

Caregiving Strategies in Families of Children with Congenital Heart Disease: A Qualitative Study

Abstract

Background: The families of children with Congenital Heart Disease (CHD) experience challenges in taking care of their child, which may affect the whole family. Therefore, the families need to manage and organize the caregiving process for the child. In order to help families provide optimized and quality care for their child, it is important to understand how they manage caregiving challenges. This study was conducted with the aim to explore the strategies used by families for managing family caregiving for their child. **Materials and Methods:** This qualitative study was conducted on families of children with CHD referred to hospitals in Mashhad, Iran. The participants were selected using a purposive sampling method. The data were collected from among 40 eligible participants using in-depth and semi-structured interviews from November 2017 to December 2018. Conventional content analysis was used for data analysis and MAXQDA software for managing the coding process. **Results:** According to the results, effort to manage caregiving emerged as the main theme, which included the 4 categories of “monitoring the child’s health conditions,” “organizing family life,” “optimizing family life,” and “establishing interaction.” **Conclusions:** The families used various strategies to manage caregiving including monitoring of the child’s health conditions, organization, and optimization of family life, and effective interaction based on their knowledge, experiences, beliefs, and available sources. The results of the present study can help healthcare professionals and nurses to develop family-centered empowerment programs in order to promote families’ abilities to manage family caregiving for a child with CHD.

Keywords: Caregivers, child, congenital heart defects, family

Introduction

Congenital Heart Disease (CHD) is a common birth defect with geographic variations in prevalence rates in Europe, North America, and Asia.^[1] The prevalence rate of CHD is less than 1% live births in Iran.^[2] Children with CHD experience physical, emotional, and behavioral problems, and neurodevelopmental deficits.^[3,4] The families of these children experience significant stress in caregiving because of physical exhaustion, emotional upset, and family member burden^[3,5]; which influence all the dimensions of children’s and families’ Quality of Life (QOL).^[4,6]

CHD is managed as a chronic disease,^[5] and children with CHD require numerous hospitalizations, surgeries, interventional therapies, care services by a specialist team, and lifelong follow-up.^[7] According to Eiser, as cited in Smith *et al.*, living with chronically ill children can cause

challenges because of illness-specific needs such as maintaining care and treatment regimes, maintaining family relationships, and financial and social constraints.^[8] This condition causes major changes in the routine of family life, which may affect the whole family.^[9,10] It is essential to provide integral, continuous, and individual care based on the children’s daily needs considering their limitations.^[9] However, many parents experience some difficulties in managing the child’s illness and their caregiving role^[11]; the families need to reschedule activities, integrate the child’s needs into family life, and use strategies to manage the conditions.^[8,9,12] The results of qualitative studies have revealed that strategies of mothers/families for managing the care of children with CHD/chronic illnesses include accepting the situation, enduring difficulties, seeking social support, personal empowerment, adjusting and changing routines, and balancing care and life.^[12,13]

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Some differences in cultural norms and values shape the caregiving experiences,^[14] and families' caregiving practices are influenced by socioeconomic contexts, available resources, and support.^[13,15] It is important to understand how families respond to the illness and manage their daily life despite caregiving challenges.^[3] The families of children with CHD experience challenges in the child's caregiving process, which need to be managed; however, and to our knowledge, very few qualitative researches have been conducted on these families' caregiving strategies. Moreover, family caregiving experiences can be influenced by the cultural beliefs and healthcare systems of each cultural context. Therefore, it is essential to have a deep understanding of how families manage caregiving challenges to help them provide quality care. Thus, a qualitative study is needed to gain their experiences. This study aimed to explore strategies used by families of children with CHD for managing the caregiving process.

Materials and Methods

This qualitative study was conducted using a conventional content analysis approach. The participants included family members of children with CHD referring to Imam Reza and Ghaem hospitals affiliated to Mashhad University of Medical Sciences, Iran, and Javad Al-Aeme Cardiovascular Hospital in Mashhad from November 2017 to December 2018. The participants were selected through purposive sampling. To collect in-depth and accurate data, maximum diversity was considered based on participants' education level, age, and socioeconomic status, and children's age and type of CHD. The inclusion criteria were Iranian families of a child with CHD, ability to speak Persian, willingness to participate in the study, no confirmed cognitive disorders, age range of 6 months to 11 years for the child, and diagnosis of CHD for the child at least 6 months before the study (because families are initially in shock and then experience anxiety, and therefore, need time to adjust).^[3] Parental distress is usually resolved 3-6 months after the child's diagnosis.^[16]

Data were collected using in-depth and semi-structured interviews with 40 participants, including 27 mothers, 8 fathers, 2 grandmothers, and 3 siblings. The interviews were performed and recorded individually in a private room at the suitable times in the hospital. The interview questions included "*What problems did/do you face during taking care of your child?*", "*How did/do you manage your child's care?*", "*How did/do you manage the problems related to your child's care?*", "*How did/do you manage family and life conditions for child caregiving?*". Some questions were asked in order to obtain more information and for further clarification such as "*What do you mean by?*", and "*Can you explain it in detail?*". Data collection continued until data saturation was achieved and no new code or category was obtained. The interviews lasted between 30 and 80 min, and in total, 40 interviews (39

in-person interviews, 1 telephone interview) were conducted. There was no need for supplementary interviews. The telephone interview was performed with a child's sister because of the long distance of their place of residence from the hospital. Three participants were 11–15 years of age, so the same interview questions were asked with slight modifications based on their understanding. The recorded interviews were transcribed in the shortest possible time. Conventional content analysis was used for data analysis and MAXQDA software (Ver. 2010; VERBI GmbH, Berlin, Germany) for managing the coding process.

Graneheim and Lundman's (2004) qualitative conventional content analysis method was used in the present study.^[17] Interview transcripts were read several times to gain a deep understanding. Then, the texts related to the participants' experiences about strategies used by them for managing the caregiving process were placed in a text to form the analysis unit. Subsequently, meaning units and condensed meaning units were identified, and the codes were extracted. Similar codes were grouped together into 1 subcategory, and similar subcategories were placed into 1 category. Finally, themes were extracted from the categories according to the underlying meaning and latent content. Eventually, 194 codes, 9 subcategories, and 4 categories as the main theme were obtained. Lincoln and Guba's (1985) criteria including credibility, dependability, confirmability, and transferability were used to ensure the trustworthiness and rigor of the data.^[18] Data credibility was obtained through prolonged engagement by spending sufficient time to review and analyze the data, member check by getting feedback on the interview text and codes from 3 participants, and sampling with maximum diversity. Dependability was achieved through peer-review by an external reviewer; 3 experts in qualitative research reviewed and confirmed some of the interview texts, codes, categories, and emerged themes. Confirmability was achieved through audit trail. In addition, transferability was provided via a full description of the context, sampling, data collection, and analysis.

Ethical considerations

This present study was approved by the Ethics Committee of Mashhad University of Medical Sciences, Iran (IR.MUMS.REC.1396.256). The participants were assured of the confidentiality of the data and the right to withdraw from the study. Moreover, written informed consent was obtained from all the participants. However, for the participants aged 11–15 years, it was obtained from their parents.

Results

This study included 40 participants, 27 mothers, 8 fathers, 2 grandmothers, and 3 siblings with a mean (SD) age of 32.48 (6.47), 37.88 (4.64), 58 (2.82), and 12.67 (2.08) years, respectively. The demographic characteristics of the

participants are presented in Table 1. According to data analysis, 9 subcategories and 4 categories as the main theme were obtained. The main theme was effort to manage caregiving. The 4 categories included monitoring the child's health conditions, organizing family life, optimizing family life, and establishing interaction [Table 2].

Monitoring the child's health conditions

This category covers the 2 subcategories of paying attention to the child's physical needs and paying attention to the child's psychological needs, which indicate family effort, especially that of mothers, to provide the child with care according to its health and developmental needs.

Paying attention to the child's physical needs

The child's physical needs included nutrition, medication, preventing infection, activity limitation, and other physical problems. Most participants tried to follow both the physician's instructions and their own experiences regarding the growth and weight gain of children using nutritious foods according to the child's conditions. Some participants tried to improve the child's appetite. "I started to feed my child under the supervision of a pediatrician when she was 4 months old. I gave her appetizing syrup or zinc sulfate and feed her with milk, meat broth, poultry broth, nuts powder, and fruit juice for weight gain. I did not make chocolate, chips, soft drinks, or junk foods available to her" (P1, mother, 37 y/o).

The most important problem of all participants was preventing common cold. They tried to prevent it by avoiding crowded places, contacting others, and getting close to people with a cold or contagious disease, as well as providing an environment with suitable temperature, vaccination against flu, and home remedies. "My baby

catches a cold with the slightest cold weather, so I vaccinate him against the Flu every autumn. I try to keep him away from sick people. I put eucalyptus on the heater and dress him in warm clothes when he is going outside" (P24, mother, 42 y/o).

Participants were faced with their child's physical problems and activity limitations due to cardiac disease. Respiratory problems and cyanosis were mentioned by most participants as one of the physical symptoms that became worse with crying. They tried to prevent crying and cyanosis in various ways. "I try not to make my baby cry. When he cries, his breath stops, and he gets cyanotic. In these situations, I hug him or put him in a knee-chest position as the doctor said" (P20, mother, 34 y/o).

Participants were also aware of CHD-induced activity limitations. They tried to prevent heavy activities and fatigue in children by closely monitoring and teaching them. "I am very careful that he does not get excited in playing or run. When he plays too much, his heart beats fast, and his breath shortens. I taught him to sit in these situations. He knows to sit when he gets tired" (P12, mother, 37 y/o).

Paying attention to the child's psychological needs

During caregiving, participants were faced with affective and behavioral problems such as bad temper and aggressive behavior in their children. They tried to control these behaviors through mild punishments and prevented the child's dependency. "When my daughter is in a bad mood, I try to leave her alone for 10 min as punishment. I try to make her independent and not be a spoiled baby" (P7, mother, 32 y/o).

Some participants also tried to treat their child so as either not to feel weak or different from others. They also

Table 1: Demographic characteristics of participants

Description	Mothers	Fathers	Grandmothers	Siblings
Age				
-Range (years)	(20-45)	(32-42)	(56-60)	(11-15)
-Mean (SD)	32.48 (6.47)	37.88 (4.64)	58 (2.82)	12.67 (2.08)
Education level				
- Elementary	3	1	2	2
- High school	13	3		1
- University	11	4		
Job				
- Housewife	16	-	2	-
- Employer	9	4		
- Worker/freelance	2	4		
- Student				3
Place of Residence				
- Mashhad	10	4	2	2
- Other cities	17	4		1
Total	27	8	2	3

Table 2: Main theme, categories, subcategories, and codes emerged from data analysis

Theme	Categories	Subcategories	Codes
Effort to manage caregiving	Monitoring the child's health conditions	- Paying attention to the child's physical needs	- Feeding the child with nutrients - Avoiding junk foods - Preventing respiratory infections - Preventing dyspnea and cyanosis - Supervising the child's activities - Avoiding strenuous exercise
		- Paying attention to the child's psychological needs	- Controlling the child's mood - Preventing of the child's dependency - Building self-confidence in the child
	Organizing family life	- Meeting one's own needs	- Paying attention to one's own physical condition - Finding relief in praying - Spouse as a supporter - Feeling calm by support - Devoting time to other children
		- Meeting family needs	- Paying attention to other children's education - Changes in work/job for the child care - Changing place of residence for the child care - Creating a safe environment for the child - Providing mind games for the child
Optimizing family life	- Modifying living conditions	- Providing entertainment for the child and family members	- Paying attention to other children's hobbies - Parental collaboration in the caregiving - Involving family members in the caregiving - Getting information from other parents - Learning from other parents
		- Cooperation and collaboration of the family	- Seeking information from the medical team - Getting help from the medical team - Getting motivated to continue treatment
Establishing interaction	- Communication with peers	- Interaction with healthcare professionals	

tried to improve their children's self-confidence. "I do not want my baby to know he is different from others, I do not like people saying this baby is sick. I even tried to treat him like my other son. I give him confidence and tell him that he is strong and clever" (P36, mother, 36 y/o).

Organizing family life

This category included the 2 subcategories of meeting one's own needs and the family's needs that indicate families' efforts for organizing their needs by considering both their own needs and that of other family members alongside caring for the sick child.

Meeting one's own needs

Some participants either experienced physical problems such as headaches, migraines, fatigue, and insomnia, or their physical problems were aggravated following the child's birth and continuous care. As the families experienced high psychological stress during the baby's caregiving process, some participants tried to satisfy their psychological needs in various ways such as taking part in religious ceremonies, seeking others' support, and taking

sedatives. "I experience a high rate of stress whenever my baby is either hospitalized or undergoes surgery. I read the Quran and pray, it makes me calm" (P26, mother, 27 y/o).

"My husband supports me well. When I am tired or nervous, I prefer to talk to him. His words make me calm. Sometimes, I take herbal sedatives" (P23, mother, 31 y/o).

Meeting the family's needs

Most participants were aware of their unintentional lack of attention to their other children following the birth of their sick child. Therefore, they tried to pay more attention to them in various ways such as by trying to divide their time between all their children and helping them. "Although I and my wife are constantly engaged in caring for this baby, we try to pay attention to our other children and divide our time between them" (P18, father, 42 y/o).

"My mum is busy taking care of my sister. She cannot take me out or help me in my school assignments, so my daddy helps me in my assignments" (P3, sister, 12 y/o).

Optimizing family life

The other strategy of families for caregiving management was optimizing life conditions including the 3 subcategories of modifying living conditions, paying attention to entertainment of the child and family, and cooperation and collaboration of the family, which indicate families' efforts to provide suitable conditions for the welfare and convenience of the child and other family members by working together.

Modifying living conditions

Most families tried to change either their work or living conditions in order to make optimal care possible. Some parents had to reduce their working hours, take leave, and change their job or living place. *"I have to take care of my baby, I cannot go to work. So, I took a leave for now. I told my husband that we should get a house near my work, so I can visit my baby throughout the day"* (P30, mother, 33 y/o).

Most families also tried to provide a safe and suitable environment for their child by eliminating allergens, installing air conditioning, and avoiding polluted air or cigarette smoke. *"We tried to remove allergens such as flowerpots, carpets, etc., We have installed air conditioning at home and we do not take him where there is cigarette or hookah smoke"* (P5, father, 37 y/o).

Providing entertainment for the child and family members

Some participants paid attention to the child's entertainment by providing possibilities for safe playing according to her/his ability and activity limitations: *"My child cannot be active, he gets tired soon. So, I bought her a sketchbook and colored pencils. It makes her more intelligent and reduces her activity"* (P7, mother, 32 y/o).

Cooperation and collaboration of the family

Most participants asked their husband, other children, and relatives for help in taking care of the child and doing house chores when necessary. They focused on the necessity of the collaboration of all family members in taking care of the child, which indicates the importance of family collaboration. *"I and my husband plan and cooperate with each other in caring for our baby and doing house chores to prevent any interference in our work. All family members should collaborate in taking care of these children"* (P33, mother, 36 y/o).

Establishing interaction

This category includes communication with peers and interaction with healthcare professionals (physician/nurse), which indicates the necessity of effective communication with healthcare professionals and other families to acquire information for providing optimal care.

Communication with peers

Some participants tended to communicate with other families they met in the clinic or hospital and use their

knowledge and experience about the disease and care process of their children. *"When I bring my baby to the clinic or hospital, I ask questions from the other mums, for example, what they do to increase their baby's appetite. I have learned some things about taking care of my baby from other mothers"* (P32, mother, 20 y/o).

Interaction with healthcare professionals

Some participants preferred to interact with healthcare professionals to receive correct caregiving information from nurses or physicians. The behavior of professionals highly influenced the continuation of this interaction. *"Dr. A. treats us very well, he listens to our questions and guides us accurately. Most often, he helps us through telephone conversations; hence, I continue the treatment process of my child with him"* (P15, mother, 33 y/o).

In general, the results of this study showed that the families paid attention to the child's health needs in managing the care process; moreover, they tried to change their living conditions in accordance to the care process while organizing family life and provide the child with suitable care through effective communication.

Discussion

According to the results, the families of children with CHD used various strategies to manage family caregiving for their child including monitoring the child's health conditions, organizing family life, optimizing life conditions, and establishing effective interaction.

In the present study, the strategies that families applied for monitoring the child's health conditions were paying attention to the child's physical needs, such as nutrition, medication, infection control, physical symptoms, and activity, and psychological needs. They acted based on their own experiences and followed their physician's instructions on suitable nutrition and diet limitations based on the child's cardiac disease in order for the child to gain weight, which is consistent with the results of similar studies.^[13,15] As children with CHD cannot eat well because of fatigue, tachypnea, and dyspnea, most often, they do not gain weight and they have anorexia. Therefore, parents are recommended to feed their child using formula and high-calorie foods.^[3]

Respiratory infections prevention is a crucial part of the care procedure in children with CHD, because respiratory infection can worsen hypoxemia.^[3] In the present study, families prevented common colds in their children in various ways. In a similar study, families tried to prevent colds and pneumonia in their child by avoiding cold weather, crowded, and polluted places, as well as following hygiene recommendations.^[15] However, Verberne *et al.*^[4] reported that the overprotection of children in order to prevent infection and the worsening of the symptoms/the disease led to parental protective behavior and increased

workload of parents,^[19] but considering the complications of respiratory infections, it seems crucial that families have strategies for the prevention of respiratory infections.

Cyanotic attacks, hypoxia, and hyperpnoea may occur in some children with CHD, which may be preceded by crying, feeding, or defecation.^[3] In the present study, families also tried to prevent crying and cyanosis or dyspnea in children. Moreover, these children face restricted physical activity and lower exercise capacity.^[20] Thus, families tried to supervise their children's activities to prevent fatigue and dyspnea, and teach them about it. In a similar study, parents tried to prevent activities which increased the heart rate.^[15] In addition, in previous studies, teaching children self-care such as how to act during dyspnea, lack of physical vigor, and temperature changes have been considered as families' caregiving strategies.^[12,13] It is necessary that families consult cardiac pediatricians about the level of limitations in children's activities and sports in order to manage children's playing. Furthermore, in the present study, families followed their special ways of meeting the affective needs of children by giving them attention and affection. It is essential to meet the child's psychological needs related to affection, love, and acceptance in providing care for children with chronic disease.^[9] Nevertheless, parents' fear of the child's death and providing excessive support or affection can lead to the child's over-dependency.^[3] In the present study, families also tried to control the child's dependency. Parents should be aware of the hazards of dependency and its influence on the child's development over time. It seems that establishing individual methods for discipline and behavior modification may prevent dependency.

In this study, some participants tried to apply strategies for increasing self-confidence in their children. In the meta-analysis by Pinquart, the self-esteem of chronically ill children was lower than their healthy peers.^[21] According to Delaney *et al.*, children with CHD need social interaction with their peers,^[3] but it seems that their physical limitations can influence their interactions. Therefore, parents, pediatricians, and teachers should promote positive and successful experiences of communication between children and their peers.^[21] The present study showed how families managed their child's psychological needs, which have been less studied in previous studies despite their importance in children's health.

It has been shown that children's cardiac disease can influence all physical, psychological, and social aspects of families' QOL and reduce parents' health-related QOL.^[6,22] In the present study, participants used strategies, such as finding relief through religious practices, and seeking help and emotional support from relatives, to handle the stress and challenges of family caregiving for the child. In similar studies, mothers/parents needed support to gain their wellbeing and strength,^[10] and spirituality had

an important role in providing calmness and emotional support in different cultures.^[12,13] They received social and emotional support from their spouse, family, physician/nurse, peers, workplace, and the community.^[23,24] Some studies found that parents did not receive enough support and they were dissatisfied, which was inconsistent with the present study findings.^[25,26] Perceived social support can be influenced by culture,^[27] and diversity in available sources and healthcare systems results in a variety of sources of support in different cultures. The present study showed that Iranian families receive more emotional support from relatives than other social sources, which may be due to the lack of access to other sources.

Moreover, one of the most important concerns of families is devoting time to the siblings of the sick child and not neglecting them.^[19,25] In the present study, families handled their other children using their own strategies. In previous studies, parents tried to organize a good family life, devote time to their other children, and satisfy them while taking care of their sick child.^[19,28] Strengthening family cohesion was the positive aspect of these strategies.^[8] Hence, healthcare professionals should encourage parents/families to meet their individual needs and take care of other family members while taking care of their sick child in order to maintain a balanced family life.

In the present study, families tried to optimize life conditions by changing their job and place of residence in order to provide comfort to the child and other family members and insure their welfare, which is consistent with the results of the studies by Salvador *et al.*,^[12] Nematollahi *et al.*,^[13] and Pelentsov *et al.*^[25] that illustrated that some parents had to give up their education and work. The other strategy of the present study participants was providing entertainment according to the physical condition and activity limitations of the children. In similar studies, parents tried to provide an atmosphere for playing brain games, special toys, and computer games that provided an intellectual activity for their child.^[13,19] In this study, families tried to provide a safe and suitable environment for their child by avoiding polluted air or allergens, which is consistent with the results of the study by Salvador *et al.*^[12] The presence of a patient in a family can influence several aspects of life of the family members, such as social activities and leisure time.^[29] Thus, paying attention to joyful activities for the family can optimize family life.

In the present study, family members collaborated in the child's care. Previous studies found that a child's disease could take a huge part of the parents' time, so most parents divided the caregiving responsibilities and delegated some of it to the siblings of the child,^[12,19] which could affect family relationships. Jackson *et al.* found that co-parenting challenges because of increasing responsibilities led to an added stress to the parents' relationship,^[30] but in other studies, the cooperation of family members led to a

positive change in family relationships, closer relationships between family members, and creation of a healthy and pleasant environment for the child.^[12,31] The present study showed that family relationships and modifications of the environment can improve the family atmosphere, which may influence the management of family caregiving for the child.

In the present study, families tried to interact with their peers and healthcare professionals in order to acquire information, which is consistent with previous studies^[8,10,13] However, Pelentsov *et al.* reported that some parents were dissatisfied with healthcare professionals because of their low level of knowledge about diseases in children and helping the family of these children.^[25] In fact, effective and successful communication between parents and healthcare professionals can be built on empathy, mutual respect, and trust.^[3,32] Furthermore, identification of the family's information needs and responding to them can facilitate this communication.^[32] Healthcare professionals should pay attention to families' understanding and their personal impression, because they are influenced by the individual's socio-cultural aspects.^[33] In the present study, effective interactions motivated families to continue treatment. It seems that motivation is an important factor in the caregiving process. Hence, healthcare professionals should provide comprehensive education based on the specific needs of the children and families and encourage them to continue their treatment.

The present study revealed the caregiving management strategies used by families of a child with CHD in the face of caregiving challenges. The results can help healthcare professionals and nurses to design educational programs and appropriate interventions based on families' needs, and provided them with strategies to strengthen their ability to manage the caregiving process.

The strength of this study was that we explored all family members' experiences including parents, siblings, and grandmothers, whereas other studies had only explored the mothers' or parents' experiences. The limitations of the study were the qualitative nature of the research and its performance in a particular geographic region, and thus, its generalizability is limited. Moreover, the telephone interview may have limited the participant's ability to fully share her experiences.

Conclusion

The current study showed that families of children with CHD used various caregiving management strategies including monitoring of the child's condition, organization and optimization of family life, and effective interaction based on their abilities, knowledge, experiences, beliefs, relationships, and available sources in the face of caregiving challenges. The results can help healthcare professionals and nurses to develop family-centered interventions and

educational and supportive programs to empower families and promote their abilities and caregiving management skills. It is also important to consider each family and child as unique in developing interventions. It is suggested that interventions be designed with a focus on recognizing individual needs, providing support, and having effective interactions with the aim to improve family life and the caregiving process for the child. However, further studies are needed to investigate families' experiences and effective interventions in other contexts.

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Conflicts of interest

Nothing to declare.

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