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Perception of sickle cell haemoglobinopathy among 'would-be' counsellors

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Abstract

Fifty-six paramedical personnel in training as Community Health Officers (CHO) and Nurse Tutors were interviewed by a self administered questionnaire as to personal information and what they know and believed about sickle cell haemoglobinopathy. Even after the normal course of lectures on the haemoglobinopathies as given for their training as CHO's, many of them still did not fully understand the topic as shown by mixed up and confusing answers given to questions. As a result of the maturity and exposure as community health workers, they are being proposed for retraining as counsellors with regards to the haemoglobinopathies. From our findings to this study it appears that using a formal lecture schedule would not be adequate in intimating this group with the problems they would likely encounter as CHO's in practice. A training programme should also include organised group discussions designed to detect biases and prejudices and correct them before certification as community health officers.

Résumé

Cinquante - six personnel paramedical en formation comme les inspectuers de l'hygiène communautaire (CHO) et less directrices infirmières étaient interrogés avec un questionnaire demandant l'information personnelle et ce qu'ils connaissent et ce qu'ils croyent de l'anémie à hématies falciformes. Même après le cours normal des lectures sur l'anémie à hématies falciformes, un grand nombre d'eux tonjours ne comprenaient pas complètement le sujet montrant par les fausses résponses dangéreusement confondues donnant aux questions. En raison de leur maturité et leur exposition comme less inspecteurs de l'hygiène communautaire, il est proposé qu'ils se-donnent une nouvelle formation en ce qui concerne l'anémie à hématies falciformes. Employant un programme formal des lectures n'est pas suffisant de faire connaître intimement le sujet par ce groupe des problèmes qu'ils rencontrentreront en pratique. Le problème peut être minimisé par employant un format structural ou par les discussions en groupes pour découvrir les tendences et less préjugés prets par ces soi-disants conseillers pour qu'ils ne transmettent pas ces idées fausses comme une verité génétique.

Introduction

It is no longer the usefulness of genetic counselling in hereditary conditions that attracts controversy but the counselling process itself. Counselling, whether at the individual level or nationally coordinated programmes have been known to be fraught with problems. Such problem include simplifying complicated terminologies and technical details, decoding an entirely different detail from the coded message and logistic problems [1]. Such was the case with the nationwide sickle cell screening programmes in North America which was embarked upon without defining the objectives to be achieved by the physician, the persons conducting the tests and the families being tested [2]. Evaluation of the abandoned counselling programmes showed that they were embarked upon without due consideration for

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the curriculum content, personal biases, prejudices and instructional qualities of would-be counsellors. The rate at which new knowledge is being generated in the field of genetics remains high. Methods of diagnosis, treatment and prevention of congenital and hereditary diseases daily add a new element to the physicians' role, including that of instructing and guiding parents and patients in genetic principles and in counselling. Using the physicians in this way is a luxury that Africa cannot afford at present in view of shortage of skilled manpower. Whitten *et al* found that trained lay persons could successfully transmit sickle cell information [3]. The recommended doctor/patient ratio has not been achieved for most parts of Africa. Countries that claim to have achieved this in Sub-Saharan African always fail to mention that the bulk of these doctors reside and practice in the urban centres away from where the bulk of the people live [4]. This leaves the rural areas grossly understaffed with medical personnel. In advanced countries where the doctor/patient ratio is better, counselling centres are spread fairly evenly to cover most areas of the countries. The African situation calls for a special solution. There are no counselling centres and alternatives must be sought to carry out counselling at least with regards to the haemoglobinopathies, as this is Africa's greatest genetic problem. Another educable group of people must be trained to handle her counselling needs with regards to specific problems such as sickle cell haemoglobinopathy. It has earlier been proposed that the Community Health Officers (CHO) who are currently being trained to man the primary health care centres be retrained to include genetic counselling with regard to sickle cell haemoglobinopathy as part of their functions [5].

To assess the suitability of the CHO's for this counselling task, and to avoid the North American experience, we embarked on this study in order to discover their misconception's and attitudes towards sickle cell haemoglobinopathy.

Subjects and methods

The subjects were fifty-six nursing and health superintendent staff in training as community health officers and nurse tutors at the University College Hospital, Ibadan, the School of Health Technology, Ibadan and the Faculty of Health Sciences of the Obafemi Awolowo University, Ile-Ife, Nigeria. There was a good geographical spread of the students. The trainees were from all the states of the federation except Akwa- Ibom and Kano States.

Self administered questionnaires were distributed to all the students numbering seventy-five and the analysis was done on the fifty-six who agreed to participate in the study and submitted their returns.

Results

Demography

A total of fifty-six subjects were tested: Forty (71.4%) were female and sixteen (28.6%) were male. Their ages ranged from 30 to 50 years (mean 36.9 ± 4.9 years). The number of years they had been in service ranged between 10 and 28 years (mean 16.3 ± 5.3 years). All except a 30 year old female were married. Of the fifty-five who responded to the question as to the number of children, 54 had children and the unmarried lady had none. The number of children per subject ranged from 1 to 9 (mean 4.12).

The highest formal educational training prior to their professional training ranged from the primary school to university education. Fifty-four responded to the question on the level of formal education, 3 (5.5%) had only up to the primary school level. These were some of the public health superintendents. Four (7.4%) passed out of the teacher training colleges. The majority, 37 (66.7%) obtained the GCE Ordinary Level (O/L) Certificate and 7 (13%) obtained the Higher School Certificate while three nurse tutors were university graduates (table 1).

Professionally, six were Health Superintendents whilst the rest were either nurses or health educators. Ten (18.5%) of the fifty- four had their basic training in mission hospitals and 21 (38.9%) were trained in general hospitals. Only 4 were trained in specialist hospital and 13 (24.1%) had their basic training in university teaching hospitals. The 6 health superintendents were trained in various schools of health technology.

Forty-four out of 56 (78.6%) knew their haemoglobin electrophoresis but 12 (21.4%) did not. Four out of these 12 (33.3%) did not consider the knowledge of haemoglobin genotype of any importance. Three (25%) were scared to find out the result and would rather take whatever fate has to offer (table 2). Two of the 12 did not know their haemoglobin electrophoresis as a result of non-availability of the facility for testing in their communities. The remaining 3 gave no reasons for

not knowing their haemoglobin genotype. Of the 43 who knew their haemoglobin genotype, 1 (2.3%) was SS, 30 (69.8%) were AA's and 13 (30.2%) were AS.

Knowledge of sickle cell haemoglobinopathy

It was noted that 4 out of 55 who responded to the questionnaire first heard about the condition in the primary school, 10 (18.2%) had their first knowledge in the post primary institutions, 38 (69.1%) in their schools of nursing, and 2 (3.6%) during their practice as nurses. One of those interviewed had the first knowledge about this condition from neighbours.

Table 1: Basic formal education of would-be counsellors

Basic educational qualification	Nurse	Health superintendent	Nurse tutors	Health educators	Total
Primary school leaving Cert.		3(5.6%)			3(5.6%)
Teacher training college	1(1.85%)	2(3.7%)	1(1.85%)		4(7.4%)
GCE O/L	31(57.4%)	1(1.85%)	2(3.7%)	3(5.6%)	37(68.5%)
Higher school certificate (HSC)	5(9.3%)			2((3.7%)	7(13%)
University bachelors degree	1(1.85%)			2(3.7%)	3(5.6%)
Total	38(70.4%)	6(11.1%)	3(5.6%)	7(13%)	54(100%)

Table 2: Reasons given by would-be counsellors for not knowing their haemoglobin genotype

	Nurse	Health superintendent	Nurse tutors	Health educators	Total
The knowledge is not important	2(16.7%)		1(8.3%)	1(8.3%)	4(33.3%)
Too scared to find out	2(16.7%)	1(8.3%)			3(25%)
No facility for testing	1(8.3%)	1(8.3%)			2(16.7%)
No reasons given		2(16.7%)		1(8.3%)	3(25%)
Total	5(41.7%)	4(33.3%)	1(8.3%)	2(16.7%)	12(100%)

Forty-nine out of 56 (87.5%) considered this disease a preventable disorder but the remaining 7(12.5%) did not. Thirty-seven (63.8%) thought sickle cell haemoglobinopathy was a hereditary disease and 2 (3.6%) considered it a malignancy. Twenty-seven had a fairly good working knowledge of its inheritance, these mentioned the necessity of both parents being either carriers or a carrier and the other a sickle cell disease patient. Some within this group even discussed the risk to each pregnancy from such unions. Twenty-one (37.5%) among those who believed the disease to be hereditary did not know how it is inherited.

Eight (14.3%) made statements that were partially true and partially false. These included statements such as "sickle cell is inherited from the mother's blood", "the first child escapes the disease and the subsequent ones are affected", "both parents have to be sicklers before the offspring shows the disease".

Table 3: Per cent within each professional group that did not know their haemoglobinopathy genotype

	Nurse	Health superintendent	Nurse tutors	Health educators	Total
Total no. of subjects in the study	38	6	3	7	54
No. that did not know their haemoglobin electrophoresis	5	4	1	2	12
% of those who did not know	13.2%	66.7%	33.3%	28.6%	22.2%

Table 4: Assessment of would-be counsellors response to questions on knowledge about sickle cell haemoglobinopathy

Compound examined	No answer	Correct answers	Misconception	Total
Inheritance of sickle cell	21(37.5%)	24(48.2%)	8(14.3%)	56(100%)
Knowledge of sickle cell trait	11(19.6%)	35(58.9%)	12(21.4%)	56(100%)
Prevention (among those who said it was preventable)	8(16%)	40(80%)	2(4%)	50(100%)
How sickle cell affects reproductive capability	43(76.8%)	10(17.9%)	3(5.3%)	56(100%)

Thirty-three out of 56 (58.9%) knew what the sickle cell trait was. These gave answers such as "those who have the genetic expressions of 'S' gene but no clinical manifestations". Others simply wrote 'AS' as examples. Eleven (19.6%) did not know what the trait was; these offered no answers but 12 (21.4%) offered wrong answers. Some of these labelled the trait as "disease states" or mentioning "SS or SC as traits" and that "traits are transmitted from one parent to the other". Three categorically stated that "heterozygotes suffer as much as homozygotes". When asked to mention specific ways they suffer, they mentioned that "they usually have excruciating bone pains in old age". Two believed that the major difficulty the heterozygotes (traits) may have is limitation in the choice of marriage partners since they may not want to marry another heterozygote for the fear of producing homozygotes.

In describing the specific preventive measures, 40 out of the 50 (80%) who agreed that the disease was preventable mentioned premarital genotype screening and counselling with or without prenatal diagnosis as an effective means of prevention. Eight (16%) suggested that the disease was preventable but could not offer any means of prevention. Two (4%) made suggestions such as "not allowing homozygotes to marry themselves only", and "not allowing heterozygotes to intermarry". The remaining six did not believe the disease to be preventable.

Twenty-eight of the 56 interviewed (50%) believed that sickle cell haemoglobinopathy affects reproductive capability of the homozygotes. Only 10 (35.7%) of this group mentioned anything that could be related to affectation of reproductive capability. They mentioned facts such as foetal wastage occuring as a result of repeated crises. Others mentioned delayed puberty and clotting problems in the mother during pregnancy among other points. From their answers, a further 15 (53.6%) of the 28 above did not know how the disease may affect reproductive capability. Three of these (10.7%) made such statements as "the sicklers are always lethargic and so would not be able to perform at night, coupled with the loss of libido that they usually experience". Some even suggested that their reproductive capabilities are impaired because "they are retarded mentally and are infertile". Figures were even given that "40% of their offsprings die at child birth"

Discussion

The overall knowledge of sickle cell haemoglobinopathy among the population interviewed in this study is fair. However, where as many as 36% of them did not know that the condition is inherited raises concern as to their competence in counselling clients with sickle cell anaemia. Also, the number of misconceptions detected in the responses of good number of them strongly suggest the necessity for further training if they would be charged with the responsibility of counselling.

The Community Health Officers (CHOs) have been proposed to be retrained and adapted to carry out the counselling, on account of their maturity and special training which prepares them for community work. It is not enough to load them with ideas which they are supposed to transmit. Situations may occur that would make them go outside of their training format. Questions could be asked beyond the classroom lectures. Nigeria and indeed Africa has multilingual communities and interpretations may need to be made in conveying these counselling messages. It is in situations like these that preconceived ideas creep into messages.

In drawing up the curriculum content that would be used in the training of these CHO's, medical, genetic and social aspects of the disease should be included. It is also pertinent to design a pretraining test that would reveal preconceived ideas, prejudices and biases so as to determine the depth of the teaching format. This could help in debunking some of these prejudices. A post training test should also be applied to find out how much of these ideas have been replaced during the training programme.

Genetics is not an easy concept to understand, even for medical practitioners [8]. A minimum level of formal education should be set for those who would be trained as counsellors. Not all who participate in the CHO training should be automatically co-opted as earlier advocated. Some of these trainees had formal education only to the primary school level. The extent to which this group would understand genetic terminologies and have a good grasp of the problem would certainly be lower than those who had formal GCE O/L certificate before their professional training. Many of the trainees already fall within this category (table 1). Whitten *et al.* also found education and age among counselee characteristics were related to successful

learning about sickle cell trait counselling [3]. This should be more so with the counsellors.

That the bulk of African's health problems are preventable is also true with regards to some genetic conditions. Sickle Cell Haemoglobinopathy is an important example of such inheritable condition. As elsewhere, the best form of management is prevention. Genetic counselling is preventive medicine [7]. The people must be educated, screened, counselled and left to take informed decisions. Screening programmes should be carried out after adequate consideration has been given to professional and lay education. The curriculum of the CHO programme must be structured in such a way that at the end of the training, these health personnel are able to effectively counsel families or individuals with sickle cell haemoglobinopathy.

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