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Original Article

Living with a Foggy Future: Experiences of Caregivers of Hemodialysis Patients

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Abstract

Background: Caregivers of hemodialysis patients experience several daily challenges due to the specific condition of their patients. It is necessary to study the challenges of this group to reduce the adverse effects on the caregivers and the patients. Accordingly, the present study aimed to describe the caregivers' lived experiences of caring for hemodialysis patients.

Methods: This was a qualitative study conducted using a phenomenological approach. The participants were 21 caregivers of hemodialysis patients from three hemodialysis centers in Qazvin, Iran who were selected using purposive and snowball sampling. Data were collected through in-depth semi-structured interviews and analyzed using Colaizzi's seven-step method.

Results: A total of 107 primary codes, 15 subcategories, 7 categories, and 3 main themes were extracted from the analysis of the interviews. The main themes included caregiver as the central pillar, fear of the foggy future, and the heavy burden of being judged by others.

Conclusion: Caring for patients with hemodialysis constantly imposes many challenges for caregivers. The managers of hospitals and hemodialysis clinics can prevent the severe consequences experienced by caregivers and patients by planning and implementing individual development training courses and effective policies to enable caregivers.

Keywords: Hemodialysis, Caregiver, Phenomenology

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Introduction

Chronic kidney disease (CKD) is one of the most critical health problems in the world (1). The worldwide incidence of end-stage renal disease (ESRD) is 242 cases per 1 million individuals, with an annual increase of 8%. In Iran, the prevalence of this disease is notably higher, reaching 380 cases per million people. At present, over 2 million individuals globally and more than 30 thousand in Iran are receiving hemodialysis treatment. It is imperative to emphasize that the provision of dialysis services significantly influences the quality of life and health outcomes of ESRD patients (2).

Although widespread access to hemodialysis as a treatment method saves and prolongs the life of many people with the disease, this complex treatment method has several limitations for these patients (1,3). These limitations can lead to physical, psychological, social, and economic complications. In such conditions, these people have to spend 2-3 hours a week i.e., several hours of their lives connected to the hemodialysis machine, which affects the living conditions of these patients (4). Furthermore, the prolonged hemodialysis treatment leads to the high dependence of these patients on caregivers, families, and healthcare systems. Therefore, most patients need support in adapting to the drastic changes resulting from the diagnosis and progression of the disease (5).

Caregivers constitute a vital and indispensable resource within the realm of healthcare. They are individuals who actively participate and provide significant assistance throughout the course of a patient's illness, aiming to facilitate adaptation and effective management of the patient's complex medical conditions. These caregivers can be categorized as either formal or informal. Formal caregivers are characterized as volunteer individuals who receive remuneration for their caregiving services and have undergone specific training in the field. On the other hand, informal caregivers, as substantiated by various studies, predominantly consist of patients' family members, namely the spouse, parents, and siblings, who assume the responsibility of caring for chronically ill family members. Consequently, families are widely acknowledged as the primary source of patient care (6,7).

In such situations, the hemodialysis caregivers' involvement in transferring patients to the hemodialysis ward, preparing appropriate food, fulfilling health needs, paying attention to the side effects of hemodialysis and managing these complications, monitoring vital signs, and emotional and psychological support puts a lot of pressure on them (8).

In addition, changes in daily social relationships, social interactions, and business are other problems for caregivers (9). In such cases, most caregivers prefer the patient's needs to their own and, as a result, take less care of their health-related issues. This hasty prioritization adversely affects the health and well-being of caregivers (10). In most studies, caregivers complain of experiencing loneliness, depression, decreased physical and mental health, fatigue, and reduced quality of patient care (11-13).

Since comprehensive support for caregivers is crucial, it is necessary to study the actual situation of caregivers precisely and scientifically and provide solutions to support them. One approach to optimally support these individuals is to understand their insights, expectations, and experiences in treating their patients (12). The effectiveness of the approaches adopted by the caregivers is so significant that in a study, Salehi Tali ‎et al stated paying attention to the opinions of the patient's spouse and family members and their reactions to the disease is far more important than the patient's reactions (14).

In confirmation of this, the results of the studies conducted in this field also indicate that the problems of this group of people in different societies should be taken into consideration by researchers. In some cases, caregivers have been given the title "hidden patients" who are never seen by the healthcare team (3,15).

Given that qualitative research provides essential and in-depth information about caregivers' feelings, attitudes, needs, and beliefs, and since understanding and analyzing these insights can provide healthcare providers with valuable information, this study was conducted using a qualitative phenomenological approach to deeply understand the care experience of caregivers of hemodialysis patients.

Methods

This study was conducted using hermeneutic phenomenology. Phenomenology is a qualitative method to determine the basic features and structures of life experiences regularly and reciprocally. Its goal is to understand the meaning of the experience as lived by the participant (16). The present study was carried out in Qazvin, northwestern Iran, in three hemodialysis clinics. Data were collected from the beginning of June to the end of December 2020. In qualitative research, the sampling method is purposive (17); hence 21 caregivers of hemodialysis patients were selected purposively based on inclusion and exclusion criteria. The inclusion criteria were willingness to participate in the study, being responsible for the direct care of a patient for at least six months, being 18 years old and above, not receiving money for care, not having a mental illness, not taking psychotropic drugs (according to participant statements), not being responsible for caring for another person, being literate, and being able to communicate verbally. The exclusion criteria included unwillingness to continue cooperation and not having the required physical and mental conditions for interviewing at the researcher's discretion.

The data were collected through semi-structured interviews. Initial communication with the selected caregivers was done by telephone or in-person. In this meeting, the researcher introduced himself and explained the goals and procedures to the caregivers. In the end, the researcher obtained informed consent, and the caregivers' opinions determined the time of the first interview session.

The interviews started with a simple structure and gradually became more structured. The researchers recorded the interviews and then transcribed them verbatim. They also used the participants' memories, poems, and writings about their lives and took field notes. The main interview questions were, "Would you please describe your experience as the caregiver of a hemodialysis patient?", "When I say care, what comes to your mind?", "Can you tell me about your pleasant experiences in patient care?", and "Would you please talk about your bitter experiences in caring for your patient?" During the interview, the researchers asked probing questions such as "Can you give me an example?" or "What do you mean?" based on the participants' responses to encourage them to describe their feelings in more detail (18). The interviews continued until saturation. Each interview lasted 45 to 60 minutes (depending on the participants' ability). The interviews were conducted in a meeting room, located in the research environment, which was a quiet place away from the noise. A total of 45 interviews were conducted, 12 of which were finalized in two sessions and the rest in three. After analyzing the interviews, 327 important statements, 107 initial codes, 15 subcategories, 7 categories, and 3 main themes were extracted.

Analysis of the data using the Colaizzi's seven-step method

Step 1: At the end of each interview and after recording the field notes, the researchers repeatedly listened to each participant's recorded statements, wrote them word for word on paper, and read them several times to understand the participant's feelings and experiences.

Step 2: After reading the participants' descriptions and feelings, the meaningful information and statements related to the phenomenon were underlined and essential statements were identified.

Step 3: After identifying the crucial statements of each interview, a concept was extracted from each statement that expressed its meaning and the fundamental part of the individual's thought. After obtaining these concepts, the relevance of the provided meanings to the introductory sentences was examined to ensure the correctness of the relationship between them.

Step 4: The developed concepts were carefully studied and categorized based on the similarity of the concept to thematic categories or subthemes and thematic categories of the concepts were formed.

Step 5: The related concepts were merged into a more general category to describe the phenomenon comprehensively.

Step 6: The phenomenon was comprehensively described as the final theme without ambiguity.

Step 7: The findings were validated by referring to each sample and designing and evaluating the final classes and themes (19).

The criteria proposed by Guba and Lincoln, including credibility, dependability, confirmability, and transferability were used to validate the data (20). Credibility was verified by the researcher's long-term involvement with the subject (the researcher was in direct contact with the participants for 18 months). Dependability was also confirmed by transcribing the recordings as soon as possible, using peer reviews (14 peer reviews, mostly by hemodialysis staff), and re-reading the whole data. Confirmability was ensured using triangulation and maximum variety sampling, and transferability was assured by detailed explanations of contextual variables and findings (18).

Results

A total of 21 caregivers of hemodialysis patients (13 females and 8 males) participated in this study. The mean age of the participants was 49.71 years, and the mean duration of caring for the hemodialysis patient was 3.91 years. Table 1 shows the demographic characteristics of the participants.

After analyzing the interviews, 327 important statements, 107 primary codes, 15 subcategories, 7 categories, and 3 main themes were identified. The main themes included *caregiver as the central pillar*, *fear of the foggy future*, and *the heavy burden of being judged by others*. Table 2 shows the identified themes and subthemes.

Caregiver as the central pillar

The first main theme obtained was *caregiver as the central pillar*. According to the participants, a caring attitude towards this role can affect all aspects of the caregiver's life as well as that of the patient and other family members. The participants believed that a caregiver could make the continuation of the path easy for the patient and other family members via careful planning or, conversely,

Table 1. Demographic characteristics of the participants

Participant number	Age	Gender	Education	Occupation	Length of care	Caregiver's relationship with patient
1	29	Female	Middle school	Housewife	1 year	Spouse
2	25	Female	High school diploma	Housewife	2 years	Child (single)
3	41	Female	Middle school	Housewife	7 years	Child (married)
4	72	Male	Elementary school	Retired	14 years	Spouse
5	37	Female	High school diploma	Housewife	8 months	Child (single)
6	70	Female	Illiterate	Housewife	2 years	Spouse
7	54	Female	Illiterate	Self-employed	5 years	Spouse
8	37	Female	High school diploma	Housewife	9 years	Child (single)
9	41	Female	Elementary school	Housewife	1 year	Mother
10	61	Male	High school diploma	Retired	5 years	Spouse
11	80	Male	Elementary school	Retired	9 years	Spouse
12	51	Male	Elementary school	Retired	4 years	Father
13	69	Male	Elementary school	Retired	2 years	Spouse
14	78	Male	Illiterate	Retired	1 years	Spouse
15	42	Female	Elementary school	Housewife	10 years	Child (divorced)
16	54	Male	Illiterate	Worker	8 months	Spouse
17	39	Female	Bachelor's degree	Housewife	4 years	Child (single)
18	22	Female	High school diploma	Student	2 years	Child (single)
19	43	Female	Middle school	Housewife	18 months	Child (divorced)
20	64	Female	Elementary school	Housewife	4.5 years	Spouse
21	35	Male	Associate degree	Self-employed	8 years	Child (married)

Table 2. Subcategories, categories, and main themes

Themes	Categories	Subcategories
Caregiver as the central pillar	Need for adult caregivers Need for personal development Need for reinforcing social interactions between caregiver and patient	The importance of a mature and developed caregiver The need for fun and personal privacy Balancing the needs of patients and caregivers The need for positive energy and optimism Patients in need of intensive care Being cautious about saving the patient from premature death
Fear of the foggy future	Despair and helplessness Futility of care	Uncertainty about future The futility of care Lack of control Negative energy of the hemodialysis ward Caregiver as a full-fledged victim
The heavy burden of being judged by others	Pity and simultaneous rejection Lack of awareness and understanding in society	Unnecessary pity and compassion for others Shame for having a hemodialysis patient Lack of public awareness about the caregivers' and patients' problems Rejection of hemodialysis patients and caregivers in the community

make the path tedious and stressful with indifference and negligence.

Participant 21 stated, *"If a family member like me does not take on the responsibility of caring, the whole family will be involved, leading to a disaster. It annoys both the patient and the family. One day a son must come, one day a daughter, another day a daughter-in-law. I take responsibility for what is important to me, and I dedicate myself to it"*.

The participants believed that their patient thinks the caregiver is more important than the hemodialysis machine and the caregiver controls the machine.

Participant 2 said, *"I take care of my patient in such a way that every moment he thinks I am better than that machine, and I control it. Nevertheless, I do not know the first thing about this machine"*.

The subcategories of this theme included *the importance of a mature and developed caregiver, the need for fun and personal privacy, balancing the needs of patients and caregivers, the need for positive energy and optimism, patients in need of intensive care*, and *being cautious about saving the patient from premature death.*

The importance of a mature and developed caregiver

One of the participants stated, *"If a family member like me does not take on the responsibility of caring, the whole family will be involved, leading to a disaster. It annoys both the patient and the family. One day a son must come, one day a daughter, another day a daughter-in-law. I take responsibility for what is important to me, and I dedicate myself to it"* (Participant 21).

Participant 8 mentioned, *"Look, I am not steel, I get tired but I don't go to Rome. You should not show it when you have a sick person at home. You know, you have to deal with your patient in a way that she doesn't understand your tiredness, doesn't feel discomfort, doesn't understand your pain"*.

The need for fun and personal privacy

Participant 17 pointed out, *"In addition to my father, I have my mother, I also have my own shopping, but I handle everything. I respect myself a lot. I am important to myself. Taking care of my father did not make me ignore my importance or my needs. For example, I changed my father's dialysis hours so that I could get my driver's license, and none of them made any problems for me. Only 5 people were accepted, only my father was on dialysis among those 70 people. This will make me regain energy and be able to take care of my father with more strength"*.

Balancing the needs of patients and caregivers

Participant 3 stated, *"When I'm at home and I'm responsible for someone else, I do my best to take good care of her. Now, even if I'm bothered or tired, my eyes are red, it's midnight, no matter what, I have to do my responsibilities in my own home. I concentrate on doing my best for my wife. I will not miss anything"*.

The need for positive energy and optimism

One of the participants said, *"One day before my wife comes, I go home and line up everything. But even if you prepare everything, what should happen will happen. There is pressure or anything else, but it is very difficult to have positive energy, which means you have to be meticulous. All this comes back to sincere and heartfelt love, and this is true"* (Participant 21).

Patients in need of intensive care

Participant 15 believed, *"Those who do not receive special care like this will die very soon, whether they are young or old. This has many consequences. Their job here is just to drain the poison from the patient's body. Nutrition and medicine are no longer taken for and it all comes back to the patients themselves and their caregivers. The patient's life, even the quality of the dialysis, depends a lot on this. This dialysis or care is really important for them"*.

Participant 16 mentioned, *"Such patients need special care like patients with cancer or MS. However, dealing with these patients and even those who are hospitalized for two months is much easier than caring for hemodialysis* *patients. Hemodialysis is not once a month or once a week. The patients are constantly involved. I constantly control his medicine and food; it's not just to be here for a few hours. You have to control everything outside, in the street, in the car".*

Being cautious about saving the patient from premature death

One of the participants said, *"I take care of my patient in such a way that every moment he thinks I am better than that machine, and I control it. Nevertheless, I do not know the first thing about this machine" (Participant 2).*

Participant 17 pointed, *"When someone tells me how many years your father will be on dialysis, I say a few years, two or three years. I'm not telling the truth. I say they will wink at some point (laughing) because my father is very well. The weight is good and this is all because I take good care of him. Other patients always say, 'look how good it is'. I am even aware of all these. I even know that the scale shows 100 grams more, but I don't tell others. Only I know".*

Fear of the foggy future

The second theme identified in this study was *fear of the foggy future*. Most participants believed the future was very unpredictable for them as they witnessed the physical and mental problems of hemodialysis patients and the severe and sudden changes in these conditions.

Participant 13 stated, *"With these problems that happened to my spouse, I do not know what will happen in the end. I do not know how long this situation will continue. What will happen to us?"*

Participant 4 also mentioned, *"I think so much that I got sick myself. My stomach and my feet hurt. I have gone to a hundred doctors so far. They believed it happens due to stress. Now I do not know what to do. What should I do about my illness? What can I do about my lady?"*

One of the most important reasons for the caregivers' fear of future is patients' job instability. This was so disturbing that some participants acknowledged that even if they had a kidney transplant, there would not be a guarantee that their patient could have a job and personal income.

Participant 1 said, *"His job is critical. Now, if they transplant, they still have to care for the transplant and he cannot go to work again. Going to work is very important".*

Uncertainty about future, the futility of care, lack of control, negative energy of the hemodialysis ward, and *caregiver as a full-fledged victim* were the subcategories of this theme.

Uncertainty about future

Participant 13 believed, *"With this thing that happened to my wife, I don't know what will happen in the end? Finally, I don't know how long this situation will continue? What will happen to us with this physical condition that I have? God, where will our future end..."*

Futile Care

One of the participants pointed out, *"It doesn't help. If it would get better, yes, you would say, for example, that we have been taking care of this patient for four years now, and thank God, he got better. He does his work himself and there is no problem. But now I am on the same first step as I was. Nothing got better from the first day we started until today, we're on the same stairs we were the past four years. My condition has worsened and not improved. A child on dialysis cannot grow, neither intellectually nor physically"* (Participant 12).

Participant 11 also said, *"There is no point in taking care of him now. What's the point when his kidney will never recover? But I can't let go because of my heart. Even if we come here to accompany our patient, it doesn't hurt. It is only because of our own heart that we accompany them, otherwise it will not reduce the pain of our patient. We only tire ourselves".*

Lack of control

In this regard, participant 13 stated, *"One day I come here. I have to prepare the food, wash the dishes, and clean the house. Then, after chatting for a while, I have to get up again and think about dinner. Like a factory. I am both the man and the woman of the house. Now that they come here, there is a four-hour dialysis. I am forced to do my personal work in these four hours, or I do the shopping, then I come back, and we go home together".*

Negative energy of the hemodialysis ward

Participant 7 mentioned, *"The environment here is very uncomfortable. When someone dies here, I get very sad. It affects my mood. I've been thinking about my wife for a long time. Sometimes I say to myself, what should I do if this happens to me? Or if I get sick and hospitalized, then who should take care of my patient? I'm too old, maybe one day I'll get sick and I won't be able to take care of my wife. My son doesn't come, my daughter doesn't come at all...".*

Participant 10 also said, *"I take my wife regularly when she needs it, that's how it is now. Well, it has a mental toll. Mental pressure means that I bring her here, see different individuals with different conditions getting dialysis, or other illnesses they have. I always think that one day I might end up like this too. The doctor has told me to take blood pressure medication due to this stress".*

Caregiver as a full-fledged victim

Participant 7 stated, *"If my spouse didn't need dialysis, I would have been at ease. I would have stayed home and relaxed. I also need rest. I'm at an age now where my own legs hurt, and I can't take care of myself. I want to rest, but well, I have to endure the pain myself and take care of her;*

what else can I do?"

Participant 5 also said, *"For the sake of my mother, so that she would not be alone, I decided to never get married. If I want to get married, my mother will be very lonely; I don't want to leave her alone".*

The heavy burden of being judged by others

The analysis of the interviews showed that most participants were under pressure of being judged by others and the community. They believed that unwarranted compassion and the cruel judgments of others would annoy them.

In this regard, participant 12 stated, *"Sometimes people show sympathy but we do not feel good about it. For example, they say, 'Poor fellow! look what happened!' We do not like it. That's why most of the time we hide our problems. We don't like others to know much about it because they say something annoying".*

Most participants believed that accepting a patient with hemodialysis by the community is difficult which increases the psychological pressure on them. For instance participant 2 said, *"I deal with my mother's dialysis issue. I accepted it. Nevertheless, I'm sad about peoples' approach. They know nothing about our problems".*

One of the recurring concerns of single participants was people's judging about their marriage.

Participant 5 mentioned, "*Although I know my mother's disease is not contagious at all, other people have a different idea. If they find out my mother is on dialysis, they might be afraid to marry me. They might suppose I would have this problem as well. It irritates me".*

Unnecessary pity and compassion for others, *shame for having a hemodialysis patient*, *lack of public awareness about the caregivers' and patients' problems*, and *rejection of hemodialysis patients and caregivers in the community* were the subcategories of this theme.

Unnecessary pity and compassion for others

Participant 3 stated, *"Since my father has been on dialysis, I have a greater sense of compassion. But I sympathize more with my father who is sick. Compared to before my father was on dialysis, our sympathy for others has increased by 10, for example, from 50 to 60. We are kind, compassionate, and caring towards others. I am satisfied to be on this path for a few years and help other patients besides my father".*

Shame for having a hemodialysis patient

Participant 12 said, *"When they say, 'Oh, this child is on dialysis', and they show unnecessary sympathy, it annoys me. It's nice if they show kindness by giving the child a piece of chocolate to make them happy. But when they point it out needlessly with their fingers that yes, this child is on dialysis, and they don't do anything else, it makes me upset, and I feel embarrassed".*

Participant 13 also pointed out, *"For example, now that his dialysis is over, his hand must be taped so that it does not bleed, we cannot go anywhere that day because we will be ashamed of his hand being taped. People look at him badly and say, 'What happened to his hand?'"*

Lack of public awareness about the caregivers' and patients' problems

Participant 5 said, *"While I am aware of my mother's non-contagious illness, I often find myself thinking that people may not understand the situation fully. We don't hold any ill will towards them, but there's a chance they might discover that my mother undergoes dialysis. Hearing others talk about her condition and the possibility of me needing dialysis in the future saddens me".*

Rejection of hemodialysis patients and caregivers in the community

Concerning this subcategory, participant 12 mentioned, *"My problem is that in this era, people don't really accept someone who has dialysis. If they understand you are on dialysis, they won't hang out with you. They won't even take your kindness from you anymore. They say how do you know that dialysis is not contagious. I say it is a disease given by God. Why do they say this? I am really sad".*

Discussion

The first theme identified in this study was *caregiver as the central pillar*. The participants believed that hemodialysis patients need more intensive care than other chronic patients, both physically and mentally. They believed that even patients with cancer or MS have better conditions than hemodialysis patients. Since hemodialysis patient care is not limited to a few days or months, caregivers are involved in caring for their patients for a long time. Previous studies have also revealed that hemodialysis patients' caregivers, compared to other chronic patients' caregivers, have several problems, including the need for frequent hospitalizations, monitoring of multiple medications, monitoring of patient symptoms, and frequent visits to the dialysis ward (1,21). This has been confirmed by the studies comparing the care load of hemodialysis patients with that of other chronic patients (7,22). Meanwhile, Parlevliet et al found that the care load of the caregivers of hemodialysis patients is higher than that of the caregivers of cancer patients (23). These results confirm the findings of the present study.

Another reason for the importance of caregivers' role is the need for much effort and unique capabilities to maintain a balance between personal life and the patients' needs. Participants believed that in such a situation, they would experience severe confusion and conflict and would not know how to deal with it. It significantly increases the stress on the caregiver and leads to other adverse consequences. These findings are consistent with Ebadi and colleagues' findings. They also found that caregivers often have to balance their personal life with care activities due to the complexity of the caregiver's role and patients' high dependence on them. This compulsion leads to problems such as limitations in deciding for the future and not paying enough attention to themselves (24).

Another study showed that the caregivers of hemodialysis patients always try to balance their life with living with the patient (25). Erlingsson et al also found that home caregivers often experience job setbacks, job loss, marital disruption, or system crises while balancing patient care responsibilities with other responsibilities (26). According to Rajkhowa, the stress of caring for hemodialysis patients leads to anxiety, worry, and internal turmoil for the caregivers. It makes it difficult for them to adapt to the situation and balance caring activities and personal life, leading to interference between personal life and patient care (27).

The findings of the present study also revealed that the participants often experienced despair, hopelessness, and fear of the future due to the uncertainty of their patient's condition. Wightman et al showed that although some caregivers of hemodialysis patients are so immersed in the work related to their patient's treatment, they do not know about their patient's future. However, some caregivers have many unknown concerns about their child's future, including the unpredictable nature of the disease and the consequent mortality, seeing their child's future in a haze of ambiguity (28). Frontini et al found that caregivers of patients with ESRD are always afraid of their patient's future and struggle with the fear of the patient becoming ill or dying (29). Besides, in the study by Rezaei et al, constant fear and constant mental fatigue were found as two main themes that mothers with chronically ill children as caregivers always face (30). These findings are all consistent with the findings of the present study.

One of the critical findings of the present study is that caregivers expect to see changes in their patient's condition through caring activities. However, when they do not see any improvement in their patient's condition, they often feel that their care is ineffective and useless. It has become a factor in creating a sense of hopelessness and despair. Eslami et al also indicated in their study that the constant suffering and confusion of the caregivers due to facing the patient's problems lead them to despair. They often find that despite their best efforts to care for their patients, they see no improvement in their despair (31).

The participants in the present study also acknowledged that even if their patients had a kidney transplant, they would not be relieved entirely of such conditions. They believed kidney transplantation is associated with problems no less than their current situation. These findings are in line with Pourghaznein and colleagues' findings who identified the confusion between hope and despair as one of their main themes. The participants in the study felt that they were constantly oscillating between hope and despair. Sometimes, hearing the results of a successful kidney transplant surgery gave them hope for their child's future. However, awareness of the possibility of kidney transplant rejection led to feelings of hopelessness about their child's future. Fear of their patient's future and fate was another concern for caregivers (32). In the study by Ebadi et al ambiguity in life situations was identified as a theme. In line with the present study, the results of this study showed that although the lives of hemodialysis patients were affected by rotational rhythmic care activities, the participants were afraid of their future and hoped that kidney transplants would let them get rid of this condition (24).

The analysis of the findings also showed that most caregivers of hemodialysis patients are under pressure to be judged by others and the community. In such situations, most caregivers prefer to hide the details of their patient's condition and the quantity and quality of care from others. Limited studies have been conducted on the fear of being judged by others among caregivers of hemodialysis patients. However, one of the critical factors influencing this feeling is how to accept the caregiver's role in different cultures. In Nigeria, for example, home caregivers often hide the illness of a family member to keep in touch with relatives (32). Conversely, a study on caregivers of chronically ill people in Sweden emphasized that a family member's illness is accepted and considered normal, and the perception and acceptance of behavioral responses associated with the disease has increased (33).

Other reasons for a caregiver to hide the illness were rejection by others, loss of marriage opportunities, and feelings of shame. Khorsandi et al found that one of the sources of stress for caregivers was the fear of others' perceptions of their child's illness, and the other was the pity of those around them. They also believed it is difficult for them to tolerate pity and compassion when talking to their relatives and friends about their child's illness. Most parents believed this would lead to feelings of weakness, disability, and humiliation. Participants in the study also believed that others' blaming or talking about their child and peers' adverse reactions lead to tensions between parents and children (33).

The participants in the study by Donald et al also stated that coping with the consequences of CKD, such as social isolation, disease-related stigma, and depression, was the key to having a good life with the disease. They also found that caregivers often tried to hide the disease due to financial problems, preventing the unemployment of the head of the family as a dialysis person, and preventing dismissal from work (13). Contrary to these findings, Oyegbile and Brysiewicz showed factors such as acceptance of the role of caregivers by caregivers or the duty to care for themselves led caregivers not to feel ashamed, upset, and angry about their role (34).

According to the analysis of the interviews, one reason for this wrong perception of caregivers was the community's lack of understanding of these people. This is vital because caregivers of patients with ESRD who are undergoing hemodialysis and have less social support are reported to face an increased burden of care and a lower quality of life and health. The burden of caring, which plays a role in lifestyle changes, leads to depression, anxiety, decreased physical health, social isolation, and financial stress for the caregiver (35).

One limitation of this study was the participants' characteristics and intellectual and mental challenges in the interview process, which may have affected their responses. The researcher tried to pay attention to their readiness before interviewing by providing full explanations to the participants and establishing a friendly atmosphere as much as possible to overcome this limitation.

Conclusion

Hemodialysis patient care constantly imposes many challenges for caregivers. The results of the present study conducted on the caregivers of hemodialysis patients in three hemodialysis centers in Qazvin led to the identification of three main themes including caregiver as the central pillar, fear of the foggy future, and the heavy burden of being judged by others. Tolerating such pressures and experiencing internal conflicts can lead to many physical and mental injuries in caregivers and their patients. The hospitals' officials, managers, and hemodialysis clinics can prevent the severe consequences of desperation experienced by caregivers and patients by planning and implementing individual development training courses and formulating effective policies to make caregivers more capable.

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Authors' Contribution

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Competing Interests

The authors declared no conflict of interest.

Ethical Approval

Ethical approval was obtained from the ethics committee of Qazvin University of Medical Sciences, Qazvin, Iran (IRQUMS.REC.1398.35. Before conducting the interviews, the participants were provided with detailed explanations of the study and its procedure. Each participant signed an informed consent form and received a copy. The participants were assured that the transcripts of all interviews were used for academic purposes only and that the data would be kept confidential. Moreover, code numbers were used to present the data and all data were stored on the researcher's personal computer.

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