Determinants of the Caregiver Burden of CKD Patients Undergoing Hemodialysis

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Abstract -- *Families who treat chronic kidney disease (CKD) patients are at risk of experiencing caregiver burden. The family caregiver burden depends on the ability of the families to care for their family members who experience CKD when undergoing hemodialysis. The purpose of this study was to determine the factors associated with the caregiver burden of caring families (primary caregivers). This study used quantitative research and a cross-sectional design. The sample consisted of 95 respondents determined using consecutive sampling from the population in the Hemodialysis room of Muhammadiyah Lamongan Hospital. The variables of this study were caregiver burden (Y), Age (X1), Gender (X2), Educational level (X3), Salary (X4) and Treating the patient's time (X4). The research instrument consisted of the Zarit Burden Interview (ZBI) method to determine the caregiver burden. Multivariate analysis was done using logistic regression. The results showed that the caregiver model shows a significant burden with a variable in salary and age. The accuracy of the model when predicting caregiver burden was 62.1%. These two variables can explain the burden of the caregivers by 10%. The equation model obtained the results of Caregiver burden= -0,277+0,818*salary-1,313*age (adults)-0,738*age (elderly). There is a need for social support from other families who care. Support system can influence the level of caregiver stress.*

***Keywords** – Caregiver; Burden; Hemodialysis; Chronic Kidney Disease*

I. INTRODUCTION

Chronic kidney disease and hemodialysis therapy is a burdensome and complex therapy that requires a lot of support from the family [1]. Hemodialysis can reduce the patient's energy level and affect the patient's ability to work and perform daily activities. This disrupts the normal life of the patient and their family [2]. The families often experience a tremendous burden associated with caring for hemodialysis patients.

Jafari et al research showed that 42.7% of families had a moderate level of care burden, 32.5% had a high level, and 4.9% had a very high level [3]. A systematic review by Gilbertson et al concluded that the burden and quality of life of families where a family member was on hemodialysis was worse than the general population. This is comparable to other chronic diseases. The burden of care for hemodialysis patients is comparable to dialysis peritoneal patients. The quality of life of families post-kidney transplant is better than that of dialysis patients [1]. The results of the 2 studies are

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different because they are viewed from different points of view. It can still be concluded that families experience a significant burden when treating patients with hemodialysis.

The caregiver or family challenges and burdens increase with the progression of the disease. Families experience physical burdens were associated with a lack of social support and lower health-related quality of life for both the patients and their families [5]. Disorders related to quality of life and family burden in the hemodialysis patients places a double burden on them which interferes with the treatment process [3].

Several factors affect the burden of care such as the level of the patient's ability to care for themselves (self-care), chronic comorbidities, level of education and the patient's family age. If the patient's self-care ability is low, there is an incident of chronic disease accompanying the patient, a low level of education and increasing family age, then the level of care burden on the family will increase [3]. Care burden is a term used by the caregivers or their families to refer to the hardships experienced when caring for the patients [6]. This burden covers the physical, psychological, social, and financial aspects. Increased care burden and decreased quality of life can cause complications such as depression. There is also a significant relationship between increasing the burden of care and decreasing the ability of care provided by the family because the burden of care can greatly impact an individual. The amount of stress experienced by the family due to the experience of caring for patients with a chronic illness is a serious, hidden disease [6]. The burden of care affects the quality of life of the family and it results in the provision of care being reduced. Thus, the condition of patients with a chronic illness worsens. The worsening of the patient's condition can increase the burden of care and cause a repetitive cycle. If a timely intervention is not carried out, then it can cause gradual fatigue in the family [3].

The purpose of this study was to determine the factors associated with caregiver burden regarding patients with hemodialysis. We can use this to determine the direction of advanced care planning. Family-centered care has been proposed to address the problem by meeting the needs of not only the patients but also their family members [7]. Efforts undertaken to prepare the families for the care of hemodialysis patients include more family-centered care, the provision of appropriate education early on, and interventions that target the readiness of the care partners. This is in addition to communication that focuses on the state of readiness between the health care providers and the patients' family members, and the establishment of a dynamic relationship between the family and patient [8]. The formation of psycho-educational support groups can also empower the families by providing the knowledge and emotional support needed for successful care [9].

II. METHODS

This study used quantitative research and a cross-sectional design [10]. The variables of this study were caregiver burden (Y), age (X1), gender (X2), educational level (X3), salary (X4) and treating the patient's time (X4). The research instruments consisted of the Zarit Burden Interview (ZBI) to determine the caregiver burden [11], [12]. Multivariate analysis was done using logistic regression.

- Data collection

The study subjects were taken on a consecutive basis from those who meet the criteria. The sample size was calculated using sample size software. From the calculation results, we obtained a minimum sample size of 95 respondents from the Hemodialysis room of Muhammadiyah Lamongan Hospital.

- Sample and Sampling

The sample consisted of the primary caregivers of CKD patients who had undergone treatment for hemodialysis. The criteria for the caregivers is that they have directly cared for CKD patients for at least one month after the patient has undergone hemodialysis while not caring for other patients for a long and concurrent time.

- Instruments

The research instrument was the Zarit Burden Interview (ZBI) to determine the caregiver burden. The Zarit Burden Interview (ZBI) method was used to explore the extent of the caregiver burden. It contains 22 items used for investigating the 5 domains of caregiver burden. The questionnaire items were rated using a 5-point Likert scale with 0 (rarely) being the lowest and 4 (nearly al-ways) being the highest. The total score can explain the level of caregiver burden. A score of 0–20 indicates little or no burden, 21–40 is a mild to moderate burden, 41–60 is moderate to severe burden and 61–88 is a severe burden is present [11], [12].

III. RESULTS

- General Characteristics of the Participants

The demographic data of the respondents (Table 1) showed that the caregivers of the patients with CKD undergoing hemodialysis were made up of 48,4% elderly (more than 45 years old), 60% female; 64,2% graduates of senior high school; 56,8% with a salary > 2 million/month and 43,2% were treating the patient for more than > 3 years. The studies showed that the caregivers of the patients with hemodialysis were mostly women and elderly people [8], [12], [13], [14], [15]. The studies conducted by Jafari, et al showed that the caregivers of patients with CKD had a high school level of education [3], [15]. Income is categorized based on the Lamongan Regency minimum wage, which is low if it is less than 2.2 million, and high if it is more than 2.2 million per month [16].

Table 1. General characteristics (N=95)

Demographic data	$\sum$	%	Mean	SD
Age			2.33	7.36
Teenagers (< 25th)	15	15.8		
Adult (25th – 45th)	34	35.8		
Elderly (> 45th)	46	48.4		
Total	95	100		
Gender			1.40	0.496
Female	57	60		
Male	38	40		
Total	95	100		
Education level			2.98	0.601
Elementary school	0	0		
Junior high school	18	18.9		
Senior high school	61	64.2		
University	16	16.8		
Total	95	100		
Salary			1.57	0.498
< 2 million/month	41	43.2		
> 2 million/ month	54	56.8		
Total	95	100		
Treating patient's time			2.22	0.774
< 1th	20	21.1		
1-3th	34	35.8		
>3th	41	43.2		
Total	95	100		

- Descriptive Analysis of ZBI

The family burden when treating patients with CKD undergoing hemodialysis is in the category of no burden or low burden for 55 families (57.9%). There burden was felt by 40 families (42.1%). This does not follow Jafari's research showing that 42.7% of families had a moderate level of care burden, 32.5% had a high level, and 4.9% had a very high level [3]. The differences in these findings can be attributed to the culture of Indonesians who care for their family members sincerely. This is in addition to the differences in the research environment and the number of supporting facilities available for the caregiver to access. However, the family care burden is still high at 42,1%. This indicates the need for attention and solutions.

- Chi square test

    The variables assessed using the Chi-square test were age, sex, education, economy (salary), and the length of care of the patients. The variable that will be removed is any variable with a $p > 0.250$. The Chi-square test results showed that the sex variable had a $p = 0.525$, so that variable was not included in the logistic regression test.

Table 2. Chi square test results

Demographic data	Chi square
Age	0.134
Gender	0.525
Educational level	0.057
Salary	0.117
Treating patient's time	0.127

- Logistic Regression Test

    The variables tested using logistic regression were age, educational level, salary, and treating the patient's time. Treating the patient's time and the education level variables were not significant in relation to the caregiver burden variable with $p = 0.034$ and $p = 0.023$. These variables were removed from the model. Based on this research, salary is the determinant factor of caregiver burden.

    The caregiver burden model is significant in relation to the variables of salary and age. The accuracy of the model when predicting caregiver burden is 62.1%. These 2 variables can explain the caregiver burden by 10%. The model equation obtained is:

Caregiver burden= -0,277+0,818*salary-1,313*age (adults)-0,738*age (elderly)

Based on the caregiver burden model, families with an economy of <2 million / month have a risk of experiencing a burden when treating patients as much as 2,262 times compared to families with an economy of> 2 million / month. Families in adulthood (25-45 years old) are at risk of experiencing a burden when caring for patients of 0.269 compared to the families of adolescents (<25 years). Elderly families (> 45 years old) are at risk of experiencing a burden when caring for patients of 0.478 compared to the families of adolescents (Table 3).

Table 3. Caregiver Burden Model

		B	S.E.	Wald	Df	Sig.	Exp(B)
Step 1[a]	Salary(1)	.816	.445	3.364	1	.067	2.262
	Age			4.781	2	.092	
	Age(1)	-1.313	.679	3.735	1	.053	.269
	Age(2)	-.738	.475	2.411	1	.120	.478
	Constant	-.227	.344	.434	1	.510	.797

a. Variable(s) entered in Step 1: Salary, Age.

IV. DISCUSSION

Family members are often involved in the treatment of chronic kidney disease patients as their care partners. As care partners, the family members are involved in many important activities, some of which include administering medication, overseeing medication compliance, assisting in daily care activities, scheduling and providing transportation when attending medical appointments, monitoring patient health, advocating for the patients and offering support emotionally [5]. The role of the family is beneficial for both the patients and health care providers. For patients, the involvement of their family members is associated with improved behavior, self-management care and adherence to therapy, in addition to improving their quality of life, reducing the risk of death, reducing anxiety and depressive symptoms, and decreasing the hospital admission opportunities. For the healthcare providers, the family members are invaluable partners in the task of caring for patients with chronic kidney disease [8].

The caregivers of patients on hemodialysis are at a high risk of emotional development, psychological distress, low quality of life, and increased burden. They have a variety of psychosocial concerns because of the length of the treatment. They usually experience an increased workload, limited personal and social activities, and financial problems. They feel tired, angry, depressed, helpless, guilty, isolated, that they are losing their freedom, fearful, vulnerable, and that they are neglecting their health. Interventions and supportive information are very important for the caregivers because they can help them to improve their quality of life and their ability to cope effectively with the care of their patients. Caregivers need appropriate knowledge, special skills, education, and guidance to help their patients to achieve better adherence to hemodialysis treatment [17].

The family caregivers of palliative care sufferers often experience enormous physical burdens in addition to the emotional and financial responsibilities associated with providing care. The caregiver burden increases over time non-linearly from the initial diagnosis to the death of the patient [18]. Care for the family caregivers (Family Care Giver) is needed in all domains of quality of life (physical, psychological, social and spiritual) [9].

The caregiver burden model is significant in relation to the variables of salary and age. This is relevant to the study stating that caregivers with an inappropriate economic status are significantly more prone to care burden [2]. Mashayekhi et al. found there to be a statistically significant relationship between their income and the level of care burden felt by the caregiver. Thus the caregivers of lower-income patients experience a higher level of care load [19]. The conceptual model of caregiver burden expressed by Gabriel is based on Lazarus and Folkman's theories, which show that an individual's response to stress is influenced by the primary appraisal, secondary appraisal, and available resources. According to this model, primary appraisal, secondary appraisal, and the availability of interacting resources ultimately have an impact on the individual stress response. Caregivers assess the effects of various aspects of care on themselves in the primary appraisal, which includes potential factors for patients and caregivers. The caregiver characteristics include caregiver demographics, employment status and family income. Transactions between the external resources in the form of social support and internal resources in the form of self-efficacy can affect the burden of care [20].

Bayoumi reported there to be a positive and significant correlation between total care burden and patient age. There was also a significant but negative correlation between total care burden and nurse age, patient education level and

caregiver education level. The difference in our findings and the results of the study above could be due to the low sample size (50 caregivers) in the Bayoumi study because the low sample size reduces the level of study transferability and the opportunity to find any correlations and relationships between the variables [21]. Several factors affect the burden of care such as the level of the patient's ability to care for themselves (self-care), chronic comorbidities, level of education and the patient's family age. If the patient's self-care ability is low, there is an incident of chronic disease accompanying the patient, a low level of education and an increased family age, then the level of care burden felt by the family will increase [3].

A comprehensive understanding of the family carers' unmet needs is needed to develop a long-term care plan for the family caregivers [22]. The palliative system must take on a more active role involving patients and their families as partners in order to manage the treatments and side effects and to achieve the best patient outcomes. They must be able to evaluate the patients and caregivers in order to determine what tasks they will be able to do before making sure that they have the training and resources to carry out these tasks [23].

V. CONCLUSION

The caregiver model is a significant burden with a variable in relation to salary and age. The determinant factor of caregiver burden for CKD patients is the economic factors. Families with a poor economic status will be more vulnerable to the burden of care. The caregivers of low-income patients experience higher levels of care load. A person's burden can be removed by the utilization of available resources. The role of the family members is needed to reduce the caregiver's burden.

CONFLIC OF INTEREST

No conflicts of interest have been declared.

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