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The Socioeconomic and Cultural Impact of Sickle Cell Disease in Nigeria

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Abstract

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by

Jejelola Adeyiwola Bakare

Dissertation Submitted in Partial Fulfillment

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Abstract

Sickle cell disease (SCD) is a genetic health condition that has continued to increase globally. SCD is prevalent in developing countries like Nigeria with 20 to 30% of the population living with SCD. The aim of this study was to explore the effect of the socioeconomic and cultural factors that affect the quality of life (QOL) of individuals with SCD in Nigeria. The framework for the study is secondary prevention. Secondary prevention allows for opportunities to improve QOL amongst people living with SCD focusing on the health beliefs, and socioeconomic wellbeing. A phenomenological approach was used to collect in-depth data on the effect of socioeconomic and cultural factors from 30 randomly selected individuals living with SCD in Nigeria. Thematic content analysis of participant responses was the qualitative methodology used for this study. Study results indicated that among individuals living with SCD in Nigeria, socioeconomic and cultural factors of the disease contributed to diminishing QOL. Common themes included limited education and awareness, financial support, and cultural beliefs as impactful on an individual's capacity to manage their SCD, leading to diminished QOL. A potential positive social change of this study is to share study results and recommendations with public health officials to promote public health policy and practices that can encourage increased awareness, and treatment of SCD to stimulate a better QOL of individuals living with SCD.

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Dedication

I dedicate this dissertation to all individuals living with sickle cell disease in Nigeria with diminished quality of life. To my husband, Abiodun Owotomo, thank you for your support and love. To my daughter Omooluwanimi Owotomo, thank you for your patience. To my parents, Mr. and Mrs. Bakare, for your believe in me, and for encouraging me through out the duration of my studies. To my brothers, sister, and a dear friend, I cannot appreciate or thank you enough for support. This could not have been done without every one you supports.

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Chapter 1: Introduction to the Study

Introduction

Sickle cell disease (SCD) is a genetic disorder that can be acquired if both parents carry the disease trait (World Health Organization [WHO], 2010). In SCD, the red blood cells clump together causing the originally round-shaped red blood cells to appear as a semicircular shaped red blood cells (National Institute of Health [NIH], 2013; National Library of Medicine [NLM], 2012). Sickle cell disease is categorized as a disease accompanied by frequent pain, low red cell blood count, and infection (NLM, 2012). Sickle cell disease affects red blood cell protein called hemoglobin. This hemoglobin carries oxygen to the entire body; however, with SCD the red blood cells are crescent shaped and unable to pass through the blood vessels appropriately (Sickle Cell Disease Association of America [SCDAA], 2015). The inability of the crescent-shaped red blood cells to pass through the blood vessels decreases the level of oxygen carried from the lungs to rest of the body. The sickle shape causes red blood cells to deteriorate early, which leads to anemia (NLM, 2012). The long-term effect of SCD over time leads to a progressive and systemic weakening of multiple organs. The resulting symptoms include repeated occurrences of severe pain, anemia, organ damage, and infection (NLM, 2012).

Previously, researchers have primarily focused on the psychosocial impact of SCD and or impact of genetic counseling on SCD. There is limited information on how SCD complications impact quality of life (QOL) of those affected by the disease. Existing SCD literature that was reviewed does not describe the impact of socioeconomic and cultural factors on the QOL of people with SCD.

This chapter describes the background of the study, the problem statement, purpose of the study, and the research question. The chapter also elaborates on the theoretical and conceptual framework of the study, nature of the study, and definition of key concepts. Furthermore, the assumptions, scope, delimitations, limitations, and significance of the study are discussed.

Background

Sickle cell disease is a life-threatening disease that can damage how red blood cells break down (Steinberg, 1999). Sickle cell disease causes damage to the spleen as blood accumulates in it or when the bone marrow stops manufacturing red blood cells due to the presence of infection (Steinberg, 1999). Sickle cell disease patients who experience frequent crisis develop multisystem organ damage including but not limited to renal failure, pulmonary disease, cerebral vascular accidents, weakening of the bone, destruction to the eye, and damage to the central nervous system (Steinberg, 1999). Further complications include priapism (unwanted, painful penile erection) and respiratory problems (Steinberg, 1999). An SCD crisis can be triggered by environmental temperature changes, extreme physical exertion, and dehydration. Symptoms of SCD include jaundice, paleness, fever, shortness of breath, frequent urination, hand-foot syndrome, eye problems, delayed growth and puberty, excessive thirst and urination, fever, and pain that occurs unpredictably in any joint or body organ (Piel, Hay, Gupta, Weatherall, & Williams, 2013).

People can develop SCD when they inherit the genetic trait from both parents; however, individuals who inherited the genetic trait from one parent can pass down the

trait to their children (WHO, 2010). Late diagnosis of the disease has resulted in 92% of mortality in the early lives of individuals with SCD (Piel et al., 2013). People with SCD frequently visit the hospital; however, the symptoms vary depending on individuals, some might have severe symptoms and others with mild symptoms (NIH, 2013).

Sickle cell disease is predominantly found among people of African, Mediterranean, Arabic, and Asian decent in relation to its survival advantage against malaria (Anie Egunjobi, & Akinyanju, 2010). The disease affects millions of people globally, which leads to a shortened life expectancy (Elmariah et al., 2014; Makani et al., 2011). The life expectancy of people living with SCD in developing countries is less than 50 years of age (Makani et al., 2011). Annually, about 300,000 children are born with SCD. Seventy-five percent of these cases occur in Africa (Makani et al., 2011). In Nigeria, SCD occurs in 20 per 1,000 live births per year (WHO, 2006). The prevalence of sickle cell trait in Nigeria occurs among 20-30% of the population (WHO, 2012). Nigeria has the highest level of SCD globally (4.2%) due to the high prevalence (23.7%) of sickle cell trait (Omotade et al., 1998).

The diverse paths and severity of SCD are the result of intrinsic and extrinsic factors ranging from genetic markers, environment, ethnicity, socioeconomic status, religion, and cultural beliefs (Anie et. al., 2010; Cajado et al., 2011). These factors affect the quality of life (QOL) of persons who live with SCD. Quality of life describes the positive and negative aspects of life that can affect the mental and physical state of individuals. This is determined by health status, level of comfort, and state of happiness (Centers for Disease Control and Prevention [CDC], 2011). Quality of life displays the

balance between biophysical, psychosocial, sociocultural and spiritual aspect of life (Adegbola, 2011).

Quality of life can be determined by understanding the contributing factors and how individuals cope (Adegbola, 2011). A SCD patient can be reported to have difficulty coping with pain associated with SCD, which may obstruct with the ability to complete daily task, therefore impacting QOL (Adegbola, 2011). Sickle cell disease patients are mostly perceived as people who do not have a better social life as those without the disease (Adegbola, 2011). There is a knowledge gap in the literature related to the extent to which the family economic status relates to the accessibility to comprehensive management of SCD. In this study, I identify the specific cultural practices of Nigerians that affect the QOL of people living with SCD. Additionally, I sought to determine the relationship between socioeconomic and cultural influences on SCD. The results of this study could improve health care management for individuals diagnosed with SCD, thus enhancing the QOL.

Problem Statement

In developing countries medical dilemmas are sometimes handled with cultural and traditional solutions, which may not account for the important clinical aspects. In many African countries individuals with SCD are not handled as patients but rather spiritual victims (Adeolu, 2012; Olaide, 2012). Sickle cell disease is the cause of death among 20% of those with the disease (Quinn, Rogers, & Bachanan, 2004). The WHO (2006) noted that SCD has become a global public health dilemma. Piel et al. (2013) mentioned that between the years 2010 and 2050 an increase in the global number of

SCD cases would rise from 305,800 to 404,200 cases per year given the estimated number of people living with SCD to be 14,242,000 by 2050 (Piel et al., 2013). People with SCD in developed countries have experienced improvements in QOL and longer life expectancy unlike in developing countries like Nigeria, the most populous African country (Akodu, Diaku-Akinwumi, & Njokanma, 2013; CDC, 2011; Isoha, 2009; St. Jude Children's Research Hospital, 2014).

Cultural beliefs and socioeconomic status can affect health outcomes of people living with SCD (Anie et al., 2010; Panepinto et al., 2008). Cultural beliefs in some rural areas of Nigeria recognize SCD as reincarnation (Nzewi, 2001). This may affect the perspectives of people and the affected families toward the condition thereby not giving the disease an appropriate attention and management that it requires to maintain a good QOL. Sickle cell disease complications impact individuals with the disease causing them to be frequently hospitalized, as well as strain on a family's financial security (Mitchell et al., 2007).

Researchers have previously shown that differences in psychosocial functioning experienced by people with SCD in Nigeria might be the result of divergent levels of health (Anie et al., 2010). Anie et al., (2010) suggested the initiation of "basic psychosocial interventions by nonspecialized health workers in primary health care team" to decrease harmful feelings towards SCD, and to foster the development of SCD management techniques (pg. 5). Researchers have not fully explained the socioeconomic and cultural factors have on the perception of SCD in Nigeria. In this study, I identify the socioeconomic and cultural practices of Nigerians that may influence the QOL of

individuals living with SCD. In this study I also explore the impact of socioeconomic status and cultural practices on accessibility to comprehensive management of SCD and may inform the development of future health educational interventions to encourage behavioral change and reduce the disease burden on QOL.

Purpose of the Study

Researchers have discussed how SCD impacts life expectancy, the genetic factors, complications, and how SCD has been a social burden (Adegoke, Abioye-Kuteyi, & Orji, 2014; Dabari et al., 2006; Elmariah et al., 2014; Oguanobi et al., 2010; Platt et al., 1991; Makani et al., 2011; WHO, 2014). The majority of SCD studies were carried out in nations other than Nigeria. There is paucity of data about the socioeconomic and cultural factors affecting QOL of people living with SCD in Nigeria (Adegoke, Abioye-Kuteyi, & Orji, 2014). The main purpose of this study was to discover the effect of the socioeconomic and cultural factors that affect the QOL of individuals with SCD in Nigeria. This is socially significant, as it will inform the development of public health interventions to support and sustain the lives of those living with SCD through education and disease management.

Research Questions

Research Question 1: What are the socioeconomic factors affecting the QOL of patients living with SCD in Nigeria?

Research Question 2: What are the knowledge, attitudes, and beliefs of patients living with SCD in Nigeria, which may contribute, to the poor management of the disease that can lead to poor QOL?

Research Question 3: What are the negative impacts of SCD on the affected persons?

Research Question 4: What are the possible ways of educating people living with SCD and their families to reduce the burden of SCD and improve the QOL of the affected individuals?

Theoretical Foundation

As recommended by Unwin et al. (2001) there are three methods to manage the strain of chronic disease: (a) epidemiological surveillance, (b) prevention, and (c) secondary prevention. Burden of chronic disease is measured by evaluating the virtual effect of various diseases on populations by means of quantifying premature death, morbidity, or financial cost in terms of using disability-adjusted-life-year *DALY* (Australian Institute of Health and Welfare [AIHW], 2013; WHO, 2014). The framework of this study focuses on secondary prevention through identifying opportunities to improve QOL of persons living with SCD.

Unwin et al.'s (2001) theory of secondary prevention focuses on disease factors that should be investigated before the preventive method can be employed. Factors include health beliefs and socioeconomic wellbeing of the community at large. This includes factors that influence the pursuit of effective health care and proper treatment (Unwin, 2001). Also, the culture of a health system may influence the health outcome of a community (Unwin, 2001). Secondary prevention also aligns with community need to have access to continuous health care (Unwin, 2001). Decreased access to health care or not seeking health care can lead to diminished health status and health outcomes (Unwin,

2001). Secondary prevention facilitates how researchers can determine how populations are mostly affected by chronic disease (Unwin, 2001). Researchers must consider cultural and socioeconomic status to effectively utilize secondary preventive measures (Unwin, 2001). Secondary prevention focuses on the prevention or reduction of the complications of a disease or condition with the view to improving the QOL of people (Unwin, 2001).

Ballas (2009) mentioned that management of SCD can help prevent more complications of SCD but can put a strain on the financial stability of the family ranging from hospital admissions, clinic visits, physician fees, drug prescriptions, and other health procedures (Ballas, 2009). Secondary prevention focuses on educating SCD patients and their families or caregivers about the severity of SCD and the modifiable behaviors that can help promote a better QOL. The concepts and ideas offered by this framework are further explained in the literature review sector of Chapter 2.

This theory relates to the study approach because the basis of the study was to identify reasons for the prevalence of SCD in Nigeria. Direct contact with individuals who suffer from SCD assisted in the extraction of valid and reliable data and findings. This information helps initiate secondary prevention towards the management of SCD and improvement of QOL. In addition, the study approach was also intended to provide valid and reliable answers to the research questions.

The conceptual framework this study was the health belief model. This model highlights the perceptions and logic of specific individuals. The health belief model focuses on eliminating delays in medical attention by determining how individuals think about their health behaviors (Turner, Hunt, DiBrezzo, & Jones, 2004). The goal of this

theory is to assist with interpreting the health-related behaviors of individuals living with SCD. The major health belief model concepts include: perceived severity, perceived susceptibility, perceived benefit, perceived barriers, modifying variable, and cues of action. The health belief model concepts will be further explained in Chapter 2.

The approach provides direct contact to the study's participants; thereby exploring the negative impacts of SCD, methods of educating SCD patients, and eradicating stigmas toward the disease. This approach outlines SCD patient experience by exploring the socioeconomically and culturally effects of the disease.

Nature of the Study

This study design utilized a phenomenological approach that helped to identify and evaluate the fundamentals of SCD patient experiences (Creswell, 2009). A random sampling was used to select the participants for the study. Random sampling gives the study population an equal chance of being selected to participate in a study. Random sampling reduces the chance of bias among study samples (McKenzie et al., 2008). Thirty SCD male and female patients from two SCD clinics in Lagos, Nigeria were recruited for the study. The research data were collected using an open-ended questionnaire strategy in conjunction with telephone interview protocol. The data collected during the interview were analyzed by taking extensive field notes and audio transcriptions through a pooling of themes, patterns, categories, and relationships (Community of Learning, Inquiry, and Practice [CLIP], 2007).

Operational Definitions

Sickle cell disease (SCD): Genetic blood disease that can cause complications. (Desai & Dhanani, 2004).

Quality of life (QOL): Positive and negative aspects of life which can affect the mental and physical state of individuals, determined by health status, level of comfort and state of happiness (CDC, 2011).

Cultural belief: The norms, values, standards and expectations of an individual or group (Mathews, n.d)

Socioeconomic status: The social class of an individual or group. This can be measured by income, education and occupation (American Psychological Association [APA], 2015).

Burden of disease: A measure used to evaluate the virtual effect of various diseases on populations by quantifying premature death, morbidity, or financial cost in terms of using disability-adjusted-life-year (AIHW, 2013; WHO, 2014).

Oxygenated blood: Red blood cells that take oxygen to body cells (Fisher, 2014) Deoxygenated blood – red blood cells cannot take oxygen to body cells (Fisher, 2014)

Hemoglobin A: A normal red blood cell (Desai & Dhanani, 2004).

Hemoglobin S: An abnormal red blood cell (Desai & Dhanani, 2004).

Hemoglobin AS: When red blood cells contain both normal and abnormal red blood cells (Desai & Dhanani, 2004).

Hemoglobin SS: When red blood cells contain both abnormal blood cells which is also known as sickle cell disease (Desai & Dhanani, 2004).

Hemoglobin AA: When red blood cells contain only normal blood cells (Desai & Dhanani, 2004).

Assumptions

1. There is sufficient number of potential study participants available for the study because Nigeria has a large population of patients with SCD.
2. The SCD patients are willing to participate in the study because the participants are offered financial compensation as an incentive.
3. Participants will provide clear and honest responses to the study questionnaire because the participants are all patients of SCD who are also looking to minimize morbidity and mortality.

Scope and Delimitations

Developing countries are often fixed in their beliefs and mentality due to lack of health education. This fixed mentality is often carried into their dealings of medical dilemmas and healthcare. Traditional remedies are often utilized to handle medical issues thus diseases like SCD are usually dealt with on a spiritual basis (Adeolu, 2012; Olaide, 2012). This specific focus was chosen in order to encourage permanent changes in health behaviors and beliefs toward SCD. Once the socioeconomic and cultural impacts of SCD on the community are identified, researchers and providers will utilize the findings to establish interventions to enhance the management of SCD and QOL for SCD individuals and family.

Included in this study are adult patients with SCD; however, the excluded parties include family member of patients with SCD who do not have the disease and their

healthcare providers. These excluded individuals play a major role in the lives of the chosen SCD patients and possess a first-hand understanding of the experiences of the SCD patient. The secondary prevention theory in the framework can be applied to the excluded individuals in the sense that these individuals can assist in the continuing the management of the disease. However, the excluded participants did not participate in the study in order to maximize validity and reliability.

The issue of transferability in this case is the potential of comparison between SCD patients and family members who have not been diagnosed with the disease. Although, the findings allows for comparison of the information collected from the individuals both included and excluded from the study, this does not assume that the experiences of an individual with SCD are implicitly understood by those excluded parties. If included in the study, this may yield possible invalid results.

Delimitation criteria include:

1. The investigation is limited to adults with SCD.
2. Age and ethnic diversity of participants may affect their social and cultural behaviors.

Limitations

1. The survey was conducted in English. English is the secondary language spoken in the Nigeria, but some Nigerians may not understand the English language. Individuals who do not speak English may have a desire to participate in the study in order to express themselves; however, the research

is limited to those who speak English. This may reduce the pool of individuals that can participate in the study.

2. The study was conducted in Lagos and limited to SCD patients receiving care in Lagos, Nigeria.
3. Participants may respond in a way that makes them feel good about themselves (Kerby, Brand, Johnson & Ghouri, 2005).

The potential biases in this study include the fact that data were extracted from Lagos and responses from the participants may be conformed to what they believe a researcher wants to hear. Out of fear of judgment, participants may not feel comfortable to offer their answers to the research questionnaire in its entirety.

Methods of addressing the limitations include providing a comfortable environment for the participants – an environment that does not intimidate or pressure participants. As far as the limitation based on location, I may address this issue by gathering a diverse group of English-speaking participants from the city of Lagos and eliminating the possibility of gathering an inadequate group of participants.

Significance of the Study

This research is important because it focuses on the impact of socioeconomic factors and cultural beliefs on Nigerians with SCD. Globally, the course and severity of SCD varies as a result of several factors like genetic markers, environmental factors, ethnicity, social and economic variables, religion, and cultural beliefs (Anie et. al., 2010; Cajado et al., 2011). The number of SCD patients continues to increase exponentially in Nigeria with no strategic programmatic efforts geared towards improving the QOL of the

affected persons. This may be due to rampant misconceptions about SCD and the misdiagnosis of hemoglobin phenotypes (Kotila, 2012). After determining the socioeconomic and cultural impact of SCD on the community, researchers and providers can explore public health interventions that encourages changes in health behavior and beliefs towards SCD, while also accounting for the socioeconomic and cultural impact of SCD. This can improve the management of SCD and the QOL for individuals with SCD.

Summary

Globally, SCD contributes to 70% of the major hemoglobin disorders at birth in Africa (Modell & Darlison, 2008). The hallmark of the disease is painful recurrent crises that interfere with the QOL of the affected persons with result in frequent hospital admissions. Sickle cell disease affects a family's socioeconomic status and can interfere with the physiological and psychosocial developments of the affected individuals. The goal of this study is to provide better knowledge about the effect of socioeconomic and cultural beliefs on the QOL of people living with SCD in Nigeria. This study has a prospective for creating a positive social change as it informs future interventions that may improve the socio-cultural and economic behaviors of people towards SCD. Chapter two will utilize the literature to explain in detail the previous research offered on this study in order to full understand previous study that was conducted on SCD and the research gaps.

Chapter 2: Literature Review

Introduction

The knowledge, attitude, and beliefs related to SCD can be affected by the cultural beliefs of Nigerians (Anie et al., 2010; Ohaeri & Sokunbi, 2001). Disease complications equally affect the socioeconomic status of individuals with SCD and their families (Ballas, 2009; Kauf et al., 2009). This study was conducted to better understand the magnitude to which socioeconomic factors and cultural beliefs affect individuals with SCD and their families. The focus of this study was to understand how the daily lives of those living with SCD are affected based on age, sex, race, ethnicity, skills, spirituality, culture, knowledge, past experience, religion, beliefs, educational level, occupation, and income.

A review of previously published research on SCD, and QOL was explained in this chapter. The literature review provided a better understanding on origin, distribution, complications, and management of SCD to improve QOL. Also, the review featured a lengthy discussion of the socioeconomic impact and cultural beliefs of SCD on the affected individuals globally and more specifically Nigeria.

Background

The first known mutation of SCD occurred in the neolithic times among the Arabian Peninsula people who migrated to the western hemisphere of equatorial Africa due to climate changes (Desai & Dhanani, 2004). As described by Desai and Dhanani (2004), the gene responsible for SCD may have been carried to countries like India, eastern Saudi Arabia and equatorial Africa (Desai & Dhanani, 2004). James Herrick was

the first person to discover SCD; he confirmed the elongated shape of a red blood cell (Nandanwar & Kamdi, 2013). Sickle cell disease is a genetic autosomal recessive disorder, characterized by the sickling of the red blood cell of individuals with SCD is due to the deprivation of oxygen (Desai & Dhanani, 2004). The heterozygous state of sickle gene (also known as sickle cell trait) is known to be with no symptoms of the disease, and the homozygous state of the sickle gene shows significant amount of symptoms in individuals carrying the disease and not the sickle cell trait (Desai & Dhanani, 2004). The heterozygous states are known to have the hemoglobin AS (Hb AS) in which the blood contains the normal red blood (Hb A) cell and the sickled blood (Hb S), and the homozygous states are known to have the hemoglobin SS (Hb SS) in which the red cells are dominated by sickle hemoglobin which is also known as SCD (Desai & Dhanani, 2004). The sickled blood cell, also known as hemoglobin S (HbS) is a malformed protein that transports oxygen to the cells of the body (WHO, 2010).

Sickle cell disease is a genetic mutation in β-globin (HBB). The β-globin produces the codes that bring together the chains of the hemoglobin "A" protein, and the production of alternative forms of gene code creating malformed hemoglobin "S" (Kaur, Dangi, & Singh, 2013). Sickle cell disease is mostly found in the sub-Saharan African countries, Greece, Turkey, Central American, Italy, India, and the Carribbean; however, it is popular in Africa where malaria is endemic (Kaur et al., 2013). Sickle cell gene is commonly found in sub-Saharan Africa and it is believed that this high prevalent of sickle cell trait that confers a survival advantage against falciparum malaria (Kaur et al.,

2013; Treadwell, McClough & Vichinsky, 2006). People with the Hb AS are more resilient to malaria compared to those with the typical hemoglobin gene (WHO 2006).

The gene responsible for SCD is particularly associated with some genetic backgrounds called haplotypes, which contributes to the clinical diversity and severity of the disease. The haplotypes are named after the geographical regions where the disease was found. The different types of haplotypes include: Senegal haplotype, The Benin haplotype, Central African Republic (CAR) or Bantu haplotype, Arabian or Indian haplotype, and Cameroon haplotypes. Senegal haplotype represents those with SCD prominently residing in the western zone of Africa located above the Niger River, and individuals residing in Senegal. This category is associated with a mild form of SCD with high hemoglobin fraction (HbF) (Desai & Dhanani, 2004; Gabriel & Pryzybylski, 2012; Steinberg, 2005). The Benin haplotype is the type of SCD found in Nigeria, Benin, and the east of the Benin; they are associated with severe forms of SCD with low HbF (Desai & Dhanani, 2004; Gabriel & Pryzybylski, 2012; Steinberg, 2005). Central African Republic (CAR) or Bantu haplotype represents the nations in the south central Africa and Central African Republic. This is associated with the severe form of SCD leading to organ damage with low HbF (Desai & Dhanani, 2004; Gabriel & Pryzybylski, 2012; Steinberg, 2005). Arabian or Indian haplotype covers the Middle Eastern areas and India with a very mild form of SCD with low HbF (Steinberg, 2005). Cameroon haplotype is a rare and atypical haplotype in central India, which is associated with severe form of SCD (Niranjan, Chandak, Veerraju & Singh, 1999).

HbF among people with SCD ranges between 0.1% - 30%, 8% being the average (Steinberg, 2005). The HbF determines how severe SCD is among individuals carrying the disease. HbF is the predictor of SCD complications (Steinberg, 2005). When an individual with SCD has a high HbF, its outcome is a mild phenotype, which results in a very mild case of crisis or complications (Bianchi et al., 2009; Steinberg, 2005). Individuals with the high HbF do not need blood transfusions (Bianchi et al., 2009; Steinberg, 2005). Those with the low HbF have more recurring crises with more severe complications, and require blood transfusions (Bianchi et al., 2009). High HbF can help minimize the occurrence of organ damage in the body. Clusters of genetic known as hereditary persistence of HbF can reveal the severity of SCD (Bianchi et al., 2009).

The managements of SCD include educating those with the disease, their parents and caregivers. Education includes monitored nutrition, growth, and development of the individuals with SCD (Rees, Williamas, & Gladwin, 2010). Management of SCD also include the administration of treatments including, pneumococcus and influenza vaccinations, and provision of medications (Rees et al., 2010). Monitored vitals of blood volume, oxygen saturation and blood pressure are very essential (Rees et al., 2010). Furthermore, it is very important to monitor acute and chronic complications, and the provision of psychological support (Rees et al., 2010).

Literature Search Strategy

The literature search was performed using different research databases available at Walden University, Georgia State University and Indiana University. Databases used were Academic Search Complete (EBSCO), ProQuest, and Science Direct. Google

Scholar was used as a literature search tool. The following terms were used to identify literature: *sickle cell disease*, *psychological impact*, *cultural belief, origin*, *epidemiology/distribution*, and *socioeconomic impact.* Information about the *complication of sickle cell disease and the treatment*, *management of sickle cell disease*, is derived from a broad search for the term *sickle cell disease*. From the literature search, additional articles were identified based on the references from key literature.

During the literature search, the search identified SCD related articles of interest. The majority of related literature focused on the QOL in children and adolescents with SCD, both in Nigeria and other countries. Existing literature focuses on the impact of SCD on health status. The literature search made it apparent that there is unsatisfactory literature on the effect of socioeconomic factors and cultural beliefs on SCD and the QOL in adults. Published literature did not articulate research on QOL for adults regardless of socioeconomic status or cultural belief; also studies did not provide sufficient information on how SCD adults cope with the cultural beliefs of the society nor how they are affected by those beliefs.

Theoretical Foundation

As explained in Chapter 1, the theoretical foundation is derived from the theory performed by Unwin et al. (2001). The theory suggests three methods to regulate the burden of chronic disease, which are epidemiological surveillance, primary prevention, and secondary prevention. Unwin et al. (2001) focused on secondary prevention to allow for opportunities to improve QOL amongst people living with SCD. This theory focused on two factors: health beliefs and the socioeconomic wellbeing of the community at large

(Unwin et al., 2001). Hence, the conceptual framework of this study was centered on the health beliefs model.

Assumptions implied by this theory deal with effective management of the disease through elimination of cultural beliefs that hinder proper care for the disease. This can help reduce costs by creating cost-effective methods of managing the disease. Application of the secondary prevention methods creates a reduction in expenses based on the decrease in patients' need for frequent medical care.

The continuous care of chronic disease is less effective on individuals of low socioeconomic status, which has resulted in the leading cause of death and a high level of morbidity (WHO, 2015). As stated by WHO (2015), actions like secondary prevention can be taken to reduce the high rates of morbidity amongst individuals with chronic diseases like cancer and chronic obstructive pulmonary disease (COPD) and type II diabetes (WHO, 2015). These actions include education on the benefits of maintaining healthy lifestyles, engaging in physical activity, tobacco usage, and unhealthy diet (WHO, 2015). Another study conducted by Halpin, Morales-Suarez-Varela, and Martin-Moreno (2010) shows that secondary prevention on chronic diseases like cervical cancer prevents premature death among young women (Halpin, Morales-Suarez-Varela, & Martin-Moreno, 2010). This secondary prevention includes regular Pap smear screening (Halpin et al., 2010). This screening has been said to enable healthcare professionals to develop effective vaccines against cervical cancer, which can in turn control or eliminate the disease (Halpin et al, 2010).

Abboud et al. (2011) conducted a study on randomly selected 79 SCD children from the Stroke Prevention Trial in Sickle Cell Anemia (STOP) study. The authors explored the effect of blood transfusion a secondary prevention on the risk of silent brain infarction among patients with SCD. Addoud et al., 2011showed that the continuous use of blood transfusion among children with SCD prevented the children from silent infarcts (stroke) and abnormal magnetic resonance angiography (MRA). Those who stopped the blood transfusion continued to have silent infarct and abnormal MRA (Addoud et al., 2011).

In this research, the challenge identified is the steps necessary to implement secondary prevention methods in Nigeria, a country with fixed traditional beliefs and culture, and to make these changes permanent. The research questions closely relate to this challenge based on the fact that each question is geared towards identifying the similarities in the lifestyles of individuals living with SCD in order to effectively implement secondary prevention. By identifying the socioeconomic status, cultural traditions, quality of life, and the general lifestyle of individuals living SCD, the research was able to identify how public health professionals can implement secondary prevention to eliminate socioeconomic and cultural barriers in SCD in Nigeria.

Conceptual Framework

The framework used in this study is the health belief model. The health belief model explains the way people think about the health behaviors they cultivate, and how it can hinder pursuits for medical attention (Turner et al., 2004). This theory was used to help determine the health-related behaviors of people living with SCD. The major health

belief model concepts include: perceived severity, perceived susceptibility, perceived benefit, perceived barrier, modifying variables, cues of actions, self-efficacy.

Perceived severity is the act whereby people think SCD is as a result of reincarnation, but after realizing this disease is causing more financial consequence which can initiate the increase in money spent in the wrong direction by paying for the treatment indicated by spiritualist instead of seeking proper medical attention. The individual may perceive the disease as a serious problem (Turner et al., 2004).

Perceived susceptibility is based on SCD persons' belief of disease severity is and the consequence of the disease (Turner et al., 2004). In other words, when the SCD patients believe they are susceptible to complications or premature death, they tend to seek better health to minimize the risk of the health complications or death. However, when they believe SCD is solely a cause of reincarnation and faith, they may be said to have low perceived susceptibility; hence, this perception may lead to unhealthy behaviors (Turner et al., 2004).

Perceived benefit is when SCD individuals believe that education on how to better manage the disease can help prevent premature death. This means they believe in this particular action to help reduce susceptibility to health problem and decrease the seriousness of the disease (Turner et al., 2004).

Perceived barriers can be referred to as the obstacle behind changing health behavior (Turner et al., 2004). Even though SCD patients know they have a life threatening disease, the low socioeconomic status can pose as a barrier to getting the appropriate

health care or good access to health care (Turner et al., 2004). Also, the perception of others on SCD can also be a barrier when they base their belief on cultural aspect.

Modifying Variable includes race, sex, age, race ethnicity, educational level, socioeconomic status, knowledge, culture, skills, and religion. Cues of Action are factors that can promote the start to change in health behaviors (Turner et al., 2004). For SCD patients factors that can help change health behaviors may include media messages on how serious SCD is, take home educational pamphlets, health warning labels, education provided to family members and friends, and constant reminder of the severity of SCD on other family member or friends (Turner et al., 2004).

Self-efficacy involves the ability to have the belief of doing something (Turner et al., 2004). Generally it is known that people do not initially try to do something unless they believe they can do it (Turner et al., 2004). If SCD patients believe seeking change in health behavior is useful in order to eliminate premature death and complications, but do not think they have the capacity (barrier) to carry out the action, there is a high possibility that they will not endeavor to cultivate the change in their health behavior (Turner et al., 2004).

From this framework, I focused on identifying the cultural practices of Nigerians that might affect the QOL of individuals living with SCD. I also identify the socioeconomic and cultural factors that influence the comprehensive management of SCD.

Literature Review

The literature review provided insight on previous studies that have been performed by other researcher in relation to factors affecting SCD. It also included studies on adults with SCD, QOL in adult with SCD, socioeconomic factors affecting SCD, and cultural factors affecting SCD. Furthermore, it provided detail analysis of the studies and the relating factors with emphasis on their effect on SCD. With that being said, in this aspect of the literature review, previous researchers have done very little research and less research has been conducted in the last five years.

Adults With SCD

Literature has documented the negative impact of SCD in adult life. Previous research has examined pain associated with SCD in adults, the circumstances of deaths among adults with SCD, the impact SCD on arterial blood pressure, and how infection rates differ in adults living with SCD (Dabari et al., 2006; Oguanobi et al., 2010; Platt et al., 1991). A study conducted by Darbari et al. (2006) at the Howard University Hospital Washington, D.C., U.S. on 141 adult patients between 1976 and 2001 shows that the prominent cause of death among adults with SCD is the pulmonary hypertension (Darbari et al., 2006). As stated in Darbari et al. (2006) the other leading cause of death is the sudden death; this can be characterized as the death that was not expected from a patient either in their home or at an inpatient facility without the effect of SCD crises. This is followed by renal failure and Iron overload. The iron overload can be due to chronic blood transfusion received to treat complications like stroke and lung disease (Darbari et

al., 2006). However, Booth, Inusa, and Obaro (2008) identified the primary cause of mortality among adults living with SCD was infection (Booth, Inusa & Obaro, 2008).

Platt et al. (1991) carried out a study to determine the incidence of pain episodes among adults with SCD and associated risk factors and early death. A prospective study was conducted on 3,578 patients between 1979 and 1988. It was noted that the most common cause of morbidity among individuals with SCD is pain, for instance, bone marrow ischemia and necrosis. The pain severity has caused premature death in SCD patients above the age of 20; however, with the increment in the HbF, SCD pain episode tend to decrease (Platt et al., 1991).

A study conducted by Gladwin et al. (2004) identified a significant relationship between pulmonary hypertension and death in patients with SCD. The prospective study was carried out among 195 SCD adults using a Doppler echocardiography assessment to discover any pulmonary hypertension within the period of 18 months (Gladwin et al., 2004). The study further concluded that deaths were more likely to occur in SCD patients with pulmonary hypertension compared to those without pulmonary hypertension (Gladwin et al., 2004).

Oguanob et al. (2010) examined the impact of arterial blood pressure on adults with SCD. The arterial blood pressure can be a result of frequent “crises, weight, body mass index, body surface area and blood transfusions” (Oguanobi et al., 2010, p. 330). The study compared adults with SCD and arterial blood pressure to those without SCD. The study concluded that arterial blood pressure mostly occur in adults with SCD than those without the SCD (Oguanobi et al., 2010).

Literature has also explored how infection also plays a big role in SCD. Evidence showed that infection is the primary cause for adult morbidity and mortality, more specifically adults diagnosed and living with SCD (Booth et al., 2009). Within a 20-year period, the infection is said to have caused 20%–50% of deaths among SCD patients in the study conducted by Booth et al. (2009). Infection can cause impaired splenic function due to the susceptibility to bacteria (Booth et al., 2009). Booth et al. (2009) continued to explore how developed countries have been able to minimize the infection rates in SCD patients from childhood with the aid of prophylactics and vaccination. These interventions help minimize the mortality rates in SCD patients (Booth et al., 2009). However, in developing countries, there are still significant numbers of people who die of SCD everyday due to infection and lack of preventive measures (Booth et al., 2009).

Quality of Life

Diminished QOL among SCD individuals is influenced by factors like stigma, absence of medical care, family, unemployment, the disease process, social activities, discrimination, and social isolation (Mann-Jiles & Morris, 2009). A Study carried out by Mann-Jiles and Morriss (2009) examines "the QOL in adult patients with SCD" living in United States (Mann-Jiles & Morriss, 2009, p. 340). The study was conducted on 62 SCD adult patients who were 18 years and older receiving care at an outpatient hematological and oncological disorders clinic located on the campus of Midwestern University (Mann-Jiles & Morris, 2009). The study results show that adults with SCD tend to have diminished QOL that is relatively lower than the general population (Mann-Jiles & Morris, 2009).

The stigmatization attitudes of individuals with SCD are progressively known (Ani et al., 2012). Adeyemo et al. (2015) conducted a cross sectional study on "health related quality of life and perception of stigmatization in adolescents living with sickle cell disease in Nigeria". The study was conducted on 160 adolescents, which included 80 participants with SCD and 80 participants without SCD. Health surveys were distributed to participants to measure how stigmatization affects the HRQL. The results of the study shows that participants with SCD have lower HRQL than those without the SCD (Adeyemo et al, 2015).

Socioeconomic Implications

Economic implication of SCD is a factor that not only affects the patient, but also family members or relations (Mitchell et al., 2007). Sickle cell disease management can lead to high health care costs. Even though there are interventions to manage SCD, the costs can limit participation in those interventions. There are health care services readily available for SCD patients however patients and their families bear the burden of the costs (Mitchell et al., 2007).

Ballas (2009) mentioned that the management of SCD ranges from frequent acute pain episode requiring hospitalization, the use of intensive care units and facilities, surgical and nonsurgical treatment, and multidisciplinary method to management (Ballas, 2009). There are different indicators used to evaluate the yearly health care cost among individuals with SCD, these include: hospital admissions, clinic visits, doctors' appointments, emergency department appointments, diagnostic procedures (scans, laboratory, and radiography) cost, and prescription cost (Ballas, 2009). It is estimated that

the age lifespan of male and female with SCD is 42–45 years, and the lifetime cost is said to be about $2,696,400 for male in a total of 24 years, and $3,145,800 for adult female (Ballas, 2009). Ninety-seven percent (97%) of the hospital admission was related to painful crises, giving the average annual costs for health care to be $725,037 in 2008 (Ballas, 2009). Sickle cell disease is said to have a high utilization of medical resources mostly among adults for the care of SCD; this care is said to be inpatient hospitalizations and physician visits, in which hospitalization is the main cause of increase cost of treatment (Kauf et al., 2009).

An updated study performed by Kauf et al. (2009) on the total cost of medical care that is estimated to serve children and adults living with SCD (Kauf et al., 2009). Among the 4,294 individuals who participated in the study, the monthly per patient average cost was $1,946; for adults between the ages of 30 to 39 average cost per patient-month was at $2,853 and children between the ages of newborn to nine years were at $892 per patient-month. However, the cost of care for patients with SCD varies between $10,704 among patients between the ages of 0 and 9 to $34,266 among patients between the ages of 30 and 39 (Kauf et al., 2009). Thus, the average patient cost per year between the ages of 0 to 45 is estimated to be $953,460. At 3% discount rate, and the lifetime cost is $460,151 based on Medicaid received by the patient (Kauf et al., 2009). The authors used data from Florida's Medicaid program for SCD patients enrolled for at least six months (Kauf et al., 2009). Reducing hospitalizations helped reduce the cost of care for SCD patients. Lanzkron et al. (2006) mentioned in their study on the use of hydroxyurea to minimize the hospitalization. Researchers found that hydroxyurea reduced the

hospitalization rate by 44% and reduced medical care cost by $5,210 annually for each patient with SCD. Those placed in the placebo group did not show any significant difference on health care cost (Lanzkron et al., 2006). Recommendations for managing the disease are oral prophylactic penicillin, transcranial Doppler examinations, hydroxyurea, analgesics, physical therapy, and blood transfusion (Yawn et al., 2014).

Panepinto et al. (2008) examined the "impact of family income and SCD on health related quality of life (HRQL) of children" (Panepinto et al., 2008, p. 5). Panepinto et al. (2008) performed a cross-sectional study on "children with SCD who presented for a routine check-up and children without SCD who presented for a routine check-up" (p. 6). The study was conducted on 178 patients between the ages of 2 and 18; 104 of the participants with SCD visited the Midwest Sickle Cell Center (MSCC) (p. 6) and 74 without SCD visited the Downtown Health Center in Milwaukee, Wisconsin (p. 6). Panepinto et al. (2008) grouped family income into three which include; less than $20,000 as the lowest, $20,000-$40,000 as median, and greater than $40,000 as highest (Panepinto et al., 2008). The result showed that "low family income affects the HRQL of children with SCD" (Panepinto et al., 2008, p. 12).

Cultural Belief

Cultural beliefs are said to affect the attitude towards SCD especially in developing countries (Anie et al., 2010; Ohaeri & Sokunbi, 2001). Most people turn to their religion, ethical norms and spiritualism to seek refuge for the cause and care of SCD (Anie et al., 2010; Ohaeri & Sokunbi, 2001). This may be related to the environment culture they are surrounded by (Ohaeri & Sokunbi, 2001). Most research articles looked

into the behaviors towards SCD by understanding how people deal with the disease. Another study performed by Anie et al. (2010) stated that "150,000 children are born with SCD annually" (p. 1), this study focused on the "psychosocial impact of SCD – a Nigerian perspective" (Anie et al, 2010, p. 2). Anie et al. (2010) and Ohaeri and Shokunbi (2001) showed how beliefs influence health behaviors towards SCD. Many Nigerians believe that SCD is a result of reincarnation or *Oghanje* in the Igbo language, and *Abiku* in Yoruba language. Reincarnation in this culture refers to repeater babies who swiftly arrive into mortal existence (Anie et al., 2010; Ohaeri & Sokunbi, 2001). The myth surrounding Ogbanje and Abiku is that some people were once born in the world to realize that the world would be too difficult for them to stay or live due to laziness, and would not be able to make any impact due to competition of other children (Asakitikpi, 2008). For this reason, they die; thus, the gatekeeper in heaven returns them back to earth after finding out they died because of their laziness (Asakitikpi, 2008). However, most of the Ogbanje children do not live past their fifth birthday, and some of the children die on their wedding day (Asakitikpi, 2008, p. 60). The cycle of birth and death is repeated in the same family (Asakitikpi, 2008). In this case, the child who is reborn into the same family is given names like Malomo (don't die again), Kokumo (he is not dying again), Onwubiko (I plead you not to die again), and Akpoyoma (the world is good) (Asakitikpi, 2008). As civilization progressed children who are the victims of reincarnation are children with SCD, the escapade occurred due to lack of understanding of the disease (Asakitikpi, 2008). With the help of medical facilities and knowledge most Nigerians have better understanding of the early death of children (Asakitikpi, 2008).

Anie et al. (2010) mentioned that the religious healing such as prayer is one measure taken in addition to medical treatment to manage SCD based on the thought that SCD is supernatural or a divine retribution (Anie et al., 2010). In some other parts of the world like the United States, spirituality may be important when dealing with SCD (Cooper-Effa et al., 2001). Cooper-Effa et al. (2001) studied the religious wellbeing and coping among individuals with SCD. The results indicated that the spiritual (prayers and believing in the prayer) is associated with the improvement in the health status of people affected by SCD (Cooper-Effa et al., 2001). Pain, complications, and community attitudes toward SCD are main causes of psychosocial problems among individuals with SCD. In Nigeria, cultural and religious beliefs are mostly adapted as a coping mechanism for management of SCD (Anie et al., 2010). The positive mindset of individuals with SCD had helped improve the perception of SCD, and the patients have been able to manage life with SCD (Anie et al., 2010; Cooper-Effa et al., 2001).

Summary

The literature review presented in this chapter explained some previously published research on SCD. Information derived from these literatures has helped identify the gap of knowledge that can help identify the practices of Nigerians that affect the QOL of people living with SCD. The literature illustrated that adults with SCD mostly die of pulmonary hypertension, arterial blood pressure, and infection that is mostly seen in developing countries. In addition, adults with SCD generally have low QOL due to low socioeconomic status and diminished access to healthcare. Cultural beliefs can also be a factor to a diminished QOL due to traditions and norms fixed within

these societies. The next chapter, Chapter 3, will describe the research methodology of the study. The research method will consist of the research design and rationale, role of the researcher, methodology and ethical procedure.

Chapter 3: Research Method

Introduction

The qualitative approach explored the effect of socioeconomic factors and cultural beliefs on adults with SCD in Lagos, Nigeria. The sample populations are participants who present themselves at the Sickle Cell Foundation Nigeria (SCFN), and Lagos University Teaching Hospital (LUTH). This chapter describes the research design and rationale, role of the researcher, methodology, and issues of trustworthiness.

Nigeria is a country with 36 states and a population of 166.2 million based on the 2012 Nigeria National Bureau of Statistics (World Population Review, 2014). The population increased to173.6 million in 2014 (World Population Review, 2014). Nigeria shares borders with Benin, Niger, Chad, and Cameroon (Every Culture, 2014). The population of Lagos is 17,552,942 (Lagos State Government, 2011). Lagos' large population provides a variety of ethnic groups and support generalization of the study (Lagos State Government, 2011).

Research Design and Rationale

This qualitative study is exploratory since extensive information has not been written about the adult population of Nigeria with SCD. Therefore, the following research questions are asked to derive the root cause of a problem (Creswell, 2009).

1. What are the socioeconomic factors affecting the QOL of patients living with SCD in Nigeria?

2. What are the knowledge, attitudes, and beliefs of patients living with SCD in Nigeria that may contribute to the poor management of the disease that can lead to poor QOL?
3. What are the negative impacts of SCD on the affected persons?
4. What are the possible ways of educating people living with SCD and their families to reduce the burden of SCD and improve the QOL of the affected individuals?

The study aimed to gain better insight on the effects of the socioeconomic and cultural factors that affect the QOL of individuals with SCD in Nigeria.

Participants were drawn from SCD patients who come for routine check-up at the SCFN and LUTH. All these centers are located within the Lagos metropolis. SCFN is a dedicated center where people living with SCD visit for different clinical and laboratory investigations and genetic counseling as it relate to SCD. The average number of adult patients that attend the SCFN on a weekly basis is twenty; also, LUTH runs sickle cell clinic for adults once in a week with the average of fifteen patients per week. Health care providers at the clinics were briefed about the study details and asked to inform patients about the study.

Research design is a plan and procedure that traverses the decision of a researcher from a general idea to specified data collection and analysis methods (Creswell, 2009). This was used in the main study to ensure that data gathered provided answers to research questions or test theories as unequivocally as possible (Creswell, 2009). Research design

minimizes probabilities of drawing incorrect causal inferences from data (Creswell, 2009).

The qualitative strategy includes the phenomenological approach whereby the all experience about the origin of a problem expressed by the participants (Creswell, 2009). The phenomenological approach in turn helps understand participants' life experience. In order to understand the participants in this study, known ideas or self-experiences were set aside (Creswell, 2009). The phenomenological approach was utilized to explore how socioeconomic status and cultural belief affect adults with SCD in Nigeria. Phenomenological approach develops knowledge through description of lived experience in the sense that participants describe how their lives have been affected socioeconomically and culturally (Creswell, 2009).

Other methods of qualitative strategies have been looked into, but concluded it may be less operational in providing a detailed understanding of what SCD people experience. For instance, a grounded theory provides broad information by generating a theory about the live experience of the participants, and not providing specific information (Creswell, 2009). In other words, the theory cannot provide adequate information on what SCD individuals are experiencing. A case study strategy may not be appropriate for this study because of the different data collection method in specific stages over a period of time to detect information (Creswell, 2009). A case study approach does not provide information of experience from participants. Case study approach might have been considered for this study if the study is concerned with occurrence of experience over time; however, the study is mostly focused on current

experience that occurred as a result of phenomenon. A narrative research, which is a strategy where by researchers collect stories about the life of the participants (Creswell, 2009), is not considered for this study because the study is not planning on deriving chronological stories from participants about their life experience. The final method is ethnography strategy; this studies a "particular cultural group over a long period of time" (Creswell, 2009, p. 13). Ethnography could be used for this study if the study is only going to focus on one particular ethnic group in the community, thus this is not as accurate as phenomenological approach that focused on different ethnic groups to derive information about participants and their experience.

Advantages of using a qualitative phenomenological approach include the ability to collect historical information from the participants, researchers having control over the questions provided to the participants, and researchers do not need to directly observe participants (Creswell, 2009). Limitations to this approach include provision of indirect information which can filter the view of a researcher for the purpose of the study and eliminating possible areas for error, researchers must assign a specific location for the information to be disseminated; therefore, a field setting is not an adequate location for feedback to be dispersed from the participants, and not all participants are equally articulated (Creswell, 2009).

Role of the Researcher

Open-ended questionnaires were distributed to the participants for the purpose of the study. Due to the nature of this study, which is attempting to receive authentic answers from its participants, a business relationship was established with each

participant. A personal relationship with the study participants can potentially skew the results of this study and cause the participants to invalidate the data results (Given, 2008). The participants need to feel comfortable enough to answer all survey questions honestly without feelings being compromised or lead them to be judged. The participants were asked the questions and their responses were audio taped. Prior to the commencement of the study, medical directors and the program coordinators in charge of the SCD centers were contacted via email or telephone informing them of the study procedure. Also, the telephone interview was conducted at a location convenient to the participants. Oral informed consent was obtained and confirmation from the prospective participants and their responses were audio taped. Content of the informed consent included the study background, study procedures, risk and benefit of the study, study procedures, the voluntary nature of the study, compensation involved for participating in the study, who to contact during the study, and confidentiality in participation and responses provided. The informed consent process was completed before the questionnaire was administered to a participant. Each participant provided an audio taped oral approval to the informed consent form acknowledging participation in the study. Questionnaire responses from the participants were collected the same day questions were administered to the participants. Institutional Review Board (IRB) Walden University and the Health Research Ethics Committee (HREC) provided approval to conduct the study.

In order to avoid missing any data provided by the participants, each participant's responses were recorded, and a friendly, nonjudgmental relationship was established with the participants to encourage honest responses. Conducting this study as a native of

Nigeria who is also living with SCD, there can be ethical issues based on how I related to the study's participants. However, with that being said, the participants were not exposed to the details of the personal life of anyone else involved in the study other than their self. By establishing this level of separation and maintaining a professional environment, the participants were not only able to offer genuine answers in the survey, but the research was also less susceptible to error based on the personal lifestyle of anyone else involved in the study.

Methodology

Participant Selection Logic

In a qualitative research, the research objective and characteristics determines the number of participants to be recruited for the study. In this study, a random sampling was used in selecting participants (Creswell, 2009; McKenzie, Neiger, & Thackeray 2008). Random sampling gives study population an equal chance of being selected to participate in a study. Random sampling reduces the chance of bias among study samples (McKenzie et al., 2008).

Other types of sampling strategies like snowball or purposive strategies may be appropriate for qualitative research, but causes some restrictions towards collecting sample (Creswell, 2009; Marshall, 1996; NEU, 2012). For instance, purposive sampling strategy restricts researcher from having concrete number of participants to conduct a study; this strategy is a perfect strategy for study with no time restriction (NEU, 2012). Also, purposive sampling strategy can best fit a theoretical qualitative approach and not a phenomenological approach (NEU, 2012). Furthermore, the snowballing sampling

strategy is a form of purposive sampling also known as referral sampling (NEU, 2012). In the case of snowballing strategy, the researcher needs a social network that can help refer the researcher to potential participants (NEU, 2012). This strategy is mostly used to locate samples in hidden populations who are not easily accessible through other sampling strategies (Creswell, 2009; Marshall, 1996; NEU, 2012). Hence, the random sampling was appropriate for this study due to time restrains, and participants' accessibility.

The pool of participants consisted of 30 SCD male and female patients who were in stable health condition in Lagos, Nigeria, and were recruited from LUTH and SCFN. The target population is English-speaking adults. Participants were above age 18 and have known of their SCD diagnosis since early childhood. Also the participants were able to speak English Language fluently. People with SCD who were above the age 18 and have had SCD since their early childhood established better understanding of the experience on how having SCD have impacted them or have had SCD for at least more than five years. The study participants were also in steady state. Study shows that participants with SCD for most of their lives have been through socioeconomic or cultural constraints one way or the other (Ballas, 2009; Kauf, 2009; Panepinto et al., 2008). Those who have just recently discovered having SCD might not have experience in socioeconomic impact or cultural impact.

Exclusion criteria included SCD patients who were not in stable health condition and were currently experiencing a SCD crisis (University of Michigan Health System, 2009). For this reason, unstable participants did not take part in the study because they

may not be able to articulate questions appropriately as a result of their condition. Also, those who were recently diagnosed with SCD within the last five years or those who were not diagnosed with SCD were not included in the study. Lastly, participants below the age of 18 were excluded from the study.

Participants were drawn from SCD patients who come for routine check-up at the Sickle Cell Foundation Nigeria (SCFN) and Lagos University Teaching Hospital (LUTH). The two centers are located within the Lagos metropolis. Recruiting from these locations was undemanding based on previous relationship established with the medical directors and the program coordinator. SCFN is a dedicated center where people living with SCD visit for comprehensive management of SCD. The sickle cell clinic located in LUTH has an average of twenty patients on a weekly basis. The program coordinator at SCFN is approached to seek permission for recruitment of study participants. This process is explained further in the procedures for recruitment and participation section.

In order to give an accurate picture of how socioeconomic and cultural factors impact individuals, a sample size of 30 participants with SCD was gathered with emphasis on participant diversity with individuals coming from different ethnic groups. Most patients with SCD may be marked by the same types of experiences, being that SCD is accompanied by the same diagnosis among individuals with the disease (Indiana Hemophilia & Thrombosis Center [IHTC], 2012). Based on the type of experiences SCD patients are faced with the sample size is able to accurately depict the effect socioeconomic status and cultural belief on SCD patients (Asnani, Reid, Ali, Lipps, and Williams, 2007; Palermo, Riley, and Brian, 2008). The pool consisted of 30 participants

as opposed to 10 or 20 in order to receive diversity and variety in the sample. Also, the use 30 as opposed to 50 or 100 participants was based on the time allotted to complete this study. Within a short period of time, the study was completed with 30 participants and data were analyzed with enough time to go over any possible errors. This would not be possible with 50 or more participants. Due to the fact that SCD patients in Nigeria suffer from the same diagnosis and symptoms and are surrounded by similar cultural and socioeconomic backgrounds, the responses from each participant are bound to be similar. Therefore, the study only required 30 participants in order to be adequately saturated and fulfill the study's requirements.

Instrumentation

An open-ended questionnaire with an interview protocol was used to collect data over the phone. The interview process took approximately one hour for each participant. The questionnaire was structured into the following sections: demographics, knowledge, attitude, and practices of people living with SCD, economic factors influencing the outcome of SCD, and strategies for alleviating SCD burden in Nigeria; the questionnaire contains16 Likert scale questions, 13 open-ended questions and 10 demographic questions.

The study research questions are adapted from Burckhardt and Anderson's (2003) QOLS (Burckhardt & Anderson, 2003). The Burckhardt and Anderson (2003) QOLS adapted questionnaire was used to inform the development of study questionnaires and gave opportunity to ask probing questions. There was a 16 QOLS questions based on Flanagan's QOL scale, that are categorized into "material and physical well-being;

Relationship with other people; social, community and civic activities' personal development and fulfillment; and recreation" (Burckhardt & Anderson, 2003, p. 1; Flanagan, 1982; Mann-Jiles & Morris, 2009, p. 345). A7-point Likert scale is used to assess QOL of the adults. The participants before proceeding with the open-ended questions answered the 7-point Likert scale question. The 7-point Likert- scale was used in order to allow for a wider range of effective response from participants on QOL (Burckhardt & Anderson, 2003). "The seven responses are "delighted" (7), "pleased" (6), "mostly satisfied" (5), "mixed" (4), "mostly dissatisfied" (3), "unhappy" (2), and "terrible" (1)" (Mann-Jiles & Morris, 2009, p. 345; Burckhardt & Anderson, 2003, p. 2). The "score can range from 16 to 112; higher score are translated as higher QOL" (Mann-Jiles & Morris, 2009, p. 345). This survey is highly efficient for chronic diseases such as SCD (Burckhardt & Anderson, 2003). This instrument took approximately 10 minutes to complete. After the QOLS was completed, participants were asked to explain the reason for ranking their response to QOL. Hence, the 10 demographic questions were validated and adapted from Mann-Jiles and Morris (2009) (Mann-Jiles & Morris, 2009).

Prior to beginning the interview process, consent was established by reading the consent form to the participants and requesting an oral confirmation agreeing to participate in the study. Proof of the affirmative confirmation was audio taped. Participants in the study were represented by a unique number to protect their identity. The interview was audio taped. Each tape is labeled individually by using unique identification numbers (ID). This identification number was used on notes.

For Researcher-Developed Instruments

The instruments developed for this study was derived from the literature review for the study. I was able to compile a group of relevant questions that offer further insight into QOL and living with SCD. The literature review was the driving force guiding towards gathering the necessary group of questions. This particular study has not been studied extensively in the past; therefore, creating a relevant questionnaire for it was a challenging task. Materials and methodology of the previous literature review helps create sources for questions that are used in this study. For example, the socioeconomic aspect of SCD in the literature review provided more information and guidance on how to go about developing a questionnaire. Towards this study, Mann-Jiles and Morris (2009), was the main source of developing instrument for this study.

Grounded on the nature of the study being conducted, content validity can only be determined by analysis of data. With this study, it is important that ethics and precautions are taken in order to avoid partial data results because the data are heavily relied on for study validity. Further, by organizing the initial data collected in the categories based on themes and the types of statements given by study participants, validity was established in this sense (Creswell, 2009).

The data collection instruments being used in this study are the sources outlined in the literature review. These sources are sufficient for this study based on the nature of the topic being studied. In Nigeria, the experiences of all SCD patients are generally similar case-by-case; therefore, research findings can be carried from one researcher to another and utilized as a basis for their study. The information provided in the literature

review initiated the instruments in which the questions to the research study were answered. The instrument touches the basis on the socioeconomic and cultural impact on individuals with SCD and how their QOL is affected.

Procedure for Pilot Study

A pilot study was conducted on five individuals to test the questionnaires that were provided for the study. Program coordinators, medical directors, and any other appointed employees participated in the pilot study. Although the pilot study participants do not have SCD, they manage people with SCD on a daily basis, and they have significant idea of how SCD impacts the life of the patients. Prior to conducting the pilot study, the program coordinator and medical directors of the study locations were contacted and apprised about the purpose and procedure of conducting the pilot study. Pilot study validated the informed consent process, interview protocol, and receipt of desired responses to answer the proposed research questions. The purpose of the pilot study was to provide a framework that can be used to direct the main study (Teijlingen & Hundley, 2001; Kim, 2010). The pilot study alerts on possible problems with the study, areas for adjustment, and research feasibility (Teijlingen & Hundley, 2001; Kim, 2010). The IRB approval number for this study is 07-07-15-0237277 and the HREC approval number is ADM/DCST/HREC/404.

Procedures for Recruitment and Participation

The following procedures are carried out towards recruiting participants, collection of data, analysis of data and data validation.

1. The program coordinator and medical directors at the study locations were approached via telephone or in person to seek permission for recruitment of study participants, use of clinic facilities to complete the interviews, and to retrieve information concerning the study.
2. A descriptive letter was forwarded to the medical directors and program coordinators specifying the nature of the study, and request in assisting in recruiting participants by handing out flyers to invite participants for the study. Also, letters to the participants were given to the program coordinators and medical directors to distribute to prospective participants along with the flyer.
3. After receiving permission from the program coordinator and medical directors, health care providers at the clinics were briefed about the study details.
4. A pilot study was conducted on five participants to provide structure that can be used as a guide for the main study.
5. After a successful pilot study, flyers were posted in different study locations with contact information for people interested in taking part in the study. Included in the flyer were procedures, processes, and the compensation for participating in the study.
6. Prospective participants who were interested in participating in the study made contact via the telephone number or email address provided on the flyer to schedule an interview date and time.

7. Prospective participants selected a time between 7 a.m. and 5 p.m. Monday through Saturday to schedule an interview. The allocated date was in the fall of 2015, from October 07, 2015 to October 28, 2015.
8. On the selected interview date, each of the study participants provided an oral confirmation to the Informed Consent Form upon being read a copy of the proposed study for their perusal. The participants were informed of parts to the interview; demographic information, 7-point Likert-Type scale questions on participants' QOL, and the open-ended questionnaires. Participants were given a 1000 Nigeria Naira (five U.S. Dollars) as compensation. Participants are more inclined to partake in the study if presented with the opportunity to receive compensation (Johnston, 2009).
9. The recruitment result was as expected and saturation achieved.
10. After the interview, audio-tapes were transcribed and analyzed.
11. After the interview was completed, the procedures were briefed one more time, in order to educate the participants on the nature of their involvement in the study, and how the information provided were kept confidential. A follow-up was required if at the time of the interview, the participants request to continue the interview some other time.
12. Two graduate students carried out the validation of the transcribed interview. The graduate students were contacted via telephone or email seeking their interest in participating in the validation process of the study.

13. Unique ID numbers were assigned to the participants before the students verified the transcripts. The two graduate students were approved by the Walden University dissertation course professor to certify the students' capability to perform the validation process. The graduate students observed the ethical protection of the participants. Also, the graduate students were compensated with five US dollars per transcript.

The letters to participants were used for both the pilot study and the final study, and the flyers were used for the final study only.

Data Collection

Data were collected during one interview period for each participant. During this interview, informed consent was read and obtained by providing oral confirmation to the informed consent form; background of the participants was obtained, and followed by the open-ended interview. Based on the personal information gathered about each participant, a clear understanding of the type of family and upbringing they have was depicted.

The interview described the nature of the study and revealed information to help build affinity and created opportunity to listen to the participants experience impartially. The unrestricted question came from the research question that enables participants to provide a concrete detail of their experience. Participants were able to describe their experience and how they have been affected. The data collection process (interview) was conducted at location that best suits the participants, locations where there will be less

distraction and safe guard privacy. Also, the data were collected and tape-recorded during a three-week period, in the Fall of 2015.

Data Analysis Plan

The process of this data analysis did not need to include any software programming in order to retrieve research findings. Extensive note taking and audio transcribing was the method used to pool meaning from the collected data. The type of research at hand requires pooling themes, patterns, categories and relationship which can all be found by human eyes (CLIP, 2007).

The first step was to gather data from the participants to be transcribed. Next, two Walden University graduate students (one male and a female) were assigned with the task of verifying the transcript findings in order to remove the possibility of bias from the data analysis (CLIP, 2007). After the graduate students performed the verifications, the responses from the participants were grouped based on themes, patterns, and categories. Using this method to organize the responses allowed for easily define similarities and differences (CLIP, 2007).

Second step, detailed notes of the transcript with specifications on the document detailing which respondent the data were pooled from, were taken. Each participant was assigned an ID number; the ID was the number that the participants were recognized by (CLIP, 2007). This ID number was used to differentiate each participant's responses. A table was formulated –this table can be found in the Appendix D—to organize responses based on the ID number, question number, responses, and code. The question number which is the figure that identifies any given question; and codes were used to describe the

type of response provided by the participants. The table was organized question-by-question. The question-by-question analysis helps to easily separate and analyze data responses (CLIP, 2007).

There were five different identifying codes Socioeconomic factor not diminishing QOL result (SR), Cultural factors not diminishing QOL result (CR), Socioeconomic factors diminishing QOL (SDQR), Cultural factors diminishing QOL result, (CDQR), and socioeconomic and cultural factors diminishing QOL (SCDqR). The Meaning are listed below:

- Socioeconomic factor not diminishing QOL result (SR): In this study, this means that the socioeconomic factor of individuals with SCD does not affect or diminish their QOL.
- Cultural factors not diminishing QOL result (CR): In this study, this means that the cultural factor of individuals with SCD does not affect or diminish their QOL.
- Socioeconomic factors diminishing QOL (SDQR): In this study, this means that the Socioeconomic factor of individuals with SCD affects or diminishes their QOL.
- Cultural factors diminishing QOL result, (CDQR): In this study, this means that the cultural factor of individuals with SCD does not affect or diminish their QOL.
- Both socioeconomic and cultural factors diminishing QOL (SCDqR): In this study, this means that the Socioeconomic and cultural factors of individuals with SCD affect or diminish their QOL.

Also, an attendant form (see Appendix F) was developed to record the study identification number of participants, names of participants, and to identify those who participated in the study (CLIP, 2007).

The third step was to review the responses in order to find themes, patterns, and relationships (CLIP, 2007). The themes are identified as any central idea that was recurrent in the responses of the participants, the patterns were recognized as the form with which the participants gave the responses, and the relationship was how responses relayed to one another. The final step was to summarize the data, which includes the information on the themes, patterns, and relationship found in the data (CLIP, 2007). I discussed and took notes on what had been learned. The focal points were the themes found which was the central idea and recurrent responses of the participants.

The identification between the study data and research question "what are the socioeconomic factors affecting the QOL of patients living with SCD in Nigeria" was based on the fact that the SCD individuals are going to provide answers on a questionnaire that helps to identify the nature of the socioeconomic status in relation with their QOL. In the demographic questionnaire and the open-ended question on how SCD patients have been affected economically, SCD individuals answers questions on how their socioeconomic status has affected their QOL to date. Hence, any discrepant cases were handled by eliminating their data from the study by taking out the questionnaire and not counting their result.

Issues of Trustworthiness

This study required its own set of specific methods for establishing trustworthiness. Trustworthiness can be measured by determining the degree of credibility, transferability, dependability, and conformability (Robert Wood Johnson Foundation, 2008). Credibility refers to retrieving the validity of a study (Robert Wood Johnson Foundation, 2008). Credibility was performed in this study by conducting peer review of the findings. The peer review of the finding includes giving the transcribed documents to two graduate students for review. The graduate students checked to make sure the transcribed documents do not contain obvious mistakes made in the course of transcribing. The codes that were used during data analysis were well monitored and made sure there was no drift in the meaning of codes or using codes for other meaning. Also, prolonged contact was used to establish validity by restricting contact between the participants. This was carried out by not allowing each participant to be privy to knowledge on other participants. Another threat to validity is the social desirability. Social desirability may occur when the participants give certain response to the questionnaire to please the researcher (McKenzie, Neiger, & Thackeray, 2008). To prevent the social desirability response from the participants, an encouraging environment was provided for the participants by making them feel free and making sure there was no pressure towards answering the questionnaires.

Transferability measures the degree to which research findings can be applied to other context (Robert Wood Johnson Foundation, 2008). In this case, transferability was measured by asserting that participants taking part in the study have been diagnosed with

SCD. Once diagnosis of SCD has been established, I can analyze how the finding can be applied to other context. For instance, if the study location is changed from Nigeria to another West Africa country like Ghana, is the result similar. In this study, there is a probability of the situation being similar due to the fact that both countries have people living with SCD, and have similar cultural background.

Dependability illustrates that the research does not contain disparities, while conformability is the degree to which the respondents affect the findings without the impact of the researcher's bias or interest (Robert Wood Johnson Foundation, 2008). This study relied on external audit to measure the dependability and conformability. An external audit is the process whereby researchers provide complete documentation of the study process to another researcher to examine and evaluate the findings, interpretations and conclusions (Robert Wood Johnson Foundation, 2008).

This collection of measures to test trustworthiness created a study free of bias and increases the level of reliability, validity, and objectivity. These measures were also specific to the type of study being conducted. They were strategically assigned based on how the study was conducted.

In the case of the graduate students that participated in the study analysis, as a requirement, the graduate students were currently enrolled at least in the specialization courses of their graduate program. The graduate student did not have access to participants' personal information; hence identification numbers represented participants before the students perform data analysis. Graduate students' trustworthiness was

established by providing students with a confidentiality agreement form they must sign prior to participating in the study.

Ethical Procedure

An in-depth look into the ethics of a particular study or research is essential. The principal concern of a researcher is the safety of the participant and respecting their way of life (Adam & Callahan, 2014). The participants' privacy and confidentiality was well protected. I had a mechanism in place to carry this protection out. Protection includes informed consent, locking up data in secure place that cannot be reached by unauthorized personnel, and acquiring IRB approval from Walden University and the HREC of Nigeria. The informed consent includes disclosure of the study that explains the study procedure, nature of the study, expected benefit and risks, purpose of the study, procedure, and participants' compensation. The informed consent was written in a language that the participants could easily understand or read. The participants understood that the study was voluntary and at any time they could opt out of the study, and they were free to put thoughts into the study before agreeing to participate in the study.

Participants had the liberty to withdraw from the study at any time. Withdrawal from the study did not affect the continuation of the study because I continued to recruit more participants until saturation was satisfied or the sample size was completed. The personal information of participants who withdrew themselves from the study was kept anonymous and confidentiality was maintained.

Data collected from the participants was saved in three different places, the computer, external hard-drive and a locked cabinet where no unauthorized personnel could have access to. The documents in the computer and the external hard-drive were encrypted and were only accessible using a password. The data are archived for five years, and after the five years period, the data are to be deleted or destroyed. In order to avoid breached data results or expose the personal concerns of study participants, I kept all data and derived information anonymous and confidential. The only concern with the confidentially among participants was their interaction with one another; however, by interviewing each participant one-on-one potentially breach was avoided. Participants were not expected to meet one another or have previous knowledge of one another participating in the study. Two graduate students assisted as they also had access to the data and were educated on the ethics procedures. Furthermore, IRB approval was collected from Walden University and HREC of Nigeria are collected from LUTH so as to gain access to conduct the study on SCD patients in Nigeria. The IRB and HREC of Nigeria are presented with the proposal to gain approval needed for the protection of the all those involved with the study, and to establish opportunity for the study to be carried out efficiently.

As an individual of Nigerian descent, also a SCD patient, there were expected biases in the study; however, the graduate students who assisted in the study alleviated the scale of bias. The graduate students were also at the forefront of this study. Conflict of interest was eliminated based on the participants being randomly selected to participate

in the study. This was a self-sponsored study and the incentive provided to the participants did not affect the study because the participants were selected randomly.

Summary

The research method presented in this chapter explained the steps I took to conduct the study. The design used in this study was qualitative phenomenological approach that allows participants express their experiences of SCD, and how it affects their QOL. This was conducted using an open-ended questionnaire that was administered to obtain in-depth information on the effect of socioeconomic status and cultural belief on SCD. There were a total of 30 participants recruited from four different SCD clinics in Lagos, Nigeria. The participants were individuals who had been diagnosed with SCD from young age. A pilot study was conducted to identify any possible problem in the study before proceeding to conduct the main study. All information collected from the participants was made confidential, and the graduate students involved in the study analysis did not have access to participants' personal information, thus participants were represented with an identification number in order to keep them anonymous. In chapter 4, the pilot study, study settings, demographics, data collections, data analysis, evidence of trustworthiness in the study, and the result of the data collected in Chapter 3 will be elaborated.

Chapter 4: Results

Introduction

The purpose of this study was to explore the effect of the socioeconomic and cultural factors that affect the QOL of people living with SCD in Nigeria. There is no definitive supporting literature on the socioeconomic and cultural factors affecting QOL of SCD individuals living with SCD in Nigeria (Adegoke, Abioye-Kuteyi, & Orji, 2014). Questionnaires used during the study comprised of open-ended questions, 7-point Likert-type questions, and demographic questions to collect information from the participants. Previous studies have focused on the impact of SCD on health status, and the impact of stigmatization on individuals with SCD (Ola, Coker, & Ani, 2013); however, researchers have not made apparent how socioeconomic factor and cultural beliefs affect individuals with SCD. Dissemination of study findings may contribute to the existing literature about SCD and the public understanding of what SCD individuals in Nigeria experience.

Thirty participants who were interviewed for the purpose of this study provided detail information concerning their experiences living with SCD. The aim of the study was to examine the knowledge, attitudes, and beliefs of patients living with SCD in Nigeria that may contribute to the poor management of the disease, which may result in poor QOL. This study examined the negative impacts of SCD on the affected persons and possible ways of educating individuals living with SCD to reduce the burden of SCD, and improving QOL. In Chapter 4, more details and explanation about the conduct of the pilot study, recruitment process, collection of data, data analysis, validity of data obtained, evidence of trustworthiness and results were discussed.

Pilot Study

A pilot study is an essential stage of a research activity. The purpose of conducting a pilot study for this research was to scrutinize the viability of the instrument that was used for this study. This pilot study can be used to understand the route to recruiting participants, also the retention on the participants for the study (Leon, Davis, & Kraemer, 2012).

Five individuals who regularly provide medical care for SCD patients, who are residents of Lagos, Nigeria conducted the pilot study. The answers to the questionnaire were hypothetical, and that the pilot study participants could understand and reflect what the SCD patients experience since they serve as care providers. After the completion of the pilot study, it was confirmed that the questionnaire and interview procedures did not need to be amended as a result of the pilot study. The pilot study participants found the questions to be clear and understandable. One of the requirements for the pilot study participants is that they all have the ability to speak English language such that they can participate in the study. With this requirement, pilot study participants were able to have a clear understanding of the study requirement and in turn, the questionnaire. Also, while developing the questionnaire, layman's terms were used in order to ensure that participants without medical knowledge are able to comprehend the study.

Setting

The study setting took place in the form of recorded telephone interviews. The interview was carried out in a quiet office space, while participants were present at a quiet location of their choice. Participants were compensated with ₦1000 Nigeria Naira

($5) upon completion of the interview. Participants were informed that no other parties would have access to their responses, and their personal information will be kept confidential.

Demographic Results

The large population of Lagos State, Nigeria provides a variety of ethnic groups and supports the generalization of the study results based on its commercial attribute of the country (Lagos State Government, 2011). Lagos is the smallest state in Nigeria with a population of 9,019,534 (NgEX, 2013). Nigeria has the largest population of individuals living with SCD with prevalence of 20% and 30%, and 150,000 live births per year with a SCD diagnosis (Akodu et al., 2013; WHO, 2012). The attribute attached to Lagos State, for example, diversity in ethnicity and population, makes it more appropriate to conduct a population study (Akodu et al., 2013).

Forty prospective participants provided their phone numbers at the location where flyers were distributed, and 30 participants were randomly selected. From the initial 40 prospective participants, 30 names were randomly selected in a blind draw to perform the telephone interview. All participants were selected from Lagos, Nigeria and represented different ethnic groups. The ethnic groups of the selected individuals include: Yoruba, Igbo, and other. The other category includes include: Efik, Edo, and Ope ethnic groups.

Table 1

Participant Demographics

Demographic	*n*
Sex of Participants	
Male	14
Female	16
Age of Participants	
18-23	12
24-30	10
31-36	4
37-42	2
43-48	1
49-54	0
54 and older	1
Ethnicity	
Yoruba	17
Igbo	5
Other	8
Marital Status	
Married	3
Single	27
Separated	0
Religion	
Muslim	4
Christian	26
Traditional Worshiper	0
Educational Level	
High School Level	10
University Level	20
Annual Income	
Less than ₦ 399,999 (<$1,999.99)	24
₦ 400,000 to ₦899,999 ($2,000 to $4499.99)	2
₦ 2,400,000 to ₦2,899,999 ($12,000 to $14,499.99)	1
More than ₦3,900,000 (>$19,500)	3
Employment Status	
Not Employed/Student	14
Employed	10
Not Employed but have Employment history	4
Part Time Employed	1
Unemployed with no Occupation History	1
Sex of Participants	
Male	14
Female	16

There were 16 females and 14 males who partook in the study. Also, participants were mostly single and Christian. None of the participants reported to be separated or divorced. 19 participants were unemployed compared to the employed participants. However, some of the participants were unemployed but have previous employment History, some were unemployed with no occupation history, and one was part-time employed. A high number of participants had university level education, and few had high school level education. The annual income of participants who earned less than ₦399,999 ($1,999.99) was voluminous. Only few participants have an income above ₦400,000-₦899,000 ($2,000 to $4,499.99).

Data Collection

Between October 07, 2015 and October 28, 2015, data were collected using telephone interviews over the 3-week period from the selected 30 participants. Combinations of three instruments were used to collect data, this included: a demographic questionnaire, a quality of life 7-point Likert scale questionnaire, and an open-ended questionnaire about the experiences of the participants living with SCD. To complement the data collected using questionnaires, detailed notes were taken during the telephone-based interview. The responses from the participants were also audiotaped and transcribed for the purpose of reliability and validity.

Initially, some of the participants were uncomfortable with the study. To reduce apprehension and improve awareness of the study, I provided an informed consent form for participants to review prior to deciding whether or not to participate in the study;

however, no participant rejected to participate in the study. Participants who remained skeptical were reassured of the voluntary nature of the study and their personal information would be kept confidential.

Data Analysis

The process used to move coded units to larger representation was the use of acronyms to simplify each category for the purpose of grouping. The study includes five different codes: socioeconomic factor not diminishing QOL result (SR), cultural factors not diminishing QOL result (CR), socioeconomic factors diminishing QOL (SDQR), cultural factors diminishing QOL result, (CDQR) and both socioeconomic and cultural factors diminishing QOL (SCDqR). The Meaning are provided below:

- Socioeconomic factor not diminishing QOL result (SR): In this study, this indicates that the Socioeconomic factor of individuals with SCD does not affect or diminish their QOL;
- Cultural factors not diminishing QOL result (CR): This indicates that the cultural factor of individuals with SCD does not affect or diminish their QOL;
- Socioeconomic factors diminishing QOL (SDQR): This indicates that the Socioeconomic factor of individuals with SCD affects or diminishes their QOL;
- Cultural factors diminishing QOL result, (CDQR): This indicates that the cultural factor of individuals with SCD does not affect or diminish their QOL; and

- Both socioeconomic and cultural factors diminishing QOL (SCDqR): This indicates that the socioeconomic and cultural factors of individuals with SCD affect or diminish their QOL.

The identifying codes are significant to the study, and the process is based on the fact that each group identified characteristics of the participants relevant to the study.

During the telephone interview, participants were willing to offer detailed responses and actively engaged in the study. One participant was not as willing to provide information and I worked with the data the participant was willing to offer.

Evidence of Trustworthiness

Credibility was achieved by providing the audio recordings and transcribed interviews to two graduate students external to the study to establish the accuracy of the transcripts. The graduate students reviewed the transcripts while listening to the interviews to ensure the transcribed documents did not contain any mistakes. The study results are transferable, as all participants were verified as diagnosed with SCD based on their visits to the center for comprehensive management of SCD and routine medical care. Dependability of the study was established by avoiding biases in the study. In other words, avoiding biases in the study in regards to responses from the participants that may be conformed to what participants' believe I want to hear.

Socioeconomic and Cultural Impact Results

The results show that 12 participants of the 30 participants experienced socioeconomic and cultural impacts that diminished QOL. Seventeen of the 30

participants mentioned that only socioeconomic factors impact their QOL and one participant mentioned that there is no socioeconomic factor or cultural factors that impact their QOL. None of the participants mentioned having only cultural factors affecting their QOL.

The socioeconomic factors affecting the QOL of patients living with SCD in Nigeria include loss of employment, lack of social support, and a diminished ability to acquire new employment or even develop a career due to suffering SCD. Also, individuals who were financially stable tended to spend a large quantity of their income on medical care due to SCD. Participant 21, a 28 year-old woman, stated, "Medical bill is expensive, sometimes having to dedicate certain amount for medical care. [It] can be quite tasking." In addition, Participant 24 said, "…Now it [doctor visits, hospital stays, prescriptions and other treatments] is self-pay and it's very expensive." Participant 24 (Male, age 30). "It [health affecting participants money-wise] does a lot. Last time I was sick, I spent ₦100,000 [$500] – ₦200,000 [$1000]...I take care of myself at home when not buoyant with finance." Participant 25 (female, age 35).

Most SCD patients in Nigeria believe that there is less care or education made available for SCD patients and the environment they are surrounded by. Individuals living with SCD in Nigeria are unwilling to share the presence of this disease with friends due to a fear of stigmatization. Adeyemo et al. (2015) mentioned that stigmatization affects the HRQL of SCD individuals, also it can affect the ability to perform task with their peer group (Adeyemo et al., 2015). Finally, the research showed that 12 of the 30 participants believed they were possessed by evil spirits before being diagnosed SCD,

which led to having poor management of the disease prior to diagnosis. “They believe it is voodoo. After the diagnoses they did not believe it could be medical…by the time they realized it was medical, it was already bad.” Participant 17 (male, age 30). “They were giving me traditional herb, that was getting worse…they were not educated…this affected the leg ulcer and it was not healing.” Participant 19 (male, age 18). The study shows that SCD individuals often feel neglected which has a negative impact on the affected person’s relationship with friends and significant others. The participants also expressed experiencing a lot physical pain as well as emotional pain from feeling neglected. “Yes [SCD has impacted my life], sometimes I feel neglected.” Participant 12 (female, age 24). “Yes [SCD has impacted my life], when it comes to relationship I have to be careful when selecting a partner. There are some things I see my sister or friends do that I can’t do.” Participant 2 (female, age 24).

> Yes [SCD has impacted my life], relationship wise. The parents did not allow the relationship. People just don’t want to associate. They think they will be spending money. They think one can’t excel too, it makes me not to associate too with them. Participant 30 (female, age 30).

Some participants mentioned they were set back in their education as they were regularly recovering from SCD-related events. For example, participants mentioned that when they have crisis or the development of a leg ulcer from the SCD, it deprived them from furthering their education or sets them back educationally. “Yes [I was], never around for exam…anytime I want to do something to move my life forward, I’m always

sick. I have to repeat classes due to that…it affect relationship." Participant 27 (female, age 28). [Experience with SCD] "Educational life, not resume school at normal age. Crises arise when writing exam. Sickle cell stop me from moving ahead with my colleague…repeating class" Participant 25 (female, age 35).

Also, SCD patients are unable to participate in regular activities that their peers engage in. Participants also experience a great deal of stigmatization from peers and other members of the society. When SCD patients try to participate in activities with their peers, their peers have the impression that they are not strong enough or that they will collapse while participating in the activities. This causes them to often be left out of activities they naturally would want to participate in. This can result to their peers stigmatizing them as individuals with a disease that need to be treated differently. [Experience with SCD] "…Leg ulcer [from SCD] make me loose my WAEC [Nigeria high school final year exam], leave school because of stigma, negative thoughts by Nigerians" Participant 19 (male, age 18). [Challenges] "I had to hide my identity because of stigmatization, but now I am bold" Participant 12 (female, age 24)

The participants expressed different methods of receiving education on SCD conditions to improve QOL. These methods included; screening before marriage, bone marrow transplants, and avoidance of being exposed to cold weather and temperatures, and consumption of routine drugs like folic acid, hydroxyurea, paludrine (for malaria prevention). Participants were also taught to avoid mosquitos by using mosquito nets and utilizing home defense mosquito spray. Diet is also a lesson taught to SCD participants as water, and a balanced diet makes a difference. Participants are also required to know their

limitations and receiving early screening and diagnoses is also important. “Bone marrow transplant [is] not 100% only for children, drinking water, keeping warm, routine drugs…regular folic acid, paludrine, good food” Participants 13 (female, age 21). “More careful from stress, take my routine drug, limit myself from whatever may cause crisis.” Participant 20 (female, age 20).

Twenty of the 30 participants mentioned that their parents are more involved in their lives and two stated that their parents are not involved in their lives because their condition is a financial strain. Also, seven participants mentioned that the disease has affected their relationships with their friends, and 23 participants mentioned that the disease hasn’t affected their relationships because their friends are not aware they are living with the disease.

When asked why they chose the QOL rankings in the QOLS, 19 of the participants mentioned that that is the way that they feel at that moment. Five mentioned that they are satisfied, one mentioned that its based on their experience of having SCD, one mentioned that SCD does not allow for a better QOL, and one mentioned that finances are obstructing him/her from having a better QOL.

The 7-point Likert-type scale was used to assess QOL of the participants. Before proceeding with the open-ended questions, the 7-point Likert-type scale question was answered by the participants to retrieve a wider range of effective response from participants on QOL (Burckhardt & Anderson, 2003). Upon initial review of the study result many participants were delighted, pleased or mostly satisfied with their experience as a SCD patient. These findings caused me to perform a critical review of the study

result. I concluded that participants who experienced delight or satisfaction were patients who also had a significant amount of support from their family members. According to the result, 20 out of the 30 participants experience delight or satisfaction in their QOLS result and expressed that they also received significant support from their family in the open-ended questionnaire.

Table 2

Study Result

	n	Average *n*
SCD factors affecting QOL		
Socioeconomic and Cultural Factors Diminishing QOL (SCDqR)	12	
Socioeconomic Factors Diminishing QOL (SDQR)	17	
Socioeconomic and Cultural Factors not Diminishing QOL (SR and CR)	1	
Cultural Factors Diminishing QOL (CDQR)	0	
Parents' involvement		
Parents Involved	28	
Parents not Involved	2	
Relationship with family and friends		
SCD Affecting Relationship with friends	7	
SCD Affecting Family	2	
SCD not Affecting Friends	23	
SCD not Affecting Family	28	
Reason for QOLS ranking		
The Way Participant Feel at the Moment	19	
Feeling satisfied	5	
Based on Experienced	1	
SCD does not Allow for better QOL	1	
Quality of Life Scale		
Delighted - 7		8.875
Pleased – 6		8.75
Mostly Satisfied – 5		5
Mixed – 4		4.4
Mostly dissatisfied – 3		1.4
Unhappy -2		0.9
Terrible – 1		0.6

Table 3

Participants' Responses to Individual QOLS Items

Item	*n* Delighted	*n* Pleased	*n* Mostly Satisfied	*n* Mixed	*n* Mostly dissatisfied	*n* unhappy	*n* Terrible
Material well-being/ financial security	4	8	5	6	2	3	2
Health	9	10	3	4	1	2	1
Relationship with parents, siblings and others	13	10	3	3	1	0	0
Having and raising children	8	6	8	6	0	2	0
Relationships with spouse or significant other	6	10	6	5	0	2	0
Relationships with friends	7	10	6	6	0	0	1
Helping or encouraging others	13	10	5	1	1	0	0
Participating in organizations and public affairs	5	8	5	5	4	0	3
Attending school, improving understanding, and getting additional knowledge	10	8	5	5	0	1	1
Personal understanding of self	9	12	4	0	3	2	0
Occupational role	6	6	6	8	4	0	0
Creativity/personal expression	10	12	5	3	0	0	0
Socializing	13	6	2	3	4	2	0

The results showed that most participants are delighted, pleased, or mostly satisfied by their QOL based on their relationship with their family. However, the response provided by the participants from the open-ended questionnaire indicates that the socioeconomic and cultural status affects their QOL. Twelve of 30 participants mentioned that improvement in economic status would improve their QOL, and nine of 30 participants mentioned cultural impact of SCD also play a big role in the lives of the SCD participants, which include better awareness and education on SCD.

Summary

The setting of this study was Lagos, Nigeria. There were 30 selected participants who voluntarily participated in this study. The study was conducted over the telephone within a three-week period with 10 participants interviewed per week. Participants of this study were adults between the ages of 18 and 55 with diagnosis of SCD. The data were collected over the phone with extensive note taking while responses were recorded via audiotape. The study results shows that most participants were affected by socioeconomic factors that diminished their QOL followed by both socioeconomic and cultural factors combined that diminished their QOL. The next chapter, Chapter 5 contains an interpretation of the findings, limitation of the study, recommendations, and implications of the study.

Chapter. 5: Conclusion

Introduction

The purpose of this study was to explore socioeconomic and cultural factors that affect the QOL of individuals with SCD in Nigeria. This study is socially significant, as it may inform the development of public health interventions to help sustain the lives of those living with SCD through education and disease management. The rationale for choosing the phenomenological research design is that the information gathered will be directly and specifically from individuals who have firsthand experience with SCD, individuals who actually live with SCD. These findings will assist in significantly reducing the possibility of drawing false data from the study results. The study findings identified the fundamentals of SCD participants' experiences and offered a better perspective for evaluating their life experiences

Phenomenological qualitative approach was used in this study to gain in-depth data on the effect of socioeconomic and cultural factors on SCD patients. In order to select the participant for the study, a random sampling was used. Random sampling gives study population an equal chance of being selected to participate in a study. Random sampling reduces the chance of bias among study samples (McKenzie et al., 2008).

Thirty SCD male and female patients from four SCD clinics in Lagos, Nigeria were recruited for the study. The research data are collected using an open-ended questionnaire strategy in conjunction with telephone interview protocol. The data

collected during the interview was analyzed by taking extensive notes and audio transcriptions through a pooling of themes, patterns, categories, and relationships.

Interpretation of Findings

The findings of this study demonstrated that socioeconomic and cultural factors affect QOL of individuals living with SCD in Nigeria. Darbari et al. (2006) found that medical and physical conditions of SCD are the leading cause of death for individuals living with SCD. For example, pulmonary hypertension, arterial blood pressure, lack of preventive measures, and infection (Dabari et al., 2006). Socioeconomic and cultural factors could enable the medical and physical deterioration of individuals living with SCD (Both, Inusa & Obaro, 2008; Dabari et al., 2006; Oguanobi et al., 2010; Platt et al., 1991). In the event that SCD patient has low socioeconomic status, the chances of pulmonary hypertension, arterial blood pressure, lack of preventive measures, and infection that can cause mortality increases among SCD individuals (Both, Inusa & Obaro, 2008; Dabari et al., 2006; Oguanobi et al., 2010; Platt et al., 1991).

In the case of QOL, the study findings were able to extend current knowledge on the topic at hand. Participants described that stigmatization of their SCD diagnosis has negative effect on their QOL. Participants confirmed experiencing unemployment, diminished social activities, discrimination, absence of medical care, and social isolation, which diminished their QOL (Mann-Jiles & Morris, 2009). However, most of the participants mentioned that they are satisfied with their QOL on the QOLS. In the study of "Quality of life of adult patients with sickle cell disease," Mann-Jiles and Morris (2008) stated that "there was no significant relationship between participants' QOLS

score and their SCD types, but had a relationship with their demographic information" (Mann-Jiles & Morris, 2008, p 347). In this study, I found a relationship between participants' socioeconomic status and cultural beliefs affecting their QOL. Albeit, significant number of participants mentioned to have mostly been delighted, pleased, or mostly satisfied in their QOLS, based on their relationship with their family, they further emphasized on how socioeconomic and cultural factors continue to affect their QOL. In other words, the QOLS does not demonstrate any direct relationship with the extent to which the participants experience the symptoms of SCD, thus a majority of the participants often responded by stating quotes along the lines of "I am satisfied…this is the way I feel."

Ballas (2009) stated that a large amount of money is being spent to care for individuals with SCD. This study confirms that even with those individuals with a sufficient income, SCD patients tend to spend half of their income on treatment and care for the disease (Ballas, 2009). Even those individuals who have a sufficient amount of income require financial assistance from their immediate family and friends. The information on socioeconomic status was derived from peer-review literature written in the United States and there has not been current study conducted on this aspect of the disease in Nigeria.

Further, the peer-reviewed literature discussed the cultural factors of SCD that focus on psychological impacts of having SCD (Anie et al., 2010). However, the study shows that cultural beliefs also impact the QOL of individuals living with SCD. Participants in the study demonstrated more interest in overcoming the cultural impact of

their SCD and thus further diminishing their QOL by neglecting focus on the medical aspects. In addition, U.S. literature has discussed the use of prayer to help improve health conditions of SCD patients (Cooper-Effa et al., 2001). In this study, participants who identified as Christian often discussed that their religion has helped improve their QOL.

Within all the study conducted by the peer-reviewed authors, there were no studies conducted on a combination of the socioeconomic and cultural impacts of SCD and neither were either factor studied exclusively to identify how it contributes to SCD patients diminished QOL.

This study was also able to identify education or lack thereof as a fundamental of a secondary prevention of SCD individuals with diminished QOL. Secondary prevention detects diseases at early stage in order to implement strategies to approach the management of the diseases (CDC, 2013). Secondary prevention can help minimize the effect of diseases (CDC, 2013). Participants mentioned that lack of education, lack of knowledge among medical professionals on SCD, lack of infrastructure based on financial support for individuals with SCD is contributing to the diminished QOL. However, this has indicated that secondary prevention is significant among individuals with SCD. Implementing secondary prevention initiatives could support improved QOL and reduce morbidity and mortality among individuals diagnosed with SCD in Nigeria.

The conceptual framework indicated in this study is the health belief model which illustrates the perceived severity, perceived susceptibility, perceived benefits, perceived barriers, modifying variable, cues of action and self-efficacy. This study confirmed that there are groups of certain specific factors that describe ways in which individuals living

with SCD are affected. These groupings define the different aspects of their diminished QOL. For example participants in the study are influenced by cultural beliefs before having knowledge that they are actually suffering from the disease. Initially, participants weren't aware of their medical condition and were treating a spiritual condition. Participants stated that primarily family members believed the disease is caused by an evil spirit at a younger age, and parents were spending money to finance the treatment of the disease in this aspect rather than on the medical and physical care. After gaining knowledge of the disease, participants indicated that proper treatment was given towards the disease.

Limitations of the Study

The study was not necessarily marked by many limitations based on trustworthiness. However, I experienced certain challenges based on the fact that the study was conducted over the telephone and not face-to-face. I utilized audiotaping and note-taking tools over a telephone-based conversation. Due to the nature of the study, certain participants required more time to feel comfortable with the interview process. Most participants requested to be interviewed on another date thus rescheduling the initial interview. Hence, all participants that were selected happened to be English-speaking participants. Contrary to the general belief and idea that Nigerians are very private and hesitant to speak on personal issues such as their health conditions, participants were rather eager to share their experiences once they were comfortable. One out of 30 participants demonstrated high levels of apprehension toward the interview and research being conducted. The use of a telephone interview process provided a certain level of

comfort for the participants as the interview was conducted with each individual in the privacy of their comfort zones. Participants were not under pressure or embarrassed, as the interview was not face-to-face.

Recommendations

Additional studies exploring the socioeconomic and cultural impact of SCD on the QOL should be conducted in Nigeria. There have been a lot of studies conducted in the United States on SCD and QOL; however, current literature is necessary in Nigeria as technology has evolved, more financial infrastructure has been established, and more medical professionals are educated on this specific disease. The current strength of this study is solely based on information derived from SCD patients who are able to express themselves on what is needed for Nigeria's public health sector to support those with SCD. Unlike the United States, where citizens are able to ensure that their medical needs will be satisfied based on the government infrastructure and a system of checks and balances, Nigerians do not have the infrastructure in place (Ademiluyi & Aluko-Arowolo, 2009; Agency for Healthcare research and Quality (AHRQ), 2011; Welcome, 2011). For example, nine of 30 participants mentioned better awareness and education towards SCD. Twelve of the 30 participants mentioned financial support towards the care of SCD and others mentioned the cure and treatment for SCD and believed that these recommendations would help improve their QOL.

Implications

The study conducted may impact positive social change by informing future secondary prevention interventions that may improve the socioeconomic and cultural

behaviors of people towards SCD. For instance, policy makers can implement financial support for patients with SCD in order to be able to manage the disease so as to minimize the mortality or morbidity rate. The study supports raising awareness among individuals unaware of SCD to reduce stigmatization of those individuals suffering from SCD. This study enable further community education on SCD in order to help increase knowledge related SCD. Families are better educated on this disease and how to care for family members with SCD. Further, the study encourages policy development to help improve infrastructure and support for those with SCD. Policies could be implemented to create financial support, healthcare benefits, and proper education of medical providers on the disease. Non-governmental organizations will also be able to provide better healthcare and support for individuals with SCD through the provision of better medical treatment, also developing programs and initiatives.

This study was based on phenomenological approach in which participants express their feelings to explore how socioeconomic and cultural factors affect their QOL. Participants were willing to communicate their experiences once they were comfortable to express their feelings. The use of a telephone interview process provided a definite comfort space for the participants as the interview was conducted with each individual in the privacy of their comfort zones. This study expanded my knowledge on secondary prevention being highly recommended for SCD individuals in Nigeria to improve their QOL.

Conclusion

Upon conducting the study on the socioeconomic and cultural factors of SCD, the results of the study indicates that socioeconomic and cultural factors of SCD contribute to diminished QOL of the 30 participants. Results show that most participants are affected by the amount of money spent on the care for their SCD. Twenty-nine of 30 participants indicated that improved education and awareness as well as financial support could help to better their QOL. Twelve of the 30 participants also mentioned that cultural beliefs have impacted their way of managing their SCD that has led to diminished QOL. This study is geared towards providing health policy that can encourage better management of SCD patients, increased awareness, and treatment of SCD that influences a better QOL among the 30 participants with SCD. With SCD awareness, community members surrounding participants of the study can gain better understanding of SCD to help minimize stigmatization, and lack of social activity amongst peers of the participants with SCD. Organizations can also be aware of how to provide adequate care for those living with SCD, all while promoting initiatives and programs in their favor. Overall this study has bridged the knowledge gap on SCD and QOL in Nigeria. Upon conclusion of this study, I have been able to gather empirical evidence as to the effects of SCD amongst those who live with it and to help guide in making better decisions in the management of SCD. This can be used from a personal care standpoint also from public health management perspective. With the understanding gained from the study about the most common challenges faced by individuals living with SCD and misconceptions amongst the general population about the disease, the populace can be better educated about the

disease and help tailor more specific responses to management of the disease and improving the QOL of those living with SCD.

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Appendix A: Consent Form

CONSENT FORM

Socioeconomic and Cultural Impact of Sickle Cell Disease in the Nigeria Perspective
A qualitative Approach
Walden University

You are invited to participate in a research study of socioeconomic and cultural impact of Sickle Cell Disease (SCD) and the influence it has on the Quality of Life (QOL). I am inviting you to participate because you have reported that you have SCD. I will be reading this form and ask any questions you may have before acting on this invitation to be in the study. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part. I Jejelola Bakare, a doctoral candidate at Walden University, is conducting this study.

Background Information:

The purpose of this study is to understand your socioeconomic status and cultural factors that impact your experience as a SCD patient.

Inclusion Criteria:

- Early childhood diagnosis of SCD or have had SCD for at least more than five years.
- 18 years and above.
- Stable health condition (not having sickle cell crisis at the time of interview).
- Ability to speak English language fluently.

Procedures:

If you agree to be in this study, you will be asked to do the following:

- Participate in a research process that will take approximately one hour to respond to all questionnaires at a location of your choice.
- Give consent to participate in the study.
- Answer questions to demographic data asked by the researcher such as age, marital status, education, and occupation.
- Respond to a 7-point Likert-Type scale questions.
- Participate in an in-depth audio taped interview to discuss your experience.
- A follow-up may be required if at the time of the interview, the participants request to continue the interview some other time.

Voluntary Nature of the Study:

Your participation in this study is strictly voluntary. Everyone will respect your decision whether or not you choose to participate in the study. No one at the sickle cell foundation or centers will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the study:

The potential risk related with participating in this study is identification (ID) becoming known and experiencing discomfort answering questions. The benefit of participating in

the study may come in form of future education and support services for SCD patients informed by this study. You may refuse to answer questions you are not comfortable with.

Compensation:

There will be a compensation of one thousand Nigeria Naira ($5 US Dollars)for participants as a form of appreciation for taking part in the study.

Confidentiality:

The records of this study will be kept private. In any report of this study that might be published, the researcher will not include any information that will make it possible to identify you as a participant. Also, the researcher will not include your name or anything else that could identify you in the study reports. Unique ID numbers will be assigned to represent names of participants in the study to help protect their identity. The researcher will not use your personal information for any purpose outside of this research project. Research records will be kept in a locked file; only the researcher will have access to the records. In the tapes and transcripts derived during the interview will be collected for the purpose of collecting accurate information and will be destroyed 5 years after completion of this study.

Contacts and Questions:

You may ask any questions you have now. Or if you have questions later, you may contact the researcher via Jejelola.Bakare@waldenu.edu. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss your rights as a study participant. Her phone number is 001-612-312-1210. Walden University's approval number for this study is **07-07-15-0237277** and it expires on **July 6, 2016;** and HREC approval number for this study is **ADM/DCST/HREC/404** and it expires **September 14, 2016.**

You will receive a copy of this form from the researcher to keep.

Statement of Consent:

Do you _____hear the verbally read above information and feel you understand the study well enough to make a decision about your involvement? YES OR NO. You understand that you are agreeing to the terms described above. If you agree, do you feel comfortable to participate in this study? Please answer YES or NO.

Researcher's Signature:

Date of consent:

Appendix B: Questionnaire

This part of the questionnaire is not self-administered. Questions will be asked by the researcher to retrieve participants' demographic information.

CONFIDENTIAL

Demographic Information

Date: _____/_____/_____

ID Number: _____

Location: _____

Name of Interviewer: _____

1. Sex: ___Female ___Male
2. Age: _____
3. Ethnicity: ____Igbo ____Yoruba ____Hausa ____other
4. Marital Status: ____Married _____Divorced ____Separated ____Single
5. Religion: ____Christian ____Muslim ____Traditional Worshiper ____Other
6. Employment status:
    a. ___Not employed
    b. ___Full-time Employed
    c. ___Part-time Employed
    d. ___Not pursuing employment
7. Occupation: _____
8. Educational Level:
    a. ____Elementary School Level (Primary School)
    b. ____High School Level (Secondary School)

c. ____University Level

9. Number of household members with SCD: _____

10. Annual household income (The Dollar amount is an approximate amount with the Naira (N) amount divided by 200 rounded to the nearest three decimal places):

    a. Less than ₦399,999 ($1,999.995)

    b. ₦400,000 to ₦899,999 ($2,000 to $4499.995)

    c. ₦900,000 to ₦1,399,999 ($4,500 to $6,999.995)

    d. ₦1,400,000 to ₦1,899,999 ($7,000 to $9,499.995)

    e. ₦1,900,000 to ₦2,399,999 ($9,500 to $11,999.995)

    f. ₦2,400,000 to ₦2,899,999 ($12,000 to $14,499.995)

    g. ₦2,900,000 to ₦3,399,999 ($14,500 to $16,999.995)

    h. ₦3,400,000 to ₦3,899,999 ($17,000 to $19,499.995)

    i. More than ₦3,900,000 ($19,500)

Quality of Life Scale (QOLS)*

Instructions: each number item is circled to best describe how satisfied you are at this time. Please answer each item even if you do not currently participate in an activity or have a relationship. You can be satisfied or dissatisfied with not doing the activity or having the relationship.

There are seven numbers to choose from. The seven numbers are "delighted" (7), "pleased" (6), "mostly satisfied" (5), "mixed" (4), "mostly dissatisfied" (3), "unhappy" (2), and "terrible" (1). Circle the one that best describes how satisfied you are at this time.

ITEM	**Delighted**	**Pleased**	**Mostly Satisfied**	**Mixed**	**Mostly Dissatisfied**	**Unhappy**	**Terrible**
Material well-being/ financial security.	7	6	5	4	3	2	1
Health – being physically fit.	7	6	5	4	3	2	1
Relationship with parents, siblings and others- Communicating, visiting and helping.	7	6	5	4	3	2	1
Having and raising children.	7	6	5	4	3	2	1
Relationships with spouse or significant other.	7	6	5	4	3	2	1
Relationships with friends.	7	6	5	4	3	2	1
Helping or encouraging others.	7	6	5	4	3	2	1
Participating in organizations and public affairs.	7	6	5	4	3	2	1
Attending school, improving understanding, and getting additional knowledge.	7	6	5	4	3	2	1
Personal understanding of self – knowing your limitations and assets.	7	6	5	4	3	2	1
Occupational role - job or in home.	7	6	5	4	3	2	1
Creativity/personal expression – ability to express yourself.	7	6	5	4	3	2	1
Socializing – meeting other people, doing things, parties, etc.	7	6	5	4	3	2	1
Reading, listening to music, or observing entertainment.	7	6	5	4	3	2	1
Active participatory recreation.	7	6	5	4	3	2	1
Independence – ability to do things for yourself.	7	6	5	4	3	2	1

*Adapted from Mann-Jiles and Morris (2009), and Burckhardt and Anderson (2003)

Questionnaire

Sickle Cell Disease and Quality of Life

This part of the questionnaire is not self-administered. Questions will be asked by the researcher to retrieve an in-depth response from the participants. Participants' responses will be audio taped and the researcher will take detailed notes.

1. When were you diagnosed with SCD (you will be excused from the study if you are not diagnosed or recently diagnosed within the last five years with SCD)

2. Please explain any challenges you faced growing up with SCD

3. How has SCD affect your relationship with your family and friends, and their view or opinion of you?

4. How would you describe your parents' involvement in your life?

5. Why did you give the QOL rankings you chose in the QOLS?

6. Has SCD affected your life in a negative way? How?

7. What could be done to make your QOL better?

8. Please tell me about how you pay for your doctor visits, hospital stays, prescriptions, or other treatments to care for your SCD.

9. Please explain how your health affect you money-wise

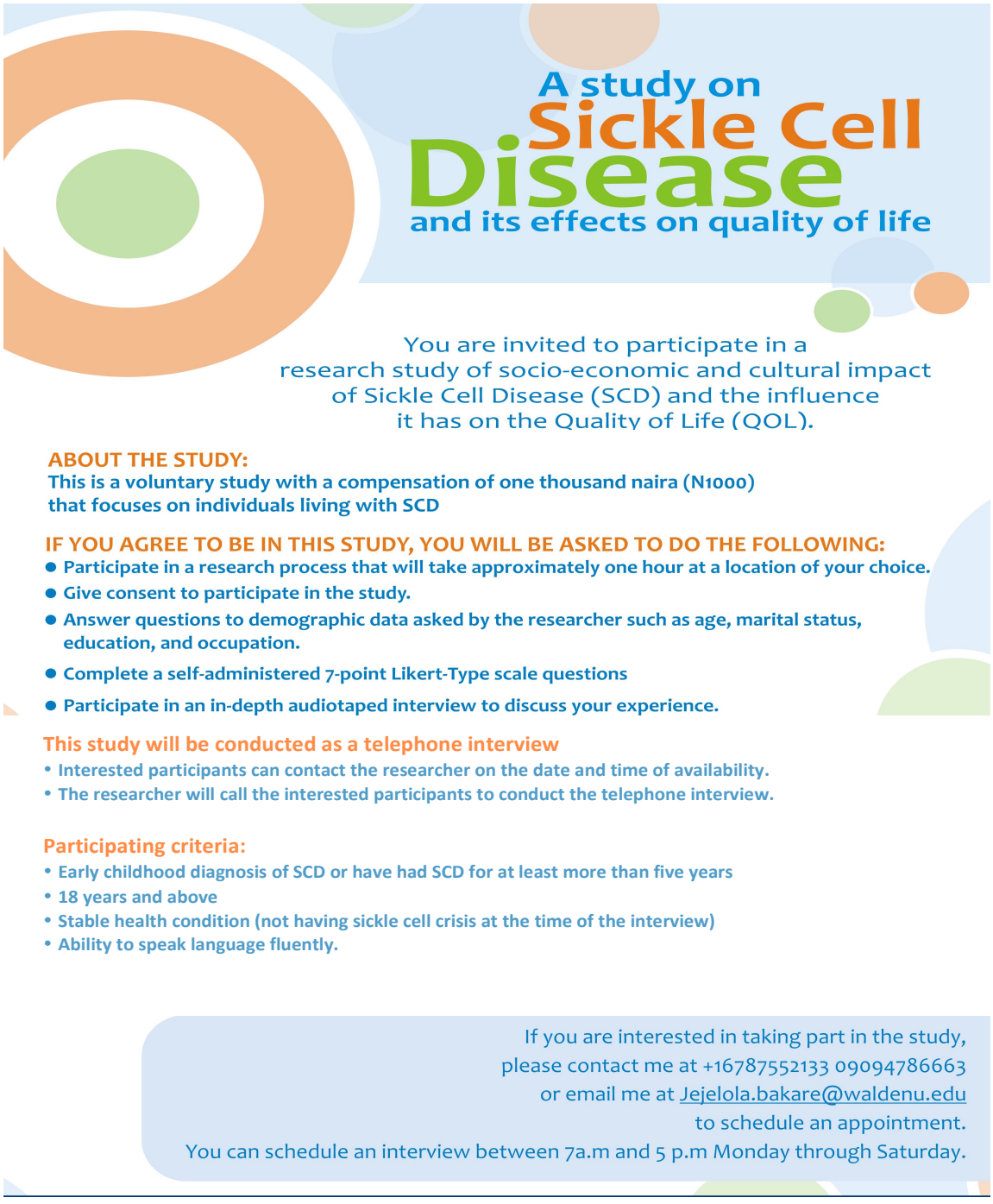
10. Please describe how your culture (For example, traditions, beliefs or religion) have affected your health or the management of SCD

11. What have you heard or learned about care for your SCD condition?

12. Is there anything else you want to tell me about your experience with SCD?

13. Is there anything else you want to tell me about your QOL?

Appendix C: Flyer



Appendix D: Attendant Form

Participants' Attendant Form

Identification Number	Participants' Name	Date Interview Completed

ID#	Question #	Response	Code

CODES: socioeconomic factor not diminishing QOL result (SR), cultural factors not diminishing QOL result (CR), socioeconomic factors diminishing QOL (SDQR), cultural factors diminishing QOL result, (CDQR) both socioeconomic and cultural factors diminishing QOL (SCDqR).

Appendix E: IRB Approval

Dear Ms. Bakare,

This e-mail serves to inform you that your request for a change in procedures, submitted on 9/8/15 has been approved. You may implement the requested changes effective immediately. The approval number for this study will remain the same.

Please note, while you are approved to modify how the interviews are done, you are still not approved to collect data at this time. Per the terms of the letters of cooperation for your community partner, as well as the conditional approval provided to you by the IRB, you must obtain approval from the Human Research Ethics Committee (HREC) of Lagos University Teaching Hospital. The approval from this HREC must be submitted to, and confirmed by, the Walden IRB before you can begin conducting your study. Until you have received confirmation from Walden, you may not interact with participants in any way (meaning flyers cannot yet be posted nor should you be obtaining consent from or conducting interviews with participants).

Both students and faculty are invited to provide feedback on this IRB experience at the link below:

http://www.surveymonkey.com/s.aspx?sm=qHBJzkJMUx43pZegKlmdiQ_3d_3d

Sincerely,
Libby Munson
Research Ethics Support Specialist
Office of Research Ethics and Compliance
irb@waldenu.edu
Fax: 626-605-0472
Phone: 612-312-1283

Office address for Walden University:
100 Washington Avenue South, Suite 900
Minneapolis, MN 55401

Information about the Walden University Institutional Review Board, including instructions for application, may be found at this link:
http://academicguides.waldenu.edu/researchcenter/orec

Dear Ms. Bakare,

This email confirms receipt of the HREC approval for the community research partner. As such, you are hereby approved to conduct research with this organization.

Congratulations!

Libby Munson
Research Ethics Support Specialist, Office of Research Ethics and Compliance

Leilani Endicott
IRB Chair, Walden University

Information about the Walden University Institutional Review Board, including instructions for application, may be found at this link:
http://academicguides.waldenu.edu/researchcenter/orec
Dear Ms. Bakare,

This email is to notify you that the Institutional Review Board (IRB) has approved your application for the study entitled, "Socioeconomic and Cultural Impact of Sickle Cell Disease: The Nigeria Perspective," conditional upon the approval of the community research partner, which will need to be documented in a signed notification of approval from the HREC. Walden's IRB approval only goes into effect once the Walden IRB confirms receipt of that HREC approval.

Your approval # is 07-07-15-0237277. You will need to reference this number in your dissertation and in any future funding or publication submissions. Also attached to this e-mail is the IRB approved consent form. Please note, if this is already in an on-line format, you will need to update that consent document to include the IRB approval number and expiration date.

Your IRB approval expires on July 6, 2016. One month before this expiration date, you will be sent a Continuing Review Form, which must be submitted if you wish to collect data beyond the approval expiration date.

Please note that this letter indicates that the IRB has approved your research. You may NOT begin the research phase of your doctoral study, however, until you have received official notification from the IRB to do so. Once you have received this notification by email, you may begin your data collection. Your IRB approval is contingent upon your adherence to the exact procedures described in the final version of the IRB application materials that have been submitted as of this date. This includes maintaining your current

status with the university. Your IRB approval is only valid while you are an actively enrolled student at Walden University. If you need to take a leave of absence or are otherwise unable to remain actively enrolled, your IRB approval is suspended. Absolutely NO participant recruitment or data collection may occur while a student is not actively enrolled.

If you need to make any changes to your research staff or procedures, you must obtain IRB approval by submitting the IRB Request for Change in Procedures Form. You will receive confirmation with a status update of the request within 1 week of submitting the change request form and are not permitted to implement changes prior to receiving approval. Please note that Walden University does not accept responsibility or liability for research activities conducted without the IRB's approval, and the University will not accept or grant credit for student work that fails to comply with the policies and procedures related to ethical standards in research.

When you submitted your IRB application, you a made commitment to communicate both discrete adverse events and general problems to the IRB within 1 week of their occurrence/realization. Failure to do so may result in invalidation of data, loss of academic credit, and/or loss of legal protections otherwise available to the researcher.

Both the Adverse Event Reporting form and Request for Change in Procedures form can be obtained at the IRB section of the Walden website:
http://academicguides.waldenu.edu/researchcenter/orec

Researchers are expected to keep detailed records of their research activities (i.e., participant log sheets, completed consent forms, etc.) for the same period of time they retain the original data. If, in the future, you require copies of the originally submitted IRB materials, you may request them from Institutional Review Board.

Office address for Walden University:
100 Washington Avenue South, Suite 900
Minneapolis, MN 55401

Information about the Walden University Institutional Review Board, including instructions for application, may be found at this link:
http://academicguides.waldenu.edu/researchcenter/orec

Appendix F: HREC Approval

LAGOS UNIVERSITY TEACHING HOSPITAL
HEALTH RESEARCH AND ETHICS COMMITTEE

PRIVATE MAIL BAG 12003, LAGOS, NIGERIA
e-mail address: luthethics@yahoo.com

Chairman
ASSOC. PROF. N. U. OKUBADEJO
MB. ChB, FMCP

Administrative Secretary
MR. D. J. AKPAN
B.Sc. BUS. ADMIN, MIHSAN

Chief Medical Director:
PROF. AKIN. OSIBOGUN
MBBS (Lagos), MPH (Columbia), FMCPH FWACP

Chairman, Medical Advisory Committee
DR. M. O. OGUNLEWE
BDS, FWACS.

LUTH HREC REGISTRATION NUMBER: NHREC: 19/12/2008a
Office Address: Room 107, 1st floor, LUTH Administrative Block
Telephone: 234-1-5850737, 5852187, 5852209, 5852158, 5852111

14th September, 2015

NOTICE OF EXPEDITED REVIEW AND APPROVAL

PROJECT TITLE: "SOCIO-ECONOMIC AND CULTURAL IMPACT OF SICKLE CELL DISEASE: THE NIGERIA PERSPECTIVE".
HEALTH RESEARCH COMMITTEE ASSIGNED NO.: ADM/DCST/HREC/404
NAME OF PRINCIPAL INVESTIGATOR: JEJELOLA ADEYIWOLA BAKARE
ADDRESS OF PRINCIPAL INVESTIGATOR: WALDEN UNIVERSITY, U.S.A.
DATE OF RECEIPT OF VALID APPLICATION: 23-07-13

This is to inform you that the research described in the submitted protocol, the consent forms, and all other related materials where relevant have been reviewed and given full approval by the Lagos University Teaching Hospital Health Research Ethics Committee (LUTHHREC).

This approval dates from 14-09-2015 to 14-09-2016. If there is delay in starting the research, please inform the HREC so that the dates of approval can be adjusted accordingly. Note that no participant accrual or activity related to this research may be conducted outside of this dates. All informed consent forms used in this study must carry the HREC assigned number and duration of HREC approval of the study. In multiyear research, endeavor to submit your annual report to the HREC early in order to obtain renewal of your approval and avoid disruption of your research.

The National code for Health Research Ethics requires you to comply with all institutional guidelines, rules and regulations and with the tenets of the code including ensuring that all adverse events are reported promptly to the HREC. No changes are permitted in the research without prior approval by the HREC except in circumstances outlined in the code. The HREC reserves the right to conduct compliance visits to your research site without previous notification.

HEALTH RESEARCH & ETHICS COMMITTEE CHAIRMAN LUTH

PROF. N. U. OKUBADEJO
CHAIRMAN, LUTH HEALTH RESEARCH ETHICS COMMITTEE