

ARAŞTIRMA / RESEARCH

Evaluation of Disability and Hopelessness in Multiple Sclerosis Patients*Multipl Skleroz Hastalarında Yeti Yitimi ve Umutsuzluğun Değerlendirilmesi*Naile ALANKAYA¹ , Nuriye DURMUŞ² ¹Canakkale Onsekiz Mart University, Faculty of Health Sciences, Department of Nursing, Canakkale²Sağlık Bilimleri University, Istanbul Sultan Abdulhamid Han Training and Research Hospital, Istanbul**Geliş tarihi/Received:** 26.02.2021**Kabul tarihi/Accepted:** 12.04.2021**Sorumlu Yazar/Corresponding Author:****Naile ALANKAYA**, Assist. Prof.
Canakkale Onsekiz Mart University Faculty of Health
Sciences Department of Nursing Terzioğlu Campus
Çanakkale/Turkey**E-posta:** naile.alankaya@gmail.com**ORCID:** 0000-0002-3950-2409**Oral presentation, 2nd International Inter-
nal Diseases Nursing Congress, Online****Abstract****Objective:** Multiple sclerosis (MS) is a chronic and irreversible neurological disease. MS patients often experience hopelessness, especially for reasons such as impaired body image caused by disability, inadequate social support, prolonged treatments, activity limitations, and dependence on someone else's care. This study was conducted to evaluate the disability and hopelessness of individuals diagnosed with MS and to determine the relationship between socio-demographic variables.**Material and Method:** This cross-sectional study was conducted with 96 MS patients. The data were collected between September 1 and December 30, 2019 using a Patient Information Form that included socio-demographic characteristics, the Brief Disability Questionnaire (BDQ), and the Beck Hopelessness Scale (BHS). Kolmogorov-Smirnov, Mann-Whitney U, Kruskal-Wallis, ANOVA, and independent samples t-test were used in the evaluation of the data; corrected Bonferroni test was used to determine the differences between the groups.**Results:** The mean score of BDQ was 9.64±6.67, and BHS was 9.32±2.23. Moreover, a negative correlation was detected between the scores of BDQ and BHS ($r=-0.28$; $p<0.01$). There is a statistically significant relationship between the mean score of BDQ and variables such as age, gender, education, had children, employment status, year of diagnosis, number of attacks, and the presence of other chronic diseases ($p<0.05$). There is no statistically significant relationship between the mean score of BHS and other variables, except the working status ($p<0.05$).**Conclusion:** This study shows that disability poses an important problem in MS patients, and this causes patients to experience hopelessness.**Keywords:** Multiple sclerosis (MS), disability, hopelessness, nursing.**Öz****Amaç:** Multipl skleroz (MS), kronik ve ilerleyici nörodejeneratif bir hastalıktır. Özellikle hastalar yeti yitiminin neden olduğu beden imajında bozulma, sosyal destekte yetersizlik, tedavilerin uzun sürmesi, aktivite sınırlılıkları, başkasının bakımına bağımlı olma gibi nedenlerle sıklıkla umutsuzluk yaşamaktadırlar. Bu araştırma, MS tanısı alan bireylerin yeti yitimi ve umutsuzluk durumunu değerlendirmek ve sosyo-demografik değişkenleri arasındaki ilişkiyi belirlemek amacıyla yapıldı.**Gereç ve Yöntem:** Tanımlayıcı ve kesitsel nitelikte yapılan araştırma 96 MS hastasıyla gerçekleştirildi. Veriler, 01 Eylül- 30 Aralık 2019 tarihleri arasında sosyo-demografik özellikleri içeren "Hasta Tanıtım Formu", "Kısa Yeti Yitimi Anketi (KYA)" ve "Beck Umutsuzluk Ölçeği (BUÖ)" kullanılarak toplandı. Verilerin normallik testi için Kolmogorov-Smirnov testi yapıldı, normal dağılım göstermeyen verilerde Mann-Whitney U ve Kruskal-Wallis testleri, normal dağılımlarda ise tek yönlü ANOVA, Independent-Samples t testi, gruplar arasındaki farklılıkların belirlenmesinde düzeltilmiş Bonferroni testi uygulandı**Bulgular:** Araştırmamızda KYA (9,64±6,67) ve BUÖ (9,32±2,23) aralarındaki ilişki negatif yönde anlamlı bulundu ($r=-0,28$, $p=0,004$, $p<0,01$). KYA puan ortalaması ile yaş, cinsiyet, eğitim durumu, çocuk sahibi olma, çalışma durumu, tanı yılı, atak geçirme sayısı, başka kronik hastalık varlığı gibi değişkenlerle arasında istatistiksel olarak anlamlı ilişki bulundu ($p<0,05$). BUÖ puan ortalaması ile ise çalışma durumu ($p<0,05$) dışında diğer değişkenler arasında ilişki istatistiksel olarak anlamsızdı.**Sonuç:** Çalışmamızda, yeti yitiminin MS hastalarında önemli bir sorun oluşturduğu ve bu durum hastaların umutsuzluk yaşamasına neden olmaktadır.**Anahtar Kelimeler:** Multipl Skleroz (MS), yeti yitimi, umutsuzluk, hemşirelik.

1. Introduction

Multiple sclerosis (MS) is an autoimmune disease that is seen especially among young and middle-aged individuals, and causes physical, economic, and psychosocial problems at varying levels (1-5). The disease is reported to affect more than 2.5 million individuals in the world and approximately 50,000 individuals in Turkey (6-7). This disease, which is generally diagnosed between the ages of 20-40, is more common in women than in men (7-10). According to Karabudak et al., out of 100,000, the prevalence of MS in Turkey is 118.7 in women and 76.0 in men (10-11).

Depending on the damage to the central nervous system (CNS), patients experience different signs and symptoms in different periods. Patients encounter symptoms such as weakness in the extremities, sensory symptoms, ataxia, bladder problems, fatigue, diplopia, dysarthria, and impairment of memory-concentration-attention more frequently and earlier (7, 12). Patients face disability at different levels within five years after diagnosis, and emotional and cognitive problems within ten years depending on the progression of the disease and increase in the frequency of attacks (13-16). Some studies revealed that in MS patients, the disability and the dependence level in Daily Life Activities (DLA) increase, and the quality of life decreases as the diagnosis year increases (13,17,18). Factors such as increased dependence level, loss of autonomy, deterioration in physiological and functional functions, lack of social support, and body image disturbance lead patients to feel hopeless. Morgante stated that 80% of MS patients experience hopelessness due to reduced self-esteem (19).

One of the important responsibilities of health professionals is to minimize the negative effects of MS, which causes chronic, progressive, and permanent disability. Some of the other responsibilities of health professionals are to maximize the neuromuscular functions of patients, increase their independent participation in daily life activities, manage psychosocial support, and increase the compliance with the treatment. Many studies have been conducted to explore anxiety, depression, loneliness, quality of life, life satisfaction, and hopelessness levels in individuals with MS (7,13,17,18). However, the number of studies exploring the relationship between disability and hopelessness status of MS patients is limited. The present study seeks to evaluate the disability and hopelessness of MS patients and to explore the relationship between demographic variables.

2. Material and Method

2.1. Study design

This is a descriptive and cross-sectional study.

2.2. Sample

This study was conducted in the Multiple Sclerosis Association of Turkey between the dates of September 1 and December 30, 2019. The sample consisted of 96 patients who followed the MS association (rehabilitation, psychological support, group treatments, etc.) between these dates, who were 18 years and over, and could read, speak, and write in Turkish, and who agreed to participate in the study.

2.3. Ethical disclosure

The principles of the Helsinki declaration were taken into account in the study. Written permission was taken from Çanakkale Onsekiz Mart University Clinical Research Ethics Committee (Decision: 27/2019-1900088326), from the directorate of the Multiple Sclerosis Association of Turkey, and from patients who voluntarily agreed to participate in the research.

2.4. Measurements/Instruments

Data were collected in face-to-face interviews using the Patient Introduction Form, Brief Disability Questionnaire (BDQ), and Beck's Hopelessness Scale (BHS). It took approximately 20-25 minutes to complete the forms.

2.4.1. Patient Introduction Form

The form was prepared by the researchers by reviewing the relevant literature (1,2,7,16,17) and consisted of 10 questions regarding the socio-demographic and disease characteristics (age, gender, education level, marital status, having a child, disease duration, attacks, having another chronic disease, working status, age at onset of disease) of patients.

2.4.2. Brief Disability Questionnaire (BDQ)

The questionnaire was developed by Stewart et al. (20) based on the General Health Survey-Short Form of the World Health Organization (WHO). It is a 3-point Likert-type form consisting of eleven questions. The answers are scored as 0 (never), 1 (sometimes), or 2 (always) points. The total score ranges between 0 and 22 points. A score between 0 and 4 indicates no disability; a score of 5-7 points indicates mild disability; a score of 8-12 points indicates moderate disability; a score of 13 points and over indicates severe disability (20). The scale was adapted to Turkish by Kaplan and the Cronbach's alpha value was found to be 0.92. (21). In our study, Cronbach's alpha value was 0.90.

2.4.3. Beck Hopelessness Scale (BHS)

The BHS was developed by Beck et al. (22) and adapted to Turkish by Durak (23). The scale consists of 20 items. The answer "yes" in 11 items and "no" in 9 items is scored 1 point. The total score ranges between 0-20 points. A score of 0-3 points indicates minimal, a score of 4-8 points indicates mild, a score of 9-14 points indicates moderate, and a score over 15 points indicates severe hopelessness (22, 23). The Cronbach's alpha value of the original scale was 0.86, and in our study, it was 0.78.

2.5. Data analysis

The data were analyzed using SPSS 22.0 (IBM). The descriptive data were analyzed using the number, percentage, mean and standard deviation. As a result of the Kolmogorov-Smirnov normality test, the data were found to show normal distribution. Therefore, the variance analysis and independent samples t-test were used in the analysis of data, and Bonferroni, post-hoc tests were used to determine the differences between the groups. In the tests, the significance level was accepted as $p < 0.05$. The significance level in the correlation between BDQ and BHS was $p < 0.01$.

3. Results

Ninety-six MS patients participated in the research. The patient mean age was 43.01 ± 11.06 years, 68.8% were female, 57.3% were married, 64.6% had at least one child, and 46.9% were high school graduates. Of the patients, 43.8% reported that they were not employed, 59.4% reported that they had MS for more than 6 years, and 22.9% reported that they had at least one chronic disease other than MS (Table 1).

The mean BDQ score was 9.64 ± 6.67 (Min=0; max=22) (Table 2) and the Cronbach's alpha value was 0.90. The mean BHS score was 9.32 ± 2.23 (Min=0; max=20) (Table 2) and the Cronbach's alpha value was 0.78. In the study, there was a statistically significant relationship between the mean BDQ score of the patients and age ($F=7.77$, $p=0.00$), sex ($t=1.98$, $p=0.05$), educational status ($F=6.60$, $p=.002$), having children ($t=2.31$, $p=0.02$), and working status ($F=12.22$, $p=0.00$) ($p<0.05$). There was a statistically significant relationship between the mean BDQ score of the patients and MS diagnosis year ($F=6.43$, $p=0.002$), the number of attacks since the diagnosis ($F=2.32$, $p=0.04$), and the presence of other chronic diseases ($F=3.57$, $p=0.03$). There was no statistically significant relationship between the mean BHS score of the patients and other characteristics except working status ($F=3.27$, $p=0.04$) (Table 1).

There was a moderate negative correlation between the mean BDQ score and the mean BHS score ($r=-0.28$, $p<0.01$) (Table 2).

4. Discussion

MS is one of the major neurological diseases that cause deficiencies besides accidents (15,18,24). Disease-based neurological deficiencies cause disability and related psychological problems in individuals. This study investigated the correlation between disability and hopelessness and the affecting factors in individuals diagnosed with MS. Since there are a limited number of studies assessing disability and hopelessness together in MS patients, the results of this research were compared with the results of others studies evaluating disability using different scales.

It was found that the mean age of the patients was 43.01 ± 11.06 and that the disability score increased with advancing age. It was observed that disability scores of the patients who were 38 years old or over were higher than those under 38 years. In Liu et al. (24), the mean age of the patients was 37.44 ± 12.24 . Other studies in the literature have stated that disability is more common among the elderly (8,24). However, our study showed that disability can occur at a younger age in MS patients.

There was no statistically significant relationship between the marital status and the mean disability score of the patients; however, there was a statistically significant relationship between the mean disability score and variables such as sex, having children, educational status, economic status, and working status. According to Shepperd et al, two-thirds of MS patients were female patients in the USA and female patients experienced disability more than male patients (2). It was observed that the domestic processes

Table 1. The differences of the BDQ and BHS scores by the demographic and disease characteristics (n=96)

	N	%	BDQ Mean \pm SD; P value	BHS Mean \pm SD; P value
Age				
18-27	7	7.30	2.28 \pm 1.38	10.14 \pm 1.57
28-37	23	24.00	6.47 \pm 5.61	9.95 \pm 2.99
38-47	35	36.50	11.11 \pm 5.82	9.37 \pm 1.78
\leq 48	31	32.30	12.00 \pm 7.11	8.61 \pm 2.02
			$F=7.77/p=0.00^*$	$F=2.05/p=0.11$
Gender				
Female	66	68.80	10.54 \pm 6.76	9.09 \pm 2.27
Male	30	31.30	7.66 \pm 6.14	9.83 \pm 2.08
			$t=1.98/p=0.05^*$	$t=-1.15/p=0.12$
Education				
Primary	15	15.60	13.00 \pm 4.73	8.33 \pm 2.46
Secondary/HighSchool	45	46.90	10.82 \pm 7.12	9.26 \pm 1.76
University	36	37.50	6.77 \pm 5.76	9.80 \pm 2.52
			$F=6.60/p=0.002^*$	$F=2.40/p=0.09^*$
Marital status				
Married	55	7.30	9.92 \pm 6.89	9.25 \pm 9.27
Single	41	42.70	9.26 \pm 6.44	9.41 \pm 2.20
			$t=0.47/p=0.6$	$t=-0.34/p=0.72$
Having Children				
Yes	62	64.60	10.79 \pm 6.92	9.14 \pm 2.47
No	34	35.40	7.55 \pm 5.73	9.64 \pm 1.68
			$t=2.31/p=0.02^*$	$t=-1.05/p=0.24$
Working status				
Not working due to illness	15	6.00	14.46 \pm 6.89	8.20 \pm 1.33
Unemployed	42	43.80	11.07 \pm 6.45	9.21 \pm 2.30
Working	39	40.60	6.25 \pm 5.07	9.87 \pm 1.97
			$F=12.22 /p=0.00^*$	$F=3.27/p=0.04^*$
Disease Duration				
\geq 1 years	14	14.60	5.64 \pm 5.07	9.28 \pm 2.12
2-5 years	25	26.00	7.68 \pm 5.66	9.72 \pm 2.79
\leq 6 years	57	59.40	11.49 \pm 6.83	9.15 \pm 1.98
			$F=6.43/p=0.002^*$	$F=0.54/ =0.58$
Attacks/during the diagnosis				
1-9 attack	72	75.00	8.70 \pm 6.37	9.50 \pm 2.77
10-19 attack	9	9.40	11.22 \pm 7.52	8.77 \pm 1.64
20-29 attack	6	6.20	11.66 \pm 4.96	8.33 \pm 3.01
\leq 30 attack	9	9.40	14.22 \pm 7.67	9.11 \pm 1.83
			$F=2.32/p=0.04^*$	$F=0.74/p=0.52$
Another Chronic Disease				
No	69	71.90	8.53 \pm 6.36	9.43 \pm 2.42
1 disease	22	22.90	12.54 \pm 6.08	8.95 \pm 1.70
\leq 2 disease	5	5.20	12.20 \pm 10.03	9.40 \pm 1.51
			$F=3.57/p=0.03^*$	$F=0.38/p=0.68$

Abbreviations: BDQ: Brief Disability Questionnaire; BHS: Beck's Hopelessness Scale; SD: Standart deviation, F: Variance analysis value (ANOVA), t: Independent-Samples t value, * $p<0.05$

Table 2. Descriptives, Cronbach's a Values, and Correlations Between Scales

Scales	Mean \pm SD	Cronbach alfa	Correlation
BDQ	9.64 \pm 6.67	0.90	$r=-0.28$, $p=0.002^*$
BHS	9.32 \pm 2.31	0.78	

Abbreviations: BDQ: Brief Disability Questionnaire; BHS: Beck's Hopelessness Scale; * $p<0.01$

and responsibilities of the patients were affected as the disability levels increased. Inabilities to fulfill the mother role, inability to care for children, being dependent on others, and inability to work are quite effective factors on disability and hopelessness. In our study, disability scores of women were higher than those of men and it was thought that this was due to women's status in our society and their greater responsibilities at home and in the family (motherhood, wifeness, cleaning, cooking, caring, etc.) compared to men. According to the global disability action plan (2014-2021) report of the WHO, women with disabilities often have additional disadvantages compared to men with disabilities and healthy women (5). Hakim et al. (25) and Glantz et al. (26) reported that unhappy marriages and divorces due to the diagnosis of chronic disease increased 6 times. Turpin et al. (27) reported that parents with MS felt more responsible for their children due to their disease, felt more fear and anxiety, felt more burden and anger. In Aşiret et al. (6), the hopelessness scores of the patients who had children, who had a low economic status, and who were not employed were found to be high. Particularly increased disability restricts working in MS patients and on the other hand, contributes to their hopelessness due to reasons such as inability to work and support the family, future anxiety, fear of uselessness, and change in the family roles (1,16,28). Studies are reporting that MS patients avoid physical activities compared to other chronic disease groups and isolate themselves, that their inactivity increases the risk of accompanying chronic diseases, and that these problems cause hopelessness and depression. Er and Mollaoglu (29) reported that as the disability of the patients increases, their self-care decreases, and they become dependent on others in daily activities. In Morgante (19), it was emphasized that MS patients with high levels of hope held better on to life, that this affected the treatment positively, and that they had positive results on the life expectancy. According to a qualitative study conducted by Soundy et al. (30), patients experienced hopelessness due to factors such as changes in social life, inability to do activities they had enjoyed before, job losses, and loneliness. Another factor that affects disability and hopelessness is education. There was a statistically significant relationship between the educational status of our patients and the mean BDQ score and this relationship is due to the differences between those who have a university degree and those who received primary school and high school education. This study finding suggests that individuals with higher educational levels can access information sources more easily, benefit from health institutions more consciously, have better self-management skills, and participate in psycho-social support groups and get help. Similar results are reported in the literature (7,16).

Studies carried out with MS patients reveal that the majority of patients experienced dysfunction and nearly half experienced physical activity limitation after 20 years from the onset of the disease (14,30,31). In Soundy et al., there was a statistically significant relationship between the mean diagnosis time (17.0 ± 9.9) and the mean disability score (30). In our study, the mean MS diagnosis time (4.60 ± 1.69) was not high; however, patients who were diagnosed for 6 years and over experienced disability more. We think that this was due to the changing structure of MS and its adverse effects on many systems. This result that the disability increased as the diagnosis time increased is consistent with other results in the literature.

There was a statistically significant relationship between the mean disability score and the variables such as the presence of chronic disease other than MS and the number of attacks since diagnosis. In our study, the mean disability score of those with two or more secondary chronic diseases other than MS was higher than those diagnosed only with MS. In MS patients, factors such as the struggle with more than one chronic disease, limitation of daily life activities, increased treatment and care costs, dependence on others also bring physical and psychosocial problems along. In Newland et al. (12), it was stated that MS patients experienced aging symptoms earlier compared to healthy individuals. It was also emphasized that young MS patients have to cope with secondary diseases at an early age. Lublin et al. observed that those who had three or more attacks per year had higher disability scores compared to other groups (32).

The mean BDQ (9.64 ± 6.67) and BHS (9.32 ± 2.23) scores were at moderate levels. The results revealed that disability and hopelessness pose important problems in MS patients. In Willingham, Backus, McCully (33), Kayes et al. (14), Sinnakaruppan et al. (3), and Mutluay, Tekeroğlu, Saip (34), the disability score of the patients was moderate; in Aşiret et al. (16), the hopelessness score was moderate; in Sinnakaruppan et al. (3), the mean hopelessness score was high.

There was a moderate negative correlation between the scales ($r=-0.28$, $p<0.01$). This moderate negative correlation revealed poor control between the uncontrollable disability of the MS individuals and the increase in perceived hopelessness with the progress of the disease process and inability. In Sinnakaruppan et al. (3), there was a strong negative correlation between the disability scale (EDSS) and BHS ($r=-0.41$; $p<0.01$).

5. Conclusion

Despite the limitations of the research, the results present important data for health professionals and researchers. In our study, it was determined that disability poses an important problem for MS patients, and this causes patients to experience hopelessness. It was determined that there was a moderate negative correlation between BDQ and BHS and that this revealed a significant relationship between disability and hopelessness. Furthermore, some of the personal characteristics of MS patients such as age, education, economic reasons, inability to work, advanced disease progress, and increased frequency of attacks were found to contribute to disability. Since the increase in disability and hopelessness levels negatively affects success potential and the ability of the individual to produce and develop solutions to the problems and use their existing knowledge effectively, nurses, as well as other healthcare workers, should conduct studies investigating the variables that support hope in individuals with MS.

6. Contribution to the field

With this study, it was revealed that patients needed professional support to solve their disability and psychological problems such as hopelessness. It is thought that these results will guide health professionals in the evaluation of MS patients.

Limitations of Research

This study was carried in one of the five branches of the MS Association located in Istanbul, which is the largest city in Turkey. The results obtained from the small sample group do not represent all MS patients since only patients living in the city center, and members of the association were included in the study. For this reason, studies with larger samples are recommended. Moreover, we believe that this study will provide a basis for future studies since it is the first study demonstrating the relationship between disability and hopelessness in individuals with MS in Turkey.

Ethical Disclosure

The principles of Helsinki declaration were taken into account in the study. Written permission was taken from Çanakkale Onsekiz Mart University Clinical Research Ethics Committee (Decision: 27/2019-1900088326), from the directorate of the of the Multiple Sclerosis Association of Turkey and from patients who voluntarily agreed to participate in the research.

Conflict of interest

This article did not receive any financial fund. There is no conflict of interest regarding any person and/or institution.

Authorship Contribution

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