

The Role of Caregiver Burden in Quality of Life and Perception of Patients with Chronic Kidney Failure on Hemodialysis

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Abstract

Background: Acute kidney failure is a common complication in critically ill patients of intensive care units.

Objectives: The objective of this study was to examine the role of caregiver burden on quality of life and perception of patients with kidney failure.

Methods: This descriptive-analytical study followed a correlational design. The statistical population included 191 patients with chronic kidney failure in the age range of 30 to 50 years old, who underwent hemodialysis at hospitals of Zahedan within 6 months, during year 2014. Overall, 54 patients were selected using the convenience sampling method. The measurement tools were the caregiver burden inventory (Novak and Guest, 1989), the quality of life scale (Rand, 1995), and the experience and perception of suffering scale (Schulz et al., 2010).

Results: The results were analyzed using Pearson correlation coefficient and regression analysis. The results of the current study indicated that caregiver burden was positively and significantly correlated with physical and mental dimensions of quality of life and it was significantly and negatively related to physical and mental dimensions of perception of suffering. In addition, the results of regression analysis revealed that caregiver burden predicted 0.05 of mental and physical quality of life, 0.07 of physical perception of suffering, and 0.05 of mental perception of suffering.

Conclusions: Therefore, development of community-based services, such as short-term hospitalizations, psychological and vocational rehabilitations, and follow-up treatments at home, which are among the main requirements of caregivers, need to be taken into consideration in national mental health programs.

Keywords: Caregiving, Quality of Life, Suffer, Chronic Kidney Failure, Hemodialysis

1. Background

Chronic kidney disease is considered as one of the major problems related to public health all around the world (1). In Iran, statistics have shown the dramatic growth of chronic kidney failure in the recent years (2). The need for hemodialysis has increased outstandingly. Chronic kidney diseases are among major public health issues worldwide (1). In the 2000 world health report, an important goal of health promotion programs was increasing lifespan, and placing greater emphasis on the mortality rate and disease symptoms. Having good feelings was considered as the primary objective of the world health organization in 2001 (3). Quality of life includes health, issues associated with lack of physical and mental health, and problems related to performance and participation in various aspects of life (4). Quality of life is closely related to diseases and conditions, which endanger people's physical and mental health (5).

The suffering and pain of patients undergoing hemodialysis effect various aspects of their lives, such

that suffering disrupts the levels of patients' daily activity and decreases their ability to perform daily activities (6). Suffering is an unpleasant feeling that ranges from a transient psychological, mental, and physical discomfort to deep sorrow and has various stages from malignant disappointment to apathy and indifference (considered as the final stage) (7).

Not only do chronic diseases interfere with patients' lives, they also effect the primary caregivers. Since caregivers of hemodialysis patients have to play a key role in supporting their dialysis patients, they may feel a heavy burden on their shoulders (8). These caregivers often spend a lot of time taking care of their patients and enduring considerable fatigue and caregiver burden (9).

Mehrer-Imhof et al. indicated that patients' quality of life depended on the quality of life of their family members, as their caregivers (10). Habibzade et al., in their study, revealed that 52% of caregivers had moderate and low quality of life and more that 60% of them were partly unsatisfied with the level of care they provided for them-

selves. Moreover, 85% of caregivers believed that social support was inadequate and 67.5% of them did not have any recreational activities in their lives (9). The results of several studies showed that disease progression in patients reduced physical well-being of their caregivers and this seriously affected patients' health and quality of life (11-13).

The results obtained from a study conducted by Shdaifat and Abdul Manaf indicated that the scores of caregivers and patients on quality of life were lower than those of the control group (14). The findings of Akosile et al. demonstrated that high levels of caregiver burden in caregivers of patients with stroke, dramatically affected patients' health and quality of life (15). Grant et al. found that caregiver burden was correlated with patients' quality of life, such that, over time, a decrease in the caregivers' quality of life resulted in a decrease in the patients' quality of life (16). The results of the study of Karakis et al. revealed that low levels of quality of life in patients with epilepsy was related to low levels of their caregivers' quality of life (17). In another study, Settineri et al. figured that caregivers, due to taking care of patients with chronic diseases, suffered from psychological, physical, and social pressures and as a result, they experienced burnout, anxiety, and depression (18).

In the same line, Abbasi et al. indicated that the levels of caregiver burden, in most cases (74.2%), were intense. Caregiver burden was significantly correlated with duration of the disease and significantly and negatively related to the ability to perform personal activities (19). Redinbaug et al. reported that caregivers' perception of patients' suffering was closely related to caregivers' psychological stress and the level of patients' physical inability (20). Schulz et al., in their study, found that caregivers' perception of suffering was correlated with patients' pain and suffering (21). The findings obtained from a study carried out by Oshodi et al. indicated that patients' caregivers suffered from high levels of psychological stress (22).

Aligned with other previous studies, Northouse et al. demonstrated a significant and positive relationship between perception of suffering and caregiver burden (23). The results of another study conducted by Alnazly and Samara showed that most caregivers experience social isolation, high levels of suffering, and issues related to their health, and devoted little time to taking care of themselves, and this affected their patients (24). The findings of Zelenikova et al. revealed that the general perception of pain and suffering could be predicted by symptoms, including understanding the problem, remembering the problem, difficulty in concentration, anxiety, weakness, and pain. Additionally, caregivers' perception of the degree of their patients' pain and suffering was the main predictor of patients' suffering (25).

Given that the level of quality of life in caregivers of patients with physical and mental diseases was very low and considering the long course of kidney failure and frequent complications of hemodialysis affecting patients' mental health and quality of life to varying degrees, the objective of the present study was to determine whether caregiver burden predicted quality of life and perception of suffering in kidney patients.

2. Methods

This was a descriptive-correlational study. The statistical population included all caregivers and patients with chronic kidney failure in the age range of 30 to 50 years, who underwent hemodialysis in hospitals of Zahedan from October 2014 to July 2015 (N = 191). Among these 191 individuals, 54 caregivers and patients were selected using the convenience sampling method.

Exclusion criteria were lack of interest in taking part in the study, abandonment of the treatment process, having a simultaneous disease, and having a mental illness. Patients and their caregivers were informed about the goals and stages of the study, and that their participation was voluntary. Once this information was received, the questionnaires were distributed among the patients and their caregivers. Whenever a question seemed vague, some additional explanations were also provided. It should be noted that these explanations were provided to avoid any kind of ambiguity and/or bias.

After obtaining their consent, the patients answered the quality of life scale and the experience and perception of suffering scale and the caregivers answered the caregiver burden inventory. Moreover, the questionnaires were read to illiterate patients and caregivers and among the mentioned answers, the one chosen by the patient or the caregiver was marked.

This study was confirmed by the ethics committee of the University of Sistan and Baluchestan, department of psychology. Ethical code of the research was 17282.

The obtained data was analyzed using Pearson correlation coefficient and stepwise regression analysis. The measurement tools were three questionnaires on perception of suffering, quality of life, and caregiver burden.

2.1. The Caregiver Burden Inventory (1989)

This 24-item inventory was developed by Novak and Guest in 1989 to measure the objective and subjective caregiver burden. This inventory has five subscales, including time-dependence burden, developmental burden, physical burden, social burden, and emotional burden. Caregivers' answers are scored based on a 5-point Likert scale

(ranging from 1 = not at all descriptive, to 5 = very descriptive). Therefore, the scores on this inventory ranged from 24 to 120. Given the mean scores on caregiver burden, scores in the range of 24 to 39 showed mild caregiver burden, of 40 to 71 indicated moderate caregiver burden, and of 72 to 120 demonstrated severe caregiver burden. The Cronbach's alpha coefficients related to its subscales ranged from 0.76 to 0.82 and the Cronbach's alpha coefficient of the whole scale was reported as 0.90 (19). McCleery et al. reported that the reliability coefficient of this scale was 0.87 (26). The reliability of this inventory in the current study was 0.89.

2.2. *The Quality of Life Scale (1995)*

This multidimensional scale, containing the questions of SF-36 and some questions related to kidney patients, was designed by Rand in 1995 to examine quality of life. This scale evaluates 12 factors related to health and quality of life, including physical functioning, general health, the effects of kidney disease on life, the imposed conditions, pain, sleep, social functioning, social support, energy, emotional roles, sexual functioning, and patient's satisfaction. The scores ranged from 36 to 150. Higher scores indicated higher quality of life. Scores in the range of 36 to 74 indicated low levels of quality of life, 75 to 110 showed moderate levels of quality of life, and 111 to 150 demonstrated high levels of quality of life. The reliability coefficient of this scale was 0.90 (27). Moreover, in a similar study, the reliability of this scale was reported as 0.84 (28). In a study conducted by Elhafeez et al., the reliability of all subscales ranged from 0.23 to 0.90 (29). In the current study, using Cronbach's alpha coefficient, the reliability of this scale was 0.82.

2.3. *The Experience and Perception of Suffering Scale (2010)*

This scale was developed by Schulz et al. to measure the experience and perception of suffering. This scale measures three dimensions of suffering including physical suffering, psychological suffering, and existential-spiritual suffering. The dimension of physical suffering includes 9 items and the dimension of psychological suffering contains 15 items. Subjects choose their answers based on a 4-point Likert-type scale ranging from 0 (very low) to 3 (very high). In addition, existential suffering is measured through applying 9 items, the scores of which are determined using a 5-point Likert-type scale ranging from 0 (very low) to 4 (very high) (30). The reliability of this scale was confirmed in three groups of African-Americans (physical 0.63, psychological 0.9, and existential-spiritual 0.86), Caucasians (physical 0.43, psychological 0.87, and existential-spiritual 0.84), and Spanish (physical 0.6, psychological 0.85, and existential-spiritual 0.83) (31). In the

present study, using Cronbach's alpha coefficient, the reliability was obtained as 0.83.

To analyze the obtained data, both descriptive statistics (mean, percentage, and standard deviation) and inferential statistics (Pearson correlation coefficient and regression analysis) were used.

3. Results

Overall, 55.6% of caregivers and patients were females and 44.4% were males. Moreover, education below diploma (48.1%) had the highest frequency and master's degree (13.0%) had the lowest frequency. However, among caregivers, bachelor's degree (55.6%) had the highest frequency and below diploma (14.8%) had the lowest frequency.

The results indicated that, among variables under study, the highest mean and standard deviation were related to caregiver burden (144.55) (Table 1). The results showed that caregiver burden was significantly and positively related to physical quality of life ($r = 0.27$) and mental quality of life ($r = 0.24$). In addition, caregiver burden was significantly and inversely correlated with physical perception of suffering ($r = -0.268$), mental perception of suffering ($r = -0.30$), and existential perception of suffering ($r = -0.263$), at 95% confidence interval (Table 2).

Table 1. The Mean and Standard Deviation of Caregiver Burden, Quality of Life, and Perception of Suffering

Variables	Mean	Standard Deviation
Caregiver burden	144.55	39.75
Mental quality of life	60.14	4.96
Physical quality of life	34.72	8.16
Physical suffering	22.42	5.56
Mental suffering	37.53	9.11
Existential suffering	25.14	3.27

Table 2. The Correlation Matrix of Caregiver Burden With Quality of Life and Perception of Suffering

Variables	Caregiver Burden	P Value
Physical quality of life	0.27*	0.02
Mental quality of life	0.26*	0.02
Physical suffering	-0.30*	0.02
Mental suffering	-0.268*	0.02
Existential suffering	-0.263*	0.02

The results of linear regression analysis conducted to predict quality of life and perception of suffering via caregiver burden, are presented in [Table 2](#). The results showed that caregiver burden was able to predict 0.05 of quality of life, including the physical dimension ($F(1, 52) = 4.23, P < 0.05$) and the mental dimension ($F(1, 52) = 3.81, P < 0.05$). Moreover, caregiver burden was able to predict 0.07 of the physical suffering (a dimension of perception of suffering) ($F(1, 52) = 5.41, P < 0.05$), 0.05 of mental suffering (a dimension of perception of suffering) ($F(1, 52) = 4.03, P < 0.05$), and 0.05 of existential suffering (another dimension of perception of suffering) ($F(1, 52) = 3.58, P < 0.05$). Since there was only one predictive variable, the correlation values of R and β are similar ([Table 3](#)).

The results of correlation of caregiver burden with quality of life and perception of suffering are presented in [Table 2](#).

4. Discussion

The present study aimed at examining the role of caregiver burden on quality of life and perception of suffering in kidney patients. The results of this study indicated that caregiver burden was significantly and negatively correlated with two dimensions of quality of life, i.e. physical and mental. Additionally, the results of regression analysis demonstrated that caregiver burden was able to predict 0.05 of physical quality of life and mental quality of life (dimensions of quality of life) and 0.07 of physical suffering (dimension of perception of suffering), 0.05 of mental suffering (dimension of perception of suffering), and 0.05 of existential suffering (another dimension of perception of suffering). These results are in line with the results obtained from some previously conducted studies determining that caregiver burden was significantly and positively related to physical and mental dimensions of quality of life and it was significantly and inversely correlated with physical, mental, and existential dimensions of perception of suffering ([14-18, 20-25](#)).

Habibzade et al., in their study, revealed that 52% of caregivers had moderate and low quality of life and more than 60% of them were partly unsatisfied with the level of care they provided for themselves. Moreover, 85% of these caregivers believed that social support was inadequate and 67.5% of them did not have any recreational activities in their lives ([9](#)). The results of several previously conducted studies showed that the disease progression in patients reduced physical well-being of their caregivers and this seriously affected patients' health and quality of life ([11-13](#)).

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Therefore, it can be inferred that stress and psychological pressures on people taking care of patients with chronic diseases are prevalent and noteworthy, and require immediate attention. Neglecting these pressures and not considering any treatments and interventions for them could reduce the level of physical and mental health of caregivers, as hidden patients. When a family member becomes ill, this usually concerns the entire family. If one of the family members takes care of the patient, this concern becomes more serious. These families should refer to nurses, consultants, social workers, and/or family trainers to receive consultancy services. In addition, holding training courses for these families could be very helpful.

The limitations of this study included interpersonal interactions among the patients' family members and pa-

Table 3. The Results of Linear Regression Conducted to Predict Quality of Life and Perception of Suffering

Variables	Predictive Variable	R	R ²	Adjusted R Square	Beta	T	F(df)	Durbin Watson	P Value
Physical quality of life	Caregiver burden	0.27	0.07	0.05	-0.27	-2.05*	4.23* (1, 52)	2.16	0.02
Mental quality of life		0.26	0.06	0.05	-0.26	-1.95*	3.81* (1, 52)	1.51	0.02
Physical suffering		0.30	0.09	0.07	0.30	2.32*	5.41* (1, 52)	1.94	0.01
Mental suffering		0.268	0.07	0.05	0.268	2.008*	4.03* (1, 52)	1.98	0.02
Existential suffering		0.263	0.06	0.05	0.263	2.05*	3.85* (1, 52)	1.90	0.02

tients' and their families' cultural background that could effect the results of this study, over which the researchers had no control.

Given the results of the current study and considering the fact that caregivers are a group of people that are physically and mentally vulnerable, ignoring the problems related to these important sources of care could reduce their ability to take care of their patients and lead to their physical and mental exhaustion, the negative consequences which effect patients.

4.1. Conclusion

Therefore, perceiving their problems and planning to solve them are among the most significant tasks of related authorities. Furthermore, it is suggested that development of community-based services, including short-term hospitalizations, psychological and vocational rehabilitations, follow-up treatments at home, which are among the most important requirements of caregivers, should be taken into consideration as part of national mental health programs.

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