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RESILIENCE AND COPING IN MOTHERS OF
CHILDREN WITH SICKLE CELL DISEASE

by

Holly Carter

A Dissertation
Submitted to the Graduate School,
The College of Nursing and Health Professions
and the School of Leadership and Advanced Nursing Practice
at The University of Southern Mississippi
in Partial Fulfillment of the Requirements
for the Degree of Doctor of Philosophy

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ABSTRACT

Sickle cell disease (SCD) is a prominent chronic illness in the United States. The Centers for Disease Control and Prevention (2016) estimated that one child out of every 365 African-American births will have SCD, affecting approximately 100,000 Americans. Supporting and promoting the integrity of the family and its' members when a child has SCD is important for each family member's well-being. Specific family characteristics, such as resilience and coping are important to understand because they can mitigate stress and create positive family outcomes (Brown et al., 1993; Cousino & Hazen, 2013; Hildenbrand, Barakat, Alderfer, & Marsac, 2015; O'Hanlon, Camic, & Shearer, 2012; Oliver-Carpenter, Barach, Crosby, Valenzuela, & Mitchell, 2011; Windle, 2010). The relationship between resilience and coping is one of great research interest in patients and families living with chronic health conditions. Research on resilience indicates it is a dynamic process that is multidimensional, indicating variation among different populations (Luthar, Cicchetti, & Becker, 2000). The literature review revealed gaps in this research interest involving mothers caring for children with SCD.

The purpose of this study was to examine the variables that may influence coping in mothers caring for a child or children with SCD and to determine if resilience contributes to coping. The resiliency model of family stress, adjustment, and adaptation (McCubbin & McCubbin, 1993) was the theoretical framework of the study. Findings are intended to assist healthcare professionals in supporting resilience interventions to produce positive outcomes. This study utilized a nonexperimental exploratory correlational design to determine variable relationships in the study population. This study was conducted online using Qualtrics. Participants were mothers, over the age of

18, caring for a child or children with SCD. The participants were a representative sample ($N=108$) from regional SCD support group agencies. Data were collected and analyzed from the participants' self-reported responses to the researcher developed demographic questions and two situational variable questions, the Connor-Davidson Resilience Scale (CD-RISC), and the Coping Health Inventory for Parents (CHIP).

Study findings indicate the strong positive relationship between resilience and coping. The mothers' responses to the situational variables, stress level and how sick their child is, were also significant in predicting resilience and coping in the study population. The findings of this study allow the researcher to predict one's coping score based on their resilience score. Interventions implemented by healthcare professionals to increase resilience in the study population can likewise increase coping and overall well-being of the entire family when caring for a child with a chronic illness such as SCD.

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DEDICATION

I dedicate this work to my family. They are the ones who kept me going during the toughest moments while on this journey. First, to my parents who always support me no matter what. Your example means the world to me. To my son, John, who is an amazing young man. You make me want to be a better person every day, and you give me the motivation to keep going. Finally, I want to thank my husband, Adam. You have seen me through this process and so much more. I would not have been able to do this without your constant love and support. Your strength kept me strong and as always, you never let me give up!

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LIST OF ABBREVIATIONS

<i>ANOVA</i>	Analysis of Variance
<i>CDC</i>	Centers For Disease Control and Prevention
<i>CD-RISC</i>	Connor-Davidson Resilience Scale
<i>CD-RISC-25</i>	Connor-Davidson Resilience Scale 25
<i>CF</i>	Cystic Fibrosis
<i>CHIP</i>	Coping Health Inventory for Parents
<i>CINAHL</i>	Cumulative Index of Nursing and Allied Health Literature
<i>SCD</i>	Sickle Cell Disease
<i>VIF</i>	Variance Inflation Factor

CHAPTER I - INTRODUCTION

Supporting and promoting the integrity of the family and its' members when a child has an inherited disorder is important for each family member's well-being. The psychosocial effects of caring for a child with an inherited disorder such as sickle cell disease (SCD), which is chronic and may have acute exacerbations, have a tremendous impact on day-to-day family member functioning. McCubbin (1990) explained stress as any demand that can interrupt a family's function and balance. McCubbin and McCubbin (1993) further describe this stress as a potential threat to a family's vulnerability and may occur when parenting a child with a chronic illness. Stress endured by parents has been associated with negative outcomes for the child as well as the family members (Melnyk, Feinstein, Moldenhouer, & Small, 2001). Specific family characteristics, such as resilience and coping, are important to understand because they can mitigate stress and create positive family outcomes (Brown et al., 1993; Cousino & Hazen, 2013; Hildenbrand et al., 2015; O'Hanlon et al., 2012; Oliver-Carpenter et al., 2011; Windle, 2010).

Resilience is defined conceptually by McCubbin and McCubbin (1993) to include all aspects of the process of positive adaptation to an adverse life event. Within healthcare, social and behavioral scientists have studied resilience to determine its impact on health promotion and overall well-being (Windle, 2010). Resilience has also been studied in parents of critically ill children to evaluate the positive outcomes and coping behaviors that result from the concept of resilience (Ye et al., 2015). McCubbin and McCubbin (1989) described coping as consisting of behaviors that can be active or passive and that sustain a family's balance during times of stress. The relationship

between resilience and coping is one of great research interest in patients and families living with chronic health conditions. Research on resilience revealed it is a dynamic process that is multidimensional, indicating further variation exists among different populations (Luthar et al., 2000).

In one Canadian qualitative study, mothers of African and Caribbean ethnicity who were raising a child with SCD were interviewed to gain a better understanding of the lived experiences of these mothers (Burnes, Antle, Williams, & Cook, 2008). The study discovered that mothers perceived gender and racial bias as an obstacle in coping with and managing the care of a chronically ill child. This study also revealed a theme of “stigma” related to parenting a child with SCD. Further, daily obstacles and stressors can negatively influence the mother’s ability to handle the daily responsibilities of caring for a child with SCD. Successful coping is pivotal in family functioning, and the avoidance of unnecessary stress and anxiety (Barbarin, Whitten, Bond, & Conner-Warren, 1999). Others also reported specifically that maternal well-being is directly correlated to the well-being of the child with SCD (Barbarin et al., 1999; Thompson et al., 1994).

Demographic and situational effects on resilience and coping are of important consideration in this study. A cross-sectional survey study on the effects of maternal behaviors on children with SCD included age, income, education, and employment as factors to consider when measuring maternal behavior and predicting positive outcomes (Jenerette & Valrie, 2010). Another study examined demographics in mothers of children with SCD and cystic fibrosis to determine their effect on maternal adjustment to parenting a child with a chronic illness (Thompson et al., 1994). Variables included in this study were the child’s gender and age, illness severity (a type of SCD), maternal age,

number of children living in the home, maternal education, marital status, and socioeconomic status (Thompson et al., 1994). However, the literature suggests further research is necessary to uncover daily coping obstacles in this specific population, as well as discover characteristics that promote overall well-being in mothers of children with SCD. For this reason, supporting and promoting resilience and coping in mothers of children with SCD is of importance to nurses who are advocating for the mother and child adjusting to the stressors of living with SCD.

Past studies of chronically ill children recognized the important role mothers have in maintaining family coping and mitigating stress (Brown et al., 1993; Burnes et al., 2008; Jenerette & Valrie, 2010; Thompson et al., 1993). Receiving a diagnosis that one's child has an inherited disorder that results in chronic illness can overwhelm a mother. Helping mothers cope with this diagnosis and its' resultant effects is important to delivering effective nursing care. Qualitative studies describing parental experiences of raising a child with an inherited disorder identified the coping challenges faced from the parents' perspectives. Themes from the mothers of children with SCD in their study were described as facing the daily challenges of fear, helplessness, and loneliness (Burnes et al., 2008). A qualitative study of both mothers and fathers concluded professional support played an important role in coping when caring for a child with SCD (Atkin & Ahmad, 2000). Further, nurses caring for these families must have knowledge of and understand how they face fear, anger, stress, anxiety, and altered family dynamics.

Positive coping strategies in children with SCD were related to positive family communication and functioning, suggesting a strong child-parent link in coping and adaptability to a chronic illness (Mitchell et al., 2007). Parents indicated a need for

support from their healthcare provider team in coping and adjusting to SCD. A study that investigates the resilience and coping of mothers of children with SCD will provide further knowledge to nurses who care for these families.

Sickle cell disease is a common genetically inherited disorder, leaving many mothers with the daily challenges of parenting a chronically ill child (Oliver-Carpenter et al., 2011). Several research studies have revealed the link between healthy parental coping and positive patient outcomes (Burnes et al., 2008; Jenerette & Valrie, 2010; Mitchell et al., 2007; Thompson, Gil, Burbach, Keith, & Kinney, 1993; Thompson et al., 1994). The role of the nurse is to assist mothers of children with SCD in successful coping, leading to improved disease management, fewer hospitalizations, and reports of increased family quality of life. The review of the literature revealed the importance of parental coping to the health of the child and the family as a whole in chronic illness conditions such as SCD.

Thompson offered the most quantitative research findings in the area of study interest. The work of Thompson and colleagues (1993) established the importance of maternal adjustment and coping with parenting a child with SCD and the resultant effects on the child's adjustment. This quantitative study included 78 mothers and their children and emphasized the benefits to both mother and child of positive coping and family functioning with SCD. A cross-sectional study by Thompson et al. (1994) suggested further research on ways to promote maternal adjustment after their study analyzed the process of maternal adjustment to parenting and caring for children with cystic fibrosis or SCD. The study found poor adjustment was related to increased levels of day-to-day stress, little family support, and palliative coping methods (Thompson et al., 1994).

Another cross-sectional survey design study reported the importance of the maternal influence on the child with SCD and how this influence promotes well-being and self-efficacy into adulthood (Jenerette & Valrie, 2010).

A systematic review and analysis of over 96 studies on caregivers of chronically ill children provided an overview of the stress encountered by parents of children with SCD as well as various other chronic illnesses (Cousino & Hazen, 2013). The review indicated an increase in the stress endured by parents was related to overall poor coping and adjustment in both the parents and the child with the illness. The literature strongly supports the significance of the mother-child relationship in producing better outcomes for children with an inherited chronic illness such as SCD.

Despite what is currently known about stress and coping in mothers of children with SCD, no specific quantitative evidence is in the literature regarding maternal resilience and its effect on coping in this population. The state of knowledge exists only at the qualitative and descriptive level. Quantitative studies are needed to fill this gap in nursing science and address the importance of resilience and coping in this population, thereby, increasing knowledge on how to help mothers and families adjust to caring for a child with SCD. A quantitative study measuring resilience and its effect on coping will help nurses understand the link between the variables and their importance to providing better care to families dealing with SCD. Further, the resiliency model of family stress, adjustment, and adaptation (McCubbin & McCubbin, 1993) can be tested and expanded, to minority mothers parenting children with SCD.

Problem Statement

The influence of resilience on coping in mothers of children with SCD is the area of research interest. This study focused on mothers, to include any maternal figure, such as stepmothers, grandmothers, and aunts, who are primary caregivers to children with SCD. The relationship between resilience and coping is significant for nurses to understand to provide complete and competent care to SCD families.

Research Questions

The major research question for this study was: Is resilience positively associated with coping in mothers of children with SCD? Related questions were: Are there differences/relationships between mothers with certain demographic/situational variables on resilience and coping? Does resilience predict coping and are coping and resilience predicted by certain demographics or situational variables?

Purpose

The purpose of this study was to examine the variables that may influence maternal coping in families who have a child or children with SCD and to determine if resilience contributes to coping. The role of resilience in coping will inform the state of knowledge in this area. Findings of this study are intended to assist healthcare professionals in supporting resilience interventions to produce positive coping for families.

Theoretical Base

The resiliency model of family stress, adjustment, and adaptation (McCubbin & McCubbin, 1993) is the theoretical framework for this study. Measurement of resilience and the effect of this variable on coping in mothers of a child with SCD will lead to a

better understanding of these variables and potentially improve outcomes for this population. A theoretical base provides the researcher with the organization and framework to conduct the study, thus allowing the nurse to implement findings after assessing mothers of children with SCD. Application of theory in this study will ultimately lead to the creation of resilience-building interventions that will be implemented in the clinical setting in the future.

The resiliency model of family stress, adjustment and adaptation is used to identify and improve coping in parents of children with a disability or chronic illness (Frain et al., 2007; Hall, Neely-Barnes, Graff, Krcek, & Roberts, 2012; McCubbin & McCubbin, 1993). The model reflects the many variables that are involved in resilience, including family function, vulnerability, stressors, and problem-solving. These variables predict resilience and, in turn, predict coping. The model guided this study in determining the correlation and influence of resilience on coping in mothers of children with SCD. If resilience is a factor associated with positive coping, the strength of this association is valuable knowledge for nurses. The resiliency model provides the framework to search for and understand the variables that make families resilient and thrive in difficult situations and become stronger through adversity (McCubbin & McCubbin, 1993; Walsh, 2003). McCubbin and associates (1983) created an instrument to measure parent coping behaviors and patterns, the Coping Health Inventory for Parents (CHIP). CHIP was used in this study to determine the coping patterns of mothers of SCD children. While a separate scale, the Connor-Davidson Resilience Scale 25 (CD-RISC-25) was used to specifically measure resilience in the participants (Connor & Davidson, 2003).

The resiliency model of family stress, adjustment, and adaptation have been used in numerous research studies conducted on families with stressors present, such as parenting a child with a chronic disorder or illness (Hall et al., 2012; O'Hanlon et al., 2012). Resilience as a concept has been described as having a positive impact on coping and adaptation when faced with difficult life situations (Luthar et al., 2000; Windle, 2010). The resiliency model of family stress, adjustment, and adaptation suggest that parents are affected by coping and resilience in the process of adapting to a stressful family event such as caring for a child with an inherited disorder. Tak and McCubbin (2002) further explain that the resiliency model was designed to assist researchers in understanding why some families cope easier to adversity than others. This model lays the framework for determining what characteristics a family may possess that makes it strong during adversity and focusing on strengthening those characteristics for continued family resilience (McCubbin & McCubbin, 1993).

When one feels vulnerable to difficult situations their perception of resilience is diminished, as is their active coping (McCubbin & McCubbin, 1993). Improvement of perceived resilience is valuable when coping with a difficult life situation. Resilience is important when understanding a mother's ability to cope with parenting a child with SCD. The power and strength of resilience on human persistence, adjustment, and coping are of particular interest in this study. The variable of resilience is assumed in this study to affect one's coping, therefore affecting a mother's and tangentially, the family's process of adjustment to caring for a child with SCD.

Parenthood is a transition for all mothers; however, additional challenges are faced by mothers who have a child with an inherited disease that causes chronic illness.

The use of the resiliency model can effectively guide this study conducted on mothers of children with SCD. Mothers can be empowered by knowing they possess resilience and that they can cope with the daily challenges of caring for a child with SCD. Isolating the strengths and/or weaknesses found in mothers when faced with adversity can lead to stronger coping in the mother, thus in the child and family unit as indicated in the literature. The ultimate goal of this study is to benefit the population by informing the healthcare professional in order to promote healthy coping.

Assumptions, Limitations, and Delimitations

Assumptions were that mothers of children with SCD who possess resilience will have greater coping, and that resilience will contribute positively to coping. The researcher also assumed that the participants would be honest and truthful with their responses. A limitation to the study was a population consisting of only mothers of children with SCD, therefore, limiting the scope of this study and generalizability of findings to other inherited disorders. Other limitations were the use of a convenience sample and self-reporting. Another limitation was that participants needed online access to complete the study questions.

Delimitations in the study included the decision to use a population of mothers of children with SCD as they are considered day-to-day primary caregivers of children with a chronic illness. The researcher gained permission from trusted and familiar SCD organizations to reduce suspicion of the research study purpose. The sickle cell agencies affiliated with this study posted a research flyer in their facility, on their website and Facebook page, as well as sent out to their client email list. If needed, computers and access to the online study were provided for any interested participants at their regional

sickle cell agencies. The regional sickle cell agencies know their clients' needs and could offer access to the online study on computers available in their facility if the participant is unable to access the study from a personal computer or device. The researcher used instruments with Likert scale responses to promote ease of completion of the questionnaires. This study followed the resiliency model of family stress, adjustment, and adaptation as a framework and a guide to determine the variables of interest.

Significance

Determining the influence of resilience on coping in mothers with children with SCD inform nurses who care for these families. The Centers for Disease Control and Prevention (CDC, 2016) estimated that 1 child out of every 365 African-American births will have SCD and that SCD affects 100,000 Americans. Additionally, 1 in every 13 African-American babies has the sickle cell trait when screened at birth (CDC, 2016). The statistics established significance in understanding SCD as one of the most prevalent genetically inherited conditions in the United States that nurses will encounter in practice.

Conclusion

Uncovering the magnitude of variables, such as resilience and the correlation to coping, sheds light on how to better care for the mother, child, and the family. The literature revealed the importance of parental coping to overall coping of the child with SCD. A study conducted on a maternal trait such as resilience and its importance to the process of coping and adjustment will add new knowledge in this area of research interest to benefit nurses caring for these families. The study also reports demographic variables, such as age, marital status, number of children with SCD, education level, and employment status, as well as their contributions to coping. Data analysis revealed

relationships between the variables studied and revealed the needs of mothers in increasing resilience and coping. The resiliency model of family stress, adjustment, and adaptation are used as a guide in determining the relationships and contribution of resilience on coping in mothers of children with SCD (Hall et al., 2012; McCubbin & McCubbin, 1993). The positive support that a mother supplies to the child, as well as the overall family, is important for the nurse to understand when implementing care and support to SCD families. Maternal coping has an impact on family outcomes making variables such as resilience, significant to an exploratory level research study in SCD families.

CHAPTER II – REVIEW OF THE LITERATURE

Introduction

This literature review focused on what is known about resiliency and parental coping, and more specifically, resiliency and coping of mothers who have a child with SCD. The evidence was analyzed, summarized, and followed by theory-related articles to provide a framework to support and guide this study. Variables related to coping were identified from research studies found in the literature review as well as in the instruments and methods used. This study's purpose, variables, and methodology were supported in the review of the literature.

A search of scholarly literature from ProQuest, Ovid, Cumulative Index to Nursing and Allied Health (CINAHL) and Google Scholar databases produced over 30 articles that met the criteria for use in this literature review. The keywords used for the search were: resilience, parental coping, chronic illness, maternal coping, and sickle cell disease. The focus was on the previous 5 years; however, older research studies were also utilized due to the lack of recent scholarly publications on the subject, and the age of the classic theoretical work by McCubbin and McCubbin (1993). Multiple searches were performed and a research librarian was consulted in the process to assure related studies were identified and the search complete. Gaps in the area of interest were noted and considered when formulating this review. Articles in the literature review are related to coping in parents of children with chronic illnesses, including SCD as well as articles specific to maternal coping. Several articles yielded results on how parental and maternal coping effects the child's ability to cope to having a chronic illness (Atkin & Ahmad, 2000; Burnes et al., 2008; Cousino & Hazen, 2013; Hildenbrand et al., 2015; Melnyk et

al., 2001; Thompson et al., 1993). The literature review also revealed research articles on the significance of McCubbin and McCubbin's (1993) resiliency model of family stress, adjustment, and adaptation on the process of coping and caring for a child with a chronic illness (Frain et al., 2007; Hall et al., 2012; McCubbin & McCubbin, 1993).

The purpose of this study was to examine the variables that influence maternal coping in families who have a child or children with SCD and to determine if resilience contributes to coping. Resilience and coping are the primary variables of interest and determining their relationship are included in the design of the study. There was an assumption that a positive correlation exists between resilience and coping in mothers of children with SCD due to the theoretical framework (McCubbin & McCubbin, 1993). Additionally, the long-term aim of the study is to promote positive coping in mothers for the benefit of the entire family unit when caring for a child with SCD. The focus on maternal coping addresses the problem statement to better understand the importance of a mothers coping abilities on the entire family's well-being. Maternal coping is significant to nurses when caring for families of children with SCD and providing interventions to support the family. The research articles found in this literature review provided the information most specific to this study's purpose and were analyzed in this review of the literature.

Resilience

The resiliency model of family stress, adjustment, and adaptation have been utilized as a framework for understanding resilience and coping. The efficacy of the model's use in families of children with SCD was found in the literature. Numerous studies have used the model as a framework to study families facing chronic illness,

including caring for a chronically ill child (Kosciulek, McCubbin, & McCubbin, 1993; McCubbin & McCubbin, 1989; McCubbin, 1988). The model has also been used in studies including African-American families experiencing the stressors of chronic illness and/or caring for a child with a chronic illness (McCubbin, McCubbin, & Thompson, 1992; McCubbin, Thompson, Thompson, McCubbin, & Kasten, 1993). Although the literature review did not reveal any studies specifically involving mothers of children with SCD that used this model, the model was well represented in similar studies involving families with chronic illness. The McCubbin and McCubbin (1993) resiliency model of family stress, adjustment, and adaptation as a framework utilizes the stress of an illness and its impact on the family to determine coping strategies, adjustment, and attainment of adaptation to the illness.

The stress of parenting a child with a chronic illness can be a threat to the family unit while coping with the illness (Hall et al., 2012; McCubbin & McCubbin, 1993). Identification of variables, such as parent's age, education level, social support, resources, coping skills, impact of stress, and problem solving that influence resilience in relation to positive family coping are of interest in research involving parents of children with chronic illness (Frain et al., 2007; Hall et al., 2012; Tak & McCubbin, 2002; Ye et al., 2015). Tak and McCubbin (2002) conducted a longitudinal study with 92 families of children with congenital heart disease to determine the relationships of variables to resilience. The results of the study showed the following variable correlations: education level to perceived social support ($r = 0.31, p < 0.005$); mother's age to coping ($r = -0.21, p < 0.05$); family stress to maternal perceived support ($\beta = -0.30, p = 0.004$); and maternal perceived support to maternal coping ($\beta = 0.39, p = 0.000$) (Tak & McCubbin,

2002). The authors found that perceived support plays an important role in maternal coping and is a resilience factor. With the use of the resiliency model, the authors concluded its usefulness to healthcare providers while evaluating and planning interventions for families with a chronically ill child (Tak & McCubbin, 2002). Walsh (2003) further recommends the use of resilience models, such as the McCubbin and McCubbin model, as a framework for practice when caring for families facing stressful health issues. The role of resilience in the adaptation and recovery in families is important to identify and understand to assure that they can live full lives (Walsh, 2003). Unfortunately, this literature search did not find studies directly examining the relationship between resilience and coping in mothers of children with SCD.

Parental Coping

The literature review indicated the importance of maternal coping and caring for positive health outcomes in children with SCD and overall well-being for the mother. Further review of the literature reveals the impact of receiving the news of having a child with SCD and the coping that follows caring for a child with a genetically inherited chronic illness. A study by Ievers, Brown, Lambert, Hsu, and Eckman (1998) of 67 parents of children with SCD found parental strain to involve more than just the day-to-day parenting, to include an emotional aspect of caring for a chronically ill child, particularly when behavior problems existed. Caregivers of children with SCD answered surveys to measure family adaptability and support. Eighty-five percent of the participants were mothers, a trend seen in the gender of participants found throughout the literature review. Demographics were collected and included age, gender, marital status, education level, and annual income. The relationships between child-related behavior

stressors and caregivers' adaptation were reported from the Symptom Checklist- 90-Revised as follows: Depression ($r = .34$, $p < .01$), hostility ($r = .40$, $p = .001$), and anxiety ($r = .36$, $p < .01$) (Ievers et al., 1998). Clinical conclusions from the study stressed the importance of interventions that focus on family systems to increase adaptation in caregivers of children with SCD (Ievers et al., 1998).

Wonkam et al. (2014) performed a research study on the psychosocial aspect of being a parent of a child with SCD. The study sought to determine the difficulty of coping and the variables that contribute to coping. The cross-sectional study included 130 parents in Cameroon having at least one child with SCD. Face-to-face interviews were conducted and of the 130 participants, 88.3% reported moderate to severe coping difficulties. Factors and stressors, including hospital visits and admissions, treatment regimens, and incidence of stroke were obtained. Demographic data were gathered and included age, gender, marital status, education level, number of children in a household, and employment status. The researchers concluded that the parents in the study experienced many stressors when caring for their child with SCD, with unemployment having a high impact on all stressors. Female gender, single marital status, lower educational level, and having more than three children in the household, also significantly increased stressor scores among participants (Wonkam et al., 2014). A recommendation of the study is the implementation of screening and counseling for parents who need help coping with these stressors (Wonkam et al., 2014).

Melnyk and colleagues (2001) reviewed parental stress and coping when caring for a child with chronic illness. Their review provided information on instruments used to measure coping and discussed nursing assessments and interventions that can assist the

parents in coping. The authors recognized the stress parents encounter when a child is initially diagnosed and during transition periods, as well as acute periods of severe illness or hospitalization. The ability to manage stress through positive coping is significant to the parent and to the child's adjustment. Nurses who work with children who are chronically ill and their parents are in contact with these families and in the position to assess the parents coping abilities and any needs they may have (Melnyk et al., 2001). The authors concluded with statements regarding positive outcomes in both parents and their children with a chronic illness when coping needs are met. Another conclusion was that nurses can assist parents in meeting their coping needs by helping them receive the support necessary to help them adjust (Melnyk et al., 2001).

Cousino and Hazen (2013), in a comparative study, examined parenting stress in families with a chronically ill child and found stress levels to be remarkably higher in these parents than parents of healthy children ($d = .40$, $p < .0001$). The study referred to the qualitative analysis theme of increased parental responsibility perceived by parents of children with a chronic illness. Higher levels of stress are associated with increased responsibilities and poorer adjustment in parents of children with a chronic illness (Cousino & Hazen, 2013). The authors included that it is important to intervene and provide support to the parents to reduce the effects of the stress on the management of the child's health. The study concluded that implementing coping and adaptation interventions to improve parental stress are key to parental adjustment when caring for a child with a chronic illness (Cousino & Hazen, 2013).

A mixed methods study by Hildenbrand et al. (2015) provided information on children coping with the stressors of SCD and the influence of coping assistance from the

parents. Fifteen children with SCD and their parents participated in the study that incorporated a qualitative interview process that was coded to better understand how children and parents cope. The qualitative interviews were followed by a quantitative study using questionnaires to yield valuable data on the stressors faced by children and parents as well as the importance of support for families of children with SCD (Hildenbrand et al., 2015). Demographic data on the parent participants were collected to report age, gender, marital status, education level, and socioeconomic status. Themes resulting from the qualitative study included ways parents deal with SCD stressors, as well as ways they help their children deal with the day-to-day stressors of having SCD. Promotion of social support, promotion of distraction techniques, expressing their emotions, and promoting acceptance were all coping strategy themes originating from the study (Hildenbrand et al., 2015). Descriptive statistics from the questionnaires were merged with the quantitative data to conclude that families living with SCD incorporate numerous methods to cope. A better understanding of these methods may increase the implementation of helpful resources by healthcare providers (Hildenbrand et al., 2015).

Maternal Coping and Child Adjustment

Thompson et al. (1993) found the adjustment of mothers of children with SCD to be significantly related to the adjustment of the child as well as significant to the mother's well-being. The authors addressed variables associated with good and poor maternal adjustment. An important finding of their work was that the severity of the child's disease was not related to adjustment; however daily stressors were related to poorer adjustment outcomes (Thompson et al., 1993). Longitudinal studies performed by Thompson et al. (1994) yielded results on the adjustment of 78 mothers to parenting

children with SCD and 68 mothers of children with cystic fibrosis (CF). Coping methods and family functioning were analyzed in the mothers of these children. Variables found associated with maternal adjustment were provided and included levels of daily stress (SCD: $R = .67$, $p > .0001$; CF: $R = .24$, $p < .05$), level of family support (SCD: $R = .70$, $p > .001$; CF: $R = .76$, $p < .001$), and adaptive coping strategies (SCD: $R = .77$, $p > .001$; CF: $R = .72$, $p < .001$) (Thompson et al., 1994).

Brown et al. (1993) analyzed family functioning in both mothers and their children with SCD. The authors emphasized the importance of family adaptive coping on a child's coping with SCD. The study compared 61 children with SCD to their siblings without sickle cell and their families (Brown et al., 1993). The Family Adaptability and Cohesion and Evaluation Scale-III was one instrument utilized in the research project by both the children and their mothers in the study to measure functioning. The authors reported a relationship between the adaptability reported by mothers and their child's adjustment ($r = 0.28$, $p = <0.05$). The research concluded that the significance of providing psychiatric consults was important to these families, particularly in times of stressful events to increase coping and functioning (Brown et al., 1993). These research studies performed in the early 1990s illustrate the importance of maternal coping to the nurse when caring for the families of children with SCD.

A study by Jenerette and Valrie (2010) yielded results on the influence of maternal behaviors in women who have children with SCD. This retrospective cross-sectional study analyzed maternal caring of children with SCD and how this related to self-efficacy of the child in adulthood. Thirty-two adults with SCD participated in the study that measured parental bonding and SCD self-efficacy. The authors also measured

demographics of maternal age, marital status, education level, and the frequency of SCD crises experienced in a year (Jenerette & Valrie, 2010). The study provided valuable data indicating that maternal caring during childhood may promote self-efficacy in adults with SCD. Correlations were reported as follows: high self-efficacy and education level ($r = .39, p = .04$), high self-efficacy and SCD crises ($r = -.41, p = .04$), high self-efficacy and maternal caring ($r = .48, p = .01$), and age ($r = .09, p = .64$), noting a positive correlation to maternal caring (Jenerette & Valrie, 2010). This study reinforces the importance of maternal influence in children with SCD, and the authors concluded that mothers should be made aware of their influence and encouraged and helped to meet these caring behaviors.

Oliver-Carpenter et al. (2011) investigated the importance of SCD management tasks and coping skills involving both the child and the family members. The cross-sectional study involving 47 youth with SCD and their caregivers suggested that interventions involving parents are related to increasing positive coping outcomes in the sickle cell population and their families. The findings are significant to all healthcare professionals caring for families of children with SCD. Parental involvement rated by parents ($t = -5.50, p < .001$) and rated by youth with SCD ($t = -6.96, p < .001$) indicate that parents should be encouraged and involved in coping and disease management tasks with their children (Oliver-Carpenter et al., 2011). The authors noted that their findings were similar to other studies that propose the importance of the parent and child partnership as integral to the child's coping as they reach young adulthood (Oliver-Carpenter et al., 2011). The importance of coping for the well-being of patients with

SCD and their family is critical, and, therefore, it is the purpose of this study to determine variables affecting coping.

Discussion

The literature review provided an overview of the research performed on parental coping when parenting a chronically ill child. Older literature specific to SCD was a theme found in the literature review, shedding light on the need for current research in this area involving such a large population of chronically ill children and their caregivers in the United States. The process also assisted in determining a gap that exists in understanding significant variables, such as resilience, related to the coping of mothers of children with SCD and the subsequent increase in their psychosocial well-being. Particularly, quantitative studies that include resilience in mothers of children with SCD are lacking in the literature. Other chronic illnesses were found in the current literature, with a noticeable gap found in the research interest of SCD. Determining the relationship between resilience and coping will benefit the families of children with SCD and may be generalized to other chronic disorders. The review also identified theory and frameworks that provide the study with guidance on identifying demographics and situational variables in mothers of children with SCD. McCubbin and McCubbin's (1993) resiliency model is a strong framework and supports a study such as this one, which identifies variables and indicates relationships among resilience and coping in mothers of children with SCD.

Conclusion

The identification and measurement of variables that exist in mothers of children with SCD that will either increase or decrease resilience and coping will be significant to

nurses when assessing the family and planning interventions to promote adjustment and overall well-being. The well-being of the family is of concern and how healthcare providers address and improve this well-being requires further research. Nurses are in the position to help mothers succeed in coping behaviors that will result in positive results for the child and the entire family; therefore, nurses must be aware of the needs of mothers when adjusting to caring for a child with SCD to benefit both mother and child in health promotion and illness management.

CHAPTER III - METHODOLOGY

Research Questions

This study was designed to answer the following research questions: Is resilience positively associated with coping in mothers of children with SCD? Are there differences/relationships between/among mothers with certain demographic/situational variables in resilience and coping? Does resilience predict coping and are coping and resilience predicted by demographics or situational variables? The methodology, including design, sample and setting, procedures, data collection, instruments, and data analyses are discussed in this chapter.

Research Design

The gaps in the literature and the focus of the research question regarding the contribution of resilience to coping in mothers of SCD children suggests a nonexperimental exploratory correlational design (Grove, Burns, & Gray, 2013). Exploratory correlational designs are appropriate for research study when the researcher is trying to determine variable relationships in their study population (Grove et al., 2013). The state of the science, determined through the review of the literature, also lends to exploratory research design and the applicability of findings to numerous populations. Polit and Beck (2012) described the correlational design as beneficial to the researcher when manipulation of variables cannot be accomplished, yet the relationship between the variables is important. This method is also appropriate when using a single group of participants. In this study, a correlational design is appropriate for the researcher to utilize to better understand the direction of the relationship between resilience and coping. By design, this type of correlational study only determines a relationship

between the variables and may suggest prediction but does not suggest causation.

Variables in this study were not manipulated. Considering these tenets of correlational design, this study is classified as nonexperimental and determined to be useful in research that involves human participants (Polit & Beck, 2012). In this study, the participants were mothers of children who have been diagnosed with SCD.

In this study, the researcher was determining if the variables of interest are related, and further analyses using simple linear regression and multiple regression examined contributions to coping because statistical assumptions were met. Normality, homogeneity, and linearity were the assumptions met (Grove et al., 2013). A correlational design was the best choice to identify and determine the relationship between the variables and suitable for exploratory level research in this area of interest. Determining whether a correlation between the variables was present, the strength of the correlation and degree of correlation to coping was important knowledge needed to help families adjust to caring for a child with SCD.

Polit and Beck (2012) summarized the strengths of correlational designs, particularly in nursing research. This design allows an option when an experimental design is not appropriate due to the unethical issues concerning the manipulation of variables. Another important strength is the efficiency of the design. Research studies, such as this one, can be conducted in a large population resulting in large amounts of data, adding strength to the study itself. Polit and Beck (2012) stated one of the strongest characteristics of correlational studies is that they are applicable to real-world situations allowing for use in practice, and further research study. Other strengths in this study's design are the use of statistically sufficient sample size and reliable instruments.

Sample and Setting

The participants were a convenience sample from regional SCD support groups in the United States, with strictly voluntary participation. The Sickle Cell Disease Association of America is a nonprofit organization with regional affiliates located throughout the United States. The regional affiliates' facility bulletin boards, websites, Facebook pages, and email lists were utilized to conduct nonrandom convenient sampling for study participants in an online setting. The facilities participating in the study were located in Alabama; however, the facilities reach sickle cell families across the United States through their websites and Facebook pages. Participants were given all study information, including consent forms, through an electronic platform. If they agreed to participate, the instruments were immediately administered online. The sample included mothers or maternal caregivers (stepmothers, grandmothers, aunts) who are the primary caregiver of a child or children with SCD. The researcher used a sample size of approximately 110 participants as determined by power analysis (see below). Grove and colleagues (2013) emphasized the importance of a sufficient sample in correlational designs to decrease the risk of causal outcomes.

Procedures

Power analysis estimated the sample size needed for the highest level of analysis, linear regression testing. The power, alpha, effect size, and the number of predictors were all considered in the power analysis. The power was set at .80 or 80%. This number is accepted in the literature for quantitative studies to detect effect. Alpha probability was set at .05 and medium effect size for linear regression was used in computing the necessary sample size for this study (Bannon, 2013; Green, 1991). The

predictor number was set at eight representing the following independent variables: (a) resilience, (b) perceived stress, (c) how sick the mother perceives their child to be, (d) maternal age, (e) marital status, (f) number of children with SCD, (g) education level, and (h) employment status. These variables were applicable to the framework of this study and were found in similar studies throughout the literature review. The power analysis formula was obtained from the literature and calculated by hand, and then verified with a statistician to assure the correct value was obtained (Green, 1991). The estimated sample size needed for this study was 110 participants.

Permission letters were received from the sickle cell agencies that agreed to participate in the recruitment process for this study (Appendix C). Recruitment for the study began after Institutional Review Board approval was received from The University of Southern Mississippi (Protocol number: 18072703). Institutional Review Board approval documents are found in Appendix D. All participants were over the age of 18 and mothers of children with SCD. The first 112 participants to complete the study questions were included in the study. Potential participants learned of the study through participating sickle cell agencies via various methods, including the recruitment flyer (Appendix E) being posted in the facility, on the agency website, agency Facebook page, or client email contact list.

Data Collection

The CD-RISC 25 and the CHIP measured resilience and coping, respectively, in the desired population. The instruments are self-reporting and use a Likert-type scale to respond to the questions. They can be administered online or in the clinical setting. The study was conducted through Qualtrics and was set to close when 112 participants had

completed the study questionnaires. This number was set to allow more data points in case of the need to reject outliers or if participants submitted incomplete data.

A letter of consent explaining the study was provided. Protecting the right of self-determination, the participant could choose to either participate or not. Potential participants were directed to click on buttons indicating “Accept” or “Do Not Accept”. They could withdraw from the study at any time without repercussions. The study is anonymous, but if participants wanted a summary of the findings, they were provided an opportunity to provide an email address at the end of the survey. Confidentiality of the participants and the data collected was maintained by the researcher on a password protected computer and removable drive. Confidentiality of the participant and the data obtained from the questionnaires are of the highest priority to the researcher. A \$10 Wal-Mart e-gift card was offered to compensate participants for their time and to motivate them to complete all of the study questions.

Data were collected over an 8-week period. All participants had to read and check the consent to participate before they could continue in the study. If consent was obtained, then each participant had to consent that they were over the age of 18 and a mother of a child with SCD. If participants answered “No” to either of these questions, they were unable to continue with the study. After consent, age requirement, and the requirement of being of the mother of a child with SCD was confirmed by the participant, they then answered 5 demographic questions, 2 situational variable questions, the 25-item CD RISC scale, and the 45-item CHIP scale.

Instruments

The variables of resilience and coping have been well defined both conceptually and operationally in the literature review. Congruency between concepts, constructs, and measures was established to provide the researcher with reliable and valid interval data collection essential to maintaining rigor in correlational research studies. The data collection instruments were used exactly as the authors of the instruments instructed. No adjustments or revisions were made in the use of the instruments or to the scoring of data obtained from the instruments, ensuring interpretations of findings in this study were in no way skewed.

Connor-Davidson Resilience Scale (CD-RISC)

Resilience and its power to help those who are involved in any type of adversity in their lives is the concept of interest in the Connor-Davidson Resilience Scale 25 (Connor & Davidson, 2003). Connor and Davidson (2003) felt strongly that the benefits of resilience in individuals whose success and recovery depended on the ability to cope and to continue to cope. The concept of resilience was clearly explained and defined conceptually in the context of the ability to “thrive” when adversity is encountered. After much research, they developed and refined a list of characteristics and variables to include in the CD-RISC that allowed them to operationally define resilience as a construct. Conceptual clarity exists in the instrument as its measurement corresponds to the definition of the construct through the content of the scale. Self-efficacy, view of change or stress as a challenge, sense of humor, patience, optimism, faith, personal goals, commitment, and secure attachments to others are just a few of the characteristics making the list (Connor & Davidson, 2003).

From the characteristics, they constructed a 25-item scale, the Connor-Davidson Resilience Scale 25 (Appendix A). Each item on the scale is marked as (0) not true at all, (1) rarely true, (2) sometimes true, (3) often true, or (4) true nearly all the time. The instructions are clearly written at the top of the scale, asking the participant to mark an “x” in the box indicating how much you agree with each of the statements. The CD-RISC has a Flesch-Kincaid score of 5.1 and, therefore, is read and understood at a 5th grade level of education (Davidson & Connor, 2016). The scale takes approximately 5-10 minutes to complete. The scale is scored by totaling each of the 25 items and gives the researcher an interval level score. A score may range from 0-100, with a higher score indicative of more resilience (Davidson & Connor, 2016).

The original study included a general population group of 577 participants, as well as 251 participants who were receiving primary and psychiatric outpatient care, including treatment for generalized anxiety disorder and posttraumatic stress disorder (Connor & Davidson, 2003). The study was conducted through the Duke University Medical Center and included the following demographics: 65% female, 35% male, 77% white, and 23% non-white (Connor & Davidson, 2003). The authors’ original study determined a Cronbach alpha score of 0.89 for the scale and test-retest reliability of .87 (Connor & Davidson, 2003). Nunnally and Bernstein (1994) stated the Cronbach’s alpha as potentially the best outcome indicator of reliability through estimation of true variance. An alpha score of 0.89 is considered adequate in a Likert-like scale such as the CD-RISC 25 (Nunnally & Bernstein, 1994).

Since the original study, the CD-RISC 25 has been utilized in hundreds of studies with participants who include both males and females of all ages and with numerous

cultures and ethnicities represented. Research studies using the scale include parents of children with cancer, congenital disease, autism, and intellectual disability. Other studies have included African American primary care and OB/GYN patients and women who are survivors of abuse (Davidson & Connor, 2016). O'Hanlon et al. (2012) successfully used the CD-RISC 25 to evaluate resilience differences in parents of children born with cleft lip/palate and those without cleft lip/palate. The authors of the instrument, as well as the literature review, provided numerous studies that utilized the CD-RISC 25 to measure the degree of resilience, further establishing its reliability and validity to measure resilience in this study. Permission to use the instrument was obtained from Dr. Jonathan Davidson (J. Davidson, personal communication, January 14, 2018). Dr. Davidson expressed interest in the use of the CD-RISC 25 in this study's population.

Coping Health Inventory for Parents (CHIP)

Coping with the day-to-day demands encountered when parenting a child with a chronic illness is the construct measured by CHIP. The creators of the scale designed the instrument to measure parents' coping behaviors and patterns while caring for their child or children with a chronic illness (McCubbin, McCubbin, Nevin, & Cauble, 1981). The authors defined coping as positive behavior patterns that emerge from parents of children with chronic illness. The original study included 100 families of children with cystic fibrosis at a university hospital in Minnesota (McCubbin et al., 1983). Emerging behaviors revealed the concept of coping operationally defined by the instrument, and these behaviors contributed to the authors' construction of three subscales (McCubbin et al., 1983). Factor analysis was used to identify three subscales which include: (a) maintaining family cooperation and optimism, (b) maintaining social support and

psychological stability, and (c) understanding the medical situation through communication with healthcare providers and other parents (McCubbin et al., 1983). The reliability of each of the three coping subscales was determined with Cronbach's alpha scores of .79 (family), .79 (social support), .71 (medical) respectively (McCubbin et al., 1983). No total score alpha was given. The alpha scores indicate sufficient estimates of instrument reliability (Nunnally & Bernstein, 1994).

The content of CHIP confirms the conceptual clarity of coping. The repeated use of the instrument found in the literature lends to the validity of the instrument in demonstrating a positive relationship between parental coping behaviors and overall family adjustment and well-being in a variety of populations (Gothwal, Bharani, & Reddy, 2015). The creation of the instrument coincided with the authors' study involving families of children with cystic fibrosis, an inherited chronic disease. The data from the study resulted in the current 45-item CHIP (Appendix B), containing three subscales, are utilized in studies that measure coping in parents of chronically ill children. The results of the initial study identified parental coping behaviors from 100 families that promoted family well-being and in turn improved the overall well-being of the child (McCubbin et al., 1983). The CHIP has been used in numerous research studies involving mother and fathers of chronically ill, seriously ill, and disabled children from multiple ethnic groups (Goldbeck, 2001; Gothwal et al., 2015; Grootenhuis & Last, 1997). Permission was obtained to use the instrument through communication with Dr. Laurie McCubbin, daughter of the McCubbins. The conversation included her interest in the use of the CHIP in this study's population (L. McCubbin, personal communication, January 30, 2018).

The CHIP scale has a Flesch-Kincaid grade level of 9.1, so it is read and understood at a 9th-grade level. Instructions on how to give a response to each item on the Likert scale are provided on the instrument and it takes approximately 15 minutes to complete. Each of the 45 items on the scale is coping behaviors that are assigned a score of 0 to 3 as to how helpful the participant finds the behavior to be, with (0) not helpful, (1) minimally helpful, (2) moderately helpful, and (3) extremely helpful. Instructions explain that if a coping behavior on the scale was not used by the participant to respond with “chose not to use” or “not possible”. The scale is scored by totaling each of the 45 items and gives the researcher interval level data to measure a parent’s coping with a child’s illness. The scores of each coping subscale are totaled with a range of 0-57 for subscale one, 0-54 for subscale two, and 0-24 for subscale three. If the researcher desires an overall score may be totaled and can range from 0-135. A higher score is indicative of more coping behavior.

In addition to using the described instruments, the participants were asked to answer two, 5-point Likert-scale questions regarding how much stress they currently perceive and how sick they believe their child is at this time. Demographic questions regarding maternal age, marital status, number of children with SCD, education level, and employment status were also asked. Demographics and situational factors were obtained from participants by using a form created by the researcher specifically for this study. The demographics obtained, as well as the two situational factors, are variables well represented in the literature review of similar studies involving mothers of chronically ill children. The two situational variables are perceived stress, and how sick the mother perceives her child to be, at the time of participation in the study. The situational

variables were collected as single-item indicators to obtain the participants' perception of stress and sickness level of their child. Single-item indicators and their psychometric consistency are supported in nursing research and in the context of this study (Youngblood & Casper, 1993).

The CD-RISC 25 and CHIP are widely accepted and the literature supports their reliability and validity in measuring the variables in this study, which are reported in the results. Content validity of both instruments is sound with the concepts defined by its creators and the instrument's ability to fully measure the variables. Both instruments contain items that are scored numerically to indicate a level of resilience and coping, which allows interval level data to be obtained for statistical testing. The use of the instruments in diverse research studies involving numerous health circumstances and conditions and among various ethnicities and cultures leads to the consistent reliability and validity of their use in this study.

Data Analysis

Data from 112 participants were exported from Qualtrics into a dataset in IBM SPSS® version 22. All data responses (frequencies) were compiled and reviewed by the researcher and the statistician to assure the questionnaires were completed in full. After review, four of the surveys were removed from the study due to only partial completion of the questionnaires. It was determined that sufficient statistical power analysis was maintained with the remaining 108 participants. The 108 participants' surveys were reviewed a second time, and there were four items (4, 14, 20, and 25) on the CD-RISC found missing, each one from four different participants. Eight items (2, 4, 15, 18, 19, 21, 28, and 38) were missing on the CHIP scale, each one from a different participant.

The mean responses for each of the missing items in question were individually determined through SPSS® analysis. The missing responses were completed by inputting the mean response from all the surveys for those particular items. A final data hygiene check was performed by auditing every 5th record and searching for any more omissions or outliers in the data. After satisfaction with the accuracy of the data, analyses were conducted.

Reliability

After data entry and hygiene procedures described above, reliability was estimated for each instrument using Cronbach's alpha analyses in SPSS® (Cronk, 2014; Grove et al., 2013; Nunnally & Bernstein, 1994). The Cronbach's alpha scores for both instruments were .8 or greater indicating good reliability in the study. The reliability data are presented in the results and displayed in tables in Chapter IV.

Statistical Tests

Determining and describing the type and strength of the relationship between resilience and coping was done by analyzing the data through statistical testing with SPSS® (Bannon, 2013; Cronk, 2014). Interval level data on resilience and coping were obtained through the scoring of the Likert-type scales. Descriptive statistics were utilized in this correlational study to describe the variables of perceived stress, how sick the mother perceives her child to be, age, marital status, number of children with SCD, education level, and employment. Statistics include, where appropriate, frequency, mean, percent, standard deviation, and range (Grove et al., 2013).

To indicate the nature of correlations between variables, (coping, resilience, perceived stress, perception of how sick the child is, maternal age, education level,

number of children with SCD, marital status, and employment) the Pearson correlation coefficient was used, as interval level data assumptions were met for the test. Grove and associates (2013) explained the Pearson coefficient is specifically designed to measure two interval-level variables in a single group of participants and give the researcher the data needed to determine the strength of the relationship, with a range from -1.0 to +1.0. The closer the results are to 1.0, the higher the relationship. Positive and negative indicate to the researcher whether or not it is a positive or negative relationship (Frey, 2016). Due to theoretical relationships, the researcher expected the correlational relationship in this study to be positive, with a high resilience score relating to a high coping score. Further, the researcher predicted, based on the resilience model and the literature review, that younger and single mothers may perceive more stress and, therefore, have lower resilience and coping scores. The researcher also expected mothers who perceive their child's severity of illness to be high will have lower resilience and coping scores. The directionality of relationships between resilience and coping and education level, number of children with SCD, and employment is expected to be varied, with both positive and negative relationships seen with these variables in the literature review.

Another statistical test performed was a simple linear regression. This analysis allowed the researcher to predict a coping score based on the resilience score. The researcher expected a positive linear relationship, with resilience being high and coping ability high. A positive linear relationship gives the researcher an indication of one variable predicting another; however, the researcher realizes the prediction is preliminary in nature and is not a completely accurate test (Grove et al., 2013).

Another analysis determining the contribution of resilience and other situational or demographic variables to coping is multiple regression. Multiple regression allows predictions of an outcome variable based on the independent variables and for the calculation of beta weights (Polit & Beck, 2012). Statistical analysis of the data from the instruments was utilized to provide valuable information on the direction of the relationship of the independent variables and the ultimate value of the contribution to the outcome, coping. Despite the strength of the relationship that results, the researcher realizes the results do not indicate causality (Grove et al., 2013). However, the utilization of two interval-level instruments with total scores allowed t-tests and ANOVAs use of demographic and situational variables to examine differences, which showed causality.

Conclusion

Multiple statistical tests were conducted to analyze the data and answer the research questions in the study. The researcher may utilize the findings from this correlational study to conduct further interventional/quasi-experimental research for the purpose of improving resilience and coping in this population. Tables and in-text descriptions of findings in Chapter IV provide a complete view of scale reliability, descriptive statistics, correlations, linear regression, and multiple regression results.

CHAPTER IV – RESULTS

The results of this study were obtained from data analyses, aimed to answer the following research questions: Is resilience positively associated with coping in mothers of children with SCD? Are there differences/relationships between mothers with certain demographic/situational variables on resilience and coping? Does resilience predict coping and are coping and resilience predicted by demographics or situational variables?

Instrument Reliability

Reliability of the instruments used in the study was estimated and established using Cronbach's alpha analysis in SPSS®. The Cronbach's alpha score was .956 for the CD-RISC (25 items). Cronbach's alpha score for the CHIP subscale I (19 items) was .924, subscale II (18 items) was .952, and subscale III (8 items) was .882. The reliability and validity of the demographic variables, as well as the situational variables in this study, were assumed through their use in multiple studies described in the review of literature in Chapter II (Frain et al., 2007; Hall et al., 2012; Ievers et al., 1998; Tak & McCubbin, 2002; Ye et al., 2015). Likewise, the framework of this study supported the reliability and validity of the demographic and situational variables utilized (Frain et al., 2007; Hall et al., 2012; McCubbin & McCubbin, 1993).

Description of the Sample

A heat map was generated using zip codes to illustrate the sample of participants (N=108) (Appendix F). The heat map illustrates the number of participants from the five major geographic areas of the country. The Southeast represents 34% (n=36) of the sample, followed by the West region with 24% (n=26), the Midwest with 17% (n=18), the Northeast with 14% (n=16), and the Southwest with 11% (n=12).

Table 1 illustrates the frequencies of the study sample ($N = 108$) demographics. The table includes the number of children with SCD, marital status, employment status, age, and education level. All participants were over the age of 18 years and are mothers of a child or children with SCD. The age of the participants ranged from 22 to 56 years with a mean age of 33.29 years. The data are bimodal with 28 and 32 each representing 11.1% of the sample. Table 1 indicates the majority of participants have one child with SCD, are married, and are employed. The education level varied considerably, though most mothers ($n=103$, 95.4%), had at least a high school education or greater.

Table 1

Frequencies of the Study Sample Demographics (N = 108)

Demographics	<i>n</i>	%
Number of children with SCD		
One	105	97.2
Two	3	2.8
Marital Status		
Single, never married	15	14.0
Married	82	75.7
Widowed	1	0.9
Divorced	8	7.5
Separated	2	1.9
Employment Status		
Employed	102	94.4
Unemployed	6	5.6
Age		
22-29	32	29.9
30-35	46	43.0
36-44	23	21.5
45-56	6	5.6
Education Level		
Below high school	4	3.7
Some high school	1	0.9
High school graduate or GED	16	15.0
Some college credits	19	17.8
Associate's degree	26	24.3
Bachelor's degree	33	29.9
Master's degree or higher	9	8.4

Descriptive Statistics

Table 2 describes the frequencies of the two situational variables in this study. Participants were asked to rate their stress level and how sick they believed their child/children to be at the time of participating in the study. Moderate stress levels were the most reported in the study sample (n=34, 31.5%). More participants reported that their child was not sick at the time of the study (n=33, 30.6%).

Table 2

Frequencies of the Situational Variables (N = 108)

Variables	<i>n</i>	%
Stress Level Today		
None	25	23.1
Little	19	17.6
Moderate	34	31.5
High	24	22.2
Extremely High	6	5.6
How Sick Do You Feel Your Child is Today		
Not Sick	33	30.6
A Little Sick	18	16.7
Moderately Sick	29	26.9
Very Sick	22	20.4
Extremely Sick	6	5.4

The mean, standard deviation, and range of the CD-RISC, and the three CHIP subscales are represented in Table 3. A participant score for the CD-RISC may range from 0-100. The scores of the CHIP subscales range from 0-57 (subscale I: family cooperation and optimism), 0-54 (subscale II: social support and stability), and 0-24 (subscale III: medical communication). The authors of the CHIP recommend scoring of

the instrument by calculating and reporting each coping subscale. Overall, mean scores report resilience and coping to be present and variable in the sample.

Table 3

Mean, Standard Deviation, and Range of Instrument Scales (N=108)

Variable	<i>M</i>	<i>SD</i>	Range
CD-RISC	73.58	17.43	14-99
CHIP Subscale 1	33.62	15.55	4-56
CHIP Subscale 2	31.11	15.47	2-53
CHIP Subscale 3	14.75	6.29	1-24

Inferential Statistics

A Pearson correlation was conducted to examine relationships between age and the resiliency and coping scores. Table 4 illustrates the correlation between age, CD-RISC, and the three CHIP subscales. Age was not significantly correlated with any of the dependent variables. However, the CD-RISC total score was significantly related to each CHIP subscale, indicating as resilience increases so do coping behaviors in this sample. The strength of the relationship of the CD-RISC indicates a strong correlation to each CHIP subscale. A correlation coefficient of over .60 is considered strong (Frey, 2016; Grove et al., 2013). As expected, the CHIP subscales are strongly correlated with one another.

Table 4

Pearson Correlation of Selected Variables

	Age	CD-RISC	CHIP I	CHIP II	CHIP III
Age	--				
CD-RISC	.011	--			
CHIP I	-.037	.695**	--		
CHIP II	.019	.696**	.963**	--	
CHIP III	.010	.632**	.917**	.914**	--

**p<.01

An independent samples t-test was conducted to examine differences in CD-RISC total score and a recoded education variable. Education was recoded into two categories: high school or below ($n = 21$) and some college or above ($n = 87$). There was a significant difference in the CD-RISC total mean scores by education. Participants with high school or below education scored eight points below those with some college to any degree, indicating higher resilience for those with more education. There were no significant differences found between education level and the CHIP subscales.

Table 5

Independent Samples t-test of CD-RISC Score (N = 108)

Variable	<i>M</i>	<i>SD</i>
High school or below	66.81	9.55
Some college to any degree	75.17	18.62

$t_{(61.86)} = -2.891, p = .005$

One-way ANOVAs examined differences in CD-RISC total scores and CHIP subscale scores and the independent variables stress level and how sick is your child. Table 6 illustrates the difference in the reported stress level of the mother as the independent variable and the CD-RISC and CHIP scores as the dependent variables.

Participants who reported no stress were found to have the highest CD-RISC and CHIP subscale scores, indicating higher resilience and coping. Interestingly, those participants with the lowest reported resilience and coping (for all three subscales) self-reported moderate stress levels.

Table 6

ANOVA of CD-RISC and CHIP by Stress Level

Variables	Stress Level	Mean	<i>n</i>	<i>F</i>	<i>df</i>	<i>p</i>
CD-RISC	Extremely High	69.33	6	10.001	4,103	.000
	High	67.08	24			
	Moderate	66.82	34			
	Little	74.15	19			
	None	89.60	25			
CHIP I	Extremely High	26.00	6	9.671	4,103	.000
	High	33.83	24			
	Moderate	24.44	34			
	Little	35.53	19			
	None	46.00	25			
CHIP II	Extremely High	26.33	6	10.025	4,103	.000
	High	32.42	24			
	Moderate	21.53	34			
	Little	31.74	19			
	None	43.56	25			
CHIP III	Extremely High	11.00	6	9.989	4,103	.000
	High	15.54	24			
	Moderate	10.82	34			
	Little	15.84	19			
	None	19.40	25			

Table 7 illustrates the difference in the mothers' assessment of how sick the child is as the independent variable and the CD-RISC and CHIP scores as the dependent variable. Participants who reported that their child was not sick were found to have the highest CD-RISC and CHIP subscale scores, indicating higher resilience and coping. Those participants with the lowest reported resilience and coping (for all three subscales) reported that their child was very sick.

Table 7

ANOVA of CD-RISC and CHIP by How Sick the Child Is

Variables	How Sick Child Is	Mean	<i>n</i>	<i>F</i>	<i>df</i>	<i>p</i>
CD-RISC	Extremely sick	71.83	6	9.476	4,103	.000
	Very sick	65.86	22			
	Moderately sick	65.17	29			
	A little sick	73.78	18			
	Not sick	86.33	33			
CHIP I	Extremely Sick	32.67	6	8.906	4,103	.000
	Very sick	26.00	22			
	Moderately sick	27.14	29			
	A little sick	32.67	18			
	Not sick	44.88	33			
CHIP II	Extremely Sick	31.50	6	7.852	4,103	.000
	Very sick	23.41	22			
	Moderately sick	25.69	29			
	A little sick	29.50	18			
	Not sick	41.82	33			
CHIP III	Extremely Sick	14.17	6	7.077	4,103	.000
	Very sick	12.05	22			
	Moderately sick	12.48	29			
	A little sick	14.11	18			
	Not sick	19.00	33			

Statistical assumptions of normality, homogeneity, and linearity were met; therefore, linear regressions were conducted to determine whether the CD-RISC score predicted the three CHIP subscale scores individually. The model summary and the ANOVA summary indicate that the CD-RISC total score significantly predicted the CHIP I subscale total score ($R^2 = .405$, $F(1, 106) = 72.057$, $p = .000$); the CHIP II subscale total score, ($R^2 = .427$, $F(1, 106) = 78.947$, $p = .000$); and the CHIP III subscale total score, ($R^2 = .356$, $F(1, 106) = 58.523$, $p = .000$). These findings are significant and allow the researcher to predict one's coping score based on their resilience score.

In examining statistical assumptions to perform multiple regression, as established with the linear regression analysis, normality, homogeneity, and linearity were met. The

other assumptions of multiple regression were assessed by creating scatterplots of the dependent variable by each independent variable. All three scatterplots displayed a linear relationship. Multicollinearity was assessed by examining tolerance and VIF (variance inflation factor) statistics. For each linear regression, tolerance exceeded values of .2 and VIF was below two, indicating that multicollinearity is not a concern. Multiple regression was conducted to examine whether the CD-RISC total score was predicted by individual CHIP subscales and how sick the mother felt her child was at the time of the survey, as illustrated in Table 8. All three CHIP subscales were not able to be entered into the regression equation at one time due to tolerance levels that exceeded 0.1, indicating multicollinearity. However, when each CHIP subscale was entered into the regression individually, along with the variable how sick is your child, each equation was significant and explained between 43.1-50.5% of the variance in the CD-RISC total score.

Table 8

*Regression of CD-RISC Total Score by CHIP Subscales and How Sick the Child Is**(N=108)*

Variables	Regression Coefficient	SE	<i>t</i>
CHIP I Subscale	0.698	0.086	8.146
How Sick Child Is	-2.412	1.051	-2.296
Model adjusted $R^2 = .499$; ($F_{(2, 105)} = 53.699$, $p = .000$)			
CHIP II Subscale	0.699	0.084	8.362
How Sick Child Is	-2.586	1.018	-2.540
Model adjusted $R^2 = .505$; ($F_{(2, 105)} = 55.599$, $p = .000$)			
CHIP III Subscale	1.505	0.219	6.862
How Sick Child Is	-3.071	1.087	-2.825
Model adjusted $R^2 = 0.431$; ($F_{(2, 105)} = 41.487$, $p = .000$)			

Another multiple regression was conducted to examine whether the CD-RISC total score was predicted by individual CHIP subscales and the stress level of the mother at the time of the survey, as illustrated in Table 9. As before, all three CHIP subscales were not able to be entered into the regression equation at one time due to tolerance levels that exceeded 0.1, indicating multi-collinearity. However, when each CHIP subscale was entered into the regression individually, along with the variable what is your stress level, each equation was significant and explained between 45.1-53.1% of the variance in the CD-RISC total scores.

Table 9

Regression of CD-RISC Total Score by CHIP Subscales and Stress Level of Mother

(*N*=108)

Variables	Regression Coefficient	SE	<i>t</i>
CHIP I Subscale	0.684	0.081	8.421
Stress Level of Parent	-3.466	1.057	-3.278
Model adjusted $R^2 = .522$; ($F_{(2, 105)} = 58.990$, $p = .000$)			
CHIP II Subscale	0.692	0.079	8.758
Stress Level of Parent	-3.581	1.009	-3.548
Model adjusted $R^2 = .531$; ($F_{(2, 105)} = 61.549$, $p = .000$)			
CHIP III Subscale	1.496	0.211	7.093
Stress Level of Parent	-3.830	1.097	-3.491
Model adjusted $R^2 = 0.451$; ($F_{(2, 105)} = 44.988$, $p = .000$)			

Conclusion

The results in Chapter IV present findings in text and in tables. The methodology outlined in the previous chapter was followed by descriptions of data collection and analyses. The following research questions were answered: Is resilience positively associated with coping in mothers of children with SCD? Are there differences/relationships between mothers with certain demographic/situational variables on resilience and coping? Does resilience predict coping and are coping and resilience predicted by demographics or situational variables? The data were able to answer each of the research questions and support many of the researcher’s theoretical assumptions. Further, the data analysis indicated several significant study findings.

The instruments in this study demonstrated high reliability for the sample. All participants were over the age of 18 and were mothers of a child with SCD. The demographic variables of age, marital status, employment status, and the number of children with SCD were not significantly related to or different when examining the dependent variables. However, Table 1 illustrates that 75.7% (n=82) of the sample were married, 94.4% (n=102) were employed, and 97.2 % (n=105) reported having only one child with SCD, indicating a lack of variability in those variables. The mean age was calculated to be 33.29 years and was not significantly related to any of the dependent variables. Education level was found to be significantly different for CD-RISC total score when recoded into categorical level groups. Table 5 demonstrates that those participants with some college to any college degree to have a higher resilience score.

Situational variables in the study showed significance in analyses. Tables 6 and 7 illustrate these findings. Table 6 demonstrates that mothers reporting no stress resulted in higher coping and resilience, and mothers reporting moderate stress had the lowest coping and resilience scores. Table 7 shows that mothers reporting their child as not being sick at the time of the study resulted in higher resilience and coping scores. These findings will be discussed in terms of the framework, the resiliency model of family stress, adjustment, and adaptation in the next chapter.

The positive correlation between resilience and coping in mothers of children with SCD is shown in Table 4. An increase in CD-RISC scores is accompanied by an increase in CHIP scores. Linear regressions conducted also determined one's resilience score may be predicted based on their coping score. This study's findings and application to theory, future research, and practice will be discussed in Chapter V.

CHAPTER V – DISCUSSION

The discussion presents the findings of the study, their significance to theory, research, and nursing practice, the limitations encountered, and recommendations for future research. This study was conducted to address a gap in knowledge on resilience and coping in mothers of children with SCD. Literature reports the importance of resilience and coping in mothers, and their impact on family life and adaptation in other populations of chronically ill children (Brown et al., 1993; Burnes et al., 2008; Jenerette & Valrie, 2010; Thompson et al., 1993). However, only a few recent studies have been performed that address how mothers, specifically of children with SCD, cope day-to-day with caring for a child with a chronic illness. The purpose of this study was to examine certain variables thought to influence maternal coping in mothers of children with SCD and to determine if resilience contributes to coping.

The CDC (2016) reports that one out of every 365 African-American births will have SCD, affecting 100,000 Americans. This study is pertinent to all healthcare providers who care for children and families with SCD. Growing concerns over the lack of research in this area, and the desire to promote awareness of what mothers' report as successful coping, gave this study focus and purpose. The study's theoretical base, the resiliency model of family stress, adjustment, and adaptation (McCubbin & McCubbin, 1993) provided the framework to guide the study. An online quantitative research design, involving mothers caring for children with SCD, was performed to meet this study's purpose.

Discussion of Findings: Theoretical Framework

The resiliency model of family stress, adjustment, and adaptation (McCubbin & McCubbin, 1993) states that resilience is a major factor in coping when caring for a child with a chronic illness. The model encourages the nursing profession to recognize the power of resilience on coping in families and to implement the promotion of resilience when appropriate.

The overall findings of the study, as evidenced in Chapter IV, support the theoretical assumption that resilience does predict coping in mothers of children with SCD. In addition, education level, stress level, and how sick their child has predicted resilience and coping in mothers of children with SCD, while age did not. Findings from this research study fit the theoretical framework and also inform nurses to recognize the importance of resilience in coping. This study demonstrated that coping could be predicted by the level of resilience. Likewise, the findings that stress and the severity of a child's illness may weaken resilience of the parent is similar to the variables identified by the model as being vital to overall coping and adaptation to parenting a child with a chronic illness. McCubbin & McCubbin (1993) emphasize the importance of resiliency in families when faced with the stressors of life while coping with a crisis. The authors of the model also explicate the significance of healthcare professionals recognizing resilience as a variable in planning care and implementing interventions for families coping with a chronic illness.

Discussion of Findings: Previous Research

The findings in this study indicate a strong positive correlation between resilience and coping in mothers of children with SCD. A strong positive correlation indicates that

as resilience increases so does coping. In addition, linear regressions were conducted to determine whether coping scores individually predicted resilience. The ANOVA summary indicated that resilience was significantly predicted by the coping subscale scores as reported in Chapter IV. These findings allow the researcher to also predict resilience based on coping.

Overall, the participants demonstrated resilience and coping; however, resilience and coping scores were lower in times of stress and when their child was severely sick. Likewise, coping followed this pattern, with fewer coping behaviors reported in times of stress or when their child was severely ill. Reported stress levels had more effect on resilience and coping behaviors than the reported severity of the child's illness. Previous studies had similar results regarding the situational variables measured, with an increase in stress leading to poor coping in parents of children with chronic illnesses (Cousino & Hazen, 2013; Thompson et al., 1993; Thompson et al., 1994). The severity of a child's disease having an impact on coping and adjustment was also found not to be as significant as stress levels in a similar research study (Thompson et al., 1993). An additional interesting finding in the study was that the mothers reporting the lowest resilience and coping scores reported moderate stress levels. This particular finding was not seen in the literature; however, the framework of the study may suggest a possible lack of adaptive response to the stress of a chronic nature.

A surprising and unexpected finding was that the age of the participant was not significantly correlated with resilience or coping in this study (Table 4). Age was an assumption by this researcher to have an effect on resilience and coping, as was seen in the literature (Hildenbrand et al., 2015; Wonkam et al., 2014). The younger the mother,

lower resilience and fewer coping behaviors were expected. However, the sample in this study had a mean age of 33.29 years and 75.7% were married. These findings indicate a possibility of some increased level of support and in an older sample.

The analysis of the other demographic variables in this study indicated that education level did influence the incidence of reporting resilience. Higher resilience scores were obtained from those participants reporting some college to a college degree. Previous studies also found the identification of education level to be of significance in reporting resilience (Frain et al., 2007; Hall et al., 2012; Tak & McCubbin, 2002; Ye et al., 2015). This study sample had a significantly higher education level as reported in Chapter IV, offering an explanation to higher resilience scores.

The majority, 95.4% (n=103), of participants in the study (Table 1) had greater than a high school education, leading to the high reliability of the instruments used, higher than reported by the authors (Connor & Davidson, 2003; McCubbin et al., 1983) as described in Chapter III. Cronbach alpha scores were .956 (CD-RISC), .924 (CHIP subscale I), .952 (CHIP subscale II), and .882 (CHIP subscale III). The strong positive correlation between resilience and coping in this study's sample is a new finding.

Significance of Findings

This study's findings add to the current body of knowledge in nursing concerning care for families of chronically ill children. Specifically, the findings will help fill the absence of research in the literature on resilience and coping in mothers of children with SCD. Mothers of children with SCD may encounter significant day-to-day challenges that mothers of healthy children do not face. Mothers who participated in the study by sharing their feelings through their responses informed the researcher in what is known

about the role resilience plays in coping. The importance of parental coping was revealed in the literature; however, this study revealed knowledge specifically related to mothers of children with SCD. The study is significant to any healthcare provider or agency caring for families of children with SCD. This study's findings also reinforce findings from studies involving other chronic illnesses that report situational variables, such as stress and times when the child is extremely ill, can negatively influence resilience and coping.

Implications for Nursing

Practice

This study's findings are important to all professionals involved in the care of sickle cell families. This group may include nurses, social workers, physicians, and those directing foundations and support groups specifically for sickle cell families. All involved should make an effort to work together to provide the necessary resources for successful coping in these families. The findings of the study are significant in reporting the strong relationship between resilience and coping. Understanding that resilience can predict coping is important to nurses and can be useful when planning care. Nurses who realize that resilience is weakened when a child is severely ill or when the mother is under a great amount of stress may intervene in these times to help the mother cope. Knowing that resilience predicts coping, and likewise that coping predicts resilience can be useful in caring for families with SCD. Clinicians should include asking about stress levels and perceptions of how sick the child is during assessment and when planning care for families of children with SCD. Nurses should also take into account marital status, education level, employment status, age, and the number of children with SCD.

Education

Application of study findings includes identifying and implementing ways to increase resilience and coping in mothers of children with SCD. As stated in the literature review, mothers who have positive coping have less day-to-day stress and will have children with better coping behaviors (Barbarin et al., 1999; Cousino & Hazen, 2013; Jenerette & Valrie, 2010; Oliver-Carpenter et al., 2011). Providers of care to children and families with SCD should recognize the significance of resilience and coping in these mothers, identify stressors, locate resources to alleviate stressors, and provide the mother with education on the importance of their personal resilience and coping. Nurses, likewise, should be educated on the importance of screening mothers of children with SCD for resilience, coping, and situational or demographic variables that may negatively influence their ability to cope. Providers' education and awareness about this study's findings among mothers of children with SCD are paramount to promoting health in mothers and their children with SCD.

The researcher plans the following methods to disseminate the results of the study to providers. Study results will be presented through presentations to healthcare providers in a national conference venue. The findings will be shared with the participating sickle cell agencies in the study, as well as the participants who indicated in the study demographics section that they would like to know the overall study findings. Finally, the researcher will submit the study results for publication in a peer-reviewed journal, thereby widely sharing with healthcare providers interested in learning more about resilience and coping in mothers of children with SCD.

Study Limitations and Recommendations for Future Research

This study provides reliable data on the correlation between resilience and coping in mothers of children with SCD. The study also describes that during high levels of stress and in times when a child is extremely sick, a mother's ability to maintain resilience and coping is impacted. While this study provides valuable data to existing research on resilience, it reveals the need for further research to uncover whether other specific variables may impact resilience in this study's population.

The study found higher education levels to be linked to higher resilience in mothers. Incidentally, the highly educated sample also increased the reliability of the instruments used in the study; however, the study sample being highly educated limits the generalizability of findings. Further, most of the participants were married, which may indicate financial and non-tangible resource support, and possibly account for higher resilience and coping. This finding is also a limitation of the research. Further research involving the effect of education level and marital status on resilience and coping is indicated in a sample more diverse in those areas. Likewise, further study on employment status and stress is recommended. Of the 108 participants in the study, 94.4% (n= 102) were employed. The impact of employment status and maintaining a job while caring for a child with a chronic illness requires further study. The researcher did not ask race, assuming that the majority of participants in the study were African-American; however, more research is indicated to determine if ethnicity is correlated to resilience and coping in mothers of children with a chronic illness. The study sample were all mothers, limiting the generalizability of the findings to fathers and to other caregivers. The overall purpose of the study to examine whether the independent

variables (resilience, situational variables of interest, and demographics) predict coping in mothers of children with SCD was successful. The findings, however, indicate the need for further research in mothers and families caring for children of SCD.

The study was conducted online through Qualtrics, which limited participation to those who had access to a computerized device and an internet connection. The study could be completed by using a computer, tablet, or smartphone; however, internet or WIFI was necessary. Another limitation was the recruitment process was performed by sending the recruitment flyer via client e-mail lists or posting the flyer on the Facebook pages and/or the websites of the participating sickle cell agencies. The recruitment flyer was also physically posted in the sickle cell agencies participating in the study. The wide dispersion of the study was due to a snowball effect, with participants forwarding links to each other. The snowball effect limited the participants to those with internet access or access to the participating facilities. This effect also may have unintentionally created bias within the sample, particularly due to social networking among friends with similar ages, education, and employment status. The researcher believes this unintentional bias is one reason why the demographic data from the study is not as diverse as it could have been. Most participants were employed, married, and had some college. A further recommendation would be to conduct a study with paper questionnaires and recruit participants from clinical settings, such as hematology clinics or sickle cell clinics. Doing so would allow those without computer access to participate by implementing different recruitment and data collection method.

An additional recommendation for future research is a qualitative study. This type of study could explore what mothers of children of SCD perceive as resilience. The

researcher may uncover the meaning of resilience, the themes involved in resilience, and perspectives of resilience specific to mothers of children with SCD. The results of a qualitative study could then be used to conduct an additional quantitative study on more specific situational variables revealed by mothers that play a role in resilience and likewise coping. A study of this nature may reveal more data on what variables contribute to resilience and pinpoint resources and ways to foster resilience in mothers of children with SCD as well as other chronic illnesses. A final recommendation for future study includes nurses who care for families of children with SCD. Nurses' perceptions of the meaning and importance of resilience and coping would provide interesting information on how to educate nurses on assisting families in meeting their coping needs and receiving the necessary support to promote resilience.

Conclusion

Overall findings suggest that resilience and coping are positively correlated. Variables such as education level, stress level, and how sick a mother perceives her child to be, were found to influence resilience and coping. Resilience was determined, through statistical analysis of study data, to predict coping. This finding is important to healthcare providers in understanding the importance of resilience and coping in mothers of children with a chronic illness such as SCD. The implications of situational variables such as stress and having an extremely sick child must also be considered when caring for these families.

The findings in this research are useful to all healthcare professionals who care for patients and families with SCD. Evaluation of the findings indicates that the strong relationship between resilience and coping should be considered when caring for families

with a child that has a chronic illness. The study suggests the positive implications for coping when mothers report a strong sense of resilience. Previous research studies, as well as the study's framework, report the benefits of coping to the mother and entire family when faced with the day-to-day stress that may be encountered when a child has a chronic illness. Other variables, such as situational stress and times when the child is extremely ill may alter a mother's sense of resilience and, therefore, lessen coping. Healthcare providers may intervene to increase resilience and coping, especially in these situations to assist mothers through counseling and referrals to local sickle cell support groups.

Despite its limitations, this study was successful in reporting the relationship between resilience and coping in mothers of children with SCD and the variables that can affect these characteristics. The study also verified the utility of the resiliency model of family stress, adjustment, and adaptation (McCubbin & McCubbin, 1993) in the study sample of mothers of children with SCD. Further, the unexpected wide dispersion of the participants helped mitigate geographical biases and differences in care and perhaps culture. The geographic dispersion lends to the validity of the study. Excellent reliability was reported, and the study also validated the use of two important instruments, one on coping and the other on resilience, in mothers of children with SCD. This study produced useable results intended to promote resilience and coping in mothers of children with SCD.

APPENDIX A – Connor-Davidson Resilience Scale 25 (CD-RISC-25)

Dear Holly:

Thank you for your interest in the Connor-Davidson Resilience Scale (CD-RISC). We are pleased to grant permission for use of the CD-RISC in the project you have described under the following terms of agreement:

1. You agree (i) not to use the CD-RISC for any commercial purpose unless permission has been granted, or (ii) research or other work performed for a third party, or (iii) provide the scale to a third party without permission. If other colleagues or off-site collaborators are involved with your project, their use of the scale is restricted to the project described, and the signatory of this agreement is responsible for ensuring that all other parties adhere to the terms of this agreement.
2. You may use the CD-RISC in written form, by telephone, or in secure electronic format whereby the scale is protected from unauthorized distribution or the possibility of modification. **In all presentations of the CD-RISC, including electronic versions, the full copyright and terms of use statement must appear with the scale. The scale should not appear in any form where it is accessible to the public, and should be removed from electronic and other sites once the project has been completed.**
3. Further information on the CD-RISC can be found at the www.cd-risc.com website. The scale's content may not be modified, although in some circumstances the formatting may be adapted with permission of either Dr. Connor or Dr. Davidson. If you wish to create a non-English language translation or culturally modified version of the CD-RISC, please let us know and we will provide details of the standard procedures.
4. Three forms of the scale exist: the original 25 item version and two shorter versions of 10 and 2 items respectively. When using the CD-RISC 25, CD-RISC 10 or CD-RISC 2, whether in English or other language, please include the full copyright statement and use restrictions as it appears on the scale.
5. A student-rate fee of \$ 30 US is payable to Jonathan Davidson at 325 Carolina Meadows Villa, Chapel Hill, NC 27517, USA, either by PayPal (www.paypal.com, account mail@cd-risc.com), cheque, bank wire transfer (in U.S.), international money order or Western Union.
6. Complete and return this form via email to mail@cd-risc.com.
7. In any publication or report resulting from use of the CD-RISC, you do not publish or partially reproduce items from the CD-RISC without first securing permission from the authors.

If you agree to the terms of this agreement, please email a signed copy to the above email address. Upon receipt of the signed agreement and of payment, we will email a copy of the scale.

For questions regarding use of the CD-RISC, please contact Jonathan Davidson at mail@cd-risc.com. We wish you well in pursuing your goals.

Sincerely yours,

Jonathan R. T. Davidson, M.D.
Kathryn M. Connor, M.D.

Agreed to by:

____Holly Carter_____
Signature (printed)

____1/14/18_____
Date

____Student_____
Title

____The University of Southern Mississippi_____
Organization

APPENDIX B – Coping Health Inventory for Parents

The Resilience, Adaptation and Well-Being Project



January 30, 2018

Holly Carter
College of Nursing
University of Southern Mississippi

Dear Holly Carter

The purpose of this correspondence is to confirm permission for your use of Coping Health Inventory for Parents measure for your research inclusive of permissions to print whatever copies you need to for your project.

We are open to answering any questions you may have.

If you make a translation of the measure into the language, other than English, please do send us a copy so we may inform others of its availability.

Let us know if we can be of assistance.

Sincerely,

A handwritten signature in black ink, appearing to read "J. Sievers".

Jason A. Sievers, PhD
Associate Director, The Resilience, Adaptation and Well-Being Project

CC: Laurie "Lali" McCubbin, PhD
CC: Hamilton I. McCubbin, PhD

Coping Behaviors:					I do not cope this way because:	
	Extremely Helpful	Moderately Helpful	Minimally Helpful	Not Helpful	Choose not to	Not Possible
1. Talking over personal feelings and concerns with spouse	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
2. Engaging in relationships and friendships	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
3. Trusting my spouse (or former spouse) to help support me and my child(ren)	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
4. Sleeping	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
5. Talking with the medical staff (nurses, social worker, etc.) when we visit the medical center	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
6. Believing that my child(ren) will get better	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
7. Working, outside employment	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
8. Showing that I am strong	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
9. Purchasing gifts for myself and/or other family members	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
10. Talking with other individuals/parents in my same situation	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
11. Taking good care of all the medical equipment at home	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
12. Eating	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
13. Getting other members of the family to help with chores and tasks at home	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
14. Getting away by myself	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
15. Talking with doctor about my concerns about my child(ren) with the medical condition	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
16. Believing that the medical center/hospital has my family's best interest in mind	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
17. Building close relationships with people	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
18. Believing in God	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
19. Develop myself as a person	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>

Coping Behavior	Extremely Helpful	Moderately Helpful	Minimally Helpful	Not Helpful	I do not cope this way because:	
					Choose Not to	Not Possible
20. Talking with other parents in the same type of situation and learning about their experiences	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
21. Doing things together as a family (involving all members of the family)	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
22. Investing time and energy in my job	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
23. Believing that my child is getting the best medical care possible	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
24. Entertaining friends in our home	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
25. Reading about how other persons in my situation handled things	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
26. Doing things with family relatives	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
27. Becoming more self reliant and independent	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
28. Telling myself that I have many things I should be thankful for	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
29. Concentrating on hobbies (art, music, jogging, etc.)	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
30. Explaining family situation to friends and neighbors so they will understand us	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
31. Encouraging child(ren) with medical condition to be more independent	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
32. Keeping myself in shape and well groomed	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
33. Involvement in social activities (parties, etc.) with friends	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
34. Going out with my spouse on a regular basis	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
35. Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
36. Building a closer relationship with my spouse	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
37. Allowing myself to get angry	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>

Coping Behavior	Extremely Helpful	Moderately Helpful	Minimally Helpful	Not Helpful	I do not cope this way because:	
					Choose Not to	Not Possible
38. Investing myself in my child(ren)	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
39. Talking to someone (not professional counselor/doctor) about how I feel	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
40. Reading more about the medical problem which concerns me	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
41. Trying to maintain family stability	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
42. Being able to get away from the home care tasks and responsibilities for some relief	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
43. Having my child with the medical condition seen at the clinic/hospital on a regular basis	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
44. Believing that things will always work out	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
45. Doing things with my children	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX C – Permission Letters



Southeast Alabama Sickle Cell Association, Inc.

4201 Martin Luther King Highway

P.O. Box 1079

Tuskegee Institute, Alabama 36087-1079

Phone: (334) 727.6120 * (800) 854-1367

Fax (334) 727.9390

May 22, 2018

Institutional Review Board
Office of Research Integrity
The University of Southern Mississippi


Dear IRB Members,

The purpose of this letter is to grant permission to Holly Carter to recruit participants for her dissertation study, "Resilience and Coping in Mothers of Children with Sickle Cell Disease" by using a recruitment flyer. The recruiter flyer will be emailed to our clients by our association, and if interested the individuals will contact Mrs. Carter by email to participate in the research study.

Sincerely,

A handwritten signature in blue ink, appearing to read "James Arrington". The signature is fluid and cursive.

James Arrington
Executive Director

 **CELEBRATING LIFE!**

**SICKLE CELL DISEASE ASSOCIATION OF
AMERICA—CENTRAL ALABAMA CHAPTER**

3813 Avenue I
Birmingham, AL 35218-3132
Email: info@sicklecellbham.org

Phone: 205-780-2355
Fax: 205-780-2368
Toll-Free: 800-735-0405

July 2, 2018

Institutional Review Board
Office of Research Integrity
The University of Southern Mississippi

Dear IRB Members,

The purpose of this letter is to grant permission to Holly Carter to recruit participants for her dissertation study, "Resilience and Coping in Mothers of Children with Sickle Cell Disease" by using a recruitment flyer. The recruiter flyer will be emailed to our clients by our association, and if interested the individuals will contact Mrs. Carter by email to participate in the research study.

Sincerely,


Sharon B. Lewis
Executive Director





Sickle Cell Disease Association of America—Mobile Chapter, Inc.

June 8, 2018

Executive Director
Keava Boswell Jones, Esq.

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Sickle Cell Client

Gary Simpson
Dupont, Retired

Ronnie L. Williams, Esq.
Williams & Associates, LLC


Institutional Review Board
Office of Research Integrity
The University of Southern Mississippi

Dear IRB Members,

The purpose of this letter is to grant permission to Holly Carter to recruit participants for her dissertation study, "Resilience and Coping in Mothers of Children with Sickle Cell Disease" by using a recruitment flyer. The recruiter flyer will be emailed to our clients by our association, and if interested the individuals will contact Mrs. Carter by email to participate in the research study.

Should you have any questions, please do not hesitate to contact me.

Regards,


Keava Boswell Jones, Esq.
Executive Director

APPENDIX D – IRB Approval Letter



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: 18072703

PROJECT TITLE: Resilience and Coping in Mothers of Children with Sickle Cell Disease

PROJECT TYPE: Doctoral Dissertation

RESEARCHER(S): Holly Carter

COLLEGE/DIVISION: College of Nursing and Health Professions

DEPARTMENT: Leadership and Advanced Practice Nursing

FUNDING AGENCY/SPONSOR: N/A

IRB COMMITTEE ACTION: Exempt Review Approval

PERIOD OF APPROVAL: 07/31/2018 to 07/30/2019

Edward L. Goshorn, Ph.D.

Institutional Review Board

RESEARCH STUDY FOR MOTHERS

Resilience and Coping in Mothers of Children with Sickle Cell Disease

The study consists of demographic questions and two questionnaires, and will take approximately 20 minutes to complete. It can be taken on your cell phone or computer. Participation is 100% voluntary and your responses are completely confidential. We know your time is valuable but hope you will please help us with the study. If you would like to participate, please click on the link below. Thank you for your consideration and time.

https://usmuw.co1.qualtrics.com/jfe/form/SV_bPHJJG eFvWtmbrv



Email holly.carter@usm.edu with any questions.

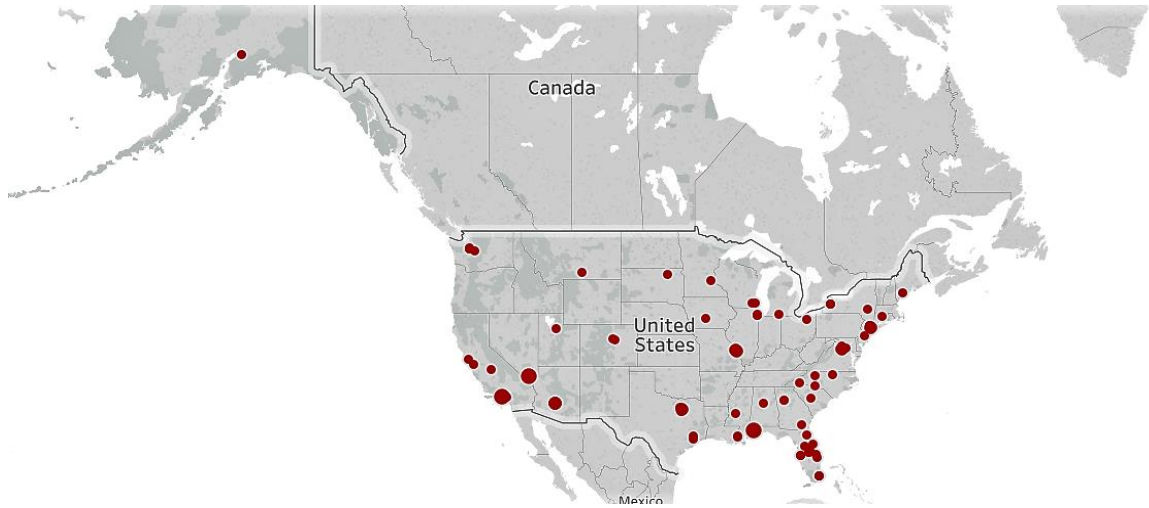
Current research study for
mothers of children with
sickle cell disease

Participants should be a
mother over the age of 18,
and have a child or
children with sickle cell
disease

Please consider taking
part in this important
study

All participants to
complete the study
will receive a \$10.00
Wal-Mart gift card
via email. In
addition, when you
complete the study
you will be entered
to win 1 of 3 \$50.00
Wal-Mart gift cards.

APPENDIX F – Heat Map



APPENDIX G – Demographics and Situational Variables Questionnaire

Please answer the following:

- 1) Are you 18 years of age or older?
 - Yes
 - No

- 2) Are you a mother of a child/children with sickle cell disease?
 - Yes
 - No

- 3) Please record your age: _____

- 4) Marital Status
 - Single, never married
 - Married
 - Widowed
 - Divorced
 - Separated

- 5) Please record the number of children you have with sickle cell disease: _____

- 6) Education Level
 - Below high school
 - Some high school
 - High school graduate or GED
 - Some college credits
 - Associate's degree
 - Bachelor's degree
 - Master's degree or higher

- 7) Employment Status
 - Employed
 - Unemployed
 - Retired

- 8) Please rate your stress level today
 - None (0)
 - Little (1)
 - Moderate (2)
 - High (3)
 - Extremely High (4)

9) How sick do you feel your child is today?

- Not sick (0)
- A Little Sick (1)
- Moderately sick (2)
- Very Sick (3)
- Extremely Sick (4)

10) Please enter your zip code: _____

11) Would you like a copy of the final study results sent to your e-mail?

- Yes
- No
-

12) Please enter your email address below to receive your \$10.00 gift card:

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