (Anderson & Coyne, 1991).

Anderson and Coyne (1991) have aptly pointed out that miscarried helping is not a behavioral attribute, but a judgment about the fit of protective behavior to the context in which that behavior occurs. Whether behavior is best viewed as overprotective rather than as reflecting appropriate vigilance and concern depends on the threat inherent in the situation and the alternative means of dealing with it. Close parental scrutiny is sometimes warranted, depending upon the chronically ill child's age, disease status, and regimen complexity, and a high degree of parental involvement is sometimes unavoidable. For many chronic illnesses, parental involvement and cooperation between parent and child is required in every area of treatment. For illnesses with complex treatment regimens that involve many aspects of the child's behavior, parents are responsible for continuous monitoring of their child's behavior and physical symptoms. Parent vigilance and a certain amount of protective behavior are often necessary for illness management (Anderson & Coyne, 1991). Thus, it is only when protective behavior becomes excessive that negative outcomes may result.

Parental Psychological Control

Three parenting behaviors emerged in early clinical child research as significant predictors of child adjustment: 1) parental acceptance; 2) behavioral control; and 3) psychological control. Schaefer (1965) was the first researcher to highlight the difference between behavioral and psychological control, defining parental psychological control as a covert method of controlling the child's activities and behaviors that does not permit the child to develop as an individual apart from the parent. In contrast, Schaefer defined

behavioral control as the degree to which the parent establishes rules and regulations, sets limits to the child's activities, and enforces these rules and limits. He defined parental acceptance as the degree to which the parent is affectionate, approving, emotionally supportive, and involved.

In children without chronic illness, parental acceptance and behavioral control have been associated with positive psychological adjustment as assessed by measures of academic performance, social competence, and behavior, whereas psychological control has been associated with negative psychological adjustment, particularly decreased self-worth and increased internalizing problems (Barber, 1996). Parents who are able to facilitate psychological autonomy in their child while continuing to provide discipline, warmth, and affection appear to facilitate the best child adjustment outcomes (Holmbeck, Johnson, Wills, McKernon, Rose, & Erklin, 2002).

Recently, Holmbeck and colleagues (2002) examined the impact of observed and perceived parenting behaviors, including parental psychological control, on psychosocial adjustment in preadolescents with spina bifida. Parent report and observational data revealed that parental psychological control was associated with negative psychosocial outcomes, specifically externalizing symptoms, in both the children with spina bifida and the healthy control children. Moreover, group comparison analyses indicated that mothers of the children with spina bifida exhibited significantly higher levels of psychological control than mothers of healthy children across both self-report and observational data. According to Holmbeck et al. (2002), parental psychological control may be particularly salient among children and adolescents with compromising health problems. Parental psychological control is expected to undermine children's levels of

self-reliance and autonomous functioning, and because children with compromising health conditions often experience lowered levels of self-reliance and autonomous functioning due to their condition, they are likely to experience even greater decreases in overall autonomy than healthy children (Holmbeck et al., 2002).

Parental Overprotection

Parental overprotection, a construct originally coined by Levy (1931), has also been associated with adjustment outcomes in children with chronic illnesses. Parental overprotection has been variously defined and conceptualized as overindulgent, oversolicitous, overprotective, and overanxious parenting (Levy, 1931; Parker, 1981; Parker, 1983). In the parental overprotection literature, an overprotective parent is generally described as one who is highly supervising, has difficulties with separation from the child, discourages independent behavior, and is highly controlling (Thomasgard & Metz, 1999). Overprotection has been studied retrospectively in adolescent and adult psychiatric populations, and this body of literature suggests that children raised in an overprotective environment may be at increased risk for anxiety and depression later in life (e.g., Parker, 1983).

Using an instrument referred to as the Parental Bonding Instrument, Parker, Tupling, & Brown (1979) extracted two factors of overprotection: caring versus indifference/rejection and control/overprotection versus allowance of autonomy/independence. Parker and colleagues (1979) considered high protection and low care overprotective parenting, and high protection and high care indulgent parenting.

Sameroff and Emde (1992) conceptualized parental overprotection as a relationship disorder. They considered parent-child relationships to have reached the

disordered level when a particular normative developmental process within the relationship, namely the separation-individuation process, was excessively or persistently restricted. Sameroff and Emde examined overprotection within the context of childhood illness and found that once a child had recovered from an illness and regained his or her previous capacity for self-regulation and independence, some parents were unable to permit their child to regain his or her autonomy. These parents retained an overprotective attitude toward their child long after the child had recovered from his or his illness (Sameroff & Emde, 1992).

As previously discussed, in the context of many illnesses, certain amounts of vigilance and protectiveness are appropriate. Parents of children with DM1 must take considerable control over their child's health and behavior (Mullins et al., 2004). Similarly, parents of children with juvenile rheumatoid arthritis are often required to monitor their child's pain, diet, exercise, sleep, school activities, recreational activities, and medications at a much more intense level that is typical for the developmental stage of the child (Powers, Dahlquist, Thompson, & Warren 2003). However, it is unclear at what point protective behaviors become maladaptive and lead to negative psychosocial outcomes in the child. According to Thomasgard and Metz (1993), in the scenario of a child who has a medical condition, the stage is set for overprotective parenting in the form of overindulgence stemming from the parent's perception that the child is vulnerable due to illness. The demands of the illness may influence parents to take on more indulgent, protective, controlling, or intrusive parenting roles.

Several authors have commented on the risks associated with overprotective parenting of children with chronic illness. Parker and Lipscombe (1979) measured

parental overprotection in children with asthma using the Parental Bonding Instrument

(PBI; Parker, Tupling, & Brown, 1979). The PBI scores of the children with asthma

were higher than the scores of their siblings, suggesting that parents may be selectively

overprotective of a child with a chronic illness, and that overprotection may be a

consequence of having a child with a chronic illness.

With regard to other illness groups, Mattson (1972) studied psychosocial

maladjustment in children with hemophilia and reported evidence of maternal

overprotection. Similarly, Spock and Stedman (1966), and Tropauer, Franz, and Dilgard

(1970) reported overprotection by parents of behaviorally maladjusted children with

cystic fibrosis. More recently, in a study examining the relative contribution of factors

associated with the psychosocial functioning in children with cystic fibrosis, Cappelli,

McGrath, and MacDonald (1988) found that maternal anxiety and overprotection

predicted the number of behavioral problems displayed by the children.

In a similar study, Cappelli and colleagues (1989) examined the association of

parental overprotection and psychosocial functioning in children with cystic fibrosis, and

compared the degree of parent-reported overprotection by parents of healthy children to

the degree of parent-reported overprotection by the parents of children with cystic

fibrosis. They found that although the degree of parental overprotection was not different

for healthy and chronically ill children, the interaction of parental overprotection and the

child's gender, age, and psychosocial functioning differed between groups. Though the

degree of maternal overprotection was generally equivalent between the cystic fibrosis

and control group, overprotection was rated significantly higher by mothers of female

children with cystic fibrosis than by control mothers. Similarly, maternal overprotection

was higher for 10-12 year-old children with cystic fibrosis than the same age controls. In addition, for children with cystic fibrosis, excessive maternal or paternal overprotection was associated with increased behavior problems. In contrast, increased behavior problems in the healthy control group were associated with either maternal neglect or lack of parental control (i.e., allowance of excessive autonomy and independence). These results suggest that lack of parental control results in increased behavioral problems in healthy children, whereas excessive control results in increased behavioral problems in children with chronic illness (Cappelli, McGrath, & MacDonald, 1989).

More recent studies also suggest that parents of children with a chronic illness manifest more overprotective, controlling, and directive behavior than parents of children without a chronic illness. Holmbeck and colleagues (2002) tested a mediational model of the associations between parental overprotection, behavioral autonomy, and psychological adjustment of adolescents with spina bifida (Holmbeck, Johnson, Wills, McKernon, Rose, & Erklin, 2002). Findings based on both questionnaire and observational data revealed that adolescents with spina bifida were more overprotected by their mothers and fathers than their able-bodied peers (although a significant portion of this association between group status and overprotection was mediated by children's cognitive ability). In addition, Holmbeck and colleagues found that the mothers and fathers in both groups who were more overprotective were less likely to grant autonomy to their children, supporting the notion that excessive parental protection is at odds with the normal developmental trajectory of early adolescent autonomy (Holmbeck et al., 2002).

In a study examining overprotection among mothers of children with severe juvenile rheumatoid arthritis (JRA), Powers and colleagues (2003) found that the JRA mothers were more directive, controlling, and evaluative than the mothers of healthy children and children with mild arthritis (Powers, Dahlquist, Thompson, & Warren, 2003). Based on these findings, they hypothesized that mothers of children with severe arthritis may feel that their children need more help with their daily activities than do healthy children, thereby motivating a higher level of directive behavior. Taken together, the results of the studies by Holmbeck and colleagues (2002) and Powers and colleagues (2003) suggest that parents of children with a chronic illness may manifest more overprotective, controlling, and directive behavior than parents of children without a chronic illness.

More recently, Mullins and colleagues (2004) examined the relationships among parental overprotection, perceived child vulnerability (see section below describing this construct), parenting stress (see section below describing this construct), and self-reported depressive symptoms in 8-12 year-old children with DM1 (Mullins, Fuemmeler, Hoff, Chaney, Van Pelt, & Ewing, 2004). Mullins and colleagues found that both perceived child vulnerability and parenting stress were associated with higher levels of depressive symptoms. Regression analysis further indicated that parenting stress moderated the relationship between perceived child vulnerability and depressive symptoms. Thus, children with DM1 whose mothers experienced a high degree of parenting stress and who perceived their children as vulnerable were more likely to experience depressive symptoms. Unlike perceived child vulnerability and parenting stress, however, parental overprotection was not found to be significantly related to child

depressive symptoms after controlling for demographic and disease parameters. One explanation for these results is that parents of children with chronic illness may perceive that their child is vulnerable, but may or may not engage in high levels of overprotective behavior. In other words, parents of children with chronic illness may show heightened vigilance for symptoms of the illness, yet they may not feel the need to discourage their child from engaging in activities appropriate to their developmental level (Mullins et al., 2004).

The results of the study by Mullins and colleagues (2004) stand in contrast with the results of the studies by Holmbeck and colleagues (2002) and Powers and colleagues (2003). Mullins and colleagues (2004) noted that the discrepancy may be explained by the fact that children with spina bifida and severe JRA evidence a wide range of orthopedic, functional ability, and cognitive deficits which may present greater medical, physical, and psychological challenges than DM1. As a result, children with spina bifida and JRA may be at higher risk for having overprotective parents than children with DM1 (Mullins et al., 2004).

Additional evidence that parents of children with chronic illness manifest more overprotective behavior than parents of healthy children comes from reports by healthcare professionals. Parental protective behaviors as observed by healthcare professionals have been found to be higher among parents of children with a chronic illness than parents of healthy children. Noll, McKellop, and Vannatta (1998) found that a group of professionals caring for children with sickle cell disease perceived the children's parents to be more protective and worried, and less effective with discipline, than parents of healthy children.

In a similar study, Davies and colleagues (1991) compared health care professionals' perceptions of parenting in families of children with cancer with parenting in families of children without a chronic illness (Davies, Delamater, Shaw, La Greca, Eidson, & Perez-Rodriquez, 1991). A marked degree of concordance was obtained among the health care professionals regarding the parenting practices in the families of children with cancer. Their reports indicated that they perceived differences in multiple areas, including overprotection, discipline, and worry about the child, in comparison with the healthy controls. Consistent with the reports by these professionals, Davies et al. (1991) found that mothers and fathers of children with cancer reported greater worry about the health of their child, and mothers indicated that they worried they were over-involved with their child.

It has been hypothesized that parents of children with a chronic illness, including cancer, may overprotect because they perceive their child to be vulnerable as a result of their medical condition, or because they are attempting to gain control over a complex and unpredictable medical situation (Holmbeck et al., 2002). Regardless of its antecedent, excessively protective parenting can be problematic, since it restricts the child's exposure to age-appropriate independent activities and may foster excessive dependency in the child (Powers et al., 2003). In addition, if the child's peer interactions are limited, his or her opportunities to gain skills in interpersonal relationships and to gain confidence in socializing with peers may be jeopardized.

Perceived Child Vulnerability

The perceived child vulnerability construct was developed by Green and Solnit (1964) in their studies examining the parental processes surrounding a child's recovery

from a life-threatening illness (Thomasgard & Metz, 1999). More recently, perceived child vulnerability has been conceptualized in the literature as anxious cognitions by parents about their child's health or susceptibility to illness or injury (Anthony, Gil, & Schanberg, 2003; Forsyth, Horwitz, Leventhal, Burger, & Leaf, 1996). Unlike the concept of parental overprotection, which refers to a specific pattern of parental *behaviors* intended to promote the safety and security of their child, perceived child vulnerability refers to parental *attitudes* or *beliefs* and their consequences. Although the terms perceived child vulnerability and parental overprotection have often been used interchangeably, these constructs represent two distinct clinical phenomena (Thomasgard & Metz, 1997; see discussion below). Notably, the perceived child vulnerability construct has not been investigated to the same extent as the overprotection construct. Among healthy child populations, increased perceptions of child vulnerability have been linked to internalizing problems in children born prematurely or at a very low birth weight (Estroff, Yando, & Burke, 1994).

Perceived child vulnerability and related cognitions have been used to explain health care use (Bush & Iannotti, 1990). Increased health care use has been reported for children whose parents report worrying more about their child's susceptibility to illness (Fiegelman, Duggan, & Bazell, 1990; Maiman, Becker, & Katlic, 1986). Forsyth et al. (1996) found that perceived child vulnerability predicted future use of healthcare services. They found that for children perceived as vulnerable, the total mean number of physician and acute medical visits during the year following enrollment in the study was significantly greater than the number of visits for children not perceived as vulnerable. Similarly, Spurrier and colleagues (2000) reported that parents of children with asthma

who perceived their children as vulnerable were more likely to take them to physicians for acute asthma care and to keep them home from school (Spurrier, Sawyer, Staugas, Martin, Kennedy, & Streiner, 2000).

Importantly, parents' perceptions that their children are vulnerable are not wholly inaccurate. Anthony et al. (2003) found that children with greater physician-rated disease severity whose parents perceived their disease to be more severe were more likely to be perceived as vulnerable, reflecting the true medical vulnerability of these children. However, Anthony and colleagues (2003) found only small to medium correlations between disease severity and parent ratings of child vulnerability, lending support to the idea that some parents may perceive their child as more susceptible to health problems than is indicated by their child's health status. This is important because although a certain amount of vigilance by parents of children with a chronic illness is to be expected and can be adaptive for both the parent and the chronically ill child (e.g., for illness management), excessive amounts of vigilance and perceptions of vulnerability by parents may lead to negative psychological and social outcomes.

Mullins and colleagues (2004) examined the association between parent reports of perceived child vulnerability and self-reported depressive symptoms in 8-12 year-old children with DM1 and found that child vulnerability was associated with increased levels of depressive symptoms. This result suggests that children with DM1 whose mothers perceive them as vulnerable are more likely to experience depressive symptoms. Mullins and colleagues described a potential mechanism for this process, suggesting that the nature of DM1, with its potential for serious, life-threatening complications, may be associated with a heightened sense by parents that their children are vulnerable. This

heightened sense by parents that their children are vulnerable may be communicated in a transactional fashion to the child, leading to poor adjustment outcomes.

The Relationship between Parental Overprotection and Perceived Child Vulnerability

Although the terms perceived child vulnerability and parental overprotection have often been used interchangeably, studies suggest that these constructs represent two distinct clinical phenomena (Thomasgard, Shonkoff, Metz, & Edelbrock, 1995b; Thomasgard & Metz, 1997). Perceived child vulnerability refers to parental attitudes or beliefs that their child is vulnerable to illness or is destined to die prematurely, whereas overprotection refers to a specific pattern of parental behaviors intended to promote the safety and security of their child.

In a series of studies, Thomasgard and colleagues demonstrated that correlations between overprotection and perceived child vulnerability are significant, but relatively small. In their study examining the relationship between parental overprotection and perceived child vulnerability, Thomasgard and colleagues (1995b) found that 20% of those children considered vulnerable were also categorized as overprotected. In a similar study, Thomasgard and Metz (1997) found that 35% of children considered vulnerable by their parents were also categorized as overprotected. According to Thomasgard and Metz (1995b), heightened concerns about a child's vulnerability to illness are not automatically associated with the separation difficulties, excessive control, and interference with emerging independence that characterize overprotection. Similarly, not all parents who behave in an overprotective manner toward their children harbor excessive anxiety about their child's underlying vulnerability.

In another study examining the stability and overlap of parental overprotection and perceived child vulnerability, Thomasgard & Metz (1996) found that perceived child vulnerability and parental reports of overprotective behaviors were generally stable across a two-year time span, with 31% of parents who perceived their child as vulnerable at time one continuing to perceive their child as vulnerable at time two, and 37% of parents who reported overprotective behaviors at time one continuing to report overprotective behaviors at time two. They also found that 20% of parents who perceived their child as vulnerable at time one subsequently reported overprotective behaviors two years later at time two. These results suggest that some, but not all, parents who initially perceive their children as vulnerable may subsequently become overprotective (Thomasgard & Metz, 1996).

In addition, the antecedents, concurrent correlates, and consequences of parental overprotection and perceived child vulnerability appear to be different. The antecedents of overprotective parenting generally have been traced to the parents' own childhood rather than the child's medical history (Parker & Lipscombe, 1981; Parker, 1981; Parker, 1983). Parental anxiety (Parker & Lipscombe, 1981) and family history of being raised in an overprotective family (Thomasgard & Metz, 1993) have been identified as potential risk factors for overprotection. Overprotection has also been associated with single parent status, lower socioeconomic status, less parental education, younger age of the parent, and younger age of the child (Parker & Libscombe, 1981; Thomasgard, Metz, Edelbrock, & Shonkoff, 1995a; Thomasgard & Metz, 1997; Thomasgard, 1998).

Thomasgard and colleagues (1995a) found that overprotection showed a steady decline with advancing child age from 2-5 years, as independence and autonomy in the

child associated with normative developmental processes increased. In a later study, Thomasgard and Metz (1997) found that parents with only one child had higher total parent protection scores, a finding that the authors suggested may be understood as reflecting the lack of competing influences from siblings, who also require parental attention. The association of less parental education with greater parental protective behavior may reflect a relative lack of knowledge regarding the child's capabilities, or the confound of an unsafe environment (Thomasgard & Metz, 1997).

Child medical conditions have not generally been associated with overprotective parental behavior (Parker & Libscombe, 1981; Thomasgard et al., 1995a; Thomasgard et al., 1995b). In addition, maternal history of fertility problems, previous premature deliveries, and complications associated with pregnancy, labor, or delivery, all of which have been associated in previous research with increased perceptions of vulnerability by parents, have not generally been associated with parental overprotective behavior. Parker and Lipscombe (1981) found that overprotective mothers could not be distinguished from other mothers by histories of obstetric difficulties prior to the child's birth, and did not differ from the other mothers by their reports of their child having experienced a serious illness, undergone medical procedures, or been involved in an accident resulting in physical injury. Similarly, Thomasgard and Metz (1997) found that parental overprotective behavior was not associated with any health-related variables, including parental report of the child having a medical condition or having experienced a previous life-threatening event.

Studies examining antecedents, concurrent correlates, and consequences of perceived child vulnerability have noted associations between perceived child

vulnerability and being first born, family socioeconomic status, parental education, rate of healthcare utilization, history of infertility, and previous life-threatening illness of the child (Thomasgard & Metz, 1997). Like children who are overprotected by parents, first-born children are perceived as vulnerable more often than other children, and family socioeconomic status and parental education have been found to be negatively correlated with perceived child vulnerability (Thomasgard & Metz, 1997). Research has also indicated that, unlike overprotected children, children who are perceived as vulnerable are more likely to have a history of previous life-threatening illness or injury and/or a concurrent medical condition (Thomasgard et al., 1995b; Thomasgard & Metz, 1997). Thomasgard (1998) found five significant correlates of perceived child vulnerability, all of which were associated with child health: 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) the child having been born prematurely; 4) the child having been at the office for a sick visit; and 5) parent report of problems or complications during pregnancy, labor, and/or delivery of the child.

Studies examining child outcomes of perceived child vulnerability have demonstrated that children perceived as vulnerable by their parents participate in significantly fewer activities and have lower school and total competence scores compared with children not viewed as vulnerable (Thomasgard & Metz, 1996). Other child outcomes of perceived child vulnerability have included psychosomatic illness, aggressive behavior, and school underachievement (Thomasgard & Metz, 1998). Data from the Fels Longitudinal Study (Kagan & Moss, 1962) indicated that protection, defined as unsolicited nurturance of the child, reward for dependent behaviors, and

overconcern when the child was ill or in danger in the first three years of life, predicted

school age passivity and adult withdrawal from stress in females. A more recent

prospective study found significant associations between parental perceptions of

vulnerability and aggressiveness and somatization in boys, and symptoms of social

withdrawal, anxiety, and depression in girls (Thomasgard & Metz, 1996). In a recent

study, increased parental perceptions of child vulnerability were related to increased

social anxiety in children, even after controlling for child age and disease severity

(Anthony et al., 2003)

In sum, the growing body of research supporting the distinct etiologies,

concurrent correlates, and child outcomes of the parental overprotection and perceived

child vulnerability constructs suggests that they are separate clinical phenomena that may

require differential clinical management strategies (e.g., Parker & Lipscombe, 1981;

Thomasgard & Metz, 1995; Thomasgard & Metz, 1996; Thomasgard & Metz, 1997).

Further, overprotection has been conceptualized by some researchers as a behavioral

manifestation, or consequence, of perceived child vulnerability, such that a subset of

parents who initially perceive their children as vulnerable may subsequently become

overprotective; in essence, parental cognitions about their child's vulnerability may lead

to ineffectual parenting behaviors such as overprotection, which may then influence child

adjustment outcomes (Anthony et al., 2003).

Parenting Stress

In addition to parental overprotection and perceived child vulnerability, the stress

of caring for a child with chronic illness is another factor that has been associated with

child distress. Findings from studies with chronically ill populations, including cystic

fibrosis and sickle cell disease, suggest that there is an association between parental distress, parenting stress, parenting styles, and child cognitive and social development (Livneh & Antonak, 1997).

Specific to pediatric cancer, Kazak and Barakat (1997) evaluated the relationship between parenting stress and parent-reported child quality of life during treatment for childhood leukemia. They found that higher levels of parenting stress for both mothers and fathers during treatment were associated with higher child state anxiety after completion of treatment. This result suggests that parenting stress plays a significant role in child wellbeing following treatment.

Steele and colleagues (2003) examined self-reported affective distress, perceived stress, and caregiver burden among a sample of mothers of children undergoing treatment for cancer (Steele, Long, Reddy, Luhr, & Phipps, 2003). Steele and colleagues administered the Caregiver Burden Scale (Poulshock & Deimling, 1984) as an index of the degree to which the mothers perceived their role as caregiver to be a source of stress. They found that whereas affective distress and perceived stress significantly decreased and then leveled off over the course of treatment, caregiver burden did not demonstrate a significant decrease over the three assessments. In addition, they found a positive correlation between caregiver burden and parenting control, suggesting that mothers who experience increased burden may exert increased parental control. These results are consistent with the notion that parents of children with cancer may exhibit overprotective behaviors under conditions of increased parenting stress or caregiver burden (Steele et al., 2003).

It remains unclear exactly how the increased parenting stress associated with childhood chronic illness might influence overprotection and perceived child vulnerability. Arguably, higher levels of parenting stress may serve to either mediate or moderate the relationship between perceived vulnerability and overprotection (Mullins et al., 2004). Parenting stress may also have a direct effect on child adjustment outcomes. Further investigation of the interactions of these variables is necessary to delineate the nature of the relationships between them.

CHAPTER III

PURPOSE OF THE PRESENT STUDY

The purpose of the present study was to investigate the relationships between discreet parenting variables, namely parental overprotection, perceived child vulnerability, and parenting stress, and emotional, behavioral, and social functioning of children with cancer.

First, the association between parental overprotection and emotional and behavioral functioning of children with cancer was examined. It was expected that increased levels of parental overprotection would be significantly associated with increased parent-reported emotional and behavioral difficulties in children diagnosed with cancer.

Second, the association between parental overprotection and social functioning of children with cancer was examined. It was expected that increased levels of parental overprotection would be significantly associated with decreased parent-reported social functioning in children diagnosed with cancer.

Third, the association between perceived child vulnerability and emotional and behavioral functioning of children with cancer was examined. It was expected that increased levels of perceived child vulnerability would be significantly associated with increased parent-reported emotional and behavioral difficulties in children diagnosed with cancer.

Fourth, the association between perceived child vulnerability and social functioning of children with cancer was examined. It was expected that increased levels of perceived child vulnerability would be significantly associated with decreased parent-reported social functioning in children diagnosed with cancer.

Fifth, the association between parenting stress and emotional and behavioral functioning of children with cancer was examined. It was predicted that parenting stress would independently contribute to child emotional and behavioral functioning, such that increased levels of parenting stress would be significantly associated with increased parent-reported emotional and behavioral difficulties in children diagnosed with cancer.

Sixth, the association between parenting stress and social functioning of children with cancer was examined. It was predicted that parenting stress would independently contribute to child social functioning, such that increased levels of parenting stress would be significantly associated with decreased parent-reported social functioning in children diagnosed with cancer.

Seventh, parenting stress was examined as a moderator of the relationship (Baron & Kenny, 1986) between parental overprotection and child emotional and behavioral functioning. It was expected that parenting stress would magnify the relationship between parental overprotection and parent-reported child emotional and behavioral difficulties. More specifically, it was expected that under conditions of higher parenting stress, the association between parental overprotection and parent-reported child emotional and behavioral difficulties would be strengthened.

Eighth, parenting stress was examined as a moderator of the relationship between parental overprotection and child social functioning. It was expected that parenting stress

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would magnify the relationship between parental overprotection and parent-reported child social difficulties. More specifically, it was expected that under conditions of higher parenting stress, the association between parental overprotection and parent-reported child social difficulties would be strengthened.

Ninth, parenting stress was examined as a moderator of the relationship between perceived child vulnerability and child emotional and behavioral functioning. It was expected that parenting stress would magnify the relationship between perceived child vulnerability and parent-reported child emotional and behavioral difficulties. More specifically, it was expected that under conditions of higher parenting stress, the association between perceived child vulnerability and parent-reported child emotional and behavioral difficulties would be strengthened.

Tenth, and lastly, parenting stress was examined as a moderator of the relationship between perceived child vulnerability and child social functioning. It was expected that parenting stress would magnify the relationship between perceived child vulnerability and parent-reported child social difficulties. More specifically, it was expected that under conditions of higher parenting stress, the association between perceived child vulnerability and parent-reported child social difficulties would be strengthened.

Ten specific hypotheses were made based on the above expected findings. The first six hypotheses posited *direct* relationships between the predictor and criterion variables. These hypotheses were as follows:

Hypothesis One

It was hypothesized that parental overprotection as reported by parents of children with cancer would be significantly associated with parent-reported child emotional and behavioral functioning, such that increased levels of parental overprotection would be significantly associated with increased emotional and behavioral difficulties.

Hypothesis Two

It was hypothesized that parental overprotection as reported by parents of children with cancer would be significantly associated with parent-reported child social functioning, such that increased levels of parental overprotection would be significantly associated with decreased social functioning.

Hypothesis Three

It was hypothesized that perceived child vulnerability as reported by parents of children with cancer would be significantly associated with parent-reported child emotional and behavioral functioning, such that increased levels of perceived child vulnerability would be significantly associated with increased emotional and behavioral difficulties.

Hypothesis Four

It was hypothesized that perceived child vulnerability as reported by parents of children with cancer would be significantly associated with parent-reported child social functioning, such that increased levels of perceived child vulnerability would be significantly associated with decreased social functioning.

Hypothesis Five

It was hypothesized that parenting stress as reported by parents of children with cancer would be significantly and directly associated with parent-reported child emotional and behavioral functioning, such that increased levels of parenting stress would be associated with increased emotional and behavioral difficulties.

Hypothesis Six

It was hypothesized that parenting stress as reported by parents of children with cancer would be significantly and directly associated with parent-reported child social functioning, such that increased levels of parenting stress would be associated with decreased social functioning.

The remaining four hypotheses examined parenting stress as a *moderator* variable. These hypotheses were as follows:

Hypothesis Seven

It was hypothesized that parenting stress as reported by parents of children with cancer would moderate the relationship between parental overprotection and child emotional and behavioral functioning, such that the relationship between parental overprotection and child emotional and behavioral functioning would be strengthened under conditions of higher levels of parenting stress.

Hypothesis Eight

It was hypothesized that parenting stress as reported by parents of children with cancer would moderate the relationship between parental overprotection and child social functioning, such that the relationship between parental overprotection and child social functioning would be strengthened under conditions of higher levels of parenting stress.

It was hypothesized that parenting stress as reported by parents of children with cancer would moderate the relationship between perceived child vulnerability and child emotional and behavioral functioning, such that the relationship between perceived vulnerability and child emotional and behavioral functioning would be strengthened under conditions of higher levels of parenting stress.

Hypothesis Ten

It was hypothesized that parenting stress as reported by parents of children with cancer would moderate the relationship between perceived child vulnerability and child social functioning, such that the relationship between perceived vulnerability and child social functioning would be strengthened under conditions of higher levels of parenting stress.

CHAPTER IV

METHODOLOGY

Participants

Participants in this study were parents of 36 children receiving outpatient

treatment for cancer at the Jimmy Everest Cancer Center (JEC) at the Children's Hospital

of Oklahoma. Parents in the sample identified themselves as Caucasian (86.1%), African

American (5.6%), Hispanic (5.6%), and Native American (2.8%). With regard to marital

status, 69.4% reported being married, 19.4% reported being single, 2.8% reported being

remarried, 2.8% reported never having been married, and 5.6% reported other. The mean

level of education for mothers was 13.3 years, and for fathers was 14.3 years. Estimated

annual family income level was obtained via self-report and is presented in Table 1 in

Appendix E.

At the time of their parent's participation in the study, the children (20 male, 16

female) being treated for cancer were between 2 and 11 years of age ($M = 6.1$, $SD =$

2.48). Duration of illness ranged from 2 to 96 months ($M = 20.9$, $SD = 1.9$). The

children's cancer diagnoses included Acute Lymphoblastic Leukemia ($n = 17$),

Neuroblastoma ($n = 9$), Ewing's Sarcoma ($n = 2$), Medulloblastoma ($n = 2$), Wilms

Tumor ($n = 2$), Brain Stem Glioma ($n = 1$), Hepatoblastoma ($n = 1$), Optic Pathway

Glioma ($n = 1$), and other ($n = 1$).

Inclusion criteria for participation in the study were as follows: 1) the child was between the ages of 2 and 11; 2) the child had been diagnosed with and was being treated for cancer (either CNS or non-CNS); and 3) at least two months had passed since the child was diagnosed with cancer (i.e., the child was not newly diagnosed with cancer).

Exclusion criteria for participation in the study were as follows: 1) the child had been diagnosed with or was being treated for a serious psychiatric disorder, a comorbid chronic illness, or a cognitive disorder; 2) the child was in the terminal phase of illness (i.e., receiving palliative care); or 3) the child was experiencing a medical crisis necessitating intensive medical intervention (e.g., the child had been admitted to the pediatric intensive care or another inpatient unit).

Measures

Parent Measures

Demographics Questionnaire. Parents completed a brief demographics questionnaire designed for this study that assessed their age, their spouse's age, their child's age, the number of individuals living in the home with the child, their race, their marital status, their occupation, their annual family income, the number of emergency room visits and hospitalizations their child had in the last 12 months, the distance they had to travel to get to the Jimmy Everest Cancer Center, and whether they were seeking counseling or psychotherapy for their child (see Appendix A).

Parent Protection Scale. Parental overprotection was measured using the Parent Protection Scale (PPS; Thomasgard, Metz, Edelbrock, & Shonkoff, 1995a). The PPS is a 25-item self-report measure designed to assess several dimensions of protective parenting behaviors. Respondents are asked to rate on a 4-point scale ranging from 0 ("never") to 3

("always") the extent to which each statement is descriptive of their behavior with their child. Items include such statements as "I comfort my child immediately when he/she cries" and "I let my child make his/her own decisions." Higher total scores represent greater overall levels of protective parenting behaviors. Factor analysis of the PPS has yielded four subscales: Supervision, Separation Problems, Dependence, and Control. Previous normative studies on the PPS have demonstrated moderate to high internal reliability coefficients (.73) and high test-retest reliability coefficients (.86; Thomasgard et al., 1995a). The internal reliability coefficient for the current sample was moderate (.69). An empirical cutoff score of 39, corresponding to one standard deviation above the mean, has been used in previous research to reflect clinical levels of overprotection (Thomasgard & Metz, 1997). The PPS has been used successfully to measure protective parenting behaviors in research with a diabetes population (Mullins et al., 2004; see Appendix B).

Child Vulnerability Scale. Parental perceptions of child vulnerability were assessed via the Child Vulnerability Scale (CVS; Forsyth, Horwitz, Leventhal, Burger, & Leaf, 1996). The CVS is an 8-item self-report measure of perceptions of child vulnerability. Respondents are asked to rate on a 4-point scale ranging from 0 ("definitely false") to 3 ("definitely true") the extent to which they perceive their child as vulnerable. Items include statements such as "In general my child seems less healthy than other children" and "I get concerned about the circles under my child's eyes." Previous studies with the CVS have demonstrated moderate to high internal reliability coefficients (.74; Forsyth et al., 1996) and high test-retest reliability (Thomasgard & Metz, 1993). The internal reliability coefficient for the current sample was moderate

(.76). The authors have recommended that an empirical cutoff score of 10 be used to reflect clinically levels of perceived vulnerability. This cutoff score was derived from a prediction model discriminating children who had either an objectively determined medically vulnerable condition or whose parent had significant concerns that their child might die from a given condition (see Appendix B).

Parenting Stress Index. Parenting stress levels were assessed with the Parenting Stress Index/Short Form (PSI/SF; Abidin, 1990). The PSI/SF is a 36-item self-report instrument and a shortened version of the full-length PSI. The PSI is designed to measure levels of stress in a parent-child system and to identify sources of the stress. The PSI yields scores on three subscales (Parental Distress, Parent-Child Dysfunctional Interactions, Difficult Child) as well as a total score. The PSI/SF is highly correlated with the full-length PSI (r = .94). The two-week test-retest reliability coefficient of the full-length PSI is .95 (Abidin, 1990). Previous research with a diabetes population demonstrated high internal reliability (Mullins et al., 2004). The internal reliability coefficient for the current sample was also high (.93).

Behavior Assessment System for Children. The Behavior Assessment System for Children-2-Parent Rating Scales (BASC-2-PRS; Reynolds & Kamphaus, 2005) is a multidimensional approach to evaluating the emotional and behavioral functioning of children. For the current study, the Parent Rating Scale form was utilized. The BASC-2-PRS measures positive (adaptive) as well as negative (clinical) dimensions of children's behavior and personality. Respondents rate the specified behavior on a scale from 0 (never) to 3 (almost always). The BASC-2-PRS also provides composite scale information, including: Externalizing Problems, Internalizing Problems, Adaptive Skills,

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and a Behavioral Symptoms Index. For the current study, the Behavioral Symptoms

Index (BSI) score was used as a measure of parent-rated child emotional and behavioral

adjustment. The BSI composite consists of the Attention Problems, Hyperactivity,

Aggression, Depression, Withdrawal, and Atypicality subscales, and reflects the overall

level of problem behavior. The BASC-2-PRS has excellent psychometric properties,

with internal consistency estimates ranging from .70s to .80s, and composite reliability

estimates ranging from high .80s to low .90s. Internal consistency coefficients for the

current sample were high for both the Preschool level and Child level forms (.90 and .93,

respectively).

Social Skills Rating System. The Social Skills Rating System (SSRS; Gresham &

Elliot, 1990) is a multi-informant system used to measure perceived frequency of social

behaviors in children ranging in age from 3 to 18 (preschool to grade 12). The system is

typically used to screen and classify children suspected of social behavior problems and

consists of teacher, parent, and child forms. For the current study, only the parent forms

were utilized. The SSRS measures positive as well as negative dimensions of children's

behavior. Parents are asked to respond to each item by circling a number from 0 to 2.

The SSRS consists of eight subtests: Cooperation, Assertion, Responsibility, Empathy,

Self- Control, Externalizing Problems, Internalizing Problems, and Hyperactivity, and

yields two composite scores, Social Skills and Problems Behaviors. For the current

study, the Social Skills composite score was utilized as a measure of parent-rated social

functioning. Administration time is approximately 15 to 25 minutes. The SSRS

demonstrates sound psychometric properties, with internal consistency estimates ranging

from .83 to .90 for the parent Social Skills composite. Test-retest reliability estimates

range from .68 to .87 for the parent Social Skills composite (Gresham & Elliot, 1990). Internal consistency coefficients for the current sample were high for both the Preschool Level and Elementary Level forms (.91 and .86, respectively).

Physician Measures

Severity of Illness Scale. The Severity of Illness Scale (SOIS; Young-Saleme & Prevatt, 2001) was used as the primary measure of illness severity. The SOIS is a 6-item Likert scale designed to be completed by medical personnel. The scale yields an overall score for severity of illness among children diagnosed with cancer. The SOIS measures six different areas of illness severity: 1) degree of impairment; 2) future outlook; 3) frequency of medical procedures; 4) number of hospitalizations; 5) ability to participate in activities; and 6) prognosis. Items are summed to create a total score, with higher scores indicating greater impairment. The SOIS demonstrates adequate psychometric properties, with acceptable internal consistency, and test-retest and interrater reliability estimates (Young-Saleme & Prevatt, 2001). Cronbach's alpha has been utilized to calculate internal consistency, yielding total alpha scores of .79 for physicians and .80 for nurses. Test-retest reliability coefficients range from .96 and .92 for time periods of 2 weeks to 3-months. Interrater reliability comparing physician ratings to nurse ratings is approximately .89. Physicians and nurses have rated the SOIS positively for brevity, ease of completion, and utility in depicting medical severity of disease (see Appendix C). Internal consistency for the current sample was moderate (.69).

Form For Medical Personnel. The following information was provided by medical staff and gathered through medical chart review: date of diagnosis, disease duration (i.e., from date of diagnosis to completion of treatment), nature and types of

treatment modalities employed (e.g., chemotherapy, radiation, surgical procedures),

complications secondary to diagnosis and treatment, number of hospitalizations in the

past year, number of clinic visits, and number of emergency room visits (see Appendix

D).

Procedure

Parents of children visiting the Jimmy Everest Cancer Center (JEC) at the

Children's Hospital of Oklahoma for treated-related appointments who met study

inclusion and exclusion criteria were approached in the waiting room, informed about the

purpose of the study, and invited to participate by a graduate research assistant involved

in the study. After they agreed to participate, consent/assent and research privacy forms

were reviewed with the parents and signatures were obtained. Parents were asked to

complete the measures during their scheduled appointment (i.e., while they were waiting

to be seen by their nurse and/or doctor). Upon completion of the measures, participating

families were offered a $20 Wal-Mart gift card for participating in the study. All

procedures were in keeping with standards established by the Oklahoma State University

and University of Oklahoma Health Sciences Center (OUHSC) Institutional Review

Boards (IRBs) and the IRB approved research protocol (see Appendix F).

CHAPTER V

OVERVIEW OF ANALYSES

<u>Preliminary Analyses</u>

Prior to conducting primary analyses, preliminary analyses were conducted. First, means and standard deviations were computed for all disease parameters and primary variables (see Table 2 in Appendix E). Next, mean PPS and CVS scores were compared to the cutoff scores for clinical significance recommended by Thomasgard and Metz (1997). The percentages of parents meeting criteria for clinical levels of overprotective behavior and for perceiving their child as highly vulnerable were calculated, as was the percentage of parents falling in the clinically significant range for parenting stress. The percentages of parents placing their child in the clinically significant range on the BASC-2 Behavioral Symptoms Index (BSI) and on the SSRS Social Skills composite scale were also calculated. Correlational analyses were then conducted for all demographic, disease, and primary variables. Demographic and disease variables found to be significantly associated with the criterion variables were controlled in subsequent regression analyses by entering them on a separate step of the regression equations.

<u>Primary Analyses</u>

To test the study hypotheses, ten separate regression analyses were conducted. Thompson's Transactional Stress and Coping Model guided the order of entry of variables in the hierarchical regression equations (e.g., Thompson & Gustafson, 1996).

According to this model, chronic illness is conceptualized as a stressor to which both the child and family must adapt, and illness parameters and demographic parameters are conceptualized as proximal variables that contribute to a set of adjustment outcomes. Based on this model, disease and demographic variables found to be significantly correlated with each criterion variable were entered on the first step of each regression, and parent variables (parental overprotection, perceived child vulnerability, and parenting stress) were entered on the second step.

The first six of these regression analyses tested the study hypotheses positing *direct* relationships between the predictor and criterion variables. These hypotheses are detailed below.

<u>Hypothesis One</u>

Hypothesis one predicted that parental overprotection would be significantly associated with parent-reported child emotional and behavioral functioning, such that increased levels of parental overprotection would be significantly associated with increased levels of emotional and behavioral difficulties. In this regression analysis, the predictor variable was parental overprotection as measured by the PPS, and the criterion variable was parent-rated emotional and behavioral functioning as measured by the BASC-2 Behavioral Symptoms Index.

<u>Hypothesis Two</u>

Hypothesis two predicted that parental overprotection would be significantly associated with parent-reported child social functioning, such that increased levels of parental overprotection would be significantly associated with decreased social functioning. In this regression analysis, the predictor variable was parental

overprotection as measured by the PPS, and the criterion variable was parent-rated social functioning as measured by the SSRS.

Hypothesis Three

Hypothesis three predicted that perceived child vulnerability would be significantly associated with parent-reported child emotional and behavioral functioning, such that increased levels of perceived vulnerability would be significantly associated with increased levels of emotional and behavioral difficulties. In this regression analysis, the predictor variable was perceived child vulnerability as measured by the CVS, and the criterion variable was parent-rated emotional and behavioral functioning as measured by the BASC-2 Behavioral Symptoms Index.

Hypothesis Four

Hypothesis four predicted that perceived child vulnerability would be significantly associated with parent-reported child social functioning, such that increased levels of perceived vulnerability would be significantly associated with decreased social functioning. In this regression analysis, the predictor variable was perceived child vulnerability as measured by the CVS, and the criterion variable was parent-rated social functioning as measured by the SSRS.

Hypothesis Five

Hypothesis five predicted that parenting stress would be significantly and directly associated with parent-reported child emotional and behavioral functioning, such that increased levels of parenting stress would be associated with increased levels of emotional and behavioral difficulties. In this regression analysis, the predictor variable was parenting stress as measured by the PSI/SF, and the criterion variable was parent-

rated emotional and behavioral functioning as measured by the BASC-2 Behavioral Symptoms Index.

Hypothesis Six

Hypothesis six predicted that parenting stress would be significantly and directly associated with parent-reported child social functioning, such that increased levels of parenting stress would be associated with decreased social functioning. In this regression analysis, the predictor variable was parenting stress as measured by the PSI/SF, and the criterion variable was parent-rated social functioning as measured by the SSRS.

The remaining four regression analyses tested hypotheses seven through ten, which examined parenting stress as a *moderator* variable. In these regression analyses, following the recommendations of Holmbeck (1997) and Aiken and West (1991), the predictor variables (parental overprotection and perceived child vulnerability) and the moderator variable (parenting stress) were centered (i.e., group mean score for each variable was subtracted from each individual's total score for that variable) to reduce multicollinearity when the interaction terms were formed. To form the interaction terms, the centered predictor variables were each multiplied by the centered moderator variable. The resulting interaction terms (parental overprotection x parenting stress and perceived child vulnerability x parenting stress) were entered on step three in each regression analysis.

Hypothesis Seven

Hypothesis seven predicted that parenting stress would moderate the relationship between parental overprotection and parent-rated child emotional and behavioral functioning, such that the relationship between parental overprotection and child

emotional and behavioral functioning would be strengthened under conditions of higher levels of parenting stress. In this regression, parental overprotection and parenting stress were entered on step two as the predictor variables, and the parental overprotection x parenting stress interaction term was entered on step three. The criterion variable in this analysis was parent-rated emotional and behavioral functioning.

Hypothesis Eight

Hypothesis eight predicted that parenting stress would moderate the relationship between parental overprotection and parent-rated child social functioning, such that the relationship between parental overprotection and child social functioning would be strengthened under conditions of higher levels of parenting stress. In this regression analysis, parental overprotection and parenting stress were entered on step two as the predictor variables, and parental overprotection x parenting stress interaction term was entered on step three. The criterion variable in this analysis was parent-rated social functioning.

Hypothesis Nine

Hypothesis nine predicted that parenting stress would moderate the relationship between perceived child vulnerability and parent-rated child emotional and behavioral functioning, such that the relationship between perceived vulnerability and child emotional and behavioral functioning would be strengthened under conditions of higher levels of parenting stress. In this regression analysis, perceived child vulnerability and parenting stress were entered on step two as the predictor variables, and the perceived child vulnerability x parenting stress interaction term was entered on step three. The criterion variable in this analysis was parent-rated emotional and behavioral functioning.

Hypothesis Ten

Hypothesis ten predicted that parenting stress would moderate the relationship between perceived child vulnerability and parent-rated child social functioning, such that the relationship between perceived vulnerability and child social functioning would be strengthened under conditions of higher levels of parenting stress. In the regression analysis to test this hypothesis, perceived child vulnerability and parenting stress were entered on step two as the predictor variables, and the perceived child vulnerability x parenting stress interaction term was entered on step three. The criterion variable in this analysis was parent-rated social functioning.

CHAPTER VI

RESULTS

Preliminary Analyses

Prior to conducting primary analyses, preliminary analyses were conducted. First,

means and standard deviations were computed for all disease parameters and primary

variables (see Table 2 in Appendix E). The mean PPS score for parent participants was

31.19 ($SD = 6.53$). Using Thomasgard and Metz's (1997) recommended cutoff score of

39 or greater, 5 (13.9%) parents met criteria for clinical levels of overprotective behavior.

The mean CVS score was 7.31 ($SD = 3.44$). Using the recommended cutoff score of 10,

9 (25.7%) parents met clinical criteria for perceiving their child as highly vulnerable.

The mean PSI score was 75.34 ($SD = 19.45$). Using the recommended cutoff score of 90,

8 (22.9%) parents fell in the clinically significant range for parenting stress. The mean

BASC-2 BSI composite score was 53.86 (SD = 9.81). Seven (20.0%) parents placed

their child in the *at-risk* range of functioning on the BSI, whereas only 3 (8.6%) parents

placed their child in the *clinically significant* range of functioning. The remainder of

parents placed their child in the average range of functioning on the BSI. The mean

SSRS Social Skills standard score was 93.58 (SD = 18.69). Six (19.4%) parents placed

their child between one and two standard deviations below the mean on this scale,

whereas 4 (12.9%) parents placed their child between two and three standard deviations

below the mean.

Next, bivariate correlation analyses were conducted to determine whether any demographic or disease variables were associated with the primary variables (see Table 3 of Appendix E). With regard to bivariate relationships between the demographic and disease variables and the predictor variables, PPS scores were significantly correlated with mother's education level ($r = -.376$, $p = .024$) and annual family income ($r = -.463$, $p = .004$), indicating that lower levels of both education and income were associated with higher levels of overprotection. PSI scores were significantly correlated with annual family income ($r = -.486$, $p = .003$), indicating that a lower income level was associated with a higher level of parenting stress. No significant bivariate relationships were found between the demographic and disease variables and CVS scores. Interestingly, no disease parameters (e.g., disease duration, disease severity) were significantly correlated with the predictor variables.

With regard to bivariate relationships between the demographic and disease variables and the criterion variables, BASC-2 BSI scores were significantly correlated with annual family income ($r = -.399$, $p = .018$), indicating that a lower income level was associated with increased emotional and behavioral difficulties. SSRS Social Skills standard scores were significantly correlated with mother's education level ($r = .496$, $p = .005$) and annual family income ($r = .424$, $p = .017$), indicating that lower levels of both education and income were associated with decreased social functioning. No disease parameters (e.g., disease duration, disease severity) were significantly correlated with the criterion variables.

With regard to bivariate relationships between the predictor and criterion variables, PPS scores were significantly correlated with BASC-2 BSI scores ($r = .482$,

p = .003) and SSRS Social Skills standard scores (*r* = -.520, *p* = .003), indicating that increased levels of overprotection by parents were associated with increased emotional and behavioral difficulties and decreased social functioning in their children. CVS scores were significantly correlated with BASC-2 BSI scores (*r* = .559, *p* < .001), indicating that increased levels of perceived child vulnerability by parents were associated with increased emotional and behavioral difficulties in their children. The bivariate relationship between CVS scores and SSRS Social Skills standard scores approached significance (*r* = -.344, *p* = .063), suggesting that increased levels of perceived child vulnerability by parents were associated to some degree with decreased social skills in their children. Finally, PSI scores were significantly correlated with both BASC-2 BSI scores (*r* = .721, *p* < .001) and SSRS Social Skills standard scores (*r* = -.482, *p* = .007), indicating that increased levels of stress in parents were associated with increased emotional and behavior difficulties and decreased social skills in their children.

Primary Analyses

Ten separate hierarchical regression analyses were conducted to assess the contributions of demographic variables, disease parameters, and parenting variables to parent-reported emotional, behavioral, and social functioning of children diagnosed with cancer (see Tables 4 to 7 of Appendix E). The first six regression analyses tested the hypotheses positing *direct* relationships between the predictor and criterion variables.

<center>Hypothesis One</center>

The hierarchical regression analysis testing hypothesis one indicated that parental overprotection significantly predicted child *emotional* and *behavioral* functioning, *t*(32) = 2.190, *p* = .036, *sr* = .331, after controlling for annual family income. The overall model

<center>64</center>

was significant, $F(2, 32) = 5.879$, $p = .007$, accounting for 26.9% of the variability in child emotional/behavioral functioning. Thus, higher levels of parental overprotection were significantly associated with higher levels of emotional and behavioral difficulties.

Hypothesis Two

The hierarchical regression analysis testing hypothesis two indicated that parental overprotection significantly predicted child *social* functioning, $t(27) = -2.110$, $p = .044$, $sr = -.319$, after controlling for mother's education level and annual family income. The overall model was significant, $F(3, 27) = 5.546$, $p = .004$, accounting for 38.1% of the variability in child social functioning. Thus, higher levels of parental overprotection were significantly associated with lower levels of social functioning.

Hypothesis Three

The hierarchical regression analysis testing hypothesis three indicated that perceived child vulnerability significantly predicted child *emotional* and *behavioral* functioning, $t(31) = 3.634$, $p = .001$, $sr = .502$, after controlling for annual family income. The overall model was significant, $F(2, 31) = 10.744$, $p < .001$, accounting for 40.9% of the variability in child emotional/behavioral functioning. Thus, higher levels of perceived child vulnerability were significantly associated with higher levels of emotional and behavioral difficulties.

Hypothesis Four

The hierarchical regression analysis testing hypothesis four indicated that perceived child vulnerability significantly predicted child *social* functioning, $t(26) = -2.156$, $p = .04$, $sr = -.328$, after controlling for mother's education level and annual family income. The overall model was significant, $F(3, 26) = 5.717$, $p = .004$, accounting

for 39.7% of the variability in child social functioning. Thus, higher levels of perceived

child vulnerability were significantly associated with lower levels of social functioning.

Hypothesis Five

The hierarchical regression analysis testing hypothesis five indicated that

parenting stress significantly predicted child *emotional* and *behavioral* functioning, $t(31)$

= 4.892, $p < .001$, $sr = .606$, after controlling for annual family income. The overall

model was significant, $F(2, 31) = 17.111$, $p < .001$, accounting for 52.5% of the

variability in emotional/behavioral functioning. Thus, higher levels of parenting stress

were significantly associated with higher levels of emotional and behavioral difficulties.

Hypothesis Six

The hierarchical regression analysis testing hypothesis six indicated that parenting

stress significantly predicted child *social* functioning, $t(26) = -2.299$, $p = .03$, $sr = -.346$,

after controlling for mother's education level and annual family income. The overall

model was significant, $F(3, 26) = 6.016$, $p = .003$, accounting for 41.0% of the variability

in social functioning. Thus, higher levels of parenting stress were significantly associated

with lower levels of social functioning.

The remaining four regression analyses tested hypotheses seven through ten,

which examined parenting stress as a *moderator* variable.

Hypothesis Seven

The hierarchical regression analysis testing hypothesis seven indicated that the

PPS x PSI interaction term did not significantly contribute to the prediction of BASC-2

BSI composite scores, R^2 change = .001, $p = .774$. Thus, parenting stress did not

moderate the relationship between overprotection and parent-reported child emotional and behavioral adjustment.

<div align="center">Hypothesis Eight</div>

The hierarchical regression analysis testing hypothesis eight indicated that the PPS x PSI interaction term did not significantly contribute to the prediction of SSRS Social Skills standard scores, R^2 change $< .001$, $p = .954$. Thus, parenting stress did not moderate the relationship between overprotection and parent-reported child social adjustment.

<div align="center">Hypothesis Nine</div>

The hierarchical regression analysis testing hypothesis nine indicated that the CVS x PSI interaction term did not significantly contribute to the prediction of BASC-2 BSI composite scores, R^2 change $= .008$, $p = .468$. Thus, parenting stress did not moderate the relationship between perceived child vulnerability and parent-reported child emotional and behavioral adjustment.

<div align="center">Hypothesis Ten</div>

The hierarchical regression analysis testing hypothesis ten indicated that the CVS x PSI interaction term did not significantly contribute to the prediction of SSRS Social Skills standard scores, R^2 change $= .001$, $p = .849$. Thus, parenting stress did not moderate the relationship between perceived child vulnerability and parent-reported child social adjustment.

CHAPTER VII

DISCUSSION

The purpose of the current study was to examine the relationships of discrete parenting variables, namely parental overprotection, perceived child vulnerability, and parenting stress, to emotional, behavioral, and social functioning in children diagnosed with cancer. Preliminary analyses indicated that a substantial number of parents met established criteria for overprotective behavior and for perceiving their child with cancer as highly vulnerable. In addition, a large percentage of parents reported experiencing clinically significant levels of parenting stress. It thus appears that the experience of having a child with cancer is associated with high levels of protective behavior and perceptions of vulnerability by parents, and high levels of parenting stress. Notably, parental overprotection, perceived vulnerability, and parenting stress were not associated with disease duration for the current sample. In addition, the total scores on measures of all three of these variables were evenly distributed over disease duration. Therefore, the levels of overprotection, perceived vulnerability, and parenting stress experienced by parents following their child's diagnosis with cancer did not attenuate with the passage of time. Such findings are not surprising given that children with cancer have to endure lengthy, intensive, and debilitating treatment protocols, which can make them weak and tired, keep them out of school, and limit their activities and interactions with peers.

Notably, a greater percentage of parents met clinical criteria for excessive levels of overprotective behavior and for perceiving their child as vulnerable in the current study (13.9% and 25.7%, respectively) than in a recent study by Mullins and colleagues (2004) measuring levels of these variables among parents of children with DM1 (4.6% and 13.9%, respectively). Such differences may be a function of the differential nature of cancer and DM1, since children with DM1 who properly manage their disease typically lead long, healthy lives, whereas cancer is still considered an imminently life-threatening illness.

With regard to child emotional and behavioral functioning, results of the primary analyses indicated that increased levels of parental overprotection, perceived child vulnerability, and parenting stress were significantly associated with increased levels of child emotional and behavioral difficulties. These results suggest that increased levels of overprotective behavior, perceived vulnerability, and parent stress may lead to emotional and behavioral problems in children with cancer. Alternatively, it may be that children who develop emotional and behavioral problems following their diagnosis with cancer elicit increased levels of overprotective behavior, perceived vulnerability, and stress in their parents.

With regard to child social functioning, results of the primary analyses indicated that increased levels of parental overprotection, perceived child vulnerability, and parenting stress were significantly associated with decreased levels of social functioning. These results suggest that increased levels of overprotective behavior, perceived vulnerability, and parenting stress may lead to decreased social functioning in children with cancer. An alternative explanation may be that children who develop problems with

social functioning following their diagnosis with cancer elicit increased levels of overprotective behavior, perceived vulnerability, and stress in their parents.

Overall, these results indicate that parental protective behaviors and the communication of perceptions of vulnerability and parenting stress to the child with cancer may directly and negatively impact the child's emotional, behavioral, and social functioning. These results are consistent with findings from two recent studies on overprotection. Holmbeck and colleagues (2002) demonstrated a relationship between parental overprotection and internalizing and externalizing behaviors in children with spina bifida. Similarly, Power and colleagues (2003) found mothers of children with severe juvenile rheumatoid arthritis to be more directive, controlling, and evaluative than mothers of healthy children. The results of the current study are also consistent with findings from a recent study on perceived child vulnerability by Anthony and colleagues (2003), who found that increased parental perceptions of child vulnerability were related to increased social anxiety in children.

Notably, parenting stress did not moderate the relationships between parental overprotection and emotional/behavioral and social functioning, or between perceived child vulnerability and emotional/behavioral and social functioning. Thus, the relationships between parental overprotection and child emotional, behavioral, and social functioning were not strengthened under conditions of higher levels of parenting stress. Similarly, the relationships between perceived child vulnerability and emotional/ behavioral and social functioning were not strengthened under conditions of higher levels of parenting stress. These results indicate that, regardless of their level of parenting stress, parents who exhibited high levels of protective behavior also perceived their child

as having high levels of emotional, behavioral, and social difficulties. Similarly, regardless of their level of parenting stress, parents who perceived their child with cancer as highly vulnerable also perceived their child as having high levels of emotional, behavioral, and social difficulties. Thus, for the current sample, parenting stress had a *direct* effect on subsequent child emotional, behavioral, and social functioning and did not magnify the relationship between overprotection and subsequent child functioning, or between perceived vulnerability and subsequent child functioning.

These results differ from those of a recent study by Mullins and colleagues (2004), who found that parenting stress moderated the relationship between perceived child vulnerability and depressive symptoms in children with DM1. This difference may be due to the differential nature of the outcome variables used in the two studies. It may be that parenting stress significantly magnifies the relationship between perceived vulnerability and depressive symptoms, but not between perceived vulnerability and the broader outcomes of emotional, behavioral, and social functioning. Alternatively, the difference may be related to the differential nature of the illness groups in the two studies. Specifically, it may be that whereas only a subgroup of parents of children with diabetes experience high levels of parenting stress, most or all parents of children with cancer experience high stress levels throughout their child's treatment course due to the imminently life-threatening nature of the disease. Additional research is necessary to determine whether parenting stress is best conceptualized as having a direct effect on child functioning or an indirect one, through moderation, in pediatric cancer populations.

This study sought to examine the relationships between discreet parenting variables and emotional, behavioral, and social functioning in children diagnosed with cancer. Although the parenting variables examined here have been examined in the context of other illness groups, including spina bifida, cystic fibrosis, asthma, and DM1, no research to date has measured the levels of these variables among parents of children with cancer or looked at the relationships between these variables and psychological outcomes among children with cancer. Thus, the present study represents a unique effort to document the association between discreet parenting variables and emotional, behavioral, and social functioning in children with cancer. In addition, the present study addressed a second gap in the literature by examining not only emotional and behavioral functioning, but also social functioning as a measure of child adjustment.

This study is subject to several limitations. First, the cross-sectional design precludes drawing any definitive conclusions regarding the direction of the relationships between the study variables. Although it is tempting to conclude that increased levels of parental overprotection, perceived child vulnerability, and parenting stress led to decreased child emotional, behavioral, and social functioning, it is equally possible that decreased child emotional, behavioral, and social functioning led to increased overprotection, perceived child vulnerability, and parenting stress.

Second, the generalizability of the findings reported here is limited by small sample size, utilization of a single disease group, and relative homogeneity of the sample with regard to ethnicity, family income, and marital status. Future research may require

the participation of multiple sites in order to achieve larger and more heterogeneous samples.

Third, the lack of a comparison group makes it difficult to conclude that the findings reported here are unique to children with cancer and are different from what would be found in a healthy sample. Future research should compare the levels of overprotection, perceived child vulnerability, and parenting stress among parents of children with cancer to levels of the same variables among parents of healthy children.

Fourth, the majority of the parent participants in the current study were mothers, and therefore the results may apply only to mothers and not to fathers. The relevance of the variables examined here to the father-child transactional relationship cannot be determined from the current sample. Efforts should be made to recruit greater numbers of fathers in future studies examining the relationships between parent variables and child adjustment outcomes.

Finally, parent-report measures were utilized in the current study to assess all study variables. As a result, the results may reflect common method variance. The use of multiple measurement modalities would provide additional information about the nature of parental overprotection, perceived child vulnerability and parenting stress. Similarly, the use of multiple informants (e.g., parents and children) would allow for comparison of parent and child reports of child functioning.

Conclusions and Implications for Practice

The current study found support for all of its hypotheses positing *direct* effects of discreet parenting variables on child functioning in the context of chronic illness. Specifically, significant associations were found between parental overprotection and

emotional, behavioral, and social functioning, perceived child vulnerability and

emotional, behavioral, and social functioning, and parenting stress and emotional,

behavioral, and social functioning. Parenting stress was not found to moderate any of the

above relationships. It thus appears that parents of children with cancer are at risk for

being excessively protective of their child with cancer, perceiving their child with cancer

as highly vulnerable, and experiencing high levels of parenting stress. In addition,

increased levels of overprotection, perceived vulnerability, and parenting stress appear to

have the potential to directly impact subsequent child emotional, behavioral, and social

functioning.

The apparent contributions of parental overprotective behaviors and perceptions

of vulnerability to child adjustment outcomes may warrant assessment and intervention

with parents of children diagnosed with cancer. Parents of children diagnosed with

cancer may benefit from referrals to psychologists and other mental health professionals

for structured interventions to address overprotective parent behaviors, increased levels

of parent perceptions of vulnerability, and increased levels of stress associated with

having a child with cancer. In addition, as discussed by Mullins and colleagues (2004),

there may be additional sources of parenting stress other than their child's cancer

diagnosis, such as sibling behavior problems or marital problems. As a result, it may be

necessary to identify additional targets for interventions with parents of children with

cancer.

Future research should continue to examine discreet parenting variables and the

relationships between these variables and emotional, behavioral and social functioning in

children with cancer and other chronic illnesses, as well as the effectiveness of parenting interventions in reducing child behavioral, emotional, and social difficulties.

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APPENDIX A

DEMOGRAPHIC INFORMATION

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? Circle a number.
Caucasian   African American   Hispanic   Native American   Asian   Other
    1   2   3   4   5   6

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:

0-4,999	_____	30,000-39,000	_____
5,000-9,999	_____	40,000-49,000	_____
10,000-14,900	_____	50,000-59,000	_____
15,000-19,900	_____	60,000 or greater	_____
20,000-29,900	_____		

How many ER visits has your child had in the last 12 months? _____

How many hospitalizations for medical problems has your child had in the last 12 months? _____

What is the distance to your family's cancer treatment center? _____

Are you currently seeking counseling/psychotherapy for your teen due his/her diagnosis?
_____

APPENDIX B

PARENT PROECTION SCALE / CHILD VULNERABILITY SCALE (PPS/CVS)

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

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

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

SEVERITY OF ILLNESS SCALE (SOIS)

SEVERITY OF ILLNESS SCALE

Patient ID#: _____

Physician: _____

Nurse: _____

Primary Diagnosis: _____   Secondary Diagnosis: _____

1. Describe the degree of impairment for this child.

1	2	3	4	5	6	7
INDEPENDENT REQUIRES NO ASSISTANCE			REQUIRES SOME ASSISSTANCE			REQUIRES COMPLETE ASSISTANCE

2. Is it likely that there will be an improvement or worsening of this child's impairment within the next year?

1	2	3	4	5	6	7
LIKELY TO IMPROVE			NO CHANGE LIKELY			LIKELY TO WORSEN

3. How often does this child require medical procedures?

1	2	3	4	5	6	7
NEVER		MONTHLY		WEEKLY		DAILY

4. Is it likely that there will be a change in this child's need for medical procedures within the next year?

1	2	3	4	5	6	7
DECREASE LIKELY			NO CHANGE LIKELY			INCREASE LIKELY

5. How many times a year does this child require hospitalization?

1	2	3	4	5	6	7
ZERO			ONE OR TWO			MANY TIMES

6. How much does this child participate in age appropriate activities (e.g., attends school, involved in church, scouts, sports, social activities)?

1	2	3	4	5	6	7
PARTICIPATION SIMILAR TO THAT OF A NON-ILL CHILD			SOME ABSTINENCE		FREQUENTLY FAILS TO ATTEND SCHOOL OR OTHER ACTIVITIES	

APPENDIX D

FORM FOR MEDICAL PERSONNEL

FORM FOR MEDICAL PERSONNEL

Subject Number: _____

Child's Diagnosis: _____

Date of Diagnosis: _____

Current Date: _____

Date off Treatment: _____

Medical Interventions Currently Being Received or Previously Received:
(Please check whether received and indicate number of times received)

Procedure	Currently or Previously 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:
_____
_____

Medications Currently Prescribed:
_____
_____
_____
_____

Number of Outpatient Clinic Visits in the Past Year: _____

Number of Relapses in the Past Year: _____

Number of Emergency Room Visits in the Past Year: _____

APPENDIX E

TABLES

Table 1

Descriptive Statistics for Demographic Variables

Demographic Parameters	*n*	%
Gender	20	55.6
Male	16	44.4
Female		
Ethnicity		
Caucasian	31	86.1
African-American	2	5.6
Hispanic	2	5.6
Native American	1	2.8
Marital Status		
Married	25	69.4
Single	7	19.4
Remarried	1	2.8
Never Married	1	2.8
Other	2	5.6
Annual Family Income		
0-4,999	2	5.6
5,000-9,999	5	13.9
15,000-19,999	3	8.3
20,000-29,999	4	11.1
30,000-39,999	4	11.1
40,000-49,999	5	13.9
60,000 and above	13	36.1

Table 2

Descriptive Statistics for Disease Parameters and Primary Variables

Variable	M	SD
Disease Parameters		
Disease Duration	20.86	22.31
Disease Severity	22.74	6.55
Predictor Variables		
PPS	31.19	6.53
CVS	7.31	3.44
PSI	75.34	19.45
Outcome Variables		
BASC-2 BSI	58.86	9.81
SSRS	93.58	18.69

Note. Disease Duration = Duration of illness in months; Disease Severity = Score on Severity of Illness Scale (SOIS); BASC-2 BSI = Behavioral Assessment System for Children-2 Behavioral Symptoms Index; SSRS = Social Skills Rating System – Social Skills Standard Score.

Table 3

Bivariate Correlations

	Variable	1	2	3	4	5	6	7	8	9	10
1.	Disease Duration	-	.272	-.313	-.063	.202	-.006	-.004	.093	.229	-.246
2.	Child Age		-	.029	.149	.245	-.301	-.119	-.174	-.083	.336
3.	Mother's Education			-	.521**	.190	-.376*	-.067	-.262	-.089	.496**
4.	Annual Income				-	.259	-.463**	-.153	-.486**	-.399*	.424*
5.	Disease Severity					-	-.143	.046	.116	.009	.069
6.	PPS Scores						-	.587**	.521**	.482**	-.520**
7.	CVS Scores							-	.574**	.559**	-.344
8.	PSI Scores								-	.721**	-.482**
9.	BASC Scores									-	-.421*
10.	SSRS Scores										-

Note. PPS = Parent Protection Scale; CVS = Child Vulnerability Scale; PSI = Parenting Stress Inventory; BASC-2 = Behavioral Assessment System for Children; SSRS = Social Skills Rating System; *$p \leq .05$; **$p \leq .01$.

Table 4

Regression Analyses for Hypotheses One, Three, and Five – Predicting BASC-2 BSI Scores

Step	Variable	*Beta*	R^2	F	*df*
Predicting BASC-2 Behavioral Symptoms Index Scores from PPS Scores (*N* = 35).					
1	Annual Income	-.399*	.159*	6.242*	(1, 33)
2	Annual Income	-.217	.269*	5.879**	(2, 32)
	PPS Total Score	.378*			
Predicting BASC-2 Behavioral Symptoms Index Scores from CVS Scores (*N* = 34).					
1	Annual Income	-.397*	.158*	5.995*	(1, 32)
2	Annual Income	-.315*	.409***	10.744***	(2, 31)
	CVS Total Score	.508***			
Predicting BASC-2 Behavioral Symptoms Index Scores from PSI Scores (*N* = 34).					
1	Annual Income	-.397*	.158*	5.995*	(1, 32)
2	Annual Income	-.076	.525***	17.111***	(2, 31)
	PSI Total Score	.686***			

Note. BASC-2 = Behavioral Assessment System for Children; PPS = Parent Protection Scale; CVS = Child Vulnerability Scale; PSI = Parenting Stress Index; *p ≤ .05; **p ≤ .01; ***p ≤ .001.

Table 5

Regression Analyses for Hypotheses Two, Four, and Six – Predicting SSRS Social Skills Scores

Step	Variable	*Beta*	R^2	F	Df
Predicting SSRS Social Skills Standard Scores from PPS Scores (*N* = 31).					
1	Mother's Education	.376	.279**	5.424**	(2, 28)
	Annual Income	.219			
2	Mother's Education	.328	.381*	5.546**	(3, 27)
	Annual Income	.061			
	PPS Total Score	-.371*			
Predicting SSRS Social Skills Standard Scores from CVS Scores (*N* = 30).					
1	Mother's Education	.395	.290**	5.507**	(2, 27)
	Annual Income	.209			
2	Mother's Education	.446*	.397*	5.717**	(3, 26)
	Annual Income	.131			
	CVS Total Score	-.335*			
Predicting SSRS Social Skills Standard Scores from PSI Scores (*N* = 30).					
1	Mother's Education	.395	.290**	5.507**	(2, 27)
	Annual Income	.209			
2	Mother's Education	.419*	.410*	6.016**	(3, 26)
	Annual Income	.022			
	PSI Total Score	.388*			

Note. SSRS = Social Skills Rating System; PPS = Parent Protection Scale; CVS = Child Vulnerability Scale; PSI = Parenting Stress Index; *p* ≤ .05; **p* ≤ .01; ***p* ≤ .001.

Table 6

Regression Analyses for Hypotheses Seven and Nine – Predicting BASC-2 BSI Scores

Step	Variable	*Beta*	R^2	F	*df*
Examining PSI as a Moderator of the Relationship between PPS and BASC-2 BSI Scores ($N = 34$).					
1	Annual Income	-.397*	.158*	5.995*	(1, 32)
2	Annual Income	-.044	.532***	11.382***	(3, 30)
	PPS Total Score	.108			
	PSI Total Score	.644***			
3	Annual Income	-.045	.534	8.297***	(4, 29)
	PPS Total Score	.102			
	PSI Total Score	.655***			
	PPS x PSI	-.038			
Examining PSI as a Moderator of the Relationship between CVS and BASC-2 BSI Scores ($N = 34$).					
1	Annual Income	-.397*	.158*	5.995*	(1, 32)
2	Annual Income	-.109	.558***	12.645***	(3, 30)
	CVS Total Score	.229			
	PSI Total Score	.537**			
3	Annual Income	-.100	.566	9.474***	(4, 29)
	PPS Total Score	.232			
	PSI Total Score	.584**			
	PPS x PSI	-.101			

Note. BASC-2 = Behavioral Assessment System for Children; PPS = Parent Protection Scale; CVS = Child Vulnerability Scale; PSI = Parenting Stress Index; *p* ≤ .05; **p* ≤ .01; ***p* ≤ .001.

Table 7

Regression Analyses for Hypotheses Eight and Ten – Predicting SSRS Social Skills Standard Scores

Step	Variable	*Beta*	R^2	F	*df*
Examining PSI as a Moderator of the Relationship between PPS and SSRS Scores ($N = 30$).					
1	Mother's Education	.395	.290**	5.507**	(2, 27)
	Annual Income	.209			
2	Mother's Education	.382*	.441*	4.932**	(4, 25)
	Annual Income	-.031			
	PPS Total Score	-.224			
	PSI Total Score	-.303			
3	Mother's Education	.378	.441	3.789*	(5, 24)
	Annual Income	-.029			
	PPS Total Score	-.223			
	PSI Total Score	-.306			
	PPS x PSI	.010			
Examining PSI as a Moderator of the Relationship between CVS and SSRS Scores ($N = 30$).					
1	Mother's Education	.395	.290**	5.507**	(2, 27)
	Annual Income	.209			
2	Mother's Education	.443*	.439	4.884**	(4, 25)
	Annual Income	.032			
	CVS Total Score	-.205			
	PSI Total Score	-.268			
3	Mother's Education	.429*	.439	3.764*	(5, 24)
	Annual Income	.036			
	PPS Total Score	-.206			
	PSI Total Score	.037			
	PPS x PSI				

Note. SSRS = Social Skills Rating System; PPS = Parent Protection Scale; CVS = Child Vulnerability Scale; PSI = Parenting Stress Index; *p* ≤ .05; **p* ≤ .01; ***p* ≤ .001.

APPENDIX F

INSTITUTIONAL REVIEW BOARD APPROVAL FORMS

Oklahoma State University Institutional Review Board

Date: Thursday, November 17, 2005

IRB Application No   AS0626

Proposal Title: The Relationship of Parental Overprotection. Child Vulnerability, and
                   Parenting Stress to Emotional, Behavioral, and Social Adjustment in
                   Children Diagnosed with Cancer

Reviewed and   Exempt
Processed as:

Status Recommended by Reviewer(s): Approved   Protocol Expires: 11/16/2006

Principal
Investigator(s

Christina Colletti	Larry L. Mullins	John M. Chaney
215 N. Murray	OUHSC 940 NE 13th St.	215 N. Murray
Stillwater, OK 74078	Okla. City, OK 73104	Stillwater, OK 74078

The IRB application referenced above has been approved. It is the judgment of the reviewers that the
rights and welfare of individuals who may be asked to participate in this study will be respected, and that
the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45
CFR 46.

▣ The final versions of any printed recruitment, consent and assent documents bearing the IRB approval
  stamp are attached to this letter. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved. Any modifications to the research protocol
   must be submitted with the appropriate signatures for IRB approval.
2. Submit a request for continuation if the study extends beyond the approval period of one calendar
   year. This continuation must receive IRB review and approval before the research can continue.
3. Report any adverse events to the IRB Chair promptly. Adverse events are those which are
   unanticipated and impact the subjects during the course of this research; and
4. Notify the IRB office in writing when your research project is complete.

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the
authority to inspect research records associated with this protocol at any time. If you have questions
about the IRB procedures or need any assistance from the Board, please contact Beth McTeman in 415
Whitehurst (phone: 405-744-5700, beth.mcternan@okstate.edu).

Sincerely,

Sue C. Jacobs, Chair
Institutional Review Board

IRB Number: 12119
Amendment Approval Date: May 24, 2005

May 26, 2005

Larry Mullins, Ph.D.
Dept of Pediatrics
940 N. E. 13th, CHO 3B3308
Oklahoma City, OK 73104-5066

RE: IRB No. 12119: The Relationship of Parental Overprotection, Child Vulnerability, and Parenting Stress to Emotional, Behavioral and Social Adjustment in Children Diagnosed with Cancer

Dear Dr. Mullins:

On behalf of the Institutional Review Board (IRB), I have reviewed your protocol modification form. It is my judgement that this modification allows for the rights and welfare of the research subjects to be respected. Further, it has been determined that the study will continue to be conducted in a manner consistent with the requirements of 45 CFR 46 or 21CFR 50 .56 as amended; and that the potential benefits to subjects and others warrant the risks subjects may choose to incur.

This letter documents approval to conduct the research as described in:

Amend Form   Dated: May 13, 2005
Protocol   Dated: May 13, 2005 Revised
Consent form - Subject   Dated: May 12, 2005 w/ Child Assent
Priv - Research Auth 1   Dated: January 06, 2005
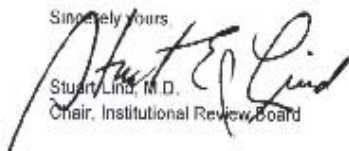
Amendment Summary:

Protocol Title changed from "...Children Newly Diagnosed with Cancer" to "...Children Diagnosed with Cancer." Associated Informed Consent and HIPAA Authorization changes.

This letter covers only the approval of the above referenced modification. All other conditions, including the original expiration date, from the approval granted April 15, 2005 are still effective.

If consent form revisions are a part of this modification, you will be provided with a new stamped copy of your consent form. Please use this stamped copy for all future consent documentation. Please discontinue use of all outdated versions of this consent form.

If you have any questions about these procedures or need additional assistance, please do not hesitate to call the IRB office at (405) 271-2045 or send an email to irb@ouhsc.edu

Sincerely yours

Stuart Lind, M.D.
Chair, Institutional Review Board

Ltr_Amend_Final_Appv_Exp

Post Office Box 26901 • 1000 S.L. Young Blvd., Room 176
Oklahoma City, Oklahoma 73190 • (405) 271-2045 • FAX: (405) 271-1677

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VITA

Christina J. M. Colletti

Candidate for the Degree of

Master of Science

Thesis: THE RELATIONSHIP OF PARENTAL OVERPROTECTION, CHILD VULNERABILITY, AND PARENTING STRESS TO EMOTIONAL, BEHAVIORAL, AND SOCIAL ADJUSTMENT IN CHILDREN DIAGNOSED WITH CANCER

Major Field: Psychology

Biographical:

Personal: Born in Burlington, Vermont in 1978; Parents: Drs. Richard B. Colletti, M.D. and Rose B. Colletti, Ph.D.

Education: Graduated from Burlington High School, Burlington, Vermont in 1996; Received Bachelor of Arts degree in Psychology from Hamilton College, Clinton, New York in May 2000; Completed the requirements for the Master of Science degree with a major in Psychology at Oklahoma State University in December 2005.

Experience: Clinical practicum experience through the A Better Chance (ABC) clinic at the University of Oklahoma Health Sciences Center, July 2005-December 2005; Graduate Research Assistant to Larry L. Mullins, Ph.D., Hematology/Oncology Section, Department of Pediatrics, University of Oklahoma Health Sciences Center; Clinical practicum experience in the Brain Tumor, Sickle Cell, and Hemophilia Clinics in the Jimmy Everest Cancer Center (JEC) at the University of Oklahoma Health Sciences Center, July 2005-December 2005; Clinical practicum experience through the Oklahoma State University Psychological Services Center (PSC), August 2003-October 2005; Instructor of laboratory component of Experimental Psychology, August 2004-December 2004; Instructor of discussion sections of Abnormal Psychology, January 2004-May 2004; Teaching Assistant for Personality, Conflict Resolution, and Honors Introductory Psychology courses, August 2003-December 2003.

Name: Christina J. M. Colletti   Date of Degree: December, 2005

Institution: Oklahoma State University   Location: Stillwater, Oklahoma

Title of Study: THE RELATIONSHIP OF PARENTAL OVERPROTECTION, CHILD
VULNERABILITY, AND PARENTING STRESS TO EMOTIONAL,
BEHAVIORAL, AND SOCIAL ADJUSTMENT IN CHILDREN
DIAGNOSED WITH CANCER

Pages in Study: 109   Candidate for the Degree of Master of Science

Major Field: Psychology

Abstract: This study examined the relationship of parental overprotection, perceived
child vulnerability, and parenting stress to parent-reported emotional,
behavioral, and social functioning in children with cancer. Parenting stress was
also examined as a moderator variable. Participants were 36 parents of
children aged 2 to 11 years and receiving treatment for cancer at a university-
affiliated medical center. Results of hierarchical regression analyses indicated
that all three parenting variables significantly predicted increased child
emotional and behavioral difficulties and decreased child social functioning
after controlling for demographic and disease parameters. Parenting stress did
not significantly moderate the relationships between overprotection and child
functioning and perceived vulnerability and child functioning. These findings
provide support for the transactional relationship between discrete parenting
variables and child emotional, behavioral, and social functioning in the context
of pediatric cancer. Structured interventions targeting overprotective parenting
behaviors and high levels of perceived vulnerability and parenting stress may
help improve child functioning.

ADVISER'S APPROVAL: John M. Chaney, Ph.D.