This article can be cited as: Tavangar H, Vaezi A A, Sherafat A, et al. Mothers' health problems of children with congenital heart disease: a qualitative method. Cardiovasc Biomed J.2023;3(1):42-50.

Original Article

Mothers' health problems of children with congenital heart disease: a qualitative method

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Article Information:
Received: 14 Apr 2023; Revised: 07 Aug 2023; Accepted: 19 Aug 2023 DOI: 10.18502/cbj.v3i1.13469

Abstract

Objectives: This study was done to address the physical and mental health problems experienced by mothers of children with congenital heart disease (CHD).

Methods: This study was conducted by a qualitative approach in 2021 at Yazd Afshar Hospital, in which 10 mothers were selected by purposive sampling technique. A semi-structured interview was used to collect data, and data analysis was performed through conventional content analysis. Two university lecturers determined the validity of the interview questions, and the reliability of the data was verified by a researcher trained in coding.

Results: Data analysis identified the base theme i.e. the threat to health, and subthemes including physical and psychological problems of the parent(s). Components of subthemes consisted of physical manifestations, physical self-harm, anxiety and worry, mental self- harm, impatience and helplessness, isolation, withdrawal, and denial.

Conclusions: The results show that mothers suffer from a variety of experiences ranging from physical problems and illnesses to mental problems. An in-depth understanding of the phases of parenting under pressure provides direction for nurses to support parents of children with CHD. Interventions that help carers of children with complex health conditions move through the phases of our parenting under pressure process can help them maintain their children's survival and their survival as parents as they manage multiple needs. Therefore, the hospital should provide supportive procedures to better deal with the problem.

Keywords: Children, congenital heart disease (CHD), Mothers, Health Problems, Qualitative research

Introduction

Congenital heart disease (CHD) [1] is a term used for varying diseases that affect a child's heart at the early stage of birth. These disorders are problems that occur during pregnancy when the baby's heart is still forming. This happens because the structure of the heart is not formed properly. CHD is the second most common disease in the world (1). The disease is considered the leading cause of death in children during the first year of life, including a significant proportion of birth defects worldwide. The number of CHD cases is significantly higher in Asia and

Europe. It is 8.2 and 9.1 per 1000 births for Europe and Asia respectively (2).

Iran is one of the countries with the highest rate of CHD. Its prevalence in Iran is 12 per 1000 live births. CHD can be attributed to different causes. Some occur due to genetic diseases and disease symptoms projecting into all organs of the body. The exact cause of CHD is unknown in most cases. However, 10-20% of the defects are ascribed to genetic conditions (Down syndrome[2], trisomy [3], Turner syndrome[4], and Digeorge syndrome[5]) as well as environmental factors. CHD Symptoms can be different in different diseases. Some diseases are so severe and symptomatic that they disrupt fetal growth, and the affected baby is born with low birth weight and a cyanotic and bruised appearance. Some other babies who mainly have cyanotic heart diseases are healthy at first, but in one or two days after birth, with the closure of the ductus arteriosus, they start to change color and become weak and short of breath so that the symptoms began to appear (3). In chronic diseases, due to their duration and severity, the physical, mental, social, and economic aspects and the quality of life undergo many changes. On the other hand, children and families face many difficulties in the treatment process. Parents of these children who are concerned about their child's uncertain future, treatment plan, and prognosis should suffer from psychological problems (4). In this regard, it is known that having a child with CHD greatly affects the child's family, especially the mothers who face many challenges and are always obsessed with the idea of providing a better life for their children. Although factors other than genetics also influence the occurrence of the disease, most mothers feel guilty about giving birth to such children and also experience emotional problems (5). On the other hand, parents of children with CHD experience negative cognitive reactions such as guilt, fear, psychological and social problems, and other problems for their children. According to the researchers, psychological and social problems include mood and sleep disorders, distress, and problems coping with the disease (6).

Furthermore, because the mothers of these children need to spend more time with their sick children, the quality of their performance in social, professional, and family roles can be strongly influenced by this abnormality(7). Misunderstanding the problems related to the management of the disease is another issue for parents of children with CHD. In this regard, it is understood that having information about the disease, communication with specialists, knowledge of its causes and treatment, and participation in a support group are among the factors that help with treatment. Therefore, if mothers of children with CHD get the support of clinical specialists, they will show less anxiety (8).

The abnormalities mentioned above can positively or negatively impact a family's lifestyle and experiences, overshadowing the family's quality of life and health and how families deal with these problems. Although there have been studies of how families of children with CHD cope with it, research is still scanty on how these families can cope with the resulting stress. Moreover, the relatively high incidence of the disease in Iran can place a heavy economic burden on families, the health system as well as society. In addition, different cultural backgrounds, beliefs, religions, and support systems can together influence families' stress experiences and their ability to cope. Therefore, it is necessary to have a thorough and comprehensive understanding of these stressful situations, the means to deal with them, as well as the available solutions (9).

In general, quantitative studies can only be useful when people understand the phenomenon in question. Due to the lack of knowledge about how to monitor the disease in the family, as well as the lack of knowledge about the psychological, emotional, and behavioral responses of parents, especially mothers, it is more appropriate to use qualitative research(10).Based on several previous investigations, it was found that most of the qualitative studies have been conducted on mothers to discover the meaning of support from the mothers' point of view or on patients instead of their parents. Sometimes they have studied a particular stage of their life course, including childhood, adolescence, or adulthood. Qualitative studies have also been conducted in countries that are different from Iran in terms of economic, social, and religious status, health care systems, diagnostic and treatment facilities, and people's beliefs in abortion.Therefore, the lack of knowledge about parenting these children in Iran has increased the need for such studies (11). In addition, conducting research focusing on mothers' experiences with children with CHD provides insight into the condition of these mothers.

Materials and Methods

This study was done regarding the health

problems of mothers of children with CHD using conventional content analysis qualitative research method in 1400 at Yazd Afshar Hospital.Qualitative content analysis is an appropriate method for obtaining various results from textual data to generate new knowledge and ideas and to provide facts and practical guidance for practice. The participants were selected through a purposive sampling method. This method is suitable for qualitative research due to its depth and flexibility. In the purposive sampling method, the researcher usually looks for people who have high experience in the subject under investigation. Participants, all referrals at Yazd Afshar Hospital, were selected from mothers with sufficient experience in challenging CHD babies and the necessary expressive ability. Data collection was conducted by the semi-structured interview method.

A total of 10 interviews were conducted in this study, through which the interviewees were allowed to elaborate on the main issue within the scope of their knowledge and experience. As for the research questions, some items in the interview were considered the main questions. And due to the semi-structured nature of the interviews, other questions were also proposed based on the answers, to clarify the meaning of the responses provided. At the end of each interview session, the participants were asked to add additional points if there was anything untapped. On average, depending on the source of information, each interview session lasted 22 minutes, with open-ended questions such as: "What is your experience of having a child with congenital heart disease? What was your reaction after hearing about your child's abnormality? What did you do? How did it affect your life?" Moreover, secondary data about the experiences of mothers and the concepts they pointed out were obtained by exploring the relevant literature review and research conducted in the context of Iran and other contexts. To ensure the validity of the results, a peer interview technique was used. Therefore, after editing, the extracted texts were presented to a psychologist and three nursing professionals (supervisors and advisors), and a detailed investigation was performed to pinpoint shortcomings and modify themes. In addition, the researcher used reflective notes at all stages of data analysis, leading to the validity of the qualitative results.

In qualitative research, the process of data collection, data analysis, and report writing are often interrelated. However, in this study the research procedure occurred in four phases illustrated as follows:

Phase1: Familiarity with data and creating concepts.

Qualitative data came in recorded audio. To engage with data, we transcribed and read all interviews several times to familiarize ourselves with the depth and breadth of the content. Power quotes were highlighted and all data (audio, transcriptions) were archived with dates to provide an audit trail and ensure data analysis confirmation.

Phase 2: Generating initial codes.

To this end, the interview transcripts were turned into paragraphs; unnecessary wording was deleted and summarized into 137 phrases. Then, repetitious phrases were deleted and 110 final phrases were extracted. Initial codes were derived by the researcher and two university professors to ensure engagement with data. Peer debriefing was done by one colleague and the reflective writing was done by the researcher to support the trustworthiness of this phase (Braun and Clarke, 2006). Then, a selective code was assigned to each group of phrases that revolved around a similar concept.

In this research, number of the codes was 97 and the coefficient of reliability which was calculated by the intra-subject agreement coefficient was 75 % which is acceptable.

Phase 3: Searching for themes.

Themes were identified by bringing together components of ideas that were meaningful when viewed alone. In this phase, a deductive approach was taken for the data analysis to find preconceived themes reflected in the existing literature. In this phase, notes were made to support audit trail and conformability, and each group of the related selective codes formed a sub-theme.

Phase 4: Reviewing Theme.

In this phase, the identified themes were refined to ensure a coherent pattern. We analyzed them to determine whether they accurately reflect the meaning of the data (Braun and Clarke, 2006). Some overlapping themes emerged while for some other codes, the theme broke down. To test referential adequacy, we returned to the raw data and compared them to the identified themes.

To raise the standard of data conformability, approval of the faculty members of the university

and additional comments from external supervisors were used in all stages of the probe for implementing, coding, and extracting the primary information. The researcher also tried to augment the transferability of the study by providing a rich description of the research report for the readers, to make the research applicable in other fields. The titles chosen for the categories were mainly suggested by the researcher (taken from the live speech of the participants and included in the research literature), and efforts were made to protect them with the highest degree of relevance and consistency with the collected data.

Findings

The participants in this study were between the ages of 20 and 30. Among them, are 6 housewives, 1 teacher, and 3 freelancers. The income of the families studied was at least about $115 and at most $500 or more. Regarding the education level of mothers, there was 1 person below the intermediate level, 5 people had intermediate and higher degrees, 3 people had university degrees and 1 person had a master's degree.All descriptive variables are shown in Table 1.

Table1: Descriptive variable of interviewees

Percentage	Frequency	Descriptive variable
Age		
60	6	20-25 years
40	4	25-30 years
Job		
60	6	Housewife
10	1	Teacher
30	3	Freelance
Income (Dollars)		
20	2	115-300
60	6	300-500
20	2	500 and higher
Education		
10	1	Under-Diploma
50	5	Diploma
30	3	Bachelor
10	1	Master

The final finding of the research included the main theme called health threat, which is presented in Table 2. This category includes two subcategories of physical problems and mental problems of mothers.

1. Mother's physical problems

All the interviewees mentioned abnormalities such as anorexia, lethargy, low blood pressure, and several other things like skin blotches, hair loss, and breathing problems. For example, one of the interviewees said: "A drop in my blood pressure and my bad mood and his father's paleness; this was a very simple and small thing when the doctor said that the condition of your child's heart is very critical and indescribable at all." Another interviewee pointed out: "I used to go in front of the mirror and think as if my face had a lot of spots and blotches. But I couldn't do anything else because of the stress."

Table2: Summary of the inductive process of abstract themes and classes from meaningful units

category	sub-category	Primary codes	Meaningful Units
Health threat	Mother's physical problems	physical manifestations	-It was very bad as we approached the 6 months. My hands were shaking, my body was getting cold -It is really hard for a mother; I have neither sleep nor food -I used to go in front of the mirror and I thought that my face was full of spots and blotches. But I couldn't do anything due to the intensity of the stress. I was telling myself at that moment that it will be fine, it's okay, it doesn't matter.
		Physical self-harm	-the day I found out that Kourosh is sick, I reached a point where I could no longer control myself; I mean, I really couldn't calm down until I started hitting myself or yelling; it couldn't be helped. I became something terrible.
	Mother's mental problems	Worry and anxiety	-I was telling his father I wish we could help him forget things. And his father said that's OK; after the surgery, he will see his body and will understand. -Mother worries about her child being scolded by people around
		Mental rumination	-Ok, but he said, he may see his body or not. But what about the monthly checkups; nothing can be done. -For example, I said to my husband who came yesterday, I wish we could do something with the child so that this matter would be removed from his mind.
		Mental self-harm	-I want to die, I want to be at ease, be relaxed. I don't want to see my child suffer.
		Boredom and helplessness	-I just wanted to sit in a corner; I didn't even want to cook. I wasn't washing my clothes when my husband said why you are like this, you have to get up and make food, the child wants to get stronger, get up, and wash clothes, but I didn't want to do anything at all.
		Isolation	-I just wanted to sit in a corner; I didn't even want to cook. I was not washing my clothes when my husband said why are you like this
		Denial	-The family told me, to give up sticking to the doctors, they may make a wrong diagnosis; don't take the child to the doctor at all.

2. Mother's mental problems

These include primary codes, worry and anxiety, distress, losing nerves, heartbreak, mental rumination (thinking too much about the disease),mental self-harm (death wish, self-blame),boredom and helplessness (unwillingness to do household chores, feeling helpless to treat the child), isolation and seclusion (unwillingness to go out of the house, silence in front of one's husband, desire to be secluded) and denial (belief in the futility of seeing a doctor), postponing the echo because of Corona, encouraging the family to stop the treatment, believing in wrong diagnosis). Mothers are highly anxious during diagnosis, ultrasound, and surgery. A mother, for example, said: "We went into the room, and when it was time for Baran's echoing I should tell that I was on the verge of unconsciousness or that it was a very terrible mood; it was not a lie at all."Most of the mothers are like this" and a mother wishes if there was a medicine to give her child to help him forget all these events. Another puts her anxiety about surgery in this way: "I can't bear it from a mental point of view that she will undergo heart surgery again."It was a very bitter and difficult time and it was as if my days didn't pass at all". For some parents of children with heart abnormalities, it can be a crisis. Therefore, they deny the problem and thus do not seek treatment or diagnosis from other doctors. For example, a mother mentioned that the father said: "The child has no problem; why are you taking the child to so many doctors?" Or another mother said: "Everyone said that his wheezing is due to a cold". The mothers' grief can be understood from statements such as continuous crying, death wish, boredom, and helplessness. Mothers faced many problems in terms of public health, physical functioning, and social functioning and had experienced

physical pain so they were suffering from good physical and mental health. One of the participating mothers in this research stated that: "All my hair has fallen out from stress. My skin is all ruined".

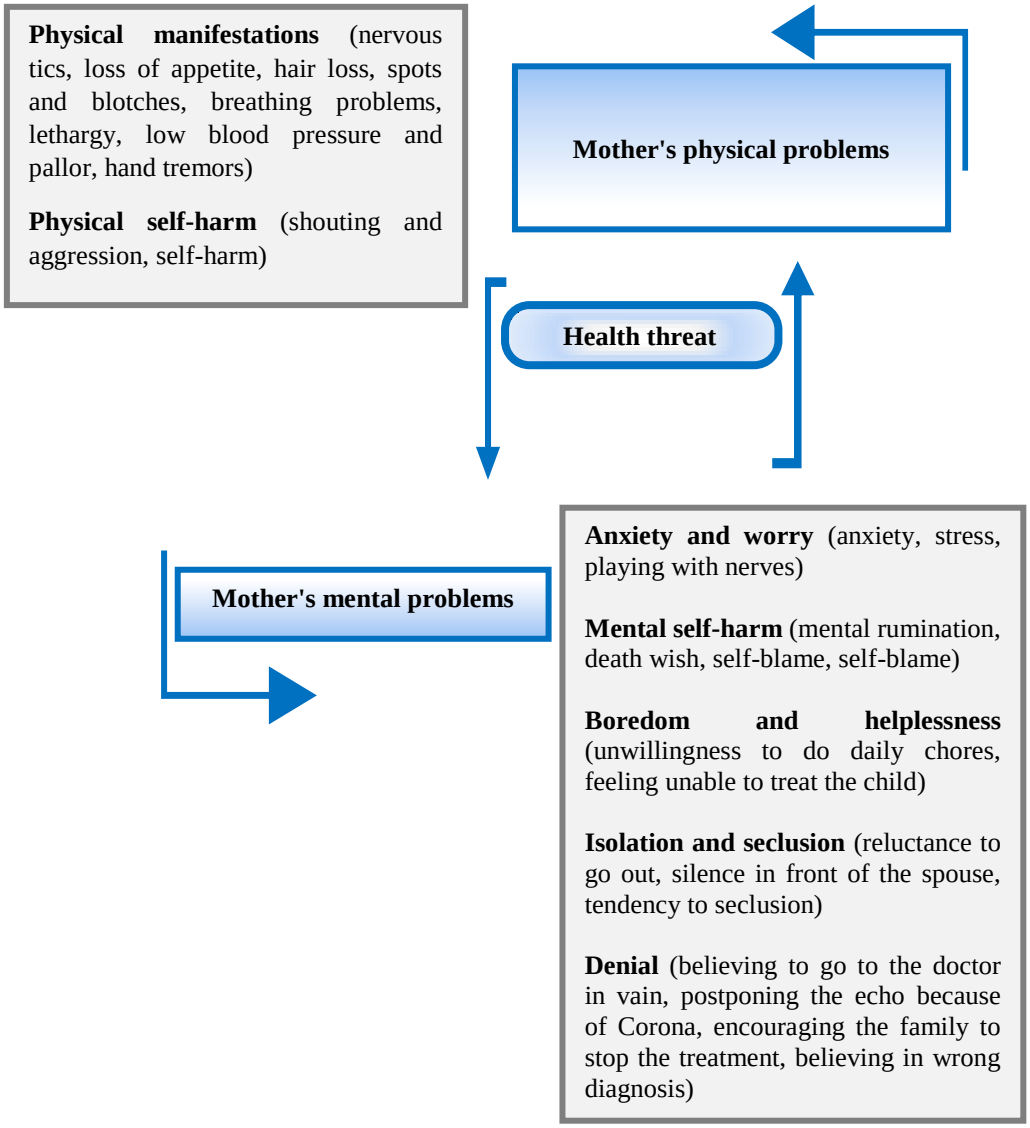

Diagram 1: Conceptual model of health threat category and its subcategories

Conclusion and Discussion

When a child is diagnosed with CHD, it is a challenging time for parents; they face mental and physical stress and socioeconomic problems. Given this fact, the health problems of mothers of CHD children have been studied in this research. The results showed that mothers of children with CHD experienced different health problems classified into two themes physical problems and mental problems. In physical health problems, they experienced abnormalities such as anorexia, lethargy, low blood pressure, and several other things like skin blotches, hair loss, and breathing problems. In mental health problems, they experienced worry and anxiety, distress, losing nerves, heartbreak, mental rumination (thinking too much about the disease), mental self-harm (death wish, self-blame).boredom and helplessness (unwillingness to do household chores, feeling helpless to treat the child), isolation and seclusion (unwillingness to go out of the house, silence in front of one's husband, desire to be secluded) and denial (belief in the futility of seeing a doctor).

According to Kasparian et al. (2017), many studies underscore that parents experience the highest level of stress in the stage before surgery. These

researchers have divided stressors into three parts: parents, children, and family members (16). The child's appearance and the permanence of his surgical scars, fears and concerns about parenting, the amount of separation parents have experienced with their child, difficulty communicating with treatment staff, uncertainty about the child's future, serious effects, insomnia, and fatigue all fit into the health threat category and also the physical and psychological problem subcategories in the current study.

Finding out about a child's illness is like a shock to parents.A collection of mothers' experiences identified by Wei et al. (2016) shows that all mothers feel guilty about their child's abnormality. For example, they ask themselves, "What did I do during pregnancy that this happened," or they hope the disease will resolve by itself and have many concerns in deciding for the operation to be performed (13). In 2017, Kolaitis et al. conducted a study entitled "Mental problems of parents of children with congenital heart disease" in which they found that parents of children with CHD experience stress and worry significantly compared to parents with healthy children(17). The findings of Lawoko and Soares in 2006 also proved that parents suffer from depression, anxiety, physical problems, and despair (18). Fonseka et al. (19) in 2012, and Bevilacqua et al. in 2013 also identified that mothers' stress level is significantly higher than fathers' stress level (20).

Additionally, Neyeri et al. (2021) aimed at investigating the experiences of parents of children with CHD. They addressed four main categories: emotional problems, the difficult burden of care, turning to spirituality, and the difficult path. The identified sub-categories of the first category confirm the findings of the current research. The sub-categories examined were: denial, shock, sadness, isolation, guilt, and understanding the moment as the most painful period of being a mother (15). Moreover, Veinberg et al. (2019) addressed shock, frustration, and helplessness in their research (21).

Burstrom et al. (2006) also found that raising children with CHD was associated with socioeconomic, physical, and psychological problems.According to Kasparian et al. (2017), many studies emphasize that parents experience the highest level of stress during the disease in the stage before surgery (16). These researchers have divided stressors into three categories: parents, children, and family members. Regarding the parents, they refer to the following: difficult and sensitive decisions regarding the choice of treatment, strong feelings related to anger, sadness, guilt, and shame, feelings of loneliness and helplessness, concern about the physical appearance of the child and the scar left after the operation, fear and anxiety about the role of being a parent, the periods of separation they have experience from their child, the difficulty of communicating with the treatment staff, uncertainty about the child's future, and the severe effects of insomnia and fatigue. These factors are consistent with physical problems and psychological problems as the two subsections of the category of health threat in the present study.

Nayeri et al. (2021), in their research on the experiences of parents with CHD children, have identified emotional failure as a main category. Emotional failure is the reaction and feelings that parents have experienced. These feelings include denial, sadness, withdrawal, shock, guilt, and the most difficult moments in parenthood. This category is in line with the codes identified in the category of psychological problems of parents in our research (15). Sileshi and Tefera (2017), Biber et al. (2019), Kaugars et al. (2017), Golfenshtein et al. (2017), Verijmut et al. in their studies identified that mothers encounter many problems in terms of general health, physical functioning, and social functioning. For the physical pain, they have experienced poor physical and mental health (12-17, 21).

Furthermore, mothers fail to communicate with others and want to stay alone at home. This category is identified in the current research with the subcategory of isolation and seclusion and is also consonant with the findings of Nayeri et al, (2021).Sometimes mothers even maintain: "Perhaps I have sinned and God has punished me in this way."Nayeri and colleagues (2021) have also identified the category of guilt (15).

In their investigations, the researchers found that all parents blame themselves for their child's illness. According to attribution theory, humans tend to come up with a reason for what they experience. This theory explains why parents try to find a reason for their child's illness and relate it to what they did during pregnancy. Treatment staffs need to make efforts to reassure parents that their child's illness is not related to their activities.

Caring for a child with CHD has a very negative impact on the quality of life of parents. Treatment costs and medical travel are other issues these

families often face (12). Diagnosing a child's illness causes many problems for parents and families, both in terms of communication and financial problems,and reduces the family's quality of life. Wei and his colleagues (2015) reviewed the results of the previous investigations conducted in the field and showed that care and education of CHD children trigger scores of financial costs for families. In Nigeria, families spent 10% of their total income on their children's medical problems. Further, in Pakistan, 40% of families need to borrow money from family and friends to continue their children's treatment. Of these, 50% of parents have lost their jobs or businesses, and a small part has had to sell their household items. Reports from Germany indicate that medical expenses constitute a large part of expenses for a family. Also in America, families have stated that they have suffered a deficit of income since the diagnosis of the disease in their children (13).

A noteworthy point in the present study is that the cost of treatment was not extracted as a checkable code as mothers did not show any worry and stress for the costs. This is probably due to the reasonable cost of treatment at the Yazd city state hospital, which doctors say is lower than the national average. In general, it is concluded that mothers of children with CHD bear various experiences ranging from physical problems to mental problems. Identifying and resolving these issues should be the focus of the treatment staff and families,and the hospital should provide supportive processes to better address the issue.

Limitations

This study has some limitations. Due to purposive sampling, the study didn't include mothers of children with high-risk and high-mortality types of CHD. With a qualitative perspective and small sample size, we did not aim to generalize the results of this study but rather to provide a first step to elucidate mothers of children with CHD over time.

It would be interesting to know if the sex or birth order of the children influenced the mother's experience. In future research, this may be worth investigating. The results of this study may help open up new perspectives and questions about the emotional and physical state of these mothers in different cultures and different cities in Iran.

Acknowledgments

The present research is part of an MS thesis with Ethic code (IR.SSU.REC.1399.270) from Shahid Sadoughi University of Medical Sciences in Yazd. Special thanks to all the esteemed participants and the respected administrative staff of Afshar Hospital for issuing the necessary permits.

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