Original Article

Knowledge of Sickle Cell Disease and Pre Marital Genotype Screening among Students of a Tertiary Educational Institution in South Western Nigeria

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Abstract

Introduction: Sickle cell disease is an inherited blood disorder with diverse clinical variability, which predisposes patients to additional complications and frequent hospitalizations.
Aims and Objectives: This study assessed the level of knowledge of students about sickle cell disease and their perception of pre-marital genotype screening.
Materials and Methods: This descriptive cross sectional research design utilized multi stage and convenience sampling techniques to select departments and participants of this study respectively. A self-structured questionnaire was used as the survey instrument, data obtained were analysed using Statistical Package for Social Sciences (SPSS) version 16.
Results: Female participants were more than male participants (58.4%, 47.3%). Most participants were knowledgeable about SCDand have heard about sickle cell disease through the media. Student's perceived benefits of premarital genotype screening was good (73.4%) as most participants affirmed that genotype screening for intending couples will prevent unnecessary worries about given birth to a child with SCD and confirm their blood compatibility in a bid to take informed decision about marriage. Few participants (27.6%) said it predisposes an individual to blood borne diseases and 28.8% of them reported it is a painful procedure.
Conclusion: In spite of high level of awareness of SCD among participants a good number still did not know their genotype despite their level of education. Hence there is need for massive health education among general populace targeting students in order to reduce incidence and burden of SCD, which has become a public health problem in our country.

Key words: sickle cell disease, knowledge, students, nursing

Introduction

Sickle cell disease is a group of hereditary disorders characterized by red cells that contain an abnormal form of haemoglobin called Hbs. The globin chain structure is changed by the substitution of the amino acid glutamic acid by valine, effectively changing the behaviour of the whole protein molecule (Guyton, 2006). One characteristic of sickle cell disease is its clinical variability. Some patients develop a more severe variant of sickle cell disease and suffer from additional complications and frequent hospitalizations, while others present with more benign symptoms, or are even asymptomatic. Although both inherited and acquired factors contribute to this clinical variability, socio-economic status stands out as one of the main factors affecting clinical manifestations, implying the importance of changes in food

quality(Nutrition), the potential for the prevention of infection (safe and hygienic practices) and timely access to quality health care services (Thomas , Higgs and Serjeant 1997).

Akinyanju (2011) reported that there is low level of awareness on SCD evidenced by a birth rate of one in 50 babies. Birth rate is used as determinant because affected children rarely survived childhood, and were, therefore, less likely to be encountered in secondary schools, universities and in the workplace. This lack of awareness fuels the growth of myths, misinformation, inappropriate treatment, frustration and stigmatisation (Akinyanju 2011).

In 2006 the World Health Organisation (WHO) pronounced Nigeria as the country with the highest number of sufferers of sickle cell anaemia in the world. The global health watch dog (WHO) also noted that Nigeria accounts for about 150,000 sickle cell anaemic children every year. The then Nigeria minister of Health, Prof OnyebuchiChukwu, at the 2010 World Sickle Cell Day Rally held in Abuja stated that, Nigeria ranks first as the sickle cell endemic country in the world with an annual infant death of 100,000, representing 8 per cent of infant mortality in the country.Nnaji, Ezeagwuna, Osakwe, Nwigwe ,Onwurah, (2013) reported prevalence rate of carrier of SCD gene of 26.4% among participants in their study. However, in Adewoyin, Alagbe, Adedokun, &Idubor, (2015) study in Benin haemoglobin variant among the study participants was AA (77.6%), followed by AS (13.5%) and 3% had sickle cell disease.

Inadequate knowledge and wrong perceptions about sickle cell disease has been observed to be the fuel for the formation and spread of misconceptions and myths about the disease (Akinyanju, 2011). Certain myths and stories have evolved around sickle cell victims and the disease. In Nigeria during the olden days, the so called victims were labeled ‘ögbanje in the eastern part of Nigeria and Ábiku’ in the south western part of Nigeria.

Olarewaju, Enwerem, Adebimpe, Olugbenga-Bello (2013) in a study carried out among secondary school students in Jos, Nigeria found out that majority (83.2%) of the students were aware of SCDs, as an inherited disorder (80.0%), affecting the red blood cells (83.0%) but only half (54%) knew that the disease can only be diagnosed through blood test. Also, they reported that only 59% of the students knew their genotype and 11. 1% claimed they haveAS genotype. However, more than one fourth (25.5%) of the students had wrong belief that SCD is caused by evil spirit while 76% showed wrong attitude involving stigmatization towards individuals with sickle cell disease. Earlier, Alao, Araoye, Ojabo (2009) reported poor knowledge of SCD among the undergraduates.

According to El-Hazmi and Warsy (2011), pre-marital genetic screening is the screening of the prospective couples for a genetic disease, genetic predisposition to a disease, or a genotype that increases risk of having a child with a genetic disease. Knowledge of pre-marital genetic screening allows a person to take steps to reduce his or her risk. Ojo, Osanyande, Irinoye and Mukoro (2001) postulated that pre-marital genetic testing and counseling is important, if ignorance and superstitions with genetic diseases are to be dispelled.

Attitudes and perceptions of genetic testing for the purpose of clinical diagnosis and management have been examined among individuals in clinical, educational, and community settings. Individuals articulate both benefits and risks of genetic testing. Participants frequently express concern for possible misuse of information gathered from genetic testing but also identified the benefit of using genetic test results for prevention. The key factors affecting attitudes towards screening are the problems of stigma against ethnic minority groups and religious views (Wyke, 2004).

In a study carried out among students of the College of Education, Edo State by Egbochukwu and Imogie (2002) to assess the student’s knowledge about presentation, acquisition and method of diagnosing sickle cell disease on marital choices and child bearing intentions, results showed that most (51.5%) of the students go for genotype screening based on personal choice followed closely (25.8%) by pre-school entry requirements and very few (4.1%) of them did it because their intending spouse requested for it.

Some of the respondents (65.5%) submitted that it is not important while 26.1% had not heard about it before.

Abioye-Kuteyi, Oyegbade, Bello and Osakwe (2009) observe that though the 69.7% of their respondents had tertiary education, only 31.0% had good knowledge of genetic disease, while about a quarter of the married respondents and those engaged to a partner did not know their partner's genetic status.

These findings indicated the necessity of functional education, early life genetic education, screening and counseling. In a study conducted by Akinde, Dosu and Oladele (2004) revealed that most of their respondents (students of school of health records LUTH) believed that genotype screening is more important than love when considering the choice of partner for marriage. Adewoyin, Alagbe, Adedokun, & Idubor, (2015) found out that only few (8.6%) of the respondents in their study expressed willingness to marry another sickle cell trait carrier despite the risk of raising children with sickle cell disease.

Objective of the Study

This study assessed the level of knowledge of students about sickle cell disease and their perception of pre-marital genotype screening.

Methodology

This study adopted a descriptive cross sectional design. The study was carried out among students of a government owned College of Education.

Taro Yammane formulae for calculation sample size was used to calculate the number of participants recruited for the study. Multi-stage sampling was adopted in selecting the students that participated in the study. There are five (5) Schools in the College of Education. First stage of sampling utilized simple balloting to select three (3) Schools out of five. In the second stage simple balloting was also employed to select two (2) Departments from each of the selected Schools. In all six (6) Departments were selected in the College. Tutorial list of students in the selected Departments serve as sample frame for the third stage of the sampling process, systematically one in three students in the sample frame were recruited to participate in the study. In all 315 students who voluntarily volunteer to participate in the study were recruited for the study.

Permission was sort from the authority of the College of Education while informed consent was sought and gained from all participants. A self-structured questionnaire developed from literature search was used for data collection which validity and reliability was ascertained before data collection. Statistical package for social sciences (SPSS) version 16 was used to analyze data.

Result

Result showed that more female (58.4%) participated in the study and most (47.3%) were in their final year. More than half of the students (61.6%) that participated in the study were less than 21 years of age and almost all of the participants (93.3%) were Yoruba.

Knowledge of sickle cell disease among the participants as shown in table 2 revealed that majority (76.8%) of the participants have heard about sickle cell disease through the media which was the highest source of information. Only very few (4.1%) of the participants knows that SCD can be detected in the blood through genetic screening. Of all the participants only 2.5% said their genotype is “SS” while 36.2% did not know their genotype. Furthermore 67.9% of the participants’ stated that sickle cell disease is premature rupture of the red blood cells; 12.4% opined that it is disease of the blood while few (5.7%) said it is a disease of the spleen.

Only 11.4% of the participants agreed that SCD is a blood disease while 8.9% agreed that it is caused by abnormal shaped haemoglobin. Only 11.4% of the participants agreed that SCD is a blood disease while 8.9% agreed that it is caused by abnormal shaped haemoglobin. If I have spoken your mind if so you might delete all in red. Results from the table also showed that 34.0% agreed that SCD is hereditary while only 16.5% agreed that it causes shortage of blood (anaemia). Only 7.9% agreed that SCD is capable of reducing life span while 11.4% agreed that people with SCD usually have bone pain.

Table 1: Socio Demographic Characteristics of the Participants

Statements	Labels	Frequency N=315	Percentage %
Age	20 years down	194	61.6
	Above 20 years	121	38.4
Sex	Male	131	41.6
	Female	184	58.4
Ethnicity	Yoruba	294	93.3
	Ibo	9	2.9
	Hausa	4	1.3
	Others	8	2.5
Religion	Christianity	260	82.5
	Islam	55	17.5
Level of Study	100 level	46	14.6
	200 level	120	38.1
	300 level	149	47.3

Table 2: Participants Knowledge about Sickle Cell Disease

Statements	Labels	Frequency N=315	Percentage %
Have you ever heard of sickle cell disease?	Yes	242	76.8
	No	73	23.2
If yes, what is your source of information?	No response	74	23.5
	Media	94	29.8
	Curriculum	65	20.6
	Friends	61	19.4
	Health workers	21	6.7
What do you understand by the term sickle cell?	No response	44	14.0
	Disease of the bone	39	12.4
	Disease of the spleen	18	5.7
	Premature destruction of red blood cells	214	67.9
It is a blood disease	True	36	11.4
	I don't know	63	20.0
	False	216	68.6
It is caused by abnormal haemoglobin	True	28	8.9
	I don't know	119	37.8
	False	168	53.3
It is hereditary	True	107	34.0
	I don't know	73	23.2
	False	135	42.9
It causes shortage of blood	True	52	16.5
	I don't know	78	24.8
	False	185	58.7
It reduces life span of people affected	True	25	7.9
	I don't know	47	14.9
	False	243	77.1
It can be detected in the blood by blood genotype screening	True	13	4.1
	I don't know	56	17.8
	False	246	78.1
People with sickle cell disease usually have bone pain and anaemia	True	36	11.4
	I don't know	75	23.8
	False	204	64.8
Which of the following is your genotype?	I don't know	114	36.2
	AA	170	54.0
	AS	23	7.3
	SS	8	2.5
Which of the following genotype is ideal for a couple?	I don't know	68	21.6
	AS + AA	138	43.8
	AA + AA	107	34.0
	AS + AS	2	0.6

Table 3: Participants Perceived Seriousness of Sickle Cell Disease

Statements	Disagreed n (%)	Undecided n (%)	Agreed n %
The thought of SCD scares me because I have come in contact with people affected	36 (11.4)	86 27.3	193 (61.3)
Sickle cell can strain the financial status of the family	27 (8.5)	68 21.7	220 (69.8)
SCD can reduce the life span of an individual	34 (10.8)	75 23.8	206 (65.4)
SCD could disrupt the academic pursuit of a child	41 (13.0)	75 23.8	199 63.2
It is better not to have a child with SCD, because it can stigmatize the child and family	46 (14.6)	75 23.8	194 61.6
Sickle cell can destabilize marriage	48 (15.2)	70 22.3	197 (62.5)

Table 4: Participants Perceived Susceptibility of SCD

Statements	Disagree n %	Undecided n %	Agree n %
My child could be prone to SCD because I have sickle cell trait	92 (29.2)	74 (23.5)	149 (47.3)
My child could be prone to sickle cell trait because my partner has sickle cell trait	90 (28.6)	105 (33.3)	120 (38.1)
My child could be prone to sickle cell trait because somebody in my family has sickle cell trait	147 (46.7	92 (29.2)	66 (24.1)

Table 5: Perceived Benefits of Premarital Genotype Screening

Statements	Disagree n %	Undecided n %	Agree n %
Genotype screening for intending couples will prevent unnecessary worries about bringing forth a child with SCD	18 (5.7)	66 (21.0)	231 (73.4)
Premarital genotype screening will help me to find out if I am compatible with my partner	21 (6.6)	87 (27.6)	207 (65.8)
If I do premarital screening, it will decrease my chance of giving birth to a child with SCD	66 (20.9)	84 (26.7)	165 (52.4)
Premarital genotype screening will help me make an informed decision if I want to marry a person that has SS trait	32 (10.1)	80 (25.4)	203 (64.5)

Table 6: Participants Perceived Barriers to pre-marital genotype screening

Statements	Disagree n %	Undecided n %	Agree n %
Pre marital genotype screening can increase my worries about SCD	74 (23.5)	67 (21.3)	174 (55.2)
Doing genotype screening will make me prone to blood borne diseases e.g. infection	129 (41.0)	99 (31.4)	87 (27.6)
Doing genotype screening may be painful	139 (44.2)	85 (27.0)	91 (28.8)
The result of my genotype test is to be kept private and confidential	69 (21.9)	94 (29.8)	152 (48.3)

Table 7:Participants' Likelihood of Performing Premarital Genotype Screening

Statements	Labels	Frequency N= 315	Percentage %
I will like to do premarital genotype screening; I am engaged to my partner	Yes	213	67.6
	No	102	32.4
If I am a carrier and my partner is also a career, I will not go into marriage with him/her	Yes	190	60.3
	No	125	39.7
Irrespective of my family peer pressure and the depth of my relationship with my partner, if I discover he is a carrier and I am equally a carrier, I will not go into marriage with him	Yes	204	64.8
	No	111	35.2
I cannot cope with the consequences of having a child with sickle cell disease	Yes	214	67.9
	No	101	32.1

Participants'perceived seriousness of SCD as presented in table 2 showed that 61.3%agreed that the thought of SCD scares them while 69.8% agreed that SCD is a strain to family financial status. More than half of the participants (65.4%) agreed that SCD can reduce life span while 63.2% agreed that it can disrupt the academic pursuit of a child. Results from the table also showed that 61.6% agreed that it is better not to have a child with SCD as it stigmatizes the child and the family while 62.5% agreed that SCD can destabilize a family. Perceived susceptibility to SCD among the participants showed that only 47.3% of the participants agreed that their child could be prone to SCD because they are carrier of SCD trait while 38.1% agreed that their child could be prone because their partner is a carrier of the trait. Also few of the participants (24.1%) agreed that their child could be prone to SCD because someone in their family has SCD trait.

Student's perceived benefits of premarital genotype screening according to participants in this showed that majority (73.4%) agreed that genotype screening for intending couples will prevent unnecessary worries about given birth to a child with SCD while 65.8% agreed that premarital genotype screening will help them to find out if they are compatible with their intending partner. About half of the students (52.4%) belief if they go for premarital counseling it will decrease their chances of giving birth to a child with SCD and 64.5% agreed that premarital genotype screening will help them to make an informed decision if they want to marry a person with genotype "SS".

A little above half of the participants believed that pre- marital genotype screening can increase their worries about SCD while only few (27.6%) agreed that it can make them prone to blood borne diseases like infections. Twenty eight point eight percent (28.8%) of the students that participated in the study agreed that genotype screening is painful while 48.3% agreed that results of their genotype test is to be kept private and confidential.

Participants likelihood of going for premarital genotype screening as shown in table 7, revealed that 67.6% of the participants said they will go for premarital genotype screening when they are engaged to their partner while 39.7% said even if they are career of the trait and their partner is also career of the trait they will still go ahead to marry. Also from the table more than half (67.9%) said they cannot cope with the consequences of having a child with sickle cell disease.

Discussion

More female were found to participate in study, this might not necessarily mean that there are more female students in the college were this study was carried out. All the participants that participated in this study were young and unmarried which make them suitable for the study. Among the participant the minimum age was found to be 16 years while the maximum was 27 years.

Most of the students are aware of sickle cell disease and they also appears to have an understanding of the disease and the major source of information was gotten to be the media, followed closely by information they got from their teachers (school curriculum), this corroborates the result gotten by Bazuaye and Olayemi (2009), where they also found that media and friends, are the primary sources of health information for young women and men of all ages. Most of the respondents know that SCD can be inherited, as previously reported among the respondents in a study conducted byAkinyanju (1996).

Olarewaju, Enwerem, Adebimpe, Olugbenga-Bello (2013) also reported 83.2% level of awareness of SCD among students. In their study they found out that 80.0% of their participants were aware that SCD is an inherited disorder (80.0%), 83.0% are aware that it affects the red blood cells (83.0%) while only (54%) knew that the disease can only be diagnosed through blood test. In our study however only 34.0% agreed that SCD is an inherited disease, 67.7% agreed that it affect the red blood cell while very few (4.1%) knew that it can be detected through blood test. This show that despite the fact that Olarewaju and colleagues carried out their study among secondary school students, their participants were still more knowledgeable about SCD than participants in our study that they were students of tertiary educational institution.

Most of the respondents picked their genotype to be HbAA, followed closely by those who don't know their genotype, this is in tune with the result gotten by Jeremiah, Okonand Jeremiah (2007). Their work showed that 75% of their subjects have HbAA genotype and 26% of them had HbAS genotype. Those that did not know their genotype was found to be more than one third of the total population of the students that participated in the study, despite their level of education. In our study 7.3% of the participants representing 11.4% of those that knows their genotype were careers of SCD traits while 2.5% representing 3.9% of those that knows their genotype were "SS". This is closely related to the submission of Olarewaju, Enwerem, Adebimpe, Olugbenga-Bello (2013) in a study carried out amongsecondary school students in Jos, Nigeria that only 59% of the students knew their genotype and 11. 1% claimed AS genotype.

It is known that an individual's perception of something or an event strongly influence the person's attitude towards it. Reports of studies conducted on attitude of people to SCD and pre-marital genotype screening was utilized to highlight this aspect of the study.This study showed that most respondents have right perception of the disease. They also have high perception of their susceptibility to SCD (personal risk of bringing forth a child with SCD), because most of them submitted that their child could be prone to SCD because they have sickle cell trait, and that their child could be prone to sickle cell trait because their partner has sickle cell trait, but most participants submitted that their child could not be prone to sickle cell trait if any of their family members does not have sickle cell trait or SCD. This goes against the findings of Moronkola & Fadairo (2007) where a large percentage of their respondents believed that the choice of getting a partner for marriage is not dependent on genotypes and that when one subjects one's self to genetic screening and counseling one is demonstrating lack of faith in God. This shows that their respondent had the wrong perception about their susceptibility to the disease. Anie, Egunjobi and Akinyanju. (2010) were of the opinion that cultural and religious values have significant impact on the attitudes of individuals to sickle cell disease especially in Nigeria as these variables influence their health behavior.

Results of this study showedthat most of the respondents were interested in going for pre-marital genetic screening to avoid bringing forth a child with sickle cell disease. This also means that they are willing to leave their present partner or partner to be, if they are at risk of bringing forth a

child with SCD. This finding is inconsistent with the submission of Adewoyin, Alagbe, Adedokun, &Idubor, (2015) where they reported that only few (8.6%) of the respondents in their study expressed willingness to marry another sickle cell trait carrier despite the risk of raising children with sickle cell disease. Most of the students submitted that doing genetic screening will be painful and that it will increase their worry about SCD. A study conducted by Egbochukwu and Imogie (2002) reported that more than half of their respondents understand the purpose of pre- marital screening and 80.6% of them would agree to genetic screening. This is in line with the findings of our study.

Implication for Nursing Practice

This study showed that there is a considerable gap in knowledge and perception of sickle cell disease amongst the participants of this study. Nurses should therefore help in facilitating information dissemination about sickle cell disease and the importance of pre-marital genotype screening. Nurses can achieve this by leading campaigns through the media and other channels of communication so that accurate information can be disseminated to the community at large; knowledge sharing should also be encouraged. Adopting this line of action will focus on the most basic level of prevention (primary prevention), which will reduce the stress and problems associated with caring for patients with the disease and also reduce its prevalence.

Nurses can also influence decision makers by getting involved in the formulation and implementation of relevant policies (both local and international) that will enhance involvement of the populace in the fight against sickle cell disease.

Conclusion

The prevalence of sickle cell disease in Nigeria is of public health concern and it will continue to be if care is not taken. The reduction in the prevalence of SCD can be achieved through premarital genotype screening and counseling. Health education should be given to students and the general populace in order to reduce the burden and incidence of SCD. People should also be encouraged to share information gotten with other people.

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