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ABSTRACT

Introduction: Caregivers of children with Sickle Cell Anaemia (SCA) are exposed to intense pressure of taking care of their children with the risk of developing psychological problems which could affect their coping abilities. The study aimed to assess the clinical impact of children with SCA on coping abilities of their caregivers in order to improve the care of the children with SCA and the coping abilities of their caregivers.

Methods: This was a cross sectional study carried out at the Sickle Cell clinic at Barau Dikko Teaching Hospital, Kaduna, North-Western Nigeria. All consecutive eligible caregivers of children with SCA attending the Sickle clinic from February to April 2016 were recruited till the desired sample size of 133 was met. The coping ability domain of the structured Sickle Cell Disease Burden Interview (SCDBI) was used. Ethical clearance was obtained from the ethical committee of Kaduna State Ministry of Health.

Results: Sixty three (47.4%) of the caregivers were more than 35 years of age. Majority were Hausas 84 (63.2%), Muslims 100 (75.2%) and married 114 (85.7%). Only 45 (33.8%) had secondary education, 43 (32.3%) were unemployed and 42 (31.6%) were unskilled laborers. There was significant association between coping ability of the caregivers and school absenteeism of their children ($p=0.030$).

Conclusion: School absenteeism of children with SCA affects the coping ability of their caregivers. There is need for prevention of recurrent crisis to avoid school absenteeism.

Keywords: Caregivers, Clinical Impact, Coping ability, SCA children.

INTRODUCTION

Sickle Cell Anaemia [SCA] is one of the most common inherited diseases, and the one with the most frequent morbidity and mortality in the world, especially in developing countries.¹ SCA is characterized by alternate cycles of steady states and acute illnesses (crisis). The crises are due to vaso-occlusive and hemolytic phenomena. Nigeria with an estimated carrier prevalence of 24%, has 20 per 1000 births affected by SCA resulting in 150,000 children with the disease born annually.²

Taking care of a child with SCA is a challenging experience for both the caregiver and the other family members.³ A person who assists a suffering person, beyond the professional role, is indicated generally by the term "caregiver". The caregiver may be "a person who helps to meet the needs of a depending individual."⁴ Caregivers to children with SCA are tasked with the responsibility for managing their child's care, which includes daily use of routine drugs, recurrent or frequent illnesses, the need for blood transfusion, regular clinic attendance and hospitalization, encouraging their child to

engage in preventive behaviors, managing pain episodes, teaching coping skills and providing adequate nutrition and hydration.

Besides the total dependence of the afflicted child on his/her caregiver for general care and treatment, caregivers, are subjected to continuous pressure and consequently, caregivers may develop psychological disorders such as depression and anxiety.⁵ The psychological burden in turns affects their overall coping ability with the stress. According to the World Health Organization, stress can be defined as a state of worry or mental tension caused by a difficult situation. Stress is a natural human response that prompts us to address challenges and threats in our lives.⁶ While Psychological burden is defined as an excessive reaction to stress caused by one's environment that may be characterized by feelings of emotional and physical exhaustion, coupled with a sense of frustration and failure.⁷

As in other chronic conditions, stressors related to SCA have the characteristic of uncontrollability, which can be translated into the occurrence of painful episodes, given that the cure is rare and there are restrictions imposed by the disease itself.^{8,9} It is very imperative to assess how the stress of taking care of children with SCA specifically their clinical status affect the coping abilities of their caregivers. This is because the psychologically traumatized caregivers can have burnout and low self-esteem and may not be able to provide necessary assistance to other family members and not able to perform homework or solve daily difficulties. The caregivers are no longer able to control the space; they lose control of their role, and feel "invaded" by their work. The stress response is coping. The individual chooses a specific way in which to deal with the stressful stimulus.¹⁰ Each caregiver develops his/her own coping strategy to manage the "family turmoil". When this attempt to restore a balance fails, the care of the children with SCA becomes affected.

Researchers tend to focus more on children with SCA without taking into cognizant the caregivers who are psychologically affected by the disease burden which could affect their coping abilities. This in turn affects the care of their children with SCA. Therefore, this study aimed at assessing the clinical impact of children with SCA on their caregivers' coping abilities. This will assist policy makers in making strategies to improve clinical status of SCA children.

METHODS

The study was carried out at the Sickle Cell clinic of the Paediatric Department of Barau Dikko Teaching Hospital, Kaduna, North-Western Nigeria. The hospital is a tertiary level teaching hospital located in Kaduna North Local Government Area of Kaduna State.

All consecutive eligible mothers/caregivers of children with SCA attending the sickle cell clinic from February to April 2016 were recruited till the desire 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 SCA children were seen over the three month period.

The sample size of 133 was estimated using the formula for calculating minimum sample size:¹¹

$$n = \frac{Z^2 pq}{d^2}$$
 where Z= the standard normal deviate usually set at 1.96 which corresponds to the 95 percent confidence interval; p = the proportion in the target population estimated to have a particular characteristic = 12.4%

Eleven participants who met the inclusion criteria were recruited weekly during the clinic hours. This gave a total of 44 caregivers recruited in a month. A total of 132 women were recruited in 12 weeks. The remaining 1 caregiver was also recruited in the last week along with others making the total 133.

Ethical clearance was obtained from the Health Research Ethics Committee of Kaduna

State Ministry of Health (MOH/ADM/744/VOL.1/401). 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 Sick Cell Disease Burden Interview (SCDBI) was used. It was initially validated by Ohaeri and Shokunbi and found to be relevant to Nigerian culture.⁸ 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 care giver's feelings (e.g depression, sorrow, anger and/or stigmatization) towards the child and the ability of the family to cope with the disease.¹² It had a total of 16 questions: three each on family finances and interactions and five each on routine family activity and parental coping ability.

This study focused on the domain of parental coping ability which has five questions. Each question has a score ranging from 0-3. 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 and the total score categorized and interpreted as follows: total score of 0 as no impact; 1-5 as insignificant impact; 6-10 as moderate impact; and scores between 11 and 15 as severe impact. However, in this study, category "no impact" and the "insignificant impact" were merged and categorized as mild impact.

The health/clinical outcome of the affected children was assessed through inquiry on: age of the child, age of the child at diagnosis, frequency of crisis over twelve months, type of crisis, number of significant bone pain

episode and hospital admissions over twelve months. General physical examination was also carried out to assess the degree of palor and jaundice, height in centimeter (cm) and weight in Kilogram (kg) using stadiometer calibrated at 0 for those above 2 years while a tape was used to measure the length in cm for those below 2years. Laboratory investigations such as Packed Cell Volume (PCV) were carried out.

Data was analyzed using EPI – INFO statistical package (3.5.3 January 2011 version). Socio-demographic 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 SCA and caregivers coping ability.

RESULTS

Complete data were available for all the 133 participants and all were analyzed. Higher proportion 63 (47.4) of the caregivers were more than 35 years of age. Majority were Hausas: 84 (63.2%), Muslims 100 (75.2%) and married 114 (85.7%). Those with secondary education were 45 (33.8%). High proportion of the caregivers were unemployed 43 (32.3%) and unskilled laborers 42 (31.6%). Nuclear family constituted a higher proportion, 85 (63.9%) and the care givers were mainly the mothers, 122 (91.7%). Those with less than 4 children were 80 (60.2%). Those having the oldest child aged more than 5 years were 105 (78.9%). Twenty eight (21.1%) and 15 (11.3%) had only one and more than one other children (siblings of their children) with SCA respectively. Source of their health care financing was mainly out-of-pocket means in 126 (94.7%) participants and higher proportion of them had an average monthly income between N 20,000 – N 50,000. Majority of the caregivers: 82 (61.7%) did not belong to any social group (Tables 1a and 1b).

Clinical status of children with SCA and the coping ability of the caregivers

The statistical analysis of the clinical status of the children with SCA on their caregivers

coping abilities revealed significant relationship between number of school absenteeism of the children and the coping abilities of the caregivers (p-value = 0.030).

Details of the Clinical status of the children with SCA and their caregivers' coping abilities are depicted in table 2.

Table 1a: Socio Demographic Characteristics of the caregivers

	No.	Percentage %
Age of care giver		
≤ 24 years	18	13.5
25 – 35 years	52	39.1
> 35 years	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
Single	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
Post Secondary	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

DISCUSSION

This study examined the caregivers' coping ability domain of the SCDB and its relationship with the clinical status of their children with SCA. The findings revealed that school absenteeism of the SCA children has

Table 1b Socio Demographic Characteristics of the caregivers

Type 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		
≤ 5 years	28	21.1
> 5 years	105	78.9
Total	133	100.0
Other Siblings with SCA		
None	90	67.7
1 sibling	28	21.1
More than 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		
< N20,000	44	33.1
N20,000 – N50,000	47	35.3
N50,000 – N100,000	30	22.6
> N100,000	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

significant effect on caregivers' coping ability. The school absenteeism could be related to the crisis experienced by the children with SCA. Managing crisis especially the painful crisis could cause the psychological distress on the caregiver

Table 2: Clinical status of the children with SCA and their caregivers' coping abilities

Clinical Status of SCA Children	Mild	Moderate	Severe Impact	Total	Chi Square	d.f	p-value
Age of the children							
< 5 yrs	14	42	1	57			
5 - 12 yrs	19	35	4	58			
> 12 yrs	3	13	2	18			
Total	36	90	7	133	5.403	4	0.248
Age of diagnosis							
< 1 yr	18	39	5	62			
1 yrs and above	18	51	2	71			
Total	36	90	7	133	2.324	2	0.313
No. of significant bone crisis over the last 12 months							
None	12	14	1	27			
1 crisis	8	17	0	25			
2 - 5 crisis	15	56	6	77			
> 5 crisis	1	3	0	4			
Total	36	90	7	133	9.961	6	0.126
Frequency of hospital admission over the last 12 months							
None	25	51	3	79			
1 time	5	24	3	32			
2 - 5 times	6	15	1	22			
> 5 times	0	0	0	0			
Total	36	90	7	133	3.900	4	0.420
Frequency of blood transfusion over the last 12 months							
None	28	63	5	96			
1 time	7	23	1	31			
2 - 5 times	1	4	1	6			
> 5 times	0	0	0	0			
Total	36	90	7	133	2.609	4	0.676
Frequency of school absenteeism over the last 12 months							
None	31	69	2	102			
1 time	1	2	0	3			
2 - 5 times	1	5	2	8			
> 5 times	3	14	3	20			
Total	36	90	7	133	14.006	6	0.030
Degree of Palor							
Nil	1	3	0	4			
Mild	31	71	5	107			
Moderate	4	16	2	22			
Total	36	90	7	133	1.827	4	0.734
Degree of Jaundice							
Nil	5	9	1	15			
Mild	28	70	4	102			
Moderate	3	11	2	16			
Total	36	90	7	133	2.776	4	0.596
Weight for age of the child							
Normal	25	71	5	101			
Abnormal	11	19	2	32			
Total	36	90	7	133	1.338	2	0.512
Height for age of children							
Normal	31	84	6	121			
Abnormal	5	6	1	12			
Total	36	90	7	133	1.773	2	0.412

especially when the caregiver realizes that the child is left behind in terms of educational achievement compared to his or her mates.

Frequent school absenteeism as a result of recurrent crises and suboptimal health is a major problem of sickle cell disease children. Anie *et al.* opined that psychosocial issues of people with sickle cell disease and their families mainly result from the impact of pain and symptoms on their daily lives and society's attitude to sickle cell disease and those affected.¹³ They went further to say that in Africa, cultural factors are particularly relevant to these problems because of beliefs and traditional practices.¹³

In Nigeria, beliefs are usually influenced by cultural and religious values, which in turn influence health behavior such as coping strategies. A study has shown that religious beliefs play a positive part in coping including prayer, faith in God and Doctors, and hopeful approach to health difficulties in Nigeria.¹³ According to Anie *et al.*, previous research also revealed that compared with people with sickle cell disease in the United Kingdom, those in Nigeria commonly used praying and hoping as an affective coping strategy, which seems to be influenced by external factors such as religion, faith in God, superstitions and stigma.¹³

Though, this study did not statistically analyze the influence of religion on caregivers coping abilities, majority of the caregivers in this study were Hausas and Muslim which might have influenced their coping abilities as there was no association between other clinical parameters of the children and the caregivers coping abilities. This could be best understood in terms of the caregivers being able to cope with all the clinical impact except for the school absenteeism.

In a study in Ibadan to determine psychologic distress and coping strategies, mild to moderate anxiety, was prevalent in 92.6% and 84.1% of caregivers of SCD and non-SCD patients, while more (13.2%) of non-SCD patients' caregivers experienced moderate

depression.¹⁴ Higher percentage of caregivers (86.6% & 61.2%) of SCD patients significantly deployed "religion" and "acceptance" as coping strategies compared to (68.7% & 26.9 %) of non-SCD patients' caregiver.¹⁴ This showed that caregivers of SCD patients had adopted their coping abilities which assisted them in overcoming the psychologic distress.

Descriptive analyses conducted for individual disease-management tasks in a study in USA revealed that caregivers reported more involvement on most tasks than did youth, although rates varied.¹⁵ In particular, caregivers took the lead on tasks such as remembering clinic appointments, telling teachers and relatives about SCA, and explaining school absences to school personnel.¹⁵ This showed that caregivers often interacted with teachers and school personnel on the disease especially when their children were absent from the school due to crises. These could be so disturbing.

A cross sectional study by Badr *et al* revealed that positive emotions were predicted by the levels of satisfaction of the caregiver with his/her health, job achievement, living conditions and the condition of the diseased child.¹⁶ A strong correlation was found between sleep quality and cognitive skills.¹⁶ This is in support of the this study which showed the association between the ill health of child resulting to school absenteeism and their ability to cope well with the situation. Therefore, when there is no school absenteeism, there is no frequent crisis and as such there would be satisfaction with the condition of the children by the caregivers which could improve their coping abilities with good sleep.

Limitations

This study is a hospital based study. Therefore, the result may not reflect the actual situation in the community as many children in the community especially in this setting are left under the care of traditional healers due to misconceptions surrounding the disease condition. Also, the study did not assess the

emotional well-being of the caregivers, the strategies they employ to cope and the support system available that assist them to cope and manage the stress

CONCLUSION

Clinical status of children with SCA such as school absenteeism as a result of crisis affects the coping ability of the caregivers. Prevention of crisis is the key to attaining good health for both sufferers and the caregivers and management of children with SCA should be comprehensive and within the context of the Family most especially the caregivers. Further studies are needed to assess the caregivers' emotional well-being, the strategies they employ to manage stress, and the support systems available to them. The findings from such a study can be valuable for healthcare professionals and policymakers in understanding the needs of caregivers and developing interventions to support them in their crucial role in managing pediatric sickle cell anemia

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