

## Assessment of Knowledge and Attitude of Sickle Cell Genetic Screening Among Fresh Undergraduate Students of Ebonyi State University, Abakaliki, Nigeria.

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### ABSTRACT

**Objectives:** The burden of sickle-cell disease (SCD) in Nigeria is increasing with the increase in population, despite recent high-level interest in SCD, including the adoption of a UN resolution recognizing SCD as a public health problem. The knowledge and attitude of genetic sickle cell screening was assessed on fresh undergraduate students of Ebonyi State University Abakaliki –Nigeria. **Method:** A descriptive survey designed with the aid of a structured, supervised questionnaire served as an interview schedule for the study on 300 fresh undergraduates' students, and modified versions of the Sickle Cell Perceptions and Knowledge Survey with SPSS version 20.0 were used to assess their knowledge and attitude towards genetic sickle cell screening using 5point Likert scale. **Results;** Most respondents demonstrated a moderate level of awareness towards SCD and genetic sickle cell screening with positive mean score values of  $3.64 \pm 0.70$  and  $3.62 \pm 0.40$  respectively. The respondents however rejected the item "that genotype should not be a barrier in marriage if both love each other" (negative mean score  $2.11 \pm 1.24$ ) while majority believed that genetic screening should only be done for intending couples (mean score  $2.38 \pm 1.28$ ). **Conclusion:** The respondents demonstrated adequate knowledge and attitude on SCD and genetic SCD screening. However, similar studies are needed to evaluate the SCD knowledge and control among the less educated or educationally disadvantaged population in same environment. Major benefits in the health and survival of patients with SCD can be achieved through the implementation of a few highly effective evidence-based preventive interventions policies.

**Keywords:** Knowledge, Attitude, Sickle cell screening, Fresh Undergraduates Students.

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## **INTRODUCTION**

Sickle cell disease comprises a variety of genetic inherited disorder resulting from the inheritance of sickle haemoglobin (Hb-S) either in a homozygous (SS) or in a heterozygous state with abnormal haemoglobin such as SC, S $\beta$ thal, SOArab, SD and SG [1]. The most severe type is the homozygous state (Hb-SS) known as sickle cell anemia (SCA) associated with chronic severe haemolytic anaemia with attendant clinical complications and psycho-social implications [2,3,4] with a major impact particularly on health care services and financing [5]. The heterozygous state; Sickle cell trait (SCT; HbAS) with less clinical consequences is seen in as many 100 million individuals worldwide, including an estimated 2.5 million Americans [6].

Although it is found among all racial groups; descents of Negroid race have the highest prevalence [7,8,9]. Nigeria has the highest burden of SCD with the prevalence of 2% at birth and 0.05% in the adult population for homozygous (Hb-SS) and between 20 -30% in different parts of Nigeria for heterozygous (Hb-S) [10,11,12]. With our population of 167M, according to the National Demographic Survey (NDS) [13]; Nigeria thus has the largest population of SCD in the world and the disease is recognised among the ten (10) priority non-communicable diseases (NCDs) and it contributes significantly to both child and adult morbidity and mortality [14].

Sickle cell disease is a genetic disorder of which the frequency of heterozygous (Sickle cell trait) predicts the prevalence of homozygous SCA. The awareness and knowledge of inheritance pattern as well as genetic screening of defective haemoglobin (Hb-S) status may help reduce the prevalence of sickle cell anaemia [7,15,16,].

Mindful of this, The National Assembly (2011) [17] in a bill sponsored by Senators Okowa and Nenadi called for the enactment of an act to provide for the prevention, control and management of Sickle Cell Disease in Nigeria. This was quickly followed by National Guidelines for the control and management of Sickle Cell Disease by the Ministry of Health (2014) [14]. For better management of the disease, early diagnosis is crucial. This however is hampered by factors such as centralized and urban localization of laboratories, high cost of diagnostic equipment and inadequate skilled manpower to operate those [18].

In all, prevention through education and genetic counselling and screening seem to be the sure way of combating the disease. Genetic counselling is a non-directive art of providing accurate, full and unbiased information in a caring relationship to an individual or family affected by a genetic disorder to enable them come to terms with and cope better with the disorder. It has been observed that a significant proportion of individuals in Nigeria are unaware of their haemoglobin genotype prior to marriage [15]. Knowledge concerning sickle cell disease is a way of preventing and controlling the scourge, since people will be well informed to take appropriate decision concerning their marriage and reproduction. In Nigeria various governmental and faith-based health intervention programmes aimed at prevention and possible control of the disease are in place and needs constant evaluation [19,20]. Prevention through public health education and other control measures therefore should be prime priority. Good knowledge regarding SCD is required for individuals especially carriers to make informed decisions about their reproductive life and other health related choices.

The burden of sickle-cell disease in Nigeria is increasing with the increase in population, despite recent high level interest in SCD, including the adoption of a UN resolution recognizing SCD as a public health problem, [21]. This has major public health and socioeconomic implications and major benefits in the health and survival of patients with SCD can e be achieved through the implementation of a few highly effective evidence-based interventions.

The African Union Assembly resolution 1(V) [22] and the United Nations General Assembly resolution 63/237 [21] both recognized SCD as a public health problem and urged Member States to raise awareness of SCD. The United Nations Assembly also suggested making June 19 of each year the SCD Day.

The SCD strategy for the WHO African Region [23], aimed towards the achievement of the Millennium Development Goals 4 and 5, seeks to increase individual and community awareness about SCD and strengthen primary prevention, reduces disease incidence, morbidity and mortality, and improves quality of life. The situation in the Region however indicates that current national policies and plans are inadequate; appropriate facilities and trained personnel are scarce; and adequate diagnostic tools and treatment are insufficient. The intent of this work therefore was to study the perception and knowledge of sickle cell (HbS) screening using undergraduate students of Ebonyi State University as a cohort for evidence-based study that may be useful for health advocacy towards robust policy formulation aimed at controlling the disease.

## **MATERIALS AND METHODS**

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### **Study area and study population:**

The study was conducted on fresh (100 level) undergraduate students male and female, age range; 18 – 49 years) of Ebonyi State University, Abakaliki – Nigeria, who presented for the mandatory routine School-Health Medical Examination. Abakaliki; the capital of Ebonyi State in the south eastern Nigeria is situated at 6.32° North latitude and 8.12° East longitude, 117 meters elevation above the sea level with population density of 141,438 according to 2006 National Census [13] (Nigeria Data Portal, 2016). A total of 300 students who were willing to participate in the study were included.

### **Ethical clearance and Anonymity**

The study protocol was reviewed and approved by Ebonyi State University Research Ethics Committee (Ref.:EBSU/REC/Vol.1/2018/085 of 6th September, 2018), the participants were well informed about the objective of the study through the participants information form and written consent obtained from each participant. Volunteer's personal details and responses were stored in a password protected computer. During processing and analysis, all data forms were recognized by the laboratory numbers without any details of the volunteer.

### **Study Design**

A descriptive cross-sectional study design was used to assess the student's knowledge and attitude towards genetic sickle cell screening between Octobers to December, 2018. A descriptive survey designed with the aid of a structured, supervised questionnaire served as an interview schedule for the study and a modified version of the Sickle Cell Perceptions and

Knowledge Survey with statistical package for Social Sciences, were used.

The sample size was determined based on modified method of Faul et al., (2007) [24] using the prevalence rate 0.218% as previously reported in the same environment [25]. The computed value of 262 was recorded but extended to 289 (allowing for 10% attrition rate).

### Data Collection and Analysis

Data were by face-to-face interview with the researchers using a pre tested, questionnaire. The questionnaire had three sections comprising; socio-demographic characteristics (age, gender, marital status, tribe, religion and Faculty of study) knowledge and attitude. In order to assess the level of awareness of sickle cell disease among the survey participants; questions (9) were asked about the definition, prevention of SCD and understanding of genetic cause of the disease. Attitude questions (8) towards genetic sickle cell screening bordered mainly on the understanding of the premarital genetic screening and counseling.

Five point Likert scale were used for some of the knowledge questions and all attitude questions/statements. Participants gave “strongly disagree, disagree, not sure, agree and strongly agree” responses to the questions/statements. Negative attitude questions/statements were scored from 5 (for those who strongly disagree) to 1 (for those who strongly agree). The opposite of this scoring system was used for positive attitude questions/statement. The mean scores were calculated and classified as:

“adequate” ( $\geq 3$ ), “inadequate” 2.5 – 2.9) and “grossly inadequate” ( $< 2.5$ ).

Data were analyzed using SPSS version 20.0 (IBM Corporation, Armonk, NY, USA) and presented in frequencies and charts.

### RESULTS

Out of the three hundred (300) copies of questionnaire administered, all were returned and two hundred and eighty five (285) of them were properly filled and fitted for analysis giving response rate of 95.0%. The study population and respondents characteristics are presented in Table 1. Majority students 120 (42.1%) and 141 (49.5%) were less than 20years of age and between 21 – 30years, respectively. More than half; 171 (60%) were males and the majority of the students 256 (89.8%) were single.

On the awareness of genotype screening for sickle cell disease, majority, 261 (91.6%) have heard about genotype screening for sickle cell disease mainly through health workers and relations while 235 (82.5%) knew their haemoglobin genotype (table 2).

Adequate (positive) responses were recorded for knowledge and attitude questions/statements with mean score values of  $3.64 \pm 0.70$  and  $3.62 \pm 0.40$  respectively (tables 3 & 4). The mean criteria of 3.0 were used for accepting an item. The respondents however rejected the item “that genotype should not be a barrier in marriage if both love each other” (negative mean score  $2.11 \pm 1.24$ ) while majority agreed that genetic screening should only be done for intending couples (mean score  $2.38 \pm 1.28$ ).

Table 1: Demographic Distribution of the students (N = 285)

Demographic Characteristics	No of Respondents	Percentage
<b>Age</b>		
< 20yrs	120	42.1%
21 - 30yrs	141	49.5%
31 - 40yrs	13	4.6%
40yrs & above	11	3.9%
<b>Gender</b>		
Male	171	60.0%
Female	114	40.0%
<b>Marital status</b>		
Single	256	89.8%
Married	22	7.7%
Divorced	3	1.1%
Separated	4	1.4%
<b>Religion</b>		
Christianity	276	96.8%
Islam	1	0.4%
Traditional	8	2.8%
<b>Ethnicity</b>		
Igbo	275	96.5%
Yoruba	2	.7%
Others (Ikwerre, Delta, Effik)	8	2.8%
<b>Faculty</b>		
Health Science	201	70.5%
Others	84	29.5%

Table 2 – Knowledge of SCD and genetic sickle cell screening:

Questions/ Statement	Respondents' No (%)
<b>Do you know your blood haemoglobin genotype? (N=285)</b>	
Yes	235 (82.5)
No	50(17.5)
<b>If yes, when was the genotype done? (N=235)</b>	
Infancy	43 (18.3)
School entry	181 (77.0)
Pre-marital screening	8 (3)
Others	4 (1.7)
<b>Do you know about genetic sickle cell screening? (N=285)</b>	
Yes	261 (91.6)
No	24 (8.4)
<b>If yes, how did you hear about it? (N=261)</b>	
Health worker	103 (39.5)
Media	28 (10.7)
Social worker	19 (7.3)
Relations	83 (31.8)
Church	24 (9.1)
Others (movies 1, friends	4 (1.5)

3)

**Table 3: Knowledge of genotype screening for sickle cell disease (N=285)**

ITEMS	SD	D	N	A	SA	Sum	Mean±SD
Sickle cell disease is an inherited blood disorder caused by abnormal haemoglobin	24	6	28	168	56	1072	3.80±1.06
Sickle cell disease cannot be cured but can be prevented	12	7	14	138	114	1190	4.18±0.95
Sickle cell disease is a communicable disease that can be transmitted by person to person contact.	81	106	16	39	43	712	3.50±1.42
Sickle cell disease can be prevented by pre-marital screening	8	20	10	122	125	1191	4.18±0.99
Sickle cell disease is neither a spiritual condition nor result of witchcraft or sorcery	7	3	19	111	145	1239	4.35±0.85
Mean of knowledge						1042	3.66±0.70

\* Cut-off point = 3.0

Key: SD - strongly disagree, D - disagree, N- neutral, A – agree, SA – strongly agree.

**Table 4: Attitude of first year students' towards genotype screening for sickle cell disease (N=285)**

ITEMS	SD	D	N	A	SA	Sum	Mean±SD
Blood genotype should determine the choice of marriage partner	8	6	13	130	128	1219	4.26±0.87
I have the right to know the blood genotype of my intending spouse.	5	2	9	108	161	1273	4.47±0.75
I will encourage my children and others to know their blood genotype before marriage	5	0	5	108	164	1272	4.51±0.71
Blood genotype screening should not be a barrier to marriage if both love each other	116	88	34	27	20	602	2.11±1.24
Blood genotype screening should only be done for intending couples.	77	116	24	39	28	677	2.38±1.28
Blood genotype testing should be part of school health program.	11	0	8	148	118	1217	4.27±0.85
Intrauterine testing should be encouraged so that affected foetus should be aborted.	37	91	64	51	41	820	2.89±1.26
Pre- and post-counselling should be part of consideration for blood genotype screening.	2	11	29	159	80	1147	4.02±0.91
Mean of Attitude						1031	3.62±0.40

\* Cut-off point = 3.0

Key: SD - strongly disagree, D - disagree, N- neutral, A – agree, SA – strongly agree.

## DISCUSSIONS

The world over, there is an ongoing debate whether care of SCD should be integrated into existing health services or whether there should be disease-specific programmes [7]. WHO recommends that countries where the SCD birth prevalence exceeds 0.5 per 1000 births should develop separate SCD programmes. Although Nigeria has a national guideline for the management of

SCD [14] and has created special centers in each geopolitical zone, these guidelines are bereft of policies aimed at prevention through advocacies, education/counseling, and inclusion in the primary health care system. Comprehensive, dedicated SCD programmes with special emphasis on follow-up care, family and patient education and counseling, and prevention and treatment of complications has been observed to have a significant impact in

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reducing morbidity and mortality [26,27,28]. Therefore this study examined the perception and awareness of genetic sickle cell screening using fresh undergraduate students of Ebonyi State University as a cohort.

The study observed adequate knowledge (positive mean score > 3.0) among the respondents. This is similar to the previous findings in the same environment [29,30] but differ at the time the respondents knew their genotype. Greater percentage only knew their genotype while school entry. Most of the students were not married, making the pre-marital screening knowledge to be low. This was attributed to better enlightenment and exposure by various educational, social and religious groups.

In Nigeria, it has been observed that most enlightened parents especially those with the knowledge of SCD and carrying one of the defective haemoglobin genes prefer knowing the children's genotype at infancy [31]. This study indicated that most of the respondents knew their haemoglobin genotype at infancy and during school entry. Most of the respondents were aware of the genetic screening for sickle cell disease. This is parity with the findings of Olarewaju et al (2013) [32], in Jos, North Central – Nigeria, and Ugwu, (2016) [30] who also observed health workers, family members and friends as the major sources of information for genetic sickle cell screening. The old misconception that SCD was due to incorporeal factors [33] was not supported by the respondents; who agreed that SCD is neither a spiritual condition nor result of witchcraft or sorcery.

Pre-marital testing and counselling has been identified as an important means of controlling the spread of the defective gene [7,14]. Greater percentage of the

respondents in this study supported this view and exhibited positive knowledge (mean score  $4.18 \pm 0.99$ ). In addition, the majority of those who had positive attitude towards genotype screening for sickle cell disease were also found to have adequate knowledge about SCD while those who have limited knowledge have negative attitude towards genotype screening for sickle cell disease. This means that negative attitude towards sickle cell disease screening may be due to inadequate knowledge about the disease. This is in agreement with the findings of Ani et al., (2012) [34]. Negative attitude towards SCD will result in denial and concealment of the disease by the affected individuals as well as carriers, with adverse consequences [35].

Elimination of negative attitudes, discrimination and stigmatization depends largely on the extent of enlightenment of the society on issues concerning SCD and this is one of the objectives this study intends to address. Overall, positive attitude was observed for the knowledge questions/statements (mean score > 3.0) but there were some negative attitudes- “blood genotype screening should not be a barrier to marriage” and “that genetic screening should only be done for intending couples”. Awareness creation through proper education therefore is of utmost important. Evidence abound on the importance of premarital counseling and testing as a means of reducing the prevalence of inherited disorders of haemoglobin, principally by identifying and offering counseling to intending couples of high-risk marriages [36,37]. Premarital counseling has been shown to have a significant advantage over neonatal screening in that while it is aimed toward primary prevention, the latter addresses secondary, or tertiary prevention (after the deed has been done). In advanced

countries with an equally significant burden of SCD, genetic counseling and testing have been well established with remarkable reduction in the chances of at-risk couples giving birth to affected children [38,39] The reverse is the case with developing countries. In Nigeria, the current utilization of genetic counseling and testing for SCD is unacceptably low [40,41]) and calls for urgent interventions so as to prevent adverse effect on health policy planning and execution. Policies aimed establishing robust preventive counseling and testing is advocated.

#### **Conclusion/Policy Recommendation:**

The fresh students of Ebonyi State University, Abakaliki-Nigeria, demonstrated adequate knowledge and attitude towards SCD and genetic SCD screening. However, similar studies are needed to evaluate the SCD knowledge and control among the less educated or educationally disadvantaged populations in the same environment. Nigeria is long overdue for a clear well-articulated policy to prevent sickle cell disease (SCD). Policy to:

1. Integrate SCD into the Primary Health Care Program of the Nation to involve government participation at all levels; Federal, state and Local Council.
2. Capacity building and development of health professionals through training and re-training on genetic counseling and testing, diagnostics and clinical management and support of persons living with SCD.
3. Establishing newborn screening program and centres for mandatory screening of all newborns.
4. Collaborate with religious institutions and faith-based organizations to sustain and improve

the quality of their various pre-marital screening programs

5. Establishing genetic counseling and testing program for the general population at primary care level (community and local councils)
6. Massive health education programs to increase awareness of SCD and need for voluntary counseling and testing.
7. Nationwide provision of adequate infrastructure and personnel for testing services.

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#### **Conflict of Interest:**

The authors have no conflicts of interest to declare.

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