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Research Article

Young People's Knowledge of Sickle Cell Disease and Willingness for Genotype Screening in Ibadan, Nigeria

Adegbite O.A. and John-Akinola Y.O.

Department of Health Promotion and Education, College of Medicine, University of Ibadan

ABSTRACT

Sickle Cell Disease (SCD) is prevalent in Nigeria with 150,000 new cases yearly, owing to poor knowledge, poverty and lack of screening. This study investigated knowledge and willingness to undergo genotype screening among young people who might be contemplating marriage or reproduction during or soon after the National Youth Service Corps (NYSC); the compulsory one-year service for all Nigerian graduates from tertiary institutions. The study was a descriptive cross-sectional design, carried out amongst 355 respondents using a stratified random sampling. Both qualitative and quantitative methods were employed with due ethical considerations and analysis. The age range was between 18 and 30 years, with more female (54.6%) respondents. Almost all (96.3%) of the respondents have heard about SCD. The prevalence of SCD in the families of the respondents was 10.1% and majority (87.0%) have had genotype screening. Many (60.6%) had good knowledge about SCD but less than half (44.5%) could state the difference between genotype and blood group. Statistical associations were recorded between level of knowledge and gender, discipline of study and willingness. Concerted efforts should be geared towards SCD health education and screening using the platform of corps members' during their orientation and weekly community development programmes.

Keywords: *Knowledge, Sickle Cell Disease, Genotype screening, Corps Members*

*Author for correspondence: Email: *zfisayo@yahoo.com;* Tel: *234-8034087648*

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INTRODUCTION

The burden of Sickle Cell Disease (SCD) is enormous with almost 100 million people affected worldwide and approximately 300,000 children born annually with SCD. Majority of SCD births occur in Sub-Saharan Africa with high rates of under-five mortality and more than 50% deaths due to complications of SCD (Sharifu *et al*, 2018). Meaning that people who have it experience short life span compared with healthier general population. Chijioke and Kolo, (2009) established that many of them now survive beyond the fourth decade. Studies have noted the prevalence rate of sickle cell trait in Nigeria, between 20 and 30%, with a suggested annual birth rate of 150,000 babies (Adewoyin *et al*, 2015; Salih, 2019). Approximately 2 to 3% of the total population in Nigerian are affected by SCD and about a quarter of Nigerians are healthy carriers of the abnormal heamoglobin gene (Afolayan and Jolayemi, 2011).

Sickle cell disease also known as Sickle Cell Anaemia (SCA) (Antwi-Baffour *et al*, 2014) is a hereditary blood disorder, which limits the effectiveness of haemoglobin (oxygen carrying pigment of the red blood cell) thereby causing the sickle shaped red blood cells (Alagbe, Susu and Dosunmu, 2013). The several forms of SCD known as heamoglobinopathies (Hb) include, HbSS, HbSC and Hbα and Hbβ+ (Alpha and Beta Thalassaemia). Findings from the studies of Antwi-Baffour *et al* (2014) and Saganuwan (2016) averred that sickling of the red blood can cause either mild or severe complications (Illness) which are sometimes elevated by bacterial, viral and parasitic infections. These illnesses include, gall stones, stroke in children, jaundice, acute chest syndrome, bone crisis (pain episodes), priapism (painful abnormal penile erection), leg ulcers, while abnormal renal function and bone marrow failure are the rare pathological conditions which require early and proper management.

The physical and psycho-social effects of SCD impact the health of carriers, their families and the nation at large, just as in other non-communicable chronic diseases. Ilesanmi (2013) stated that, children who suffer from SCD are often smaller or thinner than their healthy peers and might feel agitated and less intellectually competent because they often miss school and suffer academic challenges. Besides, when children with SCD turn to adolescents, they often suffer low self-esteem, social withdrawal and depression. High-risk pregnancies and anaemia are common occurrences among women with SCD that could complicate the underlying condition of the foetus. Earlier studies corroborated lack of awareness, ignorance, beliefs and myths as the causes of the endemic nature of SCD in Africa (Bazuaye and Olayemi, 2009; Siddiqui *et al*, 2011). The knowledge of the inheritance pattern and healthy practices, like genotype testing, marrying the right genetic

partners, neonatal screening are parts of the benefits of public health education and awareness for the prevention of SCD and enhancement of reproductive health (Omolase, Omolase and Agborubere, 2010).

This study investigated the gap in knowledge of SCD among young people who might be contemplating marriage and reproduction during or soon after the National Youth Service Corps (NYSC); the compulsory one-year service to the nation (NYSC) immediately after completion of tertiary education. This study also assessed their willingness to undergo genotype screening.

MATERIALS AND METHODS

Study Design: The study was a descriptive cross-sectional design. A stratified random sampling technique was adopted for the study.

Study Location: The study setting was based at the headquarters of the National Youth Service Corps (NYSC) in Ibadan, Oyo State, Nigeria. The study setting was purposely selected because it usually hold tangible population of the respondents according to the statistics obtained from NYSC Headquarters.

Data Collection Methods and Procedures: Both qualitative (Focus Group Discussion- FGD) and quantitative (self-administered and semi-structured questionnaire) instruments were used for data collection. There were 574 male and 695 female Corps members who were serving in that area at the time of the survey and 161 male and 194 female (355) Corps members participated. Focus group discussion questions included discussion questions on genetic and sickle cell disease, ideal time to go for genotype screening, factors hindering the adoption of genotype screening and willingness to go for genotype testing. Questionnaires measures included awareness and knowledge of sickle cell disease, attitude and willingness to undergo genotype screening. The questionnaire was pre-tested among another set of corps members in another location with similar characteristics to the study location. Cronbach Alpha technique gave a reliability of 0.70. The data was collected over two weeks. The FGDs involved three heterogeneous groups (female married (6), male single (6), female single (8) but there were no representatives for the married male corpers

Statistical Analysis: The FGDs were analysed thematically and triangulated with the quantitative results. Statistical Package for Social Sciences (SPSS) version 20 was used for quantitative data entry and analysis. Variate, bivariate and multivariate analysis were used for descriptive and inferential statistics at 5% level of significance. The overall sample size (n) was calculated using the formula for cross-sectional study, $N=Z^2pq/d^2$ with a prevalence rate at 30% including 10% of the original sample size to account for attrition or non-response. That is; n = N + (10% N); n = 322.8 + 32.3; n = 355. Each stratum for gender was calculated using the sample size (n), total number of all Corps members (T) and the number for each gender (Male and Female) that is, M/T×n and F/T×n.

Ethical Approval: This was granted by the Ministry of Health, Oyo State Research Ethical Review Committee. Permission was also taken from the Oyo State NYSC headquarters

RESULTS

There were 355 respondents, mean age was 24.41±2.16, age ranges between 18 and 30 years. There were more females (54.6%). Only 28 (7.9%) respondents were married out of whom were four males (2.5%) as seen below in Table 1. Majority (92.1%) of respondents were single and 39.5% of the respondents' discipline was in science/technology (Figure 1).

Table 1:
Socio-demographic characteristics of the respondents (N=355)

Socio-demographic Characteristics	Frequency (n)	Percentage (%)
Age (N=355)		
18-22	62	17.5
23-26	234	65.9
27-30	59	16.6
Mean Age - 24.41±2.163		
Sex (N=355)		
Male	161	45.4
Female	194	54.6
Marital status (n=355)		
Married	28	7.9
Single	327	92.1
Do you have children (n=354) [+]		
Yes	23	6.5
No	331	93.2

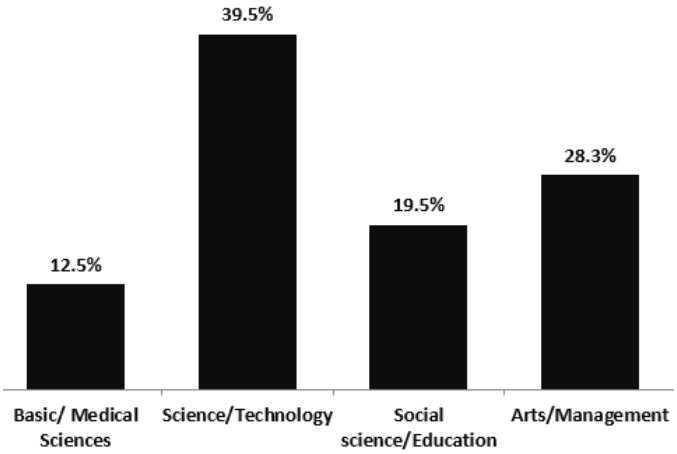

Figure 1:
Discipline of Corps members

Awareness on Sickle Cell Disease: Almost all (96.3%) of the respondents have heard about SCD, including all the FGD participants. About half (50.4%) of the respondents had been aware of SCD since childhood. The main sources of information about SCD were from educational institution (51.0%) and television (42.5%) (Figure 2). Participants in the FGDs also disclosed that school or education institution were their sources of information about SCD. For instance, one of them said he was taught about it in genetics at a biology class. Majority (89.5%) were aware of genotype screening and the prevalence of SCD in the families of the respondents was 10.1%.

Table 2:
Awareness of Corps members on SCD (N= 355)

Awareness of Respondents	Frequency (n)	Percentage (%)
Have heard about SCD (N= 354)		
Yes	342	96.3
No	12	3.4
When did you get to know (N= 347)		
Primary school/childhood	179	50.4
Secondary school/adolescence	151	42.5
University/ recently	17	4.8
Do you know someone who have SCD (N=355)		
Yes	221	62.3
No	134	37.7
Are you aware of genotype screening (N=355)		
Yes	318	89.5
No	37	10.4
Does someone have SCD in your family (N=355)		
Yes	36	10.1
No	319	89.9

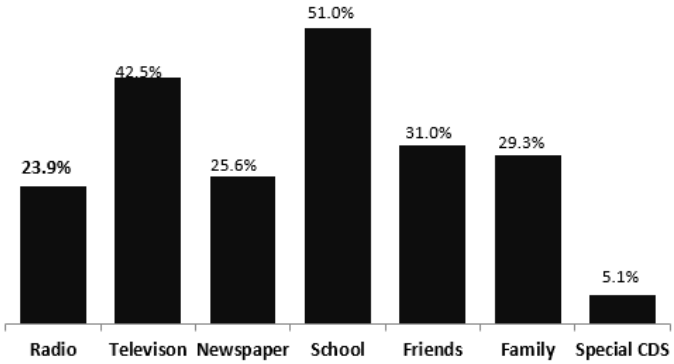

Figure 2:
Sources of information about SCD (N= 355)

Knowledge of Sickle Cell Disease
Level of knowledge was either good (0-7) or bad (8-14). Many (60.6%) of the corps members had good knowledge about SCD. Many respondents (56.3%) correctly identified HbSS as a form of SCD and many (65.1%) reported bone pain and paleness of the eye (55.2%) as signs and symptoms of SCD. These results agreed with the many of the FGD participants across groups with the following opinions:

*"Pale eye colour, kind of yellowish, they have this...They are mostly skinny when you see them"...*MSC5
*"...they used to have this kind of green or yellow ...their eyeball is not normal"...*FMC6

Majority (82.3%) reported that SCD is not infectious while 73.8% respondents indicated that genotype screening can be used to diagnose a person with SCD. Many (61.1%), reported childhood as the ideal time for genotype screening as corroborated by the statement of the FGD discussant below.

"I think there's really no ideal time a child should know his genotype. Like me, i knew my genotype since, so it was not really a problem for me. I think it's very important for an individual to know their genotype. It doesn't have to be when you want to get married, when you want to go to school, to a company (employment purpose), it's very important. Parents should enlighten their children about their genotype, it's very important".....FSC5

Over a quarter (38.3%) of the respondents reported that genotype would not inform them about their blood groups and less than half (44.5%) could state the difference between genotype and blood group. This result corroborated the FGDs, in which about half of the participants across the groups could not describe genotype screening, while a few were also confused about the difference between genotype and blood group as stated below:

"Genotype screening I think is, when, emh, may be, it's what i don't know, well".....FSC1
"Seriously, it's always confusing, I don't know the difference between blood group and genotype, let me just say".....MSC1

Majority (88.2%) reported that if a man and woman who are both carriers of the sickle cell trait get married, they are likely to have a child with the disease. Almost all (92.1%) responded that happiness is a consequence of preventing SCD. Majority (81.4%) reported that SCD is genetic and over half (56.1%) stated that it is hereditary. The Pearson Chi-square indicated no statistical association between the levels of knowledge and age of the respondents, but there was a statistical significant difference for gender and discipline (Table 3).

Results of regression analysis carried out showed the male respondents (55.3%) are about two times more likely to have good knowledge of SCD compared with the females (64.9%) respondents who also had good knowledge of SCD ($P<0.05$, OR = 1.784, 95% CI = 1.13-2.82). Respondents who had basic or medical science background (90.9%) were 9 times more likely to have good knowledge on SCD compared to the fifty-three (51.5%) respondents in Arts or management who also have good knowledge on SCD ($P<0.005$, OR = 9.434, 95% CI = 3.15-28.28) (Table 4)

Table 3:
Association between levels of knowledge and age, gender and discipline

Knowledge of Corps members on SCD					
Variable	**Good knowledge n (%)**	**Poor knowledge n (%)**	**Total (N)**	**X^2**	**p-value**
Age					
18-22	40(64.5)	22(35.5)	62	1.424	0.491
23-26	143(61.1)	91(38.9)	234		
27-30	32(54.2)	27(45.8)	59		
Total	215(60.6)	140(39.4)	355		
Sex					
Male	89(55.3)	72(44.7)	161	3.444	0.040
Female	126(64.9)	68(35.1)	194		
Total	215(60.6)	140(39.4)	355		
Discipline					
Basic/Medical Science	40(90.9)	4(9.1)	44	31.718	<0.001
Science/Technology	79(68.7)	36(31.3)	115		
Social sci./Education	43(46.2)	50(53.8)	93		
Arts/Management	53(51.3)	50(48.5)	103		
Total	215(60.6)	140(39.4)	355		

Table 4:
Logistics Regression Analysis Predicting knowledge

Knowledge of Corps members on SCD					
Variable	**Good Knowledge**	**Poor knowledge**	**Total N= 355**	**OR (95% CI)**	p-value
Gender					
Male	89	72	161	1.784 (1.13 - 2.82)	**0.013**
Female*	126	68	194	1.000	
Discipline					
Basic/Medical Science	40	4	44	9.434 (3.15- 28.29)	**0.000**
Science/Technology	79	36	115	2.070 (1.19 - 3.59)	
Social sci./Education	43	50	93	0.811 (0.46 - 1.42)	**0.010**
Arts/Management*	53	50	103	1.000	0.466

*(reference variable)

Attitude of corps members towards SCD: Almost all (91.5%) reported that SCD is not a disease of the poor and sinners and many (66.5%) agreed that SCD is deadly. Majority (86.5%) disagreed about the notion that people do not make friend with a carrier of the disease and 77.7% were not in support of the statement that people who give birth to SCD children are selfish and evil. Also, majority (86.8%) indicated that a person who has SCD should be relieved of tasks that may be rigorous. However, few (10.4%) of the respondents stated that it is being evil to give birth to children with SCD as corroborated by the opinion of a female unmarried discussant in the FGD below.

> *"No, I can't, cos, if i have a child that is SS, that's wickedness, i think, am being evil. Cos I count parents that give birth to SS as evil, cos at the end of the day, children cannot even do what they want in life, most of them, only few of them live long. Most of them die at their young ages, early stages in life"* FSC5

Furthermore, majority (94.6%) disagreed that men do not need to do genotype screening. Although more males (3.7%) than females (1.5%) agreed with the statement, the differences were not significant. The opinion of at least one discussant from each group in the FGD was in agreement with the gender report.

> *"I think a woman, women are more conscious about it, men are more relaxed, so..."*MSC2
>
> *"It's relative, no, no, no. That cannot be generalized, that question cannot be generalized, I must confess, it's a thing, it's what, it's has to do with choice, if I want it, I want it, if I don't want it, I don't want it...."*MSC1
>
> *"Guys don't like going for the test, they will be like, am perfect, it's you that has the problem. Even when a lady isn't getting to conceive, they will be like, 'lo yera e wo'* meaning *'go and check yourself', that me am okay, it may even be the guy that has the problem...."*FMC3

Majority (93.8%) disagreed that a man and woman who are into intimate relationship should not undergo genotype screening. Majority (85.4%) do not support marriage of carriers of sickle cell traits even if they have the financial capabilities. Additionally, majority (79.4%) of the respondents would not marry someone with SCD by faith. There were slight gender differences in these statements as shown in Table 5. Overall, the level of attitude was good (88.5%)

Table 5: Gender analysis of specific variables (Attitude)

Statement	Agree n (%)	Disagree n(%)	Undecided n(%)
Men do not need to do genotype screening			
Male (n = 159)	6(3.7)	149(92.5)	4(2.5)
Female (n = 193)	3(1.5)	187(96.4)	3(1.5)
A man and a woman who are into intimate relationship do not need genotype screening			
Male (n = 161)	10(6.2)	149(92.5)	2(1.2)
Female (n = 194)	7(3.6)	184(94.8)	3(1.5)
Only women do genotype screening			
Male (n = 161)	3(1.9)	154(95.7)	4(2.5)
Female (n = 194)	5(2.6)	186(95.9)	3(1.5)
A man and a woman who have SCD traits can marry if they have financial capabilities			
Male (n = 161)	19(11.8)	129(80.1)	13(8.1)
Female (n = 194)	11(5.4)	174(89.7)	9(4.6)
With faith I can marry someone who has SCD			
Male (n = 159)	17(10.6)	126(78.3)	16(9.9)
Female (n = 194)	24(12.4)	156(80.4)	14(7.2)

Table 6: Gender analysis of specific variables (willingness)

	Male		Female	
	N	**%**	**N**	**%**
Ever had a genotype screening				
Yes	127	78.9	182	93.8
No	34	21.1	12	6.2
Total	161	100.0	194	100.0
Can do genotype screening				
Yes	123	76.4	159	82.0
No	38	23.6	35	18.0
Total	161	100.0	194	100.0
Can adopt/raise a child with SCD				
Yes	78	48.4	87	44.8
No	83	51.6	107	55.2
Total	161	100.0	194	100.0

Table 7: Association between the level of willingness and gender

	Willingness of Corps member to undergo genotype screening					
Variable **Gender**	Willing n (%)	Non- willing n (%)	Total **N= 355**	X^2	df	p-value
Male	142 (88.2)	19 (11.8)	161	10.208	1	0.001
Female	188 (96.9)	6 (3.1)	194			
Total	330 (93.0)	25 (7.0)	355			

Willingness to undergo genotype screening

Only few (13.0%) respondents had never had genotype screening; more females (93.8%) than males (78.9%) had undergone genotype screening (Table 6). Majority (90.3%) of the respondents reported willingness to undergo genotype screening, with more females (96.9%) than males (88.2%) reporting willingness; there was a statistically significant difference between males and females (p=0.001) (Table 7).

In addition, majority (72.1%) are willing to repeat genotype screening. Almost all (90.4%) have confidence in the test result and 94.9% can recommend the screening to friends and family to create awareness. Majority (83.1%) agreed that genotype screening fosters marital bliss in the future and 91.8% supported genotype screening for infants and young children. However, less than half (46.5%) reported that they can adopt or help raise a child who has SCD.

The FGDs corroborated these findings, where almost all, five (5) married female discussants were not willing to raise or help adopt a child who has SCD; for example:

*"I can't o".....*FSC4

Majority (85.9%) would recommend genotype screening at National Youth Service Corps Camps. Almost all (91.0%) will support the awareness activities and majority (93%) were willing to undergo genotype screening.

There were unanimous opinions and few other contrary views across the three focused group discussants regarding genotype testing as stated below.

> *"Genotype doesn't change, at all!"....*MFC3
> *"Why not, cos am sure of myself, i know am AA, but just for confirmation".....*FSC2
> *"I don't believe mine, i don't believe am AS, so have been looking forward for.....before the month end sha, i will go for ...."* MSC3 (probably referring to a confirmation test)

However, other FGD participants reported; *ignorance, illiteracy, faith, fear and nonchalant or care free attitude, time, lack of access to medical facilities, especially in the village*, yet, another said that, *not knowing the difference between all the blood testing* could be a factor. Below are some of the responses.

> *"You know, some of them used to mistook or mistake, whatever! Genotype for HIV testing, I must confess, some believe that, if i go for my genotype, there's probability that, I will be told my HIV status ..."*MSC1
> *"Cost is a problem, i think so"*.....FMC1

DISCUSSION

The respondents' age range also falls within the reproductive age (15-45years) in Nigeria according to the National Population Commission (2013). The Nigeria Demographic and Health Survey (NPC and ICF, 2014; 2019) reported high fertility among women between age 25 and 29 years and many of the respondents were within this age. Consequently, the age of the respondent might have the potential for increasing children with SCD, if respondents fail to carry out genetic testing and counselling to identify their partner's genetic compatibility, before contemplating marriage or procreation. Nonetheless, few of them were already married with children, but the married male respondents were less compared to the females. This finding corresponds to the study carried out among Corps members in Benin City, Nigeria (Adewoyin, 2015). The minute data of male respondents who were married might be related to the report that Nigerian men do not marry early (Culture Grams 2014).

There was high level of awareness of SCD amongst the corps members. This might be due to as a result of exposure to education and the media as well as interactions with friends. Studies (Faremi, Olatubi and Lawal, 2018; Isah *et al*, 2019) have shown that schools, the media and family members provide opportunities for adolescents and young people to learn about health issues, and to form good behaviours toward healthy living. The report of the prevalence is a reflection of the high and increasing occurrence of SCD in Nigeria, where ten persons in a population of one thousand (10/1000) are carriers of the homozygous defective haemoglobin (Olatona, *et al*, 2012).

Slightly above half of the respondents could identify HbSS as a form of SCD and this outcome confirms another result emerging from this study about the inability of many respondents to differentiate between haemoglobin genotype and blood group. This observation is similar to the findings in earlier studies (Bazuaye and Olayemi, 2009; Durotoye *et al*, 2013; Faremi *et al*, 2018), among young people, which reported that less than a quarter of the respondents reported blood group as genotype. These findings have shown the need for continuous health education as in a study by Olatona *et al* (2012) to address genetic matters such as SCDs, and imperative in bridging the gap in knowledge. Additional highlight of this study was the timing to access genotype screening; 60% of the respondents reported that genotype screening should be done during childhood. Akodu, Diaku–Akinwumi and Njokanma (2013) suggested early diagnosis, in order to prevent complications as well as to give health education to the parents on SCD. However their study reported no specific timing for diagnosis due to the lack of routine screening and varying age at manifestation of the disease in those who are affected.

Although it has been asserted that men pay less attention to their health (Smith, 2006), findings from this study showed that the male corps members were about two times more likely to have good knowledge of SCD compared to the females; although there were more females than males, who had good knowledge of SCD. These findings confirmed the influence of gender on the knowledge of the respondents on SCD. Academic discipline of the respondents aided knowledge and the respondents who had highest knowledge were from the basic or medical science. The overall level of knowledge of the respondents was good. This result compares well with findings of Olubiyi *et al*., (2013) but does not compare favourably with a similar study by Adewoyin, *et al* (2015), where the respondents had fair knowledge.

Many of the respondents did not support marriage of two individuals with SCD. Sickle cell disease is a chronic disease with complications that have contributed to morbidity and mortality in those who have it (Salih, 2019). Hence, the respondents might be afraid of the burden of the disease, as reported by Annie *et al*., (2010). The results show a slight gender difference in attitude with regards to SCD, implying that men might have poor health seeking behaviour (Gough and Robertson, 2010) compared to women. Meanwhile more females than males agreed that they can marry a carrier of SCD by faith, a result that is indicative of religious beliefs (Annie *et al*, 2010).

Although majority of the respondents have had genotype screening, few had not; similar results were reported by Olatona *et al*., (2012), Olubiyi *et al*., (2013) in which the respondents either do not know their status or have not had genotype screening. This highlights the importance of harnessing the national youth service programme as a platform where a large group of young people can access genotype screening and a rationale for genetic screening centres to aid the testing. Findings showed a relationship between gender and willingness to undergo genotype screening. This result compares with the study of Oludare and Ogili, (2013), in which gender was associated with health seeking behaviours, such as genetic counselling.

In conclusion, the study shows that continuous health education and advocacy can help to gradually reduce the prevalence of SCD in Nigeria, and the national youth service

corps programme provides a favourable platform to educate young people on their health as well as a means to offer genotype screening.

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