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Sickle Cell Disease Pain Burden and Quality of Life Among Black Children in Mississippi

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of the Requirements for the Degree of

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Abstract

Acute and chronic pain is a common hallmark of sickle cell disease (SCD) in children and adolescents, which can have a profound effect on their quality of life (QOL). However, this relationship is not well quantified. The purpose of this quantitative study was to examine the relationship between SCD pain burden and QOL among Black children ages 8–17 in Mississippi with SCD. The secondary aim was to compare children and caregiver reports of SCD pain burden and QOL with SCD. The social ecological model was used to identify personal factors that influence SCD pain burden and QOL of children with SCD. Eighty-five children and caregiver pairs completed paper surveys on demographics, pain burden, and QOL. Hierarchical linear regression results indicated that increased child SCD pain burden was statistically associated with decreased child's QOL (P<.001; R^2.089, .026, .356). Children and caregivers rated overall QOL and pain burden similarly but were not in agreement regarding the physical functioning of children mean scores. Emotional, social, and school functioning of child's QOL were higher when rated by children then the caregiver (p=.003) These results can be used for positive social change to provide comprehensive interventions that can be implemented based on the reported daily functioning of children with SCD. Education materials about the impact of pain and disease management can be developed based upon the specific data collected in community health clinics. Additionally, the results can be used to influence SCD health policy by creating a systematic service that includes the perception of children with SCD as part of their healthcare management.

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Dedication

This study is dedicated to children in Mississippi who suffer from sickle cell disease. I hope and pray that the public health and healthcare communities see the importance of your point of view to develop and implement improved interventions that are appropriate for you to increase your quality of life.

Acknowledgement

First, I would like to say thank you God who ordered my steps throughout this very long process. Thank you, God, for giving me strength and the spirit of perseverance. I can do all things through Christ that strengthens me Philippians 4:13. Next I would like to acknowledge my husband and thank you for all your support and understanding. My family, church family, and friends thank you for your support, and prayers. I am very appreciative for my dissertation Chair Angela Prehn, PhD, and committee members Kiara Spooner, PhD, and Manoj Sharma, PhD thank you for your guidance and support. Dr. Prehn, you helped me to think outside the box as well as pushed me to do more than my best. I would also like to thank Suvankar Majumdar, MD for your guidance and opportunities provided.

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Chapter 1: Introduction to the Study

Introduction

My goal for this study was to determine the association of Sickle Cell Disease (SCD) pain burden and the Quality of Life (QOL) among Black children in Mississippi ages 8–17 with SCD. I compared child and caregiver self-reports of SCD pain burden and QOL of Black children in Mississippi ages 8–17 with SCD. I used the socioecological theory (SET) as the theoretical approach for this study. I used the SET to demonstrate the interrelations among the personal and environmental factors as they relate to SCD pain burden and QOL of children. The significance of this study is that it provides a better understanding of SCD pain burden and QOL in Black children in Mississippi ages 8–17 with SCD. In this chapter, I discuss the background of the study, (a) problem statement, purpose of the study, (b) research questions and hypotheses, (c) theoretical/conceptual framework, (d) nature of the study, (e) definition of terms, (f) assumptions, (g) scope and delimitation, (h) limitation, and (i) significance of the study.

Background of Study

SCD is an inherited chronic blood disorder that is found in individuals of African and Hispanic descent. It is estimated that SCD occurs in about 1 in 500 persons with African ancestry and those that are identified as Black (Lemanek & Ranalli, 2009). In the United States among the Hispanic-American population it has been estimated that 1 out of every 36,000 Hispanic-Americans are born with SCD (Centers for Disease Control and Prevention, 2012). SCD is also identified among those whose ancestors are from South America, Caribbean, Central America, Saudi Arabia, India Turkey, Greece, and Italy (Centers for

Disease Control and Prevention, 2012). Individuals born with SCD have abnormal hemoglobin S red blood cells. The red blood cells form into a crescent shape, (i.e. sickle shape) which makes it difficult to pass through small blood vessels (Sickle Cell Disease Association of America, Inc., 2012). With SCD, the cells get stuck in the small blood vessels and block the flow of blood and oxygen to organs in the body. The blockage causes severe acute and chronic pain (Centers for Disease Control and Prevention, 2012).

SCD is one of the most common genetic blood disorders in the United States. In most states SCD is not a reportable disease, which makes it difficult to determine the number of individuals with this condition (Brousseau, Panepinto, Nimmer, & Hoffmann, 2010). However, it is estimated that in the United States, there are approximately 90,000 to 100,000 children and adults living with SCD (Centers for Disease Control and Prevention, 2012). Approximately 1,800 to 2,000 infants are born with SCD each year in the United States (Brousseau, Panepinto, Nimmer, & Hoffmann, 2010; Hassell, 2010). To better identify persons with SCD, states began screening newborns for life threatening and genetic conditions that can be detected prior to symptoms.

In 1984, newborn screening testing became a mandatory law in the state of Mississippi (Mississippi State Department of Health, 2013). It was not until 1988 that legislation authorized the addition of hemoglobinopathies (e.g., SCD) for testing newborns (Mississippi State Department of Health, 2013). Newborn screening is the only reporting source in the state of Mississippi to identify infants with SCD. In 2014, the Mississippi State Department of Health's Vital Statistics reported there are approximately

40,000 live births in the state of Mississippi a year; of those live births there were approximately 74 cases diagnosed with SCD a year.

As compared to the MS State Department of Health Newborn Screening Report from 2009–2014 there was a total of 410 infants diagnosed with sickle cell disease which is an average of 68 cases a year. The total number of children and adults in the state of Mississippi with SCD is unknown; however, Hassell (2010) estimated that there were approximately 4,000 Mississippians with SCD. Significant advances in early diagnosis (e.g. newborn screening) and preventative treatments (e.g. hydroxyurea) of SCD have prolonged the lives of those with the condition. The life expectancy for individuals with SCD has increased considerably from 14 years in 1973 to the mid- to late 40s in 2004 (Jenertte, Leak, & Sandelowski, 2011). The increase in the life expectancy has placed more attention on QOL and ways to measure and improve the lives of individuals with SCD (Lim, 2009; Lim, Welkom, Cohen, Osunkwo, 2012). Although the life expectancy of individuals with SCD has increased over time, their lives are impacted by the unpredictable consistent pain that is often poorly managed over a lifetime (Benjamin, 2008).

The physical, mental, and social well-being of the SCD population has been a concern of the public health community for the past 30 years (Mann-Jiles & Morris, 2009). The activities of daily living of children (e.g., school and peer interaction) are also among the domains that are impacted by SCD (Howard, Thomas, Rawle, Cartwright, & Westdale, 2008). For children with SCD, the QOL can best be described as their ability to function during physical, social, academic, and psychological circumstances (Marion, Uzark,

Ittenbach & Drotar, 2010). Children who have SCD are at risk for maladjustments in most areas that influence daily functioning (Palermo, Riley, & Mitchell, 2008). These maladjustments may result in undesirable effects in academic achievement, peer relationships, and QOL (Centers for Disease Control and Prevention, 2012).

Most studies of children with SCD focus on the differences between children with SCD and children without SCD. For this reason, it is important to examine the population itself to determine what factors may influence their QOL. In this study, I examined a comprehensive QOL perspective that provides the perception of the child's position in life. Some important aspects of the QOL are: physical factors, psychological factors, independent factors, environmental factors, social relationships, and spirituality which may not be understood by the physician and healthcare system (Stelmack, 2009; World Health Organization, 1997). Because pain is a prominent symptom of SCD, there is a need for a better understanding of QOL in children with SCD.

Multiple factors may contribute to a child's QOL; for instance, Lim (2009) recommended that the QOL should be measured for three specific reasons. First, a health profile can be created to describe the characteristics and functional status of a child with SCD (Lim, 2009). Second, more information about children with SCD could be used for evaluating the daily impact and effectiveness of new medications (Lim, 2009). For example, healthcare providers may prescribe medication such as hydroxyurea over other medications due to the impact of potential side effects that may decrease the QOL (Thornburg, Calatroni, & Panepinto, 2011).

Third, the QOL can be utilized by multidisciplinary healthcare providers to offer the needed services and resources to children and their families (Lim, 2009). Specific interventions can be developed and implemented to concentrate on needed areas of functioning. For example, children with SCD have cognitive and academic problems because of developmental delays and missing school due to recurrent pain episodes (Daly, Kral, & Brown, 2008). Positive outcomes of QOL for children with SCD would be providing education to families and teachers about cognitive outcomes of SCD, implementing federal laws that protect the rights of children with disabilities, and lastly working with school officials to promote school reentry programs (Daly et al., 2008).

The scarcity of population-based research describing the QOL of children with SCD may perhaps partly explain why SCD is still a burden for individuals who have this condition. Because SCD is most prevalent in the United States among Blacks and other ethnic minority populations, the burden of this condition may also exist due to challenges of health disparities. In 2005, the Centers for Disease Control and Prevention determined that in the United States health disparities in the Black community can mean loss of economic opportunities, lower QOL, opinions of injustice, and early deaths (Conway, 2012). As a result, the Healthy People 2020 national health objectives continue to focus on the progress of eliminating racial and ethnic health disparities to improve the population health of individuals with SCD (Healthy People 2020, 2013).

In the United States, the population of children with SCD is largely Black (Panepinto, Pajewski, Forister, Sabnis, & Hoffmann, 2009), and Mississippi is among one of the states with the highest rate of poverty level for Black children (United States Census

Bureau, 2011). In 2012, 26.7% of Mississippians living below the poverty rate lived in rural areas as compared to the 20.4% of the Mississippians who lived in urban areas (USDA Economic Research Service, 2014). The state of Mississippi is a medically underserved (i.e., reduced access to primary care physicians) state where statistics present an extremely negative view of the overall health in the state. Nationally, Mississippi's residents rank lowest (i.e., 50th) in several overall health indicators (e.g., cancer, chronic disease and infant mortality; Mississippi State Department of Health, 2013; Americas Health Rankings, 2014).

With the substantial health disparities in Mississippi, children with SCD are often faced with issues such as racial prejudice and socioeconomic inequalities. For instance, racial bias may influence the medical treatment and other health services for children with SCD (Williams & Mohammed, 2009). Experiencing injustice and discrimination can affect their QOL, including increased chronic pain, stress, and disability (Zempsky, 2009). Many children with SCD are in families who experience low income, substandard housing, lower-quality daycare centers and schools, lack of access to healthcare, and neighborhood crime, which may complicate the consistency and quality of their care (Pettignano, Caley, & Bliss, 2011). Additionally, there is a strong relationship between socioeconomic status (SES) and increased risk of being affected by health disparities (Price, Khubchandani, McKinney & Braun, 2013), and factors related to low SES can adversely affect health outcomes (Pettignano, Caley, & Bliss, 2011).

In this study, I examined SCD pain burden and its association to QOL in Black children with SCD. I examined if pain is a significant factor of affecting the QOL of children with SCD. Further, the reports of children and caregiver's perception of SCD pain

burden and QOL were examined. Given that children with SCD experience recurrent pain that affects their daily lives, this research may be supportive in developing and implementing strategies so that interventions can be created based on the impacted factors (e.g., school, physical, social and emotional factors). Knowing that SCD pain burden may influence the QOL of children can greatly enrich the understanding of their lives by multidisciplinary public health professionals, policy makers, and the community. This information can be used to design an intervention program that improves the QOL among SCD children in Mississippi.

Problem Statement

SCD pain burden has a profound effect on the lives of those that live with this chronic condition. SCD pain is the most common symptom reported by about 100,000 Americans (Hassell, 2010). Smith and Scherer (2010) provided evidence that chronic pain occurs more in children and adolescents than reported. Children may begin to experience SCD pain as early as 4 - 6 months of age (Benjamin, 2008). SCD pain in children can be pervasive and unpredictable. For children with SCD, recurrent pain (i.e., acute and chronic pain) is a common problem that impacts their daily activities (Dampier, Ely, Brodecki & O'Neal, 2002). However, little is known about how the burden of pain may affect the lives of children with SCD. Furthermore, it is not clear how the burden of SCD pain in children may predict their QOL (e.g., school, physical, social, and emotional functions; Barakat, Patterson, Daniel & Dampier, 2008; Brandow, Brousseau, Pajewski, & Panepinto, 2009; Palermo et al., 2008).

There is a gap in the literature when it comes to empirically measuring the association between SCD pain burden and QOL. The gap that was filled with this study

was a practical assessment of the association of SCD pain burden with QOL from the perception of Black children ages 8–17 with SCD and their caregivers in Mississippi. The research on SCD pain burden and QOL is not routinely assessed for children with SCD. The literature I reviewed on this topic has focused on either (a) health-related quality of life (HRQOL) of the caregiver with a child that has SCD, (b) HRQOL of children with SCD based on the caregiver's perception, (c) impact of bodily pain caused by SCD based on the caregiver perception, (d) HRQOL as perceived by the child and caregiver,(e) impact of bodily pain caused by SCD based on the child and caregiver perception,(f) comparison of SCD to other chronic conditions, or (g) healthcare utilization.

Additionally, most literature reviews focus on (a) pain, (b) functional disabilities, (c) coping, (d) depression, and (e) the use of pain diaries based solely on parent proxy reports (Gil, Porter, Ready, Workman, Sedway, & Anthony, 2000; Panepinto, O'Mahar, DeBaun, Loberiza, & Scott, 2005; Barakat, Simon, Schwartz, Radcliffe, 2008; Gold, Yetwin, Mahrer, Carson, Griffin, Palmer, & Joseph, 2009; Gold, 2009, & Dale, Cochran, Roy, Jernigan & Buchanan, 2011). The social impact of this research addresses the roles of SCD pain burden and QOL in children, which can be a primary approach to acquiring a better understanding and improving the conditions of their daily lives. Also, the information gained from this study can be used to develop public health intervention programs that can improve the QOL of children with SCD particularly Black children ages 8 -17.

Purpose of the Study

The purpose of this quantitative study was to examine the association between SCD pain burden and the QOL among Black children ages 8 -17 in Mississippi with SCD. The second aim of this study was to assess the difference of SCD pain burden experience from the reports of the child and their caregivers and compare their responses. The third aim of this study was to assess the difference of QOL experience from the reports of children with SCD and their caregivers and compare their responses. Questionnaires were provided to children with SCD and their caregivers to explore their difference in perspectives of SCD pain burden and QOL. This study is expected to lead to a greater understanding of the QOL among the SCD child population in Mississippi, which has not been well characterized.

Research Questions and Hypotheses

A quantitative study was performed to understand the association of SCD pain and the QOL of Black children ages 8to17 in Mississippi. The research questions and hypotheses were developed from an extensive review of available literature which indicated that there may be an association between SCD pain burden and QOL of children with SCD. It was expected that age, sex, and caregiver SES may confound the association between SCD pain burden and QOL. The hypothesized association of SCD pain burden and QOL is shown below in Figure 1. More details of the methods of the study are discussed in Chapter 3. The research seeks to answer the following questions:

(RQ1): What is the association between SCD pain burden and QOL (i.e. physical, social, emotional and school functioning) in Black children ages 8–17 in Mississippi?

Alternative Hypothesis (H_a1): There is a statistically significant association between SCD pain burden and QOL, as measured by SCD Pain Burden Interview- Youth and the PedsQL in Black children ages 8–17 in Mississippi with SCD.

Null Hypothesis ($H_0$1): There is no statistically significant association between SCD pain burden and QOL, as measured by SCD Pain Burden Interview- Youth and the PedsQL in Black children ages 8–17 in Mississippi with SCD.

(RQ2): Is there a significant difference between child and caregiver reports of SCD pain burden in Black children ages 8–17 in Mississippi with SCD? **Alternative Hypothesis (H_a2):** There is a significant difference in the caregiver and child reports of SCD pain burden, as measured by SCD Pain Burden Interview- Youth in Black children ages 8–17 in Mississippi with SCD and their caregivers.

Null Hypothesis ($H_0$2): There is no significant difference in the caregiver and child reports of SCD pain burden, as measured by SCD Pain Burden Interview- Youth in Black children ages 8–17 in Mississippi with SCD and their caregivers.

(RQ3): Is there a significant difference between child and caregiver reports of QOL (i.e. physical, social, emotional and school functioning) in Black children ages 8–17 in Mississippi with SCD? **Alternative Hypothesis (H_a3):** There is a significant difference in the caregiver and child reports of QOL, as measured by Pediatric Quality of Life Inventory (PedsQL) in Black children ages in Mississippi with SCD and their caregivers.

Null Hypothesis ($H_0$3): There is no significant difference in the caregiver and child reports of QOL, as measured by PedsQL in Black children ages 8–17 in Mississippi with SCD and their caregivers.

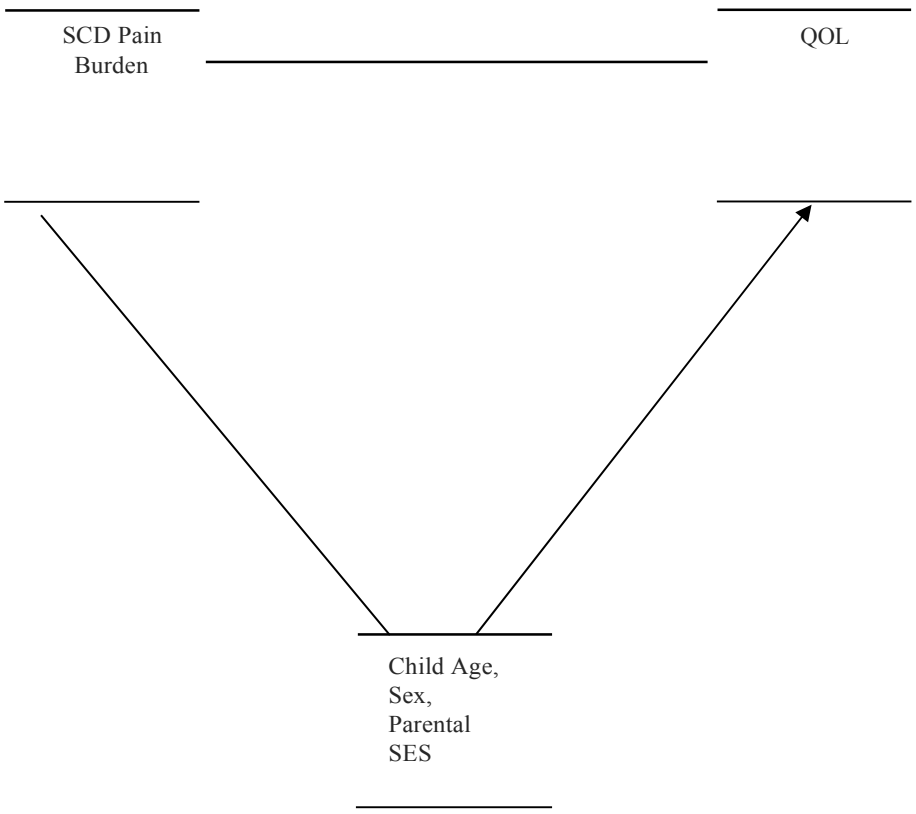

Figure 1. Hypothesized Association of Sickle Cell Disease Pain Burden and Quality of Life

Theoretical/Conceptual Framework

Using a theory as a part of this research helped to examine the question of how and why SCD pain may affect QOL of Black children ages 8-17. Also, the use of a theory provides a blueprint of how and why interventions should be developed. I used the Social Ecological Theory (SET) as the theoretical approach for this research. SET was defined in the l 970's by American psychologist Urie Bronfenbrenner (Kazak, 1989, & Bronfenbrenner, 2008). The SET is defined as the study of relationships between the

developing human being and the environment in which the person is actively involved (Kazak, 1989, and Bronfenbrenner, 2008). The SET provides a framework for understanding the QOL by addressing contextual and external variables that influences the lives of people (Tabol, 2008). The SET recommends that the health of an individual can be influenced by their (a) biological and genetic makeup, (b)social and family relationships, (c)environmental contingencies, and (d) economic status (Cassel, 2010; Smeldley & Syme, 2001).

SET is a made up of concentric circles that have a multilevel approach that emphasizes all factors associated with a health condition (i.e. physical or mental) to identify interventions for promoting health. Figure 2 provides an illustration of Bronfenbrenner 's SET model. The four multilevel approaches identified are: (1.) the microsystem which typically represents the individual in the center of a circle that symbolizes a series of concentric circles. This circle includes a more direct and ongoing interaction with: (a) parents, (b) family, (c) home, (d) peers, (e) community, (f) health services, (g) school, and (h)church; (2.) the mesosystem is the link to the microsystem in which all that are involved collaborate to provide adequate services to the child such as: (a) parent teacher relationship and (b) parent friend relationship (3.) the exosystem, is composed of the regional, state, and national levels, and affects the individual by impacting the micosystem that influences the: (a)school systems, (b) religious institutions, and (c)resources, and (4.) the macrosystem involves more versatile and complex systems such as: (a) cultural, (b) social attitudes, (c)religious and political beliefs, (d) societal norms, (e)income, and (f)how resources

are allocated (Bronfenbrenner, 2008). These levels directly and indirectly impact the QOL of children and adolescents with SCD.

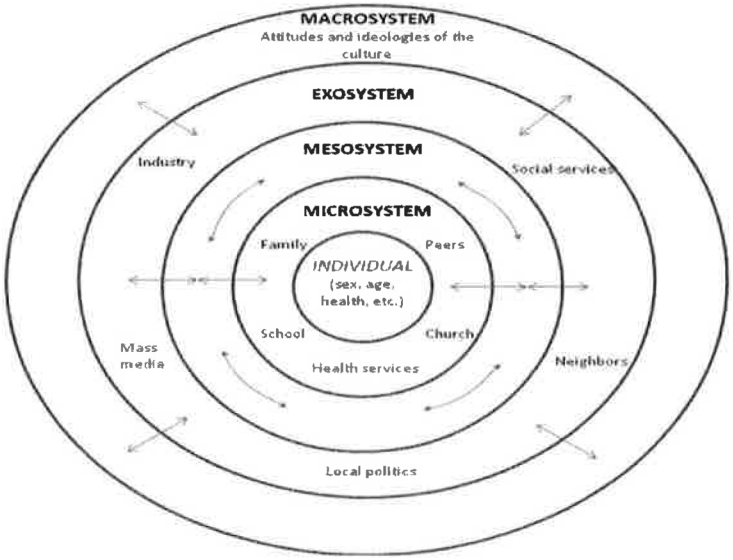

Figure 2. From "The Ecology of Human Development: Experiments by Nature and Design. Bronfenbrenner' s Ecological Theory of Development, 1979," by U. Bronfenbrenner, 1979 (https://khoerulanwarbk.files.wordpress.com/2015/08/urie_bronfenbrenner_the_ecology_of_human_developbokos-z1.pdf). In the public domain.

The SET relates the child to the center of the concentric circles and the circles represent the settings that have bidirectional influences on the child. As indicated by the SET the environment that is most crucial to the development of the child is the family system, specifically, the parent-child interaction (Bronfenbrenner, 1979). Health outcomes of children can be determined based on individual, family, and community regarding the availability of resources and socioeconomic status. Children that reside in disadvantaged communities have been linked to poorer health, developmental and psychosocial outcomes (Palermo et al., 2008). The child's view of pain can be impacted by the developmental trajectory and their caregiver's attributes for example:(a) emotional functioning, (b)behaviors, (c)health history, and (d) caregivers and child relationships. The family and child interaction, environment, and

life cycle stage can also impact the pain of the child with SCD (Palermo, Valrie, & Karlson, 2014).

At the individual level, children with SCD have experienced more intense pain, which is associated with increased symptoms of social anxiety and internalization (Palermo et al., 2008). Additionally, severe SCD pain was found to be associated with depression and poor QOL (Palermo et al., 2008). For the family level, lower income has been linked to severe SCD pain and negative thinking in adolescents (Palermo et al., 2008). Furthermore, the perception of pain may be related to: (a) an individual's biology, (b) current feelings, (c)behaviors caused by pain, and (d) limitations in daily activities (Palermo et al., 2014). From the review of this research it is clear that these factors and their interactions are shaped by the (a) physiological, (b) psychological, (c)social, and (d)emotional changes that characterize development (Palermo et al., 2014).

For this study, I evaluated the microsystem and mesosystem to explain how the interaction of these circles affects the QOL of children with SCD. The SCD pain burden and QOL of the child relates to the SET from the family, peers, and community; which is located at the microsystem, and mesosystem of the concentric circles. The two-social ecological systems represent the constructs for the QOL: (a) physical functioning, microsystem, (b) emotional functioning, microsystem, (c) social functioning, microsystem, and (d.) school functioning, microsystem. The mesosystem is used to represent the interaction between two or more microsystems (e.g., parent and child) that directly impact the child (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). These specific systems can be

the driving force of support which may depict the QOL for children who participated in this study with SCD.

The SCD pain burden is also represented in the SET by social influences, of which some of the proximal forces are: (a) family, (b)peers, and (c) the classroom setting of school; these components are described in Bronfenbrenner ecological model as the microsystem (Logan, Engle, Feinstein, Sieberg, Cohen, Conroy, & Driesman, 2012). Family, peers, and school all shape the pain experience of the individual child or adolescent, also each of the components represent a domain of functioning that is more than often impaired by chronic pain (Logan et al., 2012). According to Palermo & Chambers (2005), family influence on pediatric pain can function at multiple levels from the individual factors that may include; parenting style, parental protective responses to pain, interaction between the child and caregiver, and the family's environment. Each of these components can be influenced by pain and functional disability (Logan et al., 2012).

Five components of SCD pain burden using the social ecological theory where children with SCD are embedded was examined: (a) effect of pain burden, (b) effect of physical functions, (c) effect of social function, (d) effect of school function and (e) effect of emotional function. For SCD pain burden environmental influences such as the microenvironment and macroenviornment may be conceptualized at multiple levels. The six ideas of the microenvironments are (a) the family setting, (b) nonparental care settings, (c) peer group, and (d)neighborhood, (e) culture, and (f) social policy (Baumeister & Vohs, 2004; Forgas, Baumeister, & Tice, 2009; Hertzman & Boyce, 2010). For this study, I used the SET perspective, to hypothesize that SCD pain burden is

a significant indicator of the QOL in Black children ages 8–17 with SCD. More details about this theory and its relationship to the study are discussed further in Chapter 2.

It is very important that children with SCD receive support from their caregivers and communities; caregivers and the communities help to shape determinants of health in children. Life outcomes are often influenced by the interactions of genetics and the environment (Bertrand, Williams, & Ford-Jones, 2008; Mustard, 2008; National Collaborating Center for Determinants of Health, 2008a). This system theory shows the interconnections and relationship between the: (a)individual, (b)relationships, (c) community, and (d) societal setting. For this study I collected data on SCD pain burden, QOL, and demographic family influences such as: (a) marital status, (b)income, (c)employment status, and (d) education level.

Nature of the Study

In this study, the deductive research approach was to identify descriptive factors and quantitative trends based on the social ecological perspective. I used the following tools for this study: (a)SCD Pain Burden Interview-Youth (SCPBI-Y; Zempsky, O'Hara, Santanelli, Palermo, New, Smith-Whitley & Casella, 2013), (b)Pediatric Quality of Life Inventory 4.0 version (PedsQL 4.0; Vami, Seid, & Kurtin, 2001; Vami Seid, Knight, Uzark & Szer, 2002), and (c) Demographic Profile Questionnaire. The target population were Black children in Mississippi ages 8–17 with SCD. The independent variable is SCD pain burden, and the dependent variable is the QOL. The information obtained from the participants of this study was provided through self-administered questionnaires.

The covariates of the study included age, sex, and caregiver socioeconomic status (i.e., household income within the past 12 months and education level) which were controlled for in the study. This deductive research was informed by a similar hypothesis from a study that examined the association between SCD pain and QOL in children, and assessed whether coping moderates the relationship (Lim, 2009). A second aim of Lim's study was the relation between child age, pain, quality of life, and coping. In addition, other studies provided the framework for examining (a) SCD pain burden, (b)caregiver and child reports, (c) factors associated with QOL, and (d)caregiver and child reports (Panepinto et al.,2005; Zempsky et al., 2013).

The direction of predicting SCD pain burden and QOL was explored by taking into consideration the self-reported responses participants provided on the child and caregivers questionnaires. This study focused on the functional disability, and the impairments (i.e., physical, social/community and emotional aspect of daily function) that may be caused by SCD pain using the SCPBI-Y. Also, the study focused on the QOL as it relates to the child's and caregiver's perception using the PedsQL 4.0 questionnaire. Essentially, the results of this study demonstrate whether there is an association between SCD pain burden, and the QOL. The information provided on the specific limitations or no limitations of daily activities were perceived by the children and caregivers.

Additionally, child and caregiver concordance analysis were used for each questionnaire. The agreement or disagreement among the child and caregiver groups provide useful information in developing specific interventions for the targeted population. Further,

this information may be important to collect from both groups because as the children get older and start to care for themselves, caregiver's perception of their child's health is likely to be different from what their child may perceive (Panepinto et al., 2005). I used the SET to show how influences of the theory may predict SCD pain burden, which may contribute to QOL, health outcomes and management of the disease. This study assesses whether there is a relationship among SCD pain burden and the QOL in Black children ages 8–17. Using a convenience sampling approach, children with SCD and their caregivers were recruited from a pediatric hematology clinic. The caregivers completed a Demographic Profile Questionnaire which requested information such as their household income for the past 12months, and education level. The children and their caregivers separately completed the SCPBI-Y, and the PedsQL 4.0 questionnaires.

Definition of Key Terms

Sickle Cell Disease "is a group of inherited red blood cell disorders that cause red blood cells to become hard and sticky and look like a C-shaped farmed tool called a "sickle". The sickle cells die early which causes a constant shortage of red blood cells." When they travel through small blood vessels they get stuck and clog the blood flow. This can cause pain and other serious problems such as infection, acute chest syndrome and stroke" (Centers for Disease Control and Prevention, 2012, "Facts About Sickle Cell Disease," para. 1).

Acute Pain "is the recurrent pain that is the number 1 cause of hospitalization for SCD. Acute pain is unpredictable and may be precipitated by known or unknown risk factors and triggers. There is a sudden onset of pain in the low

back or in one or more joints or of the extremities. The pain may be localized or migratory and is continuous and throbbing" (Ballas, Gupta, & Adams-Graves, 2012, p. 3649).

Chronic Pain "is pain that persists for 3 or more months. Sources of chronic pain in SCD include bone infarction, avascular necrosis of joints, and back pain from disk protrusion into verteral bodies, leg ulcers, and chronic osteomyelitis" (Ballas and Eckman, 2009, p 497; Ballas, Gupta, & Adams-Graves, 2012, p. 3653).

Socio- Ecological Theory is the study of relationships between the developing human being and the environment in which the person is actively involved in (Bronfenbrenner, 1979; Kazak,1989).

Health Related Quality of Life "is a multi-dimensional concept that includes domains related to physical, mental, emotional and social functioning. It goes beyond direct measures of population health, life expectancy and causes of death, and focuses on the impact health status has on quality of life (Healthy People 2020, 2013, " Health Related Quality of Life and Well- Being," para. I).

Operationalized Terms

Dependent Variable

Quality of Life*:* "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (World Health Organization, 1997, p l). The QOL is measured by the Pediatric Quality of Life Inventory a 23-item tool used for assessing a child's functioning in physical, emotional, social, and school domains. The items on the

questionnaire are averaged to create a total score and summary scores for physical health and psychosocial health (Vami et al., 2002, p 177).

Independent Variable

Sickle Cell Disease Pain Burden: "encompassing pain and the burden of pain on physical function, social/community participation and emotional aspect of daily living (Zempsky et al., 2013, p2). SCD pain burden is measured by the SCD Pain Burden Interview- Youth (SCPBI-Y) for children ages 8–17 (Zempsky et al., 2013, p 2). The SCPBI-Y is a 7-item measure designed to assess the impact of pain on physical, social/community, and emotional aspects of daily functions. The questionnaire was completed by children and caregivers (Zempsky et al., 2013, p4).

Covariate Variables

Age: In this study, individuals age 8–17 will be included in the sample. This variable was self-reported and is calculated from date of birth.

Gender: This is a dichotomous variable, male or female (coded 1 for male and 2 for female).

Socio-economic Status: In this study the SES variables of the caregivers are measured independently (i.e. education level and household income in the past 12 months). The SES is defined as the caregiver' s economic status as measured by household income in the past 12 months, income, social status measured by education, and work status measured by occupation each status is considered an indicator (Centers for Disease Control and Prevention, 2014; "Social Determinants of Health", para 17). These three indicators are related but do not overlap (Centers for Disease Control and Prevention,

2014; "Social Determinants of Health", para 17). This variable is a self-report of categories indicating the caregiver's range of income and education level, as well as their work status.

Household Income in the Past 12 Months: "Income has been reviewed as an important indicator of health status" (Shavers, 2007, p 1015). "Income represents the flow of economic resources over a period of time" (Shavers, 2007, p 1015). In this study, the variable is self-reported to indicate one of eleven income ranges of the caregivers using the following income categories: 1=<$20, 000, 2=$20,000-$34,999;3= $35,000-$49,999 and 4=$50,000+ to indicate the approximate family household income in past 12 months.

Education Level: Education level was used to determine health literacy as the ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions (i.e., reading labels, keeping appointments, and understanding informed consent documents and medications dosages; National Network of Libraries of Medicine, 2014, " Health Literacy", para 1). This variable was measured by the number of years reported by each caregiver of the highest level of education completed.

Assumptions

One assumption for this study was the participants would give honest and accurate answers, and the responses from the participants would not be influenced by the researcher. This was necessary to provide valid data, and to be able to generalize findings beyond the study sample. A second assumption was the caregiver who accompanied the child at the clinic was the primary caregiver that the child lives with. The third assumption of this study was that the SES of the caregiver would represent each child.

The limitation of the second and third assumption was the caregiver that accompanies the child to their clinic visit may not be the caregiver who the child lives with. To minimize the impact of the second and third assumptions, the non-caregivers that accompany the children to their clinic appointment were excluded from the participation of this research. In addition, the children accompanied by a non-caregiver to their clinic appointment were excluded as well. The exclusions ensured that the validity of the research is honest and true to its intent (MacLean & Mohr, 1999); this is important to the research regarding receiving adequate information from the perception of the child and child's primary caregiver.

A fourth assumption was that the questionnaires used in this study represented the children's overall experience of SCD pain burden and their QOL. This demonstrates whether the questionnaires are appropriate for this study. Also, this will allow further progress for answering research questions specific to children in Mississippi with SCD, and aid in the development of educational materials to provide adequate information to key stakeholders such as: (a) healthcare providers, (b)policy makers, and (c)legislators. Lastly, the fifth assumption was there would be an adequate sample of the targeted population at the pediatric hematology clinic where data were collected.

An adequate sample size allowed me the opportunity to make suggestions about the population from the sample; which demonstrates a difference or no difference in the perspectives of the children with SCD, and their caregivers. During this study I consistently used effective evaluation methods throughout the research, proper quantitative coding methods were used, and the data developed meets the quantitative research strategies. Answers provided by the children and their primary caregivers were quantitatively evaluated.

Scope and Delimitations

This study is limited to Black children ages 8–17 with SCD who live in the state of Mississippi. The collected data only represented Black children with SCD who were patients of a pediatric hematology clinic in the Mississippi area, and their caregivers. The participants of this study do not represent all children in Mississippi with SCD. The results of this study could be used for: (a) providing input for disease management and (b) develop interventions to address multiple needs of children to increase their QOL. Special characteristics were delineated of the sample population such as (a)age, (b)gender, (c) education level, and (d) SCD type). A more detailed description of the study population and variables are provided in Chapter 3.

Limitations of the Study

I designed this study to describe the association between SCD pain burden, and the QOL among Black children ages 8–17 in the state of Mississippi. During the process of the data collection and data analysis I remained objective by not influencing these components of the research by my personal opinions. There were several limitations to this study such as, reliability of the answers provided by the children and caregivers may not reveal true feelings, and the results provided from this study will only be of Black children in Mississippi ages 8–17 with SCD who attend the clinic, and their caregivers. In addition, a limitation was that the child and the caregiver had to remember pain and QOL experiences within the last four weeks.

The data were analyzed (i.e., SCD pain burden, and QOL) based on answers from self-reported questionnaires. The participants answered the questionnaires based on their

feelings and beliefs. Answers to self-reported questionnaires were subject to bias regarding how the individual may have been feeling at the time the questionnaire was being completed. For example, if a participant was feeling good at the time of completing the questionnaire their answers might be more positive, but if the participant was not feeling well at the time the questionnaire was being completed their answers might be more negative (Donaldson & Grant-Vallone 2002).

For this study the participants were Black children ages 8–17 in Mississippi with SCD and their caregivers. This sampling approach might have limited the results due to the influence of convenience sampling of participants, and the recruiting environment. The convenience sample can lead to under representation or over representation of the targeted population. Since the clinic is a large tertiary center that provides healthcare services for children with SCD, this limitation was minimized by approaching as many children and caregivers as possible.

Lastly, the generalizability of this study is limited to a population that does not represent all children with SCD as it only included Black children ages 8–17 who were patients of the pediatric hematology clinic. The results of this study only provide the perspectives of the participants and should not be used to describe the larger population of Black children ages 8–17 in Mississippi with SCD, and their caregivers. The variables examined in this study do not provide information on how the general SCD population is affected.

Significance of the Study

SCD is a lifelong genetic condition that affects a substantial number of individuals in the United States, mainly Blacks and specifically in Mississippi. Addressing the needs of SCD from a public health perspective has become important in moving forward to improve outcomes and managing health for those that have this condition (Yusuf, Llyod-Puryear, Grant, Parker, Creary, & Atrash, 2011). As stated previously, although some public health efforts are moving forward to support SCD there are still many disparities (i.e. race, ethnicity, income, education, disability status, social factors, environment, geographic, and research) that decrease the QOL of those with the condition. Given the sparse data on the relationship of SCD pain burden, the QOL in Black children in Mississippi, and with SCD being one of the most common genetic disorders in this population, this research can provide a rich source of information to clarify these associations.

SCD is accepted at the national level as a life-threatening chronic condition, but there is no commitment to increase support of this condition. The CDC identifies SCD and thalassemia as Priority 4 in the CDC National Center on Birth Defects and Developmental Disabilities Strategic Plan; however, SCD is not listed in CDC's 2011 Health Disparities and Inequalities Report (Gibson, 2013). Smith, Oyeku, Homer, & Zuckerman (2006) indicate that there are eight times more community and health support services for individuals with cystic fibrosis than for an individual with SCD. Not much is understood about SCD pain burden and its relationship with the QOL of Black children ages 8–17 in the state of Mississippi. For instance, assessment tools that have been used to measure pain burden and QOL of children with other

chronic conditions are not as popular to use for children with SCD to determine their health outcomes. It is unknown if SCD pain burden and QOL are relevant to health outcomes within this population.

A better understanding of how children view their SCD pain burden in relation to their everyday life will contribute significantly to the literature as well as to positive social change in several ways. First, it will increase the understanding of the relationship between SCD pain burden and QOL. Second, the findings can give a foundation for policy development (e.g., inform, educate and empower, community mobilization, and leadership development for all levels of public health) for the formulation of standards to promote SCD education, accessibility, and quality of services. This may lead to an increase in community and state level planning for resources and health improvements in all jurisdictions. Third, this research can be used to emphasize the importance of linking services, and the availability and accessibility of intervention strategies that incorporate information to improve health and prevent disease. Specific interventions can be developed and implemented based on the results of this study.

Fourth, there has been very little identification of community resources to support promoting health management and the QOL. The findings provide information on the population characteristics as a reference for future studies on the influences of SCD pain burden, and the QOL. Fifth, the findings may lead to better community education specific to the SCD pain burden, and the QOL of children. This study can be used to inform the community of health problems that might exist within the group and empower the community to take ownership of the health problem.

Most children with SCD will live well into their adulthood; therefore, the information obtained from this study can bring social change by developing and implementing strategies to enhance multidisciplinary services for effective disease management, and QOL. From the multidisciplinary services the children will gain the knowledge and skills that are necessary to be successful throughout their life span. For example, developing and implementing a comprehensive SCD pediatric to adult care transition program can provide successful transfer from one level to another. This transition of care involves collaboration among the child with SCD, caregiver, and the healthcare providers, whose goal is to assist the transitioning children in attaining their full potential to live and manage their condition independently (Tredwell, Telfair, Gibson, Johnson, & Osunkwo, 2010). With an increased QOL, the life expectancy of the children may increase.

Summary

SCD is an inherited chronic blood disorder that limits the ability of hemoglobin red blood cells to properly provide oxygen to the body. Complications of SCD can place children at risk of poor daily adjustments, which can ultimately lead to a lower QOL. Chapter 1 provided the validation for the chosen research methods. The components of Chapter 1 included the population that is affected by the genetic condition of SCD, advances of medical treatments that have increased the life expectancy, how SCD pain burden may cause a decrease in the QOL, and the possible influence of the SET. Research centered on the relationship among SCD pain burden, and the QOL in children should be continued to create

evidence that can be used for strategies for reducing pain and increasing QOL. This research is important to gain an understanding of the experience to live as a child with SCD.

Chapter 2 describes the literature in detail, and the implications for public health to discuss the components related to SCD pain burden and QOL in children. Gaps in the literature such as lack of current literature, data and processes will be identified, further justifying the need for this level of research. Gaps in the literature also indicate that it is important to understand how contextual influences (i.e., SET) may impact the SCD pain burden and QOL experience. The SET and its processes as it relates to the subject and public health will be discussed. Chapter 3 provides details of the conceptual framework, variables, and the methods used for this study design. This study examined SCD pain burden and QOL in children using instruments such as; PedsQL and SCPBI-Y questionnaires, and the Demographic Profile. Additionally, Chapter 3 describes the protective measures used to protect the identity of the children and caregivers in the sample population. Chapter 4 provides the results of the research by using methods such as the Hierarchical Linear Regression to determine the association of child SCD pain burden and QOL, and Pearson Correlation Coefficients to analyze the association of child and caregiver's SCPBI-Y and PedQL scores. Results from this study highlight the need for more studies about the influence of SCD pain burden, and QOL of Black children ages 8–17 in Mississippi. Chapter 5 discusses the interpretation of findings, limitation of the research, recommendations, and limitations of the study.

Chapter 2: Literature Review

Introduction

As noted in Chapter 1, the QOL of children with SCD is heavily impacted by the manifestation of this condition. The pain of SCD has been determined by healthcare providers to be the most dominant feature of this chronic condition. There is a significant gap in current literature on the burden of SCD pain, and the QOL of children. In this chapter, I describe in detail a comprehensive review of the literature in five sections: (a) theoretical foundation of the SET, (b) SCD pain burden, (c) characteristics of QOL of children with SCD, (d) child versus caregiver scores, and (e) review related to covariates. In this study, I explored the association between SCD pain burden and QOL in Black children ages 8–17 in Mississippi.

Literature Search Strategy

To retrieve primary literature sources, I conducted a thorough search through the Walden University Library and Jackson State University Library. I obtained information through a variety of academic electronic databases such as Google Scholar, PUBMED, PsycINFO, Academic Search Premier, ProQuest, Science Direct and EBSCOhost. Some of the primary sources were obtained from numerous peer reviewed scholarly journals, and primary text books. I used the following search parameters from 2008 – 2013 for the scope of the literature reviews. I used the following key words for my search: *SCD, sickle cell anemia, SCD in black children and adolescents, children and adolescents with SCD, acute pain, chronic pain, chronic illness, chronic disease, chronic disability, quality of life, health related quality of life, socio- ecological theory in public health,*

socioecological theory in SCD, and *socioecological theory in health behavior.* Some of the search parameters included literature from 1995-2007 in an effort to provide more robust information. SCD is a reemerging area of study and most of the published research about SCD is not focused on pain burden and QOL; however, case related research literature has been referenced. The resources used for the research were all written in the English language and literature reviews were based on research conducted throughout the United States. There is no specific literature to detail the SCD pain burden and QOL of children ages 8–17 in Mississippi.

Theoretical Foundation

Public health is guided by the SET to delineate how the health status of an individual can be influenced by personal relationships, community, and other societal factors (World Health Organization, 2002). This section includes an overview of the SET. Each concentric level (i.e. microsystems, mesosystem, exosystem, and the macrosystem) of the SET may contribute to the individual's or group's well-being because of the influence that the ecological perspective has on the lives of an individual or a group (Trickett, 2009). To fully capture an ecological view of a child with SCD it is important to describe the factors that may influence a child by the social ecological level in which they most commonly exist. The microsystem is comprised of the most immediate influences that relate to the child and this includes (a)caregivers, (b) school, (c) neighborhoods, (d) church, (e) hospitals, and (f)culture; the mesosystem represents the interaction between two or more of the microsystems (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011, Steele & Aylward, 2009). I specifically chose this population because

at the individual and group level the child can experience an interruption in (a)physical, (b)emotional, (c)social, and (d)educational aspects of daily function (Palermo et al., 2008). Also, the child's functioning may influence how caregivers perceive their family system as well as how the family environment is formed (Alderfer, Fiese, Gold, Cutuli, Holmbeck, Goldbeck, Chambers, Abad, & Spetter, 2008; Herzer, Godiwala, Hommel, Driscol, Mitchell, Crosby, & Piazza-Waggoner, 2010).

There have been a few studies that explain how the socioecological framework has been used in health promotion and has focused on children with SCD. Herzer et al. (2010), described these family functioning factors such as SES, caregiver marital status, and the number of children living in the home as significant determinants of QOL and the well-being of a child with SCD or without a chronic medical condition. In addition, Palermo, Riley, and Mitchell (2008) indicated that children with SCD whose families have low SES and live in distressed neighborhoods experience lower QOL. In fact, the microsystem and mesosystem of the SET is congruent with Palermo et al. (2008) and Herzer et al. (2010) research in that children who reside in disadvantaged communities have been determined to have poorer health, developmental, and psychosocial outcomes.

Additionally, Palermo, et al. (2008) continued to point out that at the individual level, children with SCD have experienced more intense pain, which is associated with increased symptoms of social anxiety, internalization, depression, and poor QOL. These factors can influence the individual's microsystem and interaction of the mesosystem which are normally involved with the family, community, and friends. The SET also relates to the individual level "as the child's perception of pain is related to his or her

biology, current emotional state, pain behaviors, and functional disability" (Palermo, et al., 2014, p 9). "All of these factors and their interactions are shaped by the physiological, psychological, social, and emotional changes that characterize development" (Palermo, et al., 2014, p 9). Hence, it makes theoretical sense that the socioecological systems may shape the outcome of the pediatric chronic pain experience (Logan, et al., 2012). Family income, neighborhood distress, and caregiver's marital status were found to be some significant predictors of health outcomes which can also contribute to the QOL.

Schwartz et al. (2011) found that for children with chronic conditions, culture, healthcare policy, and societal values that are associated with the child's health can be important influences of the socioecological system. There is literature that highlights other chronic conditions (e.g., diabetes and obesity) that are similar to SCD regarding the usage of the SET. Carcone (2010) applied the socioecological approach to research social support for adolescents' illness management behaviors. Under the microsystem, the adolescents received support from family, peers, and caregiver's. In addition, support to the family was provided by the healthcare provider utilizing the process of the meso- or exosystem. The many characteristics of the SET distinctively influence the individual's illness and health outcomes (Carcone, 2010).

For this research, I utilized the theoretical framework of the SET to describe the specific social context in which children with SCD are embedded, and how the environment may impact their health. The SET can be used to identify new perspectives for QOL research and social change interventions. I used the SET to show how the theory

conceptualizes how an individual can be embedded within the multiple spheres. This research indicates that the SET has an influence on the pain experience of a child with SCD, and the two most common systems (i.e., microsystems and mesosystem) represent a domain of functioning which is often impaired by pain.

Given that the SET has multiple interrelated spheres that may influence the QOL of children with SCD, interventions can be developed to address not only the individual but include the family, peers, school, and community. The SET provides guidance to understanding the outcome of the QOL, by addressing the contextual variables to include severity of SCD pain, characteristics of the child, family, demographic parameters, psychosocial factors that may impact daily lives, and external variables such as public policies (Tabol, 2008). I chose the SET for this study because it represents a novel approach to understanding social influences on children with SCD. It is important to understand the bidirectional influences as they are linked to children with pain as well as the social systems that are a part of their environment (Logan et al., 2012).

Literature Review Related to Key Variables

Sickle Cell Disease Pain in Children

Acute and chronic pain is the common hallmark of SCD, which is a life threatening and incurable condition (Barakat, et al., 2008; Palermo, et al., 2008; Zempsky et al., 2013).The lack of healthy red blood cells to carry oxygen throughout the body causes recurring episodes of severe pain that may cause organ damage, serious infections, stroke, tiredness, irritability, jaundice, slow growth, fast heart rate, pale skin color, and delayed puberty (Centers for Disease Control and Prevention, 2012). Other complications of SCD are hemolytic anemia,

cerebrovascular accidents, vasoocclusions, opthamological complication, and fatigue (Frank, Allison & Cant, 1999; Gustafson, Bonner, Hardy& Thompson, 2006; National Institute of Health, 2002; Mayes, Wolfe-Christensen, Mullins & Cain, 2011).

Children with SCD experience vaso-occlusive acute pain that occurs more than 5 times a year, and sometimes lasts for up to 3 days (Lenmanek, Ranalli, Green, Biega & Lupia 2003; Lim, 2009). In addition to vaso-occlusive acute pain episodes, chronic pain is also associated with children with SCD. There has been limited discussion on the impact of chronic pain within the SCD pediatric population. Chronic pain is more common in adults and adolescents with SCD than in younger children (Schecter, 1999; Lim, 2009). The frequency of SCD chronic pain increases in a child as they mature from childhood into adolescents, and then adults (Panepinto et al., 2005).

Evidence shows that vaso-occlusive painful events significantly impact the physical and psychological functioning of children with SCD (Brandow et al., 2010), and children may continue to experience pain at home and functional limitations after receiving medical care (Brandow, Brousseau, & Panepinto, 2008). Additionally, Long, Krishnamurthy, and Palemero (2008) noted that children who have chronic SCD encompass the same behavior patterns as children who experience juvenile idiopathic arthritis and headaches. Children with chronic pain often experience sleep disturbance as a common dysfunction (Roth-Isigkeit, Stoven, Schwarzenberger, & Schmucker, 2005), and chronic pain is also associated with daytime functioning in school-age children (Long, Krishnamurthy, & Palemero, 2008).

The goal for treating SCD is to relieve pain; (a) prevent infections, (b) organ (c) damage, stroke, and (d) manage the condition. Mild to moderate pain is regularly treated at home with

over the counter medications such as heating pads, rest, and fluids (National Heart, Lung, and Blood Institute, 2013). Fluids assist in preventing dehydration, and acetaminophen (Tylenol) and nonsteroidal anti-inflammatory drugs (Ibuprofen) are provided for mild to moderate pain. Treatments for acute pain are fluids, medicines, and oxygen therapy (National Heart, Lung, and Blood Institute, 2013). Medications and procedures such as hydroxyurea, blood transfusions, and bone marrow transplants are used as alternative solutions to treat severe pain crisis. Hydroxyurea is an oral medication that is used to decrease the occurrence of painful SCD crisis and acute chest pain. Blood transfusions are provided to prevent life threatening conditions such as spleen problems, acute chest syndrome, and stroke. However, not all individuals with SCD need blood transfusions (National Heart, Lung, and Blood Institute, 2013).

As previously mentioned, children with SCD experience acute and chronic pain that can interfere with their daily functioning. Gil et al. (2000), Graumlich et al. (2001), and Palermo, Lewandowski, Long, and Burant (2008) explained that SCD related pain episodes can interfere with a child's daily living such as: social relationships, physical factors, recreational factors, emotional factors, school factors, sleep factors, and eating habits. Graumlich et al. (2001) also indicated that caregivers recognize SCD pain as being more emotionally burdened. Aspects of pain were reported more by children while cognitive and emotional factors were not considered relevant to them; however, caregivers and children had anxiety about future pain episodes (Graumlich et al., 2001). In addition, factors such as caregiver stress (Guntlett-Gilbert & Eccelston, 2007), caregiver's response to the child's pain (Peterson &

Palermo, 2004), and caregiver's attention to the child's pain (Van Slyke &Walker, 2006) have been found to impact the pain and daily functioning in children with SCD.

The perception and location of SCD pain are important to determine proper treatments and interventions. Children should be able to explain their pain experiences in regard to where and what type of pain occurs as well as how the pain may affect their daily routine. As noted by Graumlich et al. (2001), Jacob, et al. (2003), and Fosdal (2015), children and their caregivers have reported that the arms, legs, abdomen, chest, and back are the most common areas of pain. In addition, Jacob et al. (2003), and Fosdal (2015) found that the most common sensory and affective words used to describe SCD pain by children were throbbing, aching, hurting, dizziness, and crying. Frequent evaluative words used as descriptors were uncomfortable, annoying, and uncontrollable (Fosdal, 2015). Jacob et al. (2003) also found temporal words such as steady, constant, and always to be common words chosen to describe SCD pain.

Children with SCD have shared their perceptions of SCD pain, the use of medication and healthcare services, and activity reduction during pain episodes by using daily pain dairies to describe their experiences. It is the opinion of researchers and healthcare providers that the daily dairies are useful for children and caregivers to track SCD pain, and disease symptoms (Gil et al., 2000; Gil et al., 2003). Gil et al. (2000) indicated that by using daily dairies children with SCD typically reported experiencing low levels of pain that was managed at home, and sometimes without medication. Healthcare services such as narcotic medication and healthcare providers were used for children who experienced increased pain (Gil et al., 2000). Caregivers and children agreed on daily pain intensity responses, and

salient events such as healthcare services. When the child experienced an increase in pain daily activities (i.e. reduced school, household and social activities) were decreased there was an increase in pain children decreased their daily functioning's (Gil et al., 2000). In a similar study, Gil et al. (2003) assessed daily stress and mood of children with SCD by reviewing their daily dairies. Daily stress and mood of children were assessed to determine their association with pain, health care, and school activity. Gil et al., 2003 determined that daily stress and mood were associated with fluctuations in same day SCD pain. Increases in stress and negative mood on a daily basis were associated with increase in same day pain and positive mood. Gil et al., 2003 suggested that some caregivers disagreed with the collection of information through the daily diaries, deeming that the children may not provide accurate information.

Zempsky et al. (2013) disagreed with the methods of daily diaries in that the difficulties to assess the children with SCD in a clinical setting, and not being able to understand their written responses. Due to time constraints a daily dairy was not sufficient for the proposed study. To easily assess the target population of Black children ages 8–17 with SCD, and their caregiver's questionnaires were provided in a clinical setting. Although there are several assessments that have been employed in the clinical setting to assess SCD pain burden, most of these tools are long, as well as difficult to use.

Zempsky et al. (2013) developed the SCPBI-Y a brief, reliable seven item disease specific questionnaire that was recently validated to measure the impact of pain on physical, social, and emotional function in children with SCD. To date the SCPBI-Y is the only SCD specific measure of pain burden for children, adolescents, and young adults ages 7 to 21. In

addition, the SCPBI-Y questionnaire was developed to measure core QOL dimensions such as physical, emotional, social, and school functioning (Zempsky et al., 2013). The evidence shows that the SCPBI-Y is a valid and reliable multidimensional tool that can be used to evaluate SCD pain burden in children with SCD. The SCPBI-Y demonstrates strong internal consistency reliability, cross informant concordance, and test-retest reliability (Zempsky et al., 2013).

This tool shows moderate to strong evidence of construct validity and was found to have validated measures for mood, functional ability, pain, and QOL (Zempsky et al., 2013). The limitation of the SCPBI-Y is that the caregiver and child are asked to remember pain experiences from over the last month. The SCPBI-Y is a unique tool because it was designed specifically for children with SCD and there is a caregiver report version to compare across informant information (i.e., child and caregiver). It is clear that there is a strong relationship among chronic pain and function, and pain and QOL (Long et al., 2008; Gold et al., 2009; Wilson & Palermo, 2012), and specifically SCD pain (Graumlich, et al., 2001; Palermo et al., 2008)

For this study, I used the SCPBI-Y to continue the validation of this instrument for children who experience acute and chronic SCD pain. The SCD pain burden is identified as encompassing pain, burden of pain on the physical function, social/community participation, and emotional aspect of daily living. The SCPBI-Y provided the opportunity to quickly assess pain burden and broaden the understanding of how pain specially affects children with SCD, other than using pain intensity scores and healthcare utilization (Zempsky et al., 2013). A disease specific measure to indicate the interference of SCD pain burden of children can be valuable to healthcare providers and other public health practitioners to

enhance their understanding of the child's pain, and to be able to recognize behaviors that are associated with SCD pain. This assessment is deemed important to facilitate the proper interventions to provide better care for children with SCD through healthcare services, proper medication, and behavioral and physical treatments.

Quality of Life of Children with Sickle Cell Disease

With early diagnosis and advanced medical treatment children with SCD are living well into adulthood (Lim et al., 2012). Because children with SCD are living well into adulthood it is important to measure their QOL, as this population should have the ability to live independent and productive lives. The QOL a multidimensional concept has several domains and facets that can be used to measure general QOL and health (World Health Organization, 1995; Table 1). The information generated for this study is based on the defined domains and facets that can be used for facilitating an understanding of the QOL for an individual with SCD. Table 1 provides the framework that defines the QOL for assessing an individual or a group with a chronic condition such as SCD (WHOQOL Group, 1995).

Table 1

World Health Organization Quality of Life Assessment

	Domain	Facet
I.	Physical	Pain and discomfort, Energy and fatigue, Sleep and rest, Sexual activity
II.	Psychological	Positive feelings, Thinking, learning, memory and concentration, Self-esteem Body image; Negative Feelings
III.	Level of Independence	Mobility, Activities of daily living, Dependence on medication and treatments, Working Capacity
IV.	Social Relationships	Personal relationships; Social support
V.	Environment	Physical, Safety Home Environment, Financial Resources, Health and social care: available and quality, Opportunities for acquiring new information and skills, Participation in and opportunities for leisure, Physical environment: pollution, noise, and traffic Transport
VI.	Spirituality	Religion/personal beliefs

Note: Information represents the domain and facets defined by WHO to assess quality of life. Table 1: Adapted from WHOQOL GROUP, 1995.

To date more attention has been focused more exclusively on the health-related quality of life (HRQL) of children with SCD. The difference among the two is that the HRQL evaluates the individual's objective health status (Lee, Chronister, & Bishop, 2009), while the QOL determines how a health condition may influence an individual's facets of life including physical, social, economic, and psychological wellbeing (Hays, Vickery, Hermann, Derrine, Cramer, Meador, Spritzer & Devinsky, 1995; Upton, Lawford, Eiser, 2008). There is research that suggests children with SCD experience lower QOL. SCD pain can predict several facets of QOL such as: (a) lower academic performance (Schatz, 2004; Steen, Finberg-Buchner, Hankin, Weiss, Priftera & Mulhern, 2005; Howard et al., 2008), (b) decreased social activities (Forgeron King, Stinson, McGrath, MacDonald, & Chambers, 2010), (c) sleep disturbance (Long et al., 2008), and (d) school absences (Schwatz, Radcliffe, & Barakat, 2009). For example, Steen et al. (2005) found that children with SCD in kindergarten

show deficits in particular kindergarten readiness skills that are important for future academic achievements in reading and math. Further, Howard et al. (2008) indicated that SCD pain episodes in children can cause frequent and long hospital stays which may interfere with family and peer relationships, school, and social lives. Moreover, Zempsky et al. (2013), indicates that children with SCD experience have lower QOL as compared to healthy children their age.

In addition, Palermo et al. (2002) and Panepinto et al. (2005) found that the frequency of pain episodes can lead to a decreased QOL. Palermo et al. (2002), describe that children with SCD experienced psychosocial maladjustment that affects their QOL as compared to healthy children. This study also indicated that SCD related complications were reviewed from the medical charts were associated with determining the children's QOL (Palermo et al., 2002). Another major finding is that Mann-Jiles & Morris (2009) based their idea on QOL measures that are important and sometimes is a necessary component to evaluate for the determination of health outcomes. Though the research on the QOL of children with SCD is limited it is an important outcome measure to assess within this specific population. There is a need to study the QOL in children with SCD in an effort to develop and implement interventions to improve their QOL.

These studies can be used to develop and implement interventions that will help transition into adulthood or for planning appropriate treatments (King, Schwellnus, Russell, Shapiro, & Aboelele, 2005), which can be used to facilitate a better QOL. In addition, the study of this topic can ensure that health and social needs are properly evaluated (Palmero et al., 2002). It is recognized that QOL outcomes are important to measure in an effort to demonstrate that children who have chronic conditions should be

included in the decisions made on their disease management and increase their patient and provider relationships to improve their QOL (Eiser & Morse, 2001). Currently, there is not a disease specific self-report tool to measure the QOL of children with SCD.

There were three options to select from to assess the QOL of children with SCD for this study; the Youth Quality of Life Instrument (Patrick, Edwards &, Topolski, 2002), Child Health Questionnaire (CHQ; Landgraf &Ware, 2002), and the PedsQL4.0 (Vami et al., 2001; Varni et al., 2002). The Youth Quality of Life Instrument is a self-administered questionnaire designed for children with or without a chronic condition for the ages of 11-18 (Patrick et al., 2002). The Youth Quality of Life Instrument was not selected for this research because the questionnaire has 41 perceptual items which would be too long to complete in a clinical setting. In addition, the age range is only for 11-18, which does not provide the opportunity to assess the QOL of children ages 8-10. The Youth Quality of Life Instrument does have a 15-item questionnaire; however, these items are contextual, and the research proposes to collect data based on the child's perception. The CHQ has been validated as a self-report tool and found to work well in assessing children with SCD (Landgraf &Ware, 2002). However, this 87-item instrument is too long to administer in a clinical setting.

To provide a more comprehensive evaluation of the QOL in children with SCD I used the PedsQL4.0 (Vami et al.,2001; Vami et al.,2002) as a measuring tool for this study. I chose the PedsQL4 .0 for this study because it is valid and reliable for use with chronically ill children and healthy children that are the ages of 2 - 18 (Vami et al.,2001; Vami et al.,2002), and has been noted as acceptable reliability as measured by internal

consistency (Schmidt, Garratt, & Fitzpatrick, 2002). The PedsQL4.0 is (a)brief, (b) practical, (c) flexible, (d) developmentally appropriate, (e)multidimensional, (Vami et al.,2001; Vami et al.,2002), and (f) easier to administer in a clinical setting. The PedsQL4.0 generic core scales were created to assess the main health dimensions as determined by the WHO (Hullmann, Ryan, Ramsey, Chaney & Mulling, 2011). The PedsQL4.0 provide subscales scores in different domains such as physical, emotional, school, and social functioning (Vami et al., 2001; Lim, 2009; Cohen & Biesecker, 2010). For example, the PedsQL4.0 includes a social functioning subscale that is used to assess peer relationships, as compared to the CHQ caregiver report form that assesses the family and parental impact of the child's health (Palermo, Long, Lewandoski, Drotar, Quittner, & Walker, 2008).

Palermo et al. (2008) has indicated that the PedsQL4.0 is a "well established" instrument for assessing the QOL of children. Another unique feature of the PedsQL4.0 is the caregiver report version for young children, as well as a long and short version of the questionnaire (Vami et al., 2001; Vami et al., 2002; Palermo et al., 2008). Having caregiver and child versions of the tool will allow for cross-informant comparisons. The limitation of the PedsQL4.0 is that children and their caregivers are asked to recall information from the past month. For example, the child and the caregiver may not be able to complete school-related questions if the child has not recently been to school (Hullmann et al., 2011).

I selected the PedsQL4.0 for this study because children can report on their QOL in a clinical setting to provide unique information about their daily function that may influence the QOL. In addition, the PedsQL4.0 was chosen for this study because it can determine the QOL

in children and adolescents with severe (i.e. acute) and persistent (i.e. chronic) health conditions. The generic score and disease specific scores of the PedsQL4.0 questionnaire can be combined into one measurement system (Vami, 2015). The results analyzed in this study can lead to improvements to create specific public health interventions, which may foster greater social change in healthcare and public health education resources. The information utilized in this study can also be beneficial to longitudinal design studies which can provide further evidence of QOL in children with SCD.

Child-Scored and Caregiver-Scored Questionnaires

In past and current research, the information about SCD pain and the QOL have been reported from the caregiver's and child's point of view. The caregiver's and child's report of physical health are usually the same, given that the caregiver reports are based on what they see (Panepinto et al., 2005; Barakat et al., 2008). Nevertheless, caregiver and child reports can differ on the child's QOL (Eiser & Morse, 2001). Because SCD is a debilitating chronic condition caregiver have a tremendous responsibility in assuring their proper growth and development (Panepinto et al., 2005), and as the child grows and becomes more independent that caregiver may not know as much as they perceive to (Gil et al., 2000).

As stated previously the PedsQL4.0 and the SCPBI-Y has shown strong cross informant concordance among children with SCD and their caregivers and was used for this research. The PedsQL utilizes a 5- point likert scale (0= never a problem to 4= almost always a problem), and scores are reverse scored and transformed to a 0-100 scale with higher scores indicating a better QOL (Varni et al., 2001; Vami et al., 2002).

The PedsQL also developed a caregiver proxy report for children ages 8-12 to compare caregiver and child self-reports (Vami et al., 2001; Vami et al., 2002). The SCPBI-Y utilizes the following scoring none= 0, few=l, some=2, many=3, and every=4. Also, scores range from 0 (no pain burden) to 28 (severe pain burden; Zempsky et al., 2013).

Children and their caregivers can disagree or agree on their perceptions of the child's SCD pain burden and QOL. For instance, caregivers may pay more attention to the future impact of the child such as living independently, and excelling academically in school, whereas the children may focus more on immediate consequences of the illness such as missing their friends, missing out on social activities, and not being able to participate in sports (Graumlich et al., 2001; Panepinto et al., 2005). Additionally, healthcare providers and researchers have depended on the response of caregivers to depict the needs and determine the QOL of children with SCD. Graumilch et al. (2001) show pediatric SCD as being primarily measured by caregivers, or a health professional's report which neglects the child's perceptions. As noted before children should be able to express their feeling of pain, and factors that may interfere with their QOL.

The agreement and disagreement of caregiver and child perception of pediatric pain and QOL have been used in several evidenced based assessment studies. Studies have shown strong correlation between children and caregiver reports of bodily pain. Barakat et al. (2008) indicate that caregivers and children's report of child SCD pain are somewhat consistent but are mostly conflicting for interference with activities and pain descriptors. In addition, Barakat et al. (2008) point out that understanding the concordance of

children with SCD, and their caregiver reports of pain can contribute to improvements in home pain management, because SCD pain is mostly managed in the home. Barakat et al. (2008) also indicated that assessing child and caregiver responses of pain can contribute to the development of interventions that would: (a) increase caregiver and child communication about pain and pain interference, (b) confidence in disease management, and (c) improve knowledge of SCD and its care.

As compared to Barakat et al. (2008) and Graumlich et al. (2001) were able to obtain four key areas of concordance pain intensity scores for children and caregivers were similar in (a)highest for "worst home pain" and "worst hospital pain", (b) children and caregivers reported similar pain descriptors, (c)children and caregivers reported similar emotional variables, and (d)children and caregivers reported that SCD pain interferes with the daily function of the children (e.g. disliked activities and school attendance). Although caregivers of children with SCD can provide useful information about the child's SCD pain burden and QOL, their responses should not be substituted for their children's. Panepinto et al. (2005) used the caregivers and child's perspective on how SCD can impact the QOL. It was determined that the caregivers of children with SCD reported lower QOL (Panepinto et al. 2005).

Barakat et al. (2005) conducted a similar caregiver proxy study on the assessment of QOL in children with SCD. Children with SCD were compared to children with leukemia; (a) children with SCD had significantly lower QOL, (b)social competence, and (c)self-competence (Barakat et al. 2005). Both child and caregivers report on the QOL can provide important information about day to day activities and

functions of children with SCD. Lim (2009) has suggested that a prospective child report of SCD pain and the QOL are important to consider for pediatric intervention research.

Information from self-report questionnaire allow researchers and healthcare providers to retrieve important data on the children's (a)experiences, (b)feelings, (c)attitudes, or (d)beliefs about their chronic condition, (e)as well as modify their treatment to their specific needs. Caregiver and child SCD pain burden and QOL concordance data supports the need of gathering information from across informants (i.e. children and caregivers). In this study, I compared and analyzed for each question caregiver and child responses. The analysis provided information on knowing if children and caregivers agree or disagree on the burden of SCD pain and QOL. Not only would this study be valuable in reporting children and caregiver perceptions, and to also support the need to measure alternative outcomes such as child and family functioning that could ultimately improve the QOL of the child.

Review Related to Covariates

Kleinbaum & Klein (2005) defines a covariate as a secondary variable with no interest that can affect the relationship between the dependent (i.e., QOL) and independent (i.e., SCD pain burden) variables. A covariate can be correlated to both the independent and dependent variable or when independent variables combine to affect the dependent variable (Kleinbaum & Klein, 2005). As noted previously the covariates for this study include age and sex of children, and caregiver SES. The covariates were controlled to assess the association between SCD pain and QOL of children with SCD. Some literature has found a greater likelihood that age, sex, and caregiver SES are

factors that may be associated with SCD pain burden and the QOL. Palermo et al. (2002) and Palermo et al. (2008) identified age and sex of a child as well as SES as important socio-demographic variables to consider when evaluating children with SCD. In addition, Panepinto et al. (2009) interests of covariates in their study were family income and age of the child in the presence of SCD. Their results determined that children with SCD have worst HRQL and older children with severe SCD have the lowest family income (Panepinto et al., 2009).

Consequently, males may endure more SCD pain than females before expressing themselves or taking medication (Martin et al., 2006). In addition, it has been determined in pain research that pain increases with age after controlling for pain intensity (Martin et al., 2006). SCD pain has a negative impact on the QOL of children. As previously stated, pain is known to impact activities such as: (a)recreational activities, (b)school attendance, (c)peer relationships, (d)caregivers work, and (e) family activities (Schatz, 2004; Steen et al., 2005; Howard et al., 2008; Forgeron et al., 2010; Schwatz et al., 2009).

In regard to caregiver SES, a variety of outcomes for children such as: (a) cognition, (b)health behaviors, (c)antisocial behaviors, and (e)educational attainment (Conger, 2010; Patrick, Winghtman, Schoeni, & Schulenberg, 2012) have been linked to family SES. For this study, I used the definition of SES as caregiver's education (i.e. less than high school, high school diploma, GED, vocational training, some college and college graduate) and income level (i.e. approximate total family income in the past 12 months) (Centers for Disease Control and Prevention, 2014). SES is a factor in health

disparities for several chronic diseases, and researchers have demonstrated that children whose caregivers have low income suffer significantly higher morbidity from chronic disease than children whose caregivers have higher income (Feudtner & Noonan, 2009). SES disparities in health outcomes during childhood can interfere into the health as (a) an adult, social, (b)vocational, (c)economic, and (d) psychological consequence (Braveman & Barclay, 2009; Delaney & Smith, 2012; Halfon, Houtrow, Larson, & Newacheck, 2012). Additional information is needed to extend the literature on factors such as age, sex, and caregiver SES which may be associated with SCD pain burden and QOL. This study can help to develop and identify the most appropriate interventions and treatments for black children ages 8–17 with SCD.

Summary

The literature in Chapter 2 has demonstrated that the research on SET, SCD pain burden, QOL and child and caregiver concordance can be enhanced to show that there is a linear relationship. The research demonstrates that the components play a pivotal role in the QOL in children with SCD. SCD is a genetic condition that negatively impacts the lives of children and others that are a part of their lives. SCD impact on daily lives of children (i.e., physical, emotional, social and school) is very influential in shaping an individual's health trajectory. In chapter 3, the quantitative methodology used for this study is explained in detail. This process includes data collection, data management, and data analysis. The assessment tools used in this study to gain the perspectives on the lives of children and adolescents with SCD are described in detail as well. Because SCD impacts so many facets of a child's life (i.e., physical, social, academic, psychological) it is important to continue the

study of this disease. This study can also add important information about the impact of SCD.

Chapter 3 Research Methodology

Introduction

In this chapter, I defined and discussed the research methodology that I used to examine the association between SCD pain burden and the QOL among black children ages 8–17 in Mississippi with SCD. This chapter includes the research methodology, a description of the study design, sample population, instruments used, data analysis, and ethical considerations.

Research Design and Rationale

I used a cross-sectional study design and quantitative methods for this study. When a hypothesis is developed to examine the relationship of two or more distinct variables, the most appropriate approach is quantitative (Creswell, 2009). The current studies main outcome variable was the QOL, and the predictive variable was SCD pain burden. I adapted the study questionnaires from the PedsQL4.0 SCPBI-Y to investigate if there is an association between the outcome and predictive variables (Vami et al., 2001; Varni et al., 2002; Zempsky et al., 2013). I used the demographic information demonstrated in the research of Panepinto et al. (2005) and Dale et al. (2011) as a guide to development the standard questions of the Demographic Profile Questionnaire. The demographic information is important to collect meaningful data to adequately describe the characteristics of the participants.

The research provides an exploration of the association of SCD pain burden and the QOL. I determined that the correlation approach was appropriate for this study because the participants provided self-reported responses to questionnaires based on their perceptions of

SCD pain burden and QOL. SCD pain burden and QOL have not been previously examined in Black children in Mississippi with SCD. Although SCD pain burden and QOL can be assessed in Black children in Mississippi with SCD; this design cannot be used to determine causality. I collected primary data where the bias is minimized, and the data collection instruments have previously been validated. The disadvantage of collecting primary data are low response rates and unanswered questions. It was anticipated that the response rates would not be low because of the format of the questionnaires such as: minimized length of questionnaires, difficulty reading the questionnaires, simple format of the questionnaires, and the questionnaires are not ambiguous. Only necessary questions that apply to the study are asked, and clear instructions were provided to the children and caregivers.

Methodology

Population and Sampling Method

I used convenience sampling of Black children ages 8–17 with SCD and their caregivers. The sample was selected from a pediatric hematology clinic where Black children ages 8–17 with SCD were provided healthcare services. The convenience sampling strategy was chosen for this research because the subjects were readily available. In addition, the pediatric hematology clinic is the only place where the targeted population can easily be found. According to Lavrakas, 2008, the convenience sampling strategy allows the researcher to achieve the sample size that is needed in an adequate amount of time and in an inexpensive way.

After a regularly scheduled clinic visit, children and their caregivers were approached by the researcher to determine their interest in participating in the study. Approximately 275 active patients with SCD are followed at the pediatric hematology clinic in Mississippi and were the

target population for this study. Only Black children ages 8–17 with SCD, and their caregivers were included in the study. It was important for the study that caregivers and their child participate together.

If the caregivers and children were interested in participating in the study, the clinic administration assisted me with identifying them as participants. In addition, the clinic administration provided flyers that explained the study to caregivers and patients. I explained the study to the participating children and their caregivers, obtained written consent and assent, and assisted children and caregivers with completing the questionnaires if necessary. Compensation was given to the participants for their time. I determined that the amount of compensation was appropriate for the time and effort put forth by the study. The participants were offered one gift card per family.

The self-reported questionnaires were conducted face-to-face with child and caregiver while in a clinical setting. The face-to-face approach was successful in gaining the trust of the child and caregiver to receive personal answers on the questionnaires (Dolinsky, Armstrong, Walter, & Kemper, 2012). Each of the children and their caregivers received and signed an informed and assent consent form before I provided them with the questionnaires. After the consent forms were signed, the children and their caregivers were provided with the questionnaires. Each child and caregiver pair were provided with a $5.00 gift card for their time and completing the questionnaires. Children and caregivers completed the same self-reported questionnaires separately.

Findings from this research study can be generalized to Black children ages 8- 17 with SCD in Mississippi who attend the pediatric hematology clinic. In similar studies, Panepinto et

al. (2005) and Dale et al. (2011) study objectives were used to describe the HRQOL of children with SCD as reported by the child and caregiver and compare the relationship between the two. Panepinto et al., 2005 and Dale et al., 2009 used the statistical power analysis for their studies about children with SCD to determine their HRQL. I chose the statistical power analysis for this study based on their past studies. In addition, Zempsky et al., 2013 has the only current study to date that has used a tool specific to SCD to assess the burden of pain in children. I used the Statistical Package for Social Science (SPSS) software to conduct the statistical analysis for this research.

I conducted the data analysis to determine the correlation between child and caregiver scores of HRQL. Dale, et al. (2011) and Zempsky et al. (2013) used the PedsQL 4.0 questionnaire to assess HRQOL as reported by the child and caregiver. Lim (2009) used the PedsQL to assess the QOL of children with SCD. I used similar methods from these studies such as: (a) Pearson Correlations of child and caregivers scores, and (b) PEDQL4.0 and SCPBI-Y assessment tools. The objective of this study was to determine the association of SCD pain burden and the QOL as reported by the child and their caregiver, and to compare the child and caregivers reported SCD burden and QOL.

In Dale et al. (2011) and Zempsky (2013,) the sample size population ranged from 124 - 129 with the age range of 7 - 21. Similarly, in this study the sample size of $n=85$ based was used based on an expected minimum effect size = .2 for this study, which has been used by others to denote minimum clinical significance (Panepinto et al., 2005; Dale et al., 2011; Zempsky, 2013). Additionally, I used GPOWER3 as the sample size calculator to calculate the optimal sample size for power of 80% *(n=55),*

with an alpha of 0.05% and 80% confidence interval for the study population (GPOWER3, 2017). The sample size of 55 represented the caregiver and child as a pair. I expected that more than a 50% response rate to provide a cushion against lower response rates; the hematology clinic allowed the recruitment of as many participants as needed.

Participant Characteristics

The characteristics of the study participants for this primary data analysis are described in the inclusion and exclusion criteria table below.

Table 2

Participants' Characteristics for Sickle Cell Disease Pain and Quality of Life Study

Inclusion Criteria	**Exclusion Criteria**
Black male and female children ages 8-18 who have been diagnosed with SCD by a health care physician and have Mississippi residency	Non-Black Children without SCD ages 8-18
Primary caregiver of children ages 8-18 who receive healthcare services from the Pediatric Hematology Clinic and have Mississippi residency	Non-caregivers or parents of the child with SCD
Black males and females who are patients of the Pediatric Hematology Center	
The participants must have signed and dated consent and/or assent form by the child and caregiver	
Children and caregivers must speak and read English	

Note: The information explains the inclusion and exclusion of participants of this study.

Data Collection

To begin the study, I gained approval from Walden University Institutional Review Board (IRB), and the Pediatric Hematology Clinic External Review Request Committee (Walden University IRB #11-14-16-0150979, and External Request Review Committee #1032). After the IRB approvals were granted, the second step was to schedule a time and date with the Pediatric Hematology Clinic administration to begin the study. The pediatric

SCD patients were seen in the hematology clinic on Tuesdays and Fridays of each month from 8am to 5pm. The third step was the recruiting process. I recruited participants for this study, at the clinic on Tuesdays and Fridays from 8am to 5pm. As a part of the recruitment process, flyers were provided to children and their caregivers. The flyers were provided by the clinic administration during the check-in and check-out point of the child and caregiver clinic visit. In addition, flyers were placed throughout the clinic which provided information about the study. The flyers provided the researcher contact information such as: (a)phone number, (b)email address, and (c)the time and days the researcher will be at the clinic.

The informed consent and assent forms stated the purpose and methods of the study, describe confidentiality, information on risk and benefits, and informed the participant that their participation was on a volunteer basis, and they may continue or remove themselves from the study at any time. I requested a signature and date of each participant on the consent and assent forms. Upon completion of the consent/assent forms, the fourth step was to provide the children and their caregivers with questionnaires. I provided the children with two questionnaires the SCPBI-Y (Zempsky et al., 2013) and PedsQL (Varni, Seid, & Kurtin, 2001). In addition, I provided caregivers with three questionnaires, SCPBI-Y (Zempsky et al., 2013), PedsQL (Vami, Seid, & Kurtin, 2001), and a Demographic Profile.

I used the SCPBI-Y (Zempsky et al., 2013), and PedsQL (Varni, Seid, & Kurtin, 2001) questionnaires were adapted from previous validated questionnaires used among children with SCD. Additionally, caregivers provided information on a Demographic Profile Questionnaire, which included the child's age, race, sex, and education level, as well as the caregiver's education levels, income levels, and relationship to the child. I provided

caregivers with The Demographic Profile Questionnaire to request child's SCD characteristics. I anticipated that the questionnaires would take at least 15-20 minutes to complete. The caregivers and children were given the option to participate in the study by taking the questionnaires home, if their time did not allow for the completion of the questionnaires at the clinic. A self-addressed envelope was provided to potential participants, so that they were able to complete all the consent forms and questionnaires and mail to the researcher. In addition, I provided information to the potential participants about returning to the clinic to participate in the study on the days and times stated on the flyer when the researcher was present.

After the questionnaires were completed, the final step for the data collection process included collecting questionnaires from the children and caregivers. All information collected from the children and caregivers were kept confidential at all times. All of the information that I retrieved and reviewed for this study was deidentified by using identification (ID) codes and other unique identifiers. The names of the participants were not revealed for this study. I identified the participants and paired them by using ID numbers at the time of data entry. The data collected were primary; however, there was minimal to no risk to the participants. Further, I developed passwords to access the database that stores the participant's information. As the researcher, I was the only person who had a password to access the database.

I chose the questionnaires and place of recruitment based on previous studies that have recruited and collected data within a clinical setting (Zempsky, 2013, p 3; Lim 2009, p 23), also the potential limitations were noted. To get the true perspective of the children, the

caregivers were not allowed to help the children with answering their questionnaires. The children's and the caregiver's questionnaires were completed separately. If the children had a question about the questionnaires or trouble reading the questionnaires the I was available to answer questions and read the questions to the participants.

Instrumentation and Materials

For this study, I collected quantitative data using the following instruments: SCPBI-Y (Zempsky et al, 2013), PedsQL (Varni et al., 2001; Varni et al., 2002), and a Demographic Profile Form (Appendix A). Because this study examined the influence of SCD pain burden, and the QOL of children ages 8–17 these tools were found to be the most appropriate for the current study. The SCPBI- Y questionnaire was developed in a format to compare and contrast the child and caregiver perception of SCD pain burden (Zempsky et al., 2013). The PedsQL questionnaire was developed to determine the perceived QOL of children with chronic conditions (Varni et al., 2001; Varni et al., 2002). To date there is no disease specific measure that is used to assess the QOL of children and adults with SCD. I used the Background Demographic Profile Form to assess the caregiver's SES and demographic variables (i.e., age, race, gender, marital status, education levels, income levels, employment status, and relation to the child). According to Shavers (2007), SES is frequently implicated as a contributor to health disparities which may impact QOL. The participating caregivers completed the following instruments; (a) SCPBI- Y, (b) PedsQL, and (c)Demographic Profile Questionnaire. All instruments used in this study are presented in Appendix A and were self-administered and completed using pen and paper.

Sickle Cell Disease Pain Burden Interview-Youth

I examined the SCD pain burden of children with SCD, and thus the SCPBI-Y was an appropriate tool to use for measuring pain. The SCPBI-Y is a brief multi-dimensional seven item SCD specific tool that was created to determine the effect of pain on bodily, community, and emotional aspects of daily activities in children with SCD (Zempsky et al., 2013). The SCPBI-Y was created by a group of individuals who have comprehensive knowledge and skillful in the area of SCD pain. This tool was used to enhance the understanding of the burden of pain in children with SCD (Zempsky et al., 2013). To date the SCPBI-Y is the only brief self-report disease-specific measure that can be used to evaluate SCD pain burden of children in a clinical setting (Zempsky et al., 2013).

The seven questions of the SCPBI-Y use a Likert scale (i.e., none, a few, some, many and every). For example, some questions ask: (a)How many days have you had any pain, and (b)How many nights have you slept poorly (i.e., trouble falling asleep, walking up during sleep because of pain (Zempsky et al., 2013). The SCPBI-Y yields a numeric score with a higher number showing higher SCD pain burden. The following scoring was used: (a)none= 0, (b)few=l, (c)some=2, (d)many =3 and (e)every=4, and scores range from (a)0(no pain burden) to (b)28 (severe pain burden). The children and their caregivers were asked to select one response for each inquiry (Zempsky et al., 2013). The participant population used for testing the SCPBI-Y were children and young adults ages 7-21 with SCD. The study participants enrolled from four urban children's medical facilities in the eastern United States (Zempsky et al.,2013).

The SCPBI-Y demonstrates the validity and reliability for the usage in a clinical setting. Zempsky et al. (2013) study showed that the SCPBI-Y had (a)strong internal consistency reliability, (b)cross informant concordance (i.e., child- caregiver), and(c) test-retest reliability (i.e., outpatient setting; Zempsky et al., 2013). The internal reliability of the SCPBI-Y questionnaire was assessed by using a Cronbach's alpha. The SCPBI-Y indicated strong reliability among the outpatient participants (*a=.909, n=62*), inpatient participants (*a =.821 n=67*), and all participants combined (*a =.891, n=l 29*; Zempsky et al., 2013). The test-retest reliability was determined by the relationship among SCPBI-Y scores of the inpatient participants and after one week using Pearson's correlation coefficient of the outpatient participants. Of the 62 participants in the outpatient group, there were 15 participants who were reached by telephone, however were not available to participate during the designated time period of the study (Zempsky et al., 2013). As hypothesized the SCPBI-Y showed strong test-retest reliability following the one-week time frame (*n=47, r=.80, P< .001*).

The SCPBI-Y scores of the children and young adult participants, as well as the parents were evaluated by using the cross-informant concordance method (Zempsky et al., 2013). The SCPBI-Y showed strong cross-informant concordance (*n=40, r =.78, P<.001*). Moreover, the participants included young adults, and only a few parents were not available to participate. Additionally, this sample included participants who were young adults of which there was a portion of the sample who did not have parents available for the study (Zempsky et al., 2013). Strong construct validity was demonstrated by a positive relationship between higher pain burden and increased number of days of pain over the four weeks for the outpatient participants (*n=56, r= .73, P<.001;* Zempsky et al., 2013). Construct validity was used as a method to

determine the difference in the SCPBI-Y scores of the inpatient and outpatient participants (Zempsky et al., 2013).

As a result, participants in the inpatient group had significantly greater pain burden (*t [127] = -5.12, P< .001*; Zempsky et al., 2013), a difference was shown among severe and non-severe symptoms of the participants (*t [57] = -3.52, P< .001*), and the SCD classification recommended that participants with serve symptoms have greater SCD pain burden. Regarding pain, there was evidence to recommend that children with SCD experience lower levels of QOL when distinguished among peers without a chronic condition (Zempsky et al., 2013).

For the current study, I used the SCPBI-Y to determine caregiver and child concordance analyses to show validation of the study. Zempsky et al. (2013) developed a caregiver and child version of the SCPBI-Y with identical items directed to retrieve information from the primary caregiver as well as the child. Construct validity using the contrast group approach was determined by the SCPBI-Y scores of the caregiver and the children groups. It was expected that there is a difference in the perception of pain burden among the caregiver and children groups. Additionally, it was expected that higher pain sores were associated with more days of pain. Because of the validation of the SCPBI-Y there was no need to modify the questionnaire for the present study.

Pediatric Quality of Life Inventory

For the current study, I measured the QOL of children with SCD by using the PedsQL questionnaire. The PedsQL has been previously used in other studies of youth with SCD and has established reliability and validity properties (Varni et al., 2001; Vami

et al., 2002; McCleallan, Schatz, Sanchez, & Roberts, 2008; Panepinto, Pajewski, Foerster, & Hoffmann, 2008; Lim, 2009). I used the PedsQL questionnaire was used to examine the QOL of children ages 8–17 with SCD. The PedsQL is a 23-item generic self-report QOL measure designed for children and adolescents ages 2-18-year-old (Vami et al., 2001; Vami et al., 2002). For the present study, I used the PedQL Child Report (8-12) and PedsQL Teen Report (13-18) to assess children with SCD.

The PedsQL was also developed as a parent proxy report for children ages 8–17 to compare caregiver and child self-reports. The PedsQL is a paper form questionnaire that can be completed independently by the child and caregiver. The PedsQL assesses the following QOL domains in the past one-month period; (a)physical (8-items), (b)emotional (5 items), (c)social (5 items), and (d)school (5 items) functioning. In past studies, and the present study participants were asked to provide one answer for each question about their functioning over the previous 4 weeks (Varni et al., 2001; Vami et al., 2001).

The PedsQL has been used in previous studies of children with or without chronic conditions. The PedsQL utilizes a 5- point likert scale (0= never a problem to 4= almost always a problem), and scores are reverse scored and transformed to a 0-100 scale with higher scores indicating a better QOL (Lim, 2009; McCleallan et al., 2008; Panepinto et al., 2008; Varni et al., 2001; Varni et al., 2002). The PedsQL yields 3 summary scores: (a)total scale score, (b)physical health summary score, and (c)psychosocial health summary score. There are 4 scale scores involving (a)physical, (b)emotional, (c)social, and (d)school functioning. The total score is averaged of all items within PedsQL questionnaire (Varni et al. 2001; Vami et al., 2002).

The psychosocial summary score is the average of the items among the 4 scales. The physical health summary score is the average of the physical functioning scale and is the same score as the physical functioning scores (Lim, 2009; McCleallan et al., 2008; Panepinto et al., 2008; Vami et al., 2001; Vami et al., 2002). Lim (2009), McCleallan et al. (2008), Panepinto et al. (2008), Vami et al. (2001), and Vami et al. (2002), used the PedsQL in their studies and found that the questionnaire was valid and reliable for child and teen reports (Cronbach's alphas ranged from 0.68- 0.88). In addition, Lim, (2009), McCleallan et al. (2008) Palermo et al. (2008), Panepinto et al. (2008), Vami et al. (2001), and Vami et al. (2002). Panepinto, et al. (2008) considered the PedsQL to be a well-established instrument and utilized the questionnaire to determine the performance of children with SCD. Panepinto et al. (2008) hypothesized that the PedsQL questionnaire is a reliable, valid and feasible document that can be used in a clinical setting by children with SCD.

Panepinto et al. (2008) study was a cross sectional study with a target population of children with SCD ages 2-17 who received a routine medical check-up from the clinic. Informed consent was obtained from the caregivers and assent was obtained from children 7 years of age or older. Panepinto et al. (2008) research presented evidence of validity and reliability of the PedsQL as a clinical questionnaire designed to assess the QOL of children and adolescents with SCD. The reliability of the PedsQL questionnaire was acceptable in all scales and summary scores by using Cronbach alpha greater than 0.7. For the validity among the children with and without SCD difference in the median summary scores was analyzed (Panepinto et al., 2008).

Additionally, parent proxy reports showed that children with SCD had worse QOL in all summary scores when compared among children without SCD (Panepinto et al., 2008). The parent proxy reports indicated that QOL was worst in children for physical, social, and school functioning as compared to children that did not have SCD (Panepinto et al., 2008). There was no significant difference between children with SCD and children without SCD for emotional functioning. Based on the child self-reports there was no significant difference between QOL scores in other areas except for children with SCD reported worse physical functioning (Panepinto et al., 2008).

Panepinto et al. (2008) demonstrated the difference between the physical and school functioning as they relate to mild and severe pain was used to determine the validity of the parent proxy for the PedsQL questionnaire. Based on the severity of SCD the difference in the physical functioning of HRQOL was expected, also children with severe SCD were expected to have more problems with school functioning (Panepinto et al., 2008). Unlike the parent proxy, the child report did not determine whether the SCD condition was mild or severe in any of the areas. The researchers reported that the children with mild or severe SCD rated their HRQOL better than their caregivers (Panepinto et al., 2008).

For the results of the factor analysis; the researcher's analysis indicated 5 factors for the parent proxy report. There were differences related to physical items of the questionnaire. The physical functioning items "hurt or ache" and "low energy" had several responses for school functioning items such as "missed school/not well" and "miss school- doctor appointment" and with one emotional functioning item "have trouble sleeping" (Panepinto et al., 2008). Other physical function items were; "hard to walk more than a block", "hard to take bath or shower”

and "hard to do chores around the house"; which weighed heavily with emotional items such as "feel angry", and "worry about what will happen" (Panepinto et al., 2008).

Social functioning items showed that the children had trouble getting along with their peers (Panepinto et al., 2008). Panepinto et al. (2008) speculated that the caregiver reports of the PedsQL questionnaire were different from the children with severe to mild SCD and those with no disease. Also, the researchers expected for children with SCD to show worse QOL then children without SCD (Panepinto et al., 2008). Panepinto et al. (2008) study demonstrated that the PedsQL questionnaire is a valid tool that is practical to measure QOL in children with SCD. For the current study I used the PedQL to provide a better understanding of the daily functioning in the lives of the participants.

Summary

I chose the SCPBI-Y and PedsQL questionnaires for this study because of (a)the consistency of the time frame of over the previous month, (b)age ranges, (c)availability of child and caregiver versions, (d)the ability to administer the questionnaires within a clinical setting, and (c)because they have been used in previous pediatric SCD studies. Based on studies of the researchers discussed in this section, the data retrieved from the SCPBI-Y and PedsQL questionnaires has provided more robust information on the pediatric SCD population in regard to their pain burden, and QOL. Information from previous research and the current study can be used to develop disease specific SCD QOL questionnaires to increase the specificity of QOL measurements of children with SCD. No modifications were made to the instrument used in the current study. The SCPBI-Y and the PedsQL have been validated in past studies using similar populations. The current study is a new study that

describes the association between SCD pain burden and the QOL among Black children ages 8–17 in Mississippi. There is no previous research that describes the association between SCD pain burden and QOL among Black children ages 8–17 in Mississippi. This study can be used to develop focused interventions, prevention and health promotion strategies, and foster ways for better communication among health care providers.

Operationalized Terms

Dependent Variable

Quality of Life: Participants indicate their experience in the previous month with specific aspects of functioning on a 0-4 scale; with responses indicating 0- never a problem, I - almost a problem, 2- sometimes a problem, 3- often a problem and 4- almost always a problem. The responses for each item are reverse score a linearly transformed to a 0-100 scale, with higher scores representing higher QOL (Vami et al., 2001; Vami et al., 2002). The domain scores were obtained by summing the item and dividing by the number of items answered per domain to account for missing data. If more than 50% of the items in the scale are missing, the scale score was not computed. The total score was created by computing the mean as the sum of all the items over the number of items answered on all of the scales.

Independent Variables

Sickle Cell Disease Pain Burden*:* Participants indicate their experience in the previous month with specific aspects of functioning on a 0-4 scale; with 0-none, 1- a few, 2- some, 3-many and 4- every. Scores range from 0-no pain burden to 28-severe pain burden. A caregiver version of the questionnaire was administered to caregivers of

the children with SCD with identical items to obtain information from the caregivers (Zempsky et al., 2013, p4).

Confounding Variables

Age: In this study, individuals age 8–17 were included in the sample. This variable is a self-reported number of years indicating age.

Gender: In this study, children selected the dichotomous variable, male or female with responses indicating 1-male and 2- female.

Socio-economic Status: In this study the SES variables of the caregivers were measured independently (i.e. education level, and household income in the past 12 months). The SES is defined as the caregiver' s economic status as measured by income, social status measured by education, and work status measured by occupation each status is considered an indicator (Centers for Disease Control and Prevention, 2014; "Social Determinants of Health", para 17). These three indicators are related but do not overlap (Centers for Disease Control and Prevention, 2014; "Social Determinants of Health", para 17). This variable is a self-report of categories indicating the caregiver's range of income and education level, as well as their work status.

Income: Mississippi has the highest poverty rate and the median household income for Mississippi from 2009-2013 was $39,031 (U.S. Census Bureau, 2015). In this study, the income variable was self-reported to indicate one of eleven income ranges of the caregivers using the following income categories: 1= <$20, 000, 2= $20,000-$34,999, 3= $35,000-$49,999, and 4=$50,000 to indicate the approximate household income in past 12 months.

Education Level: This variable was measured by the number of years reported by each caregiver of the highest level of education completed. The education category was coded by l = less than high school, 2= high school diploma, 3= GED, 4=Vocational College, 5= Some College, 5=College Graduate.

Data Analysis

Data was entered in SPSS and screened. The presence of invalid data was assessed using frequency tables. Outliers for child age, child QOL, caregiver QOL, child SCD pain burden, and caregiver SCD pain burden were assessed using standardized scores. The occurrence and pattern of missing data was analyzed using frequencies. Child QOL, caregiver QOL, child SCD pain burden, and caregiver SCD pain burden questionnaires were reverse coded.

Data analysis conducted for research question 1 was a hierarchical linear regression. **(RQ1):** What is the association between SCD pain burden and QOL (i.e. physical, social, emotional and school functioning) in Black children ages 8–17 in Mississippi? **Alternative Hypothesis (H_al):** There is a statistically significant association between SCD pain burden and QOL, as measured by SCD Pain Burden Interview- Youth and the PedsQL in Black children ages 8–17 in Mississippi with SCD. **Null Hypothesis ($H_0$1):** There is no statistically significant association between SCD pain burden and QOL, as measured by SCD Pain Burden Interview- Youth and the PedsQL in Black children ages 8–17 in Mississippi with SCD. In Block 1, child age, child sex, caregiver age, caregiver sex, caregiver education, caregiver employment, and caregiver income were entered. In Block 2, caregiver perception of QOL was

entered. In Block 3, child SCD pain burden and caregiver perception of child's SCD pain burden were entered.

Data analysis conducted for research questions 2 and 3 were conducted to reflect cross informant concordance (association between the child and caregiver SCPBI-Y and PedsQL scores) which was determined using Pearson Correlation Coefficients for the child's and caregiver's group (Panepinto, 2005; Zempsky et al., 2013). (**RQ2):** Is there a significant difference between child and caregiver reports of SCD pain burden in Black children ages 8–17 in Mississippi with SCD? **Alternative Hypothesis (*H*$_a$2):** There is a significant difference in the caregiver and child reports of SCD pain burden, as measured by SCD Pain Burden Interview- Youth in Black children ages 8–17 in Mississippi with SCD and their caregivers.

Null Hypothesis (*H*$_0$2): There is no significant difference in the caregiver and child reports of SCD pain burden, as measured by SCD Pain Burden Interview-Youth in Black children ages 8–17 in Mississippi with SCD and their caregivers. (**RQ3):** Is there a significant difference between child and caregiver reports of QOL (i.e. physical, social, emotional and school functioning) in Black children ages 8–17 in Mississippi with SCD? **Alternative Hypothesis (*H*$_a$3):** There is a significant difference in the caregiver and child reports of QOL, as measured by PedsQL in Black children ages 8–17 in Mississippi with SCD and their caregivers. **Null Hypothesis (*H*$_0$3):** There is no significant difference in the caregiver and child reports of QOL, as measured by PedsQL in Black children ages 8–17 in Mississippi with SCD and their caregivers. The Pearson Correlation Coefficient provided significant details on the strength of the association among the independent and

dependent variables (Singelton & Straits, 2010). An item to item correlation and comparison between items from child's and caregiver's questionnaires were performed using Pearson Correlation Coefficient and a paired t-test (Panepinto, 2005).

I used the Pearson correlation to estimate the strength of linear between two continuous variables to give the correlation coefficient (r). It lies between 1.0 and -1.0 depending on the strength of association. The significance of the correlation coefficient was determined at $P<0.05$. The following correlation values were used as a guide for level of correlation <0.3 poor agreement correlations, 0.3-0.5 as moderate agreement correlation, and >0.5 strong agreement correlations which has been deemed as standard practice for statistics in social science (Panepinto,2005). Correlations for physical health and psychosocial health were examined for different informant, different scale correlations and same informant, and different scale correlations to describe discriminate validity (McClellan et al., 2008).

Threats to Internal and External Validity

Threats to internal validity may compromise the confidence that a relationship may exist between the independent (i.e., SCD burden of pain) and the dependent (i.e., QOL) variables. Self-reported questionnaires (i.e., SCPBI-Y, PedQL, and Demographic Profile Questionnaires) were completed by the children and caregiver participants of this study. The self-reported questionnaires were subject to bias which depended on how the participants were feeling and what they remembered at the time of completing the questionnaires. The relevance of the internal validity for this research is shown by the relationship among child SCD pain burden and child QOL. The covariates (i.e. child age and sex, caregiver age, sex,

education, employment and income) for this research was not statistically strong predictors of the child's QOL. To control internal validity and maintain credibility in this study, caregivers and children answered the self-reported questionnaires on their own; without the interference or opinion of the researcher which does not impact the research findings.

The threat to the external validity compromises the confidence in determining whether the study results are related to other groups (i.e., generalized; Michael, 2014). In other words, the results of this specific study were only of Black children ages 8-17 in Mississippi who are patients of a pediatric hematology clinic and their caregivers. I used the following methods to design this study and to determine results: (a)convenience sampling, (b)SCPBI-Y, (c)PedQL, and(d) Demographic Profile Questionnaires, (e)Hierarchical Linear Regression, and (f)Pearson Correlation Coefficient. These methods can be replicated to the same target population in a different pediatric hematology clinic, and the PedQL and Demographic Profile is valid to other children with chronic conditions and their caregivers, however the results may be different. To control external validity, I ensured that the data provided by the children and caregivers could be used to show their perceptions. The data can assist healthcare providers to understand the importance of communicating with the children to assess their perception of SCD pain and QOL.

Further, some of the potential threats to this study were that the children participants completed the SCPBI-Y and PedQL Questionnaires and caregiver participants completed the SCPBI-Y, PedQL, and Demographic Profile Questionnaires. Completing the questionnaires for both children and the caregivers may have seemed too long for the participants and may have created frustration. While completing the questionnaires the child participants may not

have felt comfortable providing information about their condition, and caregivers and children may not have remembered anything that took place about the child's SCD pain burden and QOL in the previous month. In addition, trustworthiness of the answers to the questionnaires from the children and caregivers may not have divulged true feelings at the time of completion. The caregivers who completed the Demographic Profile Questionnaire may not have felt comfortable providing their confidential information such as income and education level. These actions may have led to the threat of some questions being incomplete or not answered, which can influence the results of the research.

Ethical Consideration and Protection of Participants

The IRBs from Walden University and the Pediatric Hematology Clinic were approved for data collection and analysis. All information retrieved from the questionnaires are confidential and were entered into a password protected electronic data base to be analyzed for results. The paper questionnaires were stored in a locked file cabinet. The names of the participants are not shown on the questionnaires, results do not refer to any individual participant, and the participants are only identified by a code. The participant's rights were acknowledged, and these methods were outlined in the informed and assent consent forms; which explains the participant's rights are always protected throughout the process, and after the study is completed (Creswell, 2009). As previously stated, the informed and assent consent forms were provided to the participants before the questionnaire was given.

Role of the Researcher

My role as the researcher was to (a)design the study, (b)collect the data, (c)analyze the data, and (d)present the results. I was the only individual to present the

questionnaires and collect data from the participants. Participants were encouraged to answer the questionnaires honestly, and to the best of their ability. In addition, I encouraged the participates to ask as many questions as they liked; as well as omit any questions or stop the questionnaires at any time. As the researcher I am responsible for maintaining the confidentiality of the participants, and their individual responses to the questionnaires. Participants identity was de-identified, in which no one will be identified as a part of this study. The data collected from the questionnaires is stored for no more than five years. The data is also stored to allow the researcher to use other components of the study to enhance the literature on other characteristics of the targeted population. At the five-year bench mark the questionnaires will securely be disposed.

Summary and Transition

Chapter 3 included the detailed methodology for this quantitative study on SCD pain burden and QOL. This is a quantitative research study with a target population of Black children ages 8–17 in Mississippi with SCD, and their caregivers. The study samples were recruited from a Pediatric Hematology Clinic in the state of Mississippi. For this study the data were collected from children and their caregivers using the SCPBI-Y, PedsQL, and Demographic Profile Questionnaires. Data were analyzed using statistical methods such as descriptive statistics, Pearson Correlations, and Hierarchical Linear Regression to determine the association among SCD pain burden and QOL, and the differences of child and caregiver responses to the questionnaires. Informed and assent consent forms were used to protect the rights of the participants, and confidentiality was kept of all participants. Chapter 4 describes data review and study sample characteristics.

Chapter 4

Results

Between January 24, 2017and April 31, 2017, I collected data using three self-reported questionnaires. A total of 85 children and 85 caregivers consented to participate in the study. There was no refusal to participate during recruitment or time of consent. I did not exclude any of the child or caregiver pairs due to not meeting the study eligibility for participation, or not being able to effectively complete the measures. One child did not return their questionnaires resulting in a response rate of 98%. As the researcher, I assumed that some of the questions from the questionnaires were not answered due to (a)uncertainty of the answer, (b)not wanting to share an answer, or (c)time constraints. I included data from a total of 63 participant pairs for a regression analysis, and data from 81 participant pairs were included in correlation and *t*-test analysis.

Data Screening

I assessed the presence of invalid data by using frequency tables for all variables, and I determined that there was no invalid data present. I assessed for the presence and pattern of outliers for: (a)child age, (b)child QOL, (c)caregiver QOL, (d)child SCD pain burden, and (e)caregiver SCD pain burden using standardized scores. I determined there were no outliers due to the lack of standardized scores greater than +3 and less than -3. The occurrence and pattern of missing data was analyzed using frequencies.

Eighty-one participant pairs completed the data collection, and I used data from 63 participant pairs was used. One participant was missing more than 50% of the child QOL scores and was excluded from the data analysis. Two participants were missing all scores for child SCD

pain burden and were excluded from the data analysis. These three participants were excluded from further analysis. One participant was missing one score on both the child QOL questionnaire and the caregiver QOL questionnaire. One participant was missing one score on the child QOL questionnaire. One participant was missing one score on the caregiver QOL questionnaire. For participants who were missing less than 50% of score on the child QOL and caregiver QOL, missing scores were replaced with the mean. Missing scores for items 1 and 3 on the child QOL and items 4 and 16 on the caregivers QOL questionnaires were replaced with the mean of three participants. For a Demographic Profile Questionnaire child age ranged from 8-17, child age was missing three scores, caregivers age was missing eight scores, and caregiver income was missing nine scores. I used Listwise deletion to exclude these caregivers from hierarchical linear regression analysis, resulting in a sample size of 63 for the regression analysis. See Table 3 for further details regarding descriptive statistics.

For all analyses, I used reserved coding to show greater scores and demonstrate variables into two categories. Child QOL and caregiver QOL questionnaires were reverse coded so that greater scores indicated greater quality of life. Scores for the child SCD pain burden and caregiver SCD pain burden questionnaires were reverse coded so that greater scores indicated less pain. For the hierarchical linear regression, variables were recoded. Caregiver age was recoded into two categories including 18 - 44 years of age and 45 or greater years of age. Caregiver education was recoded into two categories including High school education and Greater than high school education. All participants reported race as Black. Caregiver employment was recoded into two categories including unemployed and employed, student, or retired. Caregiver income was recoded into $34,999 or less and $35,000 or greater. According to

the 2015 Census American Community Survey, the median household income for Mississippi was $40,593.00. Compared to the median United States household income, Mississippi median household income is $15, 182 lower (United States Census Bureau, 2017).

Table 3

Descriptive Statistics for Demographic Data

	N	Mean		Std. Deviation	Skewness		Kurtosis	
	Statistic	Statistic	Std. Error	Statistic	Statistic	Std. Error	Statistic	Std. Error
Child Age	78	12.82	.31	2.74	.15	.27	-1.19	.53
Child Sex	81							
Female	41							
Male	40							
Caregiver Sex	81							
Female	79							
Male	2							
Caregiver Age	73							
18-44	59							
45 or older	14							
Caregiver Education	81							
High School	31							
Greater than High School	50							
Caregiver Employment	81							
Unemployed	27							
Employed	54							
Retired or In School								
Caregiver Income	72							
$34,999 or less	57							
$35,000 or Greater	15							

Notes: Data reflects the descriptive statistics for the entire sample. A total of 84 caregiver participants completed the analysis.

Table 4

Descriptive Statistics for Quality of Life and Pain Burden Scores

	N	Mean		Std. Deviation	Skewness		Kurtosis	
	Statistic	Statistic	Std. Error	Statistic	Statistic	Std. Error	Statistic	Std. Error
Child QOL Scores	81	70	.02	.19	-.81	.26	-.34	.52
Caregiver QOL Scores	81	62	.01	.17	-.003	.26	-.83	.52
Child PB Score	81	20.04	.69	6.26	-.59	.26	-.74	.52
Caregiver PB Score	81	20.38	.68	6.19	-.72	.26	.12	.52

Notes: Data reflects the descriptive statistics for the entire sample. A total of 84 participant pairs completed the analysis. Descriptive statistics for reverse coded and re-coded variables included.

Assumptions Testing

I assessed for Normality using descriptive statistics. It was determined that scores for child QOL were normally distributed due to the absence of skewness and kurtosis values greater than +1 and less than -1. Linearity of child QOL scores was assessed using a Q-Q plot and scores were assumed linear. See Figure 3 for details. Review of a scatterplot of residual and predicted values revealed no patterns, so the assumption of homoscedasticity was met. See Figure 4 for details. Multicollinearity was assessed using Tolerance scores. Multicollinearity was assumed due to lack of Tolerance scores less than 0.5. See Table 6 for details.

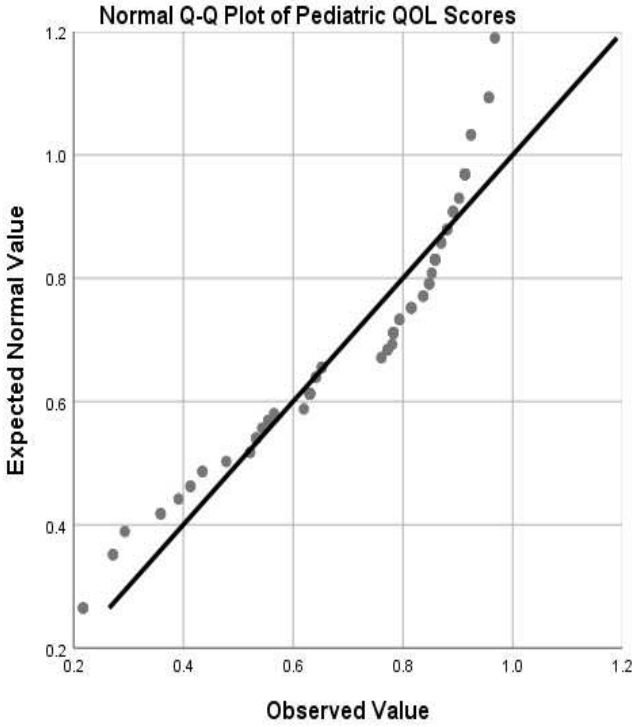

Figure 3. Linearity of Child Quality of Life Scores

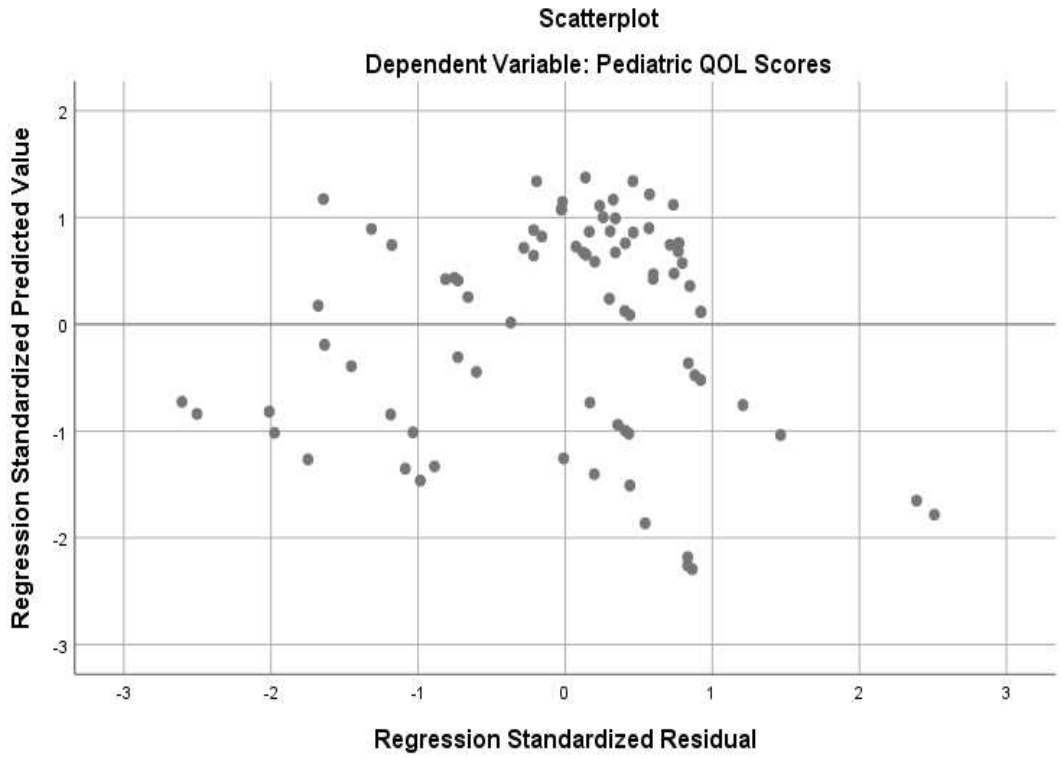

Figure 4. Homoscedasticity of Child Quality of Life Scores

Child and Caregiver Demographic Results

Table 5 shows the mean values and standard deviations for age, and frequencies for sex and SCD type of child participants. Child participants included 85 (100%) Black children diagnosed with SCD who were between the ages of 8–17 years of age, and the mean age of 13 years of age. Forty-three (51%) of the children were female. Regarding SCD type, caregivers reported 66 (78%) of the children sample have HbSS as the most common SCD type among the children; one caregiver did not report their child's SCD type.

Table 5

Child Demographic Information (N=85)

Variable	M(SD)
Age	13 (2.70)
	N (%)*
Sex	
Female	43(50.6)
Male	42(49.4)
Sickle Cell Disease Type	
HbSS	66(77.6)
HbSC	14(16.5)
HbS Beta-0	2(2.4)
Other	2(2.4)
Missing Values	1(1.1)

*Note. *Data are given as the number of children (%) expect as indicated; HbSS= Sickle Cell Hemoglobin; HbSC= Hemoglobin SC; Hbs Beta-O= Hemoglobin Sickle Beta 0 thalassemia; †=Some missing participant data. Adapted from "Health Related Quality of Life in Children with Sickle Cell Disease: Child and Parent Perception," by J.A. Panepinto, K.M. O'Mahar, M.R. DeBaun, F.R. Loberiza, and J.P. Scott, 2005, British Journal of Haematology,130, p440.*

Table 6 shows the frequencies for caregiver relationship to the child, sex, education, employment, caregiver age, and income. The majority of caregivers were between the ages of 25 - 44 (78%), and they all self-identified as Black (100%). Eighty-three (98%) of the caregivers accompanying the children to their routine clinic visits were females. Seventy-six (89%) of the female caregivers identified themselves as the child's mother. Twenty-nine (34%) of the caregivers reported less than high school education. Twenty-nine (34%) of the caregivers self-reported their education level as less then high school, and 52 (61%) were employed.

Table 6

Caregiver Demographic Information (N=85)

Variable	N (%)*
Age Group†	
18-24	3(3.9)
25-44	60(77.9)
46-64	14(18.2)
Missing Value	8
Sex	
Female	83(97.6)
Male	2(2.4)
Caregivers	
Mother	76(89.4)
Father	1(1.2)
Sister	1(1.2)
Grandparent	6 (7.1)
Legal Guardian	1 (1.2)
Education	
Less Than High School	29(34.1)
High School/GED/Vocational Training	7(8.2)
Some College	23(27.1)
College Graduate	26 (30.6)
Employment	
Employed	52(61.2)
Unemployed	31(36.5)
Retired	1(1.2)
Student	1(1.2)
Family Income in Past 12 Months†	
Less than $20,000	41(53.9)
$20,000-$34,999	20(26.3)
$35,000-$49,000	7(9.2)
$50,000 or more	8(10.5)
Missing Value	9(0.1)

*Note. *Data are given as the number of adults (%) expect as indicated; †=Some missing participant data. Adapted from "Health Related Quality of Life in Children with Sickle Cell Disease: Child and Parent Perception," by J.A. Panepinto, K.M. O'Mahar, M.R. DeBaun, F.R. Loberiza, and J.P. Scott, 2005, British Journal of Haematology,130, p440.*

Association Between Sickle Cell Disease Pain Burden and Quality of Life in Black Children Ages 8–17 in Mississippi

A total of 84 participants completed the research project. For this study, I used data from 63 participants was used to complete the hierarchical linear regression analysis. I excluded data from three participants from data analysis due to missing child QOL and child SCD pain burden scores. I also excluded data from 18 participants due to missing demographic data. Additionally, I excluded child race from the analysis because of the lack of variation in scores. Descriptive statistics for the participants included in the assessment can be found in Table 7.

Table 7

Descriptive Statistics for Hierarchical Linear Regression

	N	Mean	Std. Deviation
Child QOL Scores	63	68	.19
Child Age	63	12.75	2.80
Caregiver QOL Scores	63	.61	.18
Child PB Score	63	19.31	6.54
Caregiver PB Score	63	19.87	6.39

Notes: Data includes number, mean, and standard deviations for all variables included in the hierarchical linear regression.

Results of the hierarchical linear regression analysis are shown in Tables 8 through 10. I was able to determine that, (a)child age, (b)child sex, (c)caregiver age, (d)caregiver sex, (e)caregiver education, (f)caregiver employment, and (g)caregiver income were not statistically significant covariates in Block 1, $F(7,55) = 0.77, p=0.54$. The addition of caregiver QOL as a covariate was not statistically significant when added in Block 2, $F(8,54) = 877, P=542$. Block 3 was statistically significant with the addition of child SCD pain burden and caregiver SCD pain burden, $F(10,52) = 4.62, p<.001$. Child SCD pain burden ($p<.001$) was a statistically significant predictor of child QOL while caregiver SCD pain burden ($p=0.60$) was not.

Table 8

Model Summary (n=63)

Block	R Square	Std. Error of the Estimate	R Square Change	F Change	Sig F Change
1	.089	.19637	.089	.772	.613
2	.115	.19538	.026	1.557	.218
3	.471	.15400	.356	17.457	*.000

*Notes: Data represents the summary of the presented model. Block 1 represents child age, child sex, caregiver age, caregiver sex, caregiver education, caregiver employment, and caregiver income were entered. Block 2 represents the addition of caregiver perception of QOL. Block 3 represents the addition of child SCD pain burden and caregiver perception of child's SCD pain burden. * indicates statistical significance.*

Table 9

Analysis of Variance (63)

Model		Sum of Squares	df	F	Sig.
1	Regression	.208	7	.772	.613
	Residual	2.121	55		
	Total	2.329	62		
2	Regression	.268	8	.877	.542
	Residual	2.061	54		
	Total	2.329	62		
3	Regression	1.096	10	4.621	< .000
	Residual	1.233	52		
	Total	2.329	62		

Notes: Data represents the Analysis of Variance. Model 1 represents child age, child sex, caregiver age, caregiver sex, caregiver education, caregiver employment, and caregiver income were entered. Model 2 represents the addition of caregiver perception of QOL. Model 3 represents the addition of child SCD pain burden and caregiver perception of child's SCD pain burden.

In Block 3, the strongest predictors of child QOL were child SCD pain burden, followed by caregiver income and caregiver education. Child SCD pain burden was associated with a standardized coefficient of *0.61*, meaning every point increase in the child SCD pain burden score was associated with a *0.61* increase in the child QOL score. Caregiver income was associated with a standardized coefficient of -*0.21*, meaning that as caregiver income moved from $34,999 or less' to $35,000 or higher, child QOL scores decreased by *0.21*. Caregiver education was associated with a standardized coefficient of -*0.18*, meaning that as caregiver education moved from 'high school education' to 'greater than high school education', child QOL scores decreased by *0.18*.

Caregiver QOL was not statistically significant. Caregiver QOL was associated with a *0.008* standardized coefficient, meaning every point increase in caregiver QOL was associated with a *0.008* increase in child QOL. Although not statistically significant, caregiver SCD pain

burden was associated with a standardized coefficient of *0.06*, meaning every point increase in caregiver SCD pain burden was associated with a *0.06* increase in child QOL. See Table 10 for further details.

Table 10

Hierarchical Linear Regression Coefficients (n=63)

		Unstandardized Coefficients		Standardized Coefficients			Collinearity Statistics
	Block	B	Std. Error	Beta	T	Sig.	Tolerance
1	(Constant)	.66	.19		3.43	*.001	
	Child Age	.006	.009	.08	.63	.53	.93
	Child Sex	-.008	.05	-.02	-.15	.87	.90
	Caregiver Age	-.09	.07	-.18	-1.39	.16	.92
	Caregiver Sex	.01	.14	.01	.13	.89	.94
	Caregiver Education	-.08	.06	-.22	-1.37	.17	.63
	Caregiver Employment	.04	.05	.11	.84	.40	.84
	Caregiver Income	-.14	.07	-.31	-1.83	.07	.55
2	(Constant)	.46	.24		1.86	.06	
	Child Age	.007	.009	.10	.80	.42	.92
	Child Sex	-.002	.05	-.006	-.04	.96	.89
	Caregiver Age	-.07	.07	-.14	-1.07	.28	.87
	Caregiver Sex	.05	.14	.04	.36	.71	.90
	Caregiver Education	-.05	.06	-.13	-.77	.44	.53
	Caregiver Employment	.03	.05	.08	.57	.56	.80
	Caregiver Income	-.11	.08	-.26	-1.48	.14	.52
	Caregiver QOL Scores	.19	.15	.18	1.24	.21	.73
3	(Constant)	.33	.19		1.67	.10	
	Child Age	.006	.007	.08	.76	.45	.91
	Child Sex	-.01	.04	-.04	-.44	.65	.89
	Caregiver Age	-.001	.05	-.002	-.01	.98	.83
	Caregiver Sex	-.05	.11	-.05	-.47	.63	.87
	Caregiver Education	-.07	.05	-.18	-1.34	.18	.51
	Caregiver Employment	.02	.04	.05	.45	.65	.78
	Caregiver Income	-.09	.06	-.21	-1.50	.13	.51
	Caregiver QOL Scores	.009	.14	.008	.06	.95	.52
	Child PB Score	.01	.003	.61	5.30	*.00	.76
	Caregiver PB Score	.002	.004	.06	.51	.60	.59

Notes: Data shows the standardized coefficients, unstandardized coefficients, and collinearity statistics of the model. * indicates statistical significance.

Child and Caregiver Reports of QOL in Black Children ages 8–17 in Mississippi with Sickle Cell Disease

A total of 84 participants completed the research project. For this study, I used data from 81 participants to complete the Pearson Correlation and Paired t test analyses. I excluded data from 3 participants due to missing scores. Subscales for Child and Caregiver QOL included (a)physical functioning, (b)emotional functioning, (c)social functioning, and (d)school functioning. Mean and median scores for child (a) physical (*73,78*), (b)emotional (*71, 80*),(c) social (*76, 85*), and (d)school (*61, 60*) functioning are higher than scores for caregiver (e)physical (*60, 63*), (f)emotional (*69, 75*), (g)social (*69, 60*), and (h)school (*51,50*) functioning. See Table 11 for further details.

Table 11

Descriptive Statistics for Quality of Life Subscales

	Child Physical	Child Emotional	Child Social	Child School	Caregiver Physical	Caregiver Emotional	Caregiver Social	Caregiver School
N	81	81	81	81	81	81	81	81
Mean	73	71	76	61	60	69	69	51
Median	78	80	85	60	63	75	60	50
Std. Deviation	21	23	25	20	25	23	23	20
Minimum	28	25	0	10	3	5	20	20
Maximum	100	100	100	95	100	100	100	90

Notes: Data shows descriptive statistics for the subscales included in the child quality of life and caregiver quality of life tools.

I found a statistically significant correlation between child and caregiver emotional functioning scores (*p=.001*), and I did not find a statistically significant correlation between child and caregiver physical functioning scores, social functioning scores, school functioning

scores, or total QOL scores. As evidenced by the results of the paired t tests, I found a statistically significant difference between child and caregiver physical functioning (*p=.001*), school functioning (*p=.001*), and total QOL (*p=.003*). See Table 12 for further details.

Table 12

Quality of Life in Children with Sickle Cell Disease Comparison of Child and Caregiver Scores

				Correlation Coefficient		Paired t tests	
	Child Mean Score	Caregiver Mean Score	Parent Child Pair: Mean Difference	Child and Caregiver Pair: Correlation Coefficient	P Value	T	P Value
Physical Functioning	73	60	7	.05	0.69	3.55*	.001
Emotional Functioning	71	69	2	.37*	.001	.47	.640
Social Functioning	76	69	7	.06	.574	1.98	.05
School Functioning	61	51	10	.15	.181	3.45*	.001
Total Score				.16	.114	3.106*	.003

Notes: Data represents results for correlation coefficient and paired t tests for child and caregiver quality of life subscales.

Child and Caregiver Reports of Sickle Cell Disease Pain Burden in Black Children Ages 8–17 in Mississippi with Sickle Cell Disease

A total of 84 participants completed the research project. I used data from 81 participants to complete the Pearson Correlation and Paired t test analyses. I excluded data from 3 participants due to missing scores. I found a statistically significant correlation between scores for child and caregiver SCD pain burden (*p< 0.001*), and I did not find a statistically significant difference between child and caregiver SCD pain burden scores.

Table 13

Sickle Cell Disease Pain Burden in Children with Sickle Cell Disease Comparison of Child and Caregiver Scores

				Correlation Coefficient		Paired t tests	
	Child Mean Score	Caregiver Mean Score	Parent Child Pair: Mean Difference	Child and Caregiver Pair: Correlation Coefficient	P Value	T	P Value
Pain Burden	20.04	20.38	0.34	.41*	<.001	-.44	.66

Notes: Data represents results for correlation coefficient and paired t tests for child and caregiver sickle cell disease pain burden.

Summary

I designed this quantitative study to explore the association of SCD pain burden and QOL among Black children ages 8–17 in Mississippi. For this study, I also examined an item to item comparison of child and caregiver perceptions of SCD pain and QOL. In this research, I presented primary data of children and caregiver's self-reports from SCPBI-Y, PedQL, and Demographic Profile Questionnaire. I also used, hierarchical linear regression to analyze the association of child SCD pain burden and QOL. The results revealed that the covariates: (a)child age and sex, and (b)caregiver age, (c)sex, (d)education, (e)employment and income were not statistically significantly strong predictors of the children's QOL. For this study SES was measured as caregiver income and caregiver education were not statistically significant of child's QOL. However, child SCD pain burden was a statistically significantly predictor of child's QOL. I used Pearson Correlation Coefficients to determine the association between child and caregiver SCPBI-Y and PedQL scores. The results provided significant details on the strength of the association of SCD pain and QOL.

There were moderate correlation agreements among child and caregivers for emotional functioning. Also, the results revealed that there was a poor correlation agreement among children and caregivers for physical functioning, social functioning, and school functioning. The results for the research questions are:

(**RQ1**): Child SCD pain burden was statistically significant in predicting child QOL. In addition, caregiver SES, income and education were not statistically significant in predicting Child QOL.

(**RQ2**): The null hypothesis was rejected between the means and it was concluded that a significant difference does exist. Children perceived their QOL as higher as compared to their caregiver's perception of QOL in the areas of physical, emotional, social, and school functioning.

(**RQ3**): The null hypothesis was rejected between the means and it was concluded that a significant difference does exist. Caregivers perceived their child's SCD pain burden as higher as compared to their child's perception of SCD pain burden.

In relation to the findings revealed in Chapter 4, Chapter 5 provides a discussion of the: (a)future research, (b)relevance of findings, (c)limitation of the study, and (d)social change that could improve the disease management and health outcomes of Black children ages 8–17 with SCD.

Chapter 5 Discussion

Introduction

SCD is a debilitating acute and chronic condition, for which the main goal for treatment is to relieve pain. As mentioned previously, there has been limited discussion about how pain may impact children with SCD. The purpose of this quantitative study was to examine the association between SCD pain burden and QOL among Black children ages 8–17 in Mississippi with SCD. In addition, I assessed the differences of SCD pain burden and QOL experience from the self-reports of children and their caregivers.

Interpretation of Findings

In this study, child SCD pain burden was a statistically significant predictor of child QOL, while caregiver SCD pain burden was not. This finding implies that when assessing and attempting to improve QOL for Black children ages 8–17, child pain burden should be assessed via the child. In addition, a statistically significant correlation was found between child and caregiver emotional functioning scores ($p<0.001$), and statistically significant differences were found between child and caregiver physical functioning ($p<0.001$), school functioning($p=.01$), and total QOL ($p=.003$). I found that the present evidence suggests that caregivers may have a good understanding of the child's perception of emotional functioning, but not physical functioning or school functioning. Finally, I determined that a statistically significant correlation was found between scores for child and caregiver SCD pain burden ($p<0.001$), meaning that caregiver's perceptions of child's pain burden is similar to the child's perception of pain burden.

Predicting Child Quality of Life

Mean caregiver and child quality of scores were *62* and *70* respectively. Mean caregiver and child SCD pain burden scores were *20.38* and *20.04* respectively. Caregiver QOL and caregiver SCD pain burden were not statistically significant predictors of child QOL. While caregiver QOL was not a statistically significant predictor of child QOL, caregiver QOL shared a positive relationship with child QOL, meaning as caregiver QOL increased so did child QOL. Caregiver SCD pain burden shared a negative relationship with child QOL, meaning that as the caregiver SCD pain burden decreased, child QOL increased. In the current research, I found that child pain burden and caregiver pain burden were very similar, meaning children and their caregivers had similar perceptions of the burden of SCD pain. Graumlich et al. (2001) indicated that caregivers acknowledge SCD pain as being more of an emotional burden while children acknowledge it as physical pain

Child SCD pain burden was a statistically significant predictor of child QOL among 8-17-year old Black children with SCD. This is in line with previous research findings. Palermo et al. (2008) found that pain associated with SCD may interfere with a child's daily living routines. In addition, it was found that there is a strong relationship between pain and QOL (Long et al., 2008; Gold et al., 2009; Wilson & Palermo, 2012). Fluctuations in SCD pain are also assumed to be related to the child's daily stress and mood (Gil et al., 2000).

Researchers suggested that children with SCD experience low QOL due to pain, as well as experience low QOL in areas such as: (a)academic performance, (b)decrease in social activities, (c)sleep disturbance, and (d)school absences (Schatz, 2004; Steen, Finberg-Buchner, Hankin, Weiss, Priftera, & Mulhern, 2005; Howard et al., 2008; Forgeron King et al., 2010;

Long et al., 2008; & Schwatz, Radcliffe, & Barakat, 2009). Although, findings from the current study are not consistent with past studies. In this research, results showed that all child participants of this study experienced a high QOL, as well as a low pain and pain burden. High QOL indicates that scores were on the higher end of the scoring range, and low meaning on the lower end of the score range. An explanation of the children's positive responses of QOL and decrease in SCD pain burden may be associated with comprehensive, ongoing, and coordinated approaches of disease management received from the pediatric hematology clinic. In addition, I did not recruit children who were experiencing pain or pain crisis while visiting the pediatric hematology clinic to participate in this study.

Feudtner & Noonan (2009) suggested that caregiver's SES is an important factor in health outcomes for children with chronic conditions, as well as research has shown there is a significantly higher morbidity in children with chronic conditions whose caregivers have low income. Additionally, caregiver's education and income are known to be associated with SES status (American Psychological Association, 2017), and the impact on QOL (Litzelman et al., 2013; Pettignano, Caley, & Bliss, 2011). For this study, I determined there was low education and low income of caregivers. Covariates such as: child age, child sex, caregiver sex, caregiver education, caregiver employment, and caregiver income were not statistically significant in predicting child QOL. This is in contrast to previous research findings that the QOL of individuals with SCD is related to family income (Panepinto et al. 2009). I collected data from a clinical setting that provides services that focus on the (a)individual, (b)family, (c)health condition, and (c)offers additional assistance such as sliding scale fees to low income families. This provides a possible explanation as to why the results demonstrate as caregiver income

moved from $34, 999.00 or less to $35,000.00 or higher child QOL deceased, and as caregiver education moved from high school education to greater than high school education child QOL decreased. As the caregiver's income increased, and education increased, they were not eligible for the additional low-income assistance provided by clinic.

Child and Caregiver Quality of Life

Mean scores for total QOL, physical functioning, emotional functioning, social functioning, and school functioning for children and caregivers were *70 and 62*, *73 and 60, 71 and 69, 76 and 69, and 61 and 51* respectively. This represented scores that were on the higher end of the score range of 0-100 for both children and caregivers. This also showed that children consistently rate their own QOL higher than their caregivers. A statistically significant correlation was found between child and caregiver scores for emotional functioning. This implies that children and their caregivers have similar views on how the child functions and copes emotionally. A statistically significant difference was found between total QOL score, physical functioning, and social functioning. In all instances, caregivers perceived their child as having lower QOL than the child themselves did; thus, it was assumed that the child perceives him or herself as functioning at a higher level as it pertains to functioning and managing physically and socially. Previous research by Panepinto et al, (2005) also found that caregivers rate child's physical functioning lower than the children themselves. Like this study, Panepinto et al. (2008), indicated caregivers reported worst QOL for children for physical, social, and school functioning, and there was no significant difference among children with SCD and their compared group for emotional functioning.

Child and Caregiver Sickle Cell Disease Pain Burden

Children and caregivers both reported mean SCD pain burden scores of 20 (on a scale of 0-28 with higher scores indicating less pain). These scores reflect relatively low SCD pain burden. A statistically significant correlation and no statistically significant difference for SCD pain burden were found between child and caregiver scores. This indicates that the child and caregiver have a similar understanding of child's SCD pain burden. Currently, there is a gap in the literature about the specifics of children and caregiver understanding of the child's SCD pain burden. However, there is literature on caregiver and family influence on pain experience of children with chronic and acute pain. Palermo et al. (2004) indicated that caregiver and child relationships have become important regarding the child's chronic pain. In another study, Palermo and Chambers (2005), showed that caregivers have a significant influence on children's pain experience. Palermo, Valrie, and Karlson (2014) suggested that bidirectional influences (i.e. caregiver and family factors) of a child's pain experience is a valuable consideration in pediatric chronic pain management, for example the bidirectional influences of the SET can be used to describe the influence of caregivers or the environment to the child.

Caregiver characteristics such as emotions, behavior, and health status play a part in the children's pain experiences (Palermo, Valrie, & Karlson, 2014). Further, research indicated that parental involvement does relate to child pain experience, for instance, Oliver-Carpenter, Barach, Crosby, Valenzuela, and Mitchell (2011) showed that children with SCD have higher caregiver involvement in the child's pain and disease management activities which were related to the child having higher levels of disability. Specifically, this study of SCD pain burden and QOL of

Black children ages 8–17 in Mississippi is important to understand the dynamics and relationships of the child and caregiver's perceptions to improve the child's QOL.

Limitations

There are some limitations to consider when examining the results of this study. First, participants were excluded from the study due to missing child QOL and child SCD pain burden scores, demographic data, and child and caregiver race. Thus, the study sample decreased from 84 child participants to 63 child participants for the hierarchical linear regression. With an anticipated effect size of *0.10*, desired statistical power level of *0.75*, probability level of *0.05*, and total of 10 variables across 3 levels, 76 participants were needed. Because the desired sample size was not reached, sample size may have a role in the lack of statistical significance found among the covariates on Black children ages 8–17 with SCD in Mississippi. Therefore, the findings of this research may only be generalized to individuals with similar (a)geographic location, (b)race, and (d)age.

Third, caregiver age and caregiver income were measured on a categorical scale to increase response rate. This limited the interpretation of findings because the variables such as: as income increase or decrease versus as income moves from one category to another, were not measured on a continuous scale. Fourth, caregivers and children individually completed questionnaires. The questionnaires provided self-reported responses about child and caregiver perceptions of the child's QOL and SCD pain within the past month. Data may have been missing or not completed on the questions, because participants were not able to remember what may have happen in the previous 4 weeks. This may have caused a lack of statistical significance due to a lower number of participants. If the sample size was larger the more likely a difference

could be detected, which means more likely to have s statistical significance. Fifth, the convenience sample was recruited on a voluntary basis, so only child and caregiver pairs who wanted to be a part of the study provided data. Individuals with lower QOL or higher pain burden may have been unwilling to participate in the research study. This limitation could have resulted in higher quality of life scores and lower SCD pain burden scores, as participants experiencing pain at the time of data collection may not have been willing to participate. Sixth, the sample was recruited from a clinic that provided SCD pain treatment and pain management. This means that every person in the sample was already receiving SCD assistance, so the SCD pain burden may be lower and the QOL may be higher among these participants compared to the general population of Black children ages 8–17 in Mississippi with SCD.

Recommendations

I recommended that a longitudinal study should be conducted to recruit more children and caregivers to decrease missing or incomplete data, as well as to have a larger sample size. Furthermore, I suggest that the longitudinal study is used to establish a health profile to track outcomes of SCD pain and QOL and provide reliable scientifically sound information to improve QOL and health among the pediatric SCD population. I also recommended that this study is implemented in other states with (a) a high population of children with SCD, (b)for comparing and contrasting services, (c)policies and procedures to develop and implement a systematic model of care and resource. This strategy assists with common practices specifically for pediatric SCD population throughout medical neighborhoods within the communities. Additionally, it is recommended that research of the relationship among caregiver education and income status to determine a more defined impact on the QOL of children with SCD. This method can be used to

determine educational needs, as well as the need for income assistance programs for caregivers with low income.

Moreover, I suggested that the demographic collection of data is expanded to collect zip codes to determine the distribution of SCD in Mississippi. This can provide information on areas that are highly populated of individuals with SCD, as well as to provide specialty SCD clinics within communities. I recommend the research of SCD pain burden and QOL for only children and their responses are compared among age and sex of child participants. As children become more responsible for their disease management, it is important to understand their perception on the impact of SCD pain by evaluating the child's view point of (a)physical, (b)social, (c)emotional, and (d)school functioning. In addition, examining the perception of only the child can be valuable for community program development, and data can be used to understand the gaps in care and outcomes. Lastly, it is recommended for a more comprehensive clinical approach to define QOL of children with SCD from their perspective. This may improve doctor patient relationships as well as the clinic can expand its services as a one stop shop to provide comprehensive resource that would not normally be available.

Social Ecological Theory and Child Sickle Cell Disease Pain and Quality of Life

The SET played an important role in understanding that an individual's environment may have a unique influence on their (a)health, (b)personal relationships, (c)community, and (d)other societal factors (World Health Organization, 2002). The foundation of SET in public health suggests that there is an important relationship among an individual's environment and its influence on health (Moore, Buchanan, Fairley, & Smith, 2015). The American Psychological Association (2017) suggested that health outcomes of children can

be influenced by the (a)individual, (b)caregiver, (c)availability of resources, and (d)SES in the community. This research has shown that the microsystem and the mesosystem of SET does have an influence on the development and environment of child participants in this research. The research captured an ecological view of Black children ages 8–17 with SCD in Mississippi. The ecological view described factors that influenced the ecological level where the children most commonly exist. In this case, the child participants of this study were represented by the microsystem, which included immediate influences and support that relate to the children such as, their caregivers and pediatric hematology clinic. Also, the mesosystem characterizes their connection between two or more microsystems (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011, Steele & Aylward 2009) such as, (a)child and caregiver, (b)child and pediatric hematology clinic, and child, caregiver and the pediatric hematology clinic.

Further, the SET was used as a foundation for the interpretation of the research results. The microsystem and mesosystem were motivating forces to support the children's and caregiver's relationship of SCD pain burden and QOL. There was a significant relationship in child and caregiver perceptions of: (a)low SCD pain burden, (b)emotional functioning, and (c)QOL. This implies that there was interaction among the children and caregivers because there was similar understanding of the child's:(a) SCD pain burden, (b)emotional functioning, and (c)QOL. As mentioned previously, I selected this theory because other research showed that children can experience an interruption in: (a)physical, (b)emotional, (c)social, and (d)educational aspects of daily functions (Palermo et al.,2008). However, this research shows that children reported low SCD pain burden and high QOL

which indicates there was no interruption in the areas of: (a) physical, (b)emotional, (c)social, and (d)educational aspects of their daily functions.

Additionally, this research does support the literature in using the SET approach for social support for children illness management, and the connection with the microsystem and mesosystem (Carcone, 2010). The microsystem was suitable because children who participated in this study received significant support from their caregivers for: (a) SCD pain burden, (b)emotional functioning, and (c)QOL. Further, the mesosystem was adequate regarding children and caregivers received support from the pediatric hematology clinic regarding disease management and other supportive healthcare services. It can be assumed that the support to children from caregivers, and support from the pediatric hematology clinic to children and caregivers may have convinced the perceptions of low SCD pain burden and high QOL of the children.

Review of the literature suggested that children with SCD are a part of low income families, and there is a strong relationship with SES which may result to adverse health outcomes (Pettignano, Caley, & Bliss, 2011, Price et al. 2013). In addition, previous research implies that for the family level, low income has been linked to severe SCD pain and negative thinking in adolescents (Palermo et al., 2008). Similar to previous literature, the results of this research demonstrated that caregiver's SES was found to be a significant predictor of the children's QOL. Also, for this research the caregiver's SES were determined to be low for income and education. However, in contrast to previous research the children reported high QOL and low SCD pain burden for this research.

In relating caregivers to the SET, it was important for the caregivers (microsystem) to interact with the pediatric hematology clinic(mesosystem) to learn about the child's SCD, and services offered by the clinic such as financial support. The current research showed that caregiver's low SES did not impact the QOL of children with SCD. As caregivers QOL increased the children's QOL increased, which can possibly be attributed to the health education and financial services received from the clinic by the caregivers. The results of this research also indicated that as the caregiver's income and education increased the child's QOL decreased. As caregivers receive higher income and education they no longer meet the eligibility for financial services. The cost of healthcare may become a burden for caregivers of children with SCD. The increase or decrease of caregiver's income and education does play a pivotal role in the child's QOL, which demonstrates that there is a relationship among child health and caregiver SES.

Overall this research does support the SET in that the child's environment and support may have an impact on their health. The outcome of the children's QOL can be contributed to the characteristics of the: (a)child, (b)caregiver, (c)demographic profile, and (d)daily functioning. Support from caregivers and healthcare providers are the most logical sources of care that impact the daily functions of children with SCD, as these are the individuals that the children interact with daily. It makes theoretical sense that microsystem and mesosystem assessing SCD pain burden and QOL would be strongly related to one another. Using the SET to assess the children's environment can contribute to the development of interventions that would sustain the increase in children's daily functioning (i.e. physical, social, emotional and school functioning), disease management, and improve knowledge of child SCD. Furthermore, the SET can be used to assess the process of the pediatric hematology clinic

services in which policy and procedures can be improved to amend caregiver's eligibility of services based on SES.

Implications for Social Change

Results of this research show that for Black children ages 8–17 with SCD, child QOL was not dependent upon caregiver's perception of the child's QOL or caregiver's perception of child's pain burden. This indicated an opportunity to educate caregivers on the needs and perceptions of the child with SCD for a greater understanding to be established between the pair. This is also implied for practitioners to accurately access the child's pain burden and the child's QOL, the child should be included in their medical and nonmedical planning and process for information to be accurate. Further, it is important for the practitioner to be informed of the child's pain and QOL perceptions should the child experience a SCD pain crisis and is not able to provide information during the pain crisis or analysis. Obtaining this information from the child is also important because the information provided by the caregiver may not provide a complete picture of child SCD pain.

There is a negative statistically significant relationship between child SCD pain burden and child QOL. Thus, this study can be used to (a)develop, (b)implement and guide programs, and (c)provide policy makers with information directly from the targeted population. Although the children did not perceive themselves as having a low QOL there are still implications for interventions. On the QOL subscales, children scored lowest on school functioning and emotional functioning. Implication for positive social change include comprehensive interventions that can be implemented at home and in school systems to ensure children with SCD are functioning academically and emotionally. This can lead to

further positive outcomes for child QOL. For example, school-based programs and technology-based programs can provide education to: (a) children, (b)caregivers, (c)health care providers, and (d) teachers about the impact of SCD pain, as well as (e)how to improve disease management. In addition, these interventions demonstrate to children and caregivers how to effectively manage their pain at home and school.

Further, a health policy approach for SCD can be implemented to reduce cost of healthcare services, improve the populations health through systematic services, and enhance pediatric patient experiences by involving them creating patient centered polices and solutions. For example, using child perception data to develop and implement sterner federal laws that protect the rights of children with chronic conditions, and lastly working with school officials to promote school reentry programs.

Conclusion

The purpose of this study was to examine the relationship of SCD pain and QOL among Black children ages 8–17 in Mississippi. While research does exist to support individuals with SCD, little is known about the QOL trajectory of children with SCD. In addition, there is not much support of current information about children with SCD perception of pain. Child and caregiver participants volunteered to complete questionnaires that provided primary data on the child SCD pain burden and QOL. Child and caregiver participants agreed that Black children ages 8–17 with SCD in Mississippi experienced a high QOL and low SCD pain burden. However, child and caregiver participants were not in agreement regarding the physical functioning of children. Mean scores for all subscales of child's QOL (physical functioning, emotional functioning, social functioning, and school functioning) were higher for the child then

for the caregiver. This study will be a new addition to the body of pediatric SCD literature to discuss the relationship of SCD pain and QOL among Black children ages 8–17 in Mississippi. Caregiver SES was found to be statistically significant predictor of child QOL in this study; SET theory recommends that family functioning may guide the relationship among SES and QOL outcomes. Particularly, SET supports the idea that children and caregivers' dwell within families, and that strains on the family system has a major influence on the health and functioning of all family members (Litzelman et al. 2013). This research is deemed significant as it may inform healthcare professionals and public health practitioners of measures that should be identified to improve the QOL for Black children ages 8–17 with SCD. In addition, the research is meaningful because it shows a child SCD pain burden as a statistically significant predictor of child QOL and implies a moderate correlation among children and caregivers mean scores of SCD pain and emotional functioning.

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Appendix A

Questionnaires

Caregiver:_____

Date: _____ ___

Sickle Cell Disease Pain Burden and the Quality of Life Among Black Children in Mississippi

Caregiver and Child Demographic Profile Information

A. Please provide the requested information as they relate to you as a caregiver.

1. **Your relation to the child:** □Mother □Brother □Grandparent □Father □Sister □Legal Guardian

2. **Sex:** □Male □ Female **Age:** □18-24 □25-44 □ 45-64 □ 65 plus **Ethnicity:** □Black or African American □White □American Indian or Alaska Native □Hispanic □Native Hawaiian or Other Pacific Islander

3. **The highest education level you completed:** □Less than high school □High school/GED Vocational Training □Some College □College Graduate

4. **Work status**: □Employed □Unemployed □Retired □Student **Approximate total family income in the past 12 months:** □Less than or equal to $20,000.00 □$20,000 -34,999 □$35,000-$49,999 □Greater than or equal to $50,000

B. Please provide the requested information about your child with sickle cell disease.

1. **Sex:** □Male □Female **Age:** _____ **Date of Birth:** _____

2. **Ethnicity:** □Black or African American □White □American Indian or Alaska Native □Hispanic □Native Hawaiian or Other Pacific Islander

3. **What type of sickle cell disease does your child have?**

□ HbSS □HbS Beta- O Thalassemia □HbSD
□ HbSC □HbSE □Other: _____
□HbS Beta + Thalassemia □HbSO

Date: _____ ID#_____

Child Sickle Cell Disease Pain Burden Interview

I want you to think about your pain in the last month:

---

1. How many days have you had any pain?
   None A Few Some Many Every

2. How many nights have you slept poorly (trouble falling asleep, walking up during sleep) because of pain?
   None A Few Some Many Every

3. How many days have you had trouble taking care of yourself (dressing, going to the bathroom, showering) because of pain?
   None A Few Some Many Every

4. How many days have you missed school/work because of pain?
   None A Few Some Many Every

5. How many days have you left school/work early because of pain?
   None A Few Some Many Every

6. How many days have you been unable to do things you enjoy because of pain?
   None A Few Some Many Every

7. How many days have you felt sad, mad, or upset because of pain?
   None A Few Some Many Every

Date: _____ ID#_____

Parent/Caregiver Sickle Cell Disease Pain Burden Interview

I want you to think about your child's pain in the last month:

---

1. How many days have you had any pain?
   None A Few Some Many Every

2. How many nights have you slept poorly (trouble falling asleep, walking up during sleep) because of pain?
   None A Few Some Many Every

3. How many days have you had trouble taking care of yourself (dressing, going to the bathroom, showering) because of pain?
   None A Few Some Many Every

4. How many days have you missed school/work because of pain?
   None A Few Some Many Every

5. How many days have you left school/work early because of pain?
   None A Few Some Many Every

6. How many days have you been unable to do things you enjoy because of pain?
   None A Few Some Many Every

7. How many days have you felt sad, mad, or upset because of pain?
   None A Few Some Many Every

ID# _____ **Date:** _____

PedsQL

Pediatric Quality of Life Inventory

Version 4.0

CHILD REPORT (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past ONE month, how much of a problem has this been for you

ABOUT MY HEALTH AND ACTIVITIES ***(problems with…)***	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4
ABOUT MY FEELINGS ***(problems with…)***	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4
HOW I GET ALONG WITH OTHERS ***(problems with…)***	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. I have trouble getting along with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids my age can do	0	1	2	3	4
5. It is hard to keep up when I play with other kids	0	1	2	3	4
ABOUT SCHOOL ***(problems with…)***	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

ID# _____ Date: _____

PedsQL

Pediatric Quality of Life Inventory

Version 4.0

PARENT REPORT for CHILDREN (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month,** how much of a **problem** has your child had with …

PHYSICAL FUNCTIONING *(problems with…)*	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. Walking more than one block	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing chores around the house	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Low energy level	0	1	2	3	4
EMOTIONAL FUNCTIONING *(problems with…)*	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or blue	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying about what will happen to him or her	0	1	2	3	4
SOCIAL FUNCTIONING *(problems with…)*	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. Getting along with other children	0	1	2	3	4
2. Other kids not wanting to be his or her friend	0	1	2	3	4
3. Getting teased by other children	0	1	2	3	4
4. Not able to do things that other children his or her age can do	0	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4
SCHOOL FUNCTIONING *(problems with…)*	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. Paying attention in class	0	1	2	3	4
2. Forgetting things	0	1	2	3	4
3. Keeping up with schoolwork	0	1	2	3	4
4. Missing school because of not feeling well	0	1	2	3	4
5. Missing school to go to the doctor or hospital	0	1	2	3	4

ID# _____ Date:_____

PedsQL

Pediatric Quality of Life Inventory

Version 4.0

TEEN REPORT (ages 13-18)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month,** how much of a **problem** has this been for you……...*

ABOUT MY HEALTH AND ACTIVITIES ***(problems with…)***	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4
ABOUT MY FEELINGS ***(problems with…)***	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4
HOW I GET ALONG WITH OTHERS ***(problems with…)***	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. I have trouble getting along with other teens	0	1	2	3	4
2. Other teens do not want to be my friend	0	1	2	3	4
3. Other teens tease me	0	1	2	3	4
4. I cannot do things that other teens my age can do	0	1	2	3	4
5. It is hard to keep up with my peers	0	1	2	3	4
ABOUT SCHOOL ***(problems with…)***	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

ID#_____ Date:_____

PedsQL

Pediatric Quality of Life Inventory

Version 4.0

PARENT REPORT for TEENS (ages 13-18)

DIRECTIONS

On the following page is a list of things that might be a problem for **your teen**. Please tell us **how much of a problem** each one has been for **your teen** during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has this been for you……...

PHYSICAL FUNCTIONING ***(problems with…)***	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. Walking more than one block	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing chores around the house	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Low energy level	0	1	2	3	4
EMOTIONAL FUNCTIONING ***(problems with…)***	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or blue	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying about what will happen to him or her	0	1	2	3	4
SOCIAL FUNCTIONING ***(problems with…)***	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. Getting along with other teens	0	1	2	3	4
2. Other teens not wanting to be his or her friend	0	1	2	3	4
3. Getting teased by other teens	0	1	2	3	4
4. Not able to do things that other teens his or her age can do	0	1	2	3	4
5. Keeping up with other teens	0	1	2	3	4
SCHOOL FUNCTIONING ***(problems with…)***	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
1. Paying attention in class	0	1	2	3	4
2. Forgetting things	0	1	2	3	4
3. Keeping up with schoolwork	0	1	2	3	4
4. Missing school because of not feeling well	0	1	2	3	4
5. Missing school to go to the doctor or hospital	0	1	2	3	4