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Caregiver Burden on Caregiver with Chronic Disease

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ABSTRACT

Background: The prevalence of chronic diseases in Indonesia increases every year with various accompanying physical and psychological problems. In this state, patients require the assistance of their families as caregivers. Family caregivers are an important source of care for patients which faced physical, psychological, social, and economic challenges when providing care.

Purpose: The purpose of this study was to identify the burden among family caregivers of chronic diseases patients.

Methods: This cross-sectional study was conducted from April 2021 to November 2021 in the Hospital and Community Health Center. Purposive sampling was used to determine the inclusion and exclusion criteria for the 180 respondents in this study. The Caregiver Reaction Assessment-Indonesian Version (CRA-ID) was used to measure their burden. Data were analyzed using descriptive and bivariate analyses with independent t-tests and Pearson correlation.

Results: The results of the research showed a significant relationship between caregiver burden and age (p-value=0.000), but no relationship was found between gender, marital status, relationship with patients, caregiver education, caregiver job, and income with each p-value 0.756; 0.725; 0.791; 1.000; 0.354 and 0.301.

Conclusion: Age was significantly related to caregiver burden in caring for family members who suffered from chronic diseases. Health services were expected to provide adequate information for caregivers about caring for chronic disease patients to reduce caregiver burden.

Keywords: caregiver, caregiver burden, chronic diseases, family

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BACKGROUND

The prevalence of chronic diseases in Indonesia increases every year. Indonesia could be on the verge of an epidemic if there are no specific policies and controls for non-communicable disease (NCD) (Kusuma et al., 2019). The Indonesian Ministry of Health in the 2018 Basic Health Research stated that currently the prevalence of NCD increased from 2013, namely stroke at age > 15 by 10.9%, diabetes mellitus 2.0%, and hypertension at age > 18 by 34.11%, and kidney failure at the age of > 15 years by 0.38% (Kemenkes RI, 2018). Increased government efforts in the prevention and control of NCDs have been carried out but the increase in risk factors and morbidity remained unsettling. A comprehensive health system from primary to tertiary care in preventing and controlling the disease is currently not maximal in diagnosing populations with chronic diseases (Kusuma et al., 2019).

Patients with chronic diseases have various physical and psychological problems. Stroke patients experience limitations in movement, communication, thinking, and aphasia. This limitation resulted in psychological responses such as lack of self-acceptance, depression, and anxiety (Alifudin & Ediati, 2019). Diabetes mellitus patients also have classic symptoms of polyuria, polydipsia, polyphagia, weight loss, fatigue, and neuropathic complications. Those symptoms on visual impairment and episodes of prolonged infections (International Diabetes Federation, 2018). Chronic kidney failure patients also experience similar symptoms such as fatigue, itchiness, drowsiness, dyspnea, edema, pain, dry mouth, muscle cramps, nausea, vomiting, and psychological problems such as depression, anxiety, and social distress (Aisara et al., 2018).

Various problems that emerged in patients with chronic diseases prompted them to require caregivers or individuals who provide assistance or care in all their activities. The family as the smallest unit in the social environment functions as a caregiver for the family who suffered from diseases (Alifudin & Ediati, 2019). When chronic diseases affected one family member it became the concern of the whole family owing to its economic and psychosocial impact and affects lifestyle (Kilic & Kaptanogullari, 2017). Family caregivers are an important source of care for patients. Even though caring for family members is fun, caregivers experience several physical and psychological burdens in caring for them which will affect the quality of life of the families of hemodialysis patient caregivers (Sajadi et al., 2020). Caring for patients resulted in stress and prompted the family to make efforts in their struggle against difficult situations caused by chronic illness. Knowledge of caregiver burden and influencing factors are essential for protecting patient health, treatment planning and its methods, and nursing services (Joy et al., 2019; Kilic & Kaptanogullari, 2017).

Research showed that caregivers of stroke patients experienced stress in the form of physical fatigue, psychological fatigue, family demands, and financial problems (Fajriyati & Asyanti, 2017). Another study also showed as many as 4.3% of families had a moderate burden and 2.2% of families were moderately depressed in caring for stroke patients and there was a positive relationship between burden and depression with a p-value of 0.00 (Pahria et al., 2019). Research on the burden of family caregivers in patients undergoing hemodialysis showed that most of them experienced a light burden level of 42.9%, a moderate burden level of 34.7%, and a heavy burden level of 2.0%, while personal pressure as much as 87.8% and role pressure as much as 12.2% (Nugroho & Sabarini, 2019). A longitudinal study on caregiver burden showed a relationship between caregiver burden and depression as evidenced by $p<0.01$ (Kayaalp et al., 2020).

The caregiver burden is an unpleasant experience for the patient's care provider, which involves financial, social, psychological, and physical dimensions. Some carers of hemodialysis patients have reported a high care load. Acceptance of the carer job and the adjustments that accompany it, in addition to having a beneficial impact on patients and their families, may have a negative impact on carers' physical and mental health, as well as their social ties. It could also cause a slew of physical, emotional, and psychological issues for carers, exposing them to a variety of physical and psychological risks (Menati et al., 2020; Nugroho & Sabarini, 2019).

Caregiver burdens being experienced were negative feelings, physical health, mental and social life. The burdens experienced by the caregivers should not be overlooked because they would affect their quality of life (Nugroho & Sabarini, 2019). An awareness of what was experienced by caregivers was expected to optimize intervention actions to reduce negative impacts on caregivers' lives (Shakya, 2017). Research on caregiver burden in caregivers of patients with chronic disease has not been done much. The interventions that have been implemented have not made many changes to the caregiver burden. The researchers were interested in looking at the caregiver burden on caregivers. This is to discover the description of the caregiver burden experienced and the factors related to them.

OBJECTIVE

The purpose of the study was to identify the burden among family caregivers of chronic diseases patients.

METHODS

This research employed a descriptive-analytic design with a cross-sectional approach. It was conducted in two locations, Hospital Yogyakarta and Community in Sleman Yogyakarta working area. The population was all caregivers who cared for patients with chronic diseases. The technique was purposive sampling. The researchers selected the respondents according to inclusion and exclusion criteria. The inclusion criteria were 1) caregivers for patients with chronic diseases (stroke, diabetes mellitus, and chronic kidney failure), 2) caring for patients with chronic diseases at least 2 months after the diagnosis of the chronic disease, 3) primary family caregivers (main caregivers with the highest level of responsibility) whose family members suffer from chronic diseases, 4) signed the informed consent. The exclusion criteria in this study were formal caregivers or caregivers who were paid not by the patient's family. The number of samples in this research was 180 respondents.

The data collection instrument was in a form of a demographic characteristics questionnaire and a Caregiver Reaction Assessment-Indonesian Version (CRA-ID) questionnaire consisting of 5 domains totaling 22 questions. The answer choices comprised of strongly disagree, disagree, undecided, agree, and strongly agree. This questionnaire had been used in previous researches, namely caregiver burden in patients with cancer. The collected data were processed through the process of editing, coding, and tabulating. The data were then analyzed using descriptive statistics to describe the characteristics of the respondents and the caregiver burden, then proceed with bivariate analysis to determine differences in caregiver burden in treating chronic patients, namely stroke, diabetes mellitus (DM), and chronic kidney failure (CKD).

Statistical software was used to enter and analyze data. The descriptive normality test was used to describe the normality of the numerical data. Mean values and Standard Deviation (SD) were used when symmetrical. Median values and interquartile ranges (IQR) were used when skewed. The independent t-test was used to compare the difference in the mean of the burden according to the family caregivers' and patients' characteristics. The Pearson correlation was used to correlate the burden with the family caregivers' and patients' characteristics.

The researchers had submitted an ethical feasibility test on this research to the Health Research Ethics Commission of PKU Muhammadiyah Hospital Yogyakarta and it had been declared ethically feasible according to 7 (seven) WHO standards with the number 00129/KT.7.4/IV/2021. Each respondent who was willing to participate in this study had signed informed consent. This study conducted from April 2021 to November 2021.

RESULTS

Demographic Characteristics

The results of the investigation of the demographic characteristics in this research are shown in table 1. A total of 60 caregivers for each chronic disease suffered by the patient, namely stroke, diabetes mellitus, and chronic kidney failure so that a total of 180 respondents signed the informed consent. There were 60 respondents of stroke caregivers, 60 respondents of diabetes mellitus caregivers, and 60 respondents of chronic kidney failure caregivers. Table 1 demonstrates the characteristics of respondents in patients with chronic diseases.

Table 1. Demographic Characteristics of Caregivers in Patients with Chronic Disease (n=180)

Characteristics	Caregivers (n/%)	Patient (n/%)
Mean Age ± SD (years)	45.8 ± 13.18	57.9 ± 13.61
Gender *(f(%))*		
a. Male	65 (36.1)	81 (45.0)
b. Female	115 (63.89)	99 (55.0)
Marital Status		
a. Married	162 (90.0)	
b. Single (unmarried, widow, widower)	18 (10.0)	
Relationship with the patients		
a. Spousal	99 (55.0)	
b. Not spousal (parents, children)	81 (45.0)	
Education		
a. Primary school educated	154 (85.56)	
b. University educated	26 (14.44)	
Employment status		
a. Employed	119 (66.11)	
b. Unemployed	61 (33.89)	
Family Income		
a. < Daily Minimum Wage	99 (55.0)	
b. ≥ Daily Minimum Wage	81 (45.0)	

Source: Primary Data 2021

Table 1 demonstrates that most of the respondents were 45 years old (45.8 ± 13.18) with an average age of 58 years (57.9 ± 13.61). The majority of the respondents were women as many as 63.89% (115 people) whom majority care for female patients as many as 55% (99 people). The majority of the respondents were married as much as 90.0% (162 people). The majority of the relationship with patients were being cared for by spouses, namely husband or wife as much as 55.00% (99 people). The majority of respondents' education level was between elementary school to high school or vocational education of 85.56% (154 people).

The majority of the respondents were employed as many as 63.3% (38 people) with income mostly below or equal to the minimum wage of 51.7% (31 people).

Table 2. Caregiver Burden in Patients with Chronic Diseases (n=180)

Domain (items)	**Mean range**	**Mean±SD**
Self-esteem caregiver (6 items)	1.00-5.00	2.13±0.56
Lack of family support (5 items)	1.00-5.00	2.86±0.61
Financial impact (3 items)	1.00-5.00	2.67±0.75
Impact on schedule (5 items)	1.00-5.00	2.61±0.68
Health impact (3 items)	1.00-5.00	2.54±0.82
Total score CRA-ID (22 items)	1.00-5.00	2.56±0.73

Table 2 demonstrates the total caregiver burden based on the CRA-ID questionnaire. The average respondent had a burden of 2.56±0.73. The higher the score, the higher the perceived burden. According to the CRA-ID domain, the highest domain lied in the domain of lack of family support, which was 2.86±0.61 and the lowest was in the caregiver's self-esteem domain, which is 2.13±0.56.

The Relationship between Respondents' Characteristics and Caregiver Burden in chronic disease caregivers

The researchers also evaluated the data using bivariate analysis. In this analysis, the researchers correlated the burden of the family caregiver tending the patient with gender, age, level of education, occupation, income, length of care, and relationship with patients using the Pearson test and the Independent T-Test.

Table 3. Correlation of Respondents' Characteristics to Caregiver Burden in Chronic Diseases Patients (n=180)

Variable	**Mean±DS**[a]	**Correlation significant (r)**[b]	**p-value**
Caregiver's age		1.000	0.000*
Gender of the caregivers			
a. Male	2.57±0.36		0.756
b. Female	2.55±0.32		
Marital Status			
a. Married	2.53±0.35		0.725
b. Single (unmarried/widow/widower)	2.56±0.33		
Relationship to patients			
a. Spousal	2.57±0.35		0.791
b. Not spousal (parents, children)	2.55±0.32		
Caregiver's education			
a. Primary school educated	2.56±0.35		1.000
b. University educated	2.56±0.26		
Employment			
a. Employed	2.58±0.33		0.354
b. Unemployed	2.53±0.34		
Income			
a. Below the Minimum Regional Wage	2.58±0.35		0.301

b. Above the Minimum Regional Wage	2.53±0.32

[a]Independent *t*-test; [b]Pearson correlation or Spearman Rho; $**p < 0.01$ nilai signifikansi; $*p < 0.05$ significance value; DS. Deviation Standard

Based on the results of research on families who cared for patients with chronic kidney failure at two research sites in Yogyakarta, the variable related to family burden was the caregiver's age (p-value 0.00, r=1.000). The direction of the positive relationship was indicated by the age variable that the older you get, the higher the perceived burden. Meanwhile, the direction of the negative relationship is shown on the caregiver's gender, marital status, relationship to the caregiver, education, job, and income. Six unrelated variables were gender, marital status, relationship with patients, caregiver's education, caregiver's occupation and income with p-values of 0.756; 0.725; 0.791; 1.000; 0.354 and 0.301. From these factors, the caregiver's age was the strongest factor related to the caregiver burden with the caregiver's age (p-value = 0.000).

DISCUSSION

The majority of respondents' education level was primary to high school education or vocational education of 85.56% (154 people). The majority of the respondents worked, as many as 63.3% (38 people), with income mostly below or equal to the regional minimum wage of 51.7% (31 people). This is in line with previous research which revealed that as many as 41% had a spousal relationship between caregivers and patients. The majority of the caregivers, 56 %, were employed, and their economic status showed that most of them, 45.7 %, earned below the regional minimum wage (Shakya, 2017). The results of the research were obtained from data collection conducted on the families of patients at Hospital Yogyakarta and the Community Health Center. The results show that the total score of the CRA-ID questionnaire on the respondents has an average of 2.56±0.73. The results mean that in general the burden of treating kidney failure patients undergoing hemodialysis is above the median value. The higher the score, the higher the perceived burden. According to the CRA-ID domain, the highest domain lies in the domain of lack of family support, 2.86±0.61, and the lowest was in the caregiver's self-esteem domain, 2.13±0.56. Based on the results of research conducted on families of chronic disease patients, the figure is 2.56±0.73. The result means that in general the burden of caring for kidney failure patients undergoing hemodialysis is above the median value. Similar studies have been undertaken on families of hemodialysis patients using other measurement tools, OCBS-D. The study's findings revealed a score of 42.04.7, indicating that the family burden analysis revealed a moderate to high level of hardship among carers (Alnazly, 2021).

In this research, the majority of the subjects were middle-aged, and their average age was more than 40 years, using the Zarit Burden Interview (ZTI) score with a sample of families caring for patients on hemodialysis reveals that almost half of the families who provided care,50 (45.46%), reported light to moderate load. While 15 (13.63%) families had a moderate to heavy burden. The family was light to moderately burdened because the average burden score was 25 ± 12 (range 0-88). There was no significant relationship between the load score level and the selected sociodemographic variables of the participants (Sharma et al., 2021). The mean age of the caregiver was 45.8±13.18 years. Of all the caregivers, 63.89% were women 36.1% were men. As many as 55% of caregivers were the patient's partner. A total of 64.8% and 18.1% of caregivers had a light and moderate care burden, respectively (Kar & Zengin, 2020). The results of the analysis of family burden, in each domain, show that the respondents had the highest burden on the domain of lack of family support 3.47±0.42. The result is in agreement with the research which showed a value of 2.62 ± 0.98 that indicated that families did not get support from the people around them (Sari et al., 2018). Another research on 867 pairs of adults with family as the primary caregivers found the factors that affected the caregiver's burden. In this search, the average age of the caregiver was 55.27±13.7 years (Aung et al., 2021).

In mixed-method research, participants provided moderate assistance to patients, spent an average of 10.65 h/day, and 5.08 days/week in care. The most difficult parenting conditions were high costs (78.26%); no job (50.00%); and experiencing negative feelings (47.83%), stress (43.48%), and physical difficulties (34.78%). They also had the lowest confidence in deciding when to contact a healthcare provider ($\bar{x} = 3.31$, SD = 0.94) and find patient care services ($\bar{x} = 2.93$, SD = 1.08). The qualitative findings further 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).

Caregiver burden (as measured by ZBI) increased significantly over time ($p < 0.01$), with average scores at the beginning approximately between light burden and increased to moderate burden 12 months later. In particular, the proportion that reported moderate to severe symptoms increased significantly from 13% at baseline to 28% ($p < 0.01$) (Kang et al., 2019). A cross-sectional study was also conducted on caregivers of patients with cancer. The results showed that there was an effect of caregiving on the caregiver burden level with the magnitude of the effect being 69.9% ($p = 0.000$; $R = 0.0699$). The more varied the patient's complaints would have an impact on the imbalance of time the caregiver had to relax. They became a stressor that triggers stress, and in the long term, it can lead to caregiver burden (Werdani, 2018). Similar research with respondents, namely the main caregiver (family) aimed to look at the factors that affect the caregiver's burden. In that research, 5.5% of all respondents showed a Caregiver Burden Inventory (CBI) score of 24. The highest burden was recorded in the time dependence burden domain (25.7%). Significant related factors influencing CBI 24 were caregivers being older than 60 years, female, active smokers, having diabetes, and caring for seniors with a moderate to the severe likelihood of depression and dependence. The conclusion of this research revealed that a quarter of caregivers may experience career disruption due to the time spent caring for their families (Aung et al., 2021). That outcome was also explained in longitudinal mediational research. The caregiver burden was calculated using the CBI which measured the caregiver burden in six aspects. This research showed that caregiver burden and mental health were adequately related. Mental health problems were quite frequently experienced, starting from conflict or tension. The role of the stressful and demanding family also played a part in creating this conflict. Matters that played a role in parenting that affect caregivers include time dependence, physical social development, and emotional aspects. The increased caregiver burden would consume the available time and energy hence the work role would be reduced (Kayaalp et al., 2020).

A cross-sectional study including 340 carers of chronic renal patients receiving hemodialysis in Malaysia looked at carer burden, quality of life, social support, and anxiety and depression symptoms. The study found that 28.8% and 52.4% of carers had moderate levels of anxiety and clinical depression, respectively. Furthermore, 35.9% and 3.8% of respondents, respectively, reported clinically high levels of anxiety and depressed symptoms. According to the findings, the general quality of life was a significant predictor of anxiety and depression symptoms. Psychological burden and quality of life domain significantly predict anxiety. In addition, lack of social support was a determinant factor of depressive symptoms. Social support moderated the relationship between burden and anxiety. Caregivers with low levels of social support experienced more anxiety symptoms as their burden increased (Shukri et al., 2020). Another study used ZBI in patients with chronic kidney failure using 57 caregivers for patients with chronic kidney failure. The results showed that 28 (49.1%) caregivers had mild to moderate anxiety and 19 (33.3%) had a high burden. The average ZBI burden score was higher in female caregivers compared to male caregivers (18.30±8.11 with 14.83±6.70), p = 0.09). In this case, caregiver burden had a significant positive correlation between ZBI burden and hospital anxiety score (r = 0.539, p = <0.001) and depression score (r = 0.472, p = 0.005) (Adejumo et al., 2019).

Previous research in Iran found that carers for hemodialysis patients had a comparatively high care load (Menati et al., 2020). Another study in Indonesia employed the ZBI questionnaire on 49 carers of patients on hemodialysis for chronic renal failure. According to the study, 42.9% of carers felt a mild load, 34.7% felt a moderate burden, and 2.0% felt a significant strain (Nugroho & Sabarini, 2019). According to a qualitative study conducted in Indonesia on the experiences of families caring for patients with chronic renal failure, one of the negative effects of treatment was a lack of time for oneself. Furthermore, carers found it difficult to socialise and contribute to the surroundings. When it came to finding medical bills for patients, economic issues were also a barrier. Support for carers and patients with chronic renal failure improved everyday life quality (Naufal & Setyawan, 2018). Another research also utilized the ZBI questionnaire. The research involved 56 primary caregivers who cared for stroke patients for at least 3 months. Age, gender, employment status, income, marital status, family relationships, and family support have a significant relationship with caregiver burden in caring for stroke family members (p=value<0.005). Social and family support made caregivers stronger hence they were able to carry out their roles to the fullest by minimizing stress potential (Ariska et al., 2020). A similar study on 181 caregivers on stroke showed that when the perception of family harmony increased and the amount of time spent for caregivers decreased, the caregiver's burden was reduced. Professional support to help families adapt to their changing roles (Kes & Yildirim, 2020).

Qualitative research on caregivers' experience with stroke patients found a description of resilience in stroke patients' caregivers. The results showed that there were resilience abilities in the three subjects which were seen from the seven aspects that formed resilience, namely emotional control, impulse control, optimism, causal analysis, empathy, self-efficacy, and achievement. Respondents needed adjustment because there were changes in roles in the family. Role changes gave rise to role conflicts that could have both positive and negative behavior. Positive behavior of respondents such as being active in asking doctors about how to treat individuals with stroke, seeking information about stroke, seeking alternative medicine to recover. While negative behavior was ever feeling tired in caring for the many roles that must be carried out. The efforts of respondents by seeking information about stroke, controlling emotions when dealing with patients, beliefs, and hopes for the patient's recovery, the ability to empathize, and the ability to take positive values from events experienced by respondents represent the efforts of resilient individuals (Alifudin & Ediati, 2019).

This research, a part of a cohort study, examined the journey of caregiver burden in the first year after stroke. Caregivers were asked to complete the Caregiver Strain Index and questions about their socio-demographic characteristics 6 and 12 months after hospital admission. The results of this research on 129 caregivers showed that as many as 19 (26.4%) respondents were male, the average age was 59 (range 27-78) years. High and low load results were consistently reported by 15 (20.8%) respondents and 49 (68.1%) respondents. Meanwhile, as many as 8 (11.1%) respondents reported a high burden either in the first 6 or 12 months. Caregivers who lived with patients suffering from hemorrhagic stroke were more at risk of experiencing a high burden (Pont et al., 2020). Qualitative research that aimed to examine the nature of the role of caregivers in supporting the management of type 2 diabetes patients was carried out using a thematic analysis approach. The results of the research concluded that the three main roles of caregivers in diabetes management were direct care support, memory support/care organizer, and advocate. Three explanations for assuming a nurturing role emerged when there was a change in the patient's health, the natural evolution of family roles, and the caregiver's experience or health care training (Fields et al., 2020). A similar cross-sectional descriptive study was also conducted with caregivers of patients with type 2 diabetes mellitus. ZBI questionnaires were distributed to caregivers. The results showed that as many as 42% of caregivers experienced little or no burden, 47% had a light to a moderate burden, 8% had a moderate to a heavy burden, and 3% had a heavy burden. When the ZBI score was divided into 2 parts, namely low and high loads, as many as 89% were found to have low loads, while 11% experienced high loads. In logistic regression, women were found to be four times more likely to experience a high burden. Meanwhile, 35% of caregivers had a General Health Questionnaire (GHQ) score > 3, indicating that psychological stress and psychological pressure were found to be significantly related to caregiver burden (Jane et al., 2019).

CONCLUSION

The results of this research show that there was a significant relationship between caregiver's age and caregiver burden for chronic illness caregivers (p-value=0.000). While the unrelated variables were gender, marital status, relationship with patients, caregiver education, caregiver's occupation and income with p-value 0.756; 0.725; 0.791; 1,000; 0.354 and 0.301. Health services were expected to provide adequate information for caregivers about care for chronic disease patients to reduce caregiver burden.

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