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Living with Little Hearts: Maternal Illness Perception and Family Dynamics in Childhood Congenital Heart Disease

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ABSTRACT

Introduction:

Congenital heart disease (CHD) is among the most common chronic pediatric conditions and places substantial emotional, social, and financial burdens on families, particularly mothers who are often the primary caregivers. Caring for a child with CHD can influence maternal perceptions of illness, disrupt family routines, and affect overall family functioning.

Objectives:

To explore the illness perceptions and family dynamics of mothers caring for children with congenital heart disease in a selected tertiary care hospital and to identify areas where healthcare professionals can provide improved support.

Materials and Methods:

The study employed a mixed-method exploratory sequential design. During the qualitative phase, six mothers were selected using purposive sampling and participated in in-depth interviews. In the quantitative phase, 60 mothers were recruited through convenience sampling. Data were collected using a socio-demographic and clinical profile sheet, a semi-structured interview schedule, and the McMaster Family Functioning Scale.

Results:

Qualitative analysis revealed four major themes: understanding of illness, effects on family and everyday life, coping approaches, and sources of support. Mothers commonly reported anxiety, uncertainty about

their child's future, and disturbances in daily activities and social interactions. Many relied on spiritual beliefs, family encouragement, and peer support to manage stress. Quantitative findings showed that the majority of participants were between 21 and 30 years of age (63.33%), homemakers (66.67%), and had completed secondary education (45%). The mean family functioning score was 26.45 ± 2.95, and 76.67% of mothers demonstrated good family functioning. Significant associations were identified between family functioning and variables such as maternal age, educational status, type of family, and the child's level of physical activity.

Conclusion:
Despite experiencing considerable emotional and social challenges, mothers of children with CHD exhibited resilience and positive coping abilities. Enhancing family-centered care and psychosocial support services may improve maternal wellbeing and strengthen family adaptation.

Keywords: Congenital heart disease, illness perception, family functioning, mothers, coping strategies.

1. INTRODUCTION

Congenital heart disease (CHD) refers to structural or functional defects of the heart that are present at birth. It is one of the most common congenital disorders and a major contributor to infant morbidity and mortality worldwide. Although medical and surgical advancements have improved survival rates, families continue to face emotional, psychological, and financial burdens related to long-term treatment. Mothers, who are usually the primary caregivers, often experience significant stress after their child's diagnosis.

Illness perception describes how individuals understand and interpret a disease, including its severity, duration, causes, and controllability. Among mothers of children with CHD, these perceptions influence emotional responses, caregiving practices, and healthcare decisions. Negative perceptions may increase anxiety and helplessness, whereas positive understanding can improve coping and treatment adherence.

Family dynamics refer to communication patterns, emotional support, and role relationships within the family. The presence of CHD may disrupt normal family functioning and place additional responsibilities on mothers, leading to stress, marital conflicts, and emotional strain. Supportive family relationships can strengthen resilience and improve caregiving quality.

Despite progress in CHD treatment, the psychosocial needs of mothers and families often remain overlooked. Therefore, understanding illness perception and family dynamics is important for developing family-centred interventions that enhance coping, emotional well-being, and overall quality of life.

3. BACKGROUND OF THE STUDY

Global Level

Congenital heart disease (CHD) is one of the leading congenital abnormalities worldwide, affecting nearly 9 out of every 1,000 live births. According to the World Health Organization (2024), approximately 1.35 million infants are born with CHD each year. Advances in diagnostic and treatment approaches have increased survival rates; however, the emotional and psychological burden experienced by caregivers, especially mothers, continues to receive limited attention, particularly in developing nations.

India Level

India accounts for a considerable proportion of the global CHD burden, with an estimated 200,000 children born with the condition annually. Reports from the Indian Paediatric Cardiac Society (2023) indicate that only a small percentage of affected children receive timely intervention and treatment. Factors such as delayed diagnosis, financial difficulties, limited specialised services, and inadequate psychosocial support increase the caregiving responsibilities of mothers.

Tamil Nadu Level

Tamil Nadu has made notable progress in improving access to paediatric cardiac services through initiatives such as the Chief Minister's Comprehensive Health Insurance Scheme (2023). Despite these efforts, nearly 12,000–15,000 children are estimated to be born with CHD every year in the state. Challenges related to awareness, early detection, and family-focused psychological support still persist.

Chennai Level

Chennai is recognised for its specialised tertiary healthcare institutions, including the Institute of Child Health and Hospital for Children, Apollo Children's Hospital, and Government General Hospital, which provide advanced treatment for children with CHD. Although medical outcomes have improved, many mothers continue to experience emotional stress and psychological challenges while caring for their children, emphasising the importance of structured psychosocial and family-centred support systems.

NEED FOR THE STUDY

The management of congenital heart disease (CHD) primarily emphasizes clinical care, often overlooking the psychological well-being of mothers who are the main caregivers. Maternal illness perception and emotional resilience significantly influence caregiving quality, treatment adherence, and child outcomes.

CHD also disrupts family dynamics, causing stress, role strain, and relationship changes, which may affect maternal mental health and caregiving effectiveness. Prolonged caregiving without support can lead to anxiety, depression, and burnout.

In India, especially in Tamil Nadu and Chennai, limited research exists on these psychosocial aspects, despite the influence of cultural and socioeconomic factors.

Hence, this study is needed to explore illness perception and family dynamics among mothers of children with CHD and to support the development of family-centred interventions for improved outcomes.

STATEMENT OF THE PROBLEM

A study to assess illness perception and family dynamics among mothers of children with congenital heart disease at selected tertiary care hospitals.

OBJECTIVES

Primary Objectives:

- To explore illness perception among mothers of children with congenital heart disease.To assess family dynamics among mothers of children with congenital heart disease.

Secondary Objective:

- To determine the association between family dynamics and selected demographic and clinical variables.

RESEARCH QUESTION

What are the perceptions of mothers regarding their child's congenital heart disease, and how do these perceptions influence their emotional well-being and family dynamics.

ASSUMPTIONS

- Mothers have varied perceptions of their child's illness. Illness perception is influenced by awareness, education, and experience. Family dynamics are affected by the child's illness.

HYPOTHESIS

- **H_1:** There is a significant association between family dynamics and selected demographic and clinical variables.
- **H_0:** There is no significant association between family dynamics and selected demographic and clinical variables.

DELIMITATIONS

- 1.Limited to mothers of children with congenital heart disease.2.Conducted over a one-week period. 3.Restricted to Institute of Child Health and Hospital for Children.

RESEARCH METHODOLOGY:

The present study will adopt a mixed-method approach using an exploratory sequential research design, consisting of qualitative and quantitative phases. The qualitative phase will use a phenomenological design to explore the lived experiences of mothers of children with congenital heart disease, while the quantitative phase will employ a descriptive research design to assess illness perception and family dynamics. The study will be conducted at the Cardiology OPD of Institute of Child Health for a period of one week among mothers of children with congenital heart disease attending the OPD. The qualitative sample will include 6–8 mothers selected through non-probability purposive sampling, whereas the quantitative sample will consist of 60 mothers selected using non-probability convenience sampling.

3.9. CRITERIA FOR SAMPLE SELECTION:

3.9.1. Inclusion criteria:

1.Children aged 2-12 years with CHD .2.Mothers of children with congenital heart disease. 3.Willing to participate in this study .4.Able to read/ write and understand Tamil/ English .5.Mothers willing to share their experience.

3.9.2. Exclusion Criteria:

- Mothers with any cognitive impairment.
- Mothers who are critically ill .
- Mothers who are participating in any other research studies.

3.10. VARIABLES

3.10.1. Study variables: Illness perception and Family dynamics level of Mothers of children with congenital heart disease

3.10.2. Demographic variables:

Demographic variables included the mother's age, education, occupation, marital status, type of family, number of children, and monthly family income. Child-related details such as age, gender, and birth order were also recorded**.**

The clinical variables included the child's age at diagnosis of congenital heart disease, history of surgery, frequency of medical follow-ups, history of hospitalizations due to CHD-related issues, and the level of physical activity permitted.

DEVELOPMENT AND DESCRIPTION OF TOOL

Section – A: 1.Socio-demographic variables .2.Clinical variables

Section – B: Semi-structured interview. : A qualitative study assessing Illness Perception among mothers of children with CHD is undertaken.

Section –C: The McMaster Family Functioning Scale (MFFS) was developed by G.W. Epstein and colleagues in 1983 to assess family dynamics. It includes 12 items focused on family functioning in areas such as communication, problem-solving, decision-making, and emotional support.

VALIDITY OF THE TOOL:

The validity of the tool was assessed using content validity. Experts from Nursing and Pediatrician determined content validity. Dr.Abigali k.Mansfield-marcaccio was developed this tool and given permission to use the McMaster Family Functioning scale in my research.

RELIABILITY OF THE TOOL:

The reliability of the tool was assessed by using the Cronbach alpha method. These correlation coefficients were 0.86 very high and it is a good tool for assessing Mothers of children with congenital heart disease disorders.

ETHICAL CONSIDERATION

Vide No **IEC -MMC/APPROVAL/36042025 dated on 20/4/25.**The study was carried out after obtaining ethical clearance from the

ethical committee and the Director of the Institute of Child Health and Hospital for Children.

RESULTS:

SECTION: 1 Explore the illness perception among mothers of children with congenital heart disease.

FIG. 1. PROCESS OF THEMATIC ANALYSIS

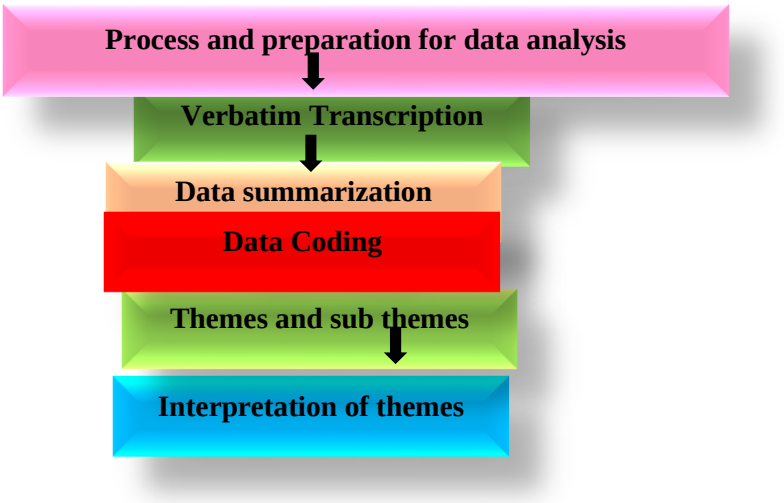


TABLE:1 THEMES, SUBTHEMES,NARRATIONS

Theme	Subtheme	Narrations
Theme 1: Illness Perception of Mothers	**1.1 Understanding of the Diagnosis**	"Doctors told me that my child has a heart problem. They also said there is a hole in the heart." – Interview 1"When I first saw my daughter, she had difficulty breathing... she told me there was a hole in her heart." – Interview 5
	1.2 Emotional Responses to the Diagnosis	"I am very scared about my child's future. I am afraid for my child." – Interview 1"I feel scared. I don't know what her future will be like." – Interview 5"I was scared. I didn't know how to save the baby." – Interview 3
	1.3 Perceived Prognosis and Uncertainty	"I'm really confused about whether he'll get better or not." – Interview 4"I feel scared and anxious. I will be happy if she recovers soon." – Interview 6
Theme 2: Impact on Daily and Family Life	**2.1 Disruption of Routine and Employment**	"Before this, I used to go to work. Now I cannot go to work." – Interview 2"I used to go for 100-days employment. Now, I can't go to work properly." – Interview 4"I'm unable to go to work regularly. They're asking me to stop going to work." – Interview 6
	2.2 Social Interaction and Strain	"My family members do not understand this illness." – Interview 1"I don't know how to talk to my friends. I don't know what to say to my relatives." – Interview 3
Theme 3: Adaptive Coping Strategies	**3.1 Religious Faith and Spirituality**	"I believe in God. Every day, I pray to God to help me take care of my child." – Interview 1"I pray to God every day." – Interview 5"I tell everything to God, madam. I have no one but God." – Interview 6
	3.2 Practical Lifestyle Changes	"I give her healthy food at the right time. I also give her the medicines." – Interview 2"I've changed the way I feed my child." – Interview 6

Theme 4: Support Systems and Social Networks	**4.1 Support from Family and Neighbors**	"I have received a lot of support from my neighbors." – Interview 1"With the support of my family, I believe my child will be healthy." – Interview 2"My family supports me. That's why I feel a bit at peace." – Interview 5
	4.2 Peer Support from Other Mothers	"There are many people like me here. I talk to them. I feel very peaceful." – Interview 4

QUANTITATIVE DATA ANALYSIS AND INTERPRETATION

SECTION-II

Frequency and percentage distribution of demographic and clinical variables among Mothers of children with congenital heart disease

MAJOR FINDINGS OF THE DEMOGRAPHIC VARIABLES

- Age of Mothers: Majority were aged 21–30 years (63.33%), followed by 31–40 years (36.67%). No mothers below 20 or above 40 years.
- Education Level: Most had secondary school education (45%), followed by primary school (26.66%), graduates (21.67%), and informal education (6.67%).
- Occupation: Majority were homemakers (66.67%), 21.66% were self-employed, 11.67% were privately employed; none worked in government jobs.
- Marital Status: Most were married (95%); small percentages were widowed, divorced, or separated (1.67% each).
- Type of Family: Equal distribution between nuclear (50%) and joint families (50%); no single-parent or adoptive families.
- Number of Children: Slightly more families had one child (51.67%) compared to two children (48.33%); none had three or more children.
- Age of Child: Majority were aged 2–4 years (60%), followed by 5–7 years (33.33%) and 8–10 years (6.67%); none aged 11–12 years.
- Gender of Child: Slightly more male children (55%) than female (45%).
- Birth Order: Most were first-born children (83.33%), followed by second-born (16.67%); no third or higher birth order.
- Family Income: All families earned less than ₹54,650 per month (100%).

MAJOR FINDINGS OF THE CLINICAL VARIABLES

- Age at Diagnosis of CHD: Vast majority were diagnosed between 0–6 months (81.67%), followed by 7–12 months (15%) and 1–5 years (3.33%); none diagnosed above 5 years.
- Surgery Status: Most children had not undergone surgery (85%); 8.34% had a single surgery, 3.33% had multiple surgeries, and 3.33% did not require surgery.
- Frequency of Medical Follow-ups: Majority attended monthly follow-ups (85%), 8.33% as needed, and 6.67% weekly; none had annual follow-ups.
- Hospitalization History: Most had been hospitalized once for CHD-related issues (86.67%), 10% twice, and 3.33% not yet hospitalized; none had multiple frequent hospitalizations.Level of

Physical Activity Allowed: Majority engaged in moderate physical activity (68.33%), 26.67% had mild activity, and 5% normal activity; none were restricted from physical activity.

SECTION III

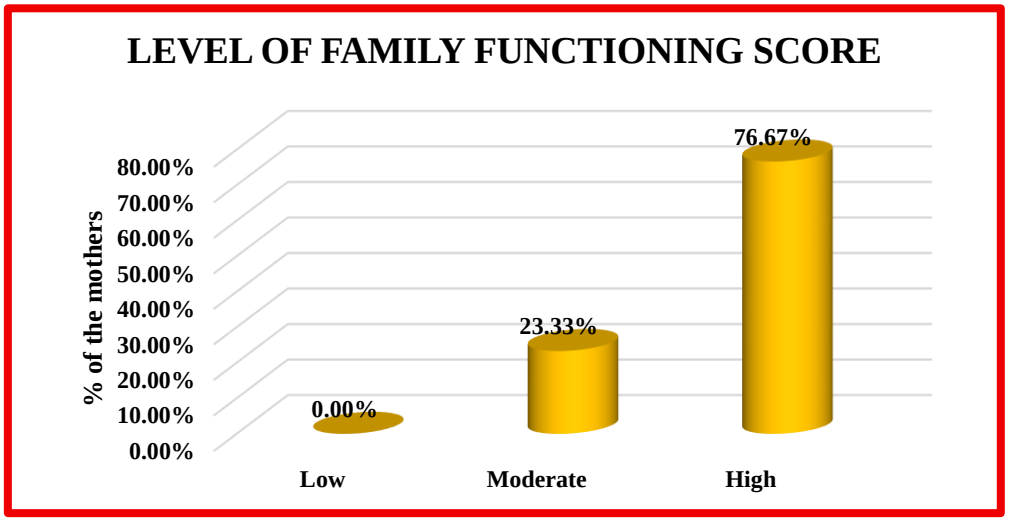
Assess the level of Family dynamics among mothers of children with congenital heart disease.

TABLE II ; EACH STATEMENTWISE PEERCENTAGE OF FAMILY FUNCTION SCORE

S. NO	STATEMENTS	SELF-EFFICACY SCORE			
		MAXIMUM SCORE	MEAN SCORE	SD	% OF MEAN SCORE
1	Planning family activities is difficult because we misunderstand each other.	4	1.88	.96	47.00%
2	In times of crisis, we can turn to each other for support.	4	2.15	.82	53.75%
3	We cannot talk to each other about the sadness we feel	4	2.68	.68	67.00%
4	Individuals are accepted for what they are.	4	2.28	.96	57.00%
5	We avoid discussing our fears and concerns	4	2.20	.82	55.00%
6	We can express feelings to each other.	4	1.82	.72	45.50%
7	There are lots of bad feelings in the family.	4	2.30	.67	57.50%
8	We feel accepted for what we are.	4	2.37	.90	59.25%
9	Making decisions is a problem in our family	4	1.97	.84	49.25%
10	We are able to make decisions about how to solve problems	4	2.25	.86	56.25%
11	We do not get along well with each other.	4	2.22	.72	55.50%
12	We confide in each other	4	2.38	.64	59.50%
	Total	48	26.47	2.95	55.15%

Mothers had more percentage of score for the statement “We cannot talk to each other about the sadness we feel 67.00%” and they had less percentage of score for the statement “We can express feelings to each

other.45.50%". Over all percentage of family function score is 55.15%.The below table shows that in general, none of them had low level of score, 23.33% of them had moderate level of score, and 76.67% of them had high level of score.



LEVEL OF FAMILY FUNCTIONING SCORE

INTEGRATION OF BOTH QUALITATIVE AND QUANTITATIVE FINDINGS

The integrated findings from the study highlight both the statistical trends and lived experiences of mothers caring for children with CHD. Qualitatively, mothers revealed emotional distress, uncertainty, and disruption of daily life, relying on religious faith, practical care adjustments, and support from family, neighbors, and peers to cope. Quantitatively, most mothers were aged 21–30 years, had secondary education, and were homemakers in either nuclear or joint families, with children predominantly first-born, aged 2–4 years, and diagnosed before six months. Family functioning scores were generally high, influenced by maternal and child characteristics. Together, these findings suggest that strong social and familial networks, combined with adaptive coping, contribute to maintaining high family functioning despite significant emotional and practical challenges.

DISCUSSION

This study explored illness perception and family dynamics among mothers of children with congenital heart disease (CHD) using both qualitative and quantitative approaches.

Demographic and Clinical Profile

The majority of mothers were aged 21–30 years, with secondary-level education, and were predominantly homemakers. Most were married and equally distributed between nuclear and joint families. Children were mainly first-born, aged 2–4 years, and diagnosed with CHD within the first six months of life. Monthly follow-ups were common, and most children were permitted moderate physical activity. These findings reflect early diagnosis patterns and consistent healthcare engagement among families.

Illness Perception and Lived Experiences

Qualitative findings revealed that mothers had limited understanding of CHD, accompanied by fear, uncertainty, and emotional distress. The condition significantly disrupted daily routines, employment, and

social interactions. Mothers primarily relied on religious faith, practical adjustments, and emotional support from family, neighbours, and peers to cope with caregiving challenges. These findings are consistent with **Navangi and de Silva** (2024), emphasizing the need for improved communication and psychosocial support.

Family Dynamics

The mean family functioning score was 26.45 ± 2.95, with most mothers demonstrating high levels of family functioning. However, challenges in emotional communication were evident. These findings align with **Xia et al.** (2025), which highlighted the influence of family management styles on child outcomes and emphasized strengthening collaborative family environments.

Association with Demographic and Clinical Variables

Higher family functioning was significantly associated with older maternal age, higher education, joint family systems, and children with normal or mild physical activity levels. Similar observations were reported by **Mireia Salvador et al.** (2021), indicating that family dynamics are influenced by both psychosocial and clinical factors.

Integration of Findings

The integration of qualitative and quantitative findings highlights that, despite emotional distress and lifestyle disruptions, mothers maintain high family functioning through adaptive coping strategies and strong social support systems. These findings are consistent with **Murni et al.** (2021), which identified the impact of social and systemic factors on CHD care and outcomes.

LIMITATIONS

1. Small sample limits generalizability.
2. Cross-sectional design can't show causality.
3. Non-random sampling may cause bias.
4. Self-reports risk social desirability bias.

CONCLUSION

This study concludes that mothers of children with CHD face significant emotional distress, uncertainty, and lifestyle disruptions, yet maintain high family functioning through adaptive coping, strong social networks, and familial support. Findings highlight the crucial role of education, communication, and culturally sensitive interventions in strengthening resilience and ensuring holistic family-centered care in pediatric cardiac contexts.

REFERENCES;

1. Marlow DR, Redding BA. Textbook of Pediatric Nursing. 6th ed. Philadelphia: Saunders; 2006.
2. Wong DL, Hockenberry MJ, Wilson D, Winkelstein ML, Schwartz P. Wong's Essentials of Pediatric Nursing. 9th ed. St. Louis: Mosby; 2013.
3. Ball JW, Bindler RC, Cowen KJ. Principles of Pediatric Nursing: Caring for Children. 6th ed. Boston: Pearson; 2013.
4. Kyle T, Carman S. Essentials of Pediatric Nursing. 3rd ed. Philadelphia: Wolters Kluwer; 2017.

5. Whaley LF, Wong DL. Nursing Care of Infants and Children. 5th ed. St. Louis: Mosby; 2000.
6. Hockenberry MJ, Wilson D. Wong's Nursing Care of Infants and Children. 11th ed. St. Louis: Mosby; 2018.
7. Macqueen S, Bruce EA, Gibson F. The Great Ormond Street Hospital Manual of Children's Nursing Practices. 2nd ed. Oxford: Wiley-Blackwell; 2012.
8. Hale TW. Medications and Mothers' Milk. 17th ed. New York: Springer; 2017.
9. Glasper EA, Richardson J, Randall D. A Textbook of Children's and Young People's Nursing. 3rd ed. Edinburgh: Elsevier; 2015.
10. Bowden VR, Greenberg CS. Children and Their Families: The Continuum of Care. 2nd ed. Philadelphia: Wolters Kluwer; 2016 .