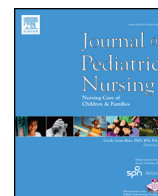




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## Iranian mothers' Experiences with Children Undergoing Hemodialysis: A Hermeneutic Phenomenological Study☆

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### ABSTRACT

*Purpose:* To describe Iranian mothers' perspectives regarding hemodialysis for their children.

*Design and Methods:* This qualitative study was conducted using the hermeneutic phenomenological approach. The sample consisted of 11 mothers, among whom five were interviewed once and six were interviewed twice, for a total of 17 interviews. The data were then analyzed using van Manen's (1997) method.

*Results:* Five themes emerged from the data: mothers enclosed by child care, emotional and psychological tension, acceptance and contrivance, the entire family being a victim of a sick child, and self-devotion.

*Conclusion:* The results indicated that the mothers of children undergoing hemodialysis experience multiple stresses in the physical, emotional–psychological, social, and economic dimensions.

*Practical Implications:* Nurses are the healthcare team members who most frequently interact with mothers of children undergoing hemodialysis. They are therefore positioned favorably to provide the information and emotional support needed by these mothers. Nurses are also among the frontline professionals who can provide services designed to assess the physical, psychological, and economic requirements of these mothers and their families.

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### Introduction

Chronic kidney disease can occur at any age during childhood (Wiedebusch et al., 2010), but its increasing prevalence (Becherucci, Roperto, Materassi, & Romagnani, 2016) has prompted significant diagnosis, care, and renal replacement therapy (RRT) advances that have led to survival and increased life expectancy among children (Bignall & Goldstein, 2015; Hemmati, 2008; Rambod, Rafii, & Hosseini, 2008). As one type of RRT, hemodialysis is a common treatment method for controlling chronic kidney disease (Borzou, Anoosh, Mohammadi, & Kazemnejad, 2014). This method, however, imposes more restrictions and results in lower quality of life (QOL) in children and their parents

compared with other alternative treatments (Tong, Lowe, Sainsbury, & Craig, 2008; Wiedebusch et al., 2010).

Studies showed that parents with children undergoing hemodialysis experience major stresses and concerns about the treatment process, which in turn, cause disruptions to family norms, financial problems, and social constraints (Geense, van Gaal, Knoll, Cornelissen, & van Achterberg, 2017; Tong, Lowe, Sainsbury, & Craig, 2010). These children are primarily cared for by mothers (Mieto & Bouso, 2014), who thus exhibit lower levels of QOL and higher levels of psychosocial tension than those exhibited by fathers (Wiedebusch et al., 2010). This finding was supported by Cimete's (2002) study in Turkey, with the author indicating that the care of children being treated with hemodialysis is a responsibility that more often falls on the shoulders of mothers, who juggle month- or even year-long care of their sick children with housework—a situation that leaves mothers exhausted, angry, depressed, and in despair. By contrast, fathers may only care for their sick children during annual leaves or off days (Cimete, 2002). Research also demonstrated that child hemodialysis brings forth radical changes in the daily lives of mothers as they are responsible for attending hemodialysis sessions with their children. In certain cases, mothers also contend with

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physical, psychological, and social problems, including job abandonment and loss of social status, sadness over their children's impending death, severe isolation, and the inability to change these conditions (Medway et al., 2015; Mieto & Bouso, 2014; Tong et al., 2008).

Providing services that align with the experiences and needs of mothers with children undergoing hemodialysis can exert profound and comprehensive effects on their physical, social, and emotional health and their ability to cope effectively; such services can also indirectly improve the medical and psychosocial outcomes of sick children (Belasco & Sesso, 2002; Tong et al., 2008; Tsai, Liu, Tsai, & Chou, 2006) and the functioning of an entire family (Bignall & Goldstein, 2015). Understanding the experiences and needs of mothers as primary caregivers can be regarded as an essential step to achieving family-based care initiatives and policies (Hanson, Craig, & Tong, 2016), which in turn, help healthcare teams support mothers in performing their role as healthcare managers (Smith, Cheater, & Bekker, 2015). These goals can be achieved beginning with maternal experience-oriented research, particularly qualitative studies, which are very valuable because they reflect the voices of mothers, enhance the comprehension of their experiences, and drive the development of responsive measures (Collins et al., 2016; Hanson et al., 2016; Marmo, 2014). Qualitative studies can also provide evidence that directs attention to previously undetermined maternal priorities and concerns (Hanson et al., 2016).

Various studies have been devoted to the problems that confront parents of children undergoing hemodialysis, but challenges that mothers in particular struggle with may be characterized by aspects that are unknown to treatment teams. Existing studies have also provided mixed findings. Cimete's (2002) research in Turkey, for example, showed that financial problems and bureaucracy are critical stress factors for parents of children undergoing hemodialysis, whereas MacDonald's (as cited in Tong et al., 2008) study in Canada identified uncertainty about disease outcomes and concerns about children's future as principal sources of stress for such parents. In the context of France, Weissman (as cited in Tong et al., 2008) reported the ambiguity of mothers' roles as one of the most challenging factors in dealing with the situations of children undergoing hemodialysis.

Given the diversity of research results and the apparent lack of similar studies focusing on Iran, the present research was conducted to explore Iranian mothers' perspectives regarding hemodialysis treatment for their children.

## Methods

### Design

This qualitative study was conducted from September 2016 to June 2017 using the hermeneutic phenomenological approach. In the past 20 years, hermeneutic phenomenology has been considerably influenced by contemporary phenomenologist Max van Manen (Dowling, 2007). Van Manen (1997) put forward six research activities for carrying out phenomenological investigations, which were performed in the current work as follows:

In accordance with the first activity, after identifying tendencies toward the phenomenon of interest (i.e., experiences of mothers with children undergoing hemodialysis), the researchers formulated related phenomenological questions and articulated expectations regarding the phenomenon. In keeping with the second activity, the research setting was selected, participants were recruited, and data were collected. For the third activity, wholistic, selective, and detailed approaches were adopted to separate the thematic elements that characterize the phenomenon, and detailed descriptions of the approaches were presented in the data analyses. The fourth activity, which emphasizes the art of writing and rewriting, involved incorporating the components of the research purpose into documentation. These components encompassed field notes, narrative anecdotes, and samples from interview transcripts, which facilitated the understanding of the nature of the phenomenon

during the writing. The fifth activity pertains to maintaining a strong and oriented relationship with a phenomenon, which was maintained in this work by being mindful of the main research question, regularly referring to it during data collection, data analyses, and theme extraction. These tasks can also prevent deviations from the main procedure in research. The sixth activity advances the hermeneutic cycle and the movement between a whole and its parts. Correspondingly, this research focused on the backward and forward movements between the whole and parts of texts in all the steps of the study, with consideration for the research question.

### Participants

After receiving approval from the Ethics Committee of Mashhad University of Medical Sciences and a letter of introduction from the university's School of Nursing and Midwifery, the researchers were referred to the Hemodialysis Division of Dr. Sheikh Pediatric Hospital in Mashhad City, Iran. The researchers fully familiarized themselves with the chosen setting following the explanation of the study's objectives to relevant authorities and obtaining permission from them. A list of children undergoing hemodialysis was provided to the researchers. Given that they had no previous relationship with the potential participants, they visited the Hemodialysis Division over the course of one week to acquaint themselves with the prospective subjects, establish a friendly relationship with them, and build trust before commencing with the phenomenological interviews. This was a good opportunity for key participant selection, which was accomplished through purposive sampling. The inclusion criteria were having a child undergoing hemodialysis for at least two months after the onset of hemodialysis, a desire to participate in the study, and the ability to communicate with the researchers.

A total of 11 mothers aged between 23 and 51 years (mean = 38, SD ± 9.00) were recruited. Their children were aged between 5 and 15 years (mean = 9, SD ± 3.00). In terms of level of education, one mother had an academic degree, three held high school diplomas, three completed primary school education, and four were illiterate. 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. The duration of hemodialysis treatment for the children ranged from two months to eight years.

### Setting

As previously stated, the research was conducted at the Hemodialysis Division of Dr. Sheikh Pediatric Hospital, which is an educational hospital that serves as the only children's hemodialysis center in Mashhad City. It consists of 11 beds, with two to three nurses on duty in each shift, and serves children and adolescents up to the age of 18 years. Because of the limited number of children's hemodialysis centers in the area, patients from surrounding cities also visit this center.

### Data Collection

After explaining the objectives of the study to the participants and obtaining written consent, their demographic profiles were derived, with the information covering the mothers' ages, educational levels and occupations, and socioeconomic statuses; the number of family members; the husbands' educational levels and occupations; the families' places of residence; the children's ages, genders, and order of birth; the age of kidney failure onset; the age of diagnosis; and the duration of hemodialysis. The subjects then participated in semi-structured interviews consisting of six general questions/prompts: "How did you notice your child's disease?", "Please recount your child care experiences since the diagnosis of kidney disease and the initiation of hemodialysis.", "Please tell us about the child care

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