

## Correlation Between Burden and Preparedness for Caregiving Among Caregivers of Patients Undergoing Hemodialysis in the First Affiliated Hospital of Guangzhou University of Chinese Medicine, Guangdong Province, the People's Republic of China

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### ABSTRACT

**Background:** Patients undergoing hemodialysis experience functional dependency, physical symptoms, and psychological problems. The impacts of hemodialysis create a burden on caregivers who take care of these patients. Preparedness for caregiving is important to reduce burden. **Aim:** To investigate burden and preparedness for caregiving as well as the relationship between burden and preparedness for caregiving among caregivers of patients undergoing hemodialysis. **Methods:** This descriptive correlational study was performed on 172 caregivers. Questionnaires included demographic surveys of patients undergoing hemodialysis and caregivers, the Zarit Burden Interview, and the Preparedness for Caregiving Scale. The Cronbach's alpha of the Zarit Burden Interview and the Preparedness for Caregiving Scale were .933 and .906 respectively. Data were analyzed using descriptive statistics and Spearman's rank correlation coefficient. **Results:** The average age of patients undergoing hemodialysis was 64.63 years old (SD=11.47). The average monthly income was 1,725.58 yuan (247.75 dollar), which was below their monthly out-of-pocket medical expenses of 2,590.41 yuan (371.97 dollar). The average age of caregivers was 57.23 years old (SD = 12.94). Most of them had a primary or junior middle school education. The mean total burden score was 38.75 (SD = 6.75). Caregivers felt a moderate level of a burden overall. The overall mean preparedness for caregiving was 2.25 (SD = .59). There was a correlation between burden and preparedness for caregiving ( $r_s = -.283$ ,  $p = .000$ ). **Conclusion and Implications:** The more preparedness for caregiving caregivers perceive, the less burden they feel. This study provides baseline information for nurses to promote caregivers' preparedness for caregiving to help reduce the burden.

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**Keywords:** Caregiver burden, Preparedness for caregiving, Hemodialysis, End-stage renal disease

## Introduction

Patients with end-stage renal disease exceed one million in China (Hyodo et al., 2017) and there were 510,101 patients on hemodialysis by the end of 2017 (Peng, Yang, Chen & Yu, 2019). Increased prevalence of aging, diabetes, hypertension, obesity, and with the broadening of medical insurance coverage and a decrease in the cost of out-of-pocket, the number of patients receiving hemodialysis would increase continuously in China (Zhou, Zeng, & Fu, 2017). Although hemodialysis is a life-saving treatment, it leads to changes in patient's normal life; subsequently increasing their dependence on their caregivers (Sajadi, Ebadi, & Moradian, 2017). Patients undergoing hemodialysis may experience functional dependency (Kurella Tamura et al., 2009), physical symptoms (Murtagh, Addington-Hall, & Higginson, 2007), and psychological problems (Niu & Liu, 2017). The impacts of hemodialysis create a burden on caregivers who provide care to those patients.

The burden is defined as the extent to which caregivers perceived their emotional or physical health, social life and financial status as suffering as a result of caring for their relatives (Zarit, Todd & Zarit, 1986). Caregivers need to provide physical support and dedicate most of their time to meet the patient's needs (Ebadi, Sajadi, Moradian & Akbari, 2018). Being compassionate and vigilant to the patient and caregiving all the time is a torture (Salehitali et al., 2018). Caregivers suffered from anxiety, depression (Bawazier, Stanley, Sianipar & Suhardjono, 2018), worry and disrupted sleep patterns as well as energy exhaustion. Moreover, previous studies revealed that caregivers of patients undergoing hemodialysis experience social isolation (Maddalena, O'Shea & Barrett, 2018), role conflicts (Ebadi et al., 2018), impaired job performance (Alnazly, 2016), and financial problems (Oyegbile & Brysiewicz, 2017). Caregiving burden is associated with decreased quality of care provided to the patient (Sajadi et al., 2017). It may also disrupt the care process and worsen the patient's condition, causing a vicious cycle (Jafari, Ebrahimi, Aghaei & Khatony, 2018). Therefore, it is critical to reducing caregiver burden.

From the literature review, the social-demographic variables of the patients such as age (Senmar, Rafiei, Yousefi, Razaghpoor & Bokharaei, 2019), medical expense, and income (Zhang, Cui & Zhuang, 2016), and social-demographic variables of the caregivers such as gender (Mollaoglu, Kayatas & Yurugen, 2013), age (Shakya, Tuladhar & Poudel, 2017), education (Jafari

et al., 2018), and relationship with the patient (Senmar et al., 2019), were related to burden. Furthermore, studies showed that preparedness for caregiving was associated with burden in the cancer population; the higher preparedness for caregiving, the lower the caregiver burden (Fujinami et al., 2015; Maheshwari & Rajinder, 2016). Preparedness for caregiving is defined as perceived readiness for multiple domains of the caregiving role (Archbold, Stewart, Greenlick & Harvath, 1990). It is assumed that knowing what should be prepared for caregiving would diminish the caregiving burden (Scherbring, 2002). When caregivers are well prepared for caregiving, they become more confident (Maheshwari & Rajinder, 2016), more informed (Pasacreta, Barg, Nuamah & McCorkle, 2000), and more controlled in caregiving (Slatyer et al., 2019). The uncertainty about the care also reduces and caregivers can set priorities for their patients (Given, Sherwood & Given, 2008); thus caregivers experience less caregiving burden.

There is no study investigating the relationship between preparedness for caregiving and the burden among caregivers of patients undergoing hemodialysis in China. Therefore, information about preparedness for caregiving and burden as well as their relationship will expand the knowledge and be useful for nurses to promote the caregivers' preparedness for caregiving to help caregivers reduce burden in China. The objectives of this study aimed to investigate preparedness for caregiving and burden as well as the relationship among caregivers of patients undergoing hemodialysis in the First Affiliated Hospital of Guangzhou University of Chinese Medicine, Guangdong Province, the People's Republic of China.

## Methods

### Design and Sample

The accessible population was the caregivers of patients undergoing hemodialysis in the hemopurification area in the First Affiliated Hospital of Guangzhou University of Chinese Medicine and there were an estimated 300 caregivers. Sample size of this descriptive correlation study was calculated by Yamane's formula (Yamane, 1967). Therefore, 172 caregivers were recruited in this study. A convenience sampling was used to recruit caregivers in the waiting area of the hemopurification area in the First Affiliated Hospital of Guangzhou University of Chinese Medicine in China.

Caregivers who met the inclusion criteria were recruited: their patients received regular hemodialysis treatment aged 18 years old or older; mostly involved in taking care of their patients during hemodialysis and at home; a family member of the patient aged 18 years old or older (e.g. parent, spouses, children, grandchildren or other relatives); providing care for at least six months; being able to understand and speak Chinese and willing to give the informed

consent; the lower likelihood of cognitive impairment. Caregivers who had mentally ill or depression were excluded.

### **Measures**

The demographic form of patients undergoing hemodialysis and their caregivers addressed personal characteristics.

The 22-item Zarit Burden Interview (ZBI) (Zarit & Zarit, 1990) is used to assess the level of burden. It is a 5-point Likert scale, for items 1-21, ranging from 0 = 'never' to 4 = 'nearly always'; for item 22, ranging from 0= 'Not at all' to 4= 'Extremely.' Total scores range from 0 to 88, with higher scores indicating a greater burden. In this study, the Cronbach's alpha of the 22-item ZBI was .933.

The Preparedness for Caregiving Scale (PCS) (Archbold et al., 1990) is used to assess caregivers' perceived preparedness for the tasks and stress of the caregiving role. It is a 5-point Likert scale, with 0= 'not at all prepared'; 4 = 'very well prepared.' The potential range score is 0.00 to 4.00 for each item. Higher scores indicate more prepared the caregiver feels for caregiving. In this study, the Cronbach's alpha of the PCS was .906.

### **Ethical considerations**

The study was approved by the ethics committee of the Faculty of Nursing, Chiang Mai University, Thailand, and the First Affiliated Hospital of Guangzhou University of Chinese Medicine, Guangdong Province, China. Participants were provided with an information sheet explaining the objectives of the study. They voluntarily participated and were informed that whether they decided to participate or not, the treatment of their patient would not be affected and they could withdraw anytime without reason. Informed consent was obtained before distributing the questionnaires.

### **Data collection**

After receiving the approval of the ethics committees, the researcher wearing causal clothes recruited caregivers of patients undergoing hemodialysis. The researcher read all the items to all caregivers and noted their responses after obtaining informed consent.

### **Data analysis**

The data analysis of the study was performed by Statistical Package for Social Science 19.0. Continuous variables (such as age, income, medical expense, burden, and preparedness for caregiving) were analyzed in terms of mean, standard deviation (SD), and range. Categorical variables (such as gender, marital status, education, and relationship with the patient) were described as frequency and percentage. The Kolmogorov-Smirnov test was used to assess normality distribution. The scores of PCS were not normally distributed and that of ZBI was normally distributed. Therefore, the relationship between burden and preparedness for

caregiving was examined by Spearman's rank correlation coefficient. The significance level was set at .05.

## Results

### Demographic characteristics of patients undergoing hemodialysis and caregivers

This study revealed that the average age of patients was 64.63 years old (SD = 11.47), and 54.1% were male. Almost all patients (89.5%) were married. The average income was 1,725.58 yuan (247.75 dollar) (SD = 1,860.91), which was below their monthly out-of-pocket medical expenses of 2,590.41 yuan (371.97 dollar) (SD = 2,318.27). The average age of caregivers was 57.23 years old (SD = 12.94) and 69.2% were female. Most caregivers had a primary or junior middle school education. Most patients (64.5%) were cared for by their spouses. Caregivers provided care to their patients for 32.31 months on average (SD = 25.39).

### Caregiver burden

The mean total burden score was 38.75 (SD = 6.75) (Table 1). Caregivers felt a moderate burden overall. The most endorsed items by caregivers were feeling that their patient is dependent upon them (item-8); feeling that they don't have enough money to care for their patient (item-15), and feeling stressed between caring for the patient and trying to meet other responsibilities for their family or work (item-3).

**Table 1** Mean and Standard Deviation of Burden and Preparedness for Caregiving (n=172)

	Mean	SD
Burden	38.75	6.75
Preparedness for caregiving	2.25	.59

### Preparedness for caregiving

The overall mean preparedness for caregiving was 2.25 (SD = .59) (Table 1). The lowest three preparedness for caregiving items were finding out about and setting up services, getting the help and information from the health care system, and responding to and handling emergencies with means (SD) of 1.25 ( .92), 1.44 ( .83), and 1.87 ( .69) respectively.

### The Relationship between Burden and Preparedness for Caregiving

Spearman's rank correlation coefficient was selected to test the relationship between burden and preparedness for caregiving. It indicated a weak negative correlation between burden and preparedness for caregiving ( $r_s = -.283$ ,  $p = .000$ ) (Table 2).

**Table 2** The Relationship between Burden and Preparedness for Caregiving (n=172)

		Total ZBI
Spearman's $\rho$	Total PCS	- .283
	Correlation Coefficient	
	Sig. (2-tailed)	.000

## Discussion

### Burden

This study showed a moderate burden overall. Some items were endorsed much by caregivers in this study. Around 90% caregivers (among those, 49.4% sometimes, 33.1% quite frequently, and 7.6% nearly always) perceived that their patients were dependent on them. It was supported by a previous study indicating that patients undergoing hemodialysis have a functional dependency and mobility impairment (Cook & Jassal, 2008). Sajadi et al. (2017) also reported that hemodialysis increases patients' dependence on their caregivers. Caregivers need to assist patients with instrumental activities of daily living to some extent. For example, they need to provide renal diets to limit the buildup of waste and fluids and it is a challenge to keep the patients from ingesting restricted foods or drinks they preferred (Isenberg & Trisolini, 2008). Moreover, the medication regimen is more complicated due to fluid restriction, making swallowing difficult. Majority caregivers (36.6% sometimes, 37.2% quite frequently, and 9.3% nearly always) felt that they did not have enough money to care for their patients. The cost for a patient undergoing hemodialysis is expensive, including hemodialysis itself, medication as well as expenses from complications and intervention, which is higher than per capita income in China (Zhou et al., 2017). Most caregivers (44.8% sometimes, 29.1% quite frequently, and 7.0% nearly always) felt stressed between caregiving and trying to meet other responsibilities. It may be because they have multiple roles or responsibilities in their life outside the caregiving, including parental role or worker (Alnazly & Samara, 2014). Chinese people need to keep the household running during caring for the patients, and those employed caregivers have to work less or switch the work shift. Therefore, the dependence of patients leaves caregivers less time and makes it more difficult to fulfill other responsibilities.

Regarding the finding indicating moderate burden overall, it could be explained with the demographic characteristics of the patients and caregivers. In terms of the characteristics of the patients, the mean age of patients in this study was 64.63 years old. Elder patients undergoing hemodialysis had functional dependency and impaired mobility (Cook & Jassal, 2008). Cagan et al. (2018) addressed a higher caregiving burden when patients were dependent

on caregivers to fulfill their daily living activities. Furthermore, the average income of the patients in this study was lower than their out-of-pocket medical expenses. Zhang et al. (2016) reported that caregiver burden was higher when patients had low income. Regarding the characteristics of the caregivers, majority caregivers (69.2%) were female. Mollaoglu et al. (2013) found that female caregivers had higher caregiving burden. Women are much more likely to assume caregiving responsibility and they have multiple roles, such as mother, household manager, and emotional supporter (Chou, 2000). Besides, the mean age of caregivers was 57.23 years old. Shakya et al. (2017) reported that burden was significantly higher in caregivers with an age of more than 40 because it is difficult for older caregivers to manage healthcare treatment for the patients than younger caregivers. Moreover, caregivers in this study did not receive high education. It was stated that caregivers who had a lower education level had higher caregiving burden (Jafari et al., 2018). Increased education level and awareness about a disease may make it more sufferable for caregivers; educated individuals are more likely to access resources (Shakya et al., 2017). Therefore, all these reasons may explain why caregivers felt a moderate burden overall.

#### **Preparedness for Caregiving**

This study revealed that caregivers of patients undergoing hemodialysis were just somewhat well prepared in caregiving, which could be explained with the demographic characteristics. Caregivers in this study were 57.23 years old on average. Petruzzio et al. (2017) reported in heart failure population that older caregivers might feel less prepared because of their declined health. Besides, only 25.6% caregivers finished senior middle school and only 5.8% received a bachelor's degree in this study. Previous study supported that caregivers who have a lower education level feel less prepared for caregiving (Hagedoorn et al., 2019). Caregivers have taken care of them for almost three years on average in this study. However, Henriksson and Arestedt (2013) indicated in palliative care, that time since diagnosis was not associated with preparedness for caregiving, because caregivers need to continuously prepare for new phases throughout illness trajectory. Holm (2016) also reported that preparing for caregiving was unpredictable, and it was influenced by many factors, such as changes in the patient's condition and prognosis, or needs. Caregivers of patients undergoing hemodialysis faced changing caregiving needs due to the complication of hemodialysis, the progression of end-stage renal disease, or frequent hospitalization of the patients. They need to prepare for caregiving continuously. These reasons may explain why caregivers perceived just somewhat well prepared for caregiving.

### **The Relationship between Burden and Preparedness for Caregiving**

The study revealed a weak negative correlation between burden and preparedness for caregiving ( $r_s = -.283$ ,  $p = .000$ ), suggesting that with the increase of preparedness for caregiving, the burden decreases. The result of this study was similar to that of Fujinami et al. (2015) which revealed that preparedness for caregiving was correlated with burden subscales, which were objective demand burden ( $r = -.195$ ,  $p = .05$ ), subjective demand burden ( $r = -.273$ ,  $p \leq .001$ ), and subjective stress burden ( $r = -.319$ ,  $p \leq .001$ ). Pasacrete et al. (2000) reported that when caregivers were prepared for a variety of skills and education that were needed to function successfully in providing home care, they felt more informed and were not more burdened even when caregiving tasks increased. It is assumed that when caregivers are well prepared for caregiving, they become more confident in caregiving (Maheshwari & Rajinder, 2016), easily make decisions, and worry less (Given et al., 2008); thus, their lives are less affected by caregiving, eventually lessening caregiving burden.

### **Conclusion and Implication**

Caregivers felt a moderate burden overall. They perceived just somewhat well prepared for caregiving. There was a negative correlation between preparedness for caregiving and burden. The findings of this study can provide information regarding preparedness for caregiving and the burden for the First Affiliated Hospital of Guangzhou University of Chinese Medicine, Guangdong Province, China. Nurses could use this baseline information to develop training programs or health education to enhance caregivers' preparedness for caregiving, especially in those areas that they perceived as less prepared, to reduce caregiver burden.

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### **Conflict of interest**

No conflict of interest

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