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Original research article

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

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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 ± 15.66, and the mean social support score was found to be 54.88 ± 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.

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].

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

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 policlinic 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 policlinic 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) at least a primary school graduate; (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.

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