

Spiritual Well-Being, and Caring Burden of Informal Caregivers of Stroke Patients

Abstract

Background: Caregivers of stroke patients face the significant burden. This study aimed to explore the relationship between caregiver burden and spiritual well-being among caregivers of stroke patients in Qom, Iran. **Materials and Methods:** This cross-sectional study included 112 caregivers of stroke patients. Participants were selected using convenience sampling from three rehabilitation centers in Qom, Iran, between March and December 2022. Data was collected using the Caregiver Burden Inventory and the Ellison and Paloutzian Spiritual Well-being Questionnaire. The data were analyzed using descriptive and analytical statistical methods, including linear regression analysis, in SPSS 24 software. **Results:** The mean (SD) caregiver burden was 67.10 (6.76), with 87.10% of participants reporting a high caregiver burden. The mean (SD) religious well-being score was 50.25 (9.41), while the mean (SD) existential well-being score was 42.78 (11.28). The stepwise multiple linear regression analysis showed that, after adjusting for demographic characteristics, care dependency ($\beta = 0.380$, $p = 0.001$) and existential well-being ($\beta = 0.277$, $p = 0.009$) were significantly associated with caregiver burden. These variables explained 38.00% of the variance in caregiver burden. **Conclusions:** The study suggests that enhancing spiritual aspects, particularly existential well-being, could reduce the perceived burden of caregivers. This valuable insight can be utilized to create interventions aimed at alleviating the challenges experienced by caregivers of stroke patients, ultimately reducing the impact of these difficulties.

Keywords: Caregiver burden, psychological well-being, spirituality, stroke

Introduction

Stroke is a critical and pervasive public health issue affecting approximately 15 million people worldwide annually.^[1,2] According to the World Health Organization, stroke is the second leading cause of death and the third leading cause of disability worldwide after heart disease.^[3] In Iran, the incidence rate of stroke is highly concerning.^[4] Despite medical advances that have increased the survival rate of stroke patients, many still experience varying degrees of disability.^[5] Statistics show that 40% of stroke patients have moderate disabilities, and 15%–30% have severe disabilities upon hospital discharge.^[1] More than half of these patients become dependent on others for their daily activities, which imposes significant physical, psychological, and economic burdens on their families and creates an urgent need for comprehensive caregiving.^[6]

Caregivers can be categorized into formal and informal types. Formal caregivers are typically healthcare professionals such as nurses and rehabilitation therapists who are paid for their services, while informal caregivers are usually family members, friends, or neighbors who provide unpaid care out of personal commitment or necessity. The concept of “caregiving burden” refers to the pressure and stress experienced by caregivers of individuals with chronic illnesses, disabilities, or aging-related conditions.^[7] This pressure can lead to an imbalance between care demands and available resources, ultimately causing multidimensional strain—physical, psychological, social, and financial.^[8] Studies have demonstrated a direct relationship between caregiving burden and various adverse outcomes, including depression, anxiety,^[9,10] poor quality of life, sleep disturbances,^[11] and diminished mental health.^[12] Caregiving responsibilities can significantly impact

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caregivers' quality of life, subjecting them to intense physical, emotional, economic, and social stress.^[13] Some research suggests that primary caregivers of stroke patients may be equally or even more vulnerable to mental health issues than the patients themselves.^[14]

Despite extensive research on the impact of caregiving burden, less attention has been given to protective factors that may help caregivers cope with these challenges. Specifically, the role of spirituality as a potential mitigating factor in reducing caregiving burden remains underexplored, particularly in the context of informal caregivers of stroke patients.

Spirituality is a powerful mechanism that helps individuals find meaning and purpose in life while fostering connections with themselves, others, nature, and transcendent dimensions.^[15,16] In this study, spirituality is conceptualized as a multidimensional construct encompassing existential well-being, religious beliefs, and spiritual coping strategies. Prior research suggests that spirituality can serve as a psychological buffer against stress and adversity, promoting emotional resilience.^[17] However, its specific effects on caregiving burden in informal caregivers of stroke patients have not been systematically investigated.

The aim of this study was to investigate the relationship between spiritual well-being and caregiver burden among informal caregivers of stroke patients. Furthermore, the study sought to determine the extent to which spiritual well-being could mitigate the caregiving burden, with the goal of providing evidence for designing holistic interventions to support caregivers.

Materials and Methods

This cross-sectional study was conducted in Qom, Iran, from March to December 2022. The study population comprised family caregivers of stroke patients receiving rehabilitation services. Participants were recruited from Shahid Beheshti Hospital Stroke Center and selected outpatient rehabilitation and physiotherapy centers in Qom, where stroke patients regularly received follow-up care. Sample size was calculated using previous studies^[6,17] and a standard formula. Based on an expected correlation coefficient of $r = 0.36$, a 95% confidence level, and 80% power, the required sample size was 100. To account for potential non-responses and incomplete data, 112 participants were recruited through convenience sampling.

Caregivers were included if they were informal caregivers (e.g., spouse, child, or other family members) primarily responsible for the patient's care, aged 18 years or older, and willing to complete the questionnaire. Patients were eligible if they had a clinical diagnosis of stroke confirmed by a neurologist, were at least 1-month post-stroke, and required assistance with daily activities due to physical

or cognitive impairments. If multiple family members shared caregiving responsibilities, one representative was selected. Caregivers, who provided incomplete responses or expressed unwillingness to continue participation were excluded. Recruitment was conducted in the waiting areas of the selected centers, and written informed consent was obtained after explaining the study objectives and confidentiality protocols.

Data were collected using a demographic profile questionnaire covering variables such as gender, education, marital status, living situation, employment, relationship to care recipient, care dependency, caregiver age, patient age, disease duration, and number of children. Caregiver burden was assessed using the Caregiver Burden Inventory (CBI) developed by Novak and Guest (1989), a multidimensional tool with five subscales: Time-Dependence, Developmental Burden, Physical Burden, Social Burden, and Emotional Burden. Each item is rated on a five-point Likert scale, yielding total scores between 24 and 120, with scores above 46 indicating a high burden.^[18,19] Spiritual well-being was assessed using the 20-Item Spiritual Well-being Questionnaire (SWBQ) by Ellison and Paloutzian, which consists of two subscales: Religious Well-being (10 items) and Existential Well-being (10 items). Each item is rated on a six-point Likert scale, with higher scores reflecting better well-being. The tool demonstrates strong psychometric properties, with reliability confirmed in Iran (test-retest reliability = 0.93; Cronbach's alpha = 0.84 in this study).^[20,21]

Data were collected through in-person or electronic completion of the questionnaires, supervised by researchers to ensure accuracy and completeness. Data were entered into SPSS version 16 and analyzed using descriptive statistics, including means and standard deviations for continuous variables and frequencies for categorical variables. Pearson's correlation coefficient was applied to examine relationships between spiritual well-being dimensions (religious and existential) and caregiver burden. Stepwise multiple linear regression was used to predict caregiver burden based on patient dependency and existential well-being.

Ethical considerations

The study received approval from the Ethics Committee of Qom University of Medical Sciences under the code IR.MUQ.REC.1400.048. Before participation, all individuals were fully informed of the research objectives and assured of the confidentiality of their information. Written informed consent was obtained from all participants, ensuring they fully understood the study's purpose, procedures, potential risks, and benefits. Additionally, participants were informed of their right to withdraw from the study at any time without any consequences.

Results

The caregivers in this study ranged in age from 18 to 66 years, with an average age of 42.07 years (SD = 12.6). 64.3% of the caregivers were female. A significant majority of participants (67.9%) had completed at least a secondary education. In terms of marital status, 74.1% of the caregivers were married. Additionally, 65.18% of caregivers resided in their own homes. The patients' ages ranged from 31 to 86 years, with an average age of 60.41 years (SD = 11.447). The disease duration varied from 1 month to 27 years, with an average duration of 2.86 years (SD = 4.35). The number of children of the patients ranged from none to 10, but 93.3% of the patients had at least one child. The characteristics of the study participants can be found in Table 1.

The study participants demonstrated an average level of spiritual well-being, with a mean score of 92.77 (± 19.3). Specifically, the religious dimension scored an average of 50.25 (± 9.41), while the spiritual dimension scored an average of 42.78 (± 11.28). Interestingly, most participants felt either average (57.3%) or high (40.6%) spiritual well-being. Caregivers in our study experienced the high mean care burden of 67.1, with 87.1% of them surpassing the cut-off point of 46 for care burden. Emotional health received the highest score, while time dependency received the lowest [Table 2].

There was a significant negative correlation between spiritual well-being and care burden, with a correlation coefficient of -0.32 . The relationship between spiritual well-being, its subscales, and the Caregiver Burden is illustrated in Table 3.

To examine the individual effect of each variable on the caregiving burden, separate simple linear regression analyses were conducted. As shown in Table 4, both religious well-being ($\beta = -0.270$, $p = 0.015$) and existential well-being ($\beta = -0.318$, $p = 0.004$) were significantly and negatively associated with caregiving burden. In contrast, variables such as caregiver's age, gender, marital status, education, and duration of illness were not significantly associated with caregiving burden. Notably, the patient's level of care dependency showed a significant negative association ($\beta = -0.451$, $p < 0.001$), indicating that greater disability was related to higher perceived burden.

To explore the predictability of study variables, specifically demographics and spiritual health, in relation to the burden of care, a multiple regression analysis with stepwise entry was conducted. The results of this analysis are shown in Table 5.

The stepwise regression process involved two key stages. Initially, the patient's level of care dependency ($\beta = 0.380$, p value = 0.001) was included in the regression model. Following this, existential health ($\beta = 0.277$, p value = 0.009) was added to the model.

Table 1: Socio-demographic information of the study sample ($n=112$)*

Variable	Category	n (%)
Gender	Male	40 (35.71%)
	Female	72 (64.29%)
Educational Status	Illiterate	7 (6.25%)
	Primary	26 (23.21%)
	Secondary	45 (40.18%)
	Higher	31 (27.68%)
Marital Status	Single	24 (21.43%)
	Married	83 (74.11%)
	Divorced/Widowed	5 (4.46%)
Residential Status	Owner	73 (65.18%)
	Tenant	35 (31.25%)
Employment Status	Employed	51 (45.54%)
	Not Employed	7 (6.25%)
	Housewife	49 (43.75%)
Care Dependency	Relative	67 (59.82%)
	Complete	39 (34.82%)
Relationship to Care Recipient	Spouse	33 (29.46%)
	Parent	19 (16.96%)
	Child	36 (32.14%)
	Brother/Sister	11 (9.82%)
	Other	13 (11.61%)
Age (years)	Mean (SD)	42.07 (± 12.60)
Variable	Category	n (%)
Gender	Male	40 (35.71%)
	Female	72 (64.29%)
Educational Status	Illiterate	7 (6.25%)
	Primary	26 (23.21%)
	Secondary	45 (40.18%)
	Higher	31 (27.68%)
Marital Status	Single	24 (21.43%)

*Totals do not equal n because of missing values in original data

Table 2: Descriptive statistics for variables of study

Variables	Mean (SD)	Possible range	Value (%)
Spiritual wellbeing	92.77 (19.30)	20–120	72.7
Religious wellbeing	50.25 (9.41)	10–60	80.5
Existential wellbeing	42.78 (11.28)	10–60	65.5
Caregiver Burden			
Development	13.58 (5.36)	5–25	42.9
Physical Health	11.23 (4.16)	4–16	60.2
Time Dependency	17.89 (5.05)	5–25	64.4
Emotional Health	10.98 (4.19)	5–25	29.9
Social Relationships	13.42 (4.61)	5–25	42.1

*Higher score indicates a better condition. **Lower scores indicate better conditions

The correlation between the burden of care and the variables from the first step was found to be 0.421, with an R Square value of 0.177. Progressing to the second step, the coefficient of determination was 0.502, and the R Square was 0.25. This indicates that 38% of the variance in the care burden can be explained by the patient's dependence and existential well-being variables [Table 5].

Table 3: The correlation between spiritual wellbeing and caregiver burden

Variables	Development	Physical Health	Time Dependency	Emotional Health	Social Relationships	Caregiver Burden
Spiritual wellbeing	-.329**	-.165	-.241*	-.217*	-.207	-.321**
Religious wellbeing	-.225*	-.135	-.200	-.189	-.215*	-.270*
Existential wellbeing	-.233*	-.198	-.388**	-.216*	-.172	-.318**

**Correlation is significant at the 0.01 level. *Correlation is significant at the 0.05 level

Table 4: Simple linear regression analyses of predictors of caring burden among informal caregivers of stroke patients

Predictor Variable	B*	SE B**	β ***	t****	p*****	95% CIs for B (Lower–Upper)
Religious Well-being	-0.545	0.219	-0.270	-2.489	0.015	-0.980 to -0.109
Existential Well-being	-0.548	0.185	-0.318	-2.961	0.004	-0.917 to -0.180
Caregiver's Age	-0.070	0.169	-0.046	-0.416	0.678	-0.407 to 0.266
Caregiver's Gender	4.158	4.230	0.107	0.983	0.328	-4.255 to 12.570
Care Dependency	-17.199	3.830	-0.451	-4.491	0.000	-24.822 to -9.577
Duration of Illness	-0.104	0.130	-0.088	-0.802	0.425	-0.362 to 0.154
Marital Status	-1.687	5.055	-0.037	-0.334	0.739	-11.744 to 8.369
Educational Level	0.421	1.303	0.036	0.323	0.747	-2.171 to 3.013

*B=Unstandardized Coefficient, **SE B=Standard Error, *** β =Standardized Coefficient, ****t=t-statistic, *****p=Significance level, %95 CI=95% Confidence Interval for B

Table 5: The results obtained from stepwise-regression analysis

Step	Variables	B	Std. error	Beta	t	p	R	R ²
1	Constant	90.31	6.51	---	13.86	p<0.001	0.421	0.177
	Care dependency	-15.24	3.87	-.421	-3.93	p<0.001		
2	Constant	107.24	8.91	---	12.03	p<0.001	0.502	0.252
	Care dependency	-13.78	3.76	-.380		p<0.001		
	Existential well-being	-.456	0.17	-.277	-3.66	0.009		

Discussion

This study investigated the relationship between spiritual well-being and caregiving burden in caregivers of stroke patients. The findings showed that most caregivers felt moderate to high spiritual well-being, but at the same time, they experienced high caregiving burdens. Statistical analyses revealed a significant inverse relationship between these two variables, such that an increase in spiritual well-being was associated with a decrease in caregiving burden. Also, the patient's dependence on the caregiver was identified as the strongest predictor of the caregiving burden, such that the greater the patient's dependence, the greater the burden. These results emphasize the importance of supporting caregivers and indicate that spiritual interventions can play an essential role in reducing caregiving burden.

Caregivers in this study demonstrated a generally moderate to high level of spirituality, reflecting a meaningful inner resource that may support them in coping with the challenges of caregiving. In addition, the results of this study are consistent with the survey's findings by Vigna (2025).^[22] This similarity suggests that caregivers' spiritual level is relatively high, even across different populations. The study found that 87.1% of caregivers experienced

higher than standard caregiving burdens. This result is consistent with the Stroke Association report that 64% of informal caregivers suffer from the emotional impacts of caregiving, and more than 80% of them experience stress, anxiety, or frustration.^[23]

Furthermore, two-thirds of informal caregiver's experience problems in their relationships with stroke patients. These findings highlight the importance of supporting caregivers to maintain their mental and physical health. Self-care programs and specialized support for informal caregivers can reduce stress and increase the quality of care. The results showed a significant inverse relationship between different dimensions of spirituality (religious, spiritual health, and existential spiritual health) and the level of caregiving burden. This means that the more existentially and religiously peaceful a person feels, the less caregiving pressure they will have. This finding is consistent with the study by Rafati *et al.* (2020),^[17] who showed that high spirituality is associated with reduced caregiver stress. Also, the survey by Delgado-Guay *et al.*^[24] emphasized that patient dependence on care is the strongest predictor of caregiver burden, which is also consistent with the findings of this study.

However, the study by González-Rivera *et al.*^[25] during the COVID-19 pandemic showed that increased spirituality

did not significantly reduce caregiver burden. This discrepancy may be due to differences in the time of the study, the conditions of the pandemic, and the overall level of stress in the community at that time. The findings of this study showed that the more dependent patients are on daily care, the more caregiver burden increases. Sun *et al.* (2020) also found that palliative care and spiritual support can help improve the mental health of patients and their caregivers.^[26] The Stroke Association (2013) also reported that caregivers of stroke patients often experience severe emotional and psychological distress.^[27] Greater patient dependence on care increases caregiver workload, may reduce positive interactions between caregivers and patients, and may increase caregiver psychological stress. Therefore, caregivers of patients with more significant functional dependence need more psychological and educational support from health professionals. Counseling programs, support services, and self-care skills training can reduce these pressures. Unlike previous studies, this study did not find a significant relationship between caregiver burden and caregiver demographic variables (such as age, gender, economic status, and education). This finding is inconsistent with some studies that have shown the effect of individual characteristics on caregiver burden.^[17,28,29] This difference could be due to differences in measurement instruments, study settings, or study populations. In studies that report demographic characteristics as influential, the distribution of demographic variables may be different, or the role of cultural and social factors may be more pronounced.

This study was conducted with a limited sample size in a single city. Additionally, the use of questionnaires in data collection can be perceived as another limitation of the current study. In addition, there are different understandings of spirituality in various cultures, countries, and religious beliefs, which can be considered a limitation of this study. Cross-cultural and interfaith research can illuminate the relationship between spirituality and caregiving burden. It is recommended that the relationship between these two variables be clarified by conducting studies to explain the mechanism of spirituality's influence in caregiving. Interventional studies on spirituality in this field can also further explain this relationship.

Conclusion

This study showed that care dependency and existential well-being were significantly associated with caregiver burden. Therefore, it is recommended that caregivers of stroke patients include spiritual practices in their care plan to reduce their burden. Providing spiritual care and teaching self-care techniques may help improve the burden caused by caregiving stimuli. Special attention should also be paid to caregivers of patients who have a greater functional dependency. Future research can investigate the mechanisms of spiritual influence in reducing the

caregiving burden of stroke patients to design spiritual interventions and self-care practices.

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Conflicts of interest

Nothing to declare.

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