

## ORIGINAL ARTICLE

# Caring Burden and Quality of Life of Family Caregivers in Patients Undergoing Hemodialysis: A Descriptive-Analytic Study

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### ABSTRACT

**Background:** Caring role, especially in chronic diseases, has a negative impact on the health of family caregivers and can affect their quality of life. Therefore, this study aimed to investigate the care burden and quality of life in family caregivers of hemodialysis patients and their relationship with some characteristics of caregivers and patients.

**Methods:** This study was conducted as a descriptive-analytic study in Isfahan from January to February 2017. Sampling was done using census. The number of participants was 254. The data gathering tools consisted of a three-part questionnaire including demographic characteristics, the Zarit questionnaire for caring burden, and SF-36 quality of life questionnaire. Data were analyzed using descriptive statistics, Pearson correlation coefficient test, Spearman's coefficient, ANOVA, and univariate general linear regression. A significant level of 5% was considered.

**Results:** The mean scores of the quality of life and caring burden were  $30.54 \pm 9.89$  and  $44.98 \pm 6.82$ , respectively in caregivers. The age of the patient under care ( $P < 0.001$ ), cost of medications ( $P = 0.008$ ), and hours of care in 24 hours ( $P < 0.001$ ) had a significant relationship with care givers' quality of life. Also, univariate general linear regression revealed that care burden had a significant relationship with the quality of life ( $P = 0.003$ ).

**Conclusion:** Family caregivers who experienced more caring burden had a low quality of life. The researchers suggest that supportive and educational programs should be designed and implemented for this group of patients and their caregivers.

**KEYWORDS:** Care burden, Caregivers, Quality of life, Renal dialysis

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## INTRODUCTION

The world population seeks to improve the level of health services, reduce mortality, and increase life expectancy for those getting old; as a result, the rate of diseases, especially chronic diseases including End Stage Renal Disease (ESRD), are on increase.<sup>1</sup> In Iran, more than 360,000 people are affected by ESRD which indicates an annual growth rate of approximately 12%.<sup>2</sup> Meanwhile, the province of Isfahan is ranked fourth in Iran in terms of the number of hemodialysis patients.<sup>3</sup>

Approximately, 47.7% of the patients with ESRD in Iran are undergoing hemodialysis.<sup>4</sup> Hemodialysis is an undeniable part of these patients' lives<sup>5</sup> and has stressful and restraining effects on the patient's life as well as their family members.<sup>6</sup> Nowadays, the role of family support has increased a lot due to the changes made in the provision of treatment and healthcare to chronic patients, including the transfer of care from hospital to home.<sup>7</sup> These changes, coupled with the chronic nature and long-term treatment of the disease, have a major impact on the performance of the patients' families suffering from chronic diseases.<sup>8</sup> Families are referred to as "caregivers" for playing such a role.

Family caregivers are in the first line of care for people with chronic illnesses,<sup>9</sup> including patients undergoing hemodialysis. They are usually one of the patient's family members, relatives or friends who should be in touch with the patients for taking care of them.<sup>10</sup> Family caregivers are the best source for caring the hemodialysis patients.<sup>11</sup> Family members of the hemodialysis patients should play their caring role both at home and outpatient clinics.<sup>12</sup> Personal hygiene, provision of medications, transfer of the patient to the dialysis center, assistance in eating food, emotional and mental support, and hospitalization are among the duties of these caregivers.<sup>13</sup>

In most studies, more attention has been paid to the patients and less to the caregivers.<sup>14</sup> However, in addition to their critical role in caring of the patient, they may also be affected

by physical and mental disorders due to this role.<sup>12</sup> Such an effect is so important that the family caregivers are referred as "hidden patients".<sup>1</sup> Also, these factors can affect the quality of life of caregivers.<sup>12, 15</sup> The effect of caring role on the emotional, psychological, vitality and life-quality dimensions of these caregivers has been reported.<sup>16</sup> Another study also reported that 52.5% of these caregivers had a moderate and low quality of life.<sup>17</sup>

Care burden is a distress or negative experience resulting from the provision of care, and includes financial, physical and mental costs.<sup>18, 19</sup> Increased distress on caregivers will result in consequences such as family isolation, lack of hope for social support, disorders in family relations, and inadequate care of the patient; eventually, the patient gives up the treatment.<sup>5, 20</sup>

Generally, family caregivers of hemodialysis patients are also vulnerable due to the effects of caring role. In some studies, it has been noted that the demographic characteristics of caregivers, including gender, age, socio-economic status and so on can have an impact on the care burden;<sup>21</sup> this relationship requires further investigation. Understanding the characteristics of caregivers is important for identification of endangered groups, establishment of support groups according to these characteristics, determination of the resources in the planning phase development of the services to be provided by the health institutions, and establishment of the health policies. Therefore, this study aimed to investigate the care burden and quality of life in family caregivers of hemodialysis patients and their relationship with some characteristics of caregivers and patients.

## MATERIALS AND METHODS

This descriptive-analytic study was carried out from January to February 2017. The population of this study consisted of all family caregivers of hemodialysis patients who referred to selected teaching hospitals affiliated to Isfahan University of Medical Sciences (Khorshid,

Amin) in Isfahan. These centers are providing 24-hour and 6-day a week care to patients with chronic hemodialysis in Isfahan. The total number of the patients under hemodialysis referred to these centers were 260. Sampling was done by census and included 254 family caregivers that had the inclusion criteria and informed consent. One family caregiver was considered for each patient.

The inclusion criteria for the patients in this study were passing at least 3 months from the patient's dialysis onset, having no known psychiatric and neurologic disorders (through direct question from the patients), having no previous history of renal transplantation, and not currently being a candidate for the transplantation. The inclusion criteria for the caregivers consisted of being the main caregiver (at patient's choice); being one of the close relatives of the patient (wife, daughter, son, sister, brother, father, mother, grandchild); having no known psychiatric and neurologic disorders (through direct inquiry from the person); not being a member of the medical or healthcare team; and finally not providing any other chronic patient with care at home. The exclusion criteria were being unwilling to participate in the study and caring for another patient with chronic illness at home. We provided the participants with key information about the study aims and emphasized that they could withdraw from the study anytime they intended. The researchers, after coordinating with the head nurses, completed the questionnaires through interview with the main caregiver who was introduced by patients in the hemodialysis ward. The data gathering tool was a three-part questionnaire including demographic characteristics, the Zarit questionnaire for caring burden, and SF-36 quality of life questionnaire.

The Zarit care burden questionnaire was developed by Zarit *et al.* (1980), and consists of 22 items. The 5 point Likert scale consisted of never (0), rarely (1), sometimes (2), often (3) and always (4). The lowest score of care burden is zero, meaning that the care burden

is not high and the highest score is 88, which means the maximum care burden.<sup>7</sup> Zero to 20 points mean little or no burden, 21–40 points mean mild to moderate burden, 41–60 points mean moderate to severe burden, and 61–88 points mean severe burden.<sup>22</sup> The reliability of the original Zarit questionnaire was 0.71 with test re-test and its internal consistency with Cronbach's alpha was 0.91. Evidence for criterion validity of the questionnaire has been demonstrated in caregivers of patients with dementia in whom the questionnaire was highly correlated with the Burden Assessment Scale.<sup>23</sup> The validity (content validity) and reliability (test re test) of the questionnaire in Iran were verified by Navidian *et al.* (2004), ( $r=94\%$ ).<sup>24</sup>

The Short Form 36 Health Survey Questionnaire (the SF-36) was developed in the USA for use in the Rand Corporation's Health Insurance Experiment. Afterward the tool has been translated into different languages and has been used around the world.<sup>25</sup> The SF-36 quality of life questionnaire has 36 questions and includes eight dimensions of physical function, physical role, emotional role, vitality, mental health, social function, pain, and general health. Each dimension consists of 2 to 10 questions. From the integration of the dimensions of physical function, physical role, general health and pain, the physical health index is obtained; and through the integration of the role of emotion, vitality, mental health and social function, the index of mental health is achieved. The scale of the scores is proportional to each dimension. In two dimensions, the options were Yes/ No and in six dimensions the options were All the time, Most times, Lots of times, Sometimes, A small amount of time, Never). To obtain the score for each dimension, one should sum up the questions of each dimension and then divide it by the number of questions. To obtain the general score, the total scores of all eight dimensions should be summed up and then divided by eight. In this questionnaire, lower scores indicate lower quality of life and vice versa, so the scores for each dimension range

between 0 and 100. Zero is the worst and the higher scores reflect the better quality of life.<sup>15</sup> This scale was translated into Persian by Montazeri *et al.* (2005), and validated through content validity (70 to 85%). Furthermore, its reliability was confirmed through internal consistency reliability (Cronbach's alpha 0.65-0.9).<sup>26</sup> In the present study, Cronbach's alpha coefficient was 0.86 and 0.9 for the quality of life questionnaire and for the caring burden questionnaire, respectively.

Data were analyzed through descriptive statistics (frequency distribution, percentage, range, mean and standard deviation to descriptive demographic variables of participants and average score of quality of life dimensions of caregivers), analytical statistics (Pearson correlation coefficient, Spearman's coefficient, Independent t-test and ANOVA to determine the relationship between quality of life, care burden of caregivers with the demographic variables of participants) and Statistical Package for the Social Sciences software (version 16, SPSS Inc., Chicago, IL, USA). In the presence of demographic variables that have a relationship with care burden and quality of life, it was possible that there was a confounding variable in the relationship between quality of life and caring burden; therefore, univariate general linear regression was used. A significant level of 5% was considered ( $P < 0.05$ ).

Ethics Committee of Isfahan University of Medical Sciences approved the study (IR. REC.1395.2.148). Verbal and written informed consent was obtained from the participants. We used numeric codes in place of personal names to secure the confidentiality of the questionnaire. The participants were free to withdraw from the study anytime.

## RESULTS

The demographic characteristics of patients and caregivers are presented in Table 1. The mean score of the quality of life and caregivers' caring burden were  $30.54 \pm 9.89$  and  $44.98 \pm 6.82$ , respectively. The highest mean score was seen

in the mental health dimension  $49.46 \pm 7.04$  and the lowest in the emotional role dimension  $12.71 \pm 6.34$  (Table 2). Pearson correlation coefficient showed that there was an inverse relationship between caring burden score and quality of life score ( $P < 0.001$ ,  $r = -0.24$ ), i.e. with increase in the caring burden, the quality of life decreased.

Pearson correlation coefficient revealed that there was a reverse relationship between the quality of life score and age of the caregivers ( $P = 0.03$ ,  $r = -0.14$ ), average caring hours ( $P < 0.001$ ,  $r = -0.36$ ), age of the patient ( $P < 0.001$ ,  $r = -0.39$ ), and the cost of medications ( $P = 0.008$ ,  $r = -0.18$ ); however, a direct relationship was shown between the quality of life score and income level ( $P = 0.001$ ,  $r = 0.21$ ), and the level of education of caregivers ( $P = 0.02$ ,  $r = 0.14$ ). Spearman's coefficient showed that there was no significant relationship between the quality of life score with the number of dialysis sessions. Independent t-test showed that the average score of the quality of life in working caregivers was significantly higher than non-working caregivers ( $P < 0.001$ ). Independent t-test revealed that the mean scores of quality of life of male and female caregivers did not differ significantly ( $P = 0.79$ ). One-way analysis of variance showed that there was no significant relationship between the caregivers' marital status and quality of life ( $P = 0.65$ ). There was a significant relationship between "relationship with the patient" variable and caregivers' quality of life ( $P < 0.05$ ), so that the offspring who were caring for their parents had a lower quality of life.

Pearson correlation coefficient demonstrated that there was a reverse relationship between the caring burden score and the duration of the illness ( $P = 0.007$ ,  $r = -0.17$ ). Also, Pearson correlation coefficient revealed that there was no significant relationship between the caring burden score and age of the caregivers ( $P = 0.35$ ,  $r = 0.06$ ), average caring hours ( $P = 0.86$ ,  $r = 0.011$ ), and income level of the caregivers ( $P = 0.07$ ,  $r = -0.12$ ). Spearman's coefficient revealed that



**Table 1:** Frequency distribution of demographic characteristics of the patients and caregivers

Variable	Participant	Patient		Caregiver	
		N (%)	Mean±SD (Range)	N (%)	Mean±SD (Range)
Sex	Male	95(37.40)	-	70 (27.56)	-
	Female	159 (62.60)	-	184(72.44)	-
Age(year)	-	-	54.30±12.87 (22-79)	-	48.19±12.80 (18-80)
Marital status	Single	84 (33.07)	-	29 (11.42)	-
	Married	155 (61.02)	-	221(87.01)	-
	Divorced	7 (2.76)	-	0(0)	-
	Widow	8 (3.15)	-	4 (1.57)	-
Education	Elementary	130 (51.20)	-	112 (44.09)	-
	High school diploma	90 (35.40)	-	74 (29.13)	-
	Associate degree	22 (8.70)	-	26 (10.25)	-
	Bachelor’s degree or higher	12 (4.70)	-	42 (16.53)	-
Employment	Employed	29 (11.42)	-	80 (31.50)	-
	Housekeeper	-	-	115 (45.27)	-
	Student	-	-	17 (6.70)	-
	Unemployed	221 (87)	-	6 (2.36)	-
	Retired	4 (1.58)	-	36 (14.17)	-
Months elapsed since diagnosis	-	-	64.31±42.88	-	-
The number of dialysis sessions per week	-	-	2.80±0.4	-	-
Settlement status	Urban	249 (98.03)	-	-	-
	Rural	5 (1.97)	-	-	-
Type of transportation to dialysis ward	By family	178 (70.08)	-	-	-
	By hospital	76 (29.92)	-	-	-
Cost of medications monthly (\$)	-	-	13.66±17.45	-	-
Average referral to health centers and physicians per month(other than hemodialysis)	-	-	1.50±0.70	-	-
Relation to patient	Parents	-	-	22 (8.66)	-
	Sister	-	-	22 (8.66)	-
	Brother	-	-	2 (0.79)	-
	Offspring	-	-	68 (26.77)	-
	Spouse	-	-	129(50.79)	-
	Grandchild	-	-	11 (4.33)	-
Hours of care in 24 hours	-	-	-	-	8.95±3.60
Income monthly (\$)	-	-	-	-	286.39±102.77

there was no significant relationship between the caring burden score and the number of dialysis sessions. Independent t-test showed that the mean score of caring burden in working caregivers was significantly higher

than non-working ones (P=0.03). One-way analysis of variance showed that there was no significant relationship between the caregivers’ marital status and caring burden (P=0.94). Furthermore, there was no

**Table 2:** Average score of the quality of life dimensions of caregivers (scale of 100)

Domain	Mean±SD
PCS <sup>a</sup>	25.51±10.85
Bodily pain	37.31±13.67
General health	18.55±16.96
Physical function	26.85±8.51
Physical role	19.62±7.42
MCS <sup>b</sup>	37.04±7.68
Mental health	49.46±7.04
Social function	43.07±15.93
Vitality	43.04±6.82
Role emotion	12.71±6.34

<sup>a</sup> Physical Component Summary; <sup>b</sup> Mental Component summary

significant relationship between “relationship with the patient” variable and caregivers’ caring burden ( $P=0.09$ ).

Univariate general linear regression demonstrated that there was a significant relationship between quality of life with care burden ( $P=0.003$ ,  $r=0.305$ ), patients’ age ( $P<0.001$ ,  $r=-0.39$ ), cost of medications ( $P=0.008$ ,  $r=-0.18$ ), and hours of care in 24 hours ( $P<0.001$ ,  $r=-0.36$ ).

## DISCUSSION

The results of the study showed that the majority of family caregivers were middle-aged women with low education and in low level of economic conditions. In other studies, most family caregivers were female as well.<sup>27, 28</sup> Regarding the culture of Iranian society, women usually play a role in caring; also, the results of our study showed that 27.56% of caregivers were male, and this reflects the participation of men in care.<sup>27</sup> Therefore, given the role of men in providing economic needs and participation in care, there is a need to pay close attention to reducing the their care burden. These caregivers spend an average of 9 hours out of 24 hours on caring for the patient. These results may indicate that taking care of these patients requires a large amount of time spent by family caregivers. Thus, with regard to slight resources support, they are faced with many problems while playing other roles along with caring role.

The result of this study revealed that the average score of caregiver’s quality of life was in a low level, and the mean of the quality of

life in the physical dimension was less than its mental dimension. These findings are consistent with the results of another study.<sup>13</sup> The result of a systematic review revealed that hemodialysis affects the physical dimension more than the spiritual dimension.<sup>29</sup> In other studies, the quality of life score in the mental dimension was low.<sup>4, 30</sup> In one of these studies, caregivers were younger than those in the present study; most of them were patients’ offspring and, therefore, other people helped them in the caregiving task. As a result, the physical problems of caregivers were less compared with our researcher.

Another finding of this study revealed that caregivers had a moderate to severe level of caring burden and this finding was confirmed by different studies.<sup>11, 12, 27, 28, 31</sup> Therefore, with an increase in the patient care duration, caregiving burden has increased, too. In addition, care burden was higher in working caregivers compared to non-working ones, and this finding was consistent with those of other studies.<sup>12</sup> The findings of a study revealed a low level of caring burden,<sup>32</sup> which may be attributed to the hemodialysis site (in their study the hemodialysis process was done at patient’s home). Therefore, with a reduced rate of commuting, as well as participation of other people, the patients would be more independent and the amount of caring hours and the level of caring burden decreased.

The findings showed that there was an inverse relationship between the caring burden score and quality of life score; that is, with increase in the caring burden, the

quality of life decreased. Caregivers play a very important role in treatment plan of patients suffering from chronic illnesses, especially ESRD. In Asian countries, with intact family structure, families of dialysis patients play a vital role in the treatment of the patients.<sup>31</sup> They undergo physical and psychological complications during the care of the patient and experience anxiety, fatigue, social isolation, stress, and exhaustion.<sup>1</sup> These factors can affect their quality of life.<sup>12, 15</sup> The quality of life of the hemodialysis patients' caregivers is affected physically, mentally and vitality. <sup>1</sup>Increased care burden can decrease the level of patient care and also compromise the physical and mental health of the caregivers.<sup>28</sup> In addition to self-care, family caregivers should also meet the caring needs of patients; consequently, they may experience high levels of physical burden, which affects their quality of life.

Maintaining and improving the health of caregivers are important not only in relationship with caregiver's performance, but also for playing the caring role.<sup>7</sup> The findings of this study show that there is an inverse relationship between the mean score of quality of life and high costs, the number of care hours, and the age of patients and caregivers, so that with increase in the above mentioned factors, caregivers' quality of life decreases. These results emphasize some approaches such as taking supportive measures to provide healthcare costs, increasing the communication skills for getting help from other family members, and taking measures for maintaining the health of caregivers themselves.

Considering the results of univariate general linear regression analysis, patient's age, cost of medications and hours of care in 24 hours had a significant relationship on the quality of life; therefore, it is important to identify the groups at risk for difficulty, to establish support groups according to these characteristics (cost of medications and hours of care in 24 hours), to determine the resources in the planning of the services for

family caregivers to be taken.

One of the strengths of this study was to determine the care burden and quality of life of family caregivers of hemodialysis patients and their relationship with characteristics of caregivers and patients for the first time in Isfahan city. The limitations of this study were the lack of assessment of the severity of the illness, the level of selfcare and the other chronic illness of patients, as well as the lack of recognition of various types of care provided by caregivers. It is suggested that these dimensions should be considered in future studies.

## CONCLUSION

Family caregivers of hemodialysis patients experience the burden of caring due to their role, which has a negative impact on their quality of life. Therefore, one of the solutions for maintaining and improving the quality of life is reducing the care burden. Considering that the cost of medications and hours of care in 24 hours are significant predictors of caregiver's quality of life, thereby reducing the cost of medications through insurance coverage and charity associations; assistance from other family members for some tasks such as doing housework can help reduce the care burden and improve the caregiver's quality of life. Also, the researchers suggest that application of other therapies such as home-based dialysis, socio-economic support including medical services and consultation in dialysis ward, free transportation, and 24-hour online support or telephone counseling can reduce the care burden of the caregivers.

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