# Understanding Caregiver Knowledge to Improve Home-Based Management of Sickle Cell Disease in Zaria, Nigeria

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*Article*

# Understanding Caregiver Knowledge to Improve Home-Based Management of Sickle Cell Disease in Zaria, Nigeria

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**Abstract**

**Background:** Sickle cell disease (SCD) is a hereditary blood disorder marked by the production of abnormally shaped, rigid red blood cells that obstruct blood flow, resulting in pain, organ damage, and increased infection risk. SCD poses a significant public health challenge in Nigeria, which has the highest global burden, with about 150,000 affected children born annually. The high prevalence is exacerbated by limited healthcare infrastructure, low public awareness, and socio-economic barriers, making effective disease management difficult. Understanding the knowledge of home-based caregivers is essential to identify gaps that may impact care quality. **Aim:** This study explores the knowledge, experiences, and educational needs of home-based caregivers of children with SCD attending the Paediatric Haematology Clinic, ABUTH, Zaria. **Methods:** A qualitative case study design was used, involving in-depth interviews with ten purposively selected caregivers. Interviews were conducted in Hausa, transcribed, and translated into English. Thematic analysis was performed. **Results:** Four themes emerged: 1.Understanding of SCD aetiology 2. Knowledge of symptoms 3. Awareness of complications and 4. Knowledge of SCD type. **Conclusion:** Home-based caregivers had limited knowledge of the genetic basis of the disease, but possess some knowledge of SCD key symptoms, enabling basic disease management and healthcare seeking. However, there is a need to enhance caregiver education to improve, care quality and health seeking behavior for children with SCD.

**Keywords:** home-based caregivers; knowledge; sickle cell disease

## 1. Introduction

Sickle Cell Disease (SCD) is a hereditary blood disorder characterized by the production of abnormal haemoglobin, known as haemoglobin S or sickle haemoglobin. This abnormal haemoglobin causes red blood cells to become rigid and sickle-shaped, which can obstruct blood flow and lead to painful episodes, organ damage, and increased risk of infection [1]. The condition is most prevalent among individuals of African, Mediterranean, Middle Eastern, and Indian ancestry, with the highest burden seen in Sub-Saharan Africa. In this region, it is estimated that about 275,000–305,000 infants are born with SCD annually, making it a significant public health concern [2–5]. In Nigeria alone, more than 150,000 newborns are affected each year, representing the highest national burden globally

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[6,7]. SCD is also a major cause of childhood mortality in Africa, accounting for up to 6% of under-five deaths in some countries [6,8].

Home-based caregivers, most often parents and close relatives, play a central role in the management of SCD, providing essential support to patients in their daily lives. The knowledge and understanding of these caregivers significantly impact the quality of care and the overall well-being of the individuals they support [8–10]. Effective caregiving for SCD requires a comprehensive understanding of the disease, including its symptoms, triggers, complications, and treatment protocols. Studies have shown that caregivers with higher levels of disease-specific knowledge are better equipped to manage acute pain episodes, recognize early signs of complications, and adhere to treatment regimens, thereby improving patient outcomes [2,4,9,10]. However, research across Africa and in Nigeria consistently finds that a substantial proportion of caregivers have inadequate knowledge of SCD and its management, particularly regarding the genetic basis, crisis triggers and potential complications [4,6,9–11]. This knowledge gap can lead to delayed or inadequate care, increasing the risk of severe complications and hospitalizations [4,6,10].

SCD remains a pressing health issue in Nigeria. In Kaduna State, many families ultimately resort to seeking care from tertiary centers [7]. Knowledge and practices of home-based caregivers in this context are crucial for effective management, significantly influencing patient outcomes and quality of life [11]. Caregivers need to be proficient in both pharmacologic and non-pharmacologic pain management strategies, including administering prescribed medications, ensuring hydration, and applying compresses [2,10]. They must also be able to identify situations that necessitate medical intervention, such as severe pain not relieved by home measures, signs of acute chest syndrome, or stroke symptoms [1,10]. However, studies indicate that many caregivers lack comprehensive understanding of SCD pathophysiology, complications, and management strategies, including awareness of triggers such as dehydration, extreme temperatures, and infections [2,4,7,9–11]. Stigma, financial barriers, and limited access to accurate information further complicate caregiving [6–8]. Knowledge gaps in these areas can result in delayed recognition of complications and poorer outcomes [6,9,10[.

This study therefore aimed to explore the knowledge of home-based caregivers on SCD in Ahmadu Bello University Teaching Hospital Zaria, Nigeria, seeking to gather in-depth insights into caregivers' experiences, perceptions, and educational needs.

## 2. Materials and Methods

A qualitative research method was employed to obtain in-depth insights into caregivers' knowledge and experiences. This approach was appropriate as it facilitated the acquisition of information, insights, and awareness, as well as exploring complex perceptions and contextual factors influencing home-based management of SCD. The study was conducted at the Paediatric Haematology Unit at Ahmadu Bello University Teaching Hospital Zaria-Nigeria, which provides care for SCD crises in children at both the emergency and main wards; and operates a weekly follow-up clinic led by Paediatricians. Data was collected from ten (10) purposively selected home-based caregivers, with five (5) having children with SCD aged 0-5 years and the other five (5) having children with SCD aged 6-10 years.

Study Population: The study population comprised home-based caregivers of children with SCD who were either admitted or attending follow-up appointments at the clinic.

Inclusion Criteria: Caregivers of children aged 6 months to 10 years diagnosed with haemoglobin SS phenotype who provided informed consent to participate in the study were included. This age range reflects the typical distribution of younger and older patients mostly seen in the clinic.

Exclusion Criteria: Caregivers of newly diagnosed patients and those with other co-morbidities in addition to SCD.

**Sampling**: Purposive sampling was used to select participants with direct care-giving experience. This method allowed us to choose a sample based on the participants' experiences,

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enabling the selection of information-rich cases that provide insights and a deep understanding of their experiences and knowledge. Saturation was achieved after interviewing 10 participants: five with children 6 months to 5 years and five with children aged 6 to 10 years. Saturation occurs when data collection reached a point of diminishing returns, with no new information being added.

**Data Collection Procedure**: In-depth interviews using an interview guide were conducted. The interviews were carried out in Hausa (the participants' local language) or English depending on participants' preference. Those willing to join the study were given written consent forms in English, translated into a language they understood (Hausa in all the cases). The interviews took place in a quiet room at the hospital, ensuring participants' anonymity and privacy, and lasted about 50 to 60 minutes. Detailed field notes capturing the environment, nonverbal cues, interruptions, and personal reflections were maintained. The interviews were audio-recorded with consent, transcribed in Hausa, and later translated into English. A pilot with two participants was conducted which guided the standardization of the interview guide, its translation into Hausa language, duration of interview and other logistics of data management and analysis. (MF, HRA and JAF)

Data Analysis. Manual Thematic content analysis was used to analyze the data, involving a descriptive presentation of qualitative data. This method entailed examining all the data to identify key themes that encapsulate the views collected. In our study, this was accomplished by coding major ideas, which were subsequently reorganized into themes that summarized the participants' insights. Thematic content analysis was conducted following an inductive approach. Transcripts were read repeatedly to ensure familiarity, coded line-by-line, and grouped into categories that were later refined into major themes. Coding was conducted manually by the primary researcher and reviewed by a second and third qualitative researcher to enhance analytic rigor and credibility (MF, NMA, JAF).

Ethical Considerations. Ethical clearance for this study was secured, along with permission from the Health Research Ethics Committee (HREC) of ABUTH, Zaria (ABUTH/HREC/). Written informed consent was obtained from all home-based caregivers prior to enrollment in the study, with assurances that their responses would remain anonymous. No participant identifiers were collected.

## 3. Results

**Knowledge of home-based caregivers on SCD in Children**. Participants were asked about their knowledge of SCD, and four overarching themes emerged from their responses.

**Theme 1: Understanding SCD aetiology**

Most caregivers had limited knowledge of the genetic basis of SCD. Only two correctly identified SCD as a hereditary condition passed from parents to children:

*"It is hereditary. If your parents have the genes, you can inherit it."* (Participant 4)

*"We were told it is genetic and passed from parents."* (Participant 10)

Several caregivers attributed SCD to misconceptions such as worms, poor feeding, or blood incompatibility:

*"Some say worms cause it when children do not eat well."* (Participant 6)

*"I think it has to do with blood types—maybe positive and negative."* (Participant 7)

**Theme 2: Knowledge of symptoms**

Caregivers demonstrated good awareness of common symptoms, including pain, fever, swelling, and difficulty breathing:

*"Sometimes his hands swell; he complains of chest and back pain." The boy sometimes has pain in his back and chest and struggles to breathe."* (Participant 1)

*"He develops fever, joint pains, and sometimes cough."* (Participant 6)

**Theme 3: Awareness of complications**

Knowledge of complications was limited. Only two caregivers identified anemia or infection as possible complications:

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*"They are very stressed and exhausted. They get tired easily, maybe from the disease."* (Participant 3)

*"Complications like anemia and infections happen."* (Participant 5)

Most caregivers recognized symptoms but could not link them to specific complications such as acute chest syndrome, stroke, or severe anemia.

**Theme 4: Knowledge of SCD Type**

Seven caregivers knew the specific genotype diagnosis (e.g., HBSS) of their children. Three caregivers were unaware:

*"They did not tell me the type my child has."* (Participant 8)

## 4. Discussion

The findings from the study revealed considerable gaps in caregivers' knowledge of SCD aetiology and complications despite adequate recognition of symptoms. While they demonstrate adequate knowledge of the signs and symptoms of SCD, such as pain, fever, and yellowing of the eyes or urine, there are significant gaps in their understanding of the underlying causes and potential complications of the disease. These findings are similar to other studies in Nigeria, Ghana and [2,11,12]. The finding that some caregivers attributed SCD to worms, poor feeding, or incompatible marriages indicates persistent myths also reported in previous Nigerian studies [13]. Such misconceptions hinder informed decision-making, including partner genotype screening and early diagnosis.

The study further highlights that most caregivers could not recognize SCD as a hereditary condition passed down from parents to children. Furthermore, a concerning number of caregivers attribute the disease to local superstitions or misconceptions, such as believing it is caused by worms or the result of certain types of marriages [13,14]. This lack of understanding about the genetic basis of SCD is a significant barrier to effective disease management and prevention. While caregivers are generally aware of the common signs and symptoms of SCD, they often struggle to effectively identify and monitor disease-related crises or complications. Only a few caregivers were able to recognize complications like anemia and infections as potential consequences of the disease [1,11]. The findings highlight the need for more comprehensive education and support for caregivers of children with SCD [9,11,13].

The limited understanding of complications is concerning. Complications like acute chest syndrome, severe infections, and stroke are major causes of morbidity and mortality among children with SCD, and caregiver recognition is critical for prompt medical intervention [15]. The inability to identify worsening symptoms increases the risk of delayed treatment and avoidable crises. Although caregivers generally recognized their children's symptoms, the gaps in underlying understanding reflect limited health literacy. Similar findings in other African contexts show that caregivers often equate SCD primarily with pain and fever while overlooking life-threatening complications [16]. The fact that most caregivers knew their child's haemoglobin status suggests effective communication at the clinic. However, this knowledge did not translate into deeper understanding of the disease process, highlighting the need for strengthened caregiver education, reinforced counseling, and culturally appropriate health communication strategies.

*Limitations*

This study is limited by the small sample size of only ten caregivers from a single tertiary institution. This limits generalizability of findings to other clinical, educational, social and geographical scenerios. The interviews were translated from English to Hausa and transcribed from Hausa to English, which may introduce loss of nuance despite efforts to ensure accuracy. The study also did not include fathers and significant other family members who may have different knowledge levels.

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## 5. Conclusions

While caregivers demonstrate a basic understanding of the symptoms of SCD, significant gaps exist in their knowledge of the disease's etiology and potential complications. This lack of comprehensive understanding and the misconceptions about disease etiology hinders effective home disease management, crisis prevention and lead to suboptimal outcomes by delaying timely medical care. To address these gaps, healthcare providers and policymakers must prioritize the development and implementation of targeted educational interventions for home-based caregivers. Strengthening health education for caregivers is essential to improving child outcomes and reducing preventable SCD-related complications in Northern Nigeria.

## 6. Recommendations

Based on the findings from this study, the following recommendations were made to address the knowledge gaps among home-based caregivers of children with sickle cell disease (SCD):

To improve the understanding of SCD's etiology and inheritance, caregiver education was re-enforced at the clinic with documentation of topics discussed during consultations. Flyers and leaflets were developed and translated into Hausa language. Caregiver support groups are formally included to promote shared learning and peer support.

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**Institutional Review Board Statement:** The study was conducted in accordance with the Declaration of Helsinki, and approved by the ABUTH Ethics Committee on 27 January 2023 (ABUTHZ/HREC/F43/2023).

**Informed Consent Statement:** Informed consent was obtained from all subjects involved in the study. Written informed consent has been obtained from the patient(s) to publish this paper.

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**Conflicts of Interest:** The authors declare no conflicts of interest. The funders had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript; or in the decision to publish the results.

## Abbreviations

The following abbreviations are used in this manuscript:

| | |
|---|---|
| ABU | Ahmadu Bello University |
| ABUTH | Ahmadu Bello University Teaching Hospital |

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| | |
|---|---|
| HBSS | Haemoglobin SS |
| HREC | Health Research Ethics Committee |
| SCD | Sickle cell Disease |

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