THE RELATIONSHIPS OF PARENTAL UNCERTAINTY AND CAREGIVER BURDEN TO ADJUSTMENT OUTCOMES IN CHILDREN WITH CANCER: THE MODERATING ROLE OF PARENTING STRESS

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TABLE OF CONTENTS

Chapter Page

I. INTRODUCTION 1

II. REVIEW OF LITERATURE..5

Chapter Overview 5
The Nature of Childhood Cancer..5
Treatment for Childhood Cancer 7
Child Adjustment to Pediatric Cancer 11
Parent and Child Adjustment to Chronic Illness...12
The Nature of Illness Uncertainty...14
Caregiver Burden 23
Parenting Stress..27
Chapter Summary 31

III. THE PRESENT STUDY 32

IV. METHOD 35

Participants...35
Measures 36
Procedures..41

V. RESULTS 43

Preliminary Analyses 43
Primary Analyses 44
Exploratory Analyses...50
Preliminary Analyses for Subset of Mothers Only 50
Primary Analyses for Subset of Mothers Only 51
Exploratory Analyses for Subset of Mothers Only.......................................56

VI. DISCUSSION...58

Strengths and Limitations 62
Future Directions 63

REFERENCES 65

Chapter Page

APPENDICES 82

Appendix A: International Classification of Childhood Cancer – 3rd Edition.......83
Appendix B: Measures...86
Appendix C: Tables and Figure 92

LIST OF TABLES

Table Page

1. Descriptive statistics for study variables.....93
2. Zero-order correlations for demographic variables and outcome variables 94
3. Zero-order correlations for illness characteristics and outcome variables.....95
4. Zero-order correlations for predictor variables and outcome variables.....96
5. Hierarchical regression for parental uncertainty and caregiver burden on externalizing problems.....97
6. Hierarchical regression for parental uncertainty and caregiver burden on internalizing problems 98
7. Hierarchical regression for parental uncertainty and caregiver burden on prosocial behaviors 99
8. Hierarchical regression for moderation of the relationship between parental uncertainty and externalizing problems by parenting stress 100
9. Hierarchical regression for moderation of the relationship between parental uncertainty and internalizing problems by parenting stress.....101
10. Hierarchical regression for moderation of the relationship between parental uncertainty and prosocial behaviors by parenting stress.....102
11. Hierarchical regression for moderation of the relationship between caregiver burden and externalizing problems by parenting stress 103
12. Hierarchical regression for moderation of the relationship between caregiver burden and internalizing problems by parenting stress.....104
13. Hierarchical regression for moderation of the relationship between caregiver burden and prosocial behaviors by parenting stress 105
14. Zero-order correlations for demographic variables and predictor variables.....106
15. Zero-order correlations for illness characteristics and predictor variables.....107
16. Zero-order correlations for demographic variables and outcome variables in sample of mothers only.....108
17. Zero-order correlations for illness characteristics and outcome variables in sample of mothers only.....109
18. Zero-order correlations for predictor variables and outcome variables in sample of mothers only.....110
19. Hierarchical regression for parental uncertainty and caregiver burden on externalizing problems in sample of mothers only.....111
20. Hierarchical regression for parental uncertainty and caregiver burden on internalizing problems in sample of mothers only.....112
21. Hierarchical regression for parental uncertainty and caregiver burden on prosocial behaviors in sample of mothers only.....113
22. Hierarchical regression for moderation of the relationship between parental uncertainty and externalizing problems by parenting stress in sample of mothers only.....114

Table Page

23. Hierarchical regression for moderation of the relationship between parental uncertainty and internalizing problems by parenting stress in sample of mothers only........115
24. Hierarchical regression for moderation of the relationship between parental uncertainty and prosocial behaviors by parenting stress in sample of mothers only........116
25. Hierarchical regression for moderation of the relationship between caregiver burden and externalizing problems by parenting stress in sample of mothers only........117
26. Hierarchical regression for moderation of the relationship between caregiver burden and internalizing problems by parenting stress in sample of mothers only........118
27. Hierarchical regression for moderation of the relationship between caregiver burden and prosocial behaviors by parenting stress in sample of mothers only........119

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LIST OF FIGURES

Figure Page

1. Regression lines for relationships between caregiver burden and child Internalizing problems as moderated by parenting stress 120

CHAPTER I

INTRODUCTION

Families of children with cancer face a host of significant challenges over the course of their child's treatment. The impact of cancer exerts system-wide influences, and both parents and their children are at risk for compromised adjustment from the time of diagnosis and well into survivorship (Kazak et al., 2005; Sahler et al., 1997; Santacroce, 2003). Following the diagnosis of pediatric cancer, parents serve as primary caregivers for their child, a role that is accompanied by considerable stress and heightened levels of perceived uncertainty. As such, they face extreme demands and may feel overwhelmed by the burden of this sudden, new role of caregiving. Not only must parents adjust to their child's diagnosis of cancer, but they must also quickly learn complicated and often confusing treatment protocols, provide comfort and support to a child who is often in great pain and discomfort, monitor medications and side effects, and communicate with medical staff. It is important to note that these new tasks are not only sudden, but they are also added to an already lengthy list of caregiving tasks exhibited by typical parents, including meeting the needs of other family members and organizing the day-to-day family activities. Furthermore, the role of caregiver may transcend a lengthy period of time, as current treatment protocols range from two to three years for the most common types of leukemia. This role also extends into survivorship, as these children remain at risk for a variety of late effects and must be monitored indefinitely.

The extant literature suggests that the majority of pediatric cancer patients appear to cope well with their disease and evidence few long-term symptoms of significant psychological distress or maladaptation (see Kazak, 1994; Kazak et al., 1997; Kupst et al., 1995; Mackie et al., 2000; Madan-Swain et al., 1994; Simms, Kazak, Golomb, Goldwein, & Bunin, 2002; Patenaude & Kupst, 2005). However, a consistent subgroup (approximately 25-30%) of children evidence subclinical difficulties in personal, family, and social domains over time (e.g., Friedman, & Meadows, 2002; Patenaude & Kupst, 2005; Vannatta & Gerhardt, 2003). Thus, efforts have turned to identifying factors that predict which children will do well, and which children will evidence continued distress (e.g., Fuemmeler, Mullins, & Marx, 2001; Kazak, 2005). Recently, researchers have given increased attention to investigating the role of family contextual variables and their effects on child adjustment to chronic illness (e.g., Thompson & Gustafson, 1996). From a transactional perspective, parent adjustment and child adjustment are seen as influencing each other in a reciprocal fashion, such that parents who cope well will have children who cope well, and vice versa. Given the robust transactional relationship between parent and child adjustment to chronic illness (Thompson & Gustafson, 1986), it stands to reason that specific parenting variables have the ability to directly influence child adjustment outcomes. Thus, the identification of such variables is a critical step in predicting which children are at greatest risk for maladaptive adjustment.

The current study sought to build on the current literature by investigating the transactional relationships between two discrete parenting variables, namely parental perceptions of illness uncertainty and parent-reported caregiver burden, and emotional, behavioral, and social adjustment outcomes in children with cancer. Further, the moderating role of parenting stress was also examined within the context of these parent variable-child adjustment relationships. The study was guided by three specific aims:

Aim 1: To determine the differential contribution of parental uncertainty and caregiver burden to the emotional, behavioral, and social adjustment of children with cancer;

Aim 2: To determine whether parenting stress moderated the relationship between parental uncertainty and child adjustment outcomes; and

Aim 3: To determine whether parenting stress moderated the relationship between caregiver burden and child adjustment outcomes.

With regard to Aim 1, it was hypothesized that heightened levels of parental uncertainty and increased levels of caregiver burden would be independently related to poorer behavioral (i.e., more acting out behaviors), emotional (i.e., more internalizing behaviors), and social (i.e., fewer prosocial behaviors) in their child.

With regard to Aim 2, it was hypothesized that the relationship between parental uncertainty and child adjustment outcomes (i.e., behavioral, emotional, and social) would be moderated by parenting stress.

With regard to Aim 3, it was hypothesized that the relationship between caregiver burden and child adjustment outcomes (i.e., behavioral, emotional, and social) would be moderated by parenting stress.

In addition to the three specific aims, two research questions were also addressed in the current study. First, the relationships between demographic variables (i.e., child age, child gender, parent age, parent education), illness parameters [i.e., age at diagnosis, illness duration, severity of illness, disease group (CNS vs. non CNS)] and the levels of parental uncertainty and caregiver burden were examined to determine if any of these variables were significantly related. Finally, the relationship between levels of parental uncertainty and caregiver burden were explored.

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CHAPTER II

REVIEW OF LITERATURE

The following is a review of the extant literature relevant to the proposed project. This review is divided up into five major sections. The first section will focus on the nature of pediatric cancer and will include a discussion of the classification of childhood cancer, incidence, prevalence, and mortality rates, and treatment. The second section includes a brief overview of the transactional relationship of parent and child adjustment to chronic illness. The third section provides an overview of the construct of illness uncertainty in addition to a review of relevant studies in the health psychology literature. The fourth section will focus on the construct of caregiver burden, specifically within the context of parents of children with chronic illness. Finally, the chapter will conclude with a brief review of the relevant studies of parenting stress.

The Nature of Childhood Cancer

Classification. Childhood cancer is not a single disease, but rather a spectrum of different malignancies, which can vary by type of histology, site of disease origin, race, sex, and age (Ries, Percy, Bunin, 1999). In contrast to the classification of cancer in adults, childhood cancer is classified by morphology, rather than by primary site (Steliarova-Foucher, Stiller, Lacour, & Kaatsch, 2005). Although the majority of childhood cancers follow this pattern, brain tumors are often classified differently.

They can be described based on histology (e.g., astrocytoma, glioma), site (e.g., supratentorial, infratentorial), or a combination of the two (e.g., brainstem gliomas) (Ris & Noll, 1994). This discrepancy in nomenclature led to the development of the International Classification of Childhood Cancer (ICCC-3), which standardizes the classification of cancer for purposes of international comparison (Steliarova-Foucher et al., 2005). The ICCC-3 is based on the International Classification of Diseases for Oncology (ICD-O) and categorizes childhood cancer in a hierarchical manner. The main classification table contains levels 1 (12 main diagnostic groups) and 2 (47 diagnostic subgroups). The extended, optional, classification is contained in level 3, where selected diagnostic subgroups are further differentiated. Please refer to Appendix A for an illustration of the current classification system.

Incidence, Prevalence, and Mortality:

Cancer is the leading cause of death by disease in children ages 1 – 14 (National Cancer Institute [NCI], 2005). It was estimated that in 2006, approximately 9,500 children were diagnosed with cancer and about 1,560 died from the disease within the United States (American Cancer Society [ACS], 2006). Notably, two major types of childhood cancer, leukemia and brain malignancies, account for more than half of the newly diagnosed cases (NCI, 2005), with the other ten subtypes leading to the remaining cases.

Although increases in childhood cancer incidence occurred between 1975 and 1995, mortality rates of childhood cancer decreased dramatically during this time. There were significant declines in each of the five age groups (< 5, 5-9, 10-14, and 15-19) for all cancers combined. Currently, the 5 year survival rate for all pediatric cancers is approximately 79% (ACS, 2006), although cure rates differs based on cancer subtype. It is estimated that in the future, 1 in every 450 individuals in the population will be a long-term childhood cancer survivor (Meadows, 2003), and currently, there more than 270,000 childhood cancer survivors living in the US (Oeffinger et al., 2006).

Treatment for Childhood Cancer

The dramatic increase in survival rates for childhood cancer that has occurred over the past four decades is a direct result of clinical research. Originally, this research was conducted by four primary pediatric research groups in North America: the Children's Cancer Group (CCG), the Pediatric Oncology Group (POG), the National Wilms' Tumor Study Group (NWTSG), and the Intergroup Rhabdomyosarcoma Study Group (IRSG). In 2000, the four groups officially merged to form the Children's Oncology Group (COG), a single organization for clinical trials of pediatric cancer (COG, 2005). The COG is comprised of pediatric surgeons and oncologists, neurologists, radiation oncologists, psychologists, researchers, and nurses who work together to develop the worldwide standard of care for pediatric cancer patients, in addition to conducting new studies to discover more effective therapies (Shiminski-Maher, Cullan, & Sansalone, 2002). To facilitate the development of new treatments, all sites participating in COG trials submit diagnostic, treatment, and follow-up data to the COG research center, where they are combined with patients from other sites to create larger samples of homogenous diagnoses. The COG (2005) notes that this coordination of data collection allows new therapies to be developed "hundreds of times faster" than they could be developed in individual cancer centers.

In general, when a child is diagnosed with pediatric cancer, the family is given the choice to participate in a clinical trial sponsored by COG, or to receive the current standard care for the diagnosis. The COG (2005) reports that there are currently over 40,000 pediatric cancer patients enrolled in 150 clinical trials in more than 230 participating medical institutions. The purpose of these clinical trials is to compare new treatments with the standard therapy for a particular diagnosis. Therefore, each patient is randomized into either the *standard care arm* or *experimental arm* of a specific trial, with the hope that the experimental arm will prove to be either more effective or less toxic than the current standard care. Once enrolled in a clinical trial, each patient receives a treatment protocol, called a *roadmap*, which serves as a timeline for the therapy and provides the patient with information regarding all of the drugs, dosages, and tests involved in each segment of the trial and follow-up. If at any point during the trial it becomes apparent that one treatment is significantly better than the other, the trial is terminated and all enrolled patients receive the superior treatment.

Types of Treatment

The most common types of treatment for pediatric cancer include surgery, radiation, chemotherapy, and stem cell transplantation. Various aspects of some or all of these therapies are combined for the treatment of a specific diagnosis. The typical therapy combinations for different types of brain tumors and leukemia will be discussed in the next section. Importantly, the actual treatment for a particular diagnosis depends on a wide variety of factors, including: the histology, stage, and location of the malignancy, and the child’s age at diagnosis. These treatments will be briefly summarized below.

Surgery. Surgery plays a vital role in the treatment of solid tumors and tumors of the CNS, since the ultimate goal of these malignancies is the total removal of the tumor mass (Shochat & Hayes-Jordan, 2000). There are a variety of surgical techniques that can be employed throughout the course of treatment. Some of the most common include biopsy, debulking, surgical resection, and surgical treatment of hydrocephalus.

Radiation Therapy. Radiation therapy is one of the oldest and most effective treatments for cancer. Over 100 years ago, it was discovered that radiation had the ability to destroy both cancerous and healthy tissue. Therefore, it was used to destroy tumors as well as the normal tissue that surrounds them. In contrast to the tumor cells, the normal tissue was able to repair itself after it had been damaged (Merchant, 2000). Radiation therapy was developed long before chemotherapy and continues to be an integral part of pediatric cancer therapies, playing a vital role in the treatment of CNS tumors as well as leukemia. Radiation therapy directs high-energy x-rays at specific areas of the body to destroy tumor cells. It is extremely effective in both reducing the size of the tumor as well as decreasing pain, but can also cause short-term side effects and sometimes permanent damage (Shiminski-Maher, Cullen, & Sansalone, 2002). Specifically, one of the most severe complications of radiation therapy is radiation-induced brain injury, which is most pronounced during the early childhood years and is the major limitation in using high-dose radiation (Strother et al., 2002). One of the most difficult aspects of using radiation therapy is determining the smallest amount of radiation that can be used without jeopardizing the cure rate.

Chemotherapy. The goal of typical pharmacotherapy is symptom reduction, not necessarily curing the underlying disease. However, this conventional approach cannot be applied to childhood cancer (Balis, Holcenberg, & Blaney, 2002). Instead, as described by the *killing paradigm,* anticancer drugs are developed with the ability to differentiate between normal host cells and cancer cells; once they have identified the cancer cells, they *kill* those cells throughout the body (Schipper, Goh, & Wang, 1995). The use of these anticancer drugs is referred to as *chemotherapy*. Although chemotherapy can consist of a single drug, research clearly demonstrates that the combined use of several drugs, given in a specific order, results in much higher cure rates (Strother, 2002). There are seven groups of chemotherapy drugs (e.g., *alkylating agents, antimetabolites, antibiotics, alkaloids, hormones, enzymes, and anti-angiogenesis agents*) that all affect cancer cells in very different ways (Shiminski-Maher, Cullen, & Sansalone, 2002) and can be used in combination to treat the various subtypes of pediatric cancer.

Stem Cell Transplantation. *Stem Cell Transplantations* (i.e., Bone Marrow Transplants) are frequently used to treat children who have relapsed following the standard treatment, which included chemotherapy and/or radiation. These transplants are most frequently used in the treatment of leukemia, although they can be beneficial for children with brain tumors as well as other forms of pediatric cancer. In a stem cell transplant, the child undergoes intensive high-dose chemotherapy and/or radiation, which can permanently damage the bone marrow. To counteract this damage, the child can be infused with their own healthy stem cells (i.e., *Analogous Transplant*), or healthy stem cells from a donor (i.e., *Allogeneic* Transplant). These transplanted cells will travel to the child’s bone marrow and begin to produce normal blood cells.

In summary, the Children’s Oncology Group (COG) has developed a multitude of successful treatment protocols for pediatric cancer. Although there are four primary treatments for pediatric cancer, these therapies are used in a variety of combinations depending on several variables, including the specific type and stage of cancer, age at diagnosis, and long-term prognosis. Currently, the five-year survival rate for all pediatric cancers combined is approximately 79%, which is a 30% increase since the 1950s (ACS, 2006). These statistics indicate that large numbers of children are surviving pediatric cancer, therefore necessitating further research on the impact that cancer has not only on the survivor, but on the other members of their family as well.

Child Adjustment to Pediatric Cancer

Althoug a complete discussion of the relatively large child adjustment to a diagnosis of pediatric cancer is beyond the scope of the current project, a brief summary of this body of work is in order to put the current study in context (please see Brown (2006) for a contemporary review of this literature). In summary, the extant literature on childhood cancer survivors suggests that a majority of survivors exhibit emotional, behavioral, and psychosocial functioning relatively comparable to that of healthy peers or siblings (e.g., Patenaude & Kupst, 2005; Noll, Bukowski, Davies, Koontz, & Kulkarni, 1993; Noll, Bukowski, Rogosch, LeRoy, & Kulkarni, 1990; Noll, et al., 1999), at least when assessed by broadband measures of adjustment or psychopathology. However, a subset of survivors will evidence significant depressive, anxious, and post-traumatic stress symptoms, which may necessitate formal clinical intervention. (Chen, Craske, Katz, Schwartz, & Zeltzer, 2000; Engstrom, Strohl, Rose, Lewandowski, & Stefanek, 1999; Hockenberry et al., 2003; Taieb, Moro, Baubet, Revah-Lévy, & Flament, 2003).

Additionally, research has identified sub-groups of survivors with higher chances of adverse psychological sequelae of their illness. Children with brain tumors and those who experience insult to their central nervous system (CNS) as a result of cancer, or as a consequence of the treatment for cancer, have been shown to be at considerably higher risk for adverse psychosocial outcomes (e.g., Mulhern, 1994). Specifically, studies have documented lower levels of social competence in childhood brain tumor survivors when compared to survivors of other types of pediatric cancer as well as healthy controls (Carpentieri, Mulhern, Douglas, & Fairclough, 1993; Foley, Barakat, Herman-Liu, Radcliffe, & Molloy, 2000). Other research has consistently demonstrated deficits in social functioning, including increased social isolation in brain tumor survivors compared to healthy controls (Mulhern, Carpentieri, Shema, Stone, & Fairclough, 1993; Mulhern, Hancock, Fairclough, & Kun, 1992). Although previous research has identified specific illness characteristics that put children at risk for maladjustment, it is possible that other factors, such as demographic variables, and parenting factors may also play a role in the child's overall adjustment to a diagnosis of pediatric cancer.

Parent and Child Adjustment to Chronic Illness

The role of family contextual variables has received increased attention in research examining child adjustment to chronic illness in recent years (e.g., Thompson & Gustafson, 1996). From a transactional perspective, parent adjustment and child adjustment are seen as influencing each other in a reciprocal fashion. In other words, parents who cope well with their child's illness are more likely to have children who also exhibit positive adjustment outcomes, and vice versa. Similarly, if parents or children are not coping well, they have the ability to negatively affect each other's adjustment outcomes. Considerable research now supports the robust nature of the parent-child adjustment outcome relationship in childhood chronic illness (Chaney et al., 1997; Eaton et al., 1992; Livneh & Antonak, 1997; Mullins et al., 1995; Thompson & Gustafson, 1996; Thompson, Gustafson, & Bonner, 2002).

The early work in the area of parent-child adjustment to chronic illness typically focused on the relationships of parental global mood states to child behaviors and/or mood states. For example, in a study of maternal and child psychological adjustment to sickle cell disease, Thompson and colleagues (1993) reported that maternal anxiety accounted for a significant portion of the variance in explaining both child internalizing and externalizing behavior problems. Similarly, in a study comparing maternal and child adaptation to either insulin dependent diabetes mellitus (IDDM) or cystic fibrosis (CF), Mullins and colleagues (1995) documented that maternal depression was significantly related to child depression in the IDDM group and to child state anxiety in the CF group.

More recently however, the research focus has shifted to investigating more discrete parenting variables that may impact child adjustment. For example, in a sample of children with spina bifida, Holmbeck and colleagues (2002) found that elevated levels of parental overprotective behavior were significantly related to less behavioral autonomy and more externalizing behavior problems in their children. In addition to parental behaviors, parental beliefs about their child’s vulnerability have the potential to affect the child’s adjustment. Specifically, elevated levels of perceived vulnerability were significantly associated with heightened levels of illness uncertainty in adolescents with Type 1 diabetes mellitus (Mullins et al., in press), and with more internalizing problems in children with cancer (Carpentier, Mullins, Wolfe-Christensen, Colletti, & McNall-Knapp, 2007).

Taken together, these studies clearly demonstrate that parental adjustment bears on child adjustment in the context of chronic childhood illness. Since the majority of studies focus on the influence of parental mood states, future research should continue to explore other aspects of parenting, including parents' behaviors, beliefs, and cognitive appraisals that could impact the child's adjustment. The remainder of this chapter will focus on three discrete parenting variables, namely perceived uncertainty, caregiver burden, and parenting stress, which have been shown to significantly affect parental adjustment, but have yet to be studied with regard to their impact on child adjustment.

The Nature of Illness Uncertainty

A hallmark characteristic of chronic illness in both children and adults is the cognitive experience of uncertainty (e.g., Jessop & Stein, 1985: Koocher & O'Malley, 1981; Mishel, 1984). The unpredictable, variable nature of many chronic illnesses, in conjunction with complex and often intrusive and painful treatment regimens, combine to create such an appraisal context. As a construct, illness uncertainty has been defined as a cognitive experience elicited in situations in which the meaning of illness-related events is unclear and outcomes are unpredictable due to a lack of sufficient information or cues (Mishel, 1990). Perceived uncertainty is thus viewed as a person-environment interaction between objective illness events for which outcomes are unknown, and an individual's cognitive appraisal of the meaning of these illness-related events (see Mishel, 1990 and Mast, 1995 for an extensive review of this construct).

Mishel's model suggests that illness uncertainty is comprised of four contributing components, including 1) perceived ambiguity concerning the state of the illness, 2) complexity regarding treatment, 3) lack of information regarding the seriousness of the illness and prognosis, and 4) perceived unpredictability of the illness course (Mishel, 1988). Although the construct of uncertainty is comprised of four parts, Mishel (1983) argues that ambiguity is the most common characteristic, which puts the individual at greatest risk for maladaptive coping. Ambiguity is defined as "the inability to place an event within a comprehensive gestalt" (Mishel, 1983, p. 325), and within the context of chronic illness, it is most often a result of the technology related to treatment and patient care. For example, frequently parents are unable to differentiate between the many aspects of their child's treatment, which leads to ambiguity about the goals of each medication or procedure.

The extant literature indicates that illness uncertainty is a consistent, robust predictor of adjustment across a range of populations, including adults, adolescents, and children with chronic illness, in addition to parents of chronically ill children. These studies have assessed the relationship between heightened levels of illness uncertainty and a range of adjustment outcomes, most notably, aspects of psychological distress. A brief summary of relevant studies is presented below.

Illness Uncertainty in Adults

Previous research has documented significant relationships between levels of illness uncertainty and adjustment outcomes in adults with a variety of chronic medical conditions, including myocardial infarction (Bennett, 1993; Christman et al., 1988), rheumatoid conditions (Braden, 1990), multiple sclerosis (McNulty, Livneh, & Wilson, 2004; Mullins, Cote, & Fuemmeler, 2001), and cancer (Christman, 1990; Hilton, 1989; Clayton, Mishel, & Belyea, 2006; Mishel & Braden, 1987; Mishel & Braden, 1988; Mishel, Hosteetter, King, & Graham, 1984; Mishel & Sorenson, 1991; Mishel, Padilla, Grant, & Sorenson, 1991; Padilla, Mishel, & Grant, 1991), among others. A comprehensive review of studies of illness uncertainty in the context of adult health conditions is beyond the scope of the current project; thus, the reader is referred to Mast (1995) for this information. A brief summary of the relevant literature is provided below.

Previous research has examined the role of illness uncertainty in the context of adaptation to illness in adults with multiple sclerosis (MS). For example, in a study examining coping styles in patients with MS, Wineman and colleagues (1994) found that increased illness uncertainty was related to emotion-focused coping strategies, while patients who reported engaging in problem-focused coping reported lower levels of illness uncertainty. With regard to the relationship between illness uncertainty and mood states in patients with MS, increased uncertainty has been found to be significantly related to diminished mood and decreased hopefulness (Wineman, Schwetz, Goodkin, & Rudick, 1996), and higher levels of depression (Wineman, 1990). Similar results were found in Mullins et al.’s (2001) study of illness intrusiveness, uncertainty, and psychological distress. Specifically, in a sample of 78 patients with MS, increased psychological distress was related to increased levels of both illness intrusiveness and illness uncertainty. Interestingly, these cognitive appraisals appear to independently affect psychological distress, as illness intrusiveness was *not* found to mediate or moderate the uncertainty-distress relationship. Finally, in a study examining perceived illness uncertainty and spiritual well-being to psychosocial adjustment in patients with MS, McNulty and colleagues (2004) reported that although both uncertainty and spiritual well-being were independent predictors of psychosocial adjustment, spiritual well-being mediated the uncertainty-adjustment relationship.

In a series of studies involving patients with gynecological cancers, Mishel and colleagues assessed both antecedents and consequences of illness uncertainty. For example, in an early study of 54 patients, newly diagnosed with various types of gynecological cancer, Mishel and colleagues (1984) found that increased uncertainty was significantly related to lower optimism and less perceived control over physical function. Additionally, poorer psychosocial adjustment and family adaptation were also related to heightened levels of uncertainty. It should be noted that this study was conducted prior to the participants beginning treatment for their cancer, which set the stage for a subsequent study that followed patients longitudinally.

In the subsequent, longitudinal study of 44 patients with gynecological cancers, Mishel and Braden (1987) followed the participants across three time points (i.e., various stages of diagnosis, during treatment, and 8 months later). At all three time points, heightened levels of illness uncertainty were related to lower levels of social support. Interestingly, consistent with findings from Mishel et al (1984), increased uncertainty was related to poorer psychosocial adjustment across all three time points as well. These results suggest that illness uncertainty has the ability to impact psychosocial adjustment consistently over time.

In a larger study of 131 patients with gynecological cancer, Mishel and Sorenson (1991) documented that perceptions of increased danger and less opportunity were both antecedents for heightened levels of illness uncertainty, while increased emotional distress served as a significant consequence. Interestingly, both problem-focused and emotion-focused coping strategies were related to decreased levels of illness uncertainty.

While the abovementioned studies utilized samples of adults who were either newly diagnosed, or were undergoing treatment for chronic health conditions at the time of participation, studies of uncertainty have also been conducted on participants who have completed their medical treatment. For example, Christman and colleagues (1988) followed 60 patients who had experienced a myocardial infarction longitudinally for four weeks after they were discharged from the hospital. Notably, three time points were included, with the first time point occurring at least 72 hours after hospital discharge. Their results indicated that patients who sought information (i.e., education) regarding their condition, and those who engaged in problem-focused coping strategies reported lower levels of illness uncertainty. Consistent with findings from other studies, increased illness uncertainty was related to more emotional distress across all three time points.

In a study of 45 young adult cancer survivors, Santacroce and Lee (2006) examined the relationships between illness uncertainty, posttraumatic stress, and health behaviors. Results revealed that heightened levels of illness uncertainty were associated with increased posttraumatic stress and fewer health promotion behaviors. Additionally, illness uncertainty mediated the relationship between posttraumatic stress and health behaviors. The authors emphasized that the mediating role of illness uncertainty is clinically meaningful, given that illness uncertainty has been successfully targeted as an outcome in previous interventions of adults with cancer (Bailey, Mishel, Belyea, Stewart, & Mohler, 2004; Mishel et al., 2005). These findings suggest that targeting illness uncertainty in samples of younger adults with cancer may be beneficial as well.

Illness Uncertainty in Children and Adolescents

Similar to the literature on adults with chronic health conditions, children and adolescents also appear to experience illness uncertainty concerning the symptoms and treatments of their condition, the possibility of illness recurrence, and their ability to engage in daily activities (Greenberg & Meadows, 1991; Hasse & Rostad, 1994). Previous research has documented significant relationships between illness uncertainty and a range of adjustment outcomes in samples of children and adolescents with a variety of chronic illnesses, including asthma, type 1 Diabetes Mellitus (DM1), cystic fibrosis, and cancer. A full review of the child/adolescent uncertainty literature is beyond the scope of the current project; thus, the reader is referred to Stewart and Mishel (2000) for a comprehensive review. It should also be noted that several of the early studies on child uncertainty in chronic illness were qualitative in nature and utilized interview methods and thematic analyses. Therefore, only studies which employed psychometrically valid measures of illness uncertainty will be reviewed below.

In a relatively early quantitative study of adolescent illness uncertainty, Mullins and colleagues (1997) investigated the relationships between illness uncertainty, attributional style, and psychological adjustment in a sample of older adolescents and young adults with asthma. Results revealed that increased level of illness uncertainty and greater stable attributions for negative events were independently associated with increased psychological distress. Further, the attribution-distress relationship was moderated by illness uncertainty, such that higher levels of illness uncertainty magnified the effect of negative attributions on psychological adjustment.

In a sample of adolescents newly diagnosed with cancer at the time of participation, Neville (1998) examined the relationships between illness uncertainty, social support, and psychological distress. Results revealed that increased levels of illness uncertainty were significantly associated with higher levels of psychological distress, as well as lower levels of social support. Further, although social support was negatively correlated with psychological distress, this relationship was found to be nonsignificant after controlling for illness uncertainty. These findings provide preliminary evidence for the existence of an uncertainty-distress outcome relationship in a sample of adolescents undergoing treatment for pediatric cancer.

Hoff and colleagues (2002) examined the relationships between illness uncertainty, perceived control, and psychological distress in a sample of 68 adolescents between the ages of 13 and 18 who had been diagnosed with type 1 diabetes. Results revealed that level of illness uncertainty was significantly related to psychological distress, such that a heightened level of uncertainty was related to greater psychological distress. Further, a significant relationship between perceived control and illness uncertainty also emerged in this sample. Specifically, heightened levels of illness uncertainty were associated with lower levels of perceived control. However, contrary to expectations, perceived control was unrelated to psychological distress. As such, perceived control did not mediate or moderate the uncertainty-distress relationship.

In a sample of older adolescents with childhood-onset asthma, Hommel and colleagues (2003) examined the differential influence of illness uncertainty to anxiety and depression. Results revealed that after controlling for demographic variables, illness parameters, and level of depression, illness uncertainty was significantly related to anxiety. In contrast, illness uncertainty did not account for a significant amount of the variance in level of depression. These findings suggest that illness uncertainty may exert differential effects on specific types of psychological distress. Thus, future studies may need to examine the relationship between illness uncertainty and specific types of adjustment outcomes, as opposed to global measures of psychological distress.

Consistent with Hommel et al. (2003), White and colleagues (2005) failed to document a direct relationship between illness uncertainty and depressive symptoms in a sample of youth with Juvenile Rheumatic Disease (JRD). However, it was found that the relationship between parent psychological distress and depressive symptoms in their children with JRD was moderated by the child's illness uncertainty. In other words, the effect of parental distress on the child's depressive symptoms was magnified under conditions of heightened level of illness uncertainty (White et al., 2005).

Taken together, the findings from the abovementioned studies clearly demonstrate the robust relationship between illness uncertainty and adjustment outcomes in samples of children and adolescents with chronic illness. Specifically, heightened levels of illness uncertainty have been associated with increased levels of depression, anxiety, and general psychological distress in addition to cognitive appraisals such as less perceived control over the illness. .

Illness Uncertainty in Parents of Children with Chronic Illness

As mentioned previously, illness uncertainty not only affects the child or adolescent with a chronic illness, but affects their parents as well. In fact, van Dongen-Melman and colleagues (1995) have documented that parental uncertainty is a hallmark characteristic of serious childhood illness, regardless of the characteristics of the specific illness. Although there are several potential sources of parental uncertainty, the majority of parents report that the "waiting time" between thinking something is wrong with their child and receiving a diagnosis is the period plagued by the most heightened levels of uncertainty (Stewart & Mishel, 2000). Additionally, while the parent's level of uncertainty changes over the course of the child's illness, it never completely resolves (Cohen, 1995; Grootenhuis & Last, 1997a) and parents consistently report continual concern regarding their child's ultimate survival (Clarke-Steffen, 1993; Cohen, 1993; Lang, 1987). In their comprehensive review of the parent and child illness uncertainty literature, Stewart and Mishel (2000) reported that virtually all of the studies involving parental uncertainty were "descriptive and largely narrative" (p. 308) and that the causal relationship between uncertainty and adjustment outcomes has yet to be tested. However, several consistent themes emerged for parents of children with a range of chronic illness conditions.

Most notably, psychological distress was reported as the most common consequence of parental uncertainty. For example, in an early study of parental adjustment to a child's chronic illness, Jessop and Stein (1985) documented that increased uncertainty was significantly related to higher levels of psychological distress in a sample of 209 mothers of children with a range of chronic conditions, including Sickle Cell Disease, Leukemia, Asthma, and congenital malformations, among others. Similarly, in a sample of 163 parents of children with cancer, Grootenhuis and Last (1997a; 1997b) reported that heightened levels of parental uncertainty were significantly associated with increased levels of depression, anxiety, loneliness, and helplessness. Additionally, in this sample, parents of children who had relapsed reported significantly higher levels of uncertainty and psychological distress than parents of children who were in remission at the time of participation.

In addition to psychological distress, parents who experience heightened levels of uncertainty are at increased risk for feelings of insecurity with regard to their ability to care for their ill child (Turner, Tomlinson, & Harbaugh, 1990). Stewart and Mishel (2000) aptly point out that feeling insecure about one's parenting ability is the characteristic that differentiates parental uncertainty from illness uncertainty in adults with a chronic illness. In this manner, parents are forced to take on a host of new responsibilities in an effort to provide care and comfort to their child. Unfortunately, heightened levels of uncertainty can negatively affect a parent's ability to make decisions that are in their child's best interest (Shewchuk, 1995), or can exacerbate the distress related to making urgent decisions regarding their child's treatment (Stewart & Mishel, 2000).

In summary, illness uncertainty is a hallmark characteristic of chronic illness, which serves as a consistent predictor of adjustment outcomes in a range of populations. Specifically, children, adolescents, and adults with a chronic illness in addition to parents of chronically ill children are at risk for heightened levels of illness uncertainty. Furthermore, increased uncertainty is significantly related to increased psychological distress, maladaptive coping strategies, and impairment in one's ability to seek out sources of social support.

Caregiver Burden

Changes in the health care field over the last 15 years have resulted in patients receiving a substantial amount of their illness-related care at home, rather than in inpatient or outpatient settings (Anderson, 1990). Although there are many benefits to this type of health service delivery, the tasks of following treatment regimens, administering medications, and coordinating medical appointments have become the responsibilities of the patient’s caregivers (i.e., family members) and while these caregiving tasks may appear relatively simple in isolation, the combination of tasks over time can lead to physical, emotional, and financial strain for caregivers, a construct referred to as *caregiver burden* (George & Gwyther, 1986). A growing body of literature has emerged that seeks to both measure this construct and examine its relationship to a variety of outcomes. This literature is briefly summarized below.

In a series of studies involving family members of adults with cancer, caregivers reported that meeting the patient’s emotional needs was the highest source of caregiver burden, followed by managing finances related to the patient’s illness, increased housework, providing transportation to and from illness-related appointments, and monitoring and reporting the patient’s medical needs (Carey, Oberst, McCubbin, & Hughes, 2001; Oberst, Thomas, Gass, & Ward, 1989). Similarly, in an additional study of family caregivers of adult cancer patients, Schumacher (1996) documented that caregivers reported an increased sense of responsibility for meeting the emotional needs of the patient in addition to other family members. Furthermore, caregivers who reported higher levels of caregiving burden also reported experiencing higher levels of uncertainty, as they felt they were learning complex treatment regimens through “trial and error” (Schumacher, 1996, p. 269). Consequently, Steele and Fitch (1996) suggest that when family members cannot meet the increased caregiving demands, the needs of other family members and their own self-care, including sleep, need for respite, and ability to seek out information can all be negatively affected.

The extant literature on family caregiving has typically focused on the impact of caring for an older family member, especially those with a diagnosis of dementia or a terminal illness (Baer, 1993; Given & Given, 1991; Schulz & Beach, 1999) and has often neglected the roles of parents of chronically ill children. Although parents of chronically ill children face many of the same caregiving demands as those mentioned above, parents must add these caregiving tasks on top of their typical parenting responsibilities (Murray, 2000). Within the context of parental caregiving, Stewart and colleagues (1994) suggest that parents face both *primary* and *secondary* burden. The primary burden is comprised of illness care, physical care, and meeting the psychosocial needs of the ill child, whereas secondary burden is comprised of meeting the needs of the other family members in addition to other external roles and activities. In addition to the illness-related caregiving role that parents face when their child is diagnosed with a chronic medical condition, Miles and colleagues (1993) have identified three additional roles that parents must navigate: *advocating* (i.e., ensuring that the child's special needs are met), *protecting* (i.e., attention towards preventing complications from treatment), and *nurturing* (giving additional support to a child with increased demands).

Parental caregiving was initially studied within the context of caring for children with congenital syndromes. In a sample of 71 two-parent families of children with congenital heart disease, the most-time consuming caregiving tasks were not necessarily perceived by the parent as being the most difficult (Svavarsdottir & McCubbin, 1996). Although mothers rated feeding their child as the most time consuming task and fathers rated providing emotional support to their spouse as their most time consuming task, both parents rated providing emotional support to their spouse as the most difficult task.

Additionally, parents who had other children to take care of reported significantly higher levels of parenting stress.

Recently, research has begun to examine the caregiving burden that is specific to parents of children with cancer. For example, in a longitudinal study over the first 6 months of the child's cancer treatment, Steele and colleagues (2003) examined changes in maternal distress, caregiver burden, perceived stress, and parenting strategies across three time points. Results revealed that although maternal distress and perceived stress both declined over the 6-month period immediately following the child's diagnosis, caregiver burden remained stable across all three time points. These findings suggest that while parents are coping relatively well with their child's diagnosis (i.e., their distress is decreasing) the caregiving burden remains stable across time.

In a recent, longitudinal study of 26 two-parent families of children with cancer, Svavarsdottir (2005) examined the relationships between parental caregiving demands, parental adjustment, and parental perceptions of their child's health status across three time points over an 18-month time period. Both mothers and fathers reported that providing emotional support for the ill child was the most time-consuming task at all three time points. Additionally, mothers rated providing emotional support for the *other* children as the most difficult task, while fathers rated providing emotional support for the ill child as the most difficult task. Overall, there were significant changes in caregiving demands over time for both mothers and fathers, such that demands decreased consistently over the 18-month period of the study. However, contrary to expectations, parents' well-being did not significantly change over time. While these findings appear discrepant with those of Steele et al. (2003), it is suggested that the differences could be attributed to the manner in which the construct was defined (i.e., caregiver burden vs. caregiver demand).

As noted earlier, the construct of caregiver burden has been generally overlooked in the pediatric chronic illness literature. However, findings from relevant studies suggest that parents of chronically ill children indeed experience caregiver burden, although the trajectory of the level of burden over time is not completely understood. It stands to reason that the level of caregiver burden can be affected by various other factors, including personality traits of the caregiver, environmental stressors, and illness-specific characteristics. It is also unclear how caregiver burden may operate in contributing to adjustment outcomes, or its role vis a vis parenting stress. In the section to follow, research regarding the role of parenting stress within the context of childhood chronic illness and its influence on parent variables-child adjustment relationships will be presented.

Parenting Stress

Parenting stress is broadly defined as a multidimensional construct that includes the parents’ perception of their own characteristics, the characteristics of their child, and situational (i.e., environmental) events (Abidin, 1990). Although parenting stress is often cited as a significant problem for parents of children with chronic illness (Kazak & Barakat, 1997; Streisand, Braniecki, Tercyak, & Kazak, 2001; Thompson & Gustafson, 1996), few studies have examined the specific role of parenting stress and its relationship to adjustment outcomes in these populations.

In a longitudinal investigation of the relationship between parenting stress, quality of life, and long-term adjustment in 29 children with leukemia and their parents, Kazak and Barakat (1997) found that for both mothers and fathers, higher levels of parenting stress while the child was undergoing treatment were significantly related to higher levels of parental state anxiety after the completion of the child's treatment. Furthermore, for fathers, posttraumatic stress after the child's treatment was also associated with earlier levels of parenting stress. The researchers suggest that based on these findings, the examination of parent-reported stress early in the child's treatment may help to identify families at risk for poorer long-term adjustment.

In a study of 35 caregivers (i.e., biological mothers and foster mothers) of children with HIV, Chalfin and colleagues (2002) found that biological mothers reported clinically significant levels of parenting stress, while the level of stress for foster mothers fell within the normal range. In addition to increased levels of parenting stress, biological mothers also reported significantly more depression and anxiety than the foster mothers. The researchers suggested that these differences were most likely due to a variety of demographic variables, which served to *protect* foster mothers. Specifically, the foster mothers were found to be significantly older than the biological mothers, and had significantly more financial resources and social support. These findings suggest that demographic variables and potentially illness-specific characteristics can affect levels of parenting stress.

In an effort to identify whether illness characteristics play a significant role in the level of parenting stress, Hung and colleagues (2004) compared the stress levels of parents of children with either a physical disability or cancer. Their results revealed that parents of children with cancer exhibited significantly higher levels of parenting stress than parents of children with a physical disability. Notably, the two groups differed on all three subscales of the Parenting Stress Index (i.e., parental distress, parent-child dysfunctional interaction, difficult child) in addition to the total parenting stress score. Furthermore, no significant relationships were found between the levels of parenting stress and a variety of demographic variables (e.g., mother's age, child's age, mother's education) in the sample. The researchers suggested that the unpredictable course of cancer could be one reason for the increased levels of parenting stress. These findings are consistent with a previous qualitative study which indicated that parents of children with cancer were more likely to conceal information or to hide their negative emotions from their child, as compared to parents of children with physical disabilities (Yeh, 2002). The researchers suggest that the behaviors of concealing information and hiding negative emotions could indeed result in increased levels of stress for parents.

In a recent study of the relationships between parenting variables (i.e., parental overprotection, perceived child vulnerability, parenting stress) and child cognitive appraisals (i.e., illness uncertainty), in a sample of children and adolescents with Type 1 diabetes mellitus, Mullins and colleagues (2007) found that perceived vulnerability and parenting stress were independently associated with the child's level of illness uncertainty. Moreover, the results indicated different interrelationships of the variables based on the age-related developmental level of the child. Specifically, the level of uncertainty for children was associated with the parent's level of parenting stress, whereas adolescents' uncertainty was associated with their parent's perceptions of vulnerability. These findings suggest that parenting stress may differentially affect child adjustment depending on the developmental level of the child.

Carpentier and colleagues (2007) extended the findings of Mullins et al (2007) by examining the relationships between parenting variables (i.e., parental overprotection, perceived vulnerability, parenting stress) and child adjustment outcomes (i.e., emotional, behavioral, social) in a sample of 68 parents of children with cancer. Their results revealed that although perceived vulnerability emerged as a significant predictor of child emotional adjustment, parenting stress was a consistent predictor of child emotional, behavioral, and social adjustment. Specifically, higher levels of parenting stress were related to more internalizing problems, externalizing problems, and fewer prosocial behaviors in their children. These findings underscore the notion that increased parenting stress not only affects the parent, but has the ability to influence child adjustment outcomes as well.

Although the abovementioned studies examined the direct relationships between parenting stress and adjustment outcomes, other studies have investigated the indirect effects of parenting stress. For example, Mullins and colleagues (2004) examined the *moderating* role of parenting stress in the relationship between parenting variables and child depression in a sample of 43 mothers of children with Type 1 diabetes. Their results indicated that although perceived child vulnerability and parenting stress were both independently related to the child’s depressive symptoms, parenting stress also moderated the relationship between perceived vulnerability and child depression. In other words, the relationship between perceived vulnerability and child depression was magnified under conditions of high parenting stress.

Although there are few empirical investigations of the relationship of parenting stress to adjustment outcomes in parents of children with chronic illness, the findings across the studies are similar. They all provide evidence that parents of children with chronic illness indeed experience increased levels of parenting stress, and that this stress is related to a variety of adjustment outcomes, including current and future parental psychological distress, child depressive symptoms, and child illness uncertainty. Moreover, these studies suggest that parenting stress can be influenced by a variety of demographic variables and illness parameters.

Chapter Summary

In summary, pediatric cancer is the leading cause of death in children ages 1 -14 (NCI, 2005). As such, a diagnosis of pediatric cancer exerts system-wide effects on the child’s family. Following the diagnosis, parents are faced with the sudden onset of a new caregiving role; one that is accompanied by increased burden, stress, and heightened levels of uncertainty regarding their child’s illness, treatment, and ultimate survival. The parents’ abilities to adjust to this new role has far reaching effects, as it is well documented that their adjustment significantly impacts the adjustment outcomes of their child. What remains to be determined are the unique roles of specific parent variables in contributing to an array of adjustment outcomes in these children.

CHAPTER III

THE PRESENT STUDY

The preceding literature review clearly demonstrates that parents of children with a chronic illness are at risk for a myriad of stressors, including uncertainty about their child’s survival, a sudden onset of new caregiving roles, and an increase in the general stress related to parenting. Moreover, previous research has documented that high levels of uncertainty, caregiver burden, and parenting stress are all independently related to a variety of poor adjustment outcomes, including psychological distress and maladaptive coping strategies. Given the transactional relationship between parent and child adjustment to chronic illness, child adjustment outcomes are greatly influenced by the adjustment of the parent. Therefore, it stands to reason that parents who experience heightened levels of parental uncertainty and increased levels of caregiver burden are putting their child at increased risk for poor adjustment outcomes.

Although the constructs of parental uncertainty and caregiver burden have been previously independently examined within the context of pediatric cancer, to our knowledge, no studies have examined their relationships to child adjustment outcomes in this population. Furthermore, the relationship between parental uncertainty and caregiver burden has not been formally assessed, although previous research suggests they are indeed related. Thus, the current study seeks to fill these gaps in the literature in addition to investigating the moderating role of parenting stress on the parenting variables-child adjustment relationships.

The present study was guided by the following aims:

Aim 1. To determine the differential contribution of parental uncertainty and caregiver burden to the emotional, behavioral, and social adjustment of children with cancer.

Hypothesis: It was hypothesized that heightened levels of parental uncertainty and increased levels of caregiver burden will be independently related to poorer emotional (i.e., more internalizing behaviors), behavioral (i.e., more acting out behaviors), and social (i.e., fewer prosocial behaviors) in their child.

Aim 2. To determine whether parenting stress moderates the relationship between parental uncertainty and child adjustment outcomes.

Hypothesis: It was hypothesized that the relationship between parental uncertainty and child adjustment outcomes (i.e., emotional, behavioral, and social) will be moderated by parenting stress.

Aim 3. To determine whether parenting stress moderates the relationship between caregiver burden and child adjustment outcomes.

Hypothesis: It was hypothesized that the relationship between caregiver burden and child adjustment outcomes (i.e., emotional, behavioral, and social) will be moderated by parenting stress.

Additional research questions addressed in the present study were as follows:

Research Question 1. Are any of the demographic variables (i.e., child age, child gender, parent age, parent education), or illness parameters [i.e., age at diagnosis, illness duration, severity of illness, disease group (CNS vs. non CNS)] significantly related to the levels of parental uncertainty and caregiver burden?

Research Question 2. Are levels of caregiver burden related to levels of parental uncertainty?

In order to test these hypotheses and explore the additional research questions, parents of children currently on treatment for pediatric cancer will be recruited from the Jimmy Everest Cancer Center in Oklahoma City, Oklahoma. All participants will be asked to complete a demographic form in addition to measures of parental uncertainty, caregiver burden, parenting stress, and child emotional, behavioral, and social adjustment. The information for each of these measures in addition to a detailed explanation of the present study's procedures will be addressed in the next chapter.

CHAPTER IV

METHOD

Participants

Participants for the current study were 46 parents (37 mothers, 6 fathers, 3 custodial grandparents) of children (29 boys, 17 girls) between the ages of 2 and 12 years old (*M* = 6.84, *SD* = 3.26) who had been diagnosed with pediatric cancer. Specifically, 29 of the children (63%) had been diagnosed with leukemia or lymphoma, 8 were diagnosed with a solid tumor (17.4%), 5 (10.8%) had a diagnosis of a brain tumor, and 2 (4.3%) had an "other" diagnosis. The children's age at diagnosis ranged from 1 to 12 years old (*M* = 5.67, *SD* = 3.25) and the duration of their illness, which was calculated by subtracting their date of diagnosis from the date of participation in the study, ranged from 1 to 66 months (*M* = 11.04, *SD* = 14.15).

The parent participants ranged in age from 23 to 74 years old (*M* = 35.35, *SD* = 9.51) and had a mean educational attainment of 13.85 years (*range:* 8 – 16). With regard to race and ethnicity, 84.8% of the sample self-identified as Caucasian, 4.3% as African American, 4.3% as Hispanic, 2.2% as Native American, 2.2% as Asian, and 2.2% as "other". The majority of parents reported being married (73.9%). Additionally, 28.3% of the sample reported an annual family income of less than $20,000, 30.5% reported an income between $20,000 and $40,000, and the remaining 28.3% reported an annual income of more than $40,000.

Inclusion criteria for the current study included: 1) the child was between the ages of 2 and 12 years old; 2) the child was receiving treatment for pediatric cancer at the time of participation in the study; and 3) the parent spoke English as his/her primary language. Exclusion criteria included: 1) the child with cancer was experiencing an imminent medical crisis necessitating significant medical intervention; 2) the child with cancer was determined to be in the terminal phase and/or was receiving palliative care; 3) the parent was currently being treated for a serious psychiatric disorder, or, evidenced mental retardation; and 4) the child with cancer evidenced mental retardation or a significant developmental delay.

Measures (See Appendix B)

Demographic Form. A demographic form was used to collect data regarding the child’s cancer treatment, including primary and secondary diagnoses, date of diagnosis, age at diagnosis, type of treatments received, number of relapses, and complications secondary to treatment. Additionally, demographic variables such as the child’s current age and grade, the number of people living in the home, the ages and occupations of the child’s parents, and annual household income were also collected.

Medical Chart Review. A medical chart review was conducted by a trained graduate research assistant to obtain information regarding the child’s diagnosis, treatment protocol (i.e., length of treatment, type and dosage of chemotherapy drugs, radiation dosage), and secondary complications.

Severity of Illness Scale. (*SOIS; Young-Saleme & Prevatt, 2001*). The SOIS is a six-item Likert-format scale yielding an overall score for severity of illness in children diagnosed with cancer. To reduce the potential for variability between raters, one clinic nurse who had frequent contact with participants was designated to complete the SOIS forms. Domains assessed by the SOIS include: (a) degree of impairment, (b) future outlook, (c) quantity of medical procedures required, (d) number of hospitalizations, (e) ability to participate in activities, and (f) prognosis. Items are summed to create a single total score, with higher scores indicating greater severity. The SOIS demonstrates good psychometric properties, with acceptable internal consistency, test-retest, and interrater reliability estimates. Internal consistency estimates have yielded total alpha scores of .79 for physicians and .80 for nurses. Test-retest reliability coefficients range from .96 to .92 for time periods of 2 weeks to 3 months. Interrater reliability comparing physician ratings to nurse ratings is approximately .89 (Young-Saleme & Prevatt, 2001). Unfortunately, due to an increase in the workload for each of the nurses in the outpatient clinic, the SOIS ratings were not able to be collected at the time of the parents' participation in the current study.

Parental Perceptions of Uncertainty Scale. *(PPUS: Mishel, 1983)*. The PPUS is a 31-item self-report measure of perceived uncertainty in reference to a child's illness. Parents were asked to rate each item on 5-point scale ranging from (1) "strongly disagree" to (5) "strongly agree." Examples of the items include: "I am unsure if my child's illness is getting better or worse", and "It is unclear how bad my child's discomfort will be". The items were summed to create a total uncertainty score, with higher scores indicating greater uncertainty. In the current study, the total score was used as the measure of parental perception of illness uncertainty. The PPUS has demonstrated high internal consistency ($\alpha = .91$). Additionally, construct validity for the PPUS was established using factor analysis and yielded 4 distinct factors that differentiated the sample on a range of medical variables (Mishel, 1983). Cronbach’s alpha for the current sample was .90.

The Care of My Child with Cancer Scale. (*CMCCS: Wells et al., 2002*). The CMCCS is a 28-item self-report questionnaire, which assesses the caregiving demand experienced by parents of children with cancer. The CMCCS assesses five distinct dimensions of caregiving: physical care of the child, emotional care of all family members, financial management, maintenance of family roles and functions, and communication with health care professionals and other related agencies. For each item, the parent was first asked to rate the amount of time they spend performing a task, on a 5-point scale ranging from “none” to “> 5 hours/week.” Next, the parent was asked to rate the effort/difficulty of the same task on a 5-point scale ranging from “none” to “a great deal.” Examples of the items included: “Preparing and giving medication by mouth” and “Coordinating, arranging, and managing medical services”. The CMCCS was scored by first calculating a “demand” score for each item, which was achieved by multiplying the “time” and “effort” scores for a particular item and then taking the square root of the product. This procedure resulted in a “demand” score ranging from 1 to 5 for each item. Next, the demand scores were summed to create a total score on the measure, with higher scores indicative of greater caregiver demand. In the current study, the total score was used as the measure of caregiver burden. The CMCCS has demonstrated high test-retest reliability (*r* = .90) over a 3-7 day period and high internal consistency (Cronbach’s alpha = .93). Finally, construct validity was established by factor analysis, which yielded a four-factor solution (Wells et al., 2002). Internal consistency for the current sample was high (Cronbach’s alpha = .92).

Parenting Stress Index/Short Form. (PSI/SF: Abidin, 1990). The relative magnitude of parenting stress in the parent-child system was measured using the Parenting Stress Index/Short Form. The PSI/SF is a 36-item parent self-report instrument with a 5-point response scale ranging from 1 (“strongly agree”) to 5 (“strongly disagree”). Items included statements such as: “I feel trapped by my responsibilities as a parent,” and “My child makes more demands on me than most children.” The PSI/SF yields three subscale scores, including stress attributable to the parent’s personal distress, distress related to the child, and relational distress between the parent and child in addition to a total stress score. In the current study, the total score was used as the measure of parenting stress. The PSI/SF is highly correlated with the full-length PSI instrument (r = .94) and two-week test-retest reliability of the full-length PSI with the PSI/SF is .95 (Abidin, 1990). Although the validity of the PSI/SF has yet to be formally assessed, Abidin (1990) suggests that the validity is similar to that of the full-length PSI given their relationship. The validity of the full-length PSI has been established in a range of populations, including parents of children with asthma (Carson & Schauer, 1992) and diabetes mellitus (Wysocki, Huxtable, Linscheid, & Wayne, 1989). The internal consistency for the current sample was high (Cronbach’s alpha = .94).

Behavior Assessment System for Children, 2nd ed. (BASC-2: Reynolds & Kamphaus, 2004). The BASC-2 is a multidimensional approach to evaluating the behavior and self-perceptions of children and adolescents. For purposes of the current project, only the Parent Rating Scale (BASC-2-PRS) was utilized. For children ages 2 – 5, the BASC-2-PRS Preschool version, containing 134 items was administered, for children ages 6 – 11, the BASC-2-PRS Child version, containing 160 items was administered, and for children ages 12-21, the BASC-2-PRS Adolescent version, containing 150 items was administered. For each item, the parent was asked to read each description and to rate how often their child exhibited that behavior on a 4-point Likert scale ranging from "never" to "almost always." The BASC-2-PRS yields 10 clinical subscales and 5 composite scales, with higher scores indicative of more problems. In the current study the Externalizing Problems composite score and Internalizing Problems composite score were used as the measures of parent-rated behavioral and emotional adjustment of their child, respectively. The BASC-2 has good psychometric properties, with internal consistency estimates ranging from .70s to .80s, and composite reliability estimates ranging from high .80s to low .90s. In the current sample, Cronbach's alpha ranged from .91 to .95 across the three versions for the Externalizing Problems composite score, and from .89 to .93 across the three versions of the Internalizing Problems composite score. The BASC-2 has demonstrated construct, convergent, and divergent validity when compared to measures such as the Child Behavior Checklist (CBCL) and the Children's Depression Inventory (CDI).

<u>*Social Skills Rating System*</u>. (*SSRS: Gresham & Elliott, 1990*). The SSRS is a multi-informant system used to measure perceived frequency of social behaviors in children ranging in age from 2 to 18 (preschool to grade 12). The system consists of teacher, parent, and child forms; in the current study, only the parent forms were utilized. Parents were asked to read the description of a social behavior and to rate how often their child exhibits that behavior, ranging from 0 ("never") to 2 ("very often"). Items included statements such as, "My child helps other children without being asked." The SSRS yields 7 subscale scores and 2 composite scores. In the current study, the Social Skills

(SS) composite score, which assesses the frequency of the child's positive social behaviors, was utilized as the measure of parent-rated social adjustment. Higher scores are indicative of more positive social behaviors, which in turn, reflect better social adjustment. The SSRS demonstrates sound psychometric properties, with internal consistency estimates ranging from .83 to .90 for the parent-rated Social Skills composite. In the current sample, internal consistency was good across the two versions (Preschool: Cronbach's alpha = .89, Elementary: Cronbach's alpha = .85). Additionally, criterion validity has been established for the SSRS by comparing it with the CBCL (Gresham & Elliott, 1990).

Procedures

Potential participants for the current study were recruited from the Jimmy Everest Cancer for Childhood Cancer and Bleeding Disorders (JEC) at the University of Oklahoma Health Sciences Center. The recruitment of participants occurred as follows: 1) the JEC's outpatient schedule was checked on a daily basis for children who were attending an oncology appointment; 2) the child's date of birth, date of diagnosis, and treatment status were identified through the clinic's database; 3) consultation was then held with the attending physician to assess medical eligibility for the study; and 4) the child and his/her parent were approached in the waiting room by a graduate research assistant trained in the process of informed consent and HIPAA research guidelines. The study was described to parent participants, and they were informed that consent to participate would in no way influence their child's medical treatment. Consent was obtained in conformity with standards of the OUHSC and OSU Institutional Review Boards (IRB) and the participants were presented with the measures to complete while they are waiting. Participants were given the opportunity to complete the measures in a private room in the clinic to insure confidentiality. Each family was compensated with a $20.00 gift card as a “thank you” for participating in the current study. A total of 50 parents were approached for recruitment into the current study. All 50 parents consented to participate, and 92% (*n* = 46) of them completed the study. The remaining 4 participants took the measures home and did not return them to the clinic, even after receiving in-clinic reminders.

Once measures were collected from the participants and double-checked for completeness by the graduate research assistant, the data was entered into a previously created database in SPSS for data analyses. Additionally, a review of the patient’s medical chart was conducted to obtain the medical data described above. All raw data was identified by a subject number and was stored in a locked filing cabinet in the research office, with consent forms, HIPAA privacy forms, and demographic forms removed and stored separately to insure confidentiality of the participants.

CHAPTER V

RESULTS

Preliminary Analyses

First, descriptive statistics were calculated for all of the variables of interest (See Appendix C: Table 1). Next, a series of bivariate correlations was conducted to determine if any of the demographic variables (i.e., child age, child gender, parent age, parent education, and annual family income) or illness parameters [i.e., age at diagnosis, illness duration, severity of illness, disease group (Central Nervous System vs. non-Central Nervous System)] were related to any of the outcome variables (i.e., externalizing problems, internalizing problems, prosocial behaviors). With regard to the demographic variables, results revealed that higher annual family income was significantly correlated with fewer externalizing problems, fewer internalizing problems, and more prosocial behaviors. Additionally, older child age was significantly correlated with more prosocial behaviors (See Table 2). With regard to illness characteristics, longer illness duration was significantly correlated with fewer prosocial behaviors, while older child age at diagnosis was correlated with more prosocial behaviors (See Table 3). No other correlations were significant.

To determine whether the parents (i.e., mothers, fathers, custodial grandparents) differed on either of the predictor variables (i.e., parental uncertainty, caregiver burden), one-way ANOVAs were conducted. Results revealed no significant differences between the groups (both *p*'s > .05). As such, all caregiver participants were included in the initial set of analyses. Finally, to determine whether significant relationships existed between the predictor variables (i.e., parental uncertainty, caregiver burden) and the outcome variables (i.e., externalizing problems, internalizing problems, prosocial behaviors), a series of bivariate correlations was conducted. Results revealed that higher levels of parental uncertainty were significantly related to more internalizing problems and fewer prosocial behaviors (See Table 4). Caregiver burden was unrelated to any of the outcome variables.

Primary Analyses

First, collinearity statistics were run for all primary analyses. These results revealed that multicollinearity was not a problem in any of the analyses. To address Aim 1 and to test the hypothesis that heightened levels of parental uncertainty and increased caregiver burden were independently related to poorer behavioral (i.e., more externalizing or acting out behavior), emotional (i.e., more internalizing problems), and social adjustment (i.e., fewer prosocial behaviors) in the child, three separate hierarchical regression analyses were utilized.

Externalizing Problems

Following Thompson and Gustafson's (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., annual family income) were entered on Step 1, and the parental uncertainty (PU) score and caregiver burden (CB) score were simultaneously entered as the predictor variables on Step 2. The BASC-2 Externalizing Problems (EP) composite score served as the dependent variable. Neither predictor variable was significantly related to externalizing behaviors in the child, nor was the overall model significant ($p > .05$; See Table 5).

Internalizing Problems

Following Thompson and Gustafson’s (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., annual family income) were entered on Step 1, and the parental uncertainty (PU) score and caregiver burden (CB) score were simultaneously entered as the predictor variables on Step 2. The BASC-2 Internalizing Problems (IP) composite score served as the dependent variable. Results revealed that the overall model was significant ($F(3,36) = 10.08$, $p < .001$, power = .99). Additionally, although parental uncertainty was not a significant predictor of internalizing problems ($p > .05$), caregiver burden showed a trend towards significance ($t(39) = -1.95$, $p = .06$; See Table 6), suggesting that there may indeed be a relationship between higher levels of caregiver burden and child internalizing problems.

Prosocial Behaviors

Following Thompson and Gustafson’s (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., child age, annual family income) were entered on Step 1, illness covariates identified by significant correlations in the preliminary analyses (i.e., duration of illness) were entered on Step 2, and the parental uncertainty (PU) score and caregiver burden (CB) score were simultaneously entered as the predictor variables on Step 3. The SSRS Social Skills (SS) score served as the dependent variable. Results revealed that the overall model was significant (*F*(5,31) = 6.05, *p* = .001, power = .99), however neither parental uncertainty nor caregiver burden emerged as independent predictors of prosocial behavior (See Table 7).

To address Aim 2 and to test the hypothesis that parenting stress would moderate the relationship between parental uncertainty and child adjustment outcomes, hierarchical regression analyses were used. To test for moderation, the parenting stress (PS) and parental uncertainty (PU) variables were centered by subtracting the mean from each individual score. Next, an interaction term was created by multiplying the centered parenting stress variable with the centered parental uncertainty variable (PS x PU) (Cohen, Cohen, West, & Aiken, 2003).

Externalizing Problems

Following Thompson and Gustafson's (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., annual family income) were entered on Step 1, while the centered PU, centered PS, and PS x PU interaction scores were entered simultaneously as predictors on Step 2. The BASC-2 Externalizing Problems (EP) composite score served as the dependent variable. Results revealed that the overall model was significant (*F*(4,37) = 4.94, *p* < .01, power = .96) and that parenting stress emerged as a significant independent predictor of externalizing problems (*t*(41) = 3.91, *p* < .01). However, the PS x PU interaction term was not significant, indicating that parenting stress did not moderate the relationship between parental uncertainty and the children's externalizing problems in this sample (See Table 8).

Internalizing Problems

Following Thompson and Gustafson’s (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., annual family income) were entered on Step 1, while the centered PU, centered PS, and PS x PU interaction scores were entered simultaneously as predictors on Step 2. The BASC-2 Internalizing Problems (IP) composite score served as the dependent variable. Results revealed that the overall model was significant ($F(4,37) = 8.24$, $p < .001$, power = .99). However, the PS x PU interaction term was not significant, indicating that parenting stress did not moderate the relationship between parental uncertainty and the children’s internalizing problems in this sample (See Table 9.

Prosocial Behaviors

Following Thompson and Gustafson’s (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., child age, annual family income) were entered on Step 1, illness covariates identified by significant correlations in the preliminary analyses (i.e., duration of illness) were entered on Step 2, and the centered PU, centered PS, and PS x PU interaction scores were entered simultaneously as predictors on Step 3. The SSRS Social Skills (SS) score served as the dependent variable. Results revealed that the overall model was significant ($F(6,32) = 9.50$, $p < .001$, power = .99) and that parenting stress emerged as a significant independent predictor of prosocial behaviors ($t(38) = -3.32$, $p < .01$). However, the PS x PU interaction term was not significant, indicating that parenting stress did not moderate the relationship between parental uncertainty and the children’s prosocial behaviors in this sample (See Table 10.

To address Aim 3 and to test the hypothesis that parenting stress would moderate the relationship between caregiver burden and child adjustment outcomes, hierarchical regression analyses were used. To test for moderation, the parenting stress (PS) and caregiver burden (CB) variables were centered by subtracting the mean from each individual score. Next, an interaction term was created by multiplying the centered parenting stress variable with the centered caregiver burden variable (PS x CB).

Externalizing Problems

Following Thompson and Gustafson's (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., annual family income) were entered on Step 1, while the centered CB, centered PS, and PS x CB interaction scores were entered simultaneously as predictors on Step 2. The BASC-2 Externalizing Problems (EP) composite score served as the dependent variable. Results revealed that the overall model was significant ($F(4,34) = 4.78$, $p < .01$, power = .95) and that parenting stress emerged as a significant independent predictor of externalizing problems ($t(38) = 3.76$, $p < .01$). However, the PS x CB interaction term was not significant, indicating that parenting stress did not moderate the relationship between caregiver burden and the children's externalizing problems in this sample (See Table 11).

Internalizing Problems

Following Thompson and Gustafson's (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., annual family income) were entered on Step 1, while the centered CB, centered PS, and PS x CB interaction scores were entered simultaneously as predictors on

Step 2. The BASC-2 Internalizing Problems (IP) composite score served as the dependent variable. Results revealed that the overall model was significant ($F(4,34) = 6.92$, $p < .001$, power = .99) and that parenting stress emerged as a significant independent predictor of internalizing problems ($t(38) = 2.53$, $p < .05$). However, the PS x CB interaction term was not significant, indicating that parenting stress did not moderate the relationship between caregiver burden and the children's internalizing problems in this sample (See Table 12.

Prosocial Behaviors

Following Thompson and Gustafson's (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., child age, annual family income) were entered on Step 1, illness covariates identified by significant correlations in the preliminary analyses (i.e., duration of illness) were entered on Step 2, and the centered CB, centered PS, and PS x CB interaction scores were entered simultaneously as predictors on Step 3. The SSRS Social Skills (SS) score served as the dependent variable. Results revealed that the overall model was significant ($F(6, 29) = 10.26$, $p < .001$, power = .99) and that parenting stress emerged as a significant independent predictor of prosocial behaviors ($t(35) = -4.95$, $p < .01$). However, the PS x CB interaction term was not significant, indicating that parenting stress did not moderate the relationship between caregiver burden and the children's prosocial behaviors in this sample (See Table 13.

To address the first research question regarding the relationships between demographic variables (i.e., child age, child gender, parent age, parent education), illness parameters [i.e., age at diagnosis, illness duration, disease group (CNS vs. non CNS)], and parental uncertainty and caregiver burden, a series of bivariate correlations were conducted. Results revealed that none of the demographic variables or illness parameters were significantly related to either parental uncertainty or caregiver burden (all *p*'s > .05; See Table 14).

To address the second research question regarding the relationship between parental uncertainty and caregiver burden, a bivariate correlation was conducted. Results revealed that higher levels of parental uncertainty were significantly related to higher levels of caregiver burden (See Table 15).

Exploratory Analyses

Findings from previous studies in pediatric cancer research have documented differential outcomes for mothers and fathers on several dimensions of psychological adjustment to their child's illness (Kazak, Barakat, Meeske, 1997; Pai, Drotar, Zebracki, Moore, & Youngstrom 2006; Pai et al., 2007). Although results from the preliminary analyses in the current study did not yield significant differences between the groups of caregivers (i.e., mothers, fathers, grandparents) on levels of parental uncertainty or caregiver burden, it is possible that this non significant finding is attributable to a small sample size and thus low power to detect differences between the groups. As such, we conducted exploratory analyses using a sample of mothers-only in an effort to reduce the variability that may be accounted for by type of caregiver.

Preliminary Analyses for Subsample of Mothers Only

A series of bivariate correlations was conducted to determine if any of the demographic variables (i.e., child age, child gender, parent age, parent education, and annual family income) or illness parameters [i.e., age at diagnosis, duration of illness, severity of illness, disease group (Central Nervous System vs. non-Central Nervous System)] were related to any of the outcome variables (i.e., externalizing problems, internalizing problems, prosocial behaviors). With regard to the demographic variables, results revealed that higher annual family income was significantly correlated with fewer externalizing problems, and fewer internalizing problems (See Table 16). With regard to illness characteristics, longer illness duration was significantly correlated with fewer prosocial behaviors, while older child age at diagnosis was correlated with more prosocial behaviors. No other correlations were significant (See Table 17). Finally, to determine whether significant relationships existed between the predictor variables (i.e., parental uncertainty, caregiver burden) and the outcome variables (i.e., externalizing problems, internalizing problems, prosocial behaviors), a series of bivariate correlations was conducted. Results revealed that higher levels of parental uncertainty were significantly related to more internalizing problems (See Table 18). In contrast, caregiver burden was not related to any of the outcome variables.

Primary Analyses for Subsample of Mothers Only

To address Aim 1 and to test the hypothesis that heightened levels of parental uncertainty and increased caregiver burden were independently related to poorer behavioral (i.e., more externalizing or acting out behavior), emotional (i.e., more internalizing problems), and social adjustment (i.e., fewer prosocial behaviors) in the child, three separate hierarchical regression analyses were utilized.

Externalizing Problems

Following Thompson and Gustafson’s (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., annual family income) were entered on Step 1, and the parental uncertainty (PU) score and caregiver burden (CB) score were simultaneously entered as the predictor variables on Step 2. The BASC-2 Externalizing Problems (EP) composite score served as the dependent variable. Neither parental uncertainty or caregiver burden were related to externalizing problems, nor was the overall model significant ($p > .05$; See Table 19).

Internalizing Problems

Following Thompson and Gustafson's (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., annual family income) were entered on Step 1, and the parental uncertainty (PU) score and caregiver burden (CB) score were simultaneously entered as the predictor variables on Step 2. The BASC-2 Internalizing Problems (IP) composite score served as the dependent variable. Results revealed that the overall model was significant ($F(3,28) = 6.75$, $p = .001$, power = .97). Additionally, although parental uncertainty was not a significant predictor of internalizing problems ($p > .05$), caregiver burden showed a trend towards significance ($t(31) = 1.84$, $p = .08$; See Table 20).

Prosocial Behaviors

Following Thompson and Gustafson's (1996) transactional model of stress and coping, illness covariates identified by significant correlations in the preliminary analyses (i.e., duration of illness, child age at diagnosis) were entered on Step 1, and the parental uncertainty (PU) score and caregiver burden (CB) score were simultaneously entered as the predictor variables on Step 2. The SSRS Social Skills (SS) score served as the dependent variable. Results revealed that the overall model was significant ($F(4,22) = 3.66$, $p = .02$, power = .86). Additionally, although caregiver burden was not a significant predictor of prosocial behavior (p > .05), parental uncertainty showed a trend towards significance (t(26) = -2.03, p = .06; See Table 21).

To address Aim 2 and to test the hypothesis that parenting stress would moderate the relationship between parental uncertainty and child adjustment outcomes, hierarchical regression analyses were used. To test for moderation, the parenting stress (PS) and parental uncertainty (PU) variables were centered by subtracting the mean from each individual score. Next, an interaction term was created by multiplying the centered parenting stress variable with the centered parental uncertainty variable (PS x PU) (Cohen, Cohen, West & Aiken, 2003).

Externalizing Problems

Following Thompson and Gustafson’s (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., annual family income) were entered on Step 1, while the centered PU, centered PS, and PS x PU interaction scores were entered simultaneously as predictors on Step 2. The BASC-2 Externalizing Problems (EP) composite score served as the dependent variable. Results revealed that the overall model was significant (F(4,29) = 8.46, p < .001, power = .99), and that parenting stress emerged as a significant independent predictor of externalizing problems (t(33) = 5.03, p < .01). However, the PS x PU interaction term was not significant, indicating that parenting stress did not moderate the relationship between parental uncertainty and the children’s externalizing problems in this sample (See Table 22).

Internalizing Problems

Following Thompson and Gustafson's (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., annual family income) were entered on Step 1, while the centered PU, centered PS, and PS x PU interaction scores were entered simultaneously as predictors on Step 2. The BASC-2 Internalizing Problems (IP) composite score served as the dependent variable. Results revealed that the overall model was significant ($F(4,29) = 6.04$, $p = .001$, power = .98). However, the PS x PU interaction term was not significant, indicating that parenting stress did not moderate the relationship between parental uncertainty and the children's internalizing problems in this sample (See Table 23.

Prosocial Behaviors

Following Thompson and Gustafson's (1996) transactional model of stress and coping, illness covariates identified by significant correlations in the preliminary analyses (i.e., duration of illness, child's age at diagnosis) were entered on Step 1, and the centered PU, centered PS, and PS x PU interaction scores were entered simultaneously as predictors on Step 2. The SSRS Social Skills (SS) score served as the dependent variable. Results revealed that the overall model was significant ($F(5,23) = 6.87$, $p < .001$, power = .99), and that parenting stress emerged as a significant independent predictor of prosocial behaviors ($t(28) = -3.44$, $p < .01$). However, the PS x PU interaction term was not significant, indicating that parenting stress did not moderate the relationship between parental uncertainty and the children's prosocial behaviors in this sample (See Table 24).

To address Aim 3 and to test the hypothesis that parenting stress would moderate the relationship between caregiver burden and child adjustment outcomes, hierarchical regression analyses were used. To test for moderation, the parenting stress (PS) and caregiver burden (CB) variables were centered by subtracting the mean from each individual score. Next, an interaction term was created by multiplying the centered parenting stress variable with the centered caregiver burden variable (PS x CB).

Externalizing Problems

Following Thompson and Gustafson's (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., annual family income) were entered on Step 1, while the centered CB, centered PS, and PS x CB interaction scores were entered simultaneously as predictors on Step 2. The BASC-2 Externalizing Problems (EP) composite score served as the dependent variable. Results revealed that the overall model was significant ($F(4,26) = 6.77$, $p = .001$, power = .99), and that parenting stress emerged as a significant independent predictor of externalizing problems ($t(30) = 4.65$, $p < .01$). However, the PS x CB interaction term was not significant, indicating that parenting stress did not moderate the relationship between caregiver burden and the children's externalizing problems in this sample (See Table 25.

Internalizing Problems

Following Thompson and Gustafson's (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., annual family income) were entered on Step 1, while the centered CB, centered PS, and PS x CB interaction scores were entered simultaneously as predictors on Step 2. The BASC-2 Internalizing Problems (IP) composite score served as the dependent variable. Results revealed that the overall model was significant ($F(4,26) = 9.13$, $p < .001$, power = .99), and that parenting stress emerged as a significant independent predictor of internalizing problems ($t(30) = -2.44$, $p < .05$). Additionally, the PS x CB interaction term was significant ($t(30) = 2.95$, $p < .01$), indicating that parenting stress indeed moderated the relationship between caregiver burden and the children's internalizing problems in this sample (See Table 26).

Prosocial Behaviors

Following Thompson and Gustafson's (1996) transactional model of stress and coping, illness covariates identified by significant correlations in the preliminary analyses (i.e., duration of illness, child's age at diagnosis) were entered on Step 1, and the centered CB, centered PS, and PS x CB interaction scores were entered simultaneously as predictors on Step 2. The SSRS Social Skills (SS) score served as the dependent variable. Results revealed that the overall model was significant ($F(5, 20) = 11.79$, $p < .001$, power = .99). Additionally, both parenting stress and caregiver burden emerged as significant independent predictors of prosocial behaviors ($t(25) = -5.51$, $p < .01$; $t(25) = 3.04$, $p < .01$, respectively). However, the PS x CB interaction term was not significant, indicating that parenting stress did not moderate the relationship between caregiver burden and the children's prosocial behaviors in this sample (See Table 27).

Exploratory Analyses for Subsample of Mothers Only

Holmbeck (2002) has warned that failing to conduct post-hoc probes of a moderational effect can lead to false positive results about the relationship of the variables. Therefore, post-hoc probes of the moderational effect of parenting stress on the relationship between caregiver burden and children's internalizing problems were conducted. Following Holmbeck's recommendations, first new conditional moderator variables (i.e., low parenting stress, high parenting stress) were created. Then, the new moderator variables were both multiplied by the centered caregiver burden score to create two new interaction terms. Finally, two hierarchical regression analyses were conducted. Following Thompson and Gustafson's (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., annual family income) were entered on Step 1, while the HighPSI, centered CB, and HighPSI x CB interaction term were entered simultaneously as predictors on Step 2. The BASC-2 Internalizing Problems (IP) composite score served as the dependent variable. Results revealed that the interaction term was indeed significant ($t(30) = 2.95$, $p = .01$). Additionally, the slope of the regression line for high parenting stress, which is determined by the significance of the caregiver burden main effect was also significant ($t(30) = 2.24$, $p = .03$) Next, following Thompson and Gustafson's (1996) transactional model of stress and coping, demographic covariates identified by significant correlations in the preliminary analyses (i.e., annual family income) were entered on Step 1, while the Low PSI, centered CB, and Low PSI x CB interaction term were entered simultaneously as predictors on Step 2. The BASC-2 Internalizing Problems (IP) composite score served as the dependent variable. Results revealed that the interaction term was indeed significant ($t(30) = 2.95$, $p = .01$). Furthermore, the slope of the regression line for low parenting stress, which is determined by the significance of the caregiver burden main effect, was also significant ($t(30) = -2.17$, $p = .04$; See Figure 1).

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CHAPTER VI

DISCUSSION

The purpose of the current study was to investigate the constructs of parental uncertainty and caregiver burden within the context of pediatric cancer. Specifically, the present study sought to determine whether levels of parental uncertainty and caregiver burden were related to adjustment outcomes in children with a diagnosis of pediatric cancer. Additionally, the moderating role of parenting stress on these parenting variables – child adjustment relationships was also examined. The present study was guided by three hypotheses and two research questions.

The first hypothesis stated that heightened levels of parental uncertainty and caregiver burden would be independently related to poorer behavioral (i.e., more acting out behaviors), emotional (i.e., more internalizing behaviors), and social (i.e., fewer prosocial behaviors) in their child. Contrary to prediction, the results revealed that after controlling for demographic and illness covariates, neither parental uncertainty nor caregiver burden was significantly related to any of the adjustment outcomes. These non-significant findings emerged in both the total sample of all parents as well as in the mothers-only sample. However, in both samples, the relationship between caregiver burden and child internalizing problems showed trends toward significance in the predicted direction, and therefore should be examined with larger samples in future studies. Notably, the overall regression models for internalizing problems and prosocial behaviors were both significant, yet these effects were driven by the strong relationship between annual family income and the outcome variables, rather than by the relationships between parental uncertainty, caregiver burden, and the adjustment outcomes. In particular, family income demonstrated a very strong relationship to child adjustment, more so than in other research conducted by in this same setting by the same set of researchers (Colletti et al., in press). Whether this is an anomalous finding remains to be determined by future research.

The second hypothesis stated that the relationship between parental uncertainty and child adjustment outcomes (i.e., behavioral, emotional, and social) would be moderated by parenting stress. Results revealed that the parent's level of stress did not moderate the relationships between level of parental uncertainty and the child's behavioral, emotional, and social functioning in either the total sample of parents, or the mothers-only sample. Notably, significant relationships did emerge between parenting stress and the internalizing problems and prosocial behavior variables in both samples. These findings suggest that although higher levels of parenting stress were associated with more internalizing problems and fewer prosocial behaviors, it does not appear that levels of parenting stress interact with levels of parental uncertainty to affect child adjustment outcomes.

The third hypothesis stated that the relationship between caregiver burden and child adjustment outcomes (i.e., behavioral, emotional, and social) would be moderated by parenting stress. Results revealed that in the total sample of parents, level of parenting stress did not moderate the relationships between level of caregiver burden and the child’s behavioral, emotional, or social functioning. However, in the mothers-only sample, parenting stress moderated the relationship between caregiver burden and the child’s internalizing problems. Specifically, children evidenced better emotional adjustment (i.e., less internalizing problems) under conditions of high caregiver burden and low parenting stress. In contrast, children evidenced poorer emotional adjustment (i.e., more internalizing problems) under conditions of low caregiver burden and low parenting stress. While there is not a clear explanation for this finding, it is suggested that mothers who are evidencing high levels of burden due to their hands-on involvement in the child’s treatment and care, but are not overwhelmed by the situation (i.e., evidencing lower stress), have children who are better adjusted with regard to their emotional functioning. On the other hand, mothers who reported low levels of both caregiver burden and parenting stress might be distancing themselves from the situation of the child’s illness. As such, it is possible that these mothers are also emotionally distancing themselves from their child, leaving him/her feeling isolated, withdrawn, sad or worried. Future research would benefit from a more comprehensive assessment of specific parent-child interactions via behavioral observation to address the interaction of parenting stress and caregiver burden.

Finally, the first research question investigated whether levels of parental uncertainty or caregiver burden were related to any of the demographic variables or illness parameters. The results revealed that for both the total sample of parents and the mothers-only sample, neither parental uncertainty nor caregiver burden were related to any of the demographic variables (i.e., child age, child sex, parent age, parent education, annual family income) or to the illness parameters (i.e., illness duration, child age at diagnosis, CNS involvement). These non-significant findings are surprising, and future research should examine the relationships between parental uncertainty, caregiver burden, and measures of parental adjustment, including psychological distress, coping style or cognitive appraisal mechanisms. Additionally, more specific aspects of the cancer treatment, such as intense chemotherapy or radiation could be independently related to heightened levels of parental uncertainty or caregiver burden. Unfortunately, these variables were not assessed in the current study.

The second research question examined whether levels of parental uncertainty and caregiver burden were significantly related to each other. In the total sample, the results indicated that parental uncertainty and caregiver burden were significantly related to each other, such that higher levels of uncertainty were related to higher levels of burden. However, when this relationship was examined in the mothers-only sample, it was not found to be significant. This finding suggests that the relationship between parental uncertainty and caregiver burden may indeed vary based on the type of caregiver (e.g., mothers, fathers, grandparents). Future studies should examine this relationship in larger, more heterogeneous samples of caregivers. Qualitative research involving focus groups or individual clinical interviews might also offer additional insight as to the interrelatedness of these two constructs in different populations of caregivers.

Although not a primary focus of the current study, it should be noted that one of the demographic variables (i.e., annual family income) was strongly correlated with all of the outcome variables (i.e., externalizing problems, internalizing problems, prosocial behaviors). The data indicated that in the current sample, lower family income was significantly correlated with more externalizing problems, more internalizing problems, and fewer prosocial behaviors. These findings are consistent with previous research on children with a chronic illness which has frequently documented lower socioeconomic status (SES) being related to poorer child adjustment outcomes (Thompson & Gustafson, 1996). It is important to consider that a higher annual family income is likely related to a higher level of parental education and more access to resources, which may serve as protective factors against psychological maladjustment. Thus, future research should focus on beginning to disentangle the interrelationships between annual income and various other demographic factors, such as parental education to determine the unique role that each of these variables plays with regard to parent and child adjustment to a chronic illness.

Strengths and Limitations

Although the current study is indeed preliminary in nature, there are several strengths that should be highlighted. First, this study utilized a relatively large sample size within the context of pediatric cancer, where studies with smaller samples sizes are often published. Second, the study included a sample of children with a wide age range who were at different stages of their cancer treatment. This allowed us to examine the relationship between “time-related” variables (i.e., child age, illness duration) and levels of parental uncertainty and caregiver burden. Finally, the current study utilized a measure of caregiver burden that was specifically designed for caregivers of children with cancer. As such, it addressed several aspects of the child’s treatment and illness that are unique to the pediatric cancer experience.

In addition to the aforementioned strengths of the current study, several limitations should also be acknowledged. First, the study is cross-sectional in nature, which precludes us from identifying causal relationships between the variables. Second, all of the measures in the current study were based on parent self-report, and thus the results might reflect shared method variance or common rater bias. Third, although attempts were made to collect data on level of illness severity, the illness severity forms were not completed by the nurse at the time of the parent's participation in the study. Although this lack of data for the entire sample is clearly a limitation of the study, previous research has documented that objective measures of illness severity are often unreliable predictors of adjustment outcomes (e.g., Stein et al., 1987). Certainly, it can be argued that illness severity could have a direct effect on a child's adjustment. As such, measures of disease status should be included in future research. Finally, given that the majority of the current sample self-identified as Caucasian, it is possible that these findings may not generalize to minority populations.

Future Directions

The current study is preliminary in nature, and although few significant relationships emerged in the context of the current sample, the results suggest that levels of parental uncertainty and caregiver burden should continue to be examined in pediatric cancer research. Future studies should utilize larger sample sizes with a variety of caregivers (i.e., mothers, fathers, grandparents, etc) to help differentiate the relationships between these parenting variables and their influence on child adjustment outcomes. Additionally, findings from the current study indicated that with regard to emotional adjustment, children of mothers who report high caregiver burden and low parenting stress appear to evidence better adjustment than children of mothers who report low levels of both caregiver burden and parenting stress. Future studies should be conducted to better investigate this finding, as a clear explanation is not available. Finally, the current study relied exclusively on measures of parent self-report. Future studies would benefit from including child self-report, especially with regard to their behavioral, emotional, and social functioning. A better understanding of the relationships and influence of parental uncertainty and caregiver burden on family adjustment in pediatric cancer research can lead to the development of interventions for families at risk for poor adjustment. These interventions can then be implemented early in the child's treatment course in an attempt to ameliorate future difficulties. As discussed previously, advances in medicine and the treatment of pediatric cancer have resulted in a 79% 5-year cure rate of all pediatric cancers combined (ACS, 2006). Although huge strides have been made in saving these children's lives, future research should be directed at improving their quality of life throughout their treatment and into survivorship.

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APPENDICES

Appendix A

INTERNATIONAL CLASSIFICATION OF CHILDHOOD CANCER, THIRD EDITION

International Classification of Childhood Cancer, Third Edition

I. Leukemias, myeloproliferative diseases, and myelodysplastic diseases

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

II. Lymphomas and reticuloendothelial neoplasms

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

III. CNS and miscellaneous intracranial and intraspinal neoplasms

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

IV. Neuroblastoma and other peripheral nervous cell tumors

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

V. Retinoblastoma

VI. Renal tumors

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

VII. Hepatic tumors

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

VIII. Malignant bone tumors

- a. Osteosarcomas
- b. Chondrosarcomas
- c. Ewing tumor and related sarcomas of bone
- d. Other specified malignant bone tumors
- e. Unspecified malignant bone tumors

IX. Soft tissue and other extraosseous sarcomas

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

X. Germ cell tumors, trophoblastic tumors, and neoplasms of gonads

- a. Intracranial and intraspinal germ cell tumors
- b. Malignant extracranial and extragonadal germ cell tumors
- c. Malignant gonadal germ cell tumors
- d. Gonadal carcinomas
- e. Other and unspecified malignant gonadal tumors

XI. Other malignant epithelial neoplasms and malignant melanomas

- a. Adrenocortical carcinomas
- b. Thyroid carcinomas
- c. Nasopharyngeal carcinomas
- d. Malignant melanomas
- e. Skin carcinomas
- f. Other and unspecified carcinomas

XII. Other and unspecified malignant neoplasms

- a. Other specified malignant tumors
- b. Other unspecified malignant tumors

CNS; central nervous system.

Appendix B

MEASURES

Demographic Form

Medical Chart Review

Severity of Illness Scale (SOIS)

(All other measures are copyrighted and must be obtained from the publisher)

DEMOGRAPHIC INFORMATION

Subject Number: __________

Today's Date: ______________

Child's Name: _____________________________Child's Gender: ____________

Mother's Name: _____________________________

Father's Name: _____________________________

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

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

Name	Relation to child	Age
__________________________	____________________________	_________
__________________________	____________________________	_________
__________________________	____________________________	_________
__________________________	____________________________	_________

What is your age? __________	What was *your age* when your child was diagnosed? _________
What is your spouse's age? __________	What was *your spouse's age* when your child was diagnosed? _________
What is your child's age? ___________	What was *your child's age* when he/she was diagnosed? _ ________

What grade is your child in? _______________________________

What is your race?

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

Parents' 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

_____ 5,000 – 9,999

_____ 10,000 – 14,999

______ 15,000 – 19,999

______ 20,000 – 29,999

______ 30,000 – 39,999

_______ 40,000 – 49,999

________ 50,000 – 59,999

________ 60,000 or greater

FORM FOR MEDICAL CHART REVIEW

Subject Number: ___________

Child's Diagnosis: ____

Date of Diagnosis: ____

Current Date: _________________

Date off Treatment: _________________________

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

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

Complications Secondary to Diagnosis and/or Treatment:
____
____
____

SEVERITY OF ILLNESS SCALE

Subject ID: ____________________ Date: ____________________

Completed By: ____

1. Describe the degree of impairment for this child.

1	2	3	4	5	6	7
Independent Functioning Requires no Assistance			Requires some Assistance (e.g., crutches)			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, sports, scouts, 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 C

TABLES AND FIGURE

Table 1. Descriptive Statistics for Study Variables

	Possible Range	Observed Range	*M*(*SD*)
Parental Uncertainty	31 - 155	47 – 111	71.35 (14.10)
Caregiver Burden	28 - 140	36.88 – 103.17	60.61 (17.42)
Externalizing Problems	35 – 100	34 – 65	46.53 (7.17)
Internalizing Problems	35 – 100	39 – 73	52.40 (9.18)
Prosocial Behaviors	35 – 140	67 – 131	99.00 (15.32)

Table 2. Zero-Order Correlations for Demographic Variables and Outcome Variables

	1	2	3	4	5	6	7	8
1. Child Sex		.33*	.27	.01	-.04	-.02	-.02	.19
2. Child Age			.26	.13	.10	-.15	-.24	.41**
3. Parent Age				-.04	-.08	-.20	-.06	.25
4. Parent Education					.51**	.15	-.22	.20
5. Annual Family Income						-.32*	-.61**	.34*
6. Externalizing Problems							.47**	-.38*
7. Internalizing Problems								-.34*
8. Prosocial Behaviors								

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

Table 3. Zero-Order Correlations for Illness Characteristics and Outcome Variables

	1	2	3	4	5	6
1. Duration of Illness		-.04	-.31*	.14	.07	-.34*
2. CNS Involvement			-.12	-.14	-.22	-.03
3.Child Age at Diagnosis				-.26	-.31	.54**
4. Externalizing Problems					.47**	-.38*
5. Internalizing Problems						-.37*
6. Prosocial Behaviors						

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

Table 4. Zero-Order Correlations for Predictor Variables and Outcome Variables

	1	2	3	4	5
1. Parental Uncertainty		.32*	.06	.31*	-.36*
2. Caregiver Burden			.11	.30	-.30
3. Externalizing Problems				.47**	-.34*
4. Internalizing Problems					-.34*
5. Prosocial Behaviors					

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

Table 5. Hierarchical Regression for Parental Uncertainty and Caregiver Burden on Externalizing Problems

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Family Income	-.32	-2.09*	.10	.10	4.39*
2	Parental Uncertainty	-.07	-.42	.01	.12	.29
	Caregiver Burden	.12	.73			

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

Table 6. Hierarchical Regression for Parental Uncertainty and Caregiver Burden on Internalizing Problems

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Family Income	-.56	-4.17**	.31	.31	17.37**
2	Parental Uncertainty	.16	1.11	.09	.41	2.84
	Caregiver Burden	.22	1.66			

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

Table 7. Hierarchical Regression for Parental Uncertainty and Caregiver Burden on Prosocial Behaviors

Step	Variable	Standardized β	t for within-step predictors	R^2 Change for step	Cumulative R^2	F Change for Step
1	Child Age	.42	2.95**	.31	.31	7.51**
	Family Income	.34	2.38*			
2	Illness Duration	-.31	-2.25*	.09	.40	5.07*
3	Parental Uncertainty	-.26	-1.67	.10	.49	2.91
	Caregiver Burden	-.16	-1.14			

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

Table 8. Hierarchical Regression for Moderation of the Relationship Between Parental Uncertainty and Externalizing Problems by Parenting Stress

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Family Income	-.27	-1.79	.07	.07	3.19
2	Parenting Stress	.74	3.91**	.27	.35	5.19**
	Parental Uncertainty	-.23	-1.65			
	PS x PU	-.24	-1.43			

*Note: PS x PU = Parenting Stress by Parental Uncertainty Interaction Term; * $p < .05$; ** $p < .01$*

Table 9. Hierarchical Regression for Moderation of the Relationship Between Parental Uncertainty and Internalizing Problems by Parenting Stress

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Family Income	-.59	-4.63**	.35	.35	21.44**
2	Parenting Stress	.30	1.76	.12	.47	2.85*
	Parental Uncertainty	.16	1.03			
	PS x PU	-.13	-.84			

*Note: PS x PU = Parenting Stress by Parental Uncertainty Interaction Term; * $p < .05$; ** $p < .01$*

Table 10. Hierarchical Regression for Moderation of the Relationship Between Parental Uncertainty and Prosocial Behaviors by Parenting Stress

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Child Age	.40	2.84**	.28	.28	6.91**
	Family Income	.32	2.22*			
2	Illness Duration	-.33	-2.44*	.11	.33	5.97*
3	Parenting Stress	-.54	-3.32**	.26	.64	7.65**
	Parental Uncertainty	.09	.63			
	PS x PU	-.08	-.60			

Note: PS x PU = Parenting Stress by Parental Uncertainty Interaction Term; $* p < .05$; $** p < .01$

Table 11. Hierarchical Regression for Moderation of the Relationship Between Caregiver Burden and Externalizing Problems by Parenting Stress

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Family Income	-.27	-1.70	.07	.07	2.88
2	Parenting Stress	.61	3.76**	.29	.36	5.09**
	Caregiver Burden	-.19	-1.17			
	PS x CB	-.24	-1.53			

*Note: PS x CB = Parenting Stress by Caregiver Burden Interaction Term; * p < .05; ** p < .01*

Table 12. Hierarchical Regression for Moderation of the Relationship Between Caregiver Burden and Internalizing Problems by Parenting Stress

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Family Income	-.53	-3.84**	.29	.29	14.76**
2	Parenting Stress	.38	2.53*	.16	.45	3.37*
	Caregiver Burden	.02	.11			
	PS x CB	.08	.57			

*Note: PS x CB = Parenting Stress by Caregiver Burden Interaction Term; * p < .05; ** p < .01*

Table 13. Hierarchical Regression for Moderation of the Relationship Between Caregiver Burden and Prosocial Behaviors by Parenting Stress

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Child Age	.44	3.05**	.32	.32	7.72**
	Family Income	.36	2.45*			
2	Illness Duration	-.29	-2.11*	.08	.40	4.45*
3	Parenting Stress	-.68	-4.95**	.28	.68	8.38**
	Caregiver Burden	.27	1.98			
	PS x CB	-.07	-.52			

*Note: PS x CB = Parenting Stress by Caregiver Burden Interaction Term; * p < .05; ** p < .01*

Table 14. Zero-Order Correlations for Demographic Variables and Predictor Variables

	1	2	3	4	5	6	7
1. Child Sex		.33*	.27	.01	-.04	-.01	-.16
2. Child Age			.26	.13	.10	-.15	-.20
3. Parent Age				-.04	-.08	-.03	-.06
4. Parent Education					.51**	-.23	.17
5. Annual Family Income						-.23	-.05
6. Parental Uncertainty							.32*
7.Caregiver Burden							

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

Table 15. Zero-Order Correlations for Illness Characteristics and Predictor Variables

	1	2	3	4	5
1. Duration of Illness		-.04	-.31*	-.21	-.16
2. CNS Involvement			-.12	.26	-.10
3.Child Age at Diagnosis				-.07	-.01
4. Parental Uncertainty					.32*
5. Caregiver Burden					

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

Table 16. Zero-Order Correlations for Demographic Variables and Outcome Variables for Mothers only

	1	2	3	4	5	6	7	8
1. Child Sex		.39*	.54**	-.06	-.19	-.10	.02	.20
2. Child Age			.52*	.06	.05	-.18	-.15	.25
3. Parent Age				.01	-.08	-.22	-.04	.33
4. Parent Education					.40*	.23	-.12	.10
5. Annual Family Income						-.34*	-.60**	.34
6. Externalizing Problems							.49**	-.56**
7. Internalizing Problems								-.27
8. Prosocial Behaviors								

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

Table 17. Zero-Order Correlations for Illness Characteristics and Outcome Variables for Mothers Only

	1	2	3	4	5	6
1. Duration of Illness		-.09	-.31	.11	.02	-.42*
2. CNS Involvement			-.13	-.17	-.27	-.03
3.Child Age at Diagnosis				-.30	-.20	.42*
4. Externalizing Problems					.49**	-.56**
5. Internalizing Problems						-.27
6. Prosocial Behaviors						

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

Table 18. Zero-Order Correlations for Predictor Variables and Outcome Variables for Mothers Only

	1	2	3	4	5
1. Parental Uncertainty		.07	.22	.35*	-.28
2. Caregiver Burden			.29	.34	-.22
3. Externalizing Problems				.49**	-.56**
4. Internalizing Problems					-.27
5. Prosocial Behaviors					

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

Table 19. Hierarchical Regression for Parental Uncertainty and Caregiver Burden on Externalizing Problems for Mothers Only

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Family Income	-.35	-2.04*	.12	.12	4.16*
2	Parental Uncertainty	.09	.46	.07	.19	1.15
	Caregiver Burden	.25	1.44			

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

Table 20. Hierarchical Regression for Parental Uncertainty and Caregiver Burden on Internalizing Problems for Mothers Only

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Family Income	-.55	-3.63**	.31	.31	13.14**
2	Parental Uncertainty	.23	1.45	.12	.42	2.77
	Caregiver Burden	.27	1.84			

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

Table 21. Hierarchical Regression for Parental Uncertainty and Caregiver Burden on Prosocial Behaviors for Mothers Only

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Child Age at Diagnosis	.31	1.64	.26	.26	4.22*
	Illness Duration	-.30	-1.60			
2	Parental Uncertainty	-.35	-2.03	.14	.40	2.55
	Caregiver Burden	-.13	-.77			

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

Table 22. Hierarchical Regression for Moderation of the Relationship Between Parental Uncertainty and Externalizing Problems by Parenting Stress for Mothers Only

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Family Income	-.30	-1.76	.09	.09	3.10
2	Parenting Stress	.80	5.03**	.45	.54	9.43**
	Parental Uncertainty	-.34	-2.11*			
	PS x PU	.06	.42			

*Note: PS x PU = Parenting Stress by Parental Uncertainty Interaction Term; * p < .05; ** p < .01*

Table 23. Hierarchical Regression for Moderation of the Relationship Between Parental Uncertainty and Internalizing Problems by Parenting Stress for Mothers Only

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Family Income	-.58	-4.04	.34	.34	16.35**
2	Parenting Stress	.26	1.52	.12	.46	2.06
	Parental Uncertainty	.14	.80			
	PS x PU	-.03	-.20			

*Note: PS x PU = Parenting Stress by Parental Uncertainty Interaction Term; * p < .05; ** p < .01*

Table 24. Hierarchical Regression for Moderation of the Relationship Between Parental Uncertainty and Prosocial Behaviors by Parenting Stress for Mothers Only

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Child Age at Diagnosis	.30	1.64	.26	.26	4.51*
	Illness Duration	-.32	-1.76			
2	Parenting Stress	-.60	-3.44**	.34	.60	6.53**
	Parental Uncertainty	.06	.34			
	PS x PU	-.07	-.49			

*Note: PS x PU = Parenting Stress by Parental Uncertainty Interaction Term; * p < .05; ** p < .01*

Table 25. Hierarchical Regression for Moderation of the Relationship Between Caregiver Burden and Externalizing Problems by Parenting Stress for Mothers Only

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Family Income	-.30	-1.67	.09	.09	2.78
2	Parenting Stress	.74	4.65**	.42	.51	7.48**
	Caregiver Burden	-.19	-1.22			
	PS x CB	.15	.99			

*Note: PS x CB = Parenting Stress by Caregiver Burden Interaction Term; * $p < .05$;*

*** $p < .01$*

Table 26. Hierarchical Regression for Moderation of the Relationship Between Caregiver Burden and Internalizing Problems by Parenting Stress for Mothers Only

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Family Income	-.52	-3.31**	.27	.27	10.94**
2	Parenting Stress	-.33	-2.44*	.31	.58	6.47**
	Caregiver Burden	-.06	-.41			
	PS x CB	.41	2.95**			

*Note: PS x CB = Parenting Stress by Caregiver Burden Interaction Term; * p < .05;*

*** p < .01*

Table 27. Hierarchical Regression for Moderation of the Relationship Between Caregiver Burden and Prosocial Behaviors by Parenting Stress for Mothers Only

Step	Variable	Standardized β	t for within-step predictors	R^2 Change for step	Cumulative R^2	F Change for Step
1	Child Age at Diagnosis	.29	1.45	.26	.26	4.07*
	Illness Duration	-.32	-1.62			
2	Parenting Stress	-.84	-5.51**	.49	.75	12.76**
	Caregiver Burden	.45	3.04**			
	PS x CB	-.10	-.67			

Note: PS x CB = Parenting Stress by Caregiver Burden Interaction Term; $* p < .05$;

$** p < .01$

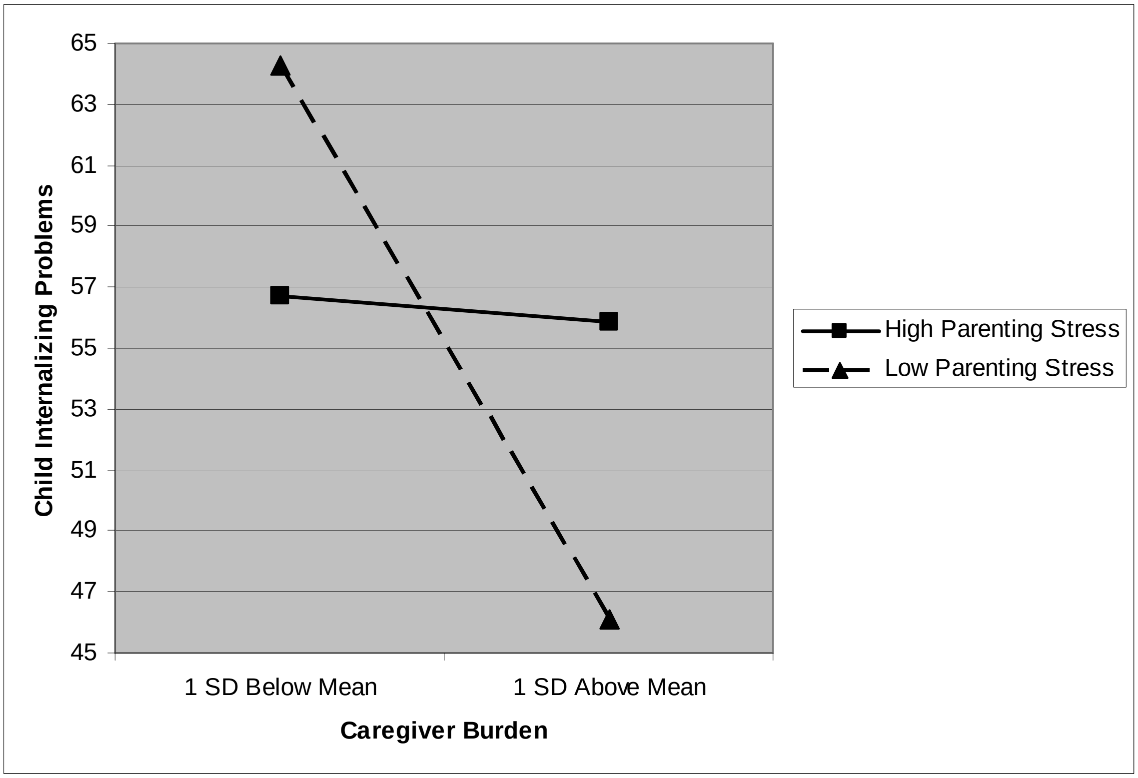

Figure 1. Regression lines for relationships between caregiver burden and child internalizing problems as moderated by parenting stress (2-way interaction). SD = standard deviation.

VITA

Cortney Brett Wolfe-Christensen

Candidate for the Degree of

Doctor of Philosophy

Dissertation: THE RELATIONSHIPS OF PARENTAL UNCERTAINTY AND CAREGIVER BURDEN TO ADJUSTMENT OUTCOMES IN CHILDREN WITH CANCER: THE MODERATIONG ROLE OF PARENTING STRESS

Major Field: Psychology

Biographical:

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Name: Cortney Wolfe-Christensen Date of Degree: December, 2009

Institution: Oklahoma State University Location: Stillwater, Oklahoma

Title of Study: THE RELATIONSHIP OF PARENTAL UNCERTAINTY AND CAREGIVER BURDEN TO ADJUSTMENT OUTCOMES IN CHILDREN WITH CANCER: THE MODERATING ROLE OF PARENTING STRESS

Pages in Study: 120 Candidate for the Degree of Doctor of Philosophy

Major Field: Psychology

Scope and Method of Study: The current study sought to determine whether levels of parental uncertainty and caregiver burden, as reported by parents of children with pediatric cancer, were related to the child's emotional, behavioral, and social functioning. Additionally, the moderating role of parenting stress in these relationships was investigated. Data were collected from 46 parents of children on treatment for cancer at the time of participation. Parents completed the Parental Perceptions of Uncertainty Scale, the Care of My Child with Cancer Scale, the Parenting Stress Index, and rated their child's functioning using the Behavior Assessment System for Children – 2nd Edition and the Social Skills Rating Scale.

Findings and Conclusions: Results indicated that contrary to expectations, neither levels of parental uncertainty nor levels of caregiver burden were significantly related to the child's emotional, behavioral, or social functioning. Additionally, although parenting stress did not moderate the relationships between parental uncertainty and child adjustment, level of parenting stress emerged as a significant independent predictor of the child's emotional and social functioning. Moreover, parenting stress did not moderate the relationship between caregiver burden and child adjustment in the total sample of parents, but did moderate the relationship between caregiver burden and child emotional functioning in the subset of mothers only. Specifically, children evidenced better emotional adjustment under conditions of high caregiver burden and low parenting stress, and poorer emotional adjustment under conditions of low caregiver burden and low parenting stress. It is suggested that mothers who are evidencing higher level of burden due to their hands-on involvement in the child's treatment and care, but are not overwhelmed by the situation (i.e., report lower stress), have children who are better adjusted with regard to their emotional functioning. On the other hand, mothers who reported low levels of both caregiver burden and parenting stress may be distancing themselves from the situation of the child's illness, and therefore distancing themselves emotionally from their child, which could result in the child feeling isolated, sad, withdrawn, or worried.

ADVISER'S APPROVAL: Larry L. Mullins, PhD