A PHENOMENOLOGICAL STUDY OF THE LIVED EXPERIENCES OF CAREGIVERS OF CHILDREN WITH SICKLE CELL DISEASE

A Dissertation

Presented To

The Graduate Faculty of The University of Akron

In Partial Fulfillment of the Requirements for the Degree

Doctor of Philosophy

Francesca K. Owoo

May, 2017
A PHENOMENOLOGICAL STUDY OF THE LIVED EXPERIENCES
OF CAREGIVERS WITH CHILDREN OF SICKLE CELL DISEASE

Francesca K. Owoo

Dissertation

Approved: ____________________________  ____________________________

Committee Chair  School Director
Dr. Karin Jordan

Committee Member  Dean of the College
Dr. Rebecca Boyle

Committee Member  Dean of the Graduate School
Dr. Rikki A. Patton  Dr. Chand Midha

Committee Member  Date
Dr. John Queener

Committee Member
Dr. Francis Broadway
ABSTRACT

This qualitative phenomenological study explored the lived experiences of primary caregivers when caring for a child with sickle cell disease (SCD). Specifically, the researcher’s goal was to understand how these experiences shape and impact a primary caregiver’s experience of daily living. The researcher provided a comprehensive review of the history of SCD along with its effects on the familial unit, as well as the primary caregiver. Social inequalities and health care disparities were also discussed in relation to the role it may play in receiving adequate health care for a child with SCD. With the integration of a focused genogram, the researcher was able to evaluate the intergenerational transmission of caregiving behaviors experienced with SCD. Six primary caregivers provided personal accounts of their experiences when caring for a child with SCD in the African American community while addressing the following research questions: (1) What is the lived experience of the primary caregiver of a child with SCD? (2) What is the lived experience of primary caregivers of a child with SCD specifically regarding child’s medical services? and (3) What are the parallels in caregiving behaviors between caregivers of a child with SCD and the caregiving behaviors of past generation caregivers? Lastly, a discussion of the findings, limitations of the study, implications for family therapists and further research were addressed.
ACKNOWLEDGMENTS

“I have set the Lord always before me: because he is at my right hand, I shall not be moved.”  Psalm 16:8

I give thanks to the Almighty Father for being the guidance and strength that I needed to push through on this journey. Thank you to my family and close friends for the support.

Dr. Karin Jordan: I would like to thank my dissertation chair for her guidance and support throughout this dissertation process as well as doctoral career. I am appreciative for her insight into the field, which has helped me greatly in my profession.

Dr. John Queener: I would like to give a special thanks to him for his ongoing support and inspirational words of wisdom throughout the duration of my doctoral career. Thank you for introducing me to the world of African-centered philosophy that has helped me develop personally, professionally, and academically.

Dr. Rebecca Boyle, Dr. Francis Broadway, and Dr. Rikki Patton: Thank you for offering your knowledge and serving as a part of my dissertation committee.

Connie Piccone, M.D. & The Sickle Cell Anemia Center at University Hospitals Rainbow Babies & Children’s Hospital: I would like to acknowledge and genuinely thank the clinical director for assisting me in the successful completion of this research
study. Also thank you to the six research participants who willingly shared their personal stories and experiences. This study would not have been possible without them.
DEDICATION

This dissertation is dedicated to my family, who continues to be a powerful force in helping me to accomplish lifelong dreams. This dissertation is not only a compilation of knowledge acquired throughout the years in the program but an extension of my family. Within the African culture there is an old proverb that states, “It takes a village to raise a child.” Not only have my parents and siblings played a fundamental role in my life, but also my elders who supported and raised me to be the woman I am today by instilling cultural values, enduring lessons, and prayers into my existence. My parents, Raphael and Felicia Owoo emigrated from Ghana, West Africa, to the United States of America in the 1970s with fervent ambitions for their children. My mother has been a pillar of strength in being a leading example of what it means to care for my brother and father who both live with sickle cell disease. Their lives serve as the foundation as to how this dissertation came into fruition.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>LIST OF TABLES</td>
<td>xi</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>xii</td>
</tr>
<tr>
<td><strong>CHAPTER</strong></td>
<td></td>
</tr>
<tr>
<td><strong>I.  INTRODUCTION</strong></td>
<td>1</td>
</tr>
<tr>
<td>Author Statement</td>
<td>2</td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>2</td>
</tr>
<tr>
<td>Sickle Cell Disease Information</td>
<td>6</td>
</tr>
<tr>
<td>Pain Management and Treatment</td>
<td>8</td>
</tr>
<tr>
<td>Purpose of the Study</td>
<td>9</td>
</tr>
<tr>
<td>Significance of the Study</td>
<td>11</td>
</tr>
<tr>
<td>Research Questions</td>
<td>11</td>
</tr>
<tr>
<td>Operational Definitions</td>
<td>12</td>
</tr>
<tr>
<td>Summary</td>
<td>16</td>
</tr>
<tr>
<td><strong>II.  REVIEW OF THE LITERATURE</strong></td>
<td>17</td>
</tr>
<tr>
<td>What is a Chronic Illness?</td>
<td>18</td>
</tr>
<tr>
<td>Sickle Cell Disease as a Chronic Illness</td>
<td>20</td>
</tr>
<tr>
<td>Significant Moments in Sickle Cell Disease Research</td>
<td>22</td>
</tr>
<tr>
<td>Funding for Sickle Cell Disease Research</td>
<td>23</td>
</tr>
<tr>
<td>Health Care Needs for Sickle Cell Disease Patients</td>
<td>24</td>
</tr>
</tbody>
</table>
# LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Funding in Research/Disease Areas</td>
<td>23</td>
</tr>
<tr>
<td>2. Demographic Summary of Participants</td>
<td>53</td>
</tr>
</tbody>
</table>
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Example of a Genogram</td>
<td>46</td>
</tr>
</tbody>
</table>
CHAPTER I

INTRODUCTION

Sickle Cell Disease (SCD) is one of the most common genetic disorders in the United States (CDC, 2015). According to the Centers for Disease Control and Prevention (2015), SCD affects 90,000 to 100,000 Americans. SCD occurs in 1 out of every 500 Black or African-Americans births, and 1 out of every 36,000 Hispanic-Americans births. It is estimated that sickle cell trait (SCT) occurs in 1 out of every 12 Black or African-Americans (CDC, 2015). Despite the prevalence of SCD and SCT in the US, little research has been conducted on this genetic illness and the family unit. It is believed that a family member with SCD, a genetic illness, can affect the patterns of family communication, and family roles particularly that of the primary caregiver. Learning about a genetic illness within the family unit can affect the patterns of communication as well as challenge the roles of each family member, especially the primary caregiver. When reviewing the limited SCD research in the US today, it is evident that there is a lack of research especially in family therapy focusing on the effects of being a primary caregiver for a child with SCD. It is highly important to do this kind of research, as it is believed that since caring for a child with SCD has systemic implications that family therapists should be aware of. In addition, it is important to further the research literature in family therapy and SCD as the field of family therapy
has been evolving and expanded into medical family therapy, and therefore family therapists should be knowledgeable about this chronic illness. Furthermore, since this chronic illness impacts a marginalized population it will be important to understand how caregiving is experienced, and how caregiving by a minority caregiver is experienced, as there might be some additional stressors and challenges they encounter.

Author Statement

In order to tackle what may appear to be an insurmountable feat at the time, one must be in the right mindset and prepared to take on the ups and downs of their journey. Writing this dissertation proved to be the greatest challenge of my doctoral career mainly due to the closeness of the topic to my own life. Both my father and older brother have lived their lives with sickle cell disease and cared for primarily by my mother. One can say that my family has an expertise in coping with the unpredictability of sickle cell disease. After entertaining multiple topics for my dissertation with my then advisor, I concluded that the topic of sickle cell disease would not be my main focus. After self-exploration and advisement of my mother over the course of several months, I decided that the narratives of this population needed to be heard. With the progression of Medical Family Therapy within the field of Marriage and Family Therapy, it was befitting that I focus on this population and give primary caregivers of children with sickle cell disease a voice.

Statement of the Problem

Chronic illness refers to a health condition that lasts anywhere from three months to a lifetime (American Academy of Pediatrics [AAP], 2015). Roughly 10 to 20 million children and adolescents in the United States have some form of chronic illness or
disability (AAP, 2015). Generally, children with a chronic illness or condition can often feel “different,” socially isolated, and restricted in their day-to-day activities (AAP, 2004). A chronically ill child can have difficulties in school and at times feel overprotected. Consequently, when these emotional hardships are not dealt with appropriately, they can lead to several issues such as anxiety, withdrawal, rebelliousness, and a decreased interest in school (AAP, 2004). Symptoms in children may manifest differently, thus instead of directly saying they are sad or depressed, they may withdraw from peers or become angry or rebellious. The child may even interfere with their own medical treatments, possibly by refusing to take their medications (AAP, 2004). Others might begin to experiment with dangerous substances such as drugs and alcohol or may even run away from home or contemplate suicide (AAP, 2004). Feelings of sadness, depression, or being overwhelmed may come and go for both the chronically ill child and the parent (AAP, 2004).

The child with a newly diagnosed chronic illness is not the only person that will need to adjust to living with an illness. There are also expected life changes for the other family members of a child with a chronic illness. Similarly to the child experiencing these symptoms, the primary caregiver needs to navigate through their own journey in caring for a chronically ill child. Primary caregivers often have feelings of guilt and may believe that somehow they are at fault for their child’s illness (AAP, 2004). According to the American Academy of Pediatrics (2004), self-blame amongst primary caregivers is quite common when the condition is present at birth, has a genetic basis, and/or when the cause is not known. The feelings of guilt and self-blame can cause
additional stress to the family and the primary caregiver, making it difficult to formulate a strong support system (AAP, 2004). Primary caregivers in particular have to deal with understanding the diagnosis and how to explain the diagnosis to their child all while concurrently learning how to adjust with this new element, a chronic illness, within the familial unit (AAP, 2004). Primary caregivers have numerous adjustments to make during this time, especially if one is caring for a child with SCD, in order to make sure that the familial unit is functioning at optimal levels.

According to Cousino and Hazen (2013), parents raising children with various chronic illnesses, ranging from asthma, cancer, cystic fibrosis, diabetes, epilepsy, juvenile rheumatoid arthritis, to SCD face a myriad of issues, such as dealing with the news of their child’s diagnosis, the medical implications of the diagnosis and the possibility of a shortened lifespan of their child. Factors that can complicate medical management of chronic illness are socioeconomics, educational background, cultural difference, and attitudes of the child, family, and healthcare professionals, all of which can affect the quality of healthcare delivery (Pack-Mabien & Haynes, 2009). For the purpose of this study, focus will be on one chronic illness that affects predominantly the African American population in the United States of America, SCD.

In addition to the chronic illness such as SCD, families with a family member with a chronic illness may face a number of external issues that include but are not limited to family structure, ethnic minority status, and lower socioeconomic status, and will often find support within extended family or the community (Barakat, Lutz, Nicolaou, & Lash, 2005; Brown et al., 1993). According to Gross et al., (2009), when addressing the issue of comprehensive care, individuals with SCD receive less
comprehensive care as opposed to their counterparts with genetic disorders such as hemophilia and cystic fibrosis. This may influence stress perceptions of the primary caregiver based on the demands placed on them by the chronic illness (Barakat et al., 2005; Brown et al., 1993).

Consistent with the aforementioned research, Sterling, Peterson, and Weekes (1997) believed that African American families dealing with family members with a childhood chronic illness, such as SCD, had a unique perspective due to the social inequalities factor, which the literature thus far existing has failed to adequately address. According to Burnes, Antle, Williams, and Cook (2008), “there is little research that aims to understand the parental perspective or to situate the experiences of families affected by SCD in the broader context of social inequalities” (p. 211). In addition to these issues, Pack-Mabien and Haynes (2009) reported that psychosocial issues, limited resources, and inadequate health insurance frequently complicate medical management of individuals with SCD. In order to better understand how the family with a child with SCD cope with these varying issues identified above, a systemic-based lens should be utilized in which the whole family unit takes part in the coping or healing process. According to the American Association for Marriage and Family Therapy (AAMFT, 2015),

> Any marriage and family therapists who work with families with health concerns (also called medical family therapists) can help individuals, couples, and families cope with challenges of communication, problem solving, and intimacy that can come with the knowledge of increased genetic risk and the experience of symptoms and treatment of disease (Genetic Disorders, 2015).

The unique perspective of these families is unequivocally relevant to family studies in SCD (Radcliffe, Barakat, & Boyd, 2006). In recent psychosocial SCD
research, a family-based approach was identified as an effective way to cope with the illness (Brown & Lambert, 1999; Kaslow et al., 2000; Wood, 2000), as well as focusing on relationships between the children’s adjustment to the chronic illness, the parental functioning factors (Barbarin, 1999; Barbarin, Whitten, Bond, & Conner-Warren, 1999; Brown et al., 2000; Devine, Brown, Lambert, Donegan, & Eckman, 1998; Logan et al., 2002) and caregiving experience. However, for the purpose of this study, the researcher will focus on the lived experiences of the primary caregiver caring for a child with SCD.

**Sickle Cell Disease Information**

According to the Centers for Disease Control and Prevention (2014), SCD can be described as a group of inherited red blood cell disorders. The SCD gene causes an abnormality in the iron-rich protein hemoglobin that is responsible for carrying oxygen through the blood and giving blood its red color. The abnormal hemoglobin (sickle hemoglobin or hemoglobin S) causes cells to become “sickle, or crescent shape” as well as stiff and sticky, resulting in irregular blood flow (CDC, 2015). The abnormal cells tend to block blood flow in the blood vessels of the limbs and organs, which can cause organ damage, severe pain, low red blood count, infections, acute chest syndrome, and stroke (CDC, 2015). SCD is diagnosed with a blood test, which can be done at birth during a routine newborn screening at the hospital (CDC, 2015). According to the CDC (2015), SCD can also be diagnosed before birth via amniocentesis. Amniocentesis is a prenatal test in which a small amount of amniotic fluid is removed from the sac surrounding the fetus for testing (CDC, 2015).

The most common types of SCD are HbSS, HbSC, and HbS beta thalassemia. HbSS is most commonly referred to as sickle cell anemia, which is also the most severe
form of the disease (CDC, 2015). In HbSS, sickle cell genes are inherited from each parent (CDC, 2015). In HbSC, a sickle cell gene (S) is inherited from one parent and a gene for abnormal hemoglobin from the other parent (CDC, 2015). HbSC is also considered the milder form of SCD (CDC, 2015). Individuals with HbS beta thalassemia inherit one sickle cell gene (S) from one parent and one beta thalassemia gene from the other parent (CDC, 2015). Beta thalassemia consists of two forms, “0” and “+” with “0” being the more severe form of SCD and “+” being the milder form of SCD. The uncommon forms of SCD are HbSD, HbSE, and HbSO. With these forms of SCD, individuals inherit one sickle cell gene (S) and one gene from an abnormal type of hemoglobin (D, E, or O). The severity of these rare types of SCD varies amongst individuals.

In examining the various types of sickle cell disease, life expectancy with each varies as well. Males with HbSS have a median life expectancy of 42 years, whereas with females 48 years is the norm (Platt et al., 1994). Males with HbSC have a median life expectancy of 60 years, whereas females can be expected to live an average of 68 years (Platt et al., 1994). In addition to varying life expectancies, the complications associated with SCD vary across the types as well, ranging from mild to severe symptomology. Vaso-occlusive pain episodes are considered the hallmark of SCD that “have been identified as an indicator of clinical severity, and has been associated with premature deaths in patients more than 20 years of age” (Martin & Moore, 1997; Platt et al., 1991, 1994). Vaso-occlusive pain episodes, also known as sickle cell crises, are caused by blocked (occluded) blood vessels. According to Pack-Mabien and Haynes
(2009), “pain episodes may be acute or chronic, lasting hours, days, or even weeks” (p. 252).

**Pain Management and Treatment**

Genetic counseling is essential for individuals born with sickle cell trait (SCT) (Pack-Mabien & Haynes, 2009). Unfortunately, carriers of SCT are often unaware of their status until their newborn has been tested and diagnosed with sickle cell disease or SCT (Pack-Mabien & Haynes, 2009). There is no widely available cure for SCD, however there are several new emerging treatments that are currently being evaluated (CDC, 2015). One option for younger patients is to have a stem cell transplant, a procedure in which diseased bone marrow is replaced by highly specialized stem cells that develop into healthy bone marrow. With SCD patients, bone marrow of a patient with SCD is exchanged for the healthy bone marrow from a donor, preferably a sibling without SCD. Although bone marrow transplants can cure SCD in a small number of young patients, it can have side effects that are life threatening in other patients (CDC, 2015).

Another treatment that has developed is gene therapy, which induces the formation of normal red blood cells by the bone marrow (CDC, 2015). New medications have also been studied which have been shown to stimulate the production of fetal hemoglobin to prevent the red blood cells from sickling (CDC, 2015). In addition to various methods of pain management, it is vitally important that a primary care physician work in conjunction with hematologists or physicians who specialize in the care of patients with SCD in order to monitor exam frequency. Individuals with
severe pain are usually prescribed opioid (e.g. morphine) medications daily along with added pain medications (CDC, 2015).

Other options that have become available to patients with SCD are red blood cell (RBC) transfusion therapy and hydroxyurea (CDC, 2015). Blood transfusions are commonly utilized when anemia becomes severe resulting from infection or enlargement of the spleen (CDC, 2015). Hydroxyurea is used to reduce the frequency of painful crises and reduce the need for blood transfusions in patients with sickle cell anemia. These procedures aid in the treatment and prevention of complications associated with SCD. Serjeant (1997) stated that learning to live with SCD, avoiding preventable complications through health maintenance, and realistic expectations can help an individual improve their survival and quality of life.

**Purpose of the Study**

The chief focus of the present research study is to explore the lived experiences of several primary caregivers who are providing care to a child with SCD. Additionally, the research study will attempt to address the gaps in the present literature that fall short in adequately discussing the primary caregivers’ psychological and emotional well being. Focus will be on the primary caregivers’ lived experience, looking at how caregiving behaviors might be passed on across generations through an Intergenerational Family Therapy lens. In addition, focus will be on the lived caregiving experience, exploring possible challenges encountered as an African-American caregiver for a child with SCD.

The researcher will achieve this goal by using qualitative methods. According to Polkinghorne (2005), the primary purpose of qualitative research is to “describe and
clarify experience as it is lived and constituted in awareness” (p. 138). Polkinghorne (2005) believes that qualitative methods are designed to factor in the characteristics of the human experience and facilitate the examination of said experience. In order to examine these experiences, the phenomenological method is best as it is used to assess areas where little is known or content is sensitive (Donalek, 2004) as to provide a comprehensive understanding of the phenomenon. By listening to the narratives of those who have experienced it, the researcher will be able to extract the core meaning of the phenomenon.

Lastly, for the purpose of this study, the term burden will be discussed briefly in order to clarify the researcher’s use of the term stressors as a substitute. In conducting a search for primary caregivers of children with SCD, the term burden appeared often in earlier dated research. Research has shown that the concept burden consists of two dimensions: objective and subjective. Objective burden can be seen as the “direct care tasks stemming from the illness” (Sales, 2003, p. 34), whereas subjective burden is the “distress experience by the caregiver in dealing with the objective stressors…” (Sales, 2003, p. 36). According to Sales (2003), most caregivers do not view taking care of a family member as a burden but rather as an “obligation that is willingly incurred” as part of the family role (p. 39). Thus the term burden has been used less frequently in the research because it has a negative connotation. According to Sales, it “ignores the contextual, affective, historical, and relational elements of the role that may be most central to caregivers” (p. 40).
Significance of the Study

SCD presents itself differently than other chronic illness in childhood, however SCD in regards to the primary caregiver experience has not been adequately addressed in the literature. The researcher desires to add to the present body of literature regarding primary caregivers’ lived experience when caring for a child with SCD from a systems perspective. The researcher emphasizes that this is a population that has potentially been marginalized within society. The study will add to the literature from an intergenerational perspective due to the lack of research in the literature regarding caregiving behaviors being transmitted across generations. Family therapists can play an important role in providing support and advocacy for the family unit by better understanding SCD and caregivers lived experience(s) when caring for a child with SCD.

Research Questions

Several research questions have been developed in order to address the purpose of this study:

1. What is the lived experience of the primary caregiver of a child with SCD?
2. What is the lived experience of primary caregivers of a child with SCD specifically regarding child’s medical services?
3. What are the parallels in caregiving behaviors between caregivers of a child with SCD and the caregiving behaviors of past generation caregivers?

The researcher’s purpose in conducting this research study is to gain awareness of the lived experiences of primary caregivers while caring for a chronically ill child with SCD. Furthermore, the researcher hopes to explore the generational patterns of
coping mechanisms being used by these primary caregivers through the use of a focused genogram. However, the researcher believes this may be a novice approach in the profession and additional research is needed specifically when focusing on SCD. The researcher identified participation criteria in Chapter III. It is anticipated that the outcome of this research study will contribute to existing research, especially in the field of family therapy, as thus far no research exists on caregivers’ lived experience when caring for a child with SCD.

**Operational Definitions**

**Caregiver stress.** High level of stress that may be experienced by people who are caring for another person, usually a family member, with some kind of illness (Lim & Zebrack, 2000).

**Caregiver lived experience.** Firsthand accounts and knowledge of living as a member of a specific group.

**Chronic Illness (children and adolescents).** Any physical, emotional, or mental condition that prevented him or her from attending school regularly, doing regular school work, or doing usual childhood activities or that required frequent attention or treatment from a doctor or other health professional, regular use of any medication, or use of special equipment (Van Cleave et al., 2010).

**Chronic Obstructive Pulmonary Disease.** A group of diseases that cause airflow blockage and breathing-related problems. It includes emphysema, chronic bronchitis, and in some cases asthma (CDC, 2015).
**Cystic fibrosis.** An inherited disorder that causes severe damage to the lungs and digestive system. Cystic fibrosis affects the cells that produce mucus, sweat, and digestive juices (National Heart, Lung and Blood Institute, 2013).

**Diabetes.** A disease in which blood glucose levels are above normal. Type 1 diabetes, commonly referred to as insulin-dependent diabetes mellitus or juvenile-onset diabetes and type 2 diabetes, the more common type, the body does not make or use insulin well (CDC, 2015).

**Differentiation of self.** Autonomy from others and separation of thoughts from feeling (Nichols, 2008).

**Emotional cutoff.** Bowen’s term for flight from an unresolved emotional attachment (Nichols, 2008).

**Epilepsy.** A disorder in which nerve cell activity in the brain is disturbed, causing seizures (CDC, 2015).

**Family projection process.** The mechanism by which parental conflicts are projected onto the children or spouse (Nichols, 2008).

**Focused genogram.** A format for clinicians to explore important areas of family life in significant detail, including attachment styles, emotions, gender, sexuality, and culture through a graphic image (DeMaria, Weeks, & Hof, 1999).

**Gene therapy.** An experimental technique that uses genes to treat or prevent disease by inducing the formation of normal red blood cells by the bone marrow (CDC, 2015).
**Genogram.** A schematic diagram of the family system, using squares to represent males, circles to indicate females, horizontal lines for marriages, and vertical lines to indicate children.

**Hemophilia.** A disorder in which blood does not clot normally (CDC, 2015).

**Intergenerational Family Therapy.** A theory describing dysfunction as a lack of differentiation, which results in marital conflict, dysfunction in a spouse, or symptoms of dysfunction in one or more children. Change comes about when you increase the ability to distinguish between thinking and feeling within self and others. Also referred to as Bowen family systems (Gehart & Tuttle, 2003).

**Interpretive phenomenology.** A qualitative research method that focuses on lived experiences and the understanding of persons within the context of families, communities, and institutions such as hospitals and schools. The emphasis is more on what it means to be a human being and less on explaining and predicting human phenomena. (Gilgun, 2005).

**Juvenile rheumatoid arthritis.** A systemic inflammatory disease that manifests itself in multiple joints of the body. Juvenile rheumatoid arthritis causes persistent joint pain, swelling and stiffness. Also referred to as juvenile idiopathic arthritis (CDC, 2015).

**Multigenerational transmission process.** Bowen’s concept for the process occurring over several generations, and which poorly differentiated persons marry equally immature partners, ultimately resulting in children suffering from severe psychological problems (Nichols, 2008).

**Nuclear family emotional process.** Emotional forces in families that operate over the years in recurring pattern (Nichols, 2008).
**Patient.** Individuals participating in the health care system for the purpose of receiving therapeutic, diagnostic, or preventive procedures.

**Primary caregiver.** An unpaid relative responsible for providing assistance and support to a loved one diagnosed with a chronic illness. A caregiver can also be described as a person who provides care to those who need supervision or assistance in illness or disability (National Alliance for Caregiving and American Association of Retired Persons, 2004).

**Risk-Resistance-Adaptation model.** How a chronically ill child’s adaptation (psychiatric presentation, social functioning, physical health) is mediated by the interaction of risk (disease/disability parameters, functional independence, stressors) and resistance factors (child variables, socioecological factors, stress processing) (Kaslow & Brown, 1995).

**Sibling position.** Development of personality characteristics based on position in the family (Nichols, 2008).

**Sickle cell anemia.** Two hemoglobin S genes, hemoglobin SS, inherited by an individual. This is the most common and often most severe kind of SCD (NHLBI, 2015).

**Sickle cell disease.** A group of inherited red blood cell disorders (CDC, 2015).

**Stem cell transplant.** A procedure in which diseased bone marrow is replaced by highly specialized stem cells that develop into healthy bone marrow (CDC, 2015).

**Societal emotional process.** How social influence on how families function (Nichols, 2008).
**Transactional stress and coping model.** How the illness-outcome association (correlation between illness parameters and demographic factors, and child and maternal adjustment to a child’s medical condition) is mediated by child and maternal processes (cognitive processes, methods of coping) and family functioning (Kaslow & Brown, 1995).

**Triangles.** Detouring conflict between two people by involving a third person, stabilizing the relationship between the original pair (Nichols, 2008).

**Summary**

This chapter provided an overview specifically on what SCD is in addition to identifying the three research questions, which are: (1) What is the lived experience of the primary caregiver of a child with SCD? (2) What is the lived experience of primary caregivers of a child with SCD specifically regarding child’s medical services? (3) What are the parallels in caregiving behaviors between caregivers of a child with SCD and the caregiving behaviors of past generation caregivers? Additionally, in this chapter the researcher addressed the research method for this study using a phenomenological methodology and a systemic lens, more specifically the intergenerational family therapy lens. Finally, this chapter provided a list of operational definitions used within the study in order to provide the reader(s) with clarity and a general understanding of the meaning of terms.
CHAPTER II

REVIEW OF THE LITERATURE

This chapter will provide an overview of the current literature focused on chronic illnesses, which includes definitions and statistical information on the prevalence of chronic illnesses in the United States. Then the researcher will discuss SCD as a chronic illness as well as historical research since the discovery of the disease, funding as it pertains to SCD, and healthcare needs of individuals with SCD. The chapter will provide information regarding health care disparities amongst the SCD population, as well as the lack of access to adequate care. It will address the history of SCD, which includes the various complications experienced by an individual living with SCD. This chapter will also provide a summation of the lived experiences by familial units as well as primary caregivers when providing care to a child with SCD. Several areas of existing research are examined, such as how members of the familial unit as well as the primary caregiver cope with the presence of a chronically ill child with SCD. International research will be included due to the lack of present research in the United Stated solely focused on primary caregivers and children with SCD. The chapter will also provide an overview of Intergenerational Family Therapy as it pertains to the experiences of primary caregivers. To reiterate, the focus of the present research study is to examine the experiences of the primary caregivers who are responsible for majority
of the caregiving of a chronically ill child with SCD. The researcher acknowledges that there is more research available about caregiver stress and coping with various chronic illnesses as well as other health issues; however, this study will focus specifically on caregiving of children with one chronic illness, SCD, an illness that affects mainly African Americans. Therefore, only a few studies on caregiver stress and coping will be included in the literature review.

What is a Chronic Illness?

According to the Dictionary of Health Services Management, a chronic disease can be described as an illness which can have one or more of the following characteristics: they are permanent, leave residual disability, are caused by nonreversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation, or care (Dictionary of Health Services Management, 1987). The Center for Managing Chronic Disease described chronic illness as a long-lasting condition that can be controlled but not cured (CMCD, 2016). Van Cleave, Gortmarker, and Perrin (2010) defined chronic health conditions in a child or adolescent as,

Any physical, emotional, or mental condition that prevented him or her from attending school regularly, doing regular school work, or doing usual childhood activities or that required frequent attention or treatment from a doctor or other health professional, regular use of any medication, or use of special equipment. (p. 624)

For the purpose of this study, the researcher utilized the definition provided by Van Cleave et al. (2010) as it embodies the psychosocial and psychological factors of chronic illness.
In the United States, according to the National Conference of State Legislatures (NCSL), the diseases and conditions that presently account for the largest toll in death are chronic illnesses such as cancer, heart disease and stroke, and diabetes (NCSL, 2016). According to the NCSL, about 1.7 million Americans die from a chronic illness each year, which would be 7 out of every 10 deaths. Chronic illness can cause disabilities and limitations to daily living in more than 1 of every 10 Americans, or 25 million people (NCSL, 2016). Heart disease is the leading cause of death amongst both women and men, followed by cancer and chronic obstructive pulmonary disease. Stroke is the fourth leading cause of death, while diabetes is the seventh. Among the U.S. population, it has been estimated that 7% to 18% of U.S. children have a chronic illness (National Health Care Statistics, 2006; Perrin, Bloom, & Gortmaker, 2007; Van Cleave et al., 2010). It is important to note that chronic diseases are costly to states because of the repeated utilization of health care services, yet the most preventable of health problems (NCSL, 2016).

Chronic illnesses affect both the individual with the disease as well as the family, particularly the primary caregiver (Burlew, Evans, & Oler, 1989). According to the National Alliance for Caregiving and American Association of Retired Persons (2004), a caregiver is an unpaid relative responsible for providing assistance and support to a loved one diagnosed with a chronic illness. A caregiver can also be described as a person who provides care to those who need supervision or assistance in illness or disability. Caregiving is also seen when dealing with chronic illness. Glasdam, Timm, and Vittrup (2010) addressed this exact phenomenon of caregiver burden and stress amongst families with a chronically ill member. According to the literature, in families
with chronic illness, close family members may experience declining psychological health (i.e., depression, anxiety, etc.), a decrease in satisfaction of their relationships, and poor physical health (Glasdam et al., 2010). Primary caregivers of children with a chronic illness, and more specifically with SCD, can experience these stressors in addition to a variety of psychosocial issues and discriminations. All in all, the terminology and definitions provided above give a succinct understanding of chronic illness in the United States, along with the statistics of how many are affected and living with a chronic illness. The next session will discuss SCD as a chronic illness.

**Sickle Cell Disease as a Chronic Illness**

As previously discussed SCD effects primarily a minority population. Research has shown that primary caregivers of a child with SCD might experience a myriad of issues in addition to coping with the complications, such as social inequalities and systemic racism (Burnes, Antle, Williams, & Cook, 2008; Sterling, Peterson, & Weekes, 1997). According to the National Conference of State Legislatures (2016),

Health disparities can be defined as population-specific differences in the presence of disease, health outcomes, quality of healthcare and access to healthcare services that exist across racial and ethnic groups. Disparities represent a lack of efficiency within the healthcare system and therefore account for unnecessary costs.

The Health Disparities and Inequalities Report by the CDC (2011) highlighted the gradual progress in improving the health and decreasing health disparities amongst United States residents, yet also recognized “health disparities by race and ethnicity, income and education, disability status, and other social characteristics still exist” (p. 1). Even though the CDC acknowledged that health disparities exist, they have not included the SCD population amongst mainstream topics of importance as they had done with
other chronic illness such as obesity, pre-term births, diabetes, asthma, HIV/AIDS, and hypertension (CDC, 2011). Even so, SCD is considered a chronic illness impacting a primarily minority populations, thus far it has not been classified as a health disparity topic by the CDC, and therefore has not received as much attention as its counterparts (CDC, 2011).

Various researchers have addressed the subject of healthcare disparities in the context of race at length over the course of several years (Egede, 2006; Fiscella 2003; Smith, Oyeku, Homer, & Zuckerman, 2006; Tapper, 1999; Wailoo, 2001). Fiscella (2003) addressed healthcare quality for minority populations and other disparity populations, which concluded that several health conditions have not been adequately monitored within the minority sector, such as asthma, maternal childcare, pain management, and sickle cell anemia. Tapper (1999) and Wailoo (2001) believed that “the question of race has been inextricably linked with SCD since its recognition as a distinct disease.” Furthermore, Telfair, Myers, and Drezner (1998) called for the professions to consider that racial bias, whether conscious or unconscious, may play an adverse role in the availability of resources, not only for research and the delivery of care, but also for the improvement of care. In examining the level of care received by SCD patients, there is evidence that racial and ethnic minorities tend to receive lower quality of care than non-minorities (Egede, 2006). Moreover, minority patients with a chronic illness experience higher levels of morbidity and mortality than non-minorities (Egede, 2006). The following section will further address the history of healthcare disparities in the United States. It will also address specific actions that were taken in an attempt to address the gaps in services for individuals with SCD.
Significant Moments in Sickle Cell Disease Research

The lack of services for individuals with SCD, a disease that mainly affects African Americans, is one with historical roots in the United States. Robert Scott had a powerful impact on the history of SCD treatment with the publications of “Health Care Priority and Sickle Cell Anemia” and “Sickle Cell Anemia: High Prevalence and Low Priority” in 1970. Scott (1970) revealed a correlation between SCD research and civil rights in arguing for “increased priority and attention by both the public and the health professions.” During this time, SCD received very little public and professional attention compared to less prevalent diseases, such as cystic fibrosis which mainly affects Whites, despite the high prevalence of SCD in the African American community.

Scott further highlighted a significant gap within the public and private sectors for research and clinical care of SCD compared to various chronic childhood illnesses (Scott, 1970), measured by the number of National Institute of Health (NIH) grants. It was discovered that cystic fibrosis and muscular dystrophy received three times as many grants than SCD.

Scott’s articles would eventually become essential in influencing congressional hearings, which ultimately led to the passage of the first major legislation concerning SCD treatment (Scott, 1970). The National Sickle Cell Anemia Control Act of 1972 increased funding for SCD (approximately $10 million), mainly through the development of SCD centers (NHLBI, 2002). Most recently the passage of the Sickle Cell Treatment Act in October 2004 offers an opportunity to improve the health outcomes for individuals with SCD (Smith et al., 2006). In most recent years, in examining the amounts of funding dedicated to specific chronic illnesses, cystic fibrosis
is not the only disorder that overshadows research for SCD. The following section discusses federal funding for several chronic illnesses in comparison to SCD from the National Institute of Heath.

**Funding for Sickle Cell Disease Research**

As previously mentioned, funding for SCD research has not amounted to much in comparison to its counterparts. In 2014, the estimates of funding for various research, condition, and disease categories based on grants, contracts, and other funding mechanisms by the national Institute of health showed the following funding for these conditions.

Table 1. Funding in research/disease areas

<table>
<thead>
<tr>
<th>Research/Disease Areas</th>
<th>2014</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Dollars in Millions)</td>
<td>Actual</td>
<td>Estimated</td>
</tr>
<tr>
<td>Alzheimer’s</td>
<td>562</td>
<td>910</td>
</tr>
<tr>
<td>Hepatitis</td>
<td>251</td>
<td>273</td>
</tr>
<tr>
<td>Asthma</td>
<td>241</td>
<td>289</td>
</tr>
<tr>
<td>Parkinson’s</td>
<td>139</td>
<td>152</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>102</td>
<td>98</td>
</tr>
<tr>
<td>Lupus</td>
<td>99</td>
<td>93</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>77</td>
<td>83</td>
</tr>
<tr>
<td>Sickle Cell Disease</td>
<td>75</td>
<td>78</td>
</tr>
</tbody>
</table>
Additionally, in recognizing this gap amongst federal funded support for various chronic illnesses, gaps exist within the private sector pertaining to research and clinical care for SCD as well. Smith et al. (2006) provided a glaring example for the year 2003 in which the Sickle Cell Disease Association of America’s (SCDAA) total revenue was $498,577 compared to $152 million for the Cystic Fibrosis Foundation, a major difference that has significant implications for SCDAA’s ability to fund research and advocacy. Overall, developing research for SCD may not be as abundant as other illnesses due to a lack of federal funded support. Health care costs amongst this population are high and, therefore, can place economic and financial stress on the family unit and primary caregiver, which will be discussed in the following section.

**Health Care Needs for Sickle Cell Disease Patients**

As one can postulate, SCD is a costly disease for everyone involved (the family unit and primary caregiver), however, federal funding does not match the needs of the public. A number of studies have focused on the economic impact of SCD on the adult population due to the continuous use of medical services (Bilenker, Weller, Shaffer, et al., 1998; Davis, Moore, Gergen, 1997; Woods, Karrison, Koshy, et al., 1997; Yang, Shah, Watson, et al., 1995). These studies provided evidence through empirical research indicating how the care of SCD contributes to increasing healthcare costs. According to Steiner and Miller (2004), the annual direct cost of hospitalizations related to SCD in 2004 was estimated to be about $488 million. Today there has been progress in the preventive and therapeutic interventions for the care of pediatric SCD over the past decade, however minimal data exists regarding healthcare utilization and costs with the
pediatric population (Bilenker, Weller, Shaffer, et al., 1998; Shankar, Arbogast, Mitchel et al., 2005).

Comprehensive care for an individual with SCD can consist of doctors, nurses, health educators, and medical social workers (NHLBI, 2002). Other health care professionals may become involved as well such as emergency room physicians, radiologists, anesthesiologists, surgeons, and critical care specialists (NHLBI, 2002). Within the first 2 years of life, well care visits (every 2-3 months) are recommended for growth monitoring, immunizations, and counseling on preventive health measures (NHLBI, 2002). After age 2, visits depend on the individual/family needs as well as access to medical consultation, but it should be at least every 6 months (NHLBI, 2002). It is quite possible to avoid complications through appropriate maintenance and comprehensive care during the child’s developmental years. In order to provide sufficient care of a chronically ill child with SCD, service providers must understand and recognize the origins of the disease and how SCD has developed over the years. Being able to understand the history of the disease and its development over the years can give service providers the necessary information to work with this population.

**History of Sickle Cell Disease**

Walter Clement Noel (1884–1916) was the first documented case of what we now call sickle cell disease. Noel was born to two wealthy landholders in the country of Grenada, a Caribbean island under British rule at the time. Despite suffering many chronic health conditions, Noel received a quality education and completed his undergraduate studies in 1904 from Harrison College in Barbados (Steensma, Kyle, & Shampo, 2010). Noel had been accepted to the Chicago College of Dental Surgery in
the city’s west side and eventually resided in the Chicago medical district. In September 1904, Noel developed a leg ulcer en route to New York from Barbados. He was treated via topical iodine solution and recovered 1 week later and continued his travels to Chicago (Steensma et al., 2010).

In November 1904, Noel began experiencing respiratory problems that lasted for more than a month. He later on sought treatment at the Presbyterian Hospital in Chicago in which he was assessed by Ernest E. Irons (1877–1959), an intern at the time. In performing a relatively new procedure, a peripheral blood smear, Irons noticed that Noel’s blood smear had “many pear-shaped and elongated forms – some small” (Steensma, et al., 2010, p. e74). Within the next 2.5 years, Noel progressed in his studies and continued to receive treatment from Irons (Steensma, et al., 2010). During this time, Noel developed bronchitis and would later develop “a bilious and muscular attack” which left him hospitalized for 2 months (Steensma et al., 2010, p. e74). This would later on become known as a pain episode or sickle cell crisis, which mainly affect an individual’s back, abdomen, chest, or extremities (Pack-Mabien & Haynes, 2009).

In 1910, at a national meeting, supervising physician, James Bryan Herrick (1861–1954), presented the case of W. C. Noel (without giving credit to Ernest Irons) and would later go on to publish a detailed report that same year. Subsequently, a few months later another case similar to that of Noel was documented in rural Virginia, Ellen Anthony (Steensma, et al., 2010). The next case occurred 5 years later by the early 1920s; thus, by this time, Vernon Mason had enough data collected in order to name the illness sickle cell disease in 1922 (Steensma, et al., 2010). Noel was able to complete his studies and returned to Grenada to practice dentistry. He died of pneumonia in 1916.
and was buried in the Catholic cemetery at Sauteurs in the north of Grenada (Steensma, et al., 2010). As knowledge of this disease more became recognizable from 1904 until the present day, there is additional information one must know about the disease itself and how it presents in individuals with SCD.

**Sickle Cell Disease Facts**

Sickle cell disease (SCD) was initially recognized in people of West African ancestry. It was most commonly found in Africa and the Caribbean Islands (Serjeant, 1997). Based on this observation, misconceptions were formulated, many of which stated that SCD affected only those of African descent (Serjeant, 1997). However, the sickle cell gene is evidenced to be widespread amongst the Mediterranean region in Sicily, southern Italy, northern Greece, the southeast coast of Turkey, Saudi Arabia (especially in the eastern province), South and Central America, the Middle East, and Central India (Serjeant, 1994, 1997). Individuals that present with SCD have C-shaped red blood cells or “sickle” red blood cells (CDC, 2015). In healthy individuals, red blood cells are round and responsible for carrying oxygen to various parts of the body. In SCD, the red blood cells become hard and sticky causing red blood cells to die early, which lead to a constant shortage of red blood cells. When these sickle red blood cells travel throughout the blood vessels, they may become stuck or block the flow of blood within the body. This can lead to complications for the individual with SCD such as vaso-occlusive episodes, anemia, infections, acute chest syndrome, and strokes (CDC, 2015). Individuals with SCD may experience several complications as well.
Complications of Sickle Cell Disease

The signs of SCD usually occur within the first year of life, generally around five months old (CDC, 2015). It is important to note that symptoms and complications of SCD present differently in each individual and range from mild to severe (CDC, 2015). Infants do not show signs of the disease at birth because fetal hemoglobin protects red blood cells from sickling (CDC, 2015). By the time an infant reaches five months of age, the fetal hemoglobin is replaced by sickle hemoglobin and begins to cause symptoms (CDC, 2015). The most common symptom of SCD is the vaso-occlusive pain episodes also known as “crises” (CDC, 2015). During pain episodes, sickle cells travel through small blood vessels causing them to get stuck and clog the blood flow. These pain episodes mainly affect an individual’s back, abdomen, chest, or extremities (Pack-Mabien & Haynes, 2009). According to Pack-Mabien and Haynes (2009), patients described their pain symptoms as “throbbing, achy, sharp, or dull with a rapid onset…episodes may be acute or chronic, lasting hours, days, or even weeks” (p. 252).

In addition to pain episodes, individuals with SCD are commonly anemic. With SCD, red blood cells have a propensity to die early, which means there are not enough red blood cells to carry oxygen throughout the body (CDC, 2015). As a result, individuals may experience tiredness, irritability, dizziness or lightheadedness, fast heart rate, difficulty breathing, pale skin color, jaundice (yellow color to skin and whites of eyes), slow growth, and delayed puberty (CDC, 2015). This type of anemia cannot be treated with iron supplements because it is caused by not having enough red blood cells rather than a lack of iron (CDC, 2015). For this reason, taking iron supplements can cause more harm because the iron builds up in the body resulting in organ damage.
Coupled with pain episodes and anemia, infants and children with SCD are more susceptible to bacterial infections (CDC, 2015). According to the CDC (2015), pneumonia is the leading cause of death in infants and children with SCD.

Another life-threatening complication amongst this population is acute chest syndrome. The signs and symptoms of acute chest syndrome are quite similar to pneumonia (CDC, 2015). Chest pain, coughing, difficulty breathing, and fever are common symptoms of acute chest syndrome. Individuals with SCD can also suffer from strokes if sickle cells get stuck in the blood vessels and clog the flow of blood to the brain. The CDC (2015) reports that at least 10% of children with SCD will have a symptomatic stroke, which can lead to learning problems and lifelong disabilities. In addition to strokes, vision loss can also occur when blood vessels become blocked with sickle cells leaving the retina to become damaged (CDC, 2015). Some individuals may even develop extra blood vessels in the eye due to the lack of oxygen (CDC, 2015). The previous literature gives a concise analysis of how SCD presents itself in a chronically ill child, along with complications of the disease. Now the research will discuss how SCD can alter the family dynamics with the presence of this chronic illness.

**Sickle Cell Disease and the Family**

According to Burlew et al. (1989), the research at that time believed that a chronic illness can affect the family on three levels. The illness can challenge the family cognitively meaning that the family “must learn about the course of the illness, the etiology and prognosis, the optimal treatment, as well as implication of the illness on their child-rearing patterns” (p. 161). Secondly, the illness can challenge the family emotionally. The family must learn to cope with the uncertainties of the disease, which
can cause anxiety amongst the family unit. Finally, the illness can challenge the family behaviorally, which means the family “must incorporate the treatment regimen into the family routine while maintaining other family functions (p. 161). Research with families with varying chronic illnesses suggests that the child’s presence can have an influence on the relationship between the parents, the relationship between the parent and the chronically ill child, and the relationship between the parents and the other children in the household (Burlew et al., 1989).

Previous research on chronic illness has guided researchers in understanding how families have been affected by the presence of a child with SCD (Burlew et al., 1989). Weiss (1981) and Gath (1977) have shown that a child presenting with a chronic illness affects the entire family. Consistent with Weiss (1981) and Gath (1977), Burlew et al. (1989), believed that the research that exists on SCD “specifically suggest that the child’s presence affects the general well-being of the primary caretaker, alters interpersonal relationships within the family, changes the dynamics of the family environment, and strains the family finances” (p. 162). The presence of a child with SCD can also increase the amount of emotional strain on the primary caregiver as well as threaten the financial stability of the family (Weiss, 1981).

Other researchers have attempted to illustrate the connection between the well being of a child with SCD to healthy family functioning. Mitchell et al. (2007) showed the correlation between healthy familial functioning and coping to the well being (health care utilization) of a child with SCD utilizing quantitative as well as qualitative methods. Fifty-three primary caregivers of 48 children with SCD participated in one of eight focus groups. All but one participant were African American (one adoptive parent was
White). Forty-six (88%) of the participants were women (43 mothers/foster mothers and 3 grandmothers/aunts) and 6 (7%) were men (3 fathers, 3 uncles/male caregivers). The mean age of the 48 children with SCD was 10.66 years and 50% (24) of the participants were female. Mitchell et al. (2007) utilized the Coping Strategies Questionnaire (CSQ), 80-item questionnaire with a 6-point Likert scale, specifically designed for the SCD population, which measured how often participants used cognitive, behavioral, and physiologic coping strategies (Geisser, Robinson, & Henson, 1994). It contains three factor scores: Coping Attempts, Negative Behavior, and Passive Adherence. The Family Assessment Device (FAD), 60-item questionnaire, was also used in order to measure family functioning based on the McMaster Model of Family Functioning (Epstein, Baldwin, & Bishop 1983). The FAD assessed seven dimensions of family functioning: Problem Solving, Communication, Roles, Affective Responses, Affective Involvement, Behavioral Control, and General Functioning.

Mitchell et al.’s (2007) study results showed several interesting aspects related to patient, family coping, and health care utilization. The research study concluded, “positive patient coping was related to positive family functioning and lower health utilization” (p. 311). General consensus amongst the focus groups showed that primary caregivers believed that SCD impacted personal and family life, including friendships, school, employment, family activities, including interaction and quality time with siblings (Epstein et al., 1983). In addition, the data implied that parents rely on the chronically ill children to monitor their own symptoms, inform the parent of when they are experiencing pain, provide the parent with direction and cues in making decisions,
and comply with parental requests regarding treatment recommendations (Mitchell et al., 2007).

While other researchers have focused on analyzing the connections between the chronically ill children, functional families and health care utilization, other researchers have investigated additional pieces that can affect how a family copes with the disease such as ethnicity, race, religion, and socioeconomic status. Kaslow and Brown (1995) discussed the impact ethnicity and socioeconomic status (SES) play in the role of therapists’ and families’ beliefs and behaviors regarding illness and health. Their research also discussed how culturally sensitive interventions can aid in a family, specifically African American families, in developing appropriate coping mechanisms. Kaslow and Brown (1995) major focus was to develop an intervention with the pediatric SCD population and their families because of the scarcity of research that falls short in focusing on the impact of SCD and the family. Kaslow and Brown (1995) believed that effective treatment for this population should include knowledge of the disease, building upon the strengths of the family, adaptability of roles, religious and moral values, optimism and determination, and resilient children. These researchers developed The SCD Project in an effort to create a developmentally and culturally sensitive, manualized treatment that is specific for each child and family. The clinical research project utilized a psychoeducational approach that incorporated a risk-resistance-adaptation perspective and the transactional stress and coping model (see Operational Definitions in Chapter I). The researchers desired to assist families and medical professional in formulating a working alliance that would bring about positive therapeutic change within the family unit. In order to simplify how this can be done and apply to family counseling, the
researchers provided a brief overview of six sessions, however the researchers did not provide information on how many families participated. Session one was centered on educating the family and child about the disease itself in order to effectively cope; session two focuses on additional information about SCD and explains preventive health care strategies that can be resistance factors; session three focuses on stress processing and coping, session four encourages family members to discuss their feelings openly, session five includes examining socioecological resistance factor and family relationships and finally session six reviews the information learned, treatment termination, and follow-up plans. Researchers reported that the families that participated in this project found it very helpful render the families more competent and being able to handle the child’s difficulties and the medical care system (Kaslow & Brown, 1995).

The aforementioned research gives a brief analysis of how a chronically ill child’s presence could cause a shift in the family dynamics. It is important to note that the following research study will focus primarily on the lived experiences of the primary caregiver. In the following section, the researcher will discuss SCD as it pertains the primary caregiver.

**Sickle Cell Disease and the Primary Caregiver**

As previously explained, a primary caregiver is an unpaid relative responsible for providing assistance and support to a loved one diagnosed with a chronic illness. Being the primary caregiver of a chronically ill family member is more complex than one might think. The physical and emotional well being of the primary caregiver has the potential to influence the health, welfare, and successful rehabilitation of persons with a chronic illness (Han & Haley, 1999). Primary caregivers can be affected in a variety of
ways: physically, psychologically, and socially, which may include decreased physical health, impaired social and family life, and increased stress levels, anxiety, and depression (Jones & Peters, 1992; Northouse & Swain, 1987; Spiegel, Leproult, & Van Cauter, 1999). Lim and Zebrack (2004) touched on this very subject of caregiver stress in stating that caregivers are often tired, overwhelmed, and have feelings of isolation due to lack of support as well as being responsible for coordination of care and symptom management.

Existing research has shown that primary caregivers are affected in multiple areas of their lives while taking care of a chronically ill family member or significant other. Moskowitz et al. (2007) examined patterns of caregiving and the psychological impact on 14 maternal caregivers of children with SCD. The participants were essentially interviewed as part of a larger study of primary caregivers and chronic illness, which consisted of 44 caregivers of children with HIV and 36 caregivers of healthy children as a comparison group. Researchers sought to measure various aspects of caregiving such as caregiving time, functional status (child), illness stigma, depressed mood, caregiving burden, and hospitalization or emergency room visits. In order to measure these aspects, the authors utilized measurements such as the Functional Status II Revised (FESIIR) (Stein & Jessop, 1990) questionnaire, Personal Stigma Scale (Silver, Bauman, Camacho et al., 2003), Epidemiologic Students Depression Scale (CES-D) (Radloff, 1977), and the Dislocations Scale (Gottlieb, 1988). Consistent with the previous research mentioned, Moskowitz et al. (2007) study showed that depressive symptom scores were higher overall amongst caregivers of children with chronic illness,
and caregiver burden was connected to the amount of crisis care for caregivers of SCD children rather than caregivers of children with HIV.

Further research has shown these same psychological aspects amongst primary caregiver populations when taking care of a child with SCD. Barakat, Patterson, Tarazi, and Ely (2007) assessed the developmental aspects of parenting stress while caring for a child with SCD. The study also looked into the association between disease-related parenting stress and family functioning, as well as the contributions of demographic variables and disease severity of 27 primary caregivers of preschool age children and 41 primary caregivers of adolescents. In utilizing the Pediatric Inventory for Parents (Streisand et al., 2001), 42-item measure, researchers were able to measure “the nature of disease-related parenting stress in terms of frequency and difficulty” of communication, emotional functioning, medical care, and role function (Barakat et al., 2007, p. 151). The Family Environment Scale (Moos & Moos, 1981) was also used in order to measure family environment in interpersonal relationship, personal growth, and system maintenance. The authors were able to determine that caregivers experienced significantly more parenting stress related to disease-related communication more so with teens. Disease-related parenting stress was also found to be higher for lower income families, while family income and family functioning were significant predictors of parenting stress (Barakat et al., 2007).

Other researchers have not only investigated the psychological stress of taking care of a chronically ill child with SCD but also the coping strategies they used when they first learned of their child’s diagnosis. Rao and Kramer (1993) investigated this very topic with 31 mothers of infants with sickle cell anemia (n = 14) or sickle cell trait
(n = 17) at a pediatric hematology unit in a major urban hospital. The researchers believed that very little was known about how parents cope with their child’s diagnosis of a sickle cell condition, which is a major limitation because a parent’s well being can affect the well-being of the child. It is important to note that fathers were not a part of this study, 78% (n = 24) of the participants were single parents. One-hour interviews were conducted with each mother at the hospital where the child was diagnosed. Initially, mothers were asked to describe when they first learned of their child’s diagnosis, the aspects of the diagnostic process that was stressful, and resources that were helpful for coping with the information. In Rao and Kramer (1993), mothers were then asked to rate the level of stress they associated with learning about the diagnosis of sickle cell anemia or sickle cell trait compared to other stressful things that occur in their life on a 7-point Likert scale. Perceived coping efficacy with the diagnosis was assessed by asking mothers to rate how well they think they were able to cope with the diagnosis on a 5-point Likert scale. In the next section of the interview, researchers assessed the stressors that mothers associated with their current experiences and caring for their child. The Ways of Coping Questionnaire (Folkman & Lazarus, 1988), a 66-item measure used to assess the types of strategies used to cope with a particular stressful event was administered after. The final portion of the interview assessed the mothers’ reactions to the newborn screening and follow-up procedures and inquired about their advice for health professionals. The results of this study showed that mothers were most worried at the time of the diagnosis, in particular, they anticipated the pain of childhood experiences. Mothers had continuing concerns about the child’s health and the extra supervision that will be needed to detect the onset of the pain crises. Mothers were more
likely to report trying to emphasize the positive growth that was part of the SCD experience as a way to cope. Secondary concerns of the participants include economic means, relations with their spouse and relatives, long waiting time to receive medical attention, and finding adequate childcare.

All in all, in order to supplement the body of literature presented, the researcher considered research outside of the United States. The majority of the research being conducted amongst the minority SCD population has been conducted outside of the United States. Therefore, the researcher thought it necessary to include it amongst the literature reviews.

**Sickle Cell Disease and International Research**

As one can see, the research surrounding SCD and the primary caregiver in the United States is lacking, thus the researcher expanded the search to international literature regarding the subject of the psychosocial impact of SCD in relation to the primary caregiver. With this in mind, the researchers Burnes et al. (2008), Adegoke and Kuteyi (2012), and van den Tweel et al. (2008) conducted various studies to add to the current body of research. These three articles focused on the psychosocial stressors of caring for child with SCD and the impact it has on the family unit.

In a qualitative study, Burnes et al. (2008) explored the experiences and perceptions of Canadian mothers of African and African Caribbean descent raising children with SCD within the context of social inequality. Burnes et al. (2008) highlighted three under-researched areas within these experiences such as “daily coping challenges (micro level); community views of SCD, such as stigma (meso level); and systemic SCD health care provision (macro level)” (p. 212). The researchers used
population health and structural social work theories as the theoretic framework for this study (Dunn & Dyck, 2000; Hayes, 1999; Mullaly, 1997; Thompson, 1998). Within this study, the researchers recruited 10 mothers who identified as primary caregivers, and mothers with children identified as having non-blood-transfused sickle cell anemia. The children in the household with SCD, eight girls and five boys, ages ranged from 6 months to 16 years old. Participants were initially interviewed, utilizing a semi-structured format of open-ended questions and perceptions related to the themes, for approximately 1.5 hours in order to reach saturation. Results from the Burnes et al. (2008) study highlighted the importance of understanding mothers’ experiences in the context of stigma and insufficient resources allocated towards SCD. Results showed that mothers faced daily emotional challenges, some of which include “constant fear of their children’s hospitalization and potential death, separation anxiety, a loss of control over their lives, helplessness, loneliness, and isolation” (Burnes et al., 2008, p. 217). These challenges are exacerbated by SCD stigma, in which mothers fear discussing the disease openly within the community. Mothers also expressed “perceived gendered parenting role expectations” meaning mothers believed they endured majority of the caregiving responsibilities and stress (Burnes et al., 2008, p. 217).

van den Tweel et al. (2010) found related results in their research study conducted in the Netherlands. In this study, researchers evaluated the quality of life of female caregivers of children with SCD. They utilized the TNO-AZL Adult Quality of Life Questionnaire (TAAQol) (Bruil, Fekkes, Vogel, & Verrips, 2004) and compared 54 female caregivers of SCD patients to a group of Dutch females and female caregivers of healthy children with the same socioeconomic status and ethnic background. The
majority of the female caregivers of the children with SCD originated from non-western countries, were single parents, and had low educational level. Burnes et al. (2008), as well as van den Tweel et al., (2010) also showed that participants had daily emotional challenges when caring for a patient with SCD. Caregivers of SCD children had a lower QoL on the subscales of depressive moods, daily activities, vitality, sleeping, happiness and cognitive functioning when the medians were compared to those of the control group.

Similarly to Burnes et al. (2008) and van den Tweel et al. (2010), Adegoke and Kuteyi (2012) conducted a descriptive cross-sectional study exploring the psychosocial impact of SCD on the primary caregiver’s well-being. Participants were being treated at the Pediatric Hematology Clinic of the University Teaching Hospital in Ado-Ekiti, Nigeria. The researchers utilized a structured questionnaire and culture-relevant disease burden interview to assess the psychosocial burden of SCD caregivers. The participants consisted of 225 caregivers (202 mothers, 15 grandmothers, and 8 fathers). Researchers used the Sickle Cell Disease Burden Interview (SCDBI), which has a total of 16 questions, validated by Ohaeri and Shokunbi and found to be relevant to Nigerian culture. It was used to assess the psychosocial burden of SCD on the caregivers as well as financial burden of the disease, the dysfunctional family interactions, and the disruption of routine family activities. It also assessed subjective domains of psychosocial burdens such as the caregiver’s feelings towards the child and the ability of the family to cope with the disease. Results from the study show that the financial burden of SCD on the caregivers and their families was high, 70% of caregivers lost income or financial benefits, while 40% of the caregivers neglected other family
members because of the demands of caregiving, and a majority of the caregivers experienced depression. Caregivers also reported coping differently, for example, some were able to cope well especially in routine family activities, whereas others coped inadequately, resulting in feelings of depression and anger towards themselves and the affected child.

Overall, the present studies focused on the psychosocial and psychological impact of SCD on the family unit and primary caregiver. One can ascertain that SCD plays a major role in how the system functions. As has been established, the gene for SCD is genetically transmitted from one generation to the next (from parent to offspring). Therefore, the researcher is hypothesizing that caregiving behaviors (communication, problem-solving, coping skills, etc.) may be similarly transmitted as well, as the researcher believes that caregiving is learned behavior from previous generations. Most human behavior is learned observationally through modeling, thus from observing others, one forms an idea of how behaviors are performed and on later occasions this coded information serves as a guide for action (Bandura, 1971). Generally speaking, a majority of the behaviors that individuals display are either deliberate or inadvertent, through the influence of example or their environment (Bandura, 1971). Primary caregivers may experience similar challenges and experiences across generations if they have cared for a child with SCD or someone with a chronic illness. As formerly stated, the researcher is looking at the primary caregiver’s caregiving behaviors, thus it is important to look at this phenomenon from a systems point of view, particularly from an intergenerational family therapy lens which will be discussed in the following section.
Overview of Intergenerational Family Therapy

Intergenerational family therapy can also be referred to as Bowen family systems, which evolved from psychoanalytic principles (Gerhart & Tuttle, 2003). Murray Bowen’s interest in working with families developed during his career as a psychiatrist at the Menninger Clinic from 1946 to 1954. In working with schizophrenic patients, Bowen began to see the importance of the relationship between the patient and the mother (Gerhart & Tuttle, 2003; Nichols, 2008). In 1954, Bowen became the first director of the Family Division at the National Institute of Mental Health (NIMH). He conducted research on schizophrenic patients and their families (Nichols, 2008). Bowen began treating the families as an “emotional unit” coupled with highlighting the importance and influence of the family, even across generations (Gerhart & Tuttle, 2003), eventually leading him to become one of the early founders of family therapy. Bowen believed that the family operated as a “multigenerational network of relationships” (Nichols, 2008, p. 127). Bowen formulated the relationship of individuality and togetherness by using these core interlocking concepts: (1) differentiation of self; (2) triangles; (3) nuclear family emotional process; (4) family projection process; (5) sibling position; (6) emotional cutoff; (7) societal emotional process; (8) multigenerational transmission process; and (9) genogram. Though this is an overview of Intergenerational Family Therapy, for the purpose of this study, the focus will be on the multigenerational transmission process, which will be discussed further on.
Differentiation of Self

According to Friedman (1991), “differentiation is a lifelong process of striving to keep one’s being in balance through the reciprocal external and internal processes of self-definition and self-regulation” (p. 141). It is an aspect of Bowen’s theory that is believed to be truly achievable. There are two types of differentiation: interpersonal and intrapsychic process (Gerhart & Tuttle, 2003). The intrapersonal aspect of differentiation refers to separation of feelings and thinking (Gerhart & Tuttle, 2003). Undifferentiated people have difficulty distinguishing thoughts and feelings, whereas differentiated people have strong emotion and logical thought. The intrapersonal aspect of differentiation refers to being able to distinguish one’s self from others (Gerhart & Tuttle, 2003). An undifferentiated person will have difficulty distinguishing their thoughts and feelings from others, whereas a differentiated person can be simultaneously autonomous and relational (Gerhart & Tuttle, 2003). One’s level of differentiation can be linked to family of origin and one’s role in the family (Gerhart & Tuttle, 2003). Lower levels of differentiation are generally linked to high levels of anxiety, personally and interpersonally (Gerhart & Tuttle, 2003).

Triangles

Triangles refer to introducing a third person, such as a child, parent, or friend into the dynamics of a troubled dyad (Gerhart & Tuttle, 2003). The level of anxiety within the current relationship influences triangles. Therefore, when a relationship becomes distant and anxiety increases, a third party or thing may be introduced in order to bring about some form of stability (Gerhart & Tuttle, 2003). The immediate benefit to an unstable relationship is to create a triangle to reduce the anxiety and/or tension that may
be present. Triangulation becomes problematic when it becomes chronic and the original dyad never engages in dialogue to resolve the issues. Triangles can play out throughout generations (Kerr & Bowen, 1988), therefore if a conflict was not resolved between, for example, great-grandparents, the present generation might act out this conflicted relationship.

**Nuclear Family Emotional Process**

The nuclear family emotional process describes “the flow of emotional process or patterns of emotional functioning in a nuclear family” (Kerr & Bowen, 1988, p. 317). The emotional processes of an individual within the family unit are interdependent with the entire family’s emotional process. Discord amongst the family unit usually develops during periods of prolonged family tension. The level of tension depends on the stress levels within the family unit, how the family adopts to the stress, and on the family connections with extended family.

**Family Projection Process**

In the family projection process parents transmit or “project” their lack of maturity and low differentiation onto their children. The process involves the replication of one’s family of origin processes in one’s present family of procreation, which can display similar patterns of triangulation, fusion, and distancing (Kerr & Bowen, 1988). The projection can impair the functioning of children within the family unit as well. According to Nichols (2008), the object of the projection process can develop low differentiation and will be more susceptible to problems. The individual may have issues adapting to other factors that precipitate dysfunction as well.
Sibling Position

Kerr and Bowen (1988) believed that “the concept of functioning position and family systems theory predicts that every family emotional system generates certain functions” (p. 315). Bowen theorized that with sibling position there are specific characteristics that are probable, which can be useful in determining a child’s role in the family emotional process (Gerhart & Tuttle, 2003). With this in mind, it is thought that the firstborn child tends to be characterized by power, authority, and self-confidence (Gerhart & Tuttle, 2003), whereas the “later born children tend to identify with the oppressed and tend to be rebellious explorers and iconoclasts” (p. 154).

Emotional Cutoff

Emotional cut off occurs when a person who is undifferentiated manages emotional intensity by “cutting self off” from their family of origin (Gerhart & Tuttle, 2003). According to Kerr and Bowen (1988), “people cut off from their families of origin to reduce the discomfort generated by being in emotional contact with them” (p. 271). Many times this action of cutting oneself off from family can be seen as “maturity”, but this is untrue. In actuality, cutting oneself off from family of origin is “often a sign of unresolved issues and lower levels of differentiation” (Gerhart & Tuttle, 2003, p. 154).

Societal Emotional Process

Lastly, societal emotional process refers to a prolonged increased in social anxiety, which can result in a gradual lowering of the functional level of differentiation of a society (Kerr & Bowen, 1988). Some examples of these prolonged social stressors include racism, sexism, classism and other forms of oppression that can affect one’s
level of functioning. Bowen believed that with higher levels of differentiation, individuals experiencing sexism, and class and ethnic prejudice can adequately cope with these destructive social influences.

**Multigenerational Transmission Process**

According to Kerr and Bowen (1988), this concept involves “individual differences and functioning and multigenerational trends in functioning that reflect an orderly and predictable relationship process that connects the functioning of family members across generations” (p. 224). In every generation, the child more involved in the family fusion moves towards a lower level of differentiation (and chronic anxiety), whereas the child less involved in the family fusion moves towards a higher level of differentiation (and less anxiety) (Kerr & Bowen, 1988). Conflict within the family unit is usually the result of relational problems across multiple generations. For example, a person with low differentiation will more than likely marry another individual at the same level of differentiation. These individuals will then create a new family unit instilling the same emotional atmosphere as their own upbringing. The level of anxiety amongst this family unit is likely to be higher. The more anxiety that is focused on one of the children, the less the child will be able to regulate their own emotions, rendering them less happy or mature. The less anxiety focused on this one child, the more likely they are to grow up with higher differentiation than their parents. As previously stated, for the purpose of this study, focus will be only on the multigenerational transmission process because it is hypothesized that caregiving behaviors are passed on from one generation to the next. Transmission occurs on several interconnected levels ranging
from conscious teaching and learning of information to the automatic and unconscious programming of emotional reactions and behaviors.

**Genogram/Focused Genogram**

The genogram, commonly used in Intergenerational Family Therapy, is a graphic representation of an individual’s family, interpersonal relationships among family members, and family history over multiple generations (Nichols & Schwartz, 1998).

![Figure 1. Example of a Genogram](image)

Traditionally, the genogram was used by family therapists to gather qualitative information about the history of the family, transgenerational influences, and family make up (McGoldrick & Gerson, 1985). Focused genograms, which were used in this study, were developed more than a decade ago and are used to address a large range of materials relevant to individuals, couples, and families (DeMaria et al., 1999). It provides guided exploration of areas such as culture, gender, emotions, attachments, and
for this study, health and caregiving behaviors. In-depth focused genograms provide a microscopic and macroscopic examination of specific issues that affect the client, the family, and social systems. The focused genogram provides a format for clinicians to explore important areas of family life in significant detail, including attachment styles, emotions, gender, sexuality, and culture (DeMaria et al., 1999). The genogram is also intended to highlight the multigenerational family processes and provide historical facts of the family from an objective standpoint. For the purpose of this study, the caregiver genogram for chronically ill children will be used. In order to assess transgenerational patterns of caregiving behaviors, a focused genogram will be used in order to provide the information necessary relating to how primary caregivers have learned to care for a chronically ill child with SCD.

Altogether, when dissecting various aspects of intergenerational family therapy, one can understand the importance of a systemic framework and the role it plays when examining the lived experiences of primary caregivers caring for a child with sickle cell disease and caregiving behaviors. With an in-depth understanding of this systems theory, the researcher was able to thoroughly explore a vitally important part of each participant’s day-to-day lived experience while caring for their chronically ill child.

Summary

This chapter provided an overview of the present literature on chronic illness, along with terminology, and the prevalence of chronic illnesses in the United States. In addition, this chapter focused on the significant research studies conducted on SCD since the discovery of it. Also the topic of funding as it pertains to developing research in SCD, and healthcare needs of individuals with SCD. This chapter further focused on the
history of SCD and the complications that come along with living with the disease. Being cognizant of the lack of research presently existing focused on people with SCD in relation to family therapy, the chapter discussed how this disease presents itself within the family unit, particularly how the family unit functions with the presence of a chronically ill child. Additionally, the chapter segues into the chief focus of this research study, the lived experiences of the primary caregiver when caring for a child with SCD. International research was also discussed in addition to the present body of research, which is currently lacking in its discussion of the lived experiences of primary caregiver with children diagnosed with SCD.
CHAPTER III
METHODOLOGY

This chapter will focus on the specific methodology utilized to conduct the present research study. It will also include the history of the research design within the field of family therapy, recruitment procedure, research participants, data collection and interview process, data analysis, ethical considerations, and reliability and validity from a qualitative researcher’s lens.

Research Design

Phenomenology was developed over 50 years ago in Europe, and subsequently brought to the University of Chicago in the U.S. (Dahl & Boss, 2005). Several theoretical perspectives are associated with phenomenology such as Erving Goffman’s (1959) dramaturgical model and Berger and Luckmann’s (1966) sociology of knowledge (Dahl & Boss, 2005). Phenomenology has a strong philosophical component, which derives from the writings of the German mathematician Edmund Husserl. Edmund Husserl developed phenomenology in the 20th century, which rejected the core belief that objects in the external world exist independently, and therefore information about objects is reliable. Husserl posited that individuals could be certain about how things appear in or present themselves to their consciousness (Groenewald, 2004).

During the 1990s, there was a surge in the use of phenomenology particularly amongst family researchers. Family researchers became overwhelmingly interested in
how each family member experienced their every day worlds as well as how their perceptions of what they experienced lead to different meanings (Dahl & Boss, 2005). At the time, more researchers and therapists began to go into families’ homes in order to explore the “family world,” the term coined by Hess and Handel (1959).

Phenomenology typically focuses on the reality and how the individual, couples, or families perceive it. Their perception of the “real” world cannot be experienced in a laboratory or clinic, but where they interact in their daily lives. The purpose of phenomenology is to “reduce individual experiences with a phenomenon to a description of the universal essence” (van Manen, 1990, p. 177). The aim of this type of research is to determine what the phenomena means to the person and to provide thorough descriptions of this phenomenon. According to Moustakas (1994), from these experiences, general or universal meanings are derived in order to extract the essence or structure of the experience itself. “In phenomenology studies the investigator abstains from making suppositions, focuses on a specific topic freshly and naively, constructs a question or problem to guide the study, and derives findings that will provide the basis for further research and reflection” (Moustakas, 1994, p. 47).

Phenomenological family researchers operate from a unique perspective by eliciting the perceptions and views of all the family members to get a complete picture. This can make the research process very complicated, but it provides realistic reflections of the family structure that includes gender, generation, sexual orientation, ethnicity, and culture. It is critical to acknowledge the exploratory nature this type of study requires when doing research to broaden the understanding of a primary caregiver caring for a chronically ill child, specifically with SCD. The present study is not widely researched
in the field the family counseling, therefore the study called for an exploratory approach using qualitative methods. For the purpose of this study, the research focused on the lived experiences of the primary caregiver who provide care to a child with SCD. The researcher hoped to fill in the gaps in the literature that do not provide adequate representation of primary caregivers within this population.

**Recruitment Procedure**

The current study focused on the lived experiences of primary caregivers who currently provide care to a child with SCD. Thus purposive sampling was used to recruit primary caregivers who identify as such. The Sickle Cell Anemia Center at the Angie Fowler Adolescent & Young Adult Cancer Institute at University Hospitals Rainbow Babies & Children’s Hospital provides services to more than 250 northeast Ohio children in cooperation with area pediatricians and family physicians. The Sickle Cell Anemia Center is involved in several national and regional clinical research projects. The Center includes pediatric hematologists, social workers, and child life specialists, amongst other professionals dedicated to assisting members of this population. The center provides services to patients and their families such as: counseling and prenatal diagnostic testing, comprehensive patient and family education, psychological counseling and guidance, pain management education, bone marrow transplantation, hydroxyurea management, and comprehensive outpatient education. With the permission of The Sickle Cell Anemia Center (SCAC) at the Angie Fowler Adolescent & Young Adult Cancer Institute at University Hospitals Rainbow Babies & Children’s Hospital, recruitment letters and fliers were distributed throughout the site in order to obtain research participants. In addition, to this, the researcher discussed the proposed
research study with the present clinical director of the SCAC, Dr. Connie Piccone, MD. Recruitment for participants continued until six participants were identified as individuals who met the criteria for the proposed research study.

**Research Participants**

A purposive sample of six primary caregivers, specifically mothers of African descent, was recruited through the SCAC via recruitment letters and fliers (see Table 2). In looking at the literature, SCD caregiving challenges are exacerbated for mothers who endure most of the caregiving responsibilities and emotional stress (Atkin & Ahmad, 2000; Hill & Zimmerman, 1995; Olley, Brieger, & Olley, 1997), and have the highest prevalence of SCD among those of African descent. The researcher created a Demographics Questionnaire (Appendix A) in order to gather information regarding the relationship status, employment background, level of education, income, and number of children with SCD in the household. The criteria for inclusion in this study were as follows: (a) must be of African descent and/or identify as African American; (b) identify as a female; (c) at least 21 years of age; and (d) identify as the primary caregiver for a child with SCD (HbSS, HbSC, HbS beta thalassemia, HbSD, HbSE, or HbSO). A sample size of six was the best fit for the phenomenological approach. Dahl and Boss (2005) believed that the main purpose of the small sample size aids in the accuracy and understanding of the meanings and establishment of possibilities, rather than generalization of findings. The researcher thus gains more insight into human behavior, rather than focusing on the numbers, which may not tell the entire story. So, therefore, randomness is less important to the phenomenologist researcher than to a positivist.
Table 2. Demographic summary of participants

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age</th>
<th>Race</th>
<th>Highest Degree</th>
<th>Relationship Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zoey</td>
<td>Female</td>
<td>46</td>
<td>African-American</td>
<td>Some College</td>
<td>Married</td>
</tr>
<tr>
<td>Brooke</td>
<td>Female</td>
<td>36</td>
<td>African-American</td>
<td>High School or Equivalent</td>
<td>Single</td>
</tr>
<tr>
<td>Charlotte</td>
<td>Female</td>
<td>43</td>
<td>African-American</td>
<td>Masters Degree</td>
<td>Married</td>
</tr>
<tr>
<td>Faith</td>
<td>Female</td>
<td>29</td>
<td>African-American</td>
<td>High School or Equivalent</td>
<td>Single</td>
</tr>
<tr>
<td>Melissa</td>
<td>Female</td>
<td>31</td>
<td>African-American</td>
<td>High School or Equivalent</td>
<td>Single</td>
</tr>
<tr>
<td>Diana</td>
<td>Female</td>
<td>28</td>
<td>African-American</td>
<td>Vocational/Technical School</td>
<td>Single</td>
</tr>
</tbody>
</table>

**Data Collection and Interview Process**

The phenomenological methodology consists of gathering deep information and perceptions through qualitative methods utilizing multiple interviews (Creswell, 2013). In order to elicit rich, descriptive responses from participants, the long method was utilized. The long interview method was mainly an informal and interactive process that used open-ended comments and questions to foster response and allow flexibility. The
foundation of phenomenological interviewing allows for flexibility, and provides an open environment for the participants to freely discuss the topic at hand. A semi-structured interview protocol was used as the primary source of data collection. The researcher chose this format to create a comfortable atmosphere for the participants to discuss in depth the particular lived experience or moment of awareness or impactful event, and then to describe it fully. Interview questions explored the challenges primary caregivers may have experienced, how the primary caregivers coped with the event while caring for the child, and perceptions of the disease via the healthcare system (medical services). Interview questions delved into the lived experiences and impact that a chronic illness can have on the well being of a primary caregiver (see Appendix B). Probing questions and clarifiers were used to stimulate more information. The semi-structured interviews lasted from 1 to 2 hours. Approximately two interviews were conducted, the initial interview and the follow up interview. The follow up interview with participants was conducted in order to share the information gathered during the first interview and for clarification on any information elicited. Interviews were conducted in person and digitally recorded. The overall goal of the interview process was for the participants to talk in-depth about their lived experiences as a primary caregiver of a child with SCD.

Data Analysis

Dahl and Boss (2005) stated that the main purpose of analysis in phenomenological research “is not to tie all loose ends together, but rather to describe and understand the experience of the participants” (p. 74). The researcher utilized the following steps to analyze the data: (1) bracketing the topic; (2) delimiting units of
meanings; (3) clustering units of meaning into themes; (4) compiling individual textual and structural descriptions (interviews); and (5) extracting themes from descriptions and creating a composite summary of meanings and essences of the phenomenon. Bracketing involves introspection in order to develop self-awareness thus eliminating any personal biases the researcher may have regarding the phenomenon. As the sole researcher of this study, it was vitally important for me to be self-aware of how my own biases may play a role in how the information was perceived. A significant marker of this analysis was the researcher’s continued effort to remain connected to the experience of the participants without taking away from their experience. This involved checking in with the participants at various intersections of this research during data collection, analysis, and the reporting process.

Following this interview process, the researcher developed a list of significant statements, meaning units/themes, derived from the interviews, eventually compiling a list of nonrepetitive, nonoverlapping statements. In order to appropriately define the meanings within the interviews, the researcher immersed in the data to observe and define said meanings. The researcher was able to do this by listening, being open to feelings, and being aware of any potential apprehensions and emotions conveyed by the participants at the time. Organization of the data began once the researcher sorted through the material diligently, examining and isolating meanings from a phenomenal analysis perspective. This procedure includes “horizontalizing the data and regarding every horizon or statement relevant to the topic and questions as having equal value” (Moustakas, 1994, p. 118). Horizontalization refers to sorting through the interview
transcripts and highlighting significant statements, sentences, or quotes that provide an understanding of how the participants experience the phenomenon (Moustakas, 1994).

From this process, the meaning units were listed, and then clustered into common categories or themes. The clustered themes and meanings were then used to develop the significant themes of the phenomenon. From these significant themes, descriptions and integration of the essences of the phenomenon were constructed (textual descriptions). Textual descriptions included verbatim examples from the participants. Next, the researcher compiled the individual textual descriptions and structural descriptions. Structural descriptions describe how the experience happened, in which the researcher prompted the participant to reflect on the setting and context in which the phenomenon was experienced.

The themes that were extracted were then compared to the research questions in an effort to determine if there were any parallels. Any information that was considered repetitive or unrelated was eliminated. Composite descriptions incorporated both the textual and structural descriptions. This is the “essence” of the experience, which described the “what” and the “how” the participants experienced the phenomenon. The several themes extracted highlighted the essence of the participants’ lives while caring for a child who is chronically ill, specifically a child with SCD. Participants were afforded the opportunity to provide input into the meaning being constructed by the researcher. Lastly, the themes were given to the participants for review in order to validate the findings, to make any corrections needed, and for feedback in the final description.
Ethical Considerations

In conducting qualitative research, it is important to discuss the ethical components within phenomenological research. It was reasonable to assume that with the following research study, participants were going to disclose information about sensitive issues. Two broad categories of ethical concerns that are important for phenomenological research are informed consent and establishment of risk-benefit equation (LaRossa, Bennett, & Gelles, 1981). Informed consent and confidentiality were highly essential to both the researcher and participant. It is a common misconception that ethical issues only occur during the data collection phase. Ethical issues can essentially occur during any phase in the research process while “conducting the study, at the beginning of the study, during data collection, in data analysis, and in reporting the data” (Creswell, p. 56, 2013). Therefore, according to Weis and Fine (2000), the researcher must consider the following:

(1) Ethical considerations involving our roles as insiders/outsiders to the participants; (2) assessing issues that we may be fearful of disclosing; (3) establishing supportive, respectful relationships without stereotyping and using labels that participants do not embrace; (4) acknowledging whose voices will be represented in our final study; (5) and writing ourselves into the study by reflecting on who we are and the people we study. (p. 56)

In order to address potential ethical issues with consent, the researcher explained the participants’ rights, both in the initial contact and with an informed consent document at the time of the data collection. In addition, in an effort to garner support and trust of the participants, the researcher explained the general scope of the present research study, the purpose of the study, and provided participants with a copy of the semi-structured
interview. It is important to note that in order to protect the confidentiality of all the research participants, specific genogram created during interviews will not be provided. As the main researcher, it was vitally important to develop rapport, and be supportive as well as empathic throughout the interviews in order to alleviate any discomfort. In addition, with phenomenological research, the researcher and participant get to know each other more closely than with positivist research, therefore the researcher discussed confidentiality in depth and asked the participants whether or not they agree with the plan for maintaining confidentiality. Participants want assurance that all identifying information will be kept private. Therefore, in the study, participants’ names and any subsequent identifying information were changed in order to protect identities. Using pseudonyms, changing demographic details, and permitting participants the right to withdraw at any time during this research can provide some protection from exposure (Dahl & Boss, 2005). Due to the amount of information recorded, genograms not attached to assure the participants’ confidentiality.

Documentation such as interview recordings, notes, transcripts, and genograms were kept in secured storage as well.

**Trustworthiness**

Traditional aspects of reliability and validity in phenomenological research are conveyed differently. Phenomenological research must be evaluated by the concept of “adequacy” (McLain & Weigert, 1979; Schutz, 1962). Dahl and Boss (2005) believed that readers “must see in the descriptions of the data the validity and applicability of any concepts presented by the researcher, and participants must also agree that the analysis is an accurate reflection of their perceptions” (p. 79). In order to establish this
trustworthiness, Lincoln and Guba (1985) utilized the terms credibility, authenticity, transferability, dependability, and confirmability. To foster this kind of credibility, participants were asked at the time of data collection whether they would be willing to be contacted and subsequently to clarify meanings and findings. Member checking or soliciting the participants’ views of the credibility of the findings and interpretations added to the accuracy of the data. To further validate and determine the credibility of the information provided and whether it matches reality, the researcher involved multiple investigators and different sources during the analysis process to provide corroborating evidence of the phenomena. This process, triangulation of data sources, refers to the use of multiple methods or data sources in developing a comprehensive understanding of the phenomena (Patton, 1999). Triangulation was used to improve the trustworthiness of the research and evaluation of findings. To make the study transferable between the researcher and the participants, thick structural/textual descriptions were provided. Confirmability rather than objectivity is essential during this process in establishing the value of the data as well. Thus, confirmability and dependability were established through auditing of the research process. An external audit was conducted in this research study meaning an unbiased person(s) other than the researcher reviewed the study and provided critical feedback. This provided further verification that the study was relatively free from the biases of the researcher.

**Summary**

The research focused on primary caregivers caring for a child with SCD is minimal, while the literature on utilizing family therapy and a systemic approach is lacking. This research sought to explore the personal accounts of several primary
caregivers from a systemic perspective, specifically an intergenerational lens. The research questions focused on (a) lived experiences of the primary caregiver; (b) lived experiences of the primary caregiver in regards to medical services; and (c) parallels in caregiving behaviors across generation. The researcher’s purpose was to gain knowledge of these key aspects and understand the lived experiences of primary caregivers within this research area from a family therapist lens. To address these questions, the researcher utilized a qualitative framework, specifically phenomenological method to interview several primary caregivers who have experienced this phenomenon.

In following the phenomenological method, the researcher utilized semi-structured interviews with each of the participants. The researcher extracted common themes amongst these rich descriptions of the phenomenon experienced by the primary caregivers. These themes were then clustered to create significant meanings of the phenomenon. Themes were also compared to the research questions in order to determine if there were any similarities. These themes were given to the participants for review and to make any modifications necessary. To maintain the quality of this study, the researcher employed several techniques to maintain the confidentiality and trustworthiness of the study.
CHAPTER IV

RESULTS

The goal of this research study was to explore the lived experiences of several primary caregivers who are providing care to a chronically ill child with SCD. In addition, the researcher also explored how caregiving behaviors might be passed on across generations through an intergenerational family therapy lens, as well as possible challenges encountered as an African-American caregiver of a child with SCD. The study also aimed to identify the lived experiences of these caregivers that current literature inadequately addressed within the context of psychological and emotional well being of said primary caregiver.

Review of Research Questions

The following research questions were designed to provide a better understanding of the lives of primary caregivers caring for a child with SCD: (1) What is the lived experience of the primary caregiver of a child with SCD? (2) What is the lived experience of primary caregivers of a child with SCD specifically regarding child’s medical services? and (3) What are the parallels in caregiving behaviors between caregivers of a child with SCD and the caregiving behaviors of past generation caregivers?
The Participants

This qualitative study consisted of six research participants (Table 2, Chapter III). All participants fit the criteria for the study: (a) of African descent and/or identified as African American; (b) identified as a female; (c) at least 21 years of age; and (d) identified as the primary caregiver for a child with SCD (HbSS, HbSC, HbS beta thalassemia, HbSD, HbSE, or HbSO). A phenomenological approach was applied in order to capture the rich experiences and phenomenon of these six primary caregivers who identified as the main caregiver for a child with sickle cell disease (SCD). A semi-structured interview protocol was used to interview each participant (see Appendix B). Each participant’s name and identifying information was altered in order to maintain and protect identities. Pseudonyms for each research participant were used and demographic information was removed as well. All of the participants are African-American females ranging in age from 28 to 46 years old. Of the six research participants, two are married and the remaining four are single. Pertaining to education and highest degree, one participant reports some college, three participants report a high school/equivalent, one participant reports a master’s degree, and one participant reports vocational/technical school.

Participant One: Zoey

Zoey is a 46-year-old African-American female. She is married and has a household income of $10,000 to $20,000. Zoey reported her highest degree as some college, however, she did not specify an occupation. She is the caregiver of seven children (4 biological children, 3 adopted) in her home ranging from ages 9 years old to 20 years old. Zoey identified as the primary caregiver of her 10-year-old son who has
HbSS type of SCD. Her 10-year-old son also has Attention Deficit Hyperactivity Disorder, asthma, and a heart murmur. He is on several medications such as Tylenol 3 and Albuterol. His last SCD related hospitalization occurred in February and November of 2015. He usually experiences one to two SCD related pain crises in a year. Due to SCD related complications, he has missed 10 days of school in the past school year, causing her to miss 10 days of work.

Zoey’s genogram displayed an interesting pattern that showed the SCD gene skipping a generation, as well as a family history of lupus. She reported that she carries the SCT gene and her mother and father do not carry the gene at all. Zoey’s maternal grandmother has sickle cell trait (SCT) and her maternal grandfather had SCD. She reported that her maternal grandmother was the caretaker of her maternal grandfather. Zoey reported that SCD was not discussed among the family until her grandmother mentioned it before she passed away. She admitted that she knew very little of the actual disease until her son “had his first really major attack.”

**Participant Two: Brooke**

Brooke is a 36-year-old African-American female. She is single and has a household income of $20,000 to $30,000. Brooke’s highest degree obtained is a high school/equivalent, however, she did not specify an occupation. Brooke’s household consists of five children under the age of 16, as well as six adults. Brooke is the primary caregiver of her 9-year-old daughter, who has the HbSC type of SCD. Her 9-year-old does not present with any other chronic illnesses or medical conditions. Brooke’s daughter does not take any medications at the time, only multivitamins. She experienced her first pain crises at 5 months old and received her first blood transfusion at 7 years
old. She has not had any recent SCD related hospitalizations or pain crisis in the past 2 years. Her only major complication within the past 2 years has been a fever.

Brooke’s family genogram displayed several family members who carry the SCT. Brooke is a carrier of the SCT as well as her daughter’s father, which resulted in an HbSC diagnosis for her child. Brooke also has three other children who are carriers of the SCT. On the maternal side of the family, Brooke’s mother is a carrier of the trait, as well as her grandfather. Brooke reported that a cousin on her father’s side has SCD, but she “never knew much about the disease until I had to deal with it myself.” Brooke expressed being able to cope with her child’s SCD in a more positive way because her child “has not been sick in a while.”

Participant Three: Charlotte

Charlotte is a 43-year-old African-American female. She is married and has a household income of $90,000 and above. Charlotte reports a master’s degree as her highest level of education and currently works as a visual arts teacher. She has also been diagnosed with depression, which she describes as “situational depression.” Charlotte is the caretaker of three children under the age of 14 and has two other adults living in the household (her husband and her mother). Charlotte identifies as the primary caregiver of her 14-year-old son, who has the HbSS type of SCD. Her son has asthma and was diagnosed with anxiety. Charlotte reported that he is also on several medications such as Hydroxyurea, Naproxen, Oxycodone, Advar, Albuterol, Coratidine, Jadenu, and medication for bedwetting. His last hospitalization was August 2016. In one year he could experience 10 to 12 SCD related pain crises. He also experienced major complications related to SCD such as acute chest syndrome. Due to illness, he has
missed at least 10 to 15 days of school, while Charlotte missed at least 5 days of work in the past year.

Charlotte’s genogram revealed a history of SCT among the family. Her genogram consisted of various family members with SCT including herself, her husband, and her daughter. On the maternal side of the family, Charlotte’s father had SCT. On the paternal side of the family, Charlotte’s father-in-law had SCT as well. Charlotte shared an interesting story of how the family, including her father, did not know her father had SCT until he had passed away. Her son experienced his first SCD pain crisis at 6 weeks old. She reported learning how to care for her son by observing her mother’s caregiving behaviors and from the neighborhood church. Charlotte reported having family support, familial interconnectedness, and her faith as a way to cope with her son’s illness.

**Participant Four: Faith**

Faith is a 29-year-old African-American female. She is single and has a household income of $10,000. Faith’s highest level of education is high school/equivalent. She is working as temporary hospital staff. She was diagnosed with a chronic medical condition, asthma as well as Bipolar Disorder (at the age of 16), depression, anxiety, and Posttraumatic Stress Disorder. She is the primary caregiver for her daughter, who has the HbSS type of SCD. Her daughter also has asthma and a heart murmur. Due to SCD, her daughter is on several medications including Amoxicillin, Hydroxyurea, Ibuprofen, Flovent, and multivitamins. Her last SCD related hospitalization was in February 2016. She has also experienced pneumonia as a major
complication related to the disease. Her daughter has not received a blood transfusion since 2015.

Faith’s genogram showed several family members with SCT. Faith has SCT as does the father of her child, Faith’s mother, and her grandmother. The paternal grandfather of Faith’s daughter is also the carrier of the trait. Faith reported finding out that her significant other had SCT from his family only after she had gotten pregnant. Her daughter was diagnosed with SCD at less than 1 months old. Faith reported family members “not really talking about it [SCD].” Faith expressed a lack of support from family and from her significant other, who is currently in prison for 5 years.

**Participant Five: Melissa**

Melissa is a 31-year-old African-American female. She is single and has a household income of $10,000. Melissa is presently working on obtaining a GED; however, she did not specify an occupation. Melissa was diagnosed with a chronic medical condition, Crohn’s disease. She is the caregiver of four children ranging from ages 7 to 12 years old. She identifies as a primary caregiver of her 10-year-old son with the HbSS type of SCD. Her 10-year-old son also has asthma and on several medications like Amoxicillin, Hydroxyurea, Ibuprofen, Jadenu, and multivitamins. Melissa reported that her son “is old enough now to be responsible for taking his medication.” His last SCD related hospitalization was 11 months ago from his last clinic visit in August 2016. Melissa reported that her son experienced about four or more SCD pain related crises in a year. He has experienced acute chest syndrome as a major complication of the disease for the last 2 years according to Melissa. He has missed 12 days of school in the past year due to SCD symptoms.
Melissa’s genogram shed light on her family history of SCT and SCD. Melissa’s father had SCD, which was later revealed to the family and his employers only after he had fallen ill while enlisted in the army. Her father was honorably discharged due to his SCD condition. Melissa is a carrier of the trait, as are two other children in the household. Her son’s father is also a carrier of the trait and his father as well. Her son was “sick quite often as a child, at least for the first 1.5 years of his life.” According to Melissa, he was first diagnosed at birth when he was born with jaundice.

Participant Six: Diana

Diana is a 28-year-old African-American female. She is single and the highest level of education is vocational/technical school (2 years). She is employed as an environmental services worker. She did not specify a household income. She is the caregiver of two children, ages 9 and 11 years old. One other adult lives in the household. She identified as the primary caregiver of her 9-year-old son who has SCD, but did not specify the type. He is currently on various medications such as Amoxicillin, Hydroxyurea, and Exjade. His last SCD related hospitalization occurred about a year ago, in October of 2015. He experienced a stroke at the age of 2, which is directly related to his SCD diagnosis. He also receives blood transfusion every 4-5 weeks, in which Diana misses “a hand full [sic] of work.” Diana reported that he has not had any major complications since the age of 2.

Diana’s genogram highlighted a family history of SCT. SCT was dominant among the maternal side Diana’s family. Diana has SCT as well as her other child, her mother, grandmother, and great grandmother, whereas on the paternal side of the family, Diana’s father-in-law has the trait. There is one family member that Diana knows of on
her paternal side that has SCD. Diana reports that SCD was discussed among family members as early as the age of 9 years old. Diana’s son was born with jaundice and was diagnosed with SCD at birth.

Themes

The lived experiences of African American women who identified as the primary caregiver to a child with SCD was collected from semi-structured interviews and focused genograms. The following core themes were extracted from personal accounts: (1) daily primary caregiver tasks; (2) primary caregiver challenges: cognitive coping strategies and emotional coping strategies; (3) knowledge and family history of SCT/SCD; (4) experiences with the health care system; (5) societal perceptions of SCD, and (6) initial reaction to the diagnosis of SCD.

Daily Primary Caregiver Tasks

In order to gain a better understanding of the lived experiences of the primary caregivers, the researcher posed the following questions: Who is the primary caregiver and what does caregiving involve on a day-to-day basis? With these questions, the first theme was developed, daily primary caregiver tasks, in which primary caregivers attempted to understand how to meet the needs of their child. The results of this study showed that all of the primary caregivers possessed an increased sense of awareness when caring for their child with SCD. The onset of a vaso-occlusive pain episode can occur at any given time and may last indefinitely (Pack-Mabien & Haynes, 2009). Hence, several of the primary caregivers expressed a “learn as you go” philosophy on how to care for their child with SCD on a day-to-day basis in order to decrease the
possibility of a pain episode. Diana reported on what her lived experience was like
caring for her son as follows:

Yeah, he has chronic pains. It’s just a whole learning experience. You learn as
you go. Watching him go through his days, his bad days, you look out for that
and try to pay more attention to [son] but [son] hasn’t had any chronic episodes
since discharge, which I’m thankful for…Day to day basis, it’s like I’m aware of
it but due to him having his transfusion, it’s like he really doesn’t have it. The
only thing that’s a constant reminder is that he has to take his medicine. He’s a
normal kid at home. We haven’t had any problems since he was 2.

Diana also spoke on the importance of being more knowledgeable than the average
person about the disease because she must make major decisions on her child’s behalf:

Being a caregiver is actually something that you really have to be real educated
about because you might like that they have a treatment where I guess if you
have full blooded sibling, they could get the bone marrow transplant. For me,
that decision, the decisions that have worked, saying what would be best for your
child is really a complicated situation to be in because if you make the wrong
decision, it falls on you … I still wouldn’t do the blood marrow transplant
because if his body was to reject it and something was to happen, I would feel
really responsible for it and I would be on a real guilt trip. It’s really tough to be
a caregiver for a sickle cell patient because you’re making a decision for them.
It’s not like they can really speak. It’s a real hard place to be.

Two primary caregivers also described their daily caregiving tasks as having to monitor
their child’s daily hydration and nutrition. One participant described her caregiving
responsibilities and numerous roles and tasks she must take on when her child is sick.

Charlotte stated:

Making sure that he’s taking his medicine. Making sure he’s hydrated. Making
sure that he’s telling us about how he’s feeling. His nutrition, and a lot of me
looking at him because he doesn’t really talk. It’s a lot of observing him to say
“How are you today?” Making sure he gets the rest that he needs. I guess that’s
it.

Zoey reported:
We want to start when we get out of the bed. I have to dress him in the morning because he, “I can’t get up, I’m so lazy” to me having to help him ... Girl, when his legs hurt, I got to massage him, I got to run the bath water, I got to give him the hot rags when his stomach is cramping, I got to give him the juice. I mean the whole nine yards ... This is how they be, and I be like “Okay.” I’m basically mom, dad, sister, brother, comforter, best friend, doctor, lawyer, teacher ... I’m basically all of that when it comes to him because he demands it.
The unpredictability of the disease caused primary caregivers to have a heightened sense of attentiveness and be more in tune with their child’s needs. Melissa vividly described this phenomenon of the disease that can occur at any time due to dehydration, stress, or a change in the weather. Melissa stated:

In the summertime I have central air, in the summertime I really don’t turn it up real cold because I know [son] cannot stand the, being too cold. I turn my heat all the way up in the wintertime, I try to keep it at a comfortable level all year round which is a really hard task, but I try. I keep pain medicine. I have ice packs, heating pads. I try to keep little pillows, little knick knack foods, stuff that I know he likes that’s quick and easy, sometimes he gets in this mood where he don’t want to eat dinner now I don’t really know what that has to do with it. The main thing is dealing with the pain and the changing weather. It seems like every year especially the last two years, he’s been in hospital for acute chest syndrome. When the weather gets to changing he always got, even on Thanksgiving or the day before Thanksgiving it’s been like this for the last two years. I don’t know what it is. The only thing that I can think of is the change or the weather gets to him and instead of [son], I tell him, “Keep your jacket on, keep yourself zipped up, put your hood on your head.” He running and playing, he wants to take it off and run and play, “No, you’re going to get sick.” He just a kid, he wants to be like my other son who is healthy, he have not type of medical issues, no problems, no nothing. He trying to keep up with him and I have to tell [son] you not, that’s, “You’re not him, that’s your brother but you have sickle cell, he don’t. You cannot do everything that he do.” [Son] want to play football. Cannot play football but my youngest son do. The coach did give him a spot on the team to give them they water bottles, at the practice [son] gets to blow the whistles, still to make him feel like he a part of the team because I told him, I said, “I really don’t want you to play favorites, but I do understand that he cannot play. It kinda makes me sad because I feel like I take away from him and he sometime make me feel bad, being frustrated with sickle cell disease, he make me feel like I’m being mean to him when in the end I’m really not doing nothing but trying to look out for him.
In reviewing the daily caregiving tasks for each participant, four of the six primary caregivers discussed similar techniques, such as monitoring everyday behavior, medication management, and researching SCD as ways to provide the appropriate care to their child and manage the disease. A “learn as you go” philosophy was employed due to several factors, which will be discussed in the subsequent themes extracted.

**Primary Caregiver Challenges**

The researcher previously examined caregiver stress, which can be defined as the high levels of stress a caregiver may experience while caring for their chronically ill child (Lim & Zebrack, 2000). Han and Haley (1999) touched on the emotional and physical well being of the primary caregiver in relation to the chronically ill child’s positive health and rehabilitation. A primary caregiver’s overall health can potentially influence the well being of their child. The second theme emerged from asking several probing questions about the caregiver’s daily management of the disease, particularly when their child is ill. These responses showed several challenges experienced by the primary caregiver, as well as the cognitive and emotional strategies utilized in order to cope with the situation.

**Cognitive coping strategies.** One participant processed how caring for a chronically ill child with SCD shaped her life as well as the life of the entire family. Charlotte expressed some of the challenges she faced as a caregiver:

Whether you’re planning vacations, trying to plan around his transfusion, and making sure there’s a hospital nearby that you know of. When I go to work, now that he ... I’m a teacher, and he went to the school where I teach, so that made my days easier because he was with me. Now, he’s in high school, away from me, and that’s another reason why I’m feeling emotional right now because I’m not able to hover over him.
Charlotte discussed using her faith as a coping mechanism to deal with the challenges of caring for a chronically ill child with SCD.

First, we have a strong faith. We’re a Christian family, and that’s generational as well. That’s my first thing to go to…the whole family was very supportive. We all very prayerful. We really stood on our faith. A lot of people praying for me as well as I dealt with it.”

One primary caregiver explained how she managed her son’s pain episodes as they occur, almost as if she is on “autopilot” in order to cope. Zoey stated:

That’s when you got to break out the heating pads. That’s when you got to learn massage techniques to get the bones from not stiffening up because they will stiffen, and you can feel them getting hard. I’ll get him his medicine. He can’t be in a cold environment. If they get too cold, they cramp. I try to keep him warm. I try to keep extra blankets on his bed even if it’s summer time. I have to tell him put on socks and shoes. Other than that it’s basically a heat pad, a lot of warm things to drink, a lot of massages, and a lot of comforting, like “I want you to hold me, Mommy. It will make it go away.

Another participant expressed being very cautious with future generations of children and how to explain the disease to her child. Faith disclosed not wanting to pass the gene of SCD onto her grandchildren due to the complexity and stress of the disease. Faith stated:

Learning, following through keep me on my Ps and Qs, especially for the next child to come along. Very cautious. Like I said before, I have to basically focus on me. Like I said, nobody is really talking about it. Nobody knows too much about it, and the only way you really know about it is if the child happens to get sick. I already know that when push come to shove, time come with her, I have to sit down and talk to her. “You have a full disease. Anybody you come entwine with ... You going to have to be careful, baby. You bound to give the next child, the child that you have, my grandkids sickle cell, too.” I’d prefer they not to have it, because it is a lot of stress. It’s lot of hassle, going back and forth from the doctors and all this extra stuff for a disease. Not saying it’s not nothing, but it’s just, “Really, like sickle cell out of all things?” It’s crazy. It’s too much.

Due to the unpredictability of SCD, a caregiver might feel a loss of control over their surroundings. One primary caregiver delved into how she took control of a
situations when she believed that her child had not been receiving appropriate treatment.

Melissa reported:

Sometimes I feel like he a human experiment and that makes me mad. I know that they trying to do the best they can to keep my son here and everything so I try not to complain about it, but yeah, sometimes I do feel like he is a human experiment and I have to tell them like, “That’s enough, that’s it. Ain’t no more testing,” and that’s what led to him getting a port because he was getting monthly blood transfusions and he didn’t have a port. One time for some reason, he was a hard stick. They went everywhere to try to find. They poked my baby twelve times. That twelfth time, I was like, “He ain’t getting no blood transfusion today. I’m a take him home, hydrate him, let him rest today. Then we will come back up here and then we can try again, but that’s it. Y’all done poked him enough in one day for two, three days.” For a while he was really traumatized and did not want to come because he was scared of getting poked…He hasn’t been sick which really has been good because when he was a baby, I was at my wits end. I’m tired of this disease. It’s like he was in hospital every month for his whole first and a half-year of life. I told them well, “You all might as well make me an apartment because I’m be back here anyway.

**Emotional coping strategies.** Some of the primary caregivers, four out of six participants, were somewhat hesitant to discuss the effects of caring for a chronically ill child with SCD on their emotional/psychological health. One participant focused on her strengths during challenging times as a way to help her son who was experiencing a pain crisis at the time. Zoey said:

Don’t let you see you break down. Let them see you being strong about it, and then they’ll take it to be strong about it. But you can’t get a lot of [inaudible] cry so bad and I be looking at him like “Baby it’s going to be all right”. Don’t let them see you cry. Come out the room. Come out the room and shed your tears and then go back in there like, “what’s up my soldier?” This whole thing is just patience. A lot of running back and forth to the hospital. A lot of taking time off. The child is here. You have to deal with the disease on your own. A way for you to deal with the disease is for you to take it in strength. Put yourself in that child’s position. You know what I’m saying? If this was me, and I was in pain, what would I want people to do for me? You know what I mean? You establish that with your child.
As discussed by Moskowitz (2007) study, depressive symptoms were higher in caregivers of children with SCD than caregivers of children with HIV. This factor is specifically connected to the amount of crises care for these caregivers. One out of the six participants provided very detailed information on her psychological well being. She reported living a stressful life in which SCD was the primary focus. Charlotte stated:

Stressful. It’s really, really, really stressful. Emotional. I think I probably, at least while it’s going on, I numb myself just to make sure I’m good to keep calm so that he keeps calm. I don’t let myself feel the weight of it. Sometimes I do after. Once he settles down, and he’s good. If it happens like back to back, like if we just had something we got through. Last week, a couple days ago, and it comes back. Sometimes that makes me more emotional and less calm. But never in front of him, so I just try to keep it together. I just go through the emotions of what I need to do. Especially now, as he’s gotten older, doing this for years, I just put all that stuff aside. All that emotional stuff and stress, and let’s go. We just need to dig in, and do what we need to do to get him better or where he needs to go. Or whatever.

Charlotte also spoke on detaching herself from the stressful ordeal of watching her child have a pain crisis. Charlotte reported:

I just push it down. I don’t think about it. I just think of him only, and if I have only thoughts of me that come into that, I just push them away so I can deal with this. I sort of detach myself from the situation that’s mom, and I just go caregiver. What do we need to do to get you better. I hover a lot. I’ve gotten better with that. But I hover over him. If he’s having a pain crisis, and he’s super uncomfortable. I stay in the room where he is. If not next to him, and I stare at him. “What’s your number now? How you’re feeling now? Did it get any better yet?” I would do that, or I would sort of like walk back and forth past him and observe how he’s doing to see if I could see any improvement. So I won’t keep bothering him. I do. I tend to hover. But even in the midst of that, I’ll take some time to just go away, and compose myself, and go back in.

She went on to express a desire to connect with other caregivers in an effort to cope with the psychological effects of caring for a chronically ill child with SCD.

I think just meeting, I think parents would really just need support, and more so than just a therapy sort of thing, just other people who understand because I think he feels like he’s the only one dealing with sickle cell in his circle. And, I feel
like I’m the only parent in the world, even though we know that’s not true. I think having connecting to other people would probably help families deal with it to say “Hey, I’m not by myself.” You don’t have to explain to other people how you’re feeling. They just would understand what the weight of it is. It really is a life-consuming sort of thing.

In reviewing the dynamic responses to how a caregiver coped with caring for a chronically ill child with SCD, these caregivers may have in a sense neglected their own well-being in order to put the well-being and life of their child first. Caregivers may benefit from being able to connect with other caregivers who can understand the emotional, physical, and psychological stressors brought on by SCD.

**Knowledge and Family History of SCT/SCD**

The third theme that emerged from this study was the knowledge and family history of SCT and SCD. The focused genogram was essential at this stage in order to explore the family history of the trait and the disease. Pack-Mabien and Haynes (2009) stressed the importance of genetic counseling for individuals with SCT in the family planning stages. Individuals are often unaware of their status until their newborn is tested and has either the trait or the disease (Pack-Mabien & Haynes, 2009). A few of the participants reported being unaware as to whether or not they were carriers of the trait. An underlying theme of lack of familial communication regarding SCT and SCD was revealed in their responses.

The researcher was able to extract this theme by asking the following questions: Who in your family has SCD, who are the carriers of the trait, and was there any family discussion about SCT? When discussing the family history and possible carriers of the trait or disease, three of the participants eluded to lack of knowledge from that of the previous generation or a simple understanding of the disease itself. Charlotte stated:
We didn’t even find out ... I think we didn’t. I knew I got it from somewhere, but my father didn’t ... My father passed before we found out that he had it. He didn’t even know he had it. But we had assumed, but he kept saying that he didn’t. My mother was pretty sure she didn’t. It was kind of this thing where “She got it from somewhere, and she’s okay, we won’t worry about it.” My mother mentioned to me a couple of times to be careful only because that’s what the doctors told her. But it wasn’t like a big discussion of really the seriousness of it. I don’t even think they thought to tell me.

Charlotte elaborated more on the subject matter:

His oldest sister, she was still alive, and she mentioned it. But he didn’t know himself. We were just talking in passing, and she just sort of mentioned something about it after he passed. She said something like “I wonder if it had something to do with that kind of trait he had.” I was like “What trait did he have?” She said “something about sickle cell or something. Something they said the kids had when they were little.” That was it. We just went on like it wasn’t a thing. She just knew, and he never did. He was really sick in his later years, and it never came up in all of that. It’s very weird.

Similar to Charlotte’s experience, Faith explained the inner workings of how her family failed to communicate with each other about the trait and the disease. Faith stated:

Nobody really talks about ... Well, we do talk about it once we talk about [daughter] her situation, but as far as everybody sitting down on a conversation, So, who all got traits in the family?” We never really got it together, so we don’t know who all got what. I know I got to watch out for it, along with what I’m doing now...I think I found out about my trait when I was 16 or 17, 18 in job corps. I had blood work done or something, and they had told me about it is how I found out. I had to call my mother and ask her. She got to explain it to me, but I’m just now learning myself that I had the trait. That’s really where that went. Nobody never really explained who in the family or where, what, when, how. None of that.

Brooke reported having a “simple” understanding of the disease in which she reported:

No because that would have been, I didn’t, I mean, we knew something simple, we knew a little bit about the disease because I have a cousin. Because I have a younger cousin that has the full disease and he stayed in and out the hospital before, as we was little, as we was growing. Actually he’s still be in and out of hospital...
There was one participant who expressed having learned about the disease by happenstance because her biological father had SCD. While constructing the focused genogram, Melissa described how she was able to gather more information regarding the disease from an elder in her family. Melissa stated:

I would bring it up. I would say I wondered where did I get the trait from because I know that my mother didn’t have it and how it came out was, I was talking to my grandmother. I said, “Well I got the trait, my oldest daughter got the trait but [Dad] has the full sickle cell.” She said, “Well you know your father has sickle cell disease.” That’s how that came out.

Another participant also disclosed that she knew about the disease at the age of 9. She reported that her mother shared this information with her after unrelenting questioning. Diana explained, “Actually, yes. I was about 9 years old when my mother first told me that we carried the trait…Around the time when [daughter] had her episode, I was asking questions until she told me.” As the researcher continued to explore multiple generations of the trait and the disease amongst family members, some participants acknowledged to knowing very little about the disease until they had children. Charlotte stated:

It was more through my church. I had a few people in the church who had the actual disease, and they put together a couple of events where they sort of talked to us about the disease itself. I remember feeling sort of left out of the conversation because I had just the trait. I remember one time actually being told “This particular meeting is just for people who actually have sickle cell,” and so I don’t think I knew as much about it until I had a son with the disease. I didn’t know really how serious it was. I was told kind of “watch out” for who your partner would be. This is what the disease can do. I didn’t know that, so…Doctors when I was younger. But not a lot. It wasn’t like ... I just remember hearing it here and there. I think the most information I got was from my church. Even that it was more geared toward people who already had it, and not really the people who had the trait. “No, you’re okay, go.” I was saying it was probably more my doctors sort of mention it.

Faith also expounded on her initial response by stating:
We never really talked about which parents in the family, or grandparents, or cousins, but as before us had had it or anything like that, we never really sat down and talked about it. Like I said, I really didn’t know too much about it until after I got pregnant with her, and that’s when I started having to come back and forth to find out if she had it or not.

The results from this theme debunk the researcher’s hypothesis that caregiving behaviors were passed down from generation to the next through the multigenerational transmission process. At least three responses highlighted the lack of communication from generation to generation regarding family medical history. According to the participants, previous generations were unaware of family members who carried the trait for SCD or actually had the disease. Therefore, the “learn as you go” philosophy reemerged here.

**Experiences with the Health Care System**

As discussed earlier, SCD is present amongst primarily minority populations in the US. Research has shown that primary caregivers of a child with SCD not only have to cope with the unpredictability of the disease but also with social inequalities and systemic racism (Burnes, Antle, Williams, & Cook, 2008; Sterling, Peterson, & Weekes, 1997). Two studies, Tapper (1999) and Wailoo (2001), addressed how the factor of race had been invisibly linked to SCD since its recognition as a disease. Telfair, Myers, and Drezner (1998) urged the medical profession to consider the role racial bias may play in the delivery of services, availability of resources to families, and the improvement of care. The fourth theme, experiences with the health care system, emerged when the following questions were posed: What was your experience with health care regarding your child and do you perceive any marginalized care based on being African American?

One participant touched on this subject in depth as she explained an experience. At
certain points, Charlotte questioned what she had experienced and somewhat minimizes it. Charlotte stated:

I’ve never felt because we’re African-American that ... You know what, let me take that back. There are little tiny things, even here, where I guess their assumption is most of us low-income, or are on some sort of assistance. Now it’s been long enough that most of the people know our family, or know all the families here, and kind of know. There is, every now and then, something that will come up. Like, if there’s a change in medication or something. They’ll say something like ... I’ve heard just last year, and I was so surprised, I was like “I know you know we have insurance, right?” It was a medication. One of the nurses said something about “Oh, only patients with regular insurance can get this medicine.” I was like “He’s already on it.” “Oh, I’m surprised, you guys...” That’s what it was “It’s only patients with medical regular insurance so far can get the medicine.” I was like “We have regular insurance through our regular jobs.” It was sort of that thing. That kind of stuff comes up every now and then. Subtle like that, where whether it’s here or in the emergency, or some place else, something like that might come up. It just seems like that’s the first assumption. I don’t think they mean any harm, I think it’s just what they’re used to. I don’t know why that happens when they sort of make that assumption first. It comes out as without them realizing that’s what they’re saying, but I catch it because I’m like “Girl, what are you...” “Is there a problem with you guys getting ... do you have transportation?” We have cars. I don’t think they mean any harm, but when it comes out like “Well, we’re used to that being an issue.” If I call in the middle of night, and he’s having pain, “well, can you get to emergency. Do you have transportation? Are you able to drive there. We don’t need like a bus or a cab or something.” I just move on. If I had to say anything, it’s that. Feels like there’s always this assumption that most of the patients are having to receive some sort of assistance or very low-income.

A unique perspective that developed within this theme amongst some of the participants was the absence of marginalized care. Majority of the participants reported receiving exceptional care and felt supported by the medical professionals they encountered. This is in part due to the clinic specializing in the care and appropriate treatment of patients with SCD in that respective area of the community. Brooke reported:

No they treated me the same. No one ever treated me differently anything. They just come in here and they talk to me and they ask me, “Is everything okay?” If I
need anything. Actually I love it here. I don’t ever have a problem coming here. I
can call, like I said, there’s a issue I just call and they ... I have never had an issue
with anything. Despite color or anything. They treat every, from my
understanding they treat everybody the same. There’s never been a issue with
anything.

Similar to Brooke, Zoey, and Diana voiced the same sentiments regarding the
care they have both received for her children. Zoey stated:

Yes. I don’t even know if I had to choose one of the nurses, or one of the staff
members, I couldn’t. I couldn’t because all of them have been so open and warm
and ... I mean even the doctors that you meet on the floors that come and do they
rounds. They make you feel so at home. They’re going to make you feel
comfortable. They make sure that they sit down and talk to you about your son or
your daughter’s diagnosis. And if you don’t understand, then they’ll tell you,
“I’m doing my rounds right now, but if you give me maybe an hour or two hours
I come back and we can sit down personally. You can ask me whatever.” With
this being said, this really is a beautiful hospital. Nurses, doctors, staff,
housekeeping.

Melissa stated:

I mean for the most part he also, he’s getting everything that he needs. The
medicine come UPS, his PediaSure everything come UPS. I really don’t have no
issues and if I do I just call up on the phone. They fix it right away, but I hear
from older kids with sickle cell that once they turn 17, 18, that’s when the big
switching everything over, the ball gets dropped. I’m still going to be right there
with him like y’all did when he was a kid. Now that he’s grown we going to keep
the ball rolling because that’s critical for him, we don’t have time to play no
letting the ball drop games. Not know. I don’t think so, no.

Results from this theme were quite interesting. One response touched on the
assumption/microaggression that majority of individuals with SCD are of a lower
socioeconomic status, whereas the remaining participants reported not having
experienced any form of marginalized care at this particular facility. However, further
into the interviews with participants who reported no marginalized care at this particular
facility, it was revealed that they felt they did not receive adequate care from other medical facilities when their child was initially diagnosed.

**Societal Perceptions of SCD**

As detailed earlier, it is a common misconception that SCD only affects African Americans due to its initial recognition in people of West African ancestry (Serjeant, 1997). Toward the completion of the interview, the researcher inquired about any additional information that can be contributed to the study by the participants. This allowed the participants to more openly discuss their personal experiences with caring for a child with SCD if it was not examined in the previous questions. This led to the development of the fifth theme, which focused on the societal perceptions of SCD.

One participant described how she believed if SCD were not portrayed as “an African American disease” it would be more well known like other chronic illnesses. Melissa stated:

...about how it primarily effects African Americans? Because that’s not necessarily true. From what I understand, it’s not just African Americans; it can be some Arabs, certain Indians, so it’s not just a black people disease. It’s black, it’s brown, black brown however, you know what I’m saying. Don’t just label it as one specific race disease. It’s a disease just like diabetes, just like arthritis, just like Crohn’s, just like high blood pressure anything else that effect any race. Really don’t label it as African American and I honestly believe if that ever happened that way it might get more awareness out there like all the other diseases, because you don’t really see no commercials or know too much about sickle cell like you see and know about everything else. That’s just how I feel about it. Because it’s labeled for black people, it’s kind of under the rug. When it really don’t affect just black people…which is true, it’s primarily effect African Americans but the way that it sounds sometimes to me, sounds’ like it’s almost a prejudice. I could be overreacting.

Comparable to Melissa’s statement, Faith voiced these sentiments:
I do hope y’all do make a difference out here with this sickle cell situation and it gets to a lot of people, because a lot of people don’t know. They really don’t. They don’t know how to go about getting the help they need and everything…Everybody, especially African Americans across the world need to know, and they need to get tested to make sure.

Though some participants reported feeling comfortable with the care they have received at this specialized clinic for patients with SCD, on a larger scale, resources such as these provided by this clinic are scarce in highly populated African American communities.

**Initial Reaction to the Diagnosis of SCD**

In closing interviews with the participants, the researcher delved into the primary caregivers’ initial reactions to their child being diagnosed with SCD, which emerged as the last theme. Though the caregivers expressed a certain level of strength and resiliency over time, the researcher and participants acknowledged that it was not always like this. The final theme emerged after inquiring about their genuine feelings at the specific time of their child’s diagnosis. The final theme evoked true, raw emotions that all participants were more than willing to divulge. One participant, Brooke, spoke about feelings of helplessness at the time of her daughter’s diagnosis. Brooke stated:

> When I first found about [name] had sickle cell, [name] was three days old. I cried like a baby. Then, once all the doctors here, we got together and they talked. After actually talking to them, they made me feel a lot better. I still get the jitters every now and then because that’s being a mother in general. I didn’t know what to do. I felt helpless. I really didn’t know what to do. I was only 27 and I really didn’t know what do. All I know is she kept crying, she was in pain. I just didn’t know what to do. It was just really scary…

Two more participants gave detailed accounts of when they were first told that their child has SCD. It appears as if feelings of anxiety and sadness were present at the time of the diagnosis. Charlotte reported:
But finding out about it was devastating. He was six weeks old. He’s my first baby. After a year of celebration, we got married, big giant wedding, and then the baby. Everybody’s back at the shower, and everybody’s excited about this new baby. I’m excited. Then, he came. It took me some adjusting as a new mom, and around six weeks, I felt like “Oh, I think I got this. I got this thing.” Then, I got a call that he needed to be tested again because they thought maybe he might have that. We went in, and he was tested. They said “We think he has it, but it’s like a milder form or some sort of SC.” Whatever it is, he didn’t have it. As we came here to have him tested, and that’s what they found out it was SS. It was sort of this gradual devastation. It was “He has it, but maybe it’s not too bad” then it was “Oh yeah, he has full-blown, worst one.” That was devastating, and I went through probably months of just extreme anxiety. Helplessness, like this sort of state. The doctor was just being straight foreword. He said stuff like “He’s going to have a long, unhealthy life. He’ll die at a young age. He’ll have pain most of the time and sick.” I mean, I’m holding a baby. This little bitty baby. I’m still trying to process this, and that’s what he’s saying. It was awful. I think I was really very anxious the six months because they kept saying “He’s fine” for six months. For six months, I was just so worried about was going to happen at six months. That was part of my anxiety. I was just scared of everything. But then my baby decided to start having symptoms before six months, so he started having some pain and some swelling. That was devastating to see. Then, he was at the hospital several times for different things. I guess that was my initial reaction, and then as time went on, we just started to settle in to what it’s like.

Faith used the descriptive words “scared, nervous, and anxious” in regards to her feelings:

Everybody was destroyed. Don’t nobody know how to handle hearing that it’s a possibility that a child could die. Like I said, at the time I found out she was still a newborn. It was really like ... Scared, nervous, and anxious. More so scared and nervousness came with that, but I was anxious from wanting to hurry up and get her treated for the situation so it wouldn’t affect her in no other way. I was more so scared. That’s just something scary to hear, that your child got sickle cell. Sickle cell’s a life-threatening disease, and then they come out and say, “She has the worst sickle cell disease out here, SS.” She don’t have the regular sickle cell disease like most other kids. She has the worst one, SS. With that being said, to me it’s like, “Oh my god. At any time I could lose my child.” Don’t no mother want that, period. You don’t even want to think about it, let alone hear it, even if you [inaudible] about it, it’s like, “It’s not funny.” No matter how you take it, it’s just not a funny thing about losing your kid. That’s where the scared feelings were. Nervous. Nervous is more so with treatments. What we have to do here, what we got to do there, type of surgeries she may have in the future. All that stuff is like it goes back into being scared. It’s just scary. Anxious, like I said, I was just trying to make sure I got her everything she needed ahead of the game,
before it got too far and I’m burying my baby. I was more anxious, like I said, to get her treated and get all the medication she needed to make sure she was fine. My only worries is right now is the sickle cell and making sure her cold don’t affect nothing going on with the sickle cell. Anytime she catches cold, it could trigger anything. Pneumonia, anything, and she’d have been in here for pneumonia with sickle cell. We on guard with everything with her right now.

Another participant compared her feelings to a “shattered piece of glass” or a “broken puzzle.” The participant reported that during this time she had a supportive spouse, but still felt as if the stressors of this disease were placed mainly on her. Zoey stated:

Shock. Only one word. I was shocked. Like I said I’ve been panicked. I ran out of patience. I was hurt because I was like, “what did I do wrong?” I was looking at myself like I did something. Well if this is in my family and my blood is it going to happen again? Well what if he have a child, and his child gets it? That’s what was running through my head. I had so many questions. I kept doubting myself so much that it was starting to take a toll on me…I was like a shattered piece of glass. I was like a broken puzzle on the floor with half of the pieces missing. He [husband] was there to say hey baby you lost this piece right here and I’m putting it back.

The final two participants expressed having feelings of shock. Melissa reported:

When he was first diagnosed, he was born jaundiced. He had to sit under the lamp and we were in the hospital for about a week. We came home. The nurse had to come out to the house to weigh him to make sure he was eating and everything and I got a call from the sickle cell association. Me at the time not even knowing what it was, when I went in there I’m like, “Well what is this?” I had never heard nothing else about no sickle cell other then me having the trait. They did the tests and then about two or three days later, we started with this clinic but they were over in [inaudible]. When I first met the team I just cried and cried and cried and cried because I felt it was not fair to my newborn baby at the time...

Diana stated:

When he was having his stroke, when he was diagnosed they put him on folic acid, folic acid and amoxicillin. The care they give him here is totally different from the care there because they’re more aware of certain things that can occur. I was never informed that he could have a stroke at that early of an age. When I took him, when he had his stroke and I rushed him to the hospital, it was like they didn’t
really know what to do. They sent us here. I wasn’t aware. It was just a whole shocker. My world felt like it was going to end at that point.

The final theme regarding the initial diagnosis extracted varying emotions from all the participants. The participants were relatively comfortable with the researcher towards the completion of the interview, which was enough for them to disclose their initial feelings of sadness, anxiety, helplessness, and so forth. It appeared that participants understood that their own well being affected the well being and health status of their child. Over time all of the participants reported learning how to cope with caring for a child with SCD, particularly for the benefit of their child.

**Summary**

This chapter provided thorough descriptions of each participant’s lived experience as the primary caregiver of a child with SCD. The researcher utilized a focused genogram in order to examine the intergenerational transmission of caregiving behaviors across multiple generations. Through this process, six main themes were extracted: daily primary caregiver tasks, primary caregiver challenges: cognitive coping strategies and emotional coping strategies, knowledge and family history of SCT/SCD, experiences with the health care system, societal perceptions of SCD, and initial reaction to the diagnosis of SCD. From the information gathered from all the participants, it was quite apparent that a “learn as you go” philosophy benefited most of the caregivers while caring for their child with SCD.
CHAPTER V
DISCUSSION

The main purpose of this qualitative research study was to explore the lived experience of several primary caregivers caring for a child with SCD. This final chapter will address the overall findings as they are related to each of the central themes extracted and discussed in Chapter IV. The chapter will also include the limitations as well as strengths of the present study, implications of the results for marriage and family therapists, and recommendations for future research.

Summary of the Study

The present qualitative study focused on the lived experiences of individuals who identified as the primary caregiver to a child with SCD. Additionally, in order to investigate the research questions, the researcher utilized a phenomenological methodology and a systemic lens, specifically Intergenerational Family Therapy in conjunction with focused genograms. There are few research studies largely focused on the emotional and psychological well-being of primary caregivers who care for a child with SCD. As the field of marriage and family therapy expands into medical family therapy, it is essential for practicing clinicians to be well-informed on the effects of chronic illnesses on the family unit, specifically looking at SCD.

The first research question asked: What is the lived experience of the primary caregiver of a child with SCD? The themes that were identified with this research
question were daily primary caregiver tasks and primary caregiver challenges: cognitive coping strategies and emotional coping strategies. Results for this research question confirmed that primary caregivers over time had increased awareness in knowing how to provide care to their child on a daily basis. With knowing how to provide continuous care to their child with SCD, primary caregiver at times would neglect their own well-being in order to put their child first. In addition, in order to cope with stressful situations, primary caregivers noted using detachment, prayer and faith, and using “self” as an example of strength while their child experienced a pain crises.

The second research question asked: What is the lived experience of primary caregivers of a child with SCD specifically regarding child’s medical services? The themes associated with this question were experiences with the health care system and societal perceptions of SCD. The researcher’s hypothesis was not confirmed. Majority of the participants did not receive marginalized care at the SCAC, mainly due to its’ specialization in working with the SCD population. Only one participant reported prejudiced behavior from a medical professional, specifically a nurse in which the client eventually minimized her experience. Pertaining to societal perceptions of SCD, primary caregivers expressed frustrations with the belief that SCD only affects African American in the U. S. Primary caregivers also voiced the lack of government funding and general awareness amongst the population regarding the disease.

The final research question asked: What are the parallels in caregiving behaviors between caregivers of a child with SCD and the caregiving behaviors of past generation caregivers? The themes associated with this research question were knowledge and family history of SCT/SCD and initial reaction to the diagnosis of SCD. The results for
this research question disproved the researcher’s hypothesis that caregiving behaviors are transmitted from past generation caregivers to the present generation caregivers. Focused genograms showed that a lack of familial communication played a large role in how the knowledge of the disease was discussed amongst the family unit. Though primary caregivers stated not having any prior knowledge of how to care for their child at the initial diagnosis stage, caregivers reported understanding how their own well being affected that of their child in the future.

Participants

Finding and recruiting research participants for this study proved to be a unique experience and moved along fairly well with the assistance of the clinical director of the Sickle Cell Anemia Center in the Northeast part of the country. Along with the advertisements and word of mouth, more than enough individuals contacted the clinical director in regards to participating in the study. After meeting with the interested persons and determining eligibility for participation in the study, the researcher obtained verbal consent from each of the individuals. Then the researcher provided an overview and purpose of the study in which the participants signed a consent form to partake in the study. Semi-structured interviews were conducted following the signing of the consent forms in a private room provided by the Sickle Cell Anemia Center.

In order to partake in the study, participants met the following criteria: identified as African American or of African descent, identified as female, at least 21 years old, and identified as the primary caregiver to a child with SCD (HbSS, HbSC, HbS beta thalassemia, HbSD, HbSE, or HbSO). Purposive sampling was used in order to obtain six African American female participants. Participants range in age from 28 years old to
46 years old. Two participants were married and four participants were single. As for levels of education, one participant reported some college, three participants reported a high school/equivalent education, one participant reported having a master’s degree, and one participant reported a vocational/technical degree.

Data Collection and Analysis

The researcher used a phenomenological methodology to explore the lived experiences of the primary caregivers for a child with SCD. This methodology was chosen due to its ability to highlight deeper meanings and phenomenon via qualitative methods while utilizing the long interview technique. In contrast to a quantitative methodology, a phenomenological approach focuses on the reality of “how” that individual(s) perceived the phenomenon (van Manen, 1990). Each participant completed a demographics questionnaire, a semi-structured interview, and a follow-up interview. The semi-structured interview protocol along with the long interview method allowed for the interview to be an informal and collaborative process using open-ended commentary and probing questions. This allowed for flexibility and a certain amount of openness for the participants to disclose their experiences. The interview questions examined the primary caregivers lived experience caring for a child with SCD, their experience with the health care systems as an African American, and parallels in caregiving behaviors across generations.

During the semi-structured interview, the researcher and participant co-constructed a focused genogram that provided a wealth of information spanning across several generations pertaining to the medical history of the family. All of the participants in the study expressed having put their child’s well-being ahead of their own
in order to maintain everyday functionality around the home setting. The follow up interviews wrapped up any lingering thoughts the participants had pertaining to any pervious information given.

Lastly, the transcriptions for each participant interview was completed and reviewed for accuracy by the researcher and a committee member. The focused genograms were also reviewed multiple times in order to comprehend the medical history provided by the participants. During the analysis process the researcher communicated regularly with a committee member to discuss the transcripts and any possible researcher biases concerning the data. After this, the researcher evaluated and categorized the data to develop six main themes. An external audit was also conducted with an unbiased person other than the researcher and a committee member in order to review the study and provide feedback.

**Themes**

The following central themes were collected from the data and will be discussed in this section: (1) daily primary caregiver tasks; (2) primary caregiver challenges: cognitive coping strategies and emotional coping strategies, (3) knowledge and family history of SCT/SCD; (4) experiences with the health care system; (5) societal perceptions of SCD; and (6) initial reaction to the diagnosis of SCD.

**Daily Primary Caregiver Tasks**

In learning more about the daily primary caregiver tasks for parents caring for a child with SCD, majority of the research focused on quality of life (QOL) of the primary caregiver (Burnes et al., 2008; van den Tweel, 2010; Sales, 2003). The “learn as you go” philosophy was used by all primary caregivers who participated in the study when
their child experienced a pain crisis. One of the main reasons for the development of the “learn as you go” philosophy was due to minimal familial communication from previous generations regarding who in the family carried the sickle cell trait or has the disease. Participants did not have any prior knowledge to draw from regarding how to provide appropriate care to their child with SCD. Thus, caregiving behavior could not be transmitted from generation to generation regarding how to care for an individual with SCD.

In addition, primary caregivers found it helpful in educating themselves on the disease, and observing/monitoring their child’s behavior during highs and lows in order to better understand how the disease operated. Though some participants spoke of feeling powerless at times, their behavior during stressful circumstances showed the researcher otherwise. Over time, participants spoke from a position of expertise pertaining to knowing what their child needed which exemplified a form of resiliency, awareness, and attentiveness. This form of coping with the system at the present time falls in-line with systems theory that suggest that families attempt to balance themselves over time.

**Primary Caregiver Challenges**

Primary caregivers discussed the challenges they faced on a daily basis, which created two sub categories: cognitive coping strategies and emotional coping strategies. The discussion here coincided with some of the research (Han & Haley, 1999; Lim & Zebrack, 2000) that delved into the psychological aspects of caring for a child with SCD. Primary caregivers found that being more conscientious of their behaviors during stressful times was beneficial to the child with SCD as well as the family unit as a
whole. Primary caregivers reported that in doing so, they could be an example of strength to their child who endured the pain crises. Some primary caregivers were slightly reluctant about discussing the emotional hardships of caring for a child with SCD. All primary caregivers believed that it would be “selfish” to process their own feelings while their child was sick. One primary caregiver relied on her faith in order to cope, while another stated that being on “autopilot” was the most appropriate way to deal with stressful events. The researcher found that all primary caregivers exhibited some form of depressive symptoms when addressing their own emotional state. This being said, these findings suggest a need for further research by MFTs to fully understand the role chronic illness plays in the emotional and psychological health of the family as a whole. Being able to understand the coping mechanisms of several family members like the healthy sibling(s), the significant other of the primary caregiver, and so forth will give MFTs a better understanding of family dynamics.

**Knowledge and Family History of SCT/SCD**

The focused genograms posed to be a very effective tool in examining the family medical history for at least two generations of each research participant. All participants reported a lack of knowledge about the disease, which suggests that previous generations did not communicate the necessary information regarding the disease or they themselves did not know about who carried the trait or the disease itself. The researcher found that the focused genograms allowed for participants to process for themselves how the family came to know of the disease. There was an element of secrecy amongst some of the families when discussing the family history of the disease as well. The researcher also found that the primary caregivers desired to break the cycle of “not knowing” in order to
prevent future generations from enduring possible increased levels of stress, anxiety, and depression. These findings should emphasize the importance of genetic counseling within family units in which a member presents with the trait for SCD (Pack-Mabien & Haynes, 2009).

**Experiences with the Health Care System**

The data analysis revealed that all the participants believed they received exceptional care at the SCAC. However, one participant expressed a time in which she felt she experienced some form of prejudiced behavior by a nurse based on her race. The participant reported that she knew the common negative stereotype amongst medical professionals who dealt with families in which a member presented with SCD. However, the participant went on to minimize her experience and question her interpretation of the interaction. Another participant expressed fear of relocating in the future and not receiving the same quality of care as she has at the SCAC. All the participants expressed that more health care professionals outside of the SCAC would benefit from further comprehensive knowledge of the disease in order to treat a wider variety of families. At least three participants expressed fear at the initial diagnosis by another hospital that knew very little about SCD, thus referring their families to the SCAC. These findings suggest that there should be a stronger emphasis and a collaborative effort in the areas of diagnosis, treatment, and management of blood related diseases amongst professionals in varying health related fields in order to provide quality care to this population.
Societal Perceptions of SCD

The findings here indicate that as a society, we are lacking in common knowledge about a disease that affects mainly a minority population, not only amongst the family unit but in society as a whole. The lack of funding and governmental resources allocated towards quality care and educational programs focused on raising awareness in the community has not been a priority nor received adequate attention in the US. The pervasive history of racial inequality and systemic oppression towards minority groups aids in the low level of quality care for this population since its recognition as a disease in the 1970s. All participants reported a lack of knowledge in society pertaining to what the disease is and how it is managed. MFTs and other practicing mental health clinicians have the power to adequate for their clients as well as influence policies in favor of underprivileged populations, particularly populations in which an individual has SCD.

Initial Reaction to the Diagnosis of SCD

A variety of emotions emerged during this time, which highlighted the vulnerability of all the participants. By the end of the interviews, the participants felt a sense of comfort to discuss their fears, anxiety, and sadness after their child was initially diagnosed with SCD. This openness with their feelings fell in line with aforementioned research which discussed the emotional health of primary caregivers caring for a child with a chronic illness (Glasdam et al., 2010; Jones & Peters, 1992; Northouse & Swain, 1987; Spiegel, Leproult, & Van Cauter, 1999). Many of the primary caregivers stated having feelings of shock and not knowing how to handle the information about their newborn. Though two of the participants were married, both expressed feeling the
responsibility fell solely on them to care for their child. Some primary caregivers reported that it was difficult to explain the diagnosis to other family members and some did not receive the support that they expected. Findings indicate that all the participants would benefit from a support group designed to help primary caregivers to cope with feelings of isolation and anxiety.

**Reflective Statement**

Throughout the process of this research study, I maintained an appropriate level of engagement with the participants as the principal researcher. However, during an interview at the SCAC, one participant inquired as to how I cope with having a father and brother with sickle cell disease. At that moment, I felt unprepared and vulnerable due to multiple issues taking place in my life. Multiple members of my family had been diagnosed with varying illnesses. My father was experiencing complications due to his sickle cell disease, and my aging mother had developed an illness. During this time, I consulted with my dissertation chair and kept a journal in order to not allow my personal experiences cloud my interpretation of the data, as well as the results.

**Limitations of the Study**

This study emphasized an issue that has been minimally researched in the field of marriage and family therapy; nevertheless, the limitations of this study must be discussed along with its strengths. This study utilized a unique perspective on the effects a chronic illness has on the family unit, in particular the primary caregiver. One of the main strengths of this study was using a systemic lens in conjunction with focused genograms to dissect the medical history of the participants, which aided in bringing forth information that would have otherwise not been obtained from a quantitative
methodology. In order to understand the dynamics within the family system, more studies like this are needed. While this study was able to obtain the information desired, the sample size of the study was small. For example, though the present research stated that women are the main caregivers of children with SCD, there may be a population of men who identify as primary caregivers to children with SCD. It would be interesting to delve into that perspective to observe how this population perceives their lived experience. Another limitation would be obtaining the information for this study from one location that specifically catered to families in which a member has SCD. Results may have varied if the study were conducted in a different hospital and region that did not specialize in treating this specific population.

Another limitation of this study would be the lack of ethnic diversity in the sample population. As the present research stated, SCD is present in the Mediterranean region in Sicily, southern Italy, northern Greece, the southeast coast of Turkey, Saudi Arabia (especially in the eastern province), South and Central America, the Middle East, and Central India. A larger sample size spanning into other locations may yield different results pertaining to how other cultures have been able to cope with their child having SCD. Lastly, from a developmental point of view, the results from this study may have differed significantly depending on the age of the individual being taken care of by the primary caregiver. For instance, the lived experienced of a parent caring for an adult child may differ from that of a parent caring for a newborn or adolescent.

**Implications for Marriage and Family Therapists**

As the field of marriage and family therapy gradually evolves to incorporate aspects of medical family therapy, it is important for MFTs to be well-informed
regarding the role chronic illnesses play in the functionality of the family unit. Family therapists who are educated about SCD can affect the family unit, especially the child with SCD and the primary caregiver in addressing a variety of concerns. Family therapists add a unique perspective to the issues of chronic illness in the family. The use of focused genograms, along with the use of traditional marriage and family therapy theories, can assist the family unit, particularly the primary caregiver in developing positive coping mechanisms that will benefit not only the primary caregiver but to the child with SCD and the entire family unit.

Family therapists have the opportunity to support a child with SCD and could potentially influence public policy and program design for primary caregivers of children with SCD. The present research study can also assist healthcare professionals who desire to collaborate with family therapists in providing comprehensive services for a child with SCD and their family. Though the results of this study should not be a generalization of the SCD population, the results do provide insight into the future of how these families can increase their quality of life with the collaboration of family therapists and the medical professionals providing comprehensive health services. Family therapists can help the primary caregivers navigate the health care system, access information regarding the chronic illness, and connect them to support groups if needed. Primary caregivers in turn will feel more empowered in being able to address the health care needs of their child.

**Recommendations for Future Research**

During the process of data collection, a common thread developed amongst the participants. All of the participants have never taken part in a study primarily focused
on themselves as the main caregiver to children with SCD. Majority of the studies they had been a part of focused on medication trials and pain management, but rarely focused on the emotional/psychological effects of the disease on one’s mental health. All of the participants stated that further research would be beneficial to the families in which a child presents with an illness such as SCD. Therefore, the researcher suggests a need for the following research:

1. Further research studies utilizing traditional MFT theories that examine the effects of SCD on the functionality of the family unit, particularly levels of differentiation, triangulation, emotional cutoff, etc.

2. Further studies that investigate healthcare disparities within the SCD community and the effects on the primary caregiver seeking adequate health care.

3. More research to include various ethnic groups in which SCD poses as a health issue and their lived experience and the influence culture has on the development of coping mechanisms.

4. Longitudinal studies examining the effects of family counseling as a mediator with families in which a member presents with SCD.

5. Qualitative research involving the role of fathers in caring for a child with SCD as the primary caregiver or as a support to a primary caregiver.

6. Future research on the implications for MFTs regarding genetic counseling for individuals who have SCT or SCD.

7. Due to the results of the multigenerational transmission process not occurring in majority of the families examined, future research utilizing a larger sample
size investigating the multigenerational transmission process in regards to families and caregiving behaviors will give a deeper understanding of how families function across generations.

Overall, the strides in the field of marriage and family therapy have opened doors for further research to take place, in particular studies that focus on an underserved population, such as the SCD populace. Further investigation in this area will be beneficial in assisting practicing MFTs in learning how to apply various MFT theories and tenets to a diverse population. At the graduate level, appropriate training for MFTs would prove to be beneficial in learning the role chronic illness plays in the functionality of the family unit. Due to the unique systemic perspective of the practicing clinician, MFTs can aid in the development of positive coping mechanisms used within a family unit.

A critical part of the counseling field in general is advocacy—not just on an individual level but on a community as well as systemic level. As MFTs who are currently experiencing a progression into medical family therapy, it is important for us to recognize the role we can potentially play in advocating for our clients on a larger scale and how we can bring about systemic changes for the advancement of an undeserved population. It would be ideal for medical professionals and MFTs to collaborate in providing comprehensive services to diverse populations with SCD.

Summary

This qualitative research study applied a phenomenological approach to explore the lived experience of several African American women who identified as the primary caregiver to a child with SCD. Specifically, the researcher sought to examine the lived
experience of primary caregivers of a child with SCD; the lived experience of primary caregivers of a child with SCD regarding medical services; and parallels between caregivers of a child with SCD and the caregiving behaviors of past generation caregivers. The researcher used Intergenerational Family Therapy as well as Focused Genograms to delve into the participants’ family of origin within the context of medical history.

With the use of this systemic lens, the researcher was able to identify central themes affecting this population: daily primary caregiver tasks, primary caregiver challenges: cognitive coping strategies and emotional coping strategies, knowledge and family history of SCT/SCD, experiences with the health care system, societal perceptions of SCD, and initial reaction to the diagnosis of SCD. The researcher also summarized findings from the study and discussed limitations as well as the strengths of the study. The researcher also discussed implications for MFTs and made recommendations for future research.
REFERENCES


103


APPENDICES
APPENDIX A

DEMOGRAPHICS QUESTIONNAIRE

Questions about the Caregiver(s): Please mark (X)

1. Relation to Child:
   _____Mother  _____Father  _____Primary Guardian

2. Gender:
   _____Male  _____Female

3. Age: _____

4. Ethnicity:
   _____Hispanic or Latino  _____Not Hispanic or Latino

5. Race:
   _____American Indian or Alaska Native  _____Asian
   _____Black or African American  _____White
   _____Native Hawaiian or Other Pacific Islander  _____Other: __________________

6. Highest Education Level Completed:
   _____Grammar School  _____Master’s Degree
   _____High School or Equivalent  _____Doctoral Degree
   _____Vocational/Technical School (2 yr)  _____Professional Degree (MD, JD, etc.)
   _____Some College  _____Bachelor’s Degree
7. Specify occupation:
___________________________________________________________________

8. Relationship Status:
___ Single              ___ Divorced
___ Married             ___ Widowed
___ In a Relationship   ___ Engaged
___ Separated

9. Please Circle Your Approximate Total Family Income Per Year:
___ Up to $10,000         ___ $50,001 – 60,000
___ $10,001 – 20,000      ___ $60,001 – 70,000
___ $20,001 – 30,000      ___ $70,001 – 80,000
___ $30,001 – 40,000      ___ $80,001 and 90,000
___ $40,001 – 50,000      ___ $90,001 and above

10. Do you have a chronic medical condition (e.g., asthma, SCD, diabetes, etc.)?
___ YES ___ NO  If so, specify:
___________________________________________________________________

11. Have you been diagnosed with a psychosocial disorder (i.e., anxiety, depression, etc.)?
___ YES ___ NO  If so, specify:
___________________________________________________________________
Questions about the Child: Please mark (X)

1. Child’s Gender:
   ___ Male ___ Female

2. Child’s Age: ________________

3. Child’s Ethnicity:
   ___ Hispanic or Latino ___ Not Hispanic or Latino

4. Child’s Race:
   ___ American Indian or Alaska Native ___ Asian
   ___ Black or African American ___ White
   ___ Native Hawaiian or Other Pacific Islander ___ Other: ______________________

5. How many other children live in the home? _______
   a. What are their ages? ______________________________________________
   b. How many children in the home have SCD? _______
   c. How many do not have SCD? _______

6. How many other adults live in the home? _______
   a. What are their ages? _______________________________

7. What type of SCD does your child have? 
   ______________________________________

8. Does your child have a chronic illness or medical condition besides SCD (e.g., asthma, diabetes)?
   ___ YES ___ NO If so, specify:
   ________________________________

9. Has your child been diagnosed with a psychosocial disorder (i.e., anxiety, depression, etc.)?
   ___ YES ___ NO If so, specify:
   ________________________________
10. What medication(s) is your child prescribed?

___________________________________________________________________

11. Who is responsible for making sure your child takes their medication (i.e., you, child)?

___________________________________________________________________

12. When was your child’s last SCD related clinic visit?

___________________________________________________________________

13. When was your child’s last SCD related hospitalization?

___________________________________________________________________

14. How many SCD related pain crises does your child usually experience in one year?

___________________________________________________________________

15. What major complications has your child experienced related to SCD (i.e., strokes, etc.)?

___________________________________________________________________

16. How many days of school has your child missed due to SCD symptoms in the past school year? ____________

17. How many days of work have you missed due to your child’s SCD symptoms in the past year? ____________
APPENDIX B

SEMI-STRUCTURED INTERVIEW QUESTIONS

Introduction:

You are invited to participate in a research project being conducted by Francesca Owoo, a Doctoral Candidate in the School of Counseling, at the University of Akron. The study aims to explore the lived experiences of African American women caring for a child with sickle cell disease (SCD). You were selected due to your response to the recruitment process. Your participation in this interview will be confidential and your input is greatly appreciated.

1. A genogram will be constructed here. As part of the focused genogram, I will be asking the following questions:
   
   a. Who in your family has SCD?
   b. Who was the primary caregiver?
   c. What did caregiving involve?
   d. What did you learn from the previous generation in regards to caregiving?

2. What was your experience with health care regarding your child?
   
   a. Do you perceive any marginalized care based on being African American? If so, can you explain?

3. Describe your experience in caring for your child with SCD.
   
   a. When was your child diagnosed?
   b. What was your initial reaction?
Genogram – A schematic diagram of the family system, using squares to represent males, circles to indicate females, horizontal lines for marriages, and vertical lines to indicate children.

Focused Genogram – A format for clinicians to explore important areas of family life in significant detail, including attachment styles, emotions, gender, sexuality, and culture through a graphic image

Marginalized – To treat (a person, group, or concept) as insignificant
APPENDIX C

INFORMED CONSENT LETTER

The University of Akron

Title of the Study: A Phenomenological Study of the Lived Experiences of Caregivers of Children with Sickle Cell Disease

Introduction: You are invited to participate in a research project being conducted by Francesca Owuo, a Doctoral Candidate in the School of Counseling, at the University of Akron.

Purpose: The purpose of the study is to explore the lived experiences of African American primary caregivers caring for a child with sickle cell disease. Sickle cell disease, in regards to the primary caregiver’s experiences has not been adequately researched in the literature as much as other chronic illnesses. The research study attempts to address the gaps in the present literature that fall short in discussing the primary caregivers’ psychological and emotional well being. The desire is to not only explore the lived experiences but also highlight a population that is potentially marginalized within society. The purpose of this study is to also explore the similarities and differences across generations concerning caregiving behaviors.

Procedures: Data will be collected via demographic information questionnaire, an initial semi-structured interview and follow up interview to revise, clarify, and/or expand on previously generated data. Interviews will be conducted a face-to-face and will last from 1 to 2 hours. Follow-up interviews will be conducted via face-to-face in order to allow participants an opportunity to validate the findings, to make any corrections necessary, and for feedback.

Exclusion: The criteria for inclusion in this study is (a) must be of African descent and/or identify as African American; (b) identify as a female; (c) at least 21 years of age; and (d) identify as the primary caregiver for a child with sickle cell disease.

Risks and Discomforts: The possibility of a psychological risk to you, the participant, is minimal, as you will only be providing your experience regarding caring for a child with sickle cell disease. You will not be asked to share any sensitive information.
**Benefits:** The benefits to you for participating in the study may be a sense of furthering the field of family therapy. Your participation will help mental health professionals to better understand the lived experiences of African American primary caregivers when caring for a chronically ill child, specifically a child with sickle cell disease.

**Right to Refuse or Withdraw:** Participation is voluntary and refusal to participate or withdraw from the study at any time will involve no penalty or loss of benefits to which you are otherwise entitled. If you choose to withdraw, the researcher will remove data pertaining to you.

**Anonymous and Confidential Data Collection:** Any identifying information collected will be kept in a secure location and only the researcher will have access to the data. Participants will not be individually identified in any publication or presentation of the research results. Only aggregate data will be used. Your signed consent form will be kept separate from your data.

**Audio Taping:** Interviews will be audio taped and transcribed without identifying information. The audiotape will be kept in a secure file cabinet of the researcher and will be destroyed after 7 years.

**Confidentiality:** Audiotaped interviews will be kept in a secure file cabinet of the researcher. The transcribed documents will not include your name; it will include a number assigned to you in order to help maintain confidentiality.

**Contact:** If you have any questions about the study, you may call Francesca Owoo (principal investigator) at 347-563-7565 or Dr. Karin Jordan (advisor) at 330-972-5515. This project has been reviewed and approved by the University of Akron Institutional Review Board. If you have any questions about your rights as a research participant, you may call the IRB at 330-972-7666.

By signing below, you are agreeing to participate in an audio-recorded interview regarding your identification as an African American primary caregiver of a child with sickle cell disease. This consent letter will remain on file in a safe and secure location. You will be given a copy of this consent form.

________________________________      ________________________________
Signature    Date       Printed Name

Thank you for your time and consideration.
APPENDIX D
RECRUITMENT SCRIPT

Hi, my name is Francesca Owoo and I am a Doctoral Candidate in the Marriage and Family Therapy program in the School of Counseling at the University of Akron. I am seeking African American women to interview for my dissertation “A Phenomenological Study of the Lived Experiences of Caregivers of Children with Sickle Cell Disease.” I will be exploring three main areas: (1) how a primary caregiver would describe their lived experiences when caring for a chronically ill child, specifically with sickle cell disease; (2) if the primary caregiver has experienced any sort of marginalized care based on being African American; and (3) if there are any learned behaviors across generations of primary caregivers.

Your participation in this project would involve two interviews, lasting from 1 to 2 hours. These interviews will be conducted in person. I will provide you with an informed consent document that will elaborate on the study and allow you to make an informed decision about your participation. If you are interested in participating in this study, please contact the Sickle Cell Anemia Center at the Angie Fowler Adolescent & Young Adult Cancer Institute at University Hospitals Rainbow Babies & Children’s Hospital.
APPENDIX E

RESOURCE LIST

Cleveland:

Applewood Centers Inc.
3518 W 25th Street
Cleveland, OH 44109
216-741-2241

The Centers for Families and Children
4500 Euclid Avenue
Cleveland, OH 44103
216-325-9355

Behavioral Health Services of Greater Cleveland
20525 Center Ridge Road #365
Rocky River, OH 44116
1-866-466-9591

Beech Brook
11801 Buckeye Road
Cleveland, OH 44120
(216) 831-2255

Family Behavioral Services, LLC
Jefferson Park Complex, Suite 102
6559 C Wilson Mills Rd.
Mayfield Village, OH 44143
APPENDIX F

UA IRB APPROVAL

Office of Research Administration

NOTICE OF APPROVAL

Date: May 24, 2016
To: Francesca Ownon,
   School of Counseling
From: Sharon McWhorter, IRB Administrator
IRB Number: 20160507
Title: A Phenomenological Study of the Lived Experiences of Caregivers of Children with Sickle Cell Disease

Approval Date: May 24, 2016

Thank you for submitting your IRB Application for review. Your protocol represents minimal risk to subjects and
matches the following federal category for exemption:

☐ Exemption 1 – Research conducted in established or commonly accepted educational settings, involving
normal educational practices.
☐ Exemption 2 – Research involving the use of educational tests, survey procedures, interview procedures,
or observation of public behavior.
☐ Exemption 3 - Research involving the use of educational tests, survey procedures, interview procedures, or
observation of public behavior not exempt under category 2, but subjects are elected or appointed public
officials or candidates for public office.
☐ Exemption 4 – Research involving the collection or study of existing data, documents, records,
pathological specimens, or diagnostic specimens.
☐ Exemption 5 – Research and demonstration projects conducted by or subject to the approval of department
or agency heads, and which are designed to study, evaluate, or otherwise examine public programs or
benefits.
☐ Exemption 6 – Taste and food quality evaluation and consumer acceptance studies.

Annual continuation applications are not required for exempt projects. If you make changes to the study’s design or
procedures that increase the risk to subjects or include activities that do not fall within the approved exemption
category, please contact the IRB to discuss whether or not a new application must be submitted. Any such changes
or modifications must be reviewed and approved by the IRB prior to implementation.

Please retain this letter for your files. This office will hold your exemption application for a period of three years
from the approval date. If you wish to continue this protocol beyond this period, you will need to submit another
Exemption Request. If the research is being conducted for a master’s thesis or doctoral dissertation, the student must
file a copy of this letter with the thesis or dissertation.

☑ Approved consent form/s enclosed

OHIO’S POLYTECHNIC UNIVERSITY
Uniting the Arts & Humanities with Science & Technology

The Trustees of Ohio’s Polytechnic University

121
APPENDIX G

UH IRB APPROVAL

Exemption approval for IRB# EM-16-22

Connie Piccone, MD,

Upon administrative review of your project entitled “A Phenomenological Study of the Lived Experiences of Caregivers of Children with Sickle Cell Disease” (IRB # EM-16-22), the IRB has determined that this protocol meets the criteria for exemption under Federal regulation 45 CFR 46.101 (b) (Category 2).

Please note the expiration date for this exemption approval is 08/11/2022.

Continuing review is not required for research for your exempt project. However, if the research is ongoing for more than six years, you must resubmit the project for re-review as a new submission.

Please see the UHCMC IRB policy regarding Exempt Research for more information: http://www.uhhospitals.org/Portals/6/docs/research/irb/forms/May_07/IRB_Policy_Exempt_Human_Research_5_2007.doc

Please feel free to contact the Office of Institutional Review at (216) 844-1529 if you have questions.

Thank You,

UHCMC IRB Chairperson
(Signature was applied by the IRB Administration Office)