

2018-09-05

Doctoral Dissertation of
St. Luke's International University
Graduate School 2018

Experiences of Patients with Ischemic Stroke and
Their Family Caregivers in South Tangerang City, Indonesia:
Before and After Discharge

インドネシア、南タンゲラング市における
脳梗塞患者とその家族の入院中と退院後の体験

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ABSTRACT

Purpose: Despite the fact that stroke is the leading cause of death among Indonesians accounting for approximately 20% of all deaths, there has been very limited nursing and policy research regarding their continuum care. Therefore, purpose of this study was to describe the characteristics and the experiences of patients with ischemic stroke and their family caregivers before and after discharge.

Method: The study had a qualitative descriptive design including a literature review, preliminary study and a main study with semi-structured interviews. Purposive sampling was used to recruit dyads of ischemic stroke patients over 45 years old ($n = 12$) and their family caregivers over 18 years old ($n = 12$) from one public hospital in the center of South Tangerang. Data were collected from November 2017 through January 2018. The 30 minutes face-to-face interviews were conducted at the participants' homes. The data were collected from (1) medical records and (2) one-on-one interviews in separate rooms with the patients and the main family caregivers. The data were analyzed using a content analysis approach. The Research Ethics Committee of St. Luke's International University approved the study (No. 17 -A062).

Results: A total of 24 participants were eligible for analysis. The patients' characteristics included age ($M, 60.5$), mostly married, with fifty percent actively working. The patients were all living with at least four people in the same house. Four patients had a stroke accompanied by diabetes mellitus. The mean length of hospital stay was 7.8 days and the mean Barthel Index of Activity of Daily Living score was 62.5. For family caregivers the mean age was 49.3 years old and 83% of the main caregivers were spouses. There were seven phases that emerged from the transitional experiences of patients with ischemic stroke and their family caregivers. During hospitalization, there were three phases: acute phase, post-acute and at time of discharge. One month after discharge, three phases emerged: facing difficulties, seeking treatment and expecting recovery. Within three months there was one phase: resuming their normal life.

Three unique experiences regarding (1) excretory functions, (2) patients concern to return to work and (3) family caregiver awareness for providing care were influence by their religious believe and the urban characteristics background of the study participants. The spiritual believe in God was strong factor that could contribute to the patients' and families' ability to cope with problems.

Conclusion: The main finding indicated that understanding the experiences of patients and family caregivers during the transitional period is pivotal for developing appropriate and suitable care. Before hospital discharge, participants encountered many challenges resulting from limited information regarding the disease, therapy and treatments. Later at home after the discharge, participants were struggling to care for themselves while relying on their families and religious belief as their main supports. There were three gaps identified during hospitalization, two concerns related barriers to follow-up check and caring burden. Patients had barriers to have follow-up care, which could lead to discontinuity of care. The results suggested the need for a transitional care model for every phase along the transition. With the underlying message that nurses, and health providers should be aware and more sensitive in understanding the complexity of the experiences of stroke patients during their transition from the acute phase to follow-up after discharge. Future research should be addressed the refinement, feasibility and validity of this transitional care model so it could be feasibly implemented within the clinical setting with each patient who had a stroke and at in each phase of recovery. Furthermore, this transitional care model could provide a continuum care for patients with strokes and their families.

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CHAPTER 1

INTRODUCTION

Background

Aging has become a major global demographic trend in most high-income countries during the twenty-first century and that shift is recently taking place in middle income countries, as their mortality and fertility levels have decreased (UNFPA, 2014). Indonesia as one of middle-income countries is also facing the demographic transition from the high to the low fertility-low mortality stage (UNFPA, 2014). Based on the Indonesia Population Census in 2010, the population of older persons (aged 60 years and over) was 18.04 million, representing 7.6 percent of Indonesia's total population. According to the census it will increase continuously and will reach 15.8 percent by 2035 (Indonesia Health Profile, 2014). An increasing aging population is accompanied by the biological changes associated with non-communicable diseases.

Stroke is one of the non-communicable diseases, which has become a major cause of death and disability in high-income countries. However, stroke mortality rates are greater in low- and middle-income countries compared with high-income countries, largely due to the lack of primary care treatment to identify and reduce stroke risk (Norrving & Kissela, 2013). Stroke was the leading cause of death among Indonesians, causing 19.5% of all deaths in 2010 and became one of the top three causes for disability adjusted life years (DALYs) lost (Mahendradata, 2017). The percentage of stroke-induced deaths in 2009 was 15.9% in urban areas and 11.5% in rural areas (Kusuma et al., 2009).

The impact of stroke especially the changes of physical function can cause long term-disabilities for stroke patients and thus after discharge from the hospital they still require continued care and support (Almborg, et al., 2010). Even after discharge, stroke patients may

suffer from varying degrees of impairment and disability (Baumann, et al., 2014; Lutz, et al., 2011). At home, their care is placed mainly upon family caregivers who may not be equipped with appropriate skills and knowledge (Sit et al., 2004). These conditions produce stress and anxiety among the family caregivers (Coleman, 2003; Covinski, 2003; Naylor 2000). These conditions could also affect the quality of life of patients as well as increase the burden on their caregivers (Sit et al., 2004). Furthermore, the care provided may involve medication errors, leading to possible readmission (Coleman & Berenson, 2004; Giosa, 2013; Naylor et al., 2004). Studies have suggested that there is a pressing need to prepare both patients and family caregivers starting from the acute stage and during their transition period to successfully support family caregivers (Gibson et al., 2012; Sit et al., 2004) and improve care needs management (Graham et al., 2009).

The Ministry of Health of Indonesia (2010) developed the strategic plan which prioritizes the importance of community education for stroke and other non-communicable diseases (NCDs). NCD programs are mainly preventive efforts, including health promotion to raise public awareness and community-based health awareness groups, early screening and early detection and emphasize the primary health care to support family caregivers. Yet the implementation is still inadequate.

A preliminary study in urban area in Indonesia described five categories of transitional care needs for stroke patient and family caregivers at home after discharge (Damiati, 2016). The patients' needs were focused on self-care in order to improve physical function, while the family caregiver needs were focused in how to improve caregiving role. There was also an important finding from this study regarding the length of stay in the hospital (LOS), the LOS of patients in the preliminary study was 3-5 days which was considered short compared to other studies. This issue raised the question of how patients and family caregivers were dealing with difficulties after they returned home, particularly for the

first month after discharge, which represents a critical time for transition (Gustafsson & Bootle, 2013). The literature review in Western countries showed that there have been many studies exploring the transition experience before and after discharge. The trend of studies now is expanding to identify suitable approaches for transitional care program to support early discharge and to improve a continuum care for stroke patients and family caregivers. However, the information and studies related to stroke and continuum of care especially in nursing science are still inadequate for application to Indonesia. Therefore this study will explore the topic, which is still not known.

In addition, to developing a transitional care model for Indonesia and determining the most effective way to support a continuum of care for patients and their family caregivers there must first be a basic study related to their experiences of transitions. This study aimed to explore patients and family caregivers' experience as a unit (patients and their family caregivers) during discharge from the hospital to home within three months after discharged. The intention is that based on the experiences of patients and their family caregivers, health care providers' understanding regarding stroke transitions and what happened during that time will deepen.

Purpose

The purpose of this study was to describe the experiences of patients with ischemic stroke and their family caregiver before and within three months after discharge from the hospital to home.

Objectives

The objective of this study are as follows: 1) To describe patient and family caregivers' characteristics in an urban areas in Indonesia and 2) to understand the experiences of patients with ischemic stroke and their family caregivers in urban areas in Indonesia before discharge and within three months after discharge;

Definition of Terms

Patient and family caregivers' experience.

All the things that the patients and family caregivers encountered, observed, perceived, and felt will influence patients and family caregivers' perceptions.

Patient with Ischemic stroke.

Patients with ischemic stroke refers to the people aged 45 years above who have been diagnosed with first time ischemic stroke and have been discharged from the hospital after three months from the time of admission in an urban city in Indonesia.

Family caregiver.

Family caregiver is a family member who is identified by the patient as a person whose is mainly responsible for the patient's daily care at home.

Before discharge.

Before discharge defines as the period of time when a patient was in the hospital from his/her admission to just before his/her going home.

After Discharge.

After discharge refers to a period of time or situation at home when the patient was discharge from the hospital.

Significance of the study

The results of this study will be expected to be a benefit for Indonesian health care in the area of chronic disease, especially for patients with strokes and their family caregivers. The findings are also to enrich the understanding regarding the experience of patients with strokes and family caregivers before and after discharge, identify the problems in their daily life, the barriers and their needs at every stage that they went through in the transition process from hospital to home. Moreover, the findings may serve as a foundation to develop a better

transitional care to strengthening patients with strokes and family caregivers' ability for self-care and to receive sustainable/continuity of care at home after discharge. Furthermore, this study will be used to describe what kind of transitional care model patients with ischemic stroke and their family caregivers in an urban area in Indonesia might need.

CHAPTER 2

LITERATURE REVIEW

This chapter provides four sections: 1) an overview of Indonesia and South Tangerang city, 2) an overview of stroke disease and health system in Indonesia, 3) a review of the literature regarding the transitional care experience of stroke patients and family caregivers after discharge and 4) a description of implications for the study. Each section in this chapter consists of the explanation of the relevant issue and studies.

1. An overview of Indonesia and South Tangerang city

1.1. An overview of Indonesia.

Geography.

Indonesia is the largest archipelago in the world, which stretches over more than one-tenth of the Equator between Southeast Asia and Australia. The archipelago includes a chain of islands from Sabang to Merauke. The largest islands are the Kalimantan provinces on Borneo, Sumatra, Papua, Sulawesi and Java (where Jakarta, the capital city of Indonesia is located).

Population.

Indonesian total population in 2015 was around 255,461,686 inhabitants. Over two thirds of the population resides in Java, the center of the country's economic and political power. From 2010 to 2014 the population grew from 3.54 million per year to 3.70 million per year. In 2015 the growth declined slightly compared to that of 2014 to 3.34 million per year. Life expectancy is 72.45 years (Ministry of Health Report, 2015).

In 2010, the population census found that the number of people aged 60 years and above was 18.1 million, or 7.6 percent of the total population. This number is projected to increase

11.8 percent of the population, by 2025 and to reach 15.8 percent, by 2035. Indonesia's age structure is gradually shifting toward having more people in the older age groups, indicated by an increase in median age from 27.2 years in 2010 to a projected 33.7 years in 2035. The Ageing Index, which is the ratio of older persons per 100 children (aged 0-14 years), is projected to increase from 26.3 in 2010 to 73.4 in 2035.

Economy.

The economic growth in Indonesia in 2015 amounted to 5.04%, a slight increase compared to the economic growth in 2014 but lower than that in 2012 and 2013. This was due to the then ongoing crisis in the global economy (Ministry of Health, 2015).

Indonesia's GDP per capita has steadily risen, from \$857 in the year 2000 to \$3,603 in 2016. Today, Indonesia is the world's fourth most populous nation, the world's 10th largest economy in terms of purchasing power parity, and a member of the G-20. Indonesia as an emerging middle-income country, has made enormous gains in poverty reduction, cutting the poverty rate to more than half since 1999, to 10.9% in 2016 (World bank, 2017).

Education.

There has been an upward trend in the average length of study of the population aged 15 and over, from 7.85 years in 2011 to 8.32 years in 2015. In 2015, there was a higher average length of study in urban areas (9.61 years) than in rural areas (6.98 years). It is associated with the presence of more school facilities in urban areas than in rural. By gender, men tend to stay longer in school (8.69 years) than women (7.96 years). A total of nine provinces have achieved the 9-year compulsory education program, namely DKI Jakarta, Riau Islands, DI Yogyakarta, Maluku, East Kalimantan, West Papua, North Sumatera, Aceh, and North Sulawesi. The lowest average length of study belongs to the province of Papua by 6.27 years and the highest to DKI Jakarta by 10.90 years.

Culture.

Indonesia has more than 300 distinct ethnic and linguistic groups. Most Indonesians are descended from Austronesian-speaking people. Melanesians who live in the eastern part of the country are a major ethnic group. Other ethnic groups include: Sundanese (15.5%), Malay (2.27%), Madurese (3.03%), Batak (3.58%), Minangkabau (2.73%), Betawi (2.88%), Bantenese (1.97%), Banjarnese (1.74%), Balinese (1.67%), and Makassarnese (1.13%). Chinese Indonesians account for only about 3% of the population but they are influential, controlling most of the country's wealth and commerce.

The national language is Bahasa Indonesia. Bahasa Indonesia is the official language and used mostly in education, media, commerce, and administration. The language binds together people in Indonesia and made the national motto of Indonesia which is “Unity in Diversity”

Indonesians tend to place importance on the value of extended family. In 2010, about 36 percent of older persons lived with three generations in one household, providing potential support (UNFPA, 2014). Indonesian family structure is influenced by the cultural affiliation among family's members and have increasingly been affected by urbanization. In general, birth order is important in determining levels of obligation, which reflects hierarchies of responsibility.

Religion.

Indonesia is the world's most populous Muslim-majority country, the percentage of Muslims is 87%, 9.87% are Christian, 1.69% are Hindu, 0.72% are Buddhist and 0.56% practice other faiths (Indonesian census, 2010). The Indonesian constitution grants religious freedom although the government only officially recognizes Islam, Protestantism, Roman Catholicism, Buddhism, Hinduism, and Confucianism.

Islam is supported by the five pillars that Muslim are required to perform: (1) shahadah; the declaration of faith to bear witness that there is no God except of Allah WT, and

Muhammad is his messenger. (2) shalat, specific acts of worship: prayers five times a day; (3) Zakat, obligatory act (charity) ordained by Allah (The Glorified and Exalted) to be performed by every adult and able bodied Muslim; (4) Fasting in the Ramadhan month; Muslims are required to fast during **Ramadan**, the ninth month of the Islamic calendar and (5) Pilgrimage Hajj; the Muslim pilgrimage to Mecca that takes place in the last month of the year, and that all Muslims are expected to make at least once during their lifetime.

From among the five pillars of Islam, shalat is a very important act as a remembrance of Allah. A Muslim should not leave prayer regardless of the reason.

God will threaten Muslim men and Muslim women who left prayer (shalat), with a very heavy punishment (Al-Qur'an, letter AL-muddatstsir verses 42-43). Shalat can be done by standing, or sitting or lying on one side if someone has limitation, but if they are free from sickness or limitation shalat should be set as regular practice.

1.2. An overview of Tangerang city.

Geography.

South Tangerang City that is adjacent to DKI Jakarta Province in the north and east side gives opportunities to South Tangerang City as one of the supporting regions of DKI Jakarta. In addition to that, the city has become the region that connects Banten Province to DKI Jakarta Province. (Tangerang-city profile, 2015). This area was chosen for the study because of the close access to the city of Jakarta (Figure 1)

Population.

From the composition of population of South Tangerang City in 2014, there were 380,284 people (25.82%) who were included in the non-economically productive age, namely children aged 0-14 years old. While for the productive age group, that is people aged 15 - 64 years old, there were 1,072,001 (71.80%). In a no longer productive age group, senior

citizens aged 65 years old and above, there were 40,714 people (2.73%) (South Tangerang City profile, 2015). From the 2014 BPS data, the life expectancy rate at South Tangerang City in 2014 is 72.11 years, which means the capability to survive of its people can reach the age of 72.11 years.

Figure 1 South Tangerang Map



Source: map data @2013 google

Living in South Tangerang City

The location of South Tangerang City is close to the nation's capital and one of the fastest growing satellite cities. Therefore the economy is more robust and there are many employment opportunities. This attracts people from other regions to migrate to South Tangerang City. Most of the land utilization (68%) at South Tangerang City is for housing and settlements. The housing varies depending on the socio-economic status of the citizens. The people living from middle to high level economy own their house or apartment with sophisticated rooms arrangements bedroom, bathroom, living room and kitchen. For low level economy citizens are living in the rented house with small rooms and sometimes with separated bathroom from the main rooms.

The relationship of the people in community is quite close since they know each other.

The family structured from three generation sometimes could be found living in the same house. The relationship between family members is also relatively strong and close to each other. According to their religion, majority of population (89%) of South Tangerang City in 2013 were followers of Islam. The remaining population was Christian (6%), Catholic (4%), Buddhist (1%), Hindu (0.3%) and others (0.04%).

There are many people with social welfare issues and the types of issues are varied. In 2013, the group of people with social issues where the data was collected by the Regional Office of Social, Employment and Transmigration of South Tangerang City were families vulnerable to socioeconomic problems, women prone to socioeconomic problem, no livable house, person with HIV/AIDS, and other types. There are also typical urban issues such as street children and beggars, but there are also general issues like disaster victims and people with disabilities. (Health Tangerang Profile, 2015)

2. An overview of stroke and the health system in Indonesia

2.1. Trends of Non-Communicable Disease (NCD) in Indonesia

There are 10 most common disease in Indonesia according to the data of Registration System (SRS, 2014): stroke 21.1%; heart disease 12.9%, 6.7% Diabetes Mellitus, Tuberculosis 5.7%, Complications of blood pressure High 5.3%, chronic lung 4.9%, liver disease 2.7%, traffic accidents 2.6%, pneumonia 2.1%, and combined diarrhea and gastroenteritis due to infection 1.9%. The Global Burden of Disease Study 2010 (GBD, 2010) quantified levels and trends of health loss due to diseases, injuries and risk factors in Indonesia. Stroke is the leading cause of death among Indonesians, causing 19.5% of all deaths in 2010. Common risk factors include hypertension, smoking and hypercholesterolemia (Kusuma et al., 2009).

The health status in Indonesia has improved significantly over the last two and half

decades, with life expectancy rising from 63 years in 1990 to 71 years in 2012, under-five mortality falling from 52 deaths per 1000 live births in 2000 to 31 deaths in 2012, and infant mortality falling from 41 deaths per 1000 live births in 2000, to 26 deaths in 2012. However, progress on maternal mortality and communicable diseases has been slower, with maternal mortality remaining high (210 deaths per 100 000 live births in 2010), and a continuing high incidence of tuberculosis (TB) and malaria. At the same time, risk factors for NCDs, such as high blood pressure, high cholesterol, overweight and smoking, are increasing (Mahendradhata et al., 2017).

Ministry of Health of Indonesia established a unit at the directorate level, the Directorate of Non-Communicable Disease, to lead and manage NCD prevention in the country. NCD programs are mainly preventive efforts, including health promotion to raise public awareness and community-based health awareness groups, early screening and early detection. (Ministry of Health Report, 2012)

2.2. Stroke

Definition

A stroke occurs when an area of the brain is deprived of blood flow (ischemia). Most commonly, this happens when blood vessels are blocked by a clot or have become too narrow for blood to pass through. Stroke can also be caused by hemorrhage into the brain that results in death brain cells.

Trans ischemic attack (TIA) is a temporary focal loss of a neurologic function caused by ischemia of one of the vascular territories of the brain, lasting less than 24 hours and often lasting than 15 minutes. Most TIA resolve within 3 hours.

Stroke determinant

There are two determinants of stroke; first, are non-modifiable factors, which

included: age, gender, race and heredity. Second, are modifiable risk factors, which may increase the probability of stroke: hypertension, heart disease, atrial fibrillation, diabetes mellitus, hypercholesterolemia, physical inactivity, smoking, heavy alcohol use and asymptomatic carotid stenosis (Rowland & Pedley, 2010).

Symptoms.

These following symptoms could be a warning signs for a stroke: sudden numbness or weakness of the face, arm, or leg, especially on one side of the body, sudden confusion, trouble speaking or understanding, sudden trouble seeing in one or both eyes, sudden trouble walking, dizziness, loss of balance or coordination, sudden, and severe headache with no known cause (*American Heart Association, 2009*).

Type of stroke

Ischemic Stroke.

Ischemic stroke is accountable for 85% of all strokes. It results from an inadequate blood flow to the brain from partial or complete occlusion of an artery (Lewis, 2004). During an ischemic stroke the supply of blood and oxygen to the brain is blocked.

The cause of ischemic stroke;

a. Thrombotic.

The leading cause of stroke is thrombosis, or blood clots. Clots develop gradually when the inner lining of blood vessels become clogged with the build-up of cholesterol and fatty substances. This clogging is similar to the deposit of lime scale in water pipes: Eventually enough scale accumulates to narrow or totally shut off the flow of water. In blood vessels, a buildup of cholesterol from years of eating a high-fat diet may have the same effect.

b. Embolic.

The second major cause of stroke, embolism, occurs when a clot formed in a blood vessel somewhere in the body breaks off, enters the brain's circulatory system, and travels until it encounters an artery it can't pass through.

c. Hemorrhage stroke.

Accounting for approximately 15 % of all strokes are hemorrhage strokes. They result from bleeding into the brain tissue itself. There are two main types of hemorrhagic stroke: (1) intracerebral hemorrhage which happens when a blood vessel in the brain leaks blood into the brain and (2) subarachnoid hemorrhage which happens when there is bleeding under the outer membranes of the brain and into the thin fluid-filled spaces that surrounds the brain. This type of hemorrhage can cause extensive damage to the brain and is the most lethal of all strokes.

Clinical manifestations

The functions affected are directly related to the artery involved and area of the brain it supplies. Manifestation related to right- and left- brain damage differ. A stroke can have an effect on many body functions, which are described next.

Motor Function.

Motor deficit are the most obvious effect of stroke. Motor deficits include impairment of mobility, respiratory function, swallowing and speech, gag reflex and self-care abilities. Symptoms are caused by the destruction of motor neurons in the pyramidal pathway. The characteristic motor deficits include loss of skilled-voluntary movement, impairment of integration of movements, alterations in muscle tone, and alterations in reflexes.

Communication.

The left hemisphere is dominant for language skills in right-handed persons and in most left-handed persons. Language disorders involve expression and comprehension of

written and spoken words.

Affect.

Patients who have had a stroke may have difficulty controlling their emotions. Emotional responses may be exaggerated or unpredictable. Depression and feelings associated with changes in body image and loss of function can make this worse. Patients may also be frustrated by mobility and communication problems.

Intellectual function.

Both memory and judgement may be impaired as a result of stroke. These impairments can occur with stroke affecting either side of the brain. A left-brain stroke is more likely to result in memory problems related to language. Patients with left-brain stroke often are very cautious in making judgements. The patients with right-brain stroke tends to be impulsive and to move quickly.

Spatial-Perceptual Alterations.

A stroke on the right side of the brain is more likely to cause problems in spatial-perceptual orientation, although this can also occur with left-brain stroke. Spatial-perceptual problems may be divided into four categories. The first is related to the patient's incorrect perception of self and illness. This deficit follows damage to the parietal lobe. Patients may deny their illnesses or their own body parts. The second category concerns the patient's erroneous perception of self in space. The patient may neglect all input from the affected side. The third spatial-perceptual deficit is agnosia, the inability to recognize an object by sight, touch or hearing. The fourth deficit is apraxia, the inability to carry out learned sequential movements on command. Patients may or may not be aware of their spatial-perceptual alterations.

Elimination.

Fortunately, most problems with urinary and bowel elimination occur initially and are temporary. When a stroke affects one hemisphere of the brain, the prognosis for normal bladder function is excellent. Although motor control of the bowel is usually not a problem, patients are frequently constipated. Constipation is associated with immobility, weak abdominal muscles, dehydration, and diminished response to the defecation reflex. Urinary and bowel elimination problems may also be related to the inability to express needs and to manage clothing.

Prognosis

Prognosis of stroke depends on the type of stroke and is influenced by factors including age, stroke severity, stroke mechanism, infarct location, comorbid conditions, clinical findings, and related complications (Edwardson & Dummeric, 2017).

Ischemic stroke patients have an approximately 70 % chance to be able to regain their independence, 10% recover almost completely, and 25 % of patients die as a result of the stroke. The period from 12 hours to seven days after ischemic stroke onset is critical and many patients who are without complications experience moderate but steady improvement of neurologic impairments (Brown et al, 2003).

Hemorrhagic stroke type generally has a worse prognosis than ischemic stroke. Approximately 10% of aneurysmal patients with subarachnoid hemorrhage (SAH) die prior to reaching the hospital, 25% die within 24 hours of SAH onset, and about 45% die within 30 days; only 33% of patients will have a good outcome after treatment (Bederson et al., 2009; Singer et al., 2017; Swierzewski, 2014). Mortality within the first 30 days after SAH approaches 50 % and is attributed largely to the effects of initial and recurrent bleeding. The most important predictive factors for acute prognosis after SAH include level of consciousness and neurologic grade on admission, patient's age, and amount of blood on

initial CT scan.

The greatest proportion of recovery after stroke occurs in the first three to six months, although some patients experience further improvement up to 18 months. In a prospective study that evaluated more than 1100 patients from Denmark with acute stroke, those who had mild disability tended to recover within two months and those who had moderate disability recovered within three months. Patients with severe disability who recovered did so within four months, and those with the most severe disability within five months from onset. Functional recovery was preceded by neurologic recovery by two weeks on average.

Stroke Treatment

The *Stroke Treatment Guidelines* in Indonesia were made by the Indonesian Neurologist Physician Association (2011) based on the American Heart Association (AHA)/American Stroke Association (ASA), and European Stroke Organization (ESO). The treatment is including as follows:

1) Primary prevention of stroke.

Primary prevention of stroke consists of healthy lifestyle behavior (tobacco control, salt reduction, diet high in saturated fats and sugar, harmful alcohol use, physical activity) and blood pressure control.

2) Pre-Hospital management of acute stroke.

The aim of pre-hospital management is to reduce the number of morbidity and co-morbidity. The awareness of stroke symptoms is very important. Appropriate treatment at the early hours of stroke onset will decrease the chance of disability by 30%. The management includes early detection, patient transfer and ambulance system.

3) General treatment on acute stroke.

The general treatment includes treatment in the emergency unit and in a stroke unit

(inpatient). The general treatment includes: patient's anamnesis, airway and breathing stabilization, hemodynamic stabilization, intracranial pressure stabilization, bleeding control, seizure control and body temperature control.

Treatment in the stroke unit (inpatient) includes fluid, nutrition, complication prevention, and other medical treatments (monitoring blood sugar, reduce vomiting, education, rehabilitation and discharge planning).

4) Emergency care for acute stroke.

Emergency care includes the treatment for hypertension and hypotension (oral and injectable medicine), treatment for blood glucose control (oral and injectable insulin).

Treatment for medical complication.

5) Special treatment for acute stroke.

The therapy includes treatment for ischemic stroke, for intracerebral hemorrhagic stroke and subarachnoid stroke. Specific therapy for acute stroke; Application for Thrombolysis Therapy (TPA) for ischemic stroke.

6) Secondary prevention for ischemic stroke.

This includes controlling the modified risk factors, such as hypertension with lifestyle change and medication and diabetes mellitus by controlling blood sugar, making lifestyle modifications and increasing exercise.

7) Stroke rehabilitation.

The purpose of stroke rehabilitation care is to prevent stroke complications and improving the person's physical functioning. Stroke rehabilitation involves the inclusion of and collaboration with multidisciplinary professions such as physicians, nurses, physiotherapists, occupational therapists, speech therapists, psychologists, patients and family caregivers.

2.3 Health system

At the village level, the community health centers or *pusat kesehatan masyarakat* (*puskesmas*) have developed community-based integrated coaching posts named integral post or *pos binaan terpadu* (*posbindu*). The *posbindu* enables community participation in the activities of early detection, monitoring and ongoing follow-up of people with non-communicable disease risk factors independently. This activity was developed as a form of early warning system. Specific non-communicable disease risk factors that are controlled by *posbindu* services include hypertension, coronary heart disease, diabetes, cancer, chronic obstructive pulmonary disease, osteoporosis, gout, asthma, stroke, obesity (overweight), kidney stones and others.

The *posbindu* programs can be integrated into other community activities, such as those in schools, workplaces and residences. The *puskesmas* serves as a referral if there are residents who require further treatment.

Medical rehabilitation is defined in Indonesia as services aiming to restore or improve the physical and functional ability of patients suffering disability due to illnesses. Medical rehabilitation services that are commonly available in Indonesia include physiotherapy, occupational therapy, speech therapy and orthotics/prosthetics. These services are offered as a part of more comprehensive services by hospitals, community health centers, community-based rehabilitation practices or stand-alone private practices. The availability of these services varies across the country, but they are best in urban areas. In order to provide medical rehabilitation services equitably to Indonesians, the Ministry of Health developed a strategy through hierarchical services in hospitals, health centers and in communities.

Medical rehabilitation services in hospitals include specialist/subspecialist services, outreach and referral systems, with the aim of providing integrated and comprehensive patient services. Medical rehabilitation services at the community health service levels are

intended to provide primary medical rehabilitation. They provide guidance to the public through community-based rehabilitation programs (including to individuals with disabilities) and services in accordance with the guidelines for medical rehabilitation services in the community health centers (WHO, 2017)

There is the use of complementary and alternative medicine (CAM) and traditional medicine like in other regional countries; Indonesia possesses its own tradition of indigenous medicine, commonly known as *jamu*, involving the use of herbal medicines. According to The National Socioeconomic Survey (Susenas), more than a third of those who opted for self-medication use traditional or alternative medicines, such as *jamu*. The Ministry of Health (MoH) recognizes the roles of traditional and alternative medicine, and in order to protect consumers and improve the quality of services, it requires traditional/alternative practitioners to register with the health authorities. Registration is provided on the basis of an official assessment, which emphasizes the protection of patients' health. An exception applies for acupuncture, which requires a certification of competency from its professional association (MoH, 2003). The MoH has registered more than 280 000 traditional or alternative medicine practitioners (MoH, 2012).

In addition to modern medicines used by health professionals, the Indonesian people are also familiar with traditional treatments conducted by shamans (known as *dukun*). Many people, especially those who live in rural and remote areas, prefer to go to *dukuns* for treatment rather than health professionals. The Republic of Indonesia health system review notes that as part of the national culture, the *dukuns* are believed to be able to cure the patient's illnesses, including chronic diseases such as cancer, heart diseases and renal failure (WHO, 2017).

Table 1. *Different Levels of Health Facilities in Indonesia*

Administrative level	Facilities	Schedule of service	Task
Village	Community based facilities: integrated health post (pos pelayanan terpadu)	1 day per month	All facilities in villages (<i>posyandu, polindes, pustu, pusling</i>) focus on primary care (promotion and prevention). <i>Posyandus</i> are volunteer-based.
	Sub-health centers (<i>puskesmas pembantu—pustu</i>)	Daily office hours	<i>Pustus</i> extend the services of the <i>puskesmas</i> (health centers) to remote areas. They provide services similar to those of the <i>puskesmas</i> , except for dental. There are no inpatient facilities
	Mobile service units (<i>puskesmas keliling—pusling</i>)	1-4 times per month	A <i>pusling</i> is a mobile unit (car) that visits villages, usually on market day. It often stops in a big field (soccer pitch) where it offers routine services similar to those offered by <i>puskesmas</i> .
	Private clinics	Daily services, usually open after working hours	Private health services where patients consult doctors with fee
Subdistrict (Kecamatan)	Health centers (<i>puskesmas</i>) with or without an inpatient facility (including simple laboratory	Daily office hours	There are two types of health centers: 1. Inpatient facility Open 24 hours Specialist team

	facility)		Simple surgery 2. Outpatient facility Daily clinic, open during office hours. These provide promotion and prevention for primary health care and a simple laboratory facility.
	Private clinics	Daily services, usually open after working hours	Services for a fee.
District	First-referral hospital	Daily office hours for consultation with doctors	24-hour emergency unit. Focus on clinical services (surgery, etc.); provide daily consultation with specialist doctors, laboratory facilities, and emergency services.
	Private hospitals (some are designated)	Daily	Usually exist in a big district.
	Private clinics	Weekdays, after working hours	Services for a fee.
Province	Second-referral hospitals	24 hours a day, seven days a week	24-hour emergency unit. Focus on clinical services with more advanced medical equipment than hospitals at the district level.
	Private hospitals		More specialist doctors.
Center	Tertiary or top-	24 hours a	24-hour emergency unit.

	referral hospitals Hospital as center of excellence	day, seven days a week	Advanced medical technology with complete team of specialists. (National brain center hospital)
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(Source: Adapted from Joint Committee on Reducing Maternal and Neonatal Mortality in Indonesia; Development, Security, and Cooperation; Policy and Global Affairs; National Research Council; Indonesian Academy of Sciences, 2013.)

Health insurance system

Jaminan Kesehatan Nasional or National Health Insurance (JKN) began 1 January 2014. This is kind of Universal Health Coverage (UHC) is for the entire population. JKN is organized to provide health protection in the form of health care benefits in order to meet basic health needs provided to every person who either has paid the premium or has his/her premium paid by the government.

JKN provides two benefits: medical and non-medical. Medical benefits come in the form of comprehensive health services (promotive, preventive, curative and rehabilitative) based on the medical indications which are not bound by the amount of premium paid. Non-medical benefits include accommodation and ambulance. The accommodation benefits for inpatient care are based on the type of classes stated in the scheme. The ambulance benefits are only provided for referral patients between health facilities, with certain conditions set by the social security organizing body (*Badan Penyelenggara Jaminan Sosial* [BPJS]) and the national health insurance agency (*Kesehatan [JKN]*).

The benefits that JKN provides include prevention and treatment services including access to drugs and consumable medical materials in accordance with medical needs. The prevention services (both promotive and preventive) entitle JKN participants to the following: individual health counseling, which covers at least one counseling about managing disease risk factors as well as clean and healthy behavior; basic immunization, family

planning, which covers counseling, basic contraception, vasectomy and tubectomy; health screening to selected participants aimed to detect the risk of certain diseases and prevent the continued impact; counseling on types of cancer, cardiac surgery, and even dialysis (for kidney failure). Up to December 2015, the total number of JKN participants reached 156,790, 287 people. When compared with 2014, the number BPJS Kesehatan participants increased by 17.51%, from in 2015 (Indonesia Health Profile Report, 2015).

Health human resources.

In 2015, total health human resources in Indonesia amounted to 876, 984 people: 647,170 health professionals (73.8%) and 229, 814 health support workers (26.2%). Nurses were the health professionals were recorded to be the highest in number in 2015 amounting to 223,910 or 34.6% of the total health personnel, and the lowest in number were traditional health workers, amounting to only 6 or 0.001% of total health personnel. (Badan Pusat Statistik, 2015)

3. A systematic review regarding transitional care experience of patients with strokes and their family caregivers.

This systematic review was conducted base on the method described by Holly and Salmond (2013). There are seven steps in the process as follows: formulating a question, establishing the inclusion criteria, developing and performing the search strategy, selection of the articles, data extraction, data synthesis, recommendations for practice and writing the review.

Formulating a question.

The framework of: patient, problem or population, intervention, comparison, control or

comparator and outcome (PICO) was as used to formulate the research question. The purpose was to review relevant studies regarding transitional care for patients with strokes and their family caregivers to improve their quality of life after discharge. The objectives were to identify: 1) countries where the studies were conducted, 2) type of transitional care received and outcomes, 3) actors influencing the outcomes and 4) patients' and family caregivers' experiences regarding transitional care.

Inclusion criteria.

To be included, an article was required to (1) be published in a peer reviewed journal, from year 2007 through 2017, (2) report on a transitional care intervention program compared with standard hospital discharge, (3) report on patients and family caregivers experience during transitions from hospital/rehabilitation center to home, (4) explore the needs of patients with a stroke and family caregivers before and after discharge, (5) be a RCT, cohort or longitudinal study, quantitative or qualitative study, (6) be published in English, and (7) provide an analysis of outcomes that evaluated the range of improvement of health status of patients with stroke and their family caregiver.

Search Strategy.

The search keywords and index terms were taken from databases: Cochrane Library, CINAHL, and PUBMED. Several studies were found by hand searching. The keywords were transitional care, experience, patients' needs, discharge planning, continuum care, stroke, patient and family caregiver.

Selection of articles.

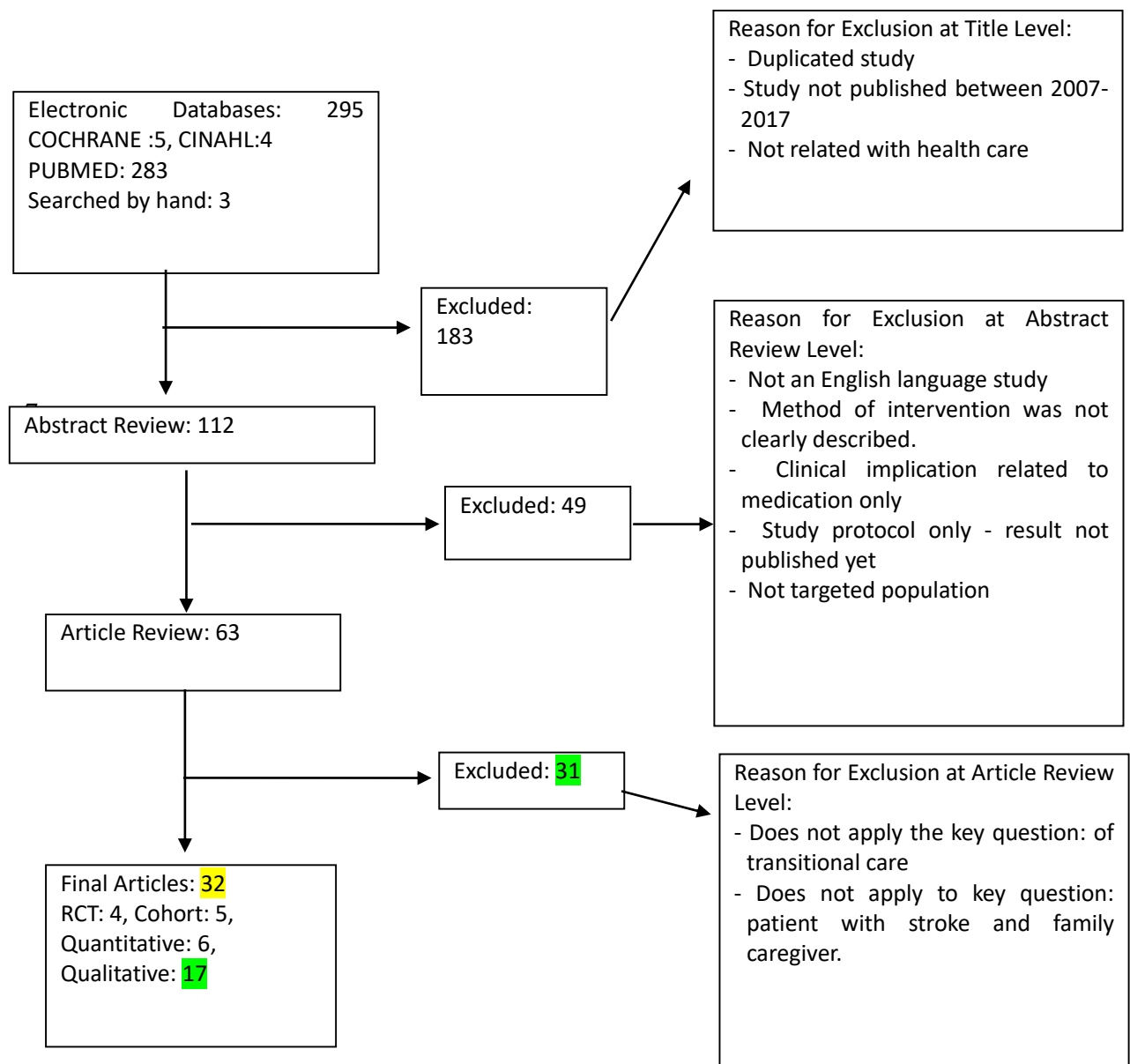
Figure 2 illustrates the summary of literature searched and number of articles included or

excluded in this study. The reason for exclusion criteria for each review level such as title review level, abstract review level and full text review were also documented.

Data extraction.

The articles were review by an independent reviewer and included or excluded by the criteria listed above. There was no blinding method for data abstraction regarding the article's author, institution or journal. See Figure 2 of the data extraction.

Figure 2. Summary of Literature Search and Number of Articles



Data Synthesis.

Narrative descriptive synthesis was used in the data synthesis of the systematic review. A descriptive synthesis provides a tabular summary of all studies related to each key piece of information identified as important and facilitates analysis of comparison across study (Holly, et al., 2012). The summary of the studies is shown in Table 2.

Findings

There were 32 studies, which met the inclusion criteria. There are four supporting studies, which were included in data synthesis, four randomize controlled trial studies (RCT), five cohort and observational studies, six quantitative studies and 16 qualitative studies.

1) Countries where the studies were conducted.

Twenty-four studies were conducted in high-income countries: USA (10 studies), Canada (4 studies), UK (3 studies) one study from UK however used setting in Indonesia, Sweden (2 studies), Australia (2 studies), Italy (1 study), Norway (1 study), and Luxemburg (1 study). In addition, eight studies were conducted in middle-income countries: China (1 study), Taiwan (3 studies), Iran (1 study), Malaysia (2 studies), and Indonesian (1 Study). There was a trend in middle-income countries to conduct the research regarding transitional care for patients with strokes to promote a continuum care for patients as well as their family caregivers. In addition to that, most studies in high-income countries tried to improve transitional care programs as one of the effective factors to reduce readmission. The studies were also addressing the family caregivers as an important focus of study for improving quality of care as well as improving quality of life of both patients and family caregivers.

2) Type of transitional care and outcomes.

Four RCT studies examined the transitional care model compared with traditional treatment or routine hospital program. There are three types of transitional care program tested in the RCT. They are described below.

(1) Model of outpatient rehabilitation (Taule et al., 2015, Norway).

This model included early supported discharge (ESD) in a day unit and ESD at home. ESD in a day unit is a treatment by the municipal health care team. The provider usually was an occupational therapist and/or physiotherapist. Treatment was mainly individualized and focused on specific function like training of memory and hand function. Group activities were included such as eating lunch and walking together.

(2) Transitional program with Omaha system framework (Rances, et al., 2014, China).

This study used the Omaha system framework as a comprehensive assessment for standard care protocol of transitional care program (TCP). TCP also combined with pre-discharge holistic assessment and care planning followed with a structured event that was implemented each week within the four-weeks post-discharge included family meetings, home visits and telephone calls.

The providers were nurses as care managers who had completed a training for this program.

(3) Transitional care program for discharge (Shyu, et al., 2010 and 2008, Taiwan).

This was a transitional care program that included in-hospital and post-hospital services. In-hospital services included assess individual discharge needs within 48 hours of admission, consultation to anticipate competing needs after discharge, provide individual discharge health educational consultation and referrals. Post-hospital services included home visit during weeks one and three after discharge and also telephone consultation. The providers were nurses who had training regarding the problems.

(4) The outcomes.

Two RCT studies reported five patient outcomes from the intervention of transitional care model: (1) improve Activity daily living (ADL) ability (Taule et al., 2015), (2) higher modified Barthel index scores, (3) better spiritual-religion scores, (4) higher satisfaction, and (5) lower depression scores (Rances, et al., 2014). In addition, family caregiver outcomes were summarized from two RCT included quality of care improvement (Shyu, et al, 2010), better evaluation of family caregiver preparation and greater satisfaction of discharge needs (Shyu, et al., 2010 and 2008).

3) The factors influencing the outcomes.

Two cohort and observational studies examined the impact of stroke: 1) patients and family caregivers' quality of life (Pucciarelli, et al., 2017) and 2) caring role on the carers of stroke survivor (Sky & O'Connel, 2007). The outcome summaries were as follows: physical function had the greater impact on the patient and there was a significant difference in improvement quality of life in the physical domain (Pucciarelli, et al., 2017; Sky & O'Connel, 2007). Moreover, one cohort study investigated the parallel life situations between patient and carers (Olaiya et al., 2017) and found that the burden of the caregiver before index admission, caregivers provided care five hours per week and after discharge 11 hours per week. The findings reported that there was an association within the dyads regarding anxiety score, Nottingham Health Profile (NHP) score and activity score and caregiver burden was generally high indicating poorer health perceptions (Olaiya et al., 2017).

There were two out of six cohort and observational studies examined stroke survivors' unmet needs at one year and longer (Olaiya, et al., 2017; Ullberg, et al., 2016), one study examined family caregivers changing needs at four time points during the transitions from intensive care unit to the neurological unit (Tsai et al., 2015). The four-time points were: before the transfer from intensive care unit to neurological unit, before discharge, two weeks

post-hospitalization, and three months post-hospitalization. The outcomes regarding survivors' unmet needs included lack of the secondary prevention (Olaiya, et al., 2017) and there should be a comprehensive long-term follow-up system to meet the needs one year post stroke, which was commonly associated with age, dependency, pain and depression (Ullberg, et al., 2016). Furthermore, the outcome also addressed family caregivers needs to obtain assistance and information related care from professionals during the course of disease (Tsai et al., 2015).

Three out of six quantitative studies investigated the stroke survivors and family caregivers' quality of life related to the following: 1) the perceived stressful experiences of the wife in the care of her spouse with a stroke (Smith-Johnson et al., 2015), 2) home care services (Baumann et al., 2014) and 3) life after discharge (Almborg, et al., 2010). Three studies evaluated depressive symptoms for stroke survivors who were already discharged at one week, three weeks, six months until one year and reported that depression was related to lack of knowledge/ information, minimal assistance from family members, and unmet needs related to home services. In addition, family caregivers' depression related to caregiving burden (Rothwell, et al., 2012, Baumann et al., 2014, Almborg, et al., 2010). One study investigated factors contributing to self-care in patients with stroke in Indonesia and reported independent self-care was associated with family support, (Mendrofa, et al., 2015).

4) Patients and family caregivers experience regarding transitional care.

Seventeen qualitative research studies with various designs and substantial results were identified from the search. The methods used in these studies were: three phenomenology studies, six grounded theory studies and eight qualitative descriptive studies. Fifteen studies used in-depth semi-structured interviews and two studies used focus groups. The studies mostly reported on the fundamental information regarding experiences of patient with a stroke and family caregivers at home after discharge, the needs of patients after the

stroke and family caregivers regarding transition process as well as unmet needs of patients and family caregivers following discharge. (Cameroon, 2014; Ing, et al., 2015; Simeonne, et al., 2016).

The experience of patients who had strokes and the caregivers (family, informal caregivers, etc. but mostly spouse) were reported as a changed life for both for patients and the caregivers (Cecil, et al., 2012; Gustafsson & Bootle, 2013; Green & King, 2009; Lutz, et al., 2011 & 2013; Simeone, et al., 2016). The themes regarding the experience described as 'life is different now', 'it's a struggle', 'life disintegration', 'incorporate the life of self and the relationship', 'stroke as a crisis', and 'relief after patient recovery'.

The needs of the stroke patients regarding the transition process, which usually happened after patient's discharge to home at the time point one month, three months until one years following discharge. The needs were based on the stroke's patients are reported as follows: (1) Rehabilitation for improving physical function (Dalvandi, et al., 2010); (2) Access to rehabilitation services at primary care (Aziz, et al., 2014); (3) Educational plan (Dalvandi, et al., 2010; Ing, et al., 2015); (4) Information regarding services (Dalvandi, et al., 2010; Simeone, et al., 2016); (5) Stroke education (Ing, et al., 2015) and (6) Risk assessment of the patients and family caregivers (Lutz, et al., 2007).

The needs of family caregivers were reported as follows: (1) Emotional readiness (Giosa, et al., 2014), (2) Assessment of the unique family situation (Giosa, et al., 2014), (3) How to cope with shifting to a new role (Cecil, et al., 2012; Giosa, et al., 2014; Lutz, et al., 2007), and (4) Preparation for caregiving (Simeone, et al., 2016).

Summary

These studies have contributed to the literature and vary considerably in the definitions used, the samples selected, the designs used, and the study domains examined.

However, these studies sharing the same commonalities regarding the research purposes. There were a limited number of RCT studies that could be found. The studies with qualitative design indicate a trend that all countries were still searching and trying to understand the lived experience of patients having strokes during their transition from hospital to inpatient rehabilitation or from hospital to home.

This trend showing the research direction for researcher to explore the understanding of patients and family caregivers is pivotal for developing appropriate and suitable care to achieve smooth transition and improving quality of life of patients and family caregivers.

Implication for the main study

Based on the literature review there are some implication that can be drawn.

- 1) Most of the studies were conducted in the USA and Europe; there was only one study relating to Indonesia. That study regarding the stroke experience was originally conducted in Indonesia but not by Indonesian researchers; moreover the perspective was not purely nursing science. So clearly research is needed that can describe the experiences of Indonesian patients and family caregivers (especially with the unique of influence of culture and religion) from both the Indonesian and nursing science perspective.
- 2) The issue of patients experience after discharge was mostly regarding physical disturbances, limited participation in daily activity and the urgent needs of patients to improve the physical function and return to a normal life. This part will be the important point of patients and family caregivers' experience exploration.
- 4) The successful transitional care for stroke patients and family caregivers based on the systematic review were: the early planning for anticipating the needs of patients at discharge planning after patient admission; including the family in the risk assessments in anticipation of caregivers' burden and the exploration for family caregivers experience is also necessary.

Table 2. *Summary of Studies for Transitional Care Experience of Stroke Patients and Family Caregivers after Discharge.*

No	Author, Year, Country	Sample	Design & Sample	RCT		
				Intervention Type	Measurements	Results
1	Taule, et al., 2015 (Norway)	To compare three models of outpatient rehabilitation, Early supported discharge (ESD) in a day unit, ESD at home and traditional treatment in the municipality (control group), regarding change in ADL ability during first three months after stroke.	A group comparison study with a randomized control trial 154 participants, 103 participants completed study (dropout rate 33,1%)	1. ESD day unit (participants were transferred from their home to a day unit for treatment by the municipal health-care team.) 2. ESD home (participants were offered the treatment in their home by the municipal health-care team) 3. Traditional treatment (control)	1. Assessment of Motor and Process Skills (AMPS). 2. modified Ranking Scale (mRS)	There were no significant group differences in pre-post changed ADL ability measured by the AMPS. Participants with ESD rehabilitation model were compared with traditional treatment were significantly associated with improve ADL ability measured by mRS.

2	Wong & Yeung, 2014 (China)	To test the effectiveness of a transitional care programme (TCP), which was a nurse-led 4-week programme designed based on assessment-intervention evaluation Omaha system framework	Randomized control trial 108 stroke patients control (n=54) and intervention groups (n=54)	4 weeks when the TCP was completed and 8 week after discharge from hospital. Repeated measure analysis of variance with intention-to-treat strategy.	1. Patient related outcomes -Quality of life (SF-36, WHO-QOL-SRPB) -patient satisfaction questionnaire (PSQ) 2. clinical outcomes - functional performance measured by Modified Barthel Index (MBI) -the depressive symptom	The intervention group had better spiritual-religion-personal measures, higher satisfaction, higher modified Barthel index scores and lower depression score when compare with control group.
3	Shyu, et al., 2010 (Taiwan)	To explore the long-term effects of a discharge-preparation programme targeting Taiwanese family caregivers of older patients with stroke.	A randomised experimental design 158 older patients (72 experimental group and 86 control group)	1. Experimental group: received hospital discharge services: in hospital (assessment after 48 hours, consultation to anticipate, provided health educational) and post hospital (home visit during first and third week after discharge. 2. Control group (routine hospital discharge)	1. patients and family caregiver's health-related quality of life by SF-36 (Taiwan version) 2. Chinese Barthel Index (CBI) 3. Family Caregiving Consequence Inventory (FCCI)	This intervention programme succeeded in improving quality of care provided by family caregivers to older patients and in decreasing the likelihood of their institutionalisation.

4	Shyu, et al., 2008 (Taiwan)	To test the effectiveness of a discharge planning programme for dyads of older stroke survivors and their family caregivers.	A randomised experimental design Control group (n=86 dyads) and experimental group (n=72 dyads)	Variables were measured by the Nurse Evaluation Of Caregiver Preparation Scale, Preparedness for Caregiving Scale, Caregiver Discharge Needs Satisfaction Scale, and Perception of Balance between Competing Needs Scale.	1. The Nurse Evaluation of Caregiver Preparation Scale 2. Caregiver's self-evaluation-> Preparedness for caregiving Scale 3. Caregiver Discharge Needs Satisfaction Scale	Caregivers in the experimental group had significantly better nurse evaluation and self-evaluation of preparation after the program. Greater satisfaction of discharge needs one month after discharge compare to control group. No significant difference between caregiver groups in perceived balance of competing needs.
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Cohort and Observational Study						
No	Author, Year, Country	Sample	Design & Sample	Intervention Type	Measurements	Results
5	Olaiya, et al., 2017 (USA)	To extensively investigate long-term unmet needs in survivors of stroke or TIA and to identify factors associated with these unmet needs.	Observational Study 485 participants	No Intervention	1. The International Classification of Function Core Sets for Stroke and Neurologic condition for post-acute care 2. Close-ended question	Survivor of stroke/TIA reported considerable unmet needs >2 years after discharge particularly in secondary prevention
6	Pucciarelli, et al., 2017 (USA)	To examine changes in stroke survivor and caregiver quality of life (QOL) and to determine whether changes in survivor physical functioning and caregiver burden.	Longitudinal design 226 stroke survivor-caregiver.	No Intervention	1. WHOQOL-BREF 2. Barthel Index 3. Caregiver Burden Inventory	Stroke survivors and caregivers varied and were greatly impacted by the physical function changes of the survivor.

7	<i>Ullberg, et al., 2016 (USA)</i>	To identify baseline predictors and 12-month factors that were associated with perceived unmet rehabilitation needs 1-year post stroke.	Observational Study 37, 383 patients	No Intervention	Postal Questionnaire from the Swedish stroke register	Unfulfilled rehabilitation needs 1 year post-stroke were common and associated with high age, dependency, pain, and depression. Long-term follow-up systems should, therefore, be comprehensive and address multiple domains of post stroke problems rather than having a single-domain focus.
8	<i>Tsai, et al., 2015 (Taiwan)</i>	To explore the changing needs of family caregivers of stroke patients and factors related to the needs in four stages, before the transfer from intensive care unit to neurological unit.	Longitudinal research 60 family participants	No Intervention	Data were collected at four time points by questionnaire 1. National Institute of Stroke Scale (NISS) 2. Barthel Index 3. Family Needs of Stroke patient questionnaire	Family caregivers expected to obtain assistance and related care information from professionals during the course of the disease.
9	<i>Ski & O'Connel, 2007 (USA)</i>	To examine the impact of the caring role on carers of stroke survivor, particularly the services provided and the levels of depression and well-being experienced.	A longitudinal design 26 participants.	No Intervention	Information was collected by using survey methods and structured interviews. 1. WHOQOL-BREF 2. Stroke Impact Scale 3. Zung Self-Rating Depression Scale	The main finding was that depression scores for carers and stroke survivors were below Australian norms at both assessment time points.

Quantitative Study						
No	Author, Year, Country	Sample	Design & Sample	Intervention Type	Measurements	Results
10	Smith-Johnson, et al., 2015 (USA)	To explore perceived stress experiences of African American wives in the care of spouse who was a stroke survivors.	A quantitative design 38 participants from rural communities in south eastern region of North Carolina.	No Intervention	Adapted version of Pearline's Caregiving and Stress Process Tools to measuring stressful situation in the family.	Forced into caregiving role although many were often not prepared, and experienced much stress related to lack of knowledge, training and minimum assistance from other family members.
11	Olai, et al., 2015 (Sweden)	To analyse whether the parallel life situation between stroke patients and their informal caregivers (dyads)	A cross sectional study 377 participants and 268 informal caregivers	No Intervention	1. Patient interview 2. MMSE 3. Nottingham Health Profile (NHP) 4. Hospital Anxiety & Depression scale 5. Gothenburg Quality of Life	There was an association within the dyads regarding anxiety score, NHP score, and activity score. Caregiver Burden score was generally high.

12	<i>Mendrofa, et al., 2015 (Indonesia)</i>	To assess indicators of self-care and model family support related to self-care.	A cross sectional study 65 participants	No Intervention	1. Participants' Characteristic data 2. Structured questionnaire 3. Medical record history 4. Barthel Index	Factors associated with independence in self-care of stroke patients is effectively improved through family support. Improving the ability of families and patients through self-efficacy, self-management and self-regulation was encouraged.
13	<i>Baumann, et al., 2014 (Luxemburg)</i>	Explores the associations between QoL and socioeconomic factors, functional impairments and self-reported dissatisfaction with received information and home-care services among survivors two years after stroke onset.	Multilevel linear regression models. 94 participants with three data collection times: 1 week after discharge, 3 months after index admission and 12 months after index admission	No intervention	1. QoL: The Newcastle Stroke-Specific Quality of Life Measure 2. Functional impairments: The American Heart Association Stroke Outcome Classification. 3. Dissatisfaction with information and home care services 4. Caregiver Burden Scale	Stroke-survivors had major alterations in QoL that reflected depressive symptoms which should be appropriately treated.

14	<i>Rothwell, et al., 2012 (UK).</i>	To investigate the feasibility of administering the Greater Manchester Stroke Assessment Tool (GM-SAT).	Survey 137 participants	No intervention	Patients needs were assessed by information, advice and support (IAS) coordinators from the UK Stroke Association using the GM-SAT	The mean number of unmet needs identified was 3. The most frequently identified unmet needs related to fatigue (34.3%), memory, concentration and attention (25.5%), secondary prevention-non life style (21.9%), and depression (19.0%)
15	<i>Almborg, et al., 2010 (Sweden)</i>	Examines different correlates to health-related quality (HRQoL) of life after discharge in patients with stroke.	Cross-sectional study 188 participants	No Intervention	1. HRQoL with SF-36 2. The Centre for Epidemiologic Studies Depression Scale (CES-D) 3. The Barthel Index 4. The Frenchay Activities Index (FAI) 5. The patient's questionnaire about participation in Discharge planning	Several variables were related to good HRQoL two or three weeks post-discharge, particularly fewer depressive symptoms: participation in social activities and performance of interests.

Qualitative Study						
No	Author, Year, Country	Sample	Design & Sample		Measurements	Results
16	<i>Simeone, et al., 2016 (Italy)</i>	To describes the experience of stroke caregivers three month after patients are discharged home from a rehabilitation hospital	Phenomenological study	No Intervention	interview	Seven themes emerged from analysis; deeply-changed life; re-appreciation of the relationship with patient and family members; increase workload; difficulties in getting support from the national health care system; lack of preparation from caregiving; difficulties in coordinating caregiving; family and personal life; relief after patient's recovery.
17	<i>Ing, et al., 2015 (USA Hawaii)</i>	To assess the overall understanding and effectiveness of current inpatient stroke education practice	A qualitative study with a phenomenological approach	No Intervention	Interview	There were three major gaps in stroke knowledge that participants noted: 1) Lack of stroke knowledge/awareness, 2) Need of stroke education, 3) Fear of recurrent stroke and comorbid disease.

18	<i>Cameron, et al., 2014 (Canada)</i>	To explore stroke survivors, caregivers and health care professionals' perception of weekend passes offered during inpatient rehabilitation and its role in facilitating the transition home.	Qualitative descriptive 51 participant (16 stroke survivors, 15 caregivers, 20 health care professionals).	No Intervention	Interview	Identified 3 key themes: 1) preparing for patients to be safe at home;2) gaining insight through the weekend pass administration and 3) the emotional context of the weekend pass.
19	<i>Abdul Aziz, et al., 2014 (Malaysia)</i>	To review provisions of post-stroke care and related problems among family medicine specialist managing public primary health care services.	constant comparison data 121 family participants	No Intervention	A semi-structured questionnaire	Post discharge stroke care guidelines and access to rehabilitation services at primary care is needed for post stroke patients residing at home in the community
20	<i>Mohd Nordin, et al., 2014 (Malaysia)</i>	To explore the perception of rehabilitation professionals and people with stroke toward long term stroke rehabilitation services and potential approaches to enable provision of these services.	A qualitative research with FGD 23 participants (15 professionals and 8 stroke survivors)	No Intervention	Interview	Both groups agreed that people with stroke may benefit from more rehabilitation compared to the amount of rehabilitation services. The group also highlighted the urgent need for a community-based stroke rehabilitation centre.

21	<i>Giosa, et al., 2014 (Canada)</i>	Explored informal family caregiver experiences in supporting care transitions between hospital and home for medically complex older adults.	A qualitative Grounded-theory approach 12 family caregivers, 6 case managers	No Intervention	In-depth semi-structured interview	Six properties characterizing caregivers needs in successfully transitioning care between hospital and home were integrated into theory addressing both transitional care timeline and the emotional journey. The six properties were: 1) assessment of the unique family situation;2) practical information education and training; 3) involvement in training process;4) agreement between formal and informal caregivers;5) time to make arrangements in personal life and 6) emotional readiness.
22	<i>Cecil, et al., 2012 (UK)</i>	To explore caring and coping among carers of stroke survivors and identify factors that had an impact on their lives	Qualitative descriptive study 30 carriers of stroke survivors	No Intervention	Interview	Nine thematic categories were identified, which fell into three broad categories: 1) The impact of the stroke event on the carrier; 2) The extrinsic factor that support caring scenario and 3) The intrinsic factors that help a carer to cope with a new role.

23	<i>Lutz, et al., 2011 (USA)</i>	To explore the needs of stroke patients and their family caregivers as they transitioned through the stroke care continuum from acute care to inpatient rehabilitation to home.	A grounded theory study 38 Participant (19 stroke survivor, 15 caregivers, 4 adult children)	No Intervention	Unstructured interview	Stroke survivor and their caregivers do not have adequate time to deal with the shock and crisis of the stroke event, let alone the crisis of discharge and all to the new responsibilities with which they must deal.
24	<i>Dalvandi, et al., 2010 (Iran)</i>	To illuminate how stroke survivors experience and perceive life after stroke.	A grounded theory study 10 Participants	No Intervention	Semi-structured interview	Lack of an educational plan, lack of access to rehabilitative services, physical and psychological problems led them to functional disturbances, poor socio-economic situation and life disintegration. The core concept of life after stroke was functional disturbances.
25	<i>Eames, et al. 2010 (Australia)</i>	To identify patients' and carers' perceived barriers to accessing and understanding information about stroke.	A qualitative content analysis 132 patients and 44 carers	No Intervention	Interview prior to and after 3 months following discharge	three categories of barriers were identified; 1) limited availability and suitability of information, 2) Barriers in the hospital environment, 3) Patients and carer barriers. Three themes were also identified, namely: 1) Who is responsible, 2) communication and 3) not knowing

26	<i>Green & King, 2009 (Canada)</i>	To explored male patients with minor stroke and their wife-caregiver's perceptions of factors affecting quality of life and caregiver strain encountered during the first year post-discharge.	Conventional content analysis 26 stroke patients and their wife-caregivers	No Intervention	Open ended questions and part of quality of life and caregiver strain scale	Patients and their wife-caregivers expend considerable time and energy re-establishing control of their lives following minor stroke in an attempt to incorporate changes to self and their relationship into the fabric of their lives.
27	<i>Vincent, et al., 2007 (Canada)</i>	To explore partially met and unmet rehabilitation needs of older adults who had suffered a stroke and who live in the community.	Focus group technique 72 participants (12 groups)	No Intervention	Group interviews and qualitative analysis strategy using Disability Creation Process model	Rehabilitation needs persist for nine capabilities, nine factors related to the environment and 11 life habits. The caregivers and health professionals identified more unmet needs and insisted on an individualized rehabilitation.
28	<i>Deniger, et al., 2015 (USA)</i>	To determine the cause of readmissions in patients participating in geriatric transitional care (GTC) program and evaluate processes and outcomes to identify potential areas of improvement.	Hospital's computerized medical charting systems 391 participants	No Intervention	Subjective measure clinical judgement	Readmission rates for the GTC program were significantly different than the hospital-wide readmission rates ($\chi^2=11.95$, $P<.05$). Discharge disposition and types of support in place after discharge were helpful in determining if readmission could have been prevented.

29	Lutz, et al., 2016 (USA)	To improve stroke caregiver readiness and identifying gaps in caregiver preparation	Grounded theory 40 family participants	No Intervention	Open ended question	Caregivers identified critical areas where they felt unprepared to assume the caregiving role after discharge from inpatient rehabilitation. Steps to improve preparation include (a) conducting a risk assessment of the patient and caregiver; (b) identifying and prioritizing gaps between the patient's needs and caregiver's commitment and capacity; and (c) developing a plan for improving caregiver readiness.
30	Lutz, et al., 2007 (USA)	To identify post discharge needs of veterans with stroke and their caregivers and to identify how to design a care coordination/home-telehealth program to address these needs.	Grounded theory 22 participants (12 veterans and 10 caregivers)	No Intervention	Open and unstructured question	Core concepts identified were 1) Assessing and managing the residual effect of stroke, 2) shifting role and responsibilities. This study also suggest that a home-based, post-stroke, care coordination telehealth program could be designed to include activities that improve functional mobility and exercise programs that are tailored to the needs and preferences of stroke survivors and their caregivers.

31	<i>Gustafsson & Bootle, 2013 (Australia)</i>	To enhance our understanding of the transition experience for clients with stroke and their carers during discharge and the first month at home	Descriptive qualitative design 11 participants and 18 carers	No Intervention	Semi-structured interview	Five clients and five carers were interviewed 1 month after discharge to home. The analysis of the client interviews yielded three themes including: rehabilitation was okay, it's a struggle, and supports and assistance. The carers interviews also yielded three themes including: the purpose of rehabilitation, life is different now and looking to the future.
32	<i>Norris, et al., 2011 (Indonesia)</i>	To explores the experience of stroke in the rural community of central Aceh, Indonesia.	Phenomenology 11 participants and 18 carers	No Intervention	Semi-structured interview	The results suggest a need to understand the experience of stroke more concretely within the specific social context of the stroke survivor and to broaden the understanding of biography to include aspects beyond the individual that are deemed key to biographical continuity.

CHAPTER 3

A PRELIMINARY STUDY

This preliminary study was conducted in an urban area of Indonesia, South Tangerang city to describe the needs of adult stroke patients and family caregiver at home after discharge from acute care facilities. The description was based on the interview data from the patients and family caregivers regarding disability, daily living care, and continuity care to improve patient and family caregivers' quality of life. This chapter describes the objectives, methods, results, discussion, and implications for the main study.

1. Objectives

The objectives of this study were to describe the following: 1) the characteristics of the patients and family caregivers; 2) the transitional care needs of adult stroke patients and family caregivers at home after discharge; 3) discharge planning from health care providers; 4) examine the feasibility of research for main study.

2. Definition of terms

Transitional care needs of adult stroke patients and family caregivers

Care provided to the patients and their family caregivers as they move from one acute care to home and refers to care that aims to provide coordination and continuity of health care along the transitions period. (Coleman, 2003; Coleman & Berenson, 2004; Jones & Foster, 1997).

Adult stroke patients

Refers to the people aged 45 years and over who have been diagnosed with first time ischemic stroke and have been discharged from the hospital after one month from

the time of admission in an urban city in Indonesia.

Family caregiver

Family caregiver is defined as a family member who is identified by the patient as a person whose mainly responsible for patient's daily care at home.

After discharge

After discharge refers to a period of time or situation at home when patients have been discharged from the hospital.

3. Methods

1) Design.

This study was a qualitative study using in-depth semi-structured interviews based on the grounded theory approach. Grounded theory is a method to develop a theory about the phenomena of interest and is grounded from available data (Strauss & Corbin, 1990). According to Creswell (2009), grounded theory is “a qualitative strategy of inquiry in which the researcher derives a general, abstract theory of process, action, or interaction grounded in the views of participants in a study” (p.). This process involves using multiple stages of data collection and the refinement and interrelationships of categories of information (Charmaz, 2006; Strauss and Corbin, 1990, 1998). Within grounded theory, the emphasis is on developing an understanding of human experiences and interaction through a process of discovery and inductive reasoning, rather than deduction and hypothesis testing (Elliot & Lazzenbat, 2005 in Giosa, et al., 2013).

In the current study, a grounded theory approach was used because there is a little known about the area of transitional care for stroke patients and family caregivers in Indonesia. This present study aimed to explore the experience of stroke patients and

family caregivers at home after discharge from the acute care facility. After being interviewed about their experiences at home after discharge, the data were gathered and analyzed using constant comparative methods. The experiences included their views and perspective regarding transition time and care that had been provided by the health providers during transitions from acute care facility to home. From the interviews, these experiences that were reported by the patients and their family caregivers were analyzed and codes were developed that were clumped into sub-categories that described specific experiences and later the researcher analyzed these. Eventually the specific needs regarding transitional care emerged from the data of patient and family caregivers' experiences. Based on this, transitional care needs of stroke patients and family caregivers from South Tangerang city, Indonesia will be described.

2) Participants and recruitment.

The inclusion criteria for *patients* were as follows: (1) aged above 21 years, (2) has been discharged from hospital at approximately one month [these criteria were revised to increase the participant's number], (3) has disability with hemiparesis or paralysis, (4) able to communicate, (5) living alone or with a caregiver or next of kin, and 6) willing to participate.

The inclusion criteria for *family caregivers* were as follows: (1) aged over 18 years, (2) able to communicate, (3) main caregiver of stroke patients, and (4) willing to participate.

The recruitment process took place in two setting: the outpatient clinic and inpatient clinic. At the outpatient clinic, an explanation of the study and a request letter were given to the participants when they were having a medical check-up. The

appointment of home visits were made after patient and family signed the inform consent.

At the inpatient unit, the participants were selected by the time of discharge approximately one month after discharge and contacted by telephone. Then during a phone call, they were given the explanation of the study. The home visit was made after they were agreed to participate. At home, they were informed regarding the study in details and asked to sign the inform consent if they agreed to participate. Five dyads (N= 10; n= 5 patients, n= 5 family caregivers) were eligible for further analysis.

3) Data collection.

The data were collected from July 20, 2016 to August 8, 2016. Face-to-face interviews were conducted at the participants' homes. Data were collected from the patients and family caregivers' interviews separately. The interview lasted for about 30 minutes each using the interview guide. The interview was conducted in the Indonesian language. The main questions asked involved the following areas: (1) the patients and family caregivers' characteristics; (2) the experience of stroke patients and family caregivers after hospital care because of the first attack of stroke (at time of discharge and approximately one month after discharge); (3) patients' feelings regarding their transition from hospital to home, and (4) type of support system that they had and mostly needed.

4) Data analysis.

The data were collected from participants' interviews and researcher's memo writing. The interview data were transcribed verbatim and after all was completed, the transcripts were translated from Indonesian to English. Memo writing was free-style

approach captured a chronological account of the researcher's and participants' process of interview. Coding, category descriptions and the process of comparative analysis following the conventions established by Charmaz (2006). Initial coding, selective coding or focused coding and axial coding (Charmaz, 2006) includes refining and indexing systems of initial codes to determine the codes that are analytically useful and using them as a basis for re-engaging with the data. Initial coding was line by line coding where the experiences of patients and their family caregivers were gathered. Later the focused coding was the second major phase in coding. These codes are more directed, selective, and conceptual than word-by-word, line-by-line, and incident by-incident coding (Glaser, 1978). One goal was to determine the adequacy of those codes. incisively and completely. Focus coding made the most analytic sense to categorize data incisively and completely (Charmaz, 2006). Next was the axial coding, the purposes of axial coding was to sort, synthesize, and organize large amounts of data and reassemble them in new ways after open coding (Creswell, 1998). In this study the experiences of patients and their family caregivers during transition were described. Next was theoretical codes which was integrative; it lent form to the focused codes that were collected. These codes may help tell an analytic story that has coherence. Hence, these codes not only conceptualize how substantive codes are related, but also move the analytic story in a theoretical direction (Glaser in Charmaz, 2006). At this phase of coding, the transitional care needs emerged from the data.

5) Ethical consideration.

An approval from the Research Ethics Committee of St. Luke's International University was obtained in June 2016 (number 16-A014). A proposal and a request letter

were also sent to the participating hospital in a suburban area in Indonesia to obtain permission to conduct study. The hospital granted permission on July 2016.

This study was performed in accordance with the Declaration of Helsinki. The participants provided written informed consent and they were given clear explanations regarding research purpose, methods, risks, and anticipated benefits. The participants were also given the opportunity to ask any questions and to withdraw any time from the study. A refusal form attached with the informed consent was provided to ensure voluntary participation. An appreciation gift was provided for participating.

4. Results

This section mainly describes the preliminary study result based on the study objectives which included: 1. Characteristics of patients and family caregivers, 2. Transitional care needs of stroke patients and family caregivers, 3. Discharge planning from health providers.

1) Characteristics of patients and family caregivers

There were five sets of participants who took part in the interviews (10 people) who were eligible for the analysis. As shown in **Table 3**, the ages of the patients were between 36-55 years. Among them, four people were men. Regarding the educational background, two people completed senior high school. Most of the patients (n=4) were still actively working. The shortest length of stay in the hospital was three days (n=2) and the longest was 10 days (n=2). The times from discharge to the time of interview were one month for two patients, two-five months for two patients, and over six months for one patient. Two patients had left hemiparesis and three patients had right hemiparesis

with communication problems (one patient with dysphasia and two patient with expressive aphasia).

The age of family caregivers ranged from 36 to 70 years. Most of the caregivers were wives (n=4). Regarding the education background, two people completed senior high school. Among the family caregivers, two caregivers were housewives, one retired, and two people worked from home. All the participants were Muslims.

Table 3. The characteristics of patients and family caregivers

Characteristics		Case 1	Case 2	Case 3	Case 4	Case 5
Patients	Age (years)	68	57	43	60	93
	Gender	Male	Male	Male	Female	Male
	Education	Senior high school	Junior high school	Senior high school	Elementary	Folk school
	occupation	Retirement	Entrepreneur	Entrepreneur	Cleaning service	Farmer
	Length of Hospital's stay	10 days	3 days	10 days	5 days	3 days
	Discharge period	> 6 months	1 month	5 months	1 month	2 months
	Dissabilities	Left hemiparesis	Left hemiparesis	Right hemiparesis	Right hemiparesis	Right hemiparesis
Family Caregivers						
	Age (years)	61	54	38	66	70
	Status	Wife	Wife	Wife	Husband	Wife
	Education	High School	Junior high school	Senior high school	Elementary	Folk school
	Occupation	Retirement	Housewife	Entrepreneur	Driver	Housewife

note: Folk school was a precursor to elementary school

2) Transitional care needs of adult stroke patients and family caregivers at home after discharge

Figure 3 is a conceptual map of transitional care needs for stroke patients and family caregivers structured by the timeline of before discharge (at the hospital) and after discharge (at home). It is divided into three phases: (1) Facing difficulty (structured from five sub-categories), (2) Seeking treatment phase (structured from three categories) and (3) Expecting recovery phase (structured from two categories).

1) Before discharge

There are two categories identified: 1) *self-initiated discharge* which included three sub-categories: (1) Patients and family caregivers misunderstand treatment implementation, (2) Lack of information regarding next treatment, and (3) Cost concerns related to health service.

The second was: *no preparation or medical advice at discharge* which included three sub-categories: (1) No advice for patients to exercise paralyzed body part, (2) No preparation for taking medicine and (3) No advice before discharge.

2) At home (After discharge)

There were three phases of transitional care needs derived at home after discharge, they were: (1) Facing difficulty phase; (2) Seeking-treatment phase and (3) Expecting recovery phase. Every phase showed specific transitional care needs of patients with a stroke and family caregivers through the time periods of one month at home after discharge. This part will describe each phase along with the experience of

transitional care needs of stroke patients and family caregivers.

(1) Facing difficulty phase

This phase happened during the first until second weeks following discharge. Stroke patients encountered disability and concern about the difficulty regarding physical function and movements.

There are five sub-categories of concern in this phase for the patients. These included the following: restricting of ADL, depending on family for ADL, seeking treatment behavior, lacking ability to go to toilet, and preferring cleanliness.

Family caregivers also faced a new role with caregiving responsibility. In this study four sub-categories of concerns from family caregivers were identified as follows: (1) Bearing the burden on caregiving roles; (2) Expecting support from extended family; (3) Accepting caregiving role as an obligation and (4) Caring for sick relative or family member as a form of worship.

(2) Seeking-treatment phase

The second phase following discharge is seeking-treatment phase. At this phase, patients and family caregiver still have the same concern regarding the previous phase, such as; they were eagerly searching the treatment in order to improve their ability and overcome the difficulties that they had. The transitional care needs of stroke patients and family caregivers were clearly seen in this phase continuing from the previous phase. The transitional care needs for patient in this phase consisted of improving physical function by family support, improving personal care of elimination and communicating well. In addition, the family caregivers described their needs as having support from extended family members based on the sub-categories and having more information regarding

stroke care.

(3) Expecting recovery phase

The third phase is expecting recovery phase. This phase happened at the fourth week where patients had the highest needs; their concerns were wanting to be able to walk again, hoping to conduct *shalat* properly and wanting to get back to work. The concerns described the needs as getting back to normal life. In addition, two sub-categories of concern: limited access to health facilities and lack of understanding related health insurance system, indicated the needs of having information related health insurance services.

At the same time family caregivers concerns in this phase were still continuing from the second phase; the family caregivers described their needs about having support from extended family members based on the sub-categories and having more information regarding stroke care.

As seen in the figure after one-month patient and family caregivers' satisfaction level after discharge was ≥ 5 scale.

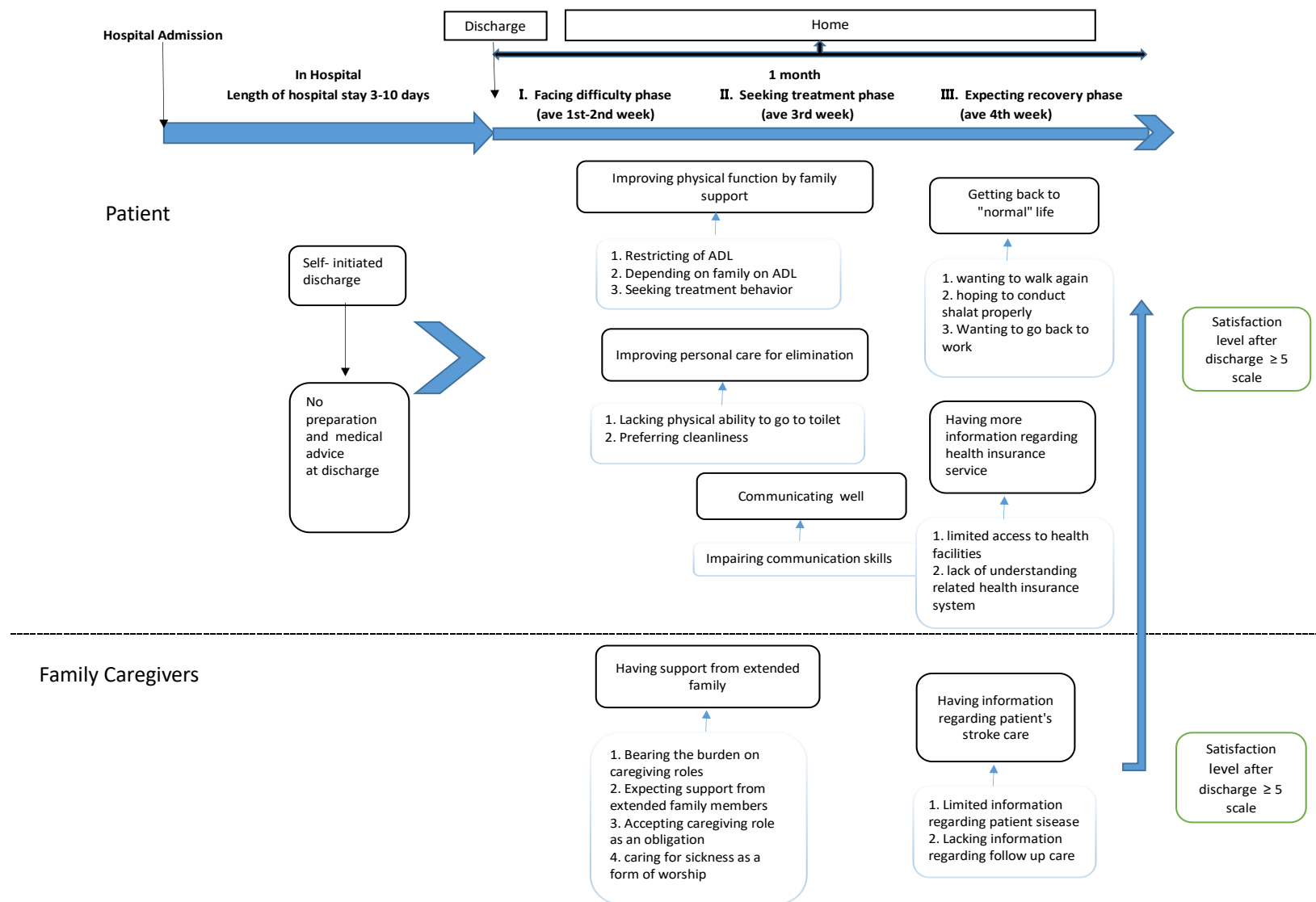


Figure 3. Transitional Care Needs for Stroke Patients and Family Caregivers at Home after Discharge

3) The transitional care needs of stroke patients

Transitional care needs of stroke patients described as shown in Table 4 as follows:

(1) Improving physical function by family support.

This need refers to the patients' urgency in strengthening their muscles of their affected body part that experienced weaknesses and functional loss of the motoric skills.

The complaints were: *"unable to hold/grasp a thing", "unable to sit", "unable to stand", and "unable to walk" because of their hemiparesis* as the case no. 3 and 4 described below.

"I couldn't move my legs, and I would keep falling if I stand. (3P- 5)

"During that time (two weeks after discharge), I couldn't do anything, I just lied down, I wasn't able to walk, wasn't able to hold anything, just lied down." (4P-8)

As the patients returned home, they were depending on family members for physical activities and particularly family caregivers were eagerly seeking the therapy to strengthening their physical function. The therapies that they received were mostly recognize as alternative medicine or complementary such as massage therapy from a reflexologist and acupuncture. One patient looked for treatment from a religious healer after they gave up the treatments from several reflexologist and acupuncture sessions. Neither the reflexologist nor the religious healer was officially registered.

“I started to look for a reflexology therapist to have a massage right after I returned home. I gradually improved my walking after I had the therapy” (1P-11)

“After returning home, some friends suggested for me to take my wife to reflexology therapy, and after several times, she discontinued the treatments. One of our neighbors recommended us to visit a healing master. The reflexologists and healing master do not have a fixed fee for their treatments. We just paid what we can afford.”

(4F-12)

(2) Improving personal care of elimination

It refers to the requirement of patients to conduct personal care particularly elimination in the bathroom even though they had restricted of physical function. All the patients reported urinating and defecating as major difficulty because they were unable to do these in the bathroom. They preferred to go to the bathroom rather than to use a bedpan in the bed.

Naturally, this kind of activity will be performed in private and needs privacy. Inability to go to the bathroom independently became important and created the need to gain independence. In regards of the patients they asked their spouse or another family member to carry them to the bathroom, otherwise they walked by themselves. One of the family members of the patient reported that the patient fell because the patient had

been told to eliminate in the bed, and his spouse was not able to assist him.

Unfortunately this 68 year old patient (case 1) was very insistent and pushed himself to walk to the bathroom alone.

However, some patients accepted their condition to eliminate in bed because the bathroom was located separately from house. As the patients described below:

“He didn't want to defecate or urinate on the bed. He insisted to go to the bathroom and walked by himself and fell down.” (1F11-12)

“After returning home, it was difficult to urinate or defecate. There were no helping tools. I insisted to go to the toilet (for urination and defecation), I asked assistance to be carried out or just forced myself to crawl.” (2P8-9).

(3) Communicating well

This meant that the patients want to be understood by others especially family members and can develop communication specially to express their needs to others.

Three out of five patients experienced right hemiparesis which affected their communication ability. The difficulty to communicate was when they were unable to express the words to speak (aphasia) and they were unable to say the words clearly (dysphasia). Two patients who experienced dysphasia described that they only have difficulty to speak in the beginning of first or two weeks, after that their ability was

gradually improving, as described below.

(4) Having more information regarding health insurance

This refers to the participants' limited access to the information regarding the health insurance system and they lacked understanding regarding services available covered by the insurance.

Patients were always worried about hospitalization because of cost concerns, thus they became passive in searching information from health facilities. Two patients did not have their own health insurance and they had to apply for it at the time of the stroke attack. Lack of understanding regarding health insurance system could hamper the services that they could get. Patients and family caregivers reported their experiences as follows:

"I never attempted searching for information regarding the nearest health facilities because of cost concerns." (2P-38)

"Actually, I didn't want to be hospitalized. I don't have BPJS (Health Insurance Service)." (2P-41)

"I need a professional helper, but I can't afford it as it will cost a lot, and I have no budget for it." (3F-19)

(5) Getting back to a “normal” life.

Patients expected to have a speedy recovery in order to be able to walk again as a “normal” condition, without using helping tools or any assistance. The “normal” was described by the patients as the condition of *able to walk again as in their previous life*.

“After being discharged from hospital, all I want is to be able to walk again. I really want to be able to walk normally, to be back to normal again.” (3P-17).

Four out of five patients (3 males and 1 female) were still actively working and were responsible for financially supporting their family. This situation necessitated them to recover faster to be able to perform their role as head of the family. Moreover, female patient in case 4 was responsible as a source of financial support because of her unemployed husband. Stroke attack appeared to become a threat for the financial security of her family. Thus the needs of ‘getting back to a “normal” life’ emerged. As described below:

“I really want to get back to work. Because if I didn’t work, what will we [she and her husband] do?” (4P-29).

“My communication is not like this (at the time of interview), previously [first – two weeks of discharge] my speech was slurred and unclear. I could understand what people say although my speech was unclear.” (4P-14).

Unfortunately, case number 3, who had aphasia showed a feeling of frustration at time of interview. He couldn't state his frustration into words but rather than showed the gesture of powerless, deep exhale and lots of sweat and finally he said he had so many things in his mind but it didn't come out.

"I also had a communication problem and difficulty in expressing it back to the person whom I have talked to. It is so hard to explain an event." (3P-7).

4) The transitional care needs for family caregivers

At the same time, family caregivers experienced two categories of transitional care needs at home after discharge: (1) having support from extended family and (2) having information regarding patient's stroke care. The explanations are as follows: (see Table. 5).

(1) Having support from extended family members

The need refers to the family caregivers demand to have more support from extended family members such as siblings, sons/daughters-in-law, brothers/sisters-in-law, and parents particularly during the early weeks at home after discharge.

The main family caregivers were mostly female and were in charge of delivering patients' care. They performed the caregiving role from morning to the night. The family caregiver from case 2 mentioned that after the patient came home, she

experienced lack of sleep, and the caregiving tasks were demanding too much of her physical energy, such as supporting patient to walk. Most of the patients relied on their caregivers to assist with their physical movement and balance. Unfortunately, for the female caregivers who were aged 60 years above such task became a burden because their limited strength. Thus, they demanded support from other family members. Family caregiver of case 2 described as follows:

Table 4. The Experiences and Transitional Care Needs of Stroke Patients after Discharge

Transitional care needs	The experiences of patients		Focused coding
Patient			
1. Improving physical function	1) Restricting ADL	(1)	Muscle weaknesses
		(2)	Eating in the bed
		(3)	Urination and defecation in the bed
		(4)	Bathing in the bed
		(5)	Unable to groom independently
		(6)	Unable to grasp
		(7)	Unable to sit
		(8)	Unable to walk independently
		(9)	Family support dependence on activities
	2) Depending on family for ADL	(1)	Support from spouse for personal care
		(2)	Support from family members for physical activities
		(3)	No help from professional helper
	2) Seeking treatment behaviour	(1)	Self - exercise at home therapy
		(2)	Seeking a Reflexologist
		(3)	Friends and neighbour information
2. Improving personal care of elimination	1) Lacking ability to go to the toilet	(1)	Unable to walk independently
		(2)	Elimination assisted by family
		(3)	Strong desire to do elimination in the toilet
	2) Preferring cleanliness	(1)	Patient's concern regarding hygiene
		(2)	Cleaning difficulty in the bed after elimination
3. Communicating well	1) impaired communication skills	(1)	Forgetfulness due to memory loss
		(2)	Inability to speak clearly
		(3)	Unable to express the word to speak
4. Getting back to a normal life	1) Wanting to be able to walk again	(1)	Feeling shame walking with a stick
		(2)	Wanting to walk again and back to normal
		(3)	Feeling depend on others is unexplainable
	2) Hoping to conduct <i>Shalat</i> properly	(1)	Praying on the bed
		(2)	Unable to walk to the mosque
	3) Wanting to go back to work	(1)	Family financial concern
		(2)	Want to be able to work

5. Having more information related health insurance	1) Limited access to health facilities	(1)	Distant between home and health facilities
		(2)	No visit after discharge
		(3)	Dependency on family to go to health facilities
		(4)	Peer-shared health information
	2) Lack of understanding related health insurance system	(1)	Didn't own health insurance before sick
		(2)	Cost concern regarding health services

Table 5. The Experiences and Transitional Care Needs of Family Caregivers after Discharge

Transitional care needs	The experiences of family caregivers		Focused coding
Family Caregivers			
1. Having support from extended family	1) Bearing the burden of caregiving roles	(1) (2) (3)	Lack of sleep during first week Physical task demand in assistance of patient Double burden of caregiver roles
	2) Expecting support from extended family	(1) (2) (3)	Expectation of extended family member support No help from professional assistance Count on the assistance of other family members
	3) Accepted caregiving role as an obligation	(1) (2) (3)	Responsibility as a spouse to take care Accepted sickness as un-avoidable Didn't feel caregiving as a burden
	4) Caring for sick person as a form of worship	(1) (2) (3)	Getting calmness from doing worship Dead or alive in the hands of God Sick as an examination from God to clean-up sins Regard caring as part of worship
2. Having information regarding patient stroke's care	1) Limited information regarding patient disease	(1)	Searching online information regarding stroke symptoms
		(2)	Stroke caused by eating goat meat
		(3)	No information regarding how to care patient previously
		(4)	Reducing salt and sweets for patient's meal
		(5)	Stroke can be cured Lack of knowledge regarding follow up treatment
	2) Lacking information regarding follow up care	(1) (2)	Looked for information regarding next treatment Wanted to have follow-up check

“I needed support like... what should I say... It’s all about physical task and I need help. Because I am a woman and if I was the only one who was doing everything alone, for the first time of discharge... I couldn’t; I needed someone’s help.” (2F-41)

There also one main family caregiver from case 3 who was pregnant and had to take care of her ill son, at the same time she was caring for her husband after his stroke. It was very challenging situation for her, as she also had to run their family business at home. Fortunately, her extended family caregivers gave her the support as she needed.

“I am involved in all forms of care. Sometimes my brother took my husband to the hospital for a check-up. Because I was taking care my ill son and my pregnancy and I have to run our business as well. I have to take care of everything. My parents also came to helping me.” (3F-6)

(2) Having information regarding stroke care for patient.

This need refers to gathering information related to patients’ disease for family caregivers who were experienced caring for stroke patients for the first time. The need for information regarding patients’ stroke care included the stroke disease, care and management for stroke patients, and follow up for medical treatment.

“I have never been informed about stroke before, but I think I need the information. However...I don't know how to get it.” (2F-26)

One of the family caregivers was lucky enough to have an explanation regarding her husband's disease from the physician and nurses at hospital before discharge. However, this information related health was not formally provided, as the main family caregiver of case 3 explained;

"The physician also told me about my husband's disease, to pay attention to his blood pressure and cholesterol, and the nurse told us not to forget to take the medicine. This information was told during hospitalization and just before discharge; however, no leaflet was provided." (3F4-5)

5) Discharge planning of health care providers

One of the objectives from this preliminary study was to identify the discharge planning by health care providers. Three of five patients had self-initiated discharge. This meant that they decided on their own to return home and receive care from family caregivers. At time of the patients' discharge, they described there were no preparation and no medical advice regarding medicine and exercise for paralyzed body part. The reasons of discharge were described by the patients because they felt more comfortable being at home, and didn't want to be hospitalized or have financial concern.

Fortunately, the family caregiver of case three described that she received information regarding her husband disease and what should be paid attention to

regarding the patient's condition at home. However, this information was still limited and a study regarding discharge planning from health care providers perspective should also reveal gaps that could be addressed.

5. Discussion

This study of patient and care-giver dyads revealed the specific needs for both patients and family caregivers following the patient's stroke. These important transitional care needs of stroke patient and family caregivers are highlighted and discussed within the context of improving patients and family caregivers' quality of life: 1) transitional care needs of stroke patients and family caregivers, 2) discharge planning by health-care providers, 3) strengths and limitation of the study. The detailed were described next.

1) Transitional care needs of stroke patients and family caregivers

After returning home, patients and family caregivers started to see clearly what were their needs for care. This was supported by the findings of Beunder, et al., (2015). In this study, from the perspectives of the participants, it appeared that stroke could be cured. In addition, this perspective led to their own effort to do self-care at home in order to perform activity daily living independently.

There are two important transitional care need's category that all the

participants described. At first, their need to perform elimination in the bathroom. There was a great desire of the patients to carry out their elimination in the bathroom rather than when they were in bed. With respect to case two, the patient crawled holding onto the wall or anything to be able to use the bathroom for elimination. In addition, the family caregiver of case one described that patient even experienced a fall because he insisted on going to the bathroom for elimination and at that time no one could assist him. The strong-will of patient showed a spirit not just to avoid embarrassment but it indicated a deeper motivation.

That motivation became a specific need that should be address from the perspective of Islam, because there was not just a privacy reason which could be an explanation for patients' preference. This preference may be influenced by the religious belief where Islam is the religion that all patients ascribed to. As a Muslim, they have the obligation to perform prayer five times a day and should be clean from urine or stools (*Hadaas*). Unfortunately, the results of the study did not reveal any further reasons for their great desire to use the bathroom.

Second transitional care need was the motivation to get back to a “normal” life. Four out of five patients were still actively working and were responsible for financially supporting their family. This situation necessitated them to recover faster to be able to

perform their role as head of the family, even though one patient of case four is female.

Unfortunately, her husband doesn't have a permanent job. The needs of getting back to a "normal" life emerged because stroke became a financial threat to the family.

Financial needs should be acknowledge by health-care providers prior to discharge so that realistic expectations can be established and patients' distress and frustration could be avoided.

At the same time, family caregivers important transitional care needs category from this finding was important to improve patient to fulfil. The first need of all the caregivers was their need of having support from extended family. Family caregivers experienced the caregiving burden during the early weeks of the patients' discharge. These were the times where most of the patients needed a lot of attention and assistance. The patients were depended on the caregivers to perform their daily activities. Thus, this condition required caregivers' to provide extra effort specially to assist patient with limited physical function. This was Especially true for case three when the family caregiver was a pregnant wife and she also had to taking care her son who experienced a bone fracture, thus they needed extended family support to be able to provide daily care to the patients.

Secondly, patients' transitional care needs involved having information

regarding the health care insurance system. Three out of five patients described that they didn't have health insurance and most of patients had limited information regarding insurance health system. This condition could cause a delay in managing the care of patients with strokes in the hospital and hamper the acceptance of the services covered by the insurance. The universal health coverage is a new system in Indonesia, which started in 2014 (Kemenkes, 2012) and information regarding health insurance system was still limited.

In summary the transitional care needs of patients mainly focused on improving physical function and for family caregivers were focused on improving caregiving roles. The transitional care that patients and family revealed was a transitional self-care of patients with strokes and their family caregivers in Indonesia and the result was supported by another study from Indonesia which investigated the independent nursing care model of survivors of ischemic stroked associated with family support (Mendrofa, et al., 2015).

2) Discharge planning by health care providers.

The self-initiated discharge was dominant in this study as the reason why patients returned to their homes. The patients motivation as they described was because they felt more comfortable to be cared for at home. Thus, the patients were not having

proper preparation or discharge planning before they self-discharged. There is necessity to explore this situation more fully especially when the process of medication was still being adjusted and evaluated and an interruption of that process could endanger patients' life.

3) Strengths and limitation of the study

The strength of this study conducted by grounded theory approach was to be able to understand new phenomena and required the researcher to be open-minded and to be able to see data from many perspectives. The result of this study showed the patients spirit or will to survive by their own effort and to do self-care. In this context, it became the strength of the patients with strokes in Indonesia and could play a pivotal role in their recovery as they exert their own initiative and effort to recover and survive at home.

However, there were several limitations in this study. First the sample size was selected a priori rather than as a function of data saturation. Therefore there were some possible gaps in information. For example the condition of patients was mild and may not have accounted for the experiences of more severe patients with strokes. There were also remaining questions unanswered especially regarding patients' ADL based on perspectives aspect of religion and cultural backgrounds, health insurance ownership of

the patients and the basic information related diagnosis.

6. Implication for the Main Study

This was the preliminary study conducted to determine feasibility. It described the transitional care needs of patients with strokes and family caregivers in an urban area in Indonesia. This study should be quite feasible to conduct as a larger study. The strengths of the qualitative method are to explore the needs of the patients and family caregivers based on their experience. However, the limitation of this study was because there was no data saturation. It is necessary to conduct the qualitative study for the main study, with bigger size of participants (10-15 sets or units of participants). Based on the preliminary results, there are the needs of patients and family caregivers regarding transitional care. However, because there is limited information regarding this topic in Indonesia, what should be done as the first step is to describe the experience of patients and family caregivers.

It is also necessary to add content of interview guide based on the previous research limitations, criteria should be listed carefully to be able to represent patients the characteristics between a mild stroke and a severe stroke condition in urban area in Indonesia. The interview contents should be confirmed again by seeking validation for the participants.

CHAPTER 4

METHOD

This chapter provides information of research methodology for the main study aimed to describe the experiences of patients with ischemic stroke and their family caregiver before and within three months after discharge from the hospital to home. This chapter includes the design, sample and participants' recruitment, data collection, data analysis and ethical consideration.

1. Study Design

The design of this research was a qualitative descriptive study involving in-depth semi-structured interviews. The qualitative descriptive study has remained a common method within nursing research. The qualitative descriptive study presents a comprehensive summary of phenomena or events in everyday terms as researchers stay close to the data as it is presented (Sandelowski, 2000). In addition to that, in-depth interviews can provide rich and in-depth information about the experiences of individuals (Blackwell, 2006). This design appropriately addresses the purpose of the present study to describe the experience of patients with ischemic stroke and their family caregivers before and after discharge from hospital to home.

2. Sample and Participants' Recruitment

Purposive sampling method was used to recruit the participants from the stroke inpatient unit of one general hospital in urban Indonesia, South Tangerang city. There were two reasons for selecting the South Tangerang city for the place of research. The reasons are as following: 1) This is the geographical area, which has the highest stroke prevalence among municipalities in the Banten province (Riskesdas, 2013) and based on the preliminary study, in this area, there was an interesting trend in using traditional medicine to improve stroke patients physical function compared to general medicine, and 2) this is the area of Syarif Hidayatullah state Islamic University (UIN) Jakarta, which already has a trusted by the community and local government and also was where the researcher worked; therefore it made a suitable study field.

The inclusion criteria for the *patient* participants were: 1) patients' age 45 years and above; 2) had stroke onset for the first time; 3) had a disability with hemiparesis or paralysis, 4) able to communicate; 5) had been discharged for no more than four months; 6) living alone or with a caregiver or next of kin; 7) living in South Tangerang city, and 8) willing to participate. For *family caregivers* participants: 1) over 18 years of age, 2) able to communicate; 3) main caregiver of patient with stroke; 4) living in South Tangerang city and 5) willing to participate. Patients or family caregivers with cognitive

impairment were excluded.

The participants were recruited from the stroke ward of an inpatient unit in one public class 'C' hospital. A 'C' hospital consists of a minimum of two types of services: four basic specialty services (internal, pediatric, obstetric, and surgery), and four supporting medical specialty services (anesthesia, radiology, rehabilitation medicine, anatomic pathology). Basic medical services have at least nine doctors and two dentists on staff and minimum of 100 beds (Broughton, et al., 2015).

After the approval to conduct a study in this hospital, the head nurse of the internal medicine ward was appointed to be a coordinator to help the researcher. The ward head nurse provided the record book regarding patients with strokes who had been admitted to the hospital and then discharge from January until November 2017. The researcher used this record book to select patients based on the inclusion criteria. The data with phone number were located and accessed in the medical record section. The prospective participants were contacted through a telephone call by the researcher who explained briefly regarding the study. If the patient agreed to a home visit then further explanation was at home regarding the research in order to get the prospective participant's approval to participating in this research. The approval from both patient and their family caregiver was required. After the patients and their family had signed

the informed consent, another agreement for an interview was made and participants were visited at mutually agreed time. Researcher also asked the participants for permission to gather their data from the medical record if additional data were necessary. There were no family caregivers under 17 years old therefore they did not need to be represented by parents to sign the inform consent. There were 12 sets of eligible participants consisting of 12 patients and 12 caregivers who were recruited.

3. Data Collection

The data were collected from November 2017 until January 2018 from one general hospital in an urban area of South Tangerang city in Indonesia. The in-depth semi-structured face to face interviews were conducted using the interview guide in Indonesian, which was the mother tongue of both the interviewer and the interviewees. Ten sets of interviews were conducted separately between patient and caregivers at the participants' home. However, two participants asked to be interviewed together (patients and family caregivers) in the same room, as they were more comfortable with that arrangement. One male patient did not comfortable being only he and the female researcher in one room that was shy he asked for his wife companion at the time of interview. Another female patient condition was still depend on caregiver assistance. Her caregiver hesitated to leave her alone. However, the caregivers agreed to remain

silent during the patient's interview and vice versa.

The data were collected from: 1) medical records (disease-related information: length of hospital stay, type of stroke, and additional disease diagnosed at that time, when was the first stroke, ADL before discharge) and 2) in-depth face-to-face semi-structured interviews in the participants' homes. The interviews lasted for 60 minutes and were audio-recorded. The one-on-one interviews in a private room were divided into two parts, 30 minutes with the patients and 30 minutes with the main family caregivers. The questions consist of five categories: a) basic information of the participants (e.g., gender, age, education, occupation, health insurance ownership); b) the experience of ischemic stroke's patients and family caregivers during hospitalization and at home after discharge such as "could you tell me your experiences at the hospital?", "Could you tell me about your experience at home, after discharge?"; c) type of support from others, and d) religious support. The questions regarding family caregivers' experiences were related in accordance to patients' experiences. The step-by-step procedures of data collection are explained next.

Data Collection Procedures

- 1) Data were collected after the participants sign the informed consent approval form.

The purpose of the study was explained to the participants, and they were informed

that they could withdraw from the study any time for any reason with the assurance that their data were kept confidential.

- 2) The interview was conducted at the participants' home at their convenient time. An approval from participant was obtained prior to the interview and when the researcher wanted to tape record the interview.
- 3) The interview began with the introduction and step by step questions progressed from general questions to the specific and direct questions following the interview guide.
- 4) Interview lasted 30 minutes for each participant and participants were asked if their condition was okay or did they want to take a break for a while.
- 5) A second interview was conducted with two participants because at that time the patients condition was not really good.
- 6) The researcher asked permission from the participants to be able to see their medical records if the researcher needed to confirm necessary data regarding their disease's record.
- 7) After finishing, a souvenir for the participants was provided by the researcher.

8) The basic information was transferred to the table and coded with the patients' name with a number. Then the information was kept in the locker with key and only the researcher can access this data.

4. Analysis

The data were analyzed using content analysis. The purpose was to organize and elicit meaning from the data collected and draw realistic conclusions (Polit & Beck, 2006). As a method, content analysis has both a quantitative (Krippendorff, 2004, Neuendorf, 2002) and a qualitative methodology, and it can be used in an inductive or a deductive way (Berg, 2001, Burnard, 1991, Catanzaro, 1988, Downe-Wambolt, 1992, Bengtsson, 2016). Qualitative content analysis is a dynamic form of analysis of verbal data that is oriented toward summarizing the informational contents of that data.

Content analysis is data-derived: that is, codes also are systematically applied, but they are generated from the data themselves in the course of the review. (Altheide, 1987; Morgan, 1993 in Sandelowsky, 2000). In this study, a manifest analysis was used, the researcher described *what* the participants actually said, stayed very close to the text, used the words themselves, and described the visible and obvious in the text (Bengtsson, 2016). The steps to conduct content analysis are included four stages as follows:

1) The decontextualization

Interviews regarding experiences of patients with ischemic stroke and their family caregivers were transcribed verbatim using Indonesian and changed into transcript to be checked by the researcher. The researcher made the English version of transcribed verbatim. To ensure confidentiality, the tapes were transcribed without the names of the participants, and instead were given the case number to identified interviews. After listening carefully from the audiotape and obtaining a sense of the whole, the data were broken down into smaller *meaning units*. A meaning unit is the smallest unit that contains some of the insights the researcher needs, and it is the constellation of sentences or paragraphs containing aspects related to each other, to be able to described what experiences they had in accordance to the purpose of this study (Catanzaro, 1988, Graneheim and Lundman, 2004 in Bengtsson, 2016). Each identified meaning unit is labeled with a code, which should be understood in relation to the context. This procedure is recognized as the “open coding process” in the literature (Berg, 2001). Codes were generated deductively because it is much easier to obtain high reliability with code lists generated deductively rather than inductively (Catanzaro, 1988). The open codings were conducted both with the data obtained from patients and their family caregivers. The questions between patients and their family caregiver were the same and

that is the reason it could be analyzed as one unit because the family caregivers respond in accordance to the process of caring for patients.

2) The recontextualization

After the meaning units were identified, the researcher checked whether all aspects of the content have been covered in relation to the aim (Burnard, 1991). The original text was re-read alongside the final list of meaning units. After being deeply involved with the data, everything seemed to be of importance; therefore the researcher let go of the unimportant information that did not correspond to the experiences of patients with ischemic stroke and their family caregivers before and after discharge.

3) The categorization

In the categorization process, categories and sub-categories were identified. However, in the literature there was no consensus for which headings or concepts were to be used in a content analysis. Sub-categories, which Burnard (1991) terms *sub-headings*, are the smallest units based on meaning units. In a manifest analysis, sometimes these are the same as the codes of the meaning units. Sub-categories (sub-headings) can be sorted into broader categories (Bengtsson, 2016). Identified themes and categories should be internally homogeneous and externally heterogeneous, which means that no data should fall between two groups nor fit into more than one group

(Krippendorff, 2004, Patton, 2002). *Theme* is an overall concept of an underlying meaning on an interpretative latent level, and it answers the question “How?”

(Graneheim & Lundman, 2004). However, this study could not reach the themes identification yet and became the study limitation. Moving meaning units back and forth between categories provided progressive development of the category outcome, how the researcher knows when the categorization is good enough depends on the aim of the study, and the categorization was finished when a reasonable explanation had been reached (Bengtsson, 2016).

4) The compilation

The writing up process began after the categories were established. In a manifest analysis, the researcher often uses the informants' words, and he/she remains aware of the need to refer back to the original text. In this way, it is possible to stay closer to the original meanings and contexts (Burnard, 1991). The data were collected from a neutral perspective and considered objectively. In a manifest analysis, the researcher works this way gradually through each identified category. The tables were presented as a summary of categorization of summary of themes, categories/sub-themes and sub-categories/sub-headings (Tables 7.3 - 9.2). In addition, the time frames from hospital to home emerged from the data as the study participants reported the time bound/duration

along with the interview. However, the variables cannot be ranked, since not all informants have had the opportunity to discuss all the phenomena that the researcher finally counted (Bengtsson, 2016).

5) Validation

The researcher revisited several patients when there was unclear interview data and obtained validation for the final check. The researcher considered how the new findings corresponded to the literature and whether or not the result was reasonable and logical (Burnard, 1991; Morse & Richards, 2002). To validate the outcome and to strengthen the validity of the study, the researcher performed a respondent validation, (a member check), which means that the researcher went back to the informants and presented the results from validation.

5. Ethical Consideration

This study was conducted in accordance with the Declaration of Helsinki (2013). This study was not a clinical trial and will not be arranged for post-trial provisions. The general principles of the Declaration of Helsinki were to promote and safeguard the health, well-being and rights of participants, and to ensure ethical consideration in research involving 1) informed consent, 2) ensuring safety of participants, and 3)

respect for confidentiality and privacy.

1) Informed consent

The participants were requested to provide written informed consent and were given clear explanations regarding the purpose, methods, and risks and anticipated benefits of the study, including that they could ask questions or withdraw from the study any time. The participants were also given a “Refusal form” in case they decided to withdraw during the interview. The participants were given the contact number of researchers in case they decided to withdraw not during interview or in advance, because this research was purely voluntary and they were free to withdraw from the interview if they felt uncomfortable with any questions. The researcher gave the participants a small gift as an appreciation for the participant’s time and participation.

2) Ensuring safety for participants

The risks to the research participants were minimal, as there was no invasive procedure or intrusive questioning. Therefore, the participants would not have any physical injury or harm in this study. However, if the participants became tired from each 30- to 60-minute interview, the interviews were temporarily stopped or rescheduled.

3) Respect for confidentiality and privacy

The arranged interviews were conducted based on participants' convenient time and place. During the interview, the interviewer did not push the patients to answer the question. The researcher moved to the next question if the participants were not willing to answer the current question. The information obtained and documented was treated confidentially and limited to the researcher. The entire interviews were tape-recorded, and anonymity was strictly kept. The recorded information was kept locked in a secure location. The results will be sent to the institutions and participants upon request. In this study, baseline data, such as patient and family caregivers' characteristics, were included to identify factors that can affect the results. All data were used only for research purposes and for academic research purposes in addition it will be destroyed three years after publication or five years after finishing data collection.

4). Research funding, sponsor, and institutional affiliation

There were no research grants or sponsors for this research; thus, the researchers have no conflicts of interest associated with this study. This study was a collaborative research between St. Luke's International University in Japan and Islamic University UIN Syarif Hidayatullah Jakarta in Indonesia where the primary researcher was affiliated.

5). Approval of ethical board and institution

Prior to the conduct of the study, the Research Ethics Committee of St. Luke's International University approved the study. The research proposal and a request letter were sent to the director of two private hospitals and one public hospital in Banten province in Indonesia to obtain permission to conduct the study. One public hospital approved the proposal and permitted the research to be conducted.

CHAPTER 5

RESULTS

This chapter describes the characteristics of participants in South Tangerang city, Indonesia and the experience of ischemic stroke patients and their family caregivers at three times frame; before discharge, at one month, and within three months after hospital discharge.

Participants

Twelve set participants were recruited from one public hospital in South Tangerang city in Indonesia. Each set of participants consisted of one stroke ischemic patient and one family caregiver. The total number of the participants was 24. Table 6 shows the characteristics of patients and their family caregivers.

Characteristics of patients.

Regarding gender, there were eight male patients and only four female patients. The average age was 60.5 years ($SD = 7.4$). The marital status of patients was married and only one patient was a widow. At the level of educational background, one patient had a university degree, one patient did not complete elementary school, and one patient had no education. Occupations included three retired patients, three patients who were

housewives, and six patients who were actively working (two entrepreneurs, two employees, one as a security guard, and one driver). Nine patients had health insurance, but three patients had no health insurance. The numbers of family members living with the patients ranged between one to eight people, with the average number being 3.5 ($SD = 1.8$). According to the medical diagnosis, eight patients were diagnosed as having single ischemic stroke and four patients had a stroke and also had a pre-existing condition of type two diabetes mellitus. There were six patients with right hemiparesis, five patients had left hemiparesis and one patient had right hemiparesis plus difficulty swallowing.

For length of stay in the hospital the longest stay was 12 days and the shortest was six days ($M = 7.8$, $SD = 1.6$). The ADL (Activity Daily Living) Barthel Index score ranged from 35 to 80 with the average score 62.5 ($SD = 13.4$).

Three out of four female patients in this study were still paralyzed within 3 months. Four out of six male patients who were still actively working in this study were already back to work. at three months after discharge. Meanwhile, the other two patients were struggling with their condition.

Characteristics of family caregivers.

The age of the family caregivers ranged from 20 to 68 years old ($M = 49.3$, $SD = 14.3$). Regarding family relationships, two caregivers were daughters of the patients, and ten caregivers were the spouses of the patients (eight were wives, and two were husbands). Most (10) of the caregivers were women and two were men. Regarding the range educational background, one caregiver completed a university degree and one caregiver had no education. Among the six family caregivers, that were actively working as employees, two were entrepreneurs, one was a kindergarten teacher and one was a traditional healer; five spouses stayed at home, and one was in retirement. The religion of all the participants was Muslims.

Table 6. *The characteristics of study participants*

PATIENTS													
	1	2	3	4	5	6	7	8	9	10	11	12	Average (SD)
Gender	Male	Male	Male	Male	Male	Male	Male	Male	Female	Female	Female	Female	
Age (years)	60	62	57	70	52	48	50	64	63	64	66	70	60.5 (7.4)
Marital Status	Married	Married	Married	Married	Married	Married	Married	Married	Widow	Married	Married	Married	–
Education	Elementary School	Technical high school	Elementary Islamic schooling	Elementary School	Senior High School	Junior High School	Senior High School	Elementary	No Education	Elementary (not completed)	Elementary	Bachelor	–
Occupation	Retired	Security	Entrepreneur	Retired	Employee	Driver	Employee	Entrepreneur	Housewife	Housewife	Housewife	Retired	–
Health Insurance owning	Yes	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes	–
Numbers family living with (persons)	8	5	1	3	2	3	3	3	2	5	4	3	3.5 (1.8)
Medical Diagnosis	Ischemic Stroke & DM Type 2	Ischemic stroke	Ischemic stroke	Ischemic stroke & DM	Ischemic stroke & KAD	Ischemic stroke	Ischemic stroke	Ischemic stroke	Ischemic stroke	Ischemic stroke	Ischemic stroke	Ischemic stroke & DM type 2	–
Dissabilities	Right Hemiparise	Left Hemiparise	Left Hemiparise	Right Hemiparise	Right Hemiparise	Right Hemiparise	Left Hemiparise	Right Hemiparise	Left Hemiparise	Right Hemiparise	Left Hemiparise	Right Hemiparise + Swallow difficulty	–
Length of Hospital's Stay (days)	9	7	8	8	8	6	6	7	7	7	8	12	7.8 (1.6)
ADL Score (Barthel Index)	50	65	70	50	75	60	75	75	60	80	55	35	62.5 (13.4)
Family Caregivers													
	1	2	3	4	5	6	7	8	9	10	11	12	Average (SD)
Gender	Female	Female	Female	Female	Female	Female	Female	Female	Female	Female	Male	Male	
Age (years)	60	56	26	60	46	48	49	50	20	46	68	63	49.3 (14.3)
Education	Elementary School	Elementary School	Diploma	No Education	Elementary School	Junior High School	Elementary School	Elementary School	Senior High School	Elementary School	Elementary School	Bachelor	–
Relationship	Wife	Wife	Daughter	Wife	Wife	Wife	Wife	Wife	Daughter	Wife	Husband	Husband	–
Status	Married	Married	Married	Married	Married	Married	Married	Married	Single	Married	Married	Married	–
Occupation	Housewife	Housewife	Kindergarden Teacher	Traditional healer	Housewife	Employee	Housewife	Entrepreneur	Employee	Housewife	Entrepreneur	Retired	–

Note: DM: Diabetes Mellitus, KAD: Ketoacidosis Diabetic

Experiences of patients with ischemic stroke and their family caregivers

The findings from this study described the experiences of patients with ischemic stroke and their family caregivers into transition time frames. It revealed the experiences into seven phases along through the transition process from hospital to home. There are as followings: 1) *acute phase*, 2) *post-acute phase*, 3) *discharge phase*, 4) *facing difficulties phase*, 5) *seeking treatment phase*, 6) *expecting recovery phase* and 7) *resuming their normal life phase*. Three phases were occurred during hospitalization and three phases were occurred one month after discharge and one phase occurred within three months after discharge. All phases are illustrated in Figure 4

These phases were time based, the time frames were described based on the study participants reports along the interview. At the time of the interview the participants explained their experiences and how long their experiences lasted. The time bond was not precisely described the duration of the experiences, however, it based on the average of participants report. The explanation regarding the phases will described next.

The first transition stage was during hospitalization and at this stage the three phases was emerged from the data: 1) *acute phase* which is structured from four categories of patients experiences and three categories of family caregivers experiences;

2) *post-acute phase* which is structured from four categories of patients experiences and four categories of family caregivers experiences; 3) *discharge phase* which was structured from two categories of patients experiences and two categories of their caregivers experiences.

The second transition stage was after discharge. There were two-time frames emerged from the data: one month and within three months after discharge. The experiences of one month after discharge was included three phases: 4) the ‘facing difficulty’ phase which was structured around five categories of patients experiences and three categories of family caregivers experiences; 2) ‘seeking treatment’ phase which was structured around three categories of patients’ experiences and three categories of family caregivers’ experiences, and 3) ‘expecting recovery’ phase which was structured from categories of patients’ experience and two categories of family caregivers’ experience.

The experiences of study participants within three months after discharge included in only one phase namely, ‘resuming the normal life’, which included ten categories of patients’ experiences and four categories of family caregivers’ experiences.

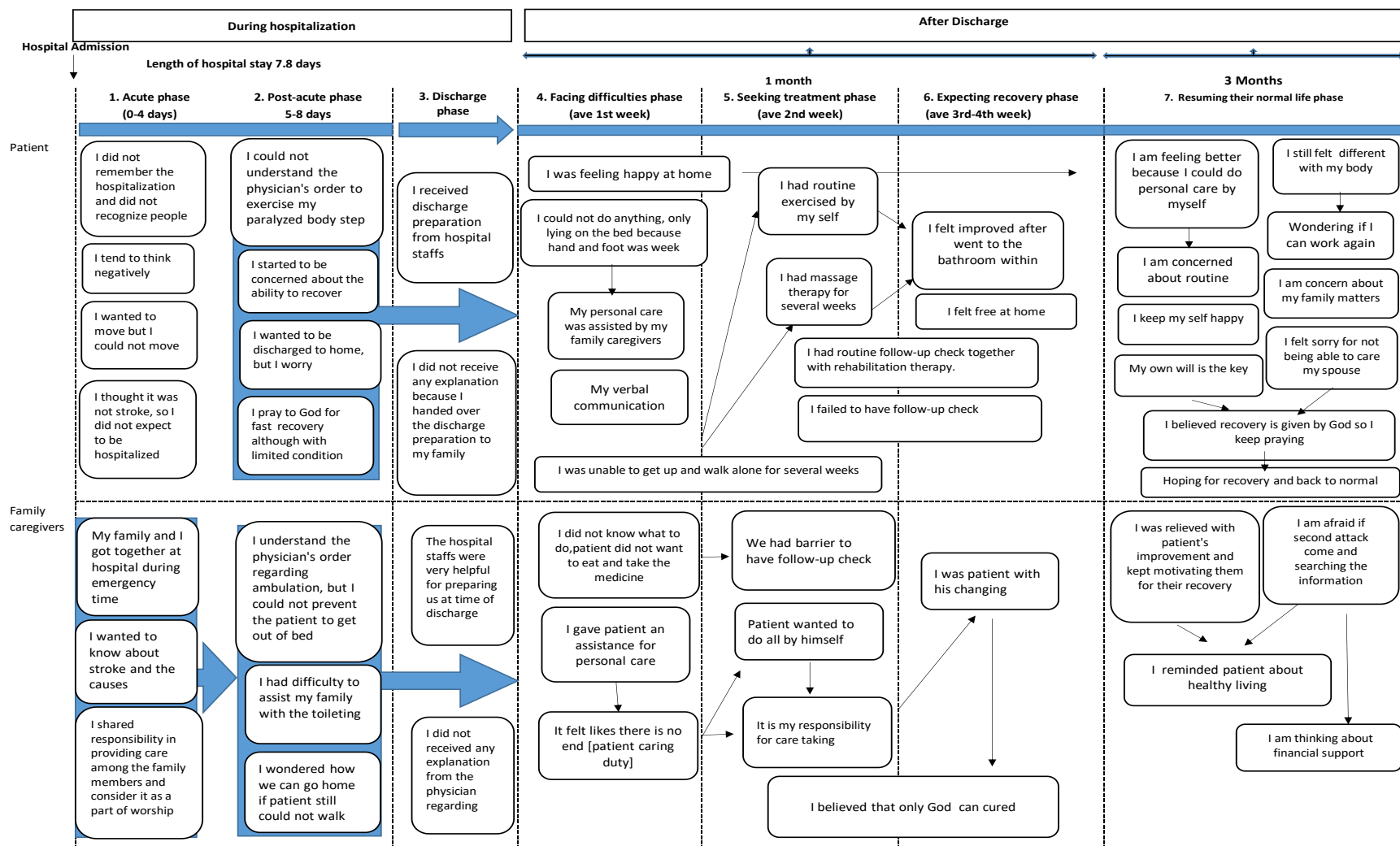


Figure 4. The experiences of Patients with Ischemic Stroke and Their Family Caregivers During Hospitalization and After Discharge

During hospitalization

During hospitalization, the experiences of the patients and their family caregivers included three phases as follows: 1) *acute phase* which was structured around four categories of patients' experiences and three categories of family caregivers' experiences; 2) *post-acute phase* which was structured around four categories of patients' experiences and four categories of family caregivers' experiences; 3) *discharge phase* which was structured around two categories of patients' experiences and two categories of their caregivers experiences. The important elements from the categories in each phase of experiences before discharge are described in the following paragraphs with representative quotes. The quotes are labelled with a [P] for a patient and [FC] for a family caregiver followed by a case number.

1) Acute phase

This phase happened in the first three to four days following patient admission. The patients were usually admitted in the emergency unit at first where they stay from several hours to a few days until a room became available in the ward. They were soon transferred to the inpatient unit following the availability of a room. The ward was not treated as a special unit for stroke patients. Instead, it was considered as a ward for patients with internal diseases such as diabetes, lung diseases, and renal disease among

others. The four categories derived from the experiences of patients and three categories derived from the family caregivers are detailed in Table 7.1 and explained next.

The experiences of patients

(1) I did not remember the hospitalization and did not recognize people

This part describes the condition when the patients had limited memory or lost their memory. This condition mostly happened to stroke patients who were unconsciousness or partly unconscious. Three patients had reported memory loss hospitalization. Stroke can affect the cognitive process of the brain, particularly a patient's thoughts, understanding, and memory. The condition was described as *(1.1) did not remember* as reported by patient one:

"I didn't remember at that time (of hospitalization), I just remembered a few days before the day I went home."(P-1)

Other patients had trouble remembering even familiar faces during this time because they were unconscious for several days, and reported that they *(1.2) could not recognize people one by one (family members).*

"My daughter said I was unconscious for days, so I didn't remember. When I woke up, I could not recognize people one by one (family members)."(P-11)

Table 7.1. Experiences of participants during the Acute-phase

No	Category	Subcategory	Code
PATIENTS			
P1	I did not remember the hospitalization and did not recognize people	P 1.1 I did not remember hospitalization	P 1.1.1. I did not remember at that time (<i>of hospitalization</i>) P 1.1.2 I forget at that moment
		P 1.2 I could not recognize people	P 1.2.1 My family told me that I always asked them, who is this? P 1.2.2 I could not recognize people one by one (family members)
P2	I tend to think negatively	P 2.1. I could not think clearly	P 2.1.1. I felt my mind was uncertain, I could not think clearly P 2.1.2. As if your mind was still somewhere, not completely here P 2.1.3. I felt so small compared to anything so that I felt I want to fall down
		P 2.2. I always had a negative image	P 2.2.1. My brain always thinks negatively P 2.2.2. I had a negative image about riding
P3	I wanted to move but I could not move	P 3.1. I wanted to move	P 3.1.1. I wanted to move P 3.1.2. I could not stay on the bed
		P 3.2. I could not move	P 3.2.1. I could not walk P 3.2.2. I keep dragged my feet P 3.2.3. I got tired of this (walking) attempt P 3.2.4. I felt angry and wanted to blew up
P4	I thought it was not stroke, so I did not expect to be hospitalized	P 4.1. I thought it was not a stroke	P 4.1.1. I feeling surprised (<i>of the attack</i>) P 4.1.2 I am not sure if it was stroke P 4.1.3 I thought it was a common disease
		P 4.2. I did not expect that I should be hospitalized	P 4.2.1 I did nott expect it (<i>to be hospitalized</i>) P 4.2.2 I refused to be hospitalized P 4.2.3 My wife insisted on me to be hospitalized
		P 4.3. It was hard to stay at the hospital	P 4.3.1 I felt it (hospitalization) was hard because the medical treatment P 4.3.2 I am afraid of needles and injection P 4.3.3 I did not feel good at hospital
FAMILY CAREGIVERS			
FC1	My family and I got together at hospital during emergency time	FC 1.1. All family members got together at the emergency unit	FC 1.1.1 My mother was unconscious several days at emergency unit FC 1.1.2 All family members were all here (waiting)
		FC 1.2. The family hoped that the patient will regain consciousness	FC 1.2.1 I am wondering when she will awake FC 1.2.2 I always whispered to my mom ears to give her motivation while being unconscious
FC2	I wanted to know about stroke and the causes	FC 2.1. I wanted to know information regarding disease	FC 2.1.1 I wanted to know information about stroke .
		FC 2.2. I wanted to know the cause of stroke	FC 2.2.1 I wanted to know why my husband had a stroke
FC3	I shared responsibility in providing care among the family members and consider it as a part of worship	FC 3.1. I consider caring for patient as a part of worship	FC 3.1.1 I had to stay 24 hours a day in the ipatient unit FC 3.1.2 I take it (caring for my husband) as a part of worship
		FC 3.2. I shared responsibility with my brother and sister in caring for patients	FC 3.2.1 We arranged our shifts on who will stay in the hospital FC 3.2.2 We took care of mom together within the FC 3.2.3 I shared responsibility with my brother and sister in taking care of my father in the FC 3.2.4 Sometimes my children substituted for me in taking care of their father in the hospital

(2) I tend to think negatively

Patients reported thinking negatively. This included two subcategories: (2.1) I could not think clearly and (2.2) I had a negative image.

(2.1) I could not think clearly

The patients were unable think clearly because their cognitive process were impaired and therefore they were not completely aware of the events. Patients reported how they experienced the cognitive impairment.

“In the first several days at the hospital, my mind was filled with many things but seemed like unclear thoughts. I could not think clearly.” (P-8).

“It felt like as if your mind was somewhere else, it was not completely there.” (P-11).

(2.2) I always had a negative image

Some patients imagined something in a negative way. The most common expression was *“always thinking negatively, “all were about bad things” and “I did not feel good”*. The patients who were admitted indicated that they did not feel good with the condition. They stated that imagining something bad will happen and it is not comfortable at all:

“After I took the neurologic medicines, I felt my mind was uncertain. I imagined about...what should I say, it was so hard to explain. But it must be a negative images, my brain always thinks negatively. All were about bad things. I did not feel good. It felt that the imagination from my mind was in front of me.” (P-7)

He continued to report that he started wondering what will happen next:

“I imagined... .. just like I imagined if I ride a motor bike and I fell down, what will be happening? How could I explain?” (P-7)

(3) I wanted to move but I could not move

Patients became aware of their paralysis. The patients started to move but realized that they had lost their ability to move half of their body.

This category included two subcategories:

(3.1) I wanted to move

Patients had a desire to move their body, after having been confined to bed for several days. The *move* actually refers to walk. Without being completely aware, the patients wanted to be able to walk.

(3.2) I could not move

However, patients had lost their ability to move. Losing the ability to move was occasionally hard and was not easy to accept. This situation often led to patient's

anxiety and frustration as described by one patient:

“I could not walk last night, I kept dragging my feet, I kept dragging and dragging... how to banish it? I felt so tired. I went back and forth, just a few seconds, I moved again. I felt anxious. I wanted to move, could not stay in one place.. but I could not move. I felt angry and wanted to blow up.” (P-7).

(4) I thought it was not stroke, so I did not expect to be hospitalized

Patients felt it was hard to accept that they had to be hospitalized because they believed that they had no stroke. This category included three subcategories:

(4.1) I thought it was not a stroke

The patients were thinking that their symptoms were related to other diseases or to their pre-existing health condition. One patient thought that it was not a serious disease and that since he had diabetes; he thought that it might be related to his previous disease:

“I thought it wasn’t a serious illness or maybe because of my diabetes. I was not sure if it was a stroke.” (P-1)

Patient thought that it was just like a severe headache and that he did not have any idea about stroke as he reported below:

“Right after I was being hospitalized, I did not know it was stroke, I thought it was another disease. Like a severe headache because I felt dizzy all the times and did not have any idea that it was a stroke.” (P-3)

(4.2) I did not expect that I should be hospitalized

The patients were not expecting to be hospitalized. Patient stated that he happened to be in the hospital because his wife insisted for him to go and the physician diagnosed his condition as stroke.

“My wife insisted that I should be hospitalized. At the beginning, I did not want to go to the hospital. Even though I was sick, I still did not want to go to the hospital. I just do not like it, I am afraid of needles and ohh... I just do not like it.” (P-6)

(4.3) It was hard to stay at the hospital

Some patients did not feel comfortable staying in the hospital, and it became harder when they felt that their symptoms worsened even though they followed the hospital staff's recommendation. Another reason also because they could not conduct regular prayers:

“It was hard to be hospitalized, I thought ‘ve I’ve all they said (physician and nurses), but I still felt pain etc..” (P-1).

“I did not expect to be hospitalized, I thought it was not so severe, only caused by the winds.” (P-2)

“I felt annoyed at the hospital, I didn’t conduct my regular prayers during my stay there.” (P-4).

The experiences of family caregivers

The family caregivers also faced an unpredictable situation wherein they had to deal with family members who had a sudden attack. In addition, the patients suddenly had of motor dysfunction or a loss of consciousness and had to be admitted to the hospital. Even though they were still in the state of shock, they had to go through the acute phase. From the family caregivers’ experiences in this phase, three categories were identified (Table 7.1):

(1) My family and I got together at hospital during emergency time

Family members tried to provide support during the survival time of the patients. This category included two subcategories:

(1.1) All family members got together at the emergency unit.

When the patients were admitted to the emergency unit, family members stayed together at the hospital. When the strokes happened, patients were at home or somewhere at work and family members were doing they own work. When they heard

about what happened, they gathered at the hospital. They all lived in the same city and that was why it was easy to congregate at the hospital.

One of the family caregivers reported that she got a call from her brother that their father became suddenly paralyzed at work. She was in a panic for a while then she tried to manage to be there as soon as possible. Together with his brother they brought their father to hospital. Later, another sister and brother came from work or from their home to the hospital.

“My father was in his workshop at that time. Coincidentally my brother was there too. When he had sudden stiffness. I got a phone call and panicked for a while; I left my work, (at that time I was cooking). And when I came, his body you know - could not be moved, his hand - like this (demonstrating paralyzed hand). So, we brought him to the hospital. On the way we called my other sister and brother. They came later when father was already admitted in the emergency unit.” (FC 3)

(1.2) *The family hoped that the patient will regain consciousness.*

Family really expected patients will survive and awake. In addition, all family members who stayed at the emergency unit were making attempts to make the patient awake. They explained the attempts were like talking to the patient and reciting *Al-*

Qur'an.

“My mother was unconscious for several days... at emergency unit. We still wait for the room in inpatient unit. The physician and nurses came several times and said that my mother still has not changed. I am wondering when she will awake. All family members were here. I tried to keep talking to her. I always whispered to my mom ears to give her motivation and recited Al-Qur'an sometimes.”(FC-11)

(2) I wanted to know about stroke and the causes

Family caregivers wanted to have explanations regarding stroke and the causes. A sudden event like stroke left questions for family caregivers: how it could happen and why it happened. This experience demonstrated the direct need of family caregivers.

The subcategories were as follows:

(2.1) I wanted to know information regarding disease

The family caregivers wanted to know the information regarding what is stroke disease and the symptoms.

(2.2) I wanted to know the cause of stroke.

The family caregivers wanted to know how stroke happens. Especially an information how could it happened to their spouses or mother/father.

As reported by family caregiver seven, she had to accompany her husband to go through diagnostic check namely CT-Scan, however the physician did not give further explanation regarding the stroke itself.

"When my husband was admitted to the hospital, and he had to go through CT scan, I asked the physician what the meaning of the result is. He just told me my husband had stroke. That was unclear. Well actually I wanted to know what stroke is. I did not know only from scan result, with my education background, what is stroke? I want to know why my husband had a stroke." (FC-7)

(3) I shared responsibility in providing care among the family members and consider it as a part of worship.

Family caregivers had to arrange the shifts regarding who and when they should accompany the patient in the ward (inpatient unit). This condition occurred when patient has transferred to the ward.

(3.1) I consider caring for patient as a part of worship.

Family caregivers have the perspectives regarding care taking for a husband/wife at the hospital for 24 hours a day as a part of worship to God. Family caregivers reported that it might looked like a burden for others, however if they felt sincere, the responsibility of taking care their sick husband/wife became their good

deeds for the sake of God.

“It looks hard, isn’t it? But I did not feel it as a burden, it is already my responsibilities. I took it as a part of worship.” (FC-5).

(3.2) I shared responsibility with my brother and sister in caring for my father

The condition where caregivers shared the responsibility with their family members in taking care of the patients. The family caregivers were the patient’s children. This kind of attitude is typically with Indonesian families. Instead of only one or two family members taking care of the patient or family member, they will share the responsibility among all the members of the family. As reported by family caregiver three:

“I could not accompany my father in the night, because I still have a small daughter, so we will take turns who guard father this day, this time. If my brother is free, and mostly he was the one who was available in the night, or my husband or my brother in law. We arranged shifts for who is going to stay at hospital among his children.” (FC-3).

"I shared responsibility with my brother and sister in caring my father. So that we were three, plus three for brother and sister in law. In total we were six and we exchange the schedule who were available. At emergency unit I and my sister

in law were responsible taking care him in the day." (FC-3).

"Sometimes my children substituted me for taken care of their father at the hospital. Sometimes at night, around 7 P.M, the patient's body should be cleaned by using a wet napkin. My children could not do that. So, before they had their turn, I will make sure to be there to clean and washed him, then I stand by again to guard him. If I need something to do at home, I asked my children to come and replaced me. I just worry if my husband wants to do elimination." (2FC11)

In the acute-phase, the overall experiences of the patients were regarding patients' unclear minds so that they did not have a clear understanding regarding stroke. They started to become aware with their body disfunction. In addition, their experience of being hospitalized was viewed as unexpected thing. For the family caregivers, this phase was also faced as an unpredictable situation. However, they realized that whether they are willing or not they have to deal with patient care and focus on patients' survival. They shared the responsibility among the family regarding providing care for the patients. This condition demonstrated that there was a strong bond among family members and it was one of a unique characteristic in urban Indonesian currently.

2) Post-Acute Phase

The post-acute phase occurred from five to eight days in the ward after the patient condition was getting stable until a physician decided that the patient can be discharge home.

There were four categories of patients experience and four categories of family caregivers experience included in this phase (Table 7.2).

Table 7.2. Experiences of participants during the Post-acute phase

No	Category	Subcategory	Code
PATIENTS			
P1	I could not understand the physician's order to exercise my paralyzed body step by step	P 1.1 I felt tired just lying on the bed	P 1.1.1 I felt tired just lie down on bed
			P 1.1.2 I refused to only lying down
			P 1.1.3 I am not allowed to walk
			P 1.1.4 I did not want to stay on bed
		P 1.2 I could not get with it (the exercise explained by the physician)	P 1.2.1 I am wondering why I should stay on bed
			P 1.2.2 Physician actively asked me to exercise on
			P 1.2.3 I could not get why I had to exercise while I could not move?
		P 1.3 I went to the bathroom for elimination	P 1.3.1 I refused to use diapers
			P 1.3.2 I wanted to do elimination in the toilet
P2	I started to be concerned about the ability to recover	P 2.1 I thought about recovery	P 1.3.3 I went to the bathroom when my family was not around and fell down
			P 2.1.1 My mind was occupied by the thoughts of how to be able to recover
			P 2.1.2 I know stroke takes a long time to recover
		P 2.2 I have to support my family	P 2.1.3 I wondering how long before I will recover?
			P 2.2.1 I thought, how can I live with my family if my recovery take a long time?
			P 2.2.2 I think I will not be able to work
P3	I wanted to be discharged to home, but I worry	P 3.1 I wanted to go home	P 3.1.1 I was just thinking why I couldn't gain
			P 3.1.2 I wanted to go home
			P 3.1.3 I did not feel good at hospital
		P 3.2 I am afraid of early discharge	P 3.2.1 Physician told me that I can go home
			P 3.2.2 I am afraid of early discharge
			P 3.2.3 I am afraid I have not actually recovered but had to go home.
		P 3.3 I wondered the medicine used would be able to prevent re-hospitalization	P 3.3.1 I Wondered was it enough to count on only the medicine
			P 3.3.2 I was afraid I might have to return to the hospital again.
P4	I pray to God for fast recovery although with limited condition	P 4.1 I asked God for fast recovery	P 4.1.1 I still conducted prayers at the hospital
			P 4.1.2 I prayed to God, so I could get home quickly
			P 4.1.3 I asked God to give me a speedy recovery
		P 4.2 I could not perform regular pray appropriately	P 4.2.1 I could not do regular prayers
			P 4.2.2 I could not pray while sick
			P 4.2.3 No one told the direction of Qibla (towards
			P 4.2.4 Difficult to pray with partially limp body

Continue of Table 7.2

FAMILY CAREGIVERS			
FC1 I understand the physician's order regarding ambulation, but I could not prevent the patient to get out of bed	FC 1.1 The physician said that ambulation is done step-by-step	FC 1.1.1	The physician explained my husband could not get up and he have to be in the same position, lying down
		FC 1.1.2	My husband only wants to sit but physician said ambulation is step by step
	FC 1.2 Patient insisted on doing elimination in the bathroom	FC 1.2.1	My husband refused to use a diaper
		FC 1.2.2	My husband insisted to go to the bathroom for elimination
FC2 I had difficulty to assist my family with the toileting in hospital	FC 1.2.3	FC 1.2.3	Nurses warn my husband to stay in bed
		FC 1.2.4	My husband tried by himeself and fell down
	FC 2.1 Patient refused to use diapers	FC 2.1.1	My husband refused to use a diaper
		FC 2.1.2	He insisted on going to the bathroom for elimination
FC3 I wondered how we can go home if patient still could not walk	FC 2.2 Patient was too heavy to be supported to the toilet	FC 2.2.1	I was not strong enough (to support) He is fat, I tried but was not strong enough
		FC 2.2.2	It was very difficult to help my father with the toileting; he is heavy
	FC 3.1 Physician decided the patient could go home	FC 3.1.1	Physician decided my husband can go home
		FC 3.1.2	But how it would be at home? how he can go home?
	FC 3.2 family caregivers considered the patient could not go home because of hand-foot disability	FC 3.2.1	My husband still stands unsteadily, He is still not able to walk.

The experiences of patients

(1) I could not understand the physician's order to exercise my paralyzed body step by step.

This means that the patients could not understand the reason why the physician did not allow them to move from the bed but suggested them to exercise their paralyzed body step by step. This category was structured by three sub-categories as follows:

(1.1) I felt tired just lying on the bed.

This showed that the patients were becoming restless and bored. Three patients reported regarding this experience. The patients were at risk of fall during the first's days of hospitalization when they were in the acute phase. Thus, they had bed rest and had to minimize their movements. And when it continued to the post-acute phase, patients complained:

"I felt tired and bored just only lying down on bed..." (P-3)

"Physician also told me to follow his suggestion but I am tired (just lying down),

I knew I am not allowed yet.. well I just lying down or lied to one side." (P-7)

(1.2) I could not get with it (with the exercise explained by the physician)

This condition was when patients felt they could not understand the physician's explanation regarding exercise in the bed with a paralyzed body.

Patient seven reported: *“I could not understand the physician’s order to exercise on the bed.”* (P-7)

When being asked to demonstrate the exercise, one patient was making motion to his paralyzed body. From the patient explanation, he had been told not to walk too soon. Instead of that he had to actively practice or exercise his paralyzed part. However what patients thought, and physician thought were quite different. As expressed by patient three below;

“Well... the physician explained it to me [regarding the exercise], for example, I should not move too soon but I thought, how can I could not move (if I had to exercise)? The physician also told me to follow his suggestion but I am tired of just lying down, I knew I am not allowed yet. Well I just lied down or lied to one side.” (P-3).

Sometimes patients even did this discreetly, however they reported when they got caught, nurses or physician would become angry for their being disobedient.

Once, the physician scolded me for sitting down on the bed. Well... I knew the recommendation is based on theory, but I felt tired, the most important thing was, it was not too much. So sometimes if a physician did not see me, I sat and walked, and if he came I back I lied down on bed.” (3P-47)

(1.3) I went to the bathroom for elimination

Frequently patients would be expected to use diapers or a bedpan for elimination to allow the body more rest. However, elimination in the bathroom is fundamental desire by the patients. In preliminary research there was an urge for patient to do elimination in the bathroom.

“I am wondering why the physician didn’t allow me to get down and walk. I wanted to use the toilet, so I went to the bathroom for elimination.” (P-5)

In this study, the reason was despite only of cleanliness preference they considered it as an indicator of being healthy.

They also refused the diapers because they felt shamed and it was not comfortable. The patient five reported this experience as follows:

“I did not want to use diapers.... It’s not comfortable at all, especially when the weather was hot.” (P-1)

“Why I should be wearing that... just like a kid.” (P-8)

Other patients were not refusing to wear it, only they did not comfortable with it.

“I had to wear it... Otherwise it will be so tiresome (to urinate in the bathroom). I just can stand if it is hot here (the weather).” (P-1)

(2) I started to be concerned about the ability to recover

The patients started to worry about their ability to recover. There were two subcategories included in this category. The explanation is as follows:

(2.1) I thought about recovery

The patients were still at middle-age and most of them are still actively working. They worried regarding the recovery time; will it be short or long because they hoped they would be able to work immediately and become active again. One patient reported as follows:

“My mind was occupied by the thoughts of how to be able to recover. So that I can get healed. Furthermore, I can get back to my work and I can be active again.” (P-3)

(2.2) I have to support my family

Patients worried if they could not recover right away and thus they could not give their family a financial support.

“If I am like this... (paralyzed), it will take time to recover. What I knew was that stroke takes a long time for recovery. It needs several months to even years. How can I provide for my family? If I am like this, I will not be able to work, I just think about that. That’s why I have to fight to recover.” (P-7)

(3) I wanted to be discharged to home, but I worry

Patients felt ambivalent; they wanted to go home but actually they were not confident and worried. They wondered what would happen after discharge with respect to their recovery ability. This category included two subcategories: *“I wanted to go home”* and *“I am afraid of early discharge.”*

(3.1) I wanted to go home

This meant that the patients “wanted to go home” when they realized that “stroke involved a long recovery time” and they “wondered if they can gain full recovery”. Patient one reported his experience as follow:

“I wondered when can I gain full recovery? I wanted to go home.” (P-1)

“When can I be healed? I wanted to go home.. the nurses said that I have to be patient because a process is needed to recover.” (P-1)

(3.2) I am afraid of early discharge

This was when the patients were not confident to be discharged to home because they still felt that they were “not completely recovered” but the “physician already decided” for them to go home. Three patients questioned why they had to go home at the early stages. When finally, the physician decided for them to be discharged, as reported by patient one:

“When physician told me, I could go home. I said, really? And he said... Yes...

You are already recovered. I am afraid I am not really able to go home, and I was afraid I should come back to the hospital again.” (P-1).

Patient two tried to bargain about the discharge decision because actually he felt that he still had not made a progress yet in terms of his recovery:

“The physician said that I could go home tomorrow, but I said... Oh doc, not now, I am still sick. What about next week? But the physician had already decided, and whether I was willing or not, I have to go home.” (P-2)

(3.3) I Wondered the medicine used would be able to prevent re-hospitalization

He also wondered what will be happen after return to home, only counted for the medicines because patients afraid for rehospitalization; patients reported they were clueless regarding life after home.

“I thought that, if in the hospital, I still feel like this (condition not yet recovered), how about at home? Here in the hospital, all I need is provided, and there are physicians and nurses. Will I recover at home? That’s what I thought....” (P-2)

(4). *I pray to God for fast recovery although with limited condition.*

When there was nothing to rely on, patients put their hope in God. This category means that patients “believe in God”, “put the rest to God” and prayed (asked) to be

given “a fast recovery” by the Almighty. This category was included two subcategories.

(4.1. I asked God for fast recovery.

Patients believed in God and prayed to be able to recover right away. Patients believed God is the Almighty and through God they can rely on everything including asking for recovery.

As patient one and five reported:

“Alhamdulillah (thank God) I could conduct shalat at hospital. I always remembered Allah through dzikir and asked for forgiveness. I believe God will grant me a fast recovery” (P-1).

“I did not feel any worries. I put the rest to God (Allah), if it’s my destiny, I accepted it sincerely. But we have to be careful though, and keep praying for recovery.” (P-5).

(4.2) I could not perform regular pray appropriately

Patients had difficulty performing daily praying as prescribed, such as conducted in standing position, perform ablution with water before praying and facing the direction of *Kibla*. Several patients reported this experience.

“ Well.. during at the hospital I didn’t pray. It should not be like that, but what can I do? It’s difficult to perform ablution before prays, even with “thayamum” (cleaning with dust)” (P-5)

“I did not know where is Kibla, but I keep praying at hospital” (P-1)

“I could not pray while at the hospital. I felt so guilty...I did not know how to do it. I could not lift my left hands and my half body.” (P-2).

The experiences of family caregivers

During post-acute phase, family caregivers accompanied patients in the hospital. Usually, they stayed next to the patient’s bed or waited outside the ward. When patients needed them, they would be called by the nursing staff. Since the patients’ conditions were stable, other challenges came to caregivers. Patients wanted to recover right away, their attempts to walk can be considered as massive attempts.

There were three categories included in this phase as explained below.

(1) I understand physician’s order regarding ambulation, but I could not prevent patient to get out of bed

This category means the condition when family caregivers could not do anything to prevent patients did walking attempts. This category was composed by two subcategories.

(1.1) The physician said that ambulation is done step-by-step

This means that family caregivers understand how the exercise should be done.

Family caregiver two reported that he received information from physician since the beginning. There were times when patients should not move and had to stay in the same position.

“After my husband had been diagnosed of stroke, the physician explained he could not move or doing anything, he had to be in the same position lying down. Even if he wanted to drink or eat I had to feed him. No complaints regarding elimination, he only wanted to be able to sit, but physician said ambulation is step by step. But thank God, day-by-day my husband showed the progress until he was allowed to go home. He was allowed to be standing and walking, but he was still not able to do that.”

(FC-2)

(1.2) My husband insisted on doing elimination in the bathroom.

Family caregivers had difficulty to prevent patients to eliminate in the bathroom. The patients eagerly got off the bed and walked by the side of the bed. If that happened and the caregiver was not available, they tried by themselves.

(2) I had difficulty to assist my family with the toileting in hospital

Family caregivers had difficulty in assisted toileting of the patients in hospital.

There were two subcategories included in this category

(2.1) Patient refused to use diapers

Patient did not want to use diapers. Patients reported rather than use diaper they would go to the bathroom for toileting and family caregivers had to assist them.

(2.2) Patient was too heavy to be supported to the toilet

Family caregivers could not bear the weight of the patients and thus make them difficult in assisting the patient. This usually happen to female family caregivers. FC number two reported;

“He still stands unsteadily, and I was not strong enough (to support). He is fat, so am I but I have less strength. I could not bear it. And I asked him to sit down and I went to find a wheelchair.” (FC-2)

Sometimes, during the week days, other family members could not substitute for her because all were working or had to taking care their children because their children also went to school.

“The nurse asked me, ‘aren’t your children coming? No. I said... they have to go to work. And also caring their children.”

(3). I wondered how we can go home if my husband still could not walk

This is the condition when caregivers felt worried about the patients' condition if being discharge. There were two categories included.

(3.1) Physician decided the patient could go home

(3.2) Family caregivers considered the patient could not go home because of hand-foot disability

All patients reported that their physician made the discharge decision. When the time to discharge came, they became doubtful because patients was still unable to walk. Plus there were other symptoms about which the patients complained. They became less sure about the patient going home.

“Physician decided my husband can go home, yes, I asked for it too. But how it would be at home? How he can go home? If he still stands unsteadily, what we can say? He is still not being able to walk. Not even crawling. He is still hanging on me. His head was dizzy not too severe, but he said it felt heavy. And his hand... could not be moved. Automatically when people were walking their hands have to be able to hold, their feet have to be able to step on the ground steadily - then they could walk. Well... This...my husband could not, his hand and his foot could not work. But he was already discharge. Well.. I just said “Liilahi ta ala, la hawla wala kuwwata” (There is no God but Allah Alone, with no

partner or associate). Hope this is the best. Then after he got home, I made every effort to continue the medicine and concern his eating life style.” (FC-1)

The post-acute phase described the condition when patients had reached the stable condition and concern about their ability to recover. At this phase, the communication gap between patients and physician was happened because patients reported that they could not understand the exercise ordered by the physician for their paralyzed body. Patients also reported their desired to go home but still felt worry. Furthermore, they believe to God for fast recovery encouraged them to go through this transition.

For the family, it was getting harder because they had to assisted patients for toileting. The patients’ demand to have toileting in the bathroom, and family have to deal with this. Actually, at the hospital, family could ask help for a nurse and they will come to help and told the patients to do elimination on the bed. Unfortunately, they will be insisting to take the patients to the bathroom. Family caregivers reported that they were understand physician's order regarding ambulation, but they could not prevent the patients to get out of bed. When they heard regarding patients’ discharge they also wandered their life after discharge.

3) Discharge phase

This transition time was just before discharge to the time patients leaved the hospital.. Patients and family caregivers usually had been told one day before the discharge. Most of the patients were discharged by physician order. At the time of discharge, the experiences of patients included two categories and the experiences of family caregivers included two categories. (Table 7.3)

Table 7.3. Experiences of participants at the Discharge phase

No	Category	Subcategory	Code
PATIENTS			
P1	I received discharge preparation from hospital staffs	P 1.1 I had information related to medicines	P 1.1.1 We got information related medicine P 1.1.2 The physician explained when to take my medication
		P 1.2 I had been told by the physician to do exercise little by little	P 1.2.1 Physician told me to move my body as often as possible, every morning for example. P 1.2.2 Physician told me to exercise little by little, don't just stay of doing nothing
		P 1.3 I got explanation about follow-up check from physician and nurse	P 1.3.1 My physician explained when to get the follow-up check P 1.3.2 I had been told regarding when we have to comeback for follow up check from a nurse
		P 1.4 I had been told by the physician the reason why I have been discharged	P 1.4.1 Physician told me I could go home because my condition has been better
		P 1.5. I was reminded by nurse about food that should be a concern	P 1.5.1 I had reminded regarding food concern by nurses
		P 1.6 I was assisted by nurse to transfer using a wheelchair	P 1.6.1 Nurse prepared the wheelchair for me at time of discharge P 1.6.2 I was helped by a nurse to transfer using a wheelchair
P2	I did not receive any explanation because I handed over the discharge preparation to my family	P 2.1 I did not receive any explanation before discharge	P 2.1.1 I did not know about any explanations before discharge P 2.1.2 I did not receive information before I went home
		P 2.2 I handed over the discharge preparation to my family	P 2.2.1 I gave this matter [things related discharge preparation] to my daughter P 2.2.2 I just knew that everything would be done
FAMILY CAREGIVERS			
FC1	The hospital staffs were very helpful for preparing us at time of discharge	FC 1.1 The physician and nurses explained about the medicines and the time prescribed	FC 1.1.1 The nurses also explained about the time to take the medicines FC 1.1.2 A nurse reminded me to give my husband the medicine regularly FC 1.1.3 I got explanation from the physician regarding the type of medicine
		FC 1.2 I was reminded by the physician and nurses to be concerned with patient's food	FC 1.2.1 I was reminded by nurses to pay attention to the problematic foods FC 1.2.2 I received explanation from the physician to lessen salt in cooking FC 1.2.3 I received explanation from the physician regarding food that should be avoided
		FC 2.1 I received information regarding exercise from the physician	FC 2.1.1 I got reminded by the physician to asked my husband to exercise his tongue FC 2.1.2 The physician explained that my husband had to exercise from sitting to walking
		FC 2.2 The nurses were very helpful for discharged preparation	FC 2.2.1 It was very helpful that the nurses already prepared the medicines FC 2.2.2 I received the letter for follow-up
FC2	I did not receive any explanation from the physician regarding the medicine	FC 2.1 I receive no information regarding patient's medicine	FC 2.1.1 I did not receive any explanation from physician about my husband's medicines
		2.2 My other family member was taking care of it	FC 2.2.1 I was not there at time of discharge, my first brother was taking care of it.

The experiences of patients

(1) I received discharge preparation from hospital staffs

This means that patients received explanation regarding several things from the physicians and nurse. This category means patients received information before discharge regarding the medicines and follow-up care. Eight participants reported it even though the information received was not merely the same.

The explanation before discharge was regarding time of discharge, follow-up care, exercise at home and diet. The type of information that was received by the patients was explained in subcategories as follows:

(1.1) I had information related to medicines

(1.2) I had been told by the physician to do exercises little by little

(1.3) I got explanation about follow-up check from physician and nurse

(1.4) I had been told by the physician the reason why I have been discharged

(1.5) I was reminded by nurse about food that should be a concern

(1.6) I was assisted by nurse to transfer using a wheelchair

Two patients were reported as follows;

“One day before we discharge, physician told me. So, we had prepared for it. On the day we discharge physician told me regarding the medicines and nurses reminded us to have follow-up care as scheduled.” (P-9).

“Before discharge, we got information related medicines, when we have to come back to have follow-up check, just that.”(P-3)

(2) I did not receive any explanation because I handed over the discharge preparation to my family

This means that patient did not receive any kinds of information at the preparation before discharged. These are two subcategories included: (2.1) I did not receive any explanation before discharge, and (2.2) I handed over the discharge preparation to my family.

They asked their children to take care the discharge matters. Patient six, handed over the admission and discharge matter to a health cadre in his neighborhood. A health cadre is voluntary work-based group to help the *PUSKESMAS* (Community Health Center) in promoting health in their neighborhood. Patient eleven also reported:

“I did not know; my daughters had taken care all the discharge matters. I did not know... Physician did not tell me anything” (P-11)

The Experiences of family caregivers

At discharge, the experiences of family caregivers included two categories, as follows:

(1) The hospital staffs were very helpful for preparing us at time of discharge

This category means at time of discharge FC felt the hospital nurses were very helpful to prepare the patients, from providing the medications, wheelchair, and explaining about what should be done at home.

This category included four subcategories: *(1.1) The physician and nurses explained about the medicines and the time prescribed, (1.2) I was reminded by the physician and nurses to be concerned with patient's food (1.3) I received information regarding exercise from the physician, (1.4) The nurses were very helpful for discharged preparation.*

They were pleased with the set of information that they received. The information itself, was not given at the same time, and was performed by either nurses or physician. However, these kinds of attitudes were very well accepted by the patients.

As family caregiver three reported:

“Allhamdulillah, at the hospital, the young man was really nice and he help me a lot. He asked me, am I ready to go home? I told him I am waiting for my

children. He already prepared the medicines, wheelchair. He also explained regarding medicines, the food that should be of concern, and had to take medicine regularly” (FC-3).

The family caregiver three also reported:

“After physician did the check-up, he asked my husband to open his mouth and moved his tongue, then asked my husband to lift his hand. And said that’s good... later at home my husband can learn to sitting on the bed, the tried to walk. My husband felt happy to hear that.” (FC-3)

(2) I did not receive any explanation from the physician regarding the medicine.

Family caregivers did not receive the information from hospital staffs before discharge. Some of them shared the responsibility with other siblings or family members. Due to their availability, at the time of discharge, somebody replaced him/her, and discharge matters were already handled by other family members.

The description could be found in these two subcategories: *(2.1) I receive no information regarding patient’s medicine, and (2.2) My other family member was taking care of it.*

The family caregivers three described her experience:

“At that time, I was in charge of transportation. So my brothers maybe... he was there and had the explanation. I did not know...” (P-3)

At time before discharge was the phase which patients were just about to leave the hospital. Two groups of patients were found from the data. First, is the group who did not receive discharge preparation because they handed this to their family. And second, is the group who received at least two or single explanation regarding medicines.

The family caregivers also experienced of not having any explanation regarding medicine. However, some family caregivers were reported that they had a very helpful staffs of the hospital.

2. After discharge

At home, it was the time where patients and family caregivers started real life and real challenges. One month has been considered as the crucial time for both patients and family caregivers (Gustafsoon & Bottle, 2013) as the care-giving role would shift from health care professionals to family members.

One month after discharge

In one month after discharged, the experiences of the patients and their family

caregivers included three phases as follows: 1). Facing difficulties phases, 2). Seeking treatment phase and 3) expecting recovery phase. The explanation of each phase included experiences of patients and family caregivers.

1) Facing difficulties phase

This phase happened during the first until two weeks following discharge.

Patients encountered disability and concern about the difficulties regarding physical functions and movements. There are five categories in this phase for patients' experience. These included the following: (1) I was feeling happy at home; (2) I could not do anything only lying on the bed because one hand and foot were weakened; (3) My personal care was assisted by my family caregivers; (4) My verbal communication was not clear; and (5) I was unable to get up and walk alone for several weeks.

Family caregivers also faced a new role with caregiving responsibility. In this study three categories of family caregivers' experience were identified as follows: (1) I did not know what to do, patient did not want to eat and take the medicine; (2) I gave patient an assistant for personal care; and (3) I felt like there is no end [patient caring duty]. (Table 8.1)

Table 8.1. Experiences of participants in the Facing Difficulties phase

No	Category	Subcategory	Code
PATIENTS			
P1	I was feeling happy at home	P 1.1 I was happy and glad to be home	P 1.1.1 I was feeling happy at home after discharge P 1.1.2 It was glad to be home
		P 1.2 I felt relax at home	P 1.2.1 I felt good to be home P 1.2.2 I felt relax at home [calm environment]
P2	I could not do anything only lying on the bed because one hand and foot were weakened.	P 2.1 My hand and leg at one side were could not move	P 2.1.1 I felt weak so I did not do anything (<i>imobilization</i>) P 2.1.2 I could not move the other side of my
		P 2.2 I was lying on the bed all day long	P 2.2.1 I was just lying down P 2.2.2 I stayed in bed during the early weeks at home
		P 2.3 My hand and leg in one side were weak	P 2.3.1 I felt weakness on the other side of my P 2.3.2 I felt weakness on my affected hand and foot
		P 2.4 My hand and foot on one side felt numb	P 2.4.1 I had numbness in my right arm and foot P 2.4.2 My left hand was so weak
P3	My personal care was assisted by my family caregivers	P 3.1 I was assisted in eating	P 3.1.1 I had to chew slowly P 3.1.2 I had difficulty in swallowing P 3.1.3 I was feeding by my wife P 3.1.4 I was assisted in eating
		P 3.2 I was assisted in bathing	P 3.2.1 I could not lift my affected arms P 3.2.2 It was difficult to hold towel, soap or bucket P 3.2.3 I was not able to bathing alone P 3.2.4 I had bed bathing P 3.2.5 I had support from wife for bathing
		P 3.3 I was assisted in toileting	P 3.3.1 I am urinating and defecating on the bed P 3.3.2 I had to wear diapers during the early week P 3.3.3 I used urinal for toileting P 3.3.4 I wanted to urinating and defecating in the bathroom P 3.3.5 I was toileting in the bathroom with assistance P 3.3.6 I didn't want to wear diapers P 3.3.7 I felt uncomfortable using diapers
		P 3.4 I was assisted in grooming	P 3.4.1 I couldn't brush my hair by myself P 3.4.2 It was difficult to put on veil and I had to be assisted P 3.4.3 I was assisted for wearing cloths
P4	My verbal communication was not clear	P 4.1 The way I talked was not clear	P 4.0.1 My speech was not clear P 4.0.2 I had slurred speech
		P 4.2 It was difficult talking in a long time	P 4.0.3 My tongue felt to thick to move P 4.0.4 I got tired from talking for a long time
P5	I was unable to get up and walk alone for several weeks	P 5.1 It was difficult to get up	P 5.1.1 It was difficult to get up alone P 5.1.2 I had to be assisted to get up P 5.1.3 I had minimal movements
		P 5.2 I wasn't able to walk alone for several weeks	P 5.2.1 I had to drag my feet when walking P 5.2.2 I was walking by holding on to the wall P 5.2.3 I walked unsteadily P 5.2.4 I was not able to walk alone for two P 5.3.1 I had no balance when standing P 5.3.2 I felt like I had no energy to walk P 5.3.3 I experienced a fall

Continue of table 8.1

FAMILY CAREGIVERS		
FC1 I did not know what to do, patient did not want to eat and take the medicine	FC 1.1 Patient did not want to eat and take the medicines	FC 1.1.1 In the beginning at home, my mother did not want to eat FC 1.1.2 My mother did not want to take medicine
	FC 1.2. I did not know what should I do, we were tried to persuade patients	FC 1.2.1 I thought, what should we do? She refused all FC 1.2.2 My sisters and I were tried of persuading her with many options
FC2 I gave patient an assistance for personal care	FC 2.1 I gave patient assistance for eating	FC 2.1.1 I feed my husband in first several days FC 2.1.2 I gave bed bath to my husband FC 2.1.3 I assisted him to get dressed FC 2.1.4 I assisted him in toileting on bed FC 2.1.5 I accompanied my wife to the bathroom
FC3 It felt likes there is no end [patient caring duty]	FC 3.1 I accompanied patient allday long like there is no end	FC 3.1.1 It was almost a day companion [taking care patients] FC 3.1.2 I was taking care of him from morning till night FC 3.1.3 It felt likes there is no end [in caring of him]
	FC 3.2.2 Patient depend on me	FC 3.2.1 I was taking care my wife together with her sister FC 3.2.2 First week he was so dependent on me on the first week

The experience of patients

The average of ADL Barthel Index score patients after discharge was 62.5, which demonstrated a moderate level of dependence. Most patients still could not do many things for themselves since they were only able to sit down on the bed. However, four patients were already able to stand up. In the facing difficulty phase, patients reported their experience into five categories:

(1) I was feeling happy at home

This means patient was feeling happy after being at home. Although before discharged patients experienced worries, home still considered as their comfort place.

One patient reported:

“Well.. I just feeling happy being home, I felt glad I am here” (P-3).

(2) I could not do anything only lying on the bed because one hand and foot was weakened.

This category means that patient had difficulty in doing many things because half of their body was paralyzed. This situation was described in four subcategories below:

(2.1) *My hand and leg at one side were could not move*

(2.2) *I was lying on the bed all day long*

(2.3) My hand and leg on one side were weak

(2.4) My hand and foot on one side felt numb

Patient two reported that he felt exhausted and that made his hand and foot feel very weak and he could not move his hand and foot on one side of his body:

“After I got home, I did not do anything...I just felt very weak but I can move my hand and leg....it's not a real matter. I just felt my body was very weak.” (P-1)

“After discharge, because I always felt dizzy in my head, I stayed at home from the first week and could not do anything. Even to sit down like this I felt tired, felt weak and could not do anything...this left part”. (P-2)

(3). My personal care was assisted by my family caregivers

Patients accepted assistance from their caregivers and other family members because they were very dependent in the first week. Their experiences were structured from four subcategories, as follows:

(3.1) I was assisted in eating, because of the difficulty to hold a utensil and difficulty swallowing.

(3.2) I was assisted in bathing, because they could not hold a bar of soap, use a towel and lift the water scoop.

(3.3) I was assisted in toileting, such as urinating and defecating. Some patients used

diapers or urinal. Other patients refused to use these aids and wanted to do elimination in the bathroom. As patient two reported:

“From the first week, I am still at home, urination was in the bed, and elimination was also in the bed. I used urinal that we bought by ourselves, like the one that provided at the hospital. Well for about two weeks we used it, not too long. After two weeks every time I wanted to urinate, my wife always accompanied me. She is a diligent person”. (P-2)

(3.4) I was assisted in grooming, in the early weeks. One female patient reported that even for putting on a veil on her head she had to wait for her husband to help her. As patient one reported:

“I had bed bathing too. I also asked my wife to help me to put on the t-shirt.”(P-1)

(4) My verbal communication was not clear.

This category means the condition of patient had a problem with unclear and slurred speech. Patients reported that they often felt too tired to attempt to speak. They also felt their tongue was heavy

“I felt my tongue heavy and my speech, it sounds strange... Sometimes if I am talking to long, I got tired.” (P-6)

“First week returned home, my brother took me to our home town, I was not able to speak clearly, the mouth tended to look asymmetrical. “ (P-8)

(5) I was unable to get up and walk alone for several weeks.

This means patients could not walk because they could not stand or even stand steadily for several weeks.

Patients reported because they have limited movements, could not get up, hold and stand. To be able to walk, there should be coordination between the hand and foot.

“I could not walk for a week, it was so hard to even lift your body to sit, and then my wife helped me. I tried to stand you know... a little dizzy. I was afraid. But I had to try, otherwise... I did not know how much I can go...but even for standing... it did not take long until I had to hold on something.” (P-3)

The Experience of family caregivers

Family caregivers hold important role at home, they were responsible not only for taking care patients, they were also housewives who had many tasks dealing with domestic chores, and husbands as the head of the family were responsible for financial support. In addition, they were also children of the patients who had their own role: a student, an employee and marital responsibilities as husband or wife. At home after

discharge the caregiving role was placed upon them. There are three categories included in the ‘facing difficulty’ phase for family caregivers’ experience.

(1) I did not know what to do, patient did not want to eat and take the medicines:

The family caregivers did not know how to deal with the patient who did not want to take meal or their medicines. This is the first experience that family caregivers encountered in the difficulty phase. When patient was not stable yet, and they refused food and medicines, family caregivers started to have a challenge. The food and medicines are very important for patient recovery, so that made them worry if it would last a long time.

“At the beginning she returned home, my mother did not want to eat, she even did not take the medicines.. Which made us, her children worried. We tried everything to persuade her, each of her daughters tried motivate her..” (FC-11)

(2) I gave patient an assistance for personal care

It means that family caregivers helped with patient’s personal care such as eating, toileting, bathing and grooming. Family caregiver two reported:

“I gave assistance for my husband almost in everything, feeding him, bathing, helping with toileting, cleaning and washing after elimination. Bathing still in the bed using wet napkin. He could not wear clothes by himself. It is a simple t-shirt though. So,

I helped him to wear clothes, and brushed his hair.” (FC-2)

(3) I felt like there is no end [patient caring duty]

This category means family caregivers felt overwhelmed because they had to take care patients twenty-four hours a day, day in and day out. They reported that even though they lived with their children, their spouses would rather walk alone than asked their children for help. Caregivers said patients felt badly and hesitated with their children when they assisted him.

“I could not be like in a situation when my husband was still healthy. Now, I have to be ready whenever he calls me, I accompanied him all day long. I could take a rest in the night when his condition was calmed down. But if he was not in a good condition, I had to be ready.” (FC-1)

The facing difficulty phase was emerged from the patients’ experiences and their family caregivers experiences who just returned home. During the first week, they were facing the crucial time dealing with the reality when they just count on to themselves and family members. In this phase, patients feeling happy when they back home but at the same time the difficulty of in everyday life was so clear. Their participation in the daily life was nearly loss. They became dependent on their family members for doing the basic task such as personal care: eating, bathing, toileting, grooming, etc. Part of the

patients reported that they talk was not clear. For the family members, they became a person who provide care for the patients and reported that having 24 hours a day beside the patients was just like no end task.

2) Seeking treatment phase

The second phase following discharge was ‘seeking-treatment’ phase. At this phase, the experience from the first phase could continue and become part of it. Seeking treatment phase is the period when patients and family caregivers were eagerly seeking rehabilitation or something that could replace it. At home, when there was no longer support from health providers they had to decide rehabilitation options all by themselves including therapy.

The patients’ experiences included four categories: (1) I had routine exercised by myself; (2) I had massage therapy for several weeks; (3) I had routine follow-up check together with rehabilitation therapy; and (4) I failed to have follow-up check. Family caregivers’ experiences included three categories: (1) Patient wanted to do all by himself; (2) We had barrier to have follow-up check; and (3) It is my responsibility for care taking. (Table 8.2)

Table 8.2. Experiences of participants in the Seeking Treatments phase

No	Category	Subcategory		Code
PATIENTS				
P1	I had routine exercised by my self	P 1.1 I believe in self effort	P 1.1.1	I believe in self effort
			P 1.1.2	I did self-exercise
		P 1.2 I had routine exercise	P 1.2.1	I did routine exercise in the morning
			P 1.2.2	I had two kilometers walking every
		P 1.3 I exercised my hand and foot	P 1.3.1	I exercised my hand
			P 1.3.2	I did running and walking exercise
P2	I had massage therapy for several weeks	P 2.1 I had massage therapy at home	P 2.1.1	My husband called the therapist to home
			P 2.1.2	I had massage therapy twice a week at home, we called the therapist
		P 2.2 I had massage therapy at the therapist center	P 2.2.1	I went to therapist to have massage twice a week
			P 2.2.2	I combined massage therapist with self exercise
P3	I had routine follow-up check together with rehabilitation therapy.	P 3.1 I attended rehabilitation and follow-	P 3.1.1	I was attended rehabilitation together with follow-up check for one month
		P 3.2 I had follow up check supported by my family as scheduled	P 3.1.2	I had visited hospital to follow up care as scheduled
			P 3.1.3	I had my family queing for the follow-up check registration and picked me up later
P4	I failed to have follow-up check	P 4.1 I failed to have follow-up check because forgot the time and cost concern	P 4.1.1	I forgot, so I did not go for follow -up check.
			P 4.1.2	I had to provide transportation fee so if I had only I will go.
		P 4.2. No companion and easy to get tired at time of follow-up check	P 4.2.1	It was difficult to have a follow up check if no one could accompany me.
			P 4.2.2	I was once there, but then I got tired so I did not want to go for next follow-up
FAMILY CAREGIVERS				
FC1	Patient wanted to do all by himself	FC 1.1 He wanted to do all by himself	FC 1.1.1	He wanted to do all (walking, going to the bathroom) by himself
			FC 1.1.2	He did not ask my help sometimes when he wanted to go to the toilet
		FC 1.2 I supported patient for what was needed	FC 1.2.1	We just holding her sometimes because she still walked unsteadily
			FC 1.2.2	I tried to support him what he needs
FC2	We had barrier to have follow-up check	FC 2.1 We forgot the schedule and document so did not attend follow-up check	FC 2.1.1	I forgot, so I did not go for follow -up check.
			FC 2.1.2	I misplaced the documents, so when we found it the time was already passed
		FC 2.2 It was difficult to have follow up check because long queing and complicated system	FC 2.2.1	It was a long queeing for follow up-check too much time to spent
			FC 2.2.2	It was difficult to have follow up check, it is complicated system
FC3	It is my responsibility for care taking	FC 3.1 This is my responsibility for taking care patients	FC 3.1.1	this is our responsibility to taking care our parents
			FC 3.1.2	I am his wife, it's my responsibility as a wife
			FC 3.1.3	I am responsible for my wife's health
		FC 3.2 Religion taught to taking care our parents and spouse	FC 3.2.1	In my religion we should take care of our parents
FC 3.2.2	It is already supposed to be like that			

Experiences of the patients

(1) I had routine exercised by myself

It means the patients were doing exercise on their own, without any instructors or guidance. They reported walking as one exercise that they always do every morning. One patient added the level of difficulty of his training each day to gain more improvement, for example, walking, going up and down the stairs and holding onto something. Another patient was using a rubber ball to exercise their palm and practicing the ability to hold something.

As reported by these patients below;

“I usually exercise at home, by myself. After Subuh pray, I went for a walk. It’s about 1-2 kilos from home to the nearest park. I tried to disciplined myself. I can get two advantages from this; exercises and exposure to the sunlight.” (P-7)

(2) I had massage therapy for several weeks

It means that patients had massage therapy several weeks to improve their motoric function. In this study, the massage therapy was the same as mentioned in the preliminary study, which was provided by an uncertified reflexologist. The patients can directly visit the therapist clinics or invited the therapist to their home and performed the therapy at home. As patient twelve reported,

“We had a massage therapist who came twice a week to our home. I felt good after I had the massage. So I continued to have it.” (P-12)

(3) I had routine follow-up check together with rehabilitation therapy.

Patients attended the follow-up check at the hospital together with the rehabilitation regularly as scheduled. Only a few patients could have a routine follow-up check and rehabilitation a. It was only two up to three people. While others described that they had the follow-up check only once or not at all.

“I always came to the hospital to have follow-up check, and after that went to the rehabilitation section. I did that routine as scheduled.” (P-7)

(4) I failed to have follow-up check.

This category means patients had difficulty to have a follow-up check if nobody could take them to the hospital and another other reason was because they felt exhausted after having follow-up check so they did not continue it for next appointment.

Other reasons reported by the participants: they forgot and missed the first schedule of the follow-up day; they did not know how to manage it and they had to provide the transportation fee and it would cost a lot because they had to call a taxi. One participant's home was far from the hospital; while he used to drive a motorbike everywhere, since he became paralyzed, he could not drive and now depended on public

transportation or other family members.

As reported by one patient.

“It took time to go there [hospital], I could not drive my own motorbike and needed to call “gojek” (public transportation that can be booked by online). And it’s expensive.” (P-10)

“It’s difficult... difficult you know... I am tired... I could not go to the hospital many times.... I got once there, the waiting time was so long... I guessed once is enough for me, no more.” (P-1)

Experiences of the family caregivers

(1) Patient wanted to do all by himself:

Some patients were discharged home with some ability to walk, and because they could walk, they felt they could do anything. Family caregivers reported that being independent was good for them. However, if they failed to have success, they became angry or sad and finally projected the anger onto the caregivers.

“I was cooking in the kitchen when I heard someone trying to get down the stairs. I was surprised to see my husband there... I told him to ask my help if he want to practice walking or going to the bathroom; I always tried to support what he needs.

Then, you see... He was upset when he failed to bear his body on the stairs. He often cried at the beginning we returned home.” (FC-3)

(2) We had barrier to have follow-up check

This category means that family caregivers felt the system for follow-up check at the hospital was complicated, thus made it difficult for them to attend. One family caregiver forgot where he put the appointment letter for the follow-up check and when it was found one week later, the date was already expired and they thought there was nothing they could do about it.

“I knew we have to come back to hospital, but I forgot where I put the letter. When we found it, it was already passed. Well I did not know how to deal with it. It’s my nephew who put all the documents together in the envelope of the CT-Scan results.”

(FC-11)

“It was complicated... dealing with the registration. Not to mention you have to queuing for so long... could you imagine we have to go very early in the morning to get the number. Then queuing again to get the check-up... I felt sorry for him, so tiresome.”(FC-7)

(3). It is my responsibility for care taking.

It means family caregivers accepted the role of caregiving as a responsibility as

part of the obligation for spouses or for parents.

“I did not mind caring for him, it’s already my responsibility as his wife... you see what could we do if one of us was sick? If he is sick, I will taking care of him and vice versa.” (FC-1)

The second phase at one month after discharge was seeking for treatment phase, at this phase patients were eagerly exercise by themselves. They also seek a therapy to improve their ability specially for walk such as a massage therapy to improve the circulation and muscle relaxation. At this time patients were divided into two group. Patients who success attended follow-up care after at least one eek discharged and group who had barrier to follow-up care. The reason for the barrier was it too much took effort and cost because they had to queuing for such a long time. Their family caregivers were gradually accepting the role of providing care as their responsibility. As their spouse or as their daughter/son. And having a strong believe to Allah SWT.

3) Expecting recovery phase

The third phase is expecting recovery phase. This phase happened at the fourth week after discharged. The experiences of patients in this phase included two categories: (1) I felt improved after I went to the bathroom within several weeks; and (2) I felt free at home. In addition, the experiences of family caregivers included two

categories: (1) I was patient with his changing emotions; and (2) I believed that only God can cure. (Table 8.3).

Table 8.3. Experiences of participants in the Expecting Recovery phase

No	Category	Subcategory	Code
PATIENTS			
P1	I felt improved after went to the bathroom within several weeks	P 1.1 I was able to walk gradually	P 1.1.1 I was gradually able to stand P 1.1.2 I was already able to walk P 1.1.3 I am able to walk gradually
		P 1.2 I went to the bathroom after two weeks	P 1.2.1 Able to urinate and defecate in bathroom P 1.2.2 I was able to take a shower in bathroom after two weeks P 1.2.3 I went to the bath room after two weeks
		P 1.3 I was feeling improved	P 1.3.1 I was gradually recovering within two weeks P 1.3.2 I was not 100% recovered, but feeling improved.
P2	I felt free at home	P 2.1 I could go and back to the toilet as I wanted	P 2.1.1 I could freely come and go to the toilet
		P 2.2 I felt free at home	P 2.1.2 I felt free at home
FAMILY CAREGIVERS			
No	Category	Subcategory	Code
FC1	I was patient with his changing emotions	FC 1.1 Patient easy to got emotional change	F 1.1.1 My husband's emotions became easily changed C F 1.1.2 My husband got angry easily if I could fill what he wanted C
		FC 1.2 I was patient eeventhough it was difficult	F 1.2.1 I just kept being patient if my was mom difficult to handle C F 1.2.2 I wasn't prepare for such emotional
FC2	I believed that only God can cured	FC 2.1 I always pray to God for patient to be healed	F 2.1.1 I always reminded my husband to pray to God to be healed C F 2.1.2 I always prayed for my husband to be healed C
		FC 2.2 I believed God can cured	F 2.2.1 I believed God is the almighty, his will is done C F 2.2.2 I believed that any kind of disease could be cured by God C

The experiences of patients

(1) I felt improved after went to the bathroom within several weeks.

It meant that patients felt the improvement of their ability regarding physical function gradually within two until three weeks after discharged. The improvement was marked by several activities that can be achieved by the patients. The category was structured by three subcategories, as follows:

(1.1) I was able to walk gradually

It meant that patients ability to walk was a process not something that would happen suddenly, but one that required a great number of attempts. The achievement was marked by their ability to perform toileting in the bathroom. In this study, toileting was considered to be a fundamental or basic need of patients. According to the patients, ability to perform toileting in the bathroom demonstrated their improvement from the weakness or paralysis.

(1.2) I went to the bathroom after two week.

It means that patients gain the ability within two weeks. The time frame was different for each patient. Some of patients reported three weeks or somewhere in between those times.

(1.3) I was feeling improved

The feeling of improvement was very subjective and depended on each participant. Some patients reported the percentage to describe how much they improvement they gained. As patients three explained:

“I felt the improvement, that’s why I am feeling good and it motivated me to be more discipline in exercise. I started from a crawl then and now I am able to stand and walk. Then went to the bathroom. It is not 100% but I felt improved, well I will say that it was 80 % getting better.”

(2) I felt free at home.

It means that patients feeling free being home. From the interview patients described that after they returned home, (2.1) I could go and back to the toilet as I wanted. They went to the bathroom for elimination because toileting in the bathroom was fundamental from the patients’ perspective. And (2.2) I felt free at home. At home, they felt more comfort and home provided their privacy. As explained by patient nine:

“I felt free at home, you want to go everywhere... you can go back and forth to the bathroom, just free... it was not like when I still at the hospital. It felt so difficult to go the bathroom.” (P-9)

The experiences of family caregivers

(1) I was patient with his changing emotions

It means family caregiver understood that patient's emotion changed easily and being patient was a way to cope with that. The mood swings of patients became part of the challenge in this phase for family caregivers that they had to face. Family caregivers explained that at first, they were not prepared for such a situation. However, after several weeks they learned that it was part of the process of recovering from a stroke and therefore they created suitable coping for themselves.

"He cried in the early weeks, because he could not walk or even to stand.

" (FC-3)

"After he got home, my husband was easy to anger, I know this kind of disease changed people, so I kept being patient." (FC-7)

(2) I believe that only God can cure

It means that family believes in God and that only God can cure. Family caregivers believed the power beyond the impossible thing that is God.

"I kept tell him to be patient and to ask God for recovery... in that way I reminded myself to be patient and leaved it to God, the Almighty." (FC-1)

This expecting recovery phase was characterized regarding patients gradually

feeling improved. Their ability for toileting has become fundamental and important to grade the progress of recovery. And patients described their feeling as free at home for achieved this activity. As for family caregivers, at this phase they were reported tried to cope with patients change mood by being patient.

Within three months after discharge

After three months, several patients reported that they were gradually improved, while others still remained the same. This time frame only included one phase: resuming their normal life.

Resuming their normal life phase

After three months the participants were trying to come back to normal life. Resuming their normal life phase means that the participants were beginning to continue their life again after facing certain difficulties of ADL restriction and struggling for recovery caused by stroke. Some of the patients were already back to work, while others are still trying to overcome their problems with the difficulties. This phase was structured by 10 categories of patients' experiences and four categories of family caregivers' experiences.

The Experiences of patients

This phase was structured by 10 categories of patients' experiences (Table 9.1)

The categories are as follows:

(1) I am feeling better because I could do personal care by myself

This category means that patients feeling better because of they can gain the improvement of ability to do personal care.

This category was structured around four sub-categories: *(1.1) I was able to eat by myself, (1.2) I was able to walk alone to the bathroom for toileting and bathing, (1.3) I was able to get dressed by myself and (1.4) My recovery is obvious.*

"I am feeling better now...it's not like 100% recover, but I can say that it felt like 80% improved. I can lifted my hand up, performed toileting by myself, and got dressed by myself even though it still takes time." (P-3).

(2) I still felt different about my body

It meant that patients felt the complaints especially regarding numbness, heavy on the other side of the body.

" I felt the numbness in my hand or leg, it is one part then the other day I felt my mouth was heavy. But it's gone when I drink the medicine." (P-3)

Table 9.1. Experiences of patients in Resuming Their Normal Life phase

No	Category	Subcategory	Code
PATIENTS			
P1	I am feeling better because I could do personal care by myself	P 1.1. I was able to eat by my self P 1.2. I was able to walk alone to the bathroom for toileting and bathing P 1.3. I was able to get dressed by myself P 1.4. My recovery is obvious	P 1.1.1 I was able to eat by myself P 1.1.2 I was able to lifted my right hands P 1.2.1 I was able to walk P 1.2.2 I was able to go to the bathroom P 1.2.3 I had bathing in the bathroom P 1.3.1 I had urinating and defecating in the bathroom P 1.3.2 I was able to get dressed by myself even though it took long time P 1.3.3 I could get into my pants by myself P 1.4.1 I am feeling better P 1.4.2 Feeling 80% recovery
P2	I still felt different with my body	P 2.1 I still felt different P 2.2 I had hand numbness and stiffness P 2.3 I had uncontrolled saliva and speaking problem P 2.4 I got tired easily	P 2.1.1 Still felt different (in my body) P 2.1.2 I guessed I could not recover 100% P 2.2.1 Had hand numbness sometimes P 2.2.2 Still felt muscle stiffness P 2.3.1 Had uncontrolled saliva P 2.3.2 Still felt slow and difficulty in speaking P 2.4.1 Easy to get tired
P3	I am concerned about routine exercise and diet	P 3.1 I still conduct exercise routinely P 3.2 I am concerned about the diet and following physician rules	P 3.1.1 I still conduct routine exercise P 3.1.2 I used ball for hand exercise P 3.2.1 I kept being concerned about food P 3.2.2 I was following physician rules regarding diet
P4	I felt sorry for not being able to care my spouse	P 4.1 I could not use my hand P 4.2 I felt sorry for not being able to care my spouse	P 4.1.1 I couldn't hold things properly P 4.1.2 I couldn't move my right hand at all P 4.2.1 I could not cook, my husband did that P 4.2.2 I am the one who should care for him P 4.2.3 I felt sorry for my husband
P5	Wondering if I can work again	P 5.1 I am planning to work again P 5.2 Wondering if I can work again P 5.3 Not strong enough to work but need activity	P 5.1.1 I am planning to get back to work P 5.1.2 Thinking about my job P 5.2.1 No work after being sick P 5.2.2 Wondering if I can work again P 5.2.3 Wondering if I could drive again P 5.3.1 Not strong enough to work P 5.3.2 I had to have activities to make me busy
P6	I am concerned about my family matters	P 6.1 I did not want to be a burden P 6.2 I am concerned about my children	P 6.1.1 I didn't want to be a burden for family P 6.1.2 My children support us financially P 6.2.1 I want to witness my 's son marriage P 6.2.2 I will feel relieved to leave my son if he is already married
P7	Hoping for recovery and back to normal	P 7.1 I satisfied with the progress so I felt P 7.2 I believe in God and family support P 7.3 I am hoping to be normal again	P 7.1.1 I had to be confident to gain recovery P 7.1.2 I am satisfied with the progress P 7.2.1 I believe recovery is from God P 7.2.2 I believe drugs are only supporters P 7.2.3 I believe family attention is number one P 7.3.1 I am hoping to be healthy again as normal P 7.3.2 I tried everything to be able to recover
P8	I keep my self happy	P 8.1 I keep my self happy P 8.2 I avoid stressing my mind	P 8.0.1 I keep myself happy and no burden P 8.0.2 I released too much thought P 8.0.3 I tried to avoid useless comments
P9	My own will is the key to recover	P 9.1 I am focusing on my recovery P 9.2 My own will is the key to recover	P 9.1.1 I had to pushed my self to overcome the disease P 9.1.2 I was thinking only for my recovery nothing else P 9.2.1 I had strong will to heal P 9.1.2 I felt my own will is the key to recover P 9.1.3 I thought it can be healed with own strong will
P10	I believed recovery is given by God so I keep praying	P 10.1 I keep praying although with limitation P 10.2 I believe recovery is given by God	P 10.1.1 I conducted praying as I can P 10.1.2 My wife assisted me to do ablution before praying P 10.1.3 I was praying by sitting down or lying down P 10.2.1 I can be cured with God's will P 10.2.2 I believed recovery is given from God

“Sometimes I felt I can not controlled my saliva, it just come sout like that...

“ (P-7)

(3) I am concern about routine exercise and diet

It meant patients were trying to maintain their good habits especially to do exercise routinely.

(4) I felt sorry for not being able to care my spouse

Patients had a guilty feeling about their spouses who were taking care of them. This experience was reported mostly by female patients who felt that she was responsible as a homemaker that dealing with the home chores, cooking and caring their husbands.

“I felt sorry for my husband, I cannot cook for him, instead of taking care of him, he is the one who is taking care of me. I told him... later, if I already recover I will pay it back by taking care of him... but he said, no I don’t want to be sick... well it is a joke I know.” (P-9)

(5) Wondering if I can work again

Patients were concerned regarding their work and the possibilities of getting their job back.

(6) I am concerned about my family matters

Patients were also thinking about their family issues. Female patients reported this as explained by patient 12:

“I think the most important think now is I can see my son married. You know... I will feel relieved if there is a girl who is going to taking care of him. I just wish that happens immediately... then I will feel relieved.” (P-12)

(7) Hoping for recovery and back to normal

Patients still expected they would recover and have a normal life.

“ I hope I will come back again like I used to be... I can drive a car, because I am a driver. Now for only driving a motor cycle, I could not do it.” (P-6)

(8) I keep my self happy

It means patients were trying to make a positive and happy mood for themselves.

(9) My own will is the key to recover

Patients realize that to be able to recover should be come from their own will not from anybody.

“ The most important is your own will. You will get recovery as long as you believe yourself. I believe it is the key to recover.” (P-2)

(10) I believe recovery is given by God so I keep praying

It means that patients believe in God and all the possibilities including being

able to recover is by God's intervention.

"I believe Allah (God) is the Almighty, the disease came from God and Allah will cure too. We should not stop praying for asking, Allah will answer and giving me the ability to recover." (P-1)

The experiences of family caregivers

The four categories of family caregivers' experiences (Table 9.2).

(1) I was relieved with patient's improvement and kept motivating them for their recovery

Family caregivers experienced uncertainty about the patient's condition and outcome and thus worried and now were feeling relieved by patients' improvement. This achievement encourage them to supported and motivated patients to gain recovery.

(2) I reminded patient about healthy living

Family caregivers were trying to maintain patients' health lifestyle by preserving their diet and doing regular exercises,

(3) I am thinking about financial support

It means that family caregivers were thinking regarding who will support their financial needs while their husbands were still not able to work. One of the family caregivers worked to fill the needs of the family.

Table 9.2. Experiences of family caregivers in Resuming Their Normal Life phase

No	Category	Subcategory	Code
FAMILY CAREGIVERS			
FC1	I was relieved with patient's improvement and kept motivating them for their recovery	FC 1.1 I felt relieved about patient improvement FC 1.2 I motivated patients so they could get healed fast	FC 1.1. I felt relieved about his improvement FC 1.1. I am feeling lucky compared to other patients with strokes who had less opportunities 2 FC 1.2. I told my mom, if she got healed she can go anywhere FC 1.2. I told him don't overthink too much FC 1.2. I tried to motivate my husband
FC2	I reminded patient about healthy living	FC 2.1. I reminded patient about healthy diet FC 2.2. I encouraged him to continuing self-exercise	FC 2.1. I asked him to reduce salt intake FC 2.1. I keep concerned regarding his diet FC 2.1. I always reminded him about a healthy diet FC 2.2. We got tired to see her so active and asked her to get some rest 1 FC 2.2. I always encourage him to continuing self-exercise FC 2.2. My mom drank herbal medicine and we supported her
FC3	I am thinking about financial support	FC 3.1 I am thinking about who will support my family FC 3.2 I got financial support from other family members	FC 3.1. I am thinking what happens if my husband can no FC 3.1. We received financial support from my nephew, he is like a son 2 FC 3.2. I am afraid of a second attack might come FC 3.2. We received financial support from my niece, he just like my son 1 2
FC4	I am afraid if second attack come and searching the information	FC 4.1 I am afraid of a second stroke attack FC 4.2 I keep searching the information	FC 4.1. I am afraid if a second attack come FC 4.1. I am hoping there will be no more attack FC 4.2. I keep searching the information from the internet regarding the disease 1 FC 4.2. I got information from friend with the same case with my husband 2

“Well... I must work. If not me, who else? My husband has still not gained recovery one hundred percent. And we could not be counting on our children forever.

“ (FC-6)

(4) I am afraid if a second attack come and searching the information

Family caregivers were concern regarding the possibilities that patients could have another stroke. In addition to that family caregivers were searching for the information from many resources such as TV, friends etc.

“They (neighbor) told me... that stroke can happened twice, three times... so I am worried... but I did not want to think about it. He will be fine I am sure.”(FC-1)

In summary, within three months after discharge there was only one phase described by the participants. Resuming the normal life is emerged from ten categories of patients' experiences and four categories of their family caregivers' experiences. The focus was hoping for recovery and for come back to normal life. Patients were gaining ability to perform self-personal care which accelerated their confidence, and this enforced their behavior to continuing routine exercise. They also realized that their minds has important role and they tried to keep it positive. This group of patients has positive views that they believe their own way is the key to recover. Meanwhile some patients still feel the symptoms like numbness and heavy on the one side of their body, they felt worry not

being able to back to their work because of their condition. And because they also could not find the job. They became concern about the family matters because male patients tended to concern regarding financial support while female patients tended to concern their children and their role as a homemaker. Thus, they felt sorry for not being able to take care their husband and were concern regarding their unmarried children. They hope to be able to watch their son getting married was reported by one female patients. Beyond of that there was an element as a basic and when there was nothing can be rely one there always God who they believe who has power to their life and that God who will cured the disease.

CHAPTER 6

DISCUSSION

This chapter discusses the following: 1) characteristics of the participants in South Tangerang city; 2) gaps identified in the experiences of patients and their family caregivers during hospitalization; 3) concern of patients and their family caregivers experiences after discharge; 4) unique concern of the patients and their family caregivers experiences based on cultural and religious background; 5) the transitional care needs emerged from the experiences of patients and their family caregivers; 6) implications for the continuum care of patients with ischemic stroke and their family caregivers and 7) strengths and limitations of the study.

1. Characteristics of the participants in South Tangerang city.

South Tangerang city has a high prevalence of stroke compared to the other districts in Banten province (Risksedas on Banten Province, 2013). The participants in this study were mostly patients with a mild stroke. Four out of twelve patients had a pre-existing condition of type two diabetes mellitus (DM2) and longer duration of hospital stay compare to the other participants. Based on the literature review, in South Tangerang city, the prevalence of DM2 is increasing with the advancement of age. The

prevalence of DM2 was associated with people having a higher income and higher educational background (Risksedas on Banten Province, 2013).

Regarding the age, the patients in this study were divided into two age groups based on the age structure in Indonesia. The first group was in the productive age from 15-64 years old and the second group comprised the elderly, which were 65 years old and older (Indonesian Health Profile, 2014). This study founds the younger patients (age productive group) tended to have a shorter duration of hospitalization and tended to have a higher score for ADL after discharge. However as this was a qualitative study these comparisons must be cautiously interpreted.

Based on the participants' occupation, they were blue-collar workers. Half of the patients still actively worked and desired to return to work as soon as possible after hospital discharge. This was especially true for male patients who had the role as the head of the family because they had to provide financial support for their family.

Several patients reported they did not have health national insurance. However, they could access the free health services only by showing their citizen identity card as evidence that the holder was an inhabitant of South Tangerang City. The government issued a healthy card simultaneously in September (South Tangerang city profile, 2015).

The family caregivers were mostly spouses and several were daughters. One

daughter was married and had one child, so she had a double burden: caring for patient and her family. The type of extended family living in one house was still dominated in South Tangerang city. This family structure had created strong family ties. Religious background influenced the care taking. Participants considered this as an obligation of the family members. As a Muslim, the one who takes care of the elder and spouse will get the reward from God because of their good deed and will be granted with heaven. These several background situations influenced the view and perspectives of patients and their family caregivers as well as their stroke experiences during hospitalization and after discharge to home.

2. Gaps identified in the experiences of patients and their family caregivers during hospitalization

There were few studies related to patients with stroke experiences and comparing their caregivers' experiences during transition. A prior study conducted in United States had described these experiences as the stroke crisis trajectory (Lutz et al., 2011). In this study the experiences of study participants were not described as a crisis. However, the context was in line with the Lutz et al. (2012) research that patients and their family caregivers experienced concerns and worries during hospitalization. These were the

opposite things with what they believed or expected. These discrepancy created gaps and the explanation were as follows.

First, was the gap in having information/inform consent regarding the diagnosis and stroke disease. During hospitalization, the initial experience was regarding the uncertainty of patients' minds along with a sudden change of their physical functions caused by stroke. The cognitive change that occurred in the acute phase is common and will come back along with the recovery process (NHS-improvement stroke, 2011) although the recovery time was different depending on the case. This study found that study patients experienced the disbelief of the stroke diagnosis and disbelief in the necessity to be hospitalized in acute-phase. They did not expect to be hospitalized. The study conducted by Lutz et al., (2011) had the same result about the experience during hospitalization, which at that time patients who were had some cognitive function demonstrated high anxiety, shock and disbelief.

In the case of family caregivers, they had to switch their condition from being shocked to being alert, as patients got hospitalized to continue the patient's care. At this phase, family caregivers also experienced limited information regarding stroke and the causes. Family caregivers reported that although the physicians had provided some explanation, however when they needed more information they felt hesitant to ask. This

result was in line with previous study by Giosa et al., (2013) who identified that caregivers felt discourage to make inquiries that could have prepared them for the future responsibilities and they considered hospital setting as uninviting. Finding in this study also reported that caregivers did not receive any explanations regarding stroke disease. Inadequate information regarding the diagnosis might prohibit the ability of patients and family caregivers to adjust to the hospitalization. For this reason, a clear informed consent is needed prior to treatments and education about the disease is critical. Since family caregivers also can consist of more than one person, assessment to this area is a necessity.

The second gap was between the patients' understanding and the physicians' explanation regarding step-by-step exercise. It was the inability to understand the physician's order regarding the step-by-step exercise instructions. In the post-acute phase, when the condition was more stabile, patients started to become concerned about their ability to recover. One attempt was by trying to walk to the bathroom, which according to their understanding they should be able to do by themselves immediately however that seemed against the physician's recommendation. Based on preliminary research data, to perform elimination in the bathroom is considered important for the patient (Damiati, 2016). One of the patients reported, no matter how hard it will be, he never stopped the attempt. Several patients experienced falls at the hospital on their

attempt to make bathroom visits; they also had to go discreetly with the nurses as well as with the physicians. In addition, family caregivers who admitted that they did not understand the physicians' orders unfortunately were not able to prevent patients from attempting walking to the bathroom. These results suggest the needs for a survey study of patient falls resulting from attempts to walk to the bathroom after stroke as an evidence to find the best solution. In addition to that the physician explanation regarding the exercise and mobilization after stroke should be delivered through an effective health education for patients' and family caregivers' included an effective evaluation to improve their understanding.

The third gap was the desire of patients and their family caregivers to be discharged home but felt worried. This study reported that at the time of discharge, patients and family caregivers hesitated to be discharged home. They expected to be discharged immediately because being discharged home meant that they had already recovered. However, when the physician decided the time of discharge, patients did not feel confident, and tried to negotiate the decision. Because family caregivers also felt the same, they reported that they could not imagine what should be done when they got home with the condition that was still far from what they imagined was "recovery." While at the hospital they had the physicians' and nurses' support. This happened

because patients and family caregivers were not well prepared for discharge. And there might be a gap in understanding progress of recovery between participants and the physicians. A study by Giosa et al., (2013) described that there were several instances of miscommunication and information sharing errors during discharge and that the caregivers expressed to have the opportunity to make necessary arrangements in acute care prior to their discharge. Therefore, this experience also can be considered as a sign that patients and their family caregivers did not have any idea what may be required at home and thus the discharge readiness assessment should be obtained to identify their problem and find out the solution. Furthermore, there should be an effective discharge planning to make the discharge are meaningful.

3. Concern on patients and their family caregivers' experiences after discharge

The concerns after discharge were as followings.

3.1 Barrier to have follow-up check

The findings of this phase identified an important category reported from both patients and their family caregivers. The category is “it was difficult to have a follow-up check”. At discharge, participants received a letter for a follow-up check from the hospital staff. It used to be scheduled between five and seven days following discharge. A follow-up check is important for patients to consult their condition with the physician,

to have re-medication, and rehabilitation. On the other hand, they found it was difficult to follow up. The major reasons described by the participants were because it was “too much effort”, “the system was so complicated” and “cost concern”. The hospital was a public district hospital where the patients were abundant. The registration for the follow up check should be done early in the morning prior to their arrival; otherwise they could not secure the waiting list number. Participants were not really sure if it could be done online or not. They reported that at least they had to arrive at the hospital before dawn. After securing the number they still had to wait since the outpatient clinics officially opened at 8 A.M. Later they were also required to queue for the check-up. This whole process was considered as too much effort by all participants and the needed cost for transportation. Most of the patients had one successful follow-up check, after they experienced it, they did not want to continue.

Participants admitted that they became tired after enduring the first follow-up check. The registration done by the family members and patients would come after that, usually at the time of queuing in front of the physician’s room. However, they had to prepare transportation fees to pick up the patients. The systems issue should be taken into account.

3.2 Caregivers burden

Meanwhile, the family caregivers who became responsible for the patients felt overwhelmed because during the first week at home; patients should be accompanied 24 hours a day. They described this task as “caring was like without end”, not to mention they were facing many difficulties and worries at the same times because patients refused to eat and take the medicine. It is important to note their need of having support from their extended family. According to the characteristics of participants, this need could be fulfilled because the participants mostly lived with extended family. However, this need still remains for the participants who live only with their spouse.

4. Specific concern on the study participants experiences based on cultural and religious background

These were unique concern on the experiences of the patients with ischemic stroke and their family caregivers related to the Indonesian culture especially for participant who live in South Tangerang city and their religious believe. The first was regarding the patients’ excretory function, the second was the male patients’ concern about returning to work and third was family caregivers’ awareness of their caregiving role. These issues are explained next.

First, the excretory function means the ability of the patients to conduct urine and bowel elimination in the bathroom. Since the post-acute phase at the hospital when patients became aware of their difficulty in moving, they insisted to do this function in the toilet except for the patients who were really too weak or unconscious. For those in such a condition the patients accepted using diapers and performed elimination on the bed. After discharge, one of the reasons for reporting feeling happy and free at home was because they could go back and forth to the toilet without feeling guilt. The result was similar to the findings from the preliminary study (Damiati, 2016) that there is an urge to perform elimination in the toilet. This preference may be influenced by the religious belief of Islam, which was the predominate religion of the participants. In Islam, they have the obligation to perform five times prayer in a day. Thus, leaving out one of the prayers is considered a sin. In performing prayers (*shalah*) the person should be clean from urine or stool (*hadaas*). Accordingly, after the elimination patients should wash their perineal area with water. Then they have to wash their hands, face, feet and several areas with water (a wet ablution) before conducted prayers. The area of praying should be clean from *hadaas* too, for this reason they were afraid that if they conducted the elimination in the bed the environment would become dirty from stool or urine. This unique finding was really different from the Western literature. In this study, patients

were trying to maintain their religious activity even though they were limited. The purpose of there behavior was in to be able to pray properly. Praying is an important act of patients as well as for the family caregivers. Norris et al., (2012) described that prayers were a key activity for all participants and one which was maintained despite their physical limitation. The patients' limitation included the ability to perform *shalah* with standing position in the mosque, and conduct ablution before praying. Their ability to maintain their religious activity help them to rebuild their confidence and something they could rely on when everything else seemed impossible. One study described the physician roles as the mechanism for receiving help, with God providing the cure (Ypinazar & Margolis, 2006)

The second issue was the patients concern about returning to work. Mostly male patients especially in younger age groups experienced this. This group was considered in the productive age group and the role as the head of family as a provider for financial support. In addition, this role become one of the pressures for patients to seek treatment or to practice exercises to improve their motoric function and increase their participation in activities at home such as personal care. In the urban area, cost of living was high compared to the rural area and there were increasing needs to earn money by working.

The third issue was the family caregivers' awareness of their role in providing care for patients. The type of extended family living in one house was not really a typical pattern of urban life. However, in South Tangerang city the characteristics of this living pattern demonstrated a strong family bond. Since the patients were admitted to the hospital, family members got together in the hospital and they started to arrange the care and shared the responsibility among them. The family caregivers, mostly spouses or several children considered the caregiving as a part of worship. In Islam, a wife who sincerely cares for her husband will be rewarded in heaven and also children for caring for their parents. That was how they sincerely enacted the caregiving role even though they also reported the task as a "no end" task. In the Green and King (2009) study researchers described the experiences of male patients and wife-caregivers. The themes that emerged were being vulnerable and realization. In realization they were focusing time and energy on elements of the recovery process. In addition, for female patients the reverse role they felt sorry because their husband was taking care of the household chores such as cleaning the house, cooking, laundering etc. that were typically the women's job.

5. The transitional care needs emerged from the experiences of study participants

The main purpose of this study was to describe the patients and family caregivers' experiences. From their experiences, this study provided an image of what patients with ischemic stroke and their family caregivers were dealing during the transition from hospital to home. In this study, the participants encountered difficulties and challenging experiences in every phases which created gaps and barriers. Then finally the pressing needs of services or care from the health providers emerged from the experiences of patients and their family caregivers for in order to facilitate a transition and improve patients and their family caregiver's quality of life. The care or services to facilitate smooth transition across the setting and involve multidisciplinary team is termed transitional care (Naylor, 2011)

Qualitative studies primary focus on the needs of caregivers. One study identified caregivers support needs from gaps in caregiving experiences and roles (Cameron, 2007). Another study developed a theory of caregiver support needs during care transition from hospital to home, which was divided into four time frames: Acute-phase, discharge, in-patient rehabilitation and home (Giosa et al., 2013). A conceptual framework from Cameron et al. (2008) described caregivers support needs across the care continuum included three settings: (1) acute care (event/diagnosis, stabilization) (2)

acute care/in-patient rehabilitation (preparation) and (3) community (implementation, adaptation).

In this study, based on the discussion above the timeline of transitional was divided into seven phases as follows: 1) Acute-phase, 2) post-acute phase, 3) at time of discharge, 4) facing difficulty phase, 5) seeking treatment phase, 6) expecting recovery phase and 7) resuming normal life. Three phases occurred in hospital setting and four last phases were at home. Despite the needs for caregivers support this study also included for patients support needs. This study participants were patients with mild strokes, however the transitional care for stroke patients should include for more severe patients for sustainable life at home.

The description regarding phase characteristics and specific support needs will be explained next.

(1) Acute phase

At this phase stroke as unexpected event, some patients experienced loss of consciousness, had limited of memories and unclear minds so that they did not have a clear understanding regarding stroke. The focus of treatment was for life survival lasting for few days until weeks (Cameron et al., 2008; Giosa et al., 2013). For the family caregivers, this phase was faced as an unpredictable situation when they have to deal with

patient care and focus on patients' survival. They shared the responsibility among the family regarding providing care for the patients.

Nurses and health providers should be aware and more sensitive to understand the complexity of the experiences of stroke patients since patients were admitted to the hospital. Due to limited memory, patients relied on the family caregivers to "fill the gaps about what happened" (Lutz et al, 2013, p.4). Patients need support for physical dysfunction. Patient and family caregivers need information regarding the disease, patient's condition, prognosis and treatment option (Cameron et al., 2008), emotional support (Cameron et al., 2008; Lutz et al., 2013). Based on this study finding, the care will add the spiritual support. Patients' assessment and family caregivers assessment should be started as early as possible (Lutz, et al., 2016). Discharge planning should be started with the assessment of individual discharge needs within 48 hours of admission (Shyu, et al., 2008 & 2010). These needs can be provided by involving various health professions: physician, nurses, physiotherapist, and religious leader (*ustadz*). The outcome is assessment of patients and family caregivers knowledge regarding disease, prognosis and treatment (Tsai, et al., 2015): cause, prognosis and treatment, emotional distress, and enhance decision making ability, and spiritual care support.

(2) Post-acute phase

The post-acute phase described the condition when patients had reached the stable condition and concern about their ability to recover. Patients reported that they could not understand the exercise ordered by the physician for their paralyzed body. Patients also reported their desired to go home but still felt worry. For the family, care taking was harder because they need to assisted patients for toileting and prepare for returned home.

Previous study suggested the development of an education plan (Dalvandi et al., 2010; Ing, et al., 2015). In this study the support needs for patient was health education regarding management of stroke and rehabilitation therapy for the example based on this study finding is exercise for paralyzed body. The education should include the time and room for patients and their family caregivers' consultation and well as the evaluation of the education and training. A study from 'For family caregivers' it is a good chance to give training related to how to assist ADL and rehabilitation therapy. The health professional should involve physicians, nurses, physiotherapists, nutritionists, and pharmacists (Cameron, et al., 2008; Lutz, et al., 2008; Mendrofa, 2015)

(3) At time after discharge

At time before discharge was the phase which patients were just about to leave the

hospital. Patients did not aware regarding discharge preparation. Many patients did not receive adequate discharge planning. The family caregivers also experienced not having any explanation regarding medicine. However, some family caregivers reported that they had a very helpful staffs of the hospital. The focus of care should emphasis discharge preparation and returning patient to home. The transitional care including monitoring of patients in performing ADLs safely, introduction of secondary prevention (medical adherence, diet, healthy living), family care readiness assessment including assessment of health facilities utilize. In accordance of the short duration of hospitalization and the limited time frame, the plan should provide written material such as leaflet and brochure (Giosa, et al., 2013). The plan should be supported by the multidisciplinary team: Physician, nurses, pharmacist, nutritionist, physiotherapist, occupational therapist and social worker.

(4) Facing difficulty phase

The facing difficulty phase occurred when patients and their family caregivers just returned home. In this phase, they were facing the crucial time. Limited ADL and mostly became dependent on their family members for doing the basic task such as personal care: eating, bathing, toileting, grooming, etc. Part of the patients reported that their speech was not clear. For the family members, they became a person who provided care for the

patients and reported that having 24 hours a day beside the patients was just like no end task.

The focus of care to adjust to life at home and follow up care. The continuity of care can be provide by home visits and telephone calls (Naylor, et al., 2011; Shyu, et al., 2010). This support care can be done from the first week and continuing with an assessment and consultation for patients and family caregivers. The providers can involve community health nurses, home visiting nurses and community physician. The outcomes aim to improve patient's self-efficacy, the use of health facility in community, emotional distress and psychological health.

(5) Seeking-treatment phase

At this phase patients were eagerly exercising by themselves and searching for the alternative for traditional treatment for rehabilitation. They also sought a therapy to improve their ability to walk such as a massage therapy. This phase sometime could be overlapping with facing difficulty phase and expecting recovery phase. The focus was similar with the previous phase.

(6) Expecting recovery phase

This expecting recovery phase was characterized by patients gradually feeling improved. Their ability for toileting has become fundamental and important to judge the

progress of recovery. Patients described their feeling as free at home for achieving this activity. As for family caregivers, at this phase they reported trying to cope with patients changing and unpredictable moods by being patient. This phase was also considered similar because the duration of these three phases was approximately one month. The focus of care was slightly the same. However, there was additional family support as patients experienced many mood changes.

(7) Resuming their normal life

Patients were improved and gaining ability to perform personal self-care. These achievements accelerated their confidence, and this enforced their behavior to continue routine exercise. The focus was to come back to normal life. Some patients still felt the post stroke symptoms like numbness and felt worried about not being able to return to their work because of their condition. They also became more concerned about the family matters. Male patients tended to concern regarding financial support while female patients tended to be concerned about their children and their role as a homemaker. The focus of care in this phase was to re-integrate into the community life as well as the acceptance of their condition. The continuity of care could still be provided by home visit and telephone calls (Naylor, et al., 2011; Shyu, et al., 2010)

6. Implications for the continuum care of patients with ischemic stroke and their family caregivers

As described from the previous section, the results suggest practice implications to improve patients and their family caregivers going through transition from hospital to home. During hospitalization, participants had limited information regarding disease, therapy and treatments. The result suggests that nurses and health providers should be aware and more sensitive to understand the complexity of the experiences of stroke patients during transition. Family caregivers also have the main role because they will care for patients at home. The preparation should not merely focus on knowledge, but also how to physically and psychologically prepare. The assessment regarding patients and family caregivers should initiate the treatment of the patients and family caregivers. The assessment will give direction to the develop of the pre-discharge program. The multi-discipline team collaboration will be needed since patients need information from different aspects. The team includes physicians, nurses, physiotherapists, pharmacists and nutritionists.

Later at home after discharge, patients were struggling with their own efforts and the main supports are their family and their religious beliefs. These two main support systems were positive aspects that patients and family caregivers could rely on.

However, they also failed to have follow-up checks which could lead to hospital re-admission. There were the pressing needs of having a continuous care between patients with ischemic stroke and their family caregiver's life during hospitalization and their life after discharge. Therefore, the needs and the model of continuum of care for patients with strokes emerged from these findings. Several authors (Giosa, et al., 2013; Lutz, et al., 2016; Naylor, 2011; Shyu, et al., 2008 & 2010) developed intervention programs for patients with strokes post discharge. These interventions included home visits, problem solving and educational information to help caregivers to cope with new roles. Based on the findings, this research suggests telephone calls to the patients and family caregivers at the first week after discharge in correspondence to the barriers to have follow up check experienced by the patients and family caregivers. This telephone call will be provide by the hospital nurses of outpatient clinic in the previous hospital able to assess their condition and identify any problems faced after discharge. This telephone call also functions as a consultation of patients latest condition, if there was a problem, the nurses will facilitate the family caregivers for decision making to have a follow-up check in advance. There should be a link between patients and family caregivers that could connect them with the hospital and promote sustainable care for continuum care of patients with strokes.

The transitional care as explained in the discussion above could be potentially facilitate the focus for each phases of the transition time both for patient and family caregivers. This model was focused on the condition of both patients and their family caregivers at each stage and addressed the needs of stroke care continuum. A transitional care model can be implemented in the clinical setting, hospital and community. The model should be a tool and can be generalized to medical condition in every level of stroke. Future research is needed to clarify the stages and validate the model itself. There is a need to develop a suitable model of transitional care especially with Indonesian cultural and religious background, the involvement of community health services (*puskesmas*) as the front line of health services in Indonesia.

7. Strengths and limitation of the study

The strength of qualitative research is this that it is an excellent method for gathering detailed information about peoples' experiences. By employing this method, researchers can also explore various phenomena and social processes of events. This recent study aimed to explore the experiences of patients with ischemic stroke and family caregivers going through the transitional period from hospital to within three months after discharge at home. This method described not only detailed information but also the process along the period of transition.

The limitations of this study were due to the nature of the qualitative research data collected which was highly dependent on the respondents' ability to answer accurately and honestly about details of their lives, circumstances, thoughts, opinions, or behaviors. Consequently, there is a possibility of bias with the participants' answers. However, validation or re-confirmation was applied to minimize the bias.

CHAPTER 7

CONCLUSION

This qualitative descriptive study was conducted to describe the experiences of patients with stroke and their family caregivers in South Tangerang city, Indonesia. Two main results summarize as follows:

1. The participants in this study were mostly patients with a mild stroke and several patients had a pre-existing condition of type two diabetes mellitus (DM2). Most of the participants included in productive age group and still actively worked and desired to return to work as soon as possible after hospital discharge. The role as the head of the family to provide financial support for their family as the reason for that. Several patients reported they did not have health national insurance. However, they could access the free health services only by showing their citizen identity card as evidence that the holder was an inhabitant of South Tangerang City.

The family caregivers were mostly spouses and several were daughters. The caring burden happened to the family caregiver who already married and has their own family. The type of extended family living in one house was still

dominated in South Tangerang city. Religious background influenced the care taking. Participants considered this as an obligation of the family members with the Muslim as the majority.

2. The experiences of patients with ischemic stroke and their family caregivers in urban Indonesian especially in South Tangerang city were describe into seven phases of transition time frames during hospitalization and after discharge. The phases were as follows: 1) acute phase, 2) post-acute phase, 3) discharge phase, (4) facing difficulty, (5) seeking-treatment phase, (6) expecting recovery phase, and (7) resuming their normal life. The three first phase was occurred during hospitalization. The next three phases were occurred at one month after discharge. And last phase was occurred within three months after discharge, This phase indicated the patients were improved and gaining ability to perform personal self-care. These achievements accelerated their confidence, and this enforced their behavior to continue routine exercise.

The main finding indicated that understanding the experiences of patients and family caregivers during the transitional period is pivotal for developing appropriate and suitable care. Before hospital discharge, participants encountered many challenges

resulting from limited information regarding the disease, therapy and treatments. Later at home after the discharge, participants were struggling to care for themselves while relying on their families and religious belief as their main supports. There were three gaps identified during hospitalization, two concerns related barriers to follow-up check and caring burden. Patients had barriers to have follow-up care, which could lead to discontinuity of care. The results suggested the need for a transitional care model for every phase along the transition. With the underlying message that nurses, and health providers should be aware and more sensitive in understanding the complexity of the experiences of stroke patients during their transition from the acute phase to follow-up after discharge. The limitations of this study were due to the nature of the qualitative research data collected which was highly dependent on the respondents' ability to answer. Future research should be addressed the refinement, feasibility and validity of this transitional care model so it could be feasibly implemented within the clinical setting with each patient who had a stroke and at in each phase of recovery. Furthermore, this transitional care model could provide a continuum care for patients with strokes and their families.