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THE ANGKOLA BATAK FAMILY CAREGIVER'S EXPERIENCE IN PREVENTING SECONDARY STROKE: A PHENOMENOLOGICAL STUDY

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ABSTRACT

To explore the experience of Angkola Batak family caregivers in preventing secondary stroke. Design: Qualitative study with phenomenological design. Through purposive sampling, using 11 participants (all women) who are family caregivers with primary stroke in the Angkola Batak tribe community in Padangsidimpuan City, North Sumatra Indonesia. Data were collected by conducting in-depth interviews with participants, and thematic analysis was conducted. Thematic analysis showed four themes and 13 sub- themes: 1) Family caregiver knowledge about secondary stroke prevention (secondary stroke risk factors, treatment regimen, healthy lifestyle); 2) Obligations of family caregivers in preventing secondary stroke (helping to meet basic needs, accompanying taking medicine, accompanying health checks, providing support; 3) Barriers of family caregivers in preventing secondary stroke (fatigue, time and multiple roles, financial, patient non-compliance); and 4) Coping mechanisms of family caregivers in preventing secondary stroke (Emotion-oriented, problem-oriented). This study highlights the real-life experiences of Angkola Batak family caregivers caring for primary stroke patients and providing care to prevent secondary stroke. Their insights provide valuable information about the challenges they face and the care strategies they use. By understanding their experiences, health care professionals, policy makers, and communities can develop better support systems, educational programs and related resources to improve the quality of life of stroke patients.

KEYWORDS: Caregiver; Family; Angkola Batak Tribe; Preventing Secondary Stroke; Qualitative Study.

1. INTRODUCTION

Stroke is one of the critical health problems worldwide. According to the World Stroke Organization (WSO), stroke causes 80 million deaths and 50 million disabilities worldwide. In the United States, stroke causes 6.6 million deaths (Emelia, et al, 2017). Disability due to stroke can be long- term disability, with more than 89% of patients unable to function independently in daily life and 11% of stroke patients unable to walk independently (Markus & Brainin, 2020). The incidence of stroke in Indonesia increased from 7% in 2013 to 10.9% in 2018 (Nursiswati, et al, 2022). The prevalence of stroke in Indonesia is also increasing, along with increasing life expectancy (Sari, et al, 2023). In general, stroke survivors in Indonesia rely on their families to fulfill their daily needs. After six months of discharge from hospital, the dependency rate of stroke patients has not even decreased (Markus & Brainin, 2020). North Sumatra Province is included in the 20 regions with the highest prevalence of stroke in Indonesia (Sari, 2021). The results of research on 100 stroke patients at H. Adam Malik Medan Hospital found that the tribe that suffered the most strokes was the Batak tribe as many as 63 (63%) (El-Harizah, 2003). The cause of the high incidence of stroke in the Batak tribe is due to modifiable risk factors, namely genetic and modifiable stroke risk factors (Sjahrir, 2003) found in the Batak tribe. The Batak tribe has the characteristics of eating more than other tribes (Nainggolan & Pasaribu, 2015), and typical Batak food also contains a lot of cholesterol and salt Manurung & Diani, 2015). The Batak tribe is more temperamental and emotional than other tribes who are obese (Nainggolan & Pasaribu, 2015), so it can cause increased blood pressure and heart disease (Williams Je, 2005). Stroke not only affects the patient themselves, but can also affect their caregivers, especially family members who are their caregivers. For example, stroke patients experience physical, emotional and social impacts; moreover, disabilities that affect mobility and functional stability make it difficult for patients to perform their daily activities and affect their image (Utaisang, et al, 2021; Kyler M, 2013). Stroke is an incurable chronic disease, and leaves survivors vulnerable to relying on caregivers for the rest of their lives (Kyler M, 2013). A family with a stroke patient can suffer all aspects of consequences such as physical, emotional, and social problems, concerns about prognosis, and also financial (Kardawati et al, 2019). In particular, family members assigned as the primary caregiver have to live up to their role as a caregiver caring for the patient, which also affects their income (Jeong Yg, et al, 2015). Caring for sick family members is an obligation due to cultural and religious traditions. Caring for stroke patients at home is a new responsibility for families who have previously faced this challenge. The challenges faced by families include the need for knowledge regarding appropriate care for their loved ones, financial constraints that prevent them from meeting long-term needs, and inadequate facilities that hinder the completion of daily activities at home (Fauziah, et al, 2022). Caring for a disabled or paralyzed stroke patient requires knowledge, skills, patience, love, which can cause stress, anxiety, fatigue, or other health problems for the caregiver. (Olai L, et al, 2015) From the above background, it is known that the Batak tribe suffers the most strokes caused by an unhealthy lifestyle by consuming foods that contain ingredients that can cause strokes, consuming unhealthy foods in large quantities, and having a temperamental and emotional nature. Therefore, the purpose of this study was to determine the experience of Angkola Batak family caregivers in preventing secondary stroke. The findings obtained can be used to develop health service readiness designed to improve the health outcomes of stroke patients and caregivers, especially for the Batak Tribe in Padangsidimpuan City, North Sumatera Province, Indonesia.

2. METHODS

2.1. Research Design

Phenomenology served as the basis for the qualitative design of this study. This design was adopted to ensure an authentic and thorough representation of the Batak Angkola family caregiver experience in preventing secondary stroke. This design also allowed for the exploration, analysis and direct description of the family caregiver's experience offering valuable insights that cannot be measured using quantitative methodologies (Creswell, 2014). This study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist consisting of 32 items to ensure comprehensive and standardized reporting of qualitative research practices (Tong A, et al, 2007).

2.2. Participants

Purposive sampling was used to collect in-depth and representative data. Participants were selected based on the characteristics of age, gender, relationship with the patient, education level, and length of care, aiming to capture diverse family perspectives. Specifically, participants were the primary caregivers in the care of stroke patients at

home. There were 11 participants in this study.

2.3. Data Collection

Data collection was conducted in March 2025, using in-depth interviews. In-depth interviews were the main tool for data collection. The interview process was conducted carefully, ensuring participants understood the purpose of the research and gave informed consent. Triangulation techniques, including data and researcher triangulation, were applied to ensure data quality (Tashakkori A, et al, 2010). Interviews were conducted using an interview guide. The interview guide was used after a *Content Validity Index* assessment of three *experts* with a score of 0.87 (Sugiharni, 2018). The interview guide was created using four open-ended questions: (1) What do you know about stroke and recurrent or secondary stroke? (2) What is your experience of caring for a family member who has had a stroke? (3) How do you prevent recurrent stroke? (4) What barriers do you experience to prevent recurrent stroke? (5) How do you utilize health services to prevent recurrent stroke?

2.4. Data Analysis

Data analysis in this study was carried out by thematic content analysis and presented in the form of narratives. The analysis technique is carried out by means of *data reduction* (simplification, grouping data so that it is easier to process and understand, *data display* (data is presented in a form that is easy to understand), and data *conclusion drawing / verification* (drawing conclusions with: data interpretation, identifying the meaning of the data that has been analyzed) (Matthew, 2014). The validity of the data in this study was carried out using the *credibility* test, *transferability, dependability* test and *confirmability* test (Creswell, 2014).

2.5. Ethical Considerations

This research has received ethical approval from the Faculty of Public Health, Hasanuddin University Makassar with No. 326/UN4.14.1/TP.01.02/2025.

3. RESULTS

3.1. Characteristics Of Participants

Participants in this study were family members who cared for families who had a stroke. The number of participants in this study was eleven people. All participants were female with ages ranging from 27 to 43 years old. Educational background participants on average have a high school education. The relationship between the caregiver and the patient is mostly as the patient's husband. While the length of treatment of stroke patients is 1 to 5 years. Characteristics of Participants are in Table 1 below.

Table 1: Characteristics of Participants.

Participants	Gender	Age	Education	Relationship with patient	Length of treatment
P1	Female	36	S1	Mother-in-law	1 year
P2	Female	41	High School	Husband	3 years
P3	Female	38	High School	Husband	2 years
P4	Female	27	S1	Mom	2 years
P5	Female	42	S1	Mom	5 years
P6	Female	44	High School	Husband	3 years
P7	Female	35	High School	Father	1 year
P8	Female	38	High School	Father	2 years
P9	Female	42	High School	Husband	2 years
P10	Female	40	High School	Husband	1 year
P11	Female	35	High School	In-laws	3 years

3.2. Angkola Batak Family Caregiver Experience in Preventing Secondary Stroke

Data analysis revealed 4 themes and 13 sub-themes: (1) family caregiver knowledge about secondary stroke prevention; (2) family caregiver obligations in secondary stroke prevention; (3) family caregiver barriers in secondary stroke prevention; and (4) family caregiver stress coping behaviors in secondary stroke prevention. Theme Matrix of Angkola Batak Family Caregiver Experience in Preventing Secondary Stroke Preventing Secondary Stroke: A **Phenomenological Study are in table 2 below.**

Table 2: Theme Matrix of Angkola Batak Family Caregiver Experience in Preventing Secondary Stroke Preventing Secondary Stroke: A Phenomenological Study.

Theme 1: Family caregiver knowledge of secondary stroke prevention

1. Risk factors for secondary stroke	1. Stroke may recur 2. Controlling blood pressure 3. Food can cause secondary stroke
2. Treatment regimen	1. Make a schedule for taking medication 2. Take medicine on time
3. Healthy lifestyle	1. Eat foods low in salt, sugar and fat 2. Physical activity
Theme 2: Obligations of family caregivers in secondary stroke prevention	
1. Fulfilling basic needs	2. Nutrition 3. Personal hygiene 4. Elimination 5. Activity
2. Medication support	1. Make a schedule 2. Administering medication
3. Health check companion	1. Arrange a schedule 2. Bring to health facility
4. Provide support	1. Emotional 2. Informative 3. Appreciation
Theme 3: Family Caregiver barriers to secondary stroke prevention	
1. Fatigue	1. Physical 2. Emotional
2. Time and multiple roles	1. Other responsibilities 2. Limited time
3. Financial	1. Treatment and recovery 2. Transportation to health facilities
4. Patient non-compliance	1. Medication 2. Healthy food 3. Emotional control 4. Physical activity
Theme 4: Family caregiver stress coping behaviors in secondary stroke prevention	
1. Emotion-oriented	1. Patience and sincerity 2. Pray 3. Comforting oneself 4. Sharing experiences
2. Problem-oriented	1. Seeking information about stroke 2. Seeking treatment 3. Task sharing

Theme 1: Family Caregiver Knowledge of Secondary Stroke Prevention.

Participants were aware of Risk factors for secondary stroke, treatment regimens, and emphasizing patients to adopt a healthy lifestyle.

Risk factors for secondary stroke

"*I know from doctors and nurses at hospitals and health centers that patients who have had a stroke can have a stroke again if they are not taken care of properly*" [P1]. "*The cause can be due to rising blood pressure, usually if the average stroke must have high blood pressure, blood pressure is always high, then it can stroke again. So, we have to keep the blood pressure from rising*" [P2].

"*Stroke is a sign that something is paralyzed in the body, for example the legs or hands, the body is weak and cannot walk, so people who can have a stroke are because they eat foods that the doctor says they shouldn't eat*" [P3].

Treatment regimen

"*The doctor only said to take the medicine, then the pharmacist also said to take the medicine three times a day, some twice, but the time is not said at what time. So, I made a schedule for taking medicine*" [P7]

"*As far as I know, eating medicine must be done on time so that the benefits of the medicine are good*" [P9].

Healthy lifestyle

"*The doctor said that stroke patients should not eat salty foods, then sweets such as canned drinks that contain a lot of sugar and those that are not fatty, coconut milk*" [P8].

"*When you just had a stroke, you can't move, but when you get healthy, I help you to move, like what you were taught at the hospital when you were in control*" [P10].

Theme 2: Obligations of Family Caregivers in Secondary Stroke Prevention

Efforts to recover from the disease and prevent secondary strokes are carried out by fulfilling the patient's basic needs, helping with medication support, Health check companion, and providing support to the patient.

Fulfilling the patient's basic needs

"*When I just had a stroke, I must have helped with everything, bathing, helping to defecate, and everything was done in bed, but now I can be helped to walk to the*

bathroom, but we still help" [P6].

"Eating is fed, drinking is also helped" [P8]

"Now my husband has started to be able to move, so I help my husband with daily activities" [P10].

Medication support

"Make a schedule for taking medicine, always write it down so you don't forget" [P6]

"Give medicine on time as recommended by the doctor" [P3]

Health check companion

"Every month we go to the hospital for control, so we write down when we go" [P7] *"I accompany my mother to the hospital, whether it's for control or stroke exercises"* [P4].

Providing support

"If we don't give her encouragement and attention, how can she recover quickly, she could have another stroke, she is already stressed thinking about her illness" [P2]

"I always tell him to eat healthy food so that my husband wants to eat it. So that I don't get another stroke" [P3]

"Alhamdulillah, if there is progress with my husband, I always say, thank God, my brother is making healthy," [P10].

Theme 3: Family Caregiver Barriers in Preventing Secondary Stroke

Participants stated that they faced barriers in providing care to patients to prevent secondary stroke, such as: fatigue, limited time and multiple roles, financial problems, and patient non-compliance with doctor's recommendations. Fatigue

"I often wake up in the middle of the night to help my husband to the bathroom. I'm also tired of taking care of my husband all day" [P6].

"Yes, sometimes I get stressed thinking about everything, sometimes I get angry easily"

[P2].

Time and multiple roles

"There is no rest, taking care of the stroke, not to mention the house work, we can't run out of work, not to mention taking care of the children" [P7]

"Like there's not enough time to do all this" [P4]

Financial

"Because money is limited, so sometimes I don't take the treatment, because the becak fare is already how much, right [P5]

"Understand that everything needs money, so not everything is done for treatment, so just take it to the easy ones like ribs, pay as sincerely as possible" [P10].

Patient non-compliance

"Maybe my father is tired of his illness, so he refuses to take me for treatment, even though I want my father to recover quickly" [8]

"This is how bad we Batak people are, the food must have a salty taste, it must be coconut milk so that it is good to eat. If there is no flavor, I don't want to eat" [P11]. *"I see that sometimes my husband cannot control his emotions because I know he is stressed by his illness, so he gets angry quickly, even though the doctor said not to stress, look for activities to avoid stress"* [P6].

"My mother is lazy to move her body, I told her to move slowly so that she can walk later, she said" [P4].

Theme 4: Family Caregiver Stress Coping Behaviors in Secondary Stroke Prevention.

The results of the study showed that the stress-coping behavior of family members caring for stroke patients was emotion-oriented and problem-oriented.

Emotion-oriented

"At first I did not accept the situation of my in-laws, but I was concerned, so I was patient and sincere taking care of my in-laws" [P11].

"Surrendering to God, asking that patience and strength be given to me to take care of my husband and my husband is given healing" [P2].

"Yes, don't forget to take care of my health because I take care of my husband, so I don't want to be stressed, watch, open my cellphone" [P9].

"Sometimes I like to vent too with friends" [P9]

Problem-oriented

"Like looking at my cellphone to find out about stroke, sometimes ask people too" [P4] *"Often looking for information about treatment for my mother, like where to get ribs for people who have had a stroke"* [P5]

"My husband likes to help me take care of my in-laws" [P1]

4. DISCUSSION

This study aims to understand the daily struggles faced by Batak Angkola family caregivers who care for their family members who have had a stroke to prevent secondary strokes. The results of the study showed four themes. The first theme is the knowledge of family caregivers about secondary stroke prevention. Caregivers have quite good knowledge about secondary stroke prevention and strive to provide the best care to prevent secondary strokes. Information was obtained by caregivers from health workers, such as hospitals and community health centers in Padangsidimpuan City. Health workers must provide information about stroke care to caregivers (Day Cb, et al., 2018). Because information about stroke care is the most important need for caregivers after the patient returns home (Daulay & Febriany, 2014). Nurses must provide support to families ranging from health education to ongoing assistance. Systematic discharge planning involves the family in the

patient's care process so that the family is ready to care for the patient at home. And regular follow-up to ensure the patient's condition progress (Choliq, et al., 2020). Information obtained from nurses about risk factors for secondary stroke, treatment regimens, and living a healthy lifestyle. Nurses must have the knowledge to provide information to patients and families, making it easier for them to care for the patient. Optimal recovery will be easier if nurses are aware of the treatment process and the actions taken to improve the condition (Tarigan, 2024).

Public awareness of stroke risk factors and warning signs is crucial to ensuring adequate access to treatment and prevention (Saad S, et al., 2017). Caregivers must understand stroke, its risk factors, and recovery. Failure to do so will hinder optimal recovery. Providing patients and caregivers with the knowledge and support they need to utilize effective coping mechanisms allows them to adapt to their new circumstances as individuals with a post-stroke identity (Norlander A, et al., 2022)..

The second theme is the responsibilities of family caregivers in secondary stroke prevention. Family members who act as caregivers replace the duties of caregivers at home. They must know and understand how to carry out their responsibilities. For this reason, caregivers should be provided with information on how to care for post-stroke patients at home (Choliq I, et al., 2020). Caregivers must help meet basic needs, administer medications, accompany patients to healthcare facilities, and provide support. There is no single "job description" that describes the responsibilities of caregivers caring for stroke patients. All caregivers perform these roles, and each caregiver differs according to the unique needs of stroke patients. Role changes and new skills may need to be learned. Common caregiver responsibilities include: providing physical assistance with personal care and transportation, monitoring behavior to ensure safety, managing household chores and meal preparation, coordinating healthcare and monitoring or administering medications, and helping patients maintain learned rehabilitation skills (AHA, 2015 and Anderson & White, 2018).

Caregivers are also responsible for transporting patients to healthcare facilities. Without caregivers, patients cannot recover on their own. When the patient desires to resume bodily functions and caregivers share this desire for recovery, such as through physiotherapy in the hospital, recovery progresses smoothly, particularly increasing the chances of motoric improvement (Volz Lj, et al., 2016). Family support positively impacts patient psychology by making them feel cared for and appreciated. This increases motivation to recover and helps prevent secondary strokes. Therefore, social support from the family is a fundamental pillar in motivating someone to continue their treatment (Cedeño M, et al., 2019).

The third theme concerns the barriers faced by family caregivers in secondary stroke prevention. These barriers include fatigue, time constraints due to dual roles, financial issues, and patient non-compliance with treatment. Caregiver fatigue arises from the high care needs of post-stroke patients, who often rely on caregiver assistance. Furthermore, patients' physical limitations and cognitive changes, which can change over time, also increase the burden of care for caregivers (Schlemmer, 2023). Adequate support is essential for caregivers to continue providing optimal care. Caring for post-stroke patients can cause emotional stress and fatigue for caregivers, especially when combined with other responsibilities such as childcare. Therefore, healthcare professionals need to assess caregivers' needs and provide appropriate support and interventions. Clinical practice guidelines also recommend identifying vulnerable caregivers, monitoring patients after hospital discharge, and implementing evidence-based interventions to reduce caregiver burden (Tziaka et al., 2024). Research shows that caregivers incur significant costs for recovery and secondary stroke prevention, including costs for nursing care, physiotherapy, and transportation to healthcare facilities. This situation places financial strain on families, particularly due to high healthcare costs and decreased household income. As a result, caregivers often require support from other family members. Previous research also shows that the cost of stroke care is often a financial burden for caregivers (Tziaka et al., 2024). Secondary stroke prevention still faces various barriers, particularly patient non-compliance with medication, a healthy diet, emotional control, and physical activity. Although adherence to secondary prevention therapy has been shown to reduce the risk of recurrent stroke (Rahayu LP, et al., 2019), the level of compliance among stroke patients remains low (Glader EL, et al., 2010). In the Batak community, these barriers are also influenced by cultural and lifestyle factors, such as the habit of consuming foods high in cholesterol, salt, and fatty foods (Nainggolan, et al., 2015; Manurung & Noor, 2015; Wati NR, et al., 2016). Furthermore, the Batak community's known temperamental and expressive nature in expressing anger also presents a barrier for caregivers in managing patients' emotions during the care process

(Nainggolan, et al., 2015; Hasmayni B., 2012). Uncontrolled emotions can increase blood pressure and the risk of heart disease, thus triggering a secondary stroke (Williams JE, 2001). Furthermore, patient reluctance to engage in physical activity is also a barrier to secondary stroke prevention. However, early physical activity in post-stroke patients has been shown to be beneficial and can reduce the risk of cardiovascular disease and recurrent stroke, including through basic daily activities at home (Bailey RR, 2017; Saunders DH, et al., 2014).

The fourth theme is family caregiver coping behavior in secondary stroke prevention, which includes emotion-oriented and problem-oriented coping. Caregiver stress arises from the burden of caring for stroke patients and assisting with almost all of the patient's daily activities (Nur Y & Setia, 2017). Emotionally, caregivers cope with stress by accepting the patient's condition, being patient, drawing closer to God, and hoping for the patient's recovery (Yunitia, 2020; Dharma KK, et al., 2021). Caregivers also reduce stress by sharing stories with friends or neighbors and seeking entertainment through social media (Dharma KK, et al., 2021).

Problem-oriented coping involves seeking information about stroke and its treatment to increase caregiver confidence in caring for the patient (Caroline Van Heugten, 2006). Furthermore, caregivers seek treatment for the patient's recovery and require social support from the family to share caregiving responsibilities (Dharma KK, et al., 2021).

5. CONCLUSION

Batak Angkola family caregivers have a basic understanding of secondary stroke prevention, especially the importance of medication adherence, dietary management, blood pressure control, and stress avoidance. This knowledge is obtained both from caring experiences and information from health workers, although not all of them are based on structured medical education. In the Angkola Batak culture, caring for family members who have experienced a stroke is considered an obligation, rooted in family values. Caregivers feel responsible for maintaining the patient's health so that they do not experience a re-attack, with full support from the extended family structure. However, the care process is not free from various obstacles, such as limited costs for routine controls and drug purchases, lack of patient understanding of the importance of lifestyle changes, physical and emotional exhaustion of caregivers, and limited access to stroke rehabilitation services. To overcome this, caregivers use various forms of coping, including spiritual approaches such as prayer, seeking social support, and implementing adaptive strategies such as dividing care tasks within the family.

Limitations of the Study: The experiences expressed by participants may vary depending on the stage of stroke disease (acute, sub-acute and chronic phases) and the length of time as a caregiver of stroke patients. This may affect the differences in meaning and perceived burden, but was not explained in this study.

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Conflicts Of Interest: The authors declare that there is no conflict of interest in the conduct of this research. The entire research process was conducted independently without any pressure, influence, or personal, institutional, or financial interests that could affect the results or interpretation of the data.

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