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Original Article

Prescription, Compliance and Barriers to Prophylactic Regimen among Children with Sickle Cell Disease at Mama Lucy Kibaki Hospital

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Sickle Cell Disease, Prescription Compliance, Prophylaxis, Barriers, Mama Lucy Kibaki Hospital.

ABSTRACT

Background: Especially in sub-Saharan Africa, sickle cell disease (SCD), a severe hereditary hemoglobinopathy, is a major cause of morbidity and mortality. To lower problems, hospitalizations, and mortality, preventative regimens such as Hydroxyurea (HU), Penicillin V, and folate supplements are essential. Notwithstanding the established advantages, following these regimens is still very difficult, and there is a dearth of information on prescription trends and compliance rates in Kenya. The objective of this study was to assess the trends in prescriptions, adherence levels, and obstacles to adherence among children with sickle cell disease at Mama Lucy Kibaki Hospital. **Methods:** A cross-sectional mixed-methods study was conducted among children with SCD attending Mama Lucy Kibaki Hospital. A total of 144 caregiver-child pairs were recruited using consecutive sampling. Quantitative data were collected using semi-structured questionnaires, while qualitative data were obtained through Focus Group Discussions (FGDs) and Key Informant Interviews (KIIs). Descriptive statistics were used to analyze quantitative data, while qualitative data were thematically analyzed. The study adhered to ethical research standards, with approvals obtained from relevant authorities. **Results:** The most frequently prescribed prophylactic medications were folate (97.9%), penicillin V (86.9%), and hydroxyurea (81.3%). Despite high prescription rates, compliance and dosing accuracy varied. Only 39.3% of children received the correct hydroxyurea dosage, and 70.2% were underdosed on penicillin V. Overall, 66.4% of children were compliant with at least one prophylactic medication. Forgetting (46.5%), not understanding the significance of the drugs, medicine shortages at the institution, and children refusing to take their meds were the most frequently mentioned obstacles to compliance. From provider interviews, challenges such as lack of prescription standardization, limited diagnostic and dosing tools, and inadequate staffing were noted as contributors to poor adherence to national SCD treatment guidelines**.** **Conclusion:** Children with sickle cell disease at Mama Lucy Kibaki Hospital do not always follow their preventive regimens, especially when it comes to antimalarial prophylaxis. Adherence may increase if medication stock-outs are

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addressed, caregiver education is improved, and routine clinic follow-up is reinforced. In environments with limited resources, these results highlight the necessity of focused interventions to enhance SCD outcome.

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INTRODUCTION

Sickle cell disease is an inherited genetic disorder that occurs due to a mutation in the haemoglobin. This mutation leads to the formation of abnormal haemoglobin, haemoglobin S (HbS). This arises when there is a mutation in the beta globin chain resulting in a substitute of thymine with adenine leading to the coding of valine instead of glutamate. Exposure of HbS to oxidative stress results in distortion of the haemoglobin structure and solubility and thus formation of Sickle-shaped red blood cells. This distortion explains the profound clinical manifestations that result from SCD (Inusa et al., 2019).

The incidence of SCD globally is about 5%, however it is on the rise. A systematic review done between 2000 and 2021 showed a global increment of 13.7% in the number of newborns with the disease and the overall growth of people living with SCD to 42.4% (Thomson et al., 2023; WHO, 2024). In Africa, about 300,000 infants are born with SCD and 200000 have Sickle cell anaemia annually (Thomson et al., 2023) The majority of these births, 80%, occur in low resource setups and have limited access to management options (Weatherall, 2011). The majority die before the age of 5 and those who survive, have end organ damage and thus a shortened life span. In Kenya, the majority die undiagnosed under the age of 5 due to a lack of routine screening protocols (Guedenon et al., 2022).

Morbidity and mortality in SCD are mainly due to acute and long-term effects of vaso-occlusion and hemolysis which are irreversible once tissue infarction and vasculopathy have occurred (Ochocinski et al., 2020). Therefore, the timely introduction of prophylaxis medications among children with SCD plays a huge role in reducing mortality and morbidity. The use of hydroxyurea in prophylaxis results in an increase in the production of fetal haemoglobin HbF a2y2 and a decreased production of adult haemoglobin HbA a2b2 (Pourfarzad et al., 2013). This prolongs the life span of red blood cells by reducing the formation of Sickle red blood cells, improving red cell hydration, decreasing hemolysis and reducing red blood cell adhesion to the endothelium (Inusa et al., 2019). As a result, blood flow through the microcirculation is

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improved and vasoocclusive crises are less likely to occur (Ochocinski et al., 2020), (Yasara et al., 2021). Apart from reducing vasooclusive crises, the REACH trial showed that hydroxyurea also reduces the frequency of blood transfusions and infections in SCD patients which also play a major role in morbidity and mortality of SCD patients (McGann et al., 2018) (Battersby et al., 2010).

Daily doses of prophylactic Penicillin V and vaccination with the pneumococcal conjugate vaccine have remarkably reduced incidences of pneumococcal disease in SCD patients (Oligbu et al., 2019). In developed countries with structured early neonatal screening programs and augmented immunisation schedules especially with Pen v and pneumococcal vaccine, less than 1% of cases of bacteremia have been reported (Ochocinski et al., 2020). It is therefore important for healthcare providers to promote the uptake of these medications and to ensure that patients, parents and /guardians understand the importance of compliance. Supplementation with folic acid on a daily basis is recommended globally due to the chronic hemolysis in SCD patients resulting in foliate depletion in the body. (SCD guidelines)

Non-adherence to medications results in serious repercussions some of which include reduced efficacy and effectiveness of the drugs, increased risk of complications such as overwhelming sepsis and a significant increase in health care expenses due to frequent visits and readmission (Hodges et al., 2020). The concepts of intentional vs unintentional adherence are currently lacking in SCD adherence literature. This has resulted in the literature mainly focusing on individual factors contributing to non-adherence while neglecting external influences. Factors contributing to unintentional non-adherence include misunderstanding of medical institutions, the burden of complex treatment regimens, never being offered the drug, removal from the regimen because of a medical team's decision and the quality and strength of the patient-provider relations (Hodges et al., 2020). Understanding these categories of non-adherence could play an important role in helping healthcare providers to fully understand adherence behaviours among SCD patients.

There are limited studies in Sub-Saharan Africa describing the prescription, compliance and barriers to recommended Sickle cell disease medications. Due to the lack of proper effective tracking mechanisms, monitoring compliance with SCD prophylactic medications is a significant barrier and poses a great challenge in most healthcare setups. Existing approaches to assessing and monitoring compliance may not give reliable data on non-adherent clients (Walsh et al., 2014).

This study aims to shed light on various factors such as socio-economic constraints, health care access, patient education and psychosocial factors in order to improve the understanding of barriers to prescription and compliance. This data is essential in advancing the understanding of challenges faced by the pediatric population living with SCD at Mama Lucy Kibaki Hospital in order to improve clinical outcomes, influence healthcare policies, promote the quality of care given to children living with SCD and contribute to the advancement of pediatric care.

MATERIALS AND METHODS

Study Design

This study employed a cross-sectional study design with a mixed-methods approach to evaluate the prescription, compliance, and barriers to prophylactic regimens among children aged between 0-18 years with sickle cell disease (SCD) at Mama Lucy Kibaki Hospital (MLKH). The quantitative component involved structured questionnaires, while the qualitative aspect consisted of Focused Group Discussions (FGDs) and Key Informant Interviews (KIIs).

This design is justified by its ability to concurrently capture quantitative data on prescription, compliance rates and identify associated barriers,

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while also exploring the nuanced caregiver and drug-related factors influencing adherence through qualitative insights.

Study Setting

The study was conducted at Mama Lucy Kibaki Hospital (MLKH), Nairobi, Kenya, a Level 5 public hospital. MLKH is the largest public health facility in Embakasi, serving a catchment population of approximately two million people and a total bed capacity of 150 in-patients and attends to over 48,000 patients annually, The hospital has a specialized pediatric clinic with over 400 registered patients and approximately 70 children with sickle cell disease are reviewed at the hospital per month in both outpatient and inpatient.

Sample Size

The required sample size was determined using Fischer's formula (1998) for prevalence studies, estimating a minimum of 144 children with SCD. The calculation was adjusted based on the expected number of SCD cases at MLKH within the study period to ensure a representative and statistically reliable sample.

Study Population

The study included children aged 0-18 years diagnosed with sickle cell disease, attending either the inpatient or outpatient departments at MLKH. Caregivers of children with SCD are responsible for ensuring adherence to prescribed medications. Healthcare providers, including consultant paediatricians, medical officers, registrars, and clinical officers, who directly participate in managing SCD patients at MLKH.

Inclusion and Exclusion Criteria

Children aged 0-18 years diagnosed with sickle cell disease and receiving care at MLKH, caregivers of children with SCD who consent to participate in the study and healthcare providers involved in SCD management at MLKH were included in the study. Children whose parents/guardians declined to provide informed consent or assent for participation and caregivers or healthcare providers who declined to participate in interviews or discussions were excluded from the study.

Variables

The dependent variables in this study were Prescription practices, Medication compliance levels and barriers to compliance. While independent variables included patient-related factors, caregiver-related factors and healthcare provider factors.

Data Management

Questionnaires were used to collect demographic data, medication use, and compliance levels; and the Modified Morisky Scale was used to evaluate medication adherence. In order to ensure confidentiality, all data was filtered out, kept in digital formats that require a password, and backed up in a secure location. Interview audio recordings were also transcribed and encrypted. Focused group discussions (FGDs) were used to examine patient and caregiver perspectives on medication compliance barriers; Key Informant Interviews (KIIs) were used to obtain expert insights from healthcare providers on prescription trends and systemic challenges; structured. Data accuracy and confidentiality were maintained throughout the process to ensure reliable and valid findings for meaningful interpretation and conclusions.

Statistical Analysis

Using SPSS version 27, quantitative data was analyzed using descriptive statistics like means, frequencies, and standard deviations to summarize patient characteristics; chi-square tests were used to look at relationships between independent variables and compliance levels; for qualitative data, the audio files were transcribed and stored in an encrypted flash disk. Themes and sub-themes were developed in line with the research questions. Common patterns or trends and relevant emerging concepts guided their development and data

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presentation is based on these themes and sub-themes.

Ethical Considerations

Ethical approval was obtained from the Jomo Kenyatta University of Agriculture and Technology (JKUAT) Institutional Ethics Review Committee (ISERC) reference number (JKU/ISERC/02317/1350) The National Commission for Science, Technology, and Innovation (NACOSTI), The reference number {NACOSTI/P/24/39431}, Nairobi County and the MLKH Ethical Review Board. Written informed consent was obtained from caregivers, and children ten years and older were asked to assent. The Kenya Data Protection Act (2019) will be followed to ensure that no identifying information is gathered and that all records are securely stored.

RESULTS.

Sociodemographic Properties

This study included 144 children with their respective caregivers. Males were slightly more at 52.1% compared to females. The majority, 79.9% of the children were taken care of by their mothers with the remaining percentage cared for by their father 13.2%, grandmother 2.8%, stepmother 1.4%, aunt 1.4% or uncle 0.7%. The majority of the participants were under 5 years, 43.1%, and only 5.6% of the participants(n=8) were older than 15 years. Most of the caregivers were casual workers at (36.8%) as compared to unemployment status representing (28.5%) with both self-employed and formal employment having the same distribution of (17.4%) each**.** Among these caregivers, the majority, 46.5% had secondary school level education, 28.5% university level, 22.9% primary school level and 2.1% no formal education.

Clinical Characteristics

Among the participants, 36.1% had done both the sickling test and haemoglobin electrophoresis for diagnosis a lesser percentage, 31.9% had done only haemoglobin electrophoresis, 29.9% had only done the sickling test and 2.1% had attended the clinic on clinical suspicion only. The number of visits to the hospital varied, with 35.4% visiting the hospital every month, 28.5% every 2 months, 22.9% every 3 months and a smaller percentage of 13.2% visiting every 4 months or more. Most of the participants, 78.5% had not received a blood transfusion in the previous 1 year. 69.4% had not missed any follow-up clinic visits, 97.2% had only SCD and no other chronic conditions and 61.1% had experienced a complication related to SCD.

Table 1: Clinical Characteristics

Demographic Information	Response	Count (N)	Percentage (%)
Gender	Male	75	52.1%
	Female	69	47.9%
Diagnostic test used	Both Sickling and Hb electrophoresis	52	36.1%
	Hb Electrophoresis	46	31.9%
	Sickling Test	43	29.9%
	Clinical suspicion only	3	2.1%
Blood transfusion in last one year	Yes	31	21.5%
	No	113	78.5%
Frequent visits to hospital	Every month	51	35.4%
	Every 2 months	41	28.5%
	Every 3 months	33	22.9%
	Every 4 months or more	19	13.2%
Missed clinic in the last 3 months	Yes	44	30.6%

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Demographic Information	Response	Count (N)	Percentage (%)
	No	100	69.4%
A child with any other chronic condition	Yes	4	2.8%
	No	140	97.2%
The child has sickle cell Anemia complication	Yes	88	61.1%
	No	56	38.9%

The Prophylactic Regimen Prescribed among Children With SCD

To establish the prophylactic regimen prescribed for the children diagnosed with sickle cell disease, three types of the regimen were examined and the results are shown below in **Table 2.** The overview indicated most of the children were on the folate regimen as compared to the other two types of the regimen administered. Almost all the children with the SCD condition were on folate dose with 97.9% representing a total of 141 out of the total of 144, for the Pen V dose, 86.8% of the children indicated they were using it while only 19 out of 144 with 13.2% did not. Considering the Hydroxyurea dosage slightly smaller percentage were on this medication with 117 (81.3%). Thus, this indicates that the Hydroxyurea dose was not the most commonly used in this case.

Table 2: Distribution of Prophylactic Regimen Prescribed

Prescribed Regimen	Response	Count	Percentage (%)
Folate	Yes	141	97.9
	No	3	2.1
Penicillin V	Yes	125	86.8
	No	19	13.2
Hydroxyurea	Yes	117	81.3
	No	27	18.7

Prophylactic Regimen Dosages

Table 3 below summarizes dosage results for three medical regimens: Folate, Pen V, and Hydroxyurea, across the varying number of children prescribed to use any of the three regimens. Folate was administered normally to the majority (65.0%), with 15.0% underdosed and 20.0% overdosed. For Pen V, underdosing was predominant (70.2%), while only 29.0% received the correct dosage and 0.8% were overdosed. In contrast, Hydroxyurea showed a more varied distribution: 30.8% normal doses, 32.5% underdoses, and the highest overdose rate at 36.7%. This highlights underdosing as a common issue for Pen V, while Hydroxyurea had the highest significant rate of overdosing across the three drugs. The results indicated that there was a need to establish what challenges or barriers the caregiver goes through towards having their children be underdosed or overdosed.

Table 3: Distribution of the Regimen Dosage

		Dosage		
Regimen	N	Normal	Underdose	Overdose
Folate	140	91 (65.0%)	21 (15.0%)	28 (20.0%)
Pen V	124	36 (29.0%)	87 (70.2%)	1 (0.8%)
Hydroxyurea	117	36 (30.8%)	38 (32.5%)	43 (36.7%)

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The study results also revealed that several challenges and practices among caregivers (as shown in Table 4 below) affected the level of compliance. Nearly half (46.5%) of the respondents admitted to forgetting to administer medication to their children, leading to 64.6% of the caregivers indicating that at some point in the past two weeks, their children could have missed receiving the Hydroxyurea drugs and where 36.1% reported forgetting to bring the medication along when needed. Despite some of these compliance challenges, the majority of the caregivers (98.6%) did not stop giving Hydroxyurea (HU) without consulting a doctor, and thus, 93.1% stated they did not discontinue the medication even when symptoms seemed under control. However, 43.8% expressed feeling hassled about adhering to the drug plan, while 50.0% reported rarely or never forgetting to give HU, with 29.2% experiencing occasional forgetfulness.

To further understand the regimen compliance, education and access to medication are critical for compliance. Thus, the majority of caregivers (92.4%) had been counselled about Hydroxyurea, Folic Acid, and Penicillin V, and the same percentage reported receiving prescriptions during sickle cell clinic visits. However, challenges in accessing medication persist, with only 14.6% obtaining refills from hospital pharmacies, while the rest relied on over-the-counter sources (27.1%) or other chemists/pharmacies (58.3%). This reliance on external sources may increase the risk of inconsistent drug availability or incorrect dosing hence the mentioned cases of overdose or underdose. Additionally, while over half (52.1%) of caregivers administered HU daily as prescribed, 27.1% gave it inconsistently, such as twice or thrice a week and 20.8% diluted the capsule, highlighting potential gaps in understanding correct administration practices.

Table 4: Compliance to Prescribed Prophylactic Regimen

Compliance with the prescribed prophylactic regimen		Frequency	Percentage (%)
Forget to give the child their medication	No	77	53.5
	Yes	67	46.5
On any Days the child did not receive Hydroxyurea	No	51	35.4
	Yes	93	64.6
Stopped giving the child HU without telling your doctor because he/she felt worse after taking it	No	142	98.6
	Yes	2	1.4
Forget to bring along your child's medication	No	92	63.9
	Yes	52	36.1
Do you stop giving him/her HU when you feel symptoms are under control	No	134	93.1
	Yes	10	6.9
Do you feel hassled about sticking to your child's HU drug plan	No	81	56.3
	Yes	63	43.8
Often difficulty in remembering to give the child his/her HU	Never/Rarely	72	50.0
	Once in a while	24	16.7
	Sometimes	42	29.2
	Occasionally	6	4.2
Been counselled about Hydroxyurea, folic acid and Pen-V	No	11	7.6
	Yes	133	92.4
Drugs always prescribed when visiting the sickle cell clinic	No	11	7.6
	Yes	133	92.4
	Hospital Pharmacy	21	14.6

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Where do you typically obtain refills for your child's medication from	Over the counter	39	27.1
	Other pharmacy/chemist	84	58.3
How do you get the correct dose of hydroxyurea?	Give a capsule daily?	75	52.1
	Dilute hydroxyurea capsule?	30	20.8
	Give a capsule twice or thrice a week?	39	27.1

The Compliance to Prescribed Prophylactic Regimen

Using the modified Morisky medication adherence scale the compliance levels of the participants were as follows, 54.2% low, 31.3% medium and 14.6% high.

Table 5: The Compliance to Prescribed Prophylactic Regimen

Response	Frequency (N)	Percentage (%)
Low compliance	**78**	**54.2**
Medium compliance	**45**	**31.3**
High compliance	**21**	**14.6**
Total	**144**	**100.0**

Factors Influencing Compliance

The results in Table 6 revealed that compliance levels for the folic, pen v, and hydroxyurea regimen were significantly influenced by various factors. Considering the Folic regimen, forgetfulness (OR = 3.731, p = 0.009) was a major reason for non-compliance. Financial constraints (OR = 1.840, p = 0.027) also had a significant impact, lack of understanding about why the child needs folic acid (OR = 2.546, p = 0.047) contributed to poor compliance. Additionally, refusal by the child to take the medication (OR = 3.311, p = 0.003) was another major barrier. Other factors like side effects and availability at clinics did not show a strong statistical significance.

For the pen v regimen, forgetfulness (OR = 1.418, p = 0.006) and financial challenges (OR = 1.284, p = 0.008) significantly affected compliance, though to a lesser extent compared to folic acid. A lack of understanding of the medication's purpose was borderline significant (p = 0.062), suggesting that caregiver education could still improve adherence. Child refusal (p = 0.027) also contributed to non-compliance. Interestingly, the unavailability of medication at the clinic did not significantly impact adherence (p = 0.208).

The hydroxyurea regimen showed notable compliance challenges, with forgetfulness (OR = 1.576, p = 0.002) and financial constraints (OR = 2.959, p = 0.007) being significant factors. Lack of knowledge about the medication's importance (OR = 3.031, p = 0.039) was another major reason for non-compliance. Child refusal (OR = 1.992, p = 0.027) and medication unavailability (OR = 1.606, p = 0.008) also played crucial roles. Unlike Pen V, being away from home (OR = 0.856, p = 0.001) was strongly associated with low compliance for hydroxyurea. However, side effects and illness did not significantly affect adherence.

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Table 6: Inferential Analysis of Factors Influencing Compliance

							95% Confidence Interval	
		Estimate	Std. Error	Wald	df	Sig.	Lower Bound	Upper Bound
Dependent variable	Low Compliance = 1	6.648	3.213	4.281	1	.039	1.351	12.945
	Medium Compliance = 2	8.748	3.245	7.269	1	.007	3.589	15.108
Folic Dose	Forgetfulness	3.731	1.424	6.862	1	.009	1.929	6.522
	Lack of finance	1.840	1.057	.631	1	.027	1.033	2.912
	Not knowing the reason for the child taking Folic	2.546	.873	3.440	1	.047	1.145	3.236
	Refusal by the baby	3.311	1.115	8.812	1	.003	1.125	5.496
	No medication at the clinic	.196	.587	.027	1	.069	.131	2.523
	The child was very sick	.628	.976	.413	1	.220	.286	2.541
	You were not home	1.350	1.310	3.218	1	.073	.918	3.917
	Side effects	.641	1.068	.360	1	.149	.453	2.735
Pen V	Forgetfulness	1.418	.975	2.115	1	.006	1.029	2.493
	Lack of finance	1.284	.587	.235	1	.008	1.005	2.266
	Not knowing the reason for the child taking Pen V.	1.138	.449	.831	1	.062	.986	2.309
	Refusal by the baby	.712	.954	4.903	1	.027	.591	1.243
	No medication at the clinic	-1.606	.975	1.588	1	.208	-2.892	3.105
	The child was very sick.	-.189	.844	.032	1	.859	-1.896	2.274
	You were not home	.816	.416	3.766	1	.091	.731	2.081
	Side effects	.874	.830	.720	1	.396	-1.145	2.894
Hydroxyurea	Forgetfulness	1.576	.576	.997	1	.002	1.054	2.905
	Lack of finance	2.959	.782	1.503	1	.007	1.574	3.492
	Not knowing the reason for the child taking hydroxyurea.	3.031	.662	.002	1	.039	1.328	5.267
	Refusal by the baby	1.992	.954	4.903	1	.017	1.181	3.243
	No medication at the clinic	1.606	1.275	1.588	1	.008	1.992	4.105
	The child was very sick.	-1.809	.664	.032	1	.109	-2.896	2.274
	You were not home	.856	.416	11.766	1	.001	1.004	2.081
	Side effects	-.959	.782	1.503	1	.220	-.574	1.062

The Barriers to Compliance to Prophylactic Regimen

Compliance with medication for sickle cell disease (SCD) is difficult and influenced by multiple factors and barriers. The degree of medication adherence among children and adolescents living with SCD significantly impacts their clinical outcomes and quality of life. Thus, the results in Table 4.18 below highlight some of the socioeconomic factors that may play a crucial role in accessing healthcare for children with sickle cell anaemia. The output indicated that nearly half (47.2%) of the caregivers reported a monthly income of Ksh 5,001–10,000, while 22.9% earned between Ksh 10,001–20,000. A smaller proportion (18.8%) earned above Ksh 20,000, and 11.1% reported an income of less than Ksh 5,000. These figures suggest that the majority of families fall within low to moderate income brackets, which could pose financial challenges in managing the costs associated with sickle cell disease, such as transportation, medication, and hospital visits.

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Based on transportation as another barrier to accessing healthcare facilities for the child's medication also reflects varied levels of accessibility. A majority of the people providing care for the children (68.1%) relied on buses for travel to the hospital, while 26.4% had to walk to access medical services, this may likely indicate the proximity to healthcare centres for some families. Only a small proportion used motorcycles (3.5%) or taxis (2.1%), suggesting that more expensive transport options are less viable for most caregivers in the study. Furthermore, 95.8% of parents and those providing care to their children had to spend less than Ksh 500 on transportation per hospital visit, reflecting a preference for cost-effective travel methods. This was supported by the evidence that most of them earned less than 10,000 Ksh per month hence, posing a major challenge to access the hospital and pay for the services for their sick child.

From the results, the cost of medication for the SCD disease poses an additional financial strain, with 41.0% spending between Ksh 2,001–3,000 monthly, followed by 36.1% spending Ksh 1,001–2,000. A smaller percentage (18.8%) reported spending less than Ksh 1,000, while only 4.2% spent between Ksh 3,001 and 4,000. The monthly income of less than 10,000 per month, most using buses as a means of transport or even walking and the medical expenditures of about 2,000 to 3,000 shillings highlighted the ongoing financial demands of managing sickle cell anemia, particularly for families in lower income brackets.

Table 7: Distribution of Financial Status

		Frequency	Percentage (%)
Average monthly income in Ksh	Less 5000	16	11.1
	5001-10000	68	47.2
	10001-20000	33	22.9
	Above 20000	27	18.8
Type of transport used for travelling from home to the hospital	Walk	38	26.4
	Motorcycle	5	3.5
	Bus	98	68.1
	Taxi (Online/offline)	3	2.1
Money spent on transport to and from the hospital in Ksh	Less 500	138	95.8
	501-1000	6	4.2
Money spent on medications per month in Ksh	Less 1000	27	18.8
	1001-2000	52	36.1
	2001-3000	59	41.0
	3001-4000	6	4.2

Qualitative Results

Current Prescription Practices for Children with Sickle Cell Disease

Trying to understand the prescription practices for children with SCD, most of them indicated that the children were under three available regimens that Folate, Pen V and Hydroxyurea as mentioned by almost all the Key Informants; KII 1 *"…Penicillin V, Folate, Hydroxyurea…".* The study also established the experience the specialists had in the given section where they were working, it was indicated all of them had more than one year of experience to a maximum of eleven years; KII 8 *"…I have been managing them for eleven years…".* The common experience they have witnessed during the service to the patients they mentioned that most of the caregivers struggle to pay for medication services for their children KII 4 *"…social economic issue due to expense issue parents don't visit clinics frequently expense…"* with a major concern being financial challenge like

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KII 2 *"…HU is expensive to most parents…".* This means most of the medical specialists have the right experience in managing the SCD and they have realized that the medical expenses for this type of disease are very expensive hence most of the children *"…most of them are not on prophylaxis in terms of regimen…"*.

Patient Compliance and Barriers

To understand the compliance and barriers that the patients face during the treatment and management of the disease, eight questions were used to gather the information including; exploring factors influencing compliance with medication and prophylactic, such as socioeconomic challenges (financial constraints, transportation), cultural beliefs, stigma, and caregiver education gaps. They also address barriers to adherence, the impact of stigma, and which support systems lack at Mama Lucy Kibaki Hospital. Additionally, they seek insights into successful strategies used elsewhere to improve compliance and their potential feasibility at the hospital. Like KII 7 mentioned that

> *"… Finance if there is family history SCD the management is easier, …Learning about the disease, …Financial constraints, … It has bad impact drug-seko cell crisis and multiple, … those who believe that sick cell is a devil disease don't comply with medication, … if there are no family history father deny care to their child making the mother the only source of support, … providing support to the mothers, providing enough human resources, having education before clinic, … It is feasible if enough willingness is to implant strategies refer to points…".*

This means that most families with children who have SCD condition face a lot of challenges in the treatment and management of the disease, hence better policies if well-established will help in improving the care of such children. Considering questions about support systems that may be initiated to help in the management and treatment of the disease, some of them recommended that *"…Drug availability and constitutional of HU…"* based on KII 4 and also KII 2 said that *"…support system-support groups for both patients and caregivers, resources reconstitution of HU, syrup for formulation…"*. From evidence-based data, it shows that there was a need for most of the caregivers to be supported to acquire HU drugs for their children.

Focused Group Discussion (FGDs)

Considering the eight questions provided to the KIIs same were administered to two groups for the FGDs with the following outcome. Sharing their views on the challenges the children with sickle cell disease face in following their prescription and prophylactic regimen, the two groups mentioned that most of the children their caregivers can't afford the financial requirements for the treatment and management of the disease, no syrup formulation specifically for the HU regimen, lack of knowledge by the caregivers on condition hence they need to be educated on how to handle the disease. As mentioned by FGD 1 *"…Unaffordable HU, so many tablets to remember, drug not made as syrup, clinician not explaining well, … Feel like drugs are more than necessary, scanty information on the condition…".*

Concerning the main reason for most of the non-compliance among the patients it was clear that most that the medication service was expensive for most of them, forgetfulness and child refusal to take the drugs "*…Forget when travelling, not in my budget freely drugs esp. HU, … Child fake taking the drugs Pricey drug esp. Hydroxyurea…"* FGD 2. In terms of the barriers related to accessing medication most had to say that the cost of medication was high and no syrup formulation for drugs like HU, *"…Drug Cost a lot of money esp. HU, No syrup formula…*". The major socioeconomic factor behind the difficulties experienced during caregiving for the SCD children was financial constraints as mentioned in FGD 1 *"…Unable to buy medicine due to financial constraints…"*. The cultural beliefs and practices

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that may hinder the medical service provision to the patient, some believed that it was a curse from God or ancestors *"…Belief the scud is a curse from ancestors, …Beliefs scud is a curse from God…"*.

For the educational gaps or misunderstandings among caregivers, it was indicated that such challenges existed at the great influence *"…Medical clinics to educate the masses, … Scantily information about their condition…"* based on both the two groups. There existed stigma caused among the children where some believed the disease was a curse *"…Believes SCD is a curse from ancestors…"*. On what support systems or resources are currently lacking at Mama Lucy Kibaki Hospital most compliant that there was no syrup formulation, understaffing of SCD specialist, expensive medication and poor follow-up plan, *"…Lack of syrup formulation, inconsistent system for tracking, SCD clinic combined with other clinics, Unable to buy medicine due to financial…"* as per the FGD 2. Lastly, on the successful strategies or initiatives have you seen or heard of in other settings that could be implemented to improve adherence, most mentioned that there was a need to set up a special clinic for SCD patients rather than mixing them with other sections within the hospital, and also introduce an organized follow-up plan for the patients, *"…proper patient tracing, separating SCD clinic from other clinics…"*. The results from the FGDs and the KII provided supportive information on some of the reasons why there was non-compliance like financial constraints among the caregivers.

DISCUSSION

This study included 144 children with each gender almost equally represented, with males at 52.1% which is in contrast to other studies which have shown that SCD is more common in females, for instance, a retrospective study (Nwabuko et al., 2022) which revealed that the ratio of male to female was 1:3. However, the study by Nwabuko was done in a more diverse age group ranging from 7 months old to 41years old and also included participants with sickle cell anaemia which could account for the gender disparities. Most of the children, 79.9%, enrolled were under the care of their mothers with very few of them being under the care of close relatives such as aunts or uncles. These results were similar to other studies (Madani et al., 2018) which found that the majority of SCD patients were cared for by their mothers who were of low socioeconomic class with insufficient financial support. This means that most of the children were under the care of their mothers supported by a key informant interview indicating that fathers deny care to the children when the child was found to have the condition. From this, it is evident that societal structures that support patients with SCD such as support groups for both the patients and the caregivers would be highly beneficial to them.

The study also found that most of the participants had financial constraints as most of the caregivers were casual workers and unemployed, 36.8% and 28.5% respectively and this finding was also supported by the focus group discussion. This finding is similar to the findings of a study by (Kilonzi et al., 2022) which found that some caregivers were unable to afford the medication due to financial constraints.

This study found that the commonly administered drugs were folate at 97.7%, Pen V at 86.8% and the least commonly used drug was hydroxyurea at 81.3%. Hydroxyurea was the least prescribed drug despite it being the cornerstone in the management of SCD. However, this percentage is still higher than some other studies (Brousseau et al., 2019) which found that only 1 in 4 children were on hydroxyurea therapy despite the study being done in a developed country with presumably more resources.

Some of the reasons discovered from KII as to why hydroxyurea was used by fewer people were the price of the drug, the drug's lack of syrup formulation and some of the caregivers' lack of information on how to administer the drug. The rates of antibiotic prophylaxis in using Penicillin V have been low in other studies (Reeves et al., 2018)

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which found that only 18% of children had been given antibiotics in the last 300 days. This difference may be due to the differences in the sample sizes between this study and the study by Reeves since their sample size was more than 10 times of this study and was carried out over several years. This study also identified that among the three drugs given, errors in dosing were common. Pen V had the highest error with 70.2% instances of undergoing, hydroxyurea had 32.5% underdose and an overdose rate of 36.7% while folate was rarely mis-dosed at 15% underdose and 20% overdose. The errors in dosing of the three most used drugs in SCD management have not been extensively studied by other researchers according to our knowledge. This highlights a need for further research into this and the need for specialised SCD clinics with SCD specialists to provide the required knowledge to caregivers and reduce such cases.

Compliance Levels to the Prescribed Prophylactic Regimen

According to this study, the majority of the participants had a low level of compliance with 54.2% of participants having a low compliance level. A meta-analysis conducted in 2015 (Loiselle et al., 2016) found that the overall medication regimen adherence score was 50% which is almost similar to the results of this study meaning that in the last 10 years, adherence has not changed much therefore more emphasis needs to put into improving it by addressing the barriers that hinder the compliance.

Barriers to Compliance with Prophylactic Regimen

Compliance with medication for sickle cell disease (SCD) is difficult and influenced by multiple barriers both social and economic factors. The degree of medication adherence among children and adolescents living with SCD significantly impacts their clinical outcomes and quality of life (Odityo, 2023 n.d.) Thus, (47.2%) of the caregivers reported a monthly income of Ksh 5,001–10,000, while 22.9% earned between Ksh 10,001–20,000. A smaller proportion (18.8%) earned above Ksh 20,000, and 11.1% reported an income of less than Ksh 5,000. These income figures suggest that the majority of families fall within low to moderate income brackets as supported by their occupational characteristics where most unemployed and casual workers are, which could pose financial challenges in managing the costs associated with sickle cell disease, such as transportation, medication, and hospital visits, "…*Financial constraints, …"*. with limited insurance cover which is also the case in Ally and Balandya study (Ally & Balandya, 2023)

Another challenge was transportation to access healthcare facilities for the child's medication also reflects varied levels of accessibility. This was also the case in a study by Philips et al where lack of reliable transportation, long distance to the clinic or provider, public or insurance-funded transportation, transportation expenses, and difficulties with finding transportation were also established as a barrier among 38.3% of surveyed participants. (Phillips et al., 2022)

In our study majority relied on the buses 68.1%, those walking had 26.4% while only a small percentage of 3.5% of them used taxis or motorbikes. This suggested that more expensive transport options are less viable for most caregivers in the study based on their occupation characteristics. Caregivers had to spend less than Ksh 500 representing about 95.8%, reflecting a preference for cost-effective travel methods. This was supported by the evidence that most of them earned less than 10,000 Ksh per month hence, posing a major challenge to access the hospital and pay for the services for their sick child like "…*not in my budget freely drugs esp. HU…"*.

With most of the caregivers earning less than Ksh 10,000 per month, the cost of medication for the SCD disease poses an additional financial strain, where 41.0% spending between Ksh 2,001– 3,000 monthly, followed by 36.1% spending Ksh 1,001–2,000, while only 4.2% spent between Ksh 3,001–

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4,000. Thus, most of them are forced to use buses as a means of transport or even walk and the medical expenditures of about 2,000 to 3,000 shillings highlighted the ongoing financial demands of managing sickle cell anaemia *"…Unable to buy medicine due to financial constraints…"*, particularly for families in lower income brackets (KWENA, 2021).

The study also tried to identify some of the unintentional factors that possibly impact the sickle cell disease medication challenge. The main challenge was the finances to acquire the drugs for the standardized medication for the children with SCD 61.8% while others mentioned that they did know the reason for the child to be given hydroxyurea accounting for 29.2%. Forgetfulness and no medication at the clinic had the same distribution with only four caregivers mentioning while the list was refused by the child to take Hydroxyurea and they were not at home to give their children the required medication same was the case from the FGDs where one mentioned that, "*…Forget when travelling, not in my budget freely drugs esp. HU, "… Child fake taking the drugs Pricey drug esp. Hydroxyurea…"*

CONCLUSION AND RECOMMENDATIONS

This study identifies important obstacles that Mama Lucy Kibaki Hospital's sickle cell disease (SCD) patients face when following preventative measures. The majority of children are dependent on their mothers, who often have limited resources, which results in inadequate medication compliance. Folic acid (97.9%), Penicillin V (86.8%), and Hydroxyurea (81.3%) are the most often prescribed preventive regimens; nevertheless, Hydroxyurea is still underutilized because of its expensive cost, lack of syrup formulation, and low caregiver awareness. Problems with overdosing and underdosing, especially with hydroxyurea and penicillin V, point to deficiencies in caregiver education.

Compliance is further hindered by forgetfulness (46.5%), difficulty accessing medication, and reliance on over-the-counter refills, resulting in inconsistent dosing. Socioeconomic factors such as financial constraints, high medication costs, transportation difficulties, and hospital stock-outs significantly impact adherence. There are strong statistical associations between adherence and factors such as income, transport, medication costs, and access to counselling. To improve compliance, targeted interventions such as specialized SCD clinics, structured adherence programs, financial assistance, improved hospital-based medication dispensing and enhanced caregiver education are needed. Additionally, mobile reminder systems and telehealth follow-ups could help mitigate forgetfulness, ensuring consistent medication use and ultimately improving health outcomes for children living with SCD.

Strength and Limitations

The use of a mixed-methods approach that combines quantitative data with qualitative insights from caregivers and healthcare providers, ultimately highlighting real-world challenges in SCD management and offering practical recommendations for implementation at both policy and clinical levels were the major strengths in this study.

Being limited only to one hospital, which may not fully represent the experiences of SCD patients in other healthcare facilities or regions, relies on self-reported adherence data that may introduce recall bias affecting accuracy, follows a cross-sectional design that does not allow for longitudinal assessment of adherence trends over time, and had a small sample size that may impact the generalizability of findings to the broader population of children with SCD.

Authorship

The idea of this study was conceived by, AK, WMK, JG and PK. AK also took the lead in manuscript writing with support from JG and WMK.

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Data Availability Statement

The support data on the findings of this study can be availed by the corresponding authors upon reasonable request.

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