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The other side of the coin in renal replacement therapies: the burden on caregivers

Simge Bardak[1] · Serap Demir[1] · Eda Aslan[2] · Kenan Turgutalp[1] · Havva Didem Celikcan[3] · Murside Esra Dolarslan[1] · Cennet Kılıcarslan[1] · Filiz Karasu[4] · Ayse Jini Gunes[4] · Cemal Kurt[4] · Ahmet Kıykım[1]

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Abstract

Purpose Living with end-stage renal disease may be burdensome, not only for patients, but also for caregivers. In this study, we aim to compare caregiver burden, psychological symptoms in caregivers of peritoneal dialysis (PD), hemodialysis (HD), and transplantation (TX), and find out associated factors.

Methods A total of 43 PD, 42 HD, 42 TX patients and a total of 127 caregivers that were actively involved with the care of their patients' dialysis were enrolled. Patients had been on renal replacement therapy at least for 6 months and caregivers had given care at least for 6 months. The World Health Organization Quality of Life short version and hospital anxiety and depression scale (HAD) were applied to the patients. Symptom Checklist-90-Revised and Zarit caregiver burden scale were applied to the caregivers.

Results Zarit caregiver burden score was found highest in HD group, which was significantly higher than PD and TX. All three groups had similar HAD anxiety scores, whereas the HAD depression score was highest in HD group, lower in PD, and lowest in TX. Quality of life was lowest in HD group. Zarit caregiver burden score was found higher in caregivers with symptoms like somatization, anxiety, obsessive–compulsive, depression, interpersonal sensitivity, psychoticism, paranoid ideation, hostility, and additional psychological symptoms than the ones who did not have these symptoms. Psychological symptoms were similar in PD, HD, and TX groups.

Conclusion Caregiver burden was found highest in HD group. Educational, social, and psychological support interventions may be considered for caregivers.

Keywords Caregivers · Caregiver burden · Psychological symptoms · Renal replacement therapy

Background

Living with end-stage renal disease (ESRD) and having dialysis may be burdensome, not only for ESRD patients, but also for caregivers [1, 2]. Although renal transplantation (TX) is a great opportunity for ESRD patients due to excellent quality of life and greater survival, most of the ESRD patients may not have this opportunity and need dialysis for the rest of their lives [3]. Patients with ESRD may require caregiving, assistance for hospital visitation, and supervised administration. Thus, caregivers may be affected physically, emotionally, and socially [1, 4].

All physical and psychosocial challenges faced by ESRD patients need to be managed also by caregivers [3]. Although initially caregivers may be enthusiastic, as time passes fatigue and exhaustion may progress causing serious social and psychological problems [5]. Physical, psychological, social, and financial problems faced during care may cause caregiver burden [6], and may decrease caregivers' quality of life [7]. Caregiver burden may adversely impact health care provided to the patients [8, 9].

✉ Simge Bardak
bardaksimge@gmail.com

[1] Department of Internal Medicine, Division of Nephrology, School of Medicine, Mersin University, Ciftlikkoy, Yenisehir, Mersin, Turkey

[2] Department of Psychiatry, School of Medicine, Mersin University, Mersin, Turkey

[3] Department of Biostatistics and Medical Informatics, Mersin University, Mersin, Turkey

[4] Department of Internal Medicine, Division of Nephrology, Mersin State Hospital, Mersin, Turkey

In clinical practice, patients are used to be the main focus, whereas caregivers often receive little attention [6]. Although the aim of renal replacement therapies (RRT) is to prolong and improve patient's life [6], caregiver's life should also be considered. Renal replacement therapies may cause reduction of living standards of caregivers, and thus physical and psychological problems may arise. We aim to compare caregiver burden and psychological symptoms in caregivers of peritoneal dialysis (PD) with hemodialysis (HD) and TX, and find out associated factors.

Patients and methods

Cross-sectional study design was approved by local Human Research Ethics Committee (date: 28/04/2016, number: 2016/136). Patients on RRT and their caregivers who admitted to the Mersin University Hospital and Mersin State Hospital between April 2016 and June 2016 were enrolled to the study. Informed consent was taken from each participant. Patients and their caregivers, aged above 18 years, were grouped according to their RRT options. The HD patients underwent dialysis regularly three times a week. Caregiver was defined as person who has the greatest involvement in patient care and assistance during the course of the disease [4]. Patients who had been on RRT at least for 6 months and caregivers who had given care at least for 6 months were enrolled. Presence of comorbid diseases like diabetes, hypertension, cardiovascular disease, chronic obstructive pulmonary disease, cirrhosis, neoplastic diseases, and dementia were investigated. Patients who had diagnosis of dementia, and patients with more than 2 comorbidities (other than ESRD) were excluded.

A total of 43 PD (29 continuous ambulatory peritoneal dialysis [CAPD], 14 automated peritoneal dialysis [APD]), 42 HD, 42 TX patients and a total of 127 caregivers that were actively involved with the care of their patients' dialysis were enrolled. Medical and sociodemographic features of patients and caregivers were recorded.

Quality of Life (QoL) of patients were assessed by the World Health Organization Quality of Life short version (WHOQOL-BREF) which consists a total of 27 questions related with different domains like physical health [phy], psychological [psy], social relationships [s], environment [e], total [t]. The hospital anxiety and depression scale (HAD) which consists of 2 parts (anxiety subscale and depressive symptoms subscale, a total of 14 questions) was applied to the patients. Symptom Checklist-90-Revised (SCL-90) (90 questions) and Zarit caregiver burden scale (22 questions) were administered to the caregivers. All of the questionnaires were applied to subjects face to face by 2 nurses (CK, FK). Reliability and validity of The Turkish version of WHOQOL-BREF, HAD, SCL-90, Zarit caregiver burden scale were introduced previously [10–13].

Statistical analysis

The distribution of variables was assessed by the Shapiro–Wilk and Kolmogorov–Smirnov tests. Spearman correlation coefficient was used to assess correlation between the HAD score and life quality. Spearman correlation coefficient was also used to investigate the correlation between HAD score and Zarit caregiver burden scale score. Mann–Whitney U test was used for 2 groups comparisons which were not normally distributed. Median values (25–75%) and minimum–maximum values were given as summary statistics. Independent samples t test was used for parametric 2 groups comparisons. Normally distributed data were expressed as mean ± standard deviation. Chi-square test was used for categorical variables of psychological symptoms, and Chi-square test of homogeneity was performed to compare different groups. Frequency and percentage values were used in descriptive statistics of the categorical data. Analysis of variance (ANOVA) method and Kruskal–Wallis test were used for statistical analysis of more than two groups comparisons. Conover Test was performed to find out which group makes the difference among Zarit caregiver burden scores. Bonferroni post hoc test was performed for pairwise multiple comparisons to determine which means differ between groups. p value lower than 0.05 was considered as statistically significant.

Results

Demographic features of patient groups and caregivers are summarized in Tables 1 and 2, respectively.

Zarit caregiver burden scores of 3 groups and factors affecting Zarit caregiver burden

There was statistical significance between three groups ($p = 0.009$). Zarit caregiver burden score was found highest in HD group, and it was significantly higher than PD and TX groups (Fig. 1). Gender, age, occupation, marital status, education level of caregivers and patients were not associated with Zarit caregiver burden score ($p > 0.05$). Zarit caregiver burden score was also not associated whether caregiver takes all responsibility alone or not ($p > 0.05$). Duration of hemodialysis affected the Zarit caregiver burden ($p = 0.328$).

HAD of patient groups

All three groups has similar HAD anxiety scores ($p > 0.05$). There was significant difference between HAD depression

Table 1 Demographic features of patient groups

	TX (*n*:42)	HD (*n*:42)	PD (*n*:43)	Difference (*p* value)
Sex, female/male (*n*)	18/24	17/25	21/22	> 0.05
Age (years)	41.74 ± 15.65	55.14 ± 18.30	52.12 ± 17.00	0.001*
Married/single (*n*)	29/13	26/16	33/10	> 0.05
Educational level (*n*)				> 0.05
Illiterate	8	13	7	
Primary school	19	17	25	
Secondary school	10	10	9	
University	5	2	2	
Hospitalized (*n*)	4	3	2	> 0.05
Psychiatric drug use (*n*)	3	5	8	> 0.05
Diabetes (*n*)	10	13	11	> 0.05

TX transplantation, *HD* hemodialysis, *PD* peritoneal dialysis

*TX group was significantly younger than PD and HD groups ($p < 0.05$)

Table 2 Demographic features of caregiver groups

	TX (*n*:42)	HD (*n*:42)	PD (*n*:43)	Difference (*p* value)
Sex, female/male (*n*)	19/23	33/9	29/14	0.005
Age (years)	42.02 ± 13.74	43.62 ± 15.91	44.70 ± 12.70	> 0.05
Married/single (*n*)	32/10	33/9	33/10	> 0.05
Educational level (*n*)				
Illiterate	4	9	7	> 0.05
Primary school	22	19	15	
Secondary school	8	9	14	
University	8	5	7	
Occupation (*n*)				
Unemployed	18	29	25	> 0.05
Self-employment	16	9	10	
Officer	2	2	3	
Student	6	2	5	
Relationship to the patient (*n*)				
1. Degree	41	41	42	> 0.05
2. Degree	1	0	1	
Non-relative	0	1	0	
Living in the same house (*n*)	36	35	40	> 0.05
Taking all care alone (*n*)	27	29	32	> 0.05
Financial support (*n*)	11	26	16	0.003

TX transplantation, *HD* hemodialysis, *PD* peritoneal dialysis

scores of three groups ($p = 0.010$). The HAD depression score was highest in HD group, lower in PD, and lowest in TX (Fig. 2). There was weak positive association between HAD and Zarit caregiver burden score ($p < 0.5$, $r < 0.5$).

WHOQOL of patient groups

Hemodialysis group had significantly lower score for WHOQOL-phy than PD and TX ($p < 0.05$). Scores of WHOQOL-psy were similar between 3 groups ($p > 0.05$). Scores for WHOQOL-s of TX were significantly higher than PD and TX ($p < 0.05$), whereas WHOQOL-e scores were highest in TX, lower in PD, and lowest in HD group ($p = 0.011$). According to post hoc (Tukey) analysis, the difference between WHOQOL-e scores was related to the difference between TX and HD group ($p < 0.05$). WHOQOL-t scores were higher in TX, lower in PD, and lowest in HD group ($p < 0.001$). The difference was related to the

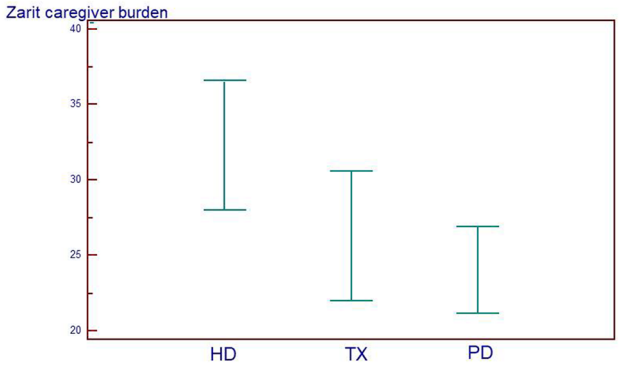

Fig. 1 Zarit caregiver burden of hemodialysis, renal transplantation, and peritoneal dialysis groups. *HD* hemodialysis, *TX* transplantation, *PD* peritoneal dialysis

difference of HD group than the other two groups ($p < 0.001$, $p = 0.028$, respectively) (Fig. 2).

Interpretation of SCL-90 test results

The results of SCL-90 test are shown in Table 3. Caregivers who had somatization and depressive symptoms were mostly females (74.6%, 75%, respectively). A total of 50.8% of caregivers who had somatic symptoms, 56.7% of caregivers who had depressive symptoms, and 50.9% of caregivers who had interpersonal sensitivity were graduated from primary school. A total of 68.3% of caregivers with depressive symptoms, 68.4% of caregivers who had interpersonal sensitivity, 84.2% of caregivers with psychoticism symptoms, and 66.7% of caregivers with paranoid ideation were unemployed. Phobic anxiety symptoms of caregivers were associated with longer caregiving hours ($p = 0.039$). Caregivers with somatization symptoms had lower salary than the ones who did not ($p = 0.047$).

Zarit caregiver burden score was found higher in caregivers with symptoms like somatization, anxiety, obsessive–compulsive, depression, interpersonal sensitivity, psychoticism, paranoid ideation, hostility, and additional psychological symptoms than the ones who did not have these symptoms ($p < 0.05$ for all).

Caregivers of patients who had higher HAD anxiety score had more anxiety symptoms ($p = 0.034$). Caregivers with somatization, anxiety, hostility, and additional psychological symptoms were found associated with lower WHOQOL-psy of patients ($p = 0.011$, 0.041, 0.006, 0.013, respectively).

Discussion

End-stage renal disease and RRT methods may have various effects on the physiological, psychological, functional ability, social, financial, and independence status of caregivers [3, 6, 14]. Important lifestyle changes would be inevitable in caregivers' lives. Caregivers may have less time for self care and need to reschedule their time for working, resting, and social life [15]. The challenges and responsibilities may lead caregivers to feel tired, isolated, and overwhelmed [16], and the stress factor for caregiver may lead to an increased prevalence of psychological symptoms like anxiety and depression [9, 14, 17]. In our study, among RRT methods, HD group had highest Zarit caregiver burden in comparison to PD and TX groups, whereas psychological symptoms were found similar in all groups.

Dialysis may negatively affect the psychological state of ESRD patients [18]. Among RRT options, PD, a home-based RRT, gives ESRD patients a greater independence, and flexibility with fewer hospital visits. Peritoneal dialysis may be time saving as travel time to hospital is eliminated, and risk of cross infections may also be reduced [19]. Peritoneal dialysis may have some other advantages like no

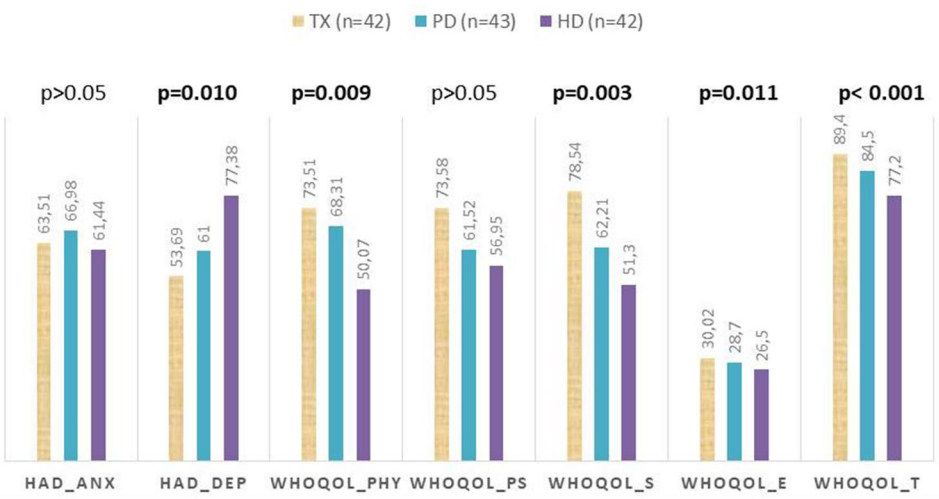

Fig. 2 Hospital anxiety and depression scores (HAD) and quality of life (WHOQOL) of transplantation, peritoneal dialysis, and hemodialysis groups (Mean values). *TX* transplantation, *PD* peritoneal dialysis, *HD* hemodialysis, *HAD_ANX* hospital anxiety and depression scale-anxiety score, *HAD_DEP* hospital anxiety and depression scale-depression score, *WHOQOL* The World Health Organization Quality of Life, *WHOQOL_PHY* physical health, *WHOQOL_PS* psychological, *WHOQOL_S* social relationships, *WHOQOL_E* environment, *WHOQOL_T* total

Table 3 Association of SCL-90 test results of caregivers

	Somatization	Anxiety	Obsessive–compulsive	Depression	Interpersonal sensitivity	Psychoticism	Paranoid ideation	Hostility	Phobic anxiety	Additional
Age (CG)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Gender (CG)	$p=0.030$	NS	NS	$p=0.021$	NS	NS	NS	NS	NS	NS
Marital status (CG)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Education (CG)	$p=0.035$	NS	NS	$p=0.042$	$p=0.034$	NS	NS	NS	NS	NS
Occupation (CG)	NS	NS	NS	$p=0.046$	$p=0.042$	$p=0.014$	$p=0.017$	NS	NS	NS
Relationship to the patient (CG)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Living in the same house (CG)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Taking all care alone (CG)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Duration of care (CG)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Caregiving days/week	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Caregiving h/day	NS	NS	NS	NS	NS	NS	NS	NS	$p=0.039$	NS
Salary (CG)	$p=0.047$	NS	NS	NS	NS	NS	NS	NS	NS	NS
Age (P)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Gender (P)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Marital status (P)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Present RRT	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Occupation (P)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Duration of RRT	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Number of hospitalization	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Zarit CG burden	$p<0.01$	$p<0.001$	$p=0.001$	$p<0.001$	$p=0.016$	$p<0.001$	$p=0.006$	$p<0.001$	NS	$p=0.001$
HAD_anxiety (P)	NS	$p=0.034$	NS	NS	NS	NS	NS	NS	NS	NS
HAD_depression (P)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
WHOQOL_phy (P)	NS	$p=0.023$	NS	NS	NS	NS	NS	NS	NS	NS
WHOQOL_psy (P)	$p=0.011$	$p=0.041$	NS	NS	NS	NS	NS	$p=0.006$	NS	$p=0.013$
WHOQOL_s (P)	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS

CG caregiver, *P* patient, *RRT* renal replacement therapy, *HAD_anxiety* hospital anxiety and depression scale-anxiety score, *HAD_depression* hospital anxiety and depression scale-depression score, *WHOQOL* The World Health Organization Quality of Life, *WHOQOL_phy* physical health, *WHOQOL_ps* psychological, *WHOQOL_s* social relationships, *NS* non-significant

need for a vascular access, less limitation in diet, and well preservation of residual renal function in comparison to HD [20]. It is presumed to improve quality of life in ESRD patients [7]. This study demonstrated that PD patients were less depressed than HD patients, whereas the anxiety scores were similar. Besides, life quality of PD patients was found higher than HD patients as reported previously [21]. On the contrary, some previous trials reported similar life quality in HD and PD patients [22–24]. Peritoneal dialysis may be a pretty good option for patients who do not have opportunity of renal TX. However, the question then arises: Is PD a good option for caregivers too?

Factors like aging or increased number of comorbidities of patients may increase role of caregivers in the treatment of PD patients [19]. Daily exchanges of CAPD or to connect onto, disconnect from with an APD machine may needed to be managed by caregivers. Fluid management, adjustment of dialysis, adaptation of homes for the supplies required for PD, attention to stock-take of supplies, arranging and receiving deliveries, and disposing of waste drain-out bags may be challenges in a caregiver life [19]. Although it is hard to classify the degree of involvement of PD caregivers in the administration of procedure, this may result in the burden feeling in caregivers. Our study indicated that caregiver burden of HD is higher than the PD and TX. These results supported Avsar et al. who reported higher caregiver burden scores in HD group in comparison to renal TX [3], and Cantekin et al. who reported higher burden of HD in comparison to PD [18]. Avsar et al. investigated overall burden between caregivers of CAPD and renal TX patients in another study, and they concluded that caregiver burden scores were significantly higher in caregivers of CAPD patients compared with TX patients [25]. Although sociodemographic characteristics were compared, comorbidities were not mentioned in this study. This might be a confounding factor. In the presence of high number of comorbidities, higher caregiver burden may be attributed to the presence of comorbidities rather than RRT option. However in our study, we exclude patients with more than 2 comorbidities. Unlike previous studies, we compared all three RRT groups in the same study, and we did not compare only caregiver burden, but also we investigated psychological symptoms of caregivers.

Factors affecting Zarit caregiver burden were investigated previously. A study performed in HD patients documented that caregivers of male patients and patients with inadequate income had a higher caregiver burden score [6]. Duration of the disease, longer duration of dialysis, more of hours of care per day, and frequent hospitalizations of the patients were found negatively correlated with Zarit caregiver burden [6, 15, 26]. In our study, longer duration of HD was the only factor that was found positively associated with Zarit caregiver burden. Also, there was weak positive association between HAD and Zarit caregiver burden score. Traveling to the center, spending 4 h for each session, diet and fluid restrictions, hemodialysis-related complications like hypotension may possibly contribute to higher caregiver burden of HD.

Zarit caregiver burden score was found higher in caregivers with symptoms like somatization, anxiety, obsessive–compulsive, depression, interpersonal sensitivity, psychoticism, paranoid ideation, hostility, and additional psychological symptoms than the ones who did not have these symptoms in this study. Paschou A et al. investigated the association of burden and depression in spouses of patients with chronic kidney disease. They found that depression was correlated with caregiver burden ($p \leq 0.001$), and increased level of caregiver burden was related to increased level of depression and anxiety. However, they discussed that although depression was studied as an outcome of caregiver burden, it might have preexisted and might have affected the outcomes [1]. It may be either a risk factor for caregiver burden or an outcome of caregiver burden, and it is really hard to discriminate. Psychological symptoms were found similar in PD, HD, and TX groups in our study. In a previous study, higher risk for anxiety, depression was found with caregivers of PD patients than TX patients [25]. Caregivers of patients who had higher HAD anxiety score had more anxiety symptoms. Lower WHOQOL-psy of patients may lead to some psychological symptoms in caregivers like somatization, anxiety, hostility, and additional psychological symptoms.

Clinicians should be aware of the problems experienced by caregivers. Caregivers should be encouraged to improve their skills to adapt to changing situations, which may enhance the quality of the care. Educational, social, and psychological support interventions should be considered for caregivers [27]. Occupation, shortening caregiving hours, and financial support may be considered. Female caregivers and caregivers who were graduated from primary school may need to be supported more. Psychosocial support from caregiver may indirectly affect and improve patient's life [3, 4, 6, 17].

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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