Knowledge And Attitude Of Youth Corps Members In Lagos To Sickle Cell Disease

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Abstract

Sickle cell disease has remained a public health problem in Nigeria. This study was carried out to determine the knowledge and attitudes of unmarried NYSC members in Lagos State to sickle cell disease and screening.

This study was a cross sectional study. Multistage sampling technique was used to select the respondents. Data was collected from 220 Youth Corps Members in Lagos State using a self administered questionnaire. *Almost all the respondents were aware of sickle cell but* only 25.3% had good level of knowledge about it. Most of the respondents had positive attitudes to many aspects of sickle cell disease. However, their perception of risk of the trait in relatives and partners, as well as the risk of the disease in children was very low. There was a significant relationship between level of knowledge on sickle cell and having a genotype test ($p<0.05$).

Many respondents have a poor level of knowledge and a low perception of the risk of sickle cell in their proposed children. Health education and screening programmes should be targeted at undergraduates and new graduates to improve their knowledge and attitude towards sickle cell disease so that they can make informed decisions concerning procreation.

Keywords: Knowledge, attitude, Sickle Cell Disease , Screening, Youth Corps members.

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Introduction

Sickle cell disease refers to a group of autosomal recessive disorders caused by inheritance of a pair of abnormal haemoglobin genes, including the sickle cell gene. Sickle cell trait occurs in people with one sickle cell gene and one normal gene and such people do not have any clinical manifestation of illness. Genetic testing however can identify persons with the trait who can transfer the gene to their offspring leading to the disease, if their partners also transfer the gene.

About 5% of the world's population carries genes responsible for haemoglobinopathies. Sickle-cell anaemia is particularly common among people whose ancestors come from Sub-Saharan Africa, India, Saudi Arabia and Mediterranean countries. In some areas of Sub-Saharan Africa, up to 2% of all children are born with the condition[1].

The prevalence of the sickle-cell trait ranges between 10% and 40% across equatorial Africa and decreases to between 1% and 2% on the north African coast and <1% in South Africa. In West African countries such as Ghana and Nigeria, the frequency of the trait is 15% to 30% whereas in Uganda it shows marked tribal variations, reaching 45% among in the west of the country. In Nigeria, about 24% of the population are carriers of the mutant gene [1]. The frequencies of the carrier state determine the prevalence of sickle-cell disease at birth. Each year about 300 000 infants are born with major haemoglobin disorders in the world; including more than 200 000 cases of sickle-cell anaemia in Africa .

Sickle cell disease has remained an unresolved health problem in Nigeria It is the commonest genetic disorder in Nigeria and WHO puts its prevalence (at birth) in Nigeria in 2006 at 20 per 1000 births which means that about 150,000 children are born with sickle cell disease genotype annually in Nigeria alone[1] The country harbours the highest number of sickle cell disease sufferers in the whole world.

In affected children, symptoms usually begin about the fourth month of life by which time the level of Hb F which prevents polymerization has considerably reduced. Haemoglobin S gene causes the red cells to become hard, sticky and sickle-shaped, making them easily destroyed and causing blockage of blood vessels and depriving body organs of blood and oxygen. This results in a chronic, slow deterioration of

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simple random sampling method (balloting). Lagos Island local government area was selected from the division using simple random sampling. The corps members in the eligible batch for the study (batch b 2007/2008) were about two hundred and eighty (280), out of which two hundred and thirty nine (239) were unmarried. All the eligible corps members in that batch were recruited for the study.

Data collection was through quantitative method using semi-structured, self administered anonymous questionnaire with the assistance of the field/zonal inspectors.

Questionnaire was pre-tested.

Ethical approval was obtained from the Ethics and Research Committee of the Lagos University Teaching Hospital. Informed consent was obtained from each of corps members.

The Epi Info software was used for data entry, validation, cleaning and analysis. In determining the level of knowledge, scales were developed by the researcher based on the number of questions answered correctly. The maximum obtainable point for knowledge about the disease was sixteen (16) those who scored six points or less were considered as having poor knowledge; those who scored between seven andnine points (7 -9) were considered as having fair knowledge, while those who scored between ten and sixteen points (10-16) wereconsidered as having good knowledge. In determining the level of knowledge about genotype screening, the maximum obtainable points was 6, therefore those who scored two points or less (< or =2) were considered as having poor knowledge; those who scored either three or four points (3-4) were considered as having fair knowledge. while those who scored either five or six points (5-6) were considered as having good knowledge about screening.

Results

Two hundred and twenty (220) questionnaires were fully completed and retrieved.

The respondents' ages ranged from 19 to 33 years. The mean age of the respondents was 25.0 ± 2.2 years. More than half of the respondents (53.6%) were females. Social sciences were the commonest courses studied by respondents followed by pure and applied sciences. Majority (91.8 %) were Christians.

Almost all (99.1%) the respondents were aware of sickle cell disease. Only 28.0% correctly knew that SCD occurs more amongst black people while majority (88.10%) correctly identified 'inheriting genes from parents' as the cause of SCD. Less than half of the respondents (45.4%) however knew that sickle cell disease occurs if both parents have at least one HbS and have children. Majority (84.4%) knew that SCD is a serious disease. Most of them (73.4%) also knew that SCD cannot be cured easily in Nigeria today. Only 11% of the respondents knew stroke to be a complication of SCD while 29.8% knew infections as complications. Most of them (62%) were able to identify severe debilitating pain as a complication. Only 41% of the respondents knew that sickle cell disease is not manifested in carriers. (Table 1, Table 2)

Only about half (51%) of the respondents knew that prenatal screening is possible, while 56.4% knew that neonatal screening is possible. About half (51.8%) also knew that sickle cell haemoglobin can be detected by blood test. Only 15.6% of the respondents had good level of knowledge about screening for sickle cell disease. There was no relationship between sex of respondents and level of knowledge about SCD.(Table 3)

Majority of the respondents (67.9%) considered sickle cell disease as a major health problem in Nigeria. Many of them (68.3%) believed that all the people who have SCD are normal, except for the blood defect; while only 38.5% believed that they can achieve as much as their mates in life. Myths and misconceptions exist as 7% believed that they are reincarnates known as abiku or ogbanje. (Table 4)

Less than half (45%) believed that SCD could exist in their families while 33.5% thought it was not possible. More than 60% of the respondents had stable proposed marriage partners. Majority of the respondents who had proposed marriage partners (66.7%) were aware of their partner's genotype while 33.4% were not aware. Only 11.1% of those whose partners had not done genotype believed that their partners could be carriers of SCD (Table 5). Almost half of the respondents (44.4%) would change marriage plans if they discover that they and their partners had sickle cell trait (SCT). Only about 8% would do prenatal screening with selective abortion, while about 12% would freely accept if their children had sickle cell disease. Majority of the respondents (93%) also believed that couples should have genotype test before marriage while 92.7% would be willing to ask their partners to do genotype test before marriage.

Majority of the respondents (85.3%) believed that genotype screening is useful to the society. About 39.9 % agreed that prenatal screening and selective abortion is a good practice while 33.5% disagreed. Majority of the respondents (80%) supported mandatory newborn screening (Table 6). Majority of the respondents (92%) believed in the usefulness of knowing one's genotype. Majority of respondents (60.6%) agreed that individuals should not pay for genotype test the government should and only 4.6% believed that genotype test is painful. Majority of the respondents (83%) knew their genotypes. About one

multiple organ systems culminating in recurrent episodes of severe pain, anaemia *(6-8g/dl)*, serious infections and damage to vital organs. Further complications include stroke, kidney damage, respiratory problems, bone marrow failure, growth failure and maturational delay in children, high maternal and fetal morbidity, mortality and other complications in pregnancies,.

Its impact on human health may be assessed against the yardsticks of infant and under-five mortality. As not all deaths occur in the first year of life, the most valid measure is under-five deaths. Increasing proportions of affected children now survive past five years of age but remain at risk of premature death. When health impact is measured by under-five mortality, sickle-cell anaemia contributes the equivalent of 5% of under-five deaths on the African continent, more than 9% of such deaths in West Africa, and up to 16% of under-five deaths in individual West African countries[1].

In the United States of America, median survival was estimated in 1994 to be 42 years for men and 48 years for women, whereas comparable figures for Jamaica published in 2001 suggested 53 years for men and 58.5 years for women .The median survival age of patients with sickle-cell anaemia on the African continent is estimated to be less than 5 years . In sub-Saharan Africa, *most of the affected children do not survive childhood largely because of malaria and bacterial infections and lack of access to appropriate care*

Sickle-cell disease also has major social and economic implications for the affected child as well as the family. When compared with a similar study of cancer patients, relatives of patients in SCD crisis perceived similar financial, family routine burdens and psychological distress scores. Recurrent sickle-cell crises interfere with the patient's life, especially with regard to education, work and psychosocial development. Studies have also shown that quality of life is affected in children with sickle cell disease (SCD) and to a lesser extent in those with sickle cell trait (SCT) . Moreover there's recurrent huge national expenditure on the management of the condition.

In high-resource countries several methods are available for the management of the disease. Examples of such methods include: prenatal and neonatal screening programs, long-term treatment with hydroxyurea, bone marrow and cord blood transplantation *(unattainable to all but the fortunate minority)*. In Africa however, overall treatment of patients is still poor and, in some places, inadequate.

Therefore for Africans and in particular Nigerians, an important approach for controlling the disease is preventive; and this depends upon education, the detection of carriers, genetic counseling, prenatal screening for fetal genotype done in couples who are both carriers and newborn screening for sickle cell genotype. There is, however, a palpable lack of information and education about the disorder[11], which, with the increasing prevalence, has encouraged the growth of myths, misinformation, inappropriate treatment, frustration and stigmatization . A study among new graduates of Nigerian tertiary institutions, who may be described as educated and elite by Nigerian standards revealed severely deficient knowledge on the transmission of sickle cell disease and implications of heterozygous state. It was concluded that unmarried youths in or graduating from higher institutions may be a most suitable target for information, carrier detection and genetic counseling in the prevention of sickle cell disease.[12]

The concern about genetic testing is that those with the trait are generally healthy; therefore many might not make informed decision at the time of marriage or procreation. People should know their genotype before considering marriage, receive genetic counseling if necessary and be informed about possible consequences and options available which may help them to make the right decisions for themselves and their families.

People who are close to making a decision on who to marry or have just made such a decision are a good target group for health education on sickle cell disease and screening. Such people can be found among new graduates of higher institutions because people at that age usually give much thought to issues about marriage. The National Youth Service Corps programme offers a unique access to a good sample of such unmarried new graduates. Most of the "corps members" are usually between the ages of 20 and 30 years, unmarried (about 90%) and represent different ethnic, socio-economic, cultural and religious groupings in Nigeria.[12]

This study aims to assess the level of knowledge and attitude of unmarried youth corps members in Lagos State to sickle cell disease and screening and generate data that would be usefull in designing evidence based health education programmes on sickle cell disease and screening for unmarried undergraduates and new graduates as part of efforts to control the disease.

Methodology

This cross sectional study was conducted in Lagos, Nigeria among the National Youth Service Corps members. Graduates of tertiary institutions in Nigeria are enrolled into the corps immediately after graduation for a one year national service. A multistage sampling technique was used to select the respondents. Lagos division was selected from the five administrative divisions in Lagos State using

Table 1: Respondents' knowledge about aspects of sickle cell disease.

Knowledge of sickle cell disease	Freq (%)
Occurs more among black people	61(28)
Caused by inheriting genes from parents	192 (88.1)
Occurs if both parents have at least one HbS and have children	99 (45.4)
Carriers do not manifest the disease	89 (40.8)
It's a serious disease	183(84.4)
Cannot be cured easily	160(73.4)

Table 2: Distribution of respondents knowledge scores about sickle cell disease

Level of knowledge about SCD (scores)	Freq %
Poor (0 to 6)	84 (38.6)
Fair (7 to 9)	75 (34.4)
Good (10 to 16)	59 (27.0)
Total (16)	218 (100)

Table 3: Distribution of respondents by level of knowledge about genotype screening

Level of knowledge about screening	Freq %
Poor (0 to 2)	87 (40.0)
Fair (3 to 4)	97 (44.4)
Good (5 to 6)	34 (15.6)
Total (6)	218 (100)

Table 4: Respondents' attitudes to people with sickle cell disease

Attitude to people with sickle cell disease	n=218 Freq (%)
Normal except for the blood defect.	149 (68.3)
Can ever achieve as much as their males	84 (38.5)
Reincarnates known as abiku /ogbanje	15 (6.9)
All die young before 15 yrs	30 (13.8)

Table 5: Attitude of respondents who were not aware of their partners' genotypes to the possibility of partners being carriers.

Partner being A carrier	n=45 Freq (%)
Possible	5 (11.1)
Not possible	40 (88.9)
Undecided	0 (0.0)
Total	45

Table 6: Respondents' attitudes to prenatal screening with selective abortion and mandatory newborn screening pre-intervention

Prenatal screening and selective abortion	Freq (%)
Strongly agree	44 (20.2)
Agree	43 (19.7)
Undecided	58 (26.6)
Disagree	32 (14.7)
Strongly disagree	41 (18.8)
Mandatory new-born screening	
Support	173 (79.4)
Do not support	28 (12.8)
Undecided	17 (7.8)
Total	218 (100)

quarter of respondents (26.5%) who had not done their genotype didn't do so because they didn't know about it while 23.5% didn't do it because they didn't believe they were at risk of SCT.

Only 22% of those who had not done their genotype test believed that it is possible for their children to be at risk of SCD. However 73% of them would like to be tested for their genotypes. Only 30.4% of respondents who had had genotype test did it out of personal choice. About 20.4% did it as a request from a school on gaining admission while only 4.4% did it based on request from intending spouse. Less than half (i.e 45.2%) of those who had SCD or SCT had ever received genetic counseling. Among the rest who had not received, only 35.3% were willing to receive it. Majority of those who had SCT (73.3%) were willing to discuss their status with their partners. About 80.9% of the respondents were willing to have more information about sickle cell disease.

Discussion

Majority of the respondents were Christians, had university education and were within the age group 24-29 years. This was expected since most people would not have graduated from higher institution until they are about twenty years old and the age limit for compulsory service in the NYSC is 30 years.

Almost all the respondents (99.1%) were aware of sickle cell disease. A lot of the respondents (44%) obtained their information about SCD from the school while about 36% got it from the media. Friends were a commoner source of information than the health institutions. Information received from friends may not be accurate. A study conducted in Ile-Ife had similar findings where 23% had heard of SCD through news media, 29% through friends and relations, 21% obtained the information through health workers. Another study in Nigeria also revealed that the health institutions in the locality and the electronic media were poor sources of information on sickle cell anaemia.

Majority (88.1%) correctly identified 'inheriting genes from parents' as the cause of SCD but less than half of the respondents (45.4%) knew that sickle cell disease occurs if both parents have at least one HbS and have children. The knowledge of aetiology without understanding the pattern of inheritance is not enough for an individual to take preventive actions. This finding was similar to some studies conducted among the African American women, which showed that majority of the participants believed that sickle cell disease was a hereditary blood disorder, but only a few

understood the inheritance pattern . However, a contrasting result was obtained in Ile-Ife where the majority of the respondents (69.5%) appreciated the role of both parents in the transmission of the disease [24]. Other studies in Ibadan and Oakland USA have also confirmed that natural/genetic aetiologies were the most (more than 70%) commonly proffered by respondents

Majority knew that SCD is a serious disease (84.4%) and cannot be cured easily in Nigeria today (73.4%). This agreed with other studies [29] including those among the African Americans where the women of childbearing age had a high perception of severity of sickle cell disease. It was however different from a study conducted in 2002 in Nigeria on the issue of treatment of SCD where 27.4% of the respondents said it could not be cured. These contrasting results may be attributed to an increase in the awareness of SCD over the few years interval between the two studies.

The proportion of the respondents who knew the complications was generally poor except for severe debilitating pain which was identified by 62% of the respondents. Only 29.8% of respondents knew infections as complications while 11% of the respondents knew stroke to be a complication of SCD. The complications identified were similar to a study conducted among the African Americans, where most women recognized pain (94%), infections (80%) and strokes (40%) as complications of sickle cell disease [26]. However, the proportions who knew each complication among the African Americans were higher than among these Youth Corps members in Nigeria where the disease is most prevalent.

This study revealed that only about half (51%) of the respondents knew that prenatal screening is possible while 56.4% knew the possibility of newborn screening. The proportion of respondents who had knowledge of these types of screening is too low considering the prevalence, severity and non-availability of definitive cure of the disease and hence the need for these methods of prevention . The findings are similar to a study in Ile-Ife, Nigeria where 44% of the respondents were aware that SCA could be diagnosed in pregnancy [24].

Only 25.3% of respondents had good level of knowledge about SCD and screening. The finding was similar to that of Adewuyi in year 2000 which showed that there was severely deficient knowledge on the transmission of sickle cell disease among the 20-32 year old graduates [12]. However, reports from Oakland in USA where the prevalence of SCD is much lower revealed that majority of community survey respondents (86.2%) had correct general knowledge about the genetic basis and severity of sickle cell disease [29]. Good level of knowledge usually aids taking preventive action and this was demonstrated in this study as there was a significant positive relationship between level of knowledge and awareness of individual's genotype($p<0.05$)

There was no relationship between sex of respondents and level of knowledge about SCD.($p>0.05$) A higher proportion of those who attended University had good level of knowledge about SCD than those who attended Polytechnic in both groups but the relationship between higher institution attended and level of SCD knowledge was not statistically significant. This was not strange since it has been shown that for most respondents, the educational institutions attended, may not influence information on sickle cell anaemia [20].

Majority of the respondents (67.9%) recognized sickle cell disease as a major health problem but only 38.5% believed that they can ever achieve as much as their mates in life. This finding confirms the misinformation, myths and stigmatization of people who have the disease in our society. However, only about 7% believed that they are reincarnates known as ""abiku" or "ogbanje". The majority of the respondents having positive attitude may be attributed to their level of education compared to many other people in the traditional societies . A study conducted in Ibadan also revealed that 8.6% of the respondents believed in re-incarnation theory for SCD while another study among students in the University of Ibadan showed that majority had a positive attitude toward sickle cell disease.

Almost half of the respondents (44.4%) would change marriage plans if they discover that they and their partners had SCT. Only about 8% would do prenatal screening with selective abortion, while about 12% would freely accept if their children had sickle cell disease. The acceptability of prenatal screening and selective abortion as a likely decision was quite low probably due to low level of awareness of this mode of control in Nigeria [24] and the termination of pregnancy involved. Those who would freely accept to have children with sickle cell disease might not have understood the complications and other consequences of the disease. About 26% of respondents in each group did not know what they would do if faced with the situation. This shows that many youths are not prepared to make informed decision that could help in the control of the disease. Findings are similar to that of a study in University of Benin where 37.7% of the respondents said they would not continue with marriage plan if intending partner is a carrier just like them and many of them (41.8%) were not sure what decision they would take [32].

This study revealed that less than half (45%) of all respondents believed that SCD could exist in their families; only 11.1% of those whose partners had not

done genotype believed that their partners could be carriers of SCD while only 22% of those who had not done their genotype test believed that it is possible for their children to be at risk of SCD. These attitudes could hinder the respondents from taking necessary health actions even when they know some facts about the disease.

The attitudes regarding genetic diagnosis are markedly different among various societal groups. In this study, majority (85%) of the respondents believed that genotype screening is useful to the society, believed in the usefulness of knowing one's genotype (92%), supported mandatory newborn screening (79%), supported premarital screening (93%) and would be willing to ask their partners to do premarital genotype test (92.7%).

This is in consonance with a study in Pakistan where a large proportion (88.5%) agreed to the idea of genetic diagnostic screening, premarital carrier screening was favoured by 77% of the respondents, 63% of the parents' favoured making genetic screening mandatory. Another study in Benin is in consonance with the high proportion supporting premarital screening and newborn screening [32]. Moreover, 85.45 % of those who agreed with premarital screening in that study would ask their partners to do genotype test before marriage [32]. Reports among African American women also revealed that they had a high perception of benefit to sickle cell trait testing [31].

Although prenatal screening has been available for many years, it is not acceptable to many owing to issues relating to termination of pregnancy. In this study, about 39.9 % strongly agreed/agreed that prenatal screening and selective abortion is a good practice. This finding is similar to that of a study in Ilelfe where only 45% would opt for termination of affected pregnancy.

Only 4.6% of respondents believed that genotype test is painful but 60.5% strongly agreed/agreed that the government should pay for genotype test. This could pose as a barrier to even those who have a right attitude to the screening since they may be waiting for the government to make screening available free of charge before taking any action. In contrast African American women are reported to have a low perception of barriers to testing for sickle cell trait [31].

A high proportion of the respondents (83%) were aware of their genotypes. The finding is in consonance with the study conducted in Benin where more than half (65%) of them had done their genotype test [32] and another one among the African American women, where only eleven percent of the women were unaware of their sickle cell trait status. The study is however in contrast with another study in Oakland in USA which revealed that in a community survey only 16% (n=45) of respondents knew their own trait status [29]. It was observed that higher proportion of females knew their genotypes than males but the relationship was not statistically significant (p=0.331). This study however revealed a significant relationship between level of SCD knowledge and awareness of one's genotype ($p < 0.05$).

About one quarter of those who had not done their genotype didn't do it because they didn't believe they were at risk of SCT or they didn't know about it while more than 40% didn't have any reason at all for not doing it. 30.4% of respondents who had had genotype test did it out of personal choice. Only 4.4% did it based on request from intending spouse. The proportion of respondents various reasons are similar to the findings in Benin where 51.8% of those who had done their genotype test did it out of personal choice and inquisitiveness and 4.1% as requested from intending spouse [32]. The low proportion that did the test as a request from a spouse shows that at the stage when people have fallen in love and have decided to marry, they might not give much thought to genotype status.

Screening without counseling would result in individuals making decisions concerning reproduction without full knowledge of the risk and the implications of the decisions. In this study, out of those who had known their genotype to be any form of SCD or SCT, less than half (45.2%) had had genetic counseling while only 35% of those who had not received counseling would be willing to receive it. This means that more than half of those who had done their genotype test could still go ahead to have children with sickle cell disease and not know what to do about it. It is not just enough to know one's SCT status, it is important to understand the implications, the different preventive options available and be able to make informed decisions. This finding differs from a study in Ibadan where the students in the University of Ibadan had a positive attitude towards genetic counseling [36]. Majority of those who had SCT (73.3% and 90.3%) however were willing to discuss it with their partners.

Conclusion and Recommendations

The level of knowledge was poor (only 25.3% had good level of knowledge), though most of the respondents (at least 63%) had positive attitudes towards many aspects of sickle cell disease and screening except perception about the risk of the disease and payment for tests.

Sustained health education with emphasis on the risk of the disease in Nigeria, through school curriculum, mass media, NYSC orientation camps and health institutions would be relevant in an effort to influence undergraduates and new graduates to have better knowledge and attitudes towards sickle cell disease and screening. This will enable them to make informed

decisions about pro-creation later in life.
There should be a national policy about mandatory newborn screening and efforts should be made to subsidize costs of screening generally.

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