Jordan Journal of Nursing Research

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The Relationship between Family Support and Self-care among Stroke Patients

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ARTICLE INFO

ABSTRACT

Background: Stroke is caused by a disruption in blood flow to the brain. Some people die from a stroke, while others are left with disabilities that reduce their self-care, requiring assistance from others to meet their daily needs. The family becomes a crucial source of support when a patient is at home. **Purpose**: This study examines the correlation between family support and self-care in stroke patients. **Methods**: The study employed an analytic observational design with a cross-sectional approach. The samples included families and stroke patients. Samples were selected using non-probability purposive sampling, with a sample size of 75 for each group. The instruments used for data collection were the Family Support Questionnaire and the Barthel Index Questionnaire. Data was analyzed using descriptive analysis and Spearman's rank test. **Results**: The characteristics of stroke patients indicate an average age of 52 years, with an average time since suffering a stroke being 4.1 months. The gender distribution among patients is nearly equal. Family caregivers, with an average age of 43 years, also show a balanced gender distribution and the majority (49.3%) are partners. Concerning the support received from family caregivers, patients commonly receive emotional support, appreciation support and instrumental support. The analysis revealed a Spearman's correlation coefficient of $p < 0.05$ between family support and self-care. **Conclusion**: This study illustrates the importance of family support in helping improve self-care for patients with stroke undergoing outpatient care and receiving home care from family caregivers. **Implications for Nursing**: Discharge planning for stroke patients receiving outpatient care needs to highlight the significance of family competence in assisting with home care to enhance patient self-care.

Keywords: Family Support, Stroke, Self-care.

What does this paper add?

1. It provides insight into the relationship between family support and post-stroke patient self-care.
2. It increases understanding of the factors influencing post-stroke rehabilitation and supports the importance of increasing self-care for patients during recovery.
3. It emphasizes the crucial role of emotional support in family dynamics and advocates for tailored health

education programs to enhance family competency.

Introduction

Stroke is classically characterized as a neurological deficit attributed to an acute focal injury of the central nervous system (CNS) by a vascular cause, including cerebral infarction, intracerebral hemorrhage (ICH), and subarachnoid hemorrhage (SAH), and it is a major cause

of disability and death worldwide. American Heart Association (2020) predicted that Disability-induced Life Year (DALY) because of stroke will increase from 38 million to 61 million cases by 2020 (Blok et al., 2022). The results of Basic Health Research conducted by the Ministry of Health of the Republic of Indonesia in 2020 showed that stroke is the main cause of death (15.4%) in Indonesia. It was indicated that 500,000 Indonesians are expected to experience strokes annually, with 25% (125,000) of them facing mortality, while the rest may endure disabilities (Kemenkes, 2018).

The Ministry of Health's Basic Health Research (Riskesdas) data for 2018 showed that as many as 713.783 people had strokes. Moreover, in the population ≥60 years, stroke is ranked first as a cause of disability, above Heart Disease, Diabetes Mellitus (DM), joint disease, and injury (Kemenkes, 2018). Post-stroke patients' self-care can be measured by their ability to perform ADL. A study conducted at Sahlgrenska University Hospital (SU) in Sweden, involving 366 patients, revealed that only 7.7% of the respondents were able to carry out daily activities independently. Conversely, 92.3% of post-stroke patients demonstrated a high level of dependence in performing activities of daily living (ADLs) (Wurzinger et al., 2021).

Research conducted on stroke patients at the outpatient clinic of Dr. Iskak Tulungagung in Indonesia, involving 57 patients, revealed that the primary caregiver for post-stroke patients at home was the partner (64.91%). Families play a crucial role in offering support to their members dealing with stroke, aiming to prevent both physical and mental decline and enhance Activities of Daily Living (ADLs) (Setyoadi et al., 2017; Gawulayo et al., 2021). There are four aspects of family support; namely, informational, instrumental, appreciative, and emotional support. Family's appreciative support is needed to enhance confidence. Strong emotional support from families will help patients face their illness and earn a high self-esteem. Emotional support can take the form of attention and encouragement for respondents to not give up and be strong. Literature-review research on family support, encompassing 10 articles published from 2017 to 2022, indicated that the predominant type of support received by most respondents was instrumental support, while informational support was reported as the least received. Respondents expressed that families frequently assist by seeking funds, purchasing medicines, and providing

facilities for physical exercise (Rinawati et al., 2022). Kington's research, involving 400 respondents and focused on the search for health information sources, revealed that family informational support was seldom provided (75%). This scarcity was attributed to families infrequently seeking information about the illness from books, brochures, or healthcare professionals. Instead, they more commonly obtained information from social-media platforms (76%) (Kingon et al., 2021).

The results of research conducted at the Neurological Polyclinic of Arifin Achmad Hospital in Pekanbaru, Indonesia, involving 54 respondents, showed slightly different outcomes. Among the four aspects of family support, emotional support was the most widely received; however, it was observed that 65.4% of post-stroke patients did not receive adequate family support (Ramadhani et al., 2022). Patients stated that they were unhappy with their family support, such as with the way how their families communicated with them and the way how their families expressed affection and responded to emotional feelings. As a matter of fact, a proper family support will help patients get rid of problems due to burdens.

Pacitan Regional General Hospital (RSUD) is one of the referral hospitals in Pacitan Regency, Indonesia. A previous study conducted at the Medical Record Unit of Pacitan Regional General Hospital showed that one of the 10 illnesses that caused death was stroke. Most post-stroke patients suffered from motor disorders and experienced a decline in fulfilling their daily activities. The results of interviews with six stroke patients showed that they lived with their families and that supports given by the families were varied.

The high incidence of stroke and its consequent impact, such as disability leading to diminished quality of life and premature death, necessitates long-term care solutions at home. Family caregivers represent one of the primary sources of support readily available, playing a crucial role in enhancing self-care for post-stroke patients undergoing treatment at home. This study aims to analyze the relationship between family support and self-care in stroke patients receiving treatment at home.

Methods
Study Design, Setting and Participants

This study used an analytic observational design with a cross-sectional approach. This research was conducted at the Neurology Department of Pacitan

Regional General Hospital, Indonesia. The population of this research was post-stroke patients and families of post-stroke patients. The sample size was determined using the Slovin formula, considering the population during the last three months of outpatient stroke unit visits. A total of 150 respondents were included, comprising 75 family caregivers and 75 patients. The samples were selected using a purposive sampling technique over a period of one month.

The inclusion criteria for stroke patients encompass those aged less than 65 years; this criterion is established based on the understanding that stroke attacks in older patients often result in more severe damage and disability (Downer et al., 2023), willing to participate in this research, with history of first attack that received medical treatment; patients who have undergone outpatient treatment in the neurology department for 3-6 months from the first attack are included, because this duration is selected because phase 1 rehabilitation during this period has shown to contribute to increased functional independence (Koroleva et al., 2021), undergoing physiotherapy, hemiplegia or hemiparesis physical disability with 3-4 motor strength, and with ischemic stroke. The exclusion criteria encompassed stroke patients experiencing visual impairment, depression, and aphasia, as these conditions could hinder their ability to provide consent to participate in the research. Inclusion criteria for families were families that lived at the same house (spouse, child, siblings) and took care of post-stroke patients, were older than 17 years of age, able to communicate verbally, and willing to join this research.

Instrument

This research uses two types of questionnaires; namely, the Family Support Questionnaire (FSQ) to measure family support variables which were developed by researchers based on research conducted by Setyoadi et al. (2017) and Barthel Index Questionnaire (BIQ) to measure patient independence variables post stroke. The Family Support Questionnaire consists of 20 questions containing response options of always, often, sometimes, and never. Favorable statements are given a score of 4, 3, 2, and 1, while unfavorable statements were given the opposite values. The higher the score, the better the family support. Barthel Index Questionnaire consists of 10 statements about daily activities, such as bathing, eating, dressing, controlling bowel movements

and moving. The score for each statement is 1 if able to do and 0 if unable to do. The higher score obtained indicates the patient's independence.

The results of the FSQ validity test on 20 respondents using the Pearson Product Moment test with an r count of 0.4-0.9, indicating a moderate to high validity range, mean being declared valid. The FSQ reliability test used Cronbach's alpha and the coefficient value of 0.918 was greater than 0.70; so, it could be concluded that it was reliable. The validity and reliability test of the Barthel Index Questionnaire has been carried out in previous research with the same population and obtained r values in the range of 0.6-0.9, greater than 0.4, meaning that the instrument is valid. The reliability test obtained a coefficient value of 0.889, meaning a reliable instrument.

The data-collection process commences with the submission of permission to the hospital's head after receiving approval from the research ethics committee for the research proposal. Researchers, with the assistance of nurses at the Neurology Department outpatient clinic in the Regional General Hospital, Pacitan, Indonesia, conducted the data collection.

Statistical Analysis

The data-analysis process commenced with the assignment of codes to each instrument filled out by family caregiver respondents and patients. Subsequently, data entry was performed using IBM SPSS, version 23 software. Demographic data underwent analysis through descriptive analysis and the initial bivariate test utilized the Pearson Product Moment test. Bivariate analysis uses the rank Spearman's test to analyze the relationship between two variables with a significance value of 0.05.

Ethical Approval

Before initiating data collection, potential respondents underwent a screening process based on specific inclusion and exclusion criteria, facilitated by an outpatient polyclinic nurse. Subsequently, comprehensive information was provided to the individuals, encompassing the research's aims and objectives, potential benefits, possible risks, and the participant's right to discontinue involvement at any point in the research process. Upon obtaining consent, participants were requested to sign and complete the questionnaire, indicating their agreement with the study by providing their initials. This research obtained ethical

permit from the Health Research Ethics Committee, Faculty of Medicine, Brawijaya University, Malang with Number 299/EC/KEPK-s1-PSIK/11/2019.

Results

Demographic data of patient respondents and family caregivers (gender and relationship of the caregiver with the patient, as well as length of suffering) is displayed in the form of frequency distribution table proportions, while age data is displayed in the form of mean, minimum and maximum age. The results of the demographic data research indicate that the average age of patients falls within the adult age category (52 years). A majority of stroke sufferers are male, constituting 50.7%, and the duration of suffering for most patients is less than 3 months, accounting for 57.3%. In terms of demographic data for family caregivers, the average age

of caregivers is in the adult category (43 years). The majority of caregivers are female, representing 70.6%, and nearly a half of the caregivers (49.3%) have a partner relationship with the patient.

Table 2 shows the result of family support scores and the result of Barthel Index values. Respondents in this study had a mean score of family support of 37.25. The highest mean score among emotional, appreciative, informational, and instrumental supports was for emotional support (10.57).

Table 3 shows the results of bivariate test between family support and Barthel index. The result obtained from the Spearman's correlation test was $p<0.05$, meaning that H^0 was rejected. The data proved that there was a correlation between family support and self-care of post-stroke patients.

Table 1. Characteristics of the respondents (n=150)

Characteristics	n (%)	Mean (min-max)
Stroke patients:		
a. Age (years)	75 (100)	52 (35-65)
b. Sex:		
Male	38 (50.7)	
Female	37 (49.3)	
c. Duration of illness (months)		4.1 (3-6)
< 3 months	43 (57.3)	
> 3 months	32 (42.7)	
Family caregiver:		
a. Age (years)	75 (100)	43 (24-63)
b. Sex:		
Female	53 (70.6)	
Male	22 (29.4)	
c. Relation with stroke patients:		
Child	27 (3.6)	
Spouse	37 (49.3)	
Sibling	11 (14.7)	

Table 2. Family support and level of self-care (n=75)

Variable	Minimum score	Maximum score	Mean
Score of family support	14	48	37.25
Distribution of family support:			
a. Emotional	3	15	10.57
b. Appreciative	2	12	9.41
c. Informational	0	9	7.45
d. Instrumental	3	12	9.81
Level of self-care (Barthel index)	55	100	82.93

Table 3. Bivariate test results

Variable	p-value	Coefficient
Family support score	0.000	0.5625
Barthel index value		

Discussion

Family Support

The research showed that the family member who mostly accompanied post-stroke patients was spouse, numbering 53 respondents (70.6%). The result of a study conducted showed that quality of a good family support is proportional to the number of spouses living under the same roof (Choliq et al., 2020). The result of this research also showed that on average, the family member who takes care of the patient is female. Female caregivers are more concerned in treating patients; so, the patient will feel more comfortable. Female family caregivers are more attentive in treating the sick family member; so female caregivers will be able to give maximum support (Biderman et al., 2021).

The results of this study also demonstrate a notably high average value of family support, as evidenced by emotional, instrumental, and appreciation support. Emotional, instrumental, and appreciation support are deemed highly for stroke patients. Emotional support entails providing encouragement and emotional assistance to patients, contributing to improved quality of life and motivation (Lee & Won, 2022). Instrumental support involves offering physical and practical aid to patients, assisting with daily activities and personal care. Appreciative support entails recognizing and appreciating the patient's efforts and achievements, fostering increased self-confidence and motivation (Oyake et al., 2020).

In this study, the relationship between family support, such as emotional, informational, instrumental, and appreciation support, and the quality of life of stroke patients in the acute phase has been established. Optimal family support is crucial for stroke patients, as it can enhance their self-care and functional status (Kernan et al., 2021). Furthermore, family support plays a vital role in aiding stroke patients during their recovery and rehabilitation process. In other research, emotional support was identified as a crucial aspect of caring for stroke patients, helping maintain positive emotional responses and improving the patient's overall quality of

life (McCurley et al., 2019). Appreciative support was also found to play a significant role in caring for stroke patients by providing motivation and sustaining the patient's morale during recovery (Vidyanti et al., 2022). Therefore, emotional, instrumental, and rewarding support play pivotal roles in the care and recovery of stroke patients, contributing to enhanced quality of life, motivation, and self-care for these individuals.

Patients' Self-care

The study results reveal that the average self-care level among stroke patients falls within the high category. Demographic factors are identified as influencers of self-care in stroke patients. The findings indicate that the average age of patients is categorized as adults (52 years). Age is identified as a potential factor impacting self-care practices in stroke patients (Kuo et al., 2021). Adult age may be associated with challenges in physical functioning and cognitive abilities, thereby affecting self-care abilities (Hayajneh et al., 2023).

The study further highlights that adults with stroke who reside with their families and remain engaged in community activities exhibit better self-care compared to those living in institutions (Cowman et al., 2010; Yun et al., 2020). Additionally, the study notes that male stroke patients constitute the majority (50.7%). Research at Tidar Magelang Regional Hospital indicates a predominance of male stroke patients (Rexrode et al., 2022), while other studies suggest no significant relationship between gender and self-care in carrying out daily activities among stroke patients (Andrade et al., 2020).

The research also reveals that the maximum length of stay is less than 3 months. The early stages of the rehabilitation process for stroke patients may contribute to more favorable self-care outcomes (Li et al., 2023). However, the study contrasts with other research that suggests that the duration of suffering from a stroke does not significantly affect the level of independence among stroke patients (Vázquez-Guimaraens et al., 2021). It's crucial to acknowledge that factors, such as stroke

severity, socioeconomic status, and marital status, may influence a patient's self-care (Sun et al., 2023).

Self-care refers to the ability to perform daily tasks, often referred to as Activities of Daily Living (ADL). Stroke, a medical condition that can result in motor disabilities, occurs when damage affects the hemisphere of the brain that controls the opposite side of the body. For instance, the right hemisphere controls the left side, and the left hemisphere controls the right side. Consequently, post-stroke patients may experience dependence in carrying out their daily activities. The recovery of neurological function and daily life activity function following a stroke varies over time. According to Grefkes et al. (2020), the fastest recovery occurs within the first week and extends to three to six months after the stroke. Early intervention in stroke cases is crucial, as it minimizes brain damage and reduces dependence (Li et al., 2023).

Correlation between Family Support and Self-care

This research showed that there is a strong correlation between family support and independence of post-stroke patients with physical disability. If the score of family support is high, the score of independence of post-stroke patients with physical disability is also high. This result is supported by the study conducted by Thomas et al. (2017) in that the most important family support is obtained from a closest relative in the family. Family becomes a very influential factor for an individual's health and can decide what treatment regimen will be received. A study by Choliq et al. (2020) explained that family members have an important role in helping increase the independence of post-stroke patients while undergoing treatment at home or as outpatients. A study by Ugur and Erci (2019) into the impact of social support at home by family caregivers on stroke patient's health showed that the involvement of family caregivers in stroke patients can increase their ability to perform daily-life activities (Activity of Daily Living) independently and become better with social support from family, eventually increasing the psychosocial health status of post-stroke patients.

According to the researchers, a good family support can increase post-stroke patient's independence. Patients will be motivated to recover when receiving support from their families. Research results stated that higher family support will increase self-esteem and self-control, as such increase is expected to help patient's

coping ability to face stressors during the illness (Cyran-Grzebyk et al., 2023). Accordingly, Abdi et al. (2020) said that a person's independence needs chance, support, and boost from others and society around him/her. One of the supporting factors is family support. Family can independently train and motivate a post-stroke family member to return in doing daily-life activities without depending on others (Rapolienė et al., 2018). According to Henderson (1966) in Younas (2019), a nurse was defined as a person with duty to help an individual increase his/her independence as quickly as possible and help client's strength recover. Family also plays a role in this. Community nurse and family are expected to collaborate, so that the family can have knowledge and skills in taking care of post-stroke family members at home (Hamadneh, 2023). Therefore, family support is very important to increase the independence of post-stroke patients.

Conclusion

This study emphasizes the crucial role of family support in enhancing the self-care of post-stroke patients. It underscores the necessity for tailored health-education programs and collaboration with health professionals. These findings highlight the significance of acknowledging and addressing family dynamics to optimize patient outcomes in stroke rehabilitation. Family caregivers play a pivotal role in sustaining ongoing support for post-stroke individuals, fostering communication with health services, and consistently encouraging activities beneficial for the patient's self-care.

Implications for Nursing

Discharge planning for stroke patients undergoing outpatient care needs to emphasize the importance of family competence when assisting with home care in increasing patient self-care. Family-centered health-education strategies play a crucial role in maximizing the contribution and functionality of the family unit. It is recommended for further research to explore intervention strategies focused on empowering family caregivers, enhancing their competence, and augmenting their roles in providing care for family members affected by stroke. This avenue of investigation could yield valuable insights into effective approaches for supporting both caregivers and individuals recovering from stroke within a familial context.

Limitations

The research limitations are notable, as it did not extensively explore the socioeconomic and psychosocial factors influencing stroke patients and family caregivers, resulting in a discussion that lacks depth. It is recommended that future research delves into factors, such as income, educational level, marital status, health-service contacts, and access to resources. Addressing these aspects in subsequent studies could provide a more comprehensive understanding of the broader context and potential challenges faced by stroke patients and their caregivers, contributing to a more nuanced and holistic discussion of the subject matter.

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