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RESEARCH ARTICLE

# CAREGIVING BURDEN OF CAREGIVERS OF HEMODIALYSIS PATIENTS AND RELATED FACTORS

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## ABSTRACT

**Purpose:** This study was conducted to evaluate the caregiving burden of caregivers of patients receiving Hemodialysis (HD) treatment.
**Material and Methods:** This cross-sectional study was conducted with 107 caregivers of patients receiving HD treatment at State Hospital and Private Dialysis Center. The entire population was intended to be reached by avoiding the use of samples. The universe has been explored to an extent of 89%. Between 1 June and 1 July 2022, the researchers visited HD centers and conducted in-person interviews to gather the data. In this study, Descriptive Information Form and the Zarit Caregiver Burden Scale (ZCBS) were used to collect data.
**Results:** Among the patients, 39.3% were between the ages of 41-60 and 40.2% were between the ages of 61-80. 85.7% of caregivers were 60 years old or younger. 75.7% of caregivers were women. The mean caregiving burden score of the participants was 47.53 ±13.87. Patient education level and care burden were significant ($p= .034$). Caregivers of university-graduated patients had a lower care burden. The degree of caregiver burden was found to vary greatly depending on the caregiver’s age, marital status, occupation, and closeness to the patient. The caregiving burden of caregivers in the 20-30 age group was lower than those in the 60 and over age group ($p= .007$). Married caregivers had a higher caregiving burden than single caregivers ($p<0.001$). The caregiving burden of the students was lower than the others ($p<0.001$).
**Conclusion:** It was determined that the caregivers had a moderate level of caregiving burden.

**Keywords:** hemodialysis, patient, caregiving burden, caregiver

## INTRODUCTION

Chronic kidney diseases are among the important health problems seen all over the world (1, 2). Chronic renal failure is one of the disorders in which kidney functions are irreversibly lost (3). Many methods are used for the treatment of chronic renal failure. Among these, the most widely used is Hemodialysis (HD) therapy (4). According to the Turkish Nephrology, Dialysis and Transplantation Registry 2020 report, HD remains the most frequently applied renal replacement therapy in Turkey (5). In Turkey, 3 or more sessions of HD treatment per week are applied to approximately 88% of patients with chronic kidney disease (5). Patients with chronic renal failure are saved from death by hemodialysis. However, it significantly alters the way of life for the patients (6). The study, which was conducted with a sample of 7226 patients receiving HD therapy from different countries, found that 36% of the patients were self-sufficient (7). Individuals undergoing HD therapy can become dependent on another person for a variety of causes. Numerous frequent and troubling symptoms have an impact on the physical and mental health of those getting HD therapy. For instance, one of them is fatigue (8-11).

HD causes patients' energy levels to drop. In general, receiving dialysis treatment has a negative impact on a patient's capacity to work and carry out normal everyday tasks. Patients and their caregivers' daily life may be impacted by these conditions (1). Patients' care throughout illness and treatment is primarily handled by caregivers. They help patients adapt to their chronic illnesses. They also assist them in managing the illness and its therapy (4). Most patients' caregivers are family members or friends who provide daily care and support for patients' mental, physical, and social needs (12). Caregivers and family members may endure a high level of caregiver burden as a result of HD therapeutic complications and considerable lifestyle changes, which can have a detrimental effect on their mental health (4). According to several research findings, HD patients' caregivers go through emotional, physical, and financial distress. Caregivers may face some psychological and physical risks as a result of these challenges (12-14). Living with a patient receiving HD therapy creates a certain level of burden on caregivers (15). The concept of "caregiver burden" refers to the impact of caring for patients on caregivers (16). The ability of caregivers to effectively care for patients is strongly correlated with the extent of caregiver burden. An increase in the caregiving burden may result in a decline in the quality of care given that the burden can have catastrophic impacts on caregivers (17). The quality of life of caregivers is impacted by caregiver burden. Patients with chronic conditions may experience a worsening of their condition as a result of less care. The caregiver burden will rise as the patient's overall condition deteriorates. This can lead to a vicious cycle. Failure to intervene in this situation in a timely manner can lead to the gradual exhaustion of caregivers. For this reason, timely identification of the problems experienced by caregivers plays an important role in the protection and development of their physical and mental health (4). Considering the lack of information about the level of caregiving burden of caregivers of hemodialysis patients in Bingöl province and the fact that analyzing a situation is the first step in resolving potential issues, this study was conducted to examine the caregiving burden levels of caregivers of patients receiving HD therapy in Bingöl city center.

## MATERIAL AND METHODS

### Design and Population

This was a cross-sectional study. The research was conducted with 107 caregivers of patients receiving HD treatment at State Hospital and Private Dialysis Center. Between 1 June and 1 July 2022, the researchers visited HD centers and conducted in-person interviews to gather the data. Prior to beginning the study, institutional approval from State Hospital and Private Dialysis Center as well as thics committee approval from Bingöl University Health Sciences Scientific Research and Publication Ethics Committee (27.04.2022- Decision No: E-33117789-044-59831) were obtained. The demographic data of both patients and caregivers were collected using a 16-item "Descriptive Information Form" and the "Zarit Caregiver Burden Scale (ZCBS)". The population of the study consisted of all patients who received HD treatment in the city center of Bingöl, Turkey. Two institutions, one state and one private, provide HD treatment in the city center. The entire population was intended to be reached by avoiding the use of samples. The universe has been explored to an extent of 89%. Taking into account the appropriate time frame for the patients and caregivers, the researchers conducted questionnaires while the patients were in the HD session. Completing a questionnaire took about 20 minutes.

### Data Collection Tools

### Descriptive Information Form

It consists of 9 items regarding HD patients' age, gender, marital status, education level, occupation, income level, number of HD sessions per week, duration of HD therapy, and self-sufficiency state, and 7 items regarding caregivers' age, gender, marital status, education level, occupation, income level, their relationship with patients and their families.

**Table 1.** Anova and T-Test Analysis Results of Patients' Demographic and Disease-Related Information (N=107)

| Descriptive Characteristics | | | | ZCBS |
|---|---|---|---|---|
| | | N | % | Mean and Standard Deviation |
| Age | 20-40 | 16 | 15.0 | 46.80±7.69 |
| | 41-60 | 42 | 39.3 | 47.52±.9.84 |
| | 61-80 | 43 | 40.2 | 48.96±7.55 |
| | 81 or above | 6 | 5.6 | 46.16±7.96 |
| | Significance | | | p= .334 |
| Gender | Male | 50 | 46.7 | 46.84±7.85 |
| | Female | 57 | 53.3 | 47.25±9.81 |
| | Significance | | | p= .056 |
| Marital Status | Married | 72 | 67.3 | 48.85±8.41 |
| | Single | 12 | 11.2 | 46.65±7.65 |
| | Widowed or Divorced | 23 | 21.5 | 47.96±7.52 |
| | Significance | | | p= .441 |
| Education Level | Illiterate or Primary School Graduate | 70 | 41.2 | 48.85±8.65 |
| | Secondary School or High School Graduate | 28 | 38.8 | 47.86±7.98 |
| | University Graduate | 9 | 20.0 | 47.40±7.56 |
| | Significance | | | p= .034* |
| Occupational Status | Employed | 22 | 20.6 | 47.58±7.65 |
| | Unemployed | 37 | 34.6 | 47.65±7.65 |
| | Housewife | 48 | 44.9 | 48.89±8.45 |
| | Significance | | | p= .210 |
| Income Level of Patient | 0-1000 TL | 66 | 61.7 | 48.89±7.56 |
| | 1001-2000 TL | 25 | 23.4 | 47.78±7.52 |
| | 2001-3000 TL | 14 | 13.1 | 47.47±7.36 |
| | 3001 or more | 2 | 1.9 | 47.25±7.20 |
| | Significance | | | p= .237 |
| # of HD sessions per week | 2 times a week | 7 | 6.5 | 47.01±7.45 |
| | 3 times a week | 100 | 93.5 | 48.96±7.56 |
| | Significance | | | p= .060 |
| Duration of HD therapy | 12 months | 6 | 5.6 | 47.65±7.56 |
| | 13 -60 months | 31 | 29.0 | 47.89±7.58 |
| | 61-120 months | 48 | 44.9 | 48.58±8.65 |
| | 121 months or more | 22 | 20.6 | 47.96±7.65 |
| | Significance | | | p= .298 |
| Self-Sufficiency Level of Patient | Not Self-Sufficient | 37 | 34.6 | 47.75±7.85 |
| | Moderately Self-Sufficient | 45 | 42.1 | 48.65±7.96 |
| | Self-Sufficient | 25 | 23.4 | 47.48±7.58 |
| | Significance | | | p= .429 |
| ZCBS | | | | 47.53 ±13.87 |

*p<0.05

### Zarit Caregiver Burden Scale (ZCBS)

It is a 22-item questionnaire with five-item response options ranging from "never" to "nearly always", directed at the caregiver. Scores between 0 and 20 indicate little or no burden. Scores between 21 and 40 indicate mild to moderate burden. Scores between 41 and 60 indicate moderate to severe burden, whereas scores between 61 and 88 indicate severe burden (18). The validity and reliability of the ZCBS for the Turkish population was examined by İnci. The Cronbach reliability coefficient was 0.95. The Turkish version of ZCBS has been reported to have high reliability and validity in the Turkish population (19). The Cronbach Alpha Value was determined as .86 in this study.

### Statistical Analysis

SPSS 23.0 statistical program was used to analyze the data collected in the study. The data distribution was determined using the Kolmogorov Smirnov and

**Table 2.** Anova and T-Test Analysis Results of Caregivers' Demographic Information (N=107)

| Descriptive Characteristics | | ZCBS | | |
|---|---|---|---|---|
| | | N | % | Mean and Standard Deviation |
| Age | 20-30 | 21 | 19.6 | 47.45±9.52 |
| | 31-40 | 24 | 22.4 | 47.56±8.35 |
| | 41-50 | 23 | 21.5 | 47.43±8.56 |
| | 51-60 | 27 | 25.2 | 48.68±7.28 |
| | 61 or older | 12 | 11.2 | 46.25±7.24 |
| | Significance | | | p= .007* |
| Gender | Male | 26 | 24.3 | 47.53±7.66 |
| | Female | 81 | 75.7 | 47.96±10.17 |
| | Significance | | | p= .054 |
| Marital Status | Married | 78 | 72.9 | 48.91±7.54 |
| | Single | 26 | 24.3 | 47.86±9.20 |
| | Widowed or Separated | 3 | 2.8 | 47.43±9.58 |
| | Significance | | | p<0.001* |
| Education Level | Illiterate or Primary School Graduate | 59 | 55.1 | 47.90±9.38 |
| | Secondary School or High School Graduate | 36 | 33.6 | 47.45±9.37 |
| | University Graduate | 12 | 11.2 | 47.15±9.33 |
| | Significance | | | p= .169 |
| Occupational Status | Employed | 21 | 19.6 | 47.90±7.42 |
| | Unemployed | 18 | 16.8 | 47.86±7.38 |
| | Housewife | 60 | 56.1 | 48.90±8.98 |
| | Student | 8 | 7.5 | 47.75±7.36 |
| | Significance | | | p<0.001* |
| Income | 0-1000 TL | 79 | 73.8 | 48.85±7.45 |
| | 1001-2000 TL | 15 | 14.0 | 47.65±7.38 |
| | 2001-3000 TL | 9 | 8.4 | 47.54±8.47 |
| | 3001 or more | 4 | 3.7 | 47.12±7.25 |
| | Significance | | | p= .173 |
| Relationship with the Patient | Daughter-in-law/Son-in-law of the patient | 11 | 9.3 | 47.65±7.45 |
| | Child/Sister/Brother of the patient | 45 | 42.1 | 48.45±7.26 |
| | Mother/Father of the patient | 11 | 10.3 | 47.65±8.15 |
| | Spouse of the patient | 40 | 37.4 | 47.80±7.26 |
| | Significance | | | p= .023* |

*p<0.05

Shapiro-Wilk tests. The data were found to be in accordance with the normal distribution. Number, percentage, mean, standard deviation, frequency, reliability, Anova and T-test were performed to analyze the data. The Scheffe Post-Hoc test was used to determine the significance between the groups. The effect of demographic variables on the burden of care was studied using multiple regression analysis. The significance level was set at p<.005.

## RESULTS

40.2% of the patients were in the 61–80 age range. 53.3% of the patients were female, and 67.3% were married. 25.2% of caregivers were in the 51-60 age range. 75.7% of caregivers were women, and 72.9% were married. The mean scores of the participants' caregiving burden were determined as 47.53 ±13.87. The analysis revealed that there was no statistically significant difference in the caregiving burden of the participants based on the patients' age, gender, marital status, occupation, income status, number of HD sessions per week, self-sufficiency, and duration of HD therapy (p>0.05), but there was a difference based on education level (p= 0.034). According to the results of the Scheffe Post-Hoc test performed to identify which group caused this difference, it was determined that the patients who graduated from secondary or high school caused a heavier caregiving

**Table 3.** Regression Analysis of the Effect of ZCBS on Patient and Caregiver Demographic Characteristics

| Independent Variables | Demografik Değişkenler | Standartlaşmamış Katsayılar | | Standartlaşmış Katsayılar | P |
|---|---|---|---|---|---|
| | | B | Standart Hata | Beta | |
| Regression Analysis for the Patient | | | | | |
| Caregiving Burden | Duration of HD therapy | .22 | .12 | .17 | .04 |
| Regression Analysis for the Caregiver | | | | | |
| Caregiving Burden | Age | .55 | .19 | .26 | .00 |
| Caregiving Burden | Marital Status | -.24 | .07 | -.29 | .00 |
| Caregiving Burden | Education Level | -.20 | .10 | -.18 | .05 |
| Caregiving Burden | Occupational Status | -.28 | .13 | -.20 | .03 |
| Caregiving Burden | Relationship with the Patient | .49 | .16 | .28 | .00 |

burden than the university graduates (Table 1). The analysis revealed that there was a statistically significant difference in the caregiving burden of the participants based on the caregivers' age, marital status, occupational status, and the relationship with the patient (p<0.05), while there was no difference based on their gender, education level, and income level (p>0.05) (Table 2). The effect of patient and caregiver demographic variables on caregiver burden was studied using multiple regression analysis. The duration of HD treatment was found to affect the burden of care. Furthermore, it was discovered that the caregiver's age, marital status, education level, profession, and closeness to the patient all had an impact on the burden of care (Table 3).

## DISCUSSION

This study was conducted with the caregivers of the patients getting HD therapy in a state. The burden of care was found to vary significantly depending on the patient's education level. The burden of care was found to vary significantly depending on the caregiver's age, marital status, employment status, and closeness to the patient.

The caregiving burden level of caregivers of HD patients was above moderate. A study conducted in Iran (2020) found that the caregiver burden of patients receiving HD treatment was extremely high (20). Another study (2020) showed that caregivers of patients receiving HD treatment had a moderate caregiving burden (21). In a 2019 study on caregivers of HD patients, it was determined that caregivers had a mild (11.8%), moderate (56%), and high (32.2%) caregiving burden (22).

Hoang et al. (2019) found the mean caregiving burden score to be 40.15±10.46 in their study with 178 caregivers of HD patients (23). The study by Jafari et al. (2018) with 246 caregivers of HD patients determined that the total caregiving burden score was 64.8 out of 120 (24). In the literature, there are studies indicating that the caregiving burden levels of caregivers of HD patients are above moderate or severe (4, 17, 25-27). The study by Sotoudeh et al. (2019) found that 66.9% of caregivers experienced a severe caregiving burden (28). The study by Pio et al. (2022) determined that more than half of the caregivers had a very low level of caregiver burden (29).

The study by Rioux et al. (2012) revealed that caregivers experienced a low level of caregiving burden (30). This study's finding, that the care burden believed that the majority of patients receiving HD therapy three times per week contribute to the overall is moderate, is consistent with the literature. It is burden of care. Furthermore, the high proportion of people who are unable to care for themselves or require the assistance of others may increase the burden of care.

The results of this study showed that patients with college degrees caused less care burden. Rafati et al. (2020) found that among the patients receiving HD therapy, those with higher education levels caused less care burden (22). Similarly, Mollai et al. (2019) in their study investigating the caregiving burden of caregivers of cancer patients, concluded that those with higher education levels caused less care burden (31). This finding is assumed to be the outcome of patients' better opportunities to learn about the illness and its symptoms and their employment of more efficient problem-solving techniques when they have higher levels of education.

It was found that the patient's employment status and income level had no effect on the caregiver burden in our study. In contrast to the findings of our study, another research showed that when HD patients' (22). According to one study, low-income HD patients cause a higher care burden (17). A statistically significant correlation between the caregiving burden and the patient's employment status was discovered in a study conducted in Iran (22). Because HD income rises, the burden of caretakers decreases therapy costs are covered by the state, it is possible to say that it has no effect on the care burden.

It was determined that the care burden of patients who received HD therapy for a longer period of time was higher, but there was no significant difference. A study also found no correlation between the number of years spent with this disease and the caregiving burden (22). It is believed that a person who has this disease for a longer period of time may have become accustomed to it and developed better coping mechanisms for the symptoms they face. It was determined that the self-sufficiency of patients and the caregiving burden were not significantly correlated, but the caregiving burden of the patients who were not self-sufficient was higher. A study (2020) found that as the self-sufficiency level of HD patients decreases, the caregiver burden increases (22). In a study, it was determined that as the self-sufficiency level of patients increases, the caregiver burden decreases and the correlation was found to be statistically significant (24). In this study, it was determined that the sociodemographic characteristics of the caregivers affected the caregiver burden. Caregiver burden significantly changed according to the age of caregiver. Similarly, a study by Jafari et al. also found that as the age of caregivers increased, the caregiving burden increased, and there was a significant correlation between caregiver age and caregiver burden (24). A study by Hoang et al. determined that the correlation between caregiver age and caregiver burden was significant (23). The ability of the patient to provide self- care can reduce the caregiver burden. It is believed that the family members and caregivers of self- sufficient patients will be less affected by the negative aspects of the disease.

In this study, where the majority of the participants were female, it was determined that male caregivers had a higher care burden. However, the difference was not significant. In the literature, there are studies that determined that the majority of caregivers of HD patients were female (4, 26, 32). The study by Jahhav et al. also determined that the majority of caregivers were female (27). In a study conducted by Hoang et al., where the majority of caregivers (55.6%) of HD patients were female, the burden of female caregivers was significantly different (23).

In their study, Mollaoğlu et al. found that female caregivers among the family were generally more sensitive to the needs of patients, and their ability to establish close relationships with patients and manage problems was better than male caregivers (32). Our findings are associated with cultural behaviors in the region where the study was conducted. Many responsibilities, such as childcare and housework, are generally held by women in this region. Men are not accustomed to patient care, which is culturally considered the responsibility of women in this region. The fact that men were unable to fully perceive the patient's needs may have influenced the outcome. Furthermore, the inability of men to coordinate the work to be done while providing care increases the care burden.

Single care givers experience more care burden. Hu et al. (2018) found that the marital status of caregivers significantly impacted the caregiver burden (33). However, another study (2020) found that the marital status of caregivers had no significant impact on the caregiver burden (22). Caring for a HD patient interrupts the caregivers' personal, social and financial life. Single caregivers may experience a greater burden of care for these reasons.

Unemployed caregivers were found to have a significantly higher caregiver burden. Mello et al. (2017) discovered that caregiver burden increases significantly with low socioeconomic status (34). A study (2020) determined that the income level of the caregiver does not affect the burden of care (22). Unemployed caregivers may face financial and social challenges. These circumstances can be said to have an impact on the burden of care.

## Limitations of the Research

This study had several limitations. One limitation was that it took place in a city and was therefore conducted with caregivers of similar socio-cultural characteristics. Furthermore, causality could not be sufficiently assessed because of the study's cross-sectional design. Finally, the findings of the study cannot be generalized for all caregivers of hemodialysis patients in Turkey due to the study was carried out with a small sample.

## CONCLUSION

It was determined that the caregivers had a moderate level of caregiving burden. Identifying the problems and needs that caregivers face during caregiving is important for holistic care and can help reduce the burden of caregiving. For this reason, it can be recommended to carry out studies with larger sample groups to determine the problems and needs and to organize trainings to reduce the burden of caregiving.

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