

Socio-economic and Psychological Implications of Congenital Malformations of the Heart and Great Vessels in Children

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Summary

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A study of the socio-economic status of 102 children with congenital malformations of the heart, aged between nine months and twelve years, has revealed that the patients represent a cross-section of the socio-economic groups in Nigeria. A majority however, belong to the low socio-economic group. Consequently, the child's illness had serious financial impact on most of the families. Apprehension of early death, feeling of guilt, acceptance and fears were some of the parental attitudes towards the child's illness. Suggestions are made on measures to reduce the financial burden on affected families

THERE have been several studies on the social, economic and psychological aspects of heart diseases in caucasian children (Apley, 1967; Glaser, Harrison and Lynn, 1964; Landtman, *et al.*, 1960). To our knowledge, no previous study on this aspect of the disease has been undertaken in African children. The purpose of the present study was therefore to document the socio-economic and psychological implications of congenital malformations of the heart in indigenous children whose social, economic and cultural background is different from that of the Caucasians.

Materials and Methods

Interviews of parents of 102 children, aged between nine months and twelve years, with different types of congenital malformations of the heart and great arteries were conducted by a Health Visitor (VOA) and a nurse (SAA) at either the clinic or the home. A few of the older children with the malformations were also interviewed. All the family units were asked the same questions, using standard questionnaire. Similarly, all the older children were asked the same standard questions. Specific information sought included:

- (a) religion
- (b) education and occupation of the parents
- (c) parental attitudes to the children's illness
- (d) effect of the child's illness on the family
- (e) the attitude and behaviour of the affected children.

The replies obtained were coded and recorded on punch cards, but no attempt was made to analyse the data statistically. In the assessment of parental attitudes, more attention was focussed on the mother than on the father, because of the closer attachment of the child to the former than to the latter.

Results

Social and Economic Background

Information on the socio-economic background was obtained from 102 families of which both parents were alive in 97. The mother in one case, and the father in 5 cases were dead. Of the 102 families, 61 were moslems, 37 christians, and 4 belonged to unspecified religions. The majority of the patients being moslems is a reflection of the large moslem population in and around Ibadan. Forty-six (45 per cent) of the 102 fathers were polygamous. Seventy (72 per cent) of the 97 fathers who were alive, claimed ignorance of their ages; most of these fathers had never been to school. Table I summarises the occupations of the 97 fathers. It can be reasonably concluded from a study of the average annual income of the various occupational groups in the former Western State of Nigeria (Table II) that a majority of these fathers were in the low income group. Most of the mothers like their husbands never received formal education. Sixty (59 per cent) of the 101 mothers said they were engaged in small-scale trading, consisting mostly of hawking food and other merchandise in the streets. Twenty-two mothers (22 per cent) were working as clerks, nurses, teachers, etc., while the remaining mothers claimed that they were full-time housewives.

TABLE I

Occupation of 97 Fathers of Children with Congenital Malformations of the Heart

<i>Occupation</i>	<i>No. of cases</i>	<i>Per cent of total</i>
Skilled Labourer	28	28.9
*Professional	20	20.6
Clerical	12	12.4
Trader	12	12.4
Farmer	10	10.3
Unskilled Labourer	6	6.2
Self-employed	6	6.2
Unemployed	3	3.0
Total	97	100.0

*Includes Arabic and Christian primary school teachers, nurses, etc.

TABLE II

*Average Annual Income of various Occupational Groups in the former Western State of Nigeria 1968/1969**

<i>Occupational Group</i>	<i>Average Income</i>	
Farmers	N102.00	(51 pounds)
Salary/wage earner including low grade professionals and administrators	N268.00	(134 pounds)
Craftsmen	N112.00	(56 pounds)
Traders and Clericals	N258.00	(129 pounds)
Other occupations	N108.00	(54 pounds)

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Impact of the Child's Illness on the Family

Forty-six (46 per cent) of the 101 mothers said that the child's illness had adversely affected the financial commitment of the entire family; some of them claimed that as a result of the child's illness, a sibling or siblings could no longer go to school. The business or small-scale trading of 54 mothers (53 per cent) was stated to be seriously affected by the child's illness particularly because

of frequent visits to the hospital. There were 51 mothers (50 per cent) who replied that their children's illness did not affect their business or work.

in poor health for the rest of its life, while 29 mothers (28.6 per cent) expressed no fears.

Parental Attitudes to the Child's Illness

- (a) *Vague apprehension about the child:* Sixty-three (62 per cent) of the 101 mothers admitted to having vague apprehension about the child's condition since birth. The child's abnormal breathing was the commonest symptom which raised suspicion that something was wrong.
- (b) *Feeling of Guilt:* On being asked 'What do you think is the cause of the child's illness?', 45 (45 per cent) out of 101 mothers, and 47 (48 per cent) of 97 fathers replied that they thought the child 'was just born that way'. There were only 15 mothers (15 per cent) who replied that the child's illness was caused by "juju or witchcraft". Thirty-nine mothers were pregnant after being told that their children had congenital malformation of the heart. These 39 mothers were asked what they thought about their present pregnancies. Of these, 14 (44 per cent) replied that they were hopeful the baby would be normal while 22 (56 per cent) were indifferent.
- (c) *Acceptance:* Seventy-three mothers (72 per cent) out of 101, handled the sick child just as they handled the siblings and also encouraged the siblings to treat the sick child as a normal individual. There were only 15 mothers (15 per cent) who admitted to indulgence of their children because they were sick.
- (d) *Fears:* The fears expressed by the 101 mothers are listed in Table III. Forty-three of the mothers (42.6 per cent) feared that the child would die young; 13 others (12.9 per cent) feared that the child would remain

TABLE III

Fears expressed by 101 Mothers of Children with Congenital Malformations of the Heart

<i>Fear</i>	<i>No. of cases</i>	<i>Per cent of total</i>
Will die young	43	42.6
No fear	29	28.6
Poor physical health	13	12.9
Burden on the family	10	9.9
Nobody to look after him after mother's death	2	2.0
Don't know	4	4.0
Total	101	100.0

Attitude and Behaviour of the affected Children

Nineteen children (10 males and 9 females) aged between 3 years and 12 years were interviewed. On the question, 'Whom do you think your parents like best among your brothers and sisters?', 10 out of the 19 children replied that their mothers liked all of them equally well; nine said the fathers liked all equally, and only two said their parents liked them least among their siblings. There was only one other patient who said that both parents liked him. When asked 'Do you think your parents are worried about you because of your illness?' 11 of the children said that parents were worried about them. Because of the parents' worry about their illness, six of the children stated that they were not allowed to play as other children or carry heavy things. Regarding their attitude to attending the hospital, nine of the children said they were 'happy' to attend hospital, while three said they were worried and another three said that they were always nervous when they attended hospital. On being asked 'What worries you most?', four children said it was their illness; three replied that lack of energy worried them, while one child said it was the fun being made

of him by his friends and siblings. Six of the children replied that they were worried by their illness and lack of energy. Five of the patients said they had no worries.

Discussion

Studies on the social, economic and emotional implications of heart diseases in general (Bauer, 1952; Bruins, Kamphuis and Teuns 1967; Landtman, Valanne and Aukce, 1968) and of congenital malformations of the heart and great arteries in particular (Landtman *et al.*, 1960; Maxwell and Gane, 1962; Glaser, Harrison and Lynne, 1964; Apley, Barbour and Westmacott, 1967) have concerned children with different cultural backgrounds from those of Nigerian children. The primary purpose of studying these factors in any cultural group is to seek information which can help the physician in the proper management of the patient. The present study aimed at the same purpose.

By and large, the patients in our study represented a cross-section of the social and economic backgrounds of Nigerian families, even though a majority of the subjects belonged to the low socio-economic group of the population. Nevertheless, neither the present study nor those of others have shown any difference between the prevalence of the malformations in the different social classes. Poverty may of course, affect the mortality rates.

The social and economic factors revealed in the present study highlight important problems that may arise in the management of children with these malformations in any developing country. These problems are related to poverty and ignorance, which, as has been shown, occurred in the majority of the families, as well as to lack of trained personnel and facilities for the recognition and treatment of these malformations. In some of the families, the impact of the child's illness was such that the small earnings of the parents, particularly those of the

mothers were seriously affected. In such families, siblings were forced to abandon their formal education.

The growth pattern of the affected children (James and Antia, 1974) has, in contrast to that of affected children elsewhere, revealed a high incidence of marked growth retardation in most of the children. The malnourished state of these children may partly be due to poverty in the family. In addition, we have observed a high incidence of defaulting from clinic follow-up which may also be partly attributed to the poverty in the family, since the parents are often unable to afford transport fares to travel frequently and regularly to the hospital. Because of the low social background and ignorance of the parents, the serious nature of the children's illness may not be readily appreciated.

Several authors (Glaser, Harrison and Lynn, 1964; Apley, Barbour and Westmacott, 1967; Landtman, Valanne and Aukce, 1968) have reported various parental attitudes towards their children with congenital malformations of the heart and great arteries. These attitudes include early apprehension of something being wrong with the child, feeling of guilt and various fears. It is noteworthy that some of these attitudes exist among Nigerian parents with a different cultural background. In the present study, there were 62 per cent of the mothers who, because of the child's abnormal breathing, were apprehensive of some serious illness. None of the parents directly admitted any feeling of guilt. However, 45 per cent of the mothers and 48 per cent of the fathers felt that the child was 'born that way'. It may well be that some of the parents who adopted this nihilistic attitude did, indeed, entertain some unexpressed feeling of guilt.

Most Nigerians, educated and uneducated, attribute the cause of most natural phenomena and disease to 'juju or witchcraft'. Consequently, most patients in Nigeria will first seek the help of a 'juju or witchcraft' man before they seek the help of a physician. It is therefore surprising that only 15 per cent of the parents in the present

study attributed their children's illness to 'juju or witchcraft'.

With regard to acceptance of the sick child by the parents, and by the siblings, 72 per cent of the mothers treated the sick child just like any other child in the family. There were only 15 per cent of the mothers who indulged their children. This is a remarkably low incidence of indulgence. In contrast, Glaser, Harrison and Lynne (1964) have reported a much higher incidence of parental indulgence among American parents.

Some of the fears expressed by the mothers were similar to those expressed by mothers elsewhere (Landtman, Valanne and Aukee, 1968). As reported by others, the fear that the child will die young was the commonest, being expressed by 43 per cent of the mothers in the present series. This universal fear seems understandable since, in most cultures, the heart is still regarded as the place where the soul 'resides'. Other common fears expressed by the mothers included the sick child being a permanent burden on the family, as well as the child remaining in poor physical health for the rest of his or her life. Provision of satisfactory medical and surgical care for these children seems the only means by which these fears can be removed from these parents.

The attitude and behaviour of the few affected children interviewed were similar to those of children elsewhere. Because of their illness, few of the children felt that their parents liked their siblings better than themselves. It is interesting however, to note that there were many of these children who felt that their parents liked them equally as they liked their siblings. It must be admitted that the number of children involved in this aspect of the study was small, and furthermore, no enquiry was made into other emotional and behaviour disorders (bedwetting, temper tantrums, sleep problems, stuttering, etc.) which are reported to be common among affected caucasian children. Further studies into these disorders among Nigerian children are required.

In the light of the facts revealed in the present

studies, attempts should be made to minimize poverty, which appears to be an important contributory factor to defaulting from regular follow-up of these children, and also to lessen the financial burden on the affected families. This may be achieved, among other measures, through the establishment and organization of cardiac centres which are readily accessible to these families. At present, some of the patients have to travel 200-400 kilometers to attend the clinic at Ibadan. In order to reduce the financial costs to these families, it is suggested that firstly, centres be established at several places so that the distances travelled by parents are reduced. Since there are not many trained paediatric cardiologists in the country such centres as suggested above should not be sited only at University Teaching Hospitals. A single cardiologist can regularly visit these centres if they are sited in an area of 100-200 sq. miles from the existing medical teaching institutions. Secondly, the frequency of follow-up visits to the clinics should be considerably reduced for those patients without any complications such as heart failure. A reasonable interval should be five to six months.

The other important factor to be considered is non-availability of adequate facilities for surgical correction of the malformations. Our experience is that most parents become frustrated after several visits to the cardiac clinic because no surgical treatment is offered to their children. This seems to contribute also to the high default rate among patients. With the control of preventable diseases in Nigeria, the contribution of congenital malformations of the heart to childhood mortality and morbidity will be better appreciated than now. There is therefore, a great need in Nigeria to establish at some of the existing medical schools, medical and surgical units with facilities for the diagnosis and treatment of these malformations. The peripheral centres as suggested above will then act as feeders to the medical and surgical units based at medical schools.

The early recognition of the malformations particularly in the newborn, can be achieved through the few general practitioners in the country, and general duty medical practitioners in government and private hospitals. In this regard, undergraduate instruction on the recognition and simple medical management of these malformations should be given due prominence in medical schools' curricula. In addition, regular and frequent refresher courses for general practitioners, other general duty medical officers and nurses working in health centres, should be organized in all the medical schools, in order to maintain constant interest in and awareness of the malformations, by these frontline workers.

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