

Burden and dimension of social quality of life related to Disaster Preparedness among family Caregivers with chronic kidney disease

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KEYWORDS

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ABSTRACT

Background: Caregivers of chronic diseases patients have an important role in emergency and disaster preparedness. However, the lack of understanding of the relation of the caregiver's burden, dimension of quality of life, and disaster preparedness for personal caregivers with chronic kidney disease.

Aim: This study aimed to examine caregivers' burden, dimension of quality of life, and disaster preparedness of personal caregivers with chronic kidney disease.

Methods: A Cross-sectional study design was adopted in this study. Accidental sample approach was used from January up to April 2024. The Zarit Burden Interview (ZBI), the World Health Organization Quality of Life-Brief Version (WHOQOL-BREF), and the Disaster Preparedness Evaluation Tool Indonesian Version (DPET-I) were used to assess the study variables. Linear regression was used to examine caregivers' burden, dimension of quality of life and, disaster preparedness of family caregivers of chronic kidney diseases patients.

Results: Sixty family caregivers were included in this study with a family caregiver mean aged 51.8 years old. Sixty percent are male family caregivers. There were significant factors such as caregiver burden ($\beta=0.45$; $p=0.008$) and social dimension of the quality of life ($\beta=0.19$; $p=0.04$) for disaster preparedness of family caregivers with chronic kidney disease.

Conclusions: The caregiver's burden and the social dimension of quality of life confirmed the factor associated with disaster preparedness of family caregivers with chronic kidney disease. Burden care and, social dimension of quality-of-life management for caregivers and, including family caregivers for the education of disaster preparedness are recommended to increase disaster preparedness of family caregivers with chronic kidney disease.

1. Introduction

The role of family caregivers of chronic disease providing long-term care is essential [1]. Studies reported the roles of the caregivers in improving management chronic disease outcomes are diverse and significant [2] [3]. However, the procedure of chronic disease leads to an increased burden and quality of life (QoL) of the patient caregiver's [4]. Caregiver's burden includes patient subjective perspective, and also objective perspective aspects.

Perception is seen as objective or subjective patients for understand and interpret the situation. Study showed inadequate financial resources, conflict of multiple responsibilities, and lack of social activities as antecedents of caregiver's burden [5]. Quality of life is a subjective parameter about experiencing of life [6, 7]. Worse caregiving quality were influenced by a major weakening in daily life. In line conflict between work status, caregiving roles, and family daily needs were related to the burden on the caregiver.

A study reported physical and mental dimensions of patients and family caregivers regarding the quality of life during the COVID-19 pandemic were not significant related [8]. However, age, co-morbidities, and education level were found as predictors of some of the changes in the quality of life dimensions [9]. In addition, family caregiver quality of life and burden status are very important factors for maintaining the quality of life of the patients [9]. A study implicitly found that environment including social factors family caregivers are independent factors associated with the long-term care quality of life of the patients especially for chronic illness patients. Home nursing or sub-acute recovery is important to advance and maintain functional status in the elderly after hip fracture surgery, including

the home environment [10]. In line, nursing treatment for the elderly with cognitive problems be early assessment after surgery for a hip fracture to prevent a worse decline in QoL including providing safe environment [7].

Indonesian geography, demography, infrastructure and cultural are different from European country including Java Island. Yogyakarta is a province in the Java area, with an area of about 3100 km², with Merapi active volcano as the most active in Indonesia which makes the city prone to disaster when there is an eruption. Some studies highlight the role of area factors, as well as the familiarity of historical distresses, on people's perception of exposure to risk in disasters related to environmental danger incidents. When the wealth of a family is negatively changed by a disaster, then this household will feasibly developed more risk of burden, whereby insurance may play a part to prevent negative impact of tragedies [11] including for families with chronic kidney disease.

Objectives

The lack of understanding about the caregiver's burden, quality of life, and disaster preparedness of family caregivers with chronic kidney disease exists. Therefore, the study identified the relationship between caregiver burden, quality of life, and disaster preparedness of the family caregiver with chronic kidney disease.

2. Methodology

Study Design: Cross-sectional study design

Sample: Sixty family caregivers with chronic kidney disease participated in this study from January to April 2024 at a hospital in Indonesia.

Data collection: The data were collected through in-person interviews by the researchers with those who could not read, and the respondents completed the questionnaires for the respondents who could read the research instruments.

Instruments

The Burden by Zarit Burden Interview (ZBI): ZBI was used to measure the caregiving burden [12]. It covers five areas: association burden, expressive welfare, group and personal life, assets, and harm of control over life. The ZBI consists of 22 items with a 5-point Likert scale from 0 (rarely) to 4 (almost continuously), except for the last item, which has 5 response categories in order of intensity (0 = not at all; 4 extremely). Total scores range from 0 to 88, with higher scores indicating heavier loads. The Indonesian version of the ZBI has been confirmed and found to be dependable, with a Cronbach's alpha significance of 0.91 [13].

The World Health Organization Quality of Life: Brief Version (WHOQOL-BREF): WHOQOL-BREF is used to assess the quality of life in four domains: bodily health, emotional relations, group relationships and ecological health. The first two factors relate to the quality of life and general health. Each item is rated on a Likert scale from 1 to 5, where 1 represents "very dissatisfied/very bad" and 5 represents "very satisfied." The scores are then converted to a linear scale from 0 to 100, where 0 is least favorable and 100 is most favorable [14]. The Indonesian version of WHOQOL-BREF was found to be a acceptable and dependable form, and all areas met consistency criteria [14].

The Disaster Preparedness Evaluation Tool Indonesian Version (DPET-I)-Modification: The DPET tool is translated into Bahasa Indonesia. DPET-I is a valid and reliable measurement tool to assess disaster preparedness. The Cronbach's alpha value for all questions is 0.944 (Nugroho, 2017). In this study, the DPET-I was modified for caregivers. The 17 items comprise a 5-point Linkert scale ranging from 1 (argue) to 6 (powerfully agree). Cronbach's alpha rate is 0.91

Ethical consideration

Ethical approval was obtained from the hospital ethics committee (ethics number: ref 00219/2023). Informed consent was obtained from each participant before data collection.

Statistical analysis

Statistical analysis was performed using SPSS ver. 22.0 for Windows (SPSS Inc., Chicago, IL, USA). To examine the independent variables linear regression was used. The independent variables consisted of age, caregiver burden, quality of life, and independent variables; disaster preparedness of chronic kidney disease family caregivers.

3. Results and Discussion

Sample Characteristics

Sixty caregivers participated in this study, whose patients had a mean age of 51.8 years. There were 36 (60%) males and 24 (40%) females who responded. Most of respondents' educational level and degree are diploma degree (36.7%) (Table 1).

Care givers burden, dimension of quality of life (physic, psychological, social and environment) and disasters preparedness of family care givers chronic kidney disease statistical analysis

Based on the analysis of the bivariate linear regression test, the results showed that significant factors are care-givers burden ($\beta=0.45$; $p=0.008$) and social dimension of quality of life ($\beta=0.19$; $p=0.04$) for disasters preparedness of family caregivers chronic kidney disease (Table 2).

Table 1: Sample Characteristics (care giver, n=60)

Characteristics	Mean/Frequency (f)	Percentage (%)
Age	51.8	
Gender		
• Male	36	60
• Female	24	30
Education		
• Elementary School	8	13.3
• Junior High School	12	20
• Senior High School	18	30
• Diploma/Bachelor	22	36.3

Table 2: The result of the Linear regression test Care givers burden, dimension of quality of life (physic, psychological, social and environment) and disasters preparedness of family care givers chronic kidney disease statistical analysis. (n=60)

Variable	β	95% CI		p
		Lower	Upper	
Age	0.32	0.25	0.90	.26
Caregivers burden score	0.45	2.26	4.39	.008*
• Dimension of quality of life; physic	-0.14	-0.43	0.40	.94
• Dimension of quality of life; psychological	0.11	0.30	0.34	.90
• Dimension of quality of life; social	0.19	0.007	0.37	.04*
• Dimension of quality of life; environment	0.13	0.15	0.42	.34

* significant linear regression test

Discussion

The current study focuses on the aspects of quality of life, family caregiver burden, and disaster preparedness among caregivers with chronic kidney disease. In this study, the disaster preparedness was relatively moderate and caregiver problem was moderate. Statistical analysis of the results showed

a correlation among caregiver burden and social aspects of quality of life with family caregivers' ability to prepare for chronic kidney disease disasters. The caregiver readiness is the caregiver's perceived readiness to care for the patient physically and emotionally. One study found that people in poor health, including those with chronic kidney disease, are vulnerable during disasters. Additionally, disasters set the limit of the caregivers' capability to continue providing care due to stress, reduced incomes, and limited social backing [15]. This implies that disaster prevention education and training for caregivers is necessary.

Caregivers may need to practice disaster plans with the individuals they work with, including the family caregiver [16]. Formal health teams must be trained to increase interaction between prescribed caregivers, natural caregivers, and those receiving care. [17, 18]. Post-disaster training and support programs are needed for caregivers and informal care recipients to improve their resilience and independence in the face of disaster [19] especially when some caregivers are actively seeking information about how to prepare for disasters [20]; many caregivers could benefit from tailored disaster preparation awareness programs and support. Additionally, the importance of disaster preparedness for older families who depend on medications and medications for their care recipients in the event of an evacuation. One study found that chronic health care services and prescription refills were the most frequently mentioned services in evacuation shelters [21, 22]. The need for caregiving knowledge and equipment was identified as an essential step that family caregivers should take to adequately prepare themselves and their care recipients for disaster response [23].

The social aspect of quality of life is related to disaster preparedness. Complex decision-making processes are undertaken by family caregivers when preparing for disasters, including the ability to participate in their social communities. Making these potentially life-changing decisions for a family with health problems during a disaster response can be emotionally draining; placing an additional burden on those who take care [19]. Steps can be taken before a disaster during the prevention and preparation stages to reduce this emotional burden. This includes collaborating with health care providers and community organizations to create a family emergency plan that outlines the decisions informal caregivers will make based on different risk situations. This includes decisions for example whether to shelter in place or where to evacuate [24, 25]. These decisions require reflection on the social roles of the caregiver and the person being cared.

Emotional stress was also a factor in the executive method of the caregivers. [19, 26]. The decision-making process is emotionally draining because the caregivers must make important life-changing decisions [27, 28]. Community organizations and healthcare groups can play a role in building strong social support for informal caregivers and their families to avoid the unnecessary decision-making burden of preparing for disasters. This support can come in the form of integrated disaster planning assessment tools, such as those developed and tested by local healthcare providers to support patients' families Prepare for disaster [29, 30]. Working with these community support groups and health organizations before a disaster strikes can help reduce fear, feelings of stigma, and mistrust of shelters and administrative support [31, 32].

Caregiver stress is related to reduced health-related quality of life (HRQOL)[33, 34]. In addition, caregiver stress negatively affects the quality of care received by the recipient [35-37]. Increased caregiver burden raises death and hospitalization frequencies among community-dwelling adults. [20, 38, 39]. Research shows that the role of family caregivers in providing long-term care for chronic kidney disease patients is essential [1, 40, 41]. In addition, it is important for the caregivers of the patients with chronic diseases such as chronic kidney disease to prepare for emergencies. [42, 43], In addition, it is important for the caregivers of the patients with prolonged sicknesses such as chronic kidney disease and to prepare for emergencies [44, 45].

Limitations of the study

This study is limited in that not all respondents experienced an actual accident, and also disaster simulation which may have influenced the results of the study.

4. Conclusion and future scope

Caregivers' burden and, the social dimension of quality of life confirmed the factor which associated with disasters preparedness of family caregivers chronic kidney disease. Burden care and social dimension of the quality-of-life management for caregivers and, include family caregiver for education of disasters preparedness are recommended in order to increase the disasters preparedness of family caregivers of chronic kidney disease patients.

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