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Psychosocial Burden and Coping Abilities of Caregivers of Children with Sickle Cell Disease Attending Government-Owned Tertiary Health Care Facilities in Ogun State, Southwest Nigeria

Alabi AD[1ID], Ogundeyi MM[2ID], Mautin GJ[1ID], Ekundayo AA[1ID]

[1]*Department of Community Medicine and Primary Care, Olabisi Onabanjo University Teaching Hospital, Sagamu, Ogun State, Nigeria*
[2]*Department of Pediatrics, Federal Medical Centre Abeokuta, Ogun State, Nigeria*

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Abstract
Objective: Sickle cell disease is a chronic inherited haematological disorder affecting predominantly people of African, Arab and Indiana ancestries with the highest reported burden of 150,000 children in Nigeria. The chronicity and physical and psychosocial complications of the disease pose a significant psychosocial burden on children and their caregivers. This study assessed the psychosocial burden and coping abilities of primary caregivers of children with sickle cell disease.
Method: It was a descriptive cross-sectional study done in two public tertiary health institutions in Ogun State. Semi-structured interview-based validated questionnaires were administered to assess their psychosocial and health burden. The coping ability of the caregivers was determined. Descriptive statistics and non-parametric tests were used for data analysis.
Results: Two hundred and twenty-four primary caregivers were interviewed. The moderate to severe psychosocial burden was 34.4%. Some (21.4%) found it difficult to cope with the care of the children and 12.1% believed it had a severe impact on their health. Major factors reported were frequent hospitalization, emergencies, school absenteeism, crisis and hospital bills. Caring for these children caused a general atmosphere of tension and marital disharmony in 17.4% and 17.9% of the respondents, respectively. The stress level was higher among female caregivers, low socio-economic class, single parenthood and older caregivers. Female child, age and severity of illness had a significant impact on the burden and coping levels.
Conclusion: The caregivers experienced some psychosocial burden and difficulty in coping. Frequent hospitalization and the high cost of health care placed significant strain on them.

Keywords: Sickle cell disease, Children, Caregivers, Burden, Coping

Plain English Summary

Sickle cell disease (SCD)is a chronic inherited haematological disorder that affects mostly people of African, Arab and Indiana ancestries with the highest occurrence of 150,000 children in Nigeria. Its chronicity and physical and psychosocial complications of the disease cause a significant burden on the children and their caregivers. This study was done to assess the psychosocial burden and coping abilities of primary caregivers of children with sickle cell disease. It was a hospital-based study done in two public tertiary health institutions in Ogun State. Semi-structured interview-based validated questionnaires were administered. A total of 224 primary caregivers were interviewed. The overall moderate to severe psychosocial burden was 34.4% with some (21.4%) finding it difficult to cope with the care of the children. Some (12.1%) believed it had a severe impact on their health. Major factors reported were frequent hospitalization, emergencies, school absenteeism, crisis and hospital bills. The

Correspondence:
Alabi, Adekunle D
Department of Community Health and Primary Care, Olabisi Onabanjo University Teaching Hospital, Sagamu, Ogun State, Nigeria
+2348034468258, drkalabi@yahoo.com

stress level was higher among female caregivers and low socio-economic class. Female child, age and severity of illness had a significant impact on the burden and coping levels. The caregivers experienced significant psychosocial burden and difficulty in coping. Frequent hospitalization and the high cost of health care placed significant strain on them.

Background

Sickle cell disease (SCD) results from deformity in the red blood cells caused by an abnormality of the β-globin gene (1). There has been an increase in the global burden and prevalence of SCD which is expected to be more in the coming decades and SCD is now recognized as a global health problem by United Nations (UN) and World Health Organization (2, 3). Nearly 300,000 to 400,000 children are born yearly with SCD globally with up to 90% of these births occurring in low- middle-income countries (LMICs) and half of these children were in three countries: Nigeria, the Democratic Republic of Congo and India, although the disorder also occurs throughout other sub-Saharan Africa (SSA) countries with small pockets in the Middle East, Mediterranean and Caribbean regions (4). An estimated 50 million people are reported to be living with SCD globally, with Nigeria being the epicentre zone housing a projected 4-6 million victims (5). There are about 300,000 newly diagnosed SCD children born worldwide each year with Nigeria accounting for 100,000-150,000 of these newborns (5). SCD is a chronic, lifelong disorder characterized by multiple physical and psychosocial complications for those afflicted but also presents many challenges for families, communities, and health care systems (6). Health-related quality of life (HRQOL) refers to the effects an illness has on the subjective well-being of patients. Poor HRQOL has been documented in SCD patients (7, 8) due to various crises and or complications which may be experienced by the patients. Complications such as painful episodes, anaemia, infection, haemolysis, acute chest syndrome (ACS), cerebrovascular accident (CVA)/stroke, priapism, avascular necrosis of the hip, delayed growth/puberty, absenteeism from school or work and academic underachievement can be quite devastating to the patients, caregivers and the family members (9, 10).

The disease has been found to confer significant psychological and social burdens on the sufferers, caregivers and their families (11, 12). The child with SCD is not the only person who will need adjustment to live with the illness; there are expected life changes for other family members, especially the primary caregiver (13). Similar to the child's experiences, the primary caregivers also need to navigate through the journey with their wards and this may have deleterious effects on both their coping ability and psychosocial well-being (14).

According to a study (15), parents raising children with chronic illness have a myriad of psychological, social and medical issues such as dealing with the news of their child's diagnosis, feelings of guilt, the medical implications of the diagnosis and the possibility of a shortened lifespan of their child. Factors such as socioeconomic, educational background, cultural issues, attitudes of the child, family and healthcare professionals, and availability and accessibility to healthcare services may affect the quality of life of sufferers and their caregivers. This may be a great determinant of the well-being of the children and family members, especially the caregivers.

Despite the high prevalence of sickle cell disease in Nigeria, the families bear most of the financial and psychosocial burden of care for patients with this chronically disabling illness due to inadequate social welfare provisions and health care services (10). This impact may have worse effects on the families in LMICs such as Nigeria. Caregivers of these children are exposed to intense pressure with the risk of developing psychological problems which may affect their ability to take care of the afflicted children and these caregivers are often also in crucial need of support from both physicians and authorities (16). Although Nigeria has a national guideline for the management of SCD and an adapted version of the USA handbook for parents (17), there is no information in these documents that deals with how the parents/caregivers can be assisted to cope with the possible psychosocial problems they may encounter.

A systematic review showed that parenting stress is significantly greater among caregivers of children with chronic illnesses such as SCD than among caregivers of healthy children (15). In Nigeria, it was reported that more than one-third of the caregivers had difficulty coping with the care of these children (18, 19). There is a dearth of information concerning these coping abilities in Ogun state despite many institutions offering care for children living with SCD. The findings would help to plan health resources and services appropriately. It will also guide the provision of necessary support in the future as well as incorporating the psychological and counselling units into the routine outpatient clinic care. Therefore, this study was done to assess the psychosocial burden and coping abilities of parents/caregivers of children with sickle cell disease.

Methods

Study Design

The study was a hospital-based descriptive cross-sectional study involving the primary caregivers of children with SCD done over five months.

Study Location

The study was done at the Consultant Paediatric Out-patient Specialty (haematology) clinics of the two health facilities: Federal Medical Centre, Abeokuta (FMCA) and Olabisi Onabanjo University Teaching Hospital (OOUTH), Sagamu, both in Ogun State. They are public tertiary health institutions in the state and serve as referral centres for both government-owned and privately-owned health institutions in the state and some others like Lagos, Oyo and Ondo in Nigeria.

Federal Medical Centre, Abeokuta is a 250-bedded tertiary (specialist) hospital established in April 1993. OOUTH Sagamu is a 304-bed tertiary institution established in 1986 with the primary aim of training undergraduate and postgraduate medical students. It was the first state-owned teaching hospital in Nigeria.

The Paediatric department of both institutions comprises of children's emergency room (CHER), children's ward, neonatal unit and outpatient clinics, paediatrics outpatient department and Consultants' outpatient speciality clinics. All the clinics are run by Paediatricians.

The paediatric haematology clinic at FMCA runs once weekly with two genetic counsellors (including a trained Paediatric Nurse) and an average of 18-25 SCD children seen during each clinic day. OOUTH Sagamu paediatric haematology takes place once a week and is overseen by a trained Paediatric Nurse with an average clinic attendance of 10-15 children per week. There were 262 and 150 children 15 years old and above at FMCA and OOUTH respectively on the clinic register.

Study Population

The participants were primary caregivers of children with SCD who registered their wards with the haematology clinic in the hospitals and had been attending the clinics for at least 3 months before the commencement of the study.

Operational definitions

Primary caregiver: for this study, refers to the parent or non-parent who has the greatest responsibility for the daily care, providing assistance, support and rearing of the child with SCD.

Steady-state: in a child with SCD: is defined as a state or situation when the child has been free from crisis in terms of bone pains, infection and or symptom of anaemia for at least 4 weeks on the day of the interview.

SCD Crisis: exacerbation of sickle cell symptoms such as bone pains, anaemia or infection or sudden development of adverse change with the evidence of new signs and symptoms in the child.

Impact: event(s) that have a strong effect on something or their activities

Stress: Self-reported events or tension of a set of physical or psychological reactions that may challenge or threaten the primary caregivers.

Sampling

Using the Cochran formula (20), a minimum sample size of 378 was calculated based on an estimated 5% error margin. 95% confidence interval and a prevalence of 44% (0.44) of the coping ability of parents in a similar study (20). The population (N) of SCD patients for both clinics was 412, hence correction for population <10,000 (nf – calculated corrected sample size) was done to arrive at 197. A total of 224 caregivers were then recruited for the study in anticipation of a 10% response.

A two-stage technique was used to select the samples.

The first stage; the Proportional sampling technique was used to select samples in the 2 facilities in the state. The total number of Children with SCD that met the inclusion criteria in the two hospitals as retrieved from the SCD register and health records department was 412 (FMCA and OOUTH had 267 and 145 respectively). Hence, I45 and 79 respondents were selected from FMC and OOUTH, respectively.

The second stage: The systematic sampling technique was then used to select samples within each facility using the list of patients (clinic register) as the sample frame.

Recruitment: The selected caregivers of the SCD children were recruited into the study after consent was obtained following a detailed explanation of what the study was about.

Inclusion criteria:

The study included caregivers that had attended the Paediatric Haematology Clinics for at least 3 consecutive times or three months before commencement of the study. The SCD-affected child must have been living with the caregiver for at least 6months before the study. Lastly, the caregivers' child needed to be in a steady clinical state.

Exclusion criterion

Caregivers whose children were not clinically stable were excluded.

Data Collection and Analysis

A structured questionnaire was used to obtain information on the socio-demographic characteristics of the caregivers, the child's biodata, and social and medical history. Sickle Cell Disease Burden Interview (SCDBI) was also conducted. This tool was validated and adapted by other researchers (18, 21). It assessed the general burden including the burden of individual stressor factors. The instrument was 55-item stress factors using a Likert-type statement with the following sub-sections: hospital factors, family/social factors (family life, interactions and dynamics), health/physical stress factors on caregivers, child disease factors, child factors (perceived quality of life of the SCD-affected child), financial factors and parental coping ability. Two trained graduate assistants were recruited for the data collection. The 4-day training was done using didactic lectures and practical demonstrations on the administration of the tool.

The data obtained from the questionnaires were collated, entered and analysed using the Statistical Package for Social Science (SPSS data package) version 23.0. Socio-demographic characteristics of the caregivers and children with SCD were categorized. The details of the scoring of the domains (22) of the SCDBI are described in Supplementary File 1.

Frequency distribution tables were generated from the computed categorical variables and numerical data were summarised using means, median and standard deviation. Non-parametric tests were then used for further inferential statistics. All statistical tests were regarded as significant at a p-value <0.05. Data was presented using tables, figures and charts as appropriate.

Results

A total of 224 caregivers were recruited into the study from the two health facilities, 145 (64.7%) and 79 (35.3%) from Federal Medical Centre, Abeokuta (FMCA) and Olabisi Onabanjo University Teaching Hospital (OOUTH) Sagamu respectively. All the selected caregivers participated in the study.

Caregivers' socio-demographic characteristics

Table 1 highlights the caregivers' characteristics. The age range of the caregivers was between 22 and 72 years with a mean of 39.3 ± 7.8 years. The majority (42.4%) of the caregivers were aged between 30 and 39 years. A total of 186 caregivers (83%) were married and with monogamy as the family type in the majority of them (159; 71%), 7 caregivers (3.1%) were widowed. Most (155; 69.2%) of the caregivers had small family sizes ≤ 3 children with the mean number of children per family being 3.03 ± 1.52. The index patient was the only SCD child in the family in the majority of the respondents (183; 81.7%) as depicted. Fifty-three (23.7%) of the caregivers had lost at least a child in the past with the cause of death in these children attributable to SCD-related complications in the majority of these losses (43; 81.1%).

Table I: Socio-demographic characteristics of the caregivers

Variables	Number	Percentage
Age (in years)		
20 – 29	21	9.4
30 – 39	95	42.4
40 – 49	88	39.3
≥ 50	20	8.9
Religion		
Islam	96	42.9
Christianity	128	57.1
Gender		
Male	26	11.6
Female	198	88.4
Caregivers' relationship		
Parent	213	95.1
Grandparent	7	3.1
Aunt	4	1.8
Socioeconomic class		
I	2	0.9
II	43	19.2
III	74	33.0
IV	89	35.7
V	16	7.0

Number of children per family with SCD		
One	183	81.7
Two	37	16.5
Three	3	1.3
Four	1	0.4

Socio-demographic and clinical characteristics of children with SCD

Their ages ranged from 1 to 15 years with a mean of 8.06 ± 3.76 years and the median age was 7.6 years. The majority of the SCD children (106; 47.3%) were in the age range of 6 – 10 years. A total of 171 (76.4%) were in primary or pre-school with only 16 (7.1%) in senior secondary education.

Table 2 summarizes the clinical burden of SCD on the children. The majority (74.3%) had blood transfusions at least once in the last year. The time of diagnosis of SCD ranged from 6 months to 11 years with about four-fifths (184; 82.1%) of these children already diagnosed before the age of 5 years with a mean age of 2.88 ± 2.23 years. In the last 12 months, 137 (61.2%) of the Children with SCD required admission into the hospital for one form of SCD crisis or the other. One hundred and sixty (71.4%) had mild disease while none of them belonged to the severe disease category.

Concerning the complications of SCD, seventy-seven children (34.4%) have had one significant form or the other of SCD complications. Amongst the children that had suffered complications, the majority (66; 85.7%) had one complication. The most frequent complication among these children was acute chest syndrome (36; 40.9%).

Concerning drugs/medication history, all the children with SCD were on routine drugs with an average cost of NGN2125.75 ± NGN917.53 per month. About half of the caregivers (105; 46.9%) of these children administered or gave traditional medicines in the last year as a form of treatment for SCD-related illness and or as routine drugs with almost one-quarter of them given the traditional medicines at least daily or once/twice per week.

Table 2: Clinical burden of the disease on children with SCD

	Number (n)	Percentage (%)
Previous pain crisis in the last 1 year		
Yes	178	79.5
No	46	20.5
Frequency of bone pain crisis in the last 12 months		
One	64	36.0
Two	68	38.2
≥ 3	46	25.8
Previous hospital admission		
Yes	137	61.2
No	87	38.8
Frequency of hospital admission in the last 12 months		
Once	87	63.5
2 or 3 times	50	36.5
Blood transfusion in the last 12 months		
Yes	74	33.0
No	150	67.0
Frequency of blood transfusion in the last 12 months		
One	55	74.3
2 or 3	16	21.6
> 3	3	4.1
SCD-related complications		
Yes	77	34.4
No	147	65.6
Types of complications		
Acute chest syndrome	36	40.9
Osteomyelitis of the extremities	12	13.6
Cerebrovascular disease (stroke)	11	12.5
Meningitis	3	3.4

Avascular necrosis of the hip	5	5.7
Leg ulcer	5	5.7
Priapism	7	8.0
Others*	9	10.2
Total number of complications	88	100.0

*= hematuria, pulmonary hypertension, hepatopathy, septic arthritis and seizure disorder

The psychosocial burden of sickle cell disease on the primary caregiver

According to Table 3, more than half (127; 56.7%) of the caregivers found frequent hospital stays/admission to the hospital incredibly stressful. The stressful events for hospital factors when weighted together were statistically significant $\chi 2 = 13.02$, $p = 0.000$.

Table 3: Hospital factors as a psychosocial burden on the caregivers

Hospital factors	Not stressful	Stressful
Admission to hospital/ frequent hospital stay	97 (43.3)	127 (56.7)
Keeping clinic appointment	141 (62.9)	83 (37.1)
Waiting for doctors/hospital staff	159 (71.0)	65 (29.0)
Blood transfusion	174 (77.7)	50 (22.4)
Attitude of hospital staff	197 (87.9)	27 (12.1)
Hospital routine	160 (71.4)	64 (28.6)
Not getting enough support from the hospital administration	208 (92.9)	16 (7.1)
Visits to the emergency department	125 (55.8)	99 (44.2)
Hospital factors weighted	**139 (62.1)**	**85 (37.9)**

Psychosocial burden of family/social life factors on the primary caregivers

The individual stressors with the greatest stress were unhappy feelings among 88 (39.3%) of the respondents frequently or all the time. The least stressful for them was feeling of being isolated/ excluded from the community/ neighbouring activities because of their children's illness in only 4 (1.8%). Also, 43 (19.2%) felt that too much time was invested in caring for the children and also not getting enough support from other members of the family often hurt them. Thirty-nine caregivers (17.4%) were also of the opinion that caring for these Children with SCD has led to a general atmosphere of tension or hostility in the house and also caused inhibition of their movement. When all these stressors are summed together, 27 families (12.1%) and 1 (0.4%) family had moderate severe disruption respectively to their family/social life. This was statistically significant when weighted together with $\chi^2 = 126.00$, $p < 0.001$.

According to Table 4, half (112; 50%) of the respondents stated that they found a crisis at the wrong time coming with moderately to severe difficulty.

Table 4: Impact of disease (SCD) factors on caregivers' psychosocial burden

Disease (SCD) factors	Not difficult	Difficult
Recurrent crisis	129 (57.6)	95 (42.4)
People say it is an incurable disease	113 (50.4)	111 (49.6)
Thought of death at any time	185 (82.6)	39 (17.4)
Fear of sickness/infection in the child	121 (54.0)	103 (46.0)
Fear of crisis at the wrong time (night, exam period, etc.)	112 (50.0)	112 (50.0)
Fear of having another child with SCD	141 (62.9)	83 (37.1)
Disease factors weighted	**101 (45.1)**	**123 (54.9)**

Impact of children with SCD social life factors on caregivers' psychosocial burden

According to Table 5, school absenteeism most times by the children with SCD was said to have caused moderate to severe difficulty in almost one-third (67, 29.9%) of the caregivers; 40 (17.9%) had severe difficulty in the way the disease has impaired growth and physical development of their children while the majority (213; 95.1%) perceived that they got adequate support from the schools. In summing all the individual stressors under the SCD-children affected social life, it was found that 32 (14.3%) caregivers experienced moderately to severe difficulty in this psychosocial burden which was also statistically significant ($\chi^2 = 114.29$ and *p*-value < 0.000).

Ninety-eight (43.8%) and 81 (36.2%) of the respondents agreed that the cost of drugs and hospital bills respectively had a moderate to severe impact on their finances/ revenue loss due to care for these children.

Table 5: Impact of financial factors on primary caregivers' psychosocial burden.

SCD children's social life factors	Not difficult	Difficult
Absence from school	157 (70.1)	67 (29.9)
Growth and physical features impairment	184 (82.1)	40 (17.9)
Loving a particular food more than others	197 (87.9)	27 (12.1)
Rejection of foods	189 (84.4%)	35 (15.6)
SCD has made patient intelligence lower	207 (92.4)	17 (7.6)
SCD has made the patient feel inferior	203 (90.6)	21 (9.4)
Not getting enough help or support from the child's school	213 (95.1)	11 (4.9)
Children with SCD social life-weighted	192 (85.7)	32 (14.3)
Financial factors	**No impact**	**Severe impact**
Cost of drugs	126 (56.2)	98 (43.8)
Cost of blood	186 (83.0)	38 (17.0)
Hospital bill	143 (63.8)	81 (36.2)
Cost of adequate, good food	210 (93.8)	14 (6.2)
Transportation cost for clinic appointment	193 (86.2)	31 (13.8)
Loss of job/business	204 (91.1)	20 (8.9)
Inhibiting your job performance (loss of working hours or possibility of promotion)	182 (81.2)	42 (18.8)
Financial factors weighted	**169 (75.4)**	**55 (24.6)**

Table 6 highlights the physical and health burdens borne by caregivers of children with SCD. Body aches or pains have the highest (42; 18.8%) stressful impact on the physical/ health factors of the caregivers.

Table 6: Health/physical burden of caring for children with SCD on the primary caregivers

Health/ physical burden	Not stressful	Stressful
General Health	194 (86.6)	30 (13.4)
Sick most of the time	214 (95.5)	10 (4.5)
Body aches or pains	182 (81.3)	42 (18.8)
Fatigue/exhausted	198 (88.4)	26 (11.6)
Sleeplessness/lack of rest	201 (85.3)	33 (14.7)
Burnouts	205 (91.5)	19 (8.5)
Health/ physical burden weighted	**197 (87.9)**	**27 (12.1)**
Coping ability	**No difficulty**	**Difficult**
Do you or your family have difficulty coping with this child?	171 (76.3)	53 (23.7)
Do you find it difficult to accept responsibility for caring for the child?	203 (90.6)	21 (9.4)
Do you feel depressed sorrowful or sad about the child's illness?	156 (69.6)	68 (30.4)
Do you feel angry with yourself/your child because of his condition?	179 (79.9)	45 (20.1)
Do you feel stigmatized because of the child's illness?	207 (92.4)	17 (7.6)
Do you feel guilty or ashamed	161 (71.9)	63 (28.1)
Weighted total	**176 (78.6)**	**48 (21.4)**

Coping abilities of the primary caregivers of children with SCD

Table 6 also highlights the abilities of the primary caregivers to cope with overseeing children with SCD. Assessing the coping ability or adjustment to child illness, feelings of depression, sorrow and or being sad emerged as the moderate to severe difficulties encountered in almost one-third (68; 30.4%) of the caregivers and 63 (28.1%) felt guilty or ashamed most or all the times. Almost a quarter (53; 23.7) of the respondents or their family had severe difficulty coping with the child's illness, while on the other hand, the majority (203; 90.6%) had no or mild difficulty accepting the responsibility of caring for the Children with SCD, likewise 207 (92.4%) did not think they are being stigmatized because of the child's illness. When all the individual coping ability factors were weighted together, 48 (21.4%) had moderate to severe difficulty coping. Statistical significance was also observed in this domain ($\chi 2 = 73.14$, $p < 0.001$).

Table 7 shows that one-third (77; 34.4%) of all the caregivers said they experienced moderate to severe burden in caring for their Children with SCD and 48 (21.4%) had severe difficulty coping with these children. The p-value was significant at <0.001.

Table 7: General psychosocial burden and coping abilities of caregivers.

	Psychosocial burden n (%)	Coping abilities n (%)	Health burden n (%)
Not stressful	147 (65.6)	176 (78.8)	197 (87.9)
Stressful	77 (34.4)	48 (21.4)	27 (12.1)
χ2	21.88	73.14	129.02
p-value	0.000	0.000	0.000

Relationship between the psychosocial burden, health burden, coping abilities and caregivers' sociodemographic characteristics. Supplementary Tables 1 and 2

When comparing the mean ranking of the different psychosocial domains, health burden and coping abilities between the two health facilities, hospital factors and coping abilities had a higher mean rank in OOUTH than FMCA but it was not statistically significant, however, the mean ranking was higher in the other domains for FMCA but was only statistically significant among Children with SCD life factors *(p = 0.026).* There was also no significant difference in any of the psychosocial domains when compared among different genders; although mean ranking was higher in the male gender in the disease factors, Children with SCD social life and financial factors.

Among the Islamic and Christian practices, the mean ranking was higher in all the domains but was not significant except for the family social life factors with a p-value of 0.018 and coping abilities *(p =0.024)*. The mean ranking was higher among the other tribes when compared to the Yoruba tribe in all the domains but was not significant. The older age group (≥ 40 years) also had a mean higher ranking in all the domains except for the disease factors which was higher among those < 40 years with no significance except for Children with SCD social life which shows a significant level *(p = 0.003).*

When assessing the relationship between the socioeconomic classes of the responders, the mean ranking was higher among the high socioeconomic class (I & II) in the domains of hospital factors and health burden of the caregivers; higher mean ranking in the middle class (III) for the social life factors of the family and the children with SCD and was also higher in low socio-economic class (class IV and V) for financial stress, disease factors and coping abilities of these caregivers but was not significant except for the financial factors which were significant (*p = 0.010)*. Enquiring whether the caregivers were on NHIS or not, the mean ranking was higher among those respondents that were not supported but this was not significant p-value = 0.077

Relationship between caregivers' marital status, family setting/ size, number of children with SCD per family and the psychosocial/ health burden, and coping abilities Supplementary Table 3

Being separated/ divorced/ single had a significant impact (p = 0.000) only on the family social life domain although was higher among all the psychosocial burden domains. A significant impact was also noted on the health/physical burden of the caregivers among this group (p = 0.036). No significant impact on the coping ability but the mean rank was higher among separated/single/divorced respondents (p = 0.143). There were also no significant differences in the type of conjugal liaison among the caregivers in the domains of hospital, disease and Children with SCD social life factors and their coping but significant levels were found in family social life *(p =0.000)*; financial factors *(p = 0.027)* and health burden (*p = 0.050*)

Parental coping ability and financial stress factors were significantly affected with a p-value of 0.042 and 0.021 respectively in large family sizes (> 3 children/ family) when compared to those with small family sizes (≤ 3 children/ family). There was statistical significance when the family had ≥ 2 Children with SCD in all the psychosocial domains except for hospital and Children with SCD life factors. The same pattern was seen in the health burden and coping ability domains.

According to Supplementary Table 4**,** The mean ranking was higher among female SCD children than in the males in the hospital, family/ social life and Children with SCD life factors likewise in the caregiver health/ physical burden and coping abilities with statistical significance only noted in the Children with SCD life factors (*p = 0.*036). The mean ranking was higher among ≥ 5-year-olds in all the psychosocial stress factors as well as the health burden and coping abilities but was only significant in the children with SCD life factors (*p = 0.*000). Children with SCD who are at the secondary level of education had a significant impact on these children's life factors on the psychosocial burden domain with a p-value of 0.001 and the health/physical burden of the caregiver (p = 0.004) but no significant effect on other psychosocial domains and the coping ability of the caregivers.

Relationship between the children with SCD and their groups of clinical characteristics on the caregivers' psychosocial burden, health burden and coping ability

Higher mean ranking was noted in the stress areas of hospital, family social life, financial factors and the health/physical burden in heterozygous children (HbSC) though not statistically significant. It was however higher among homozygous (HbSS) in the domain of disease factors, SCD-children life factors and coping abilities of the caregivers and was also not statistically significant. (p >0.05)
A child with SCD with an established diagnosis before the age of 3 years had a higher mean ranking in the psychosocial burden of hospital, family social life and the disease factors even though not significant. The health burden and coping abilities rank were also higher among them with a p-value > 0.05.
Duration in care for ≥ 3 years had a high ranking in the family/ social life, the disease, Children with SCD life factors and the health burden and coping abilities of these caregivers despite that there was statistical significance seen.

Relationship between the clinical characteristics of children with SCD and caregivers' psychosocial, health burden and coping abilities Supplementary Tables 5 and 6
Hospitalizations, pain crisis, blood transfusion and their frequencies (≥ 2 episodes/admissions) that occurred in the last 1 year among the children/ wards of the respondents in the study had higher mean rank in all the psychosocial factors domains, in the health burden and parental coping abilities. Statistical significance (p= < 0.05) was noted for all these clinical characteristics in the hospital factors except for the presence of pain which was not significant (p= 0.068). Financial factors were also significant for all the clinical characteristics (p = <0.05). Family social life factors show a significant level (p = 0.046) in the frequency of admission alone. Being admitted into the hospital and frequency of blood transfusion were significant, while frequencies of hospitalizations and bone pain crisis had significant on the Children with SCD life factors with p-values of 0.018 and 0.000 respectively.
Even though the mean rank was higher in the health/physical burden and parental coping abilities; a significant level (p = 0.017) was observed in those groups who have had pain crises in the last 1 year and those that the cost of the hydroxyurea taken by their children ≥ #3,000 for health burden none of the clinical characteristics showed statistical significance (p >0.05) for parental coping abilities.

Discussion
There were more female respondents than males in this study which is consistent with earlier studies (23, 24) which also observed females' predominance in the care of patients with chronic illnesses. Globally women are the major providers of informal care for members of families with chronic medical conditions such as SCD as a result of several societal and cultural demands on them. The socio-economic strata of the respondents were like that of caregivers of children with other illnesses in southwestern Nigeria (18). About one-fifth (18.3%) had primary or no formal education while approximately half of the caregivers (47.8%) completed post-secondary education. The finding in this study that about one-quarter of the caregivers had lost one or more children in the past attributable to SCD may not be surprising as these children have variable life expectancies with under-five mortalities in Sub-Saharan Africa due to SCD estimated to be about 5% (25). All the respondents practised either one religion or the other; it has been recognized that regular attendance at religious services by family members of children with chronic illness has positive outcomes for them and is associated with improved mental, social and emotional well-being and these beliefs are commonly used by both medical and psychiatric patients to cope with illness and other stressful life changes (26). The care of many of these children was being borne solely by the family as less than one-fifth (18.8%) in this study were enrolled in the National Health Insurance Scheme (NHIS) which was even partial even though they need extensive social support for the care of these children. This was not too far from researchers' assertions that healthcare costs are being borne from out-of-pocket system in sub-Saharan Africa (27).
The sociodemographic characteristics of the children with SCD showed that their ages ranged from one to 15 years (median of 7 years) with a slight male preponderance (1.1:1). The age at diagnosis of SCD ranged from 6 months to 132 months (0.5-11 years) with the median age at diagnosis of 2 years and this broad variation has been documented in other parts of the country (28). Some of the reasons that can be adduced to contribute to this include poverty, socio-cultural beliefs, insufficient/inadequate information and knowledge about SCD, poor health-seeking behaviours of caregivers, and inadequate and inaccessible healthcare services. Sickle Cell Anaemia (SCA; haemoglobin phenotype HbSS) were about eight times commoner than HbSC. Children with HbSS were diagnosed earlier than HbSC. This could be because SCA children are likely to present with more severe symptoms and complications. Children with SCD presented with myriads of clinical manifestations either singly or in combination, such as bone pain crisis, infection, anaemia, acute chest syndrome, stroke etc. The frequencies of admission, bone pain

crisis and blood transfusion in the last year among children with SCD in this study was high with almost three-fifths of these children admitted for SCD-related illness. Eighty per cent of the respondents experienced at least one significant bone pain, while 33% were transfused in the preceding year. These findings were consistent with studies done in Nigeria (29, 30). This may intensify the psychosocial burden of the caregivers. None of the children with SCD in this study belonged to the severe disease stage which was also similar to another one done to determine the foetal haemoglobin and disease severity (30). The plausible reason may be the age of the children with SCD as the severity score is dependent on lifelong complications from the disease.

The use of traditional/ herbal medicine either as prophylaxis or treatment for SCD-related crisis is high (49.6%) as compared to the one done in Abeokuta (29.6%) (29) because traditional medicine intake is a common practice in Nigeria. In chronic illnesses such as SCD, it is believed that the cause of the frequent illness/crisis may be witchcraft or that medical treatment alone may be inadequate. Assessing the overall psychosocial burden of the participants showed that almost one-third (34.4%) were observed to have experienced moderate to severe burden due to the care of their children with SCD with most of the respondents having none or mild burden. This was similar to the findings from Ado-Ekiti and Iran (22, 31), but lower than reports from Cameroon (21). The differences might be because, in the Iran and USA studies, caregivers of hospitalized children were studied, hence the caregivers higher burden. The individual hospital stress factors that caused a significant burden to these caregivers were: admissions to hospitals/frequent and long hospital stays, emergency visits during crisis, and keeping clinic appointments and hospital routines. The reason for this may not be far-fetched as children with SCD may regularly need to present at healthcare facilities during any phase of their illness. The hospital environment itself may constitute a burden to the caregivers as most health facilities in SSA do not have amenities for these caregivers while their children are on admission. Irrespective of the sociodemographics of the caregivers, the stress is experienced by all although more profound with a higher mean score among those that belonged to low socio-economic class, older caregivers, single/divorced and families with at least two children with SCD.

The domain of the family social life has different effects on the respondents with the moderate to severe effect on about 40% of these caregivers who felt unhappy about their children's condition. This was comparable to data from a study done in Saudi Arabia (32) where it was reported a high proportion of feelings of unhappiness. Marital disharmony, disagreement/fighting among family members, the general atmosphere of tension in the household, more time investment in the care of children with SCD, and not getting enough support from their spouses and or relatives had severe effects on the lives of almost 20% of these caregivers. The comparatively low impact of SCD on family life could be attributed to the relatively favourable socio-demographics characteristics of respondents as almost half of these caregivers had at least junior or senior secondary education, belonged to middle or high socioeconomic class and may likely have better knowledge of SCD and pre-emptive actions to control SCD crises, and with maintenance of the needs and stability of the family. Despite this, the affectation of family social life factors in all the domains was significant among caregivers who were single/ separated/ divorced, those that have at least two children who were SCD and these children being admitted ≥2 times in the last year. The quality of life of caregivers of children with chronic illness has been documented (7, 10). This was impacted by the extent of family and social support received by them. Caregivers who were single or widowed had significantly poorer quality of life in the psychological domain as compared with those who were married. These caregivers likely faced more challenges in the absence of a spouse who could offer support and share some of the distress. Approximately 2% of these caregivers in this study reported that their families were being isolated/ excluded from the community activities and lacked privacy because of their children's illness and about 10% felt their confidence level were sometimes or frequently affected due to their care for these children.

Assessing the disease factor on the psychosocial burden showed that about half of the caregivers reported that fears of SCD crisis in these children at the wrong time (night, examination period), being told it is an incurable disease, recurrent crisis and fear of infection had moderate to severe impact on coping. This could be very devastating in a culture that places a high premium on childbearing in marriage. Also, the lives of mothers and their perceived success/ achievements are heavily attached to the lives of their children (33). More than 80% (185) did not have negative thoughts of death towards their children with SCD, which might be due to their religious inclinations with high hope and positivity. It is of note that this feeling was not affected by the sociodemographic characteristics of either the participants or their children but was more pronounced in the families with two or more children with SCD, frequent hospitalization and blood transfusions in the preceding year.

The majority (95.1%) of the caregivers felt they got enough support from their children" schools during crises. However, frequent school absenteeism on account of recurrent crises, growth and physical features impairment and rejection of food are major social life factors among children with SCD which causes moderate to severe psychosocial burden and difficulty for the caregivers to cope with. Caregivers who were above 40 years old and those with more than one SCD child per family had more difficulty than others. Frequent bone pain crises and admissions into health care facilities also contributed to school absenteeism in this study as seen in a similar study done in the USA (34) where they found that the children were hospitalised for at least 3 days with an additional 2 days for recovering post-discharge. Also, in addition to vaso-occlusive painful events, overt or silent cerebrovascular accident (stroke) and other chronic complications could potentially contribute to functional limitations and poor academic achievements. A study done in Cameroon (21) reported that 37.5% of children with SCD had mild-to-severe cognitive deficits with significant effects on their functions and attention. This was also the findings with SCD children who presented with neurocognitive deficits (35). These impaired neurocognitive deficits may negatively affect the quality of life of both the caregivers and their wards. It is important, therefore, that adequate and concrete educational plans should be developed for these children to accommodate their lost school days and regular neurocognitive evaluations. The neurocognitive rehabilitation programs for children with SCD will go a long way to ameliorate this impairment. Sociodemographic characteristics of children with SCD such as female gender, older children and those in secondary schools had significant impact probably because child life stressors increase with the age of the children. The reason for this is that as the child grows older, he/she is more socially active and are likely to be more aware of their own poor health status. The parents had also spent greater part of their time and life in caring for them which may create more tension in the family life.

The impact of caring for children with SCD on the caregivers' finances is relatively high in this study. About 40% of respondents reported that the money or funds spent on drugs and hospital bills unfavourably affected the family income. This may not be surprising in SSA like Nigeria where the major form of healthcare financing is out-of-pocket and this fact had been documented by earlier researchers (22). Nigeria, like many other LMICs, national programmes on health insurance and social welfare systems are abysmally low or absent which is supported by the finding from this study with less than one-fifth of the caregivers registered under the NHIS with only part funding which might contribute to financial burden in caring for these children. About the same proportion (20%) reported inhibition in their job performances, loss of promotion and underemployment due to the time spent caring for these children. significantly contribute to the financial burden experienced by these caregivers which was in agreement with previous findings (36). Single/ divorced caregivers, large family size (> 3 children) more than 1 child with SCD in the family and belonging to a low socioeconomic class were significantly associated with financial stress. Higher financial stress experienced by those in the low socioeconomic class and single parenthood may not be unexpected, especially in an environment where healthcare financing is predominantly out-of-pocket. Admission, pain episodes, blood transfusions in the preceding year as well as two or more occurrences of these events were the diseases-related factors that were found to cause significant financial stress to the caregivers in this study. The provision of social welfare programmes such as NHIS for the parents/ caregivers of children with chronic illnesses like SCD will likely ease the associated financial burden. For example, the provision of health insurance schemes in developed countries like the USA, and UK (37) was found to have beneficial effects on the parents/ caregivers of children with SCD and they tend to report lower financial burdens compared with their counterparts in most parts of the developing world.

The health/ physical well-being of the primary caregivers may determine the overall well-being of his/her child. More than 80% of the caregivers did not think taking care of their children with SCD had a major impact on them or made them experience burnout or illness frequently. However, more than one-tenth said caring for these children had a significant impact on their general health, fatigue/exhaustion and unable to sleep well. The highest stressful impact was reported with body aches or pains in almost all of the caregivers. Those above 40 years old in this study had higher mean scores which may be a result of physiological and mental functions that might reduce with increasing age and are likely to experience a more severe impact on their health burden than their younger counterparts. Caregivers in higher socioeconomic classes (I and II) were also noted to have higher mean scores than the lower socioeconomic classes (III -V), probably because they are likely to be more health conscious and have regular medical check-ups. Pain episodes in the preceding 12

months, older children with SCD, single parents, more than a child with SCD and the cost of hydroxyurea had a significant impact on the health burden of the caregivers. Lack of family support might be a negative predictor of the caregivers' health while more children with SCD in the family may predispose to an increase in the tension/ stress level. Hence, when there is family support there is likely going to be improved HRQOL.

The proportion of participants in this study who experienced moderate to severe difficulty coping with the care of their children with SCD was 21.4%. This was slightly higher than the 19.4% reported from Ibadan (36). This was lower than 88.3% of Cameroonian caregivers (21). Although the sociodemographic distributions of the respondents were similar in the studies, there were wide variations in the median duration of care. It was 2.2 years in this study while the study in Cameroon was 9 years as they recruited caregivers of SCD >15 years (21). More participants enjoyed some form of social support in the form of NHIS in this study which was lacking in the Cameroonian caregivers. The rate of coping differs among the caregivers, about one-quarter of them had moderate to severe difficulty coping with the care of their children, sorrowful feeling, depression and anger towards themselves and or their children with SCD in almost one-third of respondents. However, the majority (92.7%) of them did not have difficulty accepting the responsibility of caring for their children with SCD which was in agreement with studies by earlier authors (18, 21).

The difference in the coping ability as experienced by the caregivers was found not to be significantly affected by either the child's or caregivers' sociodemographic characteristics. Parents with heterozygous genotype (HbSC) children felt better than those with homozygous ones. Previous studies demonstrated that HbSS experienced more severe forms of the disease (38, 38). More children with SCD in the family, early age at diagnosis, disease-related stressors such as hospitalization, blood transfusions and bone pain crises had a significant impact on the caregivers and may weaken their coping ability. Complications had only been previously experienced by about one-third of the children in this study with the most frequent being ACS. The frequency of stroke which is a proxy of severity is low (12.5%) among those who had experienced one form of complication or the other. Access to the disease-modifying drug (hydroxyurea) was higher (29.5%) in this study which may have contributed to improved physical HRQOL, unlike in Cameroonian children with a high frequency of stroke and less (3.1%) access to hydroxyurea (21).

Study limitation

Our study was hospital-based and is, therefore, prone to selection bias.

Conclusion

The caregivers experienced significant psychosocial burden with impacts on their physical, social, and financial well-being and difficulty in coping. Frequent hospitalization and the high cost of health care placed significant strain on them.

There is an urgent need to ensure affordable access to quality healthcare for these children. Also, current clinic structures/activities need to be modified in such a way that time spent by the caregivers and their children within the hospital premises is reduced to the barest minimum.

List of Abbreviations

SCD: Sickle Cell Disease
LMIC: Low- or Middle-Income Country
SSA: Sub-Saharan Africa
UN: United Nations
HRQOL: Health-Related Quality of Life
ACS: Acute Chest Syndrome
CVA: Cerebrovascular Accident
FMCA: Federal Medical Centre, Abeokuta
OOUTH: Olabisi Onabanjo University Teaching Hospital
CHER: Children's Emergency Room
NGN: Nigerian Naira
NHIS: National Health Insurance Scheme
HbSC: Heterozygous sickle cell trait
HbSS: Homozygous sickle cell trait

Declarations

Ethical Considerations

Ethical approval for the study was obtained from the ethics committees of the FMCA and OOUTH with protocol numbers FMCA/470/HREC/01/2019/17 and OOUTH/HREC/278/2019AP, respectively. Written informed consent was obtained from all the recruited caregivers for the study. All the parents/caregiver(s) who met the inclusion criteria were allowed to decide their participation or otherwise in the study and their non-participation did not affect the care of their children. The immediate benefit was the re-enforcement of the SCD as an entity and how to care for minor illnesses at home for their wards and there was no additional risk or cost to the caregivers that participated in the study. Confidentiality was maintained and identities of the participants were duly protected throughout the study.

Consent for publication
All the authors gave consent for the publication of the work under the Creative Commons Attribution-Non-Commercial 4.0 license.

Availability of data and materials
The essential data supporting the findings of this study are available within the article. Additional data are available on request from the corresponding author due to confidential reasons.

Competing interests
Authors declare no conflict of interest

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Author contributions
All the authors actively participated in the design and planning of the research work, data collection and analysis, as well as the writing of the report.

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