

Perceived Social Stigma in Patients with Multiple Sclerosis: A Study from Iran

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Abstract

Objectives: Social Stigma is potentially a major problem in multiple sclerosis patients which strongly affects the quality of life. The aim of this study was to determine the prevalence of perceived stigma in patients with MS in a sample of Iranian population.

Methods: This cross-sectional study was performed on 305 MS patients who were referred to Iranian Multiple Sclerosis Society in 2014. The main variables were perceived stigma, age, sex, marital status, educational level, occupation, duration of the disease, type of symptoms, disability expanded status scale, family history and economic status. Social stigma was measured through a 20-item questionnaire which was developed by authors and the reliability was assessed in a pilot study.

Results: The frequency of perceived stigma was significantly associated with occupation, disease duration, and visibility of symptoms, level of disability and the economic condition. There were no significant relationships between perceived stigma and age, sex, marital status, level of education and family history. About 44 percent of patients preferred to hide their disease from others and 52.6 percent believed that this disease would stigmatize them in society. Nearly, half of patients preferred not to mention their disease in job interviews.

Conclusion: Recognition of the impacts of perceived stigma on various aspects of the patients' lives are necessary to find appropriate strategies to deal with stigma and its consequences. Training programs can improve the patients' skills for coping with stigma. Furthermore, programs aimed to upgrade public knowledge and reduce the negative attitudes toward the disease should be promoted.

Keywords: Multiple sclerosis, stigma, Iran, disability, restriction of social relations.

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INTRODUCTION

Multiple sclerosis (MS) is a potentially debilitating disease which is considered as the second leading cause of neurological disability (after trauma) in young adults^(1,3). Due of its vague and unknown etiology, being chronic, unpredictable progression, visible physical disability and lack of definitive treatment, MS can have a negative psycho-social impact on patients' lives and might lead to decrease in self-confidence and ability to adapt with the new condition^(1-2, 4-5). Social stigma is one of the major psychosocial problems in some patients. Many studies have been performed on the stigma which is associated with chronic diseases, such as epilepsy⁽⁶⁻¹¹⁾, schizophrenia⁽¹²⁻¹³⁾, HIV⁽¹⁶⁻¹⁷⁾, conditions which lead to disability^(1-2, 14-15,20) and even obesity⁽¹⁸⁾ and diabetes⁽¹⁹⁾. These studies have investigated the importance of social stigma and their consequences on quality of life. Disability can be associated with internal and external aspects of stigma. The internal aspect refers to feeling to be different from others and can hamper the patient's self-image. On the other hand, the external aspect of stigma is related to the way people encounter and interact with a disabled person and might lead to the unpleasant distinction and labeling⁽¹⁴⁾.

According to some limited evidence, MS patients experience a wide range of stigma in their social relations and social stigma is one of the major issues which might affect quality of life remarkably^(1-2, 21, 24-25, 27, 29).

Stigma is associated with several consequences, including social isolation, job loss and unemployment, loss of educational opportunities, marriage problems, loss of the sense of self-esteem, depression, anxiety and being deprived of social services^(10, 22-23). In addition, the indirect negative impact of stigma on public health is undeniable. Perceived stigma might hamper seeking medical care which can lead to poor health prognosis and increase the burden of disease on the health system⁽¹⁵⁾. Due to deleterious consequences of stigma, it is important to understand the impact of perceived stigma on various aspects of patients' lives and to find proper solutions to deal with stigma and its outcomes.

The studies on social aspects of MS, especially stigma of the disease are limited. The aim of this study was to determine the prevalence of perceived stigma in patients

with multiple sclerosis in a sample of Iranian population to better understand stigma associated with the disease and the contributing factors. Accordingly, promising strategies to cope with stigma and its consequences can be provided.

METHODS

This cross sectional study was performed on patients with multiple sclerosis who were referred to Iranian Multiple Sclerosis Society in 2013. The main variables were perceived stigma, age, sex, marital status, educational level, ethnicity, duration, type of symptoms, Disability expanded status scale, family history of MS and economic status. As there were no standardized questionnaires on measurement of the stigma in MS patients, a questionnaire was developed by the authors considering the most relevant published studies^(1-2, 24, 28).

The questionnaire consisted of 20 questions on different aspects of social stigma. In addition, some questions for demographic variables and clinical status of the patients were also developed.

We used a five-point Likert Scale to allow the individuals to express how much they agree or disagree with a particular statement. Each question was scored from strongly disagree to strongly agree, from 1 to 5 points and each patient could get a minimum of 20 to a maximum of 100 points with higher scores meaning higher perceived stigma.

The pilot study was done on 18 MS patients and the questionnaire was modified to increase clarity (Cronbach's alpha =0.87). In addition, 6 neurology experts and senior investigators confirmed the content validity of questionnaire regarding relevance, necessity of the question to measure stigma, and simplicity to be comprehended by patients. Informed consent form was signed by all participants.

Data was analyzed USING SPSS 19 using independent T test, non-parametric tests and factor analysis.

RESULTS

In this study, 305 MS patients were studied of whom 228 (% 74.8) were female. The mean age of the patients was 32 ± 9.09 years. About 40% of patients were never married, 51% were married and 6.6% were

divorced. About 59% of the patients were living in Tehran. All demographic data are summarized in Table 1. The average perceived stigma in participants was 58.6 ± 14.7 and median was 58. There was no statistically

significant difference between age groups and perceived stigma Average perceived stigma was 58.07 (SD: 14.39) in men and 58.78 (SD: 13.99) in women. There were no significant differences between males and females

Table 1. Sociodemographic background and perceived stigma

Variable group	N(Percentage)	Perceived stigma (Mean \pm SD)
Gender		
Male	77(25.2)	58.07 \pm 14.39
Female	228(74.8)	58.78 \pm 13.99
Age		
27years and lower	99 (32.5)	59.27 \pm 14.01
28 to 34 years	89 (29.2)	57.61 \pm 14.21
35 years and higher	109(35.7)	58.22 \pm 13.56
Marital status		
Single	121(39.7)	57.43 \pm 13.57
Married	155(50.8)	58.96 \pm 14.14
Divorced	20(6.6)	63.60 \pm 15.84
Widow	2(0.7)	55.00 \pm 21.21
Education		
High school graduates or lower	128(42)	59.02 \pm 13.60
A.A/A.S ¹ and B.A/B.S degrees	135(44.3)	58.79 \pm 14.76
M.A/M. S and higher degrees	40(13.1)	56.62 \pm 13.16
Occupation		
Government employees	61(20)	55.22 \pm 14.29
Self-employed	40(13.1)	54.77 \pm 14.14
housekeeper/ unemployed	89(29.2)	61.51 \pm 14.31
Student	25(8.2)	57.08 \pm 11.33

¹Associate in Art/ Associate in science

Table 2. stigma on Duration of Disease and EDSS

Variable group	Frequency (Relative frequency)	Perceived Stigma (Mean \pm SD)
Duration of disease		
Less than 4 years	99 (32.5)	56.27 \pm 14.17
4 to 8 years	77 (25.2)	58.62 \pm 13.07
More than 8 years	104 (34.1)	61.24 \pm 14.50
Disability expanded status scale		
No difficulty in walking	154 (50.5)	54.20 \pm 13.38
Difficulty in walking but able to walk about 100 meters without aid	73 (23.9)	59.69 \pm 11.88
Difficulty in walking, often require others' help using wheelchair	45 (14.8)	64.37 \pm 13.75
Totally dependent on others for personal daily routines	9 (3)	68.66 \pm 14.30
	21 (6.9)	71.33 \pm 13.33

Table 3. Items evaluating stigma

		Completely disagree (%)	Disagreed (%)	No comment (%)	Agree (%)	Completely Agree (%)
	Stigma and concealing the disease					
1	I prefer to hide my illness, because of others' reaction and behavior	18.4	25.3	18.4	22	15.8
2	I am regretful about telling the people around that I have MS	10.5	17.1	27.6	28.3	16.4
3	I want people around no to tell others that I have MS	28.3	19.7	24.3	17.4	9.9
4	I prefer not to mention my disease in job interviews.	18.7	25.2	22.3	23.3	10.5
	Stigma and its consequent Social restrictions:					
5	Because of my illness, I do not feel comfortable in social communications and I feel embarrassed	17.7	20.3	12.1	27.9	22
6	Because of people's attitudes toward MS patients, I couldn't use educational opportunities well	12.5	13.2	27	24.3	23
7	I lost some of my friends because of this disease	7.9	11.9	14.5	30	35.6
8	After I was diagnosed with MS, my friends and colleagues changed their behavior toward me.	13.2	28	21.4	22.7	14.8
9	I have limited my social activities and relations, because of people's attitude toward MS patients.	10.9	15.5	12.2	28.3	32.9
10	I have limited my social relations on my own since I was affected by this disease.					
	Stigma and overemphasizing the disease:					
11	My family members show exces kindness to me because of the disease.	9.9	22.7	20.4	31.9	15.1
12	My family members pretend that my disease is not very important and considerable, as they think I feel more comfortable this way.	28.7	36.3	16.8	12.2	5.9
13	My family members have no expectations of me and I do not have any work or responsibility in the family Because of the disease	14.2	23.8	11.6	31	19.5
14	I receive too much attention and affection from people, because of the disease, Stigma and Patients tend to limit relations just to MS patients	9.9	26.3	25.7	27.6	10.5
15	I prefer friendship with people who suffer from MS, as well If I'm single: I prefer to get married to someone with MS	10.6	17.2	27.7	24.1	20.5
16	If I am married: I think it is better for MS patients to marry with someone who has the same disease	10.9	11.6	30.5	18.9	28.1
	Stigma and psycho-social aspects:					
17	People's reaction after knowing about my disease is so that makes me sad My abilities and positive points are ignored	15.5	28	27.6	20.4	8.6
18	in the community, because of the disease.	10.5	20.4	25	28	16.1
19	I think this disease stigmatizes individuals in society	22	30.6	17.8	20.1	9.5
20	I become more sensitive to people's reactions and staring, every day more than before	16.4	25.7	21.7	20.7	15.5

regarding perceived stigma prevalence.

Similarly, there were no significant differences between single and married individuals considering perceived stigma prevalence. No significant differences were observed among different educational levels regarding the perceived stigma (pv: 0.629).

Regarding the association of perceived stigma with occupation, the observed difference was significant (pv: 0.018). Post hoc analysis specified that the main difference was between the group of non-governmental jobs and unemployed/housewives group (pv: 0.065). Average frequency of stigma in housewives and unemployed was 61.51 (SD = 14.31), which was higher than other occupational groups.

In this study, 142 participants (48.9 %) had visible symptoms and 155 patients (50.8 %) had nonvisible symptoms. The frequency of stigma in patients with visible signs and without visible signs was 62.42 (SD = 14.78) and 54.83 (SD = 12.27), respectively. There was a significant relationship between stigma and visibility of symptoms (pv < 0.001). Thus, patients with visible signs of disability perceived more stigma compared with patients without obvious disabilities.

The mean duration of disease was 7.4 ± 5.7 months. According to our findings, there was significant relationship between stigma and disease duration (pv: 0.043). The main difference was between groups with disease duration less than 4 years and those with more than 8 years (pv: 0.043). Patients with a disease duration of 8 years or more experienced more stigma than others. In essence, Patients with longer disease duration experienced more stigma than patients with short disease duration.

In this study, there was a significant association between perceived stigma and Expanded Disability Status Scale (EDSS) (pv < 0.001). Therefore, higher levels of disability were associated with higher levels of stigma and the highest levels of perceived stigma were for totally dependent patients (71.33, SD: 13.33). Thus, MS patients with higher levels of disability and dependence experienced more stigma compared to others. The results are summarized in Table 2.

In this study, 52 participants (17%) had positive family history of MS and 253 (83%) had negative family history. The prevalence of perceived stigma in groups with and without family history was 55.34 and 59.28, respectively.

There were no significant differences between participants with positive and negative family history of MS regarding perceived stigma.

Considering perceived stigma based on economic status, Statistical analysis showed that patients with weak or very weak economic situation experience significantly more stigma compared to patients with good or middle economic situation (pv: 0.001). Each participant spent $39.77\% \pm 23.73$ of his/her income for MS treatment.

Factor analysis reveals five components in our questionnaire measuring perceived stigma:

1. Concealing the disease
2. Restriction of social relations
3. Overemphasizing the disease
4. Limiting social relations to other MS patients
5. Psycho-social aspects of stigma.

Table 3 demonstrates items in questionnaire and how much participants agree or disagree with each item.

There was an optional open-ended question at the end of the questionnaire to ask what the patients' expectations from community were. About 65% of participants responded to this optional question. Many of participants mentioned financial problems and the cost of treatment, while some others just wanted to be treated normally by society, without any unnecessary compassion or judgment.

DISCUSSION

In this study, the different aspects of stigma including hiding the disease, overemphasizing the disease, the loss of educational and marital opportunities, social relations and activities restriction, ignoring patients' abilities and positive points were assessed.

To the best of our knowledge, there are no quantitative investigations on stigma in MS patients. A qualitative study which was done in this field by Grytten et al⁽¹⁻²⁾. They assessed perceived stigma in MS patients by interviewing 14 patients and their relatives. Their questions were in these fields: patient's reaction to diagnosis, change of family's and friends' attitudes, hiding disease from others, feeling embarrassed, receiving a lot of attention because of their new status, reaction to public attitudes towards the disease and adjustment to disability. The results showed that Ignoring and overemphasizing are two different aspects of stigma experienced in MS patients⁽¹⁻²⁾.

In our study participants were also experiencing Ignoring and overemphasizing. About 35% of patients believed that they received a lot of attention and affection from people and extreme kindness from their family, because of the disease (overemphasizing). Additionally, approximately 31% of the patients believed that their abilities and positive points are being ignored in the community because of the disease (Ignoring).

Non-obvious symptoms usually lead patient to be ignored. Sometimes invisible symptoms display benign view of MS and the disease is considered unimportant. On the other hand, visible symptoms usually lead to overemphasizing the disease. Physical disabilities and visible signs display malignant view of MS and cause excessive focus on disease which make patient annoyed and feel more ill. Sometimes patients try to hide their condition to perform daily activities without stigma.

Average frequency of stigma in housewives and unemployed was higher than other occupational groups. In the case of stigma of epilepsy, unemployment has also been shown to be associated with higher levels of perceived stigma. Strong relationship between stigma and unemployment and the fact that both are major issues of MS patients shows a decisive need for further studies in this field.

In our study, 42% of the patients had BA/BS degree or higher. No Significant difference was observed among different educational levels. However, in the study was done in patients with epilepsy in Tehran⁽¹¹⁾, there was a direct relationship between lower levels of education and more perceived stigma. This difference might be related to the different nature of epilepsy and MS. In epilepsy, patients with higher level of education and higher adherence can control the disease more effectively. But in MS, due to the unpredictable nature of the disease, it could progress despite the complete adherence to available treatments and cause visible disability and more perceived stigma. Epilepsy is one of the most common stigmatizing conditions in the world and unlike MS many studies have been done about the stigma perceived in patients with epilepsy⁽⁶⁻¹¹⁾. This is while there are effective treatments for epilepsy, while currently there is no definite cure for MS despite numerous efforts.

According to previous studies on stigma association with mental disorders, patients who suffer from visible

disabilities beside mental disorders experienced more stigma compared to patients with mental disorders without obvious disabilities⁽²⁶⁾. Similarly, in our study, participants with visible signs of disability felt more stigma compared with patients without obvious disabilities. This indicates the importance of physical disability in patients' further negative self-image.

Some patients tried to hide their disease to protect themselves from social isolation, exclusion of social services or losing job. Also according to previous studies, hiding the illness in the workplace is a way to prevent losing job and income⁽²²⁻²³⁾. These studies were in accordance with our study in which about 44% of the patients expressed that they prefer to hide the disease in job interviews.

In our study, 38% of patients were uncomfortable in social relationships because of their illness. Also, approximately 44% of patients preferred to hide their disease because of public reaction and behavior. 48% wanted people around not to tell others that they have MS and About 43% believed that people's reactions after understanding their disease is so that makes them sad.

Some patients think that their physical and mental performance is judged in social relations and their capabilities are being ignored. In this regard our study showed that 31% of patients believed that their abilities and positive points are being ignored in community.

The role of family in coping with stigma is so critical and living in a stigmatizing condition affects all family members. In some cases, the family spends too much attention toward the patient makes him/her feel more ill and experience more disability. Compassion and sympathy from family makes him/her more disappointed and leads to know herself as a person without any ability or responsibility. Sense of irresponsibility leads them to feel invalid in family and society. In some cases, relatives do not expect the patients to participate and have a share in the family responsibilities and duties. This leads to staying away from social activities which in turn might lead to deeper social isolation. Similarly, our study showed that 32.6% of patients believed that their family show extreme kindness to them because of the disease and 38% believed that their family has no expectations of them and they have no responsibility in family because of the disease.

About 65% of patients believed that their family

members apparently show that the disease is not so considerable to make them feel more comfortable. 41% believed that after they were diagnosed with MS, friends and colleagues' behavior was changed toward them and 20% lost some of their friends because of this disease. Finally, 52.6% believed that this disease stigmatizes them in society.

Conclusion stigma was significantly associated with disease duration, visibility of symptoms, level of disability, occupation and the economic condition. Concealing the disease and its subsequences, social restriction and discrimination, unemployment, loss of educational opportunities, marriage problems, loss of friends, Ignored capabilities and feeling invalid are the main consequences of stigma in MS patients.

Therefore, more work needs to be done to decrease perception of stigma and discrimination in Individuals suffering from MS in Iran. Training programs and Psychotherapy sessions targeted to increase the patients' self-confidence will decrease their negative self-image and also will improve the patients' skills for coping with stigma. Furthermore, programs aimed to upgrade public knowledge and reduce the negative attitudes toward the disease should be promoted.

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