

# THE KNOWLEDGE OF PARENTS OF CHILDREN WITH CONGENITAL HEART DISEASE IN DAR ES SALAAM, TANZANIA

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## ABSTRACT

Parents of children with congenital heart disease (CHD) or other heart defects face challenges when caring for these children, as most of these defects require longterm treatment and care. However, there has been no published study in Tanzania to identify parents' knowledge levels about their children's CHD.

The main objective of this study was to assess parents' knowledge about their children's CHD, their medication and the prevention of complications at a hospital in Dar es Salaam, Tanzania.

A quantitative, descriptive, cross-sectional design was adopted. Parental knowledge was assessed using a modified version of Leuven's questionnaire for assessing parents' knowledge about their children's CHD. The questionnaire contained 23 items. The sample comprised 84 parents accompanying their children with CHD for follow-up visits at the participating cardiac clinic and those staying with their children in the hospital's wards.

The findings indicated that 43% ( $n = 36$ ) of the parents could not give a meaningful explanation of their child's CHD and (76.2% ( $n = 64$ )) were unable to mention the symptoms of deterioration of the child's specific heart defect. Knowledge about the side effects of drugs, and interactions with other drugs or food were low. Parents' understanding of their children's CHD or heart defects correlated with the parents' educational backgrounds.

**KEYWORDS:** congenital heart disease/defects, paediatric care for congenital heart disease/defects, parental knowledge about heart diseases/defects, patient education, Tanzania

## **BACKGROUND INFORMATION**

Congenital heart disease (CHD) refers to any problem with the heart's structure and function due to abnormal heart development before birth. The abnormalities caused by heart defects disrupt the normal blood flow through the heart and blood vessels by slowing down the blood flow, by making the blood flow in the wrong direction, or by blocking the blood passage.

CHD comprises a wide spectrum of defects with varying severity. CHD is the most common form of birth defect causing many infants to die. It is estimated that approximately 8–10 out of every 1 000 children are born with CHD every year. These statistics have remained constant in different parts of the world but were obtained mostly from developed countries where such prevalence data are recorded (Saxena, 2005).

In Tanzania, cardiac surgery is still not well developed because of the limited resources. Children with CHD or other heart defects who need surgery are mostly sent abroad for treatment through government aid and with help from non-governmental organisations.

Only a few children receive this assistance. Most of them remain on a waiting list unsure of when, or even if, they are going to get surgical treatment. Many developing countries, including Tanzania, use estimated statistics on the prevalence of CHD at birth and on proportional mortality due to inadequate diagnostic facilities. As a result, few cases are detected and often only at the late stages, and an unknown number of cases are missed (Sani, Mukhtar-yola & Karaye, 2007).

CHD and other heart defects affecting children usually require extended follow-up periods, compliance and adherence to medication and other prescriptions. In addition to their children's medical problems parents usually also experience psychosocial issues (Beer, Haramati, Rein & Nir, 2001).

Knowledge is important for promoting health-related behaviours by increasing parents' understanding of their children's cardiac condition; improving compliance with treatment; and avoiding risk taking behaviours (Stroemberg, 2006; Wu, Moses, Lennie & Burkhart, 2008). Compliance is likely to be associated with improved quality of life and reduced risk of morbidity and mortality (Corbalev, Morrow, McGinnis, Wells, Corbaley, Orr & Shurney, 2008).

For the effective prevention of complications and optimal health of children with chronic diseases including CHD, parents need knowledge about the child's heart lesion; medication, indications and side effects; character and the limitations of surgery (not addressed in this study because the children concerned had not been scheduled for surgery); risk factors of endocarditis; and the child's physical activity limitations.

## PROBLEM STATEMENT

The incidence of children born with CHD is generally estimated to be about 8 per 1 000 live births. Advances in surgical and medical treatments have improved the life expectancy of these children who are now able to survive beyond their first year of life (Saxena, 2005). Prevalence studies of children living with CHD and other heart diseases such as rheumatic heart disease in sub-Saharan Africa (SSA) have shown that these diseases are common in these communities. A study conducted among school children in Mozambique showed a prevalence of 2.3 per 1 000 children screened for CHD (Marion, Tivana, Voicu, Vilanculos, Jani, Ferreira & Ou, 2006).

In Tanzania, no documented study could be traced that established the prevalence of children with CHDs. However, considering the estimated annual number of live births at 1 600 000 in Tanzania (UNICEF, 2006) and the documented incidence of 8 per 1 000 live births as suffering from CHD, then the number of children born with these defects would be approximately 130 00 per year. Given that the number of neonatal deaths from congenital anomalies is estimated to be 7% (WHO, 2006), more than 12 000 of these children could be added to the pool of children living with congenital defects each year. When a child is diagnosed with congenital or other chronic heart disease, it usually has some psychological implications for the family. The child's mother might respond to the diagnosis with grief, loss of her imagined healthy child; lack of knowledge about the disease/defect; and anger and difficulty in caring for a child with special healthcare needs (Upham & Medoff-Cooper, 2005). Parental understanding of the child's heart disease/defect is important as it would help the family to adjust to this new situation of bringing a baby home who needs special care.

It is expected that better knowledge of the condition will enable the parents to impart accurate information to healthcare providers who might be unfamiliar with the child's diagnosis at times of emergency. Parents could also help their children to acquire accurate knowledge about and perceptions of their cardiac condition. Distorted perceptions of CHD and other heart defects could cause unnecessary anxiety, inappropriate restrictions and impairment of the child's self perception (Danford, 2004).

Parents of children with heart diseases/defects are advocates for their children and are expected to act as conduits of information between healthcare providers and their children. However, some studies have revealed poor understanding by parents, regarding their children's heart diseases/conditions (Bulat & Kantoch, 2003; Chessa, De Rosa, Pardo, Negura, Butera, Giambert, Bossone & Carminati, 2005).

Poor knowledge about particular aspects of the disease/defect, and its treatment and preventive measures might have major consequences such as treatment non-compliance, which might cause a decreased quality of life and increased risk of morbidity and mortality for the child (Bhagat & Mazay-Mupanemunda, 2001).

Many children with CHD in Tanzania are unlikely to have access to surgery and will have to live with this chronic condition. Their quality of life depends to a large extent on the care provided by their parents, and the quality of this care depends, in turn, on the parents' knowledge about CHD. The research question to be answered was: "What do parents know about CHD, its treatment, medications, limitations and the prevention of complications?"

## **Objectives**

The objectives of the study were to determine parents' knowledge about their children's CHD, their children's medication; and factors that could cause complication(s) to the afflicted heart such as endocarditis.

The ultimate purpose of the study was to identify parents' knowledge levels about their children's CHD and make recommendations for enhancing these parents' knowledge. Better parental knowledge, and improved care could enhance these children's wellbeing and help to prevent complications, such as endocarditis.

## **RESEARCH METHODS**

A descriptive, cross-sectional, quantitative study was conducted at a hospital in Dar es Salaam, Tanzania, where most local paediatric cardiac cases are treated.

### **Population and sample**

The study's population comprised all parents of children diagnosed with CHD who received inpatient or outpatient treatment at the participating hospital. The accessible population comprised those parents of children diagnosed with CHD who visited an outpatient department of the hospital, or who were in a hospital ward with their children during the period of data collection. No sampling was done. All the parents, comprising the accessible population, were approached to participate in the study. The sample size was calculated using Daniel's formula (Naing, Winn & Rush, 2006), a 95% level of confidence and an 8% level of parents' knowledge (Nath, Kian & Maheshwari, 2008). This calculation indicated a sample size of 110 parents.

Parents who attended an outpatient clinic with their children at a participating tertiary paediatric centre from February to April 2009 were approached to be interviewed by the researcher before they were seen by the doctor. Those whose children were in hospital were also interviewed during this period. A total of 84 interviews were conducted during the time allowed for collecting data.

## **Research instrument**

The structured interview schedule was translated into Swahili, the language of the children's parents. Questions were asked about demographics; parents' knowledge about CHD; medication and side effects; the prevention of complications; the importance of skin/nail care as well as oral-dental hygiene; and physical capabilities.

A pre-test was conducted by interviewing 15 parents of children with CHD attending follow-up visits at the participating paediatric clinic. These parents were not included in the main study.

## **Data collection procedure**

The data were collected by interviewing parents of children with CHD, using the Leuven knowledge questionnaire for congenital heart disease modified with the consent of the author (Moons, Volder, Budts, Geest, Elen, Waeytens & Gewillig, 2001). The instrument had been evaluated to be reliable except for certain items regarding contraception. These items were not used in this study.

Answers to the questions were rated as: correct, does not know, incorrect. Univariate analysis was used to assess the associations between demographic and clinical variables and selected items of knowledge were performed with Chi-square tests, where appropriate. A probability value of  $p \leq 0.05$  was considered to be significant. All statistical analyses were done with SPSS version 11.5.

## **Ethical considerations**

Ethical clearance for the study was obtained from the participating hospital's research ethics committee. Parents were thoroughly informed about the study and their written consent was obtained. A consent form was signed upon agreement to participate in the study. Anonymity was guaranteed because only numbers were used on the interview schedules, no names were mentioned. Confidentiality was maintained because the interviews were conducted privately and the completed interview schedules were kept locked up. Only the researchers and the statistician had access to the raw data. Parents' rights, such as freedom to withdraw from the study at any stage and their right not to answer specific questions, were observed. No remuneration was paid for participation in the study.

## Research results

A total of 84 parents of children with CHD were interviewed during February and March 2009. The sample comprised 66 (78.6%) mothers and 18 (21.4%) fathers of the 84 CHD patients. The mean age of the parents was 28.02 (SD 3.5) years.

Some parents (61.9%;  $n = 52$ ) had a primary level education only, while 34.5% ( $n = 29$ ) had a secondary level education and only three (3.6%) parents had reportedly attained a post secondary education.

## Knowledge about diagnosis and treatment

**Table 1:** Parents' knowledge levels about the diagnosis and treatment of their children's CHD ( $n = 84$ )

	Low		Moderate		High	
	N	%	n	%	n	%
Diagnosis	36	42.8	45	53.6	3	3.6
Follow-up	1	1.2			54	64.3
Treatment	4	4.8			81	96.4
Symptom relapse	64	76.2			20	23.8

Parental knowledge was categorised as being low, moderate or high according to respective parental scores. Parents in the two highest categories were able to give explanations which would enable healthcare professionals, unfamiliar with the child's medical history, to understand the diagnosis (see table 1).

Symptoms were listed of which seven reflected deterioration of the cardiac condition, requiring appropriate medical interventions. These symptoms were shortness of breath, dizziness, palpitations, chest pain, fainting, increasing fatigue and swollen feet and legs. Only 23.8% ( $n = 20$ ) of the parents identified these signs and symptoms correctly (see table 1). An answer was considered to be correct if five or more of the relevant symptoms were mentioned.

Of the parents, 64.3% ( $n = 54$ ) had understood the reasons for follow-up visits and (96.4%;  $n = 81$ ) the treatment modes of their children's heart conditions (see table 1).

Two demographic factors showed a significant relationship with knowledge about the condition, namely the education level of the parents ( $p < 0.001$ ) and the period since diagnosis ( $p = 0.005$ ). These findings implied that better educated parents were more knowledgeable about their children's heart conditions. Parents' knowledge levels also improved over time since their children's CHD diagnosis.

## Knowledge about medications

Only 59.5% (n = 50) parents knew one or more types of medications, but 84.5% (n = 71) knew the doses of medicines to be taken by their children. Only 74 (88.1%) parents knew the schedule of giving medications to their children. Although most parents were knowledgeable about dosages and schedules of medication, 40.5% (n = 34) did not provide the correct names of their children's medications (see table 2). As many as 76 (90.5%) parents failed to mention the side effects of their children's medications, and could also not provide specific reasons why their children had to take the prescribed medications. However, 72 (85.7%) parents knew what actions to take in case their children experienced side effects of the medications. Parents were asked whether their children were on any special diets prescribed by the child's doctor. All parents said they had not been informed about special diets.

**Table 2:** Parents' knowledge about their children's medications (n = 84)

Variable	Correct (n)	Correct %	Does not know/in-correct (n)	Does not know/in-correct %
Name of the medicine	50	59.5	34	40.5
Dose	71	84.5	13	15.5
Schedule	74	88.1	10	11.9
Side effects	8	9.5	76	90.5
Function/reason	13	15.5	71	84.5
Interaction with other drugs/food	0		84	100
Proper action when child experiences side effects of drug	72	85.7	12	14.3

## Parents' knowledge about preventing complications

More than 90.0% of the parents did not know about the risk factors contributing to the onset of endocarditis such as needle contamination, dental abscesses, poor nail and skin care and cutaneous bacterial infections (see table 3). Most parents 76.2% (n = 64) were unaware that bleeding gums in a child with CHD require extra care as it might cause endocarditis.

**Table 3:** Parents' knowledge about risk factors and preventive measures

Variable	Correct (n)	Correct %	Don't know /Incorrect (n)	Don't know/incorrect %
Dental abscess	3	3.6	81	96.4
Contaminated needles	4	4.8	80	95.2
Cutaneous infection (bacterial)	1	1.2	83	98.8
Poor nail and skin care	1	1.2	83	98.8
Do bleeding gums need extra care?	64	76.2	20	23.8
Should your child clean his/her teeth at least once per day?	82	97.6	2	2.4
May your child take part in competitive sport?	0	0	84	100

All parents indicated severe restrictions of their children's involvement in competitive activities although no recorded information/doctor's prescription was available to validate their answers with respect to each child's condition.

## CONCLUSION

Parents lacked knowledge about their children's CHD, medications and prevention of associated complications, especially endocarditis. Fewer than 60% of the parents knew about the following: symptoms indicating that the child's condition is deteriorating; the side effects of medications; the reasons for specific medications; the interactions of prescribed medications with other medications or food; the risk factors for endocarditis, such as dental abscesses, contaminated needles, skin and nail infections, bleeding gums; the need for special nail and skin care; and the level of physical activity recommended for the child.

It would, therefore, seem that while certain aspects of information had been communicated successfully to parents, other aspects had not been adequately addressed. Since parents are the primary caregivers of these chronically ill children with CHD, these parents should have sufficient knowledge to prevent complications and promote their children's wellbeing.

## RECOMMENDATIONS

Parents of children with CHD spend more time with their children than healthcare providers. Consequently, parents' knowledge about CHD, its short and long-term implications from initial diagnosis to subsequent follow-up care, and hospitalisation periods, are vitally important for enhancing their children's wellbeing.

Parents with higher levels of education were more knowledgeable about CHD. More appropriate ways need to be identified and implemented to teach parents with lower levels of education to help them understand their children's heart conditions.

The paediatric clinic should use teaching methods such as: using simple illustrations or colourful diagrams to explain the problem to the parents; triaging parents according to how much educational support they need; providing leaflets for home use after follow-up visits or discharge from hospital; placing repeated emphasis on how to care for a child with CHD during follow-up visits; using simple language during explanations of CHD; and Requesting selected parents to teach other parents (under the supervision of nurses) as parents might be able to share knowledge in lay terms better understood among themselves.

Future research projects should attempt to observe parents' behaviours towards their children with CHD, not only during clinic visits and hospitalisation periods, but also at home. Such observations, against the background knowledge of the children's condition and medical prescriptions, might identify specific areas where parents' improved knowledge and skills might enhance their children's wellbeing. Such areas could include appropriate nutrition; permitted levels of physical activity; prevention of infections; routines for taking medications; and skin/nail care.

Future research should attempt to identify ways in which parents of children with CHD could be supported. Future research should obtain healthcare providers' views about enhancing health education for parents of children with CHD.

## **LIMITATIONS**

Although the sample size calculations indicated that 106 parents should be interviewed, it was possible to interview only 84.

Structured interviews were conducted with the parents and their answers were accepted as information. No observations could be done to identify parents' actual behaviours towards their children with CHD. No home visits could be conducted, which might have added another dimension of information.

Parents were only interviewed about their CHD knowledge. In-depth interviews with parents might produce valuable information about the parents' needs for knowledge and support. No interviews were done with the children with CHD, or with the healthcare professionals caring for these children.

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