



# Exploring the Lived Experiences of Family Caregivers Who Provided End-of-Life Care to Hemodialysis Patients: A Phenomenological Study in Iran

Sakineh Moghaddam Zeabadi<sup>1</sup>, Ali Razaghpoor <sup>2</sup>, Seyedehzahra Hosseinigolafshani <sup>3,\*</sup>

<sup>1</sup> Department of Emergency, School of Paramedicine, Qazvin University of Medical Sciences, Qazvin, Iran

<sup>2</sup> School of Nursing and Midwifery, Qazvin University of Medical Sciences, Qazvin, Iran

<sup>3</sup> Social Determinants of Health Research Center, Research Institute for Prevention of Non Communicable Diseases, Qazvin University of Medical Sciences, Qazvin, Iran

\* **Corresponding Author:** Social Determinants of Health Research Center, Qazvin University of Medical Sciences, Qazvin, Iran. Email: z.hosseinigolafshani@qums.ac.ir

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## Abstract

**Background:** Providing end-of-life care involves offering care and support to patients with advanced incurable diseases who are in their final stages of life. Family caregivers of these patients often dedicate substantial time to their care, which can significantly impact their physical and psychological well-being.

**Objectives:** This study aimed to explore the lived experiences of family caregivers providing care for hemodialysis patients at the end of life.

**Methods:** This qualitative study employed a descriptive phenomenological design. To ensure information-rich samples, nine family caregivers of hemodialysis patients at the end of life were selected from two dialysis centers using a purposive sampling method. Data collection involved conducting in-depth, semi-structured, face-to-face interviews, which were digitally recorded for accuracy. Analysis was conducted using van Kaam's seven-step method.

**Results:** Nine family caregivers, including 3 men and 6 women, participated in this study. They had a mean age of 59.44 years, and on average, they had been caring for their patients for 6.33 years. Four main themes and twelve sub-themes emerged from the analysis of the interviews. These themes, as well as their sub-themes, were: (1) complex care (individual-social struggles and healthcare hurdles); (2) care as an opportunity for skill development (experience of spirituality and development of mental capacity); (3) care as a chain of caregivers (ignorance of the caregiver, lifestyle adjustments, persistent concerns, questioning circumstances, and mental strain due to prolonged care); and (4) moments of misfortune (emotional exhaustion from witnessing the patient's physical deterioration, a sense of helplessness regarding the patient's mental and cognitive state, and a sense of helplessness regarding the patient's mental and cognitive state).

**Conclusions:** Caregivers expressed a spectrum of both positive and negative experiences. While some viewed their role as fostering intellectual growth and development, others described feelings of confinement, entrapment, and sacrifice. Further comprehensive research is required to determine the factors contributing to this diversity of perspectives.

**Keywords:** Qualitative Research, Hospice Care, Family Caregivers, Hemodialysis Patients

## 1. Background

Hemodialysis is a life-saving treatment for patients suffering from chronic renal failure, a condition characterized by the gradual decline in kidney function over three months or more, leading to the inability to regulate fluids, electrolytes, and metabolic waste effectively (1-4). Globally, hemodialysis is the most

widely used form of kidney replacement therapy, accounting for 69% of all such treatments and 89% of all dialysis procedures (5). In Iran, chronic renal failure is widespread, and projections suggest that the number of cases will reach 423,300 between 2020 and 2030 (6). In 2016, Iran had 30,284 hemodialysis patients, with 6,679 new cases reported (7).

Despite its life-prolonging benefits, hemodialysis is accompanied by various physical, psychological, economic, and social challenges (8). Patients frequently experience complications such as hypotension, disequilibrium syndrome, muscle spasms, chest pain, back pain, anemia, and fatigue. In more severe cases, air embolism and hemolysis, though rare, can pose life-threatening risks (9, 10). Managing these multifaceted complications becomes particularly difficult as patients enter the end stages of life, highlighting the essential role of family caregivers in supporting their well-being (11).

End-of-life care applies to patients with advanced incurable diseases, where death is anticipated within 12 months. Providing care for these patients revolves around adopting a palliative approach, aiming for a meaningful life experience and dignified death (11, 12). End-of-life care is an integral component of palliative care (12), a comprehensive approach dedicated to enhancing the quality of life for patients and their families in the face of life-limiting diseases. Palliative care focuses on alleviating patient suffering, improving symptoms, and addressing a wide range of physical, psychological, spiritual, and social struggles associated with the disease. In fact, it serves to alleviate the suffering of both the patients and their families, beginning from the moment of diagnosis and extending throughout the management of pain and other disease-related symptoms (13, 14).

In Iran, end-of-life care is frequently provided by family members who act as non-professional caregivers (15). These caregivers undertake a range of responsibilities, including assisting the patients with activities of daily living, providing psychological support, and accompanying them during the treatment procedures (16). Hence, they play a vital role in providing support to patients at the end of life, whether at home or in medical centers, which can have diverse effects on their psychological well-being (17, 18).

In this regard, Bijnsdorp et al. conducted a qualitative study on family caregivers of patients at the end of life. The findings revealed numerous unmet needs among these caregivers with regard to emotional and psychological well-being, activities of daily living, social relationships, and spirituality (19). Additionally, Salehi Tali et al. conducted a qualitative study titled "victim of situation: Experience familial caregiver with hemodialysis patient." Their findings revealed that caregivers face severe care burdens, encountering multiple difficulties and ultimately resulting in inadequate care for the patients (20).

The rise in life expectancy among chronic patients, advancements in science and technology, and significant limitations in kidney transplantation have contributed to the growing number of hemodialysis patients. This group's heavy reliance on family caregivers places a substantial burden on those providing care. To enhance caregivers' quality of life and address their daily challenges, it is crucial to thoroughly examine their experiences during the demanding process of caring for dying hemodialysis patients. While previous studies have primarily used quantitative methods with predefined questions, the deep emotions and experiences of individuals in such difficult situations can only be fully understood by investing time and immersing in their stories.

## 2. Objectives

The current study aimed to explore the lived experiences of family caregivers providing care for hemodialysis patients at the end of life, utilizing a phenomenological approach.

## 3. Methods

### 3.1. Study Design

A qualitative descriptive-phenomenology research design, also referred to as Husserlian or transcendental phenomenology, was used to explore the lived experiences of family caregivers providing care for hemodialysis patients at the end of life. Descriptive-phenomenology research design illustrates individuals' everyday life experiences, as well as the values of these experiences, as explained by those who live them (21).

### 3.2. Study Setting and Participants

This study was conducted in 2023 at the hemodialysis centers of Velayat and Booali Sina hospitals, affiliated with Qazvin University of Medical Sciences. Participants were family caregivers of hemodialysis patients who provided end-of-life care. Inclusion criteria were: Being at least 18 years old, expressing willingness to participate, being directly responsible for the care of a patient at the end of life, and having verbal communication skills. Exclusion criteria were: A history of mental illness, a prior suicide attempt, current use of psychiatric medications, and self-reported severe stress within the last month.

### 3.3. Data Collection

After obtaining the necessary permissions from the relevant authorities, the researchers referred to the study settings. Eligible participants were selected through purposive sampling, with snowball sampling used if needed. Participants were then informed about the research objectives and methodology and asked to sign the informed consent form.

Data were collected through individual in-depth and semi-structured interviews conducted by an interviewer with a Ph.D. in critical care nursing. These interviews began with gathering participants' demographic information and then proceeded with a series of questions, including: "Tell me about your daily experiences caring for your patient," "in the form of a story, describe how you care for your patient at home and how you feel about it," and "in your opinion, what is the meaning of care in such circumstances?" To delve deeper, several probing questions, such as "can you give me an example?", "Do you mean that...?", and "how...?" were asked to explore participants' experiences further. At the end of each interview, participants were invited to share any additional thoughts or topics they wished to discuss.

An interview was considered complete once participants had fully described their experiences and no further clarification was required. If necessary, a second interview was conducted to resolve any remaining ambiguities. After conducting 14 interviews, no new information, descriptions, or explanations emerged from the participants' responses. This lack of novel insights indicated that data saturation had been reached, leading to the conclusion of the data collection process.

It is worth noting that the interviews followed a predetermined protocol, which outlined guidelines for the interview process, the interview space, and the duration of the interviews. This protocol ensured that all relevant topics were covered. Appointments were scheduled with participants a week in advance, and the interviews were conducted in person in a calm and stress-free environment within the hemodialysis centers. Each interview lasted between 30 and 45 minutes, was digitally recorded, and then transcribed verbatim for analysis.

### 3.4. Data Analysis

The 14 recorded interviews, along with data from observations, memories, and other sources, were meticulously transcribed and analyzed. The analysis followed the van Kaam seven-step method (Table 1), as outlined below.

(1) Listing & grouping: Our team began by thoroughly examining the interview transcripts, listing every significant expression related to the caregivers' experiences. In this step, we ensured that each statement was considered equally valuable.

(2) Reduction & elimination: We then applied rigorous criteria to evaluate the listed statements, eliminating those that were irrelevant, repetitive, or overlapping. We focused on retaining only the statements that were essential for understanding the phenomenon and that could be clearly and distinctly categorized.

(3) Clustering of invariant constituents: The remaining significant statements were grouped into themes, reflecting the core, invariant aspects of the caregivers' lived experiences. This step allowed us to organize the data into meaningful clusters that encapsulated key themes.

(4) Final identification of invariant constituents: To ensure the accuracy of the identified themes, we verified their connection to the original data by cross-referencing each theme with the participants' actual responses. This process confirmed that our thematic analysis was grounded in the participants' authentic experiences.

(5) Construction of an individual textural description: For each participant, we developed a detailed textural description that captured "what" they experienced while providing end-of-life care. This description focused on the participants' perceptions, emotions, and interactions with the patients.

(6) Construction of an individual structural description: Next, we explored "how" the caregivers' experiences unfolded by examining the underlying context, such as the social, familial, and environmental conditions. This allowed us to understand the structural dynamics that shaped their caregiving roles.

(7) Synthesis of composite description: Finally, we synthesized the individual textural and structural descriptions into a comprehensive, composite description that reflected the shared essence of the caregivers' experiences. This synthesis allowed us to present a holistic view of the commonalities and differences across all participants (22).

Given that the study involved a total of 14 interviews, and all stages of the interviews, implementation, and analysis were conducted by the main researchers, there was no need for auxiliary software for data analysis; the analysis was performed manually. The research team held frequent meetings to discuss and analyze the written texts and interview content, ensuring a shared understanding and accurate extraction of codes and

**Table 1.** Steps of the van Kaam Method

Steps	Methodological Procedures
1st step	Listing & grouping
2nd step	Reduction & elimination
3rd	Clustering of invariant constituents
4	Final identification of invariant constituents
5	Construction of an individual textural description
6	Construction of an individual structural description
7	Synthesis of composite description

main themes. Through this thorough process, 184 key statements were identified and analyzed. These statements were then categorized into main themes and sub-themes based on their similarities and connections. Subsequently, four main themes were identified through repeated reviews of the interviews and key statements.

### 3.5. Trustworthiness

To establish the reliability and validity, Lincoln and Guba's criteria, including credibility, dependability, confirmability, transferability, and reflexivity, were used (23). Credibility was achieved through prolonged engagement with the participants and peer debriefing. Dependability was ensured by writing a quick copy, considering colleagues' opinions, and re-reading the entire data. Confirmability was attained through time triangulation and varied sampling among participants. Transferability was supported by detailed descriptions of the context and participants' experiences. Reflexivity was ensured by accurately reflecting participants' lived experiences and presenting diverse perspectives (24).

### 3.6. Ethical Considerations

This study adhered to the principles outlined in the Declaration of Helsinki and its later amendments. It also received ethical approval from the Ethics Committee of Qazvin University of Medical Sciences, Qazvin, Iran, under the ethical code of [IR.QUMS.REC.1399.078](#). Participants were fully informed about the research objectives and methodology and were assured of the confidentiality and anonymity of their data. They were informed that their data would be used solely for academic purposes and that their identities would remain confidential. To ensure this, the researcher employed codes to present the data. Participants had the right to withdraw from the study at any time and to access the research findings. Written informed consent was obtained from all participants. Additionally, the authors adhered rigorously to ethical considerations,

including avoiding plagiarism, data fabrication, and double publication.

## 4. Results

### 4.1. Demographic Information

Nine family caregivers, including 3 men and 6 women, participated in this study, all of whom were providing care for hemodialysis patients at the end of life. The participants had an average age of 59.44 years and had been caring for their patients for an average of 6.33 years. [Table 2](#) provides detailed demographic information for the participants.

Four main themes and twelve sub-themes emerged. These themes encompassed: (1) complex care; (2) care as an opportunity for skill development; (3) care as a chain of caregivers; and (4) moments of misfortune. The main themes and sub-themes are described in [Table 3](#).

### 4.2. Complex Care

In this study, the first main theme that emerged from family caregivers' experiences was complex care. This theme comprised two sub-themes: Individual-social struggles and healthcare hurdles.

Participants reported that due to the progression of the disease and the urgent need for hemodialysis treatment for their loved ones, they encountered several difficulties in fulfilling their familial roles and responsibilities. Consequently, they found themselves undergoing significant adjustments in balancing both their familial and professional roles and responsibilities. Economic concerns, such as medication expenses, transportation costs, potential job loss, and other financial burdens, were additional sources of stress, contributing to a heightened sense of insecurity. Other difficulties included limitations across various dimensions of life, such as inadequate convenience, disrupted eating habits, challenges with activities of daily living, disrupted sleep patterns, difficulties with

**Table 2.** Participants' Demographic Information

N	Age (y)	Gender	Duration of Care (y)	Relationship	Occupation	Education	Marital Status	Duration of Interview (min)
P1	45	Female	7	Daughter	Housewife	Under diploma	Widowed	45
P2	55	Female	7	Spouse	Housewife	Under diploma	Married	40
P3	62	Female	7	Spouse	Housewife	Under diploma	Married	45
P4	64	Male	5	Son	Driver	Diploma	Married	35
P5	73	Male	4	Spouse	Retired	Illiterate	Married	40
P6	53	Female	3	Daughter	Housewife	Under diploma	Married	45
P7	47	Female	6	Daughter	Unemployed	Diploma	Widowed	35
P8	83	Male	12	Spouse	Retired	Diploma	Married	40
P9	53	Female	6	Daughter	Housewife	Diploma	Married	45

**Table 3.** Main Themes and Sub-themes Identified from the Analysis

Main Themes	Sub-themes
Complex care	Individual-social struggles
	Healthcare hurdles
Care as an opportunity for skill development	Experience of spirituality
	Development of mental capacity
Care as a chain of caregivers	Ignorance of the caregiver
	Lifestyle adjustments
	Persistent concerns
	Questioning circumstances
	Mental strain due to prolonged care
Moments of misfortune	Emotional exhaustion from witnessing patient's physical deterioration
	Sense of helplessness regarding patient's mental and cognitive state
	Psychological burden due to lack of societal and institutional support

traveling, and disruptions in other daily activities. Additionally, participants faced issues related to shaldon and fistula catheters, including problems like improper functioning or infection. Moreover, their patients experienced general post-dialysis symptoms such as weakness, fatigue, mobility problems, dizziness, weight loss, and muscle cramps.

Participant No. 4 said: "We don't take him on trips at all because we have to come here every other day. My wife and kids are up north right now, but I couldn't go with them. I'm here with my father and can't leave him."

Participant No. 6 said: "It's been 2 - 3 weeks since her last dialysis session, and it's really bothering her. She keeps saying, 'I don't want to undergo dialysis. I feel terrible.' During the sessions, she always experiences a sudden drop in blood pressure, a sharp decrease in blood sugar, and high levels of stress. She often feels awful."

Participant No. 7 said: "The main issue with my spouse is taking her to the dialysis center. Some days, I can't find the car because everyone has left to take the

kids to school. That's why we end up being late. The commuting really takes a toll on her."

Participant No. 9 said: "Since we started dialysis, she's had a shaldon catheter put in her legs four times, but it kept moving. Then, it was placed in her chest twice, and now we've had to put in a new one. Each time, she had to be admitted to the hospital. We have to make sure she doesn't get infected because it can cause severe symptoms like fevers and chills. When my mom shows these symptoms, it means there's an infection, so we need to be really cautious."

Participant No. 4 said: "I used to work as a truck driver in Europe, but I had to hand over the truck to someone else because my father got sick. Now I'm here dealing with a lot of pressure."

#### 4.3. Care as an Opportunity for Skill Development

In this study, the second main theme that emerged from family caregivers' experiences was care as an opportunity for skill development. This theme

comprised two sub-themes: Experience of spirituality and development of mental capacity.

Most participants believed that despite initially experiencing discomfort, despair, and a sense of crisis or shock following the dialysis of a family member, they underwent personal growth or development. This enabled them to face the difficulties more effectively and continue supporting their patients on this journey. It seems that, after facing these difficulties and accepting the circumstances, participants found a new meaning in life, viewing life and its challenges through a different lens. Additionally, they reported increased levels of patience and resilience, finding solace in difficulties, and experiencing heightened compassion, happiness, and joy from being with their patients. These experiences indicate growth and development in their psychological well-being.

Participant No. 1 said: "Caring for my mom has been a transformative experience for me. I've noticed significant personal growth and development since I began. It's had a positive impact on all areas of my life, and I see it as a true blessing."

Participant No. 4 said: "My brother called yesterday from the United States. He said that over there, if someone can't do a task themselves, they just call for help, pay for the service, and someone comes to do the work. But I find it hard to accept the idea of paying someone to take care of my father. It's easy to say, but deep down, I struggle with it."

Participant No. 5 said: "When she acts out, it bothers and upsets me, but I try not to take it to heart. I believe there's a reward for doing the right thing, and I know God sees everything. I say to God, 'I'll help her, please help me too.'"

Participant No. 8 said: "When she acts out, it bothers and upsets me, but I try not to take it to heart. I believe there's a reward for doing the right thing, and I know God sees everything. I pray to God, 'I'll help her, please help me too.'"

Participant No. 9 said: "I'm thankful she's not completely bedridden. I'm satisfied with the current situation and grateful it hasn't gotten worse. I make sure not to say anything that might embarrass her. My only prayer is that things don't get any worse than they are now."

#### 4.4. Care as a Chain of Caregivers

In this study, the third main theme that emerged from family caregivers' experiences was care as a chain of caregivers. This theme comprised five sub-themes: Ignorance of the caregiver, lifestyle adjustments,

persistent concerns, questioning circumstances, and mental strain due to prolonged care.

Participants noted that caregivers of hemodialysis patients undergo greater self-sacrifice and make more sacrifices in their lives compared to caregivers of other chronic patients. This is attributed to the constant dependency and the need for comprehensive care and follow-up required by hemodialysis patients. As a result, caregivers dedicate a substantial portion of their lives to the care of these patients. However, this dedication comes at a cost, as caregivers often face mental, psychological, and physical difficulties, often ignoring their own well-being. In many cases, they are compelled to endure difficulties in their professional and academic pursuits, missing out on career and marriage opportunities, thus becoming victims of the caregiving role.

Participant No. 2 said: "I'm thankful she's not completely bedridden. I'm content with the current situation and grateful it hasn't gotten worse. I make sure not to say anything that might embarrass her. My only prayer is that things don't get any worse than they are now."

Participant No. 4 said: "Even though my home is in Tehran, I spend most of my time here. The commute and constant traffic are frustrating, and they often leave me feeling annoyed, both at work and in life."

Participant No. 5 said: "I recently experienced amnesia. The doctors advised me not to go to the dialysis center because it could negatively affect my mood. They suggested that the children should go instead."

Participant No. 6 said: "Many people in my mother's age group are healthy; they walk, they farm. But my mother's situation is different. She was so anxious, and that's what led to this. Otherwise, she's smarter than all of them."

Participant No. 7 said: "Most of the time, my mother's blood sugar drops, so she needs someone with her. Whenever I step out for 20-25 minutes, I get stressed about her well-being. I'm always worried about whether her blood sugar has dropped or not because she often feels sick."

#### 4.5. Moments of Misfortune

In this study, the last main theme that emerged from family caregivers' experiences was moments of misfortune. This theme comprised three sub-themes: Emotional exhaustion from witnessing a patient's physical deterioration, a sense of helplessness regarding the patient's mental and cognitive state, and a

psychological burden due to a lack of societal and institutional support.

In most interviews, participants expressed profound sadness whenever their patients required a needle for hemodialysis, experienced discomfort during and after the procedure, or had to adhere to a special diet. Some also mentioned feeling embarrassed by their patients' misbehavior and aggression towards the hemodialysis personnel or their repeated questions to the nurses, which left them feeling upset and sad. Furthermore, many of their concerns stemmed from the lack of attention or support from authorities regarding issues such as high medication expenses, transportation costs, inadequate mental health counseling, and insufficient training on care or transplantation. These unaddressed issues led to their complaints and mental stress.

Participant No. 3 said: "No one lends a hand with this at all. The kids have all gotten hitched and moved out. I'm grappling with financial woes, and despite reaching out for aid from various avenues, including the State Welfare Organization, I haven't received any assistance."

Participant No. 4 said: "At times, he's distracted, and at times, he's alright. When I escort him to the bathroom, he keeps asking about the time, which can be bothersome, but he's my father, so I have no choice. Also, when we're at the center and he spots the nurses, he keeps addressing them repeatedly, which embarrasses me. I gently remind him, 'what are you doing?' But then again, he has Alzheimer's."

Participant No. 6 said: "We're part of the Kidney Patients Association, but I'm not sure why no one has brought up the option of a transplant with us. It could be because of her fluctuating blood sugar and blood pressure, but I'm not entirely certain."

Participant No. 9 said: "Back then, she'd just pop over to my place whenever she pleased. She'd give me a ring, asking, 'are you home?' Then, she'd swing by and crash for a night or two, or she'd head to my sister's place. But now, she needs assistance to get around. Her body is really weakened, and she can't walk anymore. What more can we do?"

## 5. Discussion

This study aimed to explore the lived experiences of family caregivers providing care for hemodialysis patients at the end of life. Its novelty lies in its in-depth exploration of the lived experiences of family caregivers providing end-of-life care to hemodialysis patients in Iran. This study offers fresh insights into the difficulties faced by caregivers, which have not been extensively documented in the existing literature. By capturing

these real-life experiences through a phenomenological lens, the research provides a deeper understanding of the unique needs and struggles of caregivers. These findings can directly inform the development of targeted educational and psychological support programs, filling a critical gap in current end-of-life care strategies and enhancing the effectiveness of interventions tailored to the specific context of home caregiving in Iran. Through data analysis, four main themes emerged: (1) complex care; (2) care as an opportunity for skill development; (3) care as a chain of caregivers; and (4) moments of misfortune.

### 5.1. Complex Care

Participants' statements revealed that the caregiving process has profoundly affected every aspect of their lives, presenting various concerns and difficulties. These included fatigue from frequent commuting to and from the centers, the responsibility of closely monitoring the patient's diet and medications, difficulties with managing shaldon and fistula catheters, complications occurring during and after hemodialysis sessions, occasional urgent needs to modify convenience, financial struggles in covering treatment expenses, and disruptions in both familial and professional roles.

In line with the findings of the current study, in one study on caregivers of hemodialysis patients in Iran, Ebadi et al. revealed that the caregiving process for these patients is associated with long-term physical and mental pressures, alongside high levels of unpredictability and uncontrollability. These factors, in turn, result in various adverse consequences, including disrupted sleep patterns, fatigue, social isolation, financial and communicative constraints, and diminished overall quality of life (25). In another study on caregivers of hemodialysis patients in South Ethiopia, participants highlighted the economic burden caused by factors such as loss of financial capability, job loss due to absenteeism, and incapacity to purchase essential household consumables like food items and sanitary equipment. Moreover, they reported the difficulty of juggling numerous social responsibilities stemming from their extensive caregiving duties (26). In another study in the United States, DePasquale et al. highlighted the unexpected negative experiences of family members of dialysis patients, including unanticipated responsibilities, sleep disruptions, managing medication regimens, dialysis-related health problems, and fatigue (27). Considering these findings, it can be concluded that caregivers of hemodialysis patients must meet both their own needs as well as those of their patients simultaneously. This dual

responsibility leads to concerns and struggles across physical, emotional, social, and economic dimensions, resulting in significant changes in caregivers' lives and disruptions in their capabilities to fulfill their caregiving roles.

### 5.2. Care as an Opportunity for Skill Development

Some participants initially found living with hemodialysis patients to be very uncomfortable and stressful until they came to terms with the reality of the situation. They believed that managing the care struggles made them stronger and improved their lives, resulting in significant growth and development in many aspects, especially in the psychological and spiritual dimensions.

In line with the findings of the current study, in two studies on caregivers of hemodialysis patients, Nimah et al. (28) and Kim and Lee (29) showed that in a patient-centered life, caregivers try to reduce their burden. They develop various coping strategies to overcome difficult situations and strive to live their lives and even improve them (28, 29). In another study on hemodialysis patients and their caregivers in Australia, the United States, and Hong Kong, Baumgart et al. revealed that the participants achieved some degree of personal growth by building resilience, fostering a positive outlook, and accepting the dialysis regimen (30). Considering these findings, it can be concluded that several caregivers have experienced personal growth and achieved excellence by utilizing positive and effective coping strategies. This has led to a better balance between their personal life and caregiving responsibilities and roles.

### 5.3. Care as a Chain of Caregivers

Participants' statements revealed that some caregivers prioritized their patients' well-being over their own, ignoring their physical well-being. Their patient-centered mindset meant they ignored hobbies or leisure activities, consequently weakening their relationships with those around them. In fact, they became so absorbed in caregiving that they were effectively absent from their own lives.

In line with the findings of the current study, in one qualitative meta-synthesis study on the lives of caregivers of patients with hemodialysis, Kim and Lee revealed that caregivers often restrict their own lives while caring for their patients, leading to a patient-centered existence and ignorance of their own well-being (29). In another study on family caregivers of hemodialysis patients, Turner and Finch-Guthrie concluded that the continuous management of patients

at home demands significant effort from caregivers and other family members. Consequently, caregivers often find themselves trapped in the caregiving role, becoming overwhelmed by the process (31). The significant and thought-provoking point highlighted in these studies is that comprehensive caregiving and boundless self-sacrifice often result in the ignorance of the caregiver's own life across all dimensions. Consequently, the caregiver's quality of life gradually diminishes.

### 5.4. Moments of Misfortune

The physical, mental, and behavioral fluctuations, combined with numerous responsibilities such as ensuring compliance with diet and medications and managing the risk of bleeding after hemodialysis, along with many other potential difficulties hemodialysis patients may face, collectively pose significant hurdles for caregivers, as they often struggle to comprehend the complexity involved or lack the knowledge to effectively manage them. Consequently, caregivers constantly bear the mental burden of their patients, feeling weighed down throughout each moment of their lives. Furthermore, the absence of sufficient attention and support from authorities and medical personnel may lead caregivers to endure severe stress, fatigue, burnout, and even severe disability.

In line with the findings of the current study, in one study in Iran, Ghapanvari and Hosseinigolafshani identified the unavailability of essential medications required for hemodialysis patients and the lack of insurance coverage for these drugs as major concerns among all participants. This lack of assistance has emerged as a barrier, leading caregivers to experience heightened levels of stress and anxiety (24). In another study, Salehi Tali et al. concluded that the progressive nature of problems, along with caregivers' constant worries about their patients' physical and psychological state, medications, diet, vital signs, post-dialysis symptoms, abnormal behaviors, and mental and psychological problems, gives rise to extreme stress in caregivers. Prolonging the caregiving process casts a heavy shadow on the caregiver's life, increasing their physical, mental, and psychological vulnerability (32).

### 5.5. Study Strength & Limitations

One of the primary strengths of this study is its in-depth qualitative approach, which offers a comprehensive understanding of the complex struggles faced by family caregivers. By conducting detailed, phenomenological interviews, the researchers were able to immerse themselves in the caregivers' experiences,



providing rich, nuanced insights that go beyond what is typically captured through quantitative studies with predefined questions. This methodological approach allows for a deeper exploration of the struggles faced by caregivers, offering valuable perspectives that contribute to a more complete understanding of end-of-life care.

A notable limitation of this study is that some participants may not have fully expressed their experiences due to personal reasons, despite the researcher's efforts to build trust and communicate effectively. Additionally, the study had a lower representation of male participants compared to female participants, which may affect the generalizability of the findings. Future research should aim to include a more balanced representation of both genders. Another limitation is the lower educational level of many participants, which may influence their caregiving abilities and perceptions. Future studies could explore how educational interventions might impact caregiving practices and experiences.

### 5.6. Conclusions

In the current study, caregivers expressed a spectrum of both positive and negative experiences. While some viewed their role as fostering intellectual growth and development, others described feelings of confinement, entrapment, and sacrifice. This raises the question, "what differentiates individuals and their perspectives such that, under similar circumstances, one person believes they have evolved, while another feels like a total victim and loser?" To uncover the factors that influence such diverse insights, further extensive and in-depth research is required.

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### Footnotes

**Authors' Contribution:** Study conception and design, and review of article and final approval: S. Z. H., S. M. Z., and A. R.; data collection, data analysis and interpretation of data, and drafting of the article: S. Z. H. and S. M. Z. All authors read and approved the final manuscript.

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**Data Availability:** Interview transcripts will be available upon the reasonable request from corresponding author.

**Ethical Approval:** This study was approved by the Ethics Committee of Qazvin University of Medical Sciences (IR.QUMS.REC.1399.078). All the stages were carried out in accordance with relevant guidelines and regulations.

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