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Burden of Caregivers of Stroke Patients

İnmeli Hastaların Bakıcılarındaki Bakım Yükü

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Summary

Objective: This research was conducted as a descriptive study, in order to determine the level of burden in the caregiving tasks undertaken by the relatives of stroke patients.

Material and Method: This study included the relatives of 70 elderly stroke patients who had presented to the neurology and physical therapy and rehabilitation clinics in a university hospital in Ankara, Turkey. After a review of the relevant literature, study data were collected using a form prepared for both the patient and caregiver. The Rivermead Mobility Index (RMI) and the Zarit Caregiver Burden Scale (Burden Interview) were also used.

Results: The Caregiver Burden Scale point average of the caregivers participating in our research was determined as 42.5. The difference between the points received by the patients from the RMI and the point average of the caregiver burden was statistically significant ($p<0.05$). The difference between the point average of the caregivers who assist patients with nutrition, motion, and excretion tasks was found to be statistically significant ($p<0.05$). The difference between the caregiving burden point average of caregivers with family difficulties related to caregiving, and whose daily lives were affected, was found to be statistically significant ($p<0.05$).

Discussion: In conclusion with the results of the research, suggestions were offered to make discharge training more effective, arrange training and consultancy programs aimed at coping with the problems experienced by the caregivers, and provide the required institutional support. *(Turkish Journal of Neurology 2013; 19:5-10)*

Key Words: Stroke, elderly, caregivers

Özet

Amaç: Çalışma, inmeli hastalara bakım veren hasta yakınlarının bakım yükünün belirlenmesi amacıyla tanımlayıcı olarak yapılmıştır.

Gereç ve Yöntem: Araştırmanın örneklemini Türkiye'deki bir üniversite hastanesi nöroloji polikliniği ve fizik tedavi ve rehabilitasyon polikliniğine başvuran yaşlı inmeli hastaların bakıcılığını yapan 70 hasta yakını oluşturmuştur. Çalışmanın verileri, araştırmacı tarafından ilgili literatür incelenerek geliştirilen hasta ve bakım verene yönelik hazırlanan veri toplama formu, Rivermead Mobilite İndeksi (RMI) ve Bakım Verme Yükü Ölçeği (Burden Interview) kullanılarak toplanmıştır. Çalışmanın verileri, tanımlayıcı istatistiklerin yanı sıra korelasyon, Mann-Whitney U testi ve Benferoni düzeltmeli Kruskall-Wallis H testi kullanılarak değerlendirilmiştir.

Bulgular: Çalışmanın sonucunda araştırma kapsamına alınan bakıcıların bakım verme yükü ölçeği puan ortancası 42,5 olarak saptanmıştır. Hastanın yaşı, cinsiyeti, eğitim durumu ve ek hastalık olma durumuna göre bakım verme yükü puan ortancası incelendiğinde aradaki fark istatistik açısından anlamsız bulunurken ($p>0,05$), hastaların RMI'den aldıkları puan ile bakıcıların bakım verme yükü puan ortancası arasındaki fark istatistik açısından anlamlı bulunmuştur ($p<0,05$). Hastaların beslenme, hareket, boşaltım, tedavi gibi işlerini yapan bakıcıların puan ortancası arasındaki fark istatistik açısından anlamlı bulunmuştur ($p<0,05$). Bakım verme nedeniyle ailede güçlük yaşayan ve günlük yaşamı etkilenen bakıcıların bakım verme yükü puan ortancası arasındaki fark istatistik açısından anlamlı bulunmuştur ($p<0,05$).

Sonuç: Araştırmadan elde edilen sonuçlar doğrultusunda taburculuk eğitiminin etkinliğinin artırılması, bakıcıların yaşadıkları sorunlarla başetmelerine yönelik eğitim ve danışmanlık programlarının düzenlemesi, belirli aralıklarla bakım verenin izlenmesi ve gerekli kurumsal desteğin sağlanması önerilerinde bulunulmuştur. *(Türk Nöroloji Dergisi 2013; 19:5-10)*

Anahtar Kelimeler: İnme, yaşlı, bakıcılar

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Introduction

Stroke is the third leading cause of death worldwide, after heart disease and cancer, and the most important cause of disability (1, 2). China ranks first in deaths resulting from strokes with the USA in fourth place (3). In Turkey, based on the National Burden of Disease and Cost–Effectiveness Project Report published in 2004, stroke is the second leading cause of death among 20 fatal diseases (4).

Stroke causes disability and dependence on others in one of every three patients (5). After a stroke, patients may become dependent on others to function in daily life and some may even need long-term care. In general, the care of patients is undertaken by their families. Many studies have determined that stroke patients may incur disabilities and need the care of family members (6,7,8,9). Bethoux et al. (10) found that nearly 70-80% of stroke patients live in their own home after discharge although they need the help of their families. Greveson et al. (11) determined that 76% of patients live in their own home, and 71% of these patients continue life with disability. Ferri et al. (12) found 97.6% of stroke patients need care and that while 53.7% of stroke patients in rural China need special care, 72.7% of the stroke patients in India also need additional care. Another study in Turkey determined that 94.7% of stroke patients need help with personal hygiene tasks (13).

The care provided by the patients' family members is not limited to a single type of help but includes health care, administering medication, personal care (bathing, feeding, toilet care, dressing), planning social services, shopping and doing housework, financial management, assistance with finances, and sharing the same house. Although providing care to a family member afflicted by stroke may have its positive side, the caregiver often experiences difficulties related to the many responsibilities involved in caregiving (14). In studies conducted with caregivers of stroke patients, several factors impact the level of burden felt by caregivers. The most influential factors are individual personalities and temperaments of caregivers, daily time allocated for care, level of the patients' dependency on the caregiver for daily activities, care tasks performed, availability of the helper for care, and economic status of caregiver and patient. Long-term care causes physical and mental fatigue of caregivers and an increase in the symptoms of depression. Morimoto et al. (15) found that 50% of caregivers have at least one chronic disease, while in another study, 73% of caregivers had at least one chronic disease, and headache, hypertension, rheumatological diseases and heart disease were the most common health problems (16). Earlier studies have observed that caregivers of stroke patients have the highest levels of anxiety and depression (17,18). Another study conducted with caregivers showed that 44.7% of caregivers have depression (19). In a study carried out to determine the level of care burden experienced by the relatives giving care to family members affected by strokes McCullagh et al. (20) found that 62% of caregivers experienced social isolation.

Methods

In this descriptive study participants were selected among family members of stroke patients, caring for the patient at home. Volunteers had to be older than 18 years, able to read and write Turkish, have no communication problems, and no history of mental illness. Participation was voluntary and they had to have cared for a stroke patient for at least 3 months.

The sample for this study consisted of 70 caregivers. The sample size was finalized to include 70 caregivers with a power analysis.

Patient information was obtained from patient files, observations and interview with patients, while caregiver information was obtained by individual interviews. After examining the related literature, study data was collected using a data collection form developed and prepared by researchers, as well as the Rivermead Mobility Index (RMI) and Zarit Caregiving Burden Scale (Burden Interview) instruments. The data collection form was tested before the study with 7 stroke caregivers to identify and correct any potential problems. However, since caregivers gave positive responses to the data collection form, no changes were required. The patient data collection form had 19 questions about the socio-demographic characteristics, the illness and treatment of the patients. The caregiver form had 30 questions about the caregivers' socio-demographic characteristics, health problems, available support systems, illness and its process. Development, validity and reliability of the RMI were carried out by Collen et al. (21). The RMI's main aim is to evaluate the effectiveness of rehabilitation efforts as applied to the disabled. It is also used to determine mild or severe mobility problems resulting from other causes in both neurological diseases and the process of aging. Fourteen questions assess the hierarchical activity of patients ranging from turning in bed to running. A patient's own statement is essential in responses to questions. Only the 5th question was assessed by the interviewer. One point for each 'yes' response was given, and answers were scored based on a possible total of 0-15 points. The Zarit Caregiving Burden Scale (Burden Interview), developed by Zarit, Reever and Bach-Peterson in 1980, was used to determine the stress and caregiving burden on the caregivers. The scale consists of 22 questions with a Likert-type evaluation using words such as "never", "rarely", "sometimes", "frequently", or "almost always" with scoring values 0 to 4 points, respectively. A minimum of 0 and maximum of 88 points can be scored on the scale (22,23). Approval was obtained from the institution where the research would be conducted, and written consent was also obtained from the caregivers. In addition, oral and written approval was obtained from the authors for the scales used in the research. The Senate Ethics Committee of the University submitted to the Dean of the Faculty of Health Sciences for ethical assessment of the study and the study was approved by both.

The SPSS 15.0 software (SPSS Inc., Chicago, IL, USA) was used to evaluate the data. In addition to descriptive statistical methods (median, standard deviation), the Chi-square test was used to compare qualitative data. As the data do not have a normal distribution, RMI's Kolmogorov-Simirrov Value ($Z=0.163$, $p<0.001$), the Zarit Caregiving Burden Scale's Kolmogorov-Simirrov Value ($Z=0.970$, $p=0.043$), and the Mann-Whitney U test were used in pair-group comparisons. However, the Kruskal-Wallis H test with Benferoni correction was used in 3 or more group comparisons. The Spearman correlation analysis was used in the relationship between two variables. The results were considered statistically significant ($p<0.05$).

Results

Thirty percent of stroke patients participating in our study were 65-69 years old, 55.7% of participants were male, 88.6% were married, and 40% of them had finished primary school. Other information about the study participants is as follows: 95.7% of the patients had an additional disease; 80.6% of them had hypertension; 40.3% of patients had hypercholesterolemia, and 40.3% had coronary artery disease. Problems related to stroke were experienced by 92.9% of the patients. Sixty percent of these patients had paresis, and 40% of them had plegia. The right arm and leg of 45.3% of the patients, and the left arm and leg of 31.2% of patients were affected. Stroke had caused a speech problem in 4.7% of patients. All patients had been treated with 6±2 drugs. Researchers found that 97.1% of the patients had at least one stroke-related problem. Loss of balance was experienced by 79.4% of patients; 66.2% of participants had gait problems; urinary incontinence was a problem for 57.4% of patients; 51.5% had nutrition issues; 39.7% of patients had difficulties with communication; 26.5% of patients had vision problems; insomnia was a problem for 20.6%; and 11.8% had fecal incontinence. For those participating in the study, the median score of the Rivermead Mobility Index (RMI) was 4.0. As none of the patients in the study had scored 15 points, it was determined that all the patients were experiencing mobility issues to some degree.

Table 1. Descriptive characteristics of caregivers (n=70)

Demographic characteristics	Number	%
Age		
26-39	9	12.9
40-49	16	22.9
50-59	19	27.1
60-69	16	22.9
70 -81	10	14.2
Sex		
Female	60	85.7
Male	10	14.3
Education		
Illiterate	7	10
Graduated from primary school	26	37.1
Graduated from high school	10	14.3
Graduated from university	27	38.6
Marital status		
Married	55	78.6
Single	15	21.4
Children in Family		
Yes	53	75.7
No	17	24.3
Financial status		
Income and expenses are in balance	46	65.7
Income and expenses are not in balance	24	W34.3
Affected status by the disease of the economic situation disease		
Affected	40	57.1
Not affected	30	42.9
Health problems		
Yes	47	67.1
No	23	32.9
Distribution of health problems*		
Hypertension	23	48.9
Disc herniation	18	38.3
Stomach ulcer	13	27.7
Headache	8	17.0
Hypercholesterolemia	8	17.0
Diabetes Mellitus	6	12.8
Depression	5	10.6
Thyroid problems	5	10.6
Osteoporosis	3	6.4
Asthma	2	4.3
Relationship		
Husband / wife	30	42.9
His / her daughter	29	41.4
His / her son	6	8.6
*Other	5	7.1

*Sister, bride, groom

Caregivers (27.1%) ranged in age from 50 to 59 years; 36.8% of them were female; 36.8% had graduated from university; 78.6% of them were married; 44.3% had one or two children and 48.6 were housewives. The financial situation of 65.6% of the caregivers had been affected by the costs of caregiving. Health problems were an issue for 67.1% of the caregivers with 48.9% suffering from hypertension. The other health problems were disc herniation (38.3%), stomach ulcer (27.7%), headache (17%), and hypercholesterolemia (17%). Nearly half of the caregivers (47.8%) believed that their health problems were related to their caregiving duties, and 63.6% of the caregivers associated their health problems with sadness and stress (Table 1).

It was determined that 47.1% of the caregivers in this study had been providing care for 24 months or longer with 37.1% of the them administering 15 or more caregiving hours each day. A breakdown of caregiving tasks completed by caregivers in our study is as follows: 88.6% personal hygiene tasks, 82.9% patient feeding; 77.1% administering medications, 70% mobilizing the patient; 68.6% finance; and 57.1% grooming. Study results also revealed 71.4% of the caregivers had the help of at least one additional caregiver in patient care. However, 54% of the caregivers had just one helper in patient care whose primary duties were to assist with the physical and transport needs of the patient (60%) (Table 2).

Difficulties in caregiving for patients were experienced by 72.9% of the caregivers. These problems were related to difficulties in providing care (47.1%), strained family relationships (29.4%), and insufficient support in providing needed care (13.7%). Caregivers' strategies for coping with the problems were sharing their feelings with others (43.2%) and crying (35.3%). The daily lives of the caregivers had been affected by social isolation (55%). Caregivers were unable to get other tasks in their lives completed (23.3%). They were planning their lives according to the patients' schedules and needs (15%), and did not have enough time to take care of their own needs (6.7%). The median score of caregivers in our study according to the Caregiving Burden Scale was 42.5. Our study results also found that the median score on this scale for caregivers with children, with greater expenses than income or with health problems, was significantly high (p<0.05). Results also showed that the longer a caregiver had been caring for a patient, the their median score rose significantly on the Caregiving Burden Scale (p<0.05). When groups were compared using the Bonferroni correction, a statistically significant difference was found in the median score of the Caregiving Burden Scale of the caregivers who had been administering patient care 0-5 months and 24 months and over (p<0.008). When the median score obtained from daily care hours and the caregiving burden were compared, data showed that as the hours for patient care increased, the median score of the caregiving burden was significantly higher (p<0.05). When pair groups were compared, the difference resulted from caregivers who gave care between 1-4 and 5-9 and 10-14 hours (p<0.008). When the median score of caregivers involved in caregiving tasks related to nutrition, movement, excretion and treatment were compared, the difference was statistically significant (p<0.05).

Table 2. Patients' characteristics (n=70)WW

	Number	%
Required time for care (x:29.7 months)		
3-5 months	17	24.3
6-11 months	11	15.7
12-23 months	9	12.9
24 months or more	33	47.1
Required time for daily care/hour (x:13.5)		
1–4	14	20.0
5–9	6	8.6
	24	34.3
0–14		
15 and over	26	37.1
Caregiving tasks*		
Patient's personal hygiene	62	88.6
The patient's feeding	58	82.9
Administering medications	54	77.1
Help for activity	49	70.0
Help with finances	48	68.6
Help for elimination	40	57.1
Another helper for patient care		
Yes	50	71.4
No	20	28.6
Number of helpers assisting in patient care		
1	27	54.0
2	18	36.0
3 +	5	10.0

Type of help offered to patient*

When the status of daily life of caregivers was compared with the median score from the Caregiving Burden Scale, the difference was statistically significant (p<0.05). When the median score taken from patients' RMI was compared with the median score of the caregiving burden of the caregivers, the score taken from patients' RMI decreased, and the median score of the caregiving burden was significantly higher (p<0.05) (Table 3).

Discussion

In the studies carried out with caregivers of stroke patients, the majority of caregivers were women and wives (15,24,25), and the caregiving burden of wives was found to be heavier than that of other caregivers (26,27). Our study also determined that 42.9% of caregivers were the wives of the patients. Because women are widely considered to be more compassionate and more sensitive with an ability to establish close and strong relationships, they also seem more able to cope with the problems associated with caregiving than men (28). In addition, women have traditionally fulfilled the role of caregiver within their families, and they have also entered the workplace later than men.

Our study found that the income of 34.3% of caregivers did not cover their expenses, the financial status of 57.1% of them had been affected by their caregiving duties, and 65.6% of caregivers had financial problems due to care costs. Toseland et al. and Montgomery et al. (14,30) reported that the most frequent economic problems experienced by caregivers were an additional burden of care costs not covered by insurance, and many of them had to quit their regular employment because of their caregiving duties. In our study and others, when income status was compared with the median score of the Caregiving Burden Scale, the median score for the caregiving burden was statistically significantly high in the groups whose income was lower than their expenses (p<0.05).

Our study also found that more than half of the caregivers had at least one health problem such as hypertension, disc herniation, stomach ulcer, headache, and hypercholesterolemia. Morimoto et al. (15) determined that 50% of caregivers had at least one chronic disease. Our study found that the care burden median score of caregivers with any health problem is higher. We thought that health problems and the burden of caregiving may increase for caregivers with a high level of stress and little time to rest and take time for themselves.

The average caregiving duration was 29.7 months. This period was found to be 27.1 months in the study of Chatcheydang (31) and 27 months in the Draper et al. (32) study, The patients' need for care continued because the disability caused by their stroke possibly did not improve or recovery occurred at a slower pace than predicted. When the caregiving time was compared with the median score from the Caregiving Burden Scale, it was determined that if the caregiving duration increased, the median score on the scale increased statistically significantly (p<0.05). Pinquart and

Table 3. Correlation among RMI and Zarit Caregiving Burden Scale (n=70).

	Zarit Caregiving Burden Scale
RMI	r -0.313 p 0.008

Sorensen (34) have reported in their studies that the duration of the caregiving role is very important. The longer a person remains in the role of caregiver, the more their burden increases. This can lead to exhaustion and despair on the part of the caregiver.

Our study determined that caregivers give care to the patients an average of 13.5 hours a day. The Bugge et al. (24) study reported that caregivers devoted 13.5 hours per day in care during the first month after a patient's stroke and 16.4 hours after 6 months. This difference in daily caregiving duration seems to be due to the fact that the caregiving duration of the majority of caregivers is longer than 24 months when the caregiver is the wife or husband of a stroke patient and they share the same house with the patient. When the daily caregiving time for the patient is compared with the point average of the Caregiving Burden Scale, and when the duration of daily care hours has increased, the average score of the caregiving burden increases ($p<0.05$). The study of Macnamara et al. (35) also reported that when the hours devoted to daily care are extended, the caregiving burden increases.

Studies on caregiving show that tasks pertaining to movement, nutrition, elimination, bathing and dressing of patients are mostly done by the caregivers (15,24,31). In keeping with the literature, our study also shows that the tasks done by caregivers are personal care and hygiene (88.6%), nutrition (82.9%), treatment (77.1%), movement (70%), financial affairs (68.6%), and excretion (57.1%). When the median score obtained from the caregiving burden of caregivers who perform the nutrition, movement, excretion, and treatment tasks was assessed, the median score of caregivers who perform these activities was significantly higher ($p<0.05$). Because cleaning and dealing with finances are viewed as part of women's usual duties, these two areas may be less of a burden for caregivers.

The study results demonstrate that the majority of caregivers experience difficulty in caring for patients, and their daily lives are greatly affected by their caregiving duties. Many caregivers have experienced social isolation. They were planning their lives around the needs and schedules of their patients, and not having time to adequately take care of their own needs. Other studies have found that the caregivers caring for the elderly have experienced many hardships. They are often forced to reduce participation in social activities and have difficulties in their relationship with their family members and in the financial and business aspects of their lives (14,36). Our study determined that when caregivers are having difficulty with the care of the patient, and the affected status of their daily life were assessed using the score median of the Caregiving Burden Scale, the median score of their caregiving burden was significantly higher ($p<0.05$). Because caregivers experience a significant reduction in personal time to take care of their own life needs, at times they may feel unable to do a competent job in their caretaking activities. Feeling alone, burdened, and helpless are common emotions of caregivers. However, the burdens and negative emotions of caregivers can decrease with professional help. When we examined the ways that caregivers cope with the problems they encountered, we found that they resorted to such behaviors as crying or expressing their frustrations in talking with another person. It has been found that caregivers tend to accept their problems with a fatalistic approach by acting helpless in dealing with problems. Rather than achieving resolution, these problems only become more complicated, resulting in even more mental and/or physical distress. Kasuya et al. (36) have noted that the discussion of the problems is important in reducing caregivers' anxiety and frustrations about caregiving.

When we assessed the status of information that caregivers had been given, we found that the majority of them had been informed about the illness and treatment, while very few of them had been informed about the requirements and needs of actual home care. The study of Subgranon and Lund (37) reported that when the patients were discharged from the hospital, they had not been informed about home care by healthcare personnel, and caregivers had developed their own ways of coping with the problems encountered while delivering home care to patients. We also found that although the majority of caregivers (66.8%) needed information about care, only a small percentage of caregivers (27.2%) had stated that they wanted to obtain information about care. This suggests that caregivers do not have enough information about both the patients' care and their own self-care.

Our study also found that when the median score of the patients receiving care was compared with the median score of the caregivers' care burden, the median score of the care burden was significantly high if the patients' score on the RMI was less ($p<0.05$). The study of Magliano et al. (38) found that the care burden scores of the caregivers tending patients with a neurological deficiency were high. The median score scale of the care burden of caregivers participating in the study was 42.5, which would be considered mild to moderate. Although the level of the designated care burden was not very high, it would likely affect the caregivers' physical, social and psychological health negatively. Consequences of this could cause the caregiver to develop negative feelings for the patient, and the quality of patient care could be adversely affected.

Conclusions

Our study results indicated that the factors which may increase a caregiver's burden can vary for each individual. Therefore, education and counseling programs aimed at providing information on how to cope with the problems caregivers may encounter should be developed, and institutional support should also be provided. Discharge information and training about the needs of home care should be given by healthcare personnel starting on the first day of the patient's hospitalization, to decrease the care burden of the caregivers. Lastly, nurses should be prepared to effectively utilize their education and role as counselors in ways that will enhance both the practical skills of caregivers and the ability to cope. The goal is to lighten the burden that caregivers will most certainly encounter in providing home care to their patients.

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