International Archives of Medicine and Medical Sciences

Original Article

Print ISSN: 2705-1404; Online ISSN: 2705-1412
DOI: https://doi.org/10.33515/iamms/2019.029/29

Knowledge of sickle cell disease; attitude and practice regarding premarital genotype counseling and testing among the lecturers of Usmanu Danfodiyo University, Sokoto, Nigeria

Balarabe A. Isah*, Abdulaziz M. Danmadami, Malami M. Bello, Garu Njidda, Kasim B. Ibrahim, Stephen D. Magode

Department of Community Health, Usmanu Danfodiyo University, Sokoto, Nigeria

ABSTRACT

Background: Sickle cell disease (SCD) is one of the commonest monogenetic diseases in Nigeria. Knowledge of the disease and uptake of premarital haemoglobin genotyping has substantial influence on the choice of spouse and control of the disease. **Aim:** This study aimed to assess the knowledge of sickle cell disease; attitude and practice regarding premarital genotype counseling and testing among the lecturers of Usmanu Danfodiyo University, Sokoto, Nigeria. **Materials and Methods:** This was a descriptive cross-sectional study among 269 permanent lecturers (selected by multi-stage sampling technique) of Usmanu Danfodiyo University, Sokoto, Nigeria. A pre-designed, pretested self-administered questionnaire was used to obtain data on the research variables. Data were analyzed using the IBM SPSS version 23 statistical computer software package. **Results**: Almost all, 267 (99.3%) of the 269 respondents were aware of sickle cell disease, and most of them (89.2%) had good knowledge of the disease. Majority of respondents knew what premarital hemoglobin genotype testing is (62.5%), when it should be done (100%), and its benefits, including preventing having a child with sickle cell disease (69.1%). Only a fifth and below of respondents showed negative attitude towards the test. Although, majority of respondents (70.3%) were willing to do the test, less than half of them (47.6%) did the test before getting married. **Conclusion:** Despite good knowledge of sickle cell disease and positive attitude to premarital haemoglobin counseling and testing, uptake of the test was low among the lecturers of Usmanu Danfodiyo University, Sokoto, Nigeria. The management of the university should organize periodic haemoglobin genotype screening programs for the members of the university community.

Keywords: Knowledge, attitude, sickle cell disease, premarital screening

INTRODUCTION

Sickle cell disease (SCD) is a genetic disorder caused by an abnormality in the synthesis of the β-globin chain of the hemoglobin molecule. This abnormality results from the substitution of a polar amino acid, glutamic acid, with a non-polar amino acid, valine, in the 6th position of chromosome eleven. Under low oxygen tension, this single point mutation causes red blood cells to assume the shape of a "sickle" and leads to complications including tissue infarction, anemia, priapism, splenomegaly and reduced dietary intake (Stuart and Nagel, 2004; Serjeant 2001; Nagel and Platt, 2001). About 5% of the world's population carries the gene responsible for haemoglobinopathies and each year about 300,000 infants are born with major haemoglobin disorders including more than 200,000 cases of sickle cell anemia in Africa (WHO, 2006). About 25% of Africans are carriers of the abnormal hemoglobin gene, and Nigeria has the highest population of people with sickle cell disease, and has been estimated to have at least 150,000 newborns born with SCD annually (DeBaun and Galadanci, 2019; WHO, 2019). Choosing a partner is sometimes very challenging as it is necessary to balance the purpose of marriage including companionship, support and procreation with the enormous responsibilities associated with it in terms of time and financial commitments, and the situation of things could become terribly bad in the event of having a child or children with a chronic medical condition like sickle cell disease (Boadu and Addoah, 2018; Brake, 2016). Also, evidence from literature has shown that

***Corresponding Author:** Dr. Balarabe A. Isah, Department of Community Health, Usmanu Danfodiyo University, Sokoto, Nigeria.

E-mail: drbalaargungu@gmail.com

Received: 10-11-2019 Revised: 17-12-2019 Published: 23-12-2019

more than half of married couples enter into marriage unaware of their haemoglobin genotypes, and this is believed to account for the reported 2% annual births of children with SCD in most developing countries (Boadu and Addoah, 2018). Reports from the parents of affected children showed that they had entered into marriage without prior knowledge of their sickling status, and without knowing the symptoms of the disease in the newborn (CDC, 2019). While the current advances in diagnoses and the frequent campaigns through the mass media and by healthcare professionals are expected to increase people's knowledge about premarital counseling and sickle cell disease screening with a view to reduce the prevalence of high risk marriages, sickle cell disease is still very common in our society in spite of these efforts (Jiya et al., 2017; Amede, 2015; Akodu et al, 2013).

In addition, non-adherence to premarital sickle cell screening can lead to the birth of a child with the disorder, separation and divorce among parents, frequently going in and out of the hospital, and increased infant mortality and morbidity; and if intending couples are favorably disposed to doing premarital screening, it will help in the detection of carriers of sickle cell trait and prevent the birth of affected children. It is therefore worrisome that even though premarital sickle cell screening programs has a high potential to reduce the incidence of SCD in the population by preventing marriages among high risk couples, many people do not adhere to it (Udunbun, 2008; Acharya, 2009; Moronkola and Fadairo, 2006-2007). The school is an agent of change, and lecturers cannot promote prevention of sickle cell disease among their students (who are still young, predominantly not married, and most likely to benefit from such an intervention) if they lack knowledge of it, or have negative attitude towards it, or do not practice it. This study was conducted to assess the knowledge of sickle cell disease; attitude and practice regarding premarital genotype counseling and testing among the lecturers of Usmanu Danfodiyo University Sokoto, Nigeria.

MATERIALS AND METHODS

Study Design, Population and Area

This was a descriptive cross-sectional study among the lecturers of Usmanu Danfodiyo University, Sokoto, North-Western Nigeria. All the permanent lecturers who were present at the time of the survey and consented to participate were considered eligible for enrolment into the study, while visiting lecturers and those in the College of Health Sciences, Faculty of Veterinary Medicine, and Sciences were excluded.

Sample Size Estimation and Sampling Technique

The sample size was statistically estimated at 269 and the eligible participants were selected by multistage sampling technique. At the first stage, a list of all the faculties in the university was obtained and the selection of the faculties to be used for the study was done by simple random sampling using the balloting procedure. At the second stage, a list of the departments in the selected faculties was obtained and selection of the departments to be used for the study was done by simple random sampling technique using the balloting procedure. At the third stage, the study participants were selected in the selected departments by systematic sampling technique using the staff list in the respective departments to constitute the sampling frame. Proportionate allocation was done in the selection of participants from the respective departments based on their staff strength.

Data Collection and Analysis

A set of pretested semi-structured self-administered questionnaire was used to obtain information on the participants' socio-demographic characteristics, knowledge of sickle cell disease; and attitude and practice regarding premarital genotype counseling and testing. It was reviewed by senior researchers in the Department of Community Health, Usmanu Danfodiyo University, Sokoto, Nigeria, to ascertain content validity. The questionnaire was pretested on 25 lecturers working at Sokoto State University, Sokoto, Nigeria, and the necessary corrections were done based on the observations that were made during the pretesting. Data were analyzed using the IBM SPSS version 23 computer statistical software package. Respondents' knowledge of sickle cell disease was scored and graded on a 12-point scale. One point was awarded for a correct response, while a wrong response or a non-response received no points. Those that scored $\geq 50\%$ of the maximum score were graded as having good knowledge, while those that scored $< 50\%$ of the maximum score were graded as having poor knowledge. The categorical variables were summarized using frequencies and percentages.

Ethical Consideration

Ethical approval was obtained from the Ethics and Medical Education Committee of Usmanu Danfodiyo University, Sokoto, Nigeria. Permission to conduct the study was obtained from the management of the university, and informed written consent was obtained from the study participants prior to questionnaire administration.

RESULTS

Socio-demographic characteristics of respondents

All the 269 questionnaires administered were adequately completed and found suitable for analysis, giving a response rate of 100%. Larger proportions 103 (38.9%) and 79 (29.4%) of the 269 respondents were aged 45-64 and 35-44 years respectively. Most of the respondents were males (96.3%), married (88.8%), and practiced Islam as religion (87.7%). Close to half of respondents (44.2%) reported family history of sickle cell disease (Table 1).

Table 1: Socio-demographic characteristics of respondents

Variables	Frequency (%), n = 269
Age group (years)	
25-34	39 (14.5)
35-44	79 (29.4)
45-64	103 (38.3)
55-60	47 (17.8)
`Sex	
Male	259 (96.3)
Female	10 (3.7)
Marital status	
Single	27 (10.0)
Married	239 (88.8)
Separated	1 (0.4)
Widowed	2 (0.7)
Religion	
Islam	236 (87.7)
Christianity	33 (12.3)
Faculty	
Education	52 (19.3)
Sciences	70 (26.0)
FAIS	55 (20.4)
Agric. Sciences	29 (10.8)
Management Sciences	57 (21.2)
Law	6 (2.2)
Family history of sickle cell disease	
Yes	119 (44.2)
No	150 (55.8)

FAIS: Faculty of Arts and Islamic Studies

Knowledge of sickle cell disease among respondents

Almost all, 267 (99.3%) of the 269 respondents had heard of sickle cell disease, and the most common sources of information cited were schools (44.6%) and family members (40.5%). Most 248 (92.2%) of the 269 respondents had good knowledge of sickle cell disease. Most of them (88.1%) knew AA as normal hemoglobin (Hb) genotype, and that sickle cell disease can be inherited if both parents have SS or AS Hb genotype. Whereas, only 2 (0.7%) of the 269 respondents knew that SCD can be cured through bone marrow transplant, majority of them (53.2%) knew that it can be prevented through premarital genotype counseling and testing (Table 2).

Respondents' knowledge, attitude and practice regarding premarital sickle cell disease screening

While all the respondents (100%) knew that premarital sickle cell disease screening should be done during courtship or just before marriage, about two-thirds of them knew that the test is done to detect sickle cell disorder (62.5%), and doing the test helps to prevent having a child with sickle cell disease (69.1%). Only about a fifth and below showed negative attitudes to the test, such as believing that the test could bring conflicts between couples (20.4%), or increase the chances of not getting married (15.6%). Majority of respondents (70.3%) showed interest in doing the test., but less than half of them (46.5%) were willing to reveal the result of the test to their intending spouses. Whereas, majority of respondents (58.7%) had done hemoglobin genotype testing (58.7%) and reported being AA (58.9%), only about a third of respondents (33.1%) did sickle cell disease screening test before getting married (Table 3).

DISCUSSION

This study assessed the knowledge of sickle cell disease; attitude and practice regarding premarital genotype counseling and testing among the lecturers of Usmanu Danfodiyo University, Sokoto, Nigeria. Almost all the respondents (99.3%) were aware of sickle cell disease, and most of them (89.2%) had good knowledge of the disease.

This finding is in contrast to the finding in a study conducted among youth corps members in Benin City, Nigeria, in which only 17.8% of the respondents had good knowledge of SCD despite a high level (98.4%) of awareness (Adewoyin et al., 2015). In our study most of the respondents (95.5%) agreed that SCD is an inherited disease while about half (53.2%) knew that it can be prevented through screening before marriage. The good knowledge of SCD among the respondents may be due to their high levels of educational attainments as the minimum level of education of the respondents was university degree. This finding is similar to the finding in a study conducted among secondary school students in Jos, Nigeria in which 83.2% of respondents were aware of SCD, 80.0% knew that SCD is an inherited disorder, 83.0% knew that it affects the red blood cells, while only about half of respondents (54%) knew that the disease can only be diagnosed through blood test (Olarewaju et al., 2013).

Less than half (44.6%) of the respondents in this study obtained information about SCD at the schools, this is in contrast to the finding in a study among students of School of Nursing, Sokoto, Nigeria, in which most of the respondents (83.6%) obtained information about SCD at the schools (Isah et al., 2016). This could be due to the fact that whereas this study was conducted among

Table 2: Knowledge of sickle cell disease among respondents

Variables	Frequency (%), n = 269
Ever heard of sickle cell disease	
Yes	267 (99.3)
No	2 (0.7)
Source of information	
School	120 (44.6)
Friend	39 (14.5)
Media	68 (25.3)
Family	109 (40.5)
Transmission of sickle cell disease	
Knew AA as normal haemoglobin (Hb) genotype	237 (88.1)
Knew that SCD is caused by abnormal haemoglobin	112 (41.6)
Knew that SCD is an inherited disease	257 (95.5)
Knew that SCD can be inherited if both parents have SS or AS Hb genotypes	
Knew that SCD cannot be transmitted through blood transfusion	204 (75.8)
Knew that sickle cell disease can cause, or is associated with:	
High morbidity and mortality	101 (37.5)
Frequent illness / hospitalization	37 (13.8)
Huge financial burden	38 (14.1)
Marital discord	8 (3.0)
Knew that SCD can be diagnosed through laboratory test (Hb genotype)	248 (92.2%)
Knew that SCD can be prevented through:	
Premarital hemoglobin genotype counseling and testing	143 (53.2)
Marrying someone with AA genotype	47 (17.5)
Preventing marriage between two individuals with AS genotype	15 (5.6)
Knowledge grading	
Good	240 (89.2)
Poor	29 (10.8)

Table 3: Respondents' knowledge, attitude and practice regarding premarital sickle cell disease screening

Variables	Frequency (%), n = 269
Knowledge of premarital sickle cell disease screening	
Knew that it is a test done before marriage to rule out sickle cell disorder	168 (62.5)
Knew that it should be done during courtship or just before marriage	269 (100)
Knew that it helps to prevent having a child with sickle cell disease	186 (69.1)
Attitude towards premarital sickle cell disease screening	
Believed that doing it will expose their genetic make up to the public	29 (10.8)
Believed that it is against their cultural / religious belief	18 (6.7)
Believed that the test could bring conflicts between couples	55 (20.4)
Believed that the test could increase the chances of not getting married	42 (15.6)
Would like to do the test	180 (70.3)
Would reveal the result of the test to intending spouse	125 (46.5)
Would still prefer to marry the intending spouse irrespective of the test result	54 (20.1)
Practice of hemoglobin genotype testing	
Ever done hemoglobin genotype screening before	158 (58.7)
Hemoglobin genotype (n = 158):	
AA	93 (58.9)
AS	63 (39.9)
Has forgotten	2 (1.3)
Practice of premarital haemoglobin genotype counseling and testing	
Did the test before marriage	89 (33.1)

teachers from non-medical disciplines, the latter study was conducted among nursing students whose curriculum include epidemiology and control of endemic diseases including sickle cell disease. Less than a fifth of the respondents in this study showed negative attitude towards premarital sickle cell screening, this finding is in contrast to the finding in a study conducted on attitude of genetic screening among secondary school students in Jos, where about 38% of the students still had negative attitude towards premarital counseling and testing (Olanrewaju etal., 2013). This implies that there is hope that the uptake of premarital sickle cell screening can improve if they encourage both their students and relatives at home on the importance and the need to go for premarital screening as a means of reducing the incidence of the disease in the study area.

Majority (70.3%) of the respondents in this study were willing to do premarital SCD screening to know their haemoglobin genotype before marriage, this could be related to the high proportion of respondents (69.1%) that knew that undergoing the test helps to prevent having a child with sickle cell disease; and it is reassuring considering the fact that the more people are willing to go for the screening, the less the chance of transmitting the disease. This finding is similar to the finding in a study among students of a tertiary educational institution in South-Western Nigeria in which majority of respondents (73.4%) affirmed that genotype screening for intending couples will help prevent unnecessary worries about giving birth to a child with SCD, and were willing to confirm their haemoglobin genotype in a bid to take informed decision about marriage (Faremi et al., 2018).

Uptake of haemoglobin genotype testing was sub-optimal (58.7%), while uptake of premarital genotype counseling and testing was poor (10.4%) among the respondents in this study. These findings are disturbing in view of the high educational attainments of the respondents; and the high levels of awareness of the disease, its adverse health and social effects, and the effectiveness premarital haemoglobin genotype testing in preventing giving birth to a child with sickle cell disease among them. Of serious concern is the relatively high prevalence of HbAS genotype (39.9%) among the respondents that have ever done haemoglobin genotype testing in view of the poor uptake of genotype counseling and screening by them, as these findings imply wide gaps between knowledge and practice. Similar to the findings in this study, a study among pre-marital couples in Port Harcourt, Nigeria, reported that less than two-thirds of respondents (58.9%) had done premarital genotype testing, and about a fifth of them (21.9%) had HbAS genotype (Faremi et al., 2018). Also, a study among secondary school students in Jos, Nigeria, reported that only 59.0% of respondents knew their genotype, and of these, 11.1% had HbAS genotype. These findings underscore the need for the management of the tertiary institutions in Nigeria to promote uptake of premarital haemoglobin genotype counseling and testing among their staff and students by organizing periodic haemoglobin screening programs in their respective institutions in order to reduce the high burden of sickle cell disease in the country.

CONCLUSION

Despite good knowledge of sickle cell disease and positive attitude to premarital haemoglobin counseling and testing, uptake of the test was low among the lecturers of Usmanu Danfodiyo University, Sokoto, Nigeria. The management of the university should organize periodic haemoglobin genotype screening programs for the members of the university community.

Acknowledgements

The authors appreciate the management of Usmanu Danfodiyo University, Sokoto (UDUS), Nigeria, for giving the permission to conduct the study. They appreciate the leadership of UDUS branch of Academic Staff Union of Universities (ASUU) for facilitating the participation of their members. They also appreciate the deans of the faculties and the heads of the departments that were selected for the study, and all the lecturers that participated in the study for their cooperation.

Source of support

Nil.

Conflict of interest

None declared.

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How to cite this article: Isah BA, Danmadami AM, Bello MM, Njidda G, Ibrahim KB, Magode SD (2019). Knowledge of sickle cell disease; attitude and practice regarding premarital genotype counseling and testing among the lecturers of Usmanu Danfodiyo University, Sokoto, Nigeria. Int. Arch. Med. Med. Sci. 1(3): 14-19.