

Original Research Article

Assessment for the cost of care for children with sickle cell disease in a Tertiary Hospital in Northeastern Nigeria

Comment [M1]: SCD was used although SCA was meant. SCA is more specific whereas SCD include sickle cell traits and others

Abstract

Background: Sickle cell disease (SCD) is a chronic haemolytic anaemic condition resulting in various forms of crises leading to repeated hospitalizations, due to severe pains, infections and anaemia. Knowing this chronic symptomatic disorder that requires constant care by the caregivers of these children, the caregivers of the children with SCD undergo financial hardship in the course of taking care of them. The caregivers experience lots of financial stress from feeding them, taking them to the regular clinic for routine follow-up, paying for their regular drugs, hospital bills/beds when admitted and transportation. As of now, in Nigeria, there is no special programme or legislature to advocate for the Federal or State Government to subsidize SCD patient treatments. The cost implication of sustaining health through routine care and providing healthcare services to SCD patients during any form of crisis is very variable that is borne by the triad of the family caregiver, community or society and state health system itself. The cost of care estimation methods tends to align with these three perspectives singly or in combination with the caregiver of the SCD patient playing a major role. We, therefore, decided to look into the aspect of finances, and how the caregivers are coping as seen in the University of Maiduguri Teaching Hospital (UMTH), insurgency devastated State in Nigeria.

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Objective: To assess the cost of care for children with sickle cell disease in a Tertiary Hospital of insurgency devastated region in Nigeria.

Methods: This was a cross-sectional study of caregivers of children with SCD seen at the University of Maiduguri Teaching Hospital. A total of 130 caregivers were randomly selected and interviewed using a structured questionnaire to assess the cost of care for a child with SCD in the family. They were all administered the questionnaire during the clinic appointment, after going through the questionnaire with them over two months period. The clinic holds every Wednesday and the average clinic attendance ranges from 30 to 45.

Comment [M3]: A statement on how the random selection was done including the duration of the collection

Results: One hundred and twenty-seven questionnaires were valid for analysis. Ninety-eight (77.2%) of the respondents were mothers, two-third were from low social class and unemployed full-time housewives. The majority of the caregivers 111 (87.4%) pay for medical bills out-of-pocket, only 16 (12.6%) had registration with NHIS. Fifty-one (40.2%) of the caregivers had to borrow money to pay hospital bills, while 76 (59.8%) do not borrow money for the cost of care of their children with SCD. Of the SCA patients, 46 were not admitted in the last 1 year, 51 (40.2%) were admitted once, 16 (12.6%) were admitted twice, 10 (7.9%) thrice and 4 (3.1%) had 4 or more admissions. For just one admission, they spend an average of ₦750 – ₦4,050:00, thus for 4 admissions, ₦3,000 to ₦16,200 was spent per admission. Forty-seven (37%) of the caregivers have expenses incurred during the treatment of their children which affect their ability to provide for the family basic need, while 80 (63%) did not incur any funds for the care of their children with SCD.

Conclusion: The research demonstrated that caregivers of children with SCD experienced heavy financial burdens and this experience culminate in socio-political and economic situations occasioned by the insurgency devastation of the northeastern region of Nigeria.

Keywords: Caregiver, children, finance, sickle cell disease.

Introduction

Sickle cell disease is a chronic haemolytic anaemic condition resulting in various forms of crises leading to repeated hospitalizations, due to severe pains, infections and anaemia.¹⁻³ The prevalence of sickle cell disease (SCD) in Nigeria is about 1 to 3%.^{4,5} The Sickle cell gene is fairly evenly distributed throughout the country with reported heterozygote (AS) carrier rates of 23% in the southeast while rates of up to 25% are found in the southwestern part of the country, and 19 to 32.6 % in northern Nigeria.⁵⁻⁷ The trait AS is 32.6% with its highest prevalence among Bades of Yobe State, Garki-Kano state has 28.9%, and Kanuris from Borno State with 27.9%.⁸ Mortality is highest in the first five years of life and is largely due to factors such as overwhelming infections and acute splenic sequestration crisis, complications of which are largely preventable by appropriate utilization of available health care facilities.⁹⁻¹¹ Knowing that SCD is a chronic symptomatic disorder that requires constant care by the parents/guardians of these children, the caregivers of the children with SCD undergo financial hardship in the course of taking care of them.¹²⁻¹⁴ The parents/guardians experience lots of financial stress from feeding

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them, taking them to the regular clinic for routine follow-up, paying for their regular drugs, hospital bills/beds when admitted and transportation.^{13,14} These are often provided by the parents/guardians without any help from any Government agency or Non-Governmental organization (NGO). As of now, in Nigeria, there is no special programme or legislature to advocate for the Federal or State Government to subsidize SCD patient treatments.¹³⁻¹⁵ We, therefore, decided to look into the aspect of finances, how the caregivers are coping as seen in the University of Maiduguri Teaching Hospital (UMTH), the tertiary health care centre of the insurgency most devastated State in Northeastern Nigeria.

Statutorily, the economic cost of sustaining health or providing healthcare services to SCD patients is very variable that is borne by the triad of the family caregiver, society and state. The cost of care estimation methods tends to align with these three perspectives singly or in combination with the family caregiver of the SCD patient majorly.¹⁶ The cost from the family caregiver's perspective are the expenses incurred by the caregiver for medical products or health care services that are not under the coverage by the national health insurance scheme (NHIS) or its subsidiary. This cost may include among others the direct medical costs incurred for medical products and services used as well as costs of co-payment by the insurance and deductibility where available, direct nonmedical costs for nonmedical services that are results of chronic disease or illness such as transportation cost for follow-up, and indirect cost that results from potential productivity loss due to morbidity such as time taking for a regular follow-up visit to the clinic.¹⁷

In many developing countries including Nigeria, health care financing is still largely through out-of-pocket payment. Family caregiver out-of-pocket costs can be a significant financial burden, particularly in patients with chronic hereditary non-communicable disease such as SCA.¹⁸

Methods

A structured questionnaire using the Likert method¹⁹ was designed and pre-tested to identify general and specific concerns of caregivers of children with SCD to develop appropriate measures to be used in the studies. The questionnaire consists of open and close-ended questions which were administered to the caregivers in the Paediatric Haematology clinic and ward. The main areas explored included their monthly income, how much they spend in taking care of their

Comment [M7]: A statement of the statistical software used for the data analysis

wards, any financial support from the Government or individuals. How much do they spend out on pocket expenses.

A total of 130 caregivers, attending the clinic with their children diagnosed with SCD at outpatients' clinics at the University Teaching Hospital Maiduguri, were recruited for the study. Some whose children were admitted were also included. They were all administered the questionnaire during the clinic appointment by a team of medical students during their community medicine posting, after going through the questionnaire with them over two months. The clinic holds every Wednesday and the average clinic attendance ranges from 30 to 45. The caregivers were introduced to the study in the waiting area with an opportunity for the participants to refuse consent, informing them that this would not affect their medical treatment.

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Comment [M9]: There is need for a stronger ethical statement regarding consent.

Results

One hundred and thirty questionnaires were administered, 127 were analyzed, 1 uncompleted form, while 2 were just newly diagnosed SCA patients. The majority of the respondents were the mothers 98 (77.2%), Aunties 15 (11.8%), Fathers and grandmothers were 6 (4.7%) each and the uncles were 2 (1.6%). Twenty-six (20.5%) of the caregivers were of age 15 to 24 years old, 46 (36.2%) were 25 to 34 years old, 31 (24.4%) were 35 to 44 years while the remaining 24 (18.9%) were 45 and above.

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The majority of the children 58 (45.7%) were of the age 5 – 9 years old, 30 (23.6%) were below 5 years, 22 (17.3%) were of 10 – 14 years old and 17 (13.4%) were 15 and above.

The cost of the regular drugs, Proguanil is ₦10 per tablet, thus for 30 days they will spend ₦300, Folic acid is ₦2 per tablet, for 30 days it will be ₦60, making a total of ₦360 if on proguanil and folic acid only. If the child is on Hydroxyurea, it is ₦60 per capsule and for 30 days it will cost ₦1,800. The least a parent will spend for a child who is on hydroxyurea, proguanil and folic acid is ₦2,100:00 per month.

Table I. Shows the income of the caregivers.

Income of caregiver per month (₦)	Number of caregivers	%
< 10,000:00	12	9.4
10,001 – 30,000: 00	13	10.2
30,001 – 50,000:00	29	22.8

50,001 – 70,000:00	19	15.0
70,001 – 90,000:00	24	18.9
≥ 90,001:00	30	23.6
Total	127	100

Twenty-five (19.6%) earned less than ₦30,001, which is the said minimum wage for Nigerians now. Of the caregivers, 39 (30.7%) had some financial support from people, while 88 (69.3%) said they did not need support when their child/ ward was admitted into the ward [$X^2 = 20.661$, $df = 5$, p is 0.001]. In those with a monthly income of < ₦10,000:00, there is the possibility of seeking financial support, but in those with an income of ₦70,000:00 and above, they are not likely to seek financial support. The majority of the caregivers 111 (87.4%) pay for medical bills out-of-pocket, only 16 (12.6%) had registration with NHIS. Fifty-one (40.2%) of the caregivers had to borrow money to pay hospital bills, while 76 (59.8%) do not borrow funds for the care of children with SCD Table II.

Table II. Shows the income of caregivers and those borrowing money to offset the hospital bill when their child/ward is on admission.

Income of caregivers per month (₦)	Borrowed money		Total (%)
	Yes (%)	No (%)	
≤ 10,000:00	10 (83.3)	2 (16.7)	12 (100)
10,001:00 – 30,000:00	10 (76.9)	3 (23.1)	13 (100)
30,001:00 – 50,000:00	5 (17.2)	24 (82.8)	29 (100)
50,001:00 – 70,000:00	6 (31.6)	13 (68.4)	19 (100)
70,001:00 – 90,000:00	13 (54.2)	11 (45.8)	24 (100)
≥ 90,001:00	7 (23.3)	23 (76.7)	30 (100)
Total	51 (40.2)	76 (59.8)	127 (100)

$X^2 = 29.034$, $df = 5$, $p = < 0.001$

If the caregiver's income is ₦ 30,000:00 and below, there is the likelihood of borrowing money from friends and family members. However, those with the income of ₦ 70,001:00 – 90,000:00, had their child/ward admitted more often, thus had to seek help.

In the past 12 months, 81(63.8%) of the children were admitted into the ward. Table III is showing the monthly income of the caregivers and the cost of care per admission.

Table III. Shows cost of care per admission.

Income ₦	Cost of care per admission in Naira (₦)					Total
	< 1,000:00	1,000 – 5,000:00	5,001 – 10,000:00	10,001 – 50,000:00	50,000 – 100,000:00	
≤10,000:00	1	6	2	0	0	9
10,001 – 30,000:00	1	5	3	0	0	9
30,001 – 50,000:00	0	5	3	0	0	8
50,001 – 70,000:00	2	1	8	1	0	12
70,001 – 90,000:00	2	6	3	10	0	21
≥90,001	0	3	2	12	5	22
Total	6	26	21	23	5	81

$$X^2 = 58.158, df = 20, p = 0.000$$

Of the SCA patients, 46 were not admitted in the last 1 year, 51 (40.2%) were admitted just once, 16 (12.6%) were admitted twice, 10 (7.9%) thrice and 4 (3.1%) had 4 or more admissions. For just one admission, they will spend an average of ₦750 – ₦4,050:00, thus 4 admissions, and an average of ₦3,000 to ₦16,200 was spent per admission. The cost of doing PCV was ₦200:00, and the blood film for malaria parasite was also ₦200.

Comment [M11]: To recheck this table and the statistics including the degree of freedom. Again, there are too many empty cells- 10 to be precise.

Comment [M12]: Range not average

Table IV. Shows the income of caregivers and the cost of drugs per month.

The income per month ₦	The average cost of drugs per month (₦)				Total
	< 1,000:00	1,000 – 5,000	5,001 – 10,000	> 10,000:00	
≤ 10,000:00	7	2	1	0	10
10,001 – 30,000:00	9	4	0	0	13
30,001 – 50,000:00	8	5	2	11	26
50,001 – 70,000:00	3	9	3	3	18
70,001 – 90,000:00	4	9	6	2	23
≥ 90,001:00	3	12	9	4	28
Total	34	41	21	22	118

$$X^2 = 43.513, df = 15, p = 0.000$$

Nine (9) of the caregivers were not included in the analysis, because they can't tell what they spend on a monthly period on drugs of their children.

Ninety-one (71.7%) of the children were transfused within the last 12 months, 14 (11%) had the transfusion free, while 30 (23.6%) were not transfused and 6 (4.7%) did not respond. Thus 77 (60.7%) paid for the transfusion. Table V is showing the income of caregivers and the various amount that was paid for the blood transfusion.

Table V. Shows cost of transfusion

Income of caregivers ₦	Cost of blood transfusion			Total of caregivers
	1,000 – 3,000	3,001 – 5,000	5,001 – 10,000	
≤ 10,000:00	0	0	3	3
10,001 – 30,000	5	4	1	10
30,001 – 50,000	3	2	2	7
50,001 – 70,000	6	7	3	16

70,001 – 90,000	9	3	4	16
≥ 90,001	5	4	16	25
Total	28	20	29	77

$$X^2 = 22.13, df = 10, p = 0.014$$

Blood transfusion is done when necessary and who can afford it. The amount spent on the blood transfusion, is for the items, such as service charge, screening the blood for infections etc. some do pay for those donating also. For those who can't afford to pay for donors, pay for the only service.

Comment [M13]: NO NEED FOR THIS

Comment [M14]: NO NEED FOR THIS STATEMENT

Table VI. Shows the cost of transportation during a follow-up visit to the hospital per month.

Income of caregiver ₦	Cost of transportation during follow-up in Naira (₦)				Total of caregiver
	< 500	500 – 1,000	1,001 – 2,000	2,001 – 5,000	
≤ 10,000	7	4	1	0	12
10,001 – 30,000	5	7	1	0	13
30,001 – 50,000	10	5	4	8	27
50,001 – 70,000	13	3	3	9	19
70,001- 90,000	12	6	2	3	23
≥ 90,001	14	9	1	1	25
Total	61	34	12	12	119*

*8 of the caregivers did not respond. $X^2 = 26.447, df = 15, p = 0.034$

Forty – seven (37%) of the caregivers have expenses incurred during the treatment of their children which has affected their abilities to provide for the family basic need, while 80 (63%) did not incur any fund for the cost of care of their children with SCD.

Table VII. Shows the income of caregivers and expenses incurred during treatment of their child/ward.

Income of caregivers	Expenses incurred during treatment		Total of the caregivers
	Yes	No	
≤10,000	10	2	12
10,001 – 30,000	2	11	13
30,001 – 50,000	17	12	29
50,001 – 70,000	6	13	19
70,001 – 90,000	6	18	24
≥90,001	6	24	30
Total	47	80	127

$\chi^2 = 24.912$, $df = 5$, $p = 0.000$

Discussion

Generally, sickle cell disease together with its related comorbidities and complications results in high utilisation of medical resources such as emergency room visits and hospitalisation.²⁰⁻²²

Sickle cell disease being a chronic disorder and characterized by recurrent vaso-occlusive crises requires frequent hospitalizations. Thus, it constitutes financial stress because of the repeated hospital admissions.²³ However, the findings of our research should not be generalized, because the caregivers were not representative of the general population sample of caregivers of SCD. The socio-demographic characteristics of caregivers of patients with SCD were similar to those of a previous study of the psychosocial burden of SCD on the family in Nigeria.¹⁴ The financial burden on the caregivers of SCD in this study is very high compared to their income as the majority of them are low-income earners. More than half of the caregivers reported that the expenses of the child's ill health including the cost of management of vaso-occlusive and anaemic crises warranting transfusion adversely affect the family's basic needs such as feeding.

This is demonstrated perfectly considering the rising trend of inflation in this period of global economic recession imposed by the COVID-19 pandemic. In Nigeria, like many other developing countries, national programmes on health insurance and social welfare systems are virtually absent, making management for a child with chronic ill health such as SCD a great financial burden on the caregiver. Furthermore, about 42% of the caregivers in this study have an

Comment [M15]: This is different from the results -69.3% do not need support. 59.8% do not borrow money and 63% do not incur expenses

income of less than ₦50,000 per month and up to 40% of the caregiver's borrowed money when their ward was admitted for vaso-occlusive crises or anaemic crises warranting blood transfusion. In addition, about 50% of the caregivers in this study lost income or financial benefits due to time spent caring for their children when on admission for crises of SCD. The issue is the same in Maiduguri as in other parts of Nigeria, the predominant form of health-care financing is out-of-pocket. As observed in a previous study, job loss, underemployment and/or unemployment arising from time spent caring for a child suffering from SCD, significantly contribute to the financial burden experienced by caregivers of children with SCD.^{14,23} The cost of treatment for SCD continuous to be a great burden to parents of children living with a chronic illness like SCD as demonstrated in this study is similar to the findings of a Nigerian study that found a high financial burden on the families of people with SCD.¹³ In recent times, the cost of care in Nigerian tertiary health institutions (Teaching Hospitals and Federal Medical Centre) has increased due to the introduction of user charges in public hospitals. In rare instances, an episode of hospital admission can cost a caregiver as much as ₦100,000 (\$213). This is similar to the finding of Muoghalu's review of the burden of sickle cell disease to parents of sufferers in Nigeria.¹⁵ This is a huge amount considering the minimum wage in Nigeria is ₦30,000 (\$64), which is yet to be implemented by most States of the federation as of today. One can then imagine what a huge amount of ₦100,000 (\$213) would mean to a caregiver of a family with more than one child with SCD. This could perfectly explain why some caregivers had to borrow to pay for hospital bills of their child living with SCD, which they could not pay before another round of hospitalization of the same child or a sibling with SCD for the caregiver with more than one child with SCD. This finding is similar to what was noted in a Nigerian study, where 19.6% had to take loans to meet up with the cost of treatment.¹⁴ In the family of such caregiver, basic needs will not be met and it was found by Adegoke *et al* that 53.3% of their participants stated that the care of their children with SCD adversely affected their basic need provision.¹⁴ The impact of the COVID-19 pandemic on the general populace including caregivers of children with SCD that demand routine care most of the time, has serious implications for the health and well-being of the children with SCD. Poverty in many families with a child living with SCD when put together with frequent hospitalization and the insurgency activities in northeastern Nigeria in recent times culminates in the poor health of children with chronic illnesses such as SCD in the northeast.

In this paper, the financial cost of care for children with SCD also includes the cost of transport, loss of income on the part of caregivers and cost of treatment, because SCD is highly symptomatic that children with the condition require routine care and follow-up to the clinic even when in steady-state, the caregivers who provide such care end up not being able to fully pursue their economic activities that provide even their basic requirement. This was similar to the report of Adegoke *et al* that 73.3% of family caregivers reported that the time spent caring for the child cause them to lose income.¹⁴ This loss of income tends to deepen the high level of poverty in families with children living with SCD in the insurgency devastated northeast region and more especially during the lockdown imposed by the COVID-19 pandemic. This financial burden associated with treatment and care for children having SCD constitutes a major challenge especially for poor families whose members thrive on what they can get from daily workmanship. In the event of disruption by caring for the child with SCD, the income of such caregiver dwindles and the caregiver finds it extremely difficult to get money for the consistent care and treatment for the acute event. Such a caregiver perpetually falls into a deeper level of poverty than before. The finding of this research has exposed the weakness of the system of health care policy in Nigeria, where there is no provision to subsidize the cost of treatment for people living with chronic ill-health such as SCD. The state of hardship and stress the caregivers of children with SCD are undergoing necessitated the National assembly members of the house of Representatives to deliberate on the need to call the federal government to subsidize the cost of treatment for people living with SCD in Nigeria.²⁴ Unfortunately, this is still at the level of deliberation, since that there has not been any push further for implementation strategy to be put in place for realization of this laudable deliberation. The implementation of this policy would have alleviated the financial burden on caregivers of people living with SCD as Nigeria ranks first in SCD burden worldwide with 40 m cases.²⁵ Other measures to be targeted before they pursue this laudable effort of the lower chamber of the National assembly to reduce the impact of management of SCD on their caregivers should include limitation of family size to reduce the risk of mothers from having an additional child with SCD. Furthermore, the promotion of neonatal screening, genetic counselling and a comprehensive and holistic public health campaign should be put in place. The latter should be aimed at increasing awareness in the community on the primary prevention of the disease. Routine haemoglobin phenotype determination for adolescents before engagement in matrimonial relationships should be encouraged. This has been

Comment [M16]: Re-check

noted to offer a vital pragmatic approach in reducing the very high prevalence of the sickle cell gene and its attendant problems in the Nigerian context.²⁶

The **holocaustic** costs of management of SCD from out-of-pocket expenditure as is the practice in Nigeria could be improved by universal healthcare coverage by health insurance schemes supported by funding from governments at **the all levels** Federal, States and local **levels**. An integrated program can strengthen the primary healthcare network as demonstrated in Thailand.²⁷ increases equitable access to timely and quality medical and diagnostic services and at the same time facilitate referral linkages for needed advance care. The universally directed strategy of such magnitude especially when encouraged by coordinated education drives and backing by tax-financed schemes, ensure financial risk protection for vulnerable populations at risk of long term holocaustic and catastrophic spending on healthcare. Improvement in the effectiveness of external funding by NGOs may be an important contribution in northeastern Nigeria that is devastated by the insurgency where development assistance plays a vital role in healthcare management. The targeted basket funding programs such as maternal and child health in Nigeria have been a success story.²⁸ A highlighted finding was also that active efforts to prevent SCD crises could lead to a steady-state condition of SCD where the financial burden of the disease could be similar to well-controlled maturity-onset diabetes mellitus.^{13,29}

Comment [M17]: ?holistic

Recommendation

Sickle cell clubs and associations must be strengthened at both levels of secondary and tertiary health care. This should be aided by the government where parents and/or caregivers of children with SCD and the affected patients/adolescents can discuss freely and be rehabilitated, as this will enhance their financial and psychosocial support.

Emergency medical treatment of SCD should be entirely free or at least highly subsidized by the government at all levels of health care to make it affordable and accessible for all.

The government in collaboration with NGOs especially in the insurgency devastated northeastern Nigeria should run a rehabilitative centre for children or individuals with chronic devastating complications of SCD such as cerebrovascular accidents, avascular necrosis of the femoral head as all of these forms of vaso-occlusive crises (VOC's) demand huge sum of money to manage.

A vigorous enlightenment campaign on SCD should be strengthened and where it is not there be put in place through appropriate media such as journals, print and electronics.

Religious leaders should not be left out in educating their youths on the importance of pre-marriage genotype screening and especially before marriage engagement, and should possibly be made a criterion as it is done for Human immunodeficiency virus (HIV) screening.

Conclusion

The research showed that caregivers of children with SCD experienced a significant financial loss in the insurgency devastated northeastern region of Nigeria. It was indicated that many caregivers incur money due to frequent hospitalization and the symptomatic nature of sickle cell disease.

The research also concluded that caregivers of children with SCD experienced heavy financial burdens and this experience culminate in socio-political and economic situations occasioned by the insurgency devastation of the northeastern region of Nigeria.

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