



The relationship between the severity of the disease and burden on the caregivers

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Abstract

This study aimed to evaluate the relationship between the severity of the disease and the burden on the caregiver in rehabilitation patients. The study included 45 caregivers and 45 neurological rehabilitation patients (hemiplegia, paraplegia, and tetraplegia). Caregiver Strain Index (CSI) was applied to participants for caregiver burnout, Nottingham Health Profile (NHP) was applied for patients' quality of life, To assess sleep quality, the Pittsburgh Sleep Quality Index (PSQI) was applied and Beck Depression Inventory (BDI) was applied for symptoms of depression. The Barthel Index was used to measure patients' performance in daily life activities. The average motor functional independence score of our patients was 44.29 ± 20.70 . In the correlations of CSI with NHP, BDE, PSQI, and Barthel, CSI-PSQI ($r: 0.443$ $p: 0.002$), CSI-BDE ($r: 0.382$ $P: 0.01$), NHP2-CSI ($r: 0.417$ $p: 0.004$), and NHP social isolation-CSI were positively correlated ($r: 0.353$ $p: 0.017$). BARHEL-CSI was negatively correlated ($r: -0.332$ $p: 0.026$). According to the regression analysis, PSQI, BDE, NHP social isolation, and NHP2 values ($p: 0.002$, $p: 0.014$, $p: 0.017$, $p: 0.004$) had a significant positive effect on CSI. Barthel index had a negative effect. The higher the level of addiction in rehabilitation patients, the greater the stress experienced by caregivers. Exhaustion of those who are interested in people with disabilities will also put a burden on the patient and society.

Keywords: caregiver strain index, burden, caregiver, quality of life

1. Introduction

Stroke, which is the most common neurological disease in the world, is one of the leading causes of disability in the adult population (1). Cerebrovascular events (CVEs), paraplegia and tetraplegia in addition to causing motor function disorders, also significantly affect patients' daily life activities with emotional changes. Neurological, functional, and cognitive disabilities may leave a patient psychologically shattered and physically dependent on others (2).

Caregivers are defined as individuals who provide basic support and medical care to people with cancer, disabilities, injuries, or chronic illnesses in home and community-based settings. In dependent patients, caregivers are given significant responsibilities for the patient's ongoing care and rehabilitation (3). Caregivers may sometimes have to provide care beyond their personal resources or capacities. As the burden on caregivers increases, so do the risks in terms of psychological consequences (4).

Epidemiological studies have shown that the survival rate increases following diseases that cause motor function disorders. Especially in the prevention of complications, rehabilitation, and ensuring good care, the role of caregivers becomes even more important (5).

Neurological diseases have negative psychological effects on both families and patients.

Depression, sleep disorders, and deterioration in quality of life are commonly observed in individuals who take care of the patient during the care process, treatment, prevention of complications, and recovery at home (6-8). While there are many publications in the international literature on the incidence and severity of these problems in individuals, data is limited in our country (9,10).

Based on this, we aimed to evaluate the relationship between the severity of the disease and the burden on the caregiver, as well as the effects on the caregiver in our study.

2. Materials and Methods

In the study, 45 individuals who care for patients with neurological diseases (hemiplegia, paraplegia, tetraplegia...) aged 18 and over who applied to our hospital's Physical Medicine and Rehabilitation clinics, and 45 neurological rehabilitation patients with whom communication could be established were included.

The inclusion criteria for the study were determined as being 18 years of age or older, providing care for the patient

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for at least 3 months, providing care for 8-10 hours per day, accepting to participate in the study, and being reachable. Caregivers of patients with transient ischemic attack, professional caregivers, non-continuous caregivers, caregivers who did not understand or speak Turkish were not included in the study.

The Caregiver Strain Index (CSI) was applied to the participants for caregiver burnout, the Nottingham Health Profile (NHP) was applied for the patients' quality of life, the Pittsburgh Sleep Quality Index (PSQI) was applied to evaluate sleep quality, and the Beck Depression Inventory (BDI) was applied for depression symptoms. The Barthel Index was used to measure the patients' performance in daily life activities.

The scales were applied to the individuals by the researcher. The interviews were conducted in a separate room and in private.

The individuals were informed that their names would not be written on the scales and that the information obtained would only be used by the researcher. During the application, any unclear points were explained individually to the person without any guidance. The application of the scales took an average of 30-35 minutes for each individual.

To conduct the research, approval was obtained from the local Ethics Committee (Ethics Committee approval number: 2022-16/24). In accordance with the principles of the Helsinki Declaration, participants were informed about the research, and written and verbal consents were obtained.

Caregiver Strain Index (CSI): Covers issues such as emotional stress, physical needs, and time constraints. It consists of 13 items. Patients respond with yes (1) or no (0). The score is calculated by adding the 0 and 1 answers, giving a score range between 0 and 13 (11). Turkish validity was made by Uğur and friends (12).

Nottingham Health Profile (NHP): Consists of sub-dimensions such as Pain, Emotional Reactions, Energy, Physical Mobility, Social Isolation, and Sleep. Scoring is between 0 and 100. Low scores indicate less impact from the disease, while high scores indicate more impact. Turkish validity was made by Küçükdeveci and friends (13).

Pittsburg Quality Index (PSQI): The scale was defined in 1989 to identify good and poor sleep and to determine sleep quality. Scoring is between 0 and 21. A high score indicates poor sleep quality (14).

Beck Depression Inventory (BDI): It was developed by Aron T. Beck in 1961. It is a 21-item self-assessment scale that measures attitudes and symptoms of depression. It is an easy-to-score scale. 0-9: indicates normal level, 10-18: indicates mild symptoms of depression, 19-29: indicates moderate level

of depression, 30-63: indicates severe symptoms of depression.

Barthel Index: It is an assessment scale used to measure an individual's performance in daily life activities. Daily life activities in 10 areas are evaluated. According to the scoring, 0-20 is considered totally dependent, 21-61 is considered severely dependent, 62-90 is considered moderately dependent, 91-99 is considered mildly dependent, and 100 is considered independent(15).

3. Results

The study included 45 patients and 45 individuals who undertook patient care. 71.1% of the caregivers were female, while 28.1% were male. The average motor functional independence score of our patients was 44.29 ± 20.70 . The demographic characteristics and clinical information of the patients and caregivers included in the study are presented in Table 1. Table 2 includes the demographic and clinical characteristics of the patients included in the study. One-way ANOVA test was performed among the diagnostic groups. Depression, quality of life scales, mean \pm SD, and p-values are shown in Table 3.

Table 1. Distribution of caregivers' socio-demographic characteristics (n=45)

Socio-demographic characteristics	Number of caregivers	Number of patients
Age		
18-24	2	4
25-34	6	0
35-44	15	4
45-54	9	6
>55	13	31
Gender		
Female	32	21
Male	13	24

Table 2. Demographic and clinical characteristics of patients

Parameters	
Age (year) Avg \pmSD	63.51 \pm 12.05
Gender (%)	
Male	52
Female	58
Duration of illness (month)	9.37 \pm 8.06
Etiology (%)	
Thromboembolic	80.6
Hemorrhagic	19.4
Diagnosis n (%)	
Hemiplegia	37 (82.7)
Paraplegia	5 (11.1)
Other	3 (6.7)
Barthel index (patient)	
Motor function Avg \pm SD	44.29 \pm 20.70
Cognitive AVG \pm SD	23.47 \pm 10.95
Total AVG \pm SD	67.06 \pm 28.01

Table 3. Quality of life scales by patient groups and CSI results of caregivers

	Hemiplegia (AVG±SD)	Paraplegia (AVG±SD)	Other (AVG±SD)	p
PSQI	8.2 ±3.4	9±2.3	3.6±4.7	0.07
BDI	19.4± 13.05	24.8 ±14.2	26.3± 7.02	0.505
NHP (Pain)	70.3±36.9	60± 54.7	20.8± 23.6	0.108
NHP (Emotional)	57.5± 34.2	64.1± 34.1	55.2± 41.6	0.911
NHP (S.İ.)	50.3±43.6	92.3±13.7	47.2 ±45.6	0.117
NHP (P.A.)	56.3±34.5	26.2±39.3	64.4±21.5	0.117
NHP1	364.2±166.1	381.2±170.2	249.4±120.5	0.49
NHP2	4.8±2.6	2.8± 3.03	3.3± 0.5	0.19
CSI	8.2±4.3	11±2.2	7±4.3	0.3

NHP: Nottingham Health Profile; BDI: Beck Depression Inventory; PSQI: Pittsburg Quality Index; CSI: Caregiver Strain Index; S.İ: Social İsolation; P.A: physical activation

In the correlations of CSI with NHP, BDE, PSQI, and Barthel, CSI-PSQI (r: 0.443 p: 0.002), CSI-BDE (r: 0.382 P: 0.01), NHP2-CSI (r: 0.417 p:0.004), and NHP social isolation-CSI were positively correlated (r:0.353 p: 0.017). BARHEL-CSI was negatively correlated (r:-0.332 p: 0.026). There was no significant relationship between CSI and caregiver age (p>0.005).

According to the regression analysis, PSQI, BDE, NHP social isolation, and NHP2 values (p: 0.002, p: 0.014, p: 0.017, p: 0.004) had a significant positive effect on CSI. Barthel index had a negative effect.

The results of the regression analysis of patients' NHP, BDE, PSQI, Barthel scales, and caregivers' degree of strain are given in Table 4.

Table 4. The results of regression analysis on the relationship between patients' NHP, BDE, PSQI, Barthel scales and caregivers' level of distress.

	B	B(Beta)	p	R ²
PSQI	0.52	0.443	0.002	0.19
BDI	0.11	0.365	0.014	0.13
Barthel	-0.05	-0.33	0.026	0.11
NHP (Pain)	0.02	0.23	0.119	0.05
NHP (Emotion)	0.014	0.112	0.46	0.012
NHP (S.İ.)	0.03	0.353	0.017	0.12
NHP (P.A.)	-0.012	-0.09	0.52	0.009
NHP (Sleep)	0.03	0.26	0.07	0.07
NHP1	0.006	0.22	0.13	0.05
NHP2	0.66	0.41	0.004	0.17

NHP: Nottingham Sağlık Profili; BDI: Beck Depression Inventory; PSQI: Pittsburg Quality Index; S.İ: Social İsolation; P.A: Physical activation

4. Discussion

The aim of this study was to evaluate the relationship between the severity of illness in dependent patients and the burden on caregivers, as well as the effects on the caregiver. We found that as limitations in daily life activities, depression, and sleep quality in patients increased, the burden on caregivers also significantly increased. Linear regression analysis revealed a strong association between the Barthel index and caregiver

distress index.

Our findings, which showed a significant decrease in the caregiver's burden on CSI as the patient's dependence on the caregiver decreased, are in line with the literature (16,17). Our results indicate the potential value of targeting not only the patient but also the caregiver in dependent patients.

In situations that cause disability, women usually take on the caregiver role, and two-thirds of all caregivers are women (18). In our study, 32 (71.1%) of the caregivers were female. Rivera and colleagues found that caregivers for women with spinal cord injuries were mostly mothers, sisters, or daughters, indicating that psychological problems may be more prevalent (19). The average CSI for male and female caregivers was 8±4.96 and 9.5±2.7, respectively, with no significant difference (p=0.27). These statistics indicate that the increase in CSI is not dependent on the gender of the caregiver. Our findings contradict other studies that have observed higher levels of stress in female caregivers (20). The age group of the caregivers and the relatively short average duration of illness (9.37±8.06 months) may explain the discrepancy.

In the regression analysis results for the patients' impact evaluation, PSQI, BDE, NHP social isolation, and NHP2 values showed a significant positive effect on CSI (p: 0.002, p: 0.014, p: 0.017, p: 0.004, respectively). Sleep disorders are commonly seen in dependent patients. Poor sleep quality can worsen the patient's clinical condition and cause functional impairment. A study conducted on American adults at the national level found that patients with disabilities had shorter sleep duration compared to non-disabled individuals (21,22). Consistent with our evaluations, it was concluded that disrupted sleep quality in patients increased caregiver burden. NHP is an easy and quick test to measure the quality of life in care patients. In dependent patients, feelings of emotional and social isolation have been reported to be worse than in same-aged individuals. Additionally, dependent patients have higher levels of pain and worse sleep scores (23,24). In our study, it was also found that an increase in NHP social isolation values resulted in a significant burden on the caregiver.

We found that an increase in patients' BDI also increased caregiver burden. Depression related to disability is a condition that leads to unsatisfactory rehabilitation, low quality of life, and increased mortality (25). Our clear conclusion from evaluating all measures is that any condition that increases the burden of the disease also increases the strain on the caregiver.

Ultimately, dependency affects not only the lives of patients, but also their caregivers. The higher the level of dependency in stroke patients, the greater the stress experienced by caregivers. The exhaustion of those who take care of people with disabilities will also burden the patient and society. Minimizing exhaustion is a necessity. First, professional support should be provided instead of selecting caregivers from family members or relatives. Programs aimed at reducing caregiver burden should include practices that increase the patient's self-sufficiency and reduce psychological burden.

Limitations: It is our limit that we have a low number of patients included in the study, the degree of addiction of our patients and the more detailed grouping according to their rehabilitation status.

Conflict of interest

The authors declare that they have no financial or non-financial conflicts of interest related to the subject matter or materials discussed in this article.

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Ethical statement

To conduct the research, approval was obtained from the local Ethics Committee (Ethics Committee approval number: 2022-16/24). In accordance with the principles of the Helsinki Declaration, participants were informed about the research, and written and verbal consents were obtained.

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Authors' contributions

Concept:N.P.T., Design:N.P.T., Data Collection or Processing: N.P.T., Analysis or Interpretation:N.P.T., Literature Search: N.P.T., Writing: N.P.T.

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