

*Original Article***Spiritual well-being of patients with multiple sclerosis***Maryam Allahbakhshian\**, *Mahshid Jafarpour\*\**, *Soroosh Parvizi\*\*\****Abstract**

**BACKGROUND:** Spiritual well-being is one of the fundamental concepts in chronic diseases which creates meaning and purpose in life and is an important approach in promoting general health and quality of life. This study was performed to determine the level of spiritual health and its dimensions in patients with multiple sclerosis (MS).

**METHODS:** 236 members of Iranian MS Society volunteered to participate in a descriptive co-relational study. Spiritual well-being was evaluated by The Spiritual Well-Being Scale (SWBS) questionnaires in two religious and existential dimensions. Descriptive statistics, ANOVA, t-test and Pearson correlation coefficient were used to analyze the data.

**RESULTS:** The majority of patients (% 97.9) showed moderate spiritual well-being (mean score = 74.3, SD = 8.90). However, existential well-being (mean score = 40.3, SD= 5.51) was higher than religious well-being (mean score = 33.9, SD = 4.88). A significant relationship was seen between economic status and the spiritual well-being.

**CONCLUSIONS:** The results emphasize on the necessity of spiritual well-being as an effective factor on different aspects of these patients' life. This key point is useful and even necessary to be considered to design programs of care and cure for these patients in a country like Iran with cultural and religious beliefs. On the other hand, patients' economic status should be considered.

**KEY WORDS:** Multiple Sclerosis, quality of life, spiritual well-being, religious well being, existential well- being.

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**M**ultiple Sclerosis (MS), which is a demyelinating central nervous system disorder, is one of the most common debilitating diseases in young adult.<sup>1</sup> Prevalence of this disease is nearly two million people around the world<sup>2</sup> and four hundred thousand people in the United States<sup>3</sup> which is known as the third leading cause of disability in this country.<sup>2</sup> Prevalence of MS in Iranian population is estimated around 15-30 per 100 thousand.<sup>4</sup> Women are two times more at risk than men.<sup>2</sup> Common incident age is 20 to 35.<sup>3</sup> Therefore, the peak period of incident of MS is simultaneously with personal and professional responsibilities and dealing with situations such as family formation, career and financial security. This disease threatens the independence and abili-

ty of the individual to participate effectively in family and society. The patients feel loss of competence and confidence and are not sure about their physical and mental health. Because of the unpredictable recurrence procedure of such disease, patients think that they cannot plan for their future.<sup>5</sup> Thus, prognosis and unpredictable course of disease has significant effect on physical and mental performance, and therefore the quality of life and their health.<sup>6</sup> These patients cannot find a way to solve their problems and improve their quality of life and maintain physical, mental, and spiritual health.

There are several concepts about how to deal with such problems and stress caused by chronic diseases. One of these concepts is spiritual well-being. The spiritual dimension of health is

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a factor that integrates other health dimensions (physical, mental, and social). Spiritual health is a multi-dimensional structure, but the emphasis is over on the two religious and existential dimensions mostly. Religious well-being is the result of being satisfied with having a relationship with a superior power, while the existential well-being is interpreted as trying to understand meaning and purpose of life.<sup>7</sup>

Obviously, a chronic disabling disease like MS brings up questions about meaning and purpose of life. Spiritual well-being could be a possible answer. As quoted in Mauk and Schmid's book, Derouj believes that lack of spiritual well-being result in disorders such as depression, stress and anxiety and lack of meaning and purpose in life.<sup>8</sup> On the other hand, many patients with chronic disease identified spiritual well-being a factor of meaning and purpose in life, lifter stress and promoting quality of life.<sup>9</sup>

Several studies indicate the association between spirituality and better physical and mental health promotion and coping with the disease.<sup>10</sup> Litwinczuk in his article quoted that The results of Freiback's interviews with ten women with AIDS showed that spirituality is the major component of feeling safe and comfort. Many participants knew spirituality as a bridge between life expectancy and the meaning of life.

A similar study in patients with AIDS implicated that spirituality has a direct and meaningful relationship with, mental and functional health, and an inverse relation with symptom's exacerbation.<sup>11</sup> Moreover, McNulty cites Brook and Maston in a study with MS patients found that spiritual beliefs and faith is useful in coping with the disease.<sup>12</sup> Praslova study on immigrant and non-immigrant Russian samples showed that higher spiritual well-being scores are associated with using appropriate strategies to solve problems and more satisfaction with life.<sup>13</sup>

Concept of spirituality and spiritual well-being is not well considered in nursing procedure; especially its effect on different aspects of chronic patients' life and health. This study was performed to determine spiritual well-being and spiritual dimensions of health in patients with MS from Iranian MS Society in 1387 (2008).

## Methods

This study was a descriptive co-relational study. MS patients older than 18 years with the ability to read and write, aware of their disease and willing to cooperate participated in this research. According to correlation coefficient of 0.20 ( $p < 0.05$ ,  $\beta = 0.85$ ) 236 participants were selected whose duration of diseases was less than one year and there wasn't any sign of cognitive or any other chronic disorders.

This study was approved by the Ethics Committee of Nursing Education Department of Isfahan University of Medical Sciences. All the participants signed a written consent form and they were assured regarding the confidentiality of their data. The researcher gave information about the subject of the research and spread out spiritual well-being questionnaires to the patients. If a patient was not able to complete the questionnaire, the researcher read the questions and reflected exactly their answers.

To determine the spiritual well-being, 20 items spiritual well-being (SWBS) questionnaire was used. Questions with even numbers (10 questions), measure existential well-being and 10 questions with odd numbers measure religious well-being. Adding the results of these two subscales results in the total spiritual well-being score in the range of 20 to 120. Responses are in a Likert scale with 6 choices (strongly disagree to strongly agree). In phrase with a positive verb "strongly disagree" receives 1 and "strongly agree" receives 6. In other phrases with negative verbs, "strongly disagree" receives 6 and "strongly agree" receives 1. Three levels of spiritual well-being is considered: low (20-40), medium (41-99) and high (100-120). Content validity was assessed after translating the questionnaire to Persian and reliability was determined by Cronbach's alpha coefficient  $r = 0.82$ .<sup>14</sup> Personal information form was attached to this questionnaire.

Research data were collected in the summer of 1387 (2008) in Iranian MS Society. A self report method was used. Data was analyzed using SPSS version 16. Descriptive statistics, independent t-tests and Pearson correlation coefficient were assessed.

## Results

Socio-demographic data were as follows: 65% of the participants were women and 35% were men. Age range of the patients was 20 to 57 years (mean = 35.6, SD = 1.9); duration of disease was 1 to 30 years. 57.1% were married, 33.9% single, 7.7% divorced and 2.1% widowed. 73.6% were unemployed and 26.4% employed. 55.3% of patients reported their economic status to some extent desirable, 26.4% unfavorable and 17.9% favorable. According to education level, 39.7% of patients had academic education, 45.7% had high school diploma, 10.7% were graduated from middle school and 36% from elementary school. Among the expressions related to religious health, "in quiet prayer to God I do not feel great satisfaction" (mean= 5.55, SD= 0.63) and existential health "I feel like an unknown future" (mean= 5.49, SD= 0.61) items obtained the highest mean scores.

Spiritual well-being mean score was 74.3 (SD = 8.90) out of a total score of 120 related to existential and religious well-being score. Therefore, according to the three levels of spiritual well-being, 97.9 percent of patients were in moderate spiritual well-being group. Existential well-being (mean = 40.3, SD = 5.51) was higher than religious well-being (mean= 33.9, SD= 4.88). Women's mean scores for spiritual well-being (mean = 74.5), religious (mean= 33.8) and existential (mean = 40.7) aspects were higher than men's mean scores for spiritual well-being (mean = 73.8), religious (mean = 34.1) and existential (mean = 39.7) aspects.

According to the findings there was no statistically significant relation between spiritual well-being and age, while the relation between the age and existential well-being was statistically significant ( $p = 0.45$ ). Mean score of spiritual well-being in the age range of 40-49 years (mean = 75.3, SD= 7.34) was higher than other age groups. The results of analysis of variance showed that there was no significant relation between spiritual well-being and marital status among patients with multiple sclerosis. But a significant relationship was observed between

existential well-being and marital status ( $p = 0.03$ ). However, the mean score of the spiritual well-being for divorced and widow patients (mean = 78.4, SD = 8.18) was higher than other groups. Also by using independent t-tests and analysis of distribution, there was no significant relationship between employment and education status and spiritual well-being and its aspects. But mean score of spiritual well-being (74.1) was higher in patient who studied up to guidance school. According to our findings, existential ( $p \leq 0.0001$ ) and spiritual well-being ( $p \leq 0.0001$ ) relation with economic status were statistically significant.

## Discussion

As mentioned earlier, these findings showed moderate level of spiritual well-being in patients suffering from multiple sclerosis and they had higher existential well-being score in comparison with religious well-being score. These findings contradict with the results of Bussing et al, which showed low spirituality score in patients with MS<sup>15</sup> and the results of Rezaei et al, study regarding high scores of spiritual well-being in cancer patients<sup>16</sup> which seems to be due to degenerative nature and unpredictable course of MS in comparison with cancer. On the other hand the findings of a new cancer treatment can be seen that increased life expectancy combined with higher health status in these patients.

In addition, the existential well-being score was higher than religious well-being score in MS patients. These results contradict with the results of Rezaei et al, study. Rezaei in her studies quote that Levine and colleagues showed that creating spiritual meaning in life plays an important role in coping with stressful situations caused by disease that appears to justify these findings.<sup>16</sup>

According to our findings, although there was no statistically significant difference between gender and spiritual well-being, mean score in both religious and existential aspects were higher in women. Also Rezaei did not find a significant relationship between spiritual well-being and gender in cancer patients.<sup>16</sup> In Buss-

ing study existential well-being and in Kaczowski study, religious well-being were slightly higher in women with cancer than men; although in agreement with the present study, there was no significant relationship between gender and spiritual well-being.<sup>15</sup>

These results showed that spiritual well-being mean score in the range of 40-49 years was higher than other age groups. Results of Allen, Hangelman and Giolia study as cited by Rezaei indicate that spirituality tendency increases with age.<sup>16</sup> Tendency to spirituality is considered as a function of aging, because it is a way by which a person faces with the reality of death and adjusts with that.

According to the results, there was no significant relationship between spiritual well-being and marital status. But a significant relationship was observed between existential well-being and marital status. Mean scores of spiritual well-being were higher in divorced patients. The findings were in agreement with the results of Rezai, Reiley and colleagues showed that the existential well-being aspect in married people were higher than singles that are incompatible with the present results.<sup>7</sup> Karren believe that divorced people and those who are not happy with their common life suffer from problems in their lives. A divorced individual loses a large source of social support, family and besides double stress of the disease is impose on the patients. Thus the tendency to spirituality can be an effective adjustment for this difficult condition.<sup>3</sup>

There was no significant relationship between spiritual well-being and education. But the mean score of spiritual well-being was higher in patient who studied up to middle school. These results were in contrary agreement with Catherine results.<sup>17</sup>

The results also showed existential and spiritual well-being had a statistically significant relationship with economic status. Multiple Sclerosis imposes a large economic burden on society, families and individuals. U.S. National Institute of Nerves Disease claims that more than 2.5

billion dollars for this disease is spent in America.<sup>8</sup> On the other hand, according to this research, 73.6% of these patients are unemployed. Considering these findings and reciprocal effects of both aspects of life (economy and spiritual life), our findings are significant.

Considering the results, spiritual beliefs can influence severe disease, help patients to find meaning and purpose in life as a factor to deal with problems resulting from physical and mental illness. In a society like Iran, paying attention to the tendency to look for a meaning in life is an easier and better way for multi-dimensional humanistic cares. Culture based care, regarding meaning and having a comprehensive view of different dimensions of the patients, can help health staff to give appropriate services to chronic patients, including patients with MS presented in a country with a rich history and deep religious beliefs. This study has been done only among the members of MS society in Tehran; although this center is the main reception community, the spiritual well-being of other patients in other cities is not known yet. Qualitative research is recommended in order to better understand the influence of spirituality on health and its effect on improving the quality of life. It is also recommended to introduce the concept of spiritual well-being as one of the most important aspects of health and life satisfaction to the students during theoretical and clinical training. On the other hand it is necessary to consider programs to promote the spiritual well-being of these patients in order to promote consistency and thus improve the quality of life.

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