

Original Article

A Bicommunal Study: Burden of Caregivers of Hemodialysis Patients

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Abstract

Aim: This study was conducted to evaluate the burden of caregivers who provided care to hemodialysis patients in two different communities.

Materials and Methods: It was designed as a descriptive study and included family caregivers of 210 patients who received hemodialysis therapy. The study data were collected using the Information Form and Zarit Caregiver Burden Scale.

Results: The mean caregiver burden scale score was higher in caregivers living in the Northern Cyprus ($X=45.77$), compared to those living in Turkey ($X=31.62$). The combined effect of treatment center and age, sex marital status and educational status of the caregiver on the burden scale score of the caregiver was not statistically significant, whereas the relation of the caregiver to the patient significantly affected the caregiver burden scale score of the caregiver ($F_{(2-203)} = 4.96, p < 0.008$).

Conclusions: Supportive programs should be developed considering the cultural characteristics of the community to reduce the burden of the caregivers.

Keywords: Caregivers, culture, hemodialysis

Introduction

Dialysis therapy has been one of the most important advancements in medicine in recent years. Hemodialysis is the most commonly employed renal replacement therapy in patients with chronic renal failure (CRF) (Zhang et al., 2016). Health care professionals in HD centers are responsible for the care of the patient; however, this responsibility must be borne by the patient's family members at home (Ghane et al., 2016). Family members are those who provide the most intensive support to the patients and who suffer the most from the burden of this care (Purlusoy et al., 2011). Chronic illness of one of the family members concerns the whole family due to its economic and psychosocial consequences, and affects their lifestyles (Ghane et al., 2015, Ghane et al., 2016).

Caring an individual with a chronic disease may cause an additional stress for the family

members, who also make efforts to struggle against difficult situations imposed by the chronic illness. Loss of independence and perception of being a burden for the family is an additional source of stress for the patient, and this ideation decreases the quality of life and causes feeling of guilt (Rutkowski & Rychlik 2011).

The majority of HD patients experience difficulties in performing their personal tasks (Ghane et al., 2016). The patients often rely on their own unpaid caregivers to receive support in daily activities and medical needs (Suri et al., 2011). Therefore, caregivers have multiple responsibilities while providing care to HD patients (Alnazly & Samara 2014). The caregivers provide support in daily activities of the patient such as transport of the patient to the dialysis center, drug management, symptom management, making appointments for visits, ambulation, dressing, and preparation of renal diet (Suri et al., 2011). Providing care to HD

patients is considerably stressful process, and this affects physical and psychological well-being of the caregiver, thereby, resulting in physical and mental diseases (Mollaoglu, Kayataş & Yurugen 2013). The studies suggest that primary caregiving negatively affects quality of life of the caregiver, impairs family and work organization, decreases participation in social activities, and causes emotional stress (Ghane et al., 2015, Mashayekhi, Pilevarzadeh & Rafati 2015).

The caregivers do not spare sufficient time for their own needs while providing care to the HD patient. They devote most of their time to making appointments for physician visits, transport to dialysis center, and accompanying patient during dialysis, and preparing renal diet. The caregivers allocate less time to their own needs due to these routine tasks.

The study by Alnazly and Samara (2014) reports that caregivers experience social isolation, take little time to participate in social activities and go around with their friends, and their self-care is affected by caregiving a patient, and they experience physiological problems such as fatigue and insomnia.

The burden of caregivers directly affects the quality of care they provide to the patients. Their duty in coordinating and managing care may turn out to be a burden, if the psychosocial health of the caregivers is not maintained (Alnazly & Samara 2014). The caregivers of HD patients must be evaluated for their coping strategies, interpersonal relationships, and social support (Bayoumi, 2014).

There is currently no program or intervention set in place to reduce the burden of caregivers of dialysis patients. Thus, caregivers of dialysis patients are mostly neglected. Cultural differences and social values play an important role in defining the burden. Age, ethnic origin, education status, economic status, beliefs, cultural characteristics of the community are personal factors related to the perception of the burden by the caregiver (Atagun et al., 2011). It is therefore of primary importance to evaluate the relationship between cultural characteristics of the caregiver and burden of care.

Defining the difficulties experienced by the caregiver would increase the quality of patient care. This would also increase the health status and quality of life of all family members. To

achieve this goal, difficulties and burden experienced by the caregivers related to patient care must be determined in the first place. In addition, it is suggested that preparation of training programs aiming to increase the caregivers' strength would guide caregivers in solving problems they encounter in the clinic and establish strategies towards increasing the quality of life patients as well as caregivers. Therefore, in the present study, we aimed to evaluate the burden of caregivers who provided care to HD patients in two different communities.

Methodology

Sample and Setting

This study included family caregivers of 210 patients who received HD therapy in Hemodialysis Unit of a state hospital located in the Northern Cyprus (n=115) and a private dialysis center (n=95) in Istanbul/Turkey between April 2016 and June 2016.

Institutional Information

There are 25 dialysis machines at HD center of Dr. Burhan Nalbantoglu State Hospital and this unit works in three shift turnovers a day for six days a week. Nurses and dialysis technicians work in these units. There are no private dialysis centers in the Northern Cyprus, but this service is delivered to the patients only through the state hospitals. There are no transport services for the transfer of the patients from and to the dialysis unit. Family members carry out the transfer of patients to the dialysis units. Patients living in remote locations use public transportation services to reach dialysis units.

There are 30 dialysis machines at Private Dialysis Center in Istanbul and this unit works in three shift turnovers a days for six days a week. Nurses and dialysis technicians work in these units.

There is also a nurse instructor who provides continuous on-the-job training to the nurses and dialysis technicians. In this center, transfer of the patients to the dialysis unit is carried out by the center. There are 55,890 patients receiving HD in Turkey (Seyahi, Ateş & Suleymanlar). As there is a vast number of patients receiving HD therapy in Turkey, social security institution purchase services from both public and private dialysis centers. Of HD patients, 63.2% receive services from private dialysis centers (Dikmen, 2016).

All treatments costs of HD patients are borne by the social security institution. The subjects who consented to participate in the study and who met the inclusion criteria (i.e., the patient receiving HD at least for 6 months, caregiver age 18 years and over, having provided care to the patient for at least four months, being able to communicate) were included in the study.

Data Collection Tools

The Personal Information Form prepared by the author in accordance with the literature data (Purlusoy et al., 2011, Alnazly & Samara 2014, Mollaoglu et al., 2013, Zarit , Reever & Back-Peterson 1980) and Zarit Caregiver Burden Scale were used as the data collection tools of the study.

Zarit Caregiver Burden Scale: The Zarit Caregiver Burden Scale was used to evaluate the burden of the caregivers. The scale comprises Likert-type 22 items each responded as “never”, “rarely”, “sometimes”, “frequently”, and “always” and rated from “0” to “4” points. The lowest score of the scale is 0 points and the highest score is 88 points.

The items of the scale are generally related to social and emotional domains, and higher scores indicate the intensity of the difficulty experienced by the caregiver. In this scale, 0-20 points indicate “no burden”, 21-40 points indicate “mild burden”, 41-60 points indicate moderate burden, and 61-88 points indicate severe burden (Zarit , Reever & Back-Peterson 1980). The validity and reliability of the scale has been evaluated by Inci and Erdem, and Cronbach’s alpha value was found to be 0.95 (İnci & Erdem 2018).

Data Analysis

Statistical analysis was performed using SPSS version 22.0 (SPSS Inc., Chicago, IL, USA) in consultation with a statistics specialist. The Kolmogorov-Smirnov test was used to analyze the normally distribution of the data. Socio-demographic features of the study group and distribution of the qualifications were expressed in frequency and percentage. Independent group t-test was used to test the relationship between a continuous variable with normal distribution and a continuous variable having two categories.

Two-factor analysis of variance (ANOVA) was used to evaluate normally distributed at least one

continuous variable and simultaneously test joint effect on this variable. The Tukey least significant difference (LSD) method was used to analyze between which variables and between which groups related to these variables significant differences occurred when two-factor ANOVA showed a significant difference.

Ethical Aspects of the Study

The study subjects provided a written consent for participation in the study. In addition, EMU Scientific Research and Publication Ethics Committee issued an approval for the study (Decision no: 2016/23-14) after obtaining approval of the relevant agencies for the conduction of the study.

Results

As shown in Table 1 a total of 210 caregivers were included in the study. Of these caregivers, 45.2% were living in Turkey and 54.8% were living in the Northern Cyprus.

Of caregivers living in the Northern Cyprus, 59.5% were aged 29 years and under, 55.2% were females, 50.3% were married, 27.3% were primary school graduate, and 47.1% were the spouse of the patient. Of the caregivers, 98.1% requested transport service to reduce burden (Table 2). Of caregivers living in Turkey, 40.5% were aged 29 years and under, 44.8% were females, 49.7% were married, 72.7% were primary school graduate, and 52.9% were the spouse of the patient. Of the caregivers, 1.9% requested transport service to reduce burden while 65% did not (Table 2).

As shown in Table 3, caregiver burden scale scores of the caregivers showed a significant difference according to the treatment center ($t_{208} = -8.22, p < 0.000$). Caregiver burden scale score of the caregivers in Northern Cyprus ($X = 45.77$) were higher than the scores of the caregivers in Turkey ($X = 31.62$). The combined effect of treatment center and age ($F = 1.84, p = 0.122$), sex ($F = 3.58, p = 0.060$), marital status ($F = 0.603, p = 0.438$), and educational status ($F = 0.516, p = 0.724$) of the caregiver on the burden scale score of the caregiver was not statistically significant, whereas the relation of the caregiver to the patient significantly affected the caregiver burden scale score of the caregiver ($F_{(2-203)} = 4.96, p < 0.008$) (Table 5).

Table 1: Data of the Institutions in Which the Patients Received Hemodialysis (N = 210).

Institution	n	%
Turkey	95	45.2
TRNC	115	54.8
Total	210	100.0

Table 2: Sociodemographic Data of Caregivers of Patients Receiving Hemodialysis (N = 210).

Sociodemographic Variables	Turkey		TRNC		General Distribution	
	n	%	n	%	n	%
Age of the Caregiver						
29 Years and Below	17	40.5	25	59.5	42	20.0
30-39	22	40.7	32	59.3	54	25.7
40-49	17	44.7	21	55.3	38	18.1
50-59	19	57.6	14	42.4	33	15.7
60 Years and Above	20	46.5	23	53.5	43	20.5
Sex						
Female	65	44.8	80	55.2	145	69.0
Male	30	46.2	35	53.8	65	31.0
Marital Status						
Married	76	49.7	77	50.3	153	72.9
Single	19	33.3	38	66.7	57	27.1
Educational Status						
Literate	18	45.0	22	55.0	40	19.0
Primary School	40	72.7	15	27.3	55	26.2
Secondary School	12	44.4	15	55.6	27	12.9
High-School	14	28.0	36	72.0	50	23.8
University or higher education	11	28.9	27	71.1	38	18.1
Relation to the Patient						
Spouse	46	52.9	41	47.1	87	41.4
Child	38	44.7	47	55.3	85	40.5
Other (My grandmother/grandfather, my sibling)	11	31.4	27	23.4	38	18.1
Suggestion to Reduce Burden						
Service	1	1.9	51	98.1	52	24.8
Caregiver	6	37.5	10	62.5	16	7.6
Service + Caregiver	--	--	7	100.0	7	3.3
No suggestion	87	65.2	48	34.8	135	64.3
Total					210	100

Table 3: Caregiver Burden Scale scores according to the treatment center results of independent group t-test

Institution	N(%)	M ± SD	sd	t	p
Turkey	95(45.2)	31.62 ± 11.38	208	-8.22	p<.001
TRNC	115(54.8)	45.77 ± 13.19			

Table 4: Distribution of Caregiver Burden Scale Scores According to Treatment Center and Characteristics of the Caregiver (N=210)

Variables	Turkey		TRNC			Total M ± SD	F*	p
	n(%)	M ± SD	n(%)	M ± SD	n(%)			
Age								
29 Years and Below	17(40.5)	26.8 ± 14.3	25(59.5)	45.7 ± 11.5	42(20.0)	38.1 ± 15.6		
30-39 Years	22(40.7)	32.4 ± 9.6	32(59.3)	44.1 ± 8.7	54(25.7)	39.3 ± 10.7		
40-49 Years	17(44.7)	31.2 ± 11.1	21(55.3)	51.9 ± 13.0	38(18.1)	42.7 ± 15.9		
50-59 Years	19(57.6)	33.1 ± 9.8	14(42.4)	47.2 ± 14.8	33(15.7)	39.1 ± 13.9	1.84	.122
60 Years and Above	20(46.5)	33.6 ± 11.9	23(53.5)	41.5 ± 17.4	43(20.5)	37.8 ± 15.4		
Sex								
Female	65(44.8)	32.0 ± 12.4	80(55.2)	44.0 ± 13.7	145(69.0)	38.7 ± 14.4	3.58	.060
Male	30(46.2))	30.6 ± 8.7	35(53.8))	49.6 ± 10.9	65(31.0)	40.8 ± 13.7		
Marital Status								
Married	76(49.7)	31.7 ± 10.7	77(50.3)	44.9 ± 14.1	153(72.9)	38.4 ± 14.1	.603	.438
Single	19(33.3)	31.0 ± 13.9	38(66.7)	47.3 ± 11.0	57(27.1)	41.9 ± 14.3		
Educational Status								
Literate	18(45.0)	31.7 ± 12.4	22(55.0)	44.2 ± 14.3	40(19.0)	38.6 ± 14.7	.516	.724
Primary School	40(72.7)	33.8 ± 11.5	15(27.3)	51.7 ± 13.3	55(26.2)	38.7 ± 14.3		
Secondary School	12(44.4)	31.0 ± 11.7	15(55.6)	43.4 ± 12.1	27(12.9)	37.9 ± 13.3		
High-School	14(28.0)	28.7 ± 10.0	36(72.0)	44.6 ± 12.9	50(23.8)	40.1 ± 14.0		
University or higher education	11(28.9)	27.6 ± 10.2	27(71.1)	46.5 ± 12.9	38(18.1)	41.1 ± 14.9		
Relation to the Patient								
Spouse	46(52.9)	33.8 ± 10.4	41(47.1)	41.7 ± 15.3	87(41.4)	37.5 ± 13.5	4.96	.008
Child	38(44.7)	30.0 ± 11.0	47(55.3)	48.0 ± 10.8	85(40.5)	40.0 ± 14.1		
Other (my grandmother/grandfat her, my sibling)	11(31.4)	27.4 ± 4.8	27(23.4)	47.9 ± 12.3	38(18.1)	42.0 ± 15.9		
Total	95	31.6 ± 11.3	115	45.7 ± 13.1	210	39.3 ± 14.2		

*Two Way ANOVA test.

In other words, caregiver burden scale score of the caregiver significantly differed according to the joint effect of treatment center and relation to the patient ($F_{(2-203)} = 4.96, p < 0.008$) (Table 4).

When the treatment center was treated as a fixed variable, relation of the caregiver to the patient and caregiver burden scale score of the patients were tested using the independent group two-way ANOVA and Tukey LSD method. Accordingly, relation of the caregiver to the patient in the Northern Cyprus and burden scale score of the patients were significantly different ($F = 3.10, p = 0.049$). The Tukey LSD test was performed to analyze between which groups this difference occurred. According to this analysis, caregiver burden scale scores of the spouses acting as the caregiver ($x = 41.7$) were lower than the score of the other caregivers ($p = 0.025$).

Discussion

Chronic diseases affect not only the patients, but also caregiving relatives of the patients. Cultural differences are among important factors affecting the burden of caregivers (Casado et al., 2014). The knowledge of the caregiver burden and influencing factors is of utmost importance to protect health of the patients and plan treatment and care methods, and nursing services (Cantekin, Kavurmaci & Tan 2016).

With respect to the mean age of the caregivers, other studies in the literature, different from the present study, have reported higher mean age among the caregivers (Mollaoglu, Kayataş & Yurugen 2013, Cantekin, Kavurmaci & Tan 2016), whereas the study by Alnazly and Samara (2014) reported findings that were comparable to the findings of the current study. The finding that the majority of the caregivers in the Northern Cyprus were aged 29 years and under was attributed to the fact that 55.3% of the caregivers were also children of the patients.

The studies found that the majority of the caregivers were females (Mollaoglu, Kayataş & Yurugen 2013, Cantekin, Kavurmaci & Tan 2016, Alnazly, 2016, Nagarathnam et al, 2016). The results of our study are in parallel to those reported in the literature. In our culture, it is supposed that women, by their very nature, should give birth, do houseworks, serve the husband, and mother the children (Ersin & Bahar 2013). The finding that the majority of the caregivers were females and women being more

willing to embrace caregiving roles can be attributed to women being more compassionate and emotional and being better in coping with the difficulties of caregiving (Mollaoglu, Kayataş & Yurugen 2013).

When we examine from the perspective of the role of women in the family, women pursue the caregiving role arising from traditional and cultural values in the two communities depending on the status of the women in the family. Similar to our study, responsibility of caregiving is mostly undertaken by the spouses of the patients in other studies in the literature (Mollaoglu, Kayataş & Yurugen 2013, Ersin & Bahar 2013). The spouses being involved in caregiving can be explained by the sense of responsibility to provide care to their spouses.

Although the two communities are comparable with respect to economic status, patients living in Istanbul receive service from private dialysis centers owing to the differences in the healthcare services provided in Turkey. However, patients in the Northern Cyprus receive service only from dialysis units within the state hospitals due to unavailability of private dialysis centers. There is also a transportation service from and to private dialysis centers in Istanbul. However, such services are unavailable in Northern Cyprus and transportation is carried out by the family members of the patients, and for this reason, 98.1% of the caregivers in the Northern Cyprus have demanded transportation services in order to reduce their burden. It is considered that healthcare services currently available in Turkey and the advantaged brought about by the rivalry between different dialysis centers have affected the diversity of opportunities offered to the patients.

Cultural characteristics and beliefs of the community in which the caregiver lives are thought to affect the perceived burden of the care (Atagun et al., 2011). Although no study has evaluated the burden of caregiving to HD patients in the Northern Cyprus, studies carried out in Turkey have reported high level of perceived burden in the caregivers (Erdem et al., 2013, Gulpak & Kocaoz 2014, Mollaoglu, Kayataş & Yurugen 2013, Purlusoy et al., 2011). The present study evaluated the burden scores of the caregivers in different cultures and the mean caregiver burden scale score was found to be higher in the Northern Cyprus ($X = 45.77$),

compared to the burden scale score of the caregivers living in Turkey ($X = 31.62$) ($t_{208} = -8.22$, $p < 0.000$). Although economic status of the caregivers in the two communities was comparable, the opportunity of patients living in Istanbul to benefit from private dialysis centers and their services reduce the burden of caregivers in Istanbul. In that, comfort offered by private dialysis centers and continuous on-the-job training of the healthcare staff by a nurse instructor increases the quality of service delivered to the patients and therefore reduces burden perception of the caregivers. The caregivers in the Northern Cyprus transfer the patient to the dialysis unit through their own means and the impact of this transport on their daily life is thought to increase the burden of caregiving. In addition, the facts that 55.3% of the caregivers in the Northern Cyprus are the children of the patient and they often live in a separate house away from their parents and they embrace caregiving role in addition to their responsibilities for their own family also increase the burden of caregivers. The studies in the literature have also emphasized the relationship between receiving social support and caregiver burden (Casado et al., 2014). When we examine from the perspective of social support systems, nuclear family structure predominates in the Northern Cyprus, whereas traditional family structure predominates in Istanbul, even though there is a shift to nuclear family with urbanization. Therefore, caregivers in Istanbul are more likely to receive support from the relatives and family and social support. All these cultural characteristics are considered to have an influence on our results.

The burden of caregiving can be affected by multiple factors related to the caregiver. The combined effect of treatment center and age ($F = 1.84$, $p = 0.122$), sex ($F = 3.58$, $p = 0.060$), marital status ($F = 0.603$, $p = 0.438$), and educational status ($F = 0.516$, $p = 0.724$) of the caregiver on the burden scale score of the caregiver was not found to be statistically significant. Similar to our findings, the studies by Alnazly & Samara (2014) and Suri et al., (2011) reported no relationship between age and sex of the caregiver and the burden of caregiving, but there are also studies in the literature suggesting that female sex (Mollaoglu, Kayataş & Yurugen 2013) and advanced age of the caregiver (Gulpak & Kocaoz 2014, Purlusoy et al., 2011)

were associated with increased caregiving burden. Previous studies found variable results on the relationship between education status and caregiving burden that were different from the current study (Bayoumi, 2014, Mollaoglu, Kayataş & Yurugen 2013). Several studies suggested an increased caregiving burden in association with decreasing educational status (Bayoumi, 2014, Gulpak & Kocaoz 2014, Zhang et al., 2016), while the study by Mollaoglu et al., (2013) reported higher caregiving burden in association with higher educational status in single subjects. Caregiver burden scores did not significantly differ according to age, sex, marital status, and educational status, and it was suggested that this finding was caused by comparable demographic characteristics of the two communities. In addition, it is considered that investigation of treatment center together with the characteristics of the caregiver may have influences the results and that different results can be found if sociodemographic data of the two communities are individually evaluated for their relationship with caregiver burden.

Review of the literature reveals that the relation of the caregiver to the patient is another factor affecting caregiving burden (Mollaoglu, Kayataş & Yurugen 2013, Purlusoy et al., 2011). In the present study, caregiver burden scale scores of the spouses acting as the caregiver ($x = 41.7$) were lower than the score of the other caregivers ($p = 0.025$) in the Northern Cyprus. In the study by Purlusoy et al., (2011) the degree of kinship was associated with increasing caregiving burden with the exception of siblings. Consistent with our findings, Mollaoglu et al. (2013) reported lower caregiver burden in the spouses when compared to the other relatives of the patients. Nuclear family model predominates in the Turkish population of the Cyprus and the parents live apart from their children. The spouses, therefore, feel responsible for providing care and they perceive this role as a task rather than a burden. Burden perception of the spouses in our culture is thought to have affected the results of the study.

Conclusion

In conclusion, taking an important place in supporting patients, caregivers must be provided sufficient social and physical support.

The patient and the family must be evaluated together considering cultural characteristics of

the population within the frame of holistic approach of nursing care, and this approach is supposed to solve the problems of both patients and caregivers. With respect to the provision of social support services, healthcare personnel in the HD units should begin with determining social support sources of the caregivers and make attempts to mobilize existing support systems intended for sharing responsibilities related to the patient care. For this purpose, it would be beneficial to strengthen family and friend relationships, establish social support systems under the umbrella of associations and set up social support groups in the hospitals.

It is recommended that future studies should focus describing specific cultural structures of the families of caregivers in different cultures, constructing a risk profile for caregiving among the family members, and also attempts must be made to develop social support systems in order to reduce caregiver burden.

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