

# Examination of Caregiver Burden, Hopelessness Level and Related Factors in Chronic Neurologic Disorder: A Descriptive Cross Sectional Study

## Kronik Nörolojik Hastalıklarda Bakım Veren Yükü, Umutsuzluk Düzeyi ve İlişkili Faktörlerin İncelenmesi: Tanımlayıcı Kesitsel Bir Çalışma

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**ABSTRACT Objective:** The aim of this study is to examine the caregiving burden, hopelessness level, and related factors of individuals who care for patients with chronic neurological disease. **Material and Methods:** This descriptive cross-sectional study was conducted from June to July 2022. The study sample was created by 105 patients with a chronic neurological disease treated in the neurology clinic of a university hospital and individuals who were primary caregivers. The data was collected by the person information form, Zarit Caregiver Burden Inventory (ZBI), and Beck Hopelessness Scale (BHS). Also, for patients, the patient information form, Modified Barthel Index, Neuroquality-Stigma Scale, and Beck Depression Inventory were used. **Results:** The mean ZBI score was 23.5 ( $\pm 14.2$ ), and the BHS was 5.7 ( $\pm 4.9$ ). It was determined that caregiver burden had a significant relationship with patient gender ( $p=0.002$ ), income ( $p=0.021$ ) and patient's diagnosis ( $p=0.009$ ). The caregiving burden was higher in parents ( $p=0.005$ ). There was a negative correlation between caregiving burden and patients' functional status and a positive correlation with stigma and depression levels ( $p<0.001$ ). In addition, as the caregiver burden increased, the hopelessness levels of the caregivers increased significantly ( $p<0.001$ ). **Conclusion:** It has been determined that caregivers' burden in individuals with neurological disease is related to many factors belonging to the patient and the caregiver. In addition, it was determined that as the caregiving burden increased, the level of caregiver hopelessness increased. To reduce the burden of care, it is recommended that the patient and caregivers be evaluated comprehensively.

**Keywords:** Neurological disorder; caregiver burden; hopefulness; stigma; depressed mood

**ÖZET Amaç:** Bu çalışmanın amacı, kronik nörolojik hastalığı olan hastalara bakım veren bireylerin bakım verme yükü, umutsuzluk düzeyi ve ilişkili faktörleri incelemektir. **Gereç ve Yöntemler:** Bu tanımlayıcı kesitsel çalışma Haziran-Temmuz 2022 tarihleri arasında yürütülmüştür. Çalışmanın örneklemini bir üniversite hastanesinin nöroloji kliniğinde tedavi gören kronik nörolojik hastalığı olan 105 hasta ve bu hastalara birincil bakım veren bireyler oluşturmuştur. Veriler kişi bilgi formu, Zarit Bakım Veren Yükü Ölçeği [Zarit Caregiver Burden Inventory (ZBI)] ve Beck Umutsuzluk Ölçeği [Beck Hopelessness Scale (BHS)] ile toplanmıştır. Ayrıca hastalar için hasta bilgi formu, Modifiye Barthel İndeksi, NöroYaşam Kalitesi Stigma Ölçeği ve Beck Depresyon Envanteri kullanılmıştır. **Bulgular:** Ortalama ZBI skoru 23,5 ( $\pm 14,2$ ) ve BHS 5,7 ( $\pm 4,9$ ) idi. Bakım veren yükünün hastanın cinsiyeti ( $p=0,002$ ), geliri ( $p=0,021$ ) ve hastanın tanısı ( $p=0,009$ ) ile anlamlı ilişkisi olduğu belirlendi. Bakım verme yükü ebeveynlerde daha yüksekti ( $p=0,005$ ). Bakım verme yükü ile hastaların fonksiyonel durumu arasında negatif, damgalanma ve depresyon düzeyleri arasında pozitif bir korelasyon vardı ( $p<0,001$ ). Ayrıca bakım veren yükü arttıkça bakım verenlerin umutsuzluk düzeyleri de anlamlı olarak artmaktaydı ( $p<0,001$ ). **Sonuç:** Nörolojik hastalığı olan bireylerde bakım veren yükünün hastaya ve bakım verene ait birçok faktörle ilişkili olduğu belirlenmiştir. Ayrıca bakım verme yükü arttıkça bakım verenin umutsuzluk düzeyinin de arttığı belirlenmiştir. Bakım yükünü azaltmak için hasta ve bakım verenlerin kapsamlı bir şekilde değerlendirilmesi önerilmektedir.

**Anahtar Kelimeler:** Nörolojik hastalık; bakım veren yükü; umutsuzluk; damgalanma; depresif duygu durumu

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Neurological diseases are chronic health problems that significantly affect not only physical health but also individuals' cognitive, behavioral, and psychosocial well-being. Individuals with neurological diseases often experience problems such as decreased functional skills and maintaining activities of daily living.<sup>1,2</sup> Therefore, although the care needs of these patients vary according to the diagnosis and burden of disease, they generally require long-term care, and the burden of care can be quite high.<sup>3</sup> Caregiving refers to patients' physical, psychological, and social support; in other words, receiving holistic care. The people who primarily provide this care are defined as "caregivers", and the perceived physical, psychological, economic, and social burden is defined as "caregiver burden."<sup>4</sup> Zarit and Zarit defines care burden as "the degree of negative impact or burden perceived by the caregiver."<sup>5</sup> Caregiver burden can be affected by many factors related to the patient (sociodemographic characteristics of the patient, diagnosis of the disease, disease burden, level of independence in performing daily activities, etc.) and the caregiver (sociodemographic characteristics, general well-being level, closeness with the patient, duration of caregiving, etc.).<sup>6,7</sup> For example, the care burden of an individual whose physical, cognitive, and mental health is affected by stroke can be quite heavy. In contrast, psychosocial problems experienced by a young person with epilepsy who has no limitations in physical functions may increase the caregiver burden considerably. Similarly, caring for a patient with advanced dementia is very demanding and requires serious physical and psychological resilience.<sup>8,9</sup> Therefore, it can be said that the burden of illness and the burden of care are correlated.<sup>10</sup> The care of individuals with chronic health problems, such as neurological diseases, is usually provided by informal carers (family members, relatives, etc.). These people usually provide care all day and must support the person they care for physically and psychosocially.<sup>11</sup> The caregiver's inability to find support from different people or institutions and prolonging the caregiving period may cause many problems that may impair the health of the caregivers. Stress, sleep problems, economic and psychosocial problems, and decreased quality of life are some of them.<sup>12</sup> In addition, in-

creased care burden is correlated with decreased life satisfaction and hopelessness.<sup>3</sup> Therefore, it is important to determine the factors belonging to the patient and the caregiver that contribute to caregiver burden to reduce the burden of care. In a recent review study, it was reported that although studies on caregiver burden have increased in recent years, they are still insufficient, and more studies are needed in this field.<sup>11</sup> In addition, in caregiver burden studies, only the factors belonging to the caregiver are generally examined, and the variables belonging to the patient are not addressed.

This study aims to determine the level of care burden and hopelessness in caregivers of individuals with neurological diseases and to examine the patient and caregiver factors that may contribute to this situation.

## MATERIAL AND METHODS

Strengthening the Reporting of Observational Studies in Epidemiology checklist (for cross-sectional study) was used while conducting and writing this research.

### STUDY DESIGN AND DATA COLLECTION

This descriptive, cross-sectional study was carried out in June-July 2022 with 105 patients over 18 years of age, diagnosed with chronic neurological disease, with no communication problems, and their primary caregivers who were hospitalized in the neurology clinic of a university hospital between June and July 2022. Data were collected by face-to-face interviews with patients and their caregivers who agreed to participate in the study. Written consent was obtained from the individuals participating in the study. In order not to cause bias while collecting research data, caregivers were interviewed in different rooms than the individuals they cared for, especially when determining the level of care burden.

### ETHICAL APPROVAL

Ethical approvals were obtained from the Clinical Research Ethics Committee of Ondokuz Mayıs University (date: April 30, 2022; no: 2022/143). In all stages of the study, the ethical rules in the Declaration of Helsinki were followed.

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## SAMPLE SIZE

G\*Power 3.1.9.7 program was used to determine the study sample. Using reference sources considering the effect size as 0.5,  $\alpha$  error rate as 0.05, and power as 95%, the number of samples was calculated as 92.<sup>13,14</sup> However, considering patient/data loss (dropout rate of 10%), it aimed to reach at least 102 caregivers. The study obtained data from 105 caregivers and the same number of patients they cared for.

## VARIABLES

The dependent variables of this study are the care burden and hopelessness level of caregivers of individuals with neurologic disorder. The independent variables of this study are the sociodemographic variables of the caregivers and the sociodemographic, clinical and psychosocial variables of the patients.

### Study Questions

This study evaluated the care burden and hopelessness level of caregivers of individuals with chronic neurological diseases. In addition, patient and caregiver factors affecting caregivers' caregiving burden and hopelessness level were investigated. For this purpose, study questions were created as follows:

- What is the caregiver burden in chronic neurological diseases?
- What is the level of hopelessness in chronic neurological diseases?
- Is caregiver burden in chronic neurological diseases related to patient and caregiver factors?
- Is the level of hopelessness in chronic neurological diseases related to patient and caregiver factors?

## MEASURES

Person information form, Zarit Caregiver Burden Inventory (ZBI), and Beck Hopelessness Scale (BHS) were used for the caregivers. For patients, four separate forms, including the patient information form, Modified Barthel Index (MBI), Neurological Quality of Life (NeuroQoL)- Stigma Scale, and Beck Depression Inventory (BDI-II), were used.

### Forms used for caregivers

*Person information form:* It consists of 16 questions in total form, questioning the sociodemographic

characteristics of the individuals (age, gender, educational status, etc.).

*ZBI:* This scale was developed by Zarit et al. to determine the difficulties experienced by caregivers of individuals needing care.<sup>5</sup> The scale consists of 22 statements and is a 4-point Likert-type scale. A minimum score of 0 and a maximum score of 88 can be obtained from the scale. The items in the scale are generally aimed at determining the burden in the social and emotional domain, and a high scale score indicates that the distress experienced by caregivers or the burden of caregiving is high. The scale was adapted to Turkish, and its validity and reliability study was conducted by İnci and Erdem.<sup>15</sup> In our current study, the Cronbach alpha value of the scale was calculated as 0.87.

*BHS:* The scale was developed by Beck and Steer in 1988 to determine the level of hopelessness.<sup>16</sup> BHS is an easy-to-administer scale consisting of 20 items, scored between 0 and 1, which individuals can answer themselves. The score that can be obtained from the scale varies between 0-20. A high score indicates an increased level of hopelessness. Turkish adaptation of the inventory was carried out in two separate studies, and it was reported to be valid and reliable.<sup>17,18</sup> In our current study, the Cronbach alpha value of the scale was calculated as 0.88.

### Forms used for patients

*Patient Information Form:* It consists of questions including socio-demographic characteristics of the patients and information about their diseases.

*MBI:* Barthel index was developed by Mahoney and Barthel in 1965.<sup>19</sup> It is a simple, understandable index that includes all parameters of activities of daily living. Turkish validity and reliability were performed on neurological patients in 2000 by Küçükdeveci et al.<sup>20</sup> It consists of 10 sub-headings: eating, bathing, self-care, dressing, bladder control, bowel control, toilet use, chair/bed transfer, mobility, and stair use. Scoring varies between 0-100. A high score indicates a high level of independence in performing activities of daily living. In our current study, the Cronbach alpha value of the scale was calculated as 0.87.

*NeuroQoL-Stigma Scale:* The five-point Likert-type scale consisting of 24 questions was developed by the National Institute of Neurological Diseases

and Stroke.<sup>21</sup> The score that can be obtained from the scale varies between 24 and 120. A high score indicates that the level of stigma that patients are exposed to or feel due to their disease is high. The Cronbach's  $\alpha$  coefficient of the scale, whose validity and reliability were conducted by Karşıdağ et al., was found to be 0.95.<sup>22</sup> In our current study, the Cronbach alpha value of the scale was calculated as 0.91.

*BDI-II:* The scale with a total number of 21 items was developed by Beck et al. and the scale was adapted to Turkish by Kapci et al.<sup>23,24</sup> The scale measures the severity of depressive mood. The total score that can be obtained from the scale varies between 0-63 and a high score indicates depressive mood. In our current study, the Cronbach alpha value of the scale was calculated as 0.89.

## STATISTICAL ANALYZE

Power analysis was performed to determine the number of patients to be included in the study (G\*Power 3.1.9.7 program). IBM SPSS Statistics 22 (IBM SPSS, Armonk, NY) software was used for statistical analyses. The Kolmogorov-Smirnov test evaluated the suitability of the data for distribution. Mean, frequency, Mann-Whitney U, Kruskal-Wallis test, Spearman correlation analysis, and regression analysis were used to evaluate the data. Significance was evaluated at  $p < 0.05$  level.

## RESULTS

The mean age of the patients ( $n=105$ ) included in the study was 50.2 years ( $\pm 16.5$ ), and more than half (58.1%) were male. Most of the patients (40%) were stroke patients. The mean age of caregivers was 40.5 years ( $\pm 15.3$ ), and more than half (55.2%) were female. Of the caregivers, 60% reported that their economic, 63.8% social and 55.2% private lives were negatively affected due to caregiving. In addition, the majority of the caregivers were spouses (40%) and children (30.5%), while about half (42.9%) reported that there was no person/institution to receive caregiving support (Table 1).

When the mean caregiver burden score was compared with some sociodemographic and clinical data of the patient, significant correlations were found

**TABLE 1:** Sociodemographic and clinical characteristics of patients/caregiver.

Characteristics	Patients n (%)	Caregiver n (%)
Age ( $\bar{X} \pm SD$ )	50.2 $\pm$ 16.59	40.55 $\pm$ 15.31
Sex		
Woman	44 (41.9)	58 (55.2)
Man	61 (58.1)	47 (44.8)
Education		
Primary/secondary education	62 (59)	44 (41.9)
High school	22 (21)	33 (31.4)
University and above	21 (20)	28 (26.7)
Employment status		
Working	33 (31.4)	43 (41.8)
Homemaker	30 (28.6)	36 (34.3)
Student	4 (3.8)	8 (7.6)
Retired	29 (27.6)	8 (7.6)
Unemployed	9 (8.6)	10 (9.5)
Income		
Good	13 (12.4)	13 (12.4)
Moderate	86 (81.9)	82 (78.1)
Bad	6 (5.7)	10 (9.5)
Marital status		
Single	18 (17.1)	24 (22.9)
Married	82 (78.1)	78 (74.3)
Divorced/widowed	5 (4.8)	3 (2.9)
Did illness/caregiving negatively affected your economic life?		
Yes	65 (61.9)	63 (60)
Did the illness/caregiving negatively affect your social life?		
Yes	76 (72.4)	67 (63.8)
Did the illness/caregiving negatively affect your private life?		
Yes	69 (65.7)	58 (55.2)
Diagnosis		
Stroke	42 (40)	-
Myasthenia graves	23 (21.9)	
Multiple sclerosis	13 (12.4)	
Epilepsy	10 (9.5)	
Parkinson	6 (5.7)	
Other (Gullian Barre, neuropathy etc.)	11 (10.5)	
Caregiver		
Parent	-	10 (9.5)
Spouse		42 (40)
Child		32 (30.5)
Sibling		13 (12.4)
Other (friends, relatives etc)		8 (7.6)
Is there any person/institution that you can get care support from?		
Yes	-	60 (57.1)
No		45 (42.9)
Time spent on care		12.72 $\pm$ 8.75

SD: Standard deviation.

according to gender ( $p=0.002$ ), income level ( $p=0.021$ ), disease diagnosis ( $p=0.009$ ) and duration of diagnosis ( $p=0.001$ ). In addition, it was found that

care burden increased with increasing caregiver age (p=0.015), and those with bad income levels (p=0.020) and parents (mother-father) had the highest mean care burden score (p=0.005).

The mean hopelessness score of the caregivers showed significant correlations with the income level

(p=0.009), disease diagnosis (p=0.029), and duration of diagnosis (p=0.024) of patients. In addition, age (p<0.001), educational status (p<0.001), employment status (p=0.043), income level (p=0.002), and closeness to the patient (p=0.009) of caregivers were also found to be significant variables (Table 2).

TABLE 2: Factors associated with caregiver burden and hopelessness level.

Patients characteristics	ZBI		BHS	
	X $\pm$ SD	p value	X $\pm$ SD	p value
Age	r=0.022	0.822	r=0.044	0.653
Duration of diagnosis	r=0.309	<b>0.001</b>	r=0.22	<b>0.024*</b>
Sex				
Male	27.13 $\pm$ 14.41	<b>0.002</b>	6.37 $\pm$ 5	0.098
Female	18.59 $\pm$ 12.66		4.86 $\pm$ 4.7	
Education				
Primary/secondary education	23.12 $\pm$ 14.69	0.858	5.93 $\pm$ 4.81	0.728
High school	25.45 $\pm$ 15.78		6.00 $\pm$ 5.69	
University and above	22.80 $\pm$ 11.67		4.90 $\pm$ 4.44	
Income				
Good	25.23 $\pm$ 16.66	<b>0.021</b>	6.30 $\pm$ 4.06	<b>0.009</b>
Moderate	22.23 $\pm$ 13.63		5.29 $\pm$ 4.97	
Bad	38.83 $\pm$ 10.06		11.00 $\pm$ 2	
Marital status				
Single	25.77 $\pm$ 15.12	0.733	6.16 $\pm$ 4.99	0.908
Married	23 $\pm$ 14.29		5.68 $\pm$ 5	
Divorced/widowed	23 $\pm$ 13		5.20 $\pm$ 3.76	
Diagnosis				
Stroke	19.35 $\pm$ 12.74	<b>0.009</b>	4.54 $\pm$ 4.32	<b>0.029</b>
Myasthenia graves	19.61 $\pm$ 14.60		6.76 $\pm$ 5.05	
Multiple sclerosis	28.30 $\pm$ 17.36		8.80 $\pm$ 5.73	
Epilepsy	26.13 $\pm$ 10.73		5.39 $\pm$ 3.70	
Parkinson	44.16 $\pm$ 17.11		11.00 $\pm$ 6.69	
Others	23.27 $\pm$ 11.93		4.18 $\pm$ 5.05	
Caregiver's characteristics				
Age	r=0.236	0.015	r=0.418	<0.001
Sex				
Male	22.63 $\pm$ 13.17	0.728	5.46 $\pm$ 4.12	0.936
Female	24.29 $\pm$ 15.19		5.96 $\pm$ 5.49	
Marital status				
Single	20.08 $\pm$ 10.60	0.207	3.91 $\pm$ 4.60	0.048
Married	24.20 $\pm$ 15		6.35 $\pm$ 4.95	
Divorced/widowed	34.33 $\pm$ 14.36		4.33 $\pm$ 3.05	
Education				
Primary/secondary education	24.45 $\pm$ 16.71	0.913	7.79 $\pm$ 4.91	<0.001
High school	22.66 $\pm$ 13.13		5.06 $\pm$ 4.74	
University and above	23.17 $\pm$ 11.57		3.32 $\pm$ 3.80	
Income				
Good	19.46 $\pm$ 12.62	<b>0.020</b>	6.30 $\pm$ 4.06	<b>0.009</b>
Moderate	22.87 $\pm$ 14.38		5.29 $\pm$ 4.97	
Bad	34.40 $\pm$ 11.14		11 $\pm$ 2	
Caregiver				
Parent	36.10 $\pm$ 12.66	<b>0.005</b>	9.00 $\pm$ 3	<b>0.009</b>
Spouse	15.84 $\pm$ 7.82		3.15 $\pm$ 3.36	
Child	25.85 $\pm$ 15.24		6.76 $\pm$ 5.49	
Sibling	19.06 $\pm$ 12.32		4.81 $\pm$ 4.29	
Other (friends, relatives etc.)	26.25 $\pm$ 14.28		4.25 $\pm$ 5.33	
Time spend on care	r=0.016	0.238	r=0.095	0.337

ZBI: Zarit Caregiver Burden Inventory; BHS: Beck Hopelessness Scale; SD: Standard deviation.



The correlation of the caregiver burden and hopelessness scores with the other functional scales of the patient was analyzed. Accordingly, it was found that the caregiver burden increased as the functional independence level of the patients worsened ( $p<0.001$ ). In addition, it was determined that caregiver burden increased as the level of stigma and depression increased ( $p<0.001$ ). Also, there was a moderate positive correlation between caregiver burden and hopelessness level ( $p<0.001$ ) (Table 3).

In addition to all these analyses, logistic regression analysis was performed to identify predictors of caregiver burden. For logistic regression analysis, no care burden ( $ZBI\leq 20$ ) was coded as “0” and mild-moderate-severe care burden

( $ZBI=21-88$ ) as “1”. Hopelessness scale was coded as minimal-mild ( $BHS\leq 8$ ) and moderate-severe ( $BHS\geq 9$ ). As a result of regression analysis, the effect of patient gender, functional dependence level, and caregiver hopelessness score on care burden was found to be significant. Being male was an important variable that increased caregiver burden ( $\beta=4.21$ ,  $p=0.044$ ). In addition, as the Barthel scores of the patients worsened ( $\beta=0.96$ ,  $p=0.032$ ) and the hopelessness scores of the caregivers increased ( $\beta=1.37$ ,  $p<0.001$ ), caregiver burden increased ( $R^2=0.53$ ). The most important factors contributing to the level of caregiver hopelessness were found to be caregiver age ( $\beta=1.03$ ,  $p=0.049$ ) and caregiver burden ( $\beta=1.08$ ,  $p=0.001$ ) (Table 4).

**TABLE 3:** Relationship between caregiver burden, hopelessness and other scales.

Scales	$\bar{X}\pm SD$	Spearman rho (r)				
		1	2	3	4	5
1. ZBI (cg)	23.55±14.28	>0.999				
2. BHS (cg)	5.74±4.91	0.519**	>0.999			
3. MBI (p)	79.71±27.34	-0.414**	-0.209*	>0.999		
4. BDI-II (p)	14.65±11.78	0.363**	0.205*	-0.367**	>0.999	
5. Stigma (p)	37.29±13.47	0.418**	0.241*	-0.507**	0.534**	>0.999

\* $p<0.05$ ; \*\* $p<0.001$ ; SD: Standard deviation; ZBI: Zarit Caregiver Burden Inventory; cg: Caregiver; BHS: Beck Hopelessness Scale; MBI: Modified Barthel Index; BDI-II: Beck Depression Inventory-II.

**TABLE 4:** Regression analysis for predicting caregiver burden and hopelessness.

Variables	B	SE	Significant	Exp(B)	95% CI for Exp(B)		R <sup>2</sup>
					Lower	Upper	
<b>Caregiver burden</b>							
Sex (p)	1.43	0.56	<b>0.011*</b>	4.211	1.392	12.735	0.538
Age (cg)	-0.032	0.020	0.112	0.968	0.931	1.007	
MBI (p)	-0.036	0.014	<b>0.008*</b>	0.964	0.939	0.991	
Duration of diagnosis (p)	0.003	0.001	<b>0.005*</b>	1.003	1.001	1.004	
Stigma (p)	0.009	0.028	0.741	1.009	0.955	1.067	
Depression (p)	-0.016	0.025	0.528	0.984	0.937	1.034	
BHS (cg)	0.321	0.080	<b>&lt;0.001**</b>	1.379	1.179	1.613	
Constant	1.038	1.847	0.574	2.822			
<b>Hopelessness</b>							
MBI (p)	0.008	0.011	0.453	1.008	0.987	1.029	0.318
Stigma (p)	0.001	0.025	0.958	1.001	0.953	1.053	
Depression (p)	-0.002	0.026	0.932	0.998	0.949	1.050	
Age (cg)	0.036	0.018	<b>0.049*</b>	1.037	1.00	1.075	
Duration of diagnosis (p)	0.000	0.001	0.746	1.00	0.998	1.001	
Caregiver burden (cg)	0.077	0.022	<b>0.001*</b>	1.080	1.034	1.129	
Constant	-5.014	1.805	0.005	0.0007			

\* $p<0.05$ ; \*\* $p<0.001$ ; SE: Standard error; CI: Confidence interval; cg: caregiver; MBI: Modified Barthel Index; BHS: Beck Hopelessness Scale.

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## DISCUSSION

Individuals with neurological diseases could have many physical and psychosocial symptoms, and the disease burden is generally high. Therefore, it is expected that the care burden perceived by the caregivers of these patients will be high. Also, as the care burden increases, it can be predicted that the level of hopelessness will also increase. In this study, in which patients and their primary caregivers were included, caregiver burden, hopelessness level, and related factors were investigated.

In this study, the caregiver burden scale's mean score was 23.5 ( $\pm 14.2$ ), and mild to moderate care burden was found. A different study evaluating care burden in neurological diseases reported this average as 36.5 ( $\pm 14.3$ ). Although many factors affect the degree of care burden, the diagnosis received by the patients and the disease burden caused by the disease can be shown as the biggest factor. In the study conducted by Özkan Tuncay and Kars Fertelli, patients' independence levels are lower.<sup>25</sup> The fact that the mean Barthel score was one of the most important factors affecting the burden of care in our current study supports this situation.

Apart from this, it was also found that different variables belonging to the patient and the caregiver affected the care burden. For example, it is noteworthy that patient gender among sociodemographic characteristics is associated with caregiver burden. In regression analysis, it was found that the care burden was four times higher in caregivers of male patients. This may be explained by the roles attributed to individuals by society or cultural differences. Although it varies from society to society, it can be said that the responsibilities or roles imposed on men are less than those of women. Therefore, male patients receiving care have higher expectations, which may increase the caregiver's burden. In different studies, it has been reported that the burden of caregiving is related to gender, and the fact that the care recipient is male and the caregiver is female has been reported as a factor that increases the burden of care.<sup>6,7,26</sup> The other factor associated with caregiver burden was income level. It was found that the poor income level of both the patient and the caregiver increased the caregiver's

burden. Low-income level is expected to bring with it an increased economic burden. In our current study, more than half of the patients and caregivers (60%) reported that their economic life was negatively affected due to caregiving. The decreased labor force due to illness/caregiving and increased medical costs due to illness can be shown as the main reasons for this situation.<sup>27</sup> An important variable contributing to caregiver burden was the closeness of the caregiver to the patient. It is noteworthy that the mean caregiver burden score was highest in parents. This may be attributed to two different reasons. The first one is the age factor. In our study, it was found that the age of the caregiver was positively correlated with care burden. Therefore, it is expected that the increased age of the parents would lead to increased care burden. The other factor can be said to be the psychosocial burden felt by the parents. The families of patients whose lives are affected multidimensionally (marriage, work life, social life, etc.) due to their diseases are also directly affected by this situation. For example, it has been reported that individuals whose private, work, or social life is affected due to epilepsy have more psychiatric comorbidity, which is directly related to the caregiving burden.<sup>28,29</sup>

Among the clinical characteristics, disease diagnosis, and diagnosis duration were associated with care burden. In fact, it can be said that these two factors contribute to the burden of care similarly. Increasing the duration of diagnosis will lead to an increase in the disease burden and a decrease in the patient's level of independence. In our study, the positive correlation of the Barthel score of the patients with the burden of care supports this situation. Similarly, the burden of the disease may be heavier because Parkinson's disease is seen in advanced ages and includes many physical, psychological, and behavioral symptoms.<sup>13,30</sup> Therefore, it can be said that these patients had lower Barthel scores and higher care burden scores.

Interestingly, the time spent on caregiving was not found to be significant with care burden. In different studies, the duration of caregiving is the factor found to be associated with care burden.<sup>3,31</sup> The fact that caregivers did not distinguish between the time they spent with the patient without providing care and

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the time they spent with the patient without providing care may have caused this result. Even if the patient does not need care (e.g. a young epilepsy patient who is able to fulfil activities of daily living), caregivers may state that they take care of the patient 24 hours a day because they live in the same house. Therefore, this situation can be explained by not fully understanding the problem. It may be recommended to question this factor in more detail in different studies to be conducted.

Depressive mood and feeling stigmatized due to the disease were important factors found to be associated with care burden. It can be thought that physical health is generally impaired in neurological diseases, and this situation increases the burden of care. However, mental health and psychosocial well-being are also important factors for care burden. It is reported that individuals who are stigmatized due to their disease are more depressed, have low self-confidence, and poor quality of life.<sup>32</sup> In a recent study, it was emphasized that the care burden of individuals caring for epilepsy patients is closely related to the patients' anxiety, anxiety and depression levels.<sup>33</sup> Similarly, in a study conducted with multiple sclerosis patients and their caregivers, it was reported that neuropsychiatric symptoms as well as physical disability of the patients were important factors contributing to the burden of care.<sup>34</sup> In a recent review article, it was emphasized that the burden of care in neurological diseases is affected by the diagnosis received by the patients, the prognosis of the disease, and the level of both physical and mental health of the patients.<sup>35</sup> Therefore, it is very important to investigate the mental health and psychosocial well-being of patients as well as their physical health.<sup>36</sup> Therefore, nurses who have important roles in patient care should provide the necessary guidance for patients to receive psychological support.

Factors that increase the burden of care are generally associated with the level of hopelessness of the caregiver. In particular, the caregiver's age and the caregiving burden were the two most important predictors contributing to hopelessness. In different studies, it is seen that hopelessness is not a frequently studied subject. Instead, the relationship between caregiving burden and depression and burnout was

questioned. Similar results were obtained in these studies, and it was emphasized that depression and burnout levels increased as the care burden increased.<sup>29,37</sup> Beck et al. reported that hopelessness had a greater effect on suicide risk than depression in their comprehensive study.<sup>38</sup> This situation reveals the effect of hopelessness level on caregivers' well-being and quality of life. Therefore, one of the first things to be done to reduce the level of hopelessness of caregivers is to reduce the burden of care. The most important task for this falls to nurses. Nursing has a holistic approach, caring for the patient and educating and counseling the patient's relatives when necessary. It has been reported that different interventions nurses apply to reduce the burden of care reduce caregiver burden and depression levels, increase self-management, and strengthen coping mechanisms.<sup>39</sup> In fact, the steps to be taken to reduce the care burden of the caregiver will indirectly benefit patient care because it will not be possible for a caregiver with an increased care burden and impaired psychosocial well-being to provide quality care. Therefore, it can be said that determining the factors contributing to caregiver burden and attempts to eliminate these factors will also improve the quality of patient care.

## CONCLUSION

It has been observed that caregiver burden in neurological diseases is felt at different degrees and is associated with many factors related to the patient/caregiver contributing to this burden. In addition, caregiver burden was found to be an important predictor contributing to the level of hopelessness. Therefore, it is necessary to determine the factors contributing to caregiver burden and to plan interventions for modifiable factors.

For this purpose, first of all, caregivers should be evaluated comprehensively and their social support systems should be questioned. The units/persons from whom caregivers can receive social support (associations, patient schools, nursing homes, nurses, doctors, etc.) should be explained to caregivers. In addition, both physical and psychosocial health levels of patients should be examined. Since it is anticipated that the improvement in the health of the patients may reduce the burden of the caregiver,



holistic care should be provided to the patient by relevant persons (doctor, nurse, psychiatrist, psychologist, etc.). Efforts should be made to reduce the caregiver burden by taking initiatives to increase the quality of life of patients. In this regard, the nurse who provides holistic care to the patient has important

## STRENGTHS AND WEAKNESSES OF THE STUDY

Including both caregivers and patients within the scope of the research enables a comprehensive evaluation of the factors affecting caregiver burden and hopelessness level. This can be considered as the strength of the study. Although the caregiver burden of individuals with neurological diseases was investigated in our current study, the fact that all individuals with chronic diseases (e.g., Alzheimer's disease) and their caregivers could not be included in the study can be shown among the limitations. In addition, the symptoms, clinical course, and therefore the burden it imposes on the caregiver may be different for each neurological disease. From this perspective, discussing it under the title of "neurological diseases" without focusing on a single disease in detail can be

shown as a limitation. In addition, the unequal number of patients in each disease group included in the study (mostly stroke patients) and the fact that the study was conducted in a single center, considering cultural differences, can also be shown as limitations.

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## Conflict of Interest

*No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.*

## Authorship Contributions

**Idea/Concept:** Kübra Yeni; **Design:** Kübra Yeni; **Control/Supervision:** Kübra Yeni; **Data Collection and/or Processing:** Sümeyye Mutlu; **Analysis and/or Interpretation:** Kübra Yeni; **Literature Review:** Kübra Yeni, Sümeyye Mutlu; **Writing the Article:** Kübra Yeni.

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