

Experience Of Family As A Caregiver In Treating Stroke Patients In Mardi Rahayu Kudus Hospital

Sri Hindriyastuti^{1*}, Gardha Rias Arsy², Ika Merry Candra Dewi³

^{1,2,3}Institut Teknologi Kesehatan Cendekia Utama Kudus, Indonesia

*Corresponding Author: srihindriyastuti@gmail.com

Abstract. Stroke is a major health problem for modern society today. According to the WHO (World Health Organization) in 2016, deaths from strokes by 51% worldwide were caused by high blood pressure. Based on data from the 10 biggest diseases in Indonesia in 2018, the prevalence of stroke cases in Indonesia based on the diagnosis of health workers is 10.9 per mill. Various problems that stroke patients may experience include paralysis, weakness, balance disorders, speech disorders, etc. so that these patients need help in meeting their daily needs. This study used a qualitative method with a phenomenological approach. Informants in the study were 5 people. The selection of information is carried out using purposive sampling technique. Data collection techniques were in-depth interviews and data collection tools, such as interview guidelines. Based on the results of interviews conducted, almost all family feelings as caregivers in caring for stroke patients are sad, all participants answered that the services at Mardi Rahayu Hospital are good and fast, almost all participants' expectations for their husbands are to recover quickly, Almost all obstacles caregivers experience are a matter of time and money.

Conclusion: Based on the results of interviews conducted, almost all family feelings as caregivers in caring for stroke patients are sad, almost all participants answered that the services at Mardi Rahayu Hospital are good and fast, almost all participants' hopes for their husbands are to recover quickly, almost all the barriers experienced by caregivers are financial and time issues.

Keywords: [Family, caregiver, stroke]

INTRODUCTION

Stroke is increasingly becoming a serious problem faced almost all over the world. This is because a sudden stroke can result in death, physical and mental disability both in productive age and old age (Junaidi, 2011). According to WHO (World Health Organization) in 2016, 51% of stroke deaths worldwide were caused by high blood pressure. In addition, it is estimated that 16% of stroke deaths are caused by high blood glucose levels in the body. Pathologically high blood sugar levels in the body play a role in increasing the concentration of glycoproteins, which is the trigger for several vascular diseases. High blood glucose levels during a stroke will increase the possibility of expansion of the infarct area due to the formation of lactic acid due to anaerobic glucose metabolism which damages brain tissue.

Stroke is the third killer in the United States after heart disease and cancer, and 43 percent of the total health budget is for stroke treatment. Another fact that is quite shocking is that currently 80 percent of stroke sufferers are in developing countries, including Indonesia. Based on the 2018 Riskesdas results, the prevalence of stroke in Indonesia increases with age. The highest number of stroke cases diagnosed by health workers was aged 75 years and over (50.2%) and the lowest was in the 15-24 year age group, namely 0.6%. The prevalence of stroke based on gender is more in men (11.0%) compared to women (10.9%). Based on place of residence, the prevalence of stroke in urban areas is higher (12.6%) compared to rural areas (8.8%).

Based on data on the top 10 most common diseases in Indonesia in 2018, the prevalence of stroke cases in Indonesia based on health worker diagnosis was 10.9 per mille. The highest prevalence of stroke cases is in East Kalimantan Province (14.7%) and the lowest in Papua Province (4.1%), while Java Province Middle at 7.7%.

According to the Central Java Provincial Health Office (2012), strokes are divided into hemorrhagic strokes and non-hemorrhagic strokes. The prevalence of hemorrhagic stroke in Central Java in 2012 was 0.07 higher than in 2011 (0.03%). The highest prevalence in 2012 was Kudus Regency at 1.84%. The prevalence of non-hemorrhagic stroke in 2012 was 0.07% lower than in 2011

(0.09%). In 2012, stroke cases in the city of Surakarta were quite high. There were 1,044 cases of hemorrhagic stroke and 135 cases of non-hemorrhagic stroke.

Based on data obtained from the medical records section of Mardi Rahayu Hospital, the number of stroke cases in all age groups decreased from 2013-2016 and increased in 2017. Although there was a decrease in cases in 2013, the number of stroke cases at Mardi Rahayu Kudus Hospital was still relatively tall. In 2013 there were 1481 cases, in 2014 there were 1437 cases, in 2015 there were 1393 cases, in 2016 there were 1316 cases, in 2017 there were 1536 cases (Mardi Rahayu Hospital Medical Records Data, 2017). Stroke sufferers at Mardi Rahayu Hospital who were treated in the Stroke Unit in 2013 had 396 cases, and there was a decrease in 2014 to 352 cases, in 2015 there were 347 cases, in 2016 there were 306 cases and a slight increase in 2017 as many as 326 cases.

Various problems that stroke patients may experience include paralysis, weakness, balance disorders, speech or communication disorders, swallowing disorders and memory disorders so that these patients need help in meeting their daily needs (Mulyatsih, 2008).

The family is the main support system that provides direct care for every patient's health and illness. The role of the family as caregivers is very important in caring for stroke patients. Attention and love from those closest to you is a natural medicine that will foster enthusiasm in stroke patients.

Caregivers is an action carried out by the family of an individual who generally cares for and supports other individuals (patients) in their lives. Caregivers have the task of emotional support, caring for patients (bathing, dressing, preparing meals, preparing medicine), managing finances, making decisions about care and communicating with formal health services (Awad and Voruganti, 2008, p. 87).

Attention to caregivers is important because successful treatment and care for stroke patients cannot be separated from the help and support provided by caregivers. Caregivers are the primary source of support for individuals with stroke and are the first to respond to changes in the patient's status during any phase of the disease course.

In caring for patients with stroke, families also have obstacles in carrying out this treatment, and there are also many effects that arise when caring for patients with post-stroke. As in the research journal on stroke, the results of research show that home care for post-stroke patients is difficult, and the families who care for most of them experience fatigue and stress and around 40% of family caregivers experience somatic symptoms or experience health problems due to stress. itself and weak immune system (Sit, 2008).

With brief interviews conducted during interviews with families, caregivers can experience different experiences in caring for stroke patients in hospital. The phenomenon that occurs at Mardi Rahayu Kudus Hospital is that caregivers tend to experience obstacles in caring for patients because of the limited time they have, besides that the limited quantity of caregivers when compared to the high level of dependence of stroke patients is one of the phenomena most frequently encountered at Mardi Rahayu Hospital. Holy.

Starting from the phenomenon above, the researchers were interested in exploring in more depth the experiences of families as caregivers in caring for stroke patients at Mardi Rahayu Kudus Hospital.

METHODS

The research method used by researchers is method qualitative and using a phenomenological approach. The number of informants that will be selected by researchers in this research is 5 informants. The data collection tools used by researchers are in the form of interview guides, notebooks and pens as well as other supporting tools such as cellphones as recording tools during interviews. The data collection technique used in this research is in-depth interviews.

RESULTS AND DISCUSSION

From the results of the interviews conducted, the researcher identified descriptions of the interview results in four main themes, namely:

Theme	Answer
Variety of feelings	- Sad
	- Give thanks

Service Satisfaction	- Good
	- Fast
Hope for husband	- Get well soon and be together again
	- Get well soon, can walk, can eat by mouth
	- Get well soon and be able to work again
Caregiver barriers	- Finance
	- Time

a. Various feelings of families as caregivers in caring for stroke patients.

Based on the results of interviews that have been conducted, almost all the feelings of families as caregivers in caring for stroke patients are sad. This is in accordance with the statements of the second, third and fourth participants.

...Actually, I'm sad, sis, to see my husband like this. (P2)

...Actually, I'm sad, sis, to see my husband like this. Every night I cry while watching him sleep. (P3)

... Actually, I'm sad, Sis, to see my husband like this. Every night I cry while watching him sleep. I really never thought that he would be like this. (P4)

Some participants, namely two participants, stated that they were grateful that they could still care for their husband who was suffering from a stroke. This is in accordance with the statements of the third and fourth participants. They are as follows:

...Yes, I am grateful that I can still take care of my husband..I consider this an opportunity for me to prove my love for him (P1)

...Yes, I am grateful, sis, that I am still given the opportunity to care for my husband who is sick. (P5)

b. Service Satisfaction in Hospitals

Based on the results of interviews conducted, almost all participants answered that the service at Mardi Rahayu Hospital was good and fast. This is in accordance with the statements of the first, second, third, fourth and fifth participants.

...That's good, sis, the service here is fast, patients are handled immediately without waiting for administration and so on. (P1)

...Mardi Rahayu is famous for its good and fast service. (P2)

...Mardi Rahayu is known for its good and fast service, I have always come here when someone in my family is sick. (P3)

... If Mardi Rahayu has always been famous for its good and fast service, my neighbors in my village will definitely come here if they are sick, sis. (P4)

... That's good sis... here the service is fast... patients are treated immediately... no waiting for administration and so on.. (P5)

c. Participants' hopes for their husbands

Based on the results of the interviews that were conducted, almost all participants' hopes for their husbands were that they would recover quickly. This is in accordance with the participant's statements, first, second, third, fourth and fifth

...The hope is that my husband can recover quickly, sis, can be together again at home and can carry out activities like before. (P1)

...I hope that my husband will recover quickly, sis, be able to walk, be able to eat by mouth, be able to gather at home again and be able to carry out activities like before (P2)

... I hope that my husband will recover quickly, sis, and be able to work again because the children still need a lot of money to finish their studies. (P3)

... I hope that I will recover quickly, sis, and be able to work again, because children require a lot of money for their education. (P4)

... I hope that I will recover quickly, sis, that I can gather at home again and be able to carry out activities like before. (P5)

d. Barriers experienced by caregivers

Based on the results of interviews that have been conducted, almost all of the obstacles experienced by caregivers are financial and time problems. This is in accordance with the participant's statements, first, second, third, fourth and fifth

...Obstacles, sis...my husband is the backbone of the family, so as long as he is sick, he will definitely be the most influential regarding finances, the children's school fees, their pocket money. (P1)

...The problem is when you pick up and pick up your children from school, so I have to go back and forth from home to hospital, apart from that, I sell basic necessities at home, so for now, I'm closed. (P2)

...The problem is time sis, I accompany her all the time here so the work at home is a mess and I can't sell either...I wish she didn't stay for a while... (P3)

...The problem is sis..I accompany her all the time here so the work at home is a mess. (P4)

...The obstacles are time and costs, sis. (P5)

DISCUSSION

This research has identified descriptions of interview results regarding family experiences as caregivers in caring for stroke patients in four themes, namely:

1. Various feelings of families as caregivers in caring for stroke patients

Based on the results of the interviews, it showed that almost all participants were sad about their husbands' condition and grateful that they could still care for their husbands who were sick. The emergence of negative feelings was stated as a psychological change by all participants. Negative feelings that arise include feelings of sadness, worry, annoyance, confusion, fear, lots of thoughts and feelings of disbelief in fate. The impact of hospitalization is not only felt by the patient, but will also be felt by family caregivers.

Research conducted by Ostwald (2009) regarding the stress experiences felt by stroke patients and family caregivers during the first year after planning to be discharged from the hospital suggests that negative feelings such as fear, anxiety and worry are influenced by the characteristics of stroke patients and their level of recovery. Meanwhile, mental changes, decreased cognitive function, depression experienced by stroke patients, and aphasia, according to research conducted by Julianti (2013) regarding the experience of caregivers in caring for post-stroke patients at home in the work area of the Benda Baru Community Health Center, South Tangerang City, as experienced by The three informants who complained that the changes in the patient made them sad and angry. Can cause even more stress.

Apart from negative feelings, several participants also said that positive feelings emerged, such as feelings of gratitude when they were able to care for their husbands, the desire to laugh and joke and express jokes to other patient family caregivers. Research conducted by Drummond (2007) stated that apart from the emergence of negative feelings, family caregivers also expressed positive feelings, where they said that family ties and feelings of connectedness between family and friends were increasing.

2. Service satisfaction

Based on the interview results, it showed that almost all participants answered that the service provided by nurses at Mardi Rahayu Kudus Hospital was good and fast. Behavior provided by health workers includes paying attention, understanding and taking action to handle complaints that are felt, this is felt by caregivers when health workers try to hear, understand and intervene and when families get answers to their questions related to illness suffered by the husband. Health workers confidently carry out their competencies, carry out actions in accordance with professional knowledge and competence to handle specific problems, demonstrate professional behavior, provide information, provide emotional support, and do this continuously.

According to Tomey (2006), caring behavior carried out by health workers is the central focus of nursing which is the essence of caring for patients. By caring, the relationship between nurses and patients can build a relationship of mutual trust, patients will express the negative or positive feelings they are experiencing. Patients who receive attention feel fully helped and feel satisfaction. Nurses have access to the deepest innermost part of an individual, nurses intervene in the body/physical, but this cannot be separated and is part of emotions, thoughts and feelings.

Nurses who are concerned in providing nursing care to patients in hospitals are nurses who have a caring attitude. This is supported by the theory put forward by Potter et al., (2009) that caring is the

nurse's wholehearted attention to the patient. Caring, empathy, gentle communication and the nurse's compassion for the patient will form a therapeutic nurse-client relationship.

3. Hope for husband

Based on the results of the interviews that were conducted, almost all participants' hopes for their husbands were that they would recover quickly. The role as primary caregiver carried out by the partner can have a positive impact which is felt, including the partner feeling that his presence is more needed in helping the patient's daily activities, taking care of and maintaining the patient's diet, as well as accompanying the patient during therapy, feeling more useful by providing more meaning to the patient. partner's life, strengthen their relationship with other people, improve their spiritual quality, and also strengthen a more intense commitment to their partner through caregiving activities provided to their partner (Robert, 2006)

The love between husband and wife will provide light to family life. Harmony, familiarity, cooperation in facing life's problems and problems are characteristics of their lives (FIP-UPI Education Science Development Team, 2007).

Supported by Lum (2013) who said that stroke sufferers will be motivated to organize their lives again in a caring environment and good family support. Coombs (2007) explains that when undergoing rehabilitation, family support, especially the caring partner, is very important to foster patient compliance with the medical program. Families must be actively involved in the overall stroke rehabilitation process. Most of the care and support for post-stroke patients comes from informal sources such as family members, especially caring partners

4. Barriers for caregivers in caring for stroke patients

Based on the results of interviews that have been conducted, almost all of the obstacles experienced by caregivers are financial and time problems. Financial changes are changes that are considered to have the greatest impact on family caregivers. This financial change occurred because of the increasing living needs while caring for stroke patients in hospital and medical costs for the patients themselves. This was expressed by most participants, where they complained about increasing costs while they were in the hospital. Four participants admitted that financial changes in the form of reduced income were caused by the main breadwinner in the family suffering from illness. Apart from that, several participants also said that their stay in the hospital made them unable to work, even though they admitted that they were not the main breadwinner. According to research conducted by Ogungbo (2008), it was found that disability due to stroke significantly places a large financial burden on health services, where most of the financial burden is borne by each stroke patient's family. In the research conducted, cost constraints were one of the thoughts of family caregivers when caring for stroke patients in hospital. Most participants complained about the high cost of care and the absence of the family's main source of income.

CONCLUSION

1. Based on the results of interviews that have been conducted, almost all the feelings of families as caregivers in caring for stroke patients are sad.
2. Based on the results of interviews conducted, almost all participants answered that the service at Mardi Rahayu Hospital was good and fast.
3. Based on the results of the interviews that were conducted, almost all participants' hopes for their husbands were that they would recover quickly.
4. Based on the results of interviews that have been conducted, almost all of the obstacles experienced by caregivers are financial and time problems.

REFERENCES

- Ahmadi, R. (2016). *Qualitative research methodology*. Yogyakarta: Ar-Ruzz Media.
- Arya, WW 2011. *Strategies for Overcoming & Recovering from Stroke*, Yogyakarta: Student Library.
- Awad, A.G., & Voruganti, L.N. (2008). The Burden of Schizophrenia on Caregivers. *Journal of Pharmacoeconomics*, 26(2), 149-162.

- Brunner and Suddarth. (2002). Textbook of Medical Surgical Nursing. 8th edition volume 2. Jakarta : EGC.
- Health Office, Central Java. Health Profile of Central Java Province 2012. 2013, Semarang: Central Java Health Office
- Drummond, 2008. Young women perceived experience of caring for husband withstroke.<http://ojni.org.drummond.htm>.
- Feigin, Valery. (2006). Stroke. Jakarta: PBhuana Popuper Science Gramedia Group.
- Given, BA, Given, C.W., & Sherwood, R.P. (2011). Family & caregiver needs over the course of the cancer trajectory. *The Journal of Supportive Oncology*, 10(2), 57–64.
- Junaidi, Iskandar. (2011). Stroke Beware of the Threat. Yogyakarta: CV Andi Offset
- Julianti, (2013) regarding the experience of caregivers in caring for post-stroke patients at home in the work area of the Benda Baru Community Health Center, South Tangerang City
- Murwani, A. 2007. Family Nursing Care Concepts and Case Applications. Jogjakarta: Mitra Cendikia Press.
- Muttaqin, A. 2008. Nursing Care for Clients with Nervous System Disorders. Jakarta: Salemba Medika
- Notoatmodjo, Soekidjo. 2012. Health Research Methodology. Jakarta: Rineka Cipta.
- Nursalam . 2013. Nursing Science Research Methodology: A Practical Approach. Edition 3. Jakarta: Salemba Medika
- Ogungbo, 2008. How can we improve the management of stroke in Nigeria.Africa.<http://www.ajns>. *Peans.org.article.php.id.article*
- Ostwalld, 2008. *Education guidelines for stroke survivors after discharge home* :literature/<http://medscape.com/viewarticle>