



School of Nursing

Depression, anxiety, stress and associated factors among parents of children with congenital heart defect at governmental hospitals, Addis Ababa, Ethiopia. 2024. A cross sectional study.

By: MenberYilma

A Research thesis submitted to the Department of Medical Surgical Nursing;
in Partial fulfillment of the Requirements for the Degree of Masters in
Cardiovascular Nursing; St. Paul Hospital Millennium Medical College.

July /2024

Addis Ababa, Ethiop

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Abstract

Introduction: Depression, anxiety and stress accounted to the majority of health related burden globally. There are a number of factors that contribute to the high prevalence of depression, anxiety and stress; of which being a parent who has a child with congenital heart disease may experience extreme stress due to the intense emotions they face as well as additional practical, physical and financial challenges.

Objectives: To assess depression, anxiety stress and associated factors among parents of children with congenital heart disease at government hospitals Addis Ababa, Ethiopia. 2024.

Methods: An institutional based cross-sectional study design was employed to assess level of depression, anxiety, stress and associated factors among 422 parents of children with CHD from May10/2024 to June 10/ 2024 of at selected governmental Hospitals The sample population was obtained using a single population proportion formula with a 10 % contingency of non-respondent's rate, and the sample was proportionally allocated for each study hospital. Data using Kobotool box and exported to Statistical Package for Social Science version 26 software to be analyzed. Frequencies and proportions of variable of were described by tables and graphs, and pie chart. Association between each dependent and independent variable was assessed by using binary logistic regression and multivariate logistic regression.

Result: The prevalence of depression, anxiety and stress in the study was found to be approximately 38.4%, 36% and 32.4% respectively. Parent's rural area residency (AOR = 2.81, 95% CI: 1.033 - 2.432) lack of sleep (AOR = 1.691, 95% CI: 1.080 -2.646) and parental worries about severity of child's congenital heart disease (AOR = 1.800 , 95% CI: 1.139 - 2.843) were associated with depression. Lack of finance (AOR = 1.64, 95% CI =1.039- 2.589), child's heart surgery (AOR= 1.77, 95% CI=1.051-2.979), continuity of the child's medical treatment (AOR= 0.597, 95% CI= 0.372- 0.958) and sex of child (AOR=0.648, 95% CI=0.146-0.94) were significantly associated with anxiety. Malenss (fathers), (AOR= 1.766, 95%CI= 1.126- 2.771) and poor social support (AOR =2.021, 95% CI =1.289-3.168) were associated with stress.

Conclusion: A significant rates of depression, anxiety and stress among parents of children with congenital heart disease were observed. In order to lower the risk of depression, anxiety and stress as well as to lessen the burden of disease, preventive measures such as early intervention and mental health screening, psycho-social support financial support should be implemented.

Key Words: Congenital Heart Disease, Depression, Anxiety, Stress, social support, parent.

Acronyms and Abbreviations

AOR	Adjusted Odds Ratio
CI	Confidence Interval
COR	Crude Odds Ratio
ASD	Atria-Septal Defect
AVSD	Atrio-Ventricular Septal Defect.
CCE	Cardiac Center Ethiopia
CHD	Congenital Heart Disease
CICU	Child Intensive Cares Unit
DASS	Depression, Anxiety and Stress Scale
Dr,	Doctor
OSSS3	Oslo Social Support Scale
PCCHD	Parents of Children with Congenital Heart Disease.
PDA	Patent Ductus Arteriosus
SPSH	St. Peter Specialized Hospital
SPSS	Statistical Package for Social Science
SPHMMC	St. Paul Hospital Millennium Medical College
TOF	Tetralogy Of Fallot
TASH	TikuurAnbesa Specialized Hospital
VSD	Ventricular Septal Defect

1. Introduction

1.1. Back Ground

Congenital heart disease is one of the most common congenital anomaly in newborn babies(1). The defect is defined as a major structural abnormality of the heart or great vessels (2). Approximately one-third of all congenital birth abnormalities are caused by congenital cardiac disease (3) causing more than 20% of peri-natal deaths(4). Globally, the estimated prevalence of congenital heart disease is 8% per 1000 live births, or around 1.35 million newborns with CHD annually, though these numbers fluctuate (5). CHD was the underlying cause of an estimated 261, 247 deaths globally in 2017 (6).

A study in India has found that among 1822 births, the total prevalence of major congenital anomalies was 230.51 per 10 000 births, Congenital heart defects were the most commonly reported anomalies in the cohort with a prevalence of 65.86 per 10 000 births (7). In 2013, the prevalence of CHD in births in Africa accounted for 23% of all births worldwide (8). In Ethiopia, the prevalence of congenital heart disease is 7.9 per 1000 live births (9).

The parental involvement for a child with CHD has been linked to a number of socioeconomic, physical, and psychological problems (10). This would affect the mental health of parents. Mental health is defined as a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community (11).

The common mental health problems that parents of children especially mothers suffered from are depression, anxiety and stress(12). Depression is a mood illness that is defined by transient emotional reactions to a major medical condition that interferes with day-to-day functioning and is accompanied by symptoms including melancholy and frustration, guilt, insensibility, and interest loss (13). Anxiety is considered to be a basic negative emotion along with anger, sadness, and disgust and corresponds to a state of uncertainty. Excessive anxiety, based on unrealistic perceptions of self and others can be socially disabling (14). It is typified by anxious thoughts, tension, elevated blood pressure, heart

rate, respiration rate, perspiration, difficulty swallowing, lightheaded, and chest pain (15). A person experiences stress when they perceive a certain relationship with their surroundings as beyond their resources and posing a risk to their well-being (16).

Children with severe forms of CHD frequently undergo one or more operations in the first year of their life. This increases the chance of psychological illness in parents. After giving birth, it is known that mothers of children with CHD often have postpartum depression, which has been shown to affect up to 15% of the general population and up to 39% of mothers whose children are in the neonatal critical care unit (17).

Additionally, care burden for a child with CHD is another cause for mental health problems in parents. A study in Nepal among 97 mothers of children with CHD has found that the majority of moms 77.9% experienced regular hardship upon learning that their children's health was declining as a result of CHD. 44.2% of the mothers reported that they were always financially strapped while caring for their child; 40% of mothers reported that they had made emotional adjustments to care for their children with CHD; another 28.4% reported that they occasionally experienced sleep disturbances; and 46.3 reported that they were constantly upset because of their child's behavior (18).

In general parents of children with CHD could be in higher levels of parenting stress than parents of peers in good health. Parent's mental health problem can result poor quality of their life and difficulty of parenting their child & child's mental health will also be affected. Compared to children of parents without mental health issues, children of parents with mental health problems are more likely to experience psychological and developmental challenges (19).

1.2. Statement of the problem

There is a growing recognition that mental problems are major contributors to the burden of disease (20) (21), and account for 15% of all recognized illnesses worldwide (22) affecting over 450 million people (23). The World Health Organization has listed depression as the leading cause of disability worldwide, with an estimated 300 million people suffering from it (24). 29.19 million Africans are estimated to be depressed, with more than 7 million residing in Nigeria (25). Mental health problems are very common in sub-Saharan Africa; studies have revealed rates of anxiety, depression, and post-traumatic stress disorder ranging from 20% to 60% (26). Ethiopia has also been dealing with alarming trends in common mental health issues (27) with a prevalence of 29% depression(28) , 28% anxiety (29) and 40% mental distress(30).

Parents of children with congenital heart defects are among those who are suffering from depression, anxiety and stress. According to a study examining parental reactions to the condition, PCCHD have been shown to experience high stress more frequently than parents of healthy children (31). Because, for their survival and healthy growth, children with CHD need continuous medical, nursing, and therapeutic care. A child with CHD receives care from their parents in addition to the treatment team. Studies done in the USA have revealed that parents who have a child with CHD have physical exhaustion, irritation; depression, anxiety, and a lack of stamina to carry out social and domestic tasks are common (32). Besides this, parents' interactions and relationships with their children and other family members can be negatively impacted by stress, which can also negatively impact their behavior and communication (33).

The timing of a baby's diagnosis, operation, CICU stay and home discharge causes parents of infants with severe CHD to face increased stress (34). Parents particularly moms of children with CHD are more likely to be affected by mental health problem than parents of healthy children (35) (36). Another study has found that parents of children with critical CHD report anxiety or depression symptoms, and severe psychological distress particularly in the time following the children's heart surgery (12). Parents of children with CHD report significantly greater stress (31).

When their children receive a diagnosis, many parents may experience anxiety. They experience a sense of helplessness and fear, which can lead to excessive protectiveness and intense attachment to the child, thereby restricting their activities. The child's and the family's quality of life suffers as a result. Extreme anxiety may make it difficult for parents to accurately interpret information provided about their child's medical condition and advice on how to handle it. It can also make it difficult for parents to make the right decisions to get out of a difficult situation and participate in their child's (37).

Long-term family stress levels may rise due to the greater need for cardiac surgery and ongoing medical care, as well as the parental sense of losing control over their children. In low income countries with poor health care system treating CHD became very difficult. In Ethiopia, the expense of treating and preventing heart disease places a heavy strain on households (38).

In addition to the CHD, parent's poor mental health may further complicate the child's life and if left untreated, the parent's mental health problem can greatly affect the family's quality of life in a long run. To the best of my knowledge, there is no literature in Ethiopia about depression, anxiety, stress and their associated factors among parents of children with CHD. Ethiopia has practiced mental health services by integrating them with primary care and general medical services since 2012 (39). But there is no written literature which state about the approaches to overcome depression, anxiety and stress particularly in PCCHD at global level and in Ethiopian context. Therefore, this study is intended to assess mental health problems (depression, anxiety, and stress) and their contributing factors among parents of children with CHD at pediatric cardiac units of selected governmental hospitals in Addis Ababa, Ethiopia.

1.3. Significance of the study

Overall, the findings of this study have the potential to benefit a wide range of stakeholders, including parents, healthcare providers, and policy makers, by improving the mental well-being of parents of children with congenital heart defects and ultimately enhancing the overall quality of care for these families.

Parents of children with congenital heart defects: The primary beneficiaries of this study will be the parents of children with congenital heart defects who are experiencing high levels of depression, anxiety, and stress. By identifying the factors that contribute to these mental health issues, healthcare providers can offer targeted interventions and support to help improve the mental well-being of these parents.

The findings of this study will also benefit healthcare providers (particularly doctors and cardiac nurses) who work at pediatric cardiac units with PCCHD. By understanding the unique challenges faced by these parents, healthcare providers can tailor their support services to better meet the needs of these families. This can ultimately lead to improved outcomes for both the PCCHD and will also give positive courage for the cardiac nurses and cardiologists to perform their task ease working environment with mentally stable parents.

The findings of this study can also inform policy makers about the importance of providing comprehensive support services for families of children with congenital heart defects. By addressing the mental health needs of these parents, policymakers can help improve the overall quality of care for children with congenital heart defects and their families. The findings of this study will also serve as a reference & baseline for any further study to be carried out regarding mental health of parents of children with CHD and its contributing factors in the study areas.

2. Literature Review

2.1. General concept of congenital heart disease

Congenital heart disease is defined as a gross abnormality of the heart and intra-thoracic great vessels in children which is present at birth (40). CHD remains the commonest cause of death from structural birth defect with a global prevalence of approximately 8 per 1000 live births (41). Globally, 1.35 million live babies are diagnosed with congenital heart disease each year (3).

Africa is thought to be the birthplace of 500,000 CHD babies annually; Sub-Saharan African countries have a significantly higher prevalence rate of CHD due to their youthful population, with an average life expectancy of 60 years or less and over 50% of the population under 20 years old (32). The prevalence of CHD, is predicted to be 7.9 per 1000 live births in Ethiopia (9).

2.2. CHD and Mental health (depression, anxiety and stress)

Parents and families may be greatly impacted by cardiac issues in children. When a parent finds out their kid has a cardiac condition or is admitted to the hospital, they frequently experience fear and anxiety. Research studies indicate that parents of children with heart problems often experience difficulties with anxiety, depression, and traumatic stress related to upsetting aspects of the child's medical course (42).

Because they must deal with their children's Medical follow up, cardiac surgery procedures, lengthy hospital stays, feeding problems, and increased risk of serious respiratory illnesses, parents of children with CHD are more likely to experience depression anxiety and stress. These factors add up to significant financial, emotional, and familial costs (43). Taking care of a child with CHD often causes parents to feel stressed, anxious, and depressed (44).

2.3. Prevalence of depression, anxiety and related to CHD

The diagnosis of CHD and the treatments that followed, results in severe mental health issues in the parents (45). A systematic review of 30 studies has revealed that between 25% to 50% of parents of children with congenital cardiac defects reported having higher feelings of anxiety and depression. Between 30% to 80 %of parents of children with

CHD reported having significant stress (12). A study conducted in Sweden has found from 600 parents participated in the study, a high number of parents (n=220) reported scores of depression and (n=193) reported scores of anxiety with a proportion of 18% for depression and 15% for Anxiety(46).

Another study in Egypt has found that parents of children with CHD had greater prevalence of anxiety and depression (32.2 and 37.4%) compared to parents of healthy children (12.5 and 17.5%). Furthermore, 17.4% of Parents of children with CHD had mild depression, 13% had moderate depression, and 1.7% had severe depression. Additionally the results of level of anxiety among parents of children with CHD 1.7% had severe anxiety, 17.4% had moderate anxiety, and 18.3% had mild anxiety (47).

The intensity of distress for both mothers and fathers increased with the severity of the child's disease (48)(49). A study conducted in Australia has found that 20% of parents of children with CHD had reported a level of depression outside the normal range (50). A cross-sectional study conducted by Kasparian et al. assessed 91 mothers and 20 fathers, revealing that the participants' rates of stress, anxiety, and depression were, respectively, 26%, 27%, and 32%(51).

2.4. Factors associated to depression, anxiety and stress in parents

Mental health problems in parents of children CHD are associated with different contributing factors. In an investigation aimed at assessing the psychological condition of 38 American moms of children with congenital cardiac defects who were admitted to the hospital due to a cardiac-related problem ,depression symptoms were elevated during hospitalization (mean anxiety=5.8; mean depression=4.3); however, this markedly decreased two to four weeks later (mean anxiety=3.3, mean depression=2.2; $P<0.001$) (52).

In Sweden, the result of a prospective longitudinal study has showed that PCCHD reported psycho social issues that showed up as depression (18%), anxiety (16%), somatization (31%–38%), and hopelessness (16%). Furthermore, a range of 7% to 22% reported ongoing psychological issues after a year. Parental care giving burden, dissatisfaction with care, social isolation, and financial instability were associated with an increased risk of long-standing psycho-social morbidity (46).

Another significant source of stress is the parents' choice to allow their small kid to have heart surgery. While considering what is best for the child, parents worry that they will regret the choice they made. A study in Taiwan had discovered that mothers in this circumstance had increased stress as they attempted to comprehend the surgery and worried about their child's potential death. Along with feeling anxious about their child's surgical scar, mothers also struggled to balance the demands of their roles as caregivers and role models while preparing for surgery and getting ready for bedtime (50).

Additionally, a study of 38 Italian parents revealed that symptoms of depression were more common in mothers (46%) than in fathers (20%, $P < 0.05$) in the early postoperative period (53)(54). Similar findings were observed among Australian parents surveyed within four weeks following their child's heart surgery: 26% experienced depressive symptoms and slightly over half (51%) reported excessive concern (53).

In addition to children's disease and their severity, limited availability of social support may cause stressful life events. A study conducted on social support among parents of children with CHD, parents of children with other diseases and parents of Healthy Children has found that Care-giving time, was associated with lower availability of social support, that is with increasing care-giving time, availability of social support diminished (55). Parents with high availability of social integration reported greater satisfaction with medical care, staff attitude and total child care than those with low availability of social integration (56).

Compared to parents in rural regions, parents in cities had a higher likelihood of experiencing depression (OR = 2.81, 95% CI: 1.13-7.01 for depression) (57). Parents who have a kid with significant health care requirements might have to work fewer hours per week or leave work to attend doctor appointments (58). About 40% of Pakistani families who covered their children's medical bills without government assistance borrowed money from friends and family, 50% of the families either lost their jobs or businesses or took unpaid leave, and a tiny percentage of the families had to sell their property to cover the costs (59). Over 10% of the family income in Nigeria was spent on treating a kid with CHD, according to one-third of the families surveyed (60).

According to a study on financial burdens and mental health needs in families of children with congenital heart disease, there is a statistically significant positive correlation ($r=0.189^*$ and $r=0.212^*$, with p-values of 0.024 and 0.011, respectively) between financial stress and understanding health care situations as well as between family and work stress and overall coping (61). The physical, medical, educational, and financial demands of a child with CHD can lead to increased psychological suffering for families, on top of the financial difficulties (62).

Parents who are aware of their child's congenital heart disease, its treatment, and ways to prevent complications may also help their child develop better health-related behaviors by helping them better understand the cardiac condition, adhere to their treatment plan, and refrain from taking unnecessary risks (63). According to a study which investigates Parent's knowledge about diagnosis and management of their children with congenital heart diseases in Sudan, the majority of parents were informed about their child's diagnosis of heart problems; 78.3% of them were correctly aware of their child's cardiac lesions, and 95.8% were aware that the condition was congenital. Regretfully, 63.3% of the parents were unaware of the brand names of the drugs their children were taking, and only 9.2% were aware of the potential side effects (64).

In general, long-term family stress levels may rise due to several factors and this will affect the parents' mental health and the child's health prognosis. Therefore, this study was intended to assess the severity level of depression, anxiety, stress and their associated factors among parents of children with CHD attending their child's medical follow up at cardiac units of selected governmental hospital in Addis Ababa, Ethiopia

Conceptual Framework

Parents of children with CHD experiences depression, anxiety and stress due to a number of factors. Different studies have found that parents demographic factors(57)(53)(58), the care burden for children with CHD (46). Hospital admission (52) the perceived poor social support (55). The child's heart surgery (50), severity of the child's CHD(48), child's CHD treatment costs (43), health care related dissatisfaction among parents (46)& parents knowledge related to their child's CHD (64) were the associated factors that causes depression, anxiety and stress among parents of children with CHD

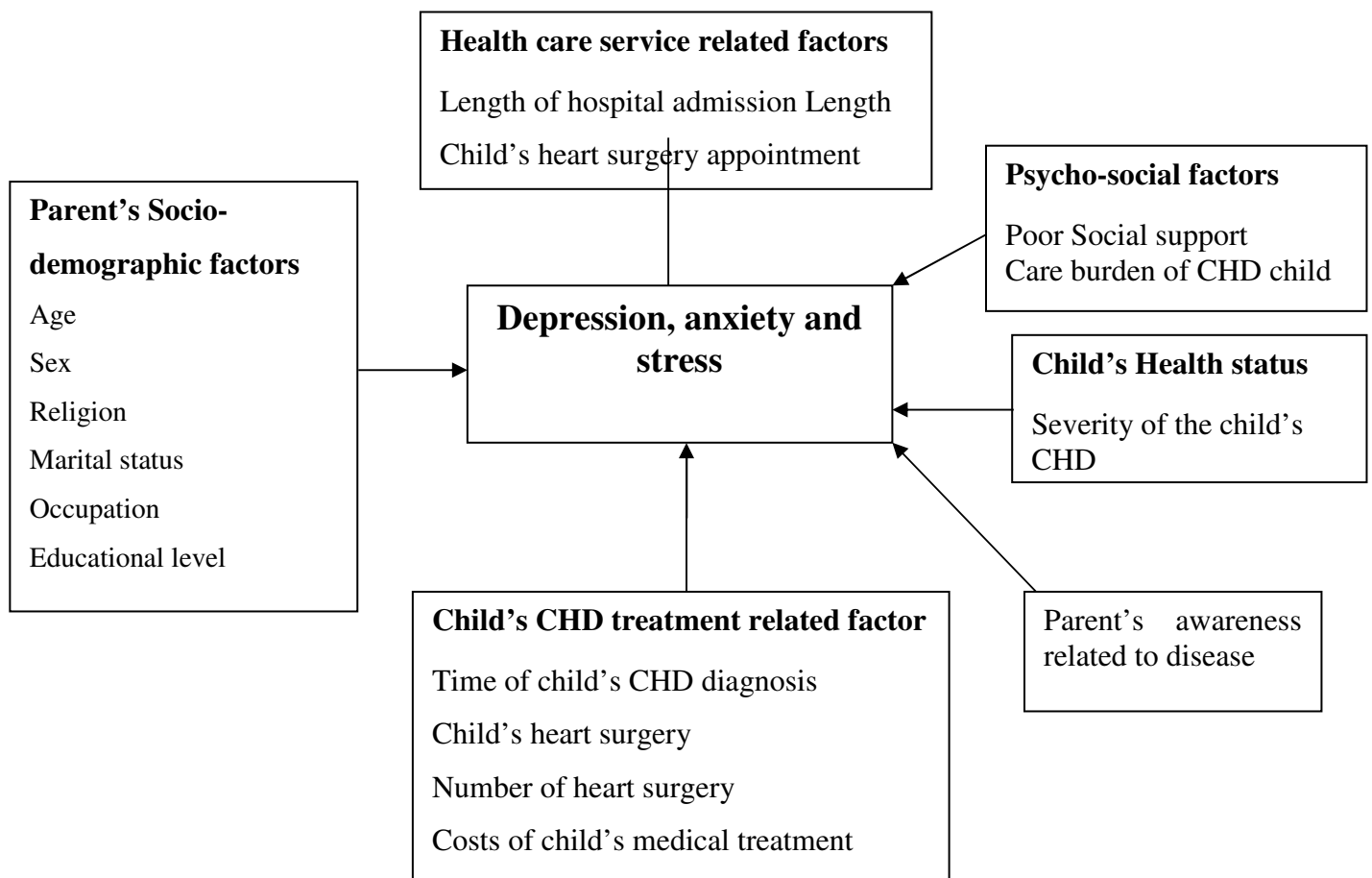


Figure1: The conceptual frame work showed that the association between mental health problem and associated factor among parents of children with CHD (43) (46) (48) (50) (52) (53) (55) (57) (58) (64).

3. Objectives

3.1. General Objective

To assess prevalence of depression, anxiety, stress and their associated factors among parents of children with Congenital Heart Disease at Cardiac units of selected government hospital Addis Ababa, Ethiopia. 2024

3.2. Specific Objective

1. To evaluate depression among parents of children with CHD at pediatric cardiac units of selected government hospital, Addis Ababa, Ethiopia. 2024
2. To determine anxiety among parents of children with CHD at pediatric cardiac units of selected government hospital, Addis Ababa, Ethiopia. 2024
3. To assess stress among parents of children with CHD at pediatric cardiac units of selected government hospital, Addis Ababa, Ethiopia. 2024
4. To identify factors associated with depression, anxiety and stress among parents of children with CHD at selected pediatric cardiac unit's governmental hospitals, Addis Ababa, Ethiopia. 2024.

4. Methods

4.1. Study area

The study was conducted at St. Paul Millennium Medical College, Tkur Anbesa Hospital and cardiac center Ethiopia, Addis Ababa Ethiopia.

St.Paul Hospital Mellenium Medical college (SPHMMC): situated in Gullele Sub-City, Addis Ababa, is the second largest public hospital in Ethiopia. It was constructed by Emperor Haile Selassie in 1969 with a mission to offer preventive, promotion, curative, and rehabilitative healthcare services in the country. The Pediatrics inpatient unit comprises 107 beds and serves an average of 1942 emergency and outpatient clients monthly, with a catchment population of over 5 million. The cardiology unit provides both inpatient and outpatient services, although it does not have a separate ward.

Tikur Anbesa Specialised Hospital (TASH): was established in 1964 by empire Hailesilassie. In 1972 the hospital become the only site for training medical doctor. In 1998 the TASH the largest referral hospital in the country with 850 beds. TASH is now the main teaching center for both clinical and preclinical training of most discipline. The hospital has a separated pediatric cardiac out patient service and on average about 375 CHD patients attended clinical follows up in one month.

Cardiac center Ethiopia(CCE): was established in 2009 by Dr, Belay Abegaz. It is a charity organization, affiliated public hospitals. This cardiac center is the first center in the country to activate cardiac surgery. The center has four cardiac surgeons, three cardiologists, three cardiac anesthesiologists three perfusionist, ten OR nurses, two cardiopulmonary bypass machines, two operating rooms, ten ICU beds and there is cardiac catheterization lab. The center performs many types of surgeries including congenital mal-formations and valvular heart disease. The institution performs one to two open heart surgeries per week with free cost. It has more than 6000 waiting lists

4.2. Study design and Period

An institutional based cross sectional study was conducted from May 10/ 2024 to June 10/ 2024.

4.3. Source population and Study population

4.3.1. Source Population

All parents of children with congenital heart disease having medical follow up at Addis Ababa.

4.3.2. Study Population

All parents of children with congenital heart disease who have medical follow up during the study period at study area.

4.3.3. Study unit

Selected Parents / care givers who accompany children with congenital heart disease who have medical follow up during the study period at study area

4.4. Inclusion Criteria & Exclusion Criteria

4.4.1. Inclusion Criteria

Parents of children with the age category of 0-14 years (65).

Parents /guardians whose children are diagnosed with CHD.

Parents of children with CHD who are attending medical follow up during the study period.

Parents who agree to take part in the research.

4.4.2. Exclusion Criteria

Parents of children with other heart diseases.

Parents who have hearing and vision impairment.

Parents who have seriously ill children

4.5. Sample size determination

To the best of my knowledge there was no study done on depression, anxiety and stress and their associated among parents of children with CHD as a country level. Therefore, I took the p value of participating parents as 50% (0.5). $Z_{\alpha/2}=1.96$ with 95% confidence level and 0.05 margin of error a sample size is calculated by using single proportion formula as:

$$n = \frac{(Z_{\alpha/2})^2 \times p(1-p)}{d^2} = \frac{(1.96)^2 \times 0.5(1-0.5)}{(0.05)^2} = 384$$

n= the required sample size = 384

Non respondent rate = 10 % = 384 × 0.1 = 38.4

Therefore the total sample size was 384+38.4 ~ 422

Table 1: Determination of sample size for associated factors (57)

Variables	AOR	Power	% of outcome in un exposed group	Ratio(exposed : unexposed)	Sample size	CI	Total result with 10% non-response rate
Parents residence	2.81	80%	25.71	1	148	95%	162
Parents age	0.35	80%	64.71	1	364	95%	401
Time of child 's CHD diagnosis	0.48	80%	30.28	1	134	95%	147
Psycho social support	1.36	80%	13.51	1	54	95%	60

4.6. Sampling Technique

Once the sample population was obtained using single population formula, study sample were proportionally allocated to each study hospitals based on the size of population served by each hospital using proportional allocation formula

Proportional allocation of sample = $\frac{\text{Total number of pediatric cardiac Patients in a specific hospital}(X)}{\text{Total number of Pediatric cardiac patients in the three study hospitals.}} \times \text{total sample}(n)$

Total number of Pediatric cardiac patients in the three study hospitals.

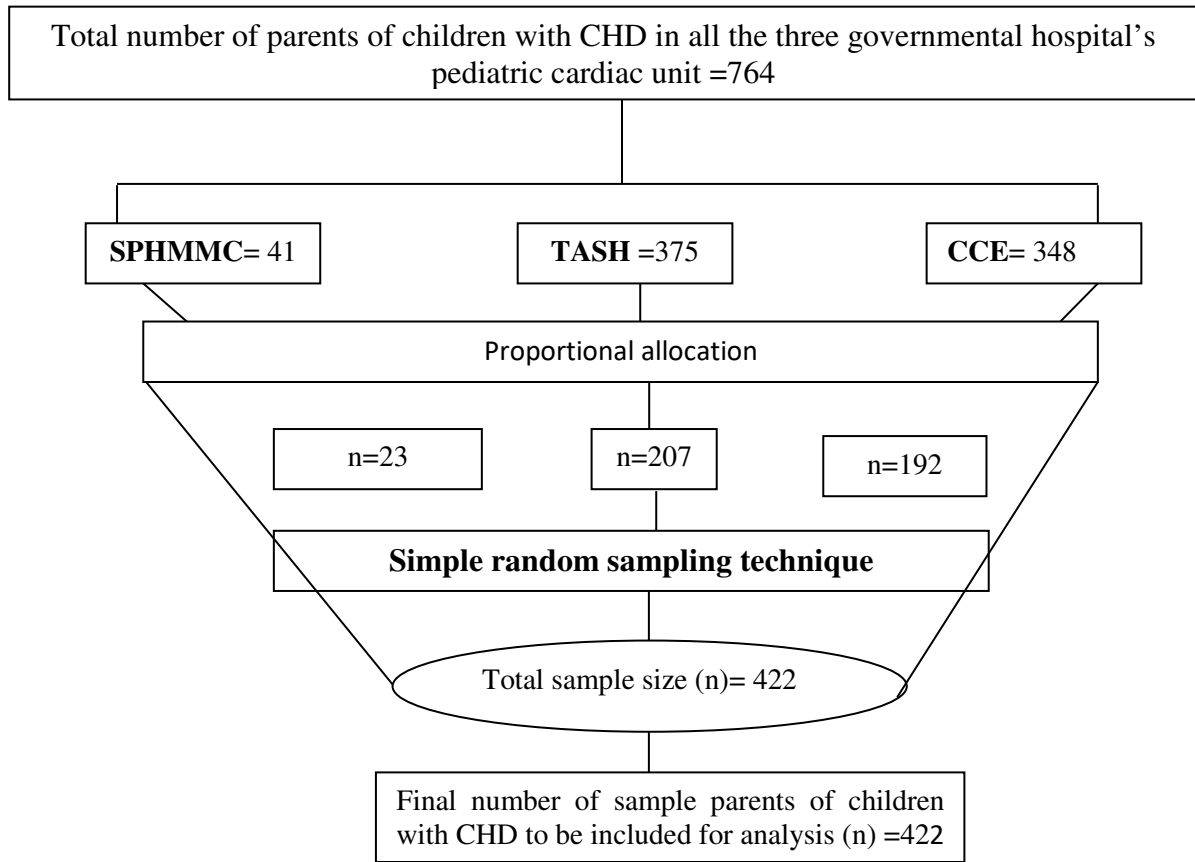


Figure 2: Flow diagram of proportional allocation and sampling of study participants at SPHMMC, TASH AND Cardiac center Ethiopia, 2024.

4.7. Study Variables

4.7.1. Dependent Variable

Depression, anxiety and stress

4.7.2. Independent Variables

Parent's Demographics related factors (age, sex, marital status, residence and education level)

Awareness of parents related to CHD

Severity of child's CHD

Child's CHD treatment related factors.

Frequency of hospital admission.

Social support and service related factors

4.8. Data collection procedure & data collection tools

The first part of the data collection tool consists of: A designed questionnaire: The study has used close ended structured interview questioner to collect parents' demographic data such as age, sex, and marital status, number of children, educational level and occupation. This tool was obtained from review literature.

The second part of data collection tool consists of: Depression, Anxiety and stress scale DASS 21. It is used to determine depression, anxiety and stress. It contains 21 items in three domains each having seven items. The items scores on a four-point scale (66). The applicability rating scale is: 0= did not apply to me at all –never, 1= Applied to me to some degree or some of the time. - Sometimes, 2= Applied to me to a considerable degree or a good part of the time - often 3= Applied to me very much or most of the time - almost always. Parents were asked to response the occurrence of indications of depression, anxiety and stress over the past week. Scores from each domain were summed. Then, the final score was multiplied by 2 and then categorized as normal, mild, moderate, severe, and extremely severe (66).

The DASS-21 has high reliability, has a factor structure that is consistent with the allocation of the items to sub-scales, and exhibits high convergent validity with other measures of anxiety and depression(67). A study has found that the Cronbach alpha test of DASS21 for depression, anxiety and stress was 0.79, 0.89 and 0.90 respectively(68).

The third part of data collection tool consists of: OSSS-3

The thirds part of data collection tool was Oslo social support scale: The OSSS-3 consists of three items to assess the social support status. The sum score ranges from 3 to 14, with high values representing strong levels and low values representing poor levels of social support (69).

4.9. Operational definition and Definition of terms

A depression score of 0–9 was considered normal, a score of 10–13 as mild, a score of 14–20 as moderate, a score of 21–27 as severe, and a score of 28 and above as extremely severe. Similarly, a score of 0–7 was considered normal for participants with anxiety, a score of 8–9 as mild, a score of 10–14 as moderate, a score of 15–19 as severe, and a score of 20 and above as extremely severe. A stress score of 0–14 was considered normal for participants with stress, a

score of 15–18 as mild, 19–25 as moderate, 26–33 as severe, and 34 and above as extremely severe (66).

Table 2: Summary of severity level of depression anxiety and stress

		Depression	Anxiety	Stress
Severity Level	Normal	0-9	0-7	0-14
	Mild	10-13	8-9	15-18
	Moderate	14-20	10-14	19-25
	Severe	21-27	15-19	26-33
	Extremely Severe	28+	20+	34+

The sum scores of ≥ 10 indicate depression, ≥ 8 indicates anxiety, ≥ 15 indicates for the stress.(70)

Social support is an intervention that protects people from the negative consequences of stressful situations. According to the OSSS3 scoring system, the sum score ranges from 3 to 14. Scores 3–8 indicates poor social support, 9–11 indicates moderate social support & 12–14 indicates strong social support. The sum scores <9 indicate poor social support whereas ≥ 9 indicates good social support (69).

Children: The age category of 0 to 14 years (65).

4.10. Data quality control & management

Structured questionnaire, DASS21 and OSSS3 were used. All the questionnaires translated from English to Amharic & back to English. Once translated, the questioners were reviewed by an expert for an opinion. The cutoff point for Cronbach alpha coefficient value >0.645 was used to maintain internal consistency, reliability and validity of DASS21 and OSSS3(65).

Training was given for data collectors on the objective of the study, method, contents and also how to maintain confidentiality and privacy of the study subjects was strictly conducted. Data was collected by three experienced staff nurses with BSc degree. Pretesting was done in 5% of the study population at SPSH, for clarity and understandability. The subject who was participated in the pretesting was excluded from the final data analysis; the data collection process was supervised on daily basis by principal investigators.

4.11. Data Analysis Plan and Procedures

The collected data using kobotool box was exported to xls to be cleared and exported to SPSS version 26 software to be analyzed. Frequencies and proportions were estimated to describe the variable. Tables, figures and graphs were used to present the findings. Association between each dependent and independent variable was assessed by using binary logistic regression, the result of p-value which was <0.25 was used in the multivariate logistic regression. A P-value of <0.05 in the multivariate analysis was used as criteria for the statistically significant association. The strength of the association was measured using the Odds ratio with corresponding 95% confidence intervals (CI).

4.12. Ethical consideration

The research was carried after approval of ethical permission obtained from SPHMMC. Priorly a support letter N/S/506835/16 was obtained from SPHMMC research committee and submitted to Cardiac Center Ethiopia, TASH and SPHMMC.

Participation to the study was based on free willingness to respond to the questionnaires. Objectives of the study were explained to be respondents, and they were informed that, the population will benefit from the research findings and there was no benefit individually because of their willingness to participate. And then, the interview was continued after informed consent was obtained from the respondent. They were also informed that the information that was received kept confidentially, and only used for the intended research purpose.

4.13. Dissemination of Results

Finally, findings of the study will be reported to the Cardiac Center Ethiopia, TASH Pediatric department and SPHMMC department of pediatrics and child health. The study finding will be used to improve the mental health and quality of life of both parents of children with CHD and their child at the study areas. The study findings will also be made publicly accessible online and published in a peer-reviewed publication. Additionally, the data might serve as a springboard for upcoming depression, anxiety and stress related studies and interventions.

5. Result

Socio-demographic characteristics of parents of children with CHD

Four hundred twenty-two subjects were included in the study and the overall response rate was 404 (96%). Majority of the respondents were female 253 (62.3%). The mean age of participants was 34.63 year (± 6.988). Three hundred ninety-three (97.3%) of them were married. Regarding the religion, majority of the respondents; 168 (41.6%) were Orthodox Christian, 138 (34.2%) respondents were Muslim. One hundred ten (27.2%) of respondents had college diploma and above where as majority of respondents [168 (39.8%)] were self-employed.

Table 3: Social-demographic characteristics of parents of children at SPHMMC, TASH and Cardiac center Ethiopia, Addis Ababa Ethiopia. 2024 (n=404).

Variables		Frequencies (n=404)	Percent (100 %)
Sex	Female	253	62.6
	Male	151	37.4
Age	≤ 30	216	53.5
	> 30	188	46.5
Marital status	Single	3	0.7
	Married	393	97.3
	Divorced	5	1.2
	Widowed	3	0.7
Religion	Orthodox	168	41.6
	Muslim	138	34.2
	Catholic	5	1.2
	Protestant	93	23.0
Residency	Urban	198	49.0
	Rural	206	51.0
Educational status	No formal education	72	17.8
	Primary (1-8)	55	13.6
	Secondary (9-10)	61	15.1
	Preparatory(11-12)	70	17.3
	Collage education	74	18.3
	University degree	57	14.1
	Master' s degree	15	3.7
Occupation	Government employed	118	29.2
	Self employed	160	39.6
	Unemployed	126	31.2

Biographic data of children's with CHD

Two hundred five (50.7%) of the children with CHD were male and 199(49.3%) were female. Two hundred thirty-eight (58.9%) of children were under five years old and 166 (41.1%) were 5 to 14 years old. Majority of the children (59.7%) were not in a formal education, 87 (21.5%) were at KG level and 76 (21.6%) were at elementary school level (grade 1-8).

Table 4: Biographic characteristics of children with congenital heart disease at SPHMM, TASH and Cardiac Center Ethiopia, 2024. (n=404).

Variables		Frequencies (n=404)	Percent (100%)
Sex	Female	199	49.3
	Male	205	50.7
Age (in year)	Under 5	238	58.9
	5-14	166	41.1
Educational status	No formal education	241	59.7
	KG	87	21.5
	Primary (grade1-8	76	18.8

Child's type of CHD and number of heart surgery

Majority of the children, 115(28.5%) were diagnosed with VSD. The second prevalent congenital heart disease was ASD, 101 (25%). Three hundred forty-four children (85.1 %) had one heart defect, 37 (9.2 %) and 60 (14.9 %) children had ≥ 2 heart defects. Only one hundred two children (25.2%) had undergone cardiac procedure (surgery and cathlab).

Table 5: Child's heart defect and cardiac surgery data at SPHMMC, TASH and Cardiac Center Ethiopia, 2024. (n=404)

Variables		Frequencies (n=404)	Percent (100 %)
Child's congenital heart defect	AVSD	26	6.4
	ASD	101	25.0
	VSD	115	28.5
	TOF	37	9.2
	PDA	88	21.8
	CAO	36	8.9
	Other	1	0.2
Number of heart defect	1	344	85.1
	≥2	60	14.9
Undergo heart surge (Cardiac procedures)	Yes	102	25.2
	No	302	74.8
Number of heart surgery	1 times	97	24.0
	2 times	5	1.2
	No surgery yet	302	78

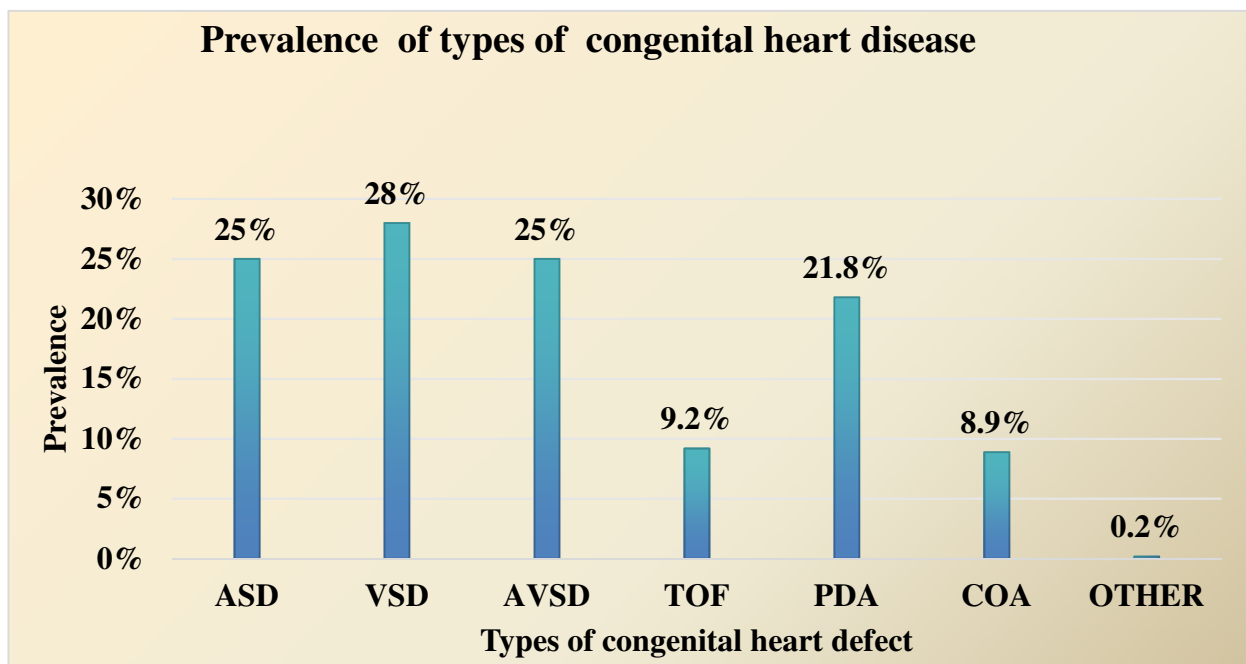


Figure 3: Types of congenital heart defect among children with congenital heart defect at SPHMMC, TASH and Cardiac center Ethiopia. 2024 (n=404)

Parent's awareness related to CHD

Majority of the respondents [258(63.8%)] had no awareness about CHD before their child were diagnosed and only 118 (28.7%) parents knew the medications that their child. Three hundred eight (94.1%) parents had believed that the child's heart defect can be reversed to normal through the medical treatments they have been receiving and 399 (98.8%) of parents has reported that their child was diagnosed for CHD after birth.

Table 6: Parents awareness related to CHD at SPHMMC, TASH and Cardiac Center Ethiopia 2024.

Variable		Frequencies (n=404)	Percent (100%)
Heard about CHD before child' s diagnosis	No	146	36.1
	Yes	258	63.9
Time of child' s CHD diagnosis	Before birth	5	1.2
	After birth	399	98.8
Believed that the heart defect can be reversed to normal	No	385	95.3
	Yes	19	4.7
knew child' s medications	No	122	30.2
	Yes	282	69.8

Challenges and worries of parents of children with CHD

One hundred seventy-five (43.3 %) of parents reported that they had lack of sleep, 122 (30.2%) of parents had difficulty of parenting other family members, 180 (44.6%) of parents had lack of finance for the child's medical treatment and 131 (32.4%) of parents had reported that continuity of the child medical treatment is a challenge for them. Worries among parents were found to be 152 (37.6%) due to child's heart disease, 169 (41.8%) due to long appointment for child's heart surgery, 145(35.9%) due to costs of child's heart disease, 144 (35.6%) due to child's hospital admission and 168 (34.2%) due to severity of child's CHD.

Table7: Challenges and worries of children at SPHMMC, TASH and Cardiac center Ethiopia, Addis Ababa Ethiopia. 2024 (n=404).

Variables			Frequency n=404	Percent (100%)
Challenges of parents	Lack of sleep	No	229	56.7
		Yes	175	43.3
	Difficulty of parenting my families	No	282	69.8
		Yes	122	30.2
	Lack of finance for child' s medical treatment	No	224	55.4
		Yes	180	44.6
	Continuity of the child' s medical treatment	No	273	67.6
		Yes	131	32.4
Worries of parents	Child' s heart surgery	No	252	62.4
		Yes	152	37.6
	Long appointment for cardiac surgery	No	235	58.2
		Yes	169	41.8
	Costs of heart surgery	No	259	64.1
		Yes	145	35.9
	Hospital admission of the child	No	260	64.4
		Yes	144	35.6
	Severity of child' s CHD	No	266	65.8
		Yes	168	34.2

Social support status of parents

Two hundred fifty-eight (63.1%) of parents had good social support while 146 (36.9%) of parents have poor social support.

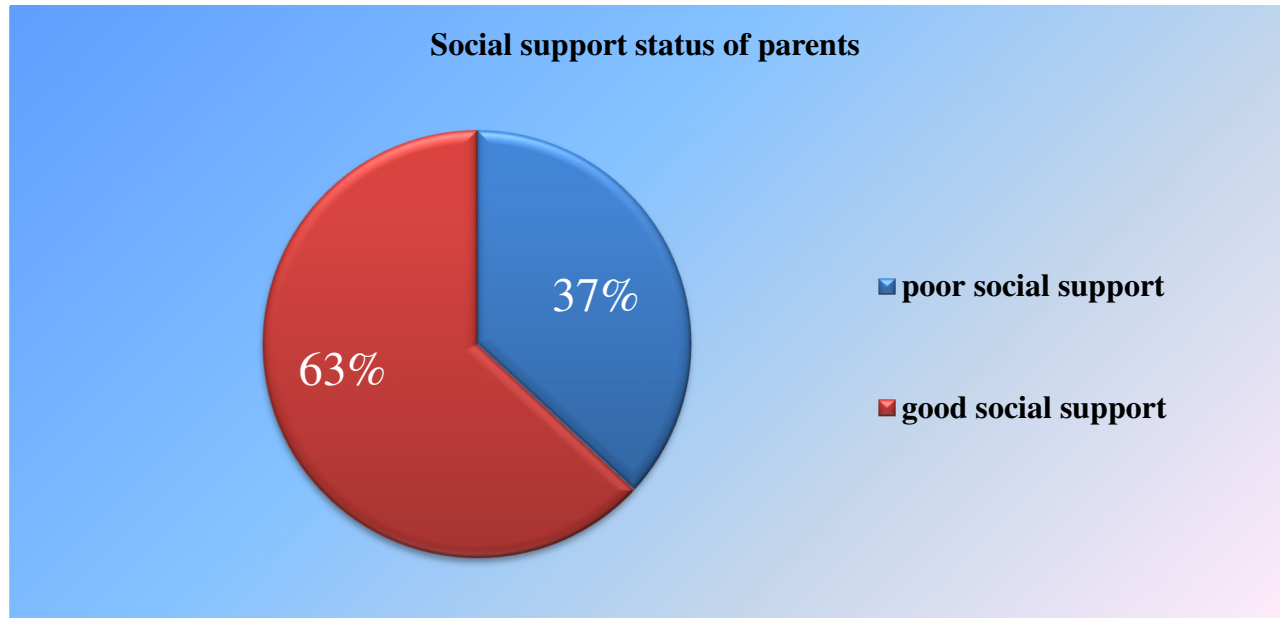


Figure 4. Social support status of parents of children with congenital heart disease at SPHMMC, TASH, and Cardiac Center Ethiopia. 2024. (n=404)

Prevalence of Depression, Anxiety and stress

The overall prevalence of depression, anxiety, and stress in this study was found to be 38.4%, 36.9%, and 32.4%, respectively. Ninety-six (23.8%) respondents had mild depression, 48 (11.9%) had moderate depression, and 4 (2.7%) had severe depression. Similarly, 60 (14.9%) respondents had mild anxiety, 74 (18.3%) had moderate anxiety, and 15 (3.7%) had severe anxiety. Seventy-nine (19.6%) respondents had mild stress, 33 (8.2%) had moderate stress, and 19 (4.7%) had severe stress.

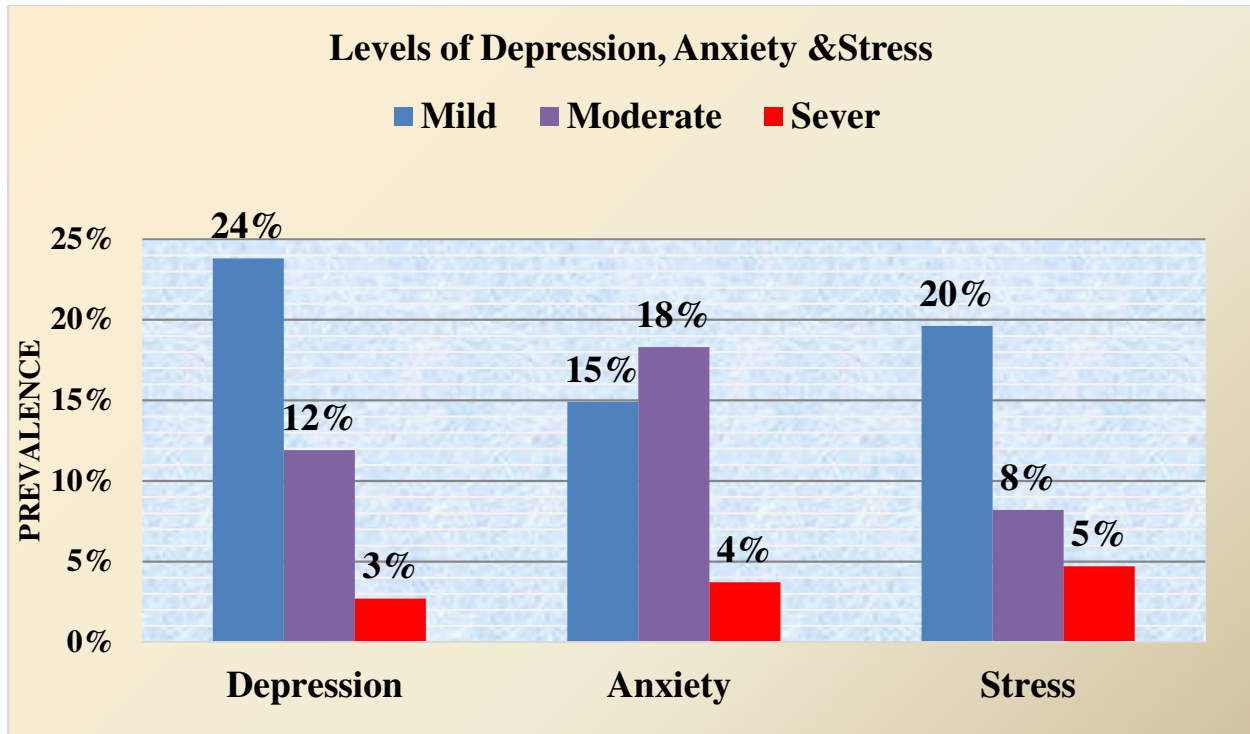


Figure 5: level of depression, anxiety and stress among parents of children with congenital heart disease, Ababa, Ethiopia, 2024

Associated factors of depression

In the bi-variable logistic regression analysis, depression was associated with parent's place of residency, age of the child (in Year), lack of sleep, difficulty of parenting my other family members, lack of finance for child's medical treatment, child's heart surgery, waiting too long for the child's heart surgery, hospital admission of the child, severity of the child's CHD, and social support status of parents ($p < 0.25$).

In the multivariate logistic regression analysis, parents' place of residency and severity of child's heart disease were significantly associated with depression ($p < 0.05$). Parents living in rural area were 1.585 times more likely to suffer from depression compared to parents living in the urban areas (AOR = 1.585, 95% CI: 1.033 - 2.432) for depression. Parents of children who had lack sleep are 1.691 times more likely to have depression than parents who had no lack of sleep (AOR = 1.691, 95% CI: 1.080 - 2.646) for depression. Those parents who were worried about the severity of child's heart disease were 1.800 times more likely to be depressed than those parents who were not worried (AOR = 1.800, 95% CI: 1.139 - 2.843) for depression.

Table 8: Factors associated with depression among parents of children with congenital heart disease at SPHMMC, TASH and Cardiac center Ethiopia, 2024.

Variables		Depression		P-value	COR (95%)	P-value	AOR (95%)	95% C.I	
		No	Yes					Lower	Upper
Social support status	Good	169 (65.5%)	89 (34.5%)				1		
	Poor	80 (54.8%)	66 (45.2%)	0.34	1.56 (1.03-2.37)	0.208	1.326	.855	2.057
Place of residency	Urban	139 (65.6%)	73 (34.4%)				1		
	Rural	110 (57.3%)	82 (42.7%)	0.088	1.42 (0.95-2.12)	0.035*	1.585	1.033	2.432
Age of the child (in Year)	Under 5	130 (58.0%)	100 (42.0%)				1		
	5-14	111 (66.9%)	55 (33.1%)	0.071	0.68 (0.45-1.03)	0.086	.679	.437	1.056
Lack of sleep	No	157 (68.6%)	723 (31.4%)				1		
	Yes	92 (52.6%)	83 (47.4%)	0.001	1.967 (1.309-2.956)	0.022*	1.691	1.080	2.646
Difficulty of parenting my families	No	166 (66.0%)	96 (24.0%)				1		
	Yes	63 (51.6%)	59 (48.4%)	0.001	1.814(1.178-2.795)	0.141	1.436	.887	2.323
Lack of finance	No	148 (66.1%)	76 (33.9%)				1		
	Yes	101 (56.1%)	79 (43.9%)	0.041	1.523 (1.0172.281)	0.519	1.162	.736	1.834
The child's heart surgery	No	168 (66.7%)	84 (33.3%)				1		
	Yes	81 (61.38%)	71 (46.7%)	0.008	1.573 (1.161-2.648)	0.180	1.380	.862	2.210
Hospital admission of child	No	174 (66.9%)	86 (33.1%)				1		
	Yes	75 (52.1%)	69 (38.4%)	0.003	1.861 (1.227-2.824)	0.129	1.419	.903	2.228
Severity of the child's CHD	No	179 (67.3%)	87 (32.7%)				1		
	Yes	70 (50.7%)	68 (49.3%)	0.001	1.999(1.035-2.372)	0.012*	1.800	1.139	2.843
Waiting long for child's cardiac procedure	No	151 (64.3)	84 (35.7%)				1		
	Yes	98 (58.0%)	71 (42.0%)	0.202	1.302 (0.868-1.958)	0.630	1.119	0.708	1.767

Statistically significant for association ($p < 0.05$). AOR= adjusted odds ratio; COR= Crude odds ratio; CI= confidence interval.

Associated factor of Anxiety

In the bi-variable logistic regression, anxiety was significantly associated with, lack of sleep, continuity of the child's medical treatment, waiting too long for the child's heart surgery, child's heart surgery, child's, hospital admission, parents social support status, lack of finance for child's medical treatment, difficulty of parenting other families, severity of the child's CHD, and sex of the child.

In the multivariate logistic regression analysis, lack of finance for child's medical treatment, child heart surgery, sex of the child and continuity of the child's medical treatment were significantly associated with anxiety ($p < 0.05$). Parents of children with CHD who had lack of finance for their child's medical treatment status were 1.64 times more likely to suffer from anxiety than those parents who had no financial challenge (AOR = 1.64, 95% CI = 1.039- 2.589). Parents of children whose child hadn't yet undergo heart surgery were 1.77 times more likely to develop anxiety than those parents whose child had undergone heart surgery (AOR= 1.77, 95% CI=1.051-2.979). Parents who had male child were 0.648 times less likely to have anxiety than parents who had female child (AOR=0.648, 95% CI=0.146-0.94). Parents who had challenges with continuity of the child's medical treatment have 40% risk to suffer from anxiety than those of parents who had no challenges with continuity of the child's medical treatment.

Table 9: Factors associated with anxiety among parents of children with congenital heart disease at SPHMMC, TASH and Cardiac center Ethiopia, 2024.

Variables		Anxiety		P-value	COR (95 %)	P-value	AOR (95 % CI)	95% CI for EXP(B)	
		No	Yes					Lower	Upper
Social support status	No	174 (67.4%)	84 (32.6%)				1		
	Yes	81 (55.5%)	65 (44.5%)	0.017	0.136 (0.0181.04)	0.083	1.475	0.951	2.290
Sex of child	Female	126 (59.2%)	87 (40.8%)				1		
	Male	129 (67.5%)	62 (32.5%)	0.82	0,696 (0.95-2.17)	0.042*	0.640	0.416	0.984
Lack of sleep	No	156 (68.1%)	73 (31.9%)		11856		1		
	Yes	99 (56.6%)	76 (43.3%)	0.017	1.641 (1.09-2.46)	0.138	1.408	0.896	2.214

Undergo heart surgery	yes	73 (73%)	27 (27%)				1		
	No	182 (59.9%)	122 (40.1%)	0.19	1.812 (1.102-2.3)	0.032*	1.770	1.051	2.979
Difficulty of parenting my families	No	189 (67.0%)	93 (33.0%)				1		
	Yes	66 (54.1%)	56 (45.9%)	0.14	1.724 (1.12-2.7)	1.239	0.332	0.827	2.144
Lack of finance for child's medical treatment	No	156 (69.6%)	68 (30.4)				1		
	Yes	99 (55.0%)	81 (45%)	0.03	1.877 (1.25-2.8)	0.034*	1.640	1.039	2.589
Continuity of the child's medical treatment	No	167 (61.2%)	273 (38.8%)				1		
	Yes	88 (67.2%)	43 (32.8%)	0.243	0.77 (0.497-1.2)	0.032*	0.597	0.372	.958
Waiting too long for the child's heart surgery	No	157 (66.8%)	78 (33.2%)				1		
	Yes	98 (56%)	71 (42%)	0.070	1.458 (0.97-2.19)	0.218	1.316	0.851	2.035
Hospital admission of the child	No	170 (65.4%)	90 (41%)				1		
	Yes	85 (59%)	59 (41%)	0.205	1.311 (0.92-1.99)	0.619	1.121	0.716	1.755
Severity of the child's CHD	No	175 (85.8%)	91 (34.2%)				1		
	Yes	80 (58%)	58 (42%)	0.123	1.394 (0.91-2.52)	0.152	1.393	0.885	2.193

Statistically significant for association ($p < 0.05$). AOR= adjusted odds ratio; COR= Crude odds ratio; CI= confidence interval.

Associated factors of stress

In the bi-variable logistic regression, stress was significantly associate with number heart defect, Sex of parents, know child's medications, lack of sleep, Difficulty of parenting my families, child's heart surgery, costs of child's heart surgery, hospital admission of the child, Severity of the child's CHD, Social support status of parents.

In the multi-variable logistic regression, sex of parents, child's hospital admission, knowing child's medication, social support status of parents and difficulty of parenting other family member were significantly associated with stress ($p < 0.05$). Male parents (fathers) were 1.766 times more likely to have stress than female parents (mothers) (AOR= 1.766, 95%CI= 1.126-2.771). Parents with poor social support status were 2.021times more likely to have stress than those parents who had received good social support (AOR =2.021, 95% CI =1.289-3.168).

Table 10: Factors associated with Stress among parents of children with congenital heart disease at SPHMMC, TASH and Cardiac center Ethiopia, 2024.

Variables		Stress		P-value	COR (95%)	P-value	AOR (95% C)	95% CI or EXP(B)	
		No	Yes					Lower	Upper
Number heart defect	1times	68 (68.0%)	32(32.0%)				1		
	2 times	205 (67.4%)	99 (32.6%)	0.009	0.319 (0.093-1.1)	0.050	2.054	0.999	4.227
Sex of parents	Female	182 (71.9%)	71 (28.1%)				1		
	Male	91 (60.3%)	60 (39.7%)	0.016	1.690 (1.104-2.6)	0.013*	1.766	1.126	2.771
know child's medications	Yes	89 (73.0%)	33 (27.0%)				1		
	No	184 (65.2%)	98 (34.8%)	0.013	1.436 (0.899-2.3)	0.137	1.457	0.887	2.396
Lack of sleep	No	163 (71.2%)	66 (28.8%)				1		
	Yes	110 (62.9%)	65 (37.1%)	0.077	1.459 (0.96-2.22)	0.496	1.174	0.740	1.861
Difficulty of parenting	No	197 (69.9%)	85 (30.1%)				1		

families	Yes	76 (62.3%)	46 (37.7%)	0.137	1.403 (0.898-2.3)	0.320	1.281	0.786	2.090
The child's heart surgery	No	197 (69.9%)	85 (30.1%)				1		
	Yes	76 (62.3%)	46 (37.7%)	0.141	1.377 (0.899-2.1)	0.647	1.120	0.690	1.819
The costs of child's heart surgery	No	197 (69.9%)	85 (30.1%)				1		
	Yes	76 (62.3%)	46 (37.7%)	0.122	1.403 (0.913-2.2)	0.199	1.366	0.849	2.198
Hospital admission of the child	No	197 (69.9%)	85 (30.1%)				1		
	Yes	76 (62.3%)	46 (37.7%)	0.066	1.496 (0.974-2.3)	0.448	1.202	0.748	1.931
Severity of the child's CHD	No	184 (70.8%)	76 (29.2%)				1		
	Yes	89 (61.8%)	55 (38.2%)	0.039	1.578 (1.024-2.4)	0.072	1.548	0.962	2.491
Social support status of parents	Good	191 (74.0%)	67 (26.0%)				1		
	poor	82 (56.2%)	64 (43.8%)	0.000	2.225 (1.448-3.4)	0.002*	2.021	1.289	3.168

Statistically significant for association ($p < 0.05$). AOR= adjusted odds ratio; COR= Crude odds ratio; CI= confidence interval.

6. Discussion

The results of this study showed that having a child with congenital heart defect induced high levels of stress as well as depressive and anxiety disorders in the vast majority of parents. Prevalence of depression in the study was found to be 38.4% (CI: 0.336-0.433) which is higher than study conducted in Egypt (32.2%) (47), Australia (26%) (51) And Sweden (18%) (46). The possible reason for this variation might be the difference in the study sample size, study design and availability of advanced congenital heart defect treatment in these countries.

The prevalence of anxiety in this study was found to be 36.9% which is in line with the study conducted in Egypt (37.4%). In contrast prevalence of Anxiety in this study 36.9 % (CI: 0.322-0.418) is higher than the study result conducted in Australia (25%)(71) and in Sweden (16-18%) (35). The discrepancy may reflect variation in sample size & methodology of study.

The current study has revealed a notable prevalence of stress among parents of children with congenital heart disease, with 32.4 % reporting significant stress level which aligns with the study conducted in Australia that stress prevalence was stress (32%) (51). This study has found that stress was more prevalent in male parents (fathers) than females (mothers) (39%). In contrast the study conducted in Italy has reported that stress levels were significantly higher in mothers than in fathers and the prevalence of stress among male in this study were less (stress: 81.8% mothers versus 60.6% father (72). the prevalence of stress in father The reasons for the variation might be the difference in culture.

In this study Parents from rural the rural area were 3.057 times more likely to suffer from depression compared to parents living in the urban areas (AOR = 3.057, 95% CI: 1.064 - 8.787) for depression. In contrast, the study conducted in Poland has revealed that compared to parents in rural regions, parents in cities had a higher likelihood of experiencing depression (OR = 2.81, 95% CI:1.13-7.01 for depression) (57). The possible reason for this variation might be due to differences in access for child's medical treatment, culture and life style between Ethiopia and Poland whereas in Ethiopia. Parents of children with CHD from rural area had indirect costs like long distance travel contributed to this challenge(73).

The study has indicated that 43.3% of parents had lack of sleep causing a significant depression which is higher than the study conducted in Nepal that 28.4% reported that occasionally they

experienced sleep disturbances (18). This variation might be due to better resilience coping ability of parents in Nepal. In this study, it was found that, 34.2 % of parents who were worried about severity of their child's CHD had significant depression. However it is higher in the present study, this result were supported by a study in Norway that 29% of the mothers whose children had severe CHD had clinically significant depression (74). The possible reason for this difference might be due to better treatment of congenital heart disease in Norway.

The present study has revealed that 45% of parents had lack of finance for child's medical treatment which is similar with the study conducted in Nepal that 44.2% of the mothers reported that they were always financially strapped while caring for their child (18) and in Pakistan, about 40% of families who covered their children's medical bills without government assistance borrowed money from friends and family, 50% of the families either lost their jobs or businesses or took unpaid leave, and a tiny percentage of the families had to sell their property to cover the costs (59) . Over 10% of the family income in Nigeria was spent on treating a kid with CHD, according to one-third of the families surveyed (60).

The study finding has found that 36.9% of parents had poor social support which is supported by the study conducted in Netherland that approximately 40% of parents of children with congenital heart disease report a need for psycho-social care (74). The present study has revealed that anxiety in 38.8% parents of children with congenital heart disease was associated with continuity of child's medical treatment. This may be because continuity of the treatment demands an increased finance and time to spend with the child causing parents to lose their job. Parents who have a kid with significant health care requirements might have to work fewer hours per week or leave work to attend doctor appointments (58).

In this study it is found that 40.1% of PCCHD whose child did not undergo cardiac surgery had anxiety. In contrast to this, a study in Australia has reported that 38.5% of parents of children undergoing surgery for a CHD had a higher rate of emotional distress (53). The possible reason for this difference might be due to being uncertain about the child's futurity and fear of child's deterioration due to the delay for the child's heart surgery in Ethiopia and parents whose child undergone heart surgery in Australia may be too much frustrate about the outcomes of heart surgery and pains the child feels during the surgery.

7. Conclusion

The study had revealed significant rates of depression, anxiety and stress among parents of children with congenital heart disease at SPHMMC, TASH and Cardiac center Ethiopia. Prevalence of depression was associated with parent's rural residence, lack of sleep and severity of child's congenital heart disease. Anxiety was prevalent in parents who had not heard about CHD before their child was diagnosed, parents who had challenges with continuity of the child's medical follow up and parents who had lack of finance. Stress was more common in male parents (fathers) and parents who had received poor social support. In order to lower the risk of depression, anxiety and stress as well as to lessen the burden of disease, preventive measures such as early intervention and mental health screening, psych-social support financial support should be implemented. This can be achieved by involving mental health professionals and community organizations.

8. Strength and limitations of the study

Strength of the study

The study is new and often lies in its ability to explore and uncover new insights or perspectives that have not been previously investigated. The finding could offer the way for further researches and practical approaches in the field.

Limitations of the study

In conducting this study using a cross sectional design, it is important to acknowledge inherent limitations, that due to the simultaneous assessment of both exposure and outcomes at a single point in time, causal relationship cannot be established. This restricts to infer whether the observed associations truly indicate cause and effect relationship. Thus, it is not possible to identify whether depression, anxiety, and stress influenced the associated factors or vice versa.

9. Recommendations

To reduce the burden of illness and the likelihood of experiencing stress, anxiety, and depression among parents of children with congenital heart disease (CHD) stakeholders can play a significant role by implementing the following suggestions.

Health professionals: should make sure parents have access to thorough education and information regarding congenital heart disease (CHD), its treatment, and the support services that are available. This can reduce ambiguity and provide parents the power to decide on their child's care with knowledge.

Non-governmental organizations (NGOs): should endeavor to guarantee parents' access to financial and social services; aid parents in resolving financial difficulties by putting them in touch with resources like financial counseling, support groups, or benefits they could qualify for. Taking care of financial stressors can alleviate overall burden in parents.

Government; should advocate for policies that support families affected by CHD, including health care service, insurance coverage, and educational accommodations and should engage with policy makers to prioritize the needs of these families.

Parents: seek information from reputable resources and health care professionals to stay informed about the child's condition and prognosis. Understand the medical aspects of CHD that can reduce uncertainty and anxiety. And should engage with family member, friends, or religious /spiritual communities who can provide assistance.

Future researchers: should investigate further to find out unaddressed challenges of parents of children with CHD in this study are.

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11. Annexes

Annexes-I Informed consent.

Participants Information Sheet and Informed Voluntary Consent Form for Participants Selected for the Study.

My name is _____ I am working as a data collector for the study being conducted on Depression, anxiety, stress and their associated factors among parents of children with congenital heart disease; I kindly request you to lend me your attention to explain you about the study.

- **Study title-:** Depression, anxiety and stress among parents of children with congenital heart disease at cardiac follow up clinic, SPHMMMC, TASH and Cardiac Center Ethiopia, Addis Ababa, Ethiopia.
- **Purpose:** The study will help to assess prevalence and severity of depression, anxiety, stress and their associated factors among parents of children with Congenital Heart disease.
- **Procedure and duration:** There are a total 47 questions to be answered where I fill the questioner by interviewing you. The interview will take around 30 minutes.
- **Risks and Benefits:** The risk of being participating in this study is very minimal, except taking some minutes, for the interview, there is no other risk that you will face. By participating in this study you will not get direct benefit but the outcome of this study will be useful tool for decision making.
- **Confidentiality:** The information, which you provide us, will be confidential. There will be no information that will identify you. Finding of study will be general for the study population and will not reflect any thing particular of individual person. The questionnaire will be coded to exclude showing names; no references will be made in oral or written reports that could link participants to the research.
- **Right:** Participation in this study is voluntary. You have the right to declare not to participate in this study.
- **Contact address:** If you have any questions or inquiries about the study or the procedures, please contact and communicate with Principal investigator at any time With this address: - MenberYilma +251929018438, menberylma6@gmail.com

Declaration of informed voluntary consent:

I have clearly understood the purpose of the research, the procedure, risks and benefits, issues of confidentiality rights of participating and contact address for any queries. I have given the opportunity to ask questions for things that may have been unclear. I am informed on that I have the right to withdraw from the study at any time; Therefore, I declamy voluntary consent to participate in this study with my signature.

Name and signature of the participants: -----date-----/-----/-----

Name and signature of data collector: -----date-----/-----/-----

Annexes- II. English version questioners.

1. Parents' socio-demographical data

Please circle the one that you belong to:

Table 11: Sociodemographic data questioners of parents of children with CHD

S.N	Variables	Answers
101	Sex	1. Male 2. Female
102	Age	_____
103	Marital status	1. Single 3. Married 2. Widowed 4. Divorce
104	Religion	1. Orthodox 4. Muslim 2. Catholic 5. Protestant 3. Other
105	Educational status	1. No formal education 5. Primary (1-8) 2. Secondary (9-10) 6. Preparatory (11- 3. College diploma 7. university degree 4. Masters degree 8. PhD. degree
106	Place of residency	1. Urban 2. Rural
107	Occupation	1. Employed 2. Unemployed

2. Childs' biographical data

Table 12: Child's demographic data questioner

S.N	Variables	Answers
201	The Child's Sex	1. Male 2. Female
202	The child's Age	_____

405. Do you know the medications of your child?

1. Yes

2. No

406. Do you have challenges of caring for your child?

1. Yes

2. No

407. If your answer is YES for question 406, what are the challenges you have been facing while you are caring for your child? More than one answer is possible

1. Lack of sleep
2. Difficulty of parenting my families
3. Lack of finance for child's medical treatment
4. Continuity of the child's medical treatment
5. Specify if there is another _____

408. What worries you about your child medical follow up? More than one answer is possible

1. The child's heart surgery
2. Waiting too long for the child's heart surgery
3. The costs of child's heart surgery
4. Hospital admission of the child
5. Severity of the child's CHD
6. Specify if there is another. _____

4. Depression, Anxiety and stress scale (DASS-21)

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you **over the past week**. There is no right or wrong answer. Do not spend too much time on any statement. The rating scale is as follows:

0= did not apply to me at all- Never

1= Applied to me to some degree, or some of the time -Sometimes

2= Applied to me to a considerable degree or a good part of time- Often

3= Applied to me very much or most of the time – almost always

Table 14: DASS 21 questioners

SN.	Questions	Never	Sometimes	Often	Always
501 (S)	I found it hard to wind down	0	1	2	3
502 (S)	I felt that I was using a lot of nervous energy	0	1	2	3
503 (S)	I found myself getting agitated	0	1	2	3
504 (S)	I found it difficult to relax	0	1	2	3
505 (S)	I was intolerant of any thing that kept me from getting on with what I was doing	0	1	2	3
506 (S)	I felt that I was rather touchy	0	1	2	3
507 (S)	I tended to over-react to situations	0	1	2	3
508 (A)	I was aware of dryness of my mouth	0	1	2	3
509 (A)	I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
510 (A)	I experienced trembling (e.g.in the hands)	0	1	2	3
511 (A)	I was worried about situations in which I might panic and make a fool of my self	0	1	2	3
512 (A)	I felt I was close to panic	0	1	2	3
513 (A)	I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	0	1	2	3
514 (A)	I felt scared without any good reason	0	1	2	3
515 (D)	I couldn't seem to experience any positive feeling at all	0	1	2	3
516 (D)	I found it difficult to work up the in initiative to do things	0	1	2	3
517 (D)	I felt that I had nothing to look forward to	0	1	2	3
518 (D)	I felt down-hearted and blue	0	1	2	3
519 (D)	I was unable to become enthusiastic about any thing	0	1	2	3
520 (D)	I felt I wasn't worth much as a person	0	1	2	3
521 (D)	I felt that life was meaningless	0	1	2	3

5. Oslo Social Support Scale OSSS-3)

601. How many people are so close to you that you can count on them if you have great personal problems?

1 None	2 1-2 people	3 3-5 people	4 5+ people
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602. How much interest and concern do people show in what you do?

1 None	2 Little	3 Uncertain	4 Some	5 A lot
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603. How easy is it to get practical help from neighbors if you should need it?

1 Very difficult	2 Difficult	3 Possible	4 Easy	5 Very easy
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Anexses III. Amharic Version questioners

ለጥናቱ ለተመረጡ ተሳታፊዎች የተሳተፉት መረጃ እና በመረጃ የተደገፈ የፈቃደኝነት ስምምነት ቅጽ።

ስሜ _____ ይባላል። በተፈጥሮ የልብ ችግር ያለባቸው ህፃናት ወላጆችን ሊያጋጥም ስለሚችል ድብርት፣ ጭንቀት፣ ውጥረት እና አባባሽ ሁኔታዎች ላይ ለሚደረገው ጥናት መረጃ ሰብሳቢ ሆኜ እየሰራሁ እገኛለሁ። ስለጥናቱ ማብራሪያ እንድሰጥዎት ትኩረት እንዲሰጡኝ በትህትና እጠይቃለሁ።

የጥናቱ ርዕስ፡- በቅ/ጳ/ሆ/ሚ/ሜ/ኮ፣ ጥቁር አንበሳ እስቴሽናል ዘዴ ሆስፒታል እና የህፃናት ልብ ህክምና ማዕከል ኢትዮጵያ አዲስአበባ፣ ኢትዮጵያ ተመላላሽ የልብ ህክምና እያደረጉ በሚገኙ በተፈጥሮ ከልብ ችግር ጋር የተወለዱ ህፃናት ወላጆች ላይ ሊያጋጥም ስለሚችል ድብርት፣ ጭንቀት እና ውጥረት እንዲሁም መንስኤዎቻቸው።

ዓላማው፡- ጥናቱ በተፈጥሮ የልብ ችግር ባለባቸው ልጆች ወላጆች መካከል ያለውን የአእምሮ ጤና ችግር (ድብርት፣ ጭንቀት እና ውጥረት) ለመገምገም እና ምክኒያቶቹንም ለይቶ ለማውጣት ይረዳል።

የአሰራር ሂደቱ እና የቆይታ ጊዜ፡- እርስዎን የምጠይቀዎት በአጠቃላይ 47 ጥያቄዎች ናቸው። ቃለመጠይቁ 30 ደቂቃ አካባቢ ይወስዳል

ስጋቶች እና ጥቅሞች፡ በዚህ ጥናት ውስጥ በመሳተፍዎ ጥቂት ደቂቃዎችን ከመውሰድ በስተቀር የሚገጥምዎት ምንም ችግር የለም። በዚህ ጥናት ውስጥ በመሳተፍዎ ቀጥተኛ ጥቅም አያገኙም ነገር ግን የዚህ ጥናት ውጤት ለውሳኔ አሰጣጥ ጠቃሚ ግብዓት ሆኖ ያገለግላል።

ምስጢራዊነት፡- እርስዎ የሚሰጡን መረጃ ሚስጥራዊ ይሆናል። ማንነትዎን የሚገልፅ ነገር አይሰጡም። የጥናቱ ግኝት አጠቃላይ በጥናቱ ለተሳተፉት ይሆናል። እናም የግለሰብን የተለየ ነገር አያንፀባርቅም። መጠይቁ ስሞችን እንዳያሳይ ኮድ ይደረጋል ተሳታፊዎችን ከጥናቱ ጋር ሊያገናኙ የሚችሉ የቃል ወይም የጽሁፍ ዘገባዎች እና ማጣቀሻዎች አይደረጉም።

መብት፡- በዚህ ጥናት ውስጥ መሳተፍ በፈቃደኝነት ላይ የተመሰረተ ነው። በዚህ ጥናት ውስጥ ያለመሳተፍ ሙሉ መብት አለዎት።

የአጥኚው አድራሻ፡- ስለ ጥናቱ ወይም አሰራሮቹ ጥያቄዎች ካሉዎት፣ እባክዎን በማንኛውም ጊዜ ከዋናው አጥኚ ጋር በዚህ አድራሻ ይነጋግሩ፡

መንበር ይልማ +251929018438፣ menberyilma6@gmail.com

የጥናቱን አላማ፣ አሰራሩን፣ ስጋቱን እናጥቅሞቹን፣ የመሳተፍ መብቶች እና ሚስጥራዊ ጉዳዮችን በግልፅ ተረድቻለሁ። ግልጽ በልሆኑ ጉዳዮች ላይ ጥያቄዎችን ለመጠየቅ እድሉን ተሰጥቻለሁ። በማንኛውም ጊዜ ከጥናቱ የመውጣት መብት እንዳለኝ ተነግሮኛል; ስለዚህ በዚህ ጥናት ላይ ለመሳተፍ ፈቃደኛ መሆኔን በፈረማዬ አረጋግጣለሁ።

የመረጃ ሰብሳቢው ስም እና ፊርማ: _____ ቀን _____

- እባክዎ ከዝርዝሩ ውስጥ አንዱን ያክብቡ:-

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2. የህፃኑ / ኗ ሰዮግራፊያዊ መረጃ

S.N	ተለዋዋጮች	ተለዋዋጮች
201	ጾታ	1. ወንድ 2. ሴት
202	ዕድሜ	_____
203.	የትምህርት ደረጃ	1. መደበኛ ትምህርት የለም 2. የመጀመሪያ ደረጃ (1-8 ክፍል) 3. ሁለተኛ ደረጃ (9-10 ክፍል)

3. የልጁ የተፈጥሮ ልብ ችግር አይነቶች እና የተደረገላቸው የልብ ቀዶ ጥገናዎች ብዛት

S.N	ተለዋዋጮች	ተለዋዋጮች
301	የልጅ የተፈጥሮ የልብ ችግር ዓይነት	1. ASD 5. VSD 2. PDA 6. TOF 3. Aortic Coarctation 7. AVSD 4. ሌላካለ _____
302	የልጅ የተፈጥሮ የልብ ችግር ብዛት	1. አንድ 3. ሶስት 2. ሁለት 4. አራት
303	ልጅዎ የልብ ቀዶ ጥገና ተደርጎለታል/ላታል	1. አዎ 2. አይ
304	ለጥያቄ ቁጥር 3 መልስዎ አዎከሆነየልጅዎየልብቀዶጥገናስንትጊዜተደረገ።	1. 1 ጊዜ 2. 2 ጊዜ 3. ከ2 ጊዜበላይ

4. በተፈጥሮ ስለሚከሰት የህፃናት የልብ ችግር የወላጆች ግንዛቤ
401. ስለልጅዎ የተፈጥሮ የልብ ችግር ከመስማትዎ በፊት በተፈትሮ ስለሚከሰት የህፃናት ልብ ችግር በቁ ግንዛቤ ነበርዎት?
1. አዎ
2. ግንዛቤው አልነበረኝም
402. ልጅዎ የተፈጥሮ ልብ ችግር እንዳለበት የተረጋገጠ መቼ ነበረ?
1. ከመወለዱ/ዷ በፊት
2. ከተወለደ/ደች በኋላ
403. የተፈጥሮ ልብ ችግር በህክምና ሊስተካከል እንደሚችል ግንዛቤ አለዎት?
1. አዎ
2. የለኝም
404. ልጅዎ እያገኘ/ችባለው ህክምና የልጅዎ የልብ ህመም ወደመደበኛው ይመለሳል ብለው ያስባሉ?
1. አዎ
2. እርግጠኛ አይደለሁም
405. በተፈጥሮ የልብ ችግር የለበትን ልጅዎን እየተንከባከቡ ባሉበት ያጋጠሙዎ ፈተናዎች አሉዎት?
1. አዎ
2. የለም

405. ለጥያቄ 406 መልስዎ አዎ ከሆነ ልጅዎን በሚንከባከቡበት ወቅት ያጋጠሙዎት ፈተናዎች ምንምን ናቸው? ከአንድ በላይ መልስ መስጠት ይቻላል።

1. እንቅልፍ ማጣት
2. ሌሎች የቤተሰብ አባላትን ለመንከባከብ መቸገር
3. ለህፃኑ/ኗ ሕክምና በቂ ገንዘብ አለማግኘት
4. ከስራ ገበታ መቅረት
5. ሌላካ ለይግለጹ። _____

406. ስለልጅዎ የሕክምና ክትትል ምን ያስጨንቀዎታል? ከአንድ በላይ መልስ መስጠት ይቻላል።

1. የህፃኑ/ኗ የሕክምና ቀጣይነት
2. የህፃኑ/ኗ የልብ ቀዶ ጥገና
2. ለህፃኑ/ኗ የልብ ቀዶ ጥገና ለረጅም ጊዜ በመጠባበቅ ላይ መሆኑ
3. የህፃኑ/ኗ ልብ ቀዶ ጥገና ወጪዎች
5. የህፃኑ የህመም ሁኔታ መባባስ
6. ሌላ ካለ ይግለጹ _____

5. የአእምሮ ድብርት፣ ጭንቀት እና የውጥረት መለኪያ ጥያቄዎች (DASS-21)

ቀጥሎ የተሰጠው መግለጫ ባለፈው ሳምንት ለእርስዎ ምን ያህል እንደሚተገበር ያመለክታል። እባክዎን እያንዳንዱን መግለጫ ያንብቡ እና ቁጥር 0, 1, 2 ወይም 3ን ያክብቡ። ትክክለኛ ወይም የተሳሳተ መልስ የለም።

0= በፍፁም አላመለከተኝም፡ 1= በተወሰነ ደረጃ ወይም በተወሰነ ጊዜ ለእኔ አመልክቷል ፡ 2= በከፍተኛ ደረጃ አመልክቶኛል ፡ 3= በጣምብዙጊዜአመልክቶኛል።

ተቁ	ጥያቄዎች	በፍፁም	አልፎአልፎ	ብዙሃኑ	ሁሉንም
501 (S)	ከከባድ ድካም ወይም አሳሳቢ ሁኔታ በኋላ ቀስ በቀስ ዘና ለማለት ተችግሬ ነበር።	0	1	2	3
502 (S)	ብዙ የነርቭ ጉልበት እየተጠቀምኩ እንደሆነ ተሰምቶኛል	0	1	2	3
503 (S)	የመናደድ ስሜት ይንፀባረቅብኝ ነበር	0	1	2	3
504 (S)	ዘና ለማለት እችላለሁ ነበር	0	1	2	3
505 (S)	በምሰራው ስራ እንዳለከናውን የሚያስተዳጉለኝን ማንኛውንም ነገር አልታገስም ነበር	0	1	2	3
506 (S)	በቀላሉ ይከፋኝ ነበር	0	1	2	3
507 (S)	ለሁኔታዎች ከመጠን በላይ ምላሽ የመስጠት ዝንባሌ ነበረኝ	0	1	2	3
508 (A)	አፌ ሲደርቅ ይታወቀኝ ነበር	0	1	2	3
509 (A)	የመተንፈስ ችግር አጋጥሞኝ ነበር	0	1	2	3
510 (A)	መንቀጥቀጥ አጋጥሞ ነበር (ለምሳሌ እጄ አካባቢ)	0	1	2	3
511 (A)	የተሳሳተ ውሳኔ እንዳልወስን እናምክኒያታዊ ያለሆነ ድንገተኛ ድንጋጤ ይሰማኝ ይሆን እያልኩ የተጨነቅሁበት ሁኔታ ነበር።	0	1	2	3
512 (A)	የፍርሃት ስሜት ይሰማኝ ነበር	0	1	2	3
513 (A)	አካላዊ እንቅስቃሴ በሌለበት የልብምቴ መጨመር እና መቀነስ ይታወቀኝ ነበር	0	1	2	3
514(A)	ያለበቂ ምክኒያት ፍርሃት ተሰምቶኝ ነበር	0	1	2	3
515 (D)	ምንም ዓይነት አዎንታዊ ስሜት የሚሰማኝ አይመስለኝም ነበር።	0	1	2	3
516 (D)	ስራ ለመስራት የመነሳሳት ችግርገጥሞኝ ነበር	0	1	2	3
517 (D)	ምንም የምጠብቀው ነገር እንደሌለኝ ተሰምቶኝ ነበር	0	1	2	3
518 (D)	የልብ ድካም ስሜት ተሰምቶኝ ነበር	0	1	2	3
519(D)	ለማንኛውም ነገር ፍላጎት (ጉጉት) የለኝም ነበር	0	1	2	3
520 (D)	እንደሰው ብዙም ዋጋ እንደሌለኝ ተሰምቶኝ ነበር	0	1	2	3
521 (D)	ሕይወት ትርጉም የለኝ እንደሆነ ይሰማኝ ነበር	0	1	2	3

6 የኦስሎ ሶሻል ሰፖርት መለኪያ (OSSS-3)

601.ትልቅ የግል ችግር ቢገጥምዎት መፍትሔ የሚሰጡ በጣም በቅርበት የሚተማመኑባቸው ሰዎች ምን ያህል ናቸው?

1. ምንም 2. ከ1-2ሰዎች 3. ከ3-5ሰዎች 4. ከ5 ሰዎች በላይ

602. እርስዎ በሚያደርጉት ነገር ሰዎች ምን ያህል ፍላጎት እና አሳቢነት ያሳያሉ?

1. ምንም 2. ትንሽ (ዝቅ ያለ) 3. እርግጠኛ አይደለሁም 4. የተወሰነ 5 ብዙ

603. እርስዎ ከጎረቤቶቻችዎ እርዳታ ቢፈልጉ ጎረቤቶቻችዎን ምን ያህል ቀሎዎት ለመጠየቅ ይሞክራሉ?

1. በጣም ከባድ 2. ከባድ 3. ይቻላል 4. ቀላል 5. በጣም ቀላል

12. Declaration

I declared that this research thesis entitled depression, anxiety, stress and associated factors among parents of children with congenital heart disease is my own work that haven't been addressed in the study area as far as my knowledge touched and all the resources I used has been indicated and acknowledged as complete reference.

Name of investigator

Signature

Date

1. _____

Name of Advisors

1. _____

2. _____