



The Relationship Between Care Burden and Coping Strategies in Caregivers of Hemodialysis Patients in Kermanshah, Iran

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Lida Menati¹

Yousef Torabi ²

Bahare Andayeshgar ¹

Alireza Khatony ³

¹Clinical Research Development Center, Imam Reza Hospital, Kermanshah University of Medical Sciences, Kermanshah, Iran; ²Student Research Committee, Kermanshah University of Medical Sciences, Kermanshah, Iran; ³Infectious Diseases Research Center, Kermanshah University of Medical Sciences, Kermanshah, Iran

Objective: The purpose of this study was to investigate the relationship between care burden and coping strategies in caregivers of hemodialysis patients.

Methods: This cross-sectional survey was conducted from September to December 2018 in Kermanshah, Iran. A total of 130 caregivers of patients admitted to the hemodialysis wards of Imam Reza and Imam Khomeini hospitals of Kermanshah, Iran were selected via convenience sampling. Data-collection tools included a demographic information form, caregiver-burden inventory, and coping inventory for stressful situations. Data were analyzed using descriptive and analytical tests.

Results: The mean age of the caregivers was 35.8±13.7 years, and 71 (54.6%) were patients' children. The mean caregiver-burden score was 58.5±20.5 out of 96. Mean scores of time-dependent, evolutionary, physical, social, and emotion-dependent care burdens were 17.5±5.3, 12.2±6.3, 9.1±4.7, 8.2±4.0, and 11.4±5.1, respectively. Mean scores of problem-focused, emotion-focused, and avoidance-oriented coping strategies were 46.0±80.8, 43.1±9.0, and 48.9±9.5, respectively. Among the strategies, only the avoidance-oriented one had a significant positive relationship with total care burden and all its subscales.

Conclusion: Caregivers of hemodialysis patients experienced a relatively high care burden. However, they did not use appropriate coping strategies; therefore, they should be trained to select an effective coping strategy.

Keywords: avoidance-oriented coping strategy, burden, coping, family caregiver, hemodialysis

Introduction

Chronic kidney disease is a major and growing health concern worldwide.¹ Based on data published in 2016, there were an estimated that 750 million people suffering from chronic kidney disease worldwide, about 3 million of whom were on dialysis.² Hemodialysis reduces patients' energy levels and affects their ability to work and perform daily activities, resulting in the disruption of patients' and caregivers' daily routines.³ Chronic disorders and their associated psychological and financial complications in a family member can affect the entire family.⁴ Caregivers of hemodialysis patients are often family members or friends of patients, providing physical, mental, and social support.^{5,6} It is known that caregivers of hemodialysis patients experience a high level of care burden.^{7,8}

Care burden is an uncomfortable experience for caregivers of patients, involving financial, social, psychological, and physical dimensions.⁹ It has been shown that

Correspondence: Alireza Khatony
Clinical Research Development Center,
Imam Reza Hospital, Kermanshah, Iran
Tel/Fax +98 38 279 394
Email Akhatony@gmail.com

some caregivers of hemodialysis patients are under a great care burden.^{9,10} Acceptance of the caregiver role and its associated changes, besides its positive effects on the patient and his/her family, can cause several negative consequences, such as reduced physical and mental health and worsened social relationships among caregivers. It can also cause a wide range of physical, emotional, and psychological problems for caregivers, exposing them to a variety of physical and psychological hazards.¹¹

Family disruption, inadequate patient care, and ultimately lack of attention to the patient are other negative consequences of care burden.¹²⁻¹⁴ Care burden can also have devastating effects on caregivers and expose them to various diseases. The burden experienced by caregivers can lead to serious diseases,⁸ which are often overlooked.¹⁵ People usually use coping strategies in the face of stressful situations to reduce or manage them.¹⁰ Coping strategies generally include problem-focused, emotion-focused, and avoidance-oriented coping strategies.^{16,17}

Problem-focused coping refers to deliberate efforts to solve a problem, reorganize the problem, or change the situation. Emotion-focused coping refers to emotional responses aimed at reducing stress, rather than rational problem-solving. On the other hand, avoidance-oriented coping is a set of behaviors to avoid a stressful situation by ignoring the problem or turning to the community as a means to relieve the stress.^{18,19} Among these coping strategies, the problem-focused strategy has a positive relationship with mental health. There is also an inverse relationship between mental health and emotion-focused coping.²⁰

In this regard, Abbasi et al suggested that use of emotion-focused coping strategies by caregivers increases their care burden.²¹ Moreover, Myaskovsky et al indicated that caregivers who used emotion-focused coping strategies had a low quality of life.²² According to Abbasi et al, which was based on a study by Ardashirzade et al, there was a direct relationship between high care burden and use of emotion-focused coping strategies.²¹

The present study was designed and conducted considering the importance of maintaining and improving the physical and mental health of hemodialysis patients' caregivers and lack of knowledge about the care burden and coping strategies of these caregivers. The aim of this study was to determine the relationship between coping strategies and care burden among caregivers of hemodialysis patients. We aimed to answer the following questions:

- What is the level of care burden in caregivers of hemodialysis patients?
- What are the most common coping strategies used by caregivers of hemodialysis patients?
- What kind of relationship is there between care burden and coping strategies in caregivers of hemodialysis patients?

Methods

Study Design

This cross-sectional study was conducted from September to December 2018 in Kermanshah, Iran.

Sample and Sampling Method

The study population included all caregivers of patients admitted to the hemodialysis wards of Imam Reza and Imam Khomeini hospitals. Sample size was estimated at 130, based on Jafari et al,⁹ who reported the proportion of caregivers under a care burden to be 0.374. Using the sample-size formula $n = Z^2 pq / d^2$, the study had 95% confidence and error of $0.222 \times P$. P represented the sample proportion, and was measured to be 0.387. Inclusion criteria were consent to participate in the study, ability to read and write, and direct responsibility for care of the patient. Convenience sampling was applied in this study.

Instrument

Data-collection tools comprised a personal information form, Caregiver Burden Inventory (CBI),²³ and Coping Inventory for Stressful Situations (CISS).²⁴ The personal information form for caregivers included six questions on age, sex, marital status, education, occupation, and relationship with the patient. Moreover, it included seven questions on age, sex, marital status, education, place of residence, occupation, and time on dialysis.

The CBI was designed by Novak and Guest in 1989,²³ and its internal consistency was investigated by McCleery et al using Cronbach's α (0.8).²⁵ The Persian version of the CBI has been also validated in Iran by Abbasi et al, who reported a Cronbach's α of 0.9.³ The CBI is a five-item scale with five subscale: time dependence (amount of time a caregiver spends daily on patient care), developmental (pressure during various stages of a caregiver's life, such as puberty, due to caring for the patient), physical (physical strain and exhaustion experienced by the caregiver during patient care), social (burden of care that affects the social aspects of the caregiver's life during patient

care), and emotional (caregiving pressure that affects the caregiver's emotions and feelings) care burdens. CBI items are scored on a five-point Likert scale: 0 = never, 1 = rarely, 2 = occasionally, 3 = frequently, and 4 = almost always. The total score ranges from 0 to 96, with scores >36 indicating a high care burden.²³

The CISS was used to measure the frequency of coping strategies used by caregivers. This scale was designed by Andler and Parker to evaluate the types of coping strategies in stressful situations.²⁴ The reliability of the CISS was evaluated by Hurt et al using Cronbach's α and test-retest methods.²⁶ The Persian version of the CISS has also been psychometrically evaluated by Shokri et al, and its internal consistency has been investigated using Cronbach's α (0.75, 0.82, and 0.73 for problem-focused, emotion-focused, and avoidance strategies, respectively).²⁶

The CISS is a 48-item scale containing 16 questions on problem-focused, emotion-focused, and avoidance-oriented coping strategies. It is scored on a five-point Likert scale: 1 = never, 2 = sometimes, 3 = usually, 4 = most often, and 5 = always. Problem-focused, emotion-focused, and avoidance coping strategies are scored from 16 to 80. The individual's score represents the dominant coping strategy. In other words, each coping strategy with the highest score is used by the caregiver. Also, obtaining the same score for two strategies indicates the use of both strategies.²⁴

Data Gathering

After obtaining approval from the ethics committee of the university, we visited the hemodialysis wards of Imam Reza and Imam Khomeini hospitals. The research objectives were explained to the participants. They also received information on how to complete the questionnaires. Finally, those who met the inclusion criteria were included in the study. The time and place for completing the questionnaires were different for the caregivers and patients. Questionnaires were then presented to the participants and collected after they had been completed.

Data Analysis

Data were analyzed in SPSS 16.0 using descriptive and inferential statistics. First, the Kolmogorov-Smirnov test was used to examine the normal distribution of care burden and coping strategies. The results of this test indicated that these variables had no normal distribution. The Mann-Whitney U test was also used to investigate the relationship between care burden and two-dimensional qualitative variables. Moreover, Spearman's rank

correlation coefficient was measured to examine the correlation of care burden and its subscales with the type of coping strategy.

Ethical Considerations

The Ethics Committee of Kermanshah University approved this study. Written informed consent was obtained from all participants, and they were assured of the confidentiality of their information. Three of the caregivers were aged <18 years and were able to consent on their own behalf. Participants were informed about the study objectives, and their questions were answered.

Results

The mean age of the caregivers was 35.8±13.7 years. A total of 82 (63.1%) caregivers were female, 63 (48.5%) married, 42 (32.3%) housewives, and 65 (50%) had a university education. In sum, 71 (54.6%) caregivers were the patients' children. In terms of patients' personal information, the mean age of hemodialysis patients was 58.7±15.1 years. The results showed that 76 (58.1%) patients were female, 105 (81.0%) married, 62 (48.4%) housewives, and 52 (44.4%) had primary education. Also, 49 (43.8%) patients had a time on dialysis <20 months (Table 1).

Based on the findings, 111 (86%) caregivers were experiencing a relatively high care burden. The mean total score of care burden was 58.5±20.5 out of 96. There was no significant relationship between the total burden of care and individual characteristics of caregivers (age, sex, marital status, education, occupation, or relationship with patient; Table 2). The mean scores of time-dependent, evolutionary, physical, social, and emotion-dependent care burdens were 17.5±5.3, 12.2±6.3, 9.1±4.7, 8.2±4.0, and 11.4±5.1, respectively. Also, the mean scores of problem-focused, emotion-focused, and avoidance-oriented coping strategies were 46.0±80.8, 43.1±9.0, and 48.9±9.5, respectively. The most common coping strategy used by the caregivers was avoidance (Figure 1 and Table 3). Among the strategies, only avoidance had a significant positive relationship with total care burden and all its subscales (Table 4).

Discussion

The aim of this study was to determine the relationship between care burden and coping strategy in caregivers of hemodialysis patients. The total care burden was relatively high in the caregivers of hemodialysis patients, which is consistent with other studies on caregivers of hemodialysis patients.^{8,9,27,28} Overall, there is a higher level of care

Table 1 Demographic characteristics of hemodialysis patients and their caregivers

Patients		
Variables		n (valid %)
Sex	Male	54 (41.5)
	Female	76 (58.5)
Occupation	Employee	5 (3.9)
	Unemployed	10 (7.8)
	Housewife	62 (48.4)
	Student	4 (3.1)
	Retired	28 (22.0)
	Self-employed	21 (14.8)
Time on dialysis (months)	1–11	49 (44.0)
	12–20	14 (12.0)
	>20	49 (44.0)
Education	Elementary	52 (44.4)
	Intermediate	25 (21.4)
	Diploma	27 (23.1)
	University	13 (11.1)
Marital status	Married	105 (81.0)
	Single	25 (19.0)
Location	Urban	116 (89.9)
	Rural	13 (10.1)
Caregivers		
Variables		n (valid %)
Sex	Male	48 (36.9)
	Female	82 (63.1)
Occupation	Employee	18 (13.8)
	Unemployed	11 (8.5)
	Housewife	42 (32.4)
	Student	26 (20.0)
	Retired	8 (6.1)
	Self-Employed	25 (19.2)
Type of relationship with patient	Friend	2 (1.5)
	Spouse	23 (17.7)
	Child	71 (54.6)
	Parent	6 (4.6)
	Sibling	14 (10.8)
	Relative	14 (10.8)
Education	Elementary	11 (8.5)
	Intermediate	15 (11.5)
	Diploma	39 (30.0)
	University	65 (50.0)
Marital status	Single	67 (51.5)
	Married	63 (48.5)

burden in developing countries, such as Iran, compared to developed countries, since the level of physical and

Table 2 Relationship between demographic characteristics and total burden of care in caregivers of hemodialysis patients

Variables		Total burden of care		Test results
		<36 (%)	≥36 (%)	
Age (years)	<50	18 (16.4)	92 (83.6)	F_{exact} $P=0.128^a$
	≥50	0	17 (100)	
Sex	Male	5 (10.4)	43 (89.6)	$\chi^2=0.796$ $P=0.372^b$
	Female	13 (16.0)	68 (84.0)	
Marital status	Single	7 (11.3)	55 (88.7)	$\chi^2=0.705$ $P=0.401^b$
	Married	11 (16.4)	56 (83.6)	
Education	School	7 (10.9)	57 (89.1)	$\chi^2=1.034$ $P=0.309^b$
	University	11 (17.2)	53 (82.8)	
Occupation	Employed	16 (14.0)	98 (86.0)	$\chi^2=0.127$ $P=0.722^b$
	Unemployed	1 (10.0)	9 (90.0)	
Type of relationship with patient	Direct ^c	17 (13.4)	110 (86.6)	F_{exact} $P=0.261^a$
	Indirect ^d	1 (50.0)	1 (50.0)	
Total		18 (14)	111 (86)	—

Notes: ^aFisher's exact test; ^b χ^2 -test; ^cincluding parents, children, spouses, and relatives; ^dincluding friends.

spiritual support for caregivers is insufficient.²⁹ Moreover, in Eastern countries, such as Iran, the family is responsible for patient care due to the dominance of traditional culture; therefore, family members are exposed to care pressure.¹⁵

Caregivers of hemodialysis patients typically use different coping strategies, including problem-focused, emotion-focused, and avoidance-oriented coping strategies, to relieve their high care burden. Papastavrou et al showed that caregivers who experience a high level of care burden do not use problem-focused strategies.²⁹ It seems that caregivers who use avoidance-oriented and emotion-focused strategies have higher levels of care burden.³⁰ In this study, avoidance-oriented coping was the most common strategy used by the caregivers. This strategy is characterized by denial of problems and avoidance of stressful situations by ignoring the problem or turning to the community (or other individuals) for relieving stress.^{18,31}

There is limited information regarding the effectiveness of avoidance-oriented coping strategies.^{32,33} It has been suggested that a problem-focused strategy is appropriate for managing problems.⁴ In this regard, Abbasi et al showed that using problem-focused coping significantly reduced the perceived caregiver burden. Caregivers who used problem-

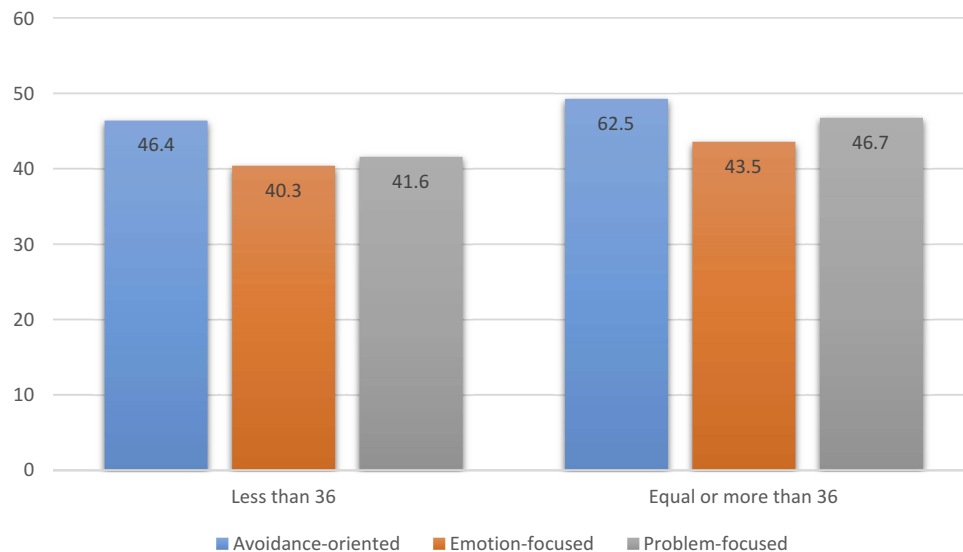


Figure 1 Comparison of coping strategies in caregivers of hemodialysis patients.

focused strategies also had less time-dependent care burden and less physical care stress.³ In addition, Ghane et al reported that the use of problem-focused coping reduced the care burden of hemodialysis patients' caregivers.⁴

Such factors as sociocultural characteristics of caregivers and level of perceived care burden by caregivers are associated with the type of selected coping strategy.^{3,9} These factors can account for the discrepancy among the

Table 3 Relationship between demographic characteristics and dimensions of care burden in caregivers of hemodialysis patients

Variables		Dimensions of burden of care, mean \pm SD				
		Time dependence	Evolutionary	Physical	Social	Emotional
Age (years)	<50	17.2 \pm 5.3	12.1 \pm 6.5	8.8 \pm 4.6	8.2 \pm 3.4	11.3 \pm 5.2
	\geq 50	19.5 \pm 5.2	11.9 \pm 4.4	10.3 \pm 5.6	8.2 \pm 4.0	11.3 \pm 5.2
	P-value	0.115	0.652	0.287	0.994	0.518
Sex	Male	18.7 \pm 4.9	13.7 \pm 7.5	9.7 \pm 4.9	9.2 \pm 5.1	11.6 \pm 5.1
	Female	16.8 \pm 5.4	11.2 \pm 5.3	8.7 \pm 4.6	7.6 \pm 3.0	11.1 \pm 5.1
	P-value	0.059	0.076	0.218	0.353	0.451
Marital status	Single	17.3 \pm 5.1	12.6 \pm 5.9	9.1 \pm 4.8	8.1 \pm 3.7	11.9 \pm 5.1
	Married	17.7 \pm 5.6	11.8 \pm 6.7	9.1 \pm 4.7	8.3 \pm 4.3	10.1 \pm 5.1
	P-value	0.572	0.306	0.975	0.903	0.330
Education	School	17.9 \pm 4.7	12.7 \pm 6.7	9.6 \pm 4.8	8.4 \pm 4.4	11.3 \pm 5.1
	University	17.3 \pm 5.8	11.7 \pm 5.9	8.6 \pm 4.6	8.0 \pm 3.5	11.4 \pm 5.0
	P-value	0.773	0.365	0.231	0.875	0.817
Occupation	Employed	17.6 \pm 5.3	12.1 \pm 6.4	9.1 \pm 4.7	8.3 \pm 4.1	11.4 \pm 5.1
	Unemployed	18.5 \pm 5.6	12.8 \pm 5.1	10.2 \pm 5.6	7.9 \pm 3.7	12.2 \pm 6.1
	P-value	0.467	0.508	0.625	0.699	0.699
Type of relationship with patient	Direct	17.6 \pm 5.2	12.2 \pm 6.3	9.1 \pm 4.7	8.2 \pm 4.1	11.5 \pm 5.1
	Indirect	9.5 \pm 6.4	9.5 \pm 6.4	7.0 \pm 4.2	11.1 \pm 1.4	7.5 \pm 3.5
	P-value	0.065	0.491	0.562	0.149	0.236
Total		17.5 \pm 5.3	12.2 \pm 6.3	9.1 \pm 4.7	8.2 \pm 4.0	11.4 \pm 5.1

Table 4 Correlations between dimensions of care burden and coping strategies in caregivers of hemodialysis patients

	Dimensions of Care Burden									
	Time dependence		Developmental		Physical		Social		Emotional	
Coping strategies	<i>r</i> ^a	<i>P</i> -value	<i>r</i>	<i>P</i> -value	<i>r</i>	<i>P</i> -value	<i>r</i>	<i>P</i> -value	<i>r</i>	<i>P</i> -value
Avoidance-oriented	0.26	0.003 ^b	0.40	<0.001 ^b	0.29	0.001 ^b	0.18	0.037 ^b	0.23	0.008 ^b
Emotion-focused	0.04	0.578	0.13	0.124	0.11	0.211	-0.04	0.651	0.02	0.752
Problem-focused	0.08	0.322	0.14	0.096	0.03	0.705	0.01	0.874	0.01	0.877

Notes: ^aSpearman's correlation coefficient; ^bcorrelation significant at the 0.01 level (two-tailed).

results of different studies. Generally, coping strategies need to be learned and trained. Since the most common coping strategy in the present study was avoidance-oriented, which is an inappropriate coping mechanism, it is necessary to establish training programs for caregivers of hemodialysis patients. On the other hand, given the effectiveness of the problem-focused strategy, it can be useful to teach this approach to caregivers of hemodialysis patients to reduce their care burden.

Chadda et al found a direct relationship between the emotion-focused coping strategy and total care burden and its subscales. In their study, caregivers who used emotion-focused coping strategies experienced more care burden.³³ Given the ineffectiveness of emotion-focused strategies, caregivers should be educated about the unintended consequences of this approach and encouraged to use the problem-based approach. Therefore, holding educational classes or preparing educational materials can be a useful solution. Overall, such factors as sociodemographic differences and different care demands of hemodialysis patients are probably affected by the interaction between care-burden variables and coping strategies.

In the present study, there was no significant relationship between total care burden and demographic variables of caregivers. However, Jafari et al reported a significant positive relationship between care burden and caregivers' age and education.⁹ In this regard, Bayoumi et al found a negative correlation between total care burden and age and education of caregivers.⁷ Differences in results reported by different studies can be attributed to differences in individual characteristics of study samples and sample size.

This study had some limitations. First, it was cross-sectional, which does not explain the cause-effect relationship between the studied variables. Second, the self-administered method of data collection could have affected the accuracy of the results. Third, the caregivers' psychological condition when completing the questionnaires might have affected

their responses to the questions, which was beyond the control of the researchers. Another limitation was the small sample and statistical power of the study, which could have influenced the results. Finally, the lack of a control group to evaluate coping strategies was another limitation, which should be considered in future studies. Evaluating and comparing the relationship between care burden and coping strategies in other geographical regions is also suggested.

Conclusion

Caregivers of hemodialysis patients experienced a relatively high level of care burden, and avoidance-oriented coping was the most common coping strategy. Among all types of coping strategies, only avoidance-oriented coping had a significant relationship with total care burden and its subscales. Based on these findings, economic, social, and psychological support should be provided by governmental and nongovernmental organizations to reduce the care burden of caregivers of hemodialysis patients. Caregivers should be also trained to select an effective coping strategy.

Data-Sharing Statement

Data are available by contacting the corresponding author.

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Disclosure

The authors declare that they do not have any conflicts of interest in this work.

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