



Knowledge, Attitude, and Prevention Practices Towards Sickle Cell Disease Among Adults in Isiala Mbano, Imo State, Nigeria: A Descriptive Survey

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Abstract

Sickle Cell Disease (SCD) is still a major inherited blood disease in Nigeria although the level of public knowledge of its mode of transmission, clinical manifestations and prevention is patchily documented at the community level. The knowledge, attitude and preventative behaviours of SCD among adults in Isiala Mbano, Imo State, Nigeria were investigated in this study. A descriptive cross-sectional survey was conducted among 364 persons aged 18 years and above, selected from a target population of 4,000 using simple random sampling. Data were obtained using a semi-structured questionnaire developed by the authors, comprising four sections, and reliability was determined using a pilot test (Pearson's product-moment correlation coefficient = 0.9). The data were examined using frequencies, percentages and multiple linear regression. All respondents (100%) had heard about SCD and 81.0% knew someone living with the illness in person. However, only 53.6% of the respondents comprehended that SCD is genetic and knew how it is inherited, and only 33.0% knew the symptoms and problems of SCD with none of the respondents (0%) being aware of any viable treatment and management options. Regarding prevention, 81.0% identified the fact that certain variables can precipitate a sickle cell crisis while knowledge of specific preventive practices was less (33.0%-68.7%). Overall attitudes were supportive with 74.2% feeling that people with SCD deserve special support from the community and all respondents (100%) agreeing that families with a history of SCD should have genetic counselling. However, only 33.0% felt that community awareness was adequate and 56.3% felt that people with SCD experience stigma. Demographic characteristics (age, gender, education, married status) were not substantially related to knowledge of SCD ($r = 0.28$, $p = 0.089$) but were significantly related to knowledge of crisis prevention ($r = 0.30$, $p = 0.023$) and to attitudes toward SCD ($r = 0.39$, $p = 0.041$). There is a high level of public awareness about SCD in Isiala Mbano but low information about the genetics, symptoms and possible management of the disease and the level of community awareness is viewed as inadequate, despite generally supportive views. Targeted community health education led by nurses and increased access to genetic counselling are needed to address these gaps.

Keywords: Sickle Cell Illness; Knowledge; Attitudes; Prevention; Genetic Counselling; Nigeria

Introduction

Sickle Cell Disease (SCD) is a hereditary haematological illness caused by a mutation in the HBB gene, leading in the generation of aberrant Haemoglobin S (HbS) and the distinctive sickling of red blood cells. It is inherited in an autosomal recessive manner, with persons inheriting two copies of the defective gene developing SCD, and those inheriting one copy having Sickle Cell Trait (SCT) and generally being asymptomatic [1]. In states such as hypoxia, dehydration, infection or physiological stress, HbS polymerises within the red blood cells, rendering them stiff, deformed and fragile. These aberrant cells can block small blood arteries causing recurring episodes of vaso-occlusive discomfort, chronic haemolytic anaemia, tissue ischaemia and progressive damage to major organs. This, in turn, puts persons with SCD at increased risk of severe complications, infection and early death [2].

SCD is among the most frequent monogenic diseases globally with the highest burden of disease in sub-Saharan Africa. Nigeria has a particularly heavy burden, estimated to have roughly one quarter of the population carrying the sickle cell gene, with about 2-3% of the population having SCD. It is also estimated that about 150,000 children are born with SCD annually in Nigeria [3]. Knowledge and comprehension of SCD among the Nigerian populace is variable despite this huge burden.

Studies undertaken in Ilorin and Benin City have shown major gaps in public knowledge, including weak understanding of the disease and low awareness of personal haemoglobin genotype [4]. This is especially alarming as haemoglobin genotype testing is reasonably inexpensive and generally available. Also, religious and community organisations have advocated more and more for genotype screening as a crucial factor before marriage [5].

Public awareness raising about SCD is very crucial for its prevention and control. Good knowledge of SCD is associated with better understanding of the importance of the haemoglobin genotype test and making educated decisions on marriage and reproductive planning. Increased understanding may also lead to more positive views toward people living with SCD and supportive behaviours within families and communities [6]. Conversely, limited awareness, misconceptions and negative attitudes can lead to poor utilisation of preventive interventions, incorrect reproductive decisions, discrimination and stigma toward those living with SCD [7].

Several studies have been conducted in Nigeria on knowledge, attitude and practices of SCD among students, healthcare workers and other selected populations. However, there is relatively little information on the level of awareness and understanding of SCD among adults in rural and semi-urban communities especially in local government areas like Isiala Mbano in Imo State. It is therefore crucial to assess the knowledge and attitudes of such communities since community perceptions and reproductive decisions could influence the prevention, early detection and social management of SCD. Hence, the study was conducted to determine the knowledge and attitudes toward sickle cell disease among adults in Isiala Mbano Local Government Area of Imo State with the aim of identifying existing knowledge gaps and providing evidence that will guide proper health education and community-based interventions.

Materials and Methods

Study design and setting

A descriptive cross-sectional survey design was adopted for the study. The study was conducted in Isiala Mbano Local Government Area of Imo State, southeastern Nigeria. The Local Government Area comprises rural and semi-urban communities and is served by various healthcare facilities, including general hospitals, private clinics, and primary healthcare centres. The study setting was considered appropriate for assessing adults' knowledge and attitudes regarding Sickle Cell Disease (SCD), given the importance of community awareness in the prevention and management of the condition.

Study population and sampling

The study population comprised adults aged 18 years and above who were residents of Isiala Mbano Local Government Area. The estimated study population was 4,000 adults. The sample size was determined using the Taro Yamane formula:

$$n = \frac{N}{1 + N(e)^2}$$

where n represents the required sample size, N represents the estimated population size, and e represents the level of precision. At a 5% margin of error ($e = 0.05$), the calculated sample size was:

$$n = \frac{4000}{1 + 4000(0.05)^2} = \frac{4000}{11} = 363.64$$

The value was rounded up to 364 respondents.

Eligible participants were adults aged 18 years and above who had resided in Isiala Mbano Local Government Area for at least the period

specified by the study protocol and who consented to participate. Respondents were selected using a simple random sampling technique to provide each eligible adult an equal opportunity of being selected.

Ethical considerations

Ethical approval for the study was obtained from the Department of Nursing Science, Imo State University, Orlu Campus, before commencement of data collection. Participation in the study was entirely voluntary. The purpose and procedures of the study were explained to each prospective participant, and informed consent was obtained before the questionnaire was administered.

Participants were informed of their right to decline participation or withdraw from the study at any time without penalty. No names or other directly identifying information were collected on the questionnaire. The anonymity and confidentiality of participants were maintained throughout the study, and the information obtained was used strictly for academic and research purposes. Completed questionnaires and research data were securely handled and made accessible only to the researchers.

Data collection instrument

Data were collected using a self-administered, semi-structured questionnaire developed by the researchers based on the study objectives and relevant literature on SCD. The questionnaire consisted of four sections. Section A assessed the respondents' socio-demographic characteristics, including age, sex, educational level, and marital status. Section B contained items assessing respondents' general knowledge of SCD. Section C assessed knowledge of measures for preventing or reducing sickle cell crises, while Section D assessed respondents' attitudes towards SCD and people living with the condition.

The questionnaire consisted predominantly of closed-ended questions to facilitate consistent responses and quantitative analysis. Appropriate response options were provided for each item, and the wording was structured to ensure clarity and ease of understanding.

Validity and reliability of the instrument

The questionnaire was subjected to content and face validation to ensure that the items adequately reflected the study objectives and were appropriate for the target population. The instrument was reviewed by the project supervisor and two experts in nursing and related health sciences. Their observations regarding the clarity, relevance, adequacy, and appropriateness of the questionnaire items were incorporated before the final version was produced.

The reliability of the instrument was assessed through a pilot study involving 10 residents of Ibeme Amaise, a community outside the main study area but with characteristics comparable to those of the study population. The questionnaire was pilot-tested to identify ambiguous or poorly structured items and to assess its consistency. Reliability analysis yielded a Pearson product-moment correlation coefficient (r) of 0.90, indicating a high level of reliability of the instrument.

Data collection

Data collection was carried out by the researchers with the assistance of trained data collectors who were adequately briefed on the objectives of the study, selection of participants, administration of the questionnaire, and ethical requirements. The questionnaires were administered to eligible respondents in the selected communities. Completed questionnaires were checked for completeness before

being coded for analysis.

Statistical analysis

Data were analysed using appropriate descriptive and inferential statistical techniques. Frequencies and percentages were used to summarise the respondents' socio-demographic characteristics and responses to the knowledge, crisis-prevention knowledge, and attitude items. Where applicable, composite scores were generated for the major outcome variables based on the respondents' responses to the relevant questionnaire items.

Multiple linear regression analysis was used to determine whether the respondents' demographic characteristics age, sex, educational level, and marital status significantly predicted the knowledge and attitude outcome scores. The regression model provided estimates of the independent contribution of each demographic variable while controlling for the effects of the other variables in the model. Statistical significance was established at $p < 0.05$.

Results

Table 1 summarises the demographic profile of the 364 respondents. Most identified as Christian (82.4%), were aged 20–30 years (55.0%), held an HND/BSc qualification (37.6%), and were married (57.7%).

As shown in Table 2, all respondents (100%) had heard of SCD before the study, and 81.0% personally knew someone with the condition. Just over half (53.6%) knew that SCD is a genetic disorder and understood its mode of inheritance, while only 33.0% were familiar with its symptoms and complications. Slightly more than half (55.0%) had received information about SCD from a healthcare professional or community organisation. Notably, none of the respondents (0%) were aware of any available treatment or management strategy for SCD.

Table 3 shows that 81.0% of respondents were aware that certain factors can trigger a sickle cell crisis, but awareness of specific preventive behaviours was more limited: only 33.0% knew that stress and emotional distress can increase crisis risk, 43.7% knew that avoiding strenuous activity helps prevent crises, 68.7% recognised the importance of a healthy lifestyle, and 57.7% were aware that avoiding temperature extremes reduces crisis risk.

Table 1:

Variable	Category	Frequency (n=364)	Percentage
Religion	Christian	300	82.4%
	Islam	35	9.6%
	Traditional	29	8.0%
Age (years)	20–30	200	55.0%
	31–40	100	27.5%
	41–50	37	10.2%
	50 and above	27	7.4%
Education	HND/BSc	137	37.6%
	Master's	120	33.0%
	PhD	50	13.7%
	Other	57	15.7%
Marital status	Married	210	57.7%
	Single	100	27.5%
	Divorced	57	15.7%

Table 2:

Item	Yes	No
Heard of SCD before	100% (364)	0% (0)
Personally knows someone with SCD	81.0% (295)	19.0% (69)
Aware SCD is a genetic disorder	53.6% (195)	46.4% (169)
Knows how SCD is inherited	53.6% (195)	46.4% (169)
Familiar with symptoms/complications	33.0% (120)	67.0% (244)
Received information from a healthcare source	55.0% (200)	45.0% (164)
Aware of available treatment/management	0% (0)	100% (364)

Table 3:

Item	Yes	No
Aware certain factors trigger a crisis	81.0% (295)	19.0% (69)
Aware stress/emotional distress raises crisis risk	33.0% (120)	67.0% (244)
Knows avoiding strenuous activity helps prevent crisis	43.7% (159)	56.3% (205)
Familiar with healthy-lifestyle role in prevention	68.7% (250)	31.3% (114)
Aware avoiding temperature extremes prevents crisis	57.7% (210)	42.3% (154)

Table 4:

Item	Yes	No
People with SCD deserve special community support	74.2% (270)	25.8% (94)
Community awareness of SCD is adequate	33.0% (120)	67.0% (244)
People with SCD experience stigma/discrimination	56.3% (205)	43.7% (159)
Government should increase support for SCD healthcare	68.7% (250)	31.3% (114)
Families with SCD history should undergo genetic counseling	100% (364)	0% (0)

As shown in Table 4, 74.2% of respondents believed that people with SCD should receive special community attention and support, but only 33.0% felt that community awareness of SCD was adequate. Over half (56.3%) believed people with SCD experience stigma or discrimination, and 68.7% supported greater government investment in SCD-related healthcare. All respondents (100%) agreed that families with a history of SCD should undergo genetic counselling.

Multiple linear regression was used to test each hypothesis (Table 5). Demographic variables (age, gender, education, marital status) were not significantly associated with knowledge of SCD ($r = 0.28$, $R^2 = 0.078$, $F = 2.14$, $p = 0.089$), so H01 was retained. Demographic variables were significantly associated with knowledge of crisis prevention ($r = 0.30$, $R^2 = 0.090$, $F = 3.15$, $p = 0.023$), so H02 was rejected. Demographic variables were also significantly associated with attitudes towards SCD ($r = 0.39$, $R^2 = 0.152$, $F = 3.85$, $p = 0.041$), so H03 was rejected.

Discussion

All respondents in this study were aware of Sickle Cell Disease (SCD) demonstrating that the disease is commonly acknowledged among the study group. This is consistent with observations of high general awareness of SCD among adults in Lagos and among the Nigerian National Youth Service Corps [9]. But the public awareness was not reflected in the adequate or thorough knowledge of the condition. Just over half of the respondents were aware of the genetic basis and pattern of inheritance of SCD, which is in line with prior reports of poor knowledge of SCD inheritance among Nigerians [10]. Moreover, only roughly one third of the respondents knew

Table 5:

Outcome	r	R ² (%)	F	P	Decision
Knowledge of SCD	0.28	7.8%	2.14	0.089	H01 retained (not significant)
Knowledge of crisis prevention	0.30	9.0%	3.15	0.023	H02 rejected (significant)
Attitude towards SCD	0.39	15.2%	3.85	0.041	H03 rejected (significant)

the key signs and problems of SCD and none reported being aware of possible treatment choices. These findings highlight a significant gap between simply being aware of SCD and having the practical information needed for prevention and optimal management. This gap is all the more relevant since that haemoglobin genotype testing and premarital counselling are accessible in Nigeria and are being regarded as crucial components of SCD prevention [11].

Most respondents were aware that some factors could provoke a sickle cell crisis, demonstrating reasonable understanding of the general susceptibility of people with SCD to environmental and behavioural triggers [12]. However, awareness of specific preventive interventions was far poorer, especially about the significance of psychological stress and emotional anguish in initiating crises. The pattern of more general awareness of risk factors than knowledge of particular and actionable preventative behaviours is similar with findings from earlier studies on knowledge, attitudes and practices concerning SCD prevention in Nigeria [13]. This data shows that health education interventions in the past may have been more geared toward raising awareness of the occurrence of SCD than toward imparting practical knowledge to individuals and families for the prevention and day-to-day treatment of SCD. Effective health education should, therefore, stress not just the nature of SCD but also how crises can be avoided by enough hydration, avoidance of identified triggers, adequate rest, reduction of stress, protection from harsh temperatures, and early care of disease.

The results also showed good sentiments toward people with SCD and strong support for increased government participation in SCD care. This is consistent with studies of positive community views regarding SCD among Nigerian students and university populations [14]. However, the fact that more than half of the respondents stated that persons living with SCD are stigmatised is still a concern. It indicates that positive personal views may co-exist with an awareness of continuing social discrimination and misconceptions about the disease. Similar worries about stigmatising attitudes toward people with SCD have been found in Nigerian high school pupils [15]. Importantly, all respondents agreed that families at risk should have genetic counselling. Such a high level of support is reassuring since it suggests that support for preventive treatments may be quite substantial in the community. Thus, barriers to genetic counselling and genotype testing may be more related to the lack of knowledge, availability, affordability, accessibility or consistency of service delivery rather than outright community resistance.

The regression analysis indicated that the demographic variables of age, sex, educational level and marital status investigated were not significant predictors of total knowledge of SCD. Conversely, these characteristics were substantially linked with knowledge of crisis prevention and attitudes about SCD, although the models accounted for a relatively moderate percentage of variance, 9.0% and 15.2% respectively. These results imply that demographic variables may influence some aspects of respondents' knowledge and perceptions of SCD, but may not sufficiently account for differences in total illness

awareness. The lack of a strong demographic correlation with public knowledge of SCD may also indicate the population's widespread recognition of the condition. Nevertheless, the low explanatory power of the regression models indicates that other factors not explored in this study, such as previous exposure to health education on SCD, family history of SCD, access to health information, personal contact with individuals affected by SCD, and socioeconomic status may influence knowledge and attitudes to a large extent [16, 17].

The findings have substantial implications for nursing and community health practice. Since awareness of SCD is already high, health education interventions should go beyond awareness campaigns and target specific knowledge deficiencies [18]. Nurses and community health workers are especially well placed to deliver accessible education around the genetic basis and inheritance of SCD, recognition of common symptoms and complications, crisis prevention, available treatment options, and the importance of genotype testing and genetic counselling. They can help reduce stigma by advocating respectful and inclusive care, addressing misconceptions, supporting affected persons and their families and incorporating SCD education into community outreach programs [19]. The substantial support for genetic counselling found in this study gives an opportunity for health care providers and policy makers to improve community-based counselling and screening services. There is also a need for more government investment to improve access to comprehensive SCD services, especially at the primary healthcare and community levels [20].

Conclusion

The study shows that the knowledge of sickle cell disease among adults in Isiala Mbano is very high, but this does not translate to a sufficiently broad understanding of the genetic basis of the disease, inheritance, symptoms, complications, treatment options and measures to prevent crisis. Although persons with SCD are generally well accepted and genetic counselling is highly advocated for families at risk, the feeling that stigma still exists is a significant concern.

The findings indicate that the key task is now not just to raise awareness of the existence of SCD, but to convert public awareness into correct, practical and effective knowledge. Hence targeted community-based health education should focus on genetics and inheritance, early recognition of difficulties, crisis prevention, accessible treatment options and necessity of genotype testing and genetic counselling. Long-term engagement of nurses, community health workers, healthcare institutions, and government agencies will be required to address these information gaps, reduce stigma, strengthen preventative behaviours, and improve the entire community response to SCD.

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