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Research Article | Araştırma Makalesi

EXPLORING THE PSYCHOLOGICAL BURDEN ON CAREGIVERS OF MULTIPLE SCLEROSIS PATIENTS

MULTIPL SKLEROZ HASTALARININ BAKIM VERENLERİ ÜZERİNDEKİ PSİKOLOJİK YÜKÜN ARAŞTIRILMASI

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ABSTRACT

Objective: Multiple sclerosis is a chronic, progressive disease, leading to significant psychological impacts on patients and their caregivers. This study focuses on the psychological impact on caregivers of Multiple Sclerosis patients, particularly examining the correlation between the severity of disability and depression, caregiver burden and self-stigma.

Methods: The study included 65 Multiple Sclerosis patients and their caregivers. Caregivers were assessed using the Beck Depression Inventory, ZARIT Burden Interview, Self-Stigma of Depression Scale and patients were evaluated using the Expanded Disability Status Scale. Statistical analysis was performed using IBM SPSS Statistics 17.

Results: The study found higher scores in Beck Depression Inventory, Self-Stigma of Depression Scale and ZARIT Burden Interview among female caregivers, indicating a greater burden. Unemployment and lower educational backgrounds were significantly correlated with increased caregiver burden. A positive correlation was observed between the severity of the patient's disability and caregiver burden. Caregivers with mental illnesses reported higher levels of burden and depression.

Conclusion: The study underscores the multifaceted impact of Multiple Sclerosis on caregivers, highlighting the need for comprehensive care approaches that include psychological support, education, and socio-economic assistance for caregivers. This holistic approach is essential for improving the overall management of Multiple Sclerosis, benefiting both patients and their caregivers.

Keywords: Multiple sclerosis, caregiver burden, depression

ÖZ

Amaç: Multipl Skleroz, hastalar ve onların bakım verenleri üzerinde önemli psikolojik etkilere yol açan kronik, ilerleyici bir hastalıktır. Bu çalışmanın amacı, Multipl Skleroz hastalarının bakım verenleri üzerindeki psikolojik etkiye odaklanarak, özellikle engelliliğin şiddeti ile depresyon, bakım verenin yükü ve kendini damgalama arasındaki ilişkiyi incelemektedir.

Yöntem: Çalışmaya 65 Multipl Skleroz hastası ve onların bakım verenleri dahil edilmiştir. Bakım verenler Beck Depresyon Envanteri, ZARIT Yük Ölçeği, Kendini Damgalama Ölçeği; hastalar ise Genişletilmiş Engellilik Durum Ölçeği kullanılarak değerlendirilmiştir. İstatistiksel analiz IBM SPSS İstatistik 17 kullanılarak yapılmıştır.

Bulgular: Araştırmada Beck Depresyon Envanteri, Kendini Damgalama Ölçeği ve ZARIT Yük Ölçeği'nde kadın bakım verenlerde daha yüksek puanlar elde edilmiştir. İşsizlik ve düşük eğitim düzeyleri artan bakım veren yükü ile anlamlı bir şekilde ilişkilendirilmiştir. Hastanın engelliliği ile bakım veren yükü arasında pozitif bir ilişki gözlemlenmiştir.

Sonuç: Çalışmamız, Multipl Skleroz'un bakım verenler üzerindeki çok yönlü etkilerini vurgulayarak, bakım veren için psikolojik destek, eğitim ve sosyo-ekonomik yardımı içeren kapsamlı yaklaşımlarının gerekliliğini vurgulamaktadır. Bu bütünsel yaklaşım, hem hastaların hem de bakım verenlerin genel yönetimini geliştirmek için esastır.

Anahtar Kelimeler: Multipl skleroz, bakım veren yükü, depresyon

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Introduction

Multiple sclerosis (MS) is a chronic inflammatory demyelinating progressive disease in the central nervous system. Progressiveness leads to neurological disabilities. The global median prevalence of MS is 33 in every 100,000. Incidence and prevalence rates continue to rise worldwide.[1]

The clinical presentation of MS is highly diverse. All kinds of neurological symptoms may occur as a result of involvement of any part of the central nervous system from the spinal cord to the cerebral cortex. The most common symptoms and signs include vision loss, sensory complaints, muscle weakness, ataxia, nystagmus, bladder dysfunction, fatigue and cognitive involvement. In addition to physical and cognitive signs, psychiatric findings are also frequent in MS patients. The lifetime risk of major depression in MS patients can reach 50%. Depression presumably affects the frontotemporal networks due to MS lesions and also develops secondary to a chronic disease.[2]

While the physical and cognitive impacts on patients are well-documented, MS also significantly affects caregivers, necessitating a comprehensive treatment approach that includes their well-being. MS is thought to affect both the patient physically, cognitively and psychologically and the caregiver as the disability increases.[3] Thus, MS treatment must be more than a patient-centered approach and include the caregiver as well.[4]

This study aims to bridge the gap in literature regarding the psychological impact on caregivers of MS patients, focusing on the severity of disability and its correlation with depression, caregiver burden, and self-stigma.

Methods

The study includes 65 patients and 65 caregivers having applied to Kocaeli University Multiple Sclerosis Outpatient Clinic in the July 2021-January 2022 period, met the exact Multiple Sclerosis criteria according to the McDonald criteria and agreed to participate in the study. Caregivers were assessed for mental health and daily contact with patients. We conducted neurological examinations using the Expanded Disability Status Scale (EDSS) and administered the Beck Depression Inventory (BDI), ZARIT Burden Interview (ZBI), and Self-Stigma of Depression Scale (SSDS) to caregivers. Ethical approval was obtained, and participants provided informed consent.

Measurement Instruments

Beck Depression Inventory (BDI)

The Inventory consists of 21 questions. The score varies between 0 and 63 and the severity of depression increases as the score rises.

ZARIT Burden Interview (ZBI)

The Interview consists of 22 items including the subgroups of Mental Tension and Private Life, Irritability and Restriction, Deterioration in Social Relations and Economic Burden. The severity of burden increases as the score rises.

Self-Stigma of Depression Scale (SSDS)

The scale is a 14-item measure consisting of Internalized Fear of Stigma and Self-Degradation subgroups. The assessment is performed by a 5-point Likert scale. A form prepared for patient relatives is also used. The higher the score, the higher the self-stigma.

Expanded Disability Status Scale (EDSS)

The Expanded Disability Status Scale is the most widely used disability scale for MS patients. The Scale provides effective and reliable assessment at every stage of the disease. This scale is mainly based on the evaluation of functional systems. The evaluation is made between 0 and 10 points. 0 points indicate normal neurological examination and 10 indicates death due to MS.

Statistical Analysis

We used IBM SPSS Statistics 17 for statistical analysis. We used histogram charts and Kolmogorov-Smirnov test for examining the conformity of the variables to normal distribution. We used mean, standard deviation, median, minimum, and maximum values to present descriptive analyses. In cases where the data did *not* show normal distribution, we evaluated groups of 2 with the Mann Whitney U test and groups of 2+ with the Kruskall Wallis test. We used the Spearman Correlation Test in the analysis of measurement data. The cases with $p \leq 0.05$ were statistically significant results.

Results

The mean age of the patients (54 female, 11 male) is 45.35±10.82. The mean age of the caregivers (26 female, 39 male) is 42.16±16.08. The caregivers are spouses (n=32), sons or daughters (n=22), mothers (n=8), fathers (n=2) and brothers or sisters (n=1). Forty-six of the caregivers are married and 19 single. The mean age of disease onset is 34.95±10.26. The mean of Disease Duration is 10.92±8.07 and the mean of Duration of Care is 8.26±7.59. The mean EDSS score of the patients is 4.28±2.20 (Table 1).

BDI Total, SSDS-social withdrawal, ZBI Total, Mental Tension and Private Life, Irritability and Restriction scores were higher in female caregivers than in males ($p \leq 0.05$). There are no significant differences between the groups in the tests for the degrees of relationship and marital status. SSDS Total, SSDS-social withdrawal, SSDS-inadequacy, ZBI Total, Mental Tension and Private Life, Irritability and Restriction, Deterioration in Social Relations, and Economic Burden scores are higher in the unemployed caregivers than in the employed ones.

Table 1. Sociodemographic Data

		*n	%
Gender of Caregiver	Female	26	40.00
	Male	39	60.00
Gender of Patient	Female	54	83.08
	Male	11	16.92
Marital Status of Caregiver	Married	46	70.77
	Single	19	29.23
Marital Status of Patient	Married	53	81.54
	Single	12	18.46
Closeness of Caregiver	Spouse	32	49.23
	Brother/Sister	1	1.54
	Mother	8	12.31
	Father	2	3.08
	Son/Daughter	22	33.85
Job Status of Caregiver	No	28	43.75
	Yes	36	56.25
Job Status of Patient	No	43	66.15
	Yes	22	33.85
Caregiver cares for another person	No	59	90.77
	Yes. 1 person.	6	9.23
Self-Care Need of Patient	No	36	55.38
	Yes	29	44.62

*n: Total number

BDI Total, SSDS-social withdrawal, SSDS-inadequacy, ZBI Total, Mental Tension and Private Life, Irritability and Restriction, Deterioration in Social Relations, Economic Burden, and Dependence scores are higher in the caregivers of the patients in need of self-care than in the caregivers of those with no self-care problems ($p \leq 0.05$). SSDS Total, SSDS-social withdrawal and SSDS-inadequacy scores are in the caregivers of the patients non-adherent to the treatment than in those with adherent patients.

BDI Total and Deterioration in Social Relations scores are higher in the non-adherent patients than in the treatment-compliant patients. We compared physical illnesses of the caregivers and any additional illnesses of the patients with BDI Total, SSDS subscales' total, ZBI Total, Mental Tension and Private Life, Irritability and Restriction, Deterioration in Social Relations, Economic Burden, and Dependence scores and found no statistically significant results.

Mental Tension and Private Life, Deterioration in Social Relations and Economic Burden scores are higher in the caregivers with mental illnesses than in those with no mental illnesses. BDI Total, SSDS Total, SSDS-social withdrawal, SSDS-inadequacy, ZBI Total, Mental Tension and Private Life, Irritability and Restriction, Deterioration in Social Relations, Economic Burden, and Dependence scores are higher in the relatives of the caregivers with mental illnesses. There are no significant differences between the caregivers' scores in terms of alcohol and cigarette use.

Considering the scale scores of the patients according to the presence of verbal violence to the caregivers, we found the scores are significantly lower in the relatives of the patients with no verbal violence.

We found an inverse relationship between Caregiver's Educational Background and SSDS Total, SSDS-social withdrawal, SSDS-inadequacy, ZBI Total, Mental Tension and Private Life, Irritability and Restriction, Deterioration in Social Relations and Economic Burden and Dependence scores ($p \leq 0.05$). There is a positive correlation between Disease Duration and ZBI Total, Mental Tension and Private Life, Irritability and Restriction and Dependence scores. There is a positive correlation between the EDSS score and SSDS Total, SSDS-social withdrawal, SSDS-inadequacy, ZBI Total, Mental Tension and Private Life, Irritability and Restriction, Deterioration in Social Relations, Economic Burden and Dependence scores.

Discussion

MS is a progressive disease that mostly affects the productive young population. Early disability and incapacity to work cause an increase in the burden for both the patient and his/her environment. The studies show that approximately 50% of MS patients will need help in walking, psychological treatment and rehabilitation, and as a result, their economic efficiency will decrease.[5]

With a wide range of findings and functional limitation, MS patients and their families adapt to major lifestyle changes and many constraints in daily life. The patient loses autonomy and begins to need the presence of a caregiver for daily activities as the disease progresses. Thus, the studies that examined the relationship between the characteristics of MS patients and of caregivers and analyzed the effect of this relationship on the quality of the caregiver's life are important for their impact on the prognosis of the disease.[2,6,7]

The findings of this study contribute valuable insights into the psychological and social burdens experienced by caregivers of multiple sclerosis patients. Our results align with existing literature, emphasizing the multifaceted impact of MS not only on patients but also on those who care for them.

The higher scores in Beck Depression Inventory (BDI), Self-Stigma of Depression Scale (SSDS), and ZARIT Burden Interview (ZBI) among female caregivers, as observed in our study, resonate with previous research indicating gender differences in caregiving burden and mental health outcomes.[8,9] This underscores the need for targeted support strategies that address the unique challenges f aced by female caregivers.

Our findings highlight the significant impact of unemployment and lower educational backgrounds on caregiver burden. This is consistent with the broader literature on chronic diseases, which suggests that socioeconomic factors play a crucial role in the wellbeing of caregivers.[10,11] These factors should be considered in the development of support programs for caregivers.

The positive correlation between disease duration, EDSS scores, and caregiver burden aligns with previous studies.[12,13] As MS progresses, the increasing physical and cognitive impairments in patients intensify the demands on caregivers, leading to greater psychological and social challenges.

Our study also found that caregivers with mental illnesses experienced higher levels of burden and depression, a finding that is echoed in the literature.[14,15] This highlights the importance of mental health support for caregivers, not just as a means of improving their own wellbeing but also as a crucial factor in the quality of care they provide.

The significant impact of verbal violence on caregiver burden is a critical finding, suggesting that the emotional aspects of the caregiver-patient relationship can profoundly affect caregiver wellbeing. This aspect of caregiving in MS has been less explored in the literature and warrants further investigation.

These findings have important implications for the management of MS. They underscore the necessity of adopting a holistic approach to MS treatment, one that extends beyond the patient to include support for caregivers. This approach aligns with the recommendations of Hauser and Cree[16] and Makhani and Tremlett[17], who advocate for comprehensive care strategies in MS that address both physical and psychological needs.

While our study provides important insights, it is not without limitations. The single-center nature and the relatively small sample size may limit the generalizability of the findings. Future research should aim to include a more diverse and larger sample, possibly incorporating longitudinal studies to better understand the evolving nature of caregiver burden over time.

In conclusion, this study highlights the significant burden borne by caregivers of MS patients, influenced by factors such as gender, employment status, educational background, and the severity of the patient's condition. Addressing these challenges requires a multifaceted approach that includes psychological support, education, and socio-economic assistance for caregivers, alongside the medical management of MS patients.

Compliance with Ethical Standards

This study was approved Kocaeli University Ethics Committee (Decision number: 2021/220, Date: 08.07.2021).

Conflict of Interest

The authors have no conflicts of interest relevant to this article.

Author Contribution

The authors contributed equally to this work.

Financial Disclosure

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