

Family Perspectives on Early Stroke Recognition: A Qualitative Descriptive Study

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Abstract

Background: Stroke is a leading cause of long-term disability worldwide. Delays in hospital presentation frequently occur due to limited family recognition of early symptoms, particularly during the critical therapeutic window.

Objective: This study aimed to explore family knowledge, responses, and caregiving practices related to early stroke recognition.

Methods: A qualitative descriptive study was conducted using in-depth interviews with seven family caregivers of stroke patients admitted to a private hospital in Yogyakarta, Indonesia. Participants were recruited through purposive sampling after the patients' conditions had stabilized. Data saturation was achieved by the fifth participant. Interviews were conducted in a private setting, lasted 30–45 minutes, and were audio-recorded and supported by field notes. Data were transcribed verbatim and analyzed using thematic analysis based on Braun and Clarke's framework with the assistance of NVivo software.

Results: Three major themes emerged: (1) misinterpretation of early stroke symptoms, (2) delayed response influenced by symptom normalization and reliance on visible neurological deficits, and (3) caregiving challenges and unmet educational needs. Most participants initially interpreted symptoms such as vomiting, dizziness, and weakness as minor conditions, resulting in delayed hospital presentation, frequently exceeding 24 hours after onset.

Conclusion: Family caregivers demonstrate limited awareness of early stroke symptoms, contributing to delayed treatment and inadequate preparedness for post-stroke care. Structured and culturally appropriate educational interventions, particularly visual-based media, are needed to improve early recognition and caregiving capacity.

Keywords

Stroke; Caregivers; Early Diagnosis; Health Knowledge, Attitudes, Practice; Qualitative Research

Introduction

Stroke remains a major neurological disorder affecting the cerebrovascular system and is a leading cause of long-term disability and mortality worldwide.^{1,2} The global burden of stroke continues to rise, particularly in low- and middle-income countries, where access to timely diagnosis and treatment remains uneven.^{3,4} In Asia, Indonesia reports one of the highest stroke burdens, with mortality rates reaching 193.3 per 100,000 person-years and a substantial disease burden.³ Recent national data further indicate that the Special Region of Yogyakarta has the highest prevalence of stroke in Indonesia, underscoring the urgency of addressing this condition at both clinical and community levels.⁵

Stroke is strongly associated with non-communicable diseases (NCDs), including hypertension, diabetes mellitus, and cardiovascular disorders, which are highly prevalent in the Indonesian population.⁶ Despite advancements in healthcare services, outcomes remain suboptimal due to delays in treatment initiation, particularly during the critical therapeutic window known as the "golden period."^{7,8} Timely hospital presentation is a key determinant of recovery; however, many patients arrive at healthcare facilities in advanced clinical conditions, reducing the effectiveness of acute interventions.^{9,10}

One of the most significant contributors to pre-hospital delay is the limited ability of family members to recognize early stroke symptoms.¹¹ As primary witnesses and decision-makers, family members play a crucial role in identifying symptom onset and initiating medical care.¹² However, existing evidence suggests that public awareness of stroke symptoms is often restricted to overt motor deficits, such as paralysis or facial asymmetry, while non-motor symptoms such as dizziness, vomiting, and general weakness are frequently overlooked or misinterpreted.¹³ This limited recognition contributes to delays in seeking care and ultimately worsens clinical outcomes.¹³

In the Indonesian context, sociocultural beliefs further complicate symptom recognition. Common cultural interpretations, such as attributing symptoms to "masuk angin" (a culturally recognized but medically non-specific condition), may lead families to underestimate the severity of early stroke manifestations.¹⁴ Additionally, situational factors such as religious activities and fasting periods may normalize symptoms like fatigue and dizziness, thereby delaying decision-making.^{15,16} These contextual influences highlight the need to understand stroke recognition not only from a biomedical perspective but also within its sociocultural environment.^{15,16}

Previous studies have examined stroke awareness and pre-hospital delay; however, most have focused on quantitative assessments of knowledge levels or clinical outcomes, with limited exploration of the lived experiences and decision-making processes of family caregivers.^{17,18} Furthermore, research addressing how cultural perceptions shape symptom interpretation and response in Indonesian families remains scarce. This gap limits the development of contextually appropriate educational interventions aimed at improving early stroke recognition and response.

Therefore, this study aims to explore family perspectives on early stroke recognition, including their knowledge, response patterns, and caregiving experiences during hospitalization. By providing an in-depth understanding of these factors, this study seeks

to inform the development of culturally sensitive and practical educational strategies to reduce delays in stroke management and improve patient outcomes.

Methods

This study employed a qualitative descriptive design to explore family perspectives on early stroke recognition, focusing on their knowledge, response patterns, and caregiving experiences. A qualitative descriptive approach was selected as it allows for a comprehensive and pragmatic understanding of participants' perceptions and experiences without imposing a strict theoretical framework, making it appropriate for applied clinical research contexts.

Participants were recruited using purposive sampling based on predefined inclusion and exclusion criteria. Eligible participants were family members (spouse, children, or siblings) who acted as primary caregivers, accompanied the patient from the onset of stroke symptoms or admission to the emergency department, and were actively involved in caregiving during hospitalization. Participants were required to be able to communicate in Indonesian and willing to provide written informed consent. Family members who were not directly involved in caregiving, had significant communication barriers, or experienced severe emotional distress were excluded. Recruitment was conducted after the patients' clinical conditions had stabilized, and participation was voluntary. Data saturation was achieved at the fifth participant, as no new codes or themes emerged; however, two additional participants were included to ensure data richness and confirm thematic consistency. This sample size is considered adequate for qualitative descriptive studies, where the aim is to achieve depth of understanding rather than statistical generalization, and is supported by the attainment of data saturation. Detailed demographic variables such as age and educational background were not systematically collected, as the study focused primarily on experiential narratives.

Data collection was conducted between March and April 2025 in a private hospital in Yogyakarta, Indonesia, specifically in inpatient wards (Galilea and Gardenia) and the Stroke Intensive Care Unit (SICU). Interviews were conducted in a quiet and private room within the hospital to ensure confidentiality and minimize external disturbances. No non-participants were present during the interviews. Each interview lasted approximately 30 to 45 minutes and was conducted in Indonesian using a semi-structured interview guide. The guide focused on four main domains: (1) knowledge of stroke symptoms, (2) initial responses to symptom onset, (3) barriers in responding to symptoms, and (4) caregiving practices during hospitalization. The interview guide was developed based on relevant literature and clinical considerations, and was reviewed internally by the research team prior to data collection. Examples of guiding questions included: "What symptoms did you first notice before the patient was diagnosed with stroke?", "What actions did you take when the symptoms first appeared?", and "What challenges did you experience while caring for the patient during hospitalization?" Repeat interviews were not conducted, as data saturation was achieved and participants had already provided comprehensive information during the initial interviews.

All interviews were conducted by a female researcher with a Master's degree in Exercise Physiology and a specialization in Physiotherapy, who had prior experience in qualitative research. The researcher had no prior relationship with the participants and was not affiliated with the hospital, thereby minimizing potential power dynamics and response bias. Participants were informed about the study objectives prior to the interview, and reflexivity was maintained through field notes and regular team discussions to identify and minimize potential researcher bias. In addition, the researcher engaged in reflexive practice by continuously reflecting on her role, assumptions, and potential influence on data interpretation throughout the research process. Analytical decisions were discussed within the research team to minimize subjective bias and ensure that findings remained grounded in participant narratives. The interview guide was not formally pilot-tested; however, it was reviewed and refined internally by the research team to ensure clarity and relevance.

All interviews were audio-recorded with participant consent and transcribed verbatim. In addition to audio recordings, field notes were documented to capture non-verbal expressions, emotional responses, and contextual observations. Transcripts were cross-checked against the original recordings to ensure accuracy. Data analysis was conducted using thematic analysis following Braun and Clarke's six-step framework, which includes familiarization with the data, initial coding, searching for themes, reviewing themes, defining and naming themes, and producing the report. Coding was performed using NVivo software to facilitate data organization and traceability. The coding process was conducted independently by two researchers, followed by discussion and consensus to ensure analytical rigor. An audit trail was maintained to document the analytical process and enhance transparency. The consistency of responses across participants and the recurrence of similar codes and themes indicated sufficient data depth to support the identified thematic structure.

To ensure trustworthiness, several strategies were employed. Credibility was strengthened through source triangulation involving three senior nurses from different units (SICU, Galilea, and Gardenia wards), who provided additional perspectives on family responses and educational needs. Member checking was conducted with selected participants to validate the accuracy of interpretations. Dependability and confirmability were supported through audit trails and peer debriefing among the research team. Ethical approval for this study was obtained from the Ethics Committee of Bethesda Hospital Yogyakarta (No. 20/KEPK-RSB/III/25). All participants provided written informed consent prior to participation, and confidentiality was maintained by anonymizing participant identities using coded identifiers.

The participant recruitment and qualitative data collection process are illustrated in Figure 1. The procedure began with the identification of patients diagnosed with stroke who were admitted to inpatient wards or the Stroke Intensive Care Unit (SICU). Eligible family caregivers were subsequently identified based on predefined inclusion criteria. Following the clinical stabilization of patients, caregivers underwent a screening process and were invited to participate in the study. Written informed consent was obtained prior to data collection. In-depth interviews were then conducted with seven participants. Data saturation was achieved at the fifth participant; however, additional participant

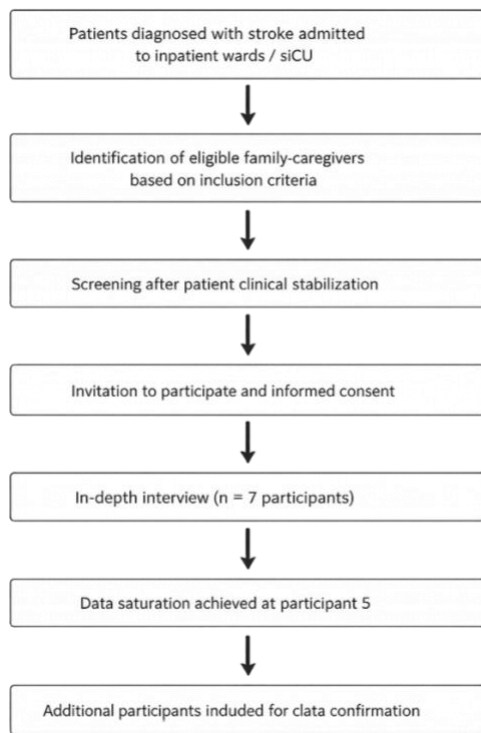


Figure 1. Flowchart of Participant Recruitment and Qualitative Data Collection Process

Results

A total of seven family caregivers participated in this study. To provide contextual clarity regarding participant characteristics, demographic information is presented separately from qualitative findings. This separation aims to enhance readability and avoid conflation between descriptive attributes and thematic results.

Table 1. Characteristics of Participants

Code	Relationship to Patient	Unit of Care	Gender	Role in Caregiving
K1	Wife	Ward	Female	Primary caregiver
K2	Child	Ward	Female	Primary caregiver
K3	Husband	SICU	Male	Primary caregiver
K4	Child	Ward	Female	Primary caregiver
K5	Family member	Ward	Female	Primary caregiver
K6	Child	Ward	Female	Primary caregiver
K7	Child	SICU	Female	Primary caregiver

Thematic analysis identified three major themes and several subthemes that describe family knowledge, response patterns, and caregiving experiences related to early stroke recognition. The presentation below reflects a structured hierarchy of themes supported by representative participant quotations.

Theme 1: Limited Knowledge and Misinterpretation of Early Stroke Symptoms

This theme reflects the limited understanding of early stroke symptoms among participants, particularly regarding non-motor manifestations. Many participants interpreted early symptoms as minor or non-threatening conditions.

Subtheme 1.1: Attribution to Common Illnesses

Participants frequently misinterpreted early symptoms such as vomiting and dizziness as common conditions.

K1 stated, "At first, there was repeated vomiting. I thought it was just a common cold due to exhaustion."

K2 reported, "There had been dizziness before, but it seemed ordinary. The hand felt numb, but we didn't think it was serious."

Subtheme 1.2: Recognition Limited to Severe Motor Symptoms

Knowledge of stroke was largely restricted to visible motor impairments.

K3 stated, "I didn't know anything before coming here. I only thought stroke meant the body couldn't move."

K4 noted, "I only knew it as dizziness and sudden weakness, not as stroke."

Subtheme 1.3: Lack of Awareness of Recurrence

Participants were unaware that stroke could recur, leading to delayed responses even in repeated events.

K2 explained, "It had happened before, but we thought it was just dizziness again."

Theme 2: Delayed Response and Reliance on Visible Clinical Signs

This theme describes how family decisions to seek care were typically triggered only by severe or visually apparent symptoms.

Subtheme 2.1: Action Triggered by Facial Drooping or Paralysis

Families sought medical care only after clear neurological deficits appeared.

K1 stated, "We only went to the clinic when the mouth became crooked."

K7 reported, "When he couldn't walk and didn't respond, we finally brought him to the hospital."

Subtheme 2.2: Symptom Normalization and Situational Justification

Symptoms were often rationalized based on daily activities or cultural context.

K6 stated, "It happened during fasting, so we thought it was just exhaustion."

Subtheme 2.3: Delay Not Influenced by Distance

Participants indicated that delay was not related to geographical barriers but rather to perception of urgency.

K3 explained, "Distance was not a problem. We would go if we knew it was serious."

Theme 3: Caregiving Challenges and Unmet Educational Needs

This theme highlights the difficulties experienced by families in providing care during hospitalization and their need for practical guidance.

Subtheme 3.1: Difficulty in Performing Daily Care Activities

Participants reported challenges in assisting with basic care tasks.

K5 stated, "She cannot get up yet. I have to bathe her, and it feels overwhelming."

K2 expressed, "I was shocked. My mother was active before, but now everything is limited."

Subtheme 3.2: Lack of Knowledge of Rehabilitation Needs

Participants were unfamiliar with post-stroke rehabilitation requirements.

K4 stated, "I didn't know that stroke patients needed physiotherapy."

Subtheme 3.3: Need for Visual and Repeatable Education

Participants expressed a preference for practical and accessible educational media.

K1 noted, "If there was a video, it would be easier because we could watch it again."

To support data credibility, perspectives from nursing staff were used for triangulation. Nurses consistently reported that patients often arrived beyond the optimal treatment window due to delayed recognition of symptoms. They also emphasized that existing education for families was largely administrative and lacked practical, skill-based guidance.

To enhance the conceptual clarity of the findings, a thematic framework was developed based on the relationships among the identified themes. As illustrated in Figure 2, the framework demonstrates a sequential and interconnected process in which early symptom misinterpretation influences family decision-making, leading to delayed responses and late hospital presentation. These delays subsequently contribute to increased caregiving burden and highlight the need for structured educational support. This visualization provides an integrated understanding of how cognitive, behavioral, and contextual factors interact in shaping family responses to stroke, and serves as a basis for developing targeted interventions to improve early recognition and caregiving preparedness.

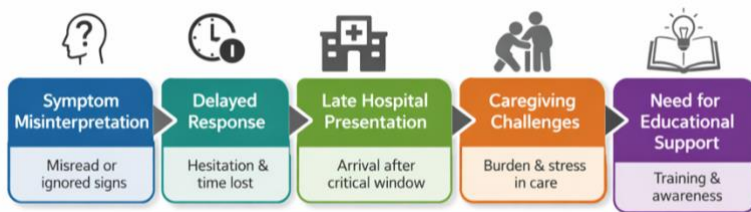


Figure 2. Thematic framework of family responses to early stroke recognition and caregiving challenges

Discussion

This study provides an in-depth understanding of how family caregivers interpret early stroke symptoms, respond to symptom onset, and manage caregiving responsibilities during hospitalization. The findings highlight three interrelated issues, namely symptom misinterpretation, delayed decision-making, and limited caregiving preparedness. These findings extend current knowledge by demonstrating how sociocultural context and experiential gaps shape family responses to stroke beyond purely biomedical explanations.

A central finding of this study is the phenomenon of symptom normalization, in which early stroke manifestations, particularly non-motor symptoms such as vomiting, dizziness, and generalized weakness, are interpreted as benign or routine conditions. This finding is consistent with previous studies indicating that stroke awareness is often limited to visible motor deficits, while atypical or non-specific symptoms are frequently overlooked.¹³ The persistence of this pattern suggests that public health education remains insufficiently comprehensive, particularly in addressing the full spectrum of stroke presentations. From a clinical perspective, this gap is critical, as early non-motor symptoms may precede severe neurological impairment and represent a narrow window for effective intervention.¹⁹ This finding is consistent with previous studies reporting limited public recognition of non-motor stroke symptoms. However, in contrast to studies conducted in high-income settings, the present findings highlight a stronger influence of sociocultural beliefs in shaping symptom interpretation.^{13,19,20}

Importantly, the findings reveal that symptom interpretation is not solely a matter of knowledge deficit but is strongly influenced by sociocultural frameworks. The use of culturally embedded concepts such as "masuk angin" to explain early symptoms reflects a contextualized health belief system that shapes illness perception and decision-making.¹⁴ This is consistent with prior research demonstrating that culturally grounded explanatory models can delay recognition of serious conditions by reframing them as non-urgent.²¹ In addition, situational contexts such as fasting during Ramadan or fatigue associated with religious activities further reinforce symptom normalization. These findings underscore the need for culturally sensitive health education strategies that explicitly address common misinterpretations within specific populations.

The delayed response observed among participants further illustrates the consequences of limited symptom recognition. Families in this study typically initiated medical action only after the appearance of overt neurological deficits, such as facial drooping or inability to move. This reliance on visible clinical indicators as a threshold for action has been documented in previous studies on pre-hospital delay, where recognition of severity rather than symptom onset drives healthcare-seeking behavior.^{11,12,20} The implication is that even when access to healthcare facilities is not a barrier, delays persist due to cognitive and perceptual factors. This finding challenges the conventional emphasis on geographic accessibility and highlights the importance of improving symptom literacy at the household level.

Another important aspect of this study is the identification of caregiving challenges during hospitalization. Participants reported significant difficulties in performing Activities of Daily Living. These difficulties were particularly evident during the early phase of care when patients experienced substantial functional limitations. This observation is consistent with evidence indicating that caregiver burden is highest during the acute phase of stroke, when families must rapidly adapt to new caregiving roles without adequate preparation.²² The lack of knowledge regarding rehabilitation needs, including physiotherapy, further reflects gaps in discharge planning and patient education.^{11,12} These findings suggest that current hospital-based education does not fully address the practical needs of caregivers.

A key implication of this study is the need to improve educational approaches by moving beyond conventional verbal instruction toward more accessible and sustainable formats. Participants consistently expressed a preference for visual and repeatable learning tools, such as video-based education. This aligns with existing literature demonstrating that digital and visual

media can enhance comprehension, retention, and caregiver confidence in performing complex care tasks.²³ Unlike one-time verbal explanations, visual resources allow caregivers to revisit instructions as needed, thereby supporting continuity of care after discharge. However, the effectiveness of such interventions should be further evaluated through future studies to ensure their relevance and feasibility in different contexts. No significant deviant or contradictory cases were identified, as participants consistently demonstrated similar patterns of symptom misinterpretation and delayed response.

Despite its contributions, this study has several limitations. The sample size was relatively small and drawn from a single hospital, which may limit the transferability of findings. Participant responses may also be influenced by recall bias, particularly when describing events surrounding stroke onset. Although triangulation was conducted with nursing staff, additional perspectives from other healthcare professionals or community settings may provide a more comprehensive understanding. Future research is recommended to adopt multi-center designs and incorporate mixed-method approaches to strengthen the evidence base.

Overall, this study highlights the critical role of family caregivers in early stroke recognition and emphasizes the importance of culturally informed, practical, and technology-supported educational interventions. Addressing gaps in symptom recognition and caregiving preparedness has the potential to reduce delays in hospital presentation and improve clinical outcomes for stroke patients.

Conclusion

This study demonstrates that family caregivers have limited understanding of early stroke symptoms, particularly non-motor manifestations, which contributes to delayed decision-making in seeking medical care. Symptom interpretation is strongly influenced by sociocultural beliefs and situational contexts, leading to the normalization of early warning signs. In addition, families experience considerable challenges in providing care during hospitalization, reflecting insufficient preparedness and limited access to practical guidance. These findings indicate that improving early stroke recognition requires not only increasing knowledge but also addressing culturally rooted perceptions and decision-making processes. Practically, healthcare providers should implement structured, culturally sensitive, and accessible education programs that emphasize early symptom identification and basic caregiving skills. The integration of visual and repeatable educational media may enhance caregiver understanding and support continuity of care. Future research is recommended to evaluate the effectiveness of technology-based educational interventions and to explore their implementation across different healthcare settings and populations.

Author Contribution

Nicholas Adi Perdana Susanto: Conceptualization, methodology, investigation, data curation, writing original draft, supervision, and corresponding author responsibilities.

Gian Lisuari Adityasiwi: Methodology, formal analysis, writing review and editing.

Ellysa Okky Gusma: Data collection, investigation, and literature review.

Nathan Agwin Khenda: Data curation, visualization, and manuscript preparation.

Hana Kristina: Validation, supervision, and final manuscript approval.

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Conflict of Interest Statement

The authors declare no conflict of interest.

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Ethics Statement

This study was approved by the Ethics Committee of Bethesda Hospital Yogyakarta (No. 20/KEPK-RSB/III/25). Written informed consent was obtained from all participants prior to data collection, and confidentiality was maintained throughout the study.

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