Knowledge And Perception Of Sickle Cell Disease Among Senior Secondary School Students In Ilorin Metropolis

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Abstract

Sickle cell disease (SCD) remains a major public health issueand inadequate knowledge of SCD and lack of centres for genetic counseling in this country probably contributed to the high prevalence. The aim of this study was to assess the level of knowledge and perception of Senior Secondary School students in Ilorin Metropolis toward SCD and to determine the proportion of the students that know their haemoglobin genotype. Descriptive cross-sectional study was undertaken among students. Multistage sampling technique was used to select 500 respondents from 10 senior secondary schools and a semi-structured, self-administered questionnaire was used as a research tool. Analysis was done using SPSS version 20 software package.The mean age of the respondents was 15.61±1.45, there were more females (54.4%) than males (45.6%). About 79.5% of the respondents have heard about SCD, but only 26.6% of them have good knowledge of SCD and haemoglobin genotype. The attitude of students toward a sickler was poor as many (51.0%) will not accept sickler as a friend and majority (90.3%) will not be willing to marry SCD patient. Only 52.0% of the respondents knew their haemoglobin genotype before the study. Female students had better knowledge score (p-value = 0.035).There is need for continuous awareness programmes on SCD especially among male students and concerted policy should be put in place by government that genotype testing be a compulsory part of pre-secondary school entrance requirements.

Keywords: Sickle cell disease, Knowledge and Perception, Secondary School Students

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Introduction

The Haemoglobinopathies are the commonest inherited, life-threatening disorders in the world with about 7% of the world population are carriers and 300,000- 400,000 affected children are born every year with major haemoglobinopathies. The majority of these (250,000) have sickle cell disease.[1]Sickle cell disease (SCD) is a pan-ethnic condition with the highest prevalence among those of African, Mediterranean, Middle Eastern, Indian, Caribbean, and Central and South American descent.[2]Nigeria has the highest number of homozygous cases in the world with a prevalence of 1.5-3.1% (Average 2%) and about 2-3 million homozygous cases (HbSS) and up to 40 million sickle cell trait (HbAS). World Health Organization estimates the prevalence of sickle cell anaemia to be 20 per 1000 live births annually which translates into about 150,000 children born annually with sickle-cell anaemia in Nigeria, thereby making her the country with the highest burden of sickle cell anaemia in the world.[1]

The clinical presentation SCD is highly variable, while heterozygotes are asymptomatic, the double heterozygotes present with mild to moderate disease and the homozygote with severe disease. [3] Those with the homozygous or SS suffer a higher than average frequency, of illness, frequent hospital admissions, recurrent blood transfusion due to anaemia and they also suffer from various complications like renal failure, anaemic heart failure, stroke, and acute chest syndrome.[4,5]

Despite the large number of people with sickle cell disorder, the level of knowledge about SCD is still low in some countries. Studies from USA have shown significant knowledge gap about sickle cell in people of reproductive age group from Dominican and African-American communities in USA. Significant difference was observed in the knowledge of SCD with only 27.0% of Dominicans correctly identify the disease as an inherited blood disorder, compared to 76.0% of African-American.[6] Another study compared the level of knowledge among University students in Texas and Enugu Nigeria, showed that on the average, students are aware of sickle cell anaemia and its carrier state, but there is paucity of knowledge about SCD especially among students in the non-medically-related faculties

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many of whom did not know their genotype.[7] Similar studies in Ghana also indicated poor knowledge despite the high prevalence of sickle cell carrier status approaching 25.0% and universal newborn screening programme being introduced recently in Ghana, many women of reproductive age group have poor knowledge and feel that the disease is incurable.[8]

Even in Nigeria, a country with the highest number of homozygous disease state various studies have indicated poor knowledge of SCD among students. In the study conducted by Adewuyi in Ilorin, Nigeria, among fresh University graduates showed poor knowledge of SCD, as only 43% of the respondents showed little understanding of the disease and just about 32% of them knew their haemoglobin genotype.[9] Similar study in Abuja among secondary school students, showed that more than half (51.7%) of the respondents did not know their genotype, while only 38.0 % of them knew the cause of SCD.[10] Similar study in Benin-City, Edo State, shows that majority of the students (55.1%) do not know their genotype and more than half of them have wrong idea of importance of premarital screening which can guide unmarried youth in mate selection and help in reducing the incidence of homozygous cases.[11]

The patients with SCD face a lot of challenges such as high level of stigma and discrimination. Stigma can lead to unjust disadvantages for the stigmatized including direct discrimination on the job, in schools, within families and these might prevent receipt of timely and quality health care.[12] The affected individual suffers a life-long disability, reduction in life expectancy and majority of affected individuals hardly survive to adult-hood in developing countries. In other to achieve Millennium Development Goals 4 and 5, there is need to intensify efforts toward educating the general populace about this preventable but devastating clinical condition.The high morbidity and mortality associated with SCD produce grief and permanent anxiety to the family, pain, frustration and a poor quality of life to the patient, serious financial stress to the family and a large drain on the national health expenditure.[13,14]The aim of this study is therefore to know the level of knowledge and perception of secondary school students towards sickle cell disease and to determine proportion of them that knows their haemoglobin genotype. This will create awareness and serves as basis for them to take informed future decision.

Materials and Methods

A descriptive cross-sectional study was carried out in 10 randomly selected senior secondary schools in Ilorin metropolis. Though, a minimum sample size of 419 was calculated using statistical formula for descriptive study ($n=z^2pq/d^2$), a total of 500 students were selected. A multistage sampling technique was used to chose the respondents from the selected secondary schools in the 3 LGAs.Pre-tested structured, open and close ended self-administeredquestionnaires were used to collect information on respondent's socio-demographic variable, knowledge, and perception of SCD and haemoglobin genotype.

Letters of introduction to the schools were obtained from the Department of Epidemiology and Community Health, University of Ilorin, and the permission of the Principals and the Teachers in the various selected classes were sought to carry out the study in their schools. Students were gathered in their classes and informed consent was signed before administration of the questionnaires by well-trained research assistants.Each correct response to knowledge questions was scored one mark and wrong response was scored zero.

Data analysis was done by SPSS version 20 software. The results were illustrated in tables, charts, chi-square and degree of freedom was established where necessary. A p-value of less than 0.05 was regarded as statistically significant frequency. Knowledge score of the respondents were determined by the number of knowledge questions answered correctly into good, fair and poor.

Results

A total of 481 from the 500respondents **(SSS 1-3)** returned their questionnaires giving a response rate of 96.2%. The mean age and standard deviation of the respondents was 15.61±1.45 years. More than 50% of the respondent'sparents have at least post-secondary education. The gender, class level, religion and ethnic origin are shown in table 1. Majority(79.5%)of the respondents heard about sickle cell disease before this present study and television was the main source of information (40.1%).

About 46.9% of the respondents knew that sickle cell disease is not acquired by contact and 51.6% thought the disease was inherited from one parents only, while (58.5%) believed that both parents contributed in passing the disease to their offspring. Some of the respondents (41.6%) believed that the disease is caused by microorganism while others (57.2%) thought it can be acquired from receiving unscreened blood (Table 2).

Concerning clinical symptoms and treatment modalities for SCD, majority (73%) knew jaundice and frequent illness is common in patients with SCD. Only few knew that leg ulcer and stroke can occur in a sickler. Less than half (38.6%) knew the significance of bone marrow transplantation as a curative measure for

TABLE1: Socio Demographic Variables

Variable	Frequency	Percentage (%)
Age (years)		
12-14	95	19.7
15-17	334	69.5
18-20	52	10.8
(Mean age 15.61±1.45)		
Sex		
Male	217	45.6
Female	259	54.4
Class in school		
SSS 1	159	33.1
SSS 2	171	35.6
SSS 3	151	31.3
Religion		
Islam	255	53.5
Christianity	214	44.9
Others	8	1.6
Ethnicity		
Hausa	67	14.4
Yoruba	335	72.2
Others	62	13.4
Mother's Educational level		
Post-secondary	244	51.9
Secondary	130	27.7
Others96	20.4	
Father's Educational level		
Post-secondary	280	59.8
Secondary	108	23.1
Others80	17.1	
Total		**100**

SCD. On the preventive strategies for SCD, majority (79.7%) believed that both couple should know their genotype and 85.3% supported genetic counseling as a very important measure in preventing SCD. Though despite aforementioned strategies, minority (28.7%) still believed that irrespective of the severity of this disease, sickle carrier can marry each other (Table 3).

Only 102 (26.6%) respondents had good knowledge, about 142 (37.1%) had fair knowledge while the remaining 139(36.3%) had poor knowledge of sickle cell disease and Haemoglobin genotype (Table 4). There was significant relationship between the gender and knowledge score, more females had better knowledge than their male counterpart (p-value=0.035).The age, level of class of respondents, religion and ethnic origin have no influence on respondents knowledge score (p= 0.485, 0.777, 0.485 and 0.668) Table 5.

Among the respondents that knew their genotype only 52% of them correctly identify the type of genotype they have and majority haveHbAA (83.7%),others were AS (14.5%), HbAC (0.6%) and HbSS (1.2%). About 23.2% of the respondents listed blood group as their genotype. Majority of those who knew their genotype had the screening at either government or private hospital (83%).

Analysis of respondents' perception towards SCD showed that more than half (51%) either disagreed or strongly disagreed on accepting a person with SCD as a friend and majority (90.3%) believed that marrying a sickler will cause problem to their matrimonial home. Most 68.8% of the respondents believed that premarital genotype screening is a good thing to do in order to avert the problem of caring for a sickler child. Majority (72.7%) either disagreed or strongly disagreed to be childless and many (69.8%) will not

Table 2: Knowledge about mode of acquiring SCD among respondents

Variables	Proportion Responding			
	Yes (%)	No (%)	Don't know (%)	Total (%)
By contact with someone who has disease	114 (33.4)	160 (46.9)	67 (19.7)	341 (100)
Can be inherited from one parent only	177 (51.6)	106 (31.0)	60 (17.5)	343 (100)
Both parents contribute in passing the disease	207 (58.5)	86 (24.3)	61 (17.2)	354 (100)
To inherit the disease, one of the parents must be a sickler	250 (67.2)	84 (22.6)	38 (10.2)	372 (100)
A sickle carrier is a person who inherits the gene from one parent only	174 (47.2)	117 (31.8)	77 (21.0)	368 (100)
Acquired by receiving unscreened blood	212 (57.2)	94 (25.3)	65 (17.	371 (100)
It is caused by infection of microorganisms	153 (41.6)	113 (30.7)	102 (27.7)	368 (100)
Sickler can live a perfectly healthy life	155 (41.9)	170 (45.9)	45 (12.2)	370 (100)

Table 3:Knowledge about symptoms/treatment /Prevention of SCD among Respondents

VariablesProportion Responding	Yes (%)	No (%)	Don't know (%)	Total (%)
Yellowness of the eyes	271(73.0)	44 (11.9)	56 (15.1)	371(100)
Frequent illness	312(84.1)	32(8.6)	27(7.3)	371 (100)
Shortage of blood/Anaemia	291(79.5)	33(9.0)	42 (11.5)	366 (100)
On and Off bone pain	238(65.5)	55 (15.2)	70(19.3)	363(100)
Leg ulcer	180 (49.6)	95(26.2)	88 (24.2)	363(100)
Stroke	130 (36.3)	142 (39.7)	86 (24.0)	481 (100)
Blood transfusion	172(49.1)	103(29.4)	75(21.5)	350(100)
Bone marrow transplantation	131(38.6)	102(30.1)	106 (31.3)	339 (100)
To know genotype of both parents	286 (79.7)	46 (12.8)	27 (7.5)	359 (100)
Genotype AS can marry AS	101 (28.7)	218 (61.9)	33 (9.4)	352 (100)
Genetic counseling is important	295 (85.3)	27 (7.8)	24 (6.9)	346 (100)

Table 4: Knowledge Score of the Respondents on Sickle Cell Disease Knowledge score

Number	Percentage (%)
Good	10226.6
Fair	14237.1
Poor	139 36.3
Total	**383100.0**

Table 5: Influence of Age, Gender, Religion, Class level and Ethnic Origin on Knowledge score of Respondents

Age Group	Knowledge Score (%)	Good	Fair	Poor p-value
Age Group				
12-14	20 (5.2)	34 (8.9)	27 (7.0)	
15-17	66 (17.3)	94(24.5)	99 (25.7)	0.485
18-20	16(4.3)	14(3.7)	13(3.4)	
Gender				
Male	40 (10.6)	56 (14.8)	76(20.1)	0.035
Female	60 (15.8)	85 (22.4)	62 (16.3)	
Class Level				
SSS 1	33 (8.6)	47 (12.3)	43 (11.2)	
SSS2	42 (11.0)	51 (13.3)	49(12.8)	0.777
SSS3	27(7.0)	44 (11.5)	47 (12.3)	
Religion				
Islam	46 (12.1)	58 (15.3)	64 (16.8)	0.485
Christianity	55 (14.5)	83(21.8)	74 (19.5)	
Ethnicity				
Hausa	16 (4.3)	19 (5.1)	25 (6.8)	
Yoruba	72 (19.6)	98 (26.5)	87 (23.7)	0.668
Others	11 (2.9)	19 (5.1)	22 (6.1)	

accept to terminate pregnancy, though only few 22.9% will accept to have termination of their pregnancy if the index pregnancy is carrying a sickler baby.Majority of the respondents (88.3%) are willing to advice their friends to go for genotype screening as well as many 86.3% will like making premarital genotype screening compulsory before marriage. About 48.8% believed that having a sickler child is by individual destiny and more than half (62.4%) also thought that irrespective of the risk, sickle cell carriers can marry each other once there is love between them (Table 6&7).

Discussion

The study revealed that majority of the respondents were aware of SCD (79.5%) similar to what was reported in Abuja where about 81.8% of the secondary schools claimed to have heard and in Jos almost 97.4% of the respondents were aware of SCD.[10,15] This is probably due to the fact that the respondents were in the senior secondary classes where Biology as a subject is made compulsory for all the students irrespective of either in science or in commercial classes. Biology as a

Table 6: Respondents Perception towards Sickle Cell Disease

Proportion responding Variable	SA	AGREE	NEUTRAL	DA	SDA	TOT AL
Willingness to have sickler as a friend	63(16.8)	97(25.8)	24(6.4)	111(29.7)	80(21.3)	375(100)
Do you believe that marrying a sickler will not cause problem to your matrimonial home	9(2.4)	13(3.5)	14(3.8)	181(48.9)	153(41.4)	370(100)
Do you think having a sickler Child is not a problem to the family	9(2.4)	2(0.5)	7(1.9)	179(47.8)	175(47.4)	372(100)
Do you think as a carrier, will you marry Without knowing your spouse genotype	21(5.7)	20(5.4)	23(6.3)	171(46.6)	132(36.0)	367(100)
Do you believe that carrying out a premarital genotype testing is good	131(35.9)	120(32.9)	13(3.6)	65(17.8)	36(9.8)	365 (100)
You will accept termination of pregnancy if prenatal diagnosis confirmed the baby to be a sickler	31(10.3)	38(12.6)	22(7.3)	98(32.6)	112(37.2)	301(100)

NOTE : SA - Strongly agree DA - Disagree SDA - Strongly disagree

Table 7: Respondent Perception towards Genotype Screening

Proportion Responding Variable	SA	AGREE	NEUTRAL	DA	SDA	Total
Do you think that advising your friends to go for genotype screening is a good thing	195(54.5)	121(33.8)	10(2.8)	15(4.2)	17(4.7)	358(100)
Do you believe that premarital genotype screening by made compulsory before marriage	196(54.4)	115(31.9)	6(1.7)	20(5.6)	23(6.4)	360(100)
Do you believe that having a sickler child is by individual destiny	73(20.4)	89(24.9)	21(5.9)	86(24.0)	89(24.8)	358(100)
Do you believe that carriers can marry themselves once there is true love	113(31.5)	111(30.9)	30(8.4)	53(14.8)	52(14.4)	359(100)
Do you believe going for genotype screening is a waste of time for individual willing to do the test	24(6.8)	34(9.7)	17(4.8)	141(40.1)	136(38.6)	352(100)
Do you believe that once there is money to take care of a sickler child carriers can marry each other.	76(21.1)	89(24.7)	27(7.5)	95(26.4)	73(20.3)	360(100)

subject has some sections on blood grouping as well as genotype; hence this may be responsible for the high level of awareness about sickle cell disease. Also WHO has set aside every 19th of June as a world sickle cell day and this is being celebrated globally every year, presence of various NGOs in the state such as, Association for prevention of sickle cell Anaemia in Nigeria (APOSCAN), friends of sickle cell and Ilorin Sickle Cell support club which also exist in Ilorin Metropolis could probably contributed to this level of SCD awareness among students.On the method of acquiring the disease,46.9% of the respondents knew that SCD is not acquired by contact with a person with disease, although up to 33.4% still thought that it may be acquired when someone come in contact with person who has SCD and describing sickle cell disease as a contagious infection. About 47.2% of the respondents believed that sickle carrier is a person who inherited the gene from one parent only. Almost half (41.6%) of the respondents believed that SCD is caused by microorganism similar to what was reported from Port-Harcourt where some respondents 19% and 21% thought that SCD is caused by evil spirit and bad food.[16] About half (57.2%) also thought it is caused by

receiving unscreened blood similar to transfusion transmissible infection as against being a hereditary disorder. This showed that there is still variation in the knowledge of SCD among respondents.

Similar study in USA among Dominicans which has the second highest prevalence of SCD in USA, only about 27% of them correctly identified SCD as inherited disorders, but in contrast to 76% among African-American.[4] In another study in Nigeria, only about 43% of graduates showed little understanding of the mode of inheritance of SCD,[9] and similar study in Abuja among secondary students indicated that only 38% knew the cause of SCD.[10] All these clearly demonstrated that, though respondents may be aware of the disease, they have little knowledge on its nature and how it is acquired.

In comparison with previous studies, the respondents' demonstrated fair knowledge about symptoms of SCD, about 41.9% believed that a person with SCD can certainly live a perfectly healthy life devoid of crises. Similar study from Jos indicated that up to 44.5% of the respondents do not know the signs and symptom of SCD.[15] Most (61.4%) respondentsdo not know that bone marrow transplantation which is the only known curative measure for sickle cell disease can be used as a form of treatment. In a similar study in Benin, about 61% believed that SCD is incurable and just only 18% of the respondents have good knowledge of bone marrow transplantation as a curative method for SCD.[11]

In Nigeria, there is a facility for stem cell transplantation in Benin-City, Edo- State and to date,three sicklers had undergone the procedure and currently doing well. The major challenge to this form of treatment is the high cost of the procedure and difficulties in finding suitable donors. Majority of the respondents (85.3%) believed that genetic counseling is an important preventive strategy which is similar to what was reported in Ife, Nigeria where about 95% of the respondents favour premarital screening.[17] In contrast however, only 40.2% students in Jos knew that genetic counseling is important in controlling SCD.[15] Study among University students towards premarital screening in Oman also indicated greater awareness of centres for genetic counseling and it relevance, about half of the respondents favoured making premarital screening obligatory before marriage, but only one-third favoured making laws and regulation to prevent marriage among carriers.[18] The facility for genetic counseling is mostly restricted to urban areas, there is a need for government at all level to make facility for genotype screening and genetic counseling available at both urban and most especially in the rural communities where many people reside. Although there is no legislation in Nigeria about preventing carrier from marrying each other, there is need for constant education for the youth to take useful decision in mate choices as financial implication of having to manage a sickler which is a life-long ailment can cause serious disharmony in the family

From this present study only 52% of the respondents knew their haemoglobin genotype some (23.2%) respondents listed blood group as their genotype. This finding is much better than what was reported in FCT and Benin City where only about 48.3% and 32% of secondary school students knew their genotype.[10,11] Many of the respondents that knew their haemoglobin genotype have Haemoglobin AA (83.7%), while others were AS (14.5%), AC (0.6%) and SS constituted about 1.2%.

Concerning respondents perception towards SCD, most respondents will show negative attitude towards SCD as more than half of the respondents in this present study (51%) will not accept sickler as a friend, similar to what was reported among trainee-teachers students in Port Harcourt where only 24% will invite a sickler to their birthday party and as much as 68% will not like to study with a peer with SCD.[16] Similar study by Bazuaye also indicated that about 18% of secondary school students will show wrong attitudes including stigmatization toward SCD patients.[11] This findings show that attitude of respondents toward sickler is poor and many will likely stigmatize the sufferer. This has serious psycho-social effect on the patients and their parents. Many of the affected patients that reach adulthood may find it difficult to get spouses, and this could result in loneliness, inferiority complex, guilt feeling and neglect.[19] Greater percentage of the respondents (69.8%) claimed they will not accept termination of pregnancy (TOP) if prenatal diagnosis revealed likelihood of sickler in their unborn baby. This finding is similar to study from Benin where majority of the respondents will not accept TOP.[11] Prenatal diagnosis with the option of planned abortion if index pregnancy is carrying sickle cell fetus could be used to reduce the incidence of SCD as it was popularly used for the control of B-thalassemia in the Mediterranean countries.[20,21] Religious inclination, cultural background as well as ethical issue may probably affect the uptake of this treatment modality in our country as abortion has not being legalized. Many of the respondents knew the importance of genotype screening and agreed it should be made mandatory before marriage, but despite that some (62.4%) still believed that once there is love and money to take care of the affected child, carriers can marry themselves. Many (88.3%) will be willing to advice their friends to go for genotype screening as well as wanting their school authority to form sickle cell club. In Nigeria, the ratio of haemoglobin AA to AS is 4:1 and finding

appropriate mate choices should not be too difficult for sickle cell carriers. Majority (78.7%) of the respondents do not believe that it is a waste of time to go for genotype screening, the cost of which if subsidized or made free by government at all levels will create avenue for people to know their genotype early and save them from the horror of need to have a sickler child. Religious leaders that are mostly involved in marriage union should be equipped with necessary knowledge of SCD so that they can also give appropriate counseling before joining carriers in wedlock.

Conclusion

This study indicated that majority of study population (79.5%) were aware of sickle cell disease and have fair knowledge score compared with previous studies, though there still exist some gaps in knowledge of symptoms, mode of acquiring the disease as well as treatment modalities for SCD. More than half of the respondents (52%) knew their haemoglobin genotypes. The perception of the respondents toward sickle cell disease is not good enough as more than 50% will not accept sickler as a friend and many (90.3%) would not accept to marry a sickler. Majority (69.8%) of the respondents would not accept TOP on religious and cultural ground and 86.3% believed that premarital genotype screening should be make compulsory before marriage.

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