

## A Cross-Sectional Study on the Relationship Between Health Literacy and Family Involvement in the Care of Stroke Patients at Regional Hospital

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### ABSTRACT

**Introduction:** Stroke was a leading cause of mortality and disability globally, with a significant prevalence in Indonesia. Health literacy and family involvement played critical roles in stroke management. This study examined the relationship between health literacy and family involvement in the care of stroke patients at Regional Hospital.

**Methods:** A cross-sectional descriptive analysis was conducted with 35 family members of stroke patients, selected using consecutive sampling. The sample size was calculated with a formula where the margin of error is 17%. Data were collected using the Health Literacy Survey-Short Form (HLS SF Q12) and the Family Engagement Measure (FAME) questionnaire, both validated and reliable. Statistical analysis using Chi-square tests evaluated the relationship between health literacy and family involvement, with a significance threshold of  $p < 0.05$ .

**Results:** The majority of respondents demonstrated high health literacy (57.14%) and high family involvement (77.14%). Research results also revealed that respondents with high health literacy also exhibited high family involvement (54.29%), whereas those with low health literacy had lower involvement (14.29%). Chi-square analysis indicated a significant positive relationship between health literacy and family involvement ( $p = 0.000$ ).

**Conclusion:** The study demonstrated that improving family health literacy positively influenced their involvement in stroke care. Educational interventions to enhance health literacy are essential to promote effective, family-centered care strategies.

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## 1. INTRODUCTION

Stroke is one of the most common neurological disorders and is the second leading cause of death worldwide (Tsao, 2023). Stroke is characterized as a central neurological shortfall of sudden onset, with side effects enduring more than 24 hours (or coming about in passing some time recently 24 hours) (Murphy & Werring, 2020). Based on the Indonesian Health Profile in 2020, the number of stroke cases in Indonesia is quite high, with 1,789,261 Indonesian residents experiencing or suffering from stroke (Kemenkes, 2020). The prevalence of stroke sufferers in East Java reached 21,120 or 12.4%, ranking 8th in

Indonesia in 2018 (Kemenkes, 2018). Based on Medical Record data from Regional Hospital, stroke is among the top 10 most common diseases in the inpatient ward, where the latest record in 2023 shows that the number of stroke patients reached 644 out of 9,643 patients in 2023. The most common type of stroke is non-hemorrhagic stroke, with 443 cases (68.79%), followed by hemorrhagic stroke with 201 cases (31.21%) (Medical record RSUD Bangil, 2024). Based on the above issues, the urgency of health literacy needs to be addressed with a family approach. This study aims to explore the relationship between health literacy and family involvement in the care of stroke patients at Regional Hospital.

According to (Kurniawati et al., 2020), there needs to be very precise support as the main source of support, which is the family. The family plays a role as a facilitator in preventing the risk of stroke among family members, ensuring that antihypertensive medication is taken regularly, and providing emotional support (Kurniawati et al., 2020). Families need to be empowered as optimally as possible to prevent and guide family members in adapting to their health conditions, so that an optimal quality of life can be achieved. In order to empower families, their knowledge about stroke and skills in helping patients adapt must be improved. For stroke patients, family involvement is critical in assisting with daily care, such as mobility, nutrition, and rehabilitation exercises. Health literacy serves as the foundation for effective, family-centered care. Improving literacy levels among patients and caregivers leads to better health outcomes, fewer complications, and improved quality of life, especially for stroke patients.

Long-term complications of stroke include seizures, musculoskeletal disorders, urinary incontinence, psychosocial issues, and cognitive impairments (Chohan et al., 2019). Complications from a stroke can be prevented with patient self-care. Complications can occur and are influenced by several factors such as age, education level, language, cultural background, education, and health literacy (Cook & Pompon, 2023). Health literacy is an individual's capacity to get to, perused, prepare, and get it wellbeing data and administrations, and to utilize wellbeing data and administrations successfully to create fitting wellbeing choices (Karasneh et al., 2020). Furthermore, the first literature on the definition and systematic model of health literacy was compiled by Sorensen et al. in 2012 (Okan et al., 2019). Health literacy can also be translated as Individuals require skills and competencies in accessing, comprehending, analyzing, and applying health information in diverse health domains like health promotion, healthcare settings, and preventive health (Tutu et al., 2024). Health literacy requires information, motivation, and community competence to get to, get it, assess, and apply data to form assessments and choices in standard of living related to healthcare, infection avoidance, and wellbeing advancement to preserve and move forward their quality of life (Yu et al., 2023). Somebody who has satisfactory health literacy will lock in decision-making, keep up their health, and get superior treatment, in this manner contributing to the advancement of their health (Asharani et al., 2021). Thus, someone with good health literacy will not only improve their own health but also that of their family members who are receiving care.

Family individuals are an important asset for the conveyance of modern healthcare, particularly within the intensive care unit. Families can engage in communication and decision-making with the healthcare group, give enthusiastic or physical back to their adored ones, and effectively contribute to the delivery of care (Goldfarb et al., 2022). Based on that

perspective, nursing care not only focuses on the individual client but also simultaneously on the family (Hagedoorn et al., 2021). However, the involvement of clients and families is still not optimal due to several significant barriers, including a lack of awareness or opportunities, as well as accessibility challenges (Hirschhorn et al., 2022). Thus, there is a need for health literacy for the families of patients undergoing treatment. Given the importance of family involvement in care, the author wants to understand the relationship between health literacy and family involvement in caring for stroke patients at Regional Hospital. The aim of this research is to determine how health literacy affects family involvement in the care of stroke patients.

## 2. METHODS

### Study Design

This research method uses descriptive analytic with an cross-sectional approach. Through this cross-sectional design, it can be determined and explained whether or not there is a relationship between variables in the study (Sidik Priadana dan Denok Sunarsi, 2021).

### Population, Samples, and Sampling

The population in this study comprised all families of stroke patients treated at Bangil Regional Hospital. The researchers employed a consecutive sampling method, selecting a total of 35 respondents in November 2024. To participate in the study, respondents needed to meet specific inclusion criteria: they had to be willing to take part as research respondents, serve as caregivers for the patients, be family members of the patients, and possess the ability to read and write. On the other hand, individuals were excluded if they were unwilling to participate, were unable to read or write, or had mental disorders that could interfere with their participation. This careful selection ensured that the respondents were suitable and capable of contributing valuable insights to the research. Health literacy, which serves as the independent variable in this study, refers to the ability of family members to understand, utilize, and manage health information related to the care of stroke patients. Meanwhile, family involvement, functioning as the dependent variable, reflects the extent to which families participate in supporting treatment, rehabilitation, and the overall care needs of the patients.

### Instruments

Data collection was conducted using two questionnaires. The Health Literacy Questionnaire uses the Health Literacy Survey-Short Form (HLS SF Q12), which has been adjusted and deciphered with a weight of 12 questions. The results of the validity and reliability test on N (30 respondents) appear that the Cronbach Alpha esteem is 0.888, with 12 questions having a rectified add up to thing relationship extending from 0.394-0.809 > R Table 0.361, showing

**Table 1.** Distribution of demographic data respondents at Regional Hospital

Characteristics of Respondents		(f)	(%)
<b>Age</b>			
1.	23 years	3	8,57
2.	2.26-35 years	6	17,14
3.	36-45 Age years	13	37,14
4.	46-55 years	7	20
5.	> 56 years	6	17,14
<b>Total</b>		35	100
<b>Gender</b>			
1.	Female	18	51,4
2.	Male	17	48,6
<b>Total</b>		35	100
<b>Education</b>			
1.	Not attending School	1	2,86
2.	Elementary School	10	28,57
3.	Junior High School	4	11,43
4.	Senior High School	17	48,57
5.	College	3	8,57
<b>Total</b>		35	100
<b>Relationship with patients</b>			
1.	Husband or Wife	6	17,14
2.	Patient's child	22	62,86
3.	Brother or Sister	7	20
<b>Total</b>		35	100

**Table 2.** Description of Health Literacy and Family Involvement of respondents Regional Hospital

Variables	(f)	(%)
<b>Health Literacy</b>		
High	20	57,14
Moderate	10	28,57
Low	5	14,29
<b>Total</b>	35	100
<b>Family Involvement</b>		
High	27	77,14
Moderate	4	11,43
Low	4	11,43
<b>Total</b>	35	100

that the HLS SF Q12 survey can be pronounced valid and reliable. The HLS SF Q12 questionnaire consists of 12 questions divided into 4 domains, namely finding information, understanding information, appraising information, and applying information (Fatmawati et al., 2023). The determination of the HLS SF Q12 questionnaire results is categorized into

three criteria: High (score 36-48), Moderate (score 28-35), and Low (score 12-28).

The Family Engagement Measure (FAME) questionnaire used has been modified and translated with a total of 12 weighted questions. The results of the validity and reliability tests on N (30 respondents) appear that the Cronbach Alpha esteem is 0.925, with the 12 questions having a rectified add up to thing relationship extending from 0.597-0.880 > R Table 0.361, indicating that the FAME questionnaire can be pronounced valid and reliable. The FAME questionnaire consists of 12 questions divided into 2 main domains: The family engagement domain (counting family nearness, family needs, communication/education, decision-making, and coordinate commitment to care) and the family-centered care domain (incorporates nobility and regard, sharing data, support, and collaboration) (Goldfarb et al., 2022). The determination of the FAME questionnaire results is assessed with a score of 0-100 with criteria of High (71-100 points), Moderate (41-70 points), and Low (poin 0-40).

### Procedure

This research has received ethical approval from the Ethics Team of Bangil Regional Hospital with number 400.14.5.4/3023/424.072.01/2024 on November 25, 2024. Informed consent was obtained from all participants, ensuring they were fully aware of the study aims, procedures, and their right to withdraw from the study at any time without consequences. Consent must be documented in writing. Regarding data confidentiality, participants' personal and health information is anonymized, stored securely, and can only be accessed by authorized personnel. Research findings should be presented in aggregate form, ensuring no personal identities are disclosed.

### Data Analysis

This study uses the Chi-square test with a importance level ( $\alpha$ ) = 5% and a certainty level of 95% to test the differences in proportions or percentages between several data groups and to determine the relationship between categorical variables and categorical variables. (Adiputra, 2021). The Chi-square test value in this study shows a p-value of  $0.00 \leq 0.05$ , showing a significant relationship between health literacy and family involvement.

## 3. RESULTS

Based on the statistic data in table 1, it appears that the larger part of respondents were female, 18 respondents (51,4%), with the biggest age gather being 36-45 years old, 13 respondents (37,14%). The educational level of the respondents was mostly Senior High School, specifically 17 respondents (48,57%) with the larger part of respondents relationship as patient's child 22 respondents (62,86%). These characteristics can be useful when considering how family involvement and health literacy are distributed, as factors such as age, gender,

**Table 3.** The Relationship between Health Literacy and Family Involvement in care of stroke patients at Regional Hospital

Variable	Family Involvement		
	Low	Moderate	High
	f (%)	f (%)	f (%)
<b>Health Literacy</b>			
1. Low	4 (11,43%)	1 (2,86%)	0 (0%)
2. Moderate	0 (0%)	2 (5,71%)	8 (22,86%)
3. High	0 (0%)	1 (2,86%)	19 (54,29%)
<b>Total</b>	4 (11,43%)	4 (11,43%)	27 (77,14%)
<b>Chi Square p value = 0,000 with p &gt; 0,05</b>			

and education level might influence a family's approach to caregiving.

Based on the statistic data in table 2, it appears that the majority of respondents Health Literacy was High, to be specific 20 respondents (57,14%). This suggests that a considerable portion of the family members involved in the care of stroke patients are relatively knowledgeable about healthcare topics, which is an encouraging finding. This high health literacy could play a significant role in how well families understand the stroke recovery process, follow medical advice, and manage post-stroke care. Additionally, Table 2 shows that most respondents were highly involved in patient care, with 27 respondents (77.14%) reporting high family involvement. This aligns with the notion that families of stroke patients who have better health literacy are more likely to engage actively in the care process.

Table 3 provides a clear picture of the relationship between health literacy and family involvement. The Chi-Square analysis reveals a significant positive correlation between health literacy and family involvement, with a p-value of 0.000 ( $p \leq 0.05$ ). This indicates that as health literacy increases, family involvement in the care of stroke patients also increases.

**High Health Literacy & High Family Involvement:** The cross-tabulation data shows that 54.29% of respondents (19 individuals) who had high health literacy were also highly involved in caregiving. This is a crucial finding, as it suggests that families with better health literacy are more likely to take an active role in managing the patient's care. This could be due to their ability to understand the medical needs of the patient, communicate effectively with healthcare professionals, and follow post-care instructions with more confidence.

**Moderate Health Literacy & Moderate Family Involvement:** There were 10 respondents (28.57%) with moderate health literacy who also exhibited moderate family involvement. While this group shows some involvement in caregiving, the level of engagement is still somewhat lower compared to those with high health literacy. This may reflect

challenges in understanding or applying medical information, resulting in less active participation in the caregiving process.

**Low Health Literacy & Low Family Involvement:** Interestingly, 14.29% of respondents (5 individuals) had low health literacy, and this group also showed lower levels of involvement in caregiving. These findings are consistent with the hypothesis that lower health literacy leads to less understanding of the patient's condition, which in turn may hinder the family's ability to effectively contribute to the patient's care. Low literacy could result in misunderstandings about care requirements, medication schedules, or the importance of rehabilitation, leading to reduced participation.

#### 4. DISCUSSION

This study shows that there's a significant relationship between health literacy and family involvement in the care of stroke patients at Regional Hospital, with a chi-square correlation test. This means that the higher level of family health literacy, the higher of family involvement in caring for stroke patients, and again, the lower level of family health literacy, the lower family involvement in caring for stroke patients. The table illustrates the relationship between family involvement in stroke care and the level of health literacy. It shows that families with low health literacy tend to be less involved in the care of the stroke patient. In contrast, families with higher levels of health literacy are more actively engaged in caregiving.

For families with low health literacy, involvement is generally low to moderate, meaning they may struggle with understanding the necessary care practices and, as a result, contribute less to the patient's recovery. On the other hand, families with moderate health literacy show a slightly higher level of involvement, though still limited compared to those with high literacy. The families with high health literacy are notably more involved, actively participating in decision-making, managing care routines, and supporting the patient's rehabilitation efforts.

This is in line with the research by (Rachmani et al., 2020) that health literacy has been proven to affect health status. A person's health behavior is influenced by their level of health literacy, and the study explains that the higher health literacy, the better person's health behavior (Tamalla & Azinar, 2022). Health literacy rates are an important thought within the avoidance, management, and rehabilitation of stroke (Cook & Pompon, 2023).

Health literacy is crucial for families of stroke patients as they play a key role in supporting recovery and care. Families with a higher level of health literacy are better able to recognize early signs of stroke, understand medical treatments, and follow post-stroke care plans effectively. This knowledge helps reduce anxiety, improves communication with healthcare providers, and ensures that the right

decisions are made for the patient's care. Health literacy also helps families overcome common barriers in stroke care, such as unclear information or poor communication with medical professionals. Families with better literacy can access, understand, and utilize medical information, which empowers them to make informed decisions. They are more engaged in the care process, ensuring the patient receives timely treatments and rehabilitation, ultimately leading to better outcomes. In short, improving health literacy among family members is essential for enhancing patient care, supporting recovery, and overcoming obstacles in managing stroke care. According to the American Heart Association, stroke patients must receive education on early stroke signs, emergency medical activation, medications, and monitoring after recovery (Kleindorfer et al., 2021). This research is supported by the study by (Flink et al., 2023), which found that a high level of health literacy can improve patients' daily activities. Thus, there is a need for a high level of health literacy among the families of patients to assist in the recovery and care of stroke patients. These comes about are in line with the research conducted by (Diannita et al., 2023) that the role of two-way communication between healthcare workers and families can enhance family participation in patient care programs. Collaboration between families, patients, and healthcare professionals is needed in direct healthcare services (Katz et al., 2020). Evidence shows that people with lower education have lower health literacy skills as compared to people with higher education. Nevertheless, health literacy and general literacy are not identical concepts. Inadequate health literacy is not uncommon among patients with a high level of education (Shahid et al., 2022). This is also the basis for the expectation that when families have a good level of literacy, they will have the knowledge, motivation, and competence to get it, evaluate, and utilize data for making decisions that can be used to help in the care of their family members who have suffered a stroke.

Health literacy can be integrated into family-based care programs in Hospitals, educating family members on stroke, post-stroke care, and rehabilitation. By improving health literacy, families are better equipped to understand the patient's condition, make informed decisions, and provide proper care.

Key strategies include providing training on stroke management, nutrition, physical rehabilitation, and mental health support. It's also essential to improve communication skills with healthcare professionals, allowing families to better understand medical instructions and be more involved in decision-making. Additionally, health literacy can be enhanced through digital tools, such as what's app group, offering families easy access to information and ongoing support. Ultimately, integrating health literacy into family care programs empowers families, improves patient outcomes, and

supports the overall recovery process for stroke patients.

## 5. CONCLUSION

Family health literacy of stroke patients has a positive relationship with family involvement in caring for stroke patients in hospital. To improve health literacy among family members of stroke patients at the hospital, several strategies can be implemented. First, regular education sessions should be organized, where family members can learn about stroke prevention, warning signs, and post-stroke care. These sessions can include information on rehabilitation exercises, lifestyle changes, and managing complications. In addition, easy-to-understand educational materials such as brochures, pamphlets, and videos should be provided to explain stroke recovery, medication management, and how to recognize early signs of complications. Personal caregiver training is also crucial, where families are taught how to assist with daily activities, help with mobility, and manage medications safely. It is trusted that future analysts can conduct inquire about with a more extensive extend and include other components that can strengthen the involvement between variables.

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