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Coping, Hardiness, and Parental Stress in Parents of Children Diagnosed with Cancer

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The University of Southern Mississippi

COPING, HARDINESS, AND PARENTAL STRESS IN PARENTS
OF CHILDREN DIAGNOSED WITH CANCER

by

Kathryn Lynch Bigalke

Abstract of a Dissertation
Submitted to the Graduate School
Of The University of Southern Mississippi
in Partial Fulfillment of the Requirements
for the Degree of Doctor of Philosophy

August 2015

ABSTRACT

COPING, HARDINESS, AND PARENTAL STRESS IN PARENTS
OF CHILDREN DIAGNOSED WITH CANCER

by Kathryn Lynch Bigalke

August 2015

Previous research has demonstrated a significant increase in stress for parents with a child in active cancer treatment. As the number of children diagnosed with cancer continues to rise, there has been a call to identify factors that may contribute to positive outcomes in these families (e.g., Sloper, 2000; Streisand, Kazak, & Tercyak, 2003). Certain effective coping strategies, particularly related to more problem-focused forms of coping and hardiness, appear to be negatively related to parental stress. However, little is known about how these strategies may impact parental stress in families of children in active cancer treatment. The current study assessed the influence of coping and family hardiness on parental stress among parents of children in active cancer treatment. The study hypothesized that: higher levels of effective coping and hardiness will predict a significant amount of variance in parental stress after accounting for symptom severity; the effect of hardiness on parental stress will be attenuated after the addition of Coping I, Coping II, and Coping III in three separate regression models; and the parallel mediation model will partially mediate the relationship between hardiness and parental stress. Results did not support the hypothesis that family hardiness and coping would emerge as significant predictors of parental stress over and above symptom severity. Effective coping was not observed as a partial mediator in the relationship between family

hardiness and parental stress. However, communication with other parents and consultation with the medical staff were found to have a significant indirect relationship between family hardiness and parental stress. The current study provides further information on the enduring impact of symptom severity and the potential relationship between family hardiness, parental stress, and coping through communication with other parents and the medical staff.

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The University of Southern Mississippi

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by

Kathryn Lynch Bigalke

A Dissertation
Submitted to the Graduate School
of The University of Southern Mississippi
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for the Degree of Doctor of Philosophy

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August 2015

DEDICATION

Listen to the MUSTN'TS, child,

Listen to the DON'TS

Listen to the SHOULDN'TS

The IMPOSSIBLES, the WON'TS

Listen to the NEVER HAVES

Then listen close to me –

Anything can happen, child,

ANYTHING can be.

- Shel Silverstein, *Where the Sidewalk Ends*

Words cannot express my gratitude to Dr. Bonnie Nicholson, who has been so much more than a dissertation chair, mentor, and training director to me. Dr. Nicholson, as well as the other devoted committee members, Dr. Michael Madson, Dr. Emily Bullock Yowell, and Dr. Richard Mohn have helped me to believe in myself and that “ANYTHING can be.”

I would also like to thank the many parents who were willing to share their stories, “pass the word,” and take the time to participate in the data collection process.

Thank you to all of my friends for hanging in there with me. Thank you for being there when I needed it and sorry for any unreturned phone calls or messages... now you can see why!

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CHAPTER I

INTRODUCTION

As pediatric cancer rates have continued to increase in the past several decades, the American Cancer Society estimates that in 2013 about 11,630 children in the United States under the age of 15 will be diagnosed with cancer. The survival rates continue to rise due to technological and treatment advances (American Cancer Society, 2013). Families of these children face significant stress as they conform to a demanding treatment regimen, potential medical side effects (Bryant, 2003), changes in daily activities (Woodgate & Degner, 2003), disruption in roles (Kazak, Simms, & Rourke, 2002), and the threat of death (Pai et al., 2007). Parents of children diagnosed with cancer report parental stress that is significantly higher than children with other chronic conditions (Hung, Wu, & Yeh, 2004) and has been associated with negative outcomes such as increased parent psychopathology (Robinson, Gerhardt, Vannatta, & Noll, 2007) and adjustment and behavioral problems in children (Wolfe-Christensen et al., 2010). While symptom severity (Kieckhefer, Churchill, Trahms, & Simpson, 2009) and length of illness (Kupst et al., 1995; Steele, Long, Reddy, Luhr, & Phipps, 2003) have been identified as potential predictors of parental stress in the pediatric cancer population, there has been recent interest in identifying predictors associated with less stress in this population. Factors such as coping skills and hardiness have been associated with fewer stress symptoms in related populations (Ben-Zur, Duvdevany, & Lury, 2005; Failla & Jones, 1991; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1998) but have not been examined in relation to parents of children with cancer. Therefore, the purpose of the

current study was to explore these potential predictors of parental stress in parents of children with cancer.

Research has indicated that certain forms of coping, particularly active problem solving and seeking social support, are negatively related to parental stress (Hoekstra-Weebers et al., 1998). Similarly, hardiness has been positively associated with factors such as social support and parental mental health (Ben-Zur et al., 2005), and problem-focused coping (Failla & Jones, 1991) and negatively associated with parental stress (Ben-Zur et al., 2005), and emotion- and avoidance-based coping (Failla & Jones, 1991). There are very few studies that examine the relationship between hardiness and stress, particularly in the population of families of children diagnosed with cancer.

There is growing interest regarding the individual and family factors that may help parents handle the stress. Yet, much remains unknown regarding the potential impact that effective coping strategies and hardiness may have on parental stress in families of children diagnosed with cancer. Therefore, the proposed study examined the roles of two protective factors, coping and hardiness, and the potential impact on parental stress in a community sample of parents of children in active cancer treatment.

Stress

The definition of stress can be traced back to Richard S. Lazarus (1966), who stated that stress occurs when an individual is dealing with a disturbance of biological and psychological functioning, which is an “unusually threatening, damaging, or demanding life condition” (p. 3). Lazarus theorized that the individual identifies the event as a threat through an appraisal process, which depends on the individual’s estimation of the harm and their available resources, the likelihood of harm/confrontation, the degree of

uncertainty in the importance of the event, and the psychological resources of the individual (Lazarus, 1966).

Various stress models have been identified within the literature. Some focus on identifying potential mediators for stress (Lazarus & Folkman, 1984), while others focus on the available energy to handle the stressor (Scott & Howard, 1970), and the potential personality characteristics within the individual (Eisdorfer, 1985). However, three main domains occur in all of the models which include: a) the sources of stress, which comprise of physical or psychological demands that alter normal functioning; b) mediators of stress, which include resources and coping behaviors that influence the stress experience, management, longitude, and effect on the outcome; and c) outcomes of stress, which include changes in functioning (Patterson, 1988).

In the current study, aspects of the Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 1988) were used as a framework to understand the influence of the variables under examination. The FAAR model incorporates previous research on stress, as well as three levels of systems: the person, the family and its subsystems, and the community; establishing links to physiological, psychological, and sociological models of stress, with an emphasis on appraisals, as theorized by Lazarus and colleagues (Patterson, 1988; Lazarus, 1966). The FAAR model originates from Hill (1949) who developed one of the first major family-stress frameworks. The ABCX Family Crisis Model in which: A (the family stresses and demands) interacts with B (the family's crisis-meeting resources and strengths) interacting with C (the definition the family makes of the event, particularly coping behaviors) produces X (the crisis or stress) (p. 141). Although this model was developed in 1949, the ABCX model continues to be the

basis of most current family stress models (Boss, 2002; Rodenburg, Meijer, Dekovic, & Aldenkamp, 2007).

The FAAR model proposes that stress experienced by the family is an outcome of the interaction between events appraised as threatening and the family's adaptive capabilities (resources and coping) to attempt to maintain normal functioning (Patterson, 1988; Kerns, 1995). Stressors can include physiological challenges such as chronic illness (Patterson, 1988; Kerns, 1995). The family attempts to maintain balance by using resistance capabilities such as resources and coping strategies to meet the stressors and strains of the situation. The ways in which the family defines and deals with the situation are important aspects in maintaining balance between the stressors/strains and the family's resistance capabilities. The adjustment stage is considered a relatively stable period where only minor changes are occurring to meet existing demands with the family's present capabilities. However, once a crisis is experienced where the stress/strain exceeds the family's available capabilities, an imbalance occurs leading to the adaptation phase. The adaptation phase is when the family tries to regain a balance through an attempt to gain additional resources and coping strategies and to reduce the stress/strain or change the way the family is defining the situation. (Patterson, 1988)

Therefore, in the current study, the diagnosis of cancer was a crisis event. It was hypothesized that, in line with the FAAR model, the way the family appraises the crisis event (hardiness) and effectively manages the crisis event (coping), influences the stress experienced by the family. Consistent with the FAAR model, it was hypothesized that higher levels of positive appraisals (hardiness) and positive coping would be related to lower stress levels. The FAAR model also suggests that coping may mediate the

relationship between the appraisal of the crisis event (hardiness) and the family's experience of stress and strain (Patterson, 1988). Research has indicated that the initial diagnosis and adjustment to treatment can be the most challenging time for families (Kupst et al., 1995; Steele et al., 2003), which may further support the FAAR model as the family works to mobilize their resources and adapt to the stress that comes from a child being diagnosed with cancer. As previous research has indicated that the severity of symptoms the child is experiencing (Kieckhefer et al., 2009) and the length of time since diagnosis (Kupst et al., 1995; Steele et al., 2003) may contribute to the stress experienced by parents, these two factors were considered as possible covariates.

Parental Stress

One such threat, parental stress, has been linked to anxiety, depression, and general distress in parents, and to negative child adjustment (Abidin, 1992; Lazarus & Folkman, 1984; Wolfe-Christensen et al., 2010). Parental stress is defined as “the result of a series of appraisals made by each parent in the context of his or her level of commitment to the parenting role” (Abidin, 1992, p. 410). The parent appraises his or her current role as a parent and that evaluation determines the level of stress the parent experiences. Parental stress is an important aspect of the Family Adjustment and Adaptation Response (FAAR) model (Patterson, 1988), as parental stress has the potential to lead to poorer functioning in the family and is an outcome of the appraisals and adaptive capabilities (such as hardiness and coping) of the family. Parental stress can also be considered a motivator prompting the parent to use the available resources and engage in specific parenting behavior (Abidin, 1992; Lazarus & Folkman, 1984).

Parental stress has been associated with negative outcomes such as parental psychopathology (Prevatt, 2003) and has been associated with the diagnosis of a child with a chronic illness (Wolfe-Christensen et al., 2010). Higher levels of parental stress in parents of children with cancer have been reported in the literature (Robinson et al., 2007; Kazak & Barakat, 1997). In a comparison of stress levels among parents of children with cancer and parents of children with physical disabilities, Hung and colleagues (2004) surveyed a group of 89 cancer patients and 92 physically disabled patients between the ages of one and 15 years old ($M = 5$, $SD = 3.2$). Results indicated that parents of children with cancer reported significantly higher parental stress than parents of disabled children. The total score on parental stress of the disability group ($M = 97.11$, $SD = 20.70$) was significantly lower than the cancer group ($M = 118.53$, $SD = 19.70$). No significant differences were found when accounting for possible confounding variables such as age, parental level of education, and socioeconomic status (Hung et al., 2004).

Parents of children diagnosed with chronic illness, have been found to have higher levels of parental stress as well as greater reports of psychological symptoms, such as depression and anxiety (Robinson et al., 2007; Kazak & Barakat, 1997). Parental stress has also been identified as an independent predictor of children's emotional, behavioral, and social adjustment (Patenaude & Kupst, 2005) and has been reported to moderate the relationship between caregiver demand and child internalizing problems (Wolfe-Christensen et al., 2010). This is an important link, as children's adjustment to a stressor has been shown to be influenced by the adjustment of the family and the family's available resources (Kazak, Rourke, & Crump, 2003; Wolfe-Christensen et al., 2010). Children diagnosed with cancer may be more vulnerable to internalizing problems if the

parent is experiencing increased stress (Dahlquist, Czyzewski, & Jones, 1996; Dockerty, Williams, McGee, & Skegg, 2000; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1999).

With such potentially negative outcomes, current research has focused on potential predictors of parental stress. Parental stress among families of children with chronic illness has been associated with several demographic variables such as having young children, parental age, race, socioeconomic status, and marital status (Kazak, 1997; Peterson, Sterling, & Weekes, 1997; Streisand, Braniecki, Tercyak, & Kazak, 2001; Barakat, Patterson, Tarazi, & Ely, 2007). Other factors that have been predictive of parental stress include negative maternal perceptions regarding the parent-child interaction (Abidin, 1992), negative parental perceptions of the child's functioning (Rodenburg, 2007), difficult child temperament (Crnic & Acevedo, 1995), lack of social support (Jennings, Stagg, & Connors, 1991), and marital dissatisfaction (Erel & Burman, 1995).

Stressors associated with parenting a child diagnosed with cancer such as caretaking for the child after painful procedures, uncertain prognoses, medical expenses, and developmental concerns, are also related to increases in parental stress (Sloper, 2000; Noll et al., 1995). Additionally, the child's symptom severity and age (Kieckhefer et al., 2009), treatment severity (Robinson et al., 2007), and length of time since the diagnosis (Kupst et al., 1995; Steele et al., 2003) are associated with greater levels of parental stress. Multiple sources have indicated that the experience of parental distress has been shown to decrease as a function of time elapsed since the diagnosis of cancer in the child (Kupst et al., 1995; Steele et al., 2003). Steele and colleagues (2003) suggest that the initial diagnosis and adjustment to treatment may be a particularly challenging time for

families as they activate coping strategies. Although parental stress has been reported to decrease over time, in Wijnberg-Williams and colleagues' study of psychological adjustment of parents of pediatric cancer patients, a significant number of parents were still experiencing clinically significant distress five years post-diagnosis (Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006). The current study examined potential covariations between parental stress and symptom severity, child age, treatment severity, and length of time since diagnosis.

Parental stress has also been associated with several negative outcomes such as behavioral problems in children (Patenaude & Kupst, 2005) and health complications in parents (Robinson et al., 2007; Kazak & Barakat, 1997) and appears to be particularly problematic in parents of children diagnosed with cancer (Hung et al., 2004). Although several different measures have been developed to assess for parental stress, few have been developed to assess parental stress related to a child's diagnosis of a chronic illness. One of the main assessments utilized to measure disease-related parental stress, the Pediatric Inventory for Parents (PIP; Streisand et al., 2001), has been found as a reliable and valid assessment in samples of parents with children diagnosed with cancer and type 1 diabetes.

In a sample of 116 parents of children treated for cancer, a significant association was observed between parental stress, as measured by the PIP, and poorer family functioning as measured by parents' problem solving, communication, roles, affective responsiveness, affective involvement, behavior control, and general functioning. Although parental stress was utilized as an independent variable in this study and the authors utilized the subscales of parental stress instead of the total score, they found that

the more frequently a parent experiences stress, the amount and quality of emotional resources to contribute to the family may be limited. The authors' suggest that more research is needed to focus on the interaction between parental stress and resilience factors that might further the understanding of what factors enable some families and individuals to handle hardship better than others (Streisand, Kazak, & Tercyak 2003).

Parental stress has been observed to predict behavioral and adjustment problems in children (Prevatt, 2003), dysfunctional parenting (Rodenburg et al., 2007) and psychopathology (Robinson et al., 1997) in adults. Parental stress has also been associated with a myriad of stressors related to parenting a child with cancer such as medical uncertainty, treatment demands, medical costs, concerns for the child's ongoing development, continued caretaking for the other family members, factors related to the child's condition, age, treatment, and length of time since the diagnosis (Clay, 2004; Noll et al., 1995; Kieckhefer et al., 2009; Robinson et al., 2007; Kupst et al., 1995). Due to the multitude of negative outcomes associated with parental stress, more research is needed to identify potential predictors of parental stress which may significantly impact the stress experienced by parents when a child is diagnosed with cancer. The purpose of the current study was to continue to gain a better understanding of potential predictors for parental stress.

Coping

According to Lazarus, once an event is appraised by the individual as threatening, internal processes begin with the function of reduction or elimination of the harm, also known as coping processes or secondary appraisals (Lazarus, 1966). Coping is an important aspect of the Family Adjustment and Adaptation Response (FAAR) model

(Patterson, 1988), as family resources are viewed as maintaining balance when a family is faced with a stressful event, such as chronic illness of a child (Kerns, 1995). Family resources may moderate stress and include physical, psychological, and social resources and coping behaviors (Kerns, 1995). Further supporting the FAAR Model, coping is now being viewed as an active process that utilizes already existing resources within a family as well as allows researchers to consider the possibility for the development of new behaviors and resources (McCubbin, McCubbin, & Thompson, 1987). The FAAR model also conceptualizes coping as a potential mediator variable that helps the family adapt to the demands of the disease (Patterson, 1988; Goldbeck, 2006). One of the purposes of the current study was to explore coping as a potential partial mediator for the relationship between parental stress and hardiness.

Lazarus and Folkman (1984) describe three main types of coping: avoidance, problem-focused, and emotion-focused coping. The authors describe avoidance in the context of an illness as ineffective due to the individual failing to engage in the coping process to decrease the danger or damage of the situation. However, they note that research regarding avoidance has uncovered both positive and negative implications. For example, avoidance may be helpful when there is no direct action that will overcome a harm or threat and may be adaptive in certain situations (e.g., patients with cancer can deny the seriousness of the situation as long as they continue to follow the medical regime) (Lazarus & Folkman, 1984). Vrijmoet-Wiersma and colleagues (2008) indicated that avoidance may be functional for parents when the child is first diagnosed with cancer; however, increased levels of emotional stress were reported of parents utilizing

avoidant coping during the active and maintenance phases of cancer diagnosis (Bigalke, 2010; Hoekstra-Weebers et al., 1999; Lindahl-Norberg, Lindblad, & Boman, 2005).

Lazarus and Folkman (1984) further distinguish between problem-focused coping which is directed at managing or altering the problem causing the stress, and emotion-focused coping which is directed at regulating emotional responses to the stress. Parents who actively problem-solve, seek social support, and work to alter the negative emotions of the situation use problem-focused coping (Judge, 1998). Emotion-focused coping is associated with detaching from the situation, trying to control one's emotions, and is often found to be used in parents of children with chronic illness and disability (Judge, 1998; Neil, 2001). Both forms of coping are usually evident in individuals dealing with a stressful situation (Lazarus & Folkman, 1984). However, it is important to note that they can facilitate and impede each other in the coping process depending on the situation (i.e., reducing emotional distress can interfere with problem-focused efforts) (Lazarus and Folkman, 1984).

Depending on the type of coping, emotion-focused and avoidance have been associated with negative outcomes and problem-focused coping has been associated with positive outcomes (Judge, 1998; Neil, 2001). In a study on parents of children with Autism, a relationship was observed between depression and both emotion-focused and avoidant coping and a negative relationship was observed between parental stress and problem-focused coping (Aldwin & Revenson, 1987). Similarly, Pottie and Ingram (2008) observed a relationship between positive daily mood and problem-focused coping and daily negative mood and avoidant and emotion-based coping.

Similarly, in a sample of parents of children with cancer, Greening and Stoppelbein (2007) reported a negative relationship between depression, post-traumatic stress, and anxiety with the parent's reported use of problem-focused appraisals to cope and a positive relationship between the reported symptoms and avoidant coping and other emotion regulation strategies. In assessing potential gender differences in coping for parents of children with cancer, Hoekstra-Weebers and colleagues (1998) reported that mothers were found to utilize more social support seeking and less problem-focused coping when compared to fathers, and both groups reported similar use of emotion-focused coping. The authors also found that problem-focused coping was related to less reported distress than emotion-focused coping.

Avoidance, problem-focused, and emotion-focused coping are just one of the many ways to operationalize coping. Researchers have now begun to identify the specific behaviors utilized to cope with stressful situations. It seems that individuals are utilizing all types of coping strategies and that these are sometimes beneficial and sometimes potentially damaging. Researchers are now asking more specific questions regarding what coping strategies parents of children with cancer are using to manage family life, if there are certain parental coping strategies that can encourage improvements in the child's health, and how to assess parental coping (McCubbin, McCubbin, Patterson, Cauble, Wilson, & Warwick, 1983). The focus is shifting to the acknowledgement that most individuals are using aspects of all three main forms of coping, but that the positive or negative implications of any coping strategy may be dependent on certain characteristics of the individual or family, as well as the available resources and characteristics of the situation (Patenaude & Kupst, 2005).

One such attempt to examine specific coping behaviors is The Coping Health Inventory for Parents (CHIP; McCubbin et al., 1983). This measure has been qualified as a “well established instrument” (Alderfer et al., 2008, p. 1054) for measuring family coping when a child has a chronic illness, has been used within the population of interest multiple times, and is based on the FAAR model. The theoretical underpinnings of the CHIP are based on the findings that families who are able to continue to attend to various aspects of family life (factors represented within the subscales) will support better family adaptation to a child’s illness and better outcomes for the child (Campbell, 1993; Cohen, 1999). The CHIP was originally developed with a sample of 185 parents with a child diagnosed with Cystic Fibrosis (McCubbin et al., 1983). The 45 items included in the measure were found to account for 71.1% of the variance. The first coping subscale (Coping I) is defined as maintaining family integration, cooperation, and an optimistic definition of the situation. The second coping subscale (Coping II) is defined as maintaining social support, self-esteem and psychological stability. The third coping subscale (Coping III) is defined as understanding the medical situation through communication with other parents and consultation with the medical staff.

The coping patterns were associated with indices of family environment such as the cohesiveness, expressiveness, organization, control, and conflict within the family. In mother’s, Coping I and III were associated with family cohesiveness, and Coping II was associated with family expressiveness. In fathers, Coping I was associated with family organization, family cohesiveness, and inversely related to family conflict and Coping III was associated with family organization and family control. As for parental coping and child’s health, parental coping patterns were also associated with changes in both health

indices. For mothers, Coping I was positively correlated with child's Height/Weight Index and Coping II was positively correlated with child's Pulmonary Functioning. In fathers, Coping II is positively correlated to both Height/Weight index and Pulmonary Functioning. In exploring demographic variables that may have influenced the findings, income and age of the child showed a significant correlation with coping patterns. Specifically, the older the child the more likely the mother was to report coping efforts for support, maintaining self-esteem, and psychological stability (Coping II). The father's reported effort to maintain family integration, cooperation, and an optimistic view of the situation (Coping I) was positively correlated with family income. As well as, the father's effort to understand the medical situation and communicate with other parents and medical staff (Coping III) was positively correlated with family income and the age of the child (McCubbin et al., 1983).

One noteworthy study that discussed coping patterns compared 25 families with a child diagnosed with cancer to 24 families in the comparison group which had a child diagnosed with either insulin-dependent diabetes mellitus or epilepsy (Goldbeck, 2006). The author utilized two coping measures: the three subscales of the CHIP and the *Trier Coping Scales* (TCS; Klauer & Filipp, 1993) which reports five coping scales: rumination, seeking social support, defense (such as optimism or minimization), seeking information, and religion. Also measured were parent and child quality of life, both reported by the parent. Results indicated that effects of diagnosis (cancer vs. diabetes/epilepsy) on parental coping were found. Parents of children with cancer reported more use of negative coping strategies such as rumination and reported less social support seeking and less maintenance of personality stability, when compared to

parents of children with diabetes or epilepsy. The authors also found that similar levels of social support seeking and religious coping within the couple were positively correlated with improvements in parental quality of life.

Similarly, negative outcomes were found in 64 couples who were assessed at diagnosis, six months, and 12 months post-diagnosis on self-reported psychological distress and the *Utrecht Coping List* (Schreurs et al., 1988) which identifies seven coping dimensions: active-problem focusing, palliative reaction pattern (doing other things to distract from the problem), avoidance behavior, social-support seeking, passive reaction pattern (become overcome by the problem, unable to do anything else), expression of emotions (expressing annoyance, anger), and comforting cognitions (thoughts related to thinking things will get better) (Hoekstra-Weebers et al., 1998). Both parents reported increased psychological distress and psychiatric symptomatology following the diagnosis of a child with cancer. Mothers were found to utilize more social-support seeking while fathers were found to use more active-problem focusing at diagnosis and less palliative reaction pattern when tested again at 12 months post-diagnosis.

Findings such as these continue to highlight the importance of the family in the adaptation of a child diagnosed with cancer. More research is needed to understand the different coping methods being utilized by parents and the effect that this may have on the parents and child. In addition to the finding by Blotcky, Raczynski, Gurwitch, and Smith (1985) that indicated that parental distress and coping appear to be important in a child's early response to the diagnosis of cancer.

Certain forms of coping, particularly related to active problem solving and seeking social support are negatively related to parental stress. Utilizing the three

subscales of the CHIP, the current study focused on the effective coping skills of: maintaining family integration, cooperation, and an optimistic definition of the situation; maintaining social support, self-esteem, and psychological stability; and understanding the medical situation through communication with others parents and consultation with the medical staff. The current study further explored the role these effective coping strategies may have as predictors of parental stress. Similar to coping, which utilizes already existing resources within a family, hardiness will also be investigated for the role it may have in relation to coping and parental stress (McCubbin et al., 1987).

Hardiness

Individuals who remain mentally and physically healthy after experiencing high levels of stress are suggested to have personality characteristics that may protect them from those who become mentally and physically ill (Kobasa, Maddi, & Kahn, 1982). One such personality characteristic, hardiness, has been defined as an individual (individual hardiness) or family's (family hardiness) internal strength in dealing with stressful circumstances (Maddi et al., 2006; McCubbin, Thompson, Pirner, & McCubbin, 1988). Resiliency, a protective factor similar to hardiness, has been identified as an important aspect of the Family Adjustment and Adaptation Response (FAAR) model (Patterson, 1988), as resiliency helps families to resist interference in the face of stress and helps families adapt to crisis events. Hardiness has been negatively associated with stress and positively associated with problem solving and perceived family support (Maddi et al., 2006).

The main components of hardiness are commitment, control, and challenge. An individual or family high in hardiness is described as having an internal sense of

commitment to learn from challenging experiences, control over life events, and a sense of meaning in life, viewing situations as challenges instead of threats (Maddi et al., 2006; McCubbin et al., 1988). Hardiness has been negatively associated with stress (Ben-Zur et al., 2005; Kobasa, 1979). It may be that hardy individuals perceive fewer stressors in their environment, focus on the positives of the situation, or have more cognitive flexibility in appraising the demands of the stressor (Kobasa, 1979). Hardiness has also been theorized as a buffer that protects individuals and families from some of the effects of stress by leading to increased resources in handling the stress (Kobasa, 1979). Indicating that hardiness may increase the use of effective coping, therefore decreasing the experience of stress.

In a meta-analysis of 180 articles related to “hardiness” and “resilience”, Eschleman and colleagues (2010) reported that hardiness was positively associated with self-esteem, optimism, extraversion, sense of coherence, and self-efficacy. Hardiness was found to be negatively associated with neuroticism, negative affectivity, trait anxiety, and trait anger. The authors also reported that hardiness was negatively related with life stressors, work stressors, coworker conflict, supervisor conflict, task uncertainty, role overload, role ambiguity, role conflict, work-family conflict, and interpersonal stressors. Hardiness was also negatively associated with psychological distress, depression, burnout, state anxiety, negative state affect, posttraumatic stress disorder, poor mental health, and frustration. The authors reported hardiness as a moderator for the relationship between stress and strain, which explained an additional 4.5% of the variance. In examining the relationship between hardiness and coping, hardiness was positively associated with problem-focused and positive intrusive thoughts and negatively related to

emotion-focused and negative intrusive thoughts. Hardiness was not found to have an association with avoidance or support seeking. The authors discussed that these findings may be due to the fact that hardy individuals appraise less events as stressful and have more resources to cope effectively with the stressors that arise (Eschleman, Bowling, & Alarcon, 2010).

Family hardiness, an extension of individual hardiness, has received little attention, but has been connected to problem solving and perceived family support (Maddi et al., 2006). There are few published studies to date in the available literature that has investigated family hardiness in parents of children with cancer. One study on mothers of children in active cancer treatment found that problem-focused coping and family hardiness did not emerge as unique predictors of parenting stress, and hardiness was not found to moderate the relationship between symptom severity and parenting stress (Bigalke, 2010). Although the hypotheses were not supported, the authors suggest future research to continue to examine the relationship among these variables.

However, similar research on family hardiness has begun to extend to families dealing with other chronic illnesses. For example, in a sample of 137 families of children with asthma, family hardiness was associated with higher levels of sense of coherence and positive well-being and lower reported levels of depression (Svavarsdottir & Rayens, 2005). Another noteworthy study on a sample of 100 mothers of adult children with intellectual disabilities, reported positive relationships between parental mental health and social support and family hardiness, and negative relationships between parental stress and mental health, family hardiness, and social support (Ben-Zur et al., 2005).

One qualitative study was found related to family hardiness and childhood cancer. Forty-two parents of children treated for cancer were interviewed to identify factors that helped the family convalesce from the diagnosis of cancer, and included: internal family rapid mobilization and reorganization, social support, and changes in appraisals to make the situation more manageable and meaningful (McCubbin, Balling, Possin, Frierdich, & Bryne, 2002). The factors identified appear to be operationalized similar to the three components of hardiness. Specifically, rapid mobilization and reorganization could also be characterized as the commitment component of hardiness, a family's motivation to turn to others to seek support and to actively confront the event (McCubbin et al., 2002). Also, the authors identified "changes in family appraisal" which could be operationalized as both the challenge component of hardiness, a family's ability to grow and readjust to change, and an active form of coping.

Relationships between Hardiness and Coping

Hardiness and coping have been identified as factors that may play a role in stress, particularly the relationship between stress and health (Klag & Bradley, 2004; Kobasa, 1979). Hardiness has been hypothesized to have a moderating effect on stress and health (Klag & Bradley, 2004; Kobasa, 1979). Kobasa (1979) published the first research proposing hardiness as a buffer to moderate the relationship between stress and illness. In a study on male business executives reporting equally high levels of stress, hardiness moderated the relationship between stress and illness indicating that low-illness executives reported higher levels of hardiness than the high-illness counterparts (Kobasa, 1979). Further, Gentry and Kobasa (1984) hypothesized that coping acts as a mediator in the relationship between hardiness and health. They hypothesized that individuals with

higher reported levels of hardiness that are experiencing stress are more likely to use positive coping strategies (e.g., problem solving, active) and less avoidance, and that this use of coping strategies results in less stress and fewer symptoms of illness (Gentry & Kobasa, 1984; Klag & Bradley, 2004).

Currently, research has supported the hypothesis that hardiness is positively related to approach coping strategies (e.g., problem focused, active) and negatively related to avoidance (Kobasa, 1982; Maddi, 1999); however, more evidence is needed to support the mediation between coping, hardiness, and stress (Klag & Bradley, 2004). For example, in a sample of 69 parents of children with physical disabilities, coping strategies accounted for a significant portion of the variance in all three components of hardiness. Further, emotion-focused coping and avoidance-based coping were negatively associated with hardiness and problem-focused coping was positively associated with hardiness (Judge, 1998). Similarly, in a sample of 57 mothers of a child with a developmental disability, higher levels of family hardiness were associated with coping behaviors that strengthened family relationships (Failla & Jones, 1991).

Also important to note, the available evidence suggests that hardy individuals may cope differently. For example, in a sample of 130 staff members employed at a large Australian university, Klag and Bradley (2004) found that relative coping mediated the relationship of hardiness on illness. Approach and avoidance coping did not mediate the effect of hardiness on illness. The authors suggested that hardy individuals may use less effective coping strategies and discussed the potential for other coping strategies, not explored in their study, which may mediate the hardiness-illness relationship (Klag & Bradley, 2004).

Hardiness has been positively associated with higher reported sense of coherence, positive well-being, parental mental health, social support, and problem-focused coping and negatively associated with parental stress, depression, and emotion- and avoidance-based coping strategies in families and children with intellectual disabilities (Ben-Zur et al., 2005), developmental disabilities (Failla & Jones, 1991), physical disabilities (Hung et al., 2004), fibromyalgia (Preece & Sandberg, 2005), and autism (Neil, 2001). There were no published studies found in the available literature that examine the relationship between hardiness and stress in the population of families of children diagnosed with cancer.

Purpose of the Study

Considering that the American Cancer Society estimates that in 2013 more than 11,630 children in the United States under the age of 15 will be diagnosed with cancer and that 80% of those children are expected to live at least five years post-diagnosis, efforts to understand the impact of a cancer diagnosis on the families of these children and to identify potential mitigating factors are vital to improving the adjustment of pediatric cancer families. The FAAR model proposes that stress experienced by the family is an outcome of the interaction between the family's definition of an event as threatening and the family's use of resources and coping strategies to attempt to maintain normal functioning (Patterson, 1988; Kerns, 1995). Coping and hardiness have both been identified as potential factors to help parents deal with the stress associated with childhood chronic illness (Judge, 1998; Canam, 1993). Certain forms of coping, particularly related to problem-solving and active coping, and hardiness have been negatively related to parental stress (Ben-Zur et al., 2005; Failla & Jones, 1991;

Hoekstra-Weebers et al., 1998). Due to previous research suggesting that time elapsed since the diagnosis and symptom severity can affect parental stress (Goldbeck, 2006; Canam, 1992; Judge, 1998), symptom severity and time since diagnosis were correlated with the criterion to look for a significant relationship for the current study. Symptom severity was found to be a significant covariate to parental stress and was accounted for during the analyses. Time since diagnosis was not accounted for due to the insignificant correlation to parental stress found in the current study. The proposed study had several aims. First, the proposed study examined the potential benefits of coping strategies and hardiness on parental stress in a sample of parents of children in active cancer treatment. Further, the proposed study tested three partial mediation hypotheses for the role of three different coping strategies in the relationship between family hardiness and parental stress. After examining the three subscales of coping separately, the third purpose of the current study was to examine all three coping subscales in an effective coping model to examine if the combination of all three coping strategies resulted in a partial mediation between family hardiness and parental stress. Results of the proposed study will add to growing literature on characteristics and strengths of parents of children in active cancer treatment. Three primary questions were examined:

1. Do higher levels of effective coping (Coping I; Coping II; and Coping III) and hardiness predict lower levels of reported parental stress when accounting for symptom severity?
2. Does effective coping (Coping I; Coping II; and Coping III) partially mediate the relationship between hardiness and parental stress, when accounting to symptom severity?

- a. Is Coping I (maintaining family integration, cooperation, and an optimistic definition of the situation) a partial mediator in the relationship between hardiness and parental stress when accounting for symptom severity?
 - b. Is Coping II (maintaining social support, self-esteem and psychological stability) a partial mediator of the relationship between hardiness and parental stress when accounting for symptom severity?
 - c. Is Coping III (understanding the medical situation through communication with other parents and consultation with the medical staff) a partial mediator of the relationship between hardiness and parental stress when accounting for symptom severity?
3. Does effective coping (Coping I; Coping II; and Coping III) in a parallel mediation model partially mediate the relationship between hardiness and parental stress?

CHAPTER II

METHODOLOGY

Participants

The online survey had a total of 270 responses. One hundred twenty-eight participants fully completed the online survey. Of the $N = 128$ cases, seven were deleted based on responding “no” to the question which asked whether they were a primary caregiver to a child diagnosed with cancer; two were deleted due to other diagnoses that could confound the results (i.e., Downs Syndrome, Autism); one was deleted due to the parent not reporting the focus child’s age; and three were deleted due to parents reporting information on children who were above the age of 18 at the time of analysis. Thus, we retained $N = 115$ respondents who met the study criteria and who completed all study measures.

Participants were 115 male (27%) and female (73%) parents of children diagnosed with cancer between the ages two to 18 years. Demographic characteristics are presented in Table 1. Participants’ selected focus child’s average age was 7.63 and the focus child’s gender was 66% male. The average time since the child’s diagnosis was 2.67 years, with a range of zero to 10 years, and the majority of children had been diagnosed within the past two years (58.3%). The sample was predominantly Caucasian/White (57.4%) and had a mean age of 35.77 years. Approximately 90 of the participants were college graduates or had attended college or a professional school. The majority were married (86.1%) and 44.3% had an income exceeding \$51,000.

The most common diagnosis was Acute Lymphoblastic Leukemia (40%), which is the most common diagnosis of this population (ACS, 2013). Participants were equally

distributed across cancer stages, and 40.9% of respondents identified the focus child as being in the Maintenance stage of treatment. Ninety-six participants reported that this was the first diagnosis and treatment of the focus child (83.5%). Eighty-five participants reported that focus child to be in chemotherapy (73.9%), with 59 participants (51.3%) reporting the child's prognosis to be greater than a 75% chance of survival. Eighty-seven participants (75.7%) reported the focus child to be in outpatient treatment, and reported that the child's diagnosis and treatment had limited his or her interactions with friends (73%). A complete demographic description of the sample is available in Table 1.

Table 1

Demographic Characteristics of the Sample

Characteristic (Range)	<i>M</i>	<i>SD</i>
Parent age (21 - 56)	35.77	8.02
Parent education in years (8 - 17)	15.66	1.70
No. children in household (0 - 5)	1.98	1.02
Focus child age (2 – 18)	7.63	4.14
Characteristic	<i>N</i>	<i>%</i>
Parent Sex		
Mother	84	73
Father	31	27
Child Sex		
Male	76	66.1
Female	39	33.9

Table 1 (continued).

Characteristic	<i>N</i>	%
Marital status (current)		
Never married or Living alone	2	1.7
Never married or Living with someone	6	5.2
Married	99	86.1
Divorced or Separated	8	7.0
Parent race		
African-American	5	4.3
Caucasian	66	57.4
Hispanic	8	7.0
Asian	26	22.6
Other	10	8.6
Income		
Less than \$10,000	9	7.8
\$10,000 - \$20,000	15	13.0
\$21,000 - \$30,000	12	10.4
\$31,000 - \$40,000	14	12.2
\$41,000 - \$50,000	14	12.2
\$51,000+	51	44.3

Table 1 (continued).

Characteristic	<i>N</i>	%
Child's Cancer Diagnosis		
Acute Lymphoblastic Leukemia	46	40.0
Acute Myelogenous Leukemia	2	1.7
Neuroblastoma	11	9.6
Osteosarcoma	4	3.5
Ewings Sarcoma	9	7.8
Rhabdomyosarcoma	2	1.7
Hodgkin disease	1	.9
Non-Hodgkin Lymphoma	4	3.5
Hepatoblastoma	4	3.5
Wilms tumor	2	1.7
Clear Cell Sarcoma	5	4.3
Germ Cell Tumors	10	8.7
Other	15	13
Child's Stage of Cancer (when applicable)		
I	20	17.4
II	17	14.8
III	9	7.8
IV	11	9.6
Child's Stage of Treatment (when applicable)		
Induction	14	12.2
Consolidation	22	19.1
Maintenance	47	40.9
Unknown	18	15.7
Relapse of Cancer		
First treatment	96	83.5
Relapse	19	16.5

Table 1 (continued).

Characteristic	<i>N</i>	%
Child's treatment		
Surgery to remove cancer	40	34.8
Chemotherapy	85	73.9
Bone marrow transplant	15	13.0
Radiation	39	33.9
Alternative Medical Treatment	17	14.8
Non-medical Treatment	4	3.5
Other diagnoses		
Intellectual	31	27.0
Genetic	13	11.3
Medical	26	22.6
Psychiatric	9	7.8
Learning	26	22.6
Child's Prognosis		
Greater than 75% chance of survival	59	51.3
Between 25 and 75% chance of survival	30	26.1
Less than 25% chance of survival	11	9.6
Child's Location		
Inpatient	28	24.3
Outpatient	87	75.7
Limitations due to condition		
Mobility	64	55.7
Interacting with friends	84	73.0
Performance in self-care routines	51	44.3

Instruments

Demographic Form

Participants completed a general demographic survey. Questions included the parent's age, age and sex of the focus child, race, education, marital status, and annual income. The demographic survey also included questions about the child's diagnosis, age at diagnosis, relapses, multiple diagnoses, treatment, and prognosis (see *Appendix A*). Time elapsed since the child's diagnosis was asked as an open-ended question for the parent to disclose the month and year of the child's diagnosis. This was reported as a continuous variable during data analysis.

Pediatric Quality of Life Inventory-Cancer Module

To account for symptom severity, the *Pediatric Quality of Life Inventory – Cancer Module* (PedsQL; Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002) was utilized. The PedsQL – Cancer Module is a 27-item, self-report scale used to assess pediatric cancer health-related quality of life for children ages 2 to 18 years. Parents rated their answers on a Likert scale from (0) Never to (4) Almost Always. Scores were totaled and ranged from 0 – 108. Higher scores indicated higher symptom severity. The PedsQL – Cancer Module was used as a variable to account for in Step 1 and the total score was used in this study.

Originally the PedsQL Cancer Module was administered to 339 families including 220 child self-reports and 337 parent proxy-reports (Varni, et al., 2002). Internal consistency of .87 was reported for the parent report using the PedsQL Cancer Module. For this study, only the parent report was used. The current study found an internal consistency of .94 for the parent report using the PedsQL.

Pediatric Inventory for Parents

Parental stress was assessed using the *Pediatric Inventory for Parents* (PIP), a 42-item self-report measure developed by Streisand and colleagues (2001). The measure is rated on a 5-point Likert scale from Not At All (1) to Extremely (5) regarding frequency (F) of the stress and level of difficulty (D) associated with the stress. The measure includes four subscales to assess communication, medical care, role functioning, and emotional functioning. For the current study, responses were added together to form an overall total F and D scores and combined to create a total score (Streisand et al., 2001). High scores indicated greater pediatric parental stress regarding frequency and difficulty of the stress associated with caring for a child with a medical illness. Streisand and colleagues (2001) report adequate internal consistency (.80-.96) and construct validity of the PIP (as compared to the Parenting Stress Index, Abidin, 1990, and the State-Trait Anxiety Inventory, Spielberger, 1983). The current study reported an internal consistency of .97 for Pediatric Inventory for Parents.

Coping Health Inventory for Parents

Coping was assessed using the *Coping Health Inventory for Parents* (CHIP), a 45-item self-report measure developed by McCubbin and colleagues (1983). The measure was rated on a 4-point Likert scale from Not At All (0) to Very Helpful (3) regarding the effectiveness of coping strategies utilized in coping with their child's illness. The measure includes three subscales that have been constructed through factor analysis: (I) maintaining family cohesion, co-operation and an optimistic definition of the situation; (II) maintaining social support and psychological stability; (III) understanding the medical situation by communication with the staff or with other parents. McCubbin and

colleagues (1983) reported adequate reliability on the three subscales (.79, .79, and .71). As described by McCubbin (1983) validity was originally assessed through discriminant analysis between low conflict and high conflict families with a child diagnosed with cerebral palsy. For both mothers and fathers, all three coping patterns were significantly higher in high conflict families than in low conflict families. In a study of families of children with cystic fibrosis, validity was assessed using the Family Environment Scale (Moos & Moos, 1983) and two indices of health status (height/weight index and pulmonary functioning index) (McCubbin, et al., 1983). Parents' use of the three coping patterns was positively associated with improvements in the child's health status (McCubbin, et al., 1983). The current study reported an internal consistency of .86 for Coping I, .87 for Coping II, and .78 for Coping III.

Family Hardiness Index

Hardiness was assessed using the *Family Hardiness Index* (FHI; McCubbin, McCubbin, & Thompson, 1987), a 20-item self-report measure. The measure is rated on a 4-point Likert scale from False (0) to True (3). Scores were totaled and range from 0-60. Higher scores indicated a family's higher internal strength in dealing with difficult circumstances. The total score was used in the analysis.

McCubbin and colleagues (1987) reported an internal consistency of .82 on a sample of 304 families. Family hardiness has also been found to be correlated with family flexibility, family time and routines, family satisfaction, marital satisfaction, and community satisfaction (McCubbin et al., 1988). The FHI has been utilized in researching parents of children with cardiac illness and diabetes, but has not focused on

the population of parents of children with cancer (McCubbin et al., 1988). The current study reported an internal consistency of .84 for the Family Hardiness Index.

Procedures

The University of Southern Mississippi's Institutional Review Board Human Subjects Protection Review Committee approved this study (See Appendix B).

Participants were recruited through various methods, including e-mail, postings on online support groups and listserves, Mechanical Turk through Amazon.com (see description below), and snowballing where individuals who completed the measures informed others about the survey. Estimation of the amount of people contacted is difficult to provide as many websites posted information regarding the current study, the number of people on many of the listserves was not provided, and the use of snowballing is unknown. The primary investigator located contact information (e-mail addresses and website addresses) for over 200 individuals or organizations involved in support for families, patients, and caregivers affected by cancer and provided a brief description of the current study to assess the appropriateness and interest in participation. Individuals who expressed interest in participation received an e-mail from the primary investigator that contained a more thorough description of the study, researcher contact information, and a link to the survey materials (See Appendix C). The initial recipient of the e-mail was encouraged to "spread the word" via individual e-mail communications or through other listserves. When the researcher utilized websites, e-mail listserves, and online support groups, a brief description of the study, researcher contact information, and a link to the survey materials was also provided. The first page of the online survey provided the informed consent (See Appendix D).

Following an IRB renewal after one year of data collection (see *Appendix E*), an incentive of a one dollar donation to pediatric cancer research per completed survey and the use of Mechanical Turk through Amazon.com was approved. These incentives were offered due to difficulties in gaining participation after one year of data collection. The use of Amazon.com's Mechanical Turk (Mturk) allowed access to an international pool of adults willing to complete surveys for payment. Participants that qualified for the inclusion criteria were directed to Qualtrics to review the consent for and begin the online survey. Mturk allows users (i.e., the researchers) to set a threshold that survey takers must complete in order to award payment. We set the threshold of 100% completion to receive the payment of one dollar.

Surveys were available through Qualtrics, a secure online service provider (www.qualtrics.com/academic-solutions/university-of-southern-mississippi). Privacy was ensured so that obtained data will be accessible by the researcher with a secure password. The online survey included an informed consent and the following measures: demographic information form, the PIP, CHIP, FHI, and Peds-QL-Cancer Module. Total time to complete the measures was approximately 30 minutes. Parents were informed of a one-dollar donation to pediatric cancer research for participation in the survey and online links were provided for parents seeking additional support at the end of the survey. Human subjects approval was maintained throughout the study.

Research Questions and Hypotheses

1. Do higher levels of effective coping (Coping I, II, and III) and hardiness predict lower levels of reported parental stress when accounting for symptom severity?

- a. Higher levels of effective coping and hardiness will predict a significant amount of variance in parental stress (a significant R^2) after accounting for symptom severity.
2. Does effective coping (Coping I; Coping II; and Coping III) partially mediate the relationship between hardiness and parental stress?
 - a. Is Coping I (maintaining family integration, cooperation, and an optimistic definition of the situation) a partial mediator in the relationship between hardiness and parental stress when accounting for symptom severity?
 - i. The effect of hardiness on parental stress will be attenuated after the addition of Coping I in the regression model.
 - b. Is Coping II (maintaining social support, self-esteem and psychological stability) a partial mediator of the relationship between hardiness and parental stress when accounting for symptom severity?
 - i. The effect of hardiness on parental stress will be attenuated after the addition of Coping II in the regression model.
 - c. Is Coping III (understanding the medical situation through communication with other parents and consultation with the medical staff) a partial mediator of the relationship between hardiness and parental stress when accounting for symptom severity?
 - i. The effect of hardiness on parental stress will be attenuated after the addition of Coping III in the regression model.

3. Does effective coping (Coping I; Coping II; and Coping III) in a parallel mediation model partially mediate the relationship between hardiness and parental stress?
 - a. The parallel mediation model will partially mediate the relationship between hardiness and parental stress.

CHAPTER III

RESULTS

Means, standard deviations, and other descriptive information for each measure are presented in Table 2. For this sample, the average score on the PedsQL was more than one standard deviation lower than the means reported in similar populations (Huang et al., 2009) suggesting that the parents in the current study were reporting less severe symptoms of cancer in their children than found in previous research. Scores on the FHI were within a standard deviation of those means reported in similar research on mothers of children with cardiac conditions (McCubbin et al., 1983). Similarly, the three CHIP subscales were within a standard deviation of the means reported in similar research on parents who have a chronically ill child (McCubbin et al., 1983). Overall, participants reported a similar level of parental stress, as evidenced by the mean scores on the PIP, as compared to means reported in similar research on parents of children undergoing cancer treatment (Streisand et al., 2001).

Table 2

Means and Standard Deviations Study Measures (N = 115)

Measures	<i>M</i>	<i>SD</i>
PedsQL (Symptom Severity)	50.10	20.07
FHI (Family Hardiness)	37.86	8.47
CHIP I (Coping I)	33.57	10.17
CHIP II (Coping II)	24.63	10.38
CHIP III (Coping III)	14.30	4.97
PIP (Parental Stress)	266.28	57.59

Note. PedsQL = Pediatric Quality of Life Inventory – Cancer Module; FHI = Family Hardiness Index; CHIP I = Coping Health Inventory for Parents I – Maintaining family cohesion, co-operation and an optimistic definition of the situation; CHIP II = Coping Health Inventory for Parents II – Maintaining social support and psychological stability; CHIP III = Coping Health Inventory for Parents III – Understanding the medical situation by communication with the staff or with other parents; PIP = Pediatric Inventory for Parents.

To determine whether the assumptions of regression were met, a series of visual and statistical analyses were performed. Regressions using squared predictor values and matrix scatterplots were examined to determine if the linearity assumption was met; neither indicated a violation of this assumption. To determine whether the homoscedasticity assumption was met, unstandardized predicted and residual values were plotted for the dependent measure. Visual inspection of the graph did not suggest heteroscedasticity. All collinearity statistics were within the acceptable range. Thus, it does not appear that the assumptions of regression were violated in the current sample.

Categorical demographic variables were dichotomized prior to testing their relationship with the parental stress criterion. These included marital status (married = 1; not married = 0), child's sex (boy = 1; girl = 0), and parent race (Caucasian = 1; all other races were recoded to equal 0). Next, a series of bivariate correlations were computed between demographic variables (i.e., parent age, parent race, parent education, marital status, income, number of children in the home, child gender, the type of cancer diagnosis, child's age, time since diagnosis, child's stage of cancer, child's stage of treatment, relapse, child's prognosis, treatment setting of the child (inpatient, outpatient), child's mobility, ability to interact with friends, and child's self-care) and the parental stress criterion. Noted significant correlations with the criterion were: symptom severity (PedsQL; $r = .537, p < .01$), the child's limited ability to independently perform self-care routines ($r = .246, p < .01$), the child's limited mobility ($r = .278, p < .01$), and the child's

limited interaction with friends ($r = .305, p < .01$). However, the symptom severity measure (PedsQL) was the most parsimonious measure to account for all potential areas of the child's illness that could affect quality of life, which include independence, mobility, and interaction with friends. Therefore, symptom severity (PedsQL) was used in subsequent analyses to account for variance associated with the child's illness.

A series of bivariate correlations were calculated to determine the relationships among the study variables (see Table 3). Parental stress, as measured by the PIP, was significantly negatively correlated with hardiness, as measured by the FHI, and Coping I (maintaining family cohesion, co-operation, and an optimistic definition of the situation), as measured by the CHIP. Hardiness was significantly positively correlated with Coping I (maintaining family cohesion, co-operation, and an optimistic definition of the situation) and Coping III (understanding the medical situation by communication with the staff or with other parents). Each of the CHIP subscales was positively correlated with each other.

Table 3

Correlation Coefficients for Study Measures

Variable	1	2	3	4	5
1. PIP	-	-.32**	-.208*	-.109	.067
2. FHI		-	.561**	.073	.255**
3. Cope I			-	.541**	.631**
4. Cope II				-	.364**
5. Cope III					-

Note. PIP = Pediatric Inventory for Parents; FHI = Family Hardiness Index; CHIP I = Coping Health Inventory for Parents I – Maintaining family cohesion, co-operation and an optimistic definition of the situation; CHIP II = Coping Health Inventory for

Parents II – Maintaining social support and psychological stability; CHIP III = Coping Health Inventory for Parents III – Understanding the medical situation by communication with the staff or with other parents; ** $p < .01$; * $p < .05$

To examine the research questions, several mediation analyses were conducted utilizing the procedures outlined by Baron and Kenny (1986). Accordingly, three assumptions must be met for partial mediation. First, the independent variable must significantly predict the proposed mediator (path a). Second, the proposed mediator must significantly predict the dependent variable (path b). Third, a previously significant relationship between the independent and dependent variables (total effect; path c') is reduced (direct effect; path c), after insertion of the mediator into the model (Baron & Kenny, 1986).

Although it is important to understand whether there is a total effect, there are instances of full mediation, known as inconsistent mediation, where there is non-significant relationship between the independent and dependent variable (MacKinnon, Fairchild, & Fritz, 2007). Within an inconsistent mediation path a , and/or path b , have an opposite sign (i.e., positive or negative) than that of the total effect (path c'). As a result of having at least one opposite sign, the indirect effect suppresses the total effect (Kenny, 2012). Thus, in order to assess for any significant inconsistent mediation, procedures outlined by Preacher and Hayes (2008) were also utilized. Any inconsistent mediations were detected using bootstrapping, a nonparametric resampling technique, which makes no assumptions for a normal distribution. The bootstrapping procedure involves resampling the data set multiple times and estimating the indirect effect each time. The data set was resampled 5000 times to generate an estimation of the indirect effect (Preacher & Hayes, 2008). Through this process a 95% confidence interval was established for the indirect effect. If the confidence interval did not cross zero then a

significant mediation was detected. Finally, if any mediation was detected the percent mediated, or ratio of indirect to total effect was examined. Analyses were conducted using SPSS and the student version of Mplus.

Hypothesis 1

To test the first hypothesis, that higher levels of effective coping and hardiness will predict a significant amount of variance in parental stress after accounting for symptom severity, scores from the PedsQL were entered into the first step of a linear multiple regression. The first step, PedsQL, explained 28.8% of the variance in parental stress and was found to be significant (see Table 4). Scores from each of the CHIP subscales (Coping I, Coping II, and Coping III) and the FHI were entered simultaneously as individual predictors in the second step. The total parental stress score, PIP, was measured as the criterion in a hierarchical multiple regression. Although the hierarchical multiple regression revealed that the total model explained 37.9% of the variance in the parental stress criterion, the second step was not found to significantly change with the addition of the variables ($\Delta R^2 = .091$, $F(5, 109) = 13.308$, $p > .05$), with none of the coping or family hardiness variables emerging as significant predictors of parental stress over and above the variability accounted for by symptom severity. There was not a significant change in R^2 at step 2, therefore, the hypothesis was not supported. Effective coping and family hardiness did not predict parental stress over and above that accounted for by symptom severity.

Table 4

Summary of Multiple Regression for CHIP Coping Subscales and Hardiness Predicting Parental Stress

Variable	β	R^2	ΔR^2
Step 1		.288*	
PedsQL	1.54		
Step 2 (Main Effects)		.379*	.091
Cope I	-.081		
Cope II	-.147		
Cope III	.347		
FHI	-.091		

Note. PedsQL = Pediatric Quality of Life Inventory – Cancer Module; PIP = Pediatric Inventory for Parents; FHI = Family Hardiness Index; Cope I = Coping Health Inventory for Parents I – Maintaining family cohesion, co-operation and an optimistic definition of the situation; Cope II = Coping Health Inventory for Parents II – Maintaining social support and psychological stability; Cope III = Coping Health Inventory for Parents III – Understanding the medical situation by communication with the staff or with other parents.

* $p < .05$

Hypothesis 2

To test the second hypothesis, that effective coping (Coping I; Coping II; and Coping III) would partially mediate the relationship between hardiness and parental stress, three separate sets of analyses were conducted with each of the three CHIP subscales as outlined above. For each of the following hypotheses, prior to adding the mediator, family hardiness did not significantly predict parental stress (*path c*; $\beta = -.564$, $p > .05$). This relationship is illustrated in Figure 1 and accounts for symptom severity. Hypothesis 2a stated that Coping I (coping through maintaining family cohesion, co-operation, and an optimistic definition of the situation) would partially mediate the relationship between hardiness and parental stress when accounting for symptom

severity. After adding Coping I, family hardiness significantly predicted Coping I (path a ; $\beta = .674, p < .001$), but Coping I did not significantly predict parental stress (path b ; $\beta = .290, p > .05$) and family hardiness did not significantly predict parental stress (path c' ; $\beta = -.733, p > .05$). Therefore, Hypothesis 2a did not meet the assumptions of mediation outlined above as illustrated in Figure 2 (mediated effect = .029 [CI = -.098 – 0.155]).

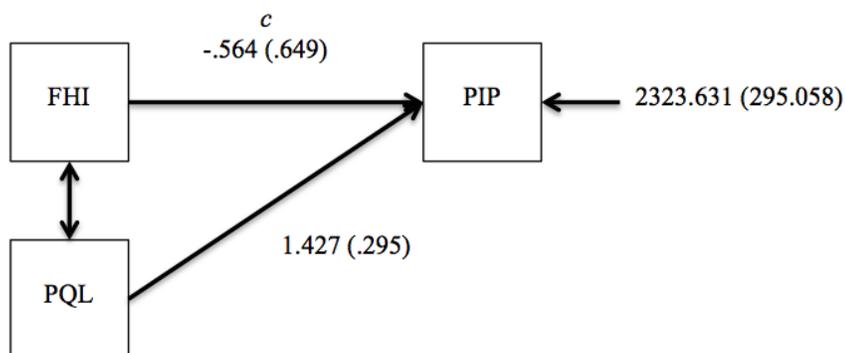


Figure 1. Total Effect of Hardiness on Parental Stress, Accounting for Symptom Severity. Note. FHI = Hardiness; PQL = Symptom Severity; PIP = Parental Stress.

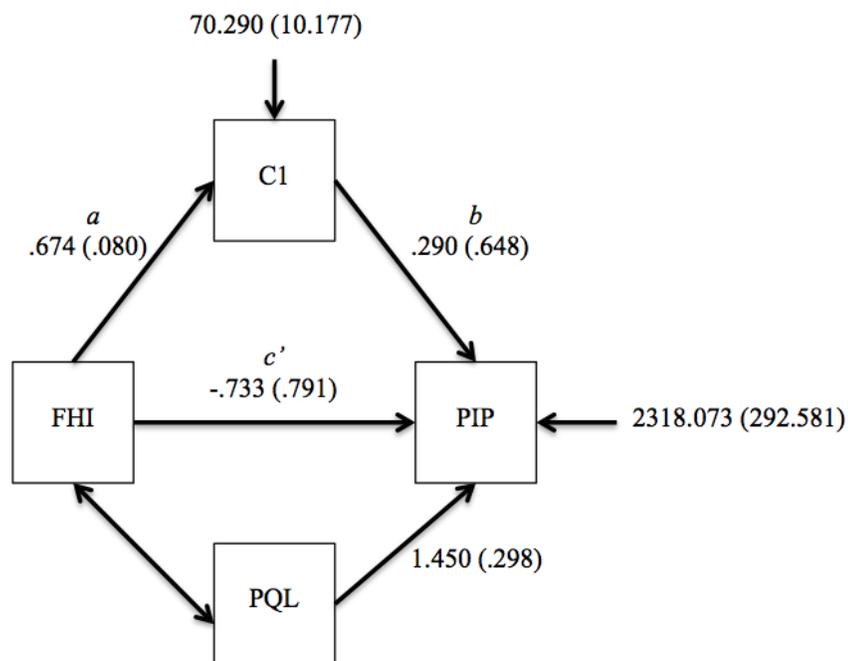


Figure 2. Non-Significant Mediating Effect of Coping I on Family Hardiness and Parental Stress. Note. FHI= Hardiness; PQL = Symptom Severity; C1 = Coping through

maintaining family cohesion, co-operation, and an optimistic definition of the situation; PIP = Parental Stress.

Hypothesis 2b stated that Coping II (coping through maintaining social support and psychological stability) would partially mediate the relationship between hardiness and parental stress when accounting for symptom severity. After adding Coping II, family hardiness did not significantly predict Coping II (path *a*; $\beta = .090, p > .05$), Coping II did not significantly predict parental stress (path *b*; $\beta = -.382, p > .05$), and family hardiness did not significantly predict parental stress (path *c'*; $\beta = -.540, p > .05$). Therefore, Hypothesis 2b did not meet the assumptions of mediation outlined above as illustrated in Figure 3 (mediated effect = $-.005$ [CI = $-.031 - .021$]).

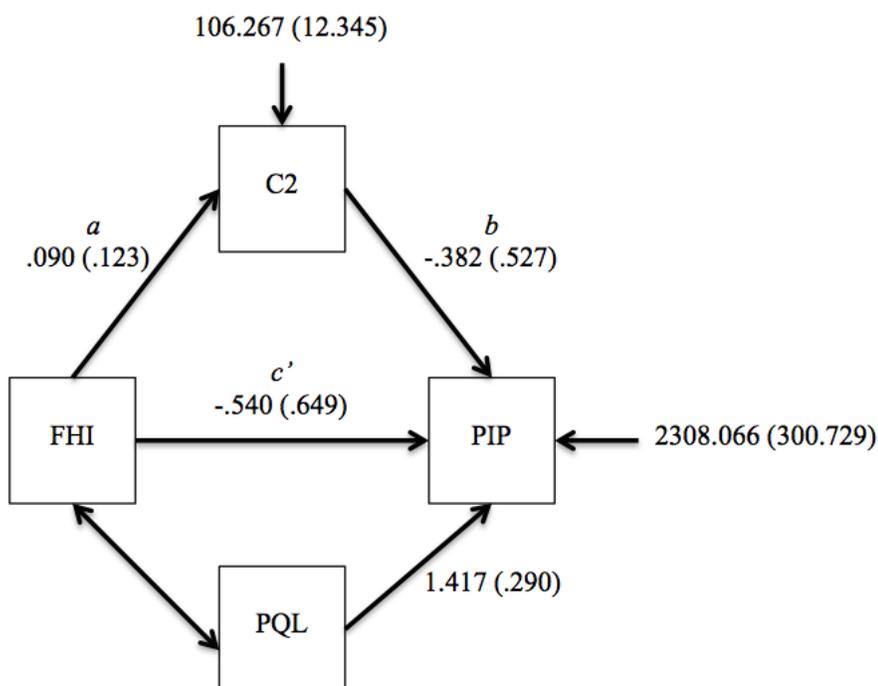


Figure 3. Non-Significant Mediating Effect of Coping II on Family Hardiness and Parental Stress. Note. FHI= Hardiness; PQL = Symptom Severity; C2 = Coping through maintaining social support and psychological stability; PIP = Parental Stress.

Hypothesis 2c stated that Coping III (coping through understanding the medical situation) would partially mediate the relationship between hardiness and parental stress

when accounting for symptom severity. After adding Coping III, family hardiness significantly predicted Coping III (path *a*; $\beta = .150, p < .01$) and Coping III significantly predicted parental stress (path *b*; $\beta = 2.90, p < .01$), but family hardiness did not significantly predict parental stress (path *c'*; $\beta = -.834, p > .05$). Coping III was found to have a significant indirect effect in the relationship between family hardiness and parental stress. However, Hypothesis 2c did not meet the assumptions of mediation outlined above as illustrated in Figure 4 (mediated effect = .062 [CI = .005 - .120]).

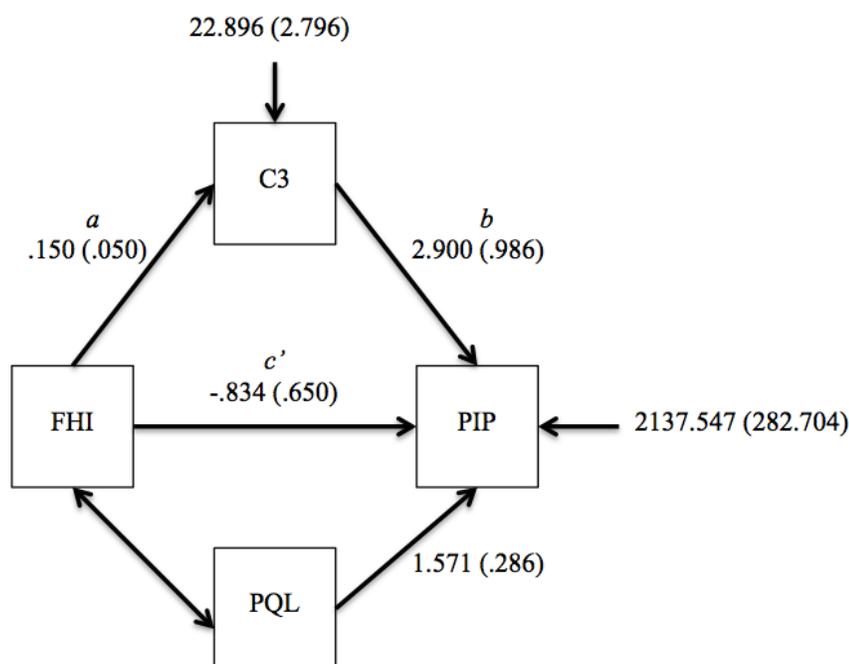


Figure 4. Significant Indirect Effect of Coping III on Family Hardiness and Parental Stress. Note. FHI= Hardiness; PQL = Symptom Severity; C3 = Coping through understanding the medical situation; PIP = Parental Stress.

Hypothesis 3

Hypothesis 3 stated that effective coping (Coping I; Coping II; and Coping III) in a parallel mediation model would partially mediate the relationship between hardiness and parental stress when accounting for symptom severity. After the addition of Coping I,

Coping II, and Coping III, family hardiness significantly predicted Coping I (path *a*; $\beta = .674, p < .001$), family hardiness significantly predicted Coping III (path *c*; $\beta = .150, p < .01$), and Coping III significantly predicted parental stress (path *f*; $\beta = 4.021, p < .001$). However, the other relationships were not found to be significant. Family hardiness did not significantly predict Coping II (path *b*; $\beta = .090, p < .05$), Coping I did not significantly predict parental stress (path *d*; $\beta = -.461, p < .05$), Coping II did not significantly predict parental stress (path *e*; $\beta = -.814, p < .05$), and family hardiness did not significantly predict parental stress (path *g*; $\beta = -.619, p < .05$). Therefore, Hypothesis 3 did not meet the assumptions of mediation outlined above as illustrated in Figure 5 (mediated effect C1 = $-.044$ [CI = $-.211 - .124$]; mediated effect C2 = $-.010$ [CI = $-.048 - .027$]; mediated effect C3 = $.085$ [CI = $.014 - .155$]).

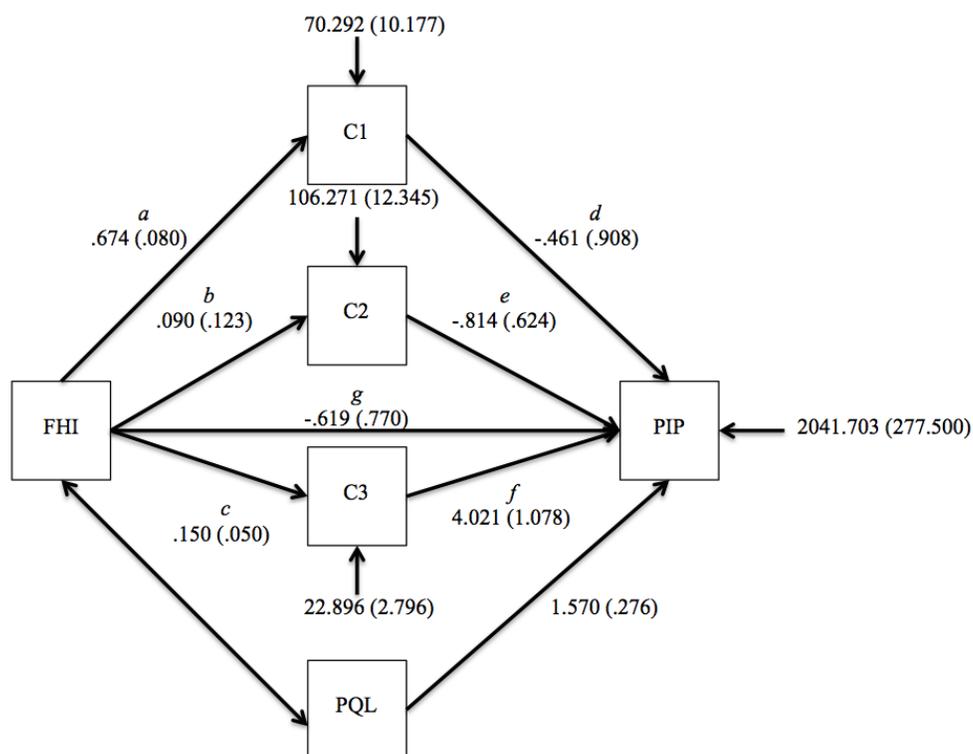


Figure 5. Non-Significant Parallel Mediating Effect of Effective Coping (Coping I, II, and III) on Family Hardiness and Parental Stress. Note. FHI= Hardiness; PQL = Symptom Severity; C1 = Coping through maintaining family cohesion, co-operation, and an optimistic definition of the situation; C2 = Coping through maintaining social support and psychological stability; C3 = Coping through understanding the medical situation; PIP = Parental Stress.

CHAPTER IV

DISCUSSION

The purpose of this study was to examine the relationships among family hardiness, effective coping, and parental stress in a sample of parents with children in active cancer treatment between the ages of two and 18. The current study found that family hardiness is related to increases in understanding the medical situation through communication with other parents and consultation with the medical staff, which in turn, leads to increases in parental stress. Symptom severity was also found to have a significant positive relationship with parental stress.

Hypothesis 1

The aim of the first hypothesis was to determine the unique influence of family hardiness, Coping I (maintaining family integration, cooperation, and an optimistic definition of the situation), Coping II (maintaining social support, self-esteem and psychological stability) and Coping III (understanding the medical situation through communication with other parents and consultation with the medical staff) on parental stress when accounting for symptom severity in our sample of parents with children in active cancer treatment. The combination of symptom severity, the three subscales of effective coping, and family hardiness was significantly related to parental stress, with approximately 37.9% of the variance in parental stress accounted for by these variables. However, these potential positive constructs were not related to parental stress over and above symptom severity. Therefore, Hypothesis 1 was not supported in the current study.

The current study found that hardiness and effective coping were no more of a predictor of parental stress, and less important to the outcome than symptom severity.

While symptom severity has been identified as a potential predictor of parental stress (Kieckhefer et al., 2009), the current study hoped to identify predictors associated with less stress in this population. Previous research has noted the positive effect of family hardiness on psychological wellbeing in mothers of children with other chronic conditions such as intellectual disabilities (Ben-Zur et al., 2005), developmental disabilities (Failla & Jones, 1991), physical disabilities (Hung et al., 2004), fibromyalgia (Preece & Sandberg, 2005), and autism (Neil, 2001). Family hardiness and positive coping skills have been associated with fewer stress symptoms in related populations (Ben-Zur et al., 2005; Failla & Jones, 1991), but had not been examined in relation to parents of children with cancer. The only available research that has looked at family hardiness and coping, operationalized as problem-focused coping, emotion-based coping, and avoidance-based coping, also did not find hardiness to be more of a predictor of parental stress than coping, and less important than parent education and symptom severity (Bigalke, 2010).

Symptom severity has been documented as a factor that positively impacts parental stress (Goldbeck, 2006; Kieckhefer et al., 2009). In a study on 89 newly diagnosed children in Taiwan and their caregivers, significant symptom severity (measured using the PedsQL) was reported in children and a significantly negative quality of life and greater parental stress was reported by their caregivers when comparing the experimental group to the control group (no chronic illness, typical development) during the first 6 months since diagnosis (Tsai et al., 2012). However, after starting chemotherapy, significant decreases in parenting stress and improvement in symptom severity were reported within the first 6 months, although still not at a level

comparable with the control group (Tsai et al., 2012). In the current study, it may be that parents did use coping and other tools effectively upon first diagnosis of their child; however, they may not be utilizing many of the resources more recently since it has been several years (average of 2.67 in the current study) since the child's original diagnosis. Therefore, they are reporting lower levels of stress and symptom severity since it has been several years (average of 2.67 years in the current study) since the child's original diagnosis.

In a study on symptom severity (discussed as quality of life in the article) of families with a child diagnosed with cancer, 47 mothers, 16 fathers, and 19 children completed measures about their own psychological functioning as well as measures about the child's symptom severity specifically related to cancer (Roddenberry & Renk, 2007). The author's found that increased symptoms of depression, anxiety, and parenting stress in mothers were related significantly to their own increased rating of their child's symptom severity. The authors note that the mothers in their study were reporting minimal levels of depression and mild levels of anxiety but that there may be a trend toward a negative relationship between mothers' symptoms and their ratings of symptom severity. The authors conclude that even mothers who are experiencing low levels of psychological symptoms may report significantly increased ratings of the symptom severity that their child is experiencing once diagnosed with cancer. However, the authors discussed that a third variable could also account for this relationship such as mother's experiencing an increase in their psychological symptoms due to noticing a decrease in quality of life in their child in response to the diagnosis and treatment of cancer. Fathers were also found to have a significant relationship between their anxiety and their ratings

of their child's symptom severity. The authors indicate that they likely found fewer significant results regarding father's characteristics and the child's symptom severity due to the low number of father's participating in the study. The authors indicate that as the child is farther along in their treatment of cancer and beginning to experience less severity of symptoms, mothers may begin to make different judgments about the symptom severity that their child is experiencing. (Roddenberry & Renk, 2007).

These findings indicate that the parent's psychological characteristics may play a role in their report of the child's symptom severity (Roddenberry & Renk, 2007). Due to the current study's finding that symptom severity was more of a predictor of parental stress than the other variables being examined and that the parent's report of their child's symptom severity was significantly less than in previous studies, it is important to note that other variables, such as psychological symptoms, may be playing a role in parental stress but were not accounted for in the current study.

Upon further investigation of the relationships between these variables, several correlations were found that are important to note. The current study found that family hardiness and the two coping subscales related to family cohesion, an optimistic view of the situation, using social support, and having psychological wellbeing had a significant negative relationship to parental stress. This finding is consistent with previous studies assessing relationships among hardiness and coping related to parental stress (Ben-Zur et al., 2005; Failla & Jones, 1991; Hoekstra-Weebers et al., 1998). When faced with life stressors, hardy families rely on a sense of efficacy and tend to actively approach challenges (Kobasa et al., 1982; Maddi et al., 2006). For hardy families, the inherent challenges of childrearing may be viewed as a way to gain personal development and to

make meaning out of life. Also inherent to the definition of family hardiness is the presence of an external challenge or stressor, such as a child being diagnosed with cancer. Upon experiencing an external stressor such as this, the hardy family activates coping strategies (Kerns, 1995; Lazarus, 1966; Patterson, 1988). However, little is known about how long these strategies are utilized or needed. As parents of children diagnosed with cancer have reported parenting to be more stressful (Hung et al., 2004), an increase in perceived parental stress may lead to activation or increased use of hardy traits and coping strategies. However, over the course of two or more years (with the average time since diagnosis for the current study being approximately 2.67 years), this hardy disposition may have resulted in a decreased parental perception of symptom severity in their child diagnosed with cancer. It may be that family hardiness and certain forms of effective coping may be more important when a child is first diagnosed with cancer and that as time goes on, the parent may have adjusted to the symptoms and treatment of cancer.

Similarly, a good prognosis may alleviate some of the initial stress felt by parents of children upon initial diagnosis. It may be that when a child is given a positive prognosis from the medical staff, that the parent's perception of symptom severity may decrease or that coping strategies may not be utilized as often. The current study consisted of mostly children with a positive prognosis (59% of the children had a greater than 75% chance of survival).

Hypothesis 2

The aim of the second hypothesis was to evaluate whether each subscale of effective coping would individually be a partial mediator of the relationship between

family hardiness and parental stress when accounting for symptoms severity in our sample of parents with children in active cancer treatment.

Hypothesis 2a and 2b

Hypothesis 2a stated that Coping I (maintaining family integration, cooperation, and an optimistic definition of the situation) would be a partial mediator in the relationship between family hardiness and parental stress when accounting for symptom severity. However, after the addition of Coping I, Hypothesis 2a did not meet the assumptions of mediation and was not supported in the current study. Similarly, Hypothesis 2b stated that Coping II (maintaining social support, self-esteem and psychological stability) would be a partial mediator in the relationship between family hardiness and parental stress when accounting for symptom severity. However, after the addition of Coping II, Hypothesis 2b did not meet the assumptions of mediation and was not supported in the current study.

Although testing effective coping as a mediator in the relationship between hardiness and parental stress has not been attempted previously, these hypotheses were based on the FAAR model (Patterson, 1988) which stated that the way a family appraises (family hardiness) a crisis event (a child being diagnosed with cancer) may be impacted by the way the family effectively manages the crisis (coping), which influences the stress experienced by the family (Patterson, 1988). Previous research has identified coping as a potential moderator and mediator to stress (Kerns, 1995; Patterson, 1988) and has suggested that effective coping strategies play an important role in decreasing parental stress (Lazarus & Folkman, 1984; Patterson, 1988). Research based on several theories related to coping including physiological, psychological, and sociological models of

stress have noted the positive effects of maintaining family integration, cooperation, an optimistic view of the situation, social support, self-esteem, and psychological stability (McCubbin et al., 1983). However, the current study did not find that maintaining family integration, cooperation, and an optimistic definition of the situation or maintaining social support, self-esteem and psychological stability partially mediated the relationship between hardiness and stress.

There are several considerations for these findings. The available research regarding coping for parents of children diagnosed with cancer is still expanding. There are many different ways to conceptualize coping, such as: problem-focused vs. avoidance-based coping (Lazarus & Folkman, 1984), effective coping through maintaining family integration, social support, and psychological wellbeing (McCubbin et al., 1983), engagement vs. disengagement coping (Aldridge & Roesch, 2007), and problem- vs. emotion-focused coping (Lazarus & Folkman, 1984; Aldridge & Roesch, 2007). Although suggestions from Bigalke (2010) hypothesized that better results may be found if utilizing coping assessments created for parents of children diagnosed with chronic illness, such as the CHIP; it may be that the items utilized to assess effective coping in this population, even with utilization of the CHIP, may have not completely captured the most important ways that families deal with a child diagnosed with cancer. This finding could also relate to the previous discussion points regarding the elapsed time since the child's original diagnosis. Thus, parents are not currently utilizing some of these strategies, but may have used them upon first diagnosis. However it may be that, due to the child's symptom severity being significantly less than previous research, less active coping was needed for these parents.

Hypothesis 2c

Hypothesis 2c stated that Coping III (understanding the medical situation through communication with other parents and consultation with the medical staff) would be a partial mediator in the relationship between family hardiness and parental stress when accounting for symptom severity. After the addition of Coping III, a significant indirect effect was observed. When Coping III was added to the family hardiness-to-parental stress model, the path from family hardiness to parental stress continued to be non-significant. However, within this indirect effect, path *a* and path *b* were found to be significant, suggesting that Coping III was found to have a significant indirect relationship between family hardiness and parental stress. In other words, rather than impacting parental stress directly, family hardiness affects parental stress through increases in Coping III. That is, family hardiness is related to increases in understanding the medical situation through communication with other parents and consultation with the medical staff, which in turn, leads to increases in parental stress.

The construct of hardiness used in the current study was defined by the family's internal strengths and resiliency, was related to a sense of control over the event, and was associated with finding meaning in life (McCubbin et al., 1988). Family hardiness was found to be positively significantly correlated with Coping III. It may be explained that individuals with a sense of control over the stressful event may utilize this sense of control to reach out to the medical staff and other parents for information and support. Delleve and colleagues stated that parental empowerment, defined as individuals gaining control over their lives, may be necessary for achieving support from health providers (Delleve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006). For example, in a sample of

parents of children with Cystic Fibrosis, understanding the medical situation through communication with other parents and consultation with the medical staff was found to be associated with family organization and family control (McCubbin et al., 1983).

Knowledge of the medical situation, social support, and communicating with medical staff have been negatively associated with parental stress and are considered important factors when a family is coping with a child diagnosed with cancer (Canam, 1993; Dellve et al., 2006). In a study on mothers of children with rare disease, the authors found that perceived parental incompetence regarding the child's condition negatively influenced well-being and caregiving in the family. However, after the parents participated in a program that developed parental competence and empowerment, the parents reported increased knowledge of the condition and increased use of active coping (Dellve et al., 2006). The author's concluded that increased parental knowledge and active coping may lead to better use of resources in the family, social network, and wider society (Dellve, et al., 2006). Based on the available information, research supports the current study's finding that family hardiness is related to increased understanding of the medical situation.

Communicating with others is an important form of social support. The literature on parenting a child with chronic illness consistently refers to the importance of social support (Canam, 1993; Judge, 1998; Maddi et al., 2006, McCubbin et al., 2002). Social support has been associated with positive psychological well-being in families of children with cerebral palsy (Sipal, Schuengel, Voorman, Van Eck, & Becher, 2010), autism (Tehee, Honan, & Hevey, 2009), child spinal surgery (Salisbury, LaMontagne, Hepworth, & Cohen, 2007), and other rare diseases (Dellve et al., 2005). In 128 parents

of pediatric cancer patients, Hoekstra-Weebers and colleagues (2001) investigated the perceived levels of support and psychological functioning at diagnosis, 6, and 12 months. Findings revealed that support mobilization was highest at the time of diagnosis and self-perceived quantity of support decreased throughout the study. Dissatisfaction with support was associated with higher levels of psychological distress (Hoekstra-Weebers et al., 2001). Kupst and Schulman (1988) also observed a positive association between social support and parental adjustment in families of children with cancer. Therefore, the research on social support supports the current study's finding that family hardiness is related to increased understanding of the medical situation through communication with other parents and consultation with the medical staff.

In the current study, although family hardiness was found to be related to increased use of coping by understanding the medical situation through communication with other parents and consultation with the medical staff; it was also found that use of this type of coping was found to be related to increases in parental stress. In the current study, Coping III was specifically about understanding the medical situation through other parents of children in cancer treatment, instead of the general idea of seeking social support from others. It may be that gaining information from other parents could increase parental stress, due to hearing about the difficulties of another family going through a similar process. Another explanation could be that if these parents gain information from other parents of children diagnosed with cancer that is dissimilar from information provided by the medical staff, this differing information can be confusing and increase the stress of the parents (Goldbeck, 2006).

The finding, that Coping III may relate to increases in parental stress, may be explained by the idea that although understanding the medical situation may decrease stress in the long-term, gaining a better understanding of the potential symptoms, side effects, and procedures for treating cancer may lead to an initial increase in parental stress. However, as Abidin (1992) and Lazarus and Folkman (1984) noted, sometimes parental stress can be considered a motivator to prompt parents to utilize available resources and engage in specific parenting behavior. It may be that parents in the current study were able to utilize the increased level of parental stress to motivate themselves to seek information and knowledge about their child's condition. It is also important to consider that the parents in the current sample were reporting less symptom severity in their children than in previous, similar samples (Bigalke, 2010; Huang et al., 2009). Perhaps, because the child's symptoms were not as severe, the parents in the current study were able to use parental stress as a motivator instead of an inhibition to functioning.

As the current study found the importance of coping through communication with the medical staff, this finding speaks to the importance for medical personnel to consider their role in the family's coping processes and perception of stress. It may be that families able to mobilize resources early after their child is diagnosed with cancer may continue to seek support and resources from the medical staff and other families of children diagnosed with cancer even when other resources and support decrease with time. Woznick and Goodheart (2002) found that parents of children diagnosed with cancer often find support through medical staff and other families. Similarly, Hoekstra-Weebers and colleagues (2001) reported that parent-perceived quantity of social support decreased

even six and 12 months post-diagnosis. It may be that the other effective coping strategies assessed in the current study may be more helpful upon first diagnosis; however, communication with other parents and consultation with medical staff may be an enduring resource for these families, particularly when other resources are depleted or unavailable.

Hypothesis 3

The aim of the third hypothesis was to evaluate a parallel mediation model to see if effective coping, incorporating the three subscales into one model (Coping I, Coping II, and Coping III), would partially mediate the relationship between family hardiness and parental stress when accounting for symptom severity. However, after the addition of all three subscales of effective coping into the model, Hypothesis 3 did not meet the assumption of mediation and was not supported in the current study.

Similar to the potential explanations discussed above, this finding may be partially explained by previous research that noted that hardy individuals may appraise fewer events as stressful and have more resources to cope effectively with the stressors that arise (Eschleman, Bowling, & Alarcon, 2010). This may explain why the current study did not find the model of effective coping to be a significant mediator in the relationship between family hardiness and parental stress. In other words, it may be that the initial crisis has already passed for these hardy families, they may have already utilized additional resources, and may not be currently mobilizing additional resources. It may also indicate that other forms of coping, potentially through religious or spiritual beliefs or humor, which were not currently assessed, may be important after the initial crisis of a child diagnosed with cancer has passed.

Limitations

Several limitations of the current study should be considered. The sample in the current study included mostly upper-middle income, married, Caucasian mothers, whose children are undergoing outpatient chemotherapy for the first time. Caution should be taken in generalizing results to fathers, and low income or ethnically diverse families as research has suggested that gender, cultural factors, and income levels may impact stress levels (Hoekstra-Weebers et al., 1998; Owens & Shaw, 2003). Also, the current sample represents a wide variability of types of cancer and treatment success rates including families with a child in inpatient treatment, as well as the majority of families with a child considered to have a high prognosis participating in outpatient treatment. Such variability makes interpretation and generalizability more complicated. Similarly, caution should be taken in generalization of the current study's results to families whose children have recently been diagnosed with cancer. Many of the respondents in the current study have a child who was diagnosed an average of 2.67 years ago, which may influence responding or the families reactions to the variables of study.

Additionally, because of protecting confidentiality, the researcher cannot speculate about third variables that may have influenced an organizations decision to inform parents about the current research as well as variables that may have influenced an individual's decision to participate. Given that the families in the current study were reporting significantly less symptom severity than in previous samples, self-selection bias may have played a role in participants' decision to respond to the survey. For example, parents experiencing less symptom severity of their child may have had more time to complete the survey than parents with children experiencing more significant symptoms.

The participants self-selected to participate in the current study and, therefore, may not be representative of the population of parents of children with cancer.

Similarly, we are not able to determine specific information about the participants that completed the survey through MTurk by Amazon.com, which may have increased access to individuals outside of the United States, who may have different access to care.

Areas for Future Research

The current study found a significant relationship between symptom severity and stress, which is similar to previous literature (Goldbeck, 2006). However, as more severe forms of cancer often have more severe symptoms and prognosis, this finding should be further investigated.

While hardiness was associated with parental stress, it was not found to be a significant, unique predictor of parental stress when accounting for symptom severity. Further research is warranted to better understand how family hardiness influences the population of parents of children diagnosed with cancer both in replicating the current study and using different measures of hardiness. As this study was one of the first to investigate hardiness in parents of children in active cancer treatment, more evidence of the role hardiness plays in families in the current population and similar populations is important.

Previous findings that utilized the Brief-COPE to investigate the use of problem-focused, emotion-focused, and avoidance-based coping in mothers of children diagnosed with cancer did not find support for those constructs (Bigalke, 2010). Therefore, the current study utilized literature suggesting the use of the CHIP to measure family coping specific to families with a child diagnosed with a chronic illness, and continued to not

find strong support for these constructs (Alderfer et al., 2008; McCubbin, et al., 1983).

Due to these findings, more research is still needed in understanding ways that families of children diagnosed with cancer are coping.

Previous research had suggested that the length of time since diagnosis (Kupst et al., 1995; Steele et al., 2003) may contribute to the stress experienced by parents.

Although the current study did not find a significant relationship between the time since diagnosis and parental stress, it may be that hardiness and coping are most relevant earlier rather than later in treatment. In research regarding hardiness in military troops, findings suggest that hardiness is susceptible to depletion over time (Vogt, Rizvi, Shipherd, & Resick, 2008), it may be that programs related to increasing parent's coping skills may be particularly useful in establishing a "hardy" mindset for families when their child has been diagnosed with cancer. Future studies should examine this hypothesis using a longitudinal design or examining the utilization of hardiness following a recent diagnosis.

Due to the current study's population being predominately white, middle class, and with an intact family, future research may explore how the current variables of study may be impacted in a more diverse sample. Bigalke (2010) found that parent education significantly related to parenting stress in a population of mothers of children diagnosed with cancer. Future research implications were discussed, and it was noted that individuals with certain health disparities, such as less education, have been found to experience more stress and that this could potentially influence the way they are treated by medical staff, as well as the parents ability to obtain information about the child's illness. Although the current study did not find a significant relationship between parental

education and parental stress, more information is needed about how health disparities may influence the current studies findings.

The current study was only able to attain participation from 31 fathers. Previous research has suggested that getting father participation is more difficult, which may be due to that fact that mother's tend to be present during most of the doctor's appointments and cancer treatments (Dellve et al., 2006; Roddenberry & Renk, 2007). Currently, it is unclear the extent to which mothers and fathers experience stress differently (Vrijmoet - Wiersma et al., 2008). Future research should continue to explore potential gender differences in the way mothers and fathers effectively cope when their child has been diagnosed with cancer should be considered.

Future researchers may examine the differences in prognosis of the child between families. The current study included families of children with differing chances of survival. Families of children with good prognoses or almost finished with treatment may have minimized the influence of families of children struggling for survival. Future researchers may also want to limit the participant sample to families who have a child recently diagnosed, in order to learn more about the potential impact of time since diagnosis.

Conclusions

The purpose of the current study was to examine the relationship among coping, family hardiness, and reported levels of parental stress in a sample of parents of children in active cancer treatment. Although researchers have examined the variables in different contexts, this is one of the first studies to evaluate all of these variables in a sample of parents of children in active cancer treatment. Findings revealed that effective coping and

family hardiness did not reach statistical significance in the prediction of parental stress over and above that accounted for by symptom severity. The current study also found a significant indirect effect of Coping III (understanding the medical situation through communication with other parents and consultation with the medical staff) in the relationship between family hardiness and parental stress.

Symptom severity was found to have an enduring impact on parental stress. This finding could be explained due to the current study's sample that consisted of children with significantly less symptom severity, diagnosed an average of 2.67 years ago, with a higher chance of survival (59% of the children had a greater than 75% chance of survival), and that coping, as measured in the current study, was not an essential task at that time. It could also be explained that symptom severity may be the most influential factor in determining how people will navigate the stress of a child diagnosed with cancer. Future researchers and clinicians may want to further investigate the significance of symptom severity, potential gender differences in the use of effective coping strategies, family hardiness as it relates to parents of children in active cancer treatment, and the most adaptive ways that families are coping with a child in active cancer treatment.

Number of adults living in the home: _____

The person completing this form is:

_____ Mother _____ Father _____ Other (please specify): _____

I am the child's primary caregiver: YES NO

Please select **one child** who is above the age of 2 and in active cancer treatment. This child will be the "focus child" for this study. Please refer to this child when completing the rest of the forms.

CHILD Date of Birth: _____

CHILD Gender: _____ Boy _____ Girl

Child is being treated for:

- _____ Acute Lymphoblastic Leukemia
 _____ Acute Myelogenous Leukemia
 _____ Neuroblastoma
 _____ Osteosarcoma
 _____ Ewings Sarcoma
 _____ Rhabdomyosarcoma
 _____ Hodgkin disease
 _____ Non-Hodgkin Lymphoma
 _____ Hepatoblastoma
 _____ Wilms tumor
 _____ Clear Cell Sarcoma
 _____ Germ Cell Tumors
 _____ Other, if so, please name and describe:

Child's first diagnosis: Month: _____ Year: _____

If applicable, what is child's stage of cancer? I II III IV

If applicable, what is child's stage of active cancer treatment? Induction
 Consolidation
 Maintenance Unknown

Is this the first treatment? YES or RELAPSE

Child's treatment includes:

_____ Surgery to remove cancer

Chemotherapy
 Bone marrow transplant
 Radiation
 Alternative Medical Treatment:

 Alternative Non-Medical Treatment:

Has your child been diagnosed with:

Intellectual disability YES NO

Learning disability YES NO

Medical Condition YES NO

If yes, please list:

Psychiatric Condition YES NO

If yes, please list:

Genetic Condition YES NO

If yes, please list:

According to my doctor, my child's prognosis is:

Greater than 75% chance of survival

Between 25 and 75% chance of survival

Less than 25% chance of survival

My child is:

Currently receiving treatment on an inpatient basis YES NO

If yes, estimated length of stay: _____

Currently receiving treatment in a hospice YES NO

My child's condition has limited his/her:

Mobility: YES NO

Opportunity to interact with friends (e.g., play dates, sleep-overs) YES NO

Independently perform self-care routines (e.g., brushing teeth, bathing) YES NO

APPENDIX B
IRB APPROVAL



INSTITUTIONAL REVIEW BOARD

118 College Drive #5147 | Hattiesburg, MS 39406-0001
Phone: 601.266.6820 | Fax: 601.266.4377 | www.usm.edu/irb

NOTICE OF COMMITTEE ACTION

The project has been reviewed by The University of Southern Mississippi Institutional Review Board in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services (45 CFR Part 46), and university guidelines to ensure adherence to the following criteria:

- The risks to subjects are minimized.
- The risks to subjects are reasonable in relation to the anticipated benefits.
- The selection of subjects is equitable.
- Informed consent is adequate and appropriately documented.
- Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
- Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
- Appropriate additional safeguards have been included to protect vulnerable subjects.
- Any unanticipated, serious, or continuing problems encountered regarding risks to subjects must be reported immediately, but not later than 10 days following the event. This should be reported to the IRB Office via the "Adverse Effect Report Form".
- If approved, the maximum period of approval is limited to twelve months.
Projects that exceed this period must submit an application for renewal or continuation.

PROTOCOL NUMBER: **13100203**

PROJECT TITLE: **Coping, Hardiness, and Parental Stress in Parents of Children Diagnosed with Cancer**

PROJECT TYPE: **New Project**

RESEARCHER(S): **Kathryn Bigalke**

COLLEGE/DIVISION: **College of Education and Psychology**

DEPARTMENT: **Psychology**

FUNDING AGENCY/SPONSOR: **N/A**

IRB COMMITTEE ACTION: **Expedited Review Approval**

PERIOD OF APPROVAL: **11/14/2013 to 11/13/2014**

Lawrence A. Hosman, Ph.D.
Institutional Review Board

APPENDIX C
INFORMATION LETTER



My name is Katie Bigalke, and I am a counseling psychology doctoral student at The University of Southern Mississippi. I am requesting the participation of parents of children in active cancer treatment to complete the following study. The purpose of this research is to gain a better understanding of factors that may influence the stress that parents of children with cancer experience.

Please forward this information on so that we can gain the perspectives of as many mothers of children in active cancer treatment as possible. Your privacy is important to us, therefore this study is completely confidential. To gain access to the survey please use the following link:

Any help that you can provide us is greatly appreciated. Thank you so much for your time and patience. Your struggle is my passion and I hope to be able to make a difference in the future. Questions concerning the research should be directed to Katie Bigalke at KLBigalke@gmail.com or Bonnie C. Nicholson, Ph.D. at bonnie.nicholson@usm.edu. This project and this consent form have been reviewed by the Institutional Review Board.

APPENDIX D
INFORMED CONSENT



AUTHORIZATION TO PARTICIPATE IN RESEARCH PROJECT titled:

Hardiness, Coping, and Parental Stress in Parents of Children Diagnosed with Cancer

Purpose: The purpose of this study is to examine current parents' experiences related to their child in active cancer treatment through stress, coping, and hardiness.

Description of Study: Participating individuals will be asked to complete questionnaires related to various ways parents cope with the stress of parenting a chronically ill child. The survey will take an estimated 30 minutes to complete. Participation in this project is completely voluntary.

Benefits to the participant: By investigating the potential factors related to parenting during a child's active cancer treatment, we can gain information that can be used to increase positive family outcomes. Identifying parents who are at an increased risk of parental stress and identifying the factors that potentially decrease the risk of stress can lead to better intervention and prevention in the future. In addition, the information obtained from this research can be used to inform future research endeavors.

Risks: Foreseeable risks associated with the proposed project may include an increase in stress, but it is unlikely that this will be more than would be expected in daily interactions. While participants are encouraged to complete the survey, there is no penalty for withdrawing from this project at any time.

Confidentiality: All efforts will be made to protect participant's privacy and to maintain the confidentiality of the data acquired through this project. Individual participants will not be identified by name. The computerized data will be maintained numerically with no identifying information. Researchers will have access to all data obtained during this study.

Subject's Assurance: Whereas no assurance can be made concerning results that may be obtained (since results from investigational studies cannot be predicted), the researcher

will take every precaution consistent with the best scientific practice. Participation in this project is completely voluntary, and subjects may withdraw from this study at any time without penalty, prejudice, or loss of benefits. Questions concerning the research should be directed to Dr. Bonnie C. Nicholson (bonnie.nicholson@usm.edu). This project and this consent form have been reviewed by the Institutional Review Board, which ensures that research projects involving human subjects follow federal regulations. Any questions or concerns about rights as a research subject should be directed to the Chair of the Institutional Review Board, The University of Southern Mississippi, Box 5147, Hattiesburg, MS 39406, (601) 266-6820.

To participate in the study please click “I agree” below. By clicking “I agree” you are acknowledging that you have been informed of the purpose, benefits, and risks of participating in this study and been given the opportunity to ask questions and have them answered to your satisfaction. By clicking “I Agree”, you are consenting to the participation of this study and stating that you are at least 18 years of age or older. Please make note of the name and phone number of the primary researcher and contact information for the Human Subjects Protection Review Committee and Institutional Review Board at USM. You can withdraw from the study without any negative consequences.

APPENDIX E

IRB RENEWAL

**INSTITUTIONAL REVIEW BOARD**

118 College Drive #5147 | Hattiesburg, MS 39406-0001

Phone: 601.266.5997 | Fax: 601.266.4377 | www.usm.edu/research/institutional.review.board**NOTICE OF COMMITTEE ACTION**

The project has been reviewed by The University of Southern Mississippi Institutional Review Board in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services (45 CFR Part 46), and university guidelines to ensure adherence to the following criteria:

- The risks to subjects are minimized.
- The risks to subjects are reasonable in relation to the anticipated benefits.
- The selection of subjects is equitable.
- Informed consent is adequate and appropriately documented.
- Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
- Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
- Appropriate additional safeguards have been included to protect vulnerable subjects.
- Any unanticipated, serious, or continuing problems encountered regarding risks to subjects must be reported immediately, but not later than 10 days following the event. This should be reported to the IRB Office via the "Adverse Effect Report Form".
- If approved, the maximum period of approval is limited to twelve months.
Projects that exceed this period must submit an application for renewal or continuation.

PROTOCOL NUMBER: CH13100203

PROJECT TITLE: Coping, Hardiness, and Parental Stress in Parents of Children Diagnosed with Cancer

PROJECT TYPE: Change to a Previously Approved Project

RESEARCHER(S): Kathryn Bigalke

COLLEGE/DIVISION: College of Education and Psychology

DEPARTMENT: Psychology

FUNDING AGENCY/SPONSOR: N/A

IRB COMMITTEE ACTION: Expedited Review Approval

PERIOD OF APPROVAL: 11/07/2014 to 11/06/2015

Lawrence A. Hosman, Ph.D.**Institutional Review Board**

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