

Relationship between stigma and symptom burden in patients with multiple sclerosis

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Abstract

Background & Objective: Patients with multiple sclerosis (PwMS) may experience discrimination and stigma. The aim of this study was to examine the relationship between stigma and the symptom burden in PwMS. **Methods:** This cross-sectional descriptive study was conducted between June 2020 and September 2021 on MS patients enrolled in the neurology outpatient clinic of a university hospital in Türkiye. Multiple Sclerosis-Related Symptom Checklist and Neuroquality of Life (Neuro-QoL)-Stigma Scale were used to collect data. **Results:** The mean age of the 195 study patients was 37.5 (\pm 9.7) years and 67.2% were female. One-fourth of the patients (26.2%) had a primary education level, and the unemployment rate was 9.7%. The patients reported that their private life (issues such as getting married, having boyfriend/girlfriend or problems in marital life) was affected the most (23.6%) by MS. The mean stigma burden scale scores of the patients were 37.9 (\pm 18.2). It was found that the stigma score of the patients was not significantly related to age, gender, education, and employment ($p > 0.05$); but was worse in divorced/widowed patients ($p = 0.039$); and was worse in patients who reported that their work, school, and private life were affected due to MS ($p < 0.05$). The regression analysis showed that neuropsychiatric ($p < 0.001$), urinary ($p < 0.001$) and sensory ($p = 0.029$) symptoms contributed the most to stigma.

Conclusions: A study on PwMS in Türkiye showed a mild level of stigma. The symptom burden of the patients correlated with the stigma level suggesting that effective symptom control may help reduce the stigma level of PwMS.

Keywords: Multiple sclerosis, stigma, symptom burden

INTRODUCTION

Multiple sclerosis (MS) is a neurological disease characterized by inflammation, demyelination and axonal damage in the central nervous system and episodes of attacks that lead to non-traumatic disability in the young adult.¹ Patients may experience many symptoms such as difficulty walking, spasticity, pain, imbalance, urinary and neuropsychiatric problems, fatigue, sleeping disorders and sexual problems.² These symptoms that vary between individuals, severely affect the psychosocial life and the quality of life.³⁻⁵ An additional burden to these problems is stigma.⁶ Goffman first described stigma as an “undesired difference, exposure to discrimination”.⁷ Thornicroft *et al.* defined stigma as consisting of insufficient information, prejudice and discrimination dimensions and as a sign of shame arising from the difference one has.⁸ Therefore,

insufficient information and misconceptions about MS patients or MS disease may cause patients to be discriminated against.⁹ This situation is defined as ‘enacted stigma’, which refers to the overt discrimination of individuals with MS.¹⁰ Patients may also think that they are different from others due to their illness and that society will exclude them, even if they are not exposed to any discrimination. This situation is defined as the ‘felt stigma’ that leads to isolation of the patients from the society, increase in neuropsychiatric comorbidity such as anxiety or depression and impaired self-management and quality of life.^{6,11-13} In studies conducted with patients with MS (PwMS), it was reported that internalizing the patients’ situation result in a significant burden on the patient.^{11,14} Although stigma is generally correlated with disability in neurological diseases, a recent study conducted with PwMS

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reported that even patients with low disability scores felt stigmatized.¹¹ Different studies have reported that PwMS feel stigmatized at different levels, and stigma contributes significantly to psychiatric comorbidity.¹⁵⁻¹⁷ In addition, stigma in MS patients is reported to be associated with inadequate health-seeking behaviour, a negative impact on social life, and more problems in education, work and marriage life.^{9,18} Some recent studies have investigated the relationship between psychiatric comorbidity and quality of life, but more studies are needed to address stigma more comprehensively in MS patients.¹⁹ Furthermore, the level of stigma, as well as factors contributing to stigma, are important subjects in PwMS. Understanding the factors that increase the stigma or that are related to stigma may help eliminate these factors and reduce the stigma. Although certain sociodemographic factors and clinical characteristics have been shown to be related to stigma in some studies^{11-13,15,17}, there is no study investigating the relationship between the symptom burden and the stigma level. The aim of this study was to investigate the relationship between the stigma level and the symptom burden in PwMS.

METHODS

Study design and participants

The data of this descriptive, cross-sectional study were collected between May 2020 and June 2021 through face-to-face data collection. A total of 195 PwMS, the records of whom had been made in the neurology clinics of a university hospital in Turkey, constituted the study patients. Patients over 18 years of age with a definitive diagnosis of MS, who could read and write and had no problem in communication and those who had no additional chronic disease that may affect the quality of life were included in the study.

Measures

The data were collected using the a structured patient information form, the Multiple Sclerosis Symptom Scale and the Neuroquality of Life (NeuroQoL)-Stigma Scale.

The *Patient Information Form* was a 14-question-form that was designed by the investigators to evaluate the sociodemographic and disease-related characteristics of the patients.

Multiple Sclerosis-Related Symptom Checklist:

This scale was designed by Gulick in order to investigate the symptoms experienced by PwMS.²⁰ The Turkish validity and reliability study of the scale was conducted by Tülek *et al.* (2017) and the Cronbach alpha coefficient was reported as 0.89.²¹ The scale has been used to define the symptoms and the frequency of the symptoms experienced by PwMS and is composed of 26 items and 5 sub-items including motor (7 items), brain stem (4 items), sensory (4 items), neuropsychiatric (3 items) and elimination (6 items), in addition to 2 independent items (fatigue, insomnia). The score of the scale range between 0 and 130, and higher scores indicate a higher symptom burden. The Cronbach alpha coefficient was determined to be 0.94 in this study.

NeuroLife Quality (NeuroQoL)- Stigma Scale:

Neuro-QoL is a scale developed by the National Neurological Impairments and Stroke Institute.²² The scale measures the level of perceived stigma (discriminatory attitude by society), enacted stigma (experience of social prejudice), and self-stigmatization (internalization of negative behaviours and low self-esteem) of individuals with neurological diseases. The Turkish validity and reliability of the scale was studied by Karşıdağ *et al.* (2019), and the Cronbach alpha coefficient was determined to be 0.90.²³ The authors tested the scale's validity with the group with epilepsy, MS, stroke, Parkinson's disease, and polyneuropathy. The scale includes 24 questions and is a five-point likert-type scale. The score of the scale ranges between 24 and 120 and higher scores indicated higher levels of stigma. The Cronbach alpha coefficient was determined to be 0.96 in this study and scale items are presented in Table 2.

Statistical analysis

The IBM SPSS Statistics 22 (IBM SPSS, Armonk, NY) program package was used for the statistical analysis. Compliance of the variables to the distribution was tested using the Kolmogorov Smirnov test. The data were evaluated using mean, percentage, the Mann Whitney U test, the Kruskal Wallis test, the Spearman correlation and the multiple linear regression analysis. Significance was defined as a p value of <0.05.

Ethical consideration

Ethics approval was obtained from the Ondokuz Mayıs University Clinical Research Ethics Committee (Ethical No:

B.30.2.ODM.0.20.08/344). Verbal consents were also obtained from patients after information had been given about the study.

RESULTS

The mean age of the 195 participants was 37.55 (± 9.75). Among those, 67.2% were female and 68.2% were married. The age at onset of PwMS was 28.60 (± 9.46) year and the duration of the disease was 9.38 (± 7.02). Of the patients, 89.2%

had no additional disease and did not use assistive device due to MS (82.1%). Close to a quarter (23.6%) of the patients reported that their private lives (issues such as getting married, having boyfriend/girlfriend or problems in marital life) had been negatively affected due to MS.

Table 2 shows the mean and standard deviations of the stigma scale items. According to this table, it was determined that the three items with the highest average were the 15., 13., and 10. items,

Table 1: Sociodemographic, clinical and psychosocial characteristic of patients with MS

Characteristics	N (%)
Age (Mean \pm Sd)	37.55 \pm 9.75
Sex	
Female	131 (67.2)
Male	64 (32.8)
Education	
Primary-secondary school	51 (26.2)
High school	59 (30.3)
University	85 (43.6)
Employment	
Employed	84 (43.1)
Homemaker	62 (31.8)
Retired	21 (10.8)
Student	9 (4.6)
Unemployed	19 (9.7)
Marital status	
Single	50 (25.6)
Married	133 (68.2)
Divorced/widow	12 (6.2)
Age of onset (Mean \pm Sd)	28.60 \pm 9.46
Duration of MS (year) (Mean \pm Sd)	9.38 \pm 7.02
Receiving treatments for attacks (steroid therapy)	
Yes	51 (26.2)
No	144 (73.8)
Having comorbidity	
Yes	21 (10.8)
No	174 (89.2)
Using an assistive device due to MS	
Yes	35 (17.9)
No	160 (82.1)
School life affected due to MS	
Yes	19 (9.7)
No	176 (90.3)
Working life affected due to MS	
Yes	43 (22.1)
No	152 (77.9)
Private life affected due to MS*	
Yes	46 (23.6)
No	149 (76.4)

*Private life: having problem getting married, having boyfriend/girlfriend or problems in marital life.

respectively. It was determined that the lowest average was the 16. item, which included the sentence “Because of my illness, people made fun of me” (Table 2).

The mean stigma score was 37.9 (± 18.2) and the mean symptom burden score was 36.72 (± 20.7). When the mean stigma score was compared according to the sociodemographic data, no significant difference, was observed with regard to age ($p=0.447$), gender ($p=0.109$) and educational status ($p=0.500$). A significant difference was observed according to the marital status, where the score was higher in divorced/single individuals ($p=0.039$). Working status was another factor that showed a difference although not significant ($p=0.098$); accordingly, unemployed individuals had a higher mean stigma score. The clinical characteristics revealed a significant positive correlation with the duration of the disease ($p=0.011$). The stigma score of PwMS who had mentioned that their private lives ($p<0.001$), educational lives ($p=0.003$) and work lives ($p<0.001$) had been affected was significantly

higher (Table 3).

The relationship between stigma and the symptom burden was investigated and a significant positive correlation was observed between all sub-dimensions of the scale and the symptom burden ($p<0.001$) (Table 4).

Regression analysis revealed that the most important sub-dimensions that contributed to stigma were neuropsychiatric ($p<0.001$), elimination ($p<0.001$) and sensory ($p=0.029$) symptoms (Table 5).

DISCUSSION

In many areas of life, stigma is one of the leading factors that result in a high burden, apart from many other factors that can negatively affect the quality of life.²⁴ Similarly, PwMS face both the direct effects of the disease and the indirect effects of stigma, from the onset of the clinical manifestation of the disease.¹⁵

In this study that investigate the stigma level and the symptom burden in PwMS in a population

Table 2: Mean of Neuro-QoL-Stigma scale items for patents with multiple sclerosis

Item no	Items	Mean \pm sd
1	Because of my illness, some people avoided me	1.41 \pm 0.87
2	Because of my illness, I felt left out of things	1.49 \pm 0.93
3	Because of my illness, people avoided looking at me	1.33 \pm 0.78
4	I felt embarrassed about my illness	1.50 \pm 1.00
5	Because of my illness, some people seemed uncomfortable with me	1.47 \pm 0.84
6	I felt embarrassed because of my physical limitations	1.53 \pm 1.03
7	Because of my illness, people were unkind to me	1.30 \pm 0.77
8	Some people acted as though it was my fault I have this illness	1.47 \pm 0.93
9	Because of my illness, I felt embarrassed in social situations	1.44 \pm 1.02
10	Because of my illness, I felt emotionally distant from other people	1.92 \pm 1.22
11	Because of my illness, people tended to ignore my good points	1.55 \pm 0.98
12	Because of my illness, I was treated unfairly by others	1.46 \pm 0.95
13	Because of my illness, I felt different from others	2.13 \pm 1.28
14	Because of my illness, I worried about other people's attitudes towards me	1.64 \pm 1.30
15	Because of my illness, I worried that I was a burden to other	2.24 \pm 1.25
16	Because of my illness, people made fun of me	1.18 \pm 0.60
17	I was unhappy about how my illness affected my appearance	1.75 \pm 1.20
18	Because of my illness, strangers tended to stare at me	1.43 \pm 0.88
19	I lost friends by telling them that I have this illness	1.27 \pm 0.72
20	Because of my illness, it was hard for me to stay neat and clean	1.71 \pm 1.12
21	I felt embarrassed about my speech	1.42 \pm 0.90
22	I avoided making new friends to avoid telling others about my illness	1.37 \pm 0.91
23	I tended to blame myself for my problems	1.66 \pm 1.15
24	People with my illness lost their jobs when their employers found out about it	1.78 \pm 1.15

Table 3: Comparison of sociodemographic and clinical characteristics with Neuro-QoL_Stigma Scale

	Mean \pm Sd	KW/ Z/r*, p
Sex		
Male	41.17 \pm 21.64	Z= -1.601
Female	35.82 \pm 15.05	p=0.109
Age		r= 0.055 p=0.447
Education		
Primary-secondary school	37.15 \pm 21.74	
High school	38.44 \pm 17.70	KW=1.384
University	37.23 \pm 14.77	p=0.500
Marital status		
Single	41.96 \pm 23.03	
Married	34.74 \pm 12.82	KW = 6.473
Divorced/widowed	50.75 \pm 27.62	p = 0.039
Employment		
Employed	36.25 \pm 17.55	KW=4.632
Others (Homemaker, retired, student)	36.98 \pm 16.28	P= 0.098
Unemployed	46.31 \pm 22.22	
Age of onset		r=-0.017 p=0.817
Duration of MS		r =0.181 p=0.011
Use of assistive device		
Yes	45.00 \pm 19.32	Z=-2.954
No	36.3 \pm 17.39	P=0.003
School life affected due to MS		
Yes	52.78 \pm 28.16	Z= -3.005
No	36.93 \pm 15.31	p =0.003
Working life affected due to MS		
Yes	53.46 \pm 26.14	Z= -5.646
No	33.08 \pm 10.78	p<0.001
Private life affected due to MS		
Yes	54.21 \pm 25.51	Z= -6.116
No	32.44 \pm 9.81	p<0.001

*Z=Mann Whitney U; KW=Kruskall Wallis test; r=Spearman correlation analysis

Note: Mann Whitney U test was used to compare stigma scale score and two categorical variables, Kruskal Wallis test for more than two categorical variables, and Spearman correlation analysis was used to compare continuous variables.

Table 4: Correlation of Neuro-QoL_Stigma Scale and MS-RS Checklist in PwMS

Scales	r	p
MS-RS_motor	0.518	<0.001
MS-RS_brainstem	0.403	<0.001
MS-RS_sensory	0.378	<0.001
MS-RS_neuropsychiatric	0.538	<0.001
MS-RS_elimination	0.515	<0.001
MS-RS_fatigue	0.395	<0.001
MS-RS_sleep issue	0.435	<0.001
MS-RS_TOTAL	0.607	<0.001

Table 5: Multiple linear regression analyses for predicting stigma in PwMS

Variable	Unstandardized		Standardized		Sig.	%95 CI		Adjusted R ²
	B	SE	β	t		Lower limit	Upper limit	
(Constant)	18.74	2.62		7.15	<0.001	13.57	23.91	0.43
MS-RS_fatigue	1.09	1.07	0.07	1.02	0.307	-1.01	3.21	
MS-RS_sleep issue	0.25	0.19	0.10	1.29	0.131	-0.38	2.97	
MS-RS_motor	0.32	0.19	0.13	1.67	0.196	-0.13	0.65	
MS-RS_brainstem	-0.27	0.35	-0.05	-0.78	0.434	-0.97	0.42	
MS-RS_sensory	-0.71	0.32	-0.17	-2.20	0.029	-1.36	-0.07	
MS-RS_neuropsychiatric	1.78	0.33	0.41	5.40	<0.001	1.13	2.44	
MS-RS_elimination	0.85	0.20	0.30	4.10	<0.001	0.44	1.26	

in Turkey, it was observed that PwMS had mild level of stigma. However, despite the level of stigma being low, previous studies had reported that the stigma can still impair the quality of life.^{11,13,15,25}

It was also observed that some sociodemographic and clinical factors were associated with stigma. We found that stigma level was significantly higher in divorced individuals. Unemployed PwMS also felt more stigmatized, although the association was not statistically significant.

In our study, we asked the question “Which fields of your life are affected due to MS?”, and 23.6% of the patients stated private lives, 22.1% stated work life and 9.7% educational life. We also found that PwMS when these areas of their life were affected, their level of stigma also increased.

When the mean scores of the stigma scale items are examined, it can be said that the felt stigma is more than the enacted stigma. In the results of the stigma scale applied to our study subjects (Table 2), three items with the highest scores were respectively: “Because of my illness, I worried that I was a burden to others”, “Because of my illness, I felt different from others”, and “Because of my illness, I felt emotionally distant from other people”. Therefore, the patients may still feel different and alienated from others due to their MS.

Previous studies reported that some PwMS had concealed their disease, especially during job interviews. The factor that help the patients in concealing their disease from others is the absence of physical disability. However, although the PwMS may be successful in avoiding enacted stigma from lack of physical disability, one may still have felt stigma¹⁴ that may explain the behavior to conceal the illness to the potential employer.

On the total score of the scale, our patients had a mildly increased stigma level (NeuroQoL-Stigma Score 37.9±18.2) and all symptoms of MS correlated with stigma. Although its severity varies from society to society, the level of stigma is not zero in PwMS. In a previous study conducted in a different region of Turkey, the same scale was used and the mean stigma score was reported to be 51.0 (±10.3), which is higher than the score observed in our study.²³

The variability of the stigma score has also been confirmed by various studies.^{11,13,15,17,25} This variability in the level of stigma may be due to sociodemographic, clinical or environmental factors. Previous studies have also reported that the disability level among clinical variables was correlated to stigma.^{17,25,26} The disability of the patients expresses the physical disability level or the independence in the daily activities of the patients. However, evaluating the relationship between physical disability and stigma would only reflect the visible signs of MS.

There are many symptoms in MS that are not visible. In a recent study where the symptom burden in MS patients was investigated, fatigue, depression, spasticity and pain were reported to be the most important symptoms.²⁷ In our study, we observed that stigma had a significant correlation with all sub-dimensions of the symptom burden scale, and that neuropsychiatric, sensory symptoms contributed to stigma at a greater extent. These emphasize that subjective symptoms should also be attended to.

Although anxiety and depression are among the frequent neuropsychiatric symptoms of MS²⁸, they may be hidden. However, as seen in our study, they are one of the most important factors that contribute to stigma. Furthermore, psychiatric comorbidity is the leading factor that

impair the quality of life in patients with MS.²⁹ Therefore, neuropsychiatric symptoms should also be attended to.

Similarly sphincter severely affect the psychosocial life of the individuals³⁰, as well as the sexual lives of the patients.³¹ Sphincter symptoms, especially at young age, may cause embarrassment, be hidden and result in social isolation. Thus, micturition symptoms should be attended to by a multidisciplinary team of physician, nurse, physiotherapist, and rehabilitation provided.

The leading sensory symptom in MS is pain and it is generally in the form of central pain. The pathophysiology of this pain is not clearly understood.³² Our study suggest that pain may also be a neglected symptom that contributes to stigma.

In conclusion, there was a mildly raised stigma score in a MS population in Turkey and was correlated with symptom burden. In addition, neuropsychiatric, urinary and sensory problems contributed the most to stigma. Therefore, effective symptom control may help to reduce the stigma level of PwMS.

The limitation of our study include the lack of data on some clinical characteristics of the patients such as EDSS or the MS type. In addition, since face-to-face data are collected from patients (although patients themselves read and mark), there may be a bias in their answers to the stigma scale.

DISCLOSURE

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