

# AWARENESS AND ACCEPTABILITY OF PREMARITAL SCREENING OF SICKLE CELL DISEASE AMONG UNDERGRADUATE STUDENTS OF THE UNIVERSITY OF BENIN, BENIN CITY, EDO STATE.

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## ABSTRACT

Premarital screening for the diagnosis of Sickle Cell Disease is helpful in the prevention of the condition. It provides information about the health of the individual while assessing their health related reproductive risk.

To evaluate the level of awareness and acceptability of premarital screening for sickle cell disease amongst undergraduate students of the University of Benin, Benin City Nigeria.

This cross-sectional, descriptive study was carried out amongst undergraduate students in the University of Benin, Benin City. A total of 400 respondents were selected using the multistage sampling method. Data was collected using pre-tested, self-administered questionnaire and analysed using SPSS version 16.0.

A total of 400 respondents participated in the study. Awareness of sickle cell disease (98.8%) and genetic screening (78.9%) for sickle cell disease were high among the participants. The level of acceptability of genetic screening for sickle cell disease by participants was high (96.6%).

There was a high level of awareness and acceptability of genetic screening for sickle cell disease amongst undergraduate students of the University of Benin. Health education is still needed to help them make well informed decisions concerning genetic screening for Sickle Cell Disease.

## Introduction

There is a global concern for the impact of haemoglobin disorders, mainly Sickle Cell Disease (SCD) on morbidity and mortality rates particularly in developing countries.<sup>1</sup> Sickle cell disease is an autosomal recessive condition that presents with severe haemolytic disorders caused by the homozygous occurrence of an abnormal S haemoglobin (HbSS). This genetic abnormality is one of the most preventable

autosomal recessive diseases that affect the Black race. The major form of sickle cell disease is HbSS (SCA) which is as a result of the inheritance of mutant haemoglobin genes from both parents.

Methods of preventing genetic diseases include pre-marital screening and genetic counselling, prenatal diagnosis, preconception diagnosis, implantation of normal embryos after in-vitro-fertilization and in-utero therapy using stem cell transplantation.<sup>2</sup> However, prevention of the disease through carrier identification and genetic counselling remains the only realistic approach to reducing the impact of the disease and allow better use of available resources in the low income countries

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**KEYWORD:** Awareness, Acceptability, Genetics Screening, Sickle Cell Disease,

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where the condition is most prevalent.<sup>2</sup> Premarital screening for diagnosis of SCD is helpful in the prevention of at risk-marriages and this will result in a decreased prevalence of the disease<sup>3</sup>. This is because inheritance is a non-modifiable risk factor for SCD.

Medical genetics and counselling are very important tools for premarital screening of SCD, in that unmarried individuals can be provided with adequate and valid information on genetic inheritance of the disease and what it means to be at risk. Premarital screening of Sickle Cell Disease not only provides information about the health and well being of the individual, it is also important in assessing their health-related reproductive risk. It helps people concerned to make important and major life decisions that will benefit family members either now or in the future.

Approximately 5% of the world's population are carriers of a trait gene for Sickle Cell Disease and Thalassaemia.<sup>4</sup> It is estimated that each year over 300,000 babies are born worldwide manifesting severe forms of SCD especially in developing countries like Nigeria.<sup>5</sup>

Sickle-cell disease contributes about 5% of under-five deaths on the African continent with up to 16% in the West African countries<sup>4</sup>. In Nigeria, 24% of the population are carriers of the mutant gene and the prevalence of sickle-cell anaemia is about 20 per 1000 births.<sup>5</sup> This means that in Nigeria alone, about 150 000 children are born annually with sickle-cell anaemia,<sup>4, 5</sup> making Nigeria the world's number one SCD endemic nation<sup>6</sup>. Deaths from Sickle Cell Disease complications occur mostly in children under five years, adolescents and pregnant women.

Tertiary institutions in Nigeria usually comprise mainly of youths who are unmarried and intend to get married and procreate in future. This group of persons are the target population who will benefit from appropriate interventions aimed at preventing and/or controlling Sickle Cell Disease. Thus, there is the need to assess their awareness and acceptability of premarital screening of SCD so as to direct interventions at reducing the reproductive risk of SCD thereby contributing to a decrease in the prevalence of SCD in Nigeria. Some published studies have shown low levels of awareness of SCD among undergraduate students.<sup>7-10</sup> The study was therefore undertaken to assess the level of awareness and acceptability of premarital screening for Sickle Cell Disease amongst undergraduate students of the University of Benin, Benin-City, Nigeria.

#### Methodology

This was a descriptive, cross-sectional study amongst full time degree students in the University of Benin, Benin City, located in Ovia North East Local Government Area of Edo State, Nigeria. The University of Benin was founded on 23<sup>rd</sup> November 1970 by the then Midwestern State Government. The institute achieved full university status in July 1971 when it was recognised by the National Universities Commission and became the University of Benin. The university was taken over by the Federal Government in August 1975 and has a total of 36,500 students.

All male and female undergraduate students who have completed at least their first year were included in the study while the part-time and diploma students were excluded because they are not always available. The standard formula for sample size determination in a cross-sectional

study was used to calculate the sample size. (cochrane)<sup>11</sup> Using a prevalence of 63.6%,<sup>12</sup> a minimum sample size of 356 was calculated, addition of 10% attrition brought the sample size to 392. However, 420 respondents participated in this study out of which 400 completed and returned their questionnaire.

The multistage sampling method was employed in selecting the respondents. In the first stage, six Faculties (Agricultural Sciences, Education, Law, Life Sciences, Pharmacy and Social Sciences) were selected from the 13 Faculties in the University using simple random sampling method. Then two Departments were selected from each of the 6 Faculties by simple random sampling method (balloting); and from these, simple random sampling method was used to select three levels (200, 300 and 400) for those faculties running a four year programme and in addition, 500 level for those running 5 and 6 years programme. Systematic sampling technique was then used to select participants in each level.

Data was collected by means of a pretested, self-administered structured questionnaire which focused on the objectives of the study. Information was sought on socio-demographic characteristics, knowledge of the cause and transmission of SCD as well as their acceptability of pre-marital screening for SCD. Data was analyzed using the Statistical Package for Social Sciences (SPSS) version 16.0 and level of significance was set at p less than 0.05

### .Results

A total of 400 out of 420 eligible undergraduate students completed and returned their questionnaire giving a response rate of 95.2%. The majority of the respondents 253 (63.3%) were in the 20-24

years age group. There were more males 207 (52.0%) than females 193 (48.0%). Christians constituted 381 (95.3%) of the respondents. A higher proportion of the respondents were in 200 Level 130 (32.5%) and in the Faculty of Law 93 (23.2%). Majority of the respondents were single 389 (97.2%). (Table 1)

Table 2 shows the knowledge of sickle cell disease and premarital screening. Three hundred and eighty-three (95.8%) of the respondents were aware of haemoglobin genotype and 395 (98.8%) had heard of Sickle cell disease. Their major sources of information about sickle cell disease include the electronic media 314 (79.5%), workshops/seminars 250 (63.3%), print media 150 (38.0%), lectures 80 (20.3%) and health facilities 66 (16.7%). Of these, 368 (93.2 %) had correct knowledge of genotype that cause sickle cell disease. Three hundred and twelve (78.9%) were aware of premarital screening for sickle cell disease and 300 (96.2%) of them had correct knowledge of what it entailed.

Awareness of sickle cell disease was higher among the respondents in the age group 25-29 years (100.0%). This was followed by the respondents in age group 20-24 years (98.8%) and those 15-19 years (98.5%) and 30-34 years (83.3%),  $\chi^2 = 12.548$  df=3 Fisher's p = 0.080. Slightly more of the male respondents (99.0%) compared to the female respondents (98.4%) were aware of sickle cell disease (99.0%),  $\chi^2 = 0.280$ , df = 1, p = 0.597. Awareness of SCD was highest among those in the Faculties of Law and Agricultural Science 93 (100.0%) and 40 (100.0%), respectively compared with the others, but this finding was not statistically significant ( $\chi^2 = 3.518$  df=5, Fisher's p=0.577). Higher proportion of the married respondents (100.0%)

compared with the single respondents (98.7%) were aware of sickle cell disease,  $\chi^2 = 0.143$ ,  $df = 1$ ,  $p = 0.705$ . (Table 3)

Table 4 shows that correct knowledge of genotype that causes SCD is higher among respondents in the age group 30-34 years (100.0%), followed by the respondents in age group 20-24 years (93.6%) and 25-29 years (93.3%),  $\chi^2 = 1.030$ ,  $df = 3$ , Fisher's  $p = 0.794$ . Correct knowledge of genotype that causes sickle cell disease was higher among the male respondents (94.6%) than the female respondents (91.6%) but this finding was not statistically significant  $\chi^2 = 1.445$ ,  $df = 1$ ,  $p = 0.229$ . Correct knowledge of genotype that causes sickle cell disease was significantly higher among those in the Faculty of Agricultural Science (100.0%) compared with the others,  $\chi^2 = 20.023$ ,  $df = 5$ , Fisher's  $p = 0.004$ . More of the respondents who had correct knowledge of genotype that causes sickle cell disease were married (100.0%),  $\chi^2 = 0.830$ ,  $df = 1$ ,  $p = 0.362$ .

Majority of the respondents in all the age groups were aware of premarital genetic screening for SCD, however, awareness was highest among participants in the age group 25-29 years (82.7%), ( $\chi^2 = 1.128$ ,  $df = 3$ , Fisher's  $p = 0.755$ ). More female respondents (81.6%) were aware of premarital genetic screening compared to the males (76.6%). This finding was not statistically significant ( $\chi^2 = 1.481$ ,  $df = 1$ ,  $p = 0.224$ ). A higher proportion of the respondents in the Faculty of Education were aware of premarital genetic screening (87.3%) compared to those in the other Faculties,  $\chi^2 = 4.915$ ,  $df = 5$ ,  $p = 0.426$ . Majority of the respondents 10 (90.9%) who were aware of premarital genetic screening were married, ( $\chi^2 = 0.969$ ,  $df = 1$ ,  $p = 0.325$ ). (Table 5)

Majority of the respondents 362 (94.2%) had a positive attitude towards premarital screening for sickle cell disease. Acceptability of premarital genetic screening was highest among the respondents in the 30-34 year age group (100). This was followed by the 20-24 years (94.7%), 25-29 years (94.4%) and 15-19 years (92.3%). This finding was not statistically significant ( $\chi^2 = 0.625$ ,  $df = 3$ ,  $p = 0.743$ ). A higher proportion of the male respondents (94.6%) accepted premarital genetic screening more when compared with the female respondents (93.9%). However, this finding was not statistically significant ( $\chi^2 = 0.092$ ,  $df = 1$ ,  $p = 0.466$ ). A higher proportion of the respondents in the Faculty of Agricultural Science (97.5%) premarital accepted genetic screening for sickle cell disease more than those in other Faculties. This finding was not statistically significant ( $\chi^2 = 8.136$ ,  $df = 5$ ,  $p = 0.248$ ). (Table 6) Majority of the respondents reported that their cultural (90.9%) and religious (95.9%) beliefs will not influence their decision to accept premarital genetic screening for sickle cell disease.

Knowledge of respondents' own genotype was significantly higher among the respondents in the age group 15-19 years (90.9%) compared with the other age groups, ( $\chi^2 = 9.871$ ,  $df = 3$ , Fisher's  $p = 0.021$ ). There were more female respondents who knew their genotype (91.2%) compared with males (81.0%), but this finding was not statistically significant ( $\chi^2 = 1.830$ ,  $df = 1$ ,  $p = 0.176$ ). A higher of the respondents in the Faculty of Pharmacy knew their genotype 61 (92.4%) compared with the other Faculties. This finding was not statistically significant ( $\chi^2 = 3.552$ ,  $df = 5$ ,  $p = 0.616$ ). More of the married respondents (90.9%) knew their genotype compared to the singles (88.9%). However,

Table 1: Socio-Demographic Profile of Respondents

<b>Characteristics</b>	<b>Frequency (n= 400)</b>	<b>Percent</b>
<b>Age group (years)</b>		
15 – 19	66	16.5
20 – 24	253	63.3
25 – 29	75	18.7
30 – 34	6	1.5
<b>Sex</b>		
Males	207	52
Females	193	48
<b>Religion</b>		
Christianity	381	95.3
Islam	16	4.0
African traditional religion	2	0.5
Echanker	1	0.2
<b>Marital status</b>		
Single	389	97.2
Married	11	2.8
<b>Level</b>		
200	130	32.5
300	109	27.3
400	91	22.8
500	45	11.2
600	25	6.2
<b>Faculty</b>		
Education	72	18.0
Pharmacy	66	16.5
Life science	72	18.0
Agricultural science	40	10.0
Social science	57	14.3
Law	93	23.2

Table 2; Knowledge of sickle cell disease and premarital screening

<b>Variable</b>	<b>Frequency</b>	<b>Percent</b>
<b>Awareness of sickle cell disease:</b>		
Yes	395	98.8
No	5	1.2
Total	400	100.0
<b>Knowledge of genotype that cause sickle cell disease:</b>		
Correct	368	93.2
Incorrect	27	6.8
Total	395	100.0
<b>Awareness of premarital screening for SCD:</b>		
Yes	312	79.0
No	83	21.0
Total	395	100.0
<b>Knowledge of premarital screening for SCD:</b>		
Correct knowledge	300	96.2
Incorrect knowledge	12	3.8
Total	312	100.0

Table 3; Awareness of SCD by selected socio-demographic characteristics of respondents.

<b>Characteristics</b>	<b>Awareness of SCD</b>		
	<b>Yes (%)</b>	<b>No (%)</b>	<b>p-value</b>
<b>Age-group (years)</b>			
15 – 19	65 (98.5)	1 (1.5)	0.080
20 – 24	250 (98.8)	3 (1.2)	
25 – 29	75 (100.0)	0 (0.0)	
30 – 34	5 (83.3)	1 (16.7)	
<b>Sex</b>			
Male	205 (99.0)	2 (1.0)	0.597
Female	190 (98.4)	3 (1.6)	
<b>Faculty</b>			
Education	71 (98.6)	1 (1.4)	0.577
Pharmacy	64 (97.0)	2 (3.0)	
Life science	71 (98.6)	1 (1.4)	
Agricultural science	40 (100.0)	0 (0.0)	
Social science	56 (98.2)	1 (1.8)	
Law	93 (100.0)	0 (0.0)	
<b>Marital status</b>			
Single	384 (98.7)	5 (1.3)	0.705
Married	11 (100.0)	0 (0.0)	
<b>Total</b>	<b>395 (98.8)</b>	<b>5 (1.2)</b>	

Table 4; Association between socio-demographic characteristics of respondents and knowledge of genotype that causes sickle cell disease.

<b>Characteristics</b>	Good knowledge N (%)	Poor knowledge N (%)	p-value
<b>Age-group (years)</b>			
15 – 19	59 (90.8)	6 (9.2)	0.794
20 – 24	234 (93.6)	16 (6.4)	
25 – 29	70 (93.3)	5 (6.7)	
30 – 34	5 (100.0)	0 (0.0)	
<b>Sex</b>			
Male	194 (94.6)	11 (5.4)	0.229
Female	174 (91.6)	16 (8.4)	
<b>Faculty</b>			
Education	68 (95.8)	3 (4.2)	0.004*
Pharmacy	52 (81.3)	12 (18.7)	
Life science	69 (97.2)	2 (2.8)	
Agricultural science	40 (100.0)	0 (0.0)	
Social science	53 (94.6)	3 (5.4)	
Law	86 (92.5)	7 (7.5)	
<b>Marital status</b>			
Single	357 (93.0)	27(7.0)	0.362
Married	11 (100.0)	0 (0.0)	
<b>Total</b>	368 (93.2)	27 (6.8)	

\*Statistically significant

Table 5; Association between socio-demographic characteristics of respondents and awareness of premarital genetic screening.

Characteristics	Awareness		p-value
	Yes (%)	No (%)	
<b>Age-group (years)</b>			
15 – 19	49 (75.4)	16 (24.6)	0.755
20 – 24	197 (78.8)	53 (21.2)	
25 – 29	62 (82.7)	13 (17.3)	
30 – 34	4 (80.0)	1 (20.0)	
<b>Sex</b>			
Male	157 (76.6)	48 (23.4)	0.224
Female	155 (81.6)	35 (18.4)	
<b>Faculty</b>			
Education	62 (87.3)	9 (12.7)	0.426
Pharmacy	50 (78.1)	14 (21.9)	
Life science	55 (77.5)	16 (22.5)	
Agricultural science	33 (82.5)	7 (17.5)	
Social science	41 (73.2)	15 (26.8)	
Law	71 (76.3)	22 (23.7)	
<b>Marital status</b>			
Single	302 (78.6)	82(21.4)	0.325
Married	10 (90.9)	1 (9.1)	
<b>Total</b>	312 (79.0)	83 (21.0)	

Table 6; Association between acceptability of premarital genetic screening and associated factors.

Characteristics	*Acceptability of premarital genetic screening		p value
	Yes (%) n = 362	No (%) n = 22	
<b>Age</b>			
15 – 19	60 (92.3)	5 (7.7)	0.743
20 – 24	234 (94.7)	13 (5.3)	
25 – 29	67 (94.4)	4 (5.6)	
30 – 34	1 (100.0)	0 (0.0)	
<b>Sex</b>			
Male	193 (94.6)	11 (5.4)	0.466
Female	169 (93.9)	11 (6.1)	
<b>Faculty</b>			
Education	65 (94.2)	4 (5.8)	0.248
Pharmacy	59 (96.7)	2 (3.3)	
Life science	67 (94.4)	4 (5.6)	
Agricultural science	39 (97.5)	1(2.5)	
Social science	43 (86.0)	7 (14.0)	
Law	89 (95.7)	4 (4.3)	
<b>Influence of cultural belief</b>			
Yes	20 (90.9)	2 (9.1)	0.364
No	342 (94.5)	20 (5.5)	
<b>Influence of religious belief</b>			
Yes	235 (95.9)	10 (4.1)	0.055
No	127 (91.4)	12 (8.6)	

\*16 respondents who were not sure were excluded from the analysis.

Table 7; Knowledge of respondents' own genotype by selected socio-demographic characteristics.

Characteristics	Knowledge of own genotype		p-value
	Yes (%)	No (%)	
<b>Age</b>			
15 – 19	60 (90.9)	6 (9.1)	0.021*
20 – 24	225 (88.9)	28 (11.1)	
25 – 29	68 (90.7)	7 (9.3)	
30 – 34	3 (50.0)	3 (50.0)	
<b>Sex</b>			
Male	180 (81.0)	27 (13.0)	0.176
Female	176 (91.2)	17 (8.8)	
<b>Faculty</b>			
Education	61 (84.7)	11 (15.3)	0.616
Pharmacy	61 (92.4)	5 (7.6)	
Life science	65 (90.3)	7 (9.7)	
Agricultural science	34 (85.0)	6 (15.0)	
Social science	50 (87.7)	7 (12.3)	
Law	85 (91.4)	8 (8.6)	
<b>Marital status</b>			
Single	346 (88.9)	43 (11.1)	0.837
Married	10 (90.9)	1 (9.1)	
<b>Total</b>	356 (89.0)	44 (11.0)	

\*Statistically significant

this finding was not statistically significant ( $\chi^2 = 0.042$ ,  $df = 1$ ,  $p = 0.837$ ) (Table 7)

### Discussion

This study revealed that there was a high level of awareness and knowledge of haemoglobin genotype and sickle cell disease among the respondents. This is not surprising since the respondents are an enlightened population and their major sources of information about sickle cell disease as revealed by the study were from the media (print and electronic), workshops/seminars, lectures and health facilities. Similar findings have been reported from studies among undergraduate students in different parts of the country,<sup>12-14</sup> while lower levels have been reported elsewhere.<sup>8, 9</sup> Other reasons for this high level of awareness among the respondents could be the mandatory health screening conducted for newly admitted undergraduate students, where haemoglobin genotype screening is one of the components of the health screening exercise. In addition, the fact that the study population includes the marriage-able age-groups who tend to be more concerned with knowing their own genotype as well as their partner's genotype. Also, the topic maybe embedded in the curriculum of some of the health-related Faculties and the presence of various non-governmental organizations (e.g. the Eki Igbinedion Sickle Cell Foundation) as well as the various programmes related to sickle cell disease in schools and health facilities may account for this high level of awareness.

Expectedly, majority of the respondents knew about premarital screening for sickle cell disease and this may be attributed to various programmes carried out by different organisations in the State to create awareness on the importance of premarital screening for sickle cell disease. This is in

contrast to a similar study in Lagos, where only one third of the respondents were aware of genetic counselling and screening as a tool for preventing sickle cell disease<sup>15</sup> but similar to the findings in a study carried out among students of University of Ibadan, Nigeria.<sup>13</sup>

Majority of the respondents (82.7%) within the age group of 25-29 years were aware of premarital genetic screening for sickle cell disease. This may be because respondents in this age group are closer to making decisions concerning marriage. This is at variance with a study done to determine the level of awareness of genetic counselling in Lagos where only 9.9% of respondents in a similar age group were aware of premarital genetic screening for sickle cell disease<sup>15</sup>.

The very high level of respondents who had positive attitude towards premarital genetic screening as shown by the high level of acceptance can be attributed to the presence of various non-governmental organizations (e.g. the Eki Igbinedion Sickle Cell Foundation and the State owned Sickle Cell Centre in Benin-City where care and support are available for sickle cell disease patients. This trend is commendable and will help make interventions such as health education more feasible. It will also contribute to a reduction in child mortality as desired in the Millenium Development Goal 4.

It is worth noting that majority of the respondents reported that their cultural and religious beliefs will not influence their decision to accept premarital screening for sickle cell disease. This will enable them to make well informed decisions concerning their future. This is at variance with the findings in a study conducted in North-Eastern part of

Nigeria,<sup>16</sup> a predominantly Islamic region, where religion was a factor militating against acceptability of prenatal diagnosis of sickle cell.

This study has revealed a high level of awareness of sickle cell disease and genetic screening for the condition as well as a high level of acceptance for genetic screening for sickle cell disease among undergraduate students of the University of Benin, Benin-City. It is recommended that wide-spread enlightenment programmes to draw people's attention to sickle cell disease and the need for genetic screening for the condition should be carried out by the government. More facilities for premarital genetic screening should be made available and easily accessible nationwide. Efforts by religious organizations (churches and mosques) to encourage intending couples to go for premarital genetic screening of sickle cell disease should be supported by the government. In addition, establishment of sickle cell clubs in tertiary institutions that would address the importance of premarital screening for sickle cell disease should be supported by government and non-governmental agencies.

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