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THE OVERVIEW OF CAREGIVER BURDEN IN FAMILIES WITH HEMODIALYSIS PATIENT

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ABSTRACT

Chronic renal failure patients undergoing haemodialysis therapy experience various conditions and require long-term care which can cause a burden on the families who care for patients. This family caregiver burden can affect the quality of life of both patients and family caregivers, and also affect the care provided to patients. The purpose of the study was to determine the description of caregiver burden in families with haemodialysis patients. This study is a quantitative descriptive study and the sample was taken using purposive sampling technique (n = 107) with the inclusion criteria of respondents as the main caregiver with family members undergoing haemodialysis therapy at RSUD Sumedang, and physically and mentally healthy. Exclusion criteria in the study were potential respondents who refused to participate and respondents who decided to stop in the middle of the study. The burden of caregivers on the family was measured using the Burden Scale for Family Caregivers Short Scale (BSFC-s) questionnaire with test results, namely r results (0.634) > r table (0.786) as well as Cronbach alpha value of 0.900 which means this questionnaire is valid and reliable. The picture of caregiver burden shows that almost half of family caregivers are in the high category (49.5%) and most experience heavy burden in the physical dimension. The results of this study are expected to be used as a reference for learning and evaluation for nurses, family caregivers, and educational institutions to be able to carry out effective interventions that can be carried out to reduce the burden of care experienced by family caregivers.

Keywords: caregiver burden; family caregiver; haemodialysis

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INTRODUCTION

Chronic renal failure is one of the diseases that cause the most death and suffering in the 21st century. According to data from Riskesdas in 2018, a total of 713,783 Indonesians have chronic kidney failure with around 6% of these patients being in severe condition and requiring renal replacement therapy (Kemenkes, 2017). Haemodialysis therapy is the most widely performed renal replacement therapy. Haemodialysis is the process of cleansing the blood of metabolic waste and excess fluid with the help of artificial kidneys and haemodialysis machines (Setiati et al., 2014). The long duration of haemodialysis causes patients to need other people to accompany the treatment process. In the process of therapy, patients will experience side effects such as hypotension, cramps, nausea and vomiting, arrhythmias, headaches, and mental disorders such as disequilibrium syndrome due to the correction of azotemia (Tjokroprawiro, 2015). The side effects that will arise then require the role of the family during the patient's treatment process, including accompanying and providing support to the patient. The form of family support provided can be various with the aim of reducing the anxiety experienced by patients about their illness, helping patients to comply with restrictions, and also supporting patients to achieve compliance (Utami et al., 2015). Families play a very important role in therapeutic health care for sick family members. Family participation and support in the recovery process is one of the most influential factors. Family support is a process that occurs throughout life (Friedman, 2015). The patient's family will provide long-term care to patients with chronic diseases. Care is provided to help patients achieve their health through the healing process by focusing on meeting the patient's health needs holistically, including efforts to restore emotional, spiritual and social health.

Caregivers of the patient consist of formal and informal caregivers. Formal caregivers are health care professionals who provide paid care, while informal caregivers provide unpaid care and are an extension of formal caregivers. Informal caregivers usually have close relationships with patients such as family, relatives, friends, or neighbours (Maulidya, 2022). In Indonesia, informal caregivers are mostly carried out by families (Rizka et al., 2021). The existence of a close family relationship makes families more involved in patient care in hospitals or at home. Caring for sick family members has become a tradition in Indonesia and is considered an obligation, this is also related to the belief values held by most Indonesians (Effendy et al., 2015).

The family as a caregiver is the first provider of care to patients with chronic diseases, including patients undergoing haemodialysis both at home and in the hospital. The care provided includes personal hygiene, providing patient medication, transferring patients to dialysis centres, helping patients eat, and providing emotional and mental support to patients (Farzi et al., 2019). Families as caregivers when caring for their family members can feel a considerable burden, tension, and stress both physically and psychologically. Stress felt in family caregivers is a sign that if not given proper treatment, it can lead to higher levels of stress which is one of the early symptoms of psychological disorders such as depression (Stuart, 2016). The adverse circumstances experienced by families will result in negative impacts both physically, emotionally, socially, and financially. The bad situation experienced by the family is called a caregiver burden (Maulidya, 2022).

Caregiver burden is a change in physical and emotional health experienced by caregivers and stress in caring for sick families for a long period of time. There are several factors that significantly affect the level of burden experienced by caregivers in caring for chronically ill family members, including caregiver’s age, gender, education level, employment status, income, marital status, family relationships, and support from family (Ariska et al., 2020). The patient's quality of life is also one of the stressors for the patient's caregiver. The more severe the level of illness suffered by the patient, the higher the burden felt by the caregiver (Joanna Briggs Institute, 2012). Caregiver burden has been shown to threaten life satisfaction, physical, mental, financial, and social well-being (Graessel et al., 2014). Diniz et al. (2018) said that the mental burden experienced by family caregivers is very large compared to other caregivers because there is emotional involvement with patients. The burden on caregivers can come from external factors including medical expenses, health facilities, transportation, and from internal factors such as physical, mental, and emotional family. The increasing burden of the family as a caregiver will affect family support, the quality of care, and the care process provided to patients (Maulidya, 2022). The burden on high family caregivers can also have an impact on the patient's worsening condition so that appropriate interventions are needed in providing social support services and improving the caregiver's psychological condition (Shakya, 2017).

Previous research conducted by Menati et al. (2020) in Iran found that caregivers of haemodialysis patients experience a relatively high burden. Another study conducted in Indonesia on caregivers of patients with chronic renal failure using the Zarit Burden Interview (ZBI) questionnaire found that family caregivers experienced a heavy burden (Nugroho et al., 2019). There are several studies conducted both abroad and in Indonesia using the Zarit Burden Interview (ZBI) questionnaire to caregivers who care for patients with CKD undergoing haemodialysis therapy, while research related to caregiver burden focused on families using the Burden Scale For Family Caregivers Short Scale (BSFC-s) questionnaire on those undergoing haemodialysis therapy is still small in Indonesia, especially in regional hospitals. Knowledge related to family caregiver burden is important to know in order to determine interventions, recommendations, and nursing care that can be done. In addition, it affects the family support that will be given to patients. The purpose of this study was to determine the description of caregiver burden on families with haemodialysys patients at RSUD Sumedang.

METHOD

This study used descriptive quantitative research methods to determine the description of caregiver burden on families with haemodialysis patients. The variable in this study is the burden of caregivers on families with haemodialysis patients. The population in the study were family members who acted as caregivers for patients undergoing haemodialysis therapy at RSUD Sumedang, with a total of 146 patients who routinely undergo therapy every month. The sample was taken using purposive sampling technique with a minimum research sample of 107 people. The minimum sample was obtained using the Slovin formula. The inclusion criteria set in the study were respondents with family members undergoing haemodialysis therapy at RSUD Sumedang, respondents as the main family caregiver who provided care to haemodialysis patients, and respondents who were physically and mentally healthy. Exclusion criteria in sample selection were prospective respondents who refused to participate or did not fill out the informed consent sheet, as well as respondents who decided to stop in the middle of the study. Caregiver burden in families with haemodialysis patients has an operational definition, namely feelings of stress in the form of negative responses related to life satisfaction, physical health, mental, financial, and social life as a result of the family's role as caregiver, which can cause several problems.

Data were collected using an instrument developed by Graessel, Litche, & Grau in 2014. The Burden Scale for Family Caregivers Short Scale (BSFC-s) questionnaire is used to examine the burden of care in relation to life satisfaction, physical, mental, financial health, and social life in family caregivers. This instrument has been translated into Indonesian by Havilah (2021) and conducted validity and reliability tests and obtained r results (0.634) > r table (0.786) as well as a Cronbach alpha value of 0.900 which means that this questionnaire is valid and reliable. Data were analysed using descriptive statistical analysis, namely frequency distribution. The research results obtained will then be interpreted in several categories of results according to Arikunto (2013). The data from the 10 BSFC-s question items will be analysed using the total score obtained from the 10 questions asked on the variables studied. Each question will be assessed using a Likert scale with a value of 0 = strongly disagree; 1 = disagree; 2 = agree; 3 = strongly agree which then the value of each question is summed up so as to get a minimum value of 0 and a maximum of 30. The results will then be divided into 3 categories including mild caregiver burden (0-4), moderate caregiver burden (5-14), and heavy caregiver burden (15-30).

RESULTS

Table 1.
Respondent Characteristics (n= 107)

Respondent characteristics	f	%
Caregiver Age		
Late adolescence (17-25 years old)	9	8,4
Early adulthood (26-36 years old)	22	20,6
Late adulthood (36-45 years old)	35	32,7
Early elderly (46-55 years old)	29	27,1
Late elderly (56-65 tahun)	9	8,4
Seniors (>65 years old)	3	2,8
Gender		
Male	36	33,6
Female	71	66,4
Tribe		
Jawa	5	4,7
Sunda	100	93,5
Minang	1	0,9
Other	1	0,9
Education Level		
Not in school	2	1,9
Primary school/equivalent	21	19,6
Junior high school/equivalent	31	29
High school/equivalent	50	46,7
College	3	2,8
Employment Status		
Not working	66	61,7
Work	41	38,3
Income		
<UMK (<Rp 3.471.134,10)	92	86
≥ UMK (≥RP 3.471.134,10)	15	14
Marital Status		
Married	94	87,9
Not married	13	12,1
Primary Caregiver Relationship with Patient		
Parents	37	34,6
Partner	45	42,1
Child	12	11,2
Siblings other than nuclear family (parents, partner, child)	13	12,1
Total Number of Caregiver		
1-2 people	83	77,6
3-4 people	24	22,4
Caregivers's Relationship with The Patient (Other Than Primary Caregiver)	96	89,7
Nuclear family (parents, partner, child)	10	9,3
Siblings other than nuclear family	1	0,9
Patient's Age		
Early adolescence (12-16 years old)	1	0,9
Late adolescence (17-25 years old)	3	2,8
Early adulthood (26-35 years old)	9	8,4
Late adulthood (36-45 years old)	14	13,1
Early elderly (46-55 years old)	27	25,2
Late elderly (56-65 years old)	31	29
Seniors (>65 years old)	22	20,6
Patient's Condition		
Fully assisted	15	14
Partially assisted	55	51,4
Independent	37	34,6

Respondent characteristics	f	%
Length of Paient Care		
1 year	25	23,4
1-2 years	34	31,8
>2 years	48	44,9

Table 1, it is found that almost half of the respondents, namely 35 respondents (32.7%) in this study, fall into the age range of 36-45 years or the late adulthood group, most of the respondents are female 71 respondents (66.4%), as many as 100 respondents (93.5%) or almost all of them are Sundanese, almost half of the respondents have a final education level of SMA / equivalent, namely as many as 50 respondents (46.75%), most of them with a total of 66 respondents (61.7%) do not work and almost all of them have an income <UMK (<Rp 3.471.134,10) with total 92 respondents (86%). Almost all respondents, 94 respondents (87.9%) were married. Almost half of them are the patient's spouse as many as 45 respondents (42.1%), 83 respondents (77.6%) or almost all of them are primary caregivers and are assisted by 1-2 caregivers who also have a relationship with the patient, namely as the patient's nuclear family. It can also be concluded that almost half of family caregivers care for patients in the late elderly group with an age range of 56-65 years as many as 31 people (29%), most caregivers are partially assisted with a total of 55 respondents (51.4%), almost half or a total of 48 respondents (44.9%) caring for patients for >2 years.

Table 2.
Families caregiver burden (n= 107)

Category	f	%
Mild Caregiver Burden Level (0-4)	4	3,7
Moderate Caregiver Burden Level (5-14)	50	46,7
Heavy Caregiver Burden Level (15-30)	53	49,5

Table 2, it shows that almost half of the frequency distribution of family caregiver burden levels in caring for haemodialysis patients at RSUD Sumedang is in the high category as many as 53 respondents (49.5%).

Table 3.
Families caregiver burden dimensions (n= 107)

Families caregiver burden dimensions	SD (0)	%	D (1)	%	A (2)	%	SA (3)	%	Total Score
Physical	9	8,4	24	22,4	68	63,5	6	5,6	178
Mental	15	14	50	46,7	39	36,4	3	2,8	137
Finansial	9	8,4	30	28	59	55,1	9	8,4	175
Social Life	13	12,1	56	52,3	34	31,7	4	3,7	136
Life Satisfaction	17	15,9	54	50,5	36	33,6	0	0	126

DISCUSSION

In this study it was found that the level of burden of family caregivers when caring for haemodialysis patients at RSUD Sumedang almost half of the respondents were in the heavy category as many as 53 respondents (49.5%). It can be concluded that the majority of respondents feel a high burden while providing care to their sick family members. The results of this study are also in accordance with the results of research conducted by Ratnawati et al. (2014) which states that the burden of care on caregivers is mostly in the heavy category. Another study conducted by Nugroho et al. (2019) showed that there were still family caregivers who felt a heavy burden in providing nursing care to patients.

The high burden experienced by caregivers can occur due to distress when providing care to sick relatives, and is mostly caused by physical, economic, and emotional exhaustion of caregivers (Kartika et al., 2023). There are several characteristics of respondents that affect the high burden experienced by caregivers, including caregiver's age, gender, ethnicity, education level, employment status, income, marital status, total number of caregivers, and caregiver relationship with the patient. In addition to the characteristics of the respondents, the characteristics of the patient also affect the high burden experienced by family caregivers, including the age of the patient, the patient's condition, and the length of time caring for the patient (Ariska et al., 2020).

In this study, most of the respondents were late adult women who were married. Female caregivers in this study mostly have a level of burden from moderate to heavy. This is in accordance with the statement of Sharma et al. (2016) which states that women are more likely to feel burden when providing care, this is due to the demands and views of society towards women in terms of taking care of their households. Female caregivers who do not work tend to be more at risk of experiencing emotional burden due to limited activities and no diversion in providing care to patients (Ariska et al., 2020). This statement is in accordance with the results of the study which show that caregivers who do not work have moderate to severe burden.

Almost half of the female caregivers in this study were spouses of patients and housewives. As a result, caregivers complained of financial decline because the head of the household could no longer earn a living since the illness. This is reinforced by the results showing that almost half of the patients were partially supported by caregivers and had low income. These factors then lead to increased burden experienced by family caregivers. The results obtained are also supported by research from Andrén & Elmståhl (2007) in Puspitasari (2017) which states that low income is associated with high burden on caregivers. Low income will be a stressor during caregiving to family members. In addition, caregivers must also solve financial problems and find sources of funding for the family. On the other hand, patients with conditions that need to be assisted in fulfilling their needs can also increase caregiver burden according to research from Rizka et al. (2021) which states that functional decline by patients will cause patients to depend on family caregivers to meet their daily needs, which will then affect the activities of family caregivers.

The results also showed that almost half of the caregivers had a moderate burden as many as 50 respondents (46.7%) and a small proportion of 4 respondents (3.7%) experienced a mild burden. This is because family caregivers have accepted the patient's health condition so that they can enjoy their role in caring for haemodialysis patients. This statement is in line with research conducted by Nugroho et al. (2019) who found that the burden of caregivers caring for chronic renal failure patients was in the mild to moderate burden category. This is because there is a relationship between the burden experienced by the family and the family's acceptance of the condition of their sick family members which will provide a positive atmosphere during treatment and then affect the level of burden felt (Wulandari & Fitriani, 2019).

Physical dimension

Based on the results of the study, it was found that almost all caregivers felt a heavy burden on the physical dimension. This is also related to the data on the characteristics of respondents which show that most patients are in a partially assisted condition (51.4%) which creates patient dependence on family caregivers in fulfilling their daily needs. The level of patient dependence will result in its own burden for caregivers because it is found from the results of the study that almost all caregivers take care of patients only alone or assisted by one other family member without using sick people's helpers (POS) due to financial limitations. This statement in line with research conducted by Kamalah et al. (2020) which states that the level of burden felt by the caregiver will be higher if the caregiver takes care of patients who experience functional decline so that the caregiver must help the patient to meet their needs.

The physical burden felt by family caregivers is due to the patient's low level of independence. It was found in the results that the patient had a level of partial dependence so that the family as a caregiver needed to provide assistance in things that could not be fulfilled by the patient himself (partly compensatory system). The low level of self-care of this patient can be caused by the patient's lack of understanding of his condition and the restriction of fluid intake and nutrition which causes the patient to depend on health services (Nurcahyati & Karim, 2016). The low level of self-care is also caused by the age of the patient who has entered the category of late elderly so that he has experienced a decline in both physical and psychological aspects. In addition, the length of therapy that has been carried out also affects the patient's level of self-care. Based on the results obtained, patients who have undergone therapy for more than two years are required to change their habits such as reducing food calories or certain components in the daily diet, thus giving a negative impression or attitude for sufferers to do and become non-compliant with their diet (Rahma, 2017). This is in accordance with research conducted by Febriani (2021) who found that patients who have undergone haemodialysis therapy for >2 years tend to be non-compliant with their diet because these patients experience more stress.

In addition to the patient's level of dependency, the high burden on the physical dimension is also due to the patient's routine haemodialysis therapy activities which are held twice a week. Family caregivers are strongly advised to escort and accompany patients during the therapy process (Adha, 2020). This is due to the possibility of side effects or complications that can be felt by patients such as hypotension, especially in chronic renal failure patients who also suffer from diabetes, hypertension, especially in patients who also have a history of hypertension, nausea and even vomiting due to the accumulation of toxins in the blood, anaemia, muscle cramps, and skin problems (American Kidney Fund, 2020). So there is a necessity for caregivers to drive and wait for patients for 4-6 hours in one haemodialysis therapy session, and this factor is also one of the causes of caregivers often feeling physically tired.

Finansial dimension

As for the financial dimension, it was found that almost all caregivers (86%) earned <UMK (<Rp 3,471,134.10). Some caregivers said that they did not have too many financial problems because the therapy activities were carried out with BPJS Health insurance, but not a few female partners/wives also stated that they experienced a financial decline because the husband as the head of the family could not earn a living due to his illness. This is in accordance with research Darwin et al. (2013) in Ariska et al. (2020) which states that the length of the treatment period, the severity of the disease condition, and the cost of expensive drugs can be one of the factors for the financial burden that can be experienced by family caregivers. Financial problems are also felt when taking patients for therapy. Some family caregivers said they felt the burden in terms of energy and transport costs because they came from out of town and came regularly at least twice a week to the hospital to take patients to therapy. In a study by Puspitasari (2017) also found a relationship between income and burden on caregivers, low income will be a stressor which then affects the emergence of stress when providing care to sick family members.

Mental dimension

Family caregivers also feel burden in the mental dimension because based on the results of the characteristics of respondents, it was found that most caregivers were married late adult women. Mental burden is also felt because the caregiver is the immediate family of the patient so that they are more emotionally attached to the patient and are the person who is fully responsible in terms of the patient's physical, mental and financial health (Diniz et al., 2018). In Indonesia, women have roles to take care of household needs, take care of the family, and care for sick family members, which can increase the burden felt by women. This state is in accordance with research conducted by Adianta & Wardianti (2018) which states that women have a higher burden of care than men because women in providing care are based on appreciation rather than knowledge of something, which will then result in women more easily feeling burdened when facing problems. Other research conducted by Maulidya (2022) stated that women have a more emotional nature which causes attachment to sick family members, and a sense of arises, especially for a mother who requires to pay more attention to the health of her family at home.

Life satisfaction dimension

In the burden dimension related to life satisfaction, it was found that almost half of caregivers (44.9%) had been caring for sick family members for >2 years, so that caregivers said they were sincere about the condition of their family members and felt it was their responsibility to care for sick family members. This is in accordance with research conducted by Joanna Briggs Institute (2012) which states that caregivers in caring for patients can feel lower levels of stress if they have been caring for patient more than two years, and vice versa. The longer the caregiver takes care of sick patients, the lower the emotional distress experienced by the family, this is because the family caregiver can adapt to the problems that arise when caring for sick family members (Puspitasari, 2017). This statement is inversely proportional to the statement written in the research of Werdani (2022) that the longer the family caregiver provides care to the patient, the higher the burden experienced which will result in the health status of the family caregiver.

Social life dimension

In the social life dimension, family caregivers feel less burdened because most caregivers are only on duty at home and do not work, so they have no difficulty in managing time between care activities and other social demands. This is in accordance with research conducted by Joanna Briggs Institute (2012) which states that caregivers who have jobs are found to experience a heavier burden due to the need to balance work and the obligation to care for patients compared to caregivers who do not work. However, the results of the study were also found to be inversely proportional to the statement in the study by Aruan & Sari (2018) who said that caregivers who do not work tend to have a limited social life so that they find caring for patients boring which results in increased burden experienced by caregivers.

CONCLUSION

This study was conducted to determine the description of the burden of care on families with haemodialysis patients at RSUD Sumedang. Based on the results of the study, it was found that almost half of the family caregivers were in the heavy burden category and most of the family caregivers felt heavy burden in the physical dimension. From the results of the study it was also found that the majority of caregivers were late adults, female and married, the last level of education was high school/equivalent, not working and have low income. The most caregiver relationship is the spouse of the patient, has been caring for the patient for >2 years with partially assisted patient conditions. The results of this study are expected to be used as a reference for learning and evaluation for nurses, family caregivers, and educational institutions to be able to carry out effective interventions that can be carried out to reduce the burden of care experienced by family caregivers.

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