

The Burden of Care: Mothers' Experiences of Children with Congenital Heart Disease

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ABSTRACT

Background: Mothers play a key role in caring for their sick children. Their experiences of care were influenced by culture, rules, and the system of health and care services. There are few studies on maternal care of children with congenital heart disease. Also, each of them has studied a particular aspect of care. The present research aimed to understand care experiences of mothers of children with congenital heart disease.

Methods: A conventional content analysis was used to obtain rich data. The goal of content analysis is “to provide knowledge and deeper understanding of the phenomenon under the study”.

The study was conducted in Kerman, Iran in 2014, on mothers of children with CHD. The purposive sampling technique was used to select the participants. Participants were 14 mothers of children with CHD and one father and one nurse of open heart surgery unit, from two hospitals affiliated with Kerman University of Medical Sciences. Eighteen semi-structured interviews were constructed. Data were analyzed using conventional content analysis. MAXQDA 2007 software (VERBI GmbH, Berlin, Germany) was used to classify and manage the coding. Constant comparative method was done for data analysis. The reliability and validity of the findings, including the credibility, confirm ability, dependability, and transferability, were assessed.

Results: According to the content analysis, the main theme was the catastrophic burden of child care on mothers that included three categories: 1) the tension resulting from the disease, 2) involvement with internal thoughts, and 3) difficulties of care process

Conclusion: The results of this study may help health care professionals to provide supportive and educational packages to the patients, mothers and Family members until improving the management of patient's care.

KEYWORDS: Congenital heart disease; Qualitative study; Family; Iran: Burden of care

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INTRODUCTION

Congenital heart diseases are one of the main reasons of child death in the first year of life which has a considerable share of congenital defects in the world. Across the globe, this disease has emerged in about 1.3 million children.¹ Studies showed that the geographical distribution of this complex disease varies and the Asian countries reported a higher proportion (9.3 children per 1000 live births).² Advances in medical sciences increased the survival of such patients; hence, the number of patients living with CHD has enhanced.³ Therefore, increase of CHD patients requires more attention to be paid to the management and programming of the treatment and care processes.

Although the severity and type of CHD is effective on its seriousness and complications, most of these patients experience common physical problems such as growth defect, chronic hypoxia, continuous exhaustion, infection, delayed neural perfection, dental problems and heart failure.^{4,5} Moreover, they usually have a bad mental self-image and experience embarrassment and humiliation.⁶ These children also suffer from several behavioral and educational problems.⁷

In addition to serious complications of this disease for the patients, heavy medical expenses⁸ and frequent hospitalizations⁹ impose other types of complications on the members of patients. Because of the type of complications and the chronic nature of heart disease, such patients are in desperate need of physical, emotional, and social cares in different stages of life. Such a care is inevitably the burden of other members of the family, especially the parents.¹⁰ On the other hand, fear from an unknown future for the child, treatment program, and prognosis of the disease can lead to emergence of psychological problems, especially in the mother.¹¹

Iran is one of the countries with the highest rate of CHD (12.3 per 1000 live births),¹² where the mothers play the key role in caring for their sick children.¹³ They have to take care of their

sick child and perform other responsibilities at their professional, social, and familial roles simultaneously. Since they have to spend more time with a sick child, the quality of performing their social, professional and familial roles may be greatly influenced by this issue.

Although various studies have investigated some dimensions of this disease on the mothers, to our knowledge, an all-dimensional report of mothers with CHD children has not been published yet. On the other hand, the culture, rules, and the system of health and care services can have an influential impact on this experience. As a result, regarding the particular culture and rules of Iran, in this qualitative study we addressed the question “How are the care experiences of having a child with CHD?”, and there was an attempt to provide a comprehensive and evidence-based response.

MATERIALS AND METHODS

The current study is part of a larger study related to a doctoral dissertation which was done as a qualitative approach using conventional content analysis to identify care experiences of the mothers of children with CHD. Qualitative content analysis is one of the approaches of qualitative research and also qualitative data analysis.¹⁴ Content analysis method contains a package of techniques for systematic text analysis¹⁵ which was suitable for this research because it is an unobtrusive technique of analysis that can simply accommodate a great amount of data.¹⁶

This qualitative study was conducted from May 2014 until September 2015 in Kerman, a south-eastern city in Iran. In Kerman, there are two educational hospitals with heart disease centers which are affiliated to Kerman University of Medical Sciences. The majority of children suffering from heart problems who reside in the south-east of Iran are referred to these two hospitals.

There is not a special clinic for pediatric heart diseases in their living place. So their

parents must travel long distances to visit the doctors. Thus, children with CHD referred to these hospitals were in advanced stages of the disease.

Participants of this study included the mothers of children with CHD. They were selected through purposive sampling method which is a non-random sample used in qualitative research; the sample was selected as the need arose during the study. The mothers whose child was referred to one of the hospitals related to Kerman University of Medical Sciences were selected. Data collection continued in theoretical sampling. We interviewed with one father and nurse (working in open heart surgery) until saturation which occurred when a new category did not appear and until the existing categories were enriched. The characteristics of the participants are shown in Table 1.

The inclusion criteria included diagnosis of the child's disease at least 6 months prior to the study, the age of child within 7 months to 14 years, and the ability of the mother to speak and understand Persian, and no cognitive

disorder after inspection by a psychiatrist. If the mother was emotionally upset during the interview, she was referred to a psychiatrist and excluded.

The researcher tried to observe maximum variation in terms of different age groups, sexes, and types of heart defects. Sampling went on until saturation of information. Data were collected through semi-structured, face-to-face interviews. Interviews were done by a skilled female nurse who was trained for deep interviews (MN, PhD candidate in nursing). She first introduced herself as a nurse and researcher, and then explained the research objectives and the interview process for the participants. Then, she asked them if they were willing to participate, and then they gave their consent by signing a form of permission. In the cases the participant was not eager to sign the written form, the text of the form was read aloud and she was asked to present her oral permission (due to the cultural structure of Iran, sometimes obtaining an informed written consent leads to distrust on the part of the participant).

Table 1: Characteristics of the participants

Participants	Gender	Age	Education	Occupation	Numbers of patient child	Diagnosis of disease of child
P1	Female	27	Bachelor's degree	Employee	1	PDA ^a
P2	Female	28	Diploma	House wife	1	ASD ^b
P3	Female	45	Illiterate	House wife	1	VSD ^c
P4	Female	48	Associate degree	Employee	1	ASD+VSD
P5	Female	50	Illiterate	House wife	1	TF ^d
P6	Female	33	Bachelor's degree	Employee	1	PDA
P7	Female	35	Diploma	Self employed	1	VSD
P8	Female	32	Master degree	Employee	1	Congenital myocardopathy
P9	Female	29	Diploma	Self employed	2	Congenital myocardopathy
P10	Female	34	Bachelor's degree	House wife	1	CA ^e
P11	Female	36	Diploma	Self employed	2	PS ^f
P12	Female	47	Diploma	House wife	1	TF
P13	Female	49	Illiterate	Housewife	1	AS
P14	Female	29	Associate Degree	Employee	1	VSD
P15	Female	37	Illiterate	House wife	1	PDA
P16	Female	38	Diploma	House wife	1	ASD+VSD
P17	Female	35	Master degree	Employee	1	CA
P18	Male	36	Illiterate	House wife	1	PS

^aPatent ductus arteriosus; ^bAtrium septal defect; ^cVentricular septal defect; ^dTetralogy fallot; ^eCoarctation of aorta; ^fPulmonary valve stenosis

Afterwards, the suitable time and place for interview was determined for each participant based on her comfort. The setting for the interview was the waiting room of open heart surgery in hospital, patients' house. At the beginning of conversation, the interviewer clarified the study aims and explained the benefits of the study and reminded the interviewee that she can leave the interview session whenever she did not want to continue. Then, the primary questions were asked. For example, "What is your perception of caring for your child?" And please describe your experience of one day of caring about your child." The interview was conducted using follow up questions such as: "Please tell me more about it", "How do you feel about them", "Please give me an example". Every interview lasted at least 30 and at most 90 minutes. Two mothers were interviewed twice. The whole interviews were recorded with previous permission of participants. Also, the key points were written during the interview.

Data Analysis

In the present study, content analysis was done according to the proposed method of Graneheim and Landman.¹⁷ First, the recorded interviews were listened for 4-5 times. In the next step, the whole interview was typed word by word in a Microsoft word document. Every transcribed interview was regarded as a unit of analysis. Every text was reviewed by the same interviewee and corrected if necessary. For better understanding, every finalized text was studied four times by one of the members of research team and the meaning units were extracted, categorized, and summarized based on similarities and differences; then, the meaning codes were extracted. According to the degree of relatedness among meaning codes, they were classified into subcategories which represented the same subject. The interrelations among subcategories were examined and the main concepts were extracted from them. At the end of each step, the processes used and the findings of that step were discussed among research

group members. The final findings were shared with the participants in a meeting and their final remarks were received. To make the classification easy, we used MAXQDA software in the data analysis step.

Trustworthiness of the Study

The reliability and validity of the findings including the credibility, confirmability, dependability, and transferability were assessed using the criteria proposed by Guba and Lincoln.^{18,19} For assuring the credibility of the data, we tried to establish a close relationship and a positive interaction with the participants and encourage them to collaborate extensively. Moreover, we used the ideas and reviews of colleagues, experts, and constant comparisons. We tried to provide the dependability of the findings through constant revisions by experts and participants as well as external observers. To promote the confirmability of the data, we did a great effort to avoid any personal judgment and experiences. To have the maximum transferability, we tried to explain the data to the extent possible.

Ethical Considerations

Ethical Considerations were observed before the beginning of the study; all the participants completed written informed consent forms and were assured that their information would remain confidential. This study was approved by the ethics committee of Kerman University of Medical Sciences (ethical codes/324/93). The researcher explained the study purposes, confidentiality of data, and recording of interviews to the participants before the interview, and their verbal agreements were obtained

RESULTS

In total, 18 participants (20 interviews) were included in the study. Among them, there were 16 mothers of children diagnosed with congenital heart disease, one father of such child, and one nurse working in open heart surgery unit. The

age range of the participants' mothers was 27-50 years old (mean 33.5). The interviewed mothers all had a child suffering from congenital heart disease with different types, degrees, and under different treatment stages.

According to the content analysis, the main theme was the catastrophic burden of child care on mothers including three categories: 1) facing the tension, 2) involvement with internal thoughts, and 3) difficulties of care process (Figure 1).

Catastrophic burden of child care on mothers:

In this study, catastrophic burden of the child care on mothers was the main theme. All mothers experienced heavy burden of care for their children with CHD. The mothers faced multiple tensions and problems in care process. They endured a lot of sufferings.

1. Facing the tension

In this study, all mothers suffered from a great tension along with the disease of their children. This tension emerged from the time of diagnosis and affected them during all stages of treatment and care, not only

physically but also mentally. Each participant had experienced the effects of tension of her child's disease both physically and mentally and expressed her symptoms.

1.1. The crisis of child's disease diagnosis

In this study, all mothers of children stated that the diagnosis of their child's disease caused crying, hopelessness in life, discomfort, and confusion. With the definite diagnosis, they experienced physical and mental tension.

One mother said: *"I was in the seventh month when I was told that my child had a heart problem. I became very upset. I was trembling. I didn't know what to do. I couldn't stop crying"* (participant 3).

1.2. Facing the challenging behavior of the child

The challenging behavior of the child for mother refers to the mother's behaviors when taking care of her child. Due to the age of the child and his/her special condition during the disease, the behavior of the child makes serious problems for mothers who are take care of them.

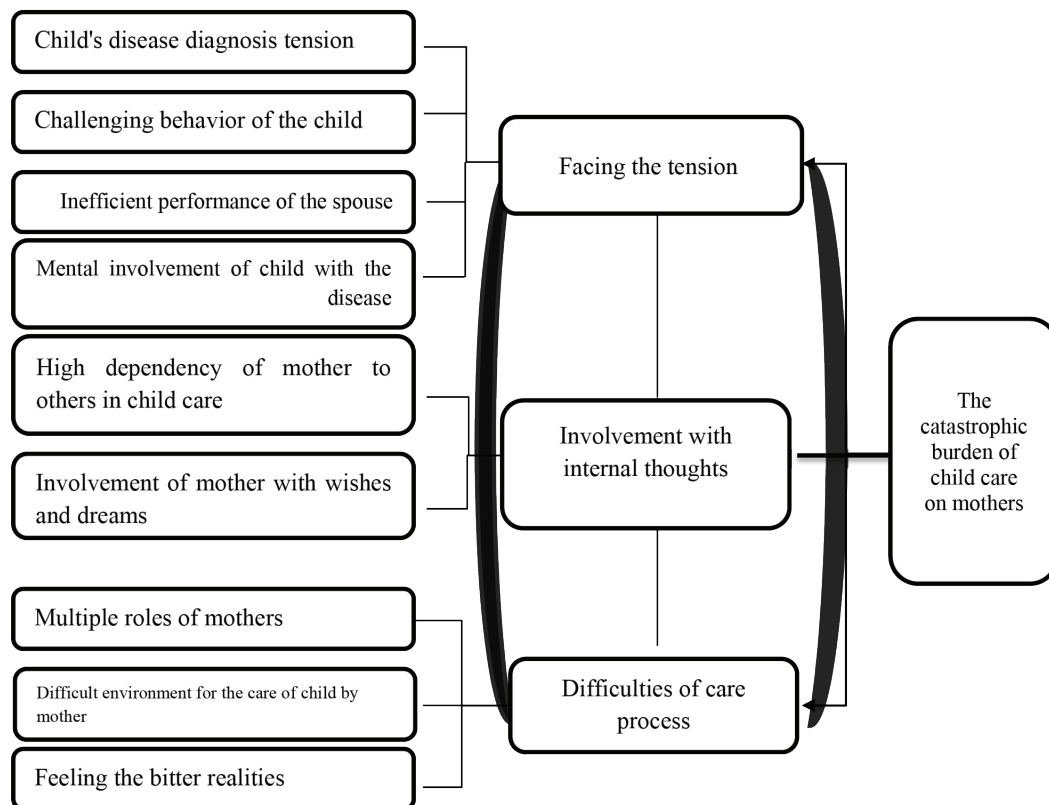


Figure 1: The mothers' difficulty in care of the child with CHD.

One mother said: *“He experienced Echocardiography since he was an infant. He made me crazy every time we did Echocardiography when he was younger. Now, he complains very much when we take him to the doctor; he is fearful. We talked to the doctor once and he said he needs to be operated while he is still a kid. But he says I’m not coming to Tehran again. I become healthy myself. I take food to become healthy”* (Participant number 4).

1.3. The inefficient performance of the spouse

The performance of the spouse refers to the physical and mental support of the mother and child during the care process. Data showed that husbands did not provide the necessary cooperation and support for the mother during the care and treatment process; even in some cases, they showed inappropriate behavior to the child and mother.

One mother said: *“it was not the case that my husband knows what the problems of the child are now; Or he does not stay with me, take care of me, and accompany me at the nights that I am awake with the child. No, never”* (Participant number 1).

1.4. Mental involvement of the child with disease

According to the participants of the study, this disease makes the child upset, sad, crying, and complaining a lot. This was indicated as a factor which causes tension and agony in mothers.

One mother said: *“My child was very unhappy; she cried and said I can’t play in the school at all; I should sit alone at a corner”* (Participant number 7).

2. Involvement with internal thoughts

In this study, mothers were faced to a number of issues and problems which prevented them from taking a good care of their child.

2.1. Mother’s dependency to others in care process

Sometimes, the mother was helped for a better-quality care from her family members such as grandmother, but this help would turn

into mother’s dependency on the grandmother in taking care of her child so that the mother would think that she cannot manage her child without the help of grandmother at all. This kind of high dependency was not helping in some cases and even led to lack of the mother’s self-confidence in tanking care of her child independently; hence, it was regarded as an obstacle for a good care.

One mother said: *“In the last days of 2009’s winter, my mother (child’s grandmother) wanted to go to Karbala; I said you will go, but this child will die if you do. I can’t take care of him. I cried a lot. I was under too much mental pressure”* (Participant number 4).

2.2. Dreams and wishes of the mother

Mental involvement of the mother with her own dreams and wishes, her expectations before the child birth of having a healthy baby was another experience of a great number of participants in different stages of treatment of the child.

One mother talked about her dreams before having a baby: *“I always dreamed having a good healthy baby. I was thinking to myself that I would provide any kind of facility for him to grow, in his studies when he grows up, but what about now?!”* (Participant number 5).

3. Difficulties of care process

In the process of caring for the sick child, mothers tolerate many difficulties in their social and personal life along with the agony of having a sick child and treatment difficulties.

3.1. The multiple roles of mothers

The mothers who participated in this study had the role of taking care from the sick child besides their other social roles: having a job, doing daily chores and taking care of other family members, and being a wife. Performing all of these roles was indicated very difficult and painful for the mother.

One mother said: *“I sewed and I couldn’t take much care of her. I was busy with my own works. She was on herself. Sometimes I had to send her to her uncles’ to be amused with her cousins so that I take care of my own works because I had to earn for our life”*(Participant

number 7).

3.2. The difficult environment for the care of children by the mother

Mothers expressed that the difficult environment for the care of children by the mothers creates problems such as Lack of independency in child care; Negative thoughts and attitudes, inadequate awareness; Using personal and others' experiences; and Uncertainty and lack of dependability.

In this regard, one mother said: *"When my child needed operation, I thought to myself what I can do when his father doesn't give the permission. I came to the hospital but they didn't permit as well and told me to convince my husband to bring him here. Otherwise, nothing can be done. At that moment, the whole world turned black. I didn't know what to do"* (Participant number 10).

Another mother said (about traditional treatments): *"I give her any galenical medicine like perspiration of eglantine, willow, etc. It seems they are effective and make her better. But sometimes I doubt. I think whether such stuff that I give to her are good or not,"* (Participant number 6).

As to the application of personal and others' experiences, one mother said: *"Because I had the experience of having Teucrium, it was good for me, and I gave it to her"* (participant number 13).

3.3. Feeling the bitter realities

Participants mentioned the bitter and painful realities such as: Feeling lonely in taking care of the child, having the experience of being ill by mother, negligence of medical care and treatment team, and observing the child's pain. Mothers were faced to bitter realities in taking care of their sick child unexpectedly. However, in many cases she was not able to do anything about them.

The majority of participants of this study were struggling alone with the care issues of the child. Participant number 15 said: *"The hardest time of my life was passed beside this child with her illness and treatment. Nobody has helped me, but at the end there is me and only me. If someone wants to help, it is for a*

while, and then they go. The two of us are alone, with each other".

DISCUSSION

In this study, the participants considered their care experiences of children with CHD. The catastrophic burden of the child care by mother was found as the main theme of this study. According to the findings, three categories for the main theme were found: facing the tension, involvement with internal thoughts, difficulties of care process. All categories existed in their experiences of participants. Moreover, eight subcategories were defined as the conceptual components of the categories. In this part, the scientific documentations on the significance of codes are explained. Although there were few qualitative studies, it was tried to use both quantitative and qualitative literature.

1. Facing the tension

Mothers face a serious mental crisis through the tension of child's disease since its diagnosis on wards.²⁰ In this study, all mothers had experienced such issues and the negative effect of child's illness at the birth and were overwhelmed with a particular fear and worry. The most serious worries of mothers were due to the stress about unknown future, the development of diseases, and the future of child. This finding is consistent with the studies that indicated a serious fear about the unknown future of the child, the progress of treatment program, and disease prognosis.^{19,21} The results of this study showed that in Iranian culture, because of the high emotional attachment among family members, child disease may cause very intensive mental impacts and mental damages to the parents, especially mothers. In one qualitative study about the impact of children's lymphoma on families, it has been shown that the children's disease affects not only the mother, but also the whole family; this issue can lead to dissolution of this small social unit.²¹ Also, a quantitative study indicated that fear of losing the child after diagnosis has been mentioned as the most and worst tension of parents.

Mothers who hospitalized their children for growth problems experience both a physical crisis and an intensive emotional crisis.²² Of course in the current study, mothers were struggling with bad behaviors of the child, such as resistance to take medicine, resistance to see a doctor or hospitalization, and constant nagging. On the other hand, no especial system of support exists in Iran to manage and guide the mothers on how to deal with this type of conduct. Hence, this issue was suggested as an intricate problem by mothers. According to some studies, the level of anxiety, stress, and depression among children with chronic diseases is significantly higher than normal healthy children.^{22,23} Therefore, in the care process of these children, one should take his/her social-mental health into account and pay attention to the physical health.^{24,25} In a qualitative study, the researcher stated that planning for the social-mental care of this group of children is possible by the support of a strong system and the effective help of child's family.²⁵

These mothers witnessed how their child wished and prayed to be healthy, how they cried because of the physical inabilities caused by their illness, and wished to be like their peers. These items lowered the spirit of the mother as the main caregiver and had a negative effect on the process of child care. In agreement to this study, some studies showed that frequent visits by doctors, changes in the treatment and medications, limitations in physical activities, and shifting nurses were very effective in creating mental problems in the patients.²⁶ By training the mothers and empowering them with child care techniques and helping the child to do the routine works appropriate to his/her condition can reduce these problems to some extent.

This study showed that the majority of the participants were dissatisfied with their husband's role and participation in the child care process. They mentioned the collaboration of their husband in child's works and nursing him/her was inadequate and very limited. However, the results of the study

conducted by another researcher revealed that the collaboration and participation of fathers in taking care of the sick child and providing mental-moral support for the mother and the child was a necessary condition for a good care given by the mother,²⁷ but the results of the current study showed that most of the men worked outside during the day and returned home very tired.

According to the findings of a qualitative study conducted by Conor, this disease usually increases the expenses of the family,⁸ and the hospitalization, medication, and frequent treatments increase the need of the family to more money and higher income as a result of more work. Involvement with work more than usual decreases the emotional support of the fathers for their family. Although some believed that implementing the project of health system reform and reduction of hospitalization expenses has created a good financial support for the families with congenital heart disease.²⁸ However, other costs are still imposed on the family. So the results of this study revealed that a comprehensive supportive plan for these families can provide the ground for better emotional support of fathers in the child care process.

2. Involvement with internal thoughts

In this study, the mothers' preoccupation was so much that it reduced their performance in improvement of the child's condition and disrupted a good child care by mother. Other studies indicated that mothers' dream to have a successful and healthy child before and during pregnancy was another experience mentioned by many mothers. Based on the findings of one research, one of the most important issues which affect the care process of the child with chronic disease is the parents' mental health.²⁸ Meanwhile, the parents of children with CHD are confronted with different stressors related to the disease, and treatment of the child in the long process of child care.^{29,30} In this study, the mothers' involvement with internal thoughts caused poor quality of care and many problems for their children. In

contrast to this study, in the study conducted by Connor, diagnosis of the sick child caused many parents to change their attitude toward life, death, life goals, their expectations and dreams and get support from health services.⁹ Consistent with the current study results, in another study said it was shown that disappointment due to the child's disease can be one of the factors of poor quality child care.²⁹ Therefore, with adequate protections of mothers, their emotional reactions can be controlled largely.

3. Difficulties of care process

In this study, the mothers tolerated many difficulties in the process of caring for their sick child. A part of this difficulty was related to multiple roles mothers had to play. In Iranian families, the main responsibility of house chores and taking care from family members are on the shoulders of the mothers. She is considered the core of family's peace and comfort. When she has to be at the service of a sick child all the time, doing her indoor and outdoor responsibilities will be very difficult and painful for her. Even some mothers expressed that these multiple roles were too much and beyond their ability to perform. Unlike the findings of the current study, some studies found that working outside and having a job brings about more independence for mothers and this makes them feel more powerful, and increases their committed care and life expectancy.²⁹

According to the results, the cultural ground for caring a sick child is not convenient and mothers have to deal with some challenges related to the society and culture besides other problems. For example, it will be very difficult for a mother to be responsible for caring her child, but does not have the authority and independence to make decisions about the child's treatment and care issues. Ashley claimed that high quality care in pediatric cases involves shared decision making between families and providers.³⁰ Thus, parents must participate in treatment decision-making and agree on treatment decisions. Differences in findings in the

current study compared to previous studies are probably due to differences in context.

In the current study, it was found that the attitude and mentality of the parents to the treatment of child was effective on the improvement of child, the treatment, and the care process. For instance, when the father did not allow surgery because of his negative attitude toward operation consequences and anesthesia side-effects, this could draw the child closer to death.

Some mothers had a positive attitude toward herbal drugs and traditional treatments and used these methods although sometimes they had doubts about it. However, pediatricians usually do not recommend these methods and sometimes ban it, especially for infants and children. This dilemma created difficult mental involvement for mothers.

The results showed that the majority of the participants were not aware about the care process, drugs complications, and health-improving activities for their child and stated that they had used the experience of other mothers, or acted based on trial and error to take care of their child. This issue brings about improper care of the child. Mothers with CHD children reported that their problem was not the seriousness of the disease, but they were mostly concerned about the child's future, treatment program, and the result.²⁵ Meanwhile, evidence of one study showed that the detailed educational programs for parents are helpful in the improvement of the care and control of the disease.⁴ In addition, another study showed that education of patients, parents and other family members who take care of him/her can also improve the control and care process.^{4,6}

In this study, it was found that since the disease had not been diagnosed early, or a suitable medical procedure had not been performed for the patient, and also due to the inconsistency in the diagnoses, prescriptions, and treatments of different doctors, the mothers were suspicious with the doctors' knowledge and expertise of. Another research revealed that this doubt is one of the main

stressors of the child's parents.²⁵

Feeling lonely in caring the child was experienced by the majority of mothers, which reduced the quality of her care significantly. Besides the reduced quality of mothers' care, this issue also affects the quality of mothers' own lives, which in turn intensifies the deficiencies in the care process.

A mother who observes the physical inabilities, limitations, isolation from peers, hospitalizations, and the frequent operations of her child becomes very upset and sensitive. On the other hand, the mother is the person who should take care of the child during the treatment and prepares the child to fight the limitations and the side effects of the disease. Results show that observing the child's pain and agony is a weakening factor for the mothers. Findings showed that a psychosocial care planning for this group of mothers with a strong support system is effective for reducing the burden of problems.^{28,31} In addition, according to Burns, having a nursing staff knowledgeable in life skills training and empowering mothers are necessary.³²

Limitations

The major limitation of this study was the fact that the findings cannot be generalized given the nature of the research method selected. Another limitation was the small sample size. However, the research includes specific participants (mothers of children with CHD) and a particular geographical location. But we believe that these findings would support further research of wider scope. The findings of this study can be generalized to other mothers, families and special professional in health services.

CONCLUSION

According to the findings of this study, mothers of children with CHD tolerate many problems in the care of their child. Results of this study showed that some mothers manage their problems alone. Also, considering the experiences of mothers caused deep cognition

of their needs. Thus, providing appropriate planning for support and education by health provider is necessary.

Nurses are recommended to try to help these mothers by appropriate interventions; empowering them by training of life skills can be very helpful in reducing the severe difficulties imposed on these women in Iran. Furthermore, determining the mothers' burden of care can be helpful in providing families with targeted interventions to improve the family function.

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