

Assessment of social stigma among multiple sclerosis patients in Saudi Arabia: A cross-sectional study

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ABSTRACT

الأهداف: تقييم الوصمة الاجتماعية تجاه مرض التصلب المتعدد في المملكة العربية السعودية.

المنهجية: أجرينا دراسة وصفية مقطعية عبر الإنترنت في المملكة العربية السعودية. وهدف الدراسة قياس مستوى الوصمة الاجتماعية بين مرضى التصلب المتعدد في المملكة العربية السعودية. تم ملء هذا الاستبيان من قبل المرضى باستخدام نماذج Google، وتم تصميم الاستبيان لقياس البيانات الديموغرافية والوصمة الاجتماعية باستخدام مقياس RSS-MS المعتمد.

النتائج: بعد أن طبقنا معايير الاستبعاد، اشتملت الدراسة على 381 مريضاً بمرض التصلب العصبي المتعدد الذين أكملوا استبيان الدراسة. وأظهرت نتائج الدراسة أن هناك مناطق في المملكة العربية السعودية ترتفع فيها الوصمة المجتمعية تجاه مرض التصلب المتعدد مقارنة بالمناطق الأخرى في المنطقة الشمالية (25.5 ± 10.0) والأدنى بين مرضى المنطقة الشرقية (17.3 ± 7.2). وأظهرت الدراسة أيضاً أن الأشخاص غير المتزوجين لديهم وصمة عار أعلى مقارنة بالمرضى المتزوجين (21.0 ± 8.3 مقابل 18.9 ± 8.0 على التوالي؛ $p = .011$).

الخلاصة: أظهرت دراستنا مدى الوصمة المجتمعية تجاه مرضى التصلب المتعدد في المملكة العربية السعودية. نوصي بمزيد من الدعم النفسي والاجتماعي لمرضى التصلب المتعدد ومزيد من الحملات التطوعية للمرض.

Objectives: To assess the social stigma towards multiple sclerosis in Saudi Arabia.

Methods: A descriptive cross-sectional online survey study was done in Saudi Arabia. It targets social stigma among multiple sclerosis patients in Saudi Arabia. This questionnaire was filled out by patients using Google Forms, and the questionnaire was designed to measure the demographic data and social Stigma using a validated RSS-MS scale.

Results: After we applied the exclusion criteria, we received 381 MS patients who completed the study

questionnaire. The results of the study showed that there are regions in the Kingdom of Saudi Arabia where the societal stigma towards multiple sclerosis is high compared to other regions in the Northern region (25.5 ± 10.0) and the lowest among Eastern region patients (17.3 ± 7.2). The study also, showed that unmarried people have a higher stigma compared to married patients (21.0 ± 8.3 vs. 18.9 ± 8.0 , respectively; $p = .011$).

Conclusion: Our study showed the extent of societal stigma towards patients with multiple sclerosis in the Kingdom of Saudi Arabia. We recommend more psychological and social support for patients with multiple sclerosis and more volunteer campaigns for the disease.

*Neurosciences 2024; Vol. 29 (4): 246-251
doi: 10.17712/nsj.2024.4.20240011*

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Received 4th February 2024. Accepted 11th July 2024.

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Multiple sclerosis (MS) is an autoimmune disorder that damages the myelin sheath surrounding nerve fibers in the spinal cord and brain. It typically develops in individuals between the ages of 20 and 40 and is more commonly diagnosed in women than in

Disclosure. The authors declare no conflicting interests, support or funding from any drug company.

men. Multiple sclerosis is considered the most prevalent and debilitating neurological disease affecting young adults. The condition demonstrates heterogeneity in its symptoms, progression, and outcomes.¹⁻³ The initial presentation most commonly involves impaired vision or sensory disturbances. Other symptoms may include cognitive impairment, difficulty walking, fatigue, weakness, depression, and bladder dysfunction.¹⁻³

Patients with MS may face discrimination, criticism, and social isolation because of their illness. The sense of being “different” and devalued by others due to an attribute linked to their condition is known as stigma.⁴ For those living with MS, this stigma can result in poor health, reduced social interaction within their community, psychological disorders (notably depression), educational difficulties, and challenges in performing daily activities.¹ Stigma typically encompasses internal and external aspects; the external aspect pertains to societal perceptions of patients with MS and their subsequent treatment, while the internal aspect concerns the patients’ own feelings about their differences from others.⁵

There is a clear association between reduced quality of life due to stigma and increased symptoms of anxiety and depression.⁶ Furthermore, patients with MS are more susceptible to stigma in the workplace; however, those who are unemployed or hold non-governmental positions perceive it to a greater extent.^{7,8} Additionally, patients with MS who disclose their illness at work experience misunderstandings and a lack of support from colleagues.⁹ According to the Atlas of MS 3rd Edition (2020), the global population of individuals with MS rose from 2.3 million in 2013 to 2.8 million by 2020. This increase in prevalence is likely due to enhanced diagnostic techniques and more accurate counting methods. The growing number of MS diagnoses underscores the necessity for expanded research and heightened awareness of the condition.

According to a study conducted in September 2018, the estimated prevalence of MS in Saudi Arabia was 40.40 per 100,000 of the total population and 61.95 per 100,000 among Saudi nationals.¹¹ The prevalence of MS in Saudi Arabia is increasing; however, the feeling of stigma among patients with MS within our local community remains unexplored. Consequently, this study aims to assess the social stigma associated with MS in Saudi Arabia.

Methods. This descriptive cross-sectional study was based on an electronic survey created using Google Forms and conducted across all regions of Saudi Arabia from May 20, 2022, to October 24, 2023. It included

all patients with MS in Saudi Arabia aged 18 and older.

We included all patients with MS in Saudi Arabia, and the minimum sample size required for this study was calculated using Raosoft. Taking into account that the population size of patients with MS in Saudi Arabia is approximately 14, 000,¹¹ with a 95% confidence interval (CI) and an anticipated frequency of 50%, and assuming a design effect of 1, the calculated sample size was 374 participants.

The questionnaire utilized in this study was distributed to the target population following the receipt of ethical approval from the Biomedical Ethics Committee of the College of Medicine at Umm Al-Qura University, Makkah.

The questionnaire gathered demographic information from participants and utilized the validated RSS-MS scale (Table 2) from a published study.¹² The first author’s email and phone number were included, along with a message offering to answer questions or address any concerns. Informed consent was obtained from all participants.

Table 1 - Personal characteristics of multiple sclerosis patients, Saudi Arabia.

Personal data	No	(%)
<i>Regions</i>		
Central region	77	(20.2)
Northern region	25	(6.6)
Eastern region	123	(32.3)
Western region	144	(37.8)
Southern region	12	(3.1)
<i>Age in years</i>		
<25	105	(27.6)
26–50	239	(62.7)
51–65	37	(9.7)
<i>Gender</i>		
Male	150	(39.4)
Female	231	(60.6)
<i>Marital status</i>		
Single	199	(52.2)
Married	182	(47.8)
<i>Educational level</i>		
Below secondary	25	(6.6)
Secondary	112	(29.4)
University	214	(56.2)
Post-graduate	30	(7.9)
<i>Employment</i>		
Unemployed	186	(48.8)
Employed	158	(41.5)
Retired	37	(9.7)

Table 2 - RSS-MS scale responses from patients with MS.

RSS-MS items	Never		Rarely		Sometimes		Often		Always	
	No	(%)	No	(%)	No	(%)	No	(%)	No	(%)
Felt that having MS ¹ was a punishment for things I had done in the past.	169	(44.4)	74	(19.4)	110	(28.9)	20	(5.2)	8	(2.1)
Felt that people were avoiding me because of my MS	189	(49.6)	62	(16.3)	85	(22.3)	29	(7.6)	16	(4.2)
Feared that I would lose my friends if they found out about having MS	206	(54.1)	50	(13.1)	76	(19.9)	33	(8.7)	16	(4.2)
Felt like people that I know were treating me differently because of my MS	85	(22.3)	57	(15.0)	131	(34.4)	60	(15.7)	48	(12.6)
Felt like people look down on me because I have MS	230	(60.4)	55	(14.4)	58	(15.2)	25	(6.6)	13	(3.4)
Avoided dating because most people don't want a relationship with someone with MS.	185	(48.6)	47	(12.3)	85	(22.3)	37	(9.7)	27	(7.1)
Avoided a situation because I was worried about people knowing I have MS	150	(39.4)	46	(12.1)	120	(31.5)	33	(8.7)	32	(8.4)
Was embarrassed about having MS	189	(49.6)	47	(12.3)	94	(24.7)	33	(8.7)	18	(4.7)
Felt that keeping my MS a secret was important	105	(27.6)	47	(12.3)	93	(24.4)	63	(16.5)	73	(19.2)
Overall score (Range; (Mean \pm SD); % of maximum)	9-45 (20.0 \pm 8.2); 44.4%									

MS - multiple sclerosis

Table 3 - Item loadings, eigenvalue, and variance for the final 1-factor RSS-MS solution.

Items	Factor loading
Felt that having MS ¹ was a punishment for things I had done in the past.	.51
Felt that people were avoiding me because of my MS	.78
Feared that I would lose my friends if they found out about having MS	.89
Felt like people that I know were treating me differently because of my MS	.70
Felt like people look down on me because I have MS	.82
Avoided dating because most people don't want a relationship with someone with MS.	.77
Avoided a situation because I was worried about people knowing I have MS	.80
Was embarrassed about having MS	.81
Felt that keeping my MS a secret was important	.55
Eigenvalue	4.9
Variance (cumulative)	54.8%

MS - multiple sclerosis

Data were collected, reviewed, and then input into the Statistical Package for Social Sciences version 26.¹³ All statistical methods were two-tailed with an alpha level set at 0.05, considering results significant if the *p*-value was less than or equal to 0.05. Descriptive analysis, based on frequency distribution and percentage, was used for categorical variables, while the mean with standard deviation and range was used to describe the overall RSS-MS scale. Tool reliability (internal consistency) was assessed using Cronbach's coefficient alpha and inter-item correlations. All assumptions, including sample size, multivariate assumptions, and normality distribution of the data, were met. Principal component factor analysis (PCA) with maximum likelihood extraction and parallel analysis was employed to assess the internal factor structure of the RSS-MS scale using factor analysis techniques.¹⁴ Factors retained

in the PCA were based on the scree plot, reflected a parsimonious solution, and had significant eigenvalues exceeding 1.0.¹⁴

Results. Descriptive analysis. A total of 381 eligible patients with MS completed the study questionnaire. Of these, 144 (37.8%) were from the Western region, 123 (32.3%) from the Eastern region, 77 (20.2%) from the Central region, and the remainder from other regions. Patient ages ranged from 19 to 65 years, with a mean age of 34.2 \pm 13.8 years. Of the participants, 231 (60.6%) were female, and 199 (52.2%) were single. Regarding education, 214 (56.2%) were university graduates, 112 (29.4%) had a secondary level of education, and 30 (7.9%) held post-graduate degrees. A total of 186 (48.8%) were not working, while 158 (41.5%) were employed (Table 1).

Table 4 - Factors associated with MS patient's stigma score and reported differences.

Factors	N	RSS-MS scores		P-value
		Mean	SD	
Region				.001*
Central region	77	18.4	7.7	
Northern region	25	25.5	10.0	
Eastern region	123	17.3	7.2	
Western region	144	22.2	8.1	
Southern region	12	19.9	7.3	
Age in years				.001*^
< 25	105	23.3	8.8	
26-50	239	18.0	7.3	
51-65	37	23.7	7.8	
Gender				.604^
Male	150	20.3	7.8	
Female	231	19.8	8.4	
Marital status				.011*^
Single	199	21.0	8.3	
Married	182	18.9	8.0	
Educational level				.144
Below secondary	25	23.1	9.6	
Secondary	112	20.5	8.7	
University	214	19.4	7.8	
Post-graduate	30	19.9	7.5	
Employment				.049*
Unemployed	186	20.0	8.9	
Employed	158	19.4	7.2	
Retired	37	22.5	8.4	

P: One Way-ANOVA, ^: Independent samples t-test, * $p < 0.05$ (significant)

Table 2 shows the frequency characteristics of RSS-MS items and responses from patients with MS. A total of 77.7% felt that people treated them differently because of their MS, while 72.4% believed that keeping their MS a secret was important. Additionally, 60.6% avoided situations due to concerns about others discovering their MS, and 55.6% felt that having MS was a punishment for past actions. Furthermore, 51.4% refrained from dating because they perceived that most people do not want a relationship with someone with MS, 50.4% felt that others were avoiding them because of their MS, and an equal percentage were embarrassed about having MS. Only 39.6% felt that people looked down on them because of their MS.

Internal structure. Factor structure. Factor analysis was conducted using PCA with maximum likelihood extraction. No factor rotation was applied, and the coefficients supported a one-factor solution. The extraction of a single component revealed an eigenvalue

greater than one, identified at the elbow point on the scree plot, which was confirmed by parallel analysis. Rotation was not applicable, as the factor loadings ranged from 0.51 for “Felt that having MS was a punishment for things I had done in the past “ to 0.89 for “Feared that I would lose my friends if they found out about having MS,” indicating good construct validity.¹⁵ All nine items were retained. The one-factor solution explained 54.8% of the total variance.

Internal consistency. The internal consistency of the 9 items of the RSS-MS for the study sample, following multiple imputation, was excellent, with a Cronbach's alpha of 0.89. Inter-item correlations ranged from 0.28 to 0.72. Removing items with low total correlations would not have improved the Cronbach's alpha; therefore, all items were retained.

Relationship to other variables. Table 4 illustrates factors associated with the stigma scores of the patients with MS and reported differences. The mean RSS score was significantly highest among patients in the Northern region (25.5 ± 10.0) and lowest among patients in the Eastern region (17.3 ± 7.2), with reported statistical significance ($p = .001$). Additionally, the mean score was highest for older patients (23.7 ± 7.8) and lowest among patients aged 26-50 years (18.0 ± 7.3 ; $p = .001$). Single patients had a significantly higher stigma score than married patients (21.0 ± 8.3 vs. 18.9 ± 8.0 , respectively; $p = .011$). Similarly, retired patients reported higher stigma than the employed group (22.5 ± 8.4 vs. 19.4 ± 7.2 , respectively; $p = .049$).

Discussion. Individuals with chronic illnesses frequently face discrimination and negative attitudes.¹⁶ Social stigma brands these individuals as “spoiled” or less valuable than those considered “normal”.¹⁷ Such stigmatization can result in diminished self-esteem and social support, elevated depression and anxiety, heightened social conflicts, and greater psychological distress.¹⁸⁻²⁰ These consequences may induce stress that compromises the immune system and impedes positive health behaviors, including routine physician visits and treatment adherence.²¹

The current study aimed to assess social stigma among multiple sclerosis (MS) patients in Saudi Arabia. The results indicated that patients with MS experienced an average level of stigma, with a stigma score of 20.0 ± 8.2 out of 45 (44.4%). The most prevalent stigma-related issues were patients feeling treated differently because of their MS, reported by over three-fourths of participants, and the perceived need to keep their MS a secret. Approximately two-thirds avoided situations for fear of others discovering their MS, and over half

believed that having MS was a punishment for past actions. About half of the patients refrained from dating due to the belief that most people do not want a relationship with someone with MS and felt that others avoided them because of the condition. Similarly, half of the patients were embarrassed about having MS. More than one-third felt looked down upon because of their MS. Higher levels of stigma were reported among individuals at the extremes of age, in certain regions, and among single parents, which may reflect their reluctance to marry due to MS or their lack of acceptance as a spouse with the disease, adding another layer of burden. Additionally, unemployed and retired patients experienced higher stigma compared to those employed, who may benefit from social relationships and acceptance by others.

Eldridge-Smith et al¹² reported that most patients with MS felt they were treated differently due to their diagnosis. Demographic differences also influenced the stigma experienced, with single or widowed/divorced/separated individuals reporting more stigma than those who were married or partnered. Additionally, unemployed patients experienced higher levels of stigma.¹² Maurino J et al⁷ concluded that work difficulties, stigma, and poor quality of life are common among MS patients, even those with low physical disability.⁷ Broersma F et al²² found that patients with MS reported moderate to severe limitations, with stigma being frequent but of low impact. A higher sense of coherence was associated with fewer limitations and less stigma.²² Grothe L et al⁴ discovered that 57.3% of MS patients had experienced stigmatization due to MS at least once.⁴ Grytten and Måseide observed²³ that 14 patients with MS often concealed or disclosed information in response to social pressures, particularly in occupational settings.²³ Vickers MH²⁴ revealed that 21 persons with MS found confronting the diagnosis to be a significant life transition filled with uncertainty and fears of being stereotyped and stigmatized.²⁴ Researchers concluded that, compared to other stigmatized conditions like HIV, MS is not within individual control, which may reduce the stigma experienced by MS patients.²⁵

In Iran, Kalantari S et al⁸ found that the frequency of perceived stigma was significantly associated with employment status, disease duration, symptom severity, disability level, and economic condition. In Portugal, Pinto AS²⁶ reported moderate to high self-stigma levels among 31.4% of MS patients. High self-stigma was significantly more prevalent in unemployed/retired patients compared to those who were employed (39.0% vs. 0%; $p=0.021$).

This study is limited by its cross-sectional nature, which precludes tracking changes over time. Further investigation with a larger sample size in this population could more comprehensively explore the various facets of social stigma. Additionally, it warrants exploration to examine whether participation in MS associations mitigates feelings of stigma and provides a supportive environment. Longitudinal studies could offer insights into the evolving dynamics of stigma perception and the potential benefits of engagement in MS associations.

Conclusion. The overview of social stigma experienced by individuals with multiple sclerosis (MS) reveals a pervasive, moderate-level stigma affecting various aspects of their lives. Global studies underscore the consistency of this stigma, linking it to disease severity, duration, employment status, and coping mechanisms among MS patients. These insights underscore the urgent need for targeted interventions and increased societal awareness to mitigate the burden of stigma faced by those living with MS.

Acknowledgement. *We extend our gratitude to the Arfa MS Society for their invaluable assistance in distributing the questionnaire among the targeted population. Their contribution greatly facilitated the data collection process for this study, and we would like to thank editage (www.editage.com) for English language editing.*

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