

# บุคคลที่เกี่ยวข้องกับระบบสุขภาพชุมชนสำหรับการดูแลผู้ป่วย ด้วยโรคหลอดเลือดสมองในอินโดนีเซีย\*

Agianto M.N.S.\*\* ขนิษฐา นันทบุตร PhD\*\*\*

# บทคัดย่อ

โรคหลอดเลือดสมอง เป็นสาเหตุการเสียชีวิตของประชากรโลกรวมถึงประชากรชาวอินโดนีเซีย และส่งผลต่อความ บกพร่องทางร่างกายและการเจ็บป่วยร้ายแรงซึ่งต้องการการดูแลในระยะยาวจากบุคคลในหลายๆ ฝ่ายเพื่อให้บรรลุเป้าหมาย ของการรักษา นอกจากนั้นยังมีความจำเป็นที่จะต้องผนวกแนวคิดทางการรักษาที่หลากหลายและการคำนึงถึงสภาพความ เป็นจริงของการรักษา เพื่อให้เห็นถึงบริบทและสภาพความเป็นโดยรวมอยู่ของผู้ป่วยด้วยโรคหลอดเลือดสมอง อย่างไรก็ตาม ที่อินโดนีเซียยังขาดกระบวนการในการดูแลผู้ป่วยด้วยโรคหลอดเลือดสมองจากหลายๆ ฝ่าย ทำให้บุคคลที่ควรจะมีส่วน เกี่ยวข้องเช่นอาสาสมัคร เพื่อนบ้าน และผู้นำชุมชนไม่ได้เข้ามามีบทบาทการดูแลผู้ป่วยด้วยโรคหลอดเลือดสมอง ดังนั้นการ วิจัยนี้จึงจัดทำขึ้นโดยมีวัตถุประสงค์เพื่อสำรวจบุคคลที่มีส่วนเกี่ยวข้องกับระบบสุขภาพชุมชนเพื่อการดูแลผู้ป่วยด้วยโรค หลอดเลือดสมองในอินโดนีเซีย การวิจัยนี้เป็นการวิจัยแบบชาติพรรณวรรณนาเชิงวิชาการ โดยมีผู้ให้ข้อมูลหลัก 64 คน ใช้วิธีการเลือกกลุ่มตัวอย่างแบบเจาะจง เครื่องมือที่ใช้ในการวิจัย ประกอบด้วย การสังเกต การสัมภาษณ์เชิงลึก และการสนทนากลุ่ม การวิเคราะห์ข้อมูลใช้วิธีการวิเคราะห์เนื้อหา

ผลการศึกษาพบว่ามีบุคคลที่เกี่ยวข้องกับการดูแลผู้ป่วยโรคหลอดเลือดสมองทั้งหมด 8 กลุ่มในเมืองบันจาร์มาซิน ประเทศอินโดนีเซีย ประกอบด้วย ผู้ให้การดูแลในครอบครัว ผู้ให้การดูแลนอกครอบครัว บุคลากรสุขภาพ เพื่อนบ้าน เพื่อน หมอนวด อาสาสมัคร และผู้นำชุมชน ซึ่งแต่ละกลุ่มมีบทบาทและหน้าที่ในการดูแลผู้ป่วยแตกต่างกันออกไป รวมทั้งมีความ สำคัญต่อการจัดการดูแลผู้ป่วยด้วยโรคหลอดเลือดสมอง ซึ่งการทำงานของพยาบาลเพียงฝ่ายเดียวนั้นไม่เพียงพอการจัดการ ระบบสุขภาพชุมชนสำหรับผู้ป่วยด้วยโรคหลอดเลือดสมอง ดังนั้นการทำงานโดยผนวกวิธีการที่หลากหลายจากหลาย ๆ ฝ่าย จะช่วยให้การดูแลบรรลุผลได้โดยง่าย

คำสำคัญ: บุคคลที่เกี่ยวข้อง ระบบสุขภาพชุมชน โรคหลอดเลือดสมอง อินโดนีเซีย

<sup>\*</sup>รายงานวิจัยฉบับนี้เป็นส่วนหนึ่งของวิทยานิพนธ์พยาบาลศาสตรดุษฎีบัณฑิต (หลักสูตรนานาชาติ) คณะพยาบาลศาสตร์ มหาวิทยาลัยขอนแก่น

<sup>\*\*</sup>นักศึกษาระดับดุษฎีบัณฑิต คณะพยาบาลศาสตร์ มหาวิทยาลัยขอนแก่น

<sup>\*\*\*</sup>ผู้ช่วยศาสตราจารย์ คณะพยาบาลศาสตร์ มหาวิทยาลัยขอนแก่น



# People who are Involved in Community Health Care System for Stroke in Indonesia

Agianto M.N.S.\* Khanitta Nuntaboot PhD\*\*

#### Abstract

Stroke is high incidence, cause of death in the world, and Indonesia. Stroke has disability problem and serious illness. It needs long-term care and many people to involve in nursing care to achieve the goal. Multi perspectives and realities to see the whole contexts and cultures scenes of people who stay with stroke patients in community is necessary to explore and develop the community care system for patients with stroke. Indonesia did not involve the volunteer, neighbors, and community leader as part of multidisciplinary team in care system of stroke patient. The objective of this study is to explore the people who are involved in community care system for stroke in Indonesia. A critical ethnography employed in this study with 64 key informants, used purposive sampling. There were three methods that used: participant observation, in-depth interview, and focus group discussion. Content analysis such as transcript, coding, typology, matrix analysis, and thematic analysis were used.

There are eight groups of people who are involved in community stroke care in Banjarmasin, Indonesia. They are family caregivers, no family caregivers, health workers, neighbors, friends, masseurs, volunteers, and community leaders. They have different roles and function during care the stroke patients. Role and functions of each person plays necessary in stroke management in community. Independent activity is not enough for nurses to work and implement the care system in community for stroke. They have to compile the method to make easily the program.

Keywords: Stakeholder; community health care system, stroke, Indonesia.

<sup>\*</sup>A part of Thesis of PhD in Nursing (International Program) Faculty of Nursing, Khon Kaen University

<sup>\*\*</sup>Ph.D. student, Faculty of Nursing, Khon Kaen University

<sup>\*\*\*</sup>Associate professor, Faculty of Nursing, Khon Kaen University



#### Introduction

Stroke in the world and in Indonesia are high prevalence as one of the communicable diseases. Mortality and morbidity are high number in this case with prevalence rate 795,000 people. This event is the fourth leading cause of death from 1992 to 2015 in ASEAN, and the top one in Indonesia<sup>1,2</sup> The prevalence rate in Indonesia increased from 2007 to 2013, and South Kalimantan is top four.3 Stroke event is higher in Banjarmasin especially at Ulin General Hospital as the tertiary hospital in South Kalimantan<sup>4,5</sup>

Stroke needs long-term care because of the disability and leading cause of serious illness. 6-11 The stroke survivals are functionally independent (50% to 70%), have disability (15% to 30%), need long-term care after three months attacks (26%). These impact to patients themselves and the families. 12 Not only that, stroke also has problem in medical care, rehabilitation, food, social and daily activity, financial, home and welfare, transportation, health care services, and universal health coverage. Collaboration in multidisciplinary is needed to achieve the maximum outcomes. 13,14 Multi perspectives and realities to see the whole contexts and cultures scenes of people who stay with stroke patients in community is necessary to explore and develop the community care system for patients with stroke.

Multidisciplinary team have responsibility in stroke management. A good team for stroke management is necessary to prevent stroke attack, minimize complication, and decrease mortality and morbidity. 13 An interdisciplinary team should provide the patients with stroke because of the unique demands on that population. 15 Stroke patients stay for long time at their home, accompanied by family caregiver to support and assist them every day. The caregivers need people who stay around them such as volunteers, family members as caregivers, neighbors, and community leader to help their role and responsibility to provide care the patients. In fact, Indonesia did not involve the volunteer, neighbors, and community leader as part of multidisciplinary team in care system of stroke patient. Contrary in Thailand, the government involved volunteers and community leaders to help the stroke patient. Moreover, the few studies about stroke care in Indonesia are other reason for this study. 4,5,16,17

Indonesia has the existing system for stroke, particularly in hospital but not in community setting. However, the system for stroke in community is very essential to minimize the number of prevalence. The prevention to get the recurrent stroke is a significant to minimize it. The care system of stroke patient in community consists of home, community, primary care unit (PCU), private clinic, secondary and tertiary hospital, private hospital, and traditional practice for massage. Stroke patients stay at their home and need long-term care from people who stay around them. The people who are in community, they will help them. They are family caregivers, volunteers, community leaders, masseurs, neighbors, friends, nurses, and other PCU-workers. Their demands are very necessary to explore before make a system of care for stroke.

Stroke survivals need attention from health personnel and people around them including family caregivers, volunteers, and community leaders. Stroke patients stay in their home with their family, spouse or may be alone. The health professional should help this group to prevent the recurrent stroke, to minimize readmission to hospital, to prevent complication, to decrease number of prevalence, and to improve quality of life. Caregiver is a part of multidisciplinary in stroke management.<sup>13</sup>

# **Objectives**

This study is to explore the people who are involved in community care system for stroke in Indonesia.

# **Research Methodology**

A critical ethnography employed in this study to describe and interpret how the behavior of people is influenced by the culture they live in and capture the social interactions within community<sup>18-20</sup> especially on stroke patients in Indonesia. This study implemented in community setting of Banjarmasin which is tertiary hospital (has stroke unit existed), a primary care unit (Puskesmas) that closed to the tertiary hospital, a private neurology clinic, traditional treatment for massage, and house hold with stroke patients. The study was started from December 17, 2016 to July 15, 2017. There were 64 key informants



in this study including 15 family caregivers, 12 patient with strokes, 8 nurses, 2 medical doctors, 6 volunteers (cadres), 5 neighbors, 6 community leaders (3 Ketua RT, 2 Ketua RW, and 1 Lurah), 4 masseurs, and 6 friends of stroke patients. Purposive sampling was used for selecting key informants who met the study's eligibility criteria. Data collected until saturated.

Inclusion criterias were 18 years old and over; family caregivers who currently living and taking care of a family member, has experienced the first occurrence of stroke (all types of stroke), and need practical assistance with ADL when discharge from hospital, had a kinship with stroke survivors; patient strokes with the first or recurrent stroke and stay at home; able to speak, and willing to participate in this study. The exclusion criterias were those who diagnosed to have terminal illnesses; have a history of substance abuse; and have a history of major debilitating diseases, such as alcoholism and dementia.

The researcher used field note, recorder, and a structure interview guideline to gather in-depth information in this study. A structure interview guideline was made by researchers based on the concepts, references, and approved by experts who were expertise in qualitative study especially ethnography study as well as in stroke care. Content analysis in this study used transcript and coding the data, typology, matrix analysis, thematic analysis, and engaging with and integrating to the related literatures. There were three methods for data collection in this study such as participant observation, in-depth interview, and focus group discussion.

- a. Researcher found a gate keeper before enter to the study site. Then, she helped the researcher to identify the key informants as selection criteria. Explanation and information had given to them before sign the informed consent. After that, researcher started to collect the data from participant observation activity that implanted from 17 December 2016 to 28 May 2017 to observe their daily activity to provided stroke patients.
- In-depth interview, researcher interviewed the key informant (family and non-family caregivers, health workers, volunteers (cadres), stroke patients if they could speak, community leaders, neighbors, friends, and

masseurs) using a structured interview guideline. The in-depth interview did about one hour for each key informant and conducted at their own place or home. Types of question that used for interview were general question, specific question and other question which was related to research questions. In depth interview conducted from 28 May-30 June 2017.

c. Focus group discussion (FGD), there was 4-10 key informants for each group in a face to face setting who engage in a series of discussion. Researcher was a moderator or facilitator in this activity to control the flow of discussion. FGD conducted during 1-15 July 2017 with separate group and implementation for each group of key informants.

Ethical Consideration: The study was approved by ethical committee (IRB) of Khon Kaen University, Thailand. The information about the study objective and procedure were provided to the potential informants. They signed the consent from when they were still interested in participating.

Trustworthiness: Credibility addressed the issue of whether there was consistency between the participants' views and the researcher's representation of them. Credibility had enhanced by the researcher describing and interpreting my experiences as researcher, and also by consulting with participants and allowing them to read and discuss the research findings. The researcher clearly followed the trail that used by the investigator and potentially arrive at the same or comparable conclusions. The researcher used dependability for each stage of the research to be traceable and clearly documented. Researcher also saw the findings could 'fit' into other contexts or not, and also saw the readers can apply the findings to their own experiences or not.

## **Result and Discussion**

There are eight groups of people who are involved in community stroke care in Banjarmasin, Indonesia. They are family caregivers, no family caregivers, health workers, neighbors, friends, masseurs, volunteers, and community leaders.



#### Family caregivers

Family caregiver is someone who is responsible for the physical, emotional, and financial supports of the family member who unable to care for him/herself due to illness, injury or disability. They play a major role in the nursing system and health care arena. They may work in close association with physicians, nurses, and other health care provider. Physicians have an important role in phase three of stroke (discharge planning), which help patients and caregivers adjust to their new way of life. The essential in caring the patients is maintain the wellness while encourage the self-care abilities on patients, family, and community.

Family caregivers help the patient every day at home for daily activity such as personal hygiene, spiritual activity, doing rehabilitation at home with simple exercise, and also brought the patient to check up to health care facilities such Puskesmas, hospital, and private clinic for neurology (Participant observation from 5 January-13 May 2017).

Family caregivers have big roles in nursing care of stroke in community and at home. They stay for long time with patients and have their own responsibilities every day. There are many roles and functions of family caregivers including helping the patient's personal hygiene, sweeping and cleaning the house, helping to do spiritual activity, cooking and offering the food, washing the clothes, preparing and buying the medicine to pharmacist, puskesmas, or hospital. They also help the patient to do active and passive rehabilitation at home. Trying to bring the patient to health care facility is one of their roles when the patient needs to check up the condition to doctor or health workers.

"Daily routine care is our responsibility and this is our obligatory to help stroke patient at home. As a part of family member, we should do these such as helping him/her for personal hygiene, sweeping the floor, cooking and offering the food, washing the clothes, and buying medicine to pharmacist. If he/she needs to go to Puskemas or hospital, we bring him/her by motor bike or becak." (FGD: Caregiver group)

There are many family members who are involved in this caring such as son, daughter, son-in-law, daughter-in-law,

grand-son, grand-daughter, brother, sister, uncle, and aunt. Family is very important in Indonesia and it is very common for extended families, including grandparents, aunts, uncles and cousins, to live together in one place; however, as with many cultures, the nuclear family is becoming more popular in contemporary urban areas. That said, elders and unmarried siblings will often reside with their families, even in modern culture. <sup>24</sup> Traditional aged care was seen as the responsibility of the family; however, the demands on modern families can make caring for an elderly loved one difficul. <sup>24</sup>

"...there are many people in my family who help him such as my uncle and aunt, my children or his grand son and daughter. But I am always beside him because I stay at the same house. Another family such as my brothers and sisters and their children come here every holiday or weekend. But sometimes they also come when they want to come. If they are here, they help me to take care father. My family also helps to bring him to hospital by car. We do not have car, so I called my family." (Caregiver: Mrs. AL, 19 years old, June 2, 2017)

Good relationship in this culture still tight and keep each other in the family. They think that culture is having in whole family in Indonesia which is as one of responsibility to people who is sick. In Indonesia, the family is a key element in caring for the ill family member. It is a tradition and considered an obligation to take care of a family member who is ill, at home as well as during hospitalization. So, it is rarely we are facing the paid caregiver in a family. We will find it if the economic status of family is good enough or high level.

## Non family caregivers

An old stroke patient who stays together with busy family is different with not busy family. This family has no time to care the patient at home. They have to work at office or their working. They need someone who can take care the patient during they are working. That people are sister-in-law and paid caregiver. The formal caregiver is someone who provides care with payment.<sup>26</sup> Family will spend the money to pay the paid caregiver every month. Role of sister in law is not too many compare with family



caregiver. She helps for offering food and medicine only. But the roles and functions of paid caregiver are quite similar with family caregiver. Those are helping the patient's personal hygiene, sweeping and cleaning the house, helping to do spiritual activity, cooking and offering the food, washing the clothes, preparing and buying the medicine to pharmacist, puskesmas, or hospital. They also help the patient to do active and passive rehabilitation at home.

"We also need other people to help us when we are not at home, especially when I go for working in morning till afternoon. Because of our duty and have to work from Monday to Friday, we have to find someone and pay them to take care our mom at home. They can help us to clean the body of my mom, giving food, and may be sweeping the house too. We pay this person every month and Alhamdulillah he is so kind for taking care our mom during we work." (FGD: Caregiver group)

#### Health workers

Doctors and nurses who work at hospital and primary care unit (Puskesmas) are totally different for roles and function. Those who work at PCU more focused on prevention and promotion than curative and treatment. Nowadays, prevention and health promotion are necessary to reduce the disease especially chronic disease like stroke.1 Health workers including nurses and medical doctors at community level work to implement national program in health such as home visit or primary health nursing program. They work together among health workers in PCU for people in community. The shift from hospital-based care to community-based care requires the gather role of health care providers, family of patient, the public at large, and policy marker function as well.23 Home visit weekly implemented even they are so busy with another duties at PCU. But, cadres as volunteers help them to do that program. Health workers encourage the family and patients as well as the neighbors, community leader (Ketua RT and ketua RW) to concern with their healthy. Empowerment community is one of ways to implement the program. Nurses can provide support and teach effective coping strategies to deal with the stressful

situations because a stressful situation during caring can result in negative caring.<sup>27</sup>

"Health workers from "Puskesmas" (primary care unit) often come to the house, if routine, they will come every week. They usually check the health condition of mother, continue to give information to our family. They also suggested us to bring our mother to public health center. The health workers who came to our home are nurses, sometime involved doctors, and in a group which consist of doctors, nurses, midwifery, and community health workers. It depends on them..." (Caregiver: Mrs. SA, 33 years old, June 8, 2017)

Health care providers should integrate scientific, religious, and cultural knowledge into their clinical practice for promoting quality of life of family caregivers and their elderly stroke relatives.<sup>22</sup>

#### Neighbors

In Indonesia, especially in Banjarmasin, neighbors are people who stay around the house and have tight connection and relation with us. They look like our family. During daily activity, neighbors always contact and communicate with us. Chatting, sharing, communicating, discussing, helping, and other activity usual happen. This situation happens in happy or sad conditions such as health and sick phase. Particularly in sick situation, neighbors will help us. These occurred in stroke family situations. They come home to visit, give motivation, bring the food, help to bring a person who sick to health care facility, and sometime give or borrow money as well to the family.

"My father is always lonely all the time from morning to evening, because my husband and I have to work to earn money. So if I would go to work, I leave him to our neighbor. Thank goodness they want to help my father at home" (Caregiver: Mrs. SB, 38 years old, May 30, 2017)

"...there is no special helping anyway. But we noticed him by offering the food, switch on the house lights, massage, and buying drugs to pharmacies (money and types of drugs given patients to neighbors). We are as his neighbors are willing to help him. We are



who live around him will help him." (Neighbor: Mrs. Y, 35 years old, May 29, 2017)

For family in low economic status, and have no vehicle, neighbors usually help them and borrow their vehicles like car or motor bike to the family. It is for helping the family to bring patients to hospital, PCU, masseur, or others. It usually happens on nuclear family where is nobody else can help the family. Family caregiver is usually used alternately with informal caregiver and can include family, friends, or neighbors. Family caregiver extends beyond the traditional family boundaries.<sup>26</sup> If the spouse of patient has to work out side, the spouse needs neighbors helping to observe and do something to patient while the spouse work. The neighbors do that as volunteer and as their own family. This is a culture that usual happens in Banjar people. Help each other is one good thing from muslim religion. They believe it and internalize in their daily life. The religious community may be a source of support in the care of the elderly.24

#### **Friends**

Friends mean people who live around the home, or work at the same office, or join the same social activity, or classmate at school, or others. Neighbors also sometimes include as friends. Friends with high solidarity will give attention to their partners or friends in term happiness or sadness. They will share and also support each other in their live. In cultural pattern in Banjarese people, a good friend will help you in every situation particularly in bad situation. There is an Indonesia proverb "berat sama dipikul, ringan sama dijinjing" means that if weight is carried together, and if lightweight is carried together too. The religious community may be a source of support in the care of the elderly.<sup>24</sup>

Friends and colleagues come to visit the stroke patients even just several times. They talk and entertain the patient to minimize the stress because of disease. A warm relationship is seen between them. Good friend will show kindness for his/her friend who is sick. They come even just say hello and chat a bit. (Participant observation from 8 February-14 May 2017)

"...sometime she would meet her friends. She usually talks and joke with her friend even just a minute. She

felt happy and laugh after meet up. That is why she likes to join "yasinan" or "burdahan". We are family just support and try to help them to meet her friend. We can call her friend to have social spiritual activity at our home." (FGD: Caregiver group)

So, if there is someone who has problem, friend will care and help to come out from that problem. Friend will try to share the happiness to someone who has problem and try to give support, and motivation as well. Family, friends, and neighbors include alternately in informal caregiver. They usually help the family and patient at home especially if the patient and family have problem.<sup>26</sup>

#### Masseurs

One of technique in physiotherapy and as important part of rehabilitation in stroke management is massage.<sup>28</sup> Massage is one of complementary therapies in rehabilitation for stroke patient. This is very good effect for stroke patients especially for ischemic stroke.<sup>29</sup> Massage also gives impact to decrease anxiety, pain, and improve quality of health in order conditions of reduced health particularly stroke.<sup>30</sup>

Masseur is person who massages the people in community. They are not specific for stroke patients but for all people who need them in massage. They also do not have massage certificate. They have massage skill by nature and some of them get the skill from learning by doing with their friends. Massage is one of culture habit for Indonesian people especially for stroke patients. In Banjarmasin, people still believe that massage will help to recover the stroke quickly than without massage. They got information about massage from neighbors, relatives, family, newspaper, radio, television. But mostly they hear from people to people. They will go to masseur's home even far away. They also will go there by motorbike with the paralyze condition on stroke patient. Patient with stroke have massage every week, every two weeks, and sometime every month.

"...we did not bring him to traditional healer. We just brought him for massage only. While he had stroke attack in the beginning, he got massage from traditional masseur. The location is far away from here and located in Martapura. He felt better after



massage. It needs about 1-2 hours for massage. Initially he had once a week for massage. Then, every two weeks, and once a month, and now he has no massage at all..." (Caregiver: Mrs. AG, 31 years old, June 1, 2017)

Family and stroke patient strongly believe this method is very good in recovery for stroke. They use this method in their live as a pattern in stroke management. So, family and stroke patient always involve masseur in stroke management particularly for rehabilitation. Not only that, the masseurs also give topical herbal when they massage the patient. Furthermore, motivation is given by masseurs to family and patient such as using herbal, check up to doctor to combine traditional therapy and medical therapy.

"...I came to their house, because the patient was not able to move, so I was going there because requested by his family. The patient had been admitted to the hospital, but no progress for the stroke, then the patient would discharge and going back home. Then ask for massage, because patients feel better if get massage. So I went to his house to massage. The patient had complained to me too, so I told him (the patient) if it could be back to normal. Then after he (patient) feels comfortable, he called me again to request a massage. He says it feels good when he's taken a massage." (Masseur: Mrs. IT, 32 years old, June 11, 2017)

#### Volunteers

For each RT/RW area, usually there will be cadres as volunteers to help Posyandu. Posyandu is an extension of puskesmas that provides integrated health services and monitoring. Posyandu activities conducted by and for the community. Cadres are members of the community who are selected from and by the community, willing and able to work together in various voluntary social activities. Volunteers and cadres are the same thing in Indonesia. They work without salary for Posyandu and Puskesmas. They usually help health workers for home visit, encouraging the patients and families, giving motivation, helping the health workers to weigh the patient's body weight, and documenting the patient and family history at Posyandu.

Health workers always involved them for every activity in community.

"There was a "posyandu" near from our house and cadres as volunteers at Posyandu also often come to home and ask about the condition of mother. She was really good, told us to bring mama to check to posyandu because it is closer than having to puskesmas or hospital. The cadre sometimes comes for home visit with health care providers from puskesmas (public health center)." (Caregiver: Mrs. SI, 26 years old, June 28, 2017)

"... I and friend do this activity voluntarily. We would care to people around us. No salary for this job. We just help health workers from Puskemas (primary care unit) for home visit. But, one day we felt very happy when our "pustu" was the winner as the best Pustu in Banjarmasin. We have many data about our activity. We got price both money and trophy for that. So, if we work sincerely, we will get the best goal after that." (Cadre: Mrs. AL, 56 years old, June 10, 2017)

The study result shows the same thing from Health Department of Republic of Indonesia about role of the cadre is to informing the day and opening hours of Posyandu to the community; preparing equipment; registering the people who come; measuring and documenting the body weight; counseling to mothers; doing home visits; approaching government officials and community leaders; conducting Survey Mawas Diri (SMD) together with officers, among others; carrying out deliberations with local communities.<sup>31</sup>

# **Community leaders**

"Ketua RT" (village chief) and "Ketua RW" (hamlet chief) are kind persons who care the people in their area. They can help the people who need them in term giving a letter, empower the community, encourage the family, and help family to bring patient to health care facility such as hospital and PCU. If someone from outside of the community, and need to find someone who stays in their area, he/she can ask to Ketua RT or RW. We also can ask about their community situation. They know very well about the people and community condition. They like to have meeting among community people and discuss about



events in their live. They try to find solution and also help person who has problem.

"This is my responsible to help people who stay here. There are many kind things that I gave to them. It is depend on their need. Sometime I help the family who had problem with transportation, and also family with low economy level which need a recommendation letter from me to process supporting funding form government." (Community leader: Mr. JU, 58 years old, June 5, 2017)

They work as volunteer for the community. And the community follow him and help him to realize a good atmosphere in peaceful and harmonize. Community leader is a policy marker in their area and necessary to be involved in health management like stroke. The public at large, and policy marker function are required to work together with health care providers, family of patient at community-based care.<sup>23</sup>

"We did all thing with our voluntarily. Because those are our responsibility. If there are persons or family need us, we help them as much as we can. We want every people happy and live peacefully." (FGD: Community leader group)

# Conclusion

Multidisciplinary and multi perspectives in community care system for stroke in Indonesia are comprehensive to achieve the goal of nursing care in community for stroke. Helping each other with different roles and functions is strongly method in a system. This is a way to strengthen the community to involve them in a community care. They should work together to help the patient and family for enhancing the quality of life of patient and family.

#### Implications and Recommendations

Health workers as part of the model aspect can implement the collaboration activities among people who contribute in stroke care in community. As we know that work alone is not effective in the system, need other people to help the implementation of activity in a system. The people inside also need to coordinate with other components in the system as the essential approached.

Cross-sectional collaboration is one of way for health workers with local government. Independent activity is not enough for nurses to work and implement the care system in community for stroke. They have to compile the method to make easily the program such as collaborative and integrative intervention during the activities. Nurses do not only understand about the nursing care in community and hospital, but they also should learn and know the cross sector communication and connection especially to community leaders, and community organization.

# **Acknowledgement**

Researchers would like to thank to Directorate General of Resources for Science, Technology and Higher Education, Ministry of Research, Technology and Higher Education of Indonesia for providing the scholarship of this research.

#### References

- WHO.World health rankings life longer live better. Retrieved June 17, 2016, from: http://www. worldlifeecpectancy.com/indonesia-stroke; 2014.
- Aditama TY. 2015. Stroke is the leading of death in Indonesia. Health research and development of Ministry of Health. Retrieved from August 20<sup>th</sup>, 2015 from http://www.litbang.depkes.go.id/node/639
- Indonesia Basic Health Research. Basic health research. Jakarta: Health Ministry of the Republic of Indonesia: 2013.
- Agianto, Nuntaboot K. The supportive care needs of stroke caregiver during hospital stay at Ulin General Hospital South Kalimantan Indonesia. Journal of Nursing Science & Health 2013, 36 (3): 1-8.
- Agianto, Setiawan H. Supportive care needs of stroke caregiver at Neurological clinic in Banjarmasin, Indonesia. Dunia Keperawatan 2017; 5 (2): 107-114.
- Sreeraj K, Thomas I, Nampoothiri M. Balan CS. Prevalence of stroke complications in South India: a descriptive study. International Journal of Pharmacy & Technology 2012; 4 (1): 3859-3868.



- Kuptniratsaikul V, Kovindha A, Suethanapornkul S, Manimmanakorn N, Archongka Y. Complications during the rehabilitation period in Thai patients with stroke. American Journal of Physical Medicine & Rehabilitation 2008; 88 (2): 92-99.
- Ali M, Khan Y. Khan H. Complications of cerebrovascular accident in two tertiary care hospital of Peshawar, Pakistan. Iranian Red Crescent Medical Journal 2008; 10 (4): 261-266.
- Dewey HM, Bernhardt J. Acute stroke patients: Early hospital management. Australian Family Physician 2007; 36(11): 904-912.
- Doshi VS, Say JH, Young S.H-Y, Doraisamy P. Complications in stroke patients: a study carried out at the rehabilitation medicine service, changi general hospital. Singapore Medical Journal 2003; 44 (12): 643-652.
- Dewit SC. Medical-surgical nursing concepts & practice. St Louis, Missouri: Saunders Elsevier; 2009.
- Lewis SL, Dirksen SR, Heitkemper MM, Bucher L. Medical-Surgical Nursing: Assessment and management of clinical problems. Volume 2. 9<sup>th</sup> Ed. Canada: Elsevier; 2014.
- Hickey JV. Livesay SL. The continuum of stroke care:
  An interprofessional approach to evidence-based care. Philadelphia: Wolters Kluwer; 2016.
- 14. MacIsaac L, Harrison MB, Buchanan D, Hopman WM. Supportive care needs after an acute stroke: a descriptive enquiry of caregivers perspective. Journal of Neuroscience Nursing 2011; 43 (3): 132-140.
- Corrigan ML, et al. Handbook of clinical nutrition and stroke, nutrition and health. New York: Springer; 2013.
- Dharma KK. The effectiveness of adaptation model intervention among post stroke (IMAPS) on adaptation response and quality of life of post stroke. Dissertation. Faculty of Nursing, University of Indonesia: Unpublished; 2015.
- Pangastuti HS. Model development of stroke patients to increase the independence of the management of risk factors for recurrence stroke. Dissertation. Faculty of Nursing, University of Indonesia: Unpublished; 2016.

- Moule P. Goodman M. Nursing Research: An Introduction. 2<sup>nd</sup> Ed. London: Sage; 2014.
- Atkinson P, Hammersley M. Ethnography: Principles in Practice. 3<sup>rd</sup> Ed. New York: Routledge; 2007.
- 20. Reeves S, Kuper A, Hodges BD. Qualitative research methodologies: ethnography. BMJ 2008; 337: 1-3.
- National Alliance for Caregiving [NAC]. 2010. Care for the family caregiver: A place to start. Retrieved from August 15, 2017, from http://www.caregiving. org/data/Emble m\_CfC10\_Final2.pdf
- Subgranon R. Caregiving process of Thai caregivers to elderly stroke relatives: A grounded theory approach. Dissertation. University of Utah; 1999.
- 23. Annisa F. Burden of family caregiver. Belitung Nursing Journal 2016; 2 (1): 10-18.
- 24. Moffatt, A. Indonesian Culture Profile. Australia: Diversicare; 2012.
- Effendy C, et al. Family caregivers' involvement in caring for a hospitalized patient with cancer and their quality of life in a country with strong family bonds. Psycho-oncology 2015; 24: 585-591.
- Lubkin IM. Larsen PD. Chronic illness impact and intervention. 8<sup>th</sup> Ed. USA: Jones & Bartlett Learning; 2013.
- Bostrom AC, Boyd MA. Schizophrenia. In M. A. Boyd (Ed.), Psychiatric nursing: Contemporary practice (3rd. ed., pp. 265-310). Philadelpia, PA: Lippincott Williams & Wilkins 2005.
- 28. Stroke Association. Physiotherapy after stroke. Stroke Association; 2012.
- Riet PVD, Dedkhard S, Srithong K. Complementary therapies in rehabilitation: stroke patient's narratives.
   Part 2. Journal of Clinical Nursing 2011; 21: 668-676.
- Lamas K, et al. Does touch massage facilitate recovery after stroke? A study protocol of a randomized controlled trial. Complementary and Alternative Medicine 2016: 16-50.
- Health Department of Republic of Indonesia. 2003.
  Pedoman Pengelolaan Kesehatan di Kelompok Usia Lanjut. Jakarta: Depkes RI.