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EXPERIENCES OF SICKLE CELL DISEASE (SCD) AMONG ADOLESCENTS ACCESSING HEALTH CARE AT THE 37 MILITARY HOSPITAL

BY

DORIS DZIGBORDI AVORTRI

(10239304)

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DECLARATION

I hereby declare that this thesis is my own work towards the Master of Public Health and that to the best of my knowledge, it contains no material previously published by another person nor material which has been accepted for the award of any other degree in the University, except where due acknowledgement has been made in the text.

…… 29-11-2022 ……

Doris Dzigbordi Avortri **Date**

Student

…….. 29-11-2022 ……

Dr. Leonard Baatiema **Date**

(Supervisor)

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DEDICATION

This work is dedicated to the almighty God for seeing me through the changing circumstances of life and the abundance of his Grace upon me thus far. To my family, my husband Mr. Richard Agbanyo, my children Seyram, Selorm and Aseye for their support and encouragement emotionally, physically and spiritually. Also, my late father and mother Mr. and Mrs. Avortri for their initial motivation towards my education.

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LIST OF ABBREVIATIONS

CBT	Cognitive-behavioral therapy
CIA	Central Intelligence Agency Hb
Hb	Hemoglobin
HRQOL	Health-related quality of life
NCD	Non communicable disease
NICU	Neonatal intensive care unit
SCD	Sickle cell disease
SCT	Sickle cell trait
VOC	Vaso-occlusive crisis

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ABSTRACT

Sickle cell disease (SCD) is the most common inherited blood disorder throughout much of Sub-Saharan Africa affecting up to 3% of births in some parts of the continent. With the increasing occurrence of SCD in the adolescents visiting 37 Military Hospital, a basic understanding of their livelihood is of importance to medical practitioners for improved and better care delivery. This study seeks to explore the lived experiences of adolescents living with SCD as well as the challenges they face accessing healthcare at the 37 Military Hospital. It further analyses the coping strategies adopted by the SCD adolescents and existing support systems.

Qualitative research methodology was employed in the study using interviews to collect data from SCD adolescents between the ages of 10 and 19 years. 25 respondents were interviewed,

The study reveals adolescents experience symptoms of depression, dejection and feel stigmatized by friends. Access to health care is another challenge they experience due to inadequate specialized clinics, physicians, health insurance coverage and high cost of medical and laboratory expenses. Adolescents adopting different coping strategies including praying, physical activity, drinking of sufficient water, taking of pain killers and self-management.

The study concludes that there is the need for the government to establish a free health care system for SCD patients across the country for easy access to healthcare and intensify education as well. Psychosocial support services and community-based support are also needed to improve the lived experiences of adolescent living with SCD.

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CHAPTER ONE

1.0 INTRODUCTION

1.1 Background to the Study

Sickle cell disease (SCD) is an inherited disorder of hemoglobin caused by a mutation in the beta globin subunit of adults. This red blood cell disorder is a lifelong condition that can affect many major organs in the body. The red blood cell of sickle cell patients' lives for a couple of weeks instead of three months as do normal red blood cells. There is therefore anemia and rapid turnover of cells. In cases of stress and hypoxia, the cells assume a sickle shape and they lock each other in the tiny blood vessels causing a blockage which then leads to the following symptoms; bone, joint, chest and abdominal pain of biting nature, Jaundice, anemia, head and foot syndrome, bone, distended abdomen, stroke, repeated infections, chronic ulcers amongst others (Porter & Kaplan, 2011). SCD affects million people all over the world, especially those of African origin, also in the Caribbean, South America, United Kingdom, France, Italy, Arab countries etc. (Zajac, 2021).

Wastnedge et al (2018) reported that global meta – estimate for the prevalence of homozygous sickle cell disease is 111.91 per 100,000 births (95% CI = 100.77 – 123). Approximately 5% of the world population are healthy carriers of a gene of sickle cell disease or thalassemia. The percentage of people who are carriers of the gene is 25% in some countries (Wastnedge et al, 2018). According to World Health Organization (WHO), sickle cell disease is the most prevalent inherited disease in the African region and in many countries 10-40% of the population carry the sickle cell gene resulting in estimated sickle cell prevalence, approximately 80% of all children

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born with SCD are in Sub-Saharan Africa (about 200,00 babies born per year with SCD) (WHO, 2010).

The mortality rate of children with SCD had been high among children under five to 23 years (about 9.3%) until the 21st century when it dropped to 2.6% in African American children. The reduction is believed to be due to the adoption of pneumococcal vaccine that was started in 2000.

Although, advances in medicine and technology have caused decline in mortality rate and children with the disease, the condition is still linked to a shorter lifespan in life expectancy. These days 90% of children with sickle cell disease in developed countries survive into adulthood due to comprehensive management including new born screening, health promotion and prevention of disease complications. However, sickle cell disease in sub-Saharan Africa contribute to 5-16% of all deaths to children under 5. Most of them are undiagnosed and untreated (Gill, 2019). Misconception about SCD, the negative thought and ideas have led to stigmatization of people living with SCD. Electronic searches of medical and psychological database revealed some psychological complications in both children and adults with sickle cell disease. These include inappropriate pain coping strategies, quality of life due to restriction in daily functioning, anxiety, depression and neurocognitive impairment. School absenteeism leads to deterioration in school performance (Anie & Haematol, 2005). A study on Care giver Perception of Sickle Cell Disease Stigmatization in Ghana identified Sickle cell disease stigma is a major community health issue. The study, explored stigma and related factors for caregivers of pediatric patients with SCD in Kumasi, Ghana. Overall, participants were knowledgeable about SCD. The study revealed three themes including; blame for SCD;

Caregivers were blamed as being under a curse for their evil deeds, public misconception about SCD; some people in the community considered the disease as devilish acquired as punishment of

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God from bad ancestors handing over from generation to generation and the shame for the financial burden of SCD. Based on these findings, it's important for steps to be taken to explore the reduction of stigmatization in other sub-Saharan countries (Buser et al, 2021).

The disease is also associated with huge economic burden worldwide. Routine and lifelong comprehensive care is needed to treat serious complications. A total of 20 studies in 10 countries between January 2014 to June 2019 on economic burden and healthcare resource utilization reveal a total direct annual cost ranged from USD 1 million to USD 3 million and the average indirect cost was found to be USD 1,293 million in the related care is negligible (Naik, Bagga & Senecai, 2019). In Congo only 60% of essential medicines for sickle cell patients for example, folic acid, multivites etc. are available in the public pharmacies. The cost of other medicines and laboratory investigations are borne by relatives (Ngolet, 2016).

Management currently, includes health maintenance measures. For example, folate supplementation, hydroxyurea, broad spectrum antibiotics (for infections), analgesics and IV hydration (for Vaso occlusive pain episodes), blood transfusions and immunizations (Porter & Kaplan, 2011). Although there is no universal cure for SCD, some treatment modifications are practiced in some countries. These include; hydroxyurea which increases fetal hemoglobin level thus reducing the rate of crises' Chronic blood transfusion, Haemopoietic stem cell transplantation, Gene therapy and L-glutamine (Porter & Kaplan). Ghana is the first to use Hydroxyurea in sub-Saharan Africa. Expensive and technologically advanced methods of care for SCD patients in UK, USA and parts of Europe are generally not affordable in Ghana and other sub-Saharan African countries.

The World Health Organization, Africa in 2010 designed some intervention strategies to prevent complications of SCD and reduce frequent hospitalization (Center for disease control and

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prevention). This strategy provides a set of public health interventions to reduce the burden of SCD in the African region through improved awareness, disease prevention and early detection. The interventions include improvement in healthcare provisions effective clinical, laboratory, diagnostic and imaging facilities adapted to different levels of the health system, screening of newborn, training of health workers and development of protocols, genetic counselling and testing, accessibility to healthcare; establishment of patient support groups; advocacy and research.

Sickle cell disease is also a significant public health burden in Ghana. According to sickle cell foundation Ghana's annual report, about 2% (15,000) of Ghanaian new-born are affected by SCD annually. About 320 children with SCD access healthcare at 37 Sickle cell clinic every month. 395 admissions were recorded in 2019 and 192 in 2020 (37 Data and Information System, 2021). The reduction might be due to intervention by hydroxyurea although the number is still high. A study conducted at Ghana institute of Clinical Genetics Korle Bu, Accra and published in 2018 revealed that Korle Bu Teaching Hospital which is the largest teaching hospital in Ghana saw 5,451 patients with 20,788 clinic visits of children with SCD between January 2013 to December 2014 (Matutes, 2018).

There are a number of traditional beliefs surrounding the origin of SCD. Ghanaians consider it as a form of rheumatism, and the names ascribed to it tend to express or describe the relentless pain suffered by those who have it Ahotutuo (Twi), Nududui (Ewe), Tswetsweetswee (Ga), Amosan (Hausa). Many consider the disease or its manifestations as inflicted upon people through witchcraft. For instance, the chronic splenomegaly experienced by some patients is thought to be a pot put in the "belly" through witchcraft. Even though SCD is ancient, it was only in 1910 that an American doctor, James B. Herrick discovered that the disease was one of red blood cells. Since this discovery, knowledge in sickle cell disease has increased and researches have led to

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improvement in the understanding of the pathophysiology and complications of sickle cell disease (Ohene-Frempong, 2005).

1.2 Problem Statement

One-year cohort study done in Ghana Institute of Clinical Genetics between 2013 and 2014 on 'Burden of Sickle Cell disease in Ghana' saw over 5451 adolescents and adults with 20788-clinic visit (Matutes, 2018). Other studies have also reported a high burden of SCD in Ghana. For example, in 2020, Poku reported a large burden of SCD with its associated complications and went further to conclude that fatigue is central to young people's day-to-day experience and impacting significantly on their self, social and emotional development and ability to have fulfilling life (Poku, 2020). Also, research at Korle Bu, Ghana institute of clinical genetics on 'Transition Experiences of Adolescents and Young Adults' revealed how majority of the adolescents had challenge adjusting to their new place of care (Kwarteng-Siaw, 2019).

Although limited, these studies points to a high burden of SCD among adolescents in Ghana. However, studies to comprehensively explore the lived experiences of adolescents living with SCD is scanty, thus leaving a major gap in our understanding of the nature and diversity of experiences of adolescents living with SCD. This is critical because adolescents are a unique population group with unique experiences of challenges likely to differ from other age groups. Furthermore, this stage is when major development growth of all organs in the systems of the body. Emotional stress is likely to occur in those who have delays in their physical growth. Also, the high frequency of psychological disorders at this stage compelled with chronic disease should not be ignored. Against this background, this study seeks to explore the lived experiences of SCD among adolescents accessing health care at the 37 Military Hospital in Ghana by exploring fully

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the experiences of sickle cell and coping strategies among adolescents living with sickle cell; Being a chronic condition, the researcher seeks to know the copping strategies they have developed over the years. The extent to which an individual is affected by a chronic illness may thus be determined by their coping responses, because dealing with its continuous demands necessitates the acquisition of new skills and changes to daily life functioning in children and adolescents" (Anie, Egunjobi, and Akinyanju, 2010).

The challenges adolescents living with sickle cell disease go through in accessing healthcare might be another worrying factor. Insurance and a lack of resources to address pain impact were identified as concrete barriers. Adolescents and adults with SCD identified provider issues (lack of knowledge, implicit bias), transportation, and a lack of social support as barriers. Negative experiences with the healthcare system contributes to more adolescents and adults with SCD choosing to manage severe pain at home (Treadwell et al, 2019.). Due to its psychosocial and economic impact on society, the researcher further wants identify and understand existing support systems from families, community, schools and healthcare settings for adolescents living with sickle cell disease. SCD education is generally lacking for the general public and within the formal education sector, leaving the population largely uninformed. Outside of the provision of health insurance schemes, which do not cover the entire population, healthcare financing is extremely limited. However, adequately trained, public health professionals in both the public and private sectors have the potential to lead the effort to shift the current trend toward a service that provides essential healthcare and basic social support to SCD patients and their families (Dennis-Antwi et al, 2007).

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Analyzing the outcome of narratives of the respondents will inform the public, families and government understand diverse issues concerning adolescents living with sickle cell disease and how to best support and plan for their care for them to live fulfilling lives.

1.3 Justification of the study

Several studies have been done in the USA and Africa on effects of SCD on adults, psychological issues with SCD, and experiences with parents with SCD and coping and adjustment in the US. Some of which are; Real stories from People Living with Sickle Cell Disease (Centre for Disease Control and Prevention, 2021), Knowledge and experiences of parents with children affected by Sickle Cell Disease in Cape Town (Niekerk, 2015), Psycho-social problems of adolescents with sickle-cell anemia in Ekiti State, Nigeria (Adegboyega, 2021).

Studies done in Ghana focused more on experiences of adults living with sickle cell disease. Some of which are; - Burden of SCD at Korle-Bu (Asare, 2018), Health care provisions for people with sickle cell disease in Ghana (Powars, 1994). Controlling sickle cell disease in Ghana (Edwin, 2011), and SCD disease awareness, Depth of knowledge (Aboagye 2019). The others done in Korle-Bu; Komfo Anokye Teaching Hospital touched on other areas of adolescents. Some of which are; Quality of life of adolescents with SCD (Meyiwa, 2019), assessment of transition readiness in adolescents and (Kwarteng – Siaw, 2017). Although the above studies are important to advance knowledge and scientific research on sickle cell disease in Ghana, research on the lived experiences of sickle cell among adolescents is limited. It is against this background that this research is designed to investigate the lived experiences of sickle cell disease among adolescents accessing healthcare at 37 Military Hospital. Engaging in reflexivity by the researcher's continuous checks on her judgement, practices and belief systems to identify biases and other characteristics that will influence the research. This will further present trustworthiness and clarity

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to the results of the study thereby holding the researcher accountable. In addition to advancing knowledge and scientific research, the findings of this study based on the specific objectives will inform healthcare providers, families, teachers and communities to better understand the condition ang give the necessary support to people living with sickle cell disease. Health institutions, NGOS and Government may also implement polices that will improve livelihood of people living with sickle cell disease.

1.4 Research Objectives

The objectives of the study were divided into general and specific as stated below.

1.5 General Objective

To explore the lived experiences of sickle cell disease among adolescents at the 37 Military Hospital.

1.5.1 Specific Objectives

i. To explore the experience of sickle cell and coping strategies among adolescents living with sickle cell.

ii. To understand the challenges adolescents living with sickle cell disease go through in accessing healthcare.

iii. To identify and understand existing support systems from families, community, schools and healthcare settings for adolescents living with sickle cell

iv. To explore the views of adolescents living with sickle cell on measures and strategies to improve access to care and quality of life.

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1.6 Research Questions

i. What are the experiences and coping strategies adopted by adolescents living with sickle cell diseases?

ii. What challenges do adolescent living with sickle cell disease face in accessing healthcare at the 37 Military Hospital?

iii. What are the existing support systems for adolescent living with sickle cell disease?

iv. What are the views of adolescents living with sickle cell on measures and strategies to improve access to care and quality of life?

Outline of the Dissertation

The presentation of the report of this study is divided into six chapters.

Chapter one reveals an accurate and deep understanding into the introduction of the study. This consist of the background to the study, statement of problem, justification, objectives and research question of the study.

Chapter two presents the literature review on experiences of adolescents living with sickle cell accessing health care at 37 Military Hospital. This chapter also provides studies done by other researchers on Global burden of sickle cell disease, Sickle cell disease sub-Saharan Africa, Context of sickle cell disease in Ghana, lived experiences of adolescents with sickle cell disease, Coping strategies among adolescents with sickle cell disease, Experiences in accessing health care, Existing support systems and Conceptual frame work.

Chapter three provides methods used to collect empirical data for the study whiles, chapter four analysis of the results obtained from the in-delph interviews by bringing out the thematic domains that were identified. Chapter five however, discusses the findings of the study in relation to the existing literature. Chapter six presents summary of the finding, recommendation and conclusion.

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CHAPTER TWO

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

2.1 Introduction

This chapter presents an overview of previous research on the burden of sickle cell disease. It also explores existing literature on the lived experiences of sickle cell diseases, access to healthcare among adolescent and other people living with sickle cell diseases. Works on the coping strategies adopted by adolescent living with sickle cell, existing support systems are also discussed and reported herein.

2.2 Burden of Sickle Cell Disease

i. Global burden of sickle cell disease

Sickle Cell Disease (SCD) is a common hematological condition that affects millions of individuals worldwide. It is particularly common in malaria-endemic areas of the tropics, where resource restrictions typically result in dismal results, with the majority of children dying before reaching maturity. As progress is achieved in lowering under-five mortality from infectious causes, noncommunicable diseases (NCDs), including SCD, have climbed to the top of the global health agenda. Regardless, the worldwide impact of SCD in terms of morbidity and death is unclear (Wastnedge et al, 2018). SCD affects around 100,000 persons in the United States, with one in every 365 Black or African-American births, one in every 16,300 Hispanic American births, and one in every thirteen Black or African-American newborns born with the sickle cell trait, according to estimates (SCT). Between 1999 and 2002, deaths caused by sickle cell disease in Black or African-American children under the age of four reduced by 42%. The advent of a vaccination against invasive pneumococcal illness in 2000 corresponded with this decrease (Centers for Disease Control and Prevention, 2022). SCD is characterized by acute pain episodes

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(the disease's hallmark), anemia, recurrent infections, and chronic end-organ destruction. Because the condition is lethal in the first few years of life, newborn screening, early diagnosis, and a comprehensive treatment program are According to Quinn et al. (2010), the SCD population in the United States has a longer life expectancy, with over 90% of babies born with SCD reaching adulthood. essential. life expectancy, with more than 90% of babies born with SCD reaching adulthood.

ii. Sickle Cell Disease in sub-Saharan Africa

Sickle cell disease (SCD) is common in Sub-Saharan Africa, affecting up to 3% of births in some countries. Sub-Saharan has become the home to almost 80% of all children born with SCD (Rees, Williams & Gladwin, 2010). Nonetheless, the disease remains a low priority for many health-care organizations. In Africa, the most common form of SCD is caused by homozygosity for the -globin S gene mutation (SS disease). Although it is widely assumed that this condition is associated with extremely high child mortality, there is no reliable data to confirm it. Reviewed available African data on SS disease mortality from published and unpublished sources, focus on two types of studies: Cross-sectional population surveys and cohort studies. The current data are insufficient to support definitive statements, and are consistent with an early-life mortality rate of 50%–90% among children born with SS disease in Africa. When there are interventions in African child survival policies and programs could benefit more children and reduce the number of deaths among SCD children (Grosse et al,

2011). Nearly 90% of the world's SCD population is concentrated in three countries: Nigeria, India, and the Democratic Republic of Congo. Estimates are difficult to come by due to the lack of federal newborn screening programs; however, approximately 700,000 births occur each year,

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and the prevalence of SCD in newborns was 3% in a regional newborn screening program (DeBaun & Galadanci, 2021).

Despite the fact that this disease has a high mortality rate in Africa, little is known about it. The lack of large-scale early-life screening has been a major impediment to progress. The majority of SCD deaths in Africa are likely to occur before cases are even diagnosed (Oron et al, 2020). In rural Tanzania, 999 neonates were examined between February and September 2019, with 31.6 percent (315/999) having sickle cell trait and 3.9 percent (39/999) having SCD. Hemoglobin C was found to be absent. Few parents were aware that their children had sickle cell anemia (0.3 percent). In rural northern Tanzania, the birth prevalence of SCD is extremely high, with 3.9 percent of newborns having SCD and 31.6 percent having sickle cell trait. It was the highest prevalence ever recorded in Tanzania and one of the highest in Sub-Saharan Africa (Eastburg et al, 2021).

Nigeria has close to half of the more than 300,000 babies born globally each year with severe hemoglobin disorders. The World Health Organization (WHO) estimates that 5% of the world's population carries trait genes for hemoglobin disorders, primarily sickle cell disease and thalassemia. According to the World Health Organization, more than 300,000 babies with severe hemoglobin disorders are born globally each year, with Sub-Saharan Africa bearing 75% of the burden, with Nigeria bearing 66% of the burden in the region. According to a World Health Organization (WHO) report, 24% of the Nigerian population carries the mutant gene, and the prevalence of sickle cell anemia is around 20 per 1,000 births. The prevalence ranges from 20 to 30% in Cameroon, the Republic of Congo, Gabon, Ghana, and Nigeria, and is as high as 45% in some parts of Uganda. Meanwhile, according to a previous study, "Nigeria has the highest sickle cell disease birth prevalence in the world, with an estimated 150,000 annual births of babies with

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sickle cell anemia, the most common form of sickle cell disease." According to the WHO (2014), "at least 100,000 babies die from the disorder in Nigeria every year."

In other Sub-Saharan African countries, the inherited blood disorder is thought to be the underlying cause of about one in every twelve newborn deaths (Alabiand & Adebowale, 2021).

A 2018 study on the 'Prevalence of Complications of Sickle Cell Disease' by Umm Al-Qura University in Makkah, Kingdom of Saudi Arabia used 145 medical files of pediatric patients with SCD ranging in age from one day to 14 years, with a mean SD of 7 3.6 years. Sickle cell anemia with Vaso-occlusive crisis (VOC) was diagnosed in cases who lived outside of Makkah, and 47.1 percent of those who lived in Makkah were diagnosed with VOC on admission. VOC SCA patients were hospitalized once on average, with 25.5 percent being admitted numerous times. Acute splenic sequestration crisis occurred in 3.1 percent of Saudi patients compared to 12.8 percent of non-Saudi patients. The team reported that VOC was the most prevalent complication of SCD, accounting for 55.9% of cases, followed by infection (9 percent). A health care practitioner with competence in SCD, ideally a hematologist, should be consulted for the prevention of acute SCD problems, according to 41.4. Furthermore, difficulties are minimized by starting penicillin prophylaxis in the neonatal period and receiving proper vaccinations, blood transfusions for those at risk of stroke (Alkot et al, 2018). Despite the low cost of many preventive SCD interventions, insufficient resources have been allocated, and progress in reducing SCD burden has lagged behind other African public-health efforts. Announcement of new huge funding recently for research into curative SCD therapies is encouraging in the long run, but it is doubtfully to help Africa's SCD children notably over the next few decades (Uyoga et al, 2020).

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iii. Context of Sickle Cell Disease in Ghana

Every year, approximately 15,000 (2%) of Ghanaian newborns are diagnosed with SCD (Matutes 2018). An earlier study from Ghana by Ohene-Frempong et al (2008) found that "55 percent of sickle cell disease children born in Ghana have the homozygous form. Ages 13 to 44 years revealed a 2:1 ratio of hemoglobin (Hb) SS to hemoglobin SC; this reversed after 44 years, possibly due to higher mortality seen in HbSS patients, who have been documented to have a more severe form of the disease" (Asare et al. 2018).

A pilot newborn screening program in one of Ghana's regions revealed a prevalence of 1.8%, (approximately 15000) newborns with SCD are born in Ghana each year. It appears that with proper use of basic medical facilities, more children with SCD are now surviving into adulthood, with the oldest patient in the cohort currently in her late twenties.' If Ghana wants to impact on SCD care, they must prioritize multidisciplinary care, including adequate primary care, as well as the development and implementation of a national sickle cell disease policy that includes, but is not limited to, universal newborn screening" (Asare et al.2018).

People with sickle cell disease (SCD) are frequently undetected until they are four years old and during a pain crisis in Ghana, a country in Sub-Saharan Africa with the world's highest SCD prevalence (Inacio 2021).

Despite having the world's highest prevalence of sickle cell disease (SCD), according to Sims et al. (2021), no nation in Sub-Saharan Africa has a universal SCD screening program. Parents in Accra, Ghana, were interviewed about SCD diagnostic trends (age at diagnosis, manner of diagnosis, and age of first pain crisis). A total of 354 people were investigated. During the neonatal period, just a few persons were diagnosed with the condition through SCD testing. Only 44% of

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children with SCD had been identified by the age of four, and 46% had had a pain crisis. The vast majority (66%) were diagnosed as a result of a pain crisis.either in an acute (49%) or primary care (17%) setting. Children were diagnosed with SCD at a younger age (74 percent by the age of four), and adults were identified at a later age (30 percent by four years old).

The findings confirmed the necessity of newborn screening programs, which are lacking in Ghana. According to the study, patients are "likely being excluded from life-saving preventative therapy." Children in Accra, Ghana, are at risk of disease complications and mortality due to the lack of a comprehensive newborn screening program for SCD. People in the study were diagnosed with SCD in an acute care setting, as well as toddlers, school-aged children, or later. Meaning that they are prevented from critical preventive care. Acknowledging the existing SCD diagnosis patterns will aid efforts to improve SCD diagnosis early and reduce disease-related mortality and morbidity in this high-prevalence community (Sims et al, 2021). A community-based cross-sectional survey of 938 children aged 1–12 years from three districts in the Volta region revealed an overall frequency of sickle cell disease of 2.0 percent, with 16.0 percent of sickling screening positive. The HbSF genotype was the most common among sickle cell disease individual genotypes (0.9 percent vs. 0.2 percent; HbSS, 0.6%; HbSC and 0.3%; HbSCF).. However, no discernible link could be found between sickle cell disease and the growth and development of the children who were screened (Oppong et al.

2020). Over the years, SCD has been overlooked as a disease of public health significance. In Ghana, statistics on deaths from major childhood diseases such as malaria, acute respiratory infections, and malnutrition-related issues have buried the health status of children with catastrophic genetic disorders such as SCD (Ohene-Frempong, 2007). According to the Central Intelligence Agency (CIA),2007). Ghana is heavily reliant on international financial and technical

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assistance, making it not possible to implement effective and adequate services, including SCD healthcare (CIA, 2007). Basic information on SCD was first included in the national child health growth monitoring plan in 2007 to raise awareness of SCD and the need for testing among mothers (Dennis-Antwi, 2007). SCD patients are treated as general outpatients, reporting to health institutions on a daily basis, with the exception of Accra,

Kumasi, and a few governmental and private treatment centers primarily in the south, such as Tema, Koforidua, Agogo, and Sunyani. Ghana, has yet to implement comprehensive SCD care. assistance (Okpala et al, 2002). The vast majority of these patients are admitted to hospitals with serious illnesses and are not always diagnosed with SCD (Orji et al, 2002).

2.3 Lived Experiences of Adolescents with Sickle Cell Disease

A study on the illness experiences of young people with sickle cell disease (SCD) looked at adolescents with SCD who were experiencing fatigue. In Ghana, 24 adolescents participated in narrative and picture-elicitation interviews. The narratives were used to build a grounded theory, "body as a machine." Fatigue was the most limiting and disruptive aspect of growing up with SCD. Its source of meaning and value was indicated by what it indicated. Fatigue was a socially undesirable and stigmatizing trait in youth due to the demands of high physicality. As a result, fatigue was a significant threat to "normalcy." The social value of the physical body and its capabilities influenced adolescents' fatigue experiences. The lives of the adolescents were dominated by the need to manage exhaustion in order to construct/maintain socially acceptable identities. As a result, acknowledgment is required if there is a need for a recognition of the significance of fatigue to adequately support young people growing up with it" (Poku, Caress & Kirk, 2020). Another integrative narrative review of literature on Adolescents' experiences of living with sickle cell disease found 683 studies, of which 40 met the inclusion criteria, and 9

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broad themes emerged: knowledge and understanding of the condition, symptom experiences, self-management, attitude to treatment, healthcare experiences, social relationships, difference and striving for normalcy, school experiences, and emotional wellbeing and coping. The study concluded that Sickle cell disease has an impact on a variety aspect of an adolescent's life. As a result, nursing care and research should place a greater emphasis on the developmental well-being of adolescents, as well as promote peer support networks among adolescents with the condition (Poku, Care & Kirk 2018). A study on the Quality of

Life of Adolescents with Sickle Disease was conducted in 2019 at the Ghana Institute of Clinical Genetics, Korle Bu Teaching Hospital. "Quality of life (QOL), a social construct measuring a person's overall well-being has been shown to be lower in adolescents with SCD due to the disease's effects. The study's goal was to assess the quality of life of adolescents attending a Sickle Cell clinic at the Ghana Institute of Clinical Genetics in Korle Bu. The study took a qualitative approach, employing the phenomenological technique. In-depth interviews were conducted with 15 adolescents with Sickle Cell Disease who were attending the Institute's Sickle Cell Clinic, and the audio was recorded and transcribed. To generate themes for data analysis, thematic analysis was performed by coding and recoding. The study found that the quality of life of adolescents with Sickle Cell Disease was good, based on their subjective meanings and interpretations of their health at this stage of life. This study's findings included the adolescent patients' perceived general, emotional, physical, social, and cultural health and well-being. Family support and clinical visits were discovered to have a significant impact. on the quality of life of SCD adolescents It was discovered that culture had no effect. There were no differences in the quality of life of male and female SCD adolescents. The researcher concluded that, in general, the adolescents' perceived quality of life was good; however, emotional health was found to be lacking in some younger

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female adolescents. Positive social factors associated with QOL should be encouraged. It is also recommended that the emotional health of younger adolescents, particularly females, be considered and prioritized in SCD care" (Meyiwa, 2019). An empirical qualitative study of six adolescents with sickle cell disease conducted in Kingston, Jamaica revealed that the majority of the adolescents had a positive self-concept. They reported feeling accepted because of strong family, school, and peer support. All were actively involved in social activities such as parties, but found it difficult to participate in sporting activities. It was thus concluded that Sickle cell disease can be extremely difficult for adolescents, but with a positive self-concept and increased social support, particularly from family and peers, these adolescents were able to effectively cope with their condition (Brown et al, 2020). A study carried out in Zambia on lived experiences of adolescent learners with SCD generated several themes that highlighted the experiences that students go through while attending school. The study documented the experiences of adolescent learners as well as their parents and teachers. Based on interviews conducted with students suffering from SCD. The following themes emerged: Being sick frequently; repeating grades; studies and extra lessons; exemption from strenuous activities and Teachers do not understand the situation, as evidenced by a number of issues raised during interviews with mothers. These highlighted their experiences. Children with sickle cell disease were used as students. The following themes emerged: children with SCD miss school; children with SCD require more attention in class; Teachers do not understand sickle cell disease and repeat extra lessons and classes. The themes that emerged from the interviews with teachers revealed teachers' perspectives on students with sickle cell disease. The following are the themes: Parents and students do not want the SCD condition to be known; Teachers' lack of understanding of the SCD; Individualized

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attention and adequate support are required for children with SCD (Ngomah, Moraes & Munsaka, 2019).

2.4 Coping Strategies among Adolescents with Sickle Cell Disease

An empirical study conducted in Kingston, Jamaica on "The lived experiences of adolescents with sickle cell disease" by (Forrester et al., 2015) revealed that “the majority of the participants reported a positive self-esteem during the interviews. Three participants stated unequivocally that they did not feel different from others. In the presence of SCD, they felt good about themselves. Due to delayed menarche, female participants were extremely anxious. Some participants also expressed frustration, sadness, and depression, particularly during painful crises. The results were the same for both male and female participants. They were afraid of dying at times, especially during severe painful crises, hospitalizations, or when a friend or peer died as a result of SCD complications. All participants stressed the importance of staying healthy in order to avoid painful SCD crises and complications. Some health-maintenance strategies included avoiding social activities and adhering to strict dress codes. They believed that following medical and dietary regimens would help them improve their health and live longer lives. "I," one participant exclaimed. make sure I have all of my medications, drink plenty of water, eat properly, and exercise, stay fit, and get my regular check-ups." Respondents relied heavily on prayer and spiritual activities as coping mechanisms. They reportedly believed in God and prayed frequently, especially when their conditions worsened. They engaged in spiritual activities such as fasting and attending church prayer meetings”.

Hurtig and White conducted another study on Psychosocial Adjustment in Children and Adolescents with Sickle Cell Disease (Hurtig & White, 1986). The study looked into how chronic illness-related stress affected adjustment. A group of 50 children and adolescents with sickle cell

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disease were chosen from a Sickle Cell Center over a long period of time, with symptoms ranging from mild to severe. The severity of the illness was assessed in terms of perceived pain, hospitalizations, and emergency room visits, as well as the nature of the presenting symptoms and levels of adjustment. The findings revealed that There were issues with a variety of adjustment variables, especially for adolescent males, and most notably in the areas of behavior problems and social adjustment. There were implications for adaptive coping with adolescent developmental processes (Anie et al., 2010).

Kofi Anie's 2010 online study investigated the psychosocial impact of sickle cell disease in 408 adolescents and adults attending three hospitals in Lagos, Nigeria. "The majority of participants believed that society as a whole had a negative perception of SCD, and they reported negative perceptions and attitudes. The findings also revealed that depressive feelings were prevalent. Even though feelings of anxiety or self-hatred were uncommon, they were experienced by nearly half of the study population" (Anie, Egunjobi & Akinyanju, 2010). In another development, adolescents (all students) with sickle cell disease who attended sickle cell outpatient clinics at Lagos University Teaching Hospital, Gbagada General Hospital, Massey Street Children's Hospital, and the National Sickle Cell Centre were recruited opportunistically over two months for a study on the psychosocial impact of SCD in a Nigerian population. The typical clinic Attendance at the three hospitals ranged from 30 to 45 people. It was discussed that "the impact of chronic illness, such as SCD, on individuals can be divided into three categories: adjusting to symptoms and incapacities, maintaining adequate relationships with health-care providers, and managing the emotional and social consequences of the illness. The extent to which an individual is affected by a chronic illness may thus be determined by their coping responses, because dealing

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with its continuous demands necessitates the acquisition of new skills and changes to daily life functioning in children and adolescents" (Anie, Egunjobi, and Akinyanju, 2010).

Kliewer and Lewis (1995) investigated the role of parenting and family variables in the overall coping processes of 39 sickle cell disease children and adolescents (SCD). Parents provided information about their children's health history, coping suggestions for their children, their own coping strategies, and family cohesion during home interviews. Children were asked to rate their general coping strategies and their level of hope. Each of the three models of family influences tested in this study received partial support. After taking into account the effects of age, gender, Children's hope was positively associated with active coping suggestions by parents, regardless of family structure or type of SCD. A cohesive family environment was associated with children's active coping, and avoidance coping was predicted by less parental use of restructuring coping and more parental use of active coping strategies. The study as a whole, provided evidence for the impact of parental coaching and modeling, as well as the family environment, on coping processes in children with SCD (Kliewer & Lewis, 1995).

A study looked at the relationships between pain, pain coping, and sleep, as well as the factors that affect pain, coping, and sleep in children with sickle cell disease (age, gender, frequency, and intensity of pain) (SCD). "An electronic visual analog scale Pain Coping Questionnaire and the Pittsburg Sleep Quality Index were completed by 66 adolescents aged 11 to 16 years SCD. Approximately two-thirds of the adolescents reported pain in the previous month, but there were no significant associations between pain and age, gender, pain intensity, or frequency. The majority of them dealt with pain by seeking information, problem solving, social support, and making positive self-statements. In males, there were significant negative correlations between worse Pain severity, behavioral distraction, and internalizing or catastrophizing are all factors to

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consider. The vast majority (91.2 percent) suffered from mild to severe sleep disturbances, with 18.2 percent requiring sleeping medication three or more times per week. It was determined that children with SCD experience pain, which affects their sleep patterns and their ability to cope with pain. Nurses must assess pain, coping, and sleep simultaneously, and promote sleep and hygiene for positive coping strategies during pain episodes" (Graves & Jacob, 2014). Coping in Sickle Cell Disease Adolescents, a pilot study was conducted to determine how adolescents use religious and spiritual beliefs to cope with a chronic illness such as sickle cell disease (SCD).

Another study that looked at coping, spirituality, and health-related quality of life in 48 adolescents with SCD found that they had high rates of religious attendance and belief in God, prayed frequently, and had high levels of spirituality (e.g., finding meaning/peace in their lives and deriving comfort from faith) (Cotton et al., 2009). For symptom management, 35% of adolescents reported praying once or more per day. Adolescents' most common positive religious and spiritual coping strategies were that 73% asked forgiveness for their sins and sought God's love and care. For adolescents with SCD, spiritual coping, particularly prayer, was important (Cotton et al., 2009)

A related study conducted during the 2007 and 2008 Sickle Cell Research and Education Day annual events held at Cincinnati Children's Hospital Medical Center (CCHMC) in Cincinnati, Ohio among Adolescents age 11-19 years with SCD via letter and flyer identified Prayer and spiritual activities as a major coping strategy for the respondents. They reportedly believed in God and prayed often, especially when there was an exacerbation of their conditions. They participated in spiritual activities such as fasting and going to church for prayer meetings Other coping strategies that were also used were diversional activities applied during periods of exacerbation of their illness as it helped take their minds off their condition and to feel good about themselves.

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Such activities included watching television or talking with close friends and families (Cotton et al., 2009).

A study on Coping and Coping Assistance among Children with Sickle Cell Disease and Their Parents discovered that "how a family copes with the physical and psychosocial challenges of SCD influences the functioning of the child and family. It was also discovered that children face a variety of stressors related to SCD and its treatment, including but not limited to pain.

Families use a variety of approach and avoidance-oriented coping strategies to deal with these stressors. In complementary and distinct ways, quantitative and qualitative assessments contributed to a better understanding of coping processes in children with SCD and their parents" (Hematol, 2015). Another study looked at the outcomes of a cognitive-behavioral therapy (CBT) intervention for pain in children with sickle cell disease using smartphones as a novel delivery modality (SCD). 46 children with SCD were given CBT coping skills training using a randomized, waitlist control design. The intervention included one CBT session and eight weeks of home practice with cellphones. Using pre-post questionnaires, the Coping Strategies Questionnaire was used to assess changes in active psychological coping and negative thinking between the randomized groups. The use of CBT skills was associated with decreases in next-day pain intensity and increases in same-day functional ability. According to daily diaries kept by the entire sample during treatment, activity A comparison of the pre- and post-groups revealed that, according to the pre-post group comparison, youngsters increased active psychological coping attempts. According to daily diary data, when children used CBT skills on days with more pain, the next day's pain intensity was reduced. It was then concluded that coping skills training using cognitive behavioral therapy (CBT) and smartphone technology can improve coping, reduce stress, and

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reduce pain severity in children with SCD; however, changes to the study protocols may be required (Pain, 2015).

Experiences in Accessing Health Care Among Adolescent's Sickle Cell Patients

Health care access is the ability to obtain healthcare services such as prevention, diagnosis, treatment, and management of diseases, illness, disorders, and other health-impacting conditions. For healthcare to be accessible it must be affordable and convenient. (Gulliford & Morgan). Many people including adolescents with sickle disease in Ghana do not have access to adequate healthcare hence are unable to live quality lives.

Kanter et al (2020) surveyed 440 sickle cell disease (SCD) adolescents and adults in Virginia, Southeast America, using 7 comprehensive programs widely recognized as leaders in SCD care. The survey results indicated "significant gaps and dissatisfaction with care, particularly in the emergency department. Patients' experiences are strongly linked to their perceptions of the quality of care. All participants expressed dissatisfaction with care for a variety of reasons, including perceived racial discrimination, access issues, and a lack of clinician confidence and knowledge in managing SCD complications, particularly pain. Furthermore, 53 percent of SCD patients who complained of discrimination more likely to disregard medical treatment and recommendations Mistrust in health-care professionals has been linked to non-adherence to medical treatment and avoidance of the emergency room in times of crisis, both of which have been linked to increased mortality. Clinician comfort with caring for SCD patients is a barrier to improving care quality, particularly in the ambulatory setting. Another survey of primary care physicians (PCPs) at Johns Hopkins Community Physicians revealed that PCPs are hesitant to care for patients with SCD.

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They are most uneasy when dealing with SCD-specific issues, such as prescribing hydroxyurea and managing pain crises. Prior experience caring for

SCD patients and knowledge gained during residency are linked to increased confidence. Patients with SCD in the United Kingdom reported in a focus group receiving poor quality care from their PCPs, owing to a perceived lack of confidence and knowledge about SCD-specific disease management, a lack of communication, and accessibility challenges Seven (7) patients still believed that their primary care physicians played an important role in their overall health management".

The United States recognized the need to invest significant resources in expanding comprehensive sickle cell centers and improving SCD self-efficacy. Efforts must be directed toward smaller communities and rural areas in order to overcome the negative impact of social determinants of health, which can be barriers to high-quality care (Oyedeji & Strouse, 2020)

A needs assessment based on pervasive disparities in the community The University of California San Francisco, Berkeley investigated the disparities in health resources and barriers to facilitators of care faced by adolescents and adults with sickle cell disease (SCD) in order to identify opportunities to support the implementation of evidence-based interventions aimed at improving care. 51 health care providers, administrators, and community-based organizers used triangulated qualitative and quantitative data from 58 adolescents and adults with SCD.

The following findings were discovered during group interviews: Insurance and a lack of resources to address pain impact were identified as concrete barriers. Adolescents and adults with SCD identified provider issues (lack of knowledge, implicit bias), transportation, and a lack of social support as barriers. Negative experiences with the healthcare system contributed to 84 percent of adolescents and adults with SCD choosing to manage severe pain at home. Providers concentrated

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on structural barriers such as a lack of access to care guidelines, comfort with and knowledge of SCD management, and poor care coordination. It was concluded that strategies for improving access to compassionate, evidence-based quality care, as well as strategies for reducing the burden of having SCD, are warranted for a medically complex population (Treadwell et al, 2019.).

According to a survey of 13 adolescents and 5 young adults in a rural community, 62% of adolescents had difficulty leaving their pediatrician. They were worried about finding an adult doctor, arranging transportation, preparing to use an adult hospital, and dealing with financial problems. They proposed services such as a transition program to provide information about adult providers, ways to take control of one's own care, and assistance in helping adult providers learn more about the disease. In a rural community, adolescents with SCD identify potential barriers to adult health care. Several barriers are similar to those reported by young adults.

Adolescents with sickle cell disease require accessible self-management interventions to better cope with their disease, improve health outcomes and health-related quality of life, and promote successful transition to adult health care services. However, there haven't been many comprehensive self-management and transitional care programs established. Internet and mobile phone technologies can increase the accessibility and acceptability of interventions to promote self-management in sickle cell disease adolescents (Eysenbach, 2018). Adolescents, parents, and health care providers described the ongoing psychosocial and stigmatization challenges that youth with sickle cell disease face. Participants saw the value in addressing some of these issues with a digital self-management tool. They suggested that "an effective digital self-management program provide appropriate sickle cell disease–related education, guidance on developing self-advocacy and communication skills, empower adolescents with information for future planning, offer options for social support, and be designed to be engaging for both adolescents and parents to

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use". A digital platform that provides these elements is an accessible and acceptable way to address adolescent self-management and transitional care needs (Kulandaivelu et al., 2018). Adolescents with SCD frequently miss clinic appointments due to competing activities involving school or peers. One adolescent stated that some participants use aids such as calendars or planners to keep track of appointments. Attendance appeared to be influenced by the adolescent's health status as well. Some focus group participants stated that they do not want to go to the clinic when they are feeling well. Participants reported that if their parents/caregivers were present, they were more likely to attend a clinic appointment. The study also discovered a number of factors related to Adolescents' interactions with the hospital system as influences on clinic attendance One of the most important factors mentioned was the relationship with providers (clinic/hospital personnel). They expressed their dissatisfaction with staff members who they felt were insufficiently trained to perform medical procedures on SCD patients. Another issue was seeing different doctors on each visit, and the providers repeatedly asking the same questions to multiple people. Adolescent patients reported difficulty understanding physician instructions and being uneasy with treatments. Patient satisfaction with care appeared to influence attendance as well. In general, comments indicated a desire for appointment scheduling flexibility (Crosby et al., 2009).

"The goals of psychosocial interventions in chronic illnesses such as SCD in the global context are to help reduce negative thoughts and feelings about the condition and to encourage the acquisition or maintenance of coping strategies. Psychological therapies, in addition to routine medical treatment, should be offered as standard care in the management of SCD, where studies of these therapies have shown encouraging results. The overall goal is to assist patients in better coping, fulfilling roles, and achieving a higher quality of life. These interventions should be age-

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appropriate and accessible in both hospital clinics and community-based settings" (Drews et al., 2010).

2.5 Existing Support Systems

Family Support System.

An investigator investigated the role of parenting and family variables in the overall coping processes of 39 sickle cell disease children and adolescents (SCD). Interviewed parents provided information about their children's health history, coping suggestions for their children, their own coping strategies, and family cohesion. Children were asked to rate their general coping strategies and their level of hope. Each of the three models of family influences tested in this study received partial support. A cohesive family environment was associated with children's active coping, and avoidance coping was predicted by less parental use of restructuring coping and more parental use of active coping strategies. This study provides evidence for the impact of parental coaching and modeling, as well as the family environment, on coping processes in children with SCD (Kliewer & Lewis, 2005).

"A study looked at the relationship between coping and family functioning and health outcomes in adolescents with SCD, taking into account sociodemographic and psychosocial risk factors. At a baseline assessment, 41 adolescents and their families (41 primary caregivers, 9 secondary caregivers, and 15 healthy siblings) completed paper-and-pencil measures of coping and family functioning (time 1). Medical file reviews were used to determine disease severity, SCD complications, healthcare utilization, and average hemoglobin level at time 1 and time 2 (1 year later). Time 1 disease-related parenting stress predicted time 2 health outcomes, but no significant associations for coping were found. Teens with increased disease severity and higher healthcare

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utilization were found in families who reported lower family functioning. Efforts should be made to investigate specific mechanisms by which adaptive family functioning contributes to health outcomes in adolescents with SCD, with a particular focus on addressing the potential role of multiple sociodemographic and psychosocial risk variables" (Barakat et al, 2007).

Another study, by Barakat et al (2008), used teen- and parent-report to clarify associations between pain, psychological adjustment, and family functioning with health-related quality of life (HRQOL) in a sample of adolescents with sickle cell disease (SCD).

"Forty-two adolescents (aged 12 to 18) with SCD and their primary caregivers completed paper-and-pencil pain, psychological adjustment, and HRQOL measures. Primary caregivers also completed a measure of disease-related parenting stress. A review of medical records determined the severity of the disease. Pearson correlations revealed significant inverse relationships between pain frequency and physical and psychosocial HRQOL domains as rated by the teen and primary caregiver. Internalizing symptoms (such as anxiety and depression) and disease-related parenting stress were also found to be significantly related to lower HRQOL. A series of regression analyses on possible mediator models confirmed that disease related parenting stress served as a mediator between pain frequency and physical and psychosocial HRQOL. Findings for mediation models involving internalizing symptoms were less consistent. Parent-rated teen depression and teen anxiety served as mediators of the association between pain frequency and HRQOL in these studies. In the context of SCD management, efforts to improve HRQOL should focus on internalizing pain symptoms as well as parenting stress" (Barakat et al., 2008).

A Family-Based Randomized Controlled Trial of Pain Intervention for Adolescents with Sickle Cell Disease determined the efficacy of a family-based cognitive-behavioral pain management intervention for adolescents with SCD, reducing pain and improving health-related variables as

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well as improving psychosocial outcomes. Each adolescent and a family support person were assigned at random to either a brief pain intervention (PAIN) (n = 27) or a disease education attention control intervention (DISEASE ED) (n = 26). At baseline (prior to randomization), post-intervention, and one-year follow-up, primary pain and health-related variables (health service use, pain coping, pain-related hindrance of goals) and secondary psychosocial outcomes (disease knowledge, disease self-efficacy, and family communication) were assessed. At either time point, there was no significant difference in outcome change by group. According to preliminary findings, comprehensive interventions that address a wide range of skills related to disease management and adolescent health concerns may be more effective in assisting teens during the healthcare transition. (Hematol, 2010).

2.6 School Support System

"Teasing and bullying are common complaints among school-aged children with SCD, according to anecdotal evidence from adolescent students aged 14 to 18 years. This was reported by 23% of the study participants. Other major psychosocial problems experienced by young people with SCD during their school years include fear of dying too soon, fear of discussing the condition with friends and teachers, embarrassment about bedwetting and reluctance to participate in school trips as a result, teasing by colleagues due to jaundice and associated discoloration of their eyes, and anger if ill-informed staff consider the child lazy and wanting to avoid school activities. Anxiety that young people with SCD experience at school may lead to the formation of a negative image of themselves, teachers, and school personnel" (Anie, Egunjobi & Akinyanju, 2010).

A researcher assessed adolescents with SCD's perceptions of school performance, SCD interference, and acceptability of educational support strategies. The relationship between school performance, SCD interference, and demographics was also investigated in order to identify

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potential risk factors. Thirty adolescents between the ages of 12 and 20 filled out demographic and SCD school performance questionnaires. Although approximately 37% of participants reported receiving special education services, more than 60% reported that SCD interfered with their academic performance. Females reported that SCD had a greater impact on their schooling than males. The study findings provide important insights into demographic risk factors and support the need for adolescents with SCD to have individualized health and educational plans.

Almost half of the participants (46.7%) reported participating in a school-sponsored extracurricular activity (e.g., sports team, band), and 16.7 percent reported participating in a school-sponsored work activity (e.g., internship, work-study job). Outside of school, 43.3 percent of participants were involved in a group activity (e.g., church youth group, sports team), 30 percent took lessons (e.g., dance, music), and 23.3 percent volunteered or performed community service. More females participate in school or community extracurricular activities. Over half of the participants agreed that educational support strategies were necessary (Crosby et al, 2016).

"On January 9, 2015, researcher advisors developed a guide to support young people with sickle cell disease at school in response to research reports indicating that schools struggle to support young people with sickle cell disease. A new law (Section 100 of the Families Act 2014) requires schools and academies to make plans to support students with medical conditions" (A guide to school policy, 2015). Schools struggle to support sickle cell patients, but the Sickle Cell Society can provide assistance and advice. "Teachers are exposed to a wide range of medical conditions, and it is unreasonable to expect them to remember the specifics of all of them." At the same time, young people with sickle cell disease dislike initiatives that highlight their differences from their peers," said Professor Simon Dyson of De Montfort University, who led the research

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team. "What was required was a policy that supported sickle cell students while remaining in the background and not overloading teachers with information."

The Guide to School Policy for Young People with Sickle Cell Disease is based on best practices and includes a template for developing an individual health care plan. It is completely free to download, print, or post on the school's website.

2.7 Health Service Support System

"Ghana is heavily reliant on international financial and technical assistance, making it difficult to implement effective and adequate services, including SCD healthcare (CIA, 2007). Understandably, the situation is different in most of Europe and the United States, where SCD screening programs are widespread on both a universal and pilot basis. SCD screening and management are governed by specific guidelines. Ghana, like most Sub-Saharan African countries, lacks a national policy, management guidelines, or national statistics on SCD, despite the fact that nearly 25% of the population, or one in every four, is a carrier and 2% of all babies born, or 20 births per 1000 live births, have a form of SCD" (Dick, 2006; OheneFrempong, 2007). So far, Ghana has begun discussions about establishing a national SCD program.

Children who live in urban and peri-urban areas are more likely to have access to better diagnostic services, which are frequently based on solubility tests, which are not sensitive enough to detect high levels of hemoglobin S. (HbS). Solubility testing is a simple test that is frequently used in clinical care laboratories in Sub-Saharan Africa to detect the presence of HbS in blood. A chemical is added to the patient's blood sample, which reduces the amount of oxygen carried by the blood. Some HbS will be present in those who carry even one sickle cell gene. These tests, however, produce inconclusive results because they do not distinguish between SCD and sickle cell trait

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(Anionwu and Atkin, 2001, American Association for Clinical Chemistry, 2006; Tshilolo et al, 2008).

"Most SCD patients in Ghana receive medical care through the existing static health facilities found within the national, regional, and district healthcare systems. Except for Accra, Kumasi, and a few public and private treatment centers in Tema, Koforidua, Agogo, and Sunyani, SCD patients are seen as general outpatients, reporting daily at health facilities. Ghana and the majority of Sub-Saharan African countries have yet to establish comprehensive SCD care services" (Okpala et al, 2002). The vast majority of these patients present to the hospital with acute illness without having been diagnosed with SCD (Orji et al, 2002). In the United Kingdom and the United States, widespread universal or selective newborn screening programs ensure early diagnosis and comprehensive management with optimal outcomes (Hilliard et al, 2004).

"SCD has not been recognized by African governments as a disease of public health importance. So far, patient care has been straightforward. Few centers provide special healthcare services for SCD patients, leaving a large proportion of affected families to attend general outpatient services in district hospitals and health centers with limited knowledge of specialist SCD care. There are few support groups to offer affected patients and families the much-needed psychosocial support. Although charismatic churches have policies for premarital testing, which raises some issues, genetic counselling services are generally lacking.

SCD education is generally lacking for the general public and within the formal education sector, leaving the population largely uninformed. Outside of the provision of health insurance schemes, which do not cover the entire population, healthcare financing is extremely limited. However, if adequately trained, public health professionals in both the public and private sectors have the potential to lead the effort to shift the current trend toward a service that provides essential

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healthcare and basic social support to SCD patients and their families. The final section of this paper proposes establishing a model for SCD provision in Africa, with a focus on Ghana" (Dennis-Antwi et al, 2007).

2.8 Community Support System

A study looked into the psychological effects of SCD in a Nigerian population. The findings support the idea that attitudes and perceptions in society have a psychosocial impact on people with SCD. According to the study's findings, "a large proportion of respondents believe that SCD as an illness that is underappreciated in society and that more awareness is needed, and that if society was more aware of people with SCD, it would be more accepting of those with the condition. As a result, appropriate psychosocial interventions must be developed in a global context. As a starting point, more public education about SCD should be provided in order to change beliefs, attitudes, and stigma. This should be followed by other interventions that are tailored to different levels and settings of access to health care. In developing countries like Nigeria, the emphasis would be on initiating basic psychosocial interventions by nonspecialized health workers in a primary care team at a Community Health Post (Level 1) or Primary Health Centre (Level 2), where psychologists or social workers are not available. This would be consistent with the World Health Organization's current priority of primary care" (Anie. 2010).

2.9 Summary of the review

The review of previous studies revealed sickle cell disease as still being the major inherited blood disorder globally. The disease has huge economic burden on countries especially sub-Saharan Africa and families. Psychosocial and health care issues remain one of the challenges facing adolescents with the disease in Africa including Ghana. In developed countries like United State of America, sickle cell disease been one the inherited health conditions that has gained recognition

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and attention by government civil societies and communities. Psychologists, social workers physicians, health centers support services are spread out and are readily available to help those living with sickle cell disease in these developed nations. Researchers have and are still carrying out investigations on the disease and to help sufferers live better lives and policies implemented for them. The United States recognized the need to invest significant resources in expanding comprehensive sickle cell centers and improving SCD self-efficacy. (Oyedeji & Strouse, 2020).

In the United Kingdom and the United States, widespread universal or selective newborn screening programs ensure early diagnosis and comprehensive management with optimal outcomes (Hilliard et al, 2004).

According to Quinn et al. (2010), the SCD population in the United States has a longer life expectancy, with over 90% of babies born with SCD reaching adulthood. essential. life expectancy, with more than 90% of babies born with SCD reaching adulthood.

However, in sub–Saharan Africa including Ghana people are now gaining awareness and health implications of sickle cell disease. Due to lack of funds and the heavy economic burden it carries governments in sub–Saharan Africa have not been able to provide adequately for the needs of adolescent with sickle cell disease. Despite the fact that this disease has a high mortality rate in Africa, little is known about it. The lack of large-scale early-life screening has been a major impediment to progress. The majority of SCD deaths in Africa are likely to occur before cases are even diagnosed (Oron et al, 2020). Only few researches have been done in Ghana on adolescents living with sickle cell disease. Psychosocial problems, challenges in accessing health care with minimal or no social support are some of their lived experiences. Over the years, SCD has been overlooked as a disease of public health significance in Ghana (Ohene-Frimpong, 2007).

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Moreover, qualitative instead of quantitative approach adopted in most of the previous study was employed in this study.

The chapters that follow present the Methods, Findings, Discussions, Conclusion and Recommendations.

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Conceptual Framework

Conceptual framework is that aspect of research process that study the subject ideas of a topic. It is an analytical tool used to make conceptual distinctions that bring together different ideas that lead to the realization of the intended objectives. It is a structure the researcher uses to best explain the natural progression of the phenomenon to be studied (Camp, 2020). It is also, a visual representation that provides a picture of the phenomenon, clearly defined relationship between different variables and their relationship to each other.

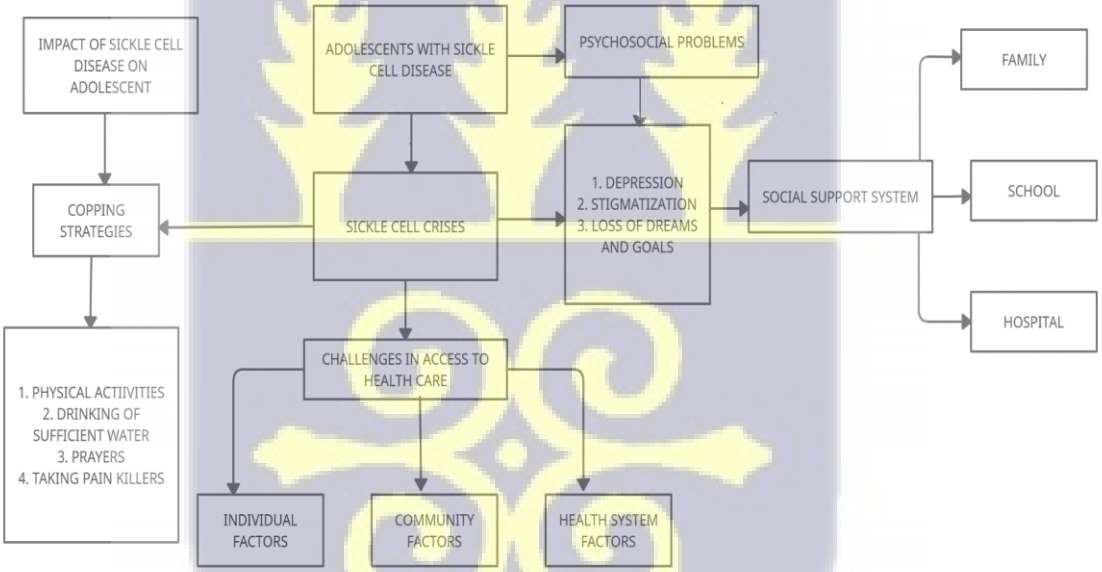

Figure 1: Experiences of Adolescents with Sickle Cell Disease Accessing Health Care at 37 Military Hospital

Authors' Conceptual Framework

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The conceptual frame work above is structural organization of the study i.e The Experiences of Adolescents with Sickle Cell. As chronic inherited condition, adolescent with sickle cell disease undergo serious psychosocial challenges of depression, stigmatization and loss of dreams and goals. There is the need therefore to establish a form of support for them in their families, schools and the hospital. The impact of the disease and frequent crises make them to develop their own coping strategies like, drinking of sufficient water, exercising, praying, and taking of pain killers. The condition also requires them to seek frequent health care in a specialized health facility but there are various factors that influence access to health care. These are; individual, community and health system factors.

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CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter presents the research methodology of the study. The chapter describes source and how data was collected. The research design and the estimation technique proposed for the study. the Population size, sampling technique used to arrive at a sample size was also justified.

Finally, the methods used for the data analysis are also thoroughly discussed.

3.2 Study Design

Philosophical Assumptions

Usually, quantitative and qualitative approaches are employed in research. The fundamental difference in these approaches depends on philosophical assumptions, According to Creswell and Poth (2018), Whether being aware, or not, always certain beliefs and philosophical assumptions shape and influence how researchers find answers to questions through information which also serve as basis of evaluation of a study. These assumptions are Ontology, which is the way researchers welcome multiple ideas of realities and report by exploring multiple realities from different people. The second is Epistemology. In this. The researchers get close contact with participants to get evidence on the views of each individual on the field. Anxiology which is the third considers both the researcher and the information gathering from the field, reporting values and biases and fourthly Methodology which are the methods used in research.

Quantitative research stems from positivism which believes in single reality and contend to only one truth (Yilmaz, 2013). While qualitative research is based on interpretivism and constructivism and believes that realities are multiple, holistic, constructed socially (Creswell & Poth, 2018;

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Yilmaz, 2013). In addition, quantitative research is deductive, explains phenomena by numerical data with well-organized data collection, test hypothesis of measurable variables by means of statistical analysis (Yilmaz, 2013).A qualitative study design was considered over quantitative for this study because in qualitative research inductive, interpretive and naturalistic approaches are used to study people cases, phenomena, social situations and processes in their natural settings (Denzin& Lincoln, 2011)It is more experiential by nature and focuses on capturing people's feelings and perspectives. It has advantages of tracking shifting views among a target group, can be used to provide context and possibly explain something that numbers alone cannot disclose. Qualitative research allows for a lot more flexibility. It provides a much more flexible approach. If useful insights are not being captured researchers can quickly adapt questions, change the setting or any other variable to improve responses. Qualitative data capture allows researchers to be far more speculative about what areas they choose to investigate and how to do so. It allows data capture to be prompted by a researcher's instinctive or 'gut feel' for where good information will be found (Vaughan, 2021).

It is therefore more convenient carrying out qualitative research on adolescents living with sickle cell disease at a setting their familiar with thus, their clinic at the 37 Military Hospital to gain insights into their lived experiences, collecting extensive data on the variables in the research topic over a period of time.

3.3 Setting

The study was conducted at 37 Pediatric Out Patient Department which takes care of children and adolescents with SCD. The 37 Pediatric Out-Patient Department runs seven special clinic including neuro, asthma, renal, HIV, NICU, and sickle cell clinics. This teaching hospital is the 37th built under the British colony in West Africa and situated about 4km from Accra International

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Airport in the Ayawaso East sub-locality in the Accra metropolis. Accra metropolis, the capital city of Ghana is an urban district and one of the five main districts in the Greater Accra region. It has a population of 1,779,165 with a population growth rate of 3.1%, the land capacity of 185km² and consists of 46.1% of the total population in the whole region making it densely populated (Ghana Statistical Service, 2010). The main ethnic groups in the district are Akans, Ga- Dangmes and Ewes with the indigenes involved in fishing and trading as the main occupation. The metropolis has a lot of schools including tertiary institutions with the premier university, University of Ghana being situated in the district. In relation to health care facilities, there are a lot of clinics, health posts, registered traditional health centers and hospitals which are either private, public or quasi-government institutions. 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 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 in post- basic nurse anesthesia, health assistants, general nursing and midwifery. The hospital also provides postgraduate residency programs 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 pediatric outpatient department. Admissions SCD patients are done from the emergency unit or the Sickle Cell clinic into the pediatric ward of the facility.

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3.4 Study Population

The population of the study included all adolescents by WHO's definition (10 – 19 years) attending sickle cell clinic at 37 Military Hospital. An estimated number of about 540 adolescents comprising males and females with SCD are presently accessing routine care at the 37 Military Hospital.

3.5 Inclusion Criteria

All adolescents aged between 10 years and 19 years who access health care at 37 Military Hospital and who were present during the period of data collection.

3.6 Exclusion Criteria

All children below the age of 10 years accessing health care at 37 Military Hospital present or not during the period of data collection including adolescents who were not willing to participate.

their routine visit, were

3.7 Sample Size

This study used the convenience sampling approach to select participants (male & female) between the ages of 10 years and 19 years (WHO definition of adolescent) for the qualitative study. Convenience sampling is collecting samples that are conveniently located around a location (Edgar, 2017). This approach was used because there is only one clinic day in a week. The respondents were selected as they came for their routine visit, were available and agreed voluntarily to participate in the study. In qualitative study, the sample size is guided by data saturation in which no new information is discovered, and this redundancy signals to researchers that data collection may cease (Faulkner, Stormy & Trotter, 2017). Saturation also means that a researcher can be reasonably assured that further data collection would yield similar results and

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serve to confirm emerging themes and conclusions. When researchers can claim that they have collected enough data to achieve their research objectives. Data collection will stop at any time when saturation is reached. In this study, saturation was reached with 25 respondents.

3.8 Quality Assurance

The researcher maintains quality assurance by ensuring that the research data and reports are accurate, complete and transparent. This allows for reconstruction and reproduction throughout the study.

3.9 Selection of Study Participants

Mostly, it is good for qualitative study like interviews to start with 5 participants and then increase by a further 5 based on how complicated the subject matter is. It may also be helpful to add additional participants especially, in new to user research (Renwick, 2018). In this study the researcher targeted Sickle cell clinic days and adolescents who were at the clinic during the period of the study were identified. The purpose of the study and procedure explained to them and their parents. Those who were willing to participate in the study were recruited. The interview process stopped when saturation was attained. In all, 25 adolescents (13 males and 12 females) living with sickle cell disease who were capable of producing useful information for the study participated in the study. Before the interview began, permission was given to them to freely opt out from the study anytime they so wished.

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3.10 Instrumentation

The interview guide was designed to collect data on the demographic information of participants, seeks information concerning lived experiences and copping strategies of SCD among adolescents, relevant support systems in the family, schools and the hospital for adolescents with SCD and assess the accessibility to health care.

3.11 Data Collection

After ethical approval, the nurse In-charge of the Sickle Clinic was informed and permission was granted. The researcher introduced herself to the participants and their parents and purpose of the study explained to them. The researcher lead in all data collection processes. However, field assistants including nurses, students, and rotation nurses were trained to assist in data collection. In-depth interviews were conducted on a one-on-one basis for 25 respondents. In-depth interview was used to enable the participants to feel more comfortable in order to bring out insightful responses. In addition, there is a chance of asking follow up questions and probe for more information. Overall, each interview lasted for 30-40 minutes. The first part was the. All relevant information of the interviews were audio-recorded using a digital recording device.

3.12 Data Entry and Processing

Research data management is concerned with organization, storage, preservation, and sharing of data collected and used in a research project. It involves the daily management of research data during the lifetime of a research project. It also involves decisions about how data will be preserved and shared after the project is completed (Surkis, 2015). Data gathered were transcribed. Back translation was also ensured for purposes of quality control of the data. Field notes taken during the interview were incorporated during transcription of the data. Pseudonyms were given to the participants based on their sex and numerical entry into the study such as M1F1 whereby

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'M1' represented the first male participant interviewed whiles 'F1' also represented the first female participant interviewed. 'M13' was the last male participant while 'F12' was the last female participant interviewed. Soft copies of the transcribed data were kept on a computer protected by a password known to the researcher alone. Other documents such as the consent forms that had identifiable information about participants were kept separately from the transcribed data. Hard copies of the transcribed data and other documents such as the consent form and field diaries were separately kept from other documents in a locked cabinet accessible to only the researcher and her supervisors.

3.13 Data Analyses

Raw data gathered from the field were analyzed immediately, following the interview. Data gathered from participants were transcribed verbatim and analyzed using thematic content analysis.

The goal of content analysis, is how the researcher seeks to understand the full context of how humans think, feel, or behave and why. The investigator creates content categories during content analysis to guide their coding process. Each content category represents an idea, behavior, or attitude relevant to the research question. The investigator then combs through the text, coding specific words relevant to each content category, to examine conceptual meanings and/or looks for patterns of occurrence. The investigator also explores how two or more concepts relate to one another within each text sample and develop a narrower research question so that no concept could be reinterpreted by others (Reis, 2021). On the other hand,

Thematic analysis is a qualitative data analysis that is defined as a method that involves reading through a data set such as transcripts from in depth interviews or focus groups, and identifying

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patterns in meaning across the data to derive themes. Thematic analysis involves an active process of reflexivity, where a researcher's subjective experience plays a central role in meaning making from data. (Braun & Clarke, 2021).

The researcher was involved in active reading repeatedly of the data collected which helped in familiarization and identification of patterns and meanings embedded in the data, noting down initial ideas. Interested segments in the data were systematically arranged and used to develop initial codes and collated the specific aspects of the data that was related to it. Using tables, all the relevant codes were collated and similar codes merged into broader themes. Individual themes were reviewed in relation to their coded extracts and the entire data set to generate new themes with various subthemes. The themes were defined and clarified to achieve coherence and to identify the narrative in the raw data that the theme conveyed. This revealed the essence of the theme in relation to the raw data. The narrative within the themes which were clear in relation to the research questions were analyzed and was used to produce a scholarly report.

3.14 Methodological Rigor

Any study's value lies in maintaining its credibility, which is attained by the research' dependability, dependability, dependability, and confirmability (Lincoln & Guba, 1985) Establishing whether or if the research findings represent trustworthy information gleaned from the participants' initial viewpoint or are an appropriate interpretation is known as credibility. (Graneheim & Lundman, 2004; Lincoln & Guba, 1985; Anney, 2014). e study findings determining whether or if the research findings are an adequate representation of information that was originally acquired from the participants' perspective. The researcher made sure that the inclusion criteria were rigorously followed for all study participants in order to achieve this goal. Furthermore, credibility was assured by formulating and posing questions that led to participants'

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giving the appropriate answers. To encourage them to freely provide information without any fear, participants were given the assurance that confidentiality would be preserved during the whole procedure

Member checks, in which interpreted replies were addressed with participants to prevent informa tion being reported incorrectly, were used to eliminate researcher biases.

The researcher and the primary supervisor independently coded some of the transcribed data in o rder to spot any discrepancies and then talked to come to a consensus. The researcher ensured external validity by thoroughly outlining the participants, background, and study conditions. Additionally, every step of the research process—including participant selection, data collecting, study settings, and final report—has been fully described. The researcher chose volunteers who were knowledgeable about the topic under investigation using the convenience sample approach. All of these initiatives will make it easier to replicate the findings.

Dependability of data gathered was ensured by using the same interview guide for all participants. The researcher also employed a code-recoding strategy whereby the same information gathered was coded twice with two weeks interval and the results compared to identify differences and similarities. To achieve confirmability, the researcher ensured that audiotaped information was transcribed verbatim. The researcher created an audit trail and decisions taken throughout the process of the study were explicitly outlined. The researcher also kept a reflexive journal which bracketed all her perceptions, experiences and opinions about the topic under study

3.15 Ethical Consideration

Ethical approval was obtained from Institutional Review Board of the 37 Military Hospital Ref. Number- 37MH-IRB/IPN/539/2021, to seek formal permission for the study to be carried out. Informed consent was sought from the parents of the respondents less than 18years and those of

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18years and above before the questionnaire administered to them. Before the interview began, the purpose of the study was explained to them. It was explained to them that the findings of the study will help improve care however there could be the risk of them going through some minor emotional state that could be resolved by reassurance. Permission was given to them to freely opt out from the study anytime they so wished. Consent forms were given to the participants to sign only when they agreed to take part in the study. Names of participants were not used on the data forms to maintain anonymity but rather codes were generated based on demographic information gathered. Privacy and confidentiality were maintained by interviewing one participant at a time in an enclosed room. Each one of the participants was thanked and given fruit juice as a form of compensation after the interview. COVID-19 safety protocols were ensured by wearing face mask by both the interviewer and the interviewee with maintaining of social distance. Data would be stored for five years and be destroyed.

Chapter three had helped us to successfully collect data after permission had been granted by Military hospital Institutional Review Board. The data collected was managed, analyzed and the following chapter reveals the results.

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CHAPTER FOUR

RESULTS

4.1 Introduction

The chapter four presents the results of the study based on the study. First, results from the demographics of the respondents used for the study are presented vis-à-vis the rate of SCD prevalence in 37 Military Hospital of Ghana. The remaining sections reports findings on the experiences of SCD patients, challenges faced by adolescents in accessing health, finally support systems necessary for people living with SCD patients and measures to improve access to care and overall quality of life of adolescents living with SCD.

4.2 Demographic Characteristics of Study Participants

The study recruited and interviewed an overall total number of 25 adolescent living with sickle cell diseases. Most (52%) of them were within the age range of 16-20 years and the rest (48%) are between 10-15 years. Table 1 presents some demographics of the respondents of the study. It presents demographics in terms of gender distribution, religion, level of education, occupation of parents and genotype distribution of the respondents of the study.

Table 1: Demographic characteristics of study participants

Characteristic	Frequency (N= 25)
Age	
10 – 15	12
16 – 20	13

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Sex	
Male	13
Female	12
Religion	
Christian	20
Muslim	5
Traditional	0
Others	0
Level of education	
Primary	4
JHS	7
SHS	8
Tertiary	6
Genotype	
SS	16
SC	9
Parents / Care givers occupation	
Soldier	6
Trader	11
Businessman/woman	8
Teacher	3
Driver	5
Others	17

4.3 Summary of Study Findings

The study reported five thematic domains of the lived experiences of sickle cell diseases among adolescents at the 37 Military Hospital and these comprised a) Experiences of adolescents living with sickle cell disease, b) challenges associated with access to health care, c) availability of social support systems d) coping strategies adopted by adolescents living with SCD and e) Measures and strategies to improve access to care and quality of life. A total of 19 sub-themes were generated from the major themes as with relevant quotes identified to support and emphasize the relevant points from participants during the in-depth interviews.

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4.4 Experiences of Living with Sickle Cell Disease

A synthesis of the results revealed that the adolescents living with sickle cell diseases has diverse experiences from the condition and this has impacted them differently. Three subthemes were identified which characterizes adolescents' experiences and the impact of the sickle diseases in their lives namely a) Psychological impact, b) Having a sickle cell crisis and episodes and c) stigmatization by colleagues/friends.

Sub-theme 1: Psychological impact

One of the most predominant experiences and impact of the sickle cell disease according to most adolescents was the impact on their psychosocial life. This was recounted by many adolescents with sickle cell as quite debilitating, devasting and depressing. This is often characterized by feeling of depression, emotional trauma, anxiety and dejection especially in crisis moments. According to the study participants, these experiences define the everyday realities of adolescents living with sickle cell conditions. The following quotes below exemplifies the accounts and experiences of some adolescents living with a sickle cell disease.

"I feel sad sometimes but there is nothing I can do about it (Female, Age:13)"

Another male participant with sickle cell disease also shared his experiences of living with the condition in the following accounts below

"It's sometimes hurt when you are not a healthier person, but I know everything will be fine. I do not feel bad or good. I am okay with myself (Male, Age 15)"

Sub-theme 2: Having a sickle cell crisis and episodes

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Pain crises is an extreme episode of periodic pain those living with sickle cell disease experience when the sickle shaped red cells blocked the tiny blood vessels carrying oxygen to joints or the abdomen chest. Crises are the major symptoms experienced by those living with sickle cell disease. Adolescents in this study recounted moments of such crisis and episodes which come with different and multiple experiences of pain and disorientation. The accounts of a male adolescents in the study had this to say:

> *"I have pains sometimes weekly and others monthly, and mostly chest pain and burning in the brain …… within a year, I usually have crises between 7 to 15 times. I mostly have Stomach pain and sometimes shortage of blood…… (Male, Age: 14)"*

Sub-theme 3: Stigmatization experiences.

Just like any chronic disease, those living with sickle cell disease are faced with stigmatization due to many challenges including stunted growth, discoloration of eyes, and frequent ill heath among others. These experiences according to the adolescents exposes them to series of ill treatment, discrimination and stigmatization at home, at the community level, in schools and sometimes at the point of accessing healthcare. The following were recorded from some of the respondents during the interview.

> *"Some of my classmates call me yellow eyes and don't like me to come closer to them, so I don't mingle with them. When I come close to them, they'll be like I'll give them my disease. so, I should go back. But my friends among them are friendly and they all like me. (Female, Age: 13) "*

Some participants admitted that experiences of unfair treatment or stigmatizing remarks from peers are sometimes done out of ignorance. Whilst some participants opined some of their friends

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deliberately make derogatory or demeaning remarks about their condition, some shared a contrary view by stating some remarks by their peers were done out of ignorance without any malicious intention. The commentary below from one participant supports this position.

> *"Yes, sometimes they [friends] ask too many questions especially the ones who don't know my condition. They will ask; why are your eyes yellow? why don't you have body and all?*
> *(Male, Age: 18)"*

Sub-theme 4: Loss of Dream/Goals in Life

An emergent theme from the analysis of interviews was participants constant refrain of losing their ambitions, goals and dreams in life due to their sickle cell condition. According to participants, the often feel the constant feeing of sickness, admissions and hospitalizations, absenteeism from school pose a major obstruction to their quest to attain their set goals in life. For example, one adolescent narrated that,

> *"...growing up I had big dreams, goals and was quite ambitious of being successful in life but later the realities of life as a sickle cell patient altered every dream and goal I had. The constant absenteeism, hospitalizations affected my performance in school and this has made me realize those dreams and ambitions are not far and not within my reach anymore.*
> *(Female, Age: 15)"*

4.5 Challenges Associated with Access to Health Care as an Adolescent Sickle Cell Patient.

Adolescents with sickle cell disease face unsurmountable challenges in accessing care. This sub theme explores the challenges adolescents or families go through to access health care. These

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challenges were influenced by factors at the individual, family/community, health service access/setting,

Sub-theme 1: Individual level factors

Most adolescents in Ghana live with their parents for that matter they are not independent to take decisions on their own concerning their health issues. Adolescents over the years have expressed their dissatisfaction in access to care. Some which are limited appointment (sickle cell clinic runs only on Thursdays at the 37 Military Hospital) with transportation issue, nonavailability of doctors missing classes and exams to meet hospital appointments which later on affect their academic performance. This is how some of them expressed it.

Respondents who also had trouble with distance and long queues at the hospital had this to say.

"*Sure! We must wake up early to beat the traffic, long queues in the hospitals. Sometime when I am in the hospital, my friends may be writing exams. I don't get the chance to write some (Male, Age: 14)".*

"*Sometimes, waking up early to bath and sometimes I must come early even sleeping in the car before we get to the hospital and missing school too and lesson going on so when I go and tell them they should teach me what they learnt. They will be like they won't give it to me because I have yellow eyes. Also, whenever I have blood transfusion replace of the blood is always a problem (Female, Age: 13)".*

Sub-theme 2: Family/community factors

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Most families in Ghana live with economic difficulties with low-income and taking care of sickle cell adolescent is an extra burden on families The high cost of drugs and laboratory charges are even a burden on the average income earner. Moreover, National Health Insurance Scheme does not cover treatment of sickle cell disease and specialist clinics are all centered far away from their communities. Caregivers pay high transportation fairs and absent themselves from work to accompany their children to the hospital, below are the way some of them react to the situation.

"*Sometimes, my father says he doesn't have money to give to mother for us to come but my mother tries to get some money for us to come (Female, Age: 12)".*

"*Sometimes too if my mum has no money to bring me, I miss my appointment and the nurses are not happy (Female, Age: 13)".*

Sub-theme 3: Healthcare providers

Due to inadequate health professionals, sickle cell patients always have to share their clinics with other patients, causing stress due to work overload on healthcare providers. Doctors are sometimes not available, and sometimes are not able to listen and provide adequate care to their clients due to the huge number of clients they have to attend to non-availability of funds also makes It difficult for them to enjoy the support they need from providers. Some had this to say about the situation. These respondents shared what they experienced sometimes when they come to the hospital.

"*Sometimes there is no doctor but the nurses are always there (Female, Age: 12)".*

"*Sometimes they keep long to see us. We have to wait for long before they come. They will just tell us they are from a meeting (Female, Age: 10)".*

Sub-theme 4: Health service access/setting

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Only few health facilities in Ghana have comprehensive sickle cell service with specialist who are dedicated to attend to these patients. This makes clients travel from far communities with poor road network to seek health care at 37 Military Hospital. Other challenges are small space to accommodate the patients that visit the hospital, delay in getting laboratory results and taking drugs from the pharmacy. Some responded to what they go through in terms of access and setting in the hospital.

"*Sometimes the lab doesn't get ready on time. So, we must go back and come on another week. This is our third week here. Third time this month. Distance - I stay at Hohoe mainly but to access good healthcare I have to come to 37 Hospital in Accra. Traveling for long distance. A hospital with good facilities is not near my house (Male, Age:12)".*

4.6 Social Support Systems for Adolescent Living with Sickle Cell Diseases

With the disease, that causes extremely painful moments, depression and anxiety, social support is a necessity for those with SCD to enjoy quality of life. This study also explored available supports for adolescents living with SCD. The sub-themes on available support systems were identified at the families, hospital and schools.

Sub-theme 1: Family

Good and strong family support between immediate or extended family members create sense of belongingness, helps in times of difficulties and helps meet personal and social needs. The contribution of family members/caregivers to their children contributes to better coping mechanisms and good outcome of the health condition. Care givers supports give satisfaction and build confidence in the children to face the future without fear. This what some adolescents in the study had to say.

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"*They encourage me and make me understand my condition. They let me feel that I can still achieve many things. They make me believe in myself (Male, Age: 12)".*

"*My mother takes care of me very well. She gives me my medications all the time and everything I ask her she gives it to me. She even doesn't allow me to work a lot (Female, Age: 12)".*

Sub-theme 2: Hospital

Due to the nature of the disease, there are several interventions put in place by hospitals like management of emergencies, routine visit care, new born screening, counselling and forming of support groups and others to improve the health of adolescents living with sickle cell. The counselling, care of the doctors and nurses combined with other forms of kind treatment they receive from 37 Military Hospital encourage them. Below are the acknowledgements expressed by the respondents.

"The health workers also teach me to rest well, take my medicine on time, eat well, drink water and come to the hospital. The hospital accepts health insurance for only consultation and free hydroxyurea from Novartis (Male, Age: 12)".

"They do everything possible to take care of us. They take our temperatures and when you have pain crisis, they make sure to give you medication that can bring the pain down.

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Sometimes they tell stories, they give balloons. They give advice on your schooling (Female, Age: 10)".

Sub-theme 3: School

The anxieties and depression that school children with sickle cell disease experience may develop negative image of themselves and their teachers. Teachers are also faced with many different medical conditions of other children and might not remember details of how to cater for those living with sickle cell disease. According to the study, some of the teachers and friends who have been informed by care givers about their wards' conditions are able to help with the lessons they miss and some teachers make another time for them to write missed examinations due to hospitalizations.

"Sometimes I missed school, but my friend stays nearby so when I don't go to school, I ask her to teach me what they were taught that day, sometimes my teacher also helps me (Female, Age: 11)".

"For my teacher and friends, I usually tell them on Wednesday that I will go for review on Thursday, so if there is any test, they let me write another day when I come back from the hospital (Male, Age: 13)".

4.7 Coping Strategies Adopted by Adolescents Living with Sickle Cell Disease

Living with sickle cell disease through childhood to adolescence is not without challenges so adolescents have devised different ways of responding to their chronic illness. Some positively and others negatively or both in some of them. Adolescents accessing health care at the 37 Military

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Hospital use the strategies like physical activity, drinking of water, prayers and taking of painkillers to cope with their ill health.

Sub-theme 1: Physical activity

Physical exercise is regular exercise of all kinds that is known to improve or add to good health at all ages. It has been revealed that heavy exercises are not recommended for people living with sickle cell disease because it alters their patho-physiological mechanism (it triggers sickle cell crisis). Intense activities that cause breathlessness is avoided; however low intense regular physical exercise controlled by a physician may be beneficial to those having SCD. This is how some adolescents attending clinic at 37 Military Hospital cope with the disease through physical exercise.

"On Fridays at school, we do P.E [Physical education] and we usually exercise our body (Female, Age: 10)".

"*I exercise myself by working sometimes I drink water and I also eat (Female, Age: 12)".*

Sub-theme2: Drinking of sufficient water

A distinguishing characteristic of sickle cell disease is cell dehydration. When those with sickle cell disease are not well hydrated the red blood cells clump together and cause sickle cell crisis. Drinking of sufficient water on a daily base is one of the recommendations of those living with sickle cell disease. Below is the account of one adolescent on the drinking of water to cope with the disease.

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"I drink water a lot, take my drugs and avoid cold and stress (Female, Age: 14)".

"*I drink water. I wear sweater when the weather is cold and trousers to prevent mosquito bites and go for short walks outside (Male, Age: 13)".*

"*Okay erm […] normally, I work out in the house and, I drink a lot of water [at least 6 to 8 sachets a day] (Male, Age: 15)".*

Sub-theme 3: Prayers

Adolescents with SCD believe that God is able to deliver, protect and heal them of every sickness. Some sickle cell patients and their caregivers also have this believe and practice as they cope with their ill health. This was a common coping strategy among most adolescents in the study. One adolescent had this to say:

"I pray all the time especially when I am in crisis. I even tell my parents and they pray for me to (Male, Age: 11)".

Sub-theme 4: Taking of pain killers

The common problem for people with sickle cell disease is pain when the sickled red blood cells blocked blood flow in the small vessels. According to adolescents, the SCD episode often affects lower backs legs, arms, chest, and belly and can be sudden or chronic. According to them, mild pains are usually managed at home with painkillers. It is a routine thing we do as one of the most reliable ways of coping with the pain associated with living with SCD. Below are some revelations about how some adolescents in the study use pain killers as coping mechanism.

"I take pain meds and use a warm towel to massage the area, and hot balms or spray (Male, Age: 16)".

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" I normally come to the hospital or take some painkillers [Brufen] (Female, Age: 13)".

"I tell my grandfather or my grandmother [grandparents] and they will give me paracetamol and my grandmother will say go and drink […] water. And when I do that, it goes (Female, Age: 13)".

Sub-theme 5: Self-Management

Self-management of SCD was also common among adolescents as a way of coping with the condition. According to them, the pain during the time of crisis is severe and therefore there will be a need to visit the hospital. Other times, the pain is mild and some basic domestic techniques can be used to reduce the pain. They believe self-management doesn't only deal with pain in crisis but also the mental state of the patients and what they go through as individuals having sickle cell disease. This is what some respondents had to say about self-management.

"Even when I am in pain, I try to behave normally, like walking on my painful leg normal like there is no pain but I'm hurting. I also try to have enough rest (Male, Age: 16)".

"Sometimes when I feel the pain, I just slide on bed, lie back on the and the pain keeps coming. Sometimes my mom gets hot water and places on the parts I'm feeling the pain (Male, Age: 13)".

4.8 Measures and Strategies to Improve Access to Care and Quality of Life

In the study, the views of the respondents were sought about the strategies government can use to improve access to care and life of sickle cell patients. Adolescents shared their views on what

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needs to be done to improve their lives and access to healthcare. The key measures and recommendations included a) the need to have specialized health center in communities, b) education on awareness of sickle cell disease and c) subsidizing the cost of drugs and expense.

Sub-theme 1: Specialized Health centers in communities

Health centers in Ghana do not provide specialized care. This makes it difficult for those living with sickle cell to seek help at the health centers in their communities. Comprehensive Sickle cell services are few and the clinics are located in urban areas only. Adolescents suggested the establishment of specialized clinics spread over the country for easy access. Below are some of the wishes of the respondents.

> *"I think it's still not getting the attention it deserves. The government needs to invest more in providing the appropriate facilities nationwide for easy access (Male, Age: 18)".*

> "*The government should create more public centers so that treatments and hospital visits for us would be easily accessible (Male, Age: 17)".*

Sub-theme 2: Education on awareness of sickle cell disease

Another key revelation by adolescents was the need to create public education about SCD and ways of preventing this. In their view, this is currently inadequate and that could be a plausible reason why their parents put them in this situation They expressed their view about how majority of the population is ignorant about sickle cell disease. They expect the government to do more educating on the disease for people to be aware and know their sickle cell status getting married This will make them stop stigmatizing them. This is an account of one adolescent in the study.

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"My suggestions to the government and hospitals are that there should be more education on the importance of checking your genotype before childbirth or marriage and also, they should provide free health care and medicine for the less privileged people living with sickle cell (Female, Age: 17)".

Sub-theme 3: Subsidizing the cost of drugs and laboratory expenses

People living with sickle cell disease are faced with numerous challenges in managing their condition. Often, treatments start from childhood and continue through lifetime, causing undue financial burden on the patient and their families. The study showed that adolescents faced financial challenges in accessing healthcare. According to them, sickle cell disease is one of the health conditions that is not fully covered and parents spend a lot of money buying their drugs and paying for laboratory services and other hospital bills. The respondents the wish cost of drugs, laboratory and other hospital charges be subsidized or made free of charge. These are some of their suggestions.

"*And also, the government should drastically subsidize the price of our medications, if possible, many of them should be free just like they do for HIV patients (Male, Age: 18)".*

"*The government should help the patients with their bills, they should also get the hospital more equipment for their work. Yeah, they should be a special time for adolescents SCD to relax them (Male, Age: 19)".*

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In summary, the findings revealed various lived experiences of adolescents living with sickle cell disease. The demographic characteristics of the participants showed all of them were enrolled in school (primary, junior high, senior high schools and tertiary institution). More hemoglobin S than hemoglobin SC. The parents of all the respondents are employed with most of them self-employed. The lived experiences of adolescents with sickle cell disease were explored using in-depth interviews. 19 sub themes were generated from 5 major themes of the narratives which were; a) Experiences of adolescents living with sickle cell disease, b) challenges associated with access to health care, c) availability of social support systems d) coping strategies adopted by adolescents living with SCD and e) Measures and strategies to improve access to care and quality of life.

In all, the findings revealed various negative psychosocial, physical and economic impacts on adolescents living with sickle cell disease. In addition, there are challenges in accessing health care in their communities and districts. Apart from good support from their families, school, community and health care support systems are inadequate. Various suggestions were made by the respondents on how they felt they could be supported by government to improve their condition.

The next chapter discusses the findings in relation to the specific objectives.

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CHAPTER FIVE

DISCUSSION

5.1 Introduction

This chapter discusses the findings in relation to the existing literature on some of the experiences adolescents with sickle cell disease go through, their challenges in accessing health care, the existing support system available for them and their views on how government will improve their care at 37 Military Hospital. The chapter also discusses the implication of the study findings for policy, research and clinical practice.

5.2 Overview of Key Findings

This study sought to explore the experiences of sickle cell disease among adolescents at 37 Military hospitals. The study revealed that living with SCD is a whole life experience, they expressed feelings of depression, rejection and stigmatization from friends but are hopeful to meet their goals in future apart from one respondent who doubts achieving her dream. Some of them expressed the ignorance of their parent on the existence of sickle cell disease that has put them in this situation. Few of them felt they were okay since there is nothing they can do, and some also stated they have good relationships with their peers. The findings again indicate that the respondents have developed their own ways of coping with the disease condition. They include, drinking sufficient water, eating well balanced diet, eating fruits and vegetable and physical exercise as some routine activities to keep them healthy. Applying "hot balm" and taking painkillers and lying down are some of the pain management strategies adopted by some.

The study found that comprehensive sickle cell clinics are not located in the district hospitals in Ghana, so the patients normally travel long distances which in itself exposes them to more danger

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(road traffic accidents). They miss classes and exams to meet appointments with their doctors which might be the cause of poor performance in school as recorded by some researchers and their parents absent themselves from work to accompany them to hospital. Moreover, non-availability of physicians, makes queues long and almost the whole day is spent in the hospitals. In addition, inadequate insurance coverage resulting in high cost of drugs and laboratory expenses make access to health care cumbersome to these adolescents and their parents. All the respondents suggested improvement in the care of sickle cell patients. They are specifically concerned about cost of hospital care and wished national Health Insurance cover their hospital expenses. They also want government to publicize awareness of sickle cell disease and encourage people to check and know their genotype before getting married and stop stigmatization. They also want more sickle cell centers to be established in the country to prevent traveling long distances to access health care.

5.3 Findings compared to previous literature

5.3.1 Lived experiences of sickle cell disease among adolescents

This study reveals that most of the respondents were unhappy with their conditions with some even suffer rejection from their friends for having "yellow eyes" and thin arms and legs.

Some of them expressed the ignorance of their parent on existence of sickle cell disease that has put them in this situation Since this is becoming a concern of Public Health, there will be a need to intensify education of the public on the awareness of sickle cell disease. Premarital test for genotype should be encouraged in families, churches, and mosques. The findings support the results of a study done in Nigeria to explore the psychosocial impact of SCD in Nigerian population which revealed majority of the participants thought that society in general had a negative image of SCD, and negative perceptions and attitudes especially (Anie et al, 2010) However, the results also showed that depressive feelings were experienced in almost half the

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study population. Few of them felt they were okay since there is nothing they can do, and some also stated they have good relationships with their peers.

Findings from this study suggest increased level of depression and rejection among adolescents living with sickle cell disease. The involvement of psychologists and social workers in the management of adolescents living with sickle cell disease is highly recommended. The study however showed positive attitude by majority of the respondents toward life as they were, however, hopeful to achieve their life visions despite one of them thought otherwise.

The findings again indicates that the respondents have developed their own ways of coping with the disease condition. They include, drinking sufficient water, eating well balanced diet, eating fruits and vegetable and physical exercise as some routine activities to keep them healthy. Applying "hot balm" and taking painkillers and lying down are some of their pain management strategies adopted by some. Kliewer & Lewis examined the contribution of parenting and family variables to the general coping processes of 39 children and adolescents with sickle cell disease (SCD). In home interviews, parents gave out their children's health history, the coping suggestions they make to their children, their own coping strategies, and family cohesion. Children rated their general coping strategies and level of hope. Children's hope was positively associated with active coping suggestions by parents. Children's active coping was associated with a cohesive family environment, and avoidance coping was predicted by less parental use of restructuring coping and greater parental use of active coping strategies. Together, the study provided evidence for the influence of parental coaching and modelling and the family environment on coping processes in children with SCD (Kliewer & Lewis, 2005). This might confirm the findings of this study at the where the respondents developed and maintained their own copping strategies because the majority of them live with their parents who have influence in their care.

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A similar study done on "The lived experiences of adolescents with sickle cell disease" in Kingston, Jamaica, revealed that majority of the participants reported a positive self-esteem during the interviews. Three participants emphatically stated that they did not feel different from others. They felt good about themselves in the presence of SCD. Female participants were highly anxious due to delayed menarche. Some participants also expressed feelings of frustration, sadness, and depression, especially during periods of painful crises. The same findings for male and female participants. All participants expressed the need to stay healthy to prevent painful crises and complications of SCD. Health maintenance strategies included some social activity avoidance and specific dress codes. They believed that adhering to medical and dietary regimes help improved their condition and prolonged their lives. One participant exclaimed: "I make sure I have all my medication, drink a lot of water, eat right, and ensure that I exercise, keep fit, and get my normal check-ups." Prayer and spiritual activities were major coping strategies for the respondents. They reportedly believed in God and prayed often, especially when there was an exacerbation of their conditions. They participated in spiritual activities such as fasting and going to church for prayer meetings (Forrester et al., 2015).

5.4 Experiences in Accessing Health Care

This objective seeks to understand the challenges the sickle cell adolescents undergo in accessing health care.

Historically, through the initiative of Dr FID Konotey-Ahulu in the 1960s, the first comprehensive SCD program was established at Korle Bu Teaching Hospital in Accra to provide specialist care for all patient's country-wide. This program eventually progressed to become the Institute of Clinical Genetics in 1974 (Denise-Antwi, 2007). Until 1992, the facility in Accra was the only one established to cater for the healthcare needs of SCD patients. In the majority of Ghanaian children

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and those in other African states. SCD diagnosis is often delayed and made only after several visits to the hospital or clinic with acute illness, rather than as an early diagnosis through neonatal screening (Ohene-Frempong and Nkrumah, 1994). Children who are fortunate to be living in urban and peri-urban communities are those who are likely to have access to better diagnostic services which are often based on solubility tests, though these are not sensitive enough to detect high levels of hemoglobin S.

Improving the Quality of Care for Adolescents and Adults with Sickle Cell Disease in relation to how World Health Organization defines quality of care as "the extent to which health care services provided to individuals and patient populations improve desired health outcomes." To achieve this quality, the health care must be safe, effective, timely, efficient, equitable, and cantered on people (WHO, 2018). The study revealed that most of the respondents have some challenges at the health facilities. This include but not limited to not having enough logistics such as chairs to sit on which leads to some standing for long hours in long queues even in their conditions. Others also include nearness to health care facilities that deal with sickle cell patients.

Some of them indicated that they were at times discouraged to come for regular reviews due to the challenges they faced in accessing health care. This confirmed the findings of Some researchers who found that sickle cell patients face difficulty in accessing health care which deters some of them from regular check-ups (Meyiwa, 2019). Since this is becoming a concern of Public Health, there will be a need to get more investment in to health facilities to prevent patients from traveling from far distances to access health care. This investment should also include provision of conducive environment to encourage patients to visit the facilities for health care such as enough doctors, logistics such as chairs and also measures to reducing the crowding. Since sickle cell crisis occurs suddenly, it is suggested that the district hospitals will be well equipped with more

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trained professionals in handling sickle cell routine and emergency services to prevent more disasters. National Insurance should extend coverage to more health care services like medicines and laboratory charges.

A survey of 440 adolescents and adults with sickle cell disease (SCD) in Virginia, Southeast America through 7 comprehensive programs widely recognized as leaders in the care of people with SCD. The results of the survey suggested significant gaps and dissatisfaction with care, especially in the emergency department. The experiences of patients have a strong association with the perception of quality of care. All the participants reported dissatisfaction with care for reasons such as perceived racial discrimination, difficulties with access, and lack of clinician confidence and knowledge in managing SCD complications. In addition, mistrust in health care professionals has been the cause of nonadherence to medical treatment and avoidance of the emergency room when in crisis were associated with increased mortality (Kanter et al, 2020). Although dissatisfaction of care was reported at 37 Military Hospital, there was no record of racial discrimination, mistrust in health care professionals were reported. The main challenges reported by the majority of the respondents were inadequate sickle cell centers and high cost of medical expenses. This confirms the findings of a total of 20 studies in 10 countries between January 2014 to June 2019 on economic burden and healthcare resource utilization which revealed a total direct annual cost ranged from USD (United State Dollar) 1 million to USD 3 million and the average indirect cost was found to be USD 1,293 million in the related care is negligible (Naik, Bagga & Senecai, 2019). In Congo only 60% of essential medicine are available in the public pharmacies. The cost of other medicines and laboratory investigations are bore by relatives (Ngolet, 2016). This is similar to the situation in Ghana where sickie cell disease is not fully covered by the insurance scheme. There is therefore the need to establish more well-equipped comprehensive

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sickle cell clinics in the country by the government and give full coverage of health insurance to adolescents with sickle cell disease to continue routine and lifelong comprehensive care needed to treat serious complications.

5.5 Existing Support Systems

This objective seeks to identify the kind of support adolescent sickle cell patients receive from family, school etc. to enable live a normal life. The study reveals that most of respondents receive all forms of support systems from family and school to enable them live normal life in their conditions. Some of these include but not limited to where family provide necessary care and support such as medications and good nutrition's to keep the patients' healthy at all times. Some of them expressed the support they receive families as "They encourage me and make me understand my condition. They let me feel that I can still achieve many things. They make me believe in myself" (Female, Age: 15). My mother takes care of me very well. She gives me my medications all the time and everything I ask her she gives it to me. She even doesn't allow me to work a lot (Female, Age: 13). The schools and some of the teachers understand their conditions and put in systems such as providing then extra tuition to catch up with their peers when they miss class and necessary materials to enable them not lag behind in class.

Some of them indicated that they get all necessary support from both family and schools (i.e., teachers, school mates) in order to live a normal life. This confirmed the findings of Some researchers like Meyiwa. who found that sickle cell patients receive maximum support from parents or care givers to enable them cope with their conditions and not miss out in life (Meyiwa, 2019). It also confirms the statement of Nikia Vaughan, a John Hopkins communication coordinator and community health worker "despite a sickle cell diagnosis, you can do anything

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you want in this life if you have support, get the information and do what you're supposed to do" (Elben, 2019).

The adolescents who disclose their sickle cell status to their friends enjoy some support from them especially, when they need help. From the findings of the study, it was realized that not all the respondents have disclosed their condition to their teachers. Teachers who are aware encourage them, make time for their missed class and exams and prevent them from strenuous work. No support at all at the tertiary level.

Due to lack of funds from government, health institutions in Ghana do not provide adequate support for sickle cell patients. According to the respondents, doctors and nurses at the 37 Military Hospital give them counsel, good medication for the condition and do everything possible to take care of them especially when they come on admission. Recently, a pharmaceutical company, Novartis is helping with free hydroxyurea for one year to help them reduce the painful crises episodes.

In the developed countries several groups and organizations have been established to improve the life of people living with sickle cell disease. Some of advocacy groups are:

Sickle Cell Anemia Awareness of San Francisco, Sickle Cell Disease Foundation of California Delaware, William E. Proudford Sickle Cell Fund Florida, The Sickle Cell Foundation, Inc. Georgia, Sickle Cell Association of New Jersey, New York etc.

Also, community support groups exist where community workers intervene in the management of the condition. This might be due to increased knowledge and publicity of the disease in developed counties which might not be similar to the situation in Ghana Findings of a study done on Awareness of Sickle Cell Trait Status among Antenatal Women in Ghana at the Korle-Bu

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Teaching Hospital, Department of Obstetrics and Gynecology revealed a deficit in the knowledge of sickle cell disease among Ghanaian pregnant women. Therefore, there is the need for public education on sickle cell disease (Amenyi et al, 2017). In Ghana, sickle cell foundation Ghana is a non-profit organization that supports the development of resources and services to improve the health and quality of life of people with sickle cell disease and related conditions. Support groups exist at other facilities and in 37 Military Hospital. Adolescent support group for sickle cell patients was formed in 2019 but not very effective. With this study, more adolescents with the condition should be encouraged to join and make the group effective to discuss issues and seek for solution concerning their health. Sickle cell disease continues to be a problem and devastating disease and support groups help patients, families and friends to understand and give hope to their relatives. Stigmatization is prevalent in Ghanaian societies. This seems to be the reason why support groups are not effective among the adolescents.

5.6 Suggestion by Adolescents Living with Sickle Cell Disease to Improve Health Care Delivery

This objective sought the views of the respondents on how to improve upon their medical care. All the respondents suggested improvement in the care of sickle cell patients which revealed the expression of their dissatisfaction of care given them and the attitude of society toward people living with sickle cell disease. They were specifically concerned about cost of hospital care and wished national Health Insurance can cover their hospital expenses. They also want government to publicize awareness of sickle cell disease and encourage people to check and know their genotype before getting married and stop stigmatization. They also want more sickle cell centers to be established in the country to prevent traveling long distances to access health care. This is the view of one respondent; “I think it’s still not getting the attention it deserves. Government

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needs to invest more in providing the appropriate facilities nationwide for easy access" (Male, Age: 18).

These findings confirmed what Kanter et al, earlier reported that most patients recommend comprehensive sickle cell centers, hub and spoke models, satellite clinics, and telemedicine (Kanter et al, 2020). Other findings in a study that explored the psychosocial impact of SCD in a Nigerian population supported the notion that society's attitudes and perceptions had a psychosocial impact on people with SCD. The findings of the study indicated that, a very large proportion of respondents thought that SCD as an illness that is less known in society and needed more awareness, and if society was more aware of people with SCD it would be more positive about those with the condition. There is therefore a need to develop appropriate psychosocial interventions within a global context. The aim should be more public education about SCD to change beliefs, attitudes, and stigma as a starting point. This should be followed by other interventions that would lead to depending on access to health care at different levels, and in different settings.

In developing countries such as Nigeria, the focus would be initiating basic psychosocial interventions by non-specialized health workers in a primary care team at a Community Health Post (Level 1) or Primary Health Centre (Level 2), where psychologists or social workers are not be available. This would be in line with the WHO's current priority of primary care (Anie. 2010). These findings were similar to the views the respondents in the study discussed above expected from the government and society. It is recommended that civil societies should develop interest in forming advocacy groups and organizations that will promote improvement in the care of adolescents living with sickle cell disease in Ghana like it is in developed countries.

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The PAN Foundation is an independent, nationwide 501(c)(3) organization dedicated to providing help and hope to underinsured patients who are unable to afford the out-of-pocket expenses for their prescribed medications. Since 2004, PAN has provided over $3 billion in financial assistance to nearly 1 million patients who would otherwise be unable to afford their medications (PAN Foundation, 2020). The foundation had opened new sickle cell disease patient assistance fund in April 2020. Health officials, adolescents and relatives can learn more about this Foundation and seek for assistance.

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CHAPTER SIX

SUMMARY, LIMITATION, CONCLUSION AND RECOMMENDATION

6.1 Introduction

This chapter presents the Summary of Finding of the study as discussed in chapter five. It then proceeds to present conclusions of the study based on the findings presented. Finally, policy implications and recommendations are also discussed.

6.2 Summary of the study

From the study, the major findings of the study are as follows:

With regards to the psychosocial effects of the SCD patients, the study found that most of them are unhappy to be living with the disease and wish they do not have it. On the average over 80% of the adolescents interviewed for the study at the 37 Military Hospital suggested that they do not have difficulty mingling with their peers and some added that this was possible because their peers did not know about their conditions. Also, over 80% indicated that they didn't not believe their condition will make them not to attain their dreams and goals and also over 80% did not feel they were being denied their right when they were restricted from engaging in activities that could adversely affect their health.

The study also revealed that the respondents have developed their own copping mechanism to live with the condition. Some of which are drinking enough water, eating fruits and vegetables, resting and keeping themselves warm. Others also applied hot balm when in pain and take painkillers.

With regards to the support systems, the study found that at homes parents or care givers do enough to ensure the respondents were well at all times. More than a half of the respondents indicated that their care givers provide them with well-nourished meals, provide for their medications and always advise them on things to keep them fit at all times. About 10% of respondents were quick to add

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that their care givers grant them their request and also give them less work at home to avoid stress. At the schools, as much as 40% of the respondents indicated that they do not receive any form of support from their school teachers and mates and this was largely because no one in the school knew about their conditions. With those who know, their teachers encourage them, they also receive advice from them on their health as well. Their colleague's also help them with writing notes when they lag behind and also support during crisis. In the hospital, all the respondents indicated that the doctors and nurses advise them on how to stay healthy and also give them the necessary medications they need to be fit at all times.

Finally, the respondents suggest amongst other measures for the government to implement free health care system to aid in treatment of SCD patients. Some also wanted a separate school or education system for SCD patients and others wanted a cue to be found.

6.3 Limitations

The researcher has admitted some limitations of the study. Using WHO definition of adolescents thus from age 10 to 19 made the younger respondents not able to express their experiences well enough since they depend on their parents to make decision. The study also used convenience sampling at the out-patient department not involving those on admission. Time constraint made it impossible for those whose appointment did not fall within the period of the study to be missed. Moreover, 37 Military Hospital is just one of several health facilities in Ghana so the results of the findings of this study may not be completely generalized. Further studies are recommended for generalization.

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6.4 Conclusion

This study seeks to understand the experiences accessing healthcare among adolescents living with sickle cell, explore the psychosocial impact of sickle cell and coping strategies among adolescents living with sickle cell also to identify and understand existing support systems from families, community, schools and healthcare settings for adolescents living with sickle cell and finally to explore the views of adolescents living with sickle cell on measures and strategies to improve access to care and quality of life.

The study employed a qualitative research design employing specifically in-depth interviews to collect data from adolescents between the ages of 10 and 19 years. Based on study, the presence of Sickle Cell Disease in these adolescents do have some negative psychosocial effect like depression, anxiety and stigmatization, majority of them had no problem mingling with friends or not achieving their goals due to their disease condition. They rather developed their individual copping strategies to the condition. It was also observed that the study participants are not entirely satisfied with government and health care providers on the issue of access to health care. Furthermore, majority of the adolescents enjoy satisfactory support from their parents but all other social support system are inadequate or absent.

Similarly, the study also concluded that the doctors and nurses also do well through advice and medications to ensure the respondents were always fit and health. With the schools, much was not done largely because the schools were not aware of the condition of the patients even though those who knew supported through advice, encouragement and some forms of exemptions in school activities that could affect their health. Finally, the study concluded that there was the need for the government to establish a free health care system for SCD patients and intensify education on awareness of sickle cell disease as well.

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6.5 Implication and Recommendations

6.5.1 Implication for public health policy and practice

Sickle cell disease (SCD), an inherited hemoglobin disorder remains to be a problem and devastating condition drawing public health concern. According to World Health Organization (WHO), sickle cell disease is the most prevalent inherited disease in the African region and in many countries approximately 80% of all children born with SCD are in sub-Saharan Africa (WHO Regional Committee for Africa, 2010). It is also a significant public health burden in Ghana (Sickle cell foundation Ghana, 2013).

The findings revealed psychosocial impacts like depression, stigmatization and rejection in the life of adolescents. Non availability of adequate comprehensive sickle cell clinics and specialist to handle the condition. Patients have to travel for long distances to access health care making them miss school and exams. High cost of medical expenses due to little support from the health insurance scheme was another worrying effect expressed by the respondents.

The study also revealed that support groups and organizations which help with providing physical, psychological and social needs of people with chronic condition is lacking making the life of adolescents living with sickle cell miserable.

6.5.2 Contribution to knowledge

This section presents the contribution of this study to knowledge in the area of policy and practice and methodology as presented below,

6.5.3 Contribution to Policy and Practice

The findings revealed psychosocial impacts like depression, stigmatization and rejection in the life of adolescents. Non availability of adequate comprehensive sickle cell clinics and specialist to

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handle the condition. Patients have to travel for long distances to access health care making them miss school and exams. High cost of medical expenses due to little support from the health insurance scheme was another worrying effect expressed by the respondents. Based the study, it is important for government to invest with a lot of interventions to aid in reducing the prevalence rate significantly. For example, the new born Screening that is done in only Ashanti Region should be extended to all the regions in Ghana for early detection and intervention The national immunization program against childhood diseases including pneumococcal vaccine should be expanded to reach every child born in Ghana since pneumonia is one of the severe infections that kill sickle cell children before five years. Finally, the 'Ahondwo" program launched by the Vice President of Ghana, Dr Maumudu Bawumia for the National Health Insurance Scheme to cover Hydroxyurea (a drug that improves the health of those living with sickle cell disease) will be very useful when implemented.

6.5.4 Contribution to methodology

The qualitative method was adopted by the researcher because this approach is descriptive and exploratory to explore and describe the experiences of adolescents with SCD in Ghana. This study design was employed to help the researcher gain an in-depth understanding of the experiences of adolescents living with sickle cell disease. Qualitative or quantitative methods or both could have been applied since similar studies done previously used any of the above methods to collect data. Quantitative methods could not have provided the same results. Further studies can be carried out at other facilities to better understand and clarify lived experiences of adolescents living with sickle cell disease.

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6.6 Recommendations.

Based on the findings of the study, the following recommendations are considered

Ministry of Health / Ghana Health Service

The findings revealed psychosocial impacts like depression, stigmatization and rejection in the life of adolescents. Non availability of adequate comprehensive sickle cell clinics and specialist to handle the condition. Patients have to travel for long distances to access health care making them miss school and exams. High cost of medical expenses due to little support from the health insurance scheme was another worrying effect expressed by the respondents.

It is therefore recommended that there should be a policy where psychologist and social workers will be employed at all sickle cell clinics to see to the psychological and social needs of adolescents. Secondly, well equipped sickle cell centers established in all communities with highly professional medical staff to reduce challenges faced in accessing health care. The study finally, recommends for government interventions to make the treatment for SCD free for adolescents and this will aid those who are unable to access health care do so. This is because some parents due to financial constraints are unable to access health care and resort to their own methods of treatment which threaten the lives of these patients.

Ministry of Education / Ghana Education Service

The study revealed ignorance of some school authorities, teachers and students about sickle cell disease. It is recommended that Ghana Education Service should make it mandatory for school children present yearly comprehensive medical report to their schools. Members should also be educated on the need to quickly identify school children with special medical condition including sickle cell disease to help in time of need.

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Guidance and Counsel units be established in schools to help the adolescents in choosing carrier and also reassure them when their anxious or depressed.

Management of the 37 Military Hospital.

In order to reduce the waiting time at the clinic, and the delay at the laboratory and the pharmacy, the study recommends the commander of the 37 Military Hospital to establish sickle cell unit that runs every day with qualified staff. Some measures can also be put in place to separate the laboratory services of adolescents from the general public. The 37 Military Hospital Chemist can also help by stocking their shelves with drugs commonly used by sickle cell patients and are under National Health Insurance cover.

Management of Sickle Cell Foundation

The study also revealed that support groups and organizations which help with providing physical, psychological and social needs of people with chronic condition is lacking making the life of adolescents living with sickle cell miserable. Management of Sickle Cell Foundation should encourage adolescents with sickle cell disease and parent to form support groups. They should also seek help from civil societies, groups and organizations all over the countries and in communities to support adolescents with sickle cell disease with their needs to lessen burdens off the government and families.

Healthcare providers at the 37 Military Hospital

The staff at the sickle cell clinic should continue to show love and compassion on these adolescents. They Should continue to be counseled, reassured and be educated on how to take good care of themselves and take their medication.

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APPENDIX I: PARTICIPANTS INFORMATION

Dear respondent,

This is survey to find out about your own personal views on the topic 'Prevalence Crisis and Experiences of Sickle Cell Disease among Adolescent Accessing Health Care at the 37 '. This interview does not aim at attempting to pry into your private life but just to collate information for academic purposes only. Could you please answer these few questions concerning your experiences of Sickle Cell disease as an adolescent?

Your responses will not be used to identify you in any way. Strict confidentiality is assured.

Your frank reply to the questions will help much to improve quality of care to all adolescents.

Interview Guide

1. Has your genotype been disclosed to you?
2. How do you feel as a sickle cell disease carrier?
3. How often do you have crisis?
4. What other complications do you go through apart from joint pain and how often?
5. Do you have problem mingling with your peers due to your health condition?
6. What do you do on a daily basis to keep fit all the time?
7. Do you sometimes think your disease condition will not make you achieve your goals in life?
8. How do you personally manage your pains?
9. What kind of thoughts occupy your mind when you are denied of your rights due to your health condition?
10. What challenges do you go through in accessing health care?
11. What do your care givers do to keep you happy and healthy?
12. What kind of support do you benefit from your class teachers and mates?
13. What do doctors and nurses do to improve your health?

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14. What are your own views on sickle cell disease and what do you suggest government do to improve the health status of sickle cell patients?

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APPENDIX II: CONSENT PROCESS

PARENTS CONSENT FORM FOR PREVALENCE CRISIS AND EXPERRIENCES OF SICKLE CELL DISEASE (SCD) AMONG ADOLESCENTS ACCESSING HEALTH CARE AT 37 MILITARY HOSPITAL.

Title: Prevalence Crisis and Experiences of Sickle Cell Disease (SCD) among Adolescents Accessing Health Care at the 37 Military Hospital.

Principal Investigator: Ms. Doris Avortri.

Address: Health Policy Planning and Management (HPPM),

School of Public Health,

University of Ghana, Legon.

General Information about the study.

Sickle cell disease (SCD) is an inherited disorder of hemoglobin caused by a mutation in the beta globin subunit of adults. This red blood cell disorder is a lifelong condition that can affect many major organs in the body. The red blood cell of sickle cell patients' lives for a couple of weeks instead of three months as do normal red blood cells. There is therefore anemia and rapid turnover of cells. In cases of stress and hypoxia, the cells assume a sickle shape and they lock each other in the tiny blood vessels causing a blockage which then leads to the following symptoms; bone, joint, chest and abdominal pain of biting nature, Jaundice, anemia, head and foot syndrome, bone, distended abdomen, stroke, repeated infections, chronic ulcers amongst others. SCD affects million people all over the world, especially those of African origin, also in the Caribbean, South America, United Kingdom, France, Italy, Arab countries etc. Several studies have been done globally on psychosocial impact and copping strategies among people living with sickle cell disease. Although, the disease is linked to shorter life expectancy, advances in medicine and technology have caused decline in mortality rate and children with the disease, are now surviving to adulthood. Not much studies have been done in Ghana on adolescents living with sickle cell disease. This study seeks to explore the prevalence of crisis and the experiences adolescents accessing health care at 37 Military Hospital go through.

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Possible Risks and Discomfort.

There may be some emotional breakdown and a little discomfort when answering the questions but will be resolved by reassurance.

Possible Benefits. Improvement of care for children and adolescents living with sickle cell disease who access health care at 37 Military Hospital.

Confidentiality.

We will protect information about your wards to the best of our ability. Your ward's information from this analysis will not be linked to his/her personal information and will remain confidential. Any data that may be published will not reveal his/her identity.

Compensation.

There will be no cost or payment to your child for participation in this study. He/she will receive reimbursement for any transportation cost associated with participation in the study but will be refreshed with fruit juice.

Voluntary Participation and Right to Leave the Study.

Your child should join the study if he/she wants to. He/she can ask as many questions as he/she likes. He/she can leave the study at any time without giving any reason and this will not affect his/her medical care.

Contacts for Additional Information.

If you have any questions or concerns, please contact Ms. Avortri Doris (0244515230), School of Public Health HPPM Department.

Your Right as a Participant.

This study has been reviewed and approved by Health Policy, Planning and Management Department, School of Public Health, Legon and Institutional Review Board, 37 Military Hospital. If you have any questions about your rights as a study participant, you can contact the 37 Institutional Review Board between the hours 0f 7:30 am – 3pm through their landline also 0302916438 or email address: irb37milhosp@gmail.com.

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VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the study titled "Experiences of Sickle Cell Disease (SCD) among Adolescents Accessing Health Care at the 37 Military Hospital" has been read and explained to me. I have been given an opportunity to have any questions about the study answered to my satisfaction.

I agree that my child should participate as a volunteer.

……. ……

Date Name & signature of Parent/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 study.

……. ……

Date Name & signature of witness

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

……. ……

Date Name & signature of person who obtained Consent

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ADOLESCENT ASSENT FORM FOR PREVALENCE CRISIS AND EXPERRIENCES OF SICKLE CELL DISEASE (SCD) AMONG ADOLESCENTS ACCESSING HEALTH CARE AT THE 37 Military Hospital.

Introduction. My name is Doris Avortri a student of Public Health School, University of Ghana, Legon. I am conducting a study titled "Prevalent Crisis and Experiences of Sickle Cell Disease Among Adolescents accessing Health Care at 37 Military Hospital" which is part of the requirement of attaining Master's Degree. This study will provide information on experiences that adolescents living with sickle cell disease go through. The information gathered will help improve the care of the patients living with the disease.

General Information

If you agree to take part in this study, you will be asked to answer some few questions while you wait to see your doctor which the researcher will record for academic purposes only. You will not be asked to mention your name. Questions should be answered as frankly as possible to mee its intended goal.

Possible Risks and Discomfort. 8

There may be few minutes taken out your time, some emotional breakdown and a little discomfort when answering the questions but will be resolved by reassurance.

Possible Benefits.

Improvement of care for children and adolescents living with sickle cell disease who access health care at 37 Military Hospital.

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.

Voluntary Participation and Right to Leave the Study.

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.

Contacts for Additional Information.

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You may ask me any question about this study. You can call me anytime on 0244515230 or talk to me the next time you see me. Please talk about the study with your parents before you 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.

Your Rights as a Participant.

This study has been reviewed and approved by the Institution Review Boards of HPPM Department, Public Health School and 37 Military Hospital. If you have any questions about your rights as a study participant, you can contact the 37 Institutional Review Board between the hours 0f 7:30 am – 3pm through their landline also 0302916438 or email address: irb37milhosp@gmail.com.

VOLUNTEER AGREEMENT

By making your mark or thumb printing below, it means that you understand and know the issues concerning this study. If you do not want to participate in the 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 study titled "Prevalence Crises and Experiences of Sickle Cell Disease (SCD) among Adolescents Accessing Health Care at the 37 Military Hospital" has been read and explained to me. I have been given an opportunity to have any questions about the study answered to my satisfaction.

I agree to participate as a volunteer.

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

Child's mark/signature: …… Researcher's Signature

Date: …… Date: ……

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APPENDIX III: ETHICAL REVIEW

Ethical Clearance

Institutional Review Board
37
Neghelli Barracks
ACCRA
Tel: 059 1759506
Email: irbmilhosp@gmail.com

October 2021

ETHICAL CLEARANCE

37MH-1RB/MAS/1PN/539/2021

On 14 October 2021 the 37 Military (37MH) Institutional Review Board (IRB) approved your protocol.

TITLE OF PROTOCOL: Experiences of Sickle Cell Disease among Adolescents Accessing Health care at the 37 Military Hospital.

PRINCIPAL INVESTIGATOR: Doris Dzigbordi Avortri

Please note that a final review report must be submitted to the Board at the completion of the 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 13 October 2022.

DR EDWARD ASUMANU
(37MH-1RB, Vice Chairman)
Cc: Brig Gen NA Obodai
Commander, 37