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Caregiver burden among family caregivers of older patients receiving hemodialysis and its relevant factors

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ABSTRACT

Introduction: One of the issues that have drawn many attentions in recent years is the matter of caregiver burden among caregivers of patients with chronic illnesses.**Objectives:** The present study was carried out with the aim of studying the caregiver burden among caregivers of older patients receiving hemodialysis and its relevant factors.**Patients and Methods:** In the present study 52 caregivers of elderly patients receiving hemodialysis for this study were recruited. Data collection was carried out using a researcher-made demographic variables checklist and Novak and Guest Caregiver Burden Inventory (CBI).**Results:** The mean age of caregivers' patients was 72.4 years. The mean total score of care burden was 57.9±20.1. Totally, 23.1%, 51.9% and 25% of the subjects had mild, moderate and severe level of burden respectively. Caregiver of ages, age of the elderlies and relationship status were effective factors on caregiver's burden ($P < 0.05$).**Conclusion:** In the present study, caregivers of older patients receiving hemodialysis reported to have high levels of burden. This issue should be addressed especially by the health care teams that provide care for older patients receiving hemodialysis.

Implication for health policy/practice/research/medical education:

In a study on 52 caregivers of elderly patients receiving hemodialysis, we found, caregivers of older patients receiving hemodialysis reported to have high levels of burden. This issue should be addressed especially by the health care teams that provide care for older patients receiving hemodialysis

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Introduction

End-stage renal disease (ESRD) is a chronic condition in which the kidneys completely lose their functions. In fact, in this condition, the calculated glomerular filtration rate is less than 15 mL/min (1). In today's world, chronic kidney disease is considered as a worldwide public health challenge (2). The number of ESRD patients is growing rapidly worldwide in recent years (1). According to the United States Renal Data System (USRDS), there were 124,114 newly reported cases of ESRD in the United States in 2015. This system also reported that substantial health care costs were paid for ESRD patients in the United States between the years 2014 and 2015 in which these costs had grown significantly from \$31 billion to \$33.9 billion (3).

In many cases, patients with chronic illnesses require others' care, and in this scenario, kidney failure patients receiving hemodialysis are not an exception (4). These

patients usually rely on their caregivers to assist them with their daily living needs. Duties taken on by caregivers include administration of medications, driving to dialysis, maintenance of personal hygiene, provision of meals (5). In longer terms, taking care of a patient with chronic illnesses may have negative effects on the caregivers (6). However, studies show that during the patients' care and treatment in hemodialysis, main focus of the treatment team is on the patient, while, patients' caregivers do not usually receive special attention (4). One of the issues that has drawn many attentions in recent years is the matter of caregiver burden among caregivers of patients with chronic illnesses. Caregiver burden, which may appear in both objective and subjective approaches, includes psychological, physical and social stress that is resulted from providing care for patients with special health care needs by caregivers (7). This matter has been studied

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among caregivers of patients receiving hemodialysis in several studies. In a study in this regard, Talebi et al have studied the caregiver burden among 154 kidney failure patients receiving hemodialysis. The results showed that nearly 74% of the subjects had severe levels of burden (8). In another study in Saudi Arabia in 2014, Bayoumi et al studied the burden on 50 family carers of patients receiving hemodialysis. The results showed that most of carers of these patients experienced moderate to severe levels of burden (9).

Today, most of the ESRD patients are older patients, which this naturally increases the number of elderly people in need of hemodialysis treatment (10-12). This can be due to increased longevity of ESRD patients, high prevalence of diseases such as diabetes and hypertension in the elderly, as well as the development of technology and health services in recent years (10-12). Studies reported that the incidence of old age issues such as falling, decreased physical activity, poor nutrition and cognitive disorders in elderly with ESRD are higher than younger patients (13). These issues can lead to a greater dependency of the older patients receiving hemodialysis and require caregivers to spend more time, energy, and resources on them. These factors can affect the level of caregiver burden experienced by the caregiver of the older patients.

Objectives

The present study aimed to study the caregiver burden among caregivers of older patients receiving hemodialysis and its relevant factors.

Patients and Methods

Patients

The present descriptive-analytic study was conducted in Qazvin in 2017. The study setting was the hemodialysis ward of Bou-Ali Sina hospital, Qazvin. This ward is the only hemodialysis center for patients in the city. The subjects of the present study were caregivers of elderly patients (over age 60 years) on hemodialysis (at least one year) who were referred to the hemodialysis center of Bou-Ali Sina hospital. Sampling lasted nearly 8 months. A convenient sampling method was used to select the participants. All the caregivers of patients were requested to participate in the study. One caregiver from each patient, who was mostly responsible for constant and daily caring, was recruited. Those who were not able to complete the questionnaires, were excluded. Caregiver, who was simultaneously taking care of other patients with chronic illnesses, were excluded as well.

Data collection

Data collection was done in the hemodialysis ward. In order to collect the data, one of the researchers was present in the ward in the morning shifts in coordination

with the head nurse. After identifying elderly patients, the researcher asked them to introduce their primary caregivers. If the primary caregivers were present, they were asked to participate in the study, and if the primary caregivers were absent, the patient was requested to bring them in the next session. After identification, the caregivers received the required information about the study's objectives and methods, and if they were willing to participate in the study, they were asked to complete the questionnaires and return it to the researcher or head nurse of the hemodialysis ward. Data collection was carried out using a researcher-made demographic variables checklist and Novak and Guest Caregiver Burden Inventory (CBI). Demographic variables included patient's age, gender, education, the duration of dialysis, caregiver's age, gender, marital status, education, financial status and relationship to the patient. CBI is a consisted of 24 items in five domains: time-dependent burden (questions 1-5), developmental burden (questions 6-10), physical burden (questions 11-14), and social burden (questions 15-19), and also emotional burden (questions 20-24). The total score ranges from 24 to 120. Scoring between 24 and 39, 40 and 71, and 72 and 120 was considered as mild, moderate and severe level of burden, respectively. In previous studies in Iran, the validity and reliability of this instrument have been set at an optimal level among caregivers of patients receiving hemodialysis (14).

Ethical issues

Human rights were respected in accordance with the Helsinki Declaration 1975, as revised in 1983. The present study was approved by the Research and Technology Department of Qazvin University of Medical Sciences (ethics code: IR.QUMS.REC.1395.27). The aims and the methods of the study were explained to the participants before their participation in the study and they were ensured that their absence in the study would not be detrimental to them. The caregivers read and signed the written informed consent, which was designed by the Research and Technology Department of Qazvin University of Medical Sciences. At all the phases of the study, the patients' names and their caregivers were not included and in the case of more confidentiality, a numerical code was assigned to each one. Caregivers were assured of maintaining data confidentiality and they were told that only researchers would have access to source data and the data would only be used for the intended purposes.

Statistical analysis

Data were analyzed using the Statistical Package for the Social Sciences 21 (SPSS-21). Independent *t* tests, one-way ANOVA and Pearson's correlation were used for analyzing data. The mean, standard deviation and frequency were also used to describe the data, while *P* value below 0.05

was considered significant.

Results

Demographic Characteristics

The mean age of caregivers was 40.7 ± 14.8 (range 18 to 74). Of all the 52 subjects, 26 were men (50%) and 26 women (50%). Of 52 caregivers, 38 were married and the rest were single. Level of education in 73.1% of caregivers was lower than diploma. The mean age of caregivers' patients was 72.4 ± 7.1 . Totally, 53.8% of the patients were women and 46.2% of them were men. The mean years of hemodialysis were 2.7 ± 1.1 years.

Caregiver burden and domains

The mean total score of care burden was 57.9 ± 20.1 (range 27 to 113). Totally, 23.1%, 51.9% and 25% of the subjects had mild, moderate and severe level of burden respectively. Among five domains, time-dependent burden score was 14.7 (SD=5.9), developmental burden score was 12.1 (SD=4.2), physical burden score was 9.7 (SD=4.7), social burden score was 11.1 (SD=4.3), and emotional burden score was 10.2 (SD=4.4).

The relationship between caregiver burden and demographic characteristics of patients and caregivers

The results of Pearson's correlation test showed a direct and significant correlation between the participants' age and the total score of burden ($r = 0.404$, $P = 0.003$) and between the total score of burden and the age of the elderlies ($r = 0.525$, $P = 0.001$). The mean score of burden in women and men were 57.8 and 58, respectively. Based on the results of independent t-test, this difference was not statistically significant between the mean score of women and men ($P = 0.978$). The mean score of burden in caregivers, who take care of male and female patients, were 61.8 and 53.2, respectively. Based on the results of independent t-test, this difference was not statistically significant between the mean score of caregivers ($P = 0.125$). The mean score of burden in single caregivers was 59.7 and in married caregivers was 52.9. Based on the results of independent t test, this difference was not statistically significant between the mean score of single and married caregivers ($P = 0.281$). The mean score of burden in caregivers who take care of married elderlies was 57.8 and single elderly was 46.6. Based on the results of independent t test, this difference was not statistically significant between the mean score of caregivers ($P = 0.348$). The mean score of burden in caregivers with lower than high school and more was 60.2 and 51.7, respectively. Based on the results of independent t-test, this difference was not statistically significant between these groups ($P = 0.179$). The results of one-way ANOVA showed a significant difference in the mean score of burden among caregivers with different relationship status. This means that patients' spouses had higher level of burden than others ($P = 0.003$). No

significant difference was observed due to the results of one-way ANOVA in the mean score of burden among patients with different financial status. However, the mean scores of burden among patients with lower average financial status were higher than other groups ($P = 0.787$). The results of this test also did not show a significant difference in the mean score of burden among caregivers of elderly patients with different financial status, although the mean score of those who took care of elderly people with poor financial status was higher than the others ($P = 0.101$). Additionally, the mean score of burden was similar among older patients with different mean duration of dialysis ($P = 0.118$).

Discussion

The present study was designed with the aim of studying the caregiver burden among caregivers of older patients receiving hemodialysis and its relevant factors. Based on the results, most of caregivers of older patients receiving hemodialysis experienced moderate to severe levels of burden. Among five domains, time-dependent burden scored the highest among caregivers. The results also showed that the high age of caregivers, the high age of patients and the caregiver-patient relationship were factors that significantly influenced the level of burden perceived by caregivers. However, it should be pointed out that men, caregivers with lower education, married caregivers and those who took care of married patients compared to women, caregivers with higher education, single caregivers and those who took care of single patients experienced a higher level of burden, but this was not significant.

An important part of taking care of older patients receiving hemodialysis is their caregivers. This is more significant in developing countries like Iran. The reason is, home care services are not well developed by healthcare systems in these countries and also, the family structure in these communities maintains its traditional culture and taking care of the elderly. Especially elderly patients with chronic illnesses, is an integral part of family life. The results of the present study showed that most of caregivers of patients receiving hemodialysis have moderate to severe levels of burden. The scientific literature includes few studies in this regard. Our searches showed only two studies in this regard. In one of the studies conducted in Brazil in 2006, Belasco et al studied the burden among caregivers of older patients receiving hemodialysis. In this study, 83 caregivers were examined. Similar to the results of the present study, the results showed that caregiver burden is very prevalent among caregivers of elderly patients receiving hemodialysis (15). The other study was a qualitative study, in which Alnazly et al studied the burden of caregivers of elderly patients receiving hemodialysis in Jordan. The results of the study showed that caregivers experience significant levels of physical and psychological stress in taking care of an older patient

receiving hemodialysis, which this negatively influences their wellbeing (16). Healthcare systems should pay special attention to caregivers of older patients receiving hemodialysis. Not only is excessive caregiver burden associated with physical and mental problems, but also can have a long-term negative impact on the patient's condition and healthcare systems (17-19). Although in recent years, due to the growth of the older population in Iran, healthcare systems have provided services including the development of fields such as gerontology, geriatric nursing, and home-based care protocols using nurses in the home and community environment, it seems that more urgent proceedings are needed to improve the situation.

The results of the present study showed that among five domains, time-dependent burden compared to other domains scored the highest among caregivers. This domain indicates the amount of time caregivers spend to take care of their patient in a day. This finding is based on the high dependency of elderly patients receiving hemodialysis and their need to be cared. Additionally, due to limited home care services in developing countries like Iran, patients need to refer to clinics and public health centers to receive the required services. Therefore, caregivers and patients spend a lot of time. The results of this study also showed that high age of caregivers and the high age of patients were both directly correlated with the burden perceived, while, older caregivers and those who take care of elderly patients experience higher levels of burden. Older elderly patients are more likely to need more care from caregivers. They often require more hours of care than younger elderly patients. In most cases, elderly patients receiving hemodialysis require 24-hour care from caregivers that these can all worsen the levels of caregivers' burden and increases stress levels and also economic costs. All of which can lead to higher levels of burden. The results also showed that hemodialysis patients' spouses experience the significant levels of burden compared to others. In Iran, elderly people live with each other as long as the spouses are alive, and in the case of illness, one of spouses take care of other one. In many cases, the family's children may be involved in care procedure, but in some cases, spouses alone are responsible to take care. Spouses of elderly patients receiving hemodialysis are more likely to have problems, limitations, and illnesses that double their efforts to take care of their elderly patients.

Conclusion

Studies regarding the caregiver burden of older patients receiving hemodialysis are very limited in the current literature. The results of this study and previous studies showed that this group of caregivers experience a considerable burden and it is necessary to give special attention to healthcare systems. It seems that the development of medical and nursing services offered to these patients at community and home environment can

be somehow effective. Social support considering in these patients and their caregivers can also be helpful. Further studies are recommended due to the lack of studies about caregivers of the older patients receiving hemodialysis.

Limitations of the study

This study is mainly limited by its relatively small sample size. Because of cultural issues in Iran, many caregivers were not willing to participate in this study. It is also recommended that in future studies, variables such as quality of life, perceived social support, and disturbances such as depression, stress and anxiety, also be considered among this group of caregivers.

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Authors' contribution

MS; Study design, data collection, manuscript writing. HF; Study design, data analysis, manuscript writing and manuscript submission. FY; study design and data collection. AR; study design and data collection. MB; data collection and analysis. All authors read and signed the final version of the manuscript.

Conflicts of interest

The authors declare that there is no conflict of interest.

Ethical considerations

Ethical issues (including plagiarism, data fabrication, double publication) have been completely observed by the authors.

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