Original Article

Family Caregivers' Experiences of Living with Hemodialysis Patients: A Descriptive Phenomenology

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Abstract

Background: Several challenges are experienced by caregivers of patients with chronic kidney disease undergoing hemodialysis treatment. These difficulties pertain to the patients, their hemodialysis treatment, and other caregiving responsibilities and concerns. Given the adverse effects of caring for individuals with such conditions on the lives of caregivers, this study aims to investigate the experiences of hemodialysis patients' family caregivers. **Materials and Methods:** A qualitative study with a descriptive, phenomenological approach was conducted in the hemodialysis department of a teaching hospital in Birjand, Iran, in 2022. Fourteen participants were selected through purposive sampling. The data were collected through semistructured interviews and analyzed using Colaizzi's method. **Results:** The participants were caregivers of dialysis patients who had a 6-month history of caring for patients and were first-degree relatives of the patient. A total of 278 initial codes emerged, which were categorized into three overarching themes and eight subthemes based on the research purpose and question. The overarching themes comprised caregiver time and cost strain, social challenges faced by the caregiver, and life challenges faced by the caregiver. **Conclusions:** Caregivers of patients with chronic kidney disease face problems in multiple dimensions and are susceptible to developing new problems. The majority of caregivers in this study were extremely vulnerable women; if they experience difficulties, the family's foundation will be weakened. Therefore, caregivers should be included in patients' treatment plans. The expression of caregivers' experiences can help solve the problems they are facing and also helps hospital managers and health planners better plan to solve problems.

Keywords: *Care, caregivers, hemodialysis units, life change events, patients, qualitative research*

Introduction

The dialysis process has a negative impact on the ability of patients and their families to engage in work and daily activities. This is primarily due to decreased energy levels, frequent hospital visits for dialysis, and associated health issues.[1] An estimated 500 million people worldwide suffer from chronic kidney disease, leading to end-stage renal disease and replacement therapies if not diagnosed and treated early.[2] In the United States, the proportion of hemodialysis treatment is 66%, 436 parts per million, and in Europe, hemodialysis treatment ratio is 58%, 456 parts per million.[3] The number of hemodialysis patients in Iran increases by approximately 16% annually. Treatment options for chronic kidney failure include hemodialysis, peritoneal dialysis, and kidney transplantation. According to national statistics, there are 25,934 patients undergoing hemodialysis, which accounts for 47.7% of all kidney replacement therapy.[4]

The care dimensions of caregivers for hemodialysis patients are influenced by the patient's condition. These care dimensions may be linked with negative consequences such as health deterioration, family isolation, disrupted relationships, inadequate patient care, disrupted activities and recreational programs, depression, anxiety, and sleep disorders. Additionally, the caregiver may experience reduced quality of life and burnout, potentially leading to patient abandonment.[5] The patient's primary caregiver is the person who, during the course of the disease and its treatment, is most involved in caring for the patient and assisting them in adapting to and managing the chronic condition.[5]

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The primary caregiver may be the patient's spouse, a close friend, or a family member.[5] Caregiving for elderly and disabled patients is estimated to be worth 196 billion dollars annually from an economic perspective.[6]

A study on hemodialysis patients indicates that certain characteristics of the patient's family members contribute to the patient's sense of vitality and influence their ability to cope with problems.[7] Patients with family support will be better able to adapt to the disease and have a longer survival rate than those without family support.[8] The care burden experienced by the patient's family while accompanying the patient leads to disability and illness within the family, as it disrupts their activities, recreation, and social communication.[9] Emotional, monetary, and social constraints present caregivers of dialysis patients with a variety of complexities and obstacles.[10]

Qualitative studies offer a deeper understanding of knowledge by exploring people's experiences, which can inform decision making in clinical activities more effectively compared to quantitative studies.[11] Descriptive phenomenology, a qualitative research approach, enhances comprehension and provides deeper insights into participants' experiences. Studying the experiences of caregivers of hemodialysis patients provides the treatment team with valuable insights into the subjective understanding of life from their perspective. Identifying the factors that influence this experience enables nurses to enhance the quality of care they deliver, thereby promoting improved education and support for these individuals. In this regard, this study aims to explore the lived experiences of hemodialysis patient caregivers using a descriptive phenomenological methodology.

Materials and Methods

A phenomenological study was conducted in 2022 to capture the lived experiences of the caregivers of hemodialysis patients referring to a teaching hospital in Birjand. Quantitative research lacks the flexibility and depth required to uncover the lived experiences of phenomena that affect human interactions in certain ways. In this regard, phenomenology is the most suitable method for understanding the depth of experience and the significance of a complex phenomenon.[12] This study utilized a descriptive phenomenological approach comprising direct comprehension, analysis, and description. At the stage of direct comprehension, the researcher is completely immersed in the phenomenon being studied. During this phase, the researcher becomes acquainted with the phenomenon as described by the participants while avoiding criticism, review, and personal opinion. In the analysis phase, the researcher attempts to identify the phenomenon's essence based on the information obtained, and as the research progresses, the researcher identifies the phenomenon's elements and components. This phase uncovers the predominant and frequent themes in the data.[13]

This study recruited caregivers of hemodialysis patients with more than 6 months of patient care experience using a purposive sampling method. Participants were interviewed both in the hospital (between dialysis sessions) and at home. Those who regularly cared for patients for longer than 6 months were considered eligible. The exclusion criteria were speech and hearing difficulties or a lack of interest in participating in the study. Participant interviews continued until the data were saturated, which was reached after 14 semistructured in-depth interviews. Saturation was assumed to occur when no new data were obtained from the participants. The interviews lasted between 40 and 60 minutes. The interviews were conducted privately with the participants' coordination and consent. Ethical principles were upheld through the provision of oral and written information about the study to participants, ensuring that they were aware of the voluntary nature of their participation. Their informed consent was obtained through a written consent form. The participants were assured that their conversations would remain private and confidential. Moreover, the participants were provided with the researcher's contact information via phone and email so that they could opt out of the study at any time and receive a copy of the results if they so desired. Interviews began with statements such as "Please describe your experiences of living with a hemodialysis patient," "Please describe your experiences as a caregiver of caring for a hemodialysis patient," and "Please describe your caring experiences and your personal life." Subsequently, additional probing questions were posed, such as "Can you elaborate?" All interviews were recorded in their entirety, and all participants were coded according to the order of the interviews. Each interview was transcribed verbatim immediately following each session, and analyses were performed after each interview to determine the ground for the next interview.

In this study, data were analyzed using Colaizzi's seven-step analysis method, which consists of the following steps: First, the participant descriptions were read to develop empathy with each individual. Second, each protocol was consulted, and key phrases were extracted. The researcher formulated the meaning or concept of each significant phrase listed under the title of set concepts. The set of concepts was then classified into thematic categories. Fifth, the findings were incorporated into a thorough description of the phenomenon under investigation. A comprehensive description of the phenomenon was expressed as a concise statement. In the final step, the findings were presented to the participants, who agreed with them.[14]

The study's trustworthiness was determined using Guba and Lincoln's criteria, including credibility, confirmability, dependability, and transferability.[14] Several measures were taken to ensure the credibility and accuracy of the data. These procedures included member checking, where participants were given the opportunity to review the data and confirm its accuracy and resonance with their experiences. The researcher also maintained continuous engagement with the data, ensuring objectivity by refraining from influencing his views and ideas during interviews (bracketing). Additionally, the data were confirmed by colleagues of the research team, two academic staff who were not part of the research team, and the participants themselves. Two members of the research team independently coded the interviews to assess dependability. There was a significant level of agreement between their evaluations. Furthermore, meticulous attention was given to the collection, transcription, and recording of data, with ample time allotted for the data collection process. The transferability of the obtained information was validated by two external faculty members and a qualitative research specialist. Furthermore, the study included a detailed description of the research topic, comprehensive participant explanations, and the incorporation of direct quotations.

Ethical considerations

This study was approved by the Research Ethics Committee affiliated with Birjand University of Medical Sciences (Approval ID: IR.BUMS. REC.1399.261. approval date: 2020-09-15). All participants signed consent forms, and the study adhered to the principles of voluntary participation, anonymity, and confidentiality for the participants. Moreover, accuracy and security were ensured for the texts. Besides, authorities granted the necessary permissions for sampling.

Results

There were 14 participants, with an average age of 49 years. The majority of caregivers were female and the spouses of the patients [Table 1]. Along with the research aim and primary question, 278 primary codes were extracted and categorized into three overarching themes and eight subthemes from the research findings [Table 2]. The themes and associated subthemes were as follows:

Caregiver time and cost strain: Costly treatment, intolerable life, caregiver's little time for the patient.

Social challenges faced by the caregiver: Caregiver isolation and loneliness, caregiver's problems in social relations.

Life challenges faced by the caregiver: Caregiver's conflict with psychological tensions, caregiver-patient life dependence, threatened patient autonomy.

One of the themes of the study is the caregiver time and cost strain, which is comprised of the subthemes of *costly treatment*, *intolerable life*, and the *caregiver's little time for the patient*.

Table 1: Demographic characteristics of the participants

Demographic characteristics	Age		Material		Relation to the patient	The duration of the disease	Cause of disease	Number of dialysis sessions per month	Number of dialysis hours per month.	Residence	Insurance	Marital status of the patient
	Patient	Caregiver	Patient	Caregiver								
1	59	25	Male	Male	Child	4	Diabetes; hypertension	12	48	Urban area	Armed Forces	Spouse deceased
2	79	62	Male	Female	Spouse	6	Hypertension	12	36	Urban area	Health	Married
3	42	39	Male	Female	Spouse	4	Diabetes; hypertension	12	48	Urban area	Social welfare	Married
4	40	38	Male	Female	Spouse	4	Diabetes; hypertension	12	48	Urban area	Social welfare	Married
5	43	40	Male	Female	Spouse	7	Hypertension; glomerulonephritis	12	48	Urban area	Social welfare	Married
6	66	58	Male	Female	Spouse	3	Diabetes; hypertension	12	48	Urban area	Social welfare	Married
7	35	55	Male	Female	Mother	15	Trauma	12	48	Urban area	Social welfare	Single
8	52	50	Male	Female	Spouse	3	Diabetes; hypertension	12	48	Urban area	Armed Forces	Married
9	58	50	Male	Female	Spouse	4	Diabetes; hypertension	12	48	Urban area	Health	Married
10	58	52	Male	Female	Spouse	4	Hypertension	12	48	Urban area	Health	Married
11	59	63	Male	Female	Spouse	3	Diabetes; hypertension	12	48	Urban area	Health	Married
12	37	33	Male	Female	Spouse	2	Nephrite	8	24	Urban area	Health	Married
13	68	73	Female	Female	Child	3	Diabetes; hypertension	12	48	Urban area	Health	Married
14	24	50	Male	Male	Father	2	Neurogenic bladder	8	32	Urban area	Bank	Single

Table 2: Extracted results based on theme and subtheme

Theme	Subtheme	Code
Caregiver time and cost strain	Costly treatment	Difficulty in providing money for medicine, providing expensive complementary medicines, the impact of treatment costs on living costs, the cost of going to and from the hospital for treatment.
	Intolerable life	All my life with illness, most of my time living in the hospital, thinking about other parts of my life, feeling helpless in life, living with suffering, not doing sick activities due to being a woman and not having enough strength
	Caregiver's little time for the patient	Decreasing my life and patient care, delaying all personal appointments, filling time with home and hospital care, high expectations of the patient to attend at night, my family members complaining about not attending
Social challenges faced by the caregiver	Caregiver's isolation and loneliness	Feeling lonely while taking care of the patient, not thinking about issues other than the patient, not participating in the mourning ceremony or parties due to spending time with the patient, not having the patience to communicate with others due to fatigue
	Caregiver's problem in social relations	Being forgotten by relatives, not attending family get-togethers, not being invited to ceremonies due to taking care of the patient, not having extra time for social activities
Life challenges faced by the caregiver	Caregiver's conflict with psychological tensions	Constant worry and anxiety, depression, nervous problems due to the patient's inactivity, the patient's laziness in not taking medicine and following the diet, my nervousness due to the patient's early suffering
	Caregiver-patient life dependence	Not going to the hospital if the caregiver is not present, not taking medicine because the caregiver is not present, the mother's dependence on the child like a child, the patient's complete dependence on the caregiver
	Threatened patient autonomy	The patient's loss of courage, spending most of the time sleeping, waiting for someone to bring a spoon, asking to cough, asking to do basic hygiene tasks

Costly treatment

The challenge of costly treatment was one of the difficulties associated with the patients. In addition to the problems caused by the disease, there are financial problems related to treatment costs and the provision of medicine and therapeutic supplements. Patients may have cardiovascular and pulmonary problems, hypertension, hyperlipidemia, and psychological issues. These problems are treated with medication, which is costly for the patient. *"In addition to enduring dialysis, our patient's expenses have increased. Moreover, he suffers from a variety of other diseases for which he uses medication, which puts a significant financial burden on the family (sighs)."* [Participant#7]

Along similar lines, participants identified the cost of patient transportation related to the treatment as a problem. Traveling to a dialysis center or the doctor's office can be very costly for those who do not have a car and must rely on public transportation. *"One of our problems is that we have to pay for transportation to the hospital and follow-up treatment, which is very annoying because the pension is insufficient."* [Participant#1]

Intolerable life

Participants believed that, due to the patient's presence in their lives, all living expenses had increased and that other family members had to contribute their share for the patient's care. Some patients are unemployed and pose a burden on their families, who rely on pensions for living costs. Besides, those who provide care cannot earn an additional income due to engagement with the illness. As a result of the rise in costs, a patient's life is subjected to increased pressure, which can be intolerable. *"Our income is fixed, and we do not receive assistance from other sources. Since my husband became ill, the entire family has been saving for his care. The prices of food items have skyrocketed, and we can no longer afford them. We do not buy or use every item we may require."* [Participant#12]

Caregiver's little time for the patient

People who care for patients at home and in hospitals recognize that they spend as much time with the patient as is necessary to meet their personal and therapeutic needs. Indeed, even going to the restroom on their own has become challenging, and the patients believe they are too dependent on the caregiver to the extent that their absence causes discomfort for some patients. *"…I am so busy with the patient that I am running out of time, and I cannot leave him because he believes that it is dangerous for him to be alone. Even if he wants to eat or do something else, I have to be there to answer his questions. Once, I was doing some work. He almost set fire to the kitchen and hurt himself. […] My working time does not allow me to spend more time."* [Participant#6]

The financial situation of individuals affected by illness undergoes significant changes, leading to a decline in income and an increase in expenses, thereby exacerbating the patient's overall quality of life. As the duration of a disease increases, the associated treatment costs also rise. These situations have a dual impact on both the patient and the caregiver, potentially jeopardizing the caregiver's life plan and income. They cannot devote enough time to the patient if they wish to earn more money.

The study also found social challenges faced by the caregiver as another overarching theme. The associated subthemes are *caregiver isolation and loneliness* and the *caregiver's problem in social relations*.

Caregiver isolation and loneliness

Illness tends to result in the patient's isolation. As a result of the limitations caused by their disease, patients avoid interpersonal relationships. Accordingly, other family members refrain from socializing due to concerns about developing personal connections. The disease is equivalent to the family's and the caregiver's isolation. *"Our patient has become grumpy and stuck on excuses after his illness; he always comes to me, and if I'm not available, he makes a fuss. I no longer have the chance to have relationships with close acquaintances."* [Participant#4]

Caregiver's problem in social relations

Caregivers are active family members, such as spouses or parents. The disease alters the disposition of the patients, which in turn alters the conditions of the caregivers' lives. Caregivers' communication and relationships with other family members and social affairs are limited, and they gradually become lonely in life. *"Our patient is completely dependent on me, and if I go to the neighbor's house, he misbehaves and makes a mess in the kitchen."* [Participant#7]

One of the important complications of the disease is loneliness and isolation of the patient, and subsequently, he becomes lonely due to the lack of caregivers in society. Social relationships are destroyed, and the patient is gradually forgotten as a result of a lack of communication with other members of society who used to play a role in the patient's and caregiver's lives. Due to the lack of communication with other members of the society who played a role in the life of the patient and the caregiver, social relationships are destroyed and the patient is gradually forgotten.

The life challenges faced by the caregiver is the third overarching theme in this study. It includes the *caregiver's conflict with psychological tensions*, *caregiver-patient life dependence*, and *threatened patient autonomy* as its subthemes.

Caregiver's conflict with psychological tensions

The misbehavior of patients has a profound adverse psychological effect on caregivers. Patients whose behavior has changed due to mental stress and disease-related thoughts may convey misbehavior to their caregivers. Interactions with patients make caregivers feel anxious, depressed, and worried. *"... I don't enjoy my life because I spend my days and nights worrying and fearing about the patient. I have become obsessed, and my mental condition is not good."* [Participant#11]

Caregiver-patient life dependence

The fact that their patients are irritable and depressed distresses the caregivers. The patients do not engage in personal and health-related activities and attempt to impose their duties on the caregivers. Consequently, they become dependent on the caregiver, which exacerbates their problems. *"Our patient is unwilling even to pour water in the glass... and she expects someone to be present at the restroom door when she goes to the restroom. The children are tired of the patient's behavior and become upset if someone is late to respond."* [Participant#13]

Threatened patient autonomy

When the patient's independence is threatened, the caregiver's life is also affected. This outcome is inevitable due to the caregivers' troubled conscience, which stems from concerns about their ability to provide sufficient care for their parent, child, or spouse who is undergoing dialysis. Consequently, when faced with the patient's loss of independence, caregivers often feel compelled to enhance their care level. *"Unfortunately, because we used to do our patient's work, now he is used to it and has become immobilized and does not even get up to drink water."* [Participant#14]

It is important to pay attention to the patient's personal life when they are suffering from a disease and to encourage them to use their abilities as far as they can. The patient's tendency to lose abilities should be considered when providing care, as dependence on others can contribute to this outcome.

Discussion

This study aimed to explore the experiences of caregivers who live with hemodialysis patients. This section analyzes and interprets three main themes and eight subthemes derived from the data analysis. The *caregiver's time and cost strain* is one of this study's overarching themes. Treatment, living sustenance, and lack of time to care for the caregiver become more costly as the patient's condition worsens. Consistent with the findings of the current study, another study has revealed that the rise in costs for hemodialysis and kidney transplant patients is one of the most significant challenges for patients, with a significant proportion of their treatment costs depending on whether they reside in a developed, developing, or underdeveloped nation. Patients' proportions of out-of-pocket expenses for medical care vary across nations.[15] In their study conducted in the Philippines, Torres *et al*. (2021)[16] cite the increase in family expenses as one of the challenges hemodialysis caregiver's experiences, which causes problems for the patient and family. Family members cannot earn additional income because they do not have spare time. The medical and nonmedical expenses of the patient primarily cause the financial burden. Moreover, there are indirect expenses due to decreased family income and a lack of opportunities to earn additional income.[17] Another study demonstrates that the financial burden on caregivers of hemodialysis patients is substantial, highlighting the need for policies and programs to reduce the burden on home caregivers and provide social and economic support for patients and caregivers.[18]

The difficulty posed by the lack of time is another finding of this study. The time insufficiency associated with the patient's affairs, as well as the inadequate time to do personal affairs, is altering the life patterns of caregivers. Consistent with our findings, another study has revealed that the care-life imbalance occurs when the caregiver can no longer care for the patient due to a lack of time; the caregiver does not have enough time to care for the patient.[19] According to another study, caregivers' life patterns undergo difficulties due to insufficient time caused by care provision for patients, as caregiving prevents them from engaging in many activities.[20] With the change in the patient's life situation in terms of eating, sleeping, dressing, and performing personal and health tasks, the caregiver's burden increases, and the caregiver must adapt to the fact that the patient's closest family member provides care. It becomes extremely difficult, and the caregiver's way of life alters.[21]

The fact that the disease and dialysis isolate the patient and the caregiver and that the caregiver's social relationships become restricted presents additional social challenges, as demonstrated by our study. Compliant with this finding, another study has revealed that caregivers and patients are reluctant to communicate with others and resort to isolation. Because most of their time is spent with patients and consumed by their problems, caregivers have less time to communicate with other community members.[22] Also, one of the findings of Hashimoto *et al*.'s[23] study is the isolation of the caregivers as a result of caring for the patient with a lack of interest and motivation in life, indifference toward the environment, and a desire to isolate him/herself; consequently, the inductive effect on caregiving will soon become apparent.

According to another result study, caregivers' social challenges are exacerbated by the heavy care burden at home and in hospitals. The social connections of caregivers with others and with their jobs decrease. Due to the patients' excessive dependence, the caregivers' social life is threatened, and both the patient and the caregiver are isolated and have fewer social ties.[24] Moreover, according to the findings of another study, the majority of the studied caregivers suffer from social isolation, health problems, and a lack of time due to numerous caregiving responsibilities. This necessitates the development of important care services and psychosocial support for caregivers to assist them in coordinating and managing the care of hemodialysis patients.[25]

In addition to these, the lives of caregivers are bound by other challenges, including the caregiver's emotional and psychological tensions, the patient's dependence on the caregiver, and the diminishing independence of the patient. Compliant with our findings, other studies indicate that, as the duration of caregiving increases, so do caregivers' psychological problems, such as worry, anxiety, and depression, which negatively impact their quality of life.[26,27] According to the findings of another study, the lengthier a hemodialysis patient's illness, the greater the patient's dependence on caregivers. Due to the increase in psychological issues among hemodialysis patients, the patient's dependence on the caregiver also increases, making the caregivers' lives more difficult.[28] A further study demonstrates that patients become more dependent on their caregivers as their quality of life diminishes and that the psychological stress of patients increases and affects their caregivers, who also exhibit signs of anxiety and worry. As such, the situation affects the caregivers' quality of life.[29]

A notable strength of the study was the researcher's affiliation with the hemodialysis department, which facilitated a greater familiarity with the caregivers. This familiarity proved advantageous in establishing trust and enhancing their engagement during the interview process. It is recommended to undertake a mixed-methods study that initially provides caregivers with education regarding the conflicts they encounter with hemodialysis patients, followed by the collection of experiences from both caregivers and patients. Given that the patients were from the only hemodialysis center in the city and from low-income families with more severe problems than usual, it is difficult to generalize the results. In addition, the caregivers were prone to emotional outbursts and conversational interruptions during the interviews as they had to cope with various issues. Therefore, the researcher allocated a great deal of time to the interviews to circumvent this problem. Furthermore, as the majority of interviews were conducted during the patients' hospitalization, the caregivers were preoccupied with the well-being of their patients. To avoid problems during the interviews, the researcher attempted to conduct more interview sessions with the caregiver.

Conclusion

In caring for hemodialysis patients, caregivers' experiences indicate that they are confronted with problems in multiple dimensions and are susceptible to experiencing new problems. Therefore, caregivers should continue to be the foundation of patient care, and health officials and planners should take the necessary steps by providing caregivers with psychological support, planning to solve their problems, and assisting the patient's family. Since most caregivers in this study are vulnerable women, they will also become vulnerable if they cannot reorganize their families. Caregivers must also be included in the care plan for the patient.

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Ethical considerations

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Conflicts of interest

Nothing to declare.

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