ORIGINAL ARTICLE   **ÖZGÜN ARAŞTIRMA**

PREPAREDNESS OF CAREGIVERS GIVING CARE TO STROKE PATIENTS FOR CAREGIVING AND THE STRESS THEY PERCEIVE

Ayşe AYDIN[1], Bilgi GÜLSEVEN KARABACAK[2]

[1]Marmara University Institute of Health Sciences, Department of Fundamentals of Nursing, İstanbul, TÜRKİYE
[2]Marmara University Faculty of Health Sciences, Department of Nursing, İstanbul, TÜRKİYE

ABSTRACT

INTRODUCTION: The descriptive and cross-sectional study sought to examine the preparedness of caregivers giving care to 167 stroke patients in a state hospital in Zonguldak province in the west of Turkey for caregiving and the stress they perceive.
METHODS: The data was collected via the Personal Information Form, the Modified Barthel Index (MBI), the Preparedness for Caregiving Scale (PCS) and the Perceived Stress Scale (PSS).
RESULTS: The MBI score of the stroke patients was found to be 42.06±39.30, the PCS score of the caregivers was found to be 19.47±7.40 and the PSS score was found to be 26.07±9.14. The patient's age and treatment time were statistically correlated with the mean PCS score in a negative direction (p<.05). The mean MBI score was statistically correlated with the mean PCS score in a positive direction; while the mean MBI score was statistically correlated with the mean PSS score in a negative direction (p<.05). The mean PCS score was significantly correlated with the mean PSS score in a negative direction (p<.05).
DISCUSSION AND CONCLUSION: The study determined that a number of variables such as the patient's functional independency, age, place of hospitalization and caregiver's affinity with patient, care experience and reasons for caregiving affect the preparedness of caregivers for caregiving and the stress they perceive. In order to increase the preparedness of caregivers for caregiving, it was recommended to give discharge training including other members of family concerning the course of disease, complications and management of care process.
Keywords: Stroke, caregiver, stress.

İNMELİ HASTALARIN BAKIM VERİCİLERİNİN BAKIM VERMEYE HAZIR OLUŞLUĞU VE ALGILADIKLARI STRES

ÖZ

GİRİŞ ve AMAÇ: Bu çalışma, Türkiye'nin batısında yer alan Zonguldak ilindeki bir devlet hastanesinde 167 inmeli hastanın bakım vericisinin bakım vermeye hazır oluşluğunu ve algıladığı stresi incelemek amacıyla tanımlayıcı ve kesitsel tipte yapıldı.
YÖNTEM ve GEREÇLER: Veriler; Kişisel Bilgi Formu, Modifiye Barthel İndeksi (MBI), Bakım Vermeye Hazır Oluşluk Ölçeği (BVHOÖ) ve Algılanan Stres Ölçeği (ASÖ) ile toplandı.
BULGULAR: İnmeli hastaların MBI puanı 42,06±39,30, bakım vericilerin BVHOÖ puanı 19,47±7,40 ve ASÖ puanı 26,07±9,14 bulundu. Hasta yaşı ve tedavi süresi ile BVHOÖ ortalaması arasında negatif yönde istatistiksel bir ilişki belirlendi (p<.05). MBI ve BVHOÖ ortalaması arasında pozitif yönde, MBI ve ASÖ ortalaması arasında negatif yönde istatiksel bir ilişki belirlendi (p<.05). BVHOÖ ortalaması ile ASÖ ortalaması arasında negatif yönde anlamlı bir ilişki bulundu (p<.05).

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TARTIŞMA ve SONUÇ: Bu çalışma ile bakım vericinin bakım vermeye hazır oluşluğu ve algıladığı stresin; hastanın fonksiyonel bağımsızlığı, yaşı, yatış yeri ve bakım vericinin hastaya yakınlığı, bakım deneyimi, bakım verme nedenleri gibi birçok değişkenden etkilendiği belirlendi. Bakım vericilerin bakıma hazır oluşluğunun arttırılmasına yönelik ailenin diğer bireylerinin de dahil edildiği hastalığın seyrine, komplikasyonlara ve bakım sürecinin yönetimine dair taburculuk eğitimi önerildi.

Anahtar Sözcükler: İnme, bakım verici, stres.

INTRODUCTION

Stroke; is characterized by a neurological disorder, which secondary to acute focal damage to the central nervous system due to a vascular cause including cerebral infarction, intracerebral hemorrhage and subarachnoid hemorrhage (1). Stroke ranks second in primary causes of death worldwide and third in the list of factors leading to disability (2).

In 1970, the World Health Organization defined stroke as 'rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin' (3).

Following stroke, patients face several problems such as sensorial, visual, cognitive and sexual dysfunctions along with balance and muscular coordination deficits and paralysis. Stroke patients who lose their functional independence due to these problems become more or less dependent on performing their daily life activities and need long-term care (4,5).

Caring of stroke patients who need long-term care is considered familial responsibility, and family members assume responsibility for meeting their care needs. In this process, we should not ignore the fact that the process affects not only patients but also caregivers (6,7,8).

Being a caregiver is not a choice-based/predictable situation for individuals. Therefore, individual's adaptation to this situation will only occur after they have to assume the caregiver position (9). One of the important indicators of early adaptation of the caregivers to the processes is their preparedness for the process and the level of stress he/she perceives during the process.

In addition to achieving positive gains such as personal development, deepening of bidirectional relations, satisfaction, social support from other people and self-esteem during the caregiving process; caregivers also face negative experiences (10,11). Somatic complaints such as indigestion, increased or decreased appetite, irregular nutrition and headaches related to caregiving are observed in caregivers. In addition, as the caregiving process gets longer, caregivers face health deterioration as well as problems impairments due to being unable to spare time for their own needs, in addition to problems such as chronic fatigue, weight loss or gain, sleep disturbance, muscle pain, impairment of concentration and clothing mess as they cannot spare time for their own needs (12).

The caregiving role includes providing physical care and emotional support, maintaining home care and coping with caregiving stress. Readiness is the perception that caregivers feel for realizing the tasks and demands in the caregiving process. Preparedness is the ability and competence to predict possible problems and generating solutions in order to better manage a crisis better before it occurs (13,14).

Purpose: Nurses, who are a part of the multidisciplinary team, have great responsibilites in ensuring that caregivers adapt to the care process that they encounter unprepared and spontaneously, in determining their physical and social needs, and in protecting and maintaining their biopsychosocial health. It is anticipated that the findings obtained from the study will form the basis for further studies in this field and draw attention to the importance of the subject.

The study sought to answer the following questions;

• What are the factors related to the patient and caregiver that affect the caregivers' preparedness level to provide care?

• What are the patient- and caregiver-related factors that affect caregivers' perceived stress?

• Is there a relationship between caregivers' perceived stress and their preparedness to provide care?

METHODS

Study Design and Sampling Method: The research was a descriptive cross-sectional study. It was conducted with the caregivers of stroke patients receiving treatment in the Neurology Clinic and Neurology Intensive Care Unit of a public hospital in Zonguldak province in the west of Turkey between 01 January-30 April 2020. The

caregivers of 296 stroke patients comprised the target population of the study. We used the G*Power software to estimate a sample size with ample statistical power to detect a statistically significant difference if one exists. Based on power analysis, a minimum sample size of 167 (alpha=0.05, power=0.80, and effect size=0.5) was determined to be sufficient for this research. The sample included caregivers of 167 stroke patients who met the following inclusion criteria and agreed to participate in the study.

Inclusion Criteria:
• Being the caregiver of a patient diagnosed with stroke for the first time,
• Aged 18 years or older,
• Speaking Turkish,
• Volunteering to take part in the research.

Collection of the Data: The data was collected via face-to-face interview and survey 24-48 hours before discharge.

Data Collection Tools

Participant Information Form: The Participant Information Form, which was prepared in line with the literatüre knowledge, consists of two sections: "Caregiver Introductory Form" and "Patient Introductory Form". The Caregiver Introductory Form has two sections as sociodemographic characteristics of the caregiver and information about care, and a total of 15 questions. There are a total of four questions in the Patient Introductory Form.

Preparedness for Caregiving Scale (PCS): Archbold and Stewart (1986) developed the Preparedness for Caregiving Scale to determine the the preparedness level of caregivers giving care to stroke patients for caregiving. Karaman (2015) adapted it into Turkish (15). The scale has eight items and also one more item examining the area in which caregivers desire to be more ready. The possible scores to be obtained from the scale are 0 and 32. Higher scores obtained from the scale indicate that caregivers feel more ready to give care, while lower scores indicate that they feel less ready. The adaptation study found the reliability coefficient to be 0.9215. This study found the Cronbach's Alpha value to be 0.972.

Perceived Stress Scale (PSS): Cohen, Kamarck and Mermelste (1983) developed the Perceived Stress Scale (PSS). Eskin et al. (2013) conducted the Turkish validity and reliability study of the scale (16). Comprising a total of 14 items, the PSS was designed to measure how stressful a person perceives certain situations in his/her life. It has two subscales as inadequate self-efficacy perception and stress/discomfort perception. The possible total scores to be obtained from the scale are 0 and 56. Higher total score indicates higher perceived stress level. The internal consistency coefficient for the PSS-14 was found to be 0.8416. This study found the Cronbach's Alpha value to be 0.905.

Modified Barthel Index (MBI): Barthel and Mahoney developed the Barthel Index in 1965 to determine the independency level of patients in their activities. Shah et al. modified the index in 1989. It is used in all patients to evaluate sensorial and motor losses. The modified version has become more specific in measuring functional independency. Küçükdeveci et al. (2000) conducted the adaptation study in Turkish patients (17). The index evaluates independency levels concerning ten functional situations such as transfer, movement, climbing up stairs, nutrition, clothing, personal care, bathing and toilet and urine-stool incontinence. The scoring ranges from 0 to 100 in total. 0 point indicates full dependency and 100 points indicate independency (17). This study found the Cronbach's Alpha value to be 0.977.

Statistical Analysis: Descriptive data of categorical variables (frequency distributions) were presented as "number" or "percentage". Numerical variables were given as "mean", "standard deviation", "minimum", and "maximum". Pearson correlation analysis was used to examine the correlation between two numerical variables, and multiple linear regression analysis was used to examine their effects on the Caregiving Readiness Scale and Perceived Stress Scale. IBM SPSS Statistics 23 program was used for statistical analysis and evaluations. The statistical significance level was set at $p<0.05$.

Ethical Dimension of the Study: For the study, we received an approval dated 11.11.2019 and numbered 205 from Marmara University Institute of Medical Sciences Clinical Research Ethics Committee and an institutional permit dated 25.12.2019 and numbered 39330677-1900367562 from Zonguldak Provincial Directorate of Health. This research was developed following the Good Clinical Practice's Guidelines and the WMA Helsinki Declaration. The caregivers who were included in the sample, gave informed consent. We adhered to ethical principles throughout the study.

RESULTS

Table 1 shows the distribution of sociodemographic characteristics of stroke patients and caregivers included in the study. Of the stroke patients, 79.6% were hospitalized in the ward and 20.4% in the intensive care unit. The mean age of the patients was 72.45±12.76 years and 53.9% of them were female. The mean stroke treatment duration was 21.04±17.75 days and all patients had social security. The MBI score of the patients was 42.06±39.30.

Table 1. Distribution of the sociodemographic characteristics related to the stroke patients and caregivers (n=167).

Sociodemographic Characteristics Related to the Stroke Patient		n	%
Place of hospitalization	Service	133	79.6
	Intensive care	34	20.4
The patient's age (year) mean±sd (min-max)		72.45±12.76 (36-98)	
The patient's sex	Female	90	53.9
	Male	77	46.1
Stroke treatment time (day) mean±sd (min-max)		21.04±17.75 (6-88)	
Modified Barthel Index score mean±ss (min-max)		42.06±39.30 (0-100)	
Sociodemographic Characteristics Related to the Caregiver		n	%
	Spouse	33	19.8
	Child	89	53.3
	Parent	1	0.6
Affinity	Sibling	5	3.0
	Relative	30	18.0
	Other (neighbor, friend, etc.)	9	5.4
Sex	Female	107	64.1
	Male	60	35.9
Age (year) mean±ss (min-max)		48.37±12.27 (19-86)	
Employment	Yes	39	23.4
	No	128	76.6
	Less	65	38.9
Income	Equal	92	55.1
	More	10	6.0
State of living with the patient	Yes	81	48.5
	No	86	51.5
Care experience	Available	55	32.9
	N/A	112	67.1
State of having support/assistant	Yes	67	40.1
	No	100	59.9
	Family responsibility	130	77.8
	Love for the patient	103	61.7
Reasons for caregiving	Having noone else to give care	67	40.1
	Lack of home care services	3	1.8
	Economic contribution	8	4.8

Of the caregivers, 53.3% were the children of the patients, 64.1% were female, and their mean age was 48.37±12.27 years. In addition, 81.4% of the caregivers were married, 83.2% had children,

89.8% had social security, 62.9% were primary school graduates and 51.5% lived with their spouses and children. Of the caregivers, 48.5% lived with the patient, 32.9% had experience in care and 40.1% had support/assistant in patient care.

Multiple linear regression analysis was used to determine the impacts of the sociodemographic factors related to the patients and caregivers on the PCS. As summarized in Table 2; the variables of place of hospitalization, living with the patient, care experience and giving care due to absence of a caregiver explained 26.7% of the total PCS variance. The model was found to be significant as p<0.001 at 99% confidence level (p<0.001; R^2=0.267). Evaluating the four variables in the model according to the β coefficients; the variables of place of hospitalization, care experience and giving care due to absence of a caregiver made the strongest contribution to the model (-5.325, 3.412 and 3.104, respectively). The other variable, living with the patient made less contribution to the model (-2.554). According to the multiple linear regression analysis, as summarized in Table 3, to determine the effects of the sociodemographic factors related to the patients and caregivers on the PSS, variables such as place of hospitalization, family responsibility and love for the patient, which are among the reasons for caregiving, explained 17.7% of the total PSS variance. The model was found to be significant as p<0.001 at 99% confidence level (p<0.001; R^2=0.177). Evaluating the three variables in the model according to their β coefficients; The strongest contribution to the model was made by the variables of hospitalization location and caregiving due to family responsibility (7.481 and -4.845, respectively). The variable of providing loving care to the patient contributed less to the model (-2.801).

In the study, features related to PSS and PCS were compared in stroke patients. Table 4 shows the variables affecting the total PSS and PCS score. The patient's MBI score showed a positive and significant correlation with PCS, and MBI showed a negative correlation with PSS (p<0.05). The patient's age and treatment duration were statistically negatively correlated with the mean PCS score (p<0.05). When the correlation between the scales is examined in Table 5; There was a significant negative correlation between PCS and PSS (p<0.05).

Table 2. Impact of the factors related to the patients and caregivers on the PCS (n=167).

	Unstandardized Coefficients		Standardized Coefficients	t	p
	B	Std. Error	Beta		
(Constant)	20.248	3.353		6.038	0.000***
Place of hospitalization	-5.325	1.279	-0.291	-4.163	0.000***
State of living with the patient	-2.554	1.013	-0.173	-2.522	0.013*
Care experience	3.412	1.081	0.217	3.156	0.002**
Having no one else to give care	3.104	1.037	0.206	2.994	0.003**

p<0.001; R²=0.267
*: p<0.05, **: p<0.01, ***: p<0.001.

Table 3. Impact of the factors related to the patients and caregivers on the PSS (n=167).

	Unstandardized Coefficients		Standardized Coefficients	t	p
	B	Std. Error	Beta		
(Constant)	26.859	3.237		8.297	0.000***
Place of hospitalization	7.481	1.610	0.331	4.647	0.000***
Family responsibility	-4.845	1.563	-0.221	-3.099	0.002**
Love for the patient	-2.801	1.334	-0.149	-2.100	0.037*

p<0.001; R²=0.177
*: p<0.05, **: p<0.01, ***: p<0.001.

Table 4. Examining the correlation between patient-specific characteristics and the PCS and PSS (n=167).

		Preparedness for Caregiving Scale	Perceived Stress Scale
Patient-Specific Characteristics			
The patient's age	r	-0.158	0.059
	p	0.042*	0.450
Treatment time	r	-0.266	0.101
	p	0.001**	0.195
Modified Barthel Index	r	0.323	-0.223
	p	0.000***	0.004**

r: Pearson's correlation coefficient *: p<0.05, **: p<0.01, ***: p<0.001.

Table 5. Examining the correlation between the scales (n=167).

		Perceived Stress Scale
Preparedness for Caregiving Scale	r	-0.506
	p	0.000***

r: Pearson's correlation coefficient *: p<0.05, **: p<0.01, ***: p<0.001.

DISCUSSION AND CONCLUSION

The purpose of the study was to examine the personal, sociodemographic and caregiving characteristics of stroke patients and their caregivers as a predictor of caregivers' preparedness and perceived stress. Our results indicated that the variables of place of hospitalization, care experience of the caregiver, reasons for caregiving and living with the patient were significant predictors. The variable of place of hospitalization significantly predicted the preparedness of caregivers and the stress they perceive (Table 2 and Table 3). Our study included the caregivers of patients receiving treatment in the service and intensive care unit. Intensive care unit is the place where the treatment process of patients continues after an unplanned and sudden incident. Relatives of patients treated in intensive care are usually in an intensely stressful mood, such as fear of losing their loved ones, dazedness and anger, due tosudden and life-threating natüre of the event (18). Accordingly, it is possible to conclude that the variable of place of hospitalization affects the mood of caregivers.

Reasons for caregiving significantly predict caregivers' preparedness and perceived stress. While providing care due to having no one else to give care significantly predicted preparedness (Table 2), giving care due to family responsibility and love for the patient significantly predicted stress (Table 3). In their research with the caregivers of Alzheimer's patients, Uygun and Taylan (2018) found that among the reasons why caregivers provide care to Alzheimer's patients are mostly family responsibilities and having no one to provide care (19). Considering the study results; It was observed that caregiving did not significantly predict preparation and stress due to its economic contribution or lack of home care services. Because reasons for caregiving are personal and vary from person to person, results in other studies may also differ.

Care experience of caregivers significantly and positively predicted the preparedness for caregiving. Experienced caregivers have a higher preparedness for caregiving compared to others (Table 2). In their study with caregivers of brain

tumor patients, Malak and Dicle (2008) found that as experience in patient care increases, the care burden decreases (20).

According to another result of our study; it was observed that living with the patient positively predicted the preparedness to provide care (Table 2). In a study conducted by Yıldırım, Engin and Başkaya (2013) with the caregivers of 80 stroke patients, it was found that 80% of the caregivers lived with the patient (21). In their study on conducted by Kalınkara and Kalaycı (2017) burnout and life satisfaction in caregivers of elderly individuals, it was found that 70.8% of caregivers lived with the patient (22). The studies conducted indicate that most caregivers live with the patient and this is associated with being the patient's child or spouses (23). In the study conducted by Henriksson and Årestedt (2013), it was stated that living with the patient positively affects the preparedness (13). Accordingly, it is possible to think that living with the patient prevents the mandatory change of the living environment after discharge and allows common personal habits to be known and maintained and the process to be followed closely. Another results obtained from our studyis that the caregiver's preparedness for caregiving increases and stress level decreases as the stroke patient's functional independency level increases (Table 4). The study conducted by Uğur and Çatıker (2017) with the caregivers of home care patients and the study conducted by Ateş and Bilgili (2013) with the caregivers of spinal cord injury patients, found that the care stress increases as the dependency level increases (24,25). The study conducted by Schumacher et al (2008) determined a negative correlation between the preparedness of caregivers for caregiving and the dependency level of patients (26). The patient's age and treatment duration in the hospital affected the preparedness. However, these variables did not affect the stress. It was thought that advanced age in stroke patients affected the functional dependence and thus affected the preparedness.

The mean PCS score was negatively correlated with the mean PSS score (Table 5). Caregivers do not usually feel ready for caregiving when trying to fulfil the responsibilities brought by patient care (27,28). Lower level of sense of preparedness and self-confidence increases the stress of caregivers and negatively affects the quality and outcomes of the care to be given (29,30). The study conducted by King et al. (2010) documented a significant correlation between the lower level of preparedness for caregiving and increased anxiety level in the caregivers of stroke patients in the acute period (31). Our finding is in agreement with this literature.

As a result of the findings obtained from our study which sought to examine the preparedness of caregivers giving care to stroke patients for caregiving and the stress they perceive; the patient's functional independency affected the preparedness and perceived stress. As the preparedness for caregiving increased, the perceived stress decreased.

In order for caregivers of stroke patients to feel ready for the care process and keep the stress they perceive in their lives at a positive level, we can recommend that the caregivers be supported in creating family environments that enhance the interaction between the patient, caregiver and other family members. It would be useful to organize training sessions with the participation of other members of the family on the course of the disease, its complications and management of the care process. As the limitation, the evaluation was collected 24 or 48 hours before the patients discharge from the hospital by independent researcher.

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Ethics