Perceptions about Sickle Cell Disease and its Prevention among Undergraduates of Tertiary Institutions in Kano State, Nigeria

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Abstract

Background

Nigeria is known to have the greatest number of sickle cell disease (SCD) patients per country in the world. Most of the studies that were carried out in Nigeria on awareness of sickle cell disease come from the southern part of the country. There is variation in the incidence of the disease within Nigeria with a higher incidence of the disease in the Northern Nigeria. Since tertiary institutions in the country have good representation of Nigerian youths, and the fact that the youths are good entry point for interventions aimed at preventing and/or controlling the disease there is the need to determine their knowledge, attitude and perceptions about sickle cell disease and its prevention.

Methods

Three hundred undergraduate students from Bayero University Kano and Federal College of Education, Kano were selected using a multi-stage sampling technique. Structured self-administered questionnaires were administered to respondents that agreed to participate in the study to assess their perceptions regarding sickle cell disease and its prevention. Data entry and analysis was done using EPI-Info software.

Results

Majority (81%) of the respondents fell within the age group 15-24. School teachers and lecturers constituted the major source of information (49%), and only 17% of the respondents got their information about SCD from health workers. Most of the respondents, 219 (73%), chose inheritance from parents as the correct way of SCD transmission. Up to 27.3% of respondents had poor knowledge of SCD prevention, and there was a statistically significant association between gender, religion and marital status with good level of knowledge of SCD and its prevention.

Conclusions

There is a deficiency in the perceptions about sickle cell disease and its prevention among undergraduates of tertiary institutions in Kano. There is a need to provide health education about SCD prevention to youths in schools and through other media; as well as strengthen prenatal

screening and premarital counseling and testing services. This should include the counseling of affected individuals and their education on their condition.

Keywords: *Perceptions, Sickle cell disease, Nigerian youths, Pre-marital counseling and testing*

Introduction

Sickle cell disease is a spectrum of diseases that encompasses a group of hemoglobinopathies in which pathology may be attributed to the presence of sickle hemoglobin HbS.[1] These hemoglobinopathies affect many races and are the major genetic diseases of Negros[1]. The most important is sickle cell anaemia, which is a chronic debilitating autosomal-recessive inherited hematological disorder that requires inheritance of homozygous sickle cell genes, according to simple Mendelian law of inheritance. However, the disease can appear in a heterozygous (HbSC) form which is less severe than HbSS.[2, 3] Sickle cell anaemia is the most common and most severe form of sickle cell disease, and has since its discovery in 1904 became a genetic disorder of major clinical importance all over the world.[4] Sickle cell patients suffer chronic ill health, mental and psychological trauma due to the illness.[5] The effect of the illness is not only limited to the patients alone as people around them i.e. parents and family suffer considerably – physically, psychologically and economically.

Sickle cell disease remains the most important hereditary disease in tropical Africa.[6] It is most common in West and Central Africa where as many as 25% of people have sickle cell trait and 1-2% of all babies are born with a form of the disease.[7] Nigeria is known to have the greatest number of sickle cell disease patient per country in the world: about 30 million people have the sickle cell trait and 2-4% of children born to Nigerian parents have sickle cell anaemia.[7] A recent WHO report showed that there are over 200,000 children born annually with sickle cell disease in Nigeria[8]. Even within Nigeria, the incidence of sickle cell disease tends to vary, with a higher incidence in the northern savannah parts of Nigeria than in the southern forest areas.[3]

Various methods have been adopted to control sickle cell disease. In North America and Europe emphasis is placed on newborn screening for sickle hemoglobin to identify affected children early for better health care while married couples at risk are also identified and counseled.

Prenatal diagnosis in early pregnancy with the option of planned abortion of an affected fetus has been practiced with good success in the Mediterranean countries for B-thalassaemia. The latter method has not been widely used in the control of sickle cell disease partly due to the poor economy and lack of access to genetic services in the sub-Saharan African and Caribbean nations in which sickle cell disease is most prevalent. The problem with these strategies is that carriers are only identified at marriage or in pregnancy and childbirth, situations in which control choices become difficult, emotionally traumatic or ethically unacceptable. Another negative factor in prenatal diagnosis is its high cost which limits its availability. Population measures are needed that reduce heterozygote mating and minimize the incidence of homozygous occurrence of the condition. These population preventive measures include; health education, public genetic counseling, mass genetic screening, premarital counseling and testing, counseling the affected individuals on regular follow-ups, proper management of clinical cases, health education, as well as psychosocial support of affected patients. As has been observed in reports by workers on sickle cell control in Cuba and Africa, an important component of any control strategy is a high level of public knowledge about the disorder, which promotes voluntary screening and acceptance of genetic counseling.[9]

Youths make up a large percentage of the students in institutions of higher learning and; and a good entry point for interventions for preventing and/or controlling SCD. It will be useful therefore, to study the knowledge, attitude and perceptions of the youths about sickle cell disease with a view to designing interventions for sensitizing them on the prevention and control of this disease.

Methodology

This study was conducted among undergraduates at all levels of study in Bayero University Kano and Federal College of Education, Kano. The calculated sample size of 304 was obtained using a prevalence of 27% obtained from another related study in Nigeria.[10] Bayero University Kano (BUK) and Federal College of Education, Kano (FCE, Kano) were randomly selected for study by balloting from amongst the twelve tertiary educational institutions in Kano State. Bayero University Kano was established in 1975 and has two campuses and eight faculties, namely: Arts and Islamic Studies, Education, Science, Technology, Law, Medicine, Agriculture,

Social and Management Sciences with a student population of approximately 17,665.

Federal College of Education (FCE), Kano is one of the biggest colleges of education in Northern Nigeria. It awards degrees, national certificates of education (NCE) and runs programs for pre-NCE, remedial programs and diplomas. The college comprises four schools: School of Social Sciences, School of Languages, School of Vocational Studies and School of Remedial Sciences. The college had a student population of about 10,000 students at the time of the study.

The study was descriptive and cross sectional in design and was carried out in 2004. Using a multistage sampling method, four faculties (Medicine, Sciences, Technology, Social and Management Sciences) were randomly selected from Bayero University Kano using simple random sampling. This was also applied to select the required sample from a list of all the students from the departments in the four faculties. At the end of the sampling process, 200 students were selected. Permission to carry out the study was obtained from the Dean of Students' Affairs, Bayero University, Kano and the Students' affairs officer of FCE, Kano. A similar process was used to select 104 students from the four Schools selected from FCE, Kano (Social Sciences, Languages, Vocational Studies, and Remedial Sciences).

A self-administered structured pre-tested questionnaire was used to collect data after seeking and obtaining verbal informed consent of the selected respondents. The questionnaires were then analyzed using Epi Info® software (version 3.3.2). The collected data were presented as tables and charts. Chi-square test of significance (χ^2) was used to test association between categorical variables. Responses to questions on knowledge were given a score of one if answered correctly, and no point was given for any wrong answer. A total of 19 points was obtainable under this section. Respondents who scored 14-19 points in this section were adjudged to have good knowledge, and those who scored 9-13 points were assessed to have fair knowledge while those with nine (9) points or less were adjudged to have poor knowledge.

Results

Socio-demographic Characteristics

A total of 300 out of the 304 respondents completed the questionnaire, giving a response rate of 98.7%. Table 1 shows that majority of respondents fell within the age group 15-24 (81%). All the females (representing 20% of the respondents) and 60% of the males fall within that group. Out of the 300 students interviewed, 72 (24%) were females and 228 (76%) were males. Majority of the respondents 264 (88%) were Muslims and the remaining 36 (12%) were Christians. Hausa/Fulani constituted the dominant ethnic group 226 (75%) followed by Yoruba 21(7%), then Igbo 9 (3%) and other ethnic groups constituted the remaining 45 (15%). Of the 300 respondents studied 272 (91%) were single and 28 (9%) were married. School teachers and lecturers were the major source of information (49%), but only 17% of the respondents got their information about SCD from health workers.

Awareness of, Knowledge and Perceptions regarding SCD and Its Prevention

Table 2 shows that majority of the respondents (290) have heard of sickle cell disease. Most of the respondents, 219 (73%), chose inheritance from parents to be the correct way of SCD transmission. Up to 33 individuals believe that SCD is transmitted maternal infection during pregnancy, while 10.7% of the respondents had no idea about the mode of transmission of SCD. Table 3 shows that majority (82%) of the respondents have good perception about the severity of SCD because they believe that SCD is a severe disease. It also shows that up to 51.7% of the respondents are of the opinion that SCD is not a curable disease. Out of the 238 subjects that said SCD can be prevented, 89.1% were of the opinion that SCD can be prevented through blood genotype determination, 93.3% said it can be prevented through premarital counseling and testing, while 59.7% said it can be prevented through prenatal diagnosis (Table 2). About a third (36%) of the respondents would prefer to terminate the pregnancy of prenatally diagnosed SCD fetus; while 31% will offer prayers as depicted in table 3. Overall, about a quarter (27.3%) of the respondents had poor knowledge of SCD prevention, whereas the remaining 175 (58.3%) and 43 (14.3%) had fair and good knowledge of SCD respectively.

Social and demographic factors influencing respondents' knowledge of SCD

The influence of social and demographic factors on respondents' knowledge of SCD and its prevention was examined using univariate analysis. Gender **(□²=25.05, df =2, p <0.05),** religion **(□²=7.51, df =2, p<0.05)** and marital status **(χ^2=12.58, df =2, p<0.05)** were found to be statistically significant as shown in table 4. On the other hand, ethnicity did not influence respondents' knowledge of SCD (χ^2**=10.14, df = 6, p >0.05).**

Discussion

The 15-24 years age group is the predominant age group commonly found in most tertiary institutions and this study was no exception. The mean age of the respondents was 22.6 years with a standard deviation of 4.7 years. The respondents were mostly males and only about a third was female. The latter can be attributed to the fact that enrolment of females into tertiary institutions is still low in this part of the country due to traditional and cultural beliefs. The Hausa/Fulani ethnic group comprised two thirds of the respondents with most being of the Muslim faith. This is in keeping with the fact that these are the major religious and ethnic groups in Kano. A large majority of respondents were still single despite being of marriageable age by the norms of this part of Nigeria. This may be attributed to the effect of education in delaying marriage. Majority of the respondents had obtained information about SCD during their secondary school education and school teachers/lecturers were the source of this information. Only a few (17%) of the respondents got their information about SCD from health workers. This finding is similar to that of a study carried out at in Southwest, Nigeria, where about 23% obtained their information from news media, 29% through friends and relations but only 21% obtained their information through health workers.[11]

Almost all (96.7%) of the respondents had heard of sickle cell disease and this is not unusual in view of the educational backgrounds of the respondents as well as the high prevalence of this condition in Nigeria. However, out of those that had heard of the disease, only 73% knew that it is inherited from parents. This is consistent with a study carried out among 147 black patients in USA wherein 98% of them had heard of SCD and 73% knew that it was a genetic disorder.[12] This finding about the correct route of transmission of SCD is also similar to the finding of 78% in a study [13] conducted in Nairobi, Kenya and 86% in another study[14] conducted in the USA.

However, some respondents had no idea of the cause of the disease, while others felt it could be caused by maternal infection during pregnancy. About a quarter of the respondents had a poor level of knowledge about SCD, which was alarming and a pointer to prevailing misconceptions about SCD, in spite of the high prevalence in Nigeria. Most (82%) respondents had good perception about the severity and possibly fatal nature of SCD which may be related to high awareness and prevalence of SCD in this part of the country. This finding is similar to that obtained in a study conducted among African-American women in the USA .[15] The latter finding is deemed to be a welcome development, because it would influence their behavior towards managing SCD. Slightly less than a third of the respondents believed that medical treatment and prayers can provide a cure to the disease, while up to (51.6%) of the respondents were of the opinion that SCD is not a curable disease. This poor perception about the curability of SCD tends to promote poor attitude towards SCD prevention programs. On the other hand over two thirds of the respondents were aware that SCD is preventable, and of those, 70.7% were of the opinion that SCD can be prevented through routine blood genotype determination, while 74% said it could be prevented through premarital counseling and testing. This finding is similar to that obtained in a study carried out in USA, where majority of African American pre-medical students and other minority students had an overall positive view of genetic counseling and testing of sickle cell disease, and supported it for preventive measure.[16] Only over a third of the respondents in this study would consider termination of the pregnancy of a prenatally diagnosed SCD fetus. This finding is close to that obtained in a study conducted in Ilorin where 44% of respondents would consider termination of pregnancy if prenatal diagnosis revealed likelihood of SCD in their unborn baby.[6] However in that study, there appeared to be a preference for genetic counseling and use of methods other than termination of pregnancy in determining the fate of a fetus with SCD.

Findings from our study show that there was a statistically significant association between gender and good knowledge of SCD prevention among the respondents **(□²=25.05, df =2, p <0.05)** with female respondents in the various institutions having relatively better knowledge of SCD prevention than male respondents, and this was in keeping with the findings of a study conducted in USA which showed that African American women believe in the severity of SCD although they do not think they are at risk of having a child with SCD.[15] This may be further

explained in the Nigerian context by the fact that problems related to child-bearing or rearing are blamed on women which makes them quite sensitive and informed. There was a statistically significant association between religion and knowledge of SCD among the respondents **(□²=7.51, df =2, p<0.05)** with Christian respondents in the various institutions having relatively better knowledge of SCD prevention than Muslim respondents, and this may also correlate with the findings of another study conducted in Northeastern Nigeria, [17] where a statistically significant number of Christians were against aborting a fetus with SCD. This may be in keeping with the fact that certain Christian sects are against abortion for any reason and widely disseminate information about all related conditions for which abortion might be conducted. There was also a statistically significant association between marital status of the respondents and their knowledge of SCD prevention **(χ^2=12.58, df =2, p<0.05)** with married students in the various institutions having relatively better knowledge regarding SCD prevention than their non-married counterparts. This is in keeping with the findings of a related study [14] which showed that respondents that are married tend to be older than respondents that are single, and the latter had better knowledge of SCD than the respondents that were single. This maybe further explained by the fact that married respondents are more concerned and knowledgeable about issues concerning child-bearing and rearing, and actively seek related information.

Conclusion

There is a deficiency in the perceptions about sickle cell disease and prevention among undergraduates of tertiary institutions in Kano. There is a need to provide health education about SCD prevention to students in tertiary institutions, as well as to strengthen prenatal screening and premarital counseling and testing services. This should include the counseling and education of affected individuals about their condition, so as to reduce the prevalence of this dreadful disease in Nigeria.

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Table 1: Socio-demographic characteristics

Socio-demographic Variables		Frequency	Percentage (%)
Age group (Years)	15-24.9	242	80.7
	25-34.9	52	17.3
	35 – 49.9	6	2.0
Sex	Males	228	76.0
	Females	72	24.0
Ethnicity	Hausa/Fulani	226	75.3
	Yoruba	21	7.0
	Igbo	9	3.0
	Others	45	15.0
Marital status	Single	273	91.0
	Married	27	9.0
	Islam	264	88.0
	Christianity	36	12.0

Table 2: Respondents' knowledge of SCD and its prevention

Parameter	Frequency
Awareness of SCD	
Heard about SCD	291 (97.0)
Knowledge of transmission	
Genetic inheritance	291 (97.0)
Maternal infections	33 (11.0)
Childhood infections	16 (5.3)
Don't know	32 (10.7)
Awareness about prevention	
SCD is preventable	238 (79.3)
Knowledge of SCD prevention	
Preventable through blood genotype determination	212 (70.7)
Preventable through premarital counseling and testing	222 (74.0)
Preventable through prenatal diagnosis	142 (47.3)
No response	21(7.0)

Table 3: Respondents' perceptions regarding SCD and Its Prevention (n=300)

Parameter	Frequency
Perceptions about the severity of SCD	
Mild disease	26 (8.7)
Moderately severe	18 (6.0)
Severe and possibly fatal	245 (81.7)
Don't know	11 (3.7)
Perception about a cure for SCD	
Curable by spiritual incantations	4 (1.3)
Curable through prayers	56 (18.7)
Curable by traditional medications	13 (4.3)
Curable by orthodox medications	64 (21.3)
Incurable by any means	155 (51.7)
Others	8 (2.7)
Perceptions regarding the fate of fetus with SCD	
Terminate the pregnancy	109 (36.3)
Offer prayers	93 (31.0)
Consult oracle/traditional healers	13 (4.0)
Others	57 (19.0)
No response	28 (9.3)

Table 4: Social and demographic factors influencing respondents' knowledge of SCD

(n=300)

Characteristics	Knowledge of SCD			Chi-square	p-value	Significance
	Good	Fair	Poor			
Sex				25.1	0.0001	Significant
Males	21	134	73			
Females	22	41	9			
Marital status				12.6	0.002	Significant
Single	33	165	74			
Married	10	10	8			
Religion				7.5	.02	Significant
Muslims	37	148	79			
Christians	6	27	3			
Ethnicity				10.1	0.12	Not significant
Hausa/Fulani	25	140	60			
Yoruba	6	8	7			
Igbo	2	4	3			
Others	10	23	12			