

# The relationship of psychological factors, demographic features and disease characteristics with self-management of multiple sclerosis patients

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## ABSTRACT

**Introduction:** Self-management is an important act of controlling the adverse outcomes in multiple sclerosis as a chronic and debilitating disease. This study was aimed to consider the relationship of psychological factors, demographic features and disease characteristics with self-management behaviors and predicting it among patients with multiple sclerosis.

**Methods:** In the correlational study, among the patients with multiple sclerosis who attended to the Iranian Multiple Sclerosis Association in Tehran, 193 patients were selected by a purposeful compliance procedure. Data were gathered with The Multiple Sclerosis Self-Management Scale, The Depression Anxiety and Stress Scales and the Demographical/Disease Characteristics Questionnaire, then were analyzed by multiple regression in the stepwise method by SPSS 18.

**Results:** Socioeconomic status and female gender had significantly positive relationship and role in prediction of self-management behaviors in patients with multiple sclerosis and also depression and anxiety had significantly negative relationship and role in prediction of self-management behaviors among these patients ( $F = (4,188) = 36.61$ ,  $P < 0.001$ ) and these four factors totally were explain 43% ( $R^2 = 0.43$ ) of self-management ( $P < 0.001$ ). Literacy, Marriage status, treatment type, age, disease duration and stress didn't have a significant role in prediction of self-management behaviors among these patients ( $P > 0.05$ ).

**Conclusion:** Depression and anxiety are important risk factors for decreased self-management among patients with multiple sclerosis. On the other hand, higher level of literacy and female gender are important factors for increased self-management among these patients. It is consequential, that pay attention to these factors in designing and implementing tailored programs of self-management and self-care promotion for controlling this disease.

**Key words:** Depression, Demographic Characteristics, Multiple Sclerosis

## Introduction:

Multiple sclerosis is one the most important and most common diseases of the central nervous system that by inflammation and destruction of the

myelin sheath, the electrical conductivity of nerve impulses in the central nervous system becomes impaired, it is associated with disability and pervasive impairment in psychosocial-social dimensions resulting a high social and economic

burden for society (1,2). The progressive disease that begins in early adulthood is one of the most important diseases of changing lifestyle (2).

Recently, multiple sclerosis disease in Iran has continued to increase, so that according to the MS Society of Iran, in 2010, approximately 18,000 patients have been registered in the MS community across the country and many are suffering from this disease that still their disease has not been recorded (3,4). Unknown disease prognosis, with a variety of psychological and physical disorders, loss and impairment of daily function, and recurrent disease will increase the importance of self-management behaviors and recognizing its determinants in coping with the symptoms and control the disease (5). Several factors are effective in acting self-care and self-management of the disease (6,7).

Self-management to devise patient-centered refers to in the field of treatment suggestion, medical symptoms management, following a diet, physical activity and follow-up rehabilitation measures for controlling the disease symptoms that as a result, it leads to improve and enhance the quality of life related to health (8,9). Self-management in patients with multiple sclerosis is influenced by individual and psychosocial- social factors that interact together in the complex act (10,11).

Although most research evidence in other societies and cultures, has emphasized on the important relation between psychological factors, Demographic characteristics and disease characteristics with self-management behaviors and its prediction in patients with multiple sclerosis, but the lack of a coherent research in this field in Iran, that study these factors simultaneously, is an important gap that with such examinations, it can be considered. Therefore, the aim of this study is to investigate the relation between psychological factors, demographic characteristics and disease characteristics with self-management behaviors and its prediction in patients with multiple sclerosis.

## Methods:

This study had a correlation plan that in this kind of research, self-management prediction based on psychological factors, demographic characteristics and disease characteristics were

studied in patients with multiple sclerosis. In this study, the statistical population included all patients with multiple sclerosis that have referred to the MS Society of Iran (Tehran) in the spring of 2013. 193 patients (68 males and 125 females) of them were selected randomly in a targeted manner as the research sample. In order to increase the power of the test, and prevent the loss or potential loss of participants, 200 patients were selected and after leaving seven of them, because of not completing the tools precisely and not having inclusion criteria, the final sample of 193 people was remained. The inclusion criteria for this study included to be younger than 65 years, the active participation and cooperation in the implementation of the study. Exclusion criteria included the simultaneous presence of chronic physical diseases such as diabetes, cancer, cardiovascular diseases, and infectious diseases, severe mental illness confirmed by a psychologist or psychiatrist, the incidence of exacerbation symptoms or hospitalization during the study period, recurrent more than 10 times, and participation in programs promoting self-care behaviors during the last six months. This study was based on respecting ethical criteria such as informed consent, medical confidentiality and protection of human subjects based on the Helsinki Declaration, attention to the participants' well-being, and their anonymity. In this study, data were collected by using patients with multiple sclerosis self-management scale (MSSM), various scales of depression, anxiety and stress (DASS -21), and demographic / disease characteristics questionnaire.

Self-management Scale of patients with multiple sclerosis (MSSM): This scale was used to evaluate self-care and self-management of the patients. This scale evaluates the important aspect of self-management of multiple sclerosis patients, such as adherence to medical treatment, attention to the physical, cognitive and emotional problems caused by multiple sclerosis, psychological distress control, knowledge and awareness about multiple sclerosis and awareness of signs and symptoms, to do behavior to keep healthy, communication with healthcare authorities and the continuation and strengthening of daily function. This scale consists of seven factors as adherence to treatment factor (factor 1), the relation between patient and health care (factor 2), emotional health and resources /

social protection (factor 3), awareness of health and disease symptoms (factor 4), knowledge and cognition about multiple sclerosis disease (factor 5), health maintenance behaviors (factor 6), and communication with health professionals about the symptoms/changes (factor 7). Revised scale of Multiple Sclerosis patients' self-management contains 39 items that are scored based on the 5 degrees Likert scale and a higher score indicates better self-care at this scale (15,16). The internal consistency with the Cronbach's alpha for these factors was in the range of 0.76 to 0.88 that shows the good internal consistency of this scale (15).

MSSM Reliability of the scale with the Cronbach's alpha was obtained 0.85 that shows this tool has a good internal consistency. The construct validity of the scale was confirmed by examining the correlation with lifestyle associated with multiple sclerosis (QOL) and scale MSIS-19 (15,16). Face and content validity of this tool was confirmed by five specialists in Iran (17).

Furthermore, its correlation was higher than 0.79 by means of multiple sclerosis quality of life and the internal consistency of this tool subscales was obtained by using the Cronbach's alpha between 0.78 to 0.94 that shows favorable reliability coefficients (17).

Scales of depression, anxiety and stress (DASS-21): This tool is made by Louie Band and by other researchers has been under extensive evaluations (18). This scale consists of three seven-item subscales that evaluate the negative emotions of depression, anxiety and stress. Depression items focus on and low mood, low self-esteem and negative attitudes to the future. Scale of anxiety focuses on the fear responses and physiological arousal and stress subscale also focuses on tension and constant arousal. The participants are asked to read every word carefully and after reading each word, grade the intensity/frequency of the mentioned symbols in the phrase over the past week by using a 4-degree scale (0 = never, 1 = often, 2 = sometimes, 3 = always). Total responses of each scale indicate the total score on the scale. The scale has construct validity, criterion validity, concurrent validity and favorable reliability (19,20).

The internal consistency of the various scales of depression, anxiety and stress and test-retest coefficients (within 3 weeks) depression, anxiety and stress in study of Asghari and colleagues was confirmed (20).

Demographic/disease characteristics questionnaire: by using this research-made tool, demographic information including age, gender, socioeconomic status, educational level, marital status and disease characteristics such as disease duration, complications, comorbid disorders, process and severity of the symptoms, treatment, and side effects of treatment were collected. Collected data were evaluated with research tools by using descriptive statistics (frequency, percentage, mean and standard deviation), correlation, and stepwise multiple regression analysis were evaluated with SPSS 18 Software.

## Results:

Respondents' ages ranged from 21 to 62 years with an average of  $9.67 \pm 38.13$ , respectively. According to the findings, patients over a period of 2 to 23 years with a mean time of  $3.66 \pm 7.96$  years suffered from multiple sclerosis. Prevalence and characteristics of participants are presented in Table 1.

Also, the average and standard deviation of the participants' scores in the various scales of research and correlation coefficients (double-stranded correlation between categorical predictors' factors with quality of life and Pearson's correlation between distance predictor factors with quality of life) are presented in Table 2.

In this study, at a confidence level of 99% ( $P < 0.01$ ) by using double stranded correlation coefficient there was a significant positive relation between female gender predictor factors, marital status (married), education (higher), socioeconomic status (favorable) and type of treatment (usual care in the management of multiple sclerosis disease) with self-management of patients with multiple sclerosis.

**Table 1. The frequency and characteristic percentage of participants (n=193)**

Variable	Kind	Frequency (Percentage)
Gender	Male	68 (35.2%)
	Female	125 (64.8%)
Socioeconomic status	Income below 900.000 toman	53 (27.5%)
	Income below two million toman	107 (55.5%)
	Income above two million toman	33 (17.1%)
	Illiterate, or in primary schools	28 (14.5%)
Level of education	Cycle	21 (10.9%)
	Diploma	58 (30.1%)
	Associate	24 (12.4%)
	Bachelor	43 (22.3%)
Marital status	Master's degree or higher	19 (9.8%)
	Single	76 (39.4%)
Treatment	Married	117 (60.6%)
	Simple and routine receiving treatment to manage the symptoms of multiple sclerosis	118 (61.1%)
	Complications of the disease in addition to conventional treatment	75 (38.9%)

**Table 2. Correlation coefficient (double stranded and Pearson), the mean and standard deviation of variables (number 193)**

The correlation coefficient	Mean±SD	1	2	3	4	5	6	7	8	9	10
1. Self-management MS	11.21 ± 123.42	1									
2. Gender	-	0.39**	1								
3. Marital status	-	0.11*	0.09	1							
4. Level of education	-	0.24*	-0.04	0.09	1						
5. Socioeconomic status	-	0.33*	0.06	0.22*	0.39**	1					
6. The type of treatment	-	0.16*	0.07	0.04	0.21*	0.34**	1				
7. Age	9.67 ± 38.13	**0.32-	*0.11-	0.03-	**0.42-	**0.34-	*0.21-	1			
8. Duration of illness	3.66 ± 7.96	**0.26-	0.05	*0.10-	*0.28-	**0.43-	**0.26-	**0.47	1		
9. Stress	5.97 ± 18.00	**0.51-	*0.12-	0.08-	**0.26-	**0.35-	*0.21-	**0.27	**0.29	1	
10. Anxiety	6.11 ± 15.50	**0.52-	*0.12-	*0.12-	**0.28-	**0.36-	*0.13-	**0.35	**0.36	**0.73	1
11. Depression	6.95 ± 16.18	**0.53-	*0.19-	*0.13-	**0.29-	**0.38-	*0.21-	**0.34	**0.32	**0.82	**0.71

**Table 3. Regression coefficients for predictor variables of self-management of multiple sclerosis patients**

Step	Predictor variable	B coeffic items	Standard error	Coefficient β	T	The significant level
4 (Final model)	Fixed Amount	18.678	19.095		9.462	0.001
	Depression	-1.934	0.757	-0.208	-2.552	0.001
	Gender	9.769	3.241	0.317	3.680	0.001
	Anxiety	-3.324	0.913	-0.289	-3.643	0.002
	Socioeconomic state	7.026	4.038	0.149	2.483	0.009

That is, the higher the score of these variables for a person, higher self-management will be. Therefore, these variables were included as dummy

variables in the regression model. Also, in Pearson correlation test, there was a significant negative relation between age, duration of the disease, stress,

anxiety, depression with self-management of patients with multiple sclerosis (Table 2).

Before using regression analysis of data distribution with multi collinearity with the help of tolerance statistic, deviated data, remained charts and missing data were reviewed and data have criteria of using this statistical test. By determining tolerances statistics for all predictor variables through regression analysis with returning other variables on that variable, it was found that the tolerance statistic has coefficients between 0.47 to 0.1 that actually it suggests the lack of linearity and it suggests the stability of the regression model. Tolerance value and variance inflation factor (VIF) for each variable in each four steps of analysis were respectively placed in the range of 0.471 to 1.00 and 1.142 to 1.855.

Former variables' regression coefficients show that in the final model, four variables of depression, gender, anxiety and Social - Economic statue can explain changes related to self-management of multiple sclerosis patients in the significant way (Table 3).

### Conclusion:

According to the purpose of this study based on reviewing the relation between psychological factors, demographic characteristics and disease characteristics with an attempt to self-management behaviors and forecasting it among patients with multiple sclerosis, the results showed that depression, female gender, anxiety and socioeconomic status have a relation with self-management and with each other, they have a significant role in predicting the self-management behaviors of these patients. Previous research had shown such findings (11,12,14).

In Ray-Grant et al. study (5) showed that demographic factors such as gender and socioeconomic status are effective on the self-management action. In line with the results of this study, in a study of Valahaytis and colleagues (13) showed that women with multiple sclerosis compared with men more attempt to manage their disease and have better adherence to the treatment plan. In this context, it can be argued that women, due to higher concern to their state of health, have less structure and social barriers than men, as well

as cultural influences compared to men, act more self-management. Also, in the study of Simmons and colleagues (21), it is demonstrated that favorable socioeconomic status, accelerate the self-management act in patients with multiple sclerosis. The desirable socioeconomic status, as an important predisposing factor increases the self-management action by providing the cost of treatment and preparing diagnosis and treatment preparation.

Also, this study is consistent with Leicester and colleagues (11) and Ghadim et al (4) studies, showed that by increasing the levels of depression and anxiety, the self-management of patients with multiple sclerosis will decrease. Psychological disorders such as depression and anxiety primarily associated with obvious impairment of psychosocial functioning and secondarily with effecting on more important biological and social indices will decrease the self-management action. Also, according to Ghadim and colleagues (4) opinion, it can be said that depression and anxiety are associated with reducing energy levels and fatigue that these factors have a significant role in reducing self-management. In fact, depression by reducing efficacy in patients for doing a behavior, continuity and that behavior follow-up over time will reduce that eventually leads to loss of self-management and disease control.

Unlike most previous studies (5,12), in this study it was shown that education, marital status, type of treatment, age, disease duration and stress have not a significant role in predicting action to self-management of these patients. There is conflicting evidence in this area. In Plogman and colleagues (6) study found that life in old age is associated with reduced self-management in patients with multiple sclerosis. Also, Ray Grant et al (5) showed that high educational level, favorable marital status and less psychosocial stress are associated with the self-management promotion in patients with multiple sclerosis. In addition, in another study it was concluded that the patient's clinical characteristics, disease duration and type of treatment are important determiners of successful self-management in the management of Multiple Sclerosis disease (22). Although these factors were highlighted factors in previous studies of self-management action, but in this study they had no significant role. Therefore, it can be argued that

these factors compared to gender, socioeconomic status, depression and anxiety have less importance than the act of self-management. Also the use of different research samples with different methodology can be considered as an important reason to achieve these conflicting results. However, improving the self-management of these patients, considering the significant factors compared with those factors are more important.

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## رابطه عوامل روانشناختی، ویژگی‌های جمعیت‌شناختی و خصوصیات بیماری با خودمدیریتی در بیماران مبتلا به مولتیپل اسکلروزیس

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### چکیده

**مقدمه:** خودمدیریتی اقدامی مهم در کنترل پیامدهای نامطلوب مولتیپل اسکلروزیس به عنوان یک بیماری مزمن و ناتوان‌کننده است. بررسی رابطه عوامل روانشناختی، ویژگی‌های جمعیت‌شناختی و خصوصیات بیماری با رفتارهای خودمدیریتی و پیش‌بینی آن در بیماران مبتلا به مولتیپل اسکلروزیس هدف مطالعه حاضر بود.

**روش کار:** در یک مطالعه همبستگی، از میان بیماران مبتلا به مولتیپل اسکلروزیس مراجعه‌کننده به انجمن ام اس ایران (تهران)، ۱۹۳ بیمار به شیوه‌ی هدفمند در دسترس انتخاب شدند. داده‌ها با استفاده از مقیاس خودمدیریتی بیماران مبتلا به مولتیپل اسکلروزیس، مقیاس‌های افسردگی، اضطراب و استرس و پرسشنامه جمعیت‌شناختی/خصوصیات بیماری جمع‌آوری شد و با تحلیل رگرسیون چندگانه به روش گام به گام بوسیله SPSS 18 تجزیه و تحلیل شد.

**نتایج:** وضعیت اجتماعی - اقتصادی و جنسیت (زن) دارای رابطه و نقش مثبت معنی‌داری در پیش‌بینی رفتارهای خودمدیریتی در مبتلایان به مولتیپل اسکلروزیس و نیز افسردگی و اضطراب دارای رابطه و نقش منفی معنی‌داری در پیش‌بینی رفتارهای خودمدیریتی این بیماران بودند ( $F(۲,۱۸۸)=۳۶/۶۱$  و  $P<۰/۰۰۱$ ) و در مجموع این چهار متغیر ۴۳ درصد ( $R^2=۰/۴۳$ ) خودمدیریتی را تبیین کردند ( $P<۰/۰۰۱$ ). تحصیلات، وضعیت تأهل، نوع درمان، سن، مدت بیماری و استرس نقش معنی‌داری در پیش‌بینی اقدام به خودمدیریتی در این بیماران نداشتند.

**نتیجه‌گیری:** افسردگی و اضطراب عوامل خطر مهم برای کاهش خودمدیریتی بیماران مبتلا به مولتیپل اسکلروزیس هستند. از طرفی، سطح تحصیلات بالا و جنسیت زن نیز عوامل مهمی در افزایش خودمدیریتی این بیماران هستند. توجه به این عوامل در تدوین و اجرای برنامه‌های متناسب شده ارتقای خودمدیریتی و خودمراقبتی در کنترل این بیماری سودمند است.

**کلیدواژه‌ها:** افسردگی، ویژگی‌های جمعیت‌شناختی، مولتیپل اسکلروزیس

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