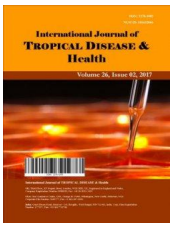

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Assessment of Knowledge of Sickle Cell Disease and Premarital Genotyping among Youths in Mairi Ward, Jere Local Government of Borno State North-Eastern Nigeria

Nelson Lola[1], Robert Teryila Kever[1*], Markus Uba[1], Sambo Danlami[2], Salamatu Ishaku[3], Mamma Jonah Tsado[4] and Abbas Umar Ibrahim[5]

[1]Department of Nursing Science, College of Medical Sciences, University of Maiduguri, Borno State, Nigeria.
[2]College of Nursing Jos, Plateau State, Nigeria.
[3]Kaduna State College of Nursing and Midwifery, Kafanchan, Nigeria.
[4]College of Nursing Sciences Bida, Niger State, Nigeria.
[5]School of Nursing and Midwifery Lafia, Nasarawa State, Nigeria.

Authors' contributions

This work was carried out in collaboration between all authors. Authors NL and RTK designed the study and wrote the protocol. Authors MU, SI and SD managed the literature search and wrote the first draft of the manuscript. Authors RTK, MJT and AUI performed the statistical analysis. All authors read and approved the final manuscript

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ABSTRACT

Knowledge on premarital genotyping and sickle cell disease among youths could constitute an important variable that influences their choice of spouse. The study assessed the knowledge on premarital genotyping and Sickle Cell Disease among youths in Mairi Ward, Jere Local Government area of Borno State, North-eastern Nigeria.

**Corresponding author: Email: robertkever72@gmail.com;*

A descriptive cross-sectional design was adopted for the study and 350 youths were selected using available non-probability sampling. The participants voluntarily completed a self- administered questionnaire. The questionnaire was structured and validated (Cronbach-Alpha of 0.85). Data were analysed using the statistical package for social science (SPSS) version 21.
The age bracket of participants was 14-35 years, modal range 26-30 years. The majority (95.6%) of the respondents had general awareness about the existence of SCD and pre-marital genotyping through internet, but comprehensive knowledge about the mode of diagnosis, signs and symptoms as well as preventive measures was low. Knowledge of Pre-Marital genotype Testing and SCD was significantly related to marital status and level of education. The study recommends that, if sickle cell disease control strategies must yield any significant results, there is need to intensify the use of mass media in imparting knowledge of SCD and premarital genotyping in the community since very many of the respondents knew sickle cell disease through mass media.

Keywords: Premarital; genotyping; knowledge; sickle cell disease.

1. INTRODUCTION

Sickle cell disease is a genetically inherited blood disorder that causes red blood cells to become a sticky and sickle shape and is responsible for considerable morbidity and mortality [1]. It is found in many parts of the world, particularly in people whose ancestors come from sub-Saharan Africa, India, Saudi-Arabia and Mediterranean country [2]. Over 300,000 babies are born worldwide with Sickle Cell Disease (SCD) mostly in low and middle-income countries, with the majority of these births in Africa [3]. Sickle cell disease is the commonest genetic disorder in Nigeria, about 24% of the populations are carriers of the mutant gene and its prevalence (at birth) is 20 per 1000 births; i.e. 150,000 children are born with sickle cell disease genotype annually in Nigeria alone [2].

The main pathology in SCD is the trapping of sickle-shaped red cells in small blood vessels resulting in blockages. This typically manifests as bone pain, which is one of the most distressing symptoms in people affected by SCD [4]. The same process can result in other complications including, strokes, bone necrosis, and kidney failure. Some affected persons also have potentially stigmatising signs including jaundice, leg ulcers, and short stature. This is often precipitated by factors such as infection, dehydration, exhaustion and a change in temperature e.t.c which may often warrant hospitalization of the clients. The disease runs a chronic course but is now curable using gene therapy and bone marrow transplantation. In Africa however, the overall treatment of patients is still poor and, in some places, inadequate [5,6].

Sickle Cell Trait (SCT) occurs in people with one sickle cell gene and one normal gene and such people can transfer the disease to their offspring though they do not have any clinical manifestation of the illness. Children born to two parents with sickle cell trait have a 25% chance of having SCD and a 50% chance of having SCT. Therefore, it is highly important for people of reproductive age group to understand the genetics of SCD, know their own blood type, and if they carry the S gene choose in advance of selecting partners for future marriages.

Therefore for Africans and in particular Nigerians where almost all marriages are contracted and consummated for the purpose of childbearing, an essential approach for controlling the disease is preventive; and this depends upon education, the detection of carriers, pre-marital genetic counselling, prenatal screening for foetal genotype done in couples who are both carriers and newborn screening for sickle cell genotype.

Premarital genotype screening presents an opportunity for individuals to become informed about their genetic predisposition to diseases and for couples to be aware of the possible genetic characteristics of their unborn children. Hence, if one holds the view that one of the reasons for marriage is procreation, then worrying about genetic compatibility and avoiding genetic inheritance of grave consequence becomes something to strongly consider. The most common genetic diseases include sickle cell disease, cystic fibrosis and Tay-Sach's disease of which sickle cell disease is the commonest [7]. Premarital screening consists of a comprehensive group of test, especially for those who are planning to get married.

There is, however, a palpable lack of information and education about the disorder which, with the increasing prevalence, has encouraged the growth of myths, misinformation, inappropriate treatment, frustration and stigmatization [8]. With the increasing prevalence of genetic diseases in developing countries e.g. Nigeria, there is the need to assess the level of knowledge of premarital genotype screening -a way of reducing and/or preventing the occurrence of genetic diseases especially sickle cell disease.

2. METHODS AND MATERIALS

A total of 350 youths within the age bracket of 14 and 35 years participated voluntarily in the study. The study was a descriptive cross-sectional study conducted in a semi-urban community among youths in Mairi ward, Jere local government area of Borno State. Jere local government is located between latitude 11 degree east and latitude 10 degree east, covering an area of approximately 7850 square kilometres. It falls within Sahel savannah zone having a flat topography with the landscape dotted with trees and thorn bushes. Most rainfall (rainy season) is seen in April, May and August with the area experiencing little rainfall per annum. The average annual rainfall ranges from 60-95 mm, with temperature ranging from 30-45 degree Celsius which makes the area conducive for mosquitoes to breed.

Questionnaire was designed and validated to elicit information on socio-demographic characteristics and knowledge of the respondents on premarital genotyping and sickle cell disease. The opinion of respondents on the prospects of married individuals with sickle cell traits having children with sickle cell disease was also sought. This semi-structured questionnaire was pre-tested among youths in Maimusari Ward, a settlement outside the study area and necessary corrections were done thereafter.

Ethical clearance to conduct this study was obtained from the University of Maiduguri Teaching Hospital ethical review committee. Informed consent was obtained from each of the participating youth after explaining the objectives of the study to them individually. Copies of the questionnaire were self- administered to the respondents, however, to avoid confusion; certain terminologies were explained to respondents during the data collection processes. Age, gender, religious affiliation, marital status, occupation and educational status of the respondents were considered independent variables that could probably influence the level of knowledge of premarital genotype testing among youths. Each correct answer given by the respondent to any of seven categorical questions about premarital genotype testing was scored one point, while an incorrect or no response was scored zero. The points were summed up; a maximum score was seven while the minimum score was zero. These final score points were considered the "premarital genotype testing and SCD knowledge score". Score points were converted to percentages and re-categorized as: poor knowledge (0- < 50%), average knowledge (≥50% to < 75%) and good knowledge (> 75%). Data through the questionnaire was checked for errors and entered into the computer for analysis. SPSS version 21 was used to analyse the data. Descriptive statistics were presented in tables; simple frequency and percentages were calculated while relationships between categorical variables of interest were determined using the Chi-square test at a significance level of less than or equal to 0.05.

3. RESULTS

A total of 350 valid copies of the questionnaire were analysed. The respondent's age ranged between 14 - 35 years with a mean age 28.5 ±1.09 years and a modal age group 26-30 years. There were more males 240(68.6%) than females110 (31.4%). Majority of the respondents were Muslim 230(65.7%) while the remaining 120 (34.3%) were Christians. In terms of occupational status, 135(38.6%) respondents were business people, 95(27.1%) were students and 65(18.6%) were civil servants. Concerning marital status, the majority of the respondents 220(62.8%) were single, 65 (18.6%) were married, 15 (4.3%) were divorcees, and the remaining 50 (14.3%) were widowed. Most of the respondents185 (52.9%) had attained secondary school education. Regarding tribal affiliations, 155 (44.3%) of the respondents were mostly Kanuri, 55 (15.7%) were Hausa, 65(18.6%) were Shuwa, and the remaining 75 (21.4%) were from other minor settlers.

Table 2 shows that the majority of the respondents 335 (95.6%) were aware of sickle cell disease while the remaining 15 (4.4%) were not aware. Major source of information include health Internet 128 (36.5%), health professional 50 (11.7%), friend 48 (13.8%) and family 64 (18.2%). Majority of the respondents 281 (80.1%) knew the disease as an inherited disorder, and

175 (50.0%) responded that they knew someone having the disease. In terms of signs and symptoms, 194 (55.5%) of the participants correctly responded that frequent illnesses are associated with individuals with SCD while 156 (45.5%) do not know that frequent illness is a common identity of individuals with the disease.

Concerning mode of diagnosis, only five (1.4%) knew that the disease can only be diagnosed with blood test, 194 (55.5%) mentioned urine test while 151 (43.1%) had no idea of mode of diagnosis. When respondents were asked about chances of each child carrying sickle cell diseases when one of the parents has sickle cell trait, only 74 (21.2%) knew correctly that none of the children will carry SCD. In response to knowledge on preventive measures of SCD, only 140 (40.0%) of the respondents mentioned that genetic counselling is a preventive measure, 210 (60.0%) were unaware that the occurrence of the disease can be prevented through genetic counselling.

Table 1. Respondents' socio-demographic information (n=350)

Item	Frequency	Percentage
Age Range		
• 16-20years	55	15.7%
• 21-25years	75	21.4%
• 26-30years	185	52.9%
• 31 and above	35	10%
Religion		
• Islam	230	65.7%
• Christianity	120	34.3%
• Others	0	0%
Occupational status		
• Civil servant	65	18.6%
• Business	135	38.6%
• Students	95	27.1%
• Others	55	15.7%
Sex		
• Male	240	68.6%
• Female	110	31.4%
Marital status		
• Single	220	62.8%
• Married	65	18.6%
• Divorce	15	4.3%
• Widow	50	14.3%
Educational status		
• Primary	35	10%
• Secondary	185	52.9%
• Tertiary	80	22.9%
• Others	50	14.2%
Tribe		
• Kanuri	155	44.3%
• Hausa	55	15.7%
• Shuwa	65	18.6%
• Others	75	21.4%

Table 2. Respondent's knowledge of pre-marital genotype testing and sickle cell disease

Variables	Frequency	Percentage
Awareness of pre-marital genotype testing and SCD		
Yes	335	95.6
No	15	4.4
Sources of information (multiple responses)		
Health professionals	50	11.7
Internet	128	36.5
Friends	48	13.8
Family	64	18.2
Causes of SCD		
Acquired	30	8.9
Inherited	281	80.1
Don't know	39	11.0
Signs and symptoms of SCD		
Frequent illness	194	55.5
Don't know	156	45.5
Know someone with SCD		
No response	32	9.1
No	143	40.9
Yes	175	50.0
How is SCD diagnosed		
Blood test	05	1.4
Urine test	194	55.5
Don't know	151	43.1
Chances of each child carrying SCD when one of the parents have SC trait		
None of the children	74	21.2
All the children	08	2.2
Half of the children	110	31.3
Quarter of the children	92	26.2
Don't know	66	19.0
Chances of each child carrying SCD when both parents have SC trait		
None of the children	02	0.6
All the children	200	57.0
Half of the children	51	14.6
Quarter of the children	30	8.6
Don't know	67	19.0
Preventive measures of SCD		
Genetic counseling	140	40.0
Don't know	210	60.0

Table 3 shows that 137 (39.1%) of the respondents had poor knowledge of premarital genotyping and SCD, 148(42.3%) had average knowledge and 65(18.6%) had good knowledge. Knowledge of premarital genotyping and SCD was significantly related to marital status and level of education ($P < 0.05$). However, there were no statistical significant relationships observed between occupational statuses, age, gender, religious affiliation and knowledge of premarital genotyping ($P > 0.05$).

4. DISCUSSION

Knowledge about SCD constitutes an important variable that influences the acceptability, practice and success of premarital genetic counselling [9]. This study was designed to assess the level of knowledge about premarital genetic counselling and SCD among youths. The respondents cut across various socio-demographic characteristics with their age ranging from 14-35 years. Majority of the respondents were between ages 26 and

30 years. The fact that most of the respondents are single makes the study most appropriate for the study group because the respondents need to be aware of the importance of premarital genotype screening before they get married. Majority of the respondents have heard and are aware of sickle cell disease as an inherited genetic disorder. Similarly, about 50% of the respondents claimed knowledge of someone with SCD which shows that the condition is common in the study area. Our finding is inconsonant with other Nigerian community-based studies in Jos [10] and Ibadan [8] where 62% and 81.8% of the respondents claimed to have heard about premarital genotyping and sickle cell disease. This is however at variance with a study among high school students in Jamaica and another study among adolescents in India where 49% and 46.2% respectively knew the disease is genetically transmitted [11,12]. A major source of information is internet which was similar to another Nigerian study where half of those who knew about the disease also mentioned mass media among others. This is possible in this internet era that has made the world a global village, and many youths are not left behind in these developments [9]. The higher level of awareness observed in this study and other studies in Nigeria can be attributed to an exponential increase in the use of internet facilities, especially social media among the Nigerian youths. Despite the high level of awareness, comprehensive knowledge on the mode of diagnosis, signs and symptoms as well as preventive measures is low hence the need for health workers especially community health nurses to focus more on community enlightenment about the causes of genetic diseases to correct and rectify these deficiencies.

Table 3. Relationship between levels of knowledge and socio-demographic characteristics of respondents

Variable	Level of knowledge				
	Poor no. (%)	Average no. (%)	Good no. (%)	Total	P value
Gender					
Male	94(39.3)	103(42.9)	43(18.0)	240	0.95
Female	43(38.8)	45(40.8)	22(20.4)	110	
Age Range					
16-20years	17(31.6)	23(42.1)	15(26.3)	55	0.59
21-25years	27(36.2)	34(44.7)	14(19.1)	75	
26-30years	79(42.9)	73(39.5)	33(17.8)	185	
31 and above	14(40.0)	18(51.4)	3(9.5)	35	
Religion					
Islam	101(43.9)	100(43.5)	29(12.6)	230	0.72
Christianity	36(30.0)	48(40.0)	36(30.0)	120	
Occupational status					
Civil servant	5(7.7)	35(53.9)	25(38.5)	65	0.11
Business	70(51.9)	50(37.0)	15(11.1)	135	
Students	39(41.1)	36(37.9)	20(21.1)	95	
Others	23(41.8)	27(49.1)	5(9.1)	55	
Marital status					
Single	109(49.6)	104(47.3)	7(3.2)	220	0.000
Married	16(24.6)	30(46.2)	19(29.2)	65	
Divorce	3(20.0)	3(20.0)	9(60.0)	15	
Widow	9(18.0)	11(22.0)	30(60.0)	50	
Level of education					
Non formal	30(60.0)	17(34.0)	3(6.0)	50	0.000
Primary	21(60.0)	8(22.9)	6(17.1)	35	
Secondary	79(42.7)	98(53.0)	8(4.3)	185	
Tertiary	7(8.8)	25(31.3)	48(60.0)	80	
Over all knowledge	137 (39.1)	148(42.3)	65(18.6)	350 (100)	

Apart from lack of comprehensive knowledge, less than 2% of the respondents do know that the diseases can be diagnosed through blood test. It is pertinent to point out that as long as very few people know the mode of diagnosis and preventive measures, it may be difficult to control the spread of the genetic anomaly in our population. This poor result is not surprising because similar studies done among university and secondary school students in same country revealed similar findings [9,8].

Majority of the respondents correctly believed that SCD was inherited from parents; a few believed that it was acquired through blood transfusion. Other studies have assessed the knowledge of sickle cell disease in some communities and all of them conclude that is there is need to sensitise communities and policymakers about the disease, including its screening and adequate management [13,14,15].

Less than half of the respondents knew that genetic counselling is a preventive measure of SCD. In Nigeria where most marriages are contracted for the purpose of childbearing, premarital and preconception genetic screening and counselling should be the main focus of efforts at controlling SCD in developing countries because screening is relatively cheap and far less invasive than pre-natal diagnosis. Besides, the psychological, religious and socioeconomic issues at stake are far easier to manage than when a couple must decide on prenatal diagnosis and selective abortion. Assessing the over- all knowledge of respondents on pre-marital genotype testing and sickle cell disease, it was revealed that less than one third of the respondents had good knowledge. The effectiveness of genotype screening programmes depends largely on the awareness of the target population [16]. This implies that the respondents ought to have good knowledge of the importance of genotype screening for them to be screened.

According to Oludare and Ogil [17], knowledge of pre-marital genotype testing and sickle cell disease is significantly related to marital status and level of education. This is consistent with the current study because the analysis of the relationship between knowledge of pre-marital genotype testing and SCD, and socio-demographic characteristics of the respondents shows that marital status and level of education are strong determinants of knowledge of pre-marital genotype testing and sickle cell disease.

5. CONCLUSION

The findings in this study showed a high level of general awareness about the existence of SCD and pre-marital genotype but comprehensive knowledge about the mode of diagnosis, signs and symptoms as well as preventive measures was low. Knowledge of pre-marital genotype testing and SCD was significantly related to marital status and level of education of the respondents.

6. RECOMMENDATIONS

1. Intensive enlightenment campaign on premarital genotype testing should be done by government and institutions through the media, alongside health education on genetic counselling and its prevention right from primary school level.
2. The use of persons with SCD as peer educators/counsellors should be explored.
3. Mass media shall be used as a way of intensifying and imparting knowledge of SCD in the community since very many of the respondents knew sickle cell disease through mass media.

CONSENT

As per international standard or university standard, patient's written consent has been collected and preserved by the authors.

ETHICAL APPROVAL

As per international standard or university standard, written approval of Ethics committee has been collected and preserved by the authors.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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