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# THE DAILY LIFE OF POST-STROKE PATIENTS IN TOMOHON CITY, NORTH CELEBES, INDONESIA

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Stroke, in this case paralytic stroke, is a sudden paralysis caused by a brain injury. As a result of paralysis, post-stroke patients will have physical, psychological and social limitations that affect their quality of life. As a consequence, patients need help from others, especially from their family to go through their daily activities. This study aimed to show the prevalence and characteristics of post-stroke patients and describe their daily life pattern of activities in Tomohon City, Indonesia. Data were collected through in-depth interviews with observations from five participants of family members who had experienced stroke. Results of this study indicated changes in the life of post-stroke patients in terms of their daily activities, eating habits, and family communication patterns. As a result of physical weakness the daily life of the five participants was limited only to home activities. Food preference and consumption were also affected. Both participants and caregivers perceived that the emotional sensitivity they had developed and the changes in terms of family roles frequently led to misunderstandings between the patients and the caregivers.

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**KEYWORDS:** daily living pattern, stroke, Indonesia

## INTRODUCTION

STROKE IS A paralysis that results in a disturbance of cerebral function (focal or global) and lasts for more than 24 hours, and may cause death caused by vascular disorders (Truelsen, Begg, & Mathers, 2000). The result encompasses disorder function in cognitive, physical, socio-emotional and/or communication aspects affecting daily activity in the long term (Miller et al., 2010). Approximately 50 million stroke survivors worldwide must overcome the physical, cognitive disorder, and emotional deficits; 25-74% of these patients need assistance partially or depend completely on caregivers for daily life activities (Miller et al., 2010). The Riset Kesehatan Dasar (Research of Basic Health) of Indonesia in 2007 listed stroke as the first cause of death in all ages (Departemen Kesehatan Republik Indonesia [Department of Health of Indonesia], 2009). The prevalence of stroke in Indonesia in 2008 was 8.3% with 6% diagnosed by the health worker (Badan Penelitian dan Pengembangan Kesehatan [Department of Research and Health Development], 2008).

North Sulawesi was ranked as the fourth province in national stroke prevalence with 8.5% based on clinical diagnosis (Dinas Kesehatan Provinsi Sulawesi Utara [North Celebes Provincial Health Department], 2009). The top three provinces in terms of stroke prevalence are NAD (10.4%), Riau (10.1%), and Jakarta (9.4%). Compared to the average national prevalence which was 6%, the prevalence of stroke was higher in North Sulawesi. Also, the percentage of stroke symptoms in North Sulawesi reached 10.4%, which indicates a higher mean compared to the national average which was only 8.3% (Dinas Kesehatan Provinsi Sulawesi Utara [North Celebes Provincial Health Department], 2009).

Tomohon, 23 km from the provincial capital of North Sulawesi, Manado, had a prevalence of 4% of stroke based on the clinical diagnosis. This number was below the average prevalence of North Sulawesi, which was 8.5%. However, when compared to the number of those who have the symptoms of stroke, the prevalence of Tomohon was 11%, slightly higher than the 10.4% average prevalence of North Sulawesi (Dinas Kesehatan Provinsi Sulawesi Utara [North Celebes Provincial Health Department], 2009).

According to Van Eeuwijk's study in 2005, majority of the patients in Tomohon, Tahuna and Manado had post-stroke

paralysis and weak movements caused by hyperuricemia. Consequently, they were depending on others with daily life activities such as washing of clothes, dressing, taking a bath, and eating. Van Eeuwijk's (2005) study focused on long-term care of elderly who suffered due to the weakness of the body caused by aging and/ or several illnesses.

### **Prevalence and Description of Stroke (and Related Diseases) in Tomohon City**

The Head of the Tomohon Health and Social Department informed that there was a total of 222 post-stroke patients in 7th Tomohon Health Center, of which 209 patients were with ischemic stroke and 13 patients with hemorrhagic stroke in the year 2010. Based on the Tomohon Health and Social Department's record, the stroke profiles were categorized as Blood Vessel Disease and Hypertension. The data on hypertension provided clues about the possibility of stroke prevalence in Tomohon. North Celebes Provincial Health Department (2009) reported that hypertension had the highest rank among 10 major diseases in Tomohon (41.6%). Hypertension was ranked first (33%) of 10 major diseases in the Health Centers<sup>1</sup> (Dinas Kesehatan dan Sosial Kota Tomohon [Department of Health and Social of Tomohon], 2011). Similarly, hypertension ranked first as the most prevalent disease for inpatients (22%) and ranked second for outpatients (16.5%)<sup>2</sup> at Bethesda Hospital and Gunung Maria Hospital (Dinas Kesehatan dan Sosial Kota Tomohon [Department of Health and Social of Tomohon], 2011).

A visit to 7 Health Centers namely Kakaskasen, Lansot, Taratara, Matani, Tinoor, Pangolombian, and Rurukan was conducted. The results showed a total of 51 post-stroke patients in 7th Tomohon Health Center during January to June 2011. Majority were 65 years old or older (62.7%), were female (58.8%), had ischemic stroke

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<sup>1</sup> The 10 top diseases are hypertension, acute respiratory tract infections, tonsillitis, gastritis, musculoskeletal system diseases, upper respiratory tract infection, allergic skin diseases, skin infections, diarrhea, and lower respiratory tract infection.

<sup>2</sup> The dominant diseases of in-patients are dyspepsia, typhoid, heart disease, diabetes mellitus, urinary diseases, dengue fever, sepsis, and tuberculosis. While the dominant diseases of outpatient are acute respiratory tract infections, hypertension, refractive disorders, diarrhea and gastritis, dyspepsia, skin diseases, diabetes mellitus, cataracts, typhoid, and ear diseases.

(94.1%), had hypertension (70.5%), and had children as caregivers (80.3%). Three post-stroke patients had recurrent stroke resulting to hemorrhagic stroke. Forty-nine out of 51 patients with post-stroke had one or more related disease diagnosed by physician, in terms of hypertension, hyperlipidemia, hyperuricemia, diabetes mellitus, heart disease, and lung complications. Most of them had weak left (21.4%) and right (37.2%) side of the body. The others had weak body movement including weak limb or hand muscle, left-sided facial nerve paralysis, difficulty swallowing, slurred speech, and hyper salivation. However, there was one patient with no physical limitations. Also, there were three patients with no data about their physical post-stroke condition.

The physical limitation made the patients dependent on others. Their daily activities were limited, mostly around the house. Moreover, social interaction became less.

## Stroke Treatment

Post-stroke treatment that patients undergo in Tomohon is varied. Generally, stroke patients directly go to the hospital. Then they are referred to a neurologist, do regular physical exercises with a physiotherapist, or choose other alternative treatments. *Ceragem* has been a popular alternative treatment in Tomohon for the past five years. It makes use of long distance beam infrared passing through jade to a certain body point in order to accelerate blood circulation and chemical processes in the body. Post-stroke patients have learned to exercise their body in *Ceragem*.

Tomohon Health and Social Department and two hospitals have made effort to manage stroke. Two Hospitals in Tomohon have provided infrastructure facilities and specialists of neurology for stroke treatment. Unfortunately, the health centers do not have the same facilities as the hospital. Only one of seven health centers, namely Tara-tara Health Center has complete supporting facilities for post-stroke rehabilitation. In addition, physiotherapist, nurse, and physician have also collaborated to address post-stroke patients' needs. Physiotherapists provide physical exercise, perform infrared radiation, and conducted educational awareness on stroke treatment. Nurses provide direct care to post-stroke patients while doctors do so in curative phase. Tomohon Health Department has an active role in stroke treatment on preventive action and promotion programs, namely

URSILA (program for elderly), PERKESMAS (community health care), SUMAPUT (control nutrient input and prevention against cardiovascular disease), and exercise activity and health promotion programs collaboration with the church.

However, several obstacles hindered the implementation of post-stroke rehabilitation process. There were two obstacles that prevented post-stroke patients to avail of Tomohon's medical program. One obstacle was the unavailability of someone who could accompany patients to visit the health center for routine check-up. Second, patients' family members lacked information on stroke treatment.

The people who are with the post-stroke patients most of the time, particularly caregivers, are affected by the stroke. The local context and background culture can influence the interaction pattern of post-stroke patients and caregivers. It is therefore important to identify the daily life of post-stroke patients and their caregivers within the context of a particular culture and locality. This paper assessed the daily life pattern of patients with post-stroke in Tomohon City which included the prevalence and characteristics of post-stroke patients and the daily life activities pattern of post-stroke patients in Tomohon City, Indonesia.

## METHODOLOGY

The study used a qualitative-descriptive method. It was conducted in June to July 2011 in Tomohon City. There were two stages used in determining the sample. First, an interview with the physiotherapist, who did home care for post-stroke patients at health centers, was conducted. There were 11 post-stroke patients who qualified and met the characteristics of the participants: those who were not hospitalized, did not have poor prognosis, did not have cognitive and linguistic impairment, and have been taken care of by family members for more than six months. Second, interview and direct observation were conducted on 11 post-stroke patients. Five participants were chosen. The others were not selected due to the following reasons: 1 patient had inability to recall past events; 1 patient did not have stroke as the CT-scan showed no ischemic or infarct tissue in the brain; 1 patient had difficulty speaking (dysphagia); 1 patient was not taken care of by a family member; 1 patient was hospitalized at Bethesda GMIM

Hospital, and the other one was taken care of by family members who work as farmers until 6 pm everyday which made it difficult to meet the caregivers.

The five participants had undergone neurological assessment and in-depth interview. Neurological assessment included [1] the cerebral function in mental status, intellectual functioning, language skills, logical thinking, emotional status, perception and motor skills; [2] the cranial nerves assessment, nervous I-XII; [3] the motor system balance and coordination, and Romberg test; [4] the sensory system of tactile sensation, pain and temperature, vibration and proprioception, which feels the sensation of position and integration; and [5] the status of the reflexes—triceps reflex, biceps reflex, brachioradialis reflex, patellar reflex, achilles reflex and response babinski.

Information obtained during the interview with the participants included [1] health profile (the impact of post-stroke, health-related problems, stroke type, recurrent stroke, stroke factors, caregivers, and stroke treatment); and [2] patterns of daily life (daily activities, eating habits, and family communication pattern between the participants and their caregivers). Interview was also conducted with caregivers and physiotherapists in order to create triangulation. Post-stroke rehabilitation in Health Centers Tomohon focused on physical exercise prepared by a physiotherapist. Physiotherapists recorded the health status of the post-stroke patients.

The participants were Mr. A (45 years old), Mrs. B (55 years old), Mrs. C (78 years old), Mrs. D (73 years old) and Mrs. E (72 years old) (see Table 1). Each participant had specific characteristics: [1] Mr. A (45 years) suffered from recurrent stroke and had emotional sensitivity. Based on the assessment neurology, Mr. A had dysphagia and could not hold emotion when questioned about his feelings towards his illness; [2] Mrs. B was depressed after her husband's death. Mrs. B had two jobs and worked hard until she did not have enough time to take rest; [3] Mrs. C had stroke and suffered over the past 10 months, and it was the shortest time compared to the other patients; [4] Mrs. D had never been hospitalized; and [5] Mrs. E fully depended on others in carrying out daily activities.

The data obtained were analyzed through open coding then categories were created. Abstractions were explained by using descriptive approach. Interview transcriptions were analyzed

until no new information was observed.

## RESULTS

### Study Participants' Profile

In-depth interview was done with five study participants (Table 1), three of whom were of working age (45-65 years old) and two, older adults (over 65 years old). Three participants had family members with stroke and degenerative diseases as follows: Mr. A's parents had diabetes mellitus and his sisters had stroke; Mrs. B's father and sister had stroke; Mrs. C's family had hypertension, diabetes mellitus, and stroke; Mrs. D and Mrs. E did not have family history of disease.

Extreme fatigue and too much burden were the major factors that triggered the onset of stroke as reported by the study participants. Three of the five participants claimed that stroke was triggered by fatigue while one said it was due to fatigue and too much burden, and one said it was due to too much burden. Two participants worked hard and did not have enough time to take rest (*e.g.*, Mr. A was a truck driver while Mrs. B was a hair stylist and tailor). Mrs. E was tired from traveling between cities within a week. Furthermore, Mrs. B was stressed after her husband died. She used her time to work. Mrs. D was depressed caused by her daughter who could not marry her partner even if they had already 3 children. They have different religion so her partner's mother was against their relationship.

### Eating habits

Observed and interviewed with the Head of Tomohon Health and Social Department, physicians, nurses, physiotherapists, study participants generally consume red meat, saltwater fish, and alcoholic drinks. This is supported by the fact that almost every Saturday and Sunday, they have a party serving all meals namely, pork, dog meat, bat and white rat meat, tuna fish, and vegetables.

Mr. A's eating habits changed after his stroke attack. When he suffered first stroke attack, he lost appetite and could only finish half of the food served. After recovering from the first attack, he felt better and was then able to finish one or more food served. He



Table 1. Profile of Study Participants in Tomohon City, Indonesia (N=5).

Initials	Highest educational attainment	Health history in last 10 years	Family health history	Kind of stroke	Trigger of stroke onset according to client	Length of suffer with stroke	Physical impact after stroke
Mr. A (45 years)	Junior High School	Recurrent stroke, HTN, and hyperlipidemia	Stroke and DM	Ischemic stroke	Fatigue	5 years	Slurred speech, hyper salivation and left-sided hemiparesis
Mrs. B (55 years)	Junior High School	Stroke, HTN, and hyperlipidemia	Stroke and HTN	Ischemic stroke	Burdened and fatigue	5 years	Right-sided hemiparesis
Mrs. C (78 years)	Junior High School	Stroke, HTN, and hyperlipidemia	Stroke, HTN, and DM	Ischemic stroke	Fatigue	10 months	Right-sided hemiparesis
Mrs. D (73 years)	Elementary School	Stroke, HTN, and hyperlipidemia	None	Ischemic stroke	Burdened	3 years	Right-sided hemiparesis
Mrs. E (72 years)	Senior High School	Stroke and HTN	None	Ischemic stroke	Fatigue	3 years	Right-sided hemiparesis



ate twice per day except when he was taking the medicine that made him eat thrice daily. He said:

*I ate more than 1 kg of pork. I loved to eat pork and drink saguer before I had the first stroke. I consumed 7-8 bottles of saguer [an alcoholic palm sap from Palm Sugar plant (Arenga pinnata)], 1 bottle of cap tikus [traditionally distilled saguer], and ate lots of durian before. After the stroke, the doctor advised me to limit the meat consumption, so I ate more vegetables, usually boiled vegetables and grilled fish, fish with soup and sometimes fried fish. I love to eat fish with spicy sauce but it's too oily so I prefer grilled fish. I also quit smoke. (Mr. A, age 45)*

Mrs. B consumed a lot of pork or dog meat, rice, and oily food. After she got stroke, she was worried about her weight. She decided to go on diet and limit food consumption. She ordered food through catering. Her daughter sometimes cooked for her. The menu was rice, food with sauces, gohu (typical food of Tomohon, with the half-ripe papaya, water, salt, red sugar, ginger and chili). She consumed pork once a week. She stated:

*I loved to eat dog meat (RW) and pork that is why I had stroke. After the stroke, I only consumed small serving of pork per week. The doctor said I have to maintain my cholesterol and sugar level because sometimes my cholesterol and sugar level are low. I am too worried with my blood pressure, but the doctor said I have to eat so I can have energy. As for the daily food, I have catering and when I got bored of the menu, my daughter cooks for us. I prepare for my own breakfast in the morning. Boiled and fried vegetables with sauce and rice are my usual food. I take 12.5 mg of captopril every morning and consumed traditional herb and vitamins after the breakfast. (Mrs. B, aged 55)*

Mrs. C rarely consumed fried food because she had high blood cholesterol. Before, she consumed rice, pork and oily food. Also she drank 1 cup [1 grem in the local] of cap tikus (traditional distilled saguer) per day. After the stroke attack, she controlled her diet. She was able to eat half of the food served and drank two glasses of water per day. She seldom drank water because she was afraid that she needed to urinate often. In addition, her diaper was replaced only at 3 pm and 6 pm. She felt uncomfortable with

a wet, full diaper. Her daily menu was porridge for breakfast, fried fish/vegetable stewed or boiled without sauce for lunch and dinner. She said:

*I am able to finish one half of the meal served. I have high cholesterol, so I limit the consumption of fried food. In the morning, I eat porridge while in noon I eat fried or boiled fish and boiled vegetables. After the stroke, I don't have much appetite anymore. I decided to limit the consumption of oily food even without the advice from doctor. I drink cap tikus a bit only so I can feel a bit warm. I only drink 1 bottle of coke and that was before my sickness. (Mrs. C, aged 78)*

Mrs. D consumed rice or potatoes, boiled vegetables and fish. She also drank 1-2 bottles of *saguer* per day. She ate thrice per day. Her menu was cassava, boiled vegetables, and fish. She could finish her served food. Sometimes, she consumed snacks like boiled potatoes or bananas between breakfast and lunch. She did not consume fried food and pork. She was an occasional alcoholic drinker with maximum of two glasses but after the stroke, she quit. She stated:

*I eat saltwater fish and vegetables, but I do not really like fish so I only eat some part of it. I eat rice for breakfast until dinner. When I got bored with rice, sometimes I change it with cassava. I can finish one serving; I usually eat fish and cassava. Sometimes I only eat two tablespoon of rice then I changed it with boiled banana and vegetables. In the past, I consumed 1-2 glass of *saguer* but I quit after I got stroke. I do not smoke, even before the stroke. (Mrs. D, aged 73)*

Mrs. E also loved to eat red meat, especially pork and oily food. She ate thrice daily. She consumed fried banana, fried cassava, or cookies between meals. However, she was able to finish only a quarter of the food served. Her daily menu after the stroke was rice, fish and vegetables. She said:

*I enjoyed eating pork before but for now I only ate vegetables, mostly boiled vegetables. I eat three times a day. After my breakfast sometimes I eat snack. At 3 pm I usually eat cookies, fried cassava, or fried banana. Also, I sometimes have snack in*

*the evening. I do not have food restriction. I mostly eat a quarter of the meal served and I am used to it. (Mrs. E, aged 72)*

## Daily Activities

Post-stroke condition leads participants to depend on caregivers to go through their daily activities. This condition results in emotional instability between study participants and their caregivers. In addition, daily activity is disturbed, *i.e.*, limited social activities only around the house.

Mr. A stopped working as a truck driver because he had slurred speech and hyper salivation and left-sided hemiparesis. He spent his day by doing physical exercises at *Ceragem* therapy and spiritual activities in his neighborhood. After undertaking physical exercises, he was able to walk and speak although not in a normal manner. He woke up before 5 am and visited *Ceragem* which is located about 1 km away from his house. After finishing the *Ceragem* treatment at 5 am, he walked around the house and slept until 7 am. He woke up again at 8 am for breakfast. He had lunch at 2 pm and then watched TV. He walked in the afternoon around the house or sat in front of the house, and slept at 9 pm. He attended spiritual worship and activities in his neighborhood every week. He narrated:

*I woke up before 5 am and start walking to Kakaskasenas. The exercise there starts at 5 am. After undergoing the Ceragem exercise, I like to sing, shout and talk. I can speak a little bit better now. I go to Ceragem everyday. Sometimes I sleep at around 8 AM after the breakfast. I have lunch at 2 pm and after that I just watch TV until dinner and then sleep. These are my daily activities—eat, sleep and exercise. We have family gathering once or twice a week, usually every Thursday or Sunday. (Mr. A, aged 45)*

Mrs. B was a tailor and a hair stylist. She also stopped working and just stayed at home. On Saturdays, she woke up at 3:30 am because she had to go to church for Worship. On weekdays, she woke up at 7 am, and then she drank water, 12.5 mg of captopril, the extract of avocado/sour soup leaf, vitamin B1 and B5, and traditional medicine *soman* (herbal medicine). After that, she took a hot shower, had breakfast, sat down and watched television

in the afternoon. She slept at 3 am after watching TV series. She used a walking stick to help her move around the house. She was able to attend the spiritual activity around the neighborhood. Furthermore, she interacted with neighbors or people in church. Her daughter used Mrs. B's living room as a salon, so she had many visiting customers to interact with. She stated:

*Every Saturday, I wake up early because I join the early Morning Prayer at 3:30 am. We go to church at 4 or 4:30 am. In other days, I wake up at 7 am and do some body stretching. After breakfast, I watch TV until evening. I could not take a nap in the afternoon. I join the other program or social gathering if the place is near my house. If I am not sick, I want and will join every program. (Mrs. B, aged 55)*

Mrs. C only stayed in the house. She woke up at 4 am, and then washed her face. She had to wait for someone else to replace her diapers and clean her body. Mrs. C was assisted by her daughter for that need. Yet, the daughter only stayed in the house on working days. She had to go back to Manado every weekend. She has a family in Manado. Therefore, Mrs. C's family paid a caregiver who is from the extended family to take care of Mrs. C during the weekend. Mrs. C's diaper was regularly changed at 3 pm and 6 pm. After she took shower in the morning, replaced her shirt and, ate breakfast, she spent her time watching television. Then, she took a nap although she could not sleep well. She had lunch at 1 pm; the food was prepared by her son. After that, she watched TV. The caregiver cleaned her body at 4 pm, then she watched TV, had dinner and slept at 9 pm. She felt lonely. In the past, she joined Christian Worship activities, but after she had stroke, she just stayed at home. She rarely did exercises, only movements like walking to turn on or off the lights in front of the house within more or less five meters. She claimed she had stiffness in her right hand and feet caused by rarely exercising. She said:

*Someone helps me to walk, take a bath and defecate in bathroom. There are family members who assist me in doing that. I don't drink too much water because no one will help me change the diaper and it is uncomfortable if the diaper is full especially in the middle of the night. I wake up at 4 am every morning, and*

*then wash my face and change the diaper with the help of the helper. My son would prepare the breakfast. When I watch TV sometime I feel asleep for 15-45 minutes. No one accompanies me for exercise, so after I wake up I go to the front house, open the door and turn on/off the light. (Mrs. C, aged 78)*

Mrs. D woke up at 4 am and cooked. She slept at around 9 pm. She cooked and cleaned the house, pulled out the grass in the yard, but could not wash the dishes. Her hand felt pain if exposed to water. She joined the *Ceragem* therapy and did exercise at home. She walked to the *Ceragem* therapy. She trained her arm strength by hanging both of her arms on the rope hanging from the ceiling; she put her arms up and down the rope for 200 times a day. After that, she was able to join the Christian worship or activities around her neighborhood. Mrs. D looked healthier compared to the other study participants. She expressed:

*I am able to do some daily activities like cooking, cleaning the house and getting rid of grass in the front yard but I cannot wash the dishes. When my hand touches the water, I feel pain in my right hand. Same thing happens when I wake up in the morning due to the cold temperature. I can feel a bit pain on my right hand. I wake up at 4 am and sleep at 9 pm. I asked my son to hang ropes on the ceiling; something looks like a small swing on the ceiling so I can exercise my hand. I can walk by myself and join the social gathering near my house. (Mrs. D, aged 73)*

Since she suffered a stroke, Mrs. E spent most of the time lying on a bed. She could not join the Christian worship in the Church or the other activities outside. She was not able to wake up alone and got exhausted easily. Her husband helped her to wake up from the bed and changed the sleep positions. She woke up at 7 am and sat in the living room. After that, she slept for a while and woke up for breakfast. Her activity only includes sitting in the living room or sleeping. She spent most of her time on the bed inside her room. She was an active person before she suffered stroke. Before, she was a PKKA member (women's association in the neighborhood) and church chorister. She visited her grandchildren in Manado and Bitung City several times. The exhaustion of long holiday trip triggered the onset of her stroke. She stated:

*I wake up at 5 am and sleep after watch TV in evening. I follow Sunday morning worship at home and sleep again after the worship. I wake up when I hear the children are going to school and meal time. Children usually go to school at 7 am. When I feel tired, I go to my bedroom. (Mrs. E, aged 72)*

### **Family Communication Patterns between Study Participants and Their Caregivers**

Family communication patterns between the participants and caregivers were affected by many factors. The main factor was emotional sensitivity. Physical, psychological, social, and emotional weakness occurred between the study participants and their caregivers. It posed ineffective communication between them. Family communication patterns indicate the quality of the relationship and interaction between the study participants and their caregivers. In-depth interviews and observations were conducted on both parties.

Mr. A's self-image has changed after the stroke. He felt low esteem because he was dependent on others especially Mrs. S (55 years old), his wife. He was not able to support his family financially. The eldest son supported Mr. A's family needs. Mrs. S also worked to meet the family's need. Although Mr. A could not speak clearly, the wife always tried to understand and accompany him. Her tasks were cooking, preparing food, washing clothes, and giving medication. They liked to talk about their four children and four grandchildren. One time, they had a misunderstanding because Mrs. S did not listen and ignored the wishes of Mr. A. She delayed to do Mr. A's request. Then, Mr. A was angry and refused to talk to her. As a result they quarreled and slept separately for a week. When interviewed, Ms. S was careful in answering the questions. She looked towards her husband and answered softly. It appeared that Mrs. S was afraid to express her opinion in front of her husband. Mr. A seemed to have developed a temper. He confessed:

*When I had the first stroke, I get angry easily. No one can speak harsh word, for I will get mad. But it changed especially when I have recurrent stroke. I could not hold my feelings. When I watch TV, I was easily influenced by the TV series. If I watch the fight scene, I will get excited and angry also, and when I watch*



*the sad scene I will cry immediately. Sometimes, my wife does not respond to me immediately. When I scold her, she does not pay attention. Sometimes I can't be better just because of my emotion. One time we slept in different rooms because she did not listen to me. It could happen for a week. (Mr. A, aged 45)*

Mrs. B tried to accept her situation after stroke. When talking about her illness, she looked disappointed. Mrs. SDM (31 years old), the first daughter, was her caregiver. Mrs. SDM complained about her mother's condition after stroke. However, she still took care of Mrs. B including spoon-feeding, replacing diapers, washing the clothes, and cleaning the house. They loved to tell jokes to each other and discussed home or salon daily. Almost every day, they also had argument. Mrs. B was burdened and stressed with her physical limitation and her daughter was burdened with household problems. Mrs. B was upset because Mrs. SDM quit college. She got pregnant and had to get married. Therefore, they quarreled almost every day. One time, they had misunderstanding and did not talk to each other. However, one of them would budge and they got along again after the quarrelling. She expressed:

*My daughter got married because she was pregnant. She stopped from school. She and her husband often fight even in front of the parents. I do not want [to] intervene with their problems so I just go to my bedroom. My daughter and I often quarrel. But she is my daughter and I still love her. I do not like to keep my emotion and I prefer to express my emotion. When we argue, it only lasts for a day and the next day everything becomes normal. (Mrs. B, aged 55)*

Mrs. C felt lonely. Before, she joined many activities outside, but after she suffered stroke, she had stayed at home. She did not have friends who accompanied her. Her caregivers were her fourth son (41 years old) and second daughter (53 years old) who took care of the housework. Family member's role had changed and made them more sensitive. Her son, Mr. D did household task. He went to the market, prepared food, and turned off the lights. Her daughter, Mrs. Y's task was to change diaper and clean Mrs. C's body. Mrs. C became angry at little things, like when Mr. D forgot to turn off the lights or he did not immediately



come when called. Mr. D was burdened with these tasks. He felt that the tasks were for women. On the other hand, Mrs. Y did not have much time to take care of Mrs. C. She has a job as a teacher. Although they lived together, they rarely had conversation. Even Mr. D admitted attempting to start a conversation but was ignored by Mrs. C. The caregivers talked to Mrs. C while they helped her eat, turn off lights, or help Mrs. Y bathe Mrs. C. This situation led Mrs. C to frequently quarrel with her caregivers and would not eat at mealtimes. She said:

*After the stroke, I get mad easily even for a little thing. People usually say to me "do not be grumpy, Grandma." I have many thoughts since I got sick. I live with two children and household task is not easy. I have several rooms for rent; it means I have to oversee the rooms. I am changed because I keep on thinking of my sickness and condition. I could not go out due to walking problem. Also, I seldomly talk with my son, some simple questions like is the food ready? Have you eaten? It is not like other mother and son conversation. We are not like mother and son. Last time, he did not answer me when I was calling him. I got mad and so [did] he. I do not like to talk to him. Sometimes, he did things that are not important. I reminded him but he did not care. (Mrs. C, aged 78)*

Mrs. D became more sensitive and had low self-esteem because of her physical limitations. Her caregivers were Mr. AK (69 year-old-husband) and Mrs. A. (25 year-old adopted daughter). Mr. AK's tasks were to accompany her and bring water for domestic use while Mrs. A's tasks were cooking, preparing food, washing the clothes, and cleaning the house. Mrs. D considered it a burden to request help from the caregivers. Hence, their relationship was not good. Mrs. D only talked with them about house condition or Mrs. A's children. She was disappointed by the caregivers. Mr. AK was always angry when she asked help to get water and Mrs. A gave less attention to the children. Mrs. D kept her disappointment and burden for a long time due to Mrs. A's problem. She was not married although she had three children from her partner. Mrs. D chose to keep her sadness related to her relationship with the caregivers. She stated:

*Honestly, my daughter is not married. The mother of her*

*partner promises to get them married. However, even until they already have 3 children, they are still not married. They have different religions. So I am always distracted with this thing. I really want them to be married officially. They have to think seriously of the future of their children. I am also burdened when I have to ask my husband to [get] the water from the well. My husband has hypertension and he got mad easily so I just keep it to myself, because it is useless to tell him. (Mrs. D, aged 73)*

Mrs. E depended completely on others. Mrs. E spent most of the time lying on a bed. Her caregiver was her husband, Mr. YK (72 years old). His tasks were to accompany her for daily conversation, help her do body exercise, and bring her for check-up at the hospital. Their daughter who lived in the same neighborhood helped them clean the house, wash clothes and prepare meals. Being always together, the couple is endeared to the neighbors. They did not like to quarrel. One time, Mr. AK did exercise even Mrs. E prohibited him because he was sick. As a consequence, he got sicker and Mrs. E did not talk to him. They did not talk to each other for several days, and they chose to keep the problem. She expressed:

*Our neighbors said they never heard us fighting. We know every couple has different opinion and tendency to argue on something. When we have argument, one of us would budge so we never fight. (Mrs. E, aged 72)*

## DISCUSSION

Stroke commonly happens to older adults with the age ranging from 55-85 years old particularly to those whose family have history of stroke and the mortality rate doubled in each year (Goldstein et al., 2006). In addition, they have one or more degenerative diseases including hyperlipidemia and hypertension which are the major risk factors of stroke (Goldstein et al., 2006). The occurrence of stroke in older adults is higher than those who are in their productive age because of the physical deterioration and weakened immune system that make them more vulnerable to degenerative disease that may lead to stroke (Nugroho, 2008). The main reasons for stroke in the productive age is unhealthy

lifestyle such as smoking, irregular exercise, unhealthy diet, and stress (Supriyono, 2008; Sitorus, Hadisaputro, & Kustiowati, 2009).

Women tend to have higher chance of stroke in postmenopausal period. This is related to the estrogen in the female body, which may reduce the risk factors of stroke in postmenopausal phase (Rossouw et al., 2002; Wassertheil-Smoller, Hendrix, Limacher, Heiss, & Kooperberg, 2003). Men have a greater potential to suffer a stroke at a young age therefore the survival rate is also higher, while women in their old age will have less chance to survive (Reeves et al., 2008; Roger et al., 2010).

Most patients have ischemic stroke than hemorrhagic stroke (National Heart, Lung, and Blood Institute, 2006). The prevalence of ischemic stroke in Western countries is 87% and the rest is hemorrhagic stroke (Roger et al., 2010).

In Asian countries with low consumption of animal protein, high in saturated fat and cholesterol, the risk of stroke increases (Sauvaget, Nagano, Hayashi, & Hamada, 2004). Gariballa (2000) stated that a balanced consumption of fruits, vegetables especially beans and limited consumption of saturated fats can prevent recurrent stroke. Smoking and consumption of alcoholic beverages are associated as stroke risk factors, therefore post-stroke patients are advised to quit smoking and drinking alcoholic beverages. Furthermore, stress can trigger stroke by atherosclerosis process, increased cardiac output, increased blood pressure, improve blood sugar, muscle tissue damage, infertility, inhibition of the inflammatory reaction, growth suppression, and suppression of immunity (Carr & Shepherd, 1998).

A caregiver's role is very important in addressing the daily needs of post-stroke patients. Miller et al, (2010) reported that majority of stroke patients who survive and continue to live in the community need help from their caregivers related to their physical limitation including hemiplegia, hemiparesis, ataxia, dysarthria and dysphagia (Smeltzer & Bare, 2009). However, caregivers are affected by the changes of the post-stroke patients condition particularly their personalities (Benny, Aldy, & Darulkutni, 2008). These changes have effects particularly on family communication pattern in terms of self-image, physical and emotional conditions, physical environment, the role of the social environment, body language and intelligence as effective

communication factors (Lunandi, 1987). The changing of these factors leads to the ineffective communication that triggers the occurrence of misunderstanding between the post-stroke patients and their family members.

## **CONCLUSIONS AND RECOMMENDATIONS**

The study showed that the data of stroke in Tomohon City was covered by physiotherapist in Primary Health Care. In Tomohon Health and Social Department, the data was classified into Vascular Disease and Hypertension group. Consequently, the health programs in Tomohon Health and Social Department refer to clients with vascular disease and hypertension only. There is no specified health program for stroke patients and their caregivers. The change of stroke patients affects the patient and their families and both parties have to deal with it.

Tomohon Primary Health Care should conduct specified health programs for stroke patients and their families. Seminars or trainings are needed for family members about their roles and function and the stroke effect on the patient and family members. They should well understand about their significant roles in supporting stroke survivors.

A holistic rehabilitation team is needed in Tomohon City. It should be a collaboration between multidisciplinary disciplines, composed of physicians, nurses, physiotherapist, speech therapists, occupational specialists, social workers, and family members of stroke patients. It should use family-centered approach. The health practitioners must involve family members in any health services during home care service so that the family members become independent to take care of the patient.

This study utilized the data from seven Tomohon primary health care centers, excluding the data from two hospitals in Tomohon, GMIM Bethesda Public Hospital and Gunung Maria Hospital in the second half of 2010. Further research using quantitative method to seek the bigger scope of stroke prevalence and family members' roles during stroke rehabilitation process is needed in Tomohon City.

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