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The University of Southern Mississippi

# PARENTING A CHRONICALLY ILL CHILD:

# SOCIAL SUPPORT, COPING, FAMILY HARDINESS, AND MATERNAL STRESS

by

Kathryn Lynch Bigalke

A Thesis Submitted to the Graduate School of The University of Southern Mississippi in Partial Fulfillment of the Requirements for the Degree of Master of Arts

Approved:

Bonnie C. Nicholson Director

Emily B. Yowell

Heather Sterling

<u>Susan A. Siltanen</u> Dean of the Graduate School

August 2011

#### ABSTRACT

#### PARENTING A CHRONICALLY ILL CHILD:

#### SOCIAL SUPPORT, COPING, FAMILY HARDINESS, AND MATERNAL STRESS

### Kathryn Lynch Bigalke

### August 2011

Parents of children with cancer experience higher stress than parents of children with other medical conditions or with no developmental concerns (Canam, 1993; Cohen, 1999). Researchers are beginning to explore a number of protective factors that may influence parental stress in parents of children with cancer. Social support (Abidin, 1992), problem-focused coping (Judge, 1998), and family hardiness (Maddi et al., 2006) have been related to lower levels of stress and more positive outcomes in parents of healthy children, but have not been fully explored in the pediatric cancer population. The current study was designed to assess the relationship between parental stress, social support, coping strategies, and family hardiness in mothers of children in active cancer treatment. It was hypothesized that: (a) problem-focused coping and social support would be inversely related to parenting stress and positively correlated with family hardiness, (b) emotion-focused and avoidance-based coping would be positively correlated with parenting stress and inversely related to family hardiness, (c) coping and family hardiness would emerge as significant predictors of parental stress when controlling for symptom severity and social support, and (d) hardiness would moderate the relationship between symptom severity and stress when controlling for social support. Results indicated 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. Future research for this population focusing on fathers, differing prognosis of the child, family hardiness of the current population, and limiting the research to specific types of cancer, treatment, or prognosis may be beneficial.

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#### CHAPTER I

### **REVIEW OF RELATED LITERATURE**

A child diagnosed with a chronic medical condition can cause significant stress to the family (Canam, 1993; Cohen, 1999; Silver, Bauman, & Ireys, 1995). Parents of chronically ill children experience higher levels of stress as they must meet the everyday stressors of parenting in addition to the necessary acceptance and daily management of the child's illness (Canam, 1993; Cohen, 1999).

In 2007, approximately 10,400 families were affected by a child under the age of 15 diagnosed with cancer (Ries et al., 2007). For children, cancer is the leading cause of death by disease among children between 1 to 14 years of age in the United States (Ries et al., 2007). Leukemias and cancers of the brain and central nervous system account for more than half of new diagnosed cases of cancer in children every year. Although survival rates increase every year, the stress of the child at greater risk for infection, bleeding, weakness, fatigue, headaches, possible hair loss or weight gain (depending on the treatment), and delayed developmental progress are part of the treatment process (Hockenberry & Coody, 1986). The severity of the child's symptoms may also account for additional parental stress (Ellis et al., 2008; Power et al., 2003). However, certain personality characteristics and coping strategies can influence the way that parents handle the diagnosis and treatment of a child with a chronic illness (Steele et al., 2003).

Although social support has been associated with lower reported levels of stress in parents of children with cancer (McCubbin, Balling, Possin, Frierdich, & Byrne, 2002), problem-focused coping and family hardiness have not been explored in pediatric cancer populations. Hardiness, a factor commonly associated with resilience, is defined as an individual's belief in the ability to deal with life stress and has been associated with positive outcomes in related populations such as parents of children with asthma (Svavarsdottir & Rayens, 2004) and physical disabilities (Judge, 1988). 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 may also be a potential link between family hardiness and a form of coping called problem-focused coping. An important aspect found to help families deal with the diagnosis of pediatric cancer was the family changing how they viewed and appraised the stressful event. This can be seen as an aspect of both family hardiness and problem-focused coping (McCubbin et al., 2002). Other research has pointed to the higher levels of self-reported psychological well-being with the use of problem-focused coping, and the often negative effects found when individuals use emotion-focused and avoidance-based coping (Judge, 1998). The current study sought to understand the role of social support, coping, and family hardiness in predicting parenting stress in mothers of children in active cancer treatment.

#### Parental Stress

Parenting stress has been defined as an experience in which expectations of the parent do not match the current experience of their role as parents and the interactions they experience with their children (Abidin, 1992; Goldstein, 1995). This often evokes a compensatory response. Low socioeconomic status (Burbach, Fox, & Nicholson, 2004), lack of child routines (Koblinsky, Kuvalanka, & Randolph, 2006), and being a mother (Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2005) have been found to be related to higher levels of parenting stress. Parenting stress has been associated with hostile

parenting and corporal punishment (Deater-Deckard & Scarr, 1996) and is related to a higher incidence of behavior problems in children (Nicholson, Fox, & Johnson, 2005).

Parenting a child with chronic illness is particularly stressful (Canam, 1993; Cohen, 1999). In fact, total parenting stress scores for the parents of children with cancer were more than one standard deviation higher than for the parents of children with a physical disability (d = 1.09; Hung, Wu, & Yeh, 2004). Parents face many challenges in managing a child's illness, such as accepting the illness, day-to-day management of illness, meeting the developmental needs of the child and the rest of the family, dealing with ongoing strain and crisis due to the illness, assisting with the coping of the rest of the family, educating others about the illness, and making and keeping a strong support system (Canam, 1993). In addition to the chronic stressors associated with parenting a child diagnosed with cancer, acute parental stress appears to occur during cancer treatment (Noll et al., 1995). The increased time demands, medical expenses, employment constrictions, childcare difficulties, along with physical, emotional, developmental, behavioral, social, and cognitive concerns related to the disease increase the stress a parent experiences (Clay, 2004; Moore et al., 2003; Morris et al., 2003). The child's age at the time of diagnosis and symptom severity both appear to impact the amount of stress reported (Goldbeck, 2006).

Increased knowledge about the disease and higher levels of social support have been negatively related to parenting stress in families of children diagnosed with chronic illness (Canam, 1993; Dellve et al., 2005). Few studies have examined the positive factors that may reduce maternal stress, especially in mothers of children with cancer. Factors such as social support, coping, and hardiness will be explored further. The purpose of this study was to examine the relationship between social support, coping, and family hardiness as possible predictors of lower levels of parental stress.

# Social Support

Research emphasizes the importance of social support for mothers of children diagnosed with cancer. As the mother often has a strong identification with the child, they are often intimately involved in the cancer experiences of their children (Woznick & Goodheart, 2002). Although mothers with children in treatment rarely take time for themselves and often feel guilt for neglecting the other family members, household obligations, and careers (Woznick & Goodheart, 2002), they are often able to find support through medical staff, other families, and friends (Woznick & Goodheart, 2002).

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 defined in many different ways, but the focus of social support has stemmed from the idea of a prospective network of available individuals often identified as friends and family members (Moxley, 1988). 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).

Only three available studies were found that examined the pediatric cancer population specifically. Findings suggested that parents of children diagnosed with cancer who reported low social support were more likely to report symptoms of depression and anxiety than parents of physically healthy controls (Speechley & Noh, 1992). 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.

Although the importance of social support is emphasized, little empirical research can be found. Further research is warranted to empirically investigate the significance of social support in mothers with children in active cancer treatment in order to continue to find ways to help this population. The current study hoped to add to the literature by exploring social support as a predictor of stress in families experiencing pediatric cancer.

### Coping

Coping has been defined as an effort to manage stress both cognitively and behaviorally. Although the literature discusses many different ways in which families cope with stressors including spirituality and hope, three main coping strategies consistently emerge: problem-focused (or task-oriented), emotion-focused, and avoidance-based coping (Sharkansky et al., 2000; Nayback, 2009). Judge (1998) defined problem-focused coping as managing stress through direct action. 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 focused on alleviating the emotional consequences of the stressor often through blame or fantasy (Sharkansky et al., 2000). 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). Emotion-focused coping has been related to negative family outcomes such as parental depression and child behavior problems (Judge, 1998; Neil, 2001). Avoidance-based coping is focused on either avoiding thoughts associated with the stressor or attempting to control the effects of the stressor (trying to control something that is seemingly uncontrollable) (Nayback, 2009; Sharkansky et al., 2009). Avoidance-based coping is associated with depressive symptoms, risk for distress, and has also been found to be used more often in parents of children with chronic illness and disability. Avoidance-based coping has been related to negative family outcomes (Neil, 2001).

Emotion-focused coping and avoidance-based coping are generally found to be negative coping skills, while problem-focused coping is a positive coping skill (Judge, 1998). Although families of children with autism experience a different diagnosis than families of children with cancer, one study linking the three main forms of coping is worth noting. Studies of parents of children with autism have found a relationship between depression and emotion-focused and avoidance-based coping, and a negative relationship between parental stress and problem-focused coping (Aldwin & Revenson, 1987). Pottie and Ingram (2008) also found a relationship between positive daily mood and problem-focused coping and daily negative mood and avoidance- and emotion-based coping.

Only two studies were found that examined coping as it relates to the current study and in relation to parenting children with cancer. Greening and Stoppelbein (2007) assessed depression, PTSD, anxiety, and coping style in 150 parents. Lower levels of parental depression, PTSD, and anxiety were observed as a function of using problem appraisal (similar to problem-focused coping) and social support more frequently. Higher levels of symptoms were observed as a function of using avoidant coping (e.g. substance use), and other emotional regulation strategies (e.g. negative self-blame). In another study by Hoekstra-Weebers and colleagues (1998), 124 parents of pediatric cancer patients selfreported psychological distress and coping styles. Mothers used more social-support seeking and less problem-focused coping compared to fathers, and both groups used the same amount of emotion-focused coping. In this study, problem-focused coping was related to less distress than emotion-focused coping.

The research in coping varies greatly in the terminology used to describe the different categories and ways to cope. This is evident by the interchangeable use of terms such as "problem-focused" and "task-oriented," both referring to the same coping style. The current study examined coping in the three broad categories of problem-focused coping, emotion-focused coping, and avoidance-based coping. Research supports that many of the specific coping styles (e.g., religious coping, the use of drugs and alcohol to cope, and problem-solving) can be subsumed under these three categories (Cosway, Endler, Sadler, & Deary, 2007). The current study was able to further explore the experience of mother's parenting stress in relation to social support, family hardiness, and coping, using the three broad categories.

#### Family Hardiness

Family hardiness is defined as the internal strength of a family in dealing with stressful circumstances (Maddi et al., 2006; McCubbin et al., 1988). A family high in

hardiness is characterized by an internal sense of control over life events, a sense of meaning in life, and a commitment to learn from challenging experiences. Purpose and control allow a family to approach life stressors (McCubbin et al., 1988). The main components of family hardiness are commitment, control, and challenge. Commitment refers to a person's motivation to turn to their family, friends, and community to seek support. Commitment allows a family to actively confront the event and not become passive or avoidant (Maddi, et al., 2006; McCubbin et al., 1998, 2002). Control enhances resistance of stress through a family's confidence of having influence and power in events and outcomes, and this feeling of influence and control comes through imagination, skill, knowledge, and choice (Maddi et al., 2006; McCubbin et al., 1988, McCubbin et al., 2002). Challenge allows a family to feel as though unexpected events are a part of life and that change brings growth, thus allowing individuals to grow and readjust rather than becoming rigid and resistant to change (Maddi et al., 2006; McCubbin et al., 1988). When the three elements of commitment, control, and challenge come together, one can formulate life's meaning and the importance of the future without regard to anxiety about uncertainty and can lead to the most beneficial life (Maddi, 2002).

Kobasa and associates (1982) suggested that individuals who remain mentally and physically healthy after experiencing high levels of stress have personality characteristics that may protect them from those who become mentally and physically ill. Hardiness has been negatively associated with stress and positively associated with problem solving and perceived family support (Maddi et al., 2006) and evidence suggests that hardiness may function to lessen the potentially negative effects of life stress (Kobasa et al., 1982). There is a link between hardiness and positive life events. In a sample of 58 healthy families, severity and number of illnesses within the family was positively related to stress. Adult hardiness was negatively associated with number of reported illnesses in the family and a significant correlation was observed between adult hardiness and positive life events (Bigbee, 1992). Hardiness may serve to moderate the relationship between stress and negative life events within families and may have a direct effect as well as a buffering effect in the relationship between stress and illness, particularly with negative events.

There is no published study to date that has investigated family hardiness in parents of children with cancer. Judge (1998) assessed family hardiness and coping in 69 parents of children with physical disabilities, which may extend to families of children with chronic illness. Judge (1998) found that coping strategies accounted for a significant portion of the variance in the hardiness characteristic of challenge. Seeking social support was the strongest factor in challenge strength. Coping strategies accounted for a significant portion of the variance in the hardiness characteristic of commitment and control. The results also suggest that emotion-focused coping and avoidance-based coping were negatively associated with characteristics of hardiness, while problemfocused coping was positively associated with characteristics of hardiness (Judge, 1998). The current study sought to replicate these findings in a sample of parents of children with canceras well as identify additional predictors including social support and coping.

Ben-Zur and colleagues (2005) studied the association between social support and family hardiness in sample of 100 mothers of adult children with intellectual disabilities. Parental mental health was found to be positively associated with social support and family hardiness, and parental stress was negatively associated with mental health, family hardiness, and social support with family hardiness accounting for the most variance in parental mental health (Ben-Zur et al., 2005).

Family hardiness and social support have also been associated with positively coping with pain in families with a member diagnosed with fibromyalgia (Preece & Sandberg, 2005), positive coping in divorced families (Greeff & Van der Merwe, 2004), and protective factors in families of children with special needs (Failla & Jones, 1991). Failla and Jones (1991) examined the relationship between family hardiness and family stressors, family appraisal, coping, social support, and satisfaction with family functioning in a sample of 57 mothers who had a developmentally disabled child. A significant portion of the variance ( $R^2 = .42$ ) in satisfaction with family functioning was accounted for by family hardiness, total functional support, family stressors, and age of the parent. Higher levels of family hardiness were associated with coping behaviors that strengthen family relationships (Failla & Jones, 1991).

There is a paucity of research evaluating family hardiness in families dealing with a child with chronic illness. For example, in one study of 137 families of children with asthma, Svavarsdottir and Rayens (2004) found that higher levels of sense of coherence, lower levels of depression, and higher reported levels of positive well-being led to higher ratings of family hardiness, as measured by the Family Hardiness Index (FHI; McCubbin, McCubbin, & Thompson, 1987). Similar findings were found 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). Only one study related to family hardiness and childhood cancer was found. McCubbin and colleagues (2002) conducted a qualitative study and interviewed 42 parents of children treated for cancer within the past three years to identify factors that helped the families recover from the diagnosis of cancer. The identified factors were internal family rapid mobilization and reorganization; social support from the healthcare team, extended family, community, and workplace; and changes in appraisals to make the situation more comprehensive, manageable, and meaningful. These factors were reported to have helped families manage the diagnosis and treatment phase for the child's cancer.

The factors identified in the McCubbin et al. (2002) study above provide the rationale for the current study and are related to the variables of interest. Specifically, rapid mobilization and reorganization were characterized as, "specific internal family strengths" (p. 105) and may be operationalized as the commitment component of family hardiness (McCubbin et al., 2002). Similar to other research, McCubbin and colleagues (2002) identified social support as the second supportive factor and as much, social support was investigated in the current study. Finally, McCubbin and colleagues (2002) identified "changes in family appraisal" (p. 108) which can be seen as the aspect of challenge in family hardiness and also problem-focused coping. Both family hardiness and coping will be explored in the current study.

Family hardiness has been associated with positive outcomes and linked to social support and coping in other populations. There are few studies examining the relationship between hardiness and stress, which suggests that additional research is needed in these areas.

#### Purpose of the Study

Coping and social support have both been found to be important factors to parents in dealing with the stress associated with childhood chronic illness (Canam, 1993; Judge, 1998). There has been limited research on families of children with cancer despite cancer being described as a particularly stressful chronic illness. Family hardiness has been associated with positive outcomes in healthy families (Bigbee, 1992) and families of chronically ill children (McCubbin et al., 2002) but not researched in families of children diagnosed with cancer. Because previous research suggesting symptom severity and social support can affect mothers' parenting stress (Canam, 1993; Ellis et al., 2008; Goldbeck, 2006; Judge, 1998; Power et al., 2003), both symptom severity and social support will be included in the proposed study. The purpose of the current study was to examine the relationships among parental stress, social support, coping, and family hardiness in mothers of children in active cancer treatment.

#### **Research Questions**

- 1. What are the relationships among coping, family hardiness, and social support in mothers of children with cancer?
- 2. Do coping and hardiness account for a significant amount of variance in predicting maternal stress beyond variance accounted for by support and symptom severity?
- 3. Does hardiness moderate the relationship between symptom severity and stress when controlling for social support?

# CHAPTER II

# METHOLOGY

### Participants

Survey instruments were posted online, and approximately 800 individuals viewed the online survey link. Two hundred sixty-nine participants began completing the survey, with 176 participants completing the entire survey. Thirty-six participants were excluded due to the focus child's age not meeting criteria for the current study; five mothers were excluded due to not being the primary caregiver; three fathers were excluded; six participants were excluded due to other diagnoses that could confound the results (e.g., Downs Syndrome, Autism, Asperger's, Evan's syndrome); and one outlier was identified when testing for standardized residuals. Upon further investigation, the outlier significantly impacted results and was removed from the dataset.

The final sample, then, included 125 mothers of children in active treatment between the ages four to 18 years. Demographic characteristics are presented in Table 1. Participants' selected focus child's gender was 60.8% male, and the child's average age at first diagnosis was 7.09 years with a range of zero to 17 years. The sample was predominantly Caucasian/White (88.0%) and had a mean age of 39.92 years. Approximately two-thirds of participants were college graduates or had attended college or a professional school. The majority were married or living with a partner and had an income exceeding \$50,000.

The majority of respondents (42.4%) had a child diagnosed with Acute Lymphoblastic Leukemia. Participants were equally distributed across cancer stages, and the majority of respondents identified the focus child as being in the maintenance stage of treatment (53.6%). Ninety-six participants reported that this was the first diagnosis and treatment of the focus child (76.8%). One hundred nineteen participants reported the focus child to be in chemotherapy (95.2%), with sixty-six participants (52.8%) reporting the child's prognosis to be greater than a 75% chance of survival. One-hundred participants (80%) 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 (76.8%). A complete demographic description of the sample is available in Table 1.

## Table 1

#### Demographic Characteristics of the Sample

Characteristic (Range)	М	SD
Parent age (28 - 56)	39.92	5.48
Parent education in years (10 - 17)	10.30	1.66
No. children in household (0 - 7)	2.36	1.12
Focus child age at diagnosis $(0 - 17)$	7.09	4.16
	N	%
Child Sex		
Male	76	60.8
Female	49	39.2
Marital status (current)		
Never married or Living alone	1	.8
Never married or Living with someone	5	4.0
Married	106	84.8
Divorced or Separated	13	10.4
Parent race/ethnicity		
African American	3	2.4

Table 1 (continued).

-	N	%
Caucasian	110	88.0
Hispanic	7	5.6
Asian	2	1.6
Other	3	2.4
Income		
Less than \$10,000	6	4.8
\$10,000 - \$20,000	5	4.0
\$20,000 - \$30,000	4	3.2
\$30,000 - \$40,000	12	9.6
\$40,000 - \$50,000	10	8.0
\$50,000+	88	70.4
	N	%
Child's Cancer Diagnosis		
Acute Lymphoblastic Leukemia	53	42.4
Acute Myelogenous Leukemia	1	.8
Neuroblastoma	12	9.6
Osteosarcoma	8	6.4
Ewings Sarcoma	6	4.8
Rhabdomyosarcoma	3	2.4
Hodgkin disease	2	1.6
Non-Hodgkin Lymphoma	5	4.0
Wilms tumor	3	2.4
Germ Cell Tumors	3	2.4
Medulloblastoma	6	4.8
Brain Tumor (unspecified)	4	3.2
Other	19	15.2
Child's Stage of Cancer (when applicable)		
Ι	9	7.2

Table 1 (continued).

	N	%
П	12	9.6
III	17	13.6
IV	23	18.4
Child's Stage of Treatment (when applicable)		
Induction	5	4.0
Consolidation	10	8.0
Maintenance	67	53.6
Unknown	25	20.0
Relapse of Cancer		
First treatment	96	76.8
Relapse	29	23.2
Child's treatment		
Surgery to remove cancer	55	44.0
Chemotherapy	119	95.2
Bone marrow transplant	16	12.8
Radiation	56	44.8
Alternative Medical Treatment	18	14.4
Non-medical Treatment	5	4.0
Other diagnoses		
Intellectual	6	4.8
Genetic	5	4.0
Medical	38	30.4
Psychiatric	10	8.0
Learning	14	11.2
Child's Prognosis		
Greater than 75% chance of survival	66	52.8
Between 25 and 75% chance of survival	38	30.4
Less than 25% chance of survival	21	16.8

Table 1 (continued).

	Ν	%
Child's Location		
Inpatient	25	20.0
Outpatient	100	80.0
Hospice	6	4.8
Limitations due to condition		
Mobility	78	62.4
Interacting with friends	96	76.8
Performance in self-care routines	49	39.2

#### Measures

Participants completed a general demographic survey. Questions included the mother's age, age and gender of the focus child, ethnicity, education, marital status, annual income, and number of children and adults living in the home. The demographic survey also included questions about the child's diagnosis, age at diagnosis, relapses, multiple diagnoses, treatment, and prognosis (see Appendix D).

Pediatric Quality of Life Inventory – Cancer Module (PedsQL; Varni et al., 2002)

Symptom severity was assessed using *The PedsQL – Cancer Module*, a 27-item, selfreport 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*. Total scores can range from 0 - 108. Higher scores indicate higher symptom severity. The total PedsQL – Cancer Module score was used as a control variable. In the current sample, the Cronbach's alpha coefficient was .922.

Originally, the *PedsQL Cancer Module* was administered to 339 families including 220 child self-reports and 337 parent proxy-reports. Internal consistency of .87 was

reported for the parent report using the *PedsQL Cancer Module*. Clinical validity was also reported in the ability to distinguish between groups of children with and without cancer (Eiser, Vance, Horne, Glaser, & Galvin, 2003).

Parental Stress Scale (PSS; Berry & Jones, 1995)

The PSS is an 18-item, self-report scale used to assess the total level of parental stress. Parents rated their answers on a Likert scale from (1) *Strongly Agree* to (5) *Strongly Disagree*. Items were reverse scored, and then all items were totaled. Total scores can range from 18 – 90. Higher scores indicate higher levels of stress. In the current sample, the Cronbach's alpha coefficient was .848.

Internal consistency of .83 and test-retest reliability of .81 were reported for the total scale in a group of 125 parents with at least one child under the age of 18 living at home (Berry & Jones, 1995). In comparing control parents and children with emotional and/or behavioral problems, the PSS was found to significantly differentiate between mothers of children who were receiving treatment for behavioral problems as compared to mothers of children who were not in treatment (t(165) = 4.29, p<.01). Additional data supporting the validity of the PSS were found in mothers of children with developmental disabilities (e.g., mental retardation, cerebral palsy) who were receiving special education services. In comparing these mothers to mothers of typically developing children, the mothers of children with developmental disabilities were found to have increased parental stress compared to the non-clinical group (t(161) = 2.03, p < .05). These findings are consistent with the Parenting Stress Index (PSI; Abidin, 1995) on parents of children with disabilities. In a sample of parents of children without special needs, correlations between the PSS and PSI were found to be .75, p < .01. Correlations have also been

reported between the PSS and the Revised UCLA Loneliness Scale; State Anxiety Scale; the Marital Satisfaction and Commitment Scale; Job Diagnostic Survey; Guilt Inventory; and the Social Support Scale (Berry & Jones, 1995). The PSS has been used to investigate caregiver stress in grandparents raising grandchildren (Gerard, Landry-Meyer, & Roe, 2006), in evaluation of parent training interventions (Griffin, Guerin, Sharry, & Drumm, 2010), and in parents of first time juvenile offenders (Caldwell, Horne, Davidson, and Quinn, 2007).

#### *The Brief-COPE* (*Brief-COPE*; *Carver*, 1997)

Participants completed a 28-item self-report measure that assesses coping style. Principal components factor analysis by Greening and Stoppelbein (2007) resulted in the following six subscales: negative self-blame/affect, social support/advice seeking, active coping, religious coping/optimism, avoidant coping, and substance use. These subscales have been further combined to form three composite scales which reflect three coping styles: problem-focused (including the active coping and religious coping/optimism subscales), emotion-focused (including the negative self-blame/affect subscales), and avoidant coping (including the avoidant coping and substance use subscales). Items are rated on a Likert scale from (1) *I haven't been using this at all* to (4) *I've been doing this a lot* (Carver, 1997). Scores are totaled for each of the composites and can range from 9 to 36 (Emotion-focused and Avoidant composites) and 10 to 40 (Problem-focused composite). Higher scores indicate higher use of that coping style. In the current sample, Cronbach's alpha coefficients were .78 (problem-focused coping), .76 (emotion-focused coping), and .77 (avoidance-based coping). In a sample of 150 parents of children with cancer, Cronbach's alpha was reported as at least moderate for the six subscales (.78 to .85), except for the avoidant factor,  $\alpha = .59$  (Greening & Stoppelbein, 2007). In a sample of 168 community residents affected by Hurricane Andrew, Cronbach's alpha was reported: self-distraction (.71), active coping (.68), denial (.54), substance abuse (.90), use of emotional support (.71), use of instrumental support (.64), behavioral disengagement (.65), venting (.50), positive reframing (.64), planning (.73), humor (.73), acceptance (.57), religion (.82), and self-blame (.69) (Carver, 1997).

Similar grouping was reported in measuring validity and reliability of the Brief-COPE in caregivers of people with dementia (Cooper, Katona, & Livingston, 2008). In reporting test-retest reliability in caregivers of people with dementia, scores on the three composite subscales of problem-focused, emotion-focused, and dysfunctional (or avoidant) coping did not change significantly (r = .72, r = .58, r = .68; p < .001) (Cooper et al., 2008). Internal consistency was also reported for problem-focused, emotion-focused, and dysfunctional subscales ( $\alpha = .84$ ,  $\alpha = .72$ ,  $\alpha = .75$ ) (Cooper et al., 2008).

Validity was reported in measuring validity and reliability of the Brief-COPE in women diagnosed with breast cancer undergoing chemotherapy (Yusoff, Low, & Yip, 2009). Discriminant validity was found in observing different coping strategies between two groups of women: women with mastectomy and women with lumpectomy (Yusoff et al., 2009). The strategies of Active coping (p < 0.01), Planning (p < 0.01), and Acceptance (p < 0.05) were able to be differentiated between the two groups. Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet & Farley, 1988)

Participants completed the 12-item MSPSS self-report measure designed to assess one's perception of social support and adequacy of support. Each item asks the participant to rate their agreement with the statements provided on a 7-point Likert-type scale, (1) *Very Strongly Disagree* to (7) *Very Strongly Agree*. Summing the items yields a total quantitative measure of perceived social support with possible scores ranging from 12 to 84. Higher scores are indicative of more perceived social support. In the current sample, the Cronbach's alpha coefficient was .958.

The scale was developed by administering 24 items being considered for the MSPSS and the Hopkins Symptom Checklist (HSCL; Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974), which is a symptom checklist to 275 undergraduate university students. The symptom checklist was used to assess depression and anxiety as the literature reveals a strong inverse relationship between these factors with social support. Items that did not clearly address perceived social support were omitted and 12 items remained. Three separate dimensions of social support emerged, confirming the subscale groupings. Cronbach's alpha for each subscale as well as for the total scale are as follows: Significant Other, .91, Family, .87, and Friend, .85, and total scale, .88. The MSPSS has also been used to access pregnant women, adolescents living abroad with family, and pediatric residents (Zimet et al., 1990); however, has not been used in research with parents of children with cancer.

The MSPSS was found to be strongly correlated with the Social Support Behaviors scale and showed little correlation to social desirability (Kazarian & McCabe, 1991). Construct validity was also reported after analysis of an inverse correlation with depression (r = -.25) (Kazarian & McCabe, 1991).

Family Hardiness Index (FHI; McCubbin, McCubbin, & Thompson, 1987)

Participants completed a 20-item, self-report scale assessing the family's internal strengths when dealing with difficult circumstances. Participants rated their answers on a Likert scale from (0) *False* to (3) *True*. Nine items are reverse scored and all items were totaled and scores can range from a possible 0 - 60. Higher scores indicate higher family hardiness. For the current study, the Cronbach's alpha was .802.

The FHI was normed on a sample of 304 families and has been used to access families experiencing a variety of life stressors (McCubbin et al., 1987). Internal consistency was found with a Cronbach's alpha of .82. 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). As the literature is limited, the FHI has not been used to measure family hardiness with parents of chronically ill children.

#### Procedure

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

Participants were recruited through various methods, including e-mail, postings on online support groups and listserves, 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 135 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. 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.

Surveys were developed through PsychSurveys, a secure online service provider (www.psychsurveys.org). Privacy was ensured so that obtained data were accessible by the researcher with a secure password. The online survey included an informed consent (Appendix B) and the demographic form (Appendix D), followed by computerized random order of the following measures: the PedsQL-Cancer Module, PSS, MSPSS, Brief-COPE, and FHI. Total time to complete the measures was approximately 15 to 30 minutes. Parents were informed of a \$1 donation to pediatric cancer research for participation in the survey. Human subjects approval was maintained throughout the study.

#### **Research Questions and Hypotheses**

1. What are the relationships among coping, family hardiness, and social support in mothers of children with cancer?

- a. Problem-focused coping and social support will be inversely related to parenting stress and positively correlated with family hardiness. Emotionfocused and avoidance-based coping will be positively correlated with parenting stress and inversely related to family hardiness.
- 2. Do coping and hardiness account for a significant amount of variance in predicting parent stress beyond variance accounted for by symptom severity and social support?
  - a. Problem-focused coping and family hardiness will emerge as significant, unique predictors of parenting stress beyond that accounted for by symptom severity and social support.
- 3. Does hardiness moderate the relationship between symptom severity and stress when controlling for social support?
  - a. Hardiness will moderate the relationship between symptom severity and stress when controlling for social support.

#### CHAPTER III

#### RESULTS

Means, standard deviations, and other descriptive information for each measure are presented in Table 2. Overall, scores on the PedsQL were within a standard deviation of those means reported in similar populations (Huang et al., 2009). For the current sample, the average parenting stress score, as measured by the PSS total score, was more than a standard deviation higher than in previous research (Berry & Jones, 1995). Participants reported coping scores that were more than one standard deviation higher than those reported in similar research studies (Cooper et al., 2008). Scores on the FHI were within a standard deviation of those means reported in similar research on mothers of children with cardiac conditions (McCubbinet al., 1986). Overall, scores on the MSPSS were within a standard deviation of those means reported in similar populations (Bruwer et al., 2007; Cicero et al., 2009).

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 parenting stress criterion. These included marital status (married =

1; not married = 0) and parent ethnicity (Caucasian = 0; all other races were recoded to equal 1). Next, a series of bivariate correlations were computed between demographic variables (i.e., parent age, parent ethnicity, parent education, marital status, income, number of children in the home, child gender, the type of cancer diagnosis, child's age at diagnosis, child's stage of cancer, child's stage of treatment, relapse, child's prognosis, treatment setting of the child [inpatient, outpatient, hospice], child's mobility, ability to interact with friends, and child's self-care) and the parenting stress criterion. The child's limited ability to independently perform self-care routines (r = -.223) and parent education (r = -.196) were significantly negatively related to the criterion such that parents with children with limited mobility and parents with less education reported more parenting stress. These two variables were controlled for in subsequent regression analyses.

## Hypothesis 1

The first hypothesis, that problem-focused coping and social support will be inversely related to parenting stress and positively correlated with family hardiness and that emotion-focused and avoidance-based coping will be positively correlated with parenting stress and inversely related to family hardiness, was examined using a series of bivariate correlations (see Table 2). Scores from the MSPSS, each of the three composites for the Brief-COPE (problem-focused, emotion-focused, and avoidancebased), the FHI, and the PSS, were entered into a bivariate correlation.

Results indicated that social support was significantly correlated with problemfocused coping, emotion-focused coping, and family hardiness. Problem-focused coping was significantly correlated with emotion-focused coping. Emotion-focused coping was significantly correlated with family hardiness. Avoidance-based coping was significantly and negatively correlated with family hardiness and parenting stress, such that increases in mothers' use of avoidance-based coping (e.g., behavioral disengagement, denial, selfdistraction, self-blame, substance use, and venting) were related to lower levels of hardiness as well as lower levels of parenting stress. Family hardiness was positively correlated with parenting stress, social support and emotion-focused coping and negatively correlated with avoidance-based coping. Therefore, only partial support for the hypothesis was found. Family hardiness was not found to be positively correlated with problem-focused coping. Parenting stress was not found to be negatively correlated with social support and problem-focused coping. Emotion-focused was not found to be inversely related to family hardiness. Emotion-focused and avoidant-based coping were not found to be positively correlated with parenting stress.

Table 2

Variable	M(SD)	1	2	3	4	5	6
1. MSPSS	63.05( <i>19.7</i> <i>I</i> )	1	.25**	.31**	09	.37**	.049
2. Brief-COPE – Problem-Focused	17.28(3.85)		1	.51**	.10	.17	.07
3. Brief-COPE – Emotion-Focused	26.34(5.61)			1	15	.397**	.10
4. Brief-COPE – Avoidance-Based	21.06(5.54)				1	41**	23**
5. FHI	42.08(7.88)					1	.22*

Means, Standard Deviations, and Correlation Coefficients for Study Measures

Table 2 (continued).

Variable	M(SD)	1	2	3	4	5	6
6. PSS	69.62(9.65)						1

*Note.* MSPSS = Multidimensional Scale of Perceived Social Support; FHI = Family Hardiness Index; PSS = Parenting Stress Scale; \*p < .05, \*\* p < .01.

# Hypothesis 2

To test the second hypothesis, that problem-focused coping and family hardiness would emerge as significant, unique predictors of parenting stress beyond that accounted for by symptom severity and social support, scores from the two demographic variables (child's limited ability to independently perform self-care (limited independence) and parent education), PedsQL and MSPSS scores were entered into the first step of a linear multiple regression. The first step, limited independence, parent education, PedsQL and MSPSS, explained 9.9% of the variance in parenting stress and was found to be significant (see Table 3). Scores from each of the Brief-COPE composites (problemfocused, emotion-focused, and avoidance-based) and the FHI were entered as individual predictors in the second step. The total parenting stress score, PSS, was measured as the criterion in a hierarchical multiple regression. The hierarchical multiple regression revealed that the total model explained 13.4% of the variance in the parenting stress criterion  $(R^2 = .134, F(8, 116) = 2.240, p < .05)$ , with none of the coping or family hardiness variables emerging as significant predictors of parenting stress over and above the variability accounted for by symptom severity and social support. There was not a significant change in  $R^2$  at step 2, therefore, the hypothesis was not supported. Coping and family hardiness did not predict parenting stress over and above that accounted for by symptom severity and social support.

Table 3

Summary of Hierarchical Multiple Regression

β	$R^2$	$\Delta R^2$
	.099*	
212*		
182*		
.079		
093		
	.134*	.035
.100		
015		
128		
.104		
	212* 182* .079 093 .100 015 128	.099* 212* 182* .079 093 .134* .100 015 128

*Note.* MSPSS = Multidimensional Scale of Perceived Social Support; FHI = Family Hardiness Index; PSS = Parenting Stress Scale; PedsQL = Pediatric Quality of Life Inventory – Cancer Module.

 $^*p < .05$ 

# Hypothesis 3

Hierarchical multiple regression was used to explore the hypothesis that family hardiness, as measured by the FHI, moderated the relationship between symptom severity, as measured by the PedsQL Cancer Module, and parenting stress, as measured by the PSS, when controlling for social support (MSPSS). Scores on the FHI and PedsQL were centered based on recommendations by Frazier, Tix, and Barron (2004) before the product terms of the PedsQL (predictor) and FHI (moderator) scores were calculated. A moderated multiple regression was performed with child's limited ability to perform self-care independently (limited independence), parent education, and social support (MSPSS) entered in the first step. PedsQL and FHI total scores were entered in the second step and were found to account for 11.6% of the variability in parenting stress when controlling for social support and with no significant change in  $R^2$  (see Table 4). The interaction term was entered in the third step. Note that a significant  $R^2$  change at step three is indicative of a significant moderation effect (Frazier et al., 2004). The change at the third step was not significant ( $\Delta R^2 = .008$ , p = .303; B = .006, p = .303), indicating that the effects of hardiness on parenting stress are consistent across levels of symptom severity. Therefore, the third hypothesis was not supported as family hardiness was not found to moderate the relationship between symptom severity and parenting stress (see Table 4).

Table 4

Summary of Moderated Multiple Regression for Symptom Severity and Hardiness Predicting Parenting Stress

	β	$R^2$	$\Delta R^2$
Step 1		.091*	
Parent Education	210*		
Limited Independence	206*		
MSPSS	.079		
Step 2 (Main Effects)		.116*	.025
FHI	.156		
PedsQL	044		
	В	$R^2$	$\Delta R^2$
Step 3 (Interaction)		.124*	.008

	В	$R^2$	$\Delta R^2$	
FHI X PedsQL	.006 <sup>a</sup>			

Note. MSPSS = Multidimensional Scale of Perceived Social Support; FHI = Family Hardiness Index; PSS = Parenting Stress Scale;

PedsQL = Pediatric Quality of Life Inventory – Cancer Module.

\**p* < .05

Note. Beta-weights reported for control variables and main effects.

<sup>a</sup>Unstandardized regression coefficient reported for the interaction.

#### CHAPTER IV

## DISCUSSION

The purpose of the current study was to examine the relationships among parental stress, social support, coping, and family hardiness in mothers of children in active cancer treatment.

It was hypothesized that: (a) problem-focused coping and social support would be inversely related to parenting stress and positively correlated with family hardiness, (b) emotion-focused and avoidance-based coping would be positively correlated with parenting stress and inversely related to family hardiness, (c) coping and family hardiness would emerge as significant predictors of parental stress when controlling for symptom severity and social support, and (d) hardiness would moderate the relationship between symptom severity and stress when controlling for social support. Results indicated that, although social support was positively correlated with family hardiness, the combination of coping and family hardiness variables did not significantly predict parenting stress over and above significant demographic variables (parent education and child's limited independence in self-care techniques), symptom severity, and social support. The current study did not find evidence that hardiness moderates the effects of symptom severity on parenting stress.

## Hypothesis 1

Hypothesis one predicted that problem-focused coping and social support would be inversely related to parenting stress and positively correlated with family hardiness. The first hypothesis also stated that emotion-focused and avoidance-based coping would be positively correlated with parenting stress and inversely related to family hardiness. As predicted, social support was positively correlated with family hardiness. This is consistent with previous studies finding a link between hardiness and social support (McCubbin et al., 2002).

Interestingly, problem-focused coping was not found to be related to parenting stress or family hardiness in the current sample. This is inconsistent with literature noting the positive effects of problem-focused coping (Judge, 1998; Pottie & Ingram, 2008) and therefore a surprising finding. It is unclear why this relationship was found in the current study. One possibility is that the items used to measure this construct may not have been the type of problem-focused coping typical of parents of this population. For example, it may be difficult to focus on active problem-solving when no action will change the fact that a child has been diagnosed with cancer. After examination of the items found in the composite, the problem-focused composite only included items related to active coping, instrumental support, and planning. Other aspects of problem-focused coping such as how stress is managed, seeking social support, and how negative emotions are handled, do not seem to be adequately considered in the problem-focused composite, but may be related to problem-focused coping and reductions in stress in this population.

Another interesting observation was the finding that emotion-focused coping was positively related to family hardiness. Emotion-focused coping was thought to be associated with negative outcomes because it is thought to be associated with an avoidance of emotion-related coping behavior (i.e., attempting to control emotions rather than looking for ways to solve the problem). The composites for this study were created using the suggestion by Cooper and colleagues (2008). The authors suggested that the Brief-COPE's 14 subscales can be divided into three composites: emotion-focused containing the subscales of acceptance, emotional support, humor, positive reframing, and religion; problem-focused containing active coping, instrumental support, and planning; and dysfunctional coping (avoidance-based) containing behavioral disengagement, denial, self-distraction, self-blame, substance use, and venting (Cooper et al., 2008). Upon further investigation, it appears that the emotion-focused composite explored a different construct than what was proposed in the current study. This finding sheds light on the fact that emotion-focused coping, as conceptualized by Cooper and colleagues (2008), is a positive form of coping and may not fit into the conceptualization of the construct as defined in the current study. Given the nature of the subscales that make-up the composite, this may explain why the proposed hypotheses were only partially supported. It appears that this differing operationalization of emotion-focused coping may explain the current findings.

The finding that avoidance-based coping was negatively correlated with parenting stress was also inconsistent with previous research which found connections between avoidance-based coping and negative outcomes (Nayback, 2009; Sharkansky et al., 2009). In the current study, avoidance-based coping was related to lower levels of parental stress and family hardiness. Items on the avoidance-based composite included: "I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping or shopping," and it would seem intuitive that for parents struggling with the reality of having a chronically sick child, such behaviors may be associated with decreases in overall stress. It seems likely that, in the moment, taking one's mind off of the stress might appear to decrease the experience of stress. However, the long-term consequences of avoidance-based coping in other research have been found

to negatively impact mental health and the ability to successfully manage stressful experiences (Carrico et al., 2006; Neil, 2001; Sharkansky et al., 2009). One study regarding HIV-positive gay males found that with the combination of cognitive behavioral stress management (CBSM) and medication adherence training (MAT) participants reported a greater reliance on avoidance-based coping (particularly, using denial), which was associated with decreased depression at baseline (Carrico et al., 2006). However, the authors concluded that, although avoidance-based coping may have reduced depression in the short-term, they found that reliance on denial may result in a decreased ability to "effectively manage a variety of disease-related stressors in the long term" (Carrico et al., 2006, p. 155). These findings may be similar to the results from the current study in that parents may use various methods (including avoidance) to cope with the stress associated with their child's cancer diagnosis, but long term effects of these techniques are not known.

#### Hypotheses 2 and 3

Hypothesis two predicted that problem-focused coping and family hardiness would emerge as significant, unique predictors of parenting stress beyond that accounted for by symptom severity and social support. The combination of coping, hardiness, parent education, and the child's limited ability to perform self-care was significantly related to parenting stress, with approximately 13.4% of the variance in parenting stress accounted for by these variables. These potential positive constructs did not protect parents from parenting stress over and above social support and symptom severity while controlling for parent education and child's limited independence. Hypothesis three, that hardiness will moderate the effects of symptom severity on parenting stress, was not supported in the current study.

Family hardiness has been found to have a positive effect on psychological wellbeing in mothers of 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). However, research has yet to determine whether hardiness acts as a moderator in these studies based on levels of symptom severity. Given that 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 stressful event, and was associated with finding meaning in life (McCubbin, 1988), several considerations should be taken.

The current study found that hardiness was no more of a predictor of parenting stress than coping, and less important to the outcome than the two demographic variables (parent education and the child's limited independence in performing self-care routines). Previous research has noted that increased knowledge about the disease and higher levels of social support have been negatively related to parenting stress in similar populations (Canam, 1993; Dellve et al., 2005). As the current study found parent education significantly related to parenting stress, it is plausible to think that individuals with less education experience more stress and could potentially be treated differently by hospital staff than parents who can educate themselves to the cancer experience. The current study found that when the child was reported by the mother to have limited independence in performing self-care routines, this factor was also significantly related to parenting stress.

This finding seems plausible, as it seems that parents would experience more stress when responsible for all the daily needs of a child unable to perform self-care independently.

## Limitations

Several limitations of the current study should be considered. The sample in the current study included mostly upper-middle income, married, Caucasian families, whose children are undergoing outpatient chemotherapy for the first time. Caution should be taken in generalizing results to low income or ethnically diverse families as research has suggested that cultural factors and income levels may impact stress levels (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 hospice, 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.

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. 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. However, it is important to note that the parents recruited in the current study were already actively coping by being a part of online support groups and listserves.

Another limitation, as noted above, is the possibility that the Brief COPE composite scales created may not adequately capture the ways in which parents cope with

the stress associated with parenting a child with cancer. Although it would be premature to suggest that problem-focused coping is an ineffective method of coping, rather, the current study may suggest that caution be used when creating these composites for certain populations and certainly when interpreting these findings. Additionally, scores in the current study are difficult to interpret as they are not mutually exclusive. A mother can be utilizing elements of each type of coping as she deals with the stress of a child diagnosed with cancer. In the current study it appears that emotion-focused coping and problem-focused coping are positively, significantly related to each other. This finding also suggests that the operationalization of the emotion-focused coping and differs from the way the current study defined emotion-focused coping and differs from how previous literature had defined this form of coping (Judge, 1998; Sharkansky et al., 2000).

#### Suggestions for Future Research

The findings from the current study demonstrated that problem-focused coping and social support are positively associated with family hardiness. Although this information expands the understanding of hardiness, these findings are a small addition to the literature. While the current study extends the existing parenting literature with a sample of mothers, the current findings cannot necessarily be generalized to fathers. Previous research has found differences in the use of social support and coping when comparing mothers and fathers (Hoekstra-Weebers et al., 1998); therefore, it is unclear whether father's coping and hardiness impact their level of parental stress in the same manner as mothers. Future research on the experience of father's of children diagnosed with cancer would be beneficial. Future researchers may also 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 the families of children struggling for survival. Although the current study did not find a significant relationship between prognosis and stress, previous literature had found a significant relationship between symptom severity and stress (Goldbeck, 2006). As more severe forms of cancer often have more severe symptoms and prognosis, this inconsistent finding should be further investigated.

While hardiness was associated with parenting stress, it was not found to be a significant, unique predictor of parenting stress when accounting for other demographic variables (parent education and child's independence). 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 the first to investigate hardiness in mothers of children in active cancer treatment, more evidence of the role hardiness plays in families in the current population and similar populations is important.

Although previous literature had suggested developing three composite scores (i.e., problem-focused coping, emotion-focused coping, and avoidance-based coping) from the original scales of the Brief-COPE (Cooper, Katona, & Livingston, 2008), results of the current study did not demonstrate support for these constructs. Further investigation at the subscale or item level is warranted to better understand the current findings. Additionally, future researchers may investigate varying ways in which these three coping methods may be differentially operationalized based on the stressor. It seems plausible that one may demonstrate different problem-focused coping behaviors with more tangible problems (e.g., marital conflict) than when coping with more chronic, unsolvable problems (e.g., chronic illness). As such, certain coping behaviors may be more or less adaptive based on the circumstances.

## **Clinical Implications**

Clinicians may focus on improving parents' maintenance of interpersonal relationships to enhance a family's hardiness. Psychoeducation at the family level could facilitate parents' understanding of the child's developmental, psychological, and emotional needs. Additionally, psychoeducation about the child's diagnosis could be especially important for less educated families. Increasing the family's understanding of the child's disease and some of the expectations of what is to come may increase the family's ability to handle the stress in an adaptive way.

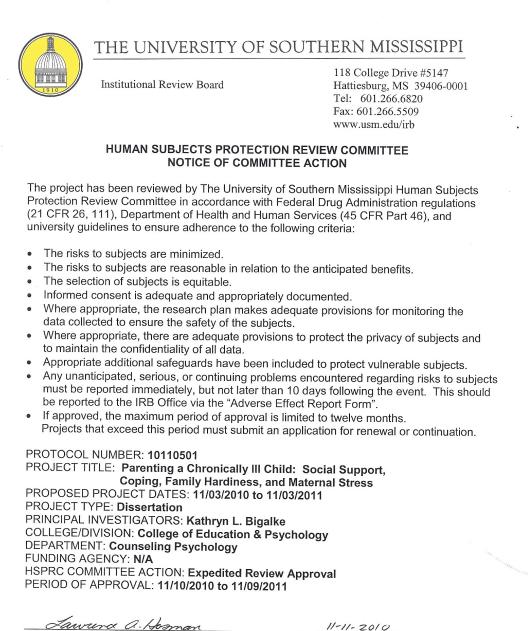
## Conclusions

The purpose of the current study was to examine the relationships among coping, social support, family hardiness, and reported levels of parental stress in a sample of mothers of children in active cancer treatment. Although researchers have examined the variables in different contexts, this is the first study to evaluate all of these variables in a sample of mothers of children in active cancer treatment. Findings revealed higher than average levels of stress, even compared to similar populations, and correlations between social support and family hardiness. Emotion-focused coping was found to be positively related to family hardiness. Avoidance-based coping was negatively related to family hardiness for avoidance-based coping are helpful to families of pediatric

cancer, as well as to further examine the long-term consequences of engaging in avoidance-based coping. Also, future researchers and clinicians may want to continue to examine hardiness, as well as if problem-focused coping should be redefined for this population.

## APPENDIX A

## **IRB APPROVAL**



Lawrence A. Hosman, Ph.D. HSPRC Chair

Date

## APPENDIX B

# PARTICIPANT CONSENT FORM

# THE UNIVERSITY OF SOUTHERN MISSISSIPPI.

# COLLEGE OF EDUCATION AND PSYCHOLOGY

# AUTHORIZATION TO PARTICIPATE IN RESEARCH PROJECT titled: Parenting a Chronically Ill Child: Coping, Social Support, Hardiness, and Maternal Stress

**<u>Purpose</u>**: The purpose of this study is to examine current mothers' experiences related to their child in active cancer treatment through stress, coping, social support, 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 mothers 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. An incentive for participation is a one-dollar donation toward the American Cancer Society for every completed survey.

**<u>Risks</u>:** 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.

<u>**Confidentiality**</u>: 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.

<u>Subject's Assurance</u>: 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 <u>Dr. Bonnie C. Nicholson (bonnie.nicholson@usm.edu)</u>. 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 C

## INFORMATION LETTER



## COLLEGE OF EDUCATION AND PSYCHOLOGY

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 mothers 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. A one-dollar donation will also be donated to St. Jude Children's Research Hospital for the completion of each survey. 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

# FAMILY AND CHILD INFORMATION FORM

The following questions are used to gather information about the types of people participating in this study. Please take a few moments to describe yourself and your family.

YOUR Gender: \_\_\_\_\_ Male \_\_\_\_\_ Female

YOUR Age: \_\_\_\_\_

YOUR Race/Ethnicity:

\_\_\_\_\_African American/Black

\_\_\_\_Caucasian/White

\_\_\_\_\_Hispanic/Latino

\_\_\_\_\_ Native Hawaiian/Pacific Islander

\_\_\_\_\_American Indian/Alaska Native

\_\_\_\_\_Asian

\_\_\_\_Other (specify) \_\_\_\_\_

YOUR number of years of education: (Please circle last grade completed)

6	7	8	9	10	11	12 Gradu		14	15	16	17+
Graduated Graduate/ High School											
College Professional											
										Schoo	1
Marital Status:Never married/living aloneDivorced/Separated Never married/living with someoneWidowed Married											
If divorced, are you the child(ren)'s primary guardian?YesNo If divorced, indicate the number of hours you spend weekly with your child(ren)?											
Annu	al Inco	ome:	\$2	s than \$10 0,000-\$30 0,000-\$50	),000	\$3	80,000-5	640,000			
Number of children living in the home:											
Number of adults living in the home:											

The person completing this form is:

\_\_\_\_\_Mother \_\_\_\_\_Other (please specify):\_\_\_\_\_

I am the child's primary caregiver: YES NO

Please select **one child** who is above the age of 5 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 age at first diagnosis	:							
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 c Chemotherapy	ancer							

\_\_\_\_\_ 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

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