

Original Article

Care Burden of Caregivers of Hemodialysis Patients and Related Factors

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Abstract

Objective: Hemodialysis (HD) therapy extends the life span of individuals, but also causes individuals to experience a distressful period. In addition to hemodialysis patients, relatives also play a role in the treatment and care process and share this distressing cycle. In this case, primary caregivers may be the most affected by the dialysis process when compared to dialysis patients. This study was conducted to examine the burden of caregivers of hemodialysis patients and some related variables.

Methods: This study is a cross-sectional study conducted on primary caregivers of patients receiving treatment at three private hemodialysis centers in Eskisehir city center between January 15 and May 1, 2015. This study included 163 caregivers who attended hemodialysis centers during the treatment of their patients and agreed to participate in the study.

Results: Of the study group, 109 (66.9%) were female and 54 (33.1%) were male. Their ages ranged from 23 to 87 years, with a mean of 52.2 ± 12.8 years. The scores obtained with the Zarit Caregivers Burden Scale varied from 0 to 82, with a median score of 46.9. In the study group, we found a higher burden of care in female caregivers and in those who were being employed by an income-generating job, having difficulty in meeting their health expenses, reporting that their role in the family and work is negatively affected, and giving care longer than 5 years ($p < 0.05$ for each). There was no correlation between the burden of care and caregivers' age group, marital status, educational status, place of residence, type of personality, smoking and alcohol consumption and number of weekly dialysis sessions ($p > 0.05$ for each).

Conclusion: This study has revealed a moderate care burden for the care providers of hemodialysis patients. It will be helpful to provide social and economic support to determine the feelings, thoughts and needs experienced by caregivers of hemodialysis patients and to reduce the care burden of these individuals.

Key words: Care Burden, Caregivers, Hemodialysis

Introduction

Chronic renal disease is an important public health problem with a high incidence in our country and in the world (Gerogianni & Babatsikou, 2014; Suleymanlar, 2007). Chronic

renal failure (CRF) is one of the chronic diseases that can lead to inadequacies in the individual's daily life and affect the quality of life (Kafkia et al., 2017; Bicer et al., 2017; Karadakovan et al., 2010). Progression of CRF increases the severity of impaired renal function and leads to the

development of end-stage renal failure (ESRF) (Rastogi et al., 2008). The number of patients with end-stage renal disease is increasing in the US, Asia and European countries and is estimated to be more than 780,000 by 2020 (Haras et al., 2008). The prevalence of end-stage renal failure is increasing in our country. For the year 2014, the point prevalence of end stage renal disease needing renal replacement therapy is found as 918 ppm in Turkey (including pediatric patients). For the year 2014, the incidence of renal replacement therapy is found as 147 ppm in Turkey (including pediatric patients). (National Nephrology, Dialysis and Transplantation Registry Report of Turkey 2014)

Hemodialysis is the most commonly used method for the treatment of end-stage renal failure. Hemodialysis is a procedure in which the patient's blood is anticoagulated and circulated extracorporeally over the surface of a semipermeable membrane and returned to the patient with reconstituted liquid and solute content (Alikari et al., 2015; Bicer et al., 2015; Guyton & Hall, 2001). Chronic renal failure is a disease that is difficult to treat and affects both patients and families negatively in psychological, social and economic terms (Ibrahim et al., 2013).

The caregiver is a person who helps individuals or regulates the assistance of these individuals who are unable to perform their self-care due to a disease, disability or old age alone. Difficulty in care-giving can be defined as the experience of difficulty, tension, feeling under pressure or being burdened by a caregiver of a member of his/her family or someone else with advanced age or a chronic disease or a disability. Difficulty in care-giving is a multidimensional response with physical, psychological, emotional, social and economic consequences associated with care-giving. The caregiver's sense of difficulty can be defined as the state of affection in his/her own life during care-giving (Ugur et al., 2017; Siegel et al. 1991; Novian, 2007).

Methods

This study is a cross-sectional study conducted on primary caregivers of patients receiving treatment at three private hemodialysis centers in Eskisehir city center between January 15 and May 1, 2015. The study group included 163 primary caregivers who were present at hemodialysis centers throughout the study and agreed to participate in the study. As a data

collection tool, we used a questionnaire form prepared by using the appropriate literature that is consistent with the aim of the study. Zarit Caregivers Burden Scale was used to assess the care burden of caregivers in the study. The Zarit Burden Interview is a self-report measure created by Zarit et al.²⁷ to assess caretaker psychological burden. The revised version contains 22 items, with the maximum score 88 corresponding to the highest level of felt burden. Each item is a statement which the caregiver is asked to endorse using a 5-point Likert scale ranging from 0=never to 4=nearly always (Zarit et al., 1980). The validity and reliability study of this scale in Turkey was carried out by Inci in 2006 (Inci et al., 2008). The data were evaluated using the Statistical Package for the Social Sciences (SPSS), Version 20.0. Mann-Whitney U test and Kruskal-Wallis test were used for analyzes. $P < 0.05$ was considered statistically significant.

Ethical Consideration:

Ethical approval for the study was taken with the number 80558721/7 from Eskisehir Osmangazi University, Faculty of Medicine, Clinical Research Ethics Committee.

Results

Of the caregivers, 109 (66.9%) were female and 54 (33.1%) were male. Their ages ranged from 23 to 87 years, with a mean of 52.2 ± 12.8 years. Eighty (49.1%) of the patients were female and 83 (50.9%) were male. Their ages ranged from 20 to 87 years, with a mean of 62.8 ± 13.35 years.

Discussion

The caregivers of dialysis patients face various challenges and complex problems due to emotional, economic, cognitive and social limitations due to chronic renal failure (Gulpak et al. 2014; Suri et al. 2011; Rutkowski & Rychlik 2011). As the responsibilities of caregivers increase, a one-way, addictive, intensive and long-term relationship occurs between the caregiver and patient (Tonga et al. 2008). In this case, the care burden of family members who provide care to patients or primary caregivers is increasing (Fan et al., 2008). In our study, caregiver scores of female caregivers were significantly higher than those of male caregivers. In the literature, it is generally stated that women are naturally held accountable by the society for home- and family-related works, and thus are considered suitable for their care giving (Kilic et al., 2017; Yuksel et al., 2007).

Table 1. Comparison of some socio-demographic characteristics and care burden scores of caregivers of hemodialysis patients

Some Socio-demographic Characteristics of Caregivers	n	Zarit Caregiver Burden Scale Median (Min-Max)	Test Value z/KW; p	Multiple Comparison
Age group				
≤49 (1)	69	34.0 (4.0-78.0)	2,281; 0,320	-
50-59 (2)	44	36.0 (12.0-79.0)		-
60≥ (3)	50	30.0 (0.0-82.0)		-
Gender				
Female	109	52.0 (4.0-81.0)	3.310; 0.001	-
Male	54	39.0 (0.0-82.0)		-
Educational status				
Middle school and under (1)	90	34.0 (0.0-82.0)	3.421; 0.181	-
High School (2)	61	37.0 (4.0-79.0)		-
University (3)	12	23.5 (2.0-57.0)		-
Marital status				
Married (1)	132	50.0 (0.0-82.0)	0.503; 0.778	-
Single (2)	14	52.5 (9.0-68.0)		-
Divorced - Dead spouses (3)	17	43.0 (15.0-74.0)		-
Number of children				
None (1)	29	30.0 (4.0-65.0)	9.082; 0.011	1-2; 1.000
1 to 2 children (2)	72	30.0 (0.0-78.0)		1-3; 0.060
3 and more (3)	62	41.0 (8.0-82.0)		2-3; 0.020
Working in an income-generating job				
Yes	27	39.0 (0.0-79.0)	3.248; 0.001	-
No	136	51.0 (4.0-82.0)		-
The degree of relationship				
Spouse	90	48.5 (0.0-82.0)	0.847; 0.655	-
Child	45	52.0 (4.0-79.0)		-
Other (mother, father, brother/sister etc.)	28	52.0 (15.0-78.0)		-
Place of residence				
Province	137	49.0 (0.0-82.0)	0.766; 0.444	-
County, town, village	26	54.0 (12.0-81.0)		-
Living with the patient				
Yes	147	50.0 (0.0-82.0)	0,430; 0,668	-
No	16	50.0 (4.0-75.0)		-
Type of Personality				
Type A	59	50.0 (4.0-82.0)	0.105; 0.916	-
Type B	104	50.0 (0.0-81.0)		-
Smoking				
Yes	56	53.0 (0.0-79.0)	1,152; 0,249	-
No	107	47.0 (4.0-82.0)		-
Alcohol consumption				
Yes	5	53.0 (12.0-71.0)	0,568; 0,570	-
No	158	50.0 (0.0-82.0)		-
Having a disease				
Yes	74	51.5 (4.0-82.0)	1,670; 0,095	-
No	89	48.0 (0.0-81.0)		-
Having a disability				
Yes	124	50.0 (0.0-81.0)	0.770; 0.441	-
No	39	50.0 (4.0-82.0)		-

Assessment of income statement				
Less than expense (1)	79	39.0 (7.0-82.0)	13.202; 0.001	1-2; 0.002
Equivalent to expense (2)	72	28.0 (0.0-78.0)		2-3; 1.000
More than expense (3)	12	25.0 (12.0-55.0)		3-1; 0.104
Difficulty in meeting the patient's health expenses				
Yes	64	53.0 (12.0-82.0)	2,248; 0,025	-
No	69	46.0 (0.0-81.0)		-
The duration of dialysis				
1-24 months	63	42.0 (0.0-82.0)	7,006; 0,030	1-2; 0.498
25-60 months	55	52.0 (4.0-78.0)		1-3; 0.025
61 months and longer	45	53.0 (12.0-81.0)		2-3; 0.594
Negative effects on role in the family and working environment due to care-giving				
Yes	75	54.0 (16.0-82.0)	3.490; 0.000	-
No	88	42.5 (0.0-81.0)		-

Table 2. Comparison of patients' ability to fulfill their daily living activities and care burden scores of caregivers

Daily activity	n	Zarit Caregiver Burden Scale Median (Min-Max)	Test Value z/KW; p	Multiple Comparison
Eating and drinking				
Dependent	50	59.5 (0.0-81.0)	2,637; 0,008	-
Independent	113	48.0 (4.0-81.0)		-
Bathing				
Dependent	80	58.0 (0.0-82.0)	3,770; 0,000	-
Independent	83	45.0 (4.0-81.0)		-
Dressing				
Dependent	68	58.0 (0.0-82.0)	3,036; 0,002	-
Independent	95	47.0 (4.0-81.0)		-
Urinating and defecating				
Dependent	104	59.0 (0.0-82.0)	3,532; 0,000	-
Independent	59	46.0 (4.0-81.0)		-
Walking				
Dependent	85	55.0 (0.0-82.0)	3,472; 0,001	-
Independent	78	43.0 (4.0-81.0)		-
Climbing stairs				
Dependent	90	55.0 (0.0-82.0)	3,221; 0,001	-
Independent	73	43.0 (4.0-81.0)		-
Shopping				
Dependent	102	53.5 80.0-81.0)	3,137; 0,002	-
Independent	61	42.0 (4.0-81.0)		-
Cooking				
Dependent	108	52.0 (0.0-82.0)	2,508; 0,012	-
Independent	55	45.0 (4.0-81.0)		-
Housekeeping				
Dependent	119	52.0 (0.0-82.0)	3,287; 0,001	-
Independent	44	38.5 (4.0-81.0)		-

Caregivers with 3 or more children were found to have a higher burden of care. Therefore, the increase in the responsibilities of caregivers is expected to lead to an increase in the burden of care.

The income status of caregivers can affect the burden of care. The burden of care for those who were being employed by an income-generating job and those with poor income were found to be significantly higher.

In addition, it was determined that caregivers who were unable to afford health care expenses have a higher median score of care burden than those who were able to afford. In order to fulfill their care responsibilities, caregivers can take a day off from paid jobs, may not work full-time or may have to leave their jobs (Gulpak et al., 2014). In a study by Montgomery et al., which examines the subjective and objective burden experiences of caregivers, it is stated that those who have low socioeconomic status have higher burden of care and an increase in health problems due to excessive care burden. Studies suggest that primary caregivers may be affected psychosocially and may experience adversities during caregiving in case of insufficient financial income (Montgomery et al., 1985).

The care burden of caregivers of patients on dialysis over 5 years was found significantly higher. With the prolongation of the care giving period, it is expected that the burden of care will increase due to the emotional, economic and social restrictions of the caregiver.

In our study, it was found that the care burden was found higher in those who stated that their role in the family and work is negatively affected because of caregiving.

In our study, it was determined that there is a higher care burden in caregivers of patients who are dependent on someone else while meeting their self-care needs such as eating and drinking, bathing, dressing, urination and defecation, walking, climbing stairs, shopping, cooking and housekeeping. The findings of the literature (Gulpak et al., 2014; Mollaoglu et al., 2011) support our research results.

Conclusions

This study has revealed a moderate care burden for the care providers of hemodialysis patients. In the context of holistic health conception, it is important to evaluate hemodialysis patients and

their relatives together, to inform caregivers about the problems they may encounter, and to develop strategies to cope with these problems. It will be helpful to provide social and economic support to determine the feelings, thoughts and needs experienced by caregivers of hemodialysis patients and to reduce the care burden of these individuals.

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