Original Article

AN OVERVIEW OF THE SOCIODEMOGRAPHIC CHARACTERISTICS OF CHILDREN WITH SICKLE CELL DISEASE AND ITS RELATIONSHIP WITH DISEASE SEVERITY: A SINGLE CENTRE STUDY

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Abstract

Background: Sickle cell anemia (SCA) is a major public health problem in Nigeria and other parts of sub-Saharan Africa, with wide variability in clinical severity among affected children. Socio-demographic factors have been suggested to influence disease outcomes but evidence remains inconsistent**.**

Objective: This study assessed the socio-demographic characteristics of children with SCA and examined their association with disease severity.

Methods: A cross-sectional study was conducted among 101 children with SCA attending clinic at Federal Teaching hospital Owerri, Imo state. Data on socio-demographic characteristics were collected using a structured proforma. Disease severity was assessed using standardized severity scoring system by Adegoke and Kuti. Data were analyzed using IBM SPSS version 26.0. descriptive statistics were used to summarize variables while Chi-square test were employed to assess associations. Statistical significance was set at $p < 0.05$.

Results: The mean age of participants were 9.31 ± 4.56 years. Males constituted 52.5% of the study population. The majority of participants belonged to the middle socio- economic class (67.3%) and most were diagnosed before the age of five years (75.2%). Overall, 71.3% of the children had mild disease while 28.7% had moderate disease severity. No statistically significant associations were found between disease severity and socio-demographic variables ($p >0.05$).

Conclusion: Most children with SCA in this study had mild disease severity. Socio- demographic factors were not significantly associated with disease severity suggesting that other biological and clinical factors may play a more important role in determining disease outcomes.

Keywords: Disease severity, Ibadin and Akpede socio-economic classification, Sickle cell anaemia, Socio-demographic characteristics

Cite this article: Ikejiaku UP, Ezeuko LC, Chimah CT. An overview of the sociodemographic characteristics of children with sickle cell disease and its relationship with disease severity: a single centre study. Niger Delta J Med Med Res. 2026;5(2):39–47.

INTRODUCTION

Sickle cell disease (SCD) is the most common monogenic disorder worldwide, caused by point mutation in the β-globin gene leading to the production of abnormal hemoglobin S(HbS).[1] In low oxygen tension, HbS polymerizes, distorting red cells into a sickled shape, resulting in chronic hemolysis, vaso-occlusion and multi-organ damage.[2] Globally, more than 300,000 infants are born annually with SCD with sub- Saharan Africa accounting for approximately 75% of cases.[3,4] In Nigeria alone, the prevalence is among the highest

worldwide, with an estimated 2-3% of the population affected making it a major public health concern.[5]

The clinical course of SCD is extremely heterogeneous. Some children experience recurrent vaso- occlusive crises, acute chest syndrome, cerebrovascular accidents, chronic anemia and early mortality while others remain relatively stable with few complications.[6-8] The variability is influenced not only by genetic modifiers (such as fetal hemoglobin levels and co- inheritance of alpha-thalassemia) but also by environmental and sociodemographic determinants.

Sociodemographic factors play a central role in shaping the health outcomes of children with SCD. Age and sex have been shown to affect crisis frequency and complication risk. Parental education and socioeconomic status (SES) strongly influence health- seeking behavior, medication adherence (particularly hydroxyurea) and the ability to access preventive care such as vaccinations, penicillin prophylaxis and routine clinic follow- up.[3,9-12] Children from low- income households are more likely to experience delayed care, poor nutrition and increased risk of infections, all of which worsen disease severity. Similarly, rural residence and long distance to tertiary care centers contribute to delayed treatment during acute crises, higher hospitalization rates and poorer overall outcomes.[10-11]

The clinical course of the disease varies greatly from patient to patient depending on age, complications and other co-morbidities. Disease severity in SCD is commonly assessed using a combination of clinical indicators such as the frequency of vaso-occlusive crises, transfusion requirements, hospitalization rates and the presence of major complications like stroke or acute chest syndrome. A national or international SCD registry that can be used to characterize and classify SCD severity currently does not exist. While several researchers have developed severity classification systems to predict outcomes and mortality in SCD,[9-12] none have been adopted in clinical practice worldwide in part because of the large number and complexity of variables in clinical presentations from region to region.

While the Cooperative Study of Sickle cell Disease (CSSCD)and Sickle cell Disease Assessment instrument (CSDAI)[13] models are practical because they use easily identified predictors, neither have been validated. In our region, children with SCD exhibit considerable variability in clinical severity; some children have infrequent complications while others experience recurrent vaso-occlusive crises, infections, organ damage and growth impairment. This can create difficulties in the management strategies employed for these affected children. Robust context- appropriate measures of clinical severity help stratify risk, guide treatment (eg hydroxyurea, transfusion programs) and allocate scarce resources. Adegoke and Kuti in 2013 introduced a scoring system to evaluate the clinical severity of SCA in Nigerian children using simple clinico- laboratory parameters which included frequency of crisis, hospital admissions and transfusions in the preceding one year, degree of liver and splenic enlargement, life- time cumulative frequency of specific complications of SCA, Packed cell volume and white blood cell count. The total scores ranged from 0-24 with less than 8 graded as mild, 8-17 moderate and more than 17 severe disease.[14]

Assessment of socioeconomic status (SES) is crucial in pediatric research and clinical practice because it influences health outcomes, access to care, nutritional status and disease severity. In Nigeria, where social stratification is often complex, several indices have been developed to provide standardized classifications. One of such adaptation is the Ibadin and Akpede social class introduced as modification of the Oyedeji classification. While widely used, Oyedeji's system had limitations; It did not account for contextual differences in occupational prestige, underrepresented unemployed/underemployed groups and sometimes misclassified families with discrepancies between maternal and paternal indices. To address these issues, Ibadin and Akpede[15] in 2001 proposed modifications. Their system refined occupational categories and allowed clearer stratification for families where one or both parents were unemployed, informal workers or subsistence farmers. Ibadin and Akpede system still uses parent's educational attainment and occupation but modifies categories to better reflect Nigerian realities:

1. Educational attainment
- No formal education/Quranic education only
- Primary education
- Secondary education

- Post -secondary education (polytechnic, college of education)
- University degree or higher

2. Occupation

- Class I: Senior public servants, professionals, managers, large- scale traders, senior military officers, industrialists
- Class II: Intermediate professionals, lecturers, senor school teachers, nurses, technicians, skilled artisans, medium scale traders
- Class III: Junior school teachers, clerks, drivers, petty traders, artisans
- Class IV: Peasant farmers, messengers, cleaners, laborers, unemployed dependent adults
- Class V: Unemployed, subsistence workers, unskilled causal laborers

Each parent is assigned a score for education and occupation. The average of the two scores (or the single caregiver if one parent is absent or dead) determines the family's social class. Families are finally grouped into: Upper(I-II), Middle (III) and Lower (IV-V) socioeconomic classes.

The aim of the study is to assess the sociodemographic characteristics of children living with SCA and examine their relationship with disease severity.

Specific Objectives include to describe the sociodemographic characteristics of children with SCA, including age, gender, parental education and socioeconomic status**,** to determine the level of disease severity among children with SCA using appropriate clinical and laboratory indicators**,** to compare disease severity across different sociodemographic subgroups of children with SCA, to examine the relationship between selected sociodemographic factors and disease severity in children with SCA.

METHODOLOGY

This study was a hospital based cross- sectional analytical study. One hundred and one children with SCA between the ages of 1 and 18 years were enrolled in the study. The study was carried out between April-December 2024. The participants were recruited consecutively from the Paediatric Sickle Cell Clinic of Federal Teaching Hospital Owerri, Imo State Nigeria.

Inclusion Criteria

Eligible patients who were previously diagnosed to have SCA using cellulose acetate electrophoresis at alkaline pH whose parents/ caregivers gave a written informed consent. Children aged 1 to 18 years were consecutively enrolled in the study during routine visits to the clinic.

Data collection

Structured questionnaire was used to obtain basic bio-demographic data such as age, sex, past medical history, parental educational level and occupation and socioeconomic class using Ibadin and Akpede social classification.

The sickle cell severity calculation: This was determined by Adegoke's Scoring system[14] which is based on clinical and laboratory parameters documented over the preceding 12 months and scored:

1. Frequencies of painful crisis requiring hospital admission
2. Frequency of blood transfusions
3. Frequency of hospital admissions
4. Degree of spleen and liver enlargements
5. The Packed cell volume and white blood cell counts
6. Presence of complications like stroke, acute chest syndrome, avascular necrosis, priapism, leg ulcers, gall stones, chronic leg

The total severity score ranged from zero to thirty-four and stratified as: <8- mild disease; 8-17- moderate disease; >17-severe disease

Data Analysis: The data were entered into the Excel spreadsheet. For the purpose of this study, the age was grouped into 4 cohorts (2–4 years, 5- 7 years, 8–13 years, and 14–18 years). IBM Statistical Package for Social Sciences (SPSS) version 26.0 was used to analyze the data. Descriptive statistics was used to summarize sociodemographic variables and disease severity. Categorical variables were presented as frequencies and percentages while continuous variables were summarized using means and standard deviations. The relationship between sociodemographic characteristics and disease severity was assessed using the Chi- square. A p-value of <0.05 was considered statistically significant.

RESULTS

Socio-demographic characteristics of participants

The greater proportion (38.6%) of the participants were aged 8 – 13 years. Over half (52.5%) of the participants were male. The greater proportion (44.6%) of mothers were aged 40 - 49 years. Nearly 47% and 44% of the mothers were educated up to the secondary and tertiary level, respectively. About 57% of fathers were aged 40 - 49 years. Nearly 42% of the mothers were educated up to the secondary level. More than two-thirds (67.3%) of the participants belonged to a middle socio-economic class. About 32% of the participants were diagnosed between ages 1 – 3 years. See Table 1.

Disease severity of pediatric SCA patients

As shown in Table 2 below, most (71.3%) of the study participants had mild disease severity, while the remainder had moderately severe SCA.

Association of socio-demographic factors with disease severity in children with SCA

Majority (16, 88.9%) of the participants aged 2 – 4 years had mild disease severity. Nonetheless, the association between age of child and SCA disease severity was not statistically significant, (χ^2 = 3.742, P = 0.291). The greater proportion (38, 71.7% and 34, 70.8%) of the male and female participants (respectively) had mild disease severity. Nonetheless, the association between gender of child and SCA disease severity was not statistically significant, (χ^2 = 0.009, P = 0.924). Likewise, the greater proportion (28, 70.0% and 44, 72.1%) of children with mothers younger than 40 years and older than 40 years respectively, had mild disease severity. Nonetheless, the association between mother's age and SCA disease severity was not statistically significant, (χ^2 = 0.054, P = 0.817). The greater proportion (34, 72.3%) of children who have mothers with tertiary level of education had mild disease severity. Nonetheless, the association between mother's level of education and SCA disease severity was found to not be statistically significant, (χ^2 = 0.048, P = 0.976). The greater proportion (8, 100%) of the participants with fathers aged 30 -39 years had mildly severe SCA. See Table 3.

Table 1: Socio-demographic characteristics of participants

Variable	Frequency (n = 101)	Percent (%)
Age	Mean = 9.31	SD = 4.562
2 - 4 years	18	17.8
5 - 7 years	21	20.8
8 - 13 years	39	38.6
14 - 18 years	23	22.8
Gender		
Male	53	52.5
Female	48	47.5
Mother's age	Mean = 41.14	SD = 8.172
Younger than 30 years	7	6.9
30 - 39 years	33	32.7
40 - 49 years	45	44.6
50 years or older	16	15.8
Mother's highest level of education		
No formal	6	5.9
Primary	4	4.0
Secondary	44	43.6
Tertiary	47	46.5
Father's age	Mean = 48.98	SD = 8.305
30 - 39 years	8	7.9

40 - 49 years	58	57.4
50 years or above	35	34.7
Father's highest level of education		
No formal	14	13.9
Primary	7	6.9
Secondary	42	41.6
Tertiary	38	37.6
Socio-economic status		
Upper	6	5.9
Middle	68	67.3
Lower	27	26.7
Age at diagnosis	Median = 36.00	IQR = 37.5
1 - 11 months	16	15.8
1 - 3 years	32	31.7
4 - 5 years	28	27.7
6 - 12 years	22	21.8
13 - 18 years	3	3.0

Table 2: Disease severity of pediatric SCA patients

Variable	Frequency (n = 101)	Percent (%)
Mild	72	71.3
Moderate	29	28.7

Table 3: Association of socio-demographic factors with disease severity in children with SCA

Variable	Disease severity		χ^2 (or Fisher's exact) statistic	P-value
	Mild	Moderate		
Age category				
2 - 4 years	16 (88.9%)	2 (11.1%)	3.742	0.291
5 - 7 years	15 (71.4%)	6 (28.6%)		
8 - 13 years	25 (64.1%)	14 (35.9%)		
14 - 18 years	16 (69.6%)	7 (30.4%)		
Gender				
Male	38 (71.7%)	15 (28.3%)	0.009	0.924
Female	34 (70.8%)	14 (29.2%)		
Mother's age				
Younger than 40 years	28 (70.0%)	12 (30.0%)	0.054	0.817
40 years or older	44 (72.1%)	17 (27.9%)		
Mother's level of education				
No formal/Primary	7 (70.0%)	3 (30.0%)	0.048	0.976
Secondary	31 (70.5%)	13 (29.5%)		

Tertiary	34 (72.3%)	13 (27.7%)		
Father's age				
30 - 39 years	8 (100.0%)	0 (0)	4.319	0.115
40 - 49 years	38 (65.5%)	20 (34.5%)		
50 years or above	26 (74.3%)	9 (25.7%)		
Father's level of education				
No formal/Primary	13 (61.9%)	8 (38.1%)	1.398	0.497
Secondary	32 (76.2%)	10 (23.8%)		
Tertiary	27 (71.1%)	11 (28.9%)		
Socio-economic status				
Upper/Middle	55 (74.3%)	19 (25.7%)	1.248	0.264
Lower	17 (63.0%)	10 (37.0%)		
Age at diagnosis				
Within age 5	35 (72.9%)	13 (27.1%)	0.119	0.730
After age 5	37 (69.8%)	16 (30.2%)		

DISCUSSION

In this study, the largest proportion of children were aged 8-13 years (38.6%), with a mean age of 9.31 years. Similar age distributions were observed in Nigerian studies of children with SCD, where school- age participants predominate due to higher diagnosis rates and clinical presentation in this age group.[16,17] The male: female ratio of 1.1:1 mirror finding in other African cohorts documenting slight male predominance in clinic attendance, although gender distribution in SCD prevalence is generally equal.[18] Parental age distributions demonstrated that most mothers and fathers fell within 40-49 years (44.6% and 57.4% respectively). This aligns with demographic patterns in Nigeria where family caregivers of children with chronic illnesses tend to be in mid- adulthood due to child-rearing ages and socio-cultural factors influencing family structure.[19] Nearly equal proportions of mothers attained secondary (43.6%) and tertiary education (46.5%) while fathers had slightly lower tertiary attainment (37.6%). These educational levels are higher than some reports in sub-Saharan Africa where caregiver education often trends toward primary/secondary levels.[20] Higher parental education has been associated with improved disease knowledge and care-seeking behaviors among families affected by SCD.[21]

The predominance of middle socio-economic status (67.3%) contrasts with studies showing significant socio-economic barriers to care among African SCD populations, with many families belonging to lower SEC.[22] However, the middle-class representation here may reflect urban study settings or clinic- based sampling bias, commonly noted in facility- based studies in Nigeria.[23] About 32% of the participants were diagnosed between ages 1-3 years which is consistent with patterns where early infancy and toddler ages represent periods of first clinical presentation and increased health interactions.[24] Early diagnosis is critical for preventive interventions and aligns with World Health Organization recommendations for newborn screening programs in high- burden countries like Nigeria.[25]

Most participants (71.3%) had mild SCD severity and none had severe disease. Previous Nigerian studies have similarly reported a predominance of mild to moderate disease phenotypes among children attending specialist clinics, attributed in part to early diagnosis and routine prophylaxis (including penicillin and vaccination) and comprehensive care programs.[26,27] Disease severity in SCD varies widely across African settings due to genetic, environmental and health service- related factors.[1]

Across all socio-demographic variables- child's age, gender, parental age and education, socio-economic status

and age at diagnosis- no statistically significant associations with SCD severity were observed in this study. Although a higher proportion of younger children (2-4 years) had mild disease, the age differences were not significant. This is in keeping with regional literature showing that age is not a reliable indicator of clinical severity among paediatric SCD populations.[28] Similarly, gender differences were negligible and statistically not significant, reinforcing that disease severity in SCD is not sex- specific.[18] Neither maternal age nor mother's education significantly influenced severity. Although higher parental education is often correlated with better health outcomes, studies from Nigeria and Ghana have shown mixed findings on its direct impact on SCD severity, possibly due to complex interactions with health service access and cultural factors.[21,29] Father's age and education also showed no association with severity, consistent with research suggesting socio- demographic predictors may be overshadowed by biological determinants of disease expression.[30]

Higher socio-economic status was associated with a non-significant trend toward milder severity. While not statistically significant, this trend resembles broader evidence from African contexts where socio-economic advantages facilitate earlier care and prophylaxis, potentially ameliorating severity patterns.[22,31] However, the lack of significant association in this study may reflect improved access to SCD care across socio-economic strata in the study location. Although children diagnosed earlier had a slightly higher proportion of mild severity, the association was not significant. Early diagnosis and intervention are widely recognized as beneficial in modifying disease course but this study suggests that other factors may attenuate the expected impact on clinical severity. Early diagnosis without comprehensive follow- up care and prophylaxis may limit its effect on measurable severity outcomes.[25, 26]

CONCLUSION

The findings from this study revealed that the majority of participants were school- aged children, with a slight male predominance and most caregivers were middle-aged parents with at least secondary education. Most children were diagnosed within the first three years of life, reflecting increasing awareness and improved access to diagnostic services in the study setting. A large proportion of the participants had mild disease severity while the remainder had moderately severe disease. Importantly, no statistically significant associations were found between disease severity and the socio-demographic variables studied including age, gender, parental age, parental education, socio-economic status and age at diagnosis. These findings suggest that socio-demographic factors alone may not be strong determinants of disease severity in children with SCA.

Overall, the study highlights the multifactorial nature of SCA severity where biological factors, genetic modifiers, access to comprehensive care and adherence to recommended management protocols may play more significant roles than socio- demographic characteristics. The predominance of mild disease observed may reflect the benefits of early diagnosis, routine follow- up and structures care available to the study population.

Recommendations

1.Health systems should continue to strengthen comprehensive sickle cell care programs including routine clinic follow- up, prophylactic medications, vaccination and caregiver education as these may contribute to milder disease expression regardless of socio- demographic background.

2. Continuous education of caregivers and communities on early recognition of complications, prompt health- seeking behavior and adherence to treatment protocols should be maintained irrespective of parental educational or socio-economic status

3. Larger, multicenter studies across different regions are recommended to improve generalizability and examine regional variations in disease severity and health system influences on outcomes among children with SCA.

Limitations

1. Participants were recruited from healthcare setting, which may limit generalizability of the study to the wider community

2. The reliance on caregiver reported information for some variables may be subject to recall bias and social desirability bias.

Declarations

Ethical approval and Consent to participate: Ethical approval was sought and obtained from the Human and Research Ethics Committee of Federal teaching hospital Owerri (FTH/OW/HREC/VOL.1/179). The information and consent were given to parents/guardians to read and sign.

Conflict of Interest: The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Funding: This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. The study was self-funded by the authors.

Consent for publication: Written informed consent was obtained from all individual participants (or their legal guardians) for publication of this study and its accompanying data.

Availability of data and materials: The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

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