

**HEALTHCARE MANAGEMENT AND PSYCHOLOGICAL WELL-BEING IN PATIENTS WITH
MULTIPLE SCLEROSIS AND THEIR PRIMARY CAREGIVERS**

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Abstract

This study attempts to assess the healthcare management and psychological well-being of both the patients and their primary caregivers. Study is a descriptive in nature, conducted on 200 Multiple Sclerosis (MS) patients and 200 primary caregiver's in 2013. For data collection, the Reef questionnaire was used to determine psychological well-being of these individuals. Data were analysed using SPSS, according to the obtained results the mean duration of MS was estimated 6.37 years. There was significant difference between final score of Psychological well-being in people with MS and in their caregivers ($P<0.05$). Subscales of psychological well-being in people with MS and their primary caregivers were more than average, comparison of mean score in psychological well-being subscales in people with MS and their primary caregivers had significant difference. Autonomy subscale in people with MS was less than average. There was no significant difference in "positive relationship" and "personal growth" between people involved with MS and their primary caregivers; as a matter of fact the primary caregivers had higher score in other psychological well-being subscales, than MS involved people.

Keywords: Healthcare Management, Multiple Sclerosis, Psychological well-being, Primary caregivers

INTRODUCTION

One important dimension of modern healthcare management is psychological well-being of patients and even in some cases, of Primary caregivers. 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 trend in the promotion of public health and quality of life (Allahbakhshian et al, 2011, pp: 29-33). Ryff's model predicts the six dimensions of health and its management:

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

Multiple Sclerosis (MS) is a myelin-related disorder of the central nervous system, in which myelin disorder leads to the individual's disability. (Hauser et al, 2001, p: 61). 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 (Yozhatiran et al, 2006, pp: 177-22). In Iran, the number of people with MS is estimated to be about 40 to 50 thousand (Taghizadeh et al, 2006).

The experience of having MS has the potential to affect each of the dimensions of health in Ryff's model; however there are few researches about these structures and their relationships with depression in the patients with MS (Hart et al, 2005, pp: 695–703). According to the chronic disability associated with this disease, this question rises that whether these people's understanding of their disease and self-acceptance, mastering the surrounding environment, and satisfaction of their personal growth will be affected by the disease? And how will this situation affect the primary caregivers of the people with MS? According to Lyubomirsky (2007), there is a strong correlation between subjective well-being, higher life expectancy, better physical health and healthier lifestyle. In studies which have examined psychological factors associated with quality of life (QOL) in MS, it appears that depression is an important factor in relation with quality of life (Allahbakhshian et al, 2011, pp: 29-33).

Since no study has been conducted so far to examine psychological well-being in the people with MS in the area of healthcare management, the current study attempts 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.

METHODOLOGY

This study included 200 male and female with MS in Isfahan who have referred to MS clinics of Al-Zahra and Kashani and were diagnosed as having MS by neurologist. The study also included the primary caregivers of the patients (n=200). Study was conducted in 2013. 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 (Lyubomirsky, 2007, pp: 363-404).

The same questionnaire was also completed by the primary caregivers of these patients. By primary caregivers it means the people who live with people involved with MS who has the most physical and emotional relationship with the patient and provides s/he with the most amount of help. 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 scale of six items: 1= strongly agree, 2= strongly disagree. The validity of the Persian version of the questionnaire was reported as favourable by the study of Bayani (Khezrimoghadam, 2012, pp: 13-22).

The subjects' information were analysed 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 related to the comparison of the mean age, birth order and the duration of the illness in the individuals of the two groups and their primary caregivers were obtained which are shown in table 1.

Table 1: Descriptive Statistics of the individuals of the two groups and their primary caregivers

	People with MS			
	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	-	-

The mean of birth order in the people with MS and their primary caregivers was respectively as 2.90 and 2.53. The mean age of the patients and their primary caregivers also was respectively as 32.29 and 40.29. And finally, the average duration of the illness was obtained as 6.37.

Also, after analysing 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.

Table 2: Mean scores of psychological well-being subscales for the individuals with MS

	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

According to the table 2, the observed one-variable t for the subscales of self-acceptance, positive relations with others, environmental mastery, purpose in life, and personal growth was significant at the level of $p \leq 0.05$. Therefore, 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.

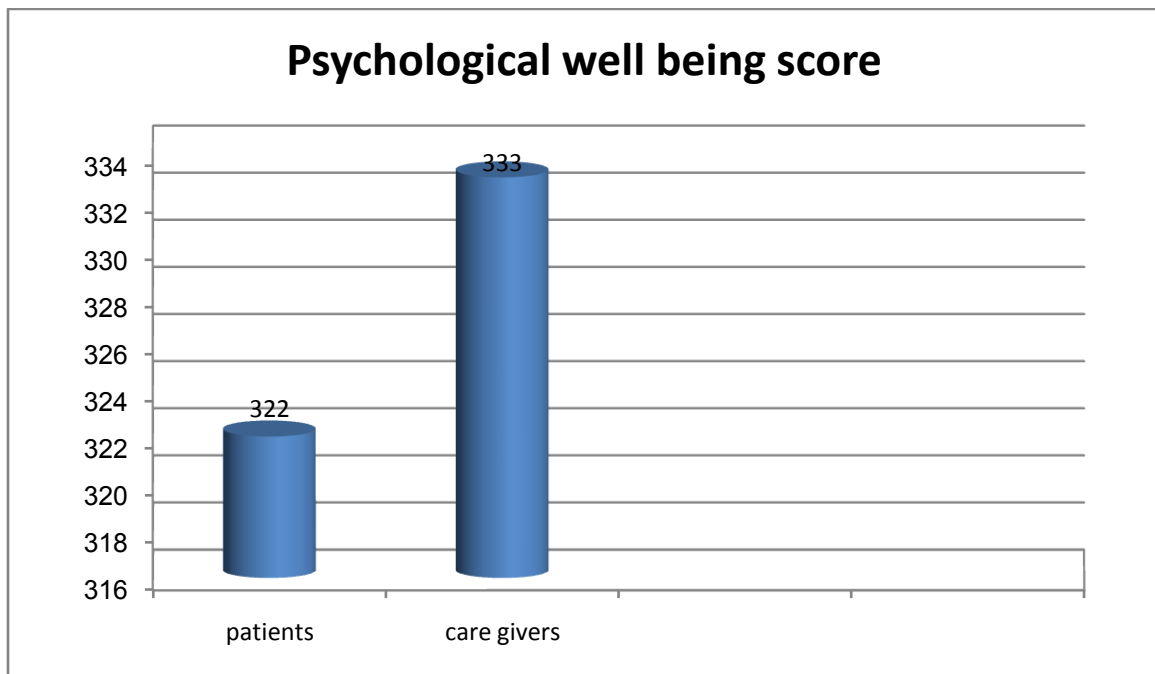
The mean scores of psychological well-being subscales for the primary caregivers of the people with MS are given in table 3. According to the table 3, the observed one-variable t for the subscales of self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth was significant at the level of $p \leq 0.05$. Therefore, these subscales for the primary caregivers of the people with MS have been higher than average level.

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

	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

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: According to the figure 1, the observed one-variable t was significant at the level of $p \leq 0.01$. Therefore, there is a significant difference between the 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), and this difference is significant.

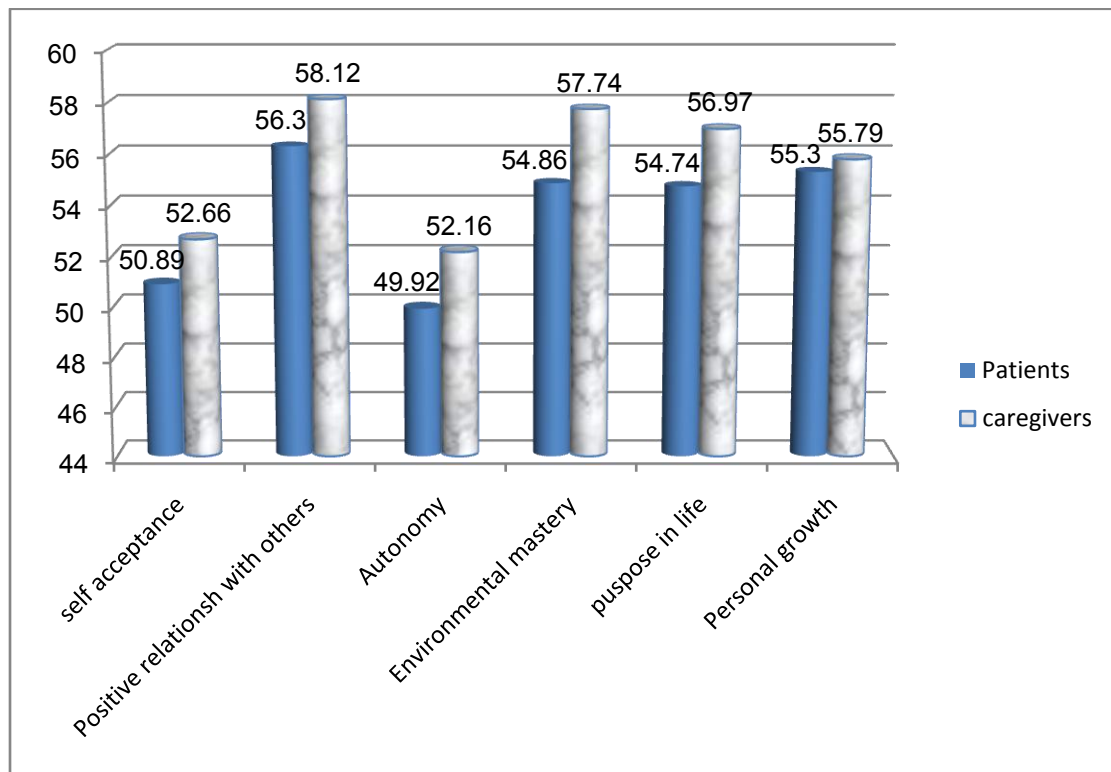
Figure 1: The comparison mean score of psychological well-being in patients with MS and their primary caregivers.



According to the figure 2, the observed one-variable 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, and the scores of the caregivers were higher than the scores of the people with MS. 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.

Figure 2: The comparison mean score of psychological well-being subscales in patients with MS and their primary caregivers



DISCUSSION

The average age of the patients and their primary caregivers has respectively been as 32.29 and 40.29. MS is more common among the young people with the range of 20 to 32 (Bayani, 2008).

In evaluating the gender distribution of the subjects, it was observed that 79.5% of the patients and 67% of the primary caregivers were female. As observed by other studies, MS is twice as common in women compared to men that the same result was obtained in our study (Kenner, 2007, PP: 303-321).

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 (Allahbakhshian, 2008, pp:

29-33). In Iran, out of every 100,000 people, 15-30 people have MS (Masoudi, 2008, pp: 21-29). The prevalence of the disease in Isfahan province is ranked higher than other provinces (Holland et al, 2005, pp: 1-10). According to the MS Society of Iran, there are 40,000 people with MS in Iran, 9000 of them have been registered (Kurtzke et al, 2000, pp: 1-32).

In a study, it was shown that depressive symptoms and psycho-social adaptations will ameliorate in the patients who have received social support (Taraghi et al, 2007, pp: 51-60). And about 25-40% suffer anxiety (Donna et al, 2002, pp: 299-312). That these problems severely affect the quality of life in these patients (Chwastiak et al, 2005, pp: 291-298).

Seligman (2003), in his studies showed that optimism is associated with the higher levels of well-being that finally will lead to psychological well-being (Janardhan et al, 2002, pp: 51- 58). 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. 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 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, 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. Using 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 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 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.

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