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Perceptions and Experiences of Sickle Cell Disease Patients and Parents/Caretakers on Alternative Treatment Options for Pain Management

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Walden University
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Abstract

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by

Elizabeth Hagan Asamoah

MSc, Texas Woman's University, 2015

BSc, Kwame Nkrumah University of Technology, Ghana, 1997

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health (Community Health Education)

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Abstract

Sickle cell disease (SCD) is marked by excruciating chronic pain, commonly known as *pain crisis*. SCD healthcare practitioners (HCPs) have been employing palliative care as a mainstream treatment option to manage SCD pain crises using mainly opioid analgesics for years. Due to the current opioid crisis, however, it has become imperative to explore alternative regimens to manage the pain and associated comorbidities of SCD. Thus, the goals of this study included exploring alternative treatment options for SCD pain crisis management with the intent of decreasing SCD patients' dependency on opioid-based or related analgesics while reducing the frequency of pain crises as well as the number of hospitalizations all geared toward improving quality of life for SCD patients in terms of health status, living standards, and life expectancy. The study was also conducted to analyze and understand the participants' experiences and perceptions of alternative treatment regimens, and is expected to offer a unique contribution to the literature.

The nature of this qualitative study was both descriptive and analytical, with a case study design. The frameworks used were the health belief model, biopsychosocial-spiritual model, and transtheoretical model. Data were collected from a sample of 11 participants, with interviews conducted by phone and email due to COVID-19. The code and coding technique was employed in data collection, processing, and analysis. The study findings would benefit SCD patients, HCPs and caretakers as they learned of these alternative regimens with the expectation of improving their pain management strategies. Nevertheless, Findings confirmed the need for further research on alternative treatments or interventions for SCD patients to prevent or reduce the frequency of pain crises and associated complications and thus increase quality of life and effect social change.

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Dedication

First and foremost, I will give thanks to the Almighty Father and our Lord and Master Jesus for sailing me safely through this challenging and lonely journey and helping me to land safely. I appreciate you so much for providing me with good health, strength, energy, support, and boldness, and for protecting and keeping me company through it all, especially during the late-night vigils. I then dedicate this doctoral research to my husband, Enoch Asamoah, for his patience and understanding, and especially to my aspiring young professor, my precious daughter, Babette Asamoah, for your love, encouragement, and support; all the wisdom, ideas, and help with my studies and research; and being the reason and the motivation for this research study. I really do love and appreciate you all so much for this. I also dedicate this doctorate degree to my parents for their love, prayers, support, and care, especially my late Dad, who always motivated and encouraged me to stretch myself and aim and go for the ultimate in everything, especially in education. I also dedicate this study to all my siblings and the rest of the family for your continuous love and support. And then last but not least, I would like to thank Drs. Linda Tchemele, Moses Owusu, and Stella Green for all your support, help, and encouragement through the entire journey. I love and appreciate each one of you. God richly bless you all.

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Chapter 1: Introduction to the Study

Sickle cell disease (SCD), according to the Centers for Disease Control and Prevention (CDC, 2020b), is a group of inherited red blood cell disorders. SCD is marked with many pain episodes for patients, usually called *pain crisis*. Pain crises represent the main reason for frequent hospital visits and admissions among SCD patients, as well as the reason for SCD patients' dependence on opioid analgesics for managing pain.

SCD, at times referred to as the "forgotten disease," is regarded as a neglected public health condition. Serjeant (1997) described SCD as the most common globin gene disorder, attributing it to a point mutation, GTG GAG, in the codon. The sixth amino acid of the standard beta chain of the hemoglobin has glutamic acid, while the sickle beta chain has valine (Serjeant, 1997). SCD is more prevalent among peoples whose ancestors came from sub-Saharan Africa; Spanish-speaking regions in the Western Hemisphere; Saudi Arabia; India; and Mediterranean countries such as Turkey, Greece, and Italy (CDC, n.d.).

Pain crisis, one of the leading clinical hallmarks of SCD, generally occurs when hard, sickled, curved, or crescent-shaped red blood cells (RBC) clog small blood vessels (U.S. Department of Health and Human Services [USDHHS], 2020). This results in obstructing the smooth flow of blood and oxygen to specific organs, resulting in excruciating pain, especially in the joints, chest, and abdomen (USDHHS, 2020). Vaso-occlusion (VOC) usually happens when blood circulation through the small blood vessels becomes blocked by sickled cells, leading to ischemic injuries with pain and irreversible organ damage (USDHHS, 2020). The pain of SCD also results from the lack of oxygen

that occurs when sickle-shaped RBCs occlude blood vessels (USDHHS, 2020).

For years, the pain of SCD patients has been treated mainly with opioid analgesics and other prescription drugs. However, with the current opioid crisis, it has become crucial to research additional or new treatment options. Mahmood et al. (2020) declared how necessary it is for adjuvant nonopioid therapies that can improve pain control to be investigated, given the side effects of opioids. Thus, this study was conducted to explore the perceptions and experiences of SCD patients and parents/caretakers related to employing alternative treatment options for pain management. It was also conducted to explore treatments with the potential to reduce the frequency of pain crisis and eradicate dependency on prescription drugs or opioid-based substances.

Background of the Study

Naik and Haywood (2015) claimed that homozygous HbS was the first inherited condition identified at the molecular level in 1949. However, they noted that issues such as "hasty adoption of early mass screening programs for SCD, implementation of targeted screening mandates for SCT in athletics, and concerns about stigmatization all have led to the numerous controversies regarding research and policy decisions for SCT" (para. 1). Further, they stated that

> the historical background of SCD and SCT has contributed towards setting up the standards on how research should be conducted in the modern era. These are expected to help reduce stigmatization, ameliorate study conclusions, and inform genetic counseling and policy decisions for SCT. (para. 1)

According to Enwonwu (1989), the sickle gene is attributed to a point mutation,

whereby GTG GAG in the codon switches with the sixth amino acid of hemoglobin, resulting in a single nucleotide substitution (A to T). This causes a glutamic acid codon (GAG) to convert to a valine codon [GTG] (Enwonwu, (1989).

The mortality rate for the SCD community is generally high, and SCD patients' life expectancy is generally low. In the past, it was common knowledge that SCD patients had short lifespans, with the notion that such patients could not live beyond the age of 20. However, Shet and Thein (2019) claimed that the survival rate of SCD patients in well-resourced countries such as the United States has significantly improved in the past 60 years, with many newborn SCD patients now expected to live to adulthood. Neville and Panepinto (2011) maintained that less than 30% of adults with SCD in the United States have a life expectancy not exceeding 70 years, with causes of death attributed to acute SCD-related complications such as pain, acute chest syndrome, stroke, pulmonary hypertension, renal failure, and infections. The mortality rate of children with SCD in developed countries, according to Neville and Panepinto, is as low as .5-1 per 100,000 children. However, according to Shet and Thein (2019), with all the improvement in survival chances, the life expectancy of SCD patients still falls 20 to 30 years behind that of the general public.

Excruciating pain crisis, the main reason for frequent hospital visits and widespread use of opioid-based analgesics among SCD patients, is a typical characteristic of SCD. As Matthie et al. (2019) asserted, acute, intermittent vaso-occlusive pain is the hallmark of SCD and is associated with substantial morbidity, impaired quality of life (QOL) and higher rates of healthcare utilization. Hence, instead of opioid analgesics,

which have been the primary treatment option for managing these pains associated with SCD for years, Matte et al. (2019) proposed two new therapeutic strategies. These are pathophysiology-related new therapies and innovations in curative therapeutic options such as hematopoietic stem cell transplantation and gene therapy (Matte et al., 2019). These pathophysiology-related novel therapies have the potential to prevent sickling or sickle red cell dehydration; treat SCD vasculopathy and sickle cell-endothelial adhesive events; and promote antioxidant agents capable of reducing inflammatory responses to pathogens (Matte et al., 2019). Though in the past, there was a notion that there was no cure for SCD, all of these new therapies have proven to be promising. Yawn et al. (2014) also strongly recommended hydroxyurea and transfusion therapy for the SCD community.

The use of "complementary and alternative medicine (CAM), which Thompson and Eriator (2014) defined as a group of diverse medical and health care systems, practices, and products that are not presently considered part of conventional medicine, has been on the rise in recent years. Examples of conventional CAM, according to Thompson and Eriator, are prayer, acupuncture, massage therapy, meditation, and relaxation techniques such as breathing exercises, guided imagery, and progressive muscle relaxation. However, SCD patients who attempt to use CAM encounter many challenges, such as lack of access to these methods, as well as to third parties or insurance to cover CAM costs (Thompson & Eriator, 2014).

In the past, most of the therapy employed for SCD patients involved palliative care using pharmaceutically based regimens, with few attempts or room for other

treatment regimens such as self-care management and lifestyle modification. Matte et al. (2019) claimed that the major objectives of therapeutic strategies targeting sickle cell vasculopathy are to reduce or prevent vascular endothelial activation and damage. When conducting the data collection and analysis for the pretest trial, one of the themes that evolved was healthful eating, patients taking good care of themselves, and using dietary supplements such as folic acid daily. According to an SCD patient who participated in data collection for the current study by filling out a questionnaire and participating in an unstructured interview, the frequency of her pain crisis had decreased over the past 4 years as she began eating a healthier diet (Hagan Asamoah, 2019).

Problem Statement

SCD is an inheritable blood disorder that mostly affects people of African, Asian, Indian, and South American descent, as well as people of Middle Eastern regions (CDC, 2020b). SCD affects millions of people globally and about 70,000 to 80,000 individuals in the United States (USDHHS, 2020). The disorder has an estimated prevalence of 1 in every 500 African Americans and 1 in every 1,000 to 1,400 Hispanic Americans in the United States (USDHHS, 2020).

Pain crisis can negatively impact the daily activities of SCD patients in diverse ways, such as missed school days and workdays, high hospital bills, fear, stress, depression, other mental disorders, and social isolation. The management of this chronic pain has been approached primarily with palliative treatment, using mainly opioid analgesics. Thus, Booker et al. (2006) posited that the nature of SCD pain is poorly understood and that such pain is often sub optimally managed. In addition, SCD patients

have reported dissatisfaction with healthcare providers' lack of empathy and inadequate management of chronic SCD pain (Booker et al., 2006). This dissatisfaction has led to mistrust toward physicians and hence patients' unwillingness to communicate their true feelings due to fear of not receiving optimal treatment.

With the current opioid crisis, it has become imperative to explore alternative regimens for managing SCD-related pain to decrease dependency on opioid analgesics. In the quest to explore alternative treatment options for pain relief, it is critical to gather information on the perspectives of members of the SCD community. The prescribing habits or attitudes and neglect of SCD patients by healthcare providers (HCPs) and the pharmaceutical industry, respectively, also need to be understood. It is also necessary to gain insight into why HCPs treating SCD patients select options such as opioid analgesics when there seem to be better treatments such as hydroxyurea, Endari, and acupuncture, among others. In this study, I sought to address these gaps in the literature. This study's aim was to explore alternatives to orthodox opioid analgesics as therapies for SCD-related pain, with a focus on therapies that have the potential to reduce the frequency of pain crisis and the number of hospitalizations.

As Neville and Panepinto (2011) posited, there are few treatment options to prevent the development of most SCD symptoms, especially painful vaso-occlusive symptoms. These authors stated that for decades, the norm has been to manage SCD symptoms mainly with traditional supportive care measures such as aggressive hydration, anti-inflammatory medications, and narcotic analgesics. Matte et al. (2019) thus suggested the need to develop new therapeutic options to manage the complexity and the

various pathophysiology's associated with the disease. There is a need to explore both pharmaceutical treatments and nonpharmaceutical therapies/coping mechanisms such as acupuncture, nutrition, massage, prayer, hot pad treatments, music for distraction, hydroxyurea, Endari, and low-dose ketamine infusion. "According to Herman and Chaudhry (2010), hydroxyurea has the potential to increase the production of fetal hemoglobin and to help reduce the pain associated with the vaso-occlusive crisis" (para. 6). Palm et al. (2018) also proposed low-dose ketamine infusion as an adjunct analgesic agent in patients with vaso-occlusive episodes, especially those who continuously report severe pain despite high-dose opioid therapy and experience opioid-induced adverse effects. The newly approved voxelotor (GBT-440) resembles an oral direct antisickling agent, which can be beneficial in SCD as it blocks HbS intermolecular contacts, preventing the generation of HbS fibers and red cell sickling (Matte et al., 2019). Vitamin D has the potential to reduce the number of pain days in SCD patients and enable them to achieve higher physical activity quality-of-life scores (Osunkwo et al., 2012).

With all of these evidence-based alternative therapies available, it is somehow ironic that HCPs prescribing treatments for SCD pain limit their options mainly to opioid analgesics, irrespective of their adverse effects. Interestingly, the cost and side effects of these analgesics and hydroxyurea are almost the same. Most of the coping strategies that patients can use to address pain, such as mindfulness, distraction, massage, diet, and hot water pad treatment, do not necessarily incur costs. Therefore, there is a need to understand why SCD prescribers do not recommend or prescribe such strategies for their patients. Given this need, patients' perceptions and experiences about the prescribing

habits of their HCPs in managing pain and their knowledge of and interest in alternative therapies were of paramount importance in this study. Through this study, I sought to fill a gap in the literature by attempting to understand the prescribing habits of HCPs treating SCD patients, assess the awareness and experiences of SCD patients concerning the use of alternative regimens, and understand SCD patients' perceptions of employing alternative regimens for pain relief.

Purpose

The primary purpose for undertaking this study was to explore pain management choices for SCD patients with the aim of creating awareness of and promoting alternative treatment regimens among SCD patients and their parents/caretakers. These alternative treatment options were explored with the intent of identifying and promoting therapies or strategies that have the potential to decrease SCD patients' dependency on opioid-based analgesics. The focus was principally on therapies that are capable of reducing the intensity, frequency, and duration of pain crisis episodes; associated comorbidities; emergency room visitations; and hospitalizations.

The study findings may help in gaining insight into the perceptions of SCD patients and their parents/caretakers on the prescribing habits or practices of SCD HCPs, as well as the challenges and experiences that SCD patients encounter as they seek pain relief. According to Shet and Thein (2019), gaps or lapses in providing resources and adequately equipping HCPs with the required skills lead to various challenges in providing effective management for the newly increased population of SCD patients. Adegbola et al. (2012) noted that, apart from pharmacologic agents, SCD patients also

employ such natural approaches as heat, massage, or phytochemicals from vegetable and fruit juices, while others use alternative therapies due to fear of side effects associated with orthodox treatment.

This study makes a unique contribution to the literature by promoting greater understanding of the prescribing habits of SCD HCPs, assessing SCD patients' awareness of alternative therapies, analyzing the perceptions and experiences of patients regarding the use of alternative regimens, and educating patients about their right to request other treatment options from their HCPs. I used the qualitative method, employing interviews to understand the prescribing habits of SCD HCPs and explore the perceptions and experiences of SCD patients and their parents/caretakers on the use of alternative regimens.

Significance

Currently, the standard treatment option for SCD pain crisis is the use of opioid-based analgesics, which can be very addictive. This approach is contrary to "the pharmaceutical companies' reassurance in the 1990s to the medical community that patients would not become addicted to opioid pain relievers" (U.S. Department of Health and Human Services [USDHHS], n.d.). The HHS declared opioid use a public health emergency in 2017. A five-point strategy has been developed to combat the opioid epidemic, which makes it critical to explore and employ alternative treatment options for SCD patients (USDHHS, n.d.). This study may advance this effort by shedding more light on why SCD practitioners choose less effective opioid treatments when they have better options.

The study may also assist in examining SCD patients' and their parents/caretakers' awareness about the availability of other regimens, as well as in promoting these regimens and then empowering and educating patients about their right to request these alternative therapies during hospital visits. The findings of the study may be used to recommend appropriate strategies and alternative therapies for proper management of SCD pain crisis. Some of the social injustices and the racial and health disparities that SCD patients face as they seek treatment for pain were also investigated.

This investigation was geared toward improving health status, living standards, and life expectancy (quality of life [QOL]) for SCD patients and their parents/caretakers. Consequently, the expected outcomes of the study were to effect positive social change by improving the living conditions of SCD patients through better pain management strategies, enhance SCD practitioners' prescribing habits, and promote measures to prevent or reduce the frequency of pain episodes. The study findings showcase the prescribing habits of SCD HCPs and the perceptions of SCD patients and their parents/caretakers on the nature of pain relief strategies and alternative regimens for pain management.

Framework (Conceptual or Theoretical)

The health belief model (HBM), transtheoretical model (TTM), and biopsychosocial-spiritual model of chronic pain (BPS-Spiritual) were combined to form the theoretical/conceptual framework that guided this research. The HBM postulates that individuals will decide to do a health screening for a health condition if they are made aware of the level of seriousness of the health condition, if they are aware that they are at

risk of the condition, if they deem it beneficial to do the testing, and if the barriers to testing are low or manageable (Gustafson et al., 2007). HBM constructs may thus be applied in educating the SCD community about a patient's perceived susceptibility to and the severity of prescription drug abuse or overdose, specifically regarding opioid analgesics with time and hence the need to explore alternative regimens emphasizing the effectiveness and benefits of these alternative therapies. Strategies to activate readiness and enhance the SCD community with self-efficacy to embrace alternative regimens such as coping strategies and disease-modifying agents (e.g., hydroxyurea and Endari) for better pain management may be explored and promoted using the HBM constructs.

The TTM may also be employed to change patients' perceptions about trying alternative regimens rather than orthodox prescribed analgesics that have traditionally been used. As Jensen et al. (2000) noted, "Patients' readiness to adopt new beliefs and coping responses to pain may predict response to multidisciplinary or cognitive-behavioral pain treatments that emphasize changes in beliefs and coping behaviors" (para. 1). TTM constructs may be used to empower SCD patients to adopt behavioral changes or lifestyle modifications, including specific diets (e.g., alkaline diets), healthy eating habits, coping strategies, self-care management, and self-awareness/mindfulness, among others. Such strategies are expected to help patients manage pain better. The BPS-Spiritual model involves a holistic approach as it embraces the whole person, encompassing the biological, psychological, sociological, and spiritual aspects of the individual (Taylor et al., 2013). By integrating the constructs of the TTM, BPS-Spiritual, and HBM, the conceptual lens of this study was established.

Research Questions

RQ1. What are the experiences of the SCD patients or their parents/caretakers regarding the current prescribing habits of their HCPs to manage SCD pain, and how do they influence their choice of treatment?

RQ2. What are the experiences and attitudes of the SCD patients or their parents/caretakers toward alternative treatment methods, and how do they influence their choice of treatment?

RQ3. What is the stage of readiness for adopting alternative treatment methods for SCD patients or their parents/caretakers?

RQ4. How does disease perception among adult SCD patients or their parents/caretakers impact their willingness to try alternative treatment methods?

Nature of the Study

This study was qualitative, with a case study design using narrative accounts from interviews with participants. Patients were interviewed to assess their knowledge or awareness of alternative therapies and get their perceptions of using such therapies. Interviews were also used to understand and learn about the diverse strategies that SCD patients are using to cope with pain, especially as the first line of defense to manage pain even before they make it to a healthcare facility. Physicians were interviewed to find out whether they encouraged or recommended other coping strategies to their patients, especially self-care management, lifestyle modifications, and praying, and how effective they deemed these strategies to be in controlling pain crisis. Additionally, physicians

were interviewed on what their general prescribing habits or choices were and why they adopted those habits or choices over others.

Case studies may be used to compare the effectiveness of different treatment options by analyzing the experiences of participants who use alternative treatment options against those of patients who do not. Guided by the critical research questions, I used the qualitative approach in designing a thorough pain, psychological, and self-management needs assessment for study participants to be administered through interviews and surveys. The study employed both descriptive and analytical processes, with interviews and questionnaires/surveys serving as data collection tools. Hence, the research design that was employed for this study was qualitative case study. According to Tetnowski (2015), a case study research design is a valuable tool for answering complex, real-world questions. This rendered it the appropriate design to use for this study in which I explored alternative treatment options, which can be deemed a "real-world" challenge for the SCD community.

Possible Types and Sources of Data

Both primary and secondary data sources were considered for this research study. Semistructured interviews (which were mainly phone interviews, given social distancing practices due to COVID-19) and surveys were administered with selected participants to determine the methods that they were currently employing for pain relief and their effectiveness based on members' experiences. Secondary data from previous studies and other accredited organizations such as CDC and WHO, as well as online support group platforms, were also reviewed, analyzed, and incorporated into the data. With the

expectation that there might be live interviews and that human participants might thus be used in collecting data for this study, I contacted the Institutional Review Board (IRB) to determine essential procedures to be followed and the ethical considerations or requirements that must be met. A purposeful sampling technique was employed to recruit participants for the study.

Definitions

Gene mutation: "A permanent alteration in the DNA sequence that makes up a gene, such that the sequence differs from what is found in most people" (USDHHS, 2020, p. xx).

Point mutations: A broad category of mutations that describe a change in a single nucleotide of DNA, such that the "nucleotide is switched for another nucleotide. The nucleotide may also be deleted, or a single nucleotide is inserted into the DNA that causes that DNA to be different" from a typical or wild type gene sequence (National Human Genome Research Institute, n.d.).

Pain crisis: An event in which the patient reports pain that is severe, uncontrolled, and causes distress for the patient, family members, or both" (Moryl et al., 2008). SCD pain crisis consists of chronic, intermittent, and unpredictable episodes of pain associated with the vaso-occlusive crisis (VOC) that usually sends SCD patients to the emergency room. Pain crisis may result in the interruption of blood flow to tissues due to clogging of blood vessels, leading to pain, acute chest syndrome, stroke, priapism, and chronic organ damage.

Vaso-occlusive crisis (VOC): Occurs when microcirculation is obstructed by

sickled RBCs causing ischemic injury to the organ supplied, resulting in excruciating pain.

Hydroxyurea: An inhibitor of DNA synthesis and an antimetabolite that is used to treat chronic and acute myelogenous leukemia and polycythemia vera, and that is used to increase the concentration of fetal hemoglobin in patients with SCD.

SCD community: Consists of healthcare practitioners (physicians, nurses, dieticians, and other HCPs) of SCD patients, their parents/caregivers, and other stakeholders.

Target/study population: Adult SCD patients and SCD patients' parents/caregivers.

Coping: A person's cognitive and behavioral efforts in response to stressors that determine how those stressors will affect physical and emotional well-being (Lazarus & Folkman, 1984; Litt & Tennen, 2015).

Coping strategies: Psychological patterns that individuals use to manage thoughts, feelings, and actions encountered during various stages of ill health. These may include information seeking, self-management, catastrophizing, and wishful thinking. Describe the extent to which individuals cope well with their pain, which may influence the quality of life.

Self-management: The decisions and behaviors that patients with chronic illness engage in that affect their health, including the care and encouragement provided to people with chronic conditions and their families to help them understand their central role in managing their illness, make informed decisions about care, and engage in healthy

behaviors (Group Health Research Institute, n.d).

Spirituality/religiosity: Spirituality is a personal belief in God or a Higher Power, which may receive expression through individual prayer, meditation, and meaning in self. In contrast, *religion* is defined as involving organizational beliefs or adherence to institutionally based belief systems or dogma (Arrey et al., 2016, para. 6).

Mindfulness: Described as a simple mental activity with the potential to reduce pain and the need for pain medication. It also increases the ability to regulate pain, emotion, and behavior mentally; alters the way in which the brain processes rewards; restores positive feelings; can be learned in a class or at home; and is an accessible alternative for managing pain (Voss et al., 2019).

Pain management: A broad and multidisciplinary approach that addresses physical, psychosocial, and spiritual dimensions (Brennan et al., 2019).

Opioid analgesics: Commonly referred to as *prescription opioids,* medications that have been used to treat moderate to severe pain in some patients. Examples are morphine, codeine, oxycodone, hydrocodone, tramadol, and fentanyl (CDC, 2021).

Opioid crisis: Devastating consequence of the opioid epidemic, which has resulted in increases in opioid misuse and related overdoses (HHS, n.d.).

Opioid dependence: Occurs when "the body adjusts its normal functioning around regular opioid use," which may result in unpleasant physical symptoms when the medication is stopped (CDC, 2021, p. xx).

Perceptions: Immediate or intuitive recognition or appreciation of moral, psychological, or aesthetic qualities. Is the insight, intuition, or discernment; awareness

or consciousness; the process, act, or faculty of perceiving (Dictionary.com, 2020).

Assumptions

There are a few assumptions that were addressed in this study. First, there was an assumption that SCD HCPs do not usually prescribe or recommend alternative therapies for their patients because of a lack of awareness and knowledge about the efficacy of these other therapies. Additionally, it was assumed that the SCD patients and their families would quickly embrace the concept of alternative treatment regimens for pain because of the current opioid crisis and all of the stigma and inconvenience associated with opioid analgesics. Moreover, I assumed that members of the SCD community would perceive exploring alternative treatment options as a step in the right direction. It was also assumed that patients and their families had substandard experiences with managing SCD-associated pains using the current treatment option, which justified the need to explore alternative options.

Scope and Delimitations

The primary purpose of this study was to conduct research into alternative treatment options for SCD pain management and patients' perceptions and experiences about such regimens. The scope of the study thus defined the parameters or boundaries under which the study was conducted, which implied taking into account the sample size, target population, time, and geographic area. For instance, I planned to recruit about 20-25 study participants in order to attain saturation or gather enough information to be able to draw a valid conclusion after the collected data had been analyzed.

Simon (2011) described delimitations as those characteristics that limit the scope

and define the boundaries of a study, with examples being the choice of objectives, the research questions, variables of interest, theoretical perspectives that the researcher adopts, and target population. This study was delimited to SCD patients or their parents/caretakers who were at least 14 years of age and could easily communicate in English, preferably, or in Twi, an African dialect that I speak fluently. Delimitations also determine the criteria for participant recruitment, the profession or organizations to involve, unique characteristics of the sample/population, the philosophical framework, methodology, and variables in the study that set the boundary base on which the findings can be established (Simon, 2011). For instance, because of the specificity of the disease, only people who had knowledge of or experience with SCD or the subject matter were recruited to participate in the study.

As this was a qualitative study, the initial data collection tools were going to be face-to-face interviews or a focus group. However, because of social and physical distancing regulations due to COVID-19, the data collection tools were delimited to mainly phone interviews, emails, video conferences or calls, texting, and messaging using various social media platforms.

Limitations, Challenges, and/or Barriers

Time management was a significant challenge, so strategies for effectively allotting specific and adequate time each day to work on the dissertation amidst other activities or responsibilities needed to be developed. I also anticipated that financial constraints would be encountered in covering all of the expenses that were accrued with the study. For example, I was unable to afford the full services of an editor and procure

other logistics necessary for the study.

The stigmatization associated with the SCD condition and community in terms of longevity, morbidities, the claim of prescription drug abuse, restrictions in terms of partner choices, and other social limitations deters many SCD patients or their families from disclosing the condition. I expected that such stigma might serve as a significant barrier to the data collection process. Moreover, correctly transcribing the collected data might also pose a challenge, given that transcription is known to be time consuming and labor intensive. I anticipated that social and physical distancing measures due to COVID-19 might place some restrictions on the data collection tools that could be used.

Summary

SCD is described as an inherited "blood disorder in which abnormal red blood cells damage the cerebrovascular system as well as organs such as the liver and spleen" (Scott & Scott, 1999, p. 1). The hemoglobin of SCD patients is defective, so red blood cells tend to cluster together and form long, rod-like structures that become stiff and assume sickle shape after they give up their oxygen (WHO, 2016). This is the reason for the excruciating pain, comorbidities or health complications, and numerous hospitalizations associated with the condition.

In the United States, SCD affects around 72,000 people, most of whose ancestors came from Africa (WHO, 2016). SCD occurs in nearly 1 in every 500 African American births and 1 in every 1,000 to 1,400 Hispanic American births, while 1 in every 12 African Americans carries the sickle cell allele (WHO, 2016). SCD has a 10% mortality rate for children within the first 5 years of their lives. In 2005, medical expenditures for

SCD children averaged $11,702 dollars for those with Medicaid coverage and $14,772 dollars for those with employer-sponsored insurance, with about 40% of both groups having at least one hospital stay that year (CDC, 2016).

SCD is marked by frequent pain episodes and severe conditions such as chronic anemia, fatigue, anxiety, depression, pulmonary hypertension, respiratory infections, urinary tract infections, chronic arthritis, and necrosis, as well as neurophysiological conditions such as strokes, seizures, and cognitive and psychological problems. Hospital stays are frequent for SCD patients due to the severity of most of the health conditions associated with the disorder. SCD patients are at high risk of being misunderstood and misdiagnosed. SCD does not get the high-profile attention that other illnesses receive, even though it is a critical health condition. Scott and Scott (1999) thus suggested the need for continued research and public awareness on SCD. Pain crisis and VOC are the clinical hallmarks of SCD, and for years these pains have been managed through palliative care using mostly opioid analgesics. With the current opioid crisis, it has become critical for different therapies to be investigated.

Chapter 2: Literature Review

SCD is a genetic blood disorder that affects the hemoglobin (Hob) within red blood cells (RBCs; WHO, 2006). SCD is associated with recurrent pain and complications that are capable of interfering with many aspects of the patient's life, including education, employment, and psychosocial development (WHO, 2006). People with SCD have RBCs containing an abnormal form of the oxygen-carrying protein hemoglobin S (WHO, 2006). As WHO (2006) explained, "Children who inherit the sickle-cell genes from both parents will develop the sickle-cell disease (SCD), while those who inherit the gene from only one parent will have the sickle-cell trait (SCT)" (p. 1). CDC (2020) has characterized SCD as a significant public health concern and is working toward raising awareness about the disease.

Neville and Panepinto (2011) noted that the incidence of SCD is higher than that of most other severe genetic disorders such as cystic fibrosis and hemophilia. Globally, there are approximately 300,000 SCD births annually, with about 10% to 40% of the population in most African countries carrying the sickle-cell gene, resulting in an estimated SCD prevalence of at least 2% (American Society of Hematology [ASH], 2016). According to USDHHS (2020), most people with SCD are of African ancestry or identify themselves as Black. However, there are also many people with SCD who come from Hispanic, southern European, Middle Eastern, or Asian Indian backgrounds. USDHHS (2020) reported that there are about 100,000 Americans who have the disease, with about 1 in 13 Black or African American babies born with sickle cell trait (SCT) and 1 in every 365 Black or African American babies born with SCD. The incidence of SCD

among Hispanic American births is about 1 out of every 16,300 (CDC, 2020).

Pain management is one of the major challenges for SCD patients. This case study was undertaken to explore alternative regimens that offer better pain management than traditional opioid treatment. In this chapter, I will present a thorough review of existing literature on such treatment options. This chapter includes a description of strategies employed to review the literature, a synopsis of the literature on the various treatment therapies investigated, a discussion of the conceptual and theoretical frameworks on which the study was grounded, and a summary of the findings of the literature review.

Literature Search Strategy

Relevant published articles were comprehensively searched for using Walden University Library's electronic database. Several search engines were used to locate recently published articles on the research topic with interest in those published between 2010 and 2020. However, it was necessary to make exceptions due to the scarcity of articles on the research topic, so the research was based on articles that dated as back as far as 1989, with most of the articles that contained information relevant to the research questions having been published beginning in the early 2000s. Search engines that were effective in retrieving appropriate articles were PubMed, Google Scholar, ProQuest, and ScienceDirect. Secondary source data—mainly statistical data and other demographic information for the study—were chiefly accessed from the websites of internationally acclaimed organizations such as WHO, NIH, ASH, NHLBI, and CDC.

The key search terms that were used to locate relevant articles for the literature review were *alternative treatment choices/options*, *sickle cell disease*, *pathophysiologies*,

opioid analgesics, pain crises, vaso-occlusive events, self-care management, spirituality/religiosity perceptions, experiences, coping strategies, nutrition, micronutrients, prescribing habits, healthcare practitioners, theoretical framework, and *qualitative research design*.

Etiology and Epidemiology

SCD is a genetic disease caused by a gene mutation. Although the mutation is claimed to have originated from West Africa, it has become a global health concern due to migration or globalization and an increase in interracial marriages (Serjeant, 1997). As Serjeant (2013) wrote, "It is … speculated that the Hobs trait is a relatively new mutation limited to West Africa where it occurs at high frequencies (> 20%) especially in central Ghana and Burkina Faso, and only 2% in Nigeria" (para. 3). Frenette et al. (2019) reported that it has been suggested that

> SCD developed from a missense mutation within the β-globin gene leading to the substitution of valine for glutamic acid on the outer surface of the globin molecule rendering the sickle cell hemoglobin ("HbS") less soluble and prone to polymerization upon deoxygenating. (para. 4)

According to USDHHS (2020), mutations in the HBB gene, which provides instructions for making beta-globin, cause two of the subunits of hemoglobin to develop the various types of SCD. Sundd et al. (2019) hypothesized that a single amino acid substitution in the β-globin chain leads to polymerization of mutant hemoglobin S, impairing erythrocyte rheology and survival. As Manwani and Frenette (2013) noted, "There is also a corroboration to all these with the claim that the development of SCD

causes the encoding of the β-globin subunit leading to polymerization of deoxygenated sickle hemoglobin and decreased deformability of RBCs" (p. 1). Further, Manwani and Frenette explained, "There is a complex interplay of adhesive events among blood cells that can obstruct the vasculature, producing episodes of pain, hemolytic anemia, organ injury, and early mortality" (p. 1).

SCD is inherited in an autosomal recessive pattern (USDHHS, 2020). Thus, both copies of the gene in each cell have mutations. This implies that the parents of an individual with the autosomal recessive condition must each carry one copy of the mutated gene, even though they may not show any signs or symptoms of the condition. As USDHHS (2020) explained, the abnormal versions of beta-globin can distort RBCs into a sickle shape, which can lead the cells to die prematurely, precipitating anemia. These inflexible, sickle-shaped cells can also get stuck or clogged in small blood vessels, which can result in serious medical complications (USDHHS, 2020), a typical example being the SCD pain crisis. USDHHS (2020) described the main types of SCD as hemoglobin Sβ0 thalassemia, Sβ+ thalassemia, SC, SD, SE, and SS.

According to the USDHHS (2020) at least one of the two abnormal genes causes a person's body to make hemoglobin S in each of the various types. The most common and severe type is sickle cell anemia, whereby the person has two hemoglobin S genes (i.e., hemoglobin SS; USDHHS, 2020.). The two other common types are the hemoglobin SC disease and hemoglobin Sβ thalassemia, with hemoglobin SD and hemoglobin SE being much less common (USDHHS, 2020). Other people, usually referred to as *carriers*, do not have full-blown SCD but have one of the mutated genes; such individuals, who

also have one normal gene, have normal RBCs. CDC (2020) asserted those with only one mutated gene, called the SCT, obtained one sickle cell gene (“S”) from one parent and one normal gene (“A”) from the other parent. These individuals usually do not exhibit any of the signs of the disease and live a healthy life, but they can pass the trait on to their children and may also have a few uncommon health problems that may be attributed to the SCT (CDC, 2020).

According to CDC (2020), SCD patients usually start to have signs of the disease during the first year of life, usually around 5 months of age. Early signs and symptoms of SCD include swelling of the hands and feet, anemia, fatigue or extreme tiredness, jaundice, infections, and delayed growth, with episodes of pain crisis evolving with time (USDHHS, 2020). Karafin et al. (2019) claimed that chronic pain is prevalent in SCD, with 30% of patients experiencing daily pain while 50% meet the criteria for chronic pain syndrome. These researchers proposed that SCD patients have synaptic changes in the central nervous system (CNS) that may contribute to the pathogenesis of chronic pain based on their study findings (Karafin et al., 2019). The disease can also result in other complications affecting the patient’s spleen, brain, eyes, lungs, liver, heart, kidneys, penis, joints, bones, or skin as the years progress.

SCD is claimed to be a lifelong illness, but the severity of the disease varies widely from person to person (USDHHS, 2020). Some patients may experience both acute and chronic signs, symptoms, and complications (USDHHS, 2020). The acute pain episodes or crises, which are described as sharp, intense, stabbing, or throbbing in their intensity, are compared to those of postsurgical pain or childbirth (USDHHS, 2020).

They can occur without warning when sickle cells block blood flow and decrease oxygen delivery (USDHHS, 2020). The pain crisis is one of the main reasons that SCD patients have frequent hospital visits or hospitalizations.

Clinical Manifestations or Pathophysiology of Sickle Cell Disease

SCD is associated with various complicated clinical manifestations. The ASH (2016) has stated that the severity of the numerous complications associated with SCD can render every stage of life extremely difficult and a challenge for patients. Shet and Thein (2019) asserted that in developed countries, the burden of disease has now shifted to adults with SCD as the disease has evolved into a debilitating condition with numerous complications associated with long-term chronic diseases coupled with all of the comorbidities that are attributed to aging.

According to CDC (2020a), SCD patients usually start to exhibit signs of the disease during the first year of life, usually around 5 months of age, with the symptoms and complications of the disease being different for each person, ranging from mild to severe. CDC (2020) asserted that SCD infants do not show symptoms at birth because of how baby or fetal hemoglobin protects RBCs from sickling. This characteristic seems to degenerate when the infant is around 4 to 5 months of age, resulting in the baby or fetal hemoglobin being replaced by sickle hemoglobin, at which point the cells begin to sickle (CDC, 2020). Thus, SCD is described as a disease that worsens over time (CDC, 2020). The Physicians Committee for Responsible Medicine and Unbound Medicine (PCRM, 2019) affirmed that SCD children who have been frequently hospitalized usually show

weak linear growth, lean body mass, and reduced fat-free mass. Some of the common complications of SCD outlined by CDC (2020) are as follows:

- *Pain episode or crisis*: The main reason that most SCD patients go to the emergency room or hospital. These pain crises occur when sickle cells traveling through small blood vessels get stuck and clog the blood flow. This results in pain that may range from mild to severe, which starts unexpectedly and can last for any length of time. According to the Sickle Cell Data Collection (SCDC, n.d.) program, in California, people with SCD seek care in the emergency department an average of 3 times per year from their late teens to their late 50s.
- *Hand-foot syndrome*: An early symptom of SCD characterized by swelling in the hands and feet. May also present with a fever, which is claimed to be caused by the sickle cells getting stuck in the blood vessels and blocking the flow of blood in and out of the hands and feet.

Painful vaso-occlusive events are the most common complication experienced by both children and adults with SCD. As Sundd et al. (2019) reported, “Erythrocyte abnormalities in SCD patients clinically manifest as hemolytic anemia, cycles of micro vascular vaso-occlusion leading to ischemia-reperfusion injury, infarction with VOC events and intravascular hemolysis promoting inflammation and redox instability” (para. 1). Moreover, SCD may result in continuous small- and large-vessel vasculopathy and molecular, cellular, and biophysical processes that can cause acute and chronic pain and end-organ injury and failure (Sundd et al., 2019). Manwani and Frenette (2013)

characterized “recurrent and unpredictable episodes of vaso-occlusion” as “the hallmark of SCD” (p. 1). HbS induces RBC membrane damage because of the cells’ deformed shape.

> This leads to calcium influx into the cell which may cause crosslinking of the membrane proteins activating channels that allow for the efflux of potassium and water from the cell thereby causing RBC dehydration worsening the sickling which may triggers VOC crisis. (Herman & Chaudhry, 2010, para. 2)

Thus, obstruction of the RBCs may develop, reducing blood flow to the vital organs and triggering ischemia, necrosis, and pain (Herman & Chaudhry, 2010).

Pain crisis is also claimed to result from damaged blood vessels, which become irritated, activating molecules in the blood called *selectins*, also known as “sticky factors” (Novartis Pharmaceuticals Corporation, 2019). These sticky factors are known to cause blood cells to stick to blood vessel walls and to each other (Novartis Pharmaceuticals Corporation, 2019). As more blood cells get sticky and adhere to each other and vessel walls, they form clusters in the bloodstream, in a process termed *multicellular adhesion* (Novartis Pharmaceuticals Corporation, 2019). These clusters build up and become blockages, making it difficult for blood and oxygen to flow generally in the vessels; this process is known as *vaso-occlusion* (Novartis Pharmaceuticals Corporation, 2019). When the blood cell clusters get more prominent, they result in episodes of sudden, unpredictable, and intense pain called *pain crises* or VOC (Novartis Pharmaceuticals Corporation, 2019). Bone infarction, necrosis, as well as bone marrow degeneration occur over time with repeated episodes of VOC (Herman & Chaudhry, 2010). As

Herman and Chaudhry reported, it has been claimed that “pain episodes can affect any bone marrow-containing structure such as the ribs, sternum, vertebral bodies, and skull” (p. 2). The life-threatening complications of bone marrow infarction in SCD patients include pulmonary fat embolism and acute chest syndrome (ACS).

Leger et al. (2018) pointed out that “SCD patients experience poor health-related quality of life (HRQOL), inadequate coping, and poor self-care management skills when compared to other chronic conditions that trigger episodic care leading to poor health outcomes” (p. 24). Further, Leger et al. noted, “SCD pains and other associated complications can negatively impact the physical, social, emotional, psychological, and spiritual domains as well as the level of self-efficacy, sufficiency, and sleep quality of affected patients and their family members” (p. 24). Other complications such as silent strokes can cause cognitive deficits, which can significantly impact the daily living activities of SCD patients, including disease management (Leger et al., 2018). According to Setty et al. (2003), nocturnal oxyhemoglobin desaturation contributes toward CNS complications associated with SCD and high rates of painful crises. “SCD is described as a hemoglobinopathy characterized by hemolytic anemia, increased susceptibility to infections, damages to organs and VOC” (Nur et al., 2011, p. 1). SCD leads to reduced QOL and life expectancy, with oxidative stress deemed responsible for most of these pathophysiologies (Nur et al., 2011). Other health challenges that SCD patients usually battle include fatigue, functional limitations, emotional effects, exhaustion from sleep deprivation, stress, and depression, which can affect their pain coping skills, self-care management, and QOL (Leger et al., 2018).

Encapsulated bacterial infections may present as splenic sequestration of sickle cells resulting in splenic congestion, as manifested by splenomegaly and reduced immune function (Herman & Chaudhry, 2010, para. 2). “SCD patients are thus more prone to getting bacteremia with pathogens like *Streptococcus pneumonia*, *Haemophilus influenzae*, and *Neisseria meningitides* which may result in life-threatening sepsis” (Herman & Chaudhry, para. 2). Pulmonary and cardiovascular complications are common health challenges in the SCD community. According to Herman and Chaudhry , neurological complications such as strokes and silent strokes are common with SCD-VOC and ACS, which may present with fevers, infarction, pulmonary fat embolism, hypoxia, and chest pains. Myocardial infarction may also happen due to VOC of the coronary arteries, and occasionally right ventricular (RV) dysfunction may develop due to pulmonary arterial hypertension in SCD patients (Herman & Chaudhry, 2010, para.2). Hemolysis is also another common clinical complication associated with SCD because of how mechanically weak the sickle cells are, according to Herman and Chaudhry. These authors also declared that when inflexible cells are trapped in the spleen and get phagocytized by the reticuloendothelial system, extravascular hemolysis results, causing a reduction in the red cell survival time. Herman and Chaudhry posited that a normal RBC survives for an average of 90-120 days, whereas a sickle cell survives for only 10-20 days. The sickle cell causes increased hemolysis complications as cholelithiasis due to excessive bilirubin production (Herman & Chaudhry, 2010).

Amer et al. (2006) posited that oxidative stress also plays a significant role in clinical manifestations of SCD, such as hemolysis, hypercoagulable state, recurrent

bacterial infections, and VOC incidences in SCD. The oxidative stress of SCD-RBC is attributed to the inherent instability of HbS and the high concentrations of iron and iron-containing compounds, such as haemin and Hob, in the plasma of the patients due to hemolysis and blood transfusions (Amer et al., 2006). According to Silva et al. (2013), sickle erythrocytes might be the trigger for multiple sources of reactive species, and SCD is intimately linked to chronic and systemic oxidative stress. These may require antioxidant therapies, which are deemed promising approaches for SCD treatment as they may constitute valuable means for preventing or delaying the development of organ complications. Edwards et al. (2005) also declared that the tissue damage associated with SCD increases patients' risk for other medical complications such as delayed growth and sexual maturation, acute and chronic pulmonary dysfunction, stroke, aseptic necrosis of the hip and shoulders, retinopathy, dermal ulcers, and severe chronic pain.

In general, SCD patients who transition from recurrent, acute pain to chronic, persistent pain may end up with more significant QOL impairment and higher rates of healthcare utilization (Matthie et al., 2019). Elander et al. (2003) observed that SCD patients with pain-related symptoms usually experience impaired activities and psychological disturbance than those with non-pain-related symptoms. Taylor et al. (2013) claimed the "BPS model of SCD pain can be used to hypothesized three categories of variables which are disease-related, psychosocial, a readiness that acts together overtime to explain the response to pain such as disability, distress, healthcare utilization in SCD" (Smith et al., 2005, para.9). These authors stated some of the disease-related variables are SCD genotype, hematocrit, fetal hemoglobin (HbF) level, SCD

complications and comorbidities, treatment variables (e.g., hydroxyurea, opiates, antidepressants), and pain location (Taylor et al., 2013).

Conditions That Trigger Pain Crisis

Examples of such conditions are extreme temperatures unusually cold and hot weather or conditions, high altitude, illness, physical and psychological stress, temperature changes, dehydration, or not drinking enough fluids, infections, pregnancy, alcohol, low oxygen tension, and extreme physical exercises or exertion.

Impact of the Opioid Crisis on Sickle Cell Disease Patients

The emerging opioid crisis has taken a significant toll on most people who suffer from chronic pain. However, the community most impacted by this crisis is SCD patients, thus making it necessary to employ alternative regimens. Ezenwa et al. (2016) claimed that SCD patients are also more likely to be accused of drug-seeking behavior and are directly or indirectly called drug addicts as compared to other populations with chronic pain. According to Su et al. (2019), opioids remained the most frequently prescribed medications for SCD, and there have been no significant changes over time in opioid prescribing. "Nevertheless, there is also evidence that SCD patients on chronic opioid therapy as a primary management strategy experience greater pain, poorer functional outcomes, and higher healthcare utilization than those who are not on opioids" (Matthie et al., 2019, p.1). Such patients also have a new challenge to deal with the increasing restrictions on opioid access due to the current opioid epidemic in the U.S. (Matthie et al., 2019). Sinha et al. (2019) conducted a qualitative study using a semistructured interview over the phone with 15 Africa American women. The participants reported how their

opioid prescriptions had become more restrictive, more closely monitored, and increasingly challenging to fill in pharmacies of late (Sinha et al., 2019). The participants also reported increased stigmatization about opioid use and how their medical care was being affected by the physician's exclusive focus on reducing pain medication use (Sinha et al., 2019). Based on the experiences of the participants as deduced from the research findings, the opioid epidemic has negatively affected patients' care by increasing barriers to access to opioids and decreased opioid dosing. In contrast, they still have to deal with the challenge of the lack of access to alternative therapies (Sinha et al., 2019). The researchers observed an emerging interest among the patients to use alternative therapies such as marijuana to manage their pains (Sinha et al., 2019), confirming how critical it is to explore alternative therapies.

Elander et al. (2003) posited that there is not enough evidence about substance dependence among SCD patients even though there are concerns about dependence on prescribed analgesia, which may compromise pain management. "Pain-related symptoms can be an indicator of how the pattern of frequent acute pain in SCD may make patients vulnerable to perceptions of drug dependence whereas non-pain-related symptoms depict more stringently defined dependence on analgesia with SCD" (Elander et al., 2003. para. 1).

Pharmacotherapy of Sickle Cell Disease

For years, one of the primary pain management strategies that have been employed for SCD patients has been palliative care treatment. The WHO (2019) defined palliative care as an approach that improves the quality of life of patients who are battling

a life-threatening illness like SCD and their families. Palliative care involves employing strategies like prevention and relief of suffering using early detection of pain episodes, appropriately assessing and treating pain and other problems, as well as enhancing the physical, psychosocial, and spiritual aspects of patient care (WHO, 2019). Opioid analgesics have been the main pharmaceutical product that has been used in this case. Neville and Panepinto (2011) described SCD as a chronic, debilitating disorder with multiple symptoms rendering it difficult or challenging to treat. These authors elaborated on how there are few treatment options to prevent the development of most of these symptoms especially painful VOC. Neville and Panepinto (2011) claimed this is because most of these regimens are mainly managed with traditional supportive care measures like aggressive hydration, anti-inflammatory, and narcotic analgesics which have been the norm for decades. Palm et al. (2018) also confirmed that the primary treatment currently employed for these episodes is supportive, using fluids and intravenous opioid and anti-inflammatory medication.

However, Manwani and Frenette (2013) proposed symptomatic management and prevention of painful VOC using the fetal hemoglobin–reactivating agent Hydroxyurea. This original non-opioid pharmaceutical product seems to have the potential to reduce the frequencies of VOC episodes. “It is also suggested that managing the VOC crisis with rehydration therapy to reverse the dehydration and hypoxia asserting that rehydration allows for increased RBC water and electrolyte uptake” (Herman & Chaudhry, 2010, para.6). “Hydroxyurea, which is capable of increasing the production of fetal hemoglobin, is recommended since the mutation is in the beta-globin, upregulation of

gamma-globin chains reduces the pain associated with VOC as fetal hemoglobin carries 2 alpha and 2 gamma-globin chains (Herman & Chaudhry, 2010, para.6). Su et al. (2019) proposed the need to increase the rate of prescribing of hydroxyurea for SCD children. Su et al. (2019) claimed there are safety and efficacy of starting Hydroxyurea in infancy and that the rate for prescribing Hydroxyurea for adults remains infrequent and considerably lower than opioids.

Nevertheless, usually, acute SCD painful episodes are managed with morphine (an opioid), while the chronic pain is managed using NSAIDs {like Ibuprofen} (Herman & Chaudhry, 2010). Transfusions can prevent SCD-related strokes as it reduces sickled cells. Also, oral hydration therapy to hydrate RBCs and oral analgesics to manage pain is recommended for Priapism, according to Herman and Chaudhry. Palm et al. (2018) also proposed low-dose ketamine infusion as an adjunct analgesic agent in patients with VOC episodes especially those who continuously report severe pain despite high-dose opioid therapy and also experiences opioid-induced adverse effects. These researchers review a retrospective case series of five patients admitted to the intensive care unit (ICU) with prolonged VOC episodes who were treated with a continuous infusion of low-dose ketamine (5μg/kg/min) after insufficient pain control with opioid analgesic therapy (Palm et al., 2018). It was observed that these patients experienced a lower reported pain score, reduced opioid-induced adverse effects, and decreased opioid dosing requirements with a median reduction of 90mg morphine (Palm et al., 2018). Jennings et al. (2013) also attested that oral antagonist ketamine has analgesic properties.

Cell Transplant (HSCT) is also highly recommended for SCD patients under the

age of 17, or those with prior SCD related organ damage like stroke, acute chest syndrome, frequent painful episodes and multiple sites of osteonecrosis (Herman & Chaudhry, 2010). According to a randomized control trial conducted by Orringer et al. (2001), a Purified Poloxamer 188 used in concomitant with Hydroxyurea for the treatment of acute vaso-occlusive crisis resulted in a decrease in the duration of painful episodes.

A newly approved pharmaceutical product, Voxelotor (GBT-440), has been developed to inhibit HbS Polymerization, enhance blood oxygen saturation and reduces hospitalization-induced VOC crisis (Nwabuko et al., 2019). Matte et al. (2019) also described Voxelotor (GBT-440) as an oral direct anti-sickling agent that can be beneficial in SCD as it blocks HbS intermolecular contacts, preventing the generation of HbS fibers and RBC sickling. Crizanlizumab, another new investigational biologic therapy manufactured by Novartis yet to be approved by the U.S. Food Drug Administration [FDA], is expected to help in the prevention of VOC or pain crisis (Nwabuko et al., 2019).

Physicians Committee for Responsible Medicine and Unbound Medicine, PCRM (2019) proposed some preventive strategies as comprehensive and multidisciplinary care that should incorporate education of both patient and family to help prevent complications of the disease. Other preventive strategies are regularly administering influenza, meningococcal and pneumococcal vaccines, and pneumococcal prophylaxis to children with SCD until age 5, especially those with a history of splenectomy or severe pneumonia (PCRM, 2019). Antibiotic prophylaxis and early immunization were used for

managing infections such as Pneumococcus and Meningococcus infections (Herman & Chaudhry, 2010) Also, a daily dose of 1mg Folic acid and an iron-free multivitamin to ensure adequate intake of nutrients that are usually deficient in SCD patients is recommended by PCRM (2019). Brousseau et al. (2004) observed decreases in the length of stay (LOS) during a pain crisis for 19 SCD children admitted at the hospital in a single-arm study conducted to determine the effect of intravenous (IV) magnesium sulfate on the LOS.

Challenges That the Sickle Cell Disease Community Faces

Cyril-Olutayo et al. (2019) proclaimed that the management of SCD had been a real challenge since its discovery in 1910 by Dr. Herrick. The CDC (2020) claimed that between1989 and 1993; there was an average of 75,000 hospitalizations due to SCD in the United States, costing approximately $475 million dollars. The CDC (2020) also reported that medical expenditures for children with SCD averaged $11,702 dollars for those with Medicaid coverage and $14,772 dollars for those with employer-sponsored insurance in 2005. About 40% of children from both groups had at least one hospital stay. The American Society of Hematology (ASH, 2016) also asserted on how SCD is associated with high treatment costs. An average person with SCD that lives to the age of 45 may incur a total lifetime health care costs estimated to be about $1 million dollars, with annual costs ranging from over $10,000 dollars for children to over $30,000 dollars for adults (ASH, 2016). The Agency for Healthcare Research and Quality in 2004 reported that 83,149 adults were hospitalized for SCD with approximately $488 million dollars in associated costs. For the community or group in the society who are more

susceptible or at high risk of having SCD, these costs are a challenge or burden considering the financial or socio-economic status of most of these families dealing with the SCD condition.

Multiple follow up and specialty clinic appointments coupled with pain episodes which constantly interrupt life activities are the main reasons for stress that leads to more absences from work, school, and fear of job loss or class placement is also another major challenge (Leger et al., 2018). Most SCD patients may also not have a primary care provider or individual health care plan, a cause of depression for them that can affect their pain coping skills, self-care management, and quality of life (Leger et al., 2018). Preoccupation with their illness may also cause the SCD patient to have poor health outcomes from negative medical experience (Leger et al., 2018).

Patients in some low or middle-income countries or communities may not have access to some vital health services like penicillin prophylaxis, broad-spectrum antibiotics, healthcare facilities, practitioners, and health insurances (Leger et al., 2018). SCD patients also have to deal with the stigma associated with the condition in terms of longevity, all the morbidities, the claim of prescription drug abuse, restrictions in terms of partner choice, and other social limitations.

Shet and Thein (2019) asserted that the gaps or lapses in providing resources and adequately equipping SCD healthcare practitioners with the required skills lead to various challenges in providing effective management for the newly increased population of SCD patients. Taylor et al. (2013) claimed that there is a lack of research on the occurrence and characteristics of chronic pain, especially in adults with SCD. Su et al. (2019)

maintained that barriers in access to specialist care remain a challenge for SCD patients. Adherence to medication or treatment regimen can be a significant challenge for many SCD patients, especially the children. According to Modi et al. (2009), forgetfulness was the primary barrier to adherence, and caregiver reminders were the primary strategies identified by both caregivers and adolescents, with the adolescents reporting significantly more barriers for pain management. Modi et al. (2009) recommended multidisciplinary treatment teams to facilitate dialogue with patients and their families about adherence barriers and strategies, which is necessary because both caregivers and adolescents seem to experience similar barriers and strategies across multiple components of the SCD treatment regimen.

Issues of Healthcare Disparities and Social Justice That Impact the Sickle Cell Disease Patient: Understanding Practitioners' Prescribing Habits

For years, SCD patients has had limited options for a treatment regimen for the management of SCD-related chronic excruciating pains. The mainstream treatment for these pains has been with opioid analgesics. Even though there are both pharmaceutical and non-pharmaceutical products that SCD-HCPs could have explored for their patients, their prescribing habits have been mainly for these opioids- related analgesics irrespective of all the stigmas that are associated with them. For instance, hydroxyurea, a pharmaceutical product that claims to have the potential to reduce the frequency of these pain episodes and its consequent hospitalizations, is rarely prescribed for SCD patients even though it has been in the market for more than twenty years. Aside from these questionable prescribing habits of SCD practitioners, the pharmaceutical manufacturing

companies seemed to have neglected the SCD community for so many years and have barely been manufacturing any products for this community. For instance, hydroxyurea has been the only pharmaceutical product manufactured or approved for SCD for about 20 years. Stone (2015) asserted that no drugs were approved between 2010 and 2013 for the treatment of SCD pain, while five new ones became approved for cystic fibrosis. Nwabuko et al. (2019) described SCD as one of the diseases of public health importance that requires political, legislative, and cultural attention. These authors asserted that legislation on SCD prevention would enable proper auditing, surveillance of the blood types of the population for precise mapping, budgeting, and allocation of resources.

Currently, there is a shortage of SCD practitioners, and there are few Oncologists/Hematologist who goes out of their way to show interest in the SCD patient. The situation is so bad that for a big metropolis like Dallas/Fort Worth foe instance, it takes six months to get an appointment for an SCD patient to see a physician. When a patient misses an appointment, it takes another six months to reschedule or get another appointment. Su et al. (2019) maintained, however, that hematologists/oncologists accounted for a higher proportion of visits by children than adults, while emergency medicine visits were higher in adults than children. CDC (2020) affirmed that the SCD patient has limited access to comprehensive team care than other people with genetic disorders like hemophilia and cystic fibrosis. Ironically, most SCD departments are attached to oncology/hematology departments in most major healthcare facilities, with most of the practitioners being oncologists/hematologists, which indicates awareness of the gravity of SCD in healthcare. However, SCD patients still do not receive much of the

attention or assistance their counterparts are receiving. With the current statistics or prevalence of the disease globally and the annual expenses per each case, SCD should be deemed as a major public health concern (CDC, 2020) and thus warrant recognition. However, Suzette Oyeku, a sickle cell expert at The Children's Hospital at Montefiore/Albert Einstein College of Medicine maintained that "there is shockingly little data on sickle cell epidemiology in the United States due to the limited national surveillance data on the condition" (Stone, 2015, para. 18). Stone asserted that “the difference in access to care and research dollars for SCD might be due to racism and economic differences claiming that there are several sources for disparities in funding and treatment of SCD as compared to other diseases” (paras. 15 &18). Meanwhile, Strouse, a researcher from Johns Hopkins, who made this observation, did not attribute these differences to racism or social justice issues, but instead to media savvy (Stone, 2015).

Booker et al. (2006) posited that the nature of SCD pain is poorly understood and is often sub-optimally managed. Stone (2015) also maintained that health care workers are prone to underestimate the patients' pains and most often treat patients as drug seekers. There are also now the humiliating drug screens by feds with the claim of ensuring that patients are taking the narcotics and not selling those (Stone, 2015). Leger et al. (2018) asserted that there is a lack of provider knowledge or irrational fear of "addiction" that leads to improper triage or inadequate pain management. Stone declared that the pain crises associated with SCD remain undertreated, which may reflect racial and gender biases. Taylor et al. (2013) proclaimed that SCD patients that experience chronic pain are often underserved, and their pain remains undertreated, which may result

in increased healthcare costs associated with emergency room visits, hospitalizations, and lost work productivity.

According to Leger et al. (2018), there is enough evidence that there is a significant delay in average time to administer initial analgesia in the ED compared to the recommended 15–20 minutes; and only a few patients received the recommended pain relief agents at the recommended dose and routes. Ezenwa et al. (2016) also declared that SCD patients usually receive inadequate and untimely treatment for pain control. They are also more likely to be accused of drug-seeking behavior and labeled as drug addicts as compared to other populations with chronic pain (Ezenwa et al., 2016). It is a norm for SCD patients to receive their first pain medication 30 minutes later than others like renal colic patients presenting with similar symptoms in the ER, increasing the tendencies for such inequities to result in health disparities with time (Ezenwa et al., 2016). Lee et al. (2012) asserted that "ER healthcare providers often respond with inadequate pain control because of overestimating drug dependence and their perceptions of drug-seeking behaviors by patients' with SCD" (para. 5). Furthermore, these authors added that "misconceptions by ED providers, combined with lack of a regular primary care provider and poor self-care management of SCD, are factors contributing to the patient's repeated use of the ED for pain management (Lee et al., 2012, para. 5). There is also a stigma from society, including even among healthcare professionals that SCD patients are more prone to develop opioid-based analgesia addictions than other diseases with similar symptoms (Booker et al., 2006). This stigma influences prescribing and nursing behaviors and has resulted in feelings of mistrust towards the physician to the point of affecting adult

patients' willingness to communicate their true feelings for fear of not receiving optimal treatment (Booker et al., 2006). Elander et al. (2004) also affirmed how the treatment of painful episodes in SCD could result in disputes between patients and HCP. This raises concerns about patient behaviors with the suspicion of either drug-seeking due to analgesic dependence and misuse or pseudo-addiction caused by under- treatment of pain (Elander et al., 2004).

According to Adegbola et al. (2012), the perceived disrespect from HCPs increased emotional pain and worsened the physical pain for the SCD patient. Patients also reported dissatisfaction with HCPs lack of empathy and inadequate management of the chronic SCD-related pain, resulting in non-therapeutic patient-HCP relationships (Booker et al., 2006). Ratanawongsa et al. (2009), however, claimed that the negative perception of SCD patients on provider attitudes affects the quality of patient-provider communication and care during VOCs. Thomas and Cohn (2006) also declared that the poor communication between SCD patients and their HCPs causes suspicion and mistrust and results in most patients feeling labeled negatively by the healthcare system and thus skeptical of opening themselves to an unsympathetic system. These researchers organized pilot courses on communication skills and cultural awareness strategies for HCPs to use in challenging situations such as patients acting hostile and aggressive towards them. It occurred that the training had a positive and enduring impact on practitioners' perceived ability and confidence in communicating with their patients (Thomas & Cohn, 2006). The authors thus concluded that the training model employed might help reduce mistrust and increase empathetic responses in healthcare professionals towards patients (Thomas &

Cohn, 2006).

Nutrition as an Alternative Treatment Option in Sickle Cell Disease Pain Management: Nutrients, Herbs, Fruits, and Veggies With Analgesics, Anti-Inflammatory, and Vasodilation Potentials

The position of nutrition in SCD pain management can be a beneficial alternative treatment regimen that needs critical investigation. Thompson and Eriator (2014) asserted that the majority of SCD patients live with chronic pains, which has resulted in many of them resorting to the use of complementary and alternative medicine (CAM). PCRM (2019) posits that SCD patients' have more significant than average requirements for both calories and micronutrients, but most patients are deficient in essential micronutrients. According to Hyacinth et al. (2010), because of the challenge in finding a cure for SCD after 100 years of its discovery, there has been a growing interest in the nutritional problems of the disease resulting in many researchers seeking nutritional alternatives as a means of decreasing morbidity and improving quality of life for SCD patients. These authors claimed that the SCD patient usually does not meet or fulfill the recommended dietary allowances (RDAs) when compared to the general population, irrespective of the fact that efficacy of macronutrient supplementation proved to be evidence-based (Hyacinth et al., 2010). Likewise, micronutrients occur to be insufficient among the SCD community, according to Hyacinth et al., (2010). These authors thus recommended the need to establish specific RDAs for SCD patients, much like the specific RDAs developed for pregnancy and growth within the general population SCD (Hyacinth et al., 2010). PCRM (2019) also recommended that diets rich in fruits,

vegetables, whole grains, and legumes (plant foods) have the potential to provide a higher proportion of essential nutrients than a typical Western diet, and have the appropriate supplementation to prevent deficiency and decreases disease exacerbation. Hyacinth et al. (2010) cited, for example, that recent findings of vitamin D deficiency among the SCD community may attribute to incomplete ossification and bone disease, one of the significant complications of SCD. According to PCRM (2019), iron overload and oxidative stress may cause the depletion of antioxidant vitamins.

Most of the herbs, fruits, and veggies that we use daily possess analgesics, anti-inflammatory, and vasodilation potentials that can play significant roles in managing the pains associated with SCD pains. Cyril-Olutayo et al. (2019) commented on how medicinal plants have been used traditionally in Africa for the management of SCD, whose treatment has been mainly palliative. These authors claimed that the following herbs or medicinal plants Zanthoxyllum xanthoxyloides, cajanus cajan, carica papaya, cnidoscolus aconitifolius have ant sickling effects which can prevent and reverse sickling of RBC (Cyril-Olutayo et al., 2019). These researchers conducted a study on the medicinal plant, Telfairia occidentalis (fluted gourd or pumpkin), a nutritious vegetable rich in vitamins, proteins, antioxidants. It was observed that this herb could treat SCD as it is capable of preventing and reversing the sickling of RBC, stabilizes the RBC membrane, reduces HbS red cell density, increases their PCV, prevents and alleviate SCD crisis in infants and adults (Cyril-Olutayo et al., 2019).

Osunkwo et al. (2012) conducted a pilot study where SCD patients who were administered high-dose vitamin D achieved higher levels of serum 25-hydroxyvitamin D,

experienced fewer pain days per week and had higher physical activity quality-of-life scores. Based on these findings, researchers suggested that vitamin D possesses the potential to reduce the number of pain days in SCD patients (Osunkwo et al., 2012). Amer et al. (2006) claimed that exposing or treating SCD patients with antioxidants such as N-acetyl-cysteine, vitamins C and E, decreased their oxidative stress or damage to RBC and platelets, thereby alleviating symptoms associated with their pathology.

PCRM (2019) recommended the importance of staying hydrated or drinking enough fluid during strenuous exercises as sickling of erythrocytes increases in SCD patients who exercise in the heat without consuming fluids, compared with those who stay well-hydrated. Omega-3 fatty acid (n-3FAs) supplements are recommended for the SCD-child patient as they are low or deficient on alpha-linolenic acid and the long-chain omega-3 polyunsaturated fatty acids (eicosapentaenoic acid [EPA] and docosahexaenoic acid [DHA]) according to this committee.

ω-3 FAs have the potential to increase the fluidity of RBC membranes, which may prevent sickle cell crises. Both EPA and DHA are known to have significant therapeutic benefits of reducing severe anemia (PCRM, 2019). Based on a double-blinded, olive oil-controlled clinical trial Tomer et al. (2001) conducted, it was observed that treatment with dietary ω-3 FAs for one year reduced the frequency of pain episodes that requires hospital visits from 7.8 events during the preceding year to 3.8 events per year as they reduce prothrombotic activity in SCD. Matte et al. (2019) also maintained that a phase II multicenter randomized, double-blinded placebo-controlled study in SCD patients reported that ω-3 fatty acid supplementation reduced pain episodes in SCD

subjects.

Franceschi (2000) speculated that dietary magnesium (Mg) pidolate (pyroglutamic acid) supplementation has the potential to inhibit K–Cl co-transport and reduce dehydration. Franceschi (2000) claimed that blocking the transport pathways that promote loss of potassium (K) is a potential therapeutic strategy for SCD as it prevents erythrocyte dehydration, one of the causes of pain crisis. Prasad et al. (1999) claimed that frequent hemolysis in SCD could attribute to zinc deficiencies in these patients. Zinc deficiency is known to impact T-helper1 (TH1) functions adversely, cell-mediated immunity, and causes decreased interleukin (IL)-2 production (Prasad et al., 1999). These researchers proposed that zinc supplementation has the potential to improve the T-helper function and decrease the incidence of infections in patients with SCD (Prasad et al., 1999). Datta et al. (2019) also maintained that there is evidence that zinc supplementation may be beneficial in reducing the risk of infections and the painful VOC in SCD patients.

According to Nwabuko et al. (2019), folic acid supplementation, L- Glutamine, Glutathione oxidase inhibitor, Thiocyanate-containing foods, Vitamin B containing diet, seaweeds, and other food supplements are recommended, since they are rich in antioxidants. Matte et al. (2019) asserted that a "multicenter, randomize, placebo-controlled double-blind phase III clinical trial with L-glutamine (0.3g/Kg twice a day) supplementation reduced the mean number and length of hospitalization, associated with the increased median time to the first crisis" (p.). Agbai (1986) claimed that the prevalence of SCD is relatively rare in Africans than in the African-American population in the United States. In contrast, SCT, the non-anemic, heterozygous condition, is about

three times more common among indigenous Africans than in African-Americans. The ratio of SCD to SCT is 1 out of 50 for African-Americans and less than 1 out of 1,000 for tropical Africans, according to Agbai (1986). This researcher attributed this etiological disparity to an anti-sickling agent, thiocyanate (SCN-) found abundantly in staple African foods, such as the African yam and cassava (Agbai, 1986). The author claims that staple American foods have negligible SCN-concentrations. In contrast, non-staple foods in the American diet, such as carrots, cabbage, and radishes, have SCN- levels far below the African yam and cassava (Agbai, 1986). SCD remains regarded as congenital deficiency anemia that can be improved by prophylactic diets with high SCN- contents (Agbai, 1986). The researcher thus concluded that "thiocyanate deficiency anemia" is a nutritionally correct clinical status for those born with the homozygous sickle hemoglobin genome and that subjects become more susceptible if they subsist on SCN-deficient food contents (Agbai, 1986). However, other thiocyanate rich foods that may easily be located in the US include turnips, broccoli, Brussels sprouts, and cauliflower.

According to Al-Momen (1995), most of the patients that have severe SCD may suffer from unrecognized vitamin B12 deficiency. Ohnishi et al. (2000) posited that dense RBCs in SCD patients tend to adhere to neutrophils, platelets, and vascular endothelial cells, which could trigger VOC and thus subsequent painful crisis. Nutritional antioxidant supplements, hydroxyl radical scavengers, and iron-binding agents could inhibit the formation of such dense cells (Ohnishi et al., 2000). Some of the nutritional supplements found to be capable of inhibiting dense cell formation by 50% aged garlic extract, black tea extract, green tea extract, Pycnogenol, α-lipoic acid, vitamin E, coenzyme Q10, and β-

carotene (Ohnishi et al., 2000). Grapefruits, for instance, are high in potassium content rendering them useful vasodilators that contribute to the widening of blood vessels and the relaxation of smooth muscles in the cells enabling smooth flow of blood in the vessels.

Coping Mechanisms/Strategies, Lifestyle Modifications, and Sickle Cell Disease Pain Management

Employing coping strategies that may range from simple strategies like hot pad massaging, relaxation, and prayers to more sophisticated ones like self-awareness/mindfulness, healthful eating habits Acupuncture, among others. These can be effective approaches to dealing with the SCD pain. Neville and Panepinto (2011) proposed that "even though there is the need for new treatments for SCD, especially for disease-modifying agents, it is also imperative to explore new approaches for improving treatment with the existing modalities"(p. 11)

Dampier (2019) posited that because of the multifactorial nature of both pain and VOC, it is imperative to explore simultaneously targeting multiple mechanisms, which may be the optimal approach for effective preventive therapies. Lee et al. (2012) proposed the coordination of interdisciplinary health team members to reduce pain episodes and any associated catastrophic complications like renal failure, pulmonary disease, and cardiovascular events. "Because of the complexity of chronic pain in SCD patients, a multidimensional perspective is needed which embraces the whole person by focusing on biological, psychological, sociological, and spiritual factors" (Taylor et al., 2013, para. 8). Angst et al. (2009) proclaimed that patients with chronic pain that engages

in an interdisciplinary treatment program such as physiotherapy, psychotherapy, part of a coping pain group, acquire information and education about the pathophysiology of disabling pain mechanisms and management, regular medical consultations, and drug therapy reported decreases in mean pain severity. They also depicted improvement in social functioning compared to patients receiving standard care as inpatient rehabilitation and drug therapy (Angst et al., 2009). Williams and Tanabe (2016) suggested that patients should be able to use non-pharmacological interventions to alleviate pain with some degree of success. These researchers also claimed three categories of non-pharmacological therapies, which are peer-support groups, educational/psycho-educational, and skill-based (Williams & Tanabe, 2016). Adebowale (2014) asserted that though there is no cure for SCD, there are cost-effective treatment options for the pain and other aspects of the disease, such as early intervention with analgesics, antibiotics, rest, proper nutrition, folic acid, high fluid intake and supplementation. Elander et al. (2003) observed that SCD patients with pain-related symptoms that impaired activities sought a more typical lifestyle. According to Lim et al. (2019), interventions should emphasize the negative impacts of emotion-focused avoidance coping and integrate other empirically supported coping strategies to improve HRQOL for SCD children presenting with high intensity of pain. Elander et al. (2019) posited the need for a brief measure of patient satisfaction with treatment for pain to help improve the treatment of painful episodes caused by SCD, especially during and after the transition from pediatric to adult care.

Self-care management can be an effective coping strategy that SCD patients can

employ to help better manage pain episodes. According to Matthie et al. (2019), self-management is vital to SCD management even though its role in chronic pain management is not proven and thus proposed the need to develop and implement effective strategies for the prevention and management of chronic pain. Edwin et al. (2011) recommended the critical importance of self-management, especially self-awareness, to enhance the quality of life for the SCD community as they are cost-effective, and consistent with sound ethical principles and good conscience. Tam et al. (2019) designed an electronic teaching module (ETM) for educating adult patients on VOC self-management and treatment options for SCD. Tam et al. (2019) claimed the ETM increased the knowledge of patients in SCD. The educational ETM has the potential to provide an immediate impact on health literacy for an underserved patient population and potentially improve disease management and disease-specific outcomes (Tam et al., 2019). Jenerette and Murdaugh (2008) proposed that vulnerability factors, such as socio-demographics, negatively affect health care outcomes. These authors suggested the use of interventions to increase self-care management resources to improve the health care outcomes of SCD patients. Examples of such self-care management resources, according to the authors, are assertiveness, self-efficacy, coping behaviors, social support, self-care ability, self-care actions, and communication skills. Jenerette and Murdaugh also asserted that because of the high cost involved in medical interventions for SCD patients, self-care management is critical and may be the best alternative option to decrease the health care costs as well as improve the health status and quality of life for persons living with SCD. Tanabe et al. (2010) organized a workshop on best self-management practices with the

Sickle Cell Disease Association of America with seven adult SCD patients as participants. Some of the themes that emerged were self-awareness, emotional support, career selection, and success factors, nourishment, advocacy, knowledge, physical, and complementary and alternative medicine (Tanabe et al., 2010). The most common reported self-management strategy was self-awareness, with emphasis on journaling and body awareness (Tanabe et al., 2010). Additionally, spiritual support, friends, family, and professional counseling continued to be forms of emotional support, and another reported the best self-management practice (Tanabe et al., 2010).

Matthie et al. (2015) maintained that home self-care contributes to proper pain management, prevent pain crisis. Matthie et al. (2015) suggested that empowering health care providers (HCP) with a better understanding of self-care would enable them to provide or equip patients with the resources and skills they required to be able to participate in their disease management. Some of the benefits that SCD patients may acquire from self-care interventions are social support, SCD self-efficacy, and access to education (Matthie et al., 2015). According to Masuda et al. (2011), acceptance and commitment therapy (ACT) promotes acceptance of severe sensations, emotions, and thoughts, which enhances functioning and quality of life for SCD adolescents and their parents. “These authors proposed that ACT interventions can be useful conceptual and therapeutic additions to the treatment of pediatric patients with SCD and the family” (Masuda et al., 2011, p. 9). According to Simmons et al. (2019), mindfulness-based intervention (MBI) is feasible and acceptable for persons with SCD experiencing chronic pain. Simmons et al. (2019) claimed that MBI could be used to provide non-

pharmacologic, behavioral pain management options for practitioners that care for SCD patients and chronic pain.

Spirituality has been one of the coping mechanisms that have been employed by the SCD community to manage pain. According to Wachholtz and Pearce (2009), chronic pain is a sophisticated experience that results from the interrelationship between biological, psychological, social, and spiritual factors. These authors affirmed that many patients that experience chronic pain uses various religious/spiritual forms of copying, such as prayer and spiritual support, to manage their pain. Wachholtz and Pearce (2009) proposed that health care professionals should participate in the exploration of spiritual matters that may contribute to the pain experience of their patients. Taylor et al. (2013) also posits that because spirituality/religion is central to the SCD community, they can be incorporated to any model of chronic pain as it is proven that spirituality/religiosity is associated with decreased pain intensity in patients. “It was concluded from a study findings that adopting positive religious strategies are associated with significantly fewer hospital admissions after adjusting for other demographic and diagnostic variables” (Bediako et al., 2011, p.1). Cotton et al. (2009) claimed that patients who engage in higher levels of religion and spirituality recover from illness more quickly, are less depressed and enjoy better HRQOL. In a study conducted by these researchers, most SCD adolescents described employing a “collaborative” religion and spirituality coping style (Cotton et al., 2009). They reported depending on God for support and on prayer for symptom relief, believing in God to “strengthen” them in such situations with those who believe in God, rating religion as necessary in their lives (Cotton et al., 2009). Patients

who attend religious services are also found to be less likely to engage in risky health behaviors and have better mental health outcomes thus less depression and anxiety (Cotton et al., 2009).

Acupuncture has been one of the coping strategies or non-pharmaceutical therapy that has been used for pain relief and can be explored for SCD pain management. Tsai et al. (2015) proposed Acupuncture has the potential to decrease pain and anxiety as well as reduced PED visits and hospitalizations for SCD pain when used to treat the acute and chronic SCD pains of a child patient. Based on a retrospective study they conducted, Lu et al. (2014) concluded that the physical insertion of the needle during the administration of Acupuncture might be useful in alleviating pain and proposed the possibility of using it as an adjuvant for pain management for the SCD population. According to Wick, (2019) complementary and integrative therapies (CIM) or complementary and alternative medicines (CAM) such as vitamins, minerals, homeopathy, meditation, acupuncture/acupressure, or deep breathing techniques involves a holistic, patient-focused approach to health care in managing pain and anxiety.

Other non-pharmacologic therapies or approaches such as massaging and relaxing can be an effective alternative regimen for SCD pain management. Bodhise et al. (2004) asserted that deep tissue/pressure massage therapy technique, including neuromuscular trigger point treatment with acupressure for SCD patients, has sound effects on pain relief and quality of life. Rees et al. (2003) proposed that because a majority of painful episodes are managed at home, SCD patients and parents should be educated as to when to seek medical help from their HCPs, health visitors, and hemoglobinopathy counselors. This is

necessary because most patients only go to a hospital only when oral analgesia is insufficient, or symptoms suggest a severe complication (Rees et al., 2003). Furthermore, educating SCD patients would help prevent or combat most of the complications associated with VOC or pain crisis.

Exploring Preventative Measures to Combat Sickle Cell Disease

Incidence/Prevalence

SCD prevalence continues to be increasing recently and becoming more widespread globally due to globalization and an increase in migration. It has resulted in interracial marriages rendering it a significant public health concern even though it has not received much recognition as other health conditions. In the quest of controlling its incidences and hence prevalence, countries like Ghana with a high prevalence of one in every three Ghanaians having the hemoglobin S or C gene has proposed such extreme preventative strategies like prenatal diagnosis (PND) and selective abortion which presents with a whole lot of ethical concerns (Edwin et al., 2011). Other standard preventative measures that are employed globally to control SCD incidences are genetic counseling and testing, as well as new-born screenings. Edwin et al. (2011), for instance, proposed preconception genetic testing and strategic reproductive choices, PND and education for carrier parents, and holistic management for the SCD community in Ghana. Nwabuko et al. (2019) recommended the need to put in place proper documentation, which may ultimately lead to the establishment of local and national Surveillance Epidemiological End-Result (SEER) statistics for SCD. These authors claimed SEER statistics for the SCD community would guarantee proper case ascertainment,

epidemiology, incidence rate, prevalence, birth rate, mortality rates, and the ABO Rhesus blood types for SCD patients. Nwabuko et al. (2019) maintains this could be life-saving as it promises to reduce the protocols of blood grouping required for emergency medical interventions, especially in cases of severe anemia due to road traffic accidents, medical and surgical conditions that would require urgent blood transfusions. Rees et al. (2003) also proposed the following guidelines to be adopted for rapid admission to hospitals, which include "a written protocol for quick assessment of pain and rapid, safe administration of analgesia and personalized care plans made available to on-call medical staff. These authors also suggested that patients should be able to carry hemoglobinopathy cards that state their diagnosis and baseline hematological data. This would make it possible to initiate an analgesia therapy within 30 minutes of arrival in hospital after a rapid initial assessment and to enable the pain to be brought under control within 60 minutes of starting analgesia (Nwabuko et al., 2019).

As part of the measure to combat SCD, Nwabuko et al. (2019) also proposed the need for a Public Health awareness campaign on SCD and campaign language should be culturally friendly, relevant, and understandable to mitigate the challenges of health literacy and culture barriers. The authors made use of mass media (radio, TV adverts), social media (i.e., Facebook, Whatsapp, Blog, Flicker, Twitter and Instagram, etcetera) as the vehicles for disseminating information. Radio and TV adverts are imperative, but they are non-existent. There is hardly anything like commercials on any radio or TV station on any aspect of the disease, not even to promote an SCD medication, unlike other chronic conditions like cancers, diabetes, hypertension, CVDs, and more. Adebowale (2014)

claimed there is an increase in the percentage of carriers and the high possibility of a continuous increase in number if not controlled. This author thus proposed incorporating social welfare counseling in social, religious, health and educational sectors and other techniques when educating carriers especially individuals yet to get married, towards the prevention and eradication of the disease (Adebowale (2014). Because of "the huge burden of SCD coupled with the associated high morbidity and mortality rates globally, it is imperative to invest more in ways of reducing the prevalence of the disorder" (Aneke & Okocha, 2016, para.1).

Unaddressed Aspects of Sickle Cell Disease Pain Management: Impact on Psychological and Mental Health

A significant effect of pain crises on SCD patients, especially the children and their HRQOL that is usually overlooked and not addressed, is on their mental health. The impact of pain crisis on the psychological or mental health of SCD patients and their caregivers is a critical aspect of the disease phase that is most often not taken into consideration by SCD health practitioners. Anie et al. (2010) described SCD as a global health problem with psychosocial implications. “Chronic pain in adults with SCD is described as a complex multidimensional experience that includes biologic, psychologic, sociologic, and spiritual factors” (Taylor et al., 2013, p.1). These authors gave some of the psychosocial variables like stress, mental health status, coping behaviors, social interactions, cognitive dysfunction, functional and socioeconomic status.

The pain crisis has the potential of inducing extreme stress and depression on both patients and caregivers as they strive to bring it under control. Many children with SCD

suffer a lot of psychological and emotional distress due to the isolated lifestyle they tend to adopt due to all the health challenges they go through. Most of them complain about how they are the ones who are always sick and have to stay away from school as compared to their colleagues and why they cannot do most of the things that other kids do like playing outside, running, playing in the snow among others. One patient retorted, "this disease is severe and can be very depressing at times" after recounting her challenges with SCD. The stigma from society and the healthcare sector towards the SCD community can also be another source of stress and psychological distress for many SCD patients and their families. Elander et al. (2003) declared psychological disturbance as a theme associated with non-pain-related symptoms. Edwards et al. (2005) asserted that because of the chronicity of SCD with its frequent hospitalizations for pain and other medical management, it has the potential to significantly impair psychosocial functioning, alter intra- and interpersonal relationships, and reduced QOL for the patient. Thus these authors concluded that due to this significant role of psychosocial issues in the trajectory and management of SCD, understanding the pathophysiology of SCD without thoroughly understanding the equally important psychosocial influences is misunderstanding SCD (Edwards et al., 2005). According to Taylor et al. (2013), factors other than biological factors, such as psychological and sociological factors examples being SCD genotype, HbF levels, comorbidities, depression, stress, mental health status, coping behaviors, social interactions, cognitive dysfunction, and functional and socioeconomic status are common among SCD adults with chronic pain. Reader et al. (2019) conducted a systematic review to assess the relationship between pain in terms of

frequency, intensity, duration, impairment, coping, and emotional functioning in children with SCD. The researchers observed a strong relationship between increased pain frequency and higher depressive and anxiety symptoms, moderate-to-strong associations between pain-related impairment and depressive symptoms, small-to-strong associations between pain-related impairment and anxiety with pain-coping strategies, and maladaptive cognitive strategies depicting the strongest association with emotional functioning. Mackey (2019) declared how stressful it could be for an SCD caregiver without any coping strategies. Wang et al. (2011) asserted that coping strategies provide a protective role in mitigating caregiving stress (Mackey (2019). "Interventions for children with SCD reporting high pain intensity should put more emphasis on negative impacts of emotion-focused avoidance coping and integrate other empirically supported coping strategies to improve HRQOL" (Lim et al., 2019, para.1).

With HBM, Pantaleao et al. (2019) hypothesized that cues to action and perceived pain burden enhances the relationships between psychosocial factors such as stress that caregivers experience communicating about SCD to their child or HCPs during ER visits. "These authors thus suggested that caregivers of children with SCD could benefit from interventions that enhance stress-management and communication skills with their child and HCPs" (Pantaleao et al., 2019, para. 1). Sadeghloo et al. (2019) maintained that positive thinking training could be an effective strategy for improving the quality of life of parents with ill children. Pecker and Darbari (2019) asserted that psychosocial and affective comorbidities are common and can impact disease outcomes in SCD. Pecker and Darbari (2019) thus proposed that addressing such comorbidities should be an

integral part of the management of SCD. According to Da Silva et al. (2019), the treatment of chronic pain, including pharmacological and non-pharmacological treatments, can have an impact on brain function. Though these researchers asserted that this trend is not well established with SCD patients, however, neuroimaging evidence indicated abnormal neural processing related to chronic pain and psychosocial comorbidities in SCD beyond ischemic stroke and cerebral hemorrhage (Da Silva et al., 2019). Consequently, the authors proposed behavior therapy as a mechanism to improve psychological symptoms as well as chronic pain and quality of life for the SCD community (Da Silva et al., 2019). Connolly et al. (2019) also claimed that SCD youth that battles persistent pain are at risk for psychosocial and neurocognitive impairments as the persistent pain may tend to be an important indicator of disease burden. Therefore, these authors suggested that disease management may be enhanced by assessing cognitive and psychosocial functioning by incorporating interdisciplinary treatments to address any impairments associated with persistent pain (Connolly et al., 2019).

Perceptions and Experiences of the Sickle Cell Disease Community Regarding Alternative Treatment Options for Pain Management

There is a gap in the perceptions and experiences of the sickle cell disease community on alternative treatment options for pain management that is the focus for this study. Few studies have attempted to address the perceptions and experiences of parents and patients and even other stakeholders of the SCD community on alternative treatment options. "Parents perspectives on care and the relationships between coping, family functioning, and health care utilization have not been given much prominence in the SCD

literature neither has much attention being given to pediatric sickle cell intervention efforts" (Mitchell et al., 2007, p.8). Atorkey (2015) also declared that the literature is insufficient on SCD patients' perceptions and beliefs and their impact on patients' treatment compliance. Smith et al. (2018) also maintained that there is little is known about parent perceptions of managing SCD pain episodes in young children.

Theoretical Foundations: Health Belief Model, Transtheoretical Model, and Biopsychosocial-Spiritual Model of Chronic Pain

"The theoretical framework is described as the foundation from which all knowledge is constructed both metaphorically and literally for a research study" (Osanloo & Grant, 2016, p. 1). "According to these authors, the theoretical framework serves as the structure and support for the rationale for the study, the problem statement, the purpose, the significance, and the research questions and provides a grounding base for the literature review, the methods and analysis" (Osanloo & Grant, 2016, p. 1). The Health Belief Model (HBM), Biopsychosocial-Spiritual Model of Chronic Pain, and the Transtheoretical Model (TTM) would form the theoretical foundations for this study.

Taylor et al. (2013) described three models of pain associated with SCD: biomedical model, the bio- psychosocial model for SCD pain, and the Health Beliefs Model. The constructs of HBM would thus be employed to assess and enhance the SCD community, especially patients' and parents' experiences and perceptions on exploring alternative treatment regimens in place of opioid analgesics through interviews. According to Gustafson et al. (2007), health screening behavior is usually influenced by several factors such as the individual's perceived susceptibility to the condition, perceived

seriousness of the disease, perceived benefit of the specific action, and barriers to the behavior. Hence, the construct perceived susceptibility can be used to provide information on the mode of operation of these opioids, that they are purposely for maintenance, relieve SCD chronic pains associated and help patients to deal with it without really doing anything to change the disease state. Perceived severity would be used to determine the target audience's experiences and perceptions of the seriousness or consequences of prescription drug abuse or overdose and consequences such as the possibility of addiction and side effects. Perceived benefits could be employed to promote alternative regimens like some of the disease-modifying agents such as hydroxyurea and endari, which are claimed to have the potential to reduce the frequencies of pain episodes. Perceived barriers would be used to analyze the target audiences' experiences with and perceptions of tangible and psychological costs to trying alternative treatment regimens and other health disparities like unequal distribution of social and health resources such as inadequate healthcare facilities, practitioners and services. With cues to action, the community's awareness of SCD symptoms and approach to pain management can be assessed base on which appropriate strategies to motivate the community to embrace an alternative regimen could be proposed. Self-efficacy could contribute towards evaluating patient's abilities to confidently manage pain episodes by employing coping strategies like self-awareness for early detection of pains and symptoms of associated comorbidities like stroke, infections of organs in the body, and mindfulness for better pain management. Taylor et al. (2013) referred to an individual's readiness to utilize care and include perceived threats that result from the non-utilization

of healthcare and perceived benefits and barriers to healthcare utilization as readiness variables.

The constructs of TTM can be employed to investigate patients' opinions and experiences with their HCPs prescribing habits and then the possible strategies to empower them to enforce changes where necessary. Prochaska and Velicer (1997) asserted that the Trans-theoretical model health behavior change involves progress through six stages of change: pre-contemplation, contemplation, preparation, action, maintenance, and termination. At this pre-contemplation stage, SCD patients/parents may have no intention of taking action, thus adopting any of alternative treatment options or coping mechanisms like self-care management practices as they may doubt their effectiveness. By creating awareness, SCD patients/caretakers may contemplate trying some of these alternative treatment practices soon. SCD patients/patients may prepare to try some of these alternative treatment practices. SCD patients may need to take action through empowerment to request for their HCP to prescribe other regimens aside from opioid analgesics and also try self-care management practices for a short period. SCD patients/prescribers adopt alternative treatment regimens or practices and continue to be maintained for the long-term, depending less on opioids for pain management. Finally, SCD patients/prescribers might decide to rely more on alternative treatment regimens or practices. It may require further studies to accomplish these behavioral changes in the SCD community, ultimately.

Taylor et al. (2013) developed the Bio-psychosocial-Spiritual Model of Chronic Pain to incorporate spirituality using the bio-psychosocial (BPS) multidimensional

approach previously developed by Turk and Gatchel ((2018) purposely for SCD patients who deemed spirituality/religiosity as an essential aspect of chronic pain management. Taylor et al. (2013) proposed the BPS-Spiritual model for adults with chronic pain from SCD since it embraces the whole person. The model accommodates the biological, psychological, sociological, and spiritual factors relevant to adults with SCD (Taylor et al., 2013).

Use of the Biopsychosocial-Spiritual Model of Chronic Pain for Sickle Cell Disease Pain Management

According to Taylor et al. (2013), the BPS model has been used effectively in other chronic pain populations and interdisciplinary treatment programs like physiotherapy, psychotherapy, and coping pain support groups. It has also been used to provide information and education about the pathophysiology of pain mechanisms and management of chronic disabling pain, regular medical consultations and drug therapy. Taylor et al. (2013) claimed there were decreases in mean pain severity and improvement in social functioning compared to patients receiving standard care like inpatient rehabilitation and drug therapy. These researchers also asserted that because spirituality/religion plays a critical role in the SCD community, it is necessary to incorporate an aspect of this dimension to any model of chronic pain in adults with SCD as spirituality/religiosity has been associated with decreased pain intensity (Taylor et al., 2013). They are promoting the BPS-Spiritual model because of its holistic approach since it embraces the whole person, thus the biological, psychological, sociological, and spiritual aspects of a person (Taylor et al., 2013). According to Turk and Gatchel (2018),

the overall goal of the BPS model of chronic pain is to help the patient become an active participant in life management skills and learn new ways of thinking about and coping with chronic pain (Taylor et al., 2013).

Summary

CDC (2020b) claimed that there are millions of people with the SCD condition globally and more prevalent among people with ancestors or background from sub-Saharan Africa; Spanish-speaking regions in the Western Hemisphere such as South America, the Caribbean, Central America; India; and Mediterranean countries such as Saudi Arabia, Turkey, Greece, and Italy. SCD is also common in areas where the prevalence of malaria is high and is claimed that people who carry the sickle cell trait are less likely to have severe forms of malaria (CDC, 2020b).

According to a study that Mitchell et al. (2007) conducted, employing both quantitative and qualitative methods with 53 parents of SCD children confirmed that positive patient coping was related to positive family functioning and lower health utilization. The study participants, however, requested the need for comprehensive health care approaches that meet the physical and psychological needs of patients and families (Mitchell et al., 2007). The participants of an exploratory study conducted by Anie et al. (2010) claimed that society, in general, had a negative image of SCD, and reported negative perceptions and attitudes. “These researchers concluded that employing psychosocial interventions in SCD would help to reduce negative thoughts and feelings about the condition and encourage the acquisition or maintenance of coping strategies”

(Anie et al., 2010. p. 5). Based on the findings of a survey conducted by Smith et al. (2018) on 51 parents of 2- to-6-year-olds SCD patients, 82% of the parents who reported using medications to manage their children's pains claimed moderate satisfaction with current management strategies and resources. However, they expressed interest in additional pain management education that could enhance better parent and child-coping skills.

Chapter 3: Research Method

Introduction

The purpose of this study was to qualitatively explore the perceptions and experiences of the SCD community on the use of alternative treatment options for pain management instead of opioid analgesics. The findings contribute insight into the prescription habits of SCD practitioners and variables (such as cost, availability of/access to alternative regimens and other health services, knowledge, and more) that influence patients' and HCPs' choices of treatment options. It also throws light on how patients' experiences and perceptions impact their choice of treatment regimens. The case study approach was employed to address these issues of interest in the study. The subsections within this chapter address the research design and rationale, participants, my role as the researcher, methodology, data collection, instrumentation, validity, ethical procedures, and trustworthiness.

Research Design and Rationale

One of the significant purposes of this study was to assess the experiences and perceptions of alternative treatment options for pain management, employing a qualitative approach. Astalin (2013) characterized qualitative research as "a systematic scientific inquiry that seeks to build a holistic, largely narrative, description to inform the researcher's understanding of a social or cultural phenomenon" (p. 1). With SCD being a genetically inheritable disease that affects a specific population in society, there are certain cultural norms and practices that may influence the perceptions of members of the SCD community and their approach to SCD management or treatment. This rendered

qualitative research the appropriate approach to use to execute this study.

"Creswell (2015) declared that the real beauty of qualitative research is that the possibilities for data collection are very extensive, noting that sources may include open-ended interviews, open-ended observations, and public and private documents such as private diaries, newspaper articles, and meeting minutes". Astalin (2013) also affirmed that qualitative research can be conducted with a combination of observations, interviews, and document review. The specific qualitative research design used for this study was the case study design, which can be carried out using various data collection tools. As Alpi and Evans (2019) explained,

> Case study research is a qualitative approach where the investigator explores a real-life, contemporary bounded (a case) or multiple bounded systems (cases) over time, through detailed, in-depth data collection involving multiple sources of information reports a case description and case themes. (p. 2)

A case study has also been described as "an intensive, holistic description and analysis of a bounded phenomenon such as a program, an institution, a person, a process, or a social unit" (Yazan, 2015, p. 6). Astalin (2013) also asserted that case studies can be used to holistically analyze people, events, decisions, periods, projects, policies, institutions, and other systems by one or more methods. Given the diverse nature of the study population in terms of geographic location, educational level, and disease type, among other characteristics, I reasoned that it might not be realistic to adopt a specific tool or source of information; rather, several tools and sources might be needed for data collection. For this reason, I judged case study to be the best design for this study. "Yazan (2015) noted,

> This type of qualitative approach is accredited with certain distinctive attributes which are particularistic which implies it focuses on a particular situation, event, program, or phenomenon; descriptive because it yields detailed, thick description of the phenomenon under study and Heuristic as it illuminates the reader's understanding of the phenomenon under study". (p. 6)

Alpi and Evans (2019) claimed that rigor in case studies depends on the research design and its components, which include the study questions, propositions, unit of analysis, logic linking the data to propositions, and criteria for interpreting the findings (Yin, 2017). Other features of case studies include the use of multiple sources of data, a case study database, and a transparent chain of evidence linking the questions asked, the data collected, and the conclusions drawn, according to Yin (2017). Common sources for data for case studies include interviews, documentation, archival records, direct observations, participant observation, and physical artifacts (Alpi & Evans, 2019). Nevertheless, this study might be considered a microcase or microlevel case study because it was conducted within a brief time frame; it was expected to be simple and straightforward; it described an apparent problem of interest; and the study findings or reporting were expected to be very brief and focused on specific points to depict the clarity of the "lesson" inherent in the case (Alpi & Evans, 2019).

Research Questions

RQ1. What are the experiences of the SCD patients or their parents/caretakers regarding the current prescribing habits of their HCPs to manage SCD pain, and how do they influence their choice of treatment?

RQ2. What are the experiences and attitudes of the SCD patients or their parents/caretakers toward alternative treatment methods, and how do they influence their choice of treatment?

RQ3. What is the stage of readiness for adopting alternative treatment methods for SCD patients or their parents/caretakers?

RQ4. How does disease perception among SCD patients or their parents/caretakers impact their willingness to try alternative treatment methods?

As is the norm with case study research designs, multiple data sources were employed in addressing the research questions. These included phone interviews, video conferences, emails, and shared or archived stories of patients. As noted earlier, face-to-face interviews and focus group methods were not possible in this study because of social and physical distancing restrictions due to COVID-19.

Role of the Researcher

According to Sutton and Austin (2015), qualitative research studies enable researchers to access the thoughts and feelings of research participants, making it possible to gain a better understanding of the meaning that people ascribe to their experiences. I have been personally involved with SCD communities for about 19 years, and one of my initial significant concerns for the community was the prescribing habits of its HCPs. I have never been comfortable with or approving of the choice of pharmaceutical products, especially opioid analgesics, for pain management, especially for younger patients, and I have been seeking better treatment options for years.

Professionally, I have had the privilege to work in specialty pharmacies for the past 14 years, where terminal or extreme diseases and health conditions such as cancers, autoimmune and genetic diseases, and skin conditions are the principal focus. However, SCD was never considered or included in these categories of health conditions. As I became more aware of how ineffective some of the pharmaceutical treatments for SCD patients can be and of the adverse or side effects and other complications associated with them, my concern heightened. Another interesting observation I made was that as more and newer medications were continually being developed and approved for other conditions, there were barely any for SCD. Stone (2015) affirmed that no drugs were approved between 2010 and 2013 for the treatment of SCD, whereas five new medications were approved for cystic fibrosis. As I switched to the public health sector professionally, my interest in alternative treatment options for SCD evolved into seeking more preventative measures employing natural products such as nutrients and other mechanisms that may be deemed more efficacious in pain management.

With all of these factors at play, there was a possibility that I would influence the data collection process in a way that might threaten the quality of the data and introduce bias. However, it was my responsibility as the researcher to ensure that the quality of the study met the required standard and that bias was avoided or limited as much as possible. According to Greenbank (2003), a researcher's morals, competency, and personal and social values have an essential influence on the research process. As such, Greenbank maintained that it is imperative for researchers to describe relevant aspects of themselves, including any assumptions, expectations, and biases, to be deemed qualified to conduct

research. As Sutton and Austin (2015) asserted, qualitative study requires reflection on the part of researchers, both before and during the research process, purposely for providing context and understanding for readers. Sutton and Austin stated that to remain reflexive, researchers should not be ignorant or avoid the possibility of their own biases, as reflexivity requires researchers to reflect upon and clearly articulate their positions and subjectivities in terms of worldview, perspective, and biases. With such information, readers can have a better understanding of the filters through which questions were asked, data were gathered and analyzed, and findings were reported (Sutton & Austin, 2015).

Greenbank (2003) posited that researchers should provide rational explanations for their actions to justify their research methods. Greenbank also proposed that researchers should adopt a participatory strategy or approach to research that involves conducting a pilot study and feeding back preliminary findings to research participants for comment and modification. I conducted a pilot study and received great feedback from the participants, some of which I incorporated into the design of the instrument that I used to collect data.

Methodology

Target Population

The population of interest for this research was SCD patients, as well as parents and caregivers of younger SCD patients. SCD, a genetic disorder, is known to be more prevalent among minority populations of African, Hispanic, Middle Eastern, and Asian descent. Study participants varied in gender, ethnicity, race, age, socioeconomic status (SES) or income level, educational level, geographic location, culture, and even

particular type of SCD (SS, SC, beta thalassemia, etc.), which might influence the type of treatment regimen that best suits each patient. According to Asiamah et al. (2017), it is necessary for a researcher to provide a proper definition or specification of a population of interest because this guides others in appraising the credibility of the sample, sampling technique(s), and outcomes of the research. Asiamah et al. also asserted that because the study population forms the primary source of data, they can influence the research credibility based on the researcher's understanding, definition, and choice of it.

Inclusion Criteria

To be selected to participate in this study, individuals needed to meet the following conditions:

- knowledgeable in or experienced with SCD or the subject, specifically SCD patients and parents/caregivers
- interested in being interviewed or ready to be interviewed to share their story/experiences and express their views
- able to speak, read, and write in English or the Twi language of the Akan people of Ghana, West Africa, in which I can easily communicate
- 14 years of age or older
- stakeholder in the SCD community

Exclusion Criteria

The following groups were excluded from participating in the study:

- young patients under the age of 14 years

- non-English-speaking community members who did not speak the Twi language of the Akan people of Ghana, West Africa

Sampling Procedures

I performed sampling to select a portion of the SCD community to participate in the study. However, because of social and physical distancing restrictions due to COVID-19, this study was not limited to a specific location, given that interviews could be conducted by phone or through online/social media platforms and tools such as email, Skype, and WhatsApp. Marshall (1996) stated that it is necessary to choose a study sample for any research project because it is impractical, inefficient, or unethical to study whole populations, noting that the purpose of a study determines the sampling method selected.

I used purposeful sampling, a very strategic sampling technique, for this study. Purposeful sampling was deemed an appropriate sampling technique because of the characteristics of the study population, the purpose of the study, and the need to be tactful, judgmental, and specific in selecting participants for the study. The participants who were included in the study were those who had experience with alternative treatment options and were intellectually capable of constructively expressing their views. Participants included parents/caregivers and patients, whom I contacted by email, text, messaging, and social media. According to Palinkas et al. (2015), purposeful sampling is widely used in qualitative research for the identification and selection of information-rich cases when resources are limited. It is appropriate for identifying and selecting participants who are exceptionally knowledgeable or experienced with a phenomenon of

interest (Creswell & Plano Clark, 2011; Patton, 2002).

Purposeful sampling was also consistent with the case study design. According to Seawright and Gerring (2008),

> case selection should be a primary role of the case study researcher as in so doing it also sets out an agenda for studying those cases which implies case selection and case analysis are intertwined to a much greater extent in case study research. (p. 2).

"However," Seawright and Gerring wrote, "to prevent the dangers of selection bias introduced whenever researchers choose their cases in a purposive fashion … perhaps case study researchers should choose cases randomly" (p. 3).

Sample Size

Onwuegbuzie and Leech (2007) asserted that selecting sample size in qualitative studies requires careful deliberation, as it determines the extent to which the researcher can make each of the four types of generalizations, irrespective of a small sample size. While Onwuegbuzie and Leech posited that sample sizes in qualitative research should not be so large that they render it difficult to extract thick, rich data, other authors have postulated that sample sizes should not be so small that it becomes difficult to achieve data saturation (Flick, 1998; Onwuegbuzie & Leech, 2007). Mason (2010) for instance, affirmed that qualitative samples must be large enough to assure that almost all relevant perceptions are captured, noting that if a sample is too large, the data become repetitive and superfluous. Mason cautioned that even though the guiding principle for sample size in qualitative research is the concept of saturation, various issues also affect it as there is

a point of diminishing return to a qualitative sample so adding more data does not necessarily lead to more information. (p. 1). Mason added that sample sizes for qualitative studies are generally much smaller than those in quantitative research. Because qualitative research designs are very labor intensive, it can be time consuming and impractical to analyze large samples (Mason, 2010). Based on the findings of the 560 studies whose contents were analyzed for their sample sizes, it was deduced that the mean sample size was 31. Taking all of these factors into consideration, I determined that the sample size for this study would be between 20 and 25 participants.

Instrumentation

Salkind (2010) described instrumentation as the tools or means with which researchers attempt to measure variables or items of interest in the data collection process; an instrument is a device used by investigators for collecting data. For this study, instruments that I used in the data collection process included phone and face-to-face interviews, videotape, audiotape, email, texting, and archived data review, among others. Salkind (2010) also asserted that instrumentation incorporates construction and assessment as well as conditions under which the designated instruments are administered.

Acharya et al. (2009) designed a questionnaire to explore knowledge, attitudes, and beliefs about SCT and SCD, and this is one of the instruments that was adopted for this study. Al-Azri et al. (2016) also developed an instrument to test knowledge and health beliefs regarding SCD, and it might also be emulated. Other researchers such as Chakravorty et al. (2018) have validated questionnaires developed through stakeholder

consultations, focus group discussions, and construct validation of questionnaires through cognitive testing and assessment of construct validity by a nationwide pilot survey, which were also used. Sample questionnaires that have been used by reputable entities such as the U.S. Food and Drug Administration (FDA, 2014) and the Thalassemia International Federation via Survey Monkey were also used for data collection. Because of the geographical distribution of the study population and COVID-19, all data were collected remotely online, by phone, by email, by text, or through social media tools such as Facebook Messenger, among others.

Procedures for Pilot Studies

In (2017) claimed a pilot study is executed to test all the procedures of the main study and validates the feasibility of the study by assessing the inclusion and exclusion criteria, data collection methods, storage and testing of the instruments for measurements in the study, and the training of researchers and research assistants. A mock pilot study has already been done when taken course RSCH - 8450H. Three participants, an SCD patient, a parent, and a pharmacist, were selected for the pilot study. A questionnaire was administered to them, followed by a semi-structured face-to-face interview with the patient and pharmacist. Fortunately, one participant is a sickle cell anemia disease (S.C.) patient and the father of the patient, so their responses were based on first-hand experiences, and their responses can be deemed to be valid and reliable. The other has no SCD or any relatives who have the condition, so basically did not have much experience in SCD, which impacted her responses and even her interest and approach to answering the questions. The research instruments used for this exercise were unstructured

interviews and a questionnaire composed of twenty-three questions, some of which were prepared by me, and others were sample questions from some renowned establishments like the U.S. Food and Drug Administration (FDA, 2014) and The Thalassemia International Federation on survey monkey. Perfect responses, feedback, and suggestions were received from them, which helped to decide on the topics or subsections to include in the literature review. The pharmacist reviewed the questionnaire with me, and we went through the questions together. The necessary modifications suggested or realized would be incorporated into the interview questions or questionnaires for the final study.

Procedure for Recruitment and Participation

Various strategies to recruit study participants were considered. Local SCD health facilities especially those I am already acquainted with example, UT Southwestern health, the Texas Oncology's SCD departments and The Sickle Cell Association of Texas Marc Thomas Foundation (SCATMTF) among others were contacted. Permission was sought from the administration and leaders, respectively from those that were interested and also in a good position to participate due to COVID to recruit study participants. Working group members or leaders of online SCD communities and platforms like Generation S, oneSCDvoice, Raremark and others were also approached for permission and help to recruit members to participate in the research. Other social media platforms like Facebook, and others were also used to recruit study participants. Last but not least, acquaintances known to have the disease or relatives with SCD were contacted for participation when it became necessary to employ snowballing sampling too due to COVID-19.

Since most of these communities are remote, most of the contact were done through emails, text messages and phone calls. Monetary gifts were used to motivate participants where necessary. A letter of consent was designed and issued to participants to explain to them the study procedures, their roles to get their agreement or approval to participate. The Walden Institutional Review Board (IRB) approval was obtained before participants were recruited and allowed to participate.

Data Collection Method

Emails, text messages, and phone calls were sent out to the participants that were purposively selected to participate in the data collection. Different categories of participants were anticipated based on the geographic distribution of the SCD community, and due to COVID, the data collection was conducted mainly through phone interviews, by emails, and other social media platforms using questionnaires. Most of interviews conducted, lasted between 40 to 90 minutes. A consent form was issued to participants to explain the terms and conditions of the whole process, what their role in the study is, that it is a voluntary process, how their information would be protected and used, among others. Thus, it was used to explain to the participants as much as possible the intent of the study. Participants were made to sign the consent form electronically by emailing back “I Consent” before they were allowed to participate in the study. The data was collected solely by me. The entire data collection process lasted for about a month and half. At the end of the data collection, the responses of some selected study participants especially the adult SCD patients were reviewed with them to guarantee that their views and contributions are correctly captured or documented. Since saturation was

attained with the 11 study participants, it was no longer necessary to gather any more information from archived data and patients shared stories from online SCD communities or groups such as Generation S sponsored by Novartis Pharmaceuticals Corporation, oneSCDvoice, Raremark.

Data Analysis Plan

Several strategies were employed in the processing and analysis of the data that were collected. An example is a content analysis, which, according to Bengtsson (2016), is purposely for organizing and obtaining meaning from the data collected in order to draw realistic conclusions from it. The principles of content analysis was used to seek out individual words, code them and developed themes from the data through which the necessary interpretations and inferences were made when all participants' responses and, audio-recordings collected and taken were studied and analyzed (Hagan Asamoah, 2018). Another strategy that was used for the data analysis is a narrative analysis whereby participants responses were used to retell or reformulate participant's stories to be able to give a better presentation of their perceptions and present the findings in a format that meet the expected requirements and expectation of a doctoral dissertation (Hagan Asamoah, 2018). Manual transcription was employed in transcribing and coding of all the enormous amount of data that were collected during the research using Microsoft Word Processing and Excel to aid in the process.

Issues of Trustworthiness

"Trustworthiness depicts how a research study has been conducted competently and ethically using a set of standards, relaying to the reader that the study has merit and

worth and that the results are credible and good to guide further research and practice" (Rallis & Rossman, 2009, p. 281). Guaranteeing the trustworthiness of the data collected is a vital aspect of the research process. Some of the ways the issues with trustworthiness were handled are by letting the dissertation chair and committee member review the questionnaire and the interview questions and also conducted a pilot study to test their efficacy and quality. The trustworthiness of the study implies how best the data collected or the findings can be trusted. Another way to ensure trustworthiness was establishing a rapport with the study participants and thus gained their trust and confidence which guaranteed reliable responses. "To guarantee trustworthiness, qualitative researchers must demonstrate that their data analysis has been conducted in a precise, consistent, and exhaustive manner through recording, systematizing, and disclosing the methods of analysis with enough detail to enable the reader to determine whether the process is credible" (Nowell et al., 2017, p. 1). Shenton (2004) claimed that the trustworthiness of qualitative research is often questioned by positivists because their concepts of validity and reliability cannot be addressed in the same way in naturalistic work" (p. 1). Employing the Guba constructs, Shenton (2004) proposed four criteria to address trustworthiness, which are credibility/ internal validity, transferability/external validity/generalizability, dependability /reliability and conformability/objectivity.

Credibility/Internal Validity

Shenton (2004) declared to resolve credibility; researchers need to demonstrate that a true picture of the phenomenon under scrutiny is being presented. Triangulation was thus employed to enhance credibility by administrating the same research questions

to different study participants, collect the data from different sources using different methods affirming case study as appropriate for the study. Member checks was also employed by letting participants review their responses to interviews or questionnaires for correctness. I had the responsibility to provide detailed descriptions of the participants' standpoints or perceptions as honestly and thoroughly as possible, that my viewpoint was integral reflecting in the report (Rallis & Rossman, 2009). These authors suggest that this can be achieved by designing the study in such a way that the data are gathered over a significant time, or, very intensively if over a short period of time and to triangulate using employing different data collection methods such as interviewing, observing, and document review (Rallis & Rossman, 2009). I also documented the process of gathering, analyzing and interpreting the data by keeping a log or journal and writing analytic memos, recording the intellectual journey of my study and thus proving to my readers and users of my findings that it was carefully and thoughtfully conducted (Rallis & Rossman, 2009).

Transferability/External Validity/Generalizability

It was expected that enough detail of the context of the fieldwork for the findings should be provided to be deemed justifiably to be able to apply it to other settings (Shenton, 2004). My findings in this study were presented in such a way that they could be used or applied in other settings. To achieve or guarantee the transferability of my study findings, Rallis and Rossman (2009) proposed complete descriptions of the conceptual framework that were used, the design of the study, the data collection methods, provide details of the implementation, themes, and categories and the

interpretations and conclusions. I used a common coding scheme, The Code and Coding Technique, to ensure and compare my findings with conflicting and similar literature (Sinkovics et al., 2008). I also tested the equivalence of the research topic example by pre-testing the definition of the concept (Sinkovics et al., 2008). A full description was adopted by giving detailed descriptions and interpretations of the data that were collected and any other situations that were observed during the study. I saw to it that the study is reproducible so that other researchers can duplicate or repeat it later.

Dependability/Reliability

Data auditing was done to enhance the dependability of the data. According to Silverman (2003), reliability can be ensured by using standardized methods to write filed notes and proper transcripts for interviews and textual studies and by comparing the analysis of the same data by several observers. Thus the responses of different participants were compared to check for consistency. The research report should be logical, transparent, and consistent and allows for replication (Sinkovics et al., 2008).

Confirmability/Objectivity

I had the responsibility to take the necessary steps to demonstrate that the findings were really from the data collected and not my views or proclivity to avoid bias. Objectivity was achieved by making use of an external audit, such as allowing participants to review and react to data and my interpretations (Sinkovics et al., 2008). I was alert and coherent of my background assumptions, the definition of behaviors, in the literature review in order not to over-represent the problem (Sinkovics et al., 2008). Though I actively participated in or was in charge of the data collection and preparation, I

still was detached enough which enabled me to make good observations (Sinkovics et al., 2008). I was conscious of my actions, perceptions, and thoughts so as not to influence the outcome of the study to avoid bias.

Ethical Procedures

Rallis and Rossman (2009) claimed that an unethical study is not a trustworthy study (Rallis & Rossman, 2009). Thus, I had the responsibility of conducting the study ethically, with deep sensitivity to the needs and interests of the study participants (Rallis & Rossman, 2009). This was achieved by employing vigilance and thoughtfulness throughout the entire research, which included an approach to critical gatekeepers, selecting study ethically by using Walden's and other professional codes of ethics or standards for conduct that are based on moral principles (Rallis & Rossman, 2009). Ethical principles were used to guide the research in addressing any issues that rose from the study in order to meet the goals of the research as well as to maintain the rights of the research participants (Orb et al., 2001). Because the data were collected remotely or digitally and considering the vulnerability of the study population, sensitivity was a priority based on how private, sacred, or stressful the management of SCD is, how much potential there is for stigmatization, and how politically controversial the issues (opioid crisis and prescription drug abuse) are (Tiidenberg, 2020). Hence, the possible consequences from participating in the study to both me and the study participants were taken into account (Tiidenberg, 2020).

Summary

In this chapter, the study design and methodology were laid out. Several sub-

sections were addressed or defined, such as the study design and the rationale, who the study population or target audience were, method that was employed to select participants, thus the sampling population using purposive sampling while employing tact in order to prevent bias and also snowballing sampling was also incorporated due to COVID-19. The data collection and analysis processes that were used, considering the study design were also discussed. Also, the necessary procedures and steps that need to be followed to ensure the study's trustworthiness and that the appropriate ethical standards and expectations would be fulfilled are presented in this chapter.

Chapter 4: Results

Introduction

This case study research was undertaken to investigate SCD patients' and their parents/caretakers' experiences and perceptions about employing alternative treatment options (both pharmaceutical and nonpharmaceutical products) in lieu of opioid analgesics for pain management. The study was built on the premise by such researchers as Majumdar et al. (2013) that CAM is effective in controlling SCD pains. Poor management of these pains usually results in poor QOL for patients and their families, as it usually impacts the psychological, sociological, physical, and spiritual aspects of the individual's life. It renders basic daily activities such as working and attending school very difficult to do and results in frequent hospital visits or hospitalizations, which may be associated with high hospital costs and hence financial burdens. Jalalian and Anokwuru (2017) suggested the need to provide healthcare plans for SCD patients to reduce hospital admission costs for patients who stay in the hospital for extended periods of time and promote more preventive therapies such as bone marrow transplantation (BMT), use of traditional medicine, and use of community care. It was based on some of these presumptions that I conducted this study.

The primary data collection instrument for the study was semi-structured interviews supplemented by reviewing patients' or family members' shared stories. The subtopics treated in this chapter include the pilot study, setting, demographics, data collection, data analysis, evidence of the trustworthiness of the data, and study results. The chapter concludes with a summary.

The study was guided by these research questions:

RQ1. What are the experiences of the SCD patients or their parents/caretakers regarding the current prescribing habits of their HCPs to manage SCD pain, and how do they influence their choice of treatment?

RQ2. What are the experiences and attitudes of the SCD patients or their parents/caretakers toward alternative treatment methods, and how do they influence their choice of treatment?

RQ3. What is the stage of readiness for adopting alternative treatment methods for SCD patients or their parents/caretakers?

RQ4. How does disease perception among adult SCD patients or their parents/caretakers impact their willingness to try alternative treatment methods?

Pilot Studies

After receiving IRB approval, I performed a pilot study with two participants, a 57-year-old parent and an 18-year-old patient. I conducted semi-structured face-to-face interviews at their home as practice, as well as to gain logistical insights and test the effectiveness or correctness of the data collection instrument. Malmqvist et al. (2019) proposed three aims of a pilot study: (a) to gather data to provide guidance for a substantive study adapted to modify research procedures and instruments, (b) to help researchers effectively utilize observational and video-recorded data, and (c) to test a theoretical model as a tool of analysis. These authors also emphasized that the importance of a pilot study, especially in case study research where semi-structured qualitative

interviews are used, is to enable researchers to be better informed (especially for novice researchers; Malmqvist et al., 2019). Pilot studies also help researchers to prepare to face the challenges that are likely to arise in their substantive studies and to gain more confidence in the instruments to be used for data collection (Malmqvist et al., 2019). Malmqvist et al. added that proper analysis of the procedures and results from a pilot study helps to identify any weaknesses of the instrument so that they can be corrected. Thus, a carefully organized and managed pilot study has the potential to increase the quality of research, as the results can inform subsequent parts of the research process (Malmqvist et al., 2019). Accordingly, I conducted this pilot study to evaluate the effectiveness or appropriateness of the interview questions, any anticipated challenges, and mistakes that needed to be corrected before administering the instrument to the main study participants.

Setting

Due to COVID-19, data collection was conducted virtually, mainly through phone calls, employing semi-structured interview techniques. Additionally, some of the interview questionnaires were administered through email or text, based on participants' choices. Thus, the study settings were the homes or residences and offices of the study participants, as well as my home. The semi-structured interviews were therefore conducted under very comfortable conditions. The participants were assured of the privacy and confidentiality of the whole process before we proceeded with it.

Participant Demographics

The target population for this study consisted of patients, parents, and caretakers in the SCD community. A recruitment flyer was posted on popular social media platforms such as Facebook, as well as on the social media sites of partner organizations such as SCATMTF and Raremark. Through Raremark, I also got linked to the Living with Sickle Cell, Inc organization, where some of the study participants were recruited. I also sent the recruitment flyer to all of my contacts using WhatsApp, Messenger on Facebook, LinkedIn, and email.

Snowball sampling had to be employed in recruiting participants as the pandemic made it difficult to find potential participants. The recruitment of study participants was done basically virtually due to COVID-19; hence, I had to also depend on some of the study participants to recruit other participants. Several people or support groups expressed interest after randomly posting on the social media of some online SCD support groups, with some of the leaders promising to assist in recruiting members from their groups. Initially, there were about 35 leads or potential participants expressing interest when the recruitment flyer ad was launched.

Employing the techniques of purposive and snowball sampling, I selected 11 individuals to participate in the study based on their experiences, availability, time constraints, time zone, financial constraints, and location (some of the groups that I contacted were international groups). All of the participants who were purposively selected to take part in the study were located in the United States, but they were located in various states (Texas, Virginia, Massachusetts, South Carolina, and Florida).

It seemed that the state in which a participant was located played a major role in their ability and confidence in managing their pain and disease based on the health services and the support systems of the state. For instance, one participant who relocated from Virginia to South Carolina stated that "in South Carolina the hospitals do not know sickle cell disorder well and the doctors … do not treat the disease well, so they always sent her child home after an ER visit or hospitalization with fever and pain". She claimed that in Virginia, health services or doctors were more knowledgeable, so the recovery time for her child during crisis tended to be a lot shorter. She also maintained that her relationships with HCPs in South Carolina were not as good as they had been Virginia. She expressed the view that HCPs in South Carolina just do not care but rather they treat cancer patients, way more than they do with SCD patients. Another participant from Virginia claimed to have a very good relationship and rapport with their HCPS and noted that a support group based there had lobbied with the government for SCD patients to be treated the same as cancer patients. This participant's main complaint was about the fact that Virginia HCPs treated all SCD patients the same way and did not try to tailor treatment plans based on the type of SCD or conditions of the patient. Further, the participant observed that because of trust issues between HCPs and patients, patients preferred to rely on support groups for emotional support.

All participants were African or African American; no patient from any other race responded to the recruitment ad posted on social media. This was consistent with SCD's higher prevalence among Black people or people of African descent. Of the 11 participants, three were males and the remaining eight were females. However, there

were 12 patients altogether, as one mother who took part in the study had two SCD patients. Among the patients, seven were males and five were females. The SS type (70%) was predominant and these participants with the SS-type seemed to have a good understanding of the condition possibly because they seemed to have frequent pain episodes and the associated complications. The ages of the study participants ranged from 23 to 70 years. However, the SCD patients' ages, based on information provided by patients or their parents, ranged from 6 to 70 years. Four of the study participants were patients, and seven were parents/guardians of SCD patients under the age of 18. All of the seven parents/caretakers who participated in the study were females or mothers, suggesting that mothers are more involved in taking care of their sick children and managing their pain. Most of the participants had some form of education; seven of them claimed to have some graduate degrees three had a college degree, and one had a vocational/trade school diploma. The income level of almost all of the participants fell below the middle-class level and may be considered low or even very low income; only three of the participants could be categorized as coming from a middle-class family.

Saturation was reached at about the 10th participant, but to avoid sampling bias and skewed data, I decided to recruit an extra participant, specifically one with a type of SCD (SC) other than SS, as 70% of the study participants were SS patients and only 30% were SC patients at the point of saturation. There were no participants representing the other types (e.g., beta-thalassemia, etc.). Table 1 gives a summary of the study participants' demographics.

Table 1

Demographic Profile of Study Participants

Study participant (SP)	Role	Age of child with SCD	Gender	Gender of child	House-hold income	Educational level	Socio-economic status (SES)	Race/ ethnicity	Type of SCD
SP1	Parent	18	Female	Female	$30,001–40,000	College/some college	Low	Black/ African	SS
SP2	Patient	23	Male	NA	$30,001–40,000	College/some college	Low	Black/ African	SS
SP3	Parent	12	Female	Female	$5,001–10,000	Graduate	Low	Black/ African American	SS
SP4	Parent	9	Female	Male	$70,001–100,000	Graduate	Middle	Black/ African American	SS
SP5	Patient	28	Male	N/A	$5,001–10,000	Graduate	Low	Black/ African	SS
SP6	Parent	6	Female	Female	$40,001–50,000	Graduate	Low	Black/ African American	SS
SP7	Parent	16	Female	Male	$10,001–20,000	Vocational/trade school	Low	Black/ African American	SS
SP8	Patient	70	Male	N/A	$10,001–20,000	Graduate	Low	Black/ African	SC
SP9	Parent	19	Female	Female	More than $100,000	Graduate	High	Black/ African	SC
SP10	Patient	25	Female	N/A	$20,001–30,000	College/some college	Low	Black/ African American	SS
SP11	Parent	13, 17	Female	Male	50,001–60,000	College/some college	Middle	Black/ African American	SC

Data Collection

Employing virtual techniques and tools, data collection was conducted using open-ended semi-structured interview questions. The design of the interview instrument was guided by an instrument used by the U.S. FDA at a public meeting conducted by the agency to hear perspectives from SCD caretakers and other patient representatives on the most significant effects of their disease and available therapies. The interviews were conducted virtually from the comfort of my and the participants' residences using phone or video calls, texting, and email. I audio-recorded the phone interviews and reviewed the recordings to capture any information missed during interview transcription.

Data Analysis

Bernard (2011) described data analysis as the search for patterns in data and for ideas that help explain why those patterns are there in the first place. As proposed, content analysis was employed alongside other feasible methods for data analysis. Babbie (2001) also described content analysis as the as a means to examine recorded human communications, characterizing it as essentially a coding operation, with coding being the process of transforming raw data into a standardized form. Ryan and Bernard (2000) also asserted that content analysis is one of the major coding traditions whereby the researcher produces a matrix by applying a set of codes to a set of qualitative data (e.g., written texts, etc.), with the assumption that the codes of interest have already been discovered and described beforehand. Though the codes used were not previously described as proposed by these researchers, they were developed based on the interview questions formulated based on the research questions.

Thus, the code and coding technique was employed in data collection, processing, and analysis. According to Strauss (1987), any researcher who wishes to become an expert at doing qualitative analysis must learn to code well and easily, as the excellence of a research study rests in large part on the excellence of the coding. The code and coding technique was deemed appropriate for this study because it makes it easy to link the data back to the research questions and propositions, rendering the interpretation of the output from a case study subtler and easier to understand (Miles & Huberman, 1994). According to these researchers, the code and coding technique uses the case-oriented approach strategy referred to as "partial ordered displays" to analyze a case study, which allows for the quick identification of segments relating to the research questions and any potential themes (Miles & Huberman, 1994).

Coding the data was imperative because, as Miles and Huberman (1994) put it, codes were used as labels to assign symbolic meaning to the descriptive or inferential information compiled during the study. Atkinson (2002) described coding as assigning "tags" or "labels" to the data collected, by which the data are organized and managed. Richards and Morse (2007) also asserted that coding is a key part of a qualitative data analysis, and at times is considered to be synonymous with the analysis or an early form of analysis, as it serves as an interpretive process of moving from the data to the idea, and from the idea to all the data pertaining to that idea.

The coding of the data was done concurrently with the data collection, which helped to speed up the process. Hartley (2004) asserted that when the data collection and analysis are developed together in an iterative process, it can become a strength for the

study. Miles and Huberman (1994) also argued that it enables the researcher to go back and forth between thinking about the existing data and generating strategies for collecting better data and also makes analysis an ongoing, lively enterprise that contributes to the energizing process of the research.

According to Kohlbacher (2006), the analysis of case study data requires a careful description of the data and the development of categories in which to place behaviors or processes. The data should be organized around certain topics, key themes, or central questions and then examined to see how well they fit or fail to fit the expected categories (Kohlbacher, 2006). Yin (2003) also claimed that data analysis consists of examining, categorizing, tabulating, testing, to address the initial propositions of a study, while Neuman (1997) argued that data analysis entails a search for patterns in data, which, once identified, are interpreted in terms of a social theory or the setting in which they occur, resulting in a more general interpretation of their meaning.

Yin (2003) proposed three general analytic strategies for analyzing case study evidence: relying on theoretical propositions, thinking about rival explanations, and developing a case description. With any of these strategies, these five specific techniques for analyzing case studies can be practiced that include: (a) pattern matching, (b) explanation building, (c) time-series analysis, (d) logic models, and (e) cross-case synthesis (Yin, 2003). Thus, I executed the following steps to analyze the data.

Step 1: Data Processing

Each study participant’s responses or data were carefully processed before being analyzed. All scribbled notes from interviews or questionnaires and interview recordings

were converted into expanded write-ups as proposed by Miles and Huberman (1994), with data entry using Microsoft Word and then data organization and analysis using Microsoft Excel. According to Miles and Huberman, a write-up is an intelligible product that anyone can read, edit for accuracy, comment on, code, and analyze using several methods.

After the write-ups, codes were generated based on the research questions. A code is defined as "a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data" (Saldaña, 2015). According to Atkinson (2002), a code might be used to identify a word, a phrase, a sentence, or a paragraph important to the research from which meanings are ascribe to the chunks of data of a research (Miles & Huberman, 1994). Hedlund-de Witt (2013) also described a code as a lower level of data analysis on the way to labels, categories, themes, and theory. Hedlund-de Witt (2013) asserted that the act of coding requires that the researcher wears an analytic lens that is based on perception and interpretation of what is happening in the data. Saldaña (2013) asserted that the level of personal involvement of a researcher as a participant observer either as a peripheral, active, or complete member during fieldwork filters how he perceives, document, and thus code his data which depends on the types of questions that are asked as well as the types of responses that were received during the interviews.

Once the initial codes were generated, the actual coding process began which involved examining chunks or segments of data from the case studies and associating them with one or more of the initial codes as proposed by Atkinson, (2002). Two main

cycles of coding were employed for this study that included a first and second cycles coding. Microsoft Excel was also used to code and analyze the data.

Step 2: The First Cycle of Coding

Basically, it is the initial coding process of the interview transcripts. Saldaña (2013) described the first cycle coding methods as codes initially assigned to the data chunks and involves applying provisional and tentative codes. Hedlund-de Witt (2013) asserted that the magnitude of the data coded during the first cycle coding can range from a single word to a full sentence, an entire page of text, or a stream of moving images which can be repeated numerous times before the second cycle coding.

A combination of descriptive and in vivo coding strategies were employed in this initial coding cycle. According to Miles and Huberman (1994), a descriptive code assigns labels, most often nouns to data to summarize it in a word or short phrase that serves as the basic topic of a data-passage. Hedlund-de Witt (2013) also claimed that descriptive coding summarizes the primary topic of the excerpt/datum. It serves as the first step of the data analysis. Thus, some of the descriptive codes created during this stage were role, gender of child, household income, educational level, SES, coping strategies, support systems among others.

In vivo coding was used to code significant or outstanding statements by participants. According to Hedlund-de Witt (2013), in vivo coding occurs when a code is taken verbatim directly from the data and placed in quotation marks and is used to highlight “participant-generated words or phrases.” Thus, it is a word -to-

word coding of participants usually placed in quotation marks. Examples are opioids treat or help with the pain faster: “fast acting” and religion: “prayers have powers”.

Step 3: The Second Cycle of Coding

A second cycle coding was conducted to reorganize, classify, prioritize, integrate, synthesize, consolidate and conceptualize the huge data and codes compiled during the first cycle coding as proposed by Onwuegbuzie et al. (2016). Hedlund-de Witt (2013) asserted that second cycle coding methods are basically for reorganizing and reanalyzing the data coded through first cycle methods. They are used to explore the interrelationships across multiple codes and categories in order to develop a sense of thematic, conceptual, and/or theoretical organization and coherence from the first cycle codes (Hedlund-de Witt, 2013).

The principle of focused coding was applied in the second cycle coding. Adu (2016) claimed that focused coding helps in identifying “the most frequent or significant initial codes” by looking for: (a) code frequencies, (b) codes relationships, (c) central codes, and (d) building categories around them. According to Hedlund-de Witt (2013), focused coding is usually executed subsequent to initial coding, and it searches for the most frequent or significant initial codes to develop the categories or themes that would be considered to be more important. Patel (2014) also asserted that focused coding categorizes coded data based on thematic or conceptual similarity. Thus, using focused coding, the significant codes derived from the first cycle coding were categorized based on conceptual similarity using the Bio-psychosocial-spiritual model of chronic pain

developed by Taylor et al. (2013). Pattern coding was also employed to group the codes into a smaller number of categories, themes, and then constructs/concepts After the second cycle coding, a code-weave was conducted where the primary codes, categories, themes, and/or concepts were compiled into a few sentences. The results are illustrated in Table 2.

Step 4: Codes to Categories

After the two levels of coding, several major categories emerged from the coded data. As Dey (1999) declared, the codes formed are used to compute the categories from which meanings were imputed to the data. Saldaña (2013) asserted that when codes are clustered together according to similarity and regularity, they actively facilitate the development of categories and thus analysis of their connections. Thus, the coding enabled me to organize and group similarly coded data into categories or "families" because they share some characteristic. Some categories contained clusters of coded data which were refined into subcategories as suggested by Saldaña (2013). Hence, about 40 major categories/subcategories were clustered together under about 15 major cluster of themes. An example from the original code, Pain Management, emerged various categories/subcategories such as Medications and Coping Strategies.

Category: Medications

Subcategory 1: Pharmaceuticals

CODE: Prescribed

CODE: Over the Counter

Subcategory 2: Purpose

CODE: Management/Purpose

CODE: Prevention

Step 5: Emergence of Themes

According to Saldaña (2013), a theme is an "outcome of coding, categorization, and analytic reflection, not something that is, in itself, coded" (p. 13). Rallis and Rossman (2003) also described a category as a word or phrase describing some segment of the data that is explicit, whereas a theme is a phrase or sentence describing more subtle and tacit processes. Using Microsoft Word and Excel, similar statements or responses by participants were organized to clusters of categories from which 15 major themes were developed. Examples of the clusters of categories formed are pain management, coping strategies, religion, ideal treatment, knowledge of symptoms, effectiveness, support system, abuse of prescribed medications, participants experience and perceptions. Table 3 depicts some of the clusters of categories, themes developed and associated research questions. Figure 1 also illustrates how the entire coding process was executed.

Table 2

Categories, Consolidated and Emerged Concepts

Significant initial codes	Emerging codes/ categories	Consolidated data	Research question	Emerged concepts
Pain crisis	Frequency Symptoms Impacts Triggers Hospitalizations	Most of the participants reported of decreased frequency in pain crisis most of them attributing it to enhanced awareness of symptoms, increased in self-confidence and improved knowledge on signs and symptoms as well as the proper management of pains. Most of the participants reported only 1 – 2 times hospitalization per year with only one patient reporting more than 10 times of hospitalization and another one 3-5 times. The oldest participant, a 70-year old SC patient reported his last crisis related hospitalization was in 1994 attributing this to increased awareness and proper management of symptoms and so was a similar story of another SC patient. This also depicts how the pain crisis and associated complications are tied to the type of SCD a patient has. Almost all participants reported how pain crisis usually results in them either not going to school, work and limiting their social activities and impact them psychologically and financially.	RQ 4	Biopsychological
Pain management	First line of defense maintenance	Almost all the participants employ some form of homecare/selfcare as simple as hot baths/pads and pain killers as first line defense for pain management especially before they head to the hospital during a crisis. Most use these also on daily bases for managing pains. Most of the participants declared they uses natural products like fruits and veggies, herbal products like shea butter, chlorophyll and nutraceuticals like vitamins and pharmaceutical products like Hydroxyurea and painkillers daily for prevention and maintenance of pains.	RQ 4	Biopsychological
Medications	Type: Pharmaceutical/ nonpharmaceutical Prescribed/OTC Management/prevention Abuse of medical prescription drugs Prescribing habits of HCPs Side effects Opioid analgesics Effectiveness	Patients uses both pharmaceutical/ nonpharmaceutical Prescribed/OTC products; mostly prescribed for the management/prevention of pain crisis. Most of the participants did not think SCD patients abuse prescription medications but rather there was this notion by some few participants that some patients are compelled to take more of their prescribed medications because SCD HCPs seemed not to really understand the caliber of the SCD-related pains, they tend to under-prescribe for their patients confirming what previous studies by Booker et al. (2016) and others proposed. Most of the participants also think HCPs still chooses to prescribe opioid analgesics over other potential medications because they are effective and fast acting and help to alleviate	RQ1	

Significant initial codes	Emerging codes/ categories	Consolidated data	Research question	Emerged concepts
		the pain quicker. Most of the patients are also taking Hydroxyurea for prevention or to reduce the frequency of pain crisis and attribute the reduction in their pain episodes to it. However, one patient who claimed has being using it for 4 years; said Hydroxyurea increases the chances of getting infections; and because it is supposed to be a chemotherapy it is affecting his hair growth; and also reduces his appetite. Another parent claimed it rather helps to prevent infections. Overall, there was no serious side effects reported for any of the other medications nevertheless the possibilities of side effects were the main reason most of the participants were skeptical in trying other or new treatment options.		(*table continues*)
Coping strategies	Natural products Self-care management Self-awareness Effectiveness	Participants gave various coping strategies they have been employing to manage their pains. This ranges from natural products, self-care management and self-awareness/mindedness. Most common strategies mentioned were keeping hydrated by drinking more water, taking hot showers or using hot pads, eating healthy, doing or managing stress, distraction, rest, massaging, prayers. Unique or new strategies learned were aromatherapy, shea-butter because of its anti-inflammatory properties, chlorophyll, air purifier, alkaline water, fasting etc.	RQ2 RQ3	Biopsychological
Alternative treatment options	Experiences Perceptions Effectiveness	Participants have had diverse experiences with their pain management but overall.it seems they have had success stories. Most of them have already tried alternative regimens and there was a split. Whilst some feel they are very effective and even though they have contributed towards the reduction in the frequency of their pain crisis episodes, others thought they were not that effective as the orthodox ones (opioid analgesics) they have been using. Almost all of them are open to exploring alternative regimen but few thought there is no need for change or try new treatments if what they are already using (opioid analgesics) is working.	RQ 2 RQ 3	Biopsychological
Religion	Prayers Meditation Effectiveness	All of the participants claimed to pray and also rely on others praying for/with them especially during crisis. Whilst some of them put more energy or focus on them because they deemed it effective, others however claimed they are not that effective as one of them put it because prayers do not actually take the pains away. Another patient rather maintained or insisted on the effectiveness or the role prayers played in managing his pains declared that he prays a lot and think that if not for God have been dead a long time ago. He claimed prayers help a lot to soothe the pains especially during hospitalizations before the analgesics administered to him	RQ 2	Spiritual

Significant initial codes	Emerging codes/ categories	Consolidated data	Research question	Emerged concepts
		start to work on him, he depends on prayers to help him stay calm and comfortable. He said there are always a hospital chaplain and a sister who usually prays with him during such times and it has been very effective. Others also attest to how helpful prayers have been to them. Few uses other religious activities like fasting, yoga and other spiritual artifacts.		(*table continues*)
Support systems	Type Knowledge Usefulness	Most of the participants belong to support group or have a form of a support system especially family members and religious/spiritual leaders/members that they lean on especially during crisis and also information and resources. One parent stated that she used to feel very lonely and unsure of herself but since she joined a support group she does not feel like that anymore and she now feel more confident especially in managing her son's pains and in handling other related issues . Another parent who happened to be a leader of a support group also claimed that when it comes to emotional or psychological issues related to SCD, most patients prefer to turn to their support group for help instead of their HCP team. However, one patient stated that he does not like joining support groups hearing and being around other SCD patients negatively impacts him: it usually make him more depressed.	RQ 2	Sociological Psychological
Ideal treatment	Purpose Safety Feasibility Affordability	Various views were given concerning what an ideal treatment should be but most wanted treatments that are safe, capable of preventing or eliminating pain crisis, easy to administer or use, less invasive on organs; no or less side or adverse effects and affordable.	RQ 1 RQ 3 RQ 4	Biopsychological
Financial	SES Insurance policy/coverage	Aside from a couple of the participants can be classified as from middle class families, almost all of the participants were of low SES, with average annual income of $20,000 to $300,000 dollars which can be a strong determining factor in the choice of treatment options, health services to engage in etc. One of the major triggers of pain crisis and with such low SES or income levels stress and their associated health issues are inevitable among SCD patients and their families. Participants had varied educational levels with some of them even at the graduate level. It was observed that participants with higher educational levels have better control of the disease as they use more sophisticated or better management strategies than those with low educational level. Actually, the oldest patient/participant, a 70 year old SC patient nicknamed "the model patient" used to be a Language Professor at Harvard University whose last pain crisis that resulted in	RQ 1 RQ 2	

Significant initial codes	Emerging codes/ categories	Consolidated data	Research question	Emerged concepts
		hospitalization was in 1994 attributes his current good health status to healthy eating habits. He claimed his pain crisis frequency reduced drastically when he learned of the importance of taking folic acid daily, eating healthy and drinking alkaline water which he has been doing for the past 15 years.		

Table 3

Categories, Emerged Themes, and Research Questions

Categories	Emerged themes	Research questions
Knowledge	Knowledge about other treatment options	RQ 1
Knowledge	Knowledge on SCD	RQ 1
Effectiveness	Effectiveness of the medication	RQ 1
Perceptions	Personal reasons such as lack of concern/care and benefits	RQ 1
Experiences	Participants' experiences	RQ 2
Perceptions	Accommodating attitude	RQ 2
Alternative treatment options	Effectiveness/efficacy, Safety/side effects, Cost/affordability	RQ 2
Pain management	Type: Coping strategies/other regimens	RQ 2
Perceptions	Participants' perceptions	RQ 3
Alternative treatment options	Resistance to change	RQ 3
Pain management	Ideal treatment	RQ 4
	Research	
Pain management	Knowledge/Awareness/Confidence in managing pains	RQ 4

Study Results

This study was conducted purposely to investigate and analyze various alternate treatment options study participants have been using, how effective and safe they have been, and if they can be applied or recommended for others. Hence, the experiences and perceptions of participants on alternative treatment options were explored as well as other related issues like practitioners prescribing habits, access to health services, challenges among others. About 15 themes evolved during the data processing and analysis which were aligned with the research questions.

Research Question 1

By addressing RQ1: What are the experiences of the SCD patients or parents/caretakers regarding the current prescribing habits of their HCPs to managing the SCD pain, and how does this influence their choice of treatment; participants gave diverse views on why their HCPs prescribe certain type of medication and why they mostly chooses to go with whatever their HCPs prescribe or recommend for them. Some of the themes that emerged under this question were:

- effectiveness of the medication
- knowledge about other treatment options
- knowledge on SCD
- personal reasons such as lack of concern/care and benefits

Theme 1: Effectiveness of the Medication

Participants claimed their HCPs are accustomed to prescribing certain medications because of their effectiveness in managing pain. According to SP1, HCPs

especially choose to prescribe opioid analgesics over others because they “help with the pain faster”; thus they are fast-acting. SP7 also affirmed that opioids are very effective which makes HCPs opt to prescribe it more. SP6 also asserted that HCPs prescribed opioids especially because they know how quick the opioids will help to alleviate the pain. SP2 claimed HCPs are open to prescribe varied medications, but they prescribed mainly opioid analgesics because pains are the main issue or challenge with SCD; it is also based on the type of the disease a patient has which determines the type of medication that may need to be prescribed for the patient. SP3 also maintained that HCPs prescribed specific medications based on the condition the patient is going through and employ different medications too with that effect.

Theme 2: Knowledge/Awareness About Other Treatment Options

Most of the participants confirmed that their HCPs are aware of other treatments and may occasionally discuss with and recommend some of these treatments to them. However, they are mostly pharmaceuticals. SP2 stated that HCPs at times expressed concern about polypharmacy because of the various medications they keep prescribing, but they still just keep switching (prescribing) to new medications without doing anything about it. Thus most of the medications prescribed are not that effective so they keep prescribing and trying new medications. SP2 happened to be one of the patients whose condition is still on the worse side and still gets frequent pain crisis (more than 10 times in a year), more hospitalizations, and associated complications. SP3 also asserted that HCPs choose to prescribe specific medications because of insurance issues. SP3 stated, “I am sure they would way more if Medicaid covered it.”

However, some of the participants believed their HCPs are not really aware or have little knowledge of other treatments, their mode of operation, and their effectiveness. According to Sohail Rana of the Center for SCD Howard University, misinformation abounds concerning Hydroxyurea so many physicians do not prescribe it or do not provide adequate information about it. SP4 declared, “HCPs have less awareness of other meds and are misrepresented.” According to SP11, the HCPs are only interested in bone marrow, stem cell therapies, or clinical trials, but patients are not given much information to help them to understand the role of these therapies in their pain management.

Theme 3: Knowledge on SCD

Most of the participants stated that their HCPs do not really have enough knowledge or really understand the caliber of the SCD pain thus tend to under prescribe in terms of dosage and strength of medications as well as influencing their choice of medications to prescribe. According to SP4, “HCPs knowledge on SCD is about a level of 7; they treat all SCD cases or patients the same way. They don’t try to tailor treatment plan based on the type or conditions of the patient.” According to SP11, HCPs prescribe only specific medications because of lack of knowledge in the disease and in other medications all because of a lack of education and recommended strongly that SCD HCPs need to be educated more on the disease itself and on alternative treatments. SP11 added how some Caucasian SCD patient acquaintances are being constantly denied SCD related health care or services specifically medications or treatment because HCPs do not think they have the disease because of the stigma that it is “a disease for predominantly

Black people or people of Africa descent and other minorities." This attests to the observation or notion made in the literature review regarding globalization and interracial marriages. SCD is no longer an "only Black people disease" but it now transcends races and has now become a global issue hence the need for the public health sector to give more attention to it. According to the WHO (2020), approximately 5% of the world's population carries trait genes for hemoglobin disorders, mainly sickle-cell disease and thalassemia. It is speculated that currently, nearly 90% of the world's sickle cell disease population lives in these three countries: India, Democratic Republic of Congo, and Nigeria with the prevalence of cases higher in India confirming that SCD is no longer a Black only disease.

Theme 4: Personal Reasons Such as Lack of Concern/Care and Benefits

Some participants also maintained that their HCPs prescribed specific medications because of personal reasons such as lack of empathy and benefits. SP3 claimed HCPs know about other treatments but being African American and poor makes them choose specific medication for her child. SP3 stated, "Also, they ask about participants concerns but you can tell they do not care." Thus, financial status of the participant plays a major role in this. Eight out of the 11 (73%) considered to be of low SES and the remaining three, middle class or SES, this may help to highlight the trend of HCPs' prescribing habits or choice of medications especially when it comes to the newly approved SCD medications as cost may play a major role in this. For instance, SP11 maintained that their family cannot afford the new medications especially endari. The family is among one of the three middle class families and one of the participants who

insisted that the SCD patients still need their opioid analgesics. The new medication, adakveo, for instance costs between $7,000 and $9,500 dollars per month but is claimed to be covered under the medical benefit and so is oxbryta which costs] $10,417 dollars a month. It is estimated that the average sickle cell disease patient is estimated to face nearly $1 million dollars in total lifetime health care costs with annual costs of more than $30,000 dollars for adult patients (Novartis International, 2019). Nevertheless, SP10 also argued that "HCPs choose to prescribe certain meds because they may receive additional money (kickbacks) from the drug maker to promote those medicines versus other therapies."

Research Question 2

In response to RQ2: What is the experience and attitude of the SCD patients or parents/caretakers toward alternative treatment methods, and how does this influence their choice of treatment? Participants have had diverse experiences with their pain management using alternative treatment methods but overall, it seems they have had success stories. Most of them have already tried alternative regimens, and there was a split. Whilst some feel they are very effective and even have contributed toward the reduction in the frequency of their pain crisis episodes, others thought they were not that effective as the orthodox ones (opioid analgesics) they have been using. Themes that were developed included:

- accommodating attitude
- participants' experiences/perceptions
- type: coping strategies/other regimens

- effectiveness/efficacy, safety/side effects, cost/affordability

Theme 1: Accommodating Attitude

Most of the participants claimed they are open to try other regimens. SP1 stated that being open to other options and would like her daughter to try them to see which one helps better. SP1 also felt alternative regimens are necessary so that patients would have a lot of options to choose from. SP4 was open to any evidence-based treatments and thought they should be incorporated into SCD treatment plans. SP5 supported the use of other treatment methods to curb pain crisis. SP7 was open but did not deem it not applicable to her now because medications her son was taking were working pretty well. Maybe in the future when her son gets older and then there is the need to explore other options, they will then do so. SP10 also supported that everyone should try and explore other options, and HCPs should be encouraged to prescribe or try these new/other therapies more due to the belief there are better therapies than what is currently being used.

Theme 2: Participants' Experiences/Perceptions

Almost all the participants seemed to have tried some form of alternative treatment ranging from homecare/selfcare to religiosity. Most commonly used regimens aside from pharmaceuticals were natural products including: (a) diets; (b) drinking more water" (c) nutraceuticals; (d) herbal products most unique ones stated were chlorophyll and shea butter; (f) homecare/selfcare management like applying hot pads, taking hot baths/showers, applying shea butter, and coconut oils; (g) listening to music and watching wrestling; and (h) massaging, yoga, rest, and religion especially prayers. SP2 stated being

very successful with alternative treatments especially diets, less stress, staying hydrated, and rest. SP2 recommended more African foods. SP2 stated, “I always encourage as much natural treatment as possible before making opioids an option.” Both SPs5 and 6 claimed that they have not tried any other regimen. SP5 mentioned not yet trying out any other regimen due to not having used nonpharmaceutical medications before. SP11 admitted to giving chlorophyll to her two sons with SCD, and it has been very effective as it helps by increasing blood level and the formation of new hemoglobin cells which may reduce or get rid of sickled cells. It was observed that educational level played a major role in the participants’ experiences and readiness to explore alternative treatment options as most of the participants who were in support of using alternative interventions were mostly of higher educational levels (graduates) with most of them confirming that they do their own research on alternative therapies that offer better treatment options. It was also observed that these participants have better control over their condition.

Theme 3: Type: Coping Strategies/Other Regimens

SP1 declared that her daughter takes hot baths especially at the onset of a pain crisis which she claimed works well and is very effective. SP1 attributed success to saying a lot of prayers, using heating pads, getting a lot of massages, and listening to music as a distraction during pain crisis. SP1’s daughter also uses biofreeze during crisis, and for prevention she uses hydroxyurea and also takes iron vitamins daily. SP1 also talked about praying always for her daughter, which has been very helpful and added “prayers have powers.” SP2 stated discussed using massage therapies including breathing exercises such as yoga, but most of them were not very effective. SP2 added doing these

therapies early before the pain intensifies might help a bit, but if the pain has already intensified, they usually do not work or help. SP2 tries to stay hydrated by drinking a lot of water and staying warm, eating healthful diets, uses prayers, hot pads therapy, music, and acupuncture as well as other pharmaceutical products. SP2 recommended eating African food products (which are mainly plant foods). SP2 stated,

> I pray a lot because if not for God, I do not think I will still be here. Praying has been very effective for me especially during hospitalizations and when my meds are not working, prayers help a lot by helping me to relax and somehow soothe the pain. My sister usually prays with me whilst I wait for a doctor and at times too I get the opportunity to communicate with the hospital chaplain who may at times pay him a visit which is also always helpful. Yes, even at the hospital there is always a chaplain to pray and counsel me which helps to release fear. I also always try to avoid stress, a major trigger for pain crisis.

SP3 asserted that staying hydrated is beneficial. SP3's daughter drinks more water, 100% juices, and smoothies which includes adding vegetables without her knowing it. SP3's daughter eats healthy and balanced diet (fruits and veggies) especially diets high in iron, takes nutraceuticals/ vitamins such as omega 3 daily, and practices skin care by applying skin moisturizers like shea butter, coconut lotions, and creams after showering and washing hands and face. SP3 also added, "I do pray. I believe God can work through the doctors, but they would have to care about their patients first." SP4 also affirmed using or applying shea-butter on his son's body daily especially during pain episodes because shea-butter has anti-inflammatory properties. SP4's son also drinks

chlorophyll liquid daily (purchased from Amazon) because it increases the oxygen level. SP4 also always uses an air purifier in the child's room so to ensure the optimum or maximum amount of oxygen. SP4 also believes in prayers which seemed to help a lot.

SP5 uses massages with hot water and application of hot ointment at the joints with pains, drink lots of water, eats hot foods always, and avoids stress and fatigue. SP5 also takes folic acid, Vitamin B complex, motivite, zincovite, and ibuprofen. Concerning employing religiosity however SP5 stated, "I do not believe it…superstitions." SP6 claimed they currently do not use any alternative therapies at home but daughter plenty of water to ensure hydration. When that does not control her pain, then they head to the emergency room. SP6's daughter also takes hydroxyurea daily to suppress pain crises and prevent infections. SP6 stated, "I do think religion and spirituality play an important role regarding the impact on managing pains." They have been using prayers and confiding in spiritual/religious leaders. SP7 employs distraction by watching wrestling which helps her son to calm down during crisis and incorporates massaging, hot pads, and listening to soft music. SP7 also depends on and always call their Pastor and his wife and church elders to pray with/and for them during crisis. However, she felt, "Prayers are not effective because they do not make the pain go away." SP8 eats more fruits, vegetables, and herbs such as lemon and avocado. SP8 maintains a diet low on peanut and meat because of the high oil content. SP8 employs prayers and fasting which due to the claim it helps with detoxification of the body. SP8 also drinks mainly alkaline water especially when taking medications and uses the Kangen machine that sieve/filter the water which increases the pH level to that of alkaline. SP8 has drank alkaline water for the past 15

years and claimed it has been very effective and believe has contributed a lot to the current improvement or good health. SP8's last pain crisis that resulted in a hospitalization and a blood transfusion was in 1994.

SP9 rests by sleeping more at times, employs massaging with hot ointments like Bengay or warm cloths, prays a lot, and engages in some religious activities which includes going to church or consulting with a pastor to pray for her daughter. Faith has played a major role, including using distractions, and eating healthy.

SP10 employs rest, drinking water, applying heating pad, and using aromatherapy with essential oils with a diffuser as it helps with relaxation and to not think about the pain. SP10 also takes multivitamins, folic acid tablets, and uses Epsom salt. SP11 also gives chlorophyll liquid to her sons which helps increases the blood level, helps form new HgB, and may reduce or get rid of sickled cells. SP11 consults/confides in spiritual/religious leaders during crisis and relies on her Christian faith.

Theme 4: Effectiveness/Efficacy, Safety/Side Effects, Cost/Affordability

The effectiveness/efficacy, safety/side effects, and cost/affordability are some of the factors that participants consider before they employ/explore a regimen. Overall, there was no serious side effects reported for any of the other remedies, but the possibility of side effects were the main reason most of the participants were skeptical in trying other or new treatment options. SP2 declared being open to alternative treatments but usually request about side effects. SP3 talked about loving and using a lot of natural treatments (produce) but thought they should be used only in extreme cases and if it there are no other options. SP2 elaborated that lots of treatments have side effects and destroy

vital organs like the liver. SP2 maintained that alternative treatment options are effective, but they come with a price and side effects. SP5 declared that some of the alternative regimens really help because constant intake of them (folic acid, Vitamin B complex, motivite, and zincovite) help to boost the immune system that will eventually produce good red blood cells in the blood without it being sickled or curved which apparently helps in reducing the number of pain crisis. SP9 also asserted that most of the alternative regimens can be very effective as they may offer better treatment options such as reducing the frequency or intensity of pain crisis. SP10 discussed being open to new therapies if they are safe to use in the body and had the perception that they are not very effective.

Research Question 3

RQ3: What is the stage of readiness for adopting alternative treatment methods for members of the SCD patients or parents/caretakers? Almost all of the participants were open to exploring alternative regimen but few thought there was no need for change or try new treatments if what they are already using (opioid analgesics, etc.) are working. Themes developed were:

- participants' perceptions
- resistance to change

Theme 1: Participants' Perceptions

The majority of the participants expressed an interest in trying new therapies and contributed diverse views to that effect. SP4 embraces any treatments that are evidence based. SP5 supported the use of using other treatment methods to curb pain crisis. SP5

stated, “Well, I will promote any new therapy positively if it is approved by food and drugs authority and if the aim in which it was used will be achieved. Purposefully!” SP6 recommended that SCD doctors/nurses should be willing to try new/other therapies so there can be many options available for different families and their choices. SP8 maintained that alternative treatments are very important and must be encouraged as due to drastic improvement of his health and overall living conditions since starting to eat healthy and drinking alkaline water. SP9 thought SCD HCPs should try other options like diets, nutrients, hot pads, massaging, prayers, and others that can also help with managing pains and may even possess the potential to reduce the frequencies of pain crisis. SP9 stated, “Alternative treatment options should be promoted since there is still no cure that works for all patients.”

Theme 2: Resistance to Change

Some of the participants seemed to be at the contemplation stage of the TTM and though claimed to be open to using alternative interventions, they still did not see the need to stop or switch from opioid analgesics as it works perfectly for them. SP1 claimed being open to other options but expressed hesitation to change when the one you are currently on is working. SP7 also claimed to be open to other regimens but did not deem them necessary for her son now due to medications or treatment plans (opioid analgesics) her son is on are working pretty well. SP7 added, however that may be in the future when her son gets older, and there is the need to explore other options they will then do so. SP7 felt that is a decision that her son needs to make himself so they will continue with the current treatment until her son gets older to make his own personal decision about

preferred regimens to use. SP11 asserted that there is no need to change or stop the current treatment regimen due to opioids such as morphine and hydrocodone working. SP11 added that blood transfusions are effective because they increase the blood level and help patients get better as they may get rid or reduce the production of sickled cells, but they have the side effect of iron overload.

Research Question 4

By addressing RQ4: How does disease perception among SCD patients/caretakers impact their willingness to try alternative treatment methods? Almost all of the participants claimed to have a pretty good knowledge of the disease including its signs/symptoms and some of the associated comorbidities which influences their choice of treatment options. Some of the themes that emerged under RQ4 were:

- knowledge/awareness/ confidence in managing pains
- ideal treatment
- research
- education/creating awareness

Theme 1: Knowledge/Awareness/Confidence in Managing Pains

Most of the participants claimed having an awareness of symptoms, increase in self-confidence, and improved knowledge on signs and symptoms as well as the proper management of pains. SP1 discussed having a pretty good knowledge about the symptoms of SCD. SP1 felt her daughter's HCPs are also very knowledgeable or understand the condition very well. SP1 felt very confident in managing her daughter's chronic pains from day to day. SP2 talked about being confident in managing pains

which affects his concentration especially during classes and easily causes him to be angry at onset of crisis. His HCPs are pretty knowledgeable about SCD and always discuss with and prescribe alternative medications although they are also concerned about the possibility of polypharmacy with the numerous medications they keep prescribing for him to help keep his pain crisis and condition under control. S6 declared that her daughter's HCP understands her daughter's condition well and is always researching new techniques and treatments. Though she claimed to know her daughter's symptoms (and gave few of them (pain in her arms, legs, chest, and stomach), she also stated that she does not have the confidence to manage her daughter's pains and uses whatever her HCP recommends or prescribes for her. SP7 claimed to be pretty confident with managing her son's pains after joining a support group because she used to feel very lonely and scared with no one to relate to. SP7 stated it is now better due to having gained enough knowledge about the disease after joining the support group as they are always sharing diverse information and resources including effective pain management strategies.

Theme 2: Ideal Treatment

Participants offered various views on what an ideal treatment should be which included treatments that are safe, capable of preventing or eliminating pain crisis, easy to administer or use, less invasive on organs, have no or less side or adverse effects, and are affordable. SP1 wished for a medicine that will eliminate pain crises. SP3 wished for a treatment that will help save patients' eyesight, a common complication for SCD patients and ways to deal during times of an epidemic and flu season. She added, "Flu shots can sometimes make them sick." SP4 claimed that gene therapy currently being employed

now as a cure for SCD involved using inactive HIV cells and also ends up wiping out the immune system which renders it unsafe and thus wishes if another mechanism can be developed that would be less invasive on organs with no or less side or adverse effects. SP6 hoped for a treatment that is able to manage pain crisis more effectively at home. SP9 wished for a treatment capable of curing or eliminating SCD and its associated complications entirely that are affordable and feasible/conducive. SP10 wanted treatment that is easy to administer at home and convenient. SP11 hoped for an interdisciplinary transitional team including a pediatrician and an adult SCD HCP team for patients as they transition to adulthood due to that being the stage most patients encounter most complications due to lack of adult SCD HCPs.

Theme 3: Research

Participants requested for more research to be conducted about SCD for the appropriate treatments to be developed for its management. SP2 suggested that more research is really done about the source of the pain so that they can tackle the problem from its source and produce medications to that effect. SP5 also proposed that there should be more research on other alternatives.

Education/Creating Awareness

The majority of participants stated that they do not think their HCPs are that knowledgeable about SCD and really understand the caliber of the SCD pains which tend to influence their prescribing habits or decisions by often under prescribing for its management and may also seem to lack knowledge or awareness on alternative therapies. Some of the participants recommended for the need for their HCPs to be educated on

SCD and alternative remedies or interventions. SP2 maintained that most none SCD HCPs have little knowledge on SCD and this makes it worse during hospital visits and requested for a better communication system between patients' SCP practitioners during hospitalization especially on treatment options. SP3 suggested,

> Schools should have a partnership with SCD treatment centers just in case of a crisis at school or for information and that teachers treated my daughter like she was diseased for the longest until I told them what it was she has.

Thus educational personnel also need to be educated on SCD and the necessary steps to take when a student is going through pain crisis during school hours. SP4 claimed HCPs have less awareness about alternative therapies for SCD. SP11 attested to this fact and declared that "HCPs tend to prescribe certain type of meds due to lack of knowledge in the disease and other meds all because of lack of education." SP11 thus recommended for HCPs to be educated more on the disease and diverse treatment options.

Evidence of Trustworthiness

Connelly (2016) described trustworthiness or rigor of a study as the degree of confidence in data, interpretation, and methods used that guarantees the quality of a study. Amankwaa (2016) also asserted that for a study to be considered credible, researchers need to establish the protocols and procedures used for the study. Elo et al. (2014) inferred that it is "imperative to scrutinize the trustworthiness of every phase of the analysis process, including the preparation, organization, and reporting of result which gives a reader a clear indication of the overall trustworthiness of a content analysis

study" (p. 1). By employing these guidelines, much work and efforts were taken to plan or prepare and execute each stage of this study starting from the choice of study methodology and analysis plan, recruitment of study participants, data collection, compilation and processing, data analysis, and reporting of the study designs. Care was taken to guarantee that all the necessary details and relevant data or information gathered were reported and presented in a systematic order. According Elo et al., a prerequisite for a successful content analysis is that the data can be reduced to concepts that describe the research phenomenon by creating categories, concepts, a model, conceptual system, or conceptual map. Thus, by following these suggestions the data collected were all subjected to a number of steps of coding from which categories and themes were developed and finally organized or grouped into the concepts based on the conceptual framework, biopsychosocial-spiritual model of chronic pain proposed by Taylor et al. (2013) and illustrated in Table 3. The necessary criteria required to guarantee trustworthiness which are credibility, dependability, confirmability, transferability and authenticity were applied to this study.

Credibility

Credibility is considered as the most important criterion and is described as the truth of the data or the participant views, the interpretation and representation of them by the researcher (Cope, 2014; Polit & Beck, 2012). According to Cope, when a researcher describes their experiences and verify the research findings with the participants, the credibility of the study gets magnified or better. Several steps were taken to achieve credibility. Though I had a bit of shortcomings as my data collection was done solely

virtually, I did not distance myself from the entire process but saw to it that I was personally and actively involved in all the stages from the recruitment stage to the reporting. I recruited mostly by posting the recruitment flyers in support groups on Facebook and sending the flyer to all my contacts through texting and e-mail. I also reached out to the leadership of the groups through email mostly establishing a relationship and building a rapport with them. Some of them volunteered to be study participants themselves and also recommended specific participants based on their conditions when I decided to incorporate snowball sampling. When I noticed that my data were getting skewed as almost all the participants were basically of the SS-type; I reached out to some of the leaders and one gave me information about some of their group members who have the SC-type. Though not all the leads provided agreed to participate in the study, one of these members became one of my best participants, a parent with two SC-type patients who provided so much information that could not be obtained from just any literature review. I also created a rapport with the participants who responded to the recruitment advertisement. Apart from emailing the consent forms and questionnaire to them, I also sent personalized emails which made them feel comfortable and made it easy for us to communicate including participants easily reaching out for clarification as often as they had questions they needed clarification on. The phone interviews were conducted professionally. I saw to it that it was not done rigidly but always created this relaxing environment or mood, rendering them more like conversations which made the participants more relaxed and enabled me to gain their trust. Almost all of them felt so comfortable and opened up providing more detailed

information than I expected. Therefore, almost all of the phone interviews surpassed 1 hour instead of the 45 minutes averaged interview time allotted to each participant. I employed member checking frequently during the interview process especially with salient points that I wanted to get right and any new information learned during the interview. I often summarized points and restated them as I understood them which gave participants the opportunity to make the necessary corrections or additions when needed. I also incorporated member checking with the participants who answered the questionnaire independently by reaching out to them for more information or clarification on any. However, not all of the participants responded to my emails when I reached out for more information or clarification of a response which proved to be a major setback of the study.

I also incorporated audit trails into the study. Cohen and Crabtree (2006) defined "an audit trail as a transparent description of the research steps taken from the start of a research project to the development and reporting of findings and are records that are kept regarding what was done in an investigation"(p.1). As proposed by Cope (2014), credibility is strengthened by the researcher when reporting a qualitative study by demonstrating their engagement, methods of observation, and audit trails.

Dependability

Polit and Beck (2012) described dependability as the constancy of the data over similar conditions. This can be observed when another researcher concurs with the decision trails at each stage of the research process or if the study findings were replicated with similar participants in similar conditions. Dependability was portrayed in

this study by the similarities observed in some of the alternative treatment options like the natural regimens and coping strategies participants have used for pain management.

Confirmability

According to Cope (2014), confirmability refers to how the researcher is able to prove that the data collected is a true representation of participants' responses and not the researcher's biases or viewpoints and depicts that the findings were derived directly from the data which can be portrayed by providing rich quotes from the participants that depict each emerging theme. This principle was applied when reporting the study results or findings by using significant statements or direct quote from participants based on the emerging themes.

Transferability

Cope (2014) described transferability as the ability to apply study findings to other settings, groups, or individuals not involved in the study to enable readers to associate the results with their own experiences. Transferability is portrayed in this study by the similarity of the experiences with alternative treatment options among the study participants even though the participants were from five different states. This demonstrates how readers and individuals from other states not represented can easily relate to the experiences of the study participants. However, it was revealed through the participants that location plays a major role in the kind of health services that patients received as well as the level of knowledge of SCD HCPs which may also influence the treatment administered. For instance, SP4 declared that her son's condition improved when she relocated from New York to Virginia because of how well the SCD community

is handled there in terms of health services and support. SP11 asserted that a support group in Virginia advocated for the SCD community to be exempt so that HCPs would be able to prescribe as much as opioid analgesics for their patients as they required without any restrictions. SP2 who is from Texas also maintained that the kind of treatment or health services offered are based on location of the health care facility. Since Houston is very good in the level of services as compared to Dallas and may even offer psychological services to patient when needed, SP2 relocated from Dallas to Houston. SP3 who also relocated from Virginia to South Carolina strongly attested and stated,

> In South Carolina the hospitals do not know sickle cell disorder well and send my daughter home with fever and pain. In Virginia it is way better first in and recovery time is a lot shorter. Doctors in South Carolina do not treat sickle cell well here. They usually do not try to keep her healthy as possible.

Authenticity

Cope (2014) declared that "authenticity is the ability and extent to which the researcher expresses the feelings and emotions of the participants' experiences in a faithful manner by adopting a descriptive approach through which readers grasp the essence of the experience through the participant quotes" (p. 1). Once again, authenticity of the study findings was also depicted by using significant statements or direct quotes by study participants when reporting the study results and throughout the entire data analysis.

Summary

The purpose of this qualitative study was to explore the experiences and perceptions of patients and parents/caretakers on alternative treatment options for SCD pain crisis management with the intent of decreasing SCD patients' dependency on opioid-base or related analgesics. Due to COVID-19, data collection was strictly virtual with most study participants recruited through social media platforms such as Facebook and Whatsapp for some SCD support groups and also through snowball sampling. About half of the participants who contacted me expressed their interest to participate after seeing the recruitment flyer on social media. The data collection format or process occurred in two categories: (a) independent completion of the interview and (b) a phone interview. Six participants opted to do the interview independently and requested for the questionnaire to be emailed to them while the remaining five participants opted for phone interviews. I sent consent forms to the participants via e-mail or text message. Consent was required before they were allowed to participate. The interview responses reflected the participants' level of understanding and knowledge on SCD which was also positively correlated with participants' educational level.

I employed the code and code technique to perform a thorough data analysis of the data collected. Overall, about 15 emerging themes were developed under the overarching theme alternative treatment options based on participants' responses. The majority of the participants declared that they are aware of alternative treatments or interventions and expressed interest in exploring such interventions. However, participants' interest to try alternative interventions especially nonpharmaceutical

products or options were more influenced by their perceived susceptibility to SCD, perceived knowledge on the seriousness of the disease, perceived benefit of the alternative remedy, and perceived barriers to that intervention as proposed by the HBM. For instance, participants were more concern about effectiveness, side effects, and at times cost before they tried an alternative treatment option.

Though the majority of the participants claimed they were open to alternative interventions like self-care management, natural remedies, and other coping mechanisms, some of them were still at the contemplation stage as they considered the effectiveness/efficacy and safety of these alternative interventions while some resisted to change with the claim of their current treatment plan (mainly opioid analgesics) being effective. The other group of participants exhibited readiness to change and were even already using some form of alternative therapy or intervention (self-care management, various forms of coping strategies, and religion). Concepts developed were based on the conceptual framework – the BPS-spiritual model by Taylor et al. (2013). A summary of participants' responses based on the themes developed were presented in detail in this chapter. In Chapter 5, an interpretation of the study findings, limitations of the study, recommendations, and social change implications will be discussed.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This qualitative case study research was conducted to examine SCD patients' or their parents/caretakers' experiences and perceptions regarding exploring alternative therapies or interventions for pain management aside from opioid analgesics. The utmost objective of the study was to learn about some of the alternative treatments that participants had used or were using that had been effective in managing their pain, including their safety, availability, cost, and transferability, among other concerns. The case study approach was employed to help answer the research questions. According to Hyett et al. (2014), "Case studies are designed to suit the case and research question" (p. 2). Content analysis was used in the data analysis". As Soroko and Dolczewski (2020) wrote,

> Content analysis is systematically applied when describing qualitative data with the use of rule-bound procedures and human-generated interpretation and may include identifying patterns in data and in categories for explanation purposes and relational context obtained from reflection on coding as a human process. (p. 1).

Chronic pain is the hallmark of SCD and a major challenge for SCD patients and their families that usually impacts their QOL or living standard. Benjamin (2008) asserted that though SCD patients are living longer now, their lives are impacted even more by unpredictable intermittent or constant pain that is often poorly managed over a lifetime. Benjamin (2008) claimed that pain management poses major public health challenges around the world. Among members of the SCD community, pain management

in the past occurred mainly through palliative care, with providers employing mostly opioid analgesics to help patients relax as they went through pain episodes. With the current opioid crisis, it has become imperative for other treatment options to be explored—hence the purpose of this study. There is a need to investigate means or interventions that can be employed to help alleviate pain episodes associated with SCD and contribute toward improving QOL for patients and their families.

Benjamin (2008) proposed an interdisciplinary team approach that would bring medical professionals together for optimal compassionate care that is coordinated from the beginning of life and throughout the patient's lifespan, adding that the management of pain in SCD has not been approached in a straightforward manner by practicing hematologists, pain experts, or generalists. Taylor et al. (2013) also asserted that chronic pain in adults with SCD is a complex, multidimensional experience that includes biological, psychological, sociological, and spiritual factors, thus affirming the need for an interdisciplinary team approach for its management. These declarations also align with some of the study participants' propositions for alternative therapies or interventions to be incorporated into the orthodox way of managing of SCD pains, which was the goal of this study.

In this chapter, I will interpret the study findings, which I developed after transcribing and analyzing participants' experiences and perceptions regarding alternative treatment options. Additionally, I will present the limitations of the study, recommendations, study implications, and conclusions.

Interpretation of Findings

The research findings make a unique contribution to the literature through the exploration and analysis of SCD community members' experiences and perceptions regarding alternative treatment regimens. Study participants shared their diverse experiences and perceptions related to alternative treatment regimens for managing their SCD pain or the pain of their charge.

The study findings also strongly correspond to findings from previous research studies. Yoon and Black (2006) conducted a similar study to investigate the prevalence and types of both pharmacological and complementary therapies used for SCD pain management by caregivers and explore caregivers' interest in using complementary therapies in the future, presented similar findings. In their cross-sectional, descriptive study of 63 SCD caregivers, Yoon and Black found that the most frequently used pain medications for children with SCD were opioid analgesics such as acetaminophen with codeine and acetaminophen with oxycodone. They reported that more than 70% of caregivers confirmed using some complementary therapies (coping strategies), including prayer, spiritual healing by others, massage, and relaxation, and that most of the caregivers were willing to try various types of complementary therapies for pain management (Yoon & Black, 2006).

Most of my study participants shared their experiences with using diverse natural products in managing pain, with most of them attesting that these products were effective and expressing interest in exploring more of such therapies. Gour et al. (2020) reported,

> In spite of unprecedented advances in modern system of medicine, people in SCD-prone areas have been taking traditional medicinal plants or plant-derived products to increase the life span of patients in addition to the numerous clinical trials that have been going on for the use of natural products and their effect in pure form or characterized phytoconstituents on particularly inhibition of hemoglobin polymerization for the symptomatic management of SCD. (p. 1)

Study participants' verbatim quotes were transcribed from both audio recorded and online interviews and were analyzed individually, with various themes evolving based on the theoretical and conceptual frameworks adopted for this study.

Emerging Themes

Various important themes emerged when the study participants' interview responses were transcribed and analyzed, depicting the numerous coping mechanisms and strategies that they had been employing over the years to manage their pain, as previously discussed in Chapter 4.

Coping Mechanisms

The study participants described the various strategies that had been working for them in managing pain, which included religion, natural products, medicines, and other palliative or coping interventions. The majority of the participants had religious beliefs and had been using various forms of religious practice, especially prayer, during pain crises, which most of them declared to have been very effective and helpful in sustaining them through those moments of distress. SP2 stated,

> I pray a lot because if not for God I do not think I will still be here. Praying has been very effective for me especially during hospitalizations and when my meds are not working, prayers help a lot by helping me to relax and somehow soothe the pain.

According to Bediako et al. (2011), positive religious coping was associated with significantly fewer hospital admissions. SP8, the oldest participant/patient (70 years old), was a former professor at Harvard University who was doing very well and strongly supported using religion as a coping strategy. SP8 went further to suggest that fasting helps to detoxify the body. However, SP7, who declared that she always called on her pastor and church elders to pray for them whenever her son, the patient, was having a pain crisis, insisted that prayer was not effective because "it doesn't really take the pain away." Cotton et al. (2012) maintained that children used religion to gain control, make meaning, and find comfort by praying to get well, to keep from getting sick, and to get out of the hospital as they described a functional God who made them take their medicine or took them to the hospital and an emotional God who made them happy and comforted them when they were sad or scared. Bediako et al. (2011) also asserted that religious practices have both psychological and physical benefits for patients, examples being prayers, meditations, and consumption of religious media which were found to be inversely related to physical health outcomes and patients seemed better adjusted psychologically if they were religious.

Distraction was another major strategy that the majority of the participants attested to have been using during pain crises that helped them to relax and take their

minds off their pain. Examples of distraction strategies were listening to music and watching wrestling.

According to the participants, one of the major triggers of pain crisis is extreme weather conditions, especially cold weather, so most of them had adopted the habit of staying warm by wearing warm clothes, avoiding eating very hot or cold foods, and using hot pads or taking hot showers, especially at the onset of crisis. Dehydration was also recognized as a major pain crisis trigger, so most of the participants declared that they drank a lot of water to stay hydrated at all times. Both stress and fatigue were also considered triggers for pain crises, so the majority of the participants fought stress and stated that they tried to get more rest to avoid developing fatigue.

The majority of the participants used diverse forms of natural products, including nutraceuticals (vitamins, dietary supplements: folic acid, omega-3 fatty acids, etc.), which they took on a daily basis as a preventative measure to either mitigate pain crisis or reduce its frequency and intensity. Some of the natural products that the study participants stated that they had been using were shea butter (because of its anti-inflammatory properties), chlorophyl, everyday fruits and veggies, and alkaline water. According to Ameh et al. (2012), in West Africa where SCD is endemic, the disease has long been treated with natural products such as herbs, especially in rural communities. Based on the findings of a study that they conducted, Ameh et al. reported three new anti-sickling herbs: mahogany (*Entandrophragma utile*), Mexican tea and wormseed (*Chenopodium ambrosioides*), and Guinea henweed (*Petiveria alliacea*). Mahogany (*Entandrophragma utile*) is known for treating rheumatism when it is massaged into

affected joints to relieve pain. There is a need for more research on medicinal products that are seen as alternative remedies for SCD pain management and prevention in order to establish their efficacy and safety, as most of the study participants proposed. As SP3 asserted, “I love and use a lot of natural treatments, they are effective but they come with a price and side effects and must only be use in extreme cases and if necessary.”

Medications

It was deduced from the participants’ responses that SCD patients rely on both pharmaceutical and nonpharmaceutical treatments, as well as both prescribed and over-the-counter (OTC) products for either management or prevention of pain crisis. For many years, SCD HCPs have been using mostly palliative care to manage pain. Painkillers—primarily opioid analgesics such as Tylenol with codeine, morphine, and oxycodone—are the most common medications that the participants stated that their HCPs usually prescribed for pain management. Sadler et al. (2019) maintained that “opioids are the main therapy for both chronic “steady state” SCD pain and acute pain that results from vaso-occlusive crisis but they are often ineffective at fully alleviating pain, are associated with unwanted side effects, and do not target the underlying pain mechanism thus supporting the need for new pain therapies to be employed for SCD patients” (p.1). Most of the participants in the current study, however, deemed these opioid analgesics to be very effective and necessary for SCD pain management and recommended that HCPs continue to prescribe them. The participants thought that HCPs choose to prescribe opioid analgesics over other potential medications because opioids are effective, are fast acting, and help to alleviate pain quickly.

"SP1 maintained that there is no need to change because the opioids works." However, she thought that alternative regimens are also necessary because patients should have a lot of options to choose from to support their well-being. SP2 stated that because pain is the mainstay of SCD, pain medications remain necessary. SP7 declared, "Opioids are very effective because I have been using it personally for years." SP11 asserted that there is no need to change the practice of prescribing opioid painkillers because these medications work, especially morphine and hydrocodone. Nonetheless, the Office of Disease Prevention and Health Promotion (n.d.) maintained that,

Opioid therapy should be delivered in the context of multimodal care and that physicians should consider additional treatment options as opioid therapy have some minimal benefit that can be augmented or maximized in the context of other therapies, stress reduction or emotional or behavioral strategies.

There were other medications that participants stated that their HCPs had been prescribing to control their pain; examples included NSAIDs such as ibuprofen and neuropathic pain drugs such as gabapentin and Lyrica, among others. Jadenu was another medication that some of the patients were taking to prevent iron overload caused by blood transfusion.

The majority of the patients were taking hydroxyurea to prevent or to reduce the frequency of pain crises and attributed the reduction in their pain episodes to the medication. However, one patient who claimed to have been using hydroxyurea for 4 years said that it increases the chance of getting infections. Further, he stated that because hydroxyurea is supposed to be a chemotherapy drug, it was affecting his hair growth and

reducing his appetite. SP11 also confirmed that hydroxyurea causes hair loss. In contrast to these claims, another parent claimed that hydroxyurea helps to prevent infections.

None of the participants indicated using any of the newly approved medications. "SP11 stated that several patients complained how most of the new meds (adakveo and oxbryta®, etc.) are not effective, especially an infusion drug and that each drug works differently for each patient." She added that the dosage forms for some of the new drugs deter patients from taking them. For example, she explained, "Endari is a vitamin in a powder form that needs to be dissolved in water so most patients don't like it." Finally, she stated that the high prices of these new drugs discouraged many parents from seeking prescriptions for them, declaring, "We cannot afford new meds, especially Endari she declared."

The majority of the participants confirmed that they used various OTC medications, mostly vitamins. In particular, they claimed that folic acid helped them manage and have an upper hand on the disease. Overall, there were no serious side effects reported for any of the medications. Nevertheless, the possibility of side effects was the main reason that most of the participants were skeptical about trying other or new treatment options.

Concerning whether SCD patients abuse prescription medications, most of the participants declared that this perception was simply the result of stigma. The majority of the participants did not think that SCD patients abuse prescription medications. SP11 claimed that it is "a stigma because of race. SCD patients are usually accused of abusing meds," adding that "no SCD patient has ever died of overdose of pain medications."

Rather, there was a notion among some of the participants that patients may be compelled to take more of their prescribed medications because SCD HCPs seem not to understand the extent of SCD-related pain and therefore tend to under prescribe for their patients, confirming the findings of previous studies by Booker et al. (2006) and others. Labbé et al. (2005) asserted that many physicians believe that SCD patients are more likely to become addicted to pain medication than are other patient populations and that these attitudes affect their pain management practices, potentially leading them to undertreat their patients' pain.

Support Systems

As asserted by Telfair and Gardner (1999), not many studies have been done on the impact of support groups on the psychological well-being (PWB) of adolescents with SCD. In a study with 99 African American adolescent SCD support group members, Telfair and Gardner found that PWB was best predicted by fewer physical symptoms and greater satisfaction with the group. Their study also revealed that belonging to or having a form of support system plays an important role in the management of SCD-related pain.

Most of the participants in my study belonged to a support group or had a support system. Often, their support systems involved family members as well as leaders and other members of religious/spiritual communities, on whom they could lean during times of crisis and consult for information and resources. One parent stated that she used to feel very lonely and unsure of herself, but since she had joined a support group, she did not feel like that anymore; she felt more confident, especially in managing her son's pains and in handling related issues. Another parent who happened to be a leader of a support

group also claimed that when it comes to emotional or psychological issues related to SCD, most patients prefer to turn to their support group for help instead of their HCP team. Telfair and Gardner (1999) detected an interaction effect between pain and group satisfaction. These authors claimed that "support groups have the potential to mitigate the detrimental effects of living with a chronic disease among adolescents, especially during times of acute pain and thus proposed health professionals should be encouraged to promote the active involvement in support groups to adolescents with SCD and other chronic conditions" (p. 7).

However, one patient stated that he does not like joining support groups because being around other SCD patients negatively impacts him; it usually makes him more depressed so he depends solely on his family especially during crisis. His family and at times hospital chaplains usually pray with him during hospital visits and when his medicines are not working. SP3 stated that her sister, a surgical technician and her daughter's father, who is also a patient, are all she has when it comes to getting the care and support she needs as they help her with transportation and advice during a crisis. SP6 declared that her daughter has "an amazing support system which includes her family, friends, school community, and church community and thus they never feel like alone in this battle and most of them are learning about the condition but for the most part they're pretty knowledgeable." She added that her family relies on each other when anything is needed and that includes childcare for her other child or transportation. SP7 belongs to a SCD support group who shares information and provides support, care, and experiences and who also have prayer sessions on every Sunday. She also relies on her pastor, his

wife, and leaders from church who pray with them whenever her son is having a crisis. SP11 who is one of the founders of a support group in Virginia stated that they decided to start this group because initially there was no support for parents and some of the services they offer to members include education, advocacy, and support on a financial level even to the extent of paying for rent and groceries when needed, technology, plan of care, provide supplemental income, emergency COVID assistance, and many other services. The support group operates on grants from Virginia Commonwealth University , and there are different organizations that also offer help to the group including the Global Blood/Drug Therapeutic (GBT).

Education/Creating More Awareness

According to Chakravorty et al. (2018), depending on the findings of a study conducted, there is a widespread prevalence of poor knowledge about SCD among healthcare providers and the public reported a poorer experience of care in the emergency setting compared to planned care, which lacks timely provision of pain relief. According to SP2, HCPs who are SCD specialist seem to be knowledgeable about the disease but when he is hospitalized, it seems most of the non SCD HCPs are not that knowledgeable so they always have to contact his specialist for help. He suggested that every hospital should try to establish an effective means to communicate better with their patients' SCD specialists. Thomas and Cohn (2006) agreed that the use of good communication skills by healthcare professionals is vital for good healthcare practice and proposed the need for training in communication skills and cultural awareness for HCPs in SCD which may have a positive and enduring impact on professionals' perceived ability and confidence in

communicating with patients with SCD. SP3 also declared that SCD HCPs are knowledgeable about the condition but because of racial disposition of most patients being African American and poor, they are inclined to adopt a certain attitude (not caring that much) toward their patents. SP11 also affirmed that HCPs do not show care or concern especially the mental health or status are not well addressed on such issues like depression. anxiety due to the fear of the disease is the reason most of the patients turn to or rely on support groups. Chakravorty et al. (2018) declared that SCD adolescents and young patents reported significantly poorer experience of care in several domains compared to children or adults according to their study findings. Thomas and Cohn (2006) also affirmed that many SCD patients felt that they were negatively labeled by the health care system and are skeptical of opening themselves to an unsympathetic system and may therefore appear hostile and aggressive when interacting with health care professionals, which in turn leads to distortions and misunderstandings between both groups. These authors thus maintained that training especially in communication skills and cultural awareness for HCPs might be helpful in reducing mistrust and result in increasing empathetic responses among health care professionals. Chakravorty et al. (2018) asserted that understanding patient views of their care experience is not optional but essential to ensure effective delivery of health care and may lead to a better patient experience which would be associated with improved treatment adherence, better use of preventive services, and healthcare utilization.

Nevertheless, SP11 strongly believed that SCD HCPs are not well educated on the disease stating how some practitioners even refused to treat SCD Caucasian patients

because they do not believe they have the disease. She maintained that HCPs lack knowledge about the disease and other medications aside from opioids all because of a lack of education. SP11 requested the need for more HCPs to be educated on the disease. SP2 rated the level of the knowledge of HCPs in SCD to be about a level of 7 and added that HCPs treat all SCD cases the same irrespective of the differences in disease types as they do not try to tailor treatments based on the type or conditions of the patient. Smith et al. (2005) proposed that the main reason for the poor understanding of pain in SCD is that adult SCD is a new "epidemic," that is poorly described epidemiologically. According to these authors, in the past, the estimated median survival for patients was 20 years, so treating the pain of SCD was primarily left solely to those caring for children (pediatricians) but with important advances in treatment options such as prophylactic penicillin for children, mortality rates in children have drastically decreased with median SCD survival now stretches well into the fourth or fifth decade (Smith et al., 2005). This has resulted in the relatively new phenomenon of adults with chronic SCD and adult medical professionals treating pain in a disease for which they have limited training and experience. SP11 asserted that most SCD patients die during the transition years due to lack of qualified SCD HCPs so young adult patients tend to rely on non SCD HCPs. Thus, for an ideal treatment, SP11 wished for a transition team including both a pediatrician and an SCD HCP adult team that works together. Consequently, Labbé et al. (2005) proposed that physicians might benefit from additional education regarding SCD, addiction to pain medication, the pharmacology of opioids, and the assessment and treatment of pain.

Limitations of the Study

There were several limitations encountered during the study partly due to COVID-19. First of all, the sample size of only 11 study participants was small even though saturation was achieved, and the participants were spread over about five states which reinforced the generalizability of the study findings. A larger sample size would have been more beneficial as that would have increased the opportunity of gathering more diverse experiences and perceptions from a larger spectrum and thus enriched the study findings more. Secondly, because of COVID, almost all of the study participants (about 65%) were recruited virtually by posting the study recruitment on some of the popular social media platforms such as Facebook, and others through snowballing. There was no prior relationship with participants which affected the communication or rapport with some of them. More time was needed to build a relationship and establish rapport with some of the participants which involved communicating with them several times through e-mail, text, and phone calls to gain their trust and confidence before they committed to participate in the study. Time was also a major constraint due to the different time zones because of the different states participants were located created a bit of confusion and resulted in missing some interviews, rescheduling, or getting participants to commit to another interview time. This also presented with another challenge such as participants' availability for phone interviews and having to resort to online interviews which lacked personal touch or rapport with participants.

About 45% of the participants opted for online interviews which negatively impacted the member checking process as some of these participants after submitting the

interview questions did not respond to any follow up emails or text messages sent to them for clarification or verification of their responses. Also, only about 37% of the participants were patients while the rest were mostly parents/caretakers so their experiences with the SCD pains and hence their management were "secondhand" as compared to patients sharing or narrating their own experiences. All SPs were all Africans/Africa Americans. no other ethnicity responded which may impact generalizability of findings due to cultural differences. Also, all the SPs also have only two types of SCD: the SS and SC, none of the other types (like the Beta-thalessemia etc) responded so may affect generalizability.

Recommendations

Based on the study findings and participants' responses to the interview questions, the following recommendations ensued. It was detected that most of the participants are already using some form of alternative treatment or expressed their interest in them. Nevertheless, they were skeptical and concerned about their safety and efficacy. Thus, it is recommended that more research should be done on these alternative remedies to guarantee their efficacy and safety. According to SP3, alternative remedies are effective but comes with a price and side effects. She stated, "Lots of treatments have side effects and tax vital organs like the liver" and thus was reluctant to recommend them but agreed that they should be used in extreme cases if there are no other options. SP2 declared being open to alternative remedies but usually requests about side effects while SP5 also asserted his support for them but recommended for more research to be done on these other alternatives.

This study targeted mostly patients and parents/caretakers as the study participants and deemed it imperative to allow SCD HCPs which would include physicians, nurses, nutritionists/dieticians, pharmacists etcetera to also express or share their perceptions and experiences on employing alternative treatments for SCD pain management. Also, with this popular notion among the SCD community that the HCPs lack knowledge on the caliber of SCD pain and hence its proper management especially with other treatment options aside from opioid analgesics, it would be appropriate if a similar study can be conducted with HCPs as the target population is geared toward creating awareness or educating them. Thus, I highly recommend further studies on exploring alternative treatment options for pain management purposely for HCPs. Study participants also requested various ideal treatment options and education for other stakeholders. For instance, SP3 recommended that schools should have partnerships with treatment centers for when SCD patients experience a crisis at school or just for information. She stated how teachers used to treat her daughter "like she was diseased for a long time until I told them what it was…" thus emphasizing the need to educate teachers or educational professionals about SCD. SP7 declared that her son's school has the 504 Plan for his school district so teachers are aware and send his work, and he can take makeups of tests when he misses school during crises. Some patients also requested for education on how to properly manage pains especially at home. SP6 requested for training in order to be able to manage pain more effectively at home. According to Dampier et al. (2002), "Recurrent acute pain from SCD can be successfully managed at home with appropriate training and supervision and suggested several areas for

intervention to improve patient outcomes" (p. 1). Also further studies, preferably a quantitative study to analyze the effectiveness of these alternative treatments specifically in managing and reducing frequency of pain episodes would be in order. Thus, document the numerical effects or impacts of such therapies on SCD pain management.

Implications

Positive Social Change

One of the main objectives for undertaking this study is that the study participants shared their experiences and perceptions would contribute toward improving the health status, living standards, and life expectancy (quality of life, QoL) for SCD patients and their families. Osunkwo et al. (2020) asserted that "the most common patient treatment goal is to improve QoL as SCD places a significant burden on patients, mostly or highly impacting patients' QoL, emotional wellbeing, the high prevalence of self-reported VOCs and other symptoms." (p. 1). Pain crisis in general has a negative impact on SCD patients and their parents. During a crisis especially if it results in hospitalization, school-aged patients and their parents and adult patients all end up staying away from or losing school and working days and even at times lose jobs respectively. This and all the financial requirements that ensue due to the crisis can easily lead to financial difficulties for the patients and their families.

Pain crisis is also associated with fear, stress, and distress and negatively impacts the emotional and mental health of both patients and their families. SCD patients especially the children generally have very restricted social lifestyle and are not able to

participate in so many normal or everyday activities such as playing outdoors, exercising, or engaging in strenuous activities, etc. SP4 stated that her son is not able to go school or go out to play during a crisis, and generally has a less social life, etc. Edwards et al. (2005) declared that because of the chronic nature of SCD which is associated with frequent hospitalizations due to the pains and other medical management, it can contribute significantly to impaired psychosocial functioning, altered intra- and interpersonal relationships, and reduced quality of life. SP2, a 23year old male patient reported how he has never been able to have a job or work and also the challenges he is having in staying at school because of the frequency of his crisis and hospitalization. At the time of the interview, SP2 now a college student failed some classes because he was hospitalized during the school year several times and was in the process of getting a deferment from the school but sadly the school authorities were not being cooperative. Fortunately, I was able to introduce him to a support group in his state who is now helping him with the necessary steps to take to be able to get the deferment from his school and also will get the chance to do some volunteer work, etc. According to Fuggle et al. (1996), SCD pain can result in over seven times increased risk of not attending school and is highly disruptive of social and recreational activities. Barbarin and Christian (1999) asserted that "there is a high evidence for claims of social deficits among adolescents and depression and work-related problems among the adults" (p.1). Barbarin and Christian (1999) also proposed that the "social context of SCD, such as issues related to socioeconomic status (SES), urbanicity, ethnicity, cultural values, and racial stigmatization, are important to include in empirical assessments and theoretical

analyses of the effects of SCD on children and their families" (p. 1). In the nutshell, SCD pain crisis affect the socio-economic status of the patient and their families and thus their QoL. As depicted by the data collected, majority of the participants (about 73%) considered themselves as of the low SES with an average annual household income level of about $25, 000 dollars. Henceforth, any alternative treatments, interventions, or coping mechanisms which especially have the capabilities of reducing the frequency of pain crises, hospitalizations, and associated complications and enhanced the social life and mental health would be very welcoming and helpful as it can effect positive social change to the SCD community by enhancing QoL.

It is expected that the results from the study, once published would also aid to better inform and educate HCPs about the SCD pains, its proper management, and evidence-based alternative regimen or coping mechanisms (both pharmaceutical and non-pharmaceuticals products; prescribed and non-prescribed medications) with the potential to offer better pain relief that participants and other stakeholders are using that they can also incorporate into their practice. Alsayegh and Mousa (2020) claimed the new and recently approved therapeutic agents for SCD should be used alongside with the available therapies with potential antiviral activity and must be considered as part of the management and classical treatment of SCD with COVID-19 for better outcomes. These authors proposed that this would be of benefit to busy HCPs until evidence-based management recommendations become available. The SCD community is considered as one of the most vulnerable communities to COVID-19.

Conclusions

According to the Healthy People (2020), SCD is an example of a genetic determinant of health and described it as a condition that people inherit when both parents carry the gene for sickle cell. Barbarin and Christian (1999) asserted that "although professionals have failed to reach a consensus about definitions of severity in SCD, frequency of pain episodes, hospitalizations, infections, fevers, and swellings are primary markers used to gauge the disease severity" (p. 2). These authors maintained that "SCD is a well-recognized source of distress in the lives of more than 50,000 African Americans and their families that often results in enduring psychosocial dysfunction (Barbarin & Christian, 1999, p. 1). Managing the SCD pain has always being a major challenge for the SCD community. Thus, any interventions that promises better living standards for patients and their families can be deemed as a laudable idea. Consequently, this study was undertaken to investigate such interventions or treatments that can be better choices for managing pain crisis in lieu of orthodox medicine in order to curb side effects and the tendency of addictions usually associated with the use of orthodox pain medications. Employing the appropriate pain management strategies for SCD related pains is imperative considering the caliber of the pains and all the associated life-threatening complications that can ensued if not well managed..

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Appendix A: Demographic Questionnaire

Which of the following best describes you? Choose all that apply:

I have sickle cell disease	
I am a parent, family member or caretaker of someone with sickle disease	
I work for a sickle cell disease patient support or advocacy organization	
I am a healthcare professional who works with sickle cell disease patients	
Other	

What is your age / your child's age? (Optional)

0 – 5	
6 – 12	
13 – 17	
18 – 22	
23 – 49	
50 or greater	

Are you / Is your child:
a. Male
b. Female

What is your Educational level? (Optional)

Graduate	
College/Some College	
High School	
None	

What is your Race / your child's Race? (Optional)

Black/African American	
Hispanic	
Middle Eastern	
Asian	
Other	

What is your SES or income level like (optional)
a) High
b) Middle
c) Low

Appendix B: Citi Completion Report

CITI PROGRAM

Completion Date 01-Jul-2020
Expiration Date N/A
Record ID 36297582

This is to certify that:

Elizabeth Asamoah

Has completed the following CITI Program course:

Not valid for renewal of certification through CME. Do not use for TransCelerate mutual recognition (see Completion Report).

Student's (Curriculum Group)
Doctoral Student Researchers (Course Learner Group)
1 - Basic Course (Stage)

Under requirements set by:

Walden University

CITI
Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?wf16885df-42ba-476d-892a-2ba06da95d61-36297582

Appendix C: Summary of the Data Collected

Data source	Stakeholder type (study participants, SP)	Qualitative data	Code
Questionnaire	Parent (SP1)	Hemoglobin SS	**Disease Type**
	Patient (SP2)	Hemoglobin SS	
	Parent (SP3)	Hemoglobin SS (not about this)	
	Parent (SP4)	Hemoglobin SS	
	Patient (SP5)	Hemoglobin SS	
	Parent (SP6)	Hemoglobin SS	
	Parent (SP7)	Hemoglobin SS	
	Patient (SP8)	Not sure	
	Parent (SP9)	Hemoglobin SC	
	Patient (SP10)	Hemoglobin SC	
		Hemoglobin SS	
Questionnaire Interview	Parent (SP1)	A sickle-cell treatment center with a hematologist	**Treatment Source**
Questionnaire	Patient (SP2)	Have SS specialist	
	Parent (SP3)	Not at a sickle cell treatment center but with a hematologist (they treat mostly cancer there, maybe a cancer clinic)	
Questionnaire	Parent (SP4)	A children's hospital with a hematologist	
Questionnaire	Patient (SP5)	At a sickle cell treatment center but with a hematologist	
	Parent (SP6)	At a sickle-cell treatment center with a hematologist	
	Parent (SP7)	Not at a sickle cell treatment center but with a hematologist: Children Medical Center with an assigned nurse.	
	Patient (SP8)	A primary care center (family medicine, internal medicine): Have about 4 Specialists.	
Questionnaire	Parent (SP9) Patient (SP10)		

		At a sickle cell treatment center but with a hematologist. A primary care center	
Questionnaire	Parent (SP1)	Frequency has decreased; occurs quarterly now; used to be at least once a month; triggered by hot and cold weather, rainy days; normally in her chest, spleen, arms, legs, stomach and is also having problems with spleen, it always prevent me from going to work.	**Pain crisis:** **Frequency**
	Patient (SP2)	Frequency reduced; used to be Monthly: Triggers by Stress, dehydration, less rest. Pain can be anywhere, especially joints with swelling; level above 10. Results in a lot of hospitalization, lengthy ones at times about 2 weeks, has never been able to work, missing school a lot, has to defer now because I failed some courses as I was sick; school authorities are not being cooperative. Affects his concentration especially during classes, get easily irritated and causes him to be angry at onset of crisis	**Symptoms** **Impacts** **Triggers**
	Parent (SP3)	May occur Quarterly/ Occasionally and during growth spurts and vaccinations. Triggers by especially by Extreme cold or hot weather is, Flu and cold seasons and when a virus is going around. I look for little rashes around the joints and watch her speech and focus. Her skin is a dead giveaway that she is in pain or got an infection or inflammation flare up. Hospitalizations is 1 – 2 times per year, Gets it during growth spurts and vaccinations	

Parent (SP4)	Occasionally (1 – 2 times): last episode/hospital visit was in October last year; son is doing very well and hardly get pain crisis. That was really shocking to hear considering the fact that he has the Hemoglobin SS. But that was one observation made; that patients/parents of higher educational levels have better control over the disease especially managing their pains as they employ various coping strategies and other treatment regimens.
Patient (SP5)	Occasionally, Usually, my knee and elbow. Triggers by exposing my body or system to cold weather or food; Weather changes It restricts me of embarking on my daily activities like working at the office.
Parent (SP6)	Quarterly. experiences pain in her arms, legs, chest, and stomach most often. My daughter is not able to participate in many activities her friends do such as swim or run for long distances.
Parent (SP7)	Quarterly. Eyes draw back, loss of concentration. Triggers by exercise, stress, allergies, weather. Terrible pains in bones and high fever and that is the sign to go the ER. Usually experience the pains in the arms, legs, feet. He does not go to school. He is on the 504 Plan for his school district so the Teachers are aware and send his work/assignments home
Patient (SP8)	

	and can also take makeups of tests missed.
Parent (SP9)	Rarely, Frequency decreased; Last crisis was in 1994; used to be very serious requiring blood transfusion; Triggers by weather changes, exercises such as running, or lifting a heavy stuff as it affects my breathing, at times feel like I am about to pass out. Usually experience the pains in the Joints (arms, elbows, knees). Crisis were very acute resulting in hospitalizing and thus not going to work.
Patient (SP10)	Occasionally Used to be mostly in the limbs (joints, arms, legs) but of late more in the abdomen. She was scheduled to do ultrasound if that might be gall stones which we were told maybe accumulation of sickle cells in the gall bladder but have to cancel appointment because of COVID-19. Is not frequent as it used to be when she was young, but it used to be missed school days and not going to work, calling in sick. This impacted any chances of promotions and also financial status on hours that I and her father too at times missed from work. It also impacted us psychologically as it always induces fear, depression and also sadness or pain to see her go through so much pain.
	Occasionally triggers by doing too much exercise and not sleeping enough. I experience the pain in my back and legs mostly I am not able to drive or engage in physical exercise during a crisis.

Questionnaire	Parent (SP1)	Have a pretty good knowledge on the symptoms on SCD and feels HCP are also very knowledgeable or understands the condition very well and feel very confident.in managing their chronic pains from day to day.	**Knowledge:**
	Patient (SP2)	My specialist seems to be knowledgeable but when on admission it seems most of the HCPs may not be that knowledgeable unless they contact my	**Patients/Caretakers**
	Parent (SP3)	specialist. Thus, have experience doubts about HCP; Believe the doctors do not really understand SCD pains very well. Slightly confident in managing pains	**HCPs**
		Slightly confident	
	Parent (SP4)	They know it well but as for being African American and poor, nope. In South Carolina, the hospitals do not know Sickle Cell Disorder well and send her home with fever and pain. In Virginia it is way better. Doctors in South Carolina do not treat Sickle Cell, well here.	
	Patient (SP5)	Pretty well, Very confident HCPs knowledge on SCD: less awareness and misrepresented.	
	Parent (SP6)	About a level of 7: they treat all cases the same way. They do not try to tailor treatments based on the SCD type or conditions of the patient.	
	Parent (SP7)	There is also the trust issue between patients and their HCPs, so patients prefer turning to support groups for especially emotional support.	
		Yes, very good relationship and rapport	

Patient (SP8)		
Parent (SP9)	Very well. They do understand the situation because they are specialized personnel who are there purposely to take care of sickle cell patients at the hospital	
Patient (SP10)	I think my HCP understands my daughter's condition well and is always researching new techniques and treatments	
	Pretty confident now after joining a support group. Used to feel very lonely and scared with no one to relate to. It is now better after joining the support group.	
	Have about 4 Specialists now for different conditions because of my age so feel very confident.	
	Very confident HCPs portrayed to be knowledgeable but wonders if they really understand SCD and what these patients deals with.	
	Very well Very confident in managing pains.	
Parent (SP1)	At the onset of a pain crisis is getting into warm water or hot bathes, takes Tylenol with codeine, ibuprofen, Bio freeze. Patient however takes hydroxyurea and iron vitamins daily which might have contributed to the decrease in the frequency of the pain crisis.	**Pain Management (First line of Defense; Maintenance**)
Patient (SP2)		

	Takes hot baths to release or relax his rigid bones.
Parent (SP3)	Uses both prescribed pharmaceutical and non-pharmaceutical as well as coping mechanisms to manage my pains. Takes Lyrica, Oxycodone, Tylenol #3; Morphine daily q12hours etc. Drink a lot water; staying warm; folic acid. Jadenu 360, Hydroxyurea: but increases the chances of getting infections; being a chemotherapy drug, it is affecting my hair growth; I have been on it for 4 years; it also reduces my appetite
Parent (SP4)	Hydration, balanced diet, daily vitamin, and skin care.
Patient (SP5)	Pain killers are last line before seeing a doctor. Tylenol otherwise doctors give her drugs in emergency room. I try not to use it because I know they tax (destroy) organs like the liver heart and such. Omega 3, Daily vitamin, skin care, and diet high in iron.
Parent (SP6)	I give him Tylenol and Motrin; Use or apply shea-butter has anti-inflammatory properties and chlorophyll liquid: I buy it from Amazon because it increases Oxygen level. Learn about it from online group.
Parent (SP7)	He also uses Air purifier always in his room so that he gets the optimum O2.
Patient (SP8)	I normally take in painkiller, drink lots of water and apply hot ointment at the joints where am having that pain. 17. Basically, I take in painkiller and

Parent (SP9)	apply ointment afterwards try as much as possible to sleep for a while or lie down.
Patient (SP10)	Since my daughter is still pretty young, I try to ask as many questions about the pain as I can before making any decisions. I will then administer over the counter pain medications and give her plenty of water to make sure she is hydrated when that doesn't control her pain, we'll head to the emergency room. We watch wrestling; helps to calm him down: distraction before we go to the ER. Take Folic acid specifically My health and overall living conditions have improved drastically since I started eating healthy and using alkaline water, I hardly gets any crisis these days. Tylenol #3 alternating with Ibuprofen every 4 hours, prayers, massaging at times with hot ointments like Bengay, hot pads/towels, sleep First line of defense: Drink water, lay down or get in bed, take my ibuprofen, apply my heating pad to where it hurts. Maintenance: Pharmaceutical: Ibuprofen (400, 600, 800 mg), Hydrocodone, Hydroxyurea Non-pharmaceutical: rest, heating pad, water, Aromatherapy with essential oils with a diffuser (It relaxes me

	and helps me to not think of my pain)	
Parent (SP1)	Takes Tylenol with codeine, ibuprofen, Bio freeze during crisis and for prevention hydroxyurea and iron vitamins daily for prevention and maintenance	
Patient (SP2)		
Parent (SP3)	Lyrica, Oxycodone, Tylenol #3; takes hot baths to release or relax his rigid bones; Morphine daily q12hours; folic acid, Jadenu 360; Hydroxyurea, Gabapentin. My specialist is aware of other meds and usually prescribe them.	Medications: Prevention, Side Effects
Parent (SP4)		
Patient (SP5)		
Parent (SP6)	Omega 3, Daily vitamin, Tylenol, Pain killers last line of treatment before seeing a doctor.	
Parent (SP7)	Tylenol and Motrin; Chlorophyll liquid	
Patient (SP8)	Paracetamol, folic acid, Vitamin B complex, multi-vitamin, and zincovite	
Parent (SP9)	My daughter takes hydroxyurea daily and Tylenol and Motrin as needed. My daughter takes hydroxyurea daily to suppress crises and prevent infection Hydrocodone, morphine, IV at ER, Tramadol. OTC: Tylenol and Ibuprofen but they were not effective, so we do not use them anymore.	
Patient (SP10)	Enbrel, Eliquix, and Prednisone are for rheumatoid arthritis Tylenol for the eye pains Folic acid specifically for SC	
	Tylenol #3, Ibuprofen	

		Tried Hydroxyurea for about a month in 2019 but interesting her HgB level rather dropped so she lost interest in it and decided to discontinue using. When we discussed this outcome with her new MD later, he informed us that Hydroxyurea works best for SS patients or those who gets frequent pain crises that results in frequent hospitalizations as that is one of its main purposes; to decrease the frequency of pain crises and hospitalizations, Management: Ibuprofen (400, 600, 800 mg), Hydrocodone Prevention: Hydroxyurea, Oxybryta. My HCP provides me with refills of hydroxyurea for 3 to 4 months	
	Parent (SP1)	Takes hot bathes which mother says works well, thus is very effective, says a lot of prayers, heating pads, a lot of massages, listening to music as a distraction	**Coping Strategies**
	Patient (SP2)	Uses massage therapies including breathing exercises such as Yoga but most of them were not very effective. But if I do or apply them early before it intensifies it helps a bit but if the pain has already intensified, they usually do not work or help. Try to stay hydrated by drinking a lot of water and staying warm, eating healthful diets, prayers, massaging, hot pads therapy, music, acupuncture etc.	
	Parent (SP3)	Hydration, skin moisturizer, healthful eating (fruits and veggies), nutraceuticals/vitamins	

	balanced diet, daily vitamin, and skin care. Give her a balanced meal but she is a picky eater being autistic… daily vitamin, omega 3 and encourage water 100% juice and smoothies which includes her veggies without her knowing it. Make sure
Parent (SP4)	after shower and washing hands and face to put on shea, coconut lotions and
Patient (SP5)	creams. Taking Omega 3, Daily vitamin, skin care, and diet high in iron.
Parent (SP6)	Use or apply shea-butter has anti-inflammatory properties and
Parent (SP7)	chlorophyll liquid: I buy it from Amazon because it increases the Oxygen level. He also uses Air purifier always in his room so that he gets the optimum or maximum
Patient (SP8)	O2.
Parent (SP9)	Massaging with hot water and application of hot ointment at the joints where am having that pain., drink lots of water. Use painkillers like paracetamol, ointment massaging, lots of intake of water, hot food always, avoiding stress and fatigue
Patient (SP10)	We currently do not use any other strategies at home.
	Distraction by watching wrestling; helps to calm him down: massaging, hot pads, listening to soft music.
	Eat more fruits and veggies; herbals example lemon, avocado; eat diets low on peanut and meat because of the high oil content. Uses the Kangen machine to sieve/filter the water which

		increases the pH level thus alkaline water. It has been very effective and believe has contributed a lot to why I am doing so well with my health	
		Rest by sleeping more at times massaging with hot ointments like Bengay, Prayers, Distraction, eating healthy.	
		Rest, applying heating pad, drinking water, Aromatherapy with essential oils with a diffuser (It relaxes me and helps me to not think of my pain). Multivitamin, Folic Acid tablets, Heating pad, Epsom salt	
	Patient (SP6)		Side Effects
	Parent (SP1)	None	
	Patient (SP2)	Psychological: depending on location of the healthcare facility, some may have counselors that patients especially Houston is very good, they have psychologists and social workers. Side effects of medicine, going to the hospital always for every treatment, frequent blood tests; costs of treatment, insurance not ready to cover most cost etc.?	**Unaddressed Issues/Concerns**
	Parent (SP3)	Child's HCPs do not address any of the psychological, financial, socioeconomic, sociological issues associated with SCD etc. Doctors in South Carolina do not treat Sickle Cell well here. After an emergency room visit most often my child's recovery is way longer or not complete so I try to treat her on my own. That maybe my fault somewhat but in South Carolina the	
	Parent (SP4)		

	hospitals do not know Sickle Cell Disorder well and send her home with fever and pain. In Virginia it is way better first in and recovery time is a lot shorter.
Patient (SP5)	Schools should have a partnership with treatment center just in case of a crisis at school or for information.
Parent (SP6)	Teachers treated her like she was diseased for the longest until I told them what it was.
Parent (SP7)	There is also the trust issue between patients and their HCPs, so patients prefer turning to support groups for especially emotional support.
Patient (SP8)	My concern is about stigmatization and support system to help sickle cell patients.
Parent (SP9)	I do not think my daughter's current treatment regimen is as effective as I would like it to be. I wish we were able to get the same medication she does at the hospital at home to manage her severe pain crises..
Patient (SP10)	None
	None
	Alternative treatment options. Psychological and sociological impact of SCD on my daughter and her family.
	None
Parent (SP1)	Great, can easily discuss daughter’s treatment plan and express concerns with Dr.
Patient (SP2)	Very good; can easily discuss treatment plan

	and express concerns with Dr. I think every hospital should try to communicate better with	Patient/HCPs relationship
Parent (SP3)	their patients SCD specialists.	
Parent (SP4)	Not good since we moved to South Carolina. It is not easy to discuss concerns with them. They ask but you can tell they do not care. I just do not believe in my state	
Patient (SP5)	and the care they have for their patients. If I can get them to care they would not have such a hard job.	
	Yes, very good relationship and rapport	
Parent (SP6)	Well, I only have access to them only on my visit to the hospital for checkups. if am being attended to by the health personnel on the day of visit for checkups, I do	
Parent (SP7)	discuss my concerns and treatment plans with them and at times other	
Patient (SP8)	alternatives will be advised by them.	
Parent (SP9)		
Patient (SP10)	The relationship between my family and my HCPs is great and I do not have many complaints. I am confident I can communicate with my HCPs at any time. We discuss treatment options with our HCPs during monthly check-ups	
	Good and can easily discuss treatment plans and other concerns with my son's SCD nurse.	
	Great	
	Very Good	
	It is very good, he always communicates with me	

		about my health; Very easy to communicate with, I can message them online	
	Parent (SP1)	1 – 2 times/yr; She use to be sick at least once a month but now it is quarterly, Missing work	
	Patient (SP2)	More than 10 times per year. Can be unpredictable. A lot of hospitalization, Last admission was on July 7- 20	
	Parent (SP3)	Usually affects my parent's ability to work. Very stressful for my parents. has never been able to work	Hospitalizations: Duration **Impact:**
	Parent (SP4)	1 – 2 times/yr.	
	Patient (SP5)	1 – 2 times/yr.; last episode in October last year; Not able to go school, go out to play, less social life etc. in the past when he used to be sick often when young	
	Parent (SP6)	3-5 times/year; In my period of pain crisis, it restricts me of embarking on my daily activities like working at the office	
	Parent (SP7)	1 – 2 times/yr. my daughter is not able to participate in many activities her friends do such as swim or run for long distances	
	Patient (SP8)	1 – 2 times/yr. He can go to school but He is on the 504 Plan for his school district so Teachers are aware and send his work and can take makeups of tests.	
	Parent (SP9)	None in the past year. Hardly. The last one was about 2 years ago Was admitted at the hospital for pneumonia and then diagnosed with rheumatoid arthritis which was triggered by a very cold weather. The last crisis related one was in 1994; was very serious	

	and required blood transfusion. .
Patient (SP10)	No times in the past year. Last ER visit was actually somewhere in 2013.
	1 – 2 times

Parent (SP1)	Was not specific but stated how taking hot baths have been an effective first line defense at an onset of a crisis.	
Patient (SP2)	Yes, being very successful with alternative treatments especially diets, less stress, staying hydrated and rest. Recommend more African foods.	**Alternative Treatment Options: Experiences**
Parent (SP3)	I always encourage as much natural treatment as possible before making opioids an option.	
Parent (SP4)	Constantly moisturize (Hydration): body and skin. Dry skin allows infection to get in… I also try to give her a balanced meal, but she is a picky eater being autistic…, uses daily vitamin, omega 3 and encourage water 100% juice and smoothies which includes her veggies without her knowing it. Make sure after shower and washing hands and face to put on her on shea, coconut lotions and creams	
Patient (SP5)	Uses or apply shea-butter on spots of pains because it has anti-inflammatory	
Parent (SP6)	properties and I give him chlorophyll liquid because it enhances the intake of oxygen. Uses an air purifier in his	
Parent (SP7)	room so that he gets the optimum amount of oxygen.	
Patient (SP8)	That is what am yet to try out because I have not used non-pharmaceutical medication before. Well I will promote it positively if it is approved by food and drugs authority and if the aim in which it was	

	used will be achieved. Purposefully!
Parent (SP9)	We have not yet tried any alternative treatments
Patient (SP10)	None, never tried new medicines My HCPs/NP have discussed some of the new meds but preferred to stick with the meds we are using now which are working for him. Take Folic acid daily, have been eating more fruits and veggies; herbs example lemon, avocado etc., eat diets low on peanuts and meat because of the high oil content and sugar and drinking manly alkaline water for the past 15 years which I think has contributed a lot to improvement in my health. Healthy eating, Prayers and faith in God, resting, massaging, distraction must be also be tried along with any pharmaceuticals the patient but this depend mostly on the type of SCD a patient has will determine what regimen would work best for the patient. They are not as effective as ibuprofen for me, they only slightly alleviate the pain.
Parent (SP1)	I will like my daughter to try them to see which one helps better. I am open to other options but why change when the one you are currently on is working. However,

	alternative regimens are also necessary	
Patient (SP2)	So that way patients would have a lot of options to choose from for their wellbeing.	
	Think more research is really required about the source of the pains so that they can tackle the problem from its source and produces meds to that combat it.	**Alternative Treatment Options: Perceptions**
Parent (SP3)	Lack of adequate research on SCD. Recommend more African foods	
Parent (SP4)	I love and use a lot of natural treatments. Think they must be used only in extreme cases and if it is no other options. Lots of treatments have side effects and tax vital	
Patient (SP5)	organs like the liver. Thus, must only be used in extreme case and if necessary, also thinks I am sure they would way more if Medicaid	
Parent (SP6)	covered it.	
Parent (SP7)	Open to any evidence-based treatments. I think they should be incorporated into treatments plan	
Patient (SP8)	I support the use of using other treatment methods to curb pain crisis. There should be more research on other alternatives.	
Parent (SP9)		
Patient (SP10)	Not certain I do think SCD doctors/nurses should be willing to try new/other therapies more so there can be many options available for different families and their choices	
	Open but don't deem it not applicable to her now as what medications her	

		son are working pretty well, maybe in the future when her son gets older and then there is the need to explore other options they will then do so. It is very important and must be encouraged as my health and overall living conditions since I started eating healthy and using alkaline water; has improved drastically. I think our HCPs should try other options like diets, nutrients, hot pads, massaging, prayers and others that can also help in managing pains. Yes, they should be promoted since still no cure that works for all patients. I am open to new things if they are safe to use on my body. I feel like everyone should give it a try and explore other options and HCPs should be encouraged to prescribe or try these new/other therapies more because I know there are better therapies. My HCP only introduces me to new medication of it will be beneficial in significant ways to my sickle cell (such as oxybryta) , which he prescribe to me about 6 months ago.	
	Parent (SP1)	Hot bathes work is well	
	Patient (SP2)	They are very effective; the pain killers that are usually prescribed for the pain only serves as a backing to these regimens	**Effectiveness**
	Parent (SP3)		
	Parent (SP4)	They are effective but they come with a price and side effects.	
	Patient (SP5)	Very effective It really helps because constant intake of the	

	above drugs helps to boost the immune system that will eventually produce good red blood cells in the blood without it being sickled or curve	
Parent (SP6)	which will apparently help in the number of pain crisis. Its effective	
Parent (SP7)	like I said, I ensure that I take in my drugs daily and not exposing my body or system to cold	
Patient (SP8)	weather or food.	
Parent (SP9)	N/A	
Patient (SP10)	Current treatment plans are effective; Prayers however is not effective because it does not make the pain go away.	
	Very effective	
	Most can be very effective as these opioids are mainly for soothing the pains it run its cause; some of these may offer better treatment options such as reducing the frequency or intensity of pain crisis.	
	Not as effective	
Parent (SP1)	Of a low-income status. Has an insurance that covers about 95% of all medical expenses	
Patient (SP2)	Low SES; have a good insurance but looking for Medicaid because even though it fully covers most of my medical expenses/treatments, however, it restrict my hospital length of stay	**Financial: SES; Insurance policy**
Parent (SP3)	even though I may not be fully recovered and thus results in being forced to be discharged early from hospitals	
Parent (SP4)	Very low SES have no insurance but on Medicaid and cannot not	

	really cover or afford	
Patient (SP5)	treatments.	
	High SES have a good insurance which covers a lot of the treatments. Have had no bad	
Parent (SP6)	experiences so far.	
	Very low SES, Insurance do not cover prescribed drugs from the doctor or specialist, it does not	
Parent (SP7)	cover most of my expenses on drugs. However, it reduces the	
Patient (SP8)	lab text fee on both urine and blood and few drugs which are not costly. Financially they are not helping in that aspect. I do not get any assistance.	
Parent (SP9)		
	Middle; good insurance; I have not incurred any out of pocket expenses	
Patient (SP10)	related to my daughter's condition.	
	Very low SES. Have an insurance but not good though it covers everything	
	Of a low-SES status. Has an insurance. Probably Medicaid considering his age; retired.	
	Some insurance companies are not ready to cover cost of some treatments; even restrict some of the health facilities we are allowed to go to	
	Low SES status. Have an insurance that covers everything.	
Parent (SP1)	None	
Patient (SP2)		
Parent (SP3)	Lack of adequate research on SCD	
Parent (SP4)	None	
		Stigmas

Patient (SP5)	Lack of research and not ready to work with out	
Parent (SP6)		
Parent (SP7)	Lack of support system to help sickle cell patients.	
Patient (SP8)		
Parent (SP9)		
Patient (SP10)		
	How the society treats SCD patients makes most patients don't want to go public about their condition due to lack of education/knowledge and awareness so it is time for the public to be educated and more publicity to create on SCD.	
Parent (SP1)	None	
Patient (SP2)	My family: do not really like being part of support groups because being around them always makes me very depressed.	Support Systems: Knowledge Type
Parent (SP3)	They are very knowledgeable about SCD and provide both emotional and physical support especially during crisis like praying with me.	
Parent (SP4)	My sister and her father are all I have really when it comes getting the care and support, she needs. Her father knows it well, he has Sickle Cell and my sister use to work as a surgical tech. Transportation and advice	
Patient (SP5)	Yes. Actively involved in a support group; one of the leaderships …. Because of trust issues between patients and HCPs. Most patients prefer turning to support groups for emotional support	

Parent (SP6)	I do not have any support system, though I receive newsletters and others from online groups purposely to educate myself more and to know what is going on around the sickle cell diseases community.
Parent (SP7)	My daughter has an amazing support system which includes her family, friends, school community, and church community and we never feel like we are alone in this battle. Our family relies on each other when
Patient (SP8)	anything is needed whether that is childcare for my other child or transportation.
Parent (SP9)	
Patient (SP10)	An SCD support group in Dallas/TX; have prayers section on every Sunday. Leaders from church. Sharing information and provide support and care and share experiences. Pastor and wife Pray with/and for us during crisis.
	Part of a Ghanaian-US-based support group. Provides information and resources but have to pay membership fees etc. which can be high.
	Family members; friends, member of an SCD support group, religious/faith-based organizations.
	Family members and sickle cell support group. They do their best to stay informed about my condition. My family helps me to do any task I need done, remind me to take my medicine.

	Parent (SP1)	Treat or helps with the pain faster that is why HCPs prefer to prescribe it	
	Patient (SP2)	Because of the caliber of the pains that needs to be curbed causes HCPs continue to prescribe them but based on the type of disease it determines the type of med that may need to be prescribed too. Pain killers serves as a backing to the other regimens so it may still be necessary for the HCPs to continue to prescribe them.	Opioid Analgesics
	Parent (SP3)		
	Parent (SP4)	Give her pain killers before we go to the hospital. Tylenol and other doctors give her drugs in emergency room. I try not to use it because I know they tax organs like the liver heart and such.	
	Patient (SP5)		
	Parent (SP6)	HCPs are more into the opioids; prescribes them more	
	Parent (SP7)	Well they do prescribe that medication based on the condition the patient is going through and I believe they do employ different medications too with that effect.	
	Patient (SP8)		
	Parent (SP9)	HCPS chooses to prescribe opioids analgesics instead of other non-opioid medications as I think this is because they know how quick the opioids will help to alleviate the pain.	
	Patient (SP10)		
		Opioids are very effective because I have been using it personally for years.	
		Not very sure as my condition is not that bad I have not had that experience.	

		Prescribe mainly opioids analgesics and nothing else. Because most HCPs lack knowledge on the effectiveness of these other medications as most of these are pretty new and was recently approved by the FDA.	
		Very effective, it always treats my pain. . I think my HCP chose to prescribe these things because he may receive additional money from the drug maker to promote the medicine versus other therapies.	
	Parent (SP1)	Not sure if SCD patients abuses prescription medicine At least not my daughter, she only takes her pain medicines when she is having crises.	**Abuse of medical prescription drugs**
	Patient (SP2)	Very false and is sad that the patients are treated with such contempt considering all the challenges they deal with and even the side effects associated with these meds. Because most of these meds do not work or help instantly, some patients may feel compelled to take more. Most of the meds are not instant relief so it may seem they do not work and thus a patient may end up taking more to be able to curb the pains.	
	Parent (SP3)	However, my HCPs expressed concern about the threat of	
	Parent (SP4)	polypharmacy because of the numerous med I take but just keeping switching to new meds.	
	Patient (SP5)	Yes. She has a family history of addiction on both sides so, I always encourage as much natural treatment as possible before making opioids an option.	

Parent (SP6)	I do not think so, because the scale of the pain is not well understood
Parent (SP7)	I think SCD abuses drugs to curb or relief pain;
Parent (SP8)	perhaps there will be different issue pertaining to the pain which might need different medication to stop that but due to the situation of managing pain they take in drugs at
Parent (SP9)	their own discretion to minimize the pain
	I do not think SCD patients abuse medical prescription drugs because I honestly think they need a high level of medication to alleviate their severe pain symptoms
	I do not believe is true.
Patient (SP10)	Not very sure as my condition is not that bad I have not had that experience
	Not my daughter but it can be possible as it seems HCPs don't actually understand the caliber of the SCD pains, they tend to under-prescribe for their patients. Also, these pain killers they usually prescribe are not that potent enough to really handle the pains, they wear out easily after some few hours so the patient may be forced to take more than prescribed by the HCP to completely control or stop the pains, and also they are mainly for maintenance, purposely to soothe the pains, help the patient feel comfortable during a crisis but doesn't really stop or shortened the duration of the crisis.

		No, I don't think we feel as if it is the only thing that will help. My HCP prescribe me extra pain medicine unless I ask for it.	
	Parent (SP1)		
	Patient (SP2)		
	Parent (SP3)		
	Parent (SP4)	SCD have not received attention as other diseases like the cancers. My organization (a support group) lobbied for SCD patients in the state of Virginia to be treated equally as cancer patients.	Health/Racial Disparities
	Patient (SP5)		
	Parent (SP6)		
	Parent (SP7)		
	Patient (SP8)	HCPs treat cancer way more than they do with sickle cell.	
	Parent (SP9)		
	Patient (SP10)	Lack of specialized healthcare facilities that are specifically for SCD and so there are few SCD specialists HCPs.	
	Parent (SP1)	Problems with spleen	
	Patient (SP2)	Multiple infections: used to be very common especially when under unsanitized conditions, Strokes: mild, Growth problems or delay in reaching puberty, Iron overload, difficulty concentrating, Problems with spleen, difficulty with breathings, affects his concentration especially during classes easily causes him to be angry at onset of crisis.	Associated Co-morbidities
	Parent (SP3)		
	Parent (SP4)	Chronic daily pain, such as joint pain or hip pain Multiple infections, Difficulty concentrating	

Patient (SP5)	Problems with eyesight (from sickle cell disease), little rashes around the joints	
Parent (SP6)	Pneumonia, anemia; Chronic daily pain, such as joint pain or hip pain, Acute chest syndrome	
Parent (SP7)	Joint pains and at times headache. In my teens I experienced priapism but now it has been years I experienced and	
Patient (SP8)	Abdominal pain	
Parent (SP9)	Was not specific	
Patient (SP10)	Difficulty concentrating; Problems with eyesight (from sickle cell disease); Acute chest syndrome; he has Asthma too, so it makes it difficult for him. He gets tired easily especially because of the Asthma medicine he uses.	
	Problems with eyesight Breathing Difficulties especially when doing anything strenuous	
	Difficulty concentrating Frequent abdominal pains; hematuria when young, breathing issues, Asthma, allergies.	
	Chronic daily pain, such as joint pain or hip pain.	
Parent (SP1)	Yes prayers: I pray always for my daughter, very helpful. Prayers have powers.	
Patient (SP2)	Yes, even at the hospital there is always a chaplain to pray and counsel me which helps to release any fear I may be having. Prays a lot because if not for God I do not think I will still be here. Praying has been very effective for me especially during hospitalizations and	**Religion: Prayers Meditation etc. Effectiveness:**
Parent (SP3)	when my meds are not working, prayers help a	

Parent (SP4)	lot by helping me to relax and somehow soothe the pain
Patient (SP5)	I do pray. I believe God can work through the doctor's, but they would have to care about their patient first.
Parent (SP6)	Prayers: I think it helps a lot
Parent (SP7)	Not at all…I do not believe it…superstitions
Patient (SP8)	I do think religion and spirituality play an important role regarding the impact on managing pains. Have been using prayers and confiding in spiritual/religious leaders.
Parent (SP9)	
Parent (SP10)	Prayers but, it is not effective because it does not make the pain go away.
	Prayers and fasting which helps with detoxification of the body.
	Yes, prayers, consulting/confiding in spiritual/religious leaders, use of some spiritual/religious artifacts and they have been very effective and have contributed a lot towards her current status with SCD.
	Prayers to God, I think prayer can help your perspective on the pain you're having. Somewhat effective, but I don't think about my pains too much after I pray.
Parent (SP1)	Have a medicine that will eliminate crises

Patient (SP2)		
Parent (SP3)	Treatment that will help save their eyesight and ways to deal during times of an epidemic and flu season. Flu shot can sometimes make them sick.	Ideal Treatment
Parent (SP4)	Bone marrow: the Gene therapy currently being employed uses inactive HIV cells and also wipes all the immune system which renders it unsafe so if something else can be developed that would be less invasive on organs with no or less side or adverse effects.	
Patient (SP5)	Adhering to basic strategies like good diet, enough fluids to avoid dehydration, not exposing body or system to cold weather or foods, visiting the clinic regularly etc. Being able to manage pain more effectively at home.	
Parent (SP6)	None	
Parent (SP7)	Prayers and fasting which even helps with detoxification of the body.	
Patient (SP8)	A treatment capable of curing or eliminating SCD and its associated complications entirely.	
Parent (SP9)	Treatments that are affordable and feasible/conducive Easy to administer, convenient, can be administered at home	

Patient (SP10)

Appendix D: Significant or Unique Statements and Their Implications

Compilation of significant or unique statements by participants	Implications
At least not my daughter, she only takes her pain medicines when she is having crises. Very false and is sad that the patients are treated with such contempt. There is a family history of addiction on both sides so, I always encourage as much natural treatment as possible before making opioids an option.	Participants responses on if SCD patients abuses prescription medications
Takes daily medication of Hydroxyurea, folate and iron vitamins	Preventative strategies
Participant thinks opioid analgesics helps with the pain faster that is why HCPs prefer to prescribe it. The type of disease determines the type of med that HCPs prescribed. Pain killers serves as a backing to other regimens. I try not to use it because I know they tax organs like the liver heart etc. (side effects). HCPs treat all SCD cases the same way. They don't try to tailor treatment based on the type or conditions of the patient	Participants perceptions on opioid analgesics and why HCPs prescribes them over others /HCP prescribing habits
I have being very successful with alternative treatments especially diets, less stress, staying hydrated and rest	Participants experiences with alternative treatments
Hot bathes work's really well. Prayers have powers, are very helpful. Prayers and counselling help to release my fears. They are effective but with a price and side effects. I just do not want anything habit forming and will have awful side effects	Participants perceptions of the effectiveness of coping strategies
That way patients have a lot of options in their well-being. I am open to other options "but why change when the one you currently on is working. I will like my daughter to try them to see which one helps out better. Should only be used in extreme cases and if it is no other options. Lots of treatments have side effects and tax vital organs like the liver	Participants perceptions/responses to exploring alternative treatment options
I pray always for my daughter. Prays a lot because if not for God I don't think I will still be here. Prayers help a lot to soothe the pain. I love and use a lot of natural treatments. Apply shea-butter because it has anti-inflammatory properties and chlorophyll liquid. Air purifier to gets the optimum amount of O_2.	Coping Strategies
I was forced to defer by failing a class awaiting medical withdrawal for deferral. A lot of hospitalization, has never been able to work, missing work. Gets easily angry or upset at the onset of crisis.	Impact of pain crisis.
I have doubts about HCP; believe the doctors don't really understand SCD pains very well. In South Carolina the hospitals/HCPs do not know or treat SCD well and always send my daughter home with fever and pain. In Virginia it is way better first in and recovery time is a lot shorter. they treat cancer way more better than they do with SCD.	Participants perceptions about HCPs knowledge on SCD.
I don't really like being part of support groups because being around them always makes me very depressed. Emotional and physical support. Schools should have a partnership with treatment center just in case of a crisis at school or for information.	Participants perceptions on Support Systems
Have a full insurance coverage but it restrict my hospital length of stay even though I may not be fully recovered but I will be forced to be discharged early from hospitals stays.	Participants financial challenges
They just do not care, no one trying to discuss nothing.	Participants responses on relationship with HCPs and their attitude