

**THE POST-STROKE CARE PROGRAM  
FOR FAMILY CAREGIVERS**

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entitled  
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FOR FAMILY CAREGIVERS**

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**ABSTRACT**

Caring for post-stroke patients is important to improve their stroke recovery and regain the ability to take care of themselves almost normally. The purpose of the quasi-experimental study was to develop and examine the effectiveness of post-stroke care program for family caregivers and its impact on post-stroke patients' outcomes. This study applied the Information-Motivation-Behavioral Skills (IMB) model for the program development. The samples consisted of family caregivers and post-stroke patients in Kamphang Phet Province, Thailand. There were 62 pairs of family caregivers and post-stroke patients with 31 pairs for each in the experimental and control groups. The research procedures were carried out during November 2015 – June 2016. The family caregivers were assessed at three periods: before the program, immediately after the end of program one-month, and the two-month follow-up. The patients were assessed at immediately after the end of program and the two-month follow-up. Data were analyzed by using descriptive statistics, paired t-test, independent t-test, and two-way repeated measure ANOVA.

The results showed that practices and self-efficacy of post-stroke care significantly improved among family caregivers in the experience group and significantly higher than the control group ( $p < .001$ ). Receiving social supports and ADL functions, among the post-stroke patients in the experimental group significantly increased over time, and were higher than the control group ( $p < .001$ ). Only one patient in the experimental group had post-stroke complication, compared to 16 of those in the control group.

The results indicated that the post-stroke care program improved necessary practices of post-stroke care and self-efficacy among the family caregivers. The after stroke patients received correct, proper, and continuous care which prevented and reduced the severity of complications and promoted the recovery well.

**KEY WORDS: STROKE / FAMILY CAREGIVERS / PRACTICING SKILLS TRAINING / SOCIAL SUPPORT / RECOVERY**

202 pages

โปรแกรมการดูแลผู้ป่วยหลังการเกิดโรคหลอดเลือดสมองสำหรับครอบครัวผู้ดูแล  
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บทคัดย่อ

การดูแลผู้ป่วยหลังการเกิดโรคหลอดเลือดสมองเป็นสิ่งสำคัญ เพื่อช่วยให้ผู้ป่วยสามารถฟื้นฟูสภาพกลับคืนสู่ภาวะใกล้เคียงปกติมากที่สุด การวิจัยกึ่งทดลองนี้มีวัตถุประสงค์เพื่อพัฒนาและศึกษาผลของโปรแกรมการดูแลผู้ป่วยหลังการเกิดโรคหลอดเลือดสมองสำหรับครอบครัวผู้ดูแล โดยประยุกต์ใช้รูปแบบการให้ข้อมูลข่าวสาร การสร้างแรงจูงใจ และการพัฒนาทักษะ (Information-Motivation-Behavioral Skills model: IMB model) เป็นแนวทางพัฒนาโปรแกรม กลุ่มตัวอย่างเป็นครอบครัวผู้ดูแลและผู้ป่วยหลังการเกิดโรคหลอดเลือดสมอง ใน จ.กำแพงเพชร จำนวน 62 คู่ โดยแบ่งเป็นกลุ่มทดลอง 31 คู่ และกลุ่มควบคุม 31 คู่ ระยะเวลาการศึกษาตั้งแต่เดือน พฤศจิกายน 2558 – มิถุนายน 2559 ครอบครัวผู้ดูแลได้รับการประเมิน 3 ครั้ง คือ ก่อนเริ่มโปรแกรม หลังสิ้นสุดโปรแกรมทันที 1 เดือน และระยะติดตามผล 2 เดือน ในขณะที่ผู้ป่วยได้รับการประเมิน 2 ครั้ง คือ หลังสิ้นสุดโปรแกรมทันที 1 เดือน และระยะติดตามผล 2 เดือน การวิเคราะห์ข้อมูลใช้สถิติเชิงพรรณนา Paired t-test Independent t-test และ Two-way repeated measure ANOVA

ผลการวิจัยพบว่า หลังเข้าร่วมโปรแกรม ครอบครัวผู้ดูแลกลุ่มทดลองมีการปฏิบัติและการรับรู้สามารถของตนเองในการดูแลผู้ป่วยหลังโรคหลอดเลือดสมองสูงกว่าก่อนเข้าร่วมโปรแกรมและมากกว่ากลุ่มควบคุมอย่างมีนัยสำคัญทางสถิติ ( $p < .001$ ) สำหรับผู้ป่วยหลังการเกิดโรคหลอดเลือดสมองพบว่า กลุ่มทดลองได้รับการสนับสนุนทางสังคม และมีความสามารถในการทำกิจวัตรประจำวันเพิ่มขึ้น และมากกว่ากลุ่มควบคุมอย่างมีนัยสำคัญทางสถิติ ( $p < .001$ ) นอกจากนี้ผู้ป่วยกลุ่มทดลองมีภาวะแทรกซ้อนน้อยกว่ากลุ่มควบคุม โดยพบว่าผู้ป่วยกลุ่มทดลองมีภาวะแทรกซ้อนจำนวน 1 ราย ในขณะที่กลุ่มควบคุมมีจำนวน 16 ราย

จากผลการวิจัยแสดงให้เห็นว่าโปรแกรมการดูแลผู้ป่วยหลังการเกิดโรคหลอดเลือดสมองและการสนับสนุนทางสังคม ช่วยพัฒนาทักษะการปฏิบัติดูแลผู้ป่วยที่จำเป็นและเพิ่มการรับรู้สามารถของตนเองในการดูแลผู้ป่วยหลังโรคหลอดเลือดสมองของครอบครัวผู้ดูแล ทำให้ผู้ป่วยได้รับการดูแลอย่างถูกต้องเหมาะสมอย่างต่อเนื่อง ซึ่งช่วยป้องกันและลดความรุนแรงภาวะแทรกซ้อนต่างๆ และช่วยฟื้นฟูสภาพผู้ป่วยให้สามารถช่วยเหลือตนเองได้เร็วขึ้นและกลับคืนสู่ภาวะปกติได้มากที่สุด

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## LIST OF ABBREVIATIONS

ADL	Activity Daily of Living
CVA	Cardio Vascular Accident
HPH	Health Promotion Hospital
IMB	Information-Motivation-Behavioral Skills
MRS	Modified Ranking Scale
NHS	National Health Service
PHN	Public Health Nurse
SHPH	Subdistrict Health Promotion Hospital
SS	Social Support
UTI	Urinary Tract Infection
VHV	Village Health Volunteer
WHO	World Health Organization

## **CHAPTER I**

### **INTRODUCTION**

#### **1.1 Background and significance**

Stroke is the loss of brain function due to an abnormality in cerebral circulation, because a blood vessel bursts or is blocked by a clot, which can cause disabilities, complications, and death. Stroke can occur with anybody at any age. Public health has concerned the continuous rise in the prevalence, mortality rate, and disabilities that caused by stroke. World Health Organization (2013) reported that in each year there were approximately 15 million people who had stroke and about six million died of stroke. According to the report of the Ministry of Public Health, stroke was the fourth cause of death and disabilities in Thailand. Stroke prevalence increased from 276.83 per 100,000 population in 2008 to 427.52 in 2012 (Bureau of Health Policy and Strategy, Ministry of Public Health, 2013). Stroke can be divided two main types; ischemic stroke which is the most common stroke or about 87 percent and hemorrhagic stroke about 13 percent. Hemorrhagic stroke has more severe impact and results in higher mortality rate than ischemic stroke. Currently, there are two stroke treatments namely medical treatment and surgical treatment. Most stroke patients will be treated as in-patients at hospital for one week and will be discharged once assessed by physician that they are stable (Suwanwela et al., 2007).

Stroke causes motor deficit, incontinence, sensation loss, visual deficit, speech deficit, memory and cognitive impairment. Stroke survivors with these symptoms therefore cannot take care of themselves and cannot do daily activities on their own. Nowadays, there has been advancement in the technology used to treat stroke. Stroke survivors are left with different symptoms and disabilities. According to the National Stroke Association report (2013), almost 50 percent of stroke survivors had moderate to severe impairment. The stroke survivors normally have paralysis, cannot take care of themselves and may have other complications. The complications that post-stroke patients have are normally results of the loss of nervous function

system. Therefore, the stroke survivors cannot chew, swallow, or control their bladder, which need to be retained NG tube and retained urinary catheter when they discharge to home. Consequently, they usually have a problem of food aspiration which can further cause aspirate pneumonia. Improper care of urinary catheter can cause urinary tract infection (UTI). The loss of movements can cause fall, pain, joint contraction, and pressure ulcer. Moreover, psychological impacts on the stroke survivors are continually resulted from the physical impairments, which cause them stress or depress. The other important complication that can occur is recurrent stroke. Recurrent stroke incidence showed that 29.11 percent of post-stroke patients have recurrent stroke in less than one year, 45.57 percent have it between one to five years, and 25.32 percent have it after five years (Tiamkao, 2009: p. 34). The risk factors of recurrent stroke include high blood pressure, high cholesterol, diabetes, incorrect and discontinued drug administration, and lost to follow-up with physicians. Therefore, the proper care providing to post-stroke patients can prevent them from complications and recurrent stroke.

Post-stroke period has impacts at different levels. It does not only affect the patients, but also their families, the society and the country. Family as a fundamental unit has a crucial role in caring for health of family members. When a family member is sick, the family is the center that cares for and rehabilitates the sick member. This concept is consistent with Friedman's family theory (1986). The theory describes the role of family when a family member is sick by creating family coping function to maintain a balance within the family. Family will face arising problems to adjust and continue to grow. When face a problem, family may sustain itself by drawing on available resources within the family and adjust behaviors and roles of each family member to solve the problems. Moreover, family may need external resources to solve problems and support the sick members (Friedman et al., 2003: p. 37-38). The impacts at family level are a result from the heavy burdens that family members need to care their stroke survivors almost 24 hours in each day, from assisting them in their daily activities, eating, taking drugs, including providing other special care such as tracheal suction, NG tube feeding, wound dressing, and physiotherapy. These responsibilities affect family caregivers in various aspects including physical health such as weariness and muscle injury from moving the

patient; and psychological impacts such as anxiety, stress, and depression which are common. Moreover, if the patient is the head of family or the main provider, the family will experience a shortage of income. The lower income and increased expenditures in caring for the stroke survivors may pose financial problem of the family. A large number of post-stroke patients who is not rehabilitated could be a burden to the community in the long term and increase financial responsibility for treatment, medicines, medical equipment, and rehabilitation. The budgetary expenses in care and treatment and the loss of human resources in working age will ultimately decelerate the development of the country.

The important issue in caring for post-stroke patients is early rehabilitation. The previous studies showed that if stroke survivors receive correct and proper care during the first three to six months, which are the golden period, they could recover significantly (Good, Bettermann & Reichwein, 2011; Chaiyawata & Kulkantrakomb, 2012). Nonetheless, in general it was found that a care for stroke survivors during the transition period or after discharge and back at home is most challenging to the family, especially within the first six months (MacKenzie et al, 2007). During this period, family caregivers are facing and adjusting to the sudden changes from caring for the after stroke patients which is more complex than general health care. Family caregivers need help and support from nurses on various aspects including knowledge and advices on the practicing of post-stroke care. The study on post-stroke patient care suggested that the success of family caregivers in caring for the patients depends on the following factors; good relationship within the family that family members help and support each other, accurate and appropriate perceptions and realizations of the family caregivers roles, the correct and adequate knowledge and skills in post-stroke care, and social support (Danzl, 2013). The understanding about these factors will be beneficial to the development of plan to build capacity of the family caregivers in caring and rehabilitating the post-stroke patients at home such as rising awareness among family caregivers about their responsibility for performing physiotherapy for the patients. They can do this without waiting for a physiotherapist, so the patients will receive early recovery and continuous therapy.

The current situation of post-stroke care in Thailand, according to Thai society emphasizes on gratefulness. Therefore, stroke survivors who are discharged

from the hospital to caring at home are the direct responsibility of family members. Most family caregivers are the patient's husband, wife, children or close relatives (Niyomthai et al., 2012). However, most family caregivers lack of experience in caring post-stroke patients; therefore the providing care is the first time in their life. As a result, most family caregivers lack of confidence in caring for the stroke survivors (Koonnarong, Thaniwatananont & Kitrungrrote, 2012).

Moreover, to improve Thai citizens' access to primary medical and health care, the government partially subsidizes health care costs for sick population who receive services at public health facilities (Kuptniratsaikul, 2009). Post-stroke care and recovery after hospital discharge are provided at nursing home or post-stroke rehabilitation centre. These services are provided by private sector, are available only in big cities and are expensive. Most of their clients are high-income population. According to the National Statistical Office (2012), income per capita in 2012 was 127,395 Thai baht or 3,962.52 US dollars per year. These data indicate that the majority of the population in Thailand is amongst the low to middle-income groups. These population groups provide care, by themselves, for their family members who are post-stroke patients at home.

In general, there are many limitations to home care for post-stroke patient, for example, the short treatment and rehabilitation period in hospital. Normally patients stay in a hospital for one or two weeks according to health care quality control system which specifies bed occupancy rate and days of admission. The short hospital stay affects the preparation of family caregivers. As a result, they do not receive adequate knowledge and skills that they need (Chamnarong et al., 2007). The available post-stroke patient care guideline (Prasat Neurological Institute, 2007) provides directions in caring post-stroke since preparation of the patients and family caregivers before discharge. It is the period when the multi-disciplinary team which consists of physician, nurse, physiotherapist, and nutritionist together plans for patient discharge. In this stage, the team will provide knowledge about post-stroke patient care, including symptoms, complications, medication, preparation of proper environment for the patient, doctor's appointment attendance, food preparation, and proper foods for stroke survivors. Family caregivers will be trained on specific skills required in caring for stroke survivors such as NG tube feeding, tracheal suction, catheter cleaning, wound

dressing, and physiotherapy. According to the discharge plan, family caregivers' knowledge and readiness must be assessed before a patient is discharged. However in practice and in general, family caregivers receive knowledge about post-stroke patient care and practice necessary skills only one time before the patient is discharged. Therefore, family caregivers lack confidence in caring for the patient. It was also found that family caregivers who participated in discharge planning process are not the main caregiver of the patient. This affects the quality of care while patient's safety is also compromised due to improper care provided (Pinyopodjane, Bualad & Rakkieattiyos, 2011).

The Post-Stroke Patient Care Guideline of Prasat Neurological Institute (2007) suggested that provincial hospital should refer patient's information to Health Promotion Hospital (HPH) prior the hospital discharge in order to promote continuing care for the post-stroke patient. Home health care team, particularly public health nurses (PHNs) and village health volunteers (VHVs), will follow and visit the patient at home including provide necessary medical equipment for the patient such as wound dressing set, suction tube, or wheelchair. However, each community has different system of post-stroke care that fits with their context. The limitations and problems in post-stroke patient care found include the delay in sending patient's information to the HPH (Ruttawongsa & Kongtahn, 2012). This information includes patient's symptoms that need further care and rehabilitation at home, their complications, and other medical document. Moreover, there are limitations within the community health center such as lack of human resources. According to the report of the Ministry of Public Health in Thailand, the ratio of health personnel in community hospitals to population was 1:1,429 (Bureau of Policy and Strategy, 2012). Furthermore, VHVs also lack knowledge and skills in caring for stroke survivors (Piyabunditgul, 2012). These limitations lead to delay and discontinue home visits, which impact on the provided support and assistance to the patient and their family caregivers.

The northern and central parts of Thailand have higher stroke morbidity rate than other regions. Khampaeng Phet Province is one of the Northern provinces where there is a continued increase in stroke incidence. According to stroke incidence report of the Department of Disease Control, a number of stroke patients in Khampaeng Phet increased from 1,740 persons or 239.29 per 100,000 population to

2,431 persons or 334.49 per 100,000 (Bureau of Policy and Strategy, 2012). These data show that the number of stroke patients doubles in five years. There were problems and challenges in providing care for post-stroke patients in Khampaeng Phet Province which were similar to other rural communities in Thailand. For example, firstly, family caregivers who participated in discharge planning process were not the main caregiver. Secondly, they did not receive adequate knowledge and skill and thus lack of confidence in caring for the post-stroke patient. Lastly, they had malpractices in disinfection techniques in wound care, food preparation, patient mobility, and rehabilitation. Moreover, according to the after stroke care guideline, healthcare providers of HPH required to conduct home visit at least one time per patient per month which depended on the patients' conditions. However, it was also found that most of the patients had delay home visit or never been received a home visit because of the limitations of HPHs, such as; delay referral patients document from hospital to HPHs, a shortage of human resources, and overwhelming in many tasks and responsibilities of the HPHs staff. These problems and limitations were consistent with medical reports and results of exploration of the real situation in the research setting. It was found that most of them had common complications after stroke such as aspirate pneumonia, pressure ulcer, UTI, joint stiffness, and recurrence stroke.

Research findings and statistics mentioned previously indicated the gap of knowledge in caring for post-stroke patients in community. In particular, family caregivers lacked of the knowledge and skills and thus were not confident and did not care for the patient properly (Jullamate et al., 2006; Danzl, 2013). As a result, the quality of care and stroke survivor's safety were compromised, and the patients might have complications and recurrent stroke. Literature review on post-stroke patient care studies showed that there were four types of needs of family caregivers. These needs included; first, the need for knowledge about the consequences of stroke, prevention of complications and recurrent stroke, strategies of ADLs support and rehabilitation and available services in the community; second, need for skills in moving the patient correctly, in performing physiotherapy and providing nursing care that suit the patient's conditions and needs, including tracheostomy wound dressing, NG tube feeding, prevention of aspiration, and catheter care (Ruttawongsa & Kongtalin, 2012; Silva-Smith, 2007; Lutz & Young, 2010). Third, primary caregivers needed assistance

from other family members in the more difficult activities in caring for the patient such as lifting or moving the patient and doing other house chores (Petchroung et al., 2013). Forth, they also needed social supports from family members, community members, and community health care team. Social supports include advices, morale support, and support for medical equipment needed for patient care and rehabilitation.

Literature reviews on factors of post-stroke recovery demonstrate that family caregivers should receive specific and necessary information and practice for skills in caring for post-stroke patients (Sangngam, 2006; Danzl, 2013). Post-stroke patient care should include early recovery, complications prevention, activities of daily living (ADLs) support, nutrition, medication, mobility, rehabilitation, and psychological care (King et al., 2012; Cameron & Gignac, 2008). Moreover, social support by family caregivers and healthcare providers after strokes critical for patient recovery. The social supports in emotional, instrumental, necessary information, and appraisal supports would enhance successful recovery of patients. Such enhancements would encourage a more hopeful outlook for recovery and better cooperation between patients and family caregivers (House, 2001).

According to the literature review on concepts and theories used to change behaviors and motivate health behaviors, the Information-Motivation-Behavioral Skills (IMB) model has been used to change behaviors of caregivers (Zarani et al., 2011; Raphael et al., 2013). The IMB model suggests that there are three factors that would influence behaviors of individuals 1) information which directly impacts individuals behavior and leads to their behavior pattern, 2) motivation which encourages individuals to perform behaviors, and 3) behavioral skills which are skills required by individuals to perform the desired behaviors. This model addresses the process through which individuals receive information, are motivated and have the necessary skills to perform the desired behaviors. These three factors influence the decision or intention to perform particular behaviors (Fisher & Fisher, 1992).

As a public health nurse, the researcher realizes the importance of applying both public health and nursing knowledge to manage health problems by focusing on individual and family levels. Nursing operations are managed at community level. The main concern of post-stroke care is to promote recovery within the golden period (three to six months), so that the patients could rehabilitate to normal as much as

possible. This could reduce the burdens on family and society as well. Family caregivers play a key role in stroke survivors' care and rehabilitation as well as providing social supports to the post-stroke patients. Most research studies conducted both in Thailand and internationally on post-stroke patient care by family caregivers studied the experiences of caregivers as well as their roles and responsibilities and impacts of post-stroke period, including capacity building of family caregivers mainly in physical rehabilitation. Nevertheless, the capacity and skill building model for family caregivers to care for and rehabilitate post-stroke patients studied in the past has not been implemented much. Therefore, the researcher is interested in development skill building program for family caregivers to care for post-stroke patients by using the IMB model as the conceptual framework to enable the proper practices to care for the after stroke patients.

This study employs the IMB model to guide the program development to solve problems and promote post-stroke patient care that is suitable to the reality and social context. The expected outcomes of this study are that the family caregivers have improved practices and self-efficacy to provide correct and proper care for post-stroke patients. These qualifications will also benefit for the post-stroke patients. The correct care provided by family caregivers will be capable of preventing complication and recurrent stroke in the post-stroke patients. The patients will be able to take care of themselves more. The research findings can also lead to the development of strategies, guidelines or policy in post-stroke patient care for community caregivers.

## **1.2 Research Questions**

1. Will a post-stroke care program, based on the IMB model, improve practices of post-stroke care and self-efficacy of family caregivers?
2. Will a post-stroke care program, based on the IMB model, improve the functional (ADLs), clinical (complications), and psychosocial (social supports) outcomes of post-stroke patients?

### **1.3 Research Objectives**

To examine the effects of the post-stroke care program for family caregivers and its impact on stroke survivors' functional, clinical, and psychosocial outcomes.

### **1.4 Research Hypothesis**

1. After participation in the post-stroke care program, the family caregivers in the experimental group had an improvement in the following topics than that before participation the program.

1.1 Practices of post-stroke care

1.2 Self-efficacy

2. Family caregivers who participated in the post-stroke care program in the experimental group had greater improvement in the following topics than those of the control group.

2.1 Practices of post-stroke care

2.2 Self-efficacy

3. After family caregivers participated in the program, the post-stroke patients in the experimental group had an improvement in the following outcomes.

3.1 Functional outcome: ADLs

3.2 Clinical outcome: complications

3.3 Psychosocial outcome: social supports

4. After family caregivers participated in the program, the post-stroke patients in the experimental group had greater improvement in the following outcomes than the control group.

4.1 Functional outcome: ADLs

4.2 Clinical outcome: complications

4.3 Psychosocial outcome: social supports

## 1.5 Scope of the Study

This research aimed to involve public health nurses in developing a program for improving knowledge and practices of post-stroke care for family caregivers in community at Primary Care Unit in Kamphang Phet province, Thailand from November 2015 to June 2016.

## 1.6 Variables of the study

### Independent variable

The post-stroke care program for family caregivers.

### Dependent variables

1. Family caregivers
  - 1.1 Practices of post-stroke care
  - 1.2 Self-efficacy
2. Post-stroke patients
  - 2.1 Functional outcome: ADLs
  - 2.2 Clinical outcome: complications
  - 2.3 Psychosocial outcome: social supports

## 1.7 Operational Definition of Terms

**Post-stroke care program** referred to an intervention that was based on the IMB model in order to improve the necessary practices for skills in caring for post-stroke patients of family caregivers. Information referred to specific knowledge about a post-stroke care for family caregivers. Motivation consisted of two components namely personal motivation and social motivation. Personal motivation referred to attitude of family caregivers about the outcomes of performing and not performing post-stroke care behaviors. Social motivation referred to having perceptions of the importance of social support for post-stroke care in family caregivers. Behavioral skills referred to family caregivers' ability and perceived self-efficacy for performing post-stroke care. In this study, the intervention focused on three major issues: 1) essential and specific

post-stroke care information: common effects after stroke and severities, important in early recovery, complications, nutrition, medication, and emotional and stress management; 2) post-stroke care training skills: disinfections care, feeding technique and aspiration prevention, patients mobility and fall prevention, and rehabilitation; and 3) social support motivation.

**Family caregiver** referred to a family member who identified his/herself as primary informal caregiver or who provided a majority of care for stroke survivors after discharge from the hospital at home. They provided post-stroke care at home without financial reimbursement.

**Practices of post-stroke care** referred to the abilities of family caregivers to perform the essential and specific of post-stroke care about disinfections care (wound care), feeding and aspiration prevention, fall prevention, patient mobility, and rehabilitation.

**Self-efficacy of family caregiver** referred to the belief of family caregivers in their ability in correctly caring for post-stroke patients about disinfections care (wound care), feeding and aspiration prevention, fall prevention, patient mobility, and rehabilitation.

**Post stroke patient** referred to stroke patient who was diagnosed with first stroke (Code I60-I64) by a physician and discharged from hospital to home and who had a moderately severe disability with a 4-score of the Modification of Rankin Scale (MRS) and received care provided by family caregiver within 2-3 weeks.

**Functional outcome** referred to the physical functional ability in activities of daily living (personal hygiene, bathing, feeding, toilet use, dressing, bowel control, bladder control, ambulation, transfer, and stair climbing) of post-stroke patients.

**Clinical outcome** referred to the common complications after stroke (aspiration pneumonia, UTI, pressure ulcer, joint contracture, and recurrent stroke) among post-stroke patients.

**Psychosocial outcome** referred to social support that post-stroke patients obtained the supports from family caregivers and VHV. According to House (1981), social support consisted of emotional support such as compliments, morale supports, care and encouragement; appraisal support such as feedback, certification or acceptance of others' behaviors; information support such as advice and information;

and instrument support such as labor, money, or time. In this study, the family caregivers and VHVs provided emotional, instrumental, information, and appraisal supports to the post-stroke patients.

## **CHAPTER II**

### **LITERATURE REVIEW**

This chapter presents the review of theoretical and empirical literature in the six major parts. The purposes are to assist in conceptualization and provide direction for the formulation of this research. The six main parts are presented as follows.

1. Stroke
2. Post-stroke care
3. Family caregiver of post-stroke care
4. Information-Motivation-Behavioral Skills Model
5. Social support
6. Relevant research

### **2.1 Stroke**

Stroke or cardiovascular accident (CVA) can cause permanent neurological damage and death. It is a major public health problem that affects not only individuals, but also their families and the society. Though preventable, number of patients is likely to continue to rise. In order to ensure that stroke survivors receive optimal recovery, the development of post stroke care program that provides the caregivers with general information and knowledge about stroke is therefore critical.

#### **2.1.1 Definition**

World Health Organization (WHO, 1976) defines stroke as rapidly developing clinical signs and symptoms of focal disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin (Sacco et al., 2013). The meaning of stroke by the National Health Service (NHS) in the United Kingdom (UK) is a serious medical condition that resulted from the interruption of the blood supply to the brain. The American Heart

Association (2013) defines stroke as an acute neurological dysfunction presumed to be caused by ischemia or hemorrhage in brain, persisting 24 hours or more.

According to the current definitions of stroke, it can be concluded that stroke is the loss of brain functions due to an abnormality in cerebral circulation as a result of the rupture or blockage of a blood vessel. Such incident breaks up oxygen supply which further causes damage to brain tissues.

### **2.1.2 Stroke statistic and impacts**

A large number of people globally are suffering from stroke. The Global and Regional Burden of Stroke Report reveals that in 2010 as many as 33 million people suffered from stroke, as high as 16.9 million people with first stroke per year and 5.9 million people died from stroke each year (Feign et al., 2014: p 248).

Studies on stroke prevalence conducted in Thailand and elsewhere reveal that stroke is the primary cause of death and disability in human while the prevalence rate is continuously growing. In the UK, approximately 152,000 people suffer a stroke each year (Stroke Association, 2013). Among the 610,000 people with stroke in the United States one of every 19 patients died thereof (American Heart Association, 2013). In Thailand, 124,532 people with stroke were treated as in-patients in 2008. This number increased to 196,159 in 2010 and to 227,848 in 2012 (Bureau of Health Policy and Strategy, Ministry of Public Health, 2013). Stroke can occur in all age groups. According to the data from the Centers for Disease Control and Prevention (CDC), the chance of having a stroke approximately doubles in people who are over 55 years old. Men have a higher risk of stroke than women, and the incidence in men is greater than women at younger ages. The ratio of male to female incidence is 1.25 at ages 55 to 64, 1.50 at ages 65 to 74, 1.07 at ages 75 to 84, and 0.76 at ages 85 and older (Hickey, 2009).

The National Stroke Association (2013) categorises post-stroke patients into two groups, deceased (15%) and survivor (85%). The survivors experience different degrees of impact and disabilities as described below.

1) Almost complete recovery (10 percent): this group hardly displays any stroke symptoms apart from numbness on their faces, arms, legs, hands or feet. Stroke

survivors in this group can be almost fully rehabilitated and eventually can perform their daily activities as they normally did.

2) Recovery with minor impairments (25 percent): this group of survivors can perform some of their daily routines such as taking a shower, getting dressed, eating, controlling bladder and bowel movement and cleaning themselves afterwards without assistance. However, some daily activities such as lifting heavy objects, walking up and down steps, driving, biking, doing laundry, ironing and cleaning are still beyond their ability now limited by some clinical causes and disabilities such as minimal motor deficit, muscle weakness or mild aphasia.

3) Recovery with moderate to severe impairments (40 percent): the survivors in this group have a good consciousness, but are often paralyzed and thus cannot do any daily activities without assistance from their care provider such as sitting up on their beds, moving from their beds to a chair, turning from side to side on the bed or walking, for example. The survivors are at risk of having complications such as bed sores, lung infection from choking on food, urinary tract infection, falling, and stiff joints. They have to require some special care and nursing care such as feeding through NG tube, wound cleansing and dressing, tracheotomy tube care and urinary catheter care

4) Survivors in severe conditions (10 percent): Most patients in this group are bed-ridden and unconscious. Their conditions are not stable. They also have severe disabilities and complications. Some may also have other co morbidities such as diabetes, high blood pressure or heart disease. They therefore require intensive nursing care at all times (Wilson et al., 2002). Once a patient is determined to be in the final stage, he or she may be discharged from the hospital to further receive palliative care at home. Such process allows families and relatives to participate in caring for the patient until his or her peaceful demise (Burton, Payne, Hall, & Jones, 2012).

### **Impacts of stroke**

Stroke is a severe disease that can cause permanent disabilities. Its impacts do not only affect the patients, but also their families and the society.

### **Impacts on patients**

1) Physical impacts: the damages to neurological and brain function have caused varied physical disabilities depending on the lesion locations in the brain. The most common physical impacts (Scottish Intercollegiate Guidelines Network, 2010; Pajaree, 2007) are as follows:

*Motor deficits* are normally the consequences of damaged motor cortex and frontal lobe. Such damages cause abnormal movement of muscles, contraction of muscle and muscle weakness. Patients may lose strength in their arm and leg on the opposite side of the brain where the damage has occurred, or may develop hemiplegic. If a stroke has affected the brain stem or the spinal cord, both legs may become weakened resulting in paraplegia or quadriplegia thereby limiting physical movements. Consequently, the patients lose control of their body and cannot take care of themselves or do any daily activities. If lesions occur at pyramidal system which controls fine movements, the patients will have difficulty picking up objects with their fingers whereas damage at the cerebellum affects the patients' balance.

*Difficulty in chewing and swallowing* is caused by the lesions in pons and medullar areas of the brain stem, which cause impairment of swallowing reflex. In this case, the patients have difficulty swallowing food and fluid (dysphasia). The lesions in the cerebral cortex are the cause of weaken lip muscles, tongue and esophagus on the opposite side of the affected brain making it difficult for the patients to chew and swallow putting them at risk of choking.

*Bowel control* is concerned. It is the lesions in the front parietal area, internal capsule, basal ganglia, pons and cerebellum that result in the patients' inability to control their bladder. In case of damaged frontal lobe, the patients lose control of their bowel movement due to non-functioning of the part of the brain concerned.

*Sensation loss* is caused by the lesions in the parietal lobes where sensory cortex is located. Such damage causes impaired sensory perception such as touch,

pain, hot and cordon the skin around the paralyzed body parts. As a result, the patients could be unaware of injuries on these parts.

*Visual deficits* are a result of the damaged occipital lobe which causes vision impairment such as blurred vision, double vision or hallucination.

*Speech deficits* are caused by the damages to the Broca's and Wernick's areas. Patients will experience language impairment which may include dysarthria, aphasia, slow or nonsensical speech leading to communication problems since the patients cannot communicate effectively with others.

*Memory and cognitive impairment* is mostly a result of the damages to the frontal lobe and prefrontal cortex. Such damages result in memory loss, confusion, intelligence loss, emotional disorder and illogical thinking. The damages to the temporal lobes affect short-term memory.

2) Emotional impacts: most emotional impacts are repercussions of physical impacts. Patients are concerned, tense or depressed about their physical conditions as well as movement, communication, thinking or memory impairments or inability to perform other activities that were normal to them prior to the stroke. These impairments result in their low self-esteem. Several studies conclude that depression is the most common emotional distress experienced by stroke survivors. The study conducted by Hadidi et al. (2009) on post stroke depression and functional outcome found that depression leads to despair and reduced energy level, concentration, self-efficacy and motivation. As these factors are related to physical rehabilitation and quality of life, the patients therefore make slow progress or cannot be rehabilitated at all.

3) Psychosocial impacts: visible physical impairments in the wake of strokes cause the patients to lose their confidence, self-esteem and sense of security. Thus, they do not want to participate in any social activities. They'd rather withdraw themselves and refrain from interacting with others. Moreover, the lesion also affects their personality, communication ability, emotional control and inappropriate emotional expression, which could further affect their sociability (Kneebone & Lincoln, 2012: p. 84). This finding is consistent with the study of Piyabanditgul (2012), which found that post stroke has physical impacts on the survivors giving them facial palsy, stiff tongue causing slurred speech and reduced ability to formulate speech in communicating with others. The fact that the patients' social role has

switched from breadwinner to dependent can cause emotional distress and affects their self-esteem as they have become a burden to their families. They therefore are withdrawn and do not want to meet either friends or relatives. Eventually, their social participation is nil.

### **Impacts on family**

Caring for post-stroke patients is burdensome to their families. Unlike general healthcare, post-stroke patients need complex care almost round the clock. Their high dependency requires constant care that leaves the family caregivers with fatigue and lack of sleep. As a result, the family caregivers may end up with muscle, ligament and joint injuries due to incorrect lifting or moving patients. The duties and responsibility of the main care provider are normally assigned to certain primary caregiver while the other family members take secondary role or step in as substitute when needed. This may entail changing roles among family members. For example, the wife may have to be the main family provider and the offspring may need to work harder to earn more income to support the family or to change job or to relocate to care for the post stroke patient. The stroke survivor's behavioral and emotional changes pose another challenge that may deprive the family members of their privacy, cause concern or stress (Piyabanditgul, 2012), which could lead to conflicts and poor relationships amongst family members. Moreover, the increasing expenditures will affect the financial status of the family. These expenditures are such as medical care and treatment, physiotherapy, medical supplies such as NG tube feeding, urine catheter or wound dressing, as well as other expenditures required to improve the living environment for safety of the patient.

### **Impacts on the society**

Treatment, caring, and rehabilitation of stroke survivors are costly and could be even more so in case of severe symptoms and complications. These high costs have repercussions on the national economic loss. It was found that stroke-related expenditure in Thailand has a direct cost of Baht 1,489.78 per day for in-patients and Baht 1,010.22 per visit for out-patients. The indirect cost incurred for sick leave and disability amounts to Baht 101,681.20 and Baht 15,766.66 in case of death.

On average the costs relating to the sickness for each patient is Baht 162,664.97 per year (Prasat Neurological Institute, 2009). Financial matter aside, disabled or paralyzed survivors cannot resume their work and thus become disadvantaged population of the country and a long-term burden to the society.

In conclusion, stroke incidence both at global and national levels is increasing. Stroke affects many aspects of the patients: physical, emotional and psychosocial thus affecting their families and the society. Fifty percent of stroke survivors suffer moderate to severe impairments leaving them unable to take care of themselves. Some may also have other complications. They are dependent on others for assistance and care. However, the severity of the symptoms varies from one patient to another depending upon the types of stroke and lesion locations in the brain.

### **2.1.3. Classification of stroke**

#### **Types of stroke**

Classification of stroke is based on path physiology of the cerebral artery. The two major types of stroke are ischemic and hemorrhagic stroke.

#### **Ischemic stroke**

Ischemic stroke is the most common type of stroke that accounts for 87% of all strokes (American Heart Association, 2013). It occurs when a blood vessel that supplies the brain becomes blocked and interrupts blood flow to the brain. Ischemic stroke is subdivided into thrombotic and embolic stroke (Kaufman, 2007: p. 247-248).

A thrombotic stroke occurs when occluded cerebral arteries by blood clot within the brain. Thrombotic stroke can be a result of a variety causes, but most are related to the development of abnormalities in the arterial vessel wall. This interrupts the supplying blood to the brain. This type of stroke can be found in a person with atherosclerosis, arthritis, dissections, hematologic disorders, and external compression of the vessels. Cerebral thrombosis can be divided into two subtypes: a large artery atherosclerotic stroke and a small artery stroke (Hickey, 2009: p. 590-592). A large artery atherosclerotic stroke is associated with the accumulation of lipid plaque that narrows the lumen of large or medium-sized arteries. This condition can lead to hypo perfusion, ischemia, and ischemic stroke. A small artery stroke or lacunars stroke commonly occurs in patients with small vessels disease, such as diabetes and

hypertension. Lacunars stroke is caused by a small penetrating artery that supplies one of the deep structure in the brain, such as internal capsule, basal ganglia, thalamus, and brainstem.

An embolic stroke is caused by an embolus or a clot from somewhere in the body other than in the brain itself and moving through bloodstream to cerebral artery. Embolic stroke often results from carcinogenic embolism from atrial fibrillation, alular disease, myocardial infraction, congestive heart failure, and other cardiac problems. The micro emboli from the heart can restrict the blood flow to the brain that results in the stroke.

### **Hemorrhagic stroke**

Hemorrhagic stroke occurs when an intracranial blood vessel ruptures, leaking blood into brain tissue, ventricles, or subarachnoid space (Miller & Elmore, 2005). Intracranial hemorrhage can be subdivided either subarachnoid or intracerebral, depending on the site and origin of the blood. The most common cause of an intracranial hemorrhage is high blood pressure (hypertension).

Subarachnoid hemorrhage stroke represents 3 percent of all strokes. It is caused by bleeding between the brain and the meninges or the membrane that covers the brain. The area of the skull surrounding the brain (the subarachnoid space) rapidly fills with blood. Subarachnoid hemorrhage is most often caused by blood leaking from cerebral aneurysms or an arteriovenous malformation (AVM). These are small areas of rounded or irregular swellings in the arteries. The swelling is most severe, the blood vessel wall become weak and prone to rupture. A patient with subarachnoid hemorrhage may have a sudden of intense headache, neck pain, nausea, vomiting, altered consciousness, and sometimes death.

Intracerebral hemorrhage (ICH) represents 10 percent of all strokes. The cause of ICH is a spontaneous hemorrhage related to hypertension and cerebral myeloid angioplasty. ICH occurs when a blood vessel within the brain bursts, leading blood to leak inside the brain. The rupture of small artery is most often a deep and penetrating vessel. ICH is a serious disease because of the highest mortality rate of all stroke and some patients dying before they reach a hospital.

The path physiology of hemorrhagic stroke is related with a sudden bleeding within brain or subarachnoid space. The usual bleeding sites are the tiny

vessels, deep arteries within the brain, or subarachnoid hemorrhage due to aneurysm rupture. The collection of blood clot after bleeding or hematoma can displace and compression surrounding brain tissue that resulting in cerebral edema, ischemic cellular responses, increase intracranial pressure (ICP), and brain hernia ion syndrome. The final outcomes of hemorrhagic stroke can release neurotoxicity, oxygen deprivation, and damage brain cells (Hickey, 2009: p. 595-597).

### **Signs and symptoms**

Signs and symptoms of patients depend on the lesion location in their brain where blockage or rupture of a blood vessel occurred. The artery that supplies blood to the brain consists of two main artery systems: carotid artery system and vertebrobasilar artery system. Kaufman (2007: p. 241-254) explained that different signs and symptoms are associated with the location of the affected blood vessels and areas in the brain as described below.

1) Carotid artery system: Carotid artery system in the brain consists of anterior cerebral artery, middle cerebral artery, lenticulostriate artery and internal carotid artery. The middle cerebral artery consists of lenticulostriate and internal carotid artery. The carotid artery supplies anterior section of the brain which covers almost all of the frontal lobe.

*Anterior cerebral artery (ACA):* the location that associates with the occlusion of the ACA is the anterior and medial of frontal lobe which controls movement, speech, thoughts, memory, intelligence, personality and feelings. The obstruction in this area results in paralysis of contra lateral foot and leg, sensory loss and cognitive impairment of patients. The damage to the bilateral anterior cerebral artery due to lack of blood supply will result in ignore environmental (apathy), cannot speak (mutest), inability to control facial movements such as chewing and speaking (pseudobullarparly), and urinary incontinence.

*Middle cerebral artery (MCA):* MCA is the largest vessel branching of the internal carotid artery where infraction mostly occurs. MCA supplies frontal, temporal and parietal lobes that lesions in each area result in the following signs and symptoms (McPhee & Papadakis, 2010; Tommasarot, 2010: p. 6-9):

- The frontal lobe contains motor cortex which controls movement of muscles on the side opposite to that of the brain. The lesion in this area will result in

hemiplegic while the lesion in the posterior frontal lobe which controls decision making and behavior will result in the patients' behavioral changes, aggressiveness, impulsiveness and attention deficit. The lesion in Broca's area which controls language proficiency will result in the inability to speak although the patients understand what they hear (aphasia). The lesion at the base of the frontal lobe will result in apathy and sensory deficits in patients.

- The temporal lobe's function involves retention of memories, behaviors, language and some parts of visual radiation. The damage in this area can result in Wernicke's aphasia, inability of the patients to repeat words, name objects and understand spoken words. Those with fluent aphasia have language disorder displayed in fluent but meaningless speech.

- The parietal lobe performs crucial function in integrating and processing emotions, including visuospatial processing. The damage to this area will result in right-left disorientation, acalculia, alexia, dressing aphasia, and homonymous inferior quadrantanopia which is visual-field deficits affecting the same half of the visual field in both eyes.

2) Vertebrobasilar artery system: blood vessels in vertebrobasilararter system include vertebral arteries that branch from aortic arch that runs pass vertebral foramen of the cervical spine into the skull. Both the left and right vertebral arteries merge to form basilar artery that branches into posterior cerebral artery at the midbrain. The circumferential branches of the posterior cerebral artery supply the cerebellum and the brainstem. Different locations of brain lesion display different signs and symptoms.

*Posterior cerebral artery (PCA):* The symptom depends on the location of the branch artery occlusions. If superficial cerebral artery occludes, the patients will have a loss of half of the field of view on the same side in both eyes (homonymous hemianopia). The penetrating branches occlusion will impact on peduncle, thalamus, and upper brainstem that can cause memory deficits, cortical blindness, lack of depth perception, failure to see objects, or visual hallucination.

*The cerebellum* controls movement, balance, muscle movement, speech and eye movement. If the cerebellum is damaged, the patients will have difficulty walking a straight line and balance problems. They may also have vertigo, nausea,

vomiting, headache, nystagmus and slurred speech. The lesion in the cerebella hemisphere may cause tremor, uncontrollable shake when approaching targets (dysmetria) and hypotonic.

*The brainstem* controls functioning of different organs of the body and movement. It also serves as a passage of the cranial nerves. The signs that patients have are linked to the functions of that parts of brainstem concerned: midbrain, Pons or medulla. The midbrain is where oculomotor nerve and trochlear nerve are located. It controls movement of eye muscles. The Pons contains abducens nerve and facial nerve which control facial muscles, taste, chewing, salivary secretion, movement and breathing. The medulla is the control centre of autonomic nervous system such as blood circulation, blood pressure, heart beat, and respiration. It is moreover the control centre for swallowing, coughing, sneezing and vomiting. Lesions in the Pons and the midbrain will cause occipital headache, weakness, diplopia and coma. Lateral medullary infarction in the brain will cause Wallenberg's syndrome and the patients will experience dizziness, ipsilateral limb ataxia (tremor, past pointing and mild hypotonia), palatal paresis, nystagmus, dysphagia, dysarthria and swallowing problems.

According to studies on the types and signs of strokes, it can be concluded that ischemic stroke is the most common cardiovascular disease. It is caused by the constrictions or blockage of blood vessels in the brain constantly reducing the flow of blood supply to the areas gradually showing signs of lesions and symptoms. As for hemorrhagic stroke, ruptured blood vessels in the brain results in hematoma that puts pressure on the brain and quickly damages it and the patients show more severe symptoms than those with ischemic stroke. However, both types of stroke disrupt the sufficient supply of oxygen and other nutrients to the brain thereby damaging the brain cells that will eventually die. Consequently, neurological deficits occur to sensory system, central nervous system, or autonomic nervous system. Human brain is a complex organ consisting of different parts that have different functions. The signs and symptoms of different types of strokes therefore vary with the lesion locations in the brain. Knowledge about strokes and the association between path physiology and the signs and symptoms promotes fundamental understanding contributing to proper care of the post-stroke patients.

**Treatment** (McPhee & Papadakis, 2010: p. 891-896)

Treatments of stroke depend on the types of stroke and the signs and symptoms of the patients. They are categorized into two main groups: medical and surgical treatments.

**Medical treatment**

Medical treatment basically uses three groups of drugs as follows.

1) Thrombolytic agents or fibrinolysis agents such as recombinant tissue plasminogen activator (rt-PA) to dissolve blood clots. This drug is used to transform plasminogen into plasmin in order to dissolve fibrin in blood clots. The drug in this group is appropriate to treating acute ischemic stroke only. In the current practice, these drugs are administered within the first three hours of the show of relevant signs or symptoms (National Stroke Foundation, 2007).

2) Antiplatelet agents are platelet inhibitors such as aspirin (ASA) and clopidogrel (Plavix). This group of medication is used by the patients who are at risk of having recurrent strokes during the first few days after occurrence of ischemic stroke.

3) Anticoagulants such as warfarin and heparin are normally used with patients having ischemic strokes. Anticoagulants reduce the ability of the blood to clot. It is very important to administer these drugs correctly and cautiously so as to prevent any adverse effects as it may cause a brain hemorrhage.

**Surgical treatment**

Hemorrhagic stroke patients have bleeding within their brains. The resultant huge blood clots can put them in a coma or even death if the blood clots compress on the brainstem. Surgery is normally performed particularly in cases that have positive prognosis that removal of the blood clots minimizes disabilities and contributes to speedier recovery compared to leaving the clots to be naturally absorbed by the body. However, a surgery is performed only when the lesion location is easily accessible on one hand and when it will not, on the other hand, end in multiple disabilities.

Both treatment methods require different lengths of hospitalization. The patients receiving medical treatment are admitted into a hospital for about a week while those requiring surgical treatment spend longer periods – varying from case to

case - in either a sub-ICU or a neurosurgical ward until their conditions are stable and safe. A team of physicians must assess a patient's condition prior to discharge to assure his/her safety. To be considered for a discharge, the patients must be free of rebreeding, swelling of the brain, and such threatening complications as pneumonia, infection, hyperthermia or hypothermia. They must have normal intracranial pressure, safe blood pressure, normal pulse and breathing including normal oxygen saturation.

It is important for the ischemic stroke patients to receive increased blood supply to the brain with the help of platelet inhibitors - the sooner the better for their safety and rehabilitation. Studies reveal that only 5.5 percent of ischemic stroke patients received rt-PA within the first three hours of the show of signs and symptoms (Ratanakorn, 2012: p. 55). This, on the other hand, indicates that a large number of patients receive delayed treatment which affects their symptoms and causes complications. In the case of hemorrhagic strokes, the blood clots can increase in size and move to compress critical areas of the brain. Physicians therefore choose to operate on the patients to prevent further severe developments which can occur suddenly. The goals of both treatment methods in treating acute strokes are to save life, minimize the degree of impacts on the brain and prevent potential complications. The patients will be discharged for further rehabilitations at home when their conditions are stable and safe (Ruttawongsa & Kongtalin, 2012).

### **Complications and Preventions**

After being discharged, the patients tend to have muscle weakness and can barely move on their own, if at all. Some may still have medical equipment attached to them such as tracheotomy tube, NG tube or urinary catheter. In such condition, they risk having complications, the most common ones of which are as follows:

1) Joint contracture: the contracture is periarticular motion impairment that muscle weakness in post-stroke patients making it impossible for them to walk, move their body or joints by themselves bringing about joint contractures due to stiffness in their muscles, tendons and ligaments. Joint contractures are reported by 3.4 percent of post-stroke patients (Watila et al., 2012: p. 192). Contractures may occur at any joints in the body. If it occurs at the ankle joint, the patients will have foot drop. Joint contractures also cause spasticity, deformities, immobility and pain (Katalinic,

Harvey & Herbert, 2011) which result in the patient's inability to perform their daily activities, walk or move.

Prevention: joint contractures can be prevented by exercising and moving joints. Extending and bending joints such as shoulders, elbows, wrists, fingers, ankles or other joints will prevent their stiffness and constriction. Care providers should teach and encourage the patients to do active exercise. For example, the patients with the right hemiplegic should use their left hand to raise and lower their right hand, support and lift their right foot with their left foot, use their left hand to turn their right wrist. Do 20 repetitions for each exercise in the morning and the evening. In addition, care providers can give the patients passive exercise such as lifting and lowering, and extending and bending their weak arms and legs. The patients can be told to squeeze particular muscles or squeeze clay or water balloon to stimulate their hand muscles. The care providers may also help the patients by supporting them or stimulating them in doing various activities (Kasornsunt, 2013).

2) Falls: Post-stroke patients are at high risk of falling while walking, doing other activities or changing positions such as sitting up on a bed, moving from their bed to a chair or turning their bodies. Risk factors for falling include visual deficit, hemiplegic, spasticity, postural instability, motor deficit or cognitive deficit. Moreover, falling could be a result of side effects of some drugs such as diuretics, antidepressants or sedatives. Falling was reported by 14 percent of the patients after their discharge from the hospital (Wagner et al., 2009).

Prevention: Care providers must have the knowledge and understanding and be able to assess patient's risk of falling and identify preventive measures such as training of strength, flexibility, balance, and cognition. Moreover, they should reduce the risk factors by rearranging the living environment to provide sufficient light, clearing the walk way and keeping the floor dry and not slippery for example (Weerdesteyn et al., 2008).

3) Aspiration: Choking in post stroke patients is normally a consequence of the weakened chewing and swallowing muscles or the malfunctioning of swallowing reflex. The patients therefore choke on food and drinks which are then lodged in the airway. For those with NG tube, incorrect feeding can cause them to choke. Aspiration is the key factor leading to aspiration pneumonia as a result of

having foreign materials and bacteria in the lung. Aspiration pneumonia can be found in 12.4 percent of the patients (Watila et al., 2012; p. 189).

Prevention: Care providers must have the knowledge and understanding and be able to assess the patients' ability to control their swallowing such as gag reflex, strength of the oral muscles such as the cheeks and the lips, movements of the muscles of mastication, closing the mouth and the sounds. The clinical conditions that relate to aspiration include dysphonic, dysarthria, abnormal gag reflex and cough (Pasuthachat et al., 2009). Before eating, care providers should seat the patients upright. Serve easy-to-swallow food such as semisolid or soft food. See to it that the patients do not speak with food or fluids in their mouth. Get them to practice swallowing by exercising their oral muscles, tongue and mandibles for smooth coordination. For the patients with NG tube, aspiration can be prevented by sitting them upright or at 30 degrees angle. Slowly pour food into feeding syringe letting it flow down the tube slowly. During feeding, watch the patients constantly and stop feeding immediately upon aspiration. Keep the patients in sitting position for another 30 minutes after feeding.

4) Urinary tract infection (UTI): The infection of urinary tract is common in post-stroke patients because of urinary incontinence. Urination while lying on their backs can also cause the infection since the patients' bladders are not completely emptied. Those with retained urinary catheter are as susceptible to UTI in the wake of improper care such as placing a urinary bag higher than a patient's bladder, incorrect cleaning of the catheter enter or long-term use of urinary catheter. UTI incidence is found in 6.3 percent of post-stroke patients (Watila et al., 2012: p. 192).

Prevention: Care providers should clean around the genital areas and urethral meatus of the patients twice a day, in the morning and evening or every time the patients have bladder and bowel movement. If the patients cannot urinate by themselves, the care providers may need to perform intermittent catheterization every four to six hours to keep the amount of urine in the bladder under 500 milliliters otherwise, the patients' bladder can be over distended. In such case, the care providers must use aseptic technique, wearing gloves, and using only sterilized catheter for the catheterization.

In the case of retained urinary catheter, the drainage bag must be placed lower than the patient's bladder if they use retained urinary catheter. This is to prevent reverse flow of urine which can cause infection. Care providers should ensure good flow of urine and that the catheter is not twisted or bent. Wipe the catheter clean with cotton balls dampened in alcohol before and after emptying the drainage bag to prevent germs from entering the bladder. Change catheter and drainage bag every month and make sure that the urinary catheterization is a closed system at all times.

5) Pressure ulcer: Pressure ulcers are caused by prolonged pressure on soft tissues, normally occurs over a bony prominence. Stroke patients are at high risk of having bedsores due to their remaining in a single position for a lengthy period coupled with other conditions including abnormal sensation, contraction, immobility, muscle and soft tissue atrophy and malnutrition. Pressure ulcers are found in 3.8 percent of post-stroke patients (Watila et al., 2012; p. 192). The fact that patients cannot control their bladder or bowel movement does increase the chance of infection of pressure ulcers.

Prevention: Care providers must have the knowledge and understanding and be able to assess the health of the compressed skin each time they turn the patients, to prevent pressure ulcers from occurring. The care providers can reduce pressure on the bony prominence by turning the patients every two hours and placing soft cushions under the compressed bony prominence. Make sure that bed sheet is taut to prevent skin irritation. Change and wash bed sheets and beddings frequently to reduce the amount of bacteria thereon. Do not drag the patients to avoid friction that can damage the tissues. Including keep the patients' skin dry and clean.

6) Depression: Depression is a psychological condition that is often found in post-stroke patients (9.2 percent) (Watila et al., 2012; p. 192). Most depression is a result of physical impairments and malfunction which also lead to disabilities. The brain pathology that changes neuroendocrine mechanism which inhibits the effectiveness of serotonin and emotional reactions may also cause depression.

Prevention: Care providers must have the knowledge and understanding and be able to assess the patients' emotions and symptoms such as their being worried, concerned, apathetic, isolated, tearful, or sleep deprived. Care providers should give the patients opportunities to express their feelings and ask questions about their own

symptoms then give them honest rational answers, explain the objectives and steps of medical care and treatment. It is advisable to allow the patients to plan and take control of their daily activities that do not conflict with the treatment plan. This may include some relaxing activities such as music or Buddhist teaching audio to the patients' liking. In addition, close attention and regularly encouragement to them are desirable (Kasornsunt, 2013).

7) Recurrent stroke: Recurrent stroke is a threat to stroke patients, especially in the early phase of stroke. Previous studies of recurrent strokes reported a recurrence rate of about 29.11 percent in a less than one year, 45.57 percent in five years, and 25.32 percent in more than five years (Tiangout, 2009). The major contributing factors of recurrent stroke are hypertension, hyperlipidemia, diabetes, lack of exercise, lack of follow up, and medication.

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Prevention: The effective way to prevent recurrent stroke is to reduce risk factors by maintaining normal blood pressure, blood sugar level and cholesterol. The patients should exercise to improve blood circulation and release tension and stress in the manner of their choice. They should stop drinking alcohol and smoking. As important are keeping follow-up appointments and religiously take the prescribed medicines, be they anticoagulants such as warfare or Coumadin or platelet inhibitors such as aspirin, clopidogrel or ticlopidine depending on the cause of their strokes. These medicines can prevent blood clots in the blood vessels in the brain.

The afore-mentioned information show that the pathology of stroke results in the loss of neurological and brain functions. Patients therefore develop functional impairments which further cause both physical and emotional complications such as contractures, falls, aspiration, urinary tract infection, pressure sore, and depression. Furthermore, other important complication is recurrent stroke which tend to occur during the five years following the first stroke. The incidence is as high as 74.68

percent. Therefore, prevention of complications and recurrent stroke is therefore crucial to minimizing the impacts of stroke on the patients themselves, their families and the society.

## **2.2 Post-stroke care**

Stroke patients who are admitted into a hospital and treated until they are out of danger and stable enough will be discharged from the hospital to continue to recover back at home. Most patients still have some disabilities. The collaborative patient care between family caregivers and the patients is therefore very important. Family caregivers should have the understanding about stages of post-stroke and psychological response of the patients in acceptance with their disabilities. This will promote optimal collaboration and care for the patients.

### **2.2.1 Stages of post-stroke patients**

Post-stroke patients' psychological responses vary from stage to stage. A number of theories explain these phases of psychological response. For example, the Kubler-Ross model, or the five stages of grief, is the series of emotional stages experienced when faced with impending death, dying, or threatening illness. The five stages are denial, anger, bargaining, depression, and acceptance (Prigerson & Maciejewski, 2008). Transtheoretical Model developed by Prochaska and Diclemente explains the readiness of individuals to change their behaviour and focuses on stages of change namely precontemplation, contemplation, preparation, action and maintenance (Ryan, 2011). Nevertheless, the literature review about responses to post-stroke situations reveals that Mauk Model developed by Kristen L. Mauk (2011) explains phases of psychological response of post-stroke patients more precisely than other models. Mauk is an experienced professor of nursing and has clinical expertise in rehabilitation and gerontology. She was interested in stroke rehabilitation and thus developed Mauk Model which consists of six phases of post-stroke as described below.

- 1) Agonizing phase: In the early stage, patients may be shocked by the severity and symptoms of the disease. They may be caught unaware by sudden loss of control, functional impairment and disability. They may fear death or continued

symptoms or even permanent disabilities. They are also in denial about the illnesses that result in physical changes such as the inability to move their body, weakened muscles or facial palsy to mention a few. Family caregivers need to provide physical care such as cleaning, feeding, administering drugs, and assisting bowel movement as well as giving emotional support to the patients. They must observe and assess the patients' concerns in order to address them and lend morale support accordingly.

2) Fantasizing phase: In the previous phase, the patients agonize over the effects of the illness so much so that they now fantasize termination of the symptoms or completely cured disabilities. Such fantasy is unrealistic and cannot happen in a short time after the disease. The lengths of the agonizing and fantasizing periods are related to the patients' age, life experience and knowledge about the disease. The same care provided to patients in the previous phase continues through this phase. In addition, the patients should be given reality orientation to keep them abreast of their actual conditions.

3) Realizing phase: After the fantasizing phase, the patients have come to grip with reality although they may not be able to accept their conditions. Expression of anger, anxiety, despair or depression is not unusual. In this phase, family caregivers should explain to the patients so they understand the impacts of stroke and encourage them to keep their faith that there are solutions to every problem. Rising of the patients' awareness about the importance of rehabilitation coupled with social support from family members, public health care providers and the respective communities will help to put them on the desirable path to recovery. In this connection, they should receive psychological support in the form of useful information about treatment and rehabilitation. Likewise, necessary equipment such as wheelchair, walker or other medical equipment should be provided.

4) Blending phase: At this stage, the patients review their thoughts on their past and present experiences, the knowledge, and advice received, that may feel increased frustration as a result. If they can cope, they will be able to adjust and change themselves for the better, for example, they will be more cooperative in treatment and rehabilitation. The roles of family caregivers in this phase thus focus on teaching and educating the patients about post-stroke care and rehabilitation, giving

advice and emotional support to encourage and enable the patients to manage the changes.

5) Framing phase: This phase is about developing cognitive framework, understanding about the illness, and managing post-stroke care. Patients are enthusiastic about finding the cause, symptoms and impacts of the disease. They will also try to seek ways and means to recover and be cured of the disease. Family caregivers should not be annoyed at having to answer questions or explain to patients. Their important role remains educating, advising and helping the patients to reflect so as to be able to understand and perceive proper practices.

6) Owing phase: In this final phase, patients accept what has happened, be it the changes, the remaining disabilities and other impacts. Therefore, they become more determined to take care of and rehabilitate themselves to return to normal. In this phase, it is noticeable that patients are no longer temperamental, but have better control of their temper. They try to do things themselves. They are more cooperative in treatment and eager to participate in rehabilitation program. The roles of family caregivers in this phase include giving advice and morale support and empowering the patients so that they can manage and solve problems as well as care for themselves.

According to the study on the stages of post-stroke shows that after a stroke the patients' mental condition and thinking process vary from phase to phase. Such variation does influence their recovery. The concept of post-stroke stages is useful for guiding the intervention for family caregivers, public health nurses, and health care team. It enables them to provide proper care to patients in accordance with their needs in each phase. At the first stage, the patients are fearful, feel the loss and deny their illness. Later on they may feel anger and depression but may not yet accept the reality. The proper care for patients in the first three phases focuses on physical care by assisting them through their daily activities and providing them with morale support. The last three phases are the important transitional period leading to patient's acceptance and understanding about their illness. Social support is therefore crucial. Family members, caregivers and health care team should explain and encourage the patients to promote their understanding and to accept their conditions. At this time, the patients become hopeful to be rehabilitated or cured of their disabilities. Post-stroke patients are now more cooperative with family caregivers in rehabilitation. In

response, family caregivers should provide morale support and information to raise their awareness about their own capacity. Eventually, the stroke survivors will be able to adapt and to care for themselves thereby alleviating the burden on their families, caregivers, and the society.

## **2.2.2 Post-stroke care at home**

Post-stroke patients tend to have lesions from the illness, which cause both physical and emotional changes. The patients normally have paralysis and possibly other neurological conditions such as confusion, difficult communication, abnormal chewing and swallowing or problematic bladder and bowel control. The stroke survivors therefore need to continue rehabilitate at home. During the early recover period, the first three to six months, is the golden period which is crucial to successful rehabilitation (Good, Bettermann & Reichwein, 2011; Chaiyawata & Kulkantrakornb, 2012). If patients receive proper care, they can be normal again. In caring for post-stroke patients, family caregivers should pay attention to such issues as prevention of complications, physical care, psychological care, nutrition, medication, and physiological rehabilitation (King, Ainsworth, Ronen, & Hartke, 2012; Cameron & Gignac, 2008).

### **2.2.2.1 Physical care**

Post-stroke patients have movement impairment and cannot care for themselves. They require assistance from family members and caregivers. Physical care includes assistance in the following areas:

**2.2.2.1.1 Daily activities:** Some patients have severe impairment and may require caregivers to do all their daily activities for them, such as personal hygiene care, dressing, eating and drinking and elimination. In case of the patients with minor or moderate impairment who can partially help themselves caregivers should encourage them to try their best first.

*Personal hygiene care and dressing:* The general personal hygiene care meaning keeping patient's body clean in order to reduce risk of infection includes brushing teeth, showering, washing hair and cutting nails. Tight or too fitting clothes are difficult for the patients to put on, therefore, comfortable clothes that are easy to remove are preferred. Putting on clothes should start on the paralyzed

side and reverse the steps for taking off. This enables the patients to use their unaffected limbs to help them get dressed. Caregivers should prepare and put toiletry and clothes within the patients' easy reach.

*Eating and drinking:* Family caregivers should clean patients' mouth before meal to stimulate saliva excretion and appetite. Since patients normally have trouble chewing and swallowing making them prone to choking, family caregivers may test their swallowing reflex starting with feeding small amounts of thick liquid or small pieces of soft food for easy swallowing (Singh & Hamdy, 2006). As for the patients who must be fed through NG tube, caregivers must follow the steps below (Bankhead et al., 2009):

- Position patients in a seated position or ensure that their head is at least 30 degrees higher than their body.
- Ensure that the feeding tube is securely placed in position.
- Open the cap on the feeding tube and bend the tube backward to prevent air from entering it. Wipe the outside of the end of the tube with cotton ball soaked in boiled water.
- Insert the feed syringe into the end of the tube so that it fits securely into the tube. Slowly pour food into the syringe and let the food flow slowly into the tube. Finish each feeding with 30 ml of water.
- At the end of each feeding bend the tube backward to prevent air from entering and remove the feed syringe.
- Wipe the end of the feeding tube clean with warm water and close the cap.

The patients should remain in seated position for at least 30 minutes after feeding to prevent choking.

*Elimination:* Most post-stroke patients have problem controlling their bladder or bowel and consequently wet and soil their bed sheets. Family caregivers must clean the patient's skin after every elimination. Some patients may wear adult diapers, which need to be changed frequently or every time after elimination to keep the area dry. For the patients able to help themselves to a certain

extent, family caregivers should assist them to go to the toilet and to clean themselves afterwards, in addition to bladder and bowel retraining.

**2.2.2.2.2 Respiration:** Family caregivers should ensure that patients receive sufficient oxygen. Post trauma patients may have had tracheotomy and return to home with a tracheotomy tube which can be obstructed by sputum. Family caregivers should assist the patients to cough up the sputum; otherwise suction must be used to clear the airway to facilitate the patients' intake of sufficient oxygen. Moreover, family caregivers must keep the tracheotomy tube and wound clean to prevent infection (Bosel et al., 2012)

**2.2.2.2.3 Mobility:** Post-stroke patients normally have weakened muscles or stiff joints in their limbs and require assistance in moving such as turning in bed, sitting up or moving from bed to chair or wheelchair until they have regained their muscle strength (Heart and Stroke Foundation, 2013).

- Moving the patients on a bed: Caregivers should stand next to the patients' affected side. Inform the patients what actions will be taken and what they must do to help. Ask them to bend their knees, placing their feet on the bed (help them if they do not have enough strength to do so) and push their body to the right or left, or up or down as they wish with their elbows.

- Turning on the sides: Caregivers should stand on the side of the bed to which the patients should turn. Place the patients' arm on the side to which they will turn on their body. Ask them to bend their knees and placing both feet on the bed (help them if they do not have the strength to do so), then turn on the side.

- Sitting up from a lying position: Caregivers should stand on the side to which the patients will turn to sit up. Ask the patients to bend their knees placing both feet and hands on the bed and use their hands to push themselves to sit up. If the patient do not have the strength to do so, caregivers must help by inserting one hand under the patient's shoulder, and the other under both legs lifting the patients' trunk up gently put their legs down on the side of the bed. The patients will sit up with both their legs by the bedside.

- Moving patients from their bed to a wheelchair or chair: Place a wheelchair or a chair close to the bed on the patient strong side so that

it faces the bed at 45 degrees angle. Ensure that both wheels of the wheelchair are locked. Bring the patient to a seated position on the bed with both their legs by the bedside. Caregiver should stand in front of the patient or by the patient's affected side. Grab the patient by the trousers' waist either on the front or at the back and ask him/her to stand up. The patient should put both hands on the chair/wheelchair's arms, after that turn themselves to sit down on the chair or in the wheelchair.

**2.2.2.2 Psychological care:** The family caregivers should understand the patient's changing emotional and psychological conditions. They must neither express anger or dissatisfaction in the patients' presence nor leave the patients by themselves for too long. They should assess the patients' mental states in observation such as their mood swing, aggressiveness, inability to control themselves, agitation, insomnia, depression or isolation. Caregivers should attentively care for them and be appropriately responsive to their needs. They should explain to the patients the changes caused by strokes, boost their self-esteem, encourage them to engage in activities and to communicate with others. Relaxation techniques such as breathing exercise, meditation or music therapy may be used to distract the patients from their illnesses as well as to reduce their anxiety and stress (Morrist et al., 2011).

**2.2.2.3 Nutrition:** Proper diet is important to the recovery of post-stroke patients. Studies have found that malnutrition among post-stroke patients is due to their chewing and swallowing problems (Dysphagia) leading to their reduced food intake. Patients with NG tube may not receive their required amounts of food and nutrition (Bouziana & Tziomalos, 2011). Therefore, preparation of suitable food for the patients is crucial. Food that consumption through the mouth should be not only chopped, grinded or cut into small pieces but also soft enough for the patients to chew easily. Liquid food is better prepared and served as puree which is easy for patients to swallow without chewing (Chaichol & Kespichayawattana, 2007). For patients who cannot chew or swallow food through their mouth and are fed through NG tube, their food must be liquid with no residue or benderized diet that can flow through the NG tube easily. Post-stroke patients normally have other illnesses such as hypertension, diabetes and hyperlipidemia, which must be taken into consideration when preparing their meals to ensure that they have sufficient energy and nutrition intake for any activities and rehabilitation. All precautions help to reduce the patients' risk of

complications and recurrent stroke. The guidance for food preparation for post-stroke patients is provided below.

1) Limit sodium intake to no more than 2,400 milligrams or about 1 teaspoon of salt per day. Avoid and reduce intake of high-sodium food such as packaged processed or ready-to-eat food, e.g. instant noodles, instant porridge, frozen food, canned food, fermented food, food with baking powder, monosodium glutamate or other seasoning. High-sodium food increases sodium in the blood and results in increased water absorption between cells or from cells into blood vessels. This mechanism causes increased water level in blood vessels and high blood pressure which is the main cause of recurrent stroke.

2) Reduce or avoid high saturated fat diet because it increases cholesterol level, blood pressure and reduces flexibility and causes inflammation of the endothelium. These are risk factors for recurrent stroke. Foods that should be avoided include high-cholesterol food such as offal, pork belly, and some seafood such as squid, shrimp, and oyster. In addition, avoid cooking food with lard, butter, and cream. Caregivers may opt for unsaturated fat for cooking such as olive oil, rice bran oil, soybean oil, or corn oil.

3) Select carbohydrate with high fiber such as unrefined grains and brown rice to reduce the patients' cholesterol, blood pressure and insulin sensitivity that are risk factors for recurrent stroke. This type of carbohydrates is also enriched with vitamin and antioxidant food.

4) Patients should eat protein which is essential for building and repairing tissues as well as an important energy source after carbohydrate and fat. The proper type of protein for post-stroke patients is lean meat and fish, especially sea fish that has omega 3 which help reduce triglyceride, blood pressure and platelet aggregation.

4) Ensure that patients eat vegetables and fruits high in folate, vitamin B6 and B12 such as broccoli, cabbage, spinach, banana, tomato, beans and grains. These vitamins are cofactors in homocysteine metabolism which can reduce homocysteine in blood vessels and risk factors for atherosclerosis (Bouziana & Tziomalos, 2011).

**2.2.2.4 Medication:** Family caregivers should make sure that post-stroke patients take correct dosage of their medicines on time. Patients must not skip or alter the dosage but strictly follow doctor or pharmacist's instructions. The objective of post-stroke care and treatment is to prevent recurrent stroke. Most post-stroke patients are prescribed the following common medications (Kirshner, 2012):

1) Drugs that control factors contributing to recurrent stroke, such as drug for controlling blood sugar level, blood pressure, and dyslipidemia.

2) Antiplatelet drug, the most common one is aspirin which inhibits platelet cyclooxygenase that reduces platelet aggregation and stops the excretion of vasoactive substance. This drug can cause such side effects as gastrointestinal disturbance in the form of stomachache or nausea after taking the drugs. As they can cause bleeding in the gastrointestinal tract, this drug should not be taken on empty stomach but, rather, immediately after meals with a lot of water.

3) Anticoagulant drugs such as warfarin which slows down and inhibits blood clots. Patients who are on warfarin should avoid accident and bleeding activities. They should also avoid any behaviors that may affect the level of drugs in their blood such as drinking alcohol and smoking. Caregivers should monitor any complications caused by medicines, such as bleeding gums, bruises on the body, rectal bleeding, black stool, vaginal bleeding or abnormally heavy menstruation, and blood in urine. These symptoms could be fatal and the patients having any of these symptoms must stop taking the drugs and be brought to a hospital soonest.

**2.2.2.5 Physiological rehabilitation:** Post-stroke patients are normally left with muscle weakness and their muscles cannot work as they used to. The patients may have muscle tension and poor balance which affect their movement and daily activities. Family caregivers must give priority to physical rehabilitation to stimulate the muscles and movements as well as to prevent joint, ligament and muscle stiffness. Furthermore, physical rehabilitation will also improve blood circulation. The proper physical rehabilitation for post-stroke patients should cover the following (Gordon, 2004):

1) Large muscle activities: Large muscle rehabilitation involves walking training for increased endurance and quicker movement. The recommended frequencies are 3-7 days/week with duration 20-60 min/session. Before the training,

family caregivers should encourage patients to exercise to build leg muscles which will enhance their ability to walk. This is done by exercising many muscle groups together such as standing up and sitting down, cycling, squatting, and walking up and down steps. Once the patients are ready, caregivers should get them to walk on level surface with the help of a cane or a walker. Caregivers must always be on the weak side of the patients to provide immediate assistance if the patients lose their strength or fall.

2) Strength: Strength training improves muscle strength by resistance that forces muscles to exert energy. This type of exercise can be done to build shoulder muscle (The National Stroke Association, 2013: p. 54-55) using elastic band to create resistance during the exercise. The patients start this exercise by lying flat on their back holding one end of the elasticized band in their weak arm. Place both arms alongside the unaffected hip, keeping elbows as straight as possible. Then, move the affected arm upward in a diagonal direction, reaching out to the side, above their head, keeping the elbow straight. The unaffected arm should remain at the patient's side throughout the exercise. Moreover, exercises for arm muscles not only strengthen the muscles but also straighten the elbows. In this exercise, the patients lie in bed with both arms beside their body. Place a rolled towel under the affected elbow. Ask the patient to bend the affected elbow and move the hand up toward the shoulder while keeping their elbow rested on the towel. Hold the position for a few seconds then extend both arms alongside their body.

3) Flexibility: This exercise focuses on joint movement by extending and bending different joints to stretch them and prevent stiff joints. This exercise consists of active and passive exercises.

*Active exercise* is the movements that are initiated by the patients.

Lifting and lowering arms: Ask the patients to interlace their fingers or grab their affected hand with their unaffected hand, then straighten their elbows and slowly lift both arms over their head. Hold the position for 10 to 30 seconds and slowly lower them down.

Moving leg joints: Patients lie on their bed with both legs extended. Bend the knee and hip joint of their unaffected leg as far as possible keeping the heel on the bed. Hold the position for 10 to 30 seconds before returning to the starting position. Repeat on the other side.

*Passive exercise* is the movements that are initiated by caregivers.

*Moving arm joints in the following steps:*

- Lifting and lowering arms: Caregiver holds the patient's arm at the wrist and the elbow. Lift the patient's arm up over the head. Hold the position for 10 to 30 seconds and slowly lower it down

- Arms abduction and adduction: Caregiver holds the patient's arm by the wrist and elbow. Lift the arm up sideways then over the head. Hold the position for 10 to 30 seconds. Slowly bringing the arm down and in.

- Rotating shoulders: Caregiver holds the patient's arm by the elbow and wrist. Lift the arm up sideways to 90 degrees angle keeping the arm on to the bed. Rotate the shoulder in and out. Hold each position for 10 to 30 seconds.

- Bending elbows: Caregiver holds the patient's arm by the elbow and wrist. Bend the elbow out and in. Hold the position for 10 to 30 seconds.

- Bending wrists: Hold the patient at their wrist and four fingers and bend the wrist up and down. Repeat.

- Caregiver assists patients to curl their fingers to make a fist, then release.

*Moving leg joints can be done as follows:*

- Bending knees and hips: Caregiver grabs the patient's ankle and knee, then bends the hip joint as far as possible, and release.

- Rotating hips: Caregiver grabs the patient's ankle and knee. Raise the leg to 90 degrees then rotate the hip joint.

- Hip abduction and adduction: Caregiver put their hand under the patient's knee and the ankle. Move the leg sideways out and back in.

- Ankles abduction and adduction: Caregiver grabs the patient's ankle and heel then bends the ankle up and down.

4) Coordination and balance activities: Exercises to improve coordination aim at training different muscle groups and using them to promote smooth and effective coordination. Caregivers should encourage patients to do various daily activities by themselves. Balance training aims to enable patients to hold correctly posture whether sitting, standing or walking positions so that they do not sway or stumble. The exercise will also help the patients to know how to transfer their

weight correctly from one point to another. Balancing is fundamental of movements and can be categorized into two types, sitting balance and standing balance. Sitting balance can be trained by seating patients in an upright position on the edge of their bed with both feet flat on the floor. Make sure that the patients do not lean onto their affected side. Caregivers then train the patients to balance themselves when they are pushed towards the side, the front or the back. As for standing balance, the patients should stand upright with their feet moderately apart and their hips and knees straightened. The patients should put their weight equally on both feet. Caregivers then push the patients from the front, back, left and right while the patients resist to remain standing.

### **2.2.3 Situations of post-stroke care and problems**

At present, treatment of stroke patients has been significantly developed. In case of acute stroke, patients are transferred to the emergency unit at a hospital where their conditions are assessed by a team of physicians. Special test such as computerized tomography brain (CT brain) may be required in order to triage, diagnose and treat the patients quickly. If the patients arrive at the hospital within 3-4.5 hours of the stroke, they will enter the stroke fast track, a standardized procedure for acute stroke patients. The fast track aims at reducing mortality, disability and post-stroke complications to the greatest extent possible. Having been diagnosed as suffering from stroke, the patients are admitted to in-patient care. Nowadays, care for stroke patients is provided in a systematic manner in the stroke unit where a multidisciplinary team provides care, treatment and rehabilitation for patients (Prasat Neurological Institute, 2007).

While in a hospital, stroke patients are treated until they are off the danger list. They then pursue a rehabilitation program and are expected to be discharge from the hospital as soon as possible. Normally the patients stay in a hospital for seven days on average. Nurses coordinate the discharge plan with the health team, caregivers and the patients. Discharge planning is aimed at preparing the patients and their family caregivers prior to the discharge. The plan includes the following (Charnnarong, 2009):

- 1) Providing knowledge about stroke, its causes and treatment. Family caregivers and the patients will learn about the causes and the symptoms of stroke,

potential complications and prevention, treatment plan, drug administration and follow-up appointments.

2) Providing knowledge and skills in some nursing care particularly for the patients who cannot take care of themselves and are at high risk of having complications. These high risk patients have trouble chewing, retained Foley catheter and retained NG tube or tracheostomy tube. Patients and their family caregivers will also learn how to monitor symptoms that may be dangerous or signs of complications. Nurses will advise and provide information to family caregivers and involve them in caring for the patients when they are still in the hospital.

3) Providing knowledge and skills in patient's rehabilitation: Rehabilitation physician, physiotherapist and occupational therapist develop a rehabilitation program and set goals for the patients. The rehabilitation program is then implemented either at the ward or the rehabilitation center. Patients and their family caregivers will be taught how to practice the physical therapy.

4) Providing psychological preparation for patients: Strokes normally occur suddenly and possibly disable patients necessitating physical and psychological adjustment. Anxiety, depression, or insomnia are main consequences facing the families of both patients and caregivers. It is therefore necessary to assess patient's psychological conditions and prepare them before their discharge from the hospital. A team of physicians and nurses will assess the seriousness of the problems and jointly identify solutions to the problems that require cooperation with and involvement of family caregivers. The family caregivers will receive guidance as to how to monitor and observe as well as deal with the patients' psychological problems.

5) Providing knowledge and skills in nutrition. Some patients cannot chew and swallow food and thus need to be fed through NG tube. Family caregivers must be prepared to NG tube feeding the patients, from preparing blender zed diet, feeding methods, to cleaning the feeding syringe and NG tube. Family caregivers and patients will receive information regarding appropriate nutrient for post-stroke patients to reduce risks of recurrence stroke.

These steps are in line with patient discharge direction of The Public Health Nursing Division (2011) that adopts DMEDTHOD principle in providing guidance to patients and their families before discharge. The DMEDTHOD consists of

diagnosis (D) - provision of knowledge about the disease and its causes; medication (M) - provision of knowledge about drugs and drug administration according to the treatment plan, their efficacy, dosage, cautions and signs of drug complications; environments and economics (E) - to provide knowledge about the necessary changes in environment to accommodate the health and conditions of accident-prone post-stroke patients who have limited mobility, to provide information on medical benefits and financial management in relation to treatment expenditures; treatment (T) - explanation about treatment plan to be followed by the patients and their family caregivers such as rehabilitation program, tracheostomy care, bed sore care, including monitoring of other abnormal symptoms that require doctor's attention such as severe headache, weakening limbs, difficult swallowing and blurred vision; health (H) - provision of knowledge about rehabilitation practices such as encouraging patients to do daily activities by themselves, exercises, and prevention of complications; outpatient referral (O) - scheduling of doctor's appointments specifying the date, time and venue, including referring patients for continuum of care format a community health center; and dietary (D) - provision of knowledge about foods for stroke patients and the foods to be avoided.

Realizing the importance of effective continuum of care for stroke patients, the Neurological Institute, a government tertiary care institute under the Ministry of Public Health and Thailand's leading academic institute in neuropathy has thus developed nursing care guideline for stroke patients. Once patients are assessed to be stable, they will be discharged from the hospital. The patients' data will then be transferred by the hospital concerned with the community health center for necessary follow-up, rehabilitation support, and health care for the patients in their homes. The Neurological Institute (2007) advises four home visits. The first two visits should be conducted within the first one or two weeks after the patients have been discharged, and the third and fourth visits in the third and fourth week. On each visit, public health nurse should assess the patient's physical, emotional, psychological, psychosocial, and neurological conditions, including muscle strengths, the ability to do daily activities, the living environment, and the equipment used in patient's care and rehabilitation. The nurse then plans further supports for the patients with a multidisciplinary team involving the patients and their families. During home visits, demonstrations and

review of nursing care, moving of patients, physiotherapy, complication prevention, medication administration, monitoring of abnormal signs and symptoms, keeping appointments with the doctors, emergency aid contacts, including medical consultation and morale support will be discussed and provided. Nonetheless, the implementation of the Neurological Institute's guideline is contingent upon the contexts of the hospitals concerned. To date, the implementation of the guideline has not yet been confirmed by any empirical evidence. It may state that this guideline remains merely suggestions for nursing care practices. The goals and objectives of the practices must be aligned with the context in which such practices will be performed. Ultimately, the guideline will be implemented at the discretion of the patient care team taking into consideration the situation within which the patients will be cared for.

#### **2.2.3.1 Problems of current situations of post-stroke care**

The true challenge in caring for post-stroke patients is when patients are discharged to recover at home. Patients are discharged as soon as their conditions have improved. This is due to the limited number of beds in hospitals, the increased health expenditures and the health care quality control system. Patients and their caregivers must be prepared for home recovery (Charnnarong et al., 2007). If hospitals fail to equip family caregivers with the necessary knowledge and skills to care for patients return to home, the family caregivers will not be able to perform their duties properly. As a result, the patients will not recover and will be at risk of recurrent stroke (Pinyopodjane, Bualad & Rakkieattiyos, 2011). The study conducted by Jullamate et al. (2006) on Thai stroke caregivers found that caregivers did not receive adequate information from hospital staffs that would enable them to care for and rehabilitate patients at home. Moreover, with the limited number of primary home health care personnel, caregivers did not receive sufficient assistance and guidance from the home health care team and thus lacked the knowledge and the confidence in caring for the patients. These findings agree with those of the study by Piyabunditgul (2012) on exploring patient's problems to improve quality of life after stroke in community. The study found that the inadequate number of personnel required to care for patients in community - nurse practitioners, physical therapists and nutritionists - has made proactive community health care not feasible.

Other factors (Piyabunditgul, 2012; Ruttawongsa & Kongtahn, 2012) that are also relevant to post-stroke patient care in community are: lack of linkage and coordination between hospitals and community health centers in patient referral which is detrimental to continued care provided to patients; the limitation of community hospitals in allocating budget for physiotherapy tools and equipment, which results in inappropriate and insufficient post-stroke care and rehabilitation for some patients; transportation constraints between a hospital and patient's home such as long distance or lack of vehicle, which make access to care and rehabilitation difficult. In addition, at community level, community health volunteers lack correct knowledge and skills in post-stroke patient care and rehabilitation. They are not able to fully apply folk wisdom and use local resources for the post-stroke care. Integrated the post-stroke care, rehabilitation policy, and network are yet to be materialized in communities.

#### **2.2.3.2 Current situation in research setting**

Kamphaeng Phet Province located in the northern part of Thailand comprises 11 districts. Muang, Phran Kratai, Khlong Lan, and Sai Ngam districts have the highest number of stroke patients than other districts according to the data from the Social Medicine Unit, Kamphaeng Phet Hospital (2013). Stroke inpatient statistics of the hospital show an increase in stroke incidence from 1,740 patients or 239.29 per 100,000 populations to 2,431 patients or 334.49 per 100,000 populations (Bureau of Non Communicable Disease, Department of Disease Control, Ministry of Public Health, 2012). Kamphaeng Phet Hospital is a tertiary-level hospital that has adopted the Prasat Neurological Institute's guideline to provide care for stroke patients. The hospital has an effective treatment system such as stroke fast track. However, due to resource constraints, a stroke unit has not yet been established. Therefore, stroke patients are admitted into a medical ward where they are cared for by a multidisciplinary stroke care team consisting of a stroke expert, nurses, physical therapist, nutritionist and social worker. The care is comprehensive.

The primary data show that most of the problems in relation to the situation of post-stroke care in Kamphaeng Phet Province are like the elsewhere of the short treatment and rehabilitation period in hospital limits the preparation of caregivers before hospital discharge. As a result, they do not receive all information

they need to care for and rehabilitate the patients. In some cases the family caregivers trained in according with the discharge plan are not the main caregivers at home. Without the knowledge, skills and confidence, these main caregivers do not care for patients as they should. The referral system and continuum of care problems in the community are similar to the situation almost anywhere in Thailand. To be more precise, the delayed coordination between the hospital and community health centers leads to delayed submission of referral documents, i.e. patient's treatment summary from admission to discharge, health problems requiring continuous care, and patient's pre-discharge assessment form. Moreover, shortage of physical therapist hinders the patients' follow-up and the family caregivers cannot follow the recommendation of the rehabilitation medicine unit, i.e. monthly post-stroke visit to assess patient's symptoms and to provide knowledge and assist family caregivers in the patients' rehabilitation. All of these shortcomings bring about delays in assessing and assisting the patients as well as their caregivers.

The literature reviews of post-stroke care situation reveals advancement in stroke treatment and systematic patient care from admission to discharge and referral. Patients are discharged from hospital as soon as their conditions have improved to the extent that they are no longer in danger. In general, the period of hospitalization is about one week. Hospitals' discharge planning prepares the patients and their family caregivers prior to discharge. During the preparation, the family caregivers are given the knowledge about stroke, complications, medication, food, nursing care, physiotherapy and environment. They are also trained to have sufficient skills for patient care. However, there are areas for improvement in the situation of post-stroke care. The problems or shortcomings found in the research setting are similar to those encountered elsewhere in Thailand. In summary, family caregivers do not receive adequate knowledge and skills and the trained caregivers are not the main caregivers at home. Consequently, the actual family caregivers lack confidence and do not care for the patients correctly. Delayed the post-stroke patient care and interrupted rehabilitation are due to delayed referral, home care team human resources constraints such as physical therapist, and unskilled health volunteers. These problems are more pronounced during the transition period when caregivers truly need help and support from home care team. Public health nurses have a crucial role in

providing knowledge and advice on post-stroke patient care, rehabilitation and prevention of complications.

## **2.3 Family caregiver of post-stroke care**

### **2.3.1 Concept of family**

Family is a part of social subsystem that within the family system consists of individual subsystem such as spousal, parental, and sibling subsystems. The term family is defined in various ways. Definitions of family differ depending on family characteristics. A family may be a group of individuals who live together to share companionship, care, and common interests (Hanson & Lynch, 2013: p. 2). Friedman (2003: p. 10) defined family as a group of two or more persons joined together by bonds of sharing and emotional closeness, including who identify themselves as being part of the family.

Family is a fundamental unit that plays a significant role in health care of family members (Friedman et al., 2003: p. 36-54). When a family member is sick, the family is the focal point for cares and rehabilitation until full recovery. The sickness of a family member inevitably affects other family members as well as the entire family because of their bond. Family nursing is therefore important. Public health nursing views the complexity of family as the client or as the subunit of the community (Eddy & Doutrich, 2010: p. 470-473). The perspective of “family as client” views family as the primary focus of assessment and intervention. The family is in the foreground and family members are in the background. The family is viewed as interaction systems that focus on internal family dynamics and relationships, the family structure and function, and the relationships of family subsystems. When a family member is sick, various familial factors associated with the illness, including supporting factors and obstacles to health care are assessed to help all family members to be appraised of the problems and to identify solutions together as a family (Friedman et al., 2003: p. 37-38).

In principle, family nursing focuses on capacity building, empowerment, and promotion of family’s self-help as well as appropriate health care for family members. Of no less important is the promotion of family’s participation in problem

solving (Eddy & Doutrich, 2012: p. 474-475). Family nursing intervention strategies consist of the following activities (Friedman et al., 2003: p. 189-202):

1) Teaching: Provision of correct and adequate knowledge and information is instrumental in enabling a family to make informed decisions, review their practices, care for their and their family members' health, and solve problems properly. Knowledge provision should cover all health care issues such as health promotion, disease prevention, illness, disability, and impacts.

2) Counseling: Nurses play an important role in family counseling by giving advice on health care and management of related problems by providing information and options so the family have a clear understanding and be able to make informed decisions.

3) Role model is an informal teaching method that significantly influences behavioral changes. Family can learn from observing behaviors of a good role model, which could promote positive health behaviors. A nurse demonstrates, for example, plays a role of family caregiver helping patient, or invite a health role model to advise the patients and their families.

4) Collaborator: The promotion of family health and capacity for own health care requires collaboration among members of health care team, which is an interdisciplinary team normally consisting of physician, public health nurse, psychologist, social worker, physical therapist, occupational therapist and nutritionist who work together to plan home health care program and problem solving directions.

5) Coordinator: Coordination is another important role of nurses. They contact and coordinate with various units to ensure that families receive appropriate assistance as needed for the highest benefits to the family and the patients. Some examples of coordination in question are that with physical therapist when family members require rehabilitation and that with social worker when a family needs social and welfare support.

In conclusion, family is an important social unit that consists of at least two members who may or may not be blood relatives, but are bonded with and help each other. When illness occurs in a family, it affects all family members. Family has significant influence on patient care and rehabilitation. Understanding family as family's health care unit can lead to proper family nursing. Various family nursing

strategies such as health education, counseling, and role model can be applied to different interventions. In such case, public health nurses serve as collaborators and coordinators in cooperation with health care team to promote continuous and effective family health care.

### **2.3.2 Family caregivers**

There are life cycles when family members become sick and need care. The family is directly responsible for care giving. National Alliance for Care giving (2010: p. 12) defines family caregiver as individual in a family who cares for family members who are unable to care for themselves due to illness, injuries or disabilities. The given care, be it physical, emotional and financial support, is without financial compensation to the caregiver. Family Caregiver Alliance (2006: p. 5) defines family caregiver as any relative, partner, friend or neighbor who has a significant personal relationship, and provides a broad range of assistance for a person with a chronic or disabling condition. Moreover, family caregiver refers to an unpaid family member, friend, or neighbor who provides care to a person who has an illness and needs assistance to manage a variety of tasks (Reinhard, Given, Petlick, & Bemis, 2008: p. 341).

Family caregivers can be classified into two types based on their functions: primary and secondary (Barbosa, Figueiredo, Sousa, & Demain, 2011).

Primary caregivers are individuals who are directly responsible for patient care, and provide continuous care longer than any other individuals. General responsibilities of primary caregivers include patients' personal hygiene, daily activities, food and medication as well as house chores.

Secondary caregivers are other individuals taking part in certain patient care activities although not regularly or continuously. The secondary caregivers spend less time in terms, i.e. fewer hours, than the primary caregivers caring for patients. Secondary caregivers may assist primary caregivers in taking the patient to hospital on a follow-up visit or occasionally stand in for the primary caregivers.

In conclusion, family caregivers are family members who help and care for, without receiving any financial compensation, other family members who are unable to take care of themselves due to sickness or disability. The family caregivers may be the patients' blood relatives, friends or neighbors. As primary caregivers carry

such heavy burden caring for the sick family members plus doing other house chores, they are at risk of facing stress and health problems.

### **2.3.3 The current situation of family caregivers with post-stroke patients**

The continuum care for post-stroke patients at home is the primary responsibility of family caregivers. In general, primary caregivers are female and are patient's spouse, daughter/son or close relative (King et al., 2012; Sakunhongsophon, Ananthachock & Hosakun, 2011). They are 53 years old  $\pm 12.76$  years on average (Janthayanont et al., 2011). Most of them care for patients 24 hours each day, alone without any assistance (Jullamate et al., 2006). Some are new caregivers with no experience in caring for post-stroke patients (Silva-Smith, 2007; Koonnarong, Thaniwatananont & Kitrungrrote, 2012). The type of care that family provides to patients includes assistance in their daily activities such as showering, dressing, eating, and elimination as well as physiotherapy, specific nursing cares such as tube feeding, tracheostomy wound dressing, and cleaning of urinary catheter (Sakunhongsophon et al., 2011).

#### **Needs of family caregivers**

The primary responsibility of family caregivers in caring for post-stroke patients is a complex and demanding task. Family caregivers therefore need assistance and support in various aspects to enable them to assist, care for and rehabilitate patients appropriately and continuously (Danzl, 2013). The four main needs of family caregivers are knowledge, skills, assistances, and social supports. Each need is described below.

**1) Knowledge:** Most family caregivers need the knowledge about post-stroke care and rehabilitation at home (Mackenzie et al., 2007; King et al., 2012; & Cameron, 2013). Family caregivers lack adequate information from hospital staffs during hospitalization of stroke patient. Since they have no prior experience in caring for stroke patients they feel inadequate to care for the patients for lack of correct and sufficient knowledge. In addition, providing knowledge to family caregivers giving post-hospitalization care of patients in rural areas may face certain constraints. As a

consequence, some family caregivers care for stroke survivors without any knowledge about stroke and proper care for the patients. Nevertheless, they do what they think is best, not what is right, for the patients. Family caregivers need information and knowledge about consequences of stroke, prevention of complications and recurrence stroke, strategies of ADLs support and rehabilitation, and available services in community (Jullamate et al., 2006). Delivery of education to communities or households is also important to promote continuous education of caregivers about patient care to promote correct practices for the safety, improved functional outcomes and recovery of the patients. Providing a lot of knowledge to family caregivers at a time may not be as effective as expected. Trainers should divide training into small sessions using different techniques. Information may be given over the telephone or via e-mail. Review of key information and knowledge should also be conducted. The study of Danzl (2013) found that the perception and understanding of family caregivers about their own roles and scope of responsibilities significantly influence the care that they provide to patients. The misperception and false realization of caregivers about their own roles do hinder patient care and rehabilitation. For example, a number of caregivers know that physiotherapy is the main responsibility of physical therapist, not theirs; hence the patients' delayed rehabilitation or none at all leading to their permanent disability.

**2) Skills:** Stroke affects various systems of human body and changes the external physical structure. Muscles can be weakened and limbs unable to move or paralyzed. These changes limit the patients' ability to take care of themselves. Care provided for post-stroke patients are therefore more specialized and complex than general health care practices. Family caregivers must have specific skills such as skills of mobility, NG tube feeding, and tracheostomy care. These skills will promote the family caregivers' confidence enabling them to care for post-stroke patients more appropriately. Many studies reveal that most family caregivers do not need only knowledge, but also skill development in patient care (Ruttawongsa & Kongtahn, 2012; Silva-Smith, 2007; Lutz & Yong, 2012). The skills that family caregivers normally need include correct moving of patients, physiotherapy and nursing care that suits the problems and needs of patients such as tracheostomy wound care, NG tube feeding and choking prevention, and catheter care. The skill needs assessment of

family caregivers is key to planning and providing appropriate skills training to suit their needs.

**3) Assistance need:** Since family caregivers have a lot to do each day, which can be too much to cope, they need assistance to alleviate their physical burden. Caring for helpless patients for almost 24 hours per day does take its toll on the caregivers who become exhausted and stressed out. Family caregivers thus need help from other family members especially with difficult and heavy tasks such as lifting or moving patients (Petchroung, Priyatruk, & Tongkeang, 2013). The study of Niyomthai et al (2010) found that the primary caregivers' burden can be lightened through sharing of responsibilities for patient care and family tasks by assigning duties to family members and involving them in caring for the patients and doing chores, social activities and financial management.

**4) Social support:** Family caregivers need social support from family members, neighbors, community members, and community health care team in various aspects such as psychological support. Family caregivers need advice, morale support, and care from family members so as to not feel isolated. These psychological supports can reduce the caregivers' despondence and stress (Petchroung et al., 2013). High spirits of family caregivers benefit their relationship with stroke survivors, a key factor in the patient care. If family caregivers have close relationship with the patients, e.g. spouses, children or relatives, they do understand, sympathize and empathize with the patients. These emotions motivate caregivers to devote themselves to caring for the patients. Moreover, they will be able to handle stress and overcome obstacles (Danzl, 2013). These findings agree with those of the study by Niyonthai et al (2010) conducted in Thailand. The study found that the strengths of family in caring for stroke survivors at home are good relationship within the family. The family's hope for successful rehabilitation and full recovery of the patient help family caregivers to overcome problems and obstacles in patient care. Moreover, the Thai society being Buddhist, Thai people are assertive about showing gratitude and gratefulness to the parents. The belief in karma also has crucial impact on patient care by the family. Furthermore, instrument support is the support in the form of objects, tools, and equipment necessary for patient care and rehabilitation such as wheel chair, walked or wound dressing set. Information support satisfies the need for information and

knowledge including advice on patient care. In addition to the above-mentioned supports, caregivers need assistance and follow-up support from home visit team particularly during the transition period when the caregivers are adapting themselves to their new role in caring for the patients. Advice and feedbacks provided by health personnel will promote confidence in patient care amongst the caregivers (Lutz & Young, 2010). Home visit is one of the channels of morale support and empowerment of family caregivers for self-adjustment and handling of crisis of changes (Piyabundigul, 2012).

In conclusion, the review of current situation of post-stroke home care points to the fact that most family caregivers are middle-aged or aging female family members having close ties with the patients. They have no experience in caring for post-stroke patients, yet have become the primary caregivers which are a considerable responsibility. Most studies reveal that family caregivers need assistance and support in various aspects such as knowledge, patient care skills development, support and assistance from family members and social support. These needs reflect the gap in post-stroke care at home. The investigation into post stroke care situation brings to light the actual care that families and stakeholders concerned provide to the post stroke patients as well as the true needs of family caregivers. This information will be beneficial to the planning for support and assistance for the family caregivers to enable their continuously correct care for post stroke patients with confidence to meet the patients' basic needs and to rehabilitate them until they regain their ability to help themselves.

## **2.4 Information-Motivation-Behavioral Skills Model**

Information-Motivation-Behavioral Skills Model or IMB model was first introduced in 1992 by Jeffrey D. Fisher and William A. Fisher. The IMB model was originally established to predict and evaluate health behavior change processes associated with HIV. However, the IMB concepts can be broadly applied to predict positive health behavior change in a range of contexts, by focusing on the availability of health and disease related information, the extent of an individual's motivation to engage in health behaviors, and the presence of a behavioral skill sufficient to

encourage health-promoting behaviors (Fisher & Fisher, 2002). The concept of IMB model addresses factors contributing to health behavior changes. The key variables that stimulate behavior changes include information, motivation, and behavior skills. Each variable is discussed further below (Fisher & Fisher, 1992, 2000, 2002).

Information is the basic knowledge about a medical condition. The IMB model assumes that individuals need to be knowledgeable about the causes of disease, the importance of performing self-care to prevent acute and chronic complications, as well as effective strategies for the disease management. The information provided on individuals should contain specific and adequate details that enable individuals to follow the advice (Osborn & Egede, 2010).

Motivation is essential factor to initiate and maintain health behaviors. The factors of behavioral intentions include the person's attitude toward performing the act, social norms, and intentions to practice preventive behaviors. Following Fisher et al. (2006) and Amico et al. (2009), the motivation construct of the IMB model was comprised of two components namely personal motivation and social motivation. The personal motivation is a function of one's beliefs about the consequences of a behavior and evaluations of these consequences. The social motivation involves perceiving normative support for health behaviors and preventive behaviors. An individual will receive the social motivation from significant persons such as family, friends, and health care providers. The social motivation is to engage in health behaviors, such as having perceptions of social support. According to House (1981), social support consists of emotional support such as compliments, morale supports, care and encouragement; appraisal support such as feedback, certification or acceptance of others' behaviors; information support such as advice and information; and instrument support such as labor, money, or time. Moreover, it is believed that motivation to perform certain behavior in order to prevent health threats is most effective, firstly, when individuals perceive the severity of or their risk to the threats and believe that changing their behaviors is an effective prevention, avoidance or elimination of such threats. Secondly, when they have confidence or expectation of their ability to change their behaviors to reduce the danger. These factors lead to performing desirable health-related behaviors.

Behavior skill of the model means an individual's ability and perceived self-efficacy for performing health behaviors as well as the performance of complication prevention behaviors (Fisher & Fisher, 2002; Kelly & St. Lawrence, 1988). According to self-efficacy concept, one's perception of own power determines one's success (Bandura, 1997: p. 151-152). In other words, the belief in one's ability or self-efficacy will be translated into one's action. Self-efficacy is the belief in one's ability to successfully implement advice. Self-efficacy can be developed by different means such as copying, learning or teaching which form the foundation for actual practice. Studies conducted in the past that demonstrated the importance of self-efficacy include the study of Seminatina & O'Conner (2012) on the relationship between self-efficacy and positive aspects of caregiving by Alzheimer's disease caregivers. The study found that caregivers with high self-efficacy provide quality care to the patients. Moreover, self-efficacy is associated with positive thinking, improved control of negative effects and enhanced motivation of caregivers. Bandura (1977: p. 191-215) suggested the ways to improve self-efficacy as described below.

1) Mastery experiences are the most effective method in developing self-efficacy since it involves direct experiences. Successful performance boosts one's confidence in own capability. In other words, confidence is built of adequate skills and successful use of the skills. Individuals who acknowledge their ability are able to deal with problems will attempt to perform their duties with a view to achieving the set goals.

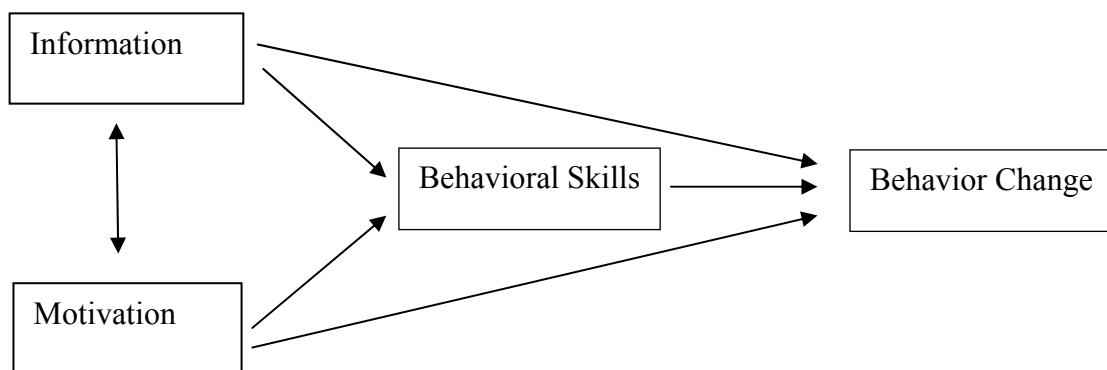
2) Modeling promotes learning from examples through observation and relating the model's behaviors to his/her success. By measuring one's ability with that of a successful model, one is more aware of one's own ability and put greater determination and effort into one's work.

3) Verbal persuasion is the use of trustworthy, successful person, who is meaningful to the individual in question to motivate and encourage him/her to succeed. The individual will take the advice and motivation into consideration and will become confident that he/she has the ability to successfully follow through on the recommendations.

4) Emotion arousal: Individuals aspire to succeed when they are positively aroused. Sometimes concerns can stimulate ability and improve the perception about

one's behaviors. Too much emotion arousal or pressure can have adverse effect and result in poor performance to the extent that the individuals feel like a failure.

The IMB model demonstrates that information is required as a prior condition for changing behavior, but in itself is insufficient to achieve this change. Motivation and behavioral skills are critical determinants of behavior change (Fisher & Fisher, 1996). Information and motivation work largely through behavioral skills to affect behavior; however, when the behavioral skills are familiar or uncomplicated, information and motivation can have direct effects on behavior (figure 2-1). Importantly, the information, motivation, and behavioral skills as the three variables of IMB model have to be specific and must directly concern to the desired behavioral outcomes (Fisher & Fisher, 2002).



**Figure 2-1:** The IMB model (Fisher, 1992)

**Implementing the IMB model to change behavior** (Fisher, Fisher, & Shuper, 2009)

There are three steps in applying IMB model in practice (Figure 2-2).

1) Elicitation is the search for empirical data and existing information about prevention information, motivation, behavioral skills and behaviors from the target population using closed-ended techniques or open-ended data collection techniques such as focus group discussions or open-ended questionnaires. The data and information acquired from this step reflects the real situation in the study setting and specific gaps in information, motivations, behavioral skills and behaviors.

2) Intervention is the step that brings data and information acquired from the elicitation phase to develop intervention and implement it with the sample population. The intervention developed corresponds to the problems of the study sites in the three aspects of the IMB model, namely information, motivation and evaluation.

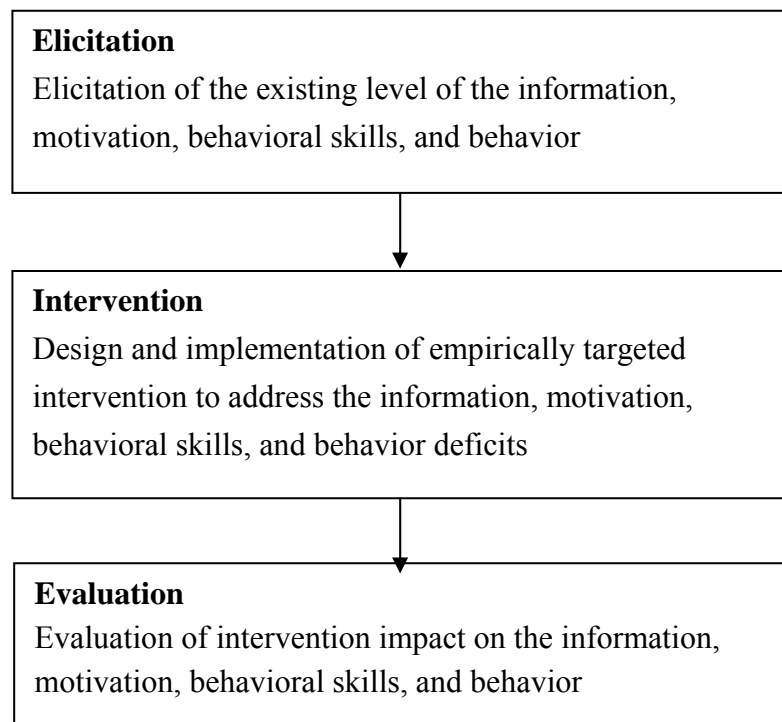
2.1) Information means the essential information unknown to the sample population; or that they needed but unable to find.

2.2) Motivation that suits the study population: personal motivation could derive from receiving moral support or encouragement from family members or people in the community and from verbal persuasion to convince them that they could perform particular behavior. This concept agrees with emotional support in social support concept (House, 1981) and with emotional arousal and verbal persuasion of the self-efficacy concept (Bandura, 1997). Moreover, personal motivation could occur from witnessing success or failure of a role model having similar attribute or facing similar situation as the study population implying that they too could succeed or fail, which agrees with modeling or vicarious experience of the self-efficacy concept (Bandura, 1997). Moreover, individuals should receive from their family, friends and healthcare providers' social motivation in terms of emotional, information, instrumental, and appraisal supports, which are in accordance with the social support concept of House (1981)

2.3) Behavioral skills may be promoted via teaching, demonstration, or viewing video and/or training followed by practice. Choice of training methods depends on the prevalent situation. Promoting individual's behavior skills agrees with the mastery experiences of self-efficacy concept (Bandura, 1997). The concept advocates direct experience through skill practice and return demonstration, upon which trainers provide feedback and advice. Individuals will then perceive their efficacy to perform the behaviors. The three aspects of motivation must be implemented together to promote behavior change.

3) Evaluation of the intervention is the final step of the application of the IMB model. Evaluation is conducted to assess changes in information, motivation, behavior skills and/or behaviors. Information could be evaluated using either closed or open-ended questionnaires that are parallel to the questionnaires used in the elicitation phase. Motivation could be evaluated by asking questions about personal attitude,

subjective norms regarding health behaviors or belief of the study population. Behavioral skills could be evaluated in various ways such as role play of critical steps in the health behaviors, use of closed-ended questions to assess self-efficacy in performing behaviors. Behaviors could be evaluated using direct measure such as self-report assessment of health behaviors and indirect measure such as health survey and complication monitoring.



**Figure 2-2:** Elicitation, Intervention, and Evaluation (Modified from Fisher and Fisher, 1993)

According to the IMB literature review, this model has been employed to study the changing health behaviors such as to promote self-management behaviors in people with diabetes (Osborn & Egede, 2010), to improve parental information, motivation, and adherence behaviors among children with sickle cell disease (Raphael et al., 2013), and to assess the effects of the IMB model-based intervention among patients undergoing a coronary artery bypass graft (CABG) surgery (Zarani et al., 2011). The studies showed that increased knowledge, personal motivation, social

support, and skill training were associated with positive health behavior change, which predicted the improved disease outcomes.

In conclusion, the IMB model is known as a theoretical model of health behavior change. The three IMB variables consist of information, motivation, and behavior skills, which lead to the outcomes of the model that focused on individual's behavioral changes. These variables can determine health behavior that an individual must be well-informed, motivated, and participated possesses of the self-efficacy behavioral skills. The IMB literature reviews show that the concept of this model can apply to induce correct and proper caring behaviors among family caregivers. Therefore, this study selects IMB model as the conceptual framework to build capacity and skills in post-stroke patient care among family caregivers.

## **2.5 Social support**

Social support is the concept that describes the structure, processes, and functions of social relationships for helping people cope with stressful situations (Glanz et al., 2002). The social support concept has been linked to many benefits for health and health-behavior change. According to review literature about definitions of social support, the meaning of this concept has been given by several researchers.

Cobb (1976) stated that social support is the information leading the individual to believe that he or she is loved, esteemed, and belongs to a network of mutual obligation.

Thoist (1982) defines social support as the condition that a person receives the emotional and social assistance or things or information that helps him be able to face with the illness or the stress more quickly.

Gottlieb (1983) defined the social support as the verbal or nonverbal information, advice, tangible aid, or activities inferred or created by the interactive process of society which these things have the emotional and behavioral effects on people who need help.

Albrecht and Adelman (1987, p. 19) defines social support as verbal and nonverbal communication between recipient and provider that help to manage uncertainty

of the situation and functions to enhance a perception of personal control in one's life experience.

According to these definitions, social support is condition or process of interaction relationship which improves person's esteem, ability to dealing with problems and helping person feel more certain in situation.

### **Types of social support**

House (1981) classified social support into four types as follows.

1. Emotional support involves the provision of caring, empathy, love and trust. The emotional support is associated with communications that meet an individual's emotion or affective needs. These are expressions of care and concern, such as sharing life experiences, listening and offering sympathy, as well as nonverbal behaviors such as facial expressions, hug, or touch.

2. Informational support refers to advice, suggestions, and needed information that a person can use to address problems. The person with an illness or health problem often needs more information about their conditions and treatment options, which can be supported by those who provide the useful information.

3. Appraisal support means the communication or information that is useful for self-evaluation purposes or the problem solving such as constructive feedback, affirmation and social comparison. This type of support refers to affirmation or expressions of agreement or rightness of some practice or point of view in health behaviors.

4. Instrumental support means the assistance and equipment services that directly assist a person in need. This type of support is associated with the various types of help such as equipment for patient care, preparing meal, housekeeping, driving to hospital, or money.

### **Source of social support**

According to four main types of social supports, an individual may need different kinds of support at different times during their treatment and recovery from different people. The sources of social supports can be obtained from various sources as following (Thiangthum et al., 2011, p. 6-7).

1. Natural support is the relationships that occur in everyday life. This support usually involves relationships with family members, friends, and neighbors.

2. Peer support refers to a person who is similar in fundamental ways and situations to the recipient of the support. A peer is in a position to offer support by virtue of relevant experiences that he or she has been successful in recovery.

3. Religious organized support is the one important factor of social support. The activities and meeting in religious are the way to motivate the belief or purpose of life and self-esteem. This mechanism in religious organized support or spiritual can be lead to a positive effect on health (Olphen, 2003).

4. Professional organized support refers to the health personal or health care providers from public health organization.

5. Nonprofessional organized support refers to health volunteers, peer groups, and the charities.

### **Social support and post-stroke care**

According to the literature reviews of social support in post-stroke care, Glass & Maddox (1992) conducted the cohort study to examine the impacts of three types of social support (emotional, instrumental, and informational supports) on the changes in functional status during stroke recovery among 44 survivors who have first-time of stroke. The changes in functional status were assessed by using the Barthel Index (BI) of activities of daily living that collected at 5 days, 30 days, 3 months and 6 months. The resulted found that the emotional, instrumental and informational supports were significantly related to post-stroke recovery of functional capacity. However, the impact of social support did not appear during the first month of rehabilitation.

Tsouna-Hadjis et al. (2000) studied the role of family social support in three stroke rehabilitation variables (functional status, depression, and social status) during a 6-month recovery period. The first-stroke patients were assessed functional status, depression, and social status before discharge and at 1, 3, and 6 months after stroke onset, in comparison with the amount of family social support received. The result found that functional, depression, and social status changes were significantly affected by higher levels of family social support. However, a significant interaction was found only with regard to functional status adjusted for initial stroke severity. The

stroke survivors with moderate or severe stroke and high levels of social support attained a significantly better and progressively improving functional status than those with less support.

In conclusion, social support means the supports provided by social relationships that affect health behaviors and well-being. An individual can receive the four types of social support including emotional interaction, the instrumental aid, the information, and the appraisal support from network in the society. According to the literature reviews of the relationship between social support and post-stroke care, it can be conclude that the social support is the key part of stroke recovery. As a result, this study selects the concept of social support as the one part of post stroke program for family caregivers. The family members and health volunteers are motivated an important of social support (such as emotional, appraisal, information, and instrument supports) to assist or support family caregivers who caring post-stroke patients at home.

## **2.6 Relevant research**

### **Relevant research on post-stroke care program**

Nessa et al. (2009: p. 62-67) conducted prospective study to determine the effects of early intervention of physical therapy on functional outcome. The objective was to compare the early intervention within first two weeks and late intervention group to determine functional outcome. Forty eight acute onset first episode stroke patients were assessed rehabilitation procedures started immediately after attending the Department of Physical Medicine and Rehabilitation. According to a comprehensive rehabilitation plan was continued for eight weeks with appropriate education to the patients and attendants. A comprehensive rehabilitation plan was made consisting of different physical therapies such as IRR (Infra-red radiation) on the affected side of stroke, exercise, speech therapy, supportive equipment, and occupational therapy. Moreover, proper mouth care, skin care, bowel and bladder training for bed ridden patients were prescribed and maintained. The result showed significant improvements ( $p$ -value  $< 0.001$ ) in early treatment group of patients. However, the study concluded that there are inadequate facilities for inpatient

rehabilitation and also lack of qualified personnel for domiciliary treatment of stroke patients. Stroke units with specially trained medical and nursing staff, coordinated multidisciplinary rehabilitation approaches and education program for patients and their families are needed to achieve better outcome.

Cramp et al. (2010) studied the effectiveness of a community-based low intensity exercise program for ambulatory patients with stroke discharged from rehabilitation. Eighteen participants were recruited 3–12 months after onset of first stroke for training. The exercise program was delivered at rehabilitation centers for 14 weeks with physiotherapy support and the minimum attendance requirement was 16 sessions. Measures included muscle strength, gait velocity, Berg Balance Scale and Nottingham Extended Activities of Daily Living. A single group repeated measures at difference three times at baseline, two weekly intervals, and after cessation of exercise. The study found that lower limb muscle strength, paretic knee extension strength, walking velocity, balance, and everyday function were significantly improved. The study concluded that this community-based exercise program was feasible and delivered positive improvements in physical function for participants. The study suggested that further issues should increase investigation of the individual response to training and the benefits of extended training.

Galvin et al. (2011: p. 681-686) conducted the Family-Mediated Exercise Intervention (FAME). The randomized controlled trial was designed to examine the impact of FAME on outcome after stroke. Forty participants with acute stroke were randomly assigned to either a control group who received routine therapy with no formal input from their family members or an experimental group who received routine therapy and additional lower limb FAME therapy for eight weeks. The outcomes of the program emphasized on achieving stability and improving gait speed and lower limb strength. The outcome measures of impairment, activity, and participation were completed at baseline, after intervention, and at a three month follow-up. The study found that there were statistically significant differences in the FAME group on all measures of impairment and activity after intervention ( $p$ -value  $< 0.05$ ). These improvements persisted at the three month follow-up but only walking was statistically significant ( $p$ -value  $< 0.05$ ). Participants in the FAME group were also significantly more integrated into their community at follow-up ( $p$ -value  $< 0.05$ ).

Family members in the FAME group reported a significant decrease in strain levels at the follow-up when compared with the control group (p-value < 0.01).

Danzl (2013) conducted the developing the Rehabilitation Education for Caregivers and Patients (RECAP) model. The objective of this study was to develop a model of rehabilitation education for caregivers and patients in the context of physical therapy and stroke rehabilitation, grounded in the experiences and perceptions of stroke survivors, their caregivers, and physical therapists. The study used qualitative research methods with a novel grounded theory approach. Semi-structured interviews were conducted with 13 stroke patients and 12 caregivers from rural Appalachian Kentucky that was area with high incidence of stroke and lower levels of educational attainment. The 13 physical therapists representing inpatient rehabilitation, outpatient, and home health, were recruited and participated in reflection activities and interviews. The theory generated from this study was physical therapists continually assess the educational needs of stroke survivors and caregivers to participate in dynamic educational interactions that delivered through diverse teaching methods and skilled communication. This phenomenon occurred within the context of the physical therapist's professional responsibility, the multidisciplinary team, a complex healthcare system, and the environmental and socio-cultural context.

McAdam1 et al. (2013) studied "Evaluation of a rehabilitation support service after acute stroke: feasibility and patient/carer benefit". The objective of study was to explore the feasibility of delivering and evaluating enhanced support to stroke survivors and their carers, with a Rehabilitation Support Worker (RSW) from the charitable care organization. The sample was composed of 16 stroke survivors and their carers over an 18-month period. Seven of patients and their carers in the control group received the usual care, rehabilitative care, and discharge planning. In the intervention group, nine patients and their carers received both usual hospital care and support from an RSW. The RSWs were trained the basic care covering the medical, physical and social aspects of stroke. After discharge, the RSW visited the patient and carer at home over the first 6 weeks to support them in practicing rehabilitation skills and finished visiting the patient at the end of the 6 week period. The results showed that participants' functional ability at week 1 was significantly higher in the intervention group. The functional ability was not significantly different between

groups at 6 and 12 weeks after discharge. Carers in the intervention group were less confident at three time points; however, this was not significant. There was no significant effect on carer strain or well-being. This finding suggested that the intervention designed should focus on specific needs of carers and clear about the process of providing support. Furthermore, the study revealed the obstacles that need to be overcome, including difficulty in identifying suitable patients, clarity of the RSW roles, and appropriate training content.

In conclusion, the literature review of post-stroke care programs abroad reveals that most studies use community-based theory as the study framework and focused on promoting physical therapy. Among the methods used are information dissemination; physical therapy skill building amongst patients and attendants; provision of comprehensive rehabilitation including exercise, speech therapy, supportive equipment and occupational therapy for patients during their follow-up visits at the rehabilitation department; and delivery of rehabilitation to home. In case of the latter, the volunteers conducting home delivery of rehabilitation were trained for enhanced knowledge and improved skills in basic care and physical rehabilitation to enable them to assist post-stroke patients and their family caregivers after their discharge from hospital. These activities were organized over 6-14 weeks beginning before the discharge or within the first two to six months after the discharge. Most studies find that early rehabilitation yields better results than delayed rehabilitation. The strengths of post-stroke patient care in other countries include the availability of rehabilitation center in the community which provides patients easy and quick access to the services, and the collaboration of the multidisciplinary team. Their problems and obstacles are the need for knowledge and skills specific to patient care and rehabilitation at home amongst rehabilitation support workers. These support workers are volunteers assisting and supporting caregivers in patient care. Their comprehensive knowledge and skills in patient care will enable them to provide proper support to caregivers in managing problems in patient care. Moreover, most studies suggest needs assessment of both patients and caregivers so as to be able to provide activities that meet their needs.

### **Relevant research in Thailand**

Sangngam A. (2006) studied the development a home-based rehabilitation program for primary caregivers of stroke patients. The objective of this research was to develop a home-based rehabilitation program by using the concept of Evidence-Based Practice model. The ten relevant researches and empirical evidences were categorized and synthesized to result in developing a home-based rehabilitation program that consisted of three phases. Phase one, the process of preparation was covered problems assessment, finding needs of post stroke care, and plan for problem solving. Phase two was the proceeding activities that composed of home visit and knowledge and skills training one time/week for six weeks, include care planning together with primary caregivers, information and emotional support, and rehabilitation training. Phase three was evaluation the patient's daily activities and caregiver's participations, including needs of stroke care at home, knowledge, general health status, and quality of life of family caregivers after six weeks. Beside, readmission rate of stroke patients was evaluated at three months after program. The recommendations for further implementation were conduct a clinical trial to test the effective of the program and development networking of people who have interest in home-based rehabilitation program for primary caregivers and stroke patients. Furthermore, health care providers have to access various stage of post stroke prior to a home-based rehabilitation program for appropriate interventions.

Oupra et al. (2008: p. 1-7) studied the effect of a community based rehabilitation program on outcomes for stroke survivors in Thailand. The aims of the study were to develop and implement the Supportive Educative Learning Program for Family Caregivers (SELF), to evaluate the effect of the SELF program on functional ability of stroke survivors, and to reduce the incidence of complications among stroke survivors. This study was a comparative study by using a two-group pretest and posttest design. The intervention groups received SELF training program that composed of education sessions, hands on training for family caregivers, a booklets and three follow-up phone calls. The findings revealed that stroke survivors in the intervention group scored better for functional outcome at three months follow-up, and had fewer readmissions for the management of stroke related complications. This research demonstrated that a structured rehabilitation skills education program for

family caregiver of stroke patients can significantly improve the functional status and prevent the common complications.

Ruttawongsa & Kongtalin (2011: p. 670-679) used the chronic care model as a framework to conduct the developing a community-based continuing home care management guideline for stroke survivors initiated by the home health care center of Kosumpisai hospital and network. The aims of study were to develop the continuing care for stroke patients and promote the surveillance and prevention of stroke in the community based on community participations. The 97 participants were composed of 23 stroke patients, 23 primary caregivers, 35 community health volunteers, and 16 health providers from all relevant sectors. The in-depth interviews and Assessment of Chronic Illness Care Forms were used for gathering baseline data and the quality of care for stroke. The home care management guideline was developed in the issues of knowledge, skills, an effective referral system, local policy, and community stroke surveillance and prevention activities. The study found that the quality of care for stroke score was increased from 5.8 to 7.8 points. The participants expressed satisfaction for continuing stroke care at 87.9 percent.

Srijumnong (2010) studied the effects of self-efficacy promotion program for family caregivers of persons with stroke at home. The study was a quasi-experimental research and aimed to determine the effects of self-efficacy promotion program on for the perceived self-efficacy of family caregivers, who caring for stroke patients,, on their perceived of self-efficacy, as well as the expected outcome expectation of stroke care, their satisfaction with the program, and readmission rate. The study sample was 30 family caregivers of patients who were diagnosed with stroke. The study used purposive sampling in selecting the study sample and employed self-efficacy concept of Bandura which covered training before patient discharge, home visit and advice giving and consultation via telephone calls. The program was implemented for six weeks with additional two weeks follow-up. Data was collected using questionnaire and telephone interviews and evaluated by comparing the differences in perceived self-efficacy of family caregivers and expected stroke care outcomes. The evaluation was done six weeks prior to the study and in the eighth week after the study. It was found that the perceived self-efficacy and expected stroke care outcome scores in the eighth week of family caregivers were statistically

significant higher than those of the sixth week ( $p$ -value  $< .01$ ). Most family caregivers were highly satisfied with the program and patients who received care from the participating family caregivers were not readmitted within 28 days. This program should therefore be implemented further to organize activities for family caregivers to continuously increase effectiveness in patient care.

Piumboriboon & Pongcharoen (2011: p. 4-21) used descriptive research study to develop care model for stroke patients in Chaopraya Yommaraj Hospital in Supanburi Province. The study used purposive sampling to select three groups of study samples namely 80 stroke patients, 80 primary caregivers and 11 multidisciplinary team personnel members from eight professional fields. The tools used included stroke knowledge test questionnaire for caregivers, Barthel ADL index evaluation, and satisfaction survey for caregivers, patient care performance evaluation forms for multidisciplinary team members and interview guides for multidisciplinary team and caregivers. The study consisted of three stages, including 1) development of stroke patient care model, 2) implementation of the model and 3) evaluation of the model. It was found that most the studied patients had the average score for their ability to do most daily activities by themselves 30 days after hospital discharge ( $\bar{x}$ = 75.08, SD = 23.890). The average score to do daily activities 30 days after hospital discharge is statistically significant higher than the score before hospital discharge ( $p$ -value  $<0.001$ ). Caregivers had the highest average score on stroke knowledge before hospital discharge ( $\bar{x}$ = 9.15, SD = 0.936) which is statistically significant higher than their score at admission ( $p$ -value  $<0.001$ ). Caregivers also highly satisfied with the services of the multidisciplinary team ( $\bar{x}$ = 34.23, SD = 2.061). Moreover, the multidisciplinary team was able to fully implement the care program and highly satisfied with the results. The researcher recommends that this study promote the roles of nurses in managing and rehabilitating stroke patients.

Tomaneepitak (2011) studied the development of a clinical nursing practice guideline to enhance caregiving knowledge and skill, and problem-solving skills in caring for stroke patients at home. The researcher used evidence-based practice model of Soukup (2000) which consists of four phases, namely evidence-triggered phase, evidence-supported phase, evidence-observed phase and evidence-based phase. This study implemented only the phase one, evidence-triggered phase,

and phase two, evidence-supported phase. The study investigated nine empirical evidences in the relevant areas, namely systemic review, meta-analysis study, randomized control trial, quasi-experimental study, and qualitative study. The evidences collected were then analyzed and synthesized to develop a clinical nursing practice guideline. This guideline was then implemented over a 13-week period in three phases: 1) preparation phase; 2) implementation phase which included four home visits to assess problems and needs in patient care, to promote knowledge and to enhance the skills in patient care and problem solving, as well as six phone calls to monitor the practice of problem solving skills; and 3) evaluation phase to evaluate the caregiver's performance, stress level and depression. The results of the study led to the recommendation for trial implementation of the clinical nursing practice guideline through coordination with the health care teams concerned and integration into the respective home visit plans. Both the process and the outcomes should be evaluated to further improve and develop the guideline to better suit the context of the health care units and the communities concerned.

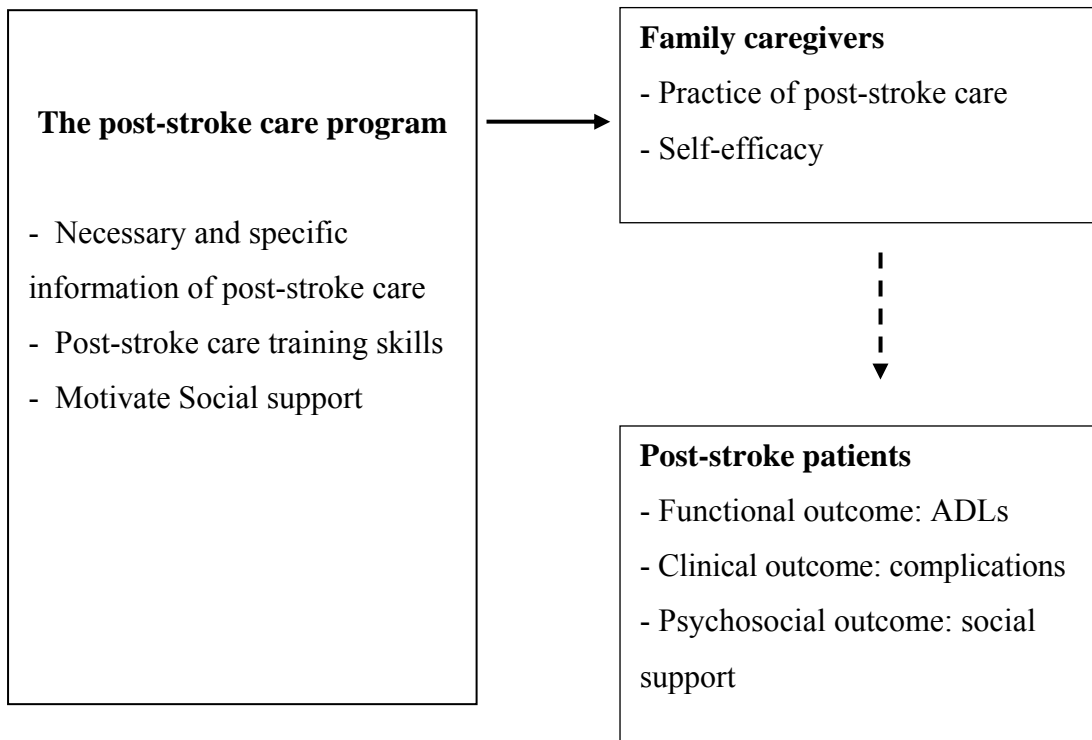
According to the review of relevant literatures on post-stroke care program conducted in Thailand, most studies focused on developing home-based and community-based rehabilitation programs by using evidence-based practice model and chronic care model as the conceptual framework. There was a study on self-efficacy promotion program using Bandura's self-efficacy concept. The studies investigated, analyzed and synthesized relevant researches and empirical evidences, then further used the collected data to develop home-based rehabilitation program. The program consisted of three phases, 1) problem and needs assessment for post-stroke care which contributed to the development of patient care model, 2) implementation of the post-stroke patient care model, and 3) evaluation of the program results. Activities were organized over 6-13 weeks, mostly once a week for six weeks. Included in the activities were patient care education and skill building particularly in physiotherapy, home visits, joint patient care planning with primary caregivers, information support and telephone consultation. The evaluation covered patient's ability to do daily activities, quality of life and readmission, as well as caregiver's recognition of their roles and responsibilities, general health status, self-efficacy and satisfaction. In general, the evaluation was conducted at three intervals, i.e. prior to program

implementation, right after the implementation, and two weeks after the implementation. The study showed that patients had higher scores for the knowledge and the ability to do daily activities by themselves and lower readmission rate. Caregivers and multidisciplinary team members were satisfied with the program. Most studies suggested that post-stroke patient care program be developed to fit with the community's context, community's participation be promoted, and coordination with health care teams concerned be included. To further improve patient care guideline, a program evaluation was also recommended. It was also found from the literature review on post-stroke care that most home-based rehabilitation program developed from evidence-based practice model had not yet been tried. Program development in the past therefore remained only at phase one.

The review of relevant literatures above indicates that there has been no study that focuses on concretely promoting necessary practical skills in patient care amongst family caregivers. Therefore, the researcher is interested in developing a practical post-stroke care skills program for family caregivers with a focus on developing skills in assisting patients to do daily activities, preventing complications, preparing foods and assisting with drug administration, including other specific activities such as feeding, urine catheter care and wound dressing, and physiotherapy. The program will be developed based on the IMB model to encourage family caregivers' favorable behavioral changes to ultimately promote optimal recovery of the patients.

**Independent variable**

**Dependent variables**



**Figure 2-3:** Conceptual Framework

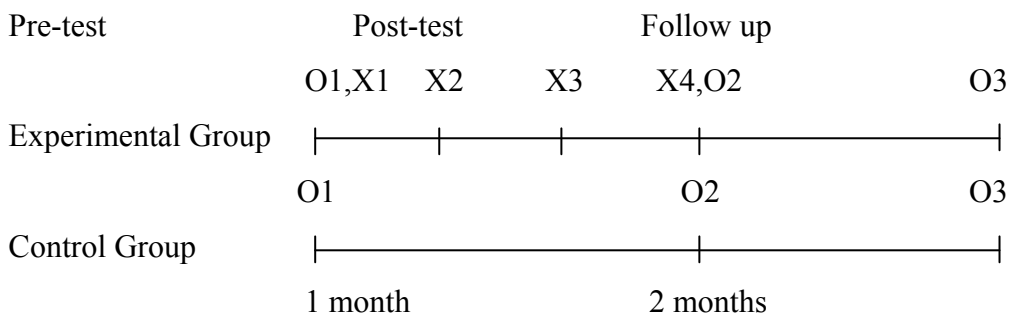
## CHAPTER III

### METHODOLOGY

This chapter presents the research design and methodology adopted in the development of post-stroke care program for family caregivers. The methodology includes research design, setting, participants, protection of human rights, research procedures and data collection, research instruments, and data analysis.

#### 3.1 Research design

The study utilized a quasi-experimental design to examine the effects of the post-stroke care program on family caregivers' and patients' outcomes. The experimental group received the post-stroke care program while the control group received routine care from the sub-district health promotion hospitals (SHPHs). The timeframe for data collection and intervention is shown as follow.



O1      observed and measured practices of post-stroke care and self-efficacy in family caregivers.

O2      observed and measured practices of post-stroke care and self-efficacy in family caregivers and ADLs, complications, and social support in post-stroke patients in both groups immediately upon the completion of the intervention program.

O3 observed and measured practices of post-stroke care and self-efficacy in family caregivers and ADLs, complications, and social support in post-stroke patients in both groups at two-month follow up.

X1 referred to week 1 of the post-stroke care program: the essential and specific information and practices of skills for post-stroke care at home which were given to the experimental group.

X2 referred to week 2 of the post-stroke care program: reviewed the information and returned demonstration of the practices of post-stroke care which were given to the experimental group.

X3 referred to week 3 of the post-stroke care program: reviewed the information and returned demonstration of the practices of post-stroke care which were given to the experimental group.

X4 referred to week 4 of the post-stroke care program: home visit which was given to the experimental group.

### **Research setting**

The study was conducted in Muang, Phran Kratai, Khlong Lan, and Sai Ngam districts in Kamphaeng Phet Province, since there were the largest number of stroke survivors and similar socioeconomic contexts and health care service provision of the SHPHs.

## **3.2 Population and samples**

The samples in this study were family caregivers and post-stroke patients. There were eleven districts in Kamphaeng Phet Province, four of which had the highest number of stroke patients. The simple random sampling was used to divide the four districts into two experimental and two control groups. In each month, there were approximately 10 to 20 stroke patients discharged from the Kamphaeng Phet hospital. There were about 3 to 7 pairs of the patients and family caregivers who met the inclusion criteria (Appendix B).

**Inclusion and exclusion criteria were listed below.****Inclusion criteria****Family caregivers**

Family caregivers were recruited in this study with the criteria of: 1) the primary caregivers, 2) being able to communicate in Thai language, 3) living in Muang, Phran Kratai, Khlong Lan, and Sai Ngam districts, Kamphang Phet Province, 4) living in the same house with the post-stroke patient, 5) willing to participate in and throughout the study period, and 6) willing to give informed consent to participate in the study.

**Post stroke patients**

Post-stroke patients were recruited in this study with the criteria of: 1) being able to communicate verbally or nonverbally, 2) living in Muang, Phran Kratai, Khlong Lan, and Sai Ngam districts, Kamphang Phet Province, 3) having the first episode of stroke attack 4) being discharged from the hospital within one month with moderately severe disability according to the Modified Ranking Scale (Van Swieten et al., 1988), 5) no complications, and 6) willing to participate in the study.

**Exclusion criteria****Family caregivers**

Family caregivers who were ill and unable to participate in the study.

**Post stroke patients**

Post-stroke patients who had severe complications, re-admission, or a severe progressive condition to death.

**Discontinuation criteria**

Family caregivers and post-stroke patients were asked to discontinue their participation in the study when

1. They had been unable to attend the activities rather than twice,
2. The family caregiver had been replaced,
3. They moved out of the area where had been conducting research, or
4. They decided to quit participating in this research study.

### Sample size

The sample size for this study was calculated by using power analysis (Glass, 1976: p. 3-5) as shown below.

$$d = \frac{\bar{X}_E - \bar{X}_C}{SD_C}$$

d = Effect size

$\bar{X}_E$  = Mean score of experimental group

$\bar{X}_C$  = Mean score of control group

SD<sub>C</sub> = Standard deviation of control group

The approximate sample size was determined based on statistical power, significance of .05 and desired power of .80. The power analysis is based on a study of the effect of a supportive education program on knowledge, perceived self-efficacy, and strain from worry regarding caregiving among caregivers of stroke patients (Rattanasit, 2004: p. 48). Study findings indicate that the mean perceived self-efficacy score in the experimental group was 69.36; the mean score in the control group was 56.36 and the standard deviation in the control group was 10.24.

$$d = \frac{69.36 - 56.36}{10.24} = 1.26$$

From the calculation, the effect size, 1.26, was used to estimate the sample size ( $\alpha = .05$ , power = .80) using the Power Table (Cohen, 1988: p. 55). The minimum number of the sample size for a group was 26 samples. A study of a residential care for stroke rehabilitation indicated that the attrition rate was 17.6% (Chau et al., 2013). For this study, the calculated sample size was inflated 20% to compensate for potential missing or incomplete data (Boswell & Cannon, 2011: p 156). Using power analysis and taking into account attrition, the final sample size was 31 in each group.

However, at the beginning of the screening process, there were the post-stroke patients and their family caregivers who met inclusion criteria 31 pairs of the experimental group and 33 pairs of the control group. Two patients of the control group passed away before the first posttest. Finally, there were 31 pairs in the experimental and control groups.

### **3.3 Research procedures and data collection**

The research procedure was based on the Information Motivation Behavioral Skills (IMB) model divided into three steps (Fisher, Fisher, & Shuper, 2009) including 1) elicitation, 2) intervention, and 3) evaluation.

#### **Step 1 Elicitation**

The initial step was elicitation to explore and draw out the facts of the existing post-stroke care in community. Based on literature review and studying a situation of post-stroke care in Kamphang Phet province, the draft of post-stroke care and social support program was developed by the researcher. However, the elicitation step constructed to improve the program for more appropriate intervention with the context of post-stroke care in the research setting. The elicitation was conducted with the family caregivers, stroke survivors, and health providers, to empirically identify the specific deficits and assets in post-stroke care's information, motivation, and behavioral skills. All family caregivers and their post-stroke patients who were discharged from the Kamphang Phet hospital during September 2015 were recruited in the elicitation step. They were in-depth interviewed and observed until the data saturation.

The researcher explored the existing post-stroke care in community by in-depth interviews, observing and field note taking, and focus group discussion.

#### **1) In-depth interviews**

The semi-structured in-depth interviews with seven family caregivers were conducted to encourage the family caregivers share their experiences on how to provide post-stroke cares at home, the problems and barriers, and needs for assistances. Their age ranged from 24 to 62 years. Two of them were daughters, another two were sons of stroke survivors, and the rest were wife, mother, and niece. The individual interviews were audio records for subsequent transcription and lasted approximately 45 minutes.

The family caregivers revealed that their roles and functions of caring the after stroke patients consisted of assistances the activities of daily living, food preparations, feeding, medication managements, moving patients, and rehabilitation. Before discharge, the health care team in hospital provided them some knowledge

about the patients' medication, appropriated food for stroke survivors and feeding, rehabilitation, and medical appointment; however, this information was not enough to care patients at home. Most of them felt overwhelmed with lots of information of the hospital's discharge plan. Two of them were not able to remember all of the information. In addition, the family caregivers expressed that they lacked of confidences in practicing post-stroke cares. All of them did not have previous experiences regarding caring for stroke survivors. The family caregivers had to deal with many difficult tasks of caring for post-stroke patients including the emotional changes. For exemplars,

*"I could not remember all advices from the hospital. Each day, my duties are assisting my grandmother for bathing, dressing, feeding, turning her from side to side on the bed, and changing diapers. Also, I help her do rehabilitation by lifting her arm and leg once a day, but not every day. I'm not sure that I do it right or wrong for physical rehabilitation. Because I have many things to do and many times I practice cares to her in a rush."* (Niece, 30 years old)

*"I quit my job to care my mother. It is my first time to look after the post-stroke patient. I have to deal with many tasks in each day. My duties are not only caring tasks but also the housework. My older sister and brother assist me in moving mom, some housework, and financial support. Sometimes, I pay for the massager 300 baht per time, who is the village health volunteer, to massage my mom. It is quite expensive and is not much help."* (Daughter, 32 years old)

*"I feel like I have no confidence on the caring tasks, especially how to move my husband from bed to wheelchair and how to do physical rehabilitation. I feel exhausted and overwhelmed with many responsibilities."* (Wife, 47 years old)

Regarding the family caregivers' responsibilities and the experienced problems, they needed necessary information and methods of post-stroke care such as the early recovery, complication prevention, patient mobility, and rehabilitation. Furthermore, they needed social support to enable them to care after patients having stroke appropriately and continuously, from family members and health care providers. For exemplars,

*"I want my son get arms and legs (his weak side) better. Could you please advise me? To date, I do everything that I think it can help him to get back to normal. I*

*do exercise for his arms and legs about 2-3 times per week and bring him to the private medical clinic for treatment. Does he get back to normal? When he has a full recovery?” (Mother, 54 years old)*

*“After the hospital discharge, I try to provide the practical cares to my mother as the doctor’s and nurse’s suggestions. However, many caring activities are harder than I thought. The more I do, the more I have low confidences in caring, especially on two weeks. I am so reluctant whether it is right or wrong of the care method. How can I help her to recover soon?” (Son, 52 years old)*

*“When he first left the hospital and came home, he had sores in his bottom. I took him to the hospital every day for dressing until they were completely healed. He did not have any sore, I think; I didn’t really notice any. He spends most of his time each day in bed. I help turn him over from time to time but he does not cooperate. He always scolds me and tells me to leave him alone. I do encourage him to turn over from side to side by himself, but he rarely does it.” (Wife, 47 years old)*

## **2) Observing and field note taking**

The researcher visited seven families with the post-stroke patients and the family caregivers at their homes. The stroke survivors were observed about symptoms of post-stroke, complications, personal hygiene, the environment of stroke survivors unit where they lived or slept, and receiving social supports from family caregivers and healthcare providers. Furthermore, the family caregivers’ practices of post-stroke care were observed that included disinfection care, feeding and aspirated prevention, patient mobility, and rehabilitation. Field notes were taken during observations and interviews.

Six to eight month observation of post-stroke patients aged between 40 and 86 reveals that most of them had moderately severe disability. They were discharged without having been provided medical appliances such as tracheostomy tube, NG-tube feeding, and/or urinary catheter. Complications that the patients had included joints (shoulder, knee, hip) stiffness and pressure ulcer around the tailbone. Some patients had bruises in their arms and legs from falling. In terms of their personal hygiene, it was observed that most patients had good hygiene. Only some had poor

hygiene such as having food scraps interproximal space of their teeth, bad breath, disheveled hair, long and dirty nails and scurf around joints.

As for the living environment, it was found that the interior home improvement to suit the patient's condition and accommodate patient care varies from family to family. Some enabled to arrange for the patients to sleep downstairs and install railing in the bathroom; whereas others neither made any improvement nor took care of the patients' unit. The sleeping area was dirty, bed sheet and pillow case were stained, all windows in the bedroom were closed, hence poor ventilation and stench. Moreover, it was also observed that the patients' living unit was dimly lit and cluttered thereby putting the patients at risk of tripping and falling.

Social support from family caregivers: as observed emotional support provided by caregivers in the form of encouraging words, hugs and holding hands made the patients smile and tear up. According to the experiences shared by the patients during the observation, it was learnt that the caregivers always gave verbal support particularly when they first came back home after hospital discharge. However, as time goes by, verbal support lessened to nil. Moreover, it was observed that most caregivers carried on with their routine works without providing information that is necessary to the patients such as rehabilitation time during post-stroke phase, encouraging early recovery and informing patients the proper self-conduct for early recovery. Nor did they appraise the patients' physical exercise performance while encouraging them to carry out the exercises on their own. Nonetheless, caregivers did provide instrumental support such as pulleys for arm exercise and bamboo railing to support walking. In some families there were other family members who occasionally helped the main caregiver in lifting or moving the patient, doing house chores, taking the patient to see doctor when they had doctor's appointment or giving money to the main caregiver to help with expenditures incurred such as food or equipment or materials required for caring of the patients.

Social support from health care providers: According to the patients and family caregivers, it was found that village health volunteers (VHVs) visited the patients at home mainly when they knew that the patients had been discharged from hospital. The patients who had relatives as volunteers or lived near by a volunteer would receive a home visit within one week. Others would be visited at home only

when the volunteers were informed by public health nurses (PHNs) and usually delayed. As a result, some were visited at home two months after hospital discharge or never. During home visit, the volunteers and/or PHNs provided verbal emotional support. Most volunteers did not provide information necessary for patient care and rehabilitation. They only asked about patient's condition in general and inform PHNs accordingly. Only a few cases were patients and their caregivers given necessary information and appraisal support by PHNs during home visit. For example, the PHNs would recommend the patients be turned to the other side or put in different positions in bed every two hours when they assessed that the patients were at risk of developing pressure ulcers from lying in the same position for a prolonged period. In terms of instrumental support, some patients' family borrowed a wheelchair, a patient bed, a cane or a walker from sub-district health promotion hospital (SHPH). These equipment must be returned when the patients are recovered or almost fully recovered.

Observation of family caregivers' skills in caring for post-stroke patients reveals their incorrect disinfection care of pressure ulcers and unsuitable meal planning resulting in the patients being daily fed with porridge with minced pork without vegetables. Moreover, the food was sometimes served in big pieces. In addition, the patients were fed not in fully sitting up position and were assisted to lie down immediately after meal which put them at risk of choking. In terms of patient mobility, it was found that patients were transferred incorrectly. For example, patients were dragged upward on the bed or to the side of the bed, were pulled by their arms to sit up and pushed in the back to lie on their side. Most family caregivers did not perform physical therapy for the patients correctly or did not complete all the steps. For example, they did not exercise all joints, did not assist the patients to work on their balance when they sat or stood up. It was also observed that the caregivers did not motivate the patients for early recovery but usually left them lying in bed almost all day long and let them have their way should they decide against physical therapy or practicing sitting or standing up.

### **3) Focus group discussion**

The focus group discussion aimed to explore the current post-stroke care in the community and the problems and barriers. The focus group discussion was

conducted in the health promoting hospital divided into two groups. All discussions were audio recorded and field note taken and lasted approximately one hour in each group.

Group 1: The health care providers of the Naimuang sub-district Health Promoting Hospital (SHPH) comprised of three public health nurses and two public health technical officers. The questions focused on the existing health care services provided to stroke survivors in their community, and the problems and obstacles faced.

The focus group discussion revealed that all HPHs in Kamphang Phet province had the same guideline of caring the patients after stroke. The post-stroke patient care guideline suggested that health care providers of the HPH should conduct the patients' home visit at least one time within the first month after hospital discharge. After the first home visit, the health care providers would consider the other times of home visit upon the patients' conditions. Activities during home visit included assessing patient's condition and problems, assessing their ability to carry out daily routine and providing suggestions relevant to patient's condition or risks of developing complications such as recommending lying alternately on different sides to prevent pressure ulcer, pressure ulcer care, physical therapy, and need responsive nursing care such as how to re-insert NG tube if the patient pulled it out, how to change NG tube, urinary catheter and urine bag every month or every three months for example. The home visit was ended when the patient needs minimal assistance or 15-19 scores of the Barthel Index of daily activities of living. However, the health care providers revealed that it is very difficult to follow the guideline completely because of the shortage of human resources and the delay referral patient's documents from the hospital. For examples,

*“In general, the first home visit of after stroke patients was belated. We cannot follow the patients at home within the first month after hospital discharge as the guidelines' recommendation because of the shortage of human resources and the delay referral patient's documents. Normally, home visit was conducted about one or two times depended on the patient's symptoms and conditions, by the first home visit at the second or the third month after the patients have been discharged.”*

*“Nursing care provided was mostly recommendations or care in response to the symptoms or problems facing the patients. For example, caregivers were shown proper dressing, recommended to change patients' bed position at least every two*

*hours, advised on medication and encouraging the patients to do physical therapy. Sometimes volunteers or caregivers would request a nurse at SHPH to change NG tube, Foley catheter or urine bag at patient's home."*

*"The Naimuang sub-district HPH has responsibility in 12 communities. Three nurses of the HPH have many responsibilities, for instance, health promotion, maternal and child health, and elderly care. So, we will assign the village health volunteers to help us to follow the post-stroke patients at home. I accept that it was difficult to follow the post-stroke patient guideline of the HPH."*

Group 2: The Village Health Volunteers (VHVs) comprised of ten members by representatives from the two Naimuang sub-district Health Promoting Hospitals (SHPHs). The questions consisted of the participants' perception of the roles and responsibilities when stroke survivors had been discharged from the hospital and returned to their respective communities, as well as the problems and barriers.

The VHVs perceived that their duties on the after stroke patients care were following the patients' symptoms by home visit, reporting the information of home visit to PHNs, and coordination with the SHPH to support the necessary medical equipment for the patients. Many VHVs had attended the knowledge training of chronic illness care of DM, HT, and stroke, the elderly care, the caring for patients with bed ridden, and the long term care. However, they viewed that they might have insufficient knowledge of post-stroke care and recovery. For examples,

*"The PHNs will inform me by phone calling of the home visit for the after stroke patients to follow the patients' symptoms and their needs of assistances. I will report the patients' information to the PHNs immediately after the end of home visit. However, I would like the PHNs participate in each time of visiting the post-stroke patients at home."*

*"When we (volunteers) arrive at patient's home, we talk to them and observe their conditions to see if they have any abnormal symptoms or complications. We also recommend them to sit up occasionally, not lying down all the time and recommend them to do physical therapy every day. We try to give moral support to both the patients and their caregivers. In case of problems, we'll inform the nurse. We also ask the patients and caregivers if they need help with anything. Some need wheelchair or walker. We then coordinate with the SHPH to borrow the needed*

*equipment for use in patient's home. Since there's only limited number of equipment we sometimes raise funds to buy it for the patients who really need it."*

*"I have been trained about the elderly care and the caring for bedridden patient. But, generally, the contents we reemphasized on the basic of caring patients in each training course. I never had the skill training. When I had to take care of the patients or advise the caregivers, I feel reluctant to do so."*

From focus group discussion, it was found that the community played a role in supporting post-stroke patient care. Patient's relatives, neighbors, community leaders, and/or volunteers would visit them to follow up on their health and living condition as well as to give moral support or to provide equipment needed for physical therapy or walking aid, or informing health care providers at the SHPH about the patient's and caregiver's need for support.

Elicitation step provided empirical data of actual situation within research setting, which can be categorized into three areas based on IMB model – Information, Motivation and Behavioral skills. The findings under each area can be summarized as follows: 1) Information: prior to patients' discharge caregivers received general information about post-stroke patient care, specifically regarding proper diet and feeding, medication, physical therapy, and follow-up appointments. In reality, patient care is complicated and the knowledge provided proved to be inadequate for proper care for the patients. Since some caregivers could not remember all the details received from the hospital, a refresher session and additional information about post-stroke care are required; 2) Motivation: owing to encouragement and equipment support from patients' relatives, neighbors, volunteers, and healthcare providers at the SHPH, family caregivers were motivated to care for the patients particularly right after the patients' discharge from the hospital. Family caregivers also received financial support from family members which motivated them to care for the patients; and 3) Behavioral skills: caregivers were not confident to provide care and did not care for patients correctly and properly where feeding, pressure ulcer prevention and care, prevention of falling, moving patients and carrying out physical therapy are concerned. Moreover, social support: post-stroke patients need ongoing supports of encouragement, medication and rehabilitation instrument, necessary information, and appraisal from family caregivers and healthcare providers.

These findings indicated that family caregivers did not receive adequate information, motivation, and behavioral skill about post-stroke patient care and thus did not care for the patients correctly and properly. They lacked confidence in providing care and thus became discouraged to continuously care for the patients. They also lacked awareness of the importance of providing social support to the patients. These findings were used to develop interventions for post-stroke care program.

**Table 3-1** Summary of the consistency between the information obtained from elicitation step and literature review

<b>Elicitation</b>	<b>Literature review</b>
<p>1. Information</p> <ul style="list-style-type: none"> <li>- Family caregivers had insufficient information of caring the patients after stroke.</li>   <li>- They needed the necessary and specific information about the methods of stroke recovery and prevention of complications.</li>   <li>- Most of them felt anxieties about the patients' symptoms and recovery.</li> </ul>	<ul style="list-style-type: none"> <li>- The previous studies in Thailand revealed that family caregivers frequently received an inadequate preparation of knowledge and skills and confessed to lacking confidence to care for post-stroke patients (Oupra, R., Ruengkhome, C., Wongpalee, J., &amp; Kantawong, E., 2008; Jullamate P, De Azeredo Z, Paul C, Subgranon R., 2006)</li>   <li>- In caring for post-stroke patients, caregivers should have knowledge about physical care, psychological care, food preparation and nutrition for post-stroke, medication, rehabilitation, and complication prevention (King, Ainsworth, Ronen, &amp; Hartke, 2012; Cameron &amp; Gignac, 2008).</li>   <li>- The issues of emotional and stress management are required for caregivers to reduce their anxiety and stress (Morrist et al., 2011).</li> </ul>

**Table 3-1** Summary of the consistency between the information obtained from elicitation step and literature review (cont.)

<b>Elicitation</b>	<b>Literature review</b>
<p>2. Motivation</p> <ul style="list-style-type: none"> <li>- Family caregivers lacked of motivation to provide early recovery and continuing post-stroke care.</li> <li>-Stroke survivors were not motivated to early recovery and they needed social supports from their family caregivers and health care providers in the aspects of encouragement, rehabilitation instrument, necessary information of stroke recovery, and appraisalment.</li> </ul>	<ul style="list-style-type: none"> <li>- Necessary information, encouragement, and social support are important for caregivers to motivate them to care for and rehabilitate patients appropriately and continuously (Danzl, 2013; Lutz &amp; Yong, 2010).</li> <li>- Social support is one of the factors related to stroke recovery. Caregivers and health care providers should provide the supports in information, instrument, emotional, and appraisalment (Glass &amp; Maddox,1992; Tsouna-Hadjis et al.,2000)</li> </ul>
<p>3. Behavioral skills</p> <ul style="list-style-type: none"> <li>- Family caregivers lacked of confidences to practice of post-stroke care for their stroke survivors.</li> <li>- Family caregivers did incorrect and inappropriate cares for their stroke survivors in the procedure of feeding and aspiration prevention, pressure ulcer prevention, wound care, fall prevention, mobility, and physical rehabilitation.</li> </ul>	<p>Post-stroke care is more complicated than other illnesses. Therefore, caregivers should have the necessary and specific skills as following (Heart and Stroke Foundation, 2013; Silva-Smith, 2007; Lutz &amp; Yong, 2012).</p> <ul style="list-style-type: none"> <li>- Feeding and aspiration prevention</li> <li>- Preventions of pressure ulcer and procedures of wound care</li> <li>- Fall prevention</li> <li>- Procedures of patient mobility: moving the patient on a bed, changing the patients' position from lying to sitting, and moving them from bed to chair or wheelchair</li> <li>- Procedures of physical rehabilitation in the upper and lower extremities</li> </ul>

**Table 3-2** The IMB concept driven to develop the post-stroke program

<b>IMB</b>	<b>Apply IMB in the intervention program</b>
<p>1. Information:</p> <ul style="list-style-type: none"> <li>- Basic knowledge about a medical condition and causes of disease</li> <li>- Information should contain specific and adequate details that enable individuals to follow the advice</li> <li>- Prevention of acute and chronic complications</li> <li>- Strategies for the disease management</li> </ul>	<ul style="list-style-type: none"> <li>- Instruction on the basic knowledge about stroke pathology, prognosis, impacts after stroke, and stroke severity</li> <li>- Explanation on the specific and essential information of post-stroke care such as ADL support, early recovery, patient mobility, rehabilitation, fall prevention, nutrition, medication, and emotional and stress management</li> <li>- Explanation on prevention of complications after stroke</li> <li>- Providing a booklet of post-stroke care and recovery at home that covered the specific and essential information of procedures in practices of post-stroke care to the family caregivers</li> </ul>
<p>2. Motivation:</p> <ul style="list-style-type: none"> <li>- Personal motivation: the personal attitudes toward performing acts and intentions to practice behaviors</li> </ul>	<ul style="list-style-type: none"> <li>- Using a positive model: the video about the exemplar of post-stroke successes and challenges; stroke survivor and family caregiver shared their successes or challenges regarding post-stroke care and recovery</li> <li>- A negative model: the researcher illustration the exemplars of the failure cases of stroke recovery</li> <li>- Providing the checklist worksheet of post-stroke care records for family caregivers covered the issues of turning the patients on bed, wound cleansing, feeding, medication care, ambulation, rehabilitation, and complications.</li> </ul>

**Table 3-2** The IMB concept driven to develop the post-stroke program (cont.)

<b>IMB</b>	<b>Apply IMB in the intervention program</b>
<ul style="list-style-type: none"> <li>- Social motivation: the individual perception of social support for health behaviors</li> </ul>	<ul style="list-style-type: none"> <li>- Explanation to the family caregivers and VHV's about the importance and types of social support for post-stroke patients</li> <li>- Motivation the family caregivers and VHV's to promote social supports to post-stroke patients</li> <li>- Home visit</li> </ul>
<p>3. Behavior skill:</p> <ul style="list-style-type: none"> <li>- Individual's ability to perform necessary adherence-related tasks</li> <li>- Perceived self-efficacy for performing health behaviors</li> </ul>	<ul style="list-style-type: none"> <li>- Teaching and demonstration of the necessary and specific practices of post-stroke care which covered the procedures of feeding and aspiration prevention, wound prevention, wound care, fall prevention, patient mobility, and rehabilitation</li> <li>- Providing time for family caregivers to practice each procedures of post-stroke care</li> <li>- Family caregivers returned demonstration of the practice of post-stroke care</li> <li>- The researcher provided feedback to family caregivers</li> </ul>

## **Step 2 Intervention**

The second step aimed to design the post-stroke care program and implement the program to the family caregivers. The researcher combined the information gathered from literature review and findings retrieved from elicitation phase to design interventions in the care program to suit the research setting. The intervention focused on three major issues as shown below:

1. The essential post-stroke care information
  - 1.1 The common effects after stroke and severities
  - 1.2 The importance in early recovery
  - 1.3 Complications (aspiration pneumonia, UTI, pressure ulcer, joint stiffness, and recurrent stroke), risks of complications, and complication preventions
  - 1.4 Nutrition: essential nutrients to support stroke recovery, kinds and amounts of food for post-stroke patients, preparing food, and nutritional status assessment
  - 1.5 Medication: medication knowledge including types of medications, the important of medication, side effects, and the basic five rights of medication administration
  - 1.6 Emotional and stress management
2. Social support
  - 2.1 Types of social support such as emotional, instrumental, informational, and appraisal supports
  - 2.2 Motivated family caregivers and VHV's to provide the four types of social support to post-stroke patients
3. Post stroke care training skills of practices
  - 3.1 Disinfection care practices
  - 3.2 Feeding technique and aspiration prevention
  - 3.3 Patient mobility and fall prevention: moving the patient on a bed, turning the patient on the sides, sitting up the patient from a lying position, and moving patient from bed to a wheelchair or chair

3.4 Rehabilitation: the muscle strength and flexibility of the upper and lower extremities to prevent joint stiffness, and coordination and balance activities

The intervention program was implemented over five days during week 1. During weeks 2 and 3, the researcher reviewed the content with family caregivers, who had to give a return demonstration of their skills. This activity was a one-time session. At the two-month post-intervention the researcher made a home visit. The activities in each week are described as below.

**Week 1** Essential information and practices of post-stroke care at home

**Day 1** Life after stroke and essential information of post-stroke care

Objective: To provide correct and necessary knowledge on the following topics:

- 1) Impact and severity of post-stroke symptoms, potential complications, risks and prevention of complications
- 2) The importance of early recovery and rehabilitation during the golden period

Participants: Family caregivers

Activities: This session lasted 2 hours by the researcher.

- 1) Greeting and introduction of objectives of Day 1 activity.
- 2) Provision of basic knowledge about stroke pathology; symptoms; the impacts and severity of post-stroke symptoms; possible complications such as aspiration pneumonia, pressure ulcer, wound infection, UTI, joint stiffness, and recurrent stroke; and risks and prevention of complications. Flipbook with images was used in providing the information to the participants.
- 3) Explanation of ways and techniques to assist patients in carrying out their daily routine such as personal hygiene care, bathing, getting dressed, assisting in using toilet and cleanliness, and safety of patients' living environment.
- 4) Screening of videos on the experiences of stroke survivors and family caregivers regarding post-stroke symptoms and impacts on the patients and family caregivers as well as caring for patients until they are almost fully recovered. This activity aimed to promote understanding amongst the participants about the problems

and severity of post-stroke symptoms so as raise their awareness about patient care and early recovery.

5) Explanation of recovery periods of post-stroke patient to promote family caregivers' realization that correct and proper patient care could bring about recovery within three to six months, which is the golden period of post-stroke patient recovery. Further information and necessary care for patients were included in the next day's activity.

6) Summary of key information from Day 1 activities with participation of the participants, i.e. post-stroke symptoms, severity and complications; the importance of early recovery; and rehabilitation of patients during the golden period. The participants were welcome to ask questions or seek clarification and briefed on next day's activities.

## **Day 2** Disinfection care training

### Objectives

- 1) To acquire knowledge about potential infections such as pressure ulcer infection and UTI, their causes, severity and prevention
- 2) To develop practices in wound care and urinary catheter care
- 3) To promote self-efficacy amongst the participants in patient care and prevention of wound infection and UTI

Participants: Family caregivers

Activities: This session lasted 2 hours by the researcher.

- 1) Recapitulation of information provided in Day 1 by questioning the participants about complications and their symptoms and prevention, and duration of the golden period for recovery.
- 2) Initiation of activities through participants' sharing of their experiences with pressure ulcer, UTI, symptoms, wound care and urinary catheter care.
- 3) Provision of information on causes and risks of getting pressure ulcer and wound infection, symptoms, severity and different stages of pressure ulcer and their prevention. Flipbook with images was used during the session.

4) Demonstration of wound care method and introduction of equipment needed for wound care followed by practical session and return demonstration by the participants and researcher's suggestions and feedback.

5) Provision of information about the causes and risks of UTI, and its symptoms and prevention using flip book with images.

6) Demonstration of correct urinary catheter care and introduction of equipment needed by patients who retained urinary catheter followed by practical session and return demonstration by the participants and researcher's feedback and suggestions.

7) Summary of key information from Day 2 activities with participation of the participants about risks of developing pressure ulcer, wound infection and UTI, how to observe patient's symptoms, and how to prevention of possible infections. The participants were welcome to ask questions or seek clarification and briefed on next day's activities.

### **Day 3 Nutrition and medication**

#### **Objectives**

1) To provide necessary and specific information on patient's nutrition and medication

2) To develop the practicing skills in feeding techniques and aspiration preventions

3) To promote participants' self-efficacy in preparing proper food for the patients, feeding, aspiration prevention, and medication.

Participants: Family caregivers

Activities: This session lasted 2 hours by the researcher.

1) Recapitulation of information provided on Days 1 and 2 by questioning the participants about different complications and their prevention, pressure ulcer care and urinary catheter care.

2) Initiation of activities through questioning the participants about the importance of nutrition and medication to the patients, sharing of experience in preparing food, feeding the patients, and assisting them with their medication as well as challenges encountered.

3) Provision of information about the proper type and amount of food for post-stroke patients, food preparation, basic assessment of patient's nutrition by means of weight and BMI to monitor and prevent malnutrition. Flipbook with images was used during the session.

4) Demonstration of feeding techniques depending on patients' condition e.g. feeding through the mouth or NG-tube, prevention of aspiration, and how to care for the patients if they had aspiration. The demonstration was followed by return demonstration by the participants and feedback and suggestions on the correct practices by the researcher.

5) Provision of information about patient's medication and its side effects, prevention of adverse side effects and the five basic rights of medication administration.

6) Summary of key information from Day 3 activities with participation of the participants about correct and proper nutrition and medication for post-stroke patients. The participants were welcome to ask questions or seek clarification and briefed on next day's activities.

#### **Day 4** Mobility and rehabilitation

##### Objectives

1) To develop the practicing skills in patient mobility promotion, fall prevention, and rehabilitation

2) To promote participants' self-efficacy in transferring patients, fall prevention, and rehabilitation

Participants: Family caregivers

Activities: This session lasted 2 hours by the researcher.

1) Recapitulation of the necessary information provided on Days 1, 2 and 3 through questioning the participants regarding possible complications and preventions, wound care, feeding techniques and aspiration prevention, and medication administration.

2) Initiation of Day 4 activities via participants' sharing of experiences in patient transfer and rehabilitation, including problems and challenges encountered.

3) Provision of knowledge and demonstration of transfer of patients in a bed, turning to the other side, changing position from lying to sitting, transfer from bed to chair or wheelchair, preventing fall during transfer, and any other possible problems during patient transfer. The participants had an opportunity to practice and provide return demonstration.

4) Provision of knowledge and demonstration of physical therapy for the patients which included therapy for upper and lower extremities, coordination and balance practice in seated and standing up positions, and how to address any problems that may occur during physical therapy. The participants had an opportunity to practice and provide return demonstration.

5) Provision of feedback and suggestions on the correct way to transfer patients and provide physical therapy for the patients after each return demonstration.

6) Summary of key information from Day 4 activities with participation of the participants about correct and proper patient transfer and physical therapy. The participants were welcome to ask questions or seek clarification, and briefed on next day's activities.

### **Day 5** Emotional and stress management and social support

#### Objectives

- 1) To provide necessary information about emotion and stress management for family caregivers
- 2) To raise awareness about the importance of social support for family caregivers

Participants: Family caregivers and VHVs

Activities: This session lasted 2 hours by the researcher.

1) Recapitulation of Days 1 to 4 by asking the participants about patient care to prevent complications, feeding and aspiration prevention, patient transfer and physical therapy.

2) Initiation of Day 5 activities by asking the participants to share their experience about psychological problems of the patients and caregivers such as mood swing or stress and how they dealt with those situations as well as any challenges

faced. The participants were also asked about social supports that they provided to post-stroke patients.

3) Provision of knowledge about psychological problems that may occur to both the patients and caregivers and information about how to deal with patient's emotions and stress. Caregivers should encourage the patients to accept their conditions, demonstrate understanding and listen to the patients without showing anger or boredom. They should also give the patients' opportunities to express and share their feelings. As for the emotions and stress of the caregivers relating to patient care, advice or suggestions should be sought from physician, nurse, physical therapist or volunteer or anybody who was once a patient or a caregiver. Caregivers should manage their time to care for the patients and to rest and relax and destress by asking other family members to share their patient care burden.

4) Explanation of the importance of social support and how to provide social support to patients in 4 types: emotional, information, instrumental and appraisal supports. The patients should receive social supports from family caregivers and VHV's.

5) Distribution of copies of 'Family Caregiver Manual on Stroke Survivors Rehabilitation at Home' to the participants, so that they could review the information at home. The manual was developed by the Thai Health Foundation and covers the basic knowledge about post-stroke patient care in different areas.

6) Distribution of patient care record form to encourage family caregivers to care for the patients. The form contains checklists that the caregivers could put a check mark against activities they had already performed and for activities that they did not perform. The activities included on the checklists are changing bed position of the patient every two hours, wound dressing twice a day (morning and evening), feeding or assisting the patient to eat, observing aspiration, ensuring that the patient take their medicines on time, balancing practice in seated and standing up positions, performing physical therapy for the upper and lower extremities, including observing complications such as fever, coughing, panting, burning sensation during urination or dark or smelly urine, red marks or bruises on the skin, joint pain or difficult joint movement or inability to lift their limbs.

7) Summary of key information from Days 1 to 5 with participation of the participants. The participants were welcome to ask questions or seek clarification. The researcher asked for further comments from the participants and ideas for patient rehabilitation plan to promote successful recovery during the golden period, and briefed them on next day's activities.

**Weeks 2 and 3** Review and return demonstrate of practices of post-stroke care  
Objectives

- 1) To review and retain the knowledge and necessary practices for caring the after stroke patient
- 2) To promote family caregivers' self-efficacy in performing the correct post-stroke care
- 3) To motivate family caregivers and raise their awareness about the importance of promoting recovery during the golden period

Participants: Family caregivers and VHV's

Activities: This session lasted 2 hours by the researcher.

- 1) Initiation of the session by asking family caregivers how they cared for post-stroke patients, if and how they applied the knowledge and skills learnt in week 1, and problems or challenges faced.
- 2) Review of the week 1 contents particularly different complications, risks of developing complications and complication prevention, proper nutrition and food preparation for patients, feeding, aspiration prevention, patient transfer, fall prevention, and physical therapy.
- 3) Discussion on emotional and stress management of patients and family caregivers by asking the caregivers to share their experience, including problems or challenges faced. The researcher provided suggestions or recommendations on emotion and stress management techniques suitable for different situations.
- 4) Return demonstration by the family caregivers of feeding and aspiration prevention, wound care, urinary catheter care, patient transfer and mobility, and rehabilitation. The demonstrations were followed by the researcher's feedback and suggestions.

5) Promotion of social support provision by encouragement and recommendation the family caregivers and VHVs to provide the four types of social supports to post-stroke patients. For example, they could provide emotional, information, and appraisal supports about rehabilitation to the patients, and coordinate with a SHPH to borrow walker, wheelchair or patient bed. The researcher also encouraged other family members to participate in patient care and help relieve some burden from the main caregiver by helping with moving the patient, providing physical therapy, helping with chores and taking patients to see doctor on their appointment.

6) Promotion of the participant's awareness about the importance of promoting patient's recovery during the golden period. The caregivers must provide correct and proper care to the patients as trained and practiced in week 1. They must also promote early recovery by assisting the patients to sit or stand up when they are physically ready and encourage them to do things by themselves to the best of their ability first while caregivers are only there to support them.

7) The participants were welcome to ask questions or seek clarification as well as to share their needs for support in relation to patient care. The researcher briefed them on next day's activities.

#### **Week 4 Home visit**

##### Objectives

- 1) To maintain the family caregiver's practicing skill in patient care
- 2) To encourage family caregivers to provide social support to patients
- 3) To monitor the results of the intervention program

Participants: Family caregivers, stroke survivors, and VHVs

Activities: This session lasted 2 hours by the researcher.

- 1) Conducting home visits together with the village health volunteers to assess family caregivers' performance in patient care through observations and inquiry about patient care such as patient's hygiene; food preparation method, type, and amount for the patients; feeding and aspiration prevention; prevention of complications; patient transfer; physical therapy; emotional and stress management; cleanliness and safety of the living environment of the patient's unit, including problems and challenges faced and how they were addressed as well as the caregivers'

needs for support in relation to patient care. Such needs were further shared with concerned agencies for assistance and support.

2) Observation and inquiry of the patients about the cares provided by their caregivers and giving the patients an opportunity to express their feelings and voice their needs.

3) Assessment of the intervention program by assessing post-stroke care practices and self-efficacy of the family caregivers, including the patient's ability to carry out daily activities, their complications and social support received.

4) Encouraging family caregivers, family members, and VHVs to realize the importance of the four aspects of social support, namely emotional, information, instrumental and appraisal supports and providing them to the patients and main caregivers.

5) Following home visit, underscoring the VHVs' roles in visiting the patients and family caregivers at home. These roles include observing and asking to assess patient's symptoms and complications, observing and assessing cares provided by the family caregivers, providing suggestions to the patients and caregivers about supports to promote patient recovery, prevention of complications, and asking about their needs and coordinating responsive actions with the SHPHs. The VHVs should keep public health nurses informed of any problems encountered or their uncertainty about the patients' symptoms and the cares provided by the caregivers.

6) Giving the participants opportunities to ask questions upon which the researcher provided further information and recommendations about the correct post-stroke patient care and rehabilitation, and scheduling next month's home visit.

### **Week 8 Home visit**

#### **Objectives:**

- 1) To maintain family caregiver's practicing skills in patient care
- 2) To encourage rendering social support to the patients and family caregivers

Participants: Family caregivers, stroke survivors, and VHVs

Activities: This session lasted 1 hour by the researcher.

1) Observation and inquiry of family caregivers about necessary cares they provided to post-stroke patients, their application of the knowledge and skills learnt, their social supports to the patients, and problems and challenges faced.

2) Observation and inquiry of the patients about the cares received from family caregivers, social support received from family members and healthcare providers.

3) Giving the participants opportunities to share their feelings, ask questions and express their needs for support, and coordinating responsive actions with concerned agencies.

### **Preparation before data collection**

Prior to the program implementation and data collection, the researcher conducted the following steps to approach the experimental and control groups.

1) The researcher sent the letter for permission to conduct the research study and collect data from the samples, approved by the Faculty of Graduate Studies of Mahidol University, to the Kamphaeng Phet Provincial Public Health Office, Heads of the Sub-district Health Promoting Hospitals in Muang, Phran Kratai, Khlong Lan, and Sai Ngam districts, Kamphaeng Phet Province.

2) Heads of the Sub-district Health Promoting Hospitals, Public Health Nurses (PHNs) and VHVs in Muang, Phran Kratai, Khlong Lan, and Sai Ngam districts, Kamphaeng Phet Province were contacted to explain the objectives of research study, interventions, and activities of the post-stroke care and social support program.

3) Coordination with Social Medicine Unit staff at Kamphaeng Phet Hospital to request a list of stroke survivors who had been discharged from the hospital, organized by district.

4) Review of the name list provided by Kamphaeng Phet Hospital to verify if the patients still live in the area and updating information regarding the patients' general condition. The researcher coordinated with the PHNs and VHVs concerned and asked them to inform the researcher by telephone once the patients had been discharged and returned home.

5) Upon receipt of confirmation that the patients lived in the SHPHs' area of coverage, the researcher scheduled the date and time with the VHVs to recruit the patients and family caregivers according to the study's inclusion criteria.

6) Upon identification of patients and family caregivers meeting the inclusion criteria, the researcher invited them to participate in the study by providing them the information about the study's objectives and benefits. The family caregivers and patients were provided time to consider and make decision. The family caregivers could either call the researcher at the number provided to inform the researcher of their decision or give their telephone number to the researcher to follow up.

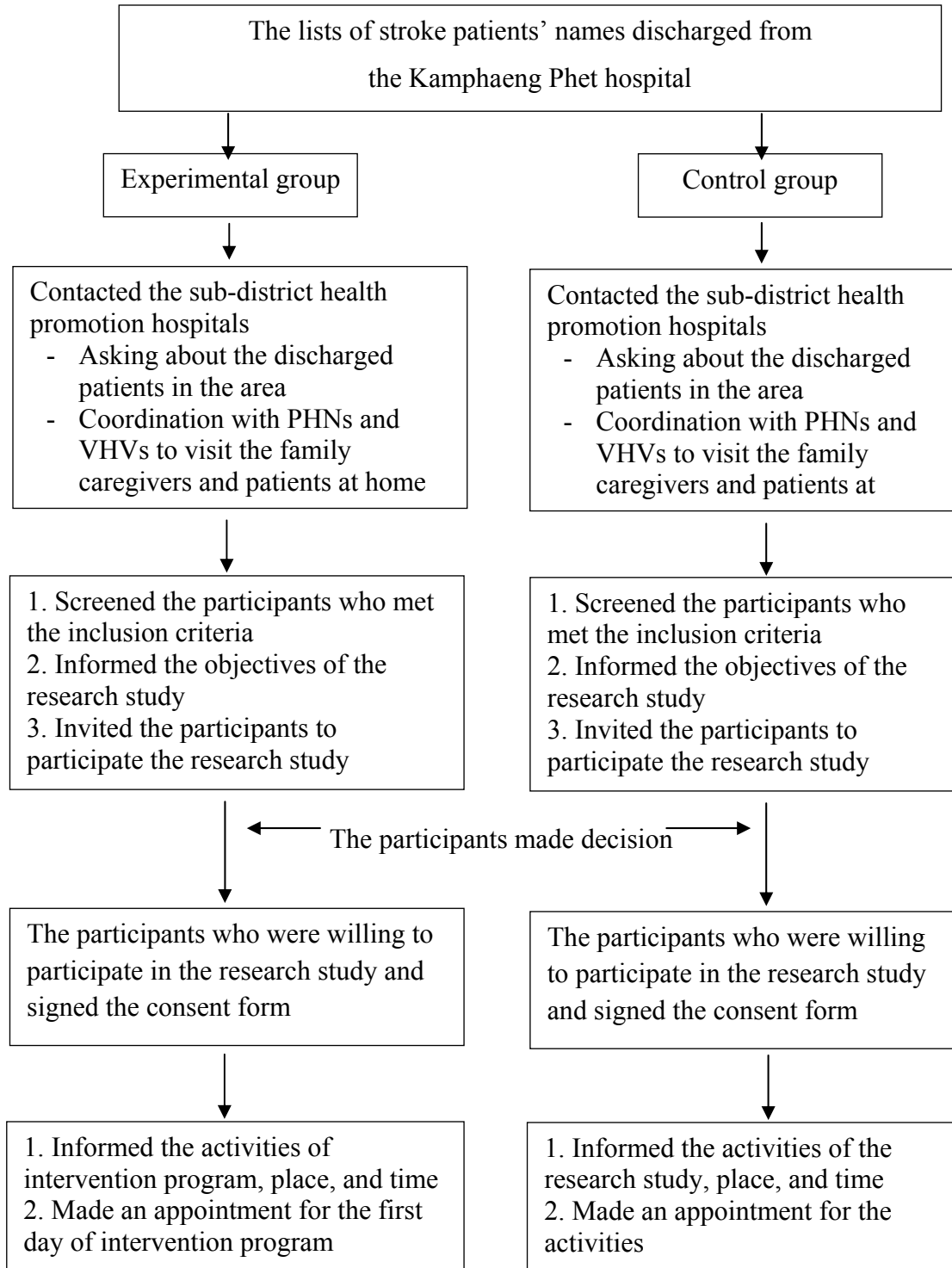
7) Once the family caregivers and patients had decided to participate in the study, the researcher informed them about the study's activities and duration, and explained their rights in details. They were then asked to sign a consent form. The date, time and venue of Day 1 activity were discussed and agreed with them.

### **Protection of human rights**

The ethical approval for the study was granted by the Ethical Committee for Human Research of the Faculty of Public Health, Mahidol University (MUPH 2015-105) before the initiation of data collection. Afterwards, the researcher met with the heads of the SHPHs in Muang, Phran Kratai, Khlong Lan, and Sai Ngam districts, in Kamphaeng Phet Province to explain the study, procedures, and data collection methods and to request their collaboration.

The human rights of the participants were respected. The researcher selected eligible participants according to the criteria. The participants were informed about the main purposes of the study, interventions, benefits, risks, length of time, and the nature of their rights as subjects. The procedures for data collection were clearly described in both verbal and written explanations. The participants were verbally assured of their privacy and the confidentiality of their personal information. To protect them, their names were not revealed in the study report. Full permission of the participants was sought prior to taking any photographs or recording any interviews. Following a complete explanation of the purposes and processes of the study, participants were asked to sign a consent form. It was explained that their participation

in the study was voluntary and they could withdraw from the study at any time without any consequences. Participants had opportunities to ask questions.



**Figure 3-1:** The process before data collection

### **Data collection**

1) After the Ethical Committee for Human Research of the Faculty of Public Health, Mahidol University approved the study, the researcher began data collection.

2) The researcher assessed practices of post-stroke care and self-efficacy of family caregivers in both the experimental and control groups at baseline in the first day of the intervention program.

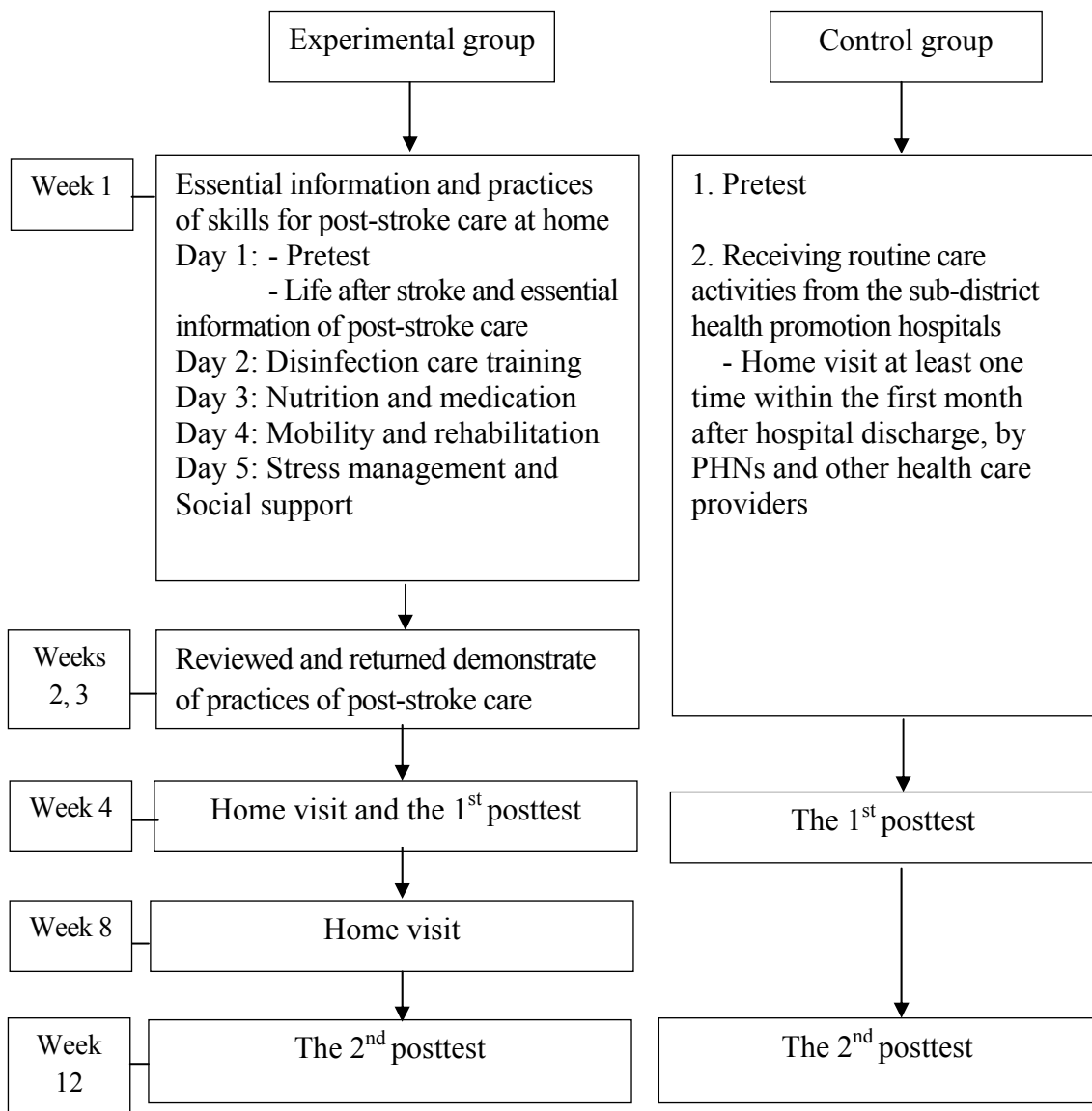
3) The researcher implemented the intervention program with family caregivers in the intervention group. On the first day, family caregivers received the essential information of post-stroke care such as the consequences of stroke, stroke severities, risk and complication preventions, recurring stroke, ADLs support, and the importance in early recovery. On Day 2, they received disinfection training skills. On Day 3, they received post stroke care knowledge about nutrition, medication, and feeding technique and aspiration prevention. On Day 4, they received training in fall prevention, mobility, and rehabilitation. Finally, on Day 5, they received general knowledge about psychological care and stress management, including social support motivation. At the second and third weeks after post-intervention, the researcher reinforced the training, gave feedback, and had family caregivers give a return demonstration. In addition, the fourth week post-intervention, the researcher followed the practical skills of family caregivers and motivated social support through home visit. Furthermore, the researcher visited family caregivers and stroke survivors at home at one month after the program end.

4) The family caregivers and post-stroke patients in the control group received a usual care which was the health promotion hospitals' routine care activities for stroke survivors. The usual care was provided to stroke survivors and their caregivers through home visit at least one time within the first month after hospital discharge by PHNs and other health care providers.

5) After immediately finishing the program and at the two-month follow up, both the experimental and control groups, family caregivers' practices and self-efficacy on post-stroke care were evaluated. The researcher assessed stroke survivors' clinical outcomes, including daily life activities and complications such as aspiration pneumonia, UTI, pressure ulcer, joint contracture, and recurrent stroke. Furthermore, the

stroke survivors were assessed the social support that they obtained from their family caregivers and health care providers.

6) After collecting posttest data at the two-month follow up in the control group, the participants received the essential knowledge and practices of post-stroke care and the post-stroke care booklet.



**Figure 3-2:** The process of implementation and data collection

### **Step 3 Evaluation**

This step aimed to evaluate the effectiveness of the post-stroke care program. The evaluation was conducted in both the experimental and the control groups. The family caregivers were evaluated practices of post-stroke care and self-efficacy over the three periods of time; before the program intervention (Time 1), after immediately the end of program (Time 2), and the two-month follow up (Time 3). The post-stroke patients were evaluated for social supports, ADL functions, and complications in the two periods of time; after immediately the end of program (Time 2) and the two-month follow up (Time 3), by using the same research instruments for data collection.

## **3.4 Research instruments**

The research instruments composed of two parts.

### **3.4.1 Instruments for data collection**

#### **1) Demographic Data Form**

Demographic data were collected through close-ended questionnaire (Demographic Data Form). This questionnaire consisted of 9 items. The instrument was designed to obtain information about family caregivers including their age, sex, type of relationship with patient, marital status, educational level, disease, occupation, family income, and income adequacy. Furthermore, the questionnaire for the post-stroke patients included age, sex, marital status, educational level, and underlying diseases.

#### **2) The practices of post-stroke care of family caregiver**

The practices of post-stroke care checklist was constructed by the researcher. The checklist was modified from the Test of Nursing Skills Check List in Fundamental Nursing to evaluate the essential post-stroke care skills of family caregiver in 5 domains including feeding and aspiration prevention (6 items), pressure ulcer prevention and wound care (6 items), fall prevention (6 items/on bed and chair and 6 items/during walking), mobility (6 items/moving on bed and 6 items/moving from bed to chair or wheelchair), and rehabilitation (6 items/upper extremities, 6 items/lower extremities, and 6 items/coordinating and balancing). Each item was

assessed for scores from 0 to 3 (0 = did not practice or did not perform the task completely and 3 = completely correct).

### 3) Family caregiver self-efficacy scale for post-stroke care

The questionnaire was developed by the researcher. It was comprised of 5 items including feeding and aspiration prevention (5 items), pressure ulcer prevention and wound care (5 items), fall prevention (5 items), mobility (5 items), and rehabilitation (6 items). Each item was scored on a five-point Likert scale (0 = not at all confident to 4 = completely confident). Higher scores indicated more confidence to provide post-stroke care.

### 4) Complications of stroke survivors

The checklist was developed by the researcher to assess the complications of stroke survivors in five areas, namely aspiration pneumonia, UTI, pressure ulcer, joint contracture, and recurrent stroke. Aspiration pneumonia and UTI were assessed based on the criteria of the Centers of Disease Control and Prevention (CDC, 2013). Pressure ulcer was developed using the criteria of the National Pressure Ulcer Advisory Panel (NPUP, 2009). Joint contracture was developed using the passive Range of Motions (ROM) for each joint, including wrist, elbow, hip, knee and ankle. The obtained values were further compared to the normal value of the motion range. If the values lower than normal ROM value accompanied by pain and contracture during joint movements indicate joint contracture (Clavet et al., 2008). Monitoring recurrent stroke was to review physician's diagnosis result in patient's medical records. All five complications were measured with the dichotomous scale (yes/no).

### 5) Modified Barthel Index (MBI)

The Modified Barthel Index developed by Shar, Vanclay, & Cooper (1989) to enhance the sensitivity of the original BI. The MBI has been widely used to measure the physical functional ability in a patient with disability and was translated into many languages. In this study, MBI Thai version developed by Loharjun, Wannapira, Palivanit, & Cumjun (2008) was used to measure the ability to perform activity of daily living among post-stroke patients. The index of 10 items consisted of personal hygiene, bathing, feeding, toilet use, stair climbing, dressing, bowel control, bladder control, ambulation, and transfer. Each item is scored as follows: 1 = unable to perform task, 2 = attempts task but unsafe, 3 = moderate help required, 4 = minimal help

required, and 5=fully independent. A total score can range from 0 to 100. A score of 0-20 suggests total dependence, 21-60 severe dependence, 61-90 moderate dependence, 91-99 slight dependence, and 100 independence.

#### 6) Social support in post-stroke patients

The social support questionnaire contained 58 items developed by the researcher. It was comprised of two parts, (a) the patient obtained social support from family caregivers 34 items and (b) the patient obtained social support from VHV's 24 items. Each part consisted of 4 dimensions including emotional, instrument, information, and appraisal supports. A five-point Likert scale (0= never and 4= always) was used to assess the frequency of obtaining social support in post-stroke patients. Higher scores indicated more social support.

### **3.4.2 Instrument for intervention**

The materials for the intervention included the following three components.

- 1) The posts-stroke care program
- 2) The instruction plan included consequences of stroke, stroke severity, risks of complications, prevention of complications, recurrent stroke, ADLs support, psychological care and stress management, nutrition, and medication.
- 3) A video about consequences after stroke, survivors' experiences and life after stroke and family caregivers' experiences in post-stroke care at home.
- 4) Flip chart focused on complications after stroke, prevention of complications, essential nutrients, food preparation, feeding and aspiration prevention, and medication care.
- 5) A post-stroke recovery at home booklet for family caregivers of the Thai Health Promotion Foundation.

### **The instrument verification**

- 1) The verification of the instrument used to collect data
  - 1.1) Content validity: The practices of post-stroke care in family caregiver checklist, the family caregivers' self-efficacy for post-stroke care questionnaires, the complications of stroke survivor checklist, and the social support in post-stroke patient questionnaires were approved of the content validity by the advisor

and then already consulted with five experts in the field of post-stroke care including one physician and four professional nurses to verify the accuracy of contents and the appropriate language usage. Content Validity Index (CVI) was analyzed as follow.

Practices of post-stroke care in family caregivers	0.88
Complications of stroke survivors	0.87
Family caregiver's self-efficacy for post-stroke care	0.80
Social support in post-stroke patients	0.97

1.2) Reliability: The researcher brought the four instruments to try out with 13 family caregivers and their post-stroke patients living in community as similar as the sample group. The inter-rater reliability of the post-stroke care practices of family caregivers observed by the research and one public health nurse in community was verified by using Pearson Correlation. The researcher used the data gained from the complications of stroke survivor checklist to calculate the reliability of KR-20 (Kuder-Richardson) and the reliability of the family caregiver's self-efficacy questionnaires and the social support questionnaires was measured by using Cronbach's alpha Coefficient. Each instrument was computed for reliability as the following.

Practices of post-stroke care in family caregivers	0.78
Complications of stroke survivors	0.75
Family caregiver's self-efficacy for post-stroke care	0.95
Social support in post-stroke patients	0.96

Moreover, validity and reliability of the Modified Barthel Index (MBI) were studied in 258 first-time stroke patients in Brisbane, Australia in 1984 (Shar et al., 1989). The index's criterion related validity was based on information from the stroke patient's performance by two observers. The internal consistency reliability coefficient was 0.90. The MBI in Thai version was assessed in 30 stroke patients referred for comprehensive rehabilitation in Buddhachinaraj Phitsanulok Hospital during January to March 2007 (Loharjun et al., 2008). The content validity was approved by physiatrists, physical therapists, and occupational therapists. The interrater reliability, interclass correlation coefficient (ICC), was 0.90. For the subscales of MBI, there was substantial interrater agreement between therapists for bowel and bladder control; the Cohen's kappa coefficients were 0.90 and

0.87. Most of the other subscales had fair agreement; the Cohen's kappa coefficient ranged from 0.46 to 0.58.

2) The verification of the instrument for intervention program

The intervention program was validated and approved by the five experts in the field of post-stroke care. The draft of the post-stroke care program for family caregivers was further revised, improved, and finalized according to the experts' suggestions and the information of exploration the existing post-stroke care in the research setting, before being implemented.

### **3.5 Data analysis**

Data were quantified and analyzed by using the Statistic Package for Social Science for Window (SPSS/FW). Statistical analyses were conducted using  $p < 0.05$  as the standard for statistical significance. Descriptive statistics were computed to assess for patterns of missing data and violations of statistical assumptions.

Prior to data analysis, the normality was tested by Kolmogorov-Smirnov test. The results showed normally distribution in all dependent variables.

The statistical methods for data analysis were performed as described below.

1) The demographic data were analyzed by descriptive statistics in terms of frequency, percentage, mean, and standard deviation to describe the general information of the study participants and study variables. Data about participants included age, sex, marital status, education level, occupation, family income, income adequacy, disease, and type of relationship with patient.

2) Two way repeated measures ANOVA was used to compare the difference of practices of post-stroke care and self-efficacy of family caregivers between the experimental and control groups and between changes over times in each group: at the before the intervention, immediately after completing the intervention program, and the two-month follow-up. In addition, multiple pairwise comparisons for these variables between each point of measurement used the Bonferroni test.

3) Paired t-test was used to compare the differences in the mean score of social support and ADLs of post-stroke patients between immediately after completing

the intervention program and the two-month follow-up in the experimental and control groups.

4) The independent t-test was used to examine the difference in the mean scores of practices of post-stroke care, self-efficacy of family caregivers, social support, and ADLs of post-stroke patients between the experimental and control groups at different times.

5) Chi-square test was used to test for the differences of complications in post-stroke patients between the experimental and control groups at the immediately intervention program end and the two-month follow up. The frequency and percentage were used to describe the complication types of stroke survivors.

## **CHAPTER IV**

### **RESULTS**

The chapter presents the findings of a two-group pretest-posttest experimental research design which aimed to examine the effects of the post-stroke care program for family caregivers and patients' outcomes. The research findings are presented as follows:

Part I Demographic characteristics of the participants

Part II Comparisons of practice of post-stroke care and self-efficacy of the family caregivers between and within groups

Part III Comparisons of social supports, activities of daily living (ADLs), and complications of the post-stroke patients between and within groups

Part IV The misunderstandings of family caregivers as revealed on weeks 2 and 3

#### **Part I Demographic characteristics of the samples**

##### **Family caregivers**

Characteristics of the family caregivers are shown in Table 4-1. The experimental and control groups had similar the average age of the participants with a mean of 49.13 (SD 11.53) and 51.32 (SD 13.39) years. Most family caregivers were ages between 40-59 years in the experimental group (38.7%) and greater than or equal to 60 years old in the control group (77.4%). In the both groups, most of them were female that they were child of the post-strokes' patients (45.1%, 61.2%), partners (35.5%, 19.4%), and relatives (19.4%, 19.4%). They were almost the marital status of the married (77.4%, 71.0%) and educational level in primary school or lower (74.2%, 77.4%). One-third of the experimental group were employee (32.3%) and agriculture (35.5%) in the control group. More than half of them had family income less than or

equal to 10,000 baht a month that it was sufficient for the experimental group (58.1%) while it was insufficient for the control group (61.3%). Most of them had no underlying diseases.

To eliminate the potential bias, demographic characteristics were tested for the difference between the participants in the experimental and control groups. There were no statistically significant differences of age, sex, relationship with the patients, marital status, educational level, occupation, family income, sufficiency of income, and the underlying disease between the experimental and control groups.

**Table 4-1** Characteristics of the family caregivers in experimental and control groups

Family Caregivers Characteristics	Experimental (n= 31)		Control (n= 31)		Statistic test value	p-value
	n	%	n	%		
<b>Age (year)</b>						
Mean ± SD	49.13±11.53		51.32±13.39		.86	.760 <sup>c</sup>
20-39	5	16.1	4	12.9		
40-59	20	64.5	18	58.1		
≥ 60	6	19.4	9	29.0		
<b>Sex</b>						
Male	6	19.4	5	16.1	.11	.740 <sup>a</sup>
Female	25	80.6	26	83.9		
<b>Relationship with patient</b>						
Child	14	45.1	19	61.2	2.23	.328 <sup>a</sup>
Partners	11	35.5	6	19.4		
Relatives	6	19.4	6	19.4		
<b>Marital status</b>						
Single/Widowed/ Divorced/Separated	7	22.6	9	29.0	.34	.562 <sup>a</sup>
Married	24	77.4	22	71.0		
<b>Educational level</b>						
Primary school or lower	23	74.2	24	77.4	.09	.767 <sup>a</sup>
Secondary school or higher	8	25.8	7	22.6		

Note <sup>a</sup> = Chi-square test, <sup>b</sup> = Fisher's Exact test, <sup>c</sup> = t-test

**Table 4-1** Characteristics of the family caregivers in experimental and control groups (cont.)

Family Caregivers Characteristics	Experimental (n= 31)		Control (n= 31)		Statistic test value	p-value
	n	%	n	%		
<b>Occupation</b>						
Housewife/ Unemployed	7	22.6	6	19.4	4.22	.378 <sup>b</sup>
Government officer	1	3.2	2	6.4		
Agriculture	5	16.1	11	35.5		
Employee	10	32.3	8	25.8		
Merchant	8	25.8	4	12.9		
<b>Family income (Baht/Month)</b>						
≤ 10,000	21	67.7	22	71.0	.08	.783 <sup>a</sup>
> 10,000	10	32.3	9	29.0		
<b>Sufficiency of income</b>						
Sufficient	18	58.1	12	38.7	2.32	.127 <sup>a</sup>
Insufficient	13	41.9	19	61.3		
<b>Underlying diseases</b>						
No	23	74.2	21	67.7	.31	.576 <sup>a</sup>
1 or more	8	25.8	10	32.3		
Hypertension (HT)	6	19.4	7	22.6		
Diabetes Mellitus (DM)	0	0.0	1	3.2		
DM and HT	0	0.0	1	3.2		
HT and Dyslipidemia	1	3.2	1	3.2		
DM, HT, and Dyslipidemia	1	3.2	0	0.0		

Note <sup>a</sup> = Chi-square test; <sup>b</sup> = Fisher's Exact test

### Post-stroke patients

The average age of post-stroke patients in the experimental group was 64.74 years old (SD 12.09) and 69.03 years old (SD 12.82) in the control group. In both groups, the patients' age was greater than or equal to 60 years old (61.3%, 77.4%) and were female (58.1%, 64.5%). More than half of them in the experimental group were married (61.3%) whereas they were single, widowed, divorced, or separated (61.3%) in the control group. Most of them in the both groups obtained the formal education (80.6%, 83.9%). In addition, almost patients in the experimental

(87.1%) and control groups (93.5%) had one or more underlying diseases such as HT, dyslipidemia, and DM. When compared between two groups, there were no significant differences in the patient characteristics (Table 4-2).

**Table 4-2** Characteristics of the post-stroke patients in the experimental and control groups

Stroke Patients Characteristics	Experimental (n= 31)		Control (n= 31)		Statistic test value	p-value
	n	%	n	%		
<b>Age (year)</b>						
Mean ± SD	64.74±12.09		69.03±12.82		1.90	.168 <sup>c</sup>
40-59	12	38.7	7	22.6		
≥ 60	19	61.3	24	77.4		
<b>Sex</b>						
Male	13	41.9	11	35.5	.27	.602 <sup>a</sup>
Female	18	58.1	20	64.5		
<b>Marital status</b>						
Single/Widowed/ Divorced/Separated	12	38.7	19	61.3	3.16	.075 <sup>a</sup>
Married	19	61.3	12	38.7		
<b>Educational level</b>						
No formal education	6	19.4	5	16.1	.11	.740 <sup>a</sup>
Received formal education	25	80.6	26	83.9		

Note <sup>a</sup> = Chi-square test; <sup>b</sup> = Fisher's Exact test, <sup>c</sup> = t-test

**Table 4-2** Characteristics of the post-stroke patients in the experimental and control groups (cont.)

Stroke Patients Characteristics	Experimental (N= 31)		Control (N= 31)		Statistic test value	p-value
	n	%	n	%		
<b>Underlying diseases</b>						
No	4	12.9	2	6.5	.73	.671 <sup>b</sup>
1 or more	27	87.1	29	93.5		
Hypertension (HT)	13	41.9	14	45.2		
Dyslipidemia	1	3.2	1	3.2		
DM and HT	1	3.2	2	6.4		
HT and Dyslipidemia	10	32.3	10	32.3		
DM, HT, and Dyslipidemia	2	6.4	2	6.4		

Note <sup>a</sup> = Chi-square test; <sup>b</sup> = Fisher's Exact test

## **Part II Comparisons of the practices of post-stroke care and self-efficacy of the family caregivers between and within groups**

### **Practices of post-stroke care**

Table 4-3 presents the two-way repeated measures ANOVA analysis to compare the scores of practices of post-stroke cares by times of measurement and groups. The results showed that the scores of feeding, pressure ulcer prevention, fall prevention, patients moving, and rehabilitation were significant differences between the experimental and control groups (p-value <0.001). There were significant differences in the score of post-stroke cares' practices between times of measurement in each group (p-value <0.001). In addition, there was an interaction between groups and times (p-value <0.001). This indicated that both groups had significantly different changes from each point of measurements.

**Table 4-3** Two-Way Repeated Measures ANOVA for the practices of post-stroke care of family caregivers

Practices of post-stroke care	SS	df	MS	F	p-value
<b>Overall practices</b>					
Group	157413.554	1	157413.554	585.810	<0.001 <sup>a</sup>
Time	69961.366	1	34980.683	616.528	<0.001 <sup>a</sup>
Time x group	19394.742	1	9697.371	192.491	<0.001 <sup>a</sup>
Error	6808.581	60	75.539		
<b>Feeding</b>					
Group	899.360	1	899.360	230.161	<0.001 <sup>a</sup>
Time	647.430	1	323.715	109.177	<0.001 <sup>a</sup>
Time x group	1051.430	1	525.715	177.304	<0.001 <sup>a</sup>
Error	355.806	60	2.965		
<b>Pressure ulcer prevention</b>					
Group	1192.694	1	1192.694	149.576	<0.001 <sup>a</sup>
Time	516.269	1	258.134	141.284	<0.001 <sup>a</sup>
Time x group	892.484	1	446.242	244.240	<0.001 <sup>a</sup>
Error	219.247	60	1.827		
<b>Fall prevention</b>					
Group	5430.242	1	5430.242	210.352	<0.001 <sup>a</sup>
Time	2883.129	1	1441.565	289.433	<0.001 <sup>a</sup>
Time x group	4749.194	1	2374.597	476.765	<0.001 <sup>a</sup>
Error	597.677	60	4.987		
<b>Moving</b>					
Group	17906.586	1	17906.586	604.126	<0.001 <sup>a</sup>
Time	13162.398	1	6581.199	604.008	<0.001 <sup>a</sup>
Time x group	11033.430	1	5516.715	506.312	<0.001 <sup>a</sup>
Error	1307.505	60	10.896		

<sup>a</sup> p-value < 0.05

**Table 4-3** Two-Way Repeated Measures ANOVA for the practices of post-stroke care of family caregivers (cont.)

Practices of post-stroke care	SS	df	MS	F	p-value
<b>Rehabilitation</b>					
Group	25456.860	1	25456.860	521.113	<0.001 <sup>a</sup>
Time	9888.613	1	4944.306	393.469	<0.001 <sup>a</sup>
Time x group	14186.140	1	7093.070	564.467	<0.001 <sup>a</sup>
Error	1507.914	60	12.566		

<sup>a</sup>p-value < 0.05

Multiple pairwise comparisons between each point of measurement were done by using the Bonferroni test (Table 4-4). In the experimental group, mean scores of the practices of post-stroke care at the two-month after the program end (Time 3) were significantly higher than the mean scores obtained from the end of the program (Time 2) and the before intervention program (Time1), respectively (Figure 4-1). In each practice demonstrated that feeding, pressure ulcer prevention, fall prevention, and rehabilitation at time 3 was significantly higher than the mean scores at times 2 and 1, respectively (p-value<0.001). However, mean scores of mobility practice at time 3 and time 2 were significantly higher than the mean scores at time 1 (p-value<0.001), but the mean score of time 3 was not significantly higher than the mean scores of time 2 (p-value=0.087).

In the control group, mean scores of the overall practices of post-stroke care at time 3 were lower than the mean scores at times 2 and 1, respectively (Figure 4-1). In each practice (Table 4-4), the mean score of rehabilitation at time 3 was significantly lower than the mean scores at times 2 and 1, respectively (p-value <0.001). The mean score of the practices of pressure ulcer and fall preventions at time 3 and 2 were significantly lower than the mean scores at time 1 (p-value<0.001), but the mean score of time 3 was not significantly lower than the mean scores of time 2 (p-value=0.851, 0.223). The mean score of mobility practice at time 3 was significantly lower than the mean scores at time1 (p-value<0.001). However, the

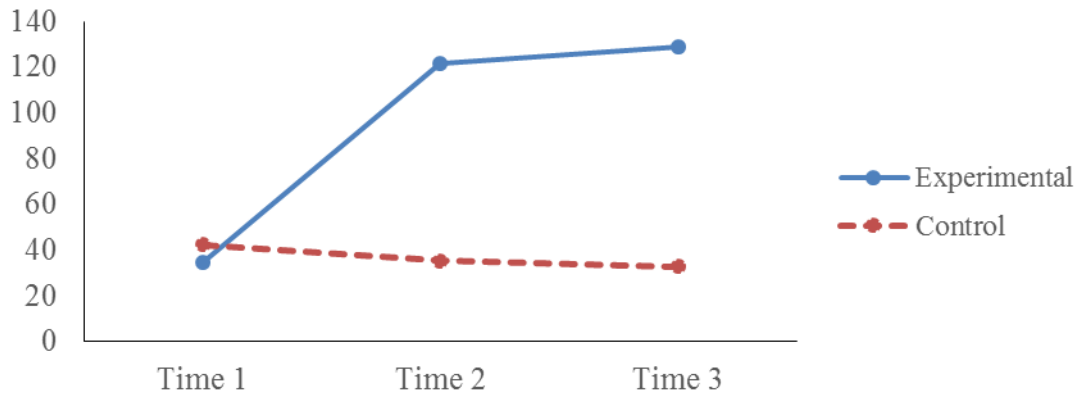
difference of the mean score of feeding practices over three times measurement was not significant ( $p\text{-value} > 0.05$ ).

**Table 4-4** Pairwise comparison of mean scores for the practices of post-stroke care in family caregivers at three periods of time in the experimental and control groups

Practices of post-stroke care	Before program (Time 1)		The end of program (Time 2)		Two months after the program end (Time 3)		Post hoc <sup>b</sup>
	M	SD	M	SD	M	SD	
<b>Experimental group</b>							
Overall practices	34.61	11.10	121.64	11.30	128.93	12.66	3>2>1 <sup>a</sup>
Feeding	6.06	1.79	14.65	1.52	15.42	1.36	3>2>1 <sup>a</sup>
Pressure ulcer prevention	6.35	2.12	14.06	1.71	14.94	1.81	3>2>1 <sup>a</sup>
Fall prevention	8.94	3.47	26.77	2.65	29.03	3.07	3>2>1 <sup>a</sup>
Mobility	4.52	3.55	24.81	2.77	25.61	2.70	2,3>1 <sup>a</sup> , 3>2
Rehabilitation	8.74	4.23	41.35	6.16	43.94	6.53	3>2>1 <sup>a</sup>
<b>Control group</b>							
Overall practices	42.55	9.93	35.29	11.54	32.81	11.01	2,3<1 <sup>a</sup> , 3<2
Feeding	8.38	1.78	7.10	2.26	7.45	2.01	2,3<1, 3>2
Pressure ulcer prevention	7.45	1.93	6.48	1.96	6.22	2.23	2,3<1 <sup>a</sup> , 3<2
Fall prevention	12.32	3.45	10.32	4.18	9.68	3.69	2,3<1 <sup>a</sup> , 3<2
Mobility	4.45	3.65	3.71	3.21	3.23	2.97	2<1, 3<2, 3<1 <sup>a</sup>
Rehabilitation	9.94	3.99	7.68	4.15	6.23	4.09	3<2<1 <sup>a</sup>

<sup>a</sup>  $p\text{-value} < 0.05$

<sup>b</sup> Bonferroni's method



**Figure 4-1:** Comparison the overall practices of post-stroke care between groups

Table 4-5 shows the comparison of the mean score of post-stroke cares’ practices between the experimental and control groups. The results found that the mean scores of practices in feeding, pressure ulcer prevention, fall prevention, mobility, and rehabilitation of the experimental group were significantly higher than those of the control group (p-value<0.001).

**Table 4-5** Comparison of the mean scores of the practices of post-stroke care in family caregivers between the experimental and control groups

Practices of post-stroke care	Experimental group (n=31)	Control group (n=31)	df	t	p-value
	Mean (SD)	Mean (SD)			
Feeding	12.04 (0.96)	7.64 (1.31)	60	15.17	<0.001 <sup>a</sup>
Pressure ulcer prevention	11.78 (1.36)	6.72 (1.86)	60	12.23	<0.001 <sup>a</sup>
Fall prevention	21.58 (2.39)	10.77 (3.39)	60	14.50	<0.001 <sup>a</sup>
Mobility	18.31 (2.17)	3.79 (3.05)	60	21.57	<0.001 <sup>a</sup>
Rehabilitation	31.34 (4.44)	7.95 (3.58)	60	22.83	<0.001 <sup>a</sup>

<sup>a</sup>p-value < 0.05

### Self-efficacy of the family caregivers

The self-efficacies of family caregivers in feeding, pressure ulcer prevention, fall prevention, patients moving, and rehabilitation were significant differences between the experimental and control groups ( $p$ -value  $<0.001$ ). There was significant difference in each component of self-efficacy at least one pair of the three times points ( $p$ -value  $<0.001$ ). In addition, the interaction between groups and times was significantly different ( $p$ -value  $<0.001$ ) that refer to the groups were significantly different in changes from each point of measurement (Table 4-6).

**Table 4-6** Two-Way Repeated Measures ANOVA for the self-efficacy in family caregivers

Self-efficacy	SS	df	MS	F	p-value
<b>Overall self-efficacy</b>					
Group	26928.194	1	26928.194	89.161	$<0.001^a$
Time	12806.527	1	6403.263	127.104	$<0.001^a$
Time x group	19394.742	1	9697.371	192.491	$<0.001^a$
Error	6045.398	60	50.378		
<b>Feeding</b>					
Group	720.194	1	720.194	63.957	$<0.001^a$
Time	548.140	1	274.070	84.684	$<0.001^a$
Time x group	758.161	1	379.081	117.131	$<0.001^a$
Error	388.366	60	3.236		
<b>Pressure ulcer prevention</b>					
Group	560.909	1	590.909	44.002	$<0.001^a$
Time	364.011	1	182.005	66.864	$<0.001^a$
Time x group	522.011	1	261.005	95.886	$<0.001^a$
Error	326.645	60	2.722		
<b>Fall prevention</b>					
Group	772.263	1	772.263	54.023	$<0.001^a$
Time	221.462	1	110.731	53.529	$<0.001^a$
Time x group	512.301	1	256.151	123.826	$<0.001^a$
Error	248.237	60	2.069		

<sup>a</sup>  $p$ -value  $< 0.05$

**Table 4-6** Two-Way Repeated Measures ANOVA for the self-efficacy in family caregivers (cont.)

Self-efficacy	SS	df	MS	F	p-value
<b>Mobility</b>					
Group	998.715	1	998.715	65.210	<0.001 <sup>a</sup>
Time	613.000	1	306.500	94.768	<0.001 <sup>a</sup>
Time x group	677.559	1	338.780	104.748	<0.001 <sup>a</sup>
Error	388.108	60	3.234		
<b>Rehabilitation</b>					
Group	2936.134	1	2936.134	105.236	<0.001 <sup>a</sup>
Time	974.333	1	487.167	85.998	<0.001 <sup>a</sup>
Time x group	1623.882	1	811.941	143.329	<0.001 <sup>a</sup>
Error	679.785	60	5.665		

<sup>a</sup> p-value < 0.05

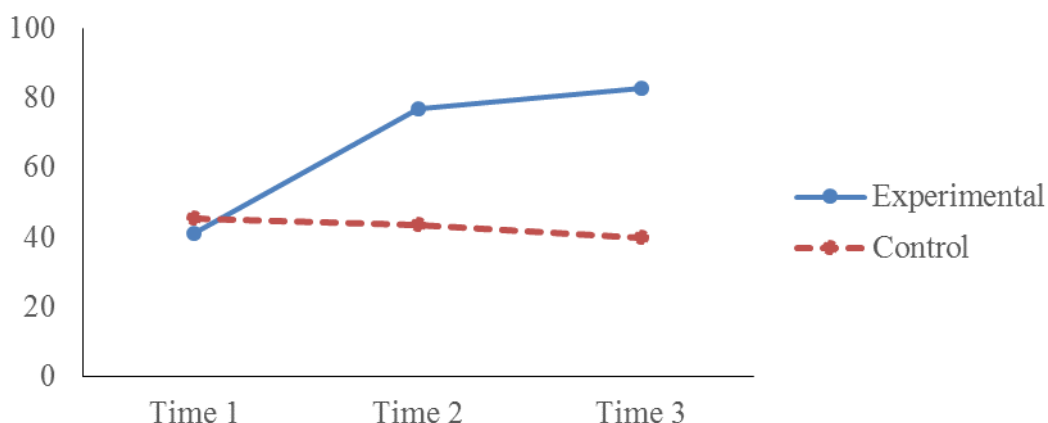
The pairwise comparison of self-efficacy in family caregivers at three periods of time between the experimental and control groups was shown in Table 4-7. In the experimental group, the mean scores of self-efficacy in feeding, pressure ulcer prevention, fall prevention, patient mobility, and rehabilitation at time 3 were significantly higher than the mean scores at times 2 and 1, respectively (p-value <0.001) (Figure 4-2).

In contrast to the control group, the mean score of overall self-efficacy at time 3 was significantly lower than the mean scores at times 2 and 1 (p-value<0.001) but the mean score at time 2 was not significantly lower than the mean scores at time 1 (Figure 4-2). The self-efficacy in feeding showed that the mean score at time 3 was significantly lower than at time 2 (p-value<0.001) (Table 4-7). The mean scores of self-efficacy in fall prevention and rehabilitation at time 3 were significantly lower than the mean scores at times 2 and 1 (p-value<0.001). However, the mean scores of self-efficacy in pressure ulcer prevention and mobility at time 3 were not significantly lower than the mean scores at times 2 and 1.

**Table 4-7** Pairwise comparison of mean scores of self-efficacy in family caregivers at three periods of time in the experimental and control groups

Self-efficacy	Before program (Time 1)		The end of program (Time 2)		Two months after the program end (Time 3)		Post hoc <sup>b</sup>
	M	SD	M	SD	M	SD	
	<b>Experimental group</b>						
Overall	41.13	12.95	77.00	7.33	82.93	8.25	3>2>1 <sup>a</sup>
Feeding	8.26	2.63	15.45	9.77	16.71	1.83	3>2>1 <sup>a</sup>
Pressure ulcer prevention	8.65	2.80	14.42	1.77	15.71	1.99	3>2>1 <sup>a</sup>
Fall prevention	9.45	2.39	14.48	1.77	15.84	1.69	3>2>1 <sup>a</sup>
Mobility	6.61	3.29	14.03	1.43	14.90	2.01	3>2>1 <sup>a</sup>
Rehabilitation	8.16	4.04	18.61	2.51	19.77	2.78	3>2>1 <sup>a</sup>
<b>Control group</b>							
Overall	45.42	11.55	43.52	13.88	39.93	13.77	3<2,1 <sup>a</sup> , 2<1
Feeding	9.90	2.59	9.77	2.68	8.94	2.66	3<2 <sup>a</sup> , 3,2<1
Pressure ulcer prevention	9.81	2.33	9.48	2.84	9.06	2.83	3<2<1
Fall prevention	9.94	2.49	9.10	3.03	8.52	3.13	3<2,1 <sup>a</sup> , 2<1
Mobility	7.32	2.70	7.39	3.14	6.93	3.09	3<2<1
Rehabilitation	8.45	3.68	7.77	4.16	6.48	4.15	3<2,1 <sup>a</sup> , 2<1

<sup>a</sup> p-value < 0.05<sup>b</sup> Bonferroni's method



**Figure 4-2:** Comparison the self-efficacy of family caregivers between groups

Table 4-8 presents that there was a significant difference in mean scores of self-efficacy in family caregivers between the experimental and control groups. The mean scores of self-efficacy in feeding, pressure ulcer prevention, fall prevention, mobility, and rehabilitation of the experimental group were significantly higher than those of the control group (p-value<0.001).

**Table 4-8** Comparison of the mean scores of self-efficacy in family caregivers between the experimental and control groups

Self-efficacy	Experimental	Control	df	t	p-value
	(n=31)	(n=31)			
	Mean (SD)	Mean (SD)			
Feeding	12.04 (0.94)	7.64 (1.31)	60	15.171	<0.001 <sup>a</sup>
Pressure ulcer prevention	11.78 (1.36)	6.72 (1.86)	60	12.230	<0.001 <sup>a</sup>
Fall prevention	21.58 (2.39)	10.77 (3.39)	60	14.504	<0.001 <sup>a</sup>
Mobility	18.31 (2.17)	3.79 (3.05)	60	21.574	<0.001 <sup>a</sup>
Rehabilitation	31.34 (4.44)	7.95 (3.58)	60	22.828	<0.001 <sup>a</sup>

<sup>a</sup> p-value < 0.05

## **Part III Comparisons of the social supports, activities of daily living, and complications of the post-stroke patients between and within groups**

### **Social supports of the post-stroke patients**

#### **The experimental group**

The overall of mean score of social supports that the post-stroke patients obtained from their family caregivers at the two-month follow up (Time 3) was significantly higher than those they obtained at the end of program (Time 2) at p-value <0.001 (Table 4-9). In each aspect of social supports showed that the mean scores of emotional, instrumental, and appraisal supports at time 3 were significantly higher than those at time 2 (p-value = 0.004, <0.001, and 0.006 respectively). However, the mean score of information support at time 3 was not significantly higher than the mean scores at time 2 (p-value=0.074).

For the social supports obtained from VHVs, the overall of mean score of social supports at time 3 was not significantly lower than those they obtained at time 2 (p-value=0.234). In each aspect of social supports, the mean score of instrumental support at time 3 was significantly higher than the mean scores at time 2 (p-value = 0.017). However, the mean scores of emotional, information, and appraisal supports at time 3 were not different from those at time 2.

#### **The control group**

The overall of mean score of social supports that the patients obtained from family caregivers at time 3 was significantly lower than those they obtained at time 2 (p-value=0.001). The mean scores of emotional, information, and appraisal supports at time 3 were significantly lower than those at time 2 (p-value= <0.001, 0.011, and 0.002 respectively). Furthermore, the mean score of instrumental support at time 3 was not significantly lower than those at time 2 (p-value=0.127) (Table 4-9).

The social supports from VHVs showed that the mean score of overall support and the three aspects in emotional, information, and appraisal supports at time 3 were significantly lower than those at time 2 (p-value = 0.001, 0.002, 0.012, and

0.002 respectively). The mean score of instrumental support at time 3 was not different from those at time 2 (p-value=0.152).

**Table 4-9** Comparison of the mean scores of social support in post-stroke patients between the end of program (Time 2) and at the two-month follow up (Time 3) in the experimental and control groups

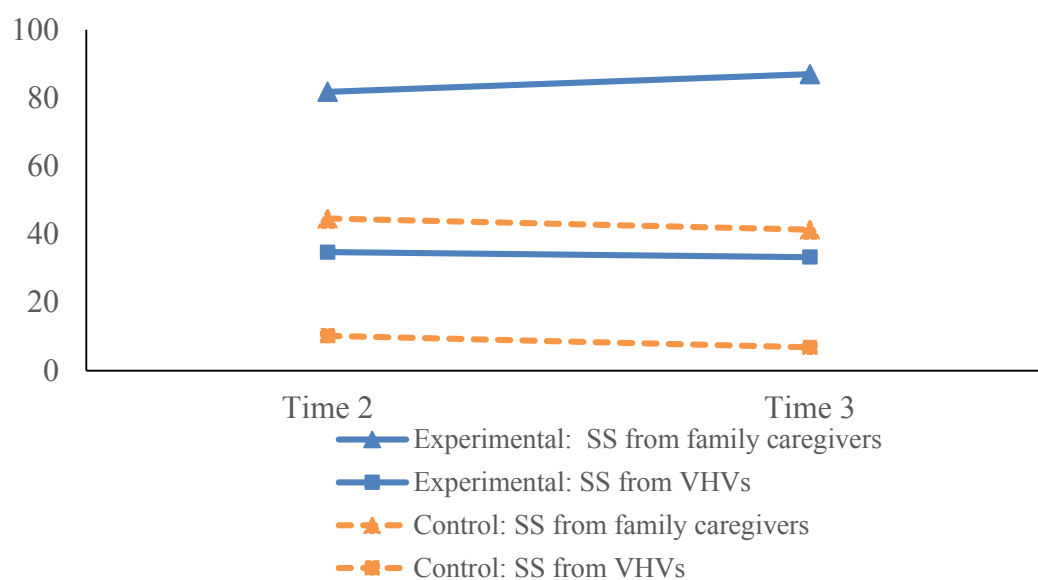
Social support (SS)	The end of program (Time 2)		Two-month follow up (Time 3)		df	t	p-value
	Mean	SD	Mean	SD			
<b>Experimental group</b>							
Overall supports	116.58	20.28	120.35	23.38	30	1.38	<0.001 <sup>a</sup>
<b>The patients obtained SS from family caregivers</b>							
Overall	81.81	11.00	87.00	12.59	30	3.99	<0.001 <sup>a</sup>
Emotional	24.55	3.45	25.81	3.46	30	2.83	0.004 <sup>a</sup>
Instrument	33.35	3.33	35.19	3.49	30	3.56	<0.001 <sup>a</sup>
Information	11.35	2.55	11.97	3.06	30	1.48	0.074 <sup>a</sup>
Appraisal	12.55	4.14	14.03	4.40	30	2.67	0.006 <sup>a</sup>
<b>The patients obtained SS from VHVs</b>							
Overall	34.77	12.71	33.35	14.27	30	.73	0.234
Emotional	11.35	3.14	10.45	3.77	30	1.41	0.083
Instrument	3.87	3.30	4.26	3.51	30	.99	0.017 <sup>a</sup>
Information	9.97	4.17	9.45	4.32	30	.85	0.200
Appraisal	9.58	4.29	9.19	4.28	30	.59	0.278
<b>Control group</b>							
Overall supports	54.87	12.56	48.26	11.44	30	4.63	<0.001 <sup>a</sup>
<b>The patients obtained SS from family caregivers</b>							
Overall	44.61	9.99	41.42	10.51	30	3.24	0.001 <sup>a</sup>
Emotional	16.61	4.10	15.35	4.53	30	4.09	<0.001 <sup>a</sup>
Instrument	24.42	5.55	23.58	5.75	30	1.16	0.127
Information	1.97	1.54	1.42	1.48	30	2.42	0.011 <sup>a</sup>
Appraisal	1.61	1.80	1.06	1.55	30	3.07	0.002 <sup>a</sup>

<sup>a</sup> p-value < 0.05

**Table 4-9** Comparison of the mean scores of social support in post-stroke patients between the end of program (Time 2) and at the two-month follow up (Time 3) in the experimental and control groups (continued)

Social support (SS)	The end of program (Time 2)		Two-month follow up (Time 3)		df	t	p-value
	Mean	SD	Mean	SD			
<b>Control group</b>							
<b>The patients obtained SS from VHV's</b>							
Overall	10.26	5.08	6.84	4.07	30	3.38	0.001 <sup>a</sup>
Emotional	6.35	1.83	5.19	1.68	30	3.01	0.002 <sup>a</sup>
Instrument	.42	1.02	.19	.75	30	1.04	0.152
Information	2.19	2.04	1.13	1.63	30	2.37	0.012 <sup>a</sup>
Appraisal	1.29	1.86	.32	.75	30	3.16	0.002 <sup>a</sup>

<sup>a</sup> p-value < 0.05



**Figure 4-3:** Comparison the receiving social supports (SS) among post-stroke patients between groups

Table 4-10 shows the comparison of the mean score of social support among post-stroke patients between the experimental and control groups. The mean scores of receiving social support from the family caregivers and the VHVs of the experimental group were significantly higher than those of the control group (p-value <0.001).

**Table 4-10** Comparison of the mean scores of social support among post-stroke patients between the experimental and control groups

Social support	Experimental group (n=31)	Control group (n=31)	df	t	p-value
	Mean (SD)	Mean (SD)			
<b>The patients obtained from family caregivers</b>					
Emotional	25.17 (3.23)	15.98 (4.23)	60	9.608	<0.001 <sup>a</sup>
Instrument	34.27 (3.09)	24.00 (5.28)	60	9.344	<0.001 <sup>a</sup>
Information	11.66 (2.57)	1.69 (1.37)	60	19.053	<0.001 <sup>a</sup>
Appraisal	13.29 (3.98)	1.34 (1.60)	60	15.505	<0.001 <sup>a</sup>
<b>The patients obtained from VHVs</b>					
Emotional	10.90 (2.98)	5.77 (1.39)	60	8.675	<0.001 <sup>a</sup>
Instrument	4.06 (3.23)	0.31 (0.67)	60	6.345	<0.001 <sup>a</sup>
Information	9.71 (3.90)	1.66 (1.36)	60	10.862	<0.001 <sup>a</sup>
Appraisal	9.39 (3.88)	0.81 (1.14)	60	11.813	<0.001 <sup>a</sup>

<sup>a</sup> p-value < 0.05

#### **Activities of daily living (ADL)**

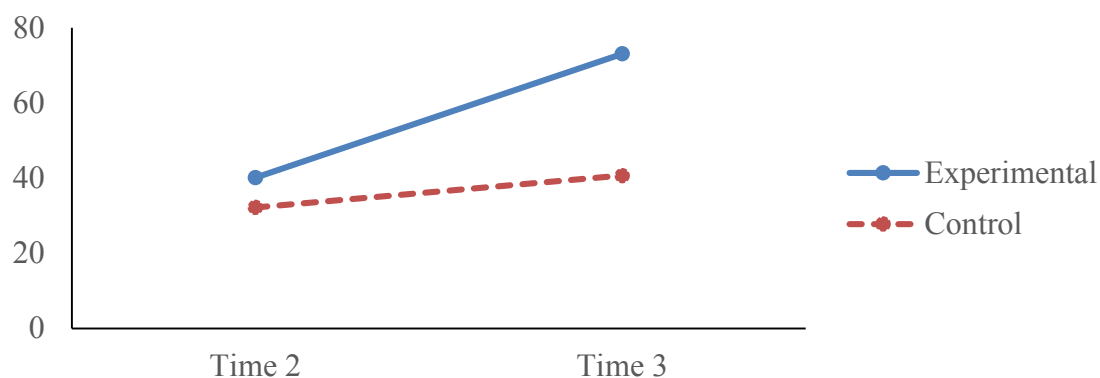
In the experimental group, the mean score of ADL in the post-stroke patients at the two-month follow up (Time 3) was significantly higher than the mean score at the end of program (Time 2) at p-value <0.001 (Table 4-11).

In the control group, the mean score of ADL among the post-stroke patients at time 3 was significantly higher than the mean score at time 2 (p-value <0.001). (Figure 4-4)

**Table 4-11** Comparison of the mean scores of ADL of the post-stroke patients between the end of program (Time 2) and at the two-month follow up (Time 3) in the experimental and control groups

Activities of daily living	The end of program (Time 2)		Two-month follow up (Time 3)		df	t	p-value
	Mean	SD	Mean	SD			
	Experimental group	40.13	8.82	73.10			
Control group	32.19	4.52	40.68	16.47	30	3.61	<0.001 <sup>a</sup>

<sup>a</sup>p-value < 0.05



**Figure 4-4:** Comparison the ADLs of the post-stroke patients between groups

The comparison of the mean score of activities daily of living in the post-stroke patients between the groups was presented in Table 4-12. The results found that the mean score of activities daily of living of the experimental group was significantly higher than that of the control group (p-value<0.001). (Figure 4-4)

**Table 4-12** Comparison of the mean scores of the activities daily of living in the post-stroke patients between the experimental and control groups

Activities daily of living	Experimental	Control	df	t	p-value
	group	group			
	(n=31)	(n=31)			
	Mean (SD)	Mean (SD)			
Activities daily of living	56.61 (9.89)	36.43(10.15)	60	7.924	<0.001 <sup>a</sup>

<sup>a</sup> p-value < 0.05

### Complications

Table 4-13 shows the difference of the complications in the post-stroke patients between the experimental and control groups. There were not significant in the complications among the post-stroke patients at immediately after the end of the program between the experimental and control groups (p-value=0.492). All the patients in the experimental group (100%) and almost the patients in the control group (93.6%) did not have complications at immediately after the end of the program. There were two patients suffered complications, namely pressure ulcer (3.2%) and joint stiffness (3.2%).

**Table 4-13** Comparison of complications of post-stroke patients between the experimental and control groups

Complications	Experimental group (n=31)		Control group (n=31)		Statistic test value	p-value
	n	%	n	%		
<b>Immediately after the program end</b>						
No complications	31	100.0	29	93.6	2.07	0.492 <sup>b</sup>
Had complications	0	0.0	2	6.4		
<b>Two months after the program end</b>						
No complications	30	96.8	15	48.4	18.23	<0.001 <sup>a</sup>
Had complications	1	3.2	16	51.6		

*Note.* The patients might have more than one type of complications

<sup>a</sup> = Chi-square test; <sup>b</sup> = Fisher's Exact test

**Table 4-14** Types of complications in stroke survivors at the two-month follow up

Complications	Experimental group	Control group
	n (%)	n (%)
Aspiration pneumonia	0 (0.0)	1 (3.2)
UTI	0 (0.0)	1 (3.2)
Pressure ulcer	0 (0.0)	4 (12.9)
Joint contracture	1 (3.2)	15 (48.4)
Recurrent stroke	0 (0.0)	2 (6.5)

The complications at the two months after the program end were significantly different between groups (p-value<0.001). Only one patient in the experimental group had joint stiffness (3.2%); whereas half of the patients in the control group had complications (51.6%). In reviewing the complications, it was found that some patients had multiple complications. One patient had UTI, pressure ulcer, and joint stiffness; one had joint stiffness and recurrent stroke; one had pneumonia and recurrent stroke; three had pressure ulcer and joint stiffness; and ten had joint stiffness. As the results, the types of complications in Table 4-14 concluded that the stroke

survivors had aspiration pneumonia (3.2%), UTI (3.2%), pressure ulcer (12.9%), recurrent stroke (6.5%), and joint stiffness (48.4%).

## **Part IV The misunderstandings of family caregivers as revealed on weeks 2 and 3**

During the review and returned demonstration on weeks 2 and 3, it was found that the family caregivers had some misconceptions regarding post-stroke care as follows:

### **Feeding and aspiration prevention**

They often prepared inappropriate food for the patients; for example, the food was not cut into small enough pieces to facilitate chewing and swallowing. In addition, to prevent risk of aspiration, they did not arrange the patients' position before and after eating to, at least, a 30-degree patients' head elevation. Moreover, the family caregivers often did not perceive the signs of aspiration before and during feeding such as coughing and choking. This resulted in a failure to halt feeding immediately upon signs of aspiration.

### **Pressure ulcer prevention**

Family caregivers often missed the early signs of pressure ulcer such as discoloured skin, skin appearing red in people with pale complexions and purple or blue in people with darker-coloured skin. The skin usually remains intact, but it may hurt or change in firmness, temperature, or may appear slightly swollen compared to surrounding areas. Family caregivers often did not understand or follow the protocol of changing the patients' position at least every two hours to relieve the prolonged pressure on soft tissues and bony protuberances contributing to the development of pressure ulcer.

### **Fall prevention**

They misunderstood the methods necessary to reduce the risks factors of falling. For examples, they might change the patients' position or move the patients too quickly in insufficient light or fail to prepare the necessary items for daily living nearby the patients for their convenience. These factors might pose a risk of falling.

Moreover, it was found that the caregivers often did not stabilize the patient during sitting on a chair or in bed.

### **Mobility**

The family caregivers did not follow some procedures of moving the patients on a bed; for example, they did not stand next to the patients' affected side and inform them what actions would be taken and what they must do to help. They did not insert their arm under the patients' shoulders and hips to move the patient's body to the right or left, or up or down.

Moreover, the family caregivers moved the patients from bed to chair or wheelchair by lift or carried them in a manner inconsistent with standard protocol and inappropriate for patient mobility. The correct protocol should be as follows; 1) place a wheelchair or a chair close to the bed on the patient's strong side so that it faces the bed at a 45 degrees angle; 2) support the patient sitting on a bed; 3) grab him/her by the trousers' waist; 4) ask and support them to stand up, and 5) ask them to put both hands on the chair/wheelchair's arm and turn themselves to sit down on the chair or wheelchair with the caregivers' support.

### **Rehabilitation**

The family caregivers often misunderstood some procedures of rehabilitation. For example, they did not exercise the patients' wrist by holding the wrist and four fingers and bending the wrist up and down as well as rotating the wrist. They did some procedure of shoulder and hip rehabilitation incompletely. The caregivers did not lift the paralyzed shoulders of the patients up over their head, and the shoulders were not rotated in and out. For the hip rehabilitation, the paralyzed hips of patients were not bent as far as possible. This incomplete procedure could result in joint stiffness.

Furthermore, they misconceived in the rehabilitation guides for improving coordination and balance in seated and standing positions. They failed to train the patients to balance themselves in an upright position, in a chair/wheelchair and during standing with both feet flat on the floor.

## **CHAPTER V**

### **DISCUSSIONS**

The study on post-stroke care program found that the intervention program has improved practices of post-stroke care and self-efficacy of the family caregivers as well as the patient's functional, clinical, and psychosocial outcomes.

This study is a quasi-experimental research applying IMB model in developing post-stroke care program. The study participants were 62 pairs of family caregivers and stroke survivors with moderately severe disability who had been discharged from the hospital no longer than one month to continue their rehabilitation at home. These participants gave their consent to participate in the study. The study participants were put into two groups, 31 pairs in the experimental group and 31 pairs in the control group. Three data collections were carried out during November 2015 – June 2016: before and after the intervention program was introduced and during the two-month follow-up period. All data collected were discussed below in two parts, research methodology and hypothesis testing.

#### **Part 1 Research methodology**

##### **Research design**

The researcher designed this study as a two-group pretest-posttest quasi-experimental study in which the participants were grouped into the experimental and control groups. This particular research design enables the researcher to compare the effects of the intervention program between groups. Since the study participants were family caregivers who cared for their family members who are post-stroke patients with moderately severe disability, it is crucial that they have the information necessary for providing proper post-stroke care to the patients, preventing complications and promoting full recovery within three to six months according to the standards of the

golden period for recovery (Good, Bettermann & Reichwein, 2011; Chaiyawata & Kulkantrakomb, 2012). Proper care and support enable stroke survivors to become independent and live their life as normal as they did before the stroke. Patient's recovery will in turn lessen the burden of family caregivers as well as the society (Srijumng, 2009). In this case, the experimental group benefited tremendously from the intervention program; whereas the control group received only the usual care from the sub-district health promotion hospitals (SHPHs). It should be noted that SHPHs normally paid delayed home visits, which implicate delayed information and recommendations from healthcare providers in relation to post-stroke care. During the delay, patients could develop complications, and both the family caregivers and patients were not given the needed encouragement to do physical rehabilitation properly and continuously. Without stimulation to their nerves and muscles, patients could develop muscle atrophy and lose muscle strength, including tightness and shortening of connective tissue, tendon and ligament which results in joint contracture. These complications significantly hinder patient's mobility and recovery. Patients could develop permanent disability and become bed-ridden (Bloomfield, 1997; Corcoran, 1991).

This study was conducted in four districts in Kamphaeng Phet Province, the experimental group was in Klong Lan and Sai Ngam districts and the control group was in Muang and Phran Kratai districts. These districts have similar local context that is they are low to middle income rural communities. Stroke survivors were cared for by family members whose knowledge and understanding of caregiving varied; hence the difference in caregiving was provided. The inquiry of the family caregivers revealed that some were visited at home by healthcare providers while others were not. They received healthcare services from SHPHs. These findings reflected the real situation of post-stroke care in rural communities.

Based on the local context, it is logical to select family caregivers as the study participants since they would provide care for stroke survivors once they were discharged from hospital to continue rehabilitation at home. This practice is consistent with the family theory (Friedman, Bowden, & Jones, 2003) which explains that family is the foundation unit that plays a significant role in caring for the health of family members. When a family member is sick, family is the core of care, support and

habilitation until the patient is fully recovered. Stroke survivors normally have very limited ability to care for themselves and thus depend on caregivers almost around the clock. In addition, and according to the standards of care, SHPHs should conduct at least one home visit within the first month of the patients' discharge from hospital to follow up on them and advise the caregivers. In reality, health care providers are unable to follow the guideline and follow up on every patient due to delay in information sharing from hospital to SHPHs. Moreover, public healthcare providers (PHPs) are also overwhelmed with different tasks and responsibilities, which in turn delay the home visits. By participating in this study, family caregivers will receive information and develop skills necessary to provide post-stroke cares. They will have enhanced capacity and be able to provide care correctly to patients by themselves without having to rely on the support from healthcare providers. These caregivers eventually become resourceful in stroke survivor care and rehabilitation and able to provide suggestions to other patients and caregivers in the community. Ultimately, they promote sustainable improvement in post-stroke care and strengthen the community.

The program was built on IMB model and social support concept. The researcher conducted literature review of research studies on post-stroke care and conducted elicitation, which is the first step of IMB model to search for empirical data through in-depth interview, observation, focus group discussion and open-ended questionnaire. The information acquired from this step revealed specific gaps in post-stroke care and the real-life situation of the study setting (Fisher, Fisher, & Shuper, 2009). The researcher used this information to further develop post-stroke care program covering a four-week period. The first week consisted of five sessions (one session per day) and focused on necessary and specific information giving and skills building in relation to practices of post-stroke care. The second and third weeks focused on reviewing the information provided in the first week and return demonstration by the participating family caregivers of the practicing skills they had learnt in the first week to retain the correct and proper patient care practice. The fourth week entailed home visits to follow up on the caregivers and patients on a one-on-one basis since each patient was discharged from hospital at different time. This structure was suitable for the study participants and local context. It also corresponds to the study on the evidence of stroke family caregivers and dyad intervention which

recommends that intervention design address the needs of caregivers. The intervention could be done by face-to-face or via phone calls and should consist of five to nine sessions (Bakas et al., 2014).

The evaluation of the intervention program was carried out with both the family caregivers and post-stroke patients. The patients could benefit from caregivers' practices and self-efficacy. Family caregivers were assessed on their practice of post-stroke care and self-efficacy, and the patients were assessed on the social supports received, ADLs, and complications. The assessment in family caregivers was divided into three parts, before the intervention, after the intervention, and two-month follow-up period to compare score differences in the three phases. The assessment in patients was divided into two parts: after the intervention and at two-month follow-up. Such assessment was appropriate in identifying the changes in family caregivers and patients in each phase.

### **Family caregivers' characteristics**

The demographic characteristics of family caregivers in the experimental and control groups did not carry any statistical significance. Their average age was 49.13 and 51.59 years old respectively. Almost all family caregivers were female. Most of them were daughters of the patients, were married and did not have congenital disease. One-third of them had diagnosis diseases such as hypertension, diabetes mellitus and dyslipidemia. These characteristics of the study participants agree with the literature that suggests that most family caregivers for stroke survivors are female, are family member of the patients and are middle-age persons (Srijumnong, 2009; Junthayanont et al., 2011). Thanks to their filial status, family caregivers provide loving and compassionate care for the patients because Thai society values filial gratitude and care for sick or aging parents (Kopachon, 2002). In terms of education, most caregivers had primary education at best, others did not attend school. Approximately one third of the family caregivers was in general employment and agricultural sector, followed by trading and was housewife/unemployed. They earn 10,000 baht per month or less. This information also agrees with the literature that suggests that low level of education is associated with low income, which put increased burden on the caregivers since post-stroke care to provide both basic and

specific needs to the patient is expensive, for example, physical therapy and treatment cost (Costa et al., 2015). Other research studies also suggest that a level of education is the key factor associated with poor knowledge (Werner, 2001).

### **Post-stroke patients' characteristics**

Similarly, the demographic characteristics of post-stroke patients in the experimental and control groups had no statistical significance. They were elderly persons with the average age of 64.74 and 69.03 years old respectively. Most of them were female. In the experimental group, most of them were married while the control group were either single, widowed, divorced or separated. Although the patients in both groups had different marital status, their family characteristics are not different. In particular, they lived in extended family and most of their caregivers are their daughters. Almost all patients had formal education and finished primary school. Both groups had moderately severe disability according to the modified ranking scale. Most of them had diagnosis diseases, including hypertension which agrees with the study of Yu et al. (2013) that more than 90% of stroke survivors had chronic disease, which is hypertension.

## **Part 2 Hypothesis testing**

### **Practices of post-stroke care**

The findings from this study suggested that after participating in post-stroke care program, family caregivers in the experimental group had higher average practice scores for all five aspects of post-stroke care, namely feeding and aspiration prevention, pressure ulcer prevention, fall prevention, mobility and rehabilitation than before they participated in the program and statistically higher than the control group ( $p$ -value  $< 0.001$ ), which supported hypothesis 1.1 and 2.1.

When compared the practices mean scores between the three phases of data collection, namely before joining the program (Time 1), immediately after the end of the program (Time 2) and the two-month follow-up period (Time 3), the mean scores for all practices during the follow-up phase were significantly higher than the

mean scores measured immediately at the end of the program and before joining the program, respectively.

Analysis of individual aspects revealed that after participating in the intervention program, the experimental group had significantly higher posttest score in all post-stroke care practices, particularly rehabilitation. This finding confirmed that family caregivers were able to provide physical therapy to the patients more correctly and comprehensively to include upper extremities, lower extremities, and coordinating and balancing. On the other hand, the control group had lower score for all practices of post-stroke care than before they participated in the study. Comparison of the mean scores of practices of post-stroke care between the experimental and control groups indicated that the mean score of the experimental group was significantly higher than the control group. This suggested that post-stroke care program did improve the practices of family caregivers in caring for stroke survivors.

Such changes in practices of post-stroke care resulted from the application of IMB model to develop the post-stroke care program. The theory explains that the key factors that contribute to behavioral skills and possible behavioral change are information that is necessary and specific to the desired health behaviors, and motivation (Fisher & Fisher, 1992). Moreover, the information acquired through the elicitation step through in-depth interviews of family caregivers and observation of post-stroke care at home showed that family caregivers did not have adequate knowledge and skills in providing post-stroke care. Some caregivers needed a review of and additional knowledge and information necessary for post-stroke care that they had received prior to the patients' discharge from hospital. In reality, caring for post-stroke patients is complicated. Patients need close and continuous care and support, which are crucial to their recovery. From observation, it was found that family caregivers did not perform procedures of post-stroke care correctly and properly, particularly in feeding and aspiration prevention, pressure ulcer prevention and dressing, fall prevention, patient transfer and physical therapy. Based on the IMB model and information collected from elicitation step, the researcher designed activities that could promote practicing skills of post-stroke care. The design consisted of three key components as described below.

First is provision of information for more effective caring for and rehabilitation of stroke survivors focusing on essential information about risks of complications, symptom observation, and prevention of common complications for stroke survivors such as aspiration pneumonia, joint stiffness, UTI, pressure ulcer, and wound infection. Other information provided included mobility, fall prevention, and rehabilitation. This information related to specific needs of the family caregivers and the patients. The contents were prioritized from simple to complex issues. These factors are consistent with the adult learning concept that the principal factor influencing individual's cognitive structure composes of organization of information, stability, and clarity of knowledge in particular information (Ausubel, Novak, & Hanesian, 1978, p. 217). Therefore, the structure of information in this study had enhanced family caregivers' learning and practicing skills of post-stroke care enabling them to care for the patients correctly and properly. This concept corresponds to the systematic review conducted by White, Cantu, and Trevino (2015) on effectiveness of interventions for family caregivers of stroke survivors. The study found that education and information provision about stroke survivor care is one of the key factors that promote practicing skill building among caregivers and contribute to their performances in caring for the patients.

Second is practice of necessary post-stroke care, including feeding technique and aspiration prevention, wound care, patient mobility and fall prevention, and rehabilitation. The researcher demonstrated each practicing skill to family caregivers, allowed them to practice with first-hand experience and provide return demonstration. The family caregivers received feedback and advice on each return demonstration to promote correct and proper care. These activities had enhanced family caregivers' practices that resulted from the content sequenced from simple to complicate procedures and each practice was taught and demonstrated step-by-step. This finding is consistent with the concept of adult learning that development of practicing skills required domain-specific and knowledge-rich, enhancing experiences by practicing, and improving skills by feedback (Boyatzis & Kolb, 1995). In addition, family caregivers were commended for correct performance to encourage them to continue to perform. Family caregivers who did not perform the practices correctly were further coached and given additional opportunities to practice until they mastered the skills. It also raised

their self-efficacy, so that they could become more confident to care for the patients, which is consistent with the study of Chiu, Wesson, and Sadavoy (2013) on Coaching, Advocacy, Respite, Education, Relationship and Simulation (CARERS). The study participants were informal caregivers of patients with dementia. The program consisted of three key components, namely group psychotherapy, problem-solving techniques and practicing skills training. Part of the practicing skills training included simulation session through which the caregivers performed patient care in an arranged situation. The simulation offered the caregivers opportunity to practice through role playing. The study found upon completion of the program that caregivers had acquired significantly higher self-perception of competence ( $p$ -value  $< 0.001$ ).

Third is promotion of motivation to encourage the family caregivers to provide care to the patients correctly and properly. The researcher applied various techniques, including 1) explaining recovery period of the patients to promote understanding of the family caregivers that with the correct and proper care the patients could recover within three to six months, which is the golden period of patient recovery. With this information in mind, both the family caregivers and the patients were aware of the benefit of proper care. Family caregivers were also motivated to care for the patients while the patients became hopeful and motivated to recover and thus were cooperative with the family caregivers; 2) using positive reinforcement by showing video clip of stroke survivors and family caregivers who shared their experiences about post-stroke symptoms and their impacts including cares that promoted recovery until the patients were almost fully recovered. This activity promoted understanding among the caregivers about problems and severity of stroke so that they may realize the importance of patient care and speedy recovery. As a result, family caregivers were motivated to care for the patients correctly and properly; and 3) using negative reinforcement by citing cases of patients who did not recover and developed various complications leading ultimately to permanent disability, bed ridden and inability to take care of themselves. These conditions directly put the burden on the family caregivers and families. Illustrations were used during the discussion to provide visual clarity and stimulate fear among the participants.

The findings from this study are consistent with the study of Shebl and Abd Elhameed (2014) titled Impact of Informal Caregivers Training Program on Geriatric

Patients' Functional Status and Post-Stroke Depression. The samples were elders with stroke and their informal caregivers. The caregivers participated in the training program that was divided into three sessions. Session one focused on providing basic knowledge about stroke, session two focused on demonstrating practices in moving the patient and the use of assistive devices, and session three focused on providing information about pressure ulcer, fecal impaction and urinary tract infection, communication skills and available community health services for the elders. The study showed that the caregivers acquired more knowledge and higher level of practice while the patients showed improvement in functional status and less depression.

During the two-month follow-up phase (T3), it was found that the experimental group had slightly higher scores in all practices of post-stroke care than those at the end of the intervention program (T2). This demonstrated that the post-stroke care program successfully improved the practices of family caregivers in caring for stroke survivors. This result is consistent with the study of Gitlin et al. (2005) which revealed that practices' skills building intervention decreased negative attitudes and increased behaviors of caregivers to care for the patients well and on a consistent basis. In addition, the slightly higher practice scores of family caregivers at the two-month follow-up resulted from the feedback received on their performances as well as advice on the necessary procedures of post-stroke care from the researcher and VHV's at the fourth and eighth weeks of home visits. Providing suggestions to caregivers increased their understanding of the caregivers' roles and how to care for the patients resulting in improving their practicing skills in patient care (Taylor & Hamdy, 2013).

However, during the two-month follow-up phase in the control group, it was found that their mean scores in pressure ulcer prevention, fall prevention, patient mobility, and rehabilitation were lower than those at the end of the intervention program. This showed that family caregivers who did not participate in the intervention program did not provide correct patient care and had the tendency to lose these practices over time. This could be attributed to the lack of, or delay in receiving, advice, practice and review of cares for pressure ulcer prevention, fall prevention, patient mobility, and rehabilitation. They thus provided cares based on their understanding albeit misconstrued. Nevertheless, the mean score of feeding and aspiration prevention during the follow-up phase was higher than that obtained at the

end of the intervention program with no statistical significance. This could be a result of home visits by healthcare provider from HPH to some family caregivers before the follow-up phase. Those family caregivers might have received some advices on feeding and aspiration prevention, which could impact upon the patients severely and fatally as it could cause aspiration pneumonia and death.

### **Self-efficacy**

The results of the study show that after participating in post-stroke care program, family caregivers in the experimental group's mean scores of self-efficacy in feeding, pressure ulcer prevention, fall prevention, mobility and rehabilitation were higher than those before joining the program and significantly higher than those of the control group (p-value <0.001). This supports the hypotheses 1.2 and 2.2.

When compared the self-efficacy mean scores between the three phases of data collection, namely before joining the program (Time 1), immediately after the end of the program (Time 2) and the two-month follow-up period (Time 3), it was found that the mean scores for all self-efficacies in practices of post-stroke care during the follow-up phase were significantly higher than the mean scores measured immediately at the end of the program and before joining the program (Time 3 > Time 2 > Time 1). This finding shows that self-efficacy of the family caregivers in all practices continuously increased as a result of their participation in post-stroke and social support program. During program development, the researcher analyzed data collected from elicitation step and found the lack of confidence amongst most caregivers in caring for post-stroke patients as a specific gap. The family caregivers were not confident whether they cared for the patients correctly and some were not confident and did not believe that cares provided to the patients would be successful or patients would be able to recover to near-normalcy. In order to fill in such gap, the researcher applied IMB model to develop an intervention as well as strategies to improve self-efficacy (Bandura, 1977), including mastery experience, modeling, verbal persuasion and emotional arousal. These approaches were aimed to enhance the perception of self-efficacy amongst the family caregivers and to promote their confidence in patient care. Previous study employed self-efficacy concept in developing self-efficacy of family caregivers of persons with stroke at home (Sirijumong, 2009). The activities

implemented under the previous study included experience sharing session prior to hospital discharge for caregivers to learn from those who had experience in caring for stroke survivors and successfully promoted their recovery, video presentation about post-stroke patient care, and teaching and demonstration of patient care with practice sessions for family caregivers. The program was followed by home visits conducted within one week after hospital discharge to assess the problems that the patient faced, provide advice to family caregivers and encourage the caregivers to recognize their efficacy in caring for patients using verbal persuasion. Follow-up via phone calls was made in weeks 2, 4 and 6. The study found that self-efficacy scores and the outcome expectation of post-stroke care after the program were significantly higher than the scores before joining the program ( $p < 0.01$ ). The current study included the following additional activities to promote self-efficacy of the family caregivers.

- 1) Mastery experience by allowing the family caregivers to practice skills and equipping them with necessary information about post-stroke care particularly in feeding, pressure ulcer prevention, fall prevention, mobility and rehabilitation. This allowed the family caregivers to perceive their efficacy from direct experience and develop the confidence in providing correct and proper patient care (Chiu, Wesson, & Sadavoy, 2013).

- 2) Modelling by using real-life examples of post-stroke care. The family caregivers viewed video presentation about stroke survivors and family caregivers and cares provided for the patient by their family until the patients were almost fully recovered. This activity allowed the family caregivers to make comparison and realize that they could practice the same behaviors (Resnick, 2008). This would motivate them to care for the patients and become hopeful that patients could recover if they have the patience and provide correct and continuous care for them.

- 3) Verbal persuasion was provided by the researcher to the family caregivers. The researcher suggested to the family caregivers the benefits of correct patient care to persuade them to provide continuous, correct and proper cares for patients (Firmawati, Songwathana & Kitrunrote, 2014) and to become confident that they could successfully promote patient recovery.

- 4) Emotional arousal by using video presentations about stroke survivors who successfully recovered as a result of the cares provided by family caregivers. This

technique was aimed to motivate the family caregivers and the patients to perform correct behaviors (Srijumong, 2009) and to stimulate apprehension about the severity and complications of stroke. During the discussion, the researcher gave some examples of patients who did not recover successfully and showed images of the severity of complications.

At the two-month follow-up phase (Time 3), the experimental group had slightly higher self-efficacy scores in all practices of post-stroke care than that at the end of the intervention program (Time 2). This resulted from the opportunity to review necessary information about patient care and practice the skills continuously after the end of program that provided by the researcher and/or VHVs through home visiting at the fourth and eighth week. During a home visit, family caregivers received feedback and advice from the researcher after every practice and return demonstration which assured them that they performed correctly. Moreover, the caregivers practiced the tasks of post-stroke care for their patients every days that the more they practices correctly, the more confidence they felt. This was consistent with the prior study of Levine, Halper, Peist, & Gould (2010) showed that repeated practices could be promote caregivers to become familiarized with the practice and confident in providing cares for patients. Furthermore, expectation of the outcome of post-stroke care did enhance the confidence of the caregivers. Once they are confident, they are not discouraged easily in the face of obstacles. This could lead to persistent and sustainable caregiving behaviors (Srijumong, 2009). Only upon seeing the step-by-step improvement in the conditions of the patients under their care do caregivers realize the success of their cares. The family caregivers then acknowledge their efficacy and become more confident in caring for the patients.

Where self-efficacy scores of control group in the three phases are concerned, the feeding mean score of the follow-up period was significantly lower than that measured immediately after the program ended. Both pressure ulcer and mobility mean scores of the follow-up period were lower, but not significantly, than those measured immediately after the program ended and before the program started (Time3<Time2<Time1). These findings suggest that family caregivers had lower perceived self-efficacy over time which could result from inadequate information about post-stroke care, insufficient practice of the necessary skills (Firmawati,

Songwathana, & Kitrungrrote, 2014) or delayed advice on post-stroke care due to the limitations of the SHPHs, including late referral of patient's document, understaffing (Ruttawongsa & Kongtalin, 2012) and increased workload of the healthcare providers which in turn delayed their home visits. The decrease in perceived self-efficacy also resulted from the failure that the caregivers felt in caring for patients when the patients showed no improvement or developed complications or their conditions worsened (Zhang, Edwards, Yates, Li, & Guo, 2014). The decreased self-efficacy would undermine the confidence in caring for patients (Van den Heuvel, Witte, Schure, Sandeman, & Jong, 2001) and inability to care for the patients correctly and properly, which affects the patient's condition and recovery. It is consistent with the study of Semiatina and O'Connor (2012) on the relationship between self-efficacy and positive aspects of caregiving in Alzheimer's disease caregivers. The mentioned study found that caregivers with high self-efficacy provided good and quality cares for patients. Moreover, this self-efficacy was associated with positive thinking, improved control of negative effects and enhanced motivation of the caregivers.

### **Social support in post-stroke patients**

The research finds that after joining the program, patients in the experimental group had significantly higher mean scores in social support received from family caregivers and VHVs than before the program started and significantly higher than those of the control group. This supports the hypotheses 3.3 and 4.3.

This study divides social supports that the patients received into two types, one from family caregiver and the other from VHVs. The findings are discussed below.

### **Social support from family caregivers**

Comparison of the mean scores for each support of the experimental group in the two times of data collection showed significantly higher mean scores for emotional, instrumental, and appraisal supports in the two-month follow-up period (Time 3) than those measured immediately after the end of program (Time 2). For the information support, the mean score at the time 3 was also higher, but not significant, than those of the time 2. These findings showed that after the family caregivers'

participation in the program, the patients received more supports from their caregivers in all areas.

The above findings resulted from the analysis of the data collected during the elicitation step. The analysis revealed that most family caregivers lacked awareness of the importance in providing social supports for patients. Not only did they not provide information regarding post-stroke recovery period and early recovery stimulation or give guidance of what the patient should do, but they also did not provide appraisal support to the patients. They did encourage the patient to perform physical therapy by themselves, but did not provide feedback as to whether the patient had done it correctly or how it could be corrected. Some families did not provide instrumental support, for example, physical therapy equipment and labor of the family caregivers in helping the patient perform physical therapy or daily routine. Most patients testified that they received emotional and instrumental supports earlier when they were discharged from hospital and received less and less support over time. This information reflected another problem of post-stroke care in community. The researcher thus applied IMB model in designing the intervention program. The activities that increased social support the patients received are as follows.

- 1) The researcher provided information to the family caregivers about the importance of social supports and ways they could be provided to patients based on the four methods (House, 1981), namely emotional, instrumental, information and appraisal supports. The study of Tilling, Coshall, McKeivitt, Daneski, and Wolf (2005) tested the interventions to support stroke survivors and their families in the community. Patients in the experimental group received information and emotional support along with their families' prevention advice from family support organizer (FSO) service. The study found that stroke survivors were satisfied with information support they received in relation to recovery and felt that someone had listened.

- 2) The researcher demonstrated to family caregivers how to provide social support to patients, particularly emotional, information and appraisal supports. Family caregivers were encouraged by the researcher every time they participated in the study activities to provide different social supports. For example, emotional support could be provided through verbal and non-verbal communication. The gestures that family caregivers had towards the patient and the verbal appraisal on patient's behaviors

would make the patient feel loved, cared for, accepted and respected and that they could trust the caregivers. These effects will promote patients' morale and motivate them to want to recover and become more cooperative with the caregivers (Cobb, 1976; House, 2001). Instrumental support includes arranging for walkers or equipment for physical therapy as well as assistance in preparing food, feeding, preparing medicine for each meal and cleaning the sleeping area for example. Information support includes providing information or advice to the patients to promote recovery and to ease the problems the patients faced such as giving information about the benefit of early recovery and post-stroke self-care to prevent complications (Reddy & Reddy, 1997). For example, tell the patients to eat slowly and chew food carefully before swallowing it to prevent aspiration, encourage the patients to turn on their side to prevent pressure ulcers, and recommend arm and leg exercise while encouraging the patients to perform the exercise by themselves. Appraisal support is the feedback provided to the patients to affirm their behaviors with which the patients could use to assess their performance (Cobb, 1976) such as appraise them when they ate food or drank water by themselves and did not choke, or when they could sit for a longer period of time, or when they walked better. Such appraisals will enable the patients to assess themselves and know their ability.

Moreover, the increased social supports from family caregivers at the time 3 were higher than that of the time 2 resulted from the family caregivers having an opportunity to review the information on the importance of social support and the ways to provide different types of social support during the home visit. The researcher encouraged the family caregivers and family members to demonstrate how to provide social supports to patients in different situations. This contributed to sustainability of social support provision over time. Such is a mutual support between the providers (caregivers) and receivers (patients) where one empowers the other. This mutual support must be balanced (Thiangtham, 2011: p. 11). As a result, the patients will feel the love and affection, will be motivated to recover and become more cooperative with the family caregivers. In return, the family caregivers will also feel motivated to continue to care for the patients. Furthermore, some patients were cared for by family caregivers or family members who were village health volunteers or were trained in caring for patients unable to care for themselves and thus received more social

supports. Those family caregivers might have experiences in providing advice and caring for the patients in similar conditions and therefore understood, realized and were able to continuously provide different proper social supports to the family member.

In the control group, all dimensions of social supports provided by family caregivers at the two- month follow-up (Time 3) were significantly lower than that measured immediately after the end of program (Time 2). These results signified that the patients in the control groups received less emotional, instrumental, information, and appraisal supports from their family caregivers which might have been due to inadequate information the caregivers received about the importance of social support, and lack of advice on ways to provide social supports to patients. Consequently, the family caregivers could not appreciate the benefits of social support and were unable to provide them to the patients adequately and properly to promote patient recovery (O'Sullivan, 2015).

### **Social support from VHV's**

In the experimental group, the mean scores of emotional, information, and appraisal supports that the patients obtained from family caregivers at the two-month follow-up (Time 3) were slightly lower than the scores at the end of program (Time 2) with no statistical difference. These results indicated that there were no differences in receiving emotional, information, and appraisal supports from their family caregivers between the two time periods. The VHV's' role and responsibility was successful in providing support to the patients in the community. However, the mean score of instrumental support in the experimental group at time 3 was significantly higher than that of the time 2. This result showed that the patients received more supports in instruments for mobility and physical rehabilitation. The changes in instrumental support after participation in the program was due to the VHV's increased concern for providing essential and appropriate instruments for the patient's condition in walking practice, balancing practice, and rehabilitation. They coordinated with the SHPHs to requests for wheelchair, cane, and/or walker as well as transporting the same to the patients. By receiving different types of social supports from social network, the patients would feel safe because they were taken care of and recognized, so they felt

that they belonged were still a part of the society and thus were able to adjust and overcome the present situation (Cohen, Gottlieb, & Underwood, 2000). If the after stroke patients received high level of social support, they would recover faster with more extensive recovery of functional status (Glass, Matchar, Belyea, & Feussner, 1993).

Moreover, the receiving social supports from VHVs in the experimental group was a result of the analysis of the data collected from elicitation step with a view to identifying problems in the provision of social supports by the VHVs. The analysis result was further used to design activities of the intervention that were suitable to the situation in the community. In particular, it was found that the healthcare providers from whom the patients received most social supports were the village health volunteers (Chinchai, Jindakham, & Punyanon, 2015). In general, patients received emotional and instrumental supports from the VHVs. However, most VHVs failed to provide information support and did not give necessary information about recovery to the patients such as the golden period of recovery, self-care to prevent complications and correct physical therapy. They also did not provide appraisal support and only asked about the patients' general symptoms which agreed with the findings of previous studies investigating problems in stroke survivor care in communities. According to those studies, the VHVs lack the knowledge and skills (Piyabunditgul, 2012) and the confidence in caring for the post-stroke patients (Pinyo et al., 2015).

Considering the above, this study engaged the VHVs in various activities to receive necessary information and to provide social supports to the patients. The researcher provided information about the importance of and methods to provide social supports based on the four methods of social support (House, 1981). This activity raised awareness of the VHVs about the benefits of social supports to patient recovery and gave them the opportunity to learn how to fulfill their roles in providing different types of social supports (Sit, 2000: p. 57). The researcher encouraged the VHVs to provide social supports such as verbal and non-verbal emotional support which could communicate the love, understanding, caring, sympathy and respect between them. This included asking the patients about their conditions, talk to the patients' or hold their hands to show support, appraising the patient when they worked

with the family caregivers in carrying out their daily routine or perform physical therapy, for example. Instrumental support included arranging for necessary equipment for patient care such as for wound dressing or for carrying out daily routine or performing physical therapy such as pulleys for arm exercise. Previous qualitative researches showed that patients needed help and supports to exercise which would improve their physical condition and social confidence (Reed, Harrington, Duggan, & Wood, 2010). Information support included advice about the causes and prevention of complications, benefits of early recovery and golden period of recovery. This information would help the patients understand and feel confident in taking care of themselves to promote recovery (Chinchai, Jindakham, & Punyanon, 2015). Appraisal support included giving advice on self-care and carrying out daily routines that the patients had not yet been able to do by themselves, providing feedback and advice on the correct way to do arm and leg exercises when the patient did them incorrectly, and commending them for their efforts to sit or walk by themselves.

As for the control group, it was found that the mean scores of emotional, information, and appraisal supports at time 3 were significantly lower than those at time 2. For the instrumental support, the mean scores at time 3 were also lower, but not significant, than those at time 2. These results showed that the patients received less of all types of social supports from the VHVs. This was due to the inadequate information the VHVs had about the importance of and methods in providing social supports to stroke survivors. They thus were not confident and unable to provide these supports to the patients properly and adequately to promote their recovery (Piyabunditgul, 2012). Moreover, their VHV's role is that of volunteers whose main duties are to earn a living and provide for their family. This limits their capacity in caring for the patients in their responsible communities. Other factors that contributed to the late provision of social supports to the patients included the delayed home visits which were a result of the delay in referring patient's document, staff shortage (Ruttawongsa & Kongtalin, 2012) as well as the heavy responsibility shouldered by VHVs. According to the patients in the control group, some of them have never been visited at home.

The results from social supports in post-stroke patients provided by family caregivers and VHVs showed that post-stroke care and social support program could

increase social supports that the patients received from both groups of providers. With such social supports, the patients would realize their self-worth and the love of their family and the society for them, become hopeful and motivated to recover so that they would no longer be the burden of their family (Cobb, 1976). This finding was consistent with the previous study that showed that social supports enable the patients to cope with stress after stroke. Receiving social supports is significantly associated with the quality of life of the patients in terms of their functional status, well-being, general health perception and global quality of life (Daapoglu & Tan, 2010).

### **Activities Daily of Living (ADLs)**

The study showed that after the family caregivers participated the post-stroke care program, the mean score of patients in the experimental group for their ability regarding activities of daily living (ADLs) at the two-month follow-up (Time 3) was significantly higher than after immediately the end of program (Time 2) and higher than that of the control group which supports the hypotheses 3.1 and 4.1.

The comparison of the mean scores of the ability to perform ADLs between patients in the experimental group and those in the control group using the Modified Barthel Index (MBI) (Shar et al., 1989). Data collection for this research was carried out two times: immediately the end of program and the two-month follow-up period. The purpose was to obtain, and subsequently compare, the mean scores of all MBI aspects, namely personal hygiene, bathing, feeding, using toilet, dressing, bowel control, bladder control, ambulation, chair/bed transfer and stair climbing.

In the experimental group, the mean score of the ability to perform ADLs during the two-month follow-up (MBI=73.10) was higher than that of the immediately the end of program (MBI=40.13). Each aspect of MBI showed that the patients had more improvement in abilities of feeding, using toilet, dressing, ambulation, transferring, and stair climbing. This means that the patients continuously became more able to perform daily activities over time. Their ADLs had improved from severe dependence (MBI = 21-60) to moderate dependence level (MBI = 61-90) meaning that while the patients were more able to take care of themselves, they still needed some assistance from their family caregivers (Loharjun, Wannapira, Palivani, & Cumjun, 2008). For example, patients were able to take shower by themselves but needed help in preparing bathing

equipment, they could feed themselves but needed the family caregiver to help preparing food and prevent aspiration, and they could walk or climb up stairs by themselves but still needed someone to support them when they walk. The two-month follow-up occurred when patients had been in post-stroke condition for about three to four months and was the minimum recuperation threshold of the golden period (three to six months) (Good et al., 2011). If the patients could maintain their efforts to perform activities by themselves, they would have a better chance to recover rapidly.

These findings suggested that post-stroke care program could improve the patient's ability to perform daily activities which could be attributed to the following factors.

First, the intervention was appropriated and related to specific needs of the family caregivers and the patients because of using the information from elicitation step to develop the intervention. The family caregivers were given information, motivation, and opportunities to practice skills to promote early recovery and to assist the after stroke patients in performing physical rehabilitation. The upper and lower extremities exercise stimulated dynamics of blood circulation (Radegran & Saltin, 1988), improved muscle strength and skeleton muscle tone (Signal, 2014), postural control, and coordinating and balancing (Persson, Hansson, Lappas, & Danielsson, 2016), all of which improved the patient's ADL functions (Pohl et al., 2007). The positive outcomes on the patients were the results of the correct and proper cares of their family caregivers which support with the IMB model. The IMB model explains that factors contributing to health behaviors of individuals are information, motivation, and behavior skills (Fisher & Fisher, 2002). Equipped with these factors, caregivers could provide correct and proper cares for patients while feeling more confident in their ability to care for patients (Osborn & Egede, 2010) resulting in improved rehabilitation and growing ability of patients to perform more daily activities over time. This consistent with the study of Li and McLaughlin (2011) which found that caregivers' confidence in their ability promoted improvement in ADL performance among the elderly persons that they cared for.

Second, patients received various social supports from family caregivers, family members, and healthcare providers. Such supports promoted their morale. They thus became hopeful and motivated to recover from post-stroke condition, wanted to

take care of themselves more without being dependent on the caregivers and to be able to live their life as normal as possible (Bays, 2001). Patients therefore became more cooperative with the family caregivers and followed caregivers and healthcare providers' suggestions strictly. Social supports included assistance from family caregivers and family members to the patients in performing physical therapy, including financial support and physical therapy equipment. These supports all have positive impacts on patient's recovery which agrees with Levine, Halper, Peist, and Gould's study (2010) that suggested that promoting family caregivers as primary care partners by providing them training and social support would result in better patient outcomes and reduced unnecessary re-hospitalizations. The findings were also consistent with the finding of the study on family support in the first-stroke recovery phase that moderate/severe stroke patients who had high level of social support had significantly better and progressively improving functional status than the patients with less support (Tsouna, Vemmos, Zakopoulos, & Stamatelopoulos, 2000).

In the control group, however, the mean score of the ability to perform ADLs during the two-month follow-up (MBI = 40.68) was significantly higher than the immediately after the end of program (MBI = 32.19). At any rate, the higher mean score during the two time periods still falls in the severe dependence range (MBI = 21-60), the same range as time 2 and time 3 scores. The activities with slightly higher scores included bathing self, feeding, using toilet, dressing, ambulation, chair/bed transfer, and stair climbing where patients still needed assistance from the family caregivers in every stage of the activities. The patients received lower scores in personal hygiene from being able to perform the activities with little support before or after the activities to needing support in every step in brushing teeth, combing hair, and washing hands and face. There was no change in the score in bowel control and bladder control.

The comparison of the mean scores of ADL functions between the experimental and control groups shown that the control group had significantly lower score (MBI=40.68) than the experimental group (MBI=73.10). The patients in the control group were in severe dependence level (MBI=21- 60) while the experimental group was in moderate dependence level (MBI=61-90). This was because the patients in the experimental group received both the usual care from the SHPHs as well as care

from family caregivers who participated in the post-stroke care program while the patients in the control group only received the usual care from the SHPHs. The ability to perform ADLs in severe dependence level (MBI = 21-60) of the patients in the control group was resulted from the lack of information about post-stroke care and recovery among the caregivers. The family caregivers thus lacked understanding about patient care that could promote patient's ability to perform daily activities, and about early recovery and physical exercise stimulation in particular which are the foundation of patient recovery (Reeves, 2004) and could improve ADLs functions of the patients (Langhammer, Linkmark & Stanghelle, 2007). Family caregivers might be burnt out from the responsibility in caring for patients who cannot care for themselves (Van den Heuvel, Witte, Schure, Sanderman, & Jong, 2001) and are dependent on the caregivers almost throughout the day. The delay in receiving information, advice and social support could also demotivate, discourage and cause hopelessness among the family caregivers and resulted in their negligence in caring for the patients (Lee, Song, & Shin, 2008: 113-114). This agrees with the study of Damush et al. (2007) suggesting that barriers of exercise after stroke included physical impairments, lack of motivation and environmental factors and that facilitators to exercise among stroke survivors included motivation, social support and exercise activity plan.

### **Complications**

Prior to the participation of family caregivers in the post-stroke care and social support program, patients in both experimental and control groups did not have complications, namely aspiration, pneumonia, UTI, pressure ulcer, joint stiffness and recurrence stroke. The comparison of complications during the three phases of data collection shows that patients in the experimental group did not have any complications after the program, except one patient who developed joint stiffness during the follow-up period, hence the rejection of the hypothesis 3.2. In the control group, two patients developed complications, namely joint stiffness and pressure ulcer, after the program. More patients in the control group developed complications during the follow-up period, which resulted in 16 patients in total who developed complications: aspiration pneumonia (1), UTI (1), recurrent stroke (2), pressure ulcer (4) and joint stiffness (15). In reviewing the complications developed, it was found

that some patients had multiple complications. One patient had UTI, pressure ulcer and joint stiffness, one had joint stiffness and recurrent stroke, one had pneumonia and recurrent stroke, and three had pressure ulcer and joint stiffness.

These findings show that patients in the experimental group developed fewer complications than the control group which supported hypothesis 4.2 that post-stroke care and social support program could prevent complications in stroke survivors. This is also a result of the application of IMB model in developing the care program to provide the family caregivers the information about complications, motivation in patient care to prevent complications, and the opportunity to practice skills in feeding and aspiration prevention, wound dressing, patient transfer, changing of bed position and physical therapy. Improved skills enabled the family caregivers to provide correct and proper cares to patients and prevent complications as discussed further below.

Aspiration pneumonia prevention: Family caregivers received information about the causes, symptoms and prevention of aspiration pneumonia, including the opportunity to practice feeding and aspiration prevention. This activity provided them a step-by-step in which they could learn with better understanding and concern about the importance of each feeding procedure to prevent aspiration. Patients thus received correct and proper care. For example, the patients must be fed with food easily to chew and swallow, appropriate amount of food, assisted to sit up to eat, observed for signs of aspiration such as coughing or sneezing, and their ability to swallow assessed (Singh & Hamdy, 2006). One patient in the control group had aspiration pneumonia. From observation and inquiry of the patient about cares provided by the family caregiver, it was found that this particular patient had dysphasia which affected chewing and swallowing ability due to weakness of the muscles that control swallowing biomechanics that put the patient at risk of aspiration. Lying in bed almost all the time, the patient often had aspiration when fed and was at risk of reduced lung expansion and diffusion capacity, not to mention inflammation in airways and lung parenchyma, risk factors for aspiration and pneumonia (Masiero, Pierobon, Previato, & Gomiero, 2008).

UTI prevention: All patients under this study both in the experimental and control groups did not have retained urinary catheter. However, most of them were

wearing diaper due to urinary incontinence. Family caregivers in the experimental group thus received information from the researcher about the risk, symptoms and care for the patients to assist the patients to empty their bladder to prevent UTI. The study found that all patients in the experimental group did not develop UTI because they received correct care from their family caregivers. In other words, they were urged not to hold in urine and were assisted into urinate position or to go to the toilet when they felt the urge to urinate to stimulate urination (Ersoz et al., 2012). As for the control group, one patient developed UTI. Observation and further inquiry revealed that this particular patient could sometimes control the bladder. Since the family caregiver and other family members work outside the house leaving the patient at home alone during the day, the patient had to hold urine often as there was nobody to assist him to the toilet. The patient commented that 'I wanted to go to the toilet, but no one was here to take me. I couldn't go by myself. If I couldn't hold it anymore I'd urinate in the diaper, but I felt I hadn't quite emptied my bladder.' This finding was consistent with the study on urinary tract infections complicating stroke (Poisson, Johnston, & Josephson, 2010) explained that UTI could occur in patients with or without Foley catheter. Bladder dysfunctions which causes urinary incontinence, and inconvenient use of urinal or bedpan for that matter may also contribute to UTI. Hemiparesis usually found in stroke survivors also limits patients' mobility and affects their transfer to the toilet or bedside commode.

Pressure ulcer prevention: The activities in the program included provision of information to family caregivers about different key topics, including cause, assessment and stages of pressure ulcers. Actual images of pressure ulcer were used to raise their awareness about severity of pressure ulcer. Information about nutrition and type of food that help prevent, and promote recovery of, pressure ulcer was also provided. The researcher provided information about patient care to prevent pressure ulcer, including how to clean patients after each urination or bowel movement; keeping bed sheet dry, clean and tight to minimize dampness and friction on the patients' skin; lifting and moving without dragging them on the bed so as to avoid friction and damage to the skin; and encouraging the patients to change position at least every two hours. The researcher demonstrated how to help turn patients on to their side and allowed the caregivers to practice until they did it correctly. This

approach was drawn on the study on the effect of designed pressure ulcer prevention program on caregivers' knowledge of immobilized patients which found that after joining the teaching program, the caregivers had higher mean score of prevention of ulcer knowledge which covered skin care, proper positions, nutrition and exercises. The more knowledgeable the caregivers, the more correct care for the patients. The study however did not assess patient's outcomes (Alhosis, Qalawa, & Abd El-Moneem, 2012). In this study, one patient in the experimental group had stage I pressure ulcer in the buttocks, so did four patients in the control group, three in stage II and one in stage III. The reason these patients developed pressure ulcer was that they laid down in the same position for an extended period. Their caregivers did not help them change position at least every two hours. Patients only changed position when they were going to take a shower or urinate or have bowel movement. The pressure on the skin caused occlusion of blood flow, tissue ischemia and cell death which resulted in pressure ulcer (Kagan et al., 2002). Moreover, most patients wore diaper almost all the time, so their skin was damp. The bacteria accumulated in soiled diapers could destroy the skin and cause pressure ulcer infection (Dolynchuk, Keast, & Campbell, 2000).

Joint stiffness prevention: Family caregivers received information about the causes, symptoms and prevention of joint contracture and had the opportunity to practice rehabilitation which is important for joint exercise for patients. The rehabilitation covers both the upper and lower extremities. Physical exercise can stimulate nerve cells and muscles, promote mobility of joints and reduce the contraction of connective tissues, tendons and ligaments and prevent joint stiffness (Blommfield, 1997). This study found that one patient in the experimental group had shoulder stiffness which occurred immediately after the program ended. The patient received one physical rehabilitation per week and had never had the rehabilitation for two consecutive weeks due to family's limitation. The patient lived with his wife who had to work outside the house to take care of both the family and patient care expenses. Fifteen patients in the control group had joint stiffness, one in the knee, five in the shoulder, five in the hips and four in both the shoulder and hips. This was due to the lack of information and skills in complication prevention. Patients in the control group thus did not receive care to prevent these complications or might have received incorrect care. The study of Skalsky and McDonald (2012) on the prevention and

management of limb contractures in neuromuscular disease confirms that physical exercise can prevent contractures. The exercise should start soonest possible before any sign of limb contracture including difficulty in moving joints or joint pain. Physical therapies to minimize the risk of developing limb contracture are daily standing and/or walking, passive stretching of muscles and joints, extension and flexion of limbs and splinting.

Recurrent stroke prevention: Family caregivers received information about methods to minimize risk of recurrent stroke, including ensuring that patients strictly adhere to their treatment and take their medicine, eat proper food, exercise to promote blood circulation and finding relaxing activities for the patients. These activities help keep blood pressure in the normal range since high blood pressure is the main cause of stroke (Schmid et al., 2009). No patient in the experimental group developed recurrent stroke which suggested that the caregivers who participated in the intervention program were able to provide care for the patients and prevent recurrent stroke correctly, properly and continuously. This finding is consistent with the study of Evans-hudnall et al. (2014) shows that the information about signs and symptoms of stroke, primary and secondary stroke risk factors, behavioral strategies for reducing recurrent stroke and resources for assistance with stroke-prevention along with dietary and exercise the caregivers received could reduce the risk of secondary stroke. Nevertheless, two patients in the control group had recurrent stroke during the follow-up phase due to patients missing doses (Tiamkoa, 2009), not receiving regular physical exercise or being under stress (Evans-hundnall et al., 2014).

Moreover, more patients in the control group than in the experimental group developed complications because they and their family caregivers received delayed home visit and social support. They were therefore not stimulated and reminded to monitor patient's symptoms and complications. Family caregivers did not have adequate and comprehensive information needed for prevention of complications (Kuptniratsaikul, Kovindha, Suethanapornku, Manimmanakorn, & Archongka, 2013) therefore lacked confidence and were not able to identify the risks and prevent the complications.

### **Limitations**

1) The study participants in this study cannot represent the population of caregivers and post-stroke patients because they were recruited through non-randomization technique due to the limited number of post-stroke patients. Nevertheless, the researcher minimized this limitation by applying the set criteria in recruiting the study samples.

2) This study was conducted in communities and may contain confounding variables, i.e. the different patterns of routine cares provided by the SHPHs in each area. The study samples might thus have received different cares from the SHPHs.

## **CHAPTER VI**

### **CONCLUSIONS**

This study is a quasi-experimental study applying two-group pretest-posttest experimental design. It was aimed to study the efficiency of the post-stroke care program on the practice and self-efficacy of family caregivers as well as stroke patient's ADL functions, complications, and social support. The study samples were 62 pairs of family caregivers and post-stroke patients with moderately severe disability. The samples were divided in halves into the experimental group and the control group. The experimental group received intervention for four weeks while the control group received routine care of the SHPHs.

This study was conducted in three steps based on the Information Motivation Behavioral Skills (IMB) model including the elicitation, intervention, and evaluation. The conclusions of the three steps, implications, and recommendations for further research are presented as follows:

#### **6.1 Conclusion**

##### **Step I Elicitation**

The real-life situation of post-stroke care in the research setting in Kamphaeng Phet Province was explored through in-depth interviews with seven family caregivers, observation of post-stroke patients and care provided by their family caregivers at homes and in focus group discussions: one with five healthcare providers and the other with ten village health volunteers (VHVs) of the Naimuang Subdistrict Health Promotion Hospital (SHPH).

These activities provided empirical data of the existing specific gaps of post-stroke care in the community. In particular, family caregivers who were the key persons in caring for the rehabilitating stroke survivors did not receive adequate

information essential for caring for post-stroke patients. They thus lacked confidence in providing care to prevent complications such as aspiration, pressure ulcers and wound care, fall prevention, including patient transfer and physical therapy. The lack of confidence affected the quality of care for, and the recovery rate of stroke survivors. Family caregivers also lacked motivation in providing continuous care for patients and did not realize the importance of giving social supports to the patients. From observation, it was noticed that post-stroke patients developed pressure ulcer, joint stiffness and loss of muscle mass, which further resulted in disability and bed-ridden condition of the patients.

Despite the guidelines, SHPHs did not conduct the prescribed one home visit - at least once - within the first month after patient's hospital discharge to follow up on the patient and to advise family caregivers. This was due to certain limitations contributing to delay and discontinued follow-up visits and supports provided to after stroke patients and family caregivers. These limitations were the delay in referring patient's medical documents from hospital, staff shortage, heavy workload covering a wide range of duties such as health promotion, disease prevention, care and treatment, rehabilitation and community environmental promotion. Information acquired in the elicitation step was further used to develop the intervention in post-stroke care program to build family caregiver's practices and enable them to care for and rehabilitate stroke patients.

### **Step II Intervention**

The researcher combined the information from literature review and elicitation phase to design the intervention program that suits the context of the community in the research setting. The intervention was based on the IMB model and social support concept.

The activities included in the program consisted of a four-week information giving and practicing skill building for family caregivers. This four-week program was provided to each family caregiver individually since stroke patients were discharged from hospital on different days. The first week focused on giving information and building practice skills necessary for caring for stroke patients and consisted of five sessions: Day 1: basic information about stroke pathology,

complications and severity of stroke, golden recovery period, assisting patient to do daily activities and complication prevention; Day 2: essential information about pressure ulcer, wound infection and UTI symptoms and practices in preventing these conditions and in wound care; Day 3: essential information and practices in post-stroke patient's nutrition and medicine; Day 4: information and practices in patient mobility, fall prevention and rehabilitation; and Day 5: information about emotion and stress management, including the importance of and ways to provide social support to post-stroke patients.

Weeks 2 and 3 focused on reviewing all information provided in the first week and allowed the family caregivers to provide return demonstration of the skills they had practiced and to ask questions about the problems or challenges faced from caring for patients. The researcher provided recommendations and advice on the correct practices care for post-stroke patients. Week 4 focused on following up on different cares for patients and conducting posttest evaluation after the intervention program as well as asking for needs for support in relation to patient care such as cane, walker or wheelchair. The researcher coordinated such needs with concerned partners for further assistance.

### **Step III Evaluation**

#### **Characteristics of participants**

Family caregivers and their post-stroke patients in both the experimental and control groups did not have significant differences in their characteristics ( $p > .05$ ) as discussed below.

Family caregivers in the experimental and control groups had similar average age of 49.13 (SD = 11.53) and 51.59 (SD = 13.39) respectively. Most family caregivers were female and 45.1% of the experimental group and 61.2% of the control group were daughters of the patients. Most of the caregivers in both groups were married, did not have medical condition, and completed at most primary education. Approximately one-third of the family caregivers were in general employment and agriculture and earn 10,000 baht or less per month.

Most post-stroke patients were elderly persons with an average age of 64.74 years (SD = 12.09) for the experimental group and 69.03 years (SD = 12.83) for the control group, and had moderately severe disability. The majority of the experimental (58.1%) and control (64.5%) groups were female. More than half of the patients in the experimental group were married, while those in the control group were single, widowed, or divorced. The patients in both groups lived in extended family. Almost all of them completed at least primary school and have hypertension.

### **Effectiveness of the post-stroke care program**

The evaluation of the program was conducted with both the family caregivers and post-stroke patients. The family caregivers were assessed for their practices and self-efficacy in post-stroke care while the post-stroke patients were assessed for their ADL functions, complications, and social support. The assessment was conducted at three times, before the program, after the end of program at week 4, and during the two-month follow-up phase (week 8). The assessment results can be summarized as follows.

#### **Practices of post-stroke care**

After participating in the program, family caregivers in the experimental group had improved practices in all five areas, namely feeding and aspiration prevention, pressure ulcer prevention, fall prevention, mobility, and rehabilitation. The mean score of all practices of the experimental group was significantly higher than that of the control group (p-value < 0.001).

#### **Self-efficacy**

After participating in the program, family caregivers in the experimental group had improved self-efficacy in feeding and aspiration prevention, pressure ulcer prevention, fall prevention, mobility and rehabilitation. The mean score of self-efficacy in all five areas of the experimental group was significantly higher than that of the control group (p-value < 0.001).

### **Social support**

By participating in the program, patients in the experimental group received more social support from family caregivers and VHV. The mean score of social support that patients in the experimental group received was significantly higher than that of the control group (p-value < 0.001).

### **Activity daily of living**

After participating in the program, patients in the experimental group had significantly improved ADL functions and ability to perform ADLs when compared to patients in the control group (p-value < 0.001).

### **Complications**

At the end of the program, no patient in the experimental group developed complications while patients in the control group (6.4%, n = 2) developed joint stiffness and pressure ulcer. There was a significant difference between the two groups in complication development during the two-month follow-up phase (p-value < 0.001). Patient in the experimental group (3.2%, n = 1) developed joint contracture while patients in the control group (51.6%, n = 16) developed complications, namely UTI, pressure ulcer and joint stiffness (1), joint stiffness and recurrent stroke (1), aspiration pneumonia and recurrent stroke (1), pressure ulcer and joint stiffness (3), and joint stiffness (10).

## **6.2 Implications**

This study offers the following recommendations on nursing role, community level care, and policy level implication:

### **6.2.1 Nursing role**

6.2.1.1 Implementation of this program should start immediately after post-stroke patients are discharged from hospital to promote correct, proper and continuous care that the patients would receive from family caregivers.

When the patients recover well, they will be able to take better care of themselves and in turn reduce the burden on and tiredness of the family caregiver.

6.2.1.2 Public health nurse should stimulate and monitor practicing skills of post-stroke care among the family caregivers, follow up on patients at their home and learn about their needs for support and assistance on a regular basis for sustainable post-stroke patient care and rehabilitation in community.

6.2.1.3 Public health nurse should conduct case management for post-stroke care in community and coordinate with experts such as physical therapist, nutritionist and physician to promote effectiveness of recovery in post-stroke patients.

## **6.2.2 Community level care**

6.2.2.1 Regarding the effectiveness of this program on improvement of ADLs and complication prevention in post-stroke patients; therefore, the SHPHs should provide this program to family caregivers who are the primary caregiving for the patients after stroke, by integration the tailored post-stroke care program into their routine care via home visiting.

6.2.2.2 Before launching the program, the SHPHs should conduct a workshop for healthcare providers and VHVs in order to prepare and improve their knowledge and capabilities to advice and demonstrate with family caregivers about post-stroke care.

6.2.2.3 This program can be used to promote post-stroke care at home in other communities with similar context to the communities under this study. It could also be adapted for disabled or elderly persons, by enrolling their family members in the program to receive information and practice skills needed to care for the after stroke patients so they have better understanding and greater confidence in taking care and promoting recovery of the patients.

6.2.2.4 SHPHs could apply this program to building capacity of VHVs who bridge families with community health centers and to promote knowledge and enhance practicing skills in post-stroke patient care and rehabilitation, both physically and psychologically. The program could also raise awareness and build capacity of the VHVs in assessing patient's condition and problems as well as the needs

of both the patients and family caregivers, and providing them continued proper social support and advices.

### **6.2.3 Policy level**

Post-stroke patient care system at community level requires a guideline at policy level to promote successful patient recovery and more effective actions by healthcare providers.

6.2.3.1 This program changed family caregiver's behavior by building their practices of post-stroke care which contribute to the positive outcomes of patients. This program should therefore be included in the standard operating procedure of the SHPHs and promoted to provide knowledge and build practicing skills of individuals who are involved in patient care and rehabilitation such as PHNs, public health officers, and VHV. The program builds practical skills of healthcare providers through regular reviews of knowledge. Every healthcare provider should take turn to participate in the program every six months.

6.2.3.2 Post-stroke care guideline should be linked with hospital's discharge planning and post-stroke patient care and rehabilitation program at home. The referral system of patients' medical document from a hospital to SHPHs should be prompt and patient's information should be complete to enable SHPHs healthcare providers to follow up and assist the patients and family caregivers on an ongoing basis.

## **6.3 Recommendations for further research**

6.3.1 Future studies should conduct participatory action research (PAR) to involve the communities in every step of the study from problem analysis on post-stroke care in community, planning, implementation, reflection, to monitoring and evaluation to promote effective and sustainable care and rehabilitation system for stroke survivors.

6.3.2 The evaluation of the study should include qualitative data collection through in-depth interview and/or focus group discussions with family caregivers and patients to understand and appreciate the actual conditions of the patients, particularly

the factors contributing to complications that the control group developed and their decreased ability to perform ADL functions.

6.3.3 Future studies should assess the effectiveness of the program at sixth, eighth months and/or one year to assess the retention of post-stroke care's skills, social support that patients received from family caregivers and health care providers and patient's condition to confirm the maximum concrete benefits to the patients

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## **APPENDICES**

## **APPENDIX A**

### **LIST OF EXPERTS**

There were five experts, who had validated the content of research instrument and intervention program.

1. Dr. Pim Pothiard  
Department of Rehabilitation Medicine  
Faculty of Medicine, Chulalongkorn University
2. Dr. Chuenrutai Yeekian  
Department of Research and Development  
Queen Savang Vadhana Memorial Hospital
3. Assist. Prof. Dr. Tanyaluk Bunlikitkul  
Faculty of Fundamentals Nursing and Nursing administration  
The Thai Red Cross College of Nursing
4. Mrs. Suparat kumhorm  
Head of Stroke Unit  
King Chulalongkorn Memorial Hospital
5. Mrs. Pattama Pongmalai  
Head of Health Promoting Hospital (Muang district)  
Municipality of Muang Kamphang Phet Province

**APPENDIX B**  
**THE NUMBER OF POST-STROKE PATIENTS IN EACH MONTH**

Setting / Districts	Year 2015				Year 2016								Final participants
	November		December		January		February		March		April		
	T	R	T	R	T	R	T	R	T	R	T	R	
<b>Experimental group</b>													
Maung	7	3	10	5	9	4	15	3	12	6	11	6	
Phran Kratai	3	0	2	0	5	1	5	1	6	1	3	0	
<b>Total</b>	<b>10</b>	<b>3</b>	<b>12</b>	<b>6</b>	<b>14</b>	<b>5</b>	<b>20</b>	<b>4</b>	<b>18</b>	<b>7</b>	<b>14</b>	<b>6</b>	<b>31</b>
<b>Control group</b>													
Khlong Lan	8	3	9	3	7	2	8	4	7	5	9	4	
Sai Ngam	3	1	3	0	6	1	7	2	5	3	6	3	
<b>Total</b>	<b>11</b>	<b>4</b>	<b>12</b>	<b>3</b>	<b>13</b>	<b>3</b>	<b>15</b>	<b>6</b>	<b>12</b>	<b>8</b>	<b>15</b>	<b>7</b>	<b>31</b>

*Note.*

T = Total numbers of post-stroke patients who discharged from the Kamphange Phet hospital

R = Recruited the post-stroke patients who met the inclusion criteria in this study

## APPENDIX C

### QUESTIONAIRS

#### แบบประเมินทักษะการดูแลผู้ป่วยหลังโรคหลอดเลือดสมองของครอบครัวผู้ดูแล

คำชี้แจง ผู้วิจัยสังเกตการปฏิบัติของ ครอบครัวผู้ดูแลในกิจกรรมการดูแลผู้ป่วยหลังโรคหลอดเลือดสมองดังต่อไปนี้ โดยทำเครื่องหมาย / ลงในช่องที่ตรงกับพฤติกรรมปฏิบัติของครอบครัวผู้ดูแล โดยมีเกณฑ์การให้คะแนน ดังนี้

4 หมายถึง ปฏิบัติได้อย่างถูกต้องทั้งหมด

3 หมายถึง ปฏิบัติได้ถูกต้องบางส่วน หรือปฏิบัติได้ถูกต้อง 2 ใน 3 ของขั้นตอนในกิจกรรมนั้น

2 หมายถึง ปฏิบัติถูกต้องเพียงเล็กน้อย หรือปฏิบัติได้ถูกต้อง 1 ใน 3 ของขั้นตอนในกิจกรรมนั้น

1 หมายถึง ปฏิบัติไม่ถูกต้องเลย หรือ ไม่มีการปฏิบัติ

N/A หมายถึง ผู้ดูแลไม่จำเป็นต้องปฏิบัติในขั้นตอนนั้น เนื่องจากไม่เกี่ยวข้องกับอาการผู้ป่วย

ทักษะ	ขั้นตอนการปฏิบัติของครอบครัวผู้ดูแล	ระดับการประเมิน				N/A
		1	2	3	4	
<b>1.การให้อาหารและการป้องกันการสำลัก</b> 1.1 กรณีผู้ป่วยรับประทานอาหารทางปาก	1) จัดให้ผู้ปวยนั่ง ..... 2) เตรียมอาหารให้เป็นชิ้นเล็กๆ ..... 3) ป้อนอาหารในปริมาณที่พอดี ..... 4) ระหว่างการป้อนอาหาร..... 5) สังเกตอาการที่เสี่ยงต่อการสำลัก ..... 6) .....					
	<b>คะแนนรวม</b>					
1.2 กรณีให้อาหารทางสายยาง	1) จัดผู้ป่วยอยู่ในท่านั่ง ..... 2) ตรวจสอบตำแหน่ง..... 3) เปิดจุกที่ปิดรูสายยางให้อาหาร ..... 4) สวมปลาย syringe feed ..... 5) พับสายยางหลัง..... 6) .....					
	<b>คะแนนรวม</b>					

ทักษะ	ขั้นตอนการปฏิบัติของครอบครัวผู้ดูแล	ระดับการประเมิน				N/A
		1	2	3	4	
<b>2. การป้องกัน และดูแลแผลกดทับ</b> 2.1 การป้องกันการเกิดแผลกดทับ	1) สังเกตผิวหนัง ..... 2) พลิกตะแคงตัวผู้ป่วย ..... 3) ใช้ม้วนผ้าหรือหมอน..... 4) ทำความสะอาดทุกครั้ง..... 5) ดูแลผ้าปูที่นอน..... 6) .....					
	<b>คะแนนรวม</b>					
2.2 การทำแผลกดทับ	1) ล้างมือ..... 2) ใช้ทิชชูเปียกทำความสะอาด ..... 3) สังเกตลักษณะแผล..... 4) เช็ดบริเวณรอบแผล ..... 5) ใช้สำลีชุบน้ำเกลือทำแผล..... 6) .....					
	<b>คะแนนรวม</b>					
<b>3. การป้องกันการพลัดตก หกล้ม</b> 3.1 การป้องกันการพลัดตก หกล้ม ขณะอยู่บนเตียง หรือ เก้าอี้	1) ผู้ดูแลสังเกตหรือถามผู้ป่วย..... 2) ค่อยๆ เปลี่ยนท่าขณะลุกนั่ง ..... 3) ช่วยประคองผู้ป่วย..... 4) ช่วยผู้ป่วยนั่งด้วยความมั่นคง เช่น ..... 5) จัดสิ่งแวดล้อม..... 6) .....					
	<b>คะแนนรวม</b>					
3.2 การป้องกันการพลัดตก หกล้ม ขณะเดิน	1) ผู้ดูแลสังเกต..... 2) ค่อยๆ เปลี่ยนท่า..... 3) ช่วยประคองผู้ป่วยขณะเดิน..... 4) ช่วยผู้ป่วยขึ้น..... 5) จัดสิ่งแวดล้อม..... 6).....					
	<b>คะแนนรวม</b>					
<b>4. การเคลื่อนย้ายผู้ป่วย</b> 4.1 การเคลื่อนย้ายผู้ป่วยบนเตียง และการพลิกตะแคงตัว	1) ยื่นค้ำที่ผู้ป่วย..... 2) การเลื่อนตัว..... 3) การเลื่อนตัวไปทางซ้าย ..... 4) การเลื่อนตัวไปทางขวา..... 5) การพลิกตะแคงตัว ..... 6) .....					
	<b>คะแนนรวม</b>					

ทักษะ	ขั้นตอนการปฏิบัติของครอบครัวผู้ดูแล	ระดับการประเมิน				N/A
		1	2	3	4	
4.2 การย้ายผู้ป่วยจากเตียงไปยังเก้าอี้หรือรถเข็น	1) นำเก้าอี้.....					
	2) ตั้งเก้าอี้หรือรถเข็น.....					
	3) จัดทำผู้ป่วย.....					
	4) ผู้ดูแลยืนอยู่ด้านหน้าผู้ป่วย.....					
	5) ใช้มือจับที่ขอบกางเกง.....					
	6) .....					
	<b>คะแนนรวม</b>					
5. การทำกายภาพบำบัด	1) นิ้ว.....					
	2) ข้อมือ.....					
5.1 Upper extremities	3) ข้อศอก.....					
	4) ไหล่และข้อศอก.....					
	5) แขน.....					
	6) .....					
	<b>คะแนนรวม</b>					
5.2 Lower extremities	1) สะโพก.....					
	2) สะโพก.....					
	3) สะโพก.....					
	4) เข่า.....					
	5) ข้อเท้า.....					
	6) .....					
	<b>คะแนนรวม</b>					
5.3 การฝึกการทรงตัวและการทำงานร่วมกันของกล้ามเนื้อ	1) กระตุ้นให้ผู้ป่วย.....					
	2) การทรงตัวในท่านั่ง.....					
	3) ขณะผู้ป่วยนั่ง.....					
	4) ผู้ป่วยนั่งบนเก้าอี้.....					
	5) การทรงตัวในท่านอน.....					
	6) .....					
	<b>คะแนนรวม</b>					
	<b>คะแนนรวมทั้งหมด</b>					

**แบบสอบถามการรับรู้ความสามารถแห่งตนในการดูแลผู้ป่วยหลังโรคหลอดเลือดสมองของครอบครัวผู้ดูแล**

คำชี้แจง ขอให้ท่านทำเครื่องหมาย /ตามความรู้สึกและความคิดเห็นของท่านในการปฏิบัติกิจกรรมการดูแลผู้ป่วย หลังโรคหลอดเลือดสมองดังต่อไปนี้ โดยมีเกณฑ์ในการเลือกตอบ ดังนี้

- ไม่มั่นใจเลย หมายถึง ท่านรู้สึกไม่มีความมั่นใจเลยในการปฏิบัติขั้นตอนการดูแลนั้น
- มั่นใจเล็กน้อย หมายถึง ท่านรู้สึกมั่นใจว่าปฏิบัติขั้นตอนการดูแลได้ถูกต้องน้อยครั้ง
- มั่นใจปานกลาง หมายถึง ท่านรู้สึกมั่นใจว่าปฏิบัติขั้นตอนการดูแลได้ถูกต้องเป็นบางครั้ง
- มั่นใจมาก หมายถึง ท่านรู้สึกมั่นใจว่าปฏิบัติขั้นตอนการดูแลได้ถูกต้องเป็นส่วนใหญ่
- มั่นใจมากที่สุด หมายถึง ท่านรู้สึกมั่นใจว่าปฏิบัติขั้นตอนการดูแลได้ถูกต้องทุกครั้ง

กิจกรรมการดูแลผู้ป่วยหลังโรคหลอดเลือดสมอง	ระดับการรับรู้ความสามารถแห่งตน				
	ไม่มั่นใจเลย	มั่นใจเล็กน้อย	มั่นใจปานกลาง	มั่นใจมาก	มั่นใจมากที่สุด
<b>การให้อาหารและการป้องกันการสำลัก</b>					
<i>กรณีผู้ป่วยรับประทานอาหารได้เอง</i>					
1. ฉันมั่นใจว่าฉันสามารถทำอาหาร.....					
2. ก่อนกินอาหารทุกมื้อ.....					
3. หลังกินอาหาร .....					
4. ....					
5.....					
<i>กรณีการให้อาหารทางสายยาง</i>					
1. ฉันมั่นใจในการจัดเตรียมอาหาร.....					
2. ก่อนกินอาหารทุกมื้อ.....					
3. ฉันมั่นใจว่า เเทาอาหาร.....					
4. ....					
5.....					
<b>การป้องกันแผลกดทับ</b>					
1. ฉันมั่นใจว่าฉันสังเกตเห็นรอยแดง .....					
2. ฉันมั่นใจว่าพลิกตะแคง.....					
3. ฉันมั่นใจว่าฉันมั่นใจว่าดูแลทำความสะอาด.....					
4.....					
5. ....					

กิจกรรมการดูแลผู้ป่วยหลังโรคหลอดเลือดสมอง	ระดับการรับรู้ความสามารถของตน				
	ไม่มั่นใจเลย	มั่นใจเล็กน้อย	มั่นใจปานกลาง	มั่นใจมาก	มั่นใจมากที่สุด
<b>การทำแผลกดทับ</b>					
1. ฉันมั่นใจว่าฉันล้างมือ.....					
2. ฉันมั่นใจว่าใช้สำลีสะอาดชุบแอลกอฮอล์.....					
3. ฉันมั่นใจว่าใช้สำลีสะอาด.....					
4.....					
5.....					
<b>การป้องกันการพลัดตก หกล้ม</b>					
1. ก่อนจะเคลื่อนย้ายผู้ป่วย.....					
2. ฉันมั่นใจว่าช่วยประคอง.....					
3. ฉันมั่นใจว่าดูแลจัดสิ่งแวดล้อม.....					
4.....					
5.....					
<b>การเคลื่อนย้ายผู้ป่วย</b>					
1. การเลื่อนตัวขึ้นหรือลง.....					
2. การเลื่อนตัวไปด้านข้าง.....					
3. การพลิกตะแคง.....					
4.....					
5.....					
<b>การทำกายภาพบำบัด</b>					
1. ฉันมั่นใจว่าจับข้อมือผู้ป่วย.....					
2. ฉันมั่นใจว่ายกแขน.....					
3. ฉันมั่นใจว่าจับข้อเท้า.....					
4.....					
5.....					
6.....					

**แบบสอบถามการได้รับการสนับสนุนทางสังคมของผู้ป่วยหลังโรคหลอดเลือดสมอง**

คำชี้แจง ขอให้ท่านทำเครื่องหมาย / ตามความรู้สึกและความคิดเห็นของท่านในการได้รับการสนับสนุนทางสังคมดังต่อไปนี้ โดยแบบสอบถามแบ่งออกเป็น 2 ส่วนคือ

ส่วนที่ 1 การได้รับการสนับสนุนทางสังคมจากสมาชิกในครอบครัว

ส่วนที่ 2 การได้รับการสนับสนุนทางสังคมจากอสม.

โดยมีเกณฑ์ในการเลือกตอบ ดังนี้

0 หมายถึง ท่านไม่เคยได้รับการปฏิบัตินั้นเลย

1 หมายถึง ท่านได้รับการปฏิบัตินั้นนานๆครั้ง หรือ 1-2 ครั้งต่อสัปดาห์

2 หมายถึง ท่านได้รับการปฏิบัตินั้นบ่อยครั้ง หรือ 3 ครั้งต่อสัปดาห์

3 หมายถึง ท่านได้รับการปฏิบัตินั้นเกือบทุกครั้ง หรือมากกว่า 3 ครั้งต่อสัปดาห์

4 หมายถึง ท่านได้รับการปฏิบัตินั้นทุกครั้ง หรือทุกวัน

**ส่วนที่ 1 การได้รับการสนับสนุนทางสังคมจากสมาชิกในครอบครัว**

ด้าน	การได้รับการสนับสนุนทางสังคม				
	ไม่เคย	นานๆครั้ง	บ่อยครั้ง	เกือบทุกครั้ง	ทุกครั้ง
<b>1. การสนับสนุนทางด้านอารมณ์</b>					
1. สอบถามอาการ.....					
2. สังเกตเห็นเมื่อท่านมีความไม่สบายใจ .....					
3. พูดยให้กำลังใจ.....					
4. คอยรับฟังปัญหา.....					
5. ชมเชย.....					
6. ....					
7. ....					
8. ....					
9. ....					
<b>2. การสนับสนุนด้านวัตถุสิ่งของ</b>					
1. จัดอาหารให้ท่านตามเวลา					
2. จัดยาให้ท่านตามเวลา					
3. ช่วยอาบน้ำและแต่งตัว					
4. คอยช่วยเหลือจับถ้ำและทำความสะอาด					
5. ....					
6. ....					
7. ....					

ด้าน	การได้รับการสนับสนุนทางสังคม				
	ไม่เคย	นานๆครั้ง	บ่อยครั้ง	เกือบทุกครั้ง	ทุกครั้ง
8.....					
9.....					
10.....					
11.....					
<b>3. การสนับสนุนด้านข้อมูลข่าวสาร</b>					
1. บอกท่านเรื่องการเคี้ยวอาหารและการกลืน.....					
2. กระตุ้นให้ท่านพลิกตะแคงตัว.....					
3.กระตุ้นให้ท่านพยายามออกกำลังแขนขา.....					
4.....					
5.....					
6.....					
<b>4. การสนับสนุนด้านการประเมินคุณค่า</b>					
1. ชมเชยเมื่อทานอาหารหรือดื่มน้ำได้เอง โดยไม่สำคัญ					
2. ชมเชยเมื่อออกกำลังแขนขา ได้เองอย่างถูกต้อง					
3. ให้คำแนะนำการออกกำลัง .....					
4.....					
5.....					
6.....					
7.....					
8.....					

**ส่วนที่ 2 การได้รับการสนับสนุนทางสังคมจากอสม.**

ด้าน	การได้รับการสนับสนุนทางสังคม				
	ไม่เคย	นานครั้ง	บ่อยครั้ง	เกือบทุกครั้ง	ทุกครั้ง
<b>1. การสนับสนุนทางด้านอารมณ์</b>					
1. สอบถามอาการของท่าน					
2. พุคให้กำลังใจว่าท่านสามารถหายได้					
3. รับฟังปัญหาของท่านอย่างเต็มใจ					
4. ....					
5. ....					
6. ....					
<b>2. การสนับสนุนด้านวัตถุสิ่งของ</b>					
1. ช่วยจัดหาอุปกรณ์ที่จำเป็นในการช่วยเดิน.....					
2. ช่วยจัดหาอุปกรณ์ที่ใช้ในการทำกายภาพ.....					
3. ....					
<b>3. การสนับสนุนด้านข้อมูลข่าวสาร</b>					
1. บอกอันตรายจากการสำลักอาหาร					
2. บอกถึงผลข้างเคียงของยา.....					
3. บอกวิธีการป้องกันการเกิดแผลกดทับ.....					
4. ....					
5. ....					
6. ....					
7. ....					
8. ....					
<b>4. การสนับสนุนด้านการประเมินคุณค่า</b>					
1. ชมเชยเมื่อออกกำลังแขนขาได้เองอย่างถูกต้อง					
2. ให้คำแนะนำวิธีการออกกำลังแขนและขาที่ถูกเมื่อท่านทำเองแล้ว ไม่ถูกต้อง					
3. ชมเชยเมื่อสามารถทำกิจวัตรประจำวัน.....					
4. ....					
5. ....					
6. ....					
7. ....					

## APPENDIX D

### ITEM ANALYSIS

#### Practices of post-stroke care

Items	Before the program				The end of program				Two-month follow-up			
	Experimental		Control		Experimental		Control		Experimental		Control	
	mean	SD	mean	SD	mean	SD	mean	SD	mean	SD	mean	SD
<b>1. Feeding and aspiration prevention</b>												
1) .....	1.16	0.64	1.68	0.54	2.90	0.30	1.45	0.62	3.00	0.00	1.52	0.62
2) .....	1.32	0.54	1.55	0.72	2.22	0.42	1.35	0.80	2.29	0.46	1.39	0.80
3) .....	1.16	0.37	1.71	0.53	2.26	0.44	1.39	0.56	2.45	0.50	1.39	0.49
4) .....	1.22	0.56	1.77	0.56	2.35	0.49	1.77	0.67	2.55	0.50	1.81	0.60
5) .....	0.52	0.51	0.77	0.67	2.19	0.48	0.52	0.62	2.29	0.46	0.68	0.70
6) .....	0.68	0.54	0.90	0.54	2.71	0.53	0.61	0.49	2.84	0.37	0.68	0.60
<b>2. Pressure ulcer prevention</b>												
1) .....	0.87	0.50	1.13	0.56	2.45	0.50	0.97	0.60	2.35	0.49	0.87	0.56
2) .....	1.11	0.60	1.42	0.50	2.48	0.51	1.19	0.48	2.81	0.40	1.11	0.54
3) .....	0.48	0.68	0.45	0.62	2.16	0.69	0.16	0.37	2.35	0.71	0.22	0.62
4) .....	1.77	0.72	2.00	0.45	2.52	0.51	1.87	0.56	2.74	0.44	1.87	0.56
5) .....	1.11	0.54	1.11	0.60	1.93	0.44	1.03	0.60	2.03	0.41	0.97	0.66
6) .....	1.03	0.41	1.35	0.55	2.52	0.51	1.26	0.51	2.64	0.49	1.19	0.54
<b>3. Fall prevention</b>												
<b>3.1 On bed or chair</b>												
1) .....	0.45	0.51	0.71	0.53	2.06	0.25	0.68	0.54	2.19	0.40	0.58	0.56
2) .....	0.77	0.56	1.22	0.67	2.45	0.50	1.11	0.65	2.61	0.49	0.90	0.70
3) .....	1.00	0.52	1.42	0.72	2.52	0.51	1.19	0.75	2.52	0.51	0.87	0.72
4) .....	0.06	0.25	0.58	0.56	2.03	0.48	0.39	0.49	2.29	0.64	0.39	0.49
5) .....	1.81	0.65	2.03	0.84	2.61	0.49	1.77	0.84	2.68	0.47	1.74	0.81
6) .....	0.48	0.62	1.06	0.73	1.97	0.55	1.23	0.67	2.22	0.50	1.16	0.69
<b>3.2 During walking</b>												
1) .....	0.39	0.50	0.32	0.47	2.03	0.31	0.22	0.42	2.22	0.42	0.19	0.40
2) .....	0.52	0.51	0.45	0.57	2.26	0.57	0.26	0.44	2.48	0.57	0.16	0.37
3) .....	0.32	0.47	0.45	0.57	2.03	0.60	0.26	0.44	2.35	0.61	0.19	0.48

**Practices of post-stroke care (continued)**

Items	Before the program				The end of program				Two-month follow-up			
	Experimental		Control		Experimental		Control		Experimental		Control	
	mean	SD	mean	SD	mean	SD	mean	SD	mean	SD	mean	SD
4) .....	0.11	0.30	0.35	0.61	1.84	0.73	0.19	0.40	2.35	0.75	0.16	0.37
5) .....	1.74	0.73	2.00	0.89	2.58	0.50	1.64	0.98	2.71	0.46	1.71	0.86
6) .....	1.29	0.69	1.71	0.78	2.39	0.49	1.48	0.81	2.39	0.49	1.61	0.71
<b>4. Mobility</b>												
<b>4.1 On bed</b>												
1) .....	0.26	0.44	0.22	0.42	2.13	0.43	0.03	0.18	2.06	0.36	0.03	0.18
2) .....	0.64	0.49	0.45	0.57	2.00	0.29	0.42	0.50	2.00	0.26	0.35	0.49
3).....	0.64	0.49	0.45	0.57	2.00	0.29	0.42	0.50	2.00	0.26	0.39	0.49
4).....	0.64	0.49	0.48	0.57	2.00	0.29	0.42	0.50	2.00	0.26	0.39	0.49
5) .....	0.77	0.50	0.71	0.59	2.19	0.40	0.59	0.50	2.19	0.40	0.55	0.50
6) .....	0.52	0.51	0.71	0.46	2.03	0.31	0.64	0.49	2.13	0.34	0.55	0.50
<b>4.2 From bed to chair/wheelchair</b>												
1) .....	0.16	0.37	0.22	0.42	2.06	0.51	0.13	0.34	2.13	0.43	0.13	0.34
2).....	0.11	0.30	0.26	0.44	1.97	0.41	0.22	0.42	2.16	0.45	0.22	0.42
3) .....	0.42	0.72	0.52	0.81	2.55	0.62	0.52	0.81	2.68	0.47	0.42	0.72
4).....	0.22	0.42	0.19	0.40	2.03	0.55	0.06	0.25	2.03	0.48	0.03	0.18
5) .....	0.13	0.34	0.16	0.37	2.03	0.55	0.13	0.34	2.19	0.65	0.06	0.25
6) .....	0.00	0.00	0.06	0.25	1.81	0.65	0.13	0.34	2.03	0.55	0.11	0.30
<b>5. Rehabilitation</b>												
<b>5.1 Upper extremities</b>												
1) .....	0.35	0.49	0.68	0.65	2.35	0.67	0.77	0.72	2.74	0.51	0.74	0.77
2) .....	0.97	0.66	1.13	0.76	2.68	0.47	0.93	0.77	2.77	0.42	0.61	0.67
3) .....	1.22	0.72	1.32	0.75	2.77	0.42	1.03	0.75	2.83	0.37	0.84	0.64
4) .....	0.22	0.42	0.16	0.37	1.87	0.67	0.06	0.25	1.90	0.60	0.03	0.18
5) .....	0.93	0.57	1.16	0.52	2.71	0.46	0.87	0.50	2.68	0.54	0.74	0.57
6) .....	0.45	0.62	0.42	0.62	2.58	0.56	0.32	0.47	2.61	0.56	0.19	0.40
<b>5.2 Lower extremities</b>												
1) .....	1.06	0.63	1.16	0.58	2.68	0.47	0.84	0.45	2.74	0.51	0.77	0.50
2) .....	0.13	0.43	0.06	0.25	1.90	0.70	0.00	0.00	1.77	0.62	0.00	0.00
3) .....	0.52	0.62	0.26	0.44	2.81	0.40	0.22	0.42	2.68	0.54	0.16	0.37
4) .....	0.81	0.75	0.93	0.68	2.84	0.37	0.52	0.62	2.77	0.50	0.42	0.56
5) .....	0.45	0.57	0.74	0.77	2.90	0.30	0.48	0.62	2.81	0.48	0.35	0.61

**Practices of post-stroke care (continued)**

Items	Before the program				The end of program				Two-month follow-up			
	Experimental		Control		Experimental		Control		Experimental		Control	
	mean	SD	mean	SD	mean	SD	mean	SD	mean	SD	mean	SD
6).....	0.61	0.76	0.58	0.81	2.68	0.47	0.39	0.68	2.81	0.48	0.29	0.64
<b>5.3 Coordination and balancing</b>												
1).....	0.74	0.57	1.06	0.81	2.26	0.63	1.11	0.94	2.68	0.60	0.97	0.91
2).....	0.19	0.40	0.13	0.34	1.81	0.48	0.06	0.25	2.13	0.56	0.03	0.18
3).....	0.32	0.18	0.06	0.25	1.77	0.50	0.03	0.18	2.10	0.54	0.03	0.18
4).....	0.32	0.18	0.06	0.25	1.68	0.48	0.03	0.18	2.03	0.48	0.03	0.18
5).....	0.00	0.00	0.00	0.00	1.58	0.72	0.00	0.00	2.03	0.55	0.00	0.00
6).....	0.00	0.00	0.00	0.00	1.48	0.68	0.00	0.00	1.83	0.52	0.00	0.00

**Self-efficacy of family caregivers**

Items	Before the program				The end of program				Two-month follow-up			
	Experimental		Control		Experimental		Control		Experimental		Control	
	mean	SD	mean	SD	mean	SD	mean	SD	mean	SD	mean	SD
<b>Feeding and aspiration prevention</b>												
1).....	1.81	0.70	2.11	0.70	3.03	0.31	2.16	0.73	3.22	0.50	2.16	0.69
2).....	1.87	0.76	2.03	0.71	3.42	0.67	2.16	0.69	3.68	0.47	1.77	0.84
3).....	1.32	0.75	1.84	0.64	3.35	0.75	1.71	0.78	3.55	0.62	1.39	0.71
4).....	1.93	0.63	2.35	0.71	2.90	0.30	2.45	0.57	3.16	0.37	2.32	0.60
5).....	1.32	0.83	1.58	0.62	2.74	0.57	1.29	0.74	3.10	0.65	1.29	0.74
<b>Pressure ulcer prevention</b>												
1).....	1.55	0.72	1.71	0.59	2.93	0.44	1.71	0.78	2.93	0.44	1.61	0.71
2).....	1.71	0.82	2.00	0.68	3.06	0.73	2.00	0.68	3.52	0.62	1.71	0.64
3).....	2.19	0.75	2.39	0.67	3.10	0.30	2.42	0.62	3.39	0.49	2.32	0.65
4).....	1.64	0.75	1.84	0.73	2.42	0.50	1.48	0.81	2.55	0.57	1.61	0.71
5).....	1.55	0.72	1.87	0.62	2.90	0.54	1.87	0.56	3.32	0.60	1.81	0.60
<b>Fall prevention</b>												
1).....	1.29	0.86	1.58	0.67	2.58	0.56	1.52	0.77	2.93	0.25	1.35	0.75
2).....	0.97	1.02	0.93	0.81	2.55	0.67	0.90	0.91	2.93	0.51	0.64	0.75
3).....	2.55	0.62	2.58	0.62	3.10	0.60	2.29	0.82	3.32	0.60	2.26	0.85

**Self-efficacy of family caregivers (continued)**

Items	Before the program				The end of program				Two-month follow-up			
	Experimental		Control		Experimental		Control		Experimental		Control	
	mean	SD	mean	SD	mean	SD	mean	SD	mean	SD	mean	SD
4).....	2.19	0.54	2.32	0.70	3.10	0.54	2.06	0.77	3.29	0.53	2.00	0.86
5).....	2.45	0.57	2.52	0.68	3.16	0.45	2.32	0.70	3.35	0.49	2.26	0.81
<b>Mobility</b>												
1).....	1.45	0.81	1.58	0.62	2.90	0.30	1.61	0.71	3.00	0.45	1.58	0.72
2).....	1.48	0.77	1.58	0.62	2.90	0.30	1.61	0.71	3.00	0.45	1.58	0.72
3).....	1.64	0.75	1.64	0.61	2.93	0.40	1.71	0.69	3.13	0.50	1.68	0.70
4).....	1.35	0.75	1.64	0.66	2.90	0.30	1.64	0.75	3.00	0.36	1.45	0.77
5).....	0.68	0.81	0.87	0.67	2.39	0.56	0.81	0.75	2.77	0.56	0.64	0.66
<b>Rehabilitation</b>												
1).....	1.58	0.81	1.71	0.74	3.26	0.44	1.55	0.81	3.42	0.50	1.32	0.79
2).....	1.64	0.88	1.68	0.75	3.26	0.44	1.55	0.81	3.35	0.49	1.29	0.82
3).....	1.48	0.77	1.58	0.67	3.22	0.50	1.42	0.81	3.35	0.55	1.16	0.73
4).....	1.54	0.77	1.58	0.72	3.32	0.47	1.42	0.85	3.42	0.50	1.26	0.81
5).....	1.54	0.72	1.58	0.81	3.29	0.46	1.48	0.85	3.45	0.50	1.22	0.80
6).....	0.35	0.66	0.32	0.54	2.26	0.63	0.35	0.61	2.77	0.62	0.22	0.50

**Social support of post-stroke patients**

Items	The end of program				Two-month follow-up			
	Experimental		Control		Experimental		Control	
	mean	SD	mean	SD	mean	SD	mean	SD
<b>Part 1 From family caregivers</b>								
<b>1. Emotional</b>								
1).....	2.68	0.54	1.84	0.52	2.77	0.56	1.61	0.56
2).....	2.55	0.67	1.68	0.54	2.74	0.63	1.61	0.56
3).....	2.29	0.64	1.03	0.79	2.39	0.80	0.81	0.79
4).....	2.52	0.68	1.68	0.54	2.71	0.69	1.39	0.61
5).....	2.03	0.66	0.52	0.60	2.13	0.76	0.42	0.56
6).....	1.97	0.79	0.39	0.67	2.03	0.87	0.26	0.51
7).....	3.32	0.83	3.06	1.03	3.58	0.81	3.10	1.04
8).....	3.29	0.53	2.93	0.81	3.52	0.51	2.84	1.00

**Social support of post-stroke patients (continued)**

Items	The end of program				Two-month follow-up			
	Experimental		Control		Experimental		Control	
	mean	SD	mean	SD	mean	SD	mean	SD
9) .....	3.90	0.30	3.48	0.81	3.93	0.25	3.32	1.08
<b>2. Instrument</b>								
1) .....	3.93	0.25	3.42	0.92	4.00	0.00	3.32	1.01
2) .....	3.97	0.18	3.42	1.02	3.97	0.18	3.52	0.99
3) .....	3.93	0.25	3.29	1.07	4.00	0.00	3.26	1.12
4) .....	3.84	0.58	3.29	1.00	3.97	0.18	3.26	0.99
5) .....	1.68	0.65	1.13	0.56	1.90	0.91	1.03	1.18
6) .....	2.11	0.47	1.30	0.69	2.48	0.72	1.19	0.54
7) .....	2.13	1.14	0.35	0.91	2.32	1.19	0.19	0.60
8) .....	1.74	1.15	0.13	0.34	2.39	1.28	0.13	0.34
9) .....	2.13	1.28	0.61	0.84	2.19	1.30	0.52	0.81
10) .....	4.00	0.00	3.61	1.20	4.00	0.00	3.29	1.49
11) .....	3.90	0.54	3.87	0.72	3.97	1.18	3.87	0.72
<b>3. Information</b>								
1) .....	1.81	0.40	0.35	0.55	1.61	0.61	0.32	0.60
2) .....	2.11	0.54	0.68	0.60	2.03	0.60	0.45	0.50
3) .....	2.16	0.69	0.45	0.62	2.19	0.70	0.35	0.55
4) .....	1.90	0.54	0.35	0.55	1.77	0.56	0.13	0.34
5) .....	1.74	0.73	0.00	0.00	1.87	0.62	0.00	0.00
6) .....	1.64	0.88	0.13	0.34	2.48	1.18	0.16	0.37
<b>4. Appraisal</b>								
1) .....	0.90	0.60	0.03	0.18	1.03	0.87	0.00	0.00
2) .....	1.55	0.58	0.13	0.34	1.48	0.68	0.10	0.30
3) .....	1.55	0.62	0.10	0.30	1.68	0.60	0.06	0.25
4) .....	1.32	0.65	0.00	0.00	1.45	0.67	0.00	0.00
5) .....	1.35	0.88	0.03	0.18	1.58	0.85	0.03	0.18
6) .....	1.93	0.68	0.52	0.63	2.22	0.56	0.26	0.44
7) .....	2.11	0.70	0.58	0.62	2.29	0.74	0.42	0.56
8) .....	1.84	0.90	0.22	0.42	2.29	0.82	0.19	0.40

**Social support of post-stroke patients (continued)**

Items	The end of program				Two-month follow-up			
	Experimental		Control		Experimental		Control	
	mean	SD	mean	SD	mean	SD	mean	SD
<b>Part 2 From VHVs</b>								
<b>1. Emotional</b>								
1) .....	1.45	0.62	0.71	0.46	1.39	0.71	0.39	0.49
2) .....	1.45	0.62	0.39	0.49	1.30	0.74	0.13	0.34
3) .....	1.45	0.62	0.68	0.47	1.32	0.65	0.39	0.49
4) .....	1.45	0.67	0.29	0.46	1.35	0.71	0.10	0.30
5) .....	1.55	0.81	0.42	0.81	1.39	0.71	0.19	0.40
6).....	4.00	0.00	3.87	0.72	3.71	1.01	4.00	0.00
<b>2. Instrument</b>								
1) .....	1.97	2.01	0.26	0.11	2.35	1.97	0.16	0.73
2) .....	0.84	1.59	0.00	0.00	0.93	1.69	0.00	0.00
3).....	1.06	0.63	0.16	0.37	0.97	0.60	0.03	0.18
<b>3. Information</b>								
1) .....	1.00	0.45	0.22	0.42	0.93	0.51	0.06	0.25
2).....	1.03	0.41	0.13	0.34	1.13	0.56	0.03	0.18
3) .....	1.22	0.56	0.29	0.46	1.11	0.47	0.19	0.40
4) .....	1.39	0.61	0.29	0.46	1.26	0.63	0.10	0.30
5) .....	1.13	0.50	0.00	0.00	1.06	0.57	0.00	0.00
6) .....	1.19	0.70	0.00	0.00	1.16	0.64	0.00	0.00
7).....	1.58	1.06	0.68	0.47	1.42	0.99	0.39	0.50
8) .....	1.42	0.85	0.58	0.50	1.39	0.88	0.35	0.49
<b>4. Appraisal</b>								
1).....	1.32	0.70	0.10	0.30	1.22	0.62	0.00	0.00
2) .....	1.19	0.48	0.06	0.25	1.11	0.47	0.00	0.00
3) .....	1.45	0.72	0.29	0.46	1.39	0.76	0.06	0.25
4).....	1.29	0.53	0.13	0.34	1.22	0.62	0.03	0.18
5) .....	1.39	0.71	0.13	0.34	1.35	0.75	0.03	0.18
6).....	1.48	0.72	0.42	0.50	1.45	0.72	0.16	0.37
7).....	1.45	0.72	0.16	0.37	1.45	0.72	0.03	0.18

**Activities of daily living (ADLs) of post-stroke patients**

Items	The end of program				Two-month follow-up			
	Experimental		Control		Experimental		Control	
	mean	SD	mean	SD	mean	SD	mean	SD
1. Personal hygiene	2.97	0.41	3.06	0.25	4.13	0.62	2.77	1.33
2. Bathing	1.58	0.92	1.03	0.41	3.52	0.51	2.48	1.18
3. Feeding	3.74	1.86	2.48	1.12	9.41	1.54	5.26	3.75
4. Toilet use	4.52	1.12	3.00	2.00	7.13	1.59	3.26	2.70
5. Dressing	2.87	1.76	2.00	0.02	7.77	1.41	4.03	2.69
6. Bowel control	9.84	0.90	10.00	0.00	9.93	0.36	10.00	0.00
7. Bladder control	9.68	0.75	9.26	1.21	9.74	0.68	9.19	1.11
8. Ambulation	1.19	2.21	0.29	0.90	8.03	4.96	1.22	2.68
9. Transfer	3.61	2.75	1.06	1.46	10.45	3.45	2.11	3.23
10. Stair climbing	0.13	0.50	0.00	0.00	3.00	2.24	0.35	1.05

## APPENDIX E

### CERTIFICATE OF ETHICAL APPROVAL



Certificate of Approval  
Ethical Review Committee for Human Research  
Faculty of Public Health, Mahidol University

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COA. No. MUPH 2015-105

Protocol Title : POST-STROKE CARE AND SOCIAL SUPPORT PROGRAM FOR FAMILY CAREGIVERS AND CLINICAL OUTCOMES

Protocol No. : 74/2558

Principal Investigator : Miss Sararin Pitthayapong

Affiliation : Doctor of Public Health (International Program)  
Faculty of Public Health, Mahidol University

Approval Includes :  
1. Project proposal  
2. Information sheet  
3. Informed consent form  
4. Data collection form/Program or Activity plan

Date of Approval : 7 May 2015

Date of Expiration : 6 May 2016

The aforementioned project have been reviewed and approved according to the Declaration of Helsinki by Ethical Review Committee for Human Research, Faculty of Public Health, Mahidol University.

A handwritten signature in black ink, appearing to read 'S. Nantham'.

(Assoc. Prof. Dr. Sutham Nanthamongkolchai)

Chairman of Ethical Review Committee for Human Research

A handwritten signature in black ink, appearing to read 'Prayoon F.'.

(Assoc. Prof. Dr. Prayoon Fongsatitkul)

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## **BIOGRAPHY**

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<b>SCHORLARSHIP</b>	Thai Red Cross Society
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