Original Article

Dedication in Caring of Hemodialysis Patients: Perspectives and Experiences of Iranian Family Caregivers

Ahmad Ali Eslami, Leili Rabiei, Majid Shirani[1], Reza Masoudi[2]

Department of Health Education and Promotion, School of Health, Isfahan University of Medical Sciences, Isfahan, [1]Department of Urology, School of Medicine, Shahrekord University of Medical Sciences, [2]Community-Oriented Nursing Midwifery Research Center, Shahrekord University of Medical Sciences, Shahrekord, Iran

Abstract

Background: Although dialysis treatment is considered as a life-saving treatment for chronic renal failure patients, the caregivers face challenges in caretaking of these patients. **Objectives:** This study is aimed to explain the perspectives and experiences among caregivers of the patients undergoing hemodialysis in Iran. **Methods:** A qualitative design, based on a thematic analysis approach, was used to reach the study aim. In this study, 25 hemodialysis family caregivers were selected by purposeful sampling. The data were gathered through in-depth and unstructured interview and field observation and analyzed by the inductive thematic approach. **Results:** The three main themes were generated from the analysis of the data indicating that the caregivers face challenges such as heavy burden of care, tension in care, and emotional exhaustion. **Conclusion:** Caretaking of the hemodialysis patients is constantly accompanied with challenges and concerns regarding the effective care for patients. Health-care providers need to address these concerns based on both patient- and caregiver-focused approaches, rather than only patient focused, to the design and planning for helping the patients and their caregivers.

Keywords: Dedication, family caregivers, Iran, long-term care

INTRODUCTION

Prevalence of chronic renal failure (CRF) is increasing not only in Western communities but also in developing countries. Overall, an average of 1/10 people suffers from renal diseases, with 110 billion dollars spent each year for the treatment of renal failure. In Iran, the prevalence of CRF has been estimated approximately 514 people and its incidence 70 people/1 million population.[1]

The patients under hemodialysis suffer from several complications due to the disease. Because of these tensions, incidence of negative reactions such as anger, depression, and even suicide, loss of self-esteem as well as family problems is very likely in these patients.[2]

In addition to dependency and the above-mentioned complications, undergoing hemodialysis three times a week can affect the daily lives of patients and their families.[3] Furthermore, the complications and restrictions arising from hemodialysis influence all domains of life including physical, occupational, and economic and could be considered a negative dimension of quality of life (QoL), increasing the patients' dependency on other family members.[4]

Living with hemodialysis patients can be worrisome, restrictive, and stressful for both patients and caregivers; it is therefore highly important to understand the family caregivers' challenges and concerns and identify their needs to provide the high-quality care.[5] Compared with caregivers of patients with other chronic disease, hemodialysis patients' caregivers are faced with additional difficulties including repeated hospitalization and taking several drugs.[1,6]

The caregivers prefer the patients' needs over their own and therefore spend lower time practicing the behaviors of health promotion, which affects health and QoL negatively.[7] Since family caregivers often assume heavy responsibilities of care without adequate preparation and training, many difficulties

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Address for correspondence: Dr. Reza Masoudi,
Faculty Member of Nursing and Midwifery School, Shahrekord University of
Medical Sciences, Shahrekord, Iran.
E-mail: masoodi1383@yahoo.com

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may happen to them.[8] Although care and support of caregivers are very important, sufficient attention is not paid to them and they are not supported in Iran's health-care context.

The need for clarifying effective factors on caregivers and their needs should be investigated in future studies.[9] In Given *et al*. review article, the need for research on promotion of knowledge and skill in the caregivers of chronic disease patients were noted. Meanwhile, it is critical to use relevant intervention.[10] Besides that, if the caregivers' needs are not investigated and explained satisfactorily, the patients may not receive the optimal services the caregivers can offer to them, not to mention potential risks threatening their mental and physical health. Therefore, the needs of the caregivers, as hidden patients, should be investigated as with patients' needs and health-promoting and support programs should be developed for them.[7] Therefore, the present study was conducted to investigate the Iranian family caregivers' experiences among the caregivers of the patients undergoing hemodialysis.

METHODS

Study design

A descriptive–exploratory qualitative design, based on a thematic analysis approach, was used to reach the study aim. This design is an approach to qualitative research, particularly if there is inadequate data on the subject of study.[1,8]

Setting and sample

This study was conducted in 2014–2016 in Isfahan, Iran. The participants were 25 family caregivers. The participants were selected by purposeful sampling. The inclusion criteria were being the main and family caregiver, having spent several months caring for hemodialysis patients, being consent to participate in the study, having ability to communicate in Persian, and no other patients needing care in the family. The participants were permitted to discontinue participation at any step of the study.

Ethical consideration

The ethical approval was obtained from the Research and Technology, Deputy of the Isfahan University of Medical Sciences (Ethical code: 393792). The participants were informed about the aims and significance of the research, and then they provided written informed consent to participate in the study. In addition, the participants were ensured that participation in the study is voluntary and they can withdraw from the study at any step of the study.

Data collection and procedure

The interviews were conducted in Persian. First, the interviews were unstructured and started with the question "Would you please explain about your experiences of caring for your patient?" Probing questions such as "Could you say more about that?," "What did you think then?," and "Could you please give an example?" were asked depending on the participants' response, to enrich the data further. Eventually, after conducting 34 interviews (2–3 nonsuccessive sessions for each participant), the list of codes was merged into themes, with the analysis continuing until all the thematic categories were saturated.

Any interviews, lasted for 45–60 min, were recorded by MP3 with the participants' consent. To supplement the data gathering, field note-taking was conducted as well.

Data analysis

A thematic analysis approach was used to figure out the patterns within the texts.[11] Initially, the interviews were transcribed word for word and reviewed repeatedly and meticulously to ensure the data immersion. The first author gathered the data through face-to-face interviews, which were the main tools of data gathering. Throughout data collection, the researcher asked certain probing questions in the next interview.[12] The analysis continued by reading the text several times to determine the differences and similarities. Finally, after 34 interviews, the list of codes was merged into themes, and the analysis continued until all thematic categories were saturated, that is, there was no new clear concept to detect and the categories were coherent or meaningful.

Rigor of research

The data were collected from multiple sources (interviews and field note-taking). The interview transcripts and field notes were read several times to obtain a more accurate understanding of the data. To increase the validity of coding, all of the interview transcripts and the list of codes and themes were reviewed and encoded by the researcher's colleagues and compared with the initial coding. Then, some inconsistencies were discussed and corrections made, if necessary. The initial coding of each interview was returned to the interviewee so that he/she may confirm its accuracy and recognize the codes as valid. Few codes which from the participants' viewpoints did not represent their ideas were corrected. Moreover, the diversity in sampling was ensured by enrolling the participants at different ages and from different health-care centers.

RESULTS

Fifteen (60%) family caregivers were female and 10 (40%) male; the participants were 20–69 years old (mean ± standard deviation = 47 ± 3.9 years). Twelve (48%) were married and the rest single. The relationship of the caregiver to the patient, most were the spouse ($n = 15$) or daughter ($n = 10$). Furthermore, the mean length of care per day was 10 h and the length of time of caring for their patients was 7 years. From the interviews, some codes and themes emerged, consisting of three main themes and nine subthemes. Then, the relevant themes were explained to the caregivers, and therefore, they could confirm them with further explanations.

Heavy care burden

A key theme generated from the experiences of the caregivers in the present study was heavy care burden, consisting of three subthemes:

Multifaceted and complex problems

The caregivers' experiences demonstrated that numerous physical and psychological difficulties and complex conditions of the disease brought about many challenges for them, and therefore, they had to tolerate the heavy burden of caretaking the patient. A caregiver said:

"*… As his illness is chronic, everyday something is added to his problems and the circumstances become more complicated for us. Every day, he is worse than the day before…*" (Caregiver 13).

Another caregiver said:

"*…When my patient's kidney stopped functioning, then his body's toxins were not excreted well and these made him feel worse and his plights* [*become*] *further for us…*" (Caregiver 4).

Continuous and excruciating caretaking

Constantly talking of making efforts continuously, paying attention to the patient, and enduring hard circumstances, the caregivers perceived caretaking of a hemodialysis patient as continuous and excruciating. A caregiver talked of his experience as follows:

"*…* [*Till*] *now, for two years days and nights we have been preoccupied with our patient and always caring for him…*" (Caregiver 11).

Another caregiver recapitulated his experience as follows:

"*… His affairs have got too burdensome. His repeated repositioning and bathing and his daily works impose much pressure on us, me and my sister, who are taking care of him…*" (Caregiver 11).

Changing nature of needs

A concern of the caregivers that led to a decline in their caring capacity was changing the nature of the patients' needs. These patients were always engaged in actual and potential problems because of chronic nature of the disease.

A caregiver' experience was as follows:

"*… His problems do not remain fixed and are continuously changing. That's way, the works get difficult and it is not possible to pursue them monotonously and routinely …*" (Caregiver 11).

Another caregiver said:

"*… His mental problems differ every day; in addition to malnutrition, anemia, infections and repeated hospitalizations altogether are troubles that have engaged my mind and body and turned into the most widespread concern of my life …*" (Caregiver 13).

Tension in caretaking

The psychological pressure due to caretaking of the patients under hemodialysis brought about anxiety and concerns associated with anxiety and turbulence in the caregivers' mind. In fact, the atmosphere of caretaking of the patients was infused with tension and turbulence, consisting of four subthemes as follows:

Variety of tasks and unspecialized caregivers

The caregivers constantly talked of the variety of tasks and lack of necessary expertise to do these tasks:

"*… As I* [*made an attempt to*] *feed him, it's time of his medicine* [*taking*], *then I should massage his feet, move him and* [*do*] *other jobs, I am much busy with him and no one has trained me what to do …*" (Caregiver 9).

Another caregiver said:

"*… For nutrition I don't know at all what agrees with him and what is bad for him. Days and nights I'm with him as well and my affairs are numerous and no one also guides me. Physician and nurse also do not tell me as they should do …*" (Caregiver 7).

Disease interference with normal process of caregiver's life

The caregivers' experiences indicated as the disease progressed; the caregiver's life was further disturbed. A caregiver said:

"*… I have to cut my own and my children's time. For instance, previously I was also employed but gradually for taking care of my father I was forced to leave my job …*" (Caregiver 12).

This disease affects caregivers' QoL through interfering with daily activities, occupation, exercise, and recreation as well as the process of sleep.

"*… All our life somehow has become engaged with this disease, our own normal life has been paralyzed; no recreation has then remained for us. Even, our sleep and waking have been disturbed as well; we don't distinguish day and night …*" (Caregiver 15).

Intensification of disease and adaptability

The caregivers argued that as the family member's disease intensified, coping with and adaptability to new conditions became more and more difficult. One of the caregivers said:

"*… We are living a sad life. It's a bad disease and not about to recover. His fistula got infected and constantly his conditions are worsening and life has got hard and breathtaking for us …*" (Caregiver 7).

Another caregiver described intensification of the disease and difficult adaptability as follows:

"*… Water and his electrolytes are not balanced and toxins in his body are abundant, just these toxins in his body have made him disorganized and get nervous, distressed and exhausted, and we also can't cope with him …*" (Caregiver 11).

Caregiver's emotional exhaustion

Another concern of the caregivers was to tolerate hard and excruciating psychological conditions, which was due to the patients' constant suffering and discomfort. Emotional exhaustion was a concern of the caregivers and families as well as a challenge facing health system. This theme consisted of three subthemes as follows:

Fatigue and wearing out

An aspect of caregiver's emotional exhaustion was feeling fatigued and worn-out in encountering hard conditions of the disease. A caregiver talked of his experience as follows:

"… *Enduring hard and excruciating conditions of disease isn't for one month or two months.*[*Till*] *now, we have been involved for three years and have somehow got tired and frustrated then! These conditions* [*will*] *ruin us…*" (Caregiver 6).

Seeing the patients weepy and sometimes crying influenced the caregivers greatly. A caregiver said:

"… *When I see him continuously* [*in*] *such conditions and think about our life and children, I got much sad and depressed. Chronic disease also makes the caregiver develop chronic fatigue …*" (Caregiver 12).

Declined stamina of caregivers

The caregivers considered the complicated problems and their intensification as well as no recovery to be other factor contributing to declining their stamina.

"… *The patient's getting worse and his illness's intensification has a continuous process and has taken our stamina. Constantly, his disease is progressing and will leave no energy and stamina for us…*" (Caregiver 17).

The experience of another caregiver was as follows:

"… *It's much hard to survive with a chronic disease like my patient's and for whole three years to invest all stamina for him. You took him and then he falls down. Really I have such conditions …*" (Caregiver 13).

Continuous suffering and hopelessness

Continuous suffering and turbulence of a caregiver due to encountering patient's problems leads him/her to hopelessness. As the experience of a caregiver demonstrated:

"… *I see that he doesn't get better with all these attempts and so suspended. We'v also got disorganized and blame ourselves …*" (Caregiver 8).

Another caregiver described his experience as:

"… *We've got irritable and resentful when we see father with such conditions. Hopelessness and wearing out are our conditions of these days …*" (Caregiver 18).

DISCUSSION

The present study sought to investigate the perspectives and experiences of the family caregivers of patients under hemodialysis. In this regard, the four general themes were generated. The first theme was heavy burden of care which was derived as a very significant problem among the caregivers. The heavy burden was a complicated, multifaceted problem derived from the care experiences. Relevantly, Suri *et al*. argue that the caregivers of hemodialysis patients may consider the care burden to be heavy because they have to contribute greatly to caring for hemodialysis patients. Besides that, they need further mental support to tolerate the heavy burden of disease-related difficulties, irrespective of what problem their patients are suffering from.[11,13]

In Bartolo *et al*. study, the care burden was inversely, significantly associated with the patients' autonomy and QoL.[14] In fact, if the caregiver does not receive adequate support to tolerate the disease burden, not only does he/she hurt but also his/her patient is affected and care-related function and efficiency decline. Chang *et al*. demonstrated that the longer per day the caregivers took care of their patients, the greater burden they endured and the poorer mental health they had.[15] Indeed, enduring great care burden influences the caregiver's mental health and leads to nothing except for patient's irritation and increased care burden.

The caregivers reported that the presence of a hemodialysis patient in the family caused tension and psychological complications such as anxiety and depression in them and other family members, because they considered themselves to be guilty for such difficulties in the family. Al-Arabi believed that prolonged treatment and numerous problems facing the caregivers gradually decline families' and friends' attention paid to the caregivers and patients. However, the acquisition of CRF and the variations in patient's and caregiver's life due to hemodialysis increases the dependency on others and seeking out their assistance.[16]

On the other hand, the changing nature and complicated problems of the disease intensified the burden of disease for caregiver and put the caregiver in difficult circumstances, which led to an intensification of the care burden of the disease. Similarly, Al-Arabi reported that dependency on others; losing role, declined self-esteem, and frustration in patient and family were some tension-triggering agents in end-stage renal disease patients. Restricted life and changed lifestyle were significant findings, resulting in intensification of the care-induced stress on caregivers.[16]

Suffering from a chronic disease is a constant and progressive experience and consists of a complicated communication with caregiver and surroundings for the patient.[17] Hemodialysis and related factors are stressful for caregiver and family, and a caregiver who previously lived independently and is currently seeing a patient dependent on hemodialysis is highly predisposed to mental- and adaptation-related difficulties. These make the caregiver and patient have a feeling of wandering between the death and life and experience certain challenges such as permanent stress, loss, anxiety, depression, anger, and incompatibility.[18]

In Yeh and Chou study, the most common strategies were emotion-based strategies, avoidance and thoughts of withdrawal. In fact, caretaking of hemodialysis patients includes a plethora of physical and emotional stressors associated with the disease and dialysis treatment.[19]

When caregivers experience several difficulties and adversities in taking care of patients, they gradually degenerate, lose the ability required to provide the care, and develop emotional exhaustion.[8] These were clear throughout the caregivers' experiences in Iran. Notably, hemodialysis as a solution to treat CRF is chronically stressful by itself, causing a variety of psychological difficulties in patients for several reasons.[20] This intensifies the psychological burden imposed on the caregivers. An important observation was exacerbation of the patient's inability accompanied with failure to receive adequate support from the health-care team as well as the loss of hope in the process of recovery and endurance of other patient-related challenges. This caused fatigue and loss of energy needed to continue caretaking in caregivers.

CONCLUSION

As cultural variables and caregivers' experiences in dealing with challenges and stressors in hemodialysis patients have not been yet explained adequately in Iran, health-care staff and planners should be assisted through a more elaborate explanation of the experiences among hemodialysis patients' caregivers and their caretaking-related challenges so that necessary strategies can be developed to deliver holistic care to patients. Therefore, explaining the experiences and attitudes of caregivers toward their conventional concerns can be useful to meet their healthcare-related needs.

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Conflicts of interest

There are no conflicts of interest.

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