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ORIGINAL ARTICLE

Knowledge, Attitude and Willingness to Screen Younger Infants for Sickle Cell Disease among Mothers attending Immunization Clinic in an Urban Community in Lagos, Nigeria

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Keywords

Sickle cell disease; Knowledge; Attitude; Willingness to screen; Mother-Infant pair; Lagos.

ABSTRACT

Background: Over 300,000 babies are born worldwide with sickle cell disease, mostly in low- and middle-income countries with the majority of these births in Africa. Nigeria has the largest population of people with sickle cell disease with about 150,000 children born with the disease every year. This study assessed the knowledge, attitude and willingness to screen younger infants for sickle cell disease among mothers attending immunization clinic in an urban community in Lagos, Nigeria.

Methods: A cross-sectional descriptive study was carried out at primary health care centres in Somolu Local Government Area in Lagos, Nigeria. Two hundred and ninety-one mother-infant pairs were consecutively recruited from August 2019 to January 2020. Data were collected with a pre-tested, interviewer-administered questionnaire. The analysis was done using SPSS version 22 software. Univariate and bivariate analysis were conducted with the level of significance set at $p<0.05$.

Results: The mean age of respondents was 29.9 ± 5.4 years. Most 212 (72.9%) were aware of sickle cell disease. One hundred and fifty-one (71.2%) of those who were aware of sickle cell disease had good knowledge while 148 (69.8%) had a positive attitude towards SCD prevention. Majority of the respondents 180 (84.9%) were willing to screen their infants for sickle cell disease. A statistically significant association was found between good knowledge and positive attitude towards SCD ($p<0.001$).

Conclusion: There is the need for increased education of mothers of younger infants attending routine immunization clinic about SCD for better knowledge, attitude and willingness for early infants screening of SCD.

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INTRODUCTION

Sickle cell disease (SCD) is the "first molecular human disease" discovered in 1904. It is a genetically inherited blood disorder caused by a single gene mutation causing red blood cells to become sticky and sickle in shape leading to a wide range

of severe and life-threatening consequences.[1,2] Sickle cell disease is caused by a single error in the DNA coding for haemoglobin, a protein responsible for carrying oxygen in the blood either in a homozygous form (HbSS), called sickle cell anaemia or in combination with other abnormal haemoglobins such as sickle cell haemoglobin C disease (HbSC) and sickle cell β-thalassaemia (Hb Sβ-Thal). As a result of this alteration, individuals with SCD go through a lifetime of complications including anaemia, infections, stroke, tissue damage, organ failure, severe painful episodes and even premature death.[3-7] The distressing symptoms, routine treatment and care required by people living with SCD often lead to a limitation in education, career prospects, and eventually the quality of life.[7]

SCD has been recognized as a disease with significant public health priority by the World Health Organisation and a burden that must be given focused attention if recent improvements in overall child survival are to be effective.[8,9] Approximately 5% of the world's population are healthy carriers of the sickle cell gene. [2] SCD is a preventable inherited disease and a common problem in Africa and many other parts of the world with significant morbidity and mortality.[10,11] The prevalence of HbSS in Nigeria ranges between 1-3% and it constitutes a severe burden on the people living with SCD and their families.[3] A couple with sickle cell trait each has 25% chances of giving birth to a child with SCD in every pregnancy and 50% chance of having a child with sickle cell trait (SCT). It is therefore important for women of childbearing age to have good knowledge of SCD since the disease is common among couples who are ignorant of their Hb genotypes.[11-12]

Over 300,000 babies are born worldwide with SCD with the majority of these births in Africa. Nigeria has the largest population of people with SCD where approximately 20 out of 1,000 births are diagnosed with SCD, resulting in about 150,000 children born with the disease every year.[2,13-14] SCD is the sixth cause of deaths among children below the age of five in Nigeria with approximately 50% of deaths occurring between the ages of six months and one year.[15,16] New-born screening programme for SCD which should target mothers of younger infants is yet to become routine in Nigeria due to cost and logistics.

Even with the large burden of SCD in Nigeria, awareness and knowledge of SCD has been documented to be relatively low.[12,17] Knowledge of sickle cell disease among reproductive-age women may constitute an important variable that influences their attitude and uptake of early infant screening for SCD. Several studies have been conducted globally among different groups of respondents but research among mothers of younger infants less than three months of age is scarce. This study was unique because it required exploration among mothers of younger infants (between 2 to 10 weeks of age) who are the targets for a national screening programme for SCD. This study conducted in Somolu LGA in Lagos, Nigeria assessed the knowledge, attitude and willingness of mothers attending first or second immunization clinics in Primary Health Care (PHC) centers to screen their infants for SCD. The findings of this study may contribute to decision making regarding policy development for an early infant screening programme for SCD in Nigeria.

METHODOLOGY

Study area: Lagos State is the economic capital of Nigeria, located in the Southwest geopolitical zone of the country. This study took place in one of the 20 Local Government Areas (LGAs) in Lagos State. Somolu LGA is a cosmopolitan community with a mixture of Nigeria ethnic groups dominated by the Yoruba ethnic group. The LGA had an estimated population of 1,025, 123 as of 2006 census, with a projection of 3.4% growth rate gave an increase of about 453,102 and an estimated population of 1, 478, 225 in 2019. The LGA has an area of 10.3 km² and density of 132,190/km² and ten primary healthcare centres.[18-19]

Study design and selection of participants: The study was cross-sectional in design, conducted between August 2019 and January 2020. The study population comprised mothers of infants between 2 to 10 weeks of age attending routine immunization clinics in two PHC centres selected through random sampling by ballot in Somolu LGA. Mothers who were 18 years and above, who had resided in the LGA for at least six months and consented were recruited consecutively. Cochrane formula for the descriptive study was used for sample size calculation ($n=z^2pq/d^2$)[20] with a standard normal deviation at 95% confidence interval (1.96), p being the proportion of mothers who had good knowledge of SCD as an

inherited disease in a similar study in Nigeria (23.3%)[21] and error of precision at 5% (0.05). The minimum sample size calculated was 274 which was increased to 291 to make up for incomplete data.

Data collection: Data was collected with the pretested, interviewer-administered ques-tionnaire which was developed following the review of similar studies.[1,22-23] The questionnaire was pretested in a PHC at Oshodi-Isolo LGA, Lagos State. Research assistants were two graduates of physiotherapy from the College of Medicine, University of Lagos.

Data analysis: The data were double-entered, cleaned and analyzed with Statistical Package for Social Sciences (SPSS) version 22. Descriptive analyses including frequencies, percentages, means, and standard deviations (SD) were carried out. Chi-square test was used to test for association between socio-demographic variables and knowledge of SCD. Level of significance was set at $p < 0.05$. The questionnaire consisted of 13 statements on knowledge of SCD. Each correct response was awarded a score of 1, while wrong/don't know responses scored 0. The maximum knowledge score was 13 and the minimum was 0. Total knowledge score was converted to a percentage and scores ≥ 50% were graded as good knowledge while <50% as poor knowledge. The 10 statements on attitude were rated on a 5-point Likert scale. The median score was calculated and scores greater or equal to the median were categorized as positive attitude while scores below the median were categorized as a negative attitude.

Ethical considerations: Ethical approval for this study was obtained from the Health Research Ethics Committee (HREC) of the College of Medicine, University of Lagos *(CMUL/HREC/03 /19/503)*. Written inform-ed consent was obtained from each respondent with an assurance of confidentiality of the information and their right to withdraw from the study at any point in time. The respondents were counselled to understand that involvement in the study was voluntary.

RESULTS

Two hundred and ninety-one (291) respondents took part in the study. The mean ± SD age of respondents was 29.9 ± 5.4 years. Almost all 285 (97.9%) were married, most 137 (47.1%) had secondary level of education and 241 (82.2%) were employed. Almost all 287 (98.6%) registered for an antenatal clinic (ANC)

during pregnancy and most 173 (60.4%) attended between 10-19 times with a mean ± SD attendance of 12.2 ± 4.2. Majority 245 (84.2%) of the respondents' infants were five weeks or more of age. (Table 1)

Table 2 shows that 212 (72.9%) of the respondents were aware of SCD. Two hundred and fifty (85.9%) of the respondents had ever checked their Hb genotype of which most 161 (64.4%) stated Hb AA. One hundred and eighty-nine (64.9%) of the respondents knew their spouse's Hb genotype while 201 (69.1%) were aware of premarital genotype test of which 149 (74.1%) did the test before marriage.

Table 3 shows that the majority 198 (93.4%) of respondents knew that children with SCD fall ill often, 191 (90%) knew that SCD can be passed from parents to children through blood while 190 (90%) correctly said that SCD cannot be transmitted by physical contact. About half (54%) correctly mentioned that SCD traits cannot develop into disease while very few 41 (19%) knew that children with SCD have an increased risk of stroke. Overall, 151 (71.2%) of respondents who were aware of SCD had good knowledge of the disease with a mean (± SD) score of 9.4±2.5.

Table 4 shows that almost all 202 (95.3%) of the respondents agreed that everybody should know his/her genotype before marriage while 190 (89.6%) agreed that knowing the risk of having a child with SCD should influence the choice of a life partner. Also, 170 (80.1%) disagreed that infants diagnosed with SCD should be isolated from other children while 199 (93.8%) agreed that infants diagnosed with SCD should be registered at the clinic immediately for management. Overall, 148 (69.8%) of the respondents who were aware of SCD had a positive attitude towards disease prevention. Majority 180 (84.9%) of the respondents who were aware of SCD were willing to screen their infants for the disease.

Table 5 shows that most respondents 128 (76.6%) who were aware of premarital test had good knowledge of SCD compared to 23 (51.1%) of those who were not aware and this was statistically significant, $p<0.001$.

Table 1: Socio-demographic characteristics of mother-infant pairs

Variables	Frequency	Percent
Age* (n=291)		
18-28	123	42.3
29-38	145	49.8
39-48	23	7.9
Marital status (n=291)		
Single	6	2.1
Married	285	97.9
Level of Education (n=291)		
None	3	1.0
Primary	19	6.5
Secondary	137	47.1
Tertiary	132	45.4
Employment status (n=291)		
Unemployed	50	17.2
Employed	241	82.2
Monthly income (₦) (n=241)		
<50,000.00	52	21.6
≥50,000.00	31	12.9
No response	158	65.5
ANC Attendance (n=291)		
Yes	287	98.6
No	4	1.4
Place of ANC (n=287)		
Teaching hospital	2	0.7
Traditional Birth Attendants	12	4.2
General hospital	52	18.1
Primary Health Centers	56	19.5
Private hospital	165	57.5
No of ANC visits (n=287)		
1-9	60	20.9
10-19	173	60.3
≥20	11	3.8
No response	43	15.0
Mean ± SD= 12.26 ± 4.27		
Age of infant (weeks) (n=291)		
<5	46	15.8
≥5	245	84.2
Mean ± SD= 7.42 ± 2.36		
Sex of infant (n=291)		
Male	153	52.6
Female	138	47.4

**Mean age ± SD= 29.94± 5.43years*

Table 2: Awareness and screening practices of SCD among respondents

Variables	Frequency	Percent
Aware of SCD (n=291)		
Yes	212	72.9
No	79	27.1
Medium of information (n=212)		
Multiple sources	106	50.0
Health professional	63	29.7
Family or friends	28	13.2
Media	10	4.7
Cannot remember	5	2.4
Knew someone with SCD (n=212)	100	47.2
Yes	112	52.8
No		
Relationship with the person (n=100)		
Friends/colleagues	42	42.0
Neighbours	30	30.0
Relatives	17	17.0
Others	11	11.0
Ever checked genotype (n=291)		
Yes	250	85.9
No	41	14.1
Hb genotype (n=250)		
AA	161	64.4
AS	48	19.2
AC	5	2.0
SC	1	0.4
Cannot remember	35	14.0
Knew spouse's genotype (n=291)		
Yes	189	64.9
No	102	35.1
Aware of premarital genotype test (n=291)		
Yes	201	69.1
No	90	30.9
Had pre-marital genotype test (n=201)		
Yes	149	74.1
No	52	25.9

Table 3: Knowledge of SCD among respondents

Knowledge statements (n=212)	Correct answers only Frequency	Percent
Children with SCD fall ill often	198	93.4
SCD can be passed from parents to children through the blood	191	90.1
SCD can be transmitted by physical contact with an affected person	190	89.6
Early screening and treatment can prolong the life of children with SCD	182	85.8
Children with SCD need to take some routine/daily drugs	178	84.0
For a child to have SCD, both parents must be carriers of SCD gene	177	83.5
SCD can be passed to a child if one of the parents has SCD, and the other is an AA	160	75.5
Children with SCD usually have normal intelligence	153	72.2
Pain in the joints is common among people with SCD	144	67.9
A child can have the trait for SCD if at least one of the parents has the trait	132	62.3
There is a cure for SCD	129	60.8
Over time, children who have the trait for SCD can develop SCD	115	54.2
Children with SCD have an increased risk of stroke	41	19.3
Overall Knowledge of respondents (n=212)		
Good	151	71.2
Poor	61	28.8

Mean score ± SD of 9.4±2.5

Similarly, most of the respondents who knew their genotype 145 (74.0%) had good knowledge of SCD compared to 6 (37.5%) of those who did not know and the finding was statistically significant, p=0.002. Also, most of the respondents who knew their spousal's genotype 118 (78.7%) had good knowledge of SCD compared to 33 (53.2%) of those who did not know and this was statistically significant, p<0.001. Furthermore, most of the respondents 149 (72.3%) with a secondary level of education and above had good knowledge of SCD, however, the association was not statistically significant, p=0.058. Majority 119 (78.8%) of the respondents with good knowledge of SCD had a positive attitude towards its prevention, p<0.001 (Table 6).

Table 4: Attitude of respondents towards SCD prevention

Attitude statements	*SD n (%)	D n (%)	N n (%)	A n (%)	SA n (%)
Everybody should know his/her genotype before marriage	2 (0.9)	0(0.0)	8 (3.8)	29 (13.7)	173 (81.6)
Knowing the risk of having a child with SCD should influence the choice of life partner	2 (0.9)	1 (0.5)	19 (9.0)	43 (20.3)	147 (69.3)
Marriage plan should be discontinued if both partners have the traits for SCD	12 (5.7)	6 (2.8)	39 (18.4)	37 (17.5)	118 (55.7)
Knowing the risk of having a child with SCD should change how one plan a pregnancy	5 (2.4)	6 (2.8)	26 (12.3)	40 (18.9)	135 (63.7)
Infants screening for SCD should be made compulsory in Nigeria	3 (1.4)	0(0.0)	14 (6.6)	61 (28.8)	134 (63.2)
Infants 'screening for SCD should be made available at all health centers in Nigeria	4 (1.9)	1 (0.5)	8 (3.8)	21 (9.9)	178 (84.0)
Infants diagnosed of SCD should be isolated from other children	130 (61.3)	40 (18.9)	25 (11.8)	7 (3.3)	10 (4.7)
Early diagnosis and commencement of treatment is a way of preventing complications of SCD	0 (0.0)	3 (1.4)	13 (6.1)	24 (11.3)	172 (81.1)
Infants diagnosed of SCD should be registered at SCD clinic immediately for management.	1 (0.5)	1 (0.5)	11 (5.2)	17 (8.0)	182 (85.8)
My child doesn't need to be screened because I believe my child cannot have the SCD	87 (41.0)	39 (18.4)	70 (33.0)	6 (2.8)	10 (4.7)

*n=212; Median (IQR) =2.00(2.00) *SA-strongly agreed; A-agree; N-neutral; D-disagree; SD- strongly disagree*

DISCUSSION

The age range of the respondents in this study was 18 to 48 years, which represents the reproductive age group for women. A similar study conducted in Ibadan, Nigeria among mothers of infants, reported age range of 18-42 years.[16] Close to three-quarter of the respondents in this study (72.9%) were aware of SCD. This finding is low compared to a study on knowledge of sickle cell disease among parturient mothers in Benin city, Nigeria which reported that 608 (97.7%) were aware of children popularly referred to as "sicklers"[21] and another study on maternal knowledge and attitudes about newborn screening for sickle cell disease in Illinois found that almost all respondents had heard of SCD (96%).[24]

Multiple sources which include health professional, internet, media, friends and family members were the major mode of information among the respondents in this study. This finding is similar to the study

Table 5: Factors influencing respondents' knowledge of SCD

Variables	Knowledge of SCD		Test Statistics/ p-value
	Poor (n=61) n (%)	Good (n= 151) n (%)	
Aware of premarital test			
Yes	39 (23.4)	128 (76.6)	x^2=11.278
No	22 (48.9)	23 (51.1)	p= **0.001**
Knew genotype			
Yes	51 (26.0)	145 (74.0)	x^2=9.605
No	10 (62.5)	6 (37.5)	p= **0.002**
Knew spousal genotype			
Yes	32 (21.3)	118 (78.7)	x^2=13.854
No	29 (46.8)	33 (53.2)	p**<0.001**
Age group (years)			
18-28	27 (33.8)	53 (66.3)	x^2=1.556
29-38	29 (25.7)	84 (74.3)	p= 0.459
39-48	5 (26.3)	14 (73.7)	
Marital status			
Single	1 (33.3)	2 (66.7)	x^2=0.031
Married	60 (28.7)	149 (71.3)	p= 1.000*
Level of Education			
Primary and below	4(66.7)	2 (33.3)	x^2=4.326
Secondary and above	57 (27.7)	149 (72.3)	p= 0.058*
Occupation			
Unemployed	6 (19.4)	25 (80.6)	x^2=1.572
Employed	55 (30.4)	126 (69.6)	p**=** 0.210
ANC Registration			
Yes	60 (28.4)	151 (71.6)	x^2=2.489
No	1 (100.0)	0 (0.0)	p= 0.288*
Age of infants			
< 5 weeks	5(18.5)	22 (81.5)	x^2=1.588
≥ 5 weeks	56 (30.3)	129 (69.7)	p= 0.208

**Fisher's exact p-value*

Table 6: Association between knowledge of and attitude towards SCD

Knowledge of respondents	Attitude of respondents		Test Statistics/ p-value
	Negative (n=64) n (%)	Positive (n=148) n (%)	
Poor	32 (52.5)	29 (47.5)	x^2=20.155
Good	32 (21.2)	119 (78.8)	**p<0.001**

on mother's knowledge of sickle-cell anaemia in Nigeria which reported doctors and nurses were among the main sources of information on SCD.[25] The finding of our study is expected as the respondents were mothers of infants attending PHC centres for routine immunization and might have been educated about SCD by healthcare workers during the ANC visits.

This study found 71.2% of the respondents who were aware of SCD had good knowledge of the disease. Among the knowledge deficiencies identified included the fact that about half of the respondents felt that children who have the trait for SCD can develop the disease over time, while the majority did not know that children with SCD have an increased risk of stroke and quite a large number felt there is a cure for SCD. Similar to the study among mothers of infants in Ibadan, Nigeria which reported that more than 70% of the mothers did not know SCD could cause stroke and fewer than half of the mothers had moderate knowledge of SCD.[16] Another study on maternal knowledge and attitudes about newborn screening for sickle cell disease and cystic fibrosis reported average SCD knowledge score of 66% among the respondents.[24]

The high burden of SCD in sub-Saharan Africa with its attendant high morbidity and mortality among the affected persons raise the need for increased knowledge especially among women of reproductive age who are mothers of infants to reduce the SCD burden.[26] Less than three-quarter of the respondents in this study had good knowledge of SCD and about a quarter did not do premarital Hb genotype test before marriage. This points to a deficit of SCD education and its genetic inheritance among women of childbearing age. The deficit in SCD education may lead to some children being born with SCD because their parents entered into marriage without previous knowledge of their Hb genotype status. Knowledge about SCD before marriage is essential to be able to reduce the prevalence of SCD. Hence, increasing awareness and education of SCD among women of childbearing age is encouraged.

The high level of knowledge found among the respondents in this study in relation to other similar studies in Ibadan and Illinois was not a surprise since almost all the respondents in our study registered and attended antenatal care (ANC) during pregnancy. SCD is one of the topics usually discussed by healthcare workers

during health education sessions in the clinic as an important component of prenatal care which addresses different aspects of pregnancy, delivery, and infant care among pregnant women.[27] Therefore, informal lectures and provision of information and education by healthcare workers to pregnant women during antenatal care visits should be encouraged. Also, most of the respondents in this study had secondary level of education and education is a key factor in decision making for women, hence a higher number of respondents with good knowledge of SCD. Although, there was no statistically significant association between education and knowledge of SCD in this study. This differs from the report of the study in Ibadan, Nigeria which reported better knowledge of SCD among mothers with a higher level of education.[16]

The majority (95.7%) of the respondents in this study agreed that everybody should know his/her genotype before marriage and 90.1% agreed that knowing the risk of having a child with SCD should influence the choice of a life partner. The study in Ibadan, Nigeria found about half of the primary group mothers and some secondary group mothers who reported that knowing their child's risk for SCD would not impact on how they plan a pregnancy.[16] The finding of the present study points to the positive attitude of premarital screening and the benefits of Hb genotype testing as a preventive measure to prevent SCD among the respondents. This finding is similar to that of a study in Ghana which reported that 78.0% of public servants agreed to call off the marriage if they become aware of genetic incompatibility.[28] Generally, this study found a high proportion of respondents with a positive attitude towards SCD prevention. This finding is similar to a study in Benin City, Nigeria (66.9%),[1] but lower compared to a study among undergraduates in Abakaliki, Southeastern, Nigeria (88.4%).[23] A study in Jos, Nigeria reported that 76% of the respondents with negative attitude to SCD prevention,[12] while a study in Nepal reported 51.4% of respondents with a positive attitude,[22] and another study in Saudi Arabia reported 41% positive attitude.[26] The difference in attitude level found could be due to the different study population in the various studies.

The high level of willingness to screen younger infants for SCD among respondents (84.9%) in this study is creditable and could be a step in the right

direction towards the national implementation of neonatal/early infant screening to reduce the burden of SCD in Nigeria. This finding is similar to that of a multi-centre survey of acceptability of newborn screening for SCD in Nigeria (86.0%).[29] Another similar study at a catholic hospital in Benin City, Nigeria, reported 99.7% acceptance.[21] This figure is higher compared to that reported in the study in Ibadan, Nigeria (64.9%).[16]

Awareness of mothers about SCD and their perspectives towards the disease screening have been reported to be significantly associated with willingness to participate in neonatal screening program for SCD.[16] Therefore, the gaps in awareness and knowledge among respondents need to be adequately addressed especially by healthcare workers among women of reproductive age seeking services in PHCs who are caregivers, to increase the uptake of early infant screening for SCD. Creating the awareness of the opportunity of diagnosing SCD in the younger infants and the associated benefits of early detection and management could also stimulate mothers in accepting early infant screening. The importance of government policy formulation to increase uptake of SCD screening by mothers of younger infants cannot be over-emphasized.

This study found that most respondents who were aware of premarital test, most who knew their own genotype and most who knew their spousal's phenotype had good knowledge of SCD prevention and these were all statistically significant. Similarly, majority of respondents who had good knowledge of SCD had positive attitude towards SCD prevention, and the association was statistically significant. Similar reports have been documented by other studies in Nigeria.[11,23]

Limitations of the study: The cross-sectional nature of the study does not allow for causal inferences. Furthermore, data were collected from only one Local Government Area in Lagos State, though representative of an urban LGA but generalization to the entire state cannot be made. However, this study adds to the body of evidence on SCD.

Conclusion: This study found that less than three quarters of the respondents were aware of SCD, had good knowledge and positive attitude towards SCD prevention. However, the majority of the respondents who were aware of SCD showed willingness to screen their infants early for SCD.

There is the need to intensify efforts in creating awareness and education by healthcare workers about SCD among mothers of younger infants attending routine immunization clinics for increased knowledge, attitude and willingness towards early infants screening for SCD. Emphasis should be made on the benefit of early diagnosis of SCD for early detection and management of SCD to prevent complications.

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Conflict of Interest: None

Authors' contributions: EOO was responsible for the concept, study design, literature search, data collection and review, data analysis, drafting and review of the manuscript. TAA was responsible for concept, study design, and critical review of the manuscript. Both authors approved the final manuscript and declares that the manuscript represents honest work.

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