

A Survey of the Knowledge of and Attitude of University of Portharcourt (Nigeria) Undergraduates Towards Premarital Genetic Counselling in Relation to Sickle Cell Anaemia

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ABSTRACT

This descriptive study was carried out to survey the knowledge of and attitude towards premarital genetic counseling in relation to sickle cell disease of Uniport undergraduates. The study was carried out using random sampling method by means of an anonymous questionnaire. A total of 287 questionnaires were returned by respondents and subsequently analysed. 13 respondents either did not fill their questionnaires or else did not complete it according to the instructions and so could not be processed. A total of 197 males (73.2%) and 59 females (21.9%) were obtained with 12 students (0.3%) failing to indicate their sex and one being equivocal.

42.3% of respondents think of the disease as a killer disease like AIDS. 25.5% believes that the victim of the disease is someone who will be always sick while 1% think of the victim is an Abiku/Ogbanje of African traditional superstition. 4.2% gave no response as to what their opinion is about the nature of the disease while 27% gave an unacceptably equivocal opinion of it. 89.6% knew it was inherited from parents. 1.4% thought it is got from sexual intercourse and 1.7% thought it is got from contamination from close contact with a sickler. 2.8% thought it is got by other unspecified means.

73.8% had knowledge of the existence of premarital genetic counseling in relation to the disease but 7.3% were ignorant of it. While 18.9% gave no response.

70.9% were willing to undergo premarital counseling. 9.6% would not, 19.5% gave no response. 65% will not marry their would-be partners if their genotype is incompatible. 19.3% will marry for love despite incompatible genotype and 9.9% will marry believing God not to have an affected child and that God will heal any child if affected. 16.6% gave no response to this and 2.5% were equivocal in their response.

Key words: Sickle cell disease, Genotype, Genetic counselling.

INTRODUCTION

The sickle cell disease was discovered in England in 1910¹. It is a Haemoglobinopathy which is genetically inherited from parents. The sickle cell gene that codes for the abnormal Hb is a recessive one and is inherited in a simple mendelian fashion. The normal HB is HBA. In the heterozygous state (AS) otherwise called sickle cell trait or carrier state,

there is no clinical manifestation and the victim is entirely healthy but the homozygous state SS or S in combination with any other haemoglobinopathy e.g SC, SD, S-that is called sickle cell disease.

The basic pathology is in the production of abnormal HB in the red blood cells (RBC) which at low oxygen tension in the blood causes the RBCs to sickle which are then recognized and destroyed

by the reticulo-endothelial system (RES) especially in the spleen resulting in a chronic anaemic state and its sequelae. In addition at intervals depending on the age and level of medical care may present in four main types of clinical conditions called crises viz:

- (a) Hyperhemolytic crisis in which there is a sudden hemolysis of RBCs in the RES resulting in severe anaemia and its sequelae.
- (b) Aplastic crisis in which for not clearly understood reasons, the bone marrow temporarily shuts down production of RBCs and a life threatening severe anaemia results.
- (c) Vasoocclusive or thrombotic crisis in which thrombosis occurs in the microcirculation of various organs due to the sickled RBCs and such patients may present with severe bone pain, priapism, encephalopathy, nephropathy, retinopathy, etc.
- (d) Sequestration crisis in which the RBCs are suddenly pooled in the RES especially the spleen and liver within a very short time with a rapid drop in the HB level and the patient may collapse and die if immediate measures are not taken.

All these combine to produce an ugly and unhappy childhood for its victim with severe growth retardation, ugly facies with other physical features and a life punctuated more or less by regular episodes of miserable crisis not to talk of the huge financial burden from regular medication, loss of school days and the heavy demand placed on health workers. All these summed together shows that the nation stands to lose for every new sickler baby that is born into it.

Genetic counseling is the providing of information by physicians or other specially trained health care professionals to those who consult them regarding the risks, diagnostic procedures, available treatments and possible prevention of congenital or hereditary disorders². Sickle cell anaemia is a public health malady which preventive medicine could effectively control using the formidable means of premarital genetic counseling.

Little work has been done so far on the knowledge of and attitude of Nigerian undergraduates towards premarital genetic

counseling in relation to sickle cell disease. Since undergraduates represent the potentially influential leaders of tomorrow, it is important to determine this since the incidences of as high as 20-30% are known for the heterozygotes in tropical Africa.

Genetic screening and counseling should not only be limited to Africa alone if an impact is to be made towards a near total eradication of the homozygous state on a global scale. In one study, 1000 consecutive US Army Negro recruits were screened with 7.5% been positive and another in San Francisco detected 8.7% of 4,028 people of all ages³

Despite the vast distribution and popularity of the condition, most people even in educated circles still lack clear knowledge about it. If in a citadel of intellectualism like the University, superstitious beliefs could still be nursed about this disease then expectedly in the general population it might be very high thus making the handling of the problem by genetic counseling even more elusive.

If any timely meaningful impact about the condition is to be made here in Nigerian in particular, programmes of genetic screening whether small or large should be voluntary and should also be preceded by an effective balanced education programme. It has been advised by experts that genetic counseling should best be done in genetic clinics⁴ which are special centres with trained personnel and simple illustrative and explanative facilities.

Should premarital genetic counseling campaign programme be recommended, the important question that comes to mind is that it cost effective to embark on such preventive programmes? There is something to learn from the Quebec experience: Report from a study there showed an offer of economic perspective on prevention of B-Thalassaemia disease by means of genetic screening and counselling programme in Quebec Province. The programme screened 805 of at risk person in the high risk communities, provided diagnosis to 75% of at risk couples and prevented 2/3 of new cases in the period of study. Additional cost was measured in Canadian dollars of medical and public health resources both incurred

Table 1: Age distribution among respondents

Age	No.	%
15-19	42	14.6
20-24	179	62.4
25-29	51	17.8
30-34	4	1.4
>35	1	0.3
NR	1	0.3
Equivocal	2	0.7
TOTAL	287	

Table 2: Sex distribution among respondents

SEX	NO.	%
Male	197	73.2
Female	59	21.9
NR	12	4.5
Equivocal	1	0.3

Table 3: Marital status respondents

Marital status	NO.	%
Single	277	96.5
Married	3	0.01
No. response	7	0.02

Table 4: Means of initial knowledge

Means	no.	%
TV/Newspaper(s)	68	23.5
Hospital	21	7.3
Gist	75	26.0
Classroom	97	33.6
Medical student	3	1.0
Others	8	2.8
No response	6	2.1
Equivocal	11	3.8

Table 5: Understanding SCD

Understanding	No.	%
A killer disease	121	42.3
Abiku/Ogbanje	3	1.0
Some that is always sick	73	25.5
No response	12	4.2
Equivocal	77	27.0

Table 6: Knowledge of inheritance

Knowledge	No.	%
Inheritance from parents	258	89.6
From sexual intercourse	4	1.4
Contamination from close contact	5	1.7
Others	8	2.8
No response	12	4.2
Equivocal	1	0.3

Table 7: View of respondents towards sickle cell Gene carriers intermarriage

View	No.	%
Will marry for love	16	5.6
Will not marry because of risks	18.5	65.4
Will marry and believe God for the best	2.8	9.9
No response	47	16.6
Equivocal	7	2.5

Table 8: Knowledge of Genotype

	NO.	%
Yes	144	50.2
No	108	37.6
NR	35	12.2

and avoided resulting from use of these case preventive services. The total direct cost per case prevented in the programme was less than the cost for a single year of treatment for an individual with the disease and the cost effectiveness of the programme was confirmed⁵

The objectives of premarital genetic counseling are

1. To assist the consultants to understand the medical facts in the matter e.g the crisis etc.
2. To understand the role of hereditary in the propagation of the disease.
3. To understand the options for treatment and management available especially as it affects reproduction.
4. To enable the consultants chose among the

Table 9: Preparedness for Premarital genotype check

	No.	%
Yes	230	80.1
No	36	12.5
NR	26	7.0
Equiv.	1	0.3

Table 10: Knowledge of premarital genetic counseling by a doctor or other health professionals

	No.	%
Yes	211	73.8
No	21	7.3
NR	54	18.9

Table 11: Intention for premarital genetic counseling by a doctor or other health professionals

	No.	%
Yes	207	70.9
No	28	9.6
NR	57	19.5

options appreciate for them without bias from the counselee i.e you do not pre-empt or stampede them into any decision.

5. To enable the consultants to adjust to the reality of the disease (if he or she already has it) both medically, emotionally and socially.

In a certain study on volunteer sample of students, three colleges of King Faad University were surveyed for knowledge, attitude and health promotion behavior and result showed that there was no significant difference between medical and allied students on health promotion behavior. Medical students were a little better than allied medical students and together they displayed better attitudes than science students⁶

Methodology

The data was obtained through an anonymous questionnaire, each of which contained brief note of introduction and instruction to the respondent on completion and handling of each questionnaire.

The questionnaires were randomly administered by hand and retrieved in the same manner. The respondents were served the questionnaires where each faculty have their lectures and in their hall of residence where each faculty members reside.

DISCUSSION

A total of 287 questionnaires were completed, returned and analysed. 73.9% of respondents were males while 21.9% were females. 4.5% could not indicate their sex while 0.3% of them gave an equivocal response to their sex. This tallied roughly with the estimated 3.1 male: Female ratio in the University. 62.4% of all respondents were of age of 20-24 while 17.8% were 25-29, 14.6% were 15-19 and 1.4% were 30-34 and 0.3% were 35 and above. 2.8% gave no response and 0.75 were equivocal. 96.5% were single, 0.01% were married and 0.02% gave no response.

95.4% of all respondents had heard of sickle cell disease with the initial means of information being the classroom for 33.6% of all

respondents, 26% through gist and 23.5% through TV/Newspapers. 7.3% was through the hospital and 1% through medical students, 2.8% was through other means. It is quite impressive the high proportion of those who have heard of the disease but is their information really correct? 42.3% think of the disease as a killer disease (like AIDS), 2.5% think that the victim is somebody always sick while 1% think of it as Abiku/Ogbanje superstition (evil spirit). 4.2% gave no response of their opinion of the nature of the disease and 275 gave equivocal and statistically irrelevant response. That the majority think of it as a killer disease suggest an exaggeration of the disease threat even though this will imply that they will be more careful to develop attitudes that will prevent them from contacting the disease. This would also infer excessive discrimination against known sicklers in the community. This is not a surprise considering that the majority (52.3%) heard of the disease through gists and TV/Newspaper with a propensity to overstate and exaggerate facts. That only 33.6% have heard of it through the classroom for students who have climbed through primary and secondary schools clearly reveals the inadequacy of health education and awareness in our general education system considering the extremely wide distribution of the disease in Nigeria and may call for a routine inclusion of, and implementation of health education programmes that teaches in reasonable details, common disease in our environment and their prevention.

Do our undergraduates know how the disease is got? It is encouraging to note that 89.6% of them know it is inherited from parents. 1.4% think it is got from contamination from a close contact with a sickler. 2.8% think it is got by other unspecified means. However, if the eradication efforts against the disease is to have full impact, the knowledge of how the disease is got should be very thorough and clearly understood as is the case of AIDS by anybody who has had education up to the University level.

Leaving the means of enlightenment about the disease to mere gist amongst students and the mercy of TV/Newspapers is grossly inadequate and a suggestion of its inclusion into the general studies (GES) in the first year of the University which all

students irrespective of faculty or department compulsory have to pass before being allowed to proceed to the next class is a wonderful suggestion that might go a long way to enlighten the undergraduates about the important point about the disease. 73.8% knows of the existence of premarital genetic counseling while 7.3% gave no response as to whether or not they know of such services.

Only 70.9% intend to seek for premarital genetic counseling. 9.6% have no intention to do so and 19.5 gave no response whether or not they intend to seek such help. This may reflect the vagueness of understanding of the severity of the effect physically, psychologically and financially a sickler has on his/her immediate family. Where the current knowledge about a socially important disease is not adequate to instill some level of fear on a person he/she might not develop enough forceful attitude necessary for preventive purpose and this might be why some of the students do not see the dire necessary for such a precaution before marriage.

5.6% will go ahead to marry for love even if their genotype gives risky combination while 65.4% will not take the risk of going in to marriage with such and one should their genotype prove incompatible. 9.9% will marry and believe God not to have an affected child and that God will heal any affected child if at all. 16.6 gave no response. The influence of the power of emotion and religion/beliefs on human will is enormous and there is hardly anything anyone can do in these aspects in relation to influencing human attitude. The best that public health custodians can hope for in this case is to give the people a right and thorough knowledge on this socially important disease and if this is effectively done they should have met their obligations to society and the decision is left to the individual to take being responsible for the consequences.

CONCLUSION

This study has revealed that University of Port Harcourt undergraduates have a good general knowledge of the sickle cell disease and of the existence of premarital genetic counseling. However, that the source of this knowledge being

predominantly through mere gist and TV/Newspaper is rather not to be relied upon and enough emphasis weighty enough to have a long term effect on preventive attitude of premarital genetic counseling cannot be guaranteed.

Only 33.6% of them have the classroom as their initial source of information perhaps at the secondary school level where the understanding and will has not been fully developed and articulate. It is our submission therefore that the teaching of public health disease particularly sickle cell disease, its inheritance pattern, nature, physical,

psychological and financial effects should be taught preferably in the first year of the student as part of the compulsory general studies. Also that; other sources of information like the TV/Newspaper should be fully exploited to drive in the awareness of the disease and its prevention into the people for, repetition they say, makes for emphasis.

These can only be an effective segmental approach on a target population of undergraduates in the multifaceted approach to eradicate the disease from Nigeria as much as possible.

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