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Original Article

Progressive exhaustion: A qualitative study on the experiences of Iranian family caregivers regarding patients undergoing hemodialysis

Shahriar Salehitali^a, Fazlollah Ahmadi^b, Ali Hasanpour Dehkordi^a, Kobra Noorian^a, Malek Fereidooni-Moghadam^c, Kouroush Zarea^{d,*}^a Nursing Department, Faculty of Nursing & Midwifery, Shahrekord University of Medical Sciences, Shahrekord, Iran^b Nursing Department, Faculty of Medical Sciences, Tarbiat Modares University, Tehran, Iran^c Nursing and Midwifery Care Research Center, Faculty of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran^d Nursing Care Research Center in Chronic Diseases, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran

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ABSTRACT

Objective: The aim of this study was to explore the burden of care for patients undergoing hemodialysis from the experiences of family caregivers.**Methods:** In this qualitative study, a content analysis approach was used for data collection and analysis. Participants were 16 family caregivers selected through purposive sampling from four medical education centers affiliated with Ahvaz Jundishapur University of Medical Sciences, Iran. Semi-structured interviews were held to collect data.**Results:** Four categories were developed as follows: 'care challenges', 'psychological vulnerabilities', 'the chronic nature of care' and "care in the shade". The categories led to the development of the main theme of 'progressive exhaustion' experienced by the family caregivers during the provision of care to patients undergoing hemodialysis.**Conclusion:** Family caregivers have a significant role in the process of patient care, and this role leads them to progressive exhaustion; therefore, the overall health of the caregivers should be taken into account and more attention should be paid to their quality of life, social welfare, and satisfaction level.© 2018 Chinese Nursing Association. Production and hosting by Elsevier B.V. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

1. Introduction

More than three million patients with chronic renal failure all around the world are undergoing hemodialysis [1]. In addition, about 7% is added to this number annually [2]. In 2008, more than 12,000 patients in Iran were undergoing hemodialysis. According to the statistics in 2015, more than 27,000 patients in 500 dialysis centers were undergoing the regular hemodialysis therapy [3].

Long-term hemodialysis therapy imposes a huge amount of burden on patients, family caregivers and the healthcare system [4]. The involvement of caregivers in patients' transfer to the dialysis ward, the preparation of appropriate foods for patients, meeting their personal health needs, managing the side effects of hemodialysis, administration of medication and monitoring their vital

signs impose a massive burden on family caregivers [5,6]. Furthermore, family caregivers may be late for work and even have to leave their own job to provide care to patients at home [7].

The dependency of hemodialysis patients on caregivers [8], long-time care, the long course of disease, complications of hemodialysis and life style changes impose a lot of burden on family caregivers of hemodialysis patients [9–11]. The increased burden of care negatively affects psychological, emotional, social, physical, and financial status of patients and their caregivers [12–14]. Accordingly, a study conducted by Hashimoto et al. (2013) demonstrated that physical health, social functioning, the level of energy, general health and the mental health scores of the caregivers of patients undergoing hemodialysis were significantly low [15,16].

The mental condition of family caregivers may have serious effects on the health of patients with chronic diseases [17,18]. Therefore, there is a need to investigate the characteristics of family caregivers and the impacts of the burden of care on their quality of life. Such findings can help to improve the patients' mental and

* Corresponding author.

E-mail addresses: Zarea_k@ajums.ac.ir, kouroush1685@gmail.com, editor@jjchronic.com (K. Zarea).

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physical health and design an appropriate model for reducing the negative effects of the burden of care on family caregivers [15,19,20].

A few quantitative studies were conducted on the burden of care on family caregivers of patients undergoing hemodialysis [7,21]. However, the mental burden of caring for patients on family caregivers' experiences and attitudes has not been studied [22,23]. Available studies on the burden of family caregivers have mostly focused on the impact of patients' symptoms and social functions. Some other studies have documented a weak association between the clinical ratings of the patients' functional status and the burden of care [10]. Qualitative research provides information about the perspectives, attitudes, needs, beliefs and feelings of family caregivers. Understanding family caregivers' perspectives can help healthcare providers with the provision of support regarding the treatment process and psychological aspects of caring to hemodialysis patients.

It is emphasized to assess the burden of care on family caregivers for improving their quality of life and general welfare [24,25]. In addition, the increase in life expectancy in patients with chronic diseases [26–28], science and technology advancements [29] and restrictions of kidney transplantation have increased the number of patients undergoing hemodialysis. Therefore, family caregivers are mainly involved in the provision of care to hemodialysis patients [30,31]. Iran is an Islamic country, which has a population of about 80 million, most of whom are Muslims, and in Muslim culture, respect for the patient is deemed very valuable. The provision of care to patients undergoing hemodialysis imposes extreme care burden on family caregivers [32]. A few studies were available to provide information about the life of family caregivers during the provision of care to hemodialysis patients. Therefore, this study was conducted to explore the burden of care for patients undergoing hemodialysis from the experiences of family caregivers.

2. Methods

2.1. Study design

A qualitative design using a content analysis approach was used in this study. Qualitative research aims to explore complex phenomena experienced by clinicians, healthcare providers, policy-makers and consumers in the healthcare system [33]. Content analysis is the process of identifying, interpreting, and conceptualizing the inner meanings of qualitative data [34]. Therefore, it is used to answer questions about issues experienced by a particular group of respondents for identifying their typical responses [35].

2.2. Participants

Participants consisted of 16 family caregiver of patients undergoing hemodialysis who were selected using purposeful sampling. Inclusion criteria used to choose the participants were as follows: 'having a direct responsibility for the provision of care to hemodialysis patients at home', 'being able to communicate and share their experiences' and 'willingness to participate in this study'. They were from four hemodialysis centers affiliated with Ahvaz Jundishapur University of Medical Sciences, Iran.

To achieve a comprehensive description of the experiences of caregivers in the process of caring or different caregivers, a maximum variation in sampling in terms of age, gender, level of education, duration of treatment, and socioeconomic status was used [36]. The socio-economic level of the family caregivers was different from the low to middle classes. All participants were responsible for the provision of care, and monitoring and following up their patients' therapeutic regimens.

The participants were 7 males and 9 females with the age range from 25 to 70 years. The duration of care was 3–11 years and their education level was from primary education to academic degree. The caregivers often were the patients' father, mother, daughter, son, spouse or grandfather (Table 1).

2.3. Data collection

Semi-structured interviews and observations were performed and field notes were taken by the first author (ShS). The data were collected using in-depth interviews from January 2014 to May 2016. The first author took field notes about the family members' interactions following each interview. At the beginning of the interview, the questions were designed in order to gain insight, trust, and full recognition of the patient's caregivers, then the interviews were focused on the family caregivers' experiences of problems and challenges in the process of caring for patients undergoing hemodialysis.

The main questions used in the interview were: "What do you feel of the provision of care to hemodialysis patients?", "Will you please tell me about your experiences as the caregiver of hemodialysis patients?" and "Will you please explain issues during the provision of care to patients?". Probing questions also were asked to identify challenges experienced in the care process and how they overcame them in patient care. Subsequently, the participants were asked to add supplementary information not addressed during the interviews.

The interviews lasted for 60–90 min and were audiotaped and

Table 1
The characteristics of participants.

N	Gender	Age (year)	Relationship	Duration of care	Residence	Education
P1	Male	55	Spouse	5	Urban	Academic
P2	Male	45	Son	12	Urban	Academic
P3	Female	70	Spouse	12	Urban	Illiterate
P4	Female	35	Spouse	10	Urban	Diploma
P5	Female	40	Mother	11	Urban	Academic
P6	Male	55	Father	6	Rural	Illiterate
P7	Female	25	Daughter	4	Urban	Academic
P8	Female	50	Mother	7	Rural	Primary
P9	Male	40	Spouse	5	Urban	Academic
P10	Female	40	Mother	12	Rural	Primary
P11	Female	22	Daughter	5	Urban	Diploma
P12	Male	60	Grandfather	4	Rural	Primary
P13	Male	45	Father	7	Rural	Second sc
P14	Male	30	Son	6	Rural	Diploma
P15	Male	40	Nurse	9	Urban	Academic
P16	Female	38	Doctor	10	Urban	Academic

Table 2
The development of the theme “Care Challenges”.

Main themes	Subthemes	Opening code	Meaning unites
Care Challenges	Job challenges	Decreased concentration and efficiency in the workplace because of caregivers' obsession with patients.	I am a teacher. When I'm teaching in the class, out of the blue, my mind goes to my sick father. I become really upset and feel extremely low, so lose my concentration. This issue has reduced the efficiency of my work as a teacher.
	Family challenges	Disruption in the caregivers' family structure due to caring	When I come to give a hand to my father to run his errands, some problems may happen to my wife and kids at home at the same time. But I cannot do anything for them because I'm at my father's home and caring for him. This experience has happened not once but several times to me and caused numerous problems for me and my family.
	Sexual challenges	Patients' sexual dysfunction as the base for caregivers' oblivion of sexual needs	We've got married about 10 years ago, but we've had no sexual contact even once. Probably it's because of the inability of Mr or many problems and misfortunes we've encountered in our life.

transcribed verbatim. The interviews were conducted at the participants' houses and the hemodialysis ward. The data collection and analysis were conducted simultaneously. The sampling process was continued until data saturation was reached as no new category was identified [37].

2.4. Data analysis

The process of analysis is based on the three stages of Elo S, Kyngäs [37], in the preparation phase, the interviews were transcribed *verbatim*. The transcriptions as the unit of analysis were read several times to get the sense of whole. In the organization phase, an inductive approach was used. The semantic units associated with the research questions were assigned with primary codes, initial codes were further classified into subcategories. In the next phase, subcategories with similar meanings were assigned into main categories. A sample of the condensation-abstraction process is shown in Table 2.

2.5. Trustworthiness

Rigor is the process of the application of appropriate techniques and research methods for achieving consistent and reliable data [38]. The following measures were taken to ensure rigor in this study:

- Verification of the codes with the participants and engagement with the study phenomenon;
- Comparison of the text with the initial codes to ensure of the homogeneity of the extracted ideas [39];
- For peer checking, the codes and categories were given to two qualitative experts to confirm the coding and analyzing process [40].
- The maximum variation in sampling in terms of age, sex, education level, duration of care and socioeconomic status enhanced the validity of the data that enabled the researchers to capture a wide range of experiences and perspectives [41].

2.6. Ethical consideration

Ethics Committee affiliated with Ahvaz Jundishapur University of Medical Sciences, Iran approved the study's research proposal (ir.ajums.rec.1394.180). The informed consent form was signed by those participants who granted the permission to record their voices and were willing to take part in this study. The time and location of the interviews were determined in accordance with the participants' will. The participants were also assured that they could withdraw from the study at any time without being penalized.

3. Findings

Four categories were developed as follows: 'care challenges', 'psychological vulnerabilities', and 'the chronic nature of care' and 'Care in the shade. The categories led to the development of the main theme of 'progressive exhaustion' (Table 3), experienced by the family caregivers during the provision of care to patients undergoing hemodialysis.

3.1. Care challenges

Providing care to patients undergoing hemodialysis both inside and outside home by a family caregiver disrupted their life career, family structure and sexual needs. This category consisted of three subcategory as follow: *job challenges*, *family challenges* and *sexual challenges*.

3.1.1. Job challenges

The process of caring for hemodialysis patients caused several problems for the caregivers and led to tensions and a reduction in their job performance. A caregiver who was a teacher said:

"I am a teacher. When I'm teaching in the class, out of the blue, my mind goes to my sick father. I become upset and feel extremely low; so lose my concentration. This issue reduced the efficiency of my work as a teacher." (Male, 10 years of caring for the father).

The process of taking care of patients might not only reduce the efficiency of the caregivers' performance, but also made them feel stressed and tense in the workplace. One of the caregivers stated:

"I'm an employee. If I'm in a meeting and someone calls me and says, "Your dad feels under the weather." In this situation, I face a dilemma and can neither leave the meeting nor stop thinking about my dad." (Male, 11 years of caring for the father).

The intense dependency of hemodialysis patients resulted in the loss of caregivers' job positions. One of the caregivers stated:

"I do all of my mom's chores. Now, the opportunity of teaching in the rural areas comes along, but I cannot leave my mom alone. Therefore, I have to close my eyes to the suggested position; however, I am in an urgent need for this job." (Female, 4 years of caring for the mother).

3.1.2. Family challenges

Devoting the time and energy to caring for patients, the family caregivers unintentionally prepared the ground for negligence and marginalization of other family members and caused serious harm

Table 3
Main theme, categories and subcategories developed during data analysis.

Main themes	Subthemes	categories	subcategories
Progressive Exhaustion	Care challenges	Job challenges	The oblivion of sexual needs Sexual needs' replacement with social activities The effect of patients' conditions on the sexual status
		Family challenges	
		Sexual challenges	
	Psychological vulnerabilities	The psychological impact of long-term care Difficulty in accepting the situation by the patient Stress caused by the patients' physical and psychological statuses	
Chronic nature of care		Constant distress	A permanent involvement in caring Progressive nature of problems The physical impact of long-term care Difficulty in understanding the situation of caregivers
		A permanent involvement in caring	
		Progressive nature of problems	
Care in the shade			

Difficulty of the position of the caregivers compared to the patients.

to the family integrity. One of the caregivers shared their experiences as follow:

"When I come to give a hand to my father to run his errands, some problems may happen to my wife and kids at home at the same time. However, I cannot do anything for them, because I'm at my father's home and caring for him. This has happened not once but several times to me and caused numerous problems for me and my family." (Male, 10 years of caring for the father).

Similarly, another caregiver said:

"My dad and I live in a house. When my dad's illness takes its toll, our home is fraught with extreme stress and anxiety. I'm his son, but my wife is annoyed and always protests against this situation. I do not know what to do." (Male, 11 years of caring for the father).

The caregivers have to meet the high cost of living due to caring for a patient with chronic illnesses at home. They have to work more that disrupted their family relationships. One caregiver declared:

"I have to provide my living cost, I have to work late outdoors. Mostly I do not see my children when I want to go to sleep. My life's integrity has been destroyed." (Male, 5 years of caring for the girl).

3.1.3. Sexual challenges

Sexual dysfunction and nervous tensions were created followed by renal failure in hemodialysis patients. The caregivers tolerated an increased burden of care, which led to spouses facing sexual challenges.

The wife of a patient said:

"I'm a human and I have my own needs. Animals also need sexual relationships. I am this man's second wife. We've got married about 10 years ago, but we've had no sexually contact even once. Probably it's because of his sexual dysfunctions and misfortunes we've encountered in our life." (Female, 10 years of caring for the husband).

Sexual dysfunction in female patients created many issues for their husbands so that the foundation of their family life was undermined. A caregiver with a higher education level asserted:

"My wife is on dialysis for about 5 years. In the first and second years, we had approximately no problems. But this disease destroys

the dialysis person's sexual feelings and severely affects the patient's spouse, while underlying nervous tensions." (Male, 5 years of caring for his wife)

3.2. Psychological vulnerabilities

The long-term caring process by the caregivers and patients' health conditions caused psychological and mental damage to the caregivers. This category consisted of the following subcategories: 'the psychological impact of long-term care', 'difficulty in the acceptance of the situation by the patient' and 'stress caused by patients' physical and psychological statuses'.

3.2.1. The psychological impact of long-term care

During the provision of care to patients, the caregivers dealt with various problems, deficiencies and worries. Therefore, they were under considerable mental and psychological stress. A caregiver said:

"When there are so many problems and concerns, is it possible to overlook them? Well, obviously, we may be affected by and suffer from anxiety, stress, fatigue, anger and sometimes frustration and helplessness." (Female, 6 years of caring for a patient).

Furthermore, meeting the healthcare needs of patients, preparation of food, and provision of help in living daily activities, medication administration and patients' transfer to the hemodialysis ward made the caregivers exhausted. A caregiver said:

"These patients have lots of difficulties and miseries such as transfer to the hemodialysis ward, doing household tasks, handling the patient's bad temper, suffering from insomnia and so on. What should I say? They all affect the caregivers' soul and mind so that I am willing to die." (Female, 8 years of caring for the patient).

3.2.2. Difficulty in the acceptance of situation by the patient

Refusing the position by the patients is one of the most serious sources of stress for caregivers, whatever the acceptance of the condition is delayed by the patients, the caregivers and patients are under further stress. One of the caregivers who was a doctor said:

"The acceptance of this condition depended on the age of the patient. Adults easily accept this situation, but it's very difficult for a teenager to accept it. The rejection of such a situation made so

many problems for caregivers and family member.” (Female, 3 years of caring for the patient).

3.2.3. Stresses caused by patients' physical and psychological statuses

The physical, emotional, and behavioral fluctuations of patients were the main stress resources for many caregivers. Most caregivers found it difficult to deal with this situation and did not know how to satisfy patients. A caregiver said:

“The physical status of the patient is so that they get quickly bored. The patient has no physical stability and feels well once, and two hours later, he/she feels under the weather. Sometimes, he/she shouts and sometimes is calm and quiet. This creates a lot of pressure and imposes stress on the caregivers.” (Male, 5 years of caring for the patient).

However, the management of patients' psychological conditions and abnormal behaviors damaged the caregivers' soul and psychological well-being. One of the caregivers who was a doctor said:

“Being compassionate toward the patient undergoing hemodialysis requires the destruction of caregivers' soul and mind, because the patient does not enjoy any certain logic, so he/she has a need that under no circumstances the caregiver can meet. The patient's condition is always unstable. All of these conditions affect the caregiver's soul and mind.” (Female, 3 years of caring for the child).

As hemodialysis is continued and neurological side effects are increased, the patients are susceptible to be more irritable and oversensitive. The girl who took care of his father for five years said:

“The hemodialysis patient experiences certain conditions; I mean, as dialysis is prolonged, the patient becomes very sensitive and fragile. This is very important to the caregiver, because he/she does the best not to bother the patient, but the caregiver have to withstand severe pressure.” (Female, 5 years of caring for the patient).

3.3. Chronic nature of care

The chronic nature of the disease prepared the ground for long-term care, permanent involvement in the provision of care and constant worries. The progressive nature of problems in the context of long-term care aggravated the burden and distress of the caregivers.

This category consisted four subcategory including ‘the physical impact of long-term care’, ‘the progressive nature of problems’, ‘constant worries’ and ‘a permanent involvement in caring’.

3.3.1. The progressive nature of problems

When the patient chose hemodialysis as an alternative treatment, his/her survival was improved. However, many physical and psychological problems occurred. The longer the treatment continued, the greater the problems would be. Therefore, the burden of care to the caregivers was increased. A caregiver said:

“It is the nature of this disease; I mean the longer the duration of hemodialysis, the bigger the patient's problems are. Particularly, the patients suffer more from impatience, aggression, low tolerance and physical complications that put more pressure on the caregiver and family members.” (Male, 5 years of caring for the patient).

The ongoing process of hemodialysis was accompanied by patients' severe and progressive side effects, which made the caregivers' situation difficult and their problems further. A caregiver declared:

“As hemodialysis continues, numerous physical complications may appear such as hepatitis, osteoporosis, heart failure, and hyperparathyroidism, which are the sources of problems for the family caregivers.” (Female, 7 years of caring for the patient).

3.3.2. Constant worries

Long-term care, mental issues, fluctuations in vital signs, adherence to the diet and medication regimes, bleeding after hemodialysis and many other issues might occur to patients undergoing hemodialysis, which affected the caregivers. A mother described her experiences as follow:

“I took my kid from the hemodialysis ward to home. Now, I regularly check his/her fistula site to see as to whether it bleeds or not. I am always worries about taking medications on time, eating inappropriate foods, not drinking plenty of liquids, his/her blood pressure so on. I am involved and worried about being engaged mentally in the patient care.” (Female, 3 years of caring for the child).

3.3.3. A permanent involvement in caring

The chronic identity of the disease and the long-term process of care prepared the ground for the caregivers' permanent involvement in the provision of care. A caregiver said:

“The patient's care process is lengthy. The caregiver should get up at 6 am in the morning and take the patient to a dialysis ward. He/she should spend 3–4 hours over the patient's bed in the hemodialysis ward. When the patient comes back home, the caregiver should massage his/her legs for half an hour and check whether he/she has any bleeding. This process is repeated three times a week. I certainly assert that caregivers are permanently getting involved in the process of care.” (Female, 6 years of caring for the patient).

The caregivers who had further experiences put more emphasis on the above-mentioned fact. The boy who was caring for the father for ten years said:

“When I care for a hemodialysis patient, I have to put up with lots of things; for example, I should follow whatever he/she says, not argue with him/her, and increase my tolerance. These are not just for a year or two, because I should always remain beside the patient.” (Female, 8 years of caring for the patient).

3.3.4. The physical impact of long-term care

The long-term care of hemodialysis patients caused physical injuries. One of the caregivers asserted:

“As a woman, I had to put a 50 kg-oxygen tank on my shoulders and take it to the second floor. Once it broke my collarbone. Unfortunately, it is not healed yet.” (Female, 10 years of caring for the patient).

Many physical injuries happened during taking care of hemodialysis patients. Another caregiver stated:

“My kid had a shortness of breath, so he/she used supplemental oxygen at night. Once, I was lying down beside his/her bed and the oxygen tank unexpectedly fell on me. My ribs and my head were broken and also my foot was bruised. I busied myself with the injuries for a month. There’s still a bruise under my eyes.” (Male, 7 years of caring for the patient).

3.4. Care in the shade

Difficulties in understanding the situation of caregivers in the process of care, difficulty of the position of caregivers compared to patients in addition disregard the treatment team to the caregivers lead them to shadow.

3.4.1. Difficulty in understanding the situation of caregivers

Understanding the situation of caregivers of hemodialysis patients required the person to remain in the same situation. A caregiver said:

“Understanding the caregiver’s situation and the issues facing by him/her sound very difficult. The difficulty of their situation cannot be understood by only talking to them; someone should put him/herself in his/her shoes.” (Female, 4 years of caring for the patient).

Another caregiver said

“Here is an Iranian proverb that says: ‘Hearing is never like seeing (i.e., a picture is worth a thousand words).’ You should live with them to understand how hard a caregiver is living.” (Female, 6 years of caring for the patient).

3.4.2. Difficulty of the position of caregivers compared to patients

The pressure and hardship that the caregivers suffered were more than those of the patients, because family caregivers should be responsibilities toward patients. They may not have enough time to take care of themselves. A caregiver said:

“Looking after a sick person is harder than being sick; I believe getting sick is much better than taking care for a sick person.” (Female, 5 years of caring for the patient).

Another caregiver stated

“The patient’s caregiver gets involved in the situation more than the patient. Also, the caregiver is under more pressure than the patient, because the caregiver should meet the needs of the patient. On the one hand, the caregiver looks for drugs and the cost of living; on the other hand, he/she does the patient’s affairs at home. Now, judge for yourself! Who suffers more?” (Female, 10 years of caring for the patient).

4. Discussion

The findings of this qualitative study revealed that the caregivers of hemodialysis patients encountered a very hazardous situation. Taking care of patients, managing their abnormal behaviors due to physical, mental, and emotional complications, bearing deficiencies during the care process along with numerous occupational, familial, and sexual challenges damaged the physical, emotional, and psychological aspects of caregivers and led to

progressive exhaustion.

Challenges posed to the caregivers by the situation were the main factors affecting progressive exhaustion. Family challenges were developed as a result of caregivers’ involvement in patients’ affairs. The caregivers had to be away from other family members mostly due to the provision of care to patients. Therefore, these challenges provided grounds for the collapse of the family stability. These results were consistent with the findings of a study conducted by Tong et al. (2010) in which one of the themes was *disrupting family norms*. The spousal tension, severe dependency, sibling neglect, and ultimate disturbances in family planning underlined this theme [42]. The study of Habibzadeh et al. (2009) in Iran revealed that the long-term involvement of patients’ caregivers not only changed their health conditions, but also led to changes in the structure of their family relationships [43].

Moreover, challenges had an obvious influence on the progressive exhaustion process among the caregivers. Mansilla Francisco et al. (2012) described patients with advanced chronic renal failure who were undergoing hemodialysis and their family caregivers faced functional challenges. Therefore, challenges posed serious threats to the health and structure of the patients’ family [44]. Also, Bayhakki and Hatthakit’s study (2012) demonstrated that due to being busy with taking care of patients, many caregivers experienced not only physical, psychological and relationship changes, but also modifications in their family structure, role and performance [45].

In the current study, the sexual dysfunction of patients due to renal failure and psychological and physical stress imposed on the caregivers led to sexual challenges. The results of the study by Khaira et al. (2012) confirmed that hemodialysis and the burden of care caused severe depression in patients and their spouses. Depression is the main cause of severe dissatisfaction in the spouses on hemodialysis patients. Dissatisfaction is evident in men more than women [46]. Furthermore, in the exploration of the characteristics of home care perceived by patients and their caregivers, Luk (2002) reported that sexual dissatisfaction was one of the negative reactions caused by the burden of care [47]. The results of the study by Chuluunbaatar et al. (2017) among informal caregivers of patients with stroke confirmed that the burden of care was associated with changes in the caregivers’ marital status, the caregiver’s relationship with the patient, financial difficulties, and the patient’s sex and dependency [48]. Therefore, sexual, job and familial challenges exacerbated the burden of care in caregivers.

Long-term care of patients’ ‘psychological problems and the management of patients’ abnormal behaviors caused a psychological vulnerability in the caregivers. The study conducted by Murray et al. (2014) demonstrated that long-term hemodialysis in patients with kidney failure made physical, emotional and psychological changes among patients and their caregivers [49]. Avsar et al. (2013) asserted that the peritoneal dialysis of patients with chronic renal failure needs a request change of the dialysis solution. Therefore, it can cause fluctuations in patients’ behaviors and affect their family members and caregivers [30]. Yen et al. (2010) indicated that any increase in duration of treatment in patients with schizophrenia may lead to negative feelings in caregivers and psychological, emotional, social, physical, and financial problems [14,50,51]. Bahrami et al. (2014) also set forth that the long-term care of patients with congestive heart failure had physical and psychological effects on caregivers. These effects are manifested in caregivers through physical expressions such as fatigue, muscle and skeletal system problems and psychological expressions such as anxiety and depression [52].

In this study, the chronic nature of care, patients’ physical condition, medications, diet, complications after hemodialysis and the progressive nature of the disease give rise to the extreme stress in

the caregivers and family members. Einollahi et al. (2009) conduct a study in Iran and demonstrated that anxiety in the caregivers of patients with kidney transplantation was high [6]. Navaro et al. (2007) believed that the role of the primary caregiver was stressful, which interfered with family health [53]. The caregivers of patients with chronic diseases experienced a great amount of pressure due to the burden of care. In addition, a lack of support by health officials exacerbated their concerns and led to severe stress [54]. Tong et al. (2010) reported that the family members of patients undergoing hemodialysis had a dual role for parenting and medical caregiving, which gave rise to fatigue, severe stress, exhaustion and severe disability [42]. Shimoyama et al. (2003) in Japan expressed that taking care of patients with hemodialysis was accompanied with severe physical and psychological tensions, which significantly reduced physical health, social functions, the level of energy, general health and mental health in the caregivers of hemolysis patients [16].

The long-term disease meant the permanent involvement of the caregiver in patient care. The result of a study by Tretteteig et al. (2017) showed that caregivers had a complex role with responsibilities, new tasks, and emotional and relational challenges expressed through emotional distress and demands for interactions [55]. It is believed that the condition of patients with chronic diseases especially patients undergoing hemodialysis induces an intense stress on caregivers. This kind of stress threatens caregivers' physical and psychological health.

The difficulty in understanding the situation of caregivers, hard positioning caregivers in addition to the treatment team's disregard for caregivers lead them to shadow. Mashayekhi et al. (2015) stated that 72.5% of caregivers experienced moderate to severe levels of care burden, which had many effects on their physiological, psychological, functional aspects of their life and lifestyle. Also, they were ignored by healthcare officials [29]. Ziegert and Fridlund (2001) found the theme of *a feeling of a threatening future* in the exploration of the experiences of caregivers of hemodialysis patients indicating their despair about their future life [56]. The vulnerability and difficult situation of caregivers of patients undergoing hemodialysis were confirmed by the findings of Celik et al.'s study (2012). They stated that the quality of life of caregivers of hemodialysis patients was much worse than their patients. Therefore, the caregivers experienced more unfavorable conditions [57]. Paying attention to the vulnerability of caregivers is so important that Beth et al. (2010) believed that paying attention to spouses' and family members' questions about chronic diseases and their reactions were more important than those of the patients [58]. Additionally, Aavage and Sawatzky (2013) argued that the family members of patients with chronic diseases were called *hidden patients* and never were checked up by health officials [59,60]. Hence, it was indicated that the patients' caregivers had more vulnerability than their patients putting them into the shadow.

5. Conclusion

Different factors can cause extreme stress for the caregivers of hemodialysis patients such as the progressive nature of the disease, the constant distress of the caregivers about the physical and psychological status of patients, patients' adherence to the diet and medication regimes and complications of hemodialysis. It also encompassed the management of patients' abnormal behaviors and their psychological problems. Therefore, the family caregivers were exposed to physical, emotional and psychological pressures. The difficulty in understanding the caregivers' conditions compared to those of the patients made them suffer from progressive exhaustion. Nevertheless, health officials, especially nurses

did not pay attention to this group of people who were actually the hidden patients or patients in the shadow. Monitoring the caregivers' experiences and attitudes toward the burden of care reflected the effects of care on their physical, emotional, social and functional statuses. Paying attention and assessing the burden of care helps with improving the quality of life and social well-being of the family caregivers, which improves the quality of care delivered to patients.

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Conflicts of interest

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Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.ijnss.2018.01.005>.

References

- [1] Shaw C, Pruthi R, Pitcher D, Fogarty D. UK Renal Registry 15th annual report: chapter 2 UK RRT prevalence in 2011: national and centre-specific analyses. *Nephron Clin Pract* 2013 Jan;123(Suppl):29–54.
- [2] Collins AJ, Foley RN, Chavers B, Gilbertson D, Herzog C, Johansen K, et al. United States renal data system 2011 annual data report: atlas of chronic kidney disease & end-stage renal disease in the United States. *Am J Kidney Dis* 2012 Jan;59(1 Suppl 1). A7, e1–420.
- [3] Hemayati R, Lesanpezeszki M, Seifi S. Association of dialysis adequacy with nutritional and inflammatory status in patients with chronic kidney failure. *Saudi J Kidney Dis Transpl* 2015 Nov;26(6):1154–60.
- [4] Walker RC, Morton RL, Tong A, Marshall MR, Palmer S, Howard K. Patient and caregiver preferences for home dialysis—the home first study: a protocol for qualitative interviews and discrete choice experiments. *BMJ Open* 2015 Jan;5(4). e007405.
- [5] Suri RS, Larive B, Garg AX, Hall YN, Pierratos A, Chertow GM, et al. Burden on caregivers as perceived by hemodialysis patients in the Frequent Hemodialysis Network (FHN) trials. *Nephrol Dial Transplant* 2011 Jul;26(7):2316–22.
- [6] Einollahi B, Taheri S, Nemati E, Abbaszadeh S, Pourfarziani V, Nourbala MH. Burden among care-givers of kidney transplant recipients and its associated factors. *Saudi J Kidney Dis Transpl* 2009 Jan;20(1):30–4.
- [7] Alnazly E. Coping strategies and socio-demographic characteristics among Jordanian caregivers of patients receiving hemodialysis. *Saudi J Kidney Dis Transpl. Saudi Arabia* 2016;27(1):101–6.
- [8] Belasco A, Barbosa D, Bettencourt AR, Diccini S, Sesso R. Quality of life of family caregivers of elderly patients on hemodialysis and peritoneal dialysis. *Am J Kidney Dis* 2006 Dec;48(6):955–63.
- [9] Suri RS, Larive B, Garg AX, Hall YN, Pierratos A, Chertow GM, et al. Burden on caregivers as perceived by hemodialysis patients in the Frequent Hemodialysis Network (FHN) trials. *Nephrol Dial Transplant* 2011 Jul 1;26(7):2316–22.
- [10] Möller-Leimkühler AM, Wiesheu A. Caregiver burden in chronic mental illness: the role of patient and caregiver characteristics. *Eur Arch Psychiatr Clin Neurosci* 2012 Mar 3;262(2):157–66.
- [11] Denham SA. Family routines: a structural perspective for viewing family health. *ANS Adv Nurs Sci*. 2002 Jun;24(4):60–74.
- [12] Grover S, Pradyumna, Chakrabarti S. Coping among the caregivers of patients with schizophrenia. *Ind Psychiatr J* 2015 Jan;24(1):5–11.
- [13] Gupta S, Isherwood G, Jones K, Van Impe K. Assessing health status in informal schizophrenia caregivers compared with health status in non-caregivers and caregivers of other conditions. *BMC Psychiatr* 2015 Jan;15:162.
- [14] Saunders JC. Families living with severe mental illness: a literature review. *Issues Ment Health Nurs* 2003 Mar;24(2):175–98.
- [15] Alvarez-Ude F, Valdés C, Estébanez C, Rebollo P. Health-related quality of life of family caregivers of dialysis patients. *J Nephrol* 2004 Jan;17(6):841–50.

- [16] Shimoyama S, Hirakawa O, Yahiro K, Mizumachi T, Schreiner A, Kakuma T. Health-related quality of life and caregiver burden among peritoneal dialysis patients and their family caregivers in Japan. *Perit Dial Int* 2003 Dec;23(Suppl 2):S200–5.
- [17] Chappell NL, Reid RC. Burden and well-being among caregivers: examining the distinction. *Gerontologist* 2002 Dec;42(6):772–80.
- [18] Hasanpour-Dehkordi A, Khaledi-Far A, Khaledi-Far B, Salehi-Tali S. The effect of family training and support on the quality of life and cost of hospital readmissions in congestive heart failure patients in Iran. *Appl Nurs Res* 2016 Aug;31:165–9.
- [19] Hope J. A patient perspective on the barriers to home dialysis. *J Ren Care* 2013 Jan;39(Suppl 1):3–8.
- [20] Ziegert K, Fridlund B, Lidell E. Professional support for next of kin of patients receiving chronic haemodialysis treatment: a content analysis study of nursing documentation. *J Clin Nurs* 2007 Feb;16(2):353–61.
- [21] Salehi-tali S, Ahmadi F, Zarea K, Fereidooni-Moghadam M. Commitment to care: the most important coping strategies among family caregivers of patients undergoing haemodialysis. *Scand J Caring Sci* 2017 May 19. in press.
- [22] Robinson K. The relationships between social skills, social support, self-esteem and burden in adult caregivers. *J Adv Nurs* 1990 Jul;15(7):788–95.
- [23] Weatherburn CJ, Heath CA, Mercer SW, Guthrie B. Physical and mental health comorbidities of epilepsy: population-based cross-sectional analysis of 1.5 million people in Scotland. *Seizure* 2017 Feb 23;45:125–31.
- [24] Dias A, Dewey ME, D'Souza J, Dhume R, Motghare DD, Shaji KS, et al. The effectiveness of a home care program for supporting caregivers of persons with dementia in developing countries: a randomised controlled trial from Goa, India. *PLoS One* 2008 Jan;3(6), e2333.
- [25] Yu HD, Petrini MA. The HRQoL of Chinese patients undergoing haemodialysis. *J Clin Nurs* 2010;19(5–6):658–65.
- [26] Dehkordi AH, Heydarnejad MS. Effect of booklet and combined method on parents' awareness of children with beta-thalassemia major disorder. *J Pak Med Assoc.* 2008 Sep;58(9):485–7.
- [27] Hasanpour-Dehkordi A. Self-care concept analysis in cancer patients: an evolutionary concept analysis. *Indian J Palliat Care* 2016;22(4):388–94.
- [28] Hasanpour-Dehkordi A, Mohammadi N, Nikbakht-Nasrabadi A. Re-designing Orem's self-care theory for patients with chronic hepatitis. *Indian J Palliat Care* 2016;22(4):395–401.
- [29] Mashayekhi F, Pilevarzadeh M, Rafati F. The assessment of caregiver burden in caregivers of hemodialysis patients. *Mater Sociomed* 2015 Oct;27(5):333–6.
- [30] Avsari U, Avsari UZ, Cansever Z, Set T, Cankaya E, Kaya A, et al. Psychological and emotional status, and caregiver burden in caregivers of patients with peritoneal dialysis compared with caregivers of patients with renal transplantation. *Transplant Proc* 2013 Apr;45(3):883–6.
- [31] Cukor D, Coplan J, Brown C, Friedman S, Cromwell-Smith A, Peterson RA, et al. Depression and anxiety in urban hemodialysis patients. *Clin J Am Soc Nephrol* 2007 May;2(3):484–90.
- [32] Papastavrou E, Kalokerinou A, Papacostas SS, Tsangari H, Sourtzi P. Caring for a relative with dementia: family caregiver burden. *J Adv Nurs* 2007 Jun;58(5):446–57.
- [33] HassanpourDehkordi A, Mohammadi N, NikbakhtNasrabadi A. Hepatitis-related stigma in chronic patients: a qualitative study. *Appl Nurs Res* 2016 Feb;29:206–10.
- [34] Gerilobindo Wood JH. Nursing research method and critical appraisal for evidence base practice. eighth ed. St. Louis: Elsevier Mosbey; 2014. 347 pp.
- [35] Green J, Thorogood N. No TQualitative methods for health research. London: sage; 2004.
- [36] Polit DFBC. No TitleEssential of nursing Research: appraising evidence for nursing practice. seventh ed. Philadelphia: Wolters Kluwer ,Lippincott Williams & Wilkins; 2010.
- [37] Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs* 2008 Apr;62(1):107–15.
- [38] James WD. How is qualitative research taught at the master's level? *J Soc Work Educ* 2008;44(1):85–101.
- [39] Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004 Feb;24(2):105–12.
- [40] Drisko JW, Maschi T. *Content Analysis*. Tony Tripodi D, Emeritus OSU, (Eds.), New York, Oxford University Press, 2016, p. 125.
- [41] Dattalo P. *Determining sample size: balancing power, precision, and practicality*. New York: Oxford University Press; 2008.
- [42] Tong A, Lowe A, Sainsbury P, Craig JC. Parental perspectives on caring for a child with chronic kidney disease: an in-depth interview study. *Child Care Health Dev* 2010 Jul;36(4):549–57.
- [43] Habibzadeh H, Jafarizadeh H, Mohammadpoor Y, Kiani P, Lak KHBA. No Title. A survey on quality of life in hemodialysis patients care giver. *J Urmia Nurs Midwifery Fac* 2009;7(3):128–35.
- [44] Mansilla Francisco JJ, Díez De los Ríos Cuenca F, Cabrera Azaña S, Cortés Torres J, Macías López MJ, González Castillo JA, et al. Impact of incident comorbidity on functional loss in elderly chronic kidney disease patients undergoing hemodialysis. *CANNT J* 2012 Jan;22(1):25–9.
- [45] Bayhakki, Hatthakit U. Lived experiences of patients on hemodialysis: a meta-synthesis. *Nephrol Nurs J* 2012 Jan;39(4):295–304. quiz 305.
- [46] Khaira A, Mahajan S, Khatri P, Bhowmik D, Gupta S, Agarwal SK. Depression and marital dissatisfaction among Indian hemodialysis patients and their spouses: a cross-sectional Study. *Ren Fail* 2012 Jan;34(3):316–22.
- [47] Luk WS-C. The home care experience as perceived by the caregivers of Chinese dialysis patients. *Int J Nurs Stud* 2002 Mar;39(3):269–77.
- [48] Chuluunbaatar E, Pu C, Chou Y-J. Changes in caregiver burden among informal caregivers of stroke patients in Mongolia. *Top Stroke Rehabil* 2017 Jan 18:1–8.
- [49] Murray PD, Dobbels F, Lonsdale DC, Harden PN. Impact of end-stage kidney disease on academic achievement and employment in young adults: a mixed methods study. *J Adolesc Health* 2014 Oct;55(4):505–12.
- [50] Awad AG, Voruganti LNP. The burden of schizophrenia on caregivers: a review. *Pharmacoeconomics* 2008 Jan;26(2):149–62.
- [51] Yen WJ, Teng CH, Huang XY, Ma WF, Lee S, Tseng HC. A theory of meaning of caregiving for parents of mentally ill children in Taiwan, a qualitative study. *J Clin Nurs* 2010;19(1–2):259–65.
- [52] Bahrami M, Etemadifar S, Shahriari M, Farsani AK. Caregiver burden among Iranian heart failure family caregivers: a descriptive, exploratory, qualitative study. *Iran J Nurs Midwifery Res* 2014 Jan;19(1):56–63.
- [53] Navarro-Sandoval C, Uriostegui-Espiritu LC, Delgado-Quiñones EG, Sahagún-Cuevas MN. Depression and burden on primary caregivers of elderly persons with physical dependence of the UMF 171. *Rev Med Inst Mex Seguro Soc*, 55(1) 25–31.
- [54] Cousineau N, McDowell I, Hotz S, Hébert P. Measuring chronic patients' feelings of being a burden to their caregivers: development and preliminary validation of a scale. *Med Care* 2003 Jan;41(1):110–8.
- [55] Tretteteig S, Vatne S, Rokstad AMM. The influence of day care centres designed for people with dementia on family caregivers – a qualitative study. *BMC Geriatr* 2017 Dec 5;17(1):5.
- [56] Ziegert K, Fridlund B. Conceptions of life situation among next-of-kin of haemodialysis patients. *J Nurs Manag* 2001 Jul;9(4):231–9.
- [57] Celik G, Annagur BB, Yilmaz M, Demir T, Kara F. Are sleep and life quality of family caregivers affected as much as those of hemodialysis patients? *Gen Hosp Psychiatr* 2012 Jan;34(5):518–24.
- [58] Khaira A, Mahajan S, Khatri P, Bhowmik D, Gupta S, Agarwal SK. Depression and marital dissatisfaction among Indian hemodialysis patients and their spouses: a cross-sectional study. *Ren Fail* 2012 Apr 23;34(3):316–22.
- [59] Savage S, Bailey S. The impact of caring on caregivers' mental health: a review of the literature. *Aust Health Rev* 2004;27(1):111–7.
- [60] Sawatzky JE, Fowler-Kerry S. Impact of caregiving: listening to the voice of informal caregivers. *J Psychiatr Ment Health Nurs* 2003 Jun;10(3):277–86.