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Understanding Parents' Disease-Managing Strategies for Children With Sickle Cell Disease

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Abstract

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MA, Dallas, Baptist University, 2010

BS, Wayland Baptist, 1998

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Health Services

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Abstract

Sickle cell disease (SCD) is one of the most difficult and stressful chronic diseases for parents of afflicted children to manage. Managing SCD can be traumatic for parents particularly if they have no specific coping strategies for managing the disease or ensuring the child visits the doctor as scheduled. The use of certain coping strategies may affect the parents' and patients' perceptions of the illness and influence their decisions regarding treatment, which can have a lasting impact on their lives. Effective parental strategies such as positive thinking can aid in disease management, but there is limited research on the coping strategies used by parents of children with SCD specifically. The purpose of this phenomenological study, which was guided by Thompson and Gustafson's transactional stress and coping model, was to describe parents' coping strategies in managing their young child's SCD as it relates to use of health services. Data collection included one-to-one, open-ended interviews with 10 parents of children with SCD. Colaizzi's method of phenomenological data analysis was used to identify themes. Five themes emerged from data analysis and they are: parental methods of coping with SCD, participants' understanding of SCD, SCD family and support, managing SCD with hydration and medication, and experience accessing healthcare. These results indicated the participants' coping strategies varied according to their individual situations. Insight from this study could lead to positive social change by helping to identify specific coping strategies parents can use to better manage their child's disease and effectively access available health services.

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Dedication

This journey was not given to the swift or the battle to the strong but to the one that endured to the end. Lord Jesus, I dedicate this study, line by line and words by words first to you. Oh God, you sustained me with life, great health, and support during the writing of this dissertation. I am forever grateful. I dedicate this research to my husband, Clarence Mackey, thank you for your love, support and unbelievable patience throughout this journey and for never giving up on me, baby! I love you so much. I also dedicate this study to my brilliant sons, Clarence Jr., and Christawn Isaiah Mackey. You two royal kings have inspired me to always pray, persevere, and believed that the Lord is a healer and we can do anything with his help. Thank you for praying for your mother. I love you two! To my parents, the late Sylvester James Noble, I love and miss you deeply daddy and to my 96 year old mother, Olner Relaford Noble, who cared for seventeen children, with me being the youngest and the first Ph.D., in the family. I thank you mother for singing songs, reading the newspapers, and the Bible to me and making sure the foundation was laid. I love you dearly. Finally, I dedicate this research to the parents of children with sickle cell disease around the universe, hang in there! I am praying for you all.

Acknowledgments

Education is the most powerful weapon which you can use to change the world (Nelson Mandela) in conjunction with prayer and teamwork. Dr. JaMuir M. Robinson, Chair, your expertise and education has helped many students including me change the world. Thank you for inspiring me to conduct quality research and for your intelligence, expertise, and support during the writing of my dissertation. You were an inspiration to work with because of your passion to see students that are sincere achieve their doctorate. When I was tired of the mountains of revisions, you continued to inspire me to give more and search deeper and narrow my literature review. You have always responded in a timely manner. Your guidance will never go unnoticed. Because of professors like you, I will make a social change in society by helping parents of children with sickle cell disease cope better. I am forever grateful to the Lord who has allowed you and me to work together. Thank you from the bottom of my heart. You are phenomenal!

Every student has the equipment and potential to be great if only they will (Edgar Guest). Dr. Jacquie Fraser, Committee Member, I want to thank you for your humor and expertise in the guidance of my qualitative data analysis. Your explanation and teaching of Colaizzi's (1978) seven steps for data analysis made a big difference in keeping volumes of data together. Thank you for your guidance. I was tired but your comments motivated me to work harder. I am forever grateful to you. Thank you Dr. Sriya Krishnamoorthy, URR member as well.

To my sixteen siblings, my sisters, Margaret Tabbs, Minnie D, Fletcher, Bernadine Dale, Evelyn Noble, Laverne Noble, Clementenia Noble, Janice Young, Velda

Rollinson, and Coatney Marcella Noble, and brothers the late David Noble, and Harold Noble, I miss you two deeply, Carlvin Noble, Wendell L. Noble Sr., Avery Noble and Marease Noble thanks for your prayers, encouraging words, and faith in God who has helped me complete this journey. To the late Leroy Mackey Jr., my father- in-law, I miss you dearly. To my nieces, nephews, aunts, uncles, and cousins in the Mackey, Noble, and Relaford families, thank you for your encouraging words and prayers. To my goddaughter, Nifemi Tella and godson, Jonah Tucker. I love you both. Finally, to my prayer partners, Wanda Albritton, Arbur Henderson, Barbara Johnson, and JoAnn Thomas. Thank you for praying for me and never giving up. The Lord is faithful. He did it. Yes, God did it for me!

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Chapter 1: Introduction to the Study

Caring for a child with sickle cell disease (SCD) causes emotional stress and a burden for the parent (Derlega et al., 2014). Barakat, Daniel, Smith, Robinson, and Patterson (2014) found that parents of children with SCD reported their child to have lower physical, psychological, and social health related quality of life (HRQOL) compared to children without SCD. The lower physical HRQOL has been associated with frequent pain and family and community distress (Barakat et al., 2014)

More than one thousand babies in the United States are born with SCD every year (Derlega et al., 2014). The Centers for Disease Control and Prevention (CDC; 2016) reported that SCD affects approximately 100,000 Americans and costs the United States over $475 million a year in healthcare. Although other racial and ethnic groups are affected by SCD, African Americans represent the largest population in the United States with SCD (Derlega et al., 2014). SCD is global disease impacting people of African, Asian, Mediterranean, and Middle-Eastern origins. Imhonde, Ndom, and Ehon (2013) reported that, according to the World Health Organization (WHO), 200,000 infants are born with sickle-cell in Africa every year, with Nigeria accounting for about three-quarters of these births. Sixty percent of the 200,000 will die as infants. The disease occurs in about 1 in every 500 African American births and 1 in every 36,000 Hispanic American births (Hildenbrand, Barakat, Alderfer, & Marsac, 2015). More than 2 million people are genetic carriers of the sickle cell trait (Thompson & Eriator, 2014).

Hoyt Drazen, Abel, Lindsey, and King (2014) suggest the most prevalent and serious form of SCD is the hemoglobin SS in which the blood cells form a sickle shape

instead of the typical round form. Sickle cells have a shorter life span than normal red blood cells. The abnormal cells become trapped in blood vessels, causing vasoocclusion, and pain, the most common morbidity associated with the disease (Hoyt Drazen et al., 2014). SCD has a vast impact on the quality of life for the child as well as the entire family. The disease is associated with adjustment difficulties such as increased depression and anxiety (Cotton, Grossoehme, & McGrady, 2012). Amid and Odame (2014) defined SCD as inherited disorders of abnormal hemoglobin synthesis that is associated with pain and progressive multi organ damage with significant impact on the patients' quality of life.

It is estimated that between one to two thirds of children with SCD experience significant psychological symptoms and impaired health-related quality of life (Barakat et al., 2014; Dale, Cochran, Roy, Jernigan, & Buchanan, 2011; Hildenbrand et al., 2015). SCD can result in physiological, cognitive, and psychosocial comorbidities such as chronic and acute anemia, infection, stroke, severe pain episodes, delayed puberty, and academic underachievement (Sehlo & Kamfar, 2015).

A child with SCD is at risk for poor HRQOL due to medical, sociodemographic and psychosocial factors (Barakat et al., 2014). SCD remains a severe, long-lasting medical illness for many children and young people. With all the advanced medicine and technology, the disease continues to be a significant health concern. There is no cure for SCD. Parent help to manage their children's activities of daily living and provide the necessary care that their children need to manage SCD. Proper management of the disease is essential to the life of the child and how the family functions.

Background of the Study

Edmond, Graves, Whiting, and Karlson (2016) conducted a qualitative study that revealed African American parents who have young children with SCD struggle to cope with the disease. Pain is the hallmark of SCD. The children have more frequent hospitalizations and miss more days of school than the average child. Caring for a child with SCD causes emotional stress and a burden for the parents (Edmond et al., 2016). SCD presents challenges for the family functioning. To understand the significance of disease management and the effect it has on the family functioning, Montero-Marin et al. (2014) indicated the family should possess coping strategies. People will be psychologically vulnerable to a particular situation if they do not possess sufficient coping resources to handle it adequately. Snyder (1999) defined coping as those plans that are used in reducing an undesirable load. Hildenbrand et al. (2015) found that parents of children with SCD lack coping skills to deal with their child's disease due to limited decision making and problem solving skills; they also visit the hospital emergency department (ED) more frequently than parents who have a plan to help them manage the illness.

Problem Statement

Managing SCD and accessing health services is stressful (Cotton et al., 2012; Edmond et al., 2016). SCD causes stress, making it difficult for the parents to cope and manage the disease (Cotton et al., 2012). Managing SCD can be traumatic for parents, particularly if they have no specific plans for managing the disease or ensuring the child visits the doctor as scheduled (Edmond et al., 2016). Parents who know how to cope with

SCD will ensure that their children receive the care that is needed (Derlega et al., 2014; Van Houtum, Rijken, & Groenewegen, 2015). The parent has a central role to play in the treatment of a child with a chronic disease. For example, parents who have good knowledge of their child's disease are more likely to use health services more routinely (Raphael, Rattler et al., 2013).

Bakri, Ismail, Elsedfy, Amr, and Ibrahim (2014) found that it is essential for parents of children with SCD to understand the disease and what is needed to help treat children's pain at the onset. For example, parents who learned to deal with their child's illness in a positive way were able to manage their child's SCD and use their child's specialist rather than the hospital ED and reduce frequent hospitalizations (Barakat et al., 2014).

Children with SCD may experience a number of debilitating symptoms including acute and chronic pain, fatigue, immunodeficiency, and organ and tissue damage (Mainous et al., 2015). For example, between 50% and 60% of all emergency room visits by pediatric SCD patients are for painful events, and between 60% and 80% of hospitalizations for pediatric SCD patients are pain related. Parents who do not know how to manage the disease use the ED more often than they use the child's specialist (Miller & Meier, 2012). There is an association between managing the disease and how the parents care for the child. The use of certain coping strategies may affect the parent and patients' perceptions of their illness and influence their decisions regarding treatment, which can have a lasting impact on their lives. While there is evidence in the literature (Barakat et al., 2014; Derlega et al., 2014) that an effective parental strategy

such as positive thinking can aid in disease management, there is limited research on the coping strategies used by parents of children with SCD specifically.

Purpose of the Study

The literature supports an association between coping strategies and disease management (Barakat et al., 2014; Derlega et al., 2014; Oliver-Carpenter, Barach, Crosby, Valenzuela, & Mitchell, 2011). The purpose of this study was to describe parents' coping strategies in managing their young child's SCD as it relates to use of health services. In this qualitative study, I explored the coping strategies of parents of children with SCD in order to better understand the ways these coping strategies relate to the use of health services. The types of health services that were of interest in this study included use of primary care, specialty clinic, ED, pain management, complementary and alternative medicine (CAM), and access to health providers with expertise in the management of SCD

Research Questions

RQ1**:** What coping strategies are used by parents of children with SCD when managing their child's disease?

RQ2: What are the experiences of parents of children with SCD related to managing their child's healthcare treatment?

Theoretical Framework

Thompson and Gustafson's (1996) transactional stress and coping (TSC) model provided the theoretical framework for this study. In this model, Thompson and Gustafson (1996) describe chronic illness as a stressor in which the children, parents

(maternal is used to represent the parents in this model) and families attempt to adapt. The way in which the parents adapt plays a central role in the children's quality of life.

Figure 1 provides a graphical depiction of the TSC model.

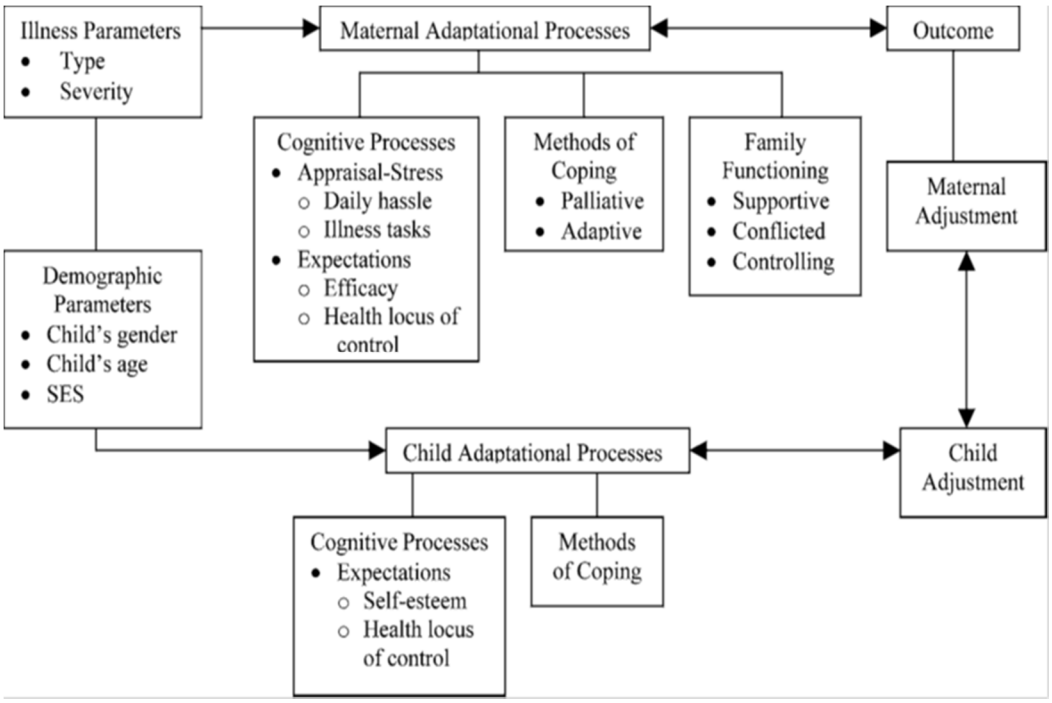

Figure 1. Transactional stress and coping model of adjustment to a chronic illness. Hocking, M. C., & Lochman, J. E. (2005). Applying the transactional stress and coping model to sickle cell disorder and insulin-dependent diabetes mellitus: Identifying psychosocial variables related to adjustment and intervention. *Clinical Child and Family Psychology Review*, *8*(3), 221-246. doi: 10.1007/s10567-005-6667-2

According to the model, adaptation to a chronic illness includes the illness parameters (type and severity), demographic parameters (child's age, gender, and social economic status) and child and maternal adaptational processes. The first component of the TSC model is the cognitive processes (evaluation of the stressor). In the parents, that

included appraisal stress involving the daily hassle of the stress and the illness tasks (Thompson and Gustafson, 1996). The cognitive process also includes expectations of treatment efficacy (in parents) or self-esteem in children and health locus of control. The second component is the method of coping that includes adaptive coping (problem focused coping) and palliative coping. Adaptive coping or problem-focused coping involves altering the stressful transaction between the environment and person by attempting to change the environment of the individual. There is also palliative coping, where there is a combination of avoidance, wishful thinking, and emotion-focused coping, where attempts are made to regulate the emotions that are associated with stress. The third component that applies just to parents is family functioning. Supportive, conflicted, and controlling are the three types of family functioning associated with maternal adaptation process. How the children adjust to the chronic illness is impacted by the adjustment of their parent (depicted as maternal adjustment in the TSC model).

Hocking and Lochman (2005) found that the TSC model can be used to view adaptation to a childhood chronic illness as mediated by several psychosocial factors. For example, stress and depression are two psychosocial factors experienced by parents who have children with SCD. The model has been used to help construct research on how parents and their children deal with chronic illnesses that are considered stressful (Mullins et al., 2015; Thompson & Gustafson, 1996). For example, the child's disease and treatment is considered a potential stressor. Children with chronic illness tend to communicate and model the same behavior their parents use to deal with the disease (Mullins et al., 2015). The child's adjustment influences the parents' adjustment, and in

turn, parents' adjustments influence the child's adjustment. In this model, there is a strong emphasis on the transactions that take place between the child and mother with reciprocal influence taking place. However, in this study, both parents were included. I applied the model to the development of the interview questions that guided this study. I used the TSC model to interpret the findings of the coping strategies used by parents of children with SCD as related to healthcare use and disease management. Further discussions of the TSC model in relation to this study are included in Chapter 2.

Nature of the Study

This qualitative research study included a phenomenological approach to gain knowledge through the description of lived experiences of the coping strategies parents use to manage SCD and use available healthcare services. Phenomenological approaches explore how human beings make sense of experiences and transform experiences into consciousness both individually and as shared meaning (Patton, 2002). The origins of phenomenology are the writings of Husserl (Koch, 1995) and the advancement of his thoughts by Merleau-Ponty, Heidegger, Gadamer, and Ricoeur. Koch (1995) explained that Husserl focused on the experience itself. In contrast, Heidegger's attention was on the process of understanding the experience (Koch, 1995). Heidegger was concerned with ontological questions on the nature of being, while Husserl focused on questions of epistemology, the nature of knowledge (Koch, 1995; McConnell, Henry, Chapman & Francis, 2009; Ray, 1994). Dahlberg, Drew, and Nystrom (2001) stated that the philosophical foundation of the phenomenological approach is the world as it is experienced, in all its variety. Heidegger's focus on the process of understanding the

experience was not appropriate for this study because the phenomenon that was the focus of this study was the coping strategies of parents who have children with SCD and how they access health services. I chose Husserl's transcendental phenomenological approach because I examined participants' lived experiences to explore their thoughts and perceptions related to their shared experiences (see Moustakas, 1994). A transcendental phenomenological approach allows for the identification and exploration of a particular phenomenon through the lived experiences of participants (Moustakas, 1994). I conducted interviews to gain insight into these lived experiences. The interview questions allowed the study participants to share their personal experiences and how they cope with their children having SCD and use available healthcare services. For this study, a purposive sample of 10 parents from the Sickle Cell Association of Texas Marc Thomas Foundation (SCATMTF) was used.

Definitions

Chronic illness: A disease that persists for a long time. A chronic disease is one lasting 3 months or more (Centers for Disease Control and Prevention, U.S. National Center for Health Statistics, 2016).

Chronic pain: Characterized as persistent pain with substantial restriction of life activities lasting 6 months or more (Von Korff et al., 2016).

Complementary or alternative medicine (CAM): A group of diverse medical and health care system, practices and products that are not presently considered part of conventional medicine (Thompson & Eriator, 2014).

Coping: A cognitive and behavioral effort to manage specific internal and or external demands that are appraised as taxing or exceeding the person's resources (Montero-Marin et al., 2014).

Disease management: A system of coordinated care; close involvement by parents and medical professionals (Oliver-Carpenter et al., 2011).

Evidenced-based practice: The conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients (Munn, Porritt, Lockwood, Aromataris, & Pearson, 2014).

Health related quality of life: The physical, psychological, and social domains of health that are influenced by individuals' experiences, beliefs, and perceptions (Dale et al., 2011).

Parent as Teacher: A home-based parent education curriculum used to provide information, support and encouragement to help children reach developmental milestones during the first few years of life (Hoyt Drazen et al., 2014).

Parental stress: Any demand that creates system changes within a family or has the possibility of creating these changes is a stressor (Hall et al., 2012).

Patient-centered medical home (PCMH): A model of the organization of primary care that delivers the core functions of primary health care (Liem et al., 2014).

Primary care physician (PCP): Doctors holding a medical degree and include general practitioners, family doctors, family physicians, family practitioners, and other generalist physicians working in primary healthcare settings who fulfil primary health care tasks (Gosden & Sibbald, 2003).

Sickle cell crisis: Red blood cells lose their flexible disc shape and become rigid and crescent or sickle-shaped. These altered cells block vessels resulting in tissue and organ damage and give rise to episodes of severe pain lasting a few minutes to several days or, in some cases, months (Keane & Defoe, 2016).

Assumptions

A few assumptions were inherent in the study. First, I assumed that the participants would respond truthfully to the interview question. Second, I assumed that all participants would offer unique information to the questions I asked because of their experience with their child having SCD. Third, I assumed that interviewing these participants would yield information that may aid in understanding experiences of other parents of children with SCD.

Scope and Delimitations

The scope of the study refers to the parameters under which the study was conducted. The problem that researchers seek to address fits in certain parameters (Simon & Goes, 2013). The scope of this research included the parents of children ages 5-10 with SCD and how they cope with the chronic illness and use available healthcare services. The parents may or not use health services to manage their child's disease. I explored the coping strategies of parents of children with SCD in order to better understand the ways these coping strategies relate to the use of health services.

Simon and Goes (2013) define delimitations as those characteristics that arise from limitations in the scope of the study and by the conscious exclusionary and inclusionary decisions made during the development of the study plan. Delimitations

result from specific choices of the researcher. There is limited research on the coping strategies used by parents of children with SCD specifically (Barakat et al., 2014; Derlega et al., 2014). Therefore, I chose to limit the focus of this study to the parents of children ages 5 to 10 instead of the adult population and their coping strategies. I conducted face to face interviews with the parents of children living with SCD. I did not conduct direct observations or other methods of exploring the experience of these parents.

Limitations

Study participants were limited to the parents of children with SCD in the Austin, Texas region. Therefore, the findings cannot be generalized to all families of children with SCD because of the small sample size. I used purposeful sampling approaches to identify the participants in this study. Simon and Goes (2013) indicated a limitation associated with qualitative study is related to validity and reliability. However, the areas of most concern for qualitative research are transferability, confirmability, credibility, and dependability. The use of face-to-face interviews with the SCATMTF members provided the opportunity to validate and confirm the information. A potential issue can occur if the participants voice beliefs based on what they think the researcher wants to hear. The participants may not provide truthful responses during the interview. Therefore, the methods of addressing limitations include ensuring participant confidentiality and providing a quiet and comfortable place to conduct the interviews where the environment is such that participants do not feel pressured or intimidated.

Significance of the Study

Van Houtum et al. (2015) found that there is a connection between pain management and coping. A group of nurses reported that when a parent is empowered and has an understanding of the child's illness, it makes caring for the child easier (Panicker, 2013). It also helps the parents to gain mastery and provide control over their child's care. Research has shown that people with a chronic illness experience tension between managing and controlling their chronic illness while being able to do what they would like to do daily (Van Houtum et al., 2015).

The results of the study may be used to understand coping strategies of parents of children with SCD and to help medical providers have a better understanding of how these strategies may impact disease management and use of health services. Furthermore, the results of this study may be useful for developing interventions for parents who have not adopted coping strategies in managing the disease (Amid & Odame, 2014). This study may add to the existing literature by providing information on parental SCD management strategies and possible barriers to use of specialty clinics instead of the ED. The identification of strategies used by parents of children with SCD may yield information that could lead to better disease management and more effective use of health services.

Insight from this study could lead to positive social change by helping to identify specific coping strategies parents can use to better manage their child's disease and effectively use available health services. Another implication for social change is the possibility of both broader and more in-depth research on how the parent, child, and the

SCD community can improve their coping strategies. Although SCD pain crisis is an experience that many parents of children with SCD go through, positive coping strategies can be significant in appropriate use of health services, reducing morality rates and helping the child and the family function and improve quality of life.

In summary, this study was needed to help describe the coping strategies the parents of children with SCD use to access health services and manage their child's chronic illness. I aimed to explore the lived experiences of the parents who have children with SCD and how they deal with the chronic illness and use health services. The results of this research contribute to the existing knowledge on the coping strategies of parents with children who have SCD and provide a better understanding of those strategies being used to help the parent manage the disease.

Summary

SCD is an inherited disorder of abnormal hemoglobin synthesis that is associated with pain and progressive multi organ damage with significant impact on the patients' quality of life (Amid & Odame, 2014). The disease is associated with adjustment difficulties such as increased depression and anxiety. Managing SCD and using health services is difficult for parents of children with SCD. SCD presents challenges for the family functioning. However, parental coping has been found to affect appropriate disease management and health service use (Amid & Odame, 2014).

There is evidence in the literature (Barakat et al., 2014; Derlega et al., 2014) that an effective parental plan such as thinking positively can help parents with managing SCD; there is limited research on the coping strategies used by parents of children with

this chronic disease. This phenomenological study addressed the parental disease management strategies of children with SCD. In Chapter 2, I provide a review of the relevant literature on parental coping strategies, use of and access to health services, parental health education experiences of children with SCD, coordinated care, barriers to care for parents who have children with SCD, pain management, treatment, and CAM.

Chapter 2: Literature Review

More than one thousand babies in the United States are born with SCD every year. The CDC (2015), National Center on Birth Defects and Developmental Disabilities (2015), and the Division of Blood Disorders (2015) consider SCD a significant health and global concern. Children with SCD face many challenges associated with living with the chronic disease that requires lifetime medical attention and efficient parental management (Ekinci, Çelik, Ünal, & Özer, 2012). Parents who have children with SCD often struggle to deal with the child's illness. The purpose of this study was to examine the coping strategies and to understand how parents of children with SCD manage their child's illness and use health services. In this chapter, I examined the existing literature on the kinds of disease management strategies used by parents of children with SCD. This chapter includes a description of the literature review strategy and (a) a synthesis of the literature on SCD and coping, (b) a discussion of the conceptual framework for the study (c) and a summary of the literature findings.

Literature Search Strategy

The literature search strategy included an in-depth search in Walden University Library research databases. The databases included all EBSCO host databases; including Medline, Academic Search Complete, ProQuest, and PubMed. I examined organizational websites such as the CDC, Sickle Cell Disease Foundation, and the U.S. Department of Health and Human Services to locate additional articles of interest related to SCD that focused on the connections between coping strategies and health service use published

between the years 1978 and 2018. I examined international studies because of the limited research on parental coping plans for children with SCD in the United States

The literature search identified full-text articles published from 2010 through 2018. I searched for the most recent literature but included three seminal studies that were influential to subsequent research: a study published in 1978 regarding Colaizzi's method of phenomenological data analysis, a study published in 1996 that was the first study to introduce the TSC model, and a study published by Lazarus and Folkman (1984) that described the relationship between the TSC model, chronic illness, and stress. The key search terms and combinations of search terms for the literature review included: *sickle cell disease, disease management, chronic anemia, children and sickle cell disease, blood disorder, stress, parents coping skills, hardship, frequent hospitalization, hospital admission for children with sickle cell disease, sickle cell disease clinics, pain crises, disease management, pain management, coping with sickle cell disease pain, chronic illness, faith, religious coping, spirituality, caregiver, hydroxyurea, health-related quality of life, problem solving, health services, pediatric sickle cell disease, acceptance and commitment therapy, functioning, intervention, utilization, complementary or alternative medicine, spirituality coping model of resilience,* and *Thompson and Gustafson's transactional stress and coping model (TSC)*.

Theoretical Foundation: Transactional Stress and Coping Model

The TSC model is a framework used to evaluate the processes of coping with stressful events. It has been the foundation of research studies on chronic illness (Burlew, 2002; Lazarus & Folkman, 1984). It is one of the most widely used models for explaining

child adjustment to chronic illness (Sieh, Oort, Visser-Meily, & Meijer, 2014). In this model, Thompson and Gustafson (1996) described chronic illness as a stressor in which the children and their families attempt to adapt. The ways in which the parents adapt play a central role in the children's quality of life (Hocking & Lochman, 2005; Thompson & Gustafson, 1996). According to Thompson and Gustafson (1996) the relationship between chronic illness (a potential stressor) and adaptation varies as a function of biomedical, developmental, and psychosocial processes. The TSC includes three constructs relating to the maternal (parent) adaptational processes: cognitive processes, methods of coping, and family functioning. Two of the constructs, cognitive processes and methods of coping are common to both the parent and the child's adaptational processes. Parent adaptational processes include the family functioning as a third construct.

The first construct is the cognitive processes that are utilized to appraise the stress. In the cognitive processes, appraisal stress applies to parents and includes the daily hassle of the illness and the illness tasks. Expectations apply to both parents and children and include efficacy (parents) or self-esteem (children) and health locus of control (Thompson and Gustafson, 1996). It is a task to provide care for an individual with a chronic illness. The daily task of caring for children with SCD is stressful, because of complications surrounding this chronic illness. Several studies show that feelings of self-worth account for significant portions of the variance in child adjustment, with lower levels of self-worth being associated with higher rates of depression and anxiety (Burlew et al., 2000; Thompson et al., 1998; Thompson, Gustafson, et al., 1999).

The second construct in the TSC model is the methods of coping. It involves how parents and children adapt to the chronic illness. There is palliative coping and adaptive coping. Palliative coping is a combination of avoidance, wishful thinking, and emotion-focused coping where attempts are made to regulate the emotions that are associated with stress. Adaptive coping is also known as problem focused coping, which involves altering the stressful transaction between the environment and person by attempting to change the environment or the self. Poor maternal adjustment has been associated with low use of adaptive coping and higher rates of palliative coping (Thompson and Gustafson, 1996). Chittem (2014) posited coping is a significant psychological process that involves an individual's cognitive and behavioral attempts to reduce or manage a stressor. Coping, in the case of chronic diseases, is the way in which individuals respond to the diagnosis and how they deal with the disease. During the coping process, attempts are made to regulate the emotions that are associated with the stress. The parents are seeking ways to manage the stress that comes with the chronic illness and the children are trying to adjust as well.

The third construct in the TSC model is family functioning. Supportive, conflicted, and controlling are ways a family functions when adapting to a chronic illness and are factors to help determine the psychosocial outcome. A supportive family has mutual interest, concern and support across a wide domain. Supportive families have a better outcome in adapting to chronic illness when there is less conflict. The conflicted family on the other hand, reflects a dimension of conflicts that lacks structure or support. Conflicted functioning accounted for a significant portion of behavior problems in children with chronic illness. Controlling represents the use of competition and rules to

control the family and foster dependence (Kronenberger & Thompson, 1990). The other parts of the model include illness parameters (type and severity) and the demographic parameters (child's gender, child's age, and social economic status) and their impact on maternal and child adjustment and outcomes.

The child adjustment to a chronic illness is mediated by individual actions of their family members (Thompson and Gustafson, 1996). When parents do not adjust to their child's chronic illness the child will not adjust. For example, a parent who has stress may also affect the child's health outcome (Colletti et al., 2008). The family functioning has a direct impact on the child's adjustment. Therefore, the parent is encouraged to serve as a coach and model the coping skills for the child. I used the TSC model in this study to develop the interview questions that guided this study. I also used it to organize the discussion of the findings of the coping strategies used by parents of children with SCD as related to healthcare use and disease management.

The Use of Transactional Stress and Coping in Studies of Chronic Illness

Taking care of a child with SCD can create stress, and the impact that the chronic illness has on the parents can best be understood with the TSC model (Thompson & Gustafson, 1996). Thompson and Gustafson's (1996) TSC model has been used to examine healthy coping strategies. This model has been used to study how parents and their families adapt to the child's illness (Hocking & Lochman, 2005; Thompson & Gustafson, 1996). Individuals have different ways of coping with stress. However, coping strategies are essential to understanding how parents adjust to their child diagnosed with SCD.

Mullins et al. (2015) used the TSC model in addition to two other theories in their study to develop psychosocial interventions for parents of children coping with chronic illness. The TSC model was incorporated with the family systems theory and multiple resiliency factors in their framework to better describe the complex process of adaptation and subsequent adjustment outcomes. Mullins et al. (2015) found that parent distress as measured by elevations on a parent-completed instrument measuring global distress is a consistent and significant predictor of the child's adjustment to the illness. Parents' method of coping influences their children. How parents internalize and externalize problems, even when controlling for demographic and illness characteristics is a significant predictor of how the child adjust to the chronic illness. Parents can use problem focused coping that is useful when a stressful situation is controllable or emotion focused (palliative) coping that is utilized when the individual situation is not controllable. For example, when individuals use a helpful problem-focused plan, those plans tend to decrease their palliative or emotion focused stressor. When individuals use an effective emotion-focused (adaptive) coping strategy, they have less stress and are better equipped to focus on the problem. Mullins et al. (2015) concluded this model has been used to study the potential to result in more persuasive interventions. Mullins et al. (2015) demonstrated how the TSC may be used to evaluate coping styles of parents in stressful times when dealing with their child's illness and accessing health services.

Gold, Treadwell, Weissman, and Vichinsky (2008) used the TSC model to investigate the impact of SCD on the psychological adjustment of healthy siblings of an affected child in an effort to examine the effects of the family functioning, coping

strategies, self-efficacy and perceived social support on sibling adjustment. The study included 97 healthy siblings from 65 African American families who had a child with SCD. The participants were recruited through a comprehensive SCD center in Northern California. The primary caregivers completed the Coping Health Inventory for Parents, the Family Relations Scale, and the Child Behaviour Checklist, while siblings completed the Kidcope, the Children's Self-Efficacy for Peer Interaction Scale, and the Social Support Scale for Children. The findings showed family-centered interventions stressing family expressiveness and support, while minimizing conflict will contribute to sibling psychological adjustment. The overall family functioning ($r = -0.53$, $p < 0.001$) and sibling avoidant coping strategies ($r = 0.46$, $p < 0.001$) were significantly associated with externalizing behavior problems. Results from the analyses demonstrated the robust effect of family adaptational processes on sibling well-being. Family adaptational processes, including family coping, support, expressiveness, and low conflict, were highly predictive of positive sibling adjustment, while other sets of variables, such as demographic parameters and family characteristics, did not significantly predict sibling adjustment. The family functions predicted as much as 21% of the unique variance in sibling adjustment. Specifically, families who endorsed high levels of family coping, support and expressiveness, and low levels of conflict, were associated with positive sibling adjustment.

Kelch-Oliver, Smith, Diaz, and Collins (2007) utilized the TSC model to examine major studies conducted on depression and psychosocial aspects of SCD in African American children. While individual factors such as children's illness severity and

attribution styles are related to depressive symptoms, family variables, such as maternal psychological functioning and overall family functioning, have a greater impact on children's psychological functioning. Using TSC principles, the relationship between child and maternal family psychological functioning is likely to be complex and multi-directional (e.g. the challenges of caring for a more severely ill child may increase the likelihood of maternal depression, which in turn may impact child depression, which in turn may lead to decreased adherence and increasing disease severity). TSC provides a conceptual framework that is useful in organizing the empirical literature related to African American children with SCD. Burlew et al. (2000) examined psychosocial and biomedical factors in relation to the adjustment among adolescents with SCD, and found that significantly more depressive symptoms were better explained by psychosocial factors than by biomedical indices. This finding suggests that an exclusive focus on the medical aspects of SCD does not promote healthy adaptation to the disease. This is consistent with the TSC that psychosocial factors (the child and maternal adaptation process) are more important than biomedical variables.

Hocking and Lochman (2005) used the TSC model to examine the literature on the maternal and child adaptational processes that influence child and maternal coping with SCD and other chronic illness. How mothers deal with their children's chronic illness could influence the outcome of how the children adapt to the disease (Thompson, Gil, Burbach, Keith & Kinney, 1993). Mothers who rated their children as showing behavior problems and poor adjustment also have significantly higher levels of self-reported depression, anxiety, and overall distress than mothers who rated their children as

demonstrating good adjustment (Hocking & Lochman, 2005). Poor maternal adjustment has been associated with low use of adaptive coping and higher rates of palliative coping defined as a combination of emotion-focused coping, avoidance, wishful thinking, and self-blame factors. In their research, Hocking and Lochman concluded maternal adjustment and maternal adaptational processes are factors affecting family functioning, which influences a child's adjustment to a chronic illness. Both parents coping strategies are essential when dealing with children that have a chronic illness. Although, Hocking and Lochman focused on the maternal adjust to SCD, both mothers and fathers will be included in this study.

Davis, Brown, Bakeman, and Campbell (1998) used the TSC model to examine the psychological adjustment of mothers of children with congenital heart defects in order to determine both commonalties in parental adjustment across childhood chronic illnesses a and possible disease-specific factors unique to this chronic illness. The study employed the TSC model that has demonstrated utility in delineating the psychosocial meditational processes that predict maternal adjustment in mothers of children with other chronic illnesses (i.e., cystic fibrosis, SCD). Fifty-two mothers of children with congenital heart defects were recruited from a pediatric cardiology service at a major university-affiliated medical center. The center is located in a major metropolitan area in the southeastern United States. Based on previous research employing the TSC model, Davis et al. (1998) hypothesized that the manifestation of the severity of the children's cardiac defects or demographic variables will be mediated by the psychological processes (i.e., cognitive processes, methods of coping, and family functioning) depicted in the model (see Figure

1). The findings suggest that the overall psychological adjustment of mothers of children with congenital heart defects, as well as for mothers of other chronically ill children, may be enhanced by fostering healthy adaptive coping strategies and decreasing daily stress.

Phenomenology as the Research Method

A phenomenological approach was used in this study to explore the coping strategies of parents in order to better understand the ways these coping strategies relate to managing SCD and accessing health services. Patton (2002) said phenomenology is used to gain a deeper understanding of the nature or meaning of an individual's everyday experiences. Creswell (2013) identified five kinds of qualitative approaches that may be used when conducting a study: narrative, phenomenology, grounded theory, ethnography, and case study. All five approaches have in common the general process of research that begins with a researchable problem, research questions, a collection of data and the data analysis. Other qualitative designs were reviewed for the proposed study but were not appropriate in providing a detailed understanding of what the parents of children with SCD experience. For example, narrative research, and case study are similar when the unit of analysis is singular. In this study, the focus was not on a single person but the parents of children with SCD. In grounded theory, the goal is to create a theory. However, in this study, I used a phenomenological design to gain knowledge through the description of lived experiences of the coping strategies parents use to manage SCD, and use available healthcare services.

In narrative research, the expert tells the participant's story and arranges it in chronological order. This study is not telling a story in sequential order about the parents

of the child with SCD, but providing the recent experience of the parents that have children with SCD. Ethnography would not be a valid design for this study because the researcher focuses on one particular culture and the investigation is completed in the context of the participants' culture and culture sharing group (Creswell, 2013). However, this study is not about a particular culture because SCD affects people of African, Asian, Mediterranean, and Middle Eastern origin (Morgan et al., 2014). Finally, the case study design would be less effective because the data collection is collected over an extended time (Creswell, 2013). However, the data collection in this study focuses on the current experiences and will not be gathered as the experiences occur over time.

According to Patton (2002), research using phenomenology is interpreted through different theoretical viewpoints. For example, hermeneutics philosophy was first developed by Schleiermacher and applied to human science research by Dilthey.

> Hermeneutics provides a theoretical framework for interpretive understanding, or meaning, with special attention to context and the original purpose. Hermeneutic theory argues that one can only interpret the meaning of something from some perspective, a certain standpoint, praxis, or a situational context, whether one is reporting the perspective of people being studied and thus reporting their standpoint or perspective. These ideas have become commonplace in much contemporary social science and are now fundamental in qualitative inquiry, but such was not always the case (Patton, 2002, p.115).

In the phenomenology approach, research is interpreted through different theoretical perspectives (Patton, 2002). I have chosen to use Husserl's transcendental

phenomenological approach because I provided a descriptive phenomenology of this study (Creswell, 2009).

Parental Coping Strategies

Caring for a child with SCD can be stressful when the parents have no coping plans. Parental coping strategies are essential to help parents manage their children's disease. There are different general trends in coping with stress. People have different ways to deal with chronic illness such as cognitive or behavioral coping, cognitive or behavioral avoidance, and emotion focused coping (Montero-Marin et al., 2014). Cognitive or behavioral coping refers to what someone thinks after experiencing a negative event. Cognitive or behavioral avoidance involves avoiding or managing distress by performing actions such as seeking reassurance, checking, or avoiding anxiety provoking situation and emotion focused coping are intended primarily at relieving or regulation of the emotional impact of a stressful situation (Chakraborty & Chaudhury, 2015). It is essential that parents learn ways to cope with their child having SCD that can reduce stress (Panicker, 2013).

Wang, Michaels, and Day (2011) posited coping strategies provide a protective role in moderating caregiving stress among parents of children with a variety of disabilities. For example, studies showed that high levels of problem focused coping and low levels of emotion focused coping protected the impact of high stress levels on maternal wellbeing among mothers of children with intellectual disabilities (Ganjiwale, Ganjiwale, Sharma, & Mishra, 2016; Mak & Ho, 2007). Ganjiwale et al. (2016) conducted a study on the caregivers of children with an intellectual disability to assess the

quality of life and coping mechanisms used by the caregivers of children with physical and intellectual challenges. In this cross sectional study, 116 caregivers were included and the coping style used by the caregivers was active emotional coping. The response caregivers gave for using active emotional coping is because they have accepted the child's illness and are trying to look for something good in it. One approach identified by the researchers is that caregivers attempt to make light of the situation which can provide an outlet for stress. Zablotsky, Bradshaw, and Stuart (2013) posited a parent's ability to deal with high stress levels lies in the effectiveness and quantity of the coping strategies they employ in helping manage the demands of the stressors associated with raising a child with a chronic illness.

Al-Yagon (2015) conducted a study that explored how mothers' and fathers' emotional resources (low anxious/avoidant attachment, low negative affect, and high positive affect) may explain differences in parents' coping resources (active/avoidant coping with a child-related problem, sense of coherence). The author compared the parents of children ages 8 to 12 years with a learning disability (LD) and the parents of children without a LD. The study included 107 couples with children that had a LD and 98 couples whose children did not have a LD. Caring for a child with a learning disability is challenging and stressful. The results revealed significant group differences between parents of children with and without LD in their usage of active and avoidant coping strategies. The findings demonstrated a more significant contribution of emotional resources to coping for the parents of children with LD, especially mothers, may possibly suggest that mothers of children with LD might be more vulnerable to variations in affect

than their counterparts. A possible sensitivity to parental affect in families of children with LD may stem from various sources associated with the stress and burden experienced by these parents, thereby emphasizing the potentially important role of emotional support for parents of children with LD. The study underscores that a high level of negative parental affect, especially among parents of children with LD, is a major risk factor for lower sense of coherence and higher use of avoidant strategies when coping with their children.

Gage-Bouchard, Devine, and Heckler (2013) examined the influence of parent and family characteristics on parents' use of various coping mechanisms after a child is diagnosed with cancer. Sixty caregivers of pediatric cancer patients completed a socio-demographic questionnaire, the Family Environment Scale, and the COPE inventory. The findings of the research showed that educational attainment and caregiver gender influenced caregiver coping styles following a pediatric cancer diagnosis and suggested that educational attainment rather than financial resources drive the association between social economic status and coping. The authors concluded mothers and fathers cope with their child having cancer differently, and mothers are more likely to employ active coping strategies and seek social support. However, fathers may benefit from tailored initiatives designed to meet the specific needs of men, particularly fathers who have less than a bachelor's degree education. Parental coping strategies are important variables in family adaptation to pediatric cancer. It is important to include the mother and father in the study (Frank, Blount & Brown, 1997; Gold, et al., 2008; Long & Marsland, 2011).

Barakat et al. (2014) explored parent problem solving skills as a moderator between SCD complications and psychosocial HRQOL to evaluate applicability to pediatric SCD. The study included 83 children ages 6-12 years; their primary caregiver completed measures of child HRQOL. The child's HRQOL was examined in four areas of functioning: physical, emotional, social, and school. The findings of the study showed both child age (p=.027), and the parent problem solving (p=.006) were significant independent predictors of child reported HRQOL. Post-hoc probing indicated that the relationship between child self-report psychosocial HRQOL and SCD complications was not significant for positive parent problem-solving abilities [t (81) =1.98, p=.055] but was significant for negative parent problem solving abilities [t (81) = -2.85, p=.006]. For families with negative parent problem-solving abilities, as SCD complications increased, HRQOL significantly decreased indicating that parent problem-solving skills may be one approach to improving how they deal with high SCD complications. When parents make a plan when faced with a challenge, this is considered a positive problem solving skill. On the other hand, avoiding the problem is an example of a negative problem-solving skill. Avoiding or not having a plan when the child has a crisis can cause parental stress. Parenting and caring for a child with SCD could be challenging (Barakat et al., 2014). Barakat et al. (2014) found that enhancing parent problem-solving abilities may be one approach to improving children's quality of life when they are struggling with a disease. Problem-solving skills have been associated with positive disease management and health-related outcomes in adults and children with SCD (Barakat et al., 2014).

Utilization and Access to Health Services

Hamm, Hilliard, Howard, and Lebensburger (2016) conducted a study to determine if satellite clinics provide a similar level of comprehensive care when compared with university based clinics for children diagnosed with SCD in Alabama. These centers are located in urban areas of the state, specifically Birmingham and Mobile, and are approximately 250 miles apart. The estimated number of individuals living with SCD in the state of Alabama is 3,500, of which 1,200 pediatric patients are cared for at the University of Alabama at Birmingham (UAB) Pediatric SCD clinics. Traveling to and from UAB based clinics is a major health care barrier for children with SCD in Alabama. To reduce this barrier, the UAB developed satellite clinics using four surrogate markers: 1) attendance rates, 2) percentage of patients on hydroxyurea, 3) percentage of screening MRIs obtained, and 4) percentage of transcranial dopplers completed. The results of the study revealed that satellite SCD clinics can provide a similar level of care compared with major university based SCD clinics.

According to the American Academy of Pediatrics, the PCMH is a partnership approach with families to provide primary health care that is accessible, family centered, coordinated, comprehensive, continuous, compassionate, and culturally competent that is designed to meet the health needs of the SCD population (Guo, Chock, Parlin, Yamashiroya, & Rudoy, 2013). PCMH have gained national attention because the focus is to increase accessibility to all children with SCD. However, 50% of children in the United States lack adequate access to a PCMH (Liem et al., 2014). Socio-economic and socio-demographic disparities may further extend the gap between children with and

without access to a PCMH (Liem et al., 2014). Liem et al. (2014) evaluated parental access to subspecialty clinics and their attitudes toward PCP caring for their child with SCD in the PCP setting versus SCD clinics. The findings showed that parents who do not have access to PCP frequently utilized the ED and had little knowledge of a PCMH.

Raphael, Rattler et al. (2013) investigated whether having a PCMH is associated with a reduction in emergency care (ED) utilization or hospitalizations among children with SCD. This study was the first to examine the relationships between access to the components of a PCMH and use of medical services among children with SCD. One hundred-fifty children ages 1-17 and their parents participated in the study. The authors reported only two-thirds of children with SCD received comprehensive care and 20% experienced efficient care between the primary care doctor and their specialist. For instance, the parents of children with SCD experienced more limited access to care such as extended wait times, delayed treatment, lack of communication, and difficulties in reaching their provider by telephone compared to children without SCD. The findings of the study indicated children who received comprehensive care had half the rate of ED visits and nearly half the rate of hospitalizations compared to children without comprehensive care. No other component of the PCMH was significantly associated with ED visits or hospitalizations.

Schlenz et al. (2016) conducted a needs assessment of patients (n= 2,313) with SCD using statewide data from South Carolina. The study was for 12 months regarding young adults with the illness. Schlenz et al. (2016) indicated access to quality care for patients with SCD is a significant problem in the southeastern United States particularly,

South Carolina. It is estimated that 2,500 to 5,000 patients have SCD in that state. Twenty percent of the participants in this study lived below the federal poverty level, and a larger number of the participants resided in the rural areas that are distant from comprehensive services (Schlenz et al., 2016). The finding of the study indicated the data from the hospital readmission ED is used to identify demographic gaps in care for children with SCD.

Health Education Among Parents of Children with Sickle Cell Disease

Without proper education and prophylactic care, SCD can be life threatening early in childhood (Friedrich et al., 2015). Friedrich et al. (2015) conducted a study to assess parental awareness and their perceptions of SCD. The authors used an educational session to provide opportunities for the parents to share and learn about Hematopoietic Stem Cell Transplantation (HSCT) in the treatment of children with SCD. The findings suggested that parental awareness of the curative role of HSCT for SCD is poor, but information about this option was met with interest. The authors suggested that for any chronic condition of childhood, parental education about high risk but potentially curable therapeutic options can be incorporated into routine health maintenance in a more efficient manner. Through use of replicable, standardized educational sessions, parents will be able to comprehend relative risks associated with the curative alternatives, and initially be able to retain and understand the SCD information that will be taught in the clinical setting.

On the contrary, Hoyt Drazen et al. (2014) carried out a prospective study of a home-based caregiver education program for families with infants and toddlers with

SCD. A hospital in the Midwest followed the Born to Learn curriculum provided through the Parents as Teachers National Center. The majority of the parents in the study were single mothers with a high school education and less. Hoyt Drazen et al. (2014) noted parents had limited learning strategies, therefore making it difficult to manage their child's illness and everyday stressors. The results indicated that a home based program could be feasible methods for helping the parents cope with SCD by educating them on how to manage the disease in their home environment instead of a hospital or clinical setting. The authors further concluded that the lack of understanding and perception of risk or distrust may affect the parents' willingness to communicate and participate in a parent education program that could help them learn to manage the child's illness efficiently.

Raphael, Rueda, Lion, and Giordano (2013) investigated the effectiveness of lay worker interventions in improving healthcare use, symptoms management, and family psychosocial outcomes for children with chronic illness. The interventions consisted of lay worker-family interactions through home visits, phone calls or e-mail that helped educate the parents of children with a chronic illness use health services. The authors indicated that children are vulnerable as they experience inequities in access to care, use, and unmet medical needs. In this study, the goal was to systemically assess the effectiveness of lay health workers interventions in improving health care use for minority children in low income families. The parents were trained as lay workers to provide care to their children with a chronic illness. Lay health workers are individuals who perform functions related to health care delivery. Because they have no formal or

paraprofessional training, they are typically provided with informal job-related training. The parents were trained to deliver a health-related intervention and trained in the area of accessing health services. The findings showed that interventions by lay health workers may provide an essential strategy for improving health services in children with a chronic disease.

Children with SCD are at risk for central nervous system (CNS) complications that could affect their academic performance (Daniel et al., 2015). Therefore, an educational support program is essential in helping parents improve their child's education. Daniel et al. (2015) conducted a randomized control trial of a family based intervention to promote school functioning for children with SCD (n=61). The aim of the study was to test a family-based group problem-solving intervention. The findings showed 3 interventions were developed from a focus group attended by the parents of children ages 6-12 years with SCD which included: (1) work with families to implement educational accommodations before the child starts having difficulties. (2) reduce the burden on families by holding the intervention on one weekend day, and, (3) focus on family strengths (as opposed to identifying deficits). The goal of the 3 interventions was to improve the parent problem solving to address disease complications and pursue educational accommodations during the primary grades, and child problem solving to improve the teacher and the peer communication. This study showed that increasing parents' problem solving skills with a focus on educational challenges faced by children with SCD could improve school activities. SCD can impact the child's academic performance through neurological complications and fatigue causing the child to miss

days from school. Therefore, evidence-based educational interventions that increase parental involvement in school are needed in SCD treatment plans as parents who are aware of SCD and involved in their children's routine check-ups are less likely to have children miss school due to illness (Daniel et al., 2015).

Coordinated Care

Rattler, Walder, Feng, and Raphael (2016) conducted a longitudinal study of the perspective of 101 parents on acute care use outside of the PCMH home. Care coordination (CC) is a vital element of the PCMH home that has the potential to reduce fragmented care and improve patient experiences for parents of children with SCD. The three components of CC include: (1) getting as much help as needed with coordinating care, (2) caregiver satisfaction with communication between the healthcare providers: and (3) caregiver satisfaction with communication between healthcare providers and non-medical service providers. In this study, the authors aimed to determine if CC for the child would result in lower rates of ED visits and hospitalization. The findings showed that 25% of parents did not have coordinated care. Eighteen percent reported they could use extra help coordinating care. The analysis of the ED showed one third of the children (*n*= 34) had a total of 60 ED encounters. The median of ED visits per child was 1.7; this is low for this population compared to most children with SCD who have 3.2 E D visits on the average per year in this study (Nimmer, Hoffmann, Dasgupta, Panepinto, Brousseau, 2015). Additionally, children with SCD have higher rates of readmission relative to those with other chronic conditions (Rattler et al., 2016). Two thirds of the children (*n*=67) had no ED visits. The authors concluded there were no associations

found between individual CC components and ED encounters or hospitalization of children with SCD.

In a similar study, Taylor et al. (2013) investigated the medical care for patients with chronic illness using CC. The authors suggested implementation of a CC counselor role and supporting tools such as care binders (an organizational tool for families that is used to keep track of and communicate important information about a child's heath and care), complex scheduling, community resources for families, and a care coordination network offer an integrative way to connect the patients, families and providers with services, and resources to support coordinated continuous care. Care binders include sections for medical information, family history, education and therapies, daily routines care plans, and insurance and financial information. To assess the impact of the counselor role, the authors compared the patient experience results from patient receiving CC counselor services to those receiving only the care binder. Taylor et al. (2013) found that comprehensive needs of the parent with a child with SCD are met through the collaboration of the families, child, coach counselor, pediatricians, hematologists, social workers and other clinicians. In this study, the CC counselor intervention brought together the patient, primary care physician, and the subspecialist. In comparison, the study conducted by Rattler et al. (2016) did not use a CC counselor for intervention and showed there were no associations found between individual CC components and ED encounters or hospitalization. However, implementation of a CC counselor intervention (Taylor et al., 2013) offers an integrative way to connect the SCD patient to providers with services that support continuous care.

Barriers to Care for Parents of Children with Sickle Cell Disease

Children with SCD continue to experience disabilities, higher mortality, and greater difficulty accessing healthcare services relative to children without SCD (Minkovitz, Grason, Ruderman, & Casella, 2016). Reducing healthcare barriers may improve the quality of primary care services received by children with SCD. Jacob, Childress, and Nathanson (2016) investigated parental perceptions of their child's care and the primary care experience. Parent of children with SCD were recruited from a community-based organization in southern California. Jacobs et al. (2016) used the Barriers to Care Questionnaire (BCQ) and the Parent Perception of Primary Care (P3C) to assess parental perceptions of their child's care and the primary care experience. The P3C measures six aspects of pediatric primary care: access, knowledge, communication, comprehensiveness, continuity, and coordination. The parents of children with SCD (*n*=38) reported low skills level in navigating the healthcare system, negative experiences with the child's providers, and general lack of knowledge about disease management. Seventy nine percent of the healthcare barriers were reported as occurring never or almost never resulting in high BCQ scores. Therefore, high BCQ scores indicated low barriers to care. Parents of children with SCD scored 85 % in the domain of knowledge and beliefs and marginalization with a mean of 82 % suggesting that parents had positive experiences in these domains. On the other hand, the parents of children with SCD had the lowest score in the domain of pragmatics with a mean of 74 % suggesting there were some difficulties in accessing clinic services due to transportation, wait times and

competing family priorities. The study found that limited access to primary care services might contribute to more severe SCD complications and frequent hospitalizations.

McClain, Ivy, Bryant, Rodeghier, and DeBaun (2016) posited that parents of children with SCD who had public health insurance faced barriers to specialty care access because of the reluctance by specialty clinics to accept their insurance owing to decreased reimbursements. McClain et al. (2016) examined the scheduling behaviors among specialty clinics. They showed that 66% (*n*=179) of the parents in the sample reported their child's Medicaid Children's Health Insurance Program(CHIP) coverage were denied an appointment for specialty care, when compared with 11 % of callers using Blue Cross Blue Shield insurance.

Panicker (2013) used a qualitative descriptive design to explore perceptions of how parents handled chronic illness. Fourteen registered nurses working with children with a chronic illness from a tertiary referral children hospital volunteered to participate in the study. Data collection was performed using 3focus group interviews lasting 45- 75 minutes. Open ended questions were used and all interviews were audio taped. One of the main problems to parent empowerment identified in this study was the different expectations between parents and professionals. The participants stated that this could be due to the lack of shared decision making or open communication between the parent and the professional.

In summary, as stated above, Panicker (2013) indicated that nurses are aware of the physical, psychological and economic constraints imposed by the chronic illnesses on the parents but lacked the experienced staff to empower the parents. The lack of

empowerment serves as a barrier. The studies by Hildenbrand et al. (2015) and Jacob et al. (2016) were published after Panicker (2013); they identified specific ways to empower parents that seemed successful. For instance, educating the parents about their child's health and teaching them the skills needed to handle the disease empowers the parent.

Poor Communication of Information

Kenyon et al. (2012) found that, despite recent scientific advances, children with SCD continue to experience high mortality and significant morbidity because of inconsistencies in the care provided and underuse of current services. In this study, 29 clinical staff were recruited and interviewed to participate along with parents (n= 12) of children with SCD. The parents were recruited from an urban teaching hospital. Parents and the clinical staff participated in 4 focus groups sessions. Both parents and clinical staff identified the need for effective communication of relevant patient information across discipline as an essential area for improvement. Parents reported the need for increased community awareness about SCD, including educating the school and daycare staff, enhanced parental education and peer support and self- management skills for their child to improve pediatric SCD care (Kenyon et al., 2012). The parents also reported that poor communication between the clinical staff and families causes delays in the child being treated in a timely manner. The finding of the study identified a need for quality improvement, from the clinical staff needing updated summary (electronic records) of the clinical factors that would guide the treatment of pain assessment and management for children with SCD, enhanced parental education and peer-support on accessing care that helps in preventing underutilization. The needs for quality improvement, such as efficient

communication between the parents, hematologist, primary care provider, and enhanced parental education in accessing care are connected in helping to prevent underutilizations (Kenyon et al., 2012). Lastly, 4 themes emerged from the parent focus groups including: improving communication among the care team, raising community awareness, enhancing education and peer support for parents, and transitioning to adult care. The primary care provider, the specialist, the clinical staff and the families of the child that has SCD must all be engaged in the development of a patient centered quality improvement agenda.

Cox et al. (2017) reported that adults with SCD experience problems in relationship building and information exchange during clinic visits. To explore the origin of these communication challenges, the authors compared communication in pediatric SCD, with 2 other chronic illnesses. Seventy eight children and adolescent ages 9-16 years with SCD, asthma, or type 1diabetes and their parents participated in the study. Children with SCD and their parents spent less time visiting and building a relationship with the physician compared to children with the other 2 chronic illnesses. The findings suggest opportunities to enhance communication in SCD visits with the goal of improving adherence to therapies and ultimately SCD outcomes with the children and their parents.

Sickle Cell Disease Pain Management

Pain is the hallmark of SCD and the most common cause of hospitalization (Amid & Odame, 2014). Pain management is multidimensional and includes pharmacologic, physical, and psychological strategies (Wilson & Nelson, 2015). Few studies have

examined parent involvement in disease management in pediatric SCD (Oliver-Carpenter et al., 2011). Parents of children with SCD need to work together with the medical professional, to follow complex treatment regimens to manage the illness to prevent pain episodes and other complications such as iron overload, organ damage, and infections (Oliver-Carpenter et al., 2011). How parents cope with their child's illness is a significant determinant of how well the child is able to adjust to the disease. For instance, parents can influence the ways in which the children manage their pain by coaching and modeling their own managing responses.

Oliver-Carpenter et al. (2011) conducted a study of youth with SCD and their parents, to examine the level of involvement in disease management tasks. The participants completed questionnaires examining levels of involvement in disease management tasks, daily functioning, and coping skills. The finding of the study indicated there were no significant differences in the youth and the parent report of involvement in disease management tasks. However, there were overall differences in involvement with both the youth and their parents rating the parent involvement as higher. The parents took the lead in remembering the child's clinic appointments, telling the teachers and relatives about SCD, and explaining school absences to school personnel. Equally important, the parents and the children reported similar levels of involvement for tasks such as remembering to drink fluids and taking their vitamins. Managing a chronic illness such as SCD requires effective coordination of disease management tasks with families.

In contrast to other studies, Hildenbrand et al. (2015) interviewed 15 parents and their children independently using semi structured interviews to access SCD-related stressors, as well as child coping and parent coping assistance strategies used to manage the challenges. The parents completed the Parent Socialization of Coping Questionnaire (PSCQ) and their children completed How I Cope Under Pressure Scale (HICUPS) to assess how the children coped and parents 'coping assistance. The findings showed to manage the stress of the pain that is associated with SCD, the parent as well as the child used a combination of approaches and avoidance oriented coping strategies including promoting social support, encouraging distraction, facilitating emotional expression, and promoting acceptance. Including direct problem solving, acceptance, emotion focused support, and distraction. Hildenbrand et al. (2015) found that children with SCD face an array of coping strategies to manage the stress of SCD challenges.

SCD is disrupting, stressful and can affect the entire family. Parents of children with SCD face many challenges associated with living with the chronic disease that requires lifetime medical attention and efficient parental management (Ekinci et al., 2012). Managing SCD in the ED can have negative consequences both for the individual and the healthcare system (Rattler et al., 2016). For example, the ED medical staff is unfamiliar with the children and may order unnecessary tests or provide management inconsistent with the patients' long-term clinical needs. Also, the visits to the ED can generate substantial medical expenditures and hardship for the family (Rattler et al., 2016; Schlenz et al., 2016; Williams, 2015).

Edmond et al. (2016) found that caring for a child with SCD can cause emotional distress and burden for the parents. The objective of their study was to examine the potential correlates of the parent emotional distress and burden with SCD. Fifty one percent of the children were diagnosed with SCD and their parents experienced burdens when caring for their child. The study showed the children had sleep problems pain, and emotional problems. These 3 problems were all positively associated with parent emotional distress when caring for a child with a chronic illness.

In summary, Oliver-Carpenter et al. (2011) posited that managing a chronic illness such as SCD requires effective disease management skills in families. In addition, managing SCD pain at the onset is essential in controlling the illness (Rattler et al., 2016). Nevertheless, managing SCD requires that the parents have knowledge of the disease and the kinds of treatment that are available.

Treatments Used in Managing Sickle Cell Disease

Research suggests 3 significant treatments that are more in use for treating SCD; they are hydroxyurea, red cell transfusion and hematopoietic stem cell transplantation (Amid & Odame, 2014). Hydroxyurea (HU) is defined as a drug that inhibits the synthesis of DNA and is classified as an antimetabolite. HU is the only significant disease modifying medication for patients with SCD. HU was studied in a clinical trial, and the medicine was found to decrease pain crises, acute chest syndromes, hospitalizations, and transfusions in adults and children with the disease (Creary, Zickmund, Ross, Krishnamurti, & Bogen, 2015). However, HU is underutilized in

clinical practice and results in adverse health outcomes particularly in pediatric patients with SCD.

Creary et al. (2015) conducted a qualitative study and interviewed 19 parents (caregivers). The parents reported fear of giving their child HU because the medicine is considered chemotherapy medication that is usually administered for cancer therapy and its side effects include severe stomach pains. The findings of the study suggest parents are afraid to treat their child with HU because of concerns and misconceptions and its potential to cause malignancies (Creary, 2015; Yawn & John-Sowah, 2015). Medical providers should address these areas of concern so that parents can make the necessary decisions in managing their child's illness efficiently. Despite advanced technology and stem cell research, there is no cure for SCD. However, stem cell transplantation remains the only beneficial modality for people with SCD. Stem cell transplantation has a restricted application, because only10-20% of patients have unaffected matched sibling donors and substantial concerns remain about transplant related mortality and long-term toxicities, particularly with regard to infertility (Jordan, Casella, & DeBaun, 2012; Ware, De Montalembert, Tshilolo, & Abboud, 2017). There is a growing promise of stem cell therapy. However, parents are reluctant to use the therapy.

Benjamin (2011) examined the reasons African American patients with SCD are not undergoing stem cell transplants. The author interviewed a purposive sample (n=63) of stem cell initiative stakeholders from Garvey Medical Institute, a nonprofit organization that advocates for stem cell transplants, to gather interview questions for the parents of SCD and thalassemia patients. The author subsequently interviewed parents of

children who were eligible for a transplant and were enrolled in the cord blood bank at Garvey Medical Institute, an urban teaching hospital in California. The majority of sickle cell families declined the procedure while over half of thalassemia families underwent it. The author noted that the reasons parents repeatedly gave for declining the transplant was they did not want to use an experimental procedure for their children and they did not believe the potential benefits outweighed the known risks (Benjamin, 2011). Infections, graft-versus-host disease (GVHD), failure to engraft, and death are other reasons parents are reluctant to use stem cell transplantation (Hsieh, Fitzhugh & Tisdale, 2011).

In a similar study, Hsieh et al. (2014) investigated parents' perceptions of stem cell research. The researchers explored how much risk the parents would be willing to accept to cure their child of SCD. The parents were provided a questionnaire. Fifty-four percent of parents were willing to accept some short term risk, and only 13% accepted the estimated risks at the time of a 15% mortality risk with an additional 15% risk of developing GVHD. Stem cell transplantation is associated with significant morbidity and mortality.

Jordan et al. (2012) posited that, for the best chance at transplant success, a human leucocyte antigen matched family donor is needed; however, this is only available in 14–18% of children with SCD. Most children affected with SCD lacked a suitable sibling match or donor. This is a major limitation to the use of transplant for children with SCD. Also, the number of large-scale clinical trials in patients with SCD who have received stem cell transplants is limited (Jordan et al., 2012; Thompson, Ceja, & Yang, 2012).

Complementary and Alternative Medicine

Sanchez, Karlson, Hsu, Ostrenga, and Gordon (2015) defined CAM as a group of diverse medical and health care interventions, practices, products, or disciplines that are not generally considered part of conventional medicine. However, there are no clear boundaries that distinguish CAM from conventional medicine. Sanchez et al. (2015) identified 2 kinds of CAM approaches used for children with SCD and cancer: mind body practices and natural products. Mind body practices include: prayer by parent, prayer by child, prayer by others, massage, meditation, chiropractic osteopathic, energy healing, biofeedback, and yoga. Natural products include: vitamins and minerals, vegetarian diet, juice plus, noni juice, folk remedies, herbal therapy, vegan diet and macrobiotic diet. In the United States, the most common CAM modalities used by adults with cancer are vitamins and minerals, prayer for self and intercessory prayer (Sanchez et al., 2015). Using data from the National Health Interview Survey, Sanchez et al. (2015) indicated that 1 in 9 children throughout the United States used CAM in the previous 12 months. The 3 most common types of CAM used were prayer (62.3% oncology; 60.0% SCD), vitamins/minerals (14.8% oncology; 10.0% SCD), and massage (9.8% oncology; 7.5% SCD). The main reasons for using CAM were to provide hope (50% oncology; 25% SCD), to improve quality of life (0% oncology; 50% SCD).

Seventy percent of Australians use CAM for managing chronic conditions and associated symptoms (Unantenne, Warren, Canaway, & Manderson, 2013). Unantenne et al. (2013) examined how participants with SCD incorporated spirituality in coping and managing the disease. The participants identified family members, friends, spiritual

leaders, and other adults as providing spiritual supports such as prayer, using their faith, reading religious text, fasting, and attending church when facing a pain crisis. Furthermore, by incorporating their faith and spirituality, it had a positive impact on their health and managing the chronic illness (Unantenne et al., 2013).

In a similar qualitative study, Clayton-Jones, Haglund, Belknap, Schaefer, and Thompson (2016) examined the lives, health and spirituality of 9 adolescents living with SCD. A purposive convenience sampling approach was used to recruit participants from a comprehensive SCD center located in a large Midwestern city in the United States. All 9 of the participants expressed that they drew from their spirituality to cope with the challenges of having SCD. The use of spirituality in children with SCD may be significant in coping, managing pain, affecting hospitalizations, and affecting the quality of life (Clayton-Jones & Haglund, 2015).

CAM approaches are used to treat SCD (Baverstock & Finlay, 2012). There is a relationship between coping and how the parent uses CAM. CAM helps parents deal with SCD (Derlega et al., 2014; Van Houtum et al., 2015). Baverstock and Finlay (2012) conducted a study with 63 adults and children with SCD. The goal of the study was to examine the wellbeing of the participants as it related to using CAM. Forty-two percent of the participants used CAM approaches such as bio-energetic that included: prayer, spiritual and energy healing, lifestyle, mind and body CAM relaxation techniques, exercise, imagery, diet and massages. The authors used this study to determine prevalence of the population that used CAM for SCD. In a similar study, Wood and Finaly (2011) found that 32% of the participants had used up to 7 kinds of CAM for their

children with SCD. Of those who used CAM, 44% used just 1 type and 13% used 4 or more types. Fifty percent tried massage and 31% used faith healing. CAM was positively associated with the child's age, SCD severity scale score, respondent education, and parent CAM use.

Baverstock and Finlay (2012) found that CAM interventions may help minimize SCD pain and more and more parents are turning to alternative medicine for treatment. Baverstock and Finlay (2012) suggest it is significant when parent want to learn about CAM interventions and the conversation should be encouraged. In the final analysis, the authors suggest medical providers balance protecting the welfare of the child with maintaining respect for the rights of parents to choose an alternative treatment (Baverstock & Finlay, 2012).

Summary

In Chapter 2, I presented information that focused on the current research of parents who have children with SCD and how they managed the disease and accessed health services. The information from the literature review has helped identify the gap of knowledge that were addressed in this study. The research showed that the parents of children with SCD struggled to manage their child's disease and use primary care clinics with PCMH status. Much of the literature focused on adults with SCD and not parents of children with the illness. However, few parents understand the disease and use health services efficiently. The literature illustrated gaps in the comprehensiveness and coordination of services for children with SCD in the primary care setting, making it difficult for the parent to manage SCD.

SCD is difficult and stressful to manage. Eliminating healthcare barriers for parents of children with SCD is needed to improve the delivery of pediatric services and to enable this vulnerable and high-risk population to achieve optimal health outcomes. In chapter 3, I described the research methodology of the study that included: research method, research design, and rationale, the role of the researcher and methodology.

Chapter 3: Research Method

The purpose of this qualitative study was to explore the coping strategies of parents of children with SCD in order to better understand the ways these coping strategies relate to the use of health services. SCD is stressful and difficult to manage (Derlega et al., 2014). Parental coping has been found to affect appropriate disease management and health service use (Derlega et al., 2014; Van Houtum et al., 2015). In this chapter, I describe the research design, sample recruitment, data collection, and analysis procedures. This chapter concludes with a discussion of the ethical procedures that includes the treatment of human participants and the protection of confidential data.

Research Design and Rationale

In this study, I used a qualitative approach to examine the lived experiences of parents of children with SCD with regard to coping strategies and how they access health services. I employed a phenomenology design for this study because of my focus on capturing the lived experiences or descriptions from the participants' perspectives. The hermeneutics approach offers a perspective for interpreting the data (Patton, 2002). I selected phenomenology for this study because it allowed me to study the phenomenon as it naturally occurs and explore the lived experiences of participants under study (Rudestam & Newton, 2015). The data was collected from the parents of children with SCD based on their experiences that gave me a better understanding of the phenomenon under study.

Research Questions

RQ1: What coping strategies are used by parents of children with SCD when managing their child's disease?

RQ2: What are the experiences of parents of children with SCD related to managing their child's healthcare treatment?

I used in-depth interviews of parents who have children with SCD to collect data. In depth interviews are one of the data collection methods used in qualitative research and are useful specifically with phenomenological designs (Creswell, 2009). The study aim was to gain knowledge through the description of lived experiences of the coping strategies parents use to manage SCD and use available healthcare services. Lindseth and Norberg (2004) posited that a phenomenological hermeneutic method inspired by the philosophy of Ricoeur could help to understand the lived experiences of participants. In this study, it was the coping mechanisms of parents of children with a chronic illness as revealed through interpretation of the parent perspective. I prepared interview questions in advance to collect participants' views in order to address the research questions of the study. These in-depth interviews provided the opportunity to gather data from the parents of children with SCD.

Role of the Researcher

My professional skills and education have provided me with the knowledge of working with families and their children in foster care for over 12 years and 3 years as a licensed child placing agency administrator. I served as the executive director of a foster child placing agency for 3 years and the president of this organization for the last 14

years. My role and responsibility for this study included designing the study, creating the semi structured open ended interview questions and guidelines, conducting the interviews, collecting the data, and conducting the data analysis and interpretation.

Hay-Smith, Brown, Anderson, and Treharne (2016) indicated there is a need to ensure the clinician researcher's privileged position is balanced with responsibility both to the participant and rigorous research methods. Health professionals and researchers have a code of ethics they must follow. For example, the General Medical Council and principles of ethical medical research with human participants mean that clinician researchers have a duty to act in accordance with the participants' wishes and best interests and put their well-being first in research (Hay-Smith et al., 2016). Participants should feel comfortable when being interviewed and not feel as if they are being judged.

Researcher Bias

Blair, Steiner, and Havranek (2011) indicated that researcher biases undermine the quality of the study. Researchers are encouraged to consider how biases can affect the quality of their study. However, any biases were constantly documented and addressed throughout the study. My interest in this study came from past experiences of knowing individuals living with SCD. There were no ethical issues based on how I related to the study because the participants were not exposed to details of my personal life. There are ethical challenges in a qualitative study that must be addressed before conducting the study. I had an ethical framework for dealing with any issues during the study because biases exist (Blair et al., 2011).

Methodology

Participant Recruitment

Rudestam and Newton (2015) indicated a phenomenological study usually involves identifying and locating participants who have experienced or are experiencing the phenomenon that is being explored. I used a purposeful sample to recruit the parents of children with SCD for this study. Patton (2002) indicated researchers should select information rich cases for in depth study. Information rich studies are those from which a researcher can learn a great deal about problems of central importance to the purpose of the inquiry from a purposeful sample. Qualitative inquiry typically focuses in depth on relatively small samples, even single cases selected purposefully.

For this study, I recruited 10 participants as most phenomenological studies engage a small number of participants, typically 10 or fewer (Rudestam & Newton, 2015). However, there is no set number of interviews that should be done (Patton, 2009). Saturation is a tool used for ensuring that adequate and quality data are collected to support the study (Walker, 2012). Hennink, Kaiser, and Marconi (2017) conducted research to document two different approaches to saturation and drew out the parameters that influenced saturation in each approach to guide sample size estimates for qualitative studies. Determining whether data saturation has been reached remains at the discretion of the researcher who uses their own judgment and experience (Patton, 2002; Sandelowski, 1995; Suddaby, 2006; Tuckett, 2004; Trotter, 2012; Van Rijnsoever, 2017). When no new information has been obtained after interviewing all participants, this is an indication that the researcher has reached saturation and can end data collection (Van

Rijnsoever, 2017). If saturation has not been achieved after completing 10 interviews, data collection should be extended until data saturation occurs.

I obtained permission to recruit participants for this study from among the patients and parents who use the SCATMTF facility for treatment (see Appendix A). SCATMTF is dedicated to parents of children with SCD. The mission of SCATMTF is to enhance and improve the quality of life for families living with SCD and sickle cell trait in Texas. The participants were those who came to the association for follow-up appointments and received assistance with using health care services.

The executive director of SCATMTF sent a recruitment e-mail to the members of the organization on my behalf. I was given permission to put flyers in SCATMTF facility as well. Participants were informed about the study by reading the e-mail and flyers. The potential participants who meet the study criteria and were interested in the study contacted me using the e-mail address provided in the letter of invitation and or the information on the flyer. I first screened them to ensure they meet the inclusion criteria prior to setting up interviews. The potential participants had a choice in their time of interviews, Monday through Saturday from 9 am to 6 pm.

Inclusion criteria for this research included the following: parents (mothers or fathers) of children with SCD age 5 to 10 years. The exclusion criteria included parents of children with SCD who were older than 10 years of age and younger than 5 years of age. The participants were from a convenience sample of parents who were members of or affiliated with SCATMTF, met the inclusion criteria, and agreed to be involved in the study. The participants were the experts on the phenomenon being studied.

Data Collection Method

Individuals who received e-mails and were interested in participating contacted me, and at that time, I went over the inclusion criteria again before scheduling the interview. I scheduled face-to-face interviews with the participants at a private setting at the public library and the community center. Face-to-face interviews were the method of data collection. Upon meeting with the participants, I provided an overview of the study and explained the informed consent form. The participants signed the informed consent form before I started the interviews so that they would have an understanding of the scope and purpose of the study, how their information would be used, and that their confidentiality was protected. I used the researcher-developed instrument of interview questions to interview the participants. I scheduled the interviews at the time that was convenient for the parents. The interview questions (see Appendix B) were prepared in advance and the process took no longer than 60 minutes, although no time limit was set on the interview.

I asked semi structured, opened ended questions during the interviews. All interviews were audio recorded to enhance researcher accuracy of the participants' responses. The interviews were transcribed into Microsoft Word documents. After interviewing each participant, I thanked them for their time.

Instrumentation

The theoretical framework was used to develop the instrument. The interview protocol and questions were developed from a comprehensive literature review. The interview questions were designed to allow the participants to share their experiences and

to aid me in understanding coping strategies of parents of children with SCD and how they use health services (see Appendix B). Questions for the interview were derived from the main research questions.

Procedures for Pilot Study

Pilot studies are defined as preparatory studies designed to test the performance characteristics and capabilities of study designs, measures, procedures, recruitment criteria, and operational strategies that are under consideration for use in a subsequent, often larger, study (Moore, Carter, Nietert, & Stewart, 2011). Because the instrument was self-designed, I pilot tested it prior to administering it for the full study to make sure it was well worded, understandable, and that the questions addressed the phenomena under study. I conducted the pilot study with the first 2 people who volunteered to be a part of this study. Face to face interviews were the method of data collection. Upon meeting with the participants, I provided an overview of the study and explain the informed consent form. The participants completed the informed consent form before I started the interviews so that they had an understanding of the scope and purpose of the study, how their information would be used, and that their confidentiality was protected. I used the researcher developed instrument to interview the participants. All interviews were audio recorded to enhance researcher accuracy of the participants' responses. After interviewing each participant, I thanked them for their time. I used the pilot study to enhance the interview protocol and the questions.

Procedures for Recruitment, Participation

At the time of the interview, the participants were reminded of the study aims. The informed consent process was reviewed after which the interviews took place. At the conclusion of the interviews, the participants were provided a $10.00 Target gift card as a thank you for participating in the study. Participants who did not answer all the questions were also given a gift card. The gift card was not meant to entice participation but to thank the participants for their voluntary participation in the study. The participants were informed of the voluntary nature of their participation and the confidentiality of the study. After the interviews, I transcribed the audio recordings into Word documents and NVivo 12 plus, a qualitative software program, was used to assist with analysis of the data. I shared the transcripts with the participants prior to analysis so they could confirm accuracy or clarify their responses. I sent the participants' responses via their e-mail to review and confirm or if they prefer I scheduled an in person meeting with participants at SCATMTF prior to the analysis.

Qualitative Data Analysis Plan

Unit of Analysis

The unit of analysis represents the smallest unit from which information may be collected in the study. Patton (2002) suggests groups, organizations, individual people, clients, or students are the unit of analysis. This means that the primary focus of data collection was on the phenomenon happening to the individuals in a setting and how individuals are affected by the setting. I collected data from the parents of children with SCD. The parents were the unit of analysis for this study.

Data Management

I used NVivo12 plus software to help manage and analyze the data. NVivo 12 plus was used to analyze the transcripts for common themes, patterns, and categories. NVivo 12 Plus provided security for coding, storing the data, and keeping the single files together. The use of NVivo 12 Plus allowed for the sorting of similar words that help form the themes.

Researchers' approaches to handling missing and discrepant data could have a significant influence on study outcomes, as the amount of data meeting one or both of these criteria is often, although not always substantial (Hilbert, de Zwaan, & Braehler, 2012; Rø et al., 2012). If any discrepant cases arise, I addressed and report the data from the study and include this information.

Method of Data Analysis

In this study, I used Colaizzi's (1978) method of phenomenological data analysis to analyze the study data. Rudestam and Newton (2015) posited when selecting a phenomenological study, the student needs to be familiar with the kinds of data inquiry procedures. The purpose of using Colaizzi's (1978) method was to uncover the shared essences of the study participants' lived experiences (Wang & Volker, 2013). By using Colaizzi's (1978) seven step approach to data analysis, I created an interpretation of the deeper meaning of the data with an emphasis on the coping strategies the parents of children with SCD use to gain access to health services and manage the disease. In accordance with the steps of Colaizzi's (1978):

1. Interviews conducted with each of the parents of children with SCD were transcribed verbatim and read and reread to gain an understanding of their personal experiences. Transcripts were shared with the participants for feedback prior to analysis.
2. After reviewing the transcripts, significant statement phases relating to the experiences under research were extracted. For example, coping strategies and accessing health services.
3. I formulated units of meaning from all significant statements
4. The formulated meanings were organized into clusters and themes from the experience.
5. I used the themes to describe the parents' experiences with SCD.
6. In my description of the themes I included direct quotes from the participants.
7. I e-mailed a synopsis of my findings to the participants and ask for their input.

The data that was collected from the participants were analyzed to identify themes. I used those 7 steps to determine themes and meaning from the interviews data I collected. Each interview was coded separately and all codes were combined to compare, contrast and build themes. These themes were used to write a textural description, a description of what the participants experienced and a structural description, a description of the context or setting that influenced how the participants experienced the phenomenon (Creswell, 2007). Qualitative researchers often observe that themes can be identified in repeated ideas, sentences, concepts, words, images, and sounds; in similarities among units that make up the analysis material (Bendassolli, 2013).

Evidence of Trustworthiness

Credibility

Lincoln and Guba (1985) indicated ensuring credibility is one of most important factors in establishing trustworthiness. Credibility deals with the focus of the research and refers to confidence in how well the data and processes of analysis address the intended focus (Polit & Hunfler, 1999). To ensure credibility, I chose an appropriate well recognized research methods, studied peer reviewed articles on SCD, and developed early familiarity with the participating organization. In the write up of the analysis, I included representative quotations from the transcribed text. Credibility means how believable the perception of the participants' experience is told (Munn et al., 2014). Member checking can be the most significant way to ensure credibility (Guba & Lincoln, 1994). Member checking is when the participants are able to review their statements and verify the findings (Harper & Cole, 2012). I used member checking to further bolster credibility. I e-mailed a synopsis of my findings to the participants and ask them to confirm accuracy or clarify their responses. I asked the participants to review the synopsis to make certain it sufficiently documents their comments and correctly reflects the information they revealed during the data collection process. For example, participants who specify that their words were misrepresented were asked to correct any identified inconsistencies. Member checking is a significant quality control process in qualitative research (Harper & Cole, 2012).

Transferability

To show transferability, Shenton (2004) suggests provision of background data to establish the context of the study and detailed descriptions of the phenomenon in question to allow comparisons to be made. Polit and Hungler (1999) indicated trustworthiness includes the question of transferability which refers to the extent to which the findings can be transferred to other settings or groups. The researcher can give suggestions about transferability, but it is the reader's decision whether or not the findings are transferable to another context. To address transferability, I gave clear and distinct descriptions of my data collection process, and recruitment and characteristics of the participants, with specific attention to the interviews and the environment. A rich and vigorous presentation of the findings together with appropriate quotations also enhanced transferability.

Dependability

Lincoln and Guba (1985) suggest dependability in qualitative research refers to reliability or repeatability of the findings within a study. I increased dependability in my study by ensuring that the same interview questions were asked of all participants (Shamsaei, Cheraghi & Esmaeilli, 2015). Shamsaei et al. (2015) posit numerous quotations from the participants need to be presented in the study to shed light on their experiences. I gave an in depth description of the research design and documentation of the interview process.

Confirmability

Confirmability is the qualitative investigator's comparable concern to objectivity, allowing the findings to be linked back to the participant data rather than to an individual

researcher's set of assumptions (Shenton, 2004). Koch (2006) suggests that a study's trustworthiness may be established if a reader is able to audit the events, influences and actions of the researcher, while Akkerman, Admiral, Brekelmans and Oost (2006) indicated that audit trails represent a means of assuring quality in qualitative studies. Audit trails document the course of development of the completed analysis. The audit trail tracks the steps taken in the research process. In developing an audit trail, I provided an account of all research decisions and activities throughout the study. I described the study method and procedures in explicated details so that the reader can follow the actual sequence of how the data was collected, processed, and used (Meadows, 2003).

Ethical Procedures

I obtained Institutional Review Board approval before I started conducting research with human participants and gather any data. Walden's University approval number for this study was 08-02-18-0333579. I was committed to maintaining confidentiality and protecting the participants throughout the study. The participants in the study were 18 years and older and were the parents of children with SCD. I had each participant signed the informed consent form before I begin interviewing. The informed consent covered the purpose of the research, the rights of the participant, the procedures that were used to collect data, how the information was used, what was asked during the interview, confidentiality, and the risks and benefits of being involved in the study. All the recorded data was de-identified and confidential to avoid revealing participants' personal identity. I interviewed the participants one at a time to avoid personal contact with each other.

Because the participants in this study were the parents of children with SCD, describing past experience could be difficult and painful. Should participants indicate they were having difficulty handling the stress of managing their child's SCD. I would have referred them to the licensed counselor at SCATMTF. I did not get involved in any counseling. Therefore, to minimize the risk, I would inform the participants that their participation is voluntary and they could withdraw from the study at any time without giving an explanation. I was committed to supporting the participants in providing honest and candid information throughout the interviews. I would encourage participants to elaborate on responses that need additional explanation.

All the data for this study such as the participants' transcribed interviews, recorded dialogue, and notes from the interviews were stored in a secured and locked file. Data collected from the participants were saved in 3 different areas, my laptop, an external hard drive, and a locked cabinet in my home office where the public has no access. The data was stored on an external hard drive and laptop that are password protected with anti-virus protection that is safe from public access as well. My committee and I were the only people with access to the data collected for this study. The final approval of the dissertation from Walden University, the data collected for this study would be kept for a period of 5 year before the data are destroyed permanently. The participants in this study are not a part of my work environment; this eliminated any ethical issues in the work place environment. I would not have any conflict of interest or personal incentives that would arise as a result of this study.

Summary

In Chapter 3, I presented a detailed explanation of the methodological procedure that I used in this study. I applied a phenomenological design using in depth interviews to collect data of lived experiences of the coping strategies parents use to manage SCD and use available healthcare services. The purpose of this qualitative study was to explore the coping strategies of parents of children with SCD in order to better understand the ways these coping strategies relate to the use of health services. This chapter also included the participant informed consent process, and their right to withdraw from the study. Ensuring trustworthiness, the method to data collection, and the analysis is presented in this chapter. Also, the role of the researcher is discussed with emphasis on protecting human participants in research according to the requirements of Walden University Institutional Review Board. In Chapter 4, I presented the result of the study analysis.

Chapter 4: Results

Introduction

The objective of this phenomenological study was to explore the coping strategies of parents of children age 5 to 10 years with SCD in order to better understand the ways these coping strategies relate to the use of health services. The study evolved from other researchers who suggested that there is an association between coping strategies and disease management (Barakat et al., 2014; Derlega et al., 2014; Oliver-Carpenter et al., 2011). Researchers have also suggested that the child's adjustment to a chronic illness is mediated by individual actions of their family members (Thompson and Gustafson, 1996). The ways in which the parents adapt play a central role in the children's quality of life (Hocking & Lochman, 2005; Thompson & Gustafson, 1996). My research was based on the lived experiences of coping strategies used by parents who have children with SCD and how the parents access health services. For this study, the data analysis was conducted through interviews with 10 parents of children with SCD. Two of the parents were in the pilot study. This chapter is divided into several sections including pilot study, research setting, demographics, data collection, data analysis, evidence of trustworthiness, study results, and summary.

The following research questions guided the study:

RQ1**:** What coping strategies are used by parents of children with SCD when managing their child's disease?

RQ2: What are the experiences of parents of children with SCD related to managing their child's healthcare treatment?

In the first sections, I present information regarding the pilot study which was conducted to ensure that the instrument was well worded, understandable, and that the questions addressed the phenomena under study. This section also includes the setting, demographics and data collections. In the following section I discuss the data collection and data analysis. Finally, I discuss study results, evidence of trustworthiness, and the summary.

Pilot Study

Prior to the implementation of the main study, I conducted a pilot study to determine the appropriateness of the research instrumentation (Appendix B). Pilot studies are defined as preparatory studies designed to test the performance characteristics and capabilities of study designs, measures, procedures, recruitment criteria, and operational strategies that are under consideration for use in a subsequent, often larger, study (Moore et al., 2011). The research interview questions consisted of 16 open ended questions. The pilot study included recruitment of study participants and an interview with each participant. The pilot study participants were recruited from SCATMTF located in the Austin metropolitan area. The executive director of the organization informed the participants about the study. Two participants met the criteria for the pilot study. Both pilot study participants have children age 5 to10 with SCD. I provided an overview of the study and explained the pilot study informed consent. Both participants signed the pilot study informed consent form. I interviewed and audio recorded the interviews with the 2 pilot participants. The interviews took 30- 45 minutes each. Both participants were engaged in the interview and felt that the questions were appropriate and understandable.

Based on their responses, I did not need to make any changes to the interview questions. After the conclusion of the pilot study, I began recruiting for the main study.

Setting

I conducted interviews in a private setting at the public library and the community center. The room temperature was comfortable for the study participants and me. The room was set with comfortable chairs and appropriate lightning. There were no known personal or organizational conditions that emerged during the interviews that may have influenced participants or their experiences at the time of the pilot study or the main research study.

Demographics

The population of interest for this study was the parents of children with SCD who were members of the SCATMTF in south Texas, an area that consists of 3 regions, Austin, San Antonio, and Houston. Study participants were required to have a child age 5 to10 years with SCD. Following 2 months of recruitment, 8 additional parents of children with SCD participated in the study. The 2 parents from the pilot study were included in the study sample bringing the total number of participants to 10. As the 2 pilot study participants had no recommended changes to the interview questions and they provided rich responses to the interview questions, it was appropriate to include their responses as part of the full study. Table 1 displays participants' demographics relevant to this research study (Appendix C).

Table 1

Participants' Demographics

Name	Age group	Gender	Marital	Age of Child with SCD	Education
M01	31-40	Male	Divorced	7 yrs	College Degree
F02	41-50	Female	Married	5 yrs	Some College
F03	41-50	Female	Divorced	7 yrs	Graduate School
M04	41-50	Male	Married	8 yrs	High School Grad
F05	31-40	Female	Married	5 yrs	High School Grad
F06	41-50	Female	Married	10 yrs	Graduate School
F07	31-40	Female	Single	9 yrs	Some College
F08	30-40	Female	Single	6 yrs	College Degree
F09	30-40	Female	Divorce	7 yrs	College Degree
M10	41-50	Male	Married	6 yrs	College Degree

Data Collection

I collected data for this study through interviews. I developed the interview instrument from Thompson and Gustafson's (1996) TSC model. I tested the instrument during a pilot study conducted prior to the main study. I interviewed 8 parents for the main study and 2 for the pilot study. I conducted the interviews in private locations that were convenient for the participants in the public library and the community center over a period of 4 weeks. Each interview session lasted an average of 30 minutes each. I used a

digital voice recorder to record the interviews, which were then transferred to a Microsoft Word document.

Before starting the interview, I explained to the participant the interview process, the purpose of the study, and the informed consent, which each participant signed. I allowed the participants to express any adverse feelings or thoughts they may have had as a result of the data collection process. At the end of the interview process, participants were given an opportunity to discuss any related comments regarding the topic. At the conclusion of each interview, all participants were reminded that they could call or e-mail me if they had any concerns. The interviews were transcribed over a 3-week time frame. I e-mailed all participants a copy of their transcribed interview and asked them to confirm the accuracy of the transcript or clarify their responses. Three participants formally replied confirming they had received their transcript via e-mail, 1 replied with a verbal telephone call, and 1 replied via text message indicating they received their e-mailed transcript and that it was accurate. I received a response from a total of 5 participants. The remaining 5 participants did not respond.

Data Analysis

In the data analysis phase I applied Colaizzi's (1978) seven-step method for analyzing descriptive phenomenological data, which I outlined in Chapter 3. By using Colaizzi's (1978) seven-step approach to data analysis, I created an interpretation of the deeper meaning of the data with an emphasis on the coping strategies the parents of children with SCD used to gain access to health services and manage the disease. The data were organized using NVivo 12 Plus. I initially proposed using NVivo 10. However,

QSR International upgraded the software to NVivo 12 Plus, so I used this version to help code and establish themes. This version of the software is best for researchers who need to analyze and understand text such as interviews. NVivo 12 Plus helps the researcher save time. I automatically grouped the information such as themes and positive or negative sentiment from large volumes of text in minutes (QSR International, 2018). I applied Colaizzi's (1978) steps as I read and reread the transcribed interviews to gain an understanding of the main messages shared in the interviews, which helped me create codes and identify themes.

Step 1: Transcripts

Each transcript was typed and formatted with page numbers and columns. I read and reread each transcript 6 times to gain an understanding of the interviews. All 10 transcripts were imported from Word to NVivo 12 plus qualitative software program. In NVivo 12 plus, I set up a file for each participant interview that outlined all of the demographics (Table 1). Also, I created notes and made memos of the participant interviews. I kept a journal of recorded ideas, repeating word phrases and thoughts, and any concerns for bracketing purposes.

Step 2: Significant Statements and Phrases

During this phase of the analysis, I identified and highlighted significant statements and phrases that pertained to the lived experiences of parents of children with SCD. Descriptions of coping strategies and how parents accessed health services were extracted from each interview. This process required me to review the data and identify and separate significant statements.

Step 3: Formulated Meanings

In Step 3, I formulated units of meaning from these significant statements. The units of meaning are the statements from parents. In this step, each extracted statement from the textural data was given a summative explanation that described the excerpt in a few words. Using NVivo 12 Plus, the data fragments were assigned to a node. The data fragments were organized under the appropriate research questions. I provide examples of the units of meanings that came from the significant statements in Table 2.

Table 2

Examples of Significant Statement of Parental Methods of Coping with SCD, and Accessing Health Services and Consistent Unit of Meanings

Significant Statements	Unit of Meanings
I am doing really well. It's just being aware and constantly trying to protect her from pain crisis and doing more and more to keep her her healthy. I have the sickle cell trait.	Participant method of coping with SCD Participant views being aware of your child's SCD and protecting them from pain crisis keeps the child healthy and reduces parental stress
Adjusting to the emotions from watching him in the hospital. If I was panicky, he was panicky when they worked with him. I adjusted to the nurse behavior and started being calm around him and he watched me and stayed calm.	Participants understanding of SCD the child adjusts to the behavior of the parent (TSC model) adjustment
I get a lot of support from the child's father. I get support from my church and faith through prayer.	SCD family and support Participants view their faith as ways to cope with child's SCD Families working together
I managed my daughter SCD with Hydroxyurea and a lot of water. Hydration is essential.	Parent have similar ways of managing SCD. Parents experiences managing.
I have no health insurance, I cannot Afford my child's medications. No Medicaid.	Participants experience accessing healthcare

Step 4: Categories

In Step 4, the units of meanings were organized into clusters and themes from the reported coping experiences of parents who have children with SCD. The purpose of this step was to arrange the data into themes that represented the essence of the participants' experiences. In this step, the units of meanings, as described in Step 3, were clustered so

that similar or identical units were gathered into an overarching response or experience (Table 3). I used NVivo 12 Plus to organize similar parents' statements into clusters. A tabulation of 20 clusters emerged and were identified as: coping, pain treatment, pain crisis, hospital, accessing healthcare, family, parents experience, routine daily, support, prayer, faith and God, SCD, hematologist, conflict, emotional, hydrated, medications, stress, understanding, and diet. Those clusters were then grouped into 5 themes that describes the participant's' lived experiences: parental methods of coping with SCD, participants' understanding of SCD, SCD family and support, managing SCD with hydration and medication and, experience accessing healthcare. Table 4 illustrates the construction of themes from formulated clusters.

Table 3

How Clusters Were Developed

Unit of Meaning	Formulated Clusters
Child free of pain, praying, awareness, no pain crises, Accepting, getting along	Coping
Tylenol, warm baths, cuddles, Faith, prayer	Pain treatment
Extreme Pain, SC hemoglobin SS hemoglobin, Red blood cells Sickle shape Sickles clotted Extreme heat/water balance Extreme cold/water	Pain crisis
SAMH hematologist team Hospital	Hospital
Hematologist Managing Medications Access to the pediatrician Private insurance	Accessing healthcare
Family, Sickle cell support group Team Support from family A team of caring nurses and doctors Child's school nurse very supportive and teachers	Family
Communication was poor Problem Accessing Information	Parents experiences
Handling your business Pain crises	Routine daily
Team Support from family A team of caring nurses and doctors Child's school nurse very supportive and teachers	Support
Prayer group at my church	Prayer
Pray and call on others to pray for the child	Faith in God

table continues

Painful, affects family functions Managing daily care for the child Give medications for pain and fever	SCD
Caring doctors and a caring team Helpful hematologist and social worker Proper healthcare and supportive	Hematologist
No family support, no support from the child's father lack of community support	Conflict
Child pain crisis, crying Coping, No support from the family No support from the fathers	Emotional
Water Hydration lots of water Give child plenty of water to drink	Hydrated
Tylenol, oxycodone, Motrin pain medications Hydroxyurea	Medications
No control nothing, coping, no medical insurance Hospital E D	Stress
Sickle cell is a platelet problem Developmentally genetic, adjustment Form of Cancer, stressful, child adjust to parent behavior. Do not know much about the disease Blood flows crescent moon shape	Parents understanding of SCD
Natural Supplements Give child green vegetables	Diet

Table 4

Themes Developed from Formulated Clusters

Formulated Clusters	Themes
Coping, routine daily, Faith in God, stress, emotional	Parental Methods of Coping with SCD
Pain treatment, pain crisis, SCD, Parents understanding SCD	Participants' Understanding of SCD
Support, hospital, family, Prayer, Hematologist	SCD Family and Support
Hydrated, medications Diet	Managing SCD with Hydration and Medications
Accessing healthcare, Parents experiences, conflict,	Experience Accessing Healthcare

Step 5: Exhaustive Description of the Phenomenon

In Step 5, the results of the data analysis were integrated into an exhaustive description of the phenomenon under study. I used the themes identified in this study to describe the parents' experiences with SCD.

Step 6: Fundamental Structure

In Step 6, I included direct quotes from the participants to validate the core theme as demonstrated throughout the study.

Step 7: Validation of Exhaustive Description and its Fundamental Structure

When interviewing the participants, they were informed of the member checking process and agreed to review and make any necessary changes to the findings. I e-mailed

a synopsis of my findings to the participants and ask for their input and to contact me for further response.

Study Results

In this study, I sought to answer two research questions to gain an understanding of the lived experience of the coping strategies of parents of children with SCD when managing as related to accessing health services. Five themes emerged overall during the analysis.

Research Question 1

In response to the first question, what coping strategies are used by parents of children with SCD when managing their child's disease? The participants in this study used a range of preventive, emotional, and avoidance coping strategies when managing their child's disease. The participants' coping strategies varied according to their individual situations. Several of the participants reported that they cannot control their child's SCD, while other participants reported they were controlling the disease. There were 3 themes specific to this research question:

- Parental Methods of Coping with SCD
- Participants' Understanding of SCD
- SCD Family and Support

Theme 1: Parental Methods of Coping with SCD. The participants described their various approaches of coping with their child's SCD by doing whatever they needed to do to keep them free of pain. The participants reported that coping with SCD is a daily task in which the parent gives the child daily medications, plenty of water to help the

blood flow, prayers, crying, hugs and cuddles and to know the triggers that causes pain crisis. Most participants indicated that they used more than one method to help them cope with the stress of caring for a child with SCD. Each participant defined coping and indicated that they understood what it means to cope with their child's SCD. For example, F03 said, "Coping with SCD is accepting what it is and figuring out what to do with what is happening in the situation." Participant F07 responded that coping with their child SCD is "being able to handle a situation and make it less stressful."

Many of the participants expressed that their method of coping depended on the severity of the child's pain. Some of the participants relied totally on medications to help them cope with the child's pain crisis while others used a combination of medications, warm baths, hugs, cuddling, and prayers. Several of the participants felt that their faith had helped to keep them and their child and family strong, and to maintain a positive attitude since the child's diagnosis of SCD. For example, F 07 said,

> You need to go along and get along to handle the disease I do it with a lot or prayers. I look at it like God does not put anything on you that you cannot handle. I know that in him giving me this child he is one of three tries. I lost two babies before I had him. God gave me this child with SCD for a reason. He has given me a lot of purpose and directions in my life so I stay in prayer in dealing with these things.

Most of the participants in the study indicated that their method of coping involved crying because no parent wants to see their child in pain. Some of them expressed that they do not cry in the front of the child because they do not want their child pain crisis or

SCD getting worse or the child adjusting to their behavior. Most of the participants felt that their children adjust to the coping method of the parents.

While most of the participants reported similar meaning of coping, M01 said, "I deal with my daughters SCD from a mental state. It is what it is. You try to make the best of it and give as much prevention as you can." F06 said, "Coping with SCD is being able to handle the situation and make it less stressful." Many of the participants expressed that SCD is a chronic disease and no two children are the same every individual copes with the disease differently. The majority of the participants indicated that SCD is stressful and difficult to deal with and or control because the disease gives no warning and causes the entire family to function differently.

Participants in this study described various methods of coping with chronic illness as noted by Montero-Marin et al. (2014) such as mental or behavioral coping, cognitive or behavioral avoidance, and emotion focused coping. For example, F02 said, "I cannot say that I handle SCD. I cannot plan for anything; I just go with it and take what is given each day. It does not make any sense, I just take what comes. I just roll with the punches." On the other hand, F09 said, she has accepted the disease and this helps them to cope. They use a checklist each day and plan for SCD crisis. "Now that they are older, I put some of the responsibility on them to hold them accountable to help me cope and help them understand this is your disease that you have to live with and I am training them to know. They both have a checklist with what they need to have each day."

The majority of the parents in this study indicated they influence the ways in which their child copes with their SCD by modeling good coping methods and having the

child take some of the responsibility of caring for themselves. Although most of the parents indicated that they are their child's role model when coping with SCD, some participants expressed they struggled to cope with their child's SCD and felt that they have limited ways to cope. Other participants felt that since it is hard for them as an adult to drink a lot of water, it would be hard for their child to drink a liter of water a day. Participant F08 indicated that coping is keeping the child hydrated by giving a lot of water. For example,

> I make sure my child is hydrated and takes a minimum of two liters of water daily. We struggle because even as an adult to take one liter is hard. I tell my child that she has to take the water so she can stay away from the hospital.

This participant said it has been difficult keeping her child hydrated. Overall, the participants in this study felt that it is difficult getting their child to drink plenty of water daily but they work hard to make sure their child stays hydrated. The participants expressed they use various methods of coping with their child's SCD and expressed similar goals of making sure their child is healthy and lives a quality life that is free of pain.

The majority of the participants reported they are emotional when coping with SCD because they do not like to see their child in pain. They described their emotions as crying, restless, not sleeping, not eating, tired, feeling drained, and worried. Participant F08 said,

> She just wakes up and says mama my hands are aching, my legs are aching, my back is aching and immediately I am off balance there is nothing I can do to ease

> the pain but take her to the ER. I get very emotional when the pain problem comes because the hospital is a thirty-minute drive from my home.

F07 said,

> No parent wants to watch their child be in pain and agony. With the stress that comes with taking care of a child with SCD, I have a psychiatrist for other reasons so when I need to see that doctor and if anything that is related to my child's SCD I can talk about it.

Some of the participants reported they got emotional as soon as the child complained of pain. The parent adjusted to the child's emotions of dealing with the pain and vice versa. Within the one participant clearly indicated that her child watched her reactions while in the hospital for SCD and reacted to her behavior. Participant F05 said, "If I was panicky, he was panicky. I adjusted to the nurse's calmness when they worked with him. I adjusted to the nurse behavior and started being calm around him and he watched me and stayed calm." F02 indicated that if she is crying her child starts to cry and her husband does not need both of them crying.

Many participants reported that it is essential the medical team work together with the parents when managing SCD or it will cause emotional stress. The majority of the participants indicated that it takes time managing and caring for a child with SCD. The participants indicated they sometimes need to take three to five days off from work when the child has a crisis. The majority of the participants indicated that their jobs are aware of their child's SCD and give them no problems. They indicated they managed their

child's SCD like a job to make sure the child is free of pain and to help their family function.

The majority of the participants reported they believed their faith in God has helped them cope with their child having SCD. Several of the participants said, they did not fully understand but they feel so much better when they pray with their child during the pain crisis. F03 said, she relied on her

> faith in God to heal her child from SCD, I handle problems through prayer. I have a good support system with my friends and church. The minute I call and tell them about her pain crisis they all start immediately praying. I cannot fully understand what it is about for her. It's hard watching her but I do know that she will be okay because of my faith. I have always even before she was born spoke the word over her and I believe that has made a big difference over her. I told her that you are healthy and whole and that God is Jehovah Rapha. I have had her to say this from the time she could speak and now she speaks it daily that God is Jehovah Rapha and you are healthy and whole. I believe that speaking the word of God over her health has made a big difference in every situation that has come.

M04 had a similar response that he is a Christian and he must believe and pray for God to help him and make his children better. F02 said when her child was in the hospital with a stroke caused by sickle cell, she knew it was the Lord that blessed her child to live. She said "I thank God for blessing us." The participants responded similarly that their faith in God through praying has helped them support each other and care for a child with

SCD. The participants reported that when their families support each other with prayer, there is less stress and conflict coping with the disease.

Theme 2: Participants' understanding of SCD. Understanding their child's SCD was a significant part of the participants coping strategies. Study participants felts that understanding SCD made them better able to care for their children and extend their quality of life. The participants believed that coping with SCD required them to understand their child's disease. Most of the participants understood that SCD is developed genetically. They described the disease as sickle shaped blood cells, crescent moon shaped that get clogged in the children's veins and cause extreme swelling and pain. Participant M10 reported his understandings of SCD.

> "My understanding is that sickle disease is that his platelets are the problem as the hematologist explained to us in details, a problem that is going on inside of him and how he feels. He has SC hemoglobin."

Participant F07 said, "I understand he has it developmentally, it's genetic and that is how he got SCD." Some of the participants expressed they understood their child's SCD only at a basic level. Participant F09's understanding of SCD is that

> I feel like I know my children but I do not feel like I know as much as I should know about the disease. My understanding when I am describing it to someone who has no clue is just imagine that our veins are really tiny and the blood that flows through our veins are oval shape and sometimes the blood that flows through the vein becomes crescent moon shape and when it becomes crescent moon shapes the blood cannot pass through. It will cause extreme pain. You will

> then see swelling and pain. For my child she will nurse her arm. She will hold her arm or she will not walk and it will cause extreme pain and discomfort.

F09 felt that her fear of not understanding her child's SCD could be fatal. She said, SCD causes extreme pain and fever and if the parent does not know what to do, the child could die. Most of the participants reported they gained a better understanding of SCD from their child's doctor and nurses. They felt that SCD is not talked about as much as other diseases. They felt that it was important to learn and understand as much as they could about SCD because of the complications with the disease. One of the participants thought that SCD was a form of cancer. Participant F08 felt that "SCD is a cancer and both diseases are life threatening". The majority of the participants stated that SCD is fatal and their child could die at an early age if they are not cared for properly. However, communicating and discussing about the death of their child was not a topic the participants expressed they ever care to discuss. Participant M01 was very clear on his understanding of SCD, he expressed:

> The whole hope is you got to understand that there is a mortality type conversation that I must be aware. Long term pain is that pain crisis is a beautiful thing compared to a mortality conversation. I am doing all I can to preserve life as much as I can to have a healthy child.

Most of the participants reported feeling afraid and helpless when coping with the pain and complications associated with SCD and that it could one day be fatal. Participants expressed that they have accepted their children have SCD, but there is no cure for the disease and that is a thought that is always in the back of their minds. The

majority of the participants felt that SCD is a problem because of the pain crisis that comes at any time without warnings. However, participant M04 said, “My understanding is when the child has pain and complaining of pain to the legs, hand, arms and fingers there is a problem and we need to go to the ER.” He related the disease to a problem because he stated he has three children diagnosed with SCD and their crises come in at different places and at different times. He stated no children are the same when dealing with pain a crisis.

While all the participants felt they understood SCD to be a problem that caused the child extreme pain, they believe that to cope with the pain, the parent needs to understand their child’s diagnosis and accept the disease. Understanding SCD is complex said, F02 since “you cannot plan for pain crisis or control when they come. You just do what you got to do.” Other participants responded similarly that taking the child to the ED to get medication to stop the pain are their primary ways to cope with the disease. The participants reported to cope with SCD, parents must have an understanding of the disease.

Theme 3: SCD family and support. The participants reported that SCD affects the whole family and that they relied on their families, faith and medical staff support to help them cope and understand their child’s disease. The participants felt that family support is essential in coping with their child’s disease. They expressed that without the support of their family it would be difficult to care for their child’s SCD. Many of the participants felt that the more family support they received the shorter the child’s pain crisis and less stress. For example, participant M10 said, “My family and I work as a

team. We do a great job by staying on top of my son's SCD." He said when the child is sick and feeling down he cries and they call a close friend of their family to come by and cheer him up. He stated the friend would show the child funny pictures on his cell phone and allow the child to play games with his cell phone. He stated those are the kinds of things they do to lift the child's spirit to help them all deal with SCD.

Other participants depended on their siblings for support and felt that they worked as a team and partner when caring for a child with SCD. F03 said, "My sister is supportive she listens and respects what I say. I keep her informed." M01 and F02 responded similarly that their sisters and step mom are very supportive when needing someone to help care for their children. Several participants indicated that the children grandparents were supportive and helped them whenever they needed to have some free time to themselves. Most of the participants reported that they worked as a team when caring for their child with SCD and that the more support they had the better their family seemed to function. Participant F02 expressed that, "My husband and I are a team." She said, "I married my partner. We do everything together for this child." She said when there is a pain crisis, "Mama is cuddling while daddy is starting dinner." Other participants responded similarly that without family support it would be difficult to take care of a child with SCD.

The majority of the participants in the study reported the more understanding they have about SCD, and the more support they have from their families and friends, the easier it is to cope with the child when there are pain crises and hospitalizations. The participants responded similarly that taking care of a child with SCD is a daily task and

the entire family needs to support each other. F07 said, “I get a lot of support from the child’s father side of the family. The child spends time with them and they all know how to care for his SCD.”

The majority of the participants indicated they received support from their child’s school nurse and teacher. Participant F07 said, the child’s school nurse and teachers are supportive. They were willing to educate themselves by taking a training course on understanding SCD. Other participants indicated that the child’s school nurse and teacher sent them e-mails throughout the day letting them know how the child was doing at school after a pain crisis. The participants stated the nurse made sure that their child had their water bottles with them in every class and took their medications on time while at school. The participants expressed that this type of care and concern from school nurses and teachers reduces their stress and gave them a sense of peace and comfort knowing that some educators care and are aware of their child’s SCD.

Some of the participants responded that the lack of family support causes conflicts and stress in the family when caring for a child with SCD. Several of the participants felt that conflict and stress affect the health of the child as well as the whole family and create anxiety and fear. Several of the participants reported that there is conflict in their family when dealing with their child’s father. For example, participant F03 indicated, “I say let’s go to the doctor, let’s do what the doctor says, he says my child does not have this disease.” The participant expressed that it is frustrating not to have full support when the doctors are telling you to take the child to the hospital for SCD and a fever and one of the parents is saying the fever is not that high yet. A fever can be fatal for a child with SCD.

The participant reported there are several other things that could be going on in the child's body when a fever is present with SCD. Other participants indicated that it is difficult to cope with the child's SCD when the father refuses to follow the doctor's orders. Participant F05 experienced a similar situation as F03. Participant F05 said,

> My husband was skeptical about the protocol sometimes about having to take our child to the ER when there is a fever. He says it's just a fever what is the big deal. It took him a long time to understand the seriousness of a fever. A fever can be fatal.

Participant F05 felt that the lack of support caused conflict in their family as well. Another participant who reported lack of support from her partner, F08, expressed that she was going through it because there is no family support for her child. She indicated that her family does not know what she is going through emotionally when her child is in pain. She said that she has "No support from the father; there is always conflict when he comes around, I am too emotional to deal with added stress." Overall the participants felt that a supportive family that includes working as a team with the school nurses, teachers and their faith helps them to cope with their child's SCD.

The majority of the participants reported that their child's medical nurses, pediatricians and hematologists have been a support team for their child. They expressed that the child's doctors helped them to understand SCD. M04 said, "I only get support from the hospital." F06 reported they have a "Great support system." She said when her child is having a pain crisis they can call the nurse and the child's hematologist directly. F06 indicated that the nurse "scolded at me and told me she does not care what time it is

text me if you need help." The participants said they felt blessed to have a good medical support team. Other participants responded that the hematologist is a friend to their family and gives them the "VIP treatment" when taking the child to the hospital for pain crisis. Several of participants felt that the child's pediatrician and hematologist are very supportive and they can call them at any time. On the other hand, F08 said, she has no medical insurance for her child. "I applied for Medicaid and was denied." The participant said a caseworker was trying to help her but was unsuccessful in getting health insurance. Therefore, she has no support from the hospital staff. The participants indicated that to work as a team with their child's medical staff helps them to build a rapport and a lasting relationship.

Research Question 2

Research question two was what are the experiences of parents of children with SCD related to managing their child's healthcare treatment? The participants in this study relied on the medications, ED, communications with their hematologist and pediatrician, and hydration to help manage the disease. Two themes emerged as it related to this research question: managing SCD with hydration and medications, and experience accessing healthcare

Theme 1: Managing SCD with hydration and medications. All of the participants in this study indicated that they managed their child's SCD with plenty of water to keep them well hydrated and medications. They expressed that it is essential to keep the child hydrated so that healthy oxygen flows through the blood and keeps the veins from collapsing. Some of the participants reported they do combinations of

managing that depend on the severity of the SCD pain crisis. There are many statements in the participants' descriptions that support this theme. For example, F09 said her children's SCD is managed with water and medication. The participant said,

> I have two children with SCD that takes two different dosages of Hydroxyurea. I have steps that we follow in my home to help manage SCD. I make sure they are well hydrated by drinking three to four bottles of water daily. They both have water bottles they take to school or wherever they go. When either of my children says they are in pain we start with Tylenol. If that medication does not help the pain, I will give them Motrin. We will alternate the two medications. I set the alarms on my phone and type notes in my phone to keep up with the steps I have taken. If those two medications do not help the pain the third step is to give them Oxycodone. If that medicine is not helping the pain, then I will take them to the ER for I V medications.

F07 responded similarly that she manages her child's SCD with Hydroxyurea daily and makes sure he eats a healthy diet and drinks a lot of water. The majority of the participants reported that keeping their child well hydrated is significant when dealing with a pain crisis. The participants felt that their child has fewer crises when they are well hydrated. F06 said her family manages their child's SCD with medications such as Hydroxyurea and that they purchased particular water known as Alkine for their child to drink daily because it helps hydrate better.

Several of the participants in the study indicated that they struggled getting their child to drink plenty of water each day. The participants reported that their child faces a

pain crisis and other triggers when the child is not well hydrated. The participants felt that knowing the triggers that cause a pain crisis is important when caring for a child with SCD. Some of the participants reported triggers such as having their house too hot or cold could trigger a pain crisis or taking their child swimming in too cool or hot water. Participant F02 said "There is no swimming in cold water or playing outside in water because he usually ends up in the hospital." F06 said "Extreme temperatures from going outside from hot to cold or in and out of the pool triggers pain crisis. We bundle her up in a blanket before bringing her into the cool house." M04 said he manages his child's SCD with Tylenol to help stop the pain and if that does not help "I will take the child to the ER for stronger pain medication or a blood transfusion."

M01 indicated he used medications to manage his child's SCD along with a natural supplement called "Kyani" that is a part of the Noni juice family. He stated his child's doctor did not prescribe this medication. He said he started giving this medication to his daughter when he ran out of pain medications while the two of them were on a cruise. He stated "Kyani helps to open the blood flow of the veins and I use this product on a daily basis." Participants M04 and F08 expressed that they give their children natural supplements along with their prescribed medications but did not remember the names of the supplement.

Overall the majority of the participants reported that their child drinks plenty of water and takes their medications when managing their SCD. The participants felt that keeping their child well hydrated, along with taking Hydroxyurea has made a big difference in their child's life. Four of the ten participants indicated that hydroxyurea is a

medication that is given to a child with cancer. The participants reported that the medicine has helped decrease their child's pain crisis. They expressed that there are various side effects to Hydroxyurea and it was very hard giving it to their child in the beginning because the child was sick and having nose bleeds and other complication after starting the medicine. The participants felt that the medication is needed and they understands the risk but would like to learn more if new medications are offered for SCD.

The majority of the participants reported managing SCD with medications, they caused their child emotional distress if they had to go to the ED. Some reported that a pain crisis is managed with IV medications from the ED when they cannot control the pain crisis at home. Seven out of ten participants said they had a hematologist and a pediatrician to help manage the disease. Some participants reported that it is difficult to manage the disease by visiting the ED. F09 said she had an emotional and unpleasant experience when taking her child to the ED for pain crisis.

> I remember one time I took my daughter to the hospital for a pain crisis and they kept asking her did you fall, did you get hurt. I remember I was raging and I told them my daughter has sickle cell SS disease, she is in pain and she needs pain medications, she did not fall. She needs Rocephin, a chest x-rays and labs. I gave them a check list of everything they needed to do. The doctor said no we are not giving her Rocephin and I got on the phone and called my team in south Texas and told them that they were refusing to give my daughter Rocephin.

Participant F09 stated the child's hematologist called and informed the ED doctor and his team to collaborate with the mother because she is experienced and does a good job in

managing her child's SCD. Participant F09 felt that she is an advocate for her children with SCD, and that every parent should be a voice for their child. The participant said it was difficult coordinating care with the ED and plans to never visit this ED again. The participant felt that going to the ED was stressful and conflicted with her children's care.

Theme 2: Experience accessing healthcare. The majority of the participants reported that accessing healthcare was an essential part of their child's life when coping with SCD. The participants expressed that having health insurance and a pediatrician to check on their child's health routinely is important. The majority of the participants in this study indicated that they have health insurance, a hematologist and a pediatrician that provides routine care for their child. The majority of the participants have a good rapport with their child's hematologist and pediatrician. Participant M01 felt that his child's doctor is "A close friend of the family and gives us VIP services" whenever they need to go to the hospital. Several of the participants had similar responses such as, participant M10 expressed that his family is pleased with the services and care the hospital provides for his child.

Several participants thought that it is less stressful when their child has health insurance because it gives them access to their child's doctors and medications. Other participants responded similarly. M10 felt that he has no problem accessing healthcare for his child. F02 reported, she has great insurance for her child and she is satisfied with the treatment that his doctors provide. F02 felt that her child's hematologist allowed them to manage their child's SCD For example, "He looks at me and says I don't know what to do, what you think?" The participant said she felt her child's hematologist is loyal and

trusts her to help coordinate his care. Two of the 10 participants in this study expressed that they had experienced barriers accessing healthcare. F09 said she struggled to get an appointment for her children to see a hematologist when she relocated to another city to be closer to her family. She stated she felt "unplugged because, I am still going back and forth trying to find my children a hematologist that will take my health insurance." She felt there was a gap in communication that caused stress. For example, participant F09 said,

> I am about to lose it. I feel like I am getting a lot of run around when I call them, they do not call me back and they are not pleasant to deal with because they are not explaining themselves. When I lived in south Texas it was much better and organized.

Other participants responded similarly regarding accessing healthcare. F08 said it was difficult for her to access healthcare because she has no health insurance for her child. The participant said she cannot afford to pay for health insurance and they have denied her Medicaid twice but she will continue to apply until her child has health insurance. Overall the majority of the participants expressed that they had access to healthcare and the treatment that their child is receiving from their hematologist and pediatricians are efficient. Eight out of the ten participants felt they did well accessing healthcare. The participants said communicating about their child's treatment and working with the medical staff makes understanding SCD, coping and accessing healthcare easier.

Evidence of Trustworthiness

Lincoln and Guba (1985) proposed the quality criteria most often cited by qualitative researchers is trustworthiness. They suggested 4 criteria for developing the trustworthiness of a qualitative inquiry: credibility, dependability, confirmability, and transferability. Creswell (2009) suggested the use of several validity approaches to check for efficient of the research findings that assisted me in attaining evidence to support credibility, dependability, confirmability, and transferability. Among them were members checking. Member checking can be the most significant way to ensure credibility (Guba & Lincoln, 1994). Member checking is when the participants are able to review their statements and verify the findings (Harper & Cole, 2012).

Credibility

Credibility deals with the focus of the research and refers to confidence in how well the data and processes of analysis reflect the true and accurate experience of the participants. To ensure credibility, I used an audit trail to keep track of the research process from the participant's initial recruitment to the interview phases. I used the audit trail for journaling my thoughts, ideas and about the research. In the write up of the analysis, I included representative quotations from the transcribed text. I used member checking to further bolster credibility. I e-mailed a synopsis of my findings to the participants and asked them to review the synopsis to make certain it sufficiently documented their comments and correctly reflected the information they revealed during the data collection process. I received feedback from 5 of the 10 participants. These 5 participants did not have any corrections that needed to be made to their transcripts or

any concerns. I did not receive a reply by e-mail or a call from the remaining 5 participants.

Transferability

Transferability lies with the reader's decision whether or not the findings are transferable to another context (Patton, 2002). To address transferability, I gave clear and distinct descriptions of my data collection process, recruitment, and characteristics of the participants, with specific attention to the interviews and the environment. I used NVivo 12 Plus to code the participants' transcripts and identify themes. A rich and vigorous presentation of the findings together with appropriate quotations enhanced transferability. In the result section, I used text from the participants' direct quotes to present the coping strategies of the parents who have children with SCD and how they access healthcare to show a clearer picture of five themes.

Dependability

Dependability in qualitative research refers to reliability or repeatability of the findings within a study (Lincoln & Guba, 1985). I increased dependability in my study by ensuring that the same interview questions were asked of all participants. A pilot study was conducted to ensure the interview questions were well worded, understandable, and that the questions addressed the phenomena under study. The study was carried out in a consistent and stable manner. I included numerous quotations from the participants that are presented in the study to shed light on their experiences. I provided an in depth description of the research design and I used an audit trail to keep track of my research study.

Confirmability

Confirmability was achieved through the analysis of the data and the audit trail. The findings were linked back to the participant data rather than to my assumptions which led to the study conclusions and interpretation (Shenton, 2004). The audit trail tracks the steps taken in the research process. In developing an audit trail, I provided an account of all research decisions and activities throughout the study. I used Colaizzi's (1978) seven step method for analyzing descriptive phenomenological data to establish themes and exhaustive descriptions. The participants shared their experience on their coping strategies as related to accessing healthcare during interviews. The interviews were coded separately and the codes were combined to compare, contrast, and build themes. The themes can be traced back to the participants.

Summary

The study analysis was driven by two research questions to understand the coping strategies of parents who have children with SCD as related to managing the disease and accessing health services. Caring for a child with SCD is stressful and affects the whole family. Some participants in this study faced some challenges when accessing health services. For most of the participants, they planned for their child's SCD pain crisis. Overall the participants responded similarly that they cope with their child's SCD by giving medications, keeping the child hydrated with plenty of water, their faith, going to the ED, as needed and doing what is essential to prevent pain crises.

Summary of Research Question 1

RQ1: What coping strategies are used by parents of children with SCD when managing their child's disease?

This research question was addressed by 3 themes. The themes include the parental methods of coping with SCD. The participants provided similar approaches of coping and reported to cope you need to give the child medication for pain crisis and to have an understanding of their child's SCD. Most of the participants reported how they planned for their child's SCD pain crises. They reflected on their coping strategies and consider ways that could help them cope better and build a stronger support system. The majority of the participants relied on their faith, family and doctors for support. They noted you must be a team when caring for the child.

Summary of Research Question 2

RQ2: What are the experiences of parents of children with SCD related to managing their child's healthcare treatment?

Two themes emerged from this research that answered this question. The participants had a range of experiences when managing their child's SCD and accessing health care. All participants except 2 reported being satisfied with their child's treatment and healthcare. Accessing healthcare and making sure their child was free of pain was their top priority. The participants had different experiences when taking their child to the ED but similar experiences when taking the child to their hematologist. Overall, the participants reported that the experience when dealing with their child's hematologist

supporting than going to the ED. I provide a discussion of my findings, and suggest recommendations, and present the study conclusion in Chapter 5.

Chapter 5: Discussion, Conclusion, and Recommendations

The objective of this phenomenological study was to explore the coping strategies of parents of children with SCD in order to better understand the ways these strategies related to the use of health services. In this study, I used a phenomenological approach to gain knowledge through the description of lived experiences of the coping strategies parents use to manage SCD and use available healthcare services. Patton (2002) said phenomenology is used to gain a deeper understanding of the nature or meaning of an individual's everyday experiences.

Smaldone, Findley, Manwani, Jia, and Green (2018) indicated that SCD is an inherited disorder that affects approximately 100,000 Americans, most commonly in African American and Latino people. The disease is associated with chronic anemia, pain, and organ dysfunction, leading to multiple acute and chronic complications, high healthcare utilization, premature mortality, and a poor quality of life. There is no cure for SCD. Taking care of a child with SCD is a challenging experience for the parent and the entire family. In this study, participants reported that dealing with SCD was stressful and affected the whole family. Parents continue to face challenges when managing their child's SCD (Smith, Reinman, Schatz, & Roberts, 2018). Research showed that effective parental strategies such as positive thinking can benefit in disease management, but there is limited research on the coping strategies used by parents of children with SCD specifically (Barakat et al., 2014; Derlega et al., 2014).

In this chapter, I interpret the findings of my study with 10 parents who have children with SCD and were aware of their child's SCD. The parents used various coping

approaches to help them and their families manage the child's pain crisis and access health services.

Key Findings

In this phenomenological study, I explored parental coping strategies and experiences accessing healthcare among the parents of children with SCD. Through the analysis of the participants' interviews I identified 5themes that I presented in Chapter 4. In this chapter, I discuss the key findings by themes. In analyzing the first theme, parental methods of coping with SCD, I found that the participants used a combination of approaches including acceptance and emotion-focused support. Overall, the participants experienced similar coping strategies. The majority of the participants relied on their faith such as praying to God to help them cope with their child having SCD. In the second theme, participants' understanding of SCD, the participants overall had an understanding of their child's SCD. As the parent adjusted to their child's SCD, the child also adjusted. Parents felt that to cope with the pain they needed to understand the disease and ensure that the child was well hydrated and took their medication.

In analyzing the third theme, SCD family and support, I found that the majority of participants relied on their faith and extended family for support. The participants noted that SCD affected the whole family. Some of the participants reported their child's doctors and medical team were supportive. Regarding the fourth theme, managing SCD with hydration and medication, the participants' managed their child's SCD with medications and ensured their children drank plenty of water each day to keep them hydrated. Seven of 10 participants were giving their children Hydroxyurea for SCD. The

participants reported that the medication has severe side effects initially, but it was very helpful once the child took it consistently. In analyzing the fifth theme, experience accessing healthcare, I found that participants continued to face barriers in accessing healthcare. Overall, the participants were satisfied with their child's treatment. In the next section, interpretation of findings, I discuss these findings more in depth.

Interpretation of Findings

Findings from this study are largely reflective of findings from previous research. Parents of children with SCD have the task of caring for their children daily. The parents coped by using medications, hydration, the ED, family support, emotions (crying, cheering), and prayer. Smith et al. (2018) indicated that parents' primary way of coping with their child's SCD is medications because young children have limited coping skills and ability to communicate their pain, leaving it up to the primary caregiver to correctly interpret and treat the pain that the child may be experiencing. All the participants in this study said their primary method of coping with their child's SCD was using pain medications.

The finding of this study was understood within the context of Thompson and Gustafson (1996) TSC model which I used in this study. The theory aided me in understanding the parents' coping strategies and how the parents managed their child's disease and access to healthcare. As reported by Montero-Marin et al. (2014), people have different ways of dealing with chronic illness such as cognitive or behavioral coping, cognitive or behavioral avoidance, and emotion-focused coping. The parents'

coping strategies were influenced by cognitive processes, method of coping, and the family functioning.

Cognitive Processes

The cognitive processes are related to the TSC model used in this study. In the cognitive processes, appraisal stress applies to parents and includes the daily hassle of the illness and the illness tasks (Thompson & Gustafson, 1996). In this study, the cognitive processes as related to the TSC model included the participants' awareness of their child's SCD and their daily care. The participants stated they often thought about their child having SCD and understood the word *cope* as it related to how they cared for their child each day. The study findings showed that the participant coping strategies were a combination of palliative and adaptive coping and functioned as supportive and conflicted families.

Methods of Coping

Methods of coping are associated with the TSC model. The model involved ways parents and their children adapted to the chronic illness. In this study, the participants' method of coping included palliative and adaptive coping. In palliative coping the participants used a combination of avoidance, wishful thinking, and emotion-focused coping to regulate the emotions that were associated with the stress of caring for a child with SCD and accessing healthcare. Study findings showed the participants had accepted that their child had SCD, but they got emotional when dealing with the child's pain crises, when the child stayed in the hospital for an extended time, when they had no health insurance, or when they lacked family support. The majority of the participants

stated they want their children to be normal and not have any more pain. Some of them wished that there was a cure for SCD. In adaptive coping, the study finding showed participants viewed SCD as a problem and cause of stress for the parent and the entire family, but they would take time out to go to the movies, church, or out to dinner once the child pain crisis was over.

Family Functioning

Family functioning is related to the TSC model. It involves the way a family functions when adapting to a chronic illness and includes factors that help determine the psychosocial outcome. In this study, the family functions included supportive, conflicted, and controlling when adapting to the child's SCD. The study findings showed the majority of participants considered their family to be supportive. The families had mutual methods of coping with and understanding SCD. The families had similar ways of accessing healthcare and were concerned with the care of their child. The majority of the participants reported no conflict in their family related to caring for a child with SCD, and they received support from extended family members, friends, church members and leaders, nurses, hematologists, and pediatricians. Supportive families have a better outcome in adapting to chronic illness when conflict is minimized (Kronenberger & Thompson, 1990). The participants felt that having a supportive family is helpful and reduces stress. I found that the family functioning has a direct impact on the child's adjustment. The findings indicated that families who reported supportive family functioning also reported positive adjustment among the children.

Theme 1: Parental methods of coping with SCD. The findings showed that participants coped with their child's SCD using a combination of approaches including acceptance and emotion-focused support. This finding is related to the theme of parental methods of coping with SCD. The participants viewed SCD to be a major stressor that they learned to adjust to daily by giving the child medications and doing whatever they had to do to deal with the emotions involved. Also, communicating with their child and doctors, acceptance, adjusting to their behavior, knowing the pain crisis triggers, and figuring out what to do as each pain crisis occurred contributed to the parents' ways of coping with the chronic illness. The results of the study supported findings from various studies shared in the literature review. For example, Hildenbrand et al. (2015) found that to manage the stress of the pain that is associated with SCD, the parent as well as the child used a combination of approaches and avoidance oriented coping strategies including promoting social support, encouraging distraction, facilitating emotional expression, and promoting acceptance.

The participants in this study reported they did whatever was needed to keep their child free of pain. They gave them cuddles, hugs, and warm baths. Cognitive or behavioral avoidance involves avoiding or managing distress by performing actions such as seeking reassurance, checking in, or avoiding anxiety-provoking situations, and emotion-focused coping is intended primarily to relieve or regulate the emotional impact of a stressful situation (Chakraborty & Chaudhury, 2015).

Theme 2: Participants understanding of SCD. The findings showed that parents of children with SCD had an understanding of their child's SCD, and they

attributed their understanding to the ability to adjust. Understanding SCD is complex and stressful. They related the disease to severe pain, stress, a problem, and visits to the ED. Understanding their child's SCD helped the participants cope with the disease. Mullins et al. (2015) explored how parents used a problem focus to adjust to a chronic illness. Parents can use problem-focused coping that is useful when a stressful situation is controllable, or they can use emotion-focused (palliative) coping that is used when the individual situation is not controllable. For example, when individuals use a helpful problem-focused plan, those plans tend to decrease their palliative or emotion-focused stressor. When individuals use an effective emotion-focused (adaptive) coping strategy, they have less stress and are better equipped to focus on the problem. The participants in this study indicated they are focusing on making sure the child is free of pain. In this study, I found that the majority of the participants used more problem focused coping that is used when the stressful situation is controllable. The participants felt they controlled their child's SCD using medications and making sure the child is free of pain. The participants said they also used preventive measures such as keeping the child well hydrated, keeping routine doctors' appointments, and knowing the triggers that cause pain crises to help control the stress and emotions that go with taking care of a child with SCD.

Barakat et al. (2014) reported that when parents make a plan when faced with a challenge, this is considered a positive problem-solving skill. On the other hand, avoiding the problem is an example of a negative problem-solving skill. Avoiding or not having a plan when the child has a crisis can cause parental stress. Consistent with research by

these authors I too found that 2 participants felt that they can never plan for an SCD pain crisis because the crisis gives them no warning. This is an example of negative problem-solving skills. However, the majority of participants said they plan for the pain crisis by following several steps to make sure the child does not experience pain. For example, participant F09 said she had a checklist that her 2 children with SCD follow every day. In addition, she takes 5 simple steps when they complain of pain. The use of the checklist and the subsequent steps are examples of the positive problem-solving skills described by parents in this study.

Theme 3: SCD family and support. As reported by Kronenberger and Thompson (1990), a supportive family has mutual interest, concern and support across a wide domain. Supportive families have a better outcome in adapting to chronic illness when there is less conflict. The conflicted family on the other hand, reflects a dimension of conflicts that lacks structure or support. In this study, 9 out of 10 participants described having a supportive family in caring for a child with SCD. The family functioning has a direct impact on the child's adjustment. Just like, Colletti et al. (2008) reported parents are encouraged to serve as a coach and model the coping skills for their child. The family support system is essential in caring for a child with SCD. In this study, during the interviews several of the participants said that their extended families, friends, and their faith provided support in coping with their child's SCD. For example, the participants felt that praying for their child has made a difference in their SCD. Participant F03 said,

> "I told her that you are healthy and whole and that God is Jehovah Rapha. I have had her to say this from the time she could speak and now she speaks it daily that

God is Jehovah Rapha and I am healthy and whole. I believe that speaking the word of God over her health has made a big difference in every situation that has come."

Participant M04 had a similar response and said,

"It is very stressful taking care of a child with SCD. I have three children with SCD. Because I am a Christian I must believe, give them medicine and pray for God to help them. God will make them better"

As reported by Unantenne et al. (2013) SCD participant who incorporated their faith and spirituality, had a positive impact on their health and managing the chronic illness. Consistent with prior research, Clayton-Jones and Haglund (2015) found that the use of spirituality in children with SCD may be significant in coping, managing pain, affecting hospitalizations, and affecting the quality of life.

Theme 4: Managing SCD with hydration and medications. Wilson and Nelson (2015) suggest that pain management is multidimensional and includes pharmacologic, physical, and psychological strategies which support how the parents in this study managed their child's SCD. The participants described their approaches to managing their child's SCD in this study. During their interviews, several of the participants indicated they had knowledge of their children SCD. They said that they managed the disease with pain medications and hydration. They gave their children plenty of water to drink daily, received support from their families, encouraged their children, took them to their pediatrician, hematologist, gave them warm baths, hugs and cuddles and made sure their children stayed healthy. Because the children are still young, the participants said

they take most of the responsibility in making sure the child takes their medications and dresses appropriately. Participant F02 said, managing her child's SCD involved "Giving him seven different medications twice a day, and making sure how he dresses whether he is warm or not and keeping him cool and away from others who are sick."

As reported by Edmond et al. (2016) caring for a child with SCD can cause emotional distress and burden for the parents. Participants in this study noted that managing SCD causes emotional stress for them. They indicated that pain cannot be seen; however, they need to watch the child's facial expression, body movements or ask them their pain level. The participants felt that they all were doing an effective job in managing their child's SCD along with help from their families and the child's medical team.

Theme 5: Experiences accessing healthcare. Childress and Nathanson (2016) found that limited access to primary care services might contribute to more severe SCD complications and frequent hospitalizations for children with SCD. The participants in this study indicated that having health insurance and an understanding with their child's pediatrician and hematologist caused less stress for the family. Most of the participants indicated they have health insurance and had no problems accessing their child's doctors and that treatment options make a significant difference in how the family functions.

Two of the 10 participants in this study reported they faced barriers when accessing healthcare. Participant F09 moved to a new location to be closer to her family for support. She indicated that "I am still going back and forth trying to find them a hematologist. They do not take certain insurance and I am about to lose it." One

participant, F08 said she takes her child to the ED because they have no health insurance or access to a pediatrician or hematologist.

I found that coordinating care and communication were barriers for participants who were not able to access healthcare. The participants expressed fear, anxiety and stress when they could not afford their child's medications, or communicate effectively with their child's doctors. As reported by Taylor et al. (2013), coordinating care is essential in the quality of life for a child with SCD. Research has consistently shown that, coping with SCD and how the parent accesses health services are related. Coordinating care offers an integrative way to connect the SCD patient to providers with services that support continuous care.

Limitations of the Study

There were several limitations with this study. First, the study involved a small sample size of parents who have children with SCD in Austin metropolitan area. The small size was not intended to represent the general population of parents who have children with SCD. Second, the study was limited to the parents of children ages 5 to 10 years with SCD. The criteria may have an impact on the study because of the limited age range of the participants. The third limitation regarding confidentiality, it is possible that the participants may have been reluctant to share information that would cast a negative light on their responses.

The fourth limitation is the single site population of the participants of children with SCD. There were no other sites in that region. The fifth limitation is only 5 out of

the 10 participants responded back to the member checking request. Participants' feedback is useful and helps to strengthen the study results.

Recommendations

The coping strategies parents used to manage SCD and use available healthcare services should continue to be explored by future researchers to help parents and medical providers understand those strategies. Despite advanced technology and stem cell research, there is no cure for SCD (Creary et al., 2015). SCD causes emotional stress and affects the entire family. Managing the disease is complex and the parents of children with SCD can benefit from interventions that focus on coping strategies that will provide them with resources to enhance their coping plans. Few studies have examined parent involvement in disease management in pediatric SCD and this warrants additional research (Oliver-Carpenter et al., 2011).

Parental methods of coping are important variables in family adaptation to pediatric chronic illness (Gage-Bouchard, Devine, & Heckler, 2013). Parents of children with SCD need emotional support to help cope with the stress of the child having SCD (Al-Yagon, 2015). In this study, several participants reported they have multiple children with SCD living in the same home and it is difficult at times caring for the children and trying to balance their lives. Findings from the current investigation also support the need for research on more support programs for the parents of children with SCD. Three participants in the study reported limited SCD support groups in their region, and more support groups are needed. This is in keeping with the findings of Keane and Defoe (2016) who reported support for families in their own communities appears to be limited.

I recommend that a support groups be implemented to understand the limited support from the community as it relates to the coping strategies of the parents who have children with SCD.

In this study, some of the participants of children with SCD continued to face healthcare barriers such as; no health insurance or no access to a hematologist or primary care physician. From the literature review, Jacob et al. (2016) reported that eliminating healthcare barriers for children with SCD is needed to improve the delivery of pediatric services and to enable this vulnerable and high risk population to achieve optimal health outcomes. I recommend that additional interventions are needed to determine whether specific interventions such as educational programs designed to improve the understanding of parents of children with SCD of maintaining affordable healthcare insurance that will give them access to healthcare.

Edmond et al. (2016) suggested a range of psychosocial factors such as financial stress, child pain and lack of sleep, and child's emotional behavioral symptoms influence the caregiver distress and burden. Given the importance of supportive care for the entire family unit, health care professionals such as psychologists, social workers, and nurses should advocate for comprehensive psychosocial screening and appropriate referrals. The child's symptoms may play an important role in the development of caregiver distress and caregiver burden. Future research is needed to study the influence of psychosocial factors like the impact of stress on parents' ability to access healthcare.

In this study, I identified several themes from participants' responses. Those themes were parental methods of coping with SCD, participants' understanding of SCD,

SCD family and support, managing SCD with hydration and medications, and experience accessing healthcare. Each of the themes could be investigated more in depth in future research with larger samples of parents who have children with SCD to show additional information as it pertains to their coping strategies and accessing available healthcare. More research should be conducted that gives the parents of children with SCD an opportunity to express their experiences when taking their child to the ED for pain crisis.

Implications

Positive Social Change

The results from the current study, once published, could help medical providers have a better understanding of the coping strategies used by parents who have children with SCD when managing the disease and using health services. Participants in this study viewed caring for their child with SCD as a task and stressor. The findings can help parents develop better ways to cope with the emotions and the stress associated with caring for a child with SCD. These findings could be used to develop a SCD educational program that will improve the parents coping strategies.

Parents of children with SCD face many challenges associated with living with the chronic disease that requires lifetime medical attention and efficient parental management (Ekinci et al., 2012). Assisting parents of children to cope with the stress of SCD and access healthcare will require support from hematologists, caseworkers, families and community advocates. The results of this study can be used to help this researcher develop a coping app to assist parents of children with SCD when they are struggling. Several churches in this region promote blood drives seeking members and

individuals to donate blood. According to the Division of Blood Disorders (2015), individuals with SCD need blood transfusion from time to time. I will do presentations with these churches to help increased SCD awareness and provide educational material to the parents of children who are struggling to cope with the disease.

Dissemination of dissertation findings could be an important step in inspiring social change. I will seek to do presentations with the Sickle Cell Association who works together with the parents of children with SCD. The association has local and national offices. After contacting local and state organizations, I could do an educational session and present my findings to their members to increased SCD awareness and provide them with an educational workbook on understanding coping strategies of parents of children between the ages of 5-10 with SCD and how they manage and access health services. I also plan to present my finding at a healthcare professional conference. I will share my findings with people who are advocates for children and their families coping with SCD and accessing healthcare.

Stakeholders, together with doctors, nurses and, healthcare administrators, may use the finding from my presentation, to understand the coping strategies of parents who children with SCD and their various reasons for not accessing health services and promote healthcare policies that will ensure every parent who has a child with SCD in the United States has health insurance and access to a hematologist and pediatrician. SCD causes emotional stress for the parent (Edmond et al., 2016). The participants of this study consistently discussed the emotional stress associated with caring for a child with

SCD. These findings can be used to implement a SCD support group that promotes positive coping strategies of parents.

Conclusions

Parental management and efficient coping strategies are essential in the life of a child who has SCD. There is an association between parental coping strategies and how parents managed the disease. There is evidence in the literature (Barakat et al., 2014; Derlega et al., 2014) that an effective parental plan such as thinking positive can assist parents with managing SCD. There is limited research on the coping strategies used by parents of children with SCD. In this study, all of the participants had an understanding of SCD and had a desire to learn more. SCD presents emotional and physical challenges for the parent as well as the child. By exploring the lived experiences of the parents coping strategies and how they managed the disease to access health services, there is more to add to research from the parents' perspective. Parents of children with SCD used similar methods in coping with their child's disease. Some of the participants indicated they tried to have fun and make their child laugh when coping with pain crisis. They were aware of their child's SCD and many had access to healthcare. However, some of the parents continued to face barriers accessing health services. Consistent with the TSC model the parents' in this study coped using a combination of palliative and adaptive coping and functioned as supportive and conflicted families. The parents coped by using medications, the ED, family support, emotions (crying, laughing, cheers), and prayer.

This study may help researchers understand that parents have similar coping strategies when caring for a child's SCD. Some of the parents in this study felt fear of

their child dying. Currently, there is no cure for SCD, but through continuous educational workshops, managed care, efficient parental strategies and support from family, hematologists, pediatricians, nurses, churches, SCD Associations and the community parents of children with SCD may improve the use of positive coping strategies. The study could increase awareness by sharing positive coping strategies, and better ways parents could manage their child's SCD. The results of this research will contribute to the existing knowledge on the coping strategies of parents with children who have SCD and provide a better understanding of those strategies being used in order to help parents.

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Appendix A: Letter Granting Approval to Recruit Participants

July 19, 2018

To Whom It May Concern:

Please let this letter serve as proof that the Sickle Cell Association of Texas would like to collaborate with Michelle Mackey as part of her research study, as a student at Walden University. Ms. Linda Wade, the Sickle Cell Association of Texas's President and CEO, has given consent to work with with Ms. Mackey in her clinical endeavors. Ms. Wade has given consent for Ms. Mackey to recruit participants from within our organization for her study and use our facility to conduct interviews. All of clinical services within the agency are at no cost to our clients, we do not charge for services. We look forward to communicating with Ms. Mackey in regards to our collaboration in the near future. If you have any questions and/or concerns please do not hesitate to contact us at the contact information below.

Sincerely,

Emily O'Shea, LCSW

Emily O'Shea, LCSW
Sickle Cell Association of Texas
314 East Highland Mall Blvd, Suite 411
Austin, TX 78752
512-458-9767 (office)

Appendix B: Instrumentation

Research Questions	Interview Questions	TSC Construct of Model
RQ 1: What coping strategies are used by parents with children that have SCD when managing their child's disease?	1. What are the daily task involved in caring for your child's SCD? 2. Describe your understanding of your child's SCD? 3. How effective are you in managing your child's SCD?	**Cognitive Processes**
	4. How do you define and understand the word coping? 5. Tell me about a time you encountered an emotional situation by when dealing with your child's SCD. How did you control the situation? 6. How do you handle problems involving your child's SCD?	**Methods of Coping**
	7. What kind of family support do you receive from others when dealing with your child's SCD? 8. What are some of the things do you and or (you and your) family do when dealing with conflict involving your child having SCD? 9. Tell me who makes all the decisions about controlling your child's SCD. Has this process led to any conflict in the family?	**Family Functioning**

RQ 2: What are the experiences of parents of children with SCD related to managing their child's healthcare treatment?	10. What are some of the things you or (you and your) family do at home to help deal with your child's SCD? 11. What are some of your experiences accessing health services for your child's SCD? 12. Tell me about how effective is the care and treatment that your child receives for SCD.	**Cognitive Processes**
	13. What are some of the things you and your family do to adjust to the emotions that are associated with the stress of your child's SCD?	**Methods of Coping**
	14. Tell me about a time when you and your family were in conflict as a result of dealing with your child's SCD. 15. Tell me about a time you encountered support for you and your family in dealing with your child's SCD. 16. Tell me about a time you and or your family competitive with each other when dealing with your child's SCD?	**Family Functioning**
Closing Questions	Are there any related comments that you would like to share regarding the topic we discussed?	

Appendix C: Demographic Questionnaire

	Name
	Mailing Address
	City State Zip
	Email: Phone: ( )

The current age of your child with sickle cell disease	_____ years old

Marital Status: Check one :

Single	
Married	
Divorced	
Widowed	

Please indicate your gender:

Male: _____

Female: _____

Education: Check Highest Level of Education

Graduate School	
College Degree	
Some College	
High School Graduate (Grad)	
Did not Complete High School	