

Barriers and facilitators to adherence to clinic appointments among children with sickle cell anaemia attending Mulago National Referral Hospital, Uganda: A qualitative study.

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Page | 1

Abstract

Background:

Adherence to clinic appointments is essential for effective management of sickle cell anaemia (SCA) in children. However, caregivers may face financial, caregiver, health-system, and sociocultural barriers to regular attendance. This study explored barriers and facilitators to adherence to clinic appointments among children with SCA aged one to 14 years attending the Mulago National Referral Hospital (MNRH) Sickle Cell Clinic (SCC).

Methods:

A qualitative exploratory study nested within a larger cross-sectional mixed-methods study was conducted at the MNRH SCC from January to June 2023. Ten caregivers participated in in-depth interviews (IDIs) and 10 healthcare workers in key informant interviews (KIIs). Purposive maximum-variation sampling was used, and data collection continued until saturation. Interviews were audio-recorded, transcribed verbatim, translated where necessary, and analysed thematically using the Socio-Ecological Model (SEM).

Results:

Seven major barrier themes were identified: financial and geographic access constraints; limited perceived value of clinic attendance; scheduling conflicts and competing responsibilities; drug stockouts and supply challenges; long clinic waiting times; inadequate communication and appointment coordination; and cultural beliefs, alternative health-seeking, and non-acceptance of SCA. Facilitators included caregiver health literacy, biological parental responsibility, and female caregiver engagement. An unexpected finding was that informal caregiver networks helped families identify when medicines had been restocked, temporarily increasing attendance. Among caregivers, 8/10 were female, 6/10 were biological parents, and ages ranged from 18 to 58 years.

Conclusions:

Adherence is shaped by interacting structural, caregiver, health-system, and sociocultural factors.

Recommendations:

Strengthening medicine availability, improving caregiver education and appointment reminders, reducing waiting and access barriers, offering more flexible scheduling, and engaging fathers and non-biological caregivers.

Keywords: Sickle cell anaemia; clinic appointment; barriers; caregivers; Uganda

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Background

Sickle Cell Anaemia (SCA) is a hereditary haemoglobin disorder characterized by recurrent vaso-occlusive pain crises, acute chest syndrome, stroke, splenic sequestration, and frequent hospitalization. [1] Uganda bears one of the

highest global burdens of SCA, with an estimated 20,000 children born with the condition annually, accounting for 1–2% of births and up to 10–15% of under-five deaths. [2][3]. The Mulago National Referral Hospital (MNRH) Sickle Cell Clinic (SCC) in Kampala is among the largest tertiary-

level SCA facilities in East Africa, with over 15,500 registered patients, of whom only approximately 4,000 are actively attending, representing a profound gap in retained care.

Regular clinic attendance is indispensable for effective SCA management. Scheduled appointments allow healthcare providers to monitor disease progression, optimize pharmacological treatment (including hydroxyurea, prophylactic antibiotics, and analgesics), detect complications early, and deliver caregiver education. The Centers for Disease Control and Prevention recommends that infants with SCA be reviewed at least every three months, and older children at least annually. [3]. Non-adherence to these appointments is associated with disease exacerbations, preventable hospitalizations, and increased mortality. [4][5].

Despite the clinical imperative of regular follow-up, adherence remains a formidable challenge across sub-Saharan Africa. Previous studies have identified socioeconomic constraints, health-system deficiencies, and sociocultural beliefs as key determinants of poor adherence in Kenya, Tanzania, and Northern Uganda. [6, 7]. However, qualitative evidence from Uganda that deeply explores the lived experiences of caregivers navigating these barriers or that identifies factors enabling adherence remains scarce. Mothers' involvement in paediatric chronic care has been relatively better studied in Uganda, but fathers and non-biological caregivers remain an understudied group. [8].

Therefore, this study aimed to explore, through the voices of caregivers and healthcare workers, the barriers and facilitators to adherence to clinic appointments among children with SCA aged one to 14 years attending the MNRH SCC.

Methods

Research design

This was a qualitative exploratory study nested within a larger cross-sectional mixed-methods study. The qualitative component was conducted concurrently with, and independently analyzed from, the quantitative arm. This design was chosen for its suitability in generating detailed, context-rich insights. [10] about caregiver experiences of navigating SCA clinic appointments. Qualitative data were collected through in-depth interviews with caregivers and key informant interviews with healthcare workers. Analysis used a hybrid thematic content approach in which transcripts were repeatedly reviewed to generate meaning units, codes, sub-themes, and themes, which were subsequently mapped onto the SEM.

Study setting

The study was conducted at the MNRH Sickle Cell Clinic, Kampala, Uganda. MNRH is a national referral hospital situated in Mulago Hill, approximately 5 km north of Kampala's central business district. The SCC operates Monday to Friday, 08:00–17:00, receiving an average of 70–80 patients per clinic day. It is staffed by paediatric haematologists, haematology fellows, medical officers, senior house officers, nurses, pharmacy technicians, and laboratory personnel. Standard care includes penicillin V prophylaxis, analgesia, folic acid supplementation, malaria prophylaxis, and hydroxyurea on a limited, largely self-funded basis. Routine follow-up appointments are scheduled every one to three months depending on clinical condition. The SCC was selected as the study site because it is the largest dedicated SCA facility in Uganda, serving patients from Kampala and its surrounding districts, as well as a significant proportion of patients from upcountry regions.

Participants

Caregiver inclusion criteria were: being a caregiver of a child with SCA aged one to 14 years attending the MNRH SCC, being present during the study period, and providing written informed consent. Caregiver exclusion criteria were failure to meet these eligibility requirements or declining participation. Healthcare workers were eligible for KIIs if they provided care at the SCC and had been present for at least three consecutive clinic cycles; those who did not meet these criteria or did not consent were excluded.

Sample size

The study was conducted among ten IDIs with caregivers of children with SCA attending the MNRH SCC and ten KIIs with healthcare workers from the SCC. Data collection continued until data saturation was attained, that is, until additional interviews ceased to generate new information in line with methodological literature on saturation of qualitative data. [11, 12]. The KII participants included two paediatric haematologists/fellows, two medical officers, two senior house officers, two nurses, one pharmacy technician, and one laboratory officer.

Sampling and recruitment

Participants were enrolled through purposive sampling to collect information-rich data. Recruitment of IDI participants was purposively based on diversity in sex, caregiver relationship to child (biological parent, grandmother, other guardian), educational level, residence, and adherence status. Caregivers were identified by SCC nursing staff, who referred them to the principal investigator or research assistants to assess eligibility and obtain consent.

For KIIs, healthcare workers were recruited purposively according to cadres to ensure coverage of clinical, nursing, pharmacy, and laboratory perspectives.

Data collection

The data collection tools were developed based on study objectives and reviewed by the research team and supervisors. Data were collected using semi-structured IDI guides with caregivers and KII guides with healthcare workers. Interviews were conducted in a private room at the SCC in the participant's language of choice (English or Luganda) and audio-recorded using a digital voice recorder. Each interview lasted approximately 30 to 60 minutes. Recordings were transcribed verbatim by research assistants and translated into English where necessary; translations were independently back-checked and discrepancies resolved by consensus. Caregiver interviews were conducted before KIIs to identify concerns that could be probed with healthcare workers.

Trustworthiness of the study

To ensure credibility, the principal investigator checked and pilot-tested data collection tools before the main study to confirm they captured data aligned with the study objectives. The interview process was guided, audio-recorded, and representative participant quotations from interviews are included throughout the findings. Confirmability was ensured through maintenance of an audit trail comprising notes on interview decisions and emerging issues. An experienced social scientist supervised all qualitative data collection and participated in an audit of the analytical process. Transferability of the findings was ensured through varied description of participant sociodemographic characteristics, detailed description of the methodology, and description of the study setting.

Data analysis

Sociodemographic characteristics of participants were described. Data collection and analysis were conducted concurrently, with the SEM [9] guiding interpretation. At the end of each day, the research team held a debriefing meeting to review emerging issues and identify areas

requiring further exploration. Audio recordings were transcribed verbatim, and the principal investigator reviewed transcripts against the recordings for accuracy. Two researchers independently coded the transcripts using inductive thematic content analysis; codes were grouped into categories, sub-themes, and themes, which were then mapped onto the SEM. Triangulation was undertaken by comparing findings from caregiver IDIs and healthcare worker KIIs. Major themes were illustrated with participant quotations, using codes to mask identities. All records were stored on a password-protected computer accessible only to the research team.

Ethical considerations

The study was conducted in accordance with the Declaration of Helsinki. Ethical approval was obtained from the School of Medicine Research Ethics Committee (SOMREC), Makerere University (reference: Mak-SOMREC-2023-676) on 15/01/2024. The study was conducted in accordance with the Declaration of Helsinki. Written informed consent was obtained from all adult participants before data collection. Participation was voluntary, and participants could withdraw at any time without penalty. The study posed minimal risk and did not influence healthcare provided to the children. Interview guides were coded without participant names, and all information was kept confidential.

Results

Baseline characteristics of participants

The study included 10 caregivers of children with SCA with diverse sociodemographic characteristics, the majority being female (8/10) and biological mothers (7/10). Caregiver ages ranged from 18 to 58 years, and participants were drawn from Kampala, peri-urban Wakiso, and upcountry districts. Detailed caregiver characteristics are presented in Table 1 below.

Additionally, 10 healthcare workers were interviewed, comprising two paediatric haematologists, two medical officers, two senior house officers, two nurses, one pharmacy technician, and one laboratory officer, with experience at the SCC ranging from one to twelve years.

Table 1: Sociodemographic characteristics of caregivers of children with SCA attending MNRH SCC (N=10)

Variable	Frequency (N=10)
Female	8
Male	2
Biological parent	6
Other guardian	4
18–35	6
Above 35	4
No formal education	1
Primary	2
Secondary	4
Tertiary/University	3
Employed	7
Unemployed	3
Kampala and peri-urban	8
Upcountry / rural	2
1–19	7
11–14	3
Adherent (attended last appointment)	5
Non-adherent (missed last appointment)	5

Barriers to adherence to clinic appointments

Seven major barrier themes emerged from the analysis across the SEM: financial and geographic access constraints; limited perceived value of clinic attendance; scheduling conflicts and competing responsibilities; drug

stockouts and supply challenges; long clinic waiting times; inadequate communication and appointment coordination; and cultural beliefs, alternative health-seeking, and non-acceptance of SCA. These are summarized in Table 2 and described below.

Table 2: Thematic presentation of barriers to adherence to clinic appointments at the MNRH SCC

SEM Level	Theme	Sub-themes
Individual / Socioeconomic	Financial and Geographic Access Constraints	•Transport unaffordability • Geographic access burden • Delayed resource mobilisation
Individual	Limited Perceived Value of Clinic Appointment	• Belief appointments unnecessary during wellness • Pharmacy drug substitution • Failure to appreciate psychosocial/monitoring value
Individual / Interpersonal	Scheduling Conflicts and Competing Responsibilities	• School–clinic scheduling conflict • Employment-related constraints • Household caregiving burdens
Health System / Organizational	Drug Stockouts and Supply Challenges	• Perceived attendance futile during stockouts • Dependence on informal restock information networks
Health System / Organizational	Long Clinic Waiting Times	• Extended delays before seeing clinicians • Laboratory turnaround time
Health System / Organizational	Inadequate Communication and Appointment Coordination	• No appointment reminder systems • Unilateral scheduling without caregiver input
Community / Sociocultural	Cultural Beliefs, Alternative Health-seeking, and Non-acceptance of SCA	• Herbalist advising discontinuation of hospital treatment • Spiritual/supernatural illness attribution • Temporary disengagement for herbal treatment • Difficulty accepting SCA diagnosis • Recourse to prayer and traditional healers

Individual and socioeconomic barriers

Financial constraints

Financial constraints were the most consistently cited barrier across IDIs and KIIs. Caregivers reported that the cost of transportation to MNRH was prohibitive, particularly for those residing in peri-urban or rural areas. Multiple participants described situations in which the scheduled appointment date had passed before they could raise sufficient transport funds.

"Transport is hard to get, and when the appointment reaches before getting the money, you have no choice but to miss that day." (IDI, Mother, 28 years, Wakiso)

Healthcare workers corroborated this, noting transport costs as among the most frequently cited reasons for missed appointments. Geographic access burden was a distinct sub-theme, with some families residing in districts far from Kampala, including Mubende, Lira, and Kasese.

"Most of the ones we lose to follow-up are from upcountry. They come once, and you don't see them again for months. The distance is just too much for them to manage regularly." (KII, Medical Officer)

Limited perceived value of clinic attendance

A substantial proportion of caregivers demonstrated limited appreciation of the comprehensive nature of SCA clinic visits beyond medication refill. This manifested as pharmacy drug substitution, obtaining prescribed medications from nearby pharmacies, and reasoning that the clinical visit added no further value, as well as reduced urgency when the child appeared clinically stable.

"Sometimes I buy drugs from the nearby pharmacy because even if I come here, they usually write for us the same drugs. I don't bother coming if I know I can buy the same drugs from the pharmacy and save time." (IDI, Mother, 22 years)

"When the child gains weight and looks healthy, many parents feel less motivated to come back for review." (IDI, Mother, 33 years)

Healthcare workers noted that caregivers frequently failed to appreciate the importance of psychosocial support, laboratory monitoring, vaccination updates, and early complication detection services uniquely available at the SCC.

Scheduling conflicts and competing responsibilities

Scheduling conflicts between clinic appointments and children's school attendance represented a significant structural barrier. Caregivers frequently prioritized schooling over clinic visits when their child was not acutely unwell.

"My child was at school by the time we were supposed to come back to the clinic. She was not feeling bad, and I decided to leave her to study. I wish we would be coming here only during holidays." (IDI, Mother, 42 years)

Household caregiving burdens, particularly the absence of alternative carers to supervise other children at home and employment constraints among caregivers working for unsympathetic employers, were additional barriers at this level.

"My employer gave me only one day off. The child's appointment takes two days; you must go the evening before to register. I cannot keep asking for two days every month." (IDI, Grandmother, 54 years)

Health system and organizational barriers Drug stockouts and supply chain challenges

Recurring stockouts of essential SCA medications at the MNRH SCC constituted a health-system-level barrier that directly eroded caregiver motivation to attend. Caregivers reported that after experiencing appointments where medications were unavailable, they were reluctant to undertake the cost and effort of travel only to leave empty-handed. Healthcare workers confirmed this pattern and noted that informal caregiver networks functioned as substitutes for formal communication systems, with attendance surging whenever word spread that medications had been restocked.

"When they come, and they don't find drugs, they be like: even if I go I will not find the drugs, so let me just sit back. But through their connections, they get to know that the drugs are available and you see them coming in big numbers." (KII, Nursing Officer)

Long clinic waiting times

Extended waiting times at the MNRH SCC were identified as a significant organizational barrier. Caregivers described

arriving early in the morning and departing late in the evening, with prolonged waits attributable to high patient volumes, limited staffing, and laboratory turnaround delays. For children with SCA who may already be fatigued, such extended waits imposed additional physical and psychological burdens.

"If you do not come early, you will find other people, and you will have to wait in line. Other days we come late and find many people waiting, so we return home before being attended to because we are tired." (IDI, Child participant, 13 years)

Healthcare workers acknowledged this problem and attributed it to the high patient-to-provider ratio and the lack of a triage or streaming system to separate sick children requiring urgent attention from those due for routine review.

Inadequate communication and appointment coordination

The absence of structured appointment reminder systems was identified as a modifiable health-system barrier. Healthcare workers acknowledged that the clinic lacked the resources to proactively contact caregivers to schedule appointments. Caregivers also reported that appointment dates were set unilaterally by providers without consideration of individual caregivers' circumstances.

"We don't have any communication to them because, however much we get their numbers, we don't take that concern of finding out why they have not come because we don't have airtime to call them." (KII, Nurse)

Community and sociocultural barriers

Cultural beliefs, alternative health-seeking, and non-acceptance of SCA

The use of herbal remedies as an alternative to conventional SCA management was a prominent community-level barrier. Caregivers reported being advised by herbalists to discontinue clinic-prescribed medications in favor of herbal treatments, resulting in temporary disengagement from the SCC.

"There was a woman who told me not to return to hospital and just give the child herbal like hibiscus, and the child will be fine. I tried for two months. When the child got a crisis, I came back." (IDI, Mother, 48 years)

Attribution of SCA to supernatural causes, including witchcraft and spiritual affliction, led some caregivers to seek care from traditional healers or to invest in intercessory prayer instead of clinic attendance. Healthcare workers routinely encountered patients who returned to the SCC only after traditional or spiritual interventions had failed.

"Others say I went for prayers; they believe that it is witchcraft. They only come back when the

prayers have failed, and the child is in crisis." (KII, Nursing Officer)

Cultural beliefs, alternative health-seeking practices, and non-acceptance of SCA influenced clinic attendance. Some caregivers reported being advised by herbalists to discontinue hospital treatment, while others attributed SCA to witchcraft or spiritual affliction and sought traditional or spiritual care. A subgroup also initially struggled to accept the diagnosis and treated the child as though ordinarily ill until complications prompted re-engagement with the SCC.

"I came here, and doctors told me my child is a Sickler. It was hard for me to believe. I tried several other ways such as prayers and witch

doctors; when they failed, I came back here again in fear." (IDI, Mother, 38 years)

Healthcare workers noted that denial was more common among caregivers who first received the diagnosis when the child presented with an acute crisis rather than through newborn screening, as the sudden nature of the diagnosis allowed less time for adjustment.

Facilitators of adherence to clinic appointments

Three key facilitators of adherence were identified from the qualitative data, each corroborated by quantitative findings from the wider study. These are summarized in Table 3.

Table 3: Thematic presentation of facilitators to adherence to clinic appointments at the MNRH SCC

SEM Level	Theme	Sub-themes / Codes
Individual	Caregiver Health Literacy and Education	• Disease-specific health literacy • Awareness of complications prevented by follow-up • Recognition of importance of continuous care • Fear of disease complications
Interpersonal	Biological Responsibility	• Emotional investment in child's wellbeing • Parental identity as primary protector • Appreciation of preventive care value
Interpersonal / Sociocultural	Female Caregiver Sex	• Culturally constructed maternal responsibility • Deep-felt sense of duty to attend clinic

Caregiver health literacy and education

Higher caregiver educational attainment emerged as the strongest facilitator of adherence. Caregivers with tertiary-level education demonstrated greater understanding of SCA pathophysiology, its complications, and the rationale for regular medical review. In the quantitative component of the wider study, caregivers with tertiary education were 6.2 times more likely to adhere compared to those with no formal education (aOR = 6.216; p = 0.029).

"As someone who went to school, I know what sickle cell disease is, and I follow what doctors tell me to do for the good of my child." (IDI, Caretaker, 49 years)

Disease-specific health literacy, including awareness of preventable complications and appropriate fear of disease exacerbations, motivated sustained clinic engagement even among caregivers with lower formal educational attainment.

"The medicines help me, and doctors check on me, and I know that if I miss appointments, I am bound to get sick again." (IDI, Child participant, 13 years)

Biological parental responsibility

Caregivers who were biological parents of children with SCA were significantly more likely to adhere to scheduled appointments compared to non-biological guardians. Biological parents described a profound sense of parental identity and emotional investment in the child's health, which motivated sustained engagement even in the face of financial or logistical barriers. In the quantitative component, biological parents were 1.64 times more likely to adhere (aOR = 1.644; p = 0.039).

"This is my blood, and by all means I have to look after my child. Her dad abandoned me, claiming that for them they don't give birth to children with sickle cell, but as a woman, I will always try to look after my blood." (IDI, Mother, 39 years)

Healthcare workers also acknowledged that biological parents, particularly mothers, displayed greater persistence in attending the SCC despite barriers, and were more likely to seek out information about their child's condition.

Female caregiver sex

Female caregivers were significantly more likely to adhere to clinic appointments than male counterparts. Observational data from the clinic and healthcare worker accounts confirmed that the overwhelming majority of caregivers attending clinic visits were women. Qualitative data revealed that child health-seeking behaviour is culturally constructed as a maternal responsibility in Uganda, with fathers rarely assuming an active role. In the quantitative component, female caregivers were 1.96 times more likely to adhere (aOR = 1.962; $p = 0.002$).

"For me, my husband has never thought of bringing the child to the clinic. Just as you see here today, there are very few men; they always leave the responsibility to us women." (IDI, Mother, 22 years)

Health workers affirmed this observation and noted that the few male caregivers who did attend the SCC were often only present because the mother was ill or otherwise unavailable, rather than as a matter of routine paternal involvement.

"Most men only come once. After that, they send the wife. You rarely see a father come consistently. When you do, it is usually because the mother is admitted or sick." (KII, Senior House Officer)

Discussion

Adherence to clinic appointments among children with SCA attending the Mulago National Referral Hospital Sickle Cell Clinic is shaped by interrelated financial, health-system, sociocultural, and caregiver-level factors, highlighting the need for integrated rather than single-level interventions. Financial constraints, particularly transport costs and delayed mobilization of funds, emerged as a major structural barrier, consistent with evidence from other East African settings [6,7]. These constraints reflect broader inequities associated with centralized specialized care and resulted in missed or delayed appointments when caregivers could not raise resources in time. Closely linked to this was the limited perceived value of routine clinic attendance, driven partly by inadequate disease-specific health literacy. Many caregivers associated hospital visits primarily with acute illness management rather than preventive care, indicating a gap in understanding the chronic nature of SCA and the need for continuous monitoring [13].

Health-system weaknesses further compounded these barriers. Drug stockouts reduced trust in the health system and discouraged return visits, while long waiting times and inadequate appointment coordination increased opportunity costs for resource-constrained households [6,14]. These system-level inefficiencies collectively undermined perceived service reliability and weakened adherence even among motivated caregivers.

Sociocultural beliefs also shaped care-seeking behaviour. Misattribution of SCA to spiritual causes and reliance on herbal remedies led to delayed or interrupted clinic attendance, reflecting culturally grounded interpretations of disease and healing [15]. These findings suggest that adherence is not only a biomedical or logistical issue but is also mediated by local explanatory models of illness.

Structural misalignment between clinic schedules and caregivers' daily responsibilities, particularly school attendance and work commitments, further constrained consistent attendance, suggesting the need for more flexible or context-responsive appointment systems for paediatric chronic conditions.

Against these barriers, several facilitators supported adherence. Caregiver health literacy emerged as the most influential enabling factor, as better understanding of SCA and its long-term management promoted recognition of the importance of regular follow-up. [13]. Biological parental responsibility also enhanced adherence, likely reflecting stronger emotional attachment and perceived duty of care. In contrast, caregiving by non-biological guardians appeared more vulnerable to disruption, suggesting the need for additional targeted support in such contexts. Gender dynamics were also evident, with female caregivers predominantly responsible for clinic attendance, reflecting entrenched sociocultural norms that position child healthcare as a maternal responsibility. While this supports continuity of care, it also places a disproportionate burden on women and highlights the underutilized role of fathers and male caregivers, who may require intentional engagement strategies to improve shared responsibility. Overall, these findings demonstrate that adherence is determined by a complex interplay of structural, sociocultural, and relational factors. Addressing these requires multi-level interventions that strengthen health system reliability, improve caregiver understanding of SCA, and actively engage broader household and community support systems.

Conclusions

Adherence to clinic appointments among children with SCA at the MNRH SCC is shaped by interdependent financial, health-system, sociocultural, and caregiver-level factors operating across SEM levels. Caregiver health literacy, biological parental responsibility, and female caregiver engagement promote attendance, but these are undermined by transport costs, drug stockouts, inefficient clinic processes, limited appointment systems, and culturally grounded beliefs about illness.

Overall, non-adherence was not driven by a single factor but by the convergence of system inefficiencies, socioeconomic hardship, and limited biomedical understanding of SCA within households. Improving adherence therefore requires

multi-level health-system strengthening that addresses service reliability, caregiver knowledge, access barriers, and socio-cultural context.

Strengths and limitations

A key strength of this study is the use of a dual qualitative approach, combining caregiver in-depth interviews with healthcare worker key informant interviews, which enabled triangulation and a more comprehensive understanding of factors influencing clinic attendance. The application of the Socio-Ecological Model provided a structured lens for analyzing barriers and facilitators across multiple levels beyond the individual, while the use of data saturation strengthened confidence in thematic completeness.

However, several limitations should be considered. The study was conducted at a single tertiary referral centre, which limits statistical generalizability and transferability to lower-level facilities and rural contexts. Nevertheless, the purposive maximum-variation sampling and detailed description of the setting and participants support analytical transferability to comparable paediatric SCA clinics serving similar populations. In addition, only caregivers and healthcare workers were interviewed; children's perspectives were not captured, which may have omitted relevant experiential insights. Social desirability and courtesy bias may have influenced responses, although this was mitigated by using research assistants not involved in clinical care. Finally, purposive sampling was appropriate for qualitative inquiry but does not allow estimation of the frequency or distribution of identified barriers and facilitators.

Future research

Future research should evaluate multi-level strategies that combine reliable medicine supply, caregiver health-literacy interventions, appointment reminders, flexible scheduling, and approaches that engage fathers and non-biological caregivers. Implementation research should also assess which combinations of these interventions are feasible and effective for improving continuity of care in tertiary and lower-level SCA services.

Recommendation

Based on the findings, the MNRH SCC should strengthen essential medicine supply and appointment-reminder systems, streamline clinic flow to reduce waiting times, consider flexible appointment scheduling, provide targeted disease-specific education for caregivers, and deliberately engage fathers and non-biological caregivers in the child's care.

List of Abbreviations

CDC: Centers for Disease Control and Prevention; IDI: In-Depth Interview; KII: Key Informant Interview; LMIC: low- and middle-income country; MNRH: Mulago National Referral Hospital; SCA: Sickle Cell Anaemia; SCC: Sickle Cell Clinic; SEM: Socio-Ecological Model; SOMREC: School of Medicine Research Ethics Committee.

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Authors' contributions

MF conceived and designed the study, collected data, conducted thematic analysis, and drafted the manuscript. JK contributed to study design, provided oversight of the qualitative methodology, and critically revised the manuscript for intellectual content. ME, GN, and GF supervised the study and provided critical revision of the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

The qualitative datasets generated and analyzed during the current study are not publicly available to protect participant confidentiality but are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

Ethical approval was obtained from the School of Medicine Research Ethics Committee (SOMREC), Makerere University (reference: Mak-SOMREC -2023-676). The study was conducted in accordance with the Declaration of Helsinki. Written informed consent was obtained from all adult participants prior to data collection. Participation was voluntary, and confidentiality was maintained throughout.

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Not applicable

Conflict of interest

The authors declare that they have no conflict of interest.

Author biographies

Mwoko Faisal is affiliated with the Department of Pediatrics and Child Health, School of Medicine, Makerere University, and conceived and conducted the study and thematic analysis. Joshua Kitimbo is affiliated with the Department of Community Health and Behavioural Sciences, Makerere University College of Health Sciences, and contributed to qualitative methodology and manuscript revision. Mupere Ezekiel, Geriga Fadhil, and Grace Ndeezi are affiliated with the Department of Pediatrics and Child Health, Makerere University, and provided study supervision and critical manuscript review.

Competing interests

The authors declare no competing interests.

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