EXPLORING THE BARRIERS AND FACILITATORS TOWARDS ADHERENCE TO SICKLE CELL TREATMENT GUIDELINES AMONG MEDICAL DOCTORS AT MULAGO HOSPITAL, UGANDA

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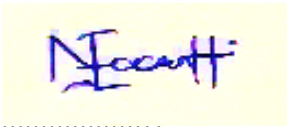
DECLARATION

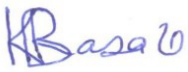
I, Nasige Joan declare that this study titled "Exploring the barriers and facilitators towards adherence to Sickle Cell treatment guidelines among medical doctors at Mulago hospital, Uganda" is my original work and has never been submitted for any academic award in any other institution.

Signature: …  Date: 09TH/01/2025

Nasige Joan

APPROVAL

I hereby certify that this dissertation titled "Exploring the barriers and facilitators towards adherence to sickle cell treatment guidelines among medical doctors at Mulago Hospital - Uganda" has been done under my supervision.

Signature:……  … Date: 09TH/01/2025

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DEDICATION

I dedicate this work to my dear parents; Mr. Wenwa Jonathan and Mrs. Buganza Florence for their prayers, support and encouragement as I was pursuing the course.

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To begin with, I thank the Almighty God for guiding me through this entire process. It was not an easy journey, but I am glad the Lord has successfully guided me through it. My heartfelt appreciation goes to all those who, in one way or another, contributed to the successful completion of this research study and all its processes. Writing this dissertation involved a lot of sacrifices, but most importantly, joint efforts from several people to whom I am so grateful. Words alone are not enough to explain my gratitude, but my prayer is that the Lord shall richly bless them with the utmost desires of their hearts.

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LIST OF ABBREVIATIONS AND ACRONYMS

CFIR	Consolidated Framework for Implementation Research
CME	Continuing Medical Education
EHR	Electronic Health Records
HbS	Hemoglobin S
HCPs	Healthcare providers
JHO	Junior House Officer
KI	Key Informants
MO	Medical officer
MNRH	Mulago National Referral Hospital
MoH	Ministry of Health
REC	Research Ethics Committee
RBC	Red Blood Cells
SCA	Sickle Cell Anemia
SCC	Sickle Cell Clinic
SCD	Sickle Cell Disease
SHO	Senior House Officer
UCU	Uganda Christian University
WHO	World Health Organization
IRB	Institutional Review Board

DEFINITION OF TERMS

TERM	DEFINITION
Barriers	Any factors that obstruct the capacity of health care workers to implement treatment guidelines.
Facilitators	Any factors that enable the capacity of health care workers to implement treatment guidelines.
Guideline adherence	This is the proportion of patients that are treated according to the recommendations of the guidelines, these represent best care practice.
Treatment guidelines	Treatment or clinical guidelines are systematically developed scientific statements designed to help healthcare workers to consistently and effectively apply scientific evidence in their daily practice.
Medical doctors	This includes the medical officers, senior house officers, junior house officers and specialist doctors working in the MNRH sickle cell clinic.

ABSTRACT

Background: Sickle Cell Disease (SCD) is a major global health issue, affecting over 4.4 million people, with 10%-40% of Africa's population suspected to be impacted. Sub-Saharan Africa accounts for 80% of cases, and the mortality rate for children under 5 is 90%, contributing to 7.3% of under-5 deaths in Africa in 2018. Uganda, with a national prevalence of 0.9%, faces a significant burden, especially in high-prevalence areas where rates reach 45%. Despite this, Uganda struggles with managing SCD, particularly due to non-adherence to treatment guidelines. This study examined the barriers and facilitators affecting medical doctors' adherence to treatment protocols at MNRH.

Method: This study used a phenomenological design, data was collected through key informant and in-depth interviews with the doctors working at the Sickle Cell Clinic of MNRH. These included the JHOs, SHOs, Medical Officers, and specialists/consultants. Participants were purposively selected, and the data was thematically analyzed through coding.

Findings: Key facilitators to adherence included clinical experience, knowledge, continuous medical education, collaborative networks, supportive leadership, and accessible treatment guidelines. Barriers included individual factors like burnout, fatigue, and low motivation, as well as systemic issues such as lack of physical guidelines, fragmented care, heavy workload, inadequate staffing, and resource constraints, all of which impacted adherence to treatment guidelines.

Discussion: Despite medical doctors' awareness of the treatment guidelines, factors like burnout, inadequate infrastructure, lack of physical guidelines, and resource shortages prevent consistent long-term adherence. The study highlighted the need for improved resource allocation and infrastructure, better access to essential medications and equipment, and continuous education for healthcare workers to enhance adherence to the treatment guidelines.

CHAPTER ONE

INTRODUCTION

1.0 Overview of Sickle Cell Disease

Sickle Cell Disease (SCD) is a blood disorder that's characterized by production of abnormal hemoglobin S (HbS) secondary to a mutation in the HBB gene, that encodes the beta-globin subunit of hemoglobin (Elendu et al., 2023). It's a genetically transmitted disorder, the mutation occurs at the sixth position of the beta-globin chain thereby leading to the substitution of valine for glutamate. HbS molecules polymerize under low oxygen conditions culminating in the formation of stiff and sticky, sickle-shaped red blood cells (RBCs).

Normal RBCs being flexible and biconcave in shape allows them to easily navigate through the system of tiny blood vessels in the body. Whereas, sickle-shaped RBCs are rigid. These can therefore block in small blood vessels heralding to various complications. Vaso-occlusion is the primary pathophysiological consequence of this sickling process (Manwani & Frenette, 2013). This process impedes blood flow and reduces oxygen delivery to tissues in the long run resulting in vaso-occlusive crisis that's characterized by acute and chronic pain episodes.

Sickle cell anemia (SCA), which is the most severe form of SCD is commonly found in malaria prevalent regions such as Asia, Africa, the Mediterranean and the Middle East (Egesa et al., 2022). The geographical distribution above is attributed to the carriers of one sickle cell gene (sickle cell trait) that have a survival advantage against malaria, hence the higher numbers of the HbS gene in these groups (Piel et al., 2010).

SCD involves almost all organ systems and the clinical features can vary widely. Typically complications with variable severity include vaso-occlusive pain crises, acute chest syndrome, stroke, and splenic sequestration that are potentially fatal (Tanabe et al., 2019).

Strict treatment guidelines adherence is essential for the effective management of SCD. This includes making an accurate diagnosis coupled with consistent medication regimens with regard to timing, dosage, and duration. Adherence is often rather challenging leading to poor health outcomes and increased healthcare costs. Non-adherence has been associated with poor patient outcome and also high economy burden (Mohiuddin, 2023). Therefore, efforts to improve adherence in the management of SCD are globally critical.

1.1 Background to the study

According to Adigwe et al. (2023), Sickle Cell Disease (SCD) is a major public health matter that's affecting more than 4.4 million people worldwide. This burden is disproportionately high in Africa, it's estimated that 10% to 40% of the population is affected with 80% of the sufferers coming from sub-Saharan Africa. SCD accounted for about 7.3% of under-5 mortality in Africa in 2018 with a mortality rate of 90% for children below 5 years (Thomson *et al.*, 2023). According to Hernandez et al., (2021), Uganda, is highly burdened with SCD, having a national prevalence of 0.9% with some heavily burdened areas having prevalence as high as 45% (Adigwe et al., 2023). Uganda is still faced with unique impediments in the management of SCD despite its reported high burden (Egesa et al., 2022).

SCD is characterized by the presence of abnormal hemoglobin S that culminates in the sickle shape secondary to distortion of the red blood cells, leading up to complications such as vaso-occlusive crises, hemolytic anemia, and increased susceptibility to infections (Elendu et al., 2023). If not managed effectively, the above complications result in frequent hospitalizations, poor quality of life, and premature death.

According to Ogu et al., (2021), approach to SCD management is comprehensive, this entails prevention and treatment of complications, pain management, regular health maintenance, and patient education. World Health Organization (WHO) and other health bodies have provided internationally accredited guidelines for the management of SCD. These have outlined evidence-based practices for the optimal care of people living with SCD ranging from pharmacological treatments, such as the use of hydroxyurea and prophylactic antibiotics, to non-pharmacological strategies such as patient education and regular health check-ups.

Empirical literature review by (Pizzo *et al*., 2023) reported low prescription rates of hydroxyurea that were attributed to patient and provider factors despite the established evidence of this drug in SCD management. Physicians providing care to SCD patients have been found to adhere to some guidelines more than others (Ismail *et al., 2023*).

In Uganda, Mulago National Referral Hospital (MNRH), is a crucial center for the management of SCD (Munube *et al.,* 2016). Adherence to treatment protocols by the health workers remains inconsistent in spite of the availability of treatment guidelines. This undermines the quality of care received by the SCD patients, leading to poor health outcomes (Bulafu *et al.,* 2023). Understanding the factors that influence adherence to

the guidelines is crucial for improving SCD management at MNRH. Various challenges hinder healthcare workers from following treatment protocols effectively, such as lack of awareness or familiarity with the guidelines, limited access to resources, inadequate training, and high patient burden (Wang *et al.,* 2023). In addition to that, systemic issues like insufficient infrastructure, poor working conditions, and limited support from the healthcare system potentially hinder adherence. Conversely, adherence facilitators include ongoing professional development opportunities, supportive management, resource availability, and a conducive work environment.

This study aimed to explore the specific barriers and facilitators that affect the adherence of medical doctors to the treatment guidelines during management of SCD at MNRH. Through identifying these factors, the study was to offer insights that guide strategies to improve adherence, ultimately improving the quality of care provided to SCD patients (Namaganda et al., 2024). Such improvements could potentially lead to better health outcomes, and overall better quality of life for people with SCD in Uganda.

This study's significance cannot be overstated. Improved consistency and effective management of SCD can be leveraged through addressing the barriers and leveraging the facilitators to guideline adherence (Masese *et al.,* 2019). This could serve as a model for other healthcare settings within Uganda and similar contexts hence improving the health outcomes for SCD patients throughout the region.

1.2 Problem statement

According to Smeltzer et al., (2021), guidelines in the management of SCD have not been widely integrated into clinical practice. Many barriers to guideline adherence in SCD management among clinicians in their everyday practice have been described (Cabana *et al*., 2019). MNRH that serves as a primary center for management of the disease is faced with a significant gap in adherence to the treatment protocols by health workers despite the presence of well-established treatment guidelines (Kaudha *et al.,* 2023, Namaganda *et al.,* 2024).

Within Uganda, SCD care is provided by a wide range of professionals who have a variable range of training and expertise, leading to inconsistencies in the care provided. Ofakunrin et al., (2021) reported high hydroxyurea utilization rates among hematologists and pediatricians as compared to general practitioners.

Inconsistencies in adherence result in suboptimal care, culminating to increased occurrence of preventable complications, frequent hospitalizations, high morbidity and mortality rates among SCD patients (Yang *et al.,* 2022).

Multiple factors are attributed to the suboptimal adherence to treatment guidelines among health workers, including limited awareness and understanding of the guidelines, inadequate training and continuing education opportunities, and high burden (Bulafu et al., 2023). System related issues like insufficient medical supplies, poor infrastructure, and lack of institutional support aggravate the issue, affecting health workers consistency in applying the recommended practices.

Conversely, potential facilitators that could improve adherence are, professional development programs, resources availability, supportive management practices, and

a conducive work environment (Holtzman *et al.,* 2015). However, these facilitators are not fully integrated into the healthcare system at MNRH and therefore underutilized. Guideline adherence serves a critical role in improving patient outcomes, however, specific barriers and facilitators influencing adherence to SCD treatment guidelines within MNRH have not been comprehensively studied (Namaganda et al., 2024). Therefore, there is a critical knowledge gap that hinders effective interventions development. Without better understanding these factors, efforts to boost adherence and improve patient outcomes remain fragmented and ineffective.

This study therefore sought to systematically explore and identify the key barriers and facilitators affecting health workers' adherence to SCD treatment guidelines at Mulago National Referral Hospital. Through this, it aimed to provide a detailed understanding of the challenges and opportunities within this healthcare setting. This study will provide insights that insights will be instrumental in the formulation of targeted strategies that enhance guideline adherence, ultimately leading to better management of SCD in Uganda.

1.3 Objectives of the study

The study's general and specific objectives were:

1.3.1 General objective

To explore the barriers and facilitators towards adherence to the treatment guidelines in the management of Sickle Cell Disease among medical doctors at Mulago National Referral Hospital in Uganda.

1.3.2 Specific objectives

i. To assess the facilitators of adherence to the treatment guidelines among medical doctors in the management of SCD at Mulago National Referral Hospital.
ii. To explore the barriers of adherence to the treatment guidelines among medical doctors in the management of SCD at Mulago National Referral Hospital.

1.4 Research questions

The research questions were:

i. What are the facilitators towards adherence to treatment guidelines among medical doctors in the management of SCD at Mulago National Referral Hospital?
ii. What are the barriers of adherence to treatment guidelines among medical doctors in the management of SCD at Mulago National Referral Hospital?

1.7 Scope of the study

1.7.1 Geographical scope

The study was carried out at Mulago National Referral Hospital, situated in Kampala, Uganda. MNRH offers specialized services, one of them being the treatment and management of SCD. In order to foster in-depth exploration of the barriers and facilitators towards adherence to treatment guidelines, MNRH served as a model due to the large population of SCD patients it serves.

1.7.2 Content scope

The study examined adherence to SCD treatment guidelines among the medical doctors at MNRH. This entailed identifying the specific barriers and facilitators that either hindered or enhanced adherence to the guidelines respectively. Various factors were explored during the study, including medical doctors' knowledge and awareness of the

guidelines, resource availability, opportunities for training and professional development, and systemic issues within the facility. Additionally, the study examined the impact of these factors on patient outcomes and the quality of care provided to SCD patients within the facility.

1.7.3 Time scope

The study was carried out between June and November 2024. This timeframe included the planning phase, data collection, analysis, and reporting of the findings. The time duration above was sufficient enough to gather meaningful data and provide actionable insights to foster adherence to treatment guidelines.

1.5 Justification of the study

Uganda is faced with a high burden of Sickle Cell Disease, MNRH serves as a key hub for managing this condition within the country. However, the adherence of health workers at this facility is inconsistent despite the existence of well-established treatment guidelines, culminating in poor patient outcomes (Kaudha *et al.,* 2023). To achieve improved quality of care for SCD patients, the gap between presence of guidelines and there implementation has to be understood.

This study sought to assess the key barriers and facilitators that affected medical doctors' adherence to the treatment guidelines. Bridging the gap between theory and practice could be achieved through in depth analysis of these factors. The findings also provided valuable insights into how systemic issues within the healthcare environment impact guideline adherence. This information could be crucial for policymakers, hospital administrators, and healthcare providers to enable them create a conducive

work environment that supports the consistent application of the treatment guidelines in SCD management.

Furthermore, improved adherence to treatment guidelines aligns with the Sustainable Development Goals through enabling the achievement of lower morbidity and mortality rates and enhancing patients' quality of life in the long run. (Ally et al., 2023).

1.6 Significance of the study

The significance of this study lay in its ability to foster meaningful improvements in the management of SCD at MNRH and other settings. Through identifying the key barriers and facilitators towards guideline adherence, the research laid a foundation for strategies development in order to improve the quality of care for SCD patients. Improved adherence to treatment guidelines has been associated with effective management of the disease through reduced frequency and severity of complications, decreased hospital readmissions, and ultimately lower mortality rates (Mbaezue *et al.,* 2023). Understanding the challenges medical doctors experience while adhering to guidelines could guide the process of development of interventions such as training programs, resource allocation, and changes in hospital policies. This could lead to improved competency and performance among the health workers.

The study findings would be instrumental for policymakers during policy formulation aimed to address the identified barriers and leverage facilitators hence promoting sustainable improvements in SCD management. Through highlighting the specific areas of resource underutilization and shortage from the study, there could be more efficient

allocation and utilization of resources. The study insights could serve as a model for other health facilities and similar settings in Uganda. For instance, the strategies developed to enhance guideline adherence within MNRH could be adapted and implemented in other health facilities, therefore amplifying the effect of this research study.

Finally, this study contributed to the global body of knowledge regarding SCD management, especially in low-resource settings. These findings could guide international efforts hence leading to standardization and improved SCD care worldwide.

1.8 Theoretical framework

The Consolidated Framework for Implementation Research (CFIR) that's constructed from various implementation theories was the foundation of the theoretical framework. Through application of the CFIR, there was comprehensive assessment of the various factors that could influence the application of healthcare interventions (Kirk *et al.*, 2016, Damschroder *et al.*, 2022). The CFIR entails five domains, i.e. intervention characteristics, outer setting, inner setting, characteristics of individuals, and implementation process. These domains were applied in the identification of key barriers and facilitators and also provided an approach for thematic data analysis (Keith *et al.*, 2017). Through this, the CFIR was crucial aspect of formulation of the theoretical framework as it provided an exhaustive and systematic approach for exploring the study objectives in a complex healthcare setting like MNRH (Peters, Tran and Adam, 2013).

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter presents a discussion of the relevant literature that guided this research. It highlights the theoretical and empirical literature as well as the gaps in the literature that the study set out to address.

2.1 Adherence to Sickle Cell Disease treatment guidelines

The management of SCD includes preventive and therapeutic measures. Makani *et al.,* (2013) recorded some of the preventive measures which encompassed neonatal screening, prophylactic penicillin for preventing infections, vaccinations, hydroxyurea to increase the fetal hemoglobin level, which reduces the frequency of pain crises and other complications, pain management, regular blood transfusion, and bone marrow transplants.

Despite advancing comprehension and management of SCD, the disorder still proves to be a massive public health challenge. In most low-resource settings including Sub-Saharan Africa (SSA) where the disease burden is the highest i.e. greater than 75% of the patients living with SCD, access to comprehensive care is seriously lacking (Ally *et al.*, 2023). A limited number of qualified health personnel, absence of treatment guidelines, lack of infrastructure, and disease-modifying medicines like hydroxyurea compromise care for these patients.

Jiao et al. (2023) reports that the life expectancy of SCD patients in the United States is 52.6 years, which contrasts sharply with Sub-Saharan Africa, where 90% of children with SCD do not survive past their fifth birthday (Ally et al., 2023).

According to WHO, 70% of the deaths attributed to SCD are preventable through cost friendly interventions such as provision of comprehensive care. This can be achieved through timely treatment of acute episodes, infection prevention through vaccination and penicillin prophylaxis (Makani et al., 2011). All the above can be easily attained through treatment guideline adherence.

In resource-limited settings, adherence to treatment guidelines varies; however, children treated according to these guidelines have shown lower inpatient mortality rates compared to those who are not (Opoka et al., 2019). For instance, few children in Eastern Uganda have been initiated on hydroxyurea, a disease-modifying drug recommended by the Uganda Clinical Guidelines for managing SCD (Olupot-Olupot *et al.*, 2020).

This highlights the need for significant efforts to enhance care for individuals with sickle cell disease in local settings. Ongoing research, improved healthcare infrastructure, culturally sensitive patient education, and system-wide efforts to promote adherence to treatment guidelines are crucial for better outcomes for SCD patients.

Although the importance of adhering to treatment guidelines is well recognized, there is a lack of information on the actual adherence levels in managing SCD. No studies have yet been conducted in Uganda to determine the extent of adherence to these guidelines.

Furthermore, no comprehensive studies had been done to examine the impact of continuous professional education, policies, institutional support and multidisciplinary

care models on adherence rates. These gaps were addressed in this study through exploring the key facilitators and barriers towards adherence to SCD treatment guidelines among healthcare workers.

2.2 Importance of adherence to Sickle Cell Disease treatment guidelines

Adherence to the established treatment protocols in SCD management improves clinical outcomes through practicing evidence-based care. For example, prophylactic penicillin and pneumococcal vaccination have been associated with reduced frequency of severe infections in children with SCD (Cober & Phelps, 2010), whereas repeated blood transfusions prevent complications like stroke (Fortin et al., 2018). Also, hydroxyurea use coupled with periodic transfusions can prevent both acute and chronic complications, such as painful crises and recurrent strokes respectively (McGann & Ware, 2015).

Treatment guidelines adherence aims to improve the quality of life for SCD patients through controlling pain, preventing infections, and decreasing admission rates leading to improved physical and psychological well-being (Elendu et al., 2023). Patients who follow treatment regimens experience fewer complications which enhances their functionality. Preventive care through frequent blood transfusions and vaccinations was found to be more cost-effective than treating complications like strokes or severe infections (Wiyeh et al., 2018).

Compliance with the SCD treatment guidelines is associated with reduced mortality through preventing life-threatening events and implementing timely interventions for various acute complications (Ogu et al., 2021).

Guideline adherence is associated with standardization of care across all healthcare levels. This limits variation in care and enables tracking of patient outcomes and treatment response (Sevransky et al., 2021).

Adherence to treatment guidelines ensures good patient care through emphasis that health workers apply the most current and effective treatments based on scientific evidence. This is achieved through staying updated on advancements in management of the disease that are usually outlined in the periodically revised guidelines (Adewoyin, 2015).

2.3 Facilitators towards adherence to SCD treatment guidelines among medical doctors

The facilitators towards adherence to Sickle Cell Disease treatment guidelines are classified below as individual and non-individual factors.

Individual factors

Knowledge and awareness

Facilitating adherence to SCD treatment guidelines among medical doctors is crucial while ensuring that patients receive the best care possible (Masese et al., 2019). Multiple strategies and practices could improve health workers' ability to follow established protocols culminating in good treatment outcomes (Isa et al., 2023). This can be through awareness of the existence of the treatment guidelines and a positive attitude towards the outcomes associated with adherence to treatment guidelines. The level of knowledge is also directly affected by the level of education as well as work experience. Situations in which clinicians don’t comply with treatment guidelines have been associated with insufficient care coordination and inconsistency, especially with

provider-to-patient communication (Phillips *et al.,* 2022). Patients will therefore receive conflicting information regarding their care plan, which in the long run compromises the quality of care provided. Longer work experiences can affect health workers perceptions of treatment guidelines through their expected outcomes from specific interventions. Therefore, treatment guidelines provide uniformity regardless of cadre or work experience which leads to better provider-provider coordination in the provision of care to patients with SCD.

Health workers wellbeing and mental health support

This is another crucial facilitator of adherence to treatment guidelines (Vera San Juan *et al.,* 2020). Addressing the psychological and emotional needs of healthcare providers helps prevent burnout and maintain high levels of job satisfaction. Access to counseling services, peer support groups, and wellness programs that promote physical and mental health can help healthcare workers manage stress and remain committed to providing high-quality care (Simms *et al.,* 2023). A supportive work environment that recognizes and values the contributions of healthcare workers fosters a positive culture and encourages adherence to guidelines (Maassen *et al.,* 2021).

Non-individual factors

Comprehensive and continuous professional education

Ongoing training programs, such as continuing medical education (CME) courses, workshops, and seminars, keep healthcare workers up to date with the latest research, treatment guidelines, and best practices in SCD management (Merry *et al.,* 2023). E-learning modules provide flexible access to educational resources, allowing healthcare workers to learn at their own pace and convenience. Educational initiatives like these

ensure that health providers are knowledgeable and competent in management of SCD, thereby encouraging adherence to the guidelines (Mahdavi Ardestani *et al.,* 2023).

Multidisciplinary team approach

SCD management often requires the expertise of multiple healthcare professionals, i.e. hematologists, pediatricians, nurses, social workers, and psychologists (Adewoyin, 2015). Through encouraging a team-based care model, health workers can effectively collaborate in order to comprehensively tackle the needs of these patients. Communication and coordination within the healthcare team can be improved through frequent team meetings and case discussions, ensuring that all aspects of patient care are addressed according to the established guidelines (Babiker *et al.,* 2014). This approach culminates in provision of holistic care and improved adherence to the treatment protocols.

Adequate staffing and resource allocation

Through availability of adequate numbers of trained professionals within the facilities, there is reduced workload on individual healthcare workers, this allows them to focus on quality of care provided (Kovacs & Lagarde, 2022). Also, access to the necessary diagnostic tools and medications is crucial in the effective implementation of SCD treatment guidelines. Offering financial support for SCD management programs through trainings and infrastructure development ensures that healthcare workers have the necessary resources to remain adherent to the guidelines and therefore provide optimal care (Dua *et al.,* 2022).

Institutional support and robust healthcare policies

Health policy and institutional support play a significant role in facilitating adherence (Vaismoradi *et al.,* 2020). Development and dissemination of clear, evidence-based protocols to guide SCD management within hospitals provides a standardized approach for the healthcare team to follow. Commitment from administrators and policy-makers ensures appropriate resource availability which caters for favorable support systems that enhance guideline adherence in the long run (Bhati *et al.,* 2023). Through quality improvement initiatives like regular adherence monitoring, areas for improvement are identified. This further strengthens the commitment to guideline-based care.

Cultural competence and communication skills

Enhanced cultural competence and good communication skills among healthcare workers has been associated with better adherence to the treatment guidelines (Walkowska *et al.,* 2023). Focus on training programs aimed at cultural sensitivity helps healthcare workers understand and respect patients' cultural values, beliefs, and preferences, fostering a trusting relationship. Also, effective communication strategies like the use of language interpretation services and culturally tailored educational materials, improves patient engagement and the overall understanding of the treatment plan (Andrulis & Brach, 2007). Patients are more likely to adhere to treatment recommendations when they feel understood and respected, this in turn encourages healthcare workers to follow the guidelines diligently (Krist et al., 2017).

2.4 Barriers towards adherence to SCD treatment guidelines among medical doctors

Various barriers that impede adherence to treatment guidelines have been identified. These have been classified into individual and non-individual factors as discussed below.

Individual factors

Insufficient training and knowledge

Insufficient training and knowledge among healthcare workers regarding SCD and its management is a major barrier towards adherence to the guidelines (Phillips *et al.*, 2022). Some health practitioners may lack comprehensive knowledge on the complexities of SCD, culminating in inadequate implementation of the treatment guidelines. Continuous medical education is necessary to ensure that healthcare workers are aware of the latest treatment protocols and can apply them in their day to day practice (Jonathan et al., 2022).

Burnout and fatigue

Caring for patients with chronic illnesses such as SCD has been associated with a psychological/emotional burden that often leads to burnout thereby affecting the overall health workers' adherence to treatment the guidelines (Ohaeri & Shokunbi, 2002). Cumulative stress from occasional poor patient outcomes affects healthcare workers' mental well-being and job performance (De Hert, 2020). Provision of mental health support and promoting a supportive work environment are essential for mitigating burnout and enhancing adherence the treatment guidelines.

Non-individual factors

Heavy workload

Heavy workloads and time constraints that are often encountered by healthcare workers often limit their ability to adhere to the treatment guidelines diligently (Portoghese *et al.,* 2014). Resource-limited settings usually suffer a high patient-to-provider ratio that leads to rushed consultations and limited time for an elaborative interaction between the parties involved. This has been associated with non-adherence for both parties (Iacob *et al.,* 2017). There is need for system reforms aimed at improving the staffing levels in order to reduce the patient burden per provider, and therefore ensure sufficient time for patient education and care.

Fragmented care

Care for patients with SCD calls for multidisciplinary approach involving multiple specialists like hematologists, pediatricians, and social workers etc. Poor coordination among the different health care teams is a major barrier towards guideline adherence (Phillips *et al.,* 2022). Lack of coordination and poor communication within the healthcare providers often leads to inconsistencies in care, missed follow-ups, and non-adherence to the guidelines (Tiwary *et al.,* 2019). Therefore, applying integrated care models and improving communication systems within healthcare teams could boost care coordination and adherence to guidelines.

Inaccessibility to drugs and equipment

Resource limitations and poor infrastructure in healthcare facilities is associated with non-adherence and substandard SCD management (Ally & Balandya, 2023). A study by Marahatta *et al.,* (2020) found that limited access to diagnostic tools, medications, and

specialized care services hindered treatment guidelines implementation and application. Equipping healthcare facilities adequately with the necessary resources and infrastructure is essential if healthcare workers are to deliver optimum care.

Institutional support

This plays a crucial role in enabling healthcare workers adhere to SCD treatment guidelines. Limited administrative support like inadequate funding for training programs, insufficient staffing, and no easy access to updated clinical guidelines negatively impacts healthcare workers' capability to provide guideline-based care (Wang *et al.,* 2023). Institutional support can be strengthened through favorable policies formulation and increased funding opportunities that prioritize quality management of SCD.

Cultural and communication barriers

Barriers in communication between healthcare workers and patients impact adherence to the treatment guidelines. Additionally, misunderstandings, language barrier, and cultural differences could impede effective communication and the delivery of culturally sensitive care (Schyve, 2007). Healthcare workers therefore need training in cultural competence as well as access to language interpretation services to bridge these gaps. With this, they are equipped to provide patient-centered care that recognizes and respectsvariable cultural values and preferences (Saha *et al.,* 2008).

2.5 Summary

Treatment guidelines adherence is essential for improving patient outcomes thereby reducing healthcare costs, and preventing complications. Establishing the adherence level to these guidelines and associated factors in SCD management is crucial. These findings can be applied in the development of monitoring interventions which could ultimately improve the quality of care provided by health workers to SCD patients. Continuous medical education, multidisciplinary care, adequate staffing and resources, institutional support, and competence are some key facilitators of guideline adherence among healthcare workers. Conversely, barriers like insufficient training, heavy workloads, fragmented care, inadequate resources, and communication challenges that hinder guideline adherence in SCD management ought to be mitigated.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

The methods and procedures used to select, identify, and analyze information related to the topic of study are addressed in this chapter.

3.2 Research design

The study undertook a qualitative and phenomenological design. This approach was chosen to gain an in-depth understanding of the complex, context-specific factors influencing adherence, which are best captured through qualitative methods. Key informant and in-depth interviews were conducted among medical doctors to explore their barriers and facilitators towards adherence to sickle cell treatment guidelines.

3.3 Area of study

The research was carried out at the Sickle Cell Clinic (SCC) at MNRH, which serves as Uganda's National Referral Hospital and a teaching hospital for Makerere University's College of Health Sciences. The SCC is open five days in a week with more than 15,000 registered patients and receives about 60-80 sickle cell patient daily with over 70 new patients monthly. Patients usually come for checkups, refills and acute care and crises management (Kaudha *et al.*, 2023). The study area was equipped with a variety of diverse professional cadres, it has a specialized clinic (sickle cell) of the study focus and easily accessible underscoring the essence of its selection.

3.4 Sources of information

The informants (medical doctors serving in the sickle cell clinic at Mulago Hospital) were the primary source of information. Depending on the level of seniority, part of

this group was described as the key informants; these were the consultant/specialist doctors. The other respondents were the Senior House Officers (SHOs), Medical officers (MOs), and Junior House Officers (JHOs). This group participated in the in-depth interviews while the former took part in the key-informant interviews.

3.5 Study population and sampling techniques

All medical doctors who were working in the Sickle Cell Clinic at Mulago National Referral Hospital and actively engaged in the delivery of sickle cell care were interviewed. These included the senior house officers, junior house officers, medical officers and the specialist pediatricians and hematologists. Purposive sampling technique was applied in the selection of the participants to ensure they fit the selection criteria. The medical doctors were interviewed until saturation point.

3.5.1. Inclusion criteria

The inclusion criteria were:

All the doctors, who were actively engaged in the delivery of sickle cell care, with at least one month experience working in the Sickle Cell Clinic of Mulago National Referral Hospital.

3.5.2. Exclusion criteria

The exclusion criteria were:

i. Doctors who did not provide informed consent to participate in the study and those who were absent during the data collection period.
ii. Doctors with less than one month experience working in the Sickle Cell Clinic.

3.6 Interviews

3.6.1 Key informant interviews

The key informant interviews (KI) were aimed at pediatricians/specialists working in the sickle cell clinic of MNRH. They were expected to have worked in the SCC for a minimum of one month. The purpose of the interviews was to obtain valuable insights regarding guideline adherence in the management of sickle cell disease patients. The key informants provided critical perspectives on clinical challenges and the available systemic support within the hospital setting. These interviews were conducted till saturation point.

3.6.2 In-depth interview

In-depth interviews were undertaken by the SHOs, JHOs and Medical Officers who were working in the Sickle Cell Clinic and met the inclusion criteria of the study. These interviews provided insights on awareness of the treatment guidelines in this group and also examined their perceptions and experiences regarding adherence to the treatment guidelines in SCD management.

3.7 Sample size

To reach data saturation, qualitative research studies need a minimum of 12 participants (Braun & Clarke, 2006). With regard to this, the attained sample size of 13 participants was deemed sufficient for qualitative analysis.

3.8 Procedure for data collection

Using a semi-structured interview guide, data was collected from the healthcare workers through key informant and in-depth interviews. Potential participants who met the inclusion criteria were identified through purposive sampling. Initial contact was

made through mobile calls and physical interactions from which they were given an overview regarding the purpose of the study and were requested to participate. Those who accepted to participate were briefed on the study's purpose, session format, and confidentiality issues at the beginning of each interview. Eligible participants consented voluntarily by appending a signature to the consent form.

The face-to-face interviews were conducted by the principal investigator and research assistant and lasted between 35 and 60 minutes. The interviews took place in a secure and convenient room within the hospital. They were assigned a unique identifier to maintain anonymity. The interview was audio-recorded, ensuring no identification of participants. This was to ensure data quality, confidentiality, accuracy, and to create a conducive environment for the participants to provide in-depth insights on the topic of study.

Saturation was achieved when the participants yielded no new insights or themes, indicating that a sufficient amount of data had been collected to address the research question.

3.9 Data collection instruments

The interview guides were developed based on the Consolidated Framework for Implementation research (CFIR) (Silver *et al.*, 2023). Two interview guides were prepared i.e. the key informant and the in-depth interview guide. They included questions directed towards the health care workers under (Appendix-III). The framework was chosen for its focus on implementation research and its ability to assess for both barriers and facilitators towards implementation of processes such as a treatment guideline. The CFIR tools contained 13 open-ended questions with probes to

elicit rich descriptions from participants related to barriers and facilitators that influenced adherence to sickle cell treatment guidelines.

3.10 Quality control

To maintain quality and minimize errors, this study undertook various measures:

Given that each individual researcher was more likely to come up with different conclusions. The research tools were pretested prior to the study to ensure that they were valid and reliable. Two health workers, one of which was a key informant, took part in the pretesting activity, there comments and recommendations regarding the tool were sought. This was to ensure precision and relevance of the questions in the guide in order to yield credible information.

One research assistant was trained and worked alongside the principle investigator during the data collection process. This provided for consistency during the process of data collection.

Furthermore, there was use of verbatim transcriptions for accuracy, independent testing and refining of the codebook by three coders. High inter-coder reliability was ensured by involving a third experienced qualitative researcher. Additionally, audio recordings of interviews and the use of a validated framework enhanced data validity and reliability. Confidentiality was strictly maintained by assigning unique identifiers to participants and securely storing data.

Reflexivity was attained through practicing mindfulness and self-awareness among the researchers. All individuals that were involved in data collection and analysis were sensitized on how individual subjectivity regarding the topic of study could affect the credibility of the research. This enabled the research team to remain as objective as

possible and therefore not influence the participants responses during data collection as well as the results interpretation during analysis.

3.11 Data processing and analysis

The interviews were audio-recorded, transcribed word-for-word, and analyzed through a thematic framework based on the Consolidated Framework for Implementation Research (CFIR).

Thematic analysis was conducted to identify key facilitators and barriers, with coding based on a template derived from the CFIR domains. A minimum of two researchers independently tested and refined the codebook, coded the data and where there was disagreement, a third experienced qualitative researcher provided guidance, therefore achieving high inter-coder reliability. The obtained summaries were aggregated into a matrix to identify crosscutting themes. Data analysis involved developing a thematic framework through five steps: familiarization, identifying a thematic framework, indexing, charting, as well as mapping and interpretation. Ultimately, themes were distilled into major themes, capturing key facilitators and barriers. The process was then followed by qualitative research reporting criteria.

3.12 Ethical considerations

Ethical approval was sought from the Research Ethics Committee (REC) of Uganda Christian University (UCU) and the Research Committee of Mulago National Referral Hospital, subsequent endorsement from the head of department of the SCC for a go ahead with data collection was attained.

All the healthcare workers were fully informed about the study's objectives, procedures, and risks, with informed consent obtained before participation.

Participation was voluntary, with the right to withdraw at any time. Verbal consent for interviews was recorded, while written consent was captured on the consent forms. All data was kept confidential and secure through anonymization and storage in password-protected and encrypted files. Access was limited to the research team. The interviews were conducted in safe environments.

CHAPTER FOUR

RESULTS

4.0 Introduction

This chapter presents the findings of the study in accordance with the research objectives. The general objective of the study was to explore the barriers and facilitators of adherence among medical doctors to treatment guidelines in SCD management at Mulago National Referral Hospital, Uganda.

4.1 Sociodemographic details of the participants

Table 1 presents the sociodemographic characteristics of the medical doctors at the Sickle Cell Clinic.

Table 1: Sociodemographic attributes of the health workers at the Sickle Cell Clinic

Respondents NO	Sex	Duration working in the SCC	Cadre /level of education
1	Female	7 weeks	SHO-year 2
2	Female	6 weeks	SHO-year 2
3	Female	3 months	SHO-year 2
4	Male	3 months	JHO
5	Male	6 months	JHO
6	Male	2 years	SHO-year 3
7	Male	3 years	SHO-year 3
8	Male	6 months	JHO
9	Female	1 month	JHO
10	Male	3 years	MO
Key informant 1	Female	30 years	Pediatrician (senior consultant)
Key informant 2	Male	10 years	Pediatrician(Hematologist/oncologist)
Key informant 3	Male	15 years	Pediatrician (Hematologist/oncologist)

Thirteen (13) medical doctors participated in the study, duration of work experience in the SCC was ranging from one and a half months to 30 years. Three (3) of these

individuals were the key informants i.e. consultants/specialists working in the sickle cell clinic. Five (5) were Senior House Officers [SHO], these are doctors who are enrolled in the master's program in pediatrics and child health. One (1) participant was a Medical Officer [MO], MOs are doctors who have a Bachelor's degree in Medicine and Surgery. Four (4) of the participants were Junior House Officers [JHO], these are doctors, but may only practice medicine with guidance and supervision. All the above had to have worked in the SCC for at least a month. The latter group of health workers took part in the in-depth interviews.

4.2 Themes and sub-themes

The qualitative data collected was analyzed using thematic analysis with a hybrid of both deductive and inductive approaches. The themes that emerged from the data were categorized into sub-themes.

Table 2 describes the sub-themes that emerged from the data collected during the study. The predetermined themes described in the table were classified as individual and non-individual facilitators versus individual and non-individual barriers.

Table 2: Predetermined and sub-themes

Objectives	Predetermined themes	Sub-themes
Facilitators to adherence	Individual facilitators	• Clinical experience and exposure • Knowledge and awareness
	Non-individual facilitators	• Continuous Medical Education (CME) • Collaborative networks and partnerships • Supportive leadership and hospital management • Having easy and accessible treatment guidelines
Barriers to adherence	Individual barriers	• Burnout and fatigue • Motivation.
	Non-individual barriers	• Lack of physical treatment guidelines • Infrastructure • Caretaker's/Patient's attitude and knowledge • Heavy workload and inadequate staff • Resource constraints.

4.3 Facilitators of adherence to Sickle Cell Disease treatment guidelines among medical doctors

4.3.1 Individual facilitators

Clinical experience and exposure

Medical doctors reported that clinical experience and exposure enhanced their adherence to the treatment guidelines. Repeated exposure to clinical situations enabled them learn from their past mistakes, improved their understanding of why, when and how a particular intervention had to be applied. For example, the application of the transfusion protocol in patients with stroke refined their adherence to the treatment protocols over time. Additionally, junior healthcare workers such as the SHOs and JHOs noted that they benefited from observing and receiving guidance from the senior staff, that is the specialists and fellows which strengthened their understanding and application of the guidelines. Such learning was facilitated through contact hours and consultations with the specialists while at the clinic.

> Respondent two remarked, "*At the beginning, you are uncertain about what steps to follow, especially when I was a JHO and in my first year as an SHO, but over time, as I keep practicing and getting exposed to the guidelines… I think experience taught me how to manage the patients better while adhering to the guidelines*."

Some respondents also mentioned that repeated use of the guidelines led to memorization, making adherence easier in the long run as explained by respondent three:

"Having many patients gives me more opportunity to practice more of these guidelines. The guidelines for managing stroke are not the same as those for managing just simple anemia. So, I will practice the guidelines of anemia more commonly, if those are the only patients I'm getting, without practicing the ones of managing stroke. However, as an SHO here now, in an environment where I have a stroke patient, or severe anemia, or acute chest syndrome, I get to practice more of those guidelines. And to even understand them better, because I'm practicing them."

It was also noted that with more experience, they become more confident and better able to handle complex cases, at the same time they became more familiar with the protocols.

Respondent seven pointed out, "*You need time and patience, I am in my final year of pediatrics, but it takes time to understand and apply all treatment guidelines… applying them by yourself. Looking back, some cases that were complex in first year are not that complex because I have practiced them for some good time… I have learned how to handle complex cases while sticking to the guidelines and with minimal supervision.*"

Knowledge and awareness

All respondents acknowledged that knowledge and awareness of sickle cell treatment guidelines facilitated their adherence to the treatment guidelines. When healthcare professionals have a thorough understanding of the protocols and a solid foundation of knowledge about sickle cell disease, they are more likely to follow the treatment guidelines consistently.

Respondent seven emphasized the importance of knowledge stating, *"When I know what I am doing, when I understand the problem, here the problem is sickle cell. If I have the knowledge of sickle cell, and I have the standard guidelines or protocols to handle this… All those things will actually empower or facilitate proper use of this guideline, meaning that it will actually empower and enrich our adherence to me as a clinician and others, because you know the reason, you know how important it is. So, I think knowledge is very important and it will basically facilitate… it will empower that good adherence."*

Respondent four added, *"Understanding the disease and how it comes about and the pathology helps one make sense of why these protocols are in place. It makes the guidelines make more sense. So, if I understand them, this is why they're telling me the hemoglobin level must be 8, not below 8 and not above 10 when you're managing a patient with a stroke. When I know the pathology, then I understand why the guidelines are stated that way. Then I know why I must follow them to prevent the other complications."* Healthcare workers who had strong mindfulness of the treatment procedures developed trust in their effectiveness. They indicated that understanding the evidence and criteria behind the protocols allowed them to follow them unswervingly.

4.3.2 Non-individual facilitators

Continuous Medical Education (CME)

Participation in CMEs regularly was associated with assisting the doctors stay up-to-date with the recent treatment protocols and best practices. Healthcare workers reported that attending CMEs increased their confidence in managing complex cases, as these

sessions often included trainings on how to handle rare and difficult conditions. In addition to refreshing their knowledge, CMEs were seen as an essential tool for continuous learning and maintaining adherence to evolving treatment protocols.

Respondent three highlighted the practical impact of CMEs:

"I once had a child with a priapism on the ward in sickle cell disease. It was the first time I've seen one in a number of years. We thought it's just pain control, give adequate fluids, but we had done everything and it hadn't worked. That week, we had a teaching on how to manage a patient with priapism. We had done all we thought we knew how to and the child was actually not improving. But after we had this CME and they told us how to intervene in the first 24 hours, and if it's past 24 hours, what else you can do, how to follow up. That CME helped me manage the next patients and it got better, got easier."

Respondent one echoed the value of regular CMEs:

"I think we can do CMEs like monthly or if it's really bad, every three months, because we can forget what should be done, it is good to remind people, when you remind people, they'll be able to adhere to the what… to the guidelines, compared to when you just leave us and we don't have anything and we may also not know the importance of adherence to the guidelines if you don't remind us, you know we need reminding, humans need reminding."

Respondent ten noted the collaborative nature of CMEs:

"we had a CME about blood transfusion in children that have sickle cell. Of course, you always see the children and you always write for them blood

transfusions. But the CMEs help because they are more comprehensive. They cover what you already know, but they also cover a few things that may not be very typical… But also, they bring all of you on the same... You see, when you have the specialist, you have the MO, you have the intern, you have the SHO, everyone has their level of experience and usually everyone is clearing their line. So, you may not interact as much. You can consult, but just briefly. But in the CMEs, you actually have the time. You're not seeing patients. You are discussing a particular topic and then addressing it at the same time. So that helps all of you to sort of level up in a way. So, it helps the juniors… us the juniors, to sort of pick up their knowledge."

CMEs not only provided opportunities for knowledge reinforcement but also fostered peer learning and discussions, which improved the overall quality of care. By consistently attending CMEs, healthcare workers are reminded of the importance of standardized protocols, leading to more reliable and effective application of the guidelines.

Collaborative networks and partnerships

Almost all respondents revealed that collaboration and networking with other institutions were crucial facilitators of adherence to sickle cell treatment guidelines. Partnerships with hospitals, research institutions, NGOs, and international organizations gave healthcare workers access to advanced knowledge, resources, and best practices. These collaborations enhance the capacity of healthcare workers to implement evidence-based guidelines, improve resource availability, and offer opportunities for ongoing learning and professional development.

Respondent one shared: *"I think there is a sickle cell association… actually, people are putting a lot of energy into sickle cell, there is, and there is a lot of research going on about sickle cell, and that has helped because I think they even provide some medication… they donate some medications to patients at the clinic. For, then also the partnerships, let me say with the blood bank, sometimes you don't have blood here in Mulago, and you can actually easily access blood, you just call the people there and you tell them we need this blood, and as long as it's available, they see how to deliver it. It helps because, you know, we need blood in the management of sickle cell disease sometimes. Yes, I think partnerships are important and they have improved patient care…"*

Further,

Respondent two also said, *"But then also, there are complications, and you need consultations of other wards like nephrologist. So, all the time you're writing consultations to the nephrologist, calling them, then pulmonologist calling them. Some patients need consultations from other units like surgery, mainly surgery. So, we call them actually when you're rotating on that ward, you have to befriend some SHOs in the surgical unit for your patients to be seen. Because, you know, on a daily you may need… you may have a patient who needs a surgical review, especially the stroke patients. Yeah, sometimes they have hemorrhagic stroke. They need immediate surgery. You have to have their contacts. You have to befriend them so that they can come and review your patients. Yeah. Then also the ICU, you also interact with them a lot especially for acute chest. My patients get respiratory distress a lot. So, you have to have the number. You*

have to know who is rotating in ICU on a daily basis. Yeah, another unit is the chest CTS cardiothoracic because of the pulmonary complications? Yeah, also those ones. We even have the numbers pinned of those people. Yeah. So, interact with them. They come; they give us the prescriptions of what to do. And then we want to change anything we call them.

Still,

Key informant two revealed, *"We work closely with the Ministry of Health and Communicable Diseases. And specifically, we work together to develop the sickle cell care guidelines. And also, we have benefited from supplies like medication supplies, donations, hydroxyurea and all that. So that has facilitated us to ensure that our patients have medicine and therefore indirectly, are working towards adherence to the guidelines."*

Further,

Key informant two added, *"For example, previously we did not have the transcranial Doppler which is used to assess the stroke risk in the patients with sickle cell anemia. But it was through studies. And yet, as a guideline, every child between year 2 and year 16 is supposed to have yearly transcranial Doppler. So, you have it as a treatment guideline, management guideline. But then, you don't have a transcranial Doppler machine. So, it is through partnership with research studies that we managed to secure two transcranial Dopplers. And we've tried to, beyond the study, we've tried to extend the service to the patients. Though it's not 100% that every year everyone gets. But at least*

some of them have gotten some transcranial Doppler assessments. Through this network with external parties."

Collaboration and networking with other institutions has strengthened medical doctors' adherence to sickle cell treatment guidelines by fostering knowledge exchange, providing access to resources, and enhancing training opportunities. These partnerships bridge gaps in expertise and resources, ensuring that healthcare workers can deliver the highest standard of care possible.

Supportive leadership and hospital management

The study showed that effective leadership creates a culture of accountability and ensures that the doctors are provided with the necessary resources, infrastructure, and training to follow protocols. By fostering open communication, offering continuous support, and investing in staff development, hospital management empowers healthcare workers to consistently apply the guidelines, improving both patient care and outcomes.

Key informant one shared, *"when you are there, everybody will tend to do their best. Yes, when you are working with them, everybody will tend to do their best. But most of the time, when I go to the sickle cell clinic, it will be for supervision. I rarely go there to sit and see patients. I will only sit and see patients when there is a gap. Also, I ensure that the patients are properly managed according to the protocols."*

Also,

Respondent eight said, *"Basically, when I feel like I have insufficient information, my guidelines are here. I'm on to the guidelines straight away. The*

only other good thing is that for us, we have consultants that are in and out. Actually, they are always on call. So, I… anything that I do not know, we have direct contacts with consultants. At any one time, I can always call any of those now, and they guide you through.

Still,

Key informant two share, *"When I walk into the clinic. I don't really go straight to the Clinical room. I first go to the waiting area and I scan through. I greet my people as I scan through. Because I know we don't have a perfect triage system. So, my purpose of walking through the clinic, the waiting area, the daycare center is to support those who need urgent care. And many times, they have been missed."*

He added, *"I usually look at supporting as many people as possible, my doctors and patients to be able to alleviate. Or relieve the burden. That is a responsibility to me. And for example. We came up with this idea. That we are about five. Hematologists, Pediatricians and specialists in blood conditions. Including sickle cell. So, we allocate a day to ourselves. Today Monday. Is mine. Okay. And then Tuesday is Annet (not real name). Thursday, Friday and so on. But for each of those days. Whoever is there? Is the overseer, he/she provides support to the juniors present."*

By prioritizing staff needs and creating a supportive work environment, hospital leadership has played a crucial role in strengthening adherence to treatment guidelines and ensuring high-quality patient care.

Having accessible and easy treatment guidelines

Some respondents revealed that the treatment guidelines were readily available and easy to use and interpret. They reported having immediate access to physical or digital copies of the guidelines which helped with ensuring that they stick to them at all times.

> Respondent four said, *"So them being available is already number one to support their adherence as compared to having something maybe which is online. Like currently at the clinic, we have papers."*

Many of the respondents found the guidelines easy and elaborate enough to allow them have uniformity in the care they provided despite their different cadres.

Further,

> Respondent six said, *"We just can't do without a guideline because the guideline just simplifies everything. It takes away the science and brings forth the recommendations. Because the science is a lot and we can get confused and agile about the science. But it just puts forth the recommendations. So that makes it easy, from specialist to junior, to be able to follow something uniform at their level of specialty. Because it does not give a lot of explanations. Why, why, why? But it tells you, do this, tells you what, what, what. Which I think is okay."*

Also,

> Respondent eight revealed, *"When I looked at the guidelines, I was actually surprised. They are well-detailed. I think they were well done. That's why I believe it. They are well done. They are comprehensive. They support adherence. Okay. Actually, the guidelines, you use them according to your level of knowledge because there are all kinds of management from down to top.*

There are kinds of management that are for specialists, and for us juniors. So, you use them according to your knowledge."

4.4 Barriers to adherence to Sickle Cell treatment guidelines among medical doctors

4.4.1 Individual barriers

Burnout and fatigue

Many of the respondents expressed that they experienced burnout and fatigue, this was attributed the very high patient burden at the sickle cell clinic. Some of the participants explained how the heavy workload and long work hours led to exhaustion, making it difficult to adhere to the protocols.

Respondent five said, *"If you tell the patient, give the child a lot of water to drink, you really need to follow up if they are doing so. If you tell them, do morphine after four hours, you really need to follow up if they are doing so. Can you do that when you are having many patients? No, no. Do you know, for us, by the time we finish the ward round, you are really tired, you have even forgotten that you are supposed to take off samples from a patient for cross-matching."*

Further,

Respondent Six echoed, *"The staff will support. The nurses are doing their job, but we have many patients. Sometimes they are overworking, you get tired… motivation… You see there have many things to do and patients are many. Sometimes you rough though just to keep up with the demand."*

Moreover,

> Respondent Four revealed, *"Once you have many patients, you work hard to clear the line. Because you can sit there at 9:00 am and you only have to stand up at about, maybe, 4 p.m. that's exhausting. You also sympathize with the patient who came at eight or at nine and you're seeing them at 3.30. So, the more the number, the more you have to just run through faster. Then you might not stick to the guidelines for every patient. You only stick to the guidelines for specific patients."*
>
> Respondent three added, *"I don't know what to say. I don't want to remember these things. They are sad. You know, sometimes you've never been here. You know how sad sometimes the situation can be."*

Motivation

Majority of the medical doctors reported lack of motivation, this was attributed to them being overworked and lack of access to necessary resources like drugs, equipment and readily accessible treatment guidelines.

> Respondent two said, "*Without physical copies of the guidelines, you have to remember everything or consult others. Over time, it gets tiring, and you lose the motivation to keep doing everything by the book*"

In addition,

> Respondent one said, "*It's frustrating when you know what the guidelines say, but the medications or tools aren't available. It makes it hard to stay motivated when you know you can't give the full care*."

Also,

Respondent five stated, "*Every doctor wants to see his patients well, but sometimes, medicines, equipment and the huge numbers you know… in as much as you want to provide the best for my patients, certain circumstance may fail you and it affects the zeal. It hard to adhere completely especially when you're overwhelmed.*"

4.4.2 Non individual barriers.

Infrastructure

Many respondents highlighted that inadequate infrastructure, including limited space, poor information management, and outdated diagnostic tools, hampers quality care and adherence to treatment guidelines. This poor infrastructure leads to overcrowding and treatment delays, making it difficult for healthcare workers to consistently follow protocols. As a result, there is a significant gap between recommended guidelines and what is feasible in practice, especially in resource-limited settings like MNRH.

Respondent four revealed, *"The clinic is too small. The patients are very many in a very small space. We have four clinicians all sitting in one room. There is no privacy. In fact, the place is just small. That's what you can know. So, if the place is small, of course, it being small, so you have congestion, you have to work faster, you have to just, yeah, something like that. So even though you have the guidelines, because of the congestion, you have to move quicker."*

Moreover,

Respondent one shared, *"when you go to the daycare clinic, adolescents are not catered for, the beds are tiny, so they have to, they share, the babies share the beds, I think there are like five beds in that daycare clinic, but you can want,*

let me say, to give fluids to many babies, maybe transfuse a baby and they go back home, you understand? For infrastructure, we don't, like, it needs to be."

Also,

Key informant two revealed, *"So, we lack that platform that ensures that we can, at a snapshot, see how the patient has performed in the clinic. You have to go manually; they look out for a file. If they missed filing one of the important forms, the CRS, then it means you missed out that visit. So, the technological infrastructure is outdated."*

Caretakers/Patient's attitude and knowledge

The study revealed that when patients and their caretakers lack adequate knowledge about sickle cell disease, its management, and the importance of following treatment protocols, adherence to these guidelines is compromised. Misconceptions, limited understanding of the disease, and distrust in medical advice by can lead to non-compliance, further complicating the healthcare workers' efforts to implement standardized care.

Respondent four revealed, *"Patients, patient caretakers may not be informed of the condition. Maybe they have limited knowledge even about the care. So, they tend to… they might tend to refuse medication. Some like hydroxyurea actually, they fear that it's an anti-cancer drug, something like that. So, like the mother of a child can be willing to take it up but the dad can refuse. Or you can have a child who keeps having, having what? Having splenic sequestration or something like that. And they have this chronic anemia with hypersplenism. Then you counsel them about splenectomy. But still, because they don't have,*

maybe they don't have adequate information or they have certain beliefs and then they will not consent to the procedure."

Furthermore,

Key Informant one shared, *"some patients do not believe in what you prescribe. Some patients will tell you they will not give their children hydroxyurea. They do not believe in it. Some of the even educated patients will say, I have read everything about hydroxyurea. It causes bone marrow separation. It causes ABC. I will not give it to my child."*

Further,

Respondent ten said, *"If you get a Jehovah witness, for them…their religious beliefs don't allow transfusion so they are always not interested in blood transfusion, something like that. So, you have to… you don't have to follow the guidelines. You have to just leave everything there. You can't force the patient."*

In addition,

Respondent seven shared, *"Parents believe in religion… culture. Those are the things that I can look at to influence adherence from the external setting. Because your guidelines are saying, we do this for this child. And the parents take is, I will first ask the Jaja. I will first ask the pastor. So, those are the things that affect adherence."*

Inaccessibility to drugs and equipment

The study results revealed that inaccessibility to essential drugs and medical equipment as a major institutional barrier towards adherence to sickle cell treatment guidelines.

Doctors have to rely on a consistent supply of medications such as hydroxyurea, pain relief medications, and blood products, as well as diagnostic tools and equipment, to effectively manage sickle cell disease. However, the lack of availability and delays in procurement of these critical resources hinder healthcare workers' ability to implement treatment protocols accurately and efficiently.

> Key Informant one shared, *"The patients you write, you prescribe. And the drugs are out of stock. And you tell them, please go and buy this. And they cannot buy. They have financial constraints."*

In addition,

> Respondent seven added, *"It is the biggest challenge because infrastructure is a big thing. One, you don't have privacy, you are four clinicians in the same room. That is a big deal. Yeah, so no privacy, end up breaching confidentiality. I'm hearing, you are hearing, the other one is hearing. You know, all those things."*

Moreover,

> Respondent One emphasized, "*Hydroxyurea is expensive, and there are days when we don't have it. You prescribe it, but the patient can't get it*"

He further added,

> "*You have to check the CBC, liver, and renal function tests, but sometimes we don't have reagents or tools to do these tests*"

Still,

Respondent three stated, "*Blood transfusions are a critical part of the protocol for managing severe anemia or acute chest syndrome, but when there is no blood available, we are left with no option but to delay or alter the treatment plan*"

Lack of physical treatment guidelines

Many doctors reported not to have access to physical treatment guidelines. They highlighted that when treatment guidelines are not available in physical form, such as printed copies or posters displayed in clinical areas, they may forget critical aspects of care or resort to inconsistent practices, especially in high-pressure situations. This lack of accessibility can often result in deviations from standardized treatment protocols.

Respondent one noted, "*We don't have like... they will not say these are the guidelines or what... I cannot say I've seen physical guidelines.*"

Similarly,

Respondent two pointed out, "*They are not pinned enough... you may be knowing what is supposed to be done, but when they don't pin them up... giving people books maybe in the clinics or on the walls would help to follow the guidelines.*"

She added,

"*Without having the guidelines in front of me, sometimes I have to rely on what I remember, and that's not always enough. Physical guidelines would ensure that we don't miss any critical steps*"

Also,

> Key informant one echoed, *"But I think we need to improve on having laminated desk copies which are pinned on the desk so that somebody just looks at a glance. It's not feasible that everyone is going to the notice board."*

Heavy workload and inadequate staff

The study results reveal that heavy workload and inadequate staffing levels at the sickle cell clinic affected their adherence to the treatment guidelines. They expressed how when they are overwhelmed by high patient volumes and insufficient staffing levels, they are often forced to prioritize immediate needs over comprehensive care. This work overload not only leads to fatigue and burnout but also reduces the time and attention healthcare workers can dedicate to following treatment protocols accurately.

> Respondent one shared, *"You can see as many as 20 patients. You can even see more than that. It depends on how busy that clinic is on that day and how many people are available to see their patients. But the numbers don't allow you to spend quality time for the patient, you sometimes rush through."*

Moreover, regarding tasks and workload, respondent seven exclaimed,

> Interviewer: *Okay. And then, what of tasks and workload in the sickle cell clinic?*
>
> Respondent Seven: *My God, nightmare. That one, nightmare.*

Furthermore,

> Respondent ten said, *"Because you also have a couple of people you need to finish seeing, you will write that I have counseled the mother on starting hydroxyurea. And then you let them go. But ideally, you would actually sit down and give them the time. And say, okay, so you want to wait for this period. How*

about this? How about that? But the system can't allow you, it's not feasible, the workload is too much."

Still,

Respondent four said, *"the first thing is that when we are few and one of us gets tired and you end up not always doing the right thing for the patient. Like you forget because you're tired. It's not that you don't want, but so that is one way. Because there are very many instances when that happens."*

4.5 Summary of findings

Most of the study participants were aware of the presence of the treatment guidelines and also reported being adherent to them. However, they reported that they faced many challenges during their practice that led them to deviate from the expected standard of care despite the adequate support that was extended to them by their seniors.

The majority of the respondents acknowledged that clinical experience and exposure coupled with knowledge and awareness about the treatment guidelines were significant facilitators towards adherence to treatment guidelines in the management of Sickle Cell Disease. They explained how attaining both experience, knowledge, and awareness through repeated exposure was associated with better management of complex cases with minimal deviation from the guidelines.

Concerning the non-individual factors, all the respondents cited CMEs to be an important facilitator of adherence to the treatment guidelines as these helped them understand the guidelines even better. Also, many respondents acknowledged that the leadership and management at the Sickle Cell Clinic was good and therefore supported

adherence to the guidelines. This is true, although the respondents were faced with a constant shortage of drugs and equipment like hydroxyurea that in the long run hindered their adherence to treatment guidelines.

In addition to that, heavy workload and limited infrastructure were the most mentioned barriers towards adherence to the sickle cell treatment guidelines, with the clinic serving about 1500 patients per month.

Collaborative networks and partnerships were highlighted as facilitators of adherence to the treatment guidelines among the majority of the respondents, for example, they improved the availability of drugs and blood products in situations of scarcity. However, there is still a need for more collaboration in order to address the barrier of fragmented care that in the long run impeded adherence to the guidelines.

Therefore, the study conducted at the Sickle Cell Clinic of MNRH revealed that the majority of the medical doctors at the clinic were adherent to the treatment guidelines. However, they were faced with a set of challenges and setbacks, most of these arising from within the clinic that led to situations of non-adherence during their practice.

CHAPTER FIVE

DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.0 Introduction

This chapter discusses the findings and further presents conclusions, and recommendations derived from the study's findings on the facilitators and barriers towards adherence to sickle cell treatment guidelines.

5.1 Facilitators of adherence to Sickle Cell Disease treatment guidelines among medical doctors

The facilitators towards adherence to treatment guidelines in managing Sickle Cell disease are discussed in the next text. The facilitators are further classified as individual and non-individual factors.

5.1.1 Individual factors

Clinical experience and exposure

The study revealed enhanced adherence to treatment protocols among medical doctors in sickle cell disease (SCD) management following repeated exposure to the condition. Frequent interactions with diverse SCD complications, encompassing acute crises and chronic difficulties, enhanced their therapeutic proficiency. As respondents acquired experience, they became more conversant at making informed judgments, corroborating the findings of Ngonde et al. (2024), which indicated a favorable association between job experience and compliance with clinical procedures. Moreover, Bijani et al. (2021) observed that seasoned healthcare professionals were more inclined to adhere to guidelines rigorously than their less experienced peers. The

lack of or insufficient experience is a problem for medical doctors in making clinical choices and adversely impacts adherence to recommendations.

Clinical experience also enabled the doctors to adapt to unique patient presentations, which may not be explicitly covered by the guidelines but still require guideline-based management. This is consistent with Namuju, et al. (2023), who observed that healthcare workers with greater experience were better at handling deviations while ensuring adherence to core guidelines. This demonstrates clinical exposure's critical role in fostering guideline adherence and clinical flexibility.

Knowledge and awareness

The study revealed that the majority of the respondents were aware of the availability of the treatment guidelines. Respondents acknowledged that staying informed about SCD treatment guidelines enabled them to stay up to date with best practices and reduced reliance on outdated methods therefore ensuring good clinical practices and maintaining a good standard of care.

This agrees with Bulafu et al. (2023), who found that healthcare workers with higher knowledge levels were 1.35 times more likely to have good adherence to treatment guidelines, awareness of updates to treatment guidelines was particularly important, as protocols evolve based on new research findings. This aligns with the study by Mohammed et al. (2024) who revealed that a lack of awareness of guideline updates significantly correlates with lower adherence rates among healthcare workers.

Respondents noted that knowledge and awareness reduced uncertainty in decision-making, particularly for complex cases. Familiarity with SCD and treatment guidelines enabled healthcare workers to make informed decisions quickly. This highlights the role

of knowledge in improving clinical judgment and minimizing complications in high-pressure situations. This aligns with a study by Baratta et al. (2023) that showed that inadequate knowledge leads to poor adherence to chronic disease treatment which seriously compromises the effectiveness of therapy.

5.1.2 Non-individual factors

Continuous Medical Education (CME)

The study revealed CME programs as crucial facilitators of learning and professional development, especially in a teaching hospital such as MNRH. Participants emphasized that these sessions, via case presentations by senior physicians, improved the capacity of SHOs and JHOs to treat intricate SCD cases while following established guidelines. This discovery agrees with Forsetlund et al. (2021), who indicated that instructional seminars might improve adherence to preferred practices. Research in Malaysia indicated that CME boosted the knowledge, abilities, and clinical practices of health professionals, addressing the current requirements of general doctors and nurses in primary care (Lim et al., 2020).

Participants said that CME sessions promoted peer learning by enabling healthcare professionals to exchange experiences, analyze case studies, and resolve intricate issues. This collaborative atmosphere enhanced compliance with treatment guidelines and strengthened their implementation throughout the staff. This corresponds with research indicating that peer support programs significantly improved adherence to treatment regimens in individuals with hypertension (Haidari et al., 2017).

Findings by Zarei et al. (2022) substantiate the significance of peer contact in CME programs, indicating that the exchange of experiences among colleagues can enhance adherence and improve patient outcomes. By remaining informed through Continuing Medical Education, healthcare professionals are more inclined to adhere to the recommendations, hence enhancing patient outcomes.

Collaborative networks and partnerships

Participants revealed that collaborative networks offer external resources to deal with issues such as diagnostic tools, drug shortages, and training materials, therefore bridging resource deficiencies and facilitating adherence to guidelines. This aligns with Alderwick et al. (2021), who emphasized that cooperation is a strategy for improving health outcomes, including adherence among health workers and the promotion of health equity. Moreover, Scott et al. (2017) highlighted those collaborations with external entities enables access to contemporary training, finance, and medical supplies, all of which enhance adherence to guidelines (Nakanjako et al., 2021).

The study indicated that collaborative networks encourage peer learning and shared experiences, enabling healthcare professionals to learn from one another. This partnership advances compliance with requirements by presenting workers with diverse alternatives. This corresponds with Schwartz and Axelrad (2015), who observed that healthcare collaborations provide significant insights to enhance pediatric adherence and diminish treatment failures.

Consequently, collaborative networks and partnerships are vital for improving compliance with sickle cell therapy protocols by promoting information exchange and resource sharing among healthcare stakeholders. These collaborations assist healthcare professionals in remaining informed about best practices and obtaining external assistance for improved patient outcomes. Stimulating such networks advances care quality and compliance with treatment guidelines.

Supportive leadership and hospital management

Participants in this study revealed the beneficial influence of leadership at the sickle cell clinic in advancing adherence to protocols. They valued the daily presence of a senior physician supervising clinic operations and offering assistance as required. This corresponds with Smith et al. (2019), who revealed that healthy leadership in hospitals improves compliance with treatment procedures by ensuring that healthcare personnel are sufficiently supplied with critical resources.

Supportive leadership fosters training and professional growth, shown by monthly CME seminars, which safeguard healthcare personnel remain updated about the newest treatment techniques. This investment in training improves compliance with clinical protocols. Haidari et al. (2017) demonstrated comparable findings, indicating that consistent staff training advances compliance with standards.

Furthermore, hospital leadership is crucial in nurturing a supportive work atmosphere that inspires healthcare professionals to adhere to treatment standards. Fauset et al.

(2024) highlighted that supportive leadership encourages open communication, aiding employees to seek assistance and confront obstacles to compliance.

Effective leadership equips healthcare personnel with the essential support to adhere to clinical protocols, access resources, and obtain training. This assistance increases motivation and allows employees to comply with treatment protocols, resulting in improved care for patients with sickle cell disease.

Having accessible and easy treatment guidelines

Respondents revealed that the guidelines were available at the SCC in both hard copy and digital formats. Establishing clear and accessible rules guarantees uniform adherence to evidence-based approaches. Panteli et al. (2019) contended that this homogeneousness reduces inconsistency in clinical decision-making, resulting in more predictable and superior patient care. Furthermore, it nurtures responsibility, since compliance with rules can be assessed and tracked (Lugtenberg et al., 2009). This can improve patient outcomes by improving care coordination, reducing mistakes, and guaranteeing that all patients receive optimal and consistent care, irrespective of the location or provider of treatment.

Participants observed that convenient access to protocols, particularly via mobile and digital platforms, enables patient care and boosts adherence, especially in environments where paper guidelines are impractical. Panteli et al. (2019) documented this, noticing that digital access to recommendations advances real-time compliance in

clinical environments. Improving the accessibility of these procedures is essential for enhancing compliance in healthcare environments.

5.2 Barriers to adherence to Sickle Cell treatment guidelines among medical doctors

5.2.1 Individual factors

Burnout and fatigue

The study indicated stress and exhaustion as significant obstructions to adhering to sickle cell treatment protocols. They said that fatigue affected their decision-making, follow-up, focus, and overall performance, resulting in deviating from the established protocols. This underscores how tiredness harms the cognitive insight necessary for rigorous compliance with treatment standards. Lerner (2018) found that healthcare professionals experiencing burnout were more vulnerable to errors and less motivated to adhere to clinical recommendations, attributed to cognitive fatigue and reduced concentration.

Managing patients with chronic illnesses, such as sickle cell disease, can result in compassion fatigue, causing healthcare professionals to experience emotional depletion that affects their capacity to deliver treatment in accordance with established protocols. Emotional tiredness, coupled with physical depletion, creates a substantial obstacle to compliance. Du et al. (2024) documented similar results, signifying that emotional tiredness in healthcare environments resulted in disengagement from patient care and diminished compliance with clinical standards.

Motivation

The study revealed low motivation as a substantial factor influencing compliance with sickle cell treatment guidelines. Participants reported high patient volumes, inadequate laboratory apparatus for crucial examinations, and shortage of important pharmaceuticals, worsened by patients' financial constraints. These concerns led to reduced adherence to procedures.

Akindele et al. (2020) conducted research that corroborates this idea, revealing that healthcare professionals suffering from burnout often come across motivational challenges, resulting in greater nonconformities to treatment protocols.

Moreover, when healthcare professionals see the significance of adhering to treatment protocols for the welfare of their patients, their compliance intensifies. This inner encouragement may oblige healthcare personnel to emphasize adherence to guidelines; nevertheless, extrinsic variables such as excessive workloads and insufficient support systems in due course undermine it over time.

5.2.2 Non-individual factors

Infrastructure

Healthcare professionals revealed that insufficient infrastructure, including congested wards and restricted space, were a hindrance to compliance with treatment protocols. They were compelled to accelerate patient assessments and deliver care under inadequate conditions. This put at risk patient privacy, increased the likelihood of infection risks, and made difficult adherence to recommendations. Research conducted

by Jeffery and Pickler (2014) revealed that healthcare institutions with constrained resources had substantial challenges in complying with clinical standards due to their helplessness to execute vital diagnostic and therapeutic processes.

The study results correspond with the research conducted by Morley et al. (2018), which indicated that congested healthcare environments lead to a decline in care quality and less compliance with treatment protocols.

The absence of reliable technology and data management systems hindered adherence to treatment standards. Healthcare professionals emphasized the necessity for electronic medical records and devices to monitor patient data and guarantee continuity of service. In the absence of technology support, the possibility of mistakes and inconsistencies in care increased. Research by Ghobadi et al. (2024) revealed that healthcare facilities lacking sufficient technological infrastructure for monitoring and assessment are predisposed to higher rates of guideline non-adherence which is attributed to challenges in obtaining essential patient information.

Caretakers/Patient's attitude and knowledge

The study indicated that deficiencies in understanding about sickle cell disease led to misunderstandings among patients and caregivers, later impacting adherence. Healthcare professionals said that they dodged treatment protocols in these circumstances, recognizing that caregivers would not adhere to the recommended treatments.

This aligns with research by Asnani et al. (2016), which revealed that caregivers with insufficient knowledge of sickle cell disease were less inclined to comply to treatment protocols, underscoring the necessity of educational interventions to improve comprehension and foster compliance.

Participants indicated that the views of patients and caregivers, influenced by cultural or religious beliefs, affected adherence to treatment methods. Misconceptions and insufficient understanding of sickle cell illness mired the adoption of medical advice. Opposing attitudes towards therapy hampered healthcare staff' efforts to apply standards efficiently. The connection between healthcare personnel and patients or their caregivers can markedly affect treatment results, including compliance with clinical standards. Research conducted by Ball et al. (2015) substantiates this, indicating that patient participation and grasp of their treatment programs result in improved adherence and overall health outcomes.

Inaccessibility to drugs and equipment

The accessibility of vital pharmaceuticals and medical apparatus is crucial for efficient sickness care. Participants revealed that insufficiencies in drugs such as hydroxyurea and blood products, along with the absence of critical equipment such biochemistry analyzers for liver and kidney assessments, obstructed compliance to treatment protocols. Kvarnström et al. (2021) indicated that deficient availability of essential pharmaceuticals was markedly connected with reduced adherence to treatment procedures across diverse healthcare environments.

The absence of key medical apparatus, including CBC machines and transcranial Doppler ultrasound scans, hinders the diagnosis and treatment of sickle cell patients. Health workers highlighted the necessity for operational diagnostic instruments to monitor patients competently. Studies indicate that healthcare institutions which do not have essential equipment have significant difficulties in adhering to treatment standards (Jeffery & Pickler, 2014).

The overpriced cost of pharmaceuticals was recognized as a noteworthy challenge, principally for economically underprivileged patients, resulting in treatment adherence gaps. This emphasizes the necessity for healthcare systems to factor in treatment affordability when formulating adherence guidelines.

Lack of physical treatment guidelines

Participants indicated concerns over the absence of tangible or physical treatment protocols in clinical environments. They proposed laminated copies or pocket-sized manuals for expedient access and transportation. Research by Panahi et al. (2022) supports this result, expressing that healthcare workers with instant access to tangible copies of recommendations are more likely to conform to treatment guidelines. This underscores the necessity of accessible guidelines as repeated reminders of established standards for healthcare professionals.

In busy hospital environments, noticeable reminders of treatment protocols help in stressing their significance and promoting adherence. In the absence of these pointers, healthcare professionals may emphasize urgent activities at the expense of adhering to

rules. Printed materials or posters function as critical visual cues, promoting compliance and consistency in patient care. This corresponds with research by Bulafu et al. (2023) that establishes the necessity of tangible reminders to enhance compliance.

The lack of physical standards might result in irregular procedures among healthcare professionals, since various practitioners may interpret protocols differently. The absence of uniformity can unpleasantly impact patient outcomes. Wang et al. (2009) discovered that access to printed clinical guidelines distinctly improved adherence rates, especially among less experienced healthcare practitioners.

Heavy workload and inadequate staff

Participants revealed excessive workloads at the clinic, from time to time attending to more than 20 patients a day and finding it difficult to comply with rules owing to the urgency to reduce the patient backlog. Insufficient staffing, particularly during employee absences, diminishes healthcare personnel' capacity to adhere to treatment standards, adversely affecting patient care. Research conducted by Abrahamson et al. (2012) substantiates this conclusion, revealing that healthcare professionals experiencing high workloads were markedly less inclined to comply with clinical guidelines, as the necessity to oversee numerous patients frequently resulted in expedient practices and hurried care.

Moreover, research by Akindele et al. (2020) demonstrated that inadequate staffing results in heightened stress and burnout, substantially diminishing healthcare personnel' compliance with treatment protocols.

Excessive workloads might impede communication and collaboration among healthcare teams, since overburdened personnel have reduced time to discuss patient issues or explain treatment techniques. The absence of well-organized communication may result in inconsistencies in care and compliance with standards. Research conducted by Alsabri et al. (2022) established a clear correlation between good cooperation and communication and improved compliance with clinical recommendations, highlighting the need of sufficient personnel in promoting a collaborative atmosphere.

5.3 Strengths and limitations of the study

5.3.1 Strengths

The qualitative approach employed in the study allowed for the examination of in-depth phenomena, including the experiences, attitudes, and behaviors of the medical doctors working at the SCC, and the impact of these factors on their ongoing adherence to the treatment guidelines.

The approach generated thorough descriptions of the setting and statements from the participants, which facilitated understanding of the factors that either facilitated or impeded adherence to the guidelines.

5.3.2 Limitations

Social desirability bias may have been introduced by self-reported data gained during interviews. To reduce the aforesaid bias, anonymity and confidentiality were ensured as well providing a secure environment thus consolidating the correctness of the data.

The study's generalizability was limited by the small sample size. Nevertheless, thematic saturation guaranteed that the results were representative of the broader population.

5.4 Conclusion

This study identified facilitators and barriers towards adherence to sickle cell treatment guidelines among medical doctors. Clinical experience, continuous medical education (CME), supportive leadership, and the availability of collaborative networks and partnerships were key enablers, which boosted healthcare workers' capacity to adhere to the treatment guidelines well. However, significant barriers such as burnout, lack of motivation, inadequate staffing, and the inaccessibility of essential medications and equipment were found to undermine adherence to the guidelines. The absence of physical treatment guidelines in clinical settings also hampered consistency in care.

All respondents highlighted that there was good leadership at the SCC and they had adequate support from the senior doctors. They also expressed the need to strengthen the CME programs as this made it easier for them to catch up with management of the disease. This was mainly with the junior doctors like the JHOs and first year SHOs.

The heavy work load at the sickle cell clinic stood out as the biggest barrier to guideline adherence coupled with limited access to essential medicines like hydroxyurea and equipment to monitor the patients i.e. a chemistry machine for monitoring liver and kidney function.

Few participants were not aware about the presence of the guidelines and therefore relied on articles and journals to guide them during the management of the disease. However, the majority found the guidelines easy to understand and apply, they however wished these would be made more readily available as laminated copies for easy access. Therefore, addressing institutional barriers such as resource shortages, heavy workloads, and the absence of readily available treatment protocols is essential to improve overall adherence. Through tackling these challenges, healthcare systems can strengthen the implementation of sickle cell treatment guidelines and ultimately improve patient outcomes.

5.5 Recommendations

5.5.1 Recommendations for action and policy

I. The SCC management should lobby for more funds through the finance department of MNRH and also create more external collaborations to enable them avail essential medicines and equipment at the clinic.

II. MNRH should look into recruitment of more doctors to support the constrained team that attends to the many patients served at SCC. This will reduce burnout and improve their capacity to adhere to treatment protocols.

III. The SCC department should look into availing the treatment guidelines as easily accessible hardcopies like the pocket handbooks or laminated copies to ensure easy access for all.

IV. The SCC should further strengthen the CME programs provided to the doctors through providing more regular sessions focused on management of SCD, these should be aimed at the new teams in the clinic i.e. the JHOs and the first year SHOs.

5.5.2 Recommendations for further studies

I. Further research is needed to determine the extent of non-adherence in the SCC of MNRH, as the current study did not establish its magnitude. The study focused on understanding why health workers may or may not follow treatment guidelines, but did not assess the overall level of non-adherence.

II. The findings of this study are specific to the SCC at Mulago National Referral Hospital. Further research comparing these results to other settings could provide a broader understanding of the factors influencing adherence to SCD management guidelines, offering valuable insights for policymakers to develop more effective, universally applicable strategies.

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APPENDICES

Appendix-I: Participant Information Sheet

Introduction

We are inviting you to take part in this research project: Exploring the barriers and facilitators towards adherence to Sickle Cell treatment guidelines among medical doctors at Mulago Hospital, Uganda.

Before you decide, it is important for you to understand why we are doing this research and what it involves. Please take time to read the following information and decide whether or not you wish to take part. Ask us if anything is unclear.

Why are we doing this research?

We know that the best way to improve patient care is to collect and regularly use data that helps us understand what happens. The data can then be used to track change and encourage healthcare teams to work hard to improve their care. We want to understand what medical doctors think about the facilitators and barriers to sickle cell treatment guidelines adherence. This will allow us to understand the challenges and design approaches to improve adherence and ultimately patient care outcomes.

Why have I been invited?

We are inviting medical doctors who have experience using sickle cell treatment guidelines and have worked in the sickle cell clinic of Mulago national referral hospital for at least one month. The healthcare workers, will include clinic administrators, nurses, doctors, specialists and consultants as well as laboratory personnel.

Do I have to take part?

No. It is up to you to decide whether or not to take part. There is compensation for taking part. If you decide to take part, we will ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

We will ask you to tell us about what you think of the facilitators and barriers to adherence to sickle cell treatment guidelines. This may be as a semi structured interview with one of our research teams. We will ask for your permission to record the conversation so that we can save it and listen to it afterwards. This will allow us to reflect on your comments and understand more about perceptions towards sickle cell treatment guidelines adherence.

What are the possible risks and benefits of taking part?

There are no risks associated with taking part. The benefit of taking part means that we will be able to improve our understanding on the facilitators and barriers to sickle cell treatment guidelines adherence among healthcare workers and this information can successfully be used to improve patient care and outcomes.

What if I am not happy about the research project?

If you are unhappy about anything related to this research project, please contact the lead researcher Dr. Joan Nasige (0775194166) or Uganda Christian University (UCU) Research & Ethics Committee Chairperson, Prof. Peter Waiswa (0772405357).

Confidentiality

All information collected as part of this project will be kept fully confidential. Recordings will be stored in Uganda in accordance with strict data protection laws.

Who is organizing and funding the research?

The research is being organized by Dr. Nasige Joan under the supervision of Prof. Robert Basaza from Uganda Christian University. This project is undertaken as part of the requirements for a Master's degree in Public Health at UCU, within the Department of Public Health under the Faculty of Health Sciences. It has been funded independently by the principal investigator.

Participation

Your decision to participate in this study is completely voluntary and a compensation of 20,000 Uganda shillings will be provided for your time and inconvenience. Not participating in this study will not affect your duties and responsibilities in any way.

Who has reviewed the research project?

This has been reviewed by Uganda Christian University Research & Ethics Committee (UG-REC-026) and the MNRH Research Committee (MHREC 2787)

What will happen to the results of this research?

It is important to us to share the results of our research with you. We will make a presentation of our findings in sickle cell clinic of Mulago Hospital after the project has been completed. This presentation will be open to anyone who would like to attend. We also hope to publish the results in a scientific journal. It will not be possible to identify any individual who has taken part from this presentation or in the scientific report.

Appreciation.

Thank you for considering taking part and for reading this information sheet, which is yours to keep. If you decide to take part, you will be given a copy of your signed consent form

Appendix-II: Consent Form

CONFIDENTIAL

Title of Project: Exploring the barriers and facilitators towards adherence to sickle cell treatment guidelines among medical doctors at Mulago Hospital-Uganda

Unique Participant ID for this Study

ID No……..

1. I agree that I have read and understood the information sheet. I have had the chance to think about the information, ask questions and have had these answered satisfactorily.
2. I understand that taking part is voluntary and I am free to withdraw consent at any time, without need to give a reason, without any consequences.
3. I understand that information collected during this study, may be looked at by individuals from Uganda Christian University. I give permission for these individuals to have access to my recorded conversations.
4. I hereby declare that I have not been pressured into giving this consent
5. I agree to take part in this process evaluation.

Signing this declaration does not affect your right to decline to take part in any future study.

---------- ----------

Name of participant Signature

Date---------- ---------- -

Name of staff obtaining consent Signature

Date---------- ----------

Name of witness Signature ----------

Date----------

Appendix-III: Semi-Structured Interview Guide

Interview objective: To explore the barriers and facilitators towards adherence of medical doctors to treatment guidelines in the management of sickle cell disease at Mulago National Referral Hospital in Uganda.

Before starting:

- Ensure that each participant has agreed to take part, is happy the interview will be recorded and provides recorded verbal consent after being read the information leaflet.
- Thank participant for his/her willingness to take part in the project
- Provide a brief reminder of how the findings will be used
- Remind him/her that he/she is able to stop the recording and stop the interview at any time.

Appendix-III a: Key informant interview guide

<table>
<tr><td colspan="3">KEY INFORMANT INTERVIEW GUIDE FOR HEALTHCARE WORKERS</td></tr>
<tr><td colspan="3">Facilitators and barriers to adherence to sickle cell treatment guidelines among medical doctors</td></tr>
<tr><td>Information about the healthcare workers (KI)</td><td>1. How many healthcare workers are involved in the management and treatment of sickle cell disease in the clinic?
<table><tr><th>Categories</th><th>Yes</th><th>No</th><th>No.</th></tr><tr><td>Nursing aids</td><td></td><td></td><td></td></tr><tr><td>Registered nurses</td><td></td><td></td><td></td></tr><tr><td>Nursing officers</td><td></td><td></td><td></td></tr><tr><td>Clinical officers</td><td></td><td></td><td></td></tr><tr><td>MOs</td><td></td><td></td><td></td></tr><tr><td>SHOs</td><td></td><td></td><td></td></tr><tr><td>Consultants</td><td></td><td></td><td></td></tr><tr><td>Others (Specify).</td><td></td><td></td><td></td></tr></table>2. What could be the estimated patient to healthcare worker ratio?</td><td>1. What is the estimated number of healthcare workers in the clinic?
2. What is the estimated patient to healthcare worker ratio in the clinic?</td></tr>
</table>

Facilitators and barriers to adherence to sickle cell treatment guidelines among medical doctors	
Domain	**Questions and probes**
Cadre / level of professional	1. What is your cadre / level of profession? …… **Probe:** *Are you a Pediatricians, SHO, MO or JHO?*
	How would you describe your role and influence, as a higher-level administrator / professional, on ensuring healthcare workers adhere to sickle cell treatment guidelines at SCC Mulago? **Probe:** *What specific examples of actions or strategies have you taken to improve adherence among healthcare workers?*
Work experience	How long is your work experience in the sickle cell clinic / care of such patients? …… **Probe:** *What is your work experience in months / years?*
	How would you describe the way your work experience supports or impends healthcare workers' adherence to sickle cell treatment guidelines? **Probe:** *Does work experience support or impedes adherence to guidelines? How?*
Knowledge	1. How would you define sickle cell treatment guidelines adherence among healthcare workers, in your own words? **Probe:** *What key factors do you believe are crucial for healthcare workers to consider when adhering to sickle cell treatment guidelines?*

<table>
<tr><td></td><td>What particular examples or criteria do you use to assess medical doctors' adherence to these guidelines?
Probe: What are the primary indicators you look for to assess if healthcare workers are following sickle cell treatment guidelines?</td></tr>
<tr><td>Training / CME</td><td>Have you organized or participated in any recent continuous medical education (CME) or training for healthcare workers specifically focused on sickle cell disease management in relation to the current treatment guidelines?
<table><tr><td>Yes:</td><td>No:</td></tr></table>Probe: Can you provide details on the topics covered in this recent CME sessions?</td></tr>
<tr><td colspan="2">Source of the guidelines (sickle cell treatment guidelines)</td></tr>
<tr><td rowspan="2">Treatment guidelines evidence-base</td><td>What kind of sickle cell treatment guidelines are used in the sickle cell clinic?
Probe: Can you elaborate on the specific treatment guidelines currently in use at SCC?</td></tr>
<tr><td>Have you participated or developed any sickle cell treatment guidelines in this clinic?
Probe: Have you had a role in either participating in or developing these guidelines?</td></tr>
</table>

	Is there any elements missing in the sickle cell treatment guidelines in use at the SCC? Yes; No: If yes what is it? **Probe:** *Are there any aspects or elements that you believe are missing from the current treatment guidelines, and if so, what improvements or additions would you suggest?*
Relative advantage	Is adherence to established treatment guidelines more effective than relying on traditional management practices, such as clinical experience and exposure, for treating patients with sickle cell disease? If so, how does it improve patient outcomes? **Probe:** *Can you provide specific examples or evidence that demonstrate how adherence to established treatment guidelines has improved patient outcomes compared to traditional management practices based on clinical experience and exposure?*
Complexity and Design	As an administrator/consultant, can you describe how you utilize the sickle cell treatment guidelines in your practice and in what specific circumstances you refer to them? **Probe:** *Can you provide specific examples of situations where the sickle cell treatment guidelines were particularly beneficial or challenging to use? How do these guidelines influence your decision-making process in complex cases?*

	From your perspective, how would you rate the complexity of the sickle cell treatment guidelines in terms of their appearance and format? How does this complexity impede adherence to the SCD treatment guidelines? **Probe:** *Can you elaborate on specific aspects of the treatment guidelines' appearance and format that you find either helpful or problematic? How have these elements affected the adherence of staff to these guidelines in practice?*
Outer setting (referrals, Mulago hospital, Ministry of Health, Government, Professional bodies etc.)	
Critical incidences	Are there any recent unanticipated external events that may influence adherence to sickle cell treatment guidelines? If so, how might these events impact adherence to these guidelines? Yes: No: **Probe:** *What recent unanticipated external events have emerged that could affect adherence to sickle cell treatment guidelines, and in what ways might these events impact patients' ability to follow these guidelines?*
Local condition (Institutional support)	What support from external sources is necessary to influence and improve adherence to sickle cell treatment guidelines among healthcare workers? **Probe:** *What specific types of support from; MoH, Hospital, others (external sources) would most effectively enhance adherence to sickle cell treatment guidelines, and how can we ensure these supports are adequately provided?*

Partnership and & Connections (Team approach)	Effective sickle cell management relies on a strong network of collaborators and partners. To what extent are you connected with external organizations and stakeholders? Please explain these connections and how they have impacted adherence to treatment guidelines. **Probe:** *Which external organizations or stakeholders do you interact with most often, and how have these interactions influenced your adherence to treatment guidelines?*
	How often do you network or exchange information with colleagues outside your department? Please describe these interactions and their impact on adherence to sickle cell treatment guidelines among healthcare workers. **Probe:** *Which departments or colleagues outside your department do you most frequently interact with and how these interactions have directly influenced adherence to treatment guidelines?*
Policies & Laws	What types of Outer Setting legislation, regulations, or recommendations that might influence adherence to sickle cell treatment guidelines, either positively or negatively? **Probe:** *How do current external regulations and legislation either support or hinder healthcare workers' adherence to the SCD treatment guidelines?*
External pressure	What external factors influence the ability to follow sickle cell treatment guidelines outside of the clinical environment, either supporting or hindering adherence?

	Probe: *How do you evaluate the effect of Ministry of Health, hospital, and community support programs on improving healthcare workers' adherence to sickle cell treatment guidelines?*
Inner setting (sickle cell clinic (SCC) of Mulago hospital)	
Infrastructure	How does the current infrastructure in the SCC interact with, support, or hinder adherence to sickle cell treatment guidelines? i.e. Infrastructure *structures, leadership, finances and communication tools* ***Probe**: Can you provide specific examples of how the existing infrastructure in SCC either facilitates or presents challenges to healthcare providers in adhering to sickle cell treatment guidelines*?
Technological infrastructure	Could you please describe how the technology infrastructure within a sickle cell clinic interacts with, supports, or impedes adherence to treatment guidelines for sickle cell disease? **Probe:** *In what specific ways does the current technology infrastructure at SCC facilitate or hinder healthcare providers' ability to consistently adhere to treatment guidelines?*
Work infrastructure	How do your daily tasks and workload within the sickle cell clinic impact adherence to sickle cell treatment guidelines? **Probe:** *Have you encountered any specific challenges or barriers in adhering to the treatment guidelines due to your workload or tasks***?**

	How do staffing levels in the sickle cell clinic affect adherence to sickle cell treatment guidelines? **Probe:** *In your experience, what roles or staffing positions are crucial for maintaining high adherence to treatment guidelines in the SCC?*
Available Resource	How have you ensured that adequate resources are available to effectively promote adherence to sickle cell treatment guidelines? **Probe:** *To what extent do current resource allocations hinder or facilitate healthcare providers' adherence to sickle cell treatment guidelines in clinical settings?*
Materials & Equipment	What is the current availability of necessary materials (guides) and equipment (lab) in SCC, and how does this availability impact adherence to sickle cell treatment guidelines?" **Probe:** *Could you provide specific examples of how shortages or inadequacies in materials (guides etc.) and equipment (Lab etc.) for sickle cell treatment have directly affected adherence to treatment guidelines in your practice?*
Outcomes	

Consequences	What are the consequences, both positive and negative, for administrators and consultants, resulting from adherence or non-adherence to sickle cell treatment guidelines? **Probe:** *How does strict adherence to sickle cell treatment guidelines impact patient outcomes and hospital resources?* **Probe**: *In your experience, what are the typical repercussions for healthcare workers who do not adhere to sickle cell treatment guidelines?*
Strategies to improve adherence	What strategies can administrators and consultants adopt to improve healthcare workers' adherence to sickle cell treatment guidelines? **Probe:** *How can administrators and consultants successfully implement and assess interventions to enhance adherence to sickle cell treatment guidelines?*
Closing	Thank you for your cooperation and participation. Is there anything else that you would like to talk about adherence to sickle cell treatment guidelines? **Probe:** *What do you think we have not addressed that you would prefer to add onto this conversation?*

Appendix-III b: In-depth Interview Guide

IN-DEPTH INTERVIEW GUIDE FOR HEALTHCARE WORKERS		
Facilitators and barriers to adherence to sickle cell treatment guidelines among medical doctors		
Domain	**Question**	**Probes**
Individual characteristic (The roles and characteristics of individuals.)		
Domain	**Questions**	**Probes**
Cadre / level of professional	1. What is your cadre / level of profession? …… 2. How would you describe your cadre and roles and its influence to adherence to sickle cell treatment guidelines?	*1. Are you a Pediatrician, SHO, Medical officer or JHO?* *2. Are there any actions or strategies taken under your capacity to influenced adherence to SCD treatment guidelines?*
Work experience	1. How long is your work experience in the sickle cell clinic / care of such patients? …… 2. How would you describe your work experience and how it supports or impedes adherence to sickle cell treatment guidelines?	*1. Your work experience in months / years?* *2. Does work experience support or impedes adherence to guidelines? How?*

	3. Guidelines are revised after a period of time, does work experience override adherence to treatment guidelines?	*3. Work experience versus guideline, what dominates?*
Knowledge concerning SCD and the guidelines	1. In your own words, define SCD? 2. What do you understand by treatment guidelines? 2. How would you describe adherence to sickle cell treatment guideline? 4. Does knowledge about SCD, treatment guideline and Adherence support or impede compliance to sickle cell treatment guidelines? How?	1 .*In your own words, what is SCD, Treatment guidelines and Adherence.* 2. *Does lack of knowledge about SCD and guideline impede adherence to treatment guidelines? How?*
Training / CME	1. Have you had any recent continuous medical education (CME) / training in sickle cell disease management in relation to the guidelines? Yes; No; 2. In your opinion, how often should the CME occur, and why? 3. How do the CMEs support adherence to sickle cell treatment guidelines?	*What was the topic, and in which month and organizers?* *How frequent do you have CMEs and what is the ideal frequency in your opinion?* *Can you describe an example on how CMEs have improved your*

		adherence to guidelines?
Source of the guidelines (sickle cell treatment guidelines)		
Treatment guidelines evidence-base	Are you aware of the developers of the sickle cell treatment guidelines used in the SCC? What kind of guidelines to you follow in the SCC? 2. In your daily practice, describe how adherence to guidelines has improved your patient outcomes?	*Is it the institution / clinic or ministry of health or any other organs that develop the guidelines?* *Apart from the UCG, are there some other guidelines being followed, describe the differences from the UCG?*
Relative advantage	1. Is adherence to guidelines better than traditional management like basing on experience and exposure to patients of sickle cell disease? How?	*What are the advantages and disadvantage of adhering to guidelines?*
Complexity and Design	1. Describe how you use the sickle cell treatment guides and in what circumstances do you refer to them?	1. *Do you refer to guidelines on every patient, memorize them or through CMEs?*

	2. Rate how complex is the sickle cell treatment guide, in terms of appearance and format, and how this supports or impedes adherence?	2. *Identify cases of complexity.*
Outer setting (referrals, Mulago hospital, Ministry of Health, Government, Professional bodies etc.)		
Local condition (Institutional support)	What level of support (if any) is needed from the outer settings to influence adherence to the sickle cell treatment guidelines?	*What support / distribution that influences adherence to sickle cell treatment guidelines? i.e. Staffing, resources (Guides),*
Partnership and & Connections (Team approach)	1. Sickle cell management requires a network of collaborator and partners, to what extent do you network or exchange information with colleagues? Please describe these relationships and its influence to adherence to sickle cell treatment guidelines.	*How influential is internal collaborations to sickle cell treatment adherence?* 2. *Identify the importance of team approach to adherence to guidelines*

Policies & Laws	What kinds of existing outer setting legislation or regulations, might help or hinder adherence to sickle cell treatment guidelines?	*What policies or regulation by the outer setting that may support or impede adherence to treatment guidelines?*
External pressure	What kinds of pressures outside sickle cell clinic that may support or impede adherence to sickle cell treatment guidelines?	*Are there any external pressure that influence adherence to guidelines, what are they?*
Inner setting (sickle cell clinic (SCC) of Mulago hospital)		
Infrastructure	Please describe how the infrastructure in SCC may interact with, support, or impede adherence of sickle cell treatment guidelines?	*How does the clinic structure, leadership, finances and communication tools support, or impede adherence of sickle cell treatment guidelines.*
Technological infrastructure	Please describe how the technology infrastructure in sickle cell clinic may interact with, support, or	*How do electronic medical systems and technology support or*

	impede adherence of sickle cell treatment guidelines?	*impede adherence to guidelines?*
Work infrastructure	1. Describe how your tasks and workload in sickle cell clinic may interact with, support, or impede adherence of sickle cell treatment guidelines? 2. Describe how general staffing levels in the sickle cell clinic may interact with, support, or impede adherence of sickle cell treatment guidelines?	*1. Describe how your tasks and workload in the clinic support or impede adherence to guidelines?* *2. How does clinic general staffing levels support or impede adherence to guideline?*
Available Resource	To what extent are necessary resources available to influence adherence to sickle cell treatment guidelines?	*Are there copies of the Uganda clinical Guidelines, from whom? How often do you refer to these guidelines? Have you had any support supervision specifically on adherence to the sickle cell guidelines,*

Outcomes		
Consequences	What consequences emanate from adhering and non-adherence to sickle cell treatment guidelines	*What achievements / consequences emanate from adherence or non-adherence to guidelines?*
Strategies to improve adherence	What strategies could be put in place to improve adherence to sickle cell treatment guidelines?	*Strategies to enhance compliance to treatment guidelines by the different stakeholders.*
Closing	Thank you for your cooperation and participation. Is there anything else that you would like to talk about adherence to sickle cell treatment guidelines?	*What does she/he think we have not addressed or that we should consider researching about next in the same line?*

Appendix IV: Budget

	Budget Item	Unit cost (Shs)	Amount (Shs)	Justification
	Approval			
i.	Research Committee fee	50,000	50,000	MNRH approval required for data collection
	Data collection: Material and Supplies:			
i.	Papers	165,000	165,000	Research instruments, consents, & information sheet
ii.	Pens, batteries	50,000	50,000	Pens for writing and batteries for the audio-recorder
iii.	Audio-digital recorder	350,000	350,000	Recorder for capturing audios from the participants
iv.	Backup external disk	150,000	150,000	Hard disk for backing up the recording from recorder
v.	Research assistants(RA)	450,000	900,000	2-research assistants' allowance for one month
vi.	Training of RA	50,000	100,000	2-days training; refreshments and transport refund
vii.	Travel costs	20, 000	300,000	Travel cost to the site for at least one month
viii.	Compensation fee	10000	300000	Participant's compensation for taking part in the study
	Data analysis:			
i.	Consultation services	500,000	500,000	Qualitative expert consultation regarding analysis
	Report writing			
i.	Dissertation reports	50,000	100,000	Two books; for the library and department
	Publication			
i.	Dissemination	300,000	300,000	Conference hall booking and refreshments
ii.	Article publication	1,500,000	1,500,000	Publication in a reputable international journal
iii.	Miscellaneous	250,000	250,000	To carter for any other unanticipated expenses
	GRAND TOTAL			**UGX: 5,315,000**

Appendix V: Work plan/Timeline

Activities	June	July	August	September	October
Proposal Development					
Approvals					
Data collection					
Data analysis					
Results presentation					
Results dissemination					

Appendix VI: Approval letter from UCU REC

UGANDA CHRISTIAN UNIVERSITY
A Centre of Excellence in the Heart of Africa

26th July, 2024

Nasige Joan
Uganda Christian University
0775194166
Email: nasigejoan1@gmail.com

UG-REC-026 APPROVAL NOTICE

To: Nasige Joan, Principal Investigator

Re: UCU-REC Application titled: **Exploring The Barriers And Facilitators Towards Adherance To Sickle Cell Disease Treatment Guidelines Among Healthcare Workers At Mulago Hospital, Uganda**

Application Number: **UCUREC-2024-961**

Version: 4.0

Type: [ ] **Initial Review**
[ ] Protocol Amendment
[ ] Letter of Amendment (LOA)
[ ] *Continuing Review*
[ ] Material Transfer Agreement
[ ] Other, Specify:

UGANDA CHRISTIAN UNIVERSITY APPROVED 26 JUL 2025 RESEARCH ETHICS COMMITTEE

I am pleased to inform you that the **UG-REC-026;** UCUREC approved the above referenced application.

Approval of the research is for the period from **26th July, 2024**, to **26th July, 2025**
This research is considered minimal risk category.
As Principal Investigator of the research, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and additions to the protocol or the consent form must be submitted to the REC for re-review and approval **prior** to the activation of the changes. The REC application number assigned to the research should be cited in any correspondence.
3. Reports of unanticipated problems involving risks to participants or other must be submitted to the REC. New information that becomes available which could change the risk: benefit ratio must be submitted promptly for REC review.

4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by subjects and/or witnesses should be retained on file. The REC may conduct audits of all study records, and consent documentation may be part of such audits
5. Regulations require review of an approved study not less than once per 12-month period. **Therefore, a continuing review application must be submitted to the REC eight weeks prior to the above expiration date of 26th July, 2025 in order to continue the study beyond the approved period.** Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study, at which point new participants may not be enrolled and currently enrolled participants must be taken off the study.
6. The REC application number assigned to the research should be cited in any correspondence with the REC of record.
7. Your research details have been shared with the Executive secretary of Uganda National Council for Science and Technology (UNCST) and you are not required to get clearance since you are a Masters Degree research. Refer to UNCST Research registration and clearance Policy and guidelines (July 2016) in Uganda section 6(e).

The following is the list of all documents approved in this application by **UG-REC _026:**

	Document Title	Language	Version	Version Date
1.	Protocol	English	1.0	2024-07-11
2.	Informed Consent Form	English	1.0	2024-07-11
3	Interview guides	English	1.0	2024-07-11

Signed and Stamped

Prof. Peter Waiswa.
UCUREC Chairperson,
pwaiswa@musph.ac.ug

UGANDA CHRISTIAN UNIVERSITY APPROVED 26 JUL 2025 RESEARCH ETHICS COMMITTEE

Appendix VII: Letter of clearance from Mulago National Referral Hospital research committee

TELEPHONE : +256 41554008/1
FAX : +256 414 5325591
E-mail: admin@mulago.or.ug
Website: www.mulago.or.ug

IN ANY CORRESPONDENCE ON THIS SUBJECT PLEASE QUOTES NO.....

MULAGO NATIONAL REFERRAL HOSPITAL
P. O. Box 7051
KAMPALA, UGANDA

13 August 2024.

Ms. Nasige Joan
Principal Investigator
Uganda Christian University

Dear Ms. Nasige,

RE: ADMINISTRATIVE CLEARANCE TO CONDUCT A STUDY AT MULAGO NATIONAL REFERRAL HOSPITAL.

The Management of Mulago National Referral Hospital is pleased to inform you that you have been offered clearance to conduct the study titled **MHREC 2787: "Exploring the Barriers and Facilitators towards Adherence to sickle cell disease Treatment Guidelines among Healthcare workers at Mulago Hospital."**

The above clearance is granted to you on the following conditions;

- That you will follow the research ethical processes
- Agreed to comply with all institutional policies and regulations of Mulago National Referral Hospital
- Agreed to provide end of study report and acknowledge Mulago hospital in all publications

Administrative clearance is valid for one (1) year effective from 13 August 2024 to 12 August 2025.

By copy of this letter, we reiterate our commitment to support this study.

DR. NAKWAGALA FREDERICK NELSON
AG.EXECUTIVE DIRECTOR
MULAGO NATIONAL REFERRAL HOSPITAL.

Copied to;
1. **Incharge – Sickle cell clinic**

Vision: "To be the leading centre of Health Care Services"

UGANDA CHRISTIAN UNIVERSITY

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UGANDA CHRISTIAN UNIVERSITY

SCHOOL OF RESEARCH & POSTGRADUATE STUDIES

DISSERTATION CORRECTION COMPLIANCE REPORT BY THE CANDIDATE (POST VIVA FORM)

Date: …15TH/04/2025…….

Name of Candidate: ……NASIGE JOAN …….. **Reg.No:** **RM22M21/012**……

Title of Dissertation …… EXPLORING THE BARRIERS AND FACILITATORS TOWARDS ADHERANCE TO SICKLE CELL TREATMENT GUIDELINES AMONG MEDICAL DOCTORS AT MULAGO HOSPITAL, UGANDA ……..

……

……..

SN	COMMENTS BY EXTERNAL EXAMINER	ACTION TAKEN	INDICATOR
1	**BACKGGROUND:** OBJECTIVES: The candidate should state the objectives in a qualitative language. Instead	i. To assess the facilitators of adherence to the treatment guidelines among medical doctors in	

	of using to "determine" the candidate could use words such as To understand, to explore and to assess barriers and facilitators.	the management of Sickle cell Disease (SCD) at Mulago National Referral Hospital (MNRH). ii. To explore the barriers of adherence to the treatment guidelines among medical doctors in the management of SCD at MNRH.	
2	CONCEPTUAL FRAMEWORK: The candidate states both the theoretical and conceptual frame works. For this qualitative work only the theoretical frame work is needed.	Conceptual framework to be deleted	
3	PROBLEM STATEMENT: One wonders what the problem is. Yes, sickle cell is a public health concern but the candidate is looking at adherence to sickle cell treatment guidelines. The candidate should have stated the magnitude of adherence of non-adherence with sickle cell treatment guidelines: globally, regionally and locally. What has been done about the problem and the existing gap the candidate is addressing.	According to Smeltzer et al., (2021), guidelines in the management of SCD have not been widely integrated into clinical practice. Many barriers to guideline adherence in SCD management among clinicians in their everyday practice have been described (Cabana et al., 2019). The MNRH that serves as a primary centre for management of the disease is faced with a significant gap in adherence to the treatment protocols by health workers despite the presence of well-established treatment guidelines (Kaudha et al., 2023 et al., 2024). Within Uganda, SCD care is provided by a wide range of professionals who have a variable range of training and expertise, leading to inconsistencies in the care provided. Ofakunrin et al., (2021) reported high hydroxyurea utilization rates among hematologists and pediatricians as compared to general practitioners. Inconsistencies in adherence result in suboptimal care, culminating to increased occurrence of preventable complications, frequent	

		hospitalizations, high morbidity and mortality rates among SCD patients (Yang et al., 2022).	
4	RESEARCH METHODS: The candidate should expound in the procedure how the potential participants were identified, approached, convinced to participate in the study, assessed for eligibility consented and enrolled into the study.	Using a semi-structured interview guide, data was collected from the healthcare workers through key informant and in-depth interviews. Potential participants who met the inclusion criteria were identified through purposive sampling. Initial contact was made through mobile calls and physical interactions from which they were given an overview regarding the purpose of the study and were requested to participate. Those who accepted to participate were briefed on the study's purpose, session format, and confidentiality issues at the beginning of each interview. Eligible participants consented voluntarily by appending a signature to the consent form.	

	How did the candidate determine that saturation had been achieved?	Saturation was achieved when the participants yielded no new insights or themes, indicating that a sufficient amount of data has been collected to address the research question. Repeating patterns and themes emerge repeatedly across the data.	
	How was the data managed?	Data management is highlighted in 3.11 and 3.12	
	Did the candidate get the assistance of a socio-scientist during data collection and analysis?	I am versed with qualitative research from my training at MPH coupled with guidance from my research supervisor.	
5	RESULTS, DISSCUSSION AND CONCLUSION	No comments	
6	RECOMMENDATIONS: Absent the candidate only makes recommendations for further research.	i. The managing team of the SCC should lobby for more funds through the Finance Department of MNRH and also create more external collaborations to enable them avail essential medicines and equipment at the clinic. ii. MNRH should look into recruitment of more doctors to support the constrained team that attends to the many patients served at SCC. This will reduce burnout and improve their capacity to adhere to treatment protocols. iii. The SCC department should look into availing the treatment guidelines as easily accessible hardcopies like the pocket handbooks or laminated copies to ensure easy access for all. iv. The SCC should strengthen further there CME programs through providing more regular sessions focused on sickle cell disease	

		management, these should be aimed at the new teams in the clinic i.e. the Junior House Officer (JHOs) and the first year Senior House officers (SHOs).	
SN	**COMMENTS BY INTERNAL EXAMINER**	**ACTION TAKEN**	**INDICATOR**
1	**1.1.1 Background** This section must assess the theoretical and conceptual background, objectives, rationale, clarity and precision of presentation.	Empirical literature review by (Pizzo et al., 2023) reported low prescription rates of hydroxyurea that were attributed to patient and provider factors despite the established evidence of this drug in SCD management. Physicians providing care to SCD patients have been found to adhere to some guidelines more than others (Ismail et al., 2023).	
2	**1.1. 3 Research Methods** Has the candidate used an appropriate approach to investigate the subject? Has the candidate other research methods that could have yielded better results? Assess for adequacy and relevance of data collected and the appropriateness of tools and instruments including data analytical procedures/techniques. Assess the appropriateness of the hypothesis or research question and subsequent assumptions. *The quantitative research methods used to investigate the subject were appropriate although some sections need to be clearly articulated. For instance the data collection methods used were for the same population*	The informants (medical doctors serving in the sickle cell clinic at Mulago Hospital) were the primary source of information. Depending on the level of seniority, part of this group was described as the key informants; these were the consultant/specialist doctors. The other respondents were the Senior House Officers (SHOs), Medical officers (MOs), and Junior House Officers (JHOs). This group participated in the in-depth interviews while the former took part in the key-informant interviews.	

	but different seniority and therefore this needs to be clear and on the sources of information still mixed up		
3	**1.1.4 Results** Evaluate for adequacy of data analysis, effectiveness of result presentation, accuracy, transparency, contributions from the study. *The results are adequately presented although the quotes need to be coded for easy identification*	Themes and sub themes are presented in 4.2.	
4	**1.1.5 Discussions** Does the candidate discuss his/her own findings and relates them to other researched work? Does the writer show honesty and transparency in discussing limitations? *Yes, the candidate discusses using other exiting studies. Although she should show how the two frameworks were used in the analysis of the study*	The framework i.e. the CFIR was applied mainly in the development of the tool and the second theme. The second framework has been deleted.	
5	**1.1.6 Conclusions** Does the conclusion emerge from the candidates own work? Does the study stimulate further inquiry or scholarship? *The conclusion emerges from the candidates work although she needs to highlight some*	All respondents highlighted that there was good leadership at the SCC and they had adequate support from the senior doctors. They also expressed the need to strengthen the CME programs as this made it easier for them to catch up with management of the disease. This was mainly with the junior doctors like the JHOs and first year SHOs.	

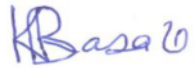
	salient findings from the study to flow with the recommendations.	The heavy work load at the sickle cell clinic stood out as the biggest barrier to guideline adherence coupled with limited access to essential medicines like hydroxyurea and equipment to monitor the patients i.e. a chemistry machine for monitoring liver and kidney function. Few participants were not aware about the presence of the guidelines and therefore relied on articles and journals to guide them during the management of the disease. However, the majority found the guidelines easy to understand and apply, they however wished these would be made more readily available as laminated copies for easy access.	
6	**1.1.7 Recommendations** Does the recommendation emerge from the candidates own work? Does the study stimulate inquiry or scholarship *The recommendations are not directed to any specific office*	The recommendations have been directed to specific offices*:* . The managing team of the SCC should lobby for more funds through the finance department of MNRH and also create more external collaborations to enable them avail essential medicines and equipment at the clinic. . MNRH should look into recruitment of more doctors to support the constrained team that attends to the many patients served at SCC. This will reduce burnout and improve their capacity to adhere to treatment protocols. . The SCC department should look into availing the treatment guidelines as easily accessible hardcopies like the pocket handbooks or laminated copies to ensure easy access for all.	

		. The SCC should strengthen further there CME programs through providing more regular sessions focused on sickle cell disease management, these should be aimed at the new teams in the clinic i.e. the JHOs and the first year SHOs.	

SN	COMMENTS BY VIVA VOCE PANNEL	ACTION TAKEN	INDICATOR
1	**Pay attention to the title especially on Health workers or medical doctors. Health workers have a role to play but you focused on medical doctors** **What made your study phenomenological? This needs to be understood and which school was used? This should be clear and maybe it should be qualitative study.**	This has been corrected to read: EXPLORING THE BARRIERS AND FACILITATORS TOWARDS ADHERANCE TO SICKLE CELL TREATMENT GUIDELINES AMONG MEDICAL DOCTORS AT MULAGO HOSPITAL, UGANDA. The study was phenomenological as it sought to understand the doctors' perceptions, perspectives and their experiences with regard to guideline adherence at the SCC. The study was phenomenological since it sought out similarities and shared experiences among the participants. This makes it unlikely to be a narrative design that looks at making sense of individual stories. The other qualitative designs i.e. grounded theory, ethnographic and case study research were not applicable. **NB**: During the viva there was reference to inductive and deductive methods as the study design, but these are the approaches to thematic analysis which were both applied in the process of data analysis.	
2	**What were the most surprising findings and what were the voices of these**	I've highlighted this in the conclusion in the table above.	

	participants. These should come out very clearly		
3	**The objectives are not qualitative, this needs to be worked on**	**i.** To assess the facilitators of adherence to the treatment guidelines among medical doctors in the management of SCD at Mulago National Referral Hospital. **ii.** To explore the barriers of adherence to the treatment guidelines among medical doctors in the management of SCD at Mulago National Referral Hospital.	
4	**The problem statement is not bringing out the adherence to the guidelines, what is the problem of adherence?**	According to Smeltzer et al., (2021), guidelines in the management of SCD have not been widely integrated into clinical practice. Many barriers to guideline adherence in SCD management among clinicians in their everyday practice have been described (Cabana et al., 2019). MNRH that serves as a primary centre for management of the disease is faced with a significant gap in adherence to the treatment protocols by health workers despite the presence of well-established treatment guidelines (Kaudha et al., 2023, Namaganda et al., 2024).	
5	**The discussion only gives the non-adherence or barriers but not the facilitators? Why did you have the bias.**	Facilitators had been discussed in the discussion- refer to section 5.1.	

6	**Conclusion would also be having barriers and facilitators and recommend to address the barriers and improve on the facilitators.**	Refer to the table above, it highlights the adjustments made in the conclusion and recommendations.	

…NASIGE JOAN……  **…… PROF. ROBERT BASAZA…….** 
…….

Candidate's Name Signature Supervisor's Name
Signature