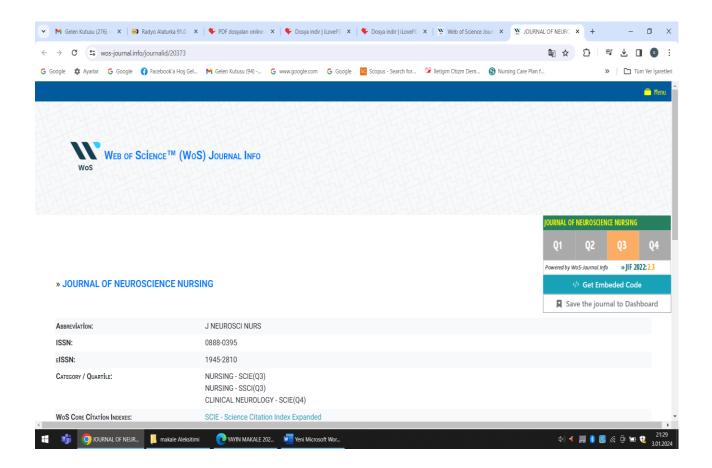
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## Alexithymia and Coping With Stress in Patients With Multiple Sclerosis: A Comparative Study

Feride Taskin Yilmaz, Selma Sabanciogullari, Gulgun Sevimligul

### **ABSTRACT**

**BACKGROUND:** Multiple sclerosis (MS), which is frequently seen in young adults, affects mental health because of disease symptoms and cognitive disorders. This study was conducted to evaluate the presence of alexithymia and problem- or emotion-focused coping strategies with stress in MS patients, determine the relationship between these variables, and compare the results of MS patients with those of healthy individuals. **METHODS:** This descriptive, cross-sectional, and comparative study was carried out with the participation of 120 MS patients presenting to a neurology clinic and outpatient clinic of a university hospital and 120 healthy individuals. Data were collected using a personal information form, the Toronto Alexithymia Scale, and the Ways of Coping Scale. **RESULTS:** The 40.8% rate of alexithymia in the MS patients use emotion-focused coping methods, such as a lack of self-confidence approach and a submissive approach, more frequently (P < .05). A significant negative correlation was found between the alexithymia and problem-focused coping strategies of MS patients (P < .01). **CONCLUSION:** Alexithymia is more common in MS patients than in healthy individuals. Alexithymia negatively affects the methods patients use to cope with stress. In the treatment and care of MS patients, nurses should plan interventions for the ability of these patients to recognize and express their emotions and develop positive coping methods.

Keywords: alexithymia, coping, multiple sclerosis, nursing care, research, stress

ultiple sclerosis (MS) is a complex disease that causes widespread demyelination and axonal damage of white and gray matter, leading to often irreversible damage and disabling neurological symptoms.<sup>1</sup> Multiple sclerosis, a chronic and progressive disease, is more common in young adults worldwide.<sup>2</sup> The prevalence of the disease ranges from 2 to 200 per 100000 depending on geography.<sup>1</sup> Although there is no prevalence study regarding

Questions or comments about this article may be directed to Feride Taskin Yilmaz, PhD RN, at feride\_taskin@hotmail.com. F.T.Y. is an Associate Professor, Faculty of Health Sciences, Internal Disease Nursing, Sakarya University of Applied Sciences, Sakarya, Turkey.

Selma Sabanciogullari, PhD RN, is Professor, Department of Psychiatric Nursing, School of Susehri Health High, Sivas Cumhuriyet University, Sivas, Turkey.

Gulgun Sevimligul, RN, Faculty of Medicine Hospital, Sivas Cumhuriyet University, Sivas, Turkey.

Feride Taskin Yilmaz, ORCID ID: 0000-0003-0568-5902

#### Selma Sabanciogullari, ORCID ID: 0000-0002-7340-7448

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Copyright © 2022 American Association of Neuroscience Nurses https://doi.org/10.1097/JNN.00000000000684 MS in Turkey on the national level, the disease is thought to be of moderate risk.<sup>3</sup>

Relapsing inflammatory demyelination attacks and gradual loss of axons were associated with common cognitive and affective disorders in MS.<sup>4</sup> Atrophy and lesions in the prefrontal cortex affecting the ventromedial and dorsolateral regions were linked to emotion processing, alexithymia, and empathy in MS patients.<sup>5</sup> Inability identifying emotional facial expressions and difficulty describing feelings to other people, accepted as a process of perspective taking or theory of mind, a more sophisticated form of empathy, were reported in patients with MS.<sup>6</sup> Alexithymia, which means "push-ing away emotions,"<sup>7,8</sup> is an individual's inability to define and understand emotions.<sup>4</sup> Individuals having alexithymia have difficulties in understanding and regulating their feelings involving components such as difficulty identifying and describing their feelings, difficulty distinguishing between their feelings, or experiencing their feelings unwittingly.<sup>7,8</sup> A systematic review revealed that the prevalence of alexithymia in MS patients varies from 10% to 53%.9

Multiple sclerosis usually progresses with remissions and exacerbations, and stress can be an important factor in the reexacerbation of the disease.<sup>10,11</sup> Symptoms such as extreme fatigue, blurry vision, unsteady gait, pain in parts of the body, paresthesia, problems with bowel and bladder function, cognitive dysfunction, tremors, and spasticity are common during

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exacerbation periods of MS.<sup>10,12</sup> The presence and severity of these symptoms negatively affect the individuals' activities of daily living, independence, family, education and work life, mental health, and coping skills.<sup>10,13–15</sup> Therefore, in MS patients, coping with stress is important for the prognosis of the disease.<sup>10</sup> It has been stated that, in MS patients coping with stress is associated with disease management, quality of life, psychosocial health, and compliance with medication.<sup>10,11,16</sup> However, MS patients use positive behaviors of coping with stress less frequently than healthy individuals do.<sup>12</sup> It was reported that those who can perceive, elaborate, and express their emotions and those who can regulate their emotions effectively cope with stress and emotional experiences more successfully.<sup>17</sup> In this case, it seems likely that alexithymic individuals will have difficulties in coping with stress.<sup>18</sup> This study was carried out to examine alexithymia and methods of coping with the stress in patients with MS, and healthy individuals, determine the relationship between alexithymia and methods of coping with stress, and compare the results between MS, patients and healthy individuals.

#### ≝Methods

This study was carried out with a descriptive, crosssectional, and comparative design. It was conducted in the neurology clinic and outpatient clinic of a unisversity hospital between September 2020 and July 2021. The sample size of the study was calculated as a minimum of 112 using the formula for a known population  $(Nt^2pq/[d^2(N-1)+t^2pq])$  considering the number of patients with MS who presented between the months of the study in the previous year. At the beginning, 120 patients who met the inclusion criteria were included in the study. The inclusion criteria were as follows: having had MS for at least 6 months, being literate and older than 18 years, and not having a problem in verbal communication. In addition, patients who were not given a diagnosis of psychiatric diseases and did not use antidepressant medication were included, because alexithymic characteristics are frequently seen in psychiatric diseases and could affect the results of the study. The control group consisted of the relatives of the patients who presented to the neurology outpatient clinic of the hospital between the same dates, and 120 healthy individuals, who matched the sociodemographic data of the MS patients, did not have speech or comprehension problems, and had no chronic diseases, were included.

Data were collected using a personal information form, the Toronto Alexithymia Scale (TAS), and the Ways of Coping Scale (WCS). The TAS consists of 20 items.<sup>19</sup> It is a self-report scale that was tested for

## Alexithymia is a lack of ability to perceive emotions.

validity and reliability in Turkish.<sup>20</sup> It has 3 subscales: difficulty identifying feelings (TAS-1), difficulty describing feelings (TAS-2), and externally oriented thinking (TAS-3). Items are rated using a 5-point Likert-type scale whereby 1 = strongly disagree and 5 = strongly agree. The TAS-20 uses cutoff values in its scoring. Scores equal to or lower than 51 indicate the absence of alexithymia, and those equal to or greater than 61 indicate the presence of alexithymia. High scores indicate high alexithymia levels.<sup>20</sup>

The WCS consists of 30 items.<sup>21</sup> Its Turkish validity and reliability study was performed by Sahin and Durak.<sup>22</sup> The scale includes 5 dimensions, namely, self-confidence approach, optimistic approach, and seeking social support (problem-focused coping strategies), and lack of self-confidence approach and submissive approach (emotion-focused coping strategies). The items are scored on a 4-point scale. Scores for each dimension are calculated separately. In the evaluation of the scale, higher scores in the self-confidence approach, optimistic approach, and seeking social support approach dimensions show that effective coping strategies are used, whereas higher scores in the helplessness approach and submissive approach dimensions indicate that ineffective coping strategies are used during the assessment process.22

Verbal information about the study was provided to the patients who were treated in the clinic or those who presented to the outpatient clinic by the nurse who was assigned to the research team. Data were collected through face-to-face interviews with individuals who agreed to participate in the study. It took an average of 20 minutes for each participant to complete the data collection forms. The data were analyzed using the SPSS 16.0 program. Percentages, means, the Mann-Whitney U test,  $\chi^2$  test, and the Spearman rank correlation coefficient were used in the statistical analyses. The Kolmogorov-Smirnov test was used to determine whether data collected from the responses of the participants to the scales had a normal distribution. Because the data did not meet parametric test conditions (nonnormal distribution), the Mann-Whitney U test was used for 2 independent groups, and the Spearman correlation coefficient was used to determine relationships.  $\chi^2$  test was used to compare the quantitative data. The level of statistical significance was designated as P < .05.

**Ethical Considerations.** Before starting the study, written permissions were obtained from the Non-Invasive Clinical Research Ethics Committee of a university (decision no.: 02/52), the Chief Physician's Office of the Hospital, and the Neurology Department. Besides, the purpose of the study was explained to the individuals, and verbal and written consent was obtained from the individuals who agreed to participate in the study.

#### Results

The mean age of the MS patients was 37.44 (9.93) years, their mean disease duration was 5.1 (4.96) years, 71.7% of the MS patients were female, 67.5% were married, 37.5% were primary school graduates, almost all of them (95%) had a nuclear family structure, 78.3% resided in the city center, and 69.2% were unemployed. The mean age of the healthy participants was 37.6 (12.05) years, 41.7% of them were female, 50.8% were married, 95.8% had nuclear families, 82.5% resided in the city center, and 56.7% were unemployed.

The mean overall TAS scale and subscale scores of the MS patients were found to be significantly higher than those of the healthy participants (P < .01; Table 1). The mean WCS self-confidence approach, submissive approach, and seeking social support subscale scores of the MS patients were found to be significantly higher than those of the healthy participants (P < .01). The mean optimistic approach and self-confidence approach WCS subscale scores of the participants did not significantly differ between the patient and healthy groups (P > .05; Table 1). According to the results of the comparison of the TAS scores of the MS patients and healthy participants based on the cutoff values, whereas 40.8% of the MS patients had alexithymic symptoms, this rate was found to be 21.7% in the healthy participants. The rate in the MS patients was significantly higher than that in the healthy participants (P < .01).

Significant negative correlations were found between the mean total TAS score of the MS patients and their mean scores in the optimistic approach (r = -0.32), self-confidence approach (r = -0.27), and seeking social support (r = -0.24) subscales of WCS (P < .01). Whereas negative relationships were found between the mean score of the MS patients in the difficulty identifying feelings subscale of TAS and their scores in the optimistic approach (r = -0.32) and self-confidence approach (r = -0.26) subscales of WCS (P < .01), no significant relationship was found between other subscales (P > .05). There was no significant relationship between the mean total WCS and WCS subscale scores of the healthy participants and their total TAS and TAS subscale scores (P > .05).

The mean WCS optimistic approach, self-confidence approach, and seeking social support subscale scores of the MS patients showing alexithymic symptoms were found to be significantly lower than those of the patients without alexithymic symptoms (P < .01). The mean WCS lack of self-confidence approach and submissive approach subscale scores of the MS patients did not show a statistically significant difference between those with and those without alexithymic symptoms (P > .05; Table 2).

#### Discussion

Alexithymia, which is described as the lack of ability of individuals to perceive their or other people's feelings,<sup>8</sup>

# **TABLE 1.** Comparison of the Total and Subscale Toronto Alexithymia Scale and Ways of Coping Scale Scores of the Multiple Sclerosis Patients and the Healthy Participants

	Multiple Sclerosis Patients	Healthy Individuals	
Scales	Mean (SD)	Mean (SD)	Test, P
Toronto Alexithymia Scale			
Overall	57.25 (6.01)	50.77 (8.48)	<.01
Difficulty identifying feelings	20.62 (3.29)	17.72 (2.68)	<.01
Difficulty describing feelings	15.35 (1.85)	13.28 (3.16)	<.01
Externally oriented thinking	21.28 (3.12)	19.75 (4.07)	<.01
Ways of Coping Scale			
Optimistic approach	10.85 (3.75)	11.76 (3.92)	>.05
Self-confidence approach	15.42 (5.04)	16.58 (5.07)	>.05
Lack of self-confidence approach	15.26 (4.92)	13.05 (2.83)	<.01
Submissive approach	10.73 (5.21)	7.95 (4.21)	<.01
Seeking social support	8.09 (1.68)	7.11 (2.07)	<.01

Downloaded from http://journals.lww.com/jnnonline by BhDMf5ePHKav1zEoum1tQft4a+kJLhEZgbsIHo4XMi0hCyw CX1AWnYQp/IIQrHD3i3D00dRyi7TvSF4Cf3VC4/OAVpDDa8K2+Ya6H515kE= on 04/10/2023 is common in neurological diseases and various psychiatric disorders.<sup>23</sup> Consistent with other publications, 41% of our sample had alexithymic symptoms.<sup>4,8,24–26</sup> A longitudinal study based on a 5-year period suggested that the frequency of alexithymia in MS patients did not differ over time. In the same study, it was found that the scores of the participants in the subscale of externally oriented thinking, a component of alexithymia, showed a significant decrease after 5 years.<sup>25</sup> This study showed that the rate of alexithymia is high in MS patients who are young adults. This was an important finding in terms of inadequate interpersonal relationships, social support, coping skills, and poor quality of life associated with alexithymia in MS patients in their future life.

Various models were proposed in relation to the neurobiological aspects of alexithymia. Moreover, it was suggested that dysfunctions in the corpus callosum and frontal lobe play a role in the development of alexithymia.<sup>5</sup> It was stated that atrophy and lesions in the prefrontal cortex affecting the ventromedial and dorsolateral regions were linked to emotion processing, alexithymia, and empathy in MS patients.<sup>4</sup> Consistent with the literature, in our study, alexithymia rates were higher in the MS patients compared with the healthy participants.<sup>8,24,26</sup> This finding is consistent with the fact that the disease causes penurobiological damage.

Psychological distress, high stress, anxiety, and depression are common in MS patients. Coping with stress in MS patients is beneficial in preventing the progression of the disease.<sup>12</sup> In our study, while coping with stress, the MS patients used the lack of self-confidence approach, submissive approach, and seeking social support components of methods for coping with stress more frequently than the healthy participants did. This indicated that the MS patients used an emotion-focused coping approach, one of the ways of coping with stress, more than a problem-focused approach. In a systematic review involving 38 studies on the coping strategies of MS patients, in line with this finding, it was found that patients mostly used emotional and avoidance strategies, and they used problem-focused active coping approaches less prevalently than the general population.<sup>16</sup> In other studies, it was found that MS patients mostly used the self-confidence approach. $^{3,10}$ Inconsistencies in the findings of different studies can be explained by the different clinical or cultural characteristics of the samples. Nevertheless, the finding of our study revealed the need for healthcare professionals to support MS patients in coping with stress related to their illness and problems in their daily lives. A qualitative study reported that many MS patients did not communicate with their doctors about stress, and patients did not receive adequate care in this field.<sup>11</sup> However, it should not be forgotten that recommending a stress-free life for patients and their relatives and keeping away from stress after their MS diagnosis may increase these patients' sensitivity to stress.<sup>10</sup> It is therefore important for healthcare professionals to evaluate the issue of how MS patients cope with the problems they experience after their diagnosis with the disease and how they cope with their increased susceptibility to stress.

Alexithymia is also one of the factors that affect the methods individuals use for coping with stress. Alexithymia reduces the possibility of turning to others for seeking social support and regulating feelings of stress.<sup>18</sup> We found that alexithymia negatively affected the stress coping skills of the MS patients, and the patients with alexithymic symptoms had lower problemfocused coping levels. Another study reported that perceived stress concentration and psychiatric symptoms such as anxiety and depression were related to ineffective coping with stress among MS patients, and psychiatric symptoms showed a positive relationship with emotion-focused coping methods.<sup>12</sup> The finding of our study showed that individuals who experience difficulty in identifying their feelings have difficulties in thinking about their feelings and coping with stressful emotions.

### **TABLE 2.** Comparison of the Ways of Coping Scale Mean Scores of the Multiple Sclerosis Patients With and Without Alexithymic Symptoms

	Alexit		
	Yes (n = 49, 40.8%)	No (n = 71, 59.2%)	
Ways of Coping Scale	Mean (SD)	Mean (SD)	
Optimistic approach	9.34 (3.59)	11.90 (3.51)	P < .01
Self-confidence approach	13.59 (4.77)	16.69 (4.86)	<i>P</i> < .01
Lack of self-confidence approach	15.73 (5.01)	14.94 (4.87)	P > .05
Submissive approach	11.16 (5.35)	10.43 (5.12)	P > .05
Seeking social support	7.46 (1.55)	8.52 (1.63)	<i>P</i> < .01

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Nurses are important healthcare professionals in the provision of effective treatment and care services at the stage of protecting and improving the health of MS patients.<sup>14</sup> To plan interventions that will facilitate adjustment to the disease and improve the quality of life of patients with a holistic perspective, it is extremely important to know the alexithymia and stresscoping levels of MS patients. This study will provide important data for nurses in identifying, understanding, and recognizing the emotions of MS patients and making the necessary plans to increase the strength of MS patients for coping with stress.

Limitations. First, because the study had a cross-sectional design, the study did not seek or report a causality relationship. Second, the sample was relatively limited. Studies carried out with larger samples will provide a better understanding of the relationship between alexithymia and coping with stress in MS patients. Despite these limitations, the study is one of the leading studies investigating the frequency of alexithymia, coping with stress, and the relationship between alexithymia and coping with stress in MS patients.

#### Conclusion

Alexithymia was more common in MS patients than in healthy participants, and the MS patients adopted emotional stress-coping methods more. Alexithymia was found to adversely affect the skills of the MS patients in coping with stress. Nurses should evaluate MS patients not only for biological treatment but also for alexithymic symptoms. The necessary psychosocial support should be provided to individuals at risk with alexithymic symptoms. Nurses should plan and implement interventions such as self-knowledge, communication, problem-solving, and relaxation techniques that will enable patients to use problem-focused coping methods that are more effective in coping with stress, and they should provide counseling and training services to MS patients regarding coping with stress.

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