Original Article

Clinical Status of Sickle Cell Anemia and the Impact on the Caregivers Finances at a Tertiary Hospital, North-West Nigeria

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Abstract

Background: Chronic condition like sickle cell anemia (SCA) is known to deplete family resource. The clinical status of children with SCA affects finances of the caregivers. **Aim:** The study aimed at determining the clinical impact of children with SCA on their caregivers' finances with the view to reduce the disease-associated financial burden. **Patients, Materials and Methods:** It was a cross-sectional study of 133 caregivers and their children with SCA managed at the sickle cell disease (SCD) clinic of the Paediatric Department of Barau Dikko Teaching Hospital, Kaduna, North-Western Nigeria conducted between February and April 2016. A structured SCD burden interview was used. It has a total of 16 questions for four domains. The domain on the family finances has 3 questions each with a score ranging from 0 to 3. The clinical status of children with SCA was assessed using clinical parameters such as number of painful crisis, hospitalization, blood transfusion, and school absenteeism over the previous year. **Results:** About 63 (47.4%) of the caregivers were more than 35 years of age. Eighty-four (63.2%) were Hausas, 100 (75.2%) were Muslims, and 114 (85.7%) were married. Those with secondary education were 45 (33.8%), 43 (32.3%) were unemployed, and 42 (31.6%) were unskilled laborers. Source of their health-care financing was mainly out of pocket in 126 (94.7%) while 47 (35.3%) had an average monthly income between ₦20,000 and ₦50,000. More than half of the caregivers 82 (61.7%) were not member of a social group. The statistical analysis of the clinical status of the children with sickle cell anemia on their caregivers finances revealed significant relationship between number of school absenteeism of the children and finances of the caregivers ($P = 0.010$). **Conclusion:** Clinical status of children with SCA affects caregivers' finances.

Keywords: Caregivers finances, children with sickle cell anemia, clinical status

Introduction

Sickle cell disease (SCD) is a group of recessive disorders that affect the hemoglobin (Hb) molecule and is a chronic lifelong condition. The most common and the most severe among the genotypes is the homozygous SS state (sickle cell anemia [SSA]).[1]

It is estimated that between 150,000 and 300,000 children are born every year with the condition in Africa.[2] Nigeria is among the countries with the highest burden of the disease where approximately 2% of all newborns are born with the disorder.[3] The course of the disease varies widely with some children exhibiting severe manifestations requiring frequent hospital visits and admissions.[2-5]

SCD has immense health and socioeconomic impacts on families and society as a result of frequent pain episodes, medical visits, hospitalization, blood transfusion, utilization of drugs, and other health-care services. Brigid and Lindy reported that mothers felt strongly that children with SCD had different needs than their healthy peers and, as such, the loss of paid income had a direct impact on family life. Keeping a home warm is essential for SCD children and mothers found this "expensive."[6]

Recurrent clinical events and hospitalization may lead to school disruption, high rate of school absenteeism, and poor academic achievement.[7] Frequent school absences up to 30 days per year

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Access this article online

Quick Response Code:

Website: www.njmonline.org

DOI: 10.4103/NJM.NJM_174_21

How to cite this article: Abubakar R, Dabo HZ, Badamasi SM, Abubakar AK. Clinical status of sickle cell anemia and the impact on the caregivers finances at a tertiary hospital, North-West Nigeria. Niger J Med 2022;31:68-73.

Submitted: 04-Oct-2021 **Revised:** 27-Nov-2021
Accepted: 30-Nov-2021 **Published:** 22-Feb-2022

on average were reported in children with SCD and were found to be a contributory factor to poor academic performance.[8,9] Affected children also scored below their peers in school grades,[10] and they have repeated grades consistently with a rate of 23%–54%, which is much higher than in the normal child population. Grade retention tends to increase the risk of school dropouts by about 2–11 times.[11]

Many studies determined the burden of SSA on caregivers' finances, however, this study determined the financial burden using SCD burden interview (SCDBI) and went further to determine the relationship between various clinical parameters of the children with the disease and financial burden on caregivers.

Patients, Materials and Methods

It was a cross-sectional study carried out at the SCD clinic of the Paediatric Department of Barau Dikko Teaching Hospital, Kaduna, North-western Nigeria. The hospital is a state university teaching hospital located in Kaduna North Local Government Area of Kaduna State.

All consecutive eligible caregivers (mainly mothers) of children with SSA attending the Sickle cell clinic from February to April 2016 were recruited till the desired sample size was met. The average number of children with SCA seen in the clinic was 160 in a month, with an average of 40 patients seen per week. A total of 480 children with SCA were seen over the 3-month period.

The sample size 133 was estimated using the formula for calculating minimun sample size:[12]

$$n = \frac{Z^2pq}{d^2}$$

Where:

Z = The standard normal deviate usually set at 1.96 which corresponds to the 95% confidence interval.

p = The proportion in the target population estimated to have burden of the disease on caregivers' finance in a study on psychosocial burden of SCD on the family in Ado Ekiti = 12.4%.

Eleven consented caregivers of children aged 2–14 years (pediatric age in the hospital is 14 years and below) who were diagnosed as SCA (HbSS) only and at least a year on follow-up were recruited weekly during the clinic hours. This gave a total of 44 caregivers recruited in a month. A total of 133 women were recruited in 12 weeks. Ethical clearance was obtained from the Health Research Ethics Committee of Kaduna State Ministry of Health. All participants participated voluntarily as they came in after signing the informed consent form.

Participants were interviewed by the researcher with the assistant of a resident doctor who was trained for that purpose. A structured SCDBI was used. It was initially validated by Ohaeri and Shokunbi[13] and found to be relevant to Nigerian culture. It was used to assess the psychosocial burden of the illness on caregivers and families and assessed three main objective psychosocial domains, namely: the financial burden of the disease, the disruption of family interactions, and the disruption of routine family activities. In addition, it assessed some subjective psychosocial burdens such as the caregiver's feelings (e.g., depression, sorrow, anger and/or stigmatization) toward the child and the ability of the family to cope with the disease.[13]

The SCDBI has a total of 16 questions. The domain on the family finances has 3 questions. Each question has a score ranging from 0 to 3. A score of 0 was given when the stressful events never occurred, 1 point was given when it occurred occasionally or had an insignificant impact on the family, 2 points were given when the stressful event occurred frequently or had a severe impact on the family. The scores were then added for the domain and the total score categorized and interpreted as follows:

- Total score of 0 as no impact, 1–3 as insignificant impact, 4–6 as moderate impact, and scores between 7 and 9 as severe impacts.

However, in this study, the categories "no impact" and "insignificant impact" were re-categorized into one category as "mild impact."

The health/clinical outcome of the affected children was assessed through inquiry on age of the child, age at diagnosis, frequency of crisis over the previous 12 months, type of crisis, number of significant bone pain episode over the previous 12 months, number of hospital admissions and school absenteeism over the previous 12 months. General physical examination was also carried out to assess the degree of palor and jaundice, height in centimeter, and weight in kilogram using stadiometer caliberated at 0 for those above 2 years while tape was used to measure the length in cm for those below 2 years. These were done to determine normal for age and abnormal for age. Laboratory investigations such as packed cell volume were carried out to determine the level of hemoglobin.

Data were analyzed using Epi Info is a statistical software for Epidemiology developed by the center for disease control and Prevention (CDC) in Atlantica, Georgia United State. Sociodemographic variables were analyzed by descriptive statistics to determine their frequencies and proportions. Test of significance using Chi-square was done on clinical status of the children with SSA and caregivers' finances.

Results

Complete data for the 133 participants were obtained and analyzed. Higher proportion 63 (47.4%) of the caregivers were more than 35 years of age. Eighty four (63.2%) were Hausas, 100 (75.2%) were Muslims, 114 (85.7%) were married, and those with secondary education were 45 (33.8%). High proportion 43 (32.3%) were unemployed and unskilled

Table 1: Sociodemographic characteristics of the caregivers

	n (%)
Age of caregiver (years)	
≤24	18 (13.5)
25-35	52 (39.1)
>35	63 (47.4)
Total	133 (100.0)
Ethnic group	
Hausa	84 (63.2)
Yoruba	10 (7.5)
Igbo	4 (3.0)
Others	35 (26.0)
Total	133 (100.0)
Religion	
Christianity	33 (24.8)
Islam	100 (75.2)
Total	133 (100.0)
Marital status	
Married	114 (85.7)
Singled	1 (8.0)
Divorced	4 (3.0)
Separated	4 (3.0)
Widow	10 (7.5)
Total	133 (100.0)
Highest education status	
None	4 (3.0)
Primary	33 (24.0)
Secondary	45 (33.8)
Postsecondary	42 (31.6)
Quranic	9 (6.8)
Total	133 (100.0)
Occupational status	
Unemployed	43 (32.3)
Unskilled	42 (31.6)
Skilled	22 (16.5)
Professional	25 (18.8)
Retired	1 (8.0)
Total	133 (100.0)
Types of family	
Single parent	11 (8.3)
Nuclear family	85 (63.9)
Extended family	35 (25.6)
Others	3 (2.3)
Total	133 (100.0)
Caregiver of the child	
Father	4 (3.0)
Mother	122 (91.7)
Grandmother	1 (0.8)
Sibling	1 (0.8)
Others	5 (3.8)
Total	133 (100.0)
Number of children	
≤4	80 (60.2)
>4	53 (39.8)
Total	133 (100.0)
Age of the oldest child (years)	
≤5	28 (21.1)
>5	105 (78.9)
Total	133 (100.0)
Other siblings with SCD	
None	90 (67.7)
1 sibling	28 (21.1)
>1 sibling	15 (11.3)
Total	133 (100.0)
Sources of HCF	
Out of pocket	126 (94.7)
Insurance	7 (5.3)
Total	133 (100.0)
Average monthly income	
<₦20,000	44 (33.1)
₦20,000-₦50,000	47 (35.3)
₦50,000-₦100,000	30 (22.6)
>₦100,000	12 (9.0)
Total	133 (100.0)
Membership of social group	
None	82 (61.7)
Religious organization	32 (24.1)
Professional group	6 (4.5)
Co-operative society	13 (9.8)
Total	133 (100.0)

SCD: Sickle cell disease, HCF: Health-care financing

laborers were 42 (31.6%) of the participants. Nuclear family constituted a higher proportion 85 (63.9%) and 122 (91.7%) of the caregivers were mainly the mothers. Those with <4 children were 80 (60.2%). Those having the oldest child aged more than 5 years were 105 (78.9%). Only 28 (21.1%) and 15 (11.3%) had 1 and more than 1 other children (siblings of their children) with SSA, respectively. Source of their health-care financing was mainly out-of-pocket means in 126 (94.7%) participants and higher proportion of them 47 (35.3%) had an average monthly income between ₦ 20,000 and ₦50,000. Majority 82 (61.7%) did not belong to any membership of social group.

Table 1 below outlines the sociodemographic characteristics of the caregivers.

Clinical status of children with sickle cell anemia and the finance of the caregivers

The statistical analysis of the clinical status of the children with SSA on their caregivers finances revealed significant relationship between number of school absenteeism of the children and finances of the caregivers ($P = 0.010$).

Details of the clinical status of the children with SSA and their caregivers' finances are depicted in Table 2 below:

Discussion

The findings in this study revealed significant relationship between school absenteeism of the children with SSA over

Table 2: Relationship between clinical status of children with sickle cell anemia and the finances of the caregiver

Health status of children	Impact of SSA on the finance of care givers				Total	χ^2	df	*P*
	No impact	Mild impact	Moderate impact	Severe impact				
Age of the children (years)								
<5	21	33	3	0	57	9.002	6	0.173
5-12	16	33	8	1	58			
>12	2	12	3	1	18			
Total	39	78	14	2	133			
Age at diagnosis of SCD (years)								
<1	21	33	8	0	62	3.771	3	0.287
1 and above	18	45	6	2	71			
Total	39	78	14	2	133			
Number of significant bone crisis over the past 12 months (years)								
None	10	14	3	0	27	9.012	9	0.436
1	10	15	0	0	25			
2-5	19	46	10	2	77			
>5	0	3	1	0	4			
Total	39	78	14	2	133			
Frequency of hospital admission over the last 12 months (times)								
None	25	47	7	0	79	12.519	4	0.051
1	10	17	5	0	32			
2-5	4	14	2	2	22			
Total	39	78	14	2	133			
Frequency of blood transfusion over the past 12 months (times)								
None	27	57	12	0	96	16.336	4	0.12
1	12	16	2	1	31			
2-5	0	5	0	1	6			
Total	39	78	14	2	133			
Frequency of school absenteeism over the past 12 months (times)								
None	32	62	8	0	102	21.716	9	0.010
1	2	1	0	0	3			
2-5	1	4	3	0	8			
>5	4	11	3	2	20			
Total	39	78	14	2	133			
Degree of parlor								
Nil	1	3	0	0	4	3.989	6	0.678
Mild	32	64	10	1	107			
Moderate	6	11	4	1	22			
Total	39	78	14	2	133			
Degree of jaundice								
Nil	4	10	1	0	15	4.646	6	0.590
Mild	31	60	10	1	102			
Moderate	4	8	3	1	16			
Total	39	78	14	2	133			
Weight for age of the child								
Normal	31	61	8	1	101	3.932	3	0.269
Abnormal	8	17	6	1	22			
Total	39	78	14	2	133			
Height for age of children								
Normal	34	74	11	2	121	4.950	3	0.176
Abnormal	5	4	3	0	12			
Total	39	78	14	2	133			

SCD: Sickle cell disease, SSA: Sickle cell anaemia

the previous 12 months and caregivers' finance. This was not unexpected as the school absenteeism mostly goes with the number of crises.

School absenteeism in this study could be attributable to the crisis, most commonly acute painful crisis (bone crisis) as the study revealed 77 (58%) children had 2-5 crises annually which could affect school attendance. Although many studies have reported frequent school absences among children with SCD,[8,10,14] and sickle cell painful episodes were the most recurrent clinical events, the retrospective cross-sectional study in Yemen examined school absenteeism and performance in children with SCD in relation to severity of their illness. The primary finding was a higher rate of school difficulties in children with SCD, which was more pronounced in those with severe disease. Further data analysis demonstrated that increased school absence, low academic achievement, and higher-grade retention rate correlated with disease severity scores.[15] In another study, school absence was almost twice in the high-frequency group (more than 4 hospitalization in a year) compared to the low-frequency group (those with one or no hospitalization) (35.7 days vs. 16.8 days). Overall academic achievement for both groups was lower than normative levels by at least one standard deviation. The authors suggested that recurrent school absence may make children lag in their schoolwork, which reinforces their motivation for school avoidance. The study in Kaduna did not assess the impact of the school absenteeism on the academic performance, therefore, there is a need for further evaluation in the future. Furthermore, unlike previous studies that determined the cumulative number of days of crisis per year, this study assessed number of crisis and school absenteeism per previous year contrary to the number of days of crisis in a year.

The previous researchers also found nonpain-related episodes in substantial number which were linked to other disease complications that required hospital admission or school disruption such as infection episodes, anemic crises, and acute chest syndrome and were not taken in consideration in their analysis. This study in Kaduna did not also take cognizant of the nonpain related crisis attributable to school absenteeism but rather considered pain crisis in assessing the clinical status of the children. This was because acute painful crises which is mainly bone pain crisis is the most common crisis in children with SCA.

The impact of school absenteeism of the children with SCA on the caregivers finance in this study is not unrelated to the out-of-pocket spending on the health-care during crisis. In this country, health-care financing is mostly out of pocket,[16-18] and most of the caregivers in this study had an average monthly income between ₦20,000 and ₦50,000. Therefore, the recurrent crisis could result to deflation of the family income considering the hike in prices of medical consumables and services. In a study in Ekiti, 19.6% of the caregivers had to take out loans to meet the expenditure of the patient's illness.[19]

The finding in this study is more disturbing considering the fact that majority of the caregivers were the mothers who were mostly unemployed and unskilled only about 30% had secondary and tertiary education, respectively. Coupling with the fact that 15 (11%) caregivers had more than 1 child with SCA, it is obvious that the low educational status of mothers could affect the health care-seeking behavior. This could be translated as high proportion of the children had 2–5 crisis over the previous 12 months but majority 79 (59%) had no hospital admission.

This study also revealed most of them did not belong to any social group that could cushion the effect of huge medical bills.

Conclusions

School absenteeism of children with SCA due to crisis significantly affects caregivers' finance. There is a need to intensify preventive measures to reduce sickle cell crisis in children.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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