

**.ASSESSMENT OF PARENTAL KNOWLEDGE ABOUT THEIR  
CHILDREN'S HEART DISEASE, MEDICATION AND  
PREVENTION OF COMPLICATIONS AT  
MUHIMBILI NATIONAL HOSPITAL  
DAR-ES-SALAAM**

**By**

**Menti Ndile**

**A dissertation Submitted in Partial Fulfilment of the Requirement for  
the Degree of Master of Science Nursing (Critical care and Trauma) of  
Muhimbili University of Health and Allied Sciences**

**Muhimbili University of Health and Allied Sciences**

**November, 2009**

**CERTIFICATION**

The undersigned certify that they have read and hereby recommend for acceptance a dissertation entitled "**Assessment of parental knowledge about their children's heart disease, medication and prevention of complications at Muhimbili National Hospital, Dar es Salaam**" in partial fulfilment of the requirement of the degree of Master of Science Nursing (Critical care and Trauma) of the Muhimbili University of Health and Allied Sciences.



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**Dr T.W Kohi**

Date November 9, 2009

**DECLARATION AND COPYRIGHT**

I, **Menti Ndile** declare that this **dissertation** is my own original work and that it has not been presented and will not be presented to any other University for a similar or any other degree award.

Signature 

Date 18/11/2009

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## ACKNOWLEDGEMENTS

Many people have contributed in one way or another from the beginning of writing the research proposal to finalising research report, with all due appreciation I would like to recognise contribution of Clara Aarts of Uppsala University in Sweden, Dr Petra Brysiewicz of University of Kwazulu Natal in South Africa, Prof Andrew Swai of Muhimbili National Hospital, Dr Julius Mwita and Patel Kiseng from Cardiology department Muhimbili National Hospital. I thank all of them for their invaluable suggestions and comments.

I would also like to appreciate contribution of Mr C.Makwaya from the department of Biostatistics at Muhimbili University of Health and Allied Sciences for his constructive comments on an area of statistics in this dissertation.

My deep appreciation goes to my principal supervisor Dr Thecla Kohi of Muhimbili University of Health and Allied Sciences and co-supervisor Prof B. Bhengu of University of Kwazulu Natal; these people have provided me with both moral and academic support without which I would not have accomplished the work.

Lastly but not least I wish to express my sincere gratitude to Dr K.Y Malima for her inputs during writing the dissertation, also sister Kowelo of cardiac paediatric clinic and Simbaulanga of paediatric ward for their tireless assistance during fieldwork.



## DEDICATION

This work is dedicated to my beloved late parents Mr and Mrs Lastone Ndile and my wife Mercy Kigodi.

## ABSTRACT

**Background:** Parents of the children with congenital heart diseases face challenges when caring for the children with the defects, taking in consideration that most of these defects require long follow-up. However, there has been no published study in Tanzania undertaken to determine parental knowledge on congenital heart disease.

**Objectives:** The main objective of this study was to assess parental knowledge about their children's heart disease, medication and prevention of associated complications at Muhimbili National Hospital. Three specific objectives guided the study; the first was to determine parental knowledge about their children's heart disease. Second was to determine parental knowledge about their children's medication and side effects, third aimed to determine parental knowledge in identifying conditions or factors that could cause complication(s) to the afflicted heart.

**Methods:** A quantitative research methodology using a descriptive cross-sectional design was adopted. Parental knowledge was assessed using a modified version of Leuven questionnaire for assessing knowledge of congenital heart disease, a 23 instrument item was used in this study, a scoring system for parental knowledge about the diagnosis of the congenital heart disease adopted from another study was also used in this study.

Study population was eighty four parents accompanying their children with congenital heart diseases for follow-up at cardiac clinic and those staying with their children in the wards. Data was analyzed using statistical packages to interpret the findings. The duration of the study was one month and half and the results will be disseminated to relevant stakeholders.

**Results:** Findings showed that 36(43%) of the Parents could not give a meaningful explanation of their child's heart condition, Two-thirds (76.2%) of the parents were not able to mention symptoms of deterioration of heart defect. Knowledge about side effects of the drug, and interaction with other drugs or food were low .The study revealed that parental understanding of the heart defect correlated with parental educational background.

**Conclusion:** Poor knowledge shown by the parents about their children's heart disease, medication and prevention of complications could have some serious implication including non-adherence and failure to take appropriate measures in time of deterioration of child's condition.



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**LIST OF ABBREVIATIONS**

UNICEF	United Nations Children's Fund
ASD	Atrio Septal Defect
VSD	Ventricular Septal Defect
AVSD	Atrioventricular Septal Defect
PDA	Patent Ductus Arteriosus
PS	Pulmonary Stenosis
TOF	Tetralogy of Fallots
MUHAS	Muhimbili University of Health and Allied Sciences
CHD	Congenital Heart Disease
MNH	Muhimbili National Hospital

## CHAPTER ONE

### 1.0 INTRODUCTION

#### 1.1 Background

Heart disease is any disorder that affects the heart's ability to function normally.<sup>1</sup> Most of heart diseases in children are linked to congenital heart diseases, the rest of these diseases are acquired in life. Congenital heart diseases alone are the most common forms of birth defects in relation to other birth defects; many infants also die from these defects in childhood.

The incidence of children born with CHD is generally estimated to be about 8 per 1000 live birth, advancement in surgical and medical treatment especially in developed countries have improved the life expectancy of these children who are now able to survive beyond their first year of life<sup>2</sup>.

Prevalence studies of children living with CHD and other heart diseases such as rheumatic heart disease in sub-Saharan Africa have shown that these diseases are common in the communities, these studies conducted among school children in Mozambique showed a prevalence of 2.3 per 1000 children screened for both congenital heart disease and rheumatic heart disease<sup>3,4</sup>. The prevalence figures from these studies unfortunately are just snapshots of the real situation, the true prevalence and burden of these diseases could be higher taking in consideration of high birth rates in these countries.

In Tanzania there is no documented study conducted to establish the prevalence rate of children with congenital and rheumatic heart diseases, but given the annual live births of around 1,600,000 from UNICEF<sup>5</sup> and documented incidence rate of 8 per



1000 live born for congenital heart disease which has shown to remain constant in many countries<sup>2</sup>, then the number of the children born with these defects will be approximately 13000 per year, given the number of neonatal deaths from congenital anomaly which is estimated to be at 7%<sup>6</sup>, then more than 12000 of these children will be added to the pool of children living with the defect each year. When a child is diagnosed with congenital or other chronic heart disease usually it has some psychological implication to the family, mother of the child may respond to the diagnosis with grief, loss of her imagined health child, lack of knowledge of the disease, anger and difficult in care giving among others<sup>7</sup>. Parental understanding of their children's heart disease is important as it may help the family adjust to this new situation of bringing a baby who needs special care.

Many studies in sub-Saharan Africa have been conducted to determine prevalence of congenital and rheumatic heart disease<sup>3,4</sup>, but few on parental knowledge about their children's heart disease, treatment and prevention of associated complications and to my knowledge non in Tanzania.

## **1.2 Statement of the problem**

Parents of the children with CHD face challenges when caring for their children with the defects considering the fact that most of these defects require long follow up and special care to protect heart function and preserve health.

In Tanzania no documented study exist which was conducted to establish the prevalence rate of children with congenital heart diseases, but given the annual live births of around 1,600,000 from UNICEF<sup>5</sup> and documented incidence rate of 8 per 1000 live born for congenital heart disease which has shown to remain constant in many countries, then the number of the children born with these defects will be approximately 13000 per year.

Considering the number of neonatal deaths from congenital anomaly which is estimated to be at 7%<sup>6</sup>, then more than 12000 of these children will be added to the pool of children living with the defect each year.

Parents of the children with heart disease are advocates and are usually expected to act as a conduit of information between health providers and their children however some studies have revealed poor understanding by parents regarding their children's heart diseases.<sup>8,9</sup>

Poor knowledge about particular aspect of the disease, treatment and preventive measures may have major consequences including non-compliance which is common in many chronic illnesses<sup>10</sup>; this may lead to lowered quality of life hence increased risk of morbidity and mortality.

It is expected that better knowledge of the disease will enable the parents to impart accurate information to health providers unfamiliar with the child's diagnosis in time of emergency; also children may have accurate concept and perception of their disease. Studies have revealed that distorted perception of congenital heart disease have been linked with unnecessary anxiety, inappropriate restrictions and impairment of child's self perception.<sup>11,12</sup>

The question for the study was: What do parents know about their children's heart disease, medication and prevention of complications? Aim of conducting this study was to assess parental knowledge about their children's heart disease, medication and prevention of complication in context of Tanzania.



### **1.3 Objectives of the study**

The main objective of the study was to assess parental knowledge about their children's heart disease, medication and prevention of complications.

#### **1.3.1 The specific objectives were;**

1. To determine parental knowledge on their children's heart disease.
2. To determine parental knowledge on their children's medication and side effects.
3. To determine parental knowledge in identifying conditions or factors that can cause complication(s) to the afflicted heart.

### **1.4 Rationale**

The study was expected to shed some light for the first time in Tanzania regarding parental knowledge about their children's heart disease, medication and prevention of complications. By shedding light, the study will be able to help health care providers assess current educational programs or methods they are using to provide information to the parents about their child's heart disease with a view of optimizing knowledge.

Nurses are the ones who are involved in providing health education to the parents of children with CHD who come to the clinic for follow-up or other reasons, results of the study will help nurses identify areas which need more educational efforts.



### **1.5 Research question**

What do parent know about their children's heart disease, medication and prevention of complications?

### **1.6 Definition of terms**

#### **Parent**

Is a father or mother, one who sires or gives birth to and/or nurtures and raises an offspring.

#### **Knowledge**

Knowledge is defined in general terms; in this study it would mean "parental understanding of their children's heart disease, medication and prevention of associated complications".

#### **Congenital heart disease/defect**

It is a defect in the structure of the heart and great vessels of a newborn.

#### **Valvular disease**

Is any disease process involving one or more of the valves of the heart (the aortic and mitral valves on the left and the pulmonary and the tricuspid on the right), the cause may be congenital (inborn) or acquired (due to another cause later in life)

#### **Rheumatic heart disease**

This is an autoimmune inflammatory disease which involve the connective tissue of the heart and may develop two to three weeks after a Group A streptococcal infection and can involve the heart, commonly appear in children aged 5 through 15 years.

#### **Prophylaxis**

Is any medical or public procedure whose purpose is to prevent rather than treat or cure a disease.

## CHAPTER TWO

### 2.0 LITERATURE REVIEW

#### 2.1 General overview

Heart disease is a broad term that is used to describe a range of diseases that affect the heart <sup>1</sup>, although most of heart diseases in children are associated with congenital heart defects, children also develop other forms of heart diseases including rheumatic heart disease.

CHD refers to the problem with the heart structure and function due to abnormal heart development before birth.<sup>13</sup> The abnormality caused by heart diseases disrupt the normal blood flow through the heart and blood vessels in various ways such as by slowing down blood flow or blood going in a wrong direction or place or by blocking blood passage.

CHD's alone comprise a wide spectrum of defects with varying severity. Statistics show that these defects are the most common forms of birth defects and many infants die of these defects compared to any other defects.<sup>2</sup> It is estimated that approximately 8-10 in every 1000 children are born with congenital heart defects every year, these statistics have remained constant in different parts of the world, mostly from developed countries where such prevalence data are tracked.<sup>14</sup>

It is not unusual to see an adult with uncorrected or untreated congenital heart defect, but primarily these defects are seen in neonates, infants and children.<sup>15</sup>



Advancement in diagnostic and treatment of congenital heart defects over the past three decades have made possible for many children to survive up to adulthood and it is estimated that this population is growing at the rate of 5% per year.<sup>15, 16</sup>

Improvement in diagnosis, management and treatment modalities although have improved life expectancy of children with heart diseases, the figures do not reflect a true situation in many developing countries. Lack or shortage of diagnostic equipments, specialists, poverty and many other factors make it impossible for majority of the children afflicted with congenital and other heart diseases in developing countries to get the necessary care which in turn lead to high morbidity and mortality.<sup>17</sup>

In Tanzania cardiac surgery is still not well developed because of the limited resources, children with congenital or other heart diseases who need surgical correction are mostly sent abroad for treatment through government aid and from non-governmental organizations, the number of children getting this assistance is small, majority of them remain in a waiting list unsure of the time they are going to get treatment. Many developing countries including Tanzania use estimated statistics on congenital heart defect prevalence at birth and on proportional mortality due to inadequate diagnostic facilities, this causes few cases to be detected and often at late stage of the disease.<sup>18</sup>

## **2.2 Parental knowledge about heart diseases.**

Congenital and other heart diseases affecting children usually require long follow up, compliance and adherence to medication and other prescriptions, in addition to medical problems parents also experience psychosocial issues.<sup>19</sup>



Parents of children with heart diseases are usually expected to act as a conduit of information between the health provider and their children; however several studies have shown that many parents are not familiar with their child's heart diseases<sup>9, 10</sup> Statistics from one study show that 41% of the parents interviewed failed to name their children's congenital heart disease, only 28.8% correctly indicated the heart lesion(s) diagrammatically, disappointingly of the 56 parents whose children were taking cardiac medication only 25(44.6%) and 4(7.1%) knew correctly the function and important side effects of the medication respectively.<sup>20</sup> Similarly other studies conducted on other heart diseases show similar trend of knowledge deficit by parents on their children's heart condition.

Many parents misunderstand surgery as a cure for their children defects and some are not aware of their children's lifelong risk of additional heart problems. Poor knowledge about particular aspect of the disease, treatment and preventive measures may have major consequences including non-compliance which is common in many chronic illnesses due to lack of knowledge.<sup>10</sup>

Knowledge is an important factor in order to promote better health related behaviour by increasing an understanding of cardiac problems, improving compliance with treatment and avoiding risk taking behaviour.<sup>21, 22</sup> Good compliance and adherence is likely to be associated with improved quality of life and reduced risk of morbidity and mortality.<sup>23</sup>

Better knowledge of the disease will enable the parents to impart accurate information to their children so that their children may as well have accurate concept and perception of their disease, it has been revealed that distorted perceptions of congenital heart disease have been linked with unnecessary anxiety, inappropriate restrictions and impairment of child's self perception.<sup>11</sup>

### **2.3 Parental knowledge about medication**

Knowledge about medication use and anticipated side effects is important in order to ensure adherence to medication prescription especially for the parents who care for chronic ill children taking in consideration that these parents are the ones who take care of these children at home in absence of healthcare providers, results of one study which was conducted to assess Asthma knowledge and medication compliance revealed that only 43.3% of parents reported adherence with prescribed medication<sup>24</sup> the major reasons of non-adherence included fear of medication side effects, tolerance and forgetting to give the child the medication. It is expected that when parents are provided with relevant information about their children's medication and expected side effects, parental compliance will improve and this will ensure good continuity of care from hospital to home.

### **2.4.0 Parental knowledge about preventive measures of complications**

#### **2.4.1. Importance of oral hygiene**

Children with congenital heart disease are at high risk of acquiring other heart complications through infection thus complicating furthermore the already fragile condition. Parental involvement and awareness is important in order to reduce or prevent these complications, however studies have shown that many parents are not aware of risk factors and what preventive measures to take in order to lessen complications. One study conducted to determine parental awareness regarding the importance of oral hygiene and prophylaxis against infective endocarditis revealed that only 8% of parents were aware of good oral-dental hygiene and need for infective endocarditis prophylaxis to protect their children from acquiring heart infection.<sup>25</sup>

Infective endocarditis is a potential complication and life threatening in any heart disease; it is an infection of the tissue that lines the heart and blood vessels.



The infection occurs as a result of bacterial infection. Poor oral hygiene, diagnostic and dental procedures can predispose a patient with heart disease to this infection hence the need for antibiotic prophylaxis cannot be overemphasized. Low knowledge shown by the parents can have serious implications to the child's health and burden to hospital care due to the fact that the illness requires prolonged treatment with antibiotics in a hospital setting.

#### **2.4.2. Physical activities**

Congenital heart disease like other chronic illnesses does not only affect the child, but also the family life style, sometimes parent find themselves unsure of how best to bring their child because they perceive the child as being vulnerable. A vulnerable child is described as the one whose parents expect to die prematurely and who later demonstrate behaviour or developmental problems.<sup>26</sup> Perceived vulnerability has made parents to be overprotective towards their children. Parental overprotection is defined as an excessive and developmentally inappropriate level of parental protectiveness.<sup>27</sup>

Parents have shown to be overprotective of their children by hiding the defect from their children or by being over restrictive on their child's participation in some physical activities.<sup>26</sup> Overprotection by parents have shown to strengthen the feeling of being different from other children, taking in consideration that the population of children growing to adulthood with cardiac malformation is increasing, the children and adults with social maladjustment may obviously increase.

It has been documented that when parents offer a realistic view on living with heart defect they may help their children to face the real impact of the disease earlier in life and thus cope with the limitation.<sup>28</sup>



Good communication between parents and health care workers may help clear misconception that parent have on their children. Studies have shown that distorted perceptions of congenital heart disease may cause unnecessary anxiety, inappropriate restrictions and impairment of child's self perception.<sup>11</sup> Generally parents of children with congenital heart and other heart diseases have shown to have an important knowledge gaps about the disease, treatment and preventive measures of complication.<sup>20, 25</sup> Knowledge deficit shown by parents may have unfavourable implication not only to the child's growth but also to the community at large

## CHAPTER THREE

### 3.0 METHODOLOGY

#### 3.1 Design

This study which assessed parental knowledge about their children's heart disease, medication and prevention of complications during follow-up visits or child hospitalization was a descriptive, cross-sectional study design which utilized quantitative method, the variable measured was knowledge. In a descriptive, cross-sectional study data are collected only at one point in time in order to describe an event, phenomenon or help define a set of attitudes, opinions or behaviours that are observed or measured at a given time and in a given environment. The study design was chosen because of limited time given to collect data (about six weeks) and once a week schedule attendance of respondents at the cardiac clinic.

#### 3.2 Setting

The study took place at Muhimbili National Hospital in Dare-es-salaam. Muhimbili was conveniently chosen as the study area because it is the only tertiary hospital where most of cardiac cases are referred or treated in Tanzania.

#### 3.3 Study population

The study involved parents of the children with congenital and acquired heart diseases accompanying their children to the cardiac clinic and those staying with their children in wards in the Muhimbili National Hospital.

### 3.4 Inclusion criteria

- Parents of children with congenital or acquired valvular heart disease who are below 18 years.
- Parents accompanying their children to the cardiac clinic who have been diagnosed with congenital or acquired valvular heart diseases in previous attendances.
- Parents staying with their children in hospital who have been diagnosed with congenital or acquired valvular heart disease (VHD)
- Parents of children who have simple congenital heart defects such as Atrial septal defect (ASD), Ventricular septal defect (VSD), Atrio-ventricular septal defect (AVSD), Pulmonary Stenosis (PS), Aortic stenosis (AS), Patent Patent Ductus Arteriosus (PDA), Tetralogy of Fallots (TOF)

### 3.5 Exclusion criteria

- Parents of the children who have received a new diagnosis of congenital or other heart disease.
- Parents of the children who are on the first visit to the clinic
- Parents of the children with complex congenital heart diseases

### 3.6 Sampling

A non-random convenient sampling method was used; this type of method allowed the researcher to interview all respondents on the first come basis guided by preset inclusion and exclusion criteria, thus all parents attending an outpatient cardiac clinic with their children and those staying with their children in cardiac wards at the time of the study were interviewed by the researcher provided they met inclusion criteria and agreed to participate.

This sampling method was chosen in order to interview as many respondents as possible because of the limited time of data collection and a once weekly time table



attendance of the respondents to the cardiac clinic (an average turn out of about 25 respondents once a week)

### 3.7 Sample size

Parents of the children with congenital heart disease have shown to have knowledge gaps in various domains of knowledge such as understanding the disease, treatment and prevention of complication.

The researcher used one study under the domain of knowledge of prevention of complication to reflect my sample size, the reason behind this was to get a manageable sample size due to time constrain but still without compromising the research findings. In the study which was conducted to determine parental awareness of how to prevent their children from getting infection of the heart through good oral-dental hygiene and the use of antibiotic prophylaxis against bacterial endocarditis, only 8% of parents had knowledge<sup>25</sup>, the researcher assumed the same proportion of research participant to have the same knowledge.

The following formula according to Daniel<sup>29</sup> was used to calculate the sample size.

$$n = \frac{Z^2 P(1-P)}{d^2}$$

Where n=sample size

Z=Z statistics for a level of confidence e.g. 1.96 (95%)

P=expected proportion or prevalence (in proportion of one e.g. if 8% then

P =0.08)

d=precision (in proportion of one e.g. if 5%, d = 0.05)

Using proportion of 8%, precision of 5% and confidence level of 95%

$$n = \frac{(1.96)^2(0.08)(1-0.08)}{(0.05)(0.05)}$$

The sample size was 110 parents of the children with congenital heart diseases.

### 3.8 Data collection.

#### 3.8.1 Instrument

Parents who attended an outpatient clinic with their child in a tertiary paediatric centre from February to April were asked for consent and interviewed by the researcher before they were seen by the doctor for an appointment; those with their child hospitalized also were interviewed.

**Table 1: Topics attributed to the three domains of knowledge in congenital heart disease**

<p><b>1. Disease and treatment</b></p> <p>(a) Reasons for and interval of follow-up</p> <p>(b) Treatment of the defect</p> <p>(c) Symptoms of deterioration</p> <p><b>2. Measures to prevent complications</b></p> <p>(a) Risk factors for endocarditis</p> <p>(b) Behaviours to prevent complications</p> <p><b>3. Physical activities</b></p> <p>Physical restriction/capacity</p>
--

A scoring criteria for assessing parental knowledge about the diagnosis of heart disease was adopted from a study by Wray et al<sup>30</sup> (Table 2) This system consists of 5 categories where a respondent is allocated according to his/her understanding of the disease, also a Likert type scoring criteria was devised in this study in order to measure parental knowledge about medication (Table 3)

**Table 2: Scoring criteria for assessing parental knowledge about the diagnosis of heart disease.**

Score	Criteria for using score
1	Parent gave correct medical terminology to explain their child's condition
2	Parent used layman's terms to describe their child's condition. The layman's terms given allowed the correct medical diagnosis to be deciphered
3	Parent used layman's terms which suggested a probable medical diagnosis but left the exact diagnosis unclear.
4	Parent aware of the vague nature of the child's condition
5	Parent had no idea of the diagnosis

Scores were combined to form three categories/levels of knowledge

- High knowledge-score 1
- Moderate knowledge-score 2
- Low knowledge –scores 3, 4 & 5

In moderate and high knowledge parents were able to give a meaningful explanation of their child's heart condition.



To assess parental knowledge about medication, an ordinal -four point Likert type scale was devised, scores were rated as;

- High knowledge –scores 1
- Moderate knowledge-score 2
- Low knowledge-score 3
- Lack knowledge -score 4

**Table 3: Scoring criteria for assessing parental knowledge about medication.**

Score	Criteria for using score
1	Parent gave correct name/dose to above half the number of medication used
2	Parent gave correct name/dose to half the number of medication used.
3	Parent gave correct name/dose to below half the number of medication used.
4	Parent had no idea or gave incorrect name/dose of medication used

Data was collected through interviewing parents of children with congenital and acquired heart diseases by using a Leuven knowledge questionnaire for congenital heart disease modified with the consent of the author<sup>31</sup> (see Appendices VI and VII for both English and Kiswahili version respectively and Appendix V for a letter of permission to use the instrument) In this study a modified Leuven questionnaire measures knowledge in three domains which are;

- The disease and its treatment
- The prevention of complications
- Physical activities

Six topics (table 1) and 23 questions involving these domains were identified.

The questionnaire was translated in Swahili language which is the language of the research participants and included questions about demographic profile (questions 2-5), questions pertaining to knowledge based on description of the disease, medication and side effects (questions 6-17), questions pertaining to prevention of complications and importance of oral-dental hygiene (18-20) and questions on physical capability (question 22)

The researcher conducted a face to face interview to all eligible respondents, no research assistants were recruited in the study, and this helped to ensure consistency of the interview process. Answers provided by the respondents regarding their children's medical diagnosis, current treatment, drug regimen and other items were counter-checked by the researcher to their respective children's medical files/records in order to verify if what they have answered was accurate, this was done after securing permission from relevant sources. Each of the answers given by the parents were evaluated as correct, does not know or incorrect, questions involving multiple answers and open questions could also be scored as incomplete.

### **3.8.2 Pre-testing**

A pilot study was conducted to 15 parents of the children with congenital heart disease on follow-up visit to paediatric clinic; however these parents were not included in the main study. The aim of pretesting was to check whether the instrument to be used in research was able to collect relevant and desired information. Responses from the study participants were compared and assessed by the researcher to see if questions were well understood by them. Changes were made where it deemed necessary before the actual field work.



### 3.8.3 Validity

Content validity of original English version of the questionnaire was examined by panel of two cardiologists working in a congenital cardiac clinic at Muhimbili National Hospital and one nursing student pursuing a Master degree at Muhimbili University; after completing the questionnaire discussion was held together with the researcher to look into issues of clarity, specificity of variable to be measured and relevance of the content of the questionnaire in our Tanzanian context, decision on what to add, modify, include or exclude questions from the original version was based on expert judgement and clinical experience. Questions regarding topic of contraception and certain area of endocardities which also had problems with regard to validity in the original version were considered not important in our context thus omitted. The instrument was then translated in Swahili version, in order to ensure validity of translated version and adaptation process the following where adhered;

- The translated version was written in simple language for easy understanding.
- Items of the meaning similar to that of the English language instrument were included
- Process of translation and back translation was performed accordingly so as to ensure comparability with the original version.

The translated text was again revised by the panel to determine whether the translation was adapted to suit the local population before it was administered for pre-testing.

### 3.8.4 Reliability

The instrument used is a Leuven questionnaire for assessing congenital heart diseases; several studies have been conducted using this questionnaire <sup>9, 20, 31</sup>. The instrument have been evaluated to be reliable except for certain items regarding contraception and endocarditis following changes in International recommendations, these items were not used in this study due to difficulties with the issue of validation and lack of importance in the local community.



### **3.9 Data analysis**

Continuous variables are presented as means, nominal as percentages and ordinal variables as median and its range. Answers to question were rated as: correct, does not know, incorrect. Univariate analysis to assess the associations between demographic and clinical variables with selected items of knowledge was performed with Chi-square test where it seemed appropriate. A probability value of  $p \leq 0.05$  was considered significant. All statistical analyses were done with SPSS version 11.5 (SPSS Inc, Chicago, Illinois, USA)

### **3.10 Limitation of the study**

This is a relatively small study involving a wide range of cardiac diagnosis; knowledge was assessed only on simple cardiac defects. The funding of the study which was 1000,000 Tsh was not enough; also interview method which involved face to face interview and time constrain made it impossible to get the minimum sample size required. Convenient sampling method was used where by parents who came for follow-up were interviewed, interview was conducted on come first basis, this could be a source of sample bias as these parents could be more adherent, motivated or knowledgeable.

### **3.11 Dissemination of the findings**

It is intended that the results of this research reach wide spectrum of readers and stakeholders, thus the results will be disseminated to;

- School of Nursing –MUHAS
- Muhimbili National Hospital
- Ministry of Health and Social Welfare
- Academic journals



### 3.12 Ethical considerations

Ethical clearance for the study was obtained from the MUHAS research ethics committee (Appendix III). Permission to conduct the study at the Muhimbili National Hospital was requested and granted from the hospital administration (see Appendix IV) Participants were thoroughly informed about the study and their written consent was sought, consent form was signed upon agreement of participation in the study.(see Appendices I and II) Confidentiality was guaranteed though participant's state of anonymity, only numbers were used to identify participants, not names. Participants rights such as freedom of withdraw from the study, freedom from not answering some questions and other rights were addressed and observed.



## CHAPTER FOUR

### 4.0 RESULTS

A total of 84 parents of the children with congenital heart disease were enrolled into the study between Februarys and March 2009. Among the study population 66(78.6%) were mothers and 18(21.4%) were fathers of 84 patients. The mean age of the study population was 28.02(SD 3.5) years

Majority of the parents 61.9% had a primary level education while those who had secondary level education were 34.5%. Post secondary education was observed to be low, it constituted 3.6%

**Table 4: Demographic characteristics of parents of the children with CHD (n=84)**

Variables	n	%
<b>Sex</b>		
Male	18	21.4
Female	66	78.6
<b>Education</b>		
Non-formal	0	0
Primary or below	52	61.9
Secondary	29	34.5
College/ University	3	3.6



### Knowledge about diagnosis and treatment

Parental knowledge were categorized as low, moderate or high according to respective parental score.(refer to table 2). 36(43%) parents were in a low knowledgeable, those who were moderately knowledgeable were 45(53.6%) High knowledgeable parents comprised of 3.6%

**Table 5: Frequency distribution of parental level of knowledge about their children's diagnosis (n=84)**

Level of Knowledge	n	percent
Low knowledge	36	43.1
Moderate knowledge	45	53.6
High knowledge	3	3.6
<b>Total</b>	<b>84</b>	<b>100</b>

48(57.2%) of the parents were able to give an explanation which could have made possible for health profession unfamiliar with the medical history to understand the diagnosis (see Table 5). Majority of the parents 81(96%) used layman's terms to give an explanation of their child's condition.

Among the study population parents who had higher education were relatively more knowledgeable about their child's diagnosis compared to those of lesser educational background ( $\chi^2 = 24.61$ , df 4 ,p < 0.001) shows a statistically significant association between parental level of knowledge and educational level.(Table 6)

**Table 6: Association between parental education and level of knowledge about their children's diagnosis**

Level of knowledge	Primary school n (%)	Secondary school n (%)	College/University n (%)	Total N (%)
Low	31(59.6)	4(13.8)	1(33.3)	36(42.9)
Moderate	20(38.5)	24(82.8)	1(33.3)	45(53.6)
High	1(1.9)	1(3.4)	1(33.3)	3(3.6)
<b>Total</b>	<b>52(61.9)</b>	<b>29(34.5)</b>	<b>3(3.6)</b>	<b>84</b>

( $\chi^2 = 24.61$ , df 4 ,p < 0.001)

To assess knowledge about management of symptoms, the questionnaire listed 11 symptoms, of which seven reflected deterioration of the cardiac disease requiring appropriate medical intervention these symptoms were shortness of breath, dizziness, palpitations, chest pain, fainting, increasing fatigue and swollen feet and legs. Only 23.8 percent of the parents identified these signs and symptoms correctly (see Table 7) an answer was considered correct if five or more of the relevant symptoms were mentioned.

The findings of the study showed that parents had impressive understanding of the reason for follow-up and the mode of treatment of their children's heart disease (see Table 7)





**Table 7: Frequency distribution of parental knowledge about their children's heart disease.**

<b>Variable</b>	<b>Correct (%)</b>	<b>Don't know/ Incorrect (%)</b>	<b>Incomplete (%)</b>
What is the main purpose of the follow up?	54/55* (98.2)	1(1.8)	-
How has the heart condition been treated to date?	81(96.4)	3(3.6)	-
Mention the symptoms which may occur if your child's heart condition deteriorates and for which you need medical help.	20(23.8)	0	64(76.2)

\*Out of 84 parents, 55 came to the clinic from home for a follow-up visit while 29 had their children hospitalized, the question asked was relevant to those who came to the clinic for follow-up.

Association was found among parents regarding the first time they were told about the diagnosis of their children, parents who were told about the diagnosis of their children in the past were more knowledgeable compared to fresh and recent ones ( $\chi^2 = 9.49$ ,  $df 4$ ,  $p = 0.005$ ) this could be related to frequent refreshment effect of their children's disease from medical personnel during subsequent follow-up.



**Table 8: knowledge about disease in relation to time of initial diagnosis**

Level of knowledge	Time since diagnosis			Total N (%)
	Month □ n(%)	1-12 months* n(%)	Year □ n(%)	
Low	11(66.0)	24(46.2)	1(7.1)	36(42.9)
Moderate	7(38.9)	26(50.0)	12(85.7)	45(53.6)
High	0	2(3.8)	1(7.1)	3(3.6)
<b>Total</b>	<b>18(21.4)</b>	<b>52(61.9)</b>	<b>14(16.7)</b>	<b>84(100)</b>

( $\chi^2 = 9.49$ , df 4, p =0.005)

\*Except in emergency situation parents are normally scheduled to attend clinic with their children once in every three months.

#### **Knowledge about medication**

Majority of the parents who were interviewed 71(84.5%) knew one or more dose(s) of medicine taken by their children. 74 (88.1%) knew the schedule of giving medication to their children. Although parents had impressive knowledge of dosage and schedule of medication still many of them 40.5% either did not know or gave incorrect name of medication. (Table 9 and 10)

**Table 9: Frequency distribution of parental knowledge about the name of medication (n=84)**

Level of knowledge	n	Percent
Lack knowledge	34	40.5
Low knowledge	29	34.5
Moderate knowledge	7	8.3
High knowledge	14	16.7
<b>Total</b>	<b>84</b>	<b>100</b>

**Table 10: Frequency distribution of parental knowledge about the dose of medication (n=84)**

Level of knowledge	n	Percent
Lack knowledge	13	15.5
Low knowledge	14	16.7
Moderate knowledge	21	25
High knowledge	36	42.8
<b>Total</b>	<b>84</b>	<b>100</b>



Parents were asked whether their children were in any special diet prescribed by the doctor, all of them said they were not told about the subject. 72 (85.7) were aware of what to do in case the child experiences side effects of medication although majority of them 76(90.5) failed to mention side effects of the medication used by their children and specific functions/reasons for taking medication.

**Table 11: Frequency distribution of parental knowledge about medication.**

Variable	Correct (%)	Does not know /incorrect (%)
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)

### **Knowledge about prevention of complications**

Parents showed poor knowledge about risk factors contributing to onset of endocarditis such as needle contamination, dental abscess, poor nail and skin care and cutaneous bacterial infection (Table 12) Majority of the parents 76.2% were not aware that bleeding gums in a child with congenital heart disease need extra care as it may predispose endocarditis



**Table 12: Frequency distribution of parental knowledge about risk factors and preventive measures**

<b>Variable</b>	<b>Correct (%)</b>	<b>Does not know/Incorrect (%)</b>
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	84(100)

### **Physical capacity**

All parents showed strong restriction of their child being involved in competitive activities although no recorded information/doctor's prescription was available to validate their answers with respect to their child condition

## CHAPTER FIVE

### 5.0 DISCUSSION

Parent of children with chronic diseases including congenital heart disease stay longer with their children compared to health providers thus knowledge about the disease, its short and long term implication from initial diagnosis to subsequent follow-up or during any period of inpatient care is vital.

The study has revealed knowledge gaps by parents in certain aspect of their children's heart disease, medication and prevention of associated complications; this corresponds to other studies of similar background.<sup>9,10</sup> Unlike in other studies where parents showed good knowledge of their children's heart disease<sup>9</sup> in this study almost half of the parents could not give a meaningful explanation of their children's diagnosis of heart disease, this could probably be related to the level of education of the respondents which the study has revealed to be low to majority of them also educational strategies used by health providers in imparting information to the parents and language barrier whereby local language is not self sufficient in providing explanation to many medical conditions.

The findings of the study revealed that there is association between parental knowledge about their children's heart disease and their educational background ( $p < 0.001$ ). Parents who had attained higher education were more knowledgeable compared to those with lower education background.



The results showed an association between parental knowledge about their children's diagnosis and the first time they were told about it ( $p=0.005$ ) Parents who were recently told about their child diagnosis scored less compared to those who were told some time in the past, this could probably be related to refreshment effect of their children condition following subsequent visits to cardiac clinic.

Majority of the parents showed impressive understanding of the purpose of the follow-up visit and type of the treatment their children were getting, this also correspond to other studies of similar background<sup>9</sup>

Despite poor knowledge about the diagnosis of their children's heart disease, parent showed good knowledge about the dose and schedule of medication taken by their children; this is very encouraging taking into consideration that parents or relatives are the ones who stay longer with the chronic ill patients both at home and hospital. Since parents who come for follow-up visits at cardiac clinic among others are given medication, for home use, good knowledge about the dose and schedule ensures good continuity of care

Results revealed that although parents showed good knowledge about the dose and schedule of medication on contrary they showed poor knowledge about the name of medication(s) used by their children, most of them could identify medicines by the colour, size, shape, form or container, knowledge about function and interaction of medicine with food or other medicine was even lower, this could probably be due to the fact that explanations about medication may involve language that is difficult for most of the parents to remember or comprehend also depending on educational approach, parents may think it is unnecessary for them to know and leave it to medical personnel.



The findings of the study showed that majority of the parents had low knowledge about symptoms of deterioration of their children's heart disease; these findings correspond to similar studies done outside the country.<sup>9,20</sup> Considering that most of the parents stay with their children away from hospital hence no continual observation from medical personnel, knowledge about symptoms of deterioration by parents should be strengthened, children with CHD may have their condition deteriorate at any time, it is imperative therefore that parents recognise early danger signs so as to enable them to take appropriate care during such an emergency situation.

The findings of the study have shown that knowledge about risk factors of endocarditis was low, this correspond to other studies conducted outside the country<sup>9,20,25</sup>, efforts should be made to address this area to the parents so as to minimize complications that may be associated with these risk factors.

The results of the study have shown that majority of the parents were not sure to what extent their children should be involved in physical activities; this area should be specified so as not to impose unnecessary restrictions by parents on their children. Studies have shown that distorted perceptions of congenital heart disease may cause unnecessary anxiety, inappropriate restrictions and impairment of child's self perception.<sup>11</sup>

Parents of the children with chronic diseases need more knowledge and help in understanding the future of their children and their daily lives activities. Good communication between parents and health care workers may help clear misconception that parent have on their children regarding physical capability.

## CHAPTER SIX

### 6.0 Conclusion

This study which was aimed on assessing knowledge of the parents about their children's cardiac disease, medication and prevention of associated complications is the first study to the best of my knowledge to be conducted in Tanzania.

The study has revealed that; Parent of children with CHD had low knowledge about their children's cardiac disease. Parental knowledge about their children's diagnosis was associated with their educational background; those who attained higher education were relatively more knowledgeable compared to those with low educational background. The study has also shown that knowledge was associated with duration of clinic attendances whereby those have attended longer were more knowledgeable compared to recent one.

Parents of the children with CHD were well knowledgeable about the dose(s) and schedule of medication taken by their children although majority of them were not able to give the name(s) of medication(s)

Parents of the children with CHD had low knowledge about symptoms of deterioration of cardiac disease and risk factors of endocarditis. Majority of the parents showed good understanding of the reasons for follow-up visits and treatment modalities of their children.



### 6.1 Recommendations

Significant knowledge gaps have been identified in various knowledge domains, this call for structuring ways of imparting information by health providers to the parents of the children with CHD so as to make sure that parents capture relevant information which will enable them to appropriately care for their children in absence of health providers.

Parental knowledge reflected their educational background; this brings to attention on better ways of explaining the problem to the parents of lower educational background so as to help them understand their children's heart disease, the Paediatric clinic may introduce/use teaching methods such as;

- Simple illustrations or colour diagrams in explaining the problem to the parents,
- Triaging parents according to how much educational support they need.
- Providing leaflets for home use after follow-up visit or discharge from hospital.
- Continuous refreshment to the parents of how to care for a child with CHD during follow-up visits.
- The use of simple language by health providers during explaining the problem to the parent

Despite the fact that parents showed good knowledge about dose and medication further research is needed to find out if this reflect adherence to cardiac medication.



## **6.2 Implications for nursing practice**

Parental understanding of their children's heart disease is important in making sure there is good transition from childhood to adulthood. The reason for poor knowledge shown by the parents in some aspect of the heart disease, medication and prevention of complications was not clear as to whether the relevant information was never passed in the first place or parents forgot, nevertheless nurses are important players in providing health education to these parents hence educational efforts should be an integral part of follow-up in order to improve understanding

There are various ways of imparting information to the patients or clients who come to the hospital; however limited assessments are carried out by nurses to find out whether the information given is well understood, it is imperative therefore to carry out periodic assessments in order to understand how much impact a particular education method/program has and what should be done to improve the situation.

Poor knowledge shown by parents in this study may have important implications such as parental anxiety, unnecessary restrictions by parents, which may compromise social integration of their child and non-adherence to medication among others, nurses are within the capacity to address these issues and change the trajectory.

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