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ADDIS ABABA UNIVERSITY COLLEGE OF HEALTH SCIENCES SCHOOL OF NURSING & MIDWIFERY
DEPARTMENT OF NURSING

ASSESSMENT OF FAMILY CAREGIVERS' KNOWLEDGE AND SELF REPORTED PRACTICE OF CARING FOR CHILDREN WITH CONGENITAL HEART DISEASSE AT THE CARDIAC CENTERE ETHIOPIA, ADDIS ABABA, ETHIOPIA

By: Feben Berihu, RN, BSc N

A THESIS SUBMITTED TO ADDIS ABABA UNIVERSITY, COLLEGE OF HEALTH SCIENCE, SCHOOL OF NURSING AND MIWIFERY, DEPARTMENT OF NURSING FOR PARTIAL FULFILMENT DEGREE OF MASTERS OF SCIENCE IN CARDIOVASCULAR NURSING

July 2021
ADDIS ABABA

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Approval by the board of examination

This thesis prepared by Feben Berihu is accepted in its present form by the board of examiners as satisfying thesis requirement for the degree of master in cardiovascular nursing.

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Declaration paper

By my signature below, I declare and affirm that this research thesis l is my own work. I have followed all ethical principles of scholarship in the preparation. All scholarly matter that is included in the thesis has been given recognition through citation. I affirm that I have cited and referenced all sources used in this document. Every effort has been made to avoid plagiarism in the preparation of this research thesis. This research thesis is submitted in partial fulfillment of the requirement for a postgraduate degree from the Addis Ababa University at College of Health Sciences, School of Nursing and Midwifery.

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List of acronyms

ASD:	atria septal deficit
AVSD:	atria ventricular septal deficit
CHD:	congenital heart disease
GBD:	global burden of disease
GC:	Gregorian colander
HRQOL:	health related quality of life
LV:	left ventricle
MS:	mitral stenosis
OR:	operation theater
PA:	pulmonary artery
PDA:	patent ductus arteriosus
PS:	pulmonary stenosis
PO:	per orris
RA:	right atrium
RL:	right atrium
RV:	right ventricle
RVOT:	right ventricular out flow tract
TS:	tricuspid stenosis
VSD:	ventricular septal deficit

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Abstract

Background: Congenital heart disease (CHD) is one of the most common birth anomalies. Around the world it has been estimated that children's have one among 100 congenital deficits due to the chromosomal abnormalities. In the last few years, the emergence of new technologies and advanced therapy the children born with CHD can make it through the adult hood. During the journey of treating children with CHD the role of family caregivers is significant. However, little is known about the family caregiver's knowledge and self-reported practice of caring for children with CHD.

Objective: The objective of this study is to assess the family caregiver's knowledge and self-reported practice of caring for children with congenital heart disease at cardiac center Ethiopia Addis Ababa Ethiopia.

Methods: The study was performed under hospital based descriptive cross-sectional study. The data was collected from families of children with CHD at the cardiac center outpatient department through written questioner. The questioner was administered by two trained nurses who work in the outpatient department of the cardiac center. The returned questionnaire was checked for completeness, cleaned manually and entered in to EPI INFO statistical software and then transferred to SPSS windows version 25 for further analysis.

Results: A total of 377 family caregivers with a response rate of 96.91% were participated in this study from which (45.1%) of the respondents had good knowledge towards care for child with CHD and (44.3%) had good practice toward scare for CHD. There was a significant relationship between family caregiver's knowledge and educational status [AOR=0.322, 95%CI.0.186, 0.557] and living area [AOR=19.274, 95% CI. 6.535, 56.84]. family caregiver's knowledge towards CHD [AOR=1.11, 95% CI 7.240, 0.002.], frequency of feeding [AOR=0.093,95%CI. 0.02, 0.53] and living area [AOR= 57.3, 95%CI 1.07, 3048.8] were significantly associated with self-reported practice towards care for child with CHD at outpatient department. The statistical significance level was declared at p-value <0.05.

Conclusion & Recommendation: The results from this study showed that family caregivers had poor knowledge towards CHD and poor self-reported practice towards care for child with CHD. Lack of guide line for proper health education and resources are contributing factors. Therefore, the hospital's administrative and supportive organizations would better to provide training regarding proper health education towards care for child with CHD and the disease condition.

Key words: congenital heart disease, knowledge, family caregivers, self- reported practice

Chapter I

1.1 Introduction

Congenital heart disease (CHD) is the most common birth anomaly which refers to an anatomical or physiological defect of the heart that is present at birth (1, 2). It results from failure of the heart or the blood vessels near the heart to develop normally and ranges in severity from simple defects to complex abnormalities: these are heart valves defects, atrial and ventricular septa defects, stenosis, the heart muscle abnormalities, and a hole inside wall of the heart which causes defect in blood circulation (3, 4). Birth defects are broadly categorized as either structural, affecting the 'shape' of the body, or 'functional' affecting the work of an organ or body system, in this case, the heart and circulation (5).

Until recently the etiology of CHD was unknown. But advances in technologies has discovered the causative agents of this birth anomaly(6). The etiology of CHD is a combination of chromosomal, genetic, and environmental factors have been. Some causes include genetic disorder (chromosomal disorder), maternal factors (the excessive alcohol consumption during pregnancy and use of medications, maternal viral infection, such as Rubella virus, measles (German), in the first trimester of pregnancy) all these are risk factors for congenital heart disease in children, and the risk increases if parent or sibling has a congenital heart defect.(4)

Congenital heart disease (CHD) accounts for nearly one-third of all major congenital anomalies. While newborns with the cardiac disorder are symptomatic and identified soon after birth, many others are not diagnosed until the disease progresses into a severe stage. Delayed diagnosis and treatment of CHD increases morbidity and mortality in children suffering from this problem (7). A pattern of late presentation accompanied by high rate of complications was found. In resource-deprived settings the approach to the management of CHD emphasizes the treatment of "curable" malformations(8). Couples with advances in medical management and surgical treatment the support given by the family caregivers play the biggest role in improving the longevity and quality of life of the having CHD(9) .

A family caregiver is defined as a person who has a significant emotional bond with the patient; this caregiver is a family member who is a part of the patient's family life cycle, offers emotional-expressive, instrumental, and tangible support, and provides assistance and comprehensive care during the chronic illness, acute illness, or disability of a child, adult, or elderly person. In the case of children with congenital heart disease, the international literature indicates that the main family caregivers are the parents, who experience adversity, risk and vulnerability associated with the consequences of care during illness.(10)

1.2. Statement of problem

Congenital heart disease (CHD) has become a global child health problem with disproportionately higher mortality in low- and middle-low-income countries(11). 1 in every 100 children has defects in their heart due to genetic or chromosomal abnormalities(4). The Global Burden of Diseases, Study (GBD) recognized cause categories for non-fatal estimates to be more anatomically oriented, clinically relevant, and structured in a way to facilitate incorporation of literature. It estimates congenital heart disease burden by five different anatomic subtypes, including consideration of remission of some subtypes of congenital heart disease. (12)

Congenital heart disease has many divisions and sub divisions. Mainly they are divided as structural and functional deficit. But some books divide it as cyanotic and non-cyanotic deficit.(13)

non cyanotic congenital heart deficits are resulting in increased volume load. The most common lesions in this group are those that cause left-to-right shunting: ASD, VSD, AVSD, and PDA. They can also result in increased pressure load. The pathophysiology of these lesions is an obstruction to normal blood flow such as PS, tricuspid stenosis (TS), mitral stenosis (MS).

The emergence of new technologies and advanced clinical therapies, more and more patients are surviving and are discharged from the hospital to return to their families. These patients have complex health care needs that often must be met at home(2, 9). Children with congenital heart disease (CHD) are at increased risk for behavioral, emotional, and cognitive problems. They often have reduced exercise capacity and participate less in sports, which is associated with a lower quality of life. Starting school may present more challenges for children with CHD and their families. (14)

Since children can’t provide the proper self-care for themselves families’ will be the one who will take the major responsibility of caring for their children. Thus, families need to possess adequate knowledge about their child’s heart disease, treatment, and prevention of complications in order to provide the required care at home. Families with adequate knowledge of the health status of their children may promote a better health and related behavior in their child by increasing the understanding of the cardiac problem, improving compliance with treatment, and avoiding risk taking behavior.(15)

A research conducted in Hong Kong shows that there is a significant knowledge gap among of who have children with CHD. Most of them didn’t know the type of cardiac lesion of their children’s case.(15) Nevertheless, there is paucity of similar studies in Ethiopia. Thus, we know little concerning the family caregivers’ knowledge and practice of caring for children with congenital heart disease in Ethiopia. Therefore, the purpose of this study is to assess the family caregiver’s knowledge and practice of caring for children with congenital heart disease at the Ethiopian Cardiac Center in Addis Ababa.

1.3. Significance of study

The result of this study helps to identify the level of knowledge and practice of family care givers on caring for their children with congenital heart disease. The finding from this study therefore will serve as evidence base for future interventions to support family caregivers on their caregiving work. Particularly health professionals working with families of children with congenital heart disease will benefit from the findings of this study. They can use the findings of this study as evidence base to design counseling and educational sessions to help family caregivers to build their caregiving skills.

Chapter II

2. Literature review

2.1 Introduction

Congenital heart disease (CHD), the most common type of birth defect, is an abnormal cardiocirculatory structure or function present at birth, results from failure of the heart or the blood vessels near the heart to develop normally and ranges in severity from simple defects to complex abnormalities(3, 16).

CHD accounts for nearly one third of major congenital anomalies.(17) Congenital heart disease is a large, rapidly emerging global health problem in child. Globally, there is 1.35 million annual birth of children with congenital heart disease which results in about 250 000 annual deaths (12).

The majority of clinical studies showed significant differences among children and there Families' responses regarding their quality of life, with a tendency of children to report greater quality of life scores than their family(18). To maintain the health of the child there must be comprehensive support from the family and from the medical care givers(3). Different situations can affect the quality of family care and treatment for children with congenital heart disease. These factors may include Scio-demographic factors, knowledge and practice of families.(19) Similarly, knowledge and self-reported practice of family care givers can be affected by the health education provided by the health professionals.

2.2. Family care for children CHD

A qualitative descriptive study conducted in Children's Hospital of Soochow University in Suzhou City, Jiangsu Province, China showed that family care at home have many roles in improving child wellbeing. As mentioned in the study roles are monitoring their diet and providing meal, monitoring their physical exercise and administering their medications(20). Improved and coordinated care and focused family-centered care for pediatric cardiac patients have positive effect on a child's health-related quality of life (HRQOL) in children with congenital heart disease (CHD)(21).

The 'Congenital Heart Disease Intervention Program (CHIP) is the evidence-based intervention in this field. It has a positive effect on child psychosocial wellbeing. The effects of CHIP-Family is seen in improved mental health and psychosocial wellbeing of CHD-children and to identify baseline psychosocial and medical predictors(22).

2.3. Socio economic and socio demographic factor

The amount of family’s monthly income and the cost experienced by parents of children with complex CHD was described as both life-changing and uncertain. It was mentioned as a big influential factor in the aspect of care providing optimal practice in care of children with CHD. Parents further described costs as a burden that affected not only their finances but their emotions and the care that they are providing for their children.(23)

On meta-analysis performed in University, Newcastle showed that children of lower SES are at increased risk of CHD-related mortality. As these children are over-represented in the CHD population, interventions targeting socio-economic inequalities could have a large impact on improving CHD survival.(24)

A study conducted in Tehran; Iran showed that there was significant relationship between mothers education, the history of angiography or surgery, and the parents’ awareness of the name of the heart disease in English or its equivalent in Persian(25). The results indicate the positive relationship between the educational level of parents and the level of the care they provide for the child.

As the research conducted in northern Taiwan showed the impact of parental educational level on patients’ knowledge, descriptive statistics showed that the total correct rate of parents was 35.2% (SD, 12.9) for junior high school and below, 48.9% (SD, 12.7) for senior high school, 56.3% (SD, 15.5) for college, and 54.5% (SD, 16.0) for graduate education. Parents with graduate-level and college-level (P = .016) education had a significantly better disease knowledge than did parents with junior high school education or below(26).

2.4. Knowledge about congenital heart disease

Based on other study conducted in in Tehran; Iran answers given to knowledge questions, the knowledge score was 45.24±23.29 for parents of children with cardiac disease and 41.10±20.45 for parents of healthy children. Independent sample t-test found no significant difference between the two groups in terms of level of knowledge. Overall, the knowledge of both groups was found to be poor and only 36% of parents of cardiac children and 24% of the control parents had a relatively good level of knowledge about oral (16).

A study conducted in Nigeria most of the parents (88.3%) knew the correct diagnosis of the diseases of their children/wards. Only 35.9% of the parents believed medication alone could correct the cardiac defect while 64.1% believe their wards will require surgical correction of their defects. Out of the one hundred and three parents recruited in this study. Ninety-one (88.3%) of the parents were able to correctly mentioned the diagnosis of their wards' cardiac defect and this had no statistically significant association with their educational status. While 27 (26.2%) of the parents were able to name one medication their wards were presently taking. 53 (51.5%) could name at least two medications; 11 (10.7%) could not mention any while (12 (11.7%) were not on any medication (19).

In the other hand the study conducted in Nepal showed that the knowledge of mothers regarding home care of children undergone cardiac surgery was found to be insufficient to enable them to take care of their children. The inadequate knowledge can be effectively strengthened through information booklet, discharge teaching and other mass media used as a source of information in educating not only the mothers of children but also other family members who acts as a care taker (27).

2.5. Practice about congenital heart disease

Regarding regular dental checkup, only 10 of the parents (18.9%) visited the dentist regularly with their children for checkup, while five of the parents (09.4%) knew that antibiotics had to be taken before the dental procedures and Almost half of the parents (51%), asked their doctors for nutritional suggestions and advices. Regarding frequency of the feeding, the majority of the parents used to offer three main feeds and they were 59 of the parents (59%), while 38 of the parents (38%) offer small frequent feeding and only three of the parents (3%) offer feeding on demand (3).

Children with CHD, especially those with single ventricles, had more negative tempers. When children were born with a single ventricle, they had to have their first heart surgery within the first week of their life and two more surgeries at age 3-6 months and 3-5 years. Parents of children with a single ventricle, for example hypoplastic left heart syndrome, reported that from the moment they made their first decision to continue the pregnancy, they began a journey of survivorship for their children as well as themselves. These parents needed to overcome uncertainties to guard their children's survivorship and to defend the treatment decisions they made for the children. Despite their awareness that their children would have unique struggles, parents tried to overcome their fears and provide a supportive environment for the children. High levels of perceived vulnerability of their child may have led parents to overprotect their children and to be more permissive in their parenting styles than parents of healthy controls(28).

2.6.Conceptual frame work

The knowledge and practice of parents could be affected by different factors. Some of the factors may be associated with their socio-demographic factors. Age, sex, religion and educational level significantly affect families' knowledge and practice towards care for child with CHD. Similarly, economic factors such as monthly income medical and surgical expenses can affect the practice on care providing. On the other health care system can also affect such as the health education provided by the health professional about one's diagnosis and support mechanism play a big role in informing and guiding appropriate knowledge and practice about CHD.(3, 19, 27) On the other hand knowledge and practice can affect each other. This condition is going to be shown in the following diagram.

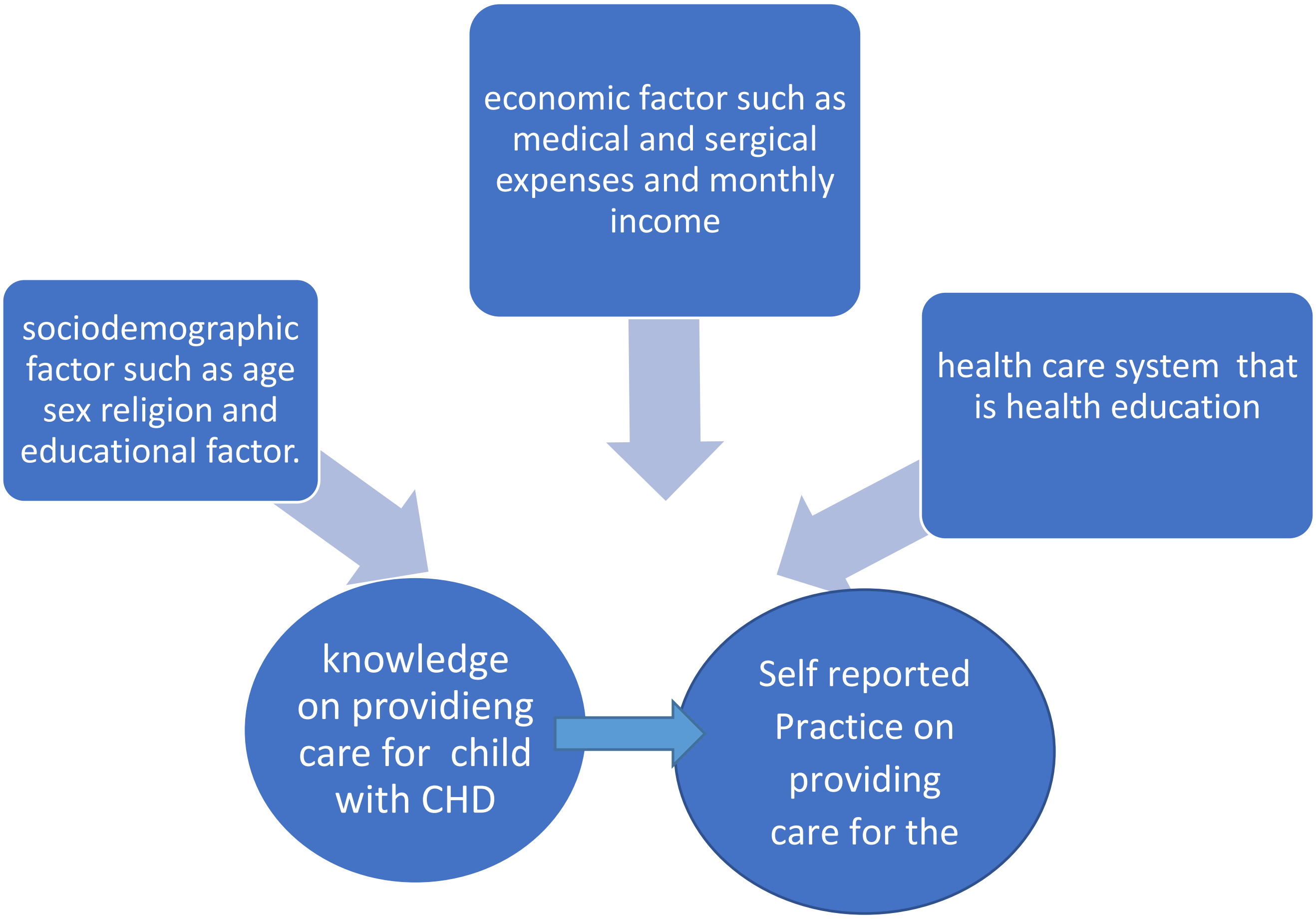

Figure 2. Conceptual frame work of Assessment of family caregiver's knowledge and practice of caring for children with congenital heart disease at the cardiac center Ethiopia, Addis Ababa Ethiopia, 2021 (3, 27)

CHAPTER III
Objectives of the Study

3.1. General objective

To assess the family caregiver’s knowledge and self-reported practice of caring for children with congenital heart disease at cardiac center Ethiopia Addis Ababa Ethiopia.

3.2. Specific objective

- To assess the family caregiver’s knowledge of caring for children with congenital heart disease.
- To assess the family caregivers self-reported practice of caring for children with congenital heart disease.
- To explore factors associated with the family caregiver’s knowledge and self-reported practice of caring for children with congenital heart disease.

CHAPTER IV

Methods and Materials

4.1. Study area and setting

The study was conducted at the Cardiac Center Ethiopia in Addis Ababa Ethiopia. The cardiac center was established in 1989 as non-governmental and charitable organization focused on helping children with coronary illness. Since 2009 the institution shifted attention to embark up on its long-term objectives i.e., to establish sustainable cardiac center and launched different programs to realize these objectives under the one and the only cardiac center-Ethiopia located at Tikur Anbessa Hospital premises in Addis Ababa Ethiopia. The institution has two Cath labs and major operation theater functioning five days a week. Since the principal day of its activity, the center rendered its service for more than 5000 patients free of charge but still there are 7000 congenital heart disease patients on waiting list.

The pediatric outpatient department of the cardiac center works five days per week, each day the department serves 50 children with congenital heart disease in average, among them 99% are already on waiting list for intervention.

4.2. Study period

The study was conducted from February 28 to June 1, 2013.

4.3. Study design

The study was hospital based descriptive cross-sectional study.

4.4. Source population

Source population of the study was all parents of CHD children in Addis Ababa.

4.4.1 Study population

The study population includes family caregivers of children with congenital heart diseased children at the outpatient clinic of the cardiac center Ethiopia during the study period.

4.4.2. Inclusion criteria

- All family caregivers of children with congenital heart disease
- The child should be less than 15 years old.

4.4.3. Exclusion criteria

- Family care givers of children with any of additional comorbidity such as down syndrome or any severe abnormalities of the central nervous system.

- Family care givers of children with new diagnosis of other cardiac problem.
- Family care givers of children with CHD less than the age of six month
- Family care givers who stayed on the follow up only for the past 2 month or less

4.5. Sample size

The sample size was calculated according to the equation:

N = sample size

Z = statistical certainty 1.96 (at 95% of confidence)

P = probability problem under study

Q= 1.0 – p

d = desired margin of error

$$n= \frac{(Z\alpha_{/2})^2 \times p(1-p)}{d^2}$$

$$n= \frac{(1.96)^2\ X0.64X0.36}{(0.05)^2}$$

$$n= \sim 354$$

Adding a non-response rate of 10%, final size = 389

Total sample size will be 389 participants.

4.6. Operational definition

Knowledge: The understanding of the families who are on the duty of giving care. The knowledge value on this research is the possible maximum score for the correct answers in knowledge-oriented questions is 15 questions (75%) (3).

Practice: Refers to actions and skills of families concerning the care. The practice value for this research is 50% correct answer of the total practice questions(3).

4.7. Study variables

4.7.1. Dependent variable

- Knowledge and practice

4.7.2. Independent variable

- Sociodemographic factor: Age, Sex, Socioeconomic status marital status and religion.
- Personal factor: educational level.
- Institutional factor: health education provided by health professionals

4.8. Data collection tool

A written questionnaire was used for data collection. The questioner was adopted from similar study conducted in Sudan and the ‘Leuven knowledge questioner for congenital heart disease’. Some modifications were used to eliminate attitude related questions and translated from English to Amharic by language experts. The tool contained socio demographic related questions, knowledge related questions and practice related questions. It was translated in to Amharic version while using the tool.

4.9. Sampling technique

As of that cardiac center Ethiopia is the only cardiac center in whole Ethiopian the study participants were selected randomly from the out-patient department. The participants were selected using simple random sampling while attending follow up at Ethiopian cardiac center Addis Ababa Ethiopia.

4.10. Data collection procedure

Data was collected by 3 BSc. Nurses who work in the cardiac outpatient department. The nurses were selected based on their experience and working area. Before the actual work, a one-day training was given to data collectors and to the supervisors on the objectives of the study, data collection tool, methods of reporting to supervisors and principal investigator. The questionnaire consists of 4 parts. Part I: information on socio demographic data of participant, Part II: children disease condition diagnosis and treatment, Part III: information regarding knowledge, part IV: information regarding practice.

4.10.1. Data processing and analysis

Data was entered into EPI INFO Version 3.5.1 statistical software and then transferred to SPSS version 25, for analysis. The study population was explained, using descriptive statistics such as means, standard deviation frequency and percentage was described in socio demographic variables. Binary logistic regression was used to determine association between dependent and independent variables. A significance level below 0.05 and 95% confidence interval were used statistical significance of the findings. Those variables which had p-value less than 0.25 and considered to be clinically important for clinical decision making in the vicariate analysis were entered into the multiple logistic regression model. Multivariable logistic regression was done with 95% confidence interval and corresponding AOR to control the influence of potential confounding variables. The statistical significance level was declared at p-value <0.05.

4.10.2. Data quality assurance

Data collectors ware instructed to check the completeness of each questionnaire whether each and every question is completely answered and also the supervisors ware rechecking the completeness of the questionnaire after submission. Although pre-test was done 1 week prior to the actual data collection day with 5% out of the total sample size at pediatrics CHD follow up clinic black lion hospital. Confidentiality of participants were assured name or physical address of participants will not use during report sharing and communication of findings. Participants ware also assured that all their personal information such as their name will protected from public and secured by the researcher.

4.11. Ethical consideration

Approval consent of the study was taken from Addis Ababa University, College of Health Sciences ethical review committee through the School of Nursing and Midwifery. Permission was obtained from the Cardiac Center Ethiopia Informed consent was taken from the study participants after explaining the objectives of the study.

4.12. Dissemination of result

Main findings of the study will be presented to Addis Ababa University, college of health sciences, department of nursing and midwifery and reported to ministry of health. The hard and soft copy of findings will also be available in the library of Addis Ababa University Tikur Anbessa. The paper will also be submitted to Ethiopian cardiac center for the purpose improving patient care service.

CHAPTER V

5.RESULTS

5.1. Socio-demographic characteristics of the Study Participants

Three hundred eighty-nine family care givers who have child that have follow up at cardiac center Ethiopia were enrolled for this study from which 377' were participated with response rate of (96.91%).

The age of the children with CHD ranged between 6 months to 15 years. Children below one year of age were 50 children (13.3%), between one to less than five years were 140 children (37.1%), between 5 to less than 10 years were 141 children (37.4%) and 46 children (12.2%) were in the age group 10-15 years. Females constituted 206 patients (54.6%) while 171 patients were males (45.4%). Female to male ratio was 1.22:1.

Almost half of the participants in the study group were from urban areas and they were 180 family care givers (47.7%), 197 family care givers (52.3%) were from rural areas (Figure 6). Among the participants less than 25 years are 50 (13.3%) and 170 family care givers are in the age group 26 - 35 with percent of 45.1 %. Participants age between 36- 45 is 98 (26.0%) and between 46 -55 are 49 (13.0%) and above 55 age counts 10 (2.7%). Their mean age was 35.10 years and (SD= +/- 9.038).

Regarding parental educational level, four of the study participants (1.1%) were illiterate, 34 of them (9.0%) can read and write, 95 participants (25.2%) attend elementary school (grade 1-8), 71 participants (18.8%) completed their secondary school, 111 had their preparatory school (29.4%) while 62 were college and above graduate (16.4%) (Figure 6).while the occupation data showed that 69 of them (18.3%) are un employed ,116 of them (57.3%) are self-employed, 15 of them (4.0%) are students and 77 of the total participants (20.4%) are employed. There was no pensioner.

Table 1: socio demographic characteristics of families care givers Addis Ababa Ethiopia, 2021

Variables	response's	Frequency(N)	Percentage (%)
Age of parents	Under 25	50	13.3%
	26-35	170	45.1%
	36-45	98	26.0%
	46-55	49	13.0%
	56 and above	10	2.7%
Sex	Male	155	41.1%
	female	222	58.9%
Marital status	Married	363	96.3%
	Un married	3	0.8%
	Divorced	6	1.6%
	Widowed	5	1.3%
Residency of parents	Urban	180	47.7%
	Rural	198	52.3%
Educational status	Illiterate	4	1.1%
	Read and write only	34	9.0%
	Elementary (1-8)	95	25.2%
	Secondary (9-10)	71	18.8%
	Preparatory (11-12)	111	29.4%
	College and above	72	16.4%
Monthly income	0-600	24	6.3%
	601-1650	147	39.0%
	1651-5250	130	34.5%
	5251-10899	73	19.4%
	Above 10900	3	0.8%
Occupation	Un employed	69	18.3%
	Self employed	216	57.3%
	Student	15	4.0%
	Employed	77	20.4%

5.2 Clinical data of patients

From total 377 patients only 56 (14.9%) received surgical intervention and the rest 321 (85.1%) do not receive the surgical intervention. Thirty of the CHD children (8%) did receive intravenous intervention for management 347 (92.0%) did not. 107 patients (28.4%) do not have medication treatment. The anthropometric measurement shows that 235 of total patients (62.33%) have less than 18.5 BMI scale and the rest 142 (37.33%) have BMI with range of 18.5-24.9.

Table 2: clinical data of patients (N=377) at Ethiopian cardiac center Addis Ababa Ethiopia 2021

Variables	Response	Frequency (N)	Percentage (%)
Did the patients therapeutic receive surgical intervention	Yes	56	14.9%
	No	321	85.1%
Did the patients receive therapeutic intravenous intervention	Yes	30	8%
	No	347	92.0%
Are they on medical treatment	Yes	270	71.6%
	No	107	28.4%
BMI	< 18.5	235	62.33%
	18.5- 24.9	142	37.33%

5.3 Family care givers knowledge towards caring for child with congenital heart disease

The possible maximum score for the correct answers in knowledge-oriented questions was 15, the attained scores by the family care givers ranged between 4-19. 231 of the family care givers (61.3%) had poor knowledge, while good knowledge was found in 146 of the parents (38.7%).

In this study, out of 377 participants only 103 (27.3%) participants can describe or can Identify the exact disease condition of their child and 75 participants (19.9%) can locate the congenital heart deficit on the cardiac diagram. About 270 (71.6%) of respondent’s child are on po medications. Among them 131 (34.7) participants cannot tell what type of medication does their child is taking. Two hundred twenty-four participants (59.4%) receive information about their child disease condition and among them 87 participants confirmed the information provided was sufficient. Most participants 334 (88.6%) understands that their child heart deficit was caused by congenital heart disease and 9 of them believes it is due to medication side effect. Two hundred seventy-five parents do not properly the correct time of medication administration and the proper dose (Table 3).

Table 3: Family care givers knowledge related to congenital heart deficit with different component at outpatient department of cardiac center Ethiopia, Addis Ababa Ethiopia, 2021 (N=377)

variables	Correctly answered		Wrongly answered	
	frequency	percentage	frequency	percentage
Can you identify your child specific congenital heart disease	103	27.3%	204	72.7%
Any medications that have been taken to CHD	270	71.6%	107	28.4%
Can you identify your child heart deficit on the cardiac diagram	75	19.9%	302	80.1%
How often did you take your child to the follow up	241	63.9%	136	36.1%
What do you think is the benefit of bringing your child to cardiac follow up clinic	229	60.74	146	39.26%
Are there any surgical interventions done for the congenital heart deficit	377	100%	0	0
Are there any interventions done for the CHD through blood vessels	377	100%	0	0
Did you receive information about your child disease condition from health professionals	224	59.4%	103	40.1%
Do you think the information provided was sufficient	87	38.3%	137	61.7%
How do you see and suggest your child's treatment	240	63.66%	137	36.44%

Table 3: Family care givers knowledge related to congenital heart deficit with different component at outpatient department of cardiac center Ethiopia, Addis Ababa Ethiopia, 2021 (N=377)

What do you think the cause of your child heart deficit	334	88.6%	43	11.4%
Select the symptoms which may occur on CHD patients and for which you need to contact the doctor	200	53.03	177	46.07
Can you identify the proper dose and time of administration of your child medication	102	27.1%	275	72.9%
Do you think medications for congenital heart deficit has adverse effects	213	56.5%	164	43.5%
Do you think all CHD patients should take same medications	151	40.05%	226	49.95%
Do you think the clinical follow up is helpful to determine your child health condition	74	19.62%	303	80.38%
What is the expected disease prognosis	100	26.52%	227	73.48%
Do you think it is necessary to follow any guide lines regarding activity levels and sport participation for your child with CHD	138	36.6%	239	63.4%
Is it appropriate to quite the medication and follow up when your child is not responding for treatment	181	48%	196	52%

5.4. Family care givers self-reported practice towards care for children with CHD and Associated Factors

Among 377 participants child 42 (11.1%) are less than one year who don’t need dental checkup. From the rest of the 247 family care givers (73.3%) do not have dental checkup for their child and 181 (53.9%) of family care givers make their child brush their teeth at list once a day. From 377 participants 219 (58.1%) receive health education from health professionals. About 122 (32.4%) family care givers avoid giving their children foods containing low calorie and high sugar in their content and only 157 (41.8%) of the family care givers give additional calorie or foods rich in more calories in order to support their child growth. Two hundred thirty-nine families (63.4%) feed their child with frequent small feed and 75 (19.9%) of the family care givers feed their child only on demand.

Table 4: Participant self-reported practice regarding care of the children with congenital heart disease at outpatient department cardiac center Ethiopia Addis Ababa, 2021 (N=377)

Variables	**Correctly answered**		**Wrongly answered**	
	frequency	**percent**	**frequency**	**Percent**
Do you take your child with CHD to regular dental check up	88	26.27%	247	73.73
Does he clean his teeth at list once a day	155	46.1%	181	53.9%
How often did you feed your child per day	63	16.72%	314	83.28%
Did you give extra calorie food in order to maintain and support the growth of your child	157	41.65%	220	58.35%
Did you avoid low calories and high sugar containing nutrients from your child meal	122	32.36%	255	67.64%
As your child has CHD, should you give him A/B immediately if he has a fever without consulting his doctor?	323	87.5%	54	12.7

5.5. Factors associated with knowledge

Each of independent variables entered into vicariate logistic regression with dependent variable and tested for significance association at ($p<=0.25$) educational level, rotation in service units and peer pressures were remained significant in both vicariate and multi logistic regressions models after controlling for the effects of potentially confounding variables ($p<=0.05$)

Family care givers who do not know the P.O. medication of their child have 25.2% less likely to have good knowledge on caring for children with congenital heart disease at home measures compared to family care givers who can describe the P.O. medication [AOR=0.748: 95% CI. 0.576, 0.970]. In addition, family care givers, who live in urban area are 19.274-times more likely to have good self-reported practice of caring for congenital heart diseased children at home compared to those who live in urban town [AOR=19.274, 95% CI. 6.535, 56.84]. Males are 75.7% less likely to have good knowledge towards caring for child with congenital heart disease than females [AOR=0.243, 95%CI. 0.079, 0.750]. family care givers who completed elementary school are 67.8% less likely to have good knowledge when compared to families who are college and above [AOR=0.322, 95%CI.0.186, 0.557]. Un employed family care givers are 56.3% less likely to have good knowledge of caring for congenital heart disease child than their employed counterparts [AOR 0.437,95%CI. 0.239, 0.798]. However, sex, marital status and health education provided form health professionals were not significantly associated with knowledge level of families towards care for child with congenital heart disease**.**

Table 5: Multiple logistic regression analyses of factors associated with knowledge towards care for child with congenital heart disease at outpatient department cardiac center Ethiopia, 2021 (N=377)

Variables	Knowledge of participants towards care for CHD		COR (95% CI)	p-value	AOR (95% CI)	p-value
occupation	Good	Poor				
un employed	16(9.4%)	53(25.6%)	(0.30,0.12, 0.79)	0.000	(0.437(,0.239,0.798	0.07
employed	74(43.5%)	142(62.6%)	0.52(0.023,0.119.)	0,00	)1	0.00
student	10(5.88%)	5(2.4%)				
government employed	70(41.17%)	7(3.38%)				
Educational status						
Illiterate	0(0%)	4(2.2%)				
Read and write	0(0%)	34(17.08%)				
Elementary (1-8)	6(3.52%)	81(40.7%)	0.006(0.002,0.02)	0.0.00	0.322,(0.186,0.557)	0.001
High school (9-10)	26(15.2%)	45(22.61%)				
Preparatory (11-12)	81(47.6%)	30(15.0%)				
College and above	57(33.5%)	5(2.5%)	1	000	1	0.000
Living area						
Urban	159(88.3%)	21(10.14%)	1	0.00	1	0.00
rural	21(11.66%)	186(89.6%)	128(59.89,273.64)	0.00	19.274,(6.535,56.84)	0.000
sex						
male	26(15.29%)	129(62.31%)	0.109(0.66,0.181)	0.000	0.243,(0.079,0.750)	0.001
female	144(84.7%)	78(37.68%)	1	0.000	1	0.000

5.6. Factors that affect self-reported practice

Family care givers who had poor knowledge had 1.11times poor practice towards care for congenital heart disease child control measures compared to those who have poor knowledge [AOR=1.11, 95% CI 7.240, 0.002.]. In addition, families who feed their child only on demand 0.093times poor practice compared to those who give frequent small feed [AOR=0.093: 95% CI. 0.02, 0.52]. However, education status and monthly income were not significantly associated with practice level of families towards care for congenital heart diseased child.

Table 6: Multiple logistic regression analyses of factors associated with self-reported practice towards care for child with congenital heart disease at outpatient department cardiac center Ethiopia, 2021

Variables	Self-reported practice of families towards CHD		COR (95%)	p-value	AOR (95%)	p-value
	Good	poor				
Living address of families Urban Rural	155 12	25 185	(95.6,46.5,196.50)	0.00 0.00	(57.3, (1.07,3048.8)	0.046
How often do you feed your child? On demand Main feed Frequent small feed	20 13 132	55 44 107	(2.4, 1.537,2.730)	0.00	(0.093, (0.02,0.53)	0.07
Knowledge Poor Good	5 165	205 2	(3382,6.47.9,17658)	0.00	(1.11,(7.240,0.002)	0.00

5.7. Discussion

Family care givers are the first line care providers for children with CHD who are on follow up. They are responsible for monitoring diet and exercise, administer medication and check for any danger sign of the child. Primarily assessing the knowledge and practice of families towards care for child with CHD helps to identify the gaps and continue to deal with accordingly. Therefore, this study aims at describing the knowledge, practices and factors associated to knowledge and practice of care for child with CHD who have follow up at cardiac center Ethiopia, Addis Ababa.

In this study, the overall good knowledge and good practice towards care of family for congenital heart diseased child at home level were 45.1% and 44.3% respectively. Regarding to knowledge about congenital heart disease my finding was higher than Teheran Iran (16) and Sudan (3), .The difference might be due to study area, study population, and cut point of knowledge level. Majority of families with educational status preparatory and college have good knowledge towards care for child with congenital heart disease (47.6% and 33.5% respectively) whereas the elementary and the lower educational level have poor knowledge (40.7% and 19.2%). This showed only a slight difference while compared to the research conducted in in Taiwan where the knowledge of parents ware 35.2% for junior high school and below, 48.9% for senior high school, 56.3% for college, and 54.5% for graduate education (26).

In this study the residency of families shoed that it has direct impact in the knowledge of families towards care for child with CHD. Those who live in urban have good knowledge (88.3%) and those who live in rural part of the country have poor knowledge (89.6%). This shows similarities when compared with research conducted in Sudan that most parents with good knowledge are from rural area of the country (3). While looking up the sex of families and their knowledge 38.19% of females have good knowledge and 34.1% of fathers have poor knowledge. When this is compared with a research conducted in Nepal it has a slight difference. the mothers with good knowledge account 55% and moderate knowledge 40% (27). The slight difference could be the result of the depth of the health education provided by health professionals.

Regarding of describing the and knowing of the exact diagnosis of parents only 27.3% can only describe the diagnosis of the family which was significantly lower than studies in Nigeria (88.3%) knew the correct diagnosis of the child (19). The discrepancy might be due to the health care system variance regarding adequate health education. Only 19.9% of the total participants were able to locate the area of the heart deficit on the cardiac diagram. On the benefit of the cardiac follow up 60.74% of parents have good knowledge and understanding. Although 63.9% of parents have good knowledge about the purpose of the clinical follow up. Furthermore about 48% of the total participants understand the child should not stop taking medications for having adverse effect unless it is ordered by the health professional. These has similarity with the study conducted in Taiwan only 20% of them were able to correctly locate the defect on a diagram and nearly 70% of them understood the purpose of the follow-up. Few parents (15.5%) knew that their child should not stop taking medication on their own if the child was experiencing side effects(26).

Regarding regular dental checkup only 23.3 %, visited the dentist with their children this was almost similar to a study conducted in Sudan where 18.9% of the participants visit the dentist with their child and 46.1% of the parents make their child clean their teeth at least once per day (3). It has a slight deference when compared to a study conducted in Iran where all children over 5 years of age personally brushed their teeth; 44% of children with cardiac diseases brushed their teeth at least twice a day (16). These could be the result of the cultural and the attitude difference among parents towards dental health.

More than half of participants 58.1% ask the for nutritional suggestions from health professional which is again similar to the study in Sudan 51%. While looking up patients BMI it shows 235 of the total participants (62.33%) have BMI lower than 18.5 kg/m^2 and the rest 37.33% are with range of 18.5 – 24.9 kg/m^2.these finding has similarity when compared to the findings on research conducted in Nigeria Some degree of malnutrition was found in sixty-nine (70%) of the children. Underweight and severe malnutrition were mostly seen in the 1–5-year age-group. These underweight scales could be the result the low providing of nutritional supplement to the patients only 58.4% of the participants provide additional nutritional supplement (19).

Regarding factors affecting family care givers knowledge towards caring for child with CHD, family care givers who ware un employed had poor knowledge on giving care for child with CHD than those who are employed (p= 0.07). This is relatively congruent with the study conducted at National Medical College and Teaching Hospital, Birgunj, Nepal. It shows that family care givers with un employed status has 8.492 lower knowledge than those who are employed at (P < .037)(27). Similarly, those family care givers with educational status elementary poor knowledge towards caring for child with CHD than those family care givers who have educational status college and above (p= 0.001). This result has difference with the study conducted in Taiwan on an evaluation of disease knowledge in dyads of parents and their adolescent children with congenital heart disease; the educational status bellow high school family care givers has slightly poor knowledge towards caring for child with CHD (p=0.016) (26). It is also congruent with the study done in Nigeria which shows that low educational level of family care givers as a factors that relationship with poor knowledge towards caring for child with CHD (p=0.008(19).

Regarding factors affecting family care givers self-reported practice towards caring for child with CHD, family care givers from urban town more likely had good practice on caring child with CHD than those who came from rural part of the country (p= 0.000). This is not congruent with the study conducted in Sudan, Nigeria and Iran which shows the living area of the family care givers has no association with the self-reported practice(3, 16, 19).

5.8. STRENGTH AND LIMITATION OF THE STUDY

Strength of the study

This study is the first of its kind in the area to investigate knowledge and self-reported practice towards care for child with congenital heart disease among family care givers. It also identified and put a base line knowledge regarding family care givers knowledge and self- reported knowledge towards caring for child with CHD.

Limitation of the study

The study did not observe the actual practices of families' as of that the data was collected in the outpatient, department; self- reported was taken under written questioner which was filled by interviewer. The other limitation this study is it was not included attitude of families towards care for child with congenital heart disease since it can be affected by social and personal biases to test. Finally, the study was cross-sectional study and can only reflect experience of families at the time of assessment only. Therefore, a causal relationship cannot be established between KP and its predictors.

Conclusion

The overall results of this study showed that families had poor knowledge, and poor practice on care for child with congenital heart disease. This showed that there is discrepancy in the, knowledge and self-reported practice of caring for child with congenital heart disease than expected. The reason behind may be the issue of knowledge, lack of basic and appropriate health education. The findings of this study also suggest that the participants need in-depth education regarding nutritional supplement and dental follow up. It also identified that if they had received suggestion about the nutritional supplement, they still have poor practice on feeding which may be due to lack of proper model and guideline for health education.

5.9.Recommendation

Based on the findings of this study, the following points are recommended:

For health care providers

- Design educational sessions special on caring recommendations and mention materials that support providing care.
- Health care worker should provide appropriate education on all care recommendations especially after follow up, and also, they should develop strong relationships with family care givers.

- It should be a practice to give advice about feeding and about nutritional supplements so that the patients could have good range of BMI and to improve the family care givers practice

To policy makers

- There should be a focused health education for family care givers who came from rural area and with elementary and below educational status about the caring for child with CHD.
- Policymakers should create family care givers societies so they can share more information on caring for child with CHD.

For researchers

- Further research is needed to explore the extent of the knowledge gap in different study areas about the knowledge and self-reported practice family care givers towards caring for child with CHD.
- The researcher should do interventional studies to determine the effect of educational programs and other factors on providing care.

For ministry of health

- The ministry of health should focus on patients from rural side of the country and increase the performance of referral hospitals on cardiac services so that patients from rural can engage in the program in the possible nearby hospital.

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ANNEXES 1: English

Information sheet for participants

Addis Ababa University

College of health science, school of Nursing and Midwifery Department of nursing

Participant information sheet

My name is ___________________________. I am working as a data collector in the study conducted by Feben Berihu MSc in Cardiovascular nursing student at Addis Ababa University, Health Science College Nursing and Midwifery department. The aim of the study is "**To assess family caregiver's knowledge and practice of caring for children with congenital heart disease at the cardiac center Ethiopia, Addis Ababa Ethiopia, 2021.** For partial fulfillment of the master's degree program.

Your involvement is important for the success of this study. You are chosen to participate in the study because you are family care giver for a child with CHD. A decision on your involvement will be made by you and only you. Your selection is based on random without any peculiar criteria and if you are going to participate, you are expected to answer certain questions on the next pages. This will take around 30 minutes.

Risk: there is no dangerous physical or psychological risk expected being involved in the study.

Benefits: you have the right to know the findings of the study. Furthermore, the results of this study have significant role for improving quality of care provided by you for the child with CHD.

Confidentiality: Your personal information will only be used for the purpose of the study. You will not be personally identified in the study report. For this purpose, the data will be secured strictly without your name and detail identification.

Participation: You have to know that your participation is largely based on your willingness and approval. You have the right to say "no" and not participate in the study. You will not be penalized and there is no loss of benefits if you decide not to participate. If you wish to withdraw from this study you can stop at any time. You are not obliged to respond to all questionnaires.

Questions: You can ask any questions about this study.

Yours sincerely Name: Feben Berihu Phone no: +251920632729

Email address: fevenberihu26@gmail.com

Participant consent (English version)

Addis Ababa University

College of health science, school of Nursing and Midwifery

Department of nursing

Participant consent

On behalf of Sr Feben Berihu ______________________has explained to me what is going to be done; the risks and benefits involved and will be available for questions at the Department Nursing**,** Addis Ababa University College of Health Sciences, on telephone number +251920632729 or e-mail address fevenberihu26@gmail.com . I understand that my decision to participate or not to participate in this study will not have any reward or punishment. In the use of information generated from this study such as presentations and publications, my identity will remain anonymous. The records of the study must be available to only authorized study personnel. I am aware that I may withdraw from the study at any time.

I understand that by signing this consent form, I do not waive any of my legal rights but merely indicates that I have been informed about the study in which I am voluntarily agreeing to participate. A copy of this form will be provided to me.

Volunteer's signature-------------------------- Date ---

English questioner

data collector name--------------------- signature------------------date---------------------

supervisor name--------------------------signature----------------date--------------------

code-------------
date of interview-------/-------/--------------

Patient data		
no	**question**	**answer**
1.1	Age of the child	------------------
1.2	Sex of the child	1. Male 2. female
1.3	Other co morbidity	1. yes 2. no
1.4	Educational level of the child	1. kindergarten 2. elementary from grade1- to grade 4 3. elementary from grade 5- grade 8
1.5	School attendance	1. good 2. many absents
1.6	Academic status	1. very good 2. good 3. medium 4. poor
1.7	Vaccination status	1. took all vaccine 2. missed at list one vaccine 3. no vaccination at all
1.8	Anthropometric measurement	height----------- weight------------ BMI---------
Family socio demographic status		
no	question	Answer
2.1	Religion	1. orthodox 2. Muslim 3. protestant 4. catholic

		5. other
2.2	Place of residence	1. urban 2. rural
2.3	Age of the family care giver	--------
2.4	Sex of the family care giver	1. male 2. female
2.5	Educational status of the family care giver	1. illiterate 2. can read and write only 3. elementary (1-8) 4. secondary school (9-10) 5. preparatory (11-12) 6. college and above
2.6	Occupation	1. un employed 2. self employed 3. student 4. employed 5. pensioner
2.7	Monthly income	1. 0-600 birr 2. 601-1650 birr 3. 1651-5250 birr 4. 5251-10899 birr 5. 10900 birr and above
2.8	Marital status	1. Married 2. Single 3. Divorced 4. Widowed
Questions that assess parental knowledge		
no	Question	Answer
3.1	Can you identify your child specific congenital heart disease	1. yes 2. no
3.2	Any medications that have been taken to CHD	1. no medication 2. medications that control heart beat (digoxin) 3. medications that decrease fluid accumulation in the body (diuretics) 4. vasodilator (captopril) 5. Others --------- 6. I don’t know
3.3	Can you identify your child heart deficit on the cardiac diagram	1. yes 2. no

3.4	How often did you take your child to the follow up	1. every month 2. every two months 3. every three months 4. only when he complained pain 5. only on the appointment day only
3.5	What do you think is the benefit of bringing your child to cardiac follow up clinic	1. to check on the child disease condition 2. to determine the damage caused by the disease 3. only to take medication 4. it has no benefit
3.6	Are there any surgical interventions done for the congenital heart deficit	1. yes 2. no
3.7	Are there any interventions done for the CHD through blood vessels	1. yes 2. no
3.8	Did you receive information about your child disease condition from health professionals	1. ye 2. no
3.9	Do you think the information provided was sufficient	1. yes 2. no 3. I don't know
3.10	How do you see and suggest your child's treatment	1. Appropriate treatment 2. In complete treatment 3. In appropriate treatment 4. I don't know
3.11	What do you think the cause of your child heart deficit	1. hereditary 2. congenital 3. caused by bacterial infection 4. caused by medication side effects
3.12	Select the symptoms which may occur on CHD patients and for which you need to contact the doctor	1. Shortness of breath 2. Sweeting associated with feeding 3. Bluish discoloration of the body 4. Leg swelling 5. Difficulty during feeding 6. others---------

3.13	Can you identify the proper dose and time of administration of your child medication	1. yes 2. no
3.14	Do you think medications for congenital heart deficit has adverse effects	1. yes 2. no
3.15	Do you think all CHD patients should take same medications	1. yes 2. no
3.16	Do you think the clinical follow up is helpful to determine your child health condition	1. yes 2. no
3.17	What is the expected disease prognosis	1. can be cured 2. cannot be cured 3. remains lifelong disease 4. I don't know
3.18	Do you think it is necessary to follow any guide lines regarding activity levels and sport participation for your child with CHD	1. yes 2. no
3.19	Are there any advices offered from health professional regarding safe exercise	1. yes 2. no
3.20	Is it appropriate to quite the medication and follow up when your child is not responding for treatment	1. yes 2. no
	Questions that assess parental practice	
no	Question	Answer
4.1	Do you take your child with CHD to regular dental check up	1. yes 2. no
4.2	Does he clean his teeth at list once a day	1. yes 2. no
4.3	How often did you feed your child per day	1. on demand only 2. frequent small feed 3. main feed only
4.4	Did you give extra calorie food in order to maintain and support the growth of your child	1. yes 2. no
4.5	How do you increase the calorie in take	1. by giving milk 2. by giving additional nutrient and formula
4.6	Did you avoid low calories and high sugar containing nutrients from your child meal	1. yes 2. no

4.6	Do ask information from your child about nutritional suggestion	1. yes 2. no
4.7	As your child has CHD, should you give him A/B immediately if he has a fever without consulting his doctor?	1. yes 2. no

Annex 2 ፡አማርኛ መጠይቅ

የመረጃ ገጽ ለተሳታፊዎች

አዲስ አበባ ዩኒቨርስቲ

የጤና ሳይንስ ኮሌጅ የነርሲንግ እና ሚድዋይፍሪ ት/ቤት

የነርሲንግ ዲፓርትመንት

ስሜ-------------------------ይባላል ። በአዲስ አበባ ዩኒቨርሲቲ ጤና ሳይንስ ኮሌጅ በነርሲንግ እና ሚድዋይፈሪ ዲፓርትመንት የካርዲዮቫስኩላር ማስተርስ ፕሮግራም የሁለተኛ አመት ተማሪ በሆነዉ በ ፌበን በሪሁ በሚካሄድ የመመረቂያ ፅሁፍ ላይ መጠይቅ አስሞላለሁ። የጥናቱ አላማ ወላጆች አብሮ የተወለደ የልብ ችግር ላለባቸው ልጆች ማድርግ ስልሚግባቸው የቤት ውስጥ እንክብካቤ ላይ ያላቸውን የእውቀት እና የተግባር መጠናቸውን የሚገመግም ይሆናል። ጥናቱ በኢትዮጵያ ልብ ማእከል የሚደረግ ነዉ።

የርሶ ተሳተፎ ለዚጥናት መሳካት ትልቅ አስተዋፅኦ አለዉ።የጥናቱ ተካፋይ የተመረጡት ልጆት በኢትዮጵያ ልብ ማእከል ተመላላሽ ኅክምና ክፍል እየተገለገለ ስለሆነ ነው። የስምምነት ዉሳኔዎ የማንም ተሳትፎ ሳይኖረዉ በርሶ ብቻ የሚደርግ ይሆናል።የጥናቱ ተሳታፊ ለመሆን ከተስማሙ ከታች የተዘረዘሩትን አንዳንድ ጥያቄዎች መመለስ አለቦት። መተይቁን ሞልቶ ለመጨረስ በአማካኝ 30 ደቂቃ የፈጃል።

ጥናቱ ሊያስከትለዉ የሚችለዉ አደጋ በጥናቱ በመሳተፎ ምንም አይነት አካላዊ ሆነም ስነልቦናዊ ጉዳት አይደርስበትም።

ጥናቱ የሚያሰገኛቸዉ ጥቅሞች በጥናቱ ላይ በመሳትፎ የጥናቱን ግኝቶች የማወቅ መብት አሎት።ከዚ በተጨማሪም የጥናቱ ዉጤት ወላጆች አብሮ ተወለደ የልብ ችግር ላለባቸው ልጆች የሚደረጉትን የሚያደርጉትን እንክብካቤ የሚያሻሽሉ መንገዶች ያሳያል።

ሚስጥራዊነት በጥናቱ ዉስጥ የርሶ የሆኑ የግል መረጃዎች አይካተቱም ። ለዚም ሲባል መረጃዉ ሲሰበሰብ ስሞት እና ተያያዥነት ያላቸዉ የግል ጉዳዮች አይጠቀሱም።

ተሳትፎ የርሶ ተሳትፎ በግል ፍቃዶት ላይ ብቻ ላይ የተመሰረተ ነዉ። ጥናቱ ላይ አልሳተፍም የማለትም ሆነ በመሃል የማቆም መብቶ የተጠበቀ ነው። አልሳተፍም በማለቶ የሚደርስቦት ምንም አይነት ቅጣት አይኖርም።በጥናቱ ዙሪያ ምንመ አይነት ጥያቄ ካሎት ማቅረብ ይችላ

ስም፡ፌበን በሪሁ

ስልክ ቁጥር፡0920632729

ኢሜይል፡ fevenberihu26@gmail.com

የተሳታፊዎች የስምምነት ወረቀት

አዲስ አበባ ዩኒቨርስቲ

የጤና ሳይንስ ኮሌጅ የነርሲንግ እና ሚድዋይፍሪ ት/ቤት

የነርሲንግ ዲፓርትመንት

የተሳታፊዎች የስምምነት ወረቀት

ስለ ሲ/ር ፌበን በሪሁ ----------------------------ስለ ጥናቱ እና ስለመጠይቁ ተገቢውን መርጃ ስታኛለች።በጥናቱ ላይ የማደርገው ተሳትፎ በፍቃደኝነት ላይ የተመሰረተ መጠይቁን መሙላት ከጀመርኩ በኋላም የማቋርጥ መብት እንዳለኝ ተረድቻለሁ።መጠይቁ ላይ የተሞሉት መረጃዎች በቀጥታ ለሚመለከተው አካል ብቻ እንደሚድርስ እና ከመጠይቁ ጋር ተያይዞ ለሚመጡ ማንኛውም ጥያቄዎችና መረጃዎች በስልክ ቁጥር 0920632729 እና ኢሜይል አድራሻ fevenberihu26@gmail.com ማቅረብ እንደምችል ተገንዝቢያለሁ።

ይህንን የስምምነት ገጽ በመፈረም የትኛውም ህጋዊ መብቴን እንደማልጋፋ እና ስለጥናቱ መጠይቅ ተገቢውን መረጃዎች እንደተስጡኝ የሚርጋግጥ ብቻ መሆኑን ተርድቻለሁ።

የተሳታፊ ፊርማ -------------------

ቀን --------------------

አማርኛ መጠይቅ

የመረጃ ሰብሳቢዉ ስም---------------------ፊርማ------------------ቀን--------------------

የተቆጣጣሪ ስም--------------------------ፊርማ------------------ቀን-------------------

መለያ--------------
መጠይቁ የተሞላበት ቀን-------/-------/--------------

የታካሚው መረጃ		
ቁጥር	ጥያቄ	መልስ
1.1	የታካሚ እድሜ	------------------
1.2	የታካሚ ፆታ	3. ወንድ 4. ሴት
1.3	የታካሚ እድገት ሁኔታ	3. የቅድመ ልጅነት ሁኔታ የዘገየ እድገት 4. ጤናማና ጊዜዉን የጠበቀ አድገት
1.4	የታካሚ የትምርት ደረጃ	4. መዋለ ህጻናት 5. የመጀመርያ ደረጃ ከክፍል1-ክፍል4 6. የመጀመርያ ደረጃ ከክፍል 5-ክፍል8
1.5	ትምህርት ቤት የመገኘት ሁኔታ	3. ጥሩ 4. ጥሩ ያልሆነ
1.6	የትምህርት ብቃት	5. እጅግ በጣም ጥሩ 6. ጥሩ 7. መካከልኛ 8. ደካማ
1.7	ልጆት ያለፈዉን ጊኤያት ክትባት በትክክል ውሰደዉል	4. አዎ 5. ያለፈዉ ክትባት አለ 6. ምንም ክትባት አልወሰደም
1.8	የልጆት የሰዉነት አካል ልኬት	ቁመት----------- ክብደት------------ BMI---------
የቤተሰብ ማህበራዊ መረጃ		
ቁጥር	ጥያቄ	መልስ

2.1	ሃይማኖት	6. ኦርቶዶክስ 7. ሙስሊም 8. ፕሮቴስታንት 9. ካቶሊክ 10. ሌላ
2.2	የሚኖሩበት በታ	3. አዲስ አበባ 4. ከአዲስ አበባ ዉጪ
2.3	እድሜ	--------
2.4	ጾታ	3. ወንድ 4. ሴት
2.5	የትምርት ደረጃ	7. ያልተማረ 8. ማንበብና መጻፍ የሚችል 9. የመጀመርያ ደረጃ(1-8) 10. ሁለተኛ ደረጃ(9-10) 11. መሰናዶ (11-12) 12. ኮሌጅ እና ከዛ በላይ
2.6	ስራ	6. የቤት እመቤት 7. የግል ተቀጣሪ 8. ተማሪ 9. የመንግስት ሰራተኛ 10. ጡረተኛ
2.7	ወርሃዊ ገቢ	6. 0-600 ብር 7. 601-1650 ብር 8. 1651-5250ብር 9. 5251-10899ብር 10. 10900 ብር በላይ
2.8	የጋብቻ ሁኔታ	5. ያገባ/ች 6. ያላገባ/ች 7. የፈታ/ች 8. የትዳር አጋሩ/ራ በህይወት የሌለ
የቤተሰብ የእዉቀት ጥያቄ		
ቁጥር	ጥያቄ	መልስ
3.1	የልጆትን አብሮ የተወለደ የልብችግር አየነት መግለጽ ይችላሉ	3. አዎ 4. አይ አልችልም

3.2	እስካሁን ያገኘዉ የህክምና አይነት በመዳኒቶች	7. የልብ ምት ጥንካሬን የሚቆጣጠሩ (digoxin) 8. በሰዉነት ዉስጥ የተጠራቀመዉን በፈሳሽ መልክ የሚያስወግድ (diuretics) 9. የደም ቧንቧ የሚያስፋ(captopril) 10. ሌሎች--------- 11. አላዉቀዉም
3.3	ከታች ባለው ስእል ላይ የልጆት የልብ ችግር የቱጋር እንዳለ ያሳዩ	3. አዎ 4. አይ አልችልም
3.4	ልጆትን ወደ ክትል ቦታ በ ምን ያህል ጊዜ ልዩነት ያመጡታል	6. በ የወሩ 7. በ2 ወር 8. በቀጠሮው ብቻ 9. ህመም ሲሰማው ብቻ
3.5	ልጆትን ወደ ክትትል ቦታ ማምጣት ጥቅሙ ምንድን ነዉ	5. የታካሚዉን ጤና ልምከታትለ 6. ብሽታው እያደረሰ ያለዉን ጉዳት ለመለየት 7. መዳኒት ለምዉስደ 8. ጥቅም የለዉም
3.6	እስካሁን ልጆት ያገኘዉ ህክምና አየነቶች በቀዶ ህክምና	3. አዎ አለ 4. የለም
3.7	እስካሁን ልጆት ያገኘዉ በደም ስር በኩል የተደረገ ህክምና	3. አዎ አለ 4. የለም
3.8	ሃኪሙ ስለልጆ የጤና ሁኔታ መረጃ ሰቶታለ	3. አዎ 4. አይ አልተሰጠኝም
3.9	ሃኪሙ የሰጠዉ መረጃ በቂ ነበር ብለዉ ያምናሉ	4. አዎ 5. ኤይ አላምንም 6. አላዉቅም
3.10	የልጆ የልብ ችግር እና ህክምና በእርሶ እይታ	5. ተስተካከለ ህክምና 6. የተጓደለ 7. የተሳሳተ ህክምና 8. እዉቀቱ የለኝም
3.11	የልጆት የልብ ችግር መንስኤዉ ምን ይመስሎታል	5. በዘር የሚተላለፍ 6. አብሮ የተወለደ 7. በተላላፊ ባክቴሪያ የሚመጣ 8. በመዳኒቶች የጎነዮሰሽ ጉዳት የመጣ

3.12	ከታች ከተዘረዘሩት ዉስጥ የትኛዉነ የልብ ችግር ምልክቶች ልጆት ላይ ሲያዩ ወደ ህክምና ቦታ ያመራሉ	7. የትንፋሽ ማጠር 8. ምግብ ሲበሉ ማላብ 9. የሰዉነት ቀለም ወደ ወይነ ጠጅ መቀየር 10. የእግር ማበጥ 11. ምግብ ሲበሉ መቸገር 12. ሌላ---------
3.13	ልጆት የሚወስዳቸው መዳኒቶች መጠኑ እና የሚወስድበት ሰአት ለይተዉ ያወቃሉ	3. አዎ 4. አይ አላውቅም
3.14	አብሮ ለተወለደ የልብ ችግር የሚወሰዱ መዳኒቶች የጎንዮሽ ችግር አላቸው	1. አዎ 2. አይ አላውቅም
3.15	አበሮ የተውለደ የልብ ህመም ላለባቸዉ ታካሚዎች ተመሳሳይ ምዳኒት ነወ ሚስጠው ብለው ያሰስባሉ	3. አዎ 4. አይ አላስብም
3.16	የህክምና ክትትሉ ጥቅም በእርሶ እይታ የልጆትን የጤና ሁኔታ ለመለየት ጠቃሚ ነዉ የላሉ	1. አዎ 2. አይ አላውቅም
3.17	በስካሁኑ ክትትል የልጆት የጤና ሁኔታ ትንበያ ምን ሊሆን ይችላል	5. ይድናል 6. አይድንም 7. የእድሜ ልክ በሽታ ሆኖ ይኖራል 8. አይ አላወቅም
3.18	ከልጆት የጤና ሁኔታ ጋር በተያያዘ የሚያደርጋቸዉን የአካል ብቃት እንቅስቃሴዎች መቆጣጠር ተገቢ ነዉ ብለዉ ያስባሉ	1. አዎ 2. አይ አላውቅም
3.19	ልጆት ማድረግ ስላለበት ተገቢ የሆነ የአካል ብቃት እንቅስቃሴ ከ ጤና ባለሞያ የተሰጦት ምክር አለ	1. አዎ 2. አይ አላውቅም
3.20	የልጆት የጤና ክትትል ተግቢዉን ዉጤት ሳያምጣ ሲቀር መዳኒቱን በገዛ ፈቃድ ማቻረጥ ተገቢ ነው	3. አዎ 4. አይ
	የቤተሰብ የተግባር ተኮር ጥያቄ	
ቁጥረ	ጥያቄ	መልስ
4.1	ወደ ጥርስ ህክምና በወክቱ ይወሰዱታል	1. አዎ 2. አይ
4.2	ልጆት ቢያንስ በቀን አንዴ ጥርሱን ያፀዳል	1. አዎ 2. አይ
4.3	ልጅዎን በቀን በየምንያህል ጊዜ የመግቡታል	4. ሲፈልግ ብቻ 5. ትንሽ ትንሽ ግን ቶሎቶሎ 6. ቁርስ ምሳ እራት ብቻ

4.4	ለልጆ ከሌላው በተለየ የሰውነት እድገቱን ለመደገፍ ብለው ብዙ ካሎሪ ያለው ምግብ ይመግቡታል	1. አዎ 2. አይ አለመግበዉም
4.5	ምግቡን እንዴት ካሎሪውን ያስተካክሉታለ	3. ወተት በብዛት በመስጠት 4. የተለያዩ የምግብ ፎርሙላዎችን በመስጠት
4.6	ብዙ ስኳር እና አነስተኛ ካሎሪ ያላቸዉን ምግቦች እንዳይበላ ይከለክላሉ	1. አዎ 2 አይ አልከለክልም
4.6	የልጆትን ሀኪም ስለ ልጆት አመጋገብ ያናግሩታል	1. አዎ 2 አይ አናግሬው አላቅም
4.7	ልጆት አብሮ የተወለደ የልብ ችግር ስላለበት የትኩሳት ምልክት ሲያሳይ ሀኪሙን ሳያማክሩ ፀረ ባክቴሪያ ይሰጡታል	3. አዎ ሰጠዋልሁ 4. አይ አልሰጠውም

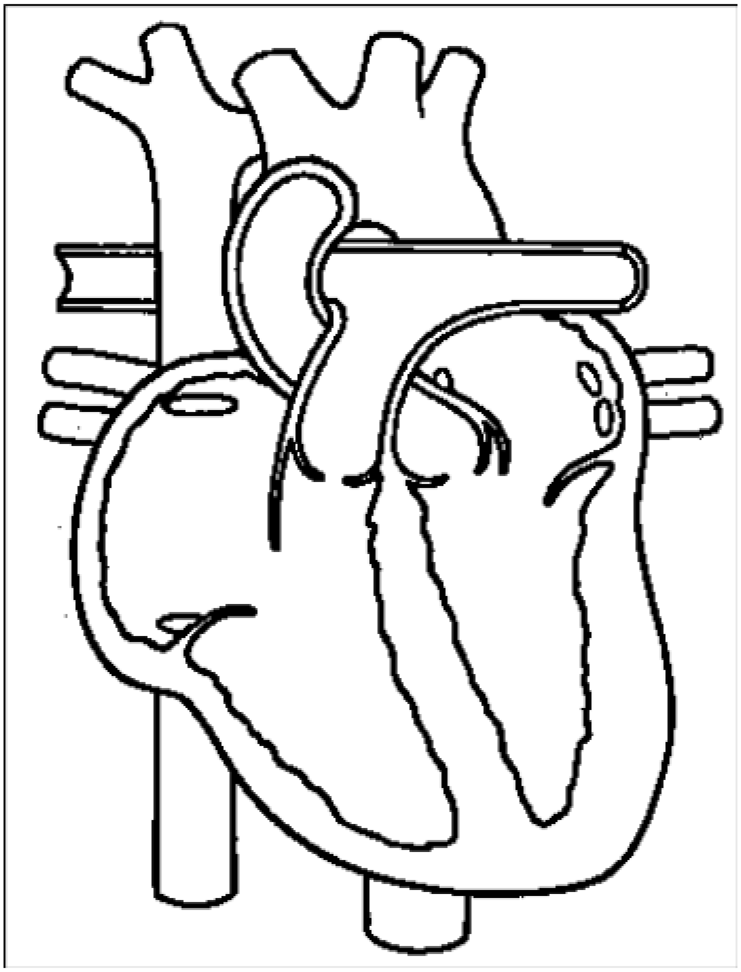

figure 2 cardiac diagram