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PERCEPTIONS OF PARENTS WITH CHILDREN WITH CONGENITAL HEART DISEASE AT THE MOI TEACHING AND REFERRAL HOSPITAL, KENYA

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ABSTRACT

Objectives; Congenital heart disease is the commonest congenital abnormality in the pediatric population; with advances in cardiac surgical techniques, corrections allow the affected children to lead near normal lives. However in resource limited regions the cost of these procedures are beyond the financial capabilities of most families, thus those patients with complex heart defects patients die in infancy, while those children with the less complex lesions live with uncorrected lesions, with its concomitant medical, economic and psychological challenges .This study explored the views of parents whose children have congenital heart disease and the repercussions on their families

Study Design; focused group discussion

Methods; Fifteen parents, whose children had congenital heart disease and were attending the pediatric cardiology clinic at the Moi teaching and cardiology clinic during the study period 2011 to 2012, were randomly picked from the telephone pool. They were divided into two groups consisting of mothers and fathers; piloted open ended questions were used to conduct the discussion.

Results; All the children who were due for surgery had not received it, this is because the parents were financial unable to meet the costs. The uncorrected nature of these conditions necessitated frequent hospitalizations, leading to financial challenges and uncertainty. Parents and their families were struggling psychologically to come to terms with having an affected child with congenital heart disease.

Conclusions; poor families must be assisted financially to access appropriate care for children with congenital heart disease. Psychological support is paramount in a pediatric cardiology clinic.

Key words

Congenital heart disease, resource scarcity, psychological and financial challenges

Background

Congenital heart disease is an abnormality in the cardio circulatory structure or function that is present at birth even if it is discovered much latter [1] These malformations remain one of the most frequent birth defects, with a live born prevalence of about 5-8 per 1,000 (0.5-0.8%)in western countries, where such prevalence data are tracked. [2-5]. In developing countries most diagnosis is done after birth and the incidence in tertiary hospitals has been reported as 5.8% of all admissions in Nepal [6], 9.3% in Nigeria [7].The prevalence in public school going children estimated at 2.3/1000 in Sub Sahara Africa [9]

In resource rich countries the diagnosis of congenital heart disease is routinely done prenatal [10, 11, 12 13,] by echocardiography and for those who missed this opportunity by the age of one month 60% will have a diagnosis. However in sub Saharan Africa, the timing of first echo diagnosis is affected by many factors such as the distance to hospital, availability of equipment, shortage of specialists and family finances [7, 8,] In a Nigerian study, 33.6% of patients presented at less than one year of age, while 69% presented at the age of 5 years or less and 10.6% at greater than 18 years of age [7]. In Kenya, the mean age of presentation to the paediatric cardiologist at one of the referral hospitals was to 16.9 months [8].

Late presentation is associated with onset of complications such as heart failure and pulmonary hypertension [14]. This may sometimes exclude need for complete surgery other than palliation especially in adolescents and adults [15]

The commonest lesions in developing countries are ventricular septal defects (VSD), atrial septal defects (ASD) and Endocardial cushion defects, for the acyanotic groups, while for the cyanotic groups it is tetralogy of fallot (TOF), Total anomalous pulmonary venous return (TAPVR) and transposition of the great arteries (TGA). [6, 7]

Due to lack of cardiac surgical facilities in sub Saharan Africa, the number of uncorrected congenital heart abnormalities anecdotally is estimated to be is high [14] and it consists of the less complex heart diseases, the more complex congenital heart diseases are usually missing most likely due to early death or as a result of failure to assess timely surgery [15]

A diagnosis of congenital heart disease is usually a great shock to most families, knowing that this is such a vital organ, it is usually accompanied by denial, anger and finally acceptance by the parents [16]

Studies indicate that Parents want to know about the etiology, the timing of diagnosis, the pathophysiology, symptomatology and the need for restriction. That a psychological process similar to mourning is required at the time of diagnosis and at corrective surgery period in order for the parents and the whole family to adjust to the illness [16],

Other than trying to adjust to the illness, African parents must also deal with inaccessibility of cardiac services, lack of drugs, and the prohibitive cost of cardiac surgery, in the context of their poverty where health services are geared towards prevention and treatment of infectious diseases rather than correction or palliation of congenital conditions [15]

This paper attempts to explore how parents of children with congenital heart disease, perceive this condition, the financial and emotional challenges that come with the diagnosis, and their thoughts on how best the children and their families can be assisted to deal with the disease.

Methods

This was a qualitative study carried out as focused group discussions amongst parents whose children have congenital heart disease and attend the cardiology clinic at the Moi Teaching and Referral Hospital (MTRH). It is the second largest referral hospital in Kenya and is located in Eldoret; it has a catchment of approximately 20 million Kenyans especially those in the western part of the country.

Two discussion groups were formed. Each group comprised 7 parents randomly identified from a database of an ongoing cross sectional descriptive study; the socio-economic impact of heart conditions on children and their families, by the same researchers. The interviews were conducted principally in Kiswahili, by a trained qualitative research assistant, who is fluent in Kalenjin, English and Kiswahili. In some instances the participants resorted to Kalenjin, their native tongue, when they felt they would best express their ideas. The research assistant was assisted by a medical doctor (TN). The research assistant does not work in the cardiology clinic, but the medical doctor does. The principal investigator who is the chief doctor in the cardiology unit stayed away from the interview in order to allow the participants to freely express their experiences.

All the parents in this study had children with congenital heart diseases and had not undergone any surgical intervention.

The social demographic data of the participants is as shown on table 1

TABLE 1; Characteristics of study participants

<u>Parents Age</u>	<u>Child's Diagnosis</u>	<u>Parents Marital status</u>	<u>Religion</u>	<u>Occupation</u>	<u>Relationship to child</u>	<u>Childs age</u>	<u>Years with diagnosis</u>
38	VSD	Married	Christian	Farmer	Father	3 years	3
58	TOF	Married	Christian	Pastor	Guardian	8 months	1

39	VSD	Married	Christian	civil servant	Father	2 years	2
21	Truncus arteriosus	Married	Christian	Farmer	Mother	10 months	1
27	TOF	Married	Christian	Farmer	Mother	8 years	1
35	TOF	Married	Christian	None	Mother	7 years	3
30	VSD	Single	Christian	none	Mother	5 years	3
33	TOF	Married	Christian	none	Mother	13 years	3
33	VSD	Married	Christian	none	Mother	3 years	3
34	TOF	married	christian	House wife	Mother	12 years	2
36	PDA	married	christian	farmer	Mother	4years	4
19	PDA	Single	christian	None	Mother	11 months	3 months
32	TOF	married	christian	teacher	Father	13 years	1
23	TOF	single	christian	farmer	Mother	1year six months	3 months

ABBREVAIATIONS. 1. VSD- Ventricular septal defect, 2. TOF; tetraloy of fallot 3.PDA; patent ductus arteriosus

The discussions were audio taped, transcribed and translated into English, by the research assistant with the help of the authors. The analysis of the data and report writing was done by authors. The analysis of the data was done through the following steps;

1) Familiarization with the material; 2) formulation of emergent themes; 3) coding of different themes; 4) charting, and rearrangement of data under different themes; and 5) interpretation and explanation of findings [17, 18]

MS word and excel spread sheets were used for data organization.

Approval to conduct the study was obtained from the Moi teaching and referral hospital/ Moi university school of medicine ethics board.

RESULTS

The main themes from the focused group discussions were analyzed into categories based on the discussants perceptions as follows;

1. Perceptions on Etiology and Diagnosis of the disease

Parents observed that it took a very long time from the time the child was born, until a diagnosis of congenital heart disease was made, on average at the age of 2 years. Prior to and after the diagnosis, all the parents reported that they were constantly worried about this particular child; their worries ranged from the child's overall well being, academic and social progress that was slow, poor physical growth finances for transport to hospital, drugs, consultation and surgery. Mothers especially reported that all their energies were challenged to the child to the detriment of the other siblings.

Death of this child was always so imminent; parents wondered whether when they awoke in the morning they would find him still alive.

Once the diagnosis of congenital heart disease was made, parents voiced the fact that they felt very responsible and guilty for somehow letting their child be born with this condition.

Mothers voiced the worry that the entire community and even their own husbands believe that they were the very genesis of the entire child's predicament.

Mothers felt very guilty about this allegation and they felt that it was through her lineage that the disease was being propagated; they viewed it as a curse, and wondered whether the family planning pills they used would have contributed to the etiology. Although fathers, felt they may have contributed, they attributed it more strongly to have come from the wife's side of the family, but always the finger pointed north towards the wife.

Culturally the responsibility of care and nurturing of children is bestowed upon mothers and as the child's growth was poor, neighbors and the extended family made the finger pointing and making matters worse by insinuating that the child might be undergoing neglect. Their anxiety was further worsened because they felt isolated by the community and the larger extended family. As one mother put it "it is like you're the one who brought the disease",.

If the first child was the one affected there were worries that all other subsequent children would have the disease. The parents explained that, although the doctors had informed them that the real cause of the disease was not known and it could be random, this had not allayed their anxieties

2. Perceptions on financial burden of the disease

This was by far the most frequently discussed theme. The parents described it as a huge burden that they have to carry. Heart disease means money is needed for hospital visits, drugs, hospitalization and where necessary a lot of money for the corrective surgery.

As one father said 'you find that it requires a lot of money, every time you need medication/drugs and that drugs need money and at one given time you may not have that money to purchase the drugs for the child;'

These funds have to be provided in the context of other family needs like food, housing, school fees, clothing for the other children and the rest of the family. Fathers reported having insomnia trying to figure out where the money would come from. The mothers reported that this brought a lot of tension in their

relationship with the husbands and the husbands were reportedly withdrawing from the family when the demands on them became unbearable.

Although relatives helped, after some point the relatives and friends also become overwhelmed and withdrew their support. In essence, economically the parents were on their own.

3. Perceptions on care at home for the unwell child

For the mothers, they reported that it was almost impossible to leave their children under the care of relatives, siblings, hired help, even for a short period of time. Everyone was afraid to be left with a child who has a heart disease, least the child dies in their care. “;there is too much isolation because people refuse to watch over the child if you want to leave with them, they will say I will not manage to take care because of the condition of the child’

This impact greatly on the mother’s ability to contribute to the family finances because she spends all her time caring for the sick child. The child is never out of her sight and emotionally they reported they were exhausted and didn’t see reprieve in the near future.

4. Perceptions on impact of the heart disease on other children at home

The other siblings were described as having an ambivalent attitude towards their sick siblings. On the one hand the well children were always anxious about their brother sister’s well being; this was manifested by their constant questioning of their parents about their sick brother/sister’s refusal to go to school, unnecessary crying and poor appetite. In their minds the heart disease had no cure and they were always apprehensive that their sibling would die any time; this brought a lot of tension in the family. However they sometimes resented the fact that the sick sibling had to use all the family resources, and they the well ones had to postpone their needs due to this factor. They felt somewhat forgotten.

They disliked being requested to constantly watch their sick brother, as it eats into their play time.

Mothers reported that the other siblings would hide when they suspected they might be requested to take care of their sick sibling. They sometimes wished he/she was dead.

5. Perceptions on effect of the disease on the afflicted child

Generally parents noted that their sick child was not growing well in terms of height weight, milestones. They said that as the child grew older, it brought anxiety upon them. The older children reported to the parents that they felt isolated by their peers especially during play time; the other children did not want to overtax their sick playmate and were scared of his temper or him dying on them during play time.

The sick older children according to the parents sometimes defied orders to stop playing. The adolescents deny being sick and are tired of the sick label.

The sick children also worried about the fact they were frequently missing school and this meant they had a dim future, that they were always tired, slept poorly and death weighed heavily upon their young minds.

The sick children worried that there will come a point where their parents will be bankrupt, unable to meet their medical bills and this will lead to their demise.

One 12 year old had devised ways of ensuring that money for his medications would never lack by ensuring that: for every 100 shillings worth of milk that he sold each day, 30 shillings was kept for him and he was responsible for hiding this money beyond anybody's reach.

6. Perceptions on interventional measures

The parents strongly felt that the disease burden was too severe on the family economically, emotionally and socially. They need support especially from the government. They proposed the following;

Subsidized costs of treatment, Setting up of a central place where the children with heart disease can be treated, Provision of specialist care closer to the district/county hospitals, since Referral centers such as those in Nairobi and India are too far and inaccessible, Promotion of health education and awareness on heart diseases to the community at large, clear description of the exact physical activities that these children can engage in should be clearly stipulated ,easier instructions on where to assess care ,early diagnosis preferably at delivery ,provide psychological care for the children and their families

DISCUSSION.

In this study the congenital nature of the heart disease in children is not well understood by the parents. Although they agreed that the health workers had tried to explain to them the disease genesis, the fact that in the majority of cases the real cause was not known, they were not convinced and still sought to know if a direct etiological agent existed or an alternate pathogenesis. Almost all mothers felt guilty that they were somewhat the cause of this disease either through their faulty family genes, the family planning pill they took or a curse in her lineage. This perception was reinforced in the mothers' opinion by the rest of the community. If the child was the first born, anxiety was further escalated by fear that all other subsequent children would be born with the same condition.

The theme of lack of proper understanding of congenital heart disease was similarly observed by Cheuk et al [19] amongst parents with children having simple congenital heart disease. There were important knowledge gaps in regard to the diagnosis of the heart lesion, symptoms and hereditary nature of the attributable to the underlying lesion. The level of understanding was determined by the type of congenital heart disease, occupation of parents and educational level, which improved the level of understanding. Our participants mainly had only primary level education; perhaps impeding their full comprehension of this disease. Like cheuk et al, we also realize that we need to give adequate educational briefing to our parents and education should be continuous.

The parents reported an apparent delay in a diagnosing congenital heart disease. They attributed this delay also to lack of trained personnel at the peripheral centers. As reported, the index of suspicion for congenital heart disease was low ,and has happened in other settings, its the less complex heart diseases that end up surviving [26], while the complex heart disease may be misdiagnosed as pneumonia or sepsis [23,24.] The diagnosis was often done late in childhood, which also compares well to findings in other centers, after complications had set in, and surgery was no longer possible [14] a reflection of scarce cardiac services and diagnostic capability in the peripheral health facilities [23] .Parents felt that screening for this disease should be a matter of routine, like for HIV/AIDS. [25]

Besides clinical identification, the cost of diagnostic tests also causes delays in diagnosis. [8,15] in this particular case, it may be attributable to the fact that, to make a firm diagnosis an echo study is needed and this is only available in a few urban areas [15].

Congenital heart disease diagnosis and its symptoms, causes a lot of emotional and psychological agony to the parents and family at large. It was often manifested initially as shock, a sense of loss and fear of the child's imminent death and subsequent constant anxiety and stress. Many fathers reported insomnia and mothers noted feeling a sense of despair. The siblings' response was ambivalent ranging from compulsion to help and expressing concern for their affected sibling to wishing the sick one was just dead. This is not uncommon. As Garson et al observed [16], many parents considered this diagnosis to child loss and projected life expectations for the child were dashed and had to be rethought. Hence for the health worker he must recognize that apart from discussing , the diagnosis, symptoms and treatment, the parents and siblings undergo a psychological process similar to mourning at the time of diagnosis and at corrective surgery and hence must be helped through this journey in order for the parents and the whole family to adjust to the illness [16]. The mothers felt helpless and disillusioned at the fact that they were going to care for this child all their lives and no one in the community was willing to help. The community members were just as terrified as the mothers that the child could die during their watch and shied away for fear of death and its attendant emotional turmoil.

Mothers are extremely vulnerable to mental anguish when a child has congenital heart disease [20, 27]. In a Norwegian study [20], mothers who had children with severe congenital heart disease had increased levels of anxiety and depression .In our study most mothers were in tears when narrating their experiences. This was as a result of them being the primary care givers which was mentally and emotionally taxing as well as blaming themselves for bringing the disease. However, the Norwegian cohort had access to surgery and financial help unlike in this study where the odds against the mother and her child are high.

The negative financial implication the disease put on the family was dwelt on greatly by parents. Money was needed for consultation, diagnosis, medication, transport to the referral center, and for surgery. In fact in this group no child and most were over five years, had had surgery because the costs were

beyond the parents' income. Moreover, they described the available resources as not even being enough to meet the basic needs of other family members. Nearly all parents were peasant farmers. The per capita income of Kenya is 820 Dollars classifying it as a low income country [21] Kenyans like many others in Sub Saharan Africa have no comprehensive social and health insurance [22] and therefore the cost of care is very steep on the families. This impacts negatively economically on the entire family members

The Kenya health system requires patients to pay for outpatient care 'out of pocket' and the existing national health insurance system is unable to meet all the inpatient costs of the chronic diseases [28], the average cost of monthly clinic visits to our referral centers are at 35 dollars to cover for transport, investigations consultations and drugs. Surgical intervention on average is about 6000 dollars, a sum out of reach for most of our patients [21]

From the study it is apparent that many families with children with congenital heart disease feel the health system and the government has left them to shoulder all the burden of the disease. Congenital heart disease worldwide is expensive to treat and some subsidize need to be offered by the government to cushion these families. It is therefore our recommendation that; The Kenya government should make cardiology services accessible in all health centers, to train workers and provide echo machines, to make surgery easily accessible and avoidable. That hospitals and cardiology units make special efforts to fully assist all parents and children with congenital heart disease in terms of the psychological component.

ATHOURS STATEMENT

We have no ethical or financial conflicts to declare. We would like to acknowledge Beatrice Koech for helping to conduct the discussion group study.

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