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Family Caregiving Behavior and its Correlation with Stroke Severity among Patients with Stroke

Ratna Yunita Sari[1*], Riska Rohmawati[2], Imamatul Faizah[3], Dyah Ika Krisnawati[4], Siti Nur Hasina[5], Duong Thi To Anh[6], Tsung-Rong Kuo[7]
[1,2,3,4,5] Department of Nursing, Faculty of Nursing and Midwifery, Universitas Nahdlatul Ulama Surabaya, Surabaya, Indonesia
[6] Thai Nguyen University of Medicine and Pharmacy, Thai Nguyen University, 284 Luong Ngoc Quyen Street, Phan Dinh Phung Ward, Thai Nguyen Province, Vietnam
[7] College of Biomedical Engineering, Taipei Medical University, Taiwan
**Corresponding author: ratna@unusa.ac.id*

ABSTRACT
Background: Stroke is a disease that requires intensive family care. Suboptimal family care can worsen a stroke patient's condition.
Purpose: This study aimed to determine family caregiving behaviours, based on the severity of the stroke, at PHC Hospital Surabaya.
Methods: The study design employed analytical observation using a cross-sectional method, with a study population of 170 respondents and a sample of 120 selected via simple purposive sampling. The independent variable in this study was family behavior, and the dependent variable was tingkat keparahan pasien stroke. The instruments used were National Institutes of Health Stroke Scale (NIHSS) Questionnaire and the Family Behaviour Questionnaire. Data analysis utilised the Spearman rank test.
Results: The results of the study showed that almost half (49.2%) had adequate behavior in caring for stroke patients and nearly half (44.2%) had severe stroke severity with a value of ρ = 0.014 correlation coefficient of 1.000, which means there is a relationship between family behavior in caring for stroke patients and the severity of stroke patients at PHC Hospital Surabaya with a robust correlation.
Conclusion: Family caregiving behavior is significantly associated with stroke severity. Improving education and guidance for families of stroke patients is crucial to supporting successful patient care and rehabilitation.

Keywords: Family Behavior, Severity, Stroke

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BACKGROUND

Stroke survivors are at risk of experiencing a recurrent stroke during and after neurological recovery, which takes 3-18 months (AHA dalam Tunik, *et al*., 2022). Recurrent strokes cause more severe conditions after the first stroke; this occurs because of the increased extent of brain damage caused by the previous stroke (Amila, et al, 2018 dalam Tunik, *et al.*, 2022). Problems that occur in stroke services, especially in Indonesia, are low awareness of stroke risk factors, lack of awareness of stroke symptoms, suboptimal stroke services, and poor adherence to treatment programs to prevent recurrent strokes. Stroke prevention can be done by everyone, especially families and those at risk, so good knowledge about stroke is very important for families and people at high risk of stroke (Venketasubramanian et al., 2022; Zainuddin et al., 2025).

Post-stroke impacts include paralysis and disability, communication disorders, emotional disturbances, pain, sleep disturbances, depression, dysphagia, and many others (Kaylor & Singh, 2023; Tiwari et al., 2021). Many families of stroke patients neglect their affected family members; this lack of attention can contribute to the severity of the stroke. This is why good family behaviour is essential for the prevention and recovery of stroke patients (Maggio et al., 2024; Wang et al., 2022; Zhang et al., 2023).

Delays in the treatment of stroke incidents are approximately 83.9% caused by pre-hospital delays. The first cause of delays as much as 62.3% is due to the lack of family knowledge about risk factors and warning symptoms of stroke so that they underestimate the early signs of stroke, families and sufferers hope the symptoms and signs will disappear 2.7% (Assbender, Balucani, Walter, Levine, & Haass, 2013 dalam Marina T dan Fitria H, 2020). The World Stroke Organisation shows that every year, there are 13.7 million cases of stroke in the world (Heni Fatmawati *et al.*, 2023). Doctor Nur Setiawan Suroto SpBS (K) (2023) explained that of the 276.4 million population in Indonesia, 2.9 million people experience stroke per year. The incidence of stroke reaches 10.9 per 1000 population, or around 2.91 million people per year. According to research at the National Brain Centre Hospital, Jakarta, stroke severity was classified using the National Institutes of Health Stroke Scale (NIHSS) in 2,443 patients, of whom 58% experienced moderate to severe stroke (Yamanie et al., 2024). A preliminary study conducted at PHC Hospital, Surabaya, from October 1, 2023, to December 31, 2023, found that 50 patients suffered from stroke attacks with a mild severity of 50%, moderate 30%, and severe 20% assessed by the NIHSS score. Said that there was a delay in stroke attacks and felt unsupported in the recovery process.

Stroke is a leading cause of death and permanent disability worldwide, and family care is crucial for managing a patient's condition after a stroke. In the early stages of a stroke, a family's rapid response to recognising symptoms and transporting the patient to a healthcare facility significantly determines the patient's prognosis. Patients with severe strokes require immediate medical attention, and delays in responding can worsen the condition and increase the severity of neurological damage. Family preparedness in handling acute situations helps reduce complications and improve rehabilitation outcomes (Blake et al., 2024). After the acute phase, the family becomes the primary support system for continuing care for stroke patients at home. The higher severity of stroke makes patients more dependent on their family for activities of daily living, such as eating, bathing, and mobilisation. The family's role becomes more complex, requiring expertise and diligence to provide comprehensive care and prevent secondary complications. Families who are able to provide care according to clinical guidelines can significantly increase the patient's chances of recovery (So & Park, 2024). However, family behaviour in caring for stroke patients varies and is not always optimal, which can affect the severity and recovery process. Previous studies have shown that family knowledge and

behaviour play a significant role in the initial management and recovery of stroke patients. This is a crucial issue because inappropriate care can worsen the patient's condition and increase the risk of complications (Bai & Chen, 2025; Madu & Ajibade, 2025; Zhou et al., 2025).

Family behaviour in caring for stroke patients is a crucial factor influencing the severity of the condition and the patient's recovery process. Previous research has demonstrated that good family functioning, encompassing effective communication, emotional support, and active involvement in care, can reduce post-stroke fatigue symptoms and enhance patient clinical outcomes (Zhu et al., 2024). This study aims to analyse the relationship between family behaviour in caring for stroke patients and the severity of stroke in stroke patients at PHC Hospital Surabaya. By understanding this relationship, the results are expected to form the basis for developing integrated and sustainable family intervention strategies. This approach is expected to increase the effectiveness of home care, reduce stroke severity, and improve the overall quality of life of patients and their families. Integrating aspects of family function into stroke care protocols is crucial for enhancing rehabilitation outcomes for stroke patients in the community (Zhang et al., 2023; Zhu et al., 2024).

METHODS

This study is an analytical observational study with a cross-sectional approach, which aims to analyse the relationship between family behaviour in caring for stroke patients and the severity of stroke patients, carried out at PHC Hospital Surabaya, by emphasising single measurements or data observations at one point in time. The population in this study consisted of 170 people, a sample size of 120 people was taken using non-probability sampling: a purposive sampling technique with the determination of inclusion criteria of family members who have time to care for stroke patients, family members who live in the same house and care for stroke patients, family members who can read and write, family members who have cared for stroke patients for more than six months. Exclusion criteria were family members who live in the same house with an age limit of less than 15 years and more than 75 years, and family members with mental disorders. Data collection used structured interviews with the National Institutes of Health Stroke Scale (NIHSS) Questionnaire (Comer et al., 2022) and the Family Behavior Questionnaire (EldiningtyasL, 2019). Data analysis will be tested using the Spearman Rank test with a p-value <0.05. The Research Ethics Committee of PHC Surabaya Hospital has issued an ethics approval letter for this study with the number 016/KEPK/RSPS-2024.

RESULTS

1. General data

Tabel 1. Subjects' Characteristics

Characteristic	f	%
Age (Years)		
Late Adolescence (17-25)	2	1.7
Early Adulthood (26-35)	9	7.5
Late Adulthood (36-45)	24	20.0
Early Old Age (46-55)	29	24.2
Late Old Age (56-65)	34	28.3
Seniors (>65)	22	18.3
Sex		
Male	55	45.8
Female	65	54.2
Education		

Basic	15	12.5
Intermediate	64	53.3
High	41	34.2
Profession		
Civil servants	64	53.4
Entrepreneur	41	34.1
House Wife	10	8.4
Does not work	5	4.1
Income		
>Rp4.725.479	51	42.5
Rp4.725.479	50	41.6
<Rp4.725.479	9	7.5
No Income	10	8.4
Long suffering		
1-5 years	76	63.3
6-10 years	40	33.3
>10 years	4	3.3
Family Relationships		
Spouse	69	57.5
Child	51	42.5
Information sources		
Health Worker	54	45.0
Family	32	26.7
Information media	34	28.3
Distance from home to rehabilitation facility		
1-5 km	30	25.0
5-10 km	43	35.8
>10 km	47	39.2

Table 1 shows that almost half of the respondents (28.3%) were classified as late elderly (56-65 years old), with the majority (54.2%) being female and (53.3%) having an intermediate education level. Most of the respondents (53.4%) worked as civil servants, with almost half (42.5%) earning >Rp4,725,479. Most (63.3%) of the respondents had suffered from stroke for 1-5 years, and most (57.5%) of the respondents were cared for by their partners. The source of information obtained by almost half (45%) was from health workers, and the distance from home to the rehabilitation facility was almost half (39.2%) >10 km.

2. Custom Data

Specific data is data obtained from collecting the results of questionnaires during research

Tabel 2. Distribution of family behavior and severity levels of stroke patients

Variabel	f	%
Family Behavior		
Low	26	21.7
Moderate	59	49.2
High	35	29.1
Stroke Severity		
Mild	8	6.7

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Moderate	37	30.8
Severe	53	44.2
Very Severe	22	18.3

Based on Table 2, it shows that almost half (49.2%) of family behaviour is in the adequate category in caring for stroke patients, while for stroke severity, almost half are in the severe category.

Tabel 3. Cross-tabulation results between family behavior with severity levels of stroke patients

Family Behavior in Caring for Stroke Patients	**Stroke Severity**								**Total**	
	Mild		**Moderate**		**Severe**		**Very Severe**			
	N	%	N	%	N	%	N	%	N	%
Low	8	30.77	10	38.46	6	23.08	2	7.69	26	100
Moderate	0	0.00	13	22.04	33	55.93	13	22.03	59	100
High	0	0.00	14	40.00	14	40.00	7	20.00	35	100
Total	8	6.70	37	30.83	53	44.17	22	18.33	120	100
Spearman Rank Statistical Test Results						ρ = *0,014*				
Correlation Coefficient						r = *1,000*				

Based on Table 3, it shows that out of 120 respondents, 26 respondents found family behaviour in caring for stroke to be inadequate, almost half (38.46%) of whom 10 respondents had moderate stroke severity. Of the 59 respondents, family behaviour in caring for stroke was adequate, with most (55.93%) of whom 33 respondents had severe severity. And of the 35 respondents who received good family care behaviour, almost half (40.00%) of whom 14 respondents had moderate and severe severity.

DISCUSSION

Research results indicate a relationship between family caregiving behaviour and stroke severity. Family caregiving behaviour plays a crucial role in determining stroke severity and quality of life. Studies show a strong correlation between family knowledge and behaviour in stroke care and stroke severity, with the better the family's caregiving behaviour, the lower the stroke severity. This is consistent with findings that family knowledge about recognising stroke signs and symptoms and prompt action significantly contribute to stroke patient outcomes (Nooreddini et al., 2025; Zhang et al., 2023). This is consistent with nearly half of the interview results, which stated that the sooner a stroke patient is taken to the hospital after an attack, the faster the patient's recovery process. Early family intervention is crucial in reducing the risk of death and disability due to stroke. Families who have good knowledge and appropriate behavior can identify early symptoms of stroke and carry out effective initial treatment such as assessment using the FAST (Face, Arm, Speech, Time) method, which ensures patients receive rapid medical care and reduces the severity of stroke (Feigin et al., 2025; Hilditch et al., 2025; Wu et al., 2025; Zang et al., 2025).

The severity of stroke in patients, aside from family caregiving behaviour, can also be influenced by the duration of the stroke (Maggio et al., 2024). This is consistent with research showing that nearly half of stroke patients experience severe stroke severity, as most patients have had their stroke for 1-5 years. Physiologically, prolonged stroke is associated with

decreased brain neuroplasticity and the accumulation of progressive tissue damage. Chronic neuroinflammatory processes lead to excessive activation of microglia and astroglia cells, leading to oxidative injury that inhibits neuronal regeneration. Furthermore, persistent disruption of cerebral microcirculation impairs the supply of oxygen and nutrients to inflamed tissue, accelerating neuronal degeneration and cerebral tissue fibrosis, which are hallmarks of higher clinical stroke severity. The duration of stroke also impacts the patient's psychosocial and cognitive functions, which are directly proportional to the severity of their physical condition. Chronic stroke patients often experience depression, anxiety, and cognitive impairment, which hinder rehabilitation. This decline in functional independence reflects the multi-dimensional complications that occur due to severe and ongoing neurological damage, thus requiring holistic care involving medical, psychological, and social aspects for patients and families (Devereux & Berns, 2023; Muhrodji et al., 2021; Soto-Cámara et al., 2020).

Stroke severity, aside from the duration of the stroke, is another factor that can worsen the condition. This is consistent with the statement by Samuthpongtorn et al., (2021) who stated that older adults tend to experience complex health problems, making the role of family care crucial to support recovery and management of stroke. This is in line with research findings showing that nearly half of the respondents were in their later stages, aged 56-65. In the elderly, susceptibility to complications and neurological decline tends to be higher due to reduced brain tissue regeneration and decreased vascular function with age. Common comorbidities in the elderly, such as hypertension, diabetes, and heart disease, also contribute to worsening stroke severity. This study found that older stroke patients experienced higher severity scores than younger patients, as reflected in poorer neurological scores and limited functional abilities post-stroke. This underscores the need for a more intensive and integrated treatment and rehabilitation approach for older adults to minimise long-term impacts and improve patient quality of life (Samuthpongtorn et al., 2021; Simmons et al., 2023).

Family care, especially by a spouse, for stroke patients has a significant impact. This is consistent with research findings, where the majority of patients cared for by their spouses reported a much greater sense of recovery and emotional and psychological support, as well as a sense of calm and gratitude that fostered greater hope and enthusiasm for recovery and maintaining their health. Patients cared for by their spouses demonstrated the importance of emotional and physical support from their spouses in stroke care. Caregivers typically have a strong emotional bond, enabling them to provide more intensive and sustainable care. Family behaviours that demonstrate high levels of attention, mental preparedness, and a sound understanding of stroke positively impact the patient's clinical severity (Gurková et al., 2025; Sun et al., 2025). Physical and psychological support from families enables stroke patients, particularly elderly women, to undergo rehabilitation more effectively and accelerate the recovery of motor and cognitive functions. The role of spouses as primary caregivers also demonstrates a strong family dynamic, but this also requires attention to potential stress and caregiver burnout. Caregiver fatigue can reduce the effectiveness of care and accelerate the progression of stroke severity in patients, so it is important to provide adequate support and training to partners as primary caregivers (Terrill et al., 2025; Zhou et al., 2025).

CONCLUSION

Family caregiving behaviours for stroke patients are significantly associated with stroke severity. Families who possess in-depth knowledge and implement appropriate caregiving behaviours increase the likelihood of a patient experiencing a less severe stroke and accelerate recovery. The speed with which families respond to stroke symptoms and provide optimal care is a key factor in reducing the risk of disability and serious post-stroke complications. Therefore, family education and caregiver empowerment as part of nursing interventions

should be a primary focus in stroke management to achieve optimal clinical outcomes and improve the patient's overall quality of life. The active role of the family not only contributes to preventing stroke recurrence but also strengthens the psychosocial support that post-stroke patients desperately need during the rehabilitation process.

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