

## Designing a Supportive Program based on the Real Needs of Mothers with Children Undergoing Hemodialysis: A Qualitative Study

### Abstract

**Background:** Mothers with children undergoing hemodialysis play the role of primary caregivers for their child and fully sacrifice themselves for care, leading to social isolation, suffering, stress, and negative effects on their health. Therefore, this study was conducted to design a supportive program based on the real needs of mothers with children undergoing hemodialysis. **Materials and Methods:** This qualitative study was conducted in the Hemodialysis Division of Doctor Sheikh Pediatric Hospital in Mashhad City, Iran, from September 2016 to February 2019. The research included phenomenological study, meta-synthesis of qualitative studies, focused group, and nominal group. Participants were selected based on purposive sampling. Eleven mothers with children undergoing hemodialysis and seven key people related to these mothers participated in the study. MaxQDA software was used to facilitate data management. **Results:** The six main areas including information needs, how to deal with the child, maintaining the mother's physical and functional health, maintaining family relationships, income earning and maintaining financial resources, and emotional-psychological support were extracted. Based on the needs of mothers, 28 support strategies were presented; then, 19 ideas were presented to screen the needs, and finally, the best idea was selected for each need. **Conclusions:** According to the findings of this study, mothers with children undergoing hemodialysis need support in various physical, psychosocial, informational, economic, and functional dimensions. The supportive program designed provides a systematic framework for screening the needs of these mothers and providing multifaceted support measures with the participation of a multidisciplinary care team.

**Keywords:** Child, chronic kidney disease, Renal dialysis, mothers, holistic nursing

### Introduction

Chronic Kidney Disease (CKD) can be a devastating disease with long-term consequences in children.<sup>[1]</sup> Hemodialysis is one of the kidney replacement therapies and a common method in controlling this disease,<sup>[2]</sup> which causes more psychological distress, lower quality of life, and more depression in the parents of these children than other alternative therapies.<sup>[3,4]</sup> Children undergoing hemodialysis are individuals with special health-care needs and are in high demand for care and supervision. Mothers play the role of primary caregivers for these children and sacrifice themselves.<sup>[5]</sup> When a child undergoes hemodialysis, the mother experiences drastic changes in her daily life.<sup>[2,5]</sup> These mothers are responsible for accompanying their children to hemodialysis sessions. The need to quit work and lose social status, anxiety about dietary restrictions, grief associated with

the impending death of the child, and their inability to change these conditions lead to their social isolation, suffering, stress, and negative effects on their health.<sup>[5,6]</sup>

Despite the increasing diagnosis of burnout, fatigue, side effects, and stress on these mothers, there is no credible evidence of supportive interventions in their required dimensions and well-being; also, their needs are often overlooked or not prioritized, while paying attention to services that are in line with the experiences and needs of the mothers of these children has profound and pervasive effects on their physical, social, and emotional health and their ability to cope effectively.<sup>[7]</sup> It indirectly leads to improvement of medical outcomes of the patient and whole family functioning.<sup>[7,8]</sup> This requires the medical staff to provide support services in various dimensions for mothers with children undergoing hemodialysis.<sup>[4]</sup>

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At present, only in some countries, including Canada and parts of the United Kingdom, children with CKD are treated at the multidisciplinary care clinic, while in most countries, including Iran, these children are treated in the nephrology ward. They are required to come to the hemodialysis ward 3 days a week with their parents, especially mothers, as the primary caregivers. Based on the available documentation and professional experience of the researcher, all the attention of the professional team is focused on performing hemodialysis of the child and their mothers are neglected as the main caregivers. Access to the experiences, needs, and beliefs of mothers of children under hemodialysis, followed by designing a supportive program for this group of people in the community, is an essential step toward achieving family-centered care and policies<sup>[9]</sup> and helps the treatment team support mothers in playing their role as caregivers.<sup>[10]</sup> Therefore, this study was conducted to design a supportive program based on the real needs of mothers with children undergoing hemodialysis.

### Materials and Methods

This qualitative study, using the phenomenological approach, meta-synthesis of qualitative studies, focused group, and nominal group, was conducted from September 2016 to February 2019. The study used the Strategic Directions for Supportive Care presented by the Victorian Government Department of Human Services.<sup>[11]</sup> This guide suggests four main steps in preparing and implementing a support program, which are: identifying the supportive care needs; capacity building for optimal supportive care; implementing supportive care screening into routine practice; and addressing supportive care needs, referral, and linkage. In the present study, the first three steps of this program were performed as follows [Figure 1].

In the first step, the needs of mothers with children undergoing hemodialysis were determined using a descriptive-interpretive phenomenological study and a meta-synthesis of available qualitative studies. Phenomenology as a qualitative study has an effective

role in clarifying the ambiguous and unknown areas of human issues and problems and achieving a deep knowledge of their experiences.<sup>[12]</sup> In this study, in order to extract the needs of mothers, descriptive-interpretive phenomenology with Van Manen’s approach was used. In total, 17 interviews were conducted with 11 mothers of children undergoing hemodialysis and referred to the hemodialysis ward of Doctor Sheikh Children’s Hospital in Mashhad, Iran. Two articles related to this part of the study have been published.<sup>[2,4]</sup> The details of the procedure are mentioned in these articles. In order to extract the needs of mothers with children undergoing hemodialysis in other countries, a comprehensive review of published articles was conducted. Based on the researcher’s searches concerning the supportive needs of these mothers, no study with quantitative approach has been conducted. Therefore, studies that examined the needs and experiences of parents with a child undergoing hemodialysis with a qualitative approach were systematically reviewed. This study was conducted within the framework of Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ).<sup>[13]</sup> In order to synthesize qualitative studies, this framework presents 21 items, which were followed in this study as well. One article related to this part of the study have been published.<sup>[14]</sup> The details of the procedure are mentioned in this article. Finally, descriptive and analytical themes extracted from the phenomenological study and literature review, which were in line with the supportive needs of mothers with children undergoing hemodialysis, were discussed by the expert panel. The panel of experts was formed with seven members, including four members of the research team and the Head of Nephrology and Hemodialysis Department and the Head Nurse and nurse of hemodialysis department of Doctor Sheikh Hospital. All extracted supportive needs were approved by the members.

In the second step, a focus group was used to assess the Strengths, Weaknesses, Opportunities, and Threats (SWOT) for finding the current status. Eight key people related to mothers with children undergoing hemodialysis were invited to participate in the group. Finally, a focus group was formed with seven key members related to the research population, whose characteristics are stated in the findings. At first, the researcher had a brief overview of the topic under discussion, research objectives, general rules, and meeting time. Then, a list of identified mothers’ needs and a guide framework with SWOT information were provided to the group members. After providing explanations and clarification on the issues under discussion, questions were raised. Since the issues were not covered in one session, the second session of the focus group was held with five members. In each session, audio recording and note taking were done. After the implementation and analysis of the sessions, in order to answer some questions in the mentioned cases, interviews were carried out with some

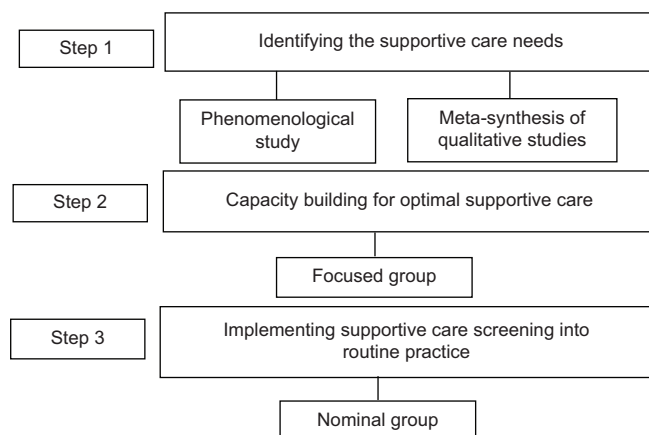


Figure 1: Steps of designing supportive program

people who were present at the meeting and had a closer relationship with the research population, including social workers, nurses, and head nurses in the hemodialysis department. After collecting data in this section, SWOT tables were designed in line with the needs extracted. Then, based on the comparison of the needs extracted from the present study with the current status, the gaps were identified. Based on existing weaknesses and opportunities as well as threats and strengths, supportive solutions were provided. Finally, the proposed support solutions were reviewed and completed by the researchers (T. P. and M. M. B). At the end of the work, these items were presented to the participants in the focused group in a tabular form and their corrective comments were applied.

In the third step, in order to use the appropriate approach for how to identify the needs of the target population, the views of a nominal group were used. First, key people related to the research population as well as four mothers with children undergoing hemodialysis were invited to participate in the group. Finally, a nominal group was formed with six members, including matron of Doctor Sheikh Hospital, Health Education Supervisor and Head of Quality Improvement Office, Head Nurse and nurse of hemodialysis department, social worker of the hospital, and a mother.

Trustworthiness of the study was confirmed using the credibility, dependability, confirmability, and transferability criteria presented by Lincoln and Guba, cited by Pourghaznein *et al.* (2018).<sup>[4]</sup> To enhance the credibility of the data, the researchers used an interview guide that was prepared on the basis of previous studies and discussions among the members of the research team. Additional credibility measures were taken in the form of selection of a diverse group of participants exhibiting considerable experience in terms of hemodialysis duration (2 months to 8 years). Also, the people who had the most contact with the research community were selected to participate in group discussions. To foster co-construction of meaning between the researchers and the participants, the former undertook prolonged engagement with the latter. Also, the first author (T. P.) 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. To ensure dependability, the researchers kept audit trails. In this regard, the process of analyses, quotes, and the emergence of themes were presented in detail. With regard to confirmability, the transcripts of some of the interviews with the extracted codes and themes were assessed by an external party to determine the accuracy of the coding process. In terms of transferability, extensive descriptions of the field and findings are presented, so that readers can decide on the uses of the results in other areas.

### **Ethical considerations**

This study was approved by the ethics committee of Mashhad University of Medical Sciences with the code

IR.MUMS.REC.1395.337. All participants were informed about the goals and type of study and they completed a written consent form. Interviews and meetings were ended whenever the participants wished. Interviews were kept confidential using pseudonyms and deleted after implementation.

### **Results**

A total of 11 mothers with children undergoing hemodialysis and seven key people related to these mothers participated in the study. The mothers were between 23 and 51 years of age. The mean (SD) score of the age of mothers was 38 (9.00). In terms of education, four mothers were illiterate, three had completed primary school education, three held high school diplomas, and one mother had an academic degree. One of the mothers was a nurse, whereas the rest were housewives. One of the participants' husbands had died, but the rest were living with their spouses. Their children were aged between 5 and 15 years; the mean (SD) score was 9 (3.00). The duration of hemodialysis treatment for the children ranged from 2 months to 8 years. The seven members participating in the group discussions included the matron of Doctor Sheikh Hospital, Head of Nephrology and Hemodialysis Department, Head Nurse and nurse of hemodialysis department, Clinical Supervisor, Health Education Supervisor and Head of Quality Improvement Office, and a social worker. Their work experiences were between 12 and 28 years; the mean (SD) score was 21.57 (5.62). The duration of their relationship with children undergoing hemodialysis was between 3 and 26 years; the mean (SD) score was 8.16 (8.84).

In the meta-synthesis section, out of 567 studies, 7 articles were reviewed. In these articles, the experience of 70 mothers with children undergoing hemodialysis in Iran, the Netherlands, Australia, Brazil, Turkey, and Canada was reviewed. All seven studies were conducted using the naturalistic paradigm and provided rich information about mothers' experiences. The main research findings are presented in the following three general sections.

### **The needs of mothers with children undergoing hemodialysis based on phenomenological studies and published articles**

From the synthesis of the results of phenomenological study and meta-synthesis of qualitative studies, finally six main themes were identified, including information needs, strategies on how to deal with children, maintaining mothers' physical and practical health, maintaining family relationships, earning money and maintaining financial resources, and emotional-psychological support. These themes were extracted in five dimensions: information, emotional, psychological, social, and economic [Table 1].

### Findings from the focused group to review the current status and support strategies

As mentioned, after collecting the data in this section, the SWOT tables were designed in line with the extracted needs. Then, based on the existing weaknesses and opportunities, as well as threats and strengths, supportive solutions were provided [Table 2].

### Results of the nominal group in relation to the appropriate approach for screening the needs of the target population

In order to use the appropriate approach for identifying the needs of the target population, the opinions of a nominal group were used. At this stage, 19 ideas were presented by the participants. In the idea clarification stage, each idea was discussed; after discussion about the proposed ideas, a secret ballot was conducted in the last stage and the best solution was selected to screen the needs of the community. Table 3 shows the appropriate approach for screening the needs extracted from the present study.

### Discussion

In this study, in order to extract the needs of the target population, a descriptive-interpretive phenomenological study was used. On the other hand, a comprehensive review of existing studies and comparison of the results with the present study showed that despite cultural, economic, and social differences in different countries including Iran,

Australia, Canada, the Netherlands, Turkey, and Brazil, the needs of mothers with children undergoing hemodialysis are similar. The complex and time-consuming nature of hemodialysis has led experts to design and implement some programs to support parents of children with chronic kidney disabilities. For example, in the United Kingdom, Swallow *et al.*<sup>[15]</sup> presented a study protocol whose aim was to understand the training details by using multidisciplinary teams to provide home care for parents of children with chronic kidney failure. The protocol was designed to involve 12 pediatric kidney units in England, Scotland, and Wales. In 2015, Swallow *et al.*<sup>[16]</sup> reported the findings of this study by describing the type of interactions between parents and treatment staff. The nature and purpose of this study is different from the present study, but the important point in this study is the focus on the burden of care imposed on parents of CKD children, which necessitates appropriate and effective interactions with the treatment team. On the other hand, the study indicates that children are supervised by multidisciplinary teams in these centers.

In the same year (2012), Swallow *et al.*<sup>[17]</sup> presented another study protocol with the aim of developing and evaluating an online educational-supportive package for parents for the home care of children with CKD. They evaluated this web application in a study in 2014.<sup>[18]</sup> With regard to the clinical information part of caregiving, parents believed that reliable and evidence-based information was not enough. Parents suggested a section called Q and A that was interactive and by which they could communicate with the treatment staff. Of course, some parents preferred phone calls and face-to-face communication. In the psychosocial support part of caregiving, parents believed that it was necessary to provide solutions to manage the stress caused by the child's future, limitations, the child's educational status, and financial problems. In addition to the shortcomings mentioned above, the implementation of such programs requires access to computers and the Internet, which some families may not be able to do or may be bored of and find it time consuming. In the same study, it was mentioned that only 37.6% of the invited people participated in the study, which could be one of the reasons for this. Also, one of the parents' preferences in this study was face-to-face communication with the treatment team. Since children undergoing hemodialysis and their parents have to be in the ward 3 days a week for 4 hours at a time, this is a good opportunity for the parents and the treatment team to communicate properly in order to meet the needs of the families. The present program is designed specifically for mothers with children undergoing hemodialysis, and the practical solutions required by this special group, including the management of child restrictions, traveling, and optimal use of hemodialysis time, have been considered.

Another study was carried out in the Netherlands by Geense *et al.*<sup>[19]</sup> with the aim of evaluating and developing an online support program for parents of children with

**Table 1: Needs of mothers with children undergoing hemodialysis based on phenomenological study data and meta-synthesis of qualitative studies**

Themes	Sub-themes
Information needs	Disease and treatment process Medicinal regimen Diet Awareness of services provided
Strategies on how to deal with children	Management of food restrictions in children Management of mental problems in children Providing educational conditions for children
Maintaining mothers' physical and practical health	Allocating time for rest Helping with household chores Helping with children's transport Helping with child care Helping with care for other children
Maintaining family relationships	Family counseling Interactions with other family members
Earning money and maintaining financial resources	Helping with securing parental employment Financial support Helping with providing housing close to hemodialysis center
Emotional-psychological support	Support by family, relatives, and friends Support by medical and health-care staff Interactions with peer groups Psychological counseling

**Table 2: Supportive strategies based on the needs of mothers with children undergoing hemodialysis**

Needs	Strategies
Information	Preparation of educational packages related to the disease and the treatment process, diet, following medication instructions, and using the services provided and financial aid Developing a systematic, transparent, documented, and appropriate educational process for stakeholders Holding counseling sessions at the beginning of treatment Applying different methods to provide in-person and electronic information (online or offline) through clinical experts, parent networks, and health-care professionals
Strategies on how to deal with children	Providing counseling services by a child psychologist to present practical solutions to justify the child and manage fluid and certain food restrictions Psychological counseling to manage the child's psychological problems and provide adequate information about disorders such as depression and aggression in these children Holding counseling sessions by a psychologist for children
Maintaining mothers' physical and practical health	Providing appropriate conditions for children to continue their education Providing appropriate facilities for transportation Identifying, organizing, and attracting family sponsors, donors, and the home care unit in order to organize home affairs and personal problems Distribution of iron-enriched snacks and multivitamins during hemodialysis hours for children and mothers Providing free invitations to leisure centers and parks Holding happy and free sports classes as much as possible in gyms near the hospital for mothers while their child is on hemodialysis
Maintaining family relationships	Allocating centers with the presence of a supervisor in order to take care of other young children in the family Providing family counseling and drawing the participation and cooperation of family members Helping solve parents' financial and employment problems
Earning money and maintaining financial resources	Interacting with insurance organizations and developing insurance coverage Interacting with health donors to gain more support Identifying the groups at higher risks with a thorough initial assessment of the family's social and economic status, including occupation, income, and place of residence More interaction with the Charity Foundation for Special Diseases Helping provide housing near the dialysis ward Consulting with some institutions and companies to allocate funds on a monthly basis to provide services to children undergoing hemodialysis
Emotional-psychological Support	Providing written programs for interaction with the medical staff, including physicians and nurses for appropriate interaction Allocating time and space to interact with peer groups and share experiences Establishing an emotional connection with the child and making the hemodialysis environment as pleasant as possible, including getting help from play therapy groups, holding parties, and giving gifts to children Holding festivals during the year with the presence of old hemodialysis patients who have undergone kidney transplantation and benefiting from their experiences Screening the psychological problems of mothers and children and performing interventions to control the identified problems

CKD. In this study, based on a review study and a focused group discussion, the needs of parents of children with CKD under different treatments were identified. According to this program, parents are strengthened in three electronic sections: educational section with information about CKD and its treatment, an interactive section where parents can communicate with other parents and health-care professionals through chat or private messages, and educational platform consisting of four items, that is, stress management, regulating limitations, communication, and effective coping with emotions. This study is a step toward family-based care and is invaluable. However, as suggested

by the researchers, the success of such programs depends on their use by parents and professionals. On the other hand, the use of web applications varies based on culture and community conditions. This study, similar to the study by Swallow *et al.* (2014),<sup>[18]</sup> included children with CKD at different stages and under different treatments, while the needs of families in different treatments for CKD were different. Several studies showed that parents of children undergoing hemodialysis experience major limitations and have different needs, and the time spent in the hemodialysis department provides a good opportunity to implement a support program, and thus could be used

**Table 3: Ideas for screening the needs of mothers with children undergoing hemodialysis**

Needs	Ideas
Information	In general, all mothers should be provided with the necessary information about the disease and treatment process, medication regimen, diet, rest, and activity. In addition, meetings should be held with mothers to assess further information needs
Strategies on how to deal with children	Evaluation by a child psychologist and, if necessary, providing periodic counseling sessions
Maintaining mothers' physical and practical health	Preparation of a questionnaire and evaluation by the social worker and the relevant nurse
Earning money and maintaining financial resources	Preparation of a questionnaire and evaluation by the social worker and the relevant nurse
Maintaining family relationships	Evaluation by a clinical psychologist and, if necessary, providing periodic family counseling sessions
Emotional-psychological support	Screening of psychological problems of mothers and children by a psychologist Codified programs for interaction with the treatment staff and peer group and establishing emotional communication with the child and making the hemodialysis environment as pleasant as possible for all clients

in a good way. The findings of this study and the available texts showed that, the problems caused by the condition of the child undergoing hemodialysis are so severe that the physical, mental, emotional, and social health of the mother, and subsequently, the functioning of the whole family are affected, which can have financial and political consequences for the health-care system. Therefore, it is suggested that mothers with children undergoing hemodialysis should be considered as nursing clients, and in addition to providing educational services and emotional support by nurses, interventions should be done in line with their needs with the participation of a multidisciplinary team. In the literature available, only in some countries, including Canada and parts of the United Kingdom, children with CKD are under care in the multidisciplinary care clinic with the presence of the specialist doctor, a kidney specialist, a nutritionist, a pharmacist, a social worker, and a clinic information manager,<sup>[17,20]</sup> while in most countries, including Iran, these children are supervised in nephrology clinics and no special supportive measures are taken for their families and especially their mothers as primary caregivers. Integrating the extracted needs in different communities increases the applicability of the designed program. However, the program is based on the situational analysis of a hospital in Mashhad, which reduces generalizability; this is considered as a limitation of this study.

### Conclusion

According to the findings of this study, mothers with children undergoing hemodialysis need support in various physical, psychosocial, informational, economic, and functional dimensions. The supportive program designed provides a systematic framework for screening the needs of these mothers and providing multifaceted support measures with the participation of a multidisciplinary care team. On the other hand, meta-synthesis of qualitative studies and integrating the extracted needs in different communities increase the applicability of the designed program.

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### Conflicts of interest

Nothing to declare.

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