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Knowledge, Attitude and Uptake of Premarital Screening for the Sickle Trait Among Married Couples in a Semi-Urban Community in South-South Nigeria

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Abstract: More than 24% of Nigerians are carriers of the sickle cell gene, while about 2% of all the newborns in Nigeria are born with the sickle cell disease. The disease is a lifelong cause of severe morbidity that often require prolonged hospital admission; even as the patients have 92% excess mortality. The prevention of the disease is therefore very important, especially in Nigeria whose contribution to the global total has been projected to increase. Premarital screening for the sickle cell gene is considered one of the best ways of preventing the sickle cell disease. This study assessed the knowledge, attitude and uptake of the premarital screening among married couples in Choba, a semi-urban community in south-south Nigeria. A descriptive cross-sectional study design was used, with the data collected using structured, interviewer-administered questionnaire that was administered on married male members of the study community. A total of 290 questionnaires were administered and retrieved. The respondents had an average age of 30.55 ±4.1 years; majority (65.86%) had a tertiary education and they were all Christians. All the respondents knew about the sickle cell disease, while 84.83% were aware of the premarital screening for the disease. All had positive attitude towards the premarital screening, with 88.97% recommending that the screening be made compulsory for all intending couples. Most (72.76%) of the respondents carried out the premarital screening when they got married. The age, educational attainment and the religious denomination of the respondents significantly influenced the uptake of the screening (p-value > 0.001). A total of 9.00% of the respondents were of the same HbAS genotype as their intended spouses; out of which 21.05% went ahead and got married, citing as reasons the difficulty of jettisoning their spouses (25.00%); and the power of God to prevent a child with sickle cell disease (75.00%). The knowledge, attitude and uptake of premarital screening for sickle cell disease are high in the study, even as the screening programme is not driven by the government. The input of the government is however required in providing health education, genetic counselling and prenatal diagnosis.

Keywords: Sickle Cell Disease, Premarital Screening, at-Risk Couple, Christian, South-South Nigeria

1. Introduction

The sickle haemoglobin (HbS) gene was developed in response to severe malaria endemicity[1]. It has been determined that up 24% of Nigerians have the sickle cell gene[2]. Multiple studies have shown that the sickle cell gene is indeed protective against malaria, as heterozygotic persons with a single sickle cell gene (AS individuals) have been shown to have a decreased risk for the disease[3, 4].

Homozygotic individuals (SS individuals) that inherited two HbS alleles from both parents are however not only at greater risk of contracting malaria, but are also at higher risk of several health problems, linked to the tendency of the altered red blood cells to become sickled, and then stick to blood vessels, causing ischaemia to multiple cells and organs of the body, and resulting in the sickle cell disease[3].

About 2% of all the newborns in Nigeria are homozygotic with the sickle cell gene, and therefore likely to suffer from the sickle cell disease[2]. The disease is a lifelong cause of severe morbidity that often require prolonged hospital

admission; and responsible for deformities like the characteristic sickle cell facie; and the disabilities that arise from sickle cell crises and the foot ulcers and infections that characterize the disease[5 – 7].

Yet, more than half of the newborn with the SS gene die in their first years of life; those that survive have an average life expectancy that is significantly less than the normal population, with reported excess mortality reaching up to 92%[8, 9]. It is also estimated that 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, including Nigeria[2].

The prevention of the inheritance of a double sickle cell gene is therefore much better than any healthcare that can be given to the patient with sickle cell disease, especially in endemic, low-resourced countries[10, 11]. This informs the recommendation of the 59th World Health Assembly that member states of the World Health Organization with sickle cell disease as a public health problem, should design and implement a comprehensive and integrated national programme, for the prevention and management of the disease.

In 2010, Nigeria was one of the three countries (Nigeria, India, and the Democratic Republic of the Congo [DRC]) that contributed 57% of the global total of newborns with sickle cell anaemia, but whereas the contributions of the two other countries have been projected to decrease by 2050, the contribution of Nigeria to the global total has been projected to increase from the present 30%, to 35% by 2050[12]. This calls for the urgent introduction of premarital screening programmes, and other preventive programmes in Nigeria, to for stale the projected increase.

Premarital screening for the identification of carriers of the sickle cell gene, and genetic counseling, especially for at-risk couples with the gene is considered one of the best ways of preventing the sickle cell disease in the newborn[10]. The premarital screening involves the use of a low-cost laboratory test that detects the sickle cell haemoglobin; while the genetic counseling is primarily the educational and non-directive counseling of the at-risk couple on the consequences of their genotype, the probability of having babies with sickle cell disease, and the ways they can prevent or reduce the risk, using informed decisions that are consistent with their own values[13].

Premarital screening is especially ideal for developing countries such as Nigeria, with high sickle cell disease burden; because it requires less technical expertise than comparable preventive measures such as prenatal diagnosis and in-vitro selection and implantation of normal embryo; and more importantly carries less ethical burden[14].

Currently, there is no formal premarital screening programme for the sickle cell gene in Nigeria, but religious bodies and other institutions that solemnize marriage in Nigeria increasingly ask intending couples to be screened for the disease. Screening programmes such as these are often able to detect a large proportion of at-risk couples, and therefore play a significant role in reducing the number of children born with a homozygotic sickle cell gene [14, 15].

The modest efforts of the religious bodies in encouraging premarital screening for the sickle cell trait have not been adequately assessed. This study assessed the knowledge, attitude and uptake of the premarital screening among married couples in Choba, a semi-urban community in south-south Nigeria, where premarital screening for the sickle cell trait has been in practice for some years. It is hoped that the results of the study would help in packaging a more comprehensive and government-led premarital screening programme in Nigeria.

2. Materials and Methods

Study site: Choba is one of the host communities of the University of Port Harcourt, with a well-organized extended family structure that form the main basis of community administration. Most of the inhabitants of Choba community are subsistent farmers of cassava, yam and vegetables, although increasingly number are now self-employed artisans and traders; or in paid employment, as the community continue to run short of agricultural land, due to urbanization. Christianity is the main religion in the community, and Christian organizations are active in the community, especially in solemnizing marriages.

Study design: A descriptive cross-sectional study design was used, with the data collected using structured, interviewer-administered questionnaire that was administered on married male members of the selected extended families of the community.

Sample size estimation: The study was designed to detect a 5% difference in knowledge of premarital screening for the sickle cell trait, with an alpha error of 5%, acceptable beta error of 20%, and a statistical power of 80%; and using the prevalence of 78.9% recorded among the undergraduate students of the University of Benin, south-south Nigeria[16]. Using the usual formula for sample size determination for descriptive studies, the minimum required sample size was thus determined to be 256, but was made up to 300, to take care of non-responses.

Data collection: The data were collected by one of the authors (BO) and trained assistants in May 2014. The respondents for the questionnaire were selected using a multi-stage sampling technique. The first stage of the sampling process involved the random selection of two extended families, from each of the four villages that make up the Choba community, using the list provided by a trusted traditional chief. The second stage is the selection of respondents from the chosen extended families, carried out using the list provided by the secretary of the extended family. A respondent is eligible for the study when he is male, and has married within the past ten years, to coincide with the commencement of the premarital screening programme of churches in the community.

The questionnaire was used to gather information on the socio-demographic characteristics of the respondents, their

knowledge and attitude towards sickle cell disease and premarital screening for the disease, and if they were screened for the sickle cell trait, when they got married.

Data analysis: The collected data were cleaned and entered into a database, and then analysed using SPSS. The knowledge of the respondents on sickle cell disease and premarital screening for the disease were assessed using a set of ten questions. Respondents were classified to have good knowledge when they have a score of 7 and above, classed as average when they have a score of between 5 and 6, and considered to have a poor knowledge with a score of less than 5. Summary measures were calculated for each outcome of interest; and bivariate analyses of interest were carried out, to test for associations. The test of significance was conducted using chi square tests, set at 95% confidence interval, with p-value of 0.05 or less considered statistically significant.

3. Results

A total of 290 questionnaires were administered and retrieved. The respondents had an average age of 30.55 ±4.1 years; majority (65.86%) had a tertiary education, were employed either as civil servants (26.90%), in private establishments (14.83%), or are self-employed (18.28%) (Table 1).

Table 1. *The socio-demographic characteristics of study participants*

Variable	Number (N= 290)	Percentage (%)
Age		
Less than 20 years	34	11.72
20 – 29 years	111	38.28
30 – 39 years	122	42.07
40 – 49 years	23	7.93
Educational status of respondents		
No formal education	11	3.79
Primary	14	4.83
Secondary	74	25.52
Tertiary	191	65.86
Occupation of respondents		
Fishing/ Farming	16	5.52
Self employed	53	18.28
Civil servant	78	26.90
Employed in private sector	43	14.83
Student	37	12.76
Unemployed	63	21.72
Religion		
Catholic	28	9.66
Protestant	73	25.17
Pentecostal	171	58.97
Spiritual	14	4.83
Traditional religion	4	1.38

Table 2 shows the knowledge and attitude of the respondents. All the respondents knew about the sickle cell disease, while 246 (84.83%) were aware of the premarital screening for the disease. Most (78.97%) of the respondents had good knowledge of the disease and the premarital screening for the disease, while 6.21% had poor knowledge. Most of the respondents got their information from health workers (33.79%), from parents and relatives (23.79%), or were taught in school (21.72%).

All the respondents had positive attitude towards premarital screening for sickle cell disease. Nearly all 278 (95.86%) of the respondents considered premarital screening as a very important public health measure, that should be taken over by the government; while 258 (88.97%) felt that the screening should be made compulsory for all intending couples.

Table 2. *Knowledge and attitude of respondents*

Variable	Number (N= 290)	Percentage (%)
Knowledge of sickle cell disease and premarital screening		
Poor	18	6.21
Average	43	14.83
Good	229	78.97
Source of information		
Health workers	98	33.79
Mass media	48	16.55
School	63	21.72
Place of worship	12	4.14
Parents and relatives	69	23.79

Table 3 shows the uptake of the premarital screening among the respondents. Most 211 (72.76%) of the respondents carried out the premarital screening when they got married; and most (87.20%) of the screenings were instigated by their churches. The age, educational attainment and the religious denomination of the respondents significantly influenced the uptake of the screening (p-value > 0.001), as shown in Table 4. Most of the respondents that carried out the screening test were older than 30 years (63.98%), Pentecostal Christians (66.35%) and had tertiary education (83.89%).

Table 3. *Uptake of premarital screening*

Variable	Number (N= 211)	Percentage (%)
Who encouraged the screening?		
Church	184	87.20
Decision of the couple	14	6.64
Decision of the parents	4	1.90
Advice of health worker	9	4.27
Result of the screening test		
HbAA/ HbAA	97	45.97
HbAA/ HbAS	51	24.17
HbAS/ HbAA	44	20.85
HbAS/ HbAS	19	9.00

A total of 19 (9.00%) of the respondents that went through the screening were of the same HbAS genotype as their intended spouses; out of which 4 (21.05%) went ahead and got married, citing as reasons the difficulty of jettisoning their spouses 1(25.00%); and the power of God to prevent a child with sickle cell disease (75.00%).

Table 4. *Uptake of the premarital screening according to the educational status and religious denomination of respondents*

Variable	Screened	Didn't screen	Total	p-value
Age				
Less than 20 years	0	34	34	
20 – 29 years	76	35	111	0.000
30 – 39 years	119	3	122	
40 – 49 years	16	7	23	
Educational status of respondents				
No formal education	0	11	11	
Primary	1	13	14	0.000
Secondary	33	41	74	
Tertiary	177	14	191	
Religion				
Catholic	17	11	28	
Protestant	53	20	73	
Pentecostal	140	31	171	0.000
Spiritual	1	13	14	
Traditional religion	0	4	4	

4. Discussion

The study showed that the respondents in a semi-urban, Christian community in south-south Nigeria have good knowledge of sickle cell disease, and the premarital screening for the disease; are positively disposed to the screening; and are patrons of the screening programme, even as the programme is not driven or provided by the government.

More than 75% of the respondents had good knowledge of sickle cell disease, and the premarital screening for the disease. This is comparable to the 78.9% recorded among undergraduate students in Benin, south-south Nigeria [16], and the 80% recorded among youths in Yaba, a suburb of Lagos, Nigeria [17]. It is however higher than the levels recorded in various communities in the Middle East[18, 19]. The high level of knowledge of the respondents in our study can be attributed to their high educational status, as over 65% of them had tertiary education. It can also be attributed to the higher prevalence of sickle cell disease in Nigeria, and the fact that the respondents in our study are older, married and were already exposed to premarital screening, in course of their getting married.

Our study also showed the positive disposition of the respondents towards premarital screening of the sickle cell trait, as over 95% of the respondents considered the screening a very important public health measure, with over 85% of them recommending that it should be made compulsory by the government, for all intending couples. This is comparable to the levels recorded about the government-directed screening programme in Saudi Arabia[18] and Iran [19]. The positive attitude of the respondents of this study can be attributed to the fact that most of them are resident in their native community, and are active members of their extended families. They are therefore more likely to be aware of the health challenges of a child with sickle cell disease, and are therefore more favourably disposed to preventive measures against the disease[16, 17].

The uptake of premarital screening among the respondents of this study is high at 72.76%, even as the screening programme was mostly instigated by religious organizations, without the input or direction of the government. This level of uptake is however comparable to the statutory and government-directed screening programme of Saudi Arabia [18] and Iran [19]; and can be attributed to the fact that the screening is made mandatory for all couples wishing to solemnize their marriage in most of the churches in the study community. Church wedding, especially in southern Nigeria is the most common way of contracting marriage, and is recognized by the Nigerian society and law to be binding. The insistence of the churches on screening for the sickle cell trait, before the church wedding therefore carries almost the same force as the statutory programmes of the countries of the Middle East[18, 19].

Our study also showed that the age, educational attainment and the religious denomination of the respondents significantly influenced the uptake of the screening. The uptake was lower among the younger respondents. This is mainly because their marriages are often unplanned, and mostly follow the pregnancy of their spouse, in a society that tolerates premarital sex, has very low contraceptive use, but is seriously against having a child outside wedlock[20]. Marriages that took place as a result of pregnancy are not usually formalized in the church, and therefore do not offer the couples the opportunity to carry out the premarital screening for the sickle cell trait. Respondents with tertiary education in contrast, mostly have planned marriages, because they have the resources and time to seek out a spouse, and to fulfill the pre-nuptial requirements. This most likely explains why more than 90% of them carried out the screening test, when they got married.

Most of the respondents that carried out the premarital screening were Pentecostal Christians. This is because the Pentecostal churches are the initial champions of the screening, and are known to be more vehement in their demand for the test. However, in recent years, more Christian denominations have also made premarital screening, for the sickle cell trait mandatory, such that the test, even without the force of law has become a widely recognized and accepted part of prenuptial formalities in southern Nigeria.

A total of 9.00% of the respondents that went through the screening were of the same HbAS genotype as their intended spouses. This is however based on the subjective information provided by the respondents. It is much higher than the 1.01% recorded in the Saudi programme[14], but can be explained by the higher prevalence of the sickle cell gene in Nigeria. Our study also did not find any of the respondents or their intended spouse with the homozygotic gene. This is in spite of the fact that the prevalence of sickle cell disease at birth in Nigeria is about 2%; but points to the prevailing high mortality rate among persons with sickle cell disease in Nigeria. A large prospective study carried out in the early 1970s in Nigeria – The Garki study had shown that the prevalence of sickle cell disease in Nigeria decrease from 2.1% among the newborns, to 0.4% in under-five children, and to 0.2% at age 5 – 14 years [21].

Four (21.05%) out of the 19 respondents that have the same Hb AS gene as their intended spouse went ahead with the marriage. This is lower than the 90% recorded when the Saudi screening programme was first introduced, but comparable with the current level in the Saudi programme[15]. The at-risk couples that went ahead with the marriage in our study cited as reasons the difficulty of jettisoning their spouses, and the power of God to prevent a child with sickle cell disease. These reasons are similar to those given by the Saudis [18]. The Saudi health authorities were able to achieve a five-fold increase in the frequency of voluntary cancellations of at-risk marriage proposals, by placing emphasis on health education, genetic counselling and prenatal diagnosis [16, 18, 22].

The health education of the public on genetics, manifestations and the prognosis of sickle cell disease would increase health literacy, reduce the belief in divine intervention, and increase the voluntary cancellation of at-risk marriage. This is where the government has to step in, as religious organizations, especially the Pentecostal Christians in Nigeria have a firm belief in miracle, and are therefore likely to encourage at-risk couples 'with the right faith' to go ahead with the marriage [23].

Genetic counselling would clearly spell out to the at-risk couple the probability of having a child with sickle cell disease, and the options for risk reduction [24]. Genetic counselling is another role that has to be taken up by the government. It would require that health workers with skills in genetic counselling are available in even primary health care facilities, to ensure that the services can easily be accessed. Genetic counselling however needs to be carried out as early as possible in the marriage process, to make it easier for at-risk couples to voluntarily break up. It has therefore been proposed that screening should be made mandatory for students, to ensure that the genotype is known long before marriage[25].

Prenatal diagnosis and termination of pregnancy are the last option for the at-risk couple. It is widely accepted [26], even in the highly conservative Muslim society [19, 22]; and makes it possible for the at-risk couple to have a normal reproductive activity [27]. It is however very technically challenging, as it requires highly specialized obstetric skills in ultrasound examination and fetal tissue sampling; and specialist cytogenetic and biochemical genetic diagnostic techniques [24]. It also carries a serious ethical burden, since it involves the termination of pregnancy. Prenatal diagnosis is also very expensive, and is currently affordable to only a minute proportion of those that require it in Nigeria [28].

5. Conclusion

The knowledge, attitude and uptake of premarital screening for sickle cell disease are high in this semi-urban, Christian community in south-south Nigeria, even as the screening programme is not driven or provided by the government. The input of the government is however required in encouraging the voluntary cancellation of at-risk marriages, by providing health education, genetic counselling and prenatal diagnosis that the religious organizations that currently champion the premarital screening are not properly equipped to provide.

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