

Determining the Relation Between the Burden of Caregivers for Individuals With Neurological Disease and Caregivers' Ways of Coping With Stress

Nörolojik Hastalığı Olan Bireylerin Bakım Vericilerinin Bakım Veren Yükü İle Stresle Başa Çıkma Biçimleri Arasındaki İlişkinin Belirlenmesi

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SUMMARY

Objectives: This analytical study was done to determine the relation between the burden of caregivers for individuals with neurological disease and caregivers' ways of coping with stress.

Methods: This study was conducted in the neurology clinic of Giresun Professor Doctor A. İlhan Özdemir Public Hospital from October 1 to December 31, 2015. The sample of the study consists of 64 people who care for patients with neurological problems and who agreed to participate in the research. An information form, the Zarit Caregiver Burden Scale and the Stress Coping Styles Scale were administered to the participants.

Results: The participants' mean caregiver burden score was 31.90 ± 15.56 . Their self-confident approach score was 2.41 ± 0.54 , their optimistic score approach was 2.42 ± 0.59 , and their helpless approach score was 1.49 ± 0.63 . Their yielding approach score was 1.64 ± 0.49 , and their social support seeking approach score was 1.79 ± 0.66 . Care giving burden was found to be higher for primary caregivers, for individuals who have another patient requiring care and for female caregivers ($p < 0.05$). A significant negative relation was found between caregiver burden, self-confident approach and optimistic approach scores, while a positive moderate relation was found between helpless and yielding approach scores.

Conclusion: Caregivers for patients with neurological problems use less self-confident and optimistic approaches and more helpless and yielding approaches as their caregiver burden increases. Female caregivers and caregivers having another patient who requires care have greater caregiving burden.

Keywords: Caregiver burden; coping; neurological disease; nursing.

ÖZET

Amaç: Bu çalışma, nörolojik hastalığı olan bireylerin bakım vericilerinin bakım veren yükü ile stresle baş etme biçimleri arasındaki ilişkinin belirlenmesi amacıyla analitik olarak yapılmıştır.

Gereç ve Yöntem: Çalışma, 1 Ekim–31 Aralık 2015 tarihleri arasında Giresun Prof. Dr. A. İlhan Özdemir Devlet Hastanesinin nöroloji kliniğinde yürütülmüştür. Çalışmanın örneklemini, nörolojik sorunu olan bir bireye bakım veren ve araştırmaya katılmayı kabul eden 64 kişi oluşturmuştur. Hastalara bilgi formu, Zarit Bakım Veren Yükü Ölçeği ve Stresle Başa Çıkma Tarzları Ölçeği uygulanmıştır.

Bulgular: Katılımcıların ölçeklerden aldıkları ortalama puanlar incelendiğinde; bakım veren yükünün 31.90 ± 15.56 , kendine güvenli yaklaşımın 2.41 ± 0.54 , iyimser yaklaşımın 2.42 ± 0.59 , çaresiz yaklaşımın 1.49 ± 0.63 , boyun eğici yaklaşımın 1.64 ± 0.49 ve sosyal destek arama yaklaşımının 1.79 ± 0.66 olduğu saptandı. Ayrıca, primer bakım verici olanlarda, bakıma muhtaç bir başka yakını olanlarda ve kadın bakım vericilerde bakım veren yükü daha yüksek bulundu ($p < 0.05$). Katılımcıların bakım veren yükleri ile kendine güvenli yaklaşım ve iyimser yaklaşım puanları arasında negatif yönde anlamlı orta düzeyde bir ilişki, çaresiz yaklaşım ve boyun eğici yaklaşımları arasında pozitif yönde anlamlı orta düzeyde bir ilişki bulundu.

Sonuç: Nörolojik sorunu olan hastaya bakım veren kişilerin, bakım veren yükleri arttıkça kendine güvenli ve iyimser yaklaşımları kullanma durumlarının azaldığı, çaresiz ve boyun eğici yaklaşımları kullanma durumlarının arttığı; primer bakım verenlerin, bakıma muhtaç başka yakını olanların ve kadın olanların bakım veren yüklerinin daha yüksek olduğu söylenebilir.

Anahar sözcükler: Bakım veren yükü; baş etme; nörolojik hastalık; hemşirelik.

Introduction

Chronic diseases cause a number of problems, including reduced functional ability, deterioration of lifestyle and poor role performance. These problems can negatively affect the

physical, psychological and social adjustment of the people who provide care to the individuals with chronic diseases.^[1] They also cause a burden to caregivers since they increase care-related responsibilities and cause trouble in their professional, domestic and social lives.^[2] A study of the diseases that cause burden to caregivers reported that particularly individuals who provide care to stroke patients had heavier caregiver burden.^[3]

The concept of caregiver burden describes the physical health problems and psychosocial reactions experienced during the provision of care to patients.^[2] It also includes financial problems, social problems and the deterioration of family

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relationships.^[4] Past studies have found that people who provide care to patients with neurological issues experience high level emotional stress.^[5,6] Other problems include emotional exhaustion and depersonalization.^[7] These psychological problems can turn into serious psychological disorders such as depression and anxiety disorder.^[8-10] Along with psychological problems, caregivers may also experience physical impairments including sleeping issues and lower back pain.^[11,12]

There are studies that demonstrate the effect of various factors on caregiver burden. The caregiver-related factors in these studies are: age, gender, marital status, education level, having health insurance, receiving help with care, patient care experiences, feelings of weakness and desperation, having health issues and individual coping methods.^[4,7,13-15] Factors related to patients affect the burden of caregivers as well. They include: physical and depressive symptoms, poor motor function, poor verbal understanding, neurological deficits, and long hospital stays.^[3,14,16] The most important social factor that affects caregiver burden is the social support received by caregivers.^[3,15,17]

Past studies have found that individuals who provide care to patients with neurological issues have a variety of physical and psychological and social problems related to increased caregiver burden. It is necessary to support caregivers to prevent or mitigate these problems. Another way to provide this support is to strengthen caregivers' coping styles. The coping styles they use should be determined along with their correlation with caregiver burden. For this reason, this study aimed to determine the correlation between caregiver burden and coping styles of the individuals who provide care to people with neurological problems. Its research questions are:

- Is there a connection between the caregiver burden and the styles of coping with stress of individuals who care for individuals with neurological problems?

- What are the factors that influence the caregiver burden of people who care for individuals with neurological problems?

Materials and Method

Study Objective

This analytical study aimed to determine the correlation between the caregiver burden and the stress-coping styles of people who provide care to individuals with neurological diseases.

The Population and Sample of the Study

This study was conducted from October 1 to December 31, 2015 at the Professor Doctor A. İlhan Özdemir Public Hospital. The population of the study included 102 individuals who provided care to patients who were being treated

in the neurology clinic from October 1 to December 31, 2015 due to their neurological problems. No sample was selected for the study, and 64 individuals who met the inclusion criteria and agreed to participate in the study were included in the study sample. The inclusion criteria were being literate, providing care to an individual with neurological issues, having sufficient cognitive level to understand the tools used by the study, and agreeing to participate after being informed about the study. The exclusion criteria were having a physical or psychological disease that would prevent understanding the study tools and not agreeing to participate. The mean age of the caregivers who met these criteria and participated in the study was 50.45 ± 11.66 years. Of them, 78.2% were married, and approximately two-thirds (68.8%) were females.

Data Collection Tools

The study data were collected using an information form created by the researchers, the Zarit Caregiver Burden Scale and the Stress Coping Styles Scale. The data were collected during personal interviews with the caregivers. Each interview lasted approximately 20 minutes.

The information form includes questions about the caregivers' individual characteristics, including: age, marital status, education level, family type, number of children, residence, employment status and income level. The information form also includes questions about the presence of a person providing primary care, degree of relation with the patient, having any other relatives that needed care, and receiving care support and psychological support from health professionals.

The Zarit Caregiver Burden Scale was created by Zarit et al. (1980). It is used to evaluate the stress experienced by people who provide care to individuals in need of care. The validity and reliability study of the Turkish version of the scale was carried out by İnci and Erdem (2008).^[18] The scale has 22 5-point Likert-type items, and each item is scored from 0 to 4. The minimum score on the scale is 0, and the maximum score is 88. Higher scores indicate greater caregiver burden. Its internal consistency coefficient is 0.95. In this study, this coefficient was 0.89.

The Stress Coping Styles Scale (SCSS) was created by Folkman and Lazarus (1980). It assesses the methods used by individuals in stressful situations and their thoughts about them. The validity and reliability study of the Turkish version of the scale was carried out by Şahin and Durak (1995).^[19] The scale has 30 4-point Likert-type items, and each item is scored from 0 to 3. It includes five subscales: self-confident approach, optimistic approach, desperate approach, yielding approach and the approach of seeking social support. The self-confident approach, the optimistic approach and the approach of seeking social support are active ways of coping that are addressed to solving problems. The desperate ap-

proach and the yielding approach are passive ways of coping that are focused on emotions. There are no total scores on the scale. An increase in each mean subscale score indicates that the coping method is used more frequently. The internal consistency coefficients were determined for each subscale, and they were 0.80 for self-confident approach, 0.68 for optimistic approach, 0.73 for desperate approach, 0.70 for yielding approach and 0.47 for the approach of seeking social support.

Statistical Analysis

The study data were analyzed using SPSS 16.0 statistics software. For the analysis of the data, the study used descriptive statistics (numbers, percentages, means and standard deviations). Pearson’s correlation analysis was used to determine the correlation between caregiver burden and stress coping styles. Since the data had a normal distribution and met the criteria for parametric tests, the study used the independent groups t-test to evaluate caregiver burden mean scores based on sociodemographic characteristics. The threshold for significance was $p < 0.05$.

Ethical Considerations

The required permission was obtained before the study from the Giresun Provincial Association of Public Hospitals General Secretary Ethical Board (permission date: 10/14/2015, permission number: 42991614/770/5241). In accordance with the principles of the Declaration of Helsinki, the participants were informed about the research and their consent was obtained.

Findings

Of the caregivers, 64% came from nuclear families, 35.9% had 3 or 4 children, and 32.9% had 1 or 2 children. Of them, 37.5% lived in the city, 23.4% were employed, and 73.4% described their income levels as moderate. Only 21.9% of them stated that they had high school or higher education. The mean hospital stay was 9.50 ± 12.54 days for the patients who received care. Of them, 81.4% had cerebrovascular diseases, 11.8% had epilepsy, and 6.8% had multiple sclerosis. An evaluation of the patients’ activity levels found that all patients who were hospitalized due to cerebrovascular disease were immobile, the multiple sclerosis patients were half-immobile, and the epilepsy patients were mobile. The caregivers stated that they had been providing care to their patients for 1.79 ± 3.98 years. Of the caregivers, 48.4% were the children of the patients, and 17.2% were their spouses. Of the patient relatives, 76.6% were the primary caregivers, 20.3% had another relative who was dependent on care, 71.9% received care support from health professionals, and 50% received psychological support from them.

The caregivers’ mean scores on the scales (Table 1) were 31.90 ± 15.56 for caregiver burden, 2.41 ± 0.54 for self-confi-

dent approach, 2.41 ± 0.59 for optimistic approach, 1.49 ± 0.63 for desperate approach, 1.64 ± 0.49 for yielding approach and 1.79 ± 0.66 for the approach of seeking social support.

Table 2 shows that the caregiver burden was heavier for females ($t = 2.630, p = 0.011$), for the primary caregivers of the patients ($t = -2.262, p = 0.027$) and for those who had another care-dependent relative ($t = 2.776, p = 0.007$). Marital status, education level and employment status did not affect caregiver burden ($p > 0.05$).

Table 3 shows the correlation between the caregivers’ burden and stress-coping styles. There was a significant, but moderate negative correlation between caregiver burden and self-confident approach and optimistic approach scores ($r = -0.355, p = 0.004$; $r = -0.258, 0.039$, respectively), and a significant, but moderate positive correlation between caregiver

Table 1. Caregivers’ mean scores on the caregiver burden and coping styles scales

| Scales | Mean±SD | Min. | Max. |
|--|-------------|------|-------|
| Caregiver burden scale | 31.90±15.56 | 2.00 | 63.00 |
| Self-confident approach | 2.41±0.54 | 1.14 | 3.00 |
| Optimistic approach | 2.41±0.59 | 0.40 | 3.00 |
| Desperate approach | 1.49±0.63 | 0.25 | 3.00 |
| Yielding approach | 1.64±0.49 | 0.50 | 2.83 |
| The approach of seeking social support | 1.79±0.66 | 0.25 | 3.00 |

SD: Standard deviation; Min.: Minimum; Max.: Maximum.

Table 2. An evaluation of the scores on the caregiver burden scale based on sociodemographic characteristics

| Sociodemographic characteristics | Caregiver burden | | | |
|---|------------------|-------------|--------|-------|
| | n | Mean±SD | t | p |
| Sex | | | | |
| Female | 44 | 35.20±14.39 | 2.630 | 0.011 |
| Male | 20 | 24.65±15.93 | | |
| Marital Status | | | | |
| Married | 50 | 31.28±14.76 | -0.605 | 0.547 |
| Single | 14 | 34.14±18.59 | | |
| Education Level | | | | |
| Lower than high school | 50 | 34.37±15.00 | 1.509 | 0.136 |
| High school or lower | 14 | 27.73±16.47 | | |
| Employment Status | | | | |
| Employed | 15 | 27.88±13.88 | -1.666 | 0.100 |
| Unemployed | 48 | 34.80±15.77 | | |
| Is he/she the primary care-giver? | | | | |
| Yes | 49 | 34.26±15.54 | -2.262 | 0.027 |
| No | 15 | 24.20±13.35 | | |
| Does he/she have an relatives that are dependent on care? | | | | |
| Yes | 13 | 42.07±11.95 | 2.776 | 0.007 |
| No | 51 | 29.31±15.40 | | |

SD: Standard deviation.

Table 3. The correlation between caregivers' burden and stress-coping styles (n=64)

| Stress-coping styles | Caregiver burden | |
|--|------------------|-------|
| | r | p |
| Self-confident approach | -0.355 | 0.004 |
| Optimistic approach | -0.258 | 0.039 |
| Desperate approach | 0.536 | 0.000 |
| Yielding approach | 0.418 | 0.001 |
| The approach of seeking social support | -0.151 | 0.235 |

burden and desperate approach and yielding approach scores ($r=0.536$, $p=0.000$; $r=0.418$, 0.001 , respectively). However, there was no correlation between caregiver burden and the approach of seeking social support ($r=-0.151$, $p=0.235$).

Discussion

This study's primary finding is that individuals who provide care to people with neurological issues have a moderate level of caregiver burden (31.90 ± 15.56). Similarly, Mollaoglu et al. (2011) conducted a study with relatives of stroke patients and found that the caregiver scale mean score was at a moderate level (33.02 ± 15.92).^[20] Another study concluded that the caregiver burden mean score of caregivers for immobile patients was 27.77 ± 8.85 .^[21] On the other hand, Tarı-Selçuk and Avcı (2016) examined the caregiver burden of caregivers for elderly people with chronic diseases and determined that their mean caregiver mean score was 60.70 ± 14.19 , but was higher for caregivers for stroke patients (68.80 ± 12.40).^[3]

This study also found that gender affects caregiver burden ($t=2.630$, $p=0.011$). The female participants' mean caregiver burden score was 35.20 ± 14.39 , while it was 24.65 ± 15.93 for males. Gündüz and Erhan (2008) conducted a study with stroke patients, and females in particular had worse physical and psychological conditions than the males.^[13] There are other studies showing that females' caregiver burden is greater than that of the males.^[15,22] In the relevant literature, there are also studies that are in contrast with this finding and did not find a statistically significant correlation between caregiver burden and gender.^[4,14] However, this study and others have found that the caregiver burden of female caregivers who provide care to individuals with neurological issues is greater than that of males. This may result from the fact that females have similar roles to play in their daily lives other than the caregiver role. Along with the caregiver role, these familial roles, including mother, spouse, daughter-in-law and child, may give too many responsibilities to women, which causes them stress.

Another finding of this study is that being a primary caregiver affected the caregiver burden of the participants ($t=-2.262$, $p=0.027$). Like this study, Watanabe et al. (2015)

found that primary caregivers who provided care at home to patients with cerebrovascular diseases for a long time had seriously high levels of caregiver burden.^[23] However, past studies have demonstrated that caregiver burden also increases as the number of care-giving hours increases.^[16,24-26] Guo and Liu (2015) also conducted a relevant study. Although they did not focus on the caregiver burden of primary caregivers for stroke patients, they determined that 71% of the caregivers had symptoms that indicated a high level of caregiver burden.^[27] Providing care to an individual who is dependent on continuous care can cause caregivers to fail to spare time for themselves, be isolated from society, have psychological problems and disrupt their other responsibilities since caregiving occupies a large portion of their time. These problems can increase caregiver burden.

Another finding of this study is that having other relatives who are dependent on care affects caregiver burden ($t=2.776$, $p=0.007$). Similarly, Duru-Aşiret and Kapucu (2013) did a study with patient relatives who looked after stroke patients and determined that caregivers with children had greater caregiver burden than those who did not.^[25] This finding also supports the second finding of this study, since females are also responsible for the care of other care-dependent people in the family (e.g., children, elderly, patients). Thus, the caregiver burden of females was determined to be higher.

Finally, this study found a correlation between the caregiver burden of caregivers for patients with neurological issues and their stress coping styles. There was a significant, but moderate negative correlation between caregiver burden and self-confident approach and optimistic approach scores, and a significant, but moderate positive correlation between caregiver burden and desperate approach and yielding approach scores. However, there was no correlation between caregiver burden and the approach of seeking social support. Similar studies conducted in neurology clinics have also determined a significant correlation between caregiver burden and coping styles.^[28-30] For this reason, using effective coping methods is an important part in the reduction of caregiver burden. If caregivers use coping methods that focus on the issues, they can overcome the difficult experience of looking after an immobile patient more easily, or they can at least adapt to this process.

Relevant studies have found that the most common coping methods used by caregivers are acceptance, avoidance, obtaining social support and problem-solving.^[28,29,31] In addition, Studies have also demonstrated that the caregivers of patients who stay in neurology clinics used emotion-focused coping methods or negative coping methods more than the others.^[30,32] These two studies found that the caregivers preferred coping methods that were not problem-focused. This study found that the caregivers used the problem-focused

method more, but did not use the approach of seeking social support that often. Considering the importance of social support in coping with stressors effectively, this result indicates a negative situation with regard to caregiver burden.

Conclusion and Suggestions

This study concluded that the caregivers with heavy caregiver burden used the desperate and yielding approaches most and used the self-confident and optimistic approaches less frequently. Female caregivers, those that were looking after another care-dependent patient, and primary caregivers had greater caregiver burden than the other caregivers. Based on these results, the study suggests that the coping strategies of the caregivers should be strengthened, and the number and accessibility of the social support resources should be improved to reduce the caregiver burden or prevent it in the first place. It is highly important that health professionals prepare caregivers for problems, make it easier for them to express themselves, convey the required information about resources and give them psychological support.

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