Evidence Based Care Journal

http://ebcj.mums.ac.ir/

Basic Needs of Mothers with Children Undergoing Hemodialysis: A Meta-synthesis of Qualitative Studies

Tayebe Pourghaznein, Zahra Sadat Manzari, Abbas Heydari, Mojtaba Mousavi Bazaz

The online version of this article can be found at http://ebcj.mums.ac.ir/article_12015.html

Evidence Based Care Journal 2019 08:14 originally published online January 2019 DOI: 10.22038/ebcj.2018.31975.1797

Online ISSN: 2008-370X





Evidence Based Care Journal

Review Article



Basic Needs of Mothers with Children Undergoing Hemodialysis: A Meta-synthesis of Qualitative Studies

Tayebe Pourghaznein¹, Zahra Sadat Manzari^{2*}, Abbas Heydari³, Mojtaba Mousavi Bazaz⁴

Received: 30/05/2018 **Accepted**: 12/12/2018

Evidence Based Care Journal, 8 (4): 14-25

Abstract

Background: Mothers of children undergoing hemodialysis encounter severe changes in their daily lives. It is of utmost importance to raise the awareness of treatment teams about the needs of these specific groups of mothers and different problems they may experience. The reason is that it can help health care professionals to support the mothers to fulfill their roles as the primary caregivers of such children.

Aim: This study aimed to identify basic needs in mothers of children undergoing hemodialysis.

Method: This meta-synthesis review of qualitative studies investigating the needs and experience of mothers whose children had kidney disease and published from January 1997 to October 2017. The articles were searched in four databases, including Web of Science, EMBASE, PubMed, and ProQuest. The search process was accomplished using the keywords "chronic kidney disease," "hemodialysis," "children," "mothers," "parents," "caregivers," "needs," "experiences," "perspectives," and "perceptions". Finally, 7 articles were chosen out of 567 papers and theses. The MAXQDA software was used to facilitate data management.

Results: The systematic review of the qualitative studies revealed three main themes, including the need for child care management skills, the need to maintain family cohesion, and the need for emotional–psychological support.

Implications for Practice: Mothers of children under hemodialysis should be considered as nursing clients. Accordingly, a multidisciplinary team can empower mothers to take care of the children under hemodialysis and preserve family coherence, as well as supporting them emotionally and psychologically.

Keywords: Care needs, Children, Chronic kidney disease, Hemodialysis, Mothers, Systematic review

^{1.} PhD Student in Nursing, Department of Medical-Surgical Nursing, School of Nursing and Midwifery, Mashhad University of Medical Sciences, Mashhad, Iran

^{2.} Ph.D. of Nursing, Assistant Professor, Department of Medical-Surgical Nursing, School of Nursing and Midwifery, Mashhad University of Medical Sciences, Mashhad, Iran

^{3.} Ph.D. of Nursing, Professor, Department of Medical-Surgical Nursing, Evidence-Based Care Research Center, School of Nursing and Midwifery, Mashhad University of Medical Sciences, Mashhad, Iran

^{4.} Associate professor, Department of Community Medicine, Faculty of Medicine, Mashhad University of Medical Sciences, Mashhad, Iran

^{*} Corresponding author, Email: manzariz@mums.ac.ir

Introduction

Children undergoing hemodialysis have special needs that heavily demand health care provision and supervision (1). Examples of such needs include continuous monitoring and the invasive and time-consuming process of hemodialysis, which can also bring great challenges for their parents (2). In fact, parents of these children experience a great deal of stress due to the hazardous nature of kidney disease and uncertain future of their children (3). They try to contend with the burden of the treatment management of their sick children, as well as balancing their daily responsibilities and caregiving role (3, 4).

Studies on these issues indicated that mothers are the primary caregivers of children undergoing hemodialysis, and suffer from lower levels of life quality and higher degrees of psychosocial stress, compared to the fathers. These mothers dedicate themselves completely to caregiving, a decision that can bring about social isolation, pain, as well as health issues (1, 5). Such mothers may encounter severe changes in their daily lives as their children undergo hemodialysis (1). Given that they are responsible for attending hemodialysis sessions with their children and establish daily routines on the basis of the hemodialysis process, they are compelled to abandon their jobs and lose their social standing. Moreover, such mothers are troubled with concerns about dietary restrictions, and have limited participation in leisure activities and the schooling of their other children. As a results, the inability of these mothers to change the conditions related to hemodialysis has detrimental effects on their mental, emotional, and social status (1).

The psychosocial and economic effects on the caregivers of children undergoing hemodialysis compel treatment teams to care for caregivers as much as the children (6). However, health care services are often focused on the interventions targeting children rather than strategies that specifically concentrate on their parents (7). Despite an increase in the recognition of the fatigue, burnout, pressure, and other side effects stemming from caregiving for these children, maternal needs are often overlooked or unprioritized (8, 9). Identification of mothers' values, needs, and attitudes is an essential step toward the development of care- and family-based policies (10). Furthermore, it is important for health care professionals to know about the basic needs and difficulties of the mothers (2), because it helps treatment teams to support mothers in their roles as care managers of children suffering from kidney disease (11).

The provision of necessary services to satisfy the basic needs of mothers can have profound and comprehensive effects on their well-being and their ability to effectively cope with their situations. These outcomes, in turn, can indirectly improve the medical and psychological outcomes of a sick child and the overall performance in families (8, 12, 13). Maternal priorities and concerns that have previously been undetermined can be directly ascertained using evidence derived from qualitative studies (10). Correspondingly, the present research identified the basic needs of mothers with children undergoing hemodialysis through a systematic review of previous qualitative studies and the recognition of common themes regarding mothers' experiences.

Methods

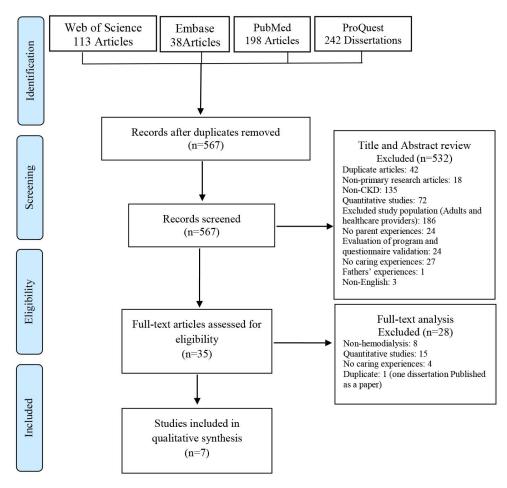
This study was based on the framework of enhancing transparency in reporting the synthesis of qualitative research (14). This framework provides 21 items grouped into five main domains, namely introduction, methods and methodology, literature search and selection, appraisal, and synthesis of findings. These domains were pursued in the current study as follows:

In the first and second domains, the purpose of the study was determined. The present research aimed to identify the basic needs of mothers with children undergoing hemodialysis through a systematic review of previous qualitative studies and the recognition of common themes regarding mothers' experiences. The researchers then came to agreement on the inclusion and exclusion criteria. This systematic review included studies, thesis, and dissertations that explored the experiences, attitudes, and needs of mothers with children undergoing hemodialysis. Additional inclusion criteria were the use of a qualitative approach, as well as publication in the English language and over the last 20 years. The third domain was the literature search and article selection. Articles, thesis, and dissertations published from January 1997 to October 2017 were searched on four databases of Web of Science, EMBASE, PubMed, and ProQuest. Electronic search was performed using the keywords of "chronic kidney disease," "hemodialysis," "renal replacement therapy," "long-term conditions," "life-limiting conditions," "children," "mothers," "parents," "caregivers," "needs," "experiences," "perspectives,"

and "perceptions." The Boolean operators "AND" and "OR" were used to fine-tune the search. The references indicated in the identified documents were also searched. In the first stage, all the articles whose titles or abstracts feature the keywords were included in the initial list. On the basis of the title and abstract review, some studies were eliminated because they were not aligned with the objectives of the current study. In the second stage, the full texts of the remaining articles were analyzed, and irrelevant studies were excluded (Figure 1). Finally, 7 papers were included out of 567 papers and theses.

In the fourth domain, the articles entered into the study were evaluated based on three dimensions of research team, research design, and data analysis (15). Based on the evaluation of studies report, no study was eliminated. Table 1 shows the characteristics of reviewed studies. Finally, the fifth domain entailed the synthesis of the findings using MAXQDA software. The results and conclusion sections were reviewed line by line and coded using the three-step thematic synthesis described by Thomas and Harden (16). Accordingly, steps one and two involved the precise review of the full texts as well as coding the themes, sub themes, and quotes presented in the articles by the first author. Subsequently, codes were classified based on the similarities and inter-relationships of the codes. Semantic units were extracted from all the articles, after which coding was conducted. The codes were then placed under the existing categories or used to form a new category, which led to the emergences of the descriptive themes. To ensure the extraction of all semantic units, the texts, initial codes, and descriptive themes were studied by two of the researchers (Z. M. and A. H.), and then there was an agreement among all the three reviewers.

In the first and second steps, the very close relationship with the findings of the main studies was maintained, and in the third step, analytical themes were created. Given that these steps are the most controversial ones in thematic synthesis, they were conducted independently by two of the researchers



CKD: chronic kidney disease

Figure 1. Literature search

		Table	<u>e 1. Chara</u>	cteristics of the i	included stud	ies
Ref. no.	Article Title	Country	Mothers N.	Methodology	Data collection methods	Result
3	The support needs of parents having a child with a chronic kidney disease: a focus group study	Netherland S	5	Thematic Analysis	Focus group interviews	Information needs (about their child's CKD, regarding their child's medication, their child's diets, managing their own work and hobbies) Emotional needs (the emotional support of their partner, family, friends, peers, and health professionals) Practical support needs (to hand over care in transportation, in financial management, in school)
17	Parental perspectives on caring for a child with chronic kidney disease: An in- depth interview study	Australia	2	Thematic Analysis	In-depth interview	Absorption of clinical environment, medicalizing parenting, disrupting family norms, coping strategies and support structures Needs to receive support from their health care providers, needs to have meetings and learn from other parents, and information needs
18	Parental perspectives on the financial impact of caring for a child with CKD	Australia	6	Thematic Analysis	Semi structured interviews	Loss of freedom and control, struggle in seeking support, instability of circumstances, adapting for survival, burden of sole responsibility
1	The mothers' experiences in the pediatrics hemodialysis unit	Brazil	11	Grounded Theory	Interview	Mother's life imprisoned by the hemodialysis machine
20	Stress factors and coping strategies of parents with children treated by hemodialysis: A qualitative study	Turkey	25	data analysis	Focus group interviews	Common stress factors of parents included financial and bureaucratic problems, growth and development of ill children, fluid-diet restriction and educational problems of children, lack of social support, and anxiety about losing their children at any moment Coping strategies of parents were to give their attention to the positive side of matters, to share their feelings with their spouse or other parents, to cry, or pray
19	Meanings of maternal Caregiving: Children with end stage renal disease	Canada	10	mixed-method (interpretive ethnographic)	Prolonged observations. In-depth interviews	Trapped caregivers, adaptive caregivers, embedded caregivers
21	Immersion in an ocean of psychological tension: The voices of mothers with children undergoing hemodialysis	[Iran	11	hermeneutic phenomenology	In-depth interview	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"

Table 1. Characteristics	of the included studies
Table 1. Characteristics	of the included studies

CKD: chronic kidney disease

(T. P. and Z. M.). The extracted themes were then discussed and agreed upon by all the three reviewers. Table 2 provides an example of the coding process. The findings in the current study presented the quotations of participants or interpretations of authors.

Table 2. An example of the coding process				
Meaning units	Primary codes	Descriptive themes	Analytical theme	
My husband lost four jobs, because he have to take vacations so that he can take our son to hospital (20).	Father's job loss			
You have to undergo your job so that you can provide ongoing care (19).	Disturbance in father's job			
Some felt they had to refuse new occupational opportunities, because they had to be highly focused on the child's medical needs (17).	Losing new job opportunities	Helping with securing parental		
Employed mothers had to leave their job (1).	Child disease prevents mother employment	employment		
"It is my job that energizes me, it is the thing that I need (3).	Need to maintain the job			
Reduced working rank or less working hours, all of which are the result of childcare (18).	Decrease rank in work or working hours			
Most parents state that they live in economic crisis (20).	Inappropriate financial situation		-	
We faced a great backwardness in work and income level, and our income did not return to the better previous level and we still live with very limited wages (17).	Financial restraint	Financial	Earning money and maintaining financial	
Need for receiving direct and indirect financial supports from the government (17).	Request for financial support	support	resources	
Consecutive periods of complete loss of financial resources, and low incomes and living below the poverty line (18).	incomes and			
Children should go to hospital several days per week, and there are only three centers for children dialysis in Netherlands in long distances (3).	Long distance between residence place and hemodialysis center		-	
Long distance between residence place and hemodialysis section incurs great financial burden on the family (21), Long distance from the hemodialysis department to the residence place imposes on households the costs of fuel, food, parking, parking, and other travel-related expenses (17).	Imposing financial burden due to distance from the center	Helping with providing housing close to hemodialysis center		
Some mothers were forced to rent a house in the city with hemodialysis center with their sick child far away from the family (18).	Renting house near the equipped center			

Results

The synthesis of the results revealed three main themes, namely, *the need for child care management skills, the need to maintain family cohesion*, and *the need for emotional–psychological support*. Table 3 indicates the structure of the extracted themes and their subthemes.

Themes		tructure of the extracted t	Ref. no.	
		Disease and treatment	Mieto & Bousso (2014), Medway & et al.	
		process	(2015)	
		Medicinal regimen	Geense & et al. (2017)	
	Information needs	Wedlemarregimen	Medway & et al. (2015), Cimete (2002),	
		Diet	Geense & et al. (2017)	
Need for		Awareness of services	Medway & et al. (2015), Nicholas (1999),	
child care		provided	Geense & et al. (2017)	
management		Management of food		
skills	Strategies on how to deal with children	restrictions in children	Medway & et al. (2015), Cimete (2002)	
		Management of mental	Medway & et al. (2015), Cimete (2002), Tong	
		problems in children	& et al. (2010)	
		Providing educational conditions for children	Geense & et al. (2017), Cimete (2002)	
		Allocating time for rest	Mieto & Bousso (2014), Cimete (2002),	
	Maintaining mothers'	Allocating time for rest	Medway & et al. (2015), Tong & et al. (2010)	
		Helping with	Medway & et al. (2015), Geense & et al.	
		household chores	(2017)	
			Mieto & Bousso (2014), Cimete (2002),	
	physical and	Helping with	Nicholas (1999)	
	practical health	children's transport	Medway & et al. (2015), Tong & et al.	
			(2010), Geense & et al. (2017)	
		Helping with child care	Geense & et al.(2017), Tong & et al (2010)	
Need to		Helping with care for	Mieto & Bousso (2014), Cimete (2002)	
maintain		other children	Medway & et al. (2015)	
family cohesion	Maintaining family relationships	Family counseling	Medway & et al. (2015), Nicholas (1999), Tong & et al. (2010)	
		Interactions with other family members	Medway & et al. (2015), Nicholas (1999)	
	Earning money and maintaining financial resources	Helping with securing parental employment	Geense & et al. (2017), Cimete & et al. (2002)	
		Financial support	Geense & et al. (2017), Cimete & et al. (2002) Nicholas (1999), Tong & et al (2010)	
		Helping with providing	Geense & et al. (2017), Nicholas (1999)	
	105001005	housing close to		
		hemodialysis center		
	Support by	2	Mieto & Bousso (2014), Cimete & et al.	
	family, relatives,		(2002), Medway & et al. (2015), Geense & et	
	and friends		al. (2017)	
	Sunnort h		Mieto & Bousso (2014), Cimete & et al.	
	Support by medical and		(2002)	
Need for	health care staff		Medway & et al. (2015), Geense & et al.	
emotional-			(2017)	
psychological	Interactions with		Medway & et al. (2015), Geense & et	
support	peer groups		al.(2017)	
		Strategies to Manage	Medway & et al. (2015)	
	D 1 1 1 1 1	Conflicting Roles	Geense & et al. (2017), Tong & et al. (2010)	
	Psychological	Screening for	Mieto & Bousso (2014), Cimete & et al.	
	counseling	Psychological	(2002)	
		Problems	(2002) Medway & et al. (2015), Tong & et al. (2010)	
		1 IOUICIIIS	(2010), (2013) , 1000 & et al. (2010)	

1. The Need for Child Care Management Skills

This theme implies that the constraints stemming from the complex process of treatment and care pose a major challenge to mothers. Therefore, mothers need to develop skills related to child care management.

1.1. Information Needs

Five of the studies reported that the mothers expressed their need to gain increasingly specialized information (1, 3, 17-19). Despite the unreliability of online sources, mothers have to search the Internet for information because health care professionals do not provide complete explanations (3). In general, these studies identified the need for more information on kidney disease, as well as its treatment, medicinal regimens, diets, and the available services.

1.1.1. Disease and Treatment Process

Transparent information and sufficient knowledge about the disease and its treatment are important since they can reduce stress and anxiety in mothers (1, 19).

1.1.2. Medicinal Regimen

Geense et al. discussed the need for more information on the negative effects, different doses, and methods of medication. The mothers participating in the study asked for practical tips on how to administer medications to their children in an accurate and regular manner (3).

1.1.3. Diet

The mothers also required information and tips on managing their children's diets, including reducing their protein, sodium, potassium, phosphorus, or liquid intake. In other words, mothers need to eliminate certain nutrients for normal child growth; accordingly, a good knowledge of alternative foods is important (3, 19).

1.1.4. Available Services

According to a study conducted by Medway et al., parents need a systematic method to ensure that they are aware of all the available services, including parking permission or child care funding (17). The participants in a study conducted by Tong et al. declared that information should be provided online or distributed by parent networks, clinical experts and health care professionals in the form of pamphlets or videos (19).

1.2. Strategies for Managing Children's Problems

Mother-child conflicts, including observing diet and water restrictions, child mood disorders, and educational backwardness, and academic failure, contribute to the despondency of mothers. In this regard, the mothers participating in the evaluated studies identified the following needs:

1.2.1. Managing Food Restrictions for Children

Tong et al. indicated that diet management and limitations on liquid intake are extremely challenging. The participants added the following statements: "*Maybe I call it chronic renal failure and you can cope with it, but the problem of food intake for a sick child is really big and troublesome.*" Withholding water from children was one of the worst requirements described by the mothers (19). In a study performed by Cimete, the mothers expressed the bitter experience of setting restrictions on the consumption of liquids and some foods for their children (20).

1.2.2. Managing Psychological Problems in Children

According to Tong et al., mothers consider the management of mental health in children difficult, and they lack adequate support and information about disorders, such as depression and aggressiveness, in children suffering from chronic kidney disease (19). Physical constraints, growth retardation, and changes in the appearance of children distance them from their peers, which led to anxiety in children, and consequently in their parents (20).

1.2.3. Providing Education for Children

In the study by Cimete, 87% of the parents stated that their children's conditions had negative effects

on their education, a problem that is a source of great sorrow for the children and their mothers. One of the mothers expressed her expectations from a hospital as follows: "I do not think my child will die in the short term, so I want to be constructive and useful in her life. There should be an opportunity for my child to continue his education in this situation." (20).

2. The Need to Maintain Family Cohesion

The incurable, invasive, and time-consuming process of hemodialysis can affect an entire family. In the reviewed studies, the mothers expressed different needs for maintaining family cohesion.

2.1. Maintaining the Physical and Functional Health of Mothers

Overwhelming care requirements, exhausting commutes, and other needs threaten the health of mothers. Some of the issues in this regard are explained below.

2.1.1. Allocating Time for Rest

Mieto and Bousso reported that the mothers allocated little time to their sleep and rest (1). Likewise, the mothers in the study by Cimete said "We don't have any day to sleep comfortably anymore." (20).

2.1.2. Helping with Household Chores

Hospital visits and in-home health care services mean that mothers cannot fulfill other family responsibilities, including cooking and cleaning (19, 21). The mothers declared that they need practical support in doing household chores; therefore, they can have more time for themselves, their spouses, family life, or their work (3).

2.1.3. Helping with Children's Commutes

It cannot be ignored that establishing daily life routines on the basis of the hemodialysis process and accompanying children three times a week pose serious challenges for mothers and their families (1, 3, 17-20).

2.1.4. Helping with Child Care

In all the reviewed studies, the participants expressed their need for assistance in terms of taking care of their sick children. Geense et al. indicated that the mothers benefit from the social support provided by in-home nurses, who can, for example, administer injectable growth hormones to children whose parents are unable to do so (3).

2.1.5. Helping with Care for Other Children

One of the major concerns of the mothers was the short amount of time that they can dedicate to their other children (1, 19-21). One of the mothers in the study by Cimete shared the following statement: *"I sometimes forget that I have another child."* (20).

2.2. Maintaining Family Relationships

Incurable diseases and the time-consuming process of treatment tremendously affect family relationships. According to the experiences of the mothers participating in the evaluated studies, the following measures are required.

2.2.1. Family Counseling

The problems that the sick children encountered, especially those at the onset of the disease, led to conflict and tension between the parents (17-20). In a study performed by Nicholas, one of the mothers revealed that her husband left them because he could not adapt himself to having a sick child (18).

2.2.2. Interacting with Other Family Members

The exhausting and time-consuming process of treatment, parental involvement, and financial problems can affect all aspects of family functioning. According to the findings of the studies conducted by Tong et al. (19) and Medway et al. (17), the participants were compelled to disregard entertaining activities, such as dining out, going on family holidays, and participating in

2.3. Earning Money and Maintaining Financial Resources

Financial problems were taken into account as the leading source of the pressure regarding taking care of children with chronic kidney disease (17). The studies needed to address these problems are as follows:

2.3.1. Securing Parental Employment

Schedule managements on the basis of the hemodialysis process can lead to employment challenges among parents, particularly mothers, who serve as the main caregivers of sick children. The results of all the reviewed studies indicated that the parents were compelled to work fewer hours or even leave their occupational status although they needed their jobs.

2.3.2. Financial Support

Problems with parental employment, medical costs, and commutes can give rise to economic crises and the need for financial support for most families (3, 17, 21). In the study by Cimete, 29 out of the 31 participants stated that they were suffering from an economic crisis: "*We sold all the furniture in our home*." (20). In the study by Nicholas, 22 out of 32 mothers described their financial problems as the complete loss of funds and moving into less expensive homes. Moreover, half of the mothers were living under the poverty line with minimum incomes (18).

2.3.3. Providing Housing Close to Hemodialysis Centers

The number of hemodialysis centers for children is limited, which makes families travel long distances to access such centers—an issue that can cause considerable tension and impose a huge financial burden on the families (3). As revealed by Medway et al., the participants living out of urban areas and away from hospitals had to deal with financial burdens originating from the costs of fuel, food, parking, car maintenance and repair, and travel (17).

3. Need for Emotional–Psychological Support

Mieto and Bousso argued that the well-being of mothers can be strengthened through interactions, including ones with medical staff, family members, and their children (1).

3.1. Support from Family Members, Relatives, and Friends

The mothers stated that they need support from their husbands, families, and friends (1, 3, 19, 20).

3.2. Support from Medical and Health Care Staff

Providing health services for mothers goes beyond meeting their health care needs. Maternal wellbeing can be strengthened through dialogues with treatment teams as such exchanges enable them to convey their mental needs better; therefore, they can provide comfort for their children (1, 19). Cimete (20) reported that only 5.4% of mothers could share their feelings and problems with nurses. One of subthemes emerged from a study conducted by Pourghaznein et al. was "neglecting maternal feelings by medical team". Most of the participants expressed that their maternal emotions and feelings have been ignored by the members of medical teams. Moreover, mothers complained that they were overlooked when they described the conditions of their children. They also believed that their needs as mothers of children with an incurable disease were unsatisfied and excluded in the decision-making process (21).

3.3. Interactions with Peer Groups

The mothers expressed their need for emotional support through interactions with their counterparts. They exhibited a liking for face-to-face communication with parents of other children suffering from chronic kidney disease (1, 3, 19). As declared by one of the mothers, *"Having mutual understanding among parents is really good"* (3). Note that the receipt of information and sharing of knowledge between mothers and their peers can be considered as a source of strength for these individuals (1).

3.4. Psychological Counseling

The mental problems of mothers and the management of interference in multiple roles necessitate psychological counseling. These consultations are necessary with two main objectives in mind.

3.4.1. Strategies for Managing Conflicting Roles

The mothers seek information from health care providers to enable themselves to balance child care and their other responsibilities. Accordingly, they can allocate more time to themselves and their hobbies. Such information can reduce their level of stress and allow them to relax (3, 18, 19).

3.4.2. Screening for Psychological Problems

Mothers can experience considerable mental, emotional, and social stress (1, 18-20). Therefore, the psychological disorders from which they suffer should be identified and controlled. For instance, a mother said "*I think that mothers undoubtedly suffer from depression and this can badly damage children. Sometimes mental-psychological health problems are much worse than physical ones*" in the study conducted by Tong et al. (19).

Discussion

According to the findings of the current study, mothers of children with hemodialysis face various needs. They need to gain a lot of information about the disease and treatment process, drug regimen, diet, and available services. Moreover, the lack of ability to manage the constraints and psychological problems of a child with hemodialysis can put mother under stress. Complicated and time-consuming treatment procedures of such a child affects the physical and functional health of the mother, and constraints family relationships, which leads to the weak financial status of the family and may even result in family collapse. Therefore, the mothers need interventions for preserving family coherence. In addition, thematic synthesis of the available studies indicated that the mothers require emotional-psychological interventions. Mothers get stronger by interactions, which include interaction with medical staff, family members, friends, and peer groups. On the other hand, the interference of various roles and psychological problems in these mothers necessitates psychological consulting.

One of the needs extracted from the studies was the need for child care management skills. In most papers, the mothers required more specialized information regarding the disease, treatment process, drug regimen, and diet (1, 3, 17-19). They refrain from asking questions for the fear of disrupting their relationships with medical staff (19). Deficiencies in nursing performance in different countries were observed despite the frequent emphasis of nursing studies on the educational roles of nurses and the importance of care and family-centered policies, particularly those for chronic diseases. Medical teams are obligated to recognize the role of mothers as primary caregivers of sick children and realize that even minimal information is critical to them (22). Without stable relationships with medical staff, mothers can also suffer from lack of confidence in child care (23); if parents become uncertain about each aspect of care, they may fail to effectively maintain therapeutic regimens (24).

One of the other needs highlighted by the mothers is how to manage mental-psychological and educational problems (18-20). Mothers with children undergoing hemodialysis face frustrating experiences, such as convincing their children to comply with health, medical, or diet restrictions. Therefore, an essential requirement is to provide psychological counseling to enable mothers to describe their children's problems and equip them with strategies on how to deal with these difficulties. The educational problems of children and their academic backwardness can also cause tremendous grief and sorrow for mothers and their children. In this regard, the mothers recommended the provision of educational facilities in hospitals (20).

Based on the results of the reviewed studies, endangering the physical and functional health of mother, confining family relationships, and weakening the financial status of the family necessitates preserving family coherence. The complex care for children undergoing hemodialysis threatens the physical well-being of mothers. Enabling mothers to perform their multiple roles, especially the maintenance of family cohesion, necessitates the implementation of measures designed to help them maintain physical. Some strategies suggested by the mothers are the involvement of informal caregivers in the management of disease, use of social nursing services at home, practical support for children's commutes from transportation companies, and practical assistance for household chores (3).

Financial weakness of such families is one of the main effective factors on the collapse of families. The findings of the current study indicated that despite the discrepancies in the context of the evaluated studies (i.e., conducted in different countries and within various cultural and economic conditions), all of them identified the financial needs of mothers who have children suffering from chronic kidney disease. The heavy financial burdens experienced by the mothers come from the costs of treatment, frequent commutes to hospitals, and in most cases, travel to remote locations of hemodialysis centers. Travel to hemodialysis centers three days a week interfered with employment opportunities of the mothers and fathers, which in turn, destabilized the economic status of the families. In several studies, financial problems were introduced as the main pressure of having children with chronic kidney disease (7, 17, 19). Note that financial problems can affect all aspects of family functioning, including the physical and mental conditions of all family members, family cohesion, education, recreation, and leisure activities of healthy children (17-19). Furthermore, the medical outcomes of children whose parents occupy lower levels of the social and economic ladder can be adversely affected (25).

Results of all reviewed studies indicated that complex care procedure of children with hemodialysis in addition to their physical health condition threaten psychological and emotional health of their mother. In order to improve the mental–psychological well-being of mothers, it is suggested to screen for psychological problems, administer corresponding interventions, and conduct family counseling. As declared by Mieto and Bousso (1), the well-being of mothers can be reinforced through effective communication with medical staff and receipt of emotional support from them. The strategies proposed in the investigated studies were the provision of locations where mothers and families can talk about their emotional status and interact with parents of other children undergoing hemodialysis (1, 3, 19). Note that the receipt of information and sharing of knowledge between mothers and their peers can be considered a source of strength and emotional support for these individuals (1).

The influence of mothers on maintaining family cohesion is an undeniable fact; accordingly, attending to the needs of mothers can exert profound and comprehensive effects on the social and emotional health of families as the building blocks of society. It is recommended to take supportive measures in the care programs for children with hemodialysis on the basis of mothers' needs.

Implications for Practice

Nurses are the members of the healthcare team that have the most frequent interactions with mothers of children undergoing hemodialysis treatment. Mothers attend 4-hour hemodialysis sessions three days a week, which can be a good opportunity to be provided with the emotional–psychological support and necessary information. Educational packages related to the disease and treatment process, diet, and pharmacological commands can be also prepared in response to the information needs of mothers. Nurses must know that mothers need attention with regard to their emotions and should be given opportunities to express their feelings about their child care. Furthermore, nurses are among front-line professionals that along with the other healthcare team members can provide services to assess physical, emotional–psychological, social, and economic needs of these mothers and their family. Therefore, nurses should provide interventions based on mother's needs with the collaboration of a multidisciplinary team members, including nephrologists, clinical psychologists, social workers, nutritionists, and charitable foundations for special diseases.

Acknowledgments

This study was a part of a doctoral thesis funded by Mashhad University of Medical Sciences, Mashhad, Iran. The researchers express their appreciation for the financial support of the university.

Conflicts of Interest

The authors declare no conflicts of interest.

References

- 1. Mieto FS, Bousso RS. The mothers' experiences in the pediatrics hemodialysis unit. J Bras Nefrol. 2014;36(4):460-8.
- 2. Tong A, Lowe A, Sainsbury P, Craig JC. Experiences of parents who have children with chronic kidney disease: a systematic review of qualitative studies. Pediatrics. 2008;121(2):349-60.

- 3. Geense WW, van Gaal BG, Knoll JL, Cornelissen EA, van Achterberg T. The support needs of parents having a child with a chronic kidney disease: a focus group study. Child Care Health Dev. 2017;43(6):831-8.
- 4. Mitra S, Banerjee S. The impact of pediatric nephrotic syndrome on families. Pediatr Nephrol. 2011;26(8):1235-40.
- 5. Wiedebusch S, Konrad M, Foppe H, Reichwald-Klugger E, Schaefer F, Schreiber V, et al. Healthrelated quality of life, psychosocial strains, and coping in parents of children with chronic renal failure. Pediatr Nephrol. 2010;25(8):1477-85.
- 6. Friedman AL. The broader burden of end-stage renal disease on children and their families. Kidney Int. 2006;70(11):1893-4.
- 7. Tsai TC, Liu SI, Tsai JD, Chou LH. Psychosocial effects on caregivers for children on chronic peritoneal dialysis. Kidney Int. 2006;70(11):1983-7.
- 8. Tong A, Sainsbury P, Craig JC. Support interventions for caregivers of people with chronic kidney disease: a systematic review. Nephrol Dial Transplant. 2008;23(12):3960-5.
- 9. Morawska A, Calam R, Fraser J. Parenting interventions for childhood chronic illness: a review and recommendations for intervention design and delivery. J Child Health Care. 2015;19(1):5-17.
- 10.Hanson CS, Craig JC, Tong A. In their own words: the value of qualitative research to improve the care of children with chronic kidney disease. Pediatr Nephrol. 2017;32(9):1501-7.
- 11.Smith J, Cheater F, Bekker H. Parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature. Health Expect. 2015;18(4):452-74.
- 12.Bignall OR, Goldstein SL. Childhood CKD affects the entire family. Am J Kidney Dis. 2015;65(3):367-8.
- 13.Belasco AG, Sesso R. Burden and quality of life of caregivers for hemodialysis patients. Am J Kidney Dis. 2002;39(4):805-12.
- 14. Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC Med Res Methodol. 2012;12:181.
- 15. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349-57.
- 16. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med Res Methodol. 2008;8:45.
- 17.Medway M, Tong A, Craig JC, Kim S, Mackie F, McTaggart S, et al. Parental perspectives on the financial impact of caring for a child with CKD. Am J Kidney Dis. 2015;65(3):384-93.
- 18. Nicholas DB. Meanings of maternal caregiving: children with end stage renal disease. Qual Health Res. 1999;9(4):468-78.
- 19. Tong A, Lowe A, Sainsbury P, Craig JC. Parental perspectives on caring for a child with chronic kidney disease: an in-depth interview study. Child Care Health Dev. 2010;36(4):549-57.
- 20.Cimete G. Stress factors and coping strategies of parents with children treated by hemodialysis: a qualitative study. J Pediatr Nurs. 2002;17(4):297-306.
- 21.Pourghaznein T, Heydari A, Manzari Z, ValizadehZare N. Immersion in an ocean of psychological tension: the voices of mothers with children undergoing hemodialysis. Iran J Nurs Midwifery Res. 2018;23(4):253-60. (Persian)
- 22. Fisher HR. The needs of parents with chronically sick children: a literature review. J Adv Nurs. 2001;36(4):600-7.
- 23.Nuutila L, Salantera S. Children with a long-term illness: parents' experiences of care. J Pediatr Nurs. 2006;21(2):153-60.
- 24.Swallow VM, Nightingale R, Williams J, Lambert H, Webb NJ, Smith T, et al. Multidisciplinary teams, and parents, negotiating common ground in shared-care of children with long-term conditions: a mixed methods study. BMC Health Serv Res. 2013;13(1):264.
- 25.Hidalgo G, Ng DK, Moxey-Mims M, Minnick ML, Blydt-Hansen T, Warady BA, et al. Association of income level with kidney disease severity and progression among children and adolescents with CKD: a report from the chronic kidney disease in children (CKiD) study. Am J Kidney Dis. 2013;62(6):1087-94.