THE RELATIONSHIP OF CORTISOL TO PSYCHOLOGICAL ADJUSTMENT IN PARENTS OF CHILDREN DIAGNOSED WITH CANCER

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CHAPTER I

INTRODUCTION

In recent decades, the five year survivorship rate of childhood cancer has climbed to upwards of 80% of all individuals diagnosed (American Cancer Society, 2008). Therefore, although the incidence rate of pediatric cancer has slightly risen over time to 14.8 per 100,000, the majority of these individuals and their families are progressing through the arduous phases of cancer treatment into long term survivorship (Ries et al., 2007). Notwithstanding this fact, the diagnosis of cancer and the subsequent treatment can exert a substantial impact on the psychological, social, and emotional well-being of the child and the entire family system. As such, it has been suggested that the majority of individuals with cancer and their families do experience some difficulties in adjustment during the time period surrounding diagnosis; however, most are thought to be resilient and evidence few long-term adjustment difficulties (e.g., Kazak, 1994; Kupst, Natta, & Richardson, 1995; Patenaude & Kupst, 2005). Unfortunately, a consistent subset (approximately 25-30%) does appear to evidence long-term maladjustment or difficulties in emotional, behavioral, or social functioning (e.g., Patenaude & Kupst, 2005; Vannatta & Gerhardt, 2003). Given these findings, researchers have focused on identification of

psychosocial predictors of these poor adjustment outcomes among children (e.g., Noll et al., 1999) and their families (e.g., Barakat et al., 1997; Reiter-Purtill et al., 2008).

In the context of adjustment to pediatric cancer, one key component of the family system that deserves particular attention is the parents. Parents serve a number of key roles specific to caring for a child with cancer. They are a primary source of emotional support for the child, are often responsible for arrangement of numerous medical visits, must insure that the child follows treatment recommendations, and provide for many of the child's basic daily needs. From a theoretical perspective, Thompson and Gustafson's (1996) Transactional Stress and Coping model and Kazak and colleagues (1995) Social Ecological model of child adjustment to a chronic illness posit that parent and child adjustment are related in a reciprocal fashion. Notably, this influence can be either positive or negative in nature. Therefore, in recent years, research has sought to identify specific factors that may facilitate a better understanding of the nature of parent maladjustment in the context of pediatric cancer (e.g., Colletti et al., 2008; Mullins et al., 2004).

Four constructs that are of particular interest for the current project are parenting stress, illness uncertainty, perceived barriers to care, and social support. Specifically, each of these constructs has been hypothesized to play a critical role in parent adjustment to a chronic illness; however, their interrelationships with psychophysiological indicators of distress have yet to be examined. These relationships should be further elucidated given the long-term physiological and psychological effects of ongoing, chronic stress. Specifically, physiological research has shown that chronic stress is related to a range of negative effects, including disrupted levels of cortisol. As a physiological marker of

stress, cortisol has been shown to be related to a decrease in memory functioning, tissue repair, and immune system functioning while concurrently increasing blood pressure and premature cell aging (Epel et al., 2004; Lupien et al., 2005). Furthermore, elevated levels of distress in parents of children with a chronic illness have been shown to be related to negative attributions, lower parent rated self-care behaviors, child-reported depressive symptoms, and parent-reported reduced quality of life (Bourdeau, Mullins, Carpentier, Colletti, & Wolfe-Christensen, 2007; Carpentier, Mullins, Wolfe-Christensen, & Chaney, 2008; Colletti et al., 2008; Kazak & Barakat, 1997; Mullins et al., 2004). Therefore, the current study seeks to expand on the parent adjustment literature by examining the constructs of parenting stress, illness uncertainty, perceived barriers to care, and social support and their relation to physiological stress, as measured by salivary cortisol in parents of children who have been receiving pediatric cancer treatment for six months or longer. In particular, the study sought to address the following three aims:

Aim 1: To determine baseline salivary cortisol levels in parents of children with cancer who have been receiving treatment for six months or longer.

Aim 2: To determine if higher levels of stress reactivity (i.e., salivary cortisol levels) is associated with elevated levels of perceived barriers to care, parental uncertainty, or parenting stress, and to reduced levels of social support in parents of children with cancer.

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

Research Question 1. Are demographic variables (i.e., child age, child gender, parent age, parent education), or illness parameters [i.e., age at diagnosis, illness

duration, severity of illness, disease group (CNS vs. non CNS)] significantly related to the levels of cortisol?

Research Question 2. Are levels of parenting stress related to levels of illness uncertainty, perceived barriers to care, and social support?

In regard to Aim 1, it was hypothesized that parents of children with cancer would evidence lower levels of salivary cortisol compared to previously published salivary cortisol norms of healthy adults (Aardal & Holm, 1995), and evidence approximately equivalent levels of salivary cortisol compared to previously published levels found in parents of children with cancer (Glover & Polland, 2002; Stoppelbein, Greening, & Fite, 2010). With regard to Aim 2, it was hypothesized that salivary cortisol would be related to elevated perceived barriers to care, parental uncertainty, and parenting stress and a negative relationship to social support in parents of children with cancer. Additionally, it was hypothesized that salivary cortisol would predict these constructs such that increased levels of cortisol would be related to increased levels of parenting stress and parental uncertainty. Alternatively, it was hypothesized that decreased levels of cortisol would be related to fewer barriers to care and social support.

CHAPTER II

REVIEW OF LITERATURE

Chapter Overview

The following section will review the existing literature of interest to the proposed project. First, the nature of childhood cancer will be briefly reviewed, concentrating on the classification, incidence, prevalence, and mortality rates, and common cancer treatments. Next, parent adjustment to childhood cancer will be broadly reviewed. Then, the role of stress and the applicability of cortisol within a chronic illness population will be discussed. Subsequently, the extant research of the specific constructs of the current project will be discussed. Specifically, the literature investigating parenting stress, illness uncertainty, perceived barriers to care, and social support will be reviewed.

Childhood Cancer

Classification of Childhood Cancer

The classification of childhood cancers are determined by a combination of cancer morphology and site (Steliarova-Foucher, Stiller, Lacour, & Kaatsch, 2005). The classification system of pediatric cancer differs from the classification of cancer in adults, which is primarily based on site alone. Childhood cancers are classified by the 3rd edition of the International Classification of Childhood Cancers (ICCC) based on the 3rd edition

of the International Classification of Diseases for Oncology. To delineate the varying cancer classifications, the ICCC uses 12 distinct groups: leukemia, lymphomas and reticuloendothelial neoplasms, CNS neoplasms, sympathetic nervous system tumors, retinoblastomas, renal tumors, hepatic tumors, soft-tissue sarcomas, germ-cell trophoblastic neoplasms, carcinomas, and unspecified neoplasms. These categories are further specified by the inclusion of specific subgroups. Furthermore, the ICCC also includes applicable morphology and site information.

Prevalence, *Incidence*, and *Mortality*

Approximately 1 to 2 children per every 10,000 in the United States will be diagnosed with cancer, with the American Cancer Society (ACS) estimating that around 10,400 children under the age of 15 have been diagnosed during their lifetime (ACS, 2007; Ries et al., 2007). Unfortunately, of these 10,400 children, it is estimated that 1,545 will die from the disease. Indeed, cancer is the leading cause of death by disease for children between the ages of 1-14 living in the United States (Ries et al., 2007). However, although the incidence rates of childhood cancer have risen to 14.8 children per 100,000, survival rates have also increased dramatically in the past two decades. Specifically, researchers are now estimating that upwards of 80% of children diagnosed with cancer are still alive five years post-diagnosis (Ries et al., 2007).

Childhood Cancer Treatment

The increasing survivorship of individuals diagnosed with childhood cancer is a direct result of advances in the medical treatment of the disease. Pediatric cancer is commonly treated through chemotherapy, surgery, radiation, bone marrow transplantation, or stem cell transplantation, with most children diagnosed with cancer

receiving a combination of these treatments over time. The specific type of cancer treatment is usually decided upon by taking into consideration the site or location of the cancer, the histology, stage or size of the cancer, and the child's age. Typically, upon diagnosis, families are given two treatment options: to receive the current standard of medical care or enroll in a clinical trial. Clinical trials serve to test newly developed treatments that are hoped to be more efficacious than the current standard of medical care while concurrently producing fewer side effects. Once enrolled in a specific modality of treatment, each family receives a "roadmap" which outlines all aspects of the treatment for families by providing a thorough, week-by-week outline (e.g., drug dosage and treatment type). These roadmaps are individually tailored for the specific cancer treatment to allow families to follow the course of treatment (Children's Oncology Group, 2010).

In sum, the effectiveness of childhood cancer treatment and care has vastly improved in recent years, and as a result, there has been a substantial increase in survivorship. However, despite improvements in the management and care of pediatric cancer, the overall incidence of childhood cancer continues to rise. An increasing number of children and families are therefore faced with the burden of a cancer diagnosis and subsequent treatment, both of which stand to have a substantial impact on the psychological, emotional, behavioral, and social functioning of all individuals within the family system. It is imperative to continue to examine the relative psychosocial impact of a diagnosis of cancer and treatment on the family.

Parent Adjustment to Chronic Illness

Children and parents are impacted by the various systems that surround them. Specifically, children and parents are influenced by several systems that vary in distal proximity to the individual themselves as outlined in the early work conducted by Urie Bonfenbrenner (1979). Bronfenbrenner's Social-Ecological Systems Theory proposed that human development is shaped by interactions between the following four systems: microsystems, mesosytstems, exosystems, and macrosystems. Microsystems include the person and the individuals with whom the person has direct and consistent contact (e.g, family members, peers, and teachers). Mesosystems are composed of two or more interacting microsystem relationships (e.g., parents and teachers or child and parent) whereas exosystems include more distal influences that the individual does not directly participate in (e.g., parental employment). Finally, macrosystems refer to cultural expectations, norms, religion, and beliefs that exert an influence over an individual's development. As a whole, the interaction among these systems is posited to direct and explain human development (Steele & Aylward, 2009). In the context of a chronic illness such as childhood cancer, the same systems interact to shape child and parent adjustment. Recently, two proposed theoretical models for adjustment to a chronic illness that stem from Bronfenbrenner's work have been proposed: Thompson and Gustafson's (1996) Transactional Stress and Coping model and Kazak and colleagues (1995) Social Ecological model.

Transactional Stress and Coping Model

Thompson and Gustafson's (1996) Transactional Stress and Coping model adapted Bronfenbrenner's (1979) theory to include chronic illnesses by proposing that the chronic illness is a potential stressor to which the family and child must attempt to adapt.

According to this model, adjustment is impacted by illness specific variables (e.g., diagnosis and severity), demographic variables (e.g., SES, child's gender, and age of child), and both child and maternal adaptation processes. Specifically, Thompson and Gustafson (1996) proposed that child adaptation is influenced by cognitive processes (e.g., expectations) and coping methods. Similarly, maternal adaptation is also shaped by cognitive processes (e.g., stress appraisal variables and expectations) and coping methods (e.g., palliative and adaptive), however, maternal adaptation is also thought to be influenced by family functioning (e.g., level of support available). Child and maternal adjustment are proposed to be interactive and influential on one another, with adaptation of either individual being additionally influenced by illness-specific and demographic variables.

There is a considerable amount of support for Thompson and Gustafson's (1996) Transactional Stress and Coping Model. Across a variety of pediatric chronic illnesses, cross-sectional studies have demonstrated that parent distress is a significant predictor of child adjustment, beyond the variance accounted for by demographic and illness parameters (e.g., Chaney et al., 1997; Thompson, Gil, Burbach, Keith, & Kinney, 1993). This theoretical model has been examined within cancer, diabetes, sickle cell disease, and asthma populations, among others (e.g., Colletti et al., 2008; Mullins et al., 2004; Mullins et al., 2007; Thompson et al., 1993). Additionally, longitudinal studies have found that child perceptions can account for a significant increase in both child and parent adjustment outcomes at follow-up (Thompson, Gustafson, George, & Spock, 1994). Collectively, these findings support the transactional nature of parent-child distress and adjustment outcomes, such that these variables work in reciprocal fashion.

Social Ecological Model

Kazak and colleagues (1995) have also taken Bronfenbrenner's social-ecological systems theory and adapted it to the specific context of pediatric chronic illness. Similar to Bronfenbrenner's model, the Social Ecological model is also composed of microsystems, mesosystems, exosystems, and macrosystems; however, substantial attention is paid to the influence of a chronic illness. Specifically, the diagnosis or illness itself and the health care system are conceptualized as additional microsystems with which the child has a direct relationship. Additional mesosystem influences include the family's interactions with the health care team and insurance agencies, among other entities. Examples of distinct exosystem influences are the hospital or health care environment and the ability of a parent to maintain employment despite increasing child care needs. Barriers to effective care due to socioeconomic status, discrimination, or financial reasons can also act as additional macrosystem influences. Moreover, cultural or religious beliefs that may influence the child's medical care can also impact development. Each of the systems is thought to be interrelated, exert an impact on one another, and have an effect on child adjustment.

A growing body of literature has examined broad parental adjustment to a pediatric chronic illness and illustrated some interesting findings within the Social Ecological framework. Similar to the Transactional Stress and Coping model, many studies have shown that parent and child adjustment are interrelated (e.g., Kazak, Rourke, & Navasria, 2009). Studies have also demonstrated that some parents can experience significant distress related to their child's diagnosis and treatment. Specifically, it has been argued that some parents are at an increased risk for depression, posttraumatic stress

disorder (PTSD), posttraumatic stress symptoms (PTSS), and anxiety shortly after their child's diagnosis, with a select subset of parents continuing to evidence further maladjustment (e.g., Dolgin et al., 2007; Patiño-Fernández et al., 2008; Kazak, Boeving, Alderfer, Hwang, & Reily, 2005). Other systems, such as the child's siblings (Barlow & Ellard, 2006; Sharpe & Rossiter, 2002) and family as a whole (Steele, Forehand, & Armistead, 1997), are also affected by the diagnosis of a chronic illness. The hospital setting and staff have even been shown to influence child and parent adjustment (Kazak et al., 2009) along with the child's peers and relations at school (Reiter-Purtill, Waller, & Noll, 2009).

Theoretical Implications

Across both of the previously reviewed theories of adjustment to a chronic illness, one area that appears to deserve specific attention is parental or parent adjustment to a chronic illness. Parents are often the primary caretakers of a child with a chronic illness. They are usually the individuals who provide the strongest support for the child, help the child cope with illness-related difficulties or issues, are with the child during procedures and treatment, are responsible for scheduling and transporting the child to medical appointments, and pay for medical services. Within these theoretical frameworks, parents interact with the child on a daily, face-to-face basis in a variety of contexts (e.g., home, hospital, school). As such, parents are considered to exert a substantial impact on the child's adjustment, be part of the child's microsystem, and are linked to several mesosystems, exosystems, and macrosystems (Kazak et al., 1995; Thompson & Gustafson, 1996).

From these theoretical perspectives, and given the parents' extensive involvement within the child's system, it stands to reason that parental adjustment to the child's diagnosis can exert a substantial influence on child and family adjustment. Indeed, a growing body of literature has examined broad parental adjustment to a pediatric chronic illness and demonstrated some interesting findings. Notably, research indicates that parents of a child with a chronic illness are at a distinct risk of developing a range of psychological sequela. A subset of these parents have been shown to be at an elevated risk for depression, PSTD, PTSS, and anxiety at shortly after diagnosis, with a select subset continuing to evidence further maladjustment (e.g., Dolgin et al., 2007; Patiño-Fernández et al., 2008; Kazak et al., 2005). Additionally, studies have delineated that parental and child adjustment is interrelated such that this increased parental maladjustment can be related to increased child maladjustment (Mullins et al., 1995; Thompson et al., 1993).

Psychophysiological Indicators of Adjustment

One area of parent adjustment to pediatric chronic illness that has received little attention is determining the possible physiological manifestations of stress. The majority of the extant research of parent adjustment focuses solely on self-report measures of stress or distress. For instance, self-reported distress has been shown to be related to parental quality of life and child-reported depressive symptoms (Kazak & Barakat, 1997; Mullins et al., 2004). However, delineating the physiological levels of stress within parents of children with cancer appears warranted, especially considering the potentially deleterious effects of chronic stress. Chronic stress in parents of children with cancer has been found to be related to premature cell aging (of approximately 10 years) in

comparison to parents of healthy children (Epel et al., 2004). Consistent stress can be related to decreases in immune system functioning and the ability of the body to repair tissue damage (Dickerson & Kemeny, 2004; Lupien et al., 2005). Chronic stress has also been found to be related to a higher risk of diabetes, hypertension, and hippocampus damage or memory loss (Lupien et al., 1997; McEwen, 1998; Boomershine, Wang, & Zwilling, 2001).

Overview of Cortisol

An indicator of stress that has been commonly used in both animal and human research across multiple disciplines is cortisol. Cortisol is a hormone and psychophysiological marker of stress that can be extrapolated from urine, blood, or saliva. In general, cortisol is a corticosteroid that is released from the hypothalamus-pituitary-adrenal (HPA) axis that can aid the body in returning to homeostasis after experiencing a stressor. Specifically, when an individual perceives a stressor, the hypothalamus is activated and releases corticotropin-releasing hormone (CRH). CRH then functions to stimulate the pituitary gland to release adrenocorticotropic hormone (ACTH). The ACTH in the bloodstream then activates the adrenal glands to release cortisol. An increase in cortisol functions as negative feedback loop to inhibit further release into the body when there is an excess. Cortisol levels are known to follow a diurnal rhythm (Chrousos & Gold, 1992) that peaks in the early morning hours upon awakening in response to increased arousal and steadily declines throughout the rest of the day. Additionally, as an adaptive process, cortisol production allows individuals to experience a short term increase of energy, immunity, and memory.

As it relates to chronic stress, however, cortisol has been found to evidence unique patterns. In a recent meta-analysis, Miller and colleagues (2007) investigated how the time since a stressor was encountered and the controllability of the stressor impacted the diurnal rhythm of cortisol. The authors found that as the time since the onset of a stressor and uncontrollability of a stressor increased, cortisol decreased. Therefore, this meta-analysis demonstrated that certain facets of chronic stress impact the HPA axis and result in dysregulation (e.g., flattened cortisol profiles) or hypocortisolism. In other words, when a stressor is first encountered the HPA axis is activated and cortisol levels increase in response, however, as chronic stressors persist the HPA axis is thought to fatigue and result in diminished cortisol output (Fries, Hesse, Hellhammer, & Hellhammer, 2005; Miller, Chen, & Zhou, 2007).

Cortisol in Parents of Children with Cancer

Parenting a child with a cancer diagnosis can be classified as a chronic stressor (e.g., Kazak et al., 2005), however, only a handful of studies have examined cortisol levels in parents of children with a chronic illness. Furthermore, most of the studies examining cortisol levels in parents of children with cancer have focused on PTSD symptomatology which is a highly debated disorder within the pediatric oncology literature. For instance, although Kazak and colleagues (2004) report high rates of PTSD symptomatology, Stoppelbein and Greening (2006) discovered that after in-depth assessment of the prevalence of PTSD in parents of children with cancer, only seven percent of parents meet diagnostic criteria. Other evidence also exists that question whether the diagnosis of cancer and cancer treatment can even be considered to be a trauma per se (Gerhardt et al., 2007). Unfortunately, the extant literature on cortisol in

PTSD also appears mixed with some individuals evidencing low cortisol levels (Yehuda, 2001; Yehuda, 2009) whereas other articles reveal higher cortisol levels in individuals with PTSD (e.g., Piman & Orr, 1990; Maes et al., 1998). The determination of cortisol levels in PTSD is therefore thought to be a complex interaction of a genetic predisposition or vulnerability, substance use, and trauma history, among other factors (Yehuda, 2001; Yehuda, McFarlane, & Shalev, 1998). In sum, given the multifaceted cortisol profiles of individuals with PTSD or PTSS, conclusions surrounding the relation of cortisol to psychological adjustment in pediatric oncology are unclear and complex. Notwithstanding, a review of the relevant articles on cortisol in parents of children with cancer is warranted for the current study.

Glover and Polland (2002) investigated PTSD in relation to cortisol, norepinephrine, and epinephrine levels in 21 mothers of childhood cancer survivors and eight control mothers. Although mothers in both groups endorsed experiencing traumas during their lifetime, mothers of children previously diagnosed with cancer selected their child's diagnosis as the most significant event. The PTSD group was composed of mothers who evidenced subthreshold levels or met full criteria for this disorder. Notably, the range of time since the child's cancer diagnosis was 1-12 years and all children were no longer receiving treatment at the time of the study. The authors found that urinary cortisol levels in mothers of children previously diagnosed with cancer with PTSD symptoms were significantly lower than other mothers of childhood cancer survivors without PTSD symptomatology. Additionally, cortisol levels in mothers of children previously diagnosed with cancer without PTSD were not significantly different to cortisol levels of the control participants, even after controlling for depressive symptoms.

Glover, Stuber, and Polland (2006) completed another investigation of allostatic load in PTSD among mothers of childhood cancer survivors. For this study, the authors used the same previously discussed sample (see Glover and Polland, 2002); however, the sample was divided into 10 mothers of survivors with PTSS, 10 mothers of survivors without PTSS, and eight control participants. The authors noted that mothers of survivors with PTSS had lower mean cortisol levels compared to the other two groups and that the sample of mothers in the PTSS group included individuals with hypercortisolism and hypocortisolism. The authors speculated that these findings may result from a combination of factors including genetics, hippocampal sensitivity, chronicity of the traumatic event, or dysregulation in negative feedback. These bi-directional results further demonstrate that a chronic stressor may lead to elevated cortisol levels in some individuals and reduced levels in others, possibly due to suppressed activation of the HPA axis (McEwen, 1998; Yehuda, 2001).

Miller, Cohen, and Ritchey (2002) conducted a study examining the impact of chronic stress on immune system functioning. Although not the focal point of their study, the authors collected salivary cortisol levels from parents of children with cancer and controls. The authors noted that parents of children with cancer evidenced a significant flattened morning cortisol slope when compared to controls; however, the two groups did not differ on their concentration levels at other tested time points throughout the day or in their overall total cortisol volume. Given that cortisol usually follows a diurnal rhythm (Chrousos & Gold, 1992), the results of the current study also demonstrated that parents of children receiving treatment for cancer can evidence flattened diurnal slopes which may be indicative of HPA axis dysregulation.

Finally, in a recent study by Stoppelbein and colleagues (2010), PTSS were examined in 27 mothers of children with cancer. Salivary cortisol levels were collected at the time of diagnosis and then monthly for 12 months. Salivary cortisol was found to significantly decrease over time. Additionally, higher cortisol levels were also found to be significantly predictive of PTSS, such that as cortisol levels increased so did PTSS. Finally, mothers who had higher rates of salivary cortisol at the onset of the study evidenced significant decreasing trends when compared to mothers who had lower levels of cortisol at the time of their child's diagnosis.

In sum, even though numerous studies in the psychophysiological literature have demonstrated that stress places individuals at risk for a number of negative outcomes, the integration of cortisol into the parent chronic illness literature is in its infancy. Since parenting a child with cancer is likely to produce chronic stress, further investigations are needed to determine if this form of chronic stress is related to cortisol dysregulation. Furthermore, although studies have examined the relationship of PTSS or PTSD to cortisol levels, no studies have examined whether cognitive appraisal mechanisms are significantly related to cortisol levels. Determining whether particular psychological constructs are related to cortisol could provide informative clinical and research implications. For instance, clinicians could target relevant cognitive appraisal mechanisms with the aim of reducing psychological and physiological distress. Researchers could also further examine if interventions aimed at reducing self-reported distress do, in fact, also have an impact on cortisol levels. Therefore, investigating the relation of cortisol to particular parent variables may be an important step in further delineating the relation of chronic stress to parental adjustment.

Specific Parent Adjustment Variables

The previously discussed theoretical models indicate that not only are parent and child adjustment closely related, but that the better a parent adjusts to the child's diagnosis and treatment, the better the child will adjust. In the past, researchers mainly focused on broad self-report measures of adjustment such as parental mood states, however, in recent years, the literature has begun an attempt to elucidate specific mechanisms for parent adjustment to chronic illness. A recent call was issued by the National Institute of Health (NIH) to identify specific parental variables that may exert an impact on adjustment (NIH, 2006). Researchers have therefore begun to examine how specific self-reported parental variables, including cognitive appraisal variables and perceived macrosystem level influences affect adjustment to a chronic illness; however, no studies have begun to examine how these specific variables of interest relate to cortisol levels. As previously mentioned, ascertaining which self-reported parental and macrosystem variables are related to physiological levels of stress would provide important clinical and research implications such as lending credence to known interventions designed to reduce parenting stress, leading to the development of clinical interventions to reduce both psychological and physiological levels of stress, and providing further validity of self-reported variables. As such, four variables of particular interest to parent adjustment and cortisol may be self-report measures of parenting stress, illness uncertainty, perceived barriers to care, and social support.

Parenting Stress

Parenting stress is a construct that appears to have a consistent impact on parents and children with a chronic illness. Parenting stress is broadly defined as consisting of a

combination of salient child and parental characteristics and situational variables related to parenting (Abidin, 1995). As such, the construct of parenting stress is conceptualized as being composed of the interplay between parental personality and pathology (e.g., depression, anxiety), attachments, social support, parenting characteristics, and child features (e.g., mood, level of demandingness). Given the unique and frequent demands of parenting a child with a chronic illness, parenting stress is often thought to be elevated within these parents, however, only a small body of research has examined this construct.

Across a range of chronic illnesses, the literature appears to suggest that increasing parenting stress has a pervasive impact on both the parent(s) and child. For instance, within a diabetes population, parents have been found to endorse higher parenting stress than controls (Wysocki, Huxtable, Linscheid, & Wayne, 1989) and perceive more demanding and moody children and less competence and social support (Hauenstein, Marvin, Snyder, & Clarke, 1989). Within the context of children with cystic fibrosis, elevated parenting stress has been shown to be related to decreased ratings of treatment compliance (Eddy et al., 1998). Researchers have also determined that parenting stress can mediate the relationship between physical pain and psychosocial health-related quality of life (Barakat, Patterson, Daniel, & Dampier, 2008). Therefore, the literature across chronic illnesses appears to demonstrate that parenting stress can indeed exert an impact on both parents and children.

In the cancer literature, a growing number of studies have examined the potential impact of parenting stress on both parent and child adjustment. In regard to parental adjustment, Kazak and Barakat (1997) longitudinally examined parenting stress in mothers and fathers of children with leukemia. Their results indicated that for both

parents, higher levels of parenting stress while the child was receiving cancer treatment were significantly related to increased levels of parental state anxiety upon treatment completion. Additionally, for fathers, on-treatment levels of parenting stress were also significantly related to off-treatment PTSS. Researchers have also demonstrated that parents of children on treatment for cancer endorsed significantly higher parenting stress than parents of children with a physical disability (Hung, Wu, & Yeh, 2004). Interestingly, parents of children with cancer reported higher total and subscale scores on the Parenting Stress Index than parents of children with a physical disability. Parents of children with cancer have also been shown to be at greater risk for developing PTSD or PTSS (e.g., Kazak et al., 1997; Kazak et al., 2005); however, the literature on the exact degree of risk has been mixed dependent upon informant or methodology (e.g., Stoppelbein & Greening, 2007).

Elevated parenting stress has also been associated with child adjustment outcomes within an oncology population. In a study conducted by Colletti and colleagues (2008), the researchers discovered that higher levels of parenting stress were a significant predictor of poorer behavioral, emotional, and social adjustment of children currently on treatment for cancer. Likewise, high maternal distress levels have been found to be predictive of children's somatic complaints, and distress levels (Steele, Dreyer, & Phipps, 2004). Child internalizing symptomatology has also been significantly linked to parental stress within this population (Robinson, Gerhardt, Vannatta, & Noll, 2007).

In sum, parenting stress appears to be a consistent predictor of global distress or adjustment in parents and children with a chronic illness. Furthermore, this research suggests that parenting stress exerts an impact on both mothers and fathers and has the

potential to lead to distress for a lengthy period of time. Although the literature has demonstrated consistent findings with regard to parenting stress and general adjustment, several areas of further study within the construct would be beneficial. Specifically, it remains unclear if self-reported parenting stress within parents of children with a chronic illness is related to physiological indicators of stress.

Illness Uncertainty

Illness uncertainty is defined as ambiguity regarding the current state of the illness and treatment while lacking salient information regarding the diagnosis and severity (Mishel & Braden, 1988). As a cognitive appraisal mechanism within the chronic illness literature, illness uncertainty has been delineated as a common characteristic for both children and adults (e.g., Jessop & Stein, 1985; Mishel, 1984). The pervasiveness of illness uncertainty within chronic illness appears to be driven by a number of factors, including the unpredictable nature and course of many diseases (e.g., cancer, juvenile rheumatoid arthritis), frequent invasive treatment regimen components, difficulties or lack of clarity in communication with the medical staff, and the lack of certainty regarding the ultimate outcome of treatment.

Illness uncertainty has been shown to have a robust relationship to numerous adjustment outcomes in both adults and parents of children with a chronic illness. Furthermore, although not the focus of the current study, a large literature that has begun to emerge has demonstrated that children and adolescents can also experience illness uncertainty and that this cognitive appraisal mechanism can exert a substantial influence on their adjustment (Hoff, Mullins, Chaney, Hartman, & Domek, 2002; Hommel et al., 2003; Mullins, Chaney, Pace, & Hartman, 1997; White et al., 2005). The following

sections will briefly outline the extant literature on illness uncertainty in adults and provide a thorough background on illness uncertainty in parents of children with a chronic illness.

Illness uncertainty in adults. Initially, the construct of illness uncertainty was investigated by Merle Mishel and her colleagues. Throughout the 1980s and 1990s, Mishel and her collaborators published a number of articles on illness uncertainty and gynecological cancer that began to define the construct and demonstrate its' widespread impact on psychosocial adjustment to an illness. Mishel and colleagues (1984) discovered that before undergoing cancer treatment, elevated levels of illness uncertainty were related to poorer psychosocial adjustment including decreased optimism. Further, in a longitudinal examination of individuals diagnosed with gynecological cancer, Mishel and Braden (1987) determined that illness uncertainty was related to decreased psychosocial adjustment and social support at the time points surrounding diagnosis, during treatment, and eight months post-treatment.

Mishel's conceptualization of illness uncertainty has been further examined in chronic illnesses beyond gynecological cancer. In adults with multiple sclerosis, higher levels of illness uncertainty were found to be predictive of global distress while controlling for illness and demographic covariates (Mullins et al., 2001). Likewise, Wineman and colleagues (1996) found that increased levels of illness uncertainty negatively predicted emotional well-being and positive mood states in a sample of adults with multiple sclerosis undergoing a clinical trial. Wineman, O'Brien, Nealon, and Kaskel (1993) also determined that individuals with multiple sclerosis who were higher in illness uncertainty were more likely to report lower mood and life satisfaction.

Furthermore, Wineman and colleagues (1994) demonstrated that illness uncertainty was often associated with emotion-focused coping styles. Similar results have also been found in young adults with childhood-onset asthma (Carpentier, Mullins, Chaney, & Wagner, 2006).

Illness uncertainty has even been found to persist after treatment has been completed. For instance, in qualitative interviews of childhood cancer survivors Parry (2003) found that uncertainty regarding reoccurrence or late effects of cancer was present in numerous individuals. This finding appears to be supported in the extant survivorship literature. For instance, Santacroce and Lee (2006) discovered that persisting post-treatment feelings of uncertainty in young adult survivors of childhood cancer mediated the relationship between PTSS and health promotion behaviors. Additionally, another study has demonstrated that illness uncertainty was related to quality of life in breast cancer survivors three years after treatment (Wonghongkul, Dechaprom, Phumivichuvate, & Losawatkul, 2006). These articles collectively demonstrate that illness uncertainty is present in adults both on and off treatment for a chronic illness.

Illness uncertainty in parents of children with a chronic illness. With the knowledge that illness uncertainty is a salient cognitive appraisal mechanism in the context of chronic illness, researchers have turned attention to parents of children with a chronic illness to determine if uncertainty has an impact on their psychosocial adjustment. As a result, several qualitative studies spanning multiple chronic illnesses have been conducted (Stewart & Mishel, 2000). Additionally, a handful of quantitative studies have also been conducted in specific and mixed samples of parents of children with a chronic illness.

Across the qualitative studies examining illness uncertainty, increased levels of uncertainty are consistently related to several maladaptive outcomes. For example, Cohen and Martinson (1988) conducted yearly qualitative interviews with families of children diagnosed with cancer. These interviews spanned a five-year time period, with the researchers concluding that increased levels of uncertainty were related to impairment in the parents' accurate appraisal of their child's health status. Through additional interviews of parents of children with life-threatening illnesses, Cohen (1993, 1995) suggested that uncertainty can evolve from the unknown nature of the illness to include situational, social, and treatment uncertainty components, among others. Further, De Graves and Aranda (2008) surmised that uncertainty surrounds the contemplation of the child's treatment and potential death in families of children who experienced a cancer relapse. Qualitative interviews have also demonstrated that illness uncertainty surrounds diagnosis and treatment even in non-life threatening conditions (MacDonald, 1996; Rydström et al., 2004; Trollvik & Severinsson, 2004). In summary, these studies indicate that illness uncertainty is a construct that can exert a significant impact on families of children diagnosed with a chronic illness.

To further underscore the influence of parent uncertainty in the context of a chronic illness, an overview of the available quantitative research is warranted. Similar to the previously discussed qualitative studies, quantitative examinations of illness uncertainty have been conducted across a select few illnesses. Within a type 1 diabetes population, Carpentier and colleagues (2006) found that among parents of children ranging in age from 5 to 20, increased levels of parental uncertainty at baseline were predictive of greater distress at follow-up. Likewise, in a study of parents of children

diagnosed with epilepsy, Mu (2005) found that uncertainty levels were predictive of depression and lower coping abilities. Finally, in a cancer population, Grootenhuis and Last (1997) reported that increased levels of uncertainty were associated with higher levels of anxiety and depressive symptoms.

In mixed chronic illness samples, illness uncertainty has also been shown to be related to maladjustment. Garwick and colleagues (2002) discovered that among families of children with chronic physical health impairments with uncertain life expectancies, parents endorsed greater distress, financial burden, and social disruption. Furthermore, unpredictable symptoms were found to be associated with increased emotional strain in mothers and social disruptions in fathers. Holm and colleagues (2008) also demonstrated that elevated levels of uncertainty were related to elevated maladaptive psychological symptomatology in a sample of parents of children with mixed chronic health conditions. Finally, in a study of mothers of children with several types of chronic illnesses (e.g., cancer, asthma, sickle cell disease, etc.), Jessop and Stein (1985) discovered that elevated levels of uncertainty were related to increased psychological distress.

Collectively, the extant literature on illness uncertainty suggests that elevated levels are consistently related to maladjustment within children, adults, and parents of children with a chronic illness. In examining the available studies on the impact of parent uncertainty, however, numerous weaknesses emerge. First, most studies are qualitative in nature. Although such studies provide a substantial amount of information and paved the way for future studies, they are limited in their generalizability. Next, the available quantitative studies are few in number, especially within an oncology population, and typically have examined global distress rather than elucidating specific constructs.

Finally, no studies have investigated whether uncertainty is related to physiological indicators of stress.

Barriers to Care

An emerging body of research has begun to demonstrate that perceived macrosystem level barriers can also impact parent and child adjustment to a chronic illness. Recently, literature has demonstrated that children, youth, and families may have unequal opportunities for medical care (e.g., Johnson, Brems, Warner, & Roberts, 2006). Families can face numerous vulnerability factors, including living in rural communities, being a patient of minority status, living in poverty, or having a lower education level. All of these factors have been shown to be associated with increasing barriers to healthcare and subsequent lower levels of care (Broffman, 1995; Coburn, McBride, & Ziller, 2002). As such, these families are at a distinct disadvantage for receiving quality pediatric care.

In the context of a chronic illness, the previously described vulnerability factors have been well documented; however, what remains to be elucidated within chronic illnesses are social and behavioral processes that can also moderate a family's experience with the health care system. These processes have been deemed by Seid and colleagues (2009) as perceived barriers to care. Barriers to care have been defined as including the following categories: 1) pragmatics, 2) health beliefs, 3) expectations, 4) skills and knowledge, and 5) marginalization. Pragmatics includes practical factors necessary in obtaining care such as financial resources, transportation, and availability to make appointments. Health beliefs are defined as the understanding related to the etiology and course of the disease whereas expectations refers to any the perceived outcome of interacting with the health care system, often based upon previous experiences. Skills and

knowledge refer to the abilities of the family to navigate the health care system appropriately. Finally, marginalization refers to personalization and internalization of any negative health care system experiences.

These perceived barriers to care stand to make a substantial impact given the families consistent contact with the health care system. In other words, since families of children with a chronic illness are repeatedly interacting with the medical staff, insurance agencies, and health care system, poor interactions may compound and influence adjustment (Seid, Opipari-Arrigan, & Sobo, 2009). In fact, researchers have hypothesized that perceived barriers to care can impact multiple facets of the family's experience of the health care system including access, navigation, the clinical encounter, and implementation of the treatment plan (Seid, Varni, & Kurtin, 2000).

Given the relatively new nature of this construct, little research has examined perceived barriers to care empirically. In an examination of mothers of children diagnosed with asthma, Seid (2008) found that increased perceived barriers to care were associated with decreased perceptions of quality of primary care. Perceived barriers to care were found to have an impact on perceptions of primary care even for parents of children with insurance, a regular source of care, and regular access to health care. Furthermore, perceived barriers to care accounted for more variance than sociodemographic factors such as race, education level, and asthma severity in predicting perceptions of primary care. Seid and colleagues (2009) further demonstrated that perceived barriers to care were higher in parents of children with asthma who were uninsured or reported having problems acquiring care. Perceived barriers to care were also found to be significantly correlated with parent- and child-reported health-related

quality of life such that fewer perceived barriers to care were associated with better functioning.

In sum, perceived barriers to care is a new construct that has only been investigated in a handful of empirical studies to date. Notwithstanding, the available literature on this construct has demonstrated that elevated perceived barriers to care are associated with a range of negative health outcomes. In particular, perceived barriers to care have not yet been examined in parents of children with pediatric cancer. Across all chronic illnesses, the related psychophysiological impact of perceived barriers to care has also not been elucidated.

Social Support

Social support can be defined as actions or behaviors an individual may receive from family, friends, or significant others that function to meet emotional or instrumental needs (House & Kahn, 1985). Although a comprehensive review of social support is beyond the scope of this project, research has suggested that social support can impact adjustment or quality of life through two separate avenues. First, social support may function as a main effect variable that encourages stability within an individual's life through consistent and often positive interactions with others. Alternatively, social support may also act as a buffer to stress by preventing or attenuating a situation being appraised as a stressor or by alleviating a stress response more quickly (Cohen & Wills, 1985; Sarason, Sarason, & Pierce, 1990). Regardless of the specific mechanism of action, social support has been found to have a host of positive effects for both psychological and physical quality of life in non-chronically ill individuals (Cohen & Wills, 1985).

The role of social support in adjustment outcomes has also been clearly demonstrated within the pediatric chronic illness literature, even being integrated as an integral component of multivariate models of parent and child adjustment to illness (e.g.,Wallander & Varni, 1998). Given the large and pervasive impact that a cancer diagnosis and treatment can exert on the family system, it follows that social support would be a construct that directly impacts parent adjustment. Indeed, higher levels of social support have been found to be significantly related to improved levels of psychosocial adjustment, especially among parents of children who are currently on treatment (Morrow, Hoagland, & Carnrike, 1981). Social support also appears to be a protective factor for mothers and fathers with research demonstrating that higher levels of social support were predictive of reduced depressive and state and trait anxiety scores (Speechley & Noh, 1992). Lower levels of social support have been shown to be linked to increased depressive and anxious symptoms for both mothers and fathers and also increased feelings of hopelessness for mothers (Bayat, Erdem, & Kuzucu, 2008).

Researchers have also demonstrated that despite fluctuations in magnitude, social support is a key construct within parents of children diagnosed with cancer across all stages of treatment. It should be noted that the amount of social support that parents report receiving has been found to increase during the time period close to diagnosis and then slowly taper as a child progresses through treatment, with the largest drop occurring around six months post diagnosis (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2001). However, social support remains to be a significant predictor of psychosocial adjustment outcomes in both mothers and fathers over time. For instance, lower levels of support have been shown to be linked to paternal psychological distress at both 6 and 12 months

post diagnosis whereas higher levels of support have been related to better psychological coping over time in clinically distressed mothers (Hoekstra-Weebers et al., 2001). Research also indicates that levels of social support may even be related to parental psychological distress up to 18 months post diagnosis (Sloper, 2000) and some psychological symptomatomlogy (e.g., posttraumatic stress symptoms) in parents of childhood cancer survivors (Kazak et al., 1998). However, other studies report that these parents reach levels reported by parents of nonchroncially ill children when they transition into survivorship (Kazak & Meadows, 1989). Notwithstanding, the extant research on social support seems to suggest that increased levels of social support are related to various components of parent adjustment and that these relations appear to be long lasting, with some evidence of social support even exerting an influence into survivorship.

One component of social support that is gaining more interest is the link between social support and physiological health. Indeed, studies have demonstrated that social support can be directly linked to physiological processes such as cardiovascular, immune, and endocrine system functioning (Uchino, Cacioppo, & Kiecolt-Glaser, 1996). These links have also been elucidated within the adult health psychology literature with studies demonstrating that social support is related to overall medical regimen adherence, including better glycemic control (DiMatteo, 2004; Griffith, Field, & Lustman, 1990). In regard to cancer, studies have even shown that social support is negatively related to cortisol in women with breast cancer (Turner-Cobb, Sephton, Koopman, Blake-Mortimer, & Spiegel, 2000). Furthermore, in the only known study to examine physiological stress and social support in parents of children with cancer (Miller et al.,

2002), the authors investigated the relation of social support to markers of inflammation and immune system functioning. Interestingly, higher tangible social support was found to be related to greater glucocorticoid sensitivity amongst parents of children on treatment for cancer. In other words, parents who endorsed more social support were found to have immune systems that were better able to respond to anti-inflammatory glucocorticoids than parents who endorsed lower levels of social support.

These results indicate that social support is a relevant construct across treatment stages for parents of children with cancer. Research has also shown that social support can impact individuals by operating as a protective factor against maladaptive physiological processes. For parents of children with cancer, one study demonstrated that social support can exert an impact on a biological level, however, what is less well known is the relation of social support to cortisol within this population. Elucidating the relation of cortisol to social support may also help determine if social support acts as a buffer to chronic physiological stress.

Chapter Summary

Collectively, a diagnosis of pediatric cancer can exert a significant impact on the family system as a whole. It is important to note that the parent's adjustment to this diagnosis and treatment has been shown to be integral to child adjustment (Kazak et al., 1995; Thompson & Gustafson, 1996). As can be seen, the extant literature has demonstrated that elevated levels of parenting stress, illness uncertainty, barriers to care, and lower levels of social support can be linked to a range of negative adjustment outcomes for the child and parent (Bourdeau et al., 2007; Carpentier et al., 2008; Colletti et al., 2008; Kazak & Barakat, 1997; Mullins et al., 2004). However, the

interrelationships with these variables and psychophysiological indicators of distress have not been examined. Therefore, the current study sought to expand on the parent adjustment literature by examining the constructs of parenting stress, illness uncertainty, perceived barriers to care, and social support and their relationship to stress reactivity, as measured by salivary cortisol.

CHAPTER III

CURRENT STUDY

Multivariate theoretical models of adjustment posit that parents are an integral component of child and family system functioning within the context of a chronic illness (e.g., Thompson & Gustafson, 1996). As the previous literature review has shown, parent and child adjustment is interrelated, with parental functioning having the capability to exert a significant impact on child wellbeing (e.g., Colletti et al., 2008).

Parents of children receiving treatment for pediatric cancer are faced with aiding in medical adherence and navigating complex treatment protocols that can last several years in addition to their normal parenting responsibilities (Ries et al., 2007). Unfortunately, the chronic stress produced from these arduous phases and continuous demands of pediatric cancer treatment can place parents of children who are diagnosed with cancer at risk for maladjustment due to elevated distress (Kazak & Barakat, 1997). Indeed, numerous studies have demonstrated that parents of children receiving treatment for cancer are susceptible to high and persistent levels of psychological sequela (e.g., Kazak et al., 2005). Additionally, the cancer treatment process is not only likely to cause parental psychological maladjustment, but also function as a source of chronic stress. As

previously noted, a wealth of literature exists outlining the deleterious effects of chronic stress on multiple systems of the body (Epel et al., 2004; Lupien et al., 2005). However, psychophysiological measurement of parent stress has been noticeably absent within the chronic illness literature.

Applicable studies examining specific parental adjustment constructs and their relation to physiological stress has also been noticeably scant, with researchers mainly focusing on PTSD or PTSS (e.g., Stoppelbein et al., 2010). As noted earlier, four parental constructs that appear to warrant further investigation within an oncology population are parenting stress, illness uncertainty, perceived barriers to care, and social support. These constructs appear relevant because previous research has demonstrated that maladaptive levels of each can be related to both poorer parent and child adjustment (e.g., Mullins et al., 2004; Seid et al., 2009) and facets of these constructs could be directly targeted in interventions or clinical practice. To date, however, no known studies have investigated the relation of these constructs to physiological markers of stress. Delineating specific parental constructs that are related to physiological stress may help clinicians reduce the downstream physical effects of chronic stress on parents and subsequently improve their long-term quality of life.

Collectively, it is clear that research that combines psychophysiological indices of stress and these parental constructs are needed not only to gain a better understanding of the toll chronic stress plays on parents, but also to determine if specific parental constructs known to impact adjustment are also related to physiological stress. Thus, the current study sought to expand the literature on parent adjustment in the context of

chronic illness by examining cognitive appraisal and macrosystem variables and their relationship to physiological indicators of distress.

The present study was guided by the following aims:

Aim 1: To determine baseline salivary cortisol levels in parents of children with cancer who have been receiving treatment for six months or longer.

Hypothesis: It was hypothesized that parents of children with cancer would evidence lower levels of salivary cortisol compared to previously published salivary cortisol norms of healthy adults (Aardal & Holm, 1995), and evidence approximately equivalent levels of salivary cortisol compared to previously published levels in parents of children with cancer (Glover & Polland, 2002; Stoppelbein et al., 2010)..

Aim 2: To determine if higher levels of stress reactivity (i.e., salivary cortisol levels) is associated with elevated levels of perceived barriers to care, parental uncertainty, or parenting stress, and to reduced levels of social support in parents of children with cancer.

Hypothesis: It was hypothesized that cortisol levels will be significant predictors of barriers to care, uncertainty, parenting stress, and social support.

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

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

Research Question 2. Were levels of parenting stress related to levels of illness uncertainty, barriers to care, and social support?

In order to test these hypotheses and explore the additional research questions, parents of children currently on treatment for pediatric cancer were recruited from the Jimmy Everest Cancer Center in Oklahoma City, Oklahoma. All participants were asked to complete a demographic form and a psychiatric screener in addition to measures of parenting stress, parental uncertainty, barriers to care, and social support. Furthermore, salivary cortisol samples were collected from each participant immediately following their consent. The information for each of these measures, in addition to a detailed explanation of the present study's procedures, is addressed in the following section.

CHAPTER IV

METHOD

Participants

Participants for the current study were 33 mothers and 10 fathers of children (21 boys, 22 girls) between the ages of 2 and 17 years old (M = 6.33, SD = 4.64) who had been diagnosed with pediatric cancer and who were actively receiving treatment or being monitored following treatment at the time of participation. Twenty-six of the children (60.5%) had been diagnosed with leukemia or lymphoma, 14 were diagnosed with a Non-CNS tumor (32.6%), and 3 (7.0%) had a diagnosis of a brain tumor. The children's age at diagnosis ranged from 1 to 16 years old (M = 5.67, SD = 4.49) and the duration of their illness, which was calculated by subtracting their date of diagnosis from the date of participation in the study, ranged from 6 to 24 months (M = 12.35, SD = 5.61).

The parent participants ranged in age from 20 to 57 years old (M = 34.19, SD = 8.00) and the majority of parents reported either partially attending college or technical school (34.9%) or receiving a college degree (34.9%). With regard to race and ethnicity, 55.8% of the sample self-identified as Caucasian, 11.6% as African American, 11.6% as Hispanic, 7.0% as Native American, 7.0% as Asian, and 7.0% as Multiracial. The majority of parents reported being married (59.5%). Additionally, 36.6% of the sample

reported an annual family income of less than $30,000, 24.4% reported an income between $30,000 and $60,000, 19.5% reported an income between $60,000 and $90,000, and the remaining 19.5% reported an annual income of more than $90,000. Forty-three parents were approached to participate in the current study. Since 41 of those 43 parents consented to participate, the consent rate was approximately 95%.

Participants were recruited from the Jimmy Everest Center for Cancer and Blood Disorders in Children (JEC) at the University of Oklahoma Health Sciences Center (OUHSC). Inclusion criteria included: 1) parents self-identify as a primary parent for their child, 2) the parent speaks English as a primary language, 3) the child is between 2 and 18 years of age, 4) the child is currently receiving treatment at the time of consent, and 5) the child was diagnosed at least six months prior to participating in the current study. Alternatively, exclusion criteria included: 1) the parent evidences mental retardation or is currently being treated for a psychiatric disorder including substance abuse, 2) the child evidences mental retardation or significant developmental delay, 3) the child was experiencing an imminent medical crisis necessitating significant medical intervention, or 4) the child was determined to be receiving palliative care.

Measures

Demographic Form. An investigator-created questionnaire was used to collect the following demographic information: parent participant's age, occupation, and relation to child, child's current age, child's date of diagnosis, annual family income, education level, number of individuals living within the home, marital status, spouse's age, occupation, and relation to child, and distance traveled to the clinic. Additionally, this form included questions about the respondent's recent use of caffeine, prescription

medication (e.g., Sudafed, birth control), sleep, and dietary intake due to their influence on cortisol level analyses. This form also contained information pertaining to their overall health (rated on a 1-10 scale), whether they had symptoms of an impending illness (e.g., fever, runny nose), and any medications they are currently taking (see Appendix A).

Psychiatric Screener. An investigator-created psychiatric screener was used to determine if participants had a positive psychiatric history. Specifically, respondents were asked whether they were currently using psychoactive medications and whether they have received previous psychiatric diagnoses. Participants were also asked whether they experienced symptoms or have been diagnosed with PTSD (see Appendix B).

Intensity of Treatment Rating 2.0. The Intensity of Treatment Rating version 2.0 (ITR-2, Werba et al., 2007) was used to assess each diagnosis a child has been given for stage or risk level on a 4-point Likert-type scale. Descriptions of intensity levels and relevant examples are given at the bottom of the measure and the physician is asked to indicate whether or not the following treatment modalities have occurred: 1) surgery, 2) chemotherapy, 3) radiation, and 4) transplant. A physician within the JEC completed this measure while examining the child's medical chart. In a recent psychometric investigation of the ITR-2, interrater reliability among pediatric oncologists was .87 (Werba et al., 2007). The measure has also shown to have good content validity (r = .95; see Appendix C).

Parenting Stress Index-Short Form. The Parenting Stress Index-Short Form (PSI-SF, Abidin, 1995) was used to measure the relative magnitude of parenting stress in the parent-child system. The PSI-SF is a 36-item, parent self-report instrument with a five-point response scale ranging from *strongly agree* to *strongly disagree*. Items include

statements such as *I feel trapped by my responsibilities as a parent* and *My child makes more demands on me than most children*. The PSI-SF yields a total summary score, which was used in the current study as the measure of parenting stress. The validity of the full-length PSI has been established in a range of populations, including parents of children with asthma (Carson & Schauer, 1992) and diabetes mellitus (Wysocki et al., 1989). Cronbach's alpha in the current study was .91.

Parental Perceptions of Uncertainty Scale. Parent uncertainty was measured using the Parental Perceptions of Uncertainty Scale (PPUS: Mishel, 1983). The PPUS is a 31- item parent completed measure that uses a 5-point Likert-type scale with answer choices ranging from *strongly agree* to *strongly disagree*. Examples of items include *I don't know what is wrong with my child* and *I am unsure if my child's illness is getting better or worse*. Answers on the PPUS were summed to create a total parent uncertainty score. The PPUS has been shown to have high internal reliability ($\alpha = .91$) and the theoretical factor structure has been validated (Mishel, 1983). Cronbach's alpha in the current study was .88 (see Appendix D).

Barriers to Care Questionnaire. The Barriers to Care Questionnaire (BCQ; Seid, Sobo, Gelhard, & Varni, 2004) is a 40-item parent completed measure that uses a 5-point Likert-type scale with answer choices ranging from *never* to *almost always*. This measure was used to assess potential barriers or problems getting health care for a child. The BCQ is composed of the following five subscales: 1) pragmatics, 2) skills, 3) expectations, 4) marginalization, and 5) knowledge and beliefs. Parents were asked to rate how often they experience problems with a range of issues including *the cost of health care* and *getting to the doctor's office*. Answers on the BCQ were summed to create a total score, with

lower scores indicating more perceived barriers to care. The BCQ has demonstrated excellent internal reliability (α = .93-.95) in chronic illness populations. Moreover, construct validity has been established by demonstrating that higher BCQ scores are related to lower quality of life and better perceptions of the patient's primary care (Seid et al., 2004; Seid et al., 2009). Cronbach's alpha in the current study was .93 (see Appendix E).

Multidimensional Scale of Perceived Social Support. The amount of social support a parent was receiving was measured using the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Powell, Farley, Werkman, & Berkoff, 1988). The MSPSS is a 12-item measure that uses a 7-point scale with answer choices ranging from *very strongly disagree* to *very strongly agree*. This measure includes family, friends, and significant other subscales that can be used to differentiate sources of social support. The total score of the MSPSS was used in the current study, with higher scores indicating greater social support. Previous studies have demonstrated that the MSPSS has strong psychometric properties including high test-retest reliability, internal reliability, and factorial invariance (e.g., Dahlem, Zimet, & Walker, 1991; Zimet, Powell, Farley, Werkman, & Berkoff, 1990). Cronbach's alpha in the current study was .97 (see Appendix F).

Procedure

Participants for the current study were recruited from the JEC at the OUHSC. Recruitment of participants was conducted by graduate research assistants. Specifically, the JEC's outpatient clinic schedule was checked on a daily basis for eligible children scheduled to attend an appointment. The graduate research assistant then verified that the

potential participant meet the previously specified inclusion criteria by examining the potential participant's electronic medical record. The parents of eligible participants were then approached in the waiting room. The study was described in detail and consent was obtained in conformity with standards of the OUHSC and Oklahoma State University Institutional Review Boards. Cortisol samples were then collected from the parent and participants were given the measures to complete while they are waiting. Participants were encouraged to complete the measures during their visit, but were permitted to return in person them during their next scheduled clinic visit or via mail. Each family was compensated with a $10.00 check for participating in the current study.

Salivary Cortisol

Salivary cortisol was collected from each parent prior to their completion of the measures by placing a cotton swab under their tongue for two minutes. Participants were asked about potential confounding influences in HPA responses including intake of food, caffeine, and nicotine at least one hour prior to saliva collection. Saliva was not collected if participants endorsed eating, sleeping, using nicotine, or consuming caffeine within the last hour. Likewise, participants endorsing medications known to impact cortisol levels (e.g., corticosteroids) were examined to determine if their cortisol levels differed compared to other participants. Saliva was obtained by having participants hold a 1 x 4 CM absorbent swab in their mouths for approximately1-2 minutes. The saturated swabs were stored at -70°C until assayed. Following Granger and colleagues (2007), samples were assayed for cortisol (enzyme immunoassay) using commercially available reagents (Salimetrics, State College, PA) without modification to the manufacturers recommended protocols. Specifically, cortisol levels are reported in micrograms per deciliter (ug/dL).

All assays were completed in duplicate whenever possible. If duplicate levels of cortisol were not feasible (e.g., inadequate saliva volume), singlet assays were conducted and used for analyses.

CHAPTER V

RESULTS

Preliminary Analyses

Data were first examined for missing values. If 5% or less of items were missing from any single measure, participant specific subscale mean values were inserted (Fairclough & Cella, 1996). Specifically, subscale specific imputations were computed for six participants on the PSI-SF, zero participants on the MSPSS, one participant on the PPUS, and one participant on the BCQ. Alternatively, if more than 5% of items were missing, pairwise deletion was used. This process resulted in slightly different numbers of participants per dependent variable of interest (i.e., PSI-SF, $n = 41$; MSPSS, $n = 42$; PPUS, $n = 40$; BCQ, $n = 43$).

In regard to salivary cortisol, samples were collected on 41 of the 43 parents. Specifically, one parent asked not to participate in saliva collection and the other did not provide a saliva sample before leaving the JEC. Of the possible 41 saliva samples, 6 samples were found to provide inadequate levels of saliva for cortisol assays to be completed. Therefore, salivary cortisol assays were conducted on the remaining 35 participants. Of these 35 participants, 27 (77%) provided adequate saliva for duplicate

assays whereas the remaining participants only provided enough saliva for assays in singlet. Investigation of the distribution of salivary cortisol levels using the Kolmogorov-Smirnov statistic revealed that the distribution did not significantly depart from normality $D(35) = .12$, $p = .200$. However, consistent with previous research (e.g., Gordis, Granger, Susman, & Trickett, 2006), investigation of the distribution plot of salivary cortisol was undertaken, revealing a slightly positively skewed distribution. Thus, a natural log transformation was conducted in order to correct for any skewness in the salivary cortisol distribution. However, the overall interpretation of the findings did not change using this transformation, and therefore all analyses involving cortisol levels are presented in raw form.

Salivary cortisol levels and the dependent variables of interest were then examined for outliers (i.e., scores ≥ 3 *SD*s above the mean). Analyses revealed two outlier cases for salivary cortisol. In order to retain as much salivary cortisol data as possible, these salivary cortisol levels were recoded to the next highest salivary cortisol level in the dataset (Tabachnick & Fidell, 2007). Outliers were not found on any of the dependent variables of interest.

Next, total scores on the descriptive statistics were then calculated for salivary cortisol and all the dependent variable of interests (see Table 1). Since the current sample included parents of children who were who were actively on treatment ($n = 36$) and parents whose children were being monitored following treatment ($n=7$), one-way ANOVAs were conducted to determine if differences existed between these groups on salivary cortisol levels or any of the dependent variables of interest. Results revealed that

no significant differences existed between groups based on treatment status (all *p*'s > .05).

Given research demonstrating that mothers and fathers may differ in their levels of adjustment to chronic illnesses, including cancer (Chaney et al., 1997; Robinson et al., 2007), one-way ANOVAs were also conducted to determine if sex differences existed within any of the dependent variables of interest. Results revealed that parenting stress, social support, parental uncertainty, and perceived barriers to care did not differ between mothers and fathers (all *p*'s > .05). Therefore, all parents were included in subsequent analyses.

Before conducting analyses to determine potential covariates, a series of partial correlations was conducted to determine if salivary cortisol levels were related to any of the dependent variables of interest while controlling for the time of day in which the cortisol sample was collected (i.e., PSI-SF, MSPSS, PPUS, and BCQ total scores). Salivary cortisol was not significantly related to any of the dependent variables of interest.

A series of bivariate correlations was then conducted to identify whether demographic (i.e., child age, child sex, parent age, parent gender, parent ethnicity, annual family income) or illness variables (i.e., duration of illness, age at diagnosis, severity of illness, and Central Nervous System involvement) were related to any of the dependent variables of interest. Analyses revealed that annual family income was significantly correlated with parenting stress, such that lower income was related to higher parenting stress (see Table 2). Furthermore, greater severity of illness was found to be significantly correlated with higher parental uncertainty and perceived barriers to care. Duration of

illness was also found to be significantly correlated with social support such that longer duration of illness was related to greater social support (see Table 3). Following Thompson and Gustafson's (1996) transactional stress and coping model, the demographic and illness variables that were significantly correlated with the dependent variables of interest were entered as covariates in subsequent analyses. Furthermore, given the diurnal pattern of cortisol (Chrousos & Gold, 1992), time of day in which the cortisol sample was collected was used as a covariate.

Primary Analyses

Baseline salivary cortisol. To determine baseline levels of salivary cortisol in parents of children with cancer (Aim 1), descriptive statistics were calculated. Measures of central tendency were examined for both men and women. Additionally, to further examine overall salivary cortisol levels, analyses by age were also conducted (see Tables 4 and 5).

Previously published results (Aardal & Holm, 1995) indicated that the expected range of cortisol values for healthy adult females ages 21-30 and 31-50 range from .11 - 1.35 ug/dL and .09 – 1.52 ug/dL, respectively. Expected cortisol values for healthy adult males ages 21-30, 31-50, and 51-70 range from .11 - .74 ug/dL, .12 – 1.55 ug/dL, and .11 - .81 ug/dL, respectively. Comparison of the salivary cortisol levels in the current sample to these previously published values revealed that all cortisol levels fell within the average range. It should be noted, however, that the majority of participants evidencing salivary cortisol levels that appear to be on the low end of the average range for healthy adults. Unfortunately, standard deviations of salivary cortisol levels were not provided in

the Aardal and Horn (1995) article, therefore direct statistical comparison across samples was not feasible.

Stoppelbein and colleagues (2007) examined salivary cortisol levels in mothers of children currently on treatment for cancer on a monthly basis for one year time period. The authors did not provide enough information for direct statistical comparison, but indicated that the monthly salivary cortisol levels of mothers ranged from .12 – 2.10 ug/dL. Compared to the current sample in which salivary cortisol values ranged from .03 - .38 ug/dL, the range of values published in the Stoppelbein et al. (2007) article appear to be higher and may have evidenced more variability.

Finally, Glover and Polland (2002) investigated 12 hour *urinary* cortisol levels in a sample of seven mothers of children who were cancer survivors. Notably, the authors also provided enough information in which to statistically compare cortisol levels across their study sample and the sample used in the current investigation. Using Welch's *t* test due to unequal sample sizes and potentially unequal variances across studies, on average, the urinary cortisol levels in the Glover and Polland (2002) study were found to be significantly higher (M = 1.79 ug/dL, SD = 0.7) than the salivary cortisol levels in the current study (M = .15 ug/dL, SD = .10; $t(40) = 13.83$, $p < .001$, 95% CI = 1.40 – 1.88).

Parenting stress. To examine a component of Aim 2 and test the hypothesis that higher levels of stress reactivity (i.e., salivary cortisol) would be associated with elevated levels of parenting stress, hierarchical linear regression was utilized. Following Thompson and Gustafson's (1996) transactional stress and coping model, annual family income was entered as covariates on Step 1. Next, time of day in which the cortisol sample was collected was entered as a covariate on Step 2. Finally, salivary cortisol

levels were entered as a predictor on Step 3. Results revealed that the overall model was significant ($F(3,28) = 3.24$, $p = .037$, *observed power* = .74). Notably, however, salivary cortisol did not emerge as a significant predictor of parenting stress (see Table 6).

Parental uncertainty. To address an additional component of Aim 2 and test the hypothesis that higher levels of salivary cortisol would be related to higher perceived barriers to care, hierarchical linear regression was utilized. Following Thompson and Gustafson's (1996) transactional stress and coping model, the child's severity of illness was entered as a covariate on Step 1. Furthermore, the time of day in which the cortisol sample was collected was entered on Step 2 and salivary cortisol levels were entered as a predictor on Step 3. Results revealed that the overall model was significant ($F(3,28) = 3.64$, $p = .025$, *observed power* = .78), however, salivary cortisol was not a significant predictor of parental uncertainty (see Table 7).

Barriers to care. To investigate the third component of Aim 2 and test the hypothesis that elevated levels of salivary cortisol would be associated with increased perceived barriers to care, hierarchical linear regression was used. Following Thomspon and Gustafson's (1996) transactional stress and coping model, the child's severity of illness was entered as a covariate on Step 1 and the time of day in which the cortisol sample was collected was entered on Step 2. Finally, salivary cortisol levels were entered as a predictor on Step 3. Results revealed that the overall model evidenced a trend towards significance ($F(3,31) = 2.76$, $p = .059$, *observed power* = .66). Analyses revealed that salivary cortisol was not a significant predictor of perceived barriers to care (see Table 8).

Social Support. To address the final component of Aim 2 and test the hypothesis that higher salivary cortisol levels would be associated with lower levels of social support, hierarchical linear regression was used. Following Thomspon and Gustafson's (1996) transactional stress and coping model, the child's duration of illness was entered as a covariate on Step 1. Next, the time of day in which the cortisol sample was collected was entered on Step 2. Finally, salivary cortisol levels were entered as a predictor on Step 3. Results revealed that the overall model was not significant ($F(3,30) = 1.17$, $p = .338$, *observed power* = .33) and that salivary cortisol was not a significant predictor of perceived barriers to care (see Table 9).

Exploratory Analyses

Exploratory analyses were conducted for two reasons. First, the current study is one of the few to examine salivary cortisol in parents of children diagnosed with cancer. Additionally, the current study is the known study to investigate whether salivary cortisol is related to parenting stress, parental uncertainty, perceived barriers to care, or social support. Exploratory analyses were therefore conducted to further investigate potential relations of salivary cortisol to other variables in an effort to delineate demographic or illness factors that may impact cortisol levels. Second, given that physiological stress was found to be unrelated to levels of illness uncertainty, perceived barriers to care, and social support, analyses were conducted to determine if self-reported parenting stress was also unrelated to these constructs. It should be noted that self-reported parenting stress was used as an independent variable in these exploratory analyses to be commensurate with previous analyses that used physiological stress (i.e., salivary cortisol) as a predictor variable.

Salivary cortisol. Partial correlations were conducted to determine if demographic variables (i.e., child sex, child age, parent gender, parent age, parent ethnicity, annual family income) or illness variables (i.e., duration of illness, age at diagnosis, severity of illness, and Central Nervous System involvement) were related to salivary cortisol levels while controlling for time of day in which the cortisol sample was collected. Analyses revealed that none of the demographic or illness variables were significantly related to salivary cortisol levels (see Tables 10 and 11).

Illness uncertainty. First, the relation of parenting stress to illness uncertainty was examined. Following Thompson and Gustafson's (1996) transactional stress and coping model, the child's severity of illness was entered as a covariate on Step 1. Next, the total score of the PSI-SF was entered as the predictor on Step 2. Results revealed that the overall model was significant ($F(2,37) = 23.47$, $p < .001$, *observed power* = 1.00). Furthermore, parenting stress was found to be a significant predictor of parental uncertainty ($\beta = .54$, $p < .001$) such that higher levels of parenting stress were related to higher levels of parental uncertainty (see Table 12).

Barriers to care. The relation of parenting stress to perceived barriers to care was then examined. Following Thompson and Gustafson's (1996) transactional stress and coping model, the child's severity of illness was entered as a covariate on Step 1 and the total score of the PSI-SF was entered as the predictor on Step 2. Analyses revealed that the overall model was significant ($F(2,38) = 3.46$, $p = .042$, *observed power* = .63), however, parenting stress was not found to be a significant predictor of perceived barriers to care (see Table 13).

Social support. Finally, the relation of parenting stress to social support was examined. Following Thompson and Gustafson's (1996) transactional stress and coping model, the child's duration of illness was entered as a covariate on Step 1 and the total score of the PSI-SF was then entered as a predictor on Step 2. Results revealed that the overall model was significant ($F(2,38) = 3.47$, $p = .041$, *observed power* = .63), however, parenting stress was not a significant predictor of social support (see Table 14).

CHAPTER VI

DISCUSSION

The current study sought to examine the relationship of chronic physiological stress (i.e., salivary cortisol) to psychosocial outcomes within the context of pediatric cancer. Specifically, parents of children who were diagnosed with pediatric cancer and receiving treatment for six months or longer were examined in the current study. The current study examined whether parenting stress, social support, parental uncertainty, and perceived barriers to care, all of which are constructs that have been previously shown to influence parent and child adjustment to illness (e.g., Mullins et al., 1997; Mullins et al., 2004, Mullins et al., 2007; Seid et al., 2009), were related to physiological measures of stress. As such, the current study was guided by two aims and two research questions.

The first hypothesis stated that parents of children diagnosed with cancer would evidence lower salivary cortisol levels compared to previously published salivary cortisol levels of healthy adults (Aardal & Holm, 1995) and evidence approximately equivalent levels of salivary cortisol compared to previously published levels found in parents of children with cancer (Glover & Polland, 2002; Stoppelbein et al., 2010). Consistent with this hypothesis, the salivary cortisol levels of parents of children with cancer were found to fall toward the low end of the previously published cortisol range of healthy adults. In

other words, within the current study parents of children with cancer were found to have similar, if not lower, levels of physiological stress as healthy adults at the time of data collection. Notably, this interpretation of the data did not change when examining salivary cortisol levels by sex or age. When comparing the average cortisol levels found in the current study (.15 ug/dL) to the previously reviewed research investigating cortisol levels in parents of children with cancer, the salivary cortisol levels in the current study also appear low. For instance, when investigating mothers of children currently on treatment, Stoppelbein and colleagues (2010) found average salivary cortisol levels up to 2.10 ug/dL which were considerably higher than the largest salivary cortisol level found within the current sample. Furthermore, when statistically comparing the salivary cortisol levels of the current sample to the urinary cortisol levels in Glover and Polland's (2002) study of mothers of childhood cancer survivors, Glover and Polland reported significantly higher levels than those found in the current study.

Taken together, the results from the current study revealed relatively low salivary cortisol levels that may be commensurate with the extant literature on chronic stress over time (Miller et al., 2007). In other words, it is possible that the current results reflect HPA axis dysregulation. As previously mentioned, cortisol follows a diurnal pattern that peaks in the early morning hours in response to increased arousal and then declines steadily throughout the day (Chrousos & Gold, 1992). The low levels of salivary cortisol in the current study could reflect a flattened diurnal rhythm in which the HPA axis is fatigued from chronic arousal. Previously published research has demonstrated that chronic stress may indeed be related to increased allostatic load and HPA axis dysregulation (Chrousos & Gold, 1998; McEwen, 2004). Furthermore, a recently published meta-analysis

demonstrated that individuals encountering chronic stress initially experience an elevation in cortisol followed by less than normal cortisol production as time since the stressor progresses (Miller et al., 2007). Although speculative, it is therefore possible that the parents in the current study have lower salivary cortisol levels which reflect flattened cortisol slopes due to the chronic nature of parenting a child receiving cancer treatment. Cortisol dysregulation has been shown to be related to significant maladjustment including lowered immune function, increased mortality, and psychological disorders (McEwen, 2004; Sephton, Sapolsky, Kraemer, & Spiegel, 2000) suggesting that even low levels of salivary cortisol in this population may be related to subsequent deleterious effects. Therefore these low levels of salivary cortisol could be indicative that parents of children receiving long-term treatment for pediatric cancer might be at risk for subsequent physical and psychological maladjustment.

Alternatively, it is possible that the low levels of salivary cortisol found in the current study do not reflect HPA axis dysregulation, but instead reflect that parents of children diagnosed with cancer for six months or longer are not experiencing elevated physiological stress. As such, these findings could be commensurate with Stoppelbein and colleagues (2010) who found that overall levels of cortisol significantly declined over treatment in mothers of children diagnosed with cancer. Although not specific to physiological stress, this interpretation of the current findings also fits well with previous self-report adjustment research demonstrating that the majority of mothers of children who were diagnosed with cancer evidenced steady improvement at 3- and 6-month follow-up time points (Dolgin et al., 2007). Additional studies have also shown that other forms of parental maladjustment (e.g., anxiety and depression) also appear to subside as

children progress through treatment (Hoesktra-Weebers et al., 2001; Steele, Long, Reddy, Luhr, & Phipps, 2003). This line of thinking could especially be true if their children followed previously published trajectories of adjustment in which distress is found to decrease over time (e.g., Dahlquist, 2003; Phipps, 2007). Further longitudinal research is needed to better determine whether these low salivary cortisol levels are indicative of HPA axis dysregulation or normal adjustment to illness.

The second hypothesis stated that higher levels of salivary cortisol would be related to greater perceived barriers to care, higher parenting stress, and elevated parental uncertainty and reduced levels of social support in parents of children with cancer. Preliminary analyses revealed that salivary cortisol levels were unrelated to the parental constructs when controlling for time of day in which the cortisol sample was taken. Additionally, contrary to hypotheses, parent salivary cortisol levels were not found to be a significant predictor of any of the parental constructs after controlling for time of day in which the cortisol sample was taken and applicable demographic or illness covariates. Results revealed that the overall model for salivary cortisol predicting parenting stress and parental uncertainty were significant, however, it appeared that the majority of the variance was accounted for by the covariates within the model.

The lack of relation of salivary cortisol to specific parental constructs was surprising. The majority of the previous studies investigating cortisol in parents of children with cancer have demonstrated a relation between cortisol levels and psychological constructs, specifically, posttraumatic stress symptoms (Stoppelbein et al., 2010). Furthermore, the current study sought to expand this literature by examining parenting stress, parental uncertainty, perceived barriers to care, and social support; all

constructs that have previously been shown to impact adjustment. A key aspect in which the current research study differed from these previous investigations that may explain these differences and null findings was the study design. The current study collected salivary cortisol levels at one time point, only whereas other studies either relied on multiple samples, such as collecting urinary cortisol over a 12 hour period (Glover & Polland, 2002) or collecting monthly salivary cortisol samples for an extended period of time (Stoppelbein et al., 2010). Therefore, the previous studies were able to average multiple salivary cortisol levels over time to gain a comprehensive picture of participants' physiological stress whereas the salivary cortisol levels obtained in the current study may only be indicative of the physiological stress that a parent was experiencing that particular day. Given these inherent design limitations, it is impossible to determine if these parent constructs are in fact unrelated to physiological stress in this population of parents. Based on previous research demonstrating that cognitive appraisals impact cortisol production (Denson, Spanovic, & Miller, 2009), future research with a larger sample size may find evidence of a relation. However, it may also be possible that parenting stress, parental uncertainty, perceived barriers to care, and social support are parental constructs that exert their greatest impact on parents at the time period close to diagnosis, consistent with the findings of other researchers (e.g., Colleti et al., 2008; Hoekstra-Weebers et al., 2001; Santacroce, 2002)

The first research question investigated whether demographic variables (i.e., child age, child sex, parent age, parent gender, parent ethnicity, annual family income) and illness parameters (i.e., age at diagnosis, duration of illness, severity of illness, and CNS involvement) were related to parent salivary cortisol levels. To answer this research

question partial correlations were conducted between demographic and illness variables and salivary cortisol levels while controlling for the time of day in which the cortisol sample was taken. Similar to the previous findings involving salivary cortisol, results revealed that none of the demographic or illness variables were related to salivary cortisol levels.

Finally, the second research question examined whether levels of parenting stress were related to levels of illness uncertainty, perceived barriers to care, and social support. Parenting stress, as measured by the PSI-SF, was found to be a significant predictor of parental uncertainty. Specifically, increased levels of parenting stress were found to be related to increased levels of parental uncertainty. Parenting stress was not a significant predictor of perceived barriers to care or social support.

The finding that self-reported parenting stress was associated with parental uncertainty expands previous research examining youth-reported outcomes. For instance, Mullins and colleagues (2007) found that parenting stress was related to youth-reported illness uncertainty in a sample of youth with diabetes or asthma. Ryan and colleagues (in press) also found that paternal parenting stress was predictive of youth-reported illness uncertainty. Therefore, although physiological stress was unrelated to illness uncertainty, the current study extends the uncertainty literature by demonstrating that parenting stress was indeed associated with parental uncertainty. These findings fit well with the conceptualization of the construct of uncertainty as being composed of events that are largely beyond a parent's control (Mishel, 1983).

Strengths and Limitations

The current represents a preliminary step in examining how the chronic nature of pediatric cancer can be related to measures of physiological stress. As such, there are several strengths that can be noted. First, the current study integrated physiological findings into an area of pediatric psychology inquiry that is largely composed of self-report methodology. Second, given that the inclusion of fathers in pediatric chronic illness research is often understudied (Ryan et al., in press), it is a strength that the current study included both mothers and fathers. The sample was also composed of parents of children who spanned a wide range of ethnicities and income levels. Therefore, the current study may be more generalizable to other pediatric cancer populations. Finally, a physician within the JEC provided illness severity ratings based on a thorough chart review. Doing so allowed for the investigation of the child's illness severity as a possible variable of interest.

Despite the previously mentioned strengths, the current study should also be considered in light of several limitations. First, the study was cross-sectional in nature, which precludes investigation of longitudinal and potentially causal relations among salivary cortisol levels and the measured parental constructs. Second, the study included a relatively small number of parents of children receiving treatment for cancer. As can be seen by the observed power estimates, more data is needed to better determine the true relation of salivary cortisol to parental constructs. As previously discussed, the research design of the current study also did not include multiple samples of salivary cortisol. It was therefore not possible to investigate the physiological stress parents were experiencing over time within a particular hospital visit or over the course of their child's

treatment. Shared method variance may also be an area of concern since the current study relied on parent self-report for all of the parent constructs.

Clinical Implications

Although the results of the current study did not find a significant link between salivary cortisol and the measured parental constructs, results revealed that parents of children who are receiving long-term cancer treatment may be experiencing HPA axis dysregulation. Given the substantial toll that chronic stress can exert on the human body, the results of the current study may suggest that clinicians continue to provide services for parents throughout the child's treatment. Specifically, it may be beneficial to continually sample salivary cortisol in order to determine when, if at all, HPA axis dysregulation begins to take place. Furthermore, salivary cortisol levels could be communicated to the parent in an effort for them to understand how their body is reacting to the stress of parenting a child with pediatric cancer.

Future Directions

Future directions for investigating parental physiological stress in the context of pediatric cancer should include more stringent research design methodology. The current study was limited by financial resources and availability of the graduate research assistants to collect samples. Therefore, although parental physiological stress was found to have no relation to parental constructs in the current study, future studies with additional resources could employ multiple cortisol assessment over time and may produce different findings. Particular concentration on morning cortisol levels may be beneficial for future studies as are longitudinal designs that include repeated sampling (Miller et al., 2007). Examining cortisol and parental constructs longitudinally may

elucidate at which time, if any, physiological stress and these parental constructs may evidence the highest relation. Additionally, given the low levels of salivary cortisol in the current sample, repeated cortisol measurement over time would also afford investigation of cortisol slopes to determine if these parents indeed evidence flattened cortisol profiles. Investigating the relation of salivary cortisol by pediatric cancer type (e.g., blood vs. solid tumor) and the parent's perception of illness severity may also bear some interesting findings. It may also be helpful to include measures of alpha amylase. Whereas cortisol is a measure of the parasympathetic nervous system, alpha amylase is a marker of the sympathetic nervous system. As such, it is possible that measuring activation of the sympathetic nervous system by alpha amylase in addition to measuring cortisol and the complementary actions of the parasympathetic nervous system may provide further detail into the underlying physiological processes within parents of children diagnosed with cancer.

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APPPENDICES

APPENDIX A

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 parent 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/ 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/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)? _____

APPENDIX B

Screener

Are you currently taking any psychoactive medication (e.g., antidepressants, anti-anxiety)?

Yes$_1$ No$_2$

Are you currently being treated for a psychiatric disorder (e.g., depression, anxiety, substance abuse)?

Yes$_1$ No$_2$

Have you ever experienced, witnessed, or were confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical injury of self or others?

Yes$_1$ No$_2$

If yes, did your response involve intense fear, helplessness, or horror? Yes$_1$ No$_2$

Please indicate how many events meeting the above description you have experienced: _____

Have you ever been diagnosed by a doctor, clinician, or mental health professional with Posttraumatic Stress Disorder (PTSD)?

Yes$_1$ No$_2$

If yes, please indicate when you were diagnosed: _____

APPENDIX C

Intensity of Treatment Rating 2.0 (ITR-2)

Directions: Please review carefully the criteria at the bottom of the page that lists examples of diseases and treatment modalities under each of the four levels of intensity. Based on the information regarding each patient's disease and treatment, use the criteria at the bottom of this page and circle one number to indicate the intensity of treatment (1, 2, 3, 4). Please make ratings based on adherence to this scale criteria rather than expert judgments.

ID #	ABSTRACTION INFORMATION								INTENSITY RATING
	Diagnosis, including if relapsed	Stage or Risk Level	Treatment Modalities						
			Surgery?		Chemo?		Radiation?	Transplant?	
			Y	n	y	n	y n	y n	1 2 3 4
			y	n	y	n	y n	y n	1 2 3 4
			y	n	y	n	y n	y n	1 2 3 4
			y	n	y	n	y n	y n	1 2 3 4
			y	n	y	n	y n	y n	1 2 3 4
			y	n	y	n	y n	y n	1 2 3 4
			y	n	y	n	y n	y n	1 2 3 4
			y	n	y	n	y n	y n	1 2 3 4
			y	n	y	n	y n	y n	1 2 3 4
			y	n	y	n	y n	y n	1 2 3 4

Level 1: Least Invasive Treatments: Includes the least intensive treatments, for these treatment modalities or diseases:

- Surgery Only – Excluding all brain tumors
- Germ Cell Tumors – Surgery Only
- Neuroblastoma – Surgery Only
- Retinoblastoma – Enucleation (unilateral disease) without chemotherapy
- Wilms' Tumor (Stages 1, 2)

Level 2: Moderately Intensive Treatments: Includes moderately intensive treatments for these treatment modalities or diseases:

- Acute Lymphoblastic Leukemia (Standard Risk)
- Brain Tumor – One treatment modality, not including biopsy
- Chronic Myeloid Leukemia – Pretransplant
- Germ Cell Tumors – With chemotherapy or radiation
- Hepatoblastoma – With chemotherapy and surgical resection, no metastatic disease
- Hodgkin Lymphoma (Stages 1, 2, 3 without bulk disease/Low or Intermediate Risk)

- Neuroblastoma (Stages 1, 2 with chemotherapy and Stage 4S)
- Non-Hodgkin Lymphoma (Stages 1, 2, 3 and Groups A, B)
- Retinoblastoma – With chemotherapy
- Rhabdomyosarcoma (Stages 1,2)

Level 3: Very Intensive Treatments: Includes very intensive treatments, for these treatment modalities or diseases:

- Relapse Protocols for Hodgkin Lymphoma & Wilms' Tumor (first relapse) Only
- Acute Lymphoblastic Leukemia (ALL) (High or Very High Risk)
- Acute Myeloid Leukemia and Down Syndrome
- Acute Promyelocytic Leukemia (APL)
- Brain Tumor – Two or more treatment modalities
- Ewings Sarcoma
- Hepatoblastoma – With metastatic disease
- Hodgkin Lymphoma (Stages 3B or 4B/High Risk)
- Juvenile Mylomonocytic Leukemia (JMML) – Pretransplant
- Nasopharyngeal Carcinoma
- Neuroblastoma (Stage 3, 4) – Without transplant
- Non-Hodgkin Lymphomas (Group C or Stage 4)
- Osteosarcoma
- Rhabdomyosarcoma (Stages 3, 4)
- Wilms' Tumor (Stages 3, 4)

Level 4: Most Intensive Treatments: Includes the most intensive treatments, for these treatment modalities or diseases:

- Relapse Protocols – Excluding Hodgkin Lymphoma or first relapse of Wilms' Tumor
- Hematopoietic Stem Cell Transplane (HSCT) – All diseases
- Acute Myeloid Leukemia (AML)
- Juvenile Myleomonocytic Leukemia (JMML) – With transplant

APPENDIX D

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	Undecided	Disagree	Strongly

Agree 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

APPENDIX E

Problems getting health care for my child

Parents often face barriers when trying to get health care for their children. We are interested in the kinds of things that interfere with getting health care for your child(ren). Please rate how much of a problem each of the following is to you.

Answer each question by completely shading the circle so that it looks like this: ●

	Never	Almost Never	Sometimes	Often	Almost Always
1. In the last 3 months, how often did the health care system work well for your child?	(0)	(1)	(2)	(3)	(4)

How often were each of the following barriers a problem in the past 3 months when trying to get health care for your child:

Problems with:	Never	Almost Never	Sometimes	Often	Almost Always
2. Getting to the doctor's office	(0)	(1)	(2)	(3)	(4)
3. Getting hold of the doctor's office or clinic by phone	(0)	(1)	(2)	(3)	(4)
4. Having to wait too many days for an appointment	(0)	(1)	(2)	(3)	(4)
5. Getting care after hours or on weekends	(0)	(1)	(2)	(3)	(4)
6. Having to take care of household responsibilities	(0)	(1)	(2)	(3)	(4)
7. Having to take time off work	(0)	(1)	(2)	(3)	(4)
8. Waving to wait too long in the waiting room	(0)	(1)	(2)	(3)	(4)
9. Knowing how to make the health care system work for you	(0)	(1)	(2)	(3)	(4)
10. Meeting the needs of other family members	(0)	(1)	(2)	(3)	(4)
11. The cost of health care	(0)	(1)	(2)	(3)	(4)
12. Doctors or nurses not fluent in your language	(0)	(1)	(2)	(3)	(4)
13. Doctors or nurses who speak in a way that is too technical or medical	(0)	(1)	(2)	(3)	(4)
14. Getting referrals to specialists	(0)	(1)	(2)	(3)	(4)
15. Understanding doctor's orders	(0)	(1)	(2)	(3)	(4)
16. Having enough information about how the health care system works	(0)	(1)	(2)	(3)	(4)

17. Needing to be more 'savvy' or knowledgeable about getting health care	(0)	(1)	(2)	(3)	(4)
18. Getting enough help with paperwork or forms	(0)	(1)	(2)	(3)	(4)
19. Offices and staff that are not child-friendly	(0)	(1)	(2)	(3)	(4)
20. Mistakes made by doctors or nurses	(0)	(1)	(2)	(3)	(4)
21. Worrying that doctors and nurses will not do what is right for your child	(0)	(1)	(2)	(3)	(4)
22. Doctors treating the symptom without finding out the cause of the illness	(0)	(1)	(2)	(3)	(4)
23. Getting a thorough examination	(0)	(1)	(2)	(3)	(4)
24. Lack of communication between my child's doctor and others in the health care system	(0)	(1)	(2)	(3)	(4)
25. Lack of communication between different parts of the health care system	(0)	(1)	(2)	(3)	(4)
26. Feeling like doctors are trying to give as little service as possible	(0)	(1)	(2)	(3)	(4)
27. Feeling like the health care system is trying to give as little service as possible	(0)	(1)	(2)	(3)	(4)
28. Impatient doctors	(0)	(1)	(2)	(3)	(4)
29. Intimidating doctors	(0)	(1)	(2)	(3)	(4)
30. Rude office staff	(0)	(1)	(2)	(3)	(4)
31. Uncaring office staff	(0)	(1)	(2)	(3)	(4)
32. Getting the doctor to listen to you	(0)	(1)	(2)	(3)	(4)
33. Getting your questions answered	(0)	(1)	(2)	(3)	(4)
34. Not knowing what to expect from one visit to the next	(0)	(1)	(2)	(3)	(4)
35. Being judged on your appearance, your ancestry, or your accent	(0)	(1)	(2)	(3)	(4)
36. Doctors rushing you and your child through the visit	(0)	(1)	(2)	(3)	(4)
37. Disagreeing with the doctor's orders	(0)	(1)	(2)	(3)	(4)
38. Doctors not believing in home or traditional remedies	(0)	(1)	(2)	(3)	(4)
39. Doctors giving you instructions that seem wrong	(0)	(1)	(2)	(3)	(4)
40. Doctors or nurses that have different ideas about health than you do	(0)	(1)	(2)	(3)	(4)

APPENDIX F

Multidimensional Scale of Perceived Social Support

We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement according to the scale below.

Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1	2	3	4	5	6	7

_____ 1. There is a special person who is around when I am in need.

_____ 2. There is a special person with whom I can share my joys and sorrows.

_____ 3. My family really tries to help me.

_____ 4. I get the emotional help and support I need from my family.

_____ 5. I have a special person who is a real source of comfort to me.

_____ 6. My friends really try to help me.

_____ 7. I can count on my friends when things go wrong.

_____ 8. I can talk about my problems with my family.

_____ 9. I have friends with whom I can share my joys and sorrows.

_____ 10. There is a special person in my life who cares about my feelings.

_____ 11. My family is willing to help me make decisions.

_____ 12. I can talk about my problems with my friends.

TABLE 1

Descriptive Statistics for Study Variables

	Possible Range	Observed Range	*M* (*SD*)
Salivary Cortisol		.026 - .377	.15 (.10)
PSI-SF	36 – 180	37 – 126	68.39 (21.46)
MSPSS	12 – 84	12 – 84	64.95 (18.45)
PPUS	31 – 155	38 – 91	64.90 (15.09)
BCQ	0 – 100	57.05 – 100	84.15 (11.87)

Note. PSI-SF = Parenting Stress Index – Short Form; MSPSS = Multidimensional Scale of Social Support; PPUS = Parental Perceptions of Uncertainty Scale; BCQ = Barriers to Care Questionnaire.

TABLE 2

Partial Correlations among Salivary Cortisol and Outcome Variables

	1	2	3	4	5
1. Salivary Cortisol		-.23	-.11	.00	.00
2. PSI-SF			-.16	.61*	-.35
3. MSPSS				.08	-.06
4. PPUS					-.61*
5. BCQ					

Note. Correlations were conducted controlling for time of day in which cortisol sample was collected. PSI-SF = Parenting Stress Index – Short Form; MSPSS = Multidimensional Scale of Social Support; PPUS = Parental Perceptions of Uncertainty Scale; BCQ = Barriers to Care Questionnaire. * $p < .001$.

TABLE 3

Bivariate Correlations among Demographic and Outcome Variables

	1	2	3	4	5	6	7	8	9	10
1. Child Age		.24	.62**	-.16	-.09	.12	.05	.10	.09	-.22
2. Child Sex			.33*	.12	-.02	.09	-.10	-.01	-.10	-.06
3. Parent Age				-.19	.10	.54**	-.12	.25	.00	-.16
4. Parent Gender					-.07	-.02	.02	-.21	-.02	.18
5. Parent Ethnicity						-.03	.07	-.12	.05	-.12
6. Annual Income							-.38*	.11	-.21	-.07
7. PSI-SF								-.21	.57**	-.27
8. MSPSS									.08	-.11
9. PPUS										-.51*
10. BCQ										

Note. PSI-SF = Parenting Stress Index – Short Form; MSPSS = Multidimensional Scale of Social Support; PPUS = Parental Perceptions of Uncertainty Scale; BCQ = Barriers to Care Questionnaire. * $p < .05$; ** $p < .01$.

TABLE 4

Bivariate Correlations among Illness and Outcome Variables

	1	2	3	4	5	6	7	8
1. Duration of Illness		.06	.11	.12	-.09	.35*	.10	-.18
2. Child Age at Diagnosis			.22	.09	.10	.06	.13	-.23
3. Severity of Illness				.14	.02	.05	.52**	-.31*
4. CNS Involvement					-.04	.09	.05	-.21
5. PSI-SF						-.21	.57**	-.27
6. MSPSS							.08	-.11
7. PPUS								-.51*
8. BCQ								

Note. PSI-SF = Parenting Stress Index – Short Form; MSPSS = Multidimensional Scale of Social Support; PPUS = Parental Perceptions of Uncertainty Scale; BCQ = Barriers to Care Questionnaire. * $p < .05$; ** $p < .01$.

TABLE 5

Examination of Salivary Cortisol Levels by Parent Gender

	Fathers	Mothers	Total Sample
N	9	26	35
Range	.34	.35	.35
Minimum	.04	.03	.03
Maximum	.38	.38	.38
Mean (*SD*)	.15 (.11)	.15 (.09)	.15 (.10)
Median	.11	.15	.15

TABLE 6

Examination of Salivary Cortisol Levels by Age

	Fathers			Mothers		
	≤ 30	31 – 50	≥ 51	≤ 30	31 – 50	≥ 51
N	1	7	1	8	18	0
Range		.19		.35	.35	
Minimum		.06		.03	.03	
Maximum		.25		.38	.38	
Mean (*SD*)		.13 (.07)		.15 (.11)	.15 (.09)	
Median		.11		.14	.15	
Value	.38		.04			

Note. Value = cortisol value of single participant if *n* = 1 within group.

TABLE 7

Hierarchical Regression for Salivary Cortisol on Parenting Stress

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Family Income	-.42	-2.50*	.17	.17	6.23*
2	Time of Cortisol	-.17	-1.02	.03	.20	.31
3	Salivary Cortisol	-.26	-1.47	.06	.26	.15

Note. * $p < .05$.

TABLE 8

Hierarchical Regression for Salivary Cortisol on Parental Uncertainty

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Severity of Illness	.52	3.37**	.28	.28	11.38**
2	Time of Cortisol	-.07	-.42	.00	.28	.18
3	Salivary Cortisol	.03	.19	.00	.28	.04

Note. * $p < .01$.

TABLE 9

Hierarchical Regression for Salivary Cortisol on Barriers to Care

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Severity of Illness	-.36	-2.18*	.13	.13	4.76*
2	Time of Cortisol	.30	1.83	.08	.21	3.37
3	Salivary Cortisol	.04	.26	.00	.21	.07

Note. * $p < .05$.

TABLE 10

Hierarchical Regression for Salivary Cortisol on Social support

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Duration of Illness	.30	1.76	.09	.09	3.10
2	Time of Cortisol	-.10	-.56	.01	.10	.31
3	Salivary Cortisol	-.09	-.50	.01	.11	.25

TABLE 11

Partial Correlations among Demographic Variables and Salivary Cortisol

	1	2	3	4	5	6	7
1. Child Age		.11	.63**	-.24	-.01	.07	-.29
2. Child Sex			.16	.06	.12	-.09	.23
3. Parent Age				-.38*	.30	.49**	-.27
4. Parent Gender					.03	-.08	.06
5. Parent Ethnicity						.13	.01
6. Annual Income							.18
7. Salivary Cortisol							

Note. Analyses conducted controlling for time of day in which salivary cortisol was collected. * $p < .05$; ** $p < .01$.

TABLE 12

Partial Correlations among Illness Variables and Salivary Cortisol

	1	2	3	4	5
1. Duration of Illness		-.12	.03	.24	.08
2. Child Age at Diagnosis			.11	.30	-.28
3. Severity of Illness				.11	-.05
4. CNS Involvement					.00
5. Salivary Cortisol					

Note. Analyses conducted controlling for time of day in which salivary cortisol was collected.

TABLE 13

Hierarchical Regression for Parenting Stress on Parental Uncertainty

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Severity of Illness	.52	3.80*	.28	.28	14.42**
2	PSI-SF	.54	4.88**	.28	.56	23.85**

Note. PSI-SF = Parenting Stress Index – Short Form. * $p < .01$; ** $p < .001$.

TABLE 14

Hierarchical Regression for Parenting Stress on Perceived Barriers to Care

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Severity of Illness	-.30	-1.93	.09	.09	3.72
2	PSI-SF	-.26	-1.74	.07	.15	3.02

Note. PSI-SF = Parenting Stress Index – Short Form.

TABLE 15

Hierarchical Regression for Parenting Stress on Social Support

Step	Variable	Standardized β	*t* for within-step predictors	R^2 Change for step	Cumulative R^2	*F* Change for Step
1	Duration of Illness	.35	2.34*	.12	.12	5.46*
2	PSI-SF	-.18	-1.19	.03	.15	1.42

Note. PSI-SF = Parenting Stress Index – Short Form; * $p < .05$.

Oklahoma State University Institutional Review Board

Date:	Thursday, September 23, 2010
IRB Application No	AS1086
Proposal Title:	Stress Reactivity and Psychophysiological Adjustment of Caregivers of Children With an Illness
Reviewed and Processed as:	Expedited

Status Recommended by Reviewer(s): Approved Protocol Expires: 7/31/2011

Principal Investigator(s):

David Fedele
116 N. Murray
Stillwater, OK 74078

Stephanie Hullmann
116 North Murray
Stillwater, OK 74078

Larry L. Mullins
116 North Murray
Stillwater, OK 74078

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

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

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

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

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the authority to inspect research records associated with this protocol at any time. If you have questions about the IRB procedures or need any assistance from the Board, please contact Beth McTernan in 219 Cordell North (phone: 405-744-5700, beth.mcternan@okstate.edu).

Sincerely,

Shelia M. Kennison

Shelia Kennison, Chair
Institutional Review Board

VITA

David Andrew Fedele

Candidate for the Degree of

Doctor of Philosophy

Thesis: ASSESSING THE DIAGNOSTIC UTILITY OF PROPOSED ADULT ADHD SYMPTOMS IN A YOUNG ADULT SAMPLE

Major Field: Clinical Psychology

Biographical: Born in Jacksonville, FL on March 3, 1984, the son of Alfred Fedele and Lynne Richenbacher.

Education:

Completed the requirements for the Doctor of Philosophy in Clinical Psychology at Oklahoma State University, Stillwater, Oklahoma in July, 2012.

Completed the requirements for the Master of Science in Clinical Psychology at Oklahoma State University, Stillwater, Oklahoma in 2008.

Completed the requirements for the Bachelor of Science in Psychology at Florida State University, Tallahassee, Florida in 2006.

Experience: Completed research within the areas of pediatric and clinical child psychology. Primary research areas include family adjustment to chronic illnesses and measurement issues within pediatric psychology.

Professional Memberships:

American Psychological Association
American Psychological Association – Division 53
American Psychological Association – Division 54
Oklahoma Psychological Association
Phi Beta Kappa

Name: David Andrew Fedele Date of Degree: July, 2012

Institution: Oklahoma State University Location: Stillwater, Oklahoma

Title of Study: THE RELATIONSHIP OF CORTISOL TO PSYCHOLOGICAL ADJUSTMENT IN PARENTS OF CHILDREN DIAGNOSED WITH CANCER

Pages in Study: 113 Candidate for the Degree of Doctor of Philosophy

Major Field: Clinical Psychology

Scope and Method of Study: The current study examined the relation of physiological stress as measured by salivary cortisol in a sample of parents of children who had been diagnosed and receiving treatment for pediatric cancer for at least six months (n = 43). Specifically, the study examined baseline levels of salivary cortisol in parents of children with cancer and the relationship of salivary cortisol to levels of parental uncertainty, perceived barriers to care, parenting stress and social support in an effort to delineate specific parental constructs that are related to physiological stress. Participants were recruited from a large teaching hospital in the Midwest and provided one saliva sample during a visit to the hospital. All participants were screened for factors known to influence cortisol (e.g., recent food, caffeine, nicotine, and sleep) prior to collection. Parents completed the Parental Perceptions of Uncertainty Scale, Barrier to Care Questionnaire, Parenting Stress Index – Short Form, and Multidimensional Scale of Social Support.

Findings and Conclusions: Consistent with hypotheses, parents of children who are receiving treatment for pediatric cancer evidenced low salivary cortisol levels. Parental salivary cortisol levels appeared to be lower than previous studies that investigated cortisol in parents of children with cancer. Additionally, the salivary cortisol levels found in the current study appeared to be toward the lower end of normative expected salivary cortisol levels in healthy adults. Salivary cortisol was also found to not be a significant predictor of parenting stress, perceived barriers to care, parental uncertainty, or social support. Moreover, salivary cortisol levels were not correlated with any of the measured demographic or illness variables. Finally, exploratory analyses revealed that although salivary cortisol was unrelated to any of the parental constructs, parenting stress was found to be a significant predictor of illness uncertainty. The current study is limited by study design and a small sample. Therefore, it is challenging to ascertain whether the lower than expected salivary cortisol levels are reflective of dysregulation of the hypothalamus-pituitary-adrenal axis or that parents of children receiving treatment for cancer are not experiencing enhanced physiological stress.

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