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## Original research article

# The care burden and social support levels of caregivers of patients with multiple sclerosis

Nuray Dayapoğlu\*, Mehtap Tan

Atatürk University, Faculty of Health Sciences, Department of Medical Nursing, Erzurum, Turkey

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## ABSTRACT

**Aim:** This study aims to identify the relationship between social support, level of disability of patients and burden of care perceived by caregivers of individuals with multiple sclerosis.

**Methods:** This descriptive and cross-sectional study was conducted with family caregivers of patients with multiple sclerosis admitted to the neurology clinic of a university hospital in eastern Turkey. Of the family caregivers of patients with MS, 98 family members participated in the study. The study data were collected using the “Zarit Caregiver Burden Inventory (ZCBI)”, “Expanded Disability Status Scale (EDSS)” and “Multidimensional Scale of Perceived Social Support (MSPSS)”.

**Results:** The mean burden of care score of the family members was  $30.67 \pm 15.66$ , and the mean social support score was found to be  $54.88 \pm 20.02$ . A negative significant correlation was found between the mean social support and burden of care scores of caregivers ( $r = -0.38, p < 0.01$ ). Furthermore, a positive correlation between mean burnout scores of caregivers and the loss of ability of the patients was found ( $r = 0.32, p < 0.01$ ).

**Conclusion:** The burden of care decreases as the social support perceived by the caregivers increases. The burden of caregivers increases with the increasing disability of the patients.

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## Introduction

Multiple sclerosis (MS) is a chronic demyelinating disease of the central nervous system characterized by disturbances in nerve conduction and manifested by various clinical features [1]. This disease affects 2.5 million people around the world and approximately 35,000 people in Turkey [2]. It

has been estimated that MS affects more than two million people worldwide, with a prevalence of about 15–145 per 1000 in industrialized populations [2, 3]. The frequency of MS occurrence in Turkey is not known exactly; however, it is estimated to be approaching 41–101 patients in 100,000, with a total of 35,000 patients in general [4].

Individuals with MS become dependent on other individuals to perform activities of daily living since they

\* **Corresponding author:** Nuray Dayapoğlu, PhD., Atatürk University, Faculty of Health Sciences, Department of Medical Nursing, Erzurum, Turkey; e-mail: [nuraydayapoglu@hotmail.com](mailto:nuraydayapoglu@hotmail.com)  
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experience various levels of decline in functional activities [5]. Although caregiving is a basic responsibility of nursing, the increase in the prevalence of chronic diseases leads to active involvement of family members in the provision of care. The terms “family caregiver” and “informal caregiver” refer to an unpaid family member, friend, or neighbor who provides care to an individual who has an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing, and taking medications to tube feeding and ventilator care [6].

Approximately 30% of the individuals with MS need supportive help in various ways. Of this assistance, 80% is either informal or unpaid care and mostly provided by family members [7, 8]. On the other hand, an individual needing constant care in a family leads to significant problems and can put a burden on family members. As the burden of care increases, caregivers may experience physical and mental health problems, economic problems, social problems, problems in family relations as well as loss of control [9]. Moreover, this often affects the quality of life of caregivers, preventing them from fulfilling their other responsibilities. Pozzilli et al. [10] reported a relationship between quality of life and depression in informal caregivers of individuals with MS. In another study, more than 20% of family caregivers helping individuals with MS were reported to have had to devote almost all of their time to provide care [6]. And, in another study, caregivers of individuals with MS were reported to take lower physical, psychological and social relations of the quality of life sub-scale, compared to caregivers of individuals with diabetes [11].

In previous studies, the physical [12, 13] and mental health [14–16], cognitive dysfunction [12, 13], psychiatric symptoms [13], quality of life [17], family relationships [18] and time spent in providing care [14] were found to be significant predictors of the burden of care.

The presence of social support sources is significant for family caregivers of individuals with chronic diseases to cope with burden of care. Providing treatment, care and maximum independence for the individual with illness or disability is very important and challenging for the family. For this reason, caregiver family members need social support to a great extent [19]. It was reported that individuals with more social support experienced less stress and did not feel insecurity, which is one of the sources of stress [20].

Due to the cultural structure of Turkish society, usually the family members are responsible for providing care to patients. On the other hand, although care was provided by the spouses of male patients with MS, unfortunately husbands of female patients do not take responsibility for the care of their wives. Moreover, male caregivers sometimes get divorced from their wives, fearing that they cannot have children and fulfill family responsibilities. This especially increases the burden of care of the female patients with MS and their families.

Many of the previous studies have focused on the burden of care and quality of life in MS; but there are a limited number of studies investigating the social support perceived by caregivers and the relationship between the level of disability in patients and care burden.

This study aims to identify the relationship between social support, level of disability of patients and burden of care perceived by caregivers of individuals with multiple sclerosis.

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## Materials and methods

### *Design and sample*

The study was designed as a descriptive and cross-sectional. The participants were 200 family caregivers who came together with MS patients to the Neurology polyclinic of a university hospital in Turkey between January and July 2015. The family caregivers were selected through convenience sampling and 110 of them were contacted but only 98 of them responded to the questionnaire. Twelve family caregivers did not participate because they were busy or unwilling.

### *Inclusion criteria*

To be included: (1) aged 18 years or more; (2) able to come to the neurology polyclinic together with the patients; (3) giving care to patients for at least 6 months; (4) living with the patients during caregiving; (5) unpaid in return for caregiving service; (6) able to understand Turkish language; (7) willing to participate in this study.

### *Instruments*

A four-part survey was used for data collection. The questionnaires included (1) Personal Information Form, (2) Zarit Caregiver Burden Interview (ZCBI) for measuring burden, (3) MSPSS for evaluating social support, and (4) Expanded Disability Status Scale (EDSS) for measuring MS disease severity.

### *Personal Information Form*

The individual information questionnaire included age, gender, marital status, education level, occupational status, income, duration of caregiving and relationship to patient.

### *Zarit Caregiver Burden Interview (ZCBI)*

The ZCBI was developed by Zarit et al. [21]. The 22 items reflect the respondent's areas of concern such as health, social, and personal life; financial situation; emotional well-being; and interpersonal relationships. The degree to which caregivers endorse each item is rated along five-point Likert-type scales. The range of possible ZCBI scores is 0–88, with higher totals reflecting a greater burden. The validity-reliability operation for Turkey was adapted by Ozer et al. [22]. The caregivers were administered the Turkish version of the ZCBI. In this study, the total Cronbach alpha parameter for ZCBI was determined as 0.86.

### *The Multidimensional Scale of Perceived Social Support (MSPSS)*

The MSPSS is a 12-item instrument used to measure perceived social support from family, friends and significant

others. The MSPSS was developed by Zimet et al. [23]. Each item is rated on a seven-point scale 1 (very strongly disagree); 7 (very strongly agree); higher scores reflect a greater perceived adequacy of support. It provides a total score, as well as three sub-scores for perceived support from family, friends, and a significant other. The validity of the Turkish version of the scale was demonstrated by Eker et al. [24]. The internal consistency (reliability) was examined by Cronbach alpha, and the total alpha of the scale was 0.92 in the study. In our study, a Turkish version of MSPSS was used to assess perceived social support in epileptics.

#### *Expanded Disability Status Scale (EDSS)*

The EDSS is the standard measure of disease progression and the severity of functional disability in clinical practice and clinical trials. The EDSS measures the extent of the neurological deficit with higher scores meaning a greater deficit. Scores for the total scale can range from 0 (no neurological abnormality) to 10 (death from multiple sclerosis). Scores of 0–3.0 are classified as mild, scores of 3.5–6.0 are classified as moderate and scores >6.5 are classified as severe [23]. The caregivers were administered the original version of the EDSS.

#### **Data collection**

The researcher visited the neurology polyclinic 3 days a week. Family caregivers who brought their patients to the neurology polyclinic for examination were interviewed in the polyclinic. The ZCBI and MSPSS scales were explained to the participants, who then read it and marked their answers on the sheets. EDSS was rated by an experienced neurologist. The time taken to complete the questionnaires was approximately 25–30 min. Family caregivers completed the questionnaire in a separate quiet room of the neurology polyclinic to ensure that they correctly understood items in the questionnaire. All of the family caregivers found the questionnaire understandable and easy to complete.

#### **Statistical analysis**

Coding and statistical analyses of data were done by using the SPSS 11.5 package program. Percentage was used to evaluate the parameters of gender, marital status, educational, occupational status, income, duration of caregiving and relationship to the patient. The *t* test was applied to determine differences between the mean caregiver burden scores according to gender and occupational status. Kruskal-Wallis variance test was applied to determine differences between the mean caregiver burden scores according to marital status, educational, income, duration of caregiving and relationship to the patient. Bonferroni's correction was used to determine the significant results in Kruskal-Wallis variance analysis. Bonferroni's correction was used when they were not homogeneous to determine the significance of situations in Kruskal-Wallis variance analysis. Pearson correlation analysis was used to detect the relationship between caregiver burden, social support

status and disability level. Bonferroni's correction was used to determine the significant results in Kruskal-Wallis variance analysis. Significance in all statistical analyses was defined as  $p < 0.05$ .

#### **Ethical considerations**

The research was also submitted to and approved by the ethics committee of the Institute of Medical Sciences of Ataturk University. Official permission was received to conduct the research at the neurology polyclinic. Family caregivers were verbally informed and their consent was received. The individuals who participated in the research were informed that they could withdraw from the study any time they wished. Individuals to be included in the research were assured about the confidentiality of their personal information and the "confidentially principle" was observed.

## **Results**

#### **Demographic background**

In total, 98 caregivers of individuals with MS responded to our questionnaires. The average age of caregivers of individuals with MS was  $36.72 \pm 14.06$  years, and 66.3% were female, 53.1% were married, 48.0% had graduated from primary school, and 35.7% were spouses of the patients (Table 1).

#### **The caregiving tasks of caregivers**

Table 2 outlines the caregiving tasks of caregivers: moving (64.3%); bathing (56.1%); dressing and transferring (53.1%); feeding (40.8%); and bowel-bladder care (32.7%) respectively.

#### **The care burden**

As a result of the study, the mean score of the caregivers taken in the Zarit Caregiver Burden Inventory (ZCBI) was found to be  $30.67 \pm 15.66$ . A statistically significant relationship was found between the mean ZCBI scores and gender, marital status and the time spent in caregiving variables, which are among the introductory characteristics of the caregivers ( $p < 0.05$ ). However, there was no relationship between the educational level, employment status, income level, type of relationship and the mean ZCBI scores ( $p > 0.05$ ) (Table 3).

#### **The social support**

Chart 1 shows the mean scores of the caregivers taken in the sub-scales of the social support scale (MSPSS). The MSPSS subscales score of the caregiver mean provided the following scores: support from family  $20.86 \pm 7.33$ , support from friend  $16.61 \pm 8.40$ , support from significant other  $17.40 \pm 7.89$  and total social support  $54.88 \pm 20.02$  (Chart 1).

**Table 1 – Demographic and characteristics of caregivers of patients with MS**

Characteristic (N = 98)	N	%
Age (18–74)	36.72 (Mean)	14.06 (SD)
Gender		
Female	65	66.3
Male	33	33.7
Marital status		
Married	52	53.1
Single	35	35.7
Widowed	11	11.2
Income		
Poor	40	40.8
Moderate	34	34.7
Good	24	24.5
Education level		
Primary school	47	48.0
High school	17	17.3
University	34	34.7
Occupational status		
Employed	45	45.9
Not employed	53	54.1
Type of relationship		
Spouse	35	35.7
Son or daughter	25	25.5
Sister or brother	28	28.6
Mother or father	10	10.2
Duration of caregiving		
6 months–2 years	28	28.6
2–5 years	34	34.7
6–9 years	16	16.3
10 years and over	20	20.4
Other dependent individuals		
Yes	24	24.5
No	74	75.5

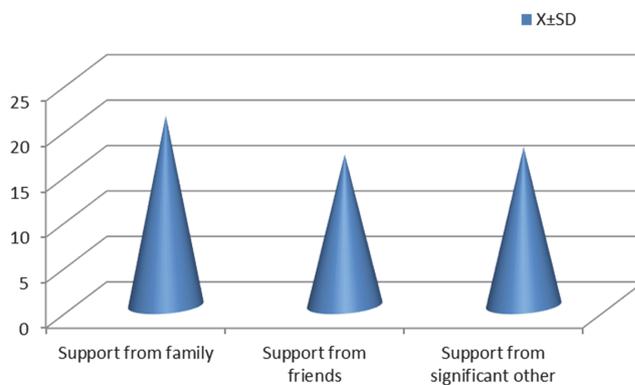
**Table 2 – Caregiving activities of caregivers**

	<sup>a</sup> N (%)
Moving	63 (64.3)
Bathing	55 (56.1)
Dressing	52 (53.1)
Transferring	52 (53.1)
Feeding	40 (40.8)
Bowel-bladder care	32 (32.7)

<sup>a</sup> More than one answer

### **The relationship between care burden, social support and disability**

There was a negative correlation between the ZCBI score and the areas of social support such as family, friends, significant other and total social support ( $r = -0.30, p < 0.01$ ;  $r = -0.32, p < 0.01$ ;  $r = -0.35, p < 0.01$ ;  $r = -0.38, p < 0.01$ , respectively). The caregiver burden decreased as the perceived social support increased. Patients with an MS mean score for EDSS was  $4.69 \pm 3.03$ . There was a positive correlation between the ZCBI score and EDSS ( $r = 0.32, p < 0.01$ ). The caregiver burden increased as the disability level increased (Table 4).

**Chart 1 – Caregiver mean MSPSS subscales scores**

## **Discussion**

The average age of caregivers of individuals with MS was  $36.72 \pm 14.06$  years. Characteristically, MS strikes between the ages of 20–40, mostly women, worldwide [25]. In Turkey, the average age of sufferers of MS has been reported to be about 30 years [26].

In this study, the vast majority of the caregivers were found to be female (66.3%) and the patient's wife. This finding is in line with the previous studies conducted on this issue [13–15]. In our study, the high number of female caregivers can be caused by the characteristics of the Turkish culture. In traditional countries like Turkey, women are responsible for the care of all family members, and women have to do the household chores such as cleaning, cooking, ironing, childcare and children's education [27].

As a result of this study, it was observed that the activities of care frequently provided by the caregivers of patients with MS were moving, bathing, dressing, transportation, feeding, and bladder management. Similarly, Forbes et al. [28] revealed in their study that the most frequent care activities provided were bathing, lifting, feeding, and bowel-bladder care. In a study by Aranson et al. [29], approximately 20% of the informal caregivers of patients with MS were reported to have provided assistance in care activities such as bathing and dressing.

In this study, we used ZCBI [22] to assess burnout or exhaustion of the caregivers, and MSPSS was used to assess the perceived social support. Specifically, both instruments have been validated in Turkish. The mean ZCBI score was found to be  $30.67 \pm 15.66$  in this study. This finding indicated that family caregivers of individuals with MS have a moderate level of burden of care. (In the scale, 21–40 points refer to a moderate level of burden of care). Different results have been reported in previous studies conducted on burden of care. In Akkuş's [30] study, the mean ZCBI score was moderate ( $36.42 \pm 18.41$ ), whereas the mean ZCBI score in a study by Rivera-Navarro et al. [15], was found to be lower ( $22.0 \pm 14.6$ ). In our study, the higher level of burnout in caregivers may be caused by the lack of home care services in Turkey.

**Table 3 – Distribution of Zarit Caregiver Burden Interview score means by caregivers' characteristics**

Characteristics (N = 98)	(N)	ZCBI The averages	Test	p-value
Gender				
Female	65	28.44 ± 15.89	$t = -2.00$	<b>0.04</b>
Male	33	35.06 ± 14.43		
Marital status			KW = 6.879	<b>0.03</b>
Married	52	34.09 ± 16.23		
Single	35	24.88 ± 13.11		
Widowed	11	32.90 ± 16.33		
Education level			KW = 3.250	0.19
Primary school	47	32.87 ± 15.86		
High school	17	32.64 ± 17.04		
University	34	26.64 ± 14.27		
Occupational status			$t = 1.04$	0.29
Employed	45	32.46 ± 15.88		
Not employed	53	29.15 ± 15.46		
Income			KW = 4.904	0.08
Poor	40	31.90 ± 17.15		
Moderate	34	25.94 ± 13.63		
Good	24	35.33 ± 14.50		
Type of relationship			KW = 5.722	0.12
Spouse	35	30.97 ± 14.42		
Son or daughter	25	31.56 ± 17.89		
Sister or brother	28	33.50 ± 15.87		
Mother or father	10	19.50 ± 9.03		
Duration of caregiving			KW = 20.02	<b>0.00</b>
6 months – 2 years	28	21.64 ± 11.71		
2–5 years	34	29.02 ± 13.80		
6–9 years	16	40.00 ± 15.83		
10 years and over	20	38.65 ± 16.22		
Other dependent individuals			$t = -0.84$	0.40
Yes	24	28.33 ± 13.70		
No	74	31.43 ± 16.26		

Statistically significant results are shown in bold.

**Table 4 – Correlations between Zarit Caregiver Burden Interview total score and dimensions of Social Support Scale and other clinical and caregiving variables (N = 98)**

	1	2	3	4	5	6	7
1. Age	–						
2. EDSS	0.20 <sup>a</sup>	–					
3. ZCBI	0.14	0.32 <sup>b</sup>	–				
4. MPSS – family	–0.13	–0.18	0.30 <sup>b</sup>	–			
5. MPSS – friend	–0.25 <sup>a</sup>	0.31 <sup>b</sup>	0.32 <sup>b</sup>	0.40 <sup>b</sup>	–		
6. MPSS – significant other	–0.13	0.37 <sup>b</sup>	0.35 <sup>b</sup>	0.55 <sup>b</sup>	0.75 <sup>b</sup>	–	
7. MPSS – total perceived support	–0.19	0.34 <sup>b</sup>	0.38 <sup>b</sup>	0.75 <sup>b</sup>	0.86 <sup>b</sup>	0.91 <sup>b</sup>	–

<sup>a</sup>  $p < 0.05$ ; <sup>b</sup>  $p < 0.01$   
EDSS, Expanded Disability Status Scale  
ZCBI, Zarit Caregiver Burden Interview  
MPSS, The Multidimensional Scale of Perceived Social Support

In this study, a negative relationship was found between the mean scores of all the sub-scales of ZCBI and MSPSS. The level of burnout was decreasing as the social support perceived by the caregivers increased. This finding is in line with the previous studies conducted with caregivers of patients with MS [18, 31]. In a study, Akkuş [30] reported

that there was a relationship between social isolation and burnout in caregivers of patients with MS. Social support resources play an important role for individuals with chronic disease and caregivers to help them to cope with the disease and sustain their lives [32].

The findings of this study suggested that the total score of social support perceived by caregivers of patients with MS was at a moderate level, and the highest social support was found in the family sub-scale. As reported previously, providing supportive care may be a particular burden for some caregivers of MS patients and this indicates that social support for caregivers is extremely important in helping families to continue in this role [8].

As a result of the study, a positive correlation was found between the mean ZCBI scores of caregivers and the mean EDSS scores of the patients. The level of burnout of the caregivers was increasing as the level of disability of the patients with MS increased. In the literature, one of the major determinants of the exhaustion of the caregivers was reported to be the level of disability [12, 15, 16]. Areas of care and duration of care provided by caregivers increased with the increasing disability of patients. As a result, the level of burnout will increase since this situation leads to the deterioration of interpersonal relations and the lifestyles of caregivers [33].

We found a significant relationship between the mean ZCBI score and the caregivers' gender, marital status and duration of care. The mean ZCBI score of the male caregivers was higher compared to female caregivers. Some studies showed different results between gender and burnout. A previous study [8] investigating the burden of care of informal caregivers of patients with MS reported that the burden of male caregivers was more than of female caregivers. In contrast, another study has found that the risk of experiencing emotional burnout was higher in females compared to males as well as the lower quality of life experienced by females [34].

The mean ZCBI score of the married caregivers was higher than of single caregivers. Although the married caregivers have to cope with problems of the patients in addition to family problems, single caregivers have lesser responsibilities. Differing from our study results, emotional exhaustion and burnout of single caregivers was found to be higher in a previous study [35].

In this study, we found that the mean ZCBI scores of the caregivers who provided care for 6 years and more was higher compared to other groups, with a significant difference between them. Rivera-Navarro et al. [15], reported that the caregivers' quality of life decreases and the burden of care decreases in line with the prolonged duration of care. It can be said that family caregivers who provide care for a longer period of time are adversely affected by caregiving. Exposure to physical and psychological distress caused by caregiving for a long time, neglecting their own health, failure to allocate sufficient time for social activities; and consequently the decrease in quality of life can be seen among the reasons of this condition.

### Limitations

This study has several limitations. First, the sample was chosen from family caregivers of individuals with multiple sclerosis staying in the polyclinic of Neurology. Second, it reflects only one geographical area of Turkey. Therefore, these findings cannot be generalized for the family

caregivers in different regions of Turkey and giving care to the individuals with other chronic diseases.

## Conclusion

Our findings emphasize that family caregivers of patients with MS have a moderate level of burden of care, and that there is a strong relationship between burnout and social support. Social support resources of family caregivers can be improved in order to reduce burnout. It is thought that the level of burnout will decrease and living standards will improve as a result of the social support provided to relatives of patients with MS. Nurses have very important responsibilities in order to develop a network of social support between relatives of patients. Informing relatives of patients with MS about their care, training them to provide care, and teaching coping strategies may reduce the burnout of caregivers. Nurses may support caregivers in determining their social and psychological needs, providing training and consulting and care activities aimed at reducing the caregivers' exhaustion. They can also encourage caregivers to share their feelings and perceptions and help promote their adjustment to the changes associated with the disease.

## Conflict of interest

No competing financial interests exist.

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