COLLEGE OF HEALTH SCIENCES

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QUALITY OF LIFE OF ADOLESCENTS LIVING WITH SICKLE CELL DISEASE IN THE ACCRA METROPOLIS

BY

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DECLARATION

I, James Mbangbe Ajusiyine do hereby declare that this thesis is my original research work, which was duly supervised, except for references made from other research and writers which have all been duly acknowledged. This thesis has neither in whole nor in part been presented to any institution for the award of any degree.

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DEDICATION

This work is dedicated to my lovely wife Miss Cecilia Awuni and our adorable children Akannamse Phyllis Michelle Ajusiyine and Anaam Ajusiyine for being a source of support and strength to me.

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LIST OF ABBREVIATIONS

GHS	Ghana Health Service
HBSC	Haemoglobin Sickling C
HBSS	Haemoglobin sickling S
HU	Hydroxyurea
MOH	Ministry of Health
SCA	Sickle Cell Anaemia
SCD	Sickle Cell Disease
SCT	Sickle Cell Trait
WHO	World Health Organization

ABSTRACT

Sickle Cell Disease (SCD) is an inherited genetic disorder characterized by chronic haemolytic anaemia, painful ischaemic episode of vaso-occlussion and progressive organ failure. SCD is endemic worldwide affecting millions of particularly children and has been declared by the World Health Organization and the United Nations as a disease of public health importance. Despite this, very little attention is given to the disease in Ghana. This study explored the quality of life of adolescents living with SCD in the Accra Metropolis. This qualitative research adopted the exploratory descriptive design. Purposive sampling was used to sample 11 adolescents receiving care at the 37 Military Hospital. All participants were interviewed face-to-face after ethical approval was sought. Thematic analysis was used to analyze data, which went on concurrently with verbatim transcription of audio recorded interviews. Four main themes and twenty-nine subthemes were derived. The four main themes include physical, psychological, social and spiritual well-being. The findings revealed that majority of the adolescents experienced fatigue, sleep disturbances, pain, and limitation in roles. All reported absenting themselves from school at some point. Again, majority reported receiving adequate family, social, financial, and emotional support. Few however, reported being stigmatized, feeling depressed, and feeling anxious. Few associated SCD with curse, and witchcraft. All the adolescents said their sources of inner strengths were their parents and God and that they had great hope they would get well. It is expected that the findings would improve care. These findings have implications for nursing practice, education, administration and research.

Key words: *Adolescents, Sickle Cell Disease, Quality of Life, and Ghana*

CHAPTER ONE

INTRODUCTION TO THE STUDY

In chapter one the background to the study, problem statement, study purpose, study objectives, research questions, significance of the study, operational definitions and organization of the thesis are presented.

1.0 Background

Sickle Cell Disease (SCD) is an inherited genetic disorder which occurs as a result of genetic mutation in the β subunit of haemoglobin (Oliveira et al., 2019). It is an inherited monogenic disorder, characterized by chronic haemolytic anaemia, painful ischaemic episode of vaso-occlusion and progressive organ failure (Houwing et al., 2019). People living with sickle cell disease have the sickle haemoglobin as the major haemoglobin. SCD is the single most important genetic disease that causes childhood mortality globally (Tluway & Makani, 2017).

Global evidence suggest that SCD is endemic worldwide affecting millions of people particularly children in every region of the world (Piel, Hay, Gupta, Weatherall, & Williams, 2013; Ware, de Montalembert, Tshilolo, & Abboud, 2017; Wastnedge et al., 2018). The World Health Organisation (WHO) and the United Nations (UN) have declared SDC as a disease of public health importance in the world (WHO, 2006). It is estimated that over 20 to 25 million people have SCD worldwide (Sharma & Brandow, 2019). Every year, 300 000 to 350 000 children are born with sickle cell disease globally (Abdullahi, DeBaun, Jordan, Rodeghier, & Galadanci, 2019; Brewin & Howard, 2017; Tavares, do Nascimento, Neto, Gonçalves, & Maria, 2017). SCD was originally very predominant in Sub-Saharan Africa, India, Saudi Arabia, and the Mediterranean countries (Boateng, Ngoma, Bates, & Schonewille, 2019; WHO, 2006).

However, it is now seen throughout the world, including the United Kingdom, United States of America and in French overseas territories (Piel et al., 2013). Approximately, 100 000 Americans are living with SCD while about 2, 000 children are born with the condition each year (Hassell, 2016; Martin, Thaniel, Speller-Brown, & Darbari, 2018). It is estimated that nearly three-quarters of SCD children live in Sub-Saharan Africa (Uyoga et al., 2019). SCD with hemoglobin SS (HBSS) is the most common form of HB defect and is responsible for 50-90% of deaths in children younger than 5 years in Africa (Uyoga et al., 2019).

Sickle cell disease is the most common, clinically significant, genetic disease in Africa, especially sub-Saharan Africa (SSA) (Hsu et al., 2018). Sub Saharan Africa (SSA) contributes about 75% of the global burden of sickle cell disease and with 50%-90% of mortality rate among children under five years (Boateng et al., 2019; Grosse et al., 2011; Uyoga et al., 2019). The prevalence of SCD is between 20% to 30% in countries such as Cameroon, Republic of Congo, Gabon, Ghana and Nigeria while in some parts of Uganda it is as high as 45% (WHO, 2016). About 150,000 babies are born yearly with SCD in Nigeria and it is estimated that by the year 2050 this figure will increase by 100% in the absence of effective and sustainable control strategies (Inusa et al., 2015; Piel et al., 2013). In Ghana, about 15,000 (2%) of newborns have SCD, and 55% of them have the homozygous (HBSS) form (Asare et al., 2018).

Evidence suggests that the situation in the African Region indicates that current national policies and plans are inadequate; appropriate facilities and trained personnel are scarce; and adequate diagnostic tools and treatment are insufficient, (Regional Committee for Africa, 2011). In Ghana for instance, even though there is a national non-communicable disease plan, it is not being implemented and there are no guidelines for management of Non-Communicable Diseases (NCDs) (Nyaaba, Stronks, Masana, Larrea- Killinger, & Agyemang, 2020). The lack of

implementation result from inadequate knowledge and awareness of the policy on NCDs, lack of intersectorial collaboration, coordination and engagement as well as insufficient funding for NCDs activities (Nyaaba et al., 2020)

Self-care is an important component in managing chronic diseases, particularly in SCD where pain crisis prevention is necessary (Matthie, Jenerette, & McMillan, 2015). Young people with SCD find it very challenging having to take care of themselves, make autonomous decisions, health choices and adapt to illness (Cecilio, Pereira, Pinto, & Torres, 2018). Self-management is the ability of an individual to manage the symptoms and consequences (physical, social, and lifestyle changes) of living with a chronic disease (McCorkle et al., 2011). It is the ability of a person in conjunction with family, community and health professionals to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of a health condition (Iregbu, 2016; Richard & Shea, 2011). Effective self-management is very crucial to improve the quality of life and health status of patients with SCD (Ashmad, Jahani, Poormansouri, Shariati, & Tabesh, 2014). Patients with SCD need to learn skills and behaviours to be able to manage their condition and prevent complications that are sometimes severe and life-threatening, including anaemia, stroke, pulmonary dysfunction, major organ complications, and unexpected and chronic pain crises (Ashmad et al., 2014).

Ghana has a large burden of SCD (Asare et al., 2018) and this has posed a huge economic burden to the patients and their families, healthcare systems and the national economy. Despite this burden, SCD remains excluded from the National Health Insurance Scheme (NHIS), and diagnosis and treatment remain very expensive for individuals and families. Over the years, SCD has barely been regarded as a disease of any public health significance in Sub Saharan Africa, and therefore is not given the needed attention in the form of resources in the sub-region

(Dennis-Antwi, Dyson, & Ohene-Frempong, 2008). This poses a serious threat to the QOL of adolescents living with the SCD and attainment of the sustainable development goal on health.

Literature on quality of life of adolescents living with SCD in Ghana is scanty. Therefore, this present study will add to existing literature and enhance the quality of life of sickle cell disease clients. The quality of life by Betty Ferrell (1997) was the model framework that was used to guide this study.

1.1 Problem Statement

Ghana has a large burden of Non-communicable Diseases (NCDs) including SCD (Abuosi et al., 2015; Yawson et al., 2016). The large burden of NCDs such as sickle cell disease has posed a huge economic burden to the patients and their families, healthcare systems and the national economy (Abuosi et al., 2015; Ministry of Health, 2012; Yawson et al., 2016). The costs of frequent hospital visits for routine care and acute illness management, the cost of frequent hospitalization, cost of medications, blood and other tests, and transportation far exceed the financial ability of many families and is not totally covered by the National Health Insurance Scheme (NHIS) (Dennis-Antwi et al., 2008). This may lead to infrequent hospital visit, non-compliance, and increased complications among adolescents suffering from SCD. Over the years, SCD has barely been regarded as a disease of any public health significance in Sub Saharan Africa, including Ghana, and therefore is not given the needed attention in the form of resources in the sub-region.

Throughout the professional carreer of the researcher as a nurse as well as trends observed during practicum training as a student, several adolescents have reported to the hospital with SCD symptoms, such as severe pain, fatigue, inability to perform activities of daily living,

loss of hope, as well as dimished trust in God, lowered inner strength, complaints of being stigmatized, social isolation, and school absenteeism. The carrier rate for sickle cell disease in Ghana stands at 30%, with a prevalence rate of 25% among the total population while 2% (15 000) of Ghanaian newborns have the disease and 1 in 3 Ghanaians has hemoglobin S and/or C gene (Dennis-Antwi et al., 2008; Edwin, Edwin, & Etwire, 2011). In Ghana, about 55% of newborns presenting with SCD have the homozygous (HBSS) form (Asare et al., 2018). HBSC is also very common in Ghana. The Korle Bu Teaching Hospital alone has over 25 000 registered SCD patients, between 10 000 to 15 000 yearly attendance, and daily average attendance of 50 patients (Asare et al., 2018). Similarly, the 37 Military Hospital's paediatric sickle cell clinic provides care for about 1000 registered children and/or adolescents with SCD (Devex, 2019).

Despite the higher burden of SCD, Ghana does not have a national policy, national guidelines for management, and national statistics on the condition (Dennis-Antwi et al., 2008). Even though there is extensive data on SCD, there is limited published data on the quality of lives of adolescents living with SCD in Ghana. Lack of support has been identified as a threat to the quality of life of adolescents living with SCD. However, little is known about the QoL experiences of adolescents living with the condition in Ghana.

Children transitioning from childhood to adolescence need to navigate the usual challenges that all adolescents face at this time such as identity formation, physical and social explorations, increased risk-taking behaviours , and at the same time, face the numerous other problems that their illness exposes them to such as decreased academic performance due to frequent school absenteeism (Asnani, Barton-Gooden, Grindley, & Knight-Madden, 2017; Epping et al., 2013). They also face poor social and financial support. Adolescents living with

SCD face huge psychosocial burden; frequently recurrent crises cause absenteeism from school leading to school dropout, and frequent stigmatization and discrimination lead to further sense of isolation from family and society (Edwin et al., 2011). Fully understanding the psychological, social, spiritual, and physical burden of sickle cell disease among adolescents will better help to offer appropriate support for them to improve their quality of life. Therefore, there is the need to explore the quality of life of adolescents living with SCD in the Accra Metropolis.

1.2 Purpose of the Research

The purpose of this study was to explore the quality of life of adolescents living with SCD in the Accra Metropolis.

1.3 Objectives

The objectives of this study were derived from the constructs of the model (Quality of life of long-term cancer survivors). The constructs are: Physical well-being (control of symptoms and maintenance of function independence), psychological well-being (maintain a sense of control in the face of life-threatening illness characterized by emotional distress, altered life priorities, and fear of the unknown, as well as positive life changes , social well-being (roles and relationships of individuals), and spiritual well-being (ability to maintain hope and derive meaning from SCD experience which is characterized by uncertainty).

1. Examine the physical well-being of adolescents living with SCD.
2. Describe the psychological well-being of adolescents living with SCD.
3. Ascetain the social well-being of adolescents living with SCD.
4. Describe the spiritual well-being of adolescents living with SCD.

1.4 Research Questions

1. What are the physical factors that influence the physical well-being of adolescents living with SCD?
2. What are the psychological factors that influence the psychological well-being of adolescents living with SCD?
3. What are the social factors that influence the social well-being of adolescents living with SCD?
4. What are the spiritual factors that influence the spiritual well-being of adolescents living with SCD?

1.5 Significance of the Study

The risk of life-threatening complications of SCD such as acute chest syndrome, vaso-occlusive crises, stroke, and other symptoms such as fatigue, anxiety related to recurrence of painful episodes, social isolation from friends and stigma, have serious implications on the physical, psychological, social and spiritual well-being of adolescents. Thus, the psychological well-being, physical well-being, spiritual well-being, and social well-being of adolescents was investigated to ascertain the magnitude of the problems that adolescents living with sickle cell disease face.

The quality of life of adolescents is important to them, their families, communities, country, and the health sector. Therefore, the significance of the study is that findings from the study will contribute to the current literature on quality of life of adolescents living with sickle cell disease and enhance self-management which is an important component of SCD management. The findings may also be used by healthcare professionals to develop an educational package to empower adolescents suffering from sickle cell disease on the best ways

to prevent and/or manage and/or delay complications. The morbidity, disability and mortality resulting from these complications will be prevented, decreased and/or delayed leading to improved quality of life among sickle cell disease patients. Resources that are used to manage these complications could be channeled to address other development priorities. The recommendations of this study will assist in policy formulation and provide evidence of putting more emphasis on preventive healthcare for curtailing sickle cell disease especially in sub–Saharan Africa. The study report will also assist the training institutions to improve their curricula to capture the needful preclinical training on managing sickle cell disease and other chronic diseases.

1.6 Operational Definitions

Adolescent*:* Refers to a person who is between the ages of 10 years up to 19 years (WHO, 2021).

Health and Well-being: The health status of the adolescent living with sickle cell disease.

Self-Management: A personal activity to take care of one's own self when having sickle cell disease.

Self-Management Practices: Self-reported performance of activities such as pain control, taking medications, dressing appropriately depending on the weather changes, and good hygienic practices.

Sickle Cell Disease: This is a genetic condition which has an abnormal haemoglobin S (HBS), which is unable to carry oxygen to cells and tissues of the body (WHO, 2010).

Quality of Life: Ability to live an optimal life devoid of infirmity.

1.7 Organization of Thesis

Chapter One presents the background to the study, problem statement, purpose of the study, objectives, research questions, significance of the study and operational definitions.

Chapter Two focused on describing relevant literature review on the study area. The theoretical framework guiding the study is first described, followed by an empirical literature review on quality of life of adolescent living with SCD. The literature is organized based on the study objectives and the constructs of the theory used.

Chapter Three presents a description of the methods used to achieve the study objectives. It includes the study design, setting, target population, sample and sampling technique(s), data collection method, data analysis and data management. Ethical consideration is also discussed on this section.

The **Chapter Four** presents the findings from the individual interviews obtained from the participants and presented in themes and subthemes. Four (4) major themes were based on the constructs of the Betty Ferrell's (1997) model. Overall, sixteen subthemes were developed. All data were thematically analyzed.

The **Chapter Five** focused on discussion of the findings of the study, in relation to existing literature. The discussion first looked at the demographic characteristics of the study, before discussing the themes of the study; physical well-being, psychological well-being, social well-being, and spiritual well-being; these themes are consistent with the constructs in Betty Ferrell's quality of life model, the theoretical framework applied to the quality of life of adolescents living with sickle cell disease in the Accra Metropolis.

Chapter Six outlines the summary of the study, its implication to nursing practice, research, administration and education. It also looked at the limitations, conclusion and recommendations of the study.

CHAPTER TWO

THEORETICAL FRAMEWORK AND LITERATURE REVIEW

In chapter two, the relevant literature of Quality of Life (QoL) of sickle cell disease were reviewed. The literature review seeks to unearth existing studies that have been carried out on the quality of life of adolescents living with SCD. A search for literature on quality of life of adolescents living with SCD was conducted using databases such as HINARI, PubMed, CINAHL, Science Direct, Medline, JSTOR, Google Scholar, Scopus, Google search, EBSCOhost, and SAGE.

Search terms: 'quality of life' used together with 'physical well-being', 'psychological well-being', 'social well-being', 'spiritual well-being', 'sickle cell disease', 'self-care', 'adolescents with sickle cell disease', 'sickle cell disease children', and 'chronic illnesses'. Boolean operators such as AND, OR, NOT, or AND NOT were very helpful in enhancing the search for research information. The justification for the choice of theoretical framework guiding the study was first described, followed by an empirical literature review on the physical, psychological, social and spiritual quality of life of adolescent living with SCD. The literature was organized based on the study objectives and the constructs of the theoretical framework. The Betty Ferrell quality of life model (1997) was the theoretical framework underpinning this study. Current relevant studies that focused on the research problem were well described in this chapter. This review was based on published literature.

2.0 Justification of Choice of Theoretical Framework

The Pain experience model by Siddall, Lovell , and MacLeod (2015), the theory of self-care management for vulnerable populations by Dorsey and Murdaugh (2003) and the

biopsychological model by Engel (1977) were found through an extensive literature search, however, these models did not contain all the relevant constructs that could help explore the right responses needed to address the issues of quality of life of adolescents living with sickle cell disease. The pain experience model by Siddall and colleagues has the biological, psychological, spiritual and social constructs and seeks to address pain among SCD patients. The quality of life of sickle cell disease patients go beyond just pain. This explains why Siddall et al (2015) model was not suitable for the current study. The theory of self-care management for vulnerable populations contains constructs such as the intra-personal factors, the contextual factors, vulnerability factors, self-care management, health status and quality of life. The biopsychological model had the biological, psychological and social domains.

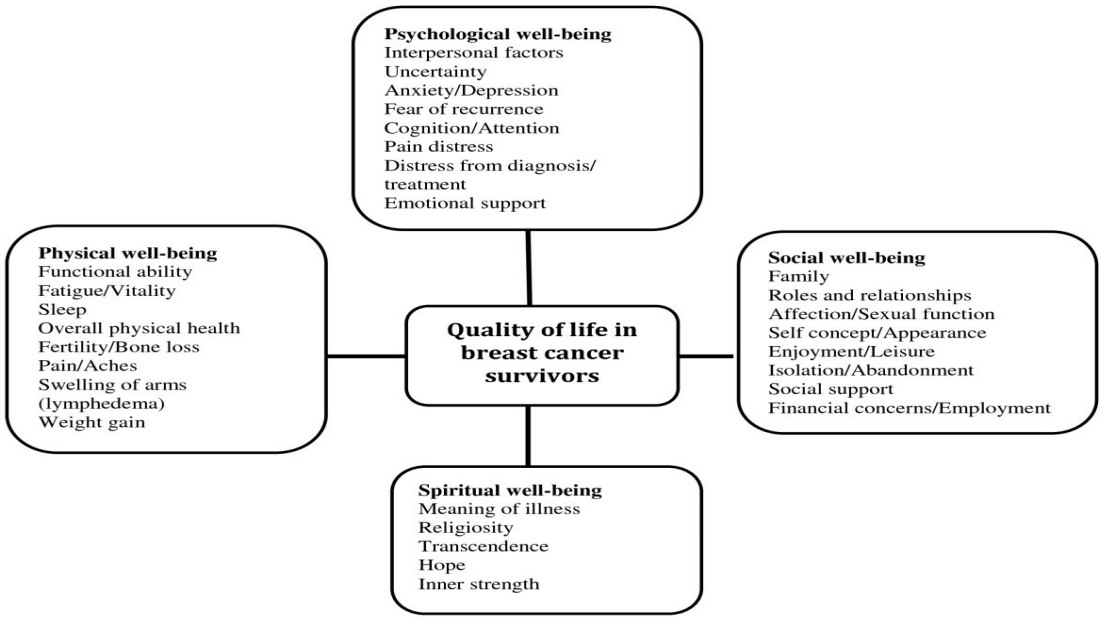
It lacked a spiritual domain which is very important for exploring the quality of life of adolescents wholly. Spirituality plays a major role in making ethical decisions and coping with suffering (Büssing, 2015; Clayton-Jones & Haglund, 2016). This explains why the biopsychological model was not suitable for this study. The quality of life of long-term cancer survivors (QoL- CS) model was adopted as the preferred choice because the model contains relevant constructs to suit the present study. The Betty Ferrell QoL (1997) model was adopted for this study because it is a simple but comprehensive theoretical framework that includes and organizes the numerous factors of quality of life into four basic domains for easy understanding and application.

2.1 The Quality-of-Life Model (Betty Ferrell)

This model was originally used in studies related to breast cancer survivors. However, other empirical studies on chronic illnesses successfully used the model to explore the QoL of persons living with chronic illnesses. The quality of life for breast cancer survivors' model by

Betty Ferrell's (1997) was found suitable for this study because all the constructs were useful and could influence the quality of life of adolescents living with SCD who face several challenges that affect their quality of life. As applied to this study, this model holds that the physical well-being, psychological well-being, social well-being and spiritual well-being influence the quality of life of adolescents living with SCD. The model was used in this study because its constructs and their concepts are relevant to adolescents living with SCD and aided in achieving the research objectives. The model has four constructs such as the physical well-being, social well-being, psychological well-being and the spiritual well-being. The theoretical position of this framework postulates that physical well-being, psychological well-being, social well-being and spiritual well-being all contribute to the quality of life of among breast cancer survivors (Ferrell & Dow, 1997). This model was adopted because of the similarities in the health needs of cancer and sickle cell disease patients; thus, chronic nature of the two conditions and pain as a common frequent experience.

Figure 2.1: Quality of Life Model (Ferrell & Dow (1997)



2.2 Description of QOL Model

Physical Well-being: Physical well-being seeks to relief or control a person's symptons without compromising basic functioning and independence of the individual (Ferrell & Dow, 1997). Key factors that may influence a person's physical well being includes pain, fatigue, poor functional ability and sleep disturbances. In effect, one may be described as having a higher quality of life if they encounter these factors in proportionate terms and are able to manage them effectively.

Psychological Well-being : This is achieved by maintaining one's composure and exhibiting a high level of self control even under extreme ill-health states. Instances such as these may be characterized by emotional distress, altered life priorities, fear of the unknown and may even include some positive life changes.Changes of concern under the psychological domains are anxiety/depression, fear of recurrence, pain distress, emotional support and uncertainties. These often eventually result marked anxiety, mood swings and depression (Ferrell & Dow, 1997).

Social Well-being: This seeks to deal with the impact of sickle cell disease on individuals, their roles, and relationships (Ferrell & Dow, 1997). The social well-being of individuals may be influenced by factors such as self-concept, enjoyment, leisure, role and relationships, isolation, abandonment, social, family and financial support.

Spiritual Well-being: This is the capacity to sustain hope and make meaning from the sickle cell experience, which is characterized by uncertainty (Ferrell & Dow, 1997). The spiritual well-being of a person could be affected by their perception and understanding of the meaning of illness, religiosity, hope, transcendence, inner strength and how these help them to cope with

illnesses. Changes in one QoL domain can influence perceptions in other domains (Ferrell & Dow, 1997). For example, a disruption in the physical well-being because of uncontrolled symptoms further affects psychological or social well-being. QoL is generally best defined from the perspective of the patient (Gill, 1994). The patient is the one to say what his quality of life looks like. The patient in expressing their quality of life views would be guided by interview guide which was designed based on the constructs and concepts in the conceptual model used here in doing so.

2.3 Prevalence of Sickle Cell Disease

SCD is caused by an inherited mutation in haemoglobin resulting in production of sickle haemoglobin, or haemoglobin S (HbSS) (Cieri-Hutcherson, Hutcherson, Conway-Habes, Burns, & White, 2019). It is a genetic disorder. Normal red blood cells (RBCs) are biconcave in shape which facilitates blood circulation and oxygen distribution to tissues and have 96 – 98% haemoglobin A (HbA). There are several types of SCD which include homozygous sickle cell anaemia (HbSS), heterozygous sickle cell hemoglobin C, sickle cell hemoglobin E disease, sickle cell hemoglobin D disease, hemoglobin Sß0 - thalassemia (HbSb0 - thalassemia), and hemoglobin Sß+ thalassemia (HbSb0+ thalassemia) (Cieri-Hutcherson et al., 2019; Ware et al., 2017). Sickle cell anaemia (HbSS) is the most severe form of SCD (Barriteau & McNaull, 2018; Wastnedge et al., 2018). Sickle cell anaemia (SCA) refers to the disorders HbSS or HbSb0 – thalassemia which are clinically similar. Sickle cell disease refers to all disease genotypes including SCA and compound heterozygous disorders. The carrier state for hemoglobin S (referred to as HbAS or sickle cell trait) is not considered to be a form of SCD.

Infection, anaemia, vaso-occlusive crisis (VOC) and associated pain, acute chest syndrome, stroke, chronic anaemia, jaundice, stroke risk and priapism are the most common

complications of SCD (Cieri-Hutcherson et al., 2019; Faremi & Olawatosin, 2020; Ware et al., 2017). It is also associated with chronic conditions such as pain, pulmonary hypertension, osteoporosis, and myocardial infarction. VOC results in sudden severe pain in the chest, back and extremities. SCD is very prevalent worldwide. Every year, about 400 000 children are born with sickle cell disease globally, out of which 80% are from Africa (Dennis-Antwi, Culley, Hiles, & Dyson, 2011). In the United States of America for instance, about 80 000 to 100 000 people are affected by the disease (Badawy et al., 2017b). In the United Kingdom, about 14 000 people are affected by SCD (Dormandy, James, Inusa, & Rees, 2018).

2.4 Current Management for People Living with Sickle Cell Disease.

Newborn screening is the most cost-effective way of diagnosing SCD early and helps to prevent morbidity and mortality (Segbefia et al., 2021). In high income countries, newborn screening has achieved excellent results. In the United States of America and United Kingdom for example, universal newborn screening has contributed to over 90% of newborns surviving into adulthood (Quinn, Rogers, McCavit, & Buchanan, 2010; Telfer et al., 2007). Despite the predominance of SCD in Sub-Saharan Africa, there is no universal newborn screening programs in place for timely diagnosing of the condition (Segbefia et al., 2021). Ghana began newborn screening for SCD in 1995 in Kumasi and later in Accra, this is yet to be implemented nationally due to lack of resources (Dennis-Antwi et al., 2011; Dennis-Antwi et al., 2008). Early screening helps in early diagnosis to begin early intervention thereby preventing complications.

Quite recently in February 2017, the SickKids Center for Global Child Health in Toronto, Canada, the Korle Bu teaching Hospital, Ghana's Ministry of Health and other partners signed a Memorandum of Understanding (MoU) to implement a multiphase SCD newborn screening in the Korle Bu Teaching Hospital and throughout Ghana (Segbefia et al., 2021). Penicillin

prophylaxis are currently being administered to people living with sickle cell disease at age 2 months to 3 months of life and stopped when they are 5 years old (Thornburg & Ware, 2018). Another routine drug for SCD is folic acid (Tezol, Karahan, & Unal, 2021). Presently, hydroxyurea is the drug of choice for the treatment of SCD and has contributed to reduction in inpatient admission (Colombatti et al., 2018). This has been reported to play key roles in reducing SCD pain, morbidity and mortality (Tshilolo et al., 2019). Besides newborn screening, penicillin prophylaxis is usually prescribed for children with SCD to prevent infection (Goldberg, Moore, Houck, Kaplan, & Barron, 2017). At age 9 months, they are then transitioned to hydroxyurea (Goldberg et al., 2017), which prevents vaso-occlusive crises.

Another important and integral aspect of SCD management is blood transfusion. Blood transfusion is done to resolve both acute and chronic complications of SCD (Sharma, Ogbenna, Kassim, & Andrews, 2020). This is done by administering red cells as a simple transfusion or exchange blood transfusion (Sharma et al., 2020). A dose of 10-15ml/kg of red cells is recommended for paediatric patients while 1-2 units is recommended for adult patients (Howard, 2016). Primary and secondary stroke prevention is the strongest indication for transfusion therapy (Sharma et al., 2020). According to DeBaun et al. (2014) in a paediatric randomized controlled trial for primary stroke prevention, chronic transfusion was beneficial in reducing episodes of recurrent acute pain compared to standard therapy. Chronic transfusions have been shown to be more effective than hydroxyurea in the prevention of recurrent severe acute pain episodes (Ware et al., 2016). Patients undergoing a blood transfusion must be monitored for complications and blood transfusion reaction.

Bone marrow transplant (Stem cell transplant) which has evolved for over the last 2 decades is currently the only curative treatment for SCD patients (Barriteau & McNaull, 2018).

Matched sibling donors are preferred for stem cell transplant over matched unrelated donors (Thornburg & Ware, 2018). The cost of stem cell transplant is expensive for average families. The success of a stem cell transplant depends largely on the self-management behaviour of the individual (Schulz et al., 2018). Medication adherence, adhering to frequent hospital visits, coping with adaptive prolonged isolation and restricted social interactions associated with stem cell transplant are desirable self-management behaviours (Schulz et al., 2018). One of the challenges that are faced by healthcare facilities in the USA after stem cell transplantation is rampant readmission (McKenna et al., 2015). Most readmissions are associated with fever. Ongoing continuous patient education need to be intensified at the OPD and on admission before discharge (McKenna et al., 2015). This could help improve on adherence to medication and health teaching instructions for self-management. Literature on the success of stem cell transplant in Ghana is very scarce. The first ever bone marrow transplant in Ghana was reported on 15th June 2018, and the patient was scheduled to have the procedure at a reported cost of Ghs 15 000 to Ghs20 000 (Graphic Online, 2018). This amount is very expensive, and unaffordable for majority of Ghanaians.

2.5 Physical well-being of adolescents living with SCD.

Adolescents with sickle cell disease face several physical factors that influence their quality of life. Among these factors are pain, fatigue, poor functional ability, sleep disturbances, and all these may affect their overall physical health. Pain is a common physical symptom among SCD adolescents and the reason for emergency department visit (Atoui et al., 2015; Oyedeji & Strouse, 2020; Sagi, Mittal, Tran, & Gupta, 2021). Pain can result in moderate to strong depression among youth (Reader et al., 2020). Acute pain is predominantly the hallmark clinical feature of SCD among adolescents, and reflects Vaso-occlusion and impaired oxygen

supply, but also infarction-reperfusion injury (Hyacinth et al., 2020; Poku, Caress, & Kirk, 2018). Vaso-occlusive crises lead to acute pain, and when left untreated, acute pain can cause morbidity and mortality in adolescents (Wilson & Nelson, 2015). The first step towards adequate pain management is proper assessment of pain (Abdo et al., 2019). A qualitative study conducted in Lebanon about daily experiences with sickle cell disease among adolescents reported that pain was the most common theme that emerged from the interviews among all the participants (Atoui et al., 2015). Acute pain is relieved with morphine, while chronic pain is dealt with by acceptance, downplaying the severity of pain and denial. Pain is commonly felt in the back, joints, chest, abdomen and extremities. Severe pain is treated with opioids or strong analgesics such as morphine and pethidine (Sagi et al., 2021), while mild pain is treated with nonopioids, such as paracetamol, ibuprofen, and diclofenac.

Non-opioids are not effective for treating severe pain (Abdo et al., 2019). Acetaminophen (paracetamol) and non-steroidal anti-inflammatory drugs (NSAIDs) are the most common drugs that are regularly taken for pain at home among patients with SCD (Abdo et al., 2019). Prevention of vaso-occlusive crises is very important. Studies have revealed that hydroxyurea is the only drug that can help prevent vaso-occlusive crises (Cieri-Hutcherson et al., 2019; Goldberg et al., 2017). Hydroxyurea increases blood haemoglobin level and decreases vaso-occlusive pain (Tshilolo et al., 2019). Lack of knowledge on the benefits, and fear of side effects of hydroxyurea use continue to pose serious threats to adherence to the drug (Cecilio et al., 2018). Adolescents should be educated on the benefits and side effects of hydroxyurea to increase compliance. This can help to improve the quality of life of adolescents.

Fatigue is another physical well-being concept that affects the quality of life of adolescents living with SCD. Fatigue is very common among SCD patients than healthy people

(Ahmadi, Poormansouri, Beiranvand, & Sedighie, 2018; Ameringer, Elswick, & Smith, 2014; Rogers & Lance, 2017). Fatigue could occur because of low haemoglobin (Toumi, Merzoug, & Boulassel, 2018). Fatigue in adolescents is sometimes dismissed and discredited by their peers and the adolescents are labeled as being lazy, weak, and incompetent (Poku, Caress, & Kirk, 2020). As a result of this, most adolescents are forced to mask the fatigue they experience and indulge in extreme work. This may result in extreme fatigue.

Sleep disturbances is one other problem that adolescents face while living with SCD. Sleep-related disorders (SRDs) affect sleep patterns and lead to insufficient amount or poor quality of sleep among adolescents living with sickle cell disease. Short duration of sleep or poor sleep patterns among adolescents has been reported in the literature in the United States of American (Rogers & Lance, 2017). An experimental study has revealed that SCD adolescents experienced worse total quality sleep than their healthy Black counterparts (Valrie et al., 2018). The findings showed that adolescents with SCD reported more problems going to bed, falling asleep, maintaining sleep, and reinitiating sleep after waking in the night than the healthy Black adolescents (Valrie et al., 2018). Consumption of caffeinated beverages and loud noises prior to bed time may be responsible for sleep disturbances (Hankins et al., 2014).

Functional ability and overall physical health are disrupted among persons living with SCD. This results in poor physical well-being and quality of life outcomes. Pain, a common symptom in SCD negatively affects the functional ability and overall physical health of adolescents (Kambasu, Rujumba, Lekuya, Munube, & Mupere, 2019). Nagshabandi and Abdulmutalib (2019), identified that inability to work could negatively affect severity of disease and SCD patients' quality of life. A systematic review reported that physical activity is safe and beneficial to patients living with SCD (Pinto et al., 2020). The paper revealed that physical

activity does not trigger Vaso-occlusive pain or result in clinical complications but rather improves exercise tolerance among SCD patients. The functional ability and overall physical health of SCD adolescents could be affected by missed school hours, inability to engage in school activities and inability to concentrate during studies (Kaya & Telfer, 2019). The ability for adolescents to perform household activities and care for themselves during pain crises and hospital admission could be compromised.

2.6 Psychological Well-being of Adolescents Living with SCD.

Psychological factors that influence the quality of life of adolescents living with sickle cell disease are distress from diagnosis and treatment, anxiety, depression, uncertainty, fear of recurrence, pain distress, and emotional support. Uncertainty, anxiety, and depression are concepts that impact on psychological well-being among sickle cell disease patients. Uncertainty remains one of the defining characteristics of the experiences of living with SCD in everyday life. Uncertainty is caused by the unpredictability of the condition, including the ever-present threat of painful episodes and complications (Blake et al., 2018; Renedo et al., 2019). Anxiety is often associated with increased pain (Brandow & DeBaun, 2018).

Increased frequency of pain is linked with higher levels of depression symptoms (Reader et al., 2020). The associations between pain frequency and depression symptoms are generally moderate to strong (Reader et al., 2020). Depression is significantly associated with poorer mental and physical health related quality of life outcomes (Adam et al., 2017) and poorer self-reported interpersonal skills (Valrie, Floyd, Sisler, Redding-Lallinger, & Fuh, 2020). It has been reported that anxiety and depression result in lower physical and mental health related quality of life scores in patients with mood disorders than those without mood disorders (Toumi et al., 2018). A systematic review reported that an estimated prevalence of 26.3% of children and

adults with SCD were depressed (Jonassaint, Jones, Leong, & Frierson, 2016). The findings of another systematic review has revealed that depression is associated with poor medication adherence (Grenard et al., 2011). Depression and anxiety are quite common among people living with SCD because of recurrent painful episodes. A mixed methods study in Nigeria among people living with SCD reports that out of 103 participants in the study, 74 of them had a level of depression (Ola, Yates, & Dyson, 2016). This may be associated with recurrent painful episodes, social isolation, and stigmatization.

Fear of recurrence and pain distress have the potential of causing poor quality of life in SCD. SCD pain can sometimes be frequently recurrent. This results in unpleasant experience of suffering from unbearable pain. Matthie and Jenerette (2017) described the pain experience of participants in their study as being "just the worst pain you can think of." "it is a constant pain though", pain is felt everywhere in their bodies and "nothing makes a pain crisis "easier". When patients experience higher fear of recurrence, it could lead to lower emotional functioning (Molnar, Kovacs, & Bartyik, 2020). These create great concerns on the quality of life of the people suffering from SCD.

Emotional support plays a key role in the management of adolescents living with SCD. Emotional support is very critical during SCD crisis. Extreme emotional disturbances are experienced mostly during a crisis (Al Adawi, Al Hamami, Al Harrasi, Al Hinai, & Al Alawi, 2021). This negatively impacts the emotional well-being of adolescents with SCD (Poku et al., 2018). When patients experience higher fear of recurrence, it could result in lower emotional functioning (Molnar et al., 2020). This may lead to low quality of life when left unattended to. Therefore, it is important for these SCD patients to have emotional support (Melita, Diaz-

Linhart, Kavanagh, & Sobota, 2019). This could help in ameliorating the suffering they go through.

2.7 Social Well-being of Adolescents Living with SCD.

The social well-being of adolescents is affected by factors such as self-concept, appearance, family, social and financial support, affection, roles and relationships, education, enjoyment, leisure, acceptance, isolation, and abandonment. Sickle cell disease is reported to negatively affect the self-concept of adolescents living with the condition (Poku et al., 2018). Adolescents are concerned about their self-concepts with regards to their appearances. They are concerned about being teased by their friends for being "skinny or bony" and look different from their friends (Zelihic, Williamson, Kling, & Feragen, 2021). A study in Kumasi, Ghana, revealed that adolescents complained of being criticized heavily for having unhealthy physical appearance; short stature, small muscles, yellow eyes and potbelly (Buser, Bakari, Seidu, Paintsil, et al., 2021). Participants in a study have being bullied and stigmatized for the way they walked, talked, behaved, having 'yellow eyes', their inability to carry heavy work, having 'soft bones' in school by their peers (Cecilio et al., 2018). Peers of adolescents with SCD often laugh at them when they disclose their diagnoses to them (Melita et al., 2019), most adolescents are reluctant to disclose to their friends that they have sickle cell disease as a result. Consequently, adolescents with SCD do everything within their powers to present a 'normal' self-identity in order to maintain a socially acceptable identity (Poku et al., 2020).

Family, social and financial support are very important in the care of adolescents living with SCD. Siblings, parents, school friends, church members, and community members provide financial aid, words of encouragement, and prayers for SCD adolescents at times of worsening illness (Gomes et al., 2019). In Saudi Arabia, a study reported that most SCD adolescents receive

support from their families (Khaled, Almaghaslah, Mutiq, & Alshehri, 2021). This may result in high financial hardships, major financial losses due to time spent caring for their children as reported by Kenya caregivers (Kuerten et al., 2020). Instead of being supported, some friends of adolescents with SCD are reported to tease and pressurize them (Faremi & Olawatosin, 2020), and this affect negatively their social quality of lives. Hawkins et al. (2020) explained that support from family, health workers and school are important to reduce the burdens of living with SCD. According to Poku et al. (2018), families support adolescents by motivating and comforting them to better cope with the SCD.

Affection, roles and relationships are unique social well-being phenomena in SCD. Social relationships among SCD adolescents are often affected negatively (Poku et al., 2018). A research study reports that SCD limits adolescents from taking part in community and household activities as well as play and this negatively affects their quality of life (Kambasu et al., 2019). A study in Lebanon revealed that all the participants in the study had significant challenges in their roles in school, particularly learning, because it was difficult for them to be able to concentrate, attend classes, and keep up with other students with their chronic illness, SCD (Atoui et al., 2015). Sometimes, parents, particularly mothers do not trust their adolescent children to be able to make relationships with others and live independently on their own (Cecilio et al., 2018). This could affect their relationships with others and abilities to care for themselves. SCD has potential for multiple psychosocial effects, such as loss of independence, feelings of isolation and loneliness, poor interpersonal relationships, and stigma (Blake et al., 2018).

The quality of life of adolescents with SCD cannot be looked at completely without considering their education, enjoyment, and leisure. SCD is reported to seriously affect the educational attainment, enjoyment and leisure of adolescents living with the condition. School

absenteeism is very common among SCD patients, and therefore, a strong collaboration among schools, medical providers, and parents would help better manage the academic achievement of SCD patients (National Academies of Sciences Engineering and Medicine, 2020). When students absent themselves from school, they are socially excluded as well (Atoui et al., 2015; Poku et al., 2018). All participants in a study in Lebanon revealed that they have common difficulties in school because it is difficult to have a chronic illness such as SCD and be able to concentrate, attend classes, and keep up with other students (Atoui et al., 2015). Their school performance is negatively affected as a result. This contrasts the findings in a study where adolescents reported that SCD had little impact on their education besides experiencing the occasional day of disruption (Constantinou, Payne, van den Akker, & Inusa, 2021). Although some participants were reluctant to admit that they were having any difficulties at school and claimed they were as ‘‘normal’’ as everyone else, further probe revealed that they were struggling, failing, or required extensive help outside of the classroom merely to pass (Atoui et al., 2015).

School absenteeism is very common among adolescents living with SCD because of being sick or hospitalized, having appointments with physicians and experiencing pain. Adolescents living with SCD miss school time due to hospitalization and those who experience pain during school are unable to focus and process information (Goldberg et al., 2017). This negatively affects their school performance. A better quality of life is necessary for students to attain better results in school (Molnar et al., 2020). Pain crises, which is a major symptom of SCD, limit them from enjoyment and leisure (Al Adawi et al., 2021).

Acceptance, isolation, and abandonment form an important part of the quality of life of SCD adolescents. A systematic review revealed that psychosocial implications among individuals with SCD included discriminatory remarks from significant others, negative

experiences, suicidal thoughts and ideations, stressful economic situations, loneliness, self-hate and somatic complaints (Quasie-Woode, Cunningham-Erves, & Mayo-Gamble, 2020). SCD adolescents are often bullied and stigmatized in school (Cecilio et al., 2018), and this discourages them from disclosing their SCD statuses (Buser, Bakari, Seidu, Paintsil, et al., 2021). Discrimination and isolation by peers and community members usually result from frequent complaint of pain and the belief that people with SCD die early (Buser, Bakari, Seidu, Paintsil, et al., 2021; Dennis-Antwi et al., 2011). A study in Nigeria revealed that individuals with SCD who were exposed to discriminatory remarks from significant others often had negative experiences and suicidal ideations (Ola et al., 2016). Stigmatization of SCD trait and associating the disease with family curse discourage the patients from seeking care in the hospital (Dennis-Antwi et al., 2018). Empowering individuals with an illness that causes them to experience stigma such as SCD can be a useful strategy to reduce the associated stigma (Blake et al., 2018). There is paucity of literature on empowerment programs available to adolescents with SCD in Ghana.

2.8 Spiritual Well-being of Adolescents Living with SCD.

The QoL factors that may affect spiritual well-being include meaning of illness, spirituality (transcendence) religiosity, hope, and inner strength. Several meanings have been associated with SCD. In some places, it is associated with curse or witchcraft. Other places it is associate SCD with a test or punishment from God. Ali and Razeq (2017) reported that SCD has a connotation with curse or a test from God. It has widely been confused with witchcraft, malediction, and sorcery, or manifestation of the anger of the ancestors (Montalembert, Tshilolo, & Allali, 2019). The findings of a study in Brazil reported that the participants, children and adolescents associated the meaning of the illness with spiritual beliefs. They associate SCD with their religious belief (Alvarenga et al., 2021). Some people in Ghana associate SCD with

witchcraft, demons, and a disease that is bought (Dennis-Antwi et al., 2011). A study in rural eastern Sierra Leone noted that SCD is as a result of witchcraft (Ibemere, Shambley-Ebron, Tanabe, & Jaja, 2021). Public education would help reshape public discourse around SCD as a curse or punishment and pave the way for the conventional medical treatment of the disease (Dennis-Antwi et al., 2018), and still give room for people to practice their faiths to cope with the complications of the disease.

Another unique concept of spiritual well-being is spirituality and religiosity. **Spirituality** refers to the innate capacity of persons to transcend themselves, to discern and experience meaning and purpose in life through contemplation and action aimed ultimately toward the sacred (Benson, Roehlkepartain, & Rude, 2003; Clayton-Jones, Haglund, Schaefer, Koenig, & George Dalmida, 2019). **Religiosity** refers to a commitment to an organized way of knowing and an orientation to a religious community's subject of worship.

Spirituality and religiosity assist individuals with SCD cope with the disease (Adzika, Glozah, Ayim-Aboagye, & Ahorlu, 2017; Alvarenga et al., 2021). Adolescents during a sickle cell crisis rely on prayers, friends, family members, spiritual leaders, and other adults for spiritual support. They worship God through music, reading religious texts, attendance to worship services and obeying the commandments of God (Gomes et al., 2019). This helps them to cope with SCD. The findings of a research study reported that adolescents who interacted with their friends while hospitalized felt this helped them to cope (Clayton-Jones, Haglund, Belknap, Schaefer, & Thompson, 2016). In the said study, most adolescents indicated having at least one friend, and these friends come from diverse ethnic and religious backgrounds. Furthermore, friends are identified as being supportive by having fun, engaging in activities, talking, gaining

insight, and visiting each other's church. Adolescents described experiencing connectedness through volunteering and service.

Adolescents have reported to engaging in activities such as dancing, music, or reading to experience transcendence. Some write in their diaries to reflect on self, others and find meaning in experiences. Despite this enormous benefit of spirituality and religiosity, little is known about S/R, coping, and health among adolescents living with SCD in Ghana. This may result in poor spiritual well-being, poor coping, and poor quality of life.

The phenomenon of hope is important for people living with chronic illnesses. Hope is a coping mechanism of living with chronic illnesses. Higher level of hope among adolescents results in greater ability to tolerate pain, the hallmark of SCD (Griggs & Walker, 2016). Hope enhances better quality of life in people with chronic illnesses (Mardhiyah, Philip, Mediani, & Yosep, 2020). The higher the hope, the better the quality of life (Mardhiyah et al., 2020). Elements that promoted hope among a study participants included controlling negative thoughts, selfcare, faith, good interpersonal relationships, exchanging experiences with friends, and psychological support (Alvarenga et al., 2021). Hope can be decreased by negative thoughts, poor interpersonal relationships with health professionals, unpredictability of disease outcome (Alvarenga et al., 2021).

Inner strength is one of the key concepts of spiritual well-being. Adolescents with chronic illnesses develop a sense of increased inner strength over time (Weitzman, Salimian, Rabinow, & Levy, 2019). They see the disease as an everyday experience and begin to accept the illness as a stable part of their self and identity (Weitzman et al., 2019). Patients who adhere to medication are noted to have higher levels of inner ability and inner strength than those who fail to adhere to

their medication (Franke, Nentzl, Jagla-Franke, & Prell, 2021). In a systematic review, the findings reported that even though resilience does not overcome chronic diseases, it promotes acceptance in the people with such conditions to their physical and social situations and adhere to their medical care and this results in healthier lives (Kim, Lim, Kim, & Park, 2019).

2.9 Summary of Literature Review

Out of all the literature reviewed, very few were from Sub-Saharan Africa, and even fewer were from Ghana. Some of the studies from Ghana include one which focused on controlling SCD disease in Ghana (Edwin et al., 2011), burden of the disease in Ghana (Asare et al., 2018), Adolescents' experiences of living with sickle cell disease (Poku et al., 2018), perceptions of SCD in Kumasi (Dennis-Antwi et al., 2011), how adolescents with SCD construct their fatigue experiences (Poku et al., 2020), relation between religious perspectives and views on sickle cell disease research and associated public health interventions in Ghana (Dennis-Antwi et al., 2018), and prevalence of positive mental health and functioning among adults with sickle cell disease in Ghana (Appiah, Tutu, Oman, & Ndaa, 2020). None of these looked at the quality of life of adolescents living with the condition. None focused on the quality of life relating to their physical, psychological, social, and spiritual well-being, demonstrating a clear gap in literature. Also, most of the literature reviewed used quantitative methods. Most studies in Ghana often focus on the adult population. This obviously reveals a serious paucity of literature on adolescents. In this study, the quality of life of adolescents living with SCD was brought to fore. Therefore, guided by the Betty Ferrell quality of life model (1997), the study employed a qualitative approach to explore the quality of life of adolescents living with sickle cell disease in the 37 Military Hospital.

CHAPTER THREE

RESEARCH METHODOLOGY

This chapter presents a description of the methods used to achieve the study objectives. It includes the study design, setting, target population, sample and sampling technique(s), data collection method, data analysis and data management. Ethical consideration is also discussed in this section.

3.0 Research Design

Research approaches involve plans and procedures used for research that include the steps from broad assumptions to detailed methods of data collection, analysis, and interpretation, and nature of research approach chosen depends on the research problem identified (Creswell & Creswell, 2018). A qualitative explorative descriptive approach was used to gather data from the study participants for analysis. Research design is an important component of research. The research design is the overall plan of obtaining conclusive answers to the questions being studied (Polit & Becks, 2010). Polit and Beck further suggest that the research design indicates how often data will be collected, the research setting and serves as the architectural backbone of the study.

Qualitative research design is flexible and elastic, combining various data collection strategies, and is holistic and the researcher gets intensely involved in the research (Astalin, 2013). A strong research design in a study is essential, and repetition of studies using different clients, different clinical settings, and at different times helps to ensure that the findings are robust (Polit & Becks, 2010).The researcher used qualitative research design, specifically, explorative descriptive approach to explore and describe the quality of life of adolescents living

with SCD in Ghana. This design enabled the researcher to gain an in-depth knowledge and understanding of the quality of life of adolescents living with SCD.

3.1 Philosophical underpinning

The constructivist paradigm was the preferred philosophical underpinning of this study (Kivunja & Kuyini, 2017; Wahyuni, 2012). This paradigm allows the researcher to understand the subjective thoughts of the study participants and the meaning they make of the context or phenomenon under study (Kivunja & Kuyini, 2017). Constructivists prefer to work with qualitative data with rich descriptions, in which research participants share their experiences and subjective meanings on given phenomena of study (Wahyuni, 2012). The main focus of this paradigm is to understand individuals as well as the meaning and interpretations they place on the world around them (Kivunja & Kuyini, 2017). Constructivist paradigm allows the researcher engage the study participants in an interactive, active process involving intermingle, dialogue, questions, listen, read, write, and record research data (Kivunja & Kuyini, 2017). Consequently, the constructivist paradigm helped the researcher in this present study to explore the experiences of adolescents living with SCD to share their understanding, subjective meaning and interprestation of SCD and how it impacted on their quality of life.

3.2 Study Setting

The study was carried out at the 37 Military Hospital located in the Ayawaso East sub-locality in the Accra metropolis. Accra metropolis is the capital city of the Greater Accra region which doubles as the capital city of the Republic of Ghana since 1877. The Greater Accra region was originally part of Eastern region until 1882 when it was carved out as a region of its own. The region occupies a total land surface of 3,245 square kilometers. This is 1.4 percent of the

total land area of Ghana. It shares borders with the North by the Eastern region, South by the Gulf of Guinea, west by Central region and east by the Lake Volta. The Greater Accra region has a total population of 4,010,054 (Ghana Statisitcal Service [GSS], 2010). According to the Ghana Statistical Service [GSS] (2010), the total population of residents in the Accra metropolis is 1,848,614. The indigenous people are referred to as Ga-Adangbe and Ga. The Ga-Adangbes speak Adangbe and the Gas, speak the Ga language.

Accra is a cosmopolitan region with almost all tribes in Ghana present here such as the Akans who speak twi and form the majority of migrant tribes in Accra. Other tribes include the Ewes, Gurusis, Dagabas, Mamprusis and Dagombas. The Greater Accra region has two (2) metropolis, nineteen (19) municipalities and five (5) district assemblies. The mayor is the political head of the metropolis and governance is administered through the local government system. In other words, political administration of the region is through the local government system. Even though Christians form the majority, the Greater Accra region is a multi-religious metropolis. The 37 Military Hospital, a major military- based hospital located in Ayawaso East sub-locality in the Accra metropolis, is a specialist hospital in the entire region after KorleBu Teaching Hospital. It is located on the main road between the University of Ghana, Legon and Accra Central near Jubilee house, the seat of government. It was established in 1941 by the British Military Officer, General George Griffard to provide medical services to troops from the 2nd world war. However, in 1956, the facility was opened to the general public and since then it has been providing specialized care to the military, the general public, United Nations and other foreigners in the sub-locality (Addae, 1997).

The hospital has a nursing training school that trains both civilians and military personnel in post- basic nurse anaesthesia, health assistants, general nursing and midwifery. The hospital

also provides postgraduate residency programmes for physicians. The hospital's healthcare personnel are either civilian or military with a bed capacity of 400 (Duncan-Wesley, 2015). The majority of the healthcare services are provided to the general public (Addo, 2016). The hospital has set up a Sickle Cell clinic that runs every Thursday at the paediatric outpatient department to provide exclusive care to the patients. Children with SCD are either admitted from the emergency unit or the Sickle Cell clinic into the paediatric ward of the facility. The hospital has fourteen (14) departments, which consists of the Medical, Surgical, Paediatrics, Obstetrics and Gynaecology, Public Health, the Ear Nose and Throat (ENT), Eye, Dialysis, Haematology, Anaesthesia, Operation Theatres and ICU, X-ray and diagnostics Department and the Department of Morbid Anatomy and the Nursing and Midwifery Training School.

It also has eleven (11) wards; divided into three (3) surgical wards, three (3) medical wards, two (2) special wards (for Very Important Personalities), one (1) paediatric and two (2) obstetrics and gynaecology ward respectively. The hospital provides a 24-hour service. Data for this study were collected from the paediatric Outpatient Department (OPD), the Paediatric Haematology and oncology ward and the Haematology and oncology day care unit. These represent the places the adolescents can be accessed for collecting the data for the study.

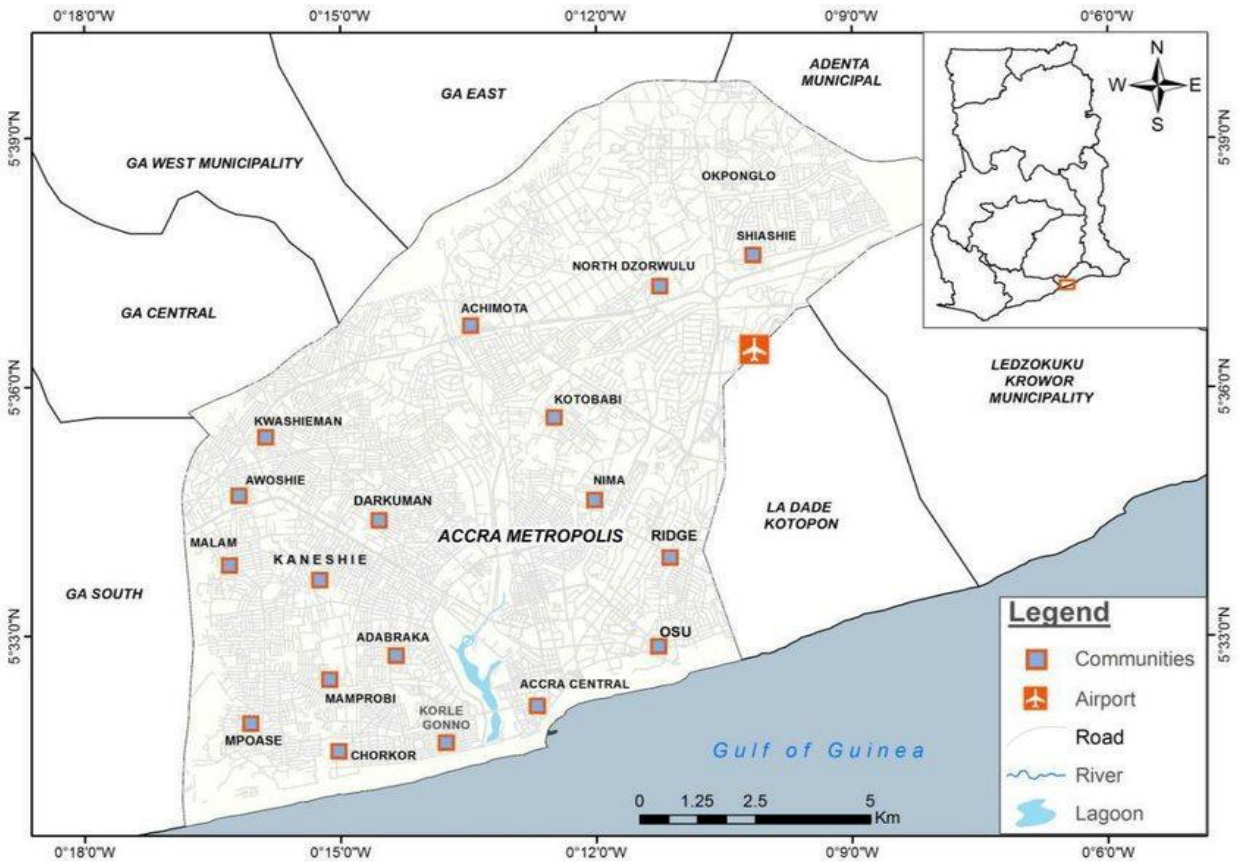


Figure 2. Geographical map of Accra Metropolis

3.3. Target Population

The entire population of interest to a researcher in which she or he would like to make generalization is the target population (Polit & Beck, 2003; Polit & Becks, 2010). In qualitative inquiry, determination of the target population would focus on selecting participants who can best share experiences and thoughts to address the qualitative research goal (Asiamah, Mensah, & Oteng-Abayie, 2017). The target population was sickle cell disease patients who sought healthcare at the paediatric Outpatient Department (OPD), the Paediatric Haematology and oncology ward and the Haematology and oncology day care unit. The target population is adolescents between the age 10-19 years.

3.4. Inclusion and Exclusion Criteria

Inclusion Criteria

The participants were eligible to participate in the study if they:

i. Are diagnosed of sickle cell disease and have been accessing health care in the hospital.

ii. Are 10 years to 19 years old.

Exclusion Criteria

Participants were excluded from this study if they:

i. Had some form of severe mental instability.

ii. Were in acute crises of SCD.

3.5 Sample Size Determination

Sample size refers to the number of subjects in a research study (Polit & Beck, 2003). The sample size for this study was based on data saturation where no new information was elicited from the study participants (Polit & C.T., 2011). This is very much in line with the tenets of qualitative sample size determination, where the sample size is determined based on the informational needs, hence, data saturation helps in deciding on the sample size (Polit & Becks, 2010). Very few individuals and sites are often involved in qualitative research, and the data obtained have extensive detail about the individuals or site (Creswell, 2013). Therefore, the number of participants recruited from the study site till saturation was achieved were eleven (11) adolescents. Data saturation was achieved when the 11th participant was interviewed.

3.6 Sampling Technique

Purposive sampling technique was employed to recruit respondents based on the inclusion criteria. In purposive sampling, participants with demonstrable or known expertise in

the area of interest for data collection are selected (Kumar, 2011). Purposive sampling technique is widely used in qualitative research for identifying and selecting information-rich participants who are very knowledgeable and experienced related to the phenomenon of interest (Palinkas et al., 2015; Polit & Becks, 2010). In a research study where the researcher wants a sample of experts, then purposive sampling helps in achieving that goal (Polit & Becks, 2010). Adolescents living with sickle cell disease, are the ones who experience the disease and therefore are the best experts to talk about their quality of life.

3.7 Data Collection Instrument

The data collection instrument refers to the protocol or tool the researcher uses to collect data (Creswell, 2013). In this study, the researcher developed and used a semi-structured interview guide attached as Appendix H as data collection instrument for data collection. The study consisted of open-ended questions and probes to help obtain in-depth information on the quality of life of adolescents living with sickle cell disease. The interview guide consisted of two main sections:

Section A (Appendix G) contained information about participants demographic data such as hospital, time, pseudo name, age, sex, tribe, level of education, area or locality and language (s) participant speaks. Sickling status/genotype, and average number of crises in a year were included in section A. Section B (Appendix H) contained questions that guided the researcher to explore the quality of life of the participants. These included, can you share with me, at what age were you diagnosed of sickle cell disease and where? Tell me how you felt when the diagnosis was confirmed, how has your physical, social, psychological, and spiritual health been like since the diagnosis of your present condition? Several probes were used to elicit extensive information from the participants during each interview.

3.8 Pre-testing

Pre-testing was done by using the data collection instrument (interview guide, appendix H) for data collection before the actual utilization (Creswell, 2013). This was done to identify questions that were not clearly framed, or did not make meaning, or were ambiguous for the purpose of improving the tool before actual data collection started. This was done after ethical clearance was obtained from the Institutional Review Board (IRB) of the 37MH (Appendix A). Pre-testing was done with two adolescents living with sickle cell disease in the Greater Accra Regional Hospital. The interviews were in the English language. After the pre-testing, the interview guide was improved by adding more probes to get detailed information to the interview guide.

3.9 Data Collection Procedure

The primary data for this study was obtained through individual interviews. The researcher obtained ethical clearance from the IRB of the 37MH (Appendix A). An introductory letter from the School of Nursing and Midwifery of the University of Ghana, Legon, to the 37 Military hospital authorities and copied to the heads of department of hematology and the nurse in-charge of the sickle cell clinic was done to have access to the study participants who met the inclusion criteria. Information on the inclusion and exclusion criteria was given to the nurse in-charge to enable her to know the types of participants that were qualified to take part in the study.

Participants were given the opportunity to ask questions on the informed consent process in a language they could understand, and all concerns were duly addressed. Those willing to take part were assisted to sign the consent form. Those who were minors, their parents or guardians signed the parental consent form, and the children signed the assent form before they partook in

the study. All participants were made to understand that the exercise was voluntary, and they were at liberty to drop out anytime during the study without any repercussions to them or their treatment regimen and health worker behaviour towards them. Participants were assured that measures were put in place to ensure that information given remains anonymous and confidential. Labels such as participant (P) 1, 2, 3,4,5…, were used for participants based on the order of recruitment until data saturation was reached at the eleventh participant. To enhance the interview skills of the researcher, a pre-test of two (2) interviews with the interview guide was conducted in the Greater Accra Regional Hospital in the Accra Metropolis to get feedback from the study supervisors.

A semi-structured interview guide (Appendix H) was used for data collection. Interviews were conducted based on the convenience of the participants. The venue was private and quiet to prevent interruptions. Demographic data were obtained, and the interview was audiotape recorded with permission from the participants to ensure that data was accurate and reflected the views of the participants. A field note was used to record mannerisms, gestures, and non-verbal cues from participants as they narrated their quality-of-life experiences. Further probing questions were used to elicit in-depth information from the participants. The interviews were in the English language. When a participant got emotionally distressed, the interview was paused temporally. In such a case, the participant could cry and referred to a clinical psychologist (Appendix D) at no cost to restore emotional health (psychologist's contact details: (Clinical psychologist's contact details: Dr Joan Laary-Afutu, Clinical Psychologist; 0244995518)

3.10 Data Management

Data management involves organizing the data properly in readiness for data analysis (Creswell, 2013). Data management involves converting large volumes of data into smaller,

more manageable segments (Polit & Beck, 2003). The thin distinction between data management and data analysis is that while data management focuses on data reduction, data analysis focuses on data construction; putting the data segments together into a meaningful conceptual pattern (Polit & Beck, 2003). Pertaining to data management, field notes were kept with the researcher while audio recordings, and transcripts were stored in a personal computer of the researcher and was managed manually. All the interviews were conducted in the English language, and transcriptions were done verbatim immediately after the interviews to prevent distorting the participant views. To prevent missing data, a separate folder was created together with proper and familiar files for the purpose of storing the electronic copy data in the personal computer of the researcher which was password protected. Field notes that were generated during the interviews were stored in the researcher's cabinet with access only allowed to him and the research supervisors. These measures were to prevent access by unauthorized persons. Only the researcher and the supervisors had access to the data. Each participant was given a pseudonym to promote easy identification by the researcher and to ensure confidentiality of the information. The data will be kept for a period of five (5) years by the researcher to ensure its availability when the need arises and destroyed afterward by burning the transcripts and deleting the audio tapes.

3.11 Data Analysis

Data analysis refers to the active and interactive process, in which a researcher scrutinizes a research data carefully by deliberately reading them over and over in search of meaning and understanding (Polit & C.T., 2011). In qualitative research, there is no universal rule for analyzing data (Polit & C.T., 2011). This makes data analysis very challenging and the absence of a standard procedure makes it very difficult to explain how to do qualitative data analysis

(Polit & C.T., 2011). Data collection and analysis in this present study went on concurrently to adhere to the principles of inductive inquiry (Polit & Beck, 2003). Data analysis were done using thematic analysis technique (Braun & Clarke, 2006).

Thematic analyss is a process used by researchers to identify, analyze, ornagize, describe and report themes in a research work (Braun & Clarke, 2006). Thematic analysis is flexible, and provides very rich and detailed data and is easy to learn and understand by people unfamiliar with qualitative methods (Braun & Clarke, 2006). There are six (6) phases or steps in thematic analysis (Braun & Clarke, 2006). (1) Familiarizing yourself with your data. The researcher in the present study read transcripts over and over to familiarize himself with the data. (2) Generating initial codes. Codes were generated in the current study as required. (3) Searching for themes. The researcher in this study generated themes after an extensive search and review of the transcripts. (4) Review themes. The researcher in this study reviewed all themes that were identified. (5) Defining and naming themes. In this study, themes were named and defined. (6) Producing the report. As required, report was produced for the present study. These steps listed above guided data analysis of the in-depth interviews in this study. The data were analyzed manually.

3.12 Methodological Rigor

Trustworthiness (Rigor)

Trustworthiness is a key step in which researchers persuade the readers that the research findings are worthy of attention (Lincoln & Guba, 1985). According to Polit and C.T. (2011) and Creswell (2013), it has been suggested by Lincoln and Guba (1985) that credibility, transferability, dependability and confirmability as the four criteria for developing the trustworthiness in a qualitative inquiry. Trustworthiness of a research seeks to ensure that it is

worthy enough (Lincoln & Guba, 1985). Rigor aims to make the study as excellent as possible in terms of detail and accuracy of information gathering.

Credibility- viewed as an overriding goal in qualitative research is the trust or faith in the truth of the data and interpretations a researcher presents, and researchers must strive to establish credence in truth in their study findings involving particular participants in a given setting or context in a research (Polit & C.T., 2011). According to Polit and C.T. (2011), Lincoln and Guba pointed out that two key steps to ensure credibility are (1) ensuring that the study is carried out in a way that enhances the believability of the findings and (2) demonstrating credibility in the research report. Prolonged engagement and respondent validation were used to ensure that the findings represent a credible analysis of the data from the participants' point of view (Lincoln & Guba, 1985). The researcher also used an in-depth interview guide. Tape recording, verbatim quotes of transcripts, accurate description, respondent validation (member checking), persistent observation, peer debriefing, and triangulation were also ensured (Lincoln & Guba, 1985).

Transferability- this refers to the extent to which the findings in a research study can be extrapolated or have applicability in other settings or groups (Polit & C.T., 2011). This can be achieve by providing sufficient descriptive data for consumers to evaluate the applicability of the findings to other contexts (Polit & C.T., 2011). Transferability was achieved through thorough, rich or thick descriptions of the findings and representative quotations to allow readers to determine the relevance of the findings to different populations (Lincoln & Guba, 1985). Other measures to achieve transferability included robustness of the study, accurate records, clear description of participants selection process, keen attention to detail, adherence to procedure, detailed description of setting, how study was conducted, representative quotations, thorough, and rich description of findings (Lincoln & Guba 1985).

Dependability- is the stability or reliability of a study findings over time and conditions (Polit & C.T., 2011). Dependability ensures that when an inquiry is replicated with same or similar participants in same or similar setting or context, the findings would be repeated (Polit & C.T., 2011). In qualitative research, dependability is required to attain credibility (Polit & C.T., 2011). Dependability was enhanced by careful documentation of the methods which were used in this study. There was logical research process, clear documentation for audit trail, review of transcription, expert review of codes and themes (Lincoln & Guba, 1985).

Confirmability- is the objectivity of a study findings, such that two or more independent people are able to reach congruence in terms of data accuracy, relevance and meaning (Polit & C.T., 2011). Confirmability ensures that the data presented represents the information the participants provided and not the invention of the researcher (Polit & C.T., 2011). Confirmability was ensured through an audit trail consisting of observation, methodological, and theoretical notes (Lincoln & Guba, 1985). To enhance confirmability, the researcher ensured interpretations and findings were from the data and how they were derived. Maintenance of a reflexive journal, audit trailing consisting of observation, methodological and theoretical notes, and bracketing were ensured (Lincoln & Guba, 1985). Bracketing refers to the process of recognizing and detaining in abeyance prejudiced beliefs, and opinions about the phenomenon in a study (Polit & Beck, 2003). As a health care provider for and researcher with persons with SCD, bracketing was ensured by acknowledging and attempting to bracket those experiences and expertise (Creswell, 2013). None of the participant had been a patient of the interviewer.

3.13 Ethical Considerations

The researcher obtained ethical clearance from the IRB of the 37MH (Appendix A) of the 37 Military Hospital. Introductory letters were sent to the hospital authorities (Appendix B) and

the institutional review board chairman (Appendix C) as part of the approval process. Only participants who willingly assented and whose parents provided consent were interviewed. Deliberate efforts were made to ensure that confidentiality, privacy, no harm to study participants, voluntary participation, and all procedures concerning the use of human participants in research were strictly adhered to in the research process. Informed parental consent was signed by guardians while the adolescents themselves signed the child assent form. The objectives and purpose of the study were explained clearly to the participants before the commencement of each interview. Participants were informed that they have the right to opt out of the study anytime they felt like doing so without any repercussions. Participants' behaviours were observed closely during the interviews to remain sensitive about their voluntary participation.

Participants were informed that the study will not harm them in anyway. Consent forms were made available for all participants to sign after they had given their approval to partake in the study. Parents and/or guardians signed the parental consent form for minors prior to data collection. Demographic data was collected before the start of interviews and permission was sought from participants before audio recording the interviews which was used solely for the study. Furthermore, participants were assured of anonymity, confidentiality and privacy. Participant (P) was used for respondents instead of their own names such as P1 for participant one, P2 for participant two, P3 participant three in that order till saturation was reached. Data are locked securely and are accessible only to the researcher and the supervisors. Data will be stored for five (5) years and destroyed afterwards.

CHAPTER FOUR

FINDINGS OF THE STUDY

This chapter presents the findings from the individual interviews obtained from the participants and presented in themes and subthemes. Four (4) major themes emerged from the data obtained from the participants as guided by the constructs of the Betty Ferrell's (1997) model adopted for this study with subthemes emerging from the content analysis of the data analyzed. The four themes include the physical well-being, psychological well-being, social well-being, and the spiritual well-being. Anonymous verbatim quotations were used to support the various themes and subthemes using pseudonyms. Participants backgrounds were also thoroughly described as captured during data collection.

4.1 Socio-demographic Characteristics of Participants

A total of eleven (11) participants, 7 females and 4 males aged between 13 and 19 years were interviewed for this study. 9 participants have the sickle cell genotype SS, 1 has SC and 1 does not know his genotype. Their tribes were: five (5) Ewes, one (1) Akan (Akwuapim), one (1) Builsa, one (1) Akan (Akyim), one (1) Ashanti and one (1) Damgbe. Ten (10) participants are Christians and one (1) is a Muslim. Four (4) of them are currently in Junior high school, two (2) are currently attending senior High school, one (1) has completed senior high school but is waiting to go to the tertiary level. According to her, she could not write her mathematics paper when she was writing the West African Secondary School Certificate Examination (WASSCE) because she had sickle cell crisis and was on admission. She has written the private November/December examination (for the mathematics paper) and will go to the tertiary level soon. Four (4) participants are currently attending school at various tertiary institutions of learning. Eight (8) participants live with both parents, one (1) participant has lost both parents to

death and lives with her siblings, one (1) participant lives with her mother; the father lives in the United States of America (USA) but is still married to the mother and one (1) participant lives with his mother; his father and mother have divorced but the reason for divorce is not related to Sickle Cell Disease.

Table 4.1

Demographic Data of Participants

Pseudo name	Age	Sex	Genotype	Tribe	Religion	Level of Education
1. Ama	19	F	SS	Akan (Akwuapim)	Christianity	SHS
2. Senam	19	M	SS	Ewe	Christianity	Tertiary
3. Esinam	18	F	SS	Ewe	Christianity	Tertiary
4. Kofi	16	M	SS	Ashanti	Christianity	SHS
5. Atsu	14	F	SS	Ewe	Christianity	JHS
6. Naa	13	F	SS	Damgbe	Muslim	JHS
7. Edem	14	M	SS	Ewe	Christianity	JHS
8. Selasi	19	F	SC	Ewe	Christianity	Tertiary
9. Awentemi	19	F	SS	Builsa	Christianity	Tertiary
10. Akos	16	F	SS	Akan (Akyim)	Christianity	SHS
11. Nana Yaw	14	M	Unknown	Ashanti	Christianity	JHS

4.2: Organization of Themes and Sub-themes.

The objectives of this study and the constructs from the Betty Ferrell quality of life of breast cancer survivors' model were used to structure the themes. Four (4) main themes were identified. These themes include physical well-being, psychological well-being, social well-being, and spiritual well-being. Sub-themes were identified and matched with the main themes. Coding of data was done through rigorous and repeated reading of transcripts. Emerging themes were also identified and added.

Table 4.2

Organization of themes and sub-themes

S/N	THEME	SUBTHEMES
1	Physical well-being	a. Functional ability and overall physical health b. Fatigue and pain c. Sleep
2	Psychological well-being	a. Distress from diagnosis and treatment b. Uncertainty, Anxiety, and depression c. Fear of recurrence and Pain distress d. Emotional support
3	Social well-being	a. Self-concept and appearance b. Family, social support, and financial concerns c. Affection, Roles, and relationship d. Education, Enjoyment, and leisure e. Acceptance, isolation, and abandonment
4	Spiritual well-being	a. Meaning of illness. b. Religiosity and spirituality c. Hope d. Inner strength

4.3 Physical Well-being

Physical well-being is an important component of quality of life among adolescents. Physical well-being focuses on the control and relief of symptoms, the maintenance of function and independence. The sub-themes under physical well-being include functional ability, overall physical health, fatigue, pain, and sleep.

4.3.1 Fatigue and Pain

Pain and fatigue are common symptoms experienced by people living with sickle cell disease, and adolescents living with the condition are not an exception from this experience. Describing their experience with fatigue and pain, all eleven (11) participants reported that pain and fatigue are key issues affecting their quality of lives. Some of them explained that while pain is not frequent due to routine medications they are put on, they easily get tired when they do heavy work. Some of them reported as below when asked if they always felt tired/pain:

Fatigue*:*

> *"Yes**,** sometimes**,** when I do a lot of things, I feel tired. sometimes lifting a lot of things, sometimes running errands, I feel tired, so I have to sit at some point and rest" (Edem, 14yrs, Male, JHS).*

> *"Sometimes, I am just there, just standing and I feel tired but nowadays it doesn't happen. In the mornings when I am washing my father's car, just that can make me tired. I have to go and sit down"* (Kofi, 16yrs, Male, SHS).

> *"That is when I walk for very long distance under the sun without taking a lot of water. Apart from that I am always in bed. I am always home. But apart from that when I walk in the sun for long distance without taking a lot of water, I feel tired" (Ama, 19yrs, Female, SHS).*

> *"Like when I walk for a long time, I feel very fatigued or when I stress out during the day, the following day I get fatigued. Sometimes when my blood haemoglobin (HB) level is low, I get very tired" (Awentemi, 19yrs, Female, Tertiary).*

Pain:

> *"Yes, I feel pains, but don't feel pains like at first. When I feel the pain, it pains me very hard. It pains me a lot"* (Nana Yaw, 14yrs, Male, JHS).

> *"Not quite often, maybe okay, I am on drugs right now (hydroxyurea, folic acid and zincovite) so the way I used to feel pain isn't the way I feel pain nowadays"* (Ama, 19yrs, Female, SHS).

> *"Mostly when the weather is cold. Mostly when I do some activity which I am not supposed to do like running or any physical activity which involves me applying force, that is when I have pain"* (Senam, 19yrs, Male, Tertiary).

To improve their fatigue and pain, all (11) of the participants reported that they always take water, apply rob ointment on the affected joints, take pain medication and rest well enough when they experience fatigue and pain. Some participants also deploy diversionary therapy such as watching movies, television, chatting with family and friends to divert their minds from the pain. The following are comments made by some of the participants:

> *"When it comes, I drink water, that is the first thing. I drink water and then sleep. I just leave whatever I am doing or leave where I am and go and sleep. So, by the time I wake up, when I feel ok, then I am ok, but then when still I feel the fatigue is still there, that is when I come to the hospital"* (Esinam, 18yrs, Female, Tertiary).

> *"I take a lot of water because I am not really the medicine type. I take a lot of water. But…sometimes when the headache comes, I feel like my head wants to fall, so I just take this paracetamol or sometimes" Gebedol* (Selasi, 19yrs, Female, Tertiary).

> *"Sometimes I watch movies to distract myself. Or I talk with my sisters. They help a lot. Sometimes they just make me laugh so that I will be distracted (from) the pain"* (Awentemi, 19yrs, Female, Tertiary).

> *"When it (pain) starts, it comes very slightly so I take my medication paracetamol or diclofenac so sometimes it ends it just there or the crises come and it will reduce it or something like that"* (Kofi, 16yrs, Male, SHS).

All the participants have underscored the importance of reporting timely to the hospital for healthcare when they feel unwell. One participant made the following comment when asked what she does when her pain comes:

> *"When the pain comes, the first thing is you try to get a car to the hospital. But if where you are staying there are no cars available that is where we get this Robb ointment then we apply them to the places where we feel the pains so that it will come down a bit so that in the morning we can come to the hospital"* (Esinam, 18yrs, Female, Tertiary).

4.3.2 Sleep disturbances

Analysis of the data revealed that difficulty sleeping is a major problem affecting most participants. According to majority (9 out of 11) of the participants, difficulty sleeping is more accentuated when they are in pain. The following are comments made by participants:

> *"I find it very difficult to sleep sometimes, especially when I am in pain…2 weeks ago, I was very sleepy but because of the pain, I was awake throughout the night"* (Awentemi, 19yrs, Female, Tertiary).

> *"When I feel pain, I don't sleep well" (Senam, 19yrs, male, tertiary).*

> *"Okay, so about the sleep you will feel sleepy alright but when you try sleeping you can't. Small time, you just wake up, then you sleep again, small time you just wake up, then you sleep again. So it is like that throughout the night"* (Esinam, 18yrs, Female, Tertiary).

Good sleep is very important for the quality of life of adolescents living with sickle cell disease. The data from the participants therefore suggests that there is the need to put measures in place to minimize, treat and if possible, prevent pain among adolescents living with sickle cell disease in order to promote good sleep and improve upon their quality of lives.

4.3.3 Functional Ability and Overall Physical Health

Functional ability/overall physical health is one of the subthemes emerged from physical well-being encountered by adolescents who were interviewed. Majority of the participants reported that they can perform many activities of daily living but with caution not to cause stress that can trigger their sickle cell crises. Others also said they feel that overall, they are physically healthy just like any other normal human being. For instance., when asked about their functional ability/overall physical health most of them said it was good and that they could do everything

their peers do, while few said it was not good and they were restricted from doing some activities their peers do. Below are some of their reports:

> *"It (overall physical health) is cool. It's ok. I'm free to do anything, but I don't stress myself, because of the stress, I don't do games at school because of the running and the sports"* (Atsu, 14yr Male, JHS).

> *"I sometimes feel different from others. I sometimes see myself different from other people because when I get sick, leaving school, come to the hospital, getting admitted. I sometimes feel bad. At times I feel what others can do, I can't do it… My physical health hasn't been that stable"* (Senam, 19yrs, Male, Tertiary).

> *"There are some things I want to do but I have been told not to stress myself and everybody thinks I am too sick to do some activities. And with my condition, there has been situations where I feel very vulnerable"* (Awentemi, 19yrs, Female, Tertiary).

Some participants have also indicated things they are unable to do due to sickle cell disease. A participant has the following to say:

> *"At school, I can't play netball, and football for the school, because of the sickle cell disease*" (Naa, 13yrs, Female, JHS).

She however stated that:

> *"I can do anything I am supposed to do in the house without the disease affecting me"* (Naa, 13yrs, Female, JHS).

medical treatment/routine medication

All the participants of this study are on routine medications prescribed for them by medical doctors. Routine medications the participants take include folic acid zincovite, penicillin V, and hydroxyurea. Some participants take folic acid, zincovite, penicillin V, hydroxyurea. Others (few participants) take only folic acid. Some participants have reported that they are not put on hydroxyurea by their doctors, hence do not take it. The participants reported the routine medications they take as follow:

"My routine drugs, I take hydroxyurea, folic acid and zincovite" (Ama, 19yrs., Female, SHS).

"Actually, the drugs prescribed to me since I had sickle cell disease is zincovite, folic acid and penicillin V. these are the drugs prescribed to me" (Senam, 19yrs., Male, Tertiary).

"Since I was diagnosed with the Sickle Cell, I have been taking folic acid and the zincovite but the hydroxyurea I started last year December" (Kofi, 16yrs., Male, SHS).

"I am only on folic acid. Sometimes, when you come to the hospital, it depends on what the doctor sees, he or she will tell you to add zincovite to it. The sickle cell anaemia daily tablets or medications are zincovite and folic acid. We don't take the zincovite that much because it contains iron and zinc, and those two are not really good for us" (Esinam, 18yrs., Female, Tertiary).

When asked if she takes hydroxyurea, Esinam reported that she does not take it and has not heard of the name before.

4.4 Psychological Well-being

This is the attempt to maintain a sense of control in the face of life-threatening illness characterized by emotional distress, altered life priorities, and fear of the unknown, as well as positive life changes. The most problematic changes affecting QOL in the psychological domain are anxiety/depression, fear of recurrence, pain distress, emotional support and uncertainties. Changes in the psychological well-being result in marked anxiety, mood swings and depression.

4.4.1 Distress from Diagnosis and Distress from Treatment

Most people with sickle cell disease are usually diagnosed at tender ages. The data revealed that most (7 out of 11) of the adolescents interviewed were diagnosed when they were young and didn't understand the implication of their diagnosis. However, some were diagnosed when they were grown and knew what the disease means to them. For example, below are

comments made by participants when asked how they felt when the diagnosis of sickle cell disease was made:

> *"At that time, I was small, so I didn't know what was going on. I was not worried or distressed"* (Kofi, 16yrs, Male, SHS).
>
> *"By then I was young, so I didn't know anything about sickle cell disease. I was not distressed"* (Atsu, 14yrs, female, JHS).
>
> *"Surprised, anxious and sometimes too nervous because I wasn't expecting to get the sickness at that time. I was young, so I was very surprised"* (Edem, 14yrs, Male JHS).
>
> *"At that age, I didn't know what sickle cell was. Until I grew up before I started knowing what it was. Actually, I sometimes feel different from others. I sometimes see myself different from other people because when I get sick, leaving school, come to the hospital, getting admitted. I sometimes feel bad. At times I feel what others can do I can't do it"* (Senam, 19yrs, Male, Tertiary).

Interestingly, while majority of the participants said they have no distress from taking the treatment one participant expressed her views about how uncomfortable it is for her to take the routine medication, particularly the hydroxyurea. She explained that sometimes she feels nauseated after taking the medication but continues to take them since, according to her, she has no choice than to do so. She reported that:

> *"The hydroxyurea, sometimes when I take them, I feel uncomfortable, I feel like vomiting and stuff, but they are my routine drugs, so I have no choice than to take them"* (Ama, 19yrs, Female, SHS).

4.4.2 Uncertainty, anxiety and depression

Uncertainty, anxiety, and depression are subthemes under the main theme psychological well-being that affect the quality of life of adolescents living with sickle cell disease. Uncertainty, anxiety, and depression culminates from sickle cell pain, crises, getting a job, missing school, death, and poor health outcomes. According to one participant, she always

remains positive but doubted God when she became ill and was admitted for a long time and was also afraid that she may die. She reported that:

> *"I always remain positive. There had been times when I was sick for a very long time, I was doubting God, apart from that, that's all… I was afraid I was going to die because it was more serious than the previous admissions"* (Ama, 19 yrs., Female, SHS).

Another participant explained that his source of depression is his inability to do things he desires to do and from people talking ill of him, he said:

> *"Things that get me depressed, you see, most at times I feel bad about myself that I can't do anything. At times people will say bad things about you. They discourage you and make you sad, they make you sad. At times I keep on thinking about it"* (Senam, 19yrs., Male, Tertiary).

Another participant reporting about depression said:

> *"Sometimes I get depressed, sometimes I will get depressed a lot that even if I am in my room and you enter the room, I will just ignore you. I won't mind you. You are asking me something I won't mind you. At that time, I just want to be alone. I will be alone in my room. I would cry a lot till my eyes become red. I will cry sometimes and refuse to eat but I eventually have to eat because of my daily tablets"* (Esinam, 18yrs., Female, Tertiary).

Anxiety and fear among some of the participants stem from the kind of information they come across, fear of not getting a job, missing school, and short life span. For example, a participant reported that she always gets scared when she reads from the internet and gets informed that people with sickle cell disease can die early or get blind. She said as follows:

> *"Sometimes, when I go online and read about sickle cell, sometimes it scares me, later on when I read more, I get to know that you have more life if you take good care of yourself…* actually, *I was just scared. When I become scared like that, I tend to ask God that he should see me through.…Like the death for instance, when I came for check-up, they said sickle cell, you can get blind as well, especially when I heard that, I became more scared. So, every year, I go and check my eye"* (Selasi, 19yrs., Female, Tertiary).
>
> *"To me personally, I thought I was going to die. I didn't know what sickle cell was. My mum will always tell me, "you will be fine, don't worry, you won't die" but deep down, I was like I am going to die. Because what at all is sickle cell disease? I didn't understand*

> *at a very young age, I wasn't understanding so I thought I was going to die. And people around my family especially my dad's side will say 'we've seen people your age, they suffered from sickle cell at the age of 17, they died, at the age of 16, they died'. That always hunted me a lot"* (Esinam, 18yrs, Female, Tertiary).

Other participants explained why they get uncertainty and anxious about sickle cell disease as follow:

> *"Getting a job, getting financially stable and all that and me being a sickle cell patient that is a lot of pressure on me because sickle cell disease limits my abilities. That makes it hard for me, so I get anxious when I think about stuff like that… Every time I am worried. I don't know how my future will look like. I don't know how to manage the disease. It's always worries"* (Awentemi, 19yrs., Female, Tertiary).

> *"People say sickle cell patients don't live long so I will be like "I am sickle cell patient, so, am I going to die"? How will my future be? How will my kids think about me?"* (Akos, 16yrs., Female, SHS).

Conversely, some participants said they are not anxious or depressed about their sickle cell disease. They know measures to put in place to curb the sickle cell crises from occurring. According to one such participant, he only gets curious about the disease but does not get anxious or depressed. When asked if he gets anxiety or depression, he reported that:

> *"No, I don't feel depressed, but curious, curiosity. Maybe there is curiosity but no anxiety or depression"* (Kofi, 16yrs., Male, SHS).

4.4.3 Fear of Recurrence and Pain Distress

Pain distress and fear of recurrence of sickle cell crisis is part of the sickle cell disease experience that adolescents living with the disease go through. Most adolescents living with sickle cell disease experience sickle cell crisis very often and may form fear that there may be a recurrence of crises. Others experience it occasionally. The data shows that all the adolescents have experienced pain distress and sickle cell crises in the past. Some adolescents reported that they know very well that they will get crises and pain distress from time to time and do not fear a

recurrence. Others say they are afraid about a recurrence and pain distress. It also suggests that most of the adolescents understand measures they have to put in place in order to minimize sickle cell crises and pain distress from being so frequent. Below are some comments from some of the participants when asked if they are sometimes afraid that they may get recurrence as well as pain distress:

> *"Oh no, no, I'm not worried about my crisis. I know what I do that brings the crisis. Like when I take too (many) sweets a day. Maybe I drink 2 bottles of drinks or anything like that, it brings my crisis and if I work too much, it brings my crisis so I know what to do so I don't get worried that I might get crisis"* (Kofi, 16yrs., Male, SHS).
>
> *"Not really. sickle cell is something that I have so I know I will get crisis. I just have to take care of myself"* (Ama, 19yrs., Female, SHS).

Other participants also explained that there are times they get afraid that they may experience recurrence of crises and pain distress. Below are some comments from some participants:

> *"Yes, there are times, and this happens when I feel some pain which I think may lead to crises or at times when I feel dizzy or when I can't breathe well at times, I feel that it may lead to crises"* (Senam, 19yrs., Male Tertiary).
>
> *"It's true. When it (the pain distress) comes, I am fed up, I am worried. Sometimes I cry and all those things. It makes me worry a lot"* (Atsu, 14yrs., Female, JHS).
>
> *"I do, even now but then whenever you are thinking of something that much, it will by all means happen. The only thing you have to do as a sickle cell anaemia patient is to take your daily tablets, drink a lot of water and just relax"* (Esinam, 18yrs., Female, Tertiary).

The data reported measures participants adopt to manage, minimize, or prevent the recurrence of the crisis and pain distress. Avoiding excessive stress, complying with their medication regimens, drinking lots of water, reporting to the hospital when not feeling well are some of the measures adopted by the participants. Some participants shared their views on this as follow:

> *"Mostly, for the crises not to come, I do not stress myself. Maybe if there is something I am supposed to do, and I know that when I do it the crises will come; I will leave that*

thing. I wouldn't do that particular thing. Or when I am feeling somehow dizzy, I will just go and lie down and take my drugs and take a lot of water and have a sleep" (Senam, 19yrs., Male Tertiary).

"No, because I take care of myself. I drink lots of water, I make sure I take my medicines well so I don't have that fear that the crisis will come again" (Atsu, 14yrs., Female, JHS).

4.4.4 Emotional Support

Emotional support is very important for adolescents living with sickle cell disease, particularly when they are in sickle cell crises. According to the participants, their source of emotional support is from friends, siblings, parents and on a few occasions extended family members. All participants reported that they have enough emotional support. Some of the participants expressed their views as captured below:

"Mostly, (I get emotional support) from my parents, from my mom. …Okay, mostly what she tells me is that I shouldn't worry because I am great, I can do things that others cannot do, God knows everything so I shouldn't worry, I should keep on pressing on for God will take me through" (Senam, 19yrs., Male Tertiary).

"My siblings are always supportive…They always make me laugh. Hanging out with them is just amazing…My sisters are the ones that bring me to the hospital. They feed me. They are usually with me, they sit with me, they talk to me. Sometimes they make me laugh so I don't focus on the pain" (Awentemi, 19yrs., Female, Tertiary).

"My friends, family and close relatives (source of emotional support) … (They tell me) it shall be well, just keep on taking your drugs. You will get better, you are not going to die" (Akos, 16yrs., Female, SHS).

4.5 Social Well-being

This talks about the efforts to deal with the impact of sickle cell disease on individuals, their roles, and relationships. Quality of life concerns affecting social well-being include self-concept/appearance, education/enjoyment /leisure, affection/roles and relationships, acceptance/isolation/abandonment/discrimination and family/social/financial support.

4.5.1 Self-concept and Appearance

Majority (10 out of 11) of the participants reported that they have positive self-concepts and are very satisfied with their appearances. They see themselves as normal as any other human being. In other words, they do not feel less of human just because of the sickle cell disease. One participant however, reported poor or negative self-concept/appearance. He sees himself as not being well. He thinks that his appearance is different from other people who do not have sickle cell disease. According to him, people who do not have sickle cell disease look muscular than those of them living with the condition. They are teased by those without sickle cell disease for being "skinny or bony". He further explained that with regards to his self-concept and appearance, he sometimes sees himself different from other people, particularly when he is sick or has to leave school and be admitted at the hospital. According to him:

"You see, what I know about the disease is that your physical appearance or your structure is different from someone who is not having the disease. An example is that you may be (slim), like you wouldn't have that kind of muscular structure, you would be skinny.. I am bony, and some kind of funny stuff. (Senam, 19yrs., Male, Tertiary).

Some of the participants who said they feel okay about their self-concept and appearance explained their views as follow:

> *"I live like a normal person. Just that I take my routine drugs. I don't feel like less human being. I just do everything by myself"* (Ama, 19yrs., Female, SHS).

> *"Well, to be honest, Sometimes I feel left out and when I say left out, I mean, I feel that there are certain places I feel I'm not wanted at because of my sickness. But then in my appearance, I am very okay with my appearance. There's nothing I don't like about my appearance, although I don't know what others think of my appearance but then, it doesn't bother me at all"* (Esinam, 18yrs, Female, Tertiary).

4.5.2 Family, Social, and Financial Support

All adolescents reported receiving support from their nuclear families, extended families, schoolteachers, school mates, friends, and church members. Most of the adolescents have reported that they have enough financial, family, and social support which helps to improve their quality of lives. According to the adolescents, most of the support they get come from their parents and siblings even though, friends and other family members provide some form of support to them as well. Explaining further the following are some of the comments the adolescents shared with the researcher when asked to explain the kind of support they get from their families, friends, and other people in the society:

> *"I am always with my family so; I get the support I need. I need people around me to talk to, apart from work, my mum is at home and my dad too, so we always talk. That is what I need, getting people around me and my siblings too… Both parents are working so I am provided for"* (Ama, 19yrs., Female, SHS).

Ama further explained that she gets enough support from some of her teachers in school:

> *"I had one teacher; he was very caring. He comes to my class to take care of me and buy me food"* (Ama, 19yrs., Female, SHS).

Other participants shared their views as follow:

> *"The support I get from my family and friends, financial support, they show me love, they make me feel better… I think I get all the support"* (Senam, 19yrs., Male, Tertiary).
>
> *"My family always makes sure I get whatever I want, they always make sure I am ok, they always make sure I am happy. And my friends were always there to support me in whatever I do. My friends and family are very supportive"* (Esinam, 18yrs., Female, Tertiary).
>
> *"My family always makes sure I drink a lot of water and I have a good rest and they try to make sure I don't stress myself. My friends like I said, any time I miss school, they usually visit me in the hospital, and they help me catch up with class"* (Awentemi, 19yrs., Female, Tertiary).

4.5.3 Affection, Roles and Relationship

The participants presented varied opinions on affection, roles and relationships. Majority (10 out of 11) of the participants said they enjoy great affection from their friends and family members while few said they sometimes feel deprived of affection from their friends. Majority of the adolescents reported that they are prevented from performing some roles because of sickle cell disease. Most of the participants said they can make and maintain good relationships with their families, friends and other loved ones. One participant reported that sometimes, she plans to go out with her friends but later, they go and leave her behind, and when she invites them for parties or get together, they do not honour her invitations. This makes her feel that the friends treat her differently because she has sickle cell disease. She reported that she has very few friends as a result of that. The participants shared their views as follow:

> *"There are some things I want to do but I have been told not to stress myself and everybody thinks I am too sick to perform some activities. And with my condition, there have been situations where I feel very vulnerable…At home, I am limited to the things I do. For example, washing, my parents will not allow me to wash and other things. They feel I am too sick to do that, but I actually feel like I can do it"* (Awentemi, 19yrs., Female, Tertiary).

> *"Yes please, A lot of people around me do not know I have sickle cell and I relate with them. When it comes to the few people that know, I'm able to cope when they're around, So yes, I'm able to maintain good relationship with everyone"* (Ama, 19yrs., Female, SHS).

> *"You see, here in school, there are some things that my colleagues do in which I cannot do. Things like football, those sports games and those things. So, at times at the end of their year in school, they give them certificates for playing in the school team but because of this condition I can't join the school team or the sports team"* (Senam, 19yrs., Male, Tertiary).

> *"Sometimes I can't go out with friends. We would make plans alright, but they'd go without me. And sometimes too if I'm having a get together or a party and I invite them, they just don't come"* (Esinam, 18yrs., Female, Tertiary).

When asked to share her views on whether she thinks her friends hated her, reason why they did not honour her invitations to parties, Esinam explained further as follows:

> *I wouldn't say I was hated; I would say I was disliked, disliked because to them, I was always "that girl that has sickle cell*" (Esinam, 18yrs., Female, Tertiary).

4.5.4 Education, Enjoyment, and Leisure

Majority of the participants have expressed concerns about school absenteeism, and exclusion from some activities particularly sports that deprives them of enjoyment and leisure. Most of them said they absent themselves from school on days they experience sickle cell crisis or must go to the hospital for medical check-up. Some of them absent themselves from a day to a few weeks particularly when in crisis or on hospital admission. School absenteeism affects academic performance of adolescents as reported by some of the participants. They miss important lessons and sometimes skip examinations when they are sick or have crisis or are on hospital admission. Furthermore, participants are unable to partake in activities that are fulfilling to them, most of these activities provide them with enjoyment and leisure, which suggests that their qualities of lives are affected by their inability to fully attend school, have full enjoyment and leisure. Participants explained their views as follow:

> *"Sickle cell disease affected my education because there was a time I absented myself for four months when I was on admission"* (Ama, 19yrs., Female, SHS).

> *"For my school performance, the sickle cell disease affects in such a way that any time I am having crises or any time I am having a particular pain which I know walking to school will increase the pain I will rather rest for the pain to come down or I will rather choose not to go to school. Due to that I am not able to learn and my friends are always ahead of me. My friends learn ahead of me and back in SHS my friends were burning all the night, which means they go deep into the night but because of my condition I can't go deep into the night because at that time the weather would be very cold and I would be feeling sleepy"* (Senam, 19yrs., Male, Tertiary).

> *"I normally get crisis within school times…I miss some of the lessons, sometimes, I miss exams"* (Naa, 13yrs., Female, JHS).

> *"When I was a child, I used to like football. it got to a while; I was told to stop. So that affected me"* (Awentemi, 19yrs., Female, Tertiary).

> *"Since I was diagnosed, I was no longer allowed to do anything sporty at school. My favourite sport was basketball. I wasn't allowed to play or (do) anything like that"* (Esinam, 18yrs., Female, Tertiary).

Esinam further reported a sad incident in which she absented herself from school for a whole term because she was prevented from taking part in sporting activities and felt discriminated by her peers. According to her, her peers despised her anytime she wanted to play with them. This made her uncomfortable. She said:

> *"It got to a point, I didn't go to school for a whole term cos that term was filled with sporting activities and I wanted to participate in some but because of the way I was treated, I didn't go to school for that whole term. I decided not to go"* (Esinam, 18yrs., Female, Tertiary).

4.5.5 Acceptance, Isolation, Abandonment and Discrimination

Majority of the participants reported that they are accepted by their families, friends, school mates, teachers, and members of the society. A few have however reported that, they are isolated, abandoned and discriminated against by their teachers and people who are not their close friends but whom they meet in school. According to participants who reported being discriminated against, the people who treat them that way know about their sickle cell disease status and purposively avoid them as a result. These people do not allow them to play or engage them in any activity, avoid them, and also make derogatory remarks about them as a result of their sickle cell disease. Painfully, few participants have reported that some extended family members such as aunties, uncles, cousins even though do not directly demonstrate discrimination, make comments suggestive of the fact that the adolescents will not live long on

account of sickle cell disease. These comments hurt the adolescents a lot. The following are some comments made by some of the adolescents:

> *"Yes, I'm accepted, everyone sees me to be like a friend. No one has rejected me or something like that"* (Kofi, 16yrs., Male SHS).

> *"I will categorize this into two. Some people who know I have the sickle cell disease (but have accepted me), that is the first category. They treat me well. Some are concerned about my health. They would ask me if I have taken my drugs, have I eaten, or wouldn't I rest, and keep me comfortable, show me love…For the acceptance, those I know who have accepted my condition (for) who I am, they are always concerned about me, like everything I do. They always make sure I do the right thing and I am in the right path, and they always keep me company"* (Senam, 19yrs., Male Tertiary).

The following comments were made by participants who reported that they were abandoned, isolated and discriminated against:

> "…*But others will just be pointing fingers like, don't play with this kid he is a Sickler, a lot of stuff, some of them will be saying bad things about you. Some too will say that very soon you will die. A lot of things, a lot of things… they are not my friends. We are all in the same class, but they are not my friends, I am not close to them. They are people who heard about my condition but don't know the actual thing wrong with me, but because of the information they had from others, they try to keep themselves away from me"* (Senam, 19yrs., Male Tertiary).

> *"You will see a teacher walking towards you and immediately they are about to get closer to you, they just pass somewhere else. It's as if maybe you have a contaminating disease that you will give to them whenever they pass by you or something like that. They just go a different way and even in class, you are not allowed to sit with someone, you sit alone.… They sometimes discriminate you. They don't allow you to get closer to them, they don't want you to get closer to their tables, their chairs, they don't want you to get closer to other children… Among your peers, you can see some of them, break time they are playing football, basketball, playing ampe, you want to join, suddenly, they just move from the place."* (Esinam, 18yrs., Female, Tertiary).

4.6 Spiritual Well-being

This is the ability to maintain hope and derive meaning from the sickle cell experience, which is characterized by uncertainty. QOL factors affecting spiritual well-being include meaning of illness, religiosity/spirituality, hope, and inner strength.

4.6.1 Meaning of Illness.

Participants expressed different views on the subtheme, meaning of illness. Some reported that they felt they were cursed when they were diagnosed of sickle cell disease, others reported that they do not see sickle cell disease as a spiritual disease or a curse. According to the participants who felt that sickle cell disease was a curse on them, they no longer feel that way now because of the education they have received on the causes of the condition. According to them, they were not cursed but rather got the disease because both of their parents were carriers. Below are the views expressed by participants:

> *"I believe it doesn't have any spiritual cause. I got it because both parents are AS"* (Ama, 19yrs., Female, SHS).
>
> *"I see it to be normal, something from my parents' blood, that has come to me. It is not anything spiritual"* (Kofi, 16yrs., Male, SHS).
>
> *"Actually, I never thought of it that this disease can be a curse from somebody, it never came to mind… From what I know, if a man and a woman come together, for example, if the man has an AS genotype and the woman has AS genotype, they might give birth to a child with the sickle cell disease"* (Senam, 19yrs., Male, Tertiary).

A participant who initially thought sickle cell disease was a curse but does not hold that view any longer reported that:

> *"Well on the spiritual aspect, growing up, I believed that sickle cell was a curse on me. That was the mindset I had. And growing up, whenever I did the tests and it came out, I always told myself it had to be a curse because I never understood why it always had to change. I kept running tests till the last 5 tests I did came out with the same results all from different hospitals. And this result came out to confirm I was indeed a sickle cell*

patient (SS). But now, I no longer take it as a curse or a spiritual thing" (Esinam, 18yrs., Female, Tertiary).

4.6.2 Religiosity, Spirituality and Transcendence

Spirituality and religiosity play key roles in the lives of adolescents living with sickle cell disease. According to the participants of this study, religiosity/spirituality means worshiping God. Others said, it is like putting one's beliefs in a spiritual being. Participants reported that they profess their faiths in God through praying to God, listening to gospel music and reading the bible. Some of the participants reported that sickle cell disease affects their religiosity/spirituality while others said it does not. Their views were captured as follow:

> *"Spirituality is like basically putting your belief in a spiritual being which is God for me. That's what I think spirituality is… I usually listen to gospel music a lot and then I pray, and I talk to God. And I read my bible especially when it is getting hard. That is what I do… Yes, Sometimes, you miss church and other church programs when you are sick"* (Awentemi, 19yrs., Female, Tertiary).

> *"It means worshipping God with your heart. I go to church. I pray always and I obey his commandments. I know when I worship God, God is there for me. He won't let anything happen to me"* (Akos, 16yrs., Female SHS).

Sickle cell disease affects the spiritual life of adolescents living with the disease. They are unable to go to church when in pain. This derails their abilities to serve God the belief has the power to save them. The participants reported that missing church worry them a lot. Below are some of participants' comments:

> *"When I am in pain, I can't go to church because I am sick, it is very severe. I feel worried because I don't miss church. So once the pain has come and I can't go to church, it worries me a lot"* (Atsu, 14yrs., Female, JHS).

> *"I am created in his own image and he protects me. And I will overcome my sickle cell and I will get 9 ones in the BECE… It (sickle cell disease) doesn't (affect my spirituality) but sometimes when I am in the church, I feel headache. Sometimes, I feel the pain in my stomach, I tell the pastor and I go to the main church. Then I go to one of the rooms then*

> *I go and lie there. When it is getting to the end of the church, they will now call me"* (Edem, 14yrs., Male, JHS).

Interestingly, a participant reported that sickle cell disease does not affect her spiritual life. She does everything possible to ensure she does not absent herself from church, even when in pain. She explained that:

> *"It doesn't affect my spiritual life. Sickle cell doesn't have anything to do with spiritual life. When I am not well, I still force and go to church, unless maybe, I don't want to go to church. We all know that God is everything. I really trust in Him and I believe in Him"* (Selasi, 19yrs., Female, Tertiary).

4.6.3 Hope

The participants expressed their views clearly on the subtheme, hope. The adolescents said they have not lost hope in life, God or themselves. They believe a strong connection with God is important to sustain their hope. Despite the challenges they face because of living with sickle cell disease, they have a strong hope in God that they would get fine. Other participants mentioned that their source of hope is from encouragement from parents, siblings and how people who started with challenges in life were able to make it and become successful. This inspires them and gives them hope. A few participants noted that there were times that they doubted God following challenges the faced, particularly when they got sick, had crisis, or were admitted to the hospital. This made them lose hope in God and by extension in life. The participants' views on hope are captured below:

> *"The source of this hope is still God, because God knows the reason why he created me and one thing is that God didn't create me to come here and suffer. I know that whatever that I am going through he is always with me, he is always keeping me in his grace. God is my hope. He is the one I always look up to, aside my parents and loved ones… I don't lose hope in God but there are times I try to somehow blame God for some things that happen to me, but I don't lose hope in him"* (Senam, 19yrs., Male, Tertiary).

> *"People's lives, other people's lives. How people have become better in life. How they started and how they are now gives me hope… sometimes, I read stories from the bible. Yes, when you read, you can get hope that this guy was like this and now God has helped him to be like this. It gives you hope in yourself"* (Kofi, 16yrs., Male, SHS).

> *"I believe no matter the pains I am going through, the reason why I am still alive if I could go through that pain, sit in a car and come to the hospital and I didn't die. After a day or two, I am still alive on the hospital bed, that means God really loves me and God wants me to see something. So, I always say God, I am sorry I doubted you but it is just that the pains were too much. But then, I have hope because I believe there is God and I believe what he sent me in this life to do, I haven't accomplished my mission yet. So that is what gives me hope"* (Esinam, 18yrs., Female, Tertiary).

Esinam explained further that, she sometimes doubts God and begins to question his existence when in severe unbearable pain. According to her:

> *"Yes, and that (doubting God) happens when you are in severe pain. At that time, the injections are not working, the drugs are not working, even if your mum holds wherever that you are feeling the pains and rubbing it, it is not working, you would be like God, do you really exist? Can you see me? Do you see the pain I am going through? It just happens… despite the fact that I doubt (God) when I am in severe pain, I don't lose hope and I don't lose hope of life"* (Esinam, 18yrs., Female, Tertiary).

4.6.4 Inner Strength

Adolescents living with sickle cell disease need to have great tenacity of mind and body to be able to deal with the disease, especially when they experience crises or pain. An inner strength helps them to deal with the physical, psychological, spiritual, and social challenges of the disease. All the participants reported that their sources of inner strengths come from God, encouragement from parents, siblings and loved ones, and from people who faced challenges in life but were able to succeed in life. Reading of the bible, learning lessons from key people's lives in the bible who found favour with God after initially going through hard times also energized some participants and give them a strong inner strength. Other participants reported that they observed other friends of theirs who had gone through worst sickle cell disease crises

and when they compare their lives with such friends, the get a sense of inner strength that their situations are better and that they can make it in live. The following views were shared by some of the participants:

> *"Mostly my inner strength come from the word of God. Any time I study God's word and study of his goodness and how faithful he has been to others in the scriptures, show them his mercies and kindness, I think God will also do the same to me. Anytime I seek the word, I feel like I am the one God is talking to. I always get the hope and strength to keep on moving in life"* (Senam, 19yrs., Male, Tertiary).

> *"In the Bible, they say that with God all things are possible so if somethings like that are in your mind, you know that you can do everything… the lyrics in the songs. I like music a lot, so every time I'm listening to music, so, I know a lot of music. The words in it, sometimes inspire you a lot"* (Kofi, 16yrs., Male, SHS).

> *"I'll say part is God, He gives me the strength to do whatever I have to do… There is this girl in my school that has it and the rate at which she misses school because of the crisis, it's serious. Sometimes I give her the advice. Some of the advice I do when I am in pain and we learn from each other. Sometimes I compare my situation to hers and I see that mine is somehow better than hers"* (Atsu, 14yrs., Female, JHS).

> *"My dad, he always encourages me. He tells me I am going to be fit, I can make it no matter the situation, circumstances, no matter the pain. So far as people are able to make it, I can make it"* (Selasi, 19yrs., Female, Tertiary).

Loss of inner strength was reported by one adolescent during the interview. According to her, severe sickle cell crisis is one source of loss of inner strength and hope. She explained that when the pain makes it very challenging for her to move or relax, her inner strength dissipates. Below is what she reported:

> *"Sometimes when my crisis comes and it is very difficult for me to move, that is when I lose hope (and inner strength)"* (Akos 16yrs., Female, SHS).

4.7 Summary of Findings

In summary, the quality of life of the adolescents in this study were explored, guided by the objectives of this study and QOL-CS model by Betty Ferrell (1997). Physical well-being,

psychological well-being, social well-being and spiritual well-being were the four major themes in the study. The adolescents shared distinct views and experiences in relation to these four main themes. The findings revealed that physical well-being was affected by pain, sleep disturbance, fatigue, functional ability, and overall physical health. All the adolescents are on routine medication for SCD. Psychological well-being was affected by anxiety, depression, distress from treatment/diagnosis, fear of recurrence of pain/pain distress and emotional support. All the adolescents reported having adequate emotional support. Stigmatization, school absenteeism, poor enjoyment of leisure was reported by the adolescents to be affecting their social well-being, while varied opinions were shared on meaning of illness, spirituality on the spiritual well-being. God, family, and close relatives remain the source of hope and inner strength to most of the adolescents as reported from the data.

In conclusion, these findings reveal the need for all key stakeholders, such as the Ghana Health Service, MOH, health staff, community members and leaders, the Ghana Education Service, patients and their relatives to collaborate in contributing their quota in putting measures in place to improve the quality of life of adolescents living with SCD.

CHAPTER FIVE

DISCUSSION OF FINDINGS

In chapter five, discussion of the findings of the study, in relation to existing literature are presented. The demographic characteristic of the study is first discussed before the themes that emerged from the study; physical well-being, psychological well-being, social well-being, and spiritual well-being; these themes are consistent with the constructs in Betty Ferrell's quality of life model, the theoretical framework applied to the quality of life of adolescents living with sickle cell disease in the Accra Metropolis.

5.1 Demographic Characteristics

The findings were consistent with the literature as majority of the participants (7 out of 11) were females (Abdo et al., 2019; Knisely et al., 2020; Nagshabandi & Abdulmutalib, 2019). The adolescents were between 13years to 19years of age and all of them are currently in school, at either junior high, second cycle or tertiary except one participant who has completed second cycle education and is waiting to enroll into the tertiary level. The demographic data revealed that majority of the adolescents (9 out of 11) had HbSS, similar to the findings in a systematic review by Poku et al. (2018), a study in Ghana (Asare et al., 2018) and in Jamaica by Bartlett et al. (2021).

5.2 Physical Well-being of Adolescents Living with Sickle Cell Disease.

Physical well-being is an important component of the quality of life of adolescents. Primarily, the physical well-being of the adolescents in this study centered on pain, fatigue, sleep disturbances, functional ability, and overall physical health. Pain is a common symptom and the hallmark of SCD (Miller, Balsamo, Pashankar, & Bailey, 2021; Oyedeji & Strouse, 2020; Sagi et

al., 2021), and was reported by all the adolescents as being one of the issues of concern affecting their physical well-being. Acute pain in SCD is generally sharp, throbbing, or both (Du, Lin, & Tao, 2019). Chronic pain is deep, achy, and persistent in nature (Ballas, Gupta, & Adams-Graves, 2012; Du et al., 2019). Children and adolescents with sickle cell disease have poor quality of life because of pain (Pandarakutty, Murali, Arulappan, & Al Sabei, 2020). All the adolescents reported that they experienced pain in their joints, forehead, back, chest, abdomen and had headache occasionally (Fisher et al., 2018; Madi & Clinton, 2018). Pain among the adolescents results from cold weathers, infection, extreme physical exertion and inadequate intake of water. This corroborates the findings in a similar study in Lebanon among adolescents' daily experiences with SCD which revealed pain as a common theme that emerged in interviews with all the participants (Atoui et al., 2015).

Furthermore, findings in a systematic review revealed increased frequency of SCD pain in youth is linked with higher levels of depressive symptoms, and that these associations are generally moderate to strong (Reader et al., 2020). This suggests that SCD pain results in depression and poor quality of life. Participants in this current study in the Accra Metropolis reported that they drank lots of water and took mild analgesics such as paracetamol, diclofenac and ibuprofen, others use rob ointment on the painful joints any time they experienced pain. It was clear from the data that the adolescents did not experience severe pain. All of them reported that they often experience mild pain occasionally. This may be the reason opioids analgesics identified in literature as the mainstay for pain treatment in sickle cell disease was not mentioned by the adolescents among the medication they took (Sagi et al., 2021).

The infrequent experience of pain among the adolescents may result from the fact that they are on routine medications such as folic acid, and hydroxyurea. These medications,

particularly hydroxyurea, limit the frequency of pain among sickle cell disease patients and can prevent stroke (Lagunju et al., 2019). In a systematic review, hydroxyurea has been revealed to be the only drug that can help prevent vaso-occlusive crises (Cieri-Hutcherson et al., 2019). Another systematic review stated that hydroxyurea can prevent stroke (Hasson, Veling, Rico, & Mhaskar, 2019). A study conducted by Tshilolo et al. (2019) revealed that hydroxyurea therapy among participants in that study led to significant increases in the hemoglobin level, and the rate of vaso-occlusive pain decreased as well. This benefit may explain why the WHO has included hydroxyurea on its Model Lists of Essential Medicines for children and adults for the treatment of sickle hemoglobinopathies (WHO, 2017).

Interestingly however, few of the adolescents reported that they do not take hydroxyurea as part of their routine medications that included folic acid, penicillin V and Zincovite. The adolescents reported that their doctors did not prescribe hydroxyurea for them. Adherence to hydroxyurea use is a challenge for patients living with SCD (Vick, Potts, Jaskowiak, & Gibson, 2021). Despite the enormous benefit of hydroxyurea among patientsliving with SCD, existing literature has reported nonadherence among patients living with the condition in Ethiopia (Cecilio et al., 2018) and Egypt (Badawy et al., 2017a). According to the participants in the study in Ethiopia referred to above, lack of understanding of the benefits of the medication, fear of side effects and resistance are some of the reasons for not adhering to their medications. This contradicts the views of the adolescents in this current study in the Accra Metropolis who reported forgetfulness as the reason for non-compliance to their routine medications. The rate of adherence to hydroxyurea was high (60%) among study participants in Nigeria, partly because their parents had to pay for the medication (Abdullahi et al., 2019). Medication adherence can be improved through reminders and targeting adolescent self-efficacy (Shih & Cohen, 2020).

Another physical effect reported by the adolescents was fatigue. Fatigue is noted as a major problem for patients with SCD compared with healthy people (Ahmadi et al., 2018; Ameringer et al., 2014). Fatigue results in lower quality of life (Ameringer et al., 2014). The adolescents in this study attributed their fatigue to over exertion while performing activities of daily living such as cleaning, cooking, weeding the compound, washing, stress, running errands, games such as football, basketball, netball and walking for long distance in the sun. This finding is consistent with a study in Iran by Ahmadi et al. (2018) and another in Ghana by Poku et al. (2020), in which most participants with SCD reported that they had fatigue.

Some participants reported that they experienced fatigue when their haemoglobin levels (Hb) were low (Toumi et al., 2018). Some of the adolescents reported experience of being labeled as being lazy or weak when they are exempted from communal and/or school activities. This finding agrees with the findings in a similar study in Ghana among patients with SCD in which their fatigue was discredited and construed as incompetence, laziness, and weakness within their social domains due to their age and normative appearance (Poku et al., 2020). Consequently, most adolescents work themselves out extensively resulting in extreme fatigue. The easy fatiguability limit the performance of activities of daily living including sports such as football, basketball, volleyball, and athletics that most adolescents in this study are so desirous to partake in their schools. This limitation results in poor physical quality of life among the adolescents.

Sleep disruption was one of the physical factors that affected the quality of life of adolescents in the current study (Maroda et al., 2021). Sleep disturbances among the adolescents is more accentuated when they are in severe pain (Fisher et al., 2018; Valrie et al., 2019). According to the adolescents, sleep disruption can be as worst that they must stay awake whole

night without any sleep. This finding is similar to the findings in a study conducted by Rogers and Lance (2017) in the USA where short duration or poor quality sleep were identified among children and adolescents with SCD. Similarly, in an experimental study between adolescents with SCD and healthy adolescents in the USA, Valrie et al. (2018) reported that adolescents with SCD reported worse total sleep quality than the healthy Black adolescents. The study further reported that adolescents with SCD reported more problems going to bed, falling asleep, maintaining sleep, and reinitiating sleep after waking in the night than the healthy Black adolescents. A study in Brazil by Ramos-Machado, Ladeia, Dos Santos Teixeira, da Anunciacao Ferreira, and Terse-Ramos (2019) also reported that participants with SCA experienced poor quality of sleep than their healthy counterparts who do not have SCA.

Sleep is very important. This finding therefore is a serious problem that must be of concern to parents, healthcare workers, policy makers and even the adolescents themselves hence there is the need to identify measures that can help ameliorate the problem of sleep disturbances. Environmental, psychological, medical and treatment factors are reported to contribute to sleep disturbances among children with SCD (Hassan, Darwish, Hussien, & El-Samed, 2019). The adolescents need to observe and monitor closely and avoid, if possible, triggers of sleep disturbances such as pain. Pharmacological and psychological interventions are helpful in resolving sleep deficiencies and promoting good sleep among adolescents (Badawy, Law, & Palermo, 2019). Parents should provide enough support to the adolescents to get enough rest, perform activities of daily living to reduce the workload on adolescents to prevent frequent pain. Policy makers and healthcare workers need to ensure that pain is adequately managed among adolescents to promote adequate sleep.

Functional ability and overall physical health also featured as physical well-being factors that affect the quality of life of adolescents living with SCD. Functional ability or physical activity is significantly compromised in people with chronic diseases (Anderson & Durstine, 2019; Brawner, Churilla, & Keteyian, 2016; Riegel et al., 2017). This results in poor overall physical health. The adolescents expressed varied views with regards to their overall physical health and functional ability. While some of them reported that they are physically healthy and can do any activity they are required to do even though with caution, others reported that they are physically unwell and are generally limited in the things they must do (Gianfrancesco et al., 2021).

Patients with SCD are unable to do physical activities, sports or exercise and often experience pain anytime they indulge in any of such activities (Omwanghe et al., 2017). Functional ability and overall physical health are negatively affected by pain (Kambasu et al., 2019). The adolescents are unable to perform activities of daily living by themselves when the experience pain. Functional ability could be improved when programs are organized to train patients with SCD on self-care skills, problem solving, as well as peer support group to interact and share ideas (Crosby, Joffe, Peugh, Ware, & Britto, 2017). Children with SCD do not indulge in most physically demanding activities such as play, like running, football, rugby or basketball, particularly in the cold environment for fear that they may get vaso-occlusive crises (Constantinou et al., 2021). Some parents, particularly mothers are overprotective and do not allow their SCD children to partake in exercises (Constantinou et al., 2021).

This is consistent with Nagshabandi and Abdulmutalib (2019) who stated that inability to work has shown to have negative effect on disease severity as well as quality of life of patients with SCD. According to the adolescents, their relatives, teachers and friends limit them from

performing many activities such as household chores and sports with the fear that physical activity may tricker SCD crises among the adolescents. This contradicts the findings in a systematic review by Pinto et al. (2020) where physical activity is reported to be safe and beneficial to patients with SCD; does not trigger vaso-occlusive events and consequent clinical complications but rather improves exercise tolerance and decrease inflammation in people with SCA. Lower rates of physical activity increases pain frequency and pain interference among SCD adolescents (Karlson et al., 2020).

The adolescents, most of whom are presently in different levels of school, junior high school, second cycle and tertiary reported that SCD sometimes limit their ability to learn, particularly when in SCD crises, or on hospital admission. They further reported that, they miss class hours, are unable to engage in school activities and are sometimes unable to concentrate when studying (Kaya & Telfer, 2019). Adolescents may need extra support from their teachers, and classmates to cover missed lessons in order not to perform poorly in their education. To improve their functional ability, overall physical health and quality of life generally, adolescents take their routine medications, keep themselves warm, maintain their hydration statuses, eat healthy diets and rest enough (Melita et al., 2019).

5.3 Psychological Well-being of Adolescents Living with Sickle Cell Disease.

The psychological well-being focused on distress from diagnosis and treatment, uncertainty, anxiety, depression, fear of recurrence, pain distress and emotional support.

Distress from diagnosis and treatment was one of the major concerns the adolescents talked about. Diagnosis of chronic disease often comes with extreme shock, turbulence, and disbelief (Nikfarid, Rassouli, Borimnejad, & Alavimajd, 2017). As expected, the data revealed that most of the adolescents were very young when they were diagnosed of SCD and did not

understand what the diagnosis meant to them. In order words, they could not tell what was going on. The data further revealed that adolescents who were diagnosed when they were much older were scared, shocked and thought they were going to die. The severity of sorrow experienced following the diagnosis of a chronic disease can be so distressful (Nikfarid et al., 2017). The late diagnosis of some of the adolescents reveals that newborn screening for SCD among children born in Ghana which started since 1995 (Dennis-Antwi et al., 2011) but is yet to have a national coverage remains a serious setback for the early diagnosis and timely management of the condition. The enormous benefit of newborn screening for SCD cannot be overemphasized (Burnham-Marusich et al., 2016; Houwing et al., 2019).

If the adolescents were to be diagnosed early enough, SCD management could have started much earlier, and this could avert the obvious fear and anxiety they experienced with thoughts of death following the late diagnosis. Again, the adolescents made interesting comments about distress associated with taking routine medication for SCD. While many stated that they have no problems taking the routine medication, it was obvious that they must be reminded by their parents and other relatives to do so. This can affect medication adherence as the parents may not be around all the time to remind them to take their medications. Non-adherence to medication can result in complications and deterioration in the quality of life of the adolescents.

One of the adolescents reported that she experiences so much distress taking the routine medication; she gets nausea frequently after taking, particularly the hydroxyurea.

Uncertainty, anxiety and depression are psychological well-being factors that were reported by the adolescents in this study. There were different opinions shared by the adolescents on these areas. For some, they remained positive but sometimes get afraid they may die. Others explained

that there are days they feel so depressed that they cry a lot, would not talk to anybody and would not eat any food. Uncertainty stems from the unpredictability of the future as well as uncertainty regarding good or bad events that could be experienced in the course of the disease (Nikfarid et al., 2017). Fears of not getting a job and becoming financially stable, and thoughts of death are the causes of anxiety among the adolescents while inability to do things that their peers do, and pain experience get them depressed. Anxiety is associated with increased pain (Brandow & DeBaun, 2018). In a systematic review, findings revealed increased frequency of SCD pain in youth is linked with higher levels of depressive symptoms, and that these associations are generally moderate to strong (Reader et al., 2020). This is contrary to the findings reported by Graves, Hodge, and Jacob (2016) who suggest that frequency of pain has no significant effect on depression and anxiety.

In a related study, depression was reported to be significantly associated with worse mental and physical health related quality of life outcome scores (Adam et al., 2017). Valrie et al. (2020) reported that increased levels of depressive symptoms were related to poorer self-reported interpersonal skills. Evidence suggests anxious and depressed patients report lower physical and mental health related quality of life scores than do those without mood disorders (Toumi et al., 2018). Evidence from a systematic review reported an estimated prevalence of 26% for depression in individuals with SCD (Jonassaint et al., 2016). A systematic review has revealed that depression is associated with poor medication adherence (Grenard et al., 2011). This finding must be a worry as non-adherence to medication may result in poor quality of life due to poorly controlled pain, risk of stroke and other complications in patients with SCD. Screening for anxiety and depression and referral for timely interventions could help improve quality of life and promote school function in adolescents with SCD (Graves et al., 2016).

Adequate pain control including prompt treatment and prevention of chronic pain where possible, are necessary in the prevention of anxiety and depression among patients with SCD. It also suggests that counselling services, regular hospital follow-up and/or visit, comprehensive physical and mental health examination for adolescents living with SCD are needful. These could play helpful roles in the prevention and management of anxiety and depression among adolescents living with SCD. Adolescents' health services need to be improved in Ghana.

The phenomenon of fear of recurrence and pain distress are worrisome experiences among adolescents living with SCD. Fear of recurrence, pain distress and death may cause frustration, sadness, and depression, especially during periods of painful crises among adolescents with SCD (Forrester, Barton-Gooden, Pitter, & Lindo, 2015). All the participants in this study have reported experiencing pain distress in the past. They reported that they do not now get pain crises frequently as they used to. Despite this, they said the anticipate that once they have SCD, they would get a recurrence of pain crises in the future, irrespective of any interventions. Higher fear of recurrence results in lower emotional functioning (Molnar et al., 2020).

The participants in this study reported that the frequency of pain crises can only be minimized but cannot be prevented completely once SCD is an incurable disease. The participants explained that when the pain crises come, it can be very distressing that they get fed-up with the pain and wish they could cure it completely. The participants reported drinking lots of water, resting adequately, and taking their routine medications adherently to prevent the pain crises from recurring. Pain distress has been reported in the literature. Participants in a study described their pain as being "just the worst pain you can think of." "it is a constant pain though" (Matthie & Jenerette, 2017). They further stated the pain is felt everywhere in their bodies and

“nothing makes a pain crisis “easier”. It is imperative to provide psychological counselling for adolescents to minimize their fear of recurrence and at the same time provide them with up-to-date medical interventions for controlling, minimizing and/or preventing pain crises that result in pain distress among the adolescents.

The issue of emotional support is critical and needs greater attention as far as SCD is concerned. People with SCD experience extreme emotional distress including self-hate, anxiety, and depression during crisis (Al Adawi et al., 2021; Ameade, Mohammed, Helegbe, & Yakubu, 2015). The source of emotional support for adolescents in the present study come from their parents, siblings, some extended family members, friends, schoolmates, and teachers. Luckily, participants in this study reported that they have enough emotional support. Their relatives and friends speak encouraging words to them, they make them laugh, give them reassurances, and take them out for fun when they are stable as part of showing them love. SCD patients are reported to experience extreme emotional disturbance during a crisis (Al Adawi et al., 2021). This greatly negatively impacts the emotional well-being of the SCD patients (Poku et al., 2018). The pressing need for emotional support during a pain crisis cannot overemphasized (Melita et al., 2019). A research finding revealed that higher fear of recurrence results in lower emotional functioning (Molnar et al., 2020). This, therefore, suggests that the reassurances, and encouraging words the adolescents reported receiving in this study are timely and helpful to them. Pain must be adequately controlled, and the adolescents must benefit counselling sessions to reduce the fear of recurrences to improve their emotional functioning.

5.4 Social Well-being of Adolescents Living with Sickle Cell Disease.

The adolescents reported on self-concept and appearance, family, social and financial support, affection, roles and relationships, and education, enjoyment and leisure, acceptance, isolation and abandonment with regards to their social well-being.

The self-concept of adolescents living with SCD is negatively impacted by the disease (Poku et al., 2018). Most of the participants in this study reported positive self-concepts about themselves, and this agrees with the findings in a study among adolescents in Jamaica (Forrester et al., 2015). Positive self-concept and adequate social support from family and friends enhance the ability to cope with SCD among adolescents (Forrester et al., 2015). They have accepted this life-long condition and see themselves as normal as other people without SCD (Constantinou et al., 2021). They are satisfied with their appearances. Others however, reported that they see themselves different from those who do not have sickle cell disease. They have a negative self-concept about themselves. They are dissatisfied about their appearances. They see themselves not to be well. They reported about their short stature, smallness, weakness and less masculinity which make them appear different from their peers who do not have the disease (Constantinou et al., 2021). They further stated that they are teased by their peers for being “skinny or bony”. These findings completely agree with Zelihic et al. (2021) who reported that adolescents with SCD often express feeling of being different from people who do not have the condition.

A study in Kumasi, Ghana, revealed that participants reported of receiving heavy criticism and negative comments directed towards them as a result of their unhealthy physical appearance; short stature, small muscles, yellow eyes and potbelly (Buser, Bakari, Seidu, Paintsil, et al., 2021). The participants complained about being bullied for always complaining about pain and are called names. Another study reported that adolescents complained of being

bullied and stigmatized for how they walked, talked or behaved, and also experienced negative expressions like ‘yellow eye’, being unable to carry out heavy work, ‘soft bones’ every day in school (Cecilio et al., 2018). This could explain why adolescents in the present study were reluctant to disclose their status of SCD to most of their friends. Disclosing their SCD diagnoses to their friends would make their friends laugh at them and treat them differently (Melita et al., 2019).

They perhaps felt that disclosing their statuses may expose them to unnecessary stigmatization and teasing from their peers. Adolescents in Jamaica said they do not want to disclose their diagnosis of SCD, particularly to their teachers because they do not want to be treated differently from their peers (Forrester et al., 2015). Sometimes, adolescents with SCD mask their health and identities to present a “normal” self-identity to maintain a socially acceptable identity (Poku et al., 2020). This finding is disturbing. If adolescents must go through all these to be accepted, it could pose heavy burdens on their physical, social, and psychological well-being. There is the need to increase sensitization among adolescents on SCD. When adolescents living with SCD are satisfied with their self-concepts and appearances, they would be able to freely socialize with their peers without any hesitation. Their peers must also avoid teasing and stigmatizing them.

Family, social, and financial support are needed to enhance the social well-being of adolescents living with SCD (Pandarakutty et al., 2020). SCD places a huge financial burden on burden on adolescents and their families (Pandarakutty et al., 2020). This support comes from parents, siblings, extended family members, church members, school friends, teachers and members of the community in the form of praying for the SCD adolescents, financial aid, words of comfort and encouragement at times of worsening illness (Gomes et al., 2019). The

adolescents in this present study reported that they have adequate family, social and financial support. Similarly, adolescents in a study in Jamaica described their families as being helpful, supportive and understanding (Forrester et al., 2015). A study in Saudi Arabia reported that majority of the participants received support from their family (Khaled et al., 2021). The adolescents may not notice any financial burdens since they are provided for by their parents and guardians. They may not be able to give adequate information about the financial pressure their parents may be going through. Further, their parents would do everything possible to ameliorate the health conditions of the adolescents in other to improve their physical, social, psychological and spiritual quality of life, masking the actual financial burden that the parents face. The findings in a study on the psychosocial burden of childhood SCD on caregivers in Kenya where financial hardship was high, and caregivers reported moderate to major financial losses due to the time spent caring for their children (Kuerten et al., 2020).

A study in Nigeria revealed that being teased by friends; troubled listening in class; felt worried; and pressured by friends were observed to be things that affected the adolescents quality of life negatively the most (Faremi & Olawatosin, 2020). Again, Hawkins et al. (2020) identified in their study that Support from family, healthcare providers and school may help individuals cope with some of their burdens. This suggests that good social network support especially from family, teachers, and friends might play an important role in improving the quality of life of adolescents living with sickle cell diseases.

Affection, roles and relationships appeared as unique social well-being concepts in this study. SCD negatively impacts the social relationships of adolescents living with the condition (Poku et al., 2018). Majority of adolescents reported enjoying affection and having good relationships with their families and close friends. Families support the adolescents to cope better

with SCD by supporting, motivating and comforting them (Poku et al., 2018). Some of the adolescents reported that some of their friends disliked them. These friends do not allow them (adolescents with SCD) to go out with them. When the adolescents with SCD invite them for parties and social gatherings like get-together, and birthday parties those healthier friends of theirs fail to honour the invitations. This significantly negatively affects the affection and social relationship of the adolescents in this study. With regards to roles, all the adolescents in this study reported that they are often prevented from doing stressful activities. Their parents, siblings, peers and teachers do not allow them to involve themselves in some roles. According to them, they are prevented from partaking in sporting activities such as football, volleyball, joining the school team, and house chore activities like washing (Constantinou et al., 2021; Forrester et al., 2015). They feel that the adolescents with SCD are too sick to perform such activities. In a related study, adolescents lamented how their mothers did not trust them to be able to go out alone, have relationships with others and live independent lives on their own (Cecilio et al., 2018). This affected their ability to care for themselves.

Sickle cell disease affects education, enjoyment, and leisure in many ways. All the adolescents reported absenting themselves from school. School absenteeism is a major problem among SCD patients and there needs to be a strong collaboration among schools, medical providers, and parents to better manage the academic achievement of students living with SCD (National Academies of Sciences Engineering and Medicine, 2020). The reasons for school absenteeism stem from SCD symptoms, hospitalization, or medical appointments. Adolescents living with SCD find it difficult to concentrate, attend classes, and keep up with other students (Atoui et al., 2015).

School absenteeism results in social exclusion (Atoui et al., 2015; Poku et al., 2018) and negatively affect educational attainments. Regular classroom attendance is associated with high grades and academic success among children and adolescents (Anderson & Durstine, 2019; Aucejo & Romano, 2016). When adolescents with SCD experience crises, it limits them from enjoyment and leisure (Al Adawi et al., 2021), by restraining them from work, school and social interaction. The inability to join friends and families for picnics, inability to attend classes due to painful episodes, lack of support from schools during a painful crisis and inability to find a suitable job, being rejected from jobs due to disease, and lack of cooperation of institution when reporting sick leave are some of the worrying challenges that patients with SCD experience. Hawkins et al. (2020) also reported that adolescents in their study expressed distress with having to 'catch-up' and miss other school related activities. These experiences affect the quality of life of the SCD patients by restricting them from the full benefits of education, and social activities that bring them fulfilment and enjoyment as well as leisure. The findings above significantly contrast with the findings in a quantitative study by AlSaleh et al. (2021) which reported that 78.8% of adolescents in their study had good quality of life. A better quality of life contributes to the better results students achieve at school (Molnar et al., 2020).

The phenomenon of acceptance, isolation and abandonment stemmed from the adolescents' interaction with family members, peers/friends in their communities, school and church, as well as interaction with teachers in school. Some adolescents reported that they are accepted by all these people mentioned above while some expressed different views, explaining that they are not accepted but are discriminated, stigmatized, isolated and abandoned. The adolescents reported that some people treat them well while other people point fingers at them, discriminate against them as if they have a contaminating disease.

The adolescents are discriminated against and isolated by peers and community members because of frequent complaint of pain, and the belief that they die early (Buser, Bakari, Seidu, Paintsil, et al., 2021; Dennis-Antwi et al., 2011). The adolescents are unable to go for parties and other social gatherings with their friends due to SCD. Limited attractive social alternatives increase the desire of adolescents to use drugs, substances or alcohol to relieve boredom (Weitzman et al., 2019). A study reported that adolescents complained of being bullied and stigmatized daily in school (Cecilio et al., 2018). They were bullied because of how they walked, talked or behaved, and also experienced stigmatizing expressions like 'yellow eye', being unable to carry out heavy work, 'soft bones' every day in school (Cecilio et al., 2018).

Painfully, some adolescents in this current study reported being discriminated against by their teachers. This is contrary to the findings of Forrester et al. (2015), in which adolescents with SCD said their teachers rather protected them and left them out when punishing their peers for wrongdoing. Teachers play a key role in the growth and development of adolescents; therefore, it is a serious problem if teachers are reported to be discriminating against adolescents with SCD. The stigmatization of the sickle cell trait and treating SCD as a family curse discourage patients from seeking care (Dennis-Antwi et al., 2018). Adolescents in this present study reported that they did not reveal their SCD status to people they interacted with. Failure to disclose their statuses may result from fear of being stigmatized and discriminated upon by community members, peers, teachers, and some extended family members (Buser, Bakari, Seidu, Paintsil, et al., 2021). Adolescents often feel that disclosing their SCD diagnoses to their peers would make those peers of theirs laugh at them and treat them differently (Melita et al., 2019).

Adolescents living with SCD rather need to be accepted and supported by all including their friends, parents, siblings, extended family members, and teachers. This will help improve

their quality of life. In a research study, it was revealed that perceived stigma was significantly higher among mid-adolescents compared with late adolescents (Okeafor, Okechukwu, & George, 2020). A systematic review also reported of significant stigmatization and discrimination against SCD patients (Bulgin, Tanabe, & Jenerette, 2018). The systematic review revealed that majority of SCD patients experienced at least one negative experience in school, as well as injustice from doctors and nurses. The stigmatizing experience results from the SCD status of the patients, stress from pain crises, and disease severity.

Similarly, Clayton-Jones et al. (2021) identified that participants in their study experienced stigma in the form of the perceptions of SCD among others in general, and emergency room staff attitude. They also identified that SCD patients were being treated differently from others while they were waiting to be seen in the emergency room, were labeled persons with disability by community members. These findings call for the pressing need to constantly screen for stigma, discrimination, isolation and abandonment against adolescents with SCD.

5.5 Spiritual Well-being of Adolescents Living with Sickle Cell Disease.

The last (fourth) objective of the study sought to describe the spiritual well-being of adolescents living with SCD. Spiritual well-being of the adolescents revolved around meaning of illness, spirituality and religiosity, hope and inner strength.

The adolescents in this study sought meaning to their illness and questioned God why they had to go through so much suffering. Adolescents presented different views on meaning of illness as far as SCD was concerned. Some of the adolescents projected that they got SCD from both parents who were carriers of the sickle cell trait (Housten et al., 2015). They did not associate SCD with a curse or spiritual connotation. Others stated that they initially thought they

were cursed with SCD. The disease has been associated with curse or a test from God (Ali & Razeq, 2017). Some adolescents in the current study did not understand why they got this disease. SCD, just like other hereditary diseases has widely been confused with malediction or witchcraft, and some parents believe that their children got SCD because of sorcery or is the manifestation of ancestors' anger (Montalembert et al., 2019). Thus, they perceive the disease as a punishment or a curse from an enemy.

A study in Brazil revealed that children and adolescents associated the meaning of the illness with their religious beliefs (Alvarenga et al., 2021), and thought that they were "paying" for past mistakes or that the disease was part of a plan of a benevolent God. In Ghana, SCD has been noted among some people unrelated to SCD patients to be a bought disease (Dennis-Antwi et al., 2011). Dennis-Antwi and her colleagues noted that such people belief that SCD has a demonic origin in which witches and wizards acquire the disease spiritually and can inflict it upon their enemies. SCD has widely been associated with curse, a bought disease, punishment for sins committed against God, or a bewitchment from someone, (Buser, Bakari, Seidu, Osei-Akoto, et al., 2021). In the mind of some people in the community, sufferers of SCD are paying back for bad things their parents may have done (Buser, Bakari, Seidu, Osei-Akoto, et al., 2021). In rural Eastern Sierra Leone, SCD has been noted to be associated with witchcraft (Ibemere et al., 2021). Public education is very important to reshape public discourses around SCD as a curse or punishment to pave way for conventional medical management of SCD (Dennis-Antwi et al., 2018), while allowing individuals to practice their faith to cope with the complications of the disease.

Another unique aspect of spiritual well-being was spirituality and religiosity. Spirituality and religiosity play important roles in coping with SCD (Alvarenga et al., 2021). Children and

adolescents consider their spiritual and religious beliefs as a critical part of their lives (Bakker, van Leeuwen, & Roodbol, 2018; Clayton-Jones & Haglund, 2016). Their relationship with God presents them with a constant source of comfort, strength and contribute to their well-being (Clayton-Jones et al., 2016). Spirituality refers to the innate aspect of humans, while religiosity refers to the chosen expression of spirituality (Clayton-Jones et al., 2016). Spirituality and religiosity are seen as coping mechanisms among adolescents living with sickle cell disease and comprises of ‘‘interconnecting with God, interconnecting with others, interconnecting with creative arts, scriptural metanarratives, transcendent experiences, and accepting and finding meaning’’ (Clayton-Jones et al., 2016).

Spirituality and religiosity can guide ethical decision making, moral behaviour, can be helpful for coping with suffering and a source of hope (Büssing, 2015). Ghanaians are generally noted to be religious (Nukunya, 2003). Ghanaians often believe in supreme powers and divined powers, miracles, and often associate occurrences they do not comprehend with these supreme powers. The adolescents all reported that they belief in the existence of God (spirituality). Their chosen way of worshiping God is through prayers (religiosity). Ten (10) of the adolescents in this study were Christians and one (1) was a Muslim. They worship God through going to church, prayers, reading the bible, listening to gospel music individual and group prayers, attendance at worship services and obeying the commandments of God (Gomes et al., 2019). This helps them draw comfort and cope with the condition. They believe that they are created in the image of God and are protected by him. They pray to God for protection, healing, and for him to take away their pain. When in pain, participants are unable to go to church and sometimes invite their pastors to the house to pray for them.

The concept of hope was mentioned by the adolescents in this study. Hope helps individuals to deal with a disease and forge towards the future (Hjorth, Lovgren, Kreicbergs, Sejersen, & Asaba, 2021). Adolescents in this study believed that a strong connection with God was important to sustain their hope. Hope in people with chronic illnesses often is strengthened by the believe in divine mercy and that their diseases are means of getting them closer to God (Nikfarid et al., 2017). Persons with high hope are better able to cope and tolerate pain which is a hallmark of SCD (Griggs & Walker, 2016). Hope promotes better quality of life, especially in patients with chronic disease (Mardhiyah et al., 2020). People with higher hope have better quality of life (Mardhiyah et al., 2020).

The participants sources of hope were from encouragement from family, friends, and people who faced serious challenges in life but subsequently succeeded. In a related study among children and adolescents in Brazil, Alvarenga et al. (2021) reported that elements that promoted hope included controlling negative thoughts, selfcare, faith, meaningful interpersonal relationships, psychological support and exchanging experiences with peers. The unpredictable nature of how the disease will impact on the future, negative thoughts, and interpersonal relationships with health professionals and with family members were identified as factors that could decrease hope and optimism among the participants (Alvarenga et al., 2021). The participants in the present study believe that despite the challenges they face with SCD pain crises, illness, which sometimes make them lose hope, they still feel they would get fine.

Inner strength is a copying strategy for people living with chronic diseases such as SCD. Living with a chronic disease has been noted to increase a sense of inner strength among some youth (Weitzman et al., 2019). Adolescents living with chronic diseases see such diseases as an everyday event or experience and with time begin to accept the disease as a stable feature of self

and identity (Weitzman et al., 2019). Great tenacity of mind and body are needed to be able to deal with SCD, particularly when in pain crises. Education and counselling services for stress management in patients with chronic illnesses could improve their inner strength by improving their psychological health, reducing depression and promoting their QoL (Kim et al., 2019). Adherence to medication is reported to be associated with higher level of inner ability and inner strength than non-adherence to medication (Franke et al., 2021).

A strong inner strength would help the adolescents to deal with the physical, psychological, spiritual and social challenges of the disease. In a systematic review, several studies that met the inclusion criteria recognized that resilience, does not overcome chronic diseases such as SCD, but promotes acceptance in patients with such conditions to their physical and social situations and comply with therapeutic care, and this ultimately results in healthier life (Kim et al., 2019). According to the adolescents in this study, their sources of inner strength were from their belief in God, encouragement from family and friends. Other sources include testimonies from people who faced challenges in life but were able to succeed in life, reading of the bible, learning lessons from key people's lives in the bible who found favour with God after initially going through hard times also energized the participants and gives them a strong inner strength. According to the adolescents, they observed other friends of theirs who had gone through worst sickle cell disease crises and when they compare their lives with such friends, the get a sense of inner strength that their situations are better and that they can make it in live.

CHAPTER SIX

SUMMARY, IMPLICATIONS, LIMITATIONS, CONCLUSION, AND RECOMMENDATIONS OF THE STUDY

In chapter six, the summary of the study, implications of the findings of the study on nursing practice, research, administration and education are presented. The chapter also presents the limitations, conclusions and possible recommendations from the study.

6.1 Summary of the Study

In Ghana, adolescents' health issues are not often given the needed attention as required. Adolescents with SCD are often confused as to whether to seek healthcare at the paediatric part of the hospital or adult section. When requiring admission, this confusion even gets problematic for health workers in most hospitals, they do not know where to admit them to, adult ward or paediatric ward. This may not be a serious problem for hospitals that have a well demarcated outline of where each age group should be attended to.

This study was set out to explore the quality of health of adolescents living with SCD. A qualitative explorative design was used to carry out the study. The Betty Ferrell (1997) quality of life model guided the study. Data collection was done through interviews, using a semi-structured interview guide. This study was undertaken within the Accra Metropolis, specifically, the 37 Military Hospital (37MH). Ethical clearance was obtained from the Institutional Review Board of the 37MH before data collection commenced. Parental consent forms were singed by the parents of the adolescents while child assent forms were signed by the adolescents themselves. During the data collection, interviews were audiotape recorded. Verbatim transcription of the interviews was done, and data was analyzed using thematic content analysis.

The key findings of the study revealed that most of the adolescents suffered pain which occurred in their joints, chest, abdomen, headache and backs of their bodies. Most of them drunk lots of water, used ointments and non-opioids to treat pain when needed. This helped to reduce pain and suffering. Fatigue and sleep disturbances worried the adolescents too. They reported frequently getting tired when exerted or involved in heavy work. When fatigued, they rested. Sleep disturbances occur when they are in pain.

Majority of the adolescents did not experience distress from treatment. However, those adolescents that were diagnosed very late at a time they could understand thought they were going to die. They experienced some distress from the diagnosis. Uncertainty among the adolescents related to unpredictability of how their futures would look like, how the job market would treat them, and how their children in future would perceive them. Few expressed concerns of depression and pain distress but expressed satisfaction with emotional support from mostly their close family members such as parents and siblings.

Self-concept and appearance among the adolescents were centered on the “skinny or bony” appearances. Some of them expressed satisfaction about their self-concepts and appearances. Few were not. Majority of the adolescents had adequate family, social and financial support. Much of the support came from their family members even though some friends and school mates and teachers offer them support too. The adolescents are mostly not allowed to get involved in strenuous activities at home and in school for fear of triggering a crisis. Sports, washing and weeding came up strongly among the adolescents as some of the roles they are prevented from playing at school and home. Even though all but one of the adolescents are in school, school absenteeism is reported. They absent themselves on account of SCD pain, hospital

appointment, and hospital admission to seek treatment. Pain mostly limits their ability to enjoy themselves and have leisure.

The most critical and worrying concern that came up strongly in this study is the issue of stigmatization, discrimination, and abandonment. Most of the adolescents expressed concerns of some form of discrimination, mostly from their school mates, teachers and some members of their communities. This is very critical because it has the potential of causing disaffection and dislike for education and can further worsen the issue of school absenteeism among the adolescents. Diverse opinions on meaning of illness were observed. Some reported SCD as a curse, witchcraft, or a punishment. Later, with good education, most of them explained that they got SCD from both parents of theirs who had the genes that transmit SCD. All of them belief in God and the power to get healing from prayers. All of them are Christians except one, who is a Muslim. Spirituality and religiosity provide them with some form of coping with SCD. The adolescents had hope in God that they would get healing from SCD and live fulfilling lives. Their hopes are strengthened by bible texts, testimonies and the lives of people who went through similar sufferings but became successful later. Encouragement from parents, siblings, friends, and members of the community enhanced their inner strengths.

6.2 Implications of the Findings

The findings of this study have implications that need attention. These implications relate to nursing research, nursing education, nursing administration and nursing practice. When appropriately addressed, this could help improve the quality of life of adolescents with SCD. The implications are presented below:

6.2.1 Nursing and Midwifery Practice

The findings of the study revealed that most of the adolescents had pain, fatigue, sleep difficulties, anxiety, depression, had concerns about their appearances, were socially excluded, stigmatized, had challenges related with schoolwork characterized by frequent school absenteeism, inability to concentrate, and inability to enjoy leisure. These results emphasize the need to implement physical, psychological, social and spiritual care when caring for adolescents with SCD, which includes addressing physical, psychological, social and spiritual needs. There is the need to identify the level of quality of life of adolescents through holistic health assessment. Health education on SCD needs to be intensified among community members on the dangers of stigma on the health of SCD adolescents.

Nurses and midwives should focus on ensuring that adolescents gain adequate knowledge on the disease, need to adhere to medication and health education instructions, and how complications can be prevented. Nurses and midwives may consider implementing family centered care, evidenced based practice, and strength-based care to ensure that information and decisions about client care are mutually shared with the clients and families, based on best practices, as well as exploring the strength of the client and family to maximize their potentials to improve their quality of lives. Interprofessional collaboration with other interprofessional team members such as the haematologists, pharmacists, clinical psychologists, and biomedical scientists, would result in the sharing of expertise to further ensure that quality care is provided for the SCD adolescents to improve their quality of lives. Nurses and midwives could consider, also, guide the adolescents to form support groups to provide them a common platform to share their challenges with their peers. This could help them get solutions to their problems and enhance their quality of lives. Adolescents' corners should be established. Adolescent friendly

services should be encouraged through organizing refresher training for nurses and midwives to update their knowledge on best ways to nurse adolescents with SCD.

6.2.2 Nursing Education

Haematology and genetic nursing curriculum should be developed for training nurses and midwives as a post basic course. This will augment the few nurses and midwives trained in haematology nursing at the Ghana College of Nurses and Midwives and equip them with the requisite skills to give holistic care to adolescents with SCD. Nursing and midwifery training institutions should focus on training students on comprehensive and holistic approaches to SCD management to include adolescents. In addition, continuous professional development programs should be organized for all healthcare workers periodically on how to manage pain, vaso-occlusive crises, and complications of SCD based on best practices. Vaso-occlusive crises, acute chest syndrome, and stroke are common complications of SCD. Therefore, it would be helpful to develop a curriculum on palliative care nursing to empower nurses with adequate knowledge and skills to handle the complications of SCD.

6.2.3 Nursing Administration

The nursing administration should lobby for genetic counselling and testing to be implemented and be made accessible to all clients and their families. They should organize periodic refresher training for nurses and midwives to keep their knowledge up to date for quality care delivery. They should ensure that the needed staff mix, logistics and other resources are available to enhance nursing care. Ensure that protocols and guidelines for the management of SCD are made available at vantage locations within the hospital. Provide motivation opportunities for staff to give out their best when caring for SCD clients. They nursing administration should identify

committed and hardworking nurses and recommend them to the hospital management for specialization in haematology and genetic nursing to improve quality healthcare delivery.

6.2.4 Future Research

The present study was conducted in urban Accra. The adolescents may have access to some social amenities that could influence their quality of lives. These may be lacking in rural set-ups. Future studies could focus on exploring the quality of life of adolescents living with SCD in rural settings with different religious, cultural, social and economic influences to determine if there are any differences in the quality of life of those adolescents.

6.3 Insight Gained

The researcher noted that, fatigue, sleep disturbances, anxiety, depression, stigmatization, and role limitation, continue to hamper the quality of life of adolescents living with SCD. Their physical, psychological, social and spiritual lives were significantly affected as a result. The focus of care for these adolescents must cover all these independent but interrelated areas of their health. As a student, I have gained much more experience on how to conduct interview from research participants such as adolescents who often feel shy and unwilling to give out much information. A key lesson I have learned is to include focused group discussion when gathering data from adolescents. They take more when in the midst of their peers. I have also gained insight on the need for continuous public education against stigmatization of SCD.

6.4. Limitations of the Study

The study occurred in one setting with a homogenous sample of participants. Therefore, the findings must be considered in that light, hence, limit generalization of the findings to other populations in similar contexts. The study was undertaken in an urban area, the findings may

differ from experiences of SCD adolescents living in rural and deprived areas. The purposive sampling of the study participants was done under the direct control of the health professionals which may have introduced biases, intentionally or unintentionally. The views expressed by the chosen adolescents are based on their analysis and interpretation, therefore, the findings may not be typical of all adolescents with SCD in Ghana.

6.5 Recommendations

The findings call for the need for the following important recommendations to be made to the ministry of Health and the 37 Military Hospital for consideration. When implemented, these recommendations could help improve healthcare delivery. This could help bring improvement in the quality of life of SCD adolescents.

6.5.1 Recommendations to the Ministry of Health (MOH)

1. The MOH should develop a national policy on education, employment, and health care for sickle cell disease patients.

2. The MOH and other stakeholders should make policies on public education focusing specifically on SCD among adolescents. Health education on SCD must be intensified. Educational materials on SCD need to be readily accessible, as well as culturally and socially sensitive to make them acceptable.

3. The ministry should make policies to reorient health services around the needs of adolescents. This can be achieved through ensuring that adolescents corners are established in all hospitals, and critical needs of adolescents incorporated into the care delivered to them.

4. The ministry should resource and collaborate with the Nursing and Midwifery Council of Ghana, and the Ghana college of Nurses and Midwives to intensify the training of specialist

nurses particularly haematology and genetic nursing. This will equip nurses and midwives with the needed knowledge and expertise to handle clients with such diseases.

5. The ministry should lobby government strongly to employ clinical psychologists to work at all hospitals, or at least each regional and district hospital, to provide counselling for adolescents with SCD. As much as possible, adolescents should have a separate unit where they can seek these services as they may feel shy to do so when mixed with adult. The clinical psychologists would help screen the adolescents for depressions, suicidal ideation, and other important mental health concerns that could be bothering adolescents living with SCD.

6.5.2 Recommendations to the Ghana Health Service (GHS)

1. The GHS together with the National Health Insurance Authority should endeavour to include all the routine medications for SCD in the essential medicines list of the NHIS. This will ensure that all people living with SCD have access to the routine medications. This will improve medication adherence and ultimately reduce complications of the disease.

2. The GHS should ensure that protocols and guidelines for the management of SCD are made available at vantage locations in all hospitals and health facilities.

2. Intensify public education on the dangers of stigmatization of SCD. Public education can be done in all hospital OPDs, wards during admission and on discharge.

3. The GHS should create innovate family and community-based caregiving programmes needed to support adolsecents living with SCD.

4. The GHS should organize continuous professional in-services training periodically for all healthworkers on management of sickle cell disease.

5. Pain assessment should be included in vital sign checking in all hospitals. This will result in timely detection of pain for timely intervention.

6. The GHS should ensure that newborn screening for SCD covers all regions, districts, and hospitals within Ghana. This will ensure that SCD is detected very early, for timely treatment to prevent complications.

6.5.3 Recommendations to the 37 Military Hospital

1. The Hospital's management should encourage nurses and midwives and sponsor them to specialize in haematology nursing to prepare them with adequate skills to better nurse patients with SCD.

2. The hospital should prepare educational materials on SCD tailored towards the needs of adolescents with the condition. These materials should be made available at all accessible places in the hospital, such as the OPD, wards, and emergency department. This will equip adolescents and their guardians with the requisite knowledge on SCD. This will help prepare them on the importance of medication adherence, potential problems to expect and what they can do to live healthier lives to improve their quality of lives.

3. The hospital management should liaise with the psychology department of the hospital to demarcate a special counselling unit for only adolescents to encourage them to openly discuss their pressing health concerns with health staffs. Mixing adolescent with adults discourages them from bringing out their health concerns. Adolescents are so critical about confidentiality and will hold back so much information that could otherwise help to detect their challenges early enough for timely interventions to prevent complications.

4. Educational talks on public health could be instituted and given at the OPD on SCD clinic days to educate the adolescents and their guardians on how to live with and manage the condition. Continuous educations would constantly remind the adolescents and their families on the need to adhere to medication, maintain good personal and environmental hygiene, drink lots of water, need to honour scheduled hospital visits and prompt reporting to the hospital when sick.

5. The staff and management of the hospital should create awareness of the public that seek healthcare in the hospital on SCD. This will bring understanding to the public on the causes of SCD to avoid stigmatizing people with SCD, associating the disease with witchcraft, curse and to provide support to patients with SCD.

6.6 Conclusion

This study sought to explore the quality of life of adolescents living with SCD. The disease is widespread across sub-Saharan Africa. Participants were interviewed, using a semi-structured interview guide, and the data were analyzed using thematic analysis. This study would help bring forth critical problems that hamper the quality of life of adolescents with SCD. Quality of life of adolescents living with SCD could be improved through: A strong social support scaling up newborn screening to cover every region and district (early detection helps to prevent complications), public education against stigmatization, and inclusion of SCD to the NHIS and reorganization of health financing to make health services affordable to people with SCD.

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APPENDICES

Appendix A: Ethical Clearance (37 Military Hospital Institutional Review Board [IRB])

Institutional Review Board
37 Military Hospital
Neghelli Barracks
ACCRA

Tel: 059 1759506
Email: irbmilhosp@gmail.com

11 November 2020

ETHICAL CLEARANCE

37MH-IRB/NF/IPN/423/2020

On 09 November 2020 the 37 Military Hospital (37MH) Institutional Review Board (IRB) approved your protocol.

TITLE OF PROTOCOL: Quality of Life of Adolescents with Sickle Cell disease in Accra Metropolis

PRINCIPAL INVESTIGATOR: James Mbangbe Ajusiyine

Please note that a final review report must be submitted to the Board at the completion of the study.

Please report all serious adverse events related to this study to 37MH-IRB within seven (7) days verbally and fourteen (14) days in writing.

This certificate is valid till 08 November 2021.

DR EDWARD ASUMANU
(37MH-IRB, Vice Chairman)

37 MILITARY HOSPITAL
INSTITUTIONAL REVIEW BOARD
DATE: 11 - 11 - 2020

Cc: Brig Gen NA Obodai
Commander, 37 Military Hospital

Appendix B: Letter of Introduction (School of Nursing and Midwifery)

UNIVERSITY OF GHANA
SCHOOL OF NURSING AND MIDWIFERY

Ref. No.:.....ID: 10543388.....

August 10, 2020

The Commanding Officer
37 Military Hospital
Neghelli Baracks
Accra.

Dear Sir/Madam,

LETTER OF INTRODUCTION

I write to introduce to you **James Mbangbe Ajusiyine**, an MPhil Nursing student in the Department of Maternal and Child Health, School of Nursing and Midwifery, University of Ghana, Legon.

As part of the requirements of the M.Phil programme, the student is to undertake a research study and he intends to use your facility as one of the main study sites for data collection.

The title of his research is **"Quality of Life of Adolescents Living with Sickle Cell Disease in the 37 Military Hospital."**

It will be appreciated if he is given the necessary assistance.

Thank you.

Yours faithfully,

Charlese A. Klutse
School Administrator

Cc: Dean, SoNM

COLLEGE OF HEALTH SCIENCES

P. O. Box LG 43, Legon, Accra, Ghana.
• Telephone: (0) 303 970 801 / 0553 089 267 • Email: nursing@ug.edu.gh • Website: www.nursing.ug.edu.gh

Appendix C: Letter of Approval

UNIVERSITY OF GHANA
DEPARTMENT OF MATERNAL AND CHILD HEALTH
SCHOOL OF NURSING

Ref. No.:.....
ID: 10543388

August 10, 2020

The Chairman
Institutional Review Board
37 Military Hospital
Neglelli Barracks
Accra.

Dear Sir/Madam,

LETTER OF APPROVAL

I write to introduce to you **James Mbangbe Ajusiyine** an MPhil student of the School of Nursing and Midwifery, University of Ghana, Legon.

The School has approved his research proposal: **"Quality of Life of Adolescents Living with Sickle Cell Disease in the 37 Military Hospital."**

I will be grateful for your approval of the proposal to facilitate data collection.

Thank you.

Yours faithfully,

Dr. Mary Ani-Amponsah
Supervisor

COLLEGE OF HEALTH SCIENCES
• P. O. Box LG 43, Legon, Accra, Ghana. • **Telephone:** +233 (0) 302 513 250 / 0289 531 213
• **Email:** mch.son@chs.ug.edu.gh • **Website:** www.nursing.ug.edu.gh

Appendix D: Clinical Psychologist Letter of Approval to provide counselling services

UNIVERSITY OF GHANA
DEPARTMENT OF PSYCHOLOGY
SCHOOL OF SOCIAL SCIENCES

Ref. No.:.....

05 November 2020

COUNSELLING SERVICES FOR RESEARCH PARTICIPANTS

I have gone through the following protocol and have agreed to provide counselling services for participants who may need such services during data collection.

TITLE OF PROTOCOL: Quality of life of adolescents with Sickle Cell Disease in the Accra Metropolis.

PRINCIPAL INVESTIGATOR: James Mbangbe Ajusiyine

Dr Joana Larry-Afutu
Clinical Psychologist/Lecturer

UNIVERSITY OF GHANA-LEGON
DEPARTMENT OF PSYCHOLOGY

COLLEGE OF HUMANITIES
• P. O. Box Lg 84, Legon, Accra-ghana. • Telephone: +233 (0) 509 144 101 / 055 634 6580
• Email: psychology@ug.edu.gh • Website: www.ug.edu.gh

Appendix E: Parental Consent Form

Parental consent form

Title of research: Quality of life of adolescents living with sickle cell disease in the Accra Metropolis.

Principal Investigator: James Mbangbe Ajusiyine

Address: Department of Maternal and Child Health,

School of Nursing and Midwifery, University of Ghana

Tel. Number: 0242749648

Email: majusiyine@yahoo.com/ mjajusiyine@st.ug.edu.gh

Purpose of the research

The purpose of this study is to explore the quality of life of adolescents living with sickle cell disease in the Accra Metropolis.

Objectives of the study

1. Describe the psychological well-being of adolescents living with SCD.
2. Ascertain the physical well-being of adolescents living with SCD.
3. Examine the social well-being of adolescents living with SCD.
4. Describe the spiritual well-being of adolescents living with SCD.

Possible Risks and Discomforts

No physical harm is anticipated to occur during the study. However, psychological disturbances like worry, distress and tears may occur when telling your story. In such a case, you or your child will be allowed to grieve and referred to a clinical psychologist (Appendix D) in the hospital at no cost to restore emotional health (Clinical psychologist's contact details: Dr Joan Laary-Afutu, Clinical Psychologist; 0244995518)

Possible Benefits

For now, there will be no direct benefit from the study. However, the study will help the general public, policy makers and healthcare professionals to appreciate what you go through as parents of these children which will facilitate programs to be designed to support you.

Confidentiality

The interview that will be carried out will be recorded and later put in words. The conversation we will have will be privy to only me and my supervisors and will be used exclusively for academic purposes. Your name will not for any reason be included in the entire process rather special numbers will be assigned. Your demographic data will be collected before the start of the interview and will not be recorded. Data will be stored for five years and destroyed after five complete years.

Compensation

During the interview you will be given water. At the end of the interview, you will be given fruit juice and cream crackers.

Voluntary Participation and Right to Leave the Research

The decision to take part in this study is solely your decision. Therefore, at any time if you decide to opt out of the study you are free to do so without fear of receiving any form of victimization from the hospital staffs.

Contacts for Additional Information

If there are any concerns or you need additional information, the following people can be contacted using these addresses.

Dr Mary Ani-Amponsah (Department of Maternal and Child Health)

School of Nursing and Midwifery, University of Ghana, P o Box LG 43, Legon

Tele/Fax: +233(0)302513250

Telephone number +233(0)244368205

Email: mary.aniamponsah@gmail.com/ :mani-amponsah@ug.edu.gh

James Mbangbe Ajusiyine (Department of Maternal and Child Health)

School of Nursing and Midwifery,

College of Health Sciences,

University of Ghana, Legon

Tel. Number: 0242749648

Email: majusiyine@yahoo.com/ mjajusiyine@st.ug.edu.gh

Mr. Prince Ashitey

IRB Administrator, 37 Military Hospital

Tele: 0243004247

Your rights as a Participant

This research has been reviewed and approved by the 37 Military Hospital Institutional Review (37MH-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 7:30am-3pm through the mobile phone 0591759506 / Prince Yaw Ashitey-IRB Administrator (0243004247) or email addresses: irbmilhosp@gmail.com and pyashitey@yahoo.com

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title (Quality of life of adolescents living with sickle cell disease in the Accra Metropolis) has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree that my child should participate as a volunteer.

_____ _____

Date Name and signature or mark of parent or guardian

If volunteers cannot read the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the child's parent or guardian. All questions were answered and the child's parent has agreed that his or her child should take part in the research.

_____ _____

Date Name and signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

_____

_____

Date Name Signature of Person Who Obtained

Appendix F: Child Assent Form

Introduction

My name is *[James Mbangbe Ajusiyine]* and I am from the *[Department of maternal and Child Health]* at *[The University of Ghana]*. I am conducting a research study entitled *[*Quality of life of adolescents living with sickle cell disease in the Accra Metropolis*]*. I am asking you to take part in this research study because I am trying to learn more about *[*exploring the quality of life of adolescents living with sickle cell disease in the Accra Metropolis.*]*. This will take *[30 minutes to one hour]*.

Tel. Number: 0242749648 Email: majusiyine@yahoo.com/ mjajusiyine@st.ug.edu.gh

General Information

If you agree to be in this study, you will be asked to *[respond to a structured interview guide questions]*. The aim of this study is to explore the quality of life of adolescents living with sickle cell disease in the Accra Metropolis and will like you to provide the researcher with information on your physical health, psychological health, social health and spiritual health. You will be interviewed to solicit the information, and this is expected to last between 30 minutes to 1 hour. Our conversation will be audiotaped. You will be required to sign the child assent form to show your willingness to participate in the interview. Interview will be conducted in a place and time convenient to you and a second interview may be conducted if necessary.

Possible Benefits

For now, there will be no direct benefit from the study. However, the study will help the general public, policy makers and healthcare professionals to appreciate what you go through with your present condition.

Possible Risks and Discomforts

No physical harm is anticipated to occur during the study. However, psychological disturbances like worry, distress and tears may occur when telling your story. In such a case, you will be allowed to grieve and referred to a clinical psychologist (Appendix D) in the hospital at no cost to restore emotional health ((Clinical psychologist's contact details: Dr Joan Laary-Afutu, Clinical Psychologist; 0244995518).

Voluntary Participation and Right to Leave the Research

You can stop participating at any time if you feel uncomfortable. No one will be angry with you if you do not want to participate.

Confidentiality

Your information will be kept confidential. No one will be able to know how you responded to the questions and your information will be anonymous.

Contacts for Additional Information

You may ask me any questions about this study. You can call me at any time *[insert contact information]* or talk to me the next time you see me.

Please talk about this study with your parents before you decide whether to participate or not to participate. I will also ask permission from your parents before you are enrolled into the study. Even if your parents say "yes" you can still decide not to participate.

If there is any concerns you need additional information, kindly contact my supervisor through:

Dr Mary Ani-Amponsah (Department of Maternal and Child Health)

School of Nursing and Midwifery, University of Ghana, P o Box LG 43, Legon

Tele/Fax: +233(0)302513250

Telephone number +233(0)244368205

Email: mary.aniamponsah@gmail.com/ :mani-amponsah@ug.edu.gh

Your rights as a Participant

This research has been reviewed and approved by the 37 Military Hospital Institutional Review Board (37MH-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 7:30 am-3:00pm through the landline on the mobile number 0591759506/ IRB Administrator (Prince Yaw Ashitey-0243004247) or email addresses: irbmilhosp@gmail.com and pyashitey@yahoo.com

VOLUNTARY AGREEMENT

By making a mark or thumb printing below, it means that you understand and know the issues concerning this research study. If you do not want to participate in this study, please do not sign this assent form. You and your parents will be given a copy of this form after you have signed it.

This assent form which describes the benefits, risks and procedures for the research titled *[insert title]* has been read and or explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate.

Child's Name: …… Researcher's Name: ……

Child's Mark/Thumbprint…… Researcher's Signature: ……

Date: …… **Date:** ……

Appendix G: Background Information Form

Demographic information

Hospital: _____ Time: _____Hours GMT

Pseudo name (initials): _____ Age: _____years

Sex: _____ Religion: _____

Tribe: _____ Level of education: _____

Area: _____ Languages: _____

Sickling status/Genotype): _____

Average number crises in a years: _____

Participant Signature/ thumbprint: _____

Date: _____

Name of Research Member: _____

Signature: _____ Date: _____

Appendix H: Interview Guide

A. GUIDING QUESTIONS

Main questions

1. Please, can you share with me, at what age you were diagnosed of sickle cell disease and where?
2. Please, tell me how you felt when the diagnosis was confirmed.

A. Physical well-being (health) of client

How has your physical health been like since the diagnosis of your present condition?

Probe: what are some of the ways you are able to care for yourself in the following areas?

Overall physical health

Sleep

Pain

Fatigue

Functional ability

B. Social well-being of client

How has your social health been like since the diagnosis of your present condition??

Probe: how do people often relate to you?

Probe

Acceptance

Rejection/ignored/ isolation

Tell me how your school attendance/performance has been like

What kind of support do you get from family and friends?

C. Psychological well-being of client

How has your psychological health been like since your diagnosis?

Probe: uncertainty

anxious/depressed

emotional support

fear of recurrence

pain distress

D. Spiritual well-being of client

3. How does the disease/diagnosis affect your spiritual life?

Probe: what does the disease mean to you in terms of the folllowing?

Religiosity/sprituality

Hope

Inner strength

4. Please may I know if you have any other information for me about your condition that I did not ask? Or anything you would like to say?

Thank you very much.