Original Article

Burden of Caregiving for Stroke Patients and The Role of Social Support Among Family Members: An Assessment Through Home Visits

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Abstract

Background: The role of family members who undertake patient care is unarguably important for stroke rehabilitation. Caregivers play a key role in facilitating recovery.
Objective: This study aimed to evaluate social support and other factors that may affect the burden of care in order to reduce the burden of care among family mambers caring for stroke patients.
Methodology: A total of 66 stroke patients and their families were included in the study. Patients and their families were visited at home by the researchers. Data was collected using the patient and caregiver Identification Form, Barthel Index, Zarit Caregiver Burden Interview, and Multidimensional Perceived Social Support Scale.
Results: It was found that income level of the family member who cared for the stroke patient, status of benefiting from home care payment, presence of another person such as a child that also needs care, duration of providing care, whether the family member's health status is affected during caregiving, and perceived social support affected the burden of care.
Conclusions: It was concluded that family members of stroke patients had advanced care burdens and that it is important to support families in reducing burden of care.

Key words: Stroke, Family Caregivers, Burden of Illness

Introductıon

Stroke is a major cause of mortality, disability and dependency in activities of daily living throughout the world. The increase in stroke prevalence during the last two decades was demonstrated in the Global Burden of Disease Study (2010). In this study, it was also indicated that the rate of stroke related deaths decreased (Feign et al., 2014). According to the "Chronic Diseases and Risk Factors Study", which was conducted in Turkey (2011), incidence of stroke across all age groups was 1.8% in men and 2.2% in women and these rates increased to 8.9% in men and to 11.1% in women during old age (Republic of Turkey Ministry of Health Public Health Agency, 2013).

Stroke rehabilitation and care quality became more important with the increased chance of survival after stroke (Feign et al., 2014). Patients and their families who are treated for about 10 days due to stroke are waiting for a long rehabilitation period (Kandemir et al., 2012; Sahin et al., 2015). In this period, institutional care is sometimes sought but patient care is generally provided by family members in the home environment (Greenwood, Pelone, Hassenkamp, 2016).

The role of family members who undertake patient care is unarguably important for stroke rehabilitation. Caregivers play a key role in facilitating recovery (Andrew et al., 2015; McCullagh et al., 2005). However, care giving is a complex concept (McCullagh et al., 2005). It can be affected by numerous factors including patient's age and the premorbid relationship between the patient and caregiver as well as the individual characteristics of the caregiver such as personal beliefs, social expectations, and coping styles (Denno et al., 2013; King et al., 2010; McCullagh et al., 2005; Peyvori et al., 2012)

Since stroke is a sudden reason of chronic disability, the caregiver is obliged to undertake a number a responsibilities related to the stroke patient's treatment, feeding, hygiene, and daily living activities without any preparations (Camak, 2015; Gbiri, Olawale, Isaac, 2015). This condition brings upon various psychological, social, physical, and financial burdens for the caregiver (Asiret and Kapucu, 2012; Atagun et al., 2011; King et al., 2010). In a study conducted in the USA, it was determined that stroke patients aged 65 years or more bring an economic burden of 14.2 billion dollars upon informal caregivers (Joo et al., 2014).

Social support plays an active role in reducing the burden of care. Higher levels of social support is associated with better health (Barth, Schneider, Von Känel, 2010). It was reported that anxiety, depression and stress are related to inadequate social support in caregivers (Cumming et al., 2008) and that the major source of stress in the caregiving process is the deteriorations in interpersonal relationships (King et al., 2010). Perceived lack of social support was shown to be associated with the prognosis and mortality of various diseases including cardiac disease (Barth, Schneider, Von Känel, 2010) and cancer (Ikeda et al., 2013; Pinquart and Duberstein, 2010).

During the period which begins with admission to the hospital and ends with recovery, nurses should prioritize the evaluation of caregiver roles and benefit from appropriate social support systems in order to reduce caregiver stress. It is of paramount importance to understand the roles of family caregivers in terms of rehabilitation and their strategies for coping with problems. Caregivers should be supported in meeting their own needs since they need to maintain self-care in order to provide appropriate care for another (Asiret and Kapucu, 2012). However, the number of studies which evaluate the burden of care in family caregivers of stroke patients and which investigate the effect of supportive interventions for caregivers of stroke patients is limited (Greenwood, Pelone, Hassenkamp, 2016).

It is important to reduce the burden of family caregivers in order to increase their contribution to the rehabilitation of stroke patients.[12] In the current study, it was aimed to determine the burden of care among family caregivers of stroke patients and to evaluate the level of social support.

Methods

This study used a cross-sectional design. This study was carried out by making home visits to patients registered to the Ministry of Health Home Care Unit in a city located at the European site of Turkey between October 2014 and March 2015. This unit had four team members including a doctor, two nurses, and a physiotherapist. Home visits covered the following services: physical examination, regulation of drug treatment, injury care, administering/changing urinary and nasogastric catheters, and sample collection for various laboratory examinations. During the data collection period, there were 165 patients registered to the Home Care Unit for various diagnosis including stroke, Parkinson's disease, cerebral palsy, Alzheimer's disease, and head trauma. Among them, 85 patients out of 98 who were diagnosed with stroke were fully dependent in activities of daily living according to the Barthel Index. The study was conducted with 66 family members who were primary caregivers for the patients, who agreed to participate in the study, and who had no barriers to communication.

Before the study, permission was taken from the institution where the study would be conducted and the ethical appropriateness of the study was approved by the local board of ethics. Before home visits, caregivers were informed through phone calls and gave consent. In order to avoid security concerns in caregivers, researcher visits were performed together with home care unit team. In the process of the study, scientific and universal ethical principles were upheld. In this context, informed consent, autonomy, secrecy and the protection of privacy, equity, and beneficialness were taken into consideration. The Helsinki Human Rights Declaration was also upheld during the study.Data was collected using the Identification Form (for caregivers and patients), the Barthel Index (BI), the Zarit Burden Interview (ZBI), and the Multidimensional Scale of Perceived Social Support (MSPSS).

a. Caregiver identification form: The form was created by the researchers according to literature. It consists of 22 items regarding the socio demographic data of the caregiver (age, gender, marital status, education level, income level, etc.) and the caregiving process (degree of kinship, how long care was provided for, impact of caregiving on caregiver health etc.).

b. Patient identification form: In this form, elements that were thought to affect the burden of the caregiver such as the age, gender, and duration of illness were recorded.

The Barthel Index (BI): The Barthel Index, developed by Mahoney and Barthel, evaluates the independence levels of patients in performing daily life activities (Mahoney and Barthel, 1965). The Turkish validity and reliability study of the BI was performed by Kucukdeveci et al. The scores of the index varies between 0 and 100, where 0-20 points shows complete dependence, 21-61 points shows advanced dependence, 62-90 points shows medium levels of dependence, 91-99 points shows mild dependence, and 100 points shows complete independence (Kucukdeveci et al., 2000).

The Zarit Burden Interview (ZBI): The scale was developed by Zarit et al. in order to evaluate caregiving burden (Zarit, Orr, Zarit, 1985). The Turkish validity and reliability study of the scale was performed by Ozer et al. The likert type scale consists of 22 items. The highest score that can be attained from the scale is 88. 0-20 points shows little or no burden, 21-40 points shows a medium level burden, 41-60 points shows advanced burden, and 61-88 points shows an excessive burden (Ozer, Yurttas, Akyil, 2012). In our study, the Cronbach alpha value of the scale was calculated as 0.82.

The Multidimensional Scale of Perceived Social Support (MSPSS): The Turkish validity and reliability study of the scale, which was developed by Zimet et al. (1988), was performed by Eker and Arkar (1995). The scale consists of 12 items regarding family, friends, and special people support sources. Each item was scored with a 7 interval answer ranging from absolutely no and absolutely yes. The total score of the scale is obtained by adding together the scores of the three sub dimensions. Higher scores show higher perceived social support (Eker, Arkar, Yaldız, 2001). In our study, the Cronbach alpha value of the scale was calculated as 0.92.

After taking ethical board permission and institutional permission, the “Home Care Unit” was informed about the study. During the home visits of the unit, the researchers interviewed the family member who provided primary care to the patient. In the first phase, the independence levels of the patients in performing their daily activities were evaluated using the BI. If the patient was completely dependent according to the Index, the Identification Form, ZBI, and MSPSS were applied. The forms were filled out via face to face interviews in a room where the patient was not present. The application of the forms took 20-30 minutes.

Data was evaluated using the SPSS 22 (Statistical Package for the Social Sciences Inc; Chicago, IL, ABD) program. Descriptive characteristics were given as averages and percentages. In defining the differences between the continuous variables, the t test was used to test the significance of the difference between two averages and in groups that didn’t comply with standard distribution, the Mann Whitney U test was used instead of the t test. In the case of more than two groups not complying with the standard distribution, the Kruskal Wallis test was applied and the relations were examined through correlation analyses. For the internal consistency analyses of the scales, the Cronbach alpha coefficient was used. The level of statistical significance was taken as $p>0,05$.

Results

The demographic and care related characteristics of the caregivers were shown in Table 1. The average age of the patients was 69.36±18.34, where %65.2 were female and %48.5 had been ill for 1-5 years. The average age of the participating caregivers was 51.57±11.60, where 86.4% were female, 75.7% were married, 27.3% were high school and higher graduates, and 71.2% perceived their income level as medium. Among the caregivers, 51.5% were patient’s child, 51.5% had been giving care to the patient for 1-5 years, 59.1% received help from other family members in giving care, 30.3% had previous experience in caregiving, 86.4% thought that their health was affected by caregiving, and 12.1% benefited from financial support for care. The mean ZBI caregivers’ score was calculated as 47.42±11.91 and they were found to perceive caregiving as an advanced burden. When the perceived caregivers’ social support levels were evaluated, the mean MSPSS score was 50.74±17.78 and the highest contribution came from the family support sub dimension with an mean score of 19.37±6.65.

In Table 2, the caregiver burden was evaluated according to the caregivers’ characteristics. Care burden was not related to patient’s gender, duration of illness, caregiver’s age, gender, education and marital status, kinship to the patient, sharing the care of the patient, and previous experiences regarding caregiving.

Table 1: Caregiver's Characteristics (N=66)

Variables	Mean ± SD or n (%)
Patient age	69.36±18.34
Patient gender	
Female	43 (65.2)
Male	23 (34.8)
Duration of stroke	
<1 year	13 (19.7)
1-5 years	32 (48.5)
>5 years	21 (31.8)
Age	51.57±11.60
Gender	
Female	57 (%86.4)
Male	9 (%13.6)
Marital status	
Married	50 (%75.7)
Single	16 (%24.3)
Education level	
No education/ Elementary school	48 (%72.7)
High school and higher	18 (%27.3)
Perceived income level	
Middle	47 (%71.2)
Low	19 (%28.8)
Financial support for care	
Yes	8 (%12.1)
No	58 (%87.9)
Relationship with the patient	
Daughter/ son	34 (%51.5)
Spouse	13 (%19.7)
Son/daughter-in-law	12 (%18.2)
Other (aunt/father/mother)	7 (%10.5)
Duration of care	
<1 year	20 (%30.3)
1-5 years	34 (%51.5)
>5 years	12 (%18.2)
Share care with other	
Yes	39 (%59.1)
No	27 (%40.9)
Care experience	
Present	20 (%30.3)
Absent	46 (%69.7)
The health effects of caregiving	
Present	57 (%86.4)
Absent	9 (%13.6)
Caregiving Burden (ZBI)	47.42±11.91
Social support (MSPSS)	
Special person	16.51±8.01
Friends	14.69±7.43
Family	19.37±6.65
Total	50.74±17.78

*Note***.** ZBI= The Zarit Burden Interview; MSPSS= The Multidimensional Scale of Perceived Social Support

Table 2: Caregiving burden according to the characteristics of caregivers (N=66)

Variables	Burden score (ZBI)	Analysis
Patient age		r=-0.258, p=0.036[a]
Patient gender		
Female	46.34±12.42	p=0.250 [b]
Male	49.43±10.88	
Duration of stroke		
<1 year	47.92±9.62	p=0.326 [c]
1-5 years	45.21±13.05	
>5 years	50.47±11.14	
Age		r =0.73, p=0.563 [a]
Gender		
Female	47.50±12.15	p=0.640 [b]
Male	46.88±10.87	
Marital status		
Married	46.70±11.79	
Single	49.68± 12.38	p=0.284 [b]
Education level		
No education / Elementary school	48.46±11.46	p=0.218 [c]
High school and higher	44.72±13.28	
Perceived income level		
Middle	45.08±11.38	
Low	53.21±11.49	p=0.008 [c]
Financial support for care		
Yes	39.00±11.66	p=0.040 [b]
No	49.12±11.44	
Kinship with the patient		
Daughter/ son	46.02±12.61	
Spouse	52.92±11.59	p=0.340 c
Son/daughter-in-law	45.66±11.93	
Other (aunt/father/mother)	47.00±7.11	
Duration of care		
<1 year	49.40±10.48	
1-5 years	44.20±11.90	p=0.041 [c]
>5 years	53.25±12.17	
Share care with other		
Yes	46.64±12.61	p=0.629 [b]
No	48.55±10.96	
Care experience		
Present	49.05±12.76	p=0.346 [b]
Absent	46.71±11.60	
Health effects of caregiving		
Present	49.22±11.41	p=0.002 [b]
Absent	36.00±8.42	

Note. ZBI= The Zarit Burden Interview

[a] Spearman correlation test coefficient was used to calculate p values

[b] Mann-Whitney U test was used to calculate p values

[c] Kruskal-Wallis test was used to calculate p values

Table 3: Correlation among perceived social support and caregiving burden (N=66)

	MSPSS							
	Special person		Friends		Family		Total	
	r [a]	p	r [a]	p	r [a]	p	r [a]	p
ZBI	-0.332	0.000	-0.526	0.000	-0.420	0.000	-0.512	0.000

*Note***.** MSPSS= The Multidimensional Scale of Perceived Social Support; ZBI= The Zarit Burden Interview

[a] Spearman correlation test coefficient was used to calculate p values

Alongside this, the income level of the caregiver, status regarding benefiting from financial support for care, duration of care, and perception of health being affected were found to affect care burden. A negative low level significant relationship between the age of the patient and care burden was found.

When the relationship between caregiver burden and perceived social support was examined, medium level negative relationships between caregiver burden scores and perceived social support total scores and friend support sub dimension scores as well as negative low level relationships between the caregiver burden scores and special people support and family support sub dimension scores were found (Table 3).

Discussion

Knowing the care burden is the first step in raising the quality of life of the caregiver and improving the care given to the patient. In each culture, the meaning given to patient care is different, and this affects the care burden perception of the family member who undertakes the care of the patient (Nir, Greenberger, Bachner, 2009). When studies performed in the Turkish society that evaluate the care burdens of the families of stroke patients, ZBI scores were found to vary between 29.7 and 49.1(Asiret and Kapucu, 2013; Karahan et al., 2014; Mollaoglu, Tuncay, Fertelli, 2011; Sirzai et al., 2015). In our study, the care burden of the family member who undertook the primary care responsibility for patients were found to be on the upper limits of this distribution with an average of 47.42±11.91.

It has been found that care burden is affected by the dependence level of the patients alongside cultural differences and that daily life activities get worse in patients and care burdens significantly increase as the level of dependency increases (Asiret and Kapucu, 2013; Carod-Artal et al., 2009; Kruithof et al., 2016; Mollaoglu, Tuncay, Fertelli, 2011; Rigby et al., 2009; Sirzai et al., 2015). Since stroke patients with advanced functional insufficiencies according to the BI were evaluated in our study, the care burden was excessive. Since the time required for care increases with increasing functional losses in the patient, this can be thought to increase care burdens (Greenwood et al., 2008; McCullagh et al., 2005).

The effect of patient age on care burden varies in studies. Although there was a negative relation between patient age and care burden in our study, Rigby et al. (2009) found a positive relation. The effect of patient age on care burden wasn't generally examined in other studies, and was found to be ineffective in the few studies where it was (Asiret and Kapucu, 2013; McCullagh et al., 2005; Mollaoglu, Tuncay, Fertelli, 2011). Since the prevalence of stroke increases with age, the ages of the patients are generally close (Andrew et al., 2015; Das et al., 2010; Gbiri, Olawale, Isaac, 2015; Karahan et al., 2014; McLennon et al., 2014). This is thought to limit or remove the effect of patient age on care burden.

The process of caregiving can disrupt the economic balance in families. Alongside the economic dimensions of caregiving, the caregivers also can't work, and these may cause economic problems in the family (Asiret and Kapucu, 2012). In the process of caregiving, 28% of caregivers have reported decreases in their income, 50% stated increases in their expenditures (Andrew et al., 2015), 21% said they had financial problems (Das et al., 2010), 34% reported that their income couldn't cover their expenditures (Asiret and Kapucu, 2013), and 29% stated that they couldn't cover care expenditures (Sirzai et al., 2015). While 28.8% of the caregivers in our study defined their income levels as bad, the care burden was higher in those with lower income. This finding is also parallel to our finding that patient families who receive financial support for care (12%) perceive lower care burden.

Financial support for care application that started in Turkey with a regulation passed in 2006 (Turkish Official Gazette, 2006). By the year 2015, the number of individuals benefiting from home care support has been stated to be 508.481 (Republic of Turkey Ministry of Family and Social Policies, 2015) in Turkey, while only 12% of the patient families in our study benefited from this support. In another recently published study, the rate of those who receive financial support was found to be 7.1% (Sirzai et al., 2015). A greater number of families of stroke patients benefiting from the financial support for care may contribute to decreasing care burden.

In our study, the care burden of stroke patients is the least in the 1-5 year period and the greatest after 5 years. The acute and sudden illness arriving for the unprepared and the burden brought about by the care process each decrease a little with the effect of the experience and the coping strategies gained by the caregivers (Jaracz et al., 2014; Nir, Greenberger, Bachner, 2009). However, according to some studies, care burden may not change at all (Kruithof et al., 2016). Caregiver burden may increase again with longer care durations, fatigue of the caregiver, exhaustion, or health problems arising in the caregiving process (Asiret and Kapucu, 2012). The lengthening of the caregiver role may show insufficient sharing of the care burden and thus insufficient social support. While the effect of illness duration on care burden has been evaluated in some studies (Gbiri, Olawale, Isaac, 2015; Mollaoglu, Tuncay, Fertelli, 2011), the effect of the duration of care has been evaluated in others (Mollaoglu, Tuncay, Fertelli, 2011). In some studies such as ours (Sirzai et al., 2015), the effects of both illness duration and the amount of time passed since the caregiver undertook the care of the patient on care burden have been evaluated separately. This should be taken into consideration when interpreting the results. While illness duration didn't affect care burden in our study, caregiving duration did. In our study, 86.4% of the caregivers stated that their health was negatively affected by caregiving and the care burden was found to be higher in this group. Among family members who care for stroke patients, 67.1% have stated that they had health problems (Asiret and Kapucu, 2013), and 51.8% stated that their health was negatively affected by providing care (Tuna and Olgun, 2010). They listed their health problems as stress (Usha, 2015), depression (McLennon et al., 2014; Peyvori et al., 2012), anxiety (Das et al., 2010; Denno et al., 2013), and sleep disorders (Das et al., 2010; Usha, 2015). Health status is an important factor affecting care burden regardless of whether it worsens during caregiving (Asiret and Kapucu, 2013; Jaracz et al., 2014; Mollaoglu, Tuncay, Fertelli, 2011). For this reason, decreasing the health problems of caregivers will decrease care burden and increase the quality of care, and is important for both the caregiver and the patient in this regard (Mollaoglu, Tuncay, Fertelli, 2011). Caregivers are mostly isolated from the society because of insufficient social support (Asiret and Kapucu, 2012; Andrew et al., 2015; Camak, 2015; McCullagh et al., 2005). In our study, the average MSPSS score of the caregiver of stroke patients was found to be 50,74±17,78 with the best social support coming from "family" with a score of 19,37±6,65. These results are very close to two studies evaluating the caregiver of stroke patients (Sirzai 2015; Tuna and Olgun 2010). In these studies, the MSPSS scores were respectively calculated as 49.1 and 49.9 (Sirzai 2015; Tuna and Olgun 2010), and both studies found the best social support to come from "family". Although the best source of social support in our study was family, friend support was found to be more effective in decreasing care burden compared to family support and special people support. The relations of caregivers with spouses and friends are negatively affected the most (Andrew, 2015). Social support decreases the depression (Kruithof et al., 2016; Nir, Greenberger, Bachner, 2009), anxiety (Kruithof et al., 2016), exhaustion level (Tuna and Olgun, 2010) and care burden (Cumming et al., 2008; Jaracz et al., 2014; Karahan eta al., 2014; McCullagh et al., 2005) of the caregiver. Since this study encompasses the caregivers of stroke patients recorded in home care units and have advanced dependency according to BI, the results can't be generalized. The home care unit tries to serve many patients with a little number of health personnel, and thus home visits can't be realized on the desired frequency. Even though it is thought to have a limited effect in decreasing care burden for this reason, more comparative studies where caregivers who don't receive home care services are also included are needed.

Conclusıon

As a result, the income level of the family member providing care to the stroke patient, status regarding benefiting from "financial support", the duration after the adoption of the caregiver role, whether the health of the caregiver was affected during care, and the level of social support perceived by the caregiver with friend support taking a leading role were all found to affect care burden in our study.

According to these results, researching the health problems of caregivers and making it easier for them to reach health services, making the programs that financial support caregivers more widespread, and the development of social support programs and policies that provide rest possibilities especially for caregivers who can't share the burden can be suggested.

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