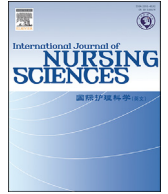


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## Progressive exhaustion: A qualitative study on the experiences of Iranian family caregivers regarding patients undergoing hemodialysis

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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.

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### 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

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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

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