

A study of psychological well-being in people with multiple sclerosis and their primary caregivers

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Abstract

Background: Multiple sclerosis (MS) is the most common disabling disease of the central nervous system. In these patients, fatigue is the most common symptom that causes disorder in the work, social activities and daily functions of the patients. Given the assumption that MS reduces the patients' psychological well-being, this study aimed at assessing the psychological well-being of both the patients and their primary caregivers.

Materials and Methods: Current research as a descriptive study was conducted on 200 MS patients and 200 primary caregivers. For data collection, the Reef questionnaire was used to determine psychological well-being of these individuals. Data were analyzed using SPSS software.

Results: According to the obtained results, the mean duration of MS was estimated 6.37 years. The psychological well-being score of the people with MS and their primary caregivers was slightly higher than average. The total score of psychological well-being in primary caregivers was higher than the patients.

Conclusion: The mean score of psychological well-being subscales was significantly different in patients and their caregivers. Regarding the autonomy subscale, there was a significant different in patients with MS, that is, it was lower than average. In terms of two subscales of "positive relationship with others" and "personal growth," there was no difference between people with MS and the primary caregivers, and for other subscales, the mean score of caregivers was higher than the patients.

Key Words: Multiple sclerosis, primary caregivers, psychological well-being

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Received: 15.02.2014, Accepted: 19.08.2014

INTRODUCTION

Multiple sclerosis (MS) is a myelin-related disorder of the central nervous system (brain and spinal cord),

in which, myelin disorder leads to the individual's disability.^[1] The onset symptoms of MS include fatigue, depression, memory impairment, pain, blurred vision, diplopia, vertigo and dizziness, limb weakness, ataxia, numbness and tingling of the extremities, and urinary and bowel problems.^[2] The highest rate of neurological disease among adults belongs to MS, so that there are more than one million people diagnosed with MS in Europe and America.^[3,4] In Iran, the number of people with MS is estimated to be about 40,000 to 50,000.^[5] Psychological well-being is a fundamental concept in chronic diseases that provides one's life with meaning and purpose, and is considered to be an important

Access this article online	
Quick Response Code:	Website: www.advbiores.net
	DOI: 10.4103/2277-9175.151545

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How to cite this article: Ghasemi M, Gorji Y, Ashtar F, Ghasemi M. A study of psychological well-being in people with multiple sclerosis and their primary caregivers. *Adv Biomed Res* 2015;4:49.

trend in the promotion of public health and quality of life.^[6] Ryff's predicts a model that offers six dimensions of health:

- Self-esteem or self-acceptance that is the ability to feel good about oneself while being aware of one's limitations
- Environmental mastery; trying to shape one's living environment in order to meet one's needs and desires
- Positive relationship with others, that is, having affirmative relations with others
- Personal growth, or improving personal skills and abilities
- Having purpose in life; ability to find meaning in one's life's difficulties or problems
- Autonomy or self-sufficiency; looking for a sense of personal independence and authority.

The experience of having MS has the potential to affect each of these aspects of health; however, there are few researches about these structures and their relationships with depression in the patients with MS.^[7] Moreover, because of the negative impacts of the illness on their daily activities, such states as frustration and depression can be observed in people with MS.^[8,9]

According to Lyubomirsky (2007),^[10] there is a strong correlation between subjective well-being, higher life expectancy, better physical health and healthier lifestyle. In the studies on psychological factors, that are associated with quality of life (QOL) in MS, depression seems to be an important factor in relation to quality of life.^[7] In examining the patients who have recently been diagnosed with MS, the percentage of depression was reported to be 34% in the patients and 40% in their parents.^[11]

According to the MS-related chronic disability, this question may raise that whether these peoples' understanding of their disease and self-acceptance, mastering the surrounding environment, and satisfaction from their personal growth will be affected by the disease? And how will this situation affect the primary caregivers of the people with MS?

Given the fact that no study has been conducted so far to examine psychological well-being of the people with MS, the current study will be done to evaluate psychological well-being of these people and their primary caregivers in order to offer guidelines for mental health promotion in this vulnerable group of people in society.

MATERIALS AND METHODS

This study was conducted in 2013 on 200 male and female Isfahanian patients with MS who have referred to MS clinics of Al-Zahra and Kashani and were diagnosed as

having MS by a neurologist. The study also included the primary caregivers of the patients ($n = 200$). The subjects of the study were selected using simple random sampling. After taking the informed consent of the patients and their primary caregivers, a questionnaire was completed by the subjects, consists of Ryff's standardized questionnaire with 84 questions for determining these people's psychological well-being.^[12] The same questionnaire was also completed by the primary caregivers of these patients. By primary caregivers it means the people who have the most physical and emotional relationship with the patients and provide them with the most amount of help. Including criteria: Having satisfaction and also ability to read questionnaire and write the answers. Excluding criteria: Having no consent to be included in the study.

In our study, the majority of caregivers are the patients' parents and spouse. In a small number of subjects, the primary caregivers were the patients' siblings or children. It should be noted that the interviewer was present at the time of completing the questionnaire to answer the possible questions of the subjects.

Psychological health was investigated using Ryff's shortened six-scale model: Self-esteem or self-acceptance, environmental mastery, positive relations with others, personal growth, purpose in life, and autonomy or independence. Each scale was composed of three components that were rated by the participants using a six-item scale: 1 = strongly agree, 6 = strongly disagree. The validity of the Persian version of the questionnaire was reported as satisfactory by the study of Bayani *et al.*^[13] The subjects' information were analyzed using SPSS statistical software, and using descriptive statistical indicators such as frequency, percentage, graphing, and *t*-test, correlation coefficient between demographic factors and psychological well-being was calculated.

RESULTS

After statistical analysis, the results of the mean age comparison, birth order and the duration of the illness in the people of the two groups and their primary caregivers were obtained which are shown in Table 1.

Table 1: The comparison of the mean age, birth order and the duration of the illness in the individual people with MS and their primary caregivers

variables	People with MS		Primary caregivers	
	Mean	Standard deviation	Mean	Standard deviation
Age	32.29	8.45	40.29	12.57
Birth order	2.90	1.91	2.53	1.47
Duration of the illness	6.37	4.88	-	-

MS: Multiple sclerosis

The minimum of the patients' age was 15 years old and about their primary caregivers was 15 years too, and also the maximum age of the patients was 48 years old and about their primary caregivers was 67 years old. The mean of birth order in the people with MS and their primary caregivers was respectively as 2.90 and 2.53. And finally, the average duration of the illness was obtained as 6.37. In evaluating the gender distribution of the subjects, 79.5% of the patients and 67% of the primary caregivers were female. Also, after analyzing the data obtained from the questionnaire, the mean scores of the psychological well-being subscales were obtained from the individuals with MS that are presented in Table 2.

According to the Table 2, the observed univariate for the subscales of "self-acceptance," "positive relations with others," "environmental mastery," "purpose in life," and "personal growth" was significant than mean of total score of psychological well-being at the level of $P \leq 0.05$, implying that these subscales in the people with MS have been higher than average. However, for the subscale of "autonomy" no significant difference was observed, indicating that people with MS are not able to be autonomous. The mean scores of psychological well-being subscales for the primary caregivers of the people with MS are given in Table 3.

According to the Table 3, the observed univariate t for the subscales of self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth was significant at the level of $P \leq 0.05$, implying that these subscales for the primary caregivers of the people with MS have been higher than average level. In comparative evaluation of the total score of psychological well-being in the people with MS and their primary caregivers the results listed in Figure 1 were obtained.

As can be seen in Figure 1, the observed univariate t was significant at the level of $P \leq 0.01$, implying that there is a significant difference between the

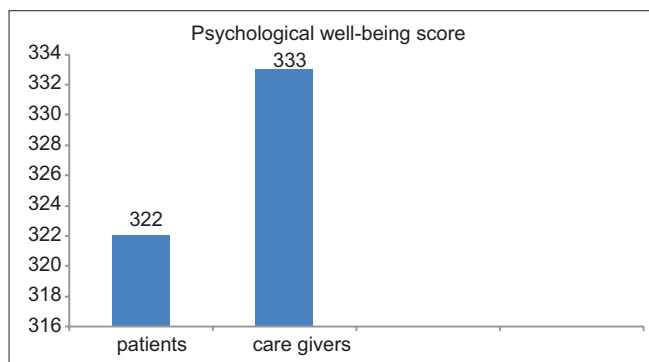


Figure 1: Comparing the mean score of psychological well-being in the patients with MS and their primary caregivers

psychological well-being total scores of the people with MS and their primary caregivers; the average score for the caregivers is 333, that is higher than the score of the individuals with MS (322), that the difference is significant.

According to Figure 2, the observed univariate t for the subscales of self-acceptance, autonomy, environmental mastery, and purpose in life was significant at the level of $P \leq 0.05$. Therefore, in terms of these subscales, there was a significant difference between people with MS and their caregivers, that is, the scores of the caregivers were higher than the scores of the people with MS. Similarly, for the subscales of "positive relation with others" and "personal growth" the situation was almost similar for both the people with MS and their primary caregivers, and although the score of the primary caregivers was somewhat higher than the score of the patients, the difference was not significant.

DISCUSSION

The average age of the patients and their primary caregivers has been 32.29 and 40.29, respectively. MS is more common among the young people with the range of 20 to 32 years.^[14] In evaluating the gender distribution of the subjects, it was observed that 79.5% of the patients and 67% of the primary caregivers were females. As observed by other studies, MS is twice as common in women as in men, which the same result was obtained in our study.^[15] Also, 67% of the primary caregivers were female that was twice as the male caregivers, that maybe is due to this fact that in Iran the responsibility of taking care of the patients falls on women.

MS is nearly twice as common in women compared to men.^[7,14,15] In Iran, out of every 100,000 people, 15-30

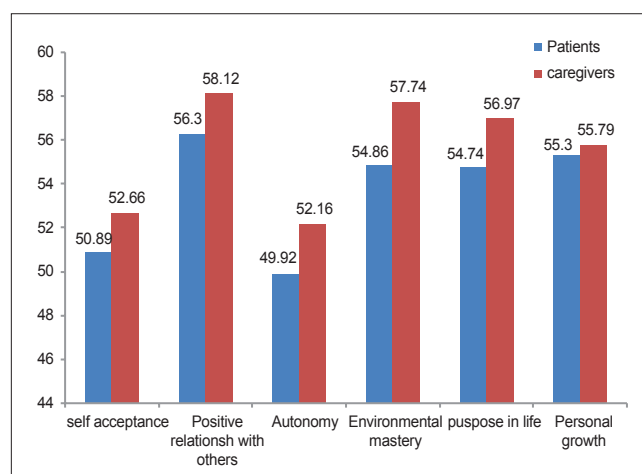


Figure 2: Comparing the mean score of psychological well-being for the people with MS and their primary caregivers

Table 2: The mean scores of psychological well-being subscales for the peoples with MS

Psychological well-being subscales	Mean±SD	T	P
Self-acceptance	50.89±8.17	2.96	0.003
Positive relation with others	56.3±10.31	9.11	0.001
Autonomy	49.92±7.93	1.49	0.137
Environmental mastery	54.86±9.89	7.61	0.001
Purpose in life	54.74±9.44	7.81	0.001
Personal growth	55.30±8.80	9.19	0.001

SD: Standard deviation, MS: Multiple sclerosis

Table 3: The mean scores of psychological well-being subscales for the primary caregivers of the people with MS

Psychological well-being subscales	Mean±SD	T	P
Self-acceptance	52.66±7.91	6.27	0.001
Positive relation with others	58.12±9.54	12.27	0.001
Autonomy	52.16±7.84	5.17	0.001
Environmental mastery	57.74±9.55	11.75	0.001
Purpose in life	56.97±8.06	12.69	0.001
Personal growth	55.79±8.51	10.25	0.001

SD: Standard deviation, MS: Multiple sclerosis

people have MS.^[16,17] The prevalence of the disease in Isfahan province is ranked higher than other provinces.^[16]

In a study, it was shown that depressive symptoms and psycho-social adaptations will be ameliorated in the patients who have received social support.^[18] Studies have demonstrated that about 50-60% of patients with MS suffer depression^[19] and about 25-40% of them suffer anxiety,^[20] that these problems severely affect the quality of life in these patients,^[21]

Seligman (2003) in his studies showed that optimism is associated with the higher levels of well-being, that is, it ultimately will lead to psychological well-being.^[22] Since optimism requires the person's positive evaluation and prediction of the outcomes of life events, it will create the feelings of love and life satisfaction in different aspects and consequently leads to psychological well-being.

Although it was thought that psychological well-being of the people with MS and their primary caregivers is lower than average, according to this study's results, psychological well-being of the people with MS and their primary caregivers was higher than average, and also, the caregivers' psychological well-being score was higher than the patients' score. Moreover, psychological well-being score of the patients and their primary caregivers for the subscales of "positive relation with others" and "personal growth" did not show a significant difference ($P > 0.05$). According to the results of the present study, the subscales of self-acceptance, positive relation with others, autonomy, environmental mastery, purpose in life,

and personal growth were significant at the level of $P \leq 0.05$, that means, the mentioned subscales have been higher than average for the primary caregivers of the people with MS. Using the *t*-test, it was observed that the subscales of self-acceptance, autonomy, environmental mastery, and purpose in life were significant at the level of $P \leq 0.05$, and therefore, these subscales were significantly different in the people with MS and their primary caregivers. Hence, the caregivers' psychological well-being score—either total score or each subscale's score—was higher than the patients' score, and in terms of psychological health, they were healthier than the patients.

According to the results of our study, the average score of psychological well-being for the people with MS was 322, and the same score for the caregivers was obtained 333, that were significant at the level of $P \leq 0.05$. This shows that psychological well-being total score for the caregivers has been higher than the patients, and caregivers were healthier. Similarly, using the *t*-test, it was observed that the subscales of self-acceptance, autonomy, environmental mastery, and purpose in life were significant at the level of $P \leq 0.05$, and therefore, these subscales were significantly lower in the people with MS than their caregivers. Hence, the caregivers, in terms of psychological health, were in a better condition. For the subscales of "positive relation with others" and "personal growth" the difference was not significant, showing that psychological well-being of the patients and their caregivers has been similar in terms of these two subscales.

The researcher thought that, in the people with MS, the subscales of self-acceptance, positive relation with others, purpose in life, and environmental mastery probably will be disturbed. Likewise, the researcher assumed that the caregivers' average score of psychological well-being for the subscales of self-acceptance, positive relation with others, autonomy, purpose in life, personal growth, and environmental mastery may be disturbed, that fortunately, according to the obtained results, the mean score of psychological well-being for the patients and their caregivers was to be higher than average.

ACKNOWLEDGEMENT

For his many helpful and constructive grammatical and linguistic comments we would like to express our endless gratitude and indebtedness to Mr. Roohollah Datli Beigi, M.A. in English Literature, University of Isfahan.

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Source of Support: Azad University of Khomeini Shahr, **Conflict of Interest:** None declared.