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PHYSICAL, PSYCHOSOCIAL AND ECONOMIC BURDEN AMONG CAREGIVERS OF CHILDREN WITH SICKLE CELL DISEASE AT MASAKA REGIONAL REFERRAL HOSPITAL, UGANDA

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Abstract

The burden of caring for children with sickle cell disease extends beyond clinical demands to include physical, psychosocial, and economic challenges. This study explored the physical, psychosocial, and economic burden experienced by caregivers of children with sickle cell disease at Masaka Regional Referral Hospital, Uganda. A phenomenological qualitative study design was employed to capture caregivers lived experiences of caregiving. The study involved caregivers of children diagnosed with sickle cell disease who were attending paediatric services at the hospital. The respondents were selected using purposive sampling until data saturation was achieved with 22 respondents. Data were collected using in-depth, semi-structured interview guides. Data were analyzed using thematic analysis following an inductive approach. Findings revealed pronounced physical burden characterized by sleep deprivation, fatigue, and continuous caregiving demands. Psychosocial burden emerged through stigma, discrimination, marital strain, social isolation, and emotional distress, often linked to community misconceptions about sickle cell disease. Economic burden was reflected in lost income, high transport costs, expensive investigations, frequent hospital visits, and medication stock-outs, which strained already limited household resources. In conclusion, the caregivers experienced a physical, psychosocial, and economic burden exacerbated by weak health system support and lack of structured psychosocial services. It is recommended that health systems strengthen psychosocial support services and integrate caregiver-focused interventions. Community-based education and peer support programmes are also recommended to reduce stigma and improve coping among caregivers.

Keywords: *Caregiver, Economic burden, Physical burden, Psychosocial stress, Sickle cell disease*

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Introduction

Sickle cell disease (SCD) is a hereditary haemoglobin disorder characterised by the production of abnormal haemoglobin, which causes red blood cells to assume a rigid, crescent shape (Besser et al., 2024). These distorted cells obstruct blood flow, resulting in recurrent pain episodes, chronic anaemia, organ damage, and heightened vulnerability to infections (Aloufi et al., 2024). SCD is a lifelong condition that begins in early childhood and requires continuous medical attention to prevent complications and premature mortality (Shdaifat, 2025). Globally, SCD represents a major public health concern, but its burden is disproportionately concentrated in low- and middle-income countries, particularly those in sub-Saharan Africa where health systems are often under-resourced (Beli et al., 2024).

The high prevalence of SCD in sub-Saharan Africa is largely attributed to the historical persistence of the sickle cell trait as a genetic adaptation conferring partial protection against malaria. According to Abdallah et al. (2025), about two-third of children born with SCD worldwide are found in sub-Saharan Africa. In this region, delayed diagnosis, limited access to specialised care, and weak health infrastructure contribute significantly to high morbidity and mortality rates among affected children (Kapke et al., 2025). Many children with SCD do not survive beyond early childhood, especially in settings where newborn screening programmes and comprehensive care services are limited.

Uganda bears a substantial share of this burden. National estimates indicate that approximately 0.73% of the Ugandan population is affected by SCD, while up to 13.3% carry the sickle cell trait (Alinda et al., 2025). This high carrier rate places future generations at continuous risk. A significant proportion of these children die before reaching their fifth birthday, largely due to late diagnosis, inadequate follow-up, and poor access to essential treatments.

Beyond its clinical manifestations, SCD imposes an extensive burden on families, particularly on caregivers who assume primary responsibility for the child's daily care (Larson et al., 2025). Caring for a child with SCD requires sustained engagement with healthcare services, frequent hospital visits, strict adherence to medication regimens, and constant vigilance to prevent or manage complications. These responsibilities are physically demanding and emotionally tasking, as caregivers must cope with recurrent pain crises, frequent hospitalisations, and uncertainty regarding the child's prognosis. The chronic nature of SCD means that caregiving demands persist over many years, often without adequate institutional or social support (Gordon et al., 2024).

The physical burden experienced by caregivers is substantial. Long hours of caregiving, night-time monitoring during pain episodes, and repeated hospital stays often lead to sleep deprivation, exhaustion, and deterioration of caregivers' own health (Tamboli et al., 2025). These physical demands are intensified in resource-limited settings, where health facilities are distant, understaffed, or inadequately equipped to provide timely care.

In addition to physical strain, caregivers face profound psychosocial challenges. Widespread misconceptions about SCD contribute to stigma and discrimination within communities (de-Montalembert et al., 2024). Cultural beliefs that associate SCD with curses or supernatural causes further exacerbate emotional distress and hinder social support. Over time, these experiences can result in chronic feelings of helplessness.

The economic burden of caregiving is equally significant. Families often incur high out-of-pocket expenses related to medical consultations, laboratory investigations, medications, special nutritional requirements, and transport to health facilities. Gordon et al. (2024) noted that these costs are compounded by loss of income, as many caregivers reduce working hours or withdraw entirely from employment to meet caregiving demands. For households already facing financial constraints, the cumulative economic impact of SCD caregiving can be devastating, reinforcing cycles of poverty and limiting access to essential care.

Masaka Regional Referral Hospital serves a large catchment population in southern Uganda and provides care to many children living with SCD. Despite its critical role, the hospital operates within a context of limited resources, staff shortages, and inconsistent availability of essential medicines and support services. Understanding caregivers' lived experiences within this setting is therefore essential for informing context-specific interventions.

Although SCD has been widely studied in terms of clinical outcomes and disease management, there remains limited empirical evidence on the multidimensional burden experienced by caregivers in Uganda. In particular, there is a paucity of qualitative research exploring how physical, psychosocial, and economic challenges intersect in the daily lives of caregivers. Addressing this gap is crucial for the development of family-centred care models and supportive interventions that respond to caregivers' actual needs.

This study sought to explore the physical, psychosocial, and economic burden experienced by caregivers of children with sickle cell disease at Masaka Regional Referral Hospital, Uganda.

Methodology

Ethical approval

Ethical approval for the study was obtained from the Institutional Ethics Review Board of Masaka Regional Referral Hospital. Written informed consent was

obtained from all respondents before their inclusion in the study. The respondents were informed about the purpose of the study, voluntary participation, confidentiality, and their right to withdraw at any time without consequences. To ensure anonymity, no personal identifiers were recorded, and all data were used strictly for research purposes.

Study design

A phenomenological qualitative study design was employed to explore the lived experiences of caregivers of children with sickle cell disease. This design was considered appropriate because it allowed the respondents to describe their experiences in their own words within the natural context of caregiving.

Sample size and sampling technique

The study included a total of 22 caregivers of children diagnosed with sickle cell disease. The sample size was determined based on data saturation rather than statistical calculation. Caregivers were approached and assessed for eligibility. Recruitment continued through purposive sampling until no new themes or meaningful insights emerged from the interviews (Data saturation).

Data collection tool

Data were collected using a semi-structured interview guide developed in line with the study objectives. The guide contained open-ended questions that explored caregivers' physical demands, psychosocial experiences, and economic challenges related to caring for children with sickle cell disease. Probing questions were used to clarify responses.

Data collection procedure

Data collection was conducted at Masaka Regional Referral Hospital in a private and quiet setting to ensure confidentiality and comfort. Eligible caregivers were identified during clinic visits and invited to participate after receiving detailed information about the study. Interviews were conducted face-to-face by the research team and lasted approximately 30–45 minutes. With the respondents' consent, interviews were audio-recorded to ensure accuracy. Field notes were also taken to capture non-verbal cues. Data collection proceeded concurrently with preliminary analysis to assess saturation.

Data analysis

Audio-recorded interviews were transcribed verbatim and reviewed for accuracy before analysis. Data were analysed using inductive thematic analysis. Transcripts were read repeatedly to achieve familiarisation, after which initial codes were generated based on emerging patterns. Similar codes were grouped into categories and further refined into themes.

Results

Table 1 presents the profile of the 22 respondents and showed they were aged 23–58 years, with a predominance of females. Most of the respondents were engaged in informal or subsistence livelihoods, including peasantry and trading. A smaller number were farmers, housewives, or employed in skilled occupations such as teaching, tailoring, and hairdressing.

Table 1: Profile of the respondents (n = 22)

Participant ID	Age	Gender	Occupation
C01	24	Female	Peasant
C02	44	Female	Peasant
C03	44	Female	Peasant
C04	24	Female	Peasant
C05	42	Female	Peasant
C06	42	Female	Peasant
C07	26	Female	Peasant
C08	58	Female	Peasant
C09	53	Female	Trader
C10	48	Female	Trader
C11	40	Female	Trader
C12	55	Female	Trader
C13	32	Female	Trader
C14	32	Female	Trader
C15	23	Female	Trader
C16	25	Female	Seamstress
C17	40	Female	Teacher
C18	50	Female	Housewife
C19	53	Female	Housewife
C20	55	Female	Farmer
C21	48	Female	Farmer
C22	46	Male	Hairdresser

n = sample size

Table 2 presents the burden of caregivers of children with sickle cell disease and showed that they experience multidimensional burdens. Physically, they face exhaustion, sleep deprivation, and constant medication management. Emotionally, they endure anxiety, depression, social isolation, and stigma. Economically, they struggle with high medical costs, transport challenges, loss of income, and inadequate nutrition. Socially, caregivers encounter moral judgment, misconceptions, and exclusion. Health system limitations, including drug stock-outs, poor access, and absence of support groups, further exacerbate these challenges, highlighting the need for holistic interventions to support caregivers and improve the wellbeing of affected children.

Table 2: Burden among Caregivers of Children with Sickle Cell Disease (n = 22)

Category	Representative Quotes	Emerging Themes
Physical Burden	"I stay awake all night monitoring my child when pain starts. Sometimes I even carry the baby on my back while looking after the younger one" (C01). "I walked many kilometres to get medicines, and sometimes I slept on the hospital floor" (C04). "I must give medicine daily and manage emergencies. It is very tiring" (C08).	Sleep deprivation, exhaustion from caregiving, medication management challenges.

Emotional / Psychosocial Burden	"I feel so stressed, thinking what will happen to my child if I am not around" (C07). "My husband left me, so I take care of all the children alone" (C18). "People say my child is cursed. Sometimes I feel isolated and blamed" (C13). "Seeing my child sick all the time makes me sick inside" (C16).	Anxiety and depression, sense of helplessness, social isolation, stigma
Economic Burden	"The hospital drugs are not always available. I buy from private pharmacies, but they are expensive" (C10). "Transport is so costly, sometimes I have to walk long distances" (C09). "I had to stop farming this season because my child needed constant care" (C21). "We cannot afford the recommended diet, fruits, or vegetables" (C05).	High out-of-pocket costs, transport challenges, loss of income, inadequate nutrition, lack of insurance
Social Stigma / Discrimination	"People say I bewitched my child, and sometimes I am called 'mother of the SCD child'" (C13). "The community thinks the disease is a curse, so I am avoided" (C15). "I keep my child separate from other children to avoid problems" (C02).	Community misconceptions, moral judgment, social isolation
Health System Challenges	"Some medicines like hydroxyurea are not available" (C17). "Access is hard because roads are bad and distances long" (C20). "There are no peer support or professional-led caregiver groups" (C06).	Inadequate healthcare access, stock-outs of essential drugs, lack of social support systems

n = sample size

Discussion

This study explored the physical, psychosocial, and economic burden experienced by caregivers of children with sickle cell disease (SCD) at Masaka Regional Referral Hospital, Uganda. Concerning physical burden, the caregivers in this study experienced profound physical strain, primarily driven by recurrent hospital admissions and the continuous demands of caregiving. Many caregivers described prolonged periods of standing in clinics, frequent walking to obtain medications, and sleeping on floors during hospital stays, which led to fatigue and musculoskeletal discomfort. These findings are consistent with Nkya et al. (2021), whose study in Tanzania highlighted the unpredictable nature of crises and repeated hospital visits as major contributors to caregiver exhaustion. Similarly, Okeke et al. (2020) emphasised that poor sleeping arrangements in hospital settings compromise caregivers' physical health and exacerbate fatigue. Long distances to health facilities further intensified the physical burden. Stock-outs of essential medicines often compelled caregivers to travel long distances to private pharmacies, which increased fatigue and time commitment. Adejumo et al. (2023) similarly noted that drug shortages exacerbate physical strain, as caregivers must expend additional effort to secure medications. The cumulative effect of these physical demands is significant. Sleep deprivation, prolonged standing, and continuous caregiving may not only affect caregivers' health but can also reduce their capacity to provide optimal care.

Regarding emotional and psychosocial burden, the study revealed that caregivers experience intense emotional stress, particularly when faced with financial constraints that limit access to treatment. Caregivers reported feelings of despair, anxiety, and worry, especially during crises such as pain episodes, malaria infection, or the need for blood transfusions. These findings align with Nkya et al. (2021), who found that caregivers experience psychological burden when children display delayed developmental milestones or chronic pain. Bangirana et al. (2020) similarly highlighted that social isolation further compounded emotional stress. The caregivers reported minimal family support, with partners and relatives frequently absent, leaving mothers to manage caregiving responsibilities alone. Nkya et al. (2021) similarly observed that fathers frequently disengage after the diagnosis of SCD, intensifying the emotional burden on mothers. These experiences contribute to a sense of helplessness and chronic stress, underscoring the importance of psychosocial support systems within and beyond hospital settings.

In terms of economic burden, the economic challenges were a salient theme in this study. Frequent stock-outs of essential drugs, including hydroxyurea, compelled caregivers to purchase medicines from private pharmacies at high costs. This finding aligns with Adejumo et al. (2023), who reported that drug unavailability in public hospitals forces caregivers into unsustainable financial hardships. In addition, the need for diagnostic tests often led caregivers to private laboratories, where costs were substantially higher than in government facilities. Nkya et al. (2021) highlighted that reliance on private diagnostic services contributes to catastrophic health expenditures, particularly in low-income households. Frequent hospital visits, both for emergencies and routine care, imposed further financial strain. Caregivers reported borrowing money to cover treatment costs, transport, and hospital stays. These observations were consistent with Adebayo et al. (2024), who demonstrated that repeated healthcare utilization significantly increases household financial distress. Additionally, many caregivers were unable to sustain income-generating activities due to caregiving responsibilities. Ogunyemi et al. (2024) similarly reported that caregivers often miss work or forgo farming

and business opportunities, resulting in substantial income loss and reduced household economic stability. The economic burden extended beyond direct medical costs. Caregivers struggled to meet nutritional needs, afford recommended diets, and provide educational support for their children. Lack of health insurance compounded these challenges, leaving families financially vulnerable. These findings underscore the importance of policies and interventions that reduce out-of-pocket healthcare costs and enhance financial protection for caregivers, such as subsidised medications, nutrition support programmes, and health insurance schemes.

Concerning social stigma and discrimination, caregivers, particularly mothers, faced significant social stigma and discrimination. Societal misconceptions about SCD often attributed blame to mothers, associating the condition with curses, negligence, or moral failings. Alinda et al. (2025) similarly reported that caregivers in Uganda face psychological distress and social exclusion due to societal misperceptions. Caregivers were advised by relatives and community members to limit investment in the education or treatment of affected children, reflecting a lack of understanding of the disease's manageability. Visible clinical manifestations, such as bone deformities, stunted growth, and yellow eyes, further heightened public scrutiny and social isolation. Caregivers reported being labelled "mother of the SCD child" and encouraged to keep the child away from peers due to fears of contagion. These experiences created emotional distress and feelings of helplessness. Belief in herbal remedies or witchcraft as causative or curative factors may have exacerbated these challenges. Caregivers felt tucked between adhering to medical recommendations and responding to societal expectations. Agaba et al. (2025) found that a substantial proportion of caregivers endorsed non-scientific causes and treatments for SCD, highlighting the need for community education and awareness campaigns.

On health system challenges, the study also highlighted systemic barriers that exacerbate caregiver burden. Long distances to health facilities, poor road infrastructure, and limited budgets impeded access to care. Stock-outs of essential medicines, and absence of peer or professional support groups compounded caregivers' challenges. These findings reflect broader health system weaknesses in Uganda, which undermine comprehensive care for children with SCD and place additional pressure on families. Addressing these systemic challenges requires targeted interventions, including decentralisation of services to improve accessibility, strengthening supply chains for essential medications, and establishing structured caregiver support systems (Alinda et al., 2025).

Implications for Practice and Policy

The findings underscore the urgent need for interventions that address the multidimensional burden on caregivers of children with SCD. Physical support measures, including designated rest areas in hospitals, are critical. Psychosocial support, counselling services, and community education programmes can alleviate emotional stress and reduce stigma. Financial interventions, such as subsidies for essential drugs, transport support, and health insurance schemes, are necessary to mitigate economic strain. Strengthening health system capacity through adequate staffing, reliable drug supply, and follow-up services is also essential.

Conclusion

Caregivers of children with sickle cell disease experience physical, emotional, psychosocial, and economic burdens. These challenges are compounded by health system weaknesses, social stigma, and lack of structured support. Family-centred interventions are essential to improve outcomes.

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Competing Interest

The authors declare no conflict of interest.

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