



# The Role of Health Team in Coping Process of Family Caregivers with Patients Under Hemodialysis: A Qualitative Study

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## Abstract

**Background:** The high dependence of hemodialysis patients on home caregivers is a great source of care burden for them; therefore, accountability with appropriate communication as well as appropriate behavior and attention to needs of caregiver by health care team is a serious impact on care burden.

**Methods:** A content analysis approach was used for data collection and analysis. The participants included 16 family caregivers selected through purposive sampling from 4 medical education centers affiliated with Ahvaz Jundishapur University of Medical Sciences, Iran. Semi-structured interviews were held to collect data.

**Results:** Data analysis led to the emergence of 3 themes including “responsive treatment team” “negative influences of the treatment team,” and “collaborative care,” which were all incorporated into the main theme of “an effective treatment team”.

**Conclusions:** The treatment team can play an effective role in improving the caregivers’ well-being by appropriate treatment, accountability, and responsiveness to the needs of patients and their caregivers; meanwhile, it provides a better position for better care, however, it will reduce the care burden.

**Keywords:** Family Caregiver, Hemodialysis, Coping, Health Team, Qualitative Study

## 1. Background

More than 3000000 patients with chronic renal failure all around the world underwent hemodialysis (1) and annually about 7% will be added to this number (2). In 2008, more than 12000 people in Iran underwent hemodialysis, however, now more than 27000 people in 500 dialysis centers undergo the regular hemodialysis therapy (3).

The long-term treatment of chronic renal failure and frequent hospitalization in the dialysis ward represent serious changes to the lives of patients and caregivers; most dialysis patients and their caregivers experience anxiety, depression, sleep disorders, and low quality of life (4-6).

The distress experienced by caregivers may result from the need to provide long-term care, the long course of the disease, the potential for hemodialysis complications, newly arising needs, and major changes in lifestyle, which can all create serious tensions and disrupt the structure of caregivers’ families (7, 8). However, provision of care for patients undergoing hemodialysis imposes an extreme burden on family caregivers, however, doing it is irrefutable (9). In addition, most of the caregivers in Iran

have a commitment for caretaking (10).

According to the documentation, the complications of care provided by caregivers are threatening their health, thus maintaining the structure and health of the family caregivers of chronic patients is needed for coping with the new situation. In this situation, the health team, especially nurses, have a special responsibility (11) due to the fact that improving the patients’ and patients’ family health is one of the most important responsibilities of the health team, especially nurses (12, 13).

The importance of nursing is to pay attention to the patient and his or her family due to the fact that the family plays an important role in the care of chronic patients. Therefore, in a care plan, attention is paid to patient caregivers such as patients. One of the most important roles of nurses in chronic patients is helping the family to adapt to a new situation (11). In another study, The maintenance and strength of the family of home caregivers of patients undergoing hemodialysis requires adaptation to existing changes, therefore, nurses and other teams will focus their care and treatment plans on a family-centered approach

(14). Although caregivers commit to care (10), health professionals should help the family caregivers cope with the caring situation and related emotional distress, however, it is not being done perfectly (15). Furthermore, the field of effectiveness of the treatment team on chronic caregivers is limited and focused on quantitative studies and less based on the caregivers experiences. However, the aim of this study was assessing the experiences of careers of hemodialysis patients on the effectiveness of the health team in adapting and accepting the care situation.

## 2. Methods

### 2.1. Design of Study

A qualitative design using a content analysis approach was used in this study. Qualitative research aims to explore complex phenomena experienced by clinical Content analysis is the process of identifying, interpreting, and conceptualizing the inner meanings of qualitative data (16). Therefore, it is used to answer questions regarding issues experienced by a particular group of respondents for identifying their typical responses (17).

### 2.2. Participants

Participants consisted of 16 family caregivers of patients undergoing hemodialysis who were selected using purposeful sampling. Inclusion criteria used to choose the participants were as follow: having a direct responsibility for the provision of care to hemodialysis patients at home, being able to communicate and share their experiences, as well as willingness to participate in this study.

For achieving a comprehensive description of the experiences of caregivers in the process of caring, a maximum variation in sampling in terms of age, gender, level of education, duration of treatment, and socioeconomic status was used (18). The socio-economic level of family caregivers was different from low to middle classes. All participants were responsible for the provision of care, monitoring, as well as following up with their patients' therapeutic regimes.

The participants were 8 males and 8 females with the age range from 25 - 70 years. The duration of care was 3 - 11 years and their education level was from primary education to academic degree. The caregivers were often the patients' father, mother, daughter, son, spouse, or grandfather (Table 1).

### 2.3. Data Gathering

Semi-structured interviews and observations were performed and field notes were taken by the first author (ShS). The data were collected using in-depth interviews from

**Table 1.** The Specifications of Participants

Characteristics	No (%)
<b>No.</b>	16 (100)
<b>Gender</b>	
Male	8 (50)
Female	8 (50)
<b>Age (mean)</b>	41.5 (years)
<b>Family caregiver</b>	
Father	1 (6.25)
Mother	2 (12.5)
Spouse	4 (25)
Son	2 (12.5)
Daughter	1 (6.25)
Grandfather	1 (6.25)
Patient	1 (6.25)
Physician	1 (6.25)
Nurse	1 (6.25)
Social worker	1 (6.25)
<b>Residence</b>	
Urban	12 (75)
Rural	4 (25)
<b>Education</b>	
Illiterate	1 (6.25)
Primary	3 (18.75)
Secondary	2 (12.5)
High school	3 (18.75)
Academic	6 (37.5)
<b>Duration of care (mean)</b>	7.34 (year)

January 2014 to June 2016. The first author took field notes regarding the family members' interactions following each interview. The focus of the interviews was on the family caregivers' experiences of problems and challenges in the process of caring for patients undergoing hemodialysis.

The main questions used in the interview were: "would you please tell me about your experiences as a caregiver of a patient under hemodialysis?" and "what is your experience with the role of the treatment team in taking care of these patients?". Probing questions (for further explanation of the details, increasing the depth of the interviews, as well as a deeper understanding of the phenomenon studied, that is, the impact of the health team on the acceptance and effectiveness of the care by caregivers was

guided. Subsequently, the participants were asked to add supplementary information not addressed during the interviews.

The interviews lasted for 60 - 90 minutes and were audiotaped and transcribed verbatim. The interviews were conducted at the participants' houses and the hemodialysis ward. The data collection and analysis were conducted simultaneously. The sampling process was continued until data saturation was reached as no new category was identified.

#### 2.4. Data Analysis

The process of analysis is based on the 3 stages of Elo S, Kyngas (19):

- In the preparation phase, the interviews were transcribed verbatim. The transcriptions as the unit of analysis were read several times to get the sense of whole.
- In the organization phase, an inductive approach was used. The semantic units associated with the research questions were assigned with primary codes.
- Initial codes were further classified into subcategories. In the next phase, subcategories with similar meanings were assigned into main categories. A sample of the condensation-abstraction process was shown in Table 2.

#### 2.5. Trustworthiness

Rigor is the process of the application of appropriate techniques and research methods for achieving consistent and reliable data (20). The following measures were taken to ensure rigor in this study:

- Verification of the codes with the participants and engagement with the study phenomenon.
- Comparison of the text with the initial codes to ensure of the homogeneity of the extracted ideas (21).
- For peer checking, the codes and categories were given to 2 qualitative experts to confirm the coding and analyzing process (22).
- The maximum variation in sampling in terms of age, sex, education level, duration of care, and socioeconomic status enhanced the validity of the data that enabled the researchers to capture a wide range of experiences and perspectives (23).

#### 2.6. Ethical Consideration

The ethics committee affiliated with Ahvaz Jundishapur University of Medical Sciences, Iran confirmed the study's research proposal with the ethical code number: ir.ajums.rec.1394.180. The informed consent form was signed by those participants who granted the permission to record their voices and were willing to take part in this

study. The time and location of the interviews were determined in accordance with the participants' will. The participants were also assured that they could withdraw from the study at any time without being penalized.

### 3. Results

Data analysis led to the emergence of 3 themes including: "responsive treatment team" "negative influences of the treatment team," and "collaborative care," which were all incorporated into the main theme of "an effective treatment team".

#### 3.1. Responsive Treatment Team

The theme of "Responsive treatment team" by the treatment team included the following 2 sub-themes: "bestowing soothing treatments and behaviors," and "shouldering responsibility". This theme suggested that the behavior and attitude of the treatment team, their attention to the needs of the patient, and their responsibility for the patient's overall care could underlie and facilitate the acceptance and recognition of the care condition by caregivers.

##### 3.1.1. Bestowing Soothing Treatments and Behaviors

In a situation where caregivers accompany the patient in the dialysis unit, appropriate communication, behavior, and attention to the needs of caregivers by the treatment team have serious effects on the caregivers. From the perspective of many participants, it was expected that nurses and doctors dealt with them kindly and compassionately due to the fact that such behaviors are very soothing and effective. One of the participants described the importance of the soothing behavior of the personnel towards caregivers as follows:

A patient's wife stated:

"The tone of speech and the hope-giving behavior of a doctor to me as a caregiver are very effective in the care process."

Another caregiver described such behavior of the healthcare team towards caregivers as follows:

"When I as a caregiver enter a unit and see nurses' good and kind behavior, so, in this case, their love for patients really gives me a real peace of mind and serves as a model for my care." (A patient's daughter)

##### 3.1.2. Shouldering Responsibility

The treatment team's good performance, precision at work, and conscientious working style will ensure the caregivers that fear, stress, and tension are not allowed in the

**Table 2.** Main Theme, Subtheme and Categories Developed During Data Analysis

Main theme	Subthemes	Categories
An effective treatment team	Responsive treatment team	Bestowing soothing treatments and behaviors
		Shouldering responsibility
	Negative Influences of the Treatment Team	Behaviors leading to tension
		Neglecting patients' needs
	Collaborative care	Cooperation potential
		Effective partnership
		Isolation of caregivers during treatment

treatment process. On the sense of responsibility and appropriate performance of the treatment team, a caregiver stated:

"The suitable caring and good monitoring patients by the staff in the ward; there is no slightest concern about injections, drug administration, the length of dialysis, eating, and the type of food my patients' have. Therefore, your stress and anxiety will be eliminated and you will feel there is no need for you to be in the dialysis unit." (A patient's mother)

Shouldering responsibility and enjoying a sense of responsibility towards the patient and doing the duty based on the defined job description expressing the general tasks, or functions, and responsibilities of the healthcare team enhance the caregivers' confidence and reliability in the medical staff. Therefore, caregivers feel there is no need to be present in the unit and indubitably their patients will undergo dialysis while their needs and desires are taken into account by the staff during dialysis. This feeling, thus, helps ease the burden of care for the caregivers and facilitates care conditions.

### 3.2. Negative Influences of the Treatment Team

This theme includes the 2 sub-themes of "behaviors leading to tension" and "neglecting patients' needs," suggesting that the inappropriate behavior of the healthcare team, especially nurses and doctors, and their disregard for patients' needs make caregivers have negative attitudes towards the healthcare team.

#### 3.2.1. Behaviors Leading to Tension

Inappropriate behaviors such as negligence, aggression, and unresponsiveness cause tension in caregivers and attendants of dialysis patients. The long-term care process, care stress, and many problems of patients affect caregivers' mental health so that their tolerance threshold is diminished. They expect that the treatment team understand their conditions more and behave in accordance with their conditions.

One of the caregivers whose patient was hospitalized in this regard stated that:

"My wife has been hospitalized for 10 days in this unit because she suffered from hand swelling and her fistula didn't work. Anyone who came would say something. Neither her doctor nor her nurse responds to me accurately; when I see such behaviors, I die a thousand times." (A patient's husband)

Another caregiver, a 70-year-old woman, described the inappropriate behavior of the medical staff as follows:

"When I accompanied my patient to the dialysis unit, I saw nurses sometimes deal so badly with me that I, an old woman, dare not say anything. When I come back home, only mourning even for 2 days can relieve me." (A patient's wife)

#### 3.2.2. Neglecting Patients' Needs

Many caregivers' experience has shown that the nursing staff, doctors, and other medical staff do not pay attention to the needs of patients and their caregivers so that their irresponsibility and disregard for the needs of patients and their caregivers are evident. A caregiver said that:

"As the patient's illness get worse, she/he screams blue murder. However, nobody will lend a hand. When his/her caregiver and attendants outside of the ward observe such issues, their nerves definitely are on edge. Here, the irresponsibility and negligence of the medical staff shout." (A patient's son)

Affirming the abovementioned theme, a caregiver who was a senior manager and whose wife had been undergoing hemodialysis for 5 years declared:

"When a patient is transferred to the dialysis unit, a nurse controls his/her weight and then the dialysis machine is attached to the patient. After 3 to 4 hours, the dialysis machine will be disconnected, but during 3 to 4 hours, the treatment staffs do not pay the least attention to the patient. As far as I know, in other countries the condition is completely different. I think this is a kind of disrespect for the needs of the patient and the caregiver." (A patient's husband)

### 3.3. Collaborative Care

This theme is composed of 3 sub-themes: “cooperation potential,” “effective partnership,” and “isolation of caregivers during treatment.” It indicates that many caregivers have many experiences regarding caring for dialysis patients, so they expect that the treatment team cares about their experiences and their views on the treatment and care process.

#### 3.3.1. Cooperation Potential

Caregivers have the ability to participate in the treatment and care processes because of their many care experiences. If the treatment team respects their ideas and ability, they will have a better feeling of care conditions.

In this regard, one of the participants declared:

“We caregivers live always with patients and carry lots of experiences. If there is someone to listen to our advices, there shall be a lot of helpful and practical comments, especially for the treatment team. Unfortunately, advice when most needed is least heeded!” (2)

Enjoying many years of experiences in the dialysis unit and at home, caregivers asserted that they had learned a lot about the caring needs of the patients and were able to do the right thing in the right condition for the patient, as a caregiver said:

“I do not want to interfere in their work, but I expect they somehow consider our words. I have been along with the sick throughout the treatment for 7 years, so I've experienced a lot of things that are very important.” (A patient's spouse)

Other caregivers also approved this issue so that one of them said:

“I was sitting beside my patient to massage his/her cramped muscle correctly to relieve his/her pain, but the staff irrationally asked me to leave the ward and did not do anything for the sick. They didn't consider I was a real caregiver, not a visitor. Unfortunately, you see they have not reached this level of understanding yet.” (A patient's son)

#### 3.3.2. Effective Partnership

From the viewpoint of caregivers, their accompaniment during dialysis and their experiences in the process of treatment and care have effective mental and psychological influences on the patient. Therefore, they believe this influence also affects their mental and emotional well-being. One of the caregivers in relation to the effective partnership said:

“Sometimes the unit is too busy so a nurse cannot care for all patients. In this situation, when a caregiver is alongside the patient, the staff can do his/her duties; thus, both the patient and the caregiver feel comfortable.” (A patient's daughter)

Caregivers believe that when they are always watching over their patient and participate in the process of care and treatment during dialysis, not only are their patients relaxed, but they become more relaxed too. A caregiver said:

“When I'm next to her/him, if a minor problem occurred to him, I'll immediately call the staff. Because I have some care experiences, I can do a bit of the needed aids; my patient feels at ease, and so do I.” (A patient's mother)

#### 3.3.3. Isolation of Caregivers During Treatment

Many caregivers feel that they are completely isolated in the process of treatment and the treatment team does not take their opinions and experiences into account. A caregiver in this regard said:

“Many times I brought my patient into the ward and talk about the patient's conditions for nurses such as about his/her high blood pressure, cramped muscle, and headache. So, I asked them to reduce or increase the time of dialysis and use the dialysis filter based on the described conditions of the patient, but they do not pay the slightest attention and, unfortunately, they never listen to any advices by caregivers.” (A patient's spouse)

The healthcare personnel's lack of proper care about and attention towards caregivers' ideas was described by another participant as follows:

“I accompanied my kid to the dialysis unit. His/hers fistula didn't work well. After 5 years, I realized that this fistula didn't work well and I said it to nurses and asked them not to inject into it. They did not give the slightest attention to my words. So, they repeated this action so that it has been completely demolished.” (A patient's father)

## 4. Discussion

The findings of the present study indicate that the treatment team's good behavior, good performance, appropriate interactions, and focus on the therapeutic, care, and educational needs of caregivers of patients, especially nurses' and doctors', not only facilitate the effectiveness of the treatment process, but also facilitate the acceptance of care conditions for caregivers. Moreover, respecting the caregiver's views in the treatment process, the healthcare team can make this condition even easier for caregivers.

Cukor et al., (2007) declare that because a lot of time is spent by patients' and their attendants at the dialysis unit, the type of their relationships with the treatment staff affects the outcomes of the treatment. The dominant dialysis unit culture and the patients' feelings of solidarity towards the dialysis staff is considered as an important factor in treatment (24). Harwood et al., emphasize that due to the importance of mental and psychological issues in the hemodialysis patients and their attendants, it is necessary

the health care personnel pay more attention to the mental and psychological needs of patients and their caregivers. Furthermore, one of the good ethical and behavioral characteristics of nurses is their friendly and intense relationship with patients, which is an important factor in helping the patient and their attendants to adapt to the situation (25).

Emotional support is one of the most prominent roles of nurses (26). Some other studies confirm the fact that nurses play an important role in providing comfort and convenience for patients and their caregivers (27). Also, in the present study, nurses' proper performances attracted the attention of caregivers. Walker's study suggests that from the perspective of patients, good nurses are those who can provide comfort, safety, and well-being for patients and their family members (28). Furthermore, the findings of Jouybari et al.'s study indicate that good nurses, from the viewpoint of patients, are those paying a rational attention to the patients' body, mind, and soul. Generally, in nursing, providing comfort and relaxation for the patient is of particular importance and paying attention to the needs of the patient and his or her family is one of the pillars of the comprehensive nursing foundations and a valuable outcome of nursing (26).

Sugimoto et al.'s study in Japan depicts that the proper responsiveness of nurses and the treatment team to patients and their attendants both enhances the satisfaction of patients and their attendants, and provides a sense of hope and serenity about the patient's health and well-being for the caregiver. In their study, it is revealed what makes the patients and their caregivers more contented is the responsiveness of the healthcare team to the questions and needs of patients and caregivers (29).

The main reason for the lack of recognition of the psychological and social needs of patients and their family members is the lack of appropriate interactions between patients and their health care providers; therefore, the most important factor in increasing the satisfaction of patients and their families and improving the health and treatment outcomes is to establish a proper interaction between nurses and patients (30). On the importance of this issue, Adams et al., argue that for the patients' families, the effective communication of the treatment team is a better and more effective way of understanding the existing situation and reducing the psychological burden of care provided by them; thus, one of their study's themes is improving nurses' communication skills (31).

The results of the current study signify that the caregivers' experiences concerning the care of a loved one asserts they can participate in the process of treatment and care, therefore, they expect the healthcare team pays more attention to their opinions and abilities in the treatment

process. They will be delighted if their views are taken into account by the healthcare providers in the care and treatment process. The results of the study conducted by Longman et al., indicate that facilitative factors between nurses and families' interactions contain spiritual care, emotional support, participation in treatment, and notification with consultation, and one of the factors influencing the strengthening of the relationship between caregivers (i.e., family members of patients) and nurses seems to be involving caregivers in the treatment process (32, 33).

On confirming the importance of recognizing and paying more attention to the feelings of caregivers and patients in the treatment units, Hagen et al. state that the basis of nursing care and support knowledge in the dialysis unit depends on the patient's recognition of his or her life situation and caregiver's status. They, regarding the clinical use of their study's results, point out the treatment team in the dialysis unit should pay attention to the experiences and feelings of patients and their caregivers; hence, such feelings and experiences should be taken into consideration by doctors and nurses during clinical trials (34). The conclusion study title with the role of nursing in coping process of family caregivers of vegetative patients was nurses can play an affective role in improving the care givers wellbeing by tiring at discharge time and during home care, helping families in providing care and support them during care process (27).

#### 4.1. Relevance to Clinical Practice

People who are involved in the care and treatment of the patients undergoing hemodialysis face a formidable challenge. In clinical practice, it is essential that nurses should consider the health status of patients and their relatives. However, these findings demonstrate that the importance of monitoring and paying attention to the caregivers' experiences by the health team is very vital to reflect their level of health status and facilitated to coping with the new situation.

#### 4.2. Conclusion

The treatment team has a great influence on facilitating the provision of good quality care conditions for caregivers. Therefore, appropriate behavior responding to the needs of caregivers in the treatment, care, educational, emotional areas, accountability, and a good work ethic alleviate caregivers' burden of care and care conditions and provide the ground for the acceptance of the care situation. Moreover, respecting the caregivers' views in the treatment and care process, the treatment team can further facilitate the condition.

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