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Acceptability of prenatal diagnosis of sickle cell anaemia by a sample of the Nigerian population

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Summary

The acceptability of prenatal diagnosis (PND) as a means of controlling sickle cell anaemia (SCA) in Nigeria was examined using a semi-structured questionnaire. The aim of the study was to examine the attitudes of well-informed, educated Nigerians to the use of PND and abortion of confirmed HbSS pregnancies in the control of SCA. There were 433 respondents comprising 204 males and 210 females (gender was not recorded for 19 respondents). They were aged 15-50 (31 ± 18) years. Forty percent had HbAA, 15% HbAS, 1.6% HbAC, 2% HbSS, and 0.2% HbSC; 153 (35%) had no knowledge of their haemoglobin electrophoretic patterns "genotypes". The majority of the respondents (69.5%) appreciated the role of both parents in the transmission of the disease. Only 45 (18%) of the respondents heard of SCA for the first time through sickle cell counsellors, 23% through newsmedia, 29% through friends and relations, 21% obtained the information through health workers, while 5% had never heard of sickle cell disease before the interview. As many as 192 (44%) of the respondents were aware that SCA could be diagnosed in pregnancy; 45% would opt for termination of the affected pregnancies. Avoidance of the problems associated with managing SCA children was the most important reason for approving pregnancy termination, whereas 73% of those rejecting pregnancy termination did so for religious and moral reasons. Seventy-eight percent of those interviewed would want PND started in Nigeria. The two approved control measure for SCA by most of the respondents were genetic counselling and PND; both should, therefore, be considered in implementing control measures for SCA in this country.

Résumé

L'acceptabilité du diagnostic prénatale (PND), comme moyen de controler l'anemie drépanocitaire (SCA) au Nigeria a été examine en utilisant un questionnaire semi-structuré. Le but de étude était d'apprécier les attitudes des femmes Nigerianes éduques et bien informés, sur lutilisation du PND et l'avortement, dans les cas confirmés de grossesses chez les drépanocitaires. Il yavait eu au total 433 respondants parmis lesquels 204 males et 210 femmelles (le sexe n'avait pas été engregistre chez 19 respondants). Ils étaient âges de 15 a 50 ans (moyenne dage 31 ± 18 ans). Quarante pourcent avait un genotype AA, 15% AS, 16% AC, 2% SS et 0.2% SC. Cent-cinquantre-trois (33%) n'avaient pas une connaissance anterieure de leur génotype. La majorite des respondants (69%), ont apprecié le rôle des 2 parents dans la transmission de la maladie. Quatre pourcent (18) seulement des répondant avait déja entrendu parler de l'anemic drépanociataire à travers des conscillers médicas, 29% a travers les amis et relations, 21 % a travers les travailleurs du domaine medicale, alors que 5% navaient Jamais entendu parler de la maladie avant l'interview. Quatre pourcent (192) des respondants étaient conscient du fait que lanemie drepanocitaire pouvait être diagnostiquer pendant la grossesse, 45% souhaiteraient arreter le cours de la grossesse. Eviter les problemes et consequence associer à l'anemie drepanocitaire etait la principale cause associe à l'avis selon la grossesse devrait être arreté, alors que 73% de ceux qui souhaiterait la contrinuation de la grossesse le faisait pour des raisons religieuses. Soixante-dixhuit pourcent des interviewés souhaiterait voir le PND commencer au Nigeria. Les deux mesures de controles d'anemie drépanocitaires approvés par la majorité des respodants, étaient le conseil genetique, et le PND. Par consequent, ces deux mesures devrait être prise en consideration dans l'implimentation des mesures de controle de l'anemie drepanocitaire dans ce pays.

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Introduction

The control of sickle cell anaemia (SCA), a disease affecting 1-3% of Nigerians is still a mirage in this country where effective population-based genetic counselling does not exist [1]. A more pragmatic measure is prenatal diagnosis (PND) and selective termination of the affected pregnancy if the couple so desire. This technique has now been simplified with the introduction of foetal DNA analysis from the chorionic villi sampling, which can be carried out from as early as 8-10 weeks of gestation [2-4].

Control of SCA by prenatal diagnosis is a relatively novel intervention that is just gaining popularity in the richer nations of the world [2-4]. It is yet to start in this country, although some wealthy at-risk Nigerians have been travelling abroad for this procedure. However, the majority of the population may never have such an opportunity because of the huge cost involved, unless of course the procedure becomes available within the country. The abortion component of the PND remains a strong limiting factor in those countries where PND is currently available [3]. The main reason for rejecting abortion by some of the affected individuals is based on religious conviction [3].

The present study was designed to examine the attitudes of a section of the Nigerian society (mainly the educated and supposedly better informed) to the PND of SCA and termination of the affected pregnancies in the context of our socioeconomic milieu.

Similar studies from Jamaica and Nigeria involved only SCA patients and some of their parents [5,6]. The majority of the respondents (> 90%) in these earlier studies favoured PND as a means of controlling the disease, although pregnancy termination was less popular among the patients; 30-35% of whom supported abortion of affected foetuses as against 46-63% of their HbAS parents [5,6]. Religion was the sole factor militating against abortion in both instances.

Respondents and methods

The target population for this study were educated adult Nigerians drawn from the cities of Benin, Ibadan, Ile-Ife, and Ilorin in southeastern Nigeria and Jos in the northern part of the country. To select these cities, centres with teaching hospitals in the country (where SCA patients are usually

managed) were listed, from which five cites were randomly selected. In the selected cities, using accidental sampling techniques, the samples of respondents were obtained. These covered people of different religious, ethnic, and professional groups. The basis for study was explained to all respondents, and those consenting were interviewed, using a semi-structured questionnaire (Appendix). The interviewers were trained to ensure standardization of the procedure.

Results

There were 433 respondents, aged 15-50 (31 $\pm$ 18) years, 204 (47%) males and 210 (48.5%) females. The gender group of 19 respondents was not recorded. Ninety percent of the respondents attended school up to secondary and post-secondary levels. There were 21% in medical and allied professions and 46% in law, teaching, administration, accounting, and other non-medical fields. University students made up 17% of those interviewed and 5% were unskilled workers. Fifty-two percent (225) of the respondents were single, 40% had HbAA, 15% had AS, while 35% had no previous knowledge of their haemoglobin phenotypes (Table 1). As many as 70% were aware of the mode of transmission of SCA, while 7% believed the disease was just an act of God. The majority (88%) believed that SCA is a very serious disease; 51% believed that it is not curable whereas 19% of the respondents believed it could be cured. Four percent of those interviewed obtained information on SCA through sickle cell counsellors, 21% through health workers, 23% from the newsmedia, 29% through friends and relation, and the other 33% from personal experience (self, affected sibs and/or children); however, 5% of the respondents denied prior knowledge of the disease at the interview. Table 2 shows that up to 49% of the respondents were not aware of PND of SCA before the interview, however the majority (78%) would like the procedure introduced to the country. (Table 3) and 45% would agree to terminate affected pregnancies (Table 4). Of those opting for termination of pregnancies, the need to avoid problem children was the main motive by 62% of involved.

Table 1: Haemoglobin genotypes of respondents

Hb. Type	Respondents	%
HbAA	173	40.0
HbAS	65	15.0
HbAC	7	2.0
HbSS	9	2.0
HbSC	1	0.2
Not Known	153	35.0
*Uncond	24	6.0
Total	433	100.0

*Uncond = unconcerned

Table 2: Previous knowledge of PND of SCA by respondent

Response	Respondents	%
Yes	192	44.0
No	212	49.0
*Uncond	29	7.0
Total	433	100.0

Religious beliefs were observed to be the main militating factor against abortion of an affected foetus in 73% of respondents while another 19% rejected abortion for fear of the possible complications, especially death and secondary infertility (table not included).

With cross tabulation, neither religion nor education status significantly influenced the reactions of respondents to acceptability of PND of SCA (Tables 5 to 7), though the two main religious groups in the country were both less enthusiastic about accepting pregnancy termination (Table 7).

Table 3: Respondents attitude to the introduction of PND of SCA to Nigeria

Response	Respondents	%
Yes	339	78.3
No	45	10.4
*Uncond	49	11.3
Total	433	100.0

Table 4: Respondents' attitude to the termination of HbSS pregnancies

Response	Respondents	%
Yes	Respondents	44.6
No	147	34.0
*Uncond	93	21.4
Total	433	100.0

*Uncond: Unconcerned

Table 5: Religion acceptance of PND of SCA

Religion	Acceptance		
	Yes	No	Total
Xtianity	249(240.4)	24(32.6)	273
Islam	75(81.9)	18(11.1)	93
Traditional	2(2.6)	1(0.4)	3
Others	13(14.1)	3(1.9)	16
Total	339	46	385

a: Expected frequencies in parentheses X^2 not significant; $P > 0.05$

Table 6: Education versus acceptability of PND of SCA

Education	Acceptance of PND		
	Yes	No	Total
Univ/Poly	242(236.85)	27(32.4)	269
Secondary	72(73.08)	11(9.9)	83
Modern IV	5(5.2)	1(0.7)	6
Primary	8(8.8)	2(1.19)	10
None	12(14.96)	5(2.03)	17
Total	339	46	385

a: Expected frequencies in parentheses X^2 not significant; $P > 0.05$

Table 7: Religion versus termination of HbSS pregnancies

Religion	Termination		
	Yes	No	Total
Xtianity	133(135.7)	106(103.3)	239
Islam	48(47)	35(35.9)	83
Traditional	1(1.7)	2(1.3)	3
Others	11(8.5)	4(6.5)	15
Total	193	147	340

a: Expected frequencies in parentheses X^2 not significant; $P > 0.05$

Discussion

This study shows that the majority of Nigerians are probably not correctly informed about SCA since only 4% of the respondents heard of the disease from trained sickle cell counsellors and as far as 23% heard of the disorder through the media before the interview. Although most of the respondents were educated and were therefore expected to be better informed, it was disappointing to note that as many as

35% had no knowledge of their haemoglobin electrophoretic patterns and yet up to 52% were still unmarried as at the time of the interview. In a population with poorly developed sickle cell counselling programmes [1], the chances of at-risk couples marrying each other is therefore very high, making control of the disorder difficult.

There have been instances where unions between some of the at-risk couples have resulted in broken marriages where the presence of the child with SCA has drained all the family resources, time, and emotion [7]. In such cases, the mothers have been abandoned with the affected children. This is not surprising in a culture where the ill-health of children is sometimes attributed to parental sins as was observed in the study of deaf children in the community [8]. If the supposedly well-informed segments of the population have such a poor knowledge of SCA as a public health matter, the situation with the over 80% less educated Nigerians in the rural areas is best imagined. Some of the possible factors responsible for the poor knowledge of SCA by most of the respondents include (a) the failure of the government to recognize the disease as a public health problem requiring serious attention; (b) lack of a coordinated and suitable counselling programme [1], and (c) poor access to correct information on SCA by most Nigerians. Our experience and those of others revealed that the media in this country have not been able to create the desired impact on the populace as there is still the general belief that 'sicklers' do not live beyond the age of 21 years! This misinformation has continued to cause a lot of psychological trauma for many of the patients to the extent that some have had to be admitted more frequently around the time of their 21st birthday, believing that they were terminally ill (DMA, personal experience). Some parents have wished they did not have such children, while some of the parents have even wished they had never been born because of the feelings of hopelessness and despair arising from the fact that the disease has no cure and that death can occur at any stage [5,10].

Although 78% of the respondents supported introduction of PND of SCA to Nigeria (Table 3), contrary to expectation, only 45% of them would opt for termination of affected pregnancies if the need arose (Table 4). This is similar to the Jamaican experience where 46% of the HbAS mothers approved abortion of the affected pregnancies, whereas more than 90% of those interviewed favored the introduction of PND as a control measure for SCA [6]. From Table 7, religion appeared to be the main militating factors against abortion according to the respondents, which is similar to the findings in the Jamaican study [6]. The disparity in the number of those who supported PND as a control measure (78%) and those who approved abortion of the affected pregnancies (45%) could be due to some other socio-cultural factors, such as the risks of abortion and often accepted association between abortion and infertility [11].

A large majority of the respondents (> 90%) also favoured genetic counselling as a control measure; this is not without its problems. The main aim of the counsellor is to allow the client(s) to take a responsible decision after given unbiased information [1]. The desired goal has always been difficult to achieve [2], at least with respect to haemoglobinopathy control due largely to the very large size of at-risk population, the cost of implementing the programme [1,12], and more importantly, the unpredictability of human nature [12]. It has been claimed that successful population genetic counselling will lead to the eradication of HbSS birth in the first generation, leaving the population with a lot more HbAS individuals [12]. Prevention of marriages between at-risk individuals will thus become unavoidable. Bleak as such a scenario may appear, it is our belief that the medical science of the future will take care of this "calamity". It was inconceivable a few decades ago that new management options such as PND and bone marrow transplants [13] would be introduced to control SCA. There is also the possibility that in the very near future, gene therapy, a potentially curative but much less harzadous treatment than marrow transplantation, may join the available management options [13,14].

The very poor knowledge of the health and social implications of SCA by most Nigerians is also of concern. If care is not taken, SCA may become one of those stigmatizing ailments to consider before contracting marriages in order to have healthy offsprings [15,16]. Such negative stigmatization will further compound the psycho-social problems [9] of the SCA patients in that it may result in the termination of marriage arrangements with the affected family [15,16]. Some SCA women have remarked that only very few men are ready to marry them [5]. The need for health education cannot, therefore, be overemphasized. Health workers and the media should endeavor to give correct information about sickle cell disease to Nigerians, particularly at school level. It is our belief that the society would be more supportive of SCA patients if necessary information were given to the public. Patients should also know that, with proper care and good diet, they can lead a very useful life.

In conclusion, the study shows that many of those interviewed are aware of the seriousness of SCA and would want the introduction of any measure to control its incidence. The two techniques that are favoured by most of the respondents are genetic counselling and PND, although the abortion component of the latter may be a serious impediment to acceptance. These two options should therefore be considered in implementing control measures for SCA in this country.

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