

Original Research Article

Phenomenological Studies: Experiences of Family Members Taking Care of Post-Stroke Patients

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Abstract: Most of the global stroke burden occurs in low- and lower-middle-income countries. The most common obstacles families face when caring for stroke patients appear to cause various tensions between patients and their families. This study examines family members' experiences of caring for patients after a stroke. This study uses a qualitative method with a descriptive phenomenological design. The research participants were 11 participants using purposive sampling techniques. Data were analyzed using NVivo 12 qualitative data analysis software, and interview results were analyzed using thematic analysis. This study identified five phenomena related to the experience of caring for patients after stroke: fulfillment of patient's daily activities, patient treatment, participant psychological response, participant support, and barriers to patient care. Most participants had a less pleasant experience caring for patients after a stroke. This is reflected in sad reactions, angry reactions, the need for help and support from the government, health workers, and other family members, and barriers to patient care. It is important to ensure good coordination between health services and patients and their families, as patients and participants do not have access to health services due to distance and physical disability.

Keywords: Family Members and Post-Stroke.

1. INTRODUCTION

Stroke is a neurological disease characterized by blockage of blood vessels. The rupture of the arteries that carry blood to the brain leads to the sudden death of brain cells (Kuriakose & Xiao, 2020). According to Alhazzani *et al.*, (2018), stroke continues to grow as a significant public health problem worldwide. Stroke is now the second leading cause of death and the third leading cause of disability, with disability-adjusted life years lost worldwide (Feigin *et al.*, 2022). The Global Stroke Factsheet published in 2022 found that the risk of stroke has increased by 50% over the past 17 years and one in four people are expected to suffer a stroke during their lifetime. By 2019, there was a 70% increase in stroke incidence, a 43% increase in stroke deaths, a 102% increase in stroke prevalence, and a 143% increase in Disability Adjusted Life Years (DALYs) (WHO, 2020).

Most of the global stroke burden occurs in low- and lower-middle-income countries. The disproportionate burden on these countries has created unprecedented problems for families with fewer resources (WHO, 2020). Furthermore, low-income countries account for 85 percent of stroke deaths (Murphy, S. J., & Werring, 2020). Strokes have increased significantly in recent decades due to population growth and aging, as well as increasing prevalence due to lifestyle changes and the high prevalence of diabetes mellitus, obesity, dyslipidemia, and hypertension, all of which are considered risk factors for stroke (Alhazzani *et al.*, 2018).

More than 80 million people worldwide suffer from stroke, a common and costly disease and a leading cause of severe long-term disability (Duncan *et al.*, 2021). A stroke reduces mobility in more than half of stroke patients ages 65 and older (CDC, 2023). The disease leads to visual impairment, speech impairment, paralysis and loss of consciousness.

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People with disabilities have difficulty engaging in physical activity. Therefore, help and support from families is needed to optimize the rehabilitation period and improve their quality of life after a stroke (Wulansari Putri Yunita, Nurmala Ira, 2020).

In 2020, 7.6 million people died from a stroke, and there were 4.4 million stroke cases in the Southeast Asian region (WHO, 2020). In these countries, the overall incidence of ischemic and hemorrhagic strokes has increased to 8594 per 100,000 over the last decade (Murphy, S. J., & Werring, 2020). Data from the Institute for Health Metrics and Evaluation (IHME) in 2019 revealed that stroke is the leading cause of death in Indonesia (19.42% of all deaths). Basic health research (Riset Kesehatan Dasar, RISKESDAS) finds that stroke prevalence in Indonesia increased by 56% from 7 per 1000 population in 2013 to 10.9 per 1000 population in 2018 (Indonesia., 2023).

Stroke patients receive most of the care from their family members, and the quality of care directly affects the patient's recovery (M. Li *et al.*, 2023). In addition to providing emotional support, high-quality nursing interventions can also improve family care (Alhazzani *et al.*, 2018). In the initial stages of caring for stroke patients, most families feel stressed because they do not know how to care for stroke patients. Therefore, assessing foster families' stress responses when caring for stroke patients and providing information on stress management, nursing skills training, and access to accompanying professionals can help families feel the warmth of caregivers and reduce physical and emotional stress (M. Li *et al.*, 2023).

According to research by Wang *et al.*, (2023), nurses face many challenges and needs when caring for stroke patients. The study provides insights into the experiences of caregivers who have suffered a stroke and find they have to deal with emotional challenges during the parenting process. By responding positively and giving compassion and attention to patients and caregivers, they face many challenges and ask for support during the care process. The research by J. Li *et al.*, (2023), state that family functioning in general varies significantly between stroke patients and their caregivers, demonstrating the importance of understanding family dynamics in stroke care. This research has implications for the support and care of stroke patients and their caregivers, as well as the importance of considering family functioning in stroke management and the mental health of patients and caregivers.

Bulukumba Regency is one of the regions where the number of strokes is increasing every year. The results of the data collection showed that the number of stroke patients in 2021 was already 139 people, in 2022 it was even 193 people and in 2023 there was a significant increase to 332 people. The many obstacles that families face when caring for patients after a stroke appear to cause various tensions for patients and family members. Family members caring for patients will experience stress because the patient's biological, social, and psychological needs exceed their own. There are also economic problems because the participants belong to the lower middle economy. Based on these issues, this study aims to explore families' experiences in caring for stroke patients. The results of this study will of course serve as input, motivation and support for other families in caring for stroke patients.

2. METHODOLOGY SECTION

This study uses a qualitative method with a descriptive phenomenological design. Qualitative research is a type of research that explores real-world problems and provides deeper insights into them (Tenny *et al.*, 2023). The research participants were 11 participants using purposive sampling techniques. The number of samples was chosen because it was sufficient to provide the information necessary to understand family experiences caring for patients after stroke. The phenomenological design aims to understand participants' life experiences and perspectives using a sample of 8–10 people (Shelton *et al.*, 2022).

The research was conducted in Bulukumba Regency by collecting data from stroke patients from the H.A. Polyclinic Sulthan Daeng Radja Bulukumba Hospital, and this research was approved by the Research Ethics Committee number 000530/KEP Stikes Panrita Husada Bulukumba/2023. The criteria for selecting participants were family members willing to participate in the study, nuclear family members, family members caring for patients > 6 months, family members aged > 18 years, family members communicating with Indonesian, family members who caring for patients for patients with paralysis, informative family members, family members in good health and family members completing the interview process.

The research instrument used in this study is an interview guide consisting of 10 question items, observation sheets, stationery, voice recorder and camera. The researcher developed a semi-structured interview guide by using the results of the study by Barlund *et al.*, modified. Participants who met the inclusion criteria were recruited for this study and contacted individually by telephone and in person. Participants were asked to provide information about the date and time of the interview and then made a home visit to each participant. Once the interview transcript is available for further coding, the results of the interview transcript will be imported, managed and analyzed by NVivo 12 qualitative data analysis software. Data from participants' interviews were analyzed using qualitative thematic analysis to enable the identification

of categories, sub-themes and major themes. The researcher uses thematic analysis to interpret the data. The levels of the analyst are:

Table 1: Stages of Thematic Analysis According to Braun and Clarke (Parmar *et al.*, 2021)

Stage 1	Familiarize yourself with the data by listening to recordings and reading transcripts.
Stage 2	Generate initial codes through an open coding process.
Stage 3	Search for themes from open code to generate categories.
Stage 4	Review categories to propose initial themes.
Stage 5	Define and name the final theme by comparing the initial theme with the raw data.

3. RESULTS

Based on the number of participants, there were most often 5 people between the ages of 31 and 40. Regarding professional characteristics, most participants had housewife status (IRT) at 63.6%, relationships with patients were older (45.4%), and duration of care for patients > 5 years was 54.5%. The degree of dependence of the patients was up to 7 people (63.6%).

Table 2: Demographic Characteristics of Participants (N=11)

Characteristic	Frequency (%)	Percentage (%)
Age:		
20-30 years old	2	18,1
31-40 years old	5	45,4
41-50 years old	2	18,1
51-60 years old	2	18,1
Gender:		
Man	0	0
Woman	11	100
Work:		
PNS	2	18,1
Self-employed	2	18,1
IRT	7	63,6
Relationship with patients:		
Husband	4	36,3
Wife	0	0
Child	2	18,1
Sibling	0	0
Parents	5	45,4
Length of Patient Care:		
1-2 years	2	18,1
>2-5 years	3	27,2
>5 years	6	54,5
Patient Dependency Level:		
Partial care	7	63,6
Total care	4	36,3

The interviews were conducted separately with other participants and repeated until no new information was obtained. The interview was conducted at the participant's home and lasted 30 to 40 minutes. After the interview session is completed, all conversations are recorded and the audio and observation forms are completed. The purpose of the observation sheet is to record each participant's actions, comments, and behaviors toward the patient (Braun *et al.*, 2019). It begins with repeatedly checking the transcript against an audio recording to ensure the correct transcription of the interview. The text data is read one word at a time to provide an in-depth look at the data in the transcript and an overview of its contents. Answers with similar content are grouped together (open coding), and this approach continues until an important subtopic label appears. All data in the subtopic is checked to ensure consistency between the data and the subtopic. Subtopics are categorized into major themes (axial coding). These topics are listed in the table below:

Table 3: Theme and Subtheme Conclusion (n=11)

Theme	Sub Theme
Fulfillment of patients' activity day living	- Partial care - Total care
Patient treatment	- Medical treatment

Theme	Sub Theme
	- Traditional/herbal medicine
Participants' psychological responses	- Sad - Stress - Sincere
Participant support	- Physical support - Financial support
Obstacles during treatment	- Obstacles from patients - Barriers to participants - No obstacles

1. Fulfillment of Activity Day Living (ADL)

In general, this theme deals with the daily needs of patients who are disturbed due to physical limitations. Participants said that almost all of the patients' basic needs are supported by their families, starting from the needs of mobilization, feeding, dressing, elimination, personal hygiene, etc. This theme leads to two sub-themes:

a. Partial Care

This sub-theme explains the form of family support for patients in meeting their basic needs. Based on the results of the study, almost all patients are partially helped in meeting their basic needs. Below are some statements from some participants:

Yes, I must help him to eat and go to the bathroom because the patient cannot lift his legs and hands, especially when he first wakes up. After all, he feels cramps (P1).

Alhamdulillah, he can walk but with the help of a cane. If he goes to the bathroom, he must be accompanied because he is afraid, he will slip. If he wants to eat, he can eat by himself, but he must be prepared for food and drink nearby (P2).

He can eat by himself but must be taken because he does not want to raise his hand (while holding the patient's left hand). The important thing is that food is prepared, so he eats himself without needing to be fed. If he goes to the bathroom, he walks alone, but it walks slowly; he only opens clothes that he can't, so he must be helped to undress (P3).

b. Fully Assisted (Total Care)

This sub-theme explains the basic needs of patients who cannot be done alone, all with the help of family. Four participants stated that all the patient's needs depend on their families. Here are quotes from some of the participants:

He couldn't, so he continued to sleep on the mattress. I gave him diapers, ate there, and wiped his body with warm water. Usually, if he wants to raise his legs, he asks for help. (P5).

I help with everything. That's why he uses diapers. If he wants to eat, he is bribed. He is also helped to go to the bathroom because it is so difficult for him to move his legs and hands (P11).

2. Patient Treatment

The theme of patient treatment is identified from the sub-themes of medical and traditional medicine. Information was obtained as an effort from the participants to overcome the problems of the disease experienced by the patient. Efforts made by the participants were taking medicine from doctors, carrying out therapy from hospitals, drinking herbal decoctions, and doing massages.

a. Medical Treatment

Medical treatment was carried out on some participants by consuming medication from a doctor and doing ray therapy on the problematic limb. Here are some excerpts from some participants:

Yes, thank God, supported by everyone and his children, he was taken to the hospital for examination and therapy like being illuminated here (while pointing at the patient's hands and feet that could not be moved) (P5).

Yes, thank God, two weeks ago, he was taken to the doctor for treatment. So, this Wednesday, he was retaken to therapy at the Hospital (P8).

b. Traditional/Herbal Medicine

This sub-theme explains the treatment of diseases by consuming herbal medicines (lemongrass, bay leaves, ginger, coriander, and cucumber) and massaging problematic limbs. The following are the results of interviews with several participants:

It is recommended that he take herbal medicines such as lemongrass, ginger, and coriander because they are effective. Usually, if he is sore again, I massage his body. Usually, in the morning, I dry him outside so that he gets the sun (P7).

Yes, I always give him herbs mixed with lemongrass, ginger, and turmeric. I also usually call a masseuse so that he feels good about his feet and hands, especially since his legs are always stiff (while massaging the patient's feet) (P10).

3. Participants' Psychological Responses

Participants said that there was a change in attitude or behavior related to the participant's psyche if they experienced certain problems. The psychological response that arises during the treatment of post-stroke patients is a feeling of sadness, stress, and sincerely accepting the patient's condition.

a. Sad

The sadness arose because the participants felt sorry to see the patient's condition; because of his condition, he was unable to do activities, so his family met all the patient's needs. The following is the statement of the participants:

It's a pity to see him because he can't do activities like before, just lying in bed. In the past, when he was still healthy, he always worked for my sales. The only thing I always remember is if I am gone (P4).

I used to tell all my children to take their father because I am too old now. I cannot take care of your father anymore (while crying). But until now, they have not taken his father. They always have many reasons (P9).

b. Stress

Stress arises from the pressure that participants feel, so it is difficult for participants to control themselves. Forms of stress experienced by participants include irritability, silence, fatigue, and economic difficulties. Three participants experienced stress. Here are some participant statements:

Lately, I've always been angry for unclear reasons because stress is also a cause of trials like this. Well, maybe it's because I'm tired of this condition, not to mention that I must rack my brain to find food, take care of the children, and take care of my sick husband (P8).

Of course, I am tired, especially since my father has been sick for four years, not to mention other problems. It seems that this is a head that wants to burst. Usually, if there are many problems, it is better to be quiet and then go to bed so that my stress is reduced (P10).

c. Sincere

This sub-theme focuses on how participants who have been caring for patients with physical limitations for a long time feel sincere about their condition. Here are some excerpts:

Alhamdulillah, because I was given the health and strength to take care of my mother, so it didn't matter if I had to take care of her. Especially as a child, you must be filial to your parents, so be sincere, especially if your parents are sick (P1).

The condition of a sick mother must be accepted, let alone anything. The important thing is that we must be able to help and take care of mothers (P7).

4. Participant Support

This theme explains participants' desire to receive support and assistance from other family members. Participant support was identified from sub-themes: support in the form of physical assistance and financial assistance.

a. Physical Assistance

This subtheme said that participants expected assistance from other family members. The following are interviews with several participants:

I also want to have his brother, who always comes here so that they can help. The problem is that I am old. But his brother also lives far away. I am not too strong to work (P4).

I used to tell all my children to take their father because I am too old now. So, I cannot take care of your father (while crying). I cannot lift him. If I'm sick, I usually don't take care of him (P9).

b. Financial Assistance

Financial assistance was delivered by the participants (P4, P5, P8, P9, P10, and P11). They said that their families had financial problems since the patient was sick, the participants expected help from other family members, the government or assistance from health workers for the patient's recovery. The following are the results of interviews with participants:

I have nothing. Look at the condition of my house (while showing the condition of the house). If I want to take my child to treatment, where can I get money? Even for eating, it's difficult. I wish there was any help from the village government or an officer who could come to my house to take care of my child, but it is not there (P4).

I can't take my father for treatment because I don't have money. Especially since the treatment is expensive, where can I get money? His other children never sent him money. Officers from the Health Center also never come to bring medicine (P11).

5. Obstacles during Patient Care

This theme explains the difficulties encountered while caring for patients. The barriers identified were from several sub-themes: barriers from patients, barriers from participants, and no barriers.

a. Obstacles from Patients

This subtheme was found because of the patient's unwillingness to be taken for treatment and given treatment for the patient's recovery, as well as the patient's sensitive feelings that sometimes make it difficult for participants to act on the patient. The participants conveyed this:

It is difficult because if he is just touched a little bit on his body, he always feels pain. That's why if he wants to be treated, he always refuses, and he thinks that he will be hurt. Even if I want to take him outside to sunbathe, he always refuses, so it's difficult. He is always in bed, and even then, he rarely leaves the room (P3).

Usually, if he wants to be treated or dictated to drink herbal medicine, he always doesn't want to. So maybe because of the age factor, his anger is usually not clear. I once tried to take him to the health center; we were ready, but he suddenly didn't want to go (P11).

b. Barriers from Participants

During the provision of care to patients, of course, participants experience many obstacles. These barriers are caused by the inability of participants to help patients physically and financially. This is due to the condition of the participants who are old (elderly), so they experience a decrease in physical function, the absence of a participant's fixed income, and no assistance from other sources. The participants conveyed this:

I can't take him to the doctor because I am too old now; I used to be sick, and my waist usually hurts. So, he usually pees on the bed, and cleaning him when I am feeling good (P4)

I don't have a salary; his brother and nephew usually help with my food and his needs. It was also difficult for me to help him lift his body because we knew the man, his weight, and the stiffness in his legs and hands. Moreover, I am old, too. I am not strong enough to take care of him. So, I usually wait for my grandson to help me change his clothes (P9).

c. No Obstacles

Four participants said that there were no obstacles while treating patients. This is because the patient's condition has improved from before, the patient is able to be invited to coordinate, as well as there are no problems with finances. Several participants delivered the statement:

Alhamdulillah, so far, there have been no obstacles. When I need help, there are always brothers, grandchildren, and other family members to help. If I lack funds, thank God there are relatives who want to help (P1).

There is not any. If I am not at home, there are still aunts, brothers, and grandchildren who always come to the house to see the condition of my mother (P2).

Alhamdulillah, there is no problem because my mother's condition has improved. Only her right hand has not been able to hold too much. However, some grandchildren accompany and help if their grandmother needs help (P6).

4. DISCUSSION

The aim of this study is to examine the experiences of family members in caring for stroke patients. This study identified five phenomena related to the experience of family members caring for patients after stroke: fulfillment of the patient's daily activities, treatment of the patient, psychological reaction of participants, support of participants, and obstacles during patient care.

The results of interviews with participants revealed the phenomenon of meeting the patient's daily activity needs, which was described as helping to meet the patient's daily activity needs both partially and completely. In this study, the family helped meet the patient's daily needs. Participants said that partial assistance was provided in the form of food needs (food preparation), mobilization, and personal hygiene. In addition, patients are offered comprehensive care. This is because the patient has unilateral or bilateral paralysis of the limbs. So that patients have a high level of dependence on the participants. The family's role must be to support the patient in carrying out daily activities independently. The family needs to think about the patient's independence and understand the level of support provided to the patient.

These results are consistent with the research of Lee & Jung-Ho (2019), which states that the hands and upper limbs are involved in most of the patient's activities. The inability to use the upper limbs can lead to deterioration in limb function, ultimately leading to sedentary behavior and interfering with daily activities (ADLs). Patients with chronic illnesses will suffer from fatigue in everyday life (Adil & Amin, 2023). Research by Li *et al.*, (2023), shows that organ dysfunction in stroke patients causes them to rely on family members to carry out their daily activities. One of the effects of stroke is the inability to meet basic needs (Dalimunthe *et al.*, 2019).

Another phenomenon in this study is patient treatment, which consists of medical treatment and traditional or herbal medicine. Participants' treatment-related efforts include transporting patients to hospitals or health centers for physical examinations and treatment, radiation therapy for paralyzed limbs, consuming herbs, and performing massages on problematic limbs. Herbal remedies are often used in a holistic approach to improve the health of these individuals. According to the results of the Mashabela & Otang-Mbeng (2023), research, ginger is used as an herbal remedy to treat various diseases. Ginger has been shown to have anti-inflammatory, anti-apoptotic, antitumor, antipyretic, antiplatelet, antitumorigenic, antihyperglycemic, antioxidant, anticoagulant, and analgesic properties (Shahrajabian *et al.*, 2019).

Patients who come to medical treatment due to their weak physical condition with a Bartels score <60, economically capable patients and patients who are supported by their children. Participants performing traditional medicine on patients were caused because the patient's condition had improved from before, the participant was unable to take the patient to the health service due to the participant's physical condition and age, and the participant was limited in terms of treatment costs. The same research was carried out by a patient who participated in home exercise and even said that he completed his rehabilitation training program and was able to complete the activity. However, some patients cannot participate in rehabilitation training due to poor cost and poor physical condition (Mahmood *et al.*, 2022). According to Kavi *et al.*, (2019), most nurses care for patients at home according to their knowledge and the knowledge of those around them.

Follow-up care is intended to speed recovery, reduce mortality, and prevent recurrence of stroke and heart disease, with the aim of reducing the risk of recurrent stroke (Duncan *et al.*, 2021). Family caregivers who care for patients often complain about personality changes in stroke patients. Detecting personality changes is particularly useful because mood disorders – rather than motor impairments or pain – have been shown to play an essential role in caregivers' quality of life and life satisfaction (Bucki *et al.*, 2019). Caregivers say that there is a lot of emotional stress, changes in daily life, and difficulties in caring for patients with dysphagia (Zeng *et al.*, 2023).

The results of interviews with participants revealed that the phenomenon of psychological reaction is based on the identification of sadness, stress and sincerity. Some participants felt sorry for the patient because his condition had not recovered and he was unable to perform activities. Other participants experienced stress because they were tired of caring for patients for many years, as well as poor economic conditions and other problems arising from their environment. Stress arises from the pressure that participants feel, making it difficult for participants to control themselves. These results are consistent with the research of Kugimoto *et al.*, (2017), who showed that psychological stress responses consist of affective responses, cognitive responses, and behavioral responses. Participants who showed a sincere response were dependent on the support of other family members, the patient's condition had improved, and they were economically able. Therefore, to reduce participants' negative psychological reactions, full support is required, especially from other family members (Alhazzani *et al.*, 2018).

Similar research was conducted by Wang *et al.*, (2023), When providing care, nurses face many challenges and urgently need help. This research shows that nurses face emotional challenges. The importance of family support for patients to be motivated, stress-free and feel accompanied (Tombong *et al.*, 2022). During the treatment of stroke patients, participants require the support of other family members in the form of physical and financial support. Some participants require physical assistance due to physical or age-related inability to assist patients or meet their basic needs. In addition, other participants also hope to receive financial support from their families or the local government to help them with their families' treatment and daily needs. This was conveyed because the economic situation of the participants was worse, and there was no one there to support the family during the time the patient suffered a stroke.

These findings are consistent with research by Alselami & Butcher (2022), on the care of stroke-affected family members in Saudi Arabia who live with uncertainty and ambiguity amid feelings of distress, worry and fear full of unfulfilled desires. The burden on families caring for stroke patients is quite high. Factors that increase the burden on the family include the feeling that caring for patients is a difficult task, confusion about caring for stroke patients, obstacles in social relationships, and the feeling that patients need maximum support in self-care (Dharma, 2018). The results of another study were presented by Wang *et al.*, (2023), who found that nurses do not view care work as a burden. Instead, they feel that what they do is important to their loved ones, despite personal difficulties.

The phenomenon of obstacles is identified as obstacles from patients, obstacles from partitions and no obstacles. The patient's unwillingness and reluctance to receive treatment as well as the patient's sensitive feelings are obstacles to patient care. Likewise, due to the condition of the old and sick participants, it is sometimes not possible to help the patient physically and financially. The results of the same study were reported by M. Li *et al.*, (2023), most of the families surveyed came from the lower middle class. Their families responded that they were under much more pressure than they thought. In meeting the patient's needs in his daily activities, the participants noted many obstacles such as difficulties as well as the condition of the non-healthy participants were able to provide maximum assistance. Another study also showed that 25

caregivers of families of stroke patients were affected, with a median age of 66 years (range 45–82 years) and 76% female gender (Qiu *et al.*, 2018). Another participant said that there were no obstacles in treating patients as the patient's condition improved compared to before, patients could be invited for coordination, and there were no financial problems. According to Kavi *et al.*, (2019), family contact with the phenomenon of caring for stroke patients is the same as treating chronic diseases. It seems to create great tension in the treatment of patients. Caregivers experience stress because the biological, social, and psychological needs of patients exceed the needs of caregivers.

5. CONCLUSION

This study examines family members' experiences in caring for stroke patients in Bulukumba Regency, South Sulawesi using a qualitative design with a phenomenological approach and thematic analysis. Most participants found caring for stroke patients less enjoyable. This is reflected in sad reactions, angry reactions, the need for help and support from the government, health workers and other family members, and barriers to patient care. Therefore, in this work, five phenomena are highlighted, namely the patient's performance of daily activities, the treatment of the patient, the psychological reaction of the participants, the support of the participants and obstacles during patient care.

Due to the distance and physical inability of patients and participants to access health services, it is important to emphasize good coordination between health services and patients and their families. Family members want services and support that provide information about the care and treatment of stroke survivors.

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