

Research Paper

The Relationship Between Spiritual Well-Being and Care Burden in Unofficial Caregivers of Elderly Patients With Dementia



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ABSTRACT

Objectives Dementia is a common disease in the elderly and imposes a heavy care burden on family members. Many factors can be associated with care burden. One of these factors can be the caregivers' Spiritual Well-Being (SWB). This study aimed to examine the relationship between SWB and care burden in caregivers of dementia patients.

Methods This correlational study was conducted on 60 caregivers (75% female and 25% male with a mean age of 47 years) of patients with dementia referred to Rasoul-e-Akram Hospital and Brain & Cognitive Clinics in Tehran, Iran in 2019. Samples were selected using purposive and convenience sampling methods. The caregivers were evaluated by using the Caregiver Burden Questionnaire and SWB Scale and a socio-demographic checklist. Data were analyzed by using Pearson's correlation coefficient and multiple linear regression analysis in SPSS software at the significance level of $P < 0.05$.

Results About 16.7% of caregivers had little care burden, 35% had moderate to severe burden, 25% moderate burden and 23.3% severe burden. Moreover, 1.7% had poor SWB, 66.7% moderate SWB and 31.7% high SWB. The care burden had a negative and non-significant relationship with religious dimension of SWB ($r = -0.089$, $P = 0.505$), and a negative and significant relationship with existential dimension of SWB ($r = -0.283$, $P = 0.032$). Linear regression model revealed that existential dimension had a relationship with care burden ($\beta = -0.298$, $P = 0.023$) and explained 9% of variation in care burden.

Conclusion SWB plays an important role in improving the overall health of caregivers. In addition to being one of determinant of care burden, it acts as a factor in enhancing other aspects of health. Overall, caregiving is a stressful job; being aware of positive topics such as spirituality helps therapists provide strategies for caregivers to reduce their stress and care burden.

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Extended Abstract

1. Introduction

Dementia is a chronic illness with different signs and symptoms such as memory impairment, language impairment, psychological changes, and behavioral disorders [1]. Cognitive impairment, increased behavioral and emotional problems and daily living activities impose a considerable care burden on individuals and society [2]. This disease is a global challenge that directly affects 47.5 million people worldwide and affects 7.7 million people each year. In most parts of the world, the prevalence of dementia in people over 60 years is 5-7% [3]. In Iran, a study in five provinces reported the prevalence of dementia as 7.7% [4]. Its prevalence is also high in old patients admitted to hospitals, about 12.9-63% [5, 6]. Given the high prevalence of this disease among the elderly, the different needs of these patients as well as its high medical costs and care burden is a challenge to health care systems [1, 7]. Family and spouses of the elderly people play an important role in improving the care of patients with dementia. Most of these caregivers play their role full time and give themselves little time. Sleep disorders, the caregiver's poor physical health, low life satisfaction, and high depression and anxiety are some of the consequences that result from high care burden for these individuals [2, 8].

Systematic reviews of the care burden among people with dementia have shown that the behavioral problems and psychological symptoms of dementia are the most important factors related to the care burden. Demographic and psychological factors of the caregiver are also another factors affecting care burden [9]. Spiritual Well-Being (SWB) is one of the psychological factors that can play an important role in reducing the care burden of caregivers. According to the World Health Organization, health is a concept with physical, social, psychological and spiritual dimensions [10]. Among these dimensions, SWB is a concept that is less understood and is more challenging. Religious beliefs

act as a shield against stress, depression, delinquency, and other health-damaging factors [11]. Numerous studies have been conducted on the relationship between SWB as a protective factor in reducing the care burden for various diseases [12, 13]. The purpose of this study was to investigate the relationship between SWB and care burden in elderly people with dementia.

2. Method

This correlational study was conducted on 60 caregivers of dementia patients referred to Rasoul-e-Akram Hospital and brain and cognition clinics in Tehran, Iran in 2018. Samples were selected by purposive sampling method. The inclusion criteria for the caregivers were: caring for patients with diagnosed disease by specialists, caregiving for at least 20 hours per week, being a relative of the patient, and having at least elementary primary education to complete the questionnaire. In addition to a form for recording demographic and contextual characteristics of patients (age, gender, education, marital status, financial status, length of caregiving, disease duration), two valid and reliable questionnaires were used including Caregiver Burden Questionnaire and SWB Scale.

3. Results

About 16.7% of caregivers had little care burden, 35% moderate to severe burden, 25% moderate burden and 23.3% severe burden. Moreover, 1.7% of caregivers had poor SWB, 66.7% moderate SWB and 31.7% high SWB. According to the results of multiple linear regression analysis, among the entered variables (some demographic factors as covariate variables and two SWB dimensions of religious and existential well-beings), only the existential well-being remained in the model ($\beta=-0.298$, $P=0.023$) which accounted for about 9% of changes in care burden (Table 1).

Table 1. Distribution of spiritual health variables in caregivers

Total Score/ Dimension	Mean (Standard deviation)
Existential Dimension	(52/10) 25/47
Religious Dimension	(33/10) 18/43
Spiritual health (Total Score)	(05/19) 53/90
Total Caregiver's burden Score	(62/21) 11/46

4. Discussion

The present study showed a significant relationship between the SWB dimension of existential well-being and care burden in spite of controlling other confounding variables. SWB has been reported as one of the psychological factors affecting the care burden. Although other studies have also reported a significant relationship between the care burden and other health dimensions. SWB as the most important health dimension, has an important role in improving the overall health of caregivers. Existential dimension of SWB, in addition to being one of determinant of care burden, acts as a factor in enhancing other aspects of health. Overall, caregiving is a stressful experience; being aware of positive topics such as spirituality, helps therapists provide strategies for caregivers to reduce stress and care burden.

Ethical Considerations

Compliance with ethical guidelines

The study obtained its ethical approval from by the Research Ethics Committee of Iran University of Medical Sciences (Code: IR.IUMS.FMD.REC.1397.16). Informed consent was obtained from all the participants. they were free to leave the study whenever they wished, they were also assured about the confidentiality of their information.

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Authors contributions

Conceptualization: Behnam Shariati; Data collection, data analysis, initial draft preparation: Mahdiyeh Salehi; Discussion: Dr Ruohollah Seddigh; Editing and Review: Vahid Rashedi; Leila Kamalzadeh, Mostafa Almasi-Dooghaee.

Conflicts of interest

The authors declared no conflict of interest.