



# The Relationship between Spiritual Well-Being and Care Burden in Family Caregivers of Patients with Multiple Sclerosis: A Cross-Sectional Study

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## Abstract

**Background:** Multiple sclerosis has a high burden of care on the patient and their family, which can affect the spiritual well-being of the family. Therefore, this study was conducted to determine the relationship between spiritual well-being and the burden of care in family caregivers of patients with multiple sclerosis.

**Methods:** In this cross-sectional study, 100 family caregivers of patients with MS referred to the MS Society of Hamadan, Iran, in 2020 were selected using the convenience sampling method. The data gathering tools were Paloutzian and Ellison's Spiritual Well Being Scale, the Zarit Burden Interview, and Expanded Disability Status Scale. Data were analyzed using descriptive/analytical statistics and SPSS software version 16.

**Results:** The mean scores of spiritual well-being and family caregiver burden were  $93.50 \pm 16.84$  and  $25.50 \pm 16.24$ , respectively. Based on the Pearson correlation coefficient, there was a significant inverse relationship between spiritual well-being and care giving burden ( $p = 0.001$ ,  $r = -0.48$ ). The multiple regression test results showed that the spiritual well-being variable significantly predicts the burden of care ( $p = 0.0001$ ,  $\beta = -0.311$ ).

**Conclusion:** In this study, spiritual well-being had a significant and inverse correlation with the burden of care. Therefore, it is emphasized to consider the spiritual well-being of family caregivers to reduce the consequences of care burden.

**Keywords:** Spirituality, Care Burden, Multiple Sclerosis, Cross-Sectional Study

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## Introduction

Multiple sclerosis (MS) can vary from benign disease to a rapidly progressive and debilitating

disease that requires extensive lifestyle adaptation (1). Patients with chronic illnesses, such as MS, face problems related to their illness, which lead to secondary complications and



limitations in their independent life (2) and affect their ability to perform activities of daily living (3). The patient might need daily help from family members. However, the regular assistance provided by family members to a disabled spouse, parent, partner, or child may have physical and economic consequences for the caregiver and result in care burden (4). Care burden is defined as the caregiver's physical, psychological, and social responses (5) resulting from an imbalance between caregiver needs and other caregiver duties. This imbalance is associated with the caregiver's social and personal roles, physical and emotional status, and financial resources (6).

With the advancement of nursing science, attention has been directed to the family, which has become an essential member in the care and a pursuer of the nurse (7). Since the chronic patient's health is dependent on the caregiver's health, it is imperative to take into account caregivers' health needs (8). Spirituality can be employed as a coping strategy for patients with chronic diseases and caregivers and lead to greater resistance to disease stress (9). Studies show that caregivers of chronic patients have confidence in the spiritual dimension as an important resource (10).

Studies have shown a significant inverse relationship between spiritual well-being and care burden perceived by family caregivers of cancer patients in Italy (11) and Iran (12), and Alzheimer's patients (13). In Iran, like other developing countries, due to an imbalance in the number of patients and healthcare providers, caregivers are responsible to take care of their patients and caregivers experience high levels of care burden (14). Therefore, this study was conducted to investigate the relationship between spiritual well-being and care burden in family caregivers of patients with MS.

## Methods

In this cross-sectional study, 100 family caregivers of patients referred to the MS Society of Hamadan, Iran, in 2020 were selected using the convenience sampling method. The number of samples was estimated to be 100 based on the study of Mollai et al. (12) considering  $\alpha = 0.05$ ,  $1 - \beta = 0.8$  and 20% drop loss.

$$n = \left[ \frac{z_{1-\frac{\alpha}{2}} + z_{1-\beta}}{c} \right]^2 + 3 = 87, c = \frac{1}{2} \left[ \ln \frac{1+r}{1-r} \right]$$

The inclusion criteria for family caregivers were attainment of at least primary education, age

over 18 years, a family member with more participation in the patient care process, and no severe physical or mental illness based on medical history.

## Instruments

1. The Patient Demographics Questionnaire
2. The Caregiver Demographics Questionnaire
3. Paloutzian and Ellison's Spiritual Well Being Scale: It assesses religious and other existential well-being with ten questions in each dimension. The spiritual well-being score is the sum of the two subgroups, ranging from 20 to 120. Responses are rated based on a 6-point Likert scale from 'strongly disagree' to 'strongly agree.' In the end, individuals' well-being indicators are divided into three categories: low (20-40), moderate (41-99), and high (100-120). Paloutzian and Ellison confirmed the validity and reliability the scale with the test-retest and Cronbach's alpha of 0.93 and internal consistency of 0.89 (15). In the present study, the scale had a Cronbach's alpha of 0.90.
4. The Zarit Burden Interview (ZBI): This inventory was designed in 1980 by Zarit et al. It has 22 items assessing personal, social, emotional, and financial pressure. All items are scored based on a 5-point Likert scale ranging from 0 (always) to 4 (nearly always), with the total score varying between 0-88. A score between 0-20 indicates low or no care burden, 21-40 indicates moderate care burden, and 41-88 indicates severe care burden (16). The validity and reliability of this inventory have been confirmed (17), and its Cronbach's alpha coefficient was 0.90 in the current study.
5. Expanded Disability Status Scale (EDSS) is a measure of disability. The score is assessed by a clinician based on the evaluation of eight functional systems of CNS, ranging from 0 (normal) to 10 (death due to MS). Some of the limitations regarding EDSS include documented weakness in inter- and intra-rater reliability and sensitivity to change. Nevertheless, EDSS is still accepted and preferred as the main disability outcome measure in MS (18).



## Statistical analysis

The data were analyzed using SPSS software version 16 and descriptive statistics, including mean, standard deviation, and a frequency distribution of variables, independent t-tests, and one-way analysis of variance (ANOVA). Non-parametric Mann-Whitney or Kruskal-Wallis tests would be used if the data were not normally distributed. After controlling other variables, multiple regression with the backward elimination method was used to investigate the effect of spiritual well-being on care burden.

## Ethical consideration

This study was approved by the Student Research Committee of the Hamadan University of Medical Sciences, Hamadan, Iran, with the ethical code of IR.UMSHA.REC.1398. Providing information about the research objectives and the need for informed consent, ensuring confidentiality, and providing freedom to leave the study were among the ethical considerations of the research.

## Results

The mean age of the family caregivers was  $40.14 \pm 12.26$ . The family caregivers' other demographics are listed in Table 1.

### Table 1:

The mean age of patients with MS was  $36.47 \pm 9.45$ . The patients' other demographics are presented in Table 2.

### Table 2:

The mean and standard deviation of care burden, spiritual well-being, religious health, and existential health were  $25.50 \pm 16.24$ ,  $93.5 \pm 16.84$ ,  $50.69 \pm 7.44$ , and  $42.8 \pm 10.55$ , respectively (Table 3).

### Table 3:

The results of the Pearson correlation coefficient showed a significant inverse relationship between spiritual well-being and care burden ( $r = -0.48$ ,  $p = 0.0001$ ) (Table 4).

### Table 4:

There was a significant relationship between the family caregivers' spiritual well-being with EDSS ( $p = 0.02$ ), patient income ( $p = 0.016$ ), family caregiver income ( $p = 0.02$ ), the patient's marital status ( $p = 0.02$ ), and the patient's current problem (spasm) ( $p = 0.003$ ). In addition, a statistically significant relationship was observed between general spiritual well-being with hours ( $p = 0.01$ ) and years of patient care ( $p = 0.045$ ). Furthermore, care burden was significantly

related to patient care hours ( $p = 0.003$ ) and number of patient care days ( $p = 0.028$ ). There was also a significant relationship between the family caregivers' care burden with EDSS ( $p = 0.0001$ ), type of patient insurance ( $p = 0.006$ ), patient income ( $p = 0.005$ ), family caregiver income ( $p = 0.002$ ), the patient's marital status ( $P = 0.015$ ), history of other diseases in the patient ( $p = 0.05$ ), recurrence frequency ( $p = 0.011$ ), the patient's current problem (imbalance) ( $p = 0.003$ ) and spasm ( $p = 0.001$ ), and drug provision. The multiple regression test result showed that spiritual well-being significantly predicted care burden ( $p < 0.0001$ ,  $\beta = -0.311$ ) (Table 5).

Also, the multiple regression model results showed the effect of the studied variables on care burden in the family caregivers of patients with MS (Table 5).

## Table 5:

### Discussion

This study aimed to investigate the relationship between spiritual well-being and care burden in family caregivers of patients with MS. In this study, care burden perceived by the family caregivers was at a moderate level ( $25.50 \pm 16.24$ ) (21-40 as moderate). In a study conducted in Turkey, the care burden of patients with MS was reported to be moderate ( $30.67 \pm 15.66$ ) (19). In another study conducted on the family caregivers of cancer patients in Tehran, the mean care burden was moderate ( $25.54 \pm 11.72$ ) in the family caregivers (12), which is in line with the present study results. In the study by Abbaszadeh et al. (2015) on the family caregivers of patients with hematological cancer in Iran, the mean care burden of the family caregivers was high (20). The discrepancy in the results may be due to type of disease, patient condition, and care might affect care burden. Furthermore, in this study, the family caregivers had spiritual well-being at an above-average level, and the mean score of religious dimension was higher than that of existential dimension, that this study was in line with the results of the study in Tehran (12). The consistency of the results between the two studies may be due to the study setting, as Iranian people pay a closer attention to spiritual well-being in challenging situations. Considering that the religious dimension in most studies was at a higher level than the existential dimension reveals that individuals pay particular attention to religion and God while facing predicaments. Spiritual well-being is a dimension of human existence that guarantees well-being and



contentment in the other world (21), increases life expectancy (22), and improves one's social functioning (23) if strengthened and well-built.

Also, the following can be mentioned in other similar researches: Baghipour sarami et al, studied Modeling of Nurses' shift Work schedules According to Ergonomics: A case study in Imam sajjad (As) Hospital of Ramsar. Mahboobi et al, discussed Assessing Ergonomic Risk Factors Using Combined Data Envelopment Analysis and Conventional Methods for an Auto Parts Manufacturer. occupational injuries are currently a major contributor to job loss around the world. Tarverdizadeh et al, studied Predicting students' academic achievement based on emotional intelligence, personality and demographic characteristics, attitudes toward education and career prospects through the mediation of academic resilience. Ghaed Amini Harouni et al, studied Effectiveness of Self-control and Aggression Reduction Skill Training of Male Juvenile Delinquents Correction and Rehabilitation Center (Including Case-Study). Nazari and Taghipour, studied The Role of Emotion Regulation Strategies and Self-Compassion in Predicting Test Anxiety (Including Case Study). Nezamivand et al, studied Compare Effectiveness of Teaching Rational Emotive Therapy on Flexibility and Mental Health Women with Sexual High risk and Substance Abuse Behaviours (Including Case-Study). Rafiee et al, studied Analyzing the concept of family-centered care in ICU: Rodgers Evolutionary Approach (28, 34).

The present study showed a significant negative correlation between spiritual well-being and care burden in the family caregivers of patients with MS, which is in line with the results of studies conducted in the United States (13), Kerala, India (24), and Iran (12, 25).

Furthermore, a significant relationship was observed between the family caregivers' spiritual well-being with patient disability status (EDSS), patient income, family caregiver income, the patient's marital status, and the patient's current problem (spasm). There was also a statistically significant relationship between overall spiritual well-being with patient care hours and years of patient care, as well as between care burden with patient care hours and the number of patient care days.

Moreover, there was a significant relationship between care burden with patient disability status (EDSS), patient insurance type, patient income, family caregiver income, the patient's marital status, the patient's other medical history items, recurrence frequency, the patient's current problem (imbalance) and (spasm), and the problem of drug provision. It was shown in a study that stress experienced by caregivers of patients with MS was significantly and positively correlated with EDSS and disease duration (26). In a similar vein, the results of the study by Buchanan et al. (2011) showed that care burden was higher in caregivers whose patients had bladder dysfunction, needed more hours of care per week, and had more limitations on the caregiver's ability to perform daily activities (27). Also, the results a study in Turkey showed a direct correlation between the mean score of family members' care burden and patients' disability ( $r=0.32$ ,  $p<0.01$ ), with care burden increasing with increased patients' disability (19). Considering the present study results, it can be concluded that family caregivers of patients with MS endure the burden during providing care, which is inversely associated with their spiritual well-being. Given that most patients in Iran live with family members and treatment and care programs are followed in the family environment, special attention should be paid to identify family caregivers' needs, perform appropriate interventions, assist health team caregivers and contribute to the provision of care by them, and reduce the consequences of care burden. Thus, family caregivers can actively participate in caring for their patients as a member of the community-based care team and attain the ability to deal with life challenges.

This study was cross-sectional, and it is preferable to conduct the study longitudinally and at different stages of the disease to find more definite results. This study can be carried out on other family caregivers of patients with MS in different parts of Iran with larger sample sizes, in which the influence of cultural factors can also be taken into account.

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**Table 1** - Socio demographic Characteristics of *the family caregivers* at Baseline

Baseline characteristic	n	%
gender		
Female	52	52
Male	48	48
Married status		
Single	16	16
Married	76	76
Separated or divorced	8	8
Education status		
High school or less	21	21
Diploma and post-diploma	69	69
Bachelor's degree and higher	10	10
Job		
Manual worker	10	10
Employee	26	26
Housewife	31	31
Other or free	33	33
Income status		
It is not enough	32	32
To some extent it is not enough	53	53
It suffices	15	15
Financial support		
Insurance	85	85
Welfare center and Relief Committee	7	7
Other cases	8	8
Relationship with the patient's parent		
Father or mother	22	22
Spouse	49	49
Sister or brother	17	17
Child	12	12

Table 2 -*Socio demographic Characteristics of the patients at Baseline*

Baseline characteristic	n	%
gender		
female	84	84
male	16	16
Married status		
single	18	18
married	71	71
Separated or divorced	11	11
Education status		
High school or less	21	21
Diploma and post-diploma	76	76
Bachelor's degree and higher	3	3
Job		
manual worker	8	8
Employee	10	10
housewife	61	61
Other or free	21	21
Income status		
It is not enough	38	38
To some extent it is not enough	47	47
It suffices	15	15
Financial support		
Insurance	80	80
Welfare center and Relief Committee	9	9
Other cases	11	11
Frequent recurrence		
without recurrence	34	34
1time	23	23
2times	20	20
3 times and more	23	23
The first sign of illness		
Visual impairment	36	36
Sphincter urinary disorder	4	4
Imbalance	28	28
Movement disorder	28	28
Sensory disorder	34	34
The most important current debilitating problem		
Weakness	27	27

Fatigue	45	45
Muscle stiffness	26	26
Visual impairment	20	20
The lack of balance	39	39

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**Table 3-** The mean score of care burden and spiritual well-being and its components in the family caregivers

variable	Care burden	p-value
<b>Spiritual well-being</b>	-0.48	<0.001
Existential health	-0.49	<0.001
Religious health	-0.38	<0.001

**Table 4** -description of care burden, spiritual well-being and its components in the family caregivers

Variable	Mean	SD	95% CI* for mean
Care burden	25.50	16.24	22.32 – 28.7
Spiritual well-being	93.50	16.84	90.2-96.8
Religious health	50.69	7.42	49.23-52.14
Existential health	42.8	10.55	40.73-44.87

**Table 5:** The results of multiple regression model of the effect of the studied variables on the burden of care in family caregivers

Parameter	B	Std. Error	95% Confidence Interval		Wald Hypothesis Test			Sig.
			Lower	Upper	Wald Chi-Square	df		
Intercept	96.077	10.7869	74.936	117.219	79.333	1	<0.001	
EDSS								
Mild	-21.348	4.8204	-30.796	-11.901	19.614	1	<0.001	
Moderate	-21.135	4.8163	-30.575	-11.695	19.257	1	<0.001	
Sever	0 <sup>a</sup>	.	.	.	.	.	.	
married status								
Single	-11.577	5.1726	-21.715	-1.439	5.009	1	.025	
Married	-5.588	4.4463	-14.302	3.127	1.579	1	.209	
Divorced	0 <sup>a</sup>	.	.	.	.	.	.	
Financial support								
Insurance	1.180	3.8266	-6.320	8.680	.095	1	.758	
Welfare	12.737	5.3647	2.223	23.252	5.637	1	.018	
center								
Other cases	0 <sup>a</sup>	.	.	.	.	.	.	
Illness except MS								
Yes	16.344	5.3804	5.798	26.889	9.227	1	.002	
No	0 <sup>a</sup>	.	.	.	.	.	.	
The first sign with urinary incontinence								
Yes	-12.655	6.0469	-24.507	-8.03	4.380	1	.036	
No	0 <sup>a</sup>	.	.	.	.	.	.	
The first sign with muscle spasm								
Yes	-5.859	2.8479	-11.441	-2.277	4.233	1	.040	
No	0 <sup>a</sup>	.	.	.	.	.	.	
The first sign With imbalance								
Yes	-4.309	2.7498	-9.698	1.081	2.456	1	.117	
No	0 <sup>a</sup>	.	.	.	.	.	.	
Spiritual well-being (Scale)								
	-.300	.0750	-.447	-.153	15.945	1	.000	
	128.719 <sup>b</sup>	18.2036	97.559	169.833				

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Dependent Variable: care burden

Model: (Intercept), EDSS, married status , Financial support, Illness except MS , The first sign with urinary incontinence , muscle spasm, imbalance, Spiritual well-being

a. Set to zero because this parameter is redundant.

b. Maximum likelihood estimate.