

UNIVERSITY OF CAPE COAST



**DETERMINANTS OF HEALTHCARE UTILIZATION AMONG
SICKLE CELL DISEASE PATIENTS IN THE UPPER WEST REGION
OF GHANA**

CLEMENT LUCIANO MOMORE

2024



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University of Cape Coast

UNIVERSITY OF CAPE COAST

COLLEGE OF HEALTH AND ALLIED SCIENCES

SCHOOL OF NURSING AND MIDWIFERY



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**BY
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**THESIS SUBMITTED TO THE SCHOOL OF NURSING AND
MIDWIFERY, COLLEGE OF HEALTH AND ALLIED SCIENCES,
UNIVERSITY OF CAPE COAST, CAPE COAST, IN PARTIAL
FULFILMENT FOR THE AWARD OF MASTER OF NURSING.**

FEBRUARY, 2024

DECLARATION

Candidate's Declaration

I hereby declare that this thesis is the result of my own original research and that no part of it has been presented for another degree in this university or elsewhere.

Candidate's Signature Date

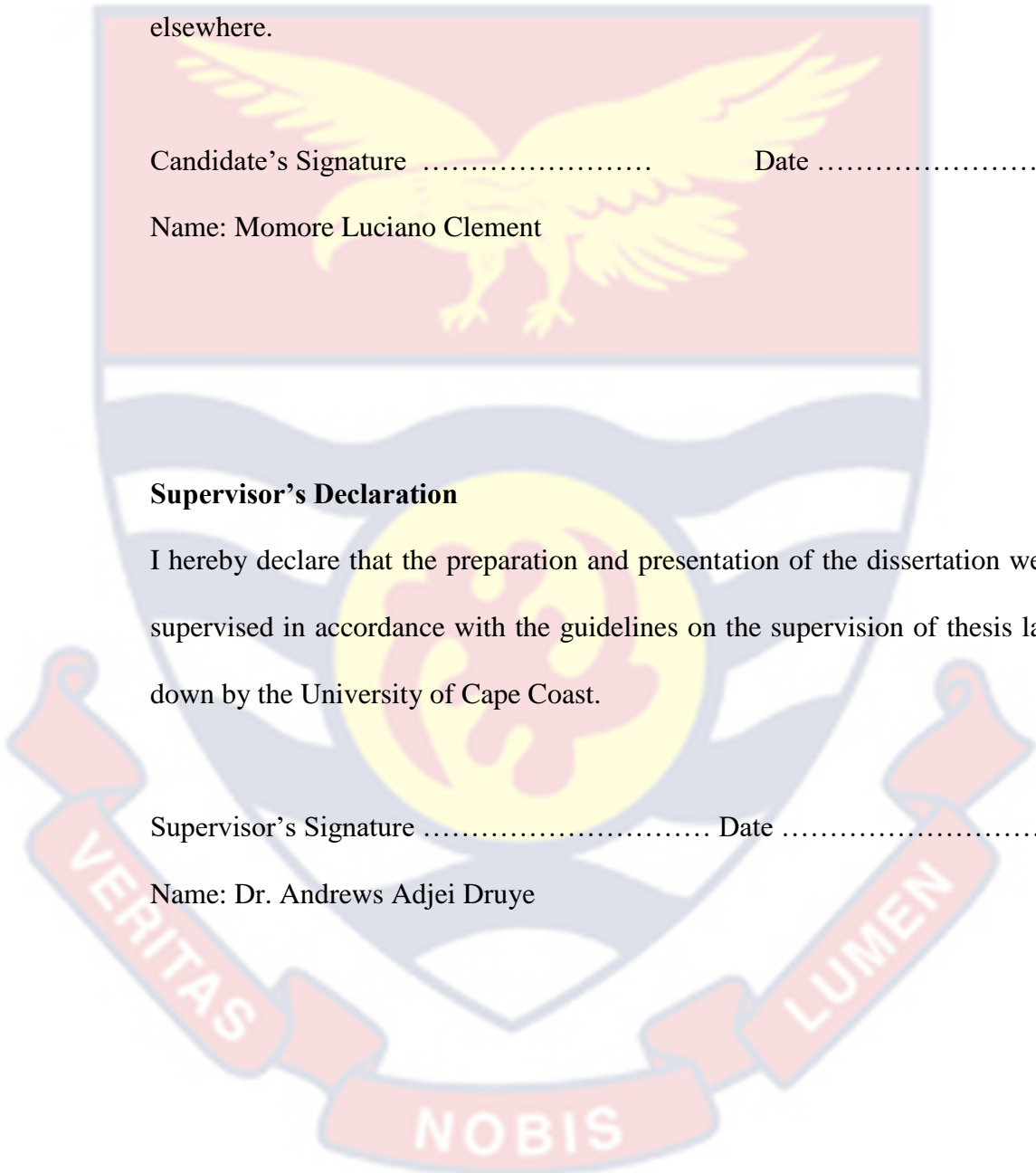
Name: Momore Luciano Clement

Supervisor's Declaration

I hereby declare that the preparation and presentation of the dissertation were supervised in accordance with the guidelines on the supervision of thesis laid down by the University of Cape Coast.

Supervisor's Signature Date

Name: Dr. Andrews Adjei Druye



ABSTRACT

Sickle Cell Disease is a chronic disease of public health concern that accounts for significant mortalities and hospitalisation worldwide. Sickle cell disease (SCD) is marked by both immediate and long-term complications, frequently necessitating the utilization of healthcare services. There is a paucity of research on the determinants of care utilization. Therefore, the determinants of healthcare service use among people living with SCD should be identified and addressed. This study aimed to assess the utilization of healthcare services and its determinants among SCD patients in the Upper West Region. The study adopted the quantitative approach using a cross-sectional survey design involving a sample size of 248. SPSS version 22.0 software was used to analyse the data. Both descriptive and inferential statistics were used. The findings showed that 92% of the respondents had used healthcare services within the last 12 months. Specifically, SCD patients had utilised OPD services 62%, Emergency services 57.7% and Inpatient services 39.5% three or more times within the last 12 months. It was also observed that 58% of the 248 respondents had poor accessibility to healthcare facilities providing SCD-specific care, with an overall mean of accessibility of 13.5. The major factors that were found to have influenced healthcare utilisation were age ($p < 0.001$) and closeness to the healthcare facility ($p < 0.005$). Healthcare service utilization was predicted by being aged 40+ years (AOR=12.6, 95%CI=1.40-113.81, $p=0.024$), and nearness to health facility (AOR=0.03, 95%CI=0.00-0.98, $p=0.026$). Efforts such as investment into healthcare infrastructure, incorporating SCD-specific care in all health facilities, and training specialists should be increased to improve accessibility, service availability, utilization, and quality of service.

KEYWORDS

Determinants of healthcare utilization

Ghana

Healthcare Accessibility

Healthcare Utilization

Sickle cell Disease

Upper West Region



ACKNOWLEDGMENTS

I acknowledge my supervisor, Dr. Andrew Adjei Druye, the head of the Department of Adult Health, School of Nursing, University of Cape Coast, for the advice and guidance offered throughout the research process. I appreciate your efforts.

I would also like to acknowledge the management and nurses of the Wa Municipal Hospital, especially the sickle cell clinic, where the participants in this study were recruited. May God richly bless you.

I would also like to acknowledge the authors of all the articles I consulted that made this work possible.

I owe a debt of gratitude to my research assistants, Mr. Richard Engmengbong and Mr. Remy Kongkuri, for their sacrifices and assistance in collecting the data. I appreciate your efforts.

I am most grateful to the Samuel and Emelia Brew-Butler-SGS/GRASAG UCC Research fund for the research grant to support this study.

I also appreciate the diverse contributions and support of my colleagues and friends. I am very grateful.

DEDICATION

To my family



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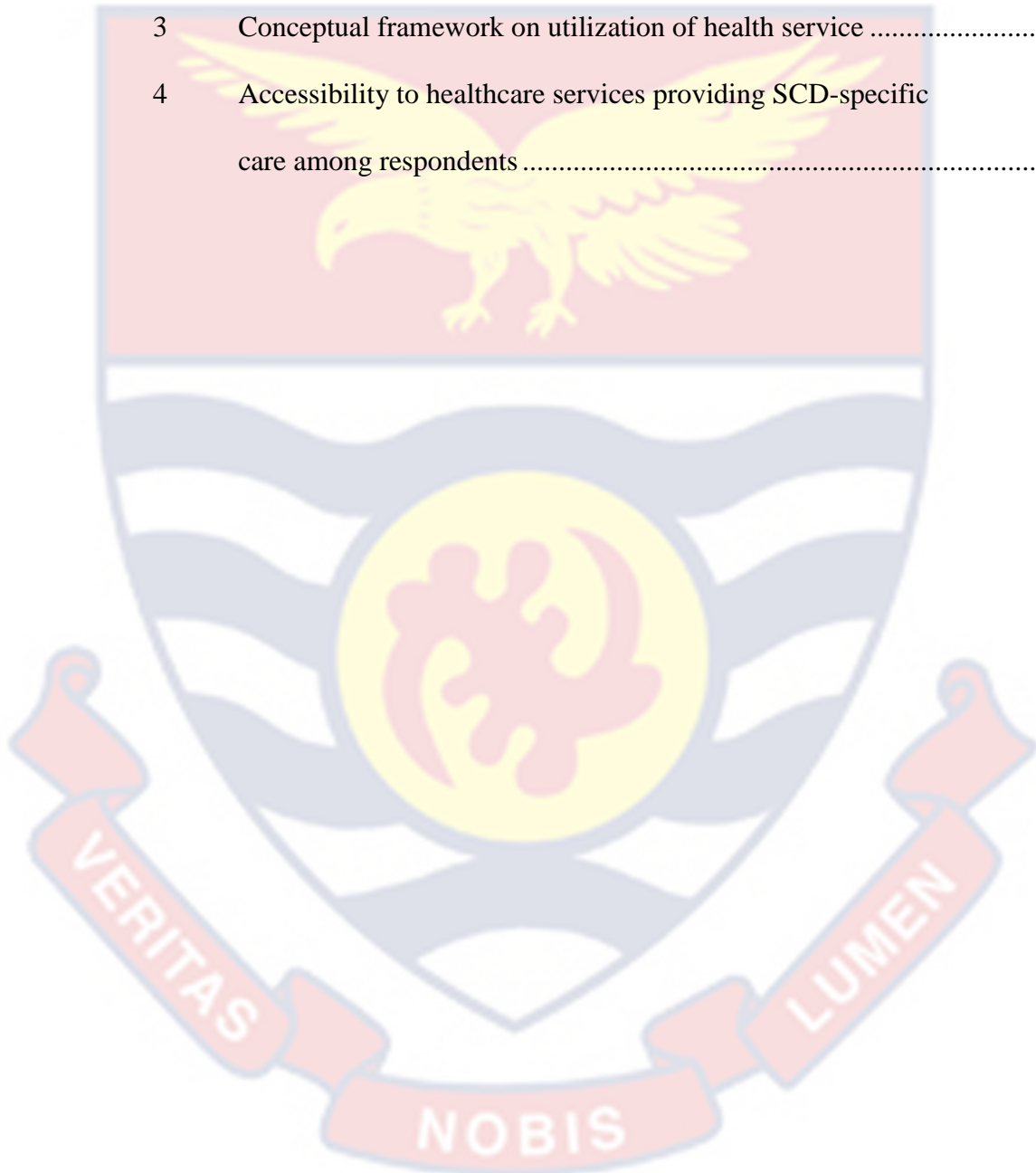
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LIST OF ACRONYMS

ACS	Acute chest syndrome
CDC	Center for Disease Control and Prevention
EDs	Emergency departments
HCU	Health care usage
OPD	Outpatient department
SCD	Sickle cell disease
VOC	Vaso-occlusion crisis
WHO	World Health Organization



CHAPTER ONE

INTRODUCTION

Chronic conditions are a global public health concern. Therefore, research in chronic conditions is gaining ground globally, where sickle cell disease is not an exception. Chronic Conditions, including SCD are linked to high healthcare use (Mvundura, Amendah, Kavanagh, Sprinz, & Grosse, 2009). In the SCD population, access to health care services and usage (HCU) are critical variables in the management because, in addition to the discomfort, patients face a slew of acute and chronic complications as well as emotional and socioeconomic challenges that significantly impact on their quality of lives (Sanders et al., 2010) . However, in most parts of Sub-Sahara Africa (SSA) including Ghana, the burden of SCD is worsened by inadequate health infrastructure. Despite efforts to provide healthcare services to SCD patients in the Upper West region, healthcare utilization among this population remains low, with patients seeking medical care only when their condition is severe. This thesis is about a study that assessed the determinants of healthcare utilization among sickle cell disease patients in the Upper West Region of Ghana. By understanding the determinants of healthcare utilisation, health care professionals and relevant stakeholders are expected to use the information to develop services that will improve access and use of healthcare services among SCD patients in the Upper West Region.

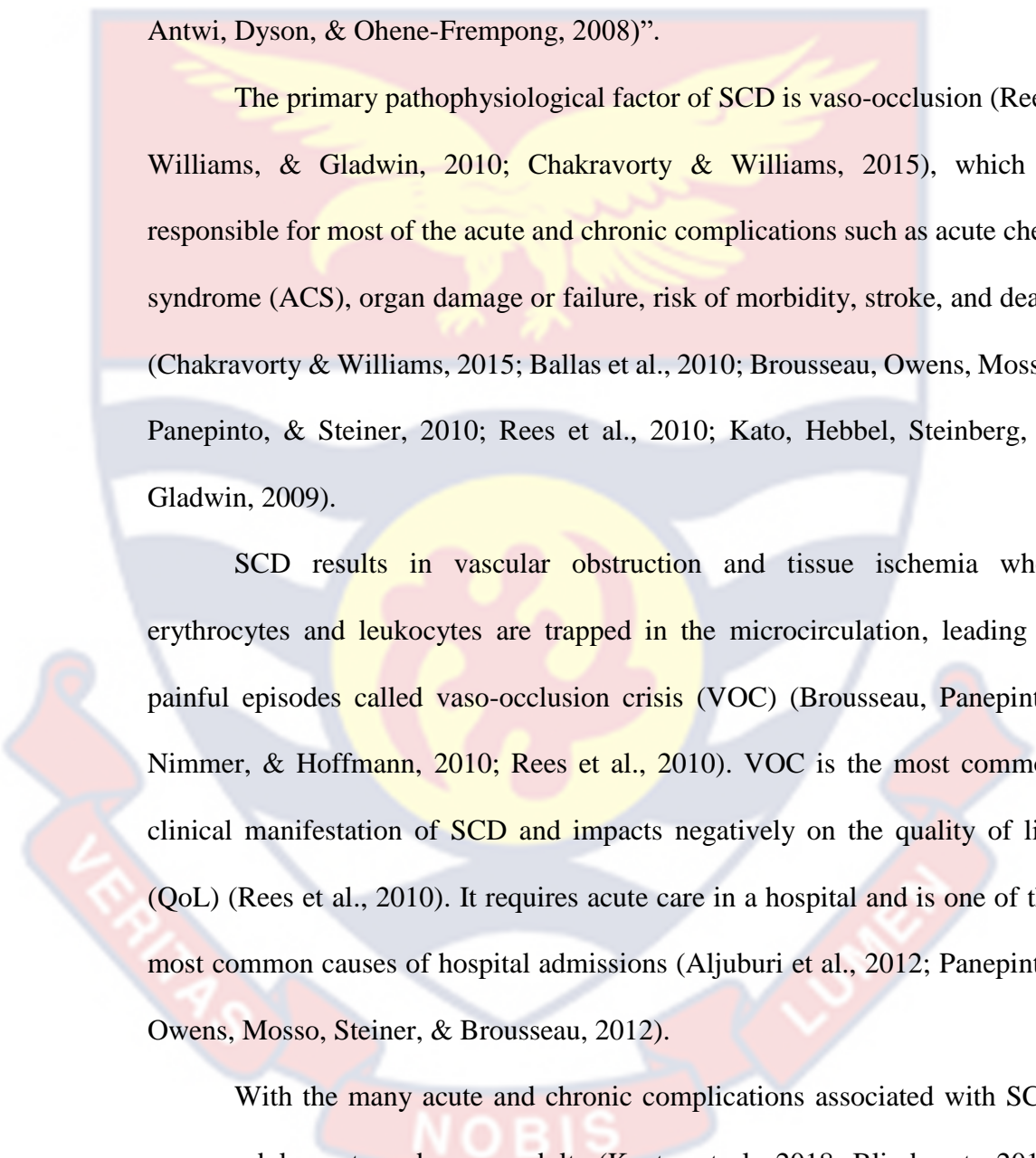
Background to the Study

Sickle cell disease (SCD) is a genetic disease that affects haemoglobin synthesis and causes erythrocytes to become rigid and develop a sickle-like shape upon deoxygenation (Lee et al., 2020). The substitution of glutamic acid

by valine in the sixth position of the β -globin chain characterizes defective haemoglobin (HbS). SCD is characterised by anaemia, vaso-occlusive complications, susceptibility to infections, and many other complications that can affect multiple organs (Tsiba et al., 2020; Conran, Franco-Penteado, & Costa, 2009). SCD is most common among people of African, Mediterranean, and Asian heritage (Asnani, Madden, Reid, Greene, & Lyew-Ayee, 2017; Centres for Disease Control and Prevention [CDC], 2017).

SCD continues to pose a global public health problem. “It has an annual estimate of about 300,000 to 400,000 infants and a reduced life expectancy of about 30 years (Piel, Steinberg & Rees, 2017). Its prevalent ranges between 2 to 30% in more than 40 countries in Africa (Adam, Adam, & Mohamed, 2019) with death from complications predominantly among children under five years, adolescents/young adults, and pregnant women (Macharia et al., 2018; Sack, Njangtang, Chemegni, & Djientcheu, 2017; Mulumba & Wilson, 2015). The developing world accounts for the vast majority of the global prevalence and incidence of SCD (Salihu & Umar, 2016).

In sub-Saharan Africa, SCD is the most common genetic disorder of the haemoglobin (Piel et al., 2017; Neville & Panepinto, 2012). The region accounts for approximately two-thirds of the more than 300,000 SCD children born yearly. Half of the global burden is borne by Nigeria, India, and the Democratic Republic of Congo (Aygün & Odame, 2012). About 200,000 to 240,000 children in Africa are born with SCD every year (Ansong, Akoto, Ocloo, & Ohene-Frempong, 2013). The burden is projected to increase to about 400,000 new-borns with SCD by 2050 (Thein & Thein, 2016).

In Ghana, approximately 15,000 (2%) of new-borns are estimated to be diagnosed with SCD annually, and like Cameroon, Republic of Congo, Gabon and Nigeria has HbS prevalence between 20 percent to 30 percent and SCD is about 2 percent (World Health Organization Africa Region, 2010; Dennis-Antwi, Dyson, & Ohene-Frempong, 2008)”.


The primary pathophysiological factor of SCD is vaso-occlusion (Rees, Williams, & Gladwin, 2010; Chakravorty & Williams, 2015), which is responsible for most of the acute and chronic complications such as acute chest syndrome (ACS), organ damage or failure, risk of morbidity, stroke, and death (Chakravorty & Williams, 2015; Ballas et al., 2010; Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010; Rees et al., 2010; Kato, Hebbel, Steinberg, & Gladwin, 2009).

SCD results in vascular obstruction and tissue ischemia when erythrocytes and leukocytes are trapped in the microcirculation, leading to painful episodes called vaso-occlusion crisis (VOC) (Brousseau, Panepinto, Nimmer, & Hoffmann, 2010; Rees et al., 2010). VOC is the most common clinical manifestation of SCD and impacts negatively on the quality of life (QoL) (Rees et al., 2010). It requires acute care in a hospital and is one of the most common causes of hospital admissions (Aljuburi et al., 2012; Panepinto, Owens, Mosso, Steiner, & Brousseau, 2012).

With the many acute and chronic complications associated with SCD among adolescents and young adults (Kanter et al., 2018; Blinder et al., 2015; Blinder et al., 2013; Quinn, 2013), utilization of health services by SCD patients is critical to their survival, and quality of life. It has been shown that advanced therapy options and increased use of preventive medicine improve the health

outcomes of SCD patients (Keller, Yang, Treadwell, Werner, & Hassel, 2014). A current standard of care includes administration of opioids for pain control along with other supportive measures, often in emergency departments (EDs) or inpatient units (Yawn et al., 2014).

The World Health Organization (WHO) (2010) estimates that 70% of SCD related mortality are preventable by implementing measures such as early diagnosis, health education, antibiotics prophylaxis for infections, pertinent vaccines, systemic treatments, and the use of disease-modifying agents such as hydroxyurea (HU) (Haywood et al., 2009; Brawley et al., 2008). However, the effectiveness of these measures remains linked to sickle cell patients' access to health services and the utilization of the health services.

In the SCD population, health care usage (HCU) is a critical variable because, in addition to discomfort, patients face a slew of other medical issues, such as acute chest syndrome, anaemia, infections, and stroke (Sanders et al., 2010). The severity of these consequences varies by patient, but they might result in repeated emergency room visits and hospitalizations (Sanders et al., 2010).

Health Services utilisation as defined by Reeves, Jary, Gondhi, Kleyn, and Dombkowski (2019) refers to patients encounter with health or medical care either by emergency, inpatient, or outpatient care for a specific health condition (Reeves et al., 2019). People with SCD seek medical help for various reasons, including avoiding and treating health problems, boosting well-being, learning about their health status and prognosis, and improving their quality of life (Reeves, Jary, Gondhi, Kleyn, & Dombkowski, 2019).

Health-care use can be evaluated from the patient's and the healthcare provider's perspectives. The patient's perspective is somewhat subjective as it focuses on patient-reported care. The second viewpoint is pragmatic because it is based on the amount of medical care provided to patients by health practitioners and reported in databases. From the health professional's viewpoint, service use measures are often based on economic metrics based on volume, such as the number of hospitalisations, medical acts, patients, and visits (Salihu & Umar, 2016).

Chronic conditions are linked to high health-care use, and SCD is not an exemption (Mvundura, Amendah, Kavanagh, Sprinz, & Grosse, 2009). Healthcare utilisation research by patients with chronic conditions is gaining ground globally. Nevertheless, the determinants of health services utilisation are the cornerstones of health care utilization among people with these chronic conditions. Determinants of health services utilisation as defined by Geitona, Zavras, and Kyriopoulos (2009) include the variables that have a major impact on health care utilisation. It encompassed the various factors that can influence the use of health services either directly or indirectly. Therefore, research studies that focus on determinants of health care utilisation, especially among populations living with chronic disease such as SCD, are important as this thesis seeks to do.

Problem Statement

People living with SCD face significant health challenges, including pain, anaemia, infections, and end organ damage. These health challenges or complications may be acute or chronic and require health service interventions to improve the health outcomes of affected people (Sanders et al., 2010).

However, in most parts of Sub-Saharan Africa (SSA) including Ghana, the burden of SCD is worsened by inadequate health infrastructure, poor nutrition and co-morbidities infections such as malaria, tuberculosis, and HIV leading to sickle cell disease related mortalities (Ware, 2013; Piel, Hay, Gupta, Weatherall, & Williams, 2013). Thus, unlike the developed countries where more than 90 percent of infants with SCD survive into adulthood due to available infrastructure for universal new-borns screening and comprehensive care (Ware, 2013; Aygun & Odame, 2012), these morbidity and mortality-reducing interventions associated with improved life expectancy are largely inaccessible to patients in low-income countries such as Ghana. It exposes SCD individuals in low-income countries to life-threatening complications like acute organ failure (Ware, 2013; Piel et al., 2013; Aygun & Odame, 2012). In these regions, almost 80 percent of babies born with SCD are undiagnosed (Aygun & Odame, 2012) and more than half (50% to 90%) die before age five, largely attributed to limited health service availability, access and use (McGann, Hernandez, Ware, 2017; Aygun & Odame, 2012; Grosse et al., 2011).

With easily accessible and appropriate healthcare service for SCD complications, these deaths may be prevented or greatly reduced. Utilization of healthcare services such as emergency care, in-patient and out-patient services are key in ameliorating common complications associated with the SCD.

The Upper West Region of Ghana has one of the highest SCD prevalence rates in Ghana, posing a significant burden on healthcare facilities (table 1), (Statistics, Wa Municipal Hospital, 2021). Despite efforts to provide healthcare services to SCD patients in the region, healthcare utilization among

this population remains low, with patients seeking medical care only when their condition is severe.

Reports from the Wa Municipal Hospital indicated that some SCD patients report complications due to late reporting, non-attendance, and defaulting (table 1) (Statistics, Wa Municipal Hospital, 2021). This trend in delayed medical care is troubling, given its potential to heighten the risks of morbidity mortality and escalate healthcare expenses

However, till date, the reasons for underutilisation of health services among SCD patients has not been explored and little is known about the phenomenon. Most studies about SCD in the Ghanaian context have focused on the prevalence, epidemiology and the general public knowledge on SCD (Sarat et al., 2019; Mburu & Odame, 2019; Asare et al., 2018; Boadu, 2018; Tusuubira et al., 2018; Piel et al., 2017; Ansong et al., 2013). Others are about, self-management strategies and recommendations for SCD patients, and the general health care services utilization (Asare et al., 2018; Druye, Robinson, & Nelson, 2018; Druye, 2017; Ameade et al., 2015; Ganle, Parker, Fitzpatrick, & Otupiri, 2014; Ansong et al., 2013; Dennis-Antwi et al., 2011) most of which have employed mixed and qualitative methods and among urban dwelling participants.

Although, reports from the Wa Municipal Hospital indicated that some SCD patients present with complications due to late reporting, non-attendance and defaulting among others (table 1), no study has explored the determinants of health care utilization among this group of patients within the region. Concerning the statistics trend (table 1), that is; defaulting 61 (10%), non-attending 61 (10.3), and late reporting 44 (7.5%). This trend is concerning and

needs attention, as delayed medical care can lead to increased morbidity, mortality, and increased healthcare costs.

There is a knowledge gap regarding the determinants of healthcare utilisation among Ghana's SCD population. This study seeks to bridge this by assessing the determinants of healthcare service utilization among sickle cell disease patients in the Upper West Region. Healthcare utilisation among SCD patients and its determinants must be assessed due to the significance of access to and use of quality and appropriate healthcare to the affected people's overall health status and quality of life.

Table 1. Trend of defaulting, non-attendance and late reporting of SCD patients

Year	Defaultant	Non-attendance	Late reporting	Total registration
2021	26(4.5%)	20(3.4%)	16(2.8%)	580
2022	25(4.2%)	28(4.7%)	19(3.2%)	590
2023(Midyear)	10(1.7%)	13(2.2%)	9.(1.5%)	593

Sources: Statistics Department, Wa Municipal hospital, 2023

Purpose of the Study

This study aimed to assess the determinants of healthcare utilisation among people living with sickle cell disease in the Upper West Region.

Research Objective

The study assessed the determinants of health care utilization among sickle cell disease patients in the Upper West Region. Specifically, it sought to:

1. Determine the level of healthcare services utilisation among sickle cell disease patients in the Upper West Region

2. To determine the level of accessibility to health care among SCD patients
3. To determine the facilitators and barriers to healthcare utilisation among sickle cell disease patients in the Upper West Region of Ghana
4. To identify the socio-demographic characteristics factors that influence healthcare utilization among sickle cell disease patients in the Upper West Region of Ghana.
5. To identify the health services-related factors that influence healthcare utilization among sickle cell disease patients in the Upper West Region of Ghana.
6. To examine the factors that predict health service utilization among patients with sickle cell disease.

Research Questions

The study answered the following research questions:

1. What is the level of healthcare services utilization among sickle cell patients in the Upper West Region?
2. What is the level of accessibility of healthcare services among sickle cell patients in the Upper West Region?
3. What are the barriers to healthcare utilization among sickle cell disease patients in the Upper West Region of Ghana?"
4. What socio-demographic factors influence healthcare utilization among sickle cell disease patients in the Upper West Region of Ghana?
5. What are the health services-related factors influence healthcare utilization among sickle cell disease patients in the Upper West Region of Ghana?

6. What are the factors that predict health service utilization among patients with sickle cell disease?

Significance of the Study

The study examined the determinants of health care services utilization among CSD patients in the Upper West Region. It is significant in adding knowledge to existing literature on healthcare service use and its determinants among people with SCD especially in the Upper West Region of Ghana. The findings of this study are also relevant to stakeholders by serving as evidence-based guidelines for their strategic planning and policy decision-making concerning improving access and use of healthcare services among SCD patients in the Upper West Region. Thus, the Upper West Regional Health Directorate will find the research significant in improving healthcare service access and utilization for people living with sickle cell disease within the region through quality improvement on the access and utilization of healthcare services in the region by policymakers as a result of the study findings. Also, the management of Upper West Municipal Hospital will find the research relevant in informing policy decision-making concerning the determinants of health care utilization among sickle cell disease patients within their care. Further, the study is also helpful in the hospital strategic planning with regard to how they can effectively operate the sickle cell clinic within the region to maximise attendance.

Delimitation of the Study

This study was delimited in scope, setting, population and methodology. In scope, the study was delimited to only determinants of healthcare utilization among people with SCD related health problems in the Upper West Region of

Ghana. The study focused on use of emergency, in-patient, and non-preventive outpatient care services and factors influencing their use. In addition, the study is also delimited to the study setting; Upper West Region. This region has its own regional socio-economic characteristics and structure which have an impact on the responses and findings of the study. Again, in terms of methodology, it was delimited to quantitative inquiry which thus, sought to answer the research questions using questionnaire by selecting representative sample from the population through systematic random sampling technique. Furthermore, in terms of population, it was delimited to persons with SCD living in the Upper West Region. Finally, the study was constrained by the sample size of the study.

Limitation of the Study

Because the data was collected at a single moment in time, the study was limited in its potential to properly forecast the future trend of determinants of health services utilization among SCD patients in the Upper West Region. Also, the study relied on self-reports which has the tendency to overestimate or underestimate behaviours. Nevertheless, participants were encouraged to provide honest responses as much as possible.

Additionally, the study may have suffered from recall bias as the participants had to provide information on their health status and healthcare service use within a year. The participants only included those accessing care at the Wa Municipal Hospital, a regional referral center; thus, findings are not representative of the people with SCD in the general population who do not access health care at Wa Municipal Hospital. However, the findings provide

some useful insight what might happen to SCD patients in settings similar to the present study.

Definition of Terms

Sickle cell disease (SCD): Sickle cell disease (SCD) is a hereditary, severely disabling illness of the red blood cell that results from a mutation in the gene that codes for sickle haemoglobin, which is produced when the HbSS or HbSC, genes are present (Lee et al., 2020).

Determinants of health services utilization as defined by Geitona, Zavras, and Kyriopoulos (2009) include the variables that have a major impact on health care utilization.

Access to health service implies how simple it is to get hold of necessary medical care in an emergency. Ability to recognise the need for health care, locate and get appropriate treatment, and have that need met are all components of health care access (Levesque, Harris, & Russell, 2013).

Health Services utilization refers to encounters with health or medical care either by emergency, inpatient, or outpatient care for a specific health condition (Reeves et al., 2019).

Operational Definitions

Person living with sickle cell disease: Any person diagnosed with sickle cell disease.

Accessibility to healthcare services: How easy or difficult it is to access healthcare services providing SCD care when in need of care for SCD and its complications.

Utilisation of healthcare services: The use of any healthcare services such as emergency, in-patient, and non-preventive out-patient care to manage SCD and its complications.

Emergency care: Care provided to resuscitate or alleviate life-threatening related complications, often provided at the emergency department of the health facility.

In-patient care: Care for SCD-related complications is provided to patients on admission to a hospital ward.

Non-preventive out-patient care: Out-patient care for SCD-related complications provided to patients at the out-patient department

Organisation of the Study

The study is organized into five chapters consisting of chapter one to five. The first chapter introduces the topic by providing a background context and describing the study problem and objectives. Chapter two provides a review of literature, relevant theories, and framework to underpin the study. Chapter three describes the methodological approaches and processes employed in the study, including respondents' selection and data collection and analysis procedures. Also, chapter four presents the study results from the analysis of the study's data and discusses the key findings in view of the conceptual framework and relevant previous studies. The final section, chapter five, provides a summary of the study and draws highlights the implications of the findings and makes recommendations based on these findings

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter reviews issues and concepts relevant to the “determinants of healthcare utilization among SCD patients in the Upper West Region.” A pertinent literature review related to the issue under investigation is presented in this section. The review comprises conceptual reviews, theoretical reviews, conceptual frameworks, and empirical reviews. The conceptual review highlights chronic disease, sickle cell disease, and associated burden, access, and utilization of healthcare services. Theoretical reviews and conceptual framework reviews theories explaining the various factors influencing healthcare utilization, and finally develops a conceptual framework to underpin the study. While the third part is the empirical review, which encompasses review of previous studies based on the study objectives: 1) To determine the level of accessibility to health care among SCD patients; 2) to Determine the level of healthcare services utilization among sickle cell disease patients in the Upper West Region; 3) To determine the facilitators and barriers to healthcare utilization among sickle cell disease patients in the Upper West Region of Ghana; 4) To identify the socio-demographic and health service factors that influence healthcare utilization among sickle cell disease patients in the Upper West Region of Ghana; 5) To identify the health services related factors that influence healthcare utilization among sickle cell disease patients in the Upper West Region of Ghana; 6) To examine the factors that predict health service utilization among patients with sickle cell disease.

Various sources, including books, journals, grey literature, and specialized databases, were used to gather the data from the vast literature. These data sources were reachable via online resources, the university library, supervisor recommendations, and books that discuss SCD as a medical condition. Research articles conducted comprehensive literature reviews on the subject, utilizing cutting-edge sources such as Google Scholar, Science-Hub, and Google and specific databases like PubMed, CINAHL, HINARI, and EBSCO Host. The bulk of the published works relevant to the research question were evaluated utilising these resources. Particular attention was paid to the regions of Sub-Saharan Africa, Africa, and Ghana. The various articles were found using basic and advanced search terms like health services utilization, chronic disease, chronic illness, sickle cell anaemia, SCD, Ghana, Africa etc. Titles and abstracts were searched using these keywords and phrases. The complete text of the documents was accessed in a pdf form, save in a file, and were thoroughly read through before reviewing them. The following sections provide an overview of the relevant information of the published research articles on the topic under study.

Conceptual Review

Concept of Sickle Cell Disease and associated burden

Sickle Cell Disease (SCD) is a global public health concern, particularly prevalent in tropical regions where malaria is endemic. This hereditary disorder, characterized by abnormal hemoglobin (HbS), poses significant challenges in terms of morbidity, mortality, and the overall well-being of affected individuals. The worldwide prevalence of chronic disorders like SCD is acknowledged as a substantial public health issue (Wastnedge et al., 2018). The geographical distribution of SCD is influenced by factors such as malaria prevalence, limited resources, and socio-economic conditions, especially affecting the survival of children in tropical regions.

The genetic underpinning of SCD is rooted in the expression of sickle cell genes that direct the synthesis of aberrant HbS (Chakravorty & Williams, 2015). Diagnosis, though, has become relatively straightforward, with simple blood tests and advanced techniques like hemoglobin electrophoresis enabling the identification of hemoglobin subtypes in blood samples (Awad, 2018). The pathophysiology involves the formation of polymers when HbS is deprived of oxygen, leading to cellular damage and a highly variable phenotype (Steinberg & Rodgers, 2001). Conditions triggering sickling, such as infections and dehydration, contribute to the unpredictable nature of the disease. While blood transfusions, stem cell transplants, and medications like hydroxyurea have shown efficacy in managing SCD (Gardner, 2018), the disease remains complex, necessitating a multifaceted approach.

Addressing the burden of SCD involves effective treatment and preventive measures. Genetic counseling for engaged couples and health education campaigns are recommended strategies to reduce the prevalence and impact of the disease (Gardner, 2018). SCD presents a range of clinical consequences, including vaso-occlusive crises, acute chest syndrome, stroke, and hip necrosis (Ansong et al., 2013). Studies in high-income populations emphasize the severe, episodic, and unpredictable nature of the systemic inflammatory response associated with SCD. While the literature provides valuable insights into the genetic, diagnostic, and therapeutic aspects of SCD, there is a limited focus on socioeconomic factors affecting disease prevalence, the challenges of implementing preventative measures in resource-limited settings, and the necessity for more comprehensive studies assessing the long-term psychosocial impact on individuals with SCD.

Concept of Access

Healthcare policy and quality improvement have focused on the different but connected notions of access and utilisation of healthcare services (Liu et al., 2006). Studies and policies have focused much emphasis on the issues of healthcare access and utilisation, especially when tackling discrepancies in health outcomes (Liu et al., 2006). Access is a crucial term in health policy and healthcare research. However, it is little understood and underutilised. Some authors define “access” as the ability to join or utilise the healthcare system, while others define it as the availability of such opportunities (Levesque et al., 2013). Liu et al. (2006) and Levesque et al. (2013) shed light on the interconnected notions of healthcare access and utilization, emphasizing their significance in healthcare policy and quality improvement. While

providing a comprehensive background, the review reveals certain gaps and opportunities for a more nuanced understanding of these concepts.

The efficiency of healthcare systems in different parts of the world depends largely on patients' ability to get the help they need. Levesque et al. (2013) define "access" as the use of health services based on the need for care. Foregone utility, maximum consumption, and care-related costs are other ways Levesque et al. (2013) define healthcare costs. In the literature on health policy, evaluation of usage and access plays a significant role because of the significance of service delivery for people (Liu et al., 2006). The complexity of the idea of universal healthcare access is shown by how academics have understood the term "access" (Liu et al., 2006). It is assessed as excellent and bad access, specifically, the capacity to recognise healthcare requirements, seek healthcare services, reach or receive them, and meet the need for services (Levesque, Harris, & Russell, 2013). The term "access" in healthcare is recognized as crucial, yet the conceptualization remains varied and sometimes ambiguous. Levesque et al. (2013) distinguish access as the ability to join or utilize the healthcare system or the availability of opportunities. This diversity in definitions underlines a potential gap in the clarity and consistency of the conceptualization of access in the literature. The term "access to health services" in this research refers to how easily one may get the required medical treatment. The particular aspects of access include accessibility, accommodation, acceptability, cost, and availability (Levesque et al., 2013).

Approachability is the ability of people with health needs to understand the availability, use, and impact of services on their health. Regarding whether or not people will accept specific aspects of the service (such as the sex or social

group of the providers and the beliefs associated with particular medical systems), acceptance also refers to whether or not it is deemed appropriate for the person to seek care (Levesque et al., 2013). The terms “accessibility” and “accommodation” relate to the ability to physically and promptly access healthcare services (either the physical location or those in healthcare positions), as well as how the supply resources are structured to welcome customers.

The capacity of individuals to spend money and time on the appropriate services is referred to as “affordability” (Levesque et al., 2013). According to Levesque et al. (2013), availability describes the link between the number and diversity of available services (and resources) and the quantity and variety of customer desires. As articulated by Levesque et al. (2013), the concepts of affordability and availability add dimensions to the understanding of access. Further exploration into the economic and systemic factors influencing affordability, as well as an examination of how availability relates to service quality, strengthen the overall access to health service.

The continuous focus on access by health services researchers and policymakers is supported by the assumption that other things being equal, people with lesser access would get less-than-appropriate medical treatment. The breadth and importance of relationships between access and consumption are still unknown, and current study results typically do not support this concept (Levesque et al., 2013). The continuous focus on access, driven by the assumption that limited access results in suboptimal medical treatment, raises questions about the breadth and importance of relationships between access and consumption. The review acknowledges the unknown nature of these

relationships, indicating a gap in understanding the nuanced impact of access on healthcare consumption.

Access and utilisation of services may be detected if segments of the population that are similar in age, sex, or other characteristics are considered individually. This method is consistent with the premise that patients' attitudes and perceptions are key drivers of health behaviour (Levesque et al., 2013), since it is based on the idea that patient dissatisfaction with a particular component of access may be prominent for some groups of patients but not for others. Access to health services, in this framework, is defined as the ease with which a person may get the treatment they need. Recognising healthcare requirements, looking for healthcare services, getting in touch with or finding healthcare services, and needing services met (Levesque, Harris, & Russell, 2013). The approach of individually considering population segments based on demographic characteristics aligns with recognizing patients' attitudes and perceptions as key drivers of health behavior. However, the demographic and contextual factors influencing access for different groups provide a more granular understanding. In general, concerning the literature, the access in this thesis concerns the accessibility and accommodation and the availability perspectives of the access dimension.

Concept of Utilisation.

"healthcare utilization" encompasses applying healthcare services, procedures, devices, or pharmaceutical drugs to preserve and improve an individual's health, prevent and treat health issues, or gain insights into one's health status and prognosis. This comprehensive concept is elucidated by

researchers such as Levesque et al. (2013), Mkanta and Uphold (2006), and Carrasquillo (2013).

According to Levesque et al. (2013), healthcare utilization can be categorised as discretionary or nondiscretionary, contingent upon who decides to use the services—whether the patient or the healthcare provider initiates it. For instance, if a patient autonomously seeks treatment at an emergency room, this would be considered a discretionary act. In contrast, if a healthcare provider decides to admit a patient, it falls under the category of nondiscretionary healthcare utilization.

This nuanced distinction becomes particularly relevant in understanding the dynamics of healthcare decision-making. The dichotomy between discretionary and non-discretionary healthcare utilization highlights the varying degrees of agency patients and healthcare providers hold in the utilization process. Recognizing this duality provides a more nuanced perspective on the factors influencing healthcare utilisation patterns, with implications for healthcare policy, resource allocation, and patient-provider relationships. The insights from Levesque et al. (2013), Mkanta and Uphold (2006), and Carrasquillo (2013) contribute significantly to our understanding of the complexities inherent in healthcare utilisation dynamics.

Levesque et al. (2013) note that healthcare use may be evaluated from both the patients' and the providers' perspectives. The assessment of patient care involves a dual perspective, with patient-reported care relying on the subjective narrative provided by the patient regarding their treatment experiences. However, an alternative method, grounded in the quantifiable provision of care documented in databases, has exhibited greater practical applicability, as

elucidated by Levesque et al. in 2013. This method diverges from the patient's personal account and emphasizes the tangible volume of care rendered. Providers often focus on economically driven metrics in the healthcare domain that revolve around the sheer quantity of healthcare activities. It encompasses parameters such as the number of hospitalizations, medical procedures, patients attended to, and overall visits, as highlighted in the insights shared by Salihu and Umar in 2016. This volume-based approach to evaluating healthcare services reflects a broader economic perspective, emphasizing efficiency and throughput.

In the context of this study, health services utilization assumes a comprehensive definition, encompassing diverse encounters with health or medical care. These encounters span the spectrum from emergency care to inpatient and outpatient care, all aimed at addressing specific health conditions, as detailed by Reeves et al. in 2019. It is crucial to recognize that health services utilization is not a one-dimensional concept but encompasses both utilization and non-utilization, acknowledging instances where individuals may not seek or require medical care for a particular health condition. This multifaceted understanding of patient-reported care and health services utilization underscores the complexity of assessing healthcare quality and outcomes, necessitating a nuanced approach that combines subjective patient perspectives with objective, data-driven metrics.

Theoretical Review

The Theory of Reasoned Action and the Healthcare Utilisation Model are the two theories most often used in literature to describe the key elements impacting access and utilisation. The theoretical review considers the Theory of Reasoned

Action and the Healthcare Utilization Model to explain the factors influencing healthcare utilization among SCD patients in the Upper West Region.

Theory of Reasoned Action

Fishbein originally put forward the Theory of Reasoned Action (TRA) in 1967 (Figure 1) (Ajzen & Fishbein, 1969). The theory of reasoned action offers a model that may explain how attitudes and behaviours are related. Social psychology was the first field to propose the notion of rational action.

According to the notion, as people are logical creatures, they weigh their options and examine the facts at hand. This suggests that a person's desire to carry out or refrain from carrying out an activity is what ultimately determines that behaviour (Ajzen & Fishbein, 1980). According to the theory of reasoned action, the most precise predictor of conduct is behavioural intention. The theory makes an effort to explain how subjective norms, attitudes, intentions, and actions are related.

A person's internalised belief that they are more likely to do something because other people are doing it is an example of a subjective norm. A person's self-perception of how others see his actions. Coworkers', friends', and family members' thoughts on the outcomes of a conduct are included here (Ajzen & Fishbein, 1980).

People's attitudes are formed by their assumptions about the outcomes of a behaviour. Depending on the individual, these perceived repercussions may have positive and negative results (Ajzen & Fishbein, 1980). People's perspectives may include their "beliefs about how they should behave" and their "evaluation of the consequences" of such behaviours. Belief in the outcome of

an action is the likelihood of that outcome being achieved. To what extent are the actions' results good or poor? They may be judged (Park & Levine, 1999).

The likelihood that a person will engage in a certain conduct is intention. As the primary driver of conduct, intention is impacted by both attitude and arbitrary standards. It offers the best accurate behaviour prediction and maintains stability throughout time (Ajzen & Fishbein, 1980).

Using the hypothesis, researchers have examined how cheating, smoking, limiting sun exposure, dieting, voting, and consuming genetically engineered foods affect people. It has also been used to examine the long-lasting influences of the past on one's current actions (Ajzen, 2002). The strength of the theory of reasoned action lies in its ability to foresee and contribute to the explanation of the elements that impact behaviour that is within the control of the agent. A weakness of the theory of reasoned action is in its individualistic approach. It does not consider the role of environmental, cultural and structural factors in the theory (Kippax & Crawford, 1993).

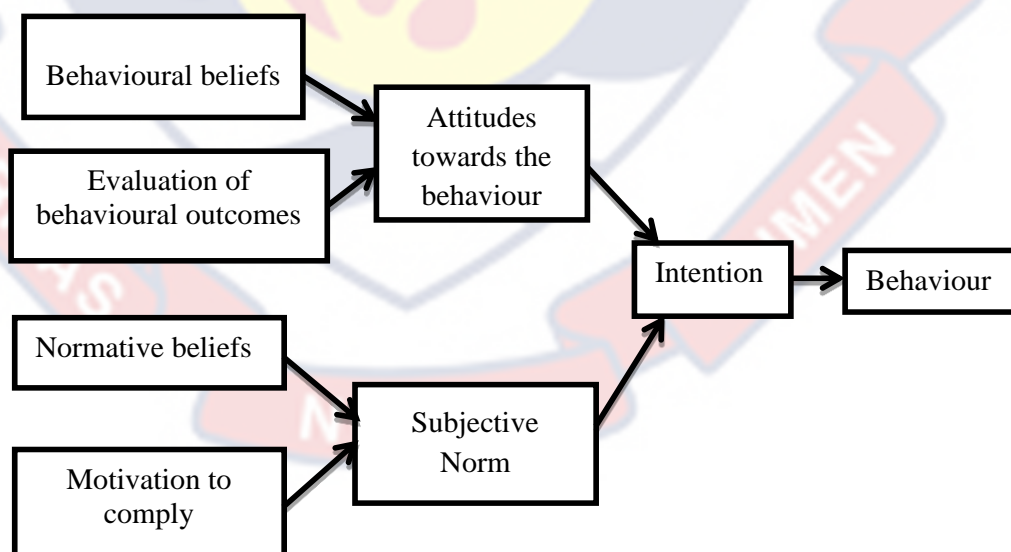


Figure 1: Theory of Reasoned Action

Source: Ajzen and Fishbein, 1980

Application of the theory to present study

This idea is pertinent to the present research because it clarifies how individuals with SCD justified their choice to seek healthcare services. Therefore, healthcare use is seen as a habit. It states that a patient with SCD's decision to utilise or not use healthcare services is directly influenced by how they will rationalise the information at their disposal (Ajzen & Fishbein, 1980). Therefore, it argues that there is a subjective standard of what close friends, family, and significant others think about sickle cell, its crises, its challenges, and whether or not it is important to seek treatment to avert the dreaded conclusion of death. Patients with SCD are acknowledged to have an attitude element that influences their decision to seek therapy, as well as the location and method of that treatment. These, along with other factors including sociodemographic variables, the accessibility of healthcare, and the availability of healthcare services, all have a role in shaping people's decisions to seek treatment. If these are unfavourable, the SCD patient will not seek medical attention, and vice versa.

Healthcare Utilisation Model

Ronald Andersen created the Healthcare Utilisation Model (HUM) in the 1960s as a conceptual framework to explain differences in utilisation rates and consumption of health services (Figure 2). The conceptual model illustrates the factors that contribute to the use of healthcare services. According to the paradigm (Andersen & Newman, 2005; Andersen, 1995), an individual's use of health services is a function of their propensity to do so, factors that facilitate or inhibit their usage, and their need for treatment. According to this model's three

components—need, enabling factors, and predisposing factors—the use of healthcare services is caused by these variables (Andersen, 1995).

Sociocultural characteristics that exist in people before they become sick are known as predisposing factors. Examples include factors that affect social structure, such as education, employment, ethnicity, social networks, interpersonal relationships, and culture, as well as health beliefs, which include people's attitudes, values, and perceptions of the healthcare system, as well as other demographic characteristics like age and gender.

Enabling factors: This group includes the practical elements of receiving care. Ability and knowledge to access health care services are prerequisites. Money, health insurance, a dependable treatment provider, the ability to travel, and the amount and quality of social relationships are other elements that contribute to personal and family support.. The accessibility of medical services and resources in a community, as well as the duration of waiting times for treatment.

Need factors: The need variables indicate both the real and perceived need for healthcare services. These variables include how individuals see their overall health and functional status and how they experience illness symptoms, pain, and health worries. They also include whether or not people think their issues are significant enough to warrant seeking professional help (Andersen, 1995).

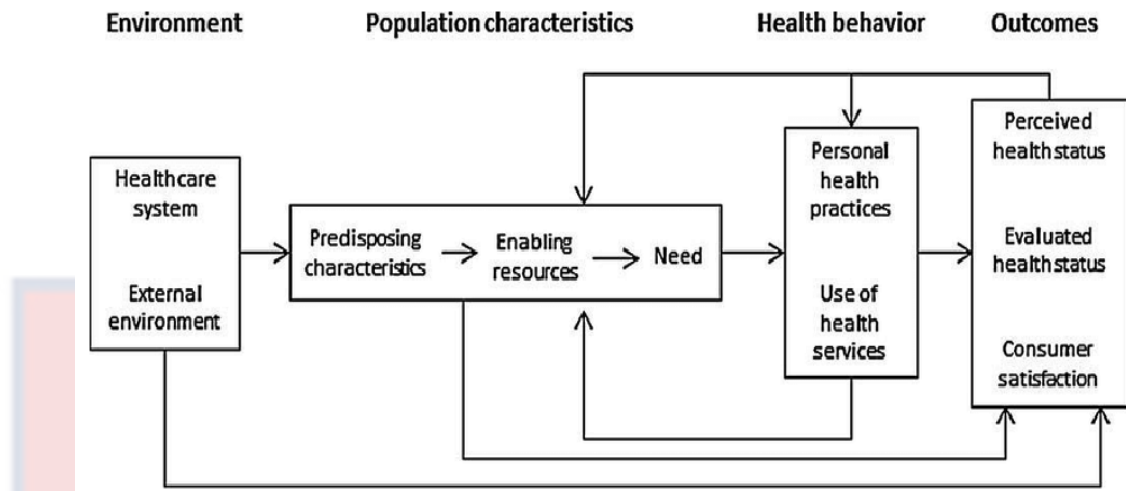


Figure 2: Healthcare Utilization Model

Source: Andersen, 1995

The HUM has been critiqued for not considering sociocultural dimensions and interactions and omitting the social construction of need (Kadushin, 2004). Also, predisposing factors might be exogenous, and enabling resources are necessary; thus, the model is considered inadequate, although it could expound on services use (Jahangir, Irazola, & Rubinstein, 2012). However, the tenets of the HUM are relevant to study objectives such as access to healthcare service utilisation; the extent of utilization of healthcare services and the determinants of healthcare services utilization.

Conceptual Framework of the Study

The Healthcare Utilisation Model (HUM) (shown in Figure 3) will serve as the theoretical basis for this investigation. There has been prior research on the issue of healthcare use; however, that research often ignored important determinants, context, and health status (Jiang et al., 2018). To better understand the elements that have been linked to changes in people's use of health care services, the Andersen model provides a useful framework. The modified model

is comprehensive in its ability to reveal all factors that may influence access to and utilisation of healthcare resources when applied to the treatment of SCD complications and illnesses. Several factors, such as the attitudes of healthcare providers, the availability of specialised facilities and professionals, the distance to healthcare facility, sociocultural norms and beliefs, and the cost involved in accessing and using healthcare services, can affect healthcare utilisation and, ultimately, health outcomes for SCD patients in this region.

The health belief model (HBM) has been adopted and utilised as a model in healthcare utilisation in literature, however its primary focus is on attitudes and beliefs. The HBM has been criticised for ignoring the impact of social norms and peer influences on people's decisions regarding health behaviour (Davidhizar, 1983) and for failing to account for environmental or economic factors that may influence health behaviours (Armitage & Conner, 2000). As a result, the HUM proposed by Andersen (1995) was used as the theoretical foundation for this investigation since it is more comprehensive in its coverage of healthcare utilisation. Potential impacts on healthcare use are divided into four broad categories: social determinants, predisposing factors, health system variables, and health status. It reveals how risk factors like age and educational level may influence healthcare service usage both directly and indirectly via ties to social determinants like an individual's health beliefs and cultural norms. Indirectly or directly, socioeconomic variables may alter components of the healthcare system, which in turn may affect SCD patients' choices and preferences towards the provision of healthcare. The likelihood and kind of healthcare use are both affected by an individual's health status. The relationship between healthcare use and health status is dynamic. Therefore,

many sets of determinants impact the healthcare use of SCD patients in various ways.

How the module applied to the research objectives

The module is constituted by healthcare utilization which addressed research objective one (healthcare use and non use). It is been influenced directly or indirectly by societal determinants (health beliefs, predominant cultural beliefs, and religious beliefs), that interact directly and indirectly with the individual health seeking behavior to influence access to healthcare services, which answered research objective two.

Health system factors (e.g distance to health facility, waiting time in the facility, cost of health services, availability of health service providers, attitude of service providers, availability of medications and supplies). Which answered research objective three and five. Pre-disposing/sociodemographic factors (age, sex, occupation, knowledge of health issues and educational level), which also address research objective four; and research objective six predicts the factors that were found to have significance association with healthcare utilization based on the analyses to ascertain the extent of the association.

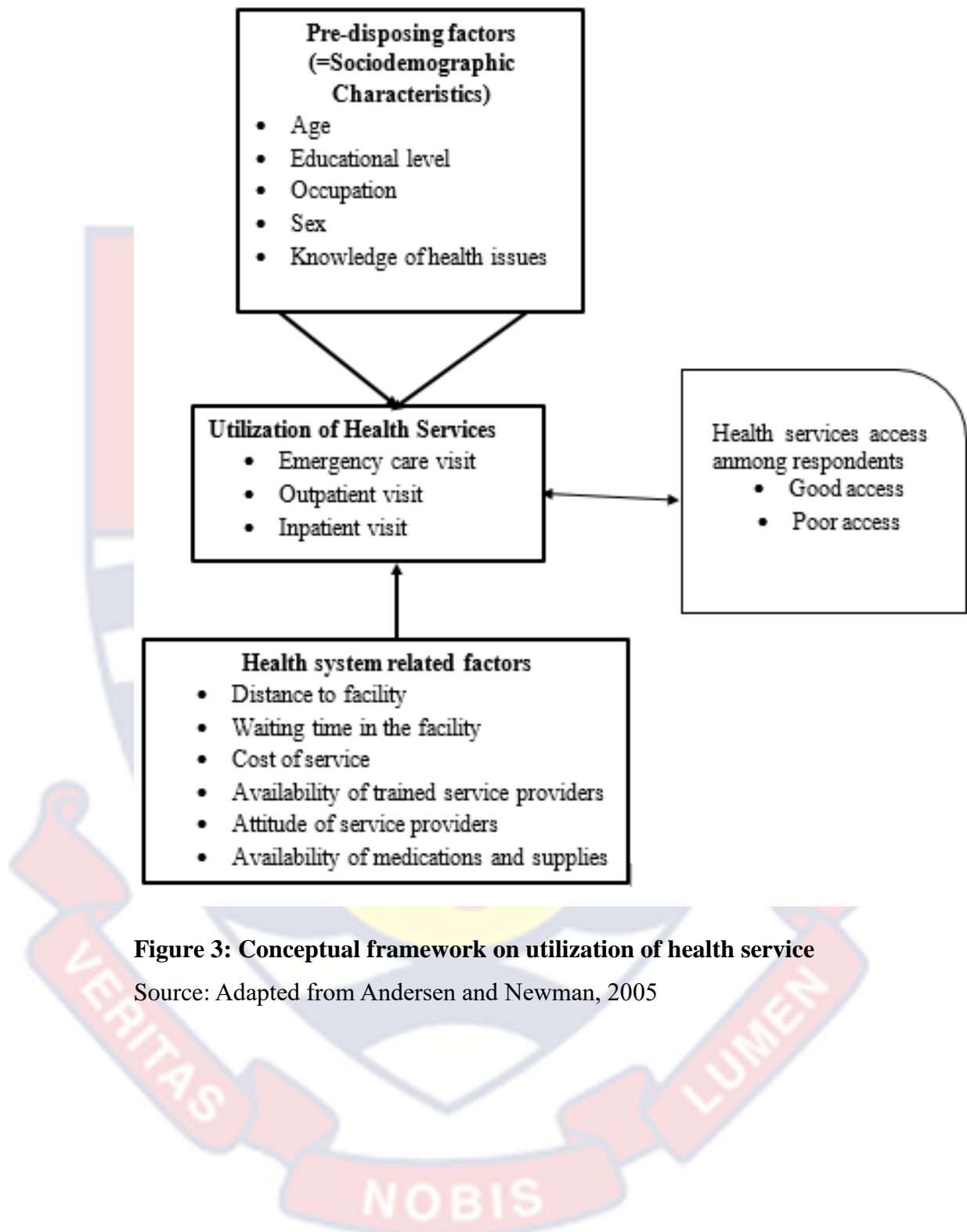


Figure 3: Conceptual framework on utilization of health service

Source: Adapted from Andersen and Newman, 2005

Empirical Review

This section reviewed related empirical studies relevant to the study, taking into cognizance, the research objectives and the conceptual framework.

Access to healthcare services among People with Sickle Cell Disease

The worldwide prevalence of sickle cell disease is a major public health issue. Since more and more individuals are now dealing with chronic illnesses, they must have easy access to the care they need to recover and lead normal lives (Kyriopoulos et al., 2014). Given the effects of the economic crisis on healthcare delivery and the increasing vulnerability of chronic patients, it is crucial to address the problem of access and the challenges faced by chronic patients in this period. Kyriopoulos et al. (2014) found that 63.5% and 58.5% of chronic patients, respectively, experience economic and waiting list difficulties, while 25% face geographical barriers. Financial barriers limit opportunities for the unemployed, the poor, and the ignorant. Women, low-income patients, and those with poor health conditions also suffer geographical barriers. People with modest earnings, those who work, and the unemployed are disproportionately represented on waiting lists.

Similar findings were observed in research by Schwarz et al. (2021), which concluded that problems with location, care coordination, financial stability, and comorbidity (e.g., taking into account the patient's mental health and other diseases) contributed to inadequate access to healthcare. Travel durations and distances were greater, and fewer medical facilities were available in outlying areas (Schwarz et al., 2021).

Vanstone (2013) found that main obstacles to receiving healthcare include geographical distance, a lack of available healthcare practitioners, and the unique cultural norms of rural areas. To begin, the remoteness of the areas in need of aid increases the likelihood that traffic and poor weather may make it harder to reach there. With the aid of rural services and community resources, maybe these difficulties might be lessened. Second, individuals may feel more defenceless if they are unable to consult with medical specialists due to factors such as illiteracy or isolation. Patients place a premium on being able to maintain a personal connection with their doctor and get personalised care close to home. Also, in the urban health care setting, patients with limited health literacy may face cultural marginalisation. Some patients may be more willing to forgo distant therapy if they live in a rural location, where there is a culture of self-reliance and community engagement (Vanstone, 2013).

According to the literature review, there are no published reports on access to healthcare services for people with sickle cell disease. The reviewed literature, however, demonstrated that people with chronic diseases, SCD included, had difficulty accessing healthcare services due to limitations such distance and a lack of healthcare professionals and facilities. When patients engage in self-destructive conduct and are less likely to seek treatment, they put themselves in danger. Patients' stories also provide insight on cultural norms, diminished resources, and joblessness. All of these factors have an impact on people's access to and use of medical care. The literature research revealed that no studies focusing on sickle cell disease patients' access to healthcare had been published. However, the reviewed literature shows that geographical distance and a lack of healthcare personnel and resources make it difficult for persons

living with chronic conditions, SCD included, to get the healthcare services they need. Unhealthy habits and a lack of motivation to seek help put patients at greater risk. Patients' perspectives also highlight cultural views, financial reduction, and joblessness. Health care availability and use are also affected by these variables. Also, the literature findings indicated poor access to healthcare by people living with chronic disease in general.

Healthcare Utilization among People with Sickle Cell Disease

Healthcare utilization (either at the emergency department, OPD, or in-patient wards) by people with SCD is usually a result of complications arising from the disease.

The most frequent acute symptom and the leading cause for seeking medical attention is the painful vaso-occlusive episode (Darbari et al., 2013). Frequent pain episodes often impact the limbs, back, chest, and abdomen (Houwing et al., 2019). At any time, severe pain might strike, necessitating immediate medical attention. Houwing et al. (2019) found that although most patients can self-manage their pain with just one inpatient stay per year, a very small number accounts for the great bulk of hospitalizations and ER visits. Some of the negative psychological impacts of sickle cell disease on this group of patients include the need for frequent hospitalisation, significant medical expenditures, and greater dependence on loved ones. From Cronin et al. (2019). There has been much study on the condition's aftereffects but much less on the variables that influence people's need for medical treatment. Research into the variables that predict health-care consumption has become increasingly important as evidence-based medicine and managed health care have increased in popularity and usage has been more monitored (Williams, Silva, Cline,

Freiermuth, & Tanabe, 2018). In an effort to reduce unnecessary hospitalisations, several facilities have devised outpatient programmes to address VOCs on a day hospital basis. Patients with SCD may get outpatient care for uncomplicated VOCs (VOCs not associated with another SCD condition or reason for hospital admission) in a day hospital (Williams et al., 2018). A day hospital visit is more cost-effective than an emergency room visit or inpatient hospitalisation, offering patients more convenience and faster recovery times. Separating sickle cell patients' ER visits from their other medical treatment is crucial (Cronin et al., 2019). If emergency department visits can be minimised while alternate treatments are promoted, healthcare use (including routine examinations) may become more efficient. According to a study of this phenomenon, 300,394 people with SCD visited emergency rooms between 1999 and 2007.

Yusuf et al. (2010) estimated that there were a total of 933,758,000 visits to emergency departments in the United States over that period (95% CI: 933,758,000, 1,073,966,000). A study conducted by Dupervil et al., 2016 in the United States estimated 584,652 weighted ER visits and inpatient admissions related to priapism among males with SCD between 2006 and 2010 using data from the National Inpatient Sample. However, their study results can not be a representative of emergency department visit and inpatients admissions for SCD patients in the United State because the study sample was limited to only male SCD patients with priapism. Patients were admitted to the hospital after 231,692 visits (about 40% of all visits) (Dupervil et al., 2016). According to Anderson and Bellot's (2014) quantitative exploratory investigation of the sickle cell disease population in Delaware's adult population, there were 518 events,

resulting in 202 hospital stays. This study results can not be generalize within SCD population in Delware, because the study exclude children with SCD within the population. In a retrospective analysis, Powell et al. (2018) counted 242 visits for SCD-related issues and 1188 for emergencies during their research. However, these findings could have been influenced by the retrospective study design. Like Silva's (2019) research, which counted 3,930 healthcare service use, 2,829 ED and day hospital interactions and 1,101 hospitalisations were recorded.

In addition, Brousseau et al.'s (2010) study on sickle cell patients' Acute Care Utilisation and rehospitalization found an annualised rate of 2.59 (95% CI, 2.53-2.65) encounters for acute care, including 1.52 (95% CI, 1.48-1.55) encounters for hospital admissions and 1.08 (95% CI, 1.04-1.11) for treat-and-release ED visits. Based on age, the yearly rate of acute care use for all patients with sickle cell disease was 1.50 (95% CI, 1.45-1.55) encounters, with almost 60% of them being inpatient hospitalisations. Acute care use was highest among patients aged 18 to 30, with an annual rate of 3.61 (95% CI, 3.47-3.75) encounters. Overall, inpatient hospitalisations accounted for between 55% and 69% of all encounters (Brousseau et al., 2010). There were 45,471 visits to the ER for diagnosis and release, and 63,873 hospitalisations.

Pneumonia accounted for 3.9% of all hospital admissions, while sickle cell crises accounted for 7.9%. Patients with sickle cell disease were more likely to attend the emergency room than those without the condition because of symptoms such as fever (3.1%), pain in a limb (3.1%), stomach pain (2.3%), or chest discomfort (2.2%) (Brousseau et al., 2010). Annual contacts among those with public insurance averaged 3.22 (3.13-3.31), while those without insurance

averaged 1.42 (1.33-1.51). Acute care utilisation peaked annually at 4.80 (95 percent CI, 4.58-5.02) visits per patient for those between the ages of 18 and 30 who were covered by public health insurance (Brousseau et al., 2010). In summary, the majority of the research (Powell et al. (2018), Brousseau et al. (2010), Silva's (2019) have shown increased rates of healthcare service use. Low healthcare use has been reported in the literature, although only by a small number of research (Anderson & Bellot, 2014). This may be the consequence of different methods being used. The research also found that age had a significant effect in healthcare utilisation, with those between the ages of 18 and 30 being the largest users of health care services and those beyond the age of 65 being the lowest patronages of healthcare services. Healthcare use is significantly affected by both age and insurance status, with the former showing a much greater rate of utilisation compared to the latter. In addition, most hospitalisations are attributed to the combination of sickle cell disease with crisis and pneumonia.

Factors Influencing Healthcare Utilization among People with Sickle Cell Disease

Sickle cell disease (SCD) patients have a greater morbidity rate and higher healthcare expenditures than those with other illnesses. Vaso-occlusive crises are a painful symptom of sickle cell disease (SCD) and need medical treatment in a hospital environment. Patients with SCD who are often hospitalised incur high healthcare expenses and get subpar clinical results. A better knowledge of the factors influencing healthcare consumption behaviours is the first step towards improved medical treatment for this patient population and decreased healthcare costs. Benenson, Jadotte, and Echevarria (2017)

performed a systematic review research on factors impacting usage of hospital services by adult sickle cell disease patients. They found that patients aged 25–35 had the greatest utilisation rate, while those aged 50+ had the lowest utilisation rate. Patients with high use rates also had a higher prevalence of acute chest syndrome and sepsis than those with moderate or low utilisation rates, according to the study. This study findings could be as a results of the study population used by the researchers (Adult SCD patients), hence, can not be generalize within the SCD population once children with SCD were not considered in the study. Other research studies have shown an association between high rates of acute care usage among SCD patients and incorrect use of healthcare (Nimmer, Hoffmann, Dasgupta, Panepinto, & Brousseau, 2015; Bundy et al., 2011), but they also noted that this association may be unavoidable due to the severity of the illness.

Another study conducted by Robert et al. (2019) on risk factors for hospitalizations and readmissions among individuals with sickle cell disease discovered that age, mental health, financial insecurity, spirituality, and clinic attendance were modifiable factors associated with SCD patients' healthcare utilization. Some researchers also point out that common risk factors associated with healthcare utilization among SCD patients were age (Glassberg et al., 2015; Sobota, Graham, Neufeld, & Heeney, 2012; Brousseau, et al., 2010; Aljuburi et al., 2012), insurance status (Glassberg et al., 2015; Brousseau et al., 2010), living in low socio-economic areas (Aljuburi et al., 2013), Lack of outpatient follow-up (Leschke et al., 2012; Frei-Jones, Field, & DeBaun, 2009), additional comorbidities such as asthma (Frei-Jones et al., 2009), and a primary care provider (Brodsky et al., 2016).

Another study by Zakaria et al. (2021) found that the most prevalent medical problems for people with SCD were vaso-occlusive crisis episodes, acute chest syndrome, and hemolytic crises which influence their healthcare usage. Higher healthcare use was also seen among those with hip avascular necrosis (Zakaria et al., 2021). Age, insurance status, and distance to the closest self-identified provider of comprehensive SCD care were shown to be a major sociodemographic predictors of healthcare utilization in a retrospective cohort study undertaken by California researchers in California to discover the sociodemographic determinants of emergency department visits. The study has outlined major predictors of healthcare utilization, however, the finding could be as a result of the study design (retrospective cohort study), and the study settings (SCD patient in California). It was also shown that characteristics such as disease severity, urbanisation, gender, race, and ethnicity all had a role. The findings of a cross-sectional study done by Benenson et al. (2015) in the United States were also made public. Both modifiable and immutable factors were identified as influences on healthcare use among SCD patients. It was shown that factors including age, sex, ethnicity, and SCD genotype could not be changed. Socioeconomic status (such as education, income, insurance status, and access to outpatient care), mental health (such as anxiety, depression, optimism, and perceptions of discrimination), and disease state (such as haemoglobin level, complications, comorbidities, pain severity, and opioid dependence) were all identified as modifiable factors by Benenson et al. (2015).

In 2015, findings from a comparable cross-sectional investigation were published by Benenson et al. Both immutable and changeable elements were identified as contributors to SCD patients' use of healthcare services. It has been

reported that the SCD genotype, age, and sex are fixed characteristics. Benenson et al. (2015) identified modifiable socioeconomic factors like education, income, insurance status, and access to outpatient care; psychological factors like anxiety, depression, perceived optimism, and perceived discrimination; and disease-related factors like haemoglobin level, presence of complications, presence of comorbidities, severity of pain, and opioid dependence as factors influencing healthcare utilization.

Similar findings from a cross-sectional research by Benenson et al. 2015 identified factors that can be changed and those that cannot in explaining why patients with SCD use healthcare services more or less often. Some variables were reported to be fixed, including the SCD genotype, age, and gender. Benenson et al. (2015) identified modifiable socioeconomic factors (including education, income, insurance status, and access to outpatient care), psychological factors (including anxiety, depression, perceived optimism, and perceived discrimination), and disease-related factors (including haemoglobin level, presence of complications, presence of comorbidities, severity of pain, and opioid dependence) as factors influencing healthcare usage.

In general, a wide range of the literature findings revealed unemployment, unstable home structure, age, insurance status, and distance to the nearest self-identified provider of comprehensive SCD care as the major predictors of health care utilization. Additional influential variables in the literature include: insurance status, disease severity, urbanicity, gender, race, ethnicity, mental health status, financial insecurity and spirituality.

However, these study findings could be as a results of the various research methods, research designs, settings and population used by the researchers.

Common Health Problems Associated with SCD Patients that influence healthcare services utilization

The sickle cell genes cause the body to create HbS, a type of defective haemoglobin which differs from normal haemoglobin (HbA) in its behaviour (Chakravorty & Williams, 2015). HbS polymerizes when it is deoxygenated. When critical amounts of HbS polymer accumulate within sickle erythrocytes, cellular injury results and a highly variable phenotype becomes apparent” (Steinberg & Rodgers, 2001). HbS causes red blood cells to shift from their regular doughnut shape under certain circumstances. It takes on the shape of a sickle, like a crescent moon. This is referred to as sickling. Colds, infections, lack of fluid in the body, low oxygen and acid produced during physical exercise trigger sickling.

A major health problem associated with SCD is poor health-related quality of life.

Adults and children with SCD have significantly lower baseline HRQOL (Dampier, et al., 2015; Panepinto & Bonner, 2012). Individuals with SCD exhibit worse HRQOL in practically every category compared to healthy people, particularly in pain, tiredness, and physical function (Keller, Yang, Treadwell, Werner & Hassell, 2014; Panepinto, 2012). Sleep quality influences the link between pain and exhaustion, according to adolescents and adults who report poor sleep quality and moderate levels of weariness (Panepinto, 2012). As stated by Kato et al. (2018), many persons with SCD have a physical

functional HRQOL that is worse than or on par with those who suffer from other chronic diseases including cancer, cystic fibrosis, or obesity. It has been shown that acute effects, including acute vaso-occlusive pain crises, are associated with worse HRQOL compared to the start of treatment (Brandow, Brousseau, Pajewski, & Panepinto, 2010). Newborns often develop them at approximately the fifth month mark. Painful episodes have been described as a stabbing or throbbing sensation that might come on suddenly. The pain may be debilitating, requiring frequent visits to the hospital or emergency room. Physiological, cognitive, and emotional effects of SCD complications such as anaemia, infection, and stroke have been documented (Brandow et al., 2010). HbS polymerization is a key pathophysiological process in SCA (Kato et al., 2018), notwithstanding the complexity of vaso-occlusion as a phenomena. The process of HbS polymerization induces modifications in the morphology and physical properties of erythrocytes, resulting in the development of haemolytic anaemia and the blockage of blood arteries, particularly in small and sometimes large capillaries. These pathological effects have the potential to inflict damage upon many organs inside the body. Haemoglobin S (HbS) polymerization may also occur among reticulocytes, a subset of red blood cells that constitute around 20% of the total red blood cell population in individuals with sickle cell anaemia (SCA). The direct and indirect consequences of haemolysis have a significant role in altering the progression and problems associated with sickle cell disease (SCD). Furthermore, the presence of HbS polymers gives rise to a multitude of cellular abnormalities, which play a significant role in the overall pathophysiology of sickle cell disease (SCD). The pathophysiology of the many genotypes of sickle cell disease (including doubly heterozygous situations or

sickle cell anaemia with modifying genes) exhibits similar characteristics. According to Manwani and Frenette (2014), individuals with sickle cell disease (SCD) have notable challenges related to physical functioning, discomfort, and sleep both during and immediately after vaso-occlusive crises. Individuals with sickle cell disease whose QoL is negatively impacted by the existence of pain post discharge, functional limits, and the impacts on caretakers are those who have had treatment for painful episodes. Why? Because it has been shown to have negative effects on health (both mental and physical), relationships, productivity at work, and academic performance (Dampier et al., 2015). Dampier et al. (2015) found that more than half of people with SCD suffer pain at least 50% of the time, and that nearly one-third of individuals with SCD have discomfort practically every day. Children with SCD who received hydroxycarbamide or chronic red blood cell transfusion therapy fared better overall and experienced less pain than those who received placebo or a poor response to treatment (Thornburg, Calatroni, & Panepinto, 2011; Beverung et al., 2015). However, these study findings could be as a results of the experimental research design employed by the researchers. Keeping tabs on the HRQOL of SCD patients while new investigational drugs are tested in clinical trials is essential.

Research by Asnani et al. (2017) looked at the connection between SCD patients' exposure to their social environments and their health. Painful crises, leg ulcers, and respiratory diseases such acute chest syndrome and asthma were shown to have a considerable influence on healthcare use as major clinical consequences of SCD (Asnani et al., 2017).

In addition, throughout the 6-month baseline period of their inquiry, 24.6% of the eligible patients were found to have at least one variation of concern (VOC) requiring hospitalisation (Shah et al., 2020). At 19.74%, infectious disease was the most common comorbidity in the baseline study by Shah et al. (2020). After that came fever (9.3%), neoplasms (7.2%), and asthma (10.9%).

In conclusion, the medical literature shows that people with sickle cell disease (SCD) have a wide range of clinical problems that have an effect on their healthcare use. Leg ulcers, painful crises, respiratory illnesses such acute chest syndrome and asthma, vaso-occlusive crises, fever, neoplasms, and infectious infections are all examples of these consequences. These factors significantly influence how SCD patients seek and utilise healthcare resources.

Impact of Healthcare Utilization on Health Outcomes of People with Sickle Cell Disease

Most healthcare utilization for SCD management is devoted to health maintenance and treating acute and chronic consequences (Brandow et al., 2010). Antibiotic treatment, pain crisis management, and blood transfusions are all recommended for patients with asplenia as part of health maintenance measures (Brandow et al., 2010). Screening or diagnostic tests for SCD-related complications are also recommended. The most promising treatment, stem cell transplantation, is also very risky and seldom used (Kamani et al., 2012; Locatelli et al., 2013). Reducing the occurrence of painful crises is an important therapeutic goal in SCD since there is currently no pharmacotherapeutic therapy and most disease management is palliative. Hydroxyurea, an anticancer medication, is often used as the first line of treatment. This medication aids in

the prevention of crises in both adults and children by increasing the amount of foetal haemoglobin present in the patient's red blood cells (RBCs), which has a number of beneficial effects on RBC structure, content, and function (Wong et al., 2014). This lowers the need for transfusions and protects against potential organ failure. More recently, the US Food and Drug Administration (FDA) authorized L-glutamine as an alternate medication for the treatment of SCD in children and adults, with the goal of minimizing severe SCD-related consequences (Sarri et al., 2018).

Despite the presence and use of hydroxyurea and L-glutamine, sickle cell disease (SCD) continues to be a disorder that lacks adequate solutions, resulting in many people experiencing unfavourable clinical outcomes in both the short and long term. Furthermore, there is a large body of data showing that SCD is significantly correlated with a major reduction in the total burden experienced by persons afflicted with SCD. Understanding the scope and severity of this deficiency in terms of humanistic aspects is complicated by the lack of clear understanding regarding the most effective patient-reported outcome (PRO) instruments used thus far to accurately assess the experience of individuals with sickle cell disease (SCD). Another drawback is the inability to examine any differences in this deficiency across various patient subgroups or at different stages of illness (Sarri et al., 2018).

Jiang et al. (2018) observed that 12.8 percent reported being in less-than-ideal health among those seeking medical attention, whereas 44.5 percent reported being in good health in their own estimation. According to Jiang et al. (2018), 16.5% of the participants had experienced hospitalisation during the

year before the research, while 14.5% had sought medical care as outpatients in hospitals or clinics within the two weeks before the study.

Summary and Conclusion Drawn from the Literature

Chronic conditions are associated with increased use of healthcare services, and sickle cell disease (SCD) is no exception. Individuals with sickle cell disease (SCD) have a significantly reduced life expectancy compared to the general population. The major purpose of this research was to examine what variables affect sickle cell disease patients' access to medical treatment. The method used in determining objectives was analysed in light of the available literature.

Conceptual review, theoretical review, and empirical review were the review's three main sections. As a result of this theoretical investigation, a conceptual framework was created that is based on ideas from the many theories considered.

This study highlighted the dearth of primary research on healthcare service availability and use for those with SCD. Most studies have shown that people with SCD have a number of problems and emergencies that need prompt medical attention, but the availability of such treatment has not been studied. This is significant since lack of access to care has been cited as a key impediment to treatment among those with chronic illnesses like SCD. Furthermore, the kind and quantity of healthcare used by SCD patients has not been investigated in most research since healthcare utilisation has been viewed as a single variable. The majority of studies were also done in urban rather than rural areas, and in developed rather than underdeveloped nations. There is a paucity of research on this issue in Africa and Ghana, and none at all in the

Upper West Region of Ghana, where this investigation takes place. The current study thus investigates healthcare accessibility and utilization taking into account the different care services used as well as its associated factors to bridge the knowledge gap in the literature.



CHAPTER THREE

RESEARCH METHODS

Introduction

The study's methodology presents the process used to collect the empirical data needed to address the study's research problems and issues. To that extent, this chapter thoroughly comprehends and explains the research approach and design. Further, this section includes population, data source, sample and sampling technique, data collection instrument, data collection procedure, data processing and analysis, and chapter summary.

Research Approach

The positivist approach (quantitative approach), which permits objective evaluation of a variable with little engagement from the researcher, served as the approach for this study (Creswell & Creswell, 2017). With this approach, important questions that characterized the information collected on the determinants of health services utilization among sickle cell disease patients could be analysed numerically, and the results presented statistically, with tables and graphs. The study assumed minimum contact with the research participants to guarantee complete neutrality (Wilson, 2010).

Research Design

A cross-sectional survey was used as the study's methodology. In determining the time points for data collection, this design allowed the researcher to draw statistical conclusions from a representative sample of the study population using the data gathered in a cross-sectional survey (Creswell, 2013). The design also allowed generalizations about the specific population

regarding a phenomenon of interest, like health service utilization (Aday & Cornelius, 2006). With cross-sectional study design, data may be collected rapidly and efficiently, even for a large sample size. Results and risk factors for the whole population may be evaluated with relative ease since the sample is representative of it (Setia, 2016). The ease with which one may collect the necessary information is inversely proportional to the data's cost-effectiveness, thus making this design ideal for the study.

Cross-sectional studies have a drawback because they do not offer a solid foundation for determining causality. Cross-sectional research can suggest a connection between the two but cannot conclusively show that one caused the other. Confounding effects are another reason why cross-sectional studies fall short. Although they would not directly change the variables of interest, other factors may impact how they relate to those variables (Setia, 2016). In nursing, cross-sectional studies are often utilized to learn more about a condition's prevalence rate, particularly during an epidemic. Examples of cross-sectional studies in nursing include the survey of nurses in Quebec, Canada, conducted by Gagné et al. in 2019, and the study conducted by Akay, Bozkurt, and Bulut (2023) on the relationship between care dependency and mental health continuum in patients with chronic obstructive pulmonary disease.

Study Settings

The research was conducted in the Upper West Region, which is one of the 16 administrative areas of Ghana. The geographical coordinates of this location in Ghana are situated in the northwestern region, namely between latitudes 9.8° and 11.0° North and longitudes 1.6° and 3.0° West. Burkina Faso borders it to the north. The region in question has an expanse of 18,476 square

kilometres, which accounts for around 12.7 percent of Ghana's overall land area (GSS, 2014). The northern region of Ghana-Burkina Faso is geographically next to the Upper East and Northern regions in the east, the Northern region in the south, the western region of Ghana-Burkina Faso in the west, and the Upper West region in the north. The region under consideration is the seventh biggest in terms of total area within the country of Ghana. It has a total of eleven districts, as reported by the Ghana Statistical Service in 2014. The Upper West Region has advantageous circumstances for international and inter-regional commerce and the development of bilateral ties as a result of its strategic location. Nonetheless, it's vital to recognise that the area is vulnerable to external negative influences like armed robbery, sickness, plague, and forest fires that spread from nearby areas. All of these things pose serious difficulties and possible dangers to the area. The Upper West Region of Ghana relies heavily on agriculture as its main source of income (Ghana Statistical Service, 2014). According to the 2010 census of population and housing results, a total of 702,110 people call the area under consideration home (GSS, 2014).

The Upper West Region has the Wa Municipality as its centre and the Regional capital. The Wa Municipality has the Wa Municipal Hospital, a secondary level health facility and 13 functional CHPS zones (GSS, 2014). The study participants were selected from the Wa Municipal Hospital's Sickle Cell unit which serves as a referral centre for SCD patients within the Region. The hospital has bed capacity of 206 and a staff strength of 11 medical doctors and 198 nurses while the sickle cell disease clinic has 8 nurses, including paediatric nurse specialists. The sickle cell clinic provides out-patient department services with a current population of 580 clients. However, some clients are admitted to

the wards depending on the severity of their conditions. Some of the services rendered at the clinic include: health education (on the condition, medications, appropriate nutrition, and possible complications), laboratory tests, and physical examination among others.

Study Population

In a research study, the population refers to the specific events, objects, or individuals that interest the researcher (Sekaran & Bougie, 2016). Accordingly, the population can be defined to cover a vast collection of cases or narrowly defined to include only a few things. As per Fink (1995), a unit's inclusion measures depend on the respondents' characteristics and criterion interest in the study. For this reason, the target population consisted of individuals diagnosed with sickle cell disease who sought healthcare services at the Wa Municipal Hospital.

Inclusion and Exclusion Criteria

People with the diagnosis of SCD (Hb SS, Hb SC) living in the Upper West Region and accessing healthcare at the Wa Municipal Hospital for at least the last six months prior to the period of data collection were included in this study. By including individuals with a longer history of healthcare utilization at the Wa Municipal Hospital, the study may benefit from increased data validity. Participants with an extended duration of engagement are likely to provide more accurate and detailed information about their experiences, contributing to the overall robustness of the study findings. The specified time frame of at least the last six months before data collection suggests focusing on individuals with recent and ongoing experiences within the healthcare system. This temporal criterion helps capture current perspectives and challenges, providing a more

relevant and timely portrayal of the healthcare landscape for individuals with SCD in the region.

However, individuals with SCD who are seriously ill (in severe crisis) were excluded from participating in the study as a result of their crisis state, which could hinder their abilities to effectively and comfortably contribute to the study findings due to the severe pains.

Sampling Procedures

Sampling is a methodical process involving selecting a subset of people from a larger group to represent the whole population properly (Lobiondo-Wood & Haber, 2010). The study used a systematic random sampling approach to choose participants for the examination. This methodology allowed the equitable opportunity for every individual within the population to be included in the research (Wilson, 2010). The methodology included using the registry of patients diagnosed with sickle cell disease (SCD) at the Wa Municipal Hospital as the sample frame. Following this, a registrant was selected at random and subsequent registrants selected using a regular interval ($k=580/248\approx 2$). Thus, every 2nd registrant after the randomly selected registrant was included and this was repeated until the minimum sample size was obtained.

Sample Size Determination

The sample size for this study was determined using Yamane's (1967) sample size calculation formula:

$$n = \frac{N}{1 + N(\alpha)^2}$$
 where n is the sample size, N is the population size (580

according to the Wa Municipal Hospital's SCD 2021 register) and α is the margin of error (0.05 at 95% confidence interval). Thus;

$$n = \frac{580}{1 + 580(0.05)^2}$$

$$n = \frac{580}{1 + 1.45}$$

$$n = \frac{580}{2.45} = 236.7$$

Considering a 5% non-response rate (Brick & Williams, 2013), the sample size for this study will be 248.

Data Collection

Data Collection Instrument

The investigation was conducted with the use of a standardised questionnaire. Questions on healthcare availability, usage, and predictors were adapted from two separate surveys (Reeves et al., 2019; Asnani et al., 2017). The questionnaire, which has four distinct parts, labelled A - D. Section “A”, was designed to gather information on the socio-demographic characteristics of the participants. Section “B” gathered data about the accessibility of health services, while section “C” concentrated on the many variables that impact the utilisation of healthcare services. This portion explored the motivations, predictors, and obstacles associated with using health services. Additionally, section D evaluated the common health problems of the respondents (Reeves et al., 2019; Asnani et al., 2017).

The questionnaires were adapted as follows; the sociodemographic data covering research questionnaire number 1 to 8 and research questionnaire number 9 through to 14 that addressed healthcare service accessibility were adapted from Reeves et al., 2019. While questionnaire number 15 to 22 that addressed healthcare services utilization and factors influencing healthcare usage were adapted from Asnani et al., 2017. Additionally, questionnaire

number 23 to 31 that evaluate the current health problem of respondents were also adapted from Asnani et al., 2017. The following questions were modified and added to the tool based on recommendations made by field experts: Question 5, which read; what is your highest level of education was added? Question 7, which read, what is your residence? Question 8, which read, how long since you were diagnosed of SCD? Question 13 which read, expensive is it to access healthcare? The question of how affordable the services provided for SCD care was replaced. Question 14: do you have difficulty going to the doctor when you want to consult? Was replaced by the question, how often did capable health professional available to care fore you? Question 15 to 17, which read, how many times do you use the following services for the last 12 months for SCD related issues Question 15 emergency care visit, question 16, inpatients visit, and question 17 non-preventive out patient visit were added.

Study Variables

The dependent variable of this study is healthcare service utilization. The independent variables include socio-demographic variables such as sex, age, religion, marital status, educational level, occupation and duration of awareness of SCD status, healthcare service accessibility, and determinants of healthcare utilization.

Pre-testing

The instrument was pre-tested among 50 SCD patients in the Wa Municipal Hospital's sickle cell unit. The pre-test sample was not part of the main data collected for the study because it was used to pre-test the data collection instrument to make any possible corrections before the main data collection. The pre-testing ensured the tools were checked for consistency and

appropriateness in assessing the needed data relevant to adequately addressing the research questions. Some questions were modified, replaced or deleted following the pre-testing to remove any ambiguities and ensure validity of the questions and responses. For example, research questionnaires number 11 and 12 were modified by combining them as question 11, which reads “How close or far is a health care facility providing SCD care to your residence“, and research questionnaire 9, which reads: what is your genotype, was taken off.

Validity and reliability of instruments

Validity is the ability of an instrument to measure what it is intended to measure appropriately and accurately (Gerrish & Lathlean, 2015). A pre-test was conducted among 50 SCD patients who were excluded from the study participants to help correct inappropriate questions and refine the instruments. The instrument was also designed per the research objectives and literature reviewed. Draft copies of the instruments was presented to my research supervisors for face validity. About content validity, experts were involved to see whether items in the instrument were duly represented in the construct to be measured (Gerrish & Lathlean, 2015).

Reliability describes the consistency with which results are obtained using the same instrument over time (Gerrish & Lathlean, 2015). To establish the internal consistency of the questionnaire, it was initially pretested and Cronbach Reliability Alpha Coefficient was calculated. A 0.71 Cronbach Alpha reliability coefficient ascertained reliability. This meant that the questionnaire had internal consistency and delivered the expected results.

Data Collection Procedure

Two research assistants helped administer the surveys over the phone and in person to collect the necessary information. The researcher hired two graduate students with skills in quantitative data collecting to work as research assistants. They were given a full day training that included everything from properly using the research instrument to an overview of the study's goals and methodologies. Furthermore, they were people who could engage in communication using the indigenous Dagaari language. The primary responsibility of the research assistants was to assist the investigator in facilitating and retrieving questionnaires from the study participants. The study used a telephone-based strategy to contact respondents residing in geographically remote places who are hard to reach and had given their agreement to participate. Conversely, face-to-face delivery of the questionnaire was employed for those who were readily accessible. Before administering the surveys, a thorough explanation of the study's objectives was provided to each chosen individual. The adults at the ages of 18 and above were then given the consent forms (Appendix IIa) while children under the age of 18 were also given the assent forms (Appendix IIb). Participant who consented to take part in the study were then included. Questionnaires were checked for completeness and validity of responses following every data collection session.

Data Management

After the data collection process, 248 questionnaires were appropriately completed and returned out of 258 questionnaires administered, and 10(3.8%) were not returned. The questionnaires were checked for completeness and validity of responses before they were kept in an envelope and sealed until the

researcher was ready to process the data. Data were entered into a template on Statistical Package for Social Sciences (SPSS) version 22.0 through a double entry process to ensure good data quality. The completed surveys were sealed in an envelope and stored securely after being entered. Manual savings were done as soon as possible throughout the data entry process to avoid data loss. At each data entry, a backup on an external drive was set up as well as on the principal researcher's Google Drive and email to prevent accidental data loss. Information obtained from respondents was coded and identified by the codes, and only the principal researcher had access to the respondents' data.

Data Processing and Analysis

Data Preparation

Subsequently, the data underwent a process of cleaning, coding, and preparation in order to facilitate analysis. Initially, a thorough verification process was conducted to cross-reference the duplicated data with the corresponding questionnaires in order to ascertain the accuracy of all inputs in the Statistical Package for the Social Sciences (SPSS). Throughout this procedure, the identification and rectification of input mistakes were conducted, while the elimination of duplicate entries and unnecessary data was also undertaken. The cases in which it was necessary to skip further questions due to the first prompt questions were examined by conducting a frequency distribution analysis to see whether the replies matched. To detect outliers in terms of age and duration of Sickle Cell Disease (SCD) diagnosis, a histogram plot was used to visualise the data. The values that deviated significantly from the median or mean were visually inspected.

Age and duration of SCD diagnosis were transformed from continuous to categorical variables by converting them into age groups and year groups, respectively. Age was grouped using 10-point interval into five groups: younger than 10, 10–19, 20–29, 30–39, and 40 or older years and coded as 1, 2, 3, 4, and 5, respectively. Duration/years with SCD diagnosis was categorized into six groups using five-point intervals, namely; less than 5, 5–9, 10–14, 15–19, 20–24, and 25 or more years and coded as 1, 2, 3, 4, 5, and 6, respectively. There were no missing values. This was achieved as a result of the fact that the questionnaire were interviewer-administered to reduce risks of omissions, they were checked for completeness of data before ending each data collection. Again, the data were entered using double data entry approach. These helped avoid missing values.

Data Analysis

The analysis involved both descriptive statistics (frequency, percentage, mean, and standard deviation) and inferential statistics (chi square and logistic regression tests). Thus, categorical variables (such as sex, educational level, occupation, ethnicity, place of residence etc.) were summarized as frequency and percentage whereas continuous variables (including age and duration of SCD diagnosis) were summarized using mean and standard deviation.

Health service accessibility was assessed using a 4-point Likert scale of 1–4 (from lowest to highest accessibility) made up of six (6) items. Total service accessibility score was calculated by summing for each participant ratings for all the 6 items. All the 6 items/variables were composited into a service accessibility index score. This was done by adding the responses for all the 6 items. The total index score ranged from a minimum of 6 to a maximum of 24.

While index score is the individual score/rating for each item in the questionnaire. Then the mean of the total index scores was computed by dividing the sum total of the index scores (3,348) by the sample size (248). Participants with total index scores less than the mean (generated from the summed total= 13.5 ± 2.127) were considered having *poor accessibility* whereas those with scores equal to or higher than the mean were graded *good accessibility* (figure 4) (Cabrera-Barona, Blaschke, & Kienberger, 2017).

The dependent variable in this study was healthcare utilization which was measured as use of any of the three healthcare services namely; emergency care, in-patient care, and non-preventive out-patient care. Healthcare service use was determined by a yes response to utilizing at least one of the three healthcare services (emergency care, in-patient care, and non-preventive out patients care). Thus, healthcare utilization was categorized as *healthcare use* indicating a use of at least one healthcare service and *healthcare non-use* indicating no use of any healthcare service. This was then analyzed by generating frequency and percentage. It was further analyzed using cross-tabulations with chi square to identify its relationship with the respondents' health problems.

To investigate the factors associated with healthcare service use, inferential statistics involving chi square test and logistic regression analysis were carried out. The chi square test is used when testing relationships between categorical variables, and was used to evaluate tests of independence variables (Swinscow & Campbell, 2002). Thus, with dependent and independent variables being categorical, the chi square test was considered most-appropriate. Also, binary logistic regression is employed to assess how well a set of variables predicts a categorical dependent variable and it is most suitable when the

variable is dichotomous (Fávero & Belfiore, 2019). The dependent variable of this study, healthcare use, is dichotomous and thus, its predictors are better analyzed using logistic regression.

Chi square tests were carried out to ascertain statistical association between dependent variable (health services utilization) and independent variables (access to health services and socio-demographic characteristics of respondents) at a statistical significance of p-value less than 0.05. After this, statistically significant variables (respondents' age group, Availability of health facilities providing sickle cell care, Closeness or farness of a health facility providing sickle cell care to residence, and Time taken to reach nearest health facility for care) were considered for bivariate logistic regression (crude odds ratio). The bivariate logistic regression test was used as it allows a closer look at the relationship between the dependent variable and any potential independent variables without considering the effect of other independent variables present (Fávero & Belfiore, 2019). Variables which were statistically significant at this stage (Age group, Closeness or farness of a health facility providing sickle cell care to residence, and Time it takes to reach nearest health facility for care) were then examined in the multivariate logistic regression (adjusted odds ratio). This test considers the interplay between all of the independent factors in addition to their effects on the dependent variable (Fávero & Belfiore, 2019). The cutoff for statistical significance was p 0.05 with a 95% level of confidence. Tables and charts were used to display the data.

Ethical Consideration

Ethical approval for the study was sought from the University of Cape Coast Institutional Review Board (IRB) and permission obtained from the managements of the Upper West Municipal Hospital. Prior to inclusion in the study, verbal and written informed consent was obtained from the adult study participants while assent was obtained from the guardians/parent of participants under 18 years old. Again, the standard for Declaration of Helsinki for Ethical Principles Involving Human Subjects (World Medical Association, 2001) was followed. In particular, anonymity and confidentiality of the study respondents were ensured. This was done by ensuring that no personal identifying information of the participants were collected but rather pseudonyms were used. Also, data collected were not shared with any third parties and have been kept under lock and key while the soft copy is password-protected on the personal computer of the principal investigator in order to ensure confidentiality of the participants. Also, there was stand-by clinical psychologist to provide psychological support for any respondent that may have psychological issues with regard to responding to the study questionnaires.

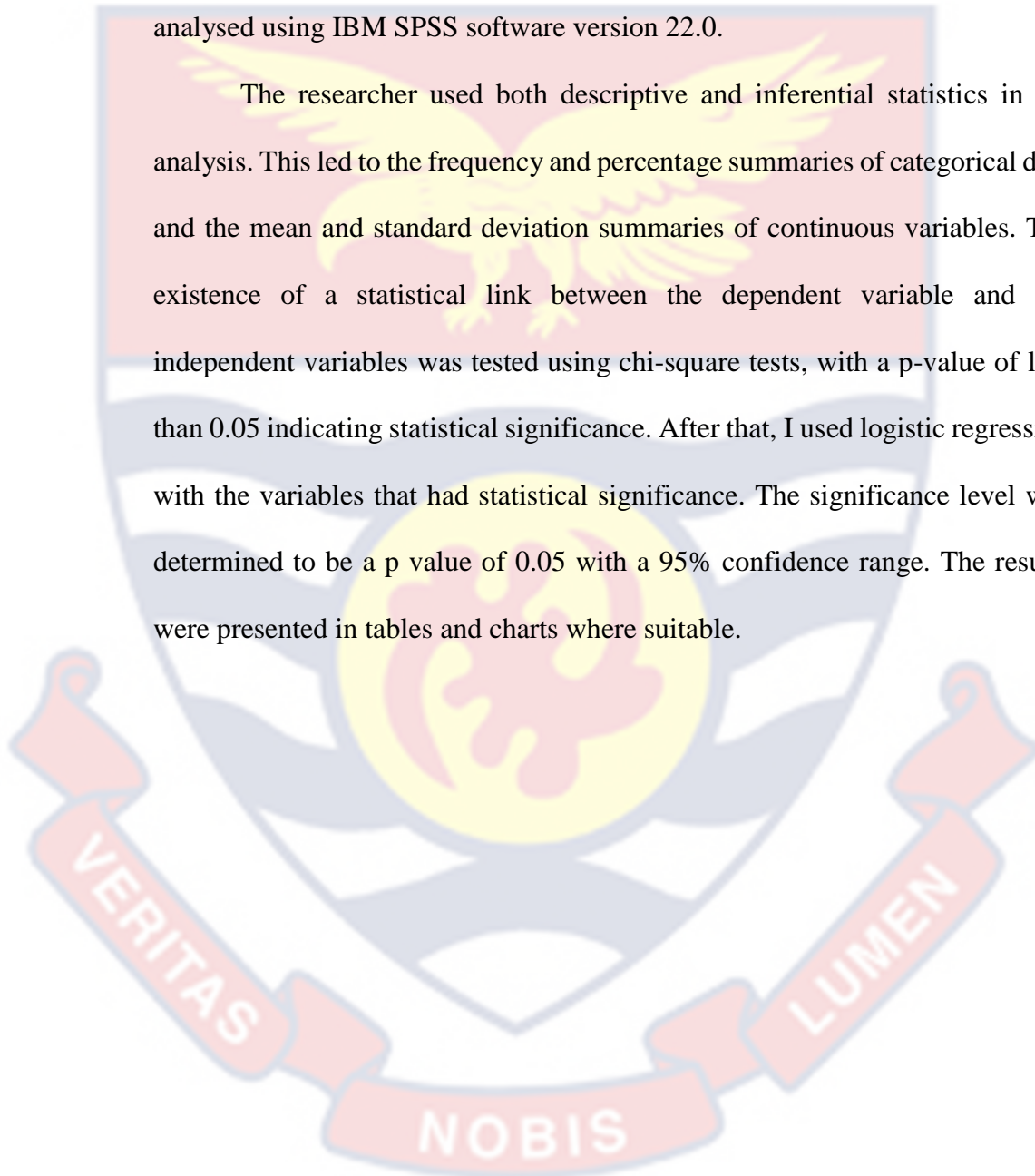
Summary of Chapter

This section discussed the methodological considerations that were made during the research process. The research was quantitative in nature, and a questionnaire-based cross-sectional design was used. Two hundred forty-eight people were selected at random from a pool of five hundred and eighty for the study. The survey's foundation was the positivist worldview. A structured questionnaire, adapted from a previously developed instrument, was utilised to gather the data for this study. The determination of the sample size for this

investigation was based on Yamane's (1967) sample size calculation method. Validity and reliability of the data were assessed, with the resulting Cronbach's alpha value being 0.71.

After data was collected from the field, cleaned, and coded, it was analysed using IBM SPSS software version 22.0.

The researcher used both descriptive and inferential statistics in the analysis. This led to the frequency and percentage summaries of categorical data and the mean and standard deviation summaries of continuous variables. The existence of a statistical link between the dependent variable and the independent variables was tested using chi-square tests, with a p-value of less than 0.05 indicating statistical significance. After that, I used logistic regression with the variables that had statistical significance. The significance level was determined to be a p value of 0.05 with a 95% confidence range. The results were presented in tables and charts where suitable.



CHAPTER FOUR

RESULTS AND DISCUSSION

Introduction

The findings from the data analysis are presented in this chapter. The article also compares the study's main conclusions to the relevant literature, standards, and conceptual framework. The presentation of the findings is based on the study's specific objectives: 1. To determine the level of accessibility to health care among SCD patients; 2. To determine the level of healthcare services utilization among sickle cell disease patients in the Upper West Region, 3. To determine the facilitators and barriers to healthcare utilization among sickle cell disease patients in the Upper West Region of Ghana, 4. To identify the socio-demographic and health service factors influencing healthcare utilization among sickle cell patients in the Upper West Region of Ghana, 5. To identify the health services-related factors influencing healthcare utilization among sickle cell disease patients in the Upper West Region of Ghana, and 6. To examine the factors that predict health service utilization among patients with sickle cell disease. The analysis includes descriptive and inferential statistics with a sample size of 248 participants.

Socio-demographic and clinical Characteristics of respondents

This section highlighted the social-demographic and clinical characteristics of the respondents.

Socio-demographic Characteristics of respondents

It included their age, gender, marital status, educational level, occupation, place of residence, religion, and years of SCD diagnosis. The

frequencies and percentages were used as a unit of analysis. The results are presented in Table 2 and discussed below.

Table 2: Socio-demographic characteristics of study respondents

Socio-demographic variable	Frequency (N=248)	Percentage (%)
Sex		
Male	105	42.3
Female	143	57.7
Age group (years)		
	Mean=20.43±15.928	
<10	79	31.9
10-19	63	25.4
20-29	53	21.3
30-39	24	9.7
40+	29	11.7
Religion		
Christian	128	51.6
Muslim	120	48.4
Marital status		
Single	187	75.4
Married	50	20.2
Widowed	11	4.4
Educational level		
No formal education	36	14.5
Primary	86	34.7
JHS/JSS	26	10.5
SHS/SSS	38	15.3
Tertiary	62	25.0
Occupation		
Unemployed	153	61.7
Farmer/breeder	10	4.0
Trader/business owner	8	3.2
Public/Civil servant	40	16.1
Other	36	14.9
Place of residence		
Rural	161	64.9
Urban	87	35.1
Duration of SCD diagnosis (years)		
	Mean=16.28±15.405	
<5	53	21.4
5-9	69	27.8
10-14	23	9.3
15-19	25	10.1
20-24	19	7.7
25+	59	23.8

Source: Field data, (2021)

Table 2 shows the socio-demographic characteristics of the study respondents. The results indicated that most (n=143, 57.7%) of the 248 participants were women. 31.9% of the respondents were less than 10 years old, 25.4% were aged 10-19, and 11.9% were 40 and older. The mean age of all respondents was 20.43 years (SD: 15.93). Most (n=128, 51.6%) of the respondents were Christians. Again, most were unmarried (n=187, 75.4%), with just 20% being married. Concerning educational level, only a few (n=62, 25.0%) had completed high school, 14.5% had no formal education, and 25.0% had completed college or above. Analysis of employment status indicated that almost two-thirds (n=153, 61.7%) were jobless, 16.1% worked in public/civil service, and 14.9% did other work. Moreover, most (n=161, 64.9%) of the respondents lived in rural areas. Regarding the duration of being diagnosed with SCD, several (n=69, 27.8%) had been diagnosed between 5-9 years, and 23.8 percent were diagnosed 25 or more years ago, with a mean year of diagnosis of 16.28 ± 15.41 years.

Clinical Characteristics of Respondents

This section highlighted the health problems associated with SCD. It included the painful crises, Acute respiratory problems, leg ulcers, renal complications, spleen problems, Acute otitis media, Pneumonia and influenza, and Mild stroke. The results are presented in Table 3 below.

Table 3: Clinical Characteristics of respondents in the last 12 months

Health problem	Health service use		Total n(%)	p-value
	Yes n(%)	No n(%)		
Painful crises				0.963
None	7(87.5)	1(12.5)	8(3.2)	
Once	12(92.3)	1(7.7)	13(5.3)	
Twice	66(91.7)	6(8.3)	72(29.0)	
Thrice	116(93.5)	8(6.5)	124(50.0)	
Four times	29(93.5)	2(6.5)	31(12.5)	
Acute respiratory problems				0.890
None	33(89.2)	4(10.8)	37(14.9)	
Once	133(93.7)	9(6.3)	142(57.3)	
Twice	38(92.7)	3(7.3)	41(16.5)	
Thrice	23(92.0)	2(8.0)	25(10.1)	
Four times	3(100.0)	0(0.0)	3(1.2)	
Leg ulcers				0.657
None	211(92.1)	18(7.9)	229(92.3)	
Once	17(100.0)	0(0.0)	17(6.9)	
Twice	1(100)	0(0.0)	1(0.4)	
Thrice	1(100.0)	0(0.0)	1(0.4)	
Renal complications				0.340
None	224(92.9)	17(7.1)	241(97.2)	
Once	2(100.0)	0(0.0)	2(0.8)	
Twice	2(66.7)	1(33.3)	3(1.2)	
Thrice	2(100.0)	0(0.0)	2(0.8)	
Spleen problems				0.585
None	217(92.3)	18(7.7)	235(94.8)	
Once	11(100.0)	0(0.0)	11(4.4)	
Twice	2(100.0)	0(0.0)	2(0.8)	
Acute otitis media				0.754
None	156(93.4)	11(6.6)	167(67.3)	
Once	41(89.1)	5(10.9)	46(18.5)	
Twice	20(95.2)	1(4.8)	21(8.5)	
Thrice	13(92.9)	1(7.1)	14(5.6)	
Pneumonia and influenza				0.821
None	58(90.6)	6(9.4)	64(25.8)	
Once	117(92.9)	9(7.1)	126(50.8)	
Twice	32(97.0)	1(3.0)	33(13.3)	
Thrice	21(91.3)	2(8.7)	23(9.3)	
Four times	2(100.0)	0(0.0)	2(0.8)	
Fever				0.323
None	7(77.8)	2(22.2)	9(3.6)	
Once	8(100.0)	0(0.0)	8(3.2)	
Twice	79(95.2)	4(4.8)	83(33.5)	
Thrice	107(91.5)	10(8.5)	117(47.2)	
Four times	29(93.5)	2(6.5)	31(12.5)	
Mild stroke				0.762
None	216(92.3)	18(7.7)	234(94.4)	
Once	12(100.0)	0(0.0)	12(4.8)	
Twice	1(100.0)	0(0.0)	1(0.4)	
Four times	1(100.0)	0(0.0)	1(0.4)	

Source: Field data, (2021)

Health problems experienced by the participants in the last one year are shown in Table 3. It shows that more than half have experienced at least once: painful crises 240 (96.5%), fever 239 (96.0%), acute respiratory problems 211 (85.1%), and pneumonia and influenza 184(74.2%). Few experienced acute otitis media 13(32.6%), mild stroke 14(5.6%), spleen problems 13(5.2%), and renal complication 7(2.8%). Most respondents, irrespective of their health problems, used health care services. Majority of those who did not experience acute otitis media 167(67.3%), renal complications 241(97.2%), spleen problems 235(94.8%), mild stroke 234(94.4%), leg ulcers 229(92.3%), still utilized healthcare services. There was no discernible correlation between health issues and healthcare use.

Research objective one: Health Services Utilization among Sickle Cell Disease Patients in the Upper West Region.

The first research objective sought to determine the level of health service utilisation among sickle cell disease patients in the Upper West Region. The result of the analysis is presented in Table 4.

Table 4: Health service utilization among sickle cell disease patients in Upper West Region

Type of healthcare service	Frequency (N=248)	Percentage
Emergency visits		
None	21	8.5
Once	15	6.0
Twice	69	27.8
Three or more times	143	57.7
Inpatient visits		
None	30	12.1
Once	22	8.9
Twice	98	39.5
Three or more times	98	39.5
Non-preventive out-patients department visits		
None	27	10.9
Once	2	0.8
Twice	64	25.8
Three or more times	155	62.5

Source: Field data, (2021)

Healthcare services used within the last one year among the respondents is shown in Table 4. Healthcare service utilization was presented as an emergency, non-preventive out-patient department, and in-patient care. The findings show that more respondents have utilized outpatient department 219(88.3%), emergency department 212(85%), and inpatient services 196(79%) twice or more within the period. While 62% of the respondents visited the outpatient facilities three or more times, 57.7% used the emergency department three or more times, and 39.5% used the inpatient department three or more within the period. Over half of these respondents utilised emergency 143(57.7%) and non-preventive outpatient services 155(62.5%). However, few respondents did not used in-patients department 30(12.1%), non-preventive out patients' services 27(10.9%) and emergency department 21(8.5%).

Overall health service use in the Upper West Region among respondents**Table 5: SCD complication leading to health service use**

Health services use variable	Frequency (N=248)	Percentage (%)
Overall, health services use		
Use	230	92.7
Non-use	18	7.3
*Common conditions leading to health service use (n=230)		
Painful crisis	188	81.7
Fever	180	78.3
Joint/body pains	176	76.5
Anaemia	107	46.5
Pneumonia	74	32.2
Respiratory problem	51	22.2
Malaria	44	19.1
Cold and headache	25	10.9
Otitis media	21	9.1
Jaundice	4	1.7
Source of care during recent complication/crises		
Hospital	222	89.5
Self-medication	14	5.6
Health centre	8	3.3
Prayers/Healing services	2	0.8
Traditional medicine	2	0.8

*Multiple responses

Source: Field data, (2021)

As shown in Table 5, almost all the respondents 230 (92.7%) used at least one healthcare service within the year. Common complications of SCD leading to healthcare service use were painful crisis 188(81.7%), fever 180(78.3), joint/body pains 176(76.5%), and mild/severe anaemia 107(46.5%).

In response to the question of the source of care for the most recent complication of SCD among the respondents, the findings show that while the majority 222 (89.5%) accessed care at the hospital, few utilized self-medication 14(5.6%), prayers/healing services 2(0.8%) and traditional/herbal medication 2(0.8%).

Research objective two: Access to Health Services among People with Sickle Cell Disease in the Upper West Region (level of accessibility)

The second research objective sought to determine the level of access to healthcare services use among sickle cell patients in the Upper West Region. The statistical results are represented in figure 4 and in table 6. Accessibility to health service was assessed based on the following dimension: the ability to identify healthcare needs, seek healthcare services, reach or to obtain healthcare services, and to need services fulfilled (Levesque, Harris, & Russell, 2013). Health service accessibility was assessed using a 4-point Likert scale of 1–4 (from lowest to highest accessibility) comprising six (6) items. The total service accessibility score was calculated by summing each participant's ratings for all 6 items. All 6 items/variables were composited into a service accessibility index score. It was done by adding the responses for all 6 items.

The total index score ranged from a minimum of 6 to a maximum of 24. While index score is the individual score/rating for each item in the questionnaire. Then, the mean of the total index scores was computed by dividing the total index scores (3,348) by the sample size (248). Participants with total index scores less than the mean (generated from the summed total=13.5±2.127) were considered having *poor accessibility* whereas those with scores equal to or higher than the mean were graded *good accessibility*. The result in presented in figure 4 below.

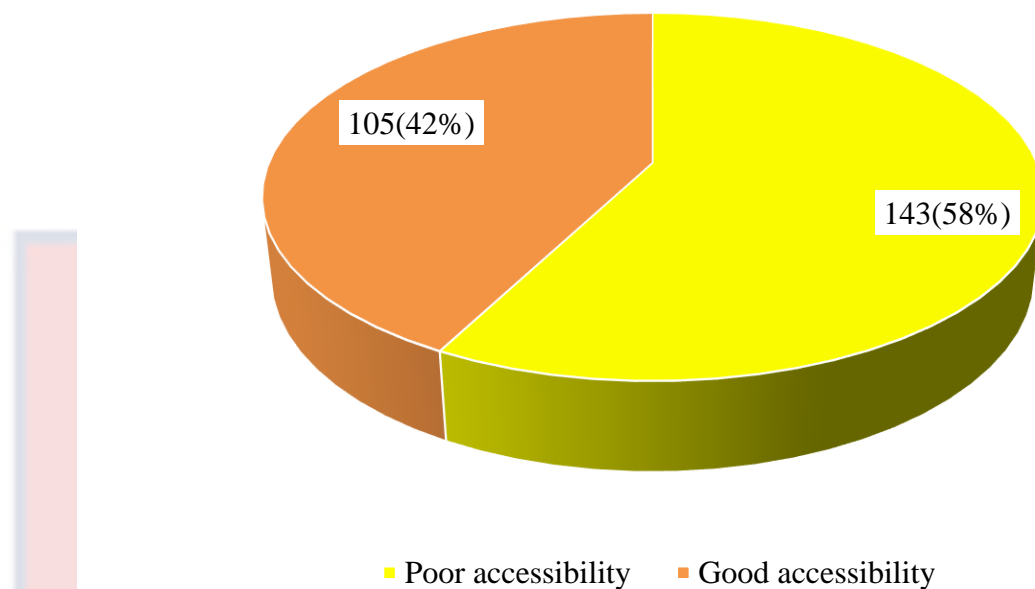


Figure 4: Accessibility to healthcare services providing SCD-specific care among respondents

Source: Field data, (2021)

As shown in Figure 4, approximately two-thirds of the respondents, 143(58%), had poor access to healthcare services providing SCD-specific care in the region. With the same preamble on the “Accessibility to healthcare services providing SCD specific care among respondents,” the means of the individual items on the health services accessibility were calculated. Participants were instructed to provide a numerical value ranging from 1 to 4 to indicate their level of agreement with each item about accessibility. A mean score of more than half (>2) meant the item had good accessibility. Accessibility to healthcare services among the respondents is presented in Table 6.

Table 6: Access to healthcare services providing sickle cell care for SCD patients

Accessibility variable	Mean (N=248)	S.D.
Feeling of easiness about accessing health service	2.48	0.576
Availability of health facilities providing sickle cell care	2.18	0.504
Closeness of a health facility providing sickle cell care to residence	2.23	0.534
Time it takes to reach nearest health facility for care	2.09	0.682
Affordability of the services provided for sickle cell care	2.06	0.464
Frequency of availability of capable health professionals to provide care	2.48	0.691
Overall accessibility	13.52	2.127

S.D. – Standard deviation; 1-very poor, 2-poor, 3-good, 4-very good

Source: Field data, (2021).

It shows that more than half of the respondents regarded accessibility as moderate in terms of availability of health facilities (mean=2.18), closeness of health facility to residence (mean=2.23), time taken to reach nearest health facility (mean=2.09), and affordability of healthcare services provided (mean=2.06). However, an appreciable number of them had the ease of accessing health services (mean=2.48) and good availability of capable health professionals to provide care (mean=2.48) as good. The overall mean of service accessibility was 13.5 ± 2.127 .

Research objective three: Facilitators and barriers to Health Service**Utilization among People with SCD in Upper West Region**

This research objective sought to determine the facilitators and barriers that influence healthcare services utilization in the Upper West Region, and this is captured as reasons for use and non-use. Reasons for the use or non-use of healthcare are shown in Table 7 below.

Table 7: Facilitators and barriers for use or non-use of health service

Reason	Frequency	Percentage (%)
facilitators for use of health service		
(n=230)		
NHIS subscription	217	94.3
Proximity to care facility	203	88.3
Availability of logistics and drugs	172	74.8
Availability of health professionals	55	23.9
Good quality of care	19	8.3
Others	5	2.2
barriers for non-use of health service		
(n=18)		
Long waiting time	16	88.9
Non-subscription of NHIS	13	72.2
Poor quality of care	13	72.2
Long distance to health facility	12	66.7
High cost of service	12	66.7
Others (religious/cultural beliefs, societal stigma, poor quality of care health beliefs etc.)	12	66.7
Lack of specialists	11	61.1
Lack of logistics	11	61.1
Lack of means of transportation	5	27.8

Source: Field data, (2021)

Table 7 shows the facilitators and the barriers for use and non-use of health service. Among those who used healthcare services, it was found out that facilitators for most included NHIS subscription 217(94.3%) and proximity to care facility 203(88.3%). Only 19(8.3) percent noted good quality of care as the main reason. Also, among the barriers to non-use of the health service, it was found that long waiting time 16 (88.9%), NHIS non-subscription 13(72.2%), poor quality of care 13(72.2%), long distance to health facility 12(66.7%), high cost of services 12(66.7%), among others, accounted for their inability to utilize health care services in the study area.

Research objective four and five: Socio-demographic and health services related factors associated with health service utilization

Tables 8a and 8b highlighted the Sociodemographic factors and factors associated with healthcare service utilization among the respondents. The factors considered for the chi-square analysis included demographic characteristics and healthcare accessibility factors. The chi-square test showed that respondents' age ($p < 0.001$), availability of health facilities ($p = 0.025$), closeness of health facility to residence ($p = 0.005$), and time taken to reach nearest health facility ($p = 0.009$) were significantly associated with healthcare service utilization.

Table 8a: Socio-demographic factors associated with health service utilization among respondents

Variable	Health service use		X ² (p-value)
	Use n(%)	Non-use n(%)	
Sex			0.095(0.758)
Male	98(93.3)	7(6.7)	
Female	132(92.3)	11(7.7)	
Age group (years)			21.08(<0.001)***
<10	76(96.2)	3(3.8)	
10-19	61(96.8)	2(3.2)	
20-29	48(90.6)	5(9.4)	
30-39	17(70.8)	7(29.2)	
40+	28(96.6)	1(3.4)	
Religion			3.30(0.069)
Christian	115(89.8)	13(10.2)	
Muslim	115(95.8)	5(4.2)	
Marital status			4.76(0.092)
Single	176(94.1)	11(5.9)	
Married	43(86.0)	7(14.0)	
Widowed	11(100.0)	0(0.0)	
Educational level			5.88(0.208)
No formal education	34(94.4)	2(5.6)	
Primary	83(96.5)	3(3.5)	
JHS/JSS	25(96.2)	1(3.8)	
SHS/SSS	33(86.8)	5(13.2)	
Tertiary	55(88.7)	7(11.3)	
Main occupation			6.112(0.191)
Unemployed	142(92.8)	11(7.2)	
Farmer/breeder	10(100.0)	0(0.0)	
Trader/business owner	6(75.0)	2(25.0)	
Public/Civil servant	36(90.0)	4(10.0)	
Other	36(97.3)	1(2.7)	
Place of residence			0.46(0.500)
Rural	148(91.9)	13(8.1)	
Urban	82(94.3)	5(5.7)	
Duration of SCD diagnosis (years)			6.87(0.231)
<5	52(98.1)		
5-9	64(92.8)	1(1.9)	
10-14	22(95.7)	1(4.3)	
15-19	24(96.0)	1(4.0)	
20-24	16(84.2)	3(15.8)	
25+	52(88.1)	7(11.9)	

Source: Field data, (2021)

Table 8b: Health Service related Factors associated with health service utilization among respondents

Variable	Health service use		X ² (p-value)
	Use n(%)	Non-use n(%)	
Feeling of easiness or difficulty about accessing health service			2.17(0.539)
Very difficult	4(100.0)	0(0.0)	
Difficult	116(90.6)	12(9.4)	
Easy	104(94.5)	6(5.5)	
Very easy	6(100.0)	0(0.0)	
Availability of health facilities providing sickle cell care			9.34(0.025)*
Not available at all	1(50.0)	1(50.0)	
Limited	195(92.9)	15(7.1)	
Somewhat available	25(100.0)	0(0.0)	
Available	9(81.8)	2(18.2)	
Closeness or farness of a health facility providing sickle cell care to residence			12.81(0.005)**
Very far	8(72.7)	3(27.3)	
Far	159(93.5)	11(6.5)	
Close	62(95.4)	3(4.6)	
Very close	1(50.0)	1(50.0)	
Time it takes to reach nearest health facility for care			11.60(0.009)**
Very long	38(84.4)	7(15.6)	
Long	130(94.9)	7(5.1)	
Short	61(95.3)	3(4.7)	
Very short	1(50.0)	1(50.0)	
Affordability of the services provided for sickle cell care			3.47(0.177)
Very expensive	19(95.0)	1(5.0)	
Expensive	177(91.2)	17(8.8)	
Affordable	34(100.0)	0(0.0)	
Frequency of availability of capable health professionals to provide care			5.32(0.150)
Seldom	13(100.0)	0(0.0)	
Sometimes	113(95.8)	5(4.2)	
Most times	91(89.2)	11(10.8)	
Always	13(86.7)	2(13.3)	
Overall accessibility to health services			1.68(0.194)
Poor accessibility	130(90.9)	13(9.1)	
Good accessibility	100(95.2)	5(4.8)	

*p<0.05 **p<0.001

Source: Field data, (2021)

Research objective six: Predictors of healthcare service use among study respondents

Factors that showed statistically significant association with healthcare utilization (age, closeness to health services, availability of health facilities and time taken to reach nearest facility) were examined using a multivariate logistic regression analysis (Table 9) to ascertain the extent of the association. The findings show that respondents aged 40+ years were 12.6 times (CI=1.40-113.81, $p=0.024$) more likely to utilize healthcare services than those aged less than 10 years. In addition, respondents who considered healthcare facilities to be very close to their residence were less likely (AOR=0.03, CI=0.00-0.98, $p=0.026$) to utilize healthcare services compared to those who considered it very far.

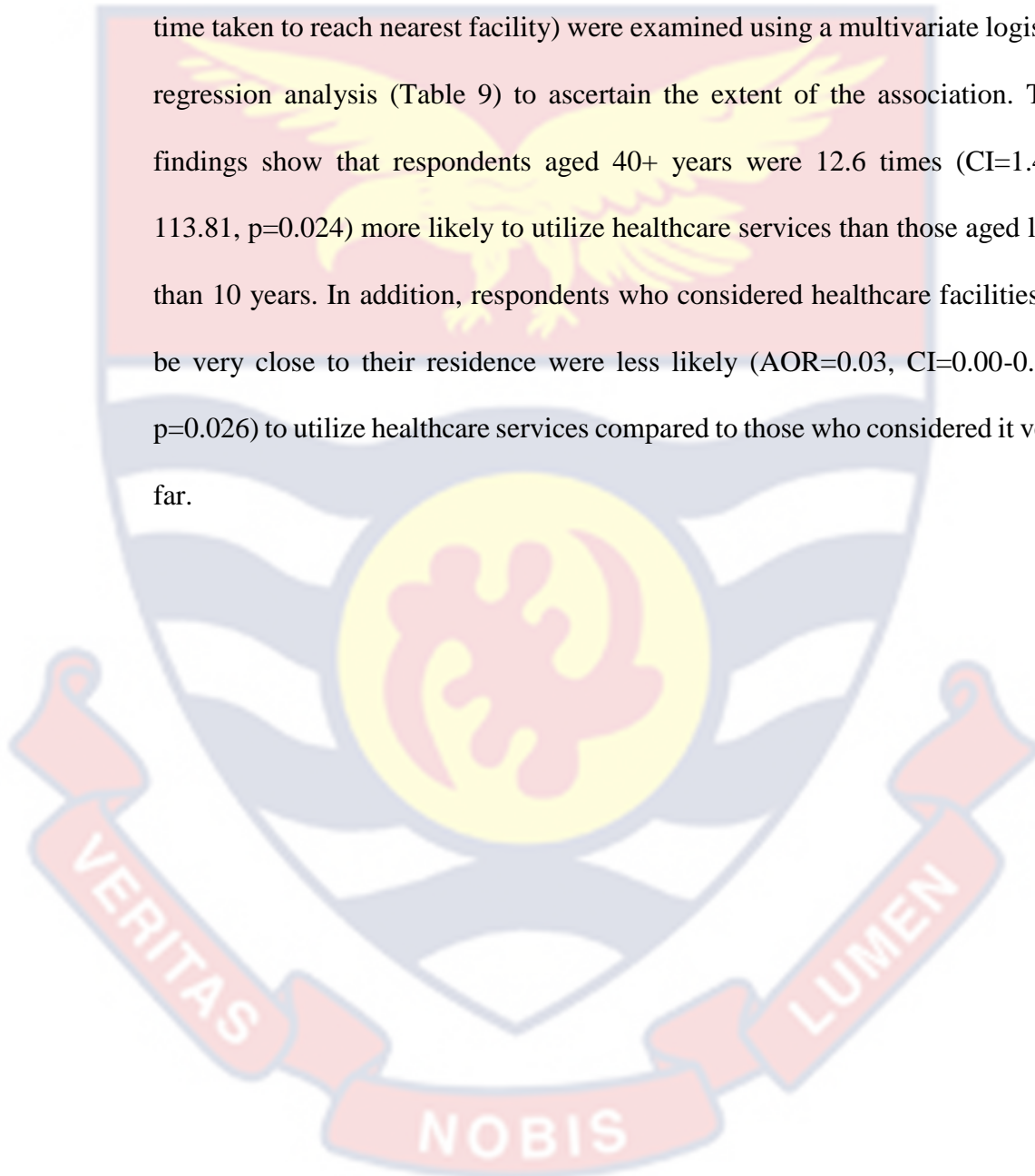


Table 9: Predictors of healthcare service use among study respondents

Variable	COR (95%CI) p-value	AOR (95%CI) p-value
Age group (years)		
<10	Ref	Ref
10-19	1.11(0.11-11.07)0.932	1.49(0.13-17.25)0.750
20-29	0.92(0.08-10.55)0.945	1.14(0.08-15.60)0.921
30-39	2.92(0.32-26.25)0.340	2.92(0.31-27.78)0.351
40+	11.53(1.30-102.02)0.028*	12.61(1.40-113.81)0.024*
Availability of health facilities providing sickle cell care		
Not available at all	Ref	
Limited	4.50(0.19-106.82)0.352	
Somewhat available	0.35(0.07-1.75)0.199	
Available	–	
Closeness or farness of a health facility providing sickle cell care to residence		
Very far	Ref	Ref
Far	0.38(0.02-8.10)0.532	–
Close	0.07(0.00-1.18)0.065	–
Very close	0.05(0.00-0.98)0.048*	0.03(0.00-0.65)0.026*
Time it takes to reach nearest health facility for care		
Very long	Ref	Ref
Long	0.18(0.01-3.30)0.251	–
Short	0.05(0.00-0.95)0.046*	–
Very short	0.05(0.00-0.99)0.049*	–
*p<0.05	COR Crude Odds Ratio	AOR Adjusted Odds Ratio

Source: Field data, (2021)

Discussion

The aim of this cross-sectional study was to evaluate the factors influencing healthcare service use among individuals with sickle cell disease in the Upper West Region. The results indicate that a majority of the participants, namely 143 individuals (58%), had limited accessibility to healthcare providers that offer sickle cell care. The results further demonstrate that a majority of participants, namely 57.7%, reported frequent visits to the emergency department. Furthermore, 39.5% of participants accessed in-patient treatment, while a significant proportion of 62.5% used non-preventive out-patient care during the course of the year. As a result, a significant majority of the participants 230 (92.7%) availed themselves of at least one healthcare service throughout the course of the year. Furthermore, the study findings indicated that those aged 40 years and above, as well as those perceiving healthcare services to be near their place of residence, were significant predictors of healthcare use. This means that SCD patients who were older than 40 years and nearness of health facilities to the residential areas of SCD patients increased the likelihood that they will use healthcare services. However, there were many barriers to healthcare service use including long waiting time n=18(88.9%), non-subscription to health insurance n=18(72.2%), poor quality of care n=18(72.2%), and high cost of service n=18(66.7%) long distance to health facility n=18(66.5%), lack of specialists n=18(61.1%) and care logistics n=18(61.1%), lack of means of transport n=18(27.8%). Common negative health outcomes reported were painful crises, fever, acute respiratory problems, pneumonia and influenza, and acute otitis media.

The observation that a majority of individuals with sickle cell disease (SCD) encountered limited access to healthcare services aligns with the findings reported in other research studies (Lee et al., 2019; Kanter & Jordan, 2015). Kanter and Jordan (2015) observed that individuals with sickle cell disease have significant obstacles in obtaining adequate healthcare services. The reason for this is because individuals with sickle cell disease (SCD) often need thorough and specialised treatment, which is mostly available at higher level healthcare institutions in many poor nations such as Ghana (Hemker et al., 2011). As a result, individuals with sickle cell disease (SCD) have more challenges in accessing adequate pain management compared to those with other chronic conditions such as hypertension and diabetes (Lee et al., 2019). They are thus unable to receive appropriate care to address crises and manage complications associated with the condition.

Also, the finding that most SCD patients utilised health services three or more times indicate that they were regular users of emergency, in-patient and non-preventive care services. This finding is consistent with Hemker et al.(2011) finding that SCD patients are in constant need of healthcare services due to crises and other complications associated with the disease. Similarly, this finding is in congruence with established observation that SCD patients have high use of healthcare services due to associated complications like vaso-occlusive pain crises (Hamilton, Desai, Williams, Moore, & Schames, 2019). It is noted that the likelihood of some common conditions and diseases resulting in life-threatening situation for this vulnerable population necessitates the need for prompt care which could result in most SCD patients utilising more healthcare services than the general population.

Due to poor health outcomes and associated complications of SCD, it is expected that most patient will experience one health problem or another necessitating the need for healthcare. Nevertheless, the study found some SCD patients 18 (7.3%) do not utilize any form of healthcare service even when they experienced some form of illness. It has been noted that people with SCD may not utilize healthcare service due to delays in being attended to and getting pain relief (Anderson & Bellot, 2014). Additionally, due to limited specialist facilities available to SCD patients, they are likely not to use healthcare services as noted by Anderson and Bellot (2014), that they experience many barriers to care in non-specialist facilities. Also, this could be attributed to existing challenges such as financial constraints and poor accessibility to care as already identified in the study (National Academies of Sciences, Engineering, and Medicine, 2020).

More so, the finding showed that those aged more than 40 years were more likely to use at least a healthcare service within the year. This is similar to the finding by Hamilton et al. (2019) where patients among the population aged 40 and over had significantly more primary care visits yearly compared with those aged lower than 40 years. Also, this is consistent with the finding in a study by Saunders, Labott, Molokie, Shelby, and Desimone (2010) which concluded that the age of SCD patients was a significant factor for their healthcare utilization. Age has been reported to be a major determinant of healthcare use in SCD patients (Kanters et al., 2019). The current result may be explained to result from increasing health issues as individuals grow older which may have directly or indirectly increased SCD patients' vulnerability to experiencing SCD complications and other conditions such as diabetes and

hypertension. Thus, this may increase healthcare needs and use among those aged 40. Age is one of the socio-demographic factors explained in the conceptual framework by Andersen (1995) to influence decision to and actual use of healthcare service.

Additionally, the odd of utilizing healthcare service was lower for those who considered their residence very close to the health facility. This is contrary to studies that have argued that being closer to a healthcare facility increases chances that an individual will use healthcare service when sick in developing countries like Malawi, Ghana, Burkina Faso, and Kenya (Quattrochi, Hill, Salomon, & Castro, 2020; Dotse-Gborgbortsi et al., 2020; Schoeps, Gabrysch, Niamba, Sié, & Becher, 2011; Feikin et al., 2009). It is a known fact that nearness to a health facility alone cannot influence how patients access and utilize such services because the other factors such as; the health facility not having professionals trained on caring for people with SCD, poor quality of care, and high cost of service can play a major role. Therefore, it is essential to implement measures that guarantee the provision of adequate structural, logistical, and professional resources in health facilities catering for individuals with sickle cell disease (SCD). This will serve to promote and facilitate the timely and consistent utilisation of healthcare services by SCD patients. This statement aligns with the assertion that individuals with sickle cell disease (SCD), especially young people, often seek medical attention in emergency departments (ED) or healthcare facilities due to a lack of primary care doctors that specialise in SCD (Hemker et al., 2011).

Furthermore, the study identified some barriers to healthcare service utilization among the respondents including long hospital waiting time, long distance to health facility, lack of specialist care providers, poor care quality, and high cost of service. Long distance to health facility poses a significant barrier to chronic disease patients including those with SCD as most of them experience a lack of transportation to the health facility in search of health care use (Syed et al., 2013).

Also, on the finding that some patients are faced with a lack of SCD-specialist care providers in close facilities, this supports the finding by Renedo et al. (2019) that mostly only non-specialist care providers are available to provide care to SCD patients. The finding is also in agreement to the observation made in previous studies that there is a lack of specialized SCD care providers in low- and middle-income countries and rural settings (CDC, 2017; American Society of Hematology, 2016; Kanter & Kruse-Jarres, 2013; Raphael et al., 2009). This comes at the backdrop that non-specialist care providers often do not have adequate understanding and knowledge of SCD and management and sometimes downplayed risks (Dougherty, 2021).

In addition, poor quality of care as a barrier to healthcare use among SCD patients has been reported in previous studies (Jacob, Daas, Feliciano, LaMotte, & Carroll, 2022; Phillips et al., 2022; Lee et al., 2019; Renedo et al., 2019). This leads to a mistrust of care providers, especially non-specialist staff may result from poor quality of care during emergency service and hospital admissions.

Another barrier observed in this study is the cost of healthcare service for SCD patients. This is consistent with the findings that high financial cost is involved in obtaining care for most SCD patients (Lee et al., 2019; Allen, Call, Beebe, McAlpine, & Johnson, 2017; Haywood et al., 2014). This is because even those with health insurance subscription, the coverage is inadequate to cover the cost involved in their seeking healthcare with health conditions linked to the SCD status (Phillips et al., 2022). In Ghana, most of the complications associated with SCD such as stroke, end stage organ failure are not covered under the National Health Insurance Scheme. Thus, most SCD patients experience financial challenges with healthcare expenditure any time they seek healthcare. This is supported by the conceptual framework where Andersen (1995) note that socio-economic factors which affect individuals' ability to afford healthcare service influences their utilization of care when unwell.

A majority of the participants reported experiencing adverse health effects, including painful crises, acute respiratory issues, pneumonia and influenza, and acute otitis media. Individuals with sickle cell disease (SCD) often face frequent and unpredictable episodes of pain, as well as other complications such as vaso-occlusive crises (VOC), kidney problems, and spleen issues (Kanter et al., 2020; Edwards et al., 2005). Consequently, the discovery of these negative health outcomes is not unexpected. Various factors related to patients, healthcare providers, and the healthcare system contribute to the suboptimal health outcomes observed among young adults with SCD during the transition period (Treadwell et al., 2016; Bemrich-Stolz et al., 2015; Sobota, Umeh, & Mack, 2015).

CHAPTER FIVE

SUMMARY, CONCLUSION, AND RECOMMENDATION

This study assessed the determinants of healthcare utilization among sickle cell disease patients in the Upper West Region. The chapter provides a summary of the study, draws conclusions from key study findings and proffers recommendations based on these implications for policy and practice.

Summary of the Study

This study investigated the determinants of healthcare service utilization among SCD patients in the Upper West Region of Ghana. The study employed a cross-sectional design involving 248 SCD patients accessing care at the Wa Municipal Hospital. The specific objectives of the study include; 1. To determine the level of accessibility to health care among SCD patients 2. To determine the level of healthcare services utilization among sickle cell disease patients in the Upper West Region, 3. To determine the facilitators and barriers to healthcare utilization among sickle cell disease patients in the Upper West Region of Ghana 4. To identify the socio-demographic and health service factors that influence healthcare utilization among sickle cell disease patients in the Upper West Region of Ghana, 5. To identify the health services related factors that influence healthcare utilization among sickle cell disease patients in the Upper West Region of Ghana, and 6. The objective of this study is to analyse the variables that are indicative of the use of health services among individuals diagnosed with sickle cell disease. The participants were selected via the use of a systematic random selection method, and the necessary data was gathered by means of an interviewer-administered pre-tested questionnaire. The data were inputted into SPSS version 22 and afterwards examined using the same

statistical method. The study included the use of both descriptive statistics and inferential statistics, specifically using the chi-square test and logistic regression. Statistical significance was established at a p-value of less than 0.05, with a confidence interval of 95%. Descriptive statistics was used to analyse the health services accessibility among respondents, health care utilization among respondents, common negative health problems experienced by respondents, and the socio-demographic characteristics of respondents. While inferential statistics was used to analysed the association between socio-demographic characteristics and health care utilization and predictors of healthcare utilization among respondents.

Summary of the Key Findings

The findings showed that 92% of the respondents had used healthcare services within the last 12months. The findings also indicate that, more SCD patients had utilised OPD services 62%, followed by Emergency services, 57.7% and inpatients services 39.5% three or more times within the last 12months. It was also observed that, many respondents, 58% of the 248 patients had poor accessibility to healthcare facilities providing SCD specific care and 42% having good accessibility with overall mean of accessibility of 13.5.

The major sociodemographic factor that was found to have influence health care utilization was age $\chi^2= 21.08$, ($p<0.001$). It was also found that, the major health related factor that influenced utilization was closeness to health care facility $\chi^2 =12.81$, ($p <0.005$) . Other health sector related factors such as, availability of logistics and drugs, availability of health professionals and good quality care were found to have influenced health care utilization positively.

However, factors such as, non-subscription to NHIS, long distance to health facility, high cost of services were the main barriers to health care utilization.

Healthcare service utilization was predicted by socio-demographic factor as being aged 40+ years (AOR=12.6, 95%CI=1.40-113.81, p=0.024).

Regarding health sector-related factors, the findings show that considering distance to health facility as very close (AOR=0.03, 95%CI=0.00-0.98, p=0.026) predicts health services utilization.

Most of the respondents were found to have experienced negative health outcomes such as painful crisis, fever, acute respiratory problems, pneumonia and influenza, as well as acute otitis media.

Conclusion and Implications

Based on the study results findings, the following conclusions were drawn:

1. The finding that most of the SCD had poor healthcare accessibility to healthcare facilities providing sickle cell disease specific care means that most of them experience grave difficulties when they are in need of healthcare. The indication of this is that many may resort to unapproved and inappropriate measures to resolve their health problems once their access to healthcare facilities providing SCD specific care is poor. This further suggest the high likelihood of late reporting of condition as well as preventable deaths from emergencies.
2. Also, the study's finding that almost all SCD patients had to use healthcare within the year indicates predominant poor health for this population, evident in the prevalence of negative health outcomes. The implication of this is the increased cost of maintaining or restoring health

keeping among this population which can lead to catastrophic healthcare expenditure, loss of productive time and poor quality of life. They are also at increased risk of dying from the disease. This also indicates that almost all the SCD population needed to seek healthcare to address one health problem or another. If not for review, utilization of healthcare is suggestive of the health status of the population.

3. The finding of high utilization of various healthcare is also an indication of SCD patients' understanding and positive healthcare seeking behaviour as well as limited barriers to using healthcare services.
4. Additionally, the finding that considering one's place of residence to be closer to a health facility being associated with lower likelihood of healthcare utilisation suggests that other issues of accessibility may be more important in this population. Aside just siting health facility closer to people, other issues that hinder access to and use of healthcare include long waiting time, inadequate specialists, and high cost of care among others. Should these barriers persist, Ghana may not achieve its sustainable development goal three target of reducing morbidities and deaths associated with chronic non-communicable diseases including sickle cell disease.
5. Furthermore, the finding that healthcare service use was predicted by being aged 40+ years suggests that people who are 40+ years and above are prone to sickle cell disease complications than those who are below 40 years due to decreased immune system function.

Recommendations

To the administrators and nurses at the institution where the research was performed, the following suggestions are made, patients with SCD and the Upper West Regional Health Directorate.

The study makes the following recommendations:

To stakeholders

1. **Improve accessibility to healthcare facilities:** Given that a significant proportion of respondents had poor accessibility to healthcare facilities providing sickle cell care, efforts should be made to improve the availability and proximity of such facilities. This can be achieved by establishing additional healthcare centers or clinics dedicated to sickle cell care in areas with limited access.
2. **Reduce geographical barriers:** The study highlighted that considering the distance to health facilities as very close was a predictor of healthcare service use. Efforts should be made to reduce geographical barriers, especially in remote areas, by improving transportation, infrastructure or implementing mobile healthcare units to reach individuals who may face challenges accessing healthcare due to distance
3. **Strengthen community support:** Establishing support groups or community-based organizations can provide a platform for individuals living with sickle cell disease to share experiences, receive emotional support, and access relevant information. These community initiatives can also play a role in raising awareness about the disease, reducing stigma, and advocating for improved healthcare services.

4. Subsidising the cost involved in SCD treatment: In view of the study findings that SCD patients who subscribed to the NHIS have higher healthcare services utilization than those who did not subscribed, the Ministry of Health and the National Health Insurance Authority should adopt innovative approach to enrolls people with SCD on the scheme and increase coverage range to cover cost of healthcare from complications associated with the disease to maximize their healthcare services patronage.

On Nursing practice

5. Enhance healthcare service provision: Since 92 percent of respondents reported using at least one healthcare service within the year, it is crucial to ensure that the quality and range of services provided meet the specific needs of sickle cell disease patients. This can involve periodic training of healthcare professionals on sickle cell disease management and establishing standardized protocols for diagnosis, treatment, and follow-up care.
6. Address barriers related to age: The study found that being aged 40+ years was a predictor of healthcare service use. It is important to address any age-related barriers that may discourage younger individuals from seeking healthcare. This can include targeted educational campaigns and outreach programs to raise awareness among younger populations about the importance of regular healthcare utilization and early intervention.
7. Emphasize preventive measures: Given the high prevalence of negative health outcomes experienced by respondents, including painful crisis, fever, respiratory problems, and otitis media, it is crucial to prioritize

preventive measures. This can involve promoting regular vaccinations, educating patients and their families about early signs and symptoms, and providing information on self-care strategies to manage their condition and prevent complications.

To the management of the Wa Municipal Hospital

8. Collaborate with stakeholders: Effective implementation of the above recommendations requires collaboration among various stakeholders, including government agencies, healthcare providers, management of the Wa Municipal Hospital, the Upper West Regional health Directorate, community leaders, and non-governmental organizations. Collaboration can help ensure coordinated efforts, resource allocation, and policy changes necessary to improve healthcare utilization and outcomes for sickle cell disease patients.

For future research

9. The researcher recommends further research into the topic area to address the limitations of this study.

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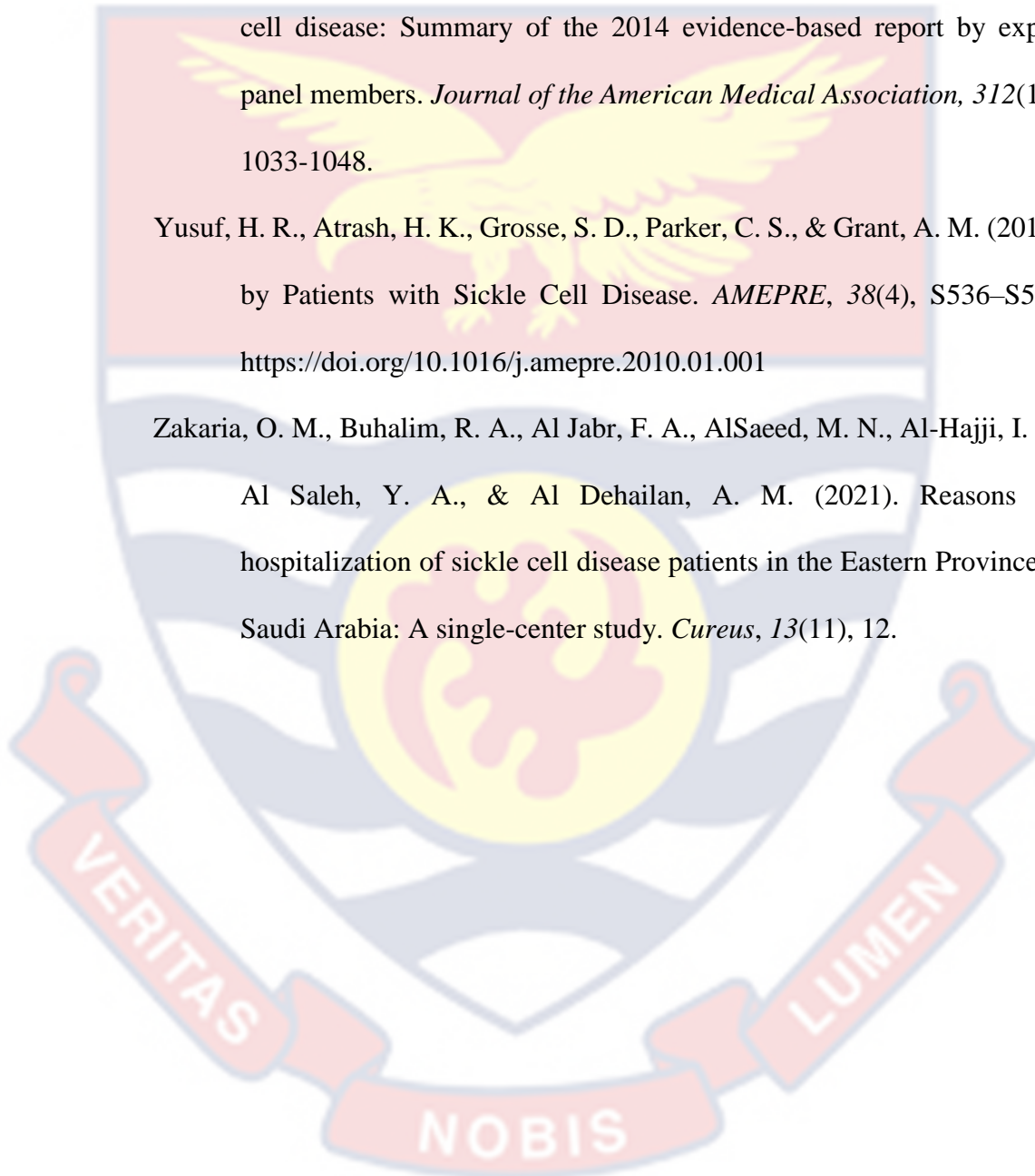
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APPENDICES

UNIVERSITY OF CAPE COAST

Introduction

The study will take 6 months from data collection to submission of final report. This starts after obtaining ethical approval to carry out the study. Data collection will be done in three weeks while coding, data entries and analysis will take about three months.

Appendix I: Budget

Items	Propose cost (GHC)
Communication (phone calls)	100
Field work	500
Transportation	700
Data management analysis	100
Printing (Draft reports, research instrument, final report)	800
Miscellaneous	450
Total	2,650

Appendix IIa: Informed Consent

INFORMED CONSENT FORM FOR ADULT

General Information about Research

I am Momore Luciano Clement, a master of nursing student of the University of Cape Coast. I am conducting a research to assess the determinants of health care utilization among sickle cell disease patients in the Upper West Region in partial fulfilment for the award of master of nursing certificate.

Procedures

To find answers to some of these questions, I invite you to take part in this research project. If you accept, you will be required to fill out a survey which will be provided and collected by Momore Luciano Clement and my two research assistants.

You are being invited to take part in this discussion because I feel that your experience as a sickle cell disease patient can contribute much to this study outcomes.

While some of the questions in the questionnaires are close-ended, others will be open-ended. In each case, you are required to provide a response (s) as appropriate as possible.

If you do not wish to answer any of the questions included in the survey, you may skip them and move on to the next question. The information recorded is considered confidential, and no one else except Momore Luciano Clement, the principal researcher will have access to your survey. The expected duration of the survey is about 15-30 minutes.

Possible Risks and Discomforts

There is no any foreseeable risk and discomfort as far as participating in this study is concerned.

Possible Benefits

There will be no instant benefit for participants of this study, however, the study findings will be beneficial in influencing policy decision with regard to the determinants of health care utilization among sickle cell disease patients in the region, thus participants will benefit from the decision. The study will also be beneficial in contributing knowledge to existing literature.

Confidentiality

All information that will be collected from you in this survey will be kept confidential. I will protect information about you to the best of my ability. You will not be named in any reports.

Therefore, you will not be required to write your name in any part of the questionnaires. **Compensation** There will be no compensation in any form for participants.

Voluntary Participation and Right to Leave the Research

Note: Participation in the research is voluntary and participant can withdraw any time without penalty.

Contacts for Additional Information

For any enquiry with regard to this study, you can contact Mr. Momore Luciano Clement, the principal investigator. Phonenumber: 0201978012.

Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of University of Cape Coast (UCCIRB). If you have any questions about your rights as a research participant you can contact the Administrator at the IRB Office between the hours of 8:00am and 4:30p.m. through the phone lines 0558093143/0508878309 or email address: irb@ucc.edu.gh.

PARTII: VOLUNTEER'S AGREEMENT

The above document describing the benefits, risks and procedures for the research title The determinants of health care utilization among sickle cell disease patients in the Upper West Region has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer. OR I have read the above document describing the benefits, risks and procedures for the research title The determinants of health care utilization among sickle cell disease patients in the Upper West Region. I have been given an opportunity to ask any question about the research and this has been answered to my satisfaction. I agreed to participate as a volunteer.

Volunteer's Name:.....

Volunteer's Mark/Thumbprint.....

Date:.....

If volunteer can not read the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Witness's Name:.....

Witness's Mark/Thumbprint:.....

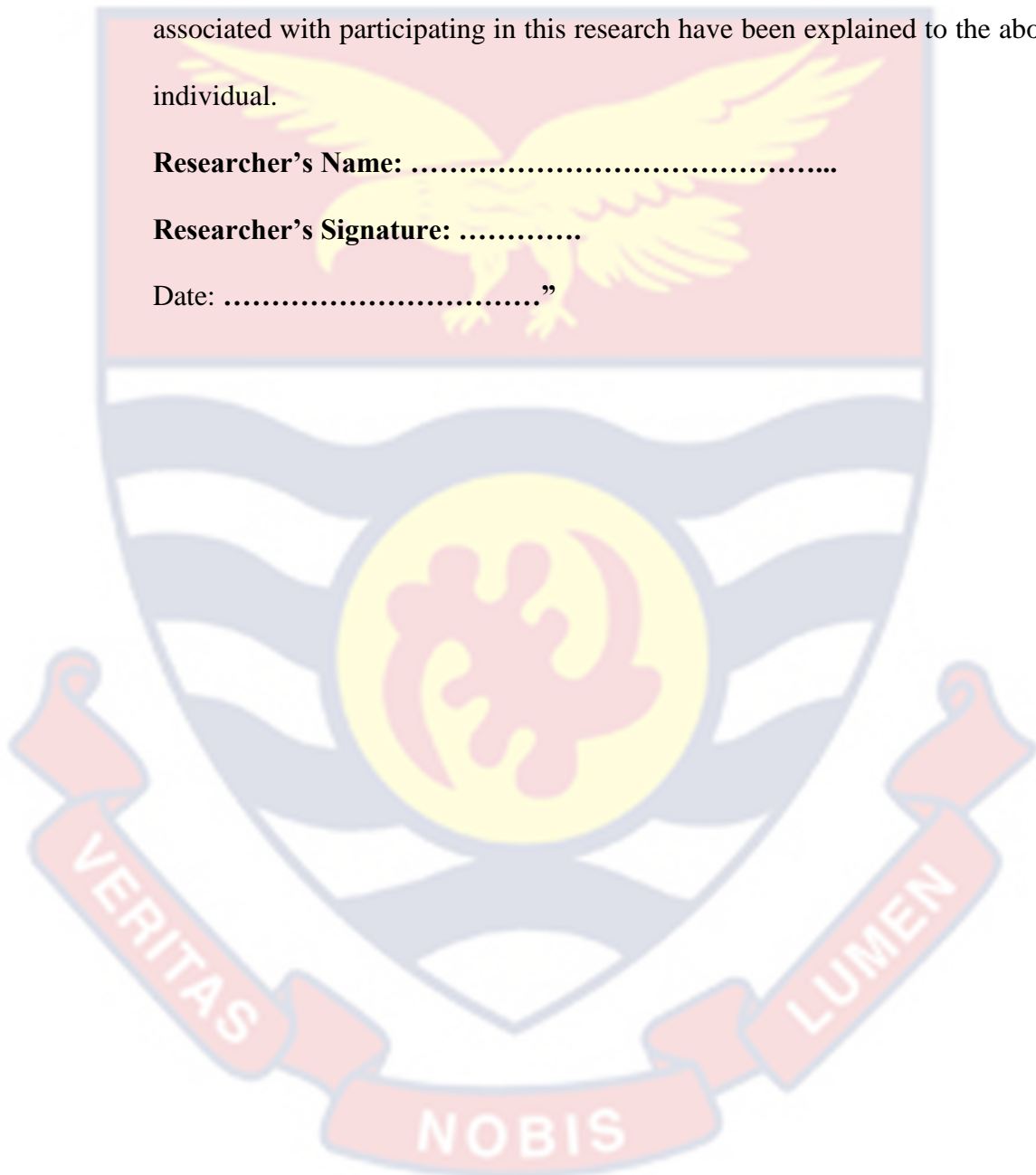
Date:.....

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

Researcher's Name:

Researcher's Signature:

Date:"



Appendix IIb: Informed Consent

CHILD ASSENT FORM

PART I: INFORMATION SHEET

Introduction

My name is Momore Luciano Clement and I am a master of nursing student of University of Cape Coast, department of adult health. I am conducting a research entitled The determinants of health care utilization among sickle cell disease patients in the Upper West Region. I am asking you to take part in this study because I am trying to learn more about the determinants of health care utilization among sickle cell disease patients in the Upper West Region.

Procedure: If you accept to be in this study, you will be asked to answer a *survey*. This will take about 15-30 minutes.

Possible Benefits

There will be no instant benefit for participants of this study, however, the study findings will be beneficial in influencing policy decision with regard to the determinants of health care utilization among sickle cell disease patients in the region, thus participants will benefit from the decision. The study will also be beneficial in contributing knowledge to existing literature

Possible Risks and Discomforts: There is not any foreseeable risk and discomfort as far as participating in this study is concerned.

Compensation: There will be no compensation in any form for participants.

Voluntary Participation and Right to Leave the Research

You are free to join this study and you can stop participating at any time if you feel uncomfortable.

No one will be angry with you or punish you if you do not want to participate or stop participating.

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

Confidentiality: All information that will be collected from you in this survey will be kept confidential. I will protect information about you to the best of my ability. You will not be named in any reports. Therefore, you will not be required to write your name in any part of the questionnaires. No one else will have access to the information that will be provided except me, the principal investigator.

Contacts for Additional Information

You may ask me, the principal investigator any question(s) about this study. You can call me at any time or talk to me the next time you see me. Phone number: 0201978012.

Your rights as a Participant: This research has been reviewed and approved by the Institutional Review Board of University of Cape Coast (UCCIRB). If you have any questions about your rights as a research participant you can contact the Administrator at the IRB Office between the hours of 8:00am and 4:30p.m. through the phone lines 0558093143/0508878309 or email address: irb@ucc.edu.gh.

PARTII: VOLUNTEER'S AGREEMENT

By making a mark or thumb printing below, it means that you understand and know the issues concerning this research study. If you do not want to participate

in this study, please do not sign this assent form. You and your parents will be given a copy of this form after you have signed it.

The information which describes the benefits, risks and procedures for the research titled **The determinants of health care utilization among sickle cell**

disease patients in the Upper West Region has been read and or explained to me. I have been given an opportunity to ask any questions about the research answered to my satisfaction. I agree to participate.

Child's Name:.....

Child's Mark/Thumbprint.....

Date:.....

Witness for volunteer must sign here:

I was present while the benefits, risks and procedures were read and explained to the volunteer. All questions were answered and the volunteer has agreed to take part in the research. **Witness's Name:**.....

Witness's Mark/Thumbprint.....

Date:.....

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above volunteer in the presence of the witness *[nameofwitness]*.

Researcher's Name:.....

Researcher's Signature:.....

Date:

Appendix III: Questionnaire

**QUESTIONNAIRES ON HEALTH SERVICES ACCESS,
UTILIZATION, HEALTH OUTCOMES AND DETERMINANTS OF
HEALTH CARE UTILIZATION AMONG SICKLE CELL DISEASE**

PATIENTS

Section A: Socio-demographic Information	Response			
1. What is your sex?	1. Male 2. Female			
2. How old are you	[.....] years			
3. What religion do you practice?	1. Christian 2. Muslim 3. Traditionalist 4. Other.....			
4. What is your marital status	1. Single 2. Married 3. Co-habiting 4. Divorce/separated 5. Widowed			
5. What is your highest level of education?	1. None 2. Primary 3. JHS/JSS 4. SSS/SHS/Vocational 5. Tertiary			
6. What is your main occupation?	1. Unemployed 2. Artisan 3. Farmer/breeder 4. Trader/businessman/woman 5. Public servant 6. Other.....			
7. Where is your residence?	1. Rural 2. Urban			
8. How long since you were diagnosed with Sickle Cell Disease?	[.....]			
Section B: Health service accessibility	Response			
9. How easy or difficult do you feel about accessing health service	Very Difficult	Difficult	Easy	Very easy"
10. How available are facilities providing sickle cell care to you?	Not available all	Limited	Somewhat available	Available
11. How close or far is a health facility providing sickle cell care to your residence?	Very far	Far	Close	Very close

12. How long does it take you to reach the health facility for care?	Very long	Long	Short	Very short		
13. How affordable is the services provided for sickle cell care?	Very expensive	Expensive	Affordable	Very affordable		
14. How often do capable health professionals available to care for you?	Seldom	Sometimes	Most times	Always		
Section C: Utilization of Health Services						
15. Have you used any health facilities when sick?	1. Yes 2. No					
16. If yes, what kind of health facility did you use?	1. Hospital 2. Clinic/Health centre 3. CHPS compound 4. Others:					
17. What factors influenced the use of this health facility? Tick all that apply	1. Proximity 2. Availability of NHIS 3. Availability of Staff 4. Quality Service 5. Availability of logistics and drugs 6. Others, specify					
18. If No, how do you treat yourself when you fall sick/had crises?	1. Self-Medication 2. Prayers/Healing service 3. Traditional/herbal medicine 4. Others, Specify:					
19. What are your main reasons for not utilizing healthcare services when sick/had crisis? Tick all that apply	1. Longer waiting time 2. Long distance 3. Poor quality service 4. High cost of service 5. Lack of NHIS 6. Lack of specialists 7. Lack of logistics and drugs 8. Health beliefs 9. Others, Specify”.....					
How many times did you use the following services within the last 1 year for SCD related health issues?						
20. a. Emergency care visits	0	1	2	3	4	5+
b. For what conditions was your visit?	1. 2. 3.					
21. a. In-patient visits	0	1	2	3	4	5+
b. For what conditions was your visit?	1. 2. 3.					

22. a. Non-preventive out-patient visits	0	1	2	3	4	5+
b. For what conditions was your visit?	1. 2. 3.					
Section D: Health Outcomes/problems	Response					
How many times did you have the following conditions within the last 1 year?	0	1	2	3	4	5+
23. Painful crises						
24. Acute respiratory problems						
25. Leg ulcers						
26. Renal complications						
27. Spleen problems						
28. Acute otitis media						
29. Pneumonia and influenza						
30. Fever						
31. Stroke"						



Appendix IV: Ethical Clearance

UNIVERSITY OF CAPE COAST

INSTITUTIONAL REVIEW BOARD SECRETARIAT

TEL: 058899142 / 058899143
 E-MAIL: ir@ucc.edu.gh
 OUR REF: UCCIRB/CHAS/2021/67
 YOUR REF:
 OMB NO: 0998-0279
 IORG: UCCG0009096

1st OCTOBER 2021

Mr. Clement Luciano Momore
 Department of Adult Health
 University of Cape Coast

Dear Mr. Momore,

ETHICAL CLEARANCE – ID (UCCIRB/CHAS/2021/67)

The University of Cape Coast Institutional Review Board (UCCIRB) has granted Provisional Approval for the implementation of your research titled *Determinants of Health Care Utilization among Sickle Cell Disease Patients in the Upper West Region*. This approval is valid from 1st October 2021 to 30th September, 2022. You may apply for a renewal subject to submission of all the required documents that will be prescribed by the UCCIRB.

Please note that any modification to the project must be submitted to the UCCIRB for review and approval before its implementation. You are required to submit periodic review of the protocol to the Board and a final full review to the UCCIRB on completion of the research. The UCCIRB may observe or cause to be observed procedures and records of the research during and after implementation.

You are also required to report all serious adverse events related to this study to the UCCIRB within seven days verbally and fourteen days in writing.

Always quote the protocol identification number in all future correspondence with us in relation to this protocol.

Yours faithfully,

Dr. Samuel Aseidu Owusu,
 UCCIRB Administrator

ADMINISTRATOR
 INSTITUTIONAL REVIEW BOARD
 UNIVERSITY OF CAPE COAST

Appendix V: Ethical Approval from the Regional Health Directorate

In case of reply, the number and date of this letter should be quoted.

OUR CORE VALUES
Professionalism
People-Centeredness
Team Work
Integrity
Discipline
Innovation



Regional Health Directorate
Ghana Health Service
P. O. Box 298
Wa
Upper West Region

My Ref: UWR/RHD/ADM/TP-51
Your Ref:

October 12th, 2021
Tel: +2330392096685
GPS Address: XW-0020-2007
Email: rhd.uwr@ghsmail.org

**THE MEDICAL DIRECTOR
REGIONAL HOSPITAL, WA**

Municipal Hospital Wa
[Handwritten Signature]

INTRODUCTORY LETTER: MR. MOMORE L. CLEMENT

The bearer of this letter is a Master of Nursing student of the Department of Adult Health, School of Nursing and Midwifery at the University of Cape Coast.

He is seeking to conduct a research on the topic "**Determinants of Health Care Utilization among Sickle Cell Disease Patients in the Upper West Region of Ghana**".

He has duly complied with all the requirements of the Ghana Health Service in conducting research.

Kindly accord him the necessary support and cooperation and take the necessary steps to ensure that the privacy and confidentiality of our staff and clients are guaranteed.

Thank you.

[Handwritten Signature]
**BASADI RICHARD
CHIEF HEALTH RESEARCH OFFICER
FOR: REGIONAL DIRECTOR OF HEALTH SERVICES**

Cc:
Research file
Momore L. Clement ✓

NOBIS

Appendix I: Introductory Letter



UNIVERSITY OF CAPE COAST
COLLEGE OF HEALTH AND ALLIED SCIENCES
SCHOOL OF NURSING AND MIDWIFERY
DEPARTMENT OF ADULT HEALTH



Telephone: 233-033-209 7282

Telegrams & Cable: University, Cape Coast

Email: adulthealth.nursing@ucc.edu.ghUNIVERSITY POST OFFICE
CAPE COAST, GHANAOur Ref: COLLAS/SNM/DAH/Vol.2/321
Your Ref:

October 7, 2021

TO WHOM IT MAY CONCERN**INTRODUCTORY LETTER**

We write to introduce Mr. Momore L. Clement, a level 850 student of Department of Adult Health, School of Nursing and Midwifery, University of Cape Coast with registration number: SN/MNS/19/0017.

As part of the requirements for the award of Master of Nursing degree, he has to undertake a research project.

The topic of his research work is "*Determinants of health care utilization among sickle cell disease patients in the Upper West Region of Ghana*".

The Department has reviewed the ethical implications of the study protocol and has approved it.

We shall therefore be grateful if he could be given the needed assistance to enable him collect relevant data for the study.

Thank you.

Yours faithfully,


 Dr. Andrews Ailjei Druye
 Head of Department