EVALUATION OF SICKLE CELL CRISIS DETERMINANTS AMONG SICKLE CELL DISEASE PATIENTS AGED 15 YEARS AND BELOW IN THREE SELECTED HEALTH FACILITIES IN NAIROBI CITY COUNTY, KENYA

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Evaluation of Sickle Cell Crisis Determinants among Sickle Cell Disease Patients Aged 15 Years and Below in Three Selected Health Facilities in Nairobi City County, Kenya

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DECLARATION

This thesis is my original work and has not been presented for a degree in any other University.

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DEDICATION

I dedicate this work to my Family, friends and mentors, whose unwavering support and encouragement have been my greatest source of strength.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF APPENDICES

ABBREVIATIONS AND ACRONYMS

CDC	Centers for Disease Control and Prevention
CSCF	Children Sickle Cell Foundation
DNA	Deoxyribonucleic Acid
HbA	Haemoglobin A (Adult Haemoglobin)
HbF	Foetal Haemoglobin
HbS	Sickle Haemoglobin
HbSS	Homozygous Sickle Haemoglobin
Ksh	Kenya Shilling
QoL	Quality of Life
RBC	Red Blood Cell
SCA	Sickle Cell Anaemia
SCD	Sickle Cell Disease
SCF	Sickle Cell Foundation
SCT	Sickle Cell Trait
WHO	World Health Organisation
χ^2	Chi-quare

DEFINITION OF OPERATIONAL TERMS

Anaemia	Pain develops when sickle-shaped red blood cells block blood flow through tiny blood vessels to your chest, abdomen and joints. Pain can also occur in your bones.
Genetic markers	a sequence of DNA with a known physical location on a chromosome.
Haemoglobin	this is the protein molecule in red blood cells that carries oxygen from the lungs to the body tissues and returns carbon dioxide from the tissues back to the lungs.
Haemoglobinopathy	group of disorders in which there is abnormal production or structure of the haemoglobin molecule.
Homozygous genotype	refers to having inherited the same versions (alleles) of a genomic marker from each biological parent.
Hydroxymorphone therapy	drug used to treat moderate to severe pain.
Hydroxyurea	A drug that inhibits the synthesis of DNA and so is classified as an antimetabolite.
Hyper-haemolytic crises	Haemolytic crisis occurs when large numbers of red blood cells are destroyed over a short time.
Jaundice	A condition in which the skin and the whites of the eyes become yellow, urine darkens, and the colour of stool becomes lighter than normal.

Morbidity	the rate at which a disease or illness occurs in a population and can be used to determine the health of a population and its healthcare needs.
Mortality	a measure of the frequency of occurrence of death in a defined population during a specified interval.
Phenotypes	The observable characteristics in an individual resulting from the expression of genes; the clinical presentation of an individual with a particular genotype.
Prevalence	refers to the total number of individuals in a population who have a disease or health condition at a specific period, usually expressed as a percentage of the population.
Prognosis	prediction of the course of a disease following its onset. It refers to the possible outcomes of a disease (e.g., death, chance of recovery, recurrence) and the frequency with which these outcomes can be expected to occur.
Proguanil therapy	is a prophylactic antimalarial drug, which works by stopping the malaria parasite, *Plasmodium falciparum* and *Plasmodium vivax*, from reproducing once it is in the red blood cells.
Psychological trauma	damage or injury to the psyche after living through an extremely frightening or distressing event and may result in challenges in functioning or coping normally after the event.
Routine services	These are the daily activities offered to children with sickle cell anaemia.

Sickle cell anaemia	Sickle cell disease is a chronic condition that is characterized by the predominance of haemoglobin S in red blood cells.
Sickle cell crises	Periodic episodes of pain, called crises, are a major symptom of sickle cell
Vaso-occlusion	crisis is a common painful complication of sickle cell anaemia in adolescents and adults.

ABSTRACT

Considering the lack of curative armamentaria for SCD and its crises, the associated management costs exert an unquantifiable burden on parents/caregivers, compounded with psychological trauma, social stigma, and other devastating effects. This study investigated factors associated with sickle cell crisis among SCD patients aged 15 years and below in three hospitals in Nairobi city County. A descriptive cross-sectional study was conducted among children aged ≤15 years with sickle cell disease (SCD), their caregivers, and healthcare professionals at three SCD-focused health facilities in Nairobi city County. A total of 193 participants were recruited using systematic sampling, while healthcare professionals were purposively selected. Data were collected using pretested structured questionnaires assessing sociodemographic and socioeconomic factors, knowledge and perceptions of SCD, medication adherence, and SCD-associated crises. Quantitative and qualitative data were analysed using descriptive statistics, thematic analysis, and multiple logistic regression in GraphPad Prism, with ethical approval and informed consent obtained prior to study commencement. The results showed that most patients aged below 15 years with SCD in the sampled hospitals were females (52.85 %). Regarding age, most affected patients were aged 0-5 years (46.63 %). 65.80 % of all the patients had primary school level of education, with a paltry 7.77 % having a secondary school level of education. Besides, most of the caregiver respondents of SCD patients aged 15 years and below were females (92.23 %). Most caregivers (37.82 %) were aged 26-30 years followed by those aged 31-35 years (26.42 %), with a minority (13.99 %) being aged 21-25 years. Most caregivers had attained primary education (53.37 %), were married (75.13 % and were peasants (63.73 %). The results showed most (96.89 %) caregivers resided in rented houses, which were mostly single-roomed (62.18 %), and most (62.69 %) earned <KSh10,000 a month. It was observed that 83.94 % of the sampled SCD patients aged 15 years and below had SCD-associated crises, namely abdominal pains (69.75 %), joint pains (72.22 %), acute chest pain (24.69 %), and bone pain (32.10 %). Most patients with sickle cell crises were females (52.47 %) while male patients with sickle cell crises accounted for 47.53 %. Multiple logistic regression showed that female gender, age-group of 6-10 years, and frequent hospital visits (more than twice a month) significantly increased the log odds for severe SCD crisis. Thus, the final fitted multiple logistic regression model for predicting SCD crisis in children aged 15 years and below was stated as follows: $\ln[P(Y=1)/P(Y=0)] = \beta0 + \beta1$(Patient gender [Female]) + β2 (Patient Age-group [11-15 years]) + β3(Patient Age-group [6-10 years])+ β4(Frequency of Hospital Visits [More than twice a month]) = 0.1588+ 1.116 (Patient Gender [Female])+0.7197(Patient Age-group [11-15 years])+2.668 (Patient Age-group [6-10 years])-1.732 (Frequency of Hospital Visits [More than twice a month]). Further, the study observed varying levels of adherence to treatment regimen requirements for SCD patients aged 15 years and below in the selected hospitals, with unaffordability, forgetiveness, unavailability of the medications, or their inaccessibility being the most cited reasons, among others, by caregivers for non-adherence. Most healthcare workers adhered to and documented the treatments for patients with SCD and associated cries, except vaccines, which were never administered. Most caregivers had a good attitude, beliefs, and perceptions towards SCD patients aged 15 years and below in this study. The female gender and age-group significantly increased the log

odds for knowledge about SCD and its crisis. Therefore, the final multiple logistic regression model for predicting knowledge about SCD in parents and caregivers of children was stated as; $\ln[P(Y=1)/P(Y=0)] = \beta0 + \beta1$(Gender [Female]) + $\beta2$ (Age-group [26-30 years]) + $\beta3$(Age-group [31-35 years])+ $\beta4$(Age-group [>36 years]) = -1.415 -1.674 (Gender [Female])+3.849 (Age-group [26-30 years])+5.220 (Age-group [31-35 years]) + 3.856 (Age-group [> 36 years]). This study showed that patient and caregiver factors influence the severity of SCD and its crises, and their appropriate modification may improve the prognosis and the wellbeing of both the patients and the caregivers. Further, appropriate strategies must be formulated and implemented to improve adherence to treatment requirements for SCD patients aged 15 years and below to improve prognosis and quality of life.

CHAPTER ONE

INTRODUCTION

1.1 Background of the Study

Sickle cell disease (SCD) is a genetic disorder affecting red blood cells, with high morbidity and mortality rates. Sickle haemoglobin (HbS) is a structural variant of normal adult haemoglobin (HbA) (Mulumba and Wilson, 2015). SCD includes a series of pathological genotypes resulting from the inheritance of HbS. Research shows that SCD affects over 20 million persons globally, and 50–80% of over 330,000 children born with SCD in Sub-Saharan Africa die before the age of 5 years (Makani *et al.*, 2011; Kimaro et al., 2019). The complications associated with SCD vary depending on various risk factors such as environmental determinants and genetic predisposition (Tewari et al., 2015).

The clinical severity of sickle cell disease (SCD) is highly variable (Piel *et al.*, 2017). Genetic and genome-wide association studies have so far only explained a small fraction of this phenotypic variability (Steinberg, 2005; Sebastiani *et al.*, 2010; Serjeant, 2013). Complications of transfusions like iron overload in SCD are common and may cause detrimental sequelae, like cirrhosis, heart failure, and death (Blinder *et al.*, 2013; Porter and Garbowski, 2013). Considering the complexity and disabling nature of SCD, appropriate ambulatory management is critical to avoid acute pain, Vaso-occlusive episodes, renal dysfunction hospitalisations, or death (Cronin et al., 2019). However, the implementation rate of preventive, promotive, and management recommendations for SCD patients by caregivers and healthcare professionals is scanty and low, especially in developing nations like Kenya (Quinn, 2016). The caregivers' and physicians' attitudes, perceptions, and beliefs toward SCD and knowledge about SCD may influence its diagnosis, management, and prognosis; however, these factors are underexplored (Mainous *et al.*, 2015).

Socio-economic factors are important determinants of health in all people, with high poverty levels associated with poor disease prognosis and worse health but remain incompletely characterised and understood (Chimbatata et al., 2021). A better understanding of SCD associates complications (crisis) and their management can help drive interventions that may avert severe sequelae (Narh et al., 2021). This is particularly relevant to SCD, most prevalent in the poorest countries, especially Sub-Saharan Africa, where over 80 % of the global disease burden lies (Abbafati et al., 2020).

Recent studies suggest that socio-economic status differs in families with SCD compared to matched families in similar settings (Narh et al., 2021). Thus, this study was designed to investigate the proportion of children with sickle cell crisis among SCD patients aged 15 years and below in three healthcare facilities in Nairobi County, the sociodemographic and socioeconomic characteristics of caregivers, the levels of adherence to treatment requirements among SCD patients, attitudes, perceptions, and knowledge of caregivers and parents of SCD patients aged 15 years and below.

1.2 Statement of the Problem

Sickle cell disease and its complications cause devastating sequelae, which severely impact the life of the affected patients (Silva et al., 2015). SCD is a significant contributor to non-communicable disease-related child mortality globally, causing 6–15% of deaths in children aged less than 5 years, with the prevalence and mortality significantly higher in Africa, particularly in malaria-endemic zones. Currently, it is estimated that at least 5% of the world population are carriers of haemoglobinopathy genes, mainly SCD and thalassemia (WHO, 2022). Between 2000 and 2021, total births of babies with SCD increased globally by 13.7% to approximately 515,000 annually, driven primarily by population growth in the Caribbean and western and central sub-Saharan Africa. Over the same period, the number of people living with SCD worldwide increased by 41.4%, from 5.46 million to 7.74 million (Thomson et al., 2023). Further research shows that every year, over 300,000 children are born with SCD globally, with

sub-Saharan Africa accounting for an estimated 50–85% of the global incidences (Uyoga et al., 2019a). More recent estimates suggest that approximately 405,000 babies were born with SCD in sub-Saharan Africa in 2021 alone, representing a 27.2% increase since 2000 — an increase largely attributed to population growth rather than changes in disease frequency (Ministry of Health- Kenya, 2023; Thomson et al., 2023).

At the regional level, sub-Saharan Africa experiences the highest SCD mortality rates globally. In 2021, approximately 29,400 individuals died from SCD in the region, a 30.1% increase from 2000, representing 2.2% of child mortality and ranking SCD as the 11th leading cause of all-cause mortality in the region. A systematic review and meta-analysis of 115 studies across Africa found a pooled SCD prevalence of 1.43% (95% CI: 1.08%–1.88%), with significant heterogeneity across countries and age groups (Jonani et al., 2025; Thomson et al., 2023). In Africa broadly, 50–90% of children born with SCD die before reaching their fifth birthday (Jonani et al., 2025)

In Kenya specifically, the burden of SCD is increasing, with an estimated 14,000 children born with the condition every year. Between 2 and 4 out of every 100 newborns in high-burden areas carry SCD, and without appropriate intervention, 50–90% of those born with the condition are estimated to die before the age of five (Ministry of Health-Kenya, 2023). In the western part of the country, approximately 4.5% of children are born with SCD and 18% with sickle cell trait, with the disease contributing significantly to under-five mortality, primarily due to late diagnosis, educational gaps among service providers, and lack of access to appropriate treatment. A landmark prospective cohort study by Uyoga et al. (2019) in Kilifi, Kenya, found mortality rates among children with SCD to be 58 per 1,000 person-years of observation, more than 23 times higher than in children without SCD, with hospital admission rates also markedly elevated, largely driven by severe anaemia (Ministry of Health- Kenya, 2023; The Lancet Haematology, 2022). Besides, medication-related costs for managing the SCD-associated complications (crises) exert an unquantifiable burden on the caregivers (Silva et al., 2015; Wastnedge et al., 2018). Moreover, SCD and its crises not only affect the patients

but also cause psychological trauma, social stigma, and other debilitating effects (Narh et al., 2021).

The socioeconomic and demographic factors associated with sickle cell anaemia among children and their adherence to recommended medication in Kenya are not well documented, and little is known about them (Uyoga et al., 2019). The economic implication of SCD affects the patient and family members or relations (Mulumba and Wilson, 2015; Narh et al., 2021). Sickle cell disease management can lead to high healthcare costs and emotional and psychological trauma to the affected and caregivers. This is compounded by limited knowledge among healthcare providers and parents (Ezenwosu et al., 2021).

Previous research has indicated considerably low awareness levels of SCD amongst communities, partly attributable to inadequate sensitisation and community education by the Ministry of Health. Besides, SCD is not included in routine health statistics, and the absence of national treatment guidelines complicates its management (Wanjiku et al., 2019). Inadequate management of SCD and associated complications leads to high morbidity and premature mortality, especially in children aged 15 years and below, with an average survival age of 14.3 years (Chimbatata et al., 2021; Russo et al., 2019). Unfortunately, a disproportionately higher burden of SCD lies in sub-Saharan African countries such as Kenya, where access to quality healthcare is challenging (Uyoga et al., 2019; Wanjiku et al., 2019).

Currently, there are no effective curative therapies for SCD, and the available treatments are only prophylactic and palliative and do not modify the course of the disease. Besides, the high non-adherence to medication requirements among SCD patients significantly impedes successive disease management, leading to severe sequelae (Arigliani et al., 2019; Badawy et al., 2017; Cronin et al., 2019). Previous studies have attributed non-compliance to medication requirements among SCD patients to economic constraints, inaccessibility, lack of knowledge, negative attitudes, beliefs, and perceptions about SCD, among others. Additionally, inadequate healthcare

infrastructure, training, and supplies have been implicated as leading causes of medication non-adherence in healthcare facilities in developing countries such as Kenya (Adewoyin Aet al., 2015; Alsayegh and Mousa, 2020; Kimaro et al., 2019).

Despite technological and scientific advances to improve the prognosis of SCD in children, its diagnosis, treatment, management, and prevention of associated complications remain a substantial public health challenge (The Lancet Haematology, 2022). The insufficient knowledge of professional healthcare providers about essential aspects of enhancing the quality of life of people with SCD, including growth and developmental consultations, immunisation, prophylactic and palliative care, and the management of life-threatening sequelae, contributes to the high burden of SCD morbidity and mortality, especially in children living in sub-Saharan African countries like Kenya (Babalola et al., 2019; Tusuubira et al., 2018; Uyoga et al., 2019).

1.3 Justification of the Study

The course and severity of SCD vary considerably due to genetic markers, environmental factors, ethnicity, social and economic variables, religion, and cultural beliefs (Babalola et al., 2019). Socioeconomic and demographic factors play a key role in the prevalence of vaso-occlusive crises, the development of complications, and mortality in SCD, particularly in low-income developing countries. Therefore, a thorough understanding of the sociodemographic and socioeconomic profile of SCD patients is essential for identifying their needs, improving resource allocation, and formulating and implementing public health policies that benefit this population (Ezenwosu et al., 2021; Narh et al., 2021). Socioeconomic challenges, including poverty, low educational attainment, and housing quality, have a significant impact on both access to care and adherence to appropriate treatments among paediatric SCD patients, yet the distribution and impact of such contextual risks in this population have not been sufficiently described, particularly in sub-Saharan African settings. Studies addressing sociodemographic and socioeconomic aspects that influence SCD prognosis

are therefore relatively scarce in Kenya and across Africa, making the present study both timely and necessary (Erhabor et al., 2022a; Thomas et al., 2019).

Despite the rapid increase in SCD incidence in Kenya, with an estimated 14,000 children born with the condition every year and between 2 and 4 out of every 100 newborns in high-burden areas affected, there are still insufficient strategic programmes and meaningful efforts to improve the quality of life of affected persons. This is partly attributable to various misconceptions about SCD crises and misdiagnosis of haemoglobin phenotypes (Alghamdi et al., 2018; Tusuubira et al., 2018a). Significant skill and knowledge gaps exist among healthcare providers regarding SCD management, particularly at primary healthcare facilities where most patients first seek care, while tertiary-level facilities have comparatively greater capacity and competencies. A 2022 multi-county survey conducted in Bungoma, Busia, Kakamega, Vihiga, and Trans Nzoia exposed major SCD service gaps and revealed a fragmented data system, with only 17.3% of individuals identified with SCD having undergone confirmatory testing (Ojowi et al., 2025). These gaps reflect a critical need for evidence-based data on the socioeconomic and demographic determinants of medication adherence among children with SCD in Kenya (Ministry of Health- Kenya, 2023).

A cross-sectional study conducted at Mama Lucy Kibaki Hospital found that children with SCD did not consistently follow their preventive regimens, especially regarding antimalarial prophylaxis, and identified medication stock-outs, inadequate caregiver education, and poor clinic follow-up as key contributors to poor adherence to national SCD treatment guidelines (Kadubo et al., 2025). These findings underscore the importance of context-specific research into adherence barriers in Kenya. Furthermore, despite the existence of evidence-informed guidelines on disease-modifying interventions for SCD management, guideline implementation across sub-Saharan Africa remains suboptimal, leading to preventable morbidity and mortality (Kadubo et al., 2025; Ministry of Health- Kenya, 2023).

Understanding the socioeconomic and cultural impacts of SCD and its associated crises can therefore spur the formulation of targeted public health interventions, promote health behaviour change, improve medication adherence, increase knowledge and awareness levels, and address the negative perceptions, attitudes, and beliefs surrounding SCD, all of which are essential to improving the prognosis and quality of life of affected patients (Erhabor et al., 2022b). Governments and health authorities need to take realistic steps to address poverty and low health literacy, as this would significantly reduce the high incidence of vaso-occlusive crises among SCD patients and improve their quality of life. This study therefore fills a critical evidence gap by assessing the socioeconomic and demographic characteristics among children with SCD in Kenya and their relationship with adherence to recommended medication, with findings intended to inform locally relevant, evidence-based health policies and interventions.

1.4 Study Objectives

1.4.1 General Objective

To determine factors associated with sickle cell crisis among sickle cell disease patients aged 15 years and below in three health facilities in Nairobi County.

1.4.2 Specific Objectives

1. To determine the proportion of sickle cell crises among children with SCD aged 15 years and below attending three selected health facilities in Nairobi County.
2. To describe the sociodemographic and socioeconomic characteristics of parents and caregivers of children with SCD aged 15 years and below attending three selected health facilities in Nairobi County.
3. To assess the level of adherence to recommended treatment requirements among children with SCD aged 15 years and below attending three selected health facilities in Nairobi County.

4. To evaluate the level of knowledge, attitudes, and perceptions about SCD among parents and caregivers of children with SCD aged 15 years and below attending three selected health facilities in Nairobi County.
5. To determine the association between sociodemographic and socioeconomic characteristics, knowledge, attitudes, and perceptions, treatment adherence among parents/guardians of children with SCD aged 15 years and below attending three selected health facilities in Nairobi County.

1.5 Research Questions

1. What is the proportion of sickle cell crises among children with SCD aged 15 years and below attending three selected health facilities in Nairobi County?
2. What are the sociodemographic and socioeconomic characteristics of parents and caregivers of children with SCD aged 15 years and below attending three selected health facilities in Nairobi County?
3. What is the level of adherence to recommended treatment requirements among children with SCD aged 15 years and below attending three selected health facilities in Nairobi County?
4. What is the level of knowledge, attitudes, and perceptions about SCD among parents and caregivers of children with SCD aged 15 years and below attending three selected health facilities in Nairobi County?
5. What is the association between sociodemographic and socioeconomic characteristics, knowledge, attitudes, and perceptions, treatment adherence among parents/guardians of children with SCD aged 15 years and below attending three selected health facilities in Nairobi County?

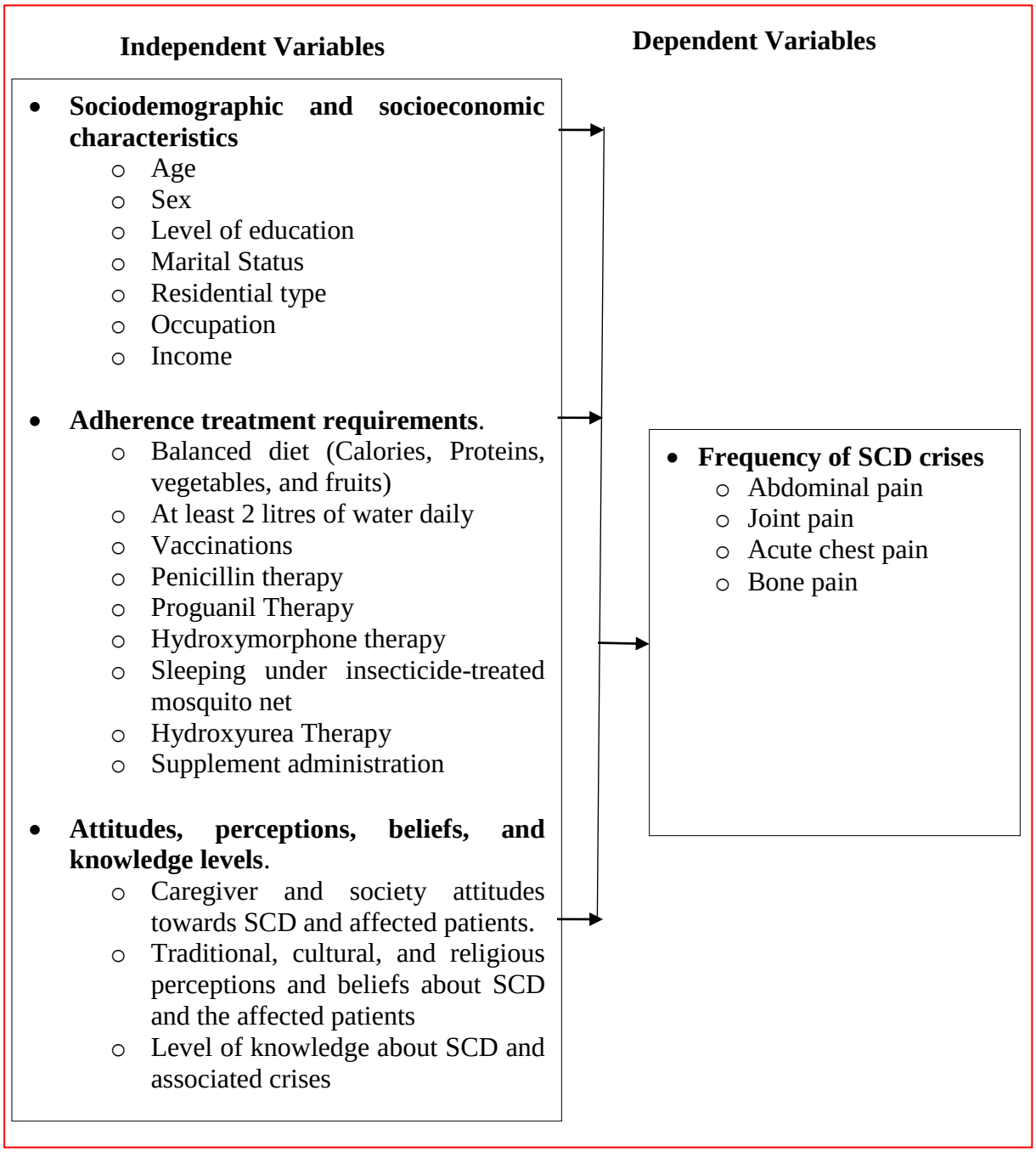

Figure 1.1: Conceptual Framework

CHAPTER TWO

LITERATURE REVIEW

2.1 Sickle Cell Disease

The term 'sickle cell disease' (SCD) refers to any condition in which the production of abnormal haemoglobin phenotype, the sickle haemoglobin (HbS), leads to severe pathophysiological sequelae if not managed adequately (The Lancet Haematology, 2022). The HbS is a structural variant of normal adult haemoglobin (HbA) caused by a mutation in the *hbb* gene, involving a substitution of valine for glutamic acid at position 6 of the β-globin subunit (β^S) of the haemoglobin molecule (Ware *et al*., 2017).

Inheritance of homozygous genotype of the β^S-mutation is commonly referred to as 'SCD SS' or 'sickle cell anaemia' (SCA) (Nagel, Fabry, and Steinberg, 2003) and is prevalent in over 70 % of the SCD incidences globally (Modell and Darlison, 2008). Besides, SCD can also result from the inheritance of β^S combined with a wide range of other *hbb* gene mutations, such as the β-globin variant β^C (SCD SC) and other β-thalassaemia mutations, which reduce the production of normal β-globin (SCD S/β-thalassaemia) (Serjeant *et al.*, 2011).

Although the sickle mutation at one allele of the beta-globin gene (heterozygosity) confers a survival advantage in malaria-endemic areas, especially for children, inheritance of the mutation at both alleles (HbSS) predisposes individuals to severe malaria and increased malaria mortality, as well as increased mortality from other complications of SCD (Lukusa Kazadi et al., 2017; Renoux et al., 2018).

Despite the marked attempts to demystify the role of genetic factors in SCD, the phenotypic variability has not been addressed substantially (Thein, 2013). The two best-characterized genetic modifiers are determinants of haemoglobin F (HbF) levels (Menzel and Thein, 2009) and the co-inheritance of α-thalassemia (The Lancet Haematology, 2022; Waye et al., 1994).

2.2 The burden of Sickle Cell Disease

Sickle cell disease is recognised as the most common severe monogenic disorder globally and constitutes the predominant form of haemoglobinopathy worldwide (Narh et al., 2021; WHO, 2022). Between 2000 and 2021, the total births of babies with SCD increased globally by 13.7% to approximately 515,000 annually, driven primarily by population growth in the Caribbean and western and central sub-Saharan Africa. Over the same period, the number of people living with SCD worldwide increased by 41.4%, rising from 5.46 million in 2000 to 7.74 million in 2021 (Thomson et al., 2023). People with SCD experience premature deaths and preventable severe chronic complications that considerably affect their quality of life, career progression, and financial status. In addition, persons with SCD are often affected by stigmatisation, which can contribute to stress and poor mental health. Importantly, inequalities affecting people with SCD are reflected in the distribution of the disease, concentrated mainly in sub-Saharan Africa, India, and the Caribbean, whereas interventions, clinical trials, and funding are mostly available in high-income countries (Jonani et al., 2025; Piel et al., 2023; Thomson et al., 2023).

Worldwide, more than 300,000 children are born with SCD every year, with over 75% of these births occurring in sub-Saharan Africa. Without intervention, 50–90% of affected children in many sub-Saharan African countries die before their fifth birthday (Jonani et al., 2025; Thomson et al., 2023). Within the WHO African Region, SCD is the predominant contributor to haemoglobinopathy-associated mortality, with the highest mortality rate at 3.68 deaths per 100,000 population and a disability burden of 41.08 years lived with disability per 100,000, with children under five years bearing a disproportionate share of mortality and disability. Disability-adjusted life years are heavily concentrated in western sub-Saharan Africa, which accounts for 71.3% of the regional burden (Ojo et al., 2025). An important contributor to this mortality disparity between high- and low-income settings is differential access to disease-modifying therapies such as hydroxyurea, which reduces the frequency of sickle cell crises and prolongs survival (Esoh et al., 2021).

The course and severity of SCD vary considerably depending on a complex interplay of intrinsic and extrinsic factors. Patients frequently encounter major obstacles in accessing advanced treatments, largely due to factors such as their geographic location, socioeconomic status, and the healthcare infrastructure available to them (Kumar & Bhattacharya, 2024). Current guidelines and management algorithms for SCD do not adequately factor in the effect of socioeconomic status (SES) on patients, despite evidence that lower SES is linked to disproportionate access to healthcare in SCD. Of all the factors that measure SES, income has been found to be the most indicative of health outcomes (Piel et al., 2023). These factors fundamentally affect the quality of life (QoL) of persons living with SCD and their caregivers. Quality of life encompasses the positive and negative aspects of life that affect an individual's mental and physical states, determined by health status, level of comfort, and state of happiness (Alsayegh and Mousa, 2020). Caring for patients with SCD imposes a high burden on informal caregivers, with significant impacts on their own health-related quality of life and economic productivity (Erhabor et al., 2022b; Kumar & Bhattacharya, 2024; Ojo et al., 2025).

Complications of SCD are wide-ranging and affect multiple organ systems. SCD results in profound anaemia, haemolysis, vaso-occlusive crises, and end-organ damage, ultimately causing a shortened lifespan (Alan et al., 2024). These include serious infections, stroke, kidney damage, respiratory problems, bone marrow failure, growth failure, cognitive impairment, maturational delay in children, and high maternal and foetal morbidity and mortality (World Health Organisation, 2022). The disease causes numerous complications that interfere with the health-related quality of life of affected children, including an impact on educational, physical, and psychosocial development (Mwazyunga et al., 2022). Recurrent complications interfere with the patient's life particularly regarding education, work, and economic and social development (Alan et al., 2024; Narh et al., 2021b)

Regarding treatment, despite advancements in the management of SCD, hydroxyurea remains the cornerstone of therapy. Its primary mechanism involves the elevation of

foetal haemoglobin (HbF), but its actions are multifaceted. Since its pivotal trial in 1995, which demonstrated a reduction in vaso-occlusive crises and blood transfusions, subsequent studies have consistently reported decreased mortality in patients treated with hydroxyurea (López Rubio & Argüello Marina, 2024). Treatment with hydroxyurea has been shown to reduce the number of crises by 44%, reduce their intensity, lower the risk of acute chest syndrome, and decrease the frequency and volume of red blood cell transfusions required (Alan et al., 2024). Blood transfusions nonetheless remain an important component of therapy for severe acute crises, particularly in resource-limited settings where access to hydroxyurea is constrained. Increased awareness and early interventions, such as newborn screening and comprehensive care, have led to considerable reductions in mortality in children younger than five years in high-income countries; however, SCD prevention and care have largely been neglected in sub-Saharan Africa, making it critical that the field urgently scales up context-appropriate interventions (Alan et al., 2024; Esoh et al., 2021; Mwazyunga et al., 2022).

2.3 Sociodemographic and Socioeconomic Factors Associated with Sickle Cell Disease

The economic implications of SCD extend well beyond clinical management to profoundly affect patients, their families, and caregivers (Narh et al., 2021). A study evaluating the economic burden of SCD at a Nigerian tertiary health institution found a median monthly economic burden of approximately US$385 per person, with outpatient costs constituting approximately 88% of the total. Hospital admissions, drugs, and blood transfusions were identified as the major cost drivers. All socioeconomic status groups suffered catastrophic health expenditure, but the poorest quartile bore the heaviest burden (Amarachukwu et al., 2022). The higher the rate of healthcare utilisation among SCD patients, the greater the out-of-pocket expenditure, particularly in low-income settings in sub-Saharan Africa where health insurance coverage remains limited. This financial burden is further compounded by the psychological impact of managing vaso-occlusive crisis-related pain (Erhabor et al., 2022b).

The disabling nature of SCD, characterised by the sporadic and severe nature of associated crises, including frequent acute pain episodes and anaemia, often necessitates repeated hospitalisation, adding both financial and psychological strain on families (Narh et al., 2021b). Research on the social determinants of health in SCD highlights educational gaps and low socioeconomic status as leading contributors to unemployment and poor health outcomes among SCD patients and their families. As patients grow older, managing a lifelong chronic illness while maintaining a stable income and simultaneously caring for sick family members becomes increasingly difficult (Khan et al., 2023). Within the family micro-environment, children with SCD require optimal family support, understanding, and care, particularly in ensuring adequate access to medications to maintain a steady and optimum state of health, making a favourable family environment a critical prognostic factor. SCD places substantial physical, social, and psychological burdens on caregivers, with documented detrimental impacts on their emotional well-being, personal lives, employability, and socioeconomic status (Alinda et al., 2025).

Evidence from East African settings demonstrates that informal social and family networks play an essential role in supporting care of children with SCD. In African cultural contexts, caregiving is often regarded as a collective responsibility shared across extended family and community networks, yet these informal support structures can be stretched thin by the chronic and unpredictable demands of SCD management (Erhabor et al., 2022b; Thomas et al., 2019). A cross-sectional study of SCD patients in south-western Nigeria found a significant, directly proportional association between financial status, educational level, and general well-being. Participants with tertiary education had significantly more hospital visits compared to those without, suggesting that higher educational attainment facilitates better health-seeking behaviour and utilisation of SCD care services (Amarachukwu et al., 2022; Khan et al., 2023).

There is a discernible pattern in the sociodemographic distribution of SCD patients across studies. A retrospective Nigerian study using the epidemiologic triad model found that SCD continues to be predominantly a paediatric condition, with an overall mean

patient age of 14 years. The pediatric mean age was 6 years compared to 27 years for adults, with a relatively equal gender ratio consistent with findings from other studies across Nigeria and Ghana (Nwabuko et al., 2022). Notably, the study found a statistically significant gender disparity in the months of SCD diagnosis, and the majority of confirmed cases were homozygous sickle-haemoglobin (SS) variants, accounting for 98.55% of diagnosed patients (Nwabuko et al., 2022). In terms of demographic characteristics of adult SCD patients and their caregivers, consistent patterns have emerged across African settings, with most patients and caregivers being female, relatively young, and having attained secondary-level education. The course of SCD differs markedly across settings due to genetic, environmental, and socioeconomic factors, underscoring the importance of context-specific demographic data to guide appropriate care and policy interventions, particularly given that genetic factors, poor healthcare infrastructure, and poverty are known to contribute significantly to disease severity across sub-Saharan Africa (Erhabor et al., 2022b; Jonani et al., 2025; Mwazyunga et al., 2022).

2.4 Treatment Adherence among Paediatric Patients with Sickle Cell Disease

Medication adherence is a fundamental determinant of treatment outcomes in SCD. Medications demonstrated to be efficacious in controlled research settings may prove substantially less effective in clinical practice due to nonadherence (King et al., 2023). Adherence is broadly defined as the extent to which a patient takes their medication as prescribed by their healthcare providers. Poor adherence to SCD medications, particularly hydroxyurea, is well recognised, with patients more frequently endorsing unintentional barriers to adherence, such as forgetfulness, logistical challenges, and complex treatment regimens, rather than intentional nonadherence driven by negative attitudes or uncertainty about medication benefits (King et al., 2023). Poor adherence reduces the effectiveness of medications, places patients at risk of severe complications, and significantly increases healthcare costs (Narh et al., 2021).

Nonadherence to antibiotic prophylaxis is of particular concern in the paediatric SCD population. A cross-sectional study of penicillin V prophylaxis adherence among SCD children in Ghana found that objective adherence, measured by urine assay, was as low as 30%, substantially lower than the self-reported adherence rate of 68%. Factors significantly associated with reduced adherence included older patient age, caregivers with divorced or married status, and the concurrent use of herbal preparations as alternative treatments for SCD (Odoom et al., 2022). A qualitative study in Uganda similarly found that adherence to penicillin prophylaxis among young children with SCD was poor, with caregivers citing distant health facilities, frequent drug stock-outs, limited health education, and long waiting times at SCD clinics as major barriers. Facilitators of adherence included drug availability at hospitals, financial support for medication procurement, and reminder systems (Rujumba et al., 2024).

At the provider level, clinicians' perceptions of adherence barriers frequently diverge from those of patients and caregivers (Buser et al., 2021a; Nwabuko et al., 2022). Evidence indicates that patients and caregivers cite worry about side effects, insufficient knowledge about the medication, and healthcare providers not recommending hydroxyurea as important barriers to use (King et al., 2023). Providers, on the other hand, may underestimate these patient-centred barriers, suggesting that a greater appreciation of patients' and caregivers' perspectives is needed to increase hydroxyurea uptake among eligible SCD patients (Treadwell et al., 2022). Among clinicians in Nigeria, identified barriers included limited knowledge of hydroxyurea, low self-efficacy to prescribe it, perceived side effects, the belief that patients prefer traditional medicine, the cost of the drug, and the expense of required laboratory monitoring (Okocha et al., 2022).

Several patient-, caregiver-, and health-system-level factors have been attributed to nonadherence to prophylactic and disease-modifying medications among paediatric SCD patients (Okocha et al., 2022). Among patients and caregivers in sub-Saharan Africa, key barriers to hydroxyurea adherence include lack of knowledge about the drug, fear of perceived side effects, cost, religious beliefs about disease causation, and the absence of

a paediatric-friendly formulation of the medication (Odoom et al., 2022; Okocha et al., 2022). A prospective cohort study of paediatric SCD patients attending a specialist clinic in Ghana found that adherence to routinely prescribed medications, including folic acid, haematinics, multivitamins, and penicillin, varied significantly across the patient population, with cost, caregiver knowledge, and clinic attendance frequency emerging as important determinants of adherence (Agyekum et al., 2024).

Findings from a multi-site survey in Nigeria highlight that patient, provider, and health system-level interventions are simultaneously needed to address the disproportionate adherence burden in sub-Saharan Africa. Interventions such as patient education, healthcare provider training, and policy reform are recommended to address both access barriers and behavioural nonadherence and thereby improve health equity for SCD patients (Okocha et al., 2022). In Kenya specifically, a cross-sectional study at Mama Lucy Kibaki Hospital found that children with SCD did not consistently follow their preventive regimens, particularly antimalarial prophylaxis, with medication stock-outs, inadequate caregiver education, and poor clinic follow-up identified as key contributors to poor adherence (Kadubo et al., 2025). These findings collectively underscore the need for context-specific, multilevel approaches to improving medication adherence among paediatric SCD patients in Kenya and across sub-Saharan Africa.

2.5 Parents'/Caregivers' Attitude and Perception of Sickle Cell Disease

Parents and caregivers of children with SCD endure numerous potentially stressful experiences and daily challenges related to the biological and psychosocial complications of the disease (Kuerten et al., 2020). These burdens destabilise the personal lives, financial standing, social relationships, and employment of caregivers, with five major burden themes documented in the literature: the burden of children's ill health; financial burden; employment challenges; psychosocial burden; and a range of other determinants of caregivers' burden (Mumuni et al., 2023). Evidence from Kenya specifically shows that caregivers of children with SCD report multiple difficulties across most quality-of-life domains, including daily activities and physical, social,

cognitive, and emotional wellbeing. Daily activities emerged as the most burdensome, while guilt and worry were the greatest indicators of parental adjustment difficulty, followed by long-term uncertainty and unresolved sorrow and anger. Financial hardship was also high, with caregivers reporting moderate to major financial losses due to time spent caring for their child (Kuerten et al., 2020).

A qualitative study of parents and caregivers of children with SCD in Kinshasa, Democratic Republic of Congo, found that the majority felt society had negative perceptions of, attitudes towards, and knowledge about SCD (Lelo et al., 2023b). Caregivers reported that children with SCD are often marginalised, ignored, and excluded from society and school, and that families face numerous challenges relating to care, management, financial difficulties, and a lack of psychological support (Lelo et al., 2023b). The psychosocial challenges for people with SCD and their families primarily stem from the impact of pain and chronic illness on daily life and from society's attitudes towards those affected. In sub-Saharan Africa, SCD-related stigma is driven by traditional beliefs and misconceptions that frequently perceive SCD as a spiritual affliction, resulting in social ostracism and discrimination that impacts affected individuals and their entire families (Anie, 2024).

A multi-country qualitative study conducted across three African countries found that SCD-related stigma is marked by prejudice, negative labelling, and social discrimination, with derogatory terms commonly used to refer to individuals with SCD (Munung et al., 2024). Drivers of stigma include frequent crises and hospitalisations, distinct physical features associated with SCD, cultural misconceptions about the disease, and its association with early mortality (Anie, 2024). Proposed strategies for mitigating stigma include public health education campaigns, integration of SCD into school curricula, healthcare worker training, and community engagement (Paintsil et al., 2024). Among caregivers in Ghana, the most significant stigma-related concerns were feeling blamed for their child having the disease, public misconceptions about SCD, and being shamed for associated financial burdens with every caregiver in the study reporting some experience of SCD-related stigma (Buser et al., 2021b).

The initial diagnosis of SCD in a child can be profoundly distressing for parents (Opoku et al., 2023). In Kenya, financial challenges, guilt, and worry have been identified among the greatest determinants of the quality of life of caregivers of children with SCD, while in Nigeria, caregivers have reported disruptions to their daily activities and an inability to provide basic needs for their children with the disease (Kuerten et al., 2020). For many parents, the emotional response includes denial, self-blame, grief, and fear, alongside a sense of inadequacy though for most these emotions are transient. For others, however, the diagnosis triggers lasting psychological distress that may manifest in strained marital relationships, social withdrawal, or decisions to disengage from the child (Narh et al., 2021).

Environmental and social factors significantly influence caregivers' ability to cope and have far-reaching implications for child development outcomes (Khan et al., 2023). SCD places substantial physical, social, and psychological burdens on caregivers, with documented impacts on their emotional wellbeing, personal lives, employability, and socioeconomic status (Al-Qattan et al., 2019). Caregivers with inadequate support networks face heightened vulnerability, particularly in resource-limited settings where financial and institutional safety nets are absent (Alinda et al., 2025). Evidence from Uganda indicates that individuals living with SCD and their families draw primarily on religion, adherence to medical treatment, and family support as coping strategies, underscoring the need to strengthen healthcare, social, religious, and vocational support structures beyond the childhood years (Ahebwe et al., 2024).

The level of parental knowledge about SCD directly shapes their attitudes towards affected children and their engagement with disease management (Esoh et al., 2021; Nwabuko et al., 2022; Tusuubira et al., 2018b). Adopting a social determinants of health lens reveals that the major complications of SCD, including intractable pain, organ failure, and death, are often triggered by environmental factors such as malnutrition, dehydration, changes in temperature, and psychosocial stress, all of which are closely tied to socioeconomic conditions and cultural practices that are more prevalent among low-income families in sub-Saharan Africa (Berghs et al., 2020). Taken together, these

findings underscore the critical need for culturally sensitive, family-centred interventions that address both the psychosocial and informational needs of caregivers of children with SCD in Kenya and across the broader sub-Saharan African region.

2.6 Knowledge and Awareness about Sickle Cell Disease

Despite technological and scientific advances to improve the prognosis of SCD, its management continues to present significant challenges for professional healthcare providers, as it involves complex aspects of diagnosis, treatment, and prevention of complications (The Lancet Haematology, 2022). A 2024 meta-aggregative review of healthcare professionals' knowledge, attitudes, and practices in the assessment and management of SCD found persistent and significant knowledge gaps across multiple settings, concluding that educational initiatives targeted at both student nurses and practising healthcare providers, coupled with the implementation of standardised protocols and guidelines, are essential for enhancing knowledge acquisition and promoting consistent, high-quality care delivery (Druye et al., 2024).

In resource-limited settings in Africa, which harbour the greatest burden of SCD globally, poor care outcomes are driven in part by a lack of trained healthcare providers and an absence of context-specific treatment guidelines appropriate to the level of healthcare facility (Khan et al., 2023; King et al., 2023). A structured training programme evaluation across 46 health facilities in Ghana found that healthcare workers had inadequate baseline knowledge of SCD management prior to training, particularly regarding acute and chronic complications, health maintenance protocols, and the use of disease-modifying therapies (Paintsil et al., 2025). A cross-sectional study of healthcare providers in Kinshasa, Democratic Republic of Congo, similarly documented critical gaps in SCD knowledge and clinical practice, highlighting a need for targeted continuing education programmes to improve care for SCD patients at all levels of the health system (Ngonde et al., 2024).

Studies point to insufficient knowledge among professional healthcare providers about important aspects of enhancing the quality of life of people with SCD, including growth and developmental consultations, immunisation, school performance, use of folic acid, prophylactic antibiotic therapy, complications due to vaso-occlusion, transfusions, the prevalence of iron overload, strokes in children, and screening of stroke risk using transcranial Doppler ultrasonography (Druye et al., 2024; Esoh et al., 2021). A large part of the poor prognosis of SCD in sub-Saharan African countries is related to poor socioeconomic conditions and weaknesses of the healthcare systems. National policies that foster the training of healthcare workers, implement systematic newborn screening, provide low-cost hydroxyurea, and increase disease awareness are crucial to reducing the burden of SCD across the region (Ranque et al., 2026). To improve the quality of care for people with SCD and to reduce morbidity and mortality rates, there is therefore a clear and urgent need to develop educational interventions to increase the knowledge and competence of professional healthcare providers about SCD management.

At the community and parental level, awareness of SCD and its screening programmes remains critically low in many parts of sub-Saharan Africa. A cross-sectional study among postnatal mothers in western Kenya found that, while most women had heard of SCD, many lacked specific knowledge about it being a blood disorder, its mode of transmission, when it can be diagnosed, and the existence of newborn screening programmes. Low knowledge and awareness were directly associated with lower acceptability of newborn screening, which is an important finding given that awareness of an intervention is a prerequisite for its uptake (Orimbo et al., 2025). In July 2021, the Kenyan Ministry of Health launched its first national guidelines for the control and management of SCD, which emphasise the importance of early diagnosis through newborn screening. Kenya has also prioritised newborn screening in the National Strategic Plan for the Prevention and Control of Non-Communicable Diseases 2021/22–2025/26, with pilot programmes already established in Kisumu, Homa Bay, Kilifi, Eldoret, and Taita-Taveta (Ministry of Health- Kenya, 2023).

Despite these policy advances, implementation gaps persist. Evidence from western Kenya suggests that prior to the implementation of newborn screening programmes, adequate awareness creation and the removal of cost barriers are essential, as those with low knowledge or awareness are significantly less likely to accept the intervention. The importance of community ownership and public participation in programme design has also been emphasised as a prerequisite for successful scale-up (Orimbo et al., 2025). Many parents continue to confuse SCD genetic screening with routine tests for jaundice, infections, or other newborn conditions, underscoring the persistent need for targeted community health education campaigns (Ezenwosu et al., 2020; Tusuubira et al., 2018b). A study of healthcare providers' knowledge, attitudes, and perceptions regarding SCD and its newborn screening in the DRC found that knowledge deficits at the provider level further compounded community-level misunderstandings about the disease, reinforcing the bidirectional nature of the awareness gap (Lukalu et al., 2025).

CHAPTER THREE

METHODOLOGY

3.1 Study Design

This study adopted a descriptive cross-sectional design to investigate the relationship between the SCD-associated crises and the study variables like sociodemographic and socioeconomic factors, level of knowledge, and medication treatment adherence (Nassaji, 2015; Doyle et al., 2020). This design was selected because it allows for the convenient collection of information from the study participants at a single point in time using a relatively shorter time and fewer resources. Additionally, this design is widely recommended for studies aimed at identifying the associations/relationships between study variables and those generating hypotheses which can be tested experimentally (Nassaji, 2015). Therefore, a descriptive cross-sectional design was appropriate for the researcher as it aided the collection of the required information to answer the research questions to achieve the formulated objectives.

3.2 Study Sites

This study was conducted in three health facilities, namely the German Doctors Nairobi-Baraka Health Centre, Oasis Health Group, and Stratus Clinics, which are members of the Sickle Cell Foundation (SCF), in Nairobi County. German Doctors Nairobi-Baraka Health Centre) was established in 1997 in Mathare valley, the second largest slum in Nairobi whose inhabitants are estimated to over 430,000, and offers priority services to patients with Sickle Cell Disease, HIV/AID and its opportunistic infections including tuberculosis, malaria, diabetes, and asthma. Besides, the Oasis Health Group and Stratus Clinics were established in 2015 and 2014, respectively, and offer fully integrated private healthcare services in all specialties. German Doctors Nairobi-Baraka Health Centre attends to about 450 children with SCD every month and is in Mathare valley, the second largest slum in Nairobi, situated 5 Km Northeast of the city. Oasis Health

Group Clinic is in the Parklands area in Nairobi County and attends to approximately 80 children with SCD per month. Stratus Clinic is located along Ngong Road in Nairobi County and attends to approximately 50 children with SCD every month.

The three health facilities were selected because of their collaboration with, and membership to the Children Sickle Cell Foundation (CSCF), an independent not-for-profit, community-based organization dedicated to improving the quality of life of persons with Sickle Cell Disease. CSCF was founded in 2001 with the guidance Dr. K.C. Wafula as the Patron and a group of parents who had children with Sickle Cell Disease due to frustrations that faced both adult and children sickle cell disease patients as well as their caregivers. The motto of the CSCF is, "Turning Sickles into Smiles" and aims to cope with the overwhelming obstacles and emotional challenges that are a part of living with a serious chronic disease that is under-funded, undervalued and the target of much ignorance, prejudice and discouraging empty complaints and rife stigma.

3.3 Study Population

The study population comprised three distinct groups recruited from three health facilities German Doctors-Baraka Health Centre, Oasis Health Group, and Stratus Health Clinics. The first group consisted of paediatric patients aged 15 years and below with a confirmed diagnosis of SCD. Given that SCD management in the paediatric population is heavily dependent on the involvement of caregivers, the second group comprised parents or primary caregivers of the eligible SCD patients. The third group consisted of healthcare professionals directly involved in the clinical management of SCD patients at the selected facilities. This multi-group approach was adopted to capture a comprehensive understanding of the experiences, challenges, and practices surrounding paediatric SCD care from multiple perspectives.

3.3.1 Inclusion Criteria

The following criteria were applied for enrolment into the study:

- Paediatric patients aged 15 years and below with a confirmed diagnosis of SCD, who had been attending any of the selected health facilities for a minimum of six consecutive months, ensuring familiarity with the healthcare setting and providing a sufficient experiential basis to meaningfully contribute to the study.
- Parents or caregivers who were identified as the primary caregiver of an eligible SCD patient, had regular and direct involvement in the child's day-to-day disease management, and provided written informed consent to participate.
- Healthcare professionals with direct clinical responsibility for the management of SCD patients at the selected facilities, with at least six months of experience in SCD care, and who provided written informed consent to participate.

3.3.2 Exclusion Criteria

The following participants were excluded from the study, regardless of meeting the inclusion criteria:

- Paediatric SCD patients who were acutely ill or hospitalised at the time of data collection, as their condition may have precluded meaningful participation and introduced response bias.
- SCD patients with known comorbid conditions unrelated to SCD (e.g., physical or intellectual disabilities) that could significantly affect their ability to engage with study procedures.
- Parents or caregivers who, despite consenting, were not the primary caregiver of the child and therefore lacked sufficient knowledge of the child's day-to-day disease management.
- Parents or caregivers with documented cognitive or mental health impairments that could compromise their ability to provide reliable responses.

- Healthcare professionals who, although present at the facility, were not directly involved in the clinical management of SCD patients and thus lacked relevant experience to inform the study objectives.
- Participants who had been enrolled in another clinical or health-related study concurrently, to minimise the risk of response fatigue and cross-study contamination.

3.4 Sample Size Determination and Sampling Technique

The sample size was determined using the Fisher formula described by Charan and Biswas, (2013) as follows:

$$n = Z^2\left(\frac{p(1-p)}{d^2}\right) \ldots\ldots\ldots\ldots\ldots \text{Equation 1}$$

Where n = the required sample size,

Z= Confidence level of 95 % with a standard value of 1.96,

p= estimated SCD prevalence in the study area(s) (10-40 %), hence an average of 25 %

was selected (Ministry of Health-Kenya, 2023).

d= margin of error (5%; 0.05).

Thus; $n = 1.96^2\left(\frac{0.25(1-0.25)}{0.05^2}\right)$= 288.12 ~288.

However, since the target population was less than 10,000, then, the desired sample size was determined as follows:

$$n = \frac{n'}{1 + \frac{(n'-1)}{N}} \ldots\ldots\ldots\ldots Equation\ 2$$

Where, n= desired sample size when study population is <10,000

N= estimated target population size= 580

n'= 288 (from Equation 1)

Thus,

$$n = \frac{288}{1 + \frac{(288-1)}{580}} = 192.66 \sim 193.$$

Paediatric SCD patients were recruited using proportionate systematic random sampling. This approach was adopted to ensure that each facility contributed to the final sample in proportion to its share of the total SCD patient population across all three sites, thereby enhancing the representativeness of the sample.

The total number of eligible paediatric SCD patients across the three facilities was 580. Using proportionate allocation, the number of participants to be drawn from each facility was calculated as:

$$\text{n} = \frac{\text{Facility total}}{\text{Overall total}} \times \text{Desired sample size}$$

Following this, a sampling interval (*k*) was computed for each facility by dividing the facility's total eligible population by its proportionate sample size. A random starting point between 1 and *k* was selected at each facility, after which every k^{th} patient on the facility's register was recruited until the required sample size was attained. The resulting sampling frame is presented in Table 3.1.

Table 3.1: Sampling Frame

Facility	**Total no. of children with SCD**	**No of sampled children with SCD**	**Sampling interval (K^{th})**
German doctors Baraka Health Centre	450	$\frac{450 \times 193}{580} = 150$	$\frac{450}{150} = 3^{rd}$
Oasis clinic	80	$\frac{80 \times 193}{580} = 27$	$\frac{80}{27} = 3^{rd}$
Stratus clinic	50	$\frac{50 \times 193}{580} = 16$	$\frac{50}{16} = 3^{rd}$

For the recruitment of parents and caregivers, each sampled child's primary caregiver was automatically enrolled, yielding a corresponding caregiver sample that mirrored the paediatric sample in size and facility distribution.

For healthcare professionals, purposive sampling was employed, as this group is small, clearly defined, and possesses specific expertise relevant to the study objectives. Three doctors and three pharmacists directly involved in the management of paediatric SCD patients were purposively selected from each of the three facilities, yielding a total of 18 healthcare professionals. This sampling strategy ensured that only participants with sufficient clinical knowledge and direct experience with the study population were recruited, thereby maximising the depth and relevance of the data obtained from this group.

3.6 Data Collection Tools

This study utilised structured self-administered questionnaires to collect the relevant information from the study respondents. The questionnaires comprised open-ended questions to enable the respondents to respond in their own words. Also, dichotomous questions were included in the questionnaire so that the respondents could choose from the given choices, such as Yes/No, and Male/Female. The questionnaires were structured in various sections to capture different sets of information from the respondents.

The first section included background information of the respondents regarding age, gender, level of education, place and nature of work/occupation, residential type, income, and medical-associated expenses, among others, to determine the sociodemographic and socioeconomic characteristics of the respondents. The second section comprised structured questions to collect relevant information regarding adherence to medication requirements for SCD patients aged 15 years and below. The third section of the questionnaire was tailored to collect information on attitudes, perceptions, and beliefs towards SCD and the affected patients and the knowledge and awareness levels of the respondent about SCD. Furthermore, a structured questionnaire was administered to the healthcare professionals attending to SCD patients aged 15 years and below in the three studied health facilities to collect information about the level of medication adherence.

3.7 Validity and Reliability of the Data Instruments

The researcher pretested the data collection instruments on 15 randomly selected respondents. Based on the respondents' responses and comments, the questionnaires were adjusted and optimised to ensure their effectiveness in collecting high-quality data during the actual study.

Besides, the validity of the data collection instruments was evaluated using the content and construct validity approach to determine their effectiveness in collecting appropriate data for a particular research domain or research concept (Cronbach and Meehli, 1955; Tavakol and Dennick, 2011). Content validity was determined by a rigorous selection of research items, relevant questions, and their careful refinement. Construct validity was ensured by pre-testing and appropriate optimisation.

Moreover, a test-retest approach was adopted to evaluate the reliability of the data collection instruments using ten randomly selected respondents. The Cronbach method was used to assess whether the respondents provided the same response or score on a particular variable if that variable was repeatedly presented to the same respondent (Cronbach and Meehli, 1955; Tavakol and Dennick, 2011). Based on a previous study, an alpha value of at least 0.70 was used to denote the reliability of the data collection instrument used in this study.

3.8 Data Management, Statistical Analysis, and Presentation

Data were derived from the questionnaires, tabulated on Excel spreadsheets (Microsoft 365), and arranged and cleaned. After that, qualitative data were descriptively analysed and presented as percentages and averages. All interviews were meticulously recorded verbatim, a process overseen by the primary researcher. These transcripts were then complemented with contemporaneous notes taken during the interviews. Subsequently, a rigorous thematic analysis was conducted in three distinct stages. During the initial stage, the transcripts underwent multiple comprehensive reviews to foster an intimate familiarity with the narratives provided by the participants. This phase also entailed the identification of themes that pertained to the pertinent research inquiries. Each identified theme was systematically tagged with a unique code, thus facilitating the compilation of a comprehensive list of sub-categories to explore various facets of the data. Microsoft Excel 2021 served as the platform for organizing the qualitative data in the form of an analysis matrix. The analysis matrix functioned as an online repository, presenting the transcription data in rows, with corresponding themes and codes allocated to distinct

columns. In the second stage, this list of subcategories was employed to code each interview transcript, utilizing the analysis matrix to effectively structure and categorize the data.

Subsequently, in the third stage, the sub-categories were synthesized into overarching categories that corresponded to the various aspects explored within the study. This synthesis process involved a meticulous search for links, commonalities, as well as distinctions within the data. Moreover, to enhance the reliability of the analysis, meticulous working notes were maintained throughout the entire process. Besides, the association between various patient variables (factors) and SCD severity. Besides, the knowledge levels about SCD and its crisis among parents/caregivers of affected children were categorised as low, moderate, and high, based on the cumulative weighted points garnered from the 6 dedicated questions (0-5=low; 6-12=moderate; 13-18=high). Then, relationship between the parent/caregiver factors and knowledge level about SCD and its crisis were determined through multiple logistic regression analysis using the GraphPad Prism Software package (version 9.5). The results were presented in tables, bar graphs, and themes, as appropriate.

3.9 Ethical Considerations

Ethical clearance was sought from the scientific committee and ethical review committee of Jomo Kenyatta University of Agriculture and Technology (JKU/2/4/896B). The appropriate authorisation was sought from the three studied hospitals' management prior to data collection. Besides, prior informed consent was obtained from the adult respondents, and assent from children participants before the study, and data collection was performed professionally and strictly adhered to confidentiality and privacy. Besides the participants were briefed on their voluntary participation in the study and they should withdraw their participation should they feel uncomfortable. Also, the participants were informed that their participation could not expose then to any risks or harm and that no monetary benefits were to be accorded to

them. All the questionnaires were coded to ensure the anonymity of the study participants.

CHAPTER FOUR

RESULTS

4.1 Demographic Characteristics of Study Participants

The sociodemographic characteristics of the study respondents including, gender, age, level of education, and marital status were documented as socio. In this study, data were derived from 193 patients and 193 caregivers, representing a 100 % response rate.

4.1.1 Distribution of Demographic Characteristics among Children with SCD Aged 15 Years and Below

The findings showed that 47.15% of patients were male while 52.85 % were female in gender distribution (Table 4.1). In terms of age, it was observed that most of the patients (46.63 %) were aged five years and below, while the least proportion (22.28 %) of the patients were aged between 11 and 15 years (Figure 4.1). The findings showed that 65.80 % of the patients had a primary school level of education, and 7.77 % had a secondary school level of education (Table 4.1). However, 26.43 % of the patient respondents were illiterate (Table 4.1).

Table 4.1: Demographic Characteristics of Children Aged 15 Years and Below with Sickle Cell Disease in the Three Health Facilities

Variables	Frequency	Percentage
Gender		
Male	91	47.15
Female	102	52.85
Age-group		
0-5 years	90	46.63
6-10 years	60	31.09
11-15 years	43	22.28
Level of Education		
No formal education	51	26.43
Primary	127	65.80
Secondary	15	7.77

N=193

4.1.2 Distribution of Demographic Characteristics among Caregiver of Children with SCD Aged 15 Years and Below

It was also observed that most caregivers were female (92.23 %), with a paltry 7.77 % being males (Table 4.2). Besides, most of the caregiver respondents (37.82 %) were aged between 26 and 30 years, while the minority (13.99 %) were aged between 21 and 25 years (Table 4.2). The proportions of caregivers aged between 31 and 35 years and above 35 years were 26.42 % and 21.76 %, respectively, while those aged between 21 and 25 years were 12.44 %, as shown in Table 4.2.

Upon assessing the level of education of the caregiver respondents, the results revealed that most of the caregivers (53.37 %) had obtained a primary level of education (Table

4.2). Additionally, 32.64 % and 13.99 % of the caregivers indicated they had a secondary and college/university level of education, respectively (Table 4.2).

Furthermore, to assess the economic status of the caregivers, their occupation, monthly income, monthly medical expenses for their patients suffering from sickle cell disease, and type of residential dwelling were recorded. The results showed that 63.73 % of the caregivers were peasants while 36.27 % were formally employed as summarised in Table 4.2. Besides, 75.13 % of the caregivers indicated they were married, 23.32 % were single, and 1,55 % were divorced (Table 4.2).

The approximate monthly income earned by the caregiver respondents from their economic activities was captured in this study. Notably, the results indicated that most caregivers (62.69 %) earned less than Ksh 5000 per month, and only a few (3.11%) earned between Ksh 15001 and Ksh 20000 every month (Table 4.2). Besides, 18.65 %, 10.88 %, and 4.66 % of the caregivers earned a monthly income range of Ksh 5001-10000, Ksh 10001-15000, and more than Ksh 20000, respectively (Table 4.2).

The residential type and size were also evaluated in this study. The results showed that most caregiver respondents (96.89 %) resided in rented houses, while 3.11 % lived in self-owned houses (Table 4.2). Additionally, it was noted that most respondents (62.18 %) lived in a single-room house, followed by those living in two-room houses (33.16 %) and three rooms (4.66 %), respectively (Table 4.2).

Table 4.2: Demographic Characteristics of Caregivers/Parents of Children Aged 15 Years and Below With Sickle Cell Disease in the Studied Health Facilities

Variables	Frequency	Percentage
Gender		
Male	15	7.77
Female	178	92.23
Age-group		
21-25 years	27	13.99
26-30 years	73	37.82
31-35 years	51	26.42
>35 years	42	21.76
Level of education		
Primary	103	53.37
Secondary	63	32.64
Tertiary (College/University)	27	13.99
Marital status		
Single	46	23.83
Married	145	75.13
Divorced	1	0.52
Widowed	1	0.52
Occupation status		
Peasant	123	63.73
Employed	93	36.27
Monthly Income (Ksh)		
0-5000	121	62.69
5001-10,000	36	18.65
10,001-15,000	21	10.88
15,001-20,000	6	3.11
>20,000	9	4.66
Residential dwelling		
Self-owned house	6	3.11
Rented house	187	96.89
Size of residential dwelling		
One room	120	62.18
Two rooms	64	33.16
Three rooms	9	4.66

4.2 Distribution, Proportion, and Frequency of Sickle Cell Disease and Associated Crises in Children Aged Below 15 Years in Selected Hospitals of the SCF in the Sickle-Cell Foundation (SCF) in Nairobi County

4.2.1 Distribution of Children Aged Below 15 Years with Sickle Cell Disease in the Selected Hospitals of the SCF in Nairobi County

Table 4.3 presents the distribution of children aged below 15 years in the selected hospitals of the SCF in Nairobi County. Generally, the German Doctors hospital had the highest number of sickle cell-affected children aged below 15 years (77.72%) compared with Oasis (13.99%) and Stratus (8.29 %), respectively (Table 4.3).

Regarding gender distribution, 53.33 % of children with sickle cell disease in the German Doctors hospital were female, while 46.67 % were male. In the Oasis medical centre, 48.15 % of children aged below 15 years were male, while 51.85 % were female (Table 4.3). Besides, the number of male and female children aged below 15 years with sickle cell disease in the Stratus medical centre was equal (50 % male and 50 % female) (Table 4.3).

Furthermore, the results revealed that most of the children with sickle cell disease in the German Doctors hospital were aged 0-5 years (46.67 %), followed by those aged 6-10 years (30.00 %), and 11-15 years (23.33 %), respectively. In the Oasis Medical Centre, most children with sickle cell disease were between 0-5 years (48.15 %), while those aged between 6-10 years and 11-15 years represented 37.04 % and 14.81 %, respectively (Table 4.3). Besides, 43.75 % of children with sickle cell disease admitted in the Stratus Medical Centre were between 0-5 years, and those between 6-10 years and 11-15 years were 31.25 % and 25.00 %, respectively (Table 4.3).

In general, 47.15 % of the children with sickle cell disease admitted in the three studied hospitals were male, while 52.85 % were female. Additionally, those aged 0-5 years

were the majority, representing 46.63 % of all the affected children, whereas those aged 6-10 years and 11-15 years were 31.09 % and 27.28 %, respectively (Table 4.3).

Table 4.3: Distribution of Children Aged Below 15 Years with Sickle Cell Disease across the Selected Hospitals of the SCF in Nairobi

Patient Characteristics		Frequency (%)			
		German Doctors	Oasis Medical Centre	Stratus Medical Centre	Total
Gender	Male	70 (46.67)	13 (48.15)	8 (50.00)	91 (47.15)
	Female	80 (53.33)	14 (51.85)	8 (50.00)	102 (52.85)
Age-group	0-5 years	70 (46.67)	13 (48.15)	7 (43.75)	90 (46.63)
	6-10 years	45 (30.00)	10 (37.04)	5 (31.25)	60 (31.09)
	11-15 years	35 (23.33)	4 (14.81)	4 (25.00)	43 (27.28)
n		150 (77.72)	27 (13.99)	16 (8.29)	193 (100.00)

n= Sample size.

4.2.2 Proportion of Children Aged Below15 Years with Sickle-Cell Crises in Select Hospitals of the SCF in Nairobi County

The findings of this study revealed that 88.57 % of the male children aged below 15 years with sickle cell disease in the German Doctors Hospital had sickle cell crises, with only a small number (11.43 %) who did not have the crisis (Table 4.4). Besides, most of the female children with sickle cell disease (87.50 %) in the German Doctors Hospital had sickle cell disease, and only a few (12.50 %) did not present any crisis associated with sickle cell disease (Table 4.4).

In the Oasis Medical centre, most male (69.23 %) and female (71.43 %) children aged below 15 years with sickle cell disease presented with sickle cell disease-associated crises (Table 4.4), while 30.77 % of the male and 28.57 % of the female children with sickle cell disease did not present any crisis (Table 4.4). On the other hand, most children aged below 15 years with sickle cell disease (Male: 75.00 %; Female: 62.50 %) admitted at the Stratus medical centre had sickle cell crises (Table 4.2). However, 25.00 % of the male and 37.50 % of the female children admitted at the Stratus medical centre did not have sickle cell crises (Table 4.4).

Most children aged 0-5 years presented with sickle cell crises in the German Doctors Hospital (92.86 %), Oasis medical centre (69.23 %), and Stratus medical centre (71.43 %) (Table 4.4). Those aged between 6-10 years with sickle cell disease-associated crises were 77.78 % in the German Doctors Hospital and 80.00 % in Oasis and Stratus medical centres, respectively (Table 4.4). Moreover, 91.43 % of 11–15-year-olds with sickle cell disease admitted to the German Doctors Hospital suffered sickle cell crises, whereas those admitted to Oasis and Stratus medical centres were 50 %, respectively (Table 4.4).

Overall, from the three studied hospitals, 83.33 % of the female and 84.62 % of the male children aged below 15 years with sickle cell disease presented associated crises (Table 4.4). Besides, most 0-5-year-olds (87.78 %) presented with sickle cell crises in this study (Table 4.4). The percentage frequency of children aged between 6-10 years with sickle cell crises in this study was 78.83 %, while those aged between 11-15 years were 88.72 % (Table 4.4). In general, 83.94 % of all the sampled children aged below 15 years with sickle cell disease admitted in the three hospitals presented with sickle cell crisis, while 16.06 % did not (Table 4.4).

Table 4.4: Proportion of Children Aged Below 15 Years with Sickle Cell Crisis across the Selected Hospitals of the SCF in Nairobi County

Patient Characteristics		Sickle Cell Crisis status	Frequency (%)			
			German Doctors	Oasis Medical Centre	Stratus Medical Centre	Total
Gender	Male	Positive	62 (88.57)	9 (69.23)	6 (75.00)	77 (84.62)
		Negative	8 (11.43)	4 (30.77)	2 (25.00)	14 (15.38)
	Female	Positive	70 (87.50)	10 (71.43)	5 (62.50)	85 (83.33)
		Negative	10 (12.50)	4 (28.57)	3 (37.50)	17 (16.67)
Age-group	0-5 years	Positive	65 (92.86)	9 (69.23)	5 (71.43)	79 (87.78)
		Negative	5 (7.14)	4 (30.77)	2 (28.57)	11 (12.22)
	6-10 years	Positive	35 (77.78)	8 (80.00)	4 (80.00)	47 (78.83)
		Negative	10 (22.22)	2 (20.00)	1 (20.00)	13 (21.67)
	11-15 years	Positive	32 (91.43)	2 (50.00)	2 (50.00)	36 (88.72)
		Negative	3 (8.57)	2 (50.00)	2 (50.00)	7 (16.28)
	n	Positive	132 (88.00)	19 (70.37)	11 (68.75)	162 (83.94)
		Negative	18 (12.00)	8 (29.63)	5 (31.25)	31 (16.06)

n= Sample size.

4.2.3 Most Frequent Sickle Cell Crises Affecting Children Aged Below 15 Years with Sickle Cell Disease in the Selected Hospitals of the SCF in Nairobi County

The results showed that 45.45 % of male and 91.76 % of female children with sickle cell crises presented with abdominal pains as the primary complaint in the studied hospitals (Table 4.5). Besides, 48.05 % of male and 94.12 % of female children had joint pains associated with sickle cell disease (Table 4.5). This study recorded acute chest pain in 6.49 % of the male and 41.18 % of the female children with sickle cell disease-associated crisis (Table 4.5). Additionally, it was observed that 15.58 % of the male and 47.06 % of the children with sickle cell disease frequently complained of bone pains (Table 4.5).

In terms of age groups, abdominal pain was the most frequently reported complaint among children with sickle cell disease-associated crisis aged between 11-15 years

(97.22 %), while those aged between 0-5 years and 6-10 years presented abdominal pains at frequencies of 79.75% and 78.72 %, respectively (Table 4.5). Joint pains were most frequently reported in children with sickle cell disease-associated crisis aged between 11-15 years (88.89 %), followed by those aged 6-10 years (80.85 %) and 0-5 years (59.49 %), respectively (Table 4.5).

Besides, acute chest pain was reported in 42.44 % of children aged 6-10 years with sickle cell disease-associated crisis, whereas only 12.66 % of those aged 0-5 years and 27.78 % of those aged 11-15 years complained of acute chest pain (Table 4.5). Moreover, bone pain was most frequently reported in children aged 6-10 years (63.83 %) compared with those aged 11-15 years (55.56 %) and 0-5 years (2.53 %). In general, joint pain was the most frequent complaint, followed by abdominal pains, bone pains, and acute chest pain, respectively, in 162 children aged below 15 years with sickle cell disease-associated crises in the sampled hospitals (Table 4.5).

Table 4.5: Most Frequent Sickle Cell Crisis Affecting Children Aged Below 15 Years with Sickle Cell Disease across the Selected Hospitals of the SCF in Nairobi County

Patient Characteristics		**Frequency of sickle cell-associated symptoms (%)**			
		Abdominal pains	**Joint Pains**	**Acute chest pain**	**Bone pain**
Gender	Male	35 (45.45)	37 (48.05)	5 (6.49)	12 (15.58)
	Female	78 (91.76)	80 (94.12)	35 (41.18)	40 (47.06)
Age-group	0-5 years	63 (79.75)	47 (59.49)	10 (12.66)	2 (2.53)
	6-10 years	35 (78.72)	38 (80.85)	20 (42.55)	30 (63.83)
	11-15 years	35 (97.22)	32 (88.89)	10 (27.78)	20 (55.56)
Total (n=162)		113 (69.75)	117 (72.22)	40 (24.69)	52 (32.10)

4.3 Relationship between Patient Factors and the Sickle Cell Crisis

Multiple logistic regression analysis was performed to examine the associations between patient factors and the severity of sickle cell disease (SCD) crisis in children aged 15 years and below. A series of nested models was developed, progressively incorporating patient characteristics to identify the most important predictors of crisis severity (Table 4.6).

Initial univariate analyses were conducted to examine each factor separately. Female gender was found to increase the odds of severe crisis by 44% (log odds = 0.44); however, this association was not statistically significant ($p = 0.206$). Similarly, children aged 6–10 years demonstrated a trend toward increased odds of severe crisis (log odds = 0.87, $p = 0.098$), while more frequent hospital visits (>2 times/month) appeared to be protective, reducing odds by 18% (log odds = −0.18, $p = 0.614$). Nevertheless, none of these univariate associations achieved statistical significance.

When patient factors were examined simultaneously in the multivariable logistic regression model, important associations emerged that were not evident in univariate analyses (Model 4, Table 4.6). Female gender was found to significantly increase the odds of severe crisis by 205% (log odds = 1.12, $p = 0.010$). Children aged 6–10 years exhibited substantially elevated odds of severe crisis, with a log odds increase of 2.67 ($p < 0.001$), representing the strongest predictor of crisis severity identified in this study. Conversely, more frequent hospital visits (>2 times/month) were significantly associated with reduced odds of severe crisis, with a reduction of 84% (log odds = −1.73, $p = 0.002$), suggesting that increased clinical monitoring may provide a protective effect against severe crisis episodes.

The fitted multivariable logistic regression model for predicting SCD crisis severity in children aged 15 years and below can be expressed as: $\ln[P(Y=1)/P(Y=0)] = \beta 0 + \beta 1$(Patient gender [Female]) + $\beta 2$ (Patient Age-group [11-15 years]) + $\beta 3$(Patient Age-group [6-10 years])+ $\beta 4$(Frequency of Hospital Visits [More than twice a month]) =

0.1588+ 1.116 (Patient Gender [Female])+0.7197(Patient Age-group [11-15 years])+2.668 (Patient Age-group [6-10 years])-1.732(Frequency of Hospital Visits [More than twice a month]).

Table 4.6: Factors Associated with SCD Crisis in Children Aged 15 Years and Below in the Three Selected Hospitals

Variable	Variable category	Estimate	P value
	Reference [Male]	-	-
Sex	[Female]	0.4406	0.2058
	Reference [0-5 Years]	-	-
Age-group	[11-15 years]	0.03774	0.9377
	[6-10 years]	0.8716	0.0975
	Reference [once a month]	-	-
Frequency of Hospital Visits	[More than twice a month]	-0.1829	0.6141
	Reference	-	-
Sex	[Female]	1.116	0.0099
Age group	[11-15 years]	0.7197	0.2183
	[6-10 years]	2.668	0.0007
Frequency of Hospital Visits	[More than twice a month]	-1.732	0.0022

N= 162; Multiple Logistic Regression Analysis.

4.4 Level of Adherence to Treatment Requirements by Caregivers and Healthcare Workers for Children Aged Below 15 Years with Sickle Cell Disease Admitted to Three Health Facilities in Nairobi County

The frequency at which the children aged below 15 years with sickle cell disease were offered the prescribed drugs by their caregivers was recorded in the present study, as indicators of treatment adherence by the caregiver respondents (parents). These factors are important determinants of the efficiency and successful management of sickle cell disease, which culminates in better outcomes, low hospitalisation rate, and reduced severity of associated crises.

Besides, the adherence to treatment prescription and documentation by the healthcare workers, significant side effects of the prescribed medicines, and major sickle cell disease crises they manage in affected children aged below 15 years were also assessed in this study. These factors are indicators of adherence to treatment guidelines by the healthcare workers, which influences therapeutic outcomes and success.

4.4.1 The Level of Treatment Recommendations Adherence by Caregivers of Children with Sickle Cell Disease

The frequency at which the patients were given the recommended treatment regimens for sickle cell disease by their caretakers was assessed in this study to determine the level of treatment adherence. The recommended regimen for sickle cell disease evaluated in the present study included taking a folic acid supplement, penicillin and proguanil, sleeping under insecticide-treated bed nets, avoiding adverse temperatures, and drinking at least eight glasses of water daily.

The findings showed that most respondents ensured that their patients took the folic acid supplement and penicillin, positing 97.93 % and 85.49 %, respectively (Figure 4.1). However, few respondents indicated they ensured the patients avoided adverse temperatures (31.08 %), slept under insecticide-treated bed nets (26.43 %), took at least

eight glasses of water daily (23.32 %), and always took proguanil (20.73 %) (Figure 4.1).

Besides, 77.20 % of the caregivers indicated their patients occasionally (sometimes) take proguanil. Additionally, 72.28 %, 62.18 %, 41.45 %, and 10.36 % of the respondents said that their patients sometimes take at least eight glasses of water, avoid adverse temperatures (too hot/cold temperatures), sleep under an insecticide-treated bed net, and take penicillin, respectively (Figure 4.1). However, none indicated that their patients sometimes take the folic acid supplement (Figure 4.1).

Notably, 32.12 % of the caregivers indicated that their patients never sleep under an insecticide-treated bed net (Figure 4.1). Whereas, few respondents indicated their patients never avoid adverse temperatures (6.74 %), take at least eight glasses of water daily (4.40 %), take penicillin (4.15 %), take proguanil (2.07 %), and take the folic acid supplement (2.07 %), respectively (Figure 4.1).

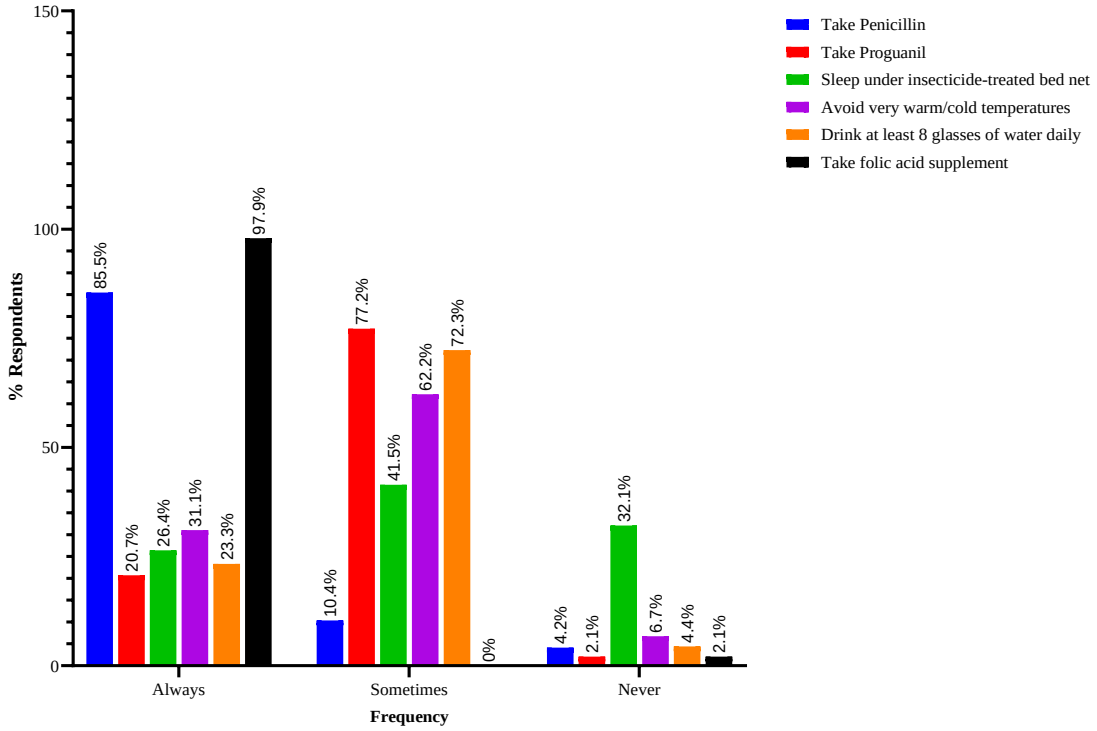

Figure 4.1: Adherence to Treatment Regimens by Children with SCD in the Three Health Facilities

Furthermore, the study respondents were requested to state the reasons for their non-adherence to the prescribed treatment schedule for their patients. Most caregivers (66.32 %) indicated that inaccessibility of the medications was the primary reason they always failed to adhere to the treatment schedule (Figure 4.2). The second most common reason the respondents did not always adhere to treatment guidelines was the unavailability of medications, as stated by 21.24 % of the respondents (Figure 4.2). Also, 9.84 % of the caregivers indicated that the unaffordability of the medications always contributed to their non-adherence to treatment recommendations (Figure 4.2). Additionally, forgetiveness and time constraints were indicated by 4.15 % of the respondents as reasons behind their non-adherence to treatment recommendations. A smaller percentage of the respondents (0.52 %) indicated that the medications' side effects were the reasons they did not always adhere to the recommended treatment regimen (Figure 4.2).

Besides, forgetiveness, unavailability and unaffordability of medications and time constraints were indicated by 72.54 %, 64.25, and 68.91 % of the caregiver respondents as the main reasons why they sometimes could not adhere to the recommended treatment regimen for their patients (Figure 4.2). In addition, 39.38 % and 23.32 % of the respondents attributed their non-adherence to treatment recommendations to occasional side effects of the medications and their inaccessibility, respectively (Figure 4.2).

Side effects of the medicines for sickle cell disease were indicated by 60.01 % of the respondents as the major reason they never adhered to treatment recommendations (Figure 4.2). Besides, unaffordability of medications, time constraints, forgetiveness, unavailability, and inaccessibility of medications, were stated by 27.46 %, 26.94 %, 23.32 %, 14.51 %, and 10.36 % of respondents, respectively, as to why they never adhered to the treatment recommendations (Figure 4.2).

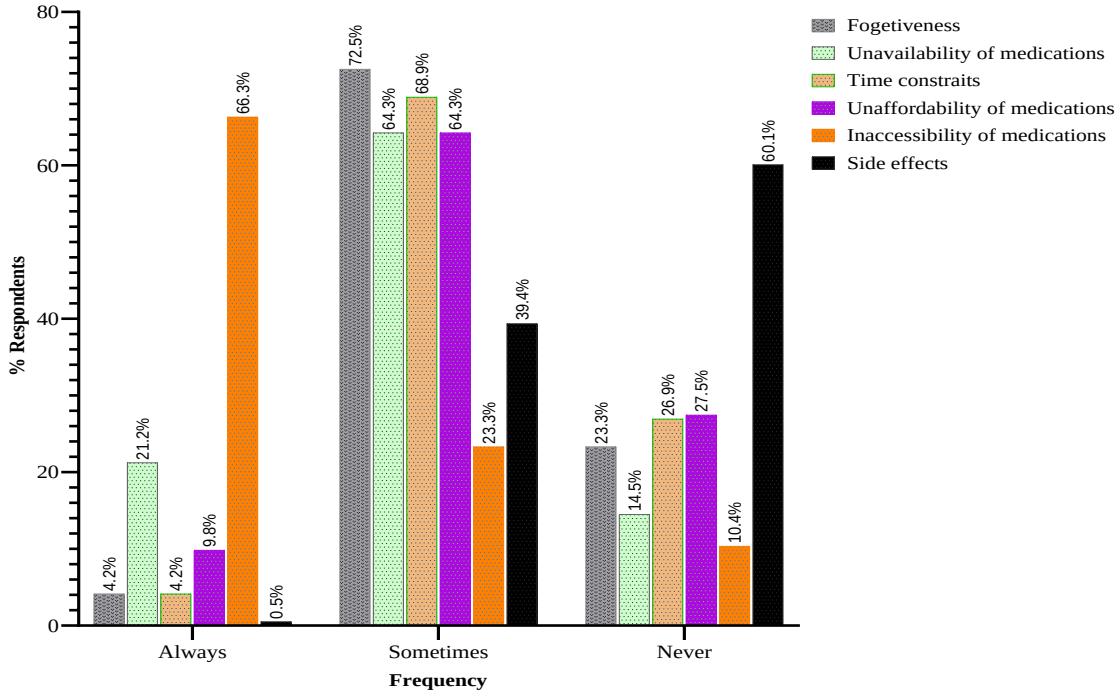

Figure 4.2: Reasons for Non-Adherence to Medications According to the Caregiver Respondents

4.4.2 The Level of Treatment Adherence for Children with Sickle Cell Disease by Healthcare Workers

In this study, 80.83 % of the healthcare personnel indicated that they administer antimetabolites, especially hydroxyurea, to children aged <15 years suffering from sickle cell disease, as recommended, while 19.17 % of healthcare workers indicated they had not followed this guideline (Figure 4.3). Penicillin and folic acid were administered according to the set guidelines, as shown by 89.64 % and 87.05 % of the healthcare officials. Further, hydromorphone, an analgesic drug, was appropriately administered by 75.65 % of healthcare workers, as opposed to 24.35 % of the respondents who indicated they did not administer it as recommended (Figure 4.3). Notably, all the healthcare staff indicated that they had not vaccinated children below 15 years with sickle cell disease as per the healthcare guidelines (Figure 4.3).

Moreover, the findings showed that 74.09 % of healthcare workers (pharmacists) had appropriately documented the prescribed/issued drugs to children aged below 15 years with sickle cell disease in their facilities (Figure 4.3). However, 25.91 % of the healthcare staff had not recorded the prescriptions as recommended (Figure 4.3).

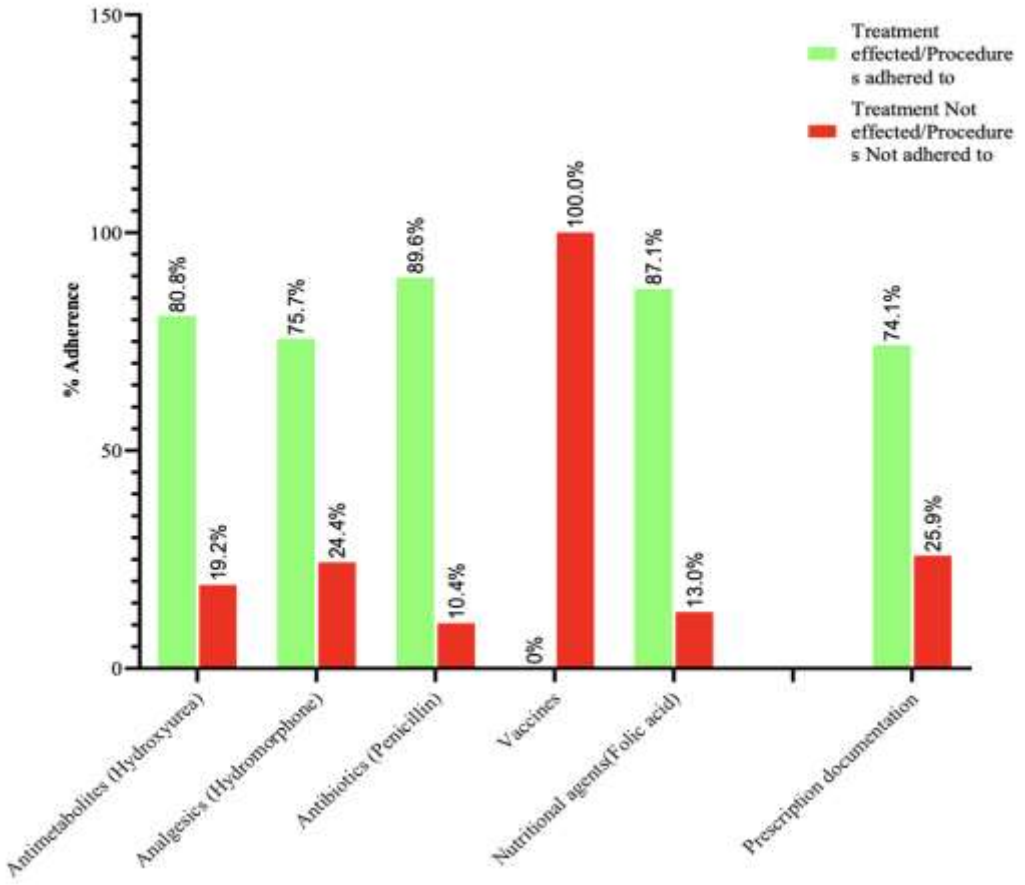

Figure 4.3: Adherence to Proper Therapeutic Management of SCD and Prescription Guidelines

Moreover, the healthcare workers were asked to indicate whether the caregivers of patients picked the prescribed medicines from the hospital pharmacy, if the prescribed drugs were available, and if the patients visited the hospital regularly to assess the major reasons for non-adherence to the therapeutic management of sickle cell disease in affected children (<15 years old).

As shown in figure 4.4, most healthcare (68.91 %) indicated that the caregivers had picked the prescribed medicines from the hospital pharmacy, while 32.64 % of the

healthcare workers indicated the caregivers did not pick the prescribed medicines for their patients (children aged below 15 years with sickle cell disease).

Notably, 81.35 % of the healthcare workers indicated that the prescribed medicines for sickle cell disease are unavailable at their pharmacies, with only 18.65 % of the healthcare workers indicating the drugs are available (Figure 4.4). Besides, 55.96 % of the healthcare workers stated that children aged below 15 years regularly visited their hospital facility for healthcare services (Figure 4.4). However, 44.04 % of the respondents indicated that sickle cell disease patients aged below 15 years did not visit the hospital regularly and only visited occasionally (Figure 4.4).

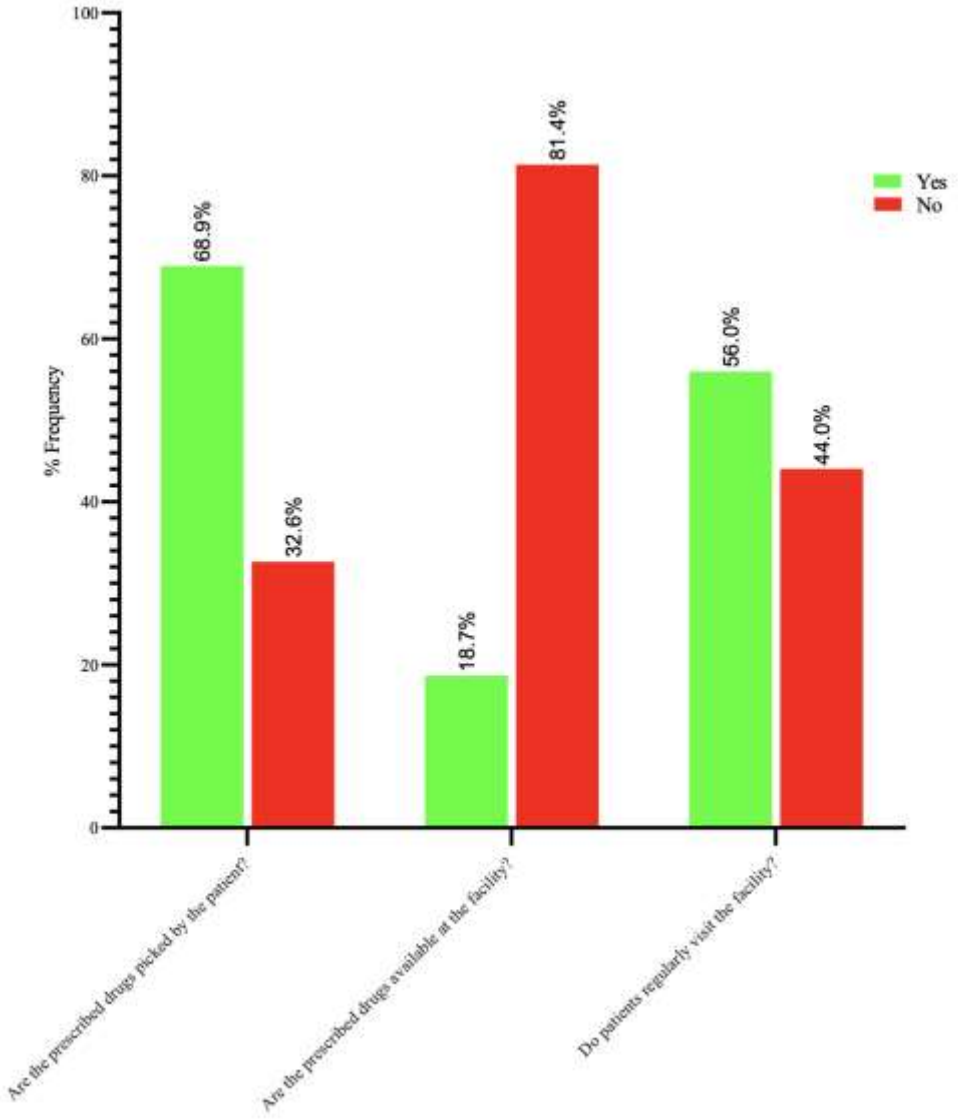

Figure 4.4: Major Reasons for Non-Adherence to SCD Treatment According to Healthcare Workers

The healthcare workers were requested to state the major side effects of medicines used to treat sickle cell disease in children below 15 years who visit their hospital facility. The results showed that 10.36 % of the respondents cited breathing difficulties as one of the most frequent side effects associated with medications for sickle cell disease in some children visiting their hospitals (Figure 4.5).

Besides, 16.58 % of the healthcare workers cited abdominal swelling, fever and vomiting as among the side effects of sickle cell disease medications (Figure 4.5). On the other hand, 26.94 %, 20.73 %, and 12.44 % of healthcare workers cited fatigue, body irritability, dizziness and light-headedness as side effects associated with sickle cell disease medications (Figure 4.5). Notably, all the healthcare workers indicated that high blood pressure is not a side effect of medications used to manage sickle cell disease (Figure 4.5).

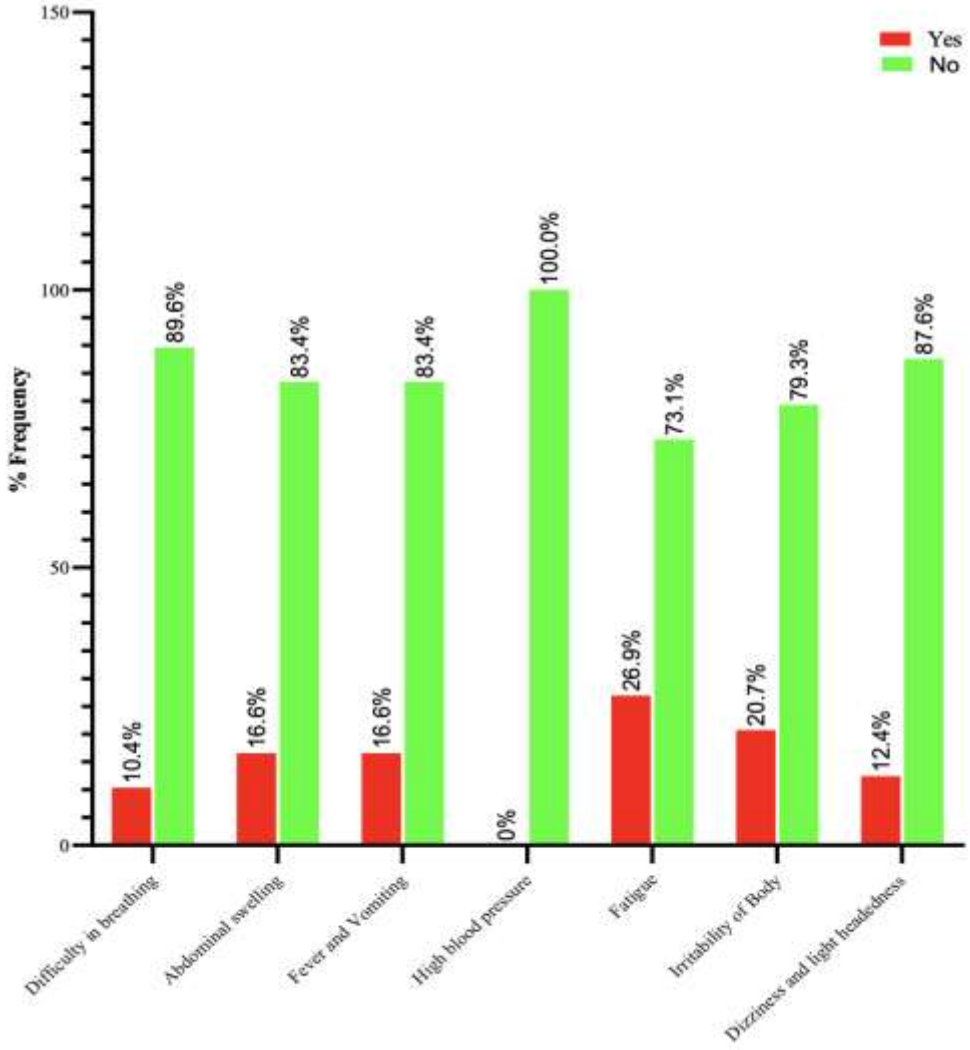

Figure 4.5: Major Side Effects Associated with SCD Medications According to Healthcare Workers

4.5 Caregiver Attitudes, Perceptions, and Beliefs towards Children aged 15 years and below with Sickle Cell Disease in the three health facilities

This study investigated the attitudes, perceptions, and beliefs of caregivers towards children under 15 years old with sickle cell disease in three health facilities Nairobi

County. The results revealed four key themes which characterised the caregivers' attitudes, perspectives, and beliefs about sickle cell disease. The identified themes were as follows.

Theme 1: Misconceptions about Sickle Cell Disease: Psychosocial impact on intelligence and identity

In terms of the caregiver's perceptions of sickle cell disease, this study noted that there were divergent opinions, with some considering it infectious. Notably, some of the caregivers reckoned that "…Sickle cell disease is an infectious disease…" However, majority of the caregivers held a contrary view and stated that '…sickle cell disease is a genetic disorder and not infectious…' Some caregivers linked the disease to intelligence, wherein some believed it affects the child's intelligence by stating that, "… it makes a child less intelligent." Interestingly, most caregivers stated that sickle cell disease does not affect the child's intelligence in any way. Nevertheless, the caregivers expressed genuine concerns about the cognitive effects of pain crises and other medical complications associated with sickle cell disease on a child's academic performance.

Theme 2: Cultural and Spiritual Interpretations of SCD: Ancestral Spirits and Beliefs

Another intricate theme pertaining to ancestral beliefs emerged in this study, where some caregivers viewed sickle cell disease as 'an ancestral spirit' that afflicts their lineage. Contrarily, majority of the caregivers acknowledged its scientific origins and refuted claims that this disease is 'an ancestral spirit' and some form of curse for evil doers.

The findings showed that some caregivers had concerns about the reproductive health of their affected children, some felt that 'persons with sickle cell disease cannot have [sire/bear] children' when they come of age. It was observed that some caregivers

interpreted sickle cell disease in their child as either a curse or some form of ancestral spirit haunting their generation for their or relative's misdeeds in the past.

Social integration became a significant focus under this theme, with caregivers largely advocating for children with sickle cell disease to socialize within the family and society, while a smaller percentage holding opposing views- linked to cultural and spiritual beliefs.

Theme 3: Influence of Socioeconomic status on sickle cell disease perceptions

The caregivers' socioeconomic perceptions about sickle cell disease and their affected children also emerged as a prominent theme in this study. The findings showed that most caregivers disagreed with the notion that sickle cell disease 'solely affects the poor and the less educated' in the society. However, some of the caregivers associated sickle cell disease with poverty and low education levels and felt that the situation would be different if they were wealthy and well educated. This theme intertwined with the belief in the curability of the disease, wherein most caregivers perceived sickle cell disease as curable, as some considered it incurable.

Theme 4: Severity and Mortality Associated with Sickle Cell Disease

This theme demystified and reflected the main challenges associated with sickle cell disease and its burden to the affected and their caregivers. The findings showed that some caregivers feared that sickle cell disease is a severe disease and might shorten their affected child's life by stating that '…people with sickle cell disease often die before attaining the age of 21 years.' Notably, a nuanced perspective about the need for automatic genetic screening of the sickle cell trait in children, with some caregivers expressing reservations. Some felt that automatically subjecting their child to such test would lead to social stigma and neglect with far-reaching repercussions. However, some caregivers held positive viewpoint that early screening would over them an opportunity

to better manage their affected children and seek proper medical attention to improve their quality of life.

4.6 Factors Associated with Knowledge about Sickle Cell Disease among Parents and Caregivers at Three Health Facilities in Nairobi County

The results showed that the majority of both male (67.66%) and female (73.03%) parents and caregivers had low knowledge levels about SCD and its associated crises, with only a small proportion demonstrating moderate or high knowledge levels (Table 4.7). Among age groups, parents and caregivers aged 21–25 years had the highest proportion of low knowledge (88.24%), while only 5.88% achieved moderate or high knowledge levels (Table 4.7).

Similarly, the majority of parents and caregivers in the older age groups—26–30 years (66.18%), 31–35 years (71.21%), and >35 years (78.57%)—had low knowledge about SCD and its associated crises, with fewer than 10% achieving high knowledge levels in any age group (Table 4.7). With respect to educational attainment, most parents and caregivers with primary-level (86.81%) and secondary-level (74.68%) education had low knowledge about SCD and its crises. In contrast, the majority of those who had attained college or university-level education (56.52%) demonstrated moderate knowledge, and 34.78% demonstrated high knowledge about SCD—a markedly better performance compared with lower educational groups (Table 4.7).

Regarding marital status, most single (62.96%) and married (74.10%) parents and caregivers had low knowledge about SCD and its associated crises; only 7.41% of single and 10.84% of married participants achieved high knowledge levels (Table 4.7). With respect to monthly income, the vast majority of parents and caregivers earning less than KSh 10,000 per month (86.62%) had low knowledge levels, while only a minority demonstrated moderate or high knowledge. Notably, among those earning more than KSh 10,000 per month, most exhibited moderate (55.56%) or high (33.33%) knowledge about SCD—a striking contrast to the lower-income group (Table 4.7).

Table 4.7: Distribution of Knowledge about Sickle Cell Disease by Parent/Caregiver Sociodemographic Characteristics

Parent/Caregiver Factors	Knowledge about SCD		
	Low	Moderate	High
Gender			
Male	10 (66.67%)	3 (20.00%)	2 (13.33%)
Female	130 (73.03%)	30 (16.85%)	18 (10.11%)
Age Group			
21–25 years	15 (88.24%)	1 (5.88%)	1 (5.88%)
26–30 years	45 (66.18%)	15 (22.06%)	8 (11.76%)
31–35 years	47 (71.21%)	10 (15.15%)	9 (13.64%)
>35 years	33 (78.57%)	7 (16.67%)	2 (4.76%)
Level of Education			
Primary	79 (86.81%)	7 (7.69%)	5 (5.49%)
Secondary	59 (74.68%)	13 (16.46%)	7 (8.86%)
College/University	2 (8.70%)	13 (56.52%)	8 (34.78%)
Marital Status			
Single	17 (62.96%)	8 (29.63%)	2 (7.41%)
Married	123 (74.10%)	25 (15.06%)	18 (10.84%)
Monthly Income			
<KSh 10,000	136 (86.62%)	13 (8.28%)	8 (5.10%)
>KSh 10,000	4 (11.11%)	20 (55.56%)	12 (33.33%)

n = 193.

Logistic regression analysis was conducted to examine the associations between sociodemographic and socioeconomic characteristics of parents and caregivers and their likelihood of achieving moderate or high knowledge about SCD and its crises in children aged 15 years and below (Table 4.8).

In Model 1, female gender was associated with a reduction in the log-odds of moderate/high knowledge about SCD by 0.3032 points; however, this association was not statistically significant (P = 0.5968; Table 4.8). In Model 2, compared with the youngest age group (21–25 years), parents and caregivers aged 26–30 years (β = 1.3440), 31–35 years (β = 1.1090), and >36 years (β = 0.7156) showed higher log-odds of moderate/high knowledge, though none of these associations reached statistical significance (all P > 0.05; Table 4.8). In Model 3, both secondary-level education (β = 0.8027; P = 0.0467) and college/university-level education (β = 4.2360; P < 0.0001) were significantly associated with increased log-odds of moderate/high knowledge about SCD and its crises relative to primary-level education (Table 4.8). In Model 4, married status was associated with reduced log-odds of moderate/high knowledge by 0.5204 points, though this association was not statistically significant (P = 0.2328; Table 4.8). In Model 5, a monthly income exceeding KSh 10,000 was significantly associated with increased log-odds of moderate/high knowledge (β = 4.2430; P < 0.0001), highlighting the substantial role of income in determining SCD knowledge among parents and caregivers (Table 4.8).

In the final multiple logistic regression model (Model 6), female gender was associated with a non-significant increase in the log-odds of moderate/high knowledge (β = 0.2559; P = 0.7519). Secondary-level education (β = 1.2080; P = 0.0800) and college/university-level education (β = 1.1620; P = 0.4244) were associated with increased log-odds, although neither reached statistical significance after controlling for other covariates. Married status was significantly associated with reduced log-odds of moderate/high knowledge (β = −2.7080; P = 0.0009), while a monthly income exceeding KSh 10,000 was significantly associated with substantially increased log-odds (β = 4.3350; P < 0.0001; Table 4.8).

Based on the multiple logistic regression results, the final predictive model (Model 6) for moderate/high knowledge about SCD among parents and caregivers of children with SCD aged 15 years and below is expressed as:

ln[P(Y=1)/P(Y=0)] = −0.6931 + 0.2559 (Gender [Female]) + 1.2080 (Education [Secondary]) + 1.1620 (Education [College/University]) −2.7080 (Marital status [Married]) + 4.3350 (Monthly income [>KSh 10,000]).

Table 4.8: Association between Parent/Caregiver Factors and Knowledge About SCD and its Crises in Children Aged 15 Years and Below

Variable	Variable category	β Estimate	SE	P-value
Gender				
	Reference [Male]	-	-	-
Sex	Female	−0.3032	0.5731	0.5968
Age Group				
	Reference [21-25 years]	-	-	-
	[26–30 years]	1.3440	0.7954	0.0911
	[31–35 years]	1.1090	0.8002	0.1658
	[>36 years]	0.7156	0.8415	0.3951
Level of Education				
	Reference [Primary]	-	-	-
	Secondary	0.8027	0.4036	0.0467
	University/College	4.2360	1.0888	<0.0001
Marital Status				
	Reference [single]	-	-	-
	[Married]	−0.5204	0.4361	0.2328
Model 5: Monthly Income				
	Reference [<KSh 10,000]	-	-	-
Monthly income	[>KSh 10,000]	4.2430	1.0906	<0.0001
Multiple Logistic Regression (Final Model)				
	Reference	-	-	-
Sex	[Female]	0.2559	0.8095	0.7519
Level of education	[Secondary]	1.2080	0.6900	0.0800
	[University/College]	1.1620	1.4547	0.4244
Marital status	[Married]	−2.7080	0.8156	0.0009
Monthly income	[>KSh 10,000]	4.3350	1.1142	<0.0001

N = 193. SE = Standard Error of the β coefficient. Multiple Logistic Regression Analysis.

CHAPTER FIVE

DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

5.1 Discussion

5.1.1 Background and Epidemiological Context of Sickle Cell Disease

Sickle cell disease (SCD) is the most prevalent monogenic haematological disorder globally, characterised by chronic haemolytic anaemia, recurrent painful vaso-occlusive episodes, progressive multi-organ damage, and heightened susceptibility to potentially fatal infections (Piel, 2013; Thiam *et al.*, 2017). These clinical manifestations result from a single point mutation in the beta-globin gene, leading to the production of an abnormal haemoglobin variant (haemoglobin S) that polymerises under conditions of hypoxia, dehydration, or physiological stress, causing erythrocyte sickling. The acute and chronic consequences of this pathophysiological process impose a profound burden on affected individuals, their families, and health systems. Globally, SCD constitutes a significant public health challenge, with an estimated 20 million people living with the condition and more than 310,000 affected neonates born annually (Piel, 2013; Eleonore *et al.*, 2020).

Alarmingly, more than 15% of children with SCD in low-resource settings die before the age of five years, a figure attributable largely to inadequate neonatal screening, delayed diagnosis, and restricted access to evidence-based therapeutic interventions (Uyoga *et al.*, 2019). Sub-Saharan Africa bears a disproportionate share of this burden, accounting for more than 75% of global SCD cases and more than 80% of SCD-related childhood deaths a stark reflection of the intersection between genetic predisposition and structural health inequities that characterise the region (Pongombo *et al.*, 2015; Kavai *et al.*, 2020). The findings of the present study are situated within this broader epidemiological landscape and contribute empirical evidence from a Nairobi County context, where SCD remains underserved by public health policy and clinical resources.

5.1.2 Sociodemographic Characteristics of Patients with Sickle Cell Disease Crisis

The present study examined a total of 386 participants (193 patients with SCD and 193 of their primary caregivers) drawn from three public health facilities in Nairobi County. Among the patients, 52.85% were female and 47.15% were male. This near-equal distribution by sex is consistent with the established understanding that SCD, as an autosomal recessive disorder, does not confer a sex-linked inheritance advantage; however, the marginally higher proportion of female patients in the present sample is consistent with evidence suggesting that girls are more frequently brought to formal healthcare settings due to differences in health-seeking behaviour and caregiver priorities (Swaleh, 2018; Thiam *et al.*, 2017; Bianga *et al.*, 2022). It is also noteworthy that the three health facilities reported a high overall burden of SCD patients, underscoring the significant prevalence of the condition in the Nairobi County context and confirming that SCD remains the most common hereditary haematological disorder, with Africa disproportionately represented in global case distributions (Piel, 2013; Eleonore *et al.*, 2020; Kavai *et al.*, 2020).

A large proportion of the SCD patients in this study were below five years of age (48.63%), while children above 11 years constituted only 22.28% of the sample. This age distribution carries significant clinical and epidemiological implications. The predominance of younger children is consistent with survival data from sub-Saharan Africa, where it is estimated that approximately 70% of SCD-related deaths occur before the fifth birthday, primarily due to overwhelming infections, severe anaemia, and the absence of early diagnosis and prophylactic treatment (Mabiala-Babela *et al.*, 2005; Bianga *et al.*, 2022; Thiam *et al.*, 2017; Pongombo *et al.*, 2015). The relative underrepresentation of older children is, therefore, likely a reflection of the substantial mortality that occurs in the youngest age cohort rather than a true reduction in SCD prevalence among older children. These findings highlight the critical need for expanded neonatal screening programmes, early enrolment in SCD care, and robust prophylactic regimens that can prevent premature morbidity and mortality in the most vulnerable age group.

5.1.3 Sociodemographic and Socioeconomic Profile of Caregivers

The sociodemographic profile of caregivers in this study reveals patterns consistent with those documented in sub-Saharan African literature, while also illuminating context-specific vulnerabilities that warrant targeted policy attention. The vast majority of caregivers were female (92.23%), with only 7.77% being male, a proportion that far exceeds even conservative estimates of female caregiving dominance reported in analogous settings (Swaleh, 2018; Adzika *et al.*, 2017). Swaleh (2018) reported that approximately 60% of caregivers were women in a comparable Kenyan study, suggesting that the present study's sample reflects an even more pronounced feminisation of the caregiving role. This disparity is attributable to deeply entrenched gender norms and societal expectations that assign primary childcare responsibility to women across much of sub-Saharan Africa (Adzika *et al.*, 2017). The implications of this dynamic extend beyond cultural description: female caregivers of children with SCD bear a disproportionate psychological, physical, and economic burden, often at the expense of their own health and livelihoods, which ultimately undermines the sustainability of care.

In terms of age, the majority of caregivers were young adults aged between 26 and 30 years a finding consistent with earlier studies documenting that SCD disproportionately affects the children of mothers in their prime reproductive years (Oluwole & Adeyemo, 2021). Educational attainment among caregivers was generally low, with only a minority having received education beyond secondary level. This is a matter of considerable clinical significance, as educational level is recognised as a key determinant of health literacy, treatment adherence, and the capacity to navigate complex healthcare systems (de Jesus *et al.*, 2018). Economically, the caregivers in this study were predominantly subsistence farmers (63.73%), with only 36.27% reporting formal employment. More than 62.69% earned less than KSh 5,000 per month, a figure that falls well below the Kenyan national poverty threshold, while only 3.11% reported monthly earnings between KSh 15,001 and KSh 20,000. These figures are consistent with the observation that SCD disproportionately affects children from economically marginalised

households, where financial constraints severely limit access to medications, transportation to specialist facilities, and the dietary quality necessary to support the elevated nutritional demands of SCD (Al Saif *et al.*, 2022). In some cases, the catastrophic cost of SCD-related healthcare compels families to liquidate productive assets, a phenomenon documented across low- and middle-income country contexts, thereby entrenching poverty and further compromising the child's long-term prognosis (Al Saif *et al.*, 2022; Viswanathan *et al.*, 2015).

5.1.4 Socioeconomic Determinants of SCD Crisis

The socioeconomic characteristics of the caregivers in this study reflect a broader pattern recognised in the international literature: SCD predominantly burdens households with limited economic resources, restricted educational attainment, and constrained access to quality healthcare, all of which perpetuate a cycle of disease severity and poor outcomes (de Jesus *et al.*, 2018; Viswanathan *et al.*, 2015). The link between poverty and adverse SCD outcomes is multi-dimensional. Low income directly limits the ability of caregivers to afford prophylactic medications such as penicillin and hydroxyurea, to access laboratory investigations, and to attend specialist follow-up appointments. Physical distance from tertiary care facilities, a barrier compounded by the high cost of transportation in urban-peri-urban settings, further restricts timely medical attention during acute crises, increasing the risk of preventable morbidity and mortality (Viswanathan *et al.*, 2015).

Low educational attainment compounds these economic constraints in important ways. Children with SCD frequently experience school absenteeism due to hospitalisation and recurrent pain crises, which impairs academic performance and long-term educational attainment (de Jesus *et al.*, 2018). Parents and caregivers with limited education may themselves have experienced disrupted schooling, limiting their capacity to understand written medical instructions, engage meaningfully with healthcare providers, or recognise early warning signs of clinical deterioration. These dynamics collectively contribute to lower health literacy, which is associated with reduced treatment

adherence, higher rates of disease complications, and a diminished quality of life for affected children (Adzika *et al.*, 2017). Residing in socioeconomically deprived neighbourhoods further compounds these effects, as such environments are frequently associated with inadequate housing, food insecurity, and restricted access to clean water, all of which can precipitate or exacerbate SCD crises. These findings underscore the imperative of integrating social support interventions, including community-based health education, financial assistance schemes, and transportation subsidies, into the management framework for children with SCD in resource-limited settings.

5.1.5 Clinical Presentation and Crisis Characteristics

The clinical presentation of SCD in the current study reflects the well-established spectrum of vaso-occlusive and haematological crises characteristic of the disease in African paediatric populations. Overall, 83.3% of female and 84.6% of male children aged under 15 years experienced at least one SCD-related crisis during the study period, underscoring the high burden of acute illness in this population. Among children in the 0–5-year age group, 87.78% presented with sickle cell crises, which is broadly consistent with the established pattern of early-onset disease severity that characterises SCD in the first years of life. Vaso-occlusive events, including episodes of acute musculoskeletal pain, abdominal pain, and chest pain, were the most commonly reported presenting complaints. Of male and female SCD children presenting to the three hospitals, 45.45% of males and 91.76% of females presented with abdominal symptoms, and 48.05% of males and 94.12% of females reported joint pain. Additionally, 6.49% of males and 41.18% of females experienced acute chest pain, while 15.58% of males and 47.06% of females reported bone pain.

The pronounced sex-disaggregated differences in symptom reporting, with female children consistently demonstrating higher rates across all presenting complaints, may reflect differences in health-seeking behaviour, caregiver responsiveness, pain expression, or biological factors, and warrant further investigation. The predominance of pain as the primary driver of hospital attendance is consistent with a substantial body of

literature confirming that painful vaso-occlusive crises represent the cardinal clinical manifestation and most common cause of emergency healthcare utilisation in SCD (Adzika *et al.*, 2017; Nai *et al.*, 2022). Anaemia-related crises, including splenic sequestration and aplastic crises, are the most common acute event type in children under five years, as documented in earlier studies from sub-Saharan Africa (Mabiala-Babela *et al.*, 2005; Babela *et al.*, 2005), and this age group's particular vulnerability is reflected in the current study's finding that infants and toddlers constitute the largest subset of hospitalised SCD patients. The intersection of infection-driven haemolysis, splenic dysfunction, and limited immune maturity creates a particularly hazardous clinical environment for this cohort, reinforcing the need for newborn screening, early enrolment in comprehensive SCD care programmes, and consistent prophylactic penicillin administration.

Of particular note is the finding that female SCD patients aged 6–10 years demonstrated a higher propensity for developing severe crises compared with other subgroups. This observation may be attributable to several interrelated factors. Children in this age group are characteristically more physically active, which increases the metabolic and haemopoietic demands placed on a system already compromised by haemolysis. Furthermore, the onset of early pubertal changes, associated with hormonal shifts that may influence haemoglobin S polymerisation kinetics and inflammatory mediator profiles, may potentiate crisis frequency and severity during this developmental window (Mulumba and Wilson, 2015; Salman and Hassan, 2015; Silva *et al.*, 2015). These findings carry important clinical management implications: enhanced monitoring and tailored educational counselling for caregivers of female children in this age group are warranted, with particular emphasis on identifying early warning signs of severe crisis, ensuring strict adherence to prescribed prophylactic and therapeutic regimens, and reducing avoidable environmental or behavioural triggers.

5.1.6 Treatment Adherence and Therapeutic Management

Treatment adherence is a central determinant of clinical outcomes in SCD, and the findings of the present study illuminate both the facilitators and barriers to adherence within the study population. The standard therapeutic regimen assessed in this study included prophylactic folic acid supplementation, penicillin administration, proguanil for malaria prevention, the use of insecticide-treated bed nets, avoidance of extreme environmental temperatures, and adequate daily hydration, each of which represents an evidence-based strategy for reducing crisis frequency and disease-related morbidity (Laing, 2015; Okoko *et al.*, 2017). Adherence to this multifaceted regimen was variable across the study population, with caregivers citing a range of barriers including inaccessibility to medications, periodic drug stockouts in facility pharmacies, forgetfulness, fear of adverse drug effects, and financial unaffordability.

Among the most clinically significant therapeutic agents for SCD is hydroxyurea, a cytoreductive agent that increases foetal haemoglobin (HbF) levels and thereby reduces the frequency of vaso-occlusive crises, acute chest syndrome, and blood transfusion requirements. The present study found a high level of healthcare worker commitment to the administration of hydroxyurea for paediatric SCD patients, which aligns with current evidence supporting its use in children with clinically severe disease (Reddy *et al.*, 2022). It is important to note, however, that hydroxyurea therapy is typically reserved for patients who have demonstrated clinical severity meeting predefined thresholds, while prophylactic penicillin, administered from early infancy, remains the first-line preventive intervention against pneumococcal sepsis, the leading cause of SCD-related mortality in young children (Okoko *et al.*, 2017). Both medications require consistent daily dosing, and adherence monitoring is therefore a critical component of SCD management programmes.

The finding that 74.09% of healthcare personnel, especially pharmacists, accurately documented prescribed and dispensed medications for paediatric SCD patients is encouraging and suggests a reasonable level of professional commitment to

pharmacovigilance within the assessed facilities. Documentation quality is an important proxy indicator of the integrity of medication management systems, and its adequacy directly influences the reliability of adherence monitoring. This finding is consistent with the broader literature demonstrating that healthcare providers play a pivotal role in optimising SCD outcomes through education, lay counselling, systematic adherence monitoring, and the maintenance of therapeutic partnerships with patients and their families (Hsu *et al.*, 2016). Notwithstanding these positive findings, the barriers to adherence identified in this study, particularly medication unaffordability and stockouts, highlight system-level failures that must be addressed through policy interventions, including the integration of essential SCD medicines into public health insurance schemes and the strengthening of pharmaceutical supply chains at the facility level. Preventive practices endorsed by medical specialists, including adequate hydration, folic acid supplementation, and the avoidance of physiological stressors, have been consistently associated with fewer pain episodes, reduced hospitalisation rates, and improved quality of life when adherence is maintained, underscoring the high return on investment of effective adherence support interventions (Viswanathan *et al.*, 2015).

5.1.7 Nutritional Status, Growth, and Development

Nutritional compromise is a well-recognised complication of SCD that interacts bidirectionally with disease severity: the hypermetabolic demands imposed by chronic haemolysis and frequent infections increase caloric and micronutrient requirements, while the resulting malnutrition further impairs immune function, erythropoiesis, and physical development. The findings of the present study are consonant with a substantial body of evidence documenting growth faltering in paediatric SCD populations across sub-Saharan Africa. Pongombo *et al.* (2015) demonstrated that poor nutritional status is a significant predictor of sickle cell crisis, particularly in patients with the homozygous SS genotype (HbSS), which is associated with the most severe clinical phenotype. Similarly, Swaleh (2018) documented a high prevalence of underweight status and low body mass index (BMI) among SCD children under five years at Kenyatta National

Hospital in Nairobi, findings that closely parallel those of the present study and point to consistent nutritional vulnerabilities within this demographic.

Growth retardation in SCD, manifesting as reduced height-for-age and weight-for-age z-scores relative to unaffected peers, has been attributed to a convergence of factors including chronic anaemia, recurrent inflammatory states, elevated basal metabolic rate, and the adverse effects of frequent hospitalisations on dietary intake (de Jesus *et al.*, 2018; Kosiyo *et al.*, 2020). It is important to note that growth retardation in SCD is most pronounced during and after puberty, when the hormonal changes of adolescence impose additional demands on an already compromised haemopoietic system (Kosiyo *et al.*, 2020). The increased energy expenditure associated with chronic haemolysis, lower circulating haemoglobin levels, and higher hospitalisation frequencies collectively widen the nutritional gap between children with and without SCD across all paediatric age groups (de Jesus *et al.*, 2018). While SCD does not necessitate a disease-specific dietary regimen per se, the presence of nutritional deficiencies, driven by the elevated metabolic requirements of the disease, significantly exacerbates clinical outcomes and contributes to the propensity for malnutrition observed in affected children (Laing, 2015; Lukusa Kazadi *et al.*, 2017).

The low socioeconomic and educational status of the caregivers documented in this study has a direct bearing on the nutritional outcomes of children with SCD, as it does in other chronic disease contexts. Financial constraints limit the ability of families to consistently provide the diverse, nutrient-rich diets necessary to meet the elevated caloric and micronutrient demands of SCD. This problem is compounded when combined with the geographic distance between households and specialist facilities, which imposes additional costs in time and resources, and results in inadequate follow-up frequency and delayed identification of nutritional deterioration (Viswanathan *et al.*, 2015). These considerations underscore the importance of incorporating systematic nutritional assessment, including anthropometric measurement and dietary history, into routine SCD clinical reviews, and of developing community-based nutritional support programmes that account for the socioeconomic constraints of affected families. Early

identification of failure to thrive and timely nutritional intervention represent high-impact opportunities to interrupt the cycle of malnutrition and worsening disease severity in this population.

5.1.8 Perceptions, Attitudes, and Cultural Beliefs about Sickle Cell Disease

The attitudinal and perceptual dimensions of SCD among caregivers represent a crucial, yet frequently underappreciated, determinant of care-seeking behaviour, treatment adherence, and patient outcomes. The present study employed a qualitative analytical approach to elicit the beliefs, attitudes, and interpretive frameworks that caregivers bring to their understanding of SCD and its management. This analysis yielded four overarching themes that provide a rich and contextually grounded account of the caregiver experience.

The psychosocial burden placed on caregivers by the demands of managing a child with SCD is substantial and multidimensional. As Madani *et al.* (2018) noted, the responsibilities of caregiving in SCD are emotionally, physically, and financially draining for both the caregiver and the patient. Caregivers frequently report elevated rates of anxiety, depression, guilt, and social isolation, psychological sequelae that are directly attributable to the chronic uncertainty and intense caregiving demands associated with SCD (Hoegy *et al.*, 2020; Adewoyin *et al.*, 2015; Alghamdi *et al.*, 2018). These findings highlight the need for integrated psychosocial support services as a component of comprehensive SCD care, not merely for the patient but for the primary caregiver as well. Furthermore, the impact of SCD extends beyond the patient-caregiver dyad to affect household finances, employment, transportation, and daily routines, all of which compound the psychosocial strain experienced by affected families (Kilonzi *et al.*, 2022; Madani *et al.*, 2018).

Theme 1: Misconceptions Surrounding Sickle Cell Disease

The first theme identified in this study concerns the pervasive misconceptions that caregivers hold about the aetiology, transmission, and consequences of SCD. A subset of caregivers incorrectly identified SCD as a communicable disease, a misconception with significant implications for social integration, treatment-seeking, and the potential for stigmatisation of affected children. The persistence of this belief in the study population is consistent with findings from analogous settings in sub-Saharan Africa, where scientific health literacy about genetic disorders remains limited due to restricted access to formal education and healthcare communication (Tusuubira *et al.*, 2018). Reassuringly, the majority of caregivers correctly identified SCD as a hereditary, non-transmissible condition, a finding that reflects at least a baseline level of genetic literacy within the study population, likely attributable to prior exposure to healthcare worker counselling during clinic visits.

A further misconception identified was the belief that SCD impairs intellectual functioning in affected children. Although chronic pain and recurrent hospitalisations may indeed affect concentration, school attendance, and academic performance, thereby creating an appearance of cognitive underperformance, the direct neurological complications of SCD (such as silent cerebral infarcts) are the primary drivers of any demonstrable cognitive effects (Buser *et al.*, 2021a). Caregivers who attribute intellectual difficulties to the disease itself, rather than to its manageable complications, may adopt a fatalistic stance towards their child's educational potential, limiting investment in schooling and rehabilitation. These attitudinal barriers underscore the critical importance of accurate, accessible health education that addresses specific misconceptions, delivered in culturally appropriate formats and local languages by trained community health workers.

Theme 2: Cultural and Spiritual Interpretations of SCD

The second theme pertains to the influence of cultural and spiritual belief systems on how caregivers interpret the aetiology and prognosis of SCD. A significant proportion of caregivers in this study attributed the origin of SCD to supernatural forces, including ancestral curses, malevolent spiritual entities, or divine punishment, while others adhered to biomedical explanatory frameworks. This coexistence of multiple aetiological belief systems within a single community is a well-documented phenomenon in sub-Saharan African health contexts and has profound implications for the acceptability of biomedical treatments (Al-Azri *et al.*, 2016; Tusuubira *et al.*, 2018; Lelo *et al.*, 2023a; Reader *et al.*, 2020). Caregivers who locate the cause of their child's illness within a supernatural framework may prioritise traditional or religious healing modalities over evidence-based medical treatment, resulting in delayed presentation, treatment interruption, or outright non-adherence.

This study also documented caregiver anxieties regarding the reproductive capacity of children with SCD, with some participants expressing the belief that individuals with SCD are incapable of reproduction. While SCD can indeed affect reproductive function, particularly in males, through mechanisms such as priapism and testicular atrophy, it does not necessarily render individuals infertile, and affected individuals can and do have children (Tusuubira *et al.*, 2018). The propagation of this misconception may discourage caregivers from investing in the long-term wellbeing and social development of affected children, reinforcing a fatalistic orientation that undermines both treatment adherence and quality of life.

An important subsidiary theme within this cultural domain concerned the social integration of children with SCD. Most caregivers expressed a desire for their affected children to participate fully in family and community life, attending school, engaging in social activities, and forming peer relationships, an attitude that is both psychologically beneficial for the child and consistent with evidence-based recommendations for promoting normal development in chronic illness (Mulumba and Wilson, 2015). A

smaller subset of caregivers, however, held more restrictive views rooted in cultural or spiritual concerns, believing that social exposure might expose their child to harmful influences. Addressing these tensions through community-level dialogue and culturally sensitive counselling is essential to promoting the social inclusion of children with SCD.

Theme 3: Socioeconomic Determinants of SCD Perceptions

The third theme illuminates the role of socioeconomic status in shaping how caregivers perceive and respond to SCD. Research consistently demonstrates that socioeconomic stratification influences not only material access to healthcare but also the cognitive frameworks through which illness is understood, managed, and communicated (Hoegy *et al.*, 2022; Reader *et al.*, 2020; Wesley *et al.*, 2016). Caregivers with greater economic resources were better positioned to access specialist medical services, obtain medications, and seek timely care during acute crises, advantages that translate directly into more favourable clinical outcomes and a more biomedically informed understanding of the condition. Conversely, caregivers experiencing economic hardship were more likely to rely on informal, community-based explanatory models, including supernatural frameworks, in the absence of consistent engagement with the formal healthcare system.

This study found that a notable proportion of caregivers held the view that SCD predominantly affects children from impoverished and less educated backgrounds, while positing that wealthier and more educated families would be protected from the condition. While this perception is understandable given the strong empirical association between socioeconomic deprivation and adverse SCD outcomes, it fundamentally misrepresents the genetic aetiology of the disease: SCD affects individuals across all socioeconomic strata, though its consequences are mediated by the degree of access to prevention, treatment, and support services (Madani *et al.*, 2018). Correcting this conflation between genetic vulnerability and socioeconomic causation is an important educational objective, as it may otherwise reinforce stigma and divert attention from the structural inequities that drive differential outcomes. Divergent views on the treatability

of SCD, with some caregivers believing the disease is amenable to cure while others considered it beyond medical intervention, were also documented. The latter belief, in particular, poses a significant threat to sustained treatment engagement and underscores the importance of clear, honest communication from healthcare providers about the nature of SCD as a manageable, though currently incurable, condition.

Theme 4: Perceived Severity, Prognosis, and Psychosocial Impact

The fourth and final theme concerns caregivers' perceptions of the severity and prognosis of SCD, as well as the broader psychosocial impact of the condition on affected children and their families. Several caregivers in this study articulated deep anxieties about the life expectancy of their affected children, with some expressing the belief, still prevalent in many communities across sub-Saharan Africa, that individuals with SCD rarely survive beyond the age of 21 years (Anie *et al.*, 2010). While this belief was historically more empirically grounded in settings where SCD care was absent, advances in comprehensive SCD management, including newborn screening, prophylactic penicillin, hydroxyurea, and haematopoietic stem cell transplantation, have significantly extended life expectancy in well-resourced settings. The persistence of this pessimistic prognosis among caregivers reflects a knowledge gap that may engender hopelessness, reduce investment in preventive care, and compromise caregiver mental health. Providing caregivers with accurate, hopeful, and evidence-informed information about contemporary SCD management and life expectancy is therefore a critical component of psychosocial support.

The theme of genetic testing and screening for sickle cell trait elicited mixed responses from caregivers. Some expressed anxiety about the potential for their child to be labelled or discriminated against based on their sickle cell status, while others welcomed genetic screening as an opportunity to inform family planning decisions and optimise health management. These divergent reactions reflect the complex interplay between clinical utility, social stigma, and individual autonomy that characterises the ethics of genetic disclosure in African healthcare contexts. The findings of this theme collectively

emphasise the pressing need for culturally responsive, community-anchored approaches to SCD education and counselling approaches that address indigenous belief systems with respect and empathy while providing accurate scientific information that enables caregivers to make informed decisions about their children's health (Al-Azri *et al.*, 2016; Buser *et al.*, 2021a; Lelo *et al.*, 2023a; Wesley *et al.*, 2016).

Assessment of caregiver knowledge of SCD constituted a central objective of this study, given its well-established relationship with treatment adherence, care-seeking behaviour, and patient outcomes. The findings reveal significant heterogeneity in knowledge levels across the caregiver population: overall, 73% of female caregivers and 53.3% of male caregivers demonstrated adequate knowledge about SCD. This differential by sex is noteworthy and suggests that female caregivers, by virtue of their more intensive engagement with the healthcare system and their primary responsibility for child health management, are exposed to greater informational inputs regarding SCD. The findings are broadly comparable to those reported by Oluwole and Adeyemo (2021) in Nigeria, where 76% of respondents demonstrated knowledge of SCD. However, both studies fall considerably short of the near-universal knowledge levels documented in some earlier investigations, notably Odunvbun *et al.* (2008), who reported 98% caregiver knowledge in Nigeria, and Lang *et al.* (2009), who documented knowledge in 96% of mothers in Illinois, USA. These discrepancies likely reflect differences in study methodology, caregiver sampling strategies, and the definition of knowledge thresholds employed across studies, as well as genuine variation in the effectiveness of health education programmes across different settings.

The primary sources of SCD knowledge in comparable studies have been identified as healthcare providers, family members, peers, the internet, and mass media (Famuyiwa and Aina, 2010; Oluwole and Adeyemo, 2021). Given that all participants in the present study were recruited from formal healthcare settings and had therefore experienced at least some exposure to clinical health education, it is plausible that healthcare workers constituted the primary knowledge source for this population. Nevertheless, the finding that fewer than three-quarters of caregivers demonstrated adequate SCD knowledge,

despite their clinic engagement, suggests that health education delivered in formal healthcare settings may be insufficiently targeted, comprehensible, or reinforced to produce lasting knowledge gains. The gap between clinic exposure and demonstrated knowledge underscores the need for structured, repeated, and iterative health education approaches, including the use of community health workers and peer educators, visual communication tools, and regular caregiver support groups.

Specific knowledge deficits identified in this, and comparable studies are particularly concerning. Babalola *et al.* (2019) found that fewer than half of mothers in Ibadan, Nigeria, possessed even a moderate understanding of SCD, and more than 70% were unaware that SCD could precipitate stroke, a life-threatening complication. Similarly, Oluwole and Adeyemo (2021) reported widespread caregiver anxiety about increased stroke risk in SCD children, often rooted in fear rather than informed understanding. These findings confirm that knowledge gaps extend beyond basic disease recognition to encompass critical clinical complications, prognosis, and evidence-based management strategies. The heterogeneity in knowledge regarding SCD's developmental consequences, particularly its neurocognitive impact, further reflects the inadequacy of current health information dissemination strategies, particularly given that most knowledgeable caregivers in the current study appear to have obtained information from non-clinical sources.

5.1.10 Predictors of SCD Knowledge among Caregivers

Logistic regression analyses conducted in this study identified several significant predictors of caregiver knowledge about SCD and its associated crises. Female gender was associated with increased log-odds of moderate/high knowledge across both simple and multiple regression models, though this association was not statistically significant in the final adjusted model (P = 0.7519). This finding is directionally consistent with the observed descriptive difference in knowledge by sex and with the broader literature, which identifies women's more active health-seeking behaviour and greater healthcare system engagement as drivers of superior health literacy in comparable caregiver

populations (Al-Qattan *et al.*, 2019; Gyamfua *et al.*, 2019; Tusuubira *et al.*, 2018a). The social role of women as primary caregivers, combined with their more frequent interaction with healthcare providers during antenatal and paediatric care visits, provides additional informational exposures that accumulate into higher knowledge levels over time.

Educational attainment emerged as a significant predictor of caregiver knowledge in the unadjusted models: secondary-level education ($\beta = 0.8027$; $P = 0.0467$) and college/university-level education ($\beta = 4.2360$; $P < 0.0001$) were both significantly associated with higher odds of moderate/high SCD knowledge relative to primary education in Model 3. These associations attenuated to non-significance in the fully adjusted multiple logistic regression model, likely due to the confounding effects of income which is itself strongly correlated with educational attainment. Nevertheless, the direction and magnitude of these associations reinforce the established understanding that higher education facilitates greater health literacy, better comprehension of biomedical information, and more effective navigation of healthcare systems, all of which are antecedents of superior disease knowledge (de Jesus *et al.*, 2018).

Monthly income was the strongest and most robust predictor of SCD knowledge in both the simple ($\beta = 4.2430$; $P < 0.0001$) and multiple logistic regression ($\beta = 4.3350$; $P < 0.0001$) models. This finding is clinically and epidemiologically significant, as it suggests that economic empowerment, through mechanisms such as improved employment, financial literacy, and access to healthcare resources, is a powerful lever for improving SCD knowledge and, by extension, care quality. Married status was significantly associated with reduced log-odds of moderate/high knowledge in the final adjusted model ($\beta = -2.7080$; $P = 0.0009$), a counterintuitive finding that merits further investigation. One possible explanation is that married caregivers may delegate healthcare decision-making and information-seeking to their spouses or extended family members, resulting in reduced individual engagement with health education activities. Alternatively, the demands of marital and family responsibilities may limit the time available for engagement with healthcare providers and educational resources. This

unexpected finding highlights the importance of disaggregating caregiver characteristics in SCD research to identify subgroups that may require tailored educational outreach.

5.1.11 Implications for Policy and Practice

The findings of this study converge on several urgent imperatives for policy, clinical practice, and community health programming in relation to paediatric SCD in Nairobi County and analogous low-resource settings. First, the high prevalence of SCD in the assessed facilities, combined with the documented poverty and low educational attainment of caregivers, calls for the systematic integration of SCD into Kenya's national health financing and social protection frameworks. Ensuring that essential SCD medicines, including prophylactic penicillin, folic acid, and hydroxyurea, are consistently available at public health facilities and covered under the national health insurance scheme is a foundational step toward equitable access.

Second, the significant knowledge deficits and misconceptions documented among caregivers necessitate a substantial investment in targeted, evidence-based health education programmes. These programmes should be designed with cultural competence, delivered in local languages, and reinforced through multiple modalities, including community health worker outreach, peer educator networks, and mobile health (mHealth) platforms. Given the finding that female gender and higher income are the strongest predictors of SCD knowledge, educational interventions should specifically prioritise the engagement of male caregivers and economically marginalised households to address the existing knowledge disparities.

Third, the psychosocial burden experienced by caregivers, including anxiety, depression, and social isolation, demands dedicated attention within the framework of comprehensive SCD care. Integrated mental health and psychosocial support services, including structured counselling and peer support groups for caregivers, should be incorporated into SCD clinic programming. Fourth, the nutritional vulnerabilities of children with SCD identified in this study call for the routine incorporation of

anthropometric assessment and dietary counselling into SCD clinical reviews, alongside community-based nutritional support initiatives for food-insecure families. Finally, addressing the structural determinants of poor SCD outcomes, including poverty, educational disadvantage, geographic barriers to care, and inadequate healthcare infrastructure, requires multi-sectoral collaboration between the health sector, education, social welfare, and community organisations, oriented towards a health equity framework.

5.1.12 Study Limitations

Several limitations of the present study merit acknowledgement. The study was conducted across three health facilities in Nairobi County, which may limit the generalisability of the findings to other geographical, cultural, and healthcare contexts within Kenya and sub-Saharan Africa. The cross-sectional design employed for the quantitative component precludes causal inferences about the relationships observed between sociodemographic factors and knowledge or clinical outcomes; longitudinal studies would be better positioned to elucidate temporal relationships and the direction of effect. Additionally, self-reported caregiver responses, particularly regarding treatment adherence and knowledge, are susceptible to social desirability bias, which may have led to overestimation of adherence and knowledge levels. Future research should employ mixed-methods longitudinal designs with objective adherence measures and validated knowledge instruments to address these limitations.

5.2 Conclusions

Based on the study findings, the following conclusions were drawn.

1. The proportion of sickle cell crises among children with SCD aged 15 years and below attending the three health facilities in Nairobi County was disproportionately high, with approximately 84% of the study population having experienced at least one crisis. This finding underscores the substantial clinical

burden of SCD in the paediatric population and highlights the urgent need for targeted interventions to reduce crisis frequency and its associated morbidity among affected children and their caregivers.

2. The majority of parents and caregivers of paediatric SCD patients were female, aged between 26 and 30 years, had attained only primary-level education, were married, and were engaged in subsistence or low-income occupations earning less than KSh 10,000 per month, residing in single-roomed rented dwellings. These sociodemographic and socioeconomic profiles indicate that a significant proportion of affected families are economically vulnerable, which likely constrains their capacity to access healthcare, afford medications, and sustain consistent disease management for their children.
3. Adherence to recommended treatment requirements among paediatric SCD patients was variable across the three health facilities, with notable gaps observed among both caregivers and healthcare providers. This inconsistency in treatment adherence is of significant concern, as suboptimal compliance with prescribed regimens, including hydroxyurea, prophylactic antibiotics, and routine follow-up, is a well-established precipitant of sickle cell crises, and its presence in this study population likely contributed to the high crisis burden observed.
4. While most parents, caregivers, and patients demonstrated generally positive attitudes and favourable perceptions towards SCD management, their overall level of knowledge about the disease, including its aetiology, triggers, and management strategies, was low. This discordance between attitudes and knowledge suggests that positive disposition alone is insufficient to drive appropriate disease management behaviours, and that knowledge gaps may have been a contributing factor to suboptimal treatment adherence observed in this population.
5. Statistically significant associations were identified between sickle cell crises and several sociodemographic and socioeconomic factors, level of knowledge, attitudes and perceptions, and treatment adherence among the study population. These findings confirm that sickle cell crises in paediatric patients are

multifactorial in nature, influenced by an interplay of individual, family-level, and healthcare system factors, rather than by any single determinant. Addressing these factors collectively is therefore essential to reducing the burden of crises in this population.

Therefore, all the research questions formulated in this study were answered accordingly.

5.3 Recommendations

The following recommendations were made based on the study conclusions, and are directed at policymakers, healthcare managers, clinicians, and community health stakeholders:

1. Given the alarmingly high proportion of crises (~84%) recorded in this study, county and national health authorities should prioritise the development and implementation of comprehensive paediatric SCD crisis prevention programmes at the facility and community levels. These programmes should incorporate early warning systems, regular clinical review schedules, and emergency response protocols to reduce crisis-related hospitalisations and complications.
2. Health facilities and policymakers should adopt a socially responsive approach to SCD management by integrating social welfare assessments into routine SCD clinic visits. Financial support mechanisms, such as subsidised medications, health insurance enrolment, and linkage to social protection programmes, should be made accessible to economically vulnerable caregiving families. Additionally, targeted community sensitisation campaigns should be designed to actively engage male caregivers and fathers, who were notably underrepresented in the study population, to promote shared responsibility in the care of children with SCD.

3. Given the low educational attainment recorded among caregivers, health communication materials and educational interventions should be designed at appropriate literacy levels, utilising visual aids, local languages, and community health workers to ensure accessibility and comprehension among low-literacy populations. Healthcare managers at the three facilities and beyond should implement structured adherence support programmes for both caregivers and healthcare providers. These should include regular caregiver counselling sessions, adherence monitoring tools such as medication diaries or mobile health reminders, and refresher training for healthcare professionals on evidence-based SCD management protocols.
4. Nutritional assessment and growth monitoring should be formally incorporated into all paediatric SCD clinic visits, enabling early identification of failure to thrive and facilitating timely nutritional interventions, which are critical components of holistic SCD crisis prevention. The gap between positive attitudes and low disease knowledge identified in this study calls for the implementation of structured patient and family education programmes within SCD clinics. These programmes should address disease aetiology, common crisis triggers, medication adherence, dietary requirements, hydration, infection prevention, and the importance of routine follow-up, thereby translating favourable attitudes into informed and effective caregiving behaviours.
5. Lay counselling services should be integrated into the SCD care pathway to reinforce caregiver knowledge, address misconceptions, and provide psychosocial support, particularly for caregivers experiencing distress related to the chronic nature of the disease.
6. Since sickle cell crises were found to be associated with a constellation of sociodemographic, socioeconomic, knowledge-related, attitudinal, and adherence-related factors, a multidisciplinary care model encompassing physicians, pharmacists, nurses, nutritionists, social workers, and community health volunteers should be institutionalised in facilities managing paediatric

SCD patients. This integrated approach is more likely to address the full spectrum of crisis determinants than single-domain clinical interventions alone.

7. Future research should employ longitudinal study designs to establish the temporal and causal relationships between the identified factors and sickle cell crises and should explore the effectiveness of specific interventions targeting the determinants identified in this study.

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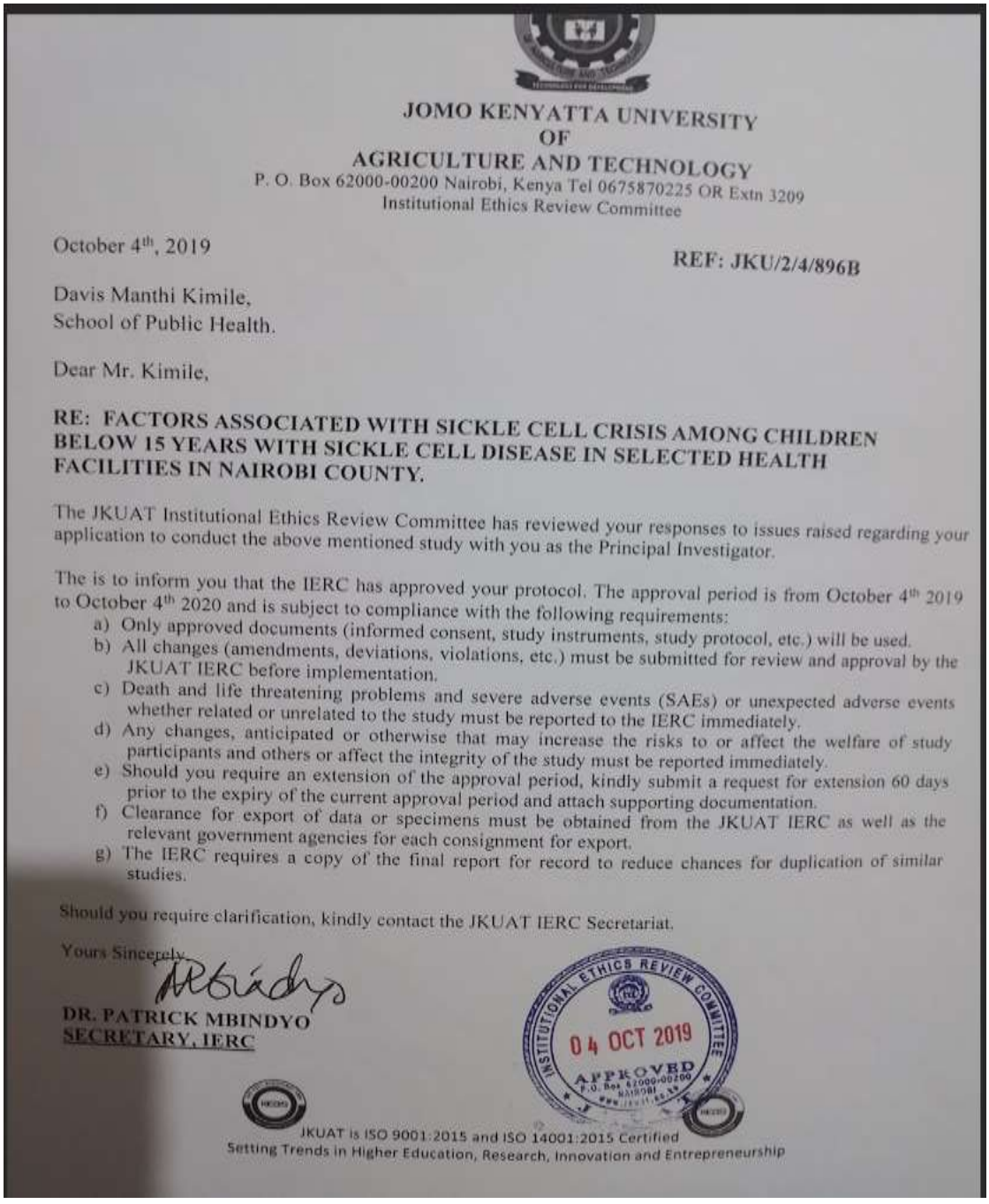
APPENDICES

Appendix I: Ethical Approval



JOMO KENYATTA UNIVERSITY
OF
AGRICULTURE AND TECHNOLOGY
P. O. Box 62000-00200 Nairobi, Kenya Tel 0675870225 OR Extn 3209
Institutional Ethics Review Committee

October 4th, 2019

REF: JKU/2/4/896B

Davis Manthi Kimile,
School of Public Health.

Dear Mr. Kimile,

RE: FACTORS ASSOCIATED WITH SICKLE CELL CRISIS AMONG CHILDREN BELOW 15 YEARS WITH SICKLE CELL DISEASE IN SELECTED HEALTH FACILITIES IN NAIROBI COUNTY.

The JKUAT Institutional Ethics Review Committee has reviewed your responses to issues raised regarding your application to conduct the above mentioned study with you as the Principal Investigator.

The is to inform you that the IERC has approved your protocol. The approval period is from October 4th 2019 to October 4th 2020 and is subject to compliance with the following requirements:

a) Only approved documents (informed consent, study instruments, study protocol, etc.) will be used.
b) All changes (amendments, deviations, violations, etc.) must be submitted for review and approval by the JKUAT IERC before implementation.
c) Death and life threatening problems and severe adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the IERC immediately.
d) Any changes, anticipated or otherwise that may increase the risks to or affect the welfare of study participants and others or affect the integrity of the study must be reported immediately.
e) Should you require an extension of the approval period, kindly submit a request for extension 60 days prior to the expiry of the current approval period and attach supporting documentation.
f) Clearance for export of data or specimens must be obtained from the JKUAT IERC as well as the relevant government agencies for each consignment for export.
g) The IERC requires a copy of the final report for record to reduce chances for duplication of similar studies.

Should you require clarification, kindly contact the JKUAT IERC Secretariat.

Yours Sincerely,

DR. PATRICK MBINDYO
SECRETARY, IERC

INSTITUTIONAL ETHICS REVIEW COMMITTEE
04 OCT 2019
APPROVED
P.O. Box 62000-00200 NAIROBI

JKUAT is ISO 9001:2015 and ISO 14001:2015 Certified
Setting Trends in Higher Education, Research, Innovation and Entrepreneurship

Appendix II: Authorization to Conduct this Research at the German Hospitals

GERMAN DOCTORS
HELP THAT LASTS

Children Sickle Cell Foundation

GERMAN DOCTORS NAIROBI
P.O. BOX 1699-00621 VILLAGE MARKET
MATHARE 4A, MATHARE VALLEY, NAIROBI
TEL: 0748 680 020, 0715 994 604
Email: info@germandoctorsnairobi.co.ke
Website:www.germandoctorsnairobi.co.ke

4th January 2020

RE: ACCEPTANCE LETTER TO CONDUCT RESEARCH.

Dear Davis Kimile,

I am pleased to inform you that your request to conduct research on "**factor associated with sickle cell crisis among children below 15 years wit sickle cell disease in selected health facilities in Nairobi county,** has been approved by hospital management and the Children Sickle cell Foundation Nairobi. You are allowed to collect Data on Sickle cell disease for period of three months (From January 2020 to March 2020) and required to consider participants ethical issues.

We hope your project brings growth and development in the Country.

Thank You,

Signed for and on behalf of
German Doctors Nairobi

George O. Audi
General Manager

www.germandoctorsnairobi.co.ke Mobile: **0728 88 63 22** email: gm@germandoctorsnairobi.co.ke

Appendix III: Study Information and Participants' Consent

Research Title: Factors Associated with Sickle Cell Crisis among Sickle Cell Disease Patients Aged 15 Years and Below in Three health facilities in Nairobi County

Introduction

Dear participant, I am Davis Kimile, a Master of Science degree student at Jomo Kenyatta University of Agriculture and Technology. This study aims at determining the factors associated with sickle cell crisis among sickle cell disease patients aged 15 years and below in three health facilities in Nairobi County. This study focuses on determining the proportion of children with sickle cell crisis among SCD patients aged 15 years and below, the sociodemographic and socioeconomic characteristics of parents and caregivers of SCD patients aged 15 years and below, the level of adherence to treatment among SCD patients aged 15 years and below, and the parents'/caregivers' level of knowledge, attitudes, perceptions about SCD in patients aged 15 years and below, in three health facilities in Nairobi County.

Please note that your participation in this study is voluntary and you are free to refuse to participate in this study. Also note that you are free to withdraw your participation at any time during the study, and no prejudice or any consequences will me meted on you. Besides, this study does not offer direct or immediate benefits, including financial gain, by virtue of participating in this study. However, your participation and the findings of this study may help influence policies that may provide welfare packages for children with sickle cell disease, and influence the introduction of SCD self-care management in genetic counselling which may in the long run help improve the health of children with SCD.

If you agree to participate in this study, you will be asked to answer some questions on your age, marital status, educational level, estimated monthly income, your knowledge levels, attitudes, perceptions, and beliefs about SCD and affected children (≤15 years

old), and adherence to medication requirements. This exercise will take about 30 minutes of your time.

Furthermore, any information you provide will be kept confidential and anonymous and will only be used for this academic research only.

Contacts and Questions

You may ask any questions you have now. Or if you have questions later, you may contact the researcher on 071262152 or daviskimile@yahoo.com. If you want to talk privately about your rights as a participant, you can call the sickle cell disease patients' welfare officer vide 0724443118.

Participants' Consent

If you feel you understand the study well enough to decide about it, please indicate your consent by signing below:

Participant's Signature…….

Researcher's Signature…….

Date of consent…….

Appendix IV: Study Questionnaires

Questionnaire 1: Sociodemographic and Socioeconomic characteristics of parents and caregivers of children below 15 years with SCD at three health facilities in Nairobi County.

Please select one response only to each of the following questions. Please answer all questions on the survey to the best of your knowledge. There are no wrong or right answers. Thank you very much for your time.

1. Participant's Code……

2. Age of Child……..

3. The child's sex (put √ when applicable)

Male □ Female □

4. Child Education: Primary school □ Secondary school □ College/University □

5. Formal Educational level for Parent/Caregiver

(a) None□ (b) Primary □ (c) Secondary □ (d) Tertiary □

6. The Parents/Care givers Age ……

7. The Caregivers Sex. Male □ Female □

8. Married Status: Single □ Married □ Divorced □ Widow □

9. Occupation: Peasant □ Employed □

10. What is the range of your income per month?

(a) 0-5000/-

(b) 5001- 10,000/-

(c) 10,001- 15,000/-

(d) 15,001- 20,000/-

(e) More than 20,000/-

11. What is family expenditure on medical bill?

a) Below 5000/- □ b) 5001-10000/- □ c) 10001-15,000/-□ d) above 15,001.-

11.How many children do you have?

(a) None □ (b) One □ (c) Two □ (d) Three □ (e) Four or more □

12. What type of housing do you live in?

(a) Self owned house

(b) Rented house

(c) Other, (specify)…….

13.What is number of rooms of your house?

(a) One

(b) Two

(c) Three

(d) Other, (specify)…….

14. On the scale of 1 to 5, with 1 being least engaged while 5 highly engaged, indicate your level of individual effort on the below listed statements.

In a week, how many times do you take the listed meals?	0	1	2	3	4	5
I. Eat at least Five servings of fruits and Vegetables each day						
II. I often eat staple like cereals (wheat, rice etc) tubers and roots (potato, yams,) and legumes. (Calories)						
III. Food from animal sources(meat, Fish, eggs, milk)						
IV. I often try to reduce fat in my diet						

15. How many litres of water do you drink in a day?(a)More than 2 litres daily □ (b) 1-2 liters daily □ (c) Less than 1 liter daily □ (d)others specify…….

Questionnaire 2: Level of treatment adherence among children below 15 years with sickle cell disease at three health facilities in Nairobi County

Please provide the most accurate answer to the following questions.

Part A: How often do you ensure that your child with sickle cell disease adheres with the following.

		Always	sometimes	Never
I.	Take penicillin.			
II.	Take proguanil.			
III.	Sleep under insecticide treated bed nets?			
IV.	Avoid very warm or cold temperatures?			
V.	Drink at least 8 glasses of water daily?			
VI.	Take folic acid supplements?			

Part B: What Factors/reasons that hinder you from adhering to medication recommendations.

		Always	sometimes	Never
I.	Forgetiveness			
II.	Difficulty getting medication			
III.	Time constraint/Busy			
IV.	Cost of medication			
V.	side effects			

Questionnaire 3: Health Care providers prescription/follow up information to the patient

Please respond to each question indicating YES or NO

i)Was the Prescription filled at the Pharmacy?	Yes □ No □
ii)Were the Following drugs administered/procedures Adhered to properly?	
a) Antimetabolites (Hydroxyurea)	Yes □ No □
b) Analgesics (Hydromorphone)	Yes □ No □
c) Antibiotics(penicillin)	Yes □ No □
d) Vaccines	Yes □ No □

e) Nutritional agents(Folic acid) f) Others…….	Yes □ No □
iii)Factors influencing adherence to Medication	
a) The prescribed drugs are picked by the Care giver b) Availability of drugs c) Regular patient visitation to the facility Clinic d) Others……	Yes □ No □ Yes □ No □ Yes □ No □
iv)Side effects of the administered medication a) Difficulty in breathing	Yes □ No □

b)	Abdominal swelling	Yes □ No □
c)	Fever and Vomiting	Yes □ No □
d)	High blood pressure	Yes □ No □
e)	Tiredness/Fatigue	Yes □ No □
f)	Irritability of Body	Yes □ No □
g)	Dizzness and Lightheadechness	Yes □ No □

v) Most Frequent sickle cell crisis in patients	Response	Severity
a) Acute chest pain	Yes □ No □	Severe □ Mild/Moderate □
b) Abdominal pain	Yes □ No □	Severe □ Mild/Moderate □
c) Joint pain	Yes □ No □	Severe □ Mild/Moderate □
d) Bone pain	Yes □ No □	Severe □ Mild/Moderate □
e) Others Specify…….		

Please respond to each question indicating True or False

1. Sickle cell disease is an infectious disease.

(a) True □ (b) False □

2. Sickle cell disease makes a child less intelligent.

(a)True □ (b) False

3. Sickle cell disease is an ancestral spirit.

(a) True □ (b) False □

4. Sickle cell disease affects only the poor people.

(a) True□ (b) False

5. Sickle cell disease affects less educated people.

(a) True □ (b)False □

6. Sickle cell disease is curable.

a) True □ (b) False □

7. People with sickle cell disease often die before 21 years.

(a) True□ (b) False □

8. People with sickle cell disease cannot have children.

(a) True □ (b) False □

Please respond to each question indicating Strongly agree, Agree, Neither agree or disagree, Disagree, Strongly disagree

10. I believe that sickle cell disease is not a serious condition.

(a) Strongly disagree □
(b) Disagree □
(c) Neither disagree nor agree □
(d) Agree □
(e) Strongly agree □

11. I believe having a child with sickle cell disease is a curse to the family.

(a) Strongly disagree □
(b) Disagree □
(c) Neither disagree nor agree □
(d) Agree □
(e) Strongly agree □

12. I think people should be automatically tested for SC trait before reaching child bearing age.

(a) Strongly disagree □
(b) Disagree □
(c) Neither disagree nor agree □
(d) Agree □
(e) Strongly agree □

13. I think people with SCD should not be allowed to socialize with other family members and society.

(a) Strongly disagree □
(b) Disagree □
(c) Neither disagree nor agree □
(d) Agree □ (e) Strongly agree □

Questionnaire 4: Knowledge on sickle cell crises among parents and caregivers at three health facilities in Nairobi county

1) Do you know about sickle cell disease? (a) Yes □ Go to 5 (b) No

2. If yes, tick what you know about sickle cell disease

a. Sickle cell disease is infectious disease □
b. Its inherited form of Anaemia □
c. Its sexually transmitted □
d. Transmitted through blood contact □

3.) How frequent does your child suffer SCD crisis monthly?

(a) Once Monthly □
(b) Twice a month □
(c) Three times a month □
(d) > four times a month

4.) How often do you attend scheduled appointments at the pediatric sickle cell clinic, and receive SCD management advice from your healthcare provider

(a) Once a week □
(b) Once a Month □
(c) Whenever child falls sick □
(d) Others (specify) _____

5.) What type of Sickle Cell Disease does your child have?

(a) HbSS □ (b)HbSC □ (c) HbS-beta thalassemia □ (d) do not know □

6. On the scale of 1 to 5, with 1 being least engaged while 5 highly engaged, indicate your level of individual effort on the below listed statements.

How often do you practice the Following?	0	1	2	3	4	5
Give Folic acid supplements daily and choose health diet.						
Give adequate water						
Avoid temperatures extreme (hot >25.5) (Cold <17.0)degree celcius						
Exercise, regularly but don't overdo it						
Give over the counter medication						

7) Are the following symptoms/complications of Sickle Cell Disease?. (*Please tick √ Yes or No)*

a) Anaemia Yes □ No □

b) Pains(Joint, Bone, Abdominal) Yes □ No □

c) Stroke Yes □ No □

d) Jaundice Yes □ No □

8) Are the following are things that can cause symptoms/complications in children with Sickle Cell Disease.

(*Please tick √ Yes or No)*

a) Dehydration Yes □ No □

b) Changes of Temperatures Yes □ No □

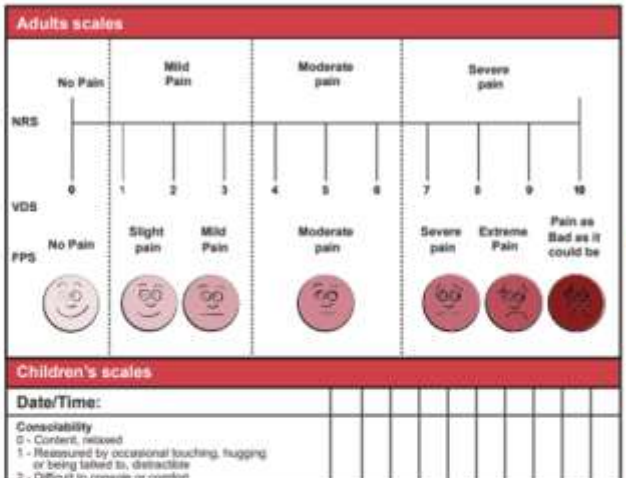
c) Excessive exercises Yes □ No □

d) Infections Yes □ No □

Appendix V: Pain Assessment Tool in SCD

Pain Assessment tool in SCD

NUMERICAL RATING PAIN SCALE AND WONG-BAKER FACES PAIN RAITNG SCALE



Children's scales

Date/Time:										
Consolability 0 - Content, relaxed 1 - Reassured by occasional touching, hugging or being talked to, distractible 2 - Difficult to console or comfort										
Face 0 - No particular expression or smile 1 - Occasional grimace or frown, withdrawn, disinterested 2 - Frequent to constant quivering chin, clenched jaw										
Legs 0 - Normal position or relaxed 1 - Uneasy, restless, tense 2 - Kicking or legs drawn up										
Activity 0 - Lying quietly, normal position, moves easily 1 - Squirming, shifting back and forth, tense 2 - Arched, rigid or jerking										
Cry 0 - No cry (awake or asleep) 1 - Moans or whimpers; occasional complaint 2 - Crying steadily, screams or sobs, frequent complaints										
Total Score										

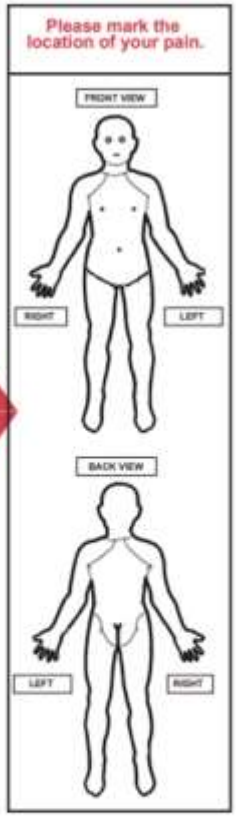


Table 6: Pain Management Based On Severity

PAIN AND APPROPRIATE MEDICAL MANAGEMENT		
MILD	**MODERATE**	**SEVERE**
Reassurance, hot packs, reposition, massage, distraction **Child: paracetamol 15mg/kg qds** **Adult: paracetamol 1g qds**	Treat as Mild pain and ADD Child: Ibuprofen 5mg/kg TDS OR Diclofenac 1mg/kg TDS Adult: Ibuprofen 400mg TDS OR Diclofenac 100mg TDS	Treat as Moderate and ADD Child: Oral morphine** 0.5mg/kg 3-4 hourly as needed Adult: Oral morphine 5-10mg 3-4 hourly as needed

Appendix VI: WHO's National Guidelines on the Control and Management of SCD

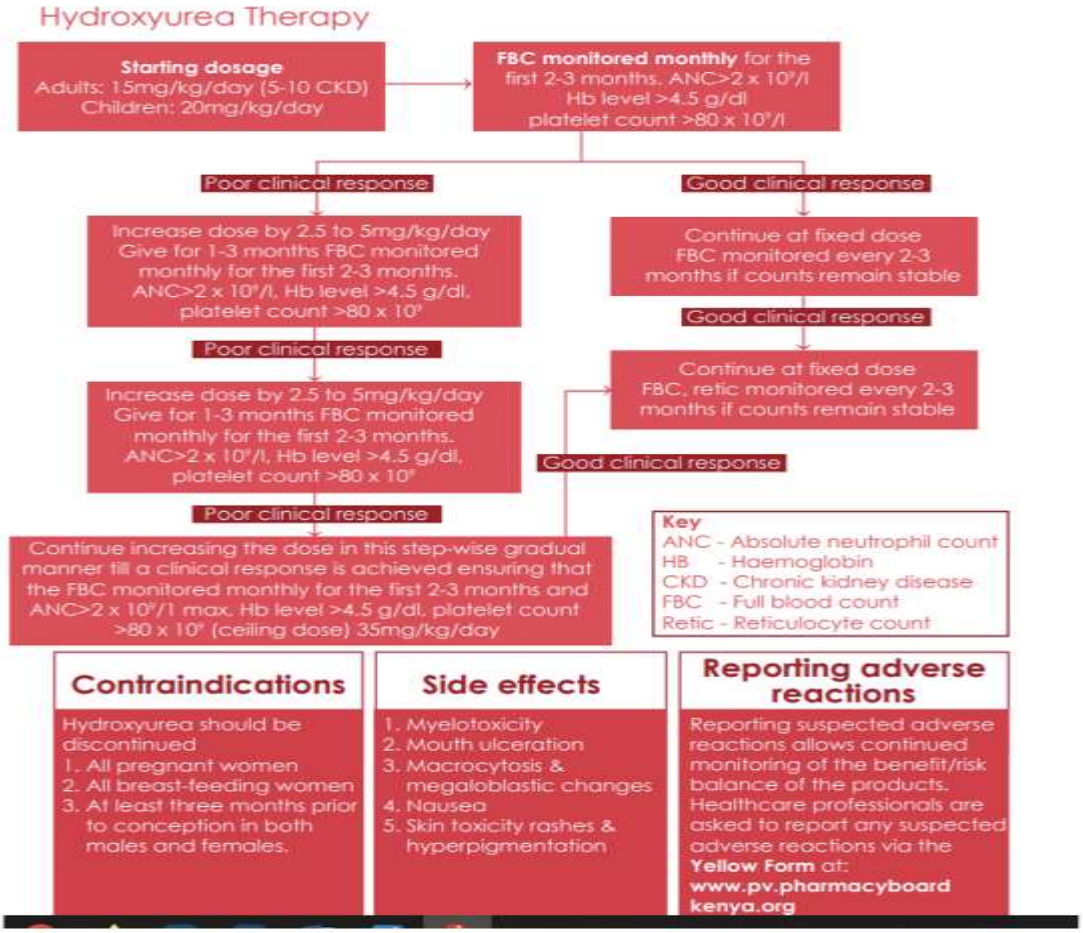


Table 3: Indications for emergency transfusion

Condition	Comment
Acute anaemia (drop in Hb >2g/dl from normal steady state Anemia <5g/dl Symptomatic anemia	Simple transfusion
Acute ischaemic sequestration	Simple transfusion
Acute ischaemic stroke	Exchange transfusion to Hb of 10g/dL, HbS <30%
Acute chest syndrome	Depending on severity: No transfusion, simple or exchange transfusion
Acute priapism	Consider simple or exchange transfusion if no response to initial treatment
Multiorgan failure, acute sickle hepatopathy, severe sepsis	Exchange transfusion to Hb 10g/dL, HbS <30%