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# Comparison of care burden of hemodialysis and kidney transplant patients

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## Abstract

**Introduction:** End-stage renal disease (ESRD) is an important health problem in which chronic, inflammatory, degenerative and irreversible.

**Objectives:** The research was conducted to compare burden of caregivers of hemodialysis (HD) and kidney transplantation (KT) patients.

**Patients and Methods:** This descriptive study was conducted with HD, KT patients and their primary caregivers in a university hospital between July 2019 and June 2020. Power analysis was used to determine the sample size of the study, and a total of 71 HD and 71 KT patients and their caregivers (n=142) were included in the study sample at a confidence interval of 85%. The Zarit Burden Interview (ZBI) scale was used in data collection. The data were analysed by using the SPSS version 22.0 software.

**Results:** As a result of the study, it was determined that the mean caregiver burden score (30.59±13.25) of the caregivers of HD patients was higher than the mean caregiver burden score (22.20±13.95) of the KT patients, and the difference was statistically significant. The difference between socio-demographic characteristics of the caregivers of HD patients and the mean ZBI score was not statistically significant. A statistically significant difference was detected between the age and marital status and the mean ZBI scale scores of the caregivers of patients who underwent KT.

**Conclusion:** As a result of the study, it was found that the care burden of HD patients was higher than the care burden of KT patients. In order to provide holistic care, healthcare professionals need to address the care burden of HD patients.

**Keywords:** Caregiver; Care Burden; Kidney transplantation; Hemodialysis, Nursing

**Please cite this paper as:** Yıldız I, Kavurmacı M. Comparison of care burden of hemodialysis and kidney transplant patients. J Parathyroid Dis. 2022;10:e10151. doi:10.34172/jpd.2022.10151.

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## Introduction

End-stage renal disease (ESRD) is an important health problem in which chronic, inflammatory, degenerative and irreversible changes occur in the renal parenchyma due to various etiologies and the glomerular filtration rate (GFR) decreases below 5-10 mL/min (1).

End-stage renal disease affects approximately 1000 people per million in the world every year and this rate is expected to increase more than double in next 10 years. The prevalence of ESRD requiring renal replacement therapy (RRT) in the United States is 2196 per million population (2,3). Patients diagnosed with ESRD should receive various RRTs such as hemodialysis (HD), peritoneal dialysis (PD) and kidney transplantation (KT) in order to survive.

The most common treatment for ESRD is HD (4). In HD procedure, the blood drawn from the patient is cleaned from fluid and metabolic wastes by the HD machine and given back to the patient. Although HD treatment is a treatment that prolongs the life of patients, in patients who become dependent on the HD machine and hospital

at certain days and hours of the week, decrease in physical activities, loss in workforce and economic areas, decrease in social activities, inadequacies brought by treatment, loss of sexual function and the possibility of divorce, and many physical and psychosocial problems are seen (5-7).

Kidney transplantation is the most prevalent treatment for ESRD. In KT treatments, different from dialysis treatments, not some but all of kidney functions are fulfilled and patient's quality of life increases (8). However, many problems such as fear of rejection, side effects of immunosuppressive drugs, changes in social activity, difficulty in meeting their own care needs, and depression may occur in patients who undergo KT (9).

Caregivers of both HD and KT patients participate in the treatment process and experience these problems with their patients. The concept of caregiving is the process of providing care activities and undertaking its responsibilities (10). Caregivers have important roles and responsibilities at every point from diagnosis stage of the disease to discharge and maintenance of home caring. These important roles and responsibilities

Received: 13 August 2021, Accepted: 6 September 2022, ePublished: 8 October 2022

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### ■ Implication for health policy/practice/research/medical education

It was found that the care burden of hemodialysis (HD) patients was higher than that of kidney transplantation (KT) patients. In order to reduce the burden of caregivers of HD patients, it would be beneficial to create trainings and support systems according to their personal needs.

increase caregivers' burden. Many serious psychological and physiological problems can arise in caregivers whose care burdens increase and their life quality is deteriorated. These problems experienced by caregivers can negatively affect the adaptation of individuals receiving treatment to the disease and their caring activities (11,12). For this reason, it is extremely important that healthcare professionals first conduct research to determine the care burden of caregivers of patients who receive RRT, and then implement necessary interventions to reduce these burdens (13).

### Objectives

There is a general opinion in literature that the care burden of HD patients is higher than the patients who receive KT patients, the number of studies on this subject is quite limited (14-16). The research was conducted in order to compare burden of caregivers of HD and KT patients.

### Patients and Methods

#### Study design

The study population is composed of patients enrolled HD and KT Unit of the hospital between July 2019-June 2020 and primary caregivers. Power analysis was used to determine the sample size of the study, and total of 71 HD, 71 KT patients and a total of 142 caregivers were included in the study sample for an 85% confidence interval.

Patients and their caregivers who were 18 years of age and older and had at least primary school education were included in the study. The patients included in the study have been receiving RRT for at least 6 months, and their caregivers have been providing primary care for at least six months.

#### Measurements

A questionnaire form was used to determine the sociodemographic characteristics of patients and caregivers in the collection of research data, and the Zarit Burden Interview Scale (ZBI scale) was used to measure the burden of care.

#### Zarit Burden Interview Scale

The ZBI scale was developed by Zarit, Reever and Bach-Peterson in 1980 (17). It is a scale used to assess the distress experienced by caregivers of individuals in need of care. The scale consists of 22 items rated on Likert scale that ranges from 0 to 4 as "never", "rarely", "sometimes", "often" or "nearly always". The internal consistency reliability

coefficient of the scale was between 0.87 and 0.94, and test-retest reliability was 0.71. The lowest score in scale is 0 and the highest score is 88. Scores are considered as (0-20) lower/no burden, (21-40) moderate burden, (41-60) high burden and (61-88) extreme burden. The high scale score demonstrates the higher care burden (18,19). In this study, the Cronbach's alpha value for ZBI was found as 0.84.

#### Data collection

The research data were collected by the researcher by face-to-face interview method on the days and hours when the patients and their caregivers were convenient. Patients and caregivers were interviewed separately. Each interview lasted an average of 25-35 minutes.

#### Statistical analysis

Data analyses were performed by using SPSS version 22.0 packaged program. Descriptive statistical methods (percentage, arithmetic mean, standard deviation, min-max), Mann-Whitney U test, Kruskal-Wallis H, independent samples *t* test, one-way ANOVA test were conducted. *P* value below 0.05 was considered significance.

### Results

According to the results 45.1% of HD patients were 61 years and older, 50.7% were male, 77.5% were married. The education level of 54.9% of HD patients was literate/primary education. For 54.9% of them, time passes after treatment was 6-35 months. 49.3% of the KT patients were between the ages of 45-60, 64.8% male, 77.5% married and 42.3% housewives. The education level of 42.3% of KT patients was literate/primary education. For 66.2% of them, time passes after treatment was 6-35 months.

In both groups the distribution of the characteristics of the caregivers except gender, marital status and caregiving period was homogeneous (Table 1,  $P > 0.05$ ). 35.2% of the caregivers of HD patients were between the ages of 36-50, 52.1% were male, 71.8% were married, 36.6% were housewives, 40.8% were literate, 64.8% were partner (husband/wife) of the patients, %24.6 of them were found to have provided patient care for 13 months-5 years. According to the results 40.8% of the individuals who cared for the KT patients were between the ages of 36-50, 67.6% were women, 85.9% were married, 47.9% were housewives, 40.8% were literate, 67.6% were partner (husband/wife) of the patients. It was found that 25.4% had provided care for the patient for 6 years or more (Table 1).

When the mean care burden of HD and KT patients' caregivers were compared; it was determined that the caregiver burden score ( $30.59 \pm 13.25$ ) of the HD patients' caregivers was higher than caregiver burden score ( $22.20 \pm 13.95$ ) of the KT patients' caregivers and the difference was statistically significant ( $P = 0.000$ ) (Figure 1).

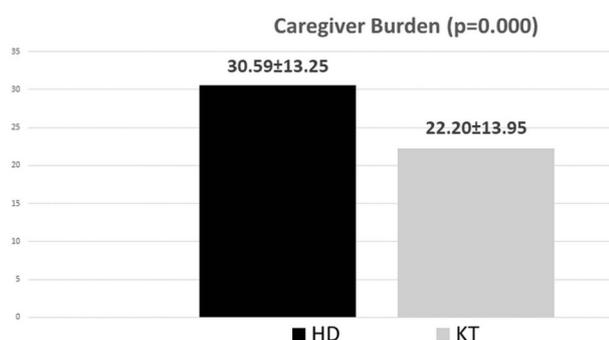
The difference between the socio-demographic

**Table 1.** Socio-demographic characteristics of caregivers

	HD (n=71)		KT(n=71)		P
	%	n	%	n	
Age (y)					
≤35	35.2	25	28.2	20	0.646
36-50	35.2	25	40.8	29	
≥51	29.6	21	31.0	22	
Gender					
Female	47.9	34	67.6	48	<b>0.017</b>
Male	52.1	37	32.4	23	
Marital status					
Married	71.8	51	85.9	61	<b>0.040</b>
Single	28.2	20	14.1	10	
Working status					
Unemployed	16.9	12	8.5	6	0.449
Officer / Worker	22.5	16	23.9	17	
Self-employment	12.7	9	8.5	6	
Retired	11.3	8	11.3	8	
Housewife	36.6	26	47.9	34	
Economical situation					
Good	83.1	59	78.9	56	0.521
Bad	16.9	12	21.1	15	
Education level					
Illiterate	1.4	1	8.5	6	0.262
Literate / Primary Education	40.8	29	40.8	29	
Literate / High School	31.0	22	25.4	18	
Undergraduate / Postgraduate	26.8	19	25.4	18	
Relation to the patient					
Partner	64.8	46	67.6	48	0.723
Family (bride/children)	35.2	25	32.4	23	
Patient care time					
6-12 months	8.5	12	10.6	15	<b>0.033</b>
13 months-5 years	24.6	35	14.1	20	
6 years and above	16.9	24	25.4	36	

characteristics of caregivers of HD patients and ZBI scale mean scores was not statistically significant (Table 2,  $P > 0.05$ ). No statistically significant difference was found between the socio-demographic characteristics of caregivers of patients who underwent KT other than age and marital status and the mean ZBI scale scores (Table 2,  $P > 0.05$ ).

It was determined that the mean ZBI scale scores of the caregivers of KT patients in the 36-50 age group were higher than the caregivers of other age groups, and the difference was statistically significant (Table 2;  $P < 0.05$ ).

**Figure 1.** Average care burden of caregivers of HD and KT patients.

The mean ZBI scale scores of the married caregivers of KT patients were higher than single caregivers and the difference was statistically significant (Table 2,  $P < 0.05$ ).

## Discussion

As a result of the study, it was determined that the mean ZBI scale scores of the caregivers of HD patients were higher than the caregivers of KT patients and the difference was statistically significant (Figure 1,  $P = 0.000$ ). Our findings are supported by other burden of care studies which compares different patient groups undergoing RRT. These studies stated that HD patients have the highest care burden, followed by PD and KT patients, respectively (14,20-24). Nagarathnam et al compared the care burden of HD, PD and KT patients and found that the care burden of HD patients was higher than that of KT patients (15). Avşar et al compared the care burden of HD patients and patients who underwent KT, they found that the care burden of HD patients was higher than that of KT patients (16).

As a result of the study, it was found that there is a statistically significant difference between the age and marital status of caregivers of KT patients and the mean ZBI scale scores. The mean care burden of married

**Table 2.** Comparison of ZBI Scores of Caregivers of Patients Receiving HD and KT Treatment

Descriptive characteristics	Caregiver Burden HD	Caregiver Burden KT
	Mean ± SD	Mean ± SD
<b>Age</b>		
35 years and under <sup>1</sup>	30.00±14.60	17.05±15.12
36-50 years old <sup>2</sup>	31.76±13.16	24.97±12.45
51 years and older <sup>3</sup>	29.90±12.16	23.23±14.07
	<b>KW:1.002</b>	<b>KW:6.257</b>
	<i>P</i> =0.606	<i>P</i> = <b>0.044</b>
	Post Hoc: <b>2&gt;1,3</b>	
<b>Gender</b>	Mean ± SS	Mean ± SS
Female	31.56±13.70	22.29±14.34
Male	29.70±12.94	22.00±13.41
	<b>t:0.587</b>	<b>MWU:547.000</b>
	<i>P</i> =0.559	<i>P</i> =0.951
<b>Marital status</b>	Mean ± SS	Mean ± SS
Married	31.04±12.10	24.11±13.78
Single	29.45±16.11	10.50±8.41
	<b>MWU:426.500</b>	<b>MWU:115.000</b>
	<i>P</i> =0.285	<i>P</i> = <b>0.002</b>
<b>Working status</b>	Mean ± SS	Mean ± SS
Unemployed	31.50±14.33	20.83±12.96
Officer / Worker	28.19±16.49	20.12±15.25
Self-employment	33.22±9.56	24.33±5.88
Retired	29.38±20.24	32.13±15.70
Housewife	31.12±9.31	20.76±13.69
	<b>KW:1.729</b>	<b>KW:5.003</b>
	<i>P</i> =0.785	<i>P</i> =0.287
<b>Economical situation</b>	Mean ± SS	Mean ± SS
Good	29.92±13.56	21.70±13.24
Bad	33.92±11.53	24.07±16.70
	<b>MWU:285.500</b>	<b>MWU:390.500</b>
	<i>P</i> =0.293	<i>P</i> =0.678
<b>Education level</b>	Mean ± SS	Mean ± SS
Illiterate	39.00±00	27.83±12.64
Literate / Primary Education	32.62±9.75	25.72±12.35
Literate / High School	27.55±13.21	19.06±14.96
Undergraduate/Postgraduate	30.58±17.58	17.78±14.69
	<b>KW:3.074</b>	<b>KW:7.824</b>
	<i>P</i> =0.380	<i>P</i> =0.050
<b>Relation to the patient</b>	Mean ± SS	Mean ± SS
Partner (husband/wife)	31.15±12.22	22.25±14.13
Family (bride / children)	29.56±15.18	22.09±13.86
	<b>MWU:512.000</b>	<b>MWU:548.000</b>
	<i>P</i> =0.448	<i>P</i> =0.961
<b>Patient care time</b>	Mean ± SS	Mean ± SS
6-12 months	34.17±18.20	22.67±18.26
13 months-5 years	30.94±11.10	21.20±13.24
6 years and above	28.29±13.47	22.56±12.64
	<b>KW:0.417</b>	<b>KW:0.298</b>
	<i>P</i> =0.812	<i>P</i> =0.861

MWU: Mann-Whitney U test, KW: Kruskal-Wallis, SD: standard deviation.

caregivers who aged 36-50 was higher than that of other caregivers (Table 2,  $P < 0.05$ ). When the studies conducted in the literature are examined, it is seen that as the age of the caregivers gets older, it becomes difficult to provide care and the care burden of married caregivers is higher than that of singles (15,21,25). Advanced age and being married increase the caregiver's burden of care as it decreases the physical competence of the caregiver and increases their roles/responsibilities.

## Conclusion

In the study comparing the care burden of caregivers of HD and KT patients; it was found that the care burden of HD patients was higher than the care burden of KT patients. Furthermore, it was determined that the age and marital status of the caregiver affected the burden of care. In line with these results; it may be suggested that increasing self-care levels of HD patients with higher care burden, supporting their decision-making about their care and participation in their care process, increasing the productivity of patients and performing trainings by healthcare professionals in order to provide them. At the same time, it is extremely important for healthcare professionals to organize trainings according to their personal needs and support them in order to reduce the burden of caregivers. It would be beneficial to support married and elderly caregivers, who are the group with more difficulty in providing care, by both healthcare professionals and other family members and social support systems.

## Limitations of the study

The present study had some limitations. It was conducted in a cross-sectional design and participants were selected only from HD units of the university hospital in eastern Turkey. Patients and caregivers in the clinic tended to have a lower socioeconomic status and education level than the total HD and KT population and therefore may not be fully representative of the general population.

## Acknowledgements

The authors would like to thank the HD and KT patients and caregivers for their contribution to the study.

## Authors' contribution

Data collection: MK and IY. Data analysis: MK, IY. Manuscript writing and revisions for important intellectual content: MK. Both authors participated in preparing the final draft of the manuscript, revised the manuscript and critically evaluated the intellectual contents. Both authors have read and approved the content of the manuscript and confirmed the accuracy or integrity of any part of the work.

## Conflicts of interest

The authors declare that they have no conflicts of interest.

## Ethical issues

The research followed the tenets of the Declaration of Helsinki. The

Ethics Committee of Atatürk University Faculty of Nursing approved this study. The institutional ethical committee at Atatürk University Faculty of Nursing approved all study protocols (2019-4/7). Accordingly, written informed consent taken from all participants before any intervention. This study was extracted from MSc thesis of Idris Yildiz at this university (Thesis #632610).

#### Funding/Support

No financing from any source.

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