

BURDEN OF FAMILY CAREGIVER IN CARING FOR STROKE PATIENTS: A MIXED METHOD RESEARCH

Siti Na'imah^{1*}, Christantie Effendy² & Supriyati Supriyati³

¹Department of Nursing Stikes Guna Bangsa Yogyakarta, Yogyakarta, Indonesia

² Department of Medical Surgical Nursing, Gadjah Mada University, Yogyakarta, Indonesia

³ Department of Health Behavior, Environment and Social Gadjah Mada University, Yogyakarta, Indonesia

Abstract

Stroke is the fifth leading cause of death in the world, stroke does not only have a negative impact on patients but also has an impact on family caregivers. This study aims to describe the burden experienced by family caregivers in caring for stroke patients. This research uses a mixed method with sequential explanatory approach. The research was conducted from August to October 2019 involved 106 family caregivers using a purposive sampling technique. Burden experienced was measured with the Zarit Burden Interview (ZBI) questionnaire. Quantitative data analysis was performed by SPSS and qualitative data analysis with Opencode. Burden experienced was at a mild level, there was a significant relationship to education variables ($p = 0.007$, $r = -0.297$), family relationships ($p = 0.001$, $r = 0.001$), number of caregivers ($p = 0.001$, $r = 0.364$), and the patient's duration of stroke ($p = 0.006$, $r = -0.322$). There are three themes in this study, that is difficulties in caring, motivation for caring and sources of support. Conclusion: Although quantitatively the family caregiver experiences a mild burden, qualitatively the family caregiver reports complaints in caring for almost all aspects, so treatment is needed to resolve this burden.

Keywords: Stroke; Burden caregiver; family caregiver; mixed method study;

Article info: Sending on December 26, 2022; Revision on January 25, 2023; Accepted on January 31, 2023

*) Corresponding author:

Email: siti.naimah193@gmail.com

1. Introduction

Stroke is a condition of neurological dysfunction caused by neurological infarction or rupture of blood vessels (Sacco et al, 2013). Stroke is caused by impaired cerebral blood flow which is characterized by histopathological changes in the area of the brain that result in nerve death. This causes physical, cognitive, and behavioral changes in patients, according to the location of the injury to the brain (Caro et al., 2018). Stroke is a health problem at the global level which is the fifth most common cause of death and disability in many developing countries such as Asia (Turana et al., 2021). The highest incidence of stroke in Asia occurred in Japan, namely 422 cases per 100,000 inhabitants. Taiwan is the second highest country in stroke cases in Asia, namely 330 per 100,000 people. Malaysia is the country with the lowest stroke cases in Asia with a stroke incidence rate of 67 cases per 100,000 people (Venketasubramanian et al., 2017).

In Indonesia, there were 479,243 Indonesians who had suffered a stroke, or around 46.1% of the total number of diseases in Indonesia (Indonesian Ministry of Health, 2018). The prevalence of stroke patients continues to increase every year.

The prevalence of stroke in Central Java province in 2017 was 12.41 per 1,000 population, consisting of non-hemorrhagic stroke of 9.36 per 1,000 population and hemorrhagic stroke of 3.05 per 1,000 population (Setyopranoto et al., 2019). These results have increased from 2016, where in that year there were 5.58 non-hemorrhagic stroke sufferers per 1,000 population and 2.68 hemorrhagic stroke sufferers per 1,000 population (Central Java Health Office, 2017).

In Indonesia there has not been much research related to the burden experienced by family caregivers in caring for stroke patients. Previous studies related to stroke focused more on patients, while research on families who cared for stroke patients (family caregivers) had not been

carried out much. Therefore researchers are interested in researching the burden of family caregivers in caring for stroke patients.

The purpose of this study is to determine the burden experienced of family caregivers in caring for stroke patients, to determine the burden based on the demographic characteristics of family caregivers, the burden of family caregivers based on the characteristics of stroke patients and the level of burden experienced by family caregivers in caring for stroke patients.

2. Method

This research is a mixed method research with a sequential explanatory research design. This research was conducted from August to October 2019. The number of respondents in this study were 106 respondents who were family caregivers for stroke patients undergoing treatment in the Dahlia ward (Stroke Unit) and Aster 5 Ward (Internal and neurological disease Unit) at the General Hospital Tidar City of Magelang, Indonesia.

The data collection used purposive sampling technique. The sample was taken based on inclusion criteria, while the inclusion criteria in this study were over 18 years of age, accompanying patients for at least one hour a day, able to communicate well, and willing to be respondents. The exclusion criteria in this study were family caregivers with psychological disorders. The instrument used to measure the burden on family caregivers used the Indonesian version of the Zarit Burden Interview (ZBI) 22 items. Quantitative data analysis by SPSS . Qualitative research results analysis with Opencode.

This research has received a research permit from Tidar Hospital Magelang and approval for research ethical feasibility from the ethics commission of FK-KMK UGM issued on August 21 2019 with number KE/FK/0979/EC/2019. The problem or difficulty that arose during this study was that not all stroke diagnoses were listed in the medical records, so researchers needed time to ask health workers. For participants who were in the Aster Ward, several participants were single caregivers so that participants refused to be interviewed because they could not leave the patient alone, so the researcher had to make a time contract with the participant before the interview. The weakness of this research is that it does not examine the patient's length of stay which may have an impact on the burden experienced by family caregivers.

3. Results and Discussion

Quantitative Research Results

Table 1 shows that the age of the respondent is 26-45 years (54%), female (71.7%), has a high school education level (42.5%), works as a private employee (33.0%) and has an income below the Magelang Regional Minimum Wage (57 %). Most of the family caregivers have a biological child relationship (47.2%), the number of caregivers is 2-3 people for 1 stroke patient (59.4%) and the caregivers live in the same house with the patient with a duration of caring for more than 6 hours each day.

Tabel 1. Frequency Distribution of Respondent and Patient's Characteristics

Category	f	(%)
Gender		
Male	76	71.7
Female	30	28.3
Age (Year)		
18-25	20	18.9
26-45	54	50.9
46-65	30	28.3
≥66	2	1.9
Mean/ SD	38.5 (± 12.8)	
Education		
Elementary School	30	28.3
Junior High School	19	17.9
Senior High School	45	42.5
College	12	11.3
Profession		
Private sector employee	35	33.0
Laborer	28	26.4
Farmer	4	3.8
Trader	12	11.3
Retired	1	0.9
Housewife	26	24.6
Income		
< Average minimum wage	57	53.8
≥ average minimum wage	49	46.2
Family Relation with Patients		
Spouse	31	29.2
Parent	2	1.9
Parent in law	1	0.9
Son/ Daughter	50	47.2
Son/ Daughter in law	12	11.3
Sibling	3	2.8
Grandchild	7	6.6
Total of family caregivers		
1	20	18.9
2-3	63	59.4
4-5	20	18.9
>6	3	2.8
Live together		
Yes	86	81.1
No	20	18.9
Duration of treating the patient in a day		

< 6 haour	25	25
6-12 haour	46	46
>12 haour	35	35
Patient gender		
Female	46	43.4
Male	60	56.6
Patient Age (years)		
≤18	1	0.9
19-25	1	0.9
26-45	11	10.4
46-65	66	62.3
≥66	27	25.5
Mean (SD)	58.9 (± 12.9)	
Length Suffering from stroke		
<6 month	51	48.1
6 month – 1 years	14	13.2
1-2 years	19	17.9
>2 years	22	20.8
Number of strokes attack		
First time	85	80.2
Repeated	21	19.8
ADL level		
Total	34	32.1
Heavy	42	39.6
Moderate	30	28.3
Mild	0	0

Based on patient characteristics, the majority were male (55%), the age of stroke patients was in the range of 14 to 85 years or an

average age of 58.9 years, they were in the elderly age category, namely 63.3% and the duration of stroke was less than 6 month (48.1%). The majority of patients experience a stroke for the first time, namely as much as 80.2% and depend on other people to perform ADLs (71.7%).

Burden level of family caregivers

Table 2. Level of Family Caregiver Burden

Burden Level	f (%)
Almost no burdens (Score 0-20)	32 (30.2)
Mild (Score 21-40)	34 (32.1)
Moderate (Score 41-60)	24 (22.6)
Heavy (Score 61-88)	16 (15.1)

Table 2 show that 32.1% of respondents experienced mild burden, while 15.1% of respondents experienced a heavy burden.

The relationship between the characteristics of family caregivers and patients with the burden they experience.

Table 3. The relationship between the characteristics of family caregivers and patients with the burden they experience

Categori	r	p value
Gender	-	0.30 ^a
Age	0.279	0.15 ^b
Education level	-0.297	0.007* ^b
Profession	0.071	0.512 ^b
Income	-1.417	0.157 ^b
Family relationship	-0.364	0.001* ^b
Total family caregiver	-3.981	0.001* ^b
Duration of treating the patient in a day	0.712	0.001* ^b
Live together	-1.545	0.122 ^a
Patients Gender	-	0.317
patient Age	-0.118	0.382
Length Suffering from stroke	-0.322	0.006* ^b
Number of strokes attack	-	0.448 ^a
ADL Level	1.174	1.151 ^b

Table 3 shows that family caregiver education, family relationships, number of caregivers, and duration of caring for patients are related to the burden experienced by family caregivers. The variable level of education obtained a correlation coefficient of -0.297 which can be interpreted that the higher the family

caregiver's education, the burden experienced is lower, as well as seen from the significance value obtained p-value = 0.007, it can be concluded that there is a relationship between the level of education and burden experienced by the family caregiver. The family relationship variable has a strong correlation with the incidence of burden (p-

value 0.001). incidence of heavy burden experienced by biological children of stroke patients (7.5%). The duration of caring for patients with a p value of 0.001 and r value of 0.712 means that family caregivers who care for stroke patients with a duration of ≥ 6 hours per day experience a heavy burden, the longer the duration of caring for the patient, the higher the burden experienced by the patient.

The patient's demographic characteristics do not correlate with the burden experienced by the family caregiver except for the patient's length of illness. the length of time caring for patients is considered to have a significant relationship to the

burden experienced by family caregivers. the value of $r -0.322$ indicates that there is a negative relationship to the length of caring for the burden experienced by family caregivers. This shows that the longer the patient is sick, the higher the burden they will experience.

Qualitative Research Results

General description of interview subjects
Interviews conducted with seven participants revealed 3 themes, namely difficulties in caring for, motivation for caring for and sources of support.

Table 4. General description of the interview subject

Code	Gender	Age (Years)	Family relationship with patients	Burden Level with quantitative data
P1	Female	60	Wife	Moderate
P2	Female	42	Mother	Heavy
P3	Female	48	Wife	Mild
P4	Female	24	Grandchild	Mild
P5	Female	36	Wife	Mild
P6	Female	20	Daughter	Almost no
P7	Female	19	Daughter	Almost no

Difficulty Caring

All participants in this study revealed difficulties in treating stroke patients. Researchers divided the difficulties experienced by the participants into four categories, namely physical complaints, mental unrest, financial difficulties and social limitations.

a) Physical complaints

Participants revealed that they experienced physical complaints while caring for stroke patients, physical complaints expressed by participants such as a lack of manpower to care for, lack of sleep, fatigue and disease recurrence. This was expressed by the participants as follows:

"... sometimes I can sleep, sometimes I can't, there are so many people passing by..." (P1, 60 years old, wife)

b) Discomfort of the soul

The mental unrest experienced by the participants was in the form of worry about the patient's disease prognosis, fear of the patient's death and other feelings that are difficult to express. These conditions were expressed by participants as follows:

"Yes..that one thing I'm afraid of (death)" (P3, 48 years old, wife)

c) Cost difficulties

Five participants in this study revealed financial complaints felt by family caregivers since the

patient had a stroke. This was expressed by the participants as follows:

"... if it's (cost) that's heavy, it's been a week here (hospital) no family has helped, while I'm not working" (P7, 19 years old, daughter)

d) Limited socialization

Limitations in socializing felt by participants such as not being able to participate in activities in the surrounding environment, unable to attend invitations from relatives, recitations, and visiting parents. This was expressed by the participants as follows:

"...make it impossible for (the patient) to be left behind...not to mention if there is an event, there are gatherings (meetings).. well, it's just a hassle" (P3, 48 years old, wife).

Motivation to care

All participants expressed their underlying motivation for caring for families who had suffered a stroke. The researchers divided these reasons into three categories, namely as a form of devotion, affection and belief.

a) Devotion

Participants stated that caring was an obligation for the wife and an opportunity to be devoted to the parents who had raised the participants. This was expressed by the participants in the following quote:

"When I was young... it was the father (patient) who was looking for money for me, now it's my turn to take care of it...what's the name of the husband and wife, so it's shared" (P1, 60 years old, wife)

b) Affection

Participants expressed feelings such as not being able to bear to see patients in constant pain, hoping to replace the patient's condition, trying to understand the patient's feelings and hiding feelings of sadness in front of the patient. This was expressed by the participants as follows:

"...the name of a mother, if the bandages hurt, we can bear it, but if you see a child who is sick, it feels like God... I don't want to change the feeling, let me be the one who gets sick..." (P2, 42 years old, Mother)

c) Belief

Participants expressed beliefs related to the patient's condition, these beliefs such as assuming the disease given to the patient is a trial from God for the patient and family, the disease is a test of loyalty for the partner and is afraid of karma if they don't take care of the patient and want their children to do good in the future the same way in caring for old participants.

This was expressed by the participants as follows:

".... one day I will become a parent, I want my children to do the same thing tomorrow as I do." (P7, 19 years old, daughter)

Support Resources

Participants revealed that there was a source of support that became a separate reinforcement for family caregivers while caring for stroke patients.

a). Financial Support

Participants revealed that financial support was obtained from assistance from children, extended family, in-laws, neighbors and others. This was expressed by the participants as follows:

"Alhamdulillah.. for costs and financial a lot of brothers and sisters to help" (P6, 20 years old, daughter)

b). Social Support

Participants expressed the social support they received, such as help from family, neighbors, and the work environment. This was expressed by the participants as follows:

"....sometimes assisted by my parents, my older siblings..." (P6, 20 years old, daughter)

c). Spiritual support

Participants expressed spiritual support such as mutually reinforcing family members, bearing the burden of caring for each other, and praying for

one another. This was expressed by the participants as follows:

"Alhamdulillah, they actually strengthen each other, encourage each other" (P1, 60 years old, wife).

Discussion

Most of the family caregivers (FC) who care for stroke patients are female (71.7%). This is in line with research conducted by (Vidyanti et al., 2022) which states that the majority of family caregivers in Indonesia are female and have a relationship as daughter (47.2%)), another study conducted Tosun & Temel, (2017) which states that parenting is mostly done by female family members, this is because caring is only woman's role. Although quantitatively there was no correlation between the caregiver's gender and the burden experienced (p value 0.30), in fact some female caregivers said they had difficulty and had limited staff to care for patients so they needed help from other people such as other patient attendants and nurses.

The majority of family caregivers' relationships with stroke patients are as children (47.3%). Caring for and providing assistance to parents is a custom that has deep roots in Indonesian society. This is in line with the qualitative research conducted that caring for parents is a child's obligation to repay parents who have cared for them when they were young. There is a negative and very significant relationship between family relationships and the burden experienced by family caregivers ($r = -0.328$, p value 0.002). The majority of the burden experienced by families is related to unclear information related to the prognosis of the patient's disease and fear of death from the patient.

The age of the family caregivers in this study ranged from 18 to 67 years and almost half of the total respondents were in adulthood with the majority having high school education (37.6%). FC age has a weak correlation to burden on family caregivers (p value 0.05). The age of the adult family caregiver is considered capable and proficient in making decisions related to the care to be performed on stroke patients, while the level of education is considered to influence the family caregiver in obtaining information and knowledge related to the care of stroke patients. Most of the family caregivers had high school education (37.6%) and there was a very significant correlation between education and the burdens experienced ($r=0.315$, $p=0.005$). The results of this study are in accordance with qualitative data conducted by Zhu & Jiang, (2019), family caregivers with elementary school education tend to be burdened and lack understanding regarding the care to be carried out.

Most of the family caregiver jobs in this study were private employees, namely as many as 32.3% and more than half (57%) earned below the regional minimum wage in Magelang City. based on interviews conducted with family caregivers, families find it difficult to pay for treatment of stroke patients even though some of the costs of treatment at the hospital are covered by health insurance. This is in accordance with research conducted by Mishra et al., which said that financial costs are closely related to the burden experienced by family caregivers in caring for stroke patients.

The majority of family caregivers cared for stroke patients with a duration of more than six hours per day as much as 72% and the duration of stroke patients was less than six months with an average number of strokes of 1.67 attacks. Based on the results of the bivariate analysis, it was found that there was a relationship between the length of time the patient had suffered a stroke and the burden experienced by the family caregiver with a p value of 0.02. The results of this study are in line with research conducted by (Vincent-onabajo et al., 2018) in Nigeria, the results of this study stated that there was a significant relationship between the duration of care and the burden experienced by family caregivers (p value <0.05). Likewise with the research conducted by Jaracz et al., regarding the burden experienced by family caregivers, in this study it was found that the main caregivers who cared for stroke patients for more than six hours per day tended to experience the burden. Family caregivers who care for stroke patients for more than 6 hours per day are prone to physical problems such as fatigue, difficulty sleeping and resting.

Patient characteristics are considered to contribute to the incidence of burden experienced by family caregivers (FC). In quantification there were no patient characteristic variables related to the burden on FC except for the length of time the patient had a stroke ($p = 0.001$). The duration of stroke patients has a significant relationship to the burden experienced by FC. This is because the majority of family caregivers who care for patients for more than 6 months tend to experience boredom, feelings of pressure and embarrassment because they are considered unable to care for patients properly. This research is in line with the research conducted.

4. Conclusions and suggestions

The conclusion of this study is that there is a family caregiver who cares for this patient, that stroke has a light burden level. There is a relationship between family caregiver education, number of caregivers, duration of caring for patients with the burden experienced by family

caregivers. There are three themes related to the burden experienced by family caregivers, namely 1) difficulties experienced by caregivers 2) caring motivation and 3) sources of support and 4) Norms subjective

5. Acknowledgments

We would like to thank to every individual, respondents and institutions who had contributed for the completion of this research.

6. References

- Caro, C. C., Costa, J. D., & Da Cruz, D. M. C. (2018). Burden and Quality of Life of Family Caregivers of Stroke Patients. *Occupational Therapy in Health Care*, 32(2), 154–171. <https://doi.org/10.1080/07380577.2018.1449046>
- Indonesian Ministry of Health. (2018). Hasil Riset Kesehatan Dasar Tahun 2018. *Kementrian Kesehatan RI*, 53(9), 1689–1699.
- Mishra, A. K., Mishra, N., & Gajjar, K. (2016). Financial burden of stroke on family and caregiver in India: a literature review. *International Journal of Reseach in Medical Science*, 4(9), 3675–3678.
- Sacco, Ralph L., scott E. Kasner, joseph P , Louis R , Antonio Culebras , Mitchell S, E. (2013). AHA / ASA Expert Consensus Document An Updated Definition of Stroke for the 21 st Century. *Aha/Asa*, 6–7. <https://doi.org/10.1161/STR.0b013e318296aeca>
- Setyopranoto, I., Bayuangga, H. F., Panggabean, A. S., Alifaningdyah, S., Lazuardi, L., Dewi, F. S. T., & Malueka, R. G. (2019). Prevalence of stroke and associated risk factors in sleman district of Yogyakarta Special Region, Indonesia. *Stroke Research and Treatment*, 2019. <https://doi.org/10.1155/2019/2642458>
- Central Java Health Office. (2017). *Profil Kesehatan Provinsi Jawa Tengah Tahun 2017* (Vol. 3511351, Issue 24).
- Tosun, Z. K., & Temel, M. (2017). Burden of Caregiving for Stroke Patients and The Role of Social Support Among Family Members: An Assessment Through Home Visits. *International Journal of Caring Sciences*, 10(3), 1696–1704. <http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=127731964&site=ehost-live>
- Turana, Y., Teng kawan, J., Chia, Y. C., Nathaniel, M., Wang, J. G., Sukonthasarn, A., Chen, C. H., Minh, H. Van, Buranakitjaroen, P., Shin, J., Siddique, S., Nales, J. M., Park, S., Teo, B. W., Sison, J., Ann Soenarta, A., Hoshide,

- S., Tay, J. C., Prasad Sogunuru, G., ... Kario, K. (2021). Hypertension and stroke in Asia: A comprehensive review from HOPE Asia. *Journal of Clinical Hypertension*, 23(3), 513–521. <https://doi.org/10.1111/jch.14099>
- Venketasubramanian, N., Yoon, B. W., Pandian, J., & Navarro, J. C. (2017). Stroke Epidemiology in South, East, and South-East Asia: A Review. *Journal of Stroke*, 19(3), 286–294. <https://doi.org/10.5853/jos.2017.00234>
- Vidyanti, A. N., Muhrodji, P., Wicaksono, H. D. A., Satiti, S., Trisnantoro, L., & Setyopranoto, I. (2022). Roles and Problems of Stroke Caregivers: A Qualitative Study in Yogyakarta, Indonesia. *F1000Research*, 10, 1–24. <https://doi.org/10.12688/f1000research.52135.2>
- Vincent-onabajo, G., Gayus, P. P., Masta, M. A., Ali, M. U., Gujba, K., Modu, A., & Hassan, S. U. (2018). *Caregiving Appraisal by Family Caregivers of Stroke Survivors in Nigeria*. 7(4), 183–188. <https://doi.org/10.15171/jcs.2018.028>
- Zhu, W., & Jiang, Y. (2019). Determinants of caregiver burden of patients with haemorrhagic stroke in China. *International Journal of Nursing Practice*, 25(2), 1–8. <https://doi.org/10.1111/ijn.12719>