Original Article

Anticipated Stigma among Patients with Multiple Sclerosis in Saudi Arabia

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Abstract

Background: Social stigma is a major problem among patients with multiple sclerosis (MS), which can affect their quality of life. There is limited research from Saudi Arabia on the anticipated stigma among patients with MS.

Objectives: To determine the levels of anticipated stigma and its predictors in patients with MS in Saudi Arabia.

Methods: This cross-sectional study included adult patients with MS across Saudi Arabia. Sociodemographic and medical information, including age, gender, marital status, educational level, duration of disease, number of MS episodes in the past 12 months, previous diagnosis of mental illness, and performing activities of daily living without assistance, were collected. Anticipated stigma was measured using an Arabic version of the Chronic Illness Anticipated Stigma Scale.

Results: A total of 222 patients with MS were included. Moderate to severe anticipated stigma was found among 70.4% of the patients. The highest anticipated stigma mean score was from work colleagues (2.96/5). Predictors of stigma were age ($P = 0.049$), gender ($P = 0.016$), marital status ($P = 0.015$), education level ($P = 0.003$), number of MS episodes in the previous year ($P < 0.001$), and previous diagnosis of a mental disorder ($P = 0.001$).

Conclusions: The findings of this study indicate the need for developing programs that reduce the anticipated stigma among patients with MS in Saudi Arabia.

Keywords: Chronic Illness Anticipated Stigma Scale, chronic illness, mental health, multiple sclerosis, Saudi Arabia, stigma

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INTRODUCTION

Multiple sclerosis (MS) is a chronic inflammatory autoimmune disease that causes neurodegeneration and demyelination in the central nervous system. It is a common cause of non-traumatic disability among young adults, typically between 20 and 40 years of age, that mostly affects women. Symptoms vary greatly among patients and can follow a relapsing–remitting or progressive form,[1] although the specific cause of this disease remains unknown.[2-5] Those diagnosed with MS have a lifetime of

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disability, with symptoms such as muscle weakness, pain, fatigue, urinary incontinence, and sexual dysfunction.[6,7] The age of onset of MS usually coincides with a critical time in people's professional careers, which can further worsen their psychological health.[8]

Stigma is a mark that labels someone in a discriminatory way. Goffman described it as an "attribute that is deeply discrediting"[9] that can lead to a loss in social status and mental well-being.[10] There are three types of stigmas: perceived, enacted, and anticipated.[11] Anticipated stigma is the belief that discrimination or prejudice is likely to occur in the future.[12] People with chronic illness are more prone to developing stigmas, which have been linked to psychosocial outcomes.[13] The Chronic Illness Anticipated Stigma Scale (CIASS) was developed to estimate anticipated stigma (i.e., stereotyping, expectations of prejudice, and discrimination) among individuals diagnosed with chronic illnesses.[11] A recent study found that the majority of patients with MS reported at least some level of anticipated stigma, including isolation stigma and experiences or fears about biased treatment. Anticipated stigma also predicts patients' attempts to conceal MS.[14]

There has been insufficient research on the anticipatory nature of stigma and the effects of stigma due to MS, especially in Saudi Arabia. The estimated projected prevalence of MS in the population within Saudi Arabia is 40.4/100,000 (61.95/100,000 among Saudis).[15] A recent study found that individuals with MS who felt stigmatized had a lower overall quality of life, were more likely to experience work productivity losses, and required more informal care.[16]

The current study was conducted primarily to assess the levels of anticipated stigma among patients diagnosed with MS in Saudi Arabia, and secondarily, to study the demographic features and MS-related predictors of anticipated stigma. The findings can help psychiatrists and neurologists gain a better understanding of the psychological state of patients with MS, which can aid better outcomes for these patients.

METHODS

Study design, setting, and participants

This cross-sectional study was conducted between April and August 2022 among adult patients (aged 17–60 years) with MS who lived in Saudi Arabia using convenience sampling. Using an online sample size calculator, the sample size was calculated as 368 with a 95% confidence level.[17]

Participants were informed that participation is voluntary. In addition, they were assured of anonymity and confidentiality of the responses, and steps were taken by the authors to ensure the same. No incentives were offered for participation. All participants provided digital informed consent before undertaking the survey. Ethical approval was obtained from the Research Ethics Committee of King Abdulaziz University.

Data collection

Data were collected through Google Forms using a two-part questionnaire: the first part elicited sociodemographic information, and the second part was the Arabic version of the CIASS. The usability and technical functionality of the questionnaire was tested before it was fielded. To avoid duplications, responses were limited to one response per user. Participants were approached through three MS organizations based in Riyadh, Jeddah, and Dammam, namely, "Jeddah MS," "Moeen," and "Arfa". The survey link was shared through the WhatsApp groups and broadcast lists of these organizations.

Questionnaire

The following sociodemographic and medical information was collected: gender, age, education level, social status, city of residence, years with MS, quality of life, diagnosis of mental illness, and the number of MS attacks in the past year.

CIASS is a validated and reliable tool that consists of the following three subscales with four items each: family and friends, work, and health care.[18] Permission for its use was obtained from the author, Dr. Valarie Earnshaw. The scales are measured across a 5-point Likert scale (1 = Very unlikely, to 5 = Very likely), with higher scores representing higher levels of anticipated stigma. A mean total for the combined items was computed for analysis. The questionnaire has a high internal reliability (Cronbach's α: 0.93).[11]

Arabic translation of the Chronic Illness Anticipated Stigma Scale

The questionnaire was forward-translated from English to Arabic by a bilingual researcher and then back-translated to English by two professional translators. Discrepancies between the translations were reconciled. The Cronbach's alpha test for internal consistency was used to assess the reliability of the Arabic version, which yielded a Cronbach's alpha of 0.89, indicating good reliability. A pilot study was conducted with 20 patients with MS to assess its clarity. There were no changes determined following the pilot study, and thus the data of the participants was included in the final analysis.

Statistical analysis

Responses to all items was mandatory for submitting the survey. Responses were captured using an automatic method through Google Forms. Data were analyzed using SPSS version 23 (IBM Corp., Armonk, NY, USA) and GraphPad Prism version 8 (GraphPad Software, Inc., San Diego, CA, USA). Categorical and nominal variables were presented as counts and percentages. Continuous variables were described as means and standard deviations. The Kolmogrove–Smirnov test and the histograms were used to assess the statistical normality of metric variables. The mean ascending rank was used to order the measured mean perceptions from lowest to highest. The bivariate Pearson's correlation test was used to assess the correlations between metric measured variables. The multivariable linear regression analysis was applied to the mean anticipated stigma score by regressing it against relevant predictors that were selected based on the literature review of patients' anticipated stigma. The associations between predictor/independent variables with the mean anticipated stigma score was expressed as multivariable adjusted beta coefficients with their associated 95% confidence intervals. The alpha significance level was considered at 0.050 level.

RESULTS

Sociodemographic characteristics

A total of 222 MS patients completed the questionnaire. Although this sample size is not adequate at a 95% confidence level, it is adequate at an 85% confidence level.[17] All respondents were undergoing treatment for MS. The mean (±SD) age was 33.1 (±8.6) years (range: 17–60 years). Most of the respondents were female (65.8%), single (47.3%), had university degrees (68.9%), and resided in the Western region of Saudi Arabia (50%). In addition, most participants had experienced one MS episode in the past 12 months (51.4%) and did not have any prior diagnosis of mental disorder (65.3%). Of those with a mental disorder, 80% had been diagnosed with depression and 61.3% with anxiety. The majority of participants did not require assistance with their activities of daily living (ADLs) (88.3%) [Table 1].

Table 1: Sociodemographic characteristics of patients with multiple sclerosis (*N*=222)

Parameters	Frequency (%)
Gender	
Female	146 (65.8)
Male	76 (34.2)
Age (years), mean±SD	33.10±8.58
Age group (years)	
19–30	103 (46.4)
31–40	84 (37.8)
41–50 or older	35 (15.8)
Marital status	
Single	105 (47.3)
Married	96 (43.2)
Divorced	21 (9.5)
Educational level	
Intermediate	6 (2.7)
Secondary	37 (16.7)
University	153 (68.9)
Post-graduate and higher	26 (11.7)
Residence	
Western Province	111 (50)
Central region	82 (36.9)
Eastern Province	16 (7.2)
Southern Province	13 (5.9)
Previous diagnoses of mental disorder	
No	145 (65.3)
Yes	77 (34.7)
Diagnosed mental disorder (*n*=77)	
Anxiety disorder	46 (61.3)
Depression	62 (80)
Delusional disorder	14 (17.3)
Obsessive compulsive disorder	5 (6.7)
Other mental disorders	4 (5.3)
Number of MS episodes in the past 1 year	
1	114 (51.4)
2	55 (24.8)
3	34 (15.3)
4	19 (8.6)
Completing ADLs without assistance	
No	26 (11.7)
Yes	196 (88.3)

SD – Standard deviation; MS – Multiple sclerosis; ADLs – Activities of daily livings

Anticipated stigma

Nearly three-fourths (70.4%) of the patients experienced moderate to severe social stigma. The most common anticipated stigma from family and friends were anger of family members (mean: 2.33/5) and family members blaming them for not getting better (mean: 2.32). The most common anticipated stigma from co-workers was people at the workplace thinking the patient cannot fulfill their work responsibilities and tasks (mean: 3.29) and employer/supervisor assigning challenging projects/assignments to another co-worker (mean: 3.22). The most common anticipated stigma from health-care workers (HCWs) was the frustration of HCWs with the patient (mean: 2.15) and HCWs blaming the patient for not improving (mean: 2.05) [Table 2].

The mean overall anticipated stigma was 2.38/5, indicative of a moderate level of anticipated stigmatization by the patients. In the sub-scales, the highest mean score was in stigma from work colleagues (2.96), indicating substantive anticipated work-related stigma by the patients, and the lowest mean score was in stigma from HCWs (2.02) [Table 3].

Predictors of anticipated stigma

In the multivariable linear regression analysis, gender was found to be a significant predictor of anticipated stigma, with males perceiving significantly higher stigma than

females (β = 0.258, P = 0.016). Age was also another significant predictor of anticipated stigma: a rise in 1 year of age resulted in the mean predicted stigma score decline by 0.017 (P = 0.049). The anticipated stigma among divorced/widowed MS patients was non-significantly higher than that of single MS patients (β = 0.339, P = 0.091); however, married MS patients had significantly higher anticipated stigma compared with unmarried patients (β = 0.298, P = 0.015). Patients with university and higher educational levels had lower mean anticipated stigma scores than those with high school or lower educational levels (β = −0.385, P = 0.003). The number of MS attacks/year was also a significant predictor of anticipated stigma: a rise in by one episode increased the mean score by 0.295 points [P < 0.001]. Disease duration and their ability to self-care and to do ADLs without assistance were not significant predictors of anticipated stigma. However, patients diagnosed with mental/psychological disorders had significantly higher anticipated stigma of MS than those without mental/psychological disorders (β = 0.334, P = 0.001) [Table 4].

Correlation analysis

Each subscale of the anticipated stigma questionnaire (i.e., work stigma, family stigma, and health worker anticipated stigma scores) was significantly positively correlated to the overall score (P < 0.010 for all). In addition, the subscales of the stigma were significantly correlated with each other. The number of MS episodes were significantly positively correlated with the overall score (r = 0.316, P < 0.010): the higher the number of episodes, the higher the anticipated stigma. The number of MS episodes were also significantly positively correlated with the mean stigma of all three subscales (P < 0.010 for all). Age was also significantly positively correlated with the MS disease duration (r = 0.607, P < 0.010) [Table 5].

Table 2: Anticipated stigma of patients with multiple sclerosis

Parameter	Mean±SD	Rank
Stigma from friends and family score		
A friend or family member will be angry with you	2.33±1.32	1
A friend or family member will blame you for not getting better	2.32±1.31	2
A friend or family member will think that your illness is your fault	1.76±1.1	4
A friend or family member will not think as highly of you	2.24±1.25	3
Stigma from work colleagues		
Your employer will not promote you	2.77±1.28	3
Someone at work will discriminate against you	2.58±1.31	4
Your employer will assign a challenging project to someone else	3.22±1.3	2
Someone at work will think that you cannot fulfill your work responsibilities	3.29±1.29	1
Stigma from HCWs		
HCW will be frustrated with you	2.15±1.16	1
HCW will give you poor care	2.01±1.1	3
HCW will blame you for not getting better	2.05±1.08	2
HCW will think that you are a bad patient	1.89±1.06	4

SD – Standard deviation; HCWs – Healthcare workers

Table 3: Patient's overall and subscale scores for anticipated stigma

Parameter	Mean±SD
Overall anticipated stigma	2.38±0.82
Stigma from friends and family	2.16±0.99
Stigma from work colleagues	2.96±1.07
Stigma from HCWs	2.02±0.96

SD – Standard deviation; HCWs – Healthcare workers

DISCUSSION

This study found that nearly three-fourths (70.4%) of the patients experienced moderate to severe social stigma. These results are similar to those of another study conducted in Spain, which found that 78.2% of patients with MS experienced severe social stigma.[19] Another study, which included 55 adult patients with MS, found that participants experienced some degree of stigma, estimated at 79.2%.[20]

However, an online survey conducted in the United States that used a combination of seven stigma measures found that perceptions of stigma were relatively low in patients with MS because patients tended to conceal their disease from others, which is a coping strategy that may help them avoid negative interpersonal interactions or becoming a target of bias and discrimination. However, the continual self-monitoring that concealment requires can be stressful and interfere with health behaviors. For instance, a study has found that patients who conceal their treatment may avoid the need for doctor visits and find treatment adherence more challenging.[21]

Our results are similar to another study that found stigma from work colleagues, more than from family and friends and from health-care workers, leads to discriminatory behavior by employers. Patients with MS who feel stigmatized or discriminated against often try to hide their diagnosis from colleagues, employers, and even occupational physicians.[22-24] Some patients with MS reported negative employer attitudes after disclosing their diagnosis. In addition, stigma, discrimination, and disclosure of MS in the workplace are potentially associated with an increased risk of premature departure from the workforce.[25,26] Although MS is more prevalent among women, we found that men were more stigmatized.

Table 4: Multivariate linear regression analysis of the anticipated stigma of patients with multiple sclerosis (*N*=222)

Variable	Unstandardized β coefficients	95% CI for β		*P*
		Lower bound	Upper bound	
Constant	2.376	1.673	3.079	<0.001
Sex (male)	0.258	0.049	0.466	0.016
Age (years)	−0.017	−0.035	0.000	0.049
Marital state (divorced/widowed)	0.339	−0.055	0.732	0.091
Marital state (married)	0.298	0.058	0.539	0.015
Education (university and higher degrees)	−0.385	−0.640	−0.129	0.003
MS disease duration (years)	0.014	−0.005	0.033	0.160
Can perform ADLs without assistance	−0.153	−0.481	0.175	0.358
Number of MS episodes in the previous year	0.295	0.191	0.400	<0.001
Previously diagnosed with mental illness	0.344	0.140	0.548	0.001

Dependent outcome variable: The chronic illness AS Questionnaire score. Model R=0.496, adjusted R^2=0.213. CI – Confidence interval; MS – Multiple sclerosis; ADLs – Activities of daily livings; AS – Anticipated stigma

Table 5: Bivariate correlation test between measured concepts and variables

Variable	Anticipated stigma score	Family and friends	Work colleagues	HCWs	Disease duration	Episodes
Overall anticipated stigma score	1					
Mean anticipated stigma from friends and family score	0.827**					
Mean anticipated stigma from work colleagues score	0.847**	0.582**				
Mean anticipated stigma from HCWs score	0.768**	0.443**	0.461**			
Duration of MS disease (years)	−0.016	−0.035	−0.032	0.031		
Number of MS episodes in the previous year	0.316**	0.313**	0.268**	0.190**	−0.119	
Age (years), mean±SD	0.004	0.048	−0.042	0.007	0.607**	−0.064

**Correlation is significant at the 0.01 level (two-tailed). MS – Multiple sclerosis; SD – Standard deviation; HCWs – Healthcare workers

The results of this study are similar to those of previous studies that found that anticipated chronic disease stigma decreased with age. MS can have a huge impact on the occupational and social life of younger patients. It is possible that those with a chronic illness at a younger age experience more stigmatization than older individuals because chronic conditions may be expected with increasing age.[27,28] Furthermore, in the current study, lower education levels were associated with higher anticipated stigma. However, in a study in Iran, no significant differences in anticipated stigma among patients with MS were observed across educational levels.[29]

In the current study, being married, divorced, or widowed was associated with greater anticipated stigma, which can be explained by more responsibilities of married individuals. Another study found no significant difference between married and single patients with MS.[29] Unexpectedly, we found that patients' disease duration, self-care abilities, and the ability to perform ADLs did not correlate significantly with their mean anticipated MS-related stigma, which could be explained by the fact that 88% of our sample did not require assistance for ADLs. Another study found that a lower quality of life was associated with higher anticipated chronic disease stigma.[30]

In our study, the number of MS episodes per year was associated with higher anticipated stigma, meaning that more episodes led to higher impact on the patient's life. Our study also found that patients who were diagnosed with a prior mental or psychological illness experienced more stigmatization.

Limitations

This study has several limitations. The study was cross-sectional, and thus, causal conclusions could not be drawn owing to the small number of participants. Further research is required to study the effect of stigma and its relationship with psychiatric diseases in patients with MS.

CONCLUSIONS

This study found moderate to severe anticipated stigma among patients with MS, especially with co-workers. There was an association between anticipated stigma and gender, marital status, duration of disease, number of MS episodes in the previous year, and a previous diagnosis of mental disorder. Further studies are required to determine effective strategies for reducing the anticipated stigma among patients with MS. Furthermore, programs aimed at upgrading public knowledge and reducing negative attitudes toward the disease should be promoted.

Ethical considerations

The study was approved by the Research Ethics Committee, King Abdulaziz University, Jeddah, Saudi Arabia (Ref. no.: 282-22; date: June 8, 2022). All study participants provided

digital informed consent before inclusion in the study. The study adhered to the principles of the Declaration of Helsinki, 2013.

Peer review

This article was peer-reviewed by two independent and anonymous reviewers.

Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Author contributions

Conceptualization: R.H.A, N.A.A, Z.I.A, A.M.A., and R.M.B.; Methodology: R.H.A, N.A.A, Z.I.A, and R.M.B.; Data analysis: R.H.A, N.A.A, Z.I.A, and R.M.B.; Writing–original draft preparation: R.H.A, N.A.A, Z.I.A, A.M.A., and R.M.B.; Writing – review and editing: R.H.A, N.A.A. Supervision: N.A.A.

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Conflicts of interest

There are no conflicts of interest.

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