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The essential care required by stroke survivors and families: an ethnography study

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Patient consent for publication: written informed consent was obtained for anonymized patient information to be published in this article.

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Abstract

From a cultural point of view, ethnographic research was needed to understand the essential care of stroke survivors and their families. Half of stroke survivors were dependent on family caregivers during neuroplasticity time, which could raise several burdens for both. This study aimed to analyze the essential care required for stroke survivors and their families. Focus ethnography design was employed with 64 participants selected purposively. The data collection methods were observation, in-depth interviews, and Focus Group Discussion (FGD). The techniques used were writing field notes for the content analysis, using thematic analysis to analyze data, and using COREX 32-items for reporting qualitative studies. The six themes identified were i) unclear information before discharge planning; ii) clear information from community nurses; iii) family brotherhood; iv) home visits; v) government health insurance obstacles; vi) counseling services for families. In this study, healthcare facilities with stroke services were preferred in stroke care, while optimal stroke care consisted of four main components that had to work together: health workers in health facilities, stroke survivors, family as successors of care in community settings, and the availability of health insurance facilities. In principle, the most important party in this situation was the family, including the nuclear or extended family; they could be the determinant in saving the lives of stroke survivors.

Introduction

The incidence rate of death by stroke is 5.5 million people, and 44 million people have gained Disability-Adjusted Life Years (DALYs).¹⁻⁵ Stroke has become one of the major problems in Asia, with 75.2% of stroke cases and 81% for DALYs, one of the most involved countries being Indonesia, which has the highest stroke population in Southeast Asia.^{6,7}

Cardiovascular disease problems cannot be solely solved by curing the patients but also through prevention activity.⁸ Some activities for treating stroke survivors cannot be secured with a single support.⁹⁻¹⁵ Adding more, taking care of stroke survivors who have just returned home from the hospital demands considerable support from others.¹⁶⁻¹⁹ Home care of stroke survivors and stroke education for caregivers establish an improved quality of life for both.²⁰ In Thailand and Indonesia, the researchers provided family empowerment with upgrading skill care by health staff could increase functional status with setback stroke complications.^{2,21} This does not stop here; some countries have developed government policies to support it. For example, Stroke Improvement Programs (SIP) and “telestroke” (stroke telemedicine).^{16,17,22}

Although several activities have been done for it, stroke care is a burden. In the poststroke period, caregivers feel objective and subjective burdens, time spent on stroke care, the uncertainty of the future, and the economic burden.²³⁻²⁵ In South Carolina, one of the causes for it is a lack of trust towards healthcare and healthcare providers, mainly rural settings.²⁶ Reduced quality of life and economic burden is the heaviest stroke survivor global burden in the world.²⁷⁻²⁹

Also, the culture of care depends on people’s perspectives and influences stroke care. Culture is connected with belief; traditional healers are essential in this term. The traditional healers are close to spiritual belief and arise from community perceptions. In Sub-Saharan Africa, aphasia, as the impact of a stroke attack is called misfortune, hell, or ill health, and is connected with the supernatural power of demons and witchcraft; because of that, their families brought stroke survivors to traditional healers. In South Africa, traditional healers are common for people who have non-communicable diseases, such as stroke, based on their community beliefs.³⁰⁻³² Like in other places, a masseur is the most traditional Indonesian healer for managing stroke symptoms.³³

Essential care for stroke means comprehensive caring for stroke, starting from prevention activity until rehabilitation and how to immerse in a community with sequelae of stroke. It can be a conventional procedure or a supportive intervention.³⁴ Personalized and tailored support and intervention between stroke survivors and families could optimize dyadic self-care in a Chinese setting.³⁵ Other research shows that the priority of relatives of people who have a stroke, especially their adult daughters, is coming to essential care for stroke survivors in Ontario, Canada.³⁶ Similarly, for the Javanese principle, family is mutual assistance; they have some Javanese principles and philosophy, such as happiness is harmony (*rukun agawe sentosa*), whereas unity of family could be good for the whole family; this also applies *vice*

versa. Another Javanese philosophy related to it is “Tega Larane ora tega patine, dudu sanak dudu kadang, yen mati melu kelangan” which means emphasis on solidarity, even if the person is not family, especially if the person is family, they will be cared for in health or illness.³⁷

In addition, based on the researcher walk interview, participants assumed and believed that the stroke was caused by their actions, hurting a family member, “karma” or God’s punishment. In others, the family talked about black magic causing their relative to have strokes. We found different perceptions of caring responsibilities between Javanese and Kutainese tradition leaders. In Javanese perceptions, women as mothers, wives, or daughters have more responsibility than others caring for the sick, but it does not happen in the Kutainese principle (fieldwork); the responsibility for caring is equal. Further, Javanese culture has two categories of diseases: physical disease (caused by viruses, bacteria, high tension, violence, accident, *etc.*) and non-physical (causes black magic, negative supernatural power, evil, demons, karma, *etc.*).^{38,39}

In conclusion, the explored upper expressed some perceptions and thoughts related to stroke that had an impact on its care; this case needed to be defined and historicized within dialog-related concept culture. Therefore, the ethnographic view could be used to compare and contextualize each theme.

Furthermore, the results reduce the gap regarding healthcare facilities and services, especially for stroke-related diseases. The cohesiveness of stroke survivors and families in stroke care must be simultaneous, which is different from the previous study.

Materials and Methods

Research design

The specific research design is a qualitative method with an ethnography study.⁴⁰⁻⁴⁵ The three methods for data collection used and the first author’s activities are described in detail.

Observation

During 2-3 months, as participant-observer, the researcher followed routine activities for stroke survivors (17) and stroke caregivers (24) in a home or community setting. Not only that, but the researcher also became a participant in observation at several health facilities recommended by stroke survivors and families, such as a community health clinic (2), a psychiatry clinic (1), and traditional healers (1), who worked in their clinic, home, or the patients’ home. The duration time went from 30 minutes to 15 hours. During this phase, the

researcher used observation forms and discussed them with the second author before going to fieldwork. After that, the researcher would ask permission from the participants before making an observation and giving the information sheet. The researcher emphasizes that the objective of observations is to learn from the participants to understand the situation of caring for stroke survivors and how they care for themselves. The other deal is not taking any pictures, following the day-by-day activity between stroke survivors and caregivers, and back again to make an agreement with the data found.

In-depth interview

Four months an in-depth interview was held to understand community values and meaning and comprehend the social symbol found with the first method. In-depth interviews were held with 50 participants in their homes. In this phase, the researcher must saturate data, therefore, back again 2 to 3 times with a duration of around 50-120 minutes for each visit, and the total time is four months. Further, add more time to discuss the results found. In addition, five stroke survivors dropped out because they died, settled in a new place, and suffered from aphasia as a consequence of stroke.

Focus Group Discussion

Focus Group Discussion (FGD) is the last method used in this research; it is a considerably interesting topic, whereas all participants used health facilities as a first aid for stroke care. Otherwise, they have several options for it, adding more in the COVID-19 pandemic. The researcher invited 11 recommended participants after discussing the issue with the gatekeeper and the second author as the research supervisor. The members of the FGD were a head office PHC (1), HRD PHC (1), a community nurse in PHC (6), a community doctor (2), and a private community nurse (1), considering their knowledge and experience of community care. After concluding, the first author returned the notes to the audience to saturate data. The FGD was conducted for 2 hours on October 18, 2021, in PHC hall.

Study participants

The author determined the participants purposively. The study participants consist of the main participants (50 participants), among whom stroke survivors (17), family (24), neurologists (1), clinician nurses (4), community nurses (1), health care professionals (2), and traditional healers (1). Another group is supporting participants (14 participants), consisting of friends of stroke survivors (1), friends of the family (3), the head of PHC (1), the HRD of

PHC (1), the health staff of PHC (6), and the leaders of the polyclinic (2). Interviews were mostly held in participants' homes or clinics. Almost all stroke survivors and caregivers are from the Java tribe, but other participants are Banjarnese and Kutainese.

Instruments and data collection

The researcher has a certificate from CITI, followed a research workshop, attended an international oral presentation, and finished a course in a doctoral program at KKU.

The data collection times start from July 1 until December 26, 2021, and all processes finish in September 2022. The first step was making a guideline for data collection methods with concept analysis. Currently, the first author is under the supervision of the second author, Associate Prof. Dr. S. R.

After that, the proposed study was sent to the Ethical Committee KKU, and a letter of approval was received with the number HE642022 from Khon Kaen University, Thailand. The data collection starts with observation; the researcher comes to participant observation and continues in-depth interviews and doing FGD; triangulation data was used to decrease bias. It caused almost all participants to be women and from the Javanese tribe, who are similar to the first author.

Data analysis

Thematic analysis is used to analyze data in seven steps.^{46,47} The first activity is to hear the interview recording (by recording device) in Indonesian with participants only. The second is transcribing and translating the document, which notes in field notes for familiar quotes during observation, in-depth interviews, and FGD. The next step is coding. The fourth step is searching the themes and then building sub-themes. The fifth step is reviewing the theme and identifying the relation of themes with a research question. The sixth step is to sort out several sub-themes in specific themes. For the last, the researcher makes a typology for the analysis study. At times, the researcher returned to fieldwork for feedback on the analysis data; all participants received the results.

Ethical clearance

The researcher was given the KKU IRB letter in HE642022 with approval on May 19, 2021.

Results

Table 1 represents the characteristics of the main participants using Statistical Package for Social Sciences (SPSS) software. Based on Table 1, it was shown that almost all stroke survivors are male: 14 (82.4%), 10 (58.8%) were aged 51-60 years, 11 (64.7%) used alternative and general medicine for rehabilitation, 47.1% of stroke survivors were in junior high school as for education, amount of 5.9% stroke survivors earned a standard regional wage. For caregivers, the dominant gender was females (70.8%), 41.7% (10) of participants were aged 51-60 years, and spouses (54.2%) were the most common relatives among stroke survivors, senior high school is 37.5% (9) as the most common level of education, and 66.7% participants earned less than a standard regional wage.

Six themes were obtained from the main and supporting participants related to essential care required by stroke survivors and families: i) unclear information before discharge planning; ii) clear information from a community nurse, iii) family brotherhood, iv) home visit; v) government health insurance obstacle; vi) counseling family services, which are detailed below.

Unclear information before discharge planning

Success for discharge planning from hospital to home care is evaluated by how the family treats the patients in the community. Some stroke survivors mentioned that they lacked information on stroke, especially regarding their cure and care in the hospital. A similar opinion with their caregiver; of 24 caregivers, 22 caregivers said they did not get good discharge planning in health facilities. Therefore, caregivers and stroke survivors were burdened with care.

“I was confused until today (harsh voice)... Nothing was explored about my stroke in the hospital. The nurse always reminded me that if I moved, my tension would go up, and I may get a recurrent stroke. But as I know, I didn't have hypertension before.”

(SS8, male, 65 years old, add partial disability)

“I just saw and followed, but no direct instructions were given by the nurse about caring for my husband (push sentences). It was my experience when I brought my husband to the hospital; the doctor's diagnosis was a stroke. The nurse didn't think about the patient's family.”

(CG1, female, 54 years old)

However, different opinions were obtained from health workers. The discharge planning prepares the families and patients to shift the location from the hospital to the community and ensure the continuation of health care. One of the representative participants talks about his experience.

“We are preparing the stroke pocketbook for guidelines in community care for stroke survivors and families who will return home. Certainly, the staff in the stroke center always learn and teach about stroke care during inpatient times. We always ensure that the stroke caregiver will exist to care in the community. On special days, like stroke day, we do a social activity to serve stroke survivors in a community setting.”

(Neuro, male, 36 years old, specialist in neurology)

Clear information from a community nurse

The explanation above differs from the families who call community nurses for their stroke survivors' health services. The community nurses give education and health information for continued self-care in a home setting. Eleven stroke survivors and 20 stroke caregivers were comfortable and more knowledgeable after the community nurse's explanation. The duration of each visit and the time needed to get health information differ; it's an average of 15-45 minutes each session. The important thing is sometimes they use the Javanese language for communication, making Nurse S. more valuable as a community nurse.

“Nurse S., as a community nurse, taught my mother-in-law and me routine exercises for stroke recovery with an easy understanding of the Javanese language. It is not like the PHC staff or hospital staff. I think it was just a simple exercise, but it was helpful for my mother's condition.”

(CG10, female, 39 years old)

Family brotherhood

Transportation, finances, and knowledge are some obstacles for stroke caregivers and survivors to get rehabilitation. However, this study found that the way out from several obstacles comes from their family. Maybe they are just a nuclear family consisting of parents

and children who stay together, but they have extended families who live not far from their homes. Just three stroke survivors do not have extended family to support them.

“I don’t have a car with which to bring my wife with stroke disease. I just asked my step-child about his mother’s condition to visit the doctor. When he has time, sometimes we ride his motorcycle, three people in one motorcycle. No money and no transportation are terrible for the care of my wife. Fortunately, I have a step-child (sad face with less sound).”

(CG9, male, 65 years old)

“What if we buy a car, my son-in-law has it. Call, and he will come if he is free from his work. We can’t estimate the money spent on my care and other family needs, but I have a good son-in-law.”

(SS5, male, 65 years old, add moderately severe disability)

Home visits

The healthcare provider becomes important in caring for the survivors and the community. Even though the caregivers and stroke survivors got discharge planning in the hospital, they must continue health recovery by themselves in a community setting. Based on the data records, 17 stroke survivors get a home visit from PHC; from that, 11 survivors receive home visits from PHC, community doctors, and traditional healers (masseurs). All participants were recorded as PHC patients.

Primary Health Care

The forefront healthcare service facility is called Primary Health Care (PHC). In the fieldwork setting, PHC was not only for outpatient service but also inpatient service. Due to COVID-19, the PHC changed to a quarantine hospital.

“Every home visit, we explained the patient and family’s health situations, motivated the patient and the family, and gave health tips like good food, exercise, signs, and symptoms, etc. But because of the pandemic, home visits were stopped.”

(PHCD, male, 55 years old, general doctor)

“It must be something the community needs when we are home visiting; each person in the community has different wants, and we, the PHC staff, must answer all questions as it is our responsibility to care in fieldwork.”

(PHC1, female, 45 years old, public health bachelor)

Community health provider

Community health providers are another option for home visits, including community doctors, nurses, and physiatrists. The number of stroke visitors in the physiatry clinic for a month is around 7 to 16 patients. Moreover, all facilities can take home calls. Commonly, the family calls community nurses for several reasons: not having transportation, being cheap, being friendly, and familiar with stroke conditions, which are impossible for outsiders.

“The stroke patient is coming here with several symptoms. When the patients and families come to my clinics for the first time, I do quick anamneses. Further, I suggest going to the hospital to get a real diagnosis of a stroke attack with a CT scan. If some condition does not support, I keep giving medicine for their health problems. Here, some conditions might cause the stroke patient to receive delayed care. Therefore, in some cases, I do home care, or I deliver them to the hospital.”

(CD2, male, 53 years old)

“I felt comfortable with physiotherapy rehabilitation compared to other treatments (little smile). The therapist has evidence and knowledge of stroke treatments, which is supported by suitable tools for rehabilitation treatment. I am inviting the therapist to my house. A little expensive, but I am more comfortable with that.”

(SS17, male, 58 years old, add partial disability)

“No need to buy a car, just call Nurse A. when my wife needs it. He comes in free duty. Even though Nurse A. did not stay here, he is a community nurse in his area and gives private care. My daughter, who is in senior high school, needs money, not less, I must manage money.” (CG13, male, 60 years old)

As we mentioned previously, the COVID-19 pandemic has changed the condition. The community doctor, community nurse, physiatry clinic, and PHC service stopped home visits during research times.

Traditional healer

Excluding health facilities or health provider services, a traditional healer is one of the community health services that could be called. Based on data, 11 stroke survivors used complementary therapy, and all participants used a masseur as a traditional healer. Their choices were friendly, cheap, easy to call, in line with their religion and beliefs, and comfortable.

“I was never determined to ask for money for health services from patients and families. Deep in my soul, I want to help others as my duty to others who are God giving more proficiency. Regarding service, I could be called to a patient’s house, or use my house. During a pandemic, I have not stopped my massage service.”

(TH1, male, 46 years old)

“I am using traditional healing methods like masseurs, as I need them. I can call them to come to my house, or I ask my son to deliver me to their home. If I go to their home, they reject money. They just accept some sugar, tea, or coffee. Not only that, they pray for me when starting to massage, and at the end of the massage, they pray for me again. I feel my body comforted and have a calm heart after going there. I am Javanese and comfortable with massage; it is so because, since I was a little, my mother always called a masseur if I was sick.”

(SS3, male, 65 years old, add moderate disability)

Government health insurance obstacle

Indonesia’s government requires citizens to use government health insurance (BPJS). Connected with this, some problems ensue, such as the distance between the PHC and citizen houses; another problem is the timing. Therefore, until today, only two stroke survivors and four caregivers used that for stroke rehabilitation.

“I never knew how to use government health insurance (BPJS). When I get a stroke, my son delivers me to the doctor in a health clinic for a private fee. One day, the leader in my area community comes and suggests making it (BPJS). We just followed him to take a photo, and I have a BPJS card now. He says it can be used if I am sick to get free care. My son supports all I need, so why do I need it?”

(SS7, male, 62 years old, add moderate disability)

“I use BPJS for first care for stroke. For now, I use private payment; it’s rapid for stroke treatment services. When using BPJS, we only stay for three days. After that, you must leave the hospital regardless of your condition. Additionally, before using it, we must get a referral from the first health facility or our family’s doctor. All those processes are lengthy.”

(SS5, male, 65 years old, add moderately severe disability)

Regarding stroke conditions, in which it is difficult to predict the time of healing, it makes some families try to find solutions. They have several options: government health insurance, private or alternate payment.

Counseling family services

Almost all stroke survivors are in nuclear families. The family has an essential role in supporting the survivors. Love-belonging, responsibility, and worship are some reasons for them. Family support was found in an in-depth interview, and the observations were physical assistance, moral support, and finding assistance.

“They constantly care for the stroke patient, caring with love and being patient. Not all, but almost all caregivers in here are doing that. I always teach them first before they do it by themselves. For example, for bathing in case of paralysis to the side of a stroke survivor’s body, after practicing and teaching, tomorrow is the family turn I am observing.”

(CN2, male, 30 years old, bachelor of nursing)

Families as stroke caregivers are doing anything for stroke survivors, too. They are given all the time, attention, and support for healing. But, half of them feel stress without enlightenment.

“When someone asks why I care for my wife, I answer because she is my “garwo” from the acronym “sigaring nyowo” or soulmate. Could you imagine if half of your body was sick? But my big problem is no one has completely taught me how to care. Sometimes I feel tired and stressed too, but I don’t know whom I could complain to. Because of that, I am just doing normally things, but more slowly because of my wife's impairment.”

(CG3, male, 65 years old)

“I often....mmmmm..... sometimes I just get angry with my mother if she rejects or disobeys my instructions. I am tired and stressed with my daily activities, and when it is time to care for her, my mother causes problems... so I use a harsh voice or slap her. I feel guilty after that, kiss her hands, cry, and say sorry. I never got information from health professionals about stress when caring and what I must do.”

(CG4, female, 58 years old)

Discussion

We have learned from the participants that the family is the most important element for stroke survivors and their caregivers in Indonesian Javanese culture. Some Javanese proverbs are embedded in several stroke survivors and their families, even though, in this study, they do not live on Java island. The family, not only their stroke caregivers, came as an important person inside the nuclear or extended family.

The first theme is unclear information before discharge planning. Some opinions from stroke survivors are that after their care in the hospital they did not receive clear health information related to stroke disease. In a community, just three stroke survivors discussed getting discharge planning, and just two stroke caregivers got it. The continuity problem for caring for stroke survivors in the community is cutting off the transmission of information for it. The caregiver is talking about how they don’t have enough information for managing the home care of stroke survivors.

Several benefits of discharge planning are improving patient satisfaction and independence from a hospital setting. Discharge planning is a complex system and needs the support of multiple health and care agencies. The actors who transfer knowledge, sources of knowledge, discharge forms, media about discharge, and culture are fundamental to promoting the discharge planning process's success.⁴⁸ In other cases, the clinician nurse shares knowledge and health information when asked questions.^{13,14,49} An ethnography study found that culturally competent discharge planning is important for effectively transitioning care from inpatient to home.⁵⁰ In other views, almost all clinician nurses said they needed more time for optimal discharge planning implementation, especially for stroke survivors and family caregivers.^{11,12} Health workers must be responsible for doing this, first, to minimize the occurrence of recurrent strokes and second, to prevent disease in the family as stroke caregivers.

The second theme is clear information from community nurses. Eleven stroke survivors used community nurse service. Of 24 caregivers, twenty caregivers have had a good experience using this service. Nurse S. is the only community nurse living in this field. Therefore, he is proud of a healthy society. He worked in a government hospital before becoming a community nurse. No stroke survivors and stroke caregivers are disturbed by his double profession.

The barriers are related to stroke survivors in a rural area with a hospital care setting, and the clinician nurse focuses on learning and teaching stroke survivors without involving their family caregivers.⁵¹ Therefore, specialists or treating physicians must share health information, including stroke education for stroke disease, rehabilitation, health services, and support organizations. Education programs between stroke and stroke caregivers provide increased understanding and promote communication.⁵²

Other literature found was different in this field of research. Here, community nurses instead focus on family caregivers. They saw the hegemony of stroke caregivers over stroke survivors. Almost all stroke sufferers are elderly, who, under normal conditions, need other support, even in the event of a stroke.

The third theme is family brotherhood. Muscle weakness is the biggest sign of stroke survivors in the area setting. Unfortunately, half of both stroke survivors and families are ignoring stroke signs, adding more distance to get a complete stroke health facility, and only two villages with a public transportation route. In addition, some stroke survivors and families must prepare extra money and infrastructure for stroke recovery in central town without time off.

Whereas the time for optimal motor recovery after a stroke attack is between 2 and 3 months.⁵³ The previous research promotes it, which transportation, finance, and knowledge of the stroke survivors and families as the caregivers are proven to delay stroke recovery.⁵⁴⁻⁵⁶ Stroke survivors who lived in nonurban areas had poorer key access to complete health service facilities for stroke care and treatments.⁸ In addition, healthcare access is particularly silent for stroke rehabilitation based on an ethnographic study in Taiwan.⁵⁷ Optimizing family empowerment with mutual assistance from the Javanese culture could be one of the problems solved. Family is not only brotherhood but also unity and relations, and they become one from several conditions, even if they do not stay in their hometown. Home visits are the fourth theme. Home visits inside of another support as PHC service. Before the COVID-19 pandemic, the PHC staff told for home visits around 12-14 stroke survivors in Palaran sub-district areas per day. But until research time, keep limited visits. Several private health facilities started services around October 2021. It differs from traditional healers who call anytime during a pandemic but keeps the second optional for stroke care services. Some problems, such as PHC staff just asked a routine activity for stroke survivors without adjustment or other suggestions for stroke survivors and families. Also, previous studies show that when the family requests a home visit facility, they must prepare an extra budget.⁵⁸ Home visits and support groups increased the knowledge among stroke patients by up to 50% and stroke caregivers by up to 45%.⁵⁹ Further, related community nursing in Italian fieldwork provided that community nurses could manage patients, especially elderly and older adults with chronic conditions.⁶⁰ The last is considering the cultural view. It has an embedded relationship with an assumption that moral failure persists in concepts of incomprehensibility, deviancy, and personal responsibility. Therefore, in the mental health survivor movement, as a consequence of psychiatric power, in this situation, a traditional healer is necessary.⁶¹ Additionally, seeking and understanding stroke survivors and caregivers rather than considering the health staff's experience of stroke care could improve home visits for stroke cases.⁶² One of the ideas for it is optimizing community empowerment by upgrading the skills of the health care staff needed to support health staff duty in the community. The fifth theme is the obstacle to government health insurance. Indonesia's government requires citizens to use government health insurance. In fieldwork, some stroke survivors and families as stroke caregivers have several opinions when using it. According to factual data, only two stroke survivors and four caregivers use that for stroke rehabilitation.

The dissemination of information related to the use of government health insurance must have been done in the past. The Healthy Indonesia Program, with one of its pillars, is the use of JKN, which is very relevant to the optimization of BPJS.^{63,64} Health financing inside the Strengthening National Health System coming to the strategic issue to achieve Indonesia's health development goals.^{53,65,66}

Regarding the government health insurance obstacle, the Indonesian President has renewed presidential decree number 82/2018 to presidential decree number 59/2024 today. The crucial change was deleted from the government health insurance (JKN) membership class, which was changed to KRIS (standard inpatient class). Based on that, I have two ideas. The first advantage of this policy is that it could decrease the stigma related to health services between rich and poor patients. However, the second disadvantage is increased payment for hospital care, and the last is criticism of customers' rights to health services. In addition, I prefer looking back for optimizations decentralization in Law No. 32/2004, which could manage harmony between de-concentration tasks and assisting tasks, thus reducing consumer payment and providing the best service based on the capability of the local area.

The last theme is counseling services for families. Several families have caregiver duties in the community: physical assistance, moral support, and finding assistance. Furthermore, five caregivers discussed obstacles to consultation regarding stroke rehabilitation and stroke caring times in a hospital setting. They must pay more for consulting services with the neurologist, and it comes to the hospital regulations in a private hospital.

Emotional, behavioral, and psychological issues have arisen regarding the role change to coming stroke caregivers. Several burdens regarding the new role in their family must be a problem-solving. The multiple responsibilities of stroke caregivers need care information from health professional staff. One treatment for families is family counseling or therapy.⁶⁷ The lack of a hospital not only knowledge from stroke survivors but also the families. It has correlated with decision-making for caring, which contributes to stroke survivors being alive.⁶⁸ Physical limitations, lack of communication, and burnout are several problems found for stroke caregivers in Jogja, Indonesia. Help maintenance and communicators to support stroke survivors, an essential role for stroke caregivers.⁶⁹

Much duty comes when someone gets a stroke in your family. Counseling services for families usually involve the discharge planning process. It is one of the important points for both stroke survivors and stroke caregivers to continue life in the community.

Conclusions

In conclusion, based on Javanese culture, where in this study, respondents do not stay in Java island, they have some opinions on stroke care. the first choice for stroke care and rehabilitation is on health facilities. However, some obstacles are coming up: the preparedness of stroke survivors and families as caregivers to get health promotion related to stroke care, health staff for the obedient scheduled visits, learning and teaching of stroke survivors and caregivers, and health insurance availability. Caring for stroke and family could be essential when all components are in synergy.

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Table 1. Characteristics of main participants (stroke survivors and stroke caregivers).

Characteristics	Stroke survivors (n=17)	Caregivers (n=24)
Gender		
Male	14 (82.4)	7 (29.2)
Female	3 (21.4)	17 (70.8)
Age		
35-40 years old		6 (25.0)
41-50 years old		6 (25.0)
51-60 years old	10 (58.8)	10 (41.7)
61-65 years old	7 (41.2)	2 (8.3)
Type of rehabilitation		
Alternative	6 (35.3)	
Alternative and conventional	11 (64.7)	
Level of education		
Elementary school	4 (23.5)	4 (16.7)
Junior high school	8 (47.1)	8 (33.3)
Senior high school	5 (29.4)	9 (37.5)
Diploma degree		1 (4.2)
Bachelor degree		2 (8.3)
Family economic status		
Below standard regional wage	8 (47.1)	16 (66.7)
Standard regional wage	9 (52.9)	8 (33.3)
Relation		
Spouse		13 (54.2)
Child		7 (29.2)
Brother/sister		2 (8.3)
Son-in-law		2 (8.3)

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