Relationship Between Spiritual Well-Being and Self-Management Among Iranian People With Multiple Sclerosis

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Background: Self-management is the cornerstone for controlling multiple sclerosis. As one's sense of meaning in life and his/her relationship with a higher power, spiritual well-being is an important coping resource in some chronic diseases. However, little is known about the role of spiritual well-being in self-management of people diagnosed with multiple sclerosis.

Objectives: This study was aimed to assess the relationship between spiritual well-being and self-management among Iranian people with multiple sclerosis.

Patients and Methods: Two hundred ninety-one people diagnosed with multiple sclerosis belonging to the Multiple Sclerosis Society of Mashhad, Iran, participated in this cross-sectional analytical study conducted in 2014. Demographic information was collected by using a demographic form. The multiple sclerosis self-management scale-revised (2011), developed by Bishop and Frain, was used to evaluate self-management of multiple sclerosis symptoms. Spiritual well-being of participants was assessed by using the spiritual well-being questionnaire developed by Paloutzian and Ellison in 1983. Descriptive statistic and inferential statistical methods including Pearson and Spearman's coefficient, stepwise multiple regression, independent t-test, Mann-Whitney U test, one-way ANOVA, and Kruskal-Wallis test were employed by using SPSS, version 16.0. The significance level was set at $P \leq 0.05$.

Results: Overall, the participants reported moderate levels of self-management and spiritual well-being as recorded on the multiple sclerosis self-management scale-revised and the spiritual well-being questionnaire. There was a significant correlation between the participants' spiritual well-being and self-management scores ($r = 0.59$, $P < 0.001$). Furthermore, participants' self-management was significantly correlated with existential health ($r = 0.52$, $P < 0.001$) and religious health ($r = 0.57$, $P < 0.001$). Finally, 40% of the variance of self-management was explained by three factors: spiritual well-being, marital status, and job type ($R^2 = 0.4$, $F(3, 286) = 65.82$, $P < 0.001$).

Conclusions: Designing strategies to improve the spiritual well-being of people with multiple sclerosis can result in improved self-management of the disease. In designing such programs, special attention should be paid to the patients' demographic characteristics such as employment type and marital status.

Keywords: Multiple Sclerosis; Self-Management; Spirituality

1. Background

As a chronic disease of the central nervous system, multiple sclerosis (MS) is associated with degeneration within the brain and spinal cord. It is the most common neurological disease among young adults, affecting women far more frequently than men (1, 2). The number of individuals diagnosed with MS is on the rise, exceeding 2.5 million across the globe and 50,000 in Iran alone (3, 4).

MS can lead to significant disability and a variety of psychological and social problems (5). People with MS can suffer from psychological disorders and behavioral changes such as anxiety, depression, euphoria, bipolar affective disorder, confabulations, paranoid ideas, and irritability (6-8).

Because the symptoms appear at a young age when s/he is likely concerned about career and family responsibilities, MS can result in patient disappointment. Thus, some families face overwhelming frustrations and problems

(9). This could explain why family conflict and divorce are common among the families of people with MS (10).

Renewing strength and leading a balanced life following diagnosis can lead to increased coping, as MS has no cure. In spite of the complications arising after the diagnosis of MS, patients can often have a more effective role in managing their lives than expected (11). Improved patient self-management promotes improved adaptation to the disease.

A central component in self-management of MS is ensuring that the individuals themselves perform the day-to-day handling of the condition, rather than their health-care providers (12).

The ability to engage in self-management among people with MS has been linked to reduced fatigue, improved depression, and enhanced quality of life (13-15). The positive effects of self-management in patients with chronic diseas-

es such as MS have been reported. In fact, self-management helps to achieve a sense of ability and self-control (16).

To assume the responsibilities of self-management, there are several concepts, one of which is spiritual well-being (17, 18). Spiritual well-being integrates other dimensions of health. Generally, spirituality is described as "the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, self, others, nature and to the significant and/or the sacred" (19). Spiritual well-being is divided into two sub-components: existential well-being which refers to understanding the meaning and purpose of life, and religious well-being which refers to satisfaction with the relationship between the person and a higher power (17).

A strong body of research shows the potential of spirituality/religiosity to improve and maintain physical and mental health, while ameliorating the harmful effects of psychosocial stress (20). Some studies in Western countries have shown the role of spiritual well-being on coping with diseases. For example, Brooks and Matson (21) found that spiritual beliefs and faith had a positive impact on coping with MS.

Spirituality is considered as an influencing factor on promoting positive health behaviors (15). In studies conducted in countries other than Iran, a positive correlation was found between spirituality and self-management of chronic disease such as diabetes (22, 23). It is noteworthy, however, that MS is different from other chronic diseases because of its unique characteristics.

To our knowledge, no study has thus far been conducted to assess the relationship between spiritual health and self-management among patients with MS. Since spirituality is affected by both culture and religion (24), the findings of studies performed on spiritual well-being in other cultures cannot be fully generalized to people with MS in Iran. Furthermore, it is evident that cultural and social beliefs form the basis for much of an individual's behaviors, such as those performed to manage his/her own illness. In other words, findings related to the relationship between spiritual well-being and self-management in people with MS are context-based.

2. Objectives

The present study aimed to assess the relationship between spiritual well-being and self-management among Iranian people with MS.

3. Patients and Methods

This cross-sectional analytical study was conducted in 2014 by using people with MS belonging to the MS Society of Mashhad, Iran. The Research and Ethics Committee of Birjand University of Medical Sciences approved the research proposal. Taking into account the results of a study by Shahbeigi and colleagues (25), this study used conve-

nience sampling of 291 people registered in the MS Society of Mashhad. Participants attended this center during the data collection period, met the eligibility criteria and volunteered to participate in the study. Inclusion criteria were: a) confirmation of the disease by a neurologist, b) absence of other acute or chronic physical, mental or psychological disorders that interfere with the self-management of patients, and c) willingness to participate in the study.

A form consisting of questions regarding age, education level, marital status, and type of job was used to collect demographic information.

Spiritual well-being of participants was assessed by using Paloutzian and Ellison's Spiritual Well-being Questionnaire (1983). This questionnaire consists of 10 items about religious beliefs (e.g. I believe that God loves me and always cares for me), and 10 other items measuring the individual's existential health (e.g. I do not know who I am, where I come from and where I'll go). Participants responded to questions on a six-point Likert scale (1 = completely disagree and 6 = completely agree). In the negative verb questions (i.e. 1, 2, 5, 6, 9, 12, 13, 16, and 18), a response of "completely disagree" equaled 6 points, while "completely agree" equaled 1 point. The total score of spiritual well-being was expressed by calculating the sum of the religious and existential health scores, ranging from 20 to 120 (26, 27). The spiritual well-being score was divided into three levels: low (20 to 40), middle (41 to 99) and high (100 to 120). Ten members of the Nursing and Midwifery Faculty of BUMS approved the content validity of this questionnaire, and its reliability was determined by using Cronbach's alpha coefficient calculation. The coefficient was 0.82, indicating satisfactory questionnaire reliability in the study.

The multiple sclerosis self-management scale-revised (MSSM-R), developed by Bishop and Frain (2011) was used to evaluate self-management. This scale consists of 24 items concerning various dimensions of self-management: 6 items regarding healthcare provider relationship and communication (e.g. My medical provider is very willing to answer all of my questions), 7 items about treatment adherence/barriers (e.g. I am confident I need to take my medication to be healthy), 3 items pertaining to social/family support (e.g. I feel I have a lot of emotional support from my friends or family), 4 items regarding MS knowledge and information (e.g. I seek out information about my MS), and 4 items about health maintenance behavior (e.g. I try to take a break when I feel myself getting tired). Participants responded to questions on a 5-point Likert scale (1 = completely disagree and 5 = completely agree). The self-management total score was determined by using the following equation:

$$(1) \qquad \text{Total score} = \frac{100\,(\text{observed score} - 24)}{120 - 24}$$

Self-management total scores range from 0 to 100 (28), and were divided into three levels: low (0 to 33), middle (34 to 67) and high (68 to 100). Ten members of the Nurs-

ing and Midwifery Faculty of BUMS approved the content validity of this questionnaire. The Cronbach's alpha coefficient was 0.80, indicating acceptable reliability.

Participants were informed of the study's objectives and methods. The voluntary nature of their participation was explained. Patients were assured of confidentiality regarding both their responses and their identity. Then, oral consent to participate was obtained.

4. Results

In this study, 10.7% of participants were younger than 20 years of age, 45.5% were between 20 to 40 years, and the rest were greater than 40 years old. The majority of the patients (55.3%) were male. In terms of education level, 25.8% of participants did not have a high school diploma, 35.7% had a high school diploma, 24.4% had an associate's degree, and 14.1% had a bachelor's or higher degree. Of the participants, 25.8% were single, 58.4% were married, 7.2% were divorced, and 8.6% of them were widows/widowers. The majority (86.6%) resided in urban areas, while 13.4% lived rurally. Finally, 23% of participants had governmental jobs, 50.2% worked in the private sector, 8.2% were retired, and 18.2% were homemakers.

The means scores of spiritual well-being, self-management, and their dimensions in respect to the demographic characteristics of participants are displayed in Table 1.

Table 1. The Mean Scores of Spiritual Well-Being, Self-Management, and Their Dimensions in Respect to the Demographic Characteristics of Participants [a,b]

Variable	Spiritual Well-Being	Existential Health	Religious Health	Self-Management	Health Maintenance Behavior	MS Knowledge and Information	Social/ Family Support	Healthcare Provider Relationship	Treatment Adherence/ Barriers	Spiritual Well-Being
Age, y										
≤ 20	80.74 ± 14.7	38.51 ± 8.02	42.22 ± 7.55	86.41 ± 12.74	14.29 ± 2.51	15.67 ± 3.67	10.48 ± 2.58	21.8 ± 3.61	24.16 ± 14.85	80.74 ± 14.7
21 - 40	79.39 ± 11.87	38.51 ± 6.52	40.79 ± 6.54	87.34 ± 13.86	13.43 ± 3.02	15.85 ± 3.45	11.21 ± 4.26	22.18 ± 4.26	24.64 ± 4.6	79.39 ± 11.87
≥ 41	80.75 ± 13.7	31 ± 6.8	41.65 ± 7.67	89.7 ± 13.39	13.68 ± 2.54	15.99 ± 3.11	11.36 ± 2.55	23.76 ± 4.65	24.89 ± 4.79	80.75 ± 13.7
P value [c]	0.67	0.6	0.49	0.2	0.25	0.95	0.23	0.009	0.7	0.67
Educational level										
Lower than high school diploma	76.44 ± 12.17	39.21 ± 6.11	40.22 ± 7.13	84.12 ± 13.14	13.18 ± 2.82	14.94 ± 3.27	10.57 ± 2.79	21.9 ± 4.29	23.5 ± 4.25	76.44 ± 12.17
High school diploma	80.01 ± 13.49	38.63 ± 7.12	41.34 ± 7.43	89.81 ± 13.38	14.28 ± 2.65	16.07 ± 3.19	11.59 ± 2.1	23.28 ± 4.83	24.56 ± 5.06	80.01 ± 13.49
Associate's degree	83.7 ± 12.7	40.94 ± 6.69	42.66 ± 6.55	90.09 ± 13.18	13.16 ± 2.94	16.52 ± 3.21	11.23 ± 2.4	23.35 ± 4.15	25.81 ± 4.57	83.7 ± 12.7
Bachelor's degree or higher	81.02 ± 12.22	40.04 ± 5.99	40.97 ± 7.41	88.9 ± 14.25	13.63 ± 2.43	16.09 ± 3.64	11. 31 ± 2.91	22.53 ± 4.51	25.31 ± 4.38	81.02 ± 12.22
P value [c]	0.008	0	0.2	0.02	0.072	0.01	0.14	0.14	0.02	0.008
Marital status										
Single	77.76 ± 12	37.01 ± 6.54	40.74 ± 6.32	81.66 ± 11.97	13.38 ± 2.72	14.66 ± 3. 46	10.8 ± 2.35	20.6 ± 3.92	22.73 ± 4.26	77.76 ± 12
Married	81.1 ± 13.32	39.41 ± 6.9	41.62 ± 7.51	90.4 ± 13.34	13.61 ± 2.75	16.17 ± 3.13	11.68 ± 2.34	23.44 ± 4.42	25.48 ± 4.83	81.1 ± 13.32
Divorced	77.9 ± 12.93	37.85 ± 6.58	40.04 ± 6.62	89.76 ± 12.45	13.71 ± 2.45	17.52 ± 2.74	9.85 ± 2.28	23.19 ± 4.47	25.47 ± 4.1	77.9 ± 12.93
Widowed	89.6 ± 13.18	40.48 ± 6.75	42.12 ± 7.69	92.52 ± 14.37	14.52 ± 3.26	16.36 ± 3.59	11.84 ± 3.06	25.16 ± 4.54	24.64 ± 4	89.6 ± 13.18
P value [c]	0.17	0.04	0.72	0	0.08	0.001	0	0	0	0.17
Types of jobs										
Governmental	84.58 ± 12.15	41.22 ± 6.29	43.25 ± 6.83	92.7 ± 13.42	13.19 ± 2.79	17.52 ± 3.19	11.53 ± 2.4	23.97 ± 3.85	26.47 ± 4.8	84.58 ± 12.15
Private sector	76.85 ± 12.79	37.07 ± 6.73	39.75 ± 7.08	84.65 ± 13.34	13.76 ± 2.76	14.89 ± 3.34	10.78 ± 2/4	21.42 ± 4.48	23.51 ± 4.81	76.85 ± 12.79
Retired	83.16 ± 10.68	39.54 ± 4.84	43.62 ± 7.08	90.62 ± 12.8	12.79 ± 2.37	15.79 ± 3.1	11.95 ± 2.74	24.5 ± 4.57	25.58 ± 3.76	83.16 ± 10.68
Homemaker	82.24 ± 13.44	40.03 ± 7.42	42.2 ± 6.99	91.56 ± 1.58	14.24 ± 2.85	16.67 ± 3.47	11.66 ± 2.61	24.6 ± 4.15	6.47 ± 4.8	82.24 ± 13.44
P value	0	0	0.001	0	0.16	0	0.01	0	0	0

[a] Data are presented as mean ± SD.
[b] n = 291.
[c] P values less than 0.05 are considered significant.

As shown in Table 1, the mean score of spiritual well-being was 80.13 ± 13. The mean score of existential health was 38.77 ± 6.8, and that of religious health was 41.32 ± 7.1. The mean score of self-management was 88.28 ± 13.56. The mean scores of healthcare provider relationship, treatment adherence/barriers, social/family support, MS knowledge and information and health maintenance behavior, were 22.84 ± 4.51, 24.7 ± 4.7, 11.2 ± 2.5, 15.89 ± 3.32, and 13.63 ± 2.77, respectively.

There was a significant positive correlation between spiritual well-being and the self-management of participants ($r = 0.59$, $P = 0.00$). There was also a significant positive correlation between both self-management and existential health, ($r = 0.52$, $P = 0.00$) and self-management and religious health ($r = 0.57$, $P = 0.00$).

There were also significant differences in the mean spiritual well-being scores of participants with differing education levels. Further analysis utilizing Tukey's test indicated that this difference was related to higher education levels. An example includes the comparison of those lacking a high school diploma to those with an associate's degree ($P = 0.004$). In other words, those lacking a high school diploma reported lower spiritual well-being scores than those with an associate's degree.

There were significant differences in the mean existential health scores of those with differing marital statuses. Tukey's test showed significant differences between both the single and married groups ($P = 0.02$), and the single and deceased spouse groups ($P = 0.01$). Both the married group and those having a deceased spouse reported higher mean existential health scores than the single group.

The mean spiritual well-being scores of those with varying jobs were significantly different. Differences were noted between both the governmental and private sector groups ($P = 0.00$), and the governmental and homemaking groups ($P = 0.04$). Participants with governmental jobs reported higher spiritual well-being scores than those working in the private sector and homemaking.

The Kruskal-Wallis test showed significant differences

in the mean healthcare provider relationship and communication dimension scores between participants with varying ages. Differences were reported between participants greater than 40 years old and those between 20 and 41 years old ($P = 0.006$), as well as between participants older than 40 years and those under 20 years old ($P = 0.02$). Participants over the age of 40 reported stronger relationships with healthcare providers than the other two groups.

One-way ANOVA testing showed variations in the mean self-management scores of participants with different education levels. Those with a high school diploma reported higher self-management scores than those without ($P = 0.02$). There was also a statistically significant difference noted between those without a high school diploma and those having an associate's degree ($P = 0.03$). The participants with an associate's degree reported higher self-management scores.

The married group reported higher mean self-management scores than singles. Those with a deceased spouse also reported a higher mean self-management score than the singles ($P = 0.002$).

In addition, the mean self-management scores among participants with varying job types were significantly different. The most significant differences were noted between the governmental and private business groups ($P < 0.001$). The mean score of those having governmental jobs was higher. Moreover, there were significant differences noted between those working in the private sector and homemakers ($P < 0.001$). The homemakers rated higher self-management scores.

Finally, a stepwise multiple regression was used to determine the extent to which the variables of demographics and spiritual well-being can predict self-management scores (Table 2). The spiritual well-being variable was entered in the first step, followed by marital status (being single). Next, the job type variable (working in the private sector) was entered. In the study, 40% of the self-management variance was explained by these three factors ($R^2 = 0.4$, $F_{(3, 286)} = 65.82$, $P < 0.001$).

Table 2. Predictors of Self-Management [a]

	B	β	T	R^2	Adjusted R^2	F
Constant	47.7		11.21	0.4	0.4	65.82 [b]
Spiritual well-being	0.55	0.52	11.2			
Marital status (being single)	-6.74	-0.21	-4.5			
Jobs types (working in the private sector)	-3.2	-0.12	-2.5			
Step 1: spiritual well-being						
Step 2: being single						
Step 3: working in the private sector						

[a] n = 291.
[b] $P < 0.05$.

According to this analysis, single participants reported self-management scores that were 0.21 lower than those who were married. Patients working in the private sector reported scores 0.12 lower than those with governmental jobs.

5. Discussion

This study was conducted to assess the relationship between spiritual well-being and self-management of Iranian people with MS.

Studies have shown a positive correlation between spiritual well-being and self-management in patients with chronic diseases. For example, Bhattacharya's qualitative study (29) conducted on 31 adult African Americans with type 2 diabetes concluded that spirituality plays a key role in self-management. Harvey (30) also illustrated the significant role of spirituality in self-management among elderly women with cardiovascular disease and arthritis.

Chronic disease such as MS and its numerous complications jeopardize patients' identities, weakening their ability to accomplish tasks and producing challenges that shake their beliefs (31).

The patients suffering from MS reported higher levels of religious health than existential health. This finding is in contrast with a study conducted by Allahbakhshian et al. (26). Rezaei (32) conducted a study assessing the level of spiritual well-being among patients with cancer receiving chemotherapy. The religious health of these patients was found to be higher than their existential health. This may be attributed to religious and cultural contexts in Iran, orienting people toward religious thoughts when adapting to critical conditions.

Participants with an associate or a higher degree reported higher mean spiritual well-being scores. Some studies have linked a number of demographic characteristics such as education level and income with spirituality and religiousness (33, 34). One possible explanation for this finding is that patients with a higher educational level have acquired greater knowledge and life vision by using different sources of data.

Consistent with Taheri Kharame et al. (35), married participants had higher mean existential health scores than singles or ones with a deceased spouse. Generally, family support such as expressions of love and affection, and giving value to the patients contributed to their overall health (32). Furthermore, patients whose spouses were deceased reported higher mean existential health scores than the singles. One can assume that after a person's spouse dies, s/he is supported by family and society more than before. This may lead to a higher level of health among those whose spouses are deceased than among those who are single.

In this study, spiritual well-being and its dimensions were higher in participants with governmental jobs than those with other jobs. According to Bredle et al. (36), age,

marital status and employment type influence spiritual well-being of people with chronic diseases. These researchers acknowledge that people with jobs have a higher spiritual well-being than others. It could be assumed that having a job with steady income gives patients with chronic diseases hope for controlling problems such as high costs of treatment. This may have helped those with governmental jobs to maintain higher integrity across different aspects of their health, including spiritual well-being.

The participants 40 years of age or older had higher mean scores in healthcare provider relationship and communications than others. Via et al. (37) believed that some demographic characteristics including old age are important factors in self-management of diseases. They explained that patients achieve a greater perception of their disease as they get older. Thus, there is a positive correlation noted between age and self-management.

In the current study, participants without a high school diploma reported lower self-management mean scores than the groups with a diploma or associate's degree. Consistent with this finding, Karter et al. (38) noted that socio-economic factors such as low education level are disruptive to self-management of patients with diabetes. Education level has been regarded as an important factor in understanding physicians' orders (39).

The mean score of self-management was higher in married patients than singles. This finding is consistent with the results of Jerant et al. (40). Married people generally receive more emotional, informational, and social support than unmarried ones (41). These issues collectively create an appropriate context for self-care of married people.

Singles reported lower mean self-management scores than those whose spouse had died. Those with deceased spouses may have obtained a deeper understanding of life, creating improved self-management.

Participants with governmental jobs had higher mean self-management scores than others. According to Rose et al. (42), job type is a significant factor in self-management and health-related behaviors. Patients with governmental jobs likely have a higher level of education and a steady source of financial support, affecting their self-management.

The patients with private businesses had lower mean self-management scores than other groups. Adams et al. (43) argued that poor socioeconomic status such as low income negatively influenced self-care behaviors. People with governmental jobs or retirees have a steady source of income, and homemakers in the current study (primarily women) receive financial support from their husbands. The men who work in the private sector, however, lack a predetermined monthly income, and must meet their own expenses as well as the financial needs of their family. According to Jerant et al. (40), the costs of treatment and lack of adequate income impede access to medical care, laboratory and diagnostic tests/procedures,

medications, preventive care, and educational programs. These issues disrupt the self-management process.

In this study, 40% of self-management variance was explained by three factors: spiritual well-being, marital status, and job type. When designing strategies to improve the self-management of people with MS, particular attention should be paid to single patients and/or those working in the private sector. In addition, future research could be conducted to study other possible variables affecting self-management of people with MS.

The present research was conducted on people with MS registered with the Mashhad MS Society. Therefore, the results should be generalized cautiously. It seems that designing strategies to improve the spiritual well-being of people with MS can result in increased self-management. Thus, nurses should integrate spirituality into the health care practice of people with MS. Nursing spirituality interventions can be grouped into two main categories: active listening and spiritual support. Active listening describes nursing actions such as being present for the client, using touch, assisting the client in finding the meaning of life, and encouraging reminiscence. On the other hand, spiritual support involves facilitating forgiveness, instilling hope, and prayer (44). Furthermore, strategies such as a one-week short-term life review (STLR) have been found to be effective in improving the spiritual well-being of patients with a chronic disease like cancer. STLR is a process in which one's consciousness returns progressively to prior experiences that can then be re-evaluated to resolve past conflicts (45). Applying these strategies may be effective in enhancing the spiritual well-being of people with MS. In designing programs to improve the spiritual well-being of people with MS, special attention should be paid to the patients' demographic characteristics such as employment type and marital status.

Finally, the nature of the sample in this research needs to be considered when interpreting the results. In this study, the results were derived from data reported by people with MS in the MS Society of Mashhad. These findings may only be representative of MS patients who lived in and around Mashhad city. Thus, future studies could be conducted in other regions for comparison with these results. Considering the cross-sectional nature of the present study, causal inferences cannot be made regarding the relationship between self-management and spiritual well-being among people with MS. Researchers can design and implement interventional studies to test the possible causal association between these two variables.

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Authors' Contributions

Seyyed Abolfazl Vagharseyyedin: study concept and design, analysis and interpretation of data, study supervision; Bahare Zarei: drafting of the manuscript, acquisition of data; Esmat Gorganie: drafting of the manuscript, acquisition of data.

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