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The Psychosocial Impact Of Sickle Cell Disease On Patients' Caregivers At Delta State's General Hospital Outpatient Clinics.

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ABSTRACT
BACKGROUND
Sickle cell disease (SCD) is a common genetic illness that often begins in infancy and mostly affects people of African heritage. Caregivers of individuals with sickle cell disease (SCD) face difficulties like absenteeism from work, heightened familial strain, and heightened caregiving responsibilities, which may be partially due to the unexpected nature of managing pain crises in SCD.
METHODOLOGY
This research was conducted in the general outpatient units of three government hospitals in the Delta North senatorial district of Delta State. It was a cross-sectional descriptive study. The data was collected using interviewers administered questionnaires, and the analysis was conducted using SPSS version 18 software, with a significance level set at 0.05.
RESULTS
The research, which included 150 participants, revealed that the majority (69.1%) of caregivers were women, with an average age of 40.2±12.4 years. Among the patients with sickle cell disease (SCD), 59.3% were female, and their average age was 11.2±7.6 years. Approximately 37.4% of SCD patients had pre-primary, primary, or secondary education. The effect of SCD varied, with 48.8% suffering a moderate-to-severe financial burden, 60.1% reporting little or no impact on family relations, 56.1% encountering interrupted usual family activities, and 52.9% having a moderate-to-severe impact on coping skills. Additionally, 42.3% never felt stigmatized, whereas 33.3% felt somewhat stigmatized owing to the child's sickness.
CONCLUSION
The study reveals that there is considerable psychological burden of SCD on caregivers and families in Delta State South-South Nigeria. It highlights the necessity for joint efforts by the government, non-governmental organizations, and stakeholders engaged in sickle cell care to promote interventions improve the psychological well-being of persons with SCD care

KEY WORDS: *psychosocial, impact, caregiver, family, sickle cell disease.*

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I. INTRODUCTION

Sickle cell disease (SCD) is a prominent childhood-onset, single-gene illness affecting mostly people of African heritage.[1] It affects up to 100 million individuals worldwide, especially among black populations in Africa, Europe, America, Arabian areas, and those of Asian heritage.[2] In Nigeria, around 150,000 infants are born with sickle cell anemia yearly, with a frequency of 20–30 per 1000 live births, and that of hemoglobin SC is roughly 0.7%.[2]

In terms of the family, caregivers of SCD patients encounter issues like loss of employment, increased family stress, and heightened care needs, partially owing to the unpredictability of pain crisis care in SCD.[3] Psychologically, the disease poses challenges on three levels for the family: cognitive (requiring understanding of

the illness, its etiology, prognosis, optimal treatment, and implications on child-rearing), emotional (coping with anxieties and uncertainties), and behavioral (incorporating treatment into family routine while maintaining other functions). [4]

Socially, caring for persons with SCD is a difficult task involving multiple stakeholders (family, school, church, and community) and requires balancing family concerns for marital peace and stable family functioning. Frequent hospitalizations are key contributions to the psychological challenges experienced by caregivers and families of SCD patients. Thus, SCD generates two groups of sufferers: those living with the illness and the parents or caregivers caring for their loved ones with the disease. [3]

Despite the critical role of caregivers and families in SCD patient care, research on the effect of the illness on these caregivers and families is sparse. This research intends to analyze the emotional effect of SCD on caregivers and families visiting government hospitals in Delta State, South-South, Nigeria. The purpose is to evaluate the psychosocial requirements of caregivers and impacted family members, concentrating on financial losses, family relationships, normal activities, coping capacities, and emotions of stigmatization. This study offers vital data for the knowledge of the psychological effect of sickle cell anemia on caregivers and families in typical Nigeria setting.

II. METHODOLOGY

The research was done between September, 2023 and November, 2023 in the General outpatient units of Government hospitals in Ibusa, Okwe, and Ogwashi Uku, all in the Delta North Senatorial Area of Delta State. These hospitals were selected owing to their active sickle cell clubs.

Study Design: A hospital-based cross-sectional descriptive design

Study Location: General outpatient units of Government hospitals in Ibusa, Okwe, and Ogwashi Uku, all in the Delta North Senatorial Area of Delta State. These hospitals were selected owing to their active sickle cell clubs.

Study Duration: The research was done between September, 2023 and November, 2023.

Sample Size: 150 respondents.

Sample Size Calculation: The minimum sample size was calculated using the Cochrane formula for descriptive Study[5] $n = \frac{z^2 pq}{d^2}$ A standard normal deviation deviation (z) of 1.96 at 95% confidence interval (Cl) and desired precision level (d) of 5%, proportion (p) of SCD in previous study done in Nigeria, was 3%).[6] This gave a sample size of 50 including 10% attrition. Each of the selected hospital was assigned 50 respondents giving a total of 150 respondents.

Sampling Method: Purposeful and convenience sample approaches were adopted owing to patients' six-month appointment dates, corresponding with the three-month research period. Caregivers and their impacted children were invited via telephone calls and text messages after proper approval.

Inclusion Criteria: The study included all caregivers of SCD patients/SCD patients visiting the outpatient units of the selected hospitals and fulfilling inclusion criteria. Participants were caregivers of patients who had visited the sickle cell clinic at least three times before admission, were aged between six and nineteen years, and lived with the caregiver for at least two years before the interview. Additionally, patients must be in a stable condition, free from crisis, on the day of the interview.

Exclusion criteria: The study excluded caregivers who were not parents, lost to follow-up during the trial, patients acting as their own caregivers, and those with caregivers having significant cognitive impairment. Also omitted were those unable to answer 20% or more of the study instruments and those with caregivers suffering from chronic, severe diseases.

Sampling Method: Data gathering employed a questionnaire with subsection on socio-demographic characteristics, biodata of the kid, clinical burden of the child, and the Sickle Cell Disease Burden Interview (SCDBI) questionnaire.[7] The validation of the questionnaire was done by Ohaeri and Shokunbi[7] in a related Nigerian study. After administering the questionnaire and performing physical exams, respondents were to carry out laboratory testing for genotyping and packed cell volume (PCV).

Statistical Analysis: The computer SPSS version 18 was used for data input and analysis, producing frequency distributions, tables, means, and standard deviations. Significance was determined at a p-value of 0.05.

Sociodemographic characteristics of caregivers: The respondents were grouped into five occupational groups. Occupational group I were professional e.g doctors, lawyers, accountants. Group II were intermediate e.g school teachers, nurses. Group III were skilled which was further subdivided into skilled (N) non-manual e.g clerical worker, secretary and skilled (M) manual e.g bus driver, carpenter. Group IV were partly skilled e.g bus conductors, postman. Group V were unskilled e.g farmers, labourers, cleaners.[8] With regards to educational qualification the respondents were categorized into no education for those with no formal education, primary level, secondary level and tertiary level of education. For average monthly income, the respondents were categorized based on the Nigerian minimum wage of 18,000 naira monthly into respondents who earned wage below the minimum and those who earned above the minimum wage. Social class were calculated using

occupational group and highest educational qualification. Occupational groups were scored as follows – group I=1, group II=2, group III=3, group IV=4 and group V=5, while educational qualification were scored as follows = tertiary level = 1, secondary level = 2, primary = 3 and none = 4. Both scores will be summated with the aggregate score ranging between 2 and 9, therefore aggregate score of 2-3= high class, 4-6 = middle class and ≥7 = low class.[9]

Clinical burden of child: Duration of care since diagnosis were classified into less than six months or greater than six months. Previous hospitalization (range 0 – 24 months) were classified into no hospitalization, once, twice and more than twice. Previous blood transfusion (range 1 – 10) were classified into none, one, twice or more than twice while significant bone pain episodes was classified into none, one, twice and more than twice.

Sickle Cell Disease Burden Interview (SCDBI)[7] The Sickle Cell Disease Burden Interview (SCDBI)[7] comprised questions with scores ranging from 0 to 3. A score of 0 signified the absence of the stressful incident; 1 point was designated for infrequent occurrence or minor impact on the family; 2 points were provided for frequent occurrence or moderate impact; and 3 points were given for regular occurrence or severe impact. The total scores were then interpreted as follows:

(a) Family Finance and Interaction: Scores of 0 were seen as having no impact, 1–3 indicated a significant impact, 4–6 designated a moderate impact, and 7–9 reflected a severe impact.

(b) Routine Family Activity: A score of 0 denoted no impact; 1–5 showed little impact; 6–10 reflected a moderate impact; and 11–15 signified a severe impact.

(c)Parental Coping Ability: A score of 0 showed no impact, 1–4 suggested negligible impact, 5–8 reflected a moderate impact, and 9–12 designated a severe impact.

For the objectives of this study, a total score of 45 was assigned to measure the psychological impact of sickle cell disease (SCD) on each caregiver or family. Scores between 1 and 10 were defined as "no significant impact," 11–20 as "low impact," 21–30 as "moderate impact" while scores beyond 30 were classified as "severe impact."

Ethical approval was acquired by the research and ethical committee of the Department of Health Planning and Research, Delta State Ministry of Health, Asaba, Delta State. Informed agreement was secured from each participant, and confidentiality was respected at every stage in accordance with clinical principles guiding physicians in medical research, as specified in the Helsinki Declaration of 1964 (as reviewed in the sixth version of 2008).[10]

III. RESULTS

A sum of 150 persons responsible for caring for children diagnosed with Sickle Cell Disease (SCD) were enrolled, and the study focused on 123 participants who met the inclusion criteria and supplied complete information.

The sociodemographic profile of caregivers: This is depicted in Table 1, where it is evident that a significant proportion (69.1%) were women, and the average age was **40.2±12.4** years. The majority (66%) were married, 20.3% were single, and 48% had attained a secondary education. Social class VI accounted for 35.8%, while the majority adhered to Christianity (91.1%). The predominant ethnic groups were Ibo (49.6%) and Urhobo (18.7%).

Table 1: Sociodemographic characteristics of the caregivers

Characteristic	Frequency (n)	Percentage (%)
Gender		
Male	38	30.9
Female	85	69.1
Age (in years)		
<29	25	20.3
30-39	41	33.3
40-49	24	19.5
50-59	24	19.5
60 and above	9	7.3
Mean±SD	**40.2±12.4**	
Marital Status		
Married	81	65.9
Single	25	20.3
Widowed	10	8.1
Divorced/Separated	7	5.7
Educational Status		
No formal education	2	1.6
Primary	11	8.9
Secondary	59	48.0
Tertiary	51	41.5
Social Class		

Class I	14	11.4
Class II	25	20.3
Class III	22	17.9
Class IV	11	8.9
Class V	7	5.7
Class VI	44	35.8
Religion		
Christianity	112	91.1
Islam	11	8.9
Ethnicity		
Ibo	61	49.6
Urhobo	23	18.7
Itsekiri	14	11.4
Yoruba	9	7.3
Hausa	8	6.5
Isoko	8	6.5

Socio-demographic features of SCD patients: As seen in table 2, 59.3% of SCD patients were female, with a mean age of 11.2±7.6 years. Educationally, 37.4% had pre-primary, and 30.9% had secondary schooling.

Table 2: Socio-demographic Characteristics of the Sickle Cell Disease Patients

Characteristic	Frequency (n)	Percentage (%)
Gender		
Male	50	40.7
Female	73	59.3
Age (in years)		
0-4	26	21.1
5-9	34	27.6
10-14	23	18.7
15-19	24	19.5
20-24	9	7.3
25+	7	5.7
Mean±SD	**11.2±7.6**	
Educational Status		
Nil	19	15.4
Preprimary/Primary	46	37.4
Secondary	38	30.9
Tertiary	20	16.3

Clinical impact of the sickle cell condition: Most patients have 1-2 siblings, with 87.0% having 1-2 siblings afflicted by the condition. A majority (77.2%) had been in care for ≥6 months. Thirteen percent (13%) had no history of past hospital admissions, whereas 65% had at least two previous hospitalizations. Twenty-one percent received blood transfusions more than twice, and 46.3% suffered vaso-occlusive crises more than twice.

Table 3: Distribution of Clinical Burden of Sickle Cell Disease

Clinical burden	Frequency (n)	Percentage (%)
Number of Siblings		
0	5	4.1
1-2	71	57.7
3-4	35	28.5
5-6	8	6.5
7+	4	3.3
Number of Affected Siblings		
0	13	10.6
1-2	107	87.0
3-4	3	2.4
Duration of Care		
<6 months	28	22.8
≥6 months	95	77.2
Previous Hospital Admission		
None	16	13.0
Once	27	22.0
Twice	34	27.6
≥Twice	46	37.4
Previous Blood Transfusion		
None	40	32.5
Once	36	29.3
Twice	21	17.1

≥Twice	26	21.1
Vaso occlusive Crisis		
None	21	17.1
Once	25	20.3
Twice	20	16.3
≥Twice	57	46.3

Indices of the burden of sickle cell illness on the family: Approximately 31% of caregivers reported a drop in income or financial benefits owing to the frequent or regular time spent caring for their kids. Additionally, 26.8% of caregivers resorted to borrowing loans routinely to handle the expenditures associated with their child's condition. Around 35% encountered charges that negatively affected the family's vital requirements.

Indices of Family Interaction Disruption: The child's sickness led to a pervasive atmosphere of stress or animosity in the house for 25% of caregivers. Disagreements or quarrels among family members were nonexistent for 35% but happened frequently or regularly for 21%. Marital conflict stemming from the child's sickness never occurred for 42.3% of caregivers, but it happened frequently or regularly for 28.4%.

Neglect of other family members owing to caring for the kid never occurred for 30.1% of caregivers but occurred for 27.6% of them. The child's sickness occasionally made it problematic for them to participate with household tasks (57.7%), and this difficulty became frequent or regular for 28.5%. Disturbances to home activities never happened for 21.1%, occurred sometimes for 41.5%, and occurred frequently or regularly for 37.4%.

Caring for the child made it difficult for 28.5% of caregivers to engage in other profitable activities frequently or regularly, while 56.9% reported this problem occurring sometimes. A large share (68.3%) encountered minimal or minor difficulties in taking responsibility for the child's care. About 34% regularly felt sorry about the child's sickness, whereas 52.8% felt this way sometimes. Additionally, 33% regularly felt furious with themselves or the kid owing to the sickness, whereas 25.2% never had such sentiments. Stigmatization owing to the child's sickness was never felt by 42.3% and was mildly felt by 33.3% of caregivers.

Table 4: Indices/pattern of impact of sickle cell disease on the family

Indices	Never Occurred n (%)	Occurred Sometimes n (%)	Occurred Frequently n (%)	Occurred Regularly n (%)
Indices of financial burden				
Loss of income/financial benefits due to time spent caring for child	26.6 (21.1)	59 (48.0)	24 (19.5)	14 (11.4)
Took a loan to meet up expenditure of the child's illness	39 (31.7)	51 (41.5)	25 (20.3)	8 (6.5)
Expenses of the child's illness adversely affected the family's basic needs	25 (20.3)	55 (44.7)	26 (21.1)	17 (13.8)
Indices of disruption of family interactions				
Child's illness causing a general atmosphere of tension or hostility in the home	36 (29.3)	56 (45.5)	14 (11.4)	17(13.8)
Child's illness or care causing disagreement or quarrels among family members	43 (35.0)	54 (43.9)	17 (13.8)	9 (7.3)
Child's illness causing marital disharmony (threat of separation or divorce)	52 (42.3)	36 (29.3)	26 (21.1)	9 (7.3)
Indices of disruption of routine family activity				
Caring of the child caused neglect of other family members	37 (30.1)	52 (42.3)	17 (13.8)	17 (13.8)
Illness made it difficult for the child to assist in household chores	17 (13.8)	71 (57.7)	27 (22.0)	8 (6.5)
Child's illness disturbs activities at home	26 (21.1)	51 (41.5)	27 (22.0)	19 (15.4)
Caring for the child made it difficult for the caregiver to engage in other gainful activities	18 (14.6)	70 (56.9)	22 (17.9)	13 (10.6)
Indices of caregivers' coping ability and their feelings towards the affected children				
Difficulty coping with child's illness	38 (31.7)	52 (42.3)	21 (17.1)	11 (8.9)
Difficulty accepting responsibility to care for the child	49 (39.8)	35 (28.5)	31 (25.2)	8 (6.5)
Feeling sorrowful or depressed about the child's illness	16 (13.0)	65 (52.8)	26 (21.1)	16 (13.0)
Feeling angry with self or the child because of his or her illness	31 (25.2)	51 (41.5)	27 (22.0)	14 (11.4)
Feeling stigmatized because of the child's illness	52 (42.3)	41 (33.3)	19 (15.4)	11 (8.9)

Impact of Sickle Cell Illness on the Family

Sickle cell illness had a moderate to severe impact on the finances of 48.8% of caretakers. However, it had negligible or minor influence on family interactions for 60.1% of caregivers. Routine family activities were considerably interrupted in 56.1% of families, and the coping skills of 52.9% of caregivers were moderately to severely impaired by the illness.

Table 5: Impact of Sickle Cell Disease on the Family

The impact of Sickle Cell Disease on the finances of the caregiver	Frequency (n)	Percentage (%)
No impact	15	12.2
Mild impact	48	39.0
Moderate impact	50	40.7
Severe impact	10	8.1
The impact of Sickle Cell Disease on family interactions		
No impact	25	20.3
Mild impact	49	39.8
Moderate impact	46	37.4
Severe impact	3	2.4
The impact of Sickle Cell Disease on routine family activities		
No impact	5	4.1
Mild impact	49	39.8
Moderate impact	64	52.0
Severe impact	5	4.1
Impact of Sickle Cell Disease on caregivers' coping ability and their feelings towards the affected children		
No impact	7	5.7
Mild impact	51	41.5
Moderate impact	61	49.6
Severe impact	4	3.3

IV. DISCUSSION

The major purpose of this research was to assess the psychological effect of sickle cell disease on family caregivers of patients with SCD in a typical Nigerian setting. The studies demonstratedthat sickle cell illness has both psychological and social implications.

Consistent with prior findings, this research found that the majority of caregivers were females, notably mothers.[11,12] This demographic trend offers a danger of financial hardship within families, especially in situations where spouses are unsupportive or jobless, while moms are either not gainfully working or fear job loss.

The research participants stated that only 13% of SCD patients had never been hospitalized, whereas 82.9% had been admitted once, twice, or more than twice for vaso-occlusive crises. Most studies as was seen in this study showed that hospital admissions were recognized as important contributions to the clinical burden on SCD patients.[2,12,13] Controlling bone pain episodes may lessen both the social and psychological difficulties associated with the condition.

Financially, sickle cell illness had a moderate to severe effect on 48% of caregivers, including loss of income and financial benefits owing to time spent caring for the kid. This correlates with results from worldwide research, underscoring the necessity for government action, such as providing free medical care or subsidizing expenses via health insurance systems.[14,15]

In terms of family contact, 60.1% of caregivers reported negligible or minor influence, with only occasional marital discord recorded. Despite the stressors involved, a large number of caregivers stayed married, probably driven by traditional values in Nigeria that emphasize caring for blood relations.[3]

Coping capacity was somewhat to severely damaged in 52.9% of caregivers. Despite the hurdles, a large number displayed adaptive coping techniques, probably driven by strong familial and spiritual values typical of developing nations. Families may adjust to the demands of the sickness and therapy over time.[3,16]

Contrary to studies in industrialized nations, this study found a minimal degree of stigmatization among relatives of patients with SCD.[17] The metropolitan area where the research was done certainly contributed to this finding, owing to better awareness about SCD in society.

LIMITATIONS

The research had drawbacks, notably its cross-sectional design, which hampered causal inference. The hospital-based aspect of the research may not adequately reflect the overall population. Additionally, cultural variables may drive participants to hide family issues, altering the study's findings.

V. RECOMMENDATIONS

Empowerment initiatives, particularly for mothers caring for people with chronic diseases like SCD should be strongly advocated.

Implementation of required health insurance coverage to minimize caregivers' out-of-pocket costs, notably for SCD patient families should be rigorously pursued.

Awareness campaigns to promote understanding and lessen stigmatization of SCD in the community should be stepped up in our national development.

The time is ripe for establishment of well-equipped sickle cell clinics with skilled staff for quick diagnosis and treatment.

VI. IMPLICATIONS FOR POLICY MAKERS AND CLINICIANS

Healthcare for caregivers of people with SCD should be emphasized, reflecting the same priority as healthcare for SCD patients. Policies on sickle cell illness in Nigeria should extend to encompass the health and well-being of caregivers. Adequate psychological support and intervention should be offered by healthcare providers, including co-management with clinical psychologists and psychiatrists for individuals in need.

VII. CONCLUSION

The study suggests that Sickle Cell Disease (SCD) has a limited effect on the psychological and social components of both caregivers and families. This highlights the significance of collaborative efforts across governmental bodies, non-governmental organizations, and stakeholders to provide psychological and economic assistance to persons impacted by sickle cell disease. Adopting this method is crucial for augmenting the availability of healthcare and raising the general standard of living for those afflicted with sickle cell sickness.

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CONFLICT OF INTEREST.

The authors have disclosed no conflicts of interest.

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