

“Immersion in an Ocean of Psychological Tension:” The Voices of Mothers with Children Undergoing Hemodialysis

Abstract

Background: Compared with other renal replacement therapies, hemodialysis treatment can impose restrictions on children with chronic renal failure and their mothers. Such pediatric illness can also lead to negative effects on mothers' physical and mental health. Knowledge about mothers' experiences can aid medical teams to support mothers in playing their roles as care managers. Providing supports to mothers can exert significant effects on mothers' health status and indirectly improve patient outcomes and whole family functioning. This study was aimed at understanding the meanings of care for children undergoing hemodialysis based on mothers' lived experiences. **Materials and Methods:** This study is a qualitative research using hermeneutic phenomenology. A total of 17 interviews were conducted with 11 mothers of children undergoing hemodialysis. The interview sessions were recorded and transcribed, after which the data were analyzed using van Manen's methodology. **Results:** The main themes identified in this study was “immersion in an ocean of psychological tension,” which suggests that the mothers of the children undergoing hemodialysis are overwhelmed by the numerous psychological pressures that they encounter during their children's treatment. This theme was constituted by the subthemes “bewilderment between hope and despair,” “endless concerns,” “agony and sorrow,” and “a sense of being ignored.” **Conclusions:** The findings indicated the need to implement multilateral support measures that align with the educational, emotional–psychological, and financial needs of mothers with children receiving hemodialysis treatment. Such measures should be taken with the participation of multidisciplinary teams.

Keywords: Child, chronic kidney disease, hemodialysis, Iran mothers

Introduction

Significant breakthroughs in the domain of medical diagnosis, care, and renal replacement therapies (RRTs) have contributed to the survival and longevity of children afflicted with chronic renal failure.^[1-3] The average prevalence of RRTs among children and adolescents aged <20 years was estimated as 65 individuals per million age-related populations worldwide.^[4] As one type of RRTs, hemodialysis is a common treatment method for the control of chronic renal failure.^[5,6] Compared with other RRTs, however, it can impose more restrictions on children and their parents.^[7,8]

Children undergoing hemodialysis are considered individuals with special health care needs and depend heavily on creating greater demands for care and supervision.^[9] Child accompaniment three times a week, resignation from work and loss of social status, adjustments to life routines based on hemodialysis sessions, feelings of concern

with regard to water and dietary restrictions on child, observation of the pain and suffering of the child, and the management of care role interference with other roles result in negative effects on the physical and emotional health of the parents.^[7,9,10]

Results of the study conducted by Geense *et al.* (2017) in the Netherlands showed that parents have major stress and concern about the treatment process, financial problems, and the management of the treatment program, and their other daily activities.^[10] The study conducted by Tong *et al.* (2010) in Australia indicated that medicalizing parenting, disrupting family norms, social restriction, and financial problems lead to stress and fatigue in parents.^[11]

Mothers have the role of primary caregivers for children undergoing hemodialysis,^[9] and they have lower levels of quality of life in terms of health, physical functioning, and daily performance, and higher levels of psychosocial stresses compared to

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fathers.^[8] When a child undergoes hemodialysis, the mother faces severe changes in her daily life. These mothers are responsible for attending hemodialysis sessions with their children. The feeling of being imprisoned along with the child by the hemodialysis machine, the need for job abandonment, loss of social status, feeling anxiety about dietary restrictions, sadness along with feeling imminent death of the child, severe isolation, and their inability to change these conditions lead to psychological, emotional, and social stress in mothers.^[9]

Thus, it is necessary that medical staff think of care for mothers as much as the sick child.^[12] Supporting mothers can exert profound and widespread effects on their physical, social, and emotional health and their ability to effectively cope with their children's illness; it can also indirectly improve the medical and psycho-social outcomes of children^[11,13] and whole family functioning.^[1]

Studies based on the experiences of mothers of children with a chronic illness are very valuable because they are a presentation of the voice of mothers and can help the treatment team to support mothers in their role as care managers.^[14,15] On the contrary, understanding mothers' experiences as caregivers for children undergoing hemodialysis is a necessary step toward achieving family-centered care and policies.^[16] Understanding mothers' caring experiences necessitates exploratory studies.^[17] In this regard, phenomenology is an exploratory method that plays an important role in clarifying ambiguous and unknown aspects of human-related issues and thereby leads to a comprehensive understanding of mothers' experiences.^[17] Phenomenological studies can also reveal the possible meanings hidden within these experiences. Heidegger's phenomenological assumption directs us to create a common ground underlain by empathy; that is, a shared consciousness and understanding of people's experiences can enable health care providers to access the complex needs of patients and their families.^[18]

Despite the variety of studies devoted to examining the experiences of mothers with children undergoing hemodialysis, medical team may still inadequately understand certain dimensions of the challenges encountered by these mothers. Additionally, to the best of our knowledge, no such studies have been carried out in Iran. So this study was carried out with the aim at elucidating the meanings of mothers' experiences in caring for children undergoing hemodialysis.

Materials and Methods

This study was conducted from September 2016 to June 2017. A hermeneutic phenomenological approach was used to carry out this study. Hermeneutic phenomenology is a systematic method of examining and interpreting a given phenomenon for the purpose of achieving a deep understanding of lived experiences during the

interpretive process.^[19,20] In the past 20 years, hermeneutic phenomenology has been considerably shaped by van Manen as a contemporary phenomenologist.^[21] He put forward six phenomenological research activities,^[19,22] which were adopted in the current work as follows:

First, activity involves focusing on the tendency toward a given phenomenon, formulating phenomenological questions, and specifying research assumptions about the phenomenon. Correspondingly, the main phenomenological questions pursued in the current work were the following: What is the nature of the lived experiences of the mothers of children undergoing hemodialysis? What understanding do they have in terms of living with their children? What does caring mean to them?

In accordance with the principles underlying second activity, the research context was chosen, participants were selected, and data were collected. The participants were selected via purposeful sampling underlain by the following inclusion criteria: having children undergoing hemodialysis for at least 2 months after the onset of treatment, willingness to participate in the study, and having the ability to communicate with the researcher (the first author).

A total of 11 mothers aged between 23 and 51 years with an average 38 years (9) were recruited. The duration of hemodialysis varied from 2 months to 8 years [Table 1]. After permits were obtained by the first author of the research and referral to the Hemodialysis Division of Dr. Sheikh Pediatric Hospital in Mashhad City, Iran, interviews were conducted with the participating mothers. The objectives of the study were explained to the participants, and written informed consent was obtained from them. Semi-structured interviews with general questions (e.g., "Please explain your experiences with the daily care of your children.", "How do you feel when you hear about child care?", "What are the caring experiences of children undergoing hemodialysis like?") were conducted. To access more information, probing questions (e.g., "What do you mean?", "Please describe your response further.", or "Can you give an example for understand ability?") were used. The interviews lasted between 54 and 85 min. The children attended hemodialysis treatments for 4 h a day, 2 to 3 days a week, which were regarded as convenient schedules at which to conduct the interviews with the mothers. The important goal in terms of data collection was to ensure that minimal stress was caused,^[20] thus, the interviews were carried out in areas with a little distance from the children's beds and after the mothers had fed them breakfast and the children no longer needed assistance with other tasks. The interviews were recorded and then transcribed verbatim on the same day. The sampling was continued until no new data could be added to the codes and data saturation regarding the examined phenomenon was reached. To ensure the richness

Table 1: Demographic characteristics of participants

Mother	Age	Marital status	Education	Occupation	Child's age	Hemodialysis duration	Number of family members
1	34	Married	Diploma	Housewife	10	1 year	4
2	42	Married	Illiterate	Housewife	13	3 years	5
3	46	Married	Fifth elementary	Housewife	5	2 months	4
4	27	Married	Fifth elementary	Housewife	10	8 months	5
5	51	Married	Illiterate	Housewife	11	2 years	7
6	46	Married	Bachelor degree	Nurse	12	3 months	5
7	38	Married	Illiterate	Housewife	6	2 months	6
8	31	Married	Diploma	Housewife	11	2.5 years	4
9	32	Married	Diploma	Housewife	9	2 years	4
10	23	Married	Fifth elementary	Housewife	6	6 months	5
11	50	Widow	Illiterate	Housewife	15	8 years	5

of data after saturation, researchers are advised to conduct interviews with one or two other participants to more confidence that no new information is overlooked. In this study, saturation occurred in the eighth interview, and three other interviews were conducted to more confidence that comprehensive data were acquired. Altogether, 17 interviews were conducted with the 11 participants. Note that nonverbal communicative elements, such as facial expressions, tone of voice, and events associated with the phenomenon of child care, were excluded from data entry during the interviews. Narrative anecdotes were used to enable reflection on the research methodology and data analysis. To facilitate data management, the MAXQDA software was used.

Data analysis was conducted based on the research activities: three to six in van Manen's methodology. Within the wholistic approach, each transcript was reread several times, and after a general understanding was derived, the researchers formulated their perceived sense of the transcript as a descriptive text. Subsequently, the descriptive text was again reviewed several times, and a one- or two-phrase overview of the text was written using a phenomenological approach. Next, the phrases or statements that could unfold the phenomenon in question were written down according to the selective approach, thus enabling the extraction of thematic sentences or paragraphs. Within the detailed approach, the researchers read the transcripts line by line and then extracted keywords or phrases associated with caring for children undergoing hemodialysis treatment. After the thematic phrases were extracted, the basic contents of each interview were compared with those of previous ones to identify similarities. The contents were then classified into subthemes based on their resemblances and interrelationships. The subthemes were also integrated according to their interrelationships, from which the main themes emerged. Throughout this procedure, the main research question was taken into account by the researchers. Reciprocating movement between the transcribed interviews and the extracted contents was also ensured.

One of the research activities suggested by van Manen is Balancing the Research Context, Parts, and Whole.

A researcher can examine a phenomenon by moving constantly between a whole and its parts—a stage called the hermeneutic cycle. To this end, the researcher needs to perpetually re-examine and place findings step-by-step in relation to an entire research context.^[19] Given the importance of this issue, the researcher (the first author) is required to consider reciprocating movement between the whole and the parts by bearing in mind the pursued research question at all stages of a study.

Van Manen suggested orientation, strength, richness, and depth as major concerns that are associated with quality in qualitative studies.^[19,23] To ensure adherence to these standards, the first author of the present study established a friendly relationship with the participants to gain their trust and motivate them to share their experiences. The researcher repeatedly engaged with the data and reviewed the participants' transcribed experiences to extract the meanings hidden within them so that such meanings could be connected to the actual experiences of the respondents with the care of their children. The four criteria proposed by Lincoln and Guba—that is, credibility, dependability, confirmability, and transferability—were also taken into consideration.^[24] In addition to engaging with the data in a constant and prolonged fashion, the first author submitted the transcribed interviews and the extracted data and themes to the other research team members, after which their comments were incorporated into the documentation, and collaborative hermeneutic conversations among the team members were carried out to increase the credibility of the data. To ensure the dependability, quotes and step-by-step analysis of emerging themes was delineated. With regard to confirmability, the transcripts of some of the interviews, along with their extracted codes and themes, were submitted to a faculty member outside of the research context for an evaluation of the accuracy of the coding process. This faculty member is an expert in the domain of qualitative analysis, especially hermeneutic phenomenology. Additionally, all the extracted codes and contents were reviewed and verified by three other faculty members outside of the project context (thesis evaluators). With regard to transferability, a detailed description of

the context and the findings was presented to readers to determine whether these are helpful in decision-making and knowledge application in the domain of health care provision.

Ethical considerations

This study was approved by the Ethics Committee of Mashhad University of Medical Sciences (IR.MUMS.REC.1395.337). All the participants were also informed about the aims and the type of the study and they signed written consent forms. Besides, the interviews could be terminated at any time as participants tended. Moreover, the participants' identity and interviews remained confidential using pseudonyms.

Results

"Immersion in an ocean of psychological tension" emerged in relation to caring for children undergoing hemodialysis. This theme suggests that psychological and mental pressures overwhelm the mothers of children undergoing hemodialysis. It was also constituted by four subthemes, namely "bewilderment between hope and despair," "endless concerns," "agony and sorrow," and "sense of being ignored." The summary of theme and subthemes is presented in Table 2.

Bewilderment between hope and despair

This subtheme indicates that the mothers of children undergoing hemodialysis feel as though they continually alternate between hope and despair. Sometimes, they are confounded by disease-related problems that can negatively affect their children's future and improvement. Awareness of prognosis can also trigger a sense that they have reached the end of the line; "care with despair" was a phrase that almost all the participating mothers used in this respect. Sometimes, hearing the results of a successful kidney transplant surgery gives them hope about the future of their children. Coupled with such awareness, however, is also a consciousness about the probability of rejection of transplanted kidneys, which leads to hopelessness about their children's future. In this study, such fluctuation between hope and despair was observed in all the mothers. As reiterated by Participant No. 10:

"I do everything with despair. There is no improvement. I have heard that those who received transplants were freed of the misery of hemodialysis treatment. It is a ray of hope for me, but there are two children in this department who received organs and rejected them. I may lose hope again".

Endless concerns

The feelings of worry among the mothers were due to the nature of the disease and its never-ending treatment process. The subtheme of endless concerns indicates that mothers with children undergoing hemodialysis are mentally preoccupied with the illness and the treatment, constantly being reminded that their children are living under abnormal conditions. In addition to the disease, the conditions of their families also add to the worries of mothers. This subtheme consisted of four other subordinate themes: "concerns about the accuracy of caring," "concerns about the uncertain future of their children," "worries about effects on family," and "anxiety and panic."

Concerns about the accuracy of caring

The caring process can be rendered more difficult by heavy medication regimens, the need to care for fistulas or catheters, the focus on close monitoring of urine output, control over children's engagement in games and activities, restrictions regarding water use, and observations of children's diet. The mothers intimated that they are always concerned about fulfilling the necessary care for their children. As stated by Participant No. 7:

"I must take care of the fistula on her hand. She should take her medications on time. She needs to drink a little water and not consume certain foods. In sum, I am always mentally engaged, and I always think about the things that she should or should not have and whether there is pressure on the fistula of her hand?"

Concerns about the uncertain future of their children

Incurable diseases can mean an uncertain future for children. Even under the best conditions and tolerable stress from surgery and kidney transplants, mothers can still worry about final results. Participant No. 1 added the following sentiments:

Table 2: The summary of theme, subthemes, and cluster themes

Theme	Subthemes	Cluster themes
Immersion in an ocean of psychological tension	Bewilderment between hope and despair	–
	Endless concerns	Concerns about the accuracy of caring Concerns about the uncertain future of their children Worries about effects on family Anxiety and panic
	Agony and sorrow	A sense of guilt due to negligence perceived as contributory to the disease Sorrow and agony due to the suffering of children
	Sense of being ignored	Neglect of maternal feelings by medical team A sense of being unsupported by family and friends

“When we think ahead a little about the future, my brain seems to stop working. I am not certain about my child’s fate. Even after the transplant, he is likely to reject the organ. If his body accepts the organ, he needs to take a lot of medications and deal with other problems”.

Participant No. 11, whose daughter has been undergoing hemodialysis treatment for 8 years, said, *“My daughter’s future is unclear. I do not know what will happen. I am very concerned. If I cannot attend the hemodialysis treatments, no one can take care of her during this time.”*

Worries about effects on family

The problems borne by sick children can affect the whole family. These children desperately need care and monitoring. Moreover, the mothers’ presence in the hemodialysis department 3 days a week and their absence at home can result in family chaos, which in turn, can also influence the physical, psychological, and educational wellbeing of the other children in the family. As declared by Participant No. 1, *“My oldest son is enrolled in high school. I have not been able to spend time with him during this 1-year hemodialysis. My oldest son is suffering from academic failure and feels depressed.”* Participant No. 4, who has two other children and lives 3 hours away from the hemodialysis center stated, *“I leave my children alone at home 3 days a week from morning to evening. I am always worried about their eating habits and activities. My little daughter is nervous.”* Distance from the hemodialysis center and the costs associated with frequent travels to the hospital, the costs of medications, and disturbances to parents’ work can impose a heavy financial burden on families. All the 11 participants expressed serious concerns about their household financial conditions and their effects on their children.

Anxiety and panic

This cluster theme reflects experiences regarding the moments of anxiety, restlessness, nervousness, fear, and panic experienced by the mothers of children undergoing hemodialysis. Hemodialysis is an invasive treatment accompanied by numerous inconveniences and complications, including periodic tests, surgery for vascular access, and repeated hospitalization because of infections or inefficiency of vascular access. These additional burdens can cause anxiety and fear among mothers. Participant No. 3, whose daughter has been undergoing hemodialysis for 6 months, shared the following sentiments:

“One time, they inserted a catheter, but it didn’t work correctly. So, they changed it but only after five hemodialysis sessions had been completed. They took my child to the operating room again and implanted the permcath. After it was used two times, the pistons broke down. Now, I must consult with a vascular surgeon regarding a fistula, and my child will have to be taken

to the operating room again. Each time they take her to the operating room, I feel so anxious that I think I have butterflies in my stomach”.

The unpleasant feelings of anxiety and panic originating from the possibility of imminent death severely hurt these mothers. These feelings, especially under fluctuating blood pressure during hemodialysis, can worsen. Seeing the hemodialysis process and the blood flowing inside dialysis tubes was frightening for the mothers, as indicated by the responses of a participant whose son has been undergoing hemodialysis for a year:

“Each time my son is connected to this machine and his blood is ejected from his body, I get really frightened, especially on days when his blood pressure goes down. Each moment, I think I am losing my son. As I sleep at night, I wake up with lots of anxiety. (Participant No. 1)”

Agony and sorrow

When the mothers consciously reviewed their experiences in caring for their children, they spoke about their heartfelt and profound suffering and bereavement. This subtheme comprised two other subordinate themes, namely “A Sense of Guilt due to Negligence Perceived as Contributory to the Disease” and “Sorrow and agony due to the suffering of children.”

A Sense of Guilt due to Negligence Perceived as Contributory to the Disease

This cluster theme reflects that the mothers feel implicated in the occurrence of their children’s disease. The belief that they were responsible for kidney failure because of untimely medication and the lack of a well-timed referral to a specialist is hurtful. The feeling that chronic renal failure could have been prevented if the mothers had the necessary information is also painful for them. The mother of a daughter who has been receiving hemodialysis treatment for 3 years, Participant No. 2, shared her experience as follows:

“My child was suffering from urine reflux. If I did not stop the antibiotics and gave them regularly to him, this disease may not have occurred. I cannot forgive myself. I listened to my neighbors’ advice that the prescribed medications had side effects, so I stop administering them to my son. If the doctor had explained everything to me in full and if I had known about it, I could have given him all the medications in a regular manner”.

Participant No. 4, whose 10-year-old daughter was suffering from chronic renal failure because of a purulent sore throat, expressed the following sentiments:

“I always think about it. My child’s life was ruined just because of a sore throat. I think this event would not

have happened if we had visited a good doctor and if we had given him only a few pills. I really feel bad. I feel guilty”.

Sorrow and agony due to the suffering of children

This cluster theme reflects that seeing the pain and suffering of children can lead to grief and agony among mothers. This agony emerges from their having to watch the use of invasive treatments, the suffering of their children, heartfelt maternal bereavement, and living with restrictions on the children. Nearly all the mothers reported that they are severely distressed by their children's pain, controlled diet, restricted activities and games, and, particularly, water consumption limits. In this regard, Participant No. 10 added the following thoughts: *“Every time they insert these huge needles into my child's small and weak hands, I feel my heart being torn. There is so much suffering when you see that your child must endure lots of pain.”* Another mother said, *“Limited food and water consumption is more painful than all the other restrictions. Sometimes, my daughter secretly goes to our neighbor's house to drink water”* (Participant No. 2). As she wiped her tears, Participant No. 9 lamented, *“My daughter and I are fighting over the use of water. It really bothers me.”*

Sense of being ignored

This subtheme suggests that the mothers feel neglected and disappointed by the care provided to their children and that they regard people around them, including families and medical staff, as failing to understand their circumstances. The theme consisted of two subthemes, namely “Ignoring the maternal feeling by medical team” and “a sense of being unsupported by family and friends.”

Neglect of maternal feelings by medical team

Most of the participating mothers feel that their maternal emotions and feelings have been ignored by members of medical teams and that they are overlooked when they describe the conditions of their children. They also believe that their needs as mothers of children with incurable diseases are unsatisfied and excluded in the decision-making process. Participant No. 3, whose son has been undergoing hemodialysis for 2 months, explained her predicament thus:

“During discharge, the nurse came and talked quickly about some issues and handed me two papers about my child's diet and medications. Everything was blurred. I did not understand what the nurse was saying. I should emphasize that the nurses working here are well-tempered, but they do not care about mothers' feelings. They did not recognize me as the mother of that child”.

“I come here and sit for 4 hours. No one speaks with me. They only connect the machine to my child early

in the morning, and if the alarm of the system goes off, they come and check it without asking ‘Are you okay?’ I like to speak with someone”.

At the end of the interview, she said, *“I express my thanks because you listened to what I had to say and asked me about my feelings as a mother. I feel a little lighter.”*

The other mothers reiterated the need to get in touch with the members of medical team and talk about their feelings. For example, Participant No. 6, who is a nurse, stated,

“I work as a member of the medical team, but I believe that this team is awful. In the previous session, I could talk with the doctor for half an hour, and I felt a little better. I really needed to speak with someone who could make sense of what I was saying”.

Participant No. 4 added to the above-mentioned sentiments, stating,

“The nurses working here are really kind, but they just connect the machine to the children and go and sit at the table. During the first session, I had lots of specific questions in my mind, and I thought that I would annoy the nurses if I asked the questions”.

Given that an opportunity to express her feelings was provided to her during the research, Participant No. 8 exhibited satisfaction at the end of the interview: *“Thanks for listening to me. Here, the nurses do not ask about people's well-being and never speak with us. I know that they do not have enough time.”* In general, all the other participating mothers felt satisfaction after the interviews because of the opportunity to express their feelings.

A sense of being unsupported by family and friends

Most of the mothers participating in the study felt that their conditions are not understood by their families, relatives, and even their husbands. For example, Participant No. 3 said, *“It is so hard; no one does understand your conditions, even your husband. They blame mothers, even when children eat something that is not good for them.”*

Participant No. 6, stated, *“With a child on dialysis, the lives of the mother disappear; no one is paying attention to the mother. My sibling thought that was just I being over dramatic.”*

Discussion

The results revealed that the participating mothers were “immersed in an ocean of psychological tension.” The feeling that a child's life depends on regular hemodialysis and the fact that this procedure is invasive, time-consuming, and accompanied by complications or inconveniences caused considerable psychological pressure. The findings are consistent with those of other investigations, in which the parents of children with chronic kidney diseases were found to endure considerable tension and emotional pressure.^[9,11]

Aside from parenting, mothers assume health care providing roles, which can significantly affect their lives and compel them to endure tremendous agony and suffering.^[11] Mieto and Bouso (2014), who conducted her study in Brazil, indicated that the psychological, emotional, and social tension experienced by mothers is caused by adjustments to life routines based on hemodialysis sessions, resignation from work and loss of social status, dietary restrictions on children, limited participation in school activities and leisure time with other children, and the inability to change these conditions.^[9] The results of a systematic review by Tong *et al.* (2008) demonstrated that parents are confronted with more problems during the hemodialysis stage than the prehemodialysis and transplant surgery stages; thus, they encounter more mental and psychological pressures.^[7]

Endless concerns were one of the subtheme that emerged in the present study, confirming the findings of other investigations, in which lack of confidence in the provision of adequate care and the fulfilment of expectations from medical personnel, uncertainty about children's future, negligence of sick children's siblings, and financial problems were identified as causes of worry in mothers.^[7,25] In the current research, one of the factors causing grave distress was financial in nature.

Almost all mothers suffered from financial distress. In studies carried out in Australia, Netherlands, and Brazil, financial problems were also a major pressure factor due to the care burden of a child with chronic renal disease.^[9,10,26]

One of the other factors causing concern was the possibility of imminent death of the children, especially during hemodialysis treatment, and observing the children's blood circulation through the hemodialysis machine, triggered extreme fear, and anxiety in the mothers. In the study carried out by Mieto and Bouso (2014), "seeing the life of a child being sucked by the hemodialysis machine" was identified as part of mothers' experiences with hemodialysis. The mothers were afraid that their children may die while using the machine.^[9]

The mothers in the current work also identified sorrow and agony as sources of tension. The agony felt by the mothers stemmed from seeing suffering in their children. In similar studies, all the parents experienced considerable suffering and grief. Seeing needles and tubes connected to the bodies of their children is very painful for the parents, and the need to withhold water from the children was considered one of the worst measures in studies conducted in different countries.^[9,11] It should be noted that child care is affected when parents suffer. Parents often endure their misery in silence under the burden of a disease, and their emotional problems are rarely identified. Thus, medical team should actively seek to identify such pressures experienced by families.^[1] The majority of the mothers participating in the present study felt that their maternal needs, emotions, and feelings have been ignored by the members of health team; sometimes, they were even disappointed by the decision-making process. These findings align with the work

of Lindblad *et al.* (2005), in which the mothers stated that the medical team spoke about the serious and incurable states of their children without regard for the needs and feelings of the mothers. The team also ignored to discuss the need of mothers to express their feelings and only sent them back home with a sick child, thus driving the mothers to regard such treatment system as awful.^[27] The mothers participating in the present study were afraid to ask questions from nurses, who gave them incomplete information at inopportune times. Tong *et al.* (2010) showed that although most parents seek information about a disease and its treatment by health care experts and specialists, some parents avoid asking questions because they are afraid to be perceived as an annoyance or they are afraid to damage their relationships with the medical staff.^[11] Parents of children with chronic diseases also need information and support from medical teams, and they may suffer from lack of confidence in caring for their children without constant interaction with medical staff.^[10] If parents are uncertain about any dimension of caring, they may fail to effectively maintain treatment regimens.^[28] Mieto and Bouso (2014) suggested that clear information and adequate knowledge about a disease and its treatment reduces the stress and anxiety felt by mothers; thus, mothers are required to familiarize themselves with new and unknown environments and the culture of hemodialysis because exposure to high-technology environments can stimulate a sense of insecurity.^[9] Furthermore, positive relationships between parents and medical staff are considered a basic component of family-centered care.^[29] Mothers also become stronger through interactions with medical employees, family members, and children. These observations highlight the necessity of providing a place dedicated to discussing mothers' knowledge, family, and interests.^[9] The findings of the current study and the review of the literature suggested that the problems of children undergoing hemodialysis affect whole family functioning—an issue that holds true across various countries despite differences in culture. The effects of mothers on family dynamics were also an undeniable fact. Attention to services designed to address these issues can have profound and widespread effects on the social and emotional health status of families as the cornerstones of society. Studies should be conducted to identify or evaluate supportive interventions for mothers with children undergoing hemodialysis. The generalizability of the findings to contexts beyond the center from which the participants were sampled cannot be guaranteed. This limitation is associated with the nature of qualitative studies.

Conclusion

The main theme and subthemes, extracted in this study, represent the voices of mothers experiencing major psychological tension from having to deal with hemodialysis treatment for their children. The findings of this study and the review of existing literature showed that in all countries and despite different socioeconomic and

cultural conditions, the problems caused by the conditions of the child undergoing hemodialysis are so heavy that they affect the mother's physical, mental, and social health. The findings underscored the essentiality of taking multilateral support measures that correspond with the educational, emotional, psychological, and financial needs of mothers as nursing clients. Such measures should be implemented with the participation of multidisciplinary care teams.

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Conflict of interest

Nothing to declare.

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