



Original Article

Immersing in problems: Challenges of women living with the husband on hemodialysis

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ABSTRACT

Background & Aim: The caregivers of hemodialysis patients experience a heavy caregiving burden. More caregiving pressure and burden have been reported of the women than men insofar as they are encountered with more physical and psychological problems. This paper explores the challenges faced by women living with husband on hemodialysis.

Methods & Materials: The study followed a conventional content analysis method. The participants were selected through a purposive sampling method in hospitals of Shahid Beheshti University of Medical Sciences, Tehran, Iran, in 2017-2018. The first author performed semi-structured, individualized interviews with 14 participants.

Results: By analyzing the data, the main category "Immersing in problems" was extracted with two following categories: 1- Inadequate support network (subcategories: inadequate informational support, inadequate instrumental support, inadequate emotional support) and 2- Difficult coexistence with problems (subcategories: role overload, worry and anxiety, fear and hope for the future, suffering of frequent dialyses).

Conclusion: The findings of the study showed that women living with the husband on hemodialysis have been encountered with challenges and numerous stressing factors in the course of caregiving. Given the challenges experienced by participants, telenursing, and community health nurses can play an essential role in eliminating the many problems of hemodialysis patients and their caregivers.

Introduction

End-stage renal disease (ESRD) is a growing and significant health problem in the world, which is associated with a high rate of morbidity and mortality (1). The prevalence of hemodialysis patients is increased from 414 patients per million population (PMP) in 2011 to 469 patients PMP in 2016 (2). In 2013, the prevalence of patients on maintenance hemodialysis was reported in the world and in Iran 1,500,000 and 25,000, respectively (3). It is expected that by 2020, there will be 1200 Patients of CKD per million population (4).

Hemodialysis patients, like all chronic patients, are exposed to severe stress. The effects of chronic illness not only disrupt the lives of patients but also affect caregivers, including spouses of patients (5). In a systematic perspective towards family, every problem for any of the family members will undoubtedly affect other members of the family as well (6).

Older people who suffer from chronic illness are not only affected themselves, but also family members who care for them may also be affected; therefore, the family cannot be ignored in the disease (7). Chronic burden experienced by family caregivers can lead to physical and mental disorders and also can affect their quality of care (8).

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The lives of patients and caregivers have been shown to be dramatically changed due to the long-term treatment of chronic renal failure and frequent hospitalization in the dialysis ward; anxiety, depression, sleep disorders and low quality of life have been the problems that most of the dialysis patients and their caregivers experience. Family caregivers may suffer from psychological, physical, and social distress and many other challenges as a consequence (9).

A study showed that 52.5 percent of caregivers of the patients on hemodialysis had a minimum quality of life (10). In another study, it was made clear that the degree of caregiving pressure of caregivers of the patients on hemodialysis has been severe in most cases (74.2 percent) (11).

No doubt, the wife of a man with a chronic illness is one of the closest relatives of the patient who has the most extensive emotional, cognitive, verbal and non-verbal relationships with her husband, and if her emotional needs are not appropriately satisfied in the family, she will have more difficulties. At this time, women take the position of the previous head of family, and in addition to enduring the problems of the chronic illness of their husbands, they should combine the roles of their husbands and the mother's role (12). Caregiver experiences in women can be different from men. Studies have shown that a range of gender differences in the experience of providing care. The sudden transition of superintendence from the husband to the woman causes a specific series of insecurities and hard responsibilities including loss of income and dual role play for women (13). The results of a study show that chronic patient's wives suffer from

more depression than other caregivers (14). Caring for a sick family member affects the entire family, but some of these seem unique to women. Studies show that female caregivers experience more stress, depression, and caregiver burden than male caregivers (12).

All research projects start with a specific question, and that question dictates the path and stages of the study. The question asked in this study is that "what are the challenges faced by women living with husband on hemodialysis?" Given the question, the adopted method should illustrate the nature of the phenomena in a natural context along with the structure and factors that influence the formation of phenomena. Thereby, a qualitative study was the best option to shed light on the nature of phenomena in its natural context. However, studies describing the challenges faced by women living with husband on hemodialysis are limited. Therefore, based on a qualitative approach, this study was carried out to understand the challenges faced by women living with husband on hemodialysis. This method can show the nature of the phenomenon in its natural context. The authors tried to find out the reality in its natural form as the women experience it.

Methods

A qualitative study was performed based on the conventional approach to content analysis. Content analysis is a research method for analyzing text data that has been used extensively in health studies in recent years. The qualitative content analysis method is the process of understanding, interpreting, and conceptualizing the underlying meanings of qualitative data. This approach is usually suitable when

existing theory on a phenomenon is limited (15, 16).

The participants were selected using purposeful sampling, and sampling was continued until data saturation was achieved. Saturation has been defined as no further data can be gained for the study phenomenon by continuing data collection (17). After the 12th interview, no new themes and substantive information were not acquired from the interviews. However, data collection continued for two more interviews to ensure that no new themes are appearing. Participants consisted of 14 wives of patients under hemodialysis, in Tehran, Iran, in 2017. They were from four hemodialysis centers affiliated with Shahid Beheshti University of Medical Sciences, Tehran, Iran, in 2017-2018. The inclusion criteria included willingness to participate in the study, being at least six months' history of hemodialysis in husbands, no known case of psychiatric disorders in women and their husbands based on the medical history and their self-report, and Persian as their native language.

Ethics Committee affiliated with Shahid Beheshti University of Medical Sciences, Tehran, Iran, confirmed the research proposal of the current study (IR.SBMU.PHNM.395). The participants, who accepted their voices to be recorded and were willing to participate in the study, signed the informed consent. The researchers also assured the participants that they could withdraw from the study whenever they want without being punished.

The first author performed Semi-structured, in-person interviews. The main questions in the interview were as follows: 'as a wife of the patient under hemodialysis how do you perceive your husband's disease?', 'Would you please tell me about your experience as a wife of the patient

under hemodialysis and 'I would like to understand more about what problems you encountered? Moreover and to have more in-depth insight into the concept under study, follow up exploratory questions were asked based on the information already given by the participant. Participants' informed consent was obtained to include them in the research and audio record their interviews. The interview appointments were arranged in advance to make sure of the convenience of the participants. The average time of each interview ranged from 35 to 45min. Each participant was interviewed one time. Also, field notes were used during data collection to document nonverbal behaviors and communication from participants.

Data analyses were performed based on the method described by Graneheim and Lundman (16). As the first step, the interviews were transcribed verbatim and reread several times in order to obtain a sense of the whole. In the second step, the essential text parts were divided into units of meaning. Then the units were condensed and labeled. In this step, sub-categories extracted. In the next step, according to the similarities and differences, the categories as the main feature of content analysis have emerged. Finally, the latent meaning of a text, which is called "themes," was introduced.

Rigor of the study was ensured by the Guba criteria (1981) for trustworthiness (18). To ensure credibility, the authors tried to manage the interviews in a cooperative environment and facilitated interactions with the participants. Also, through field notes, member checking (results were returned to participants to check and ensure accuracy and resonance with their experiences) and external checking (peer debriefing), the

credibility of the data was confirmed. For consistency, one member of the research team did interviews and coding.

Dependability was improved by a thorough description of the study processes for being easily audited by others.

Confirmability was further ensured through cross-checking by the other three members for accuracy. The research team discussed preliminary results to ensure they were a credible interpretation of participants' responses. Also, the participants with different demographic characteristics and experiences (maximum variation) regarding

age, education level, duration of husband's hemodialysis and socioeconomic status were recruited in the study for enhancing the transferability of the findings.

Results

In total, 14 participants were included in this study (Table1). Data analysis revealed 353 primary codes and based on overlapping and mixing, 123 primary codes were obtained. Afterward, the codes were compared and extracted based on similarities and differences; seven sub-categories, two categories, and one main category were extracted (Table 2).

Table 1. Participants and their husband's demographics

Code	Age	Education level	Husband's age	Job-status	Husband's education level	Job-status of husband	Dialysis duration
1	35	University	36	Employed	University	Employed	8 months
2	62	Under diploma	67	Housewife	Under diploma	Retired	10 years
3	54	Diploma	59	Housewife	Diploma	Employed	8 years
4	66	Primary school	65	Housewife	Diploma	Retired	9 years
5	65	Primary school	67	Housewife	Primary school	Retired	8 years
6	55	Under diploma	55	Housewife	Primary school	Employed	7 years
7	59	Under diploma	60	Housewife	Under diploma	Retired	5 years
8	53	Diploma	55	Employed	Under diploma	Unemployed	5 years
9	46	Diploma	47	Housewife	Diploma	Employed	2 years
10	54	Under diploma	55	Housewife	Under diploma	Retired	4 years
11	41	University	42	Housewife	University	Employed	2 years
12	48	Diploma	50	Housewife	University	Employed	2 years
13	39	University	40	Employed	University	Unemployed	4 years
14	64	Primary school	63	Employed	Under diploma	Employed	8 years

Table 2. The main category, categories, and sub-categories of findings

Main category	Categories	Sub-categories
Immersing in problems	Inadequate support network	-Inadequate informational support -Inadequate instrumental support -Inadequate emotional support
	Difficult coexistence with problems	-Role overload -Worry and anxiety -Fear and hope for the future -Suffering of frequent dialyzes

Following sections elaborate on the categories extracted from the interviews. The main category of the current study that was reported by all participants consisted of "immersing in problems" and expressed that the participants have experienced a

wide range of problems in various aspects. This theme includes two categories: Inadequate support network and difficult coexistence with problems. Inadequate support network was one of the challenges

faced by women, suggesting inadequate access to various sources of support.

This theme includes three subcategories:

Inadequate informational support", "Inadequate instrumental support," and "Inadequate emotional support." Insufficient function of relatives, health care system and even the family were among the critical problems which in various information, instrumental and emotional forms had caused difficulties for the participants.

Inadequate informational support

The provision of informational support can attempt to influence the thoughts and behaviors of the receiver; such informational support is given in an interpersonal context of caring, trust, and respect for each person's right to make his or her own decisions.

Most women who participated in the study expressed that the informational support which they received was not sufficient and they required more information about dialysis, lifestyle, diet, medicines and daily activities for providing the best care and having a better life. The majority of participants claimed that their information about caregiving of the patient at home was insufficient and sometimes the lack of information had a negative impact on their care of the patient.

One of the challenges expressed by some of the participants who had a lower education level was the incomprehensibility of some educational materials that were provided for them. One of the participants in this regard said:

"Few instructional sheets were given to me by the nurses, which were about food and medicine, but I did not understand them. I could not understand the meaning of several words. It was not much helpful".
(Participant 6)

One of the participants said:

"My information about diet was insufficient. When I come here (hemodialysis ward), I learn something from other ladies. All women have numerous questions. We ask some of these questions from each other, but we do not find the correct answer for them".

One of the most important sources for information acquisition was the health care staff. Most of the participants endorsed this issue that they had received relatively useful information from this group. However, due to lack of information, in their confrontation with new issues and problems, they had become entangled with problems.

The ninth participant said:

"Nurses and doctors provided good instructions first. They answered most of our questions about illness, but they were busy anyway. I cannot take their time for more than a few minutes. Sometimes we are encountered with new problems and questions, and we do not know what to do with them."

Inadequate instrumental support

By giving instrumental support, tangible aids, and services that directly help a person in need should be provided. Hemodialysis, like other chronic diseases, imposes heavy economic burden onto the patient's family. Many of the participants had numerous problems due to the financial pressure resulted from buying their medical facilities, laboratory test costs, medicine costs, and transportation issues. Sometimes they were forced to ask aids from others and particular institutions. Some of the participants had bad feelings about this problem. One of the participants argued:

"My husband is a retired man. Our financial condition is not good. My son helps us with the costs of medication for my husband. Of course, my children have their financial problems. Sometimes I am unable

to pay the costs of medication. It is embarrassing for me to ask for aid from my relatives." (Participant 4).

Likewise, another woman said:

"It is tough for me to ask aid from my relatives and friends for the costs of medication and life" (Participant 11).

Another participant stated:

"Our financial situation is so worse that we cannot even think of kidney transplant. My husband has no other way but dialysis for the time being, and we ask God to help us" (Participant 13).

Inadequate emotional support

By emotional support, empathy, love, trust, and care should be provided. Most of the participants were in search of emotional support. They considered the provision of emotional support a prerequisite of confrontation with the new conditions. From the participants, being understood by family, friends, doctors, and nurses were precious for them because it made them more hopeful for the future and provided an incentive for continuation of life and persuaded them to take care of the husband and family with self-esteem. However, according to the participants, this need was not sufficiently addressed, and others did not pay the due attention to their problems and restrictions; therefore the lack of emotional support on behalf of friends and family imposed numerous damages to them because it weakened their spirit and caused mental disorders.

Two participants described their experiences as follows:

"Of course, my husband and I are more in need of love and compassion from our relatives than any other time ... One of my children has taken a bank account from us and every month wires some money for us.

However, he rarely visits us ... (participant 6).

"Sometimes, I need to speak a few minutes of my problems with one of my relatives in order to become heartsome. Unfortunately, I do not have anyone to speak... Everyone is dealing with his/her own life and is doing his/her affairs" (Participant 8).

Some of the participants claimed that sometimes or in some cases, this love and compassion occurred in the form of pity that not only is not helpful but also even it disappoints the participant or the patient. The following excerpt shows this:

"Some people give pitying look at my husband and me, and they help us with pity. Such a look makes my husband more distressed and me, and as a result, sometimes I decide not to tell anything of my problems to anyone" (Participant 3).

"Pitiful look of some of our friends and relatives makes the situation worse for us. Once one of my friends told me in the presence of my husband that your husband is young why he should suffer this way, I fell pity for him whenever I see him. I got upset when I heard this, let alone my husband. We have thousands of problems, and we do not want further" (Participant 9).

The emotional support and sympathy of the doctors and nurses with the patient have significant side effects on the patients and caregivers. Some of the participants have referred to such cases as lack of sufficient and proper sympathy on behalf of the doctors and other medical staff.

"Illness is a normal matter for doctors and nurses. I and my husband are mentally devastated, and we have thousands of problems, but they say: take care of your husband".

Difficult coexistence with problems

The other category extracted from this study was difficult coexistence with the problems. The participants of this study felt continuous problems, which had influenced various aspects of their lives. This category had the following subcategories: role overload, worry and anxiety, fear and hope for the future, and suffering of frequent dialysis.

Role overload

One of the problems with which the women were encountered was role overload. The women were replaced with the former head of the family and besides bearing the difficulties of the chronic disease; they are forced to combine two roles of head of family and motherhood. One of the women said:

"I am in charge of all tasks at home and outside. My husband cannot work as before. He no longer undertakes the tasks that he did before his illness because his physical condition is dire, and I am continuously worried about his hand's fistula. The works outside the house are also done by me like shopping, paying bank installments, and the tasks related to the kids' school" (Participant 12).

Another participant explains the newly added role of caregiving as follows:

"Now the task of caregiving to my husband has been added. My husband is ill, and because of his dialysis, his condition is not well, and we should take care of him. We must give his medicine on time and take care of his diet, sleep, and situation" (Participant 14).

The suffering of frequent dialysis

Suffering resulted from frequent dialyses was another problem that haunted almost the majority of the participants and included the hardness of frequent visits and the

difficulties due to these countless visits. One of the participants said:

"It is truly agonizing to visit the hospital every other day. It is necessary, and we have to go to the hospital; otherwise, his condition will get worse. We are always at the hospital for dialysis" (Participant 17).

Worry and anxiety

Most of the participants have referred to the fear of the future of their kids, fear of the death of husband, fear, and anxiety of the worse health condition of husband and fear and tension resulted from the dialysis. Fear of the death of the husband was one of the concerns that caused agitation in women.

"I am always worried about the moment when my husband is no longer alive, what would happen to my kids and me. We do not have anyone but my husband. Finally, parents should make plans for their child's future. It is tough to do this alone. They need education, marriage, and many other things" (Participant 13).

Another participant was also worried about the health conditions of her husband and said:

"I am mostly worried about the health condition of my husband. If the dialysis does not work, his physical conditions can be even worse. If he suffers from other diseases, what would happen" (Participant 9)?

Fear and hope for the future

Most of the participants expressed that they have experienced degrees of fear and hope. They have noted that due to the nature of the illness of their husband, they always think of the occurrence of worse things in future; but they have hope for future and expect to see the problems to be solved. One of the participants described her situation as follows:

"I always hope and expect one day my husband will go under transplant operation,

and the grieve will come to end, and we will no longer need to go to the hospital. I wish we would find a kidney for my husband soon. Man is alive with hope; but, one the one hand, I am afraid that transplant would go wrong. I am also hopeful on the other hand" (Participant 12).

Some of the participants despite their hope for the betterment of life conditions had specific concerns of the possible problems after the kidney transplant, and one of the participants said:

"Of course, I have heard that the transplant itself has its problems even it may reject. I am worried about this issue. The care after transplant is hard, but we should not become disappointed because of these words and get cornered. Finally, we have to take action. Transplant is the best solution. We are struggling to make it real, but we have our concerns too" (Participant 1).

Discussion

As far as the authors know, the present study was the first qualitative study to explore the challenges of women living with the husband on hemodialysis. Most of the problems experienced by the women living with the husbands on hemodialysis in this study were the tension and stress resulted from encountering various difficulties and aspects of caregiving and the information, instrumental and emotional needs. The results showed that the women living with the husband on hemodialysis are severely affected by the illness of their husband due to their caregiving role. Notably, the lack of information in this case and insufficient emotional support can worsen the situation.

One of the themes of this study was "Inadequate support network." The majority of the participants have expressed that they required aid and support in information,

instrumental and emotional areas and insisted on the significance and critical role of these supports particularly on behalf of the family informational support includes providing advice, suggestions, and information that can be helpful to a person in solving problems (19). Evidence shows that in those cases where the caregivers have a clear understanding of the illness, signs, and effects, the pressure and tension of the care receivers are reduced, and their ability for resisting the illness is increased (20). In this regard, a study showed that hemodialysis patients and their families have little information to help them prepare for and contend with their long hemodialysis travel (21). A study that has been done to investigate the coping skills of family caregivers in caretaking of patients undergoing hemodialysis, one of the extracted themes was help-seeking skills. (22). In another study, it was made clear that the family caregivers of patients on hemodialysis had positive notion of the support offered by others, and they consulted with others for solving their problems (6). However, in studies mentioned above, the efforts of the caregivers for acquisition of information have been insisted as a way for better coping and no clear allusion has been made to satisfaction or the problems of the caregivers in the path of information acquisition.

One of the essential themes of this study, which has not been clearly stated in previous studies, was "inadequate emotional support." Emotional support, including empathy, attention, and compassion towards the patient by the relatives as well as the medical staff plays a crucial role in the reduction of stress and acquisition of the sense of peace. However, the results of the study showed that the lack of emotional

support or deficiency in it on behalf of the family, friends, colleagues, and neighbors or prominent individuals had been an essential problem for the participants. This is while Kelly and Turner believe that emotional support of relatives plays a vital role in the promotion of the quality of life of older people (23). Some of the participants have been dissatisfied with the normalization of the illness for the doctors and giving superficial answers to the patient and lack of sympathy and attention on their behalf. While emotional support of the patients besides their positive mental effects for the patients and their family improve the medical process. For when the patients feel that the doctors understand them, they would better follow the medical prescriptions (24).

Another theme of the current research was difficult coexistence with problems. Such problems as role overload, suffering from frequent dialyzes, fear, and anxiety, worry, and hope for the future have caused the participants to have hard and agonizing coexistence with their problems. A study showed that those men who played the role of caregiver of the patient suffering from renal failure had negative experiences including having challenges, hopelessness, fear, agony, force, and fatigue (25). In another study, one of the main themes extracted from the experiences of the caregivers of patients on hemodialysis was "in disease's captivity." Such experiences as uncertain future, permanent obsession, being in conditions' captivity, frustration, plight, and whirlpool of problems, channel life were the sub-themes of the central theme of "in disease's captivity "(26). In another study that has been conducted by quantitative method, it was made clear that the average number of the caregiving pressure of the

caregivers of patients on hemodialysis has been at a higher level (27).

Caregivers are potential secondary patients because the adverse effects of caregiving have undesirable impact on their health. However, the pattern of caregiving by men is very different from women. Caregiver women experience more stress than men. Adverse outcomes like caregiving pressure and burden are more in the women than the men insofar as they are entangled with more physical and psychological problems (28).

Therefore, the results of this study suggest that the caregiving conditions in dialysis patients particularly in women cause challenges and severe stress in the caregivers and this stress can not only reduce the quality of caregiving; it may threaten physical, mental and spiritual health of the caregivers. Because of the findings of current research, the caregivers having the patient on dialysis are encountered with numerous problems and challenges, and on the one hand, lack of attention on behalf of the health care system to them and insufficient support have added to the existing problems and can lead them towards falling victim to these conditions. The attention of the medical system to this group of people who are undercover patients should not be forgotten.

The results endorse the necessity of attention of the policymakers to the allocation of possibilities and facilities including educational and consulting services, the publication of educational books and pamphlets as well as establishing active societies in support of the house caregivers.

Nurses, in addition to their role in the hospital, also play essential roles in society (29, 30). Given the challenges experienced

by participants, community health nurses can play a crucial role in solving the problems and needs of patients and their caregivers in different fields. It is also possible to use telenursing, which is the use of telecommunications technology by a variety of applications, such as the use of telephone, mobile, monitoring systems, the Internet, video, and e-mail (31, 32) to follow up caring of patients and their caregivers more effectively.

Limitations

This study had no specific limitation. As a qualitative research, the findings are not generalizable to a larger population but may be transferable to similar environment.

Generally speaking, the results showed that the women living with a husband on hemodialysis are grappling with numerous problems and these problems not only may reduce the level of the care provided by them for the husband, they can also threaten their own physical and mental health. By using the results of this study, we can take more suitable measures for the betterment of the quality of life of these individuals so that both the quality of the caregiving to the patient be improved and the physical and mental health of the caregiver as a hidden patient be guaranteed.

Given the challenges experienced by participants, telenursing, and community health nurses can play an essential role in eliminating the many problems of hemodialysis patients and their caregivers. Home telenurses and community health nurses are in an excellent position to provide these women with informational, instrumental, and emotional support. Information about available resources and qualifying criteria for government assistance will help women in supplying real support.

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