

Life Scenario System of Care for Stroke Survivors and Families: An Ethnography Study



Kartika Setia Purdani¹, Somporn Rungreangkulkij²

¹Faculty of Nursing, Universitas Muhammadiyah Kalimantan Timur, Indonesia

²Faculty of Nursing, Khon Kaen University, Thailand

ABSTRACT: The Greek word “Apoplexies” or “Apoplexy” for violent who is 40-60 years old and being struck was called by Hippocrates in 460-370 BC to mention stroke today. The tardiness for 10-minute delays will increase the disability impact. The most significant effect, in this case, is stroke patients and their families. The aim of this study is to explore and describes the life scenario of stroke survivors and families in the community. Ethnography study is an approach for qualitative research in this study with details the main participants are seventeen stroke survivors and twenty-four stroke caregivers. The data collection method is observation, in-depth interviews, and continued field notes for the content analysis, the duration for collecting data is five months. The result of this study is two categories, life scenarios of stroke survivors and life scenarios of family. The life scenarios of stroke survivors support two scenarios, and the life scenario of families as stroke caregivers has three scenarios. Stroke is not a misfortune disease or a punishment from God. This disease is having a golden period for acute care and rehabilitation training times, when the stroke survivors and families optimize this time, the loss of body function is controlled. On the other hand, the main caregiver has several responsibilities in this condition. Further, both of them needed support to continue and adapt their lives to new roles.

KEYWORDS: caregiver, ethnography study, stroke, system of care

I. INTRODUCTION

Indonesia is the highest stroke population in South Asia (Venketasubramanian, Yoon, Pandian 2017). Someone who had a stroke attack and still survive can call a stroke survivor. They still live but have some effect, in relation to weakness or limited body function. Because of that, they need support from their family to avoid stroke return attacks and keep themselves alive. The role of family members who undertake patient care is unarguably important for stroke rehabilitation. Caregivers play a key role in facilitating recovery (Sari, Mubasyiroh, and Supardi 2017). The impact on stroke survivors after an attack includes psychological and physical impairment. The different circumstances on largely stroke survivors confused and frustrated. Not stop depending on activity, but also, they must bear the psychological burden (Torregosa et al. 2018). Three of characteristics stroke survivors are related to body function, coping, and the last is the quality of life (Gorski 2013; Fang and Tao et al. 2017; Torregosa et al. 2018). The stroke incident would be negative consequences for the individual as a stroke survivor, related to this condition, almost stroke survivor dependence on others. The need for care having related to the position, function, and structure of families. Because of the unique culture in the family, those with similar conditions maybe have different maintaining states of health (Kaakinen R. Joanna 2010).

Family or informal caregiving is a stressful, life-consuming activity that often impacts the social, emotional, and financial health of the caregiver. The caregiver burden has been described as a negative reaction to the impact of providing care on caregivers’ social, occupational, and personal roles. Studies of family caregivers suggest that stress and burden can affect their physical and mental health. Negative health outcomes such as depression and overall poor health including a lowered immune system and higher blood pressure have been reported. Family caregivers may also experience burnout, which can cause early nursing home placement for the care recipient. Most alarming, family caregivers experience an increased mortality rate and are at a greater risk of abusing the care recipient as a consequence of stress and burden (Eifert et al. 2015).

Related to cardiovascular disease which is one of the NCDs, in Indonesia, we have acts and policies to support health, such as Act No. 36 of 2009 for equality health service, in the MoH National Strategic Plan for Universal Health Coverage for Indonesian peoples, and six Indonesian health systems. Furthermore, the government was to support verification of the Indonesian health system,

Life Scenario System of Care for Stroke Survivors and Families: An Ethnography Study

such as; community health centers (Puskesmas) programs, for example, the community engagement program (Month) called Integrated Service Post (Posbindu) and Vigilant Village (Desa Siaga), The National Hospital Accreditation Agency (KARS), the government public insurance (BPJS), and existence of the Indonesian Medical Council (KKI) (Mahendradhata et al 2017). In Indonesia, East Kalimantan is the highest province for stroke incidents during 2013-2018. Specifically, the Palaran sub-district recorded for the sub-district with the highest number of hypertension case for 2018 and 2019.

A life scenario means describing a situation that most often immerses the respondent. The system includes elements that will stimulate the respondents' beliefs, perceptions, or attitudes. The aim of this study is to explore and describes the life scenario of stroke survivors and families in the community.

II. RESEARCH METHODS

The procedure of inquiry in this study is qualitative research. Qualitative research is one of research design with more attention to understanding and exploring meaning from individuals or groups to ground of human or social problems, add more, on qualitative research having three assumptions, no single meaning, the quality of research design, and the approach of research design. This research design benefits for knowing construct meaning from human beings, studying the context or setting for understanding and making interaction in and out with community because of their setting (Ormston Rachel, Spencer Liz, Barnard Matt 2013; Creswell 2014).

The special resonance of ethnography has consisted of anthropologists and sociologists, cited by Denzim and Lincoln (2011) this study is to pay more attention to study about beliefs, behaviors, social interaction, participation, and observation. This methodology for understanding the cultural phenomenon, which some conditions not found in quantitative research (Loshini 2012; Boellstorff et al 2013). Participants in this study consist of seventeen stroke survivors and twenty-four stroke caregivers. Methods such as observation, focus group discussion, in-depth interviews, and field notes are used to collect data in this study and continue the content analysis. It starts from July to December 2021 in the Palaran sub-district setting. Khon Kaen University Ethics Committee published the KKI IRB letter in a number of HE642022 with approval on May 19, 2021, to support this study.

III. RESULTS

The life scenarios consisted in this study is divided into two groups; there is the life scenario of stroke survivors and the second life scenario of families. The life scenario of stroke survivors inside two scenarios, there are regularly doing selfrehabilitation with family support and lying-in bed all the time with family support for daily activities. In addition, on life scenario of a family has three scenarios, such as being with stroke survivors on the side all time, multiple tasks of stroke caring, and having multiple families as caregivers.

1. Life Scenario of Stroke Survivors

The sudden incidents of stroke attacks have many responses. It would be by stroke survivors themselves or another family member. Interrupting the blood supply to the brain would impact body paralysis as one of the impacts of stroke disease. Paralysis and aphasia are problems connected with stroke attacks in the Palaran sub-district. Some stroke survivors complain about their new habits for staying life. In other scenarios, half of them is accepted sincerely. The different feelings and body conditions before and after stroke can be considered for stroke recovery too. Therefore, some of the choices for stroke rehabilitation are stroke recovery treatment or self-care, although a little piece is not doing anything.

According to that, the groups of life scenarios of stroke survivors would be supported by two life scenarios: regularly doing self-rehabilitation with family support and lying in a bed all day with family support for daily activities.

a. Regularly doing self-rehabilitation with family support.

The further phase for stroke attack conditions depends on others. The stroke survivors feel weak for everything, feeling helpless after they can't change anything. Depending on all families for activity daily living, in other cases, they need stimulants for independent activity. Paralysis is the most significant for stroke survivors in Palaran, which is the left or right side of the body and a half or all side bodies.

The COVID-19 situation today makes stroke survivors and caregivers choose self-rehabilitation in a home setting. Of seventeen stroke survivors, eleven are doing stroke self-rehabilitation at home: from this amount, one stroke survivor doing rehabilitation with family help, and ten others doing it alone.

"I treat my husband by myself in my home. I can practice some rehabilitation technic when the clinician nurse treats my husband in the hospital. At home, I do it every morning, around 30 minutes until 1 hour depending on my condition and my husband's condition. Starting with moving his paralysis hand and continuing for his foot which is paralysis too." (CG1, Female, 54 years old)

Life Scenario System of Care for Stroke Survivors and Families: An Ethnography Study

b. Lying in a bed all day with family support for daily activities

Caused by the body's conditions after a stroke attack, the first impact for stroke survivors is living with dependency. The number of two-stroke survivors depends on their families as caregivers for their daily activity or are partially dependent, and two are totally dependent on stroke caregivers. Two reasons for lying in bed are that stroke survivors feel weak for everything and feel helpless after they can't change anything with a kind of stroke recovery and rehabilitation. The second is the conditions where stroke survivors must be stimulated before stroke survivors do the activity by themselves in the acute phase after back from the hospital or because they have paralysis in the right-side body, which is not usual to use the left side for ADL.

"I can't do anything after a stroke attacks me. Day by day I feel weaker than last time. I tried several treatments for stroke, but I keep weak, I am stopped, and just lying for waiting for my timing comes with my wife serve in my daily needs." (SS2, Male, 65 years old)

In conclusion, the life scenario of stroke survivors' groups is explored; the first life scenario of the experience of stroke survivors when getting a stroke attack is regularly doing self-rehabilitation with family support and lying in bed all the time with family support for daily activities. Ten stroke survivors are told about self-exercise ability by themselves, and one stroke survivors need their family as a caregiver to help with stroke rehabilitation in- a home setting. Further, two-stroke survivors are continuing to get treatment at the hospital. They are considering that instruction for treatments must be from the health professional. Continued response to becoming a stroke survivor is dependent on others as impacts stroke symptoms. Twentytwo stroke survivors are living with their nuclear families. Based on that, the most support for their daily activity, including stroke recovery, is from families. The last life scenario for the support of this group is lying in bed all the time with family support for daily activities. Lay in bed is their selection when was do some activity or treatments for stroke healing but never or just limited to health conditions change. In other statements, it's like the hopeless phase of stroke survivors related to their conditions.

2. Life Scenario of Family

The change conditions as the impact of a stroke attack on someone in your family has happened. Almost stroke survivors in the Palaran sub-district are ahead of their families, the person with the main responsibility for family living. Therefore, after a stroke attack, it makes something different inside their family. The family role is changing, responsibility is changing, and more than it, other needs are added to supply the stroke survivors. Not only change that, some caregivers told related benefits from their family member who is getting a stroke. This group's scenario is supported by three life scenarios of families. There are being with stroke survivors on the side at all times, multiple tasks of stroke care, and multiple families as caregivers.

a. Being with stroke survivors on the side at all times.

Family is the primary care for stroke survivors caring. When the family is optimized to care, it can prevent recurrent stroke or other complications. Regarding stroke survivors' conditions, caregivers must attend to them all the time to cover all needs of stroke survivors. In these conditions, feelings, and experiences are raised about who is a caregiver of stroke survivors. Therefore, burden and worship are coming to explain the life scenarios of families, especially being with stroke survivors on the side all the time.

"My wife is totally depending on me after a stroke attack. Unfortunately, she depends on me but did not look into my situation. For example, when I am starting to sleep, she wakes me up to request something. I am a headache because I quickly weak up; when I am asking what she needs, she told us to forget what she wants. You know what my feeling at that time, angry and upset. It's often happened with me; I am burned to care for her." (CG9, Male, 65 years old)

"I am always thinking if our family conditions with my husband getting stroke are life's problem from Allah. Because of that, I am called to ibadat to care for my husband, and I am resigned about this. Yes, I am feeling tired, but never mind, it's my worship as a wife to my husband is like our holly book Qur'an direct for doing that." (CG6, Female, 60 years old)

b. Multiple tasks of stroke care

Nine of a wife is the main caregiver of stroke for their spouse, and it's becoming the most caregiver in the family. In other meaning, the stroke survivor is the head of a family or husband position. Before the stroke attacked her husband, 4 of them were workers too. Therefore, after her husband gets a stroke attack, the four of them have more responsibility, becoming the family breadwinners and the main stroke survivors caring.

Suddenly attack without a sign first of a stroke attack is making panic. Further, continued to care about several weaknesses were didn't know. The situation is different and more burdensome for a wife who is a housewife and a worker. After a stroke attacks her husband, she comes to become a housewife or starts to be a worker for family coverage living needs.

"I am stressed with our finance after the stroke attacked my husband. Maybe in the early month, it's not heavy for me; my son keeps transferring money for caring for his father and supplying my family's needs because I am just a housewife. Then, his supply

Life Scenario System of Care for Stroke Survivors and Families: An Ethnography Study

is difficult, so I am beginning to seek work. For work, I am starting from 8 am to 4 pm. Before I went to work, I was bathing and toileting my husband, preparing his breakfast, keeping stroke exercise, then entrusting my husband to my son.”
(CG1, Female, 54 years old)

c. Having multiple families as caregivers

Considering several problems and conditions as stroke survivors even during stroke disease, not only one family member is becoming a caregiver for them. In the Palaran sub-district, the researcher found too if the caregiver is not only a single person, but sometimes, they have companion caregivers. In research time, we found that 18 caregivers have companion caregivers, which would be their spouse, child, and nephew.

“I was doing everything to recover my body after a stroke attack, but I am aware if I can’t do by myself for all treatments. Fortunately, I have a good wife and my daughter. For example, to improve my condition, I am routine for a warm salt shower, my wife is helping me rub therapeutic salt three times a week, and when the timing for health control on last time, my daughter always pick-up me.” (SS5, Male, 65 years old, add moderately severe disability)

Stroke survivors and families have different needs living in the community. The problems growing up when they can’t know each other needs. Based on that, three life scenario of families was described as upper, beginning with being with stroke survivors on the side all time, multiple tasks of stroke caring, and having multiple families as caregivers.

Being with stroke survivors on the said all time is an experience for twenty caregivers who are living together in one home. Two themes in this category are burden and worship. Twenty-four caregivers are feeling burdened; some of them experience being angry, tired, and burdened, but five of the caregivers feel it’s ibadat because of worship. Multiple tasks of stroke care are rising for all caregivers. In these situations, four caregivers not only become the main caregiver but also money seekers, and all of them is the wife’s positions. The next is having multiple families as caregivers, considering paralysis, weakness from stroke survivors, and some duty as a caregiver and money seeker, not enough for one of the caregivers. Especially for they are who change roles in the family with double duty. However, the main caregivers need help for companion caregivers and it comes the last themes, having multiple families as caregiver.

IV. DISCUSSION

The existence of stroke care in Samarinda, more concern in the central government of hospitals in there is supporting stroke survivors and their families. The next problem is the stroke center capacity, where the amount of stroke patients is always increasing. Not only the capacity but the distance between Palaran and Samarinda has also raised a new problem for continuing stroke rehabilitation. These conditions do not differ in a community setting when the stroke treatment or stroke facility is, of course, not only concerned with stroke disease but also other neurologist problems, for example, the physiatry clinic in the Palaran sub-district. Related to the physiatry clinic, it has a difference in the usual time to open. Indeed, in another hospital, stroke treatment is common, beginning in the morning until the evening, but in this physiatry clinic, the starting opens in the evening. Some conditions make it comfortable, and another is a burden to getting the service.

The importance of environmental management for stroke rehabilitation is explored in Sweden’s research. It starts with the connectivity between the physical environment and health outcomes. This research is more concerned with rehabilitation based on home caring which the participant and families are weak participation (Kylén et al. 2021). It is a little different from the situation in the Palaran sub-district, in there the caregiver is seeking or utilizing various equipment at home for the rehabilitation of stroke patients, but unfortunately without instructions. Maybe several practices are painful for stroke survivors. Rehabilitation for humans includes environmental enrichment; environmental rehabilitation could be physical, cognitive, and social facilities. Therefore, the environment should promote action to optimize stroke recovery and rehabilitation (Qin et al. 2021).

Lying in bed all the time with family support for daily activities of life scenario for stroke survivors in conclusion based on two options, there are hopeless conditions and in the acute phase during recently back from the hospital. Terms of the first option are ways to solve their impaired body as impacted by stroke diseases, which is included in negative coping style. These situations arise after they are feeling depressed; outcome negative emotions. It differs when they find a positive coping style, in this time they try ways to solve problems to deal with negative emotions (Donnellan et al. 2006; Ding et al. 2015; Sastrawan, Newton, and Malik 2019).

When timing in-depth interviews with participants in the Palaran sub-district, almost participants do rehabilitation without guides. In their minds, because the stroke attack is suddenly coming, they will avoid some of the signs with quick treatments. Therefore, they try several kinds of stroke treatments, conventional, alternative, and traditional medicine, or a mix among them. But unfortunately, they don’t have a standard for doing that. After they do several treatments which trust for stroke recovery but never change or out their expectation, they feel hopeless and lie in bed all the time comes for their choice.

Life Scenario System of Care for Stroke Survivors and Families: An Ethnography Study

Meanwhile, the best timing for stroke recovery is during 2-3 years after attacking; with detail if do that more than 3 months will be a less significant recovery, and over 6 months is limited for spontaneous recovery (Grefkes and Fink 2020).

The second life scenario is the life scenario of the family. Neurological impairment is the impact of a stroke attack, a stroke survivor needs long-term support and care. Amount of 24 for a family as caregiver, the big number is the spouse (wife) and the second is the child. More than it consists of a brother, sister, and son-in-law. Family care is beginning from acute care until rehabilitation support. The nine wives are told about their experiences caring for their husbands with stroke conditions. Almost wives as stroke caregivers are part of the Javanese tribe, whereas in the Javanese cultural perspective, in a family, the men are dominant position. Based on their perspective, even though her husband is getting a stroke disease all decision is his decision. The decision for stroke care or stroke rehabilitation for example. Masculinity that connects with Javanese men is contributing and embedded with their perspective in a family on all conditions (Hidayat 2013).

In the case of families as stroke caregivers; in this study, the researcher finds two responses which opposite. Some stroke caregivers are burdened, but others feel worshiped with the new family role. The burden for the change of family role in half or almost caregivers feeling burdened. It start with fatigue, insomnia, pain, stiffness of their muscle, etc. (Settineri et al. 2014; Torregosa, Sada 2018). Another feeling or hidden feeling is worship. In this situation closely with the hand of God and grateful for learning a new skill for caring for others with stroke disease (Jackson 2014; Duthie, Roy 2015; Zarzycki and Morrison 2021). Furthermore, with several duties for caring the caregiver needs assistance to do that. It is because almost they are in a nuclear family, and the companion caregiver of stroke survivors are their other family members. Of 24 caregivers, eighteen caregivers in the Palaran sub-district have companion caregivers. The companion caregiver is usually their daughter, their son, or nephew, and only one of the caregivers needs their neighbor as his companion caregiver. The main function of companion caregivers in the stroke recovery phase is to be consultants and they could give consideration from another side of care in stroke recovery. More than it that companion caregivers in times of recovery with health professional services are improving communication and understanding of information (Andrades, Kausar, and Ambreen 2013; Tsai et al. 2015). One of the reasons for founding companion caregivers is knowing your limits. When someone becomes a stroke caregiver with a new role in their family almost feel burdened but not a little feeling of worship. But with kinds knowing your limits and capability for sharing responsibilities is more useful for continued life and avoid to come to a second victim (NIA 2017; AHA 2020).

Also, a result study explored the existence of a health facility to support stroke recovery, especially in the community. At Indonesia's health policies, it can start from the base level for health facilities; PHC, and continued to the district hospital level, and provincial hospital level (Mahendradhata et al 2017). Unfortunately, the geographic and transportations service facility provided in a previous study for coming as another problem in community fields (Islam and Aktar 2011; Kuupiel et al. 2019; Thompson et al. 2022).

V. CONCLUSIONS

Two objects strongly affected by stroke in the community are stroke survivors and their families as stroke caregivers. Almost stroke survivors in the Palaran sub-district community are men of old age; where is the large population in the Palaran subdistrict are men of aging age. In stroke conditions, some of them feel lost in self-confidence. This term is related to their selfdignity. In Javanese culture, most ethnic stroke survivors are embedded white patriarchal culture. The husband is the main breadwinner, and the spouse is domestic; the husband is the primary decision in the family, and the wife follows the decision.

The loss of confidence is not only felt by men who are stroke survivors; women with stroke disease have this experience too, even though just a small number. The incidence of stroke attacks in Indonesian women is mostly ≥ 70 years old. The women are called "wanita/wanito" in Indonesian and interpreted in the Javanese language as acronyms from "wani ditoto." In several perspectives, based on that meaning, the women's position is subordinate to the men in their family; or comes to substitute for the second position after the leading man is gone in their family with more add attention under any circumstances.

In the case of families as stroke caregivers, the two responses are opposite. Some stroke caregivers are feeling burdened but others feel worship with the new family role. In summary, some problems and grateful were coming as their capability for stroke survivors and caregivers. Stroke survivors must optimize life performance with continued and regular for doing rehabilitation, which is self-rehabilitation or rehabilitation with support from other families. For advantage is more motivated caregivers for their duty. Connecting with some problems coming after becoming a caregiver, it is wise to give attention more to family health care, not only for stroke survivors. Therefore, the family needs physical support and emotional support; it can be a psychiatry profession for it. The last is related to transferring knowledge from main caregivers to companion caregivers, which is becoming responsible for health care for discharge planning to main and companion caregivers or ensuring transferring the discharge planning from the hospital to main and companion caregivers in the home setting.

Life Scenario System of Care for Stroke Survivors and Families: An Ethnography Study

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Life Scenario System of Care for Stroke Survivors and Families: An Ethnography Study

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