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STUDY OF DETERMINANTS OF KNOWLEDGE, PERCEPTION AND ATTITUDE OF YOUTHS TO SICKLE CELL DISEASE IN SOUTHWEST NIGERIA: IMPLICATIONS FOR FAMILY HEALTH PLANNING AND POLICY

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ABSTRACT

Backgound: The study was conducted to identify determinant factors associated to knowledge of, perception and attitude to sickle cell disease. **Methodology:** A total of 1,010 undergraduates of a Nigerian Federal tertiary institution aged 17-37 years participated in this questionnaire-based survey in 2016. Their haemoglobin genotype was determined by standard electrophoresis. **Results:** Participants included 202 males (20.0%) and 808 females (80.0%). Their mean age was 23.0±2.8 years. Among the respondents, 25.5% had good knowledge of sickle cell disease while 33.6% and 40.9% had average and poor knowledge respectively. Their mean score was 5.54±2.26. Eight hundred and twenty seven (81.9%) participants were not aware of their haemoglobin genotype at the time of the study; 914 (90.6%) were aware that marriage between HbAS pairs could result in a HbSS offspring. One hundred and twenty eight (12.7%) would proceed to marry a partner with HbAS genotype despite having HbAS genotype. Female gender (p=0.001), being a Christian (p=0.013) and studying degree-awarding courses (0.018) were significantly associated to higher mean scores. **Conclusion:** Knowledge of sickle cell disease was poor. In spite of high awareness level of sickle cell disease, a sizeable portion would proceed with marriage if they and their partners were HbAS. Female gender, Christianity and educational exposure influenced knowledge positively.

KEYWORDS: Determinants, sickle cell disease, knowledge, attitude, youth, Nigeria.

INTRODUCTION

Sickle cell diseases (SCD), a group of inheritable haemoglobinopathies are a globally recognized disorder of major public health concern. The highest burden of SCD is reported in sub-Sahara Africa, Mediterranean regions, the Middle East and South-East Asia (WHO 2006).[1] The World Health Organization (WHO) reported that approximately 5% of the world's population are healthy carriers of a gene for SCD or thalassaemia.[1] More than 200,000 infants are born with SCD in Africa every year.[2] Available data suggests that about 2% of newly born babies in Nigeria have SCD annually while 20% to 30% of the Nigerian population are reportedly carriers of the trait.[3]

Against a backdrop of a huge infrastructural deficit, the mortality from SCD, particularly among under-five children, remains unacceptably high. Recent estimates have shown that without timely and adequate intervention, up to 90% of affected children will die before the age of five years.[4-5] Likewise, a very recent study in Ekiti and Ibadan captured the huge financial implications of caring and catering for a child with SCD in Nigeria, which is worsened by the out-of-pocket module of health care financing currently operational in the country.[6-7] SCD is also associated with psychological and social problems which weigh heavily on sufferers and their caregivers alike.[8] It is therefore imperative that concerted efforts must be geared towards reducing the prevalence of new born with SCD.

Currently, the Centre for Disease Control (CDC) advocates premarital screening to reduce inheritance of haemoglobinopathies.[9] Other methods of preventing new haemoglobinopathy births include genetic counselling, prenatal diagnosis, preconceptional diagnosis and implantation of normal embryos after in vitro fertilization, and in utero therapy using stem cell transplantation.[10] These methods can have a major impact on the birth rate of children with SCD and other

genetic diseases.[11-13] For instance, as early as the late 1980s and early 1990s, Anionwu et al and Petrou et al independently confirmed the importance of detecting and counselling couples at risk before pregnancy and equally emphasized the great opportunity prenatal counselling and testing could present to couples by helping them make informed decisions on marriage and pregnancies in the United Kingdom.[14-15]

However, in spite of best efforts at counselling and interventions, the number of infants born with sickle cell disease (SCD) has not reduced thus suggesting that knowledge base and attitude of young people to avoiding marriage between HbAS/SS pairs is yet to improve significantly. In the study by Abioye-Kuteyi et al, about a quarter of the married respondents and those engaged to a partner did not know the sickle cell status of their partners while only 59% of secondary school students in a study in North central Nigeria knew their genotype.[16-17]

Prevention of SCD through public education, awareness of status, pre-conception counselling and genetic screening of individuals of reproductive age remain the cornerstone for the disease control in Africa considering the religious and cultural belief about pre-natal diagnosis (PND) and selective abortion of affected foetuses among Africans.[11,18] Besides, this strategy is relatively cheaper and non-invasive unlike PND and selective abortion. The psychological complications are also easier to manage.[17] Knowledge of the genetics of SCD and awareness of self-status among young adults is essential in care for individuals with SCD and choice of marriage partner. We therefore set out to evaluate the awareness and attitude of undergraduates in a Nigerian tertiary institution to SCD and identify their determinants (if any).

MATERIALS AND METHODS

This was a descriptive, cross sectional study conducted among undergraduates of Adeyemi College of Education, a Federal tertiary institution located in Ondo State, Southwest Nigeria that receives an estimated student population of 16,000 from the 6 geopolitical zones in the country. The study ran from April to June 2016. Non-students and non-consenting students were excluded from the study.

Semi-structured, self-administered questionnaires containing close-ended questions designed to assess knowledge and attitude were administered to consecutive, consenting participants. A set of equally weighted questions were used to assess knowledge with a maximum obtainable score of 10 and a minimum score of zero. Their performance was graded into good (8-10), average (5-6) and poor (0-4).

Two millilitres (ml) of venous blood was obtained from each participant and dispensed into Ethylene Diamine Tetra-Acetate (EDTA) blood collection tubes for determination of haemoglobin genotype using the standard haemoglobin electrophoresis machine (alkaline medium, *MICROFIELD, England*).

Statistical analysis

Data was analysed using Statistical Package for Social Sciences (SPSS) version 21. Categorical variables were presented as frequency and percentage, mean±standard deviation and median. Comparison of mean was carried out using independent sample T-test and $p< 0.05$ was considered as significant at 95% Confidence Interval (CI).

Ethical approval

Approval to conduct the study was obtained from the Research and Ethics Committee of Ondo State Specialist Hospital, Akure, Nigeria. A formal permission was received from the management of Adeyemi College of Education. Each participant gave verbal consent before recruitment into the study following careful explanation of our objectives and methodology.

RESULTS

There were 202 (20.0%) males and 808 (80.0%) females. Mean age was 23.0±2.8 years and age range, 17-37 years while majority of the participants were aged 17-25years (table 1). Seven hundred and fifty two participants (74.5%) consented to haemoglobin genotype testing. One hundred and sixty six (22.1%) and 6 (0.8%) had HbAS and HbSS genotypes respectively (table 2). Two hundred and fifty eight (25.5%) had good knowledge of SCD while 339 (33.6%) and 413 (40.9%) had average and poor knowledge respectively (table 3). Their overall mean score was 5.54±2.26.

Nine hundred and twenty six (91.5%) subjects knew that HbSS is the haemoglobin genotype for sickle cell anaemia while 446 (44.2%) and 396 (39.2%) knew that red blood cells are the cell type affected by sickle cell disease and the haemoglobin genotype associated with sickle cell trait respectively. Nine hundred and fourteen (90.6%) of the participants were aware that marriage between HbAS pairs could result in a HbSS offspring (table 4).

Eight hundred and twenty seven participants (81.9%) were unaware of their haemoglobin genotype at the time of the study while 979 (97.1%) participants expressed willingness to have their genotype checked. Fifty (5%) thought SCD patients are witches or *ogbanjes.* One hundred and twenty eight (12.7%) participants would go ahead to marry a partner with HbAS genotype even if their own genotype were HbAS {one hundred (100/128, 78.1%) of whom were aware that this might result in an offspring with HbSS genotype} as shown in table 5. This set of participants took this position for the following reasons: because they believe that such a partner is God's will for them (67.2%), they love their partner (19.5%) and God will heal their partner (11.7%).

Female gender (p=0.001), being a Christian (p=0.013) and studying degree-awarding courses (0.018) were significantly associated to higher mean scores (table 6).

DISCUSSION

There was female preponderance in our study as well as a higher proportion of adolescents and young adults (17-25 years). While the former may be explained by better health-seeking behaviour of females, the younger age range for majority of the participants is similar to reports obtained from universities within and outside Nigeria.[19-20]

This study revealed a high level of awareness on the haemoglobin genotype that is specific for sickle cell anaemia and consequences of marriage between couples with the carrier traits. This finding is similar to reports presented by Faremi et al and Alao et al in their separate studies among students of some tertiary institutions in Nigeria.[21-22] The high level of awareness may not be unconnected to the persistently high prevalence of SCD in Nigeria since first reported. For instance, we have reported a prevalence of 22.1% for HbAS in our study which tallies with a range of 20-30% previously reported in Nigeria about 4 decades ago.[23] In between, other studies indicate that the prevalence appears to have remained static since the 1970s in Nigeria.[3,10,23-25] This ought to be a cause for concern for healthcare workers, government and agencies involved in the care of SCD patients in Nigeria as increasing awareness of the disease reported in majority of studies in Nigeria has not translated to reduced prevalence.

Despite the high level of awareness of SCD, participants lacked in-depth knowledge of the disease as only a quarter of them demonstrated good knowledge of the disease. This is in agreement with studies conducted by Olanrewaju et al and Uche et al who also observed that comprehensive knowledge of SCD was poor among different groups of Nigerian students.[17,26] Of particular interest is that a high proportion do not know that it is a disease of red blood cells and, that it is not curable. Knowledge is poor probably because SCD is not part of the general teaching syllabus at the higher level in non-medical institutions. Even though SCD is now taught as part of social studies in junior secondary schools in Nigeria, insufficient space is committed to it. More so, the students at that level may not be matured enough to appreciate the significance of learning about SCD at that stage of their development.

This finding is therefore worrisome as poor knowledge of which haemoglobin represents the carrier trait may explain why many have not appreciated the importance of pre-marital screening in order to avoid marrying a partner with same haemoglobin carrier trait with consequent failure to reduce the prevalence of SCD in Nigeria. Therefore more direct peer pressure campaign strategies are required among adolescents and youths just as was carried out to combat the Human Immunodeficiency Virus (HIV) epidemic.[27]

Indeed, our study revealed that despite the high awareness level of SCD among our subjects, majority (81.9%) were not aware of their haemoglobin genotype. Similar reports were obtained among undergraduates at the Lagos State University, Nigeria and in Uganda.[26,28] However, Abioye-Kuteyi et al and Olubiyi et al observed otherwise in their respective studies among undergraduate students in neighbouring Ekiti State and workers in Ile-Ife.[16,29] These contrasting reports may be due to non-existing national policy on mandatory screening for haemoglobin genotype in Nigeria. It is worthy to note that in countries where pre-marital counselling and genetic testing has been mandated, the prevalence of SCD has reduced significantly of which Cyprus (where the disease is now nearly non-existential) has become a reference point.[30-32]

More than 10% of the population sampled (12.7%) affirmed they would still proceed to marry their spouses irrespective of their haemoglobin genotype status. This is despite the fact that 78.1% of them demonstrated a high level of awareness of the possibility of having a HbSS offspring. In the study by Abioye Kuteyi et al, among those who knew both their sickle cell status and that of their partner, high proportions (up to 64.5%) of subjects with haemoglobinopathy would continue with conjugal relationships.[16] These are quite contrary to reports from Saudi Arabia where a 5-fold increase in voluntary cancellation of marriage proposals among at-risk couples was recorded.[33]

In our study, those who would proceed with marriage despite being HbAS pairs were mainly influenced by the belief that God chose their respective partners for them. Other main reasons for taking such a stance included love for such partners and belief that God will heal their partners. This is unlike the report by Nnaji et al where a significant proportion of the participants who were all Christians would discontinue the relationship in similar circumstances.[24] It is therefore pertinent that young adults be properly counselled in line with medical reality and their faith. This further corroborates the need to direct government policies to focus on mass campaign on premarital screening, counselling and public enlightenment for effective disease control. Government, religious bodies and other organizations involved in reducing the burden of SCD may have to reinvent the wheel by using means of communication that are youth-oriented; employing music, quiz, drama, choreography, movies etc. may go a long way to drive home the message.

Christians showed better knowledge of SCD than Muslims in this study. A study conducted in a predominantly Muslim region in Nigeria showed Islam as a factor militating against acceptance of prenatal diagnosis of sickle cell disease.[11] While this may be

associated with advocacy for pre-marriage counselling in most Churches nowadays it should be noted that more Christians participated in this study and that may have impacted our finding. Be that as it may, this suggests the important role the place of worship and religious leaders play in control of SCD. It also points to the importance of religious circle as a medium for effective sensitization.

It was also observed that students who enrolled into degree courses had better knowledge than those offering courses in NCE. This is similar to findings by Abioye-Kuteyi et al who reported better knowledge among subjects with tertiary education compared to those with non-tertiary.[16] Also the study by Ugwu et al showed that students and workers in the medical line have better knowledge than their counterparts.[20] These reports are indicative of the need to strategically infuse teachings on SCD into the learning curriculum from at least the secondary school level without necessarily adding to the burden of class work. This could be achieved by offering it as part of Elective Courses in the tertiary level or holiday lesson and/or part of an interesting extracurricular activity at the Secondary learning level.

Female students appeared to have better knowledge than their male counterparts. Females are often the care givers and bear more problems associated with sickle cell disease in the family. While this is similar to study among general population in Saudi Arabia with similar high prevalence of SCD as indicated by Alturaifi et al.[34] it is important to mention that there were more females in this study. One study in Nigeria shows no significant impact of female gender on knowledge even though it did impact significantly on attitude.[16] It is also worthy of note that certain proportion still holds to myth about SCD. About a quarter of the participants were still not sure about the myth of SCD being a curse, punishment from God or individuals with SCD being witches. This signifies misconception about the disease and further stresses the need to educate people about its cause and prevention.

Table 1: General characteristics of the participants.

Characteristics	Total, N (%)	Male, N (%)	Female, N (%)	P value
Gender		202(20%)	808 (80%)	
Age groups				
17-25 years	832 (82.4%)	147 (72.8%)	685 (84.8%)	0.000*
26-37 years	178 (17.6%)	55 (27.2%)	123 (15.2%)	
Religion				
Christianity	938 (92.9%)	177 (87.6%)	761 (94.2%)	0.002*
Islam	72 (7.1%)	25 (12.4%)	47 (5.8%)	
Class				
NCE 1	117 (11.6%)	23 (11.4%)	94 (11.6%)	0.204
NCE 2	53 (5.2%)	10 (5.0%)	43 (5.3%)	
NCE 3	260 (25.7%)	45 (22.3%)	215 (26.6%)	
BSc level 1	125 (12.4%)	23 (11.4%)	102 (12.6%)	
BSc level 2	149 (14.8%)	33 (16.3%)	116 (14.4%)	
BSc level 3	202 (20.0%)	41 (20.3%)	161 (20.0%)	
BSc level 4	103 (10.2%)	27 (13.4%)	76 (9.4%)	
Department				
Science-based	340 (33.7%)	85 (42.1%)	262 (32.4%)	
Non-science based	670 (66.3%)	117 (57.9%)	546 (67.6%)	
State of origin/residence				
Southwest	946 (93.7%)	187	759	0.420
Others	64 (6.3%)	15	49	

*KEY: NCE - National College of Education, BSc - Bachelor of Science, *value is significant at p < 0.05*

Table 2: Distribution of haemoglobin genotypes among participants.

Haemoglobin genotype	Frequency (N)	Percentage (%)
AA	545	72.4
AS	166	22.1
SS	6	0.8
SC	4	0.5
AC	29	3.9
CC	2	0.3
Total	752	100%

Table 3: Knowledge and mean scores of participants on sickle cell disease.				
Score	**Frequency (%)**	**Male (N=202)**	**Female (N=808)**	**Mean ± SD**
Good	258 (25.5%)	36 (17.8%)*	222 (27.5%)*	8.54±0.89
Average	339 (33.6%)	70 (34.7%)*	269 (33.3%)*	5.99±0.22
Poor	413 (40.9%)	96 (23.2%)*	318 (39.4%)*	3.29±1.06
*KEY: SD - standard deviation, *derived using the formula, n/N x100%*				

Table 4: Proportion of correct responses to questions on knowledge about sickle cell disease.		
Questions	**Expected**	**Correct response N (%)**
SCD[a] is a disease of red blood cells	Yes	446 (44.2%)
Sickle cell anaemia patients have the Hb genotype called HbSS	Yes	926 (91.7%)
Sickle cell traits have the Hb genotype called HbAS	Yes	396 (39.2%)
Africa is continent where Sickle cell disease is most prevalent	Yes	619 (61.3%)
Sickle cell disease is curable	No	624 (62.8%)
Marriage between HbAS pairs may produce HbSS	Yes	914 (90.6%)
KEY: SCD - sickle cell disease, Hb - haemoglobin		

Table 5: Attitude/perception of participants towards sickle cell disease.		
Attitude/perception of sickle cell disease	**N (1,010)**	**Percent**
Sickle cell disease is due to a curse	181	17.9%
Sickle cell disease is a punishment from God	39	3.9%
Sickle cell disease patients are witches and *ogbanjes*	50	5.0%
Pre-marital screening should be made compulsory	972	96.2%
I am not aware of my haemoglobin genotype	827	81.9%
I am willing to know my haemoglobin genotype	979	97.1%
I will marry a HbAS partner even if my haemoglobin genotype is AS	128*	12.7%*
**out of these subjects, 100 (78.1%) were aware that it could result in offsprings with HbSS*		

Table 6: Comparison of knowledge scores using Independent sample T test.				
Class	Mean score	Mean difference	P value	CI at 95%
NCE 1-3 BSc level 1-4	5.35(±2.37) 5.69 (±2.24)	-0.339	0.018*	-0.620 to -0.057
Department				
Science-based Non-science	5.71 (±2.43) 5.45 (±2.17)	0.266	0.087	-0.039 to -0.570
Gender				CI at 95%
Male Female	5.07 (±2.24) 5.66 (±2.25)	-0.590	0.001*	-0.937 to -0.244
Religion				CI at 95%
Christianity Islam	5.59 (±2.24) 4.85 (±2.42)	0.748	0.013*	0.161 to 1.334
Age				CI at 95%
17-25 years 26-37 years	5.55 (±2.26) 5.50 (±2.25)	0.048	0.796	-0.319 to 0.416
*KEY: NCE - National College of Education, BSc - Bachelor of Science, *value is significant at p < 0.05.*				

CONCLUSIONS

We thus conclude that despite good awareness about SCD, its in-depth knowledge remains poor among young adults in this study. Prevention remains the sole hope to reduce the burden of SCD in Nigeria, it therefore becomes imperative to educate young people of marriageable age group on the medical and psychosocial problems associated with sickle cell disease. Health policies including public enlightenment in schools and religious centres could be crucial towards reducing the burden of SCD.

Competing interests

The authors declare no competing interest.

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