Family Experience of Stroke Patients Regarding Prehospital Time: A Phenomenological Study

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Abstract

Background: Stroke is a neurological disease that requires immediate treatment, and family participation is very important when a stroke occurs at home.
Purpose: This study aims to explore the pre-hospital time experiences of patients' families with stroke in Kolaka Regency.
Methods: The study is a qualitative research with a phenomenological design. A total of 8 participants from families of stroke patients were recruited using a purposive sampling approach. Source triangulation was used in this study from stroke patients. Data were collected through in-depth interviews using audio-recorded then transcribed verbatim and validated between researchers. The data were analyzed using colaizzi method with a selective and focused analysis approach to obtain themes.
Results: There are two themes of this study, the first theme is responses of stroke and the second theme is medical treatment.
Conclusion: It is important that family members have a good response and knowledge so that when one of their family members has a stroke, they can be taken to the hospital at the right time. Our suggestion is that it is necessary to increase family knowledge about stroke to minimize the delay in stroke rescue time.

Keywords: family experience; Kolaka Regency; prehospital time; phenomenology; stroke.

Introduction

Stroke is often referred to as a brain attack. Stroke occurs when the supply of oxygen and nutrients to the brain is disrupted due to blocked or ruptured blood vessels (Bray et al., 2014). Stroke is the fourth leading cause of death in the United States. Death occurs on average 1 person every 4 minutes (Bray et al., 2014). Data from the Indonesian Hospital Association (PERSI) in 2009 showed that the main cause of death in hospitals due to stroke was 15%, meaning that 1 in 7 deaths was caused by stroke with a disability rate of 65% (Kemenkes RI, 2013). In Indonesia, the number of stroke victims increased from 8.3 percent to 12.1 percent in 2007, while stroke patients were 8.8 percent in Southeast Sulawesi (Kemenkes RI, 2014), In Kolaka Regency, there were 90 patients in 2018, 107 in 2019, and 116 in 2020, whereas illnesses associated with stroke risk factors, such as hypertension and diabetes mellitus, continue to rise in Kab. Kolaka (Dinkes Kab. Kolaka, 2020). Stroke is a disease that causes death and disability as much as 21% in 2014 (Mesiano, 2017).

Stroke is the most common neurological disease that can cause serious health problems and have an impact on motor and sensory dysfunctions (Lewis, Dirksen, Heitkemper, & Bucher, 2014). Motor disorders include impaired mobility, respiratory function, swallowing, speech, and the ability to perform daily activities as well as lifelong disability (Smeltzer, Bare, Hinkle,

& Cheever, 2010; Wirawan & Putra, 2009).

The problem of speed of treatment is the most important aspect in stroke management. This greatly affects the amount of damage that will occur and the type of therapy that is right for the patient. Ischemia will occur in 5 minutes if one blood artery is blocked. This causes the importance of pre-hospital time treatment in patients who experience stroke symptom (Mesiano, 2017). In the guidelines for handling stroke patients by the AHA 2013, it is explained that stroke management must be carried out as fast as possible. The dispatch of the emergency team from receiving the call to being ready to depart must be less than 90 seconds. Then, the time for the emergency team to arrive at the patient's place is < 8 minutes (Edward C Jauch, Jeffrey L Saver, Harold P Adams Jr, Askiel Bruno, J J Buddy Connors, Bart M Demaerschalk, Pooja Khatri et al., 2013). Previous research has found a link between early treatment and stroke patients' brain impairment (Batubara & Tat, 2016). Based on the information above, the authors want to explore the experiences of stroke patients' families during pre-hospital time in Kolaka Regency using a qualitative phenomenological approach.

The purpose of this study was to explore the family of stroke patients experiences regarding pre hospital time in Kolaka regency. This research is expected to increase knowledge and can be a reference for further researchers, especially stroke.

The urgency of the current research is the length of prehospital time stroke patients arrive at the hospital, causing serious problems in neurological damage, especially motor damage in patients. Knowing the experience of the patient's family during pre-hospital can be used as the basis for the cause of the time delay and what the family does during the pre-hospital time so that efforts can be made to prevent delays in pre-hospital time in stroke patients and reduce the risk of neurological damage in patients. Based on this, the question of this research is "how is the family experience of stroke patients during prehospital time?".

Methods

This research is a qualitative research with a phenomenological research design that explores the universal experience that is endured by an individual towards a phenomenon faced in everyday life, with a transcendent phenomenological approach, which focuses on individual experiences that are universal, so that research questions can be answered by the experiences explored by families of stroke sufferers during prehospital time (Afiyanti & Rachmawati, 2014).

This research was conducted from June to September 2021 in Kolaka Regency, South East Sulawesi, Indonesia. The sampling technique used purposive sampling taking participants according to certain criteria to meet the researcher's target

(Grove, Gray, & Burns, 2015; LoBiondo-Wood & Haber, 2014). The sample in this study was the families of stroke patients in Kolaka, with a total of 8 participants (Afiyanti & Rachmawati, 2014). The researcher recruited participants by waiting for patients who met the inclusion criteria in the neurology department by directly explaining the purpose of the study and asking the respondent's consent to be interviewed according to the agreed place, namely an interview in one of the hospital areas or at the participant's home, until the experience data was saturated with inclusion criteria, namely: having a family of stroke patients, being willing to be respondents, and being able to speak fluently about their experiences from the time the patient experienced stroke symptoms to caring for stroke patients.

Data collection was carried out by in-depth interviews with participants with unstructured formal interviews, researchers conducted interviews with participants twice by helping participants describe experiences related to knowledge about prehospital time for stroke patients without leading a discussion that was formed from questions given by researchers while recording using a voice recorder. Interviews were conducted in the waiting room of the Neural Clinic of Benyamin Guluh Kolaka Hospital and at the participant's house for approximately 20–30 minutes. Researchers conducted interviews with stroke patients as source triangulation.

Data analysis was carried out manually using the colaizzi approach, namely by listening to participants' verbal descriptions, reading verbatim transcripts, grouping significant statements into themes, and writing down descriptions and interpretations experienced by participants regarding phenomena (Afiyanti & Rachmawati, 2014). Trustworthiness is the responsibility or accuracy and accuracy of the data generated from qualitative studies (Afiyanti & Rachmawati, 2014). Trustworthiness in this study was obtained through triangulation of sources with the truth of the data through interviews with stroke sufferers. The researcher cannot make observations because the process experienced by the participants has passed.

This study was approved by ethics of KEPK IAKMI SULTRA with Number 74 / KEPK-IAKMI / VI / 2021. Before asking participants' consent, the researcher first explained the purpose of the study after obtaining written consent. The researcher then began to collect data by considering the ethical principles of research in the form of autonomy, beneficence, non-maleficence, confidentiality, and justice. The data collection process was carried out with ethical principles, namely: providing an explanation to the participants regarding the purpose of the study and explaining that the data obtained were intended for research purposes only, the identity of the participants will be kept confidential, participants have the right to withdraw from this study if they are not willing to become research respondents.

Results

The study produced two themes response to stroke and medical care. The sub-themes are described below.

The responses of stroke

The response to stroke is divided into three sub-themes, sub-theme 1 is affective response, sub-theme 2 is knowledge (cognitive), and sub-theme 3 is intervention by families at home.

Sub-theme 1 Affective Response is divided into three sub-sub themes, namely family emotional response, patient emotional response, and family's assessment of stroke symptoms. The family's emotional response is identified with panic, confusion, crying. These are described by keywords through participant statements as follows:

"*it turns out that maybe my feelings are afraid, because I am also a panic person, moreover, yes, I panicked because of a slight illness I immediately took action*" (P3)

"*....this tongue immediately ran in, we were all outside, we immediately went inside, we, we were confused because the tongue couldn't speak, so we were confused about what we wanted to do.. *" (P5)

"*....I'm confused what to do, I said Astaghfirullah I cried seeing her... *" (P8)

This is confirmed by the triangulation participants

"*He didn't know what he wanted to do, he just cried, he said Astaghfirullah, because he called my name right, he said Ros, Ros, why are you like that*" (Pt2)

The emotional response of patients : fear, refusing to go to the hospital, are described as follows:

"*I'm afraid like now he will be covid, Covid-19, afraid of covid later, afraid of having his blood drawn...*" (P7)

"*had refused, had refused, later there was like a month...*" (P7)

Family assessment of stroke symptoms with General condition & Awareness, Musculoskeletal symptoms, Urinary symptoms, and Gastrointestinal symptoms.

General condition and awareness is described by keywords through participant statements as follows:

"*.....already peeing here.., no, it's not like he's unconscious, so he was rushed to the health center, arrived at the health center, he checked his blood pressure, 150 that day, so he said it took a long time to be checked...*" (P1)

"*Weak, after a while about half an hour he threw up, he really felt like throwing up...*" (P3)

"*dizzy, dizzy, fell from, in front of the house, uh at first it didn't go like this, it didn't immediately .... a bit limp, then his mouth bent, yes not long after, after eating bananas, after eating bananas, immediately dropped, not long after the drop was brought to the hospital*" (P4)

"*No symptoms, just fell in front of the shop.... all of a sudden, uh, I got it right away, I was also surprised, I immediately picked it up ...*" (P6)

Musculoskeletal symptoms is described by keywords through participant statements as follows:

"*Anyway, the left side died until now....the right one didn't that's why I'm surprised*" (P3)

"*What I was surprised about was that when I took the first hospital, the body wasn't stiff, it was just, only the tongue that couldn't talk, couldn't move*" (P5)

"*....She has his eyes closed, then, uh, the left side, the hands and feet if he wants to lift half to death*" (P7)

"*I saw that his mouth was crooked and he was silent....don't know what to do.....*" (P8)

This is reinforced by triangulation of participant triangulation:

"*At first I didn't know it was a stroke, at first it was sudden, that's why I am, why is my body getting sluggish, it's on the left or right, I'm confused, isn't this a symptom of a stroke or not*" (Pt1)

Urinary symptoms is described by keywords through participant statements as follows:

"*At first he couldn't get up, I saw that he couldn't even pee, so I finally took him to the health center*" (P1)

Gastrointestinal symptoms is described by keywords through participant statements as follows:

"*It's dawn, he thinks he's just sleeping, later he wants to go pee can't wake up, seen vomiting too*" (P1)

This is reinforced by triangulation of participant triangulation :

"*.. the second time I was hit again, hit again here (shown to show), so I was hit, so I lay down, I can't shake, threw up, vomited.*" (Pt1)

Sub-theme 2 is knowledge (cognitive) which is described by the participants' statements as follows:

"*Yes, I know.. stroke.. just go up pressure with cholesterol*" (P4)

"*Not yet, we didn't know it said it was a stroke... because we panicked, because we didn't know anyway...*" (P5)

"*I don't know yet, because this is why my sister rarely gets sick, when she gets sick, it drops right away........*" (P6)

"*Oh, it's still half-assed because you have to be checked again by the doctor, eh, eh, but what's really wrong with Mom, history .... indeed high blood and sugar, so maybe when you have a lot of thoughts that trigger, yes it happens *" (P7)

Sub-theme 3 is intervention by families at home consists of sub-sub themes of first aid and care.

Sub-sub theme 1 first aid: lifting, bringing to the health center, bringing to the hospital, slapping the face, measuring blood pressure, taking medicine, given coconut water, not being taken to the hospital. Which is described by the participants' statements as follows:

"*finished, after I picked it up first anyway, I picked it up and took me straight to the health center... Oh yes, Maghrib..*" (P2)

"*I said that my sister's blood pressure was right, I had a midwife's sister, her blood pressure was 180*

and immediately went up, how come it's never like this, maybe it's because of the wrong food? ...he is taking amlodipine with paracetamol" (P3)

"*Immediately taken to the health center .... there was no sleep that day, tired, immediately went up 1 time his blood pressure was the same*" (P4)

"*Appointed, because I can't walk.. Can't walk. Two people are appointed, yes my brother... No action was given*" (P4)

"*Like coconut, coconut water in, coconut water....... No more taking medicine... I said this, oh you'll just rest* " (P5)

"*Yes, suddenly, uh, I got it right away, I was also surprised, I immediately picked it up, all the people came, please, go straight to the Puskesmas, go to the Puskesmas directly to be referred*" (P6)

"*Oh, yes, I slapped his cheek anyway, his face was crooked, so someone slapped his mouth, his mouth... So, to be aware, let him come back, it's crooked, his mouth is bent, after being slapped, he was slapped a little, uh, back to normal mouth* (P6)

"*what's that day, calm down first so that it doesn't get worse later, keep it up, calm down, rest, sleep, I offer you to the hospital, come on...*" (P7)

This is reinforced by triangulation of participant triangulation :

"*suddenly I went to the hospital, RSBG hours, yes at 4 in the morning I had a rapid test at the hospital, the results were negative I was admitted to the ER, I was treated for 1 week at the RSBG hospital*" (Pt2)

Sub-sub-theme 2 is care: feeding, providing comfort, telling rest/sleep. Which is described by the participants' statements as follows:

"*Only drinking water with rice was given to him because he had not eaten since that morning.... Nothing, immediately taken action to the puskesmas*" (P1)

"*...but it was still shaking why was this, so he asked for help to get it like food and drink warm water*" (P3)

"*Ah, is that the day, calm down first so that the condition doesn't get worse, then go ahead, calm down, rest, sleep... I'm already sleeping, so I offered to go to the hospital*" (P7)

Medical treatment

Theme 2 is medical care which consists of sub-themes distance of health facilities and time delay. Distance to health facilities: 300 m, 1 km, 4 km, Which is described by the participants' statements as follows:

"*The distance from the house to the puskesmas is about 4 kilos ... About 30 minutes..*" (P1)

"*Yes, I live in Watuliandu about how many meters it is in, Pattimura to …. approximately 300.. 300 meters close in just a few minutes*" (P3)

"*More than 5 kilos I think, four, four kilos... It's not a good road, it's almost one hour...* "(P5)

"*No, one kilometer, Yes, how is the puskesmas with the Benjamin Guluh hospital, how many meters is it, maybe there is one kilo, one kilo*" (P6)

The time delay is divided into the time delay until getting first aid at the hospital and the referral time delay (from primary health care to the hospital).

Time delay at home until first aid at the hospital: 2 hours 30 minutes, 30 minutes, 1 hour, 2 hours, 1 month, which is described by the participants' statements as follows:

"*thirty minutes in, it means that from the time I got hit, I got to the puskesmas about two and a half hours*" (P1)

"*ten minutes, right, ten minutes can't you arrive, only maybe a little longer than the two hours given...*" (P3)

"*How long is that day in, mmm, an hour maybe. He was treated right away and brought home. The next day he was taken to the Kolaka hospital for a check.... the gap between one house and the health center* " (P4)

"*Not enough for half an hour, not enough for half an hour, very fast, that's fast, ma'am, fast, fast movement, I was going to take a shower at that time, really fast, just move fast, I have to be fast, I was just about to take a shower, I I don't know if I said ade, it turns out that there was a faint in front of it*" (P6)

"*the hour. It's not enough for one hour, how many seconds, yes for what reason, the car was taken... Not enough for one hour, how many minutes, yes, how much, erm because it's fast, please help quickly*" (P6)

"*I think there will be a month later, I think in about a month, treatment is at home, in therapy, the therapy is starting to get better, he can raise his hand, talking about it has started not too umm..*" (P7)

The delay time for referral from primary health care to hospital (referral): 30 minutes, 1 day, Which is described by the participants' statements as follows:

"*The time lapse maybe 2 hours, then they were taken to the puskesmas ... The distance from the house to the puskesmas was about 4 kilos .....*" (P1)

"*Didn't spend the night, was immediately referred, oh one night I guess, one night... I didn't even know it was a midwife, there was no cure*" (P5)

"*Not enough for half an hour, not enough for half an hour, really fast, that's really fast, ma'am, fast, fast movement, I was about to take a shower at that time, really fast, just move fast, I have to be fast, I was just about to take a shower*" (P6)

Discussion

The responses of stroke

There are three responses to stroke, namely affective responses, knowledge (cognitive), and actions taken by families at home before being taken to health services. Families and patients both experience affective responses in the form of emotional response. This study shows that a person's psychological response when he sees his family having a stroke can be in the form of fear, panic, confusion, surprise and crying. This is

an emotional response to anxiety that occurs in a person when there is an anxiety stimulus, such as a study that aimed to see cortisol and anxiety levels in family members of patients treated in the ICU with the result saying that a third of family members experienced anxiety after their loved ones entered the ICU. Many family members also experience depression and post-traumatic stress (Beesley et al., 2018). Knowing that a family member has an acute illness has an emotional impact on a person. Other studies also show that 70% of families of stroke patients experience severe anxiety because of the conditions experienced by families of stroke patients (Sulistyoningsih & Al, 2018). Increased emotion and crying is a process of forgiving oneself when the family has a stroke (A'la, Yosep, & Agustina, 2017). An association between disease representation and distress exists in stroke patients, a meta-analysis showed that stroke patients' perceptions of strong disease identity, acute/chronic times, and emotional responses were significantly and positively associated with anxiety and depression (Pai, Li, Tsai, & Pai, 2019).

This study also shows that the emotional response of the sufferer himself is the fear of being taken to the hospital due to COVID-19. A qualitative study that aims to determine the understanding of Community Emergency Preparedness for Cardiovascular Disease and acute stroke during the COVID-19 Pandemic, obtained information that participants reported concerns about virus transmission. corona in the ambulance and in the hospital. Community members' attitudes and perceived behavioral control to seek emergency cardiovascular care are affected by the COVID-19 pandemic (Robles et al., 2021).

This study also showed that after a stroke occurred, there was a family assessment of the general condition and awareness, symptoms of stroke, urinary symptoms, gastrointestinal symptoms, and musculoskeletal symptoms suffered by the patient, such as: unable to urinate, vomiting, unconsciousness, weakness, feeling unwell, weakness, weak extremities, crossed eyes, facial asymmetry, and aphasia. According to a study that stroke patients experience several things when having a stroke, namely numbness, tilted face, slurred speech, saliva coming out of the mouth and paralysis (Luan, Yang, Huang, & McDowell, 2021). Sudden speech difficulties and sudden weakness on one side are the most frequently identified symptoms (Krishnamurthi et al., 2019). Speech/language impairment was the only factor independently associated with patient first aid (Soto-Cámara et al., 2019).

This study also shows that the family's knowledge (cognitive) is knowing, doubtful/not sure, and not knowing. A study showed that the better the family's knowledge about pre-hospital stroke detection, the faster the time of arrival at the hospital (Ainiyah, Izzah, Zahroh, Bistara, & Faizah, 2021). There is a relationship between family knowledge about risk factors and early symptoms of stroke and family behavior in the early treatment of stroke. The higher the value of family knowledge, the better the behavior of the family (Rosmary & Handayani, 2020). The patient's interpretation of symptoms is also important: when they think the situation cannot be self-managed, first aid is reduced to 253 minutes (Soto-Cámara et al., 2019).

Intervention by the family at home are to provide first aid and care. The first aid given included lifting the patient, bringing him to the puskesmas, bringing him to the hospital, slapping his face, measuring blood pressure, taking medicine, being given coconut water, not being taken to the hospital. Treatment given by feeding, providing comfort, telling rest/sleep. One study reported that they would call an ambulance, the most appropriate course of action, if they saw someone suffering from stroke symptoms (i.e., impaired vision, speech problems, numbness or one-sided weakness). The second most common course of action is to advise the person to see a doctor instead of consulting a doctor immediately, About 1/3 would recommend bed rest and 1/10 would suggest drinking water (Luan et al., 2021).

Participants who recognized more stroke symptoms performed each action more frequently, indicating a positive relationship between symptom recognition and action. With regard to calling an ambulance, any additional symptoms are recognized. It is likely that calling an ambulance is the most frequent course of action (Luan et al., 2021). However, this study shows that the average patient's family immediately takes stroke sufferers using their private vehicles.

Home care of the patient is the most common response to participate in regular or increased physical activity followed by eating more fruits and vegetables/having a healthier diet and quitting smoking, reducing salt intake, and a small percentage not knowing how to reduce the chance of having a stroke (Krishnamurthi et al., 2019). Knowledge of relatives that stroke is a disease that requires immediate treatment (Ningsih, Andarini, & Rachmawati, 2020). Misjudgment of symptom onset or poor awareness of stroke symptoms and emergency pathways (Pulvers & Watson, 2017). This includes family support when having a stroke, the support provided by the family can improve the patient's quality of life (Maryam, Resnayati, Riasmini, & Mambang Sari, 2018).

Medical treatment

The second theme is medical care, which consists of the distance from the health facility to the house and the time lag for receiving therapy in the hospital. The distance of health facilities is 300 m, 1 km, 4 km in the results of this study. A study revealed that there was no effect of location distance on the delay in arrival of patients after an acute ischemic stroke in the UGD (Ningsih et al., 2020). The results showed that the time lag at home to the hospital was 2 hours 30 minutes, 30 minutes, 1 hour, 2 hours,

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1 month, while the time lag from referral was 30 minutes and 1 day. A review article revealed that the average time to admission and the percentage of stroke patients arriving before the logistically critical 3 hours have shown a slight increase in the last two decades. The main factors that affect prehospital time are related to emergency medical lines, stroke symptoms, patient and bystander behavior, patient health characteristics, and awareness of stroke treatment (Pulvers & Watson, 2017). Severe stroke is one of the reasons patients are quickly taken to the hospital. Other factors associated with early arrival were related to stroke symptoms, stroke subtype, comorbidities, behavior or perception of patients and/or observers at stroke onset, and stroke onset time (Pulvers & Watson, 2017). The top three factors associated with late arrival were the general practitioner or primary care facility was visited first, referral from another hospital, and living alone (Pulvers & Watson, 2017).

The results of this study indicate that family knowledge is one of the causes of patients being immediately taken to the hospital, but because of covid 19, there is a fear of patients going to the hospital. Another important supporting factor is the delay in referral from primary care to the hospital so that patients are late in getting help.

Conclusion

Family experience in carrying out treatment during prehospital stroke is very important, where knowledge about stroke needs to be considered in prehospital stroke management. The more family knowledge increases, the sooner stroke patients are brought to the hospital. So as to reduce patient treatment delays, primary care also needs attention. Specifically in terms of making referrals to hospitals, in this study, training for primary care workers needs to get attention so as not to delay bringing patients to the hospital. After this research was conducted, the recommendation from the researchers was increasing the knowledge of the families of patients who are at risk of stroke is very important as well as a good training for primary health workers in following up stroke patients.

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