SOCIAL, ECONOMIC AND PSYCHOLOGICAL BURDENS OF SICKLE CELL DISEASE CARE AMONG HOUSEHOLDS OF SUFFERERS IN A TERTIARY HEALTH FACILITY IN NORTH-WESTERN NIGERIA

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ABSTRACT

Objectives: The study assessed the social, economic and psychological burden of sickle cell disease (SCD) care among households of SCD patients attending sickle cell outpatient clinic in Ahmadu Bello University Teaching Hospital, Zaria, Nigeria. Methods: It was a cross-sectional descriptive study conducted among 205 caregivers of SCD outpatients selected through systematic sampling. Data was collected using a structured interviewer-administered questionnaire, and analyzed using the IBM SPSS version 20.0 Results: The mean age of the SCD patients was 12.7±9.0 years and their mean duration since diagnosis was 10.9±8.7 years. In the last 12 months, 92 (44.9%) patients had been admitted at least once due to complications of SCD, 72 (35.1%) had been transfused with blood and 150 (73.1%) had experienced painful crises. Caring for SCD patients frequently reduces the amount of care that other household members were receiving 95 (46.3%), patient's illness frequently caused disagreement or quarrel among household members 150 (73.2%), and households experienced stigmatization by community members 33 (16.1%). Ninety-six (71.2%) of the households were experiencing catastrophic expenditure from providing medical care for the SCD patient. Conclusion: Households of SCD patients were experiencing various forms of psychological, social and economic burden. It is recommended that locally applicable methods of psychological, social and economic support be included in the routine care of SCD patients and their families.

Key words: Sickle Cell, Care, Burden, Zaria

INTRODUCTION

Sickle cell disease (SCD) is a disease caused by inheritance of the haemoglobin S gene either in homozygous or heterozygous state. It is a childhood-onset and lifelong disorder that affects primarily people of African descent. Worldwide, over 300,000 babies are born with SCD each year, mostly in low and middle income countries, with the majority of these births in Africa. Nigeria and Democratic Republic of Congo account for 30% of the world's sickle cell disease and sickle cell trait births.

SCD is characterized by a wide range of physiological and psycho social features and complications. Physiological features and complications of SCD include vaso-occlusive pain crises, anaemia, dactylitis or hand and foot syndrome, eye damage, splenic sequestration, decreased ability to fight infections, acute chest syndrome, delayed growth and puberty, leg ulcers, stroke, gallstones, damage to body organs and/or tissue, and priapism. The psychosocial complications that SCD patients and their families experience mainly result from the impact of pain and other symptoms on their daily lives, and the

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society's attitudes to SCD and those affected by it. Specifically, SCD has been associated with psychological maladjustments including emotional and behavioral problems, poor self-concept and interpersonal functioning and poor academic performance. Apart from the initial emotion of denial experienced by parents of newly diagnosed SCD patients, other common emotions include anger, fear and even grief. While the blame of self and partners and the feelings of inadequacies which are not uncommon are usually transient, some patients and parents may never get over this emotions.

Antibiotic prophylaxis prevents infections especially in children, and other therapies like analgesia, hydration and physiotherapy help to minimizes symptoms of the disorder. However, because of the unpredictable, frequent, and sometimes severe nature of SCD pain, and its inconsistent response to interventions, SCD pain is a challenge for both clinicians and care givers to manage.

Studies on the social, economic and psychological burden of SCD on care givers and families of SCD patients are few, and none of them in the northwest region of Nigeria. This study assessed social, economic and psychological burdens of SCD care among households of SCD sufferers attending sickle cell outpatient clinic in Ahmadu Bello University Teaching Hospital (ABUTH), Zaria, Nigeria.

MATERIALS AND METHODS

Ahmadu Bello University Teaching Hospital (ABUTH) is located in Zaria about 75km north of the capital city of Kaduna, northwestern Nigeria. It provides tertiary level specialist care in a variety of fields as well as the training of medical personnel. It currently has a bed capacity of about 1000, staff strength of over 700, and a total patient admission turnover of more than 10,000 annually.

The study was done among out-patients attending the Paediatric-Oncology Clinic in the Department of Paediatrics (15 years and below) and the Sickle Cell Clinic in the Department of Haematology (16 years and above). The sickle cell out-patient clinics currently have a total of about 300 active patients, already diagnosed through haemoglobin electrophoresis at the Haematology laboratory of the hospital, with about 20-40 of them being seen per clinic day. The clinic day is Tuesday on which patients usually have their routine laboratory tests done in the morning and are seen at the clinics by noon. The weight, height, blood pressure and other clinical parameters of patients are assessed at each visit and they are commonly given appointment for eight to twelve weeks. The care also includes counseling which is provided by doctors and nurses among others.

A cross cross-sectional descriptive study was carried out among SCD patients and the care givers of SCD patients accompanying them to the Paediatric-Oncology and Sickle Cell Clinics in ABUTH, Zaria. Data was collected through interview from adult SCD patients and care givers of the pediatric patients attending sickle cell outpatient clinics. The study excluded patients and care givers who were new or who had not attended clinic for up to one year. It also excluded children who were accompanied by care givers that were less than 18 years old or who had not been living with them for at least one year.

The study covered families of 205 SCD outpatients who were selected through a systematic sampling technique and interviewed. Where the patient was below 18 years, the interview was done with the patient's care giver. The data was collected using a structured interviewer-administered questionnaire with both closed- and open-ended questions. The questionnaire was designed by the researchers and had five sections; background information of patient, burden of SCD on routine household activities, burden of SCD on family interactions, and health expenditure on SCD. It was pretested by administering it to 21 sickle cell disease patients attending Barau Dikko Specialist Hospital in Kaduna, about 75km away, and amended based on observations from the pre-test.

Data was analysed using the IBM SPSS version 20.0. Previous studies had taken catastrophic health expenditure to be anything from 5 % to 20% of total income.[7] In this study, catastrophic health expenditure was defined as a household

expenditure on health that equaled or exceeded 5% of average monthly income.

Ethical clearance was obtained from the Health Research Ethics Committee of ABUTH, Zaria. Informed verbal consent was also obtained from respondents after they were informed about the objective and nature of the study, the voluntary nature of their participation and assured of strict confidentiality.

RESULTS

The mean age of the SCD patients was 12.7±9.0 years and the females were 114 (55.6%) slightly more than the males. Also, majority of them 145 (70.7%) were students, with 103 (50.2%) having one sibling with SCD. Majority 146 (71.2%) of the households had monthly income of ?0 - ?49,000 (Table 1).

Majority 134 (65.4%) were diagnosed more than five years ago, and the mean duration since diagnosis was 10.9±8.7 years. In the last 12 months, almost half 92 (44.9%) had been admitted at least once on account of SCD, 72 (35.1%) had been transfused with blood and 150 (73.1%) had experienced painful crises (Table 2).

Caring for SCD patients frequently reduced the quality of care that other household members were receiving in 95 (46.3%), patient's illness frequently caused disagreement or quarrel among household members in 150 (73.2%), and 33 (16.1%) households had experienced stigmatization from community 33 (16.1%) (Table 3). Almost three-quarters of the households were expending more than 5% of their total income in providing medical care for the SCD patients (Table 4), and spending appeared to increase with the average monthly income of the household (Table 5) and number of painful crises (Table 6).

DISCUSSION

The study demonstrates that the families of SCD patients studied were experiencing different forms of psychological, social and economic burden due to SCD. Most suffered from mental stress, feeling of neglect, and catastrophic expenditure due to care for the SCD patient. Also, they experienced some stigmatization and there were reports of frequent disagreements among household members arising from the health conditions of the SCD patients.

The study observed that families of SCD patients experienced stress due to the patients' illness. This could be due to psychosocial maladjustments within the family which has the potential to aggravate the problems that SCD patients do experience. This highlights the possibility that counseling and self-help group could be of benefit to such patients and their families .

The rate of hospitalizations and severe pain episodes requiring medical treatment were both high. This could be because bone pain episodes account for most hospital admissions in SCD patients. Expect edly, this study also observed that increase in the number of bone pain episodes increased the amount of money spent on health care of the patients; among the households that spent N10,000 or more, the proportion with at least four episodes of painful crisis were about four times that of those that had only one episode.

While the way parents relate with their ill children and the feeling of neglect this generates toward other siblings is a major cause of family dysfunction, this feeling of neglect especially when experienced too frequently is a risk factor in the psycho pathology of psycho social problems in chronic physical illness. The finding that about half of the care givers admitted that caring for the SCD sufferer negatively affected the amount of care that other members of the household received, is consistent with findings from another study in southwestern Nigeria.

Family life and interactions have been described as significant areas of social life of SCD patients and their families. The frequent disagreements and quarrels within households of SCD patients observed in this study (73.2%) is in contrast with that in the study by Adegoke and Kuteyi in south western Nigeria (12.4%). The finding is also unexpected because the extended family culture that is common here should have provided some ameliorating effect on the household relationships. It also contradicts the assertion that, in Nigeria,

beliefs are largely influenced by cultural and religious values, which in turn influence health behavior and coping strategies. Such contradiction may be a pointer to the severity of the negative effect of SCD burden on family dynamics.

The finding of less than one-fifth of the care givers experiencing stigmatization is similar to that of other studies which reported that stigmatization was not the most prominent social problem in SCD patients. However, this finding contradicts that of an earlier study which reported that up to half of the families of individuals with SCD were being stigmatized because of SCD.

The average amount of money spent on health care of SCD patients was N4,753.90 per month, about a quarter of the minimum wage in Nigeria. And this increased with monthly income of care givers and frequency of bone crises. The high economic burden of caring for SCD patients observed in this study is similar to the findings from south-western Nigeria. This may be because the predominant form of health-care financing in Nigeria is out-of-pocket. Moreover, the man-hour loss arising from the time spent caring for a SCD patient, could significantly contribute to the financial burden experienced by care givers and their families, but this was not studied in great detail here. In addition, the average amount spent was mostly exclusive of other forms of care not directly related to health care; suggesting that the actual cost of care of SCD patients could be even higher than what was reported. A similar finding was reported by Kauf and colleagues. Such observations highlight the need for more comprehensive studies to estimate the true financial losses among families from caring for SCD patients, especially within the context of other health expenditure, generally. This could serve as a resource for planning programmes to alleviate the financial burden on the families and as a resource for counselling them and other intending parents.

When households experience catastrophic expenditure due to health, they often have to forego other goods and services, an act which could have negative implications for living standards of the family. Also, these households try to adopt coping strategies to meet the costs associated with care-seeking; these coping mechanisms although useful in the short term, lead to impoverishment or deepen poverty among households who are already poor. Majority of the families studied experienced catastrophic expenditure due to SCD alone, increasing the proportion that would end up with catastrophic health expenditure when other expenditures due to other health conditions are considered. This is more so because majority of the health care financing in Nigeria is through out of pocket expenditure. While care givers of SCD children in many developed countries have opportunities to benefit from health insurance, and thus report lower financial burdens, their counterparts in most parts of the developing world do not.

The authors, however, recognized that this study has a few limitations. One limitation was in the reliance on a care giver to speak on behalf of his / herfamily, because it could be difficult for a single member to accurately describe the emotional stress and disturbed intra-family ties, as perceived by all members of the family. In addition, the fact that the study was done among outpatients limits the general is ability of the results to families presenting for emergency care, which may reflect a population with more severe distress.

In conclusion, this study reports some psychological, social and economic burdens experienced by families of individuals with SCD experience. It is recommended that locally applicable methods of non-pharmacological support, such as teaching methods of coping with stress, be developed to form part of routine care for SCD individuals and their families. Apart from psychological and social support, economic support especially in the form of health insurance or free care should be made available to SCD patients and their families. This will reduce their chances of experiencing catastrophic health expenditure. This information is useful for the planning of health care delivery for SCD patients and their families, and for the planning of genetic counselling and public health education to prevent SCD. Future research should explore the estimation of the exact financial and man-hour losses among families of SCD.

Table 1: Socio-Demographic profile of SCD patients studied

Characteristics	Frequency(N=205)	Percent
Age (years)		
0-4	61	29.8
5-9	35	17.1
10-14	41	20.0
15-19	28	13.7
20-24	16	7.8
25-29	15	7.3
30-34	6	2.9
35-39	3	1.5
Sex		
Male	91	44.4
Female	114	55.6
Occupation		
None	40	19.5
Student	145	70.7
Civil servant	7	3.4
Self employed	10	4.9
Others	3	1.5
Level of Education		
None	45	22.0
Primary	70	34.1
Secondary	57	27.8
Tertiary	33	16.1
Type of Marriage		
Monogamous	112	54.6
Polygamous	76	37.1
Parents not currently married	17	8.3
Number of Siblings with SCD		
0	50	24.4
1	103	50.2
2	34	16.6
3	13	6.3
≥4	5	2.4
Average Monthly Household Income		
≤49,999	146	71.2
50,000-99,999	25	12.2
100,000-149,999	12	5.9
150,000-199,999	15	7.3
≥200,000	7	3.4

Table 2: Burden of provision of medical care for the SCD patient

Burden	Frequency (N=205)	Percent
Duration since diagnosis (years)		
≤5	71	34.6
6-10	42	20.5
11-15	35	17.1
≥16	57	27.8
Number of admissions in the last 12 months		
0	113	55.1
≥1	92	44.9
Number of transfusions in the last 12 months		
0	133	64.9
≥1	92	44.9
Number of painful crises in the last 12 months		
0	55	26.8
≥3	150	73.2

Table 3: Burden of family interaction and economic activities (N=205)

Burden	Frequency	Percent
Patient's illness frequently causes disagreement or quarrel in HH	150	73.2
HH frequently borrows money to pay for patient's care	127	62.0
Patient's basic self-care frequently provided by other HH members	105	51.2
Patient's illness adversely affects provision of HH basic needs	102	49.8
Caring for patient frequently reduces care to other HH members	95	46.3
Patient's illness adversely affects general mood of HH	89	43.4
HH significantly loses income due to time spent caring for patient	87	42.4
Household has experienced stigmatisation from community	33	16.1

HH=Household

Table 4: Percentage of household income expended on SCD patient's health care

Percent of income expended	Frequency (N=205)	Percent
≤4	59	28.8
5-20	47	47.3
21-40	29	14.1
41-60	9	4.4
≥61	11	5.4

Table 5: Association between average monthly income and average monthly expenditure on SCD patient's health care

Income	Expenditure n (%)			Total
		5,000-9,900		
≤49,999	125 (84.5)	20 (13.5)	3 (2.0)	148 (100.0)
50,000 - 99,999	19 (76.0)	4 (16.0)	2 (8.0)	25 (100.0)
100,000-149,999	7 (63.6)	2 (18.2)	2 (18.2)	11 (100.0)
150,000-199,999	6 (42.9)	4 (28.6)	4 (28.6)	14 (100.0)
≥200,000	2 (28.6)	1 (14.3)	4 (57.1)	7 (100.0)
Total	159 (77.6)	31 (15.1)	15 (7.3)	205 (100.0)

X^2 = 34.591; df = 8; p<0.0001

Table 6: Association between number of painful crises in the last 12 months and average monthly expenditure on SCD patient's health care (N=150).

Number of painful crises	Expenditure n (%)			Total
	≤4,999	5,000-9,999	≥10,000	
1	36 (90.0)	2 (5.0)	2 (5.0)	40 (100.0)
2	31 (86.1)	4 (11.1)	1 (2.8)	36 (100.0)
3	29 (78.4)	5 (13.5)	3 (8.1)	37 (100.0)
≥4	20 (54.1)	11 (29.7)	6 (16.2)	37 (100.0)
Total	116 (77.3)	22 (14.7)	12 (8.0)	150 (100.0)

X^2 = 13.086; df = 8; p=0.042

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