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ORIGINAL PAPER

Caregiver Burden and Spiritual Well-being in Caregivers of Hemodialysis Patients

Foozieh Rafati[1] · Fatemeh Mashayekhi[2] · Neda Dastyar[3]

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Abstract

The number of hemodialysis patients is increasing worldwide, and the caregivers of these patients experience a great burden. This study was conducted to examine the relationship between caregiver burden and spiritual well-being in caregivers of hemodialysis patients in Kerman, Iran. This correlational study was conducted on 382 caregivers of hemodialysis patients. Data were collected using the Caregiver Burden Inventory (24 items) and Ellison and Paloutzian 20-Item Spiritual Well-being Questionnaire. Data were analyzed by descriptive and inferential statistics (*t* test, ANOVA, Spearman correlation, and linear regression analysis) in SPSS 20 software. The findings showed that 45 (11.8%) caregivers had mild, 214 (56%) moderate, and 123 (32.2%) high caregiver burden. Furthermore, 1 (0.3%) caregiver had mild, 349 (92.4%) moderate, and 32 (8.4%) high spiritual well-being. Also, Spearman correlation test showed a significant reveres relationship between caregiver burden and spiritual well-being scores ($p < 0.001$, $r = -0.41$). Moreover, the results of the regression analysis showed that the patient's income, frequency of patient dialysis per week, and patient's need to receive care and spiritual well-being were predictors of caregiver burden, which explained 41% of the burden in caregivers. The results of this study revealed that spiritual well-being was negatively related to caregiver burden and was one of its predictors. Therefore, spirituality can be used as a low-cost and effective intervention to reduce the caregiver's burden.

Keywords Hemodialysis · End-stage renal disease · ESRD · Caregiver · Burden · Spirituality · Religion

✉ Neda Dastyar
dr.neda@yahoo.com

Extended author information available on the last page of the article

Introduction

The prevalence and incidence of chronic renal failure (CRF), a progressive and irreversible impairment of renal function, are increasing worldwide, and its most common treatment is hemodialysis (Esmaili et al. 2016). In Iran, the incidence of CRF has been reported to be 253 per 1 million people (Mahdavi-Mazdeh 2012).

CRF has a negative impact on the psychological and economic dimensions of the patients and their families' life (Ibrahim et al. 2013). Because dialysis, as the most common treatment for CRF, has been defined as a family disease, often, one of the patient's family members acts as a caregiver (Alvarez-Ude et al. 2004).

A caregiver is a person who cares for the patient closely and helps him/her to manage and cope with the illness during the treatment (Gayomali et al. 2008). Living with a patient who is treated with dialysis causes a burden in caregivers (Msc and Babatsikou 2014). The concept of "caregiver burden" refers to the impact of caregiving on caregivers (Alnazly and Samara 2014). This concept refers to a dynamic and multidimensional reaction that results from an imbalance of care demands and resources and induces overload in one or more of four components: physical, psychological, social, and financial issues (Chou 2000).

Many studies have surveyed caregiver burden in dialysis patient's caregivers, and some of them have reported a high level of burden in these people (Avşar et al. 2015; Cantekin et al. 2016; Washio et al. 2012). Some studies found a correlation between caregiver burden and depression, anxiety (Avşar et al. 2015; Rioux et al. 2012; Washio et al. 2012), low quality of life, and low quality of sleep (Belasco et al. 2006). Also, other studies have shown that providing care to patients with hemodialysis causes physical injury, stress, anxiety, depression, and lack of time to take care of oneself (Alnazly and Samara 2014; Rodrigues de Lima et al. 2017; Williams 2017).

Spirituality gives meaning to life and in crisis and stress it allows us to find comfort. It is believed that without spiritual health, other dimensions of human life will not achieve their maximum performance(Mohammadi and Babaee 2011; Rahimi et al. 2013). "According to the National Interfaith Coalition on Aging (1971) spirituality well-being (SWB) defined as the affirmation of life in a relationship with God, self, community and, environment that nurtures and celebrates wholeness". Based on this definition, SWB includes both religious and existential dimensions (Ellison 1983). Some studies have found that spirituality and religious beliefs decrease distress in caregivers (Hosseini et al. 2016; Koenig 2015) and can be used as coping strategies in dealing with stressful events (Chafjiri et al. 2017). A previous study revealed that spirituality was related to better psychological coping and well-being in Korean caregivers of patients with chronic diseases (Kim, Reed, Hayward, Kang and Koenig 2011). Also, spirituality attitude was related to lower burden in caregivers of older patients with stroke in Iran (Chafjiri et al. 2017). Despite this evidence, no study has been conducted on the relationship between spirituality and caregiver burden in Iranian caregivers of hemodialysis patients and limited research was done in this area in other countries.

Iran is a religious country, and religious beliefs are important for 73% of Iranian people ("Importance of religion by country, https://en.wikipedia.org/wiki/Importance_of_religion_by_country"). In Iran, the dominant religion is Islam. There is no distinction between religion and spirituality in Islam, and religion thoughts and practices are integrated with spirituality in this religion (Cheraghi et al. 2005). Therefore, gathering information on the relationship between religion and spirituality with other dimensions of life can be helpful for any intervention in this country.

On the other hand, nursing has a holistic view, and one of the tasks of nurses is helping families to use their ability to cope with potential and actual problems (Modanloo et al. 2015). Any intervention for the family's health is beneficial to family members as well as the patient (Oliveira et al. 2011). In this regard, studying the factors affecting caregivers' burden can be helpful for nurses and policymakers to any educational and interventional program planning. Therefore, this study was conducted to determine the relationship between spiritual well-being and caregiver burden in caregivers of hemodialysis patients in Iran.

Methods

This correlational study was conducted on 382 caregivers of patients with hemodialysis. Data were collected from 6 dialysis units in cities of Kerman (2 units), Jiroft, Rafsanjan, Sirjan, Kahnooj in Kerman Province, Iran, which were selected randomly. A census method was used for sampling. Inclusion criteria for the patients were receiving hemodialysis treatment for more than 3 months and needing a caregiver. Also, inclusion criteria for the caregivers were as follows: being the main caregiver; having no known psychiatric disorders; not being a health care personnel; ability to understand the questions, read, and write; and consent to participate in the study.

Instruments

Data were collected through the following questionnaires:

1. A demographic questionnaire
2. Ellison and Paloutzian 20-Item Spiritual Well-being Questionnaire. Ten questions measured religious health and 10 questions measured existential health. Each item was scored from 1 completely agree) to 6 (completely disagree). Also, items 1, 2, 5, 6, 9, 12, 13, 16, and 18 were scored adversely. The spiritual well-being scores were divided into 3 categories: low (20–40), moderate (41–99), and high (120–110). In the early version, construct validity of the instrument was measured using exploratory Factor analysis. The test–retest reliability coefficient obtained was 0.93, and coefficient of Cronbach's alpha revealed good internal consistency (0.89) (Ellison 1983). The reliability and validity of the questionnaire were con-

firmed in a study in Iran (Soleimani et al. 2017). In this study, Cronbach's alpha coefficient was 0.84.

3. Caregiver Burden Inventory (CBI), developed by Novak and Guest. It consists of 24 items and 5 subscales, including time dependence (items 1–5), developmental burden (items 6–10), physical burden (items 11–14), social burden (items 15–19), and emotional burden (items 20–24). These factors explain 66% total variance of the instrument. Internal consistency (Cronbach's alpha coefficient) of factors was from 0.73 to 0.86. All items were scored based on a 5-point Likert scale (never = 1, almost always = 5), with higher scores representing more burden. Scores between 24 and 39, 40–71, and 72–120 are classified as a low, moderate, and severe burden, respectively (Novak and Guest 1989). The validity and reliability of this scale have been confirmed by Farahani et al. in Iran (Ashghali Farahani et al. 2016) via content validity and internal consistency (Cronbach's alpha = 0.92).

After receiving the approval of the ethics committee of the university and obtaining the permission of the hospitals authorities, the researcher referred to dialysis units and informed the participants about the study objectives, confidentiality of the data, and the right to receive the research results. After obtaining the written informed consent, the researcher asked the patients to fill out the questionnaires in a private room at the dialysis unit.

Statistical Analysis

Data were analyzed by descriptive and inferential statistics using SPSS software version 18. The Kolmogorov–Smirnov test was used to assess normality for continuous data. An independent *t* test was used to determine the relationship between the burden of caregivers with dichotomous nominal scale characteristics, including patients' and caregivers' marital status, gender, and health insurance. ANOVA and Dunnett's post hoc test were used to determine the relationship between caregiving burden of caregivers with nominal scale characteristics with more than three categories, including patients' education level, occupation, income, ability to perform daily living activities, the frequency of dialysis, and duration of dialysis; and caregivers' income, educational level, occupation status, and relationship with the patient. Spearman correlation was used to determine the relationship between caregiving burden and patients' and caregivers' age and caregivers' spiritual well-being. Because of total score of caregiver burden as the dependent variable was a quantitative continuous variable with normal distribution, multiple linear regression analysis was conducted to investigate the predictors of total score of caregiver burden. Firstly, we used a simple linear regression analysis to identify variables that have a linear relation with caregiver burden. In the second step, significant explanatory variables in the previous step were used to predict the value of the dependent variable using multiple linear regression analysis. Variables with a $p < 0.2$ were entered into the regression model. In the other words the independent variables (patient 's sex, education, employment, income, ability to perform daily living activities, frequency

of dialysis per a week, need to receive care, history of kidney transplantation and having insurance; and caregivers' age, education, employment, and income) were regressed upon caregiver burden. Dummy coding was used to prepare binary categorical variables for entry into the regression model. Collinearity between predictors was assessed by variance inflation factors and tolerance index. The significance level was set at $p < 0.05$.

Ethical Consideration

The study was approved by the research ethical committee of Jiroft University of Medical Sciences and coded as IR.JMU.REC.1398.004. Participants were informed about the confidentiality and anonymity of the data, and voluntary participation in the study. Written informed consent was obtained from all participants.

Results

The mean age was 57.4 ± 16.9 and 42.9 ± 13.9 years in patients and caregivers, respectively. 44 (11.5%) of patients and 70 (18.32%) of caregivers were single. Other patient demographics data are presented in Table 1. Caregiver demographics data are presented in Table 2.

Kolmogorov–Smirnov test results showed a normal distribution of caregiver burden scores. Also, 1 (0.26%) of the caregivers had mild, 349 (91.4%) moderate, and 32 (8.37%) high spiritual well-being. The majority of the participants had moderate spiritual health. Furthermore, 45 (11.8%) of the caregivers had mild, 214 (56%) moderate, and 123 (32.2%) high caregiver burden. Almost half of the patients had a moderate caregiver burden.

Table 1 demonstrates the relationship between patients' demographic variables and their caregivers' burden. The caregiver burden significantly differed based on the patients' education level. The burden in caregivers of illiterate or elementary level patients was higher than the burden in caregivers of patients with high school/diploma (0.029) and university degree ($p = 0.017$) education level.

A statistically significant relationship was found between the caregiving burden and patient employment status. It was found that this difference was between the mean burden scores of caregivers of employed patients with those of caregivers of unemployed patients ($p < 0.001$) and those of caregivers of housewife patients ($p = 0.001$). The caregiver burden in caregivers of the employed patients was significantly less than the other two groups.

There was a significant relationship between caregivers' caring burden with patients' income ($p < 0.001$), which means that the higher the patient income, the lower the caregiver burden.

Data revealed a significant relationship between the mean score of caregivers with the patients' ability to perform daily activities ($p < 0.001$), which indicates the lower the ability to perform personal activities, the higher the caring burden

Table 1 The relationship between caregiving burden with patient demographic variables

Variables	N (%)	Mean of caregiving burden (SD)	*p* value
Education level			
Illiterate or elementary education	307 (80.4)	62.59 (17.44)	0.001<
Secondary school–diploma	52 (13.6)	57.96 (18.86)	
University	23 (6)	52.56 (17.22)	
Occupation			
Employed	65 (17.01)	52.38 (18.16)	
Unemployed	189 (49.47)	64.77 (17.76)	
Housewives	128 (33.50)	62.77 (17.33)	
Patients' income			
< 1 million tomans per month	265 (69.37)	64.67 (17.92)	0.001<
1–1.5 million tomans per month	74 (19.37)	57.81 (17.09)	
1.5–2 million tomans per month	26 (6.80)	55.30 (18.99)	
< 2 million tomans per month	17 (4.45)	48.70 (14.94)	
Ability to do the personal activity			
Very much	19 (4.97)	47.68 (14.23)	0.001<
Much	79 (20.68)	53.10 (17.01)	
Low	175 (45.81)	64.66 (17.61)	
Very low	109 (28.53)	66.66 (17.26)	
Frequency of patient dialysis per week			
Only once a week	3 (0.78)	32.33 (7.63)	0.006
Twice a week	36 (9.42)	56.36 (15.56)	
Three times a week	340 (89)	62.87 (18.23)	
Four times a week	3 (0.78)	60 (20.42)	
Patient's need to receive care			
Very low	49 (12.8)	44.61 (12.61)	0.001<
Low	125 (37.7)	54.47 (14.82)	
High	111 (29.1)	69.80 (15.98)	
Very high	97 (25.4)	71.54 (16.35)	
History of kidney transplantation in patients			
Yes	35 (9.16)	55.51 (16.74)	0.027
No	347 (90.84)	62.65 (18.23)	
Gender			
Male	200 (52.4)	60.8 (18.85)	0.178
Female	182 (47.6)	63.31 (17.40)	
Marital status			
Single	44 (11.5)	63.63 (20.09)	0.54
Married	337 (88.5)	61.86 (17.92)	
Duration of dialysis			
< = 5 years	291 (76.17)	62.15 (18.29)	0.407
5–10 years	78 (20.41)	62.52 (17.89)	
> 10 years	13 (3.40)	55.38 (17.83)	

Table 1 (continued)

Variables	N (%)	Mean of caregiving burden (SD)	*p* value
Having insurance			
Yes	361 (94.50)	61.63 (18.31)	0.11
No	21 (5.50)	68.14 (15.03)	

Table 2 The relationship between caregivers' caregiving burden and their demographic variables

Variables	N (%)	Mean of caregiving burden (SD)	*p* value
Education			
Lower than diploma	197 (51.6)	65.39 (17.44)	0.001 <
Diploma and higher diploma	185 (58.38)	58.53 (18.32)	
Occupation			
Employed	100 (26.17)	56.39 (18.28)	0.001 <
Unemployed	92 (24.08)	68.31 (17.94)	
Housewives	183 (47.90)	62.32 (17.26)	
Student	7 (1.83)	50.57 (17.12)	
Caregivers' income			
< 1 million tomans per month	286 (74.86)	63.14 (17.94)	0.135
1–1.5 million toman per month	51 (13.35)	60.35 (19.25)	
1.5–2 million tomans per month	30 (7.85)	56.33 (17.95)	
< 2 million toman per month	15 (3.92)	57/06 (18.27)	
Marital status			
Single	70 (18.32)	63.52 (17.84)	0.43
Married	312 (81.67)	61.65 (18.28)	
Family relationship with the patient			
Son-in-law or daughter-in-law	28 (7.3)	61.5 (13.4)	0.98
Children, sisters or brothers	179 (46.9)	61.5 (19.8)	
Parents	33 (8.6)	62.8 (19.1)	
Spouse	142 (37.2)	62.4 (17.8)	

in caregivers. With post hoc test, these differences were significant between the subcategory of "too much" with the "low"($p < 0.001$) and "very low"($p < 0.001$).

A significant difference was observed between the means scores of caregiver burden in the frequency of patient dialysis per week ($p = 0.006$). Caregiving burden in the subcategory of "only once a week" was significantly lower than the subcategory of "twice a week" ($p = 0.048$).

Data showed a significant relationship between patient's need to receive care and caregiver burden. As the patient needed more care, the caregiver's burden increased. In the post hoc test results, only the difference between "high" and

Table 3 The correlation between caregiver burden with spiritual well-being and caregiver age

Variables	Spiritual well-being	Religious health	Existential health	Caregiver age
Caregiver burden	−0.416	0.352	0.399	0.123
	$p<$ 0.0001	$p<0.0001$	$p<0.0001$	$p=0.016$

Table 4 Linear regression analysis of factors predicting caregiver burden

Model	Unstandardized coefficients		Standardized coefficients	t	p value
	B	Std. error	Beta		
Constant	92.43	7.67		12.051	0.001<
Patient income	−1.904	0.918	−0.085	−2.074	0.039
Frequency of dialysis	6.633	2.039	0.1283	0.253	0.001
Patient need to caring	8.583	0.731	0.469	11.734	0.001<
Spiritual well-being	−0.464	0.056	−0.334	−8.250	0.001<

$R=0.647$. Adjusted $R^2=0.412$

"very high" was not significant ($p=0.96$), and caregiver burden in other subcategories was significantly different ($p<0.001$).

A significant difference was also seen between the mean scores of caregiver burden and kidney transplantation history of patients. The caregivers' burden means the score was higher in caregivers who their patient did not have a kidney transplant history ($p=0.027$).

Other patients' demographics (gender, age, marital status, duration of dialysis, and having insurance) variables did not have any significant relationship with caregiver burden.

The demographic parameters of the caregivers found to have an association with caregiver burden were educational level and employment status. Caregivers with lower than diploma education level had a higher burden than caregivers with the diploma and higher diploma. Also, post hoc test revealed that unemployed caregivers had burden score higher than employed ($p<0.001$) and housewife caregivers ($p=0.049$); however, there was no significant relationship between caregiver burden and caregiver's family relationship with the patient, caregiver's income, and marital status (Table 2).

The results of the Spearman correlation coefficient showed a significant inverse relationship between caregiver burden scores and spiritual well-being scores ($p<0.001$, $r=-0.41$). A positive significant relationship revealed between caregiver burden and caregiver age (Table 3).

The result of the regression analysis is presented in Table 4. Patient income, frequency of dialysis, patient's need to receive care, and spiritual well-being were significant predictors of the burden of caregivers, which explained 41% of the caregiver burden score.

Discussion

In this study, the number of the caregivers that had a high burden was similar to the finding of a study in Turkey (Cantekin et al. 2016), but was higher than what is reported in Nepal (Shakya et al. 2017). This different result may be due to differences in the instrument or the study setting.

The result of this study revealed that caregiver burden decreased with increasing patient education. This finding is in the line of Mollaei et al. study on the caregivers of cancer patients (Mollaei et al. 2019). Perhaps more literate patients have more self-care and this reduces the burden on caregivers.

Also, caregivers of the employed patient had a lower burden. This finding is not unexpected because employed patients have greater financial independence and this reduces the financial burden on caregivers.

According to linear regression analysis, patient income, frequency of dialysis, patient's need to receive care, and spiritual well-being were predictors of caregiver burden.

Caring for a hemodialysis patient interrupts the caregivers' social, personal, and financial life (Williams 2017). In Iranian culture, it is expected that the family provides financial support for the patient, and if the patient has a low income, the caregiver must pay more for patient care, and this will impose a greater burden on the caregiver. Thus, to provide suitable care for hemodialysis patients, it is recommended to develop and offer caregiver financial support strategies.

In the present study, a significant relationship was observed between caregiver burden and dialysis frequency in patients. Thus, caregivers of those patients who were dialyzed once a week had less burden than others. This may be because the renal failure of patients who undergo dialysis once a week is not very progressive, and these patients have higher levels of health and well-being and less need to receive care.

In this study, patients' need to receive care was another predictor of caregivers' burden, which is consistent with the previous studies that have shown that as patients' level of functional ability deteriorated, caregiver burden increased (Griva et al. 2016; Washio et al. 2012).

Also, caregivers of patients with kidney transplantation history had a lower burden. In Iran, all patients who need renal replacement therapy are classified as 'patients with special diseases' and are provided governmental medical insurance (Mahdavi-Mazdeh 2012). But accessing to kidney transplant centers and payment to the kidney donor needs to sufficient financial resources. The demand for kidneys is more than the free donation kidneys of brain death patients. For this reason, patients with a history of kidney transplantation are expected to have a better socioeconomic status.

The present study revealed that spiritual well-being was reversely correlated with caregiver burden, which is in line with the result of the study conducted by Chafjiri et al. in Iran on caregivers of older patients with stroke (Chafjiri et al. 2017). Two studies in the USA showed that one of the sources and coping strategies of hemodialysis caregivers was their spiritually and faith (Welch et al. 2014; Williams 2017).

Also, other studies in the USA and Pittsburg University showed that religion plays an important role in reducing the burden of caregivers of the elderly (Heo 2009; Herrera et al. 2009). Rabiei et al. conducted a qualitative study in Iran and found that in the culture of Iran, finding satisfaction and peace with faith in God was a strong facilitator for the ability to care for hemodialysis patients (Rabiei et al. 2016). A Q-methodology study in Korea showed that spirituality and religion were the coping strategies in caregivers of patients undergoing hemodialysis (Yeun et al. 2016). Also, an experimental study on caregivers of Alzheimer patients in Iran revealed that group spiritual therapy can reduce the caregivers' strain (Mahdavi et al. 2017). The results of this study add to previous knowledge about the positive impact of spirituality on reducing the caregivers' burden.

Spirituality is a human dimension that can help manage crisis and stress, gives meaning to life, and helps confront problems (Mohammadi and Babaee 2011; Rahimi et al. 2013; Seyed hamid et al. 2017). Spirituality can cause calm, high tolerance, patience, and hope (Shahrbabaki et al. 2017). Also, it is related to religion, culture, and social status. In the Iranian context, spirituality, religion, and culture are integrated (Mahdavi et al. 2017). Religion plays an important role in the life of Iranians, especially in critical situations.

In fact, in the case of chronic illnesses, families face a major challenge. Therefore, introducing strategies to promote spirituality, such as spiritual self-care, can reduce the burden of caregivers. Nurses can provide spiritual support to hemodialysis caregivers by helping them find and use appropriate spiritual resources. This is an important step to provide holistic and cultural care for caregivers, because spiritual interventions are cost-effective and simple (Chafjiri et al. 2017).

Conclusion

This study revealed a lower burden in caregivers that their patients had a higher income. Also, the caregiver burden was related to the frequency of hemodialysis and the patient need to receiving care. The results showed that one's spiritual well-being has an important role in reducing the burden of caregivers of a hemodialysis patient. Presenting strategies that help improve their spirituality, such as spiritual self-care training, can help improve their burden caused by caregiving roles.

Limitations

The limitations of this study were data collection using questionnaires, cross-sectional design, and census sampling method. More studies should be conducted to explore the relationship between spirituality and caregiver burden in different cultures and religions. Also, to understand spirituality from the point of view of caregivers of hemodialysis patients, conducting qualitative studies is highly recommended. Also, interventional studies should be conducted to determine the effect of spirituality on caregiver burden.

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Affiliations

Foozieh Rafati[1] · Fatemeh Mashayekhi[2] · Neda Dastyar[3]

Foozieh Rafati
foozieh1384@yahoo.com

[1] School of Nursing and Midwifery, Jiroft University of Medical Sciences, Sabzevaran Square, PO Box: 7861763730, Jiroft, Iran

[2] Department of Nursing, Nursing and Midwifery School, Jiroft University of Medical Sciences, Sabzevaran Square, PO Box: 7861763730, Jiroft, Iran

[3] Department of Midwifery, Nursing and Midwifery School, Jiroft University of Medical Sciences, Sabzevaran Square, PO Box: 7861763730, Jiroft, Iran