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Suspended Life Pattern: A Qualitative Study on Personal Life Among Family Caregivers of Hemodialysis Patients in Iran

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Abstract

Purpose: To determine the personal life of family caregivers of patients undergoing hemodialysis.

Methodology: In this qualitative study, individual semistructured interviews were carried out with 19 caregivers of hemodialysis patients. All interviews were recorded, typed, and imported into the Open Code Software. The Graneheim and Lundman's content analysis approach was used for the analysis.

Findings: The theme of this study was suspended life pattern that was extracted from two categories of "Imbalance between caregiving and life" and "ambiguity in life status." The category of "Imbalance between caregiving and life" included some subcategories including compulsive compliance, suspension, and deferral of roles, conflicts between leisure time and caregiving and caregivers' time limits. Moreover, the category "ambiguity in life" was extracted from two subcategories of fear and hope and life satisfaction depending on care recipients' condition.

Conclusion: Caring for hemodialysis patients leads to instability and ambiguity in a caregiver's personal life. Therefore, authorities, policymakers, and health-care providers should pay more attention to support these people.

Keywords

family caregiver, hemodialysis, life

Introduction

Families are still considered as the first and foremost support in caring for chronic patients.^{1,2} In Iran, people are deeply committed to the traditions, and there are strong emotional relations among family members. They have a specific commitment toward each other.³ This traditional structure is one of the most important sources of support for the patient.³ Caregivers of hemodialysis patients are also mostly their family members and play a key role in supporting such patients.^{4,5} Hemodialysis is a long-term process, affecting all life aspects of a patient and his family, including their physiological, psychological, functional, and social abilities as well as their welfare and lifestyle.^{2,4,6–10} Caregivers experience some degree of stress, anxiety, anger, fatigue, grief, and disappointment.^{6,11} Because of the difficulty in predicting the disease procedure and the high level of care needs of the care recipients, they have less chance of planning their activities and are anxious and afraid of their future.^{6,11,12} The caregivers allocate most of their time to meet the patient's needs.^{5,8} Their time is equivalent to money represents the lost opportunities and decreased efficiency as the caregiver could spend this time to perform his tasks or housework or leisure activities.¹³

Because of lack of free time, they avoid having social interaction with others and participating in religious activities, hobbies, and other social activities.¹⁴ Further, multiple roles may lead to role conflict, heavy role loads and feelings of pressure, welfare decline, and increased psychosocial distress.¹⁵ Caregiving also affects caregivers' performance and leads to absence from work, reduced concentration, and even quitting jobs.¹⁶ In general, taking care of the patient, although full of uncertainty and frustration for a majority of caregivers, may also be associated with interesting experiences.^{9,12} These positive and negative consequences of care provision may widely vary among the caregivers.^{9,12}

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Positive achievements for caregivers include feelings of meaningfulness, satisfaction, conscientiousness, personal growth, and a sense of magnificence and usefulness. Such feelings make the experience of care provision of sense, resulting in a decreased depression and stress.^{17,18} In addition to the existence of such contradictions among the caregivers, what is certain is that families that are responsible for taking care of hemodialysis patients are not well understood.¹ They are less considered and the patient is of main concern.⁷ Repeated hospitalization of patients and other problems associated with caregiving can aggravate depression and decrease the quality of life for the caregivers. These ultimately affect the patient's quality of care and even lead to the patient's leaving. Therefore recognition of caregivers' concerns and needs is of paramount importance.^{7,19,20} Unfortunately, despite the importance of this issue, few studies are explaining the personal life of family caregivers of the hemodialysis patients. Furthermore, these studies have been using quantitative approaches. Those qualitative studies that have been conducted in Iran have focused on care experience and caregiving burden. However, the effect of care on the daily lives of family caregivers in hemodialysis patients has not been studied. Thus, this qualitative study was conducted to explain the personal life of family caregivers of hemodialysis patients.

Methods

Study Design

This qualitative study was carried out in 2017 using a conventional content analysis approach. Key participants in this study were family caregivers of patients undergoing hemodialysis in Tehran and one of the large provinces of Iran ($n = 15$). Also, four other individuals (namely including a patient, a nurse, a physician, and a board member of the Association for the Support of Renal Patients) also participated in this study as general participants. The research environment was the hospital room for caregivers, the hospital campus, and the Office of the Association for the Protection of Renal Patients.

Inclusion Criteria

Participants in this study were people with at least 18 years of age, who had at least 6 months of caregiving experience, were mostly involved in care provision, had rich experiences and were capable of talking about the research question, and willing to cooperate and participate in the study to reveal their experiences. Exclusion criteria were refusing to continue participation.

Data Collection

Regarding the nature of qualitative studies, in-depth interviews were carried out after proper communication with family caregivers using semistructured and open questions.

The caregiver was asked to answer the question regarding the impact of caring for a hemodialysis patient on their personal life. Also, some exploratory questions were followed by open questions to delve more deeply into the experiences of the participants. Participants' informed consent was obtained to include them in the research and audio record their interviews. At the beginning of each interview, the purpose of the interview was reexpressed, and they were assured of the confidentiality of their information. The duration of the interview depended on the participants' tolerance and information as well as their willingness and agreement. The interviews lasted for an average of 45 minutes. Interviews were continued until data saturation was obtained.

Data Analysis

All interviews were recorded, typed, and subsequently imported into the Open Code Software.²¹ The content analysis of qualitative data was carried out using Graneheim and Lundman's content analysis stages as follows:

1. transcribing the entire interview following each interview;
2. reading the entire interview text to reach an overview of its content;
3. defining initial meaning units and codes;
4. classifying similar codes in more comprehensive categories; and
5. determining the hidden content in the data and extracting the theme.²²

Rigor

An important aspect of qualitative studies is their acceptability, scientific accuracy, and reliability. For this purpose, the quality criteria for the qualitative studies, including credibility, transferability, dependability, and confirmability were concerned.²³ To enhance the credibility of the study, the researchers attempted to provide appropriate communication with the participants and devote sufficient time to collect data. Also, immersion, triangulation of data sources (family caregivers, medical staff), and peer review were also considered. Also for transferability of the study, the maximum variability was considered from two aspects: social and demographic characteristics of the caregivers and social and demographic characteristics of the patients. Confirmability was assessed using the comments provided by the research team members and experts. Dependability was obtained through maintaining the study documents, using the participants' comments, and decoding the texts.

Ethical Consideration

This study was approved by the Research Ethics Committee of the Baqiyatallah University of Medical Sciences with

ethical code (IR. BMSU.REC.1395.38). Moreover, ethical research issues in Helsinki declaration and Committee on Publication Ethics were considered.

Results

In total, 19 participants were included in this study. There were 11 women and eight men aged 27 to 78 years. The care provision for the patients ranged between 6 and 84 months, with an average of 33 months. A majority of caregivers were offspring (daughter or son) or the wife/husband of the patients under hemodialysis. In this study, the maximum variability in the selection of participants was considered regarding demographic factors of caregivers and the status of their care recipients' (Tables 1 and 2). The final research findings consisted of seven subcategories, two main categories, and one theme (Table 3).

According to Table 3, the study theme is the unstable life pattern derived from two categories of imbalance between caregiving and life and ambiguities of life status. The category "Imbalance between caregiving and life" consists of compulsive compliance, suspension and deferral of roles, conflicts between leisure time and caregiving, and caregivers' time limits. Also, the category "ambiguities of life status" is derived from two subcategories of "fear and hope" as well as "caregivers' satisfaction with life depending on the care recipient's condition." The subcategories are described as follows, respectively.

Imbalance Between Caregiving and Life

Caring for a patient undergoing hemodialysis by imposing a substantial workload disrupts the balance between routine tasks and care provision tasks.

Table 1. Family Caregivers' Demographic Characteristics.

Age		Mean: 42.16 ± 48	Minimum: 27 years	Maximum: 78 years
Gender	Female		9	60%
	Male		6	40%
Marriage status	Married		10	66.7%
	Single		5	33.3%
Level of education	Illiterate		2	13.3%
	Elementary to Diploma		6	40%
	Academic		7	46.7%
Employment	Housewife		6	40%
	Employed		3	20%
	Retired		4	26.7%
	Unemployed		2	13.3%
Income status	Adequate		3	20%
	Average		4	26.7%
	Inadequate		8	53.3%
Health insurance status	Social Security		5	33.3%
	Armed Forces Medical Services Insurance		6	40%
	Iranian health insurance		2	13.3%
	Multiple		2	13.3%
Kinship to the patient	Parent		2	13.4%
	Offspring: Daughter (4) and son (3)		7	46.76%
	Spouse		6	40%
Type of care (continuity of routine care provided)	Continuous		11	73.3%
	Discontinuous		4	26.7%
Living with/without the patient	With the patient		13	86.7%
	Without the patient		2	13.3%
Being affected by diseases	Healthy		6	40%
	Patient		9	60%
Number of diseases	Mean: 4.1 ± 45.1		Minimum: 0	Maximum: 4
Care provision duration in months	Mean: 46.33 ± 97.24		Minimum: 6 Months	Maximum: 84 Months (7 years)

Table 2. Care Recipients' Demographic Characteristics.

Age	Mean: 60.37 ± 16.09	Minimum: 32 years	Maximum: 90 years
Gender	Female	9	56.3
	Male	7	43.7
Marriage status	Married	13	81.3%
	Single or widow	3	18.7%
Level of education	Illiterate	3	18.8%
	Elementary to Diploma	11	68.8%
	Academic	2	12.5%
Employment	Housewife	9	56.3%
	Employed	1	6.3%
	Retired	5	31.3%
	Unemployed	1	6.3%
Income status	Adequate	3	18.8%
	Average	3	18.8%
	Inadequate	10	62.5%
Health insurance status	Social Security	3	18.8%
	Armed Forces Medical Services Insurance	8	50%
	Iranian health insurance	2	12.5%
	Multiple	3	18.8%
Number of diseases	Mean: 56.3 ± 75.1	Minimum: 1	Maximum: 7

Table 3. Main and Subcategories Derived From Interviews With Family Caregivers of Patients Undergoing Hemodialysis.

Subcategories	Categories	Theme
Compulsive compliance	Imbalance between caregiving and life	Suspended life pattern
Suspension and deferral of roles		
Conflicts between leisure time and caregiving		
Disruptions in occupational affairs		
Caregivers' time limits		
Fear and hope	Ambiguity in life status	
Caregivers' satisfaction with life depending on the care recipient's condition		

Compulsive Compliance. Because of the instability of their physiological conditions and the need for frequent referrals to treatment centers to undergo hemodialysis, the patients undergoing hemodialysis are heavily dependent upon their caregivers. This dependence is sometimes too high that the caregivers cannot even leave their patients alone. Therefore, this creates constraints in the caregivers' life and makes them adapt their schedule to their patients' conditions.

Participants in this study pointed out some constraints such as compulsive compliance between the routine life and caregiving, care provision, limitations in making decisions for the future, and self-neglecting for the sake of the patient. Some participants stated:

You need to adjust your life with a hemodialysis person. My sister and I inform each other when we go out. We went to university when the class time did not conflict with my mother's dialysis timeline to handle it. In fact, we adjust our schedule with the patient's, not vice versa. That is it. You will lose something and get some other things. We have our mother now, but we are missing some things like us (No. 10).

Well, father is the family pillar. When the parents are ill in a family, we are obliged to ignore a couple of things. I wanted to study for a master's degree, but when I faced this situation, I unconsciously ignored some of my plans. I gave up completely (No. 9).

Suspension and Deferral of Roles. Caregivers of hemodialysis patients, in addition to caring roles, have many other roles in their own lives. This would bring about overwhelming and contradictory roles, resulting in the suspension or deferral of some roles by the caregiver. Participants in this study referred to such issues as interference between care provision and desired performance of parental roles, conflicts between care provision and proper performance of spousal roles,

a multiplicity of roles, role exchanges, a contradiction in roles, and coping with unfulfilled tasks and the sense of stagnation. Here are some comments reported by the participants:

When I am at home, I do not have time to pay attention to my husband. Well, or I am making soup for my mom or preparing a meal to take there, or I am cooking for my family. Sometimes, I am making three different foods at the same time. Do I have time to care about my husband? I do not have enough time . . . I cannot pay attention to him; I'm worried about it . . . I have no free time. Yesterday, my wife told me to allocate him more time. What time? When I go to bed, I am to die. I feel dead. It means, I am so tired and not enough sleep (No. 7).

If my mom does not feel okay, I'll take home tasks for another time. I mean, let them. I put everything away (No. 4).

Our roles have changed. My mother is a kid at home, and I'm somehow a mother, but it was just better in the past . . . We've got our mom, but we're missing things like us. Somehow, we're in a state of stagnation, neither moving up or down. The time has stopped (No. 10).

Conflicts Between Leisure Time and Caregiving. Caring conflicts and patients' unstable conditions make family caregivers unable to pass their leisure time as they wish. Participants in this study referred to issues such as conflicts with recreation, travel, participation in programs such as religious rituals, parties, makeup classes, and sports. Relevantly, some participants stated as follows:

You see, we do not have the rest as others, you can do whatever you want, you can do whatever you wish, but it is not the same for me. I along with this patient should weigh anything from meals and foods to travels and parties. For example, when my wife undertakes dialysis, we mostly try not to go to the parties and not to invite others to our house because my wife is not ok (No. 6).

Caregiving has overwhelmed most of my hobbies. For example, I cannot go traveling abroad, or I cannot even go to a friend's wedding ceremony or party. In fact, they are not that much patient to stand this kind of parties lasting for several hours. Because of this, we prefer to concern their comfort, and we do not go either (No. 5).

Disruptions in Occupational Affairs. Caregiving not only affects family tasks but also affects the caregiver's job performance. Participants in this study addressed some challenges like time conflicts between caregiving and occupational affairs, reduced work efficiency caused by care-induced fatigue, frequent leaves from work to meet the patient's needs, delay in

performing assigned tasks, reduced job incentives, decreased managers' satisfaction, and reduced mental concentration in the workplace. Some of the participants mentioned as follows:

It had happened several times when my boss asked me for something, but since I had to accompany our father, I apologized and asked him to let me take my father and promised to do the task when I returned. It was a delay, and my boss was frustrated. In this regard, I have come up with some problems and trouble (No. 3).

I do not often go outside because of taking care of my mom. I cannot have a job because I need to be at home to take care of my mom. I went looking for a job, I wanted to work part-time, but that was a full-time job. That made me out of mood (No. 14).

Caregivers' Time Limits. Multiple caring tasks would reduce the time spent by caregivers for their personal life. The participants in this study listed some time-consuming caring measures, including time spent on care provision at home, spending time on getting the patient to a dialysis facility, spending time on being along with the patient during dialysis, and spending time on the patient's clinical needs and time-consuming drug preparation process. Some subjects also added as follows:

I was supposed to have my teeth pulled out before New Year to make an implant, but I do not have time, no one can help me right now. If I want to go, my mother hurts so much. This is an example. There are many other similar issues (No. 7).

For example, I wanted to take part in a specific class; then I saw that it would take my time, consequently having not enough time for my patient at home. Well, this is necessary, but the class is optional (No. 2).

Six years ago, perhaps I spent my whole time for myself, that was just me, even if I had a little time for others, I would be upset, but not now (No. 2).

Ambiguity in the Position of Life

The life of the family caregivers of patients undergoing hemodialysis has a swirling rhythm, which is under the influence of care, in a vague range of fear and hope.

Fear and Hope. While being sad for their past and experiencing much stress, the caregivers are looking for solutions to get out of this situation. They hope to succeed in making a better future for themselves and their patients by having a successful kidney transplant. Participants in this study mentioned such issues as regretting the past, frustration, fear of uncertain

future, attempts to get out of dialysis, and hope for miracles. Some samples of their statements are shown as follows:

When my mom was healthy, we had a happy life, the hearts were so vast, and the feelings were so broader. I am feeling blue now, and everyone is silent. We are talking in a way not to annoy my mom. Our house is in dead silence (No. 10).

Their life is complicated. We have patients having undertaken hemodialysis for 7 years. Just imagine that you are supposed to refer to a dialysis facility 3 days a week for 7 years. He needs an injection. His fistula may be out of work, and he might have follow-up operations. Maybe, his permanent cutter is infected, he then needs hospitalization because of the infection. The following complications of the infections are a lot and include fever and seizures that are very painful, and their families are involved as well (No. 17; Nurse)

I am always thinking about what happens to us. Can my husband always commute on his foot like now? I'm worried (No. 1).

I am worried that my mom would not get worse. I am worried about not having my mom anymore; God forbid (No. 4).

Caregivers' Satisfaction With Life Depending on the Care Recipient's Condition. The patient and caregivers' lives are intertwined. The progression of the disease and the instability of the patient's physiological and psychological conditions require more complicated caring, reducing the caregiver's satisfaction with life. Participants in this study noted that patients' stable conditions, acceptance of the reality of life with dialysis patients, the patients' improved conditions, and successful kidney transplantation make them happy with life. Some participants stated as follows:

Dialysis is worse than cancer because the hemodialysis patients get ill at one and are left in a coma. His blood pressure rises, and this makes us nervous. Their condition is unpredictable (No. 11).

I feel like I have stopped since 2 years ago, that is, when we first got my mother for dialysis . . . We still haven't succeeded in transplanting a kidney to my mother's. I think we are still at that point. I think the quality of my life improves whenever I can do something for my mother (No. 10).

However, then we saw, its ok, this is a treatment, a model of life. It was very hard at first, but then we admitted it, and we do not anymore think the world is finished (No. 2).

The poison affects her body so hard that her behavior gets out of control. She acts in a way as if she is not our mommy. The next day, when the poison is taken out, she is OK. As daddy

says, she is like a flower that blossoms in the morning and fades at night (sadly). My mom has such a situation. I like the days after dialysis (No. 10).

Discussion

This study aimed to explain the personal life of family caregivers of patients undergoing hemodialysis. The results of this study showed that caring for hemodialysis patients leads to the formation of an unstable life for the family caregivers. The results of a qualitative study conducted by Duggleby et al.²⁴ also indicated an imbalance between the caregivers' lives and their efforts to achieve a balance at that condition. This study also suggested that the unstable life pattern is because of life-caregiving imbalance and ambiguities of the life status. Some representations of life-caregiving imbalance in this study were compulsive compliance, suspension and deferral of roles, conflicts between leisure time and caregiving, and caregivers' time limits. Other studies have also shown that a family member's chronic illness and its resulting psychological and economic consequences affect all family members and their lifestyle.²⁵ In the same vein, Bayoumi's¹ study examined the mental burden of caregivers of hemodialysis patients, confirming such a burden on a large number of caregivers. Studies have also shown that the need for frequent hemodialysis and health-related problems of dialysis patients have a negative impact on the job (e.g., absenteeism, reduced focus attention, and even quitting the jobs), family relationships, and daily activities of family caregivers.^{16,25,26} Also various tasks of patient care reduce the caregivers' time to be spent on their tasks and make them fail in self-caring.⁸ The results of the current study also indicated that family caregivers experience conditions filled with ambiguity when taking care of their patients. Schulz²⁶ also believes that caring is accompanied by a high level of unpredictability and uncontrollability. The participants of a qualitative study also stated that they were faced with unexpected and sudden changes in their life, imposing them a lot of distress.²⁴ In a coherent review study carried out by Gibbons et al.,²⁷ in 2014 on 26 investigations performed in different countries of the world, it was shown that the main theme in many studies was a lack of certainty included a lack of a clear future to be planned. Rabiei et al.'s²⁸ qualitative research on 20 family caregivers of hemodialysis patients also suggested that care provision is presented in a condition filled with uncertainty and this can affect the quality of care. This study clarified that the lives of family caregivers of patients undergoing hemodialysis are mixed with fear and hope. Duggleby et al.²⁹ reviewed 101 caring-related journals with a narrative analysis approach and concluded that family caregivers experience the anarchy (disorder) between caring and hope.²⁹ The results of other qualitative studies, from the viewpoint of caregivers, also indicated that the hope for continued caring, supporting the care recipients, and adjusting the distresses, play a more critical role in their role compliance.^{24,30}

In addition, the results of the current study showed that the caregivers' satisfaction with life depends on the care recipients' conditions. In other words, the caregivers' satisfaction with life increases as the care recipients' conditions improve. As often the patients undergoing hemodialysis experience vague, complex, and unstable situations, this adds to the obscurity of the care provision condition. In this regard, the results of a systematic review by Sajadi et al.³¹ also pointed that caregivers' quality of life depends upon the hemodialysis patients' quality of life and health status. Belasco²⁰ found that the caregivers face increased caring burden and lower quality of life as the care needs of the patient undergoing dialysis enhance.

Limitations of the Study

The study had no specific limitation. However, in this research, the researchers tried to increase the ability to generalize concerning maximum variability in the selection of participants, but the findings of this study, because of its qualitative approach, have limited generalization.

Conclusion

Caring for patients undergoing hemodialysis, who are mainly experiencing unstable and unpredictable conditions, is a challenging and stressful task. These lead to instability, confusion, and ambiguities in various aspects of the caregivers' personal life, imposing a heavy psychological burden on the caregivers. Thus, psychological counseling and improved interaction between professional caregivers, including nurses with family caregivers should be of concern as understanding the conditions of family caregivers helps them better manage their personal lives and feel secure about their future. The findings of this study can provide the health-care team including nurses with some information on the living conditions of family caregivers of patients undergoing hemodialysis. Understanding the experiences of family members by nurses enables them to define the caretaking roles and enhance the families' potentials to adapt to changing situations. These findings can be helpful to design empowerment plans and supportive and educative programs. Also, these findings are useful for policymakers to create the necessary grounds for supporting of family caregivers. Undoubtedly, these actions can lead to satisfaction with care provision and improved quality of life for patients and their families. Finally, we propose that the researchers design a specific, valid, and reliable questionnaire to assess the condition of the daily lives of this group.

Author Contributions

Abbas Ebadi was responsible for the study conception and design. Seyedeh A. Sajadi and Abbas Ebadi performed the data collection and analysis. Seyedeh A. Sajadi was responsible for the drafting of the manuscript. Abbas Ebadi, Seyedeh A. Sajadi, Seyed T.

Moradian, and Roghayaeh Akbari were responsible for the final analysis and made critical revisions to the article for important intellectual content.

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