



ORIGINAL ARTICLE

Economic Burden of Sickle Cell Disease at Tertiary Health Facilities in Tanzania: Financial Impact on Patients at Muhimbili National Hospital

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ABSTRACT

Background: Sickle cell disease (SCD) affects thousands in Tanzania, causing high healthcare costs and economic burden. This study estimates the annual cost of SCD care for patients at Muhimbili National Hospital.

Methods: This descriptive, cross-sectional study was conducted from June 2021 to May 2022 at Muhimbili National Hospital, Tanzania. A systematic sampling method was used to select 207 patients. Data were collected through structured interviews. Direct cost was also obtained from individual perspective and indirect costs were assessed using the Human Capital Method. Finally, data processing was done in Microsoft Excel, and analysis was performed using SPSS₂₀.

Results: A total of 207 patients participated, with 91.3% under 18. The average annual cost of SCD care was TZS 847,186.01 (USD 367.62), with direct costs accounting for 76.4%. Medications, tests, and consultations were the major contributors to these costs (48%), and health insurance reduced costs by 64.4%.

Conclusion: SCD in Tanzania creates a significant financial burden, primarily due to direct medical costs, along with indirect costs like lost productivity. Addressing this requires better health insurance access, reduced indirect costs, and improved healthcare infrastructure.

Keywords; Sickle Cell Disease (SCD), Healthcare costs, Tanzania, Economic burden, Muhimbili National Hospital, Patient costs

Introduction

SCD is a genetic blood disorder that affects millions globally, with a particularly high prevalence in sub-Saharan Africa. Characterized by the production of abnormal hemoglobin, SCD causes red blood cells to take on a crescent or sickle shape, leading to blockages in blood flow, severe pain crises, organ damage, and frequent hospitalizations. The disease is also associated with early mortality, significantly reducing life expectancy (1, 2).

The symptoms of SCD include chronic pain,

fatigue, frequent infections, strokes, and episodes of acute pain crises, which often require urgent medical attention. Over time, these complications can lead to long-term disability, limiting an individual's ability to engage in work or education. This is particularly concerning in low-resource settings like Tanzania, where the disease places a heavy burden on both the healthcare system and the broader economy (3, 4).

From a human capital perspective, SCD not only affects the health of individuals but also their ability to contribute to the workforce. Chronic

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illness and disability reduce the economic potential of affected individuals, as they are often unable to maintain consistent employment or educational advancement. This diminished workforce capacity has broader implications for economic productivity, as it impacts both direct labor participation and the development of human resources needed for national development (4, 5).

In Tanzania, where SCD affects thousands annually, the disease presents substantial challenges. Limited access to healthcare, compounded by financial barriers, further restricts the ability of affected individuals to manage their condition effectively. This disability, both physical and economic, hinders individuals' potential to contribute to their families and communities, exacerbating poverty and impeding economic progress (6, 7, 16, 17).

This study seeks to understand the economic impact of SCD on individuals attending the Sickle Cell Clinic at Muhimbili National Hospital (MNH), Tanzania's largest referral hospital. By quantifying the direct and indirect costs of care, the research will explore how the disease affects the lives of patients and their families, focusing on the disability and lost human capital that result from SCD. Ultimately, the study aims to provide insights that can inform policies to reduce the financial burden of the disease and improve the socioeconomic outcomes for affected individuals.

Materials and Methods

Study Design

This study was a descriptive cross-sectional COI study, using both direct and indirect cost assessments. The study was conducted at the Sickle Cell Clinic at MNH from June 2021 to May 2022 (12).

Study Population

A total of 207 patients who visited Muhimbili National Hospital Clinic during the study period were included. Among four tertiary hospitals, simple random sampling was carried out to select MNH to represent tertiary facilities. A systematic random sampling method was used to select

participants, ensuring diversity in age, gender, and disease severity (13).

Inclusion and Exclusion Criteria

The study included all SCD patients attending the outpatient sickle cell clinic at MNH, regardless of their hemoglobin genotype (Hb SS, Hb SC, or others). SCD patients who were admitted to the hospital were excluded. Those who were too old to participate due to their health conditions were excluded. Moreover, patients who did not visit the hospital at all in 2021 were excluded, as their costs would not accurately reflect a full year of evaluation for the study (12).

Data Collection

Data were collected using structured interview-based questionnaires. The questionnaire covered direct medical costs (e.g., medication, consultations, laboratory tests), direct non-medical costs (e.g., transportation, accommodation), and indirect costs (e.g., lost income, caregiver time) (12). All the costs were valued according to TSH or USD of June 2022.

Cost Valuation

Indirect costs were estimated using the Human Capital Method, which values lost productivity based on patients' and caregivers' time away from work or school and ensures equity across the studied population. The total annual costs were calculated by summing direct and indirect costs, with the average being total divided by the whole population sample examined (12, 16).

Statistical Analysis

Data analysis was performed using SPSS₂₀. Descriptive statistics were used to summarize the data, and deterministic sensitivity analyses were conducted to assess the robustness of the results by varying the cost of medicines and income levels (12).

Results

Socio-demographic characteristics of SCD clients

The majority of SCD clients were young, with 91.3% under 18 years old, and a slight male predominance (53.6%). Most clients were either employed, were housewives, or students, with a smaller portion being unemployed. A significant proportion (84.1%) had health insurance, suggesting good access to healthcare, although 15.9% lack insurance. Most clients earned less than 300,000 Tsh (USD 130.74) per month, with a mean income of approximately 328,862 Tsh. Furthermore, less than half (42%) of the cases were accompanied by a caregiver, with caregivers mainly being employed or housewives (Table 1).

Direct and indirect cost analysis

The average annual cost of accessing SCD services at MNH was TZS 847,186.01 (USD 367.62). Of this, direct costs accounted for 76.4% of the expenditure (TZS 647,573.23 or USD 281.01), while indirect costs made up 23.6% of the total amount (TZS 199,612.78 or USD 86.62) (Fig.1). Direct medical costs (including medication, laboratory tests, and consultations) accounted for 63.1% of the total cost, while direct non-medical costs (e.g., transportation) were 13.3% (Table 2).

Table 1: Socio-demographic characteristics of SCD clients

| Characteristic | Number (%) |
|------------------------------------|----------------|
| Sex | |
| Male | 111 (53.6) |
| Female | 96 (46.4) |
| Age | |
| <18 | 189 (91.3) |
| 19-29 | 15 (7.2) |
| >30 | 3 (1.4) |
| Occupation | |
| Employed | 60 (29.0) |
| Housewife | 54 (26.1) |
| Student | 51 (24.6) |
| Unemployed | 42 (20.3) |
| Health insurance possession | |
| No | 33 (15.9) |
| Yes | 174 (84.1) |
| Income per month | |
| <300,000 Tsh | 72 (82.8) |
| 300,000-1,000,000 Tsh | 9 (10.3) |
| >1,000,000 Tsh | 6 (6.9) |
| Mean income | 328,862.07 Tsh |
| Accompanied by caregiver | |
| Yes | 87 (42.0) |
| No | 120 (58.0) |
| Caregiver occupation | |
| Employed | 36 (41.4) |
| Housewife | 24 (27.6) |
| Unemployed | 27 (31.0) |

Table 2: Direct and indirect costs

| Cost element | N | Total cost | Mean total cost TSH | Standard deviation (SD) | Cost profile (%) |
|----------------------------------|-----|-----------------------|---------------------|-------------------------|------------------|
| Direct cost | | | | | |
| Direct medical cost | | | | | |
| Registration/folders | 207 | 15,927,000.00 | 76,942.03 | 65,174.05 | 9.1 |
| Consultation | 202 | 17,561,993.00 | 86,940.59 | 93,710.77 | 10.3 |
| Investigations | 198 | 18,823,200.00 | 95,066.67 | 198,843.66 | 11.2 |
| Medicines/drugs | 207 | 46,443,660.00 | 224,365.22 | 308,811.44 | 26.5 |
| Other diagnostic tests | 58 | 2,979,000.00 | 51,362.07 | 55,991.76 | 6.1 |
| Sub total | | 101,734,853.00 | 534,676.58 | 722,531.68 | 63.1 |
| Direct non-medical cost | | | | | |
| Patient | | | | | |
| Transportation and communication | 207 | 6,527,400.00 | 31,533.33 | 42,449.99 | 3.7 |
| Food and drinks | 207 | 4,649,360.00 | 22,460.67 | 17,776.40 | 2.7 |
| Caregiver | | | | | |
| Transportation and communication | 87 | 2,976,300.00 | 34,210.34 | 56,619.48 | 4.0 |
| Food and drinks | 78 | 1,926,000.00 | 24,692.31 | 30,299.50 | 2.9 |
| Sub total | | 16,079,060.00 | 112,896.65 | 147,145.37 | 13.3 |
| Total direct cost | | 117,813,913.00 | 647,573.23 | 869,677.05 | 76.4 |

| Indirect cost | | | | | |
|-----------------------------|-----|-----------------------|-------------------|--------------------|-------------|
| Patient | | | | | |
| Valued productive days lost | 102 | 5,788,180.00 | 56,746.87 | 42,084.65 | 6.7 |
| Valued traveling time | 102 | 397,300.00 | 3,895.10 | 4,874.59 | 0.5 |
| Valued waiting time | 102 | 1,019,370.00 | 9,993.79 | 3,793.66 | 1.2 |
| Caregiver | | | | | |
| Valued productive days lost | 66 | 7,672,600.00 | 116,251.40 | 156,901.22 | 13.7 |
| Valued traveling time | 66 | 249,580.00 | 3,781.57 | 5,371.55 | 0.5 |
| Valued waiting time | 66 | 590,307.00 | 8,944.05 | 3,612.81 | 1.1 |
| Total indirect cost | | 15,717,737.0 | 199,612.78 | 216,638.48 | 23.6 |
| Total costs | | 133,531,250.00 | 847,186.01 | 1,86,315.53 | 100 |

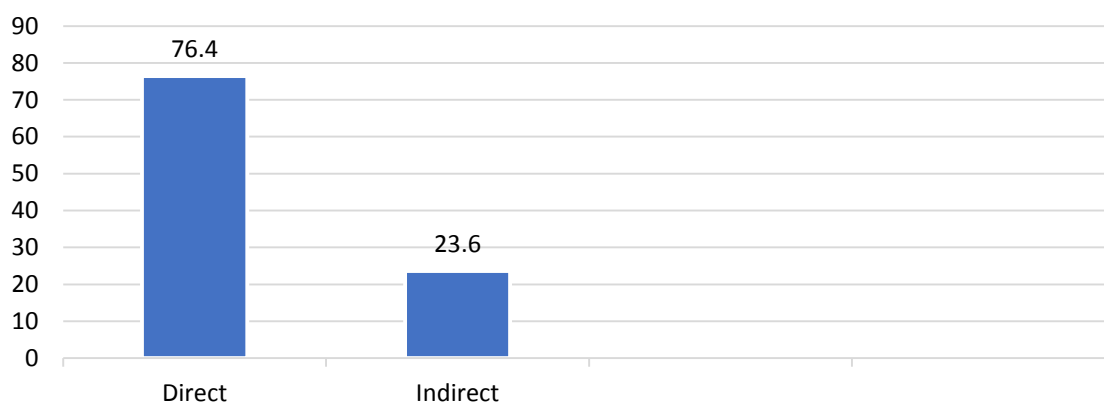


Figure 1: Breakdown distribution of SCD Costs (%)

Impact of health insurance

Health insurance significantly reduced the financial burden of SCD care. Patients with insurance paid an average of TZS 301,288.74 (USD 130.74) annually for treatment, compared to the uninsured, which spent the full TZS 847,186.01 (USD 367.62).

Income and cost burden

The average annual income of employed participants was TZS 3,946,344 (USD 1,712.46). Employed individuals with SCD allocated an average of 21.5% of their annual income to SCD treatment, while those with medical insurance spent 7.6% of their income on healthcare expenses. A significant proportion of patients (55.1%) were unemployed, which may be attributed to the debilitating nature of SCD and its detrimental impact on work attendance and productivity.

Scenario Analysis

Scenario analysis was performed using deterministic

sensitivity analyses on key cost components, including medication and wage rates, to examine their impact on total costs. The results are summarized in the table 3.

Even small increase in medication costs lead to notable increases in total treatment costs, which highlight the importance of controlling medication prices in reducing the financial burden regarding patients. Higher wage rates, which reflect the opportunity cost of lost productivity (both for patients and caregivers), also contribute significantly to the total cost.

When both medication and wage rate costs rise, the overall financial burden increases more than the sum of their individual impacts, suggesting that both components interact regarding the total cost. Both medication costs and wage rates are important cost drivers for SCD treatment. Changes in either of these factors can significantly impact the total cost of care (Table 3)

Table 3: Scenario analysis: Impact of cost components on total cost

| Scenario | Cost component | Percentage change parameter | Total Cost (TSH) | percentage Change in Cost |
|--|---------------------|-----------------------------|------------------|---------------------------|
| Base scenario | | 0 | 847,186.01 | 0.0 |
| Variation (One-way Sensitivity Analysis) | Medication | 3% | 853,910.96 | 0.8% |
| | | 5% | 858,404.26 | 1.3% |
| | | 7% | 862,891.57 | 1.8% |
| Variation (One-way Sensitivity Analysis) | Wage Rate | 3% | 863,051.86 | 1.9% |
| | | 5% | 873,629.10 | 3.1% |
| | | 7% | 884,206.35 | 4.3% |
| Multi-variation (Multi-way Sensitivity Analysis) | Medication and Wage | 3% | 869,782.82 | 2.6% |
| | | 5% | 884,847.36 | 4.4% |
| | | 7% | 899,914.91 | 6.2% |

Discussion

This study highlights the significant and multifaceted financial burden of SCD on patients attending the Sickle Cell Clinic at Muhimbili National Hospital (MNH), Tanzania. The results underscore the complexity of managing a chronic disease in a low-resource setting, where the interplay of medical, non-medical, and indirect costs creates substantial economic strain on patients and their families. Previous studies in sub-Saharan Africa have similarly documented the extensive burden of SCD, with Nigeria and Ghana reporting substantial out-of-pocket expenses for families, particularly due to the need for continuous medical care (1, 2, 14, 16).

The direct medical costs of SCD care, including medications, consultations, and investigations, represented 63.1% of the total expenditure in the study population. This was consistent with findings from other sub-Saharan African countries, where direct medical expenses for managing chronic conditions such as SCD are often the largest financial burden on patients (4, 9, 15, 16). Among these direct costs, medications accounted for the largest proportion (26.5%). SCD is a lifelong condition that necessitates continuous management, including frequent blood transfusions, pain management, and the use of disease-modifying drugs like hydroxyurea. These medications, while essential, are costly, and their availability can be limited in resource-constrained settings. Similarly, in other African nations, the

costs of these medications significantly increase the financial burden on patients (1, 3, 5, 14, 16).

The chronic and ongoing nature of SCD care means that patients face a continuous need for treatment, which translates into a high financial burden. This is exacerbated by the fact that many SCD medications, such as hydroxyurea, are often not available at public health facilities or are in limited supply, forcing patients to purchase them from private pharmacies at much higher costs (3). In addition, the cost of regular diagnostic tests, such as hemoglobin electrophoresis and blood transfusion services, adds to the financial burden of managing the disease. As such, the high proportion of direct medical costs in this study aligns with reports from other studies in sub-Saharan Africa, where medical costs for chronic conditions like SCD are often a significant barrier to care, leading to inadequate treatment and poor health outcomes (1, 2, 8, 11).

Non-medical costs, including transportation, food, and caregiver support, also represent a financial burden, accounting for 13.3% of the total costs. Notably, transportation alone was a significant contributor to this expense. This finding highlights the geographic barriers that many Tanzanians face in accessing specialized care for conditions like SCD. Many patients, particularly those from rural areas, have to travel long distances to reach the central referral hospital (MNH), and transportation costs can quickly accumulate, especially for individuals requiring

frequent visits for ongoing treatment and management. Studies in Uganda and Ghana have similarly found that transportation costs can constitute a large portion of the overall financial burden for SCD patients, especially when care is sought at distant healthcare centers (3, 16, 17).

Transportation expenses are a key challenge in sub-Saharan Africa, where healthcare infrastructure is often insufficient and patients must travel far distances to access appropriate care. Research from Uganda has demonstrated that transportation costs for SCD patients can represent up to 20% of total healthcare expenditures (17). These findings are echoed in the current study, where transportation costs not only added to the financial burden but also posed a barrier to regular treatment adherence, particularly for patients in rural or remote areas. Moreover, the costs associated with food and caregiver support, including meals and accommodation during hospital visits, further exacerbate the economic hardship faced by families. This was also observed in studies conducted in Tanzania, where the lack of financial support mechanisms for non-medical costs creates a major barrier to healthcare access (6, 7, 14).

Indirect costs, primarily attributed to lost work hours for both patients and caregivers, accounted for 8.3% of the total costs. This is a considerable financial loss, particularly for caregivers who may need to take time off work to support their children or other family members living with SCD. The burden on caregivers is often overlooked, but their loss of income due to caregiving responsibilities is a crucial factor in the overall economic impact of the disease (9, 10, 11, 16). The loss of productivity due to caregiving responsibilities can significantly affect household income, particularly in low-income households where every working member is crucial to the family's financial well-being. Additionally, studies have suggested that the overall economic cost of caregiving for SCD patients is higher compared to other chronic diseases, as it involves prolonged periods of care and frequent medical emergencies (3, 9, 16, 17).

These indirect costs are often not fully captured in traditional cost-of-illness studies, but they are essential for understanding the full economic burden of SCD.

The total annual costs estimated for SCD patients in this study are similar to those reported in other sub-Saharan African countries, including Nigeria, Ghana, and Kenya (1, 3, 14, 16). However, the results of this study underscore the unique context of Tanzania, where limited access to health insurance and a lack of public sector funding for chronic diseases intensify the financial burden. While the introduction of universal health coverage in Tanzania has the potential to reduce out-of-pocket costs for SCD patients, significant gaps remain in terms of policy implementation, infrastructure, and access to necessary treatments (5, 6).

Furthermore, the absence of comprehensive health insurance coverage in Tanzania remains a significant challenge for SCD patients. A recent study in Tanzania found that only 15% of the population is covered by health insurance, leaving most SCD patients to pay for treatment out-of-pocket, exacerbating financial strain (14). The average annual income of employed participants was USD 1,712.46, a figure that highlights the limited economic resources available to those managing chronic conditions like SCD. Among employed individuals, a significant portion of their income was allocated to SCD treatment, demonstrating the significant strain the disease places on household finances. For individuals with medical insurance, this figure decreased to 7.6%, but it still represents a considerable proportion of their income, indicating that even insured patients face financial hardship due to SCD-related expenses. Additionally, lack of coverage for expensive medications and diagnostic tests further hinders access to adequate care for individuals with SCD, and only a small proportion of patients benefit from government subsidies for such treatments (5, 6, 10, 14, 17). There is a critical need to improve access to affordable and comprehensive health insurance, especially for individuals with

chronic conditions like SCD, to reduce out-of-pocket expenses and enhance treatment adherence. Moreover, policies should be implemented to address the indirect costs, such as lost work hours for patients and caregivers, by supporting employment during treatment or offering compensation for lost income.

While this study provides valuable insights into the economic burden of SCD in Tanzania, it is important to acknowledge several limitations. Recall bias may have influenced the accuracy of reported costs, as patients and caregivers may have had difficulty accurately remembering and quantifying expenses incurred over time. Additionally, the study did not capture the costs associated with inpatient care, which could be a significant contributor to the overall financial burden. The inability to estimate intangible costs, such as pain and suffering, is another limitation of the study, as these factors could add an additional layer of economic strain that is difficult to quantify. Finally, productivity losses among students and housewives were not fully accounted for, which may have led to an underestimation of the total indirect costs. Despite these limitations, the study's use of systematic random sampling, time series events, and sensitivity analysis strengthens the reliability of the findings.

Conclusion

The economic burden of SCD in Tanzania is considerable, with direct medical costs being the largest contributor to overall healthcare expenditures. However, indirect costs related to lost productivity and non-medical expenses, such as transportation and food, also play a significant role. This study advocates for several key policy actions to alleviate the financial burden of SCD. First, there is a critical need to improve access to affordable and comprehensive health insurance, especially for individuals with chronic conditions like SCD, to reduce out-of-pocket expenses and enhance treatment adherence. Second, policies should be implemented to address the indirect costs, such as lost work hours for patients and

caregivers, by supporting employment during treatment or offering compensation for lost income. Finally, strengthening healthcare infrastructure, particularly at regional and district levels, would reduce the need for long-distance travel, lower treatment costs, and improve the quality of life for SCD patients.

Ethical Considerations

Ethical approval (with code Ref No. DA282/298/01.C/MUHAS-REC-05-2022-1140) was obtained from the MUHAS Ethics Review Board to ensure adherence to ethical standards. An introductory letter was obtained from the MUHAS School of Public Health. Approval from MNH administration was secured. Informed consent was obtained from participants, and interviews were conducted in private spaces to protect their privacy. All patient information was kept confidential between the researchers and study members.

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Authors' Contributions

J.LN was involved in Idea development, designed the research, conducted the research, analyzed the data, and wrote the manuscript; N.T designed the research, conducted the research, performed statistical analysis, contributed to editing, and did proofreading; G.MR contributed to designing the research, conducting the research, revising, editing, and writing. All authors read and approved the final manuscript.

Conflict of interest

The authors declared no conflict of interests.

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