ILLNESS UNCERTAININITY, GLOBAL PSYCHOLOGICAL DISTRESS, AND POSTTRAUMTIC STRESS IN PEDIATRIC CANCER: A NESTED MODELS PATH ANALYSIS

By

ALAYNA PAULINE TACKETT

Bachelor of Arts in Psychology

Northern Kentucky University

Highland Heights, Kentucky

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Thesis Approved:

Larry L. Mullins, Ph.D.

Thesis Adviser

John M. Chaney, Ph.D.

Christopher C. Cushing

Name: Alayna Pauline Tackett

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Abstract: Chronic health conditions, such as pediatric cancer, have been associated with a variety of stressors as parents manage multiple hospital and clinic visits, medication adherence challenges, and financial upheaval. Parents may struggle to balance the physical and emotional impact that a prolonged illness can have on the family and other negative adjustment outcomes. The goals of the present study were to further understand psychological caregiver responses to having a child diagnosed with pediatric cancer by examining the relationship of multidimensional components (i.e., factors/subscales) in illness uncertainty to posttraumatic stress, with attention paid to global psychological distress as a possible mediator of this relationship. Studies have documented significant relationships among these constructs in chronic illnesses; to our knowledge no studies have examined all three constructs concomitantly. The most thorough approach to examining these relationships is to examine theoretically meaningful pathways in one simultaneously estimated model. Path analysis is a specific type of Structural Equation Modeling) that allows testing of a causal model consisting of a series of hypotheses regarding the interrelationship of variables studied. Our analyses were driven by one research question; investigating the subcomponents of illness uncertainty and the subsequent relationship to global psychological distress and posttraumatic stress, via two competing models. Hypothesized model one represented the best fit to the data, accounted for 47.30% of the variance in posttraumatic stress symptomatology, and the subcomponent or factor of ambiguity had significant indirect effects on posttraumatic stress symptomatology, as mediated through global psychological distress, as compared to any other of the subcomponents of illness uncertainty (e.g., lack of clarity or unpredictability). The findings in this thesis, particularly those identifying subcomponent symptoms of illness uncertainty on posttraumatic symptomatology and global psychological distress, suggest that further research and greater clinical attention to parents' adjustment to childhood cancer is warranted. Future research could aim to better understand and, ultimately, reduce the array of illness uncertainty factors that might impact the psychological well-being (e.g., increase global psychological distress) in both parents and children from the onset of illness to survivorship, and therefore decrease prevalence rates of posttraumatic stress symptomatology in this unique chronic illness population.

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CHAPTER I

INTRODUCTION

Children with chronic health conditions often experience numerous clinic visits and hospitalizations, invasive medical procedures, missed school days, and periodic home healthcare, among other disruptions. As such, illness often interrupts daily routines and interferes with important family activities. These disruptions in critical aspects of everyday life pose continuous challenges, requiring families to make changes to accommodate the child's treatment plan. According to the National Survey of Children's Health, an estimated 7.8 million children currently have one or more of 16 chronic health conditions, described by their parents as moderate or severe (National Survey of Children's Health, 2007). Given these high prevalence rates, understanding the psychological impact of chronic conditions on the family is paramount. Parents who have a child diagnosed with a severe chronic illness may experience a wide variety of psychological responses due to the ambiguity of their child's diagnosis and the stress associated with disease progression and complicated treatment protocols (Siegel, et al., 2012; Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005). The family must come to terms with the diagnosis, set new priorities, and change family schedules in addition to maintaining ongoing job and home responsibilities. Any number of these demands has the potential to lead caregivers to developing negative adjustment outcomes (e.g., posttraumatic stress symptoms, depression, anxiety, diminished quality of life).

Chronic health conditions, such as pediatric cancer, have been associated with a variety of stressors as parents manage multiple hospital and clinic visits, medication adherence challenges, and financial upheaval (e.g., Brown & Bussell, 2011). Parents may struggle to balance the physical and emotional impact that a prolonged illness can have on the family; such distress can place their children at risk for compromised health-related quality of life (Sawyer, Drew, Yeo, & Britto, 2007) and other negative adjustment outcomes. Thus, a diagnosis of pediatric cancer can be particularly stressful for children experiencing the illness and even more stressful for the parents managing the subsequent care required of such a diagnosis. Understanding how parents manage this stress and providing families with adequate support during the initial treatment process has been a focus of pediatric psychology for decades.

During the past 20 years, there has been an increase in the incidence of children diagnosed with all forms of invasive cancer, from 11.5 cases per 100,000 children in 1975 to 14.8 per 100,000 children in 2004 (Surveillance, Epidemiology, and End Results (SEER) Program, 2013). In the United States, it is estimated that on average, 1 to 2 children develop pediatric cancer each year for every 10,000 children (National Cancer Institute, 2008). In 2013, an estimated 11,630 new cases are expected to occur among infants to 14 years of age (American Cancer Society, 2013). Because of the relatively high volume of newly diagnosed cases, and higher survival rates, the short term and long term psychosocial effects this diagnosis can have on families has become of increasing interest to researchers (Barakat, Kazak, Gallagher, Meeske, & Stuber, 2001; Pai, Drotar, Zebracki, Moore, & Youngstrom, 2006). Understanding the psychological effects pediatric cancer can have on the family is imperative in order to provide more effective and beneficial psychological care throughout treatment and survivorship.

Extensive research support has shown that children diagnosed with a pediatric cancer are at risk for a variety of negative adjustment outcomes (e.g., Miller, Vannatta, Compas, Vasey, McGoron, Salley & Gerhardt, 2009; Vance & Eiser, 2002; Kazak, et al., 2005; Abrams, Hazen &

Penson, 2007), and can manifest maladaptive coping styles and difficulties in managing stress (Kliewer, Sandler, & Wolchik, 1994). Studies investigating coping strategies of children and adolescents newly diagnosed with cancer suggest that initial coping is a function of a multitude of variables, including the availability of social support (e.g., caregivers, extended family and friends), the belief in a chance for recovery, and the hope for an eventual return to normalcy (Kyngas, Mikkonen, Nousiainen et al., 2001; Abrams, Hazen, & Penson, 2007). However, when support and coping resources are lacking, children with pediatric cancer rate their experience as highly stressful, burdensome, and traumatic (Kazak, 2005; Patenaude & Kupst, 2005). As a result, children with cancer are at risk to be more sensitive emotionally and isolated than their healthy peers (Vance & Eiser, 2002).

Caregivers of children with cancer are also at risk. Importantly, over 40% of caregivers of children with cancer meet diagnostic criteria for acute distress disorder, a purported precursor to post traumatic stress disorder (PTSD), within the first 2 months following their child's diagnosis of cancer and these symptoms continue throughout their child's diagnosis (Patiño-Fernández, et al., 2008; Pai et al., 2007). Posttraumatic stress symptoms (PTSS) have also been well documented in parents of children diagnosed with cancer. A PTSD/PTSS framework for conceptualization of the experience of childhood cancer and its' effect on the entire family has gained increasing attention in the literature, particularly pertaining to what has been referred to as *medically related* posttraumatic stress disorder.

The core characteristics of PTSD include intrusiveness, avoidance and hyperarousal (Horowitz, 1976). Intrusion is characterized by nightmares, unbidden visual images of the trauma or its aftermath while awake and/or intrusive thoughts about aspects of the traumatic event (Horowitz, 1976; Weiss, 2007). Avoidance is characterized as deliberate efforts to not think about the event, not talk about the event, and the avoidance of reminders of the event (i.e., places, people or situational; Horowitz, 1976; Weiss, 2007). Lastly, hyperarousal is characterized by persistent symptoms of increasing arousal (not present before the trauma), indicated by difficulty falling or staying asleep, irritability or outbursts of anger, difficulty concentrating, hyper-vigilance, and exaggerated startle response (*DSM-IV-TR*; American Psychiatric Association, 2000).

Symptoms associated with PSTD, also known as PTSS, have been documented in mothers and fathers of childhood cancer survivors (Phipps, Long, Hudson, & Rai, 2005; Kazak, 2005). Kazak and colleagues (2005) found that parents of newly diagnosed children self-reported significantly higher levels of PTSS than parents of long-term cancer survivors. Additionally, other research has found that both mothers and fathers can experience moderate to severe posttraumatic stress at time of diagnosis in comparison to caregivers of long-term survivors (Phipps et al., 2005). In summary, parents of children with cancer indeed appear to be at risk for experiencing PTSS both during the early diagnosis phase and after successful treatment.

Notably, general psychological distress in parents of children with pediatric cancer has also been of interest to researchers. Initial studies have estimated rates of global psychological distress to be as high as 51% (Sloper, 2000). Further studies have indicated high symptomatic levels of distress during the initial weeks of treatment (Sawyer, Antoniou, Toogood, Rice, & Baghurst, 1993), and have suggested that parental distress remains stable or moderately decreased throughout the course of treatment (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2001). Additional findings show that both fathers and mothers have elicited levels of self-reported psychological distress above normative means (Bonner, Hardy, Willard, & Huchinson, 2007). The failure to cope (e.g., van der Kolk, McFarlane, & Weisaeth, 1997) and lack of control (e.g., Dekel, Peleg, & Solomon, 2010; Maes, Delmeire, Mylle, & Altamura, 2001), the latter a specific component of illness uncertainty, are established predictors of PTSD. A number of studies have now also documented that a strong association exists between general or global psychological distress and PTSS in caregivers of children with cancer (Phipps et al., 2005; Kazak, 2005; Jurbergs, Long, Ticona, & Phipps, 2009). However, we currently know little about the nature of the translational relationship of PTSS to global distress.

Additional research efforts have been extended to better understand those factors that predict psychological outcomes in parents of children with cancer. Importantly, a specific cognitive construct that has been associated with parent's psychological distress during their child's illness experience is that of illness uncertainty. Mishel (1981; 1990) first proposed illness uncertainty theory as a way to better understand adjustment to acute illness. This model was then adapted to include other chronic illnesses, as uncertainty is a likely component in many chronic disease populations, including cancer. Mishel (1981; 1990) theorized that illness uncertainty is comprised of four components: *perceived ambiguity* regarding the state of the illness, *complexity regarding treatment*, *lack of information* about the seriousness of the illness and prognosis, and *perceived unpredictability* of the illness course (Mishel, 1984). Additionally, she notes that stress and uncertainty are related not just through the appraisal of an event as stressful, but by the vagueness, lack of clarity and lack of information surrounding the event. This uncertainty surrounding the illness diagnosis and treatment appears to play a major role in the parent and child's illness experience, and has been shown to be pervasive in parents' experiences across multiple health care settings (e.g., Cohen, 1995; Mishel, 1983).

Extensive literature has now documented a significant relationship between illness uncertainty and psychological distress in a multitude of disease populations, including type 1 diabetes (e.g., Hoff, Mullins, Chaney, Hartman, & Domek, 2002), asthma (Gillaspy, Hoff, Mullins, Van Pelt, & Chaney, 2002), juvenile rheumatic disease (White et al., 2005) and adult cancer (Grootenhuis & Last, 1997), among others. Furthermore, studies involving families who have been affected by chronic conditions, including cancer, have reported that uncertainty can stem from fear of death, unpredictability and severity of side effects during treatment, interruptions in school and peer relationships and unknown risk for long-term effects (Koocher & O'Malley, 1981; Cohen, 1993; Stewart & Mishel, 2000; Stewart, 2003). Extensive research has also revealed a strong association between illness uncertainty and psychological distress at the time of diagnosis, following through various stages of treatment and remission (Mishel, 1984;

Mishel & Braden, 1987; Bennett, 1993; Mast, 1998; Mishel & Sorenson, 1991). To summarize these findings, it appears that illness uncertainty places individuals at increased risk for maladaptive illness-related coping behaviors and clinically significant psychological distress (e.g., Hoff, Mullins, Chaney, & Hartman, 2003), and this appears to be a very robust relationship.

In light of these findings, it is important to better understand the complex relationship of illness uncertainty, posttraumatic stress, and general psychological distress in the context of pediatric cancer. Currently, we understand little about which subcomponents or factors of illness uncertainty (i.e., ambiguity, lack of information, lack of clarity and unpredictability) are related to PTSS and/or global psychological distress in pediatric cancer. Understanding these interrelationships may be a critical element in providing psychological resources more effectively to families experiencing distress.

To sum, numerous studies have examined the relationship between illness uncertainty to posttraumatic stress and to general psychological distress, separately (Stuber; Kazak, Meeske, Barakat, et al., 1997; Fuemmeler, Mullins, & Marx, 2001; Santacroce, 2002; Lee, 2006; Pai, et al., 2006) and psychological outcomes in caregivers and patients experiencing pediatric cancer. Significant relationships have been documented between illness uncertainty and posttraumatic stress (Lee, 2006) and between illness uncertainty and global psychological distress (Hoff, et al., 2002). Similarly, significant associations between global psychological distress and rates of posttraumatic stress have been documented in caregivers of pediatric brain tumor patients who care currently receiving medical treatment (Hutchinson, Willard, Hardy & Bonner, 2009).

The goals of the present study are to further understand psychological caregiver responses to having a child diagnosed with pediatric cancer by examining the relationship of multidimensional components (i.e., factors/subscales) in illness uncertainty to posttraumatic stress, with attention paid to global psychological distress as a possible mediator of this relationship. Although studies have clearly documented significant relationships among these constructs in pediatric cancer and other chronic illnesses, to our knowledge no studies have examined all three constructs concomitantly. Further, the examination of a potential mediating relationship of global psychological distress and the relationship between sub-dimensions of illness uncertainty and posttraumatic stress are also of interest, and would address a significant gap in the literature. Figure 1 provides an overview of the possible pathways among these variables.

The most thorough approach to examining these relationships is to examine theoretically meaningful pathways in one simultaneously estimated model. Path analysis (PA) is a specific type of Structural Equation Modeling (SEM) that allows testing of a causal model consisting of a series of hypotheses regarding the interrelationship of variables studied. To determine the combination of direct and indirect pathways that best fit the observed data, the current study will employ a series of theoretically supported nested model comparisons. Of primary interest are the direct and indirect effects of the subcomponents or factors of illness uncertainty to posttraumatic stress symptomatology, which currently are not well elaborated in the current literature and are rarely examined in empirical studies. The current study addresses a gap in the literature by providing a preliminary investigation into the subcomponents that may drive the association of illness uncertainty, global psychological distress and posttraumatic stress symptomatology experienced by caregivers of children with newly diagnosed cancer. Based on the available literature, it is hypothesized that a significant pathway will be observed from each of the illness uncertainty subcomponents (Ambiguity, Lack of Clarity, and Unpredictability). Therefore our analyses will be driven by one research question; investigating the subcomponents of illness uncertainty and the subsequent relationship to global psychological distress and posttraumatic stress, via two competing models. It is hypothesized that the first model will have the best fit to the data; a significant pathway will be observed from each of the illness uncertainty subcomponents (Ambiguity, Lack of Clarity, and Unpredictability) through global psychological distress (BSI and GSI) to higher levels of posttraumatic stress (IES-R) in caregivers.

As noted previously, research supporting the proposed theoretical hypothesis have found strong associations between illness uncertainty and posttraumatic (Santacroce, 2002; Steele, Alyward, Jensen, & Wu, 2009), illness uncertainty and global psychological distress (Stewart & Mishel, 2000) and global psychological distress on symptomatology of posttraumatic stress (Barakat, et al., 1997). Yet, to our knowledge, none of these studies have examined potential mediation between these specific constructs. While the proposed model noted above is the primary aim of the current study, it is also plausible that posttraumatic stress serves as a mediator (hypothesized competing model 2) for the effect of illness uncertainty on global psychological distress. Therefore, the current study will also explicitly test this model structure using a nested model comparison. Thus, the second hypothesis is that this alternative model will introduce significant model misfit and will be rejected.

CHAPTER II

REVIEW OF THE LITERATURE

CHAPTER OVERVIEW

The current chapter will examine the literature pertinent to the proposed study. The first section will focus on a description of the disease, including classification, incidence, prevalence, mortality, and treatment of pediatric cancer. The second section will discuss child and caregiver psychological outcomes in relation to the diagnosis and treatment of pediatric cancer. Lastly, the third section will shift focus to a specific psychological predictor variable by providing a broad overview of the construct of illness uncertainty, including research examining illness uncertainty and associations with maladaptive psychological outcomes (i.e., posttraumatic stress and general parental distress) in the context of a chronic illness.

Pediatric Cancer: An Overview of Incidence, Prevalence, and Adjustment Outcomes

Pediatric cancer has been researched extensively over the past four decades, with increasing emphasis placed on understanding the psychosocial adjustment of children and their families (e.g., (Patenaude & Kupst, 2005); (Pai, et al., 2006); (Fuemmeler, Elkin, & Mullins, 2002)). Due to the specific research focus of the current study, only the last 20 years of related research will be included.

Nature of Pediatric Cancer. An estimated 11,630 new cases of pediatric cancer are expected to occur among children 0 to 14 years of age in 2013 (American Cancer Society, 2013). Overall, pediatric cancer incidence rates increased slightly by 0.6% per year from 2005 to 2009, using the most recent 5 years of available data (US Surveillance Epidemiology and End Results (SEER), 2013). Although the incidence rate is slowly increasing, the five-year survival rate continues to improve, with 83% of pediatric cancer patients now surviving five years post-diagnosis (American Cancer Society, 2012). This represents a substantial improvement, as prior pediatric survival rates from 2002 – 2008 were documented at 68% (SEER, 2013). Because efforts to improve health outcomes in pediatric cancer have markedly increased, in the U.S. alone, there are now an estimated 270,000 survivors of pediatric cancer (American Cancer Society, 2012). However, at the same time, an anticipated 1,310 children younger than 15 years old are expected to die of the disease in 2013 (American Cancer Society, 2012).

Pediatric cancers are typically treated by a combination of therapies (surgery, radiation, and chemotherapy (Children's Oncology Group (COG), 2013), which are chosen specific to the type and stage of cancer. A team of experts, including pediatric oncologists and nurses, radiologists, pharmacists, social workers, psychologists, among others, typically coordinates treatment to assist children and their families. Typically, treatment will vary based on the stage of the cancer, the child's age, and the location of the cancer. These treatments typically include chemotherapy, radiation therapy, surgery, or some combination of all three. The vast majority of children diagnosed with cancer are now treated on standardized protocols established by the Children's Oncology Group (COG, 2013). Depending upon the type of cancer being treatment, protocols can last anywhere from a few weeks to three years. These life-saving treatment approaches carry with them the risk of further health problems (both acute and long term) in addition to the often-painful nature of treatments themselves. Extensive treatment regimens including invasive surgery followed by radiotherapy, and high dose chemotherapy (Hayat, 2007) can become grueling procedures for a pediatric patient and their families in the fight for remission or cure. Due to these intensive treatment procedures, parents can easily become overwhelmed, which in turn may negatively affect their ability to function as a parent and subsequently their child's ability to manage the treatment (Manne et al., 1996).

In summary, the treatment methods for pediatric cancer have greatly improved over the last several years, and as such, survivorship rates have increased (American Cancer Society, 2012). Although these improvements in the illness treatment have led to increased survivorship, maladaptive psychological responses surrounding the impact of the diagnosis and treatment of pediatric cancer can still occur. Assuming that incidence of pediatric cancer continues at the same rate or rise further, families will continue to face the burden and distress of pediatric cancer and the subsequent treatment.

Pediatric Cancer and Child Psychological Outcomes. The adjustment to the diagnosis and treatment of pediatric cancer has long been the target of psychological research. This research has largely focused on determining the nature and incidence of these negative outcomes, as well as predictors of these outcomes. In an early landmark study, Kupst and colleagues (1995) conducted a longitudinal study of family coping and psychological adjustment in caregivers and children diagnosed with pediatric leukemia over the course of 10 years post treatment. Kupst et al. (1995) found that families with the most difficulty at diagnosis continue to experience the highest levels of distress, even after treatment ends. Additionally, Kupst et al. (1995) demonstrated that the most significant predictor of survivors' coping and adjustment was the coping and adjustment of the mother. To expand these findings, when investigating the psychological adjustment of children undergoing cancer treatment, Witgens, Boileu, and Robacy (1997) found that while most children adjust well to the initial shock of diagnosis and the subsequent treatment demands, a subset of children experienced significant difficulties, such as mood changes and social withdrawal. These studies provided initial evidence of the importance of examining specific outcomes and predictors of those psychological adjustment outcomes in families who have a child with a diagnosis of pediatric cancer.

To date, a wide variety of adjustment outcomes have been studied in the context of pediatric cancer. Outcomes of psychological adjustment are characterized by, but not limited to, self- or parent-report levels of self-esteem, coping, posttraumatic stress, depression, anxiety, general distress, social and academic functioning (Wechsler, & Sánchez-Iglesias, 2013). Sawyer et al. (1997) prospectively measured psychological adjustment of young children during the first 2 years after their diagnosis of pediatric cancer. Their findings showed that children with cancer experienced significantly more emotional distress compared to a sample of children in the community during the period immediately after diagnosis (Sawyer et al., 1997). Interestingly, since that time the results of studies comparing adjustment levels of children with cancer compared to healthy controls is somewhat mixed. Some studies have shown that survivors of pediatric cancer are as adjusted in academic achievement, in self- and parent-reported levels of distress, depression and anxiety as healthy peers (Chao, Chen, Wang, Wu, & Yeh, 2003; Sorgen & Manne, 2002; Walco, 2005). Similarly, Wechsler and Sanchez-Iglesias (2012) found no difference between these two groups, suggesting that children undergoing active cancer treatment have similar psychological adjustment to same-aged healthy comparative peers.

Alternatively, Kazak et al. (2003) found that a small, but significant portion of children diagnosed with cancer present with elevations in psychosocial risk. Overall, pediatric cancer patients and survivors appear to be 80% more likely than their siblings to report clinically relevant impairment in mental health quality of life (Hudson, Mertens, Yasui, et al., 2003) and greater than five times more likely to report functional impairment in health related quality of life (Hudson, et al., 2003; Zeltzer, Lu, Leisenring, et al., 2008). In addition, survivors are twice as likely to report clinical levels of emotional distress compared with their siblings (Hudson, et al., 2003). Therefore, it appears that a subset of children diagnosed with pediatric cancer and their families may well manifest some form of negative psychological outcome during the course of the illness experience.

Predictors of Child Outcomes. The primary interest of the current study is to examine caregiver psychological outcomes to having a child diagnosed with pediatric cancer. However, a number of studies have sought to better understand predictors of child outcomes to the diagnosis of pediatric cancer. Therefore, the current section presents studies that have examined specific predictors of maladaptive outcomes in children diagnosed with pediatric cancer.

In an early study conducted by Phipps Fairclough, and Mulhern (1995), children diagnosed with pediatric cancer tended to use avoidant coping style more frequently than healthy controls. An early study conducted by Phipps and colleagues (1995) found that children diagnosed with pediatric cancer tended to use avoidant coping style more frequently than healthy controls. In another initial study focusing on predictors of outcomes, Frank, Blount and Brown (1997) found attributional styles avoidance coping, and negative social competence were predictors of self-reported maladaptive psychological outcomes (i.e., depression, anxiety). Using these studies as foundation, new advances in psychological adjustment of children diagnosed with pediatric cancer began to emerge. Additionally, multiple studies have suggested children who are currently receiving chemotherapy are at significant risk for psychological difficulties in social adjustment with peers (e.g., Deasy-Spinetta, 1981; Katz, Rubinstein, Hubert & Blew, 1988; Noll, LeRoy, Bukowski, Rogosh, 1991; Noll, et al., 1999) and emotional well-being (e.g., Bennett, 1993; Dolgin, Katz, Zeltzer, Landsverk, 1989; Varni, Katz, Colegrove, Dolgin, 1994). Multiple studies have found somewhat increased rates of child depressive symptoms in self-reported measurements or via caregiver report (Kashani & Hakami, 1982; Sanger, Copeland & Davidson, 1991), in children undergoing current treatment, which may then be a risk factor for feelings of social isolation and anxiety regarding medical procedures (Griffiths, Schweitzer, & Yates, 2011; Patterson, Holm, & Gurney, 2004).

Lastly, a later study conducted by Miller and colleagues (2009) found that coping mechanisms and child temperament were significant predictors of maladaptive adjustment in children with cancer. Miller and colleagues (2009) were the first to examine how coping mechanisms and processes predict outcomes of illness-specific stress and symptoms of anxiety and depression in children with cancer. It has also been documented that children with cancer who are further from diagnosis may use more avoidant coping strategies than recently diagnosed children confronted with the daily demands of active treatment (Phipps, et al., 1995).

Although many research studies have focused on child outcomes in pediatric cancer, similar research has investigated parental outcomes in pediatric cancer. The following section will provide a brief overview of studies specifically examining parental psychological outcomes in response to having a child diagnosed with pediatric cancer.

<u>Pediatric Cancer and Caregiver Psychological Outcomes.</u> In recent years, a shift in the literature is evident with an increased focus on the parental experiences to a diagnosis of pediatric

cancer. Thus, this section will present literature examining caregiver psychological outcomes associated with having a child diagnosed with pediatric cancer, with a particular focus on general distress or adjustment problems, acute stress, posttraumatic stress symptomatology, and posttraumatic stress disorder.

Although many families cope relatively well with the stress of a cancer diagnosis, a consistent subset of parents of children with cancer appear to demonstrate increased distress, and often experience higher rates of adjustment difficulties than their child with cancer (Pai et al., 2007). Around 25% to 33% of caregivers who child has pediatric cancer are estimated to develop maladaptive psychological general distress (Hoekstra-Weebers, Jaspers, Kamps, Klip, 1999). Research has consistently documented that caregivers of pediatric cancer are at increased risk for heightened general psychological distress and disturbance (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1998; Kupst & Schulman, 1988; Kangas, Henry, & Bryant, 2002) in addition to depressive symptomatology (Brown et al., 1993). Acute stress responses have also been a focus of this research. Acute Stress Disorder (ASD) includes specific clusters of symptoms that must occur within 2–28 days following a traumatic event (i.e., pediatric cancer diagnosis; Patiño-Fernández, et al., 2008), however subclinical symptoms of acute stress are also possible reactions to traumatic events (Patiño-Fernández, et al., 2008). A recent study conducted by Patiño-Fernández and colleagues (2008) found that 40% of caregivers of newly diagnosed pediatric cancer patients met criteria for ASD. Further, nearly all caregivers (82.9%) reported avoidance, arousal and reexperiencing symptoms surrounding their child's recent diagnosis (Patiño-Fernández, et al., 2008).

Relatedly, efforts have been made to further examine both posttraumatic stress (PTSS) and posttraumatic stress disorder (PTSD), which might be manifest in parents of children with cancer. Nir (1985) and Pot-Mees (1989) first described posttraumatic stress disorder (PTSD) as a possible phenomenon in childhood cancer survivors, and Stuber and colleagues published the first empirical report on the importance of studying PTSS and PTSD phenomenon in families of children with cancer (Stuber, Nader, Yasuda, Pynoos, & Cohen, 1991). These efforts supplied the foundation for subsequent research in order to amend the diagnostic criteria for PTSD in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association (APA), 1994). PTSD refers to the development of characteristic symptoms after the exposure to extreme stressors such as events that involve actual or possible death, serious injury, or other threats to the integrity of the self, family members or associates (APA, 2000). Historically, traumatic events included such experiences as natural disasters, serious accidents, assault or rape, however, as of 1994, the APA added life-threatening illness as a traumatic event to the diagnosis criteria of PTSD. Intertwined with PTSD, PTSS is subtype of PTSD exists which examines subclinical thresholds of distress (Kazak, 1994). PTSS as a construct acknowledges life-threating components of pediatric cancer diagnosis and treatment while providing a continuous foundation to treat and measure intrusive thoughts, arousal, and avoidance. In the paragraphs to follow, the literature examining PTSS will be presented first, followed by PTSD literature in pediatric cancer.

The available research to date would indicate that PTSS rates in caregivers of pediatric cancer survivors appear to range from 9.8% to 44% (Bruce, 2006). In PTSS research, a consistent finding indicates that parents, particularly mothers, are more affected than their children (Kazak et al., 2005; Patiño-Fernández et al., 2008; Pöder, Ljungman, & von Essen, 2008). Notably, parents of children with cancer appear to experience higher levels of PTSS than healthy peers (Fuemmeler, Mullins, Van Pelt, Carpentier, & Parkhurst, 2005). A recent study conducted by

Kazak and colleagues (2005) found that symptoms of PTSS are more commonly reported in both mothers and fathers whose child is undergoing active cancer treatment than caregivers whose children have survived pediatric cancer. Similarly, Phipps and colleagues (2005) found that PTSS differs in severity and frequencies of symptoms in caregivers with newly or recently diagnosed patients opposed to survivors of pediatric cancer. The literature has also documented that approximately 68% of mothers and 57% of fathers reported PTSS within the moderate-to-severe range during treatment (Kazak et al., 2005). In a recent study conducted by Yalug and colleagues (2008), specific symptoms of PTSS including reexperiencing, avoidance/numbing, and arousal symptom clusters were frequent in caregivers. Specifically, this study found that 50% of caregivers reported intrusive thoughts, concentration problems, hypervigilance, and startle reactions (Yalug et al., 2008) and 34.6% of these caregiver met clinically significant levels for PTSD (Yalug et al., 2008).

The incidence of PTSD in the general community is estimated at 1-14%, and the epidemiological rates range from 3-58% in at-risk populations (APA, 1994; Davidson & Fairbank, 1993). The current literature suggests that rates of PTSD in caregivers of pediatric cancer patients range from 6.2% – 25% (Bruce, 2006). While the majority of caregiver self-reports suggest that they are coping well, PTSD has been demonstrated in a subset of caregivers of children with pediatric cancer, with a particular increase in incidence for mothers (Barakat et al., 1997; Brown, Madan-Swain, & Lambert, 2003; Kazak & Barakat, 1997; Kazak, 1998). Alternatively, some studies have found that many families who experience pediatric cancer only meet PTSS levels of distress, and that very few actually meet full criteria for PTSD (Bruce, 2006; Barakat et al, 1997; Phipps, Jurbergs & Long, 2009). Phipps and colleagues (2009) suggested that these lower prevalence rates of PTSD could be attributed to advances in pediatric cancer therapies, reduced invasive procedures, and stronger psychosocial support, both from professional staff and family.

To sum, although pediatric chronic illness can be stressful for caregivers regardless of the diagnosis, negative outcomes are found in a consistent subset of parents of children with cancer. Importantly, research has suggested that parent and child adjustment are interrelated (e.g., Kazak, Rourke, & Navasria, 2009). A subset of parents are at an increased risk for depression, PTSS, and anxiety shortly after a child's diagnosis, with a select subset of parents continue to evidence further maladjustment over time (e.g., Dolgin et al., 2007; Patiño-Fernández, et al., 2008; Kazak et al., 2005). Using the previously noted research as a building block, the current study aims to further examine the association of general and posttraumatic stress relative to the construct of *illness uncertainty* in pediatric cancer.

Illness Uncertainty: An Overview of Theory and Psychological Adjustment

Illness Uncertainty Theory. A lack of understanding about an illness, its associated symptoms, and anticipated treatments has the potential to lead to considerable uncertainty. Illness uncertainty has been defined as a cognitive experience in which the meaning of illness-related events is unclear and outcomes are unpredictable due to a lack of sufficient information or cues and ambiguity (Mishel, 1990). Uncertainty can negatively affect the patient's quality of life and can influence how they make and determine meaning throughout their illness experience (Mishel, 1981).

Mishel posited that *illness uncertainty* is comprised of four separate components: perceived ambiguity regarding the state of the illness, complexity regarding treatment, lack of information about the seriousness of the illness and prognosis, and perceived unpredictability of the illness course (Mishel, 1984). Additionally, Mishel noted that stress and uncertainty are related not through the appraisal of an event as stressful, but by the vagueness, lack of clarity and lack of information surrounding the event. Illness uncertainty as a construct has been researched extensively over the past forty years. In the section to follow, only the most recent years of related research will be included with a specific focus on uncertainty and pediatric chronic illness.

The Relationship of Illness Uncertainty to Psychological Adjustment in Pediatric Chronic Illness. Research examining psychosocial adjustment in children with chronic illness and their families/caregivers has not only sought to identify the nature of adjustment outcomes, but also those factors that are predictive of or associated with outcomes, such as illness uncertainty (e.g., Hommel et al., 2003; White et al., 2005). Mullins, Chaney, Pace, and Harman (1997) posited that high levels of illness uncertainty are often coupled with negative outcomes (e.g., poorer disease control) and therefore increasing emotional distress. To examine the relationship between illness uncertainty and psychological distress, Mullins, Chaney, Balderson, and Hommel (2000) examined the role of illness uncertainty in older adolescents and young adults with asthma and consequently found that increased levels of illness uncertainty for negative events were associated with poorer psychological health. Hommel and colleagues (2003) also found that in older adolescents with pediatric-onset asthma, illness uncertainty contributed significant variance in anxiety symptoms after controlling for the effects of demographic variables (e.g., age, ethnicity, income), disease characteristics (e.g., type of asthma) and depressive symptomatology. Interestingly, White and colleagues (2005) found that in children diagnosed with juvenile rheumatic diseases, children's perceived illness uncertainty *moderated* the relationship between parental distress and child depressive symptoms. In addition to these findings, parent distress was associated with child depressive symptoms when child-perceived uncertainty symptoms where high (White et al., 2005). Alternatively, when child symptoms of illness uncertainty were low, parental distress was not *moderated* by child depressive symptoms (White et al., 2005). Similarly, Hoff and colleagues (2002) examined caregivers of children with Type 1 diabetes and found that maternal illness uncertainty was directly linked to child depressive symptoms, and this relationship was mediated by child uncertainty. In general, these findings suggest the potential for caregiver and child experiences of distress and uncertainty inadvertently being communicated to each other in a transactional fashion.

Other recent literature has also examined illness uncertainty and its' relationship to psychological distress (i.e., depression, maladaptive adaption) as well as health outcomes in pediatric chronic conditions. To examine these relationships, Steele and colleagues (2009) assessed parent- and youth-reported illness uncertainty as predictors of parent- and youth-reported psychological and psychosocial functioning. Consistent with previous literature (e.g., Hoff et al., 2002; Mullins et al., 2000), youth-reported illness uncertainty was significantly associated with youth-reported depressive and anxiety symptoms (Steele et al., 2009) and parent-reported illness uncertainty was significantly associated with parent-reported child behavioral functioning, internalizing problems, and adaptive functioning (Steele et al., 2009). In a more recent study examining illness uncertainty, Maikranz and colleagues (2007) investigated the relationship of hope, illness uncertainty, and depression to adherence to medical regimens in pediatric renal and liver transplant patients. Interestingly, Marikranz and colleagues (2007) found that depressive symptoms mediated the relationship between hope, adherence and illness uncertainty. Specifically, children with high-hope and low levels of illness uncertainty were more likely than children with low-hope and high levels of illness uncertainty to adhere to medical regimens (Marikranz, Steele, Dreyer, Stratman, and Bovaird, 2007).

In sum, the literature has suggested that child or caregiver reported illness uncertainty can have adverse effects on emotional adjustment (Maikranz et al., 2007). Therefore, illness uncertainty appears to place individuals at increased risk for clinically significant psychological distress. Research over the last few decades has consistently supported the importance of illness uncertainty in relation to chronic health condition outcomes and how this experience affects both the parent and child symptoms of psychological distress and post-traumatic symptoms.

Subcomponents of Illness Uncertainty and the Relationship to Posttraumatic Stress Symptomatology and General Distress. While the previous section discussed illness uncertainty and psychological variables across multiple pediatric chronic conditions, the current section focuses particularly on specific subcomponents of illness uncertainty (e.g., the experience of ambiguity) and their subsequent relationship to psychological distress (PTSS, PTSD, and general distress). Importantly, no studies to date have attempted to examine the interrelationship of each of these factors or subcomponents to both general distress and posttraumatic stress symptoms, nor have they looked at these relationships simultaneously. This is important for a number of reasons. First, while overall uncertainty may indeed be related to adjustment outcomes across a number of pediatric conditions, there may be unique features of pediatric cancer that impact upon different aspects of the uncertainty experience. For example, pediatric cancer is characterized by a diagnosis that leads to specific treatment protocol that is well laid out, specific, and timeline driven. Thus, there may not be considerable ambiguity about the treatment. At the same time, the course of treatment is often highly unpredictable, with the possibility of untoward side effects at any given time. In addition, parents whose children are being treated for cancer are now given considerable information about the diagnosis and treatment, and thus it cannot be argued necessarily that a ‘lack of information” plays a critical role in determining psychological outcomes.

To sum, we know little about how each of these factors or subcomponents differentially relates to either posttraumatic stress symptoms or general distress. Importantly, no research to date has examined the extent to which specific constructs (Ambiguity, Lack of Information, Lack of Clarity, Unpredictability) of the illness uncertainty measure for caregivers are associated with psychological distress and posttraumatic stress symptomatology.

CHAPTER SUMMARY

A diagnosis of pediatric cancer can affect the psychological functioning of both the child and the caregiver. Parents of children with cancer often encounter increased stressors during the initial stages of medical treatment and continued maintenance care. The literature has demonstrated strong associations between illness uncertainty and both global psychological distress and posttraumatic symptomatology (Santacroce, 2002; Steele et al., 2009; Stewart & Mishel, 2000; Mullins et al., 2001; Fuemmeler, Mullins & Marx, 2001; Best, Streisand, Catania & Kazak, 2001). However, no research has examined the relationship of the subscales or factor scores for illness uncertainty and their relationship to either global psychological distress or posttraumatic stress. More research is needed to better understand these sub-dimensions and the associations between these constructs, with the ultimate goal of improving the outcomes of children diagnosed with cancer.

To address the significant gap in the literature the potential associations between these constructs, the current study will utilize a path analysis via structural equation modeling (SEM) to ascertain the relationship between illness uncertainty, global psychological distress, and posttraumatic symptomatology in parents of children with cancer. Specifically, we will use two theoretically driven, competing models to examine the subcomponents of illness uncertainty independently related to posttraumatic stress as mediated by symptoms of global psychological distress.

CHAPTER III

PRESENT STUDY: METHOD

Participants and Procedure

The current study used archival data collected between 2009-2013. Caregivers (N =105; Mothers = 91.4%, Age M = 35.82, SD = 8.21) of children (Male = 52.4%; Age M = 8.55, SD = 5.03) with newly diagnosed cancer reported their levels of illness uncertainty, global psychological distress, and posttraumatic stress symptoms as part of a larger study investigating family adaptation to pediatric cancer. The majority of caregivers self-identified as Caucasian (69.8%), followed by African American (11.1%), Native American (7.9%), Hispanic American (4.8%), and multi-racial (3.2%); two caregivers declined to disclose ethnicity. The demographics of this sample are largely consistent with the demographics of the state where this data was collected.

The institutional review board at the hospital where the study was conducted approved this study and it was carried out in compliance with the American Psychological Association ethical guidelines. Participants were recruited from a pediatric hematology and oncology clinic in a large teaching hospital in the Midwest region of the United States. Eligible caregiver/child dyads were first identified through the hematology/oncology clinic patient database and medical eligibility was assessed through consultation with the attending physician. Eligibility criteria were as follows: 1) parents of children with pediatric cancer ages 2-18 years; 2) children were between 2 to 8 months post-diagnosis; 3) child must be receiving care from the Jimmy Everest Center

(JEC) hematology/oncology clinic at the University of Oklahoma Health Sciences Center (OUHSC); and 4) English as a primary language. The exclusion criteria included: (1) child is receiving palliative care; (2) child has a diagnosis of mental retardation or severe developmental delay; or (3) caregiver is being treated for serious psychiatric disorder. Eligible caregivers (n = 128) were approached during the child's scheduled outpatient appointment, and 105 were consented (85%), and asked to complete measures in a private location within the clinic. All caregivers self-identified as the legal guardian and this was confirmed by the medical team. Participants were given modest monetary compensation for study participation ($10). Additional caregiver and child demographics are reported in Tables 1 and 2 in Appendix B.

Measures

Illness Uncertainty. The Parent Perception of Uncertainty Scale (PPUS; Mishel, 1983) is a 34-item Likert questionnaire used to measure perceived uncertainty in parents of children with a health problem. Scores range from 31 to 155, with higher scores indicating greater levels of uncertainty. The PPUS is comprised of four subcomponents or factors/subscales, and a total score. Standardized sample alphas from previous literature for Ambiguity (α = .87; 13 items), Lack of clarity (α = .81; 9 items), Lack of information (α = .73; 5 items), Unpredictability (α = .72; 4 items), and the total score (α = .91) are relatively robust. In the present sample, internal consistency for the total score was high (α =. 91). Internal consistency was moderately high for three of the factors; Ambiguity (α = .86), Lack of Clarity (α =. 79), and Unpredictability (α =. 76) but considerably lower for Lack of information (α = .59). Because of the low reliability of the lack of information factor, it was excluded from further analysis. Means and standard deviations for the four factors are presented in Table 4 in Appendix A.

Posttraumatic Stress Symptomatology. The Impact of Event Scale – Revised (IES-R; Weiss, 2007) is a 22-item questionnaire to capture an individual's subjective response to a specific traumatic event based on DSM-IV criteria for PTSD. The IES-R is comprised of three subcomponents: Avoidance, Intrusion, and Hyperarousal. There are no specific clinical cut off scores for this measure; however, a total score greater than 26 is considered severe and a score greater than 33 is considered clinically significant (Weiss, 2007). In the present study, 51 of the 105 (48.57%) caregivers of children newly diagnosed with cancer in the current study reported a total PTSS score in the severe (*n* = 16) or clinically significant cutoff range (*n* = 35).

The IES-R was designed and validated using a self-reported and self-identified specific traumatic event as a reference (i.e., cancer in the current study), which in turn allows researchers to designate and target specific traumatic events. It is a brief assessment tool and has been shown to significantly correlate with DSM-IV criteria for PTSD. In the present sample, internal consistency for the total score was high (α =. 95). Internal consistency for subcomponents (i.e., subscales or factors) were as follows: Avoidance (8 items; α = .83), Intrusion (8 items; α =. 91), Hyperarousal (6 items; α = .87). The total score means and standard deviations are presented in Table 3 in Appendix A.

Global Psychological Distress. The Brief Symptom Inventory (BSI; Derogatis, 1993) BSI is a concise, 53-item self-report inventory that requires only 8-10 minutes to complete. The BSI was designed to measure the psychological symptom patterns of psychiatric and medical patients and non-patients. It has been widely used in studies of parents of children with chronic health conditions (e.g., Mullins et al., 1995; Gillaspy et al., 2002; Wagner et al., 2003). The BSI provides profiles of nine primary symptom domains and three global indices of psychological distress (Derogatis, 1993). The nine symptom domains captured within the BSI include: Somatization (7 items), Obsessive-Compulsive (6 items), Interpersonal Sensitivity (4 items), Depression (6 items), Anxiety (6 items), Hostility (5 items), Phobic Anxiety (5 items), Paranoid Ideation (5 items) and Psychoticism (5 items). Global indices scores for the BSI include the following: 1) Global Severity Index, which provides an overall psychological distress level measurement, 2) Positive Symptom Distress Index to assess for intensity of symptoms, and 3)

Positive Symptom Total quantifying the frequency of self-reported symptoms. The BSI is reported to have high internal consistency, ranging from .71 to .85. In the present sample, internal consistency for GSI was extremely high (α=. 97). Internal consistency for subscales ranged from .71 to .91. Means and standard deviations for the GSI and subscales are presented in Table 3 in Appendix A.

To measure global or general psychological distress in the current study, the GSI summary score was used. The GSI is the single best indicator of current distress levels, and is utilized in most instances where a single summary measure is required (Derogatis & Melisaratos, 1983). The GSI combines information on the numbers of symptoms and the intensity of perceived distress (Derogatis & Melisaratos, 1983).

Overview of Analyses

To test hypothesis 1, the data was entered into a multivariate path model using Mplus7 (Muthén & Muthén, 1998-2012). Three of the four factors or subcomponents (Ambiguity, Lack of Clarity, Unpredictability) from the Parent Perceptions of Illness Uncertainty were entered into the model as exogenous variables predicting the Impact of Event Scale – Revised total score of PTSD symptomatology and the Global Psychological Index from the Brief Symptom Inventory. As stated previously, the Lack of Information subcomponent was not included in our model due to insufficient reliability. To examine a an alternative model to hypothesized model 1, model 2 examined illness uncertainty, posttraumatic stress symptoms, and psychological distress, with posttraumatic stress symptoms mediating the direct relationship between the exogenous components of illness uncertainty to global psychological distress (see Figures 1 and 2).

<u>Model Specification</u>. The path analysis is a statistical model housed within the boundaries of structural equation modeling methodology (SEM). SEM is a flexible and comprehensive methodology to estimate and test a theoretical network of measured variables

(Rigdon, 1998). Prior to conducting analyses, model specification is needed. Model specification is the exercise of formally stating a model and determining which parameters are fixed or free. If a model is fixed, parameters are not estimated from the data and are set at zero. If a model is free, parameters are estimated from the data and are believed to be non-zero (Kline, 2011). In the current study, using an *a priori* hypothesis about which pathways are important in the components of the proposed structure, we identified seven parameter estimates. Previous studies recommend minimum sample sizes to be at least 100 participants (Kline, 2011) and that there should be at least 10 participants per parameter to be estimated (Bentler & Chou, 1987), which was achieved in the present study.

To investigate the direct and indirect effect of ambiguity, lack of clarity and unpredictability on PTSD and global psychological distress, a path analysis was utilized. Global psychological distress was specified as a mediator of ambiguity, lack of clarity and unpredictability subscales onto posttraumatic stress symptomatology. Consistent with current recommendations for testing mediation (Fritz & MacKinnon, 2007), the current analysis incorporated 5000 bias-corrected bootstrapped samples to better estimate the population parameters of the effect of subcomponents of illness uncertainty on posttraumatic stress symptomatology. Bias-corrected bootstrapping allows for power of .80 when samples are small and standardized correlations are moderate (Janicke, Finney, & Riley, 2001). The proposed measurement model was just identified, meaning that there were no degrees of freedom to assess model fit. Therefore, a model trimming procedure was used to remove nonsignificant parameters, and to allow for model comparisons. To assess overall model fit, results were evaluated by examining the χ^2 test of significance, comparative fit index (CFI), nonnormed fit index (NNFI), and the root mean squared error of approximation (RMSEA). Model fit is considered acceptable if the CFI and NNFI are above .90 and the RMSEA is below .10 (Hu & Bentler, 1999). Nested model comparison was evaluated using a χ^2 difference test. Please again refer to Figures 1 and 2 for a visual representation of each of these analyses

CHAPTER IV

FINDINGS

Descriptive analyses. Demographic characteristics of the current sample are presented in Tables 1 and 2. Means, standard deviations, and Cronbach alphas are presented in Tables 3 and 4, respectively. Average scores (*M* = 27.04) for our sample on the IES-R fell in the sub-diagnostic level, which suggests that PTSD may be a clinical concern and it is probable that individuals are experiencing at least some of the symptoms of posttraumatic stress (Weiss, 2007). Examinations of the psychometric properties of the IES-R have identified that total PTSS scores greater than or equal to a clinical cutoff value of 33 were predictive of a PTSD diagnosis (Rash et al., 2008; Creamer, Bell, & Falilla, 2002). A subset of the current sample (33%, *n* = 35) exhibited clinically significant posttraumatic stress symptomatology (*M* = 48.66*, SD* =14.16) according to this cutoff.

Model Specification. Mediated path analyses were next conducted to examine caregivers' self-report ratings of illness uncertainty, posttraumatic stress, and global psychological distress. Analyses were conducted in the following manner. Fist models were specified to reflect hypothesis one and tow. Model specification is the step in which parameters are determined as fixe or free. Fixed parameters are not estimated from the sample data and are typically fixed at zero, which indicated no relationship between variables (Kline, 2011).

Free parameters are estimated from the observed data and are believed to be non-zero. For hypothesized models one and two, parameters remained free, determined by a priori hypothesized models. Using these specifications and the data analytic plan, hypothesized model 1 (AIC = 1598.95) had a better fit for the data than hypothesized model 2 (AIC = 1602.81), as evidenced by a smaller Akaike Information Criterion (AIC). See Table 5 for the summary of the nested model results discussed in the following paragraphs.

Model Comparison. When compared, hypothetical model one (AIC = 1598.95) had a better fit for the data than hypothesized model 2 (AIC = 1602.81). Hypothesized model one explained 47.30% of the variance and was used in subsequent analysis to examine associations of the subcomponents of illness uncertainty in relation to posttraumatic stress symptomatology as mediated by global psychological distress via the most parsimonious model (model one, X^2= .00; df = 0; CFI = 1.00; NNFI = 1.00; RMSEA = .00). Chi-square difference tests were examined to test the statistical significance of the decrease in the overall fit statistic as each pathway is eliminated. Chi-square difference tests involve calculating the difference between the chi-square statistic for the null and alternative models, the resulting statistic is distributed chi-square with degrees of freedom equal to the difference in the degrees of freedom between the two models. First, the direct path of global distress regressed onto the unpredictability subcomponent was constrained to zero, which produced a nonsignificant change

($\Delta\chi^2$ = .01, df = 1; RMSEA = .93). The next path examined for deletion, examined the direct path of posttraumatic stress regressed on unpredictability, which also produced a nonsignificant change ($\Delta\chi^2$ = .14, df =2; RMSEA = .95). Next, the following illness uncertainty subcomponents were constrained to zero; ambiguity regressed onto global psychological distress and posttraumatic stress symptomatology ($\Delta\chi^2$ = .44, df = 3; RMSEA = .95); unpredictability regressed onto global psychological distress and posttraumatic stress symptomatology ($\Delta\chi^2$ =

1.02, df = 4; RMSEA = .94); lack of clarity regressed onto global psychological distress and posttraumatic stress ($\Delta\chi^2$ =2.06, df = 5; RMSEA = .90).

It should be noted that to examine indirect effects, no changes in degrees of freedom are needed and it does not influence the parsimony of the proposed models. Therefore, the final, most parsimonious with indirect paths estimated using 5,000 bootstrapped samples (**β** = .28; CI (95%) = .13 - .43; CFI = 1.00; NNFI = 1.00) evidenced close fit to the data. In the final model, for the direct pathways, a positive relationship between global psychological distress and posttraumatic stress symptomatology was observed (**β** = .68) as well as a positive relationship between ambiguity and global psychological distress (**β** =. 41). Upon examining the indirect pathways, a strong positive relationship was observed between ambiguity through global psychological to posttraumatic stress (**β** = .62). In addition, the indirect pathway of posttraumatic stress symptomatology regressed on global psychological distress regressed on ambiguity (**β** = .62).

In sum, hypothesized model one represented the best fit to the data, accounted for 47.30% of the variance in posttraumatic stress symptomatology, and the subcomponent or factor of ambiguity had significant indirect and direct effects on posttraumatic stress symptomatology, as mediated through global psychological distress, as compared to any other of the subcomponents of illness uncertainty (e.g., lack of clarity or unpredictability).

CHAPTER V

DISCUSSION

The purpose of the present study was to investigate the relationship of subcomponents of illness uncertainty (i.e., ambiguity, lack of clarity, unpredictability) to posttraumatic stress symptomatology and global psychological distress using a nested model approach. More specifically, we examined two competing models for the manner in which the subcomponents of illness uncertainty are associated with global psychological distress and posttraumatic stress. Illness uncertainty, posttraumatic stress and global psychological distress are constructs that have been previously shown to be interrelated constructs (e.g., Phipps et al., 2005; Kazak et al., 2005; Mullins et al., 2000; Mullins, et al., 2001). However, no study has sought to specify the precise interrelationships between these variables. As such, the current study was guided by one research question driven by two competing, theory-driven models. Our overall research question was to investigate three known constructs (illness uncertainty, posttraumatic stress and global psychological distress) related to pediatric cancer, how these constructs are related to each other, and specific pathways of illness uncertainty which may drive the relationship with posttraumatic stress and global psychological distress. The following will overview each of the hypothesized models, study results, implications and future research directions.

First, the current study aimed to compare two hypothesized models to identify direct and indirect pathways of illness uncertainty subcomponents, posttraumatic stress and global psychological distress. Model one was found to be consistent with the hypothesized association (examining illness uncertainty subcomponents relationship to posttraumatic stress symptomatology, as mediated by global psychological distress). To further investigate hypothesized model one and to examine the model fit with the current data, a second, competing hypothesized model aimed to provide an alternative theoretical model. Model two (examining illness uncertainty subcomponents relationship to global psychological distress, as mediated by posttraumatic stress symptomatology) proved to be a poorer fit to the data than model one, and therefore was not included in any further analyses. Using the hierarchical model trimming approach (Kline, 2011) we examined a just-identified model (hypothesized model one) and simplified the model by eliminating each path by constraining the previously freely estimated (non-zero) paths to zero to find the most parsimonious model that fits the data. Upon this further investigation and by trimming nonsignificant pathways, a significant indirect association was found between the subcomponent of ambiguity in illness uncertainty and posttraumatic stress. The final model (model one) accounted for 47.3% of the variance, suggesting that almost half of the variance is accounted for via caregivers' perceptions of ambiguity and the association with posttraumatic stress and global psychological distress.

Although speculative, it is possible that the current study has provided insight into a unique association of illness uncertainty and the subsequent association to posttraumatic stress and psychological distress. Particularly, the present study suggests that higher levels of ambiguity result in the experience of global psychological distress, which in turn leads to increases in posttraumatic stress symptomatology. Thus, global psychological distress may be the mechanism by which illness uncertainty (e.g., ambiguity) influences posttraumatic stress symptomatology. As previously mentioned, illness uncertainty has consistently been demonstrated to be a salient predictor of psychosocial outcomes of various disease states (McCormick, 2002). Although much of the literature has addressed uncertainty in illness as an overarching construct (Mullins et al., 2004; Fuemmeler, Mullins, & Marx, 2001; Santacroce, 2003; Mullins et al., 2001; Carpentier, Mullins, Chaney, & Wagner, 2006), to our knowledge no studies have examined the factors or subcomponents of this construct. The current study suggests that it may well be appropriate to examine these factors as more powerful predictors of psychological outcomes. To our knowledge, this is the first study to examine the subcomponents of illness uncertainty with known related constructs of posttraumatic stress (e.g., Fuemmeler, Mullins, & Marx, 2001; Santacroce, 2003) and global psychological distress (Mullins et al., 2001; Carpentier, Mullins, Chaney, & Wagner, 2006).

It has been consistently documented in the literature that high levels of distress are often observed in parents of newly diagnosed children with cancer. Particularly, the literature has shown that a subset of these parents are at an increased risk to develop depression, posttraumatic stress symtpomology, and anxiety at shortly after diagnosis, with a select subset continuing even after treatment has been completed (e.g., Dolgin et al., 2007; Patiño-Fernández et al., 2008; Kazak et al., 2005). Consistent with this literature, it is important to note that caregivers in the current study reported experiencing high levels of posttraumatic stress symptomatology. In the present study, 51 of the 105 (48.57%) caregivers of children newly diagnosed with cancer in the current study reported a total posttraumatic stress symptomatology score greater than 26, which is considered severe. Of those 51, 16 reported a score between 26 and 32, which is in the severe, but in the subclinical level (Weiss, 2007). Of those 51, 35 reported a score greater than 33, which is considered clinically significant experiences of posttraumatic stress symptomatology (Weiss, 2007).

Cancer-related posttraumatic stress symptoms and a high incidence of posttraumatic stress disorder in this population of parents have been previously reported in the literature (Phipps et al., 2006; Kazak, et al., 2004). Kazak et al. (2004) found that approximately 45 percent of mothers and 35 percent of fathers with children diagnosed with pediatric cancer reported posttraumatic stress symptomatology in the moderate to severe range. Nearly all families (99%) had at least one family member meet symptom cluster B (re-experiencing) criteria, and 20% of the sample has at least one parent with current PTSD (Kazak et al., 2004). In another study, Manne and colleagues (1996) found that 20 percent of the 65 mothers of cancer survivors reported two of three posttraumatic stress disorder symptoms and 6.2 percent were diagnosed with current posttraumatic stress disorder. Further, a review of 16 studies examining posttraumatic stress in caregivers of children with pediatric cancer, Bruce (2006) found that rates of diagnosis ranged from 25 to 44% for moderate but subdiagnostic symptoms of posttraumatic stress disorder, and 6 to 25 percent for a current posttraumatic stress diagnosis. In addition, clinical assessments also found a lifetime prevalence of cancer-related posttraumatic stress disorder ranged from 27 to 54 percent in caregivers of children with pediatric cancer (Bruce, 2006). By comparison, the lifetime prevalence of posttraumatic stress disorder in the general U.S. population of adults is approximately 8% (Diagnostic and Statistical Manual of Mental Disorders 4th ed.; DSM-IV). Thus, because of cancer-related stressors and events which may be perceived as traumatic events, the high levels of posttraumatic stress symptomatology reported by our sample is consistent with current and previous literature.

Research Implications

Clearly, one area that appears to deserve additional research attention is addressing the interrelationships between the subcomponents (e.g., subscales) of various constructs and the potential impact each subcomponent may or may not have on specific outcomes. For example, while the present study has shown a significant indirect and direct association of ambiguity (e.g., subcomponent of illness uncertainty) with posttraumatic symptomatology, as mediated by global psychological distress, it would be interesting to look at direct effects of illness uncertainty subcomponents on the specific subscales of posttraumatic stress (e.g., re-experiencing, hypervigilence) and global psychological distress (e.g., depression, anxiety).

Caregivers often have the primary role in proving support, assisting with illness-related difficulties, pre- and post-treatment and fiscal responsibilities. If the caregiver is experiencing high levels of illness uncertainty, but this is largely due to the experience of ambiguity of the illness course or duration, targeting a psychosocial intervention on education (e.g., lack of clarity or information subscale) would not be beneficial for this particular caretaker and would unnecessarily use hospital resources. Further understanding how specific subcomponents of illness uncertainty have on known psychological maladaptive outcomes such as posttraumatic stress and global psychological distress could thus provide more detailed and tailored interventions in the pediatric cancer population, where time and resources are often limited.

Lastly, the findings of the present study via hypothesized model one are complimentary to previous literature on the experiences of posttraumatic stress symptomatology in pediatric cancer. The present findings suggest that when illness experiences are ambiguous, overall psychological distress may develop. Further, it appears that this lasting experience of distress can set the stage, long term, for experiences of posttraumatic stress symptomatology. In the literature, this is evidenced as posttraumatic stress symptoms have emerged as one of the most important psychological consequences of childhood cancer (Stuber, Kazak, Meeske, & Barakat, 1998). The results of the present study provide some support for distinguishing between specific illness uncertainty variables and the development of posttraumatic stress symptoms as mediated through experiences of global psychological distress. The considerable amount of variance explained in the indirect pathway of ambiguity of illness uncertainty highlights the necessity of searching for other possible pathways within the mediating effect of global psychological distress (e.g., depression vs. anxiety) and the development of posttraumatic stress symptomatology (e.g., avoidance vs. hypervigilance). Therefore, understanding the complexities of parents and children's experience of posttraumatic stress symptomatology in pediatric cancer is paramount; as such, the present study may provide an initial insight into this multifaceted psychological construct.

Clinical Implications

Pediatric cancer, particularly during the early stages of treatment, is unpredictable and treatment is oftentimes complex. Understanding the more precise mechanisms that influence a family's ability to cope with a chronic condition such as pediatric cancer is imperative. The current study makes a unique contribution to the pediatric cancers literature. First, the present study was implemented within the first 6 months of diagnosis of pediatric cancer. This period represents a time of heightened risk for parental distress and as such is reflected in the posttraumatic stress symptomatology ratings in the present study. During high periods of psychological distress, interventions that are quick and tailored to the families specific need of uncertainty surrounding diagnosis and/or treatment outcomes could significantly reduce maladaptive psychological outcomes such as increases in global psychological distress and posttraumatic stress symptomatology.

Secondly, research has suggested that functional impairments (e.g., social functioning, quality of life, physical functioning) oftentimes accompany posttraumatic stress symptomatology and posttraumatic stress diagnoses (Meeske, Ruccione, Globe, & Stuber, 2001). Future studies should further explore how these functional impairments associated with posttraumatic stress symptomatology affect caregivers of and pediatric cancer survivors' future health and achievement of adult life goals. In addition, examining to what extent functional impairments, such as quality of life, are associated with experiences in subcomponents of uncertainty in illness and global psychological distress could provide more detailed interventions prior to-, during and post treatment.

Research has clearly identified illness uncertainty as a prominent predictor of distress among parents in children with chronic health conditions and is associated with symptoms of anxiety and depression (Stewart & Mishel, 2000; Mullins et al., 1997; Hoff et al., 2005; Mullins et al., 2012). In an earlier study conducted by Hoff and colleagues (2005), targeting illness uncertainty, as a single construct, and global psychological distress in Type 1 diabetes found that mothers in the intervention group reported significant reduction in psychological distress and child behavioral problems. While no significant changes were examined in illness uncertainty (Hoff et al., 2005), it could be suggested to examine each subcomponent of illness uncertainty to tease apart the reduction in symptoms of psychological distress that Hoff and colleagues (2005) reported. Similarly, in a recent intervention targeted to mothers of newly diagnosed pediatric cancer patients, Mullins and colleagues (2012) found the intervention reduced maternal general psychological distress, posttraumatic stress symptoms, and caregiver feelings of burden. Mullins and colleagues (2012) results suggest that early preventative and support efforts targeted at reducing global psychological distress and posttraumatic stress symptomatology may serve as a safeguard for caregivers during the highly stressful time, at first diagnosis. Using these, studies in addition to the present findings suggest a significant relationship between illness uncertainty and global psychological distress that merits further investigation.

While this present study builds on this previous literature, this is the first study to independently examine the subcomponents of the illness uncertainty construct to their respective relationship with posttraumatic stress and global psychological distress. The implications of the current finding of the present study as well as future directions should guide researchers to further investigate how the subcomponents of illness uncertainty affect psychological functioning in chronic illness throughout the illness course.

Limitations

Although the current study provides an important preliminary investigation of the illness uncertainty in relation to significant psychological variables, a number of limitations should be noted and subsequently addressed in future research.

First, the duration of time between the child's diagnosis and enrollment ranged from 2008 to 2012, and therefore most of these families participated soon after diagnosis and largely within the first year of such diagnosis. Thus, these results may not reflect the changing trajectory of these constructs over time as parents cope and adapt to their child's diagnosis and treatment. Secondly, data analyses were conducted without controlling for various caregiver demographic (e.g., age, education, race/ethnicity, child gender) and disease parameters (e.g., diagnosis type, treatment length and intensity). Future research could examine the degree to which these demographic and medical variables affect the outcomes variables of interest. Finally, the data are cross-sectional and correlational in nature, and thus causal assumptions should not be made about the direction of these interrelationships.

Conclusions

Due to increases in the prevalence of childhood cancer and marked improvement in survivorship rates, research should continue to include both initial and long-term investigations of these interrelationships. Future research could aim to better understand and, ultimately, reduce the array of illness uncertainty factors that might impact the psychological well-being (e.g., increase global psychological distress) in both parents and children from the onset of illness to survivorship, and therefore decrease prevalence rates of posttraumatic stress symptomatology in this unique chronic illness population. The findings in this thesis, particularly those identifying subcomponent symptoms of illness uncertainty on posttraumatic symptomatology and global psychological distress, suggest that further research and greater clinical attention to parents' adjustment to childhood cancer is warranted. A comprehensive understanding of the specific influence uncertainty may have in the development of posttraumatic stress and global psychological distress could lead to the development of evidence-based tailored protocols that can guide medical practitioners and pediatric psychologist in facilitating effective strategies at time of diagnosis and throughout post-treatment care.

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APPENDICES

Appendix A
MEASURES

DEMOGRAPHIC INFORMATION

Today's Date: ____________________ Subject Number: ________________

Child's Name: _____________________ Child's Gender: Boy$_1$ Girl$_2$

Child's Date of Diagnosis: __________ Child's Date of Birth: ____________

Treatment Status (circle one): ON$_1$ OFF$_2$

Biological Mother's Name: ____

Biological Father's Name: ____

Language Spoken at Home: English$_1$ Spanish$_2$ Other$_3$

Primary Language Spoken: English$_1$ Spanish$_2$ Other$_3$

Is the child currently attending regular school? YES$_1$ NO$_2$

Currently home schooled? YES$_1$ NO$_2$ Since when? ___________________

Name of School: ____

Current grade or highest grade completed: ____

What is your marital status?
1 Never Married
2 Married
3 Divorced
4 Cohabiting/Living with Partner
5 Widowed
6 Other, please specify: ____________________

Is there another primary caregiver in the home who offers support for you and your child (ex. grandparent, girlfriend, boyfriend, common law husband)? Yes$_1$ No$_2$

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	Relationship	Age	Education	Occupation

List siblings who do not live in the same house with the patient:

Name:	Age:	Education:	Occupation:
Name:	Age:	Education:	Occupation:
Name:	Age:	Education:	Occupation:

What is the mother’s age? _____

What was *the mother’s age* when the child was diagnosed? __________

What is the father’s age? ______________

What was *the father’s age* when the child was diagnosed?___________

What is your child’s age? _____________

What was *your child’s age* when he/she was diagnosed? __________

What is *the mother’s* ethnicity?

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

What is *the father’s* ethnicity?

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

What is *your child’s* ethnicity?

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

Please indicate the child’s mother’s highest level of schooling (circle):

1 - Grades 1-6

2 - Grades 7-9

3 - Grades 10-11

4 - High School Grad or GED

5 – Partial college or technical school

6 – College/University graduate

7 – Graduate/professional degree

8 – Don’t Know

Mother’s occupation:

____

Please Circle: Full Time$_1$ Part Time$_2$

Has the employment been disrupted because of child’s cancer? YES$_1$ NO$_2$

Please indicate the child’s father’s highest level of schooling (circle):

1 - Grades 1-6

2 - Grades 7-9

3 - Grades 10-11

4 - High School Grad or GED

5 – Partial college or technical school

6 – College/University graduate

7 – Graduate/professional degree

8 – Don’t Know

Father’s occupation:

____

Please Circle: Full Time$_1$ Part Time$_2$

Has the employment been disrupted because of child’s cancer? YES$_1$ NO$_2$

<u>If applicable</u>, please indicate significant other’s highest level of schooling:

1 - Grades 1-6

2 - Grades 7-9

3 - Grades 10-11

4 - High School Grad or GED

5 – Partial college or technical school

6 – College/University graduate

7 – Graduate/professional degree

8 – Don’t Know

Significant other’s occupation:

____

Please Circle: Full Time$_1$ Part Time$_2$

Has the employment been disrupted
because of child’s cancer? YES$_1$ NO$_2$

Is the child’s father currently living in the home? Yes$_1$ No$_2$

If father is <u>not</u> in the home, is he contributing financial support to the household? Yes$_1$ No$_2$

Is mother in the home? Yes$_1$ No$_2$

If mother is <u>not</u> in the home, is she contributing financial support to the household? Yes$_1$ No$_2$Please indicate your annual total family income:

(*This information will be held strictly confidential*).

________ 0 – 9,999

________ 10,000-19,999

________ 20,000-29,999

________ 30,000- 39,999

________ 40,000 – 49,999

________ 50,000 – 59,999

________ 60,000 – 69,999

________ 70,000 – 79,999

________80,000 – 89,999

________ 90,000 – 99,999

________ 100,000 or greater

In the last hour, have you consumed any caffeine? Yes$_1$ No$_2$

In the last hour, have you eaten a meal? Yes$_1$ No$_2$

In the last hour, have you taken any medication? Yes$_1$ No$_2$

If yes, what medication: ____

In the last hour, have you slept or taken a nap? Yes$_1$ No$_2$

In the last 30 minutes, have you used nicotine? Yes$_1$ No$_2$

Please rate your current level of overall health:

1 2 3 4 5 6 7 8 9 10

Not Healthy Very Healthy

Please list any medical conditions you are currently receiving treatment for:
____

Place of Residence:

Address: ____

City or Town, State: _____________ Zip Code: _________________

County (e.g., Oklahoma, Payne, Creek, Tulsa, Comanche, etc.):___________________

What is the distance from your home to the cancer treatment center?

___________miles and ____________hour(s)

How many times did you travel to the clinic in the past year (12 months)?
____

How many ER visits has your child had in the past year (12 months)? _____________________

How many hospitalizations for medical problems has your child had in the past year (12 months)? ______________________

Parental Perceptions of Uncertainty Scale

Please read each statement. Take your time and think about what each statement says. Then circle the number under the words that most closely reflect how you feel about your child's illness and treatment. Your choices range from "Strongly Agree" to "Strongly Disagree". Please respond to every statement.

1) I don't know what is wrong with my child.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

2) I have a lot of questions without answers.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

3) I am unsure if my child's illness is getting better or worse.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

4) It is unclear how bad my child's discomfort will be.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

5) The explanations they give about my child seem hazy to me.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

6) The purpose of each treatment for my child is clear to me.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

7) I don’t know when to expect things will be done to my child.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

8) My child’s symptoms continue to change unpredictably.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

9) I understand everything explained to me.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

10) The doctors say things to me that could have many meanings.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

11) I can predict how long my child’s illness will last

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

12) My child’s treatment is too complex to figure out.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

13) It is difficult to know if the treatments and medications my child is getting are helping.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

14) There are so many types of medical staff it is unclear who is responsible for what.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

15) Because of the unpredictability of my child’s illness, I cannot plan for the future.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

16) The course of my child’s illness keeps changing. He/She has good and bad days.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

17) It is vague to me how I will manage the care of my child after leaving the hospital/ doctor’s office.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

18) It is not clear what is going to happen to my child.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

19) I usually know if my child is going to have a good or bad day.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

20) The results of my child’s tests are inconsistent.

5	4	3	2	1

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

21) The effectiveness of the treatment for my child's illness is undetermined.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

22) It is difficult to determine how long it will be before I can care for my child's illness by myself.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

23) I can generally predict the course of my child's illness.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

24) Because of the treatment, what my child can and cannot do keeps changing.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

25) I am certain they will not find anything else wrong with my child.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

26) They have not given my child a specific diagnosis.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

27) My child’s distress in predictable; I know when it is going to get better or worse.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

28) My child’s diagnosis is definite and will not change.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

29) I can depend on the nurses to be there when I need them.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

30) The seriousness of my child’s illness has been determined.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

31) The doctors and nurses use everyday language so I can understand what they are saying.

5	4	3	2	1
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

Brief Symptom Inventory

Instructions: On the next page is a list of problems people sometimes have. Please read each one carefully and blacken the circlet hat best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY. Blacken the circle only for one number foe each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example before beginning and if you have nay questions please ask them now.

Example:
HOW DISTRESSED WERE YOU BY: Bodyaches

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

HOW MUCH WERE YOU DISTRESSED BY:

1) Nervousness or shakiness inside

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

2) Faintness or dizziness

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

3) The idea that someone else an control your thoughts

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

4) Feeling others are to blame for most of your troubles

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

5) Trouble remembering things

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

6) Feeling easily annoyed or irritated

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

HOW MUCH WERE YOU DISTRESSED BY:

7) Pains in heart or chest
1 2 3 4 5
Not at all A little bit Moderately Quite a bit Extremely

8) Feeling afraid in open spaces or on the stressed
1 2 3 4 5
Not at all A little bit Moderately Quite a bit Extremely

9) Thoughts of ending your life
1 2 3 4 5
Not at all A little bit Moderately Quite a bit Extremely

10) Feeling that moist people cannot be trusted
1 2 3 4 5
Not at all A little bit Moderately Quite a bit Extremely

11) Poor appetite
1 2 3 4 5
Not at all A little bit Moderately Quite a bit Extremely

12) Suddenly scared for no reason
1 2 3 4 5
Not at all A little bit Moderately Quite a bit Extremely

13) Temper outbursts that you could nto control
1 2 3 4 5
Not at all A little bit Moderately Quite a bit Extremely

14) Feeling lonely even when you are with people
1 2 3 4 5
Not at all A little bit Moderately Quite a bit Extremely

15) Feeling blocked in getting things done
1 2 3 4 5
Not at all A little bit Moderately Quite a bit Extremely

16) Feeling lonely
1 2 3 4 5
Not at all A little bit Moderately Quite a bit Extremely

HOW MUCH WERE YOU DISTRESSED BY:

17) Feeling blue

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

18) Feeling no interest in things

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

19) Feeling fearful

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

20) Your feeling being easily hurt

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

21) Feeling that people are unfriendly or dislike you

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

22) Feeling inferior to others

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

23) Nausea or upset stomach

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

24) Feeling that you are watched or talked about by others

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

25) Trouble falling asleep

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

26) Having to check and double check what you do

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

HOW MUCH WERE YOU DISTRESSED BY:

27) Difficulty making decisions

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

28) Feeling afraid to travel on buses, subways, or trains

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

29) Trouble getting your breath

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

30) Hot or cold spells

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

31) Having to avoid certain things, places, or activities because they frighten you

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

32) Your mind going blank

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

33) Numbness or tingling in parts of your body

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

34) The idea that you should be punished for your sins

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

35) Feeling hopeless about the future

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

36) Trouble concentrating

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

HOW MUCH WERE YOU DISTRESSED BY:

37) Feeling weak in parts of your body

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

38) Feeling tense or keyed up

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

39) Thoughts of death or dying

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

40) Having urges to beat, injure, or harm someone

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

41) Having urges to break or smash things

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

42) Feeling very self-conscious with others

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

43) Feeling uneasy in crowds, such as shopping or at a movie

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

44) Never feeling close to another person

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

45) Spells of terror or panic

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

46) Getting into frequent arguments

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

HOW MUCH WERE YOU DISTRESSED BY:

47) Feeling nervous when you are left alone

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

48) Others not giving you proper credit for your achievements

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

49) Feeling so restless you couldn’t sit still

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

50) Feelings of worthlessness

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

51) Feeling that people will take advantage of you if you let them

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

52) Feelings of guilt

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

53) The idea that something is wrong with your mind

1	2	3	4	5
Not at all	A little bit	Moderately	Quite a bit	Extremely

Appendix B
TABLES

Table 1. Caregiver Demographics

Age (years)	36.91 (8.70)
Relationship to Child	
Father	8.60%
Mother	91.40%
Ethnicity	
African American	9.50%
White	67.15%
Multi-Racial	3.85%
Native American	10.90%
Annual Family Income	
0 – 59,999	60.00%
60,000 – 99,999	20.10%
100,000 or Greater	16.20%

Table 2. Child Demographics.

Age (years)	8.55 (5.03)
Gender	
Male	52.4%
Female	47.6%
Ethnicity	
African American	9.50%
White	67.15%
Multi-Racial	3.85%
Native American	10.90%
Hispanic	8.60%

Table 3. Measure Total Scores and Standard Deviations

Measure	**M (SD)**
Brief Symptom Inventory (BSI)	40.56 (9.55)
Impact of Event Scale – Revised (IES-R)	27.04 (18.81)
Parent Perception of Uncertainty Scale (PPUS)	70.92 (16.17)
Ambiguity Subscale	32.07 (7.96)
Lack of Clarity Subscale	23.60 (3.09)
Unpredictability	11.40 (3.37)
Lack of Information	12.30 (1.85)

Table 4. Reliability for Illness Uncertainty, Posttraumatic Stress Symptomatology and Global Psychological Distress

Measure	**Number of Items**	**Cronbach's Alpha**
PPUS Total Score	31	.91
PPUS Ambiguity Subscale	13	.86
PPUS Lack of Information Subscale	5	.59
PPUS Lack of Clarity Subscale	9	.79
PPUS Unpredictability Subscale	4	.76
Posttraumatic Stress Symptomatology Score	22	.95
Global Psychological Distress Score	53	.97

Table 5. Nested Model Comparisons

Model Description	**$\Delta \chi^2$**	**Degrees of Freedom**
Ambiguity Constrained to 0 ➔ PTSS	.010	1
Unpredictability Constrained to 0 ➔ GPD	.141	2
Unpredictability Constrained to 0 ➔ PTSS	.441	3
Lack of Control Constrained to 0 ➔ PTSS	1.019	4
Lack of Control Constrained to 0 ➔ GPD	2.059	5

Appendix C

FIGURES

Figure 1. Hypothesized Model 1.

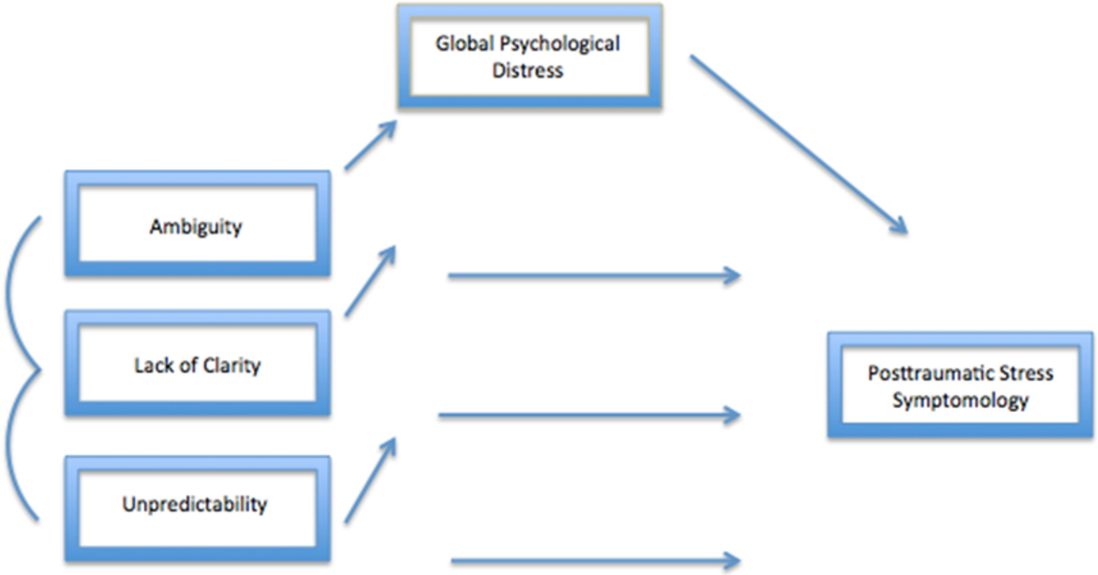


Figure 2. Hypothesized Model 2.

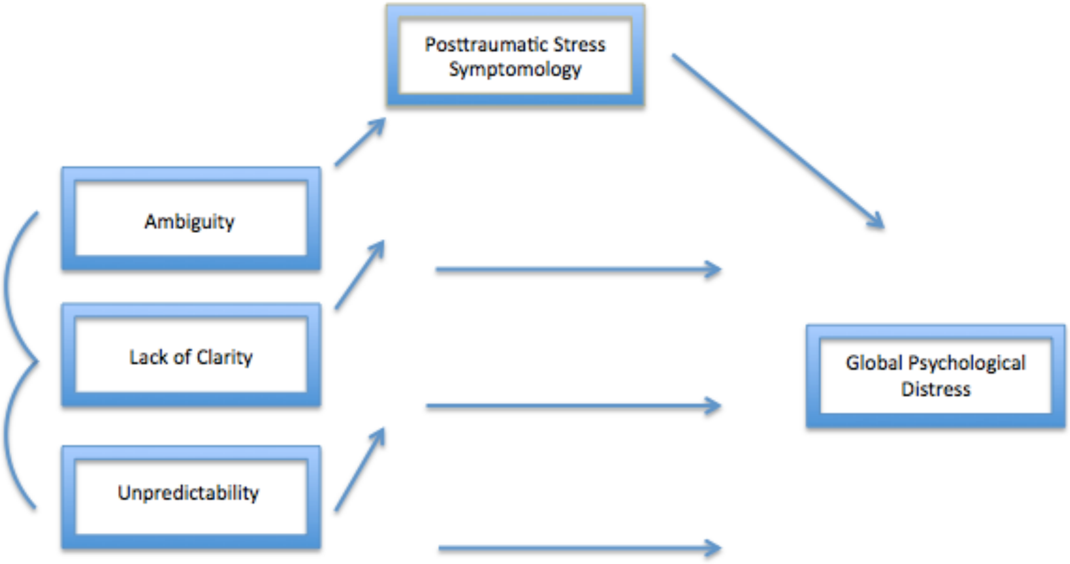
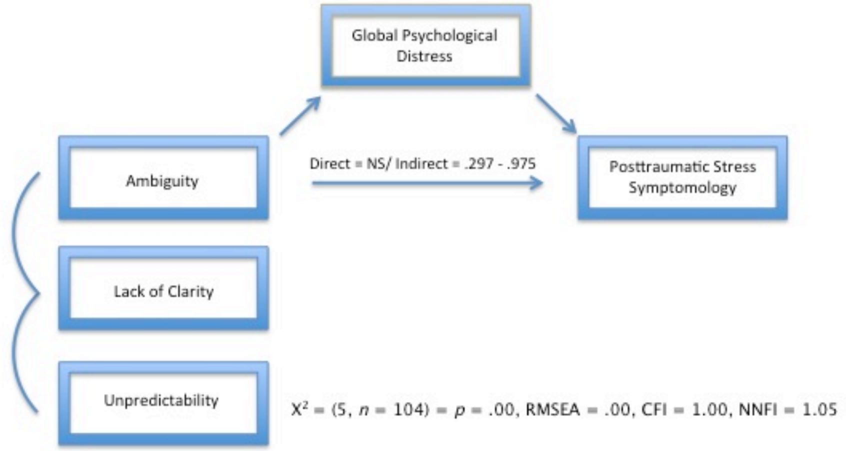


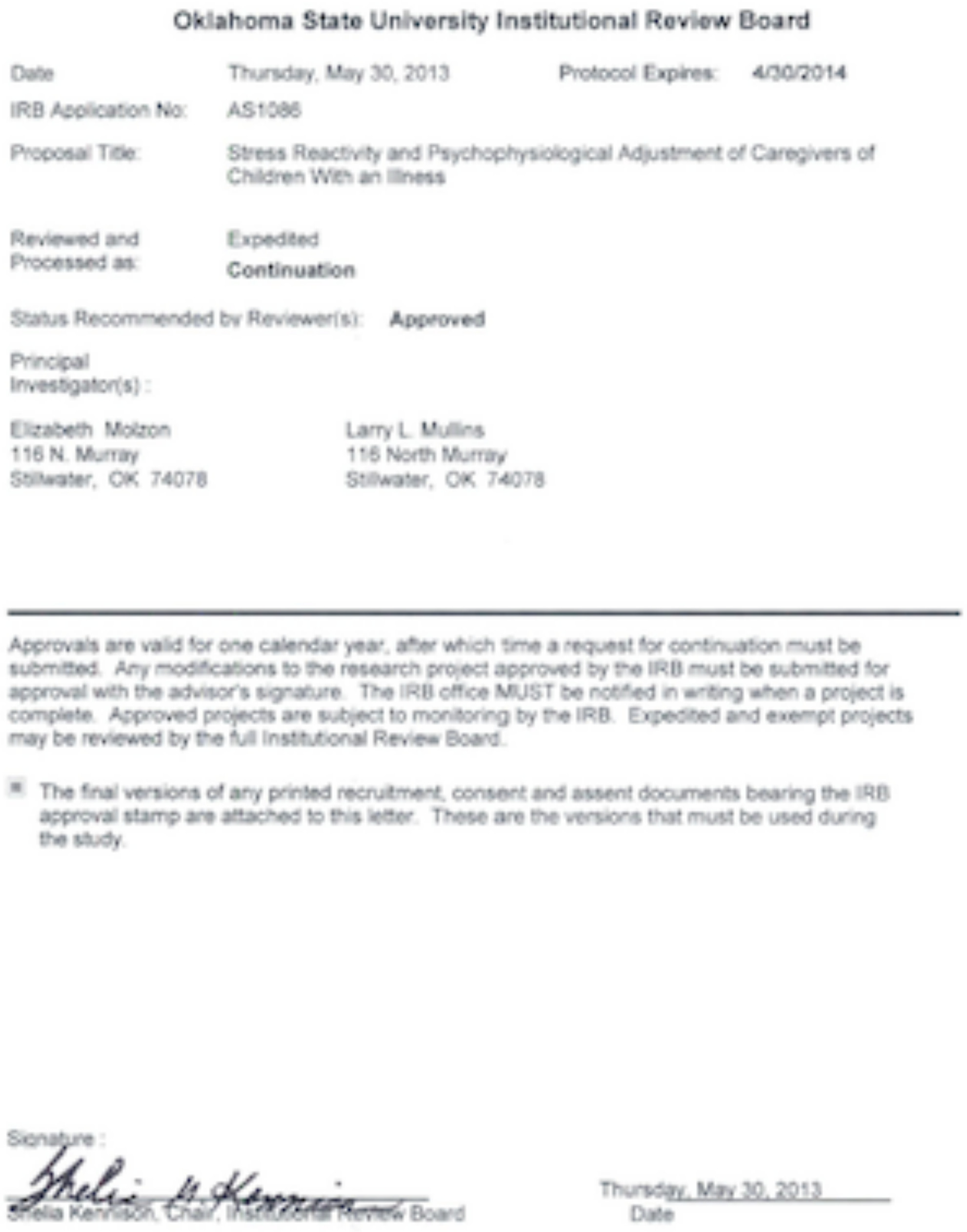
Figure 3. Final Nested Model.



X^2 = (5, n = 104) = p = .00, RMSEA = .00, CFI = 1.00, NNFI = 1.05

Appendix D

OSU IRB Approval



Oklahoma State University Institutional Review Board

Date: Thursday, May 30, 2013 Protocol Expires: **4/30/2014**

IRB Application No: AS1086

Proposal Title: Stress Reactivity and Psychophysiological Adjustment of Caregivers of Children With an Illness

Reviewed and Processed as: Expedited **Continuation**

Status Recommended by Reviewer(s): **Approved**

Principal Investigator(s) :

Elizabeth Molzon
116 N. Murray
Stillwater, OK 74078

Larry L. Mullins
116 North Murray
Stillwater, OK 74078

Approvals are valid for one calendar year, after which time a request for continuation must be submitted. Any modifications to the research project approved by the IRB must be submitted for approval with the advisor's signature. The IRB office MUST be notified in writing when a project is complete. Approved projects are subject to monitoring by the IRB. Expedited and exempt projects may be reviewed by the full Institutional Review Board.

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

Signature :

Shelia M. Kennison

Shelia Kennison, Chair, Institutional Review Board

Thursday, May 30, 2013
Date

VITA

Alayna Pauline Tackett

Candidate for the Degree of

Master of Science

Thesis: ILLNESS UNCERTAINITY, GLOBAL PSYCHOLOGICAL DISTRESS, AND POSTTRAUMTIC STRESS IN PEDIATRIC CANCER: A NESTED MODELS PATH ANALYSIS

Major Field: Clinical Psychology

Biographical:

Education:

Completed the requirements for the Master of Science in Clinical Psychology at Oklahoma State University, Stillwater, Oklahoma in May, 2014.

Completed the requirements for the Bachelor of Arts in Psychology at Northern Kentucky University, Highland Heights, Kentucky in 2009.

Experience: Graduate Research Assistant to Larry L. Mullins, Ph.D., Native American Research Team, Department of Education, Oklahoma State University, August 2012-Present; Graduate Research Assistant to Theodore L. Wagener, Ph.D., Breathe Lab, Oklahoma University Health Sciences Center, August 2012-Present; Clinical experience through Psychological Services Center Oklahoma State University, August 2012- Present.

Professional Memberships: American Psychological Association, American Psychological Association – Division 54 Pediatric Psychology, American Psychological Association – Division 53 Child and Adolescent Psychology, Association for Behavioral and Cognitive Therapies