



CAREGIVER'S BURDEN AMONG FAMILIES OF HEMODIALYSIS PATIENT: A CROSS-SECTIONAL STUDY

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ABSTRACT

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Article Info:

Submitted: 2022-01-05

Reviewed: 2022-03-23

Revised: 2022-04-11

Accepted: 2022-04-26

The end-stage renal disease affects almost every aspect of the patients' and caregivers' lives. Several studies have been conducted to explore the experiences of family caregivers in caring for hemodialysis patients. However, a survey of the burden of family caregivers has yet to be conducted in Indonesia, a country with strong family bonds among family members. This study aimed to identify the burden among family caregivers of hemodialysis patients. This study was a cross-sectional study conducted in May 2021 on 60 family caregivers of hemodialysis patients, selected using a purposive sampling technique. Semi structured questionnaires were used to measure socio-demographic. The Caregiver Reaction Assessment-Indonesian Version (CRA-ID) was used to measure their burden. Data were analyzed using descriptive analyzes and bivariate analyzes. Women represented 65% (n=39) of participants, married participants were 83.3% (n=50), and were 63.3% employed (n=38). Most of them have minimum family income (51.7%). The least common association of caregivers was the spouses of the patients (n=32, 53.3%). The analysis showed that the mean overall burden score with CRA-ID was 2.88 0.69 (ranging 1.00 to 5.00). The highest burden was the lack of family support dimension of 3.47 0.42. Caregiver burden among caregivers of patients on hemodialysis showed that the variables related to family burden were age, an education level, and family income (p-value<0,05). Caregivers of hemodialysis patients carry a significant burden. Interventions to provide appropriate social support to patients and increase caregivers' psychological conditions are critical.

Keywords:

Burden, Caregivers, Chronic illness, Hemodialysis

BACKGROUND

Chronic illness affects not only the patient, but also the caregiver's family, increasing the caregiver's burden. Chronic kidney failure is a condition that typically requires hemodialysis. The family, as the patient's closest friends, shares responsibility for the treatment.

Chronic illness in one family member is a source of concern for the entire family because of the economic and psychosocial consequences, as well as the impact on lifestyle (Kilic & Kaptanogullari, 2017). Family caregivers play an important role in the care of hemodialysis patients. Although caring for a family member is a rewarding experience, the physical

and psychological financial burden of caregiving has to have an impact on the quality of life of hemodialysis patients' family caregivers (Sajadi, Ebadi, Moradian, & Akbari, 2020). Patient care will cause stress and will require the family to make efforts to overcome difficult situations caused by chronic illness. Knowing the caregiver burden and the factors that influence it is critical for protecting patient health and planning treatment and care methods, as well as nursing services. (Joy, Abraham, & Gopalakrishnan, 2019; Kilic & Kaptanogullari, 2017).

Care burden is an unpleasant experience for patients' caregivers, including financial, social, psychological, and physical. It has been indicated that some caregivers of hemodialysis patients face a significant care burden. Acceptance of the caregiver role and its associated changes, in addition to its positive effects on the patient and their family, can result in some negative consequences, including decreased physical and mental health and worsened social relationships among caregivers. It can also cause a variety of physical, emotional, and psychological issues for caregivers, exposing them to a variety of physical and psychological risks. (Menati, Torabi, Andayeshgar, & Khatony, 2020; Nugroho & Sabarini, 2019).

Previous research conducted in Iran stated that caregivers of hemodialysis patients experience a relatively high care burden (Menati et al., 2020). Another study conducted in Indonesia used the Zarit Burden Interview (ZBI) questionnaire on 49 caregivers of patients with chronic kidney failure on hemodialysis. The study found that as many as 42.9% of caregivers experienced a light burden, 34.7% experienced a moderate burden, and 2.0% experienced a heavy burden (Nugroho & Sabarini, 2019). Qualitative research in Indonesia on the experience of families caring for chronic kidney failure patients stated that the negative impact of treatment was the lack of time for oneself. In addition, caregivers have difficulty socializing and contributing to the environment. Economic problems are also a problem when it comes to finding medical expenses for patients. Support for caregivers and patients with chronic kidney failure affects the quality of life in living their daily lives (Naufal & Setyawan, 2018).

Caregiver burdens are experienced, such as negative feelings, physical health, mental and social life. The caregiver's experience should not be underestimated. This will affect the caregiver's quality of life (Nugroho & Sabarini, 2019). An understanding of what is experienced by caregivers is expected to optimize intervention actions to reduce negative impacts on caregivers' lives (Shakya, 2017). Research

on caregiver burden on caregivers of patients with hemodialysis has not been done much. The interventions that have been implemented have not made many changes to the caregiver burden experienced by caregivers. Researchers are interested in looking at the caregiver burden on caregivers. This is to find out the description of the caregiver burden experienced and the factors related to the caregiver burden.

METHODS

This cross-sectional study began in May 2021 at the PKU Muhammadiyah Yogyakarta Hospital. The population was all caregivers who cared for patients with hemodialysis. In this study, purposive sampling was used. The researchers selected the respondents according to inclusion and exclusion criteria. The inclusion criteria were 1) patient caregivers with hemodialysis twice a week, 2) patient caregivers care for patients at least 2 months after hemodialysis, 3) primary caregivers (main caregivers with the highest level of responsibility) whose family members suffers hemodialysis. The exclusion criteria in this study were formal caregivers or caregivers who were paid not by the patient's family. The sample size was estimated to be 60.

Caregiver answered questions related to demographic variables (of patients and caregivers) and Caregiver Reactions Assessment - Indonesian Version (CRA-ID). The original CRA was developed to measure the burden of family caregivers of patients with chronic physical or mental impairment by Given et al (Given et al., 1992). The CRA was translated from the original English following the 5 cross-cultural translation steps as described by Kristanti et al. Then, Caregiver Reaction Assessment - Indonesian Version was used in this study The CRA-ID is made up of 22 items with five subscales: self-esteem (SE), lack of family support (LFS), impact on finance (IF), impact on schedule (IS), and impact on health (IH), with Likert response format options ranging from 1 to 5. (strongly disagree to strongly agree). Five items are scored in the opposite direction. The CRA assesses the impact of care on a subscale basis, and overall summative score. The CRA's total score, as the sum score of the 24 items overall, reflects the caregiver's situation. The higher scores reflect a higher burden. (Given et al., 1992; Kristanti, Vernooij-Dassen, Utarini, Effendy, & Engels, 2019). Five factors from the original instrument were confirmed with an explained variance of 54.89%. Almost all items in the CRA-ID appeared to have a similar structure as

the original version. Cronbach's alfa's ranged between 0.64 and 0.81. (Kristanti, Vernooij-Dassen, Utarini, Effendy, & Engels, 2019). Correlation between two continuous variables was verified using Pearson's continuous variables was verified using Pearson's correlation coefficient. The level of significance was considered at 5% with p value 0.05 and 95% confidence interval.

The researcher visited the hemodialysis wards after receiving permission from the hospital's ethics committee with number 00129/KT.7.4/IV/2021. The objectives of the study were explained to the participants. They were also given instructions on how to complete the questionnaires. Finally, those who met complete the questionnaires. Finally, those who met the inclusion criteria were invited to participate in the study. Questionnaires were then distributed to participants and collected after they completed them.

RESULTS

Table 1 shows a total of 60 family caregivers of patients receiving hemodialysis participated. Women represented 65% (n=39) of participants, married participants were 83.3% (n=50), and were 63.3% employed (n=38). Most of them have minimum family income (51.7%). The least common association of caregivers was the spouses of the patients (53.3%).

Based on table 2, the analysis showed that the mean overall burden score with CRA-ID was 2.88 (SD=0.69), ranging from 1.00 to 5.00. The highest burden was the lack of family support dimension of 3.47 (SD=0.42), and the lowest burden was on the caregiver's disrupted schedule dimension of 2.41 (SD=0.35).

The results of the study based on table 3 on caregiver burden among caregivers of patients on hemodialysis showed that the variables related to family burden were age (p-value = 0.006), an education level (p-value = 0.043), income (p-value = 0.002). The age variable indicates the direction of the positive relationship. This means that the older the age and the higher the education, the higher the perceived and the higher the education, the higher the perceived burden. In terms of income, it shows that the lower the payment, the heavier the burden is felt. At the same time, the negative relationship on length of care, gender, occupation, marital status, and relationship with patients means that the higher the level of education and income, the lower the perceived burden. The less often the family accompanies the patient, the lower the perceived burden in terms of the relationship.

DISCUSSION

The study results align with previous family burdens on hemodialysis patients. Previous research showed that caregivers of patients receiving hemodialysis, 69% were females, 72.9% were married, 26.2% were primary school graduates, and 41.4% were the spouse of the patient. The majority of caregivers were females, which can be attributed to women being more compassionate and emotional and being better at coping with the difficulties of caregiving. The patients' spouses assume the majority of caregiving responsibilities. The involvement of spouses in caregiving can be explained by a sense of responsibility to care for their spouses (Kilic & Kaptanogullari, 2017).

Previous research has found that caregiver burden is significantly higher in caregivers over the age of 40. This could be because older caregivers find it more challenging to travel and manage treatment for their patients than younger caregivers. More than half of the caregivers (56%) were found to be working. Estimating socioeconomic status revealed that most caregivers (45.7%) were in the upper-lower. There was a significant difference in caregiver burden based on socioeconomic status. The economic crisis in this group of people appears to have significantly increased the burden on caregivers. Among the caregivers in this study, 41% were found to be spouses. This study found a significant difference in caregiver burden by relationship, with spouses and parents having higher median caregiver burden values than other relationships (Shakya, 2017). A previous study conducted in Asia on COPD patients showed that family members in Asian cultures have strong bonds. They also believe that caring for family members is an obligation. Family caregivers' difficulties, such as a lack of family support and disruptions to their daily schedule, were secondary to their desire to care for their loved ones (Sari, Warsini, & Effendy, 2018)

A study in Turkey showed the characteristics of an average age of 48.88±14.09 years and 54.4% of caregivers aged 40-60 years. In addition, most caregivers are women, namely 59.9% and 49% of caregivers have a relationship as a partner of the patient (Kar & Zengin, 2020). Other study showed that the gender of the respondents, the majority are women (68%), education levels vary with the most being in primary education (41%) (Kang, Yu, Foo, Chan, & Griva, 2019).

Another study was conducted using the Zarit Burden Interview (ZBI) score. The research sample is a family that cares for hemodialysis patients. In this

Table 1. General Characteristics of Family Caregivers and Patients on Hemodialysis

| Characteristic | Family caregivers (n/%) | Patients (n/%) |
|---|----------------------------|-------------------|
| Age (years) (Mean±SD) | 45.8 ± 12.46 | 53.8 ± 14.20 |
| Gender | | |
| a. Male | 21 (35.0) | 31 (51.7) |
| b. Female | 39 (65.0) | 29 (48.3) |
| Education level | | |
| a. Illiterate to senior high school | 46 (76.7) | |
| b. College | 14 (23.3) | |
| Marital status | | |
| a. Married | 50 (83.3) | |
| b. Non-married (single, widow, widower) | 10 (16.7) | |
| Employment status | | |
| a. Unemployed | 22 (36.7) | |
| b. Employed | 38 (63.3) | |
| Family income | | |
| a. < Minimum income level | 29 (48.3) | |
| b. ≥ Minimum income level | 31 (51.7) | |
| Relationship with patient | | |
| a. Spouse | 32 (53.3) | |
| b. Non-spouse (parent, child) | 28 (46.7) | |

Table 2. Caregiver Burden Among Caregivers of Patients on Hemodialysis

| Domain (item) | Mean range | Mean±SD |
|----------------------------------|------------|-----------|
| Caregiver self-esteem (6 items) | 1.00-5.00 | 2.58±0.27 |
| Lack of family support (5 items) | 1.00-5.00 | 3.47±0.42 |
| Financial problem (3 items) | 1.00-5.00 | 2.52±0.85 |
| Disrupted schedule (5 items) | 1.00-5.00 | 2.41±0.35 |
| Health problem (3 items) | 1.00-5.00 | 3.42±0.45 |
| CRA total score (22 items) | 1.00-5.00 | 2.88±0.69 |

study, most subjects were middle-aged with a mean age of more than 40 years. This study also shows that there is no significant relationship between the level of burden scores and the selected sociodemographic variables of the participants (Sharma et al., 2021). This study also shows a similarity with the study results that some sociodemographics do not have a significant relationship with caregiver burden.

Similar studies that are in line with research are the mix method research which explains that the most challenging parenting conditions are economic problems with high costs (78.26%) and not working (50.00%); and experiencing negative feelings (47.83%), stress (43.48%), and physical difficulties (34.78%). Qualitative findings reveal nurturing needs and challenges in cost management, physical and psychological health, multiple role assumptions, lifestyle adjustments, and strengthening caregiver knowledge, skills, and attitudes. (Torres et al., 2021).

Based on the results of research carried out on the families of patients in hemodialysis rooms, the number is 2.88 ± 0.69 in the score range of 1-5. This means that the burden of treating renal failure patients undergoing hemodialysis is above the median value. This is in line with the caregiver burden research with the same questionnaire conducted in Indonesia with a mean result of 2.38 (SD = 0.38) (Sari et al., 2018). Another study using different measuring instruments in COPD patients in Turkey was carried out. A total of 64.8% and 18.1% of caregivers have light and moderate care burdens, respectively (Kar & Zengin, 2020). Similar studies have also been conducted on families of hemodialysis patients with a different measuring instrument, namely The Oberst Caregiving Burden Scale-Difficulty (OCBS-D). The study results showed a value of 42.0 ± 4.7 which means that the family burden analysis is at a moderate to high burden among caregivers (Alnazly, 2021).

A similar study used the ZBI score with a sample

Table 3. Caregiver Burden Among Caregivers of Patients on Hemodialysis

| Variabel | Mean±SD ^a | Correlation significant (r) ^b | p-value |
|---|----------------------|--|---------|
| Age caregiver | - | 0.350 | 0.006** |
| Gender | | | |
| a. Male | 2.89±0.22 | | 0.771 |
| b. Female | 2.87±0.20 | | |
| Education level | | | |
| a. Illiterate to senior high school | 2.90±0.21 | | 0.043* |
| b. College | 2.77±0.15 | | |
| Employment status | | | |
| a. Unemployed | 2.89±0.21 | | 0.432 |
| b. Employed | 2.85±0.21 | | |
| Family income | | | |
| a. < Minimum income level | 2.96±0.19 | | 0.002* |
| b. ≥ Minimum income level | 2.79±0.20 | | |
| Marital status | | | |
| a. Married | 2.77±0.18 | | 0.089 |
| b. Non-married (single, widow, widower) | 2.89±0.21 | | |
| Relationship with patient | | | |
| a. Spouse | 2.90±0.21 | | 0.280 |
| b. Non-spouse (parent, child) | 2.84±0.20 | | |

^aIndependent t-test; ^bPearson correlation or Spearman Rho; **p < 0.01 indicate significance; *p < 0.05 indicate significance; SD. Standard Deviation

of families caring for patients on hemodialysis. In this study, most subjects were middle-aged with a mean age of more than 40 years. The results revealed that almost half of the caring families, i.e., 50 (45.46%), reported a mild to moderate burden. While 15 (13.63%) families have a medium to a heavy burden, Families are light to moderately burdened because the average burden score is 25±12 (range 0-88) (Sharma et al., 2021).

Caregiver burden (as measured by ZBI) increased significantly over time (p < 0.01), with mean scores at baseline in the light burden range and increasing to moderate burden 12 months later. In particular, the proportion who reported moderate to severe burden symptoms increased significantly from 13% at baseline to 28% (p < 0.01) (Kang et al., 2019).

CONCLUSION

This study found that caregivers of patients receiving hemodialysis have a moderate burden significantly related to increases in the patient's age and family income. The responsibility was greater for family caregivers who spend more time caring for their patients and lack family support, health issues, and low caregiver self-esteem. Factors that may be

potential targets for preventative intervention strategies to reduce the burden include developing and implementing interventions, such as providing an education program about hemodialysis care or involving family caregivers in advanced care planning. It may be necessary for reducing the burden among family caregivers caring for a family member on hemodialysis. Further investigation of caregiver burden by age group is suggested to improve understanding of these findings and facilitate generalization to a larger population of caregivers.

Acknowledgments

The author would like to thank all caregivers, nurses, and nurse managers for their participation and support in the study. The author want to thank the Ministry of Research and Technology of Indonesia for the funding grant.

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