

## Caregiver-related challenges faced by caregivers of children aged 1-5 years with Sickle Cell Disease at China-Uganda Friendship Hospital, Kampala District. A cross-sectional study.

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### ABSTRACT

#### Background

The study aimed to identify the caregiver-related challenges faced by caregivers of children aged 1-5 years with Sickle Cell Disease at China-Uganda Friendship Hospital, Kampala District.

#### Methodology:

The study used a descriptive cross-sectional design to collect data at one point in time. It was conducted at China-Uganda Friendship Hospital, Naguru, Kampala, a public hospital providing specialized sickle cell services. The study targeted caregivers of children aged 1-5 years with sickle cell disease. Using Krejcie and Morgan's table, a sample size of 40 caregivers was selected through convenience sampling. Data were collected over four days using a semi-structured questionnaire. Data were analyzed using descriptive statistics in Microsoft Excel, with ethical approval and informed consent obtained.

#### Results:

The study involved 40 caregivers, of whom 21 (52.5%) were female and 19 (47.5%) male. Most respondents were aged 29-39 years, accounting for 23 (57.5%), followed by 10 (25%) aged 40-49, while only 7 (17.5%) were aged 18-28 years. More than half 22 (55%) knew common sickle cell crisis triggers, mainly cold exposure 10 (45.5%). Most caregivers 32 (80%) always felt stressed. Half of 20 (50%) could not afford treatment, and 27 (67.5%) reported hospital visits affected their work. Partners supported care in 24 (60%) cases.

#### Conclusion:

Caregiver-related challenges included emotional stress, financial hardship, and disrupted work schedules caused by frequent hospital visits.

#### Recommendation:

Caregivers should seek guidance from health workers on home care and complications, and adhere to follow-up visits and treatments.

**Keywords:** Caregiver challenges, Sickle Cell Disease, emotional stress, financial hardship.

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### BACKGROUND OF THE STUDY

Sickle Cell Disease (SCD) places a heavy burden on caregivers, who must manage frequent clinic visits, home care, and significant emotional and financial stress (Cardinali et al., 2019). Globally, caregivers face challenges related to limited knowledge of SCD, stigma, loss of income, and psychological distress. Studies from high-income settings have also shown that caregivers experience substantial stress due to the cost of treatment and the demands of long-term caregiving (Ampomah et al., 2024). In Sub-Saharan Africa, caregiving challenges are intensified by stigma, poverty, and limited access to health services. In Nigeria, a high proportion of caregivers experience psychological distress and income loss due to frequent sickle cell crises (Ojelabi, 2024). In Ghana, caregivers report difficulties in managing SCD at home, largely due to limited

access to essential medicines and inadequate disease knowledge (Ajinkpang et al., 2022). In East Africa, studies show that many caregivers experience emotional exhaustion and lack adequate knowledge on SCD management, which contributes to poor home care practices and repeated hospital visits (Twafleh, 2024).

In Uganda, caregiver-related challenges remain pronounced. Evidence indicates that many caregivers have limited knowledge of SCD and face financial and transport-related barriers that affect clinic attendance and continuity of care (Namaganda et al., 2024). These challenges undermine effective home management of the disease and contribute to poor outcomes among affected children. Therefore, this study aimed to identify the caregiver-related challenges faced by caregivers of children aged 1–5 years with Sickle

Cell Disease at China-Uganda Friendship Hospital, Kampala District.

## METHODOLOGY

### Study Design and Rationale

The study employed a descriptive cross-sectional study design because the study was carried out in a specific period of time without further follow-up of respondents. This design was chosen because it was easier and cheaper to carry out, and compare variables at once, which enabled me to meet the UHPAB timeline.

### Study Setting and Rationale

The study was conducted at China-Uganda Friendship Hospital, Naguru, located in Nakawa Division, Kampala District, Central Uganda. This is a public general hospital jointly established by the governments of Uganda and China and officially opened in 2012. The hospital serves as a key health facility within the Kampala Metropolitan Area and provides specialized services, including pediatric care, outpatient clinics, maternal and child health services, and management of chronic illnesses such as Sickle Cell Disease. As of 2025, China-Uganda Friendship Hospital has a catchment population of over 50,000 people with a high volume of pediatric patients, including those diagnosed with Sickle Cell Disease. The Sickle Cell clinic is well equipped with essential diagnostic tools such as hemoglobin electrophoresis machines, complete blood count analyzers, and point-of-care testing kits. It has a well-stocked pharmacy with routine medications like folic acid, antibiotics, and pain management drugs, as well as blood transfusion services for managing severe anemia. The setting was ideal for this study because it attracted a diverse group of caregivers from urban and peri-urban areas, making it possible to explore a wide range of challenges faced in the care of children aged 1–5 years with Sickle Cell Disease. Its geographical coordinates are 0.3284°N latitude and 32.6143°E longitude.

### Study Population and Rationale

The study targeted caregivers of children aged 1–5 years diagnosed with Sickle Cell Disease who were receiving care at China-Uganda Friendship Hospital, Naguru in Kampala District.

### Sample Size Determination

The sample size determination followed the guidelines provided by Krejcie and Morgan's table of 1970. *With a target population of 45 caregivers, Krejcie & Morgan's (1970) table gives a sample size of 40 respondents.* Therefore, the sample size is 40 caretakers of children under five years for the study.

### Sampling procedure

A convenience sampling technique was used to select participants. This method was used because it allowed easy access to caregivers who were readily available and willing to participate during the study period, making it practical and time-efficient within a hospital setting. Caregivers of children aged 1–5 years with Sickle Cell Disease attending the sickle cell clinic at China-Uganda Friendship Hospital were approached as they came for follow-up visits. Those who met the inclusion criteria and gave informed consent were enrolled in the study until the required sample size of 40 caregivers was achieved. Data collection was conducted over a period of 4 consecutive days, targeting an average of 10 caregivers per day.

### Inclusion Criteria

All caregivers of children aged 1-5years attending China-Uganda Friendship Hospital who consented to participate in the study, those who were only Ugandans, those who were able to read and write, and those who were present during the period of data collection.

### Exclusion criteria

Caregivers of children aged below 1 and above 5 years who were, upon informed consent, declined to participate in the study, and those who were deaf and mute.

### Independent Variables:

The independent variable of this study included; Caregiver-related challenges, which were measured by stress, financial costs, and family support

Hospital-related challenges, which were measured by waiting time, medicine availability, and staffing

### Dependent variables:

The dependent variable of this study was sickle cell disease, measured by the frequency/severity of reported issues.

### Research Instruments

A semi-structured questionnaire was used to collect data from respondents written in English. The questionnaire was divided into two sections, with section **A** describing the social-demographic, and section **B** comprising caregiver-related challenges.

### Data Collection Procedure

Upon proposal approval by the research supervisor and the institutional research committee, permission was obtained from the school administration, and an introductory letter was issued by the Dean, School of Nursing, Mildmay Uganda School of Nursing and Midwifery. Permission to conduct the study was then granted by the Director of China-Uganda Friendship Hospital, Naguru. The purpose and procedures of data collection were explained to the

Director, who authorized access to the sickle cell clinic in charge. After self-introduction and a clear explanation of the study, permission was granted to interact with respondents. Participants signed consent forms before participation and completed the questionnaires independently, with clarification provided when necessary. Data collection lasted four days, with ten respondents sampled each day until a total of 40 participants was reached.

**Data management**

Here, the study results were first checked for completeness, correction of mistakes in case found, and editing of the questionnaires to avoid missing information after losing contact with study participants. The questionnaires were then stored in secure files under lock, key, and computer password to ensure safety management and for future reference.

**Data analysis**

Data was first tallied manually in bundles, and percentages were calculated. Data was entered into Microsoft Excel (2019), analyzed using descriptive statistics and cross-tabulations, and results were presented in tables and charts.

**Validity**

This was done by setting questions that are in line with the research objectives, and also by setting questions that were in line with the intentions of the study in connection with the research study topic. The Validity helped in measuring the accuracy of study results, which helped in the formulation of proper interventions that are fit for solving the problem of the study topic.

**Reliability**

Pre-testing of the questionnaires was carried out at Mulago National Referral Hospital among 8 caretakers, and

necessary corrections were made from there and then if found within the questionnaire.

**Ethical Considerations**

Upon the proposal approval by my research supervisor and the institution's research committee, permission was got from the school administration, and an introductory letter was obtained from the Dean, School of Nursing, Mildmay Uganda School of Nursing and Midwifery, which was presented to the Director of China-Uganda Friendship Hospital, Naguru, seeking permission to carry out the study. The director then allowed me to go and interact with the person in charge of the sickle cell clinic, who, in return, allowed the researcher to interact with respondents and acquired the required responses after her making self-introduction and explained the purpose of the study well explained to each participant. During the data collection process, respondents who were found in critical ill conditions were referred to a high-level hospital. The study went on after the objectives of the study were fully and clearly explained to all respondents. Only respondents who consented were allowed to participate in the study. Then all respondents were reminded of their right of free to withdraw at any time during the period of study. The respondents were assured of maximum confidentiality of all the information given, and numbers were used instead of respondent's names. To ensure privacy, consent, confidentiality, and referral of critically ill respondents. All collected data was securely stored in a password-protected computer, and hard copies were locked in a cabinet accessible only to the investigator.

**RESULTS**

**Demographic information of respondents.**

**Table 1 shows the demographic data of the respondents**

Variables	Response	Frequency(n=40)	Percentage (%)
Gender	Male	19	47.5
	Female	21	52.5
Age	18-28	7	17.5
	29- 39	23	57.5
	40-49	10	25
Religion	Catholic	12	30
	Muslim	8	20
	protestant	20	50
current marital status	Single	3	7.5
	Married	29	72.5
	Unmarred	8	20

Table 1 shows that the majority, 21 (52.5%) of the respondents were females, while 19 (47.5%) were males. Over half 23 (57.5%) of the respondents were aged between

29–39 years whereas the least 7 (17.5%) were aged 18–28 years. Half 20 (50%) of the respondents were Protestants, 12 (30%) were Catholics, and 8 (20%) were Muslims. Most 29

(72.5%) of the respondents were married, while the least 3 (7.5%) were single.

**Caregiver-related challenges faced by caregivers of children aged 1-5 years with sickle cell disease at China-Uganda Friendship Hospital, Naguru, Kampala District**

**Table 2 shows caregiver-related challenges faced by caregivers of children aged 1-5 years with sickle cell disease at China-Uganda Friendship Hospital, Naguru, Kampala District.**

Variable	Response	Frequency(n=40)	Percentage (%)
know common triggers of sickle cell crisis	Yes	22	55
	No	18	45
Showing the triggers respondents knew (n=22)	Infection	6	27.3
	Stress	1	4.5
	Cold exposure	10	45.5
	Dehydration	5	22.7
How often do respondents feel stressed about their child's condition	Always	32	80
	Sometimes	5	12.5
	Never	3	7.5
Whether respondents are able to pay for your child's treatment	Yes	9	22.5
	No	20	50
	Sometimes	11	27.5
Hospital visits affect your work	YES	27	67.5
	Sometimes	10	25
	Not at all	3	7.5

Table 2 shows that more than half 22 (55%) of the respondents reported knowing the common triggers of sickle cell crisis, while 18 (45%) did not. Among those who knew the majority, 10 (45.5%) identified cold exposure as a trigger, while the least 1 (4.5%) cited stress. The majority, 32 (80%) of the respondents stated that they always felt stressed about their child's condition, while only 3 (7.5%) said they

never felt stressed. Half 20 (50%) of the respondents reported being unable to pay for their child's treatment the least 9 (22.5%) were able to pay consistently. Most 27 (67.5%) of the respondents indicated that hospital visits affected their work, while 3 (7.5%) reported that hospital visits did not affect their work at all.

Figure 1 shows who caretakers take care of their child (N=40)

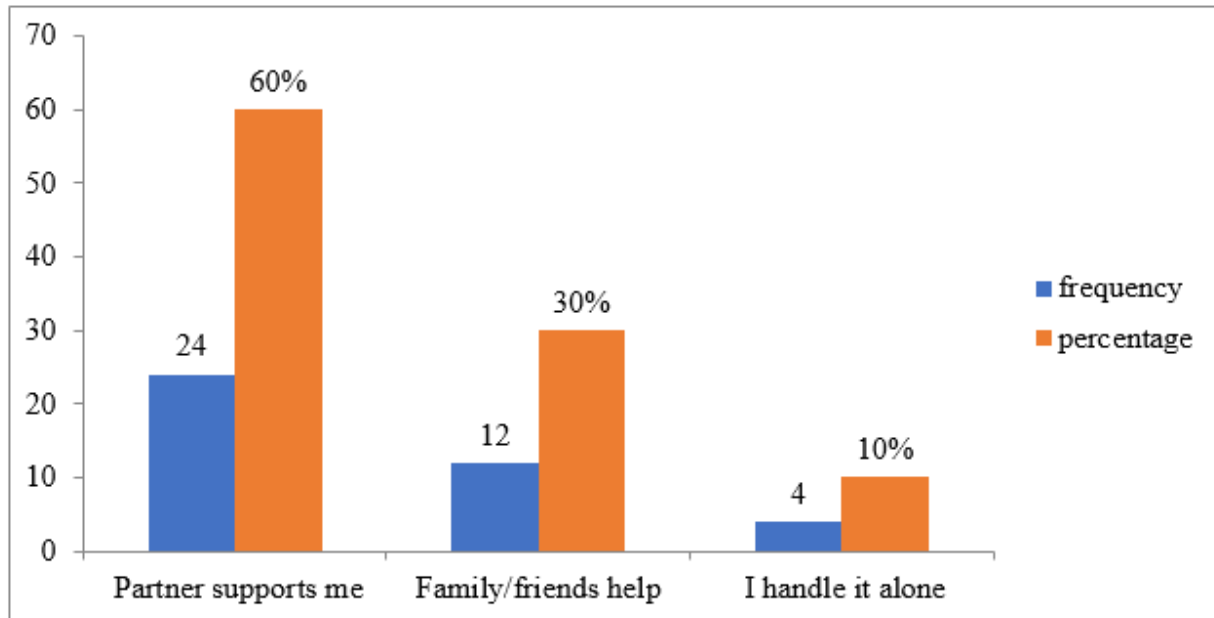


Figure 1 shows that 24(60%) of the caregivers said that their partner helped them take care of their children, whereas at least 4(10%) reported they can handle themselves.

## DISCUSSION

The purpose of this study was to identify the caregiver-related challenges faced by caregivers of children aged 1–5 years with sickle cell disease at China-Uganda Friendship Hospital, Naguru, Kampala District. The study findings showed that more than half, 22 (55%) of the respondents reported knowing the common triggers of sickle cell crisis, with nearly half (45.5%) identifying cold exposure as a major trigger. This finding suggests that some level of awareness has been created among caregivers, likely due to repeated exposure to health education during hospital visits. However, this contrasts with the study problem statement and findings from a study conducted in Nairobi, Kenya, where 72% of caregivers lacked adequate understanding of SCD triggers, medication adherence, and preventive care (Twafleh, 2024). This disparity highlights the need for consistent and reinforced caregiver education.

The study further revealed that a large majority, 32 (80%) of respondents reported experiencing constant stress related to their child's condition. This aligns with the study problem statement and reflects the chronic, unpredictable nature of sickle cell disease, compounded by emotional and financial pressures. Similar findings have been reported in Saudi Arabia, where 66% of caregivers experienced high psychological stress due to fear of child mortality, social stigma, and recurrent crises (Sharif et al., 2020).

Additionally, half 20 (50%) of the respondents reported being unable to pay for their child's treatment. This supports the problem statement and demonstrates that financial constraints remain a major barrier to consistent care and treatment adherence. These findings are consistent with previous research showing that caregivers of children with chronic illnesses often struggle to afford routine medication and clinic visits, leading to missed doses and poor disease control (Adib-Hajbaghery & Ahmadi, 2019).

## Limitations of the study

**Limited Scope:** The study was conducted in one hospital (China-Uganda Friendship Hospital, Naguru), which limits generalization of findings to other facilities with different resources or management systems. **Self-reported Data:** The study relied on self-reported responses, which may have been affected by recall bias or social desirability bias among caregivers. **Cross-sectional Design:** The design captured information at one point in time, making it difficult to determine causal relationships between the identified challenges and caregiving outcomes.

## CONCLUSION

Caregiver-related challenges included emotional stress, financial hardship, and disrupted work schedules caused by frequent hospital visits. Although most caregivers had some knowledge about disease triggers, their understanding of home care and preventive practices was still limited.

**RECOMMENDATION**

Actively seek information from health workers about home care practices and early signs of complications. Adhere to follow-up appointments and prescribed treatments to ensure better health outcomes for their children.

**JFN:** supervised the study.

**HN:** supervised the study.

**IPN:** supervised the study.

**FS:** supervised the study.

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**LIST OF ABBREVIATIONS**

<b>BBF:</b>	Blocked Blood Flow
<b>FA:</b>	Folic Acid
<b>IRC:</b>	Institution Research Committee
<b>MIHS:</b>	Mildmay Institute of Health Sciences
<b>PD:</b>	Pediatric
<b>SCD:</b>	Sickle Cell Disease
<b>UHPAB:</b>	Uganda Health Professions Assessment Board

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The study had no funding.

**CONFLICT OF INTEREST**

The authors declare no conflict of interest

**DATA AVAILABILITY**

Data is available upon request from the author

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**SK:** collected the data.

**GM:** supervised the study.

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