

# DEVELOPING A FAMILY-BASED CARING MODEL FOR STROKE SURVIVORS TO ENHANCE HEALTHY FAMILY

BY

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### THAMMASAT UNIVERSITY FACULTY OF NURSING

#### DISSERTATION

BY

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#### ENTITLED

# DEVELOPING A FAMILY-BASED CARING MODEL FOR STROKE SURVIVORS TO ENHANCE HEALTHY FAMILY

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#### ABSTRACT

Caring for stroke survivors is a heavy burden for caregivers, especially during the rehabilitation period at home. This is because family members have to provide a long-term care. Therefore, it is important to encourage family members for adjustment of their lifestyles towards an effective care for stroke survivors.

This research study aimed to develop a care model of healthy families in those with members having a stroke. The study was conducted during January 2020-February 2021, which divided into two phases. Phase 1 was a study of family life situations in caring for stroke survivors and factors that enabled families to take care and make themselves healthy. In this phase, forty primary caregivers were included. All of them were interviewed individually, with two groups of discussions (seven persons in each group). Phase 2 was a participatory action research with four cycles during a period of sixteen weeks. In this phase, there were fourteen primary caregivers who represented their families. All of them were divided into two groups with seven persons in each for group discussions and activities. Important factors from the results of Phase1 were brought to set goals, with strategies for caring of stroke survivors and ways to promote healthy family as appropriate to the context of each family. Then, participants applied those goals and strategies into their practice and observed for problems and obstacles as feedbacks for discussions and adjustments in the groups each week towards their goals. The researcher only acted as a helper and encouraged group members to express their opinions. Data were collected by the researcher in semi-urban community areas under responsibility of

the Sub-district Health Promotion Hospital, Nonthaburi Province through individual interviews, group discussions, participant/non-participant observations, and note-taking. A triangular review was conducted with data confirmed by research participants, experts, and related theories. Data were analyzed by content and theme analysis using Atlas ti.8 software package for analysis and extraction of necessary data to be presented as tables and figures.

In Phase 1, the results showed that factors influencing families in caring for stroke survivors consisted of three main concepts: 1) Caregiver characteristic: Virtue love and gratitude, Experience in caring, Good health and self-care ability, Good management of emotions, and Freedom to manage problem and obstacles; 2) Family functions and relationship: Family structure, roles and duties, relationship, and management of family problems; 3) Assisting support: Financial, health service, and environment support.

In Phase 2, the results of four-cycle group activities yielded various paradigms for changes, including Cycle 1: Strategic design and collaborating, Cycle 2: Supporting and fulfilling care potential, Cycle 3: Balance body and mind for creating positive energy, and Cycle 4: Self-improvement to happiness. Then, the researcher analyzed information from all cycles toward a caring strategy, Caring achievement, that can enhance a healthy family.

A family-based caring model was synthesized from the results of phases 1 and 2. This model shows that caregivers work together with Community Care Commanders to develop Caring Achievement for stroke survivors. Community Care Commanders promote knowledge, advice how to solve the problems, and build care capacity for caregivers. In addition, the community resourcefulness is importance for caring support to achieve the goal. Caregivers made their caring achieved towards a healthy family, including Happiness, Physical health, Financial Balancing, and Family Bonding. Ultimately, the evaluation of the aforementioned components will be feedback to the caregivers for future improvement. If the existing performance was unsuccessful, it would be led to improving goals and changing the care suitable for the family family for stroke survivors. Knowledge gained from this study could be further applied towards a better family care system in the community.

Keyword: Family-Based Caring Model, Stroke Survivors, Healthy Family, Happiness

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# LIST OF ABBREVIATIONS

Symbols/Abbreviations	Terms
ADL	Activities of Daily Living
BADLs	Basic Activities of Daily Livings
BI	Barthel Index
CFIM	The Calgary Family Intervention Model
CVA	Cerebrovascular accident
DALYs	Disability-Adjusted Life-Years
FBCM	The Family-Based Caring Model
IADLs	Instrumental Activities of Daily Livings
PAR	Participatory Action Research
WHO	World Health Organization
VHV	Village Health Volunteer
CCC	Community Care Commander

# CHAPTER 1 INTRODUCTION

#### 1.1 Background and Significance of the Problem

Stroke is the second leading cause of death worldwide and the third leading cause of long-term disability that requires long-term care. Although the percent of disability-adjusted life-years (DALYs) due to all causes tend to decline, the overall stroke burden significantly increases in both men and women of all ages from 1990 to 2016 by nearly two-fold (Feigin, Norrving, & Mensah, 2017; Lindsay et al., 2019). There are over 80 million people currently living with stroke globally (Lindsay et al., 2019). Stroke occurrence remains a crucial health problem in low-to-middle-income countries and high-income countries mainly because of population aging and advanced technology increasing the survival rates (Kim et al., 2020; Wafa et al., 2020). Like other countries, stroke incidence has tended to rise with growing frequency in younger persons (Chan et al., 2021; Krishnamurthi et al., 2018). The systematic reviews identifying recent incidence studies from many countries and the WHO database have reported stroke as a global burden in which incidence rates are higher also a strong positive correlation with mortality data (Hu et al., 2020; Kim et al., 2020; Thrift et al., 2017). For example, in the United States, stroke is the fourth leading cause of death and the primary cause of disability for adults (Ovbiagele & Nguyen-Huynh, 2011). In the country with the largest epidemic, the People's Republic of China, stroke occurrence has increased over the last three decades and turned the country into the country with the enormous stroke burden in the world where the incidence remains high in rural areas (Wang et al., 2017).

Although the trends for stroke incidence and mortality rates have decreased for developed countries in recent decades, stroke remains the leading cause of disability in many countries such as the United States (Ovbiagele & Nguyen-Huynh, 2011), the United Kingdom (Stroke Association, 2015), Korea (Shin et al., 2016), and Thailand (Butsing, Mawn, Suwannapong, & Tipayamongkholgul, 2018; Suwanwela, 2014) due to advanced technology increasing the stroke survival rate. Dependent from stroke disability is the cause of years of life lost. The average duration of stroke illness is 8.3 years (Green, 2015). More than 50 percent of all survivors and caregivers may be affected by at least one condition that leads to worse long-term outcomes (Lanctot et al., 2020).

In Thailand, Stroke incidence tends to increase over 13 years (Tiamkao et al., 2022). Stroke is the fourth leading cause of non-communicable disease (NCD) that is the leading cause of death. The number of Thai stroke survivors has increased every year, especially over 60 years, from 134,940 persons in 2016 and 203,286 persons in 2020 (Health Data Center, 2020). Approximately 70 percent of survivors exist with long-term disabilities (Suwanwela, 2014). Nearly 40 percent of survivors experience a recurrent stroke within five years (Saengsuwan & Suangpho, 2019). The recovery process has continued after survivors returned to everyday living at home. Both survivors and their families must spend time for many daily life activities and adapting to home environments.

However, most of the care for stroke survivors begins at the hospital. This care is extended to the home in the form of continuing care provided by professionals, such as training before discharge or discharge planning and home-visiting care. Unfortunately, the practice is limited to the natural pattern of stroke treatment, and shortened lengths of stay in hospital settings allow little time to prepare families for caregiving after discharge that impact their daily lives and affect recovery outcomes of stroke survivors (Creasy, Lutz, Young, & Stacciarini, 2015). After a stroke, continuing care is complicated and requires long-term care and facilities directly (Burton et al., 2018). Therefore, providing rehabilitation and home care is necessary to enhance the quality of care and health after hospital discharge.

The sudden disability of stroke usually causes a heavy burden as a medical event that is one of the leading causes of long-term care and suffering for patients and their families (Zhang & Lee, 2017). Stroke significantly impacts the quality of life and community reintegration that correlate with the high prevalence of burden on the family (Okoye et al., 2019). Stroke may limit the life abilities of survivors in the form of difficulty eating, moving, feeling, communicating, thinking and acting, all of which are associated with decreased well-being (Zahuranec, Skolarus, Feng, Freedman, & Burke, 2017). The basic activities of daily living (BADLs) are defined as eating, bathing,

toileting, dressing, and moving. The more advanced "instrumental activities of daily living" (IADLs) such as using a telephone, cooking, cleaning, driving, or managing financial affairs, all of which can affirm that survivors have more self-care ability and a higher degree of independence (Oldenkamp et al., 2016).

Stroke survivors live with their relatives and require extensive care with informal support as they learn to live together with the effects of stroke (Chuluunbaatar, Pu, & Chou, 2017; Persson et al., 2017). Dependent stroke survivors require daily time support and rehabilitation provided by others. Family members, especially caregivers, often experience difficulties in coping with the survivor's personality changes, and family members need to learn new strategies to manage complicated situations (Koukouli, Lambraki, Sigala, Alevizaki, & Stavropoulou, 2018; Pindus et al., 2018). Evidence-based practices from the literature review found many caregivers remained to suffer or burden from a mixture of feelings when managing with the functional dependency and stroke severity of stroke survivors without help from other family members (Denham et al., 2018; Dhippayom, Trevittaya, & Rattakorn, 2018; Misawa, Sanches, da Silva Rêgo, & Radovanovic, 2018; Wang et al., 2021).

Stroke survivors and family members individually come from different cultural, economic, and social backgrounds. These diverse experiences also affect families' spirituality and religion (Koukouli et al., 2018; Limpawattana, Intarasattakul, Chindaprasirt, & Tiamkao, 2015). Consequently, family members have different experiences in providing care and often find strategies for problem-solving or balancing their lives as family members to provide care for themselves and other members. Families of stroke survivors face challenges in daily life, roles, and responsibilities, thereby resulting in high levels of subjective experiences among family members, including anxiety, depression, stress, and poor social adjustment (Newcomb & Hymes, 2017). The literature indicates that long-term stroke is accompanied by dominant factors of disability that can cause family members to feel onerous burdens that worsen the quality of life of caregivers and their families (Caro, Mendes, Costa, Nock, & Cruz, 2017; Denham et al., 2018). The effects of stroke create a long-term recovery process causing every member to develop new modes of life (Jaracz et al., 2015; J. Zhang & Lee, 2017).

Stroke affects caregivers and all family members engaged in family care (Wright & Leahey, 2013). Regarding caring difficulties, the reviews show family

caregivers to face a problematic situation at the beginning of stroke care because family members have no experience and have developed no stroke care skills. A study conducted by Boonsin and Panidchakul (2016) found the overall needs of family caregivers to require high levels of information in order to prepare family caregivers for providing care for stroke survivors as well as overcoming negative impacts on activities of daily living. Similarly, the research of Gawulayo, Erasmus, and Rhoda (2021) explored family members' perspectives reported that stroke often negatively influences family functioning, and family members were forced to modify their functional patterns with the critical situations of stroke.

As a result of stroke, families often have to manage significant emotional pressure and family members are challenged by numerous adjustments to achieve new duties, e.g., heavier or lighter workloads from roles; unclear, misunderstood, or contradictory communications; lack of clear leadership, powerlessness, or inability to make decisions are included as negative consequences in the long term (Misawa et al., 2018). Emotional interdependence among family members is necessary for promoting cohesiveness and cooperation in families in order to provide protection and support for family members.

Nursing evidence from many studies has led to the design of various programs for stroke survivors and families in multiple situations to acquire knowledge, skills and confidence in properly caring for stroke survivors. This process also relieves stress and suffering from survivors and family members to help survivors and family members overcome crises (Östlund, Bäckström, Saveman, Lindh, & Sundin, 2016a; Pitthayapong, Thiangtam, Powwattana, Leelacharas, & Waters, 2017). In a systematic review of existing interventions, most of the interventions applied many methods such as educating family members about certain necessary skills in this area, psychological education, and home visits. This combination of interventions is recommended for tailored or individualized needs (Bakas, Mccarthy, & Miller, 2017; Cameron et al., 2015; Pitthayapong et al., 2017).

In addition, most of the research findings focused on difficulties encountered by survivors who were supported by family caregivers or had no access to individualized care at the family level. Similarly, health professionals usually generally predominated by objective perspectives rather than subjective family views or actual needs in family life (Visser-Meily et al., 2005). Most researchers overlook essential points such as families' real needs or integration of spirituality in the equation (Wangpitipanit, Panuthai, Sucamvang, Lasuka, & Jitapunkul, 2016). Some interventions have yielded positive outcomes from follow-ups by telephone or counseling services allowing family members to talk about any problems (Cheng, 2015; Moriarty et al., 2016). Moreover, sustainable and changeable outcomes from interventions have been minimal (Pandian et al., 2017). Thus, health professionals should assess survivors' and families' virtual environments, contexts, cultures, or beliefs. Research has suggested that home environments are the most suitable for holding conversations with survivors' families (Cheng, 2015). Logical measurements of family assessments should include family ability to meet needs, coverage of gaps in family action plans, and offers many resources to families. Additionally, some family members may feel accessible and able to join meetings and be in a relaxing atmosphere with the family rather than in clinics under pressure from professional views (Kaakinen, Coehlo, Steele, Tobacco, & Hanson, 2015).

The family is the primary unit with powerful influence in Thai society. Two essential purposes of the family unit are to meet individuals' needs and meet society's needs. Individuals have different beliefs about health and illness. Different cultures and different contexts establish the dynamic demands of each person. Moreover, individual health outcomes are influenced by interaction and reciprocity (Wacharasin, 2015). Living with stroke survivors usually affects the entire family unit. On the other hand, healthy members can also contribute subjective experiences to the unit as well as encourage quality of well-being among household members. The general health of family members may also provide feedback about members' health for family health care providers, such as appropriate information, care, or services to maintain the health and happiness of every member of the family (Liselott Årestedt, Benzein, & Persson, 2015; Årestedt, Persson, Ramgard, & Benzein, 2018).

As a developing country, Thailand has achieved significant economic and health improvements. Thai family systems differ from other countries and have been distinct for the last ten years. Thai families have many different religious and cultural beliefs in each region. In the past, extended families usually lived close to one another in Thailand. Currently, however, social and economic growth have caused increasing changes in Thai family structure. Adult people move away to work while maintaining strong links with families. Thai society's trends and prosperity show that Thailand is becoming a developed country and an aging society at the same time. The working adult population has delayed the development of new families. Family sizes are smaller and have become more nuclear with increased stress or burdens in family functions (Pupaiboon, 2017; Suwanwela, 2014). Furthermore, insufficient income has changed Thai traditions and family responsibilities in caring for relatives. Lack of financial resources may restrict the possibility of social participation with family members, thereby resulting in a deficiency in empowering care for family members and not for the family as a whole (Wangpitipanit et al., 2016). Family roles in Thai culture have shifted, and modern conveniences have replaced traditional lifestyles. Relationships and reciprocity have deteriorated in some families.

Many Thai people's lifestyles have changed from shifts to urbanization, and a more competitive society results in less time for family activities at home. Thai stroke survivors are usually dependent on caregivers, especially for daily living activities, due to loss of physical function, mind, and feelings (Nilpetchploy, 2012). Most stroke survivors prefer returning home and being cared for by families after discharge from the hospital. Very few survivors receive care in nursing homes because of the costs involved. Most stroke survivors need family members to provide the necessary support in physical activities, mental health, and spiritual wellness (Methapisal, Bunloet, & Bumrerraj, 2017). Many families believe that family members can better care for stroke survivors than hired caregivers (Suwanwela, 2014). However, some survivors stop follow-ups after discharge from the hospital because they are bedridden, have limited activity, or find transportation inconvenient. Under those circumstances, healthcare professionals should provide home care designed for selected care by family caregivers. The Thai government's policy supports long-term care for dependent older people by volunteer caregivers who have received at least 70 hours of training (National Health Security Office, 2016). However, due to a shortage of volunteers and low budget support from the government combined with deficient resources, care for stroke survivors is difficult.

Thailand continues to lack practical health measurements for the entire family and remains unable to clearly identify healthy families (Manasatchakun, Chotiga,

Roxberg, & Asp, 2016). The literature review suggested individual health assessments by professionals. Two research studies assessed families with stroke survivors in Thailand. According to the findings of Niyomthai (2009) and Sakunhongsophon (2010) explored the meaning and pattern of family strength when faced with stressful events and various social interactions among family members. They found that indicators had been created with input from the context of real family life and reported representative members to have not been involved in the family unit. However, many interventions have reflected benefits for individuals rather than the family. Each family has reciprocal relationships among members along with different environmental changes. Furthermore, Thailand has an increasing number of stroke patients every year that over 13 years (Tiamkao et al., 2022). Studies should be conducted on survivors and direct caregivers. Moreover, literature reviews have not addressed interventions capable of enhancing the ability of stroke survivors' families to become healthy.

Communities confronted with care for patients with chronic illness, particularly stroke survivors and families, nursing experience reveals the multiple effects and severe suffering experienced by family members caring for stroke survivors. Although healthcare providers and service systems collaborate to remedy problems and suffering among survivors and families to maintain function or improve health or quality of life, many problems persist. Family conflict continues to problems that inability to maintain family function and produces the lower quality of life of all family members. The family structures of stroke survivors should be assessed. Questions should include family members, responsibilities and division of responsibilities among family members, how family members perceive barriers and problems from caring for survivors at home, and how family members function healthily. Critical theories have focused on critical perspectives for the best practical consequences of research from actions, situations, and consequences of inquiries (Creswell, 2013; Wright & Leahey, 2013).

The Calgary Family Intervention (CFIM) model has advantages in guiding family practices. The model describes complex interactions between family unit members. The model's approach analyzes the complex relationships between family structure, function, and processes based on theoretical foundations such as postmodernism, system theory, cybernetics, communication theory, change theory, and cognition biology (Leahey & Wright, 2016; Wright & Leahey, 2013). Health care workers use the CFIM to promote, improve and support cognition, emotion, and behaviors involved in family functioning to establish future family unit behavioral changes to increase the family unit's competency in providing compassionate care (Duhamel & Talbot, 2004; Leahey & Wright, 2016).

Promoting family awareness of the importance of care responsibilities may increase adaptation among members to maintain family function and improve health (Khomkham, Rattanathanya, & Krainuwat, 2015). Thai families need to have a greater understanding of how a whole family conceptualizes a healthy family. A healthy family is a valuable concept for healthcare professionals to implement and provide future care for patients with consideration given to multiple individuals' abilities, values, and experiences in caring for sick members and achieving the best outcome. Suppose all family members actively understand the concept of a "healthy family" and ensured to become a healthy family.

The pragmatism philosophical concept was emphasized the knowledge and truth, which helps human to achieve their life purpose and improves their practice, but it is always changeable any time which depend upon the phenomena context and perceive of each person (Chirawatkul, 2009; Creswell, 2013). In this study, the methods for changing their practices would help stroke families turn into a healthy family. Therefore, the researcher's interest is in exploring care issues and assessing families to ascertain whether there is a need for adjustments in family practice as well as building an understanding of care situations with potential effects on lives. The Family-Based Caring Model (FBCM) was developed to explain on stroke survivors' families from the realistic and adjusted the caring experiences to achieve the goal as healthy families.

Participatory action research (PAR) provides a collaborative commitment to improving communication among participants who are family members. Practice adjustment is a self-reflective process resulting from the investigation of actual practices and studying the reality of participation by particular persons in specific environments (Kemmis, McTaggart, & Nixon, 2014; McTaggart & Kemmis, 1988; McTaggart, Nixon, & Kemmis, 2017). This study has two phases. The first phase conducted on family caregivers and include in-depth interviews to understand the family situations and collected eligible families for enrollment in Phase 2. We confirmed the result with family focus group activities as a triangulation method. The second phase developed the Family-Based Caring Model (FBCM) among stroke survivor families with PAR. Family members participated and share their caring experiences with stroke survivors (including the factor from Phase 1) and determined specific definitions for a healthy family fitting the FBCM within the stroke survivor's family. Family members created a care process to balance their lives as the research enhanced healthy families. The last spiral ensured that the FBCM was a model within the stroke survivor's family's existing contexts.

As mentioned previously, concepts about working with families and stroke illness in the community were presented in the research method. It helped healthcare professionals provide care for families with confidence in adjusting behaviors and relationships to maintain their functional abilities. The information must be communicated effectively to communities and primary healthcare services, which helped family support arrangements. This study can help nurses as primary healthcare professionals communicate better and empower family members to maintain their functions as healthy family.

#### **1.2 Research Objectives**

#### **1.1.1 General Objectives**

To develop the Family-Based Caring Model (FBCM) for stroke survivors to enhance healthy families

#### **1.2.2 Specific Objectives**

#### 1.2.2.1 Phase 1

- (1) To synthesize family life experiences and needs for caring
- (2) To identify family functions for reaching a healthy family

while caring for stroke survivors

#### 1.2.2.2Phase 2

- (1) To motivate self-directed learning to cope with family stress
- (2) To design the caring behaviors by the families
- (3) To enhance a healthy family based on the individual by

themselves

#### **1.3.1 General Questions**

How to create the Family-Based Caring Model for stroke survivors to enhance a healthy family?

#### **1.3.2 Specific Questions**

#### 1.3.2.1 Phase 1

(1) How were the family life experiences and needs on caring for stroke survivors?

(2) How do families function to reach a healthy family when caring for stroke survivors?

#### 1.3.2.2 Phase 2

(1) How do families motivate self-directed learning to cope with

the stress?

(2) How do families design the caring behaviors for stroke

survivors?

(3) How do families change their lifestyles for healthy family?

#### 1.4 Scope of the Study

This study aimed to develop the Family-Based Caring Model (FBCM) from inquiries based on the theoretical underpinning of the core concepts of the Calgary Family Intervention Model (CFIM) framework. This study focused on place that presented in the scene of a semi-urban community and interested in the time of the families caring for stroke survivors. The researcher used in-depth interviews and group discussions to analyze caregivers' perceptions, which were the empirical knowledge to develop FBCM for stroke survivors' families. The FBCM was developed with stroke survivors' families by using the Participatory Action Research (PAR) Spiral Process conducted in the semi-urban community in Nonthaburi Province, Thailand.

The PAR in the proposed study was reflective and value-laden based on the perceptions of stroke survivor families' challenge to improve caregiving and enhance healthy family life. The study helped families to create a unique definition of a healthy family while caring for stroke survivors. The family group discussion helped families develop strategies for taking care of the stroke survivors, mobilizing the family resources, enhancing the family strengths, empowering the care abilities, and caring methods with positive coping styles to balance their family life.

The participants were selected by purposive and snowball sampling methods based on the inclusion criteria from the list of stroke survivors in the sub-urbanization communities: the service area of a Sub-district Health Promoting Hospital in Nonthaburi province, Thailand. This study had two phases. The times were required nine months for collecting and analyzing data in first phase (January, 2020 to Sep, 2020) and four months for the PAR process (October, 2020 to January, 2021). In the first phase, the in-depth interviews for forty caregivers took place in the home environments. After that, fourteen caregivers participated in two group discussions for triangulating interview data. In the second phase, fourteen families were invited to participate in action processes. The process of PAR was taken place in comfortable environments to conduct by family members. The family caregivers were invited to participate four times per month in the family group discussion in a total of four months. The groups of families were divided into two groups depending on the convenience of time and place of the participants. The researcher was a facilitator and assistant to support when the family requests. This study began after The Human Research Ethics Committee of Thammasat University (Science) approval and once permission was obtained to collect data. The study's procedural step began with signing a consent form before collecting data in the first phase and before starting the participatory spiral process in the second phase.

#### **1.5 Conceptual Framework**

The essential concepts in this research focused on family functions in caring for stroke survivors at home specifically in the semi-urban community. Family experiences would design care for stroke survivors and define healthy families in life and participation by individuals to enhance healthy families.

The Calgary Family Intervention Model (CFIM) was used as the starting framework to guide the interview questions. This framework depicted the whole family as an emotional unit as the most appropriate choice for evaluating relationships and responsibilities needed in providing care for stroke survivors at home and described complex interactions in the family unit. The three major concepts of a CFIM were used to develop the interview questions. The PAR process was an option for exploring perceptions and revealing explanations about family members' care problems. PAR was viewed as the qualitative feature of feelings, views, and patterns of an individual that the researcher cannot control or manipulate (MacDonald, 2012). The CFIM framework focused on effective changes in three domains of family functions including cognitive, affective, and behavioral functions in the family system (Kaakinen et al., 2015; Wright & Leahey, 2013). Kemmis and McTaggart guided the process of this action research. This participatory action research design used a spiral of individual and collective self-reflective cycles as a methodology for the study (Kemmis et al., 2014; McTaggart et al., 2017).

We believe the family to be a system in which any changes can affect the whole family. Therefore, the proposed study focused on the core concepts and the potential functional ability of caring for stroke survivors at home to enhance family health. The caring behaviors were designed by the families to take care of stroke survivors at home specific in the semi-urban community. This process helped families create a unique meaning of a healthy family during their care experiences. The individuals' participation would enhance a healthy family in three dimensions, including caregivers themselves, caregivers and stroke survivors, and caregivers and family members, along with the critical success factors for achieving the goal of a "healthy family life." The Participatory Action Research (PAR) model was applied for the proposed study to depict a family unit in an inquiry using the core concepts of the Calgary Family Intervention Model (CFIM). This analytical was the most appropriate choice for evaluating the relationship between the responsibilities developed when caring for stroke survivors at home within the whole family.

In-depth interviews, family focus groups, and group discussions were used to explore family life of the stroke survivors' families with qualitative methods. Family caregivers collaborated on discussions, brainstorming to explore life experiences, activities, communication, decision-making, and beliefs. Next, family members harmonized to contribute to the meaning of a healthy family and created strategies for care along with the implementation to become a healthy family. The proposed study followed the research spiral based on the action research spiral method, which had four cycles. Furthermore, each cycle used a spiral of individual and collective self-reflective cycles as a methodology containing the following four steps: planning, acting, observing, and reflecting (Kemmis & McTaggart, 1988). The researcher used empirical knowledge to develop a Family-Based Caring Model (FBCM) for stroke survivors' families to enhance a healthy family. The study had two phases as follows:

The first phase of the proposed study was conducted by interviewing and conducting focus group activities with the families. The key persons in the families of the stroke survivors who met the criteria and agreed to participate were invited to participate in the in-depth interviews. This phase aimed to study the caring life of the stroke families as a situation analysis in the semi-urban community. The findings from individual interviews with family caregivers were the content for analysis coded and analyzed in emerging themes by the researcher to find essential factors and confirmed the data for triangulation with the family focus groups. Three essential factors that emerged from phase 1 were caregiver characteristics, family function, and resources support using for an action plan in the next phase of the study.

The second phase aimed at developing the Family-Based Caring Model (FBCM) with the stroke survivors' families by using the Participatory Action Research (PAR) Process. The PAR process was conducted within the family unit for enhancing family life. The family groups set the goal and discussed in detail of essential factors from phase 1 and developed caring strategies to achieve the goal. The families were selected by purposive and snowball sampling methods from the list of stroke survivors in the service area of Sub-district Health Promoting Hospitals as the areas with families suffering from a stroke in the semi-urban communities of Thailand. In the process, family members shared their family life situation together with three essential factors such as caring experiences, obstacles, changes, coping strategies for resolving and managing family lifestyles. Then, the family members created strategies for caregiving stroke survivors' families in the semi-urban community. Family members processed themselves to help together in the action research spiral's four-cycle pattern along with key success factors.

The participatory action research spiral process has four cycles. Each cycle was used as a spiral of individual and collective self-reflective cycles as a methodology containing the following four steps: planning, acting, observing, and reflecting (McTaggart et al., 2017). The last spiral ensured getting the FBCM that was a model with the existing contexts of the stroke survivors' families in the semi-urban community. The expected outcomes of the model were "Healthy Family": family have the ability for coping, changing in caring behaviors, still maintain the family function, and family members can create their self-care. The conceptual framework of the study was shown in Figure 1.1.

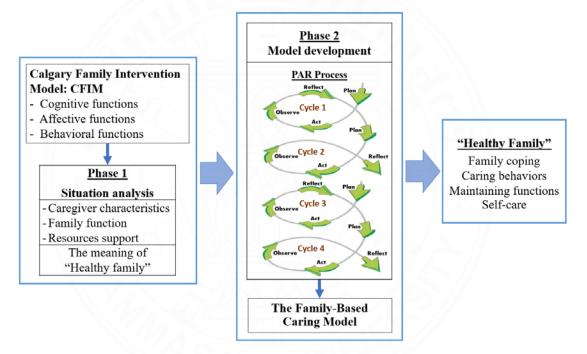


Figure 1.1 Conceptual Framework of the Study

#### **1.6 Proposition of Study**

According to the framework, the researcher developed a Family-Based Caring Model for stroke survivors capable of describing the process in the following four propositions in this study:

1.6.1 How did the domains of family functioning enhance a healthy family?

1.6.2 How did the family members holistic care for stroke survivors?

1.6.3 How should the Family-Based Caring Model for stroke survivors be?

#### **1.7 Definition of Terms**

**1.7.1 Family:** Families were defined as a group of people. A unit of the family consisted of at least two family members. All family members sensed or implied feeling like a part of the family or emotionally bonded without blood bonds or legal relationships. Individuals might live in another household, depending on the situation with mutual obligations in life.

**1.7.2 Family Caregivers:** Family caregivers lived with and cared for a stroke survivor without payment as informal caregivers. Family caregivers were defined as being in a committed relationship as the spouse or partner, family members, or friends responsible for providing at least four hours of care per day for stroke survivors at home.

**1.7.3 Families of Stroke Survivors:** Families of stroke survivors mean a group of individuals comprising stroke survivors who had experienced a stroke event, family caregivers, and other family members. All family members had a sense or implied feeling as part of the family or sharing an emotional bond with no need for blood or legal relationships. Families might live in other households, depending on the situation, with mutual obligations in life. A stroke survivor's family was viewed as a unit consisting of one member and at least two or more people who provided emotional, physical, and economic support. The context of each stroke survivor's family unit was dynamic, depending on beliefs concerning health and illness influencing family members' health outcomes.

**1.7.4 Healthy Family:** The healthy family in this study composts of 4 components including 1) Happiness that comes from within the mind considering the reflection of the family caregivers, family members, and stroke survivors, 2) Physical health of caregivers, family members, and also, the health recovery of stroke survivors, 3) Financial balancing that the caregivers experienced receiving from other members and the community, and 4) Family bonding from good relationship and reciprocity of family members.

**1.7.5 Family-Based Caring Model (FBCM):** The Family-Based Caring Model was created based on families' experiences and developed in participatory action research within stroke survivors' families within four cycles of PAR process: cycle 1

Strategic Design and collaborating, cycle 2 Supporting and fulfilling care competency, cycle 3 Balancing the body and mind for creating positive energy, and cycle 4 Self-improvement for happiness. The model comprised 4 components that would result in healthy family: 1) Caregivers, 2) Caring achievement, 3) Community Care Commander, and 4) Community resourcefulness. Family caregivers were significant family members in providing care to stroke survivors and driving the model to enhance family health to achieve targeted activities, healthy family. They utilized caring achievement as caring strategies to guide caring for their own survivors under their dimension or the family context by means of assistance from the Community Care Commander. Community Care Commander gave assistance to support various activities for achieving the goal of caring, and community resourcefulness contributed to supporting useful and necessary resources for stroke families to perform caring activities according to the targets.

#### **1.8 Expected Benefit**

**1.8.1 Families of Stroke Survivors**: Family members of the stroke survivors are able to develop their lifestyles and maintain family functions for caring together.

**1.8.2 Nursing Performance**: The FBCM can be used by nurses working in district hospitals or sub-district health promoting hospitals, healthcare providers, or healthcare services to provide future care for patients and families. The FBCM will improve care ability for entire families while also guiding caregivers to be more professional in practices when providing family-based assistance and contributing more facilities to enhance family strength toward becoming healthy families.

**1.8.3 Research Study**: Researchers are able to use this model guiding to conduct the further research. It can be used to design a care model for patients with other chronic diseases for facilitating healthy family.

**1.8.4 Health Policy**: The FBCM will be developed by family members and confirmed through the participatory action research method as a normal and sustainable model in caring for stroke survivors. The FBCM will be enhanced to help the families of stroke survivors become healthy families capable of improving confidence and

alleviating complications from the illness while saving costs from care supplies incurred by families. Furthermore, if families are healthy, admission rates will drop. This can be a strong and significant initiative for increasing funding for organizations or volunteers who support healthy families.



# CHAPTER 2 REVIEW OF LITERATURE

#### **2.1 Introduction**

This study aimed at ensuring sufficient confidence in the whole family to care for family members who were victims of the disease known as stroke and make adaptations in life to maintain family functional homeostasis in their socio-cultural contexts. This study was based on potential competency in caring for stroke survivors at home to improve family health. Individual care plans were designed by the entire family to care for stroke survivors collaboratively. This study used in-depth interviews and group discussions during two phases of the study to help families created a unique definition of a healthy family while caring for stroke survivors.

The literature review followed family experiences and needs in caring for stroke survivors. The review attempted to explore potential family functions with stroke survivors and determines how to have a healthy family life within care contexts. This section ended with Participatory Action Research (PAR) as the methodology for the study. The following seven topics were included in the literature review.

- 1) Stroke survivors and families
- 2) Evidence-based practice on stroke survivors' family interactions
- 3) Healthy family functions
- 4) Concept of the Calgary Family Intervention Model (CFIM)
- 5) Participatory Action Research (PAR) as a methodology
- 6) The cultural context of Thai family under semi-urban community
- 7) Strategic for family-based to enhance a healthy family

#### 2.2 Stroke Survivors and Families

A stroke is usually an unexpected medical event and one of the leading causes of long-term disability and suffering (Green, 2015; McCarthy & Bauer, 2015; Zhang & Lee, 2017). The frequency of stroke occurrence in the world is rapidly

increasing. Recent medical developments have increased survival rates for the disease (Abd-Allah et al., 2018; Thrift et al., 2017). Stroke is the second most common cause of deaths worldwide and the third most common cause of disability with 4.5 percent of disability-adjusted life-years (DALYs) from all causes (Feigin, Norrving, & Mensah, 2017). The most recent worldwide Global Burden of Disease (GBD) estimates reported significant increases in stroke burdens over the last two and half decades (Feigin et al., 2017). Defined by the World Health Organization as a brain injury, stroke is a clinical condition formally diagnosed as a cerebrovascular accident or CVA caused by a sudden lack of oxygen or an inadequate supply of blood to a particular part of the brain for more than 24 hours resulting in general brain impairment or permanent neurological deficiency (Amarenco et al., 2018; Davenport & Dennis, 2000). Sudden disability from stroke usually causes heavy burdens from the medical event, which is a leading cause of long-term care and suffering for patients and families (Green, 2015; McCarthy & Bauer, 2015; Zhang & Lee, 2017).

Stroke is a non-communicable disease and a complicated condition due to different etiologies and various risk factors. Causes often included hypertension, diabetes mellitus, smoking behavior, heavy alcohol consumption, hyperlipidemia, obesity, cardiac source and family history of cerebrovascular disease (Feigin et al., 2016). Stroke is usually divided into two broad classifications consisting of ischemic stroke and hemorrhagic stroke. Ischemic stroke is commonly caused by blockage of blood from localized blood clots as a thrombus or from the vascular system as an embolus. Hemorrhagic stroke often occurs from very high blood pressure rupturing blood vessels and bleeding in the brain. A stroke occurs due to lack of oxygen in a particular part of the brain resulting in neurological symptoms including paralysis, loss of sensory perception, language disturbance and vision problems (Seidel & Seidel, 2018). Different consequences after stroke are dependent on the injured area and a result of brain damage causing loss of function among individuals (Seidel & Seidel, 2018).

After a stroke, survivors begin the recovery process of returning to normal living. In the chronic stage, most stroke survivors continue to live at home and may receive care from family members (Misawa et al., 2018). The life experiences and needs of stroke survivors and families are met when stroke survivors and families live at home.

Stroke manifestation is dependent on the type of brain injury. However, survivors often suffer from symptoms after a stroke crisis including functional impairment or physical limitations and neurological disability as well as cognitive and behavioral difficulties (Meijering, Nanninga, & Lettinga, 2016; Zahuranec et al., 2017). Stroke severity is usually categorized by the Barthel Index (BI) as mild, moderate or severe based on survivors' functioning ability (Ekstam, Johansson, Guidetti, Eriksson, & Ytterberg, 2015). BI is the most appropriate and common ADL scale and BI has been widely used for assessing ADL independence, functional changes and quality of survival in rehabilitation of patients who suffered strokes. The total score of 100 points means full independence in functional abilities required by patients (Mudaliar et al., 2018; Silveira et al., 2018). Previous studies have revealed BI variation to be 44 percent when assessing patients' functional status (Silveira et al., 2018).

Expectations have focused as much as possible on recovery and the ability to return to a normal and independent life in patients' conditions. Stroke survivors and families need more information to prepare for life after discharge such as information on self-care, appropriate modifications in home environments or potential problems. Although many stroke survivors stated life has improved at more than one year becoming sick, stroke survivors remained unsatisfied because stroke survivors struggled with understanding and threats to stroke survivors' lives (Martinsen, Kirkevold, & Sveen, 2015). Suitable lodgings after discharge are dependent on family convenience. Stroke survivors do not want to be placed in nursing homes as an alternative. Most stroke survivors hope to return home and enjoy doing everything stroke survivors did previously with family and friends, particularly by returning to work life (Lutz, Ellen Young, Cox, Martz, & Rae Creasy, 2011; Martinsen et al., 2015; Prillaman & Willett, 2013). At home, stroke survivors comprehend dependence on others while stroke survivors want to be independent, if possible. Even so, many survivors have reported struggling with being at home because stroke survivors feel challenged to by managing and understanding routines (Meijering et al., 2016).

Stroke survivors usually have trouble with communicating, moving or acting due to physical limitations and cognitive changes. The most common effects are one-sided weakness or paralysis of the body, causing difficulty for stroke survivors in activities and causing stroke survivors to need assistance with sitting, standing or working. Most survivors reported significant problems when walking and dependence on wheelchairs or walkers (Ekstam et al., 2015). Basic activities of daily living (BADLs) are defined as eating, bathing, toileting, dressing and moving. More advanced "instrumental activities of daily living" (IADLs) such as using telephones, cooking, cleaning, driving or managing financial affairs can determine whether survivors have more self-care or a higher degree of independence (Chueluecha, 2012; Oldenkamp et al., 2016). Eating difficulties are an importance experience with effects on the ability to eat and other functions related to survivors' well-being, including motor function, sensory function, cognitive function, psychological and emotional function (Jones & Nasr, 2018). Most survivors have reported difficulty walking and dependence on equipment (Ekstam et al., 2015). Complications such as stiff joints, infections or bedsores may occur, thereby resulting in increased limitations on activity and forcing survivors to be more dependent and have more need for self-care. Zahuranec et al. (2017) found limitations in activities of daily living on stroke survivors who were addressing pain to be strongly associated with reduced well-being while better rehabilitation was associated with improved well-being and functional outcomes among survivors. Moreover, rehabilitation at home was not expensive, effective at reducing disability and increasing survivors' quality of life (Rasmussen et al., 2016).

Cognitive impairments of stroke survivors are commonly reported followed by communication issues, endurance problems, sensory loss, psychiatric illness and motor limitations. Frequent communication issues following stroke included issues related to attention, language, memory, visual perception and executive function. Survivors lose memory and are unable to remember much. Survivors often experience simultaneous general language impairments such as dysphagia (abnormal swallowing physiology), dysarthria (slow or slurred speech that is difficult to understand) and aphasia (the ability to hear with difficulty understanding). Survivors are confronted with communication difficulties including unstable attention, tolerance, consciousness, hearing and visual disorders with influence on emotional and behavioral style of stroke survivors (Flowers, Silver, Fang, Rochon, & Martino, 2013; Wall, Isaacs, Copland, & Cumming, 2015; Wray & Clarke, 2017).

Stroke survivors have physical limitations related to weakness, including reduced sensitivity in the arms and hands or hemiparesis, all of which are reported as rehabilitation needs. Ekstam et al. (2015) explored and found stroke survivors to need more rehabilitation within 12 months for rapid improvement associated with less severe stroke. Nearly half of stroke survivors may be able to return to work with greater independence in ADL, better cognitive ability and fewer neurological impairments. The review reported most of the survivors who were able to work to be males who had been employed in an office or professional settings (Edwards, Kapoor, Linkewich, & Swartz, 2017; McKevitt et al., 2010). Furthermore, stroke survivors who have worked may feel a lack of occupational support from services in the community or organization to return to work (Pindus et al., 2018).

However, stroke gives survivors have less time to socialize due to rehabilitation needs and lack of confidence or difficulty in performing activities. Stroke survivors do not spend time for entertainment or work with family, friends or others. Survivors have also reported extreme reductions in leisure time and negative effects on relationships between spouses, friends and family caregivers (Andrew, Kilkenny, Naylor, Purvis, & Cadilhac, 2015). Lack of confidence in communication contributes to stroke survivors' isolation and exclusion from society. Stroke survivors are sometimes separated from people and avoid communication situations, thereby causing stroke survivors to become depressed (Prillaman & Willett, 2013). Flexibility to adapt, adjust and take part in achieving activities with added meaning in stroke survivors' lives, despite communication difficulties. Psychosocial support may improve positive strengthening to prevent psychiatric problems including anxiety, depression or social isolation of stroke survivors (Martinsen et al., 2015; Wray & Clarke, 2017).

These conditions may create emotional or behavioral problems, thereby causing engagement in contrary acts towards loved ones (Ekstam et al., 2015; Nikomrack & Jenjaiwit, 2015; Wall et al., 2015; Winstein et al., 2016; J. Zhang & Lee, 2017). A quarter of stroke survivors have reported adverse changes in family relationships, especially with spouses since the occurrence of stroke (McKevitt et al., 2010). Stroke survivors might be annoyed with feelings of being upset, angry, lost, frustrated or depressed when stroke survivors' needs are not met. Martinsen et al. (2015) found stroke survivors' needs to involve difficulty accessing health services and follow-up services that need to be tailored by professionals after stroke. Stroke survivors are concerned with health-related consequences and uncertainty regarding

survivors' physical conditions. Similarly, a review conducted by Pindus et al. (2018) found lack of information regarding available and accessible services.

In the stroke management context, family members or friends are concerned about preparation and provision of physical, practical or emotional support to improve the health status of stroke survivors who may have differences in cultural contexts when caring for stroke survivors at home (Luker et al., 2017; Lutz et al., 2011). Most stroke survivors live with relatives and require extensive care and informal support (Chuluunbaatar et al., 2017; Persson et al., 2017). Many family caregivers are family members of stroke survivors consisting of various generations of family members, relatives, spouses, parents, daughters/sons, granddaughters/sons or friends. Understanding changes in the lives of families and relationships in the midst of those changes can promote families to function with better designs for healthy family lives.

Before returning home, families receive suggestions to prepare home environments such as by rearranging furniture, installing grab bars, finding adjustable beds similar to hospitals, adding bath benches in the bathroom and widening doorways for wheelchairs. These adjustments help families transfer survivors from beds to wheelchairs or other places with more comfort and safety (Prillaman & Willett, 2013). On the other hand, families may feel overwhelmed by information and stroke survivors may have dynamic needs after discharge. Although all of the information is important and necessary for stroke survivors, stroke survivors feel the information is not provided at the right time (Pindus et al., 2018).

When stroke survivors return home, both stroke survivors' and family members' roles change from observers to multi-faceted project managers and survivors and family members want to develop relationships with new functions and tasks (Prillaman & Willett, 2013). Family members are forced into caregiving roles. Stroke survivors and family members often experience difficulties in coping with stroke survivors' personality changes and feelings of abandonment related to a lack of knowledge, support and assistance from other family members (Smith-Johnson, Davis, Burns, Montgomery, & McGee, 2015). Family members need more excellent continuity of care and appropriate knowledge about stroke to learn new strategies and manage with complicated situations such as proper planning or initiating therapy in home environments (Koukouli et al., 2018; Pindus et al., 2018). Stroke survivors should

find primary caregivers who are available to attend and provide care for stroke survivors in home environments, depending on functional ability for self-care of stroke survivors. Each stroke survivor often requires different rehabilitation and complex care from families. Activities include everyday tasks, exercises, physical and occupational therapy such as transferring from beds to wheelchairs, from chairs to the toilet or getting in the car. However, despite the best planning, accidents can occur. Stroke survivors may fall while transferring or performing other activities without assistance from caregivers. Stroke survivors should be aware of how much medication stroke survivors should take at various times (Lutz et al., 2011).

Dependent stroke survivor requires daily support and rehabilitation from others. Caregivers may feel limited and have a great need for support to organize and establish routines. A review conducted by Pindus et al. (2018) found family caregivers of stroke patients to feel as though they were becoming experts in a care-giving role. Family members had to make changes in life such as use of time, technical tasks and daily activities. Many caregivers suffered from the effects of managing stroke survivors' limited motor system, impaired sensory system, weakened visualization, language or communication problems, cognitive and psychological distress (Zhang & Lee, 2017). Caro et al. (2017) studied family relationships post-stroke and found increased burden among family caregivers to be associated with reduced quality of life regarding family caregivers' health.

Many interventions have been created to help caregivers of stroke survivors who remain naturally limited. Unmet needs and association of caregivers of stroke survivors in qualitative and quantitative studies have led to future interventions. Caregivers have reported the following limitations: caregivers did not receive care after discharge, inappropriate responses to cover all situations with changing needs and lack of support for various unmet needs of caregivers (Denham et al., 2018).

Although only one person has a stroke, the effects of the stroke are widespread. Stroke deeply affects quality of life, physical and psychological health of not only caregivers but also family members and friends (Denham et al., 2018). Family members and survivors learn to live with the consequences of a stroke together. Lutz et al. (2011) found the caregivers of stroke survivors to have both physical and emotional problems in addition to feelings of being abandoned and alone with requirements for

support from health services. Families need support and education regarding the longterm implications of stroke and also need health professionals to be proactive in the community by providing care and supporting families at home (Roy, 2015). However, many researches and interventions from healthcare systems have helped individuals and caregivers to improve health outcomes. Regardless, these efforts are inadequate because stroke mostly causes permanently disabilities and creates an enormous burden on health and social care. In addition, the number of healthcare providers is insufficient for providing services at home (Krishnamurthi et al., 2018; Theofanidis & Gibbon, 2016; Thrift et al., 2017).

Moreover, recent studies have shown that family members continue to have difficulty managing different feelings and obtaining information. In addition, communication with healthcare providers is often problematic (Koukouli et al., 2018). This is consistent with a review by Pindus et al. (2018) who found families to perceive dissatisfaction concerning service quality and incomplete information as well as little and vague information among healthcare professional and patient-family communication regarding little rehabilitation or facilitation at home. The information received by stroke survivors is presented too early after a stroke, thereby causing confusion, fear and powerlessness. Stroke survivors need continual support from active healthcare services and volunteer agencies, neighbors or peers as group support when emergencies or complications occur in order to relieve stroke survivors' burdens. As such, understanding, specific information about post-stroke symptoms and management has led healthcare professionals to communicate easily with family members to assess and address meaningful conversations aimed at promoting reassurance, empowerment and improve self-management of family members to make suitable changes for the care of stroke survivors (Östlund, Bäckström, Saveman, Lindh, & Sundin, 2016b; Pindus et al., 2018).

#### 2.3 Evidence-Based Practice on Stroke Survivors' Family Interactions

Evidence-based practices have become an essential feature of health care systems and health care policy. Evidence-based practices in the context of care for stroke survivors by family units defines and discusses factors consisting of the factors and the impacts of providing care to promote active practices for healthcare providers. Moreover, evidence-based practices enable healthcare professionals to summarize the potential of the family and robust participation in family care. Evidence-based practices can help reduce negative feelings and enhance the positive feelings of caregivers and stroke survivors. Therefore, healthcare providers need to understand expressions and emotions as well as voices as they recognize new possibilities for action to create practices in everyday life in specific situations, care for individuals and stroke survivors' family units and balance care between them. This review emphasizes the impact of stroke and the unmet needs influencing family members including survivors, family caregivers, other members and overall image of the family to provide as much care for stroke survivors as possible.

Care for stroke survivors at home is a long-term condition for families — Caring is associated with quality of life or health among stroke survivors and caregivers. Chuluunbaatar et al. (2017) described changes in quality of life among stroke survivors as being similar to changes for family caregivers. This is correlated with depression and poor outcomes. Stroke survivors are often unable to manage even the simplest activities of daily living such as oral hygiene or face-washing (Kuo, Yen, Fetzer, Lee, & Chiang, 2015). Stroke survivors have effects from communication difficulties including speech problems such as aphasia, dysarthria and apraxia. This is related to psychosocial consequences beyond symptoms of medical impairment influencing social relationships, moods and activities of daily living. The struggle to communicate causes negative feelings fueling sources of emotional distress and feelings of loss and sadness among stroke survivors, leading stroke survivors to feel left out from society (Jellema, Wijnen, Steultjens, Nijhuis-van der Sanden, & van der Sande, 2018; Seidel & Seidel, 2018; Wray & Clarke, 2017). In contrast, some survivors with communication impairment use their own strategies to facilitate conversation such as writing, drawing or body signaling. These are meaningful activities leading stroke survivors to live successfully (Wray & Clarke, 2017).

Providing care knowledge and skills, obtaining and maintaining social support, and providing socio-economic support can improve stroke survivors' health. Wray and Clarke (2017) stated that survivors with growth in communication and physical abilities would perceive themselves to be living successfully because survivors were able to act independently. Lack of support from family and friends is also associated with poorer health outcomes among survivors (Krishnan et al., 2017). Higher quality of life can predict reductions in stroke survivors' disability levels. The literature review recommends that stroke survivors set and tailor goals for specific individual needs in order to increase self-management abilities for stroke survivors' conditions (Lloyd, Bannigan, Sugavanam, & Freeman, 2018).

For the family caregivers of stroke survivors commonly known as informal caregivers, family caregivers need to provide meaningful care and support for stroke survivors in every matter as a resource for stroke survivors in all decision-making (Norrving et al., 2018). Caplan (2006) illustrated caregivers' missions to perform actions similar to healthcare providers such as nurses, physicians or pharmacists. In the aforementioned study, caregivers' roles comprised diagnosing emergency symptoms, administering medications, providing care, taking stroke survivors to exercise or rehabilitating stroke survivors. In addition, caregivers need to manage unexpected complications of stroke. Sometimes, family caregivers act as cheerleaders or psychologists (Starks et al., 2018). At such times, caregivers have to act as economists or the managing director of a financial agency (Krishnan et al., 2017). Most caregivers need to learn and cope with changes and the psychological needs of survivors (Pesantes, Brandt, Ipince, Miranda, & Diez-Canseco, 2017). Family caregivers are usually any family members with the principal responsibility of managing stroke survivors such as partners, wives or husbands, daughters or sons. In some instances, caregivers are close friends. Caregivers are the most important people who take direct action and receive direct effects from stroke survivors and the indirect impacts from other family members (Caplan, 2006; Prillaman & Willett, 2013). The above findings are consistent with a statement from a caregiver of stroke survivors who was a wife. The aforementioned caregiver stated, "Stroke affects not only the patient, but the attendant stress can trigger problems for the caregiver as well," (Prillaman & Willett, 2013).

Caregivers of stroke survivors, particularly long-term family caregivers, regard caregiving as suffering causing changes in life without warning. Providing care for stroke survivors about the development of physical symptoms, psychological or emotional problems and social issues is an added task that changes the activities of caregivers (Zhang & Lee, 2017). Pesantes et al. (2017) interviewed family caregivers

of stroke survivors. All of the participants reported having experienced emotional stress and depressive symptoms as a result of caregiving (Pesantes et al., 2017). Various new roles negatively influenced and placed enormous pressure on caregivers and interpersonal relationships with others. The caregivers reported loss of freedom and independence in daily duties (Zhang & Lee, 2017). In addition to stroke survivors losing valued activities, informal caregivers have changes in daily activities after concentrating on caring for stroke survivors (Jellema et al., 2018). Loss of valuable events by stroke caregivers can result in lower levels of well-being, depression and social isolation. Activity loss has also been reported in work, cultural and recreational activities, individual break times and family activities. One reason is that caregivers do not want to leave stroke survivors alone because caregivers are concerned about stroke survivors' safety (Jellema et al., 2018; Krishnan et al., 2017). In some cases, family caregivers have no alternative relief methods due to limited networks such as family members, friends or healthcare providers.

Negative feelings and mood behavior changes affect family caregivers' health or well-being. Hu, Yang, Kong, Hu, and Zeng (2018) studied relationships between anxiety, depression and care burden of primary caregivers of stroke survivors. According to the findings, the major factors influencing the negative emotions of caregivers were care times per day, medical payment methods and education levels of caregivers. Anxiety and depression were commonly found in the family caregivers and were closely related to care burdens (Norrving et al., 2018). Primary caregivers often have high strain, anxiety, and depression leading to decline in quality of life (Hu et al., 2018). Furthermore, severity of depression in family caregivers has also been connected to education, stroke survivors' dependence and family functioning (Guo & Liu, 2015). Providing personal space for breaks and providing knowledge on stroke recovery seems to be more helpful. To benefit caregivers, caregivers should perform activities together within the family. This will lead to a new sense of closeness or positive relationships and allow family members to focus on care roles. In the meantime, unexpected roles may lead to complicated and stressful life situations (Jellema et al., 2018; Zhang & Lee, 2017). On the contrary, a literature review conducted by Starks et al. (2018) reported low levels of burdens or stress when caring for stroke survivors because care roles, were

embedded in cultural values and traditions of care while norms influenced the care experiences of family caregivers.

Normally, family caregivers often feel an obligation to take full responsibility for the care of stroke survivors. This obligation is also acquired from religious doctrines and beliefs. Although caregivers feel depressed or guilty when caring for stroke survivors, family caregivers are to provide the best care for stroke survivors (Zhang & Lee, 2017). The impact of cultural experiences among individuals is significant. Various cultural contexts are related to personal beliefs. There are fewer reviews concerning cultural backgrounds influencing the care of family caregivers caring for stroke survivors and family caregivers' health outcomes.

Pindus et al. (2018) reported that family caregivers felt ill-prepared and pressured to "become experts" in caring for stroke survivors because healthcare professionals assumed family caregivers would provide most of the necessary care as though family caregivers were experts. This increased family caregivers' feelings of lack of support from healthcare providers (Pindus et al., 2018). This finding is consistent with a study conducted by Pesantes et al. (2017) who found almost all caregivers to have expressed a need for support from professionals because caregivers claimed none of the caregivers had received training in post-stroke care after the stroke survivors' discharge and only a few caregivers had received some psychological support (Pesantes et al., 2017). Family caregivers needed more support and services based on environmental needs such as the safety of stroke survivors, access to public spaces or supporting devices. Higher needs for accommodations and mobile devices, including walkers, wheelchairs, canes, beds and safety devices were identified (Krishnan et al., 2017). Family caregivers should manage new lives with coping strategies. In this challenging process, family caregivers try their best to meet care needs and adapt to dramatic changes by making efforts to cope with life situations (Zhang & Lee, 2017).

Not only are stroke survivors and caregivers affected by stroke, but the stroke event is also a massive source of stress among family members (Hu et al., 2018). During hospitalization, family caregivers have described difficulties in caring for older adults with stroke based on experience. The problems family caregivers are concerned and began with unexpected crisis situations. The findings reported by Sirisom, Thaniwattananon, and Jittanoon (2017) highlight the difficulties of twenty-six participants in sixteen families who

explained difficulty in caring for stroke survivors consisting of difficulties in making decisions regarding treatment options, difficulty in accessing support from healthcare staff and difficulty in learning care skills. In addition, families had to make life-changing decisions within a short amount of time, which influenced decision-making among family members before returning home (Sirisom et al., 2017).

After stroke survivors are discharged, all family members are happy. However, family members are quickly turned to frustration when stroke survivors return home. According to evidence, care for stroke survivors at home leads family members to manage various feelings or suffer from mixed emotions. Unexpected changes in life or diseases in the negative sense can drive family caregivers to change behaviors. For instance, family members might increase cigarette or alcohol consumption. Some family members want to escape, thereby resulting in separation from the family, depending on family relationships (Misawa et al., 2018). Friendly interactions between family members can close gaps in communication through appropriate skills and training on effectively coping with difficulties. This encourages family members to learn new roles (Sirisom et al., 2017). Perceived stigma of family members is associated with more significant psychological distress and lower quality of life (Sanden, Pryor, Stutterheim, Kok, & Bos, 2016). Healthcare providers should promote and support family roles in improving coping strategies (Koukouli et al., 2018).

A systematic review conducted by Jellema et al. (2018) described changes in roles and activities caused by the effects of family caregiving. The review found many family members to frequently put aside needs and focus more on the survivors. Family members reported losing proper functioning including social and leisure activities such as work, entertainment activities, exercise, shopping, housework and cooking, sexual activities, traveling and family development. However, a few reviews have reported no activity loss (Jellema et al., 2018; Wright & Leahey, 2013). Family function is typically assessed in the dimensions of communication, roles, problemsolving, affective involvement, affective responsiveness and behavioral control. Family function refers to the ability of a family operate to meet family members' needs as a whole by communicating and performing activities together. Family function is related to the occurrence and health outcomes of each family member (Guo & Liu, 2015). Satisfaction of family members such as happiness in the family, family health and family relationships can also affect family life. In addition, family function can affect the quality of care provided by family caregivers (Starks et al., 2018). Pharr, Dodge Francis, Terry, and Clark (2014) conducted a qualitative study among family caregivers and found cultural values and norms to influence the perception of caregiving roles and responsibilities. Moreover, filial piety strongly prevents caregivers from refusing to provide care. Family caregivers in families with healthy function are always pleasant due to family support. Family members are willing to spend time to provide care, make decisions and offer affection for stroke survivors without adverse conditions (Pharr et al., 2014; Starks et al., 2018).

The financial effects of stroke on families are necessary due to the high care costs after stroke, particularly if stroke survivors have more complications (Walsh et al., 2018). Families face direct costs from medical expenses and indirect costs from loss of productivity. This increases financial and economic burdens (Krishnan et al., 2017). Loss of income from a family member who was working at the time of stroke stops or reduces the family member's work activities. Financial difficulties such as cost of medication or equipment, fees from other caregivers or traveling expenses arise after a stroke has occurred (McKevitt et al., 2010; Xu et al., 2018). This financial imbalance creates different feelings in families and becomes a challenge for families to overcome at the same time (Zhang, Yan, You, Li, & Gao, 2016).

With regard to the effects of service access, Pindus et al. (2018) found stroke survivors' families to feel more progress with therapy. However, stroke survivors' families receive little to no help from healthcare services and are frustrated by delays in rehabilitation after discharge. These factors cause setbacks for stroke survivors. Families feel abandoned when therapy begins. Emotional support from healthcare professionals is essential, but deficient for stroke survivors' families (Dieperink, Coyne, Creedy, & Østergaard, 2018; Pindus et al., 2018). According to the literature review, shifts in perspectives concerning the effects of care can be seen from only one person to relatives of a group or other people (Liselott Årestedt et al., 2015). Most perspectives seek to find balance in life in the context of illness because entire families are living with effects from the illness and all family members participate in managing the illness (Robinson, 2017).

The last and one of the most important effects on care outcome is the cultural contexts of families. Family systems are known to be more complex and the dynamics of each family are composed of many subsystems from various cultural constructs (Wright & Leahey, 2013; Yamaguchi, Cohen, & Uza, 2016). Yamaguchi et al. (2016) studied the effects of cultural constructs on family caregiving in Japan and found the high-context value of family cultural constructs to be more powerful in providing practical care. Many countries in Asia have similar cultural contexts with Japanese families and are deeply involved with one another such as China (Zhang et al., 2016), Taiwan (Tzeng & Yin, 2008), and Thailand (Manasatchakun et al., 2016). Understanding family cultural contexts is more valuable than realizing the perceptions of everyday life experiences and the behaviors of each family (Yamaguchi et al., 2016). Concerning family contexts when a family member has had a stroke, each family should be moving toward good family health. This involves harmonizing to create care strategies along with developing caring contexts for living with the illness and cooperating to modify alternative ways for everyday life.

# **2.4 Healthy Family Functions**

Healthy families are included in the Bible for the sake of Christ. Christians believe God took the initiative in creating a family, and the Bible mentions relationships in married life between husband and wife (Čondić & Parlov, 2017). Healthy family characteristics are written in "The Traits of a Healthy Family", a book written by Curran (1983). Curran identified healthy family traits pointed at traditional family functioning harmonized with morals and tasks (Curran, 1983). Individuals thrive when harmony is maintained in relationships and the family functioning is enhanced with the need for knowledge and skills in the areas of financial management, positive interactions, communication and marital relationships (Hwang, 2018).

In "The Traits of a Healthy Family", Curran (1983) focused on family strengths and characterized the nature of healthy families. Excellent communication and listening were the first fundamental traits in loving family relationships. Energy in caring for every person including foster table time and conversation increases closeness within families (Kaakinen et al., 2015). Healthy families should affirm support for one another by giving positive moods and respecting each other to build individual selfesteem (Curran, 1983). Although trust is established in healthy families, many families remain uncertain of trust quality and depth among family members (Curran, 1983). Family members in healthy families have a sense of play and humor, balanced interactions while sharing responsibility and leisure time among members (Curran, 1983). Shared religion and culture are important in healthy families for instructions on appropriate roles in daily family life (Curran, 1983). Family members must respect one another's privacy and volunteer services for others (Curran, 1983). When family members are confronted with problems, families always expect and consider this as a normal part of life and develop solutions (Curran, 1983). Curran believed that the perfect family does not exist because Current never met a family with all of the traits. Curran felt family conversations and assessments of natural conditions in the family environment would be positive in enhancing family life. However, Curran's healthy family trains mainly mentioned normal families rather than families with an illness and possible effects on physical, emotional, intellectual, social or spiritual functioning of families (Kaakinen et al., 2015).

Family function refers to the ability of a family to meet the needs of family members as a whole by communicating and performing activities together. Expression of family functions is closely related to the health incidents and outcomes of each person. Assessments of family functions are usually in the dimensions of communication, roles, problem-solving, affective involvement, affective responsiveness and behavioral control (Guo & Liu, 2015). Beavers and Hampson (2000) characterized healthy family function as effective functioning consisted of capable negotiation skills when managing problems, respect for individual autonomy and members' feelings, intimacy toward one another and expressions of amusement (Kaakinen et al., 2015). Family functions are defined as interactions between family members regarding communication, traditions, roles, boundaries and a sense of resilience (Dieperink et al., 2018)

When the families are pressured by unexpected situations or events from living with a chronic illness (Robinson, 2017). any changes in the family life cycle make family functions change. For example, an illness is a regular change to be confronted and families must become families living with the illness normally (Kaakinen et al., 2015). Not only are patients faced with changes from illness, families are a part of those changes (Kaakinen et al., 2015; Robinson, 2017). Families have to adjust well in order to stay together with illness, maintain balanced functions in family life and become healthy families (Robinson, 2017).

Family members who live with illness are at risk for stress from physical, mental, emotional, social and financial problems (Hwang, 2018). Robinson (2017) explained complex processes of families when a chronic illness involves family life and the possibility of finding wellness alongside illness with a grounded theory. The theory guided the development of family practices to support more main goals of living well, despite illness. As a result, family participants manage well by effectively integrating illness in family systems to the point where family life incorporates both wellness and illness (Robinson, 2017).

According to families who have lived with stroke survivors, evidencebased practice from the literature review indicates that families suffer from mixed feelings (Denham et al., 2018; Dhippayom et al., 2018; Misawa et al., 2018; Pindus et al., 2018; Zhang & Lee, 2017). Families with stroke can be have healthy family functions with collaboration to recognize the illness while sharing the responsibilities, problems, obligations, emotional and spiritual experiences of living with stroke. Moreover, families have to accept support from other people (Robinson, 2017).

### 2.5 Concept of the Calgary Family Intervention Model (CFIM)

Wright and Leahey (2013) describe complex family interactions, analyzing complex relationships between family structure, functions and processes based on the systems, cybernetics, communication, changes and biology of cognition (Dorell & Sundin, 2016; Leahey & Wright, 2016; Wright & Leahey, 2013). The Calgary Family Intervention Model (CFIM) was developed by Wright and Leahey (1994) at the Family Nursing Unit, University of Calgary, Canada. The CFIM is a useful model with an explicit focus on recognizing strength and resilience in families (Dorell & Sundin, 2016; West, Bell, Woodgate, & Moules, 2015; Wright & Leahey, 2013). This model is viewed as a dynamic and open system at the family level with an aim to maintain health in the family and facilitate healing among family members (Wright & Leahey, 2013).

The Calgary Models illustrate the family as a group of individuals who are bound by strong emotional ties, a sense of belonging, a commitment to being involved in one another's lives, and who call themselves "family" (Dieperink et al., 2018; Wright & Leahey, 2013).

According to the literature review, many studies have used the core concept of the CFIM to develop appropriate interventions, depending on research contexts with positive effects such as strengthened cognitive, affective and behavioral domains of family health (Faarup et al., 2019; Sveinbjarnardottir & Svavarsdottir, 2019; Wright & Leahey, 2013). Most previous studies have aimed to improve family functions and family strength, including individual health and relationships among others in order to provide benefits for healthcare providers in understanding and assisting family reflection to find solutions and meet needs (Leahey & Wright, 2016; Sveinbjarnardottir & Svavarsdottir, 2019). Sveinbjarnardottir and Svavarsdottir (2019) used the CFIM as theoretical underpinnings of family support as a conceptual foundation for developing the Family Strength-Oriented Therapeutic Conversation Intervention (FAM-SOTC Intervention). According to the intervention, healthcare professionals provided support for family support concerning the promotion, improvement and maintenance of effective family functions in three domains comprising cognitive, affective and behavioral supports for patients and family members, depending on needs (Sveinbjarnardottir & Svavarsdottir, 2019).

The CFIM advises nurses in an integral part of the nursing process to encourage family involvement for effective nurse-family relationships. Nurse-family relationships influence improved outcomes for patients. Misto (2018) studied nurses' perceptions of family care guided by the CFIM framework to examine how nurses appraise family care practices and encouraged improvements in family-nurse relationships. The findings showed that positive perceptions of healthcare providers were able to support and promote reciprocity in nurse-family relationships including concern for benefits when working with families (Misto, 2018).

Lee, Lin, Chen, Su, and Chiang (2018) developed a brief family-centered care intervention based on the CFIM to improve family function for hospitalized patients with bipolar disorder and family caregivers. The model provided emotional support and encouraged family caregivers to manage or communicate to solve problems

(Lee et al., 2018). Family caregivers rated conversations as a support method from healthcare professionals (Margret Gisladottir, Treasure, & Svavarsdottir, 2017). According to the findings, family conversations often focused on interactions and relationships between family members and professionals, depending on experiences and needs (Dorell, Isaksson, Östlund, & Sundin, 2017). Dorell and Sundin (2016) studied the experiences of families participating in Family Health Conversations based on the Calgary model and found families involved in excellent and adequate communication to be capable of trusting relationships with healthcare providers. Participation by family members in conversations created interactions in independent communications and helped family members to feel valued. As a result, family members reported positive experiences related to reciprocal exposure and structured speaking and listening. Family members were able to discover problems and suffering in addition to identifying resources and strengths of families (Dorell & Sundin, 2016; Pusa et al., 2019).

The theoretical foundation of the CFIM is based on a strengthening supportive model for families as an intervention model in nursing practices (Gisladottir & Svavarsdottir, 2017). Family care system interventions help families to manage changes for balance and stability in life by using the CFIM in practice as a guide in order to assess families' health and identify families' needs for more understanding of interventions for families (Haefner, 2014; Leahey & Wright, 2016; Petursdottir, Haraldsdottir, & Svavarsdottir, 2018; Wright & Leahey, 2013). The model describes improving family communication and increasing confidence and capability in living with an illness (Östlund & Persson, 2014; Sundin et al., 2015). Petursdottir et al. (2018) developed an educational intervention program from the Calgary Model framework to guide nurses when interacting with families in nursing care. The study found positive effects on the knowledge, skills and attitudes of nurses who participated in the program, which made the nurses mindful when approaching families as a unit of care and when improving positive attitudes toward family care (Petursdottir et al., 2018).

Fruitful results are not always obtained when using the CFIM in research. However, the researcher had to find an explanation by providing sufficient reasons or evidence-based practices (Leahey & Wright, 2016). One research, for example, did not meet expectations. Faarup et al. (2019) assessed the effects of

family health conversations by using circular questioning based on the CFIM and offering praise to strengthen families. However, the findings were unable to show significant effects. The researcher argued that the intervention might be helpful. Therefore, adding evidence-based knowledge about different cultural contexts among families' experiences is essential in the research process (Faarup et al., 2019; Yamaguchi et al., 2016).

While other studies have often resulted in the development of interventions focused on improving suffering among patients or family members, studies have remained focused on individuals rather than the family level (Duhamel & Talbot, 2004). Theoretical frameworks for guiding nursing interventions such as the CFIM vary widely for different practices (Östlund & Persson, 2014; Wright & Leahey, 2013). Nurses' significance when working with families should be highlighted when families are viewed as a unit of care.

In addition, family members should be encouraged to manage feelings affecting families at both the personal and family levels (Östlund & Persson, 2014) and family members should choose suitable lifestyle changes for family life (Sundin et al., 2015). When the CFIM is used in the nursing process when working with families, the fundamentals of this model will guide nurses as well as healthcare providers to promote, improve and support the cognition, emotion and behaviors of families in terms of functions, beliefs and meanings related to family problems (Duhamel & Talbot, 2004; Wright & Leahey, 2013).

According to stroke survivors' families, stroke survivors and all family members suffer from this experience (Östlund et al., 2016; Sundin et al., 2015). Application of the CFIM in stroke survivors' families to promote family healing and family health in the proposed study will be based on core concepts of the family system and potential functional abilities in caring for stroke survivors at home in order to improve family health.

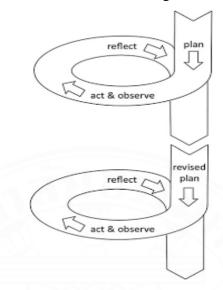
# 2.6 Participatory Action Research (PAR) as a Methodology

Participatory action research (PAR) is considered as a subset of action research and a methodology choice for qualitative research. Participatory action

research in qualitative researches is aimed at understanding and interpreting the phenomenon more than the quantitative method. All action research is aimed at taking specific (MacDonald, 2012). According to Kemmis and McTaggart, action research is not only concerned with participants' collective self-reflective inquiry for change, but also improvements in the rationality and justice of situations. Individual group members can collaborate and share ideas in practice as a means of improvement. Action research is associated with many approaches to changes in social practice. Participatory action research is often used as an approach for groups living with complex experiences in life or a natural setting with the objective of exploring for an in-depth understanding (Kemmis & McTaggart, 1988; McTaggart & Kemmis, 1988).

Action research leads to learning from collaborative and participative practices of groups of people to solve problems and adjust within new traditions until satisfaction is achieved. PAR originated from movements of free domination in society and touches on Lewin's and Freire's ideas. Kurt Lewin (1944) was recognized as the "founder of action research" and described action research as action in a spiral of steps including planning, action and evaluation of outcomes. Lewin believed that a spiral of steps can help people resolve issues and initiate change when studying the effects of particular changes. In addition, Lewin believed in group participation and believed each group to be dynamic. Paulo Freire thought critical reflection was crucial for personal adjustment and was concerned with empowerment for improving vulnerable persons. Members of the group mutually identify problems at the beginning of the general process and decide to work on consequences and concerns afterward (Balakrishnan & Claiborne, 2016; MacDonald, 2012).

PAR is a qualitative inquiry concerned with working in groups of people based on democracy, equality and autonomy without control or manipulation from the researcher in order to transform the participants from practice to praxis (MacDonald, 2012). The aim is to understand what the group is doing, conducting activities and the assessing the conditions of practices while creating new knowledge within a spiral of individual and self-reflective cycles. The PAR framework encompasses a cyclical process of fact-finding, action and reflection. The process includes planning action for change, acting and observing consequences and processes of evolution in addition to reflecting on the process before re-planning for the new cycle to repeat (Kemmis, 2009; Kemmis et al., 2014; McTaggart et al., 2017; Zuber-Skerritt, 2016). The process spiral of action research from Kemmis is described in Figure 2.1.



**Figure 2.1 Process Spirals of Action Research** 

*Note. From The Action Research Planner* (p.11), by Kemmis and McTaggart, 1988, Victoria: Deakin University.

The PAR process in each cycle is to plan, act, observe and reflect dynamically (MacDonald, 2012). In the planning phase, the researcher and participants harmonized to prepare for change by achieving the ultimate goal. At this point, the researcher obtains intuitive knowledge of the group and conveyed general information relevant to the issue. In the acting and observing phases, the change process is initiated through analysis of the situation followed by formulation of a primary hypothesis concerning emphasized issues through development and experimentation of every aspect. In the reflection phase, the participants endeavor to interpret changes in the context, explaining and broadening knowledge of specific issues (Bortoletto, 2016). After the reflection process, participants consider activities and return to realize the strengths and weaknesses of movement for adaptation or improved actions and design new plans to further achieve goals (McTaggart & Kemmis, 1988).

The PAR is not only applied to achieve social change. The PAR process also requires consideration of principles including engagement in community perspectives, ways or benefits of change, power and influence of change represented in reality (Townsend, 2013). PAR is aimed at providing means for vulnerable people to remove influence of others and action for their own destiny. PAR shares concern equally with different individuals, depending on group culture. A group's culture can be defined in three aspects of individuals' patterns consisting of language bearers or language patterns, individual actions or interaction patterns and relationships with others relationship patterns (McTaggart & Kemmis, 1988).

Participatory Action Research (PAR) is gaining popularity and is used in many institutes by academics, researchers, society or families in order to improve practices. PAR creates a path for researchers to manage multiple responsibilities as facilitators and dedicated participants in the research process (Balakrishnan & Claiborne, 2016). Turnbull, Friesen, and Ramirez (1998) provided five advantages of PAR from experience consisting of the following: (a) increased relevance of research and greater likelihood of being able to solve real problems by sharing alternative methods; (b) increased research rigor to increase the feasibility and acceptability of research methods and designs; (c) increased benefit for researchers in reducing problems; (d) increased utilization of research by participants due to access to information of high priority to participants' topics; and (e) greater empowerment of all collaborators. The PAR process aims to make practices more explicit and easier to understand, changing practices and conditions based on the intrapersonal and interpersonal views of members in the participatory group (MacDonald, 2012). PAR also focuses on perspectives on practices, relations and connections of the whole, subjective and objective aspects of individuals and society (McTaggart et al., 2017). Group participants must be confident in the ability to evaluate and understand strengths and limitations of the process within participants' knowledge in order to tailor the process and create more successful results.

PAR appears as a major project and often feels difficult for many researchers to carry out. Because PAR requires cooperation or contact with people from dynamic and diverse contexts, PAR is a dynamic process and not simply complete problem-solving in itself with the spiral of planning, acting, observing and reflecting. Researchers cannot control and judge subjects the way researchers would like. However, researchers have to work as facilitators to serve participants and meet the needs of participants' designs. Researchers require good and friendly relationships with collaborators to gain trust and allow confidentiality (Edwards-Groves & Kemmis, 2015).

Participants use PAR to discuss complex ethical issues and PAR is commonly used to improve communication and collaboration in education research to provide insights for opportunities and strategies (Balakrishnan & Claiborne, 2016; Edwards-Groves & Kemmis, 2015). All participants in studies are equal members with understanding. The participants build relationships and are free to express views to define roles and determine responsibilities for different contributions based on abilities, strengths and unique aptitude (Zuber-Skerritt, 2016). Balakrishnan (2010) decided to use PAR to conduct a research practice aimed at enhancing opportunities for students from different ethnic, religious and cultural backgrounds who sought learning and entry of moral education curriculum. The research found the participants to be at the start of a journey toward social change to protect the participants' natural environment for the future. The researcher argued that PAR increased thoughtfulness in relationships between social and educational theory and practice, further stating that PAR is not only a tool or a research technique (Balakrishnan & Claiborne, 2016). Ammentorp et al. (2018) approached multiple stakeholders by covering patients, researchers, health professionals and others in a comprehensive PAR process to identify communication challenges resulting in clinical decision-making. The process was able to improve skills and broaden understanding of health professionals toward the development of practices characterized by attentive and responsive dialogues regarding the expectations, values, concerns and hopes of patients and relatives (Ammentorp et al., 2018).

Participatory action research (PAR) in family research refers to a process whereby researchers and stakeholders (in the proposed study, families will be focused on as stakeholders) collaborate in the design and execution of all phases of the research process (Golfenshtein, Srulovici, & Deatrick, 2016; Turnbull et al., 1998). PAR requires participating family members to act in standardized tasks to solve problems with an aim to study family life and necessary issues to support family needs (Turnbull et al., 1998) and PAR often takes place in outpatients' home environments (Golfenshtein et al., 2016). Marincowitz (2003) used the PAR process to develop a deeper understanding of mutual participation among family members and friends of terminally ill patients and received positive effects in doctor-patient relationships in primary care. When PAR was used in the families, PAR might have improved the efficacy of family interactions and enhanced reciprocity among family members through new ways to achieve set goals (Golfenshtein et al., 2016).

In the proposed study, participatory action research (PAR) was conducted in the second phase (Kemmis et al., 2014). PAR is concerned fundamental aspects of action research in qualitative inquiries developed from theoretical underpinnings of the core concept of the Calgary Family Intervention Model (CFIM) framework. The proposed study was aimed at seeking family members' experiences in caring for stroke survivors and enhancing family health without control or manipulation from the researcher. The PAR process in this study used a reflective and value-laden process based on the perceived needs of stroke survivors' families for changes to improve care in order to improve family health. Family group discussions were expected to help families develop strategies for the care of stroke survivors consisting of mobilizing family resources, enhancing family strengths, empowering family care abilities and seeking methods with positive coping styles in order to balance family life. The knowledge obtained in this study was used to develop a Family-Based Caring Model (FBCM) for stroke survivors' families.

The second phase of the proposed study was aimed at developing the FBCM model in the PAR process within the family unit in order to improve family lives and achieve the goal of "healthy family life." The study was conducted in the area of Subdistrict Health Promoting Hospital where families were suffering from stroke in suburban societies in Thailand. Families were selected by purposive and snowball sampling from a list of stroke survivors. In PAR process, family members shared care experiences with stroke survivors including changes in family activities, communication strategies among family members, capabilities or resources for enhancing family resolve, managing family life and family care beliefs and culture. Family members developed strategies for the care of stroke survivors consisting of mobilizing family resources, increasing family strengths, empowering family care abilities, caring methods and positive coping styles to balance family life and set the ultimate goal for a "healthy family life" specifically for stroke survivors' families. Family members processed and helped in the four-cyclical pattern of the action research spiral along with the key success factors. The PAR process had four cycles. Each cycle used a spiral of individual and collective self-reflective cycles as a methodology with the following four steps: planning, acting, observing, and reflecting (McTaggart et al., 2017)

Regarding the steps in each cycle, the planning step was the session of family group discussions and cooperation to design strategies for the care of stroke survivors. Families set goals together to achieve unique goals in each family. In the first cycle, open-ended questions were developed from three structure concepts of the Calgary Family Intervention Model (CFIM) framework consisting of cognitive, affective, and functioning. This cycle found the key success factors helping families achieve goals for family life change activities, strategies for communication among family members, capabilities or resources to improve family solutions for barriers, and situation management while beliefs and culture support family strength. The family caregivers collaborated to develop strategies and set the ultimate goals for the care of stroke survivors consisting of mobilizing family resources, strengthening families, empowering family care abilities methods, and positive coping styles to balance family life. In the next cycle, the family caregivers generated the key success factors into new strategies in order to achieve the goal of "healthy family life." In the third cycle after families understand and perceive strategies for healthy family lives, family caregivers modified model strategies to be suitable for stroke survivors' families to achieve goals. In the last cycle, the caring model, was drawn to create the FBCM to accomplish goals with collaboration from family caregivers.

In the acting and observing step, each family bang the strategies from family group discussions and observation activities. The researcher will facilitate to motivate, support and encourage discussions concerning the progress of activities in stroke survivors' home environments. The researcher followed up on strategy implementation and observation once a week by visiting each family at home. In every cycle, each family took action or implemented strategies and observed family activities performed by family caregivers in addition to making adaptations within caregivers themselves, caregivers and stroke survivors, and caregivers and other members in each family.

The reflection step was the session for family group discussions. Seven family caregivers per group who represented each family were invited to collaborate, assess results and conclude strategies for re-planning in the next cycle. The first cycle determined strategy implementation including classification of barriers, achieved aims and recommendations for defining ways to move toward healthy family lives. The key success factors for healthy family life were emerged from this cycle. The second cycle discussed the feelings and thoughts concerning new strategies and possibilities along with key successes. Families understood and perceived the strategies for healthy family lives. The third cycle valued the model activities and addressed key successes as fitting for stroke survivors' families. The care model for healthy family lives was expected in this cycle. The fourth cycle appraised the FBCM and reported how outcomes from implementation enhanced healthy lives in each family.

Real-world as a tacit knowledge of life experiences, family life activities, communication, decision-making and beliefs were explored by in-depth interviews and group discussions with stroke survivors' family caregivers. Family members harmonized to provide a definition of healthy families and created care strategies along with implementing strategies to become healthy families. Families defined the ultimate goal of care for stroke survivors and family members made arrangements to have healthy family lives. Participation by the individuals would enhance healthy families in three dimensions consisting of caregivers, caregivers and stroke survivors, and caregivers and family members along with the critical success factors to achieve the goal of a "healthy family life." The Participatory Action Research (PAR) model was applied to this study and depicted family units in inquiries by using the core concepts of the Calgary Family Intervention Model (CFIM). These analytical instruments were the most appropriate choices for evaluating relationships between responsibilities when caring for stroke survivors at home within the entire family.

#### 2.6 The Cultural Context of Thai Family under Semi-Urban Community

During in the current situation of Thailand, Bangkok was the city that rapidly development and expansion causing to extend the urbanize community to semiurban area or suburb. The population or families living surrounding this area have to adapt and change to various lifestyles that contained with the new conditions. Semiurban areas are less densely populated than urban areas but more densely populated than rural areas. Living with the contributing factor of convenient and fast transport took family members in the suburban area worked in the city on a round trip basis. The most noticeable change in semi-urban areas is the emergence of commercial and residential neighborhoods such as condominiums and townhomes that are cheaper and affordable for middle-income earners. In addition, having government offices made it easier to access various public service systems such as electricity, water supply, roads and safety. The impact of the new urban environment required traditional communities to adapt to survive in a new lifestyle among the changing context form of society (Nathalang, 2019).

In the suburbs of Nonthaburi found that there has been an advancement of the city combined with the acceleration of developing technology to increase productivity in exports that affects the traditional way of gardeners by making the orchards transformed into industrial factories. Gardeners have to adapt their life by switching to other occupations. There are some areas that still orchards such as durian orchards, mangosteen orchards. In addition, the socio-cultural aspect has been affected to families more, for example: fewer role and relationship in kinship, more distant relationships between family members, and more selfish. The way of life the semiurban community has been changed by using various new technology, but the old traditions and cultures were still preserved in places applied for religious activities such as temples, shrines, and mosques in the community (Nathalang, 2019).

This research was specifically intended to study the semi-urban community in Nonthaburi province, situated adjacent to the Bangkok area and considered as a part of Bangkok Metropolitan Region in which the density of population was considerably less than that of urban areas. The urban sprawl phenomenon might have brought about a variety of communication and transportation, for example public buses and sky trains. Such an expansion, however, had also dealt a great impact on the agricultural areas which were eventually replaced by a number of high-rise and commercial buildings as well as the overcrowded residential areas.

The selected community of the research was in the area under the service authority of Bang Khen Health Promoting Hospital, Muang Nonthaburi district, Nonthaburi province, providing primary healthcare services to the people within its community. In support of health promotion and management on possible risk factors, the proactive service policy was adopted particularly for the people, families and community in the area of responsibility by integrating not only efficient health promotion, disease prevention and control and medical treatment, but also the rehabilitation and health recovery for certain patients which enabled such healthcare service to be transferable to the healthcare units at other levels.

Bang Khen Health Promoting Hospital is currently responsible for the population in the above-mentioned area for nine communities with approximately 15,482 people in total (retrieved on March 9, 2021). The density of population is 2,051 people per square kilometer on average with the estimate of two people per household. There is a group of patients under the hospital's responsibility – 444 patients with diabetes and 910 patients with hypertension. A total of nine medical practitioners are assigned to conduct the service which include four registered nurses, one pharmacist, one dental nurse, one public health officer, one traditional medical practitioner, and one public health technical officer (director of the local health promoting hospital). Due to the inadequacy of the available nurses, the nurse's role tends to primarily focus on the daily assigned tasks as per the policy which meanwhile limits additional care and visit to patient residences, as the majority of the visits are usually provided to the suffering and transferred patients first. Therefore, the registered nurses are required to adapt their work life as having sufficient knowledge and fundamental information of the patients as well as monitoring any health demands requested by the village health volunteers in the area.

# 2.7 Strategy for family-based to enhance a healthy family

Family caregivers are the important persons who help the health professional achieve the goal of any treatments in the community health care. In caring for patients at home, caregivers act like health personnel in a hospital, including: to act as a doctor in diagnosing abnormal symptoms of patient; to play like a pharmacist; to provide care and comfort like a nurse; Rejuvenate the body like a physiotherapist; and to take care of diet like a nutritionist. It is a challenge for caregivers to care for patients with Non-Communicable Diseases particular caring for stroke survivors that have a specificity depending on the symptoms, and severity of each stroke survivor.

Stroke is a source of stress for family members that often forces a burden on family caregivers regarding especially of the self-care deficit on daily activities of survivors depended on difference levels of stroke. The impact of stroke generates longterm dependence on families, mainly caused by the impairment of survivors on the physical mobility, thoughts, and decision in daily living (Misawa et al., 2018). Family caregivers had apportioned a high number of hours to providing care and also undertaken the caregiving responsibility (Elsheikh et al., 2022). Most significant common outcomes were caregiver burden (Bakas, McCarthy, and Miller, 2022; Okoye et al., 2019; Caro, Costa, & Da Cruz, 2018; Hekmatpou, Baghban, & Dehkordi, 2019; Kazemi et al., 2021). Previous studies showed that the experience of caring at home led family members to deal with feelings of the burden caused by the conflict in family roles and duties, and survivors reported anxiety, discouragement, frustration, and upset (Misawa et al., 2018; Kazemi et al., 2021; Zhu, & Jiang, 2018). This is consistent with research by Gawulayo, Eramus, and Rhoda (2021) found that stroke negatively influenced family functioning. Caring for stroke survivors, family caregivers perceived the impacts relationships, emotional engagement, and financial implications among family members (Hekmatpou, Baghban, & Dehkordi, 2019). The unexpected caregiving role of stroke caregivers led to complex and stressful life situations but caregivers were aware of the strength and actively sought out order and stability in their dramatically change life situation. They made effort to cope with suffering in their altered life (Zhang and Lee, 2017).

Most stroke survivors depend on their family members to provide care and help the associated problem. It is intimated that the most important period or golden period of stroke significantly recovery in which a patient can recover within 6 months after illness then family caregivers must endure for rehabilitation stroke survivors. For long-term of caring for stroke survivors, caregivers continue to assist in the activities of daily living of survivors in response to the essential needs that are important in reducing to face the occasion of complications and potentially permanent disability to survivors. It is important to assess the quality of life of family caregivers of stroke survivors, especially after hospital discharge, but there is no formal community support program for family caregivers which most families tend to take care of themselves (Bierhals, Low, & Paskulin, 2019).

The previous study suggested family caregivers for successful caring should consist of the following factors; good relationship within the family that family members help and support each other, realization perceptions of the roles that are accurate and appropriate, the knowledge and skills that are correct and adequate, and proper social support (Danzl, 2013). This is consistent with research by Robinson (2017) that families moved on with the healing process which comprised of the fight, accepting, living with a chronic condition, sharing experience, and reconstructing life. Families moved on over time toward healing where they lived well alongside chronic illness. In addition, good relationships within the family will encourage family members to be emotionally and mentally strong resulting in performing their roles in better care (Bunlikitkul, 2012). Family empowerment process or intervention developed from the professional can improve the quality of life of survivors and can help to decrease or prevent the caregiver burden (Deyhoul et al, 2020; Farahani et al, 2021).

Caregiving of stroke survivors was a fulltime job of caregivers that impacted their health and well-being (Kokorelias, Santos, Xu, Leung, and Cameron, 2020). Caring for stroke survivors were negatively impacts to the health and quality of life remarkably of family caregivers. Most intervention studies reported significant improvements in caregiver outcomes or quality of life included caregiver burden, caregiver competence, problem solving, and increased positive aspects (Bakas, McCarthy, and Miller, 2022; Okoye et al, 2019). Conversely, the study review found several studies reported nonsignificant findings of perceiving the physical health of caregivers (Bakas, McCarthy, and Miller, 2022). Therefore, it is imperative that nurses are involved in supporting stroke families to develop guideline or strategies to care for both the survivors and themselves that are appropriate in the context of the family. Silva JK (2016) recommends that nurses or healthcare teams to provide strengthened health education and encourage proactivity to family members who must provide continuous and practical care on their own.

# CHAPTER 3 RESEARCH METHODOLOGY

The main objective of this study was to develop a care model of families whose members are diagnosed with stroke in order to promote health and well-being of the families. By adopting the Participatory Action Research (PAR) under the semiurban community context and circumstance in Nonthaburi province, this research was generally divided in two different stages. The first stage aimed to study the actual situations in monitoring and treating stroke in survivors (situation analysis) and to define the meaning of a healthy family while providing healthcare to stroke survivors. On the other hand, the second stage focused on developing a care model practicable to apply to the family members suffering from stroke in a real-life situation by adopting PAR process.

Chapter 3 explicitly clarified all the research process during each stage in complete details based on these following topics:

- 1) The Research Settings
- 2) Research Design and Methodology
- 3) Triangulation
- 4) Human Subject Protection

# 3.1 The Research Setting

This research was specifically intended to study the semi-urban community in Nonthaburi province, situated adjacent to the Bangkok area and considered as a part of Bangkok Metropolitan Region in which the density of population was considerably less than that of urban areas. The urban sprawl phenomenon might have brought about a variety of communication and transportation, for example public buses and sky trains. Such an expansion, however, had also dealt a great impact on the agricultural areas which were eventually replaced by a number of high-rise and commercial buildings as well as the overcrowded residential areas. The selected community of the research was in the area under the service authority of Bang Khen Health Promoting Hospital, Muang Nonthaburi district, Nonthaburi province, providing primary healthcare services to the people within its community. In support of health promotion and management on possible risk factors, the proactive service policy was adopted particularly for the people, families and community in the area of responsibility by integrating not only efficient health promotion, disease prevention and control and medical treatment, but also the rehabilitation and health recovery for certain patients which enabled such healthcare service to be transferable to the healthcare units at other levels.

Bang Khen Health Promoting Hospital is currently responsible for the population in the above-mentioned area for nine communities with approximately 15,482 people in total (retrieved on March 9, 2021). The density of population is 2,051 people per square kilometer on average with the estimate of two people per household. There is a group of patients under the hospital's responsibility – 444 patients with diabetes and 910 patients with hypertension. A total of nine medical practitioners are assigned to conduct the service which include four registered nurses, one pharmacist, one dental nurse, one public health officer, one traditional medical practitioner, and one public health technical officer (director of the local health promoting hospital). Due to the inadequacy of the available nurses, the nurse's role tends to primarily focus on the daily assigned tasks as per the policy which meanwhile limits additional care and visit to patient residences, as the majority of the visits are usually provided to the suffering and transferred patients first. Therefore, the registered nurses are required to have sufficient knowledge and fundamental information of the patients including the population encountering problems as well as monitoring any health demands requested by the village health volunteers in the area.

As a consequence of the area's characteristics and the increased situations of patients diagnosed with stroke within the community, Bang Khen Health Promoting Hospital, was therefore required to ensure all medical treatment and rehabilitation for survivors diagnosed with stroke were closely monitored in order to prevent permanent disablement and recurrence of the disease. Even though a health recovery program was introduced for survivors with disabilities or bedridden survivors by allocating physiotherapists to educate and rehabilitate, the work overloads of the registered nurses as well as the limitation of the hiring budget prevented the families with stroke survivors from sufficient healthcare, not to mention the qualification and preparedness of most families in taking care of such survivors as they might have regarded this as one heavy burden. As a result, the researcher realized the importance in selecting this particular area for study not only because of its suitability, but also the possibility to apply the care model to improve the effectiveness for the families whose members are suffering from stroke as stated in the research objectives. It was truly believed that this research would continue to help and reduce the work overloads of the nurses as well as the additional expense incurred from the medical treatment and rehabilitation for the above-mentioned survivors.

# 3.2 Research Design and Methodology

The situations of the increased survivors diagnosed with stroke, difficulties encountered by the caregivers and families in everyday life including rehabilitating such survivors at their residence, have driven the researcher and his advisor to realize the significance of family care and therefore develop the most suitable program to look after the caregivers and families' health, aiming for the better health in their own contexts. By using Participatory Action Research (PAR) Process, all family members are to be involved in giving healthcare to the stroke survivors as well as in their own health. Such a PAR process is considerably appropriate for the caregivers of stroke survivors to acquire the strategy for self-management in order to respond to the needs of family members including other solutions towards daily life problems. The initial proceeding of this study started once the draft research proposal had been approved by the Human Research Ethics Committee of Thammasat University (Science) with the permission from Nonthaburi's Governor to conduct the study within the communities under the responsible area of Bang Khen Health Promoting Hospital, Muang district, Nonthaburi. Subsequently, all details, information, research objectives and study procedures were adequately explained to the associated community nurses and village health volunteers.

The research was conducted from January 2020 to February 2021 by dividing the research methodology into two different phases. The recruitment was

performed in a primary care or sub-district health promoting hospital. The participants were selected by purposive and snowball sampling methods based on the inclusion criteria from the list of stroke survivors in the sub-urbanization communities. Potentially eligible families were identified by community nurses of Bang khen Health Promoting Hospital included in the study. The village health volunteers who knew and were well acquainted with the stroke survivors' families contacted and assisted to take the researcher into each home for collecting data. Then, the researcher informed about the study and asked for their willingness before individual interviews.

The initial phase was mainly focused on the situation analysis of the current caregivers in handling survivors suffering from stroke under the family context by using qualitative research for data collection, i.e. in-depth interview and focus group. This would not only enable us to understand the circumstance and real fundamental needs for the families who had to take care of their stroke survivors, but also to seek the definition and possible factors in developing the family-based care model for a family's health. During the second phase of the research, the researcher applied the factors, acquired from the database regarding the caregivers of stroke survivors in the first phase of the study, to the volunteer caregivers who wished to participate in the second phase by using PAR process. This particular research procedure consists of 4 cycles with 4 stages each – planning, acting, observing, and reflecting. Every stage principally aimed at the mutual participation of the caregivers in searching the promising caregiving methods, appropriate solutions, caregiving's planning and the application to their families, observation and assessment including any improvement where needed. As a result, the finalized model for the family care with stroke survivors will successfully be completed to serve and promote the healthy family. During each phase of study, the research informants, research instruments and data collection will be soon demonstrated as follows.

# **3.2.1 Phase 1: Situational Analysis**

The study began after the Human Research Ethics Committee of Thammasat University (Science) approved and gave permission to perform data collection. The first phase was conducted in January 2020 to July 2020. The procedures of the research will be listed in full detail in the following section.

In this phase, the purpose was to study the actual situations when caring for stroke survivors and define the meaning of a healthy family. The researcher approached forty family caregivers who met the criteria and agreed to participate in the in-depth interviews. The researcher made an appointment and requested the participants' permission before conducting a face-to-face interview for 90-120 minutes at their residence. The interview questions were developed from the theoretical underpinning socalled Calgary Family Intervention Model (CFIM) frameworks, consisting of three core concepts involving cognitive, affective, and functioning aspects. The inquiry employed broad, open-ended, and probing questions to help the family caregivers reflect on their perceptions and feelings. In addition to the clarification of the family relationship, each family caregiver was to share his/her experience and needs for caring. The family caregivers were also to explore the possible factors related to family functioning which influences their family lives. For example, family life activities, communication among family members, family decision-making, and beliefs when it comes to taking care of stroke survivors. The process of the in-depth interviews started after the participants had been informed of the research objectives and procedures before giving consent to be recorded in the field notes or an audio recorder while being interviewed. The introduction from the researcher was conducted in the first place to establish a good rapport and trust with the family caregivers. Moreover, the interview appointment would be arranged at the location of the family caregivers' choice including date and time under the home environment – neighborhood, living room, or bedside on their completion of caring for the stroke survivors.

After analyzing the data from the in-depth interview process, the factors used in the PAR process activities were subsequently designed. Fourteen family caregivers were selected to participate in a focus group discussion (seven participants per group) for 60–90 minutes. The discussion in each group was conducted as per the interview guideline to clarify and validate certain topics from the in-depth interviews. The researcher enhanced transferability by triangulating the theoretical data from the systematic review. The factors used in the second phase would finally be obtained from the thematic analysis in this phase.

## **3.2.1.1 Population and Participants**

The population in this research is the caregivers responsible for providing healthcare to stroke survivors residing in Muang Nonthaburi district, Nonthaburi province.

The research participants are basically the caregivers who provide support and care to the stroke survivors in the community under the responsible areas of Bang Khen Health Promoting Hospital and Khaisang Kamnoet Mee Health Promoting Hospital, located in Muang Nonthaburi district, Nonthaburi province from January 2020 until June 2020. There were 54 participants in total – 40 of which were given an in-depth interview individually at the caregivers' residence. The remaining participants were divided into 2 groups with 7 participants each to participate in a group discussion held at the meeting room of Bang Khen Health Promoting Hospital. The participants were selected based on the purposive and snowball sampling by the following criteria:

- 1) A Thai family member and primary caregiver
- 2) At least 18 years of age
- 3) At least 4 hours per day providing healthcare
- 4) Willing and available to participate in this study

### **3.2.1.2 Research Instruments**

The instruments to be used for data collection during Phase 1 were an in-depth interview and a focus group discussion through the researcher, a demographic questionnaire, a semi-structured interview, the focus group questionguides, audio recorders, and fieldnotes.

#### (1) The Researcher

In this study, the researcher, as a key research instrument, conducted the data collection by herself. The researcher had already prepared and practiced before beginning the research in order to obtain particular knowledge and skills as follows: a) Completed a course in qualitative research, b) Attended several workshops with the specialists in qualitative research, c) Performed as a research assistant to practice her performance with respect to interviewing skills, focus groups, field notes, and observation along with the close instructions by the researcher's advisor, d) Received training for ATLAS.ti 8 software to analyze data, and e) Successfully completed the

online program for human rights protection of participants from both Thammasat University and the National Research Council of Thailand (NRCT).

#### (2) Demographic Questionnaire

The researcher developed a demographic questionnaire used in the research consisting of three major parts. The revised version was engaged in the actual data collection as shown in the Appendix. The demographic data was collected as follows.

a) The information about the family caregivers including gender, age, marital status, family status, education, occupation, the number of family members, household incomes, adequacy of income, medical rights, the duration for caring, years of caring experience, the relationship with the stroke survivor, and another person who provided caregiving.

b) The information about stroke survivors – gender, age, marital status, family status, education, occupation before being diagnosed with stroke, duration of stroke, and the most significant restriction.

c) The daily-life activities of the stroke survivors were measured by the Barthel Index tool introducing several measured abilities. Namely, feeding, bathing, grooming, dressing, toilet using, transfers, mobility, stairs, bowels, and bladder. All sections were conducted by the perception of the family caregivers participating in the study.

# Guides

# (3) Semi-Structured Interview and Focus Group Question-

Based on the literature review and the theoretical underpinning of the Calgary Family Intervention Model frameworks (CFIM), the semi-structured interview and focus group question-guides were created by the researcher under the supervision and suggestion of the advisor. The inquiries were reviewed based on theoretical consistency, clarity of the question, and language appropriacy by three experts – a qualitative research expert, a family health nursing instructor, and a community health nursing instructor. The question-guides consisted of four appraisals which included the general family structure, factors related to family functioning, ultimate goals of caring, and arrangement of healthy family life. The revised version shall be explained in the data collection shown in Appendix.

### (4) Fieldnotes

The researcher took the fieldnotes while collecting data throughout the study such as observations, interviews, and focus group discussions. The fieldnotes were shown in a variety of topics based on the literature review including the environmental atmosphere, general appearances, emotional expression and other relevant information.

# (5) Audio recorder

The digital audio recorder, Sony Walkman UX560F series, was entirely used to record the speech and conversation during the interviews and focus group discussions.

# (6) Digital Photography

The researcher used a digital photograph to caption the stimulating environment, the overall atmosphere during the interviews, group discussions and caregiving techniques, for instance. However, the photographer and the researcher were required to ask for the participants' permission before taking any photos and the participants' visage should be least focused.

# (7) Reflexive Journal

The researcher revised and wrote the essential perspectives, feelings, and experience in her reflexive journal as a means to develop self-learning process as well as to avoid any possible bias during the interview and focus group discussion, enabling the researcher to truly understand the participants.

#### **3.2.1.3 Data Collection**

The situation analysis was performed in respect to giving healthcare to stroke survivors under the sub-urbanization community context by using three major methods: in-depth interviews, focus group discussions, and observation. The researcher has collected the data from the in-depth interviews with the family caregivers through an inductive thematic content analysis approach to recall the family factors and confirmed the internal validity by the focus group discussion. The observation techniques specified hereafter were consistently used while conducting all the activities.

# (1) In-depth Interview

The in-depth interview enabled a number of useful descriptive information about the events and actions of the caregivers. In this study, the family caregivers' interviews aim to assess their families' lives in order to understand the perspectives and behaviors regarding needs, impacts, and solutions in caring for the stroke survivors, allowing further opportunity for improvement. The interview questions were developed based on the Calgary Family Intervention Model frameworks (CFIM) consisting of the following three different concepts: cognitive, affective, and functioning aspects. There were 40 family caregivers participating in the in-depth interviews in the study. The researcher had conducted the interviews in the home environment at their place so the participants would feel even more comfortable.

The in-depth interviews were conducted in January 2020 and finally completed in June 2020. Each interview session lasted approximately 90–120 minutes and may be conducted once or twice depending on data completion. All interviews were performed in a private place in a home environment just to reserve all participants' privacy. During the in-depth interview process, the researcher would sit and position herself at the same level with the interviewees so that they feel comfortable and more open to share information. According to the human subject protection, all participants had acquired a sufficient explanation regarding the research objectives and data collection procedures before giving consent for the interviews.

The in-depth interview usually began with a natural conversation to create a good relationship and gain more trust between the interviewer and participant. The participants, therefore, were able to talk openly and shared their caring experiences. Starting the conversation with a casual vibe helped reduce the hierarchical relationships between the researcher and the participants. At the same time, the participants were entitled to continue or cease the conversation anytime during the in-depth interview should they feel or present any emotional distress. In such cases, the researcher would rather suspend the interview and listen to the participants allowing them to release the tension and feel more relieved.

Last but not least, the semi-structured interview question guides, open-ended questions, audio recorder, digital photography including fieldnotes were professionally performed. However, to obtain further information, the researcher also used various probing questions during the interviews. As a result, the information about the caregivers' characteristics, caring behaviors, needs, impacts, and their strengths based on their opinions were finally concluded. At the end of the interview, the researcher would reflect all acquired data to the participants to ensure its accuracy before thanking them for sharing the information. Nevertheless, all personal information, such as names and addresses, were cautiously coded to prevent any possible data exposure; only the general information was to be demonstrated to the public.

#### (2) Focus Group Discussion

The selected participants who met the criteria were assigned to participate in a focus group discussion to validate and triangulate data internally. In order to obtain more information regarding the caregiving for stroke survivors under the suburbanized community context, the general viewpoint was truly one of the aspects believed to create a better understanding of the caregivers' challenging life. The focus group discussions, therefore, were used to collect the data based on the general caregivers' viewpoint. The selected participants invited to the discussion were divided into two groups with a total of seven caregivers per group. All of them were female and never experienced any in-depth interview in this study.

To ensure the degree of comfort in sharing personal information, the focus group discussions were arranged at the place where participants feel most comfortable with. In addition, to protect each informant's privacy, the researcher had requested to occupy the conference room at the health promoting hospital which was suitable to hold the activity in private. Conducted in July 2020, the focus group discussion lasted approximately 90–120 minutes. Similar to the in-depth interview, the focus group discussion also began with a casual conversation to earn more trust and create a good relationship between the interviewer and the participants. The researcher started the session with an informal conversation to reduce any hierarchical relationships among the group. The participants were clearly more open to talk and share information notwithstanding the rights to end or continue the discussion.

Finally, the semi-structured focus group question guides, namely, open-ended questions, audio recorder, digital photography, and fieldnotes, were professionally utilized. However, to be able to obtain more information, the researcher also used the probing technique during the focus group discussion. As a result, the information about the caregivers' characteristics, caring behaviors, needs, impacts, and their strengths based on their opinions were finally concluded. At the end of the interview, the researcher would reflect all acquired data to the participants to ensure its accuracy before thanking them for sharing the information. Nevertheless, all personal information, such as names and addresses, were cautiously coded to prevent any possible data exposure; only the general information was to be demonstrated to the public.

#### (3) Observations

The observation was an essential method to create a better understanding in this study by means of both participant observation and nonparticipant observation. The researcher would be able to use the observation methods when participating in an activity enabling her to better understand the families' lives and capture the contexts in real-life situations or home environment during the process of caregiving provided to the stroke survivors by the family members. The researcher also made use of the fieldnotes and digital photography in support of the observation. At this stage, the researcher would be able to gain the insider views and participants' subjective feelings during interviews and focus group discussions.

# **3.2.1.4 Data Analysis**

Data analysis in this study involves preparing and organizing data gathered from several methods of analysis including reducing the data into themes, drawing and verifying conclusions of the data (Creswell & Poth, 2018; Miles, Huberman, & Saldana, 2014). The researcher has collected the data along with the analysis. The computer software, known as ATLAS.ti 8.0, was used to support the qualitative data analysis whereas replacing raw data into coding schemes, drawing links and relationships of codes, sub-themes, and themes. This program was considerably helpful and able to display the data in a systematic way which facilitates the utilization of the data in this study.

In this phase, the descriptive statistics of the demographic information were used to analyze the characteristic demography of the participants and their stroke survivors. The researcher used qualitative data analysis to interpret and define the meaning of the content (Creswell & Poth, 2018; Miles et al., 2014). The qualitative data analysis also involves several coding techniques, grouping and organizing themes acquired from the participants' information which are observed, interviewed, and participated in a focus group discussion. The five general approaches involved in the data analysis process are as follows:

a) Managing and organizing the data for analysis (Creswell & Poth, 2018; Miles et al., 2014). The researcher gathered information from the interviews, fieldnotes, voice recordings transcribed into digital files as well as creating the naming system, managing file storage, and using a computer software for data analysis.

b) Reading and reading; the researcher repeatedly read the transcribed verbatim, texts, and fieldnotes for several in order to precisely define the meaning or to summarize all the ideas and thoughts before writing down into memos or jotting notes (Creswell & Poth, 2018; Miles et al., 2014).

c) Describing and classifying codes into themes (Creswell & Poth, 2018; Miles et al., 2014). The researcher encoded the words or short phrases by using first initials and assigned symbolic meaning to the key information before identifying and describing the codes in code lists as a deductive coding (Miles et al., 2014). The researcher will then finalize the code lists and descriptions into a codebook. Similar codes will be clustered together to create a smaller number of categories assigning to themes.

d) Assessing the interpretation to understand and be able to explain the situation happened in the within-case and cross-case analysis (Creswell & Poth, 2018; Miles et al., 2014). The researcher will carefully consider the feedback with the advisor and co-advisors in peers on the first data interpretation in order to establish and classify all concepts, as well as to finalize the conclusion and interpretation before making a comparison with all findings and acquired information for verification and authentication.

e) Representing and visualizing the data with mapping or diagram (Creswell & Poth, 2018; Miles et al., 2014). The researcher drew a link of codes, categories, and concepts representing the close relationship of the information into the matrix or illustrated networks with graphs.

# 3.2.2 Phase 2: Participatory Action Research Process (PAR Process) 3.2.2.1 Participants

The second phase was model development. The researcher encountered fourteen families who were selected and agreed to participate in the PAR process. The researcher used the purposive sampling method to select the stroke survivors' families who also took part in the first phase of the study. The participating group was separated into two groups – Sunday and Wednesday. Each group consisted of seven family caregivers who met the criteria and were willing to participate in the four-cycle PAR process. These PAR cycles were conducted for a four-month period with four sessions per month, from October 2020 to January 2021. The following criteria to select the participants are as follows:

- 1) A Thai family member and primary caregiver
- 2) At least 18 years of age
- 3) At least 4 hours per day providing healthcare
- 4) Willing and available to participate in this study
- 5) Have more than 2 members in the family

Such criteria will no longer be applicable in this phase should any participants intend to discontinue the process. In the event the participants cannot participate in a group discussion, the researcher would provide the collected information to them after the end of such activity.

### **3.2.2.2 Research Instruments**

The instruments used to collect the data in phase II, PAR process cycle, included the researcher, family demographic questionnaire, Participatory Action Research guideline, audio recorder, fieldnotes, digital camera, and the handbook on giving care to stroke survivors.

#### (1) The Researcher

In this study, the researcher, as a key research instrument, conducted the data collection by herself. The researcher has already prepared and practiced before beginning the research in order to obtain particular knowledge and skills as follows: a) Completed a course in qualitative research, b) Attended several workshops with the specialists in qualitative research, c) Performed as a research assistant to practice her performance with respect to interviewing skills, focus groups, field notes, and observation along with the close instructions by the researcher's advisor, d) Received a training for ATLAS.ti 8 software to analyze data and e) Successfully completed the

online program for human right protection of participants from both Thammasat University and the National Research Council of Thailand (NRCT).

### (2) Family Demographic Questionnaire

The researcher has developed a family demographic questionnaire used in the research, consisting of the demographic data and the information on the families' activities. Such demographic data included the significant information about the family members – family role, gender, age, marital status, religion, education, and the caring period per day. The information of the families' activities was given by the family members who spent time doing things together. All sections in the questionnaire were based on the perception of the family caregivers participating in the PAR process.

### (3) Participatory Action Research Guideline

The Participatory Action Research Guideline was used to guide the PAR process developed by the researcher based on the theoretical underpinning of the Calgary Family Intervention Model frameworks (CFIM). This process aimed to develop the Family-Based Caring Model for the stroke survivors' families. This guideline was examined and reviewed by three experts specialized in the area of qualitative research, family health, and community health.

### (4) Fieldnotes, Audio recorder, and Digital Photography

The researcher took a variety of fieldnotes during her observation on some of the main points and voice-recorded in the family group discussions using a digital recorder. The verbatim transcription was used in the analysis processes. However, the researcher would ask for permission before photographing during the process of the study.

### (5) Handbook on Giving Care to Stroke Survivors

This manual was considered as a primary source for the researcher to learn and understand the fundamental knowledge as well as a proper selfcare. The handbooks on Giving Care to Stroke Survivors were given to the family caregivers participating in this study. The participants and their families who had read the book would be able to apply such knowledge to promote their health within the families and help encourage the family members to be healthy to certain extent. The particular handbook was reviewed by five specialists – the doctor in the area of family medicine, two instructors from health assessment, the instructor from community health, and one nurse from a subdistrict health-promoting hospital.

### **3.2.2.3 Data Collection**

During the initial stage, the selected families were included in the research cycle for the second phase. The data was gathered from two family group discussions following the four stages (planning, acting, observing, and reflecting) of PAR process cycles. This phase was conducted by using triangulation in the PAR process cycle involving family group discussion, observations, home visit, telephone, and LINE follow-up. The PAR process cycles and the research techniques in detail are presented as follows:

### (1) PAR Process Cycles

The second phase aimed to utilize the PAR process to develop the Family-Based Caring Model (FBCM) for the stroke survivors' families. The families selected by a purposive sampling from the list of stroke survivors in a Subdistrict Health Promoting Hospital, whose responsible area demonstrates a number of strokes survivors in Thailand's semi-urban community. Fourteen family caregivers selected from the criteria were assigned to participate in a family group discussion in the PAR process. Such activity was carried out at the mutually agreed place. The participants were divided into two groups; each group was required to participate in the activities every week for four months.

After providing the information about the research objectives, procedures, and anticipated results to the participants, the researcher conducted the PAR process and acquired permission to record through field notes, photos and voice-recording. The researcher introduced the caregiving topics and agreement during the discussion. The researcher performed as a facilitator to encourage the group and assist the participants where needed. The participants in each group addressed their obstacles, targets and outcomes, and designed their activities independently. The PAR process consists of four cycles. Each cycle applies a spiral process as a methodology through four steps – planning, acting, observing, and reflecting (McTaggart et al., 2017). In each step, the group participants will have to work together for 90–120 minutes in order to come up with the suitable caring strategies as well as a goal achievement in terms of

their family's context. The researcher proceeded with the PAR process for four months, from October 2020 to January 2021. The PAR guidelines are listed in Table 3.1.

## Table 3.1 Participatory Action Research Process Guideline

*Purpose:* To use the Participatory Action Research Process to develop the Family-Based Caring Model for the stroke survivors' families

### PAR process planning:

- The researcher engages with fourteen families selected based on the criteria and agrees to participate in the PAR process.

- The participants will be selected from the list of stroke survivors in the service area of a Sub-district Health Promoting Hospital in Thailand's suburban communities by using a purposive and snowball sampling.

- Family group discussions will be divided to serve the triangulation methodology.

- The PAR process cycles will be conducted in a comfortable environment.

- The family group discussions will be conducted four times a month.

- The four cycles referred to spirals followed by four stages: planning, acting, observing, and reflecting (McTaggart et al., 2017).

### PAR Process:

1. Given a written permission from the participants, the researcher will inform the study's objectives, procedures, and expected outcomes to the participants.

2. The researcher will ask for permission to record fieldnotes, photo, and audio recording during research activities.

3. The researcher will introduce the discussion topics and perform as a facilitator and supporter to encourage the participants.

4. The participants in the group are to address their obstacles, targets and outcomes, and design their own activities.

5. Four stages of each cycle are to be conducted as follows:

- *Planning* – the participants will set the goals together and cooperate in designing the caring strategies to achieve a healthy family life.

- *Acting and Observing* – each family applies the strategies acquired from the group discussions and observe their activities.

- *Reflecting* – the participants work together to conclude the applied strategies and evaluate the activity results before replanning the strategies in the next cycle.

# With the above-mentioned the PAR process cycles, the FBCM was developed to promote a healthy family life based on three factors found during the first phase: caregivers' characteristics, family function, and resources management. The group participants worked together to develop the strategies and set the ultimate goals for a healthy family in the family context. The audio recording, photography, and fieldnotes were professionally utilized in every stage throughout the research. The researcher gathered all the information and data according to the date, time, and place as per the appointments arranged with the participant groups – Wednesday group discussion was held at the village health volunteer's place whilst Sunday's group discussion by providing the information regarding four cycles of the PAR process. Each cycle consisted of four different stages – planning, acting, observing and reflecting. All cycles are to be explained as follows:

**Cycle 1:** The participants were assigned to participate in a group discussion once a week for four weeks. The primary purpose was to build a stronger relationship between the researcher and the participants. The researcher started to adopt PAR through friendly conversation and self-introduction to develop a good rapport and familiarity among the members before introducing the main objective of the research, methods including the expected results throughout the entire research period of 16 weeks. The researcher also explained all the requirements and participation agreement and asked all participants for permission in recording, photographing as well as voice-recording during the discussions.

In this particular process, the participants had a chance to share their experiences in caregiving, learn from one another, and come up with the most suitable practice in the family context while the researcher positioned herself as a facilitator and supporter when requested. During the "planning" stage, the researcher brought up all the factors obtained from the study in Phase 1, characteristics of the caregivers, to the participants allowing them to share their knowledge towards characteristics of the caregivers of stroke survivors, their experiences including problems and difficulties. The participant group established their mutual goal in providing healthcare to the family in the best interest of their healthy families as well as the suitable caregiving practice to the stroke victims. They also realized that the education regarding giving care to the stroke survivors should be implemented.

In the "acting and observing" stage, as a nurse specialized in giving care to stroke survivors, the researcher provided intensive training and education by giving a handbook on giving caring to the stroke survivors to the participants as requested. During the activities, the researcher observed the participants' interests, facial expressions, gestures including the atmosphere while participating in the activities. Subsequently, after learning all the information, the participants have designed their own strategies to provide healthcare to the stroke victims. The information would be soon discussed in the following weeks, as per the appointments, to plan out the new strategies.

In the last week of Cycle 1 which was the "reflecting" stage, the researcher conducted a group discussion to encourage the participants to conclude all key issues, possible practice, problems and difficulties in order to integrate and improve the caregiving practice to the stroke survivors in the most suitable way under their family context.

**Cycle 2:** The participants took part in a group discussion every week as per the appointed date and time. Wednesday group's discussions were held at the residence of the village health volunteer while Sunday group's discussions were held at the participants' place. This cycle lasted for four weeks with the main objective to improve the caregiving practice to the stroke survivors after applying the practice set together during Cycle 1 to their families.

In the "planning" stage, the researcher conducted the group discussions by encouraging the participants to brainstorm and give opinions as seen appropriate. The researcher took the factor obtained from Phase 1, family function and resources support, as a part of the topics. All participants discussed the roles and responsibilities of caregivers to provide care to stroke survivors. The practice results were presented as well as problems and difficulties encountered during the practice in order to share the experience within the group and to find the best solution, improvement, change in caregiving methods to suitably serve their own families and plan the practice schedule. In "acting and observing" stage, the participants came up with the idea to conduct a home visit among the group. Wednesday planned their own visit while Sunday wished the researcher and nurses to make a visit. In this particular stage, the Wednesday participant, together with the researcher, visited the participants' residence by themselves in which participant observation was used to observe the caregiving methods, the atmosphere and environment in each house. As for the Sunday participants, the researcher made a visit to the participants with observations on the atmosphere, environment, and caregiving techniques in caring for stroke survivors of each family.

Last but not least, in the "reflecting" stage, the participants made a conclusion on the practice results obtained from the home visits including the problems and opportunity to improve or change the suitable caregiving methods to the stroke survivors in the family context, whereas the researcher facilitated, supported, and encouraged the participants to express the opinion within the group.

**Cycle 3:** The participants participated in a group discussion once a week for 4 weeks in the third cycle. The purpose of the activities was to create a guideline for giving care to stroke survivors based on the strategies mutually specified in Cycle 2 and apply them to their own families.

In the planning stage, the participants proposed the ways to take care of themselves by getting to know themselves better and enhancing mental strength through elaborated planning. In addition, the participants took part in the discussion and recalled their gratitude. They also concluded the practice results, problems, and difficulties to exchange experience and knowledge within the group in order to come up with the activity schedule.

In "acting and observing" stage through workshops, the researcher invited several specialists to educate the participants aiming to create more self-awareness according to the participants' plan, while the researcher was focusing on the participants' interests, facial expression and the training atmosphere. The participants acquired the training and workshops to create the awareness and continuously apply them throughout the research period along with the close observation should there be any changes afterwards. During the acting and observing stage, the researcher conducted the activity, supported, and stimulated all participants to express their opinions as well as following up the compliance with the activity schedule and assisting them if necessary. In this particular stage, the participants adopted the modified strategies into practice and complied with the activity schedule – meditation, practicing awareness, positive thinking, emotion management, appreciation and recall the virtues of those suffering from stroke to reciprocate them with delicacy, consideration, respect as well as the observation on their feelings and changes occurred from doing so.

In the last stage of reflecting, the participants summarized the practice results, possible benefits, problems and difficulties including what was required to improve in caregiving methods for stroke survivors in the family contexts. In addition, they also concluded the benefits from practicing self-awareness, meditating including the possibility to apply them into practice in their own context while the researcher provided support and encouragement to ensure the participation of the participants.

**Cycle 4:** The participants took part in a group discussion every week as per the appointed date and time. Wednesday group's discussions were held at the residence of the village health volunteer while Sunday group's discussions were held at the participants' place. This cycle lasted for four weeks with the main objective to summarize the proper caregiving practice to the stroke survivors after applying the specified practice during Cycle 3 to their families and to conclude all experiences including any changes after participating the activities.

In the planning stage, the research conducted the activities, provided assistance and support, and encouraged all participants to present their opinions as seen appropriate. All caregiving experiences, problems and difficulties were summarized by the participants including the changes in themselves and family members from the first day to the final weeks of the practice. They also concluded the practices to achieve the proper caregiving methods to treat stroke survivors.

During the acting and observing stage in this cycle, the researcher conducted the activities, supported and encouraged the participants to express opinion and also observed, followed up the schedule and provided assistance if necessary. Additionally, the researcher explained the details and operation plan acquired from the group to those who missed the group discussions to acknowledge and put them into practice. In this particular stage, the participants continued to put the specified practice to apply to their own families along with the observation whether there was any change to their feeling and environment. Moreover, the participants also practiced self-awareness, meditation, positive thinking, emotion management and being grateful throughout this entire cycle.

Finally, in the reflecting stage, all participants made a final conclusion based on the entire study period stating the feelings, changes, and the success achieved in this research.

The procedural steps of the study in phase 1: situation analysis, and the PAR process in phase 2 are shown in Figure 3.1.

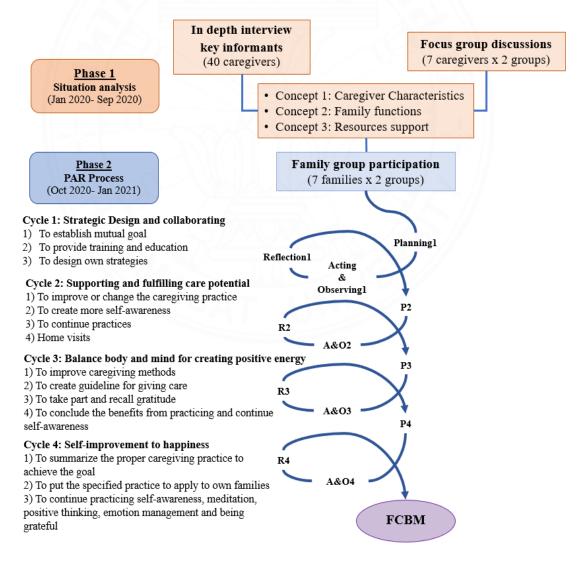


Figure 3.1 Procedural Steps of the Study

### (2) Family Group Discussion

In Phase II of the study, fourteen family caregivers were assigned to participate in a discussion group which was later divided into two groups: Wednesday and Sunday. The researcher introduced the topics for discussion and encouraged the group to actively participate in the activity. Performing as group facilitator, the researcher started the conversation in a more casual way to earn the participants' trust as well as to create a healthy relationship among them. The researcher referred the question guidelines from the core concepts of the Calgary Family Intervention Model (CFIM).

### (3) Observation

The researcher worked as a facilitator in the group in the research spiral. The researcher conducted an observation in order to better understand the families' lives as well as capturing the vital contexts during the discussion and interaction. Moreover, each family was observed by family caregivers who were the participants in the group discussion.

### (4) Home Visit

In this study, the researcher and group participants visited participants' residences to understand each family context even better. Participants observed and offered their opinions to improve their proper caring for stroke survivors in the family.

### (5) Telephone and LINE follow-up

The researcher provided the information to the participants who missed the activities through telephone or LINE. The researcher also used LINE to follow up, make an appointment and give individual consulting if needed.

### 3.2.2.4 Data Analysis

Data analysis involved preparing and organizing data gathered from several methods for analysis, reducing the data into themes, drawing and verifying conclusions of data (Creswell & Poth, 2018; Miles, Huberman, & Saldana, 2014). Data analysis and data collection occurred simultaneously during the first phase. The computer software, known as ATLAS.ti 8.0, was used to support the qualitative data analysis whereas replacing raw data into coding schemes, drawing links and relationships of codes, subthemes, and themes. Similarly to what was completed in Phase 1, the researcher used qualitative data analysis to interpret and define the meaning of the data content (Creswell & Poth, 2018; Miles et al., 2014). It also involved coding techniques, grouping and organizing themes gathered from the participants' information which were observed, interviewed, and participated in group discussions of this study. The five general approaches of the activity involved in the data analysis process are as follows:

1) Managing and organizing the data for analysis (Creswell & Poth, 2018; Miles et al., 2014). The researcher gathered information from the interviews, fieldnotes, photos and voice recordings transcribed into digital file as well as creating the naming system, managing file storage, and using a computer software for data analysis.

2) Reading and reading; the researcher repeatedly read the transcribed verbatim, texts, and fieldnotes for several in order to precisely define the meaning or to summarize all the ideas and thoughts before writing down into memos or jotting notes (Creswell & Poth, 2018; Miles et al., 2014).

3) Describing and classifying codes into themes (Creswell & Poth, 2018; Miles et al., 2014). The researcher encoded the words or short phrases by using first initials and assigned symbolic meaning to the key information before identifying and describing the codes in code lists as a deductive coding (Miles et al., 2014). The researcher will then finalize the code lists and descriptions into a codebook. Similar codes will be clustered together to create a smaller number of categories assigning to themes.

4) Assessing the interpretation to understand and be able to explain the situation happened in the within-case and cross-case analysis (Creswell & Poth, 2018; Miles et al., 2014). The researcher will carefully consider the feedback with the advisor and co-advisors in peers on the first data interpretation in order to establish and classify all concepts, as well as to finalize the conclusion and interpretation before making a comparison with all findings and acquired information for verification and authentication.

5) Representing and visualizing the data with mapping or diagram (Creswell & Poth, 2018; Miles et al., 2014). The researcher extracted links of codes, categories, and themes into the matrix, illustrated networks with mappings.

### **3.3 Triangulation**

The proposed study was conducted based on qualitative research. Triangulation can assist researchers in creating more robust research designs. In this study, applied data triangulation and investigation triangulation of different data sources and methods in the study process: interviews; focus group discussion; and PAR process. The researcher added rigor for triangulation to increase validity, enhance research quality, and provide a broader understanding of complex phenomena while collecting data in both phases of the study. These technical activities were flexible and valuable for a change in caregiving of the caregivers as much as the stroke survivors' living. The research rigors were interested in establishing the findings' trustworthiness to prevent errors of a constant or intermittent nature (Creswell, 2013; Guba & Lincoln, 1994; Miles et al., 1994, 2014).

The data in this study has been verified for its trustworthiness, according to Lincoln and Guba (1994), to ensure its accuracy and truthful information based on four aspects suggested as follows:

### 3.3.1 The Credibility

Lincoln and Guba (1994) clearly predicated that researcher should create a rigorous research methodology for the research results' credibility. In this study, the researcher utilized four methodological techniques to serve credibility, which included 1) a constant comparative method for triangulation, 2) a prolonged involvement technique for building trust, 3) peer debriefing, and 4) member checking. Those techniques are explained in detail as follows:

1) Using the constant comparative method for triangulation: The researcher collected the data of both phases from different observation procedures, voice recording, photography, and field notes. Data was validated by triangulating the information obtained from various methods. Namely, in-depth interviews, focus group discussions, field observations, and field notes were collected by the researcher who provided the supporting theories to validate evidence for triangulation in the proposed

study. A variety of methods helped the researcher to better understand all aspects of the factors that may influence the caregivers to provide care for stroke survivors.

2) The prolonged involvement technique for building trust – the researchers collected data in a systematic process. In general, the researcher developed a friendly relationship between herself and participants under the comfortable atmosphere enabling them to feel more relaxed and open. The processes started with an informal conversation to reduce any hierarchical relationship between the researcher and the participant. The researcher also developed a social connection to earn more trust and credibility from the participants without any bias. Trust and credibility aroused between the researcher and participants create the trustworthiness of feeling, attitude, opinion expressions, and perspective regarding caring for stroke survivors and themselves.

3) Peer debriefing – during the research activities along with coding and categorizing processes, the researcher reported the study's result to the experts. Namely, the researcher's advisor, co-advisor, healthcare providers, and community ensured the accuracy of the concepts presented in the study until their satisfaction was met.

4) The technique of member checking was also conducted during the data collection period. The researcher ensured to recall the summarized data to the participants in the community who gave the information and discussed it in the following appointment for focus group discussion.

### 3.3.2 Dependability

Lincoln and Guba (1985) suggested that to provide an external check on the inquiry process is a technique that strongly supports dependability creation. In this study, three experts specialized in the area of qualitative research, a family health nursing instructor, and a community health nursing instructor were invited to inspect the theoretical consistency, clarity of the question, and language suitability of inquiry throughout the research. The inquiry inspection team included the researcher's advisor and co-advisor to give feedback. The researcher was to take all suggestions from a number of discussions to articulate the better research findings. The researcher also used the same procedures to analyze the interview transcriptions, observation notes, and fieldnotes.

### **3.3.3 Transferability**

In this study, the researcher selected the participating family caregivers by a purposive sampling from the urban area. The study purpose was not intended to transfer this study to other populations as the findings were derived from the certain circumstance of the stroke caregivers' perception. The transferability shall be applicable when used to explain the similar context as a family caregiver taking care of the stroke survivors in the urban community.

### **3.3.4** Conformability

Lincoln and Guba (1985) suggested achieving confirmability, and the researcher should establish credibility, transferability, and dependability of the study. In this study, the researcher has utilized multiple techniques such as peer debriefings, theoretical triangulation, and member checking to build confirmability.

### **3.4 Human Subject Protection**

### **3.4.1 Ethical Considerations**

The researcher has completed the GCP online training (Computerbased) from Thammasat University and the online research ethics training course from the National Research Council of Thailand (NRCT) and Forum of Ethical Review Committee in Thailand (FERCIT). The permission was granted to the study by the Institutional Review Boards (IRBs) to protect human subjects prior to data collection. The research protection of human subjects was related to the confidentiality and privacy of the participants.

Before starting the program, the researcher coordinated with staff for community surveys and specification in the residential areas of stroke survivors to familiarize with the community context in respect to its religion, culture, and leaders. The researcher made an appointment with the family caregivers to inform each family's participants about the research objectives and anticipated results while building a relationship to create a learning atmosphere.

After finishing the interviews and focus group discussions in Phase 1, the participants received a souvenir for taking part as a research volunteer, including a cloth-bag, a hand exercise ball, and a Handbook on Giving Care to Stroke Survivors. For those who participated in the group discussions in Phase 1 and 2, the researcher was liable for the travel expense of THB 200 each time.

### 3.4.2 Permissions

Prior to the research study, the research proposal was presented to the Human Research Ethics Committee of Thammasat University (Science) for an approval. The Board of Directors resolved to certify on November 4, 2019, and the certificate was renewed for the first time on November 4, 2020 project no. 138/2562. The research was developed based on the responsibility to protect the rights of human subjects who are the prospective participants in the study. Subsequently, the permission from the Governor of Nonthaburi Province was granted to conduct the study within the community, which is the area of responsibility under Bang Khen Sub-District Health Promoting Hospital, Muang District, Nonthaburi Province. As a result, the researcher was permitted to conduct and continue working in the community by the director of Bang Khen Sub-District Health Promoting Hospital.

The research was completed without any therapeutic parameters; and the participants were generally preferred. The participants were informed of the research objectives, data collection procedures, duration of data collection, and possible benefits. The participants were also required to sign a consent form before participating in the study based on their freewill. The participants were able to reject any questions if seen uncomfortable during an interview or activity. The participants are entitled to withdraw from the study at all times without giving reasons and without losing any benefits. There was no effect on medical care in any cases.

### 3.4.3 Confidentiality Agreement

The essential aspects of the confidential information given by the participants in this study were protected in a strict manner. Unless required by the law, the researcher respected the participants' privacy and agreed to keep the participants' information in confidentiality from any other person. The researcher applied the codes in substitution of the participants' first and last name in the data record. All information in the researcher will be eradicated within two years after the research completion. The researcher reported the data from all perspectives including both positive results and contrary findings in addition to the overall picture.

# CHAPTER 4 RESULTS AND DISCUSSIONS

This study was Participatory Action Research (PAR) with an enhancement approach (McTaggart, Nixon, & Kemmis, 2017), aiming to develop the Family-Based Caring Model (FBCM) for stroke survivors to enhance healthy families. Data were collected in the setting of the Sub-district Health Promotion Hospital, Nonthaburi Province, as one of the areas with families suffering from a stroke in the suburban communities of the metropolitan area near Bangkok, between January 2020 and February 2021.

Regarding the study area's characteristics, it is a semi-urban area in Bang Khen Sub-district, Mueang District, Nonthaburi Province. The researcher surveyed and observed this area before collecting data. The area is a community in the metropolitan area, so most of the surroundings are not significantly different from that of the capital city. It includes high-rise buildings, commercial buildings and houses congestedly next to one another, both private homes and rental houses. In the surrounding vicinity of this community, there are large shopping malls and many convenience stores. Some fruit gardens can be seen sporadically in the distance. Moreover, the transportation is convenient with various means of travel available for selection, such as trains, private cars and buses, at all times.

Within the community, there are many public health services and private clinics. People can choose to receive services according to their needs. The Sub-district Health Promotion Hospital is a public health service facility which provides medical services, disease prevention and control, as well as health promotion relating to people in the responsible areas from birth to death. Public health volunteers in the villages, who are people in the area and accepted by everyone in the community, would act as leaders of change agents, public health news communication and coordination of public health activities between health workers and people in such community. In the meantime, they provide various public health services, such as visiting the elderly in their homes, as well as patients with chronic illnesses and disabled people, under their caring responsibilities of 8-15 households per person. Additionally, there is also a primary health care service

center in each village under the supervision of the Sub-district Health Promotion Hospital, with the village's public health volunteers taking turns to help with blood pressure measurement and provide basic health knowledge to people coming for services.

In the semi-urban community, there are more people living together than those in the rural community, but not as dense as in the urban community. They have various occupations, while their socioeconomic status ranges from very rich people with beautiful and big houses to very poor people with daily jobs and small rental rooms. Meanwhile, the relationships of people in the urban society are varied by patterns of rules and regulations, primarily under the law. People in the community do not interact intimately with each other and live a different life. Most of them have small families. The number of family members are 2-4 people, but they do not live as a single family. Even though some families only have a husband and a wife, they also care for grandchildren or parents as large families. Family members often travel from the provinces to work in the urban areas with quite high living expenses, causing them to live together in a house with many families. Each family member often has different occupations with heavy competition and the hustle in daily life and economical needs in the urban community. Thus, they have to go to work early in the morning and return home in the late evening. Some people have their day-off just only one day per week. Family members have quite little interaction among themselves and their neighbors. The elderly or those with chronic diseases can only rely on themselves and often stay at home alone. In the meantime, those who are unable to care for themselves and need assistance mostly have family members as their primary caregivers. Moreover, temples remain the places where the elderly and people in the community come for religious rituals.

After completing a preliminary study of the area, the researcher provided information about this research study and evidence of permission for data collection to the local health officials. Then, the researcher requested for cooperation from officials and village health volunteers, responsible for caring for people in their own areas, to help coordinate with families who were caregivers of stroke survivors and do a home visit for research data collection.

This research study proposes to develop a family care model towards the enhancement of healthy families especially those with members who have had a stroke by understanding the situations of caregiving to stroke survivors at home, as well as exploring problems and factors related to the caregiving of family members. The research methods emphasized the participation of caregivers in caring for stroke survivors, while identifying the definitions and changes of lifestyles to enhance healthy families with more self-care ability and find ways for more effective caregiving for the ill family members, in a bid to lower caregiver burdens and decrease anxieties among family members towards a better quality of life.

This research study was conducted to collect, analyze and synthesize data according to research procedures. The results were presented and divided into 2 phases as follows:

Phase 1: Description of caregivers and stroke survivors' characteristics, as well as situation analysis of family life while caring for stroke survivors and definitions of healthy families in the context of caregiving for stroke survivors.

Phase 2: Identification of research participants and their families' characteristics, strategies for the enhancement of a healthy family among caregivers and models of caregiving for the family of stroke survivors towards their good health.

### 4.1 Phase 1: Situation Analysis of Family Life While Caring

In the first phase, the study was conducted during January-July 2020. Data were collected by means of in-depth interviews, triangulated with focus group discussions. The SPSS and ATLAS ti 8.0 software programs were used for demographic information and qualitative data analysis. Forty participants who were family members and caregivers of stroke survivors, were intensively interviewed in their home environments by the researcher. The participants shared their experiences and needs for caregiving to stroke survivors, including factors related to their family life and definitions of a healthy family.

### **4.1.1 Personal Information of Participants**

The personal characteristics of informants were divided into two parts: caregivers and stroke survivors. There were forty participants in the first phase from an in-depth interview group and fourteen people from a focus group. For caregivers, they were male (20.4 percent) and most of them were female (79.6 percent), aged 25-84 years ( $\bar{x} = 57.31$ , S.D. = 12.83). Nearly half of them remained working (42.6 percent). The

majority of them had economic problems. Only 18.5 percent had enough spending money. Most of the caregivers maintained close relationships with the stroke survivors as couples or descendants. Three of four caregivers provided care to stroke survivors for a long time and never had any experiences before. Some of them took care of their stroke survivors alone, while having more than three to five family members in their houses. The demographic characteristics of caregivers are presented in Table 4.1.

Demographic data of caregivers	Number	percentage
Gender	7	
Male	11	20.4
Female	43	79.6
age (years)		
25-39	5	9
40-59	22	41
$\geq$ 60	27	50
Mean = 57.31, S.D. = 12.83, Min = 25, Max = 84		
Marital status	1	
Single	9	16.7
Married	39	72.2
Widowed/divorced/separated	6	11.1
Status in family	1511	
Head	26	48
Member	28	52
Education		
Primary school or lower	28	52
Lower secondary school	9	17
High school	6	11
Bachelor's degree or higher	11	20
Work		
Still working	23	42.6
Unemployment	31	57.4
Number of family member		
2 people	6	11
3-5 people	29	54
$\geq 6$ people	19	35

Table 4.1 Demographic Data of Caregivers (n=54)

Demographic data of caregivers	Number	percentage
Household incomes per month (Thai Baht)		
< 10,000	14	26
10,001-20,000	22	41
20,001-30,000	7	13
>30,001	11	20
Adequacy of income		
Saving	10	18.5
Fair	18	33.3
Indigent	15	27.8
In debt	11	20.4
Duration for caring stroke survivor		
3 months -1 year	15	28
2 -5 years	24	44
6 – 10 years	9	17
More than 10 years	6	11
Relationship with stroke survivors		
Spouse	25	46.3
Sibling	7	13.0
Offspring	18	33.3
Other	4	7.4
Having experienced for caring stroke survivor	1	
Having experienced	20	37
Never	34	63
Responsibility to care for other members		
Caring for a single stroke survivor	35	64.8
Taking care of others together	19	35.2

The essential demographics of stroke survivors in this study included males (72.2 percent) and females (27.8 percent). All of them were at the age of 37-89 years ( $\bar{x} = 68.13$ , S.D. = 11.43). Many of them suffered from a stroke for more than two years. Half of them needed help in their routine life from caregivers, depending on the abilities of each stroke survivor. The demographic characteristics of stroke survivors are shown in Table 4.2.

Demographic data of stroke survivors	Number	percentage
Gender		
Male	39	72.2
Female	15	27.8
age (years)		
< 60	12	22.2
$\geq 60$	42	77.8
Mean = 68.13, S.D. = 11.43, Min = 37, Max = 89		
Status in family before stroke		
Head	22	40.7
Member	32	59.3
Education		
Primary school or lower	38	70.4
Lower secondary school	4	7.4
High school	7	13.0
Bachelor's degree or higher	5	9.3
Work before stroke		
Still working	37	68.5
Unemployment	17	31.5
Duration of stroke experience		
3 months -1 year	17	31.5
2 - 5 years	19	35.2
6 – 10 years	12	22.2
More than 10 years	6	11.1
The activities of daily living (Barthel Index Score)		
Independent (BI = $80-100$ )	29	<b>51</b> 0
Need a little help (BI = $60-79$ )	28	51.8
_	7	13.0
Need some help (BI = $40-59$ )	3	5.6
Need a lot of help (BI= 20-39)	8	14.8
Dependent (BI< 20)	8	14.8

# Table 4.2 Demographic Data of Stroke Survivors (n=54)

# 4.1.2 Family Life Situation in the Study Area

In-depth data were collected among 40 families of volunteer caregivers for stroke survivors by purposive samplings and snowball samplings in the

target areas of Bang Khen Sub-District Health Promotion Hospital, Mueang Nonthaburi, Nonthaburi Province, Thailand, aiming to analyze caring situations, explore family life and create unique definitions of a healthy family while caring for stroke survivors. Preliminary questions were used from the core concept of Calgary Family Model (CFIM) framework, comprising three main domains of family functioning: cognitive, affective, and behavioral (Wright & Leahey, 2013) Whereas, qualitative data were analyzed by content analysis (Miles, Huberman, & Saldana, 2014) from all voluntary representatives who described their caregiving experiences, including the definitions of a healthy family life in the stroke survivor's family. Triangulation of data was performed by discussions between two groups of caregivers, which could be summarized into 3 essential factors: 1) Caregiver characteristics, 2) Family functions and relationship and 3) Resource support.

### **4.1.2.1 Caregiver Characteristics**

A caregiver is a person who plays the most important role in caring, helping, and meeting the necessary needs for stroke survivors to lead a normal life with direct support, both physically and mentally, while contacting and coordinating with a healthcare team to ensure that stroke survivors receive continuous treatment and rehabilitation, including the relief of their burdens at home. This leads to different caregiving in each family for stroke survivors (Imarhiagbe et al., 2017) This is due to the fact that stroke survivors have their limited abilities to perform various activities, depending on the pathology of each individual's brain, which leads to the reduction of self-care potential among stroke survivors, especially in cognition and memory. In addition, the context from family, knowledge and experience gained, health condition and caregiver's beliefs can be factors with relation to caregivers' readiness to meet the needs of different stroke survivors (Duthie, Roy, & Niven, 2015; Sornarkas, Deoisres, & Wacharasin, 2015) In this study, the caregivers' characteristics of family members suffering from a stroke included: 1) Virtuous love and gratitude, 2) Experiences in caring, 3) Good health and self-care, 4) Good management of emotions and 5) Freedom in dealing with problems and obstacles.

(1) Virtuous Love and Gratitude - It is a special characteristic of caregivers who care for stroke survivors. It is also an expression of being a virtuous person by providing a loving care and a consciousness of gratitude. In

a situation, caregivers have to deal with caring for stroke survivors who have the mechanism changes of structures and functions in various systems of the body, such as physical abnormalities, loss of ability to balance movement, impaired cognitive thinking and memory, limited self-care and changing moods. Thus, caregivers need to adapt and make a great effort in caring for and responding to the needs of stroke survivors.

"She has been sick for eight months. I always take care of her. I have to lift and carry her. I also help her when she goes to the bathroom and does her routine activities. In my life, I have never taken care of anyone. I have to adapt a lot." (Husband, 60 years) "Love, love, love, without expecting money. Love and pity. I have been with him for 18 years. I can't leave him." (Wife, 54 years) "It's like doing my duty. Do my best. One is my mother. Another is my grandfather. The other is my younger brother. No matter how tired I am, I need to take care of them." (Sister, 41 years).

Sometimes, this may cause caregivers to feel that caring for stroke survivors is just their own duties.

"I take care of him today only because of humanity. He has a stroke and I have to care for him." (Wife, 58 years)

"I try to take care of everything. It's something I have to do because it's my duty." (Daughter, 52 years)

"Having to take care and feeling annoyed and bored. I can say it without thinking. I do it as my duty. I take care of him because I don't want him to suffer. But, I sometimes can't deal with it. Sometimes, I feel tired and bored. However, I have to go back and take care of him again." (Nephew, 57 years)

*"The virtues have already been within me. If there is no virtue, I would slap him. Sometimes, I am angry. Sometimes, I feel hurt." (Niece, 46 years)* 

These are consistent with a study by Qi Lu that described the caregivers' experiences as living on the edge. They have to take the responsibilities alone for everything for the life of the stroke survivors. It feels like they are prisoners (Lu, Martensson, Zhao, & Johansson, 2019).

The philosopher, Benjamin Franklin, said that the person who manifests a virtue must have self-control, while knowing how to use silence in managing things or solving problems with diligence, self-sufficiency, sincerity, humility and impartiality (Fiering, 1978). This is in consonance with the views of modern psychologists, Peterson and Seligman, who categorized virtues into six broad types: courage, justice, humanity, temperance, transcendence and wisdom (Peterson & Seligman, 2004) In addition, Buddhist doctrines use the 4 Brahma Viharas as principles for people in the society to live with pure love towards others in this world, with generosity and non-maliciousness towards each other. It consists of four principles: Metta (the desire for others to be happy), Kindness (the desire for others to be free from suffering), Mudita (the joy that others experience happiness in a merit way or the cause of happiness), Upekkha (the neutralization of mind and a belief in karma of good or bad deeds with forgiveness and free from prejudice) (Bodharamik, 2018; Phra Maha Kasem Panya Waro, 2017).

Buddhist doctrines also refer to a belief in the law of karma that everything must be in accordance with the natural laws or causations. We are what we create it. The consequences arise from overall causes. If we do good deeds, we will get good consequences. Doing bad deeds will get bad consequences in return (Punjasunthorn, Onma, & Yongphet, 2018) From data collection, it was found that all caregivers were Buddhists and they believed in the doctrines of karma being done in the past and resulted in both good and bad things being encountered in the present.

"I take care of her and sometimes I think too much. I am handicapped like this and I still have to care for her. I thought it was a fate. If I am out of karma, I may not have to take care of her. It must have been a victim of the past. She had a good health before, so I would want to depend on each other when her legs were good. After a few years of marriage, she became unhealthy. I had to take care of her instead of her taking care of me. I think it's fate. It is my karma. I may have devoured her in my past life." (Husband, 68 years)

Following a belief in the law of karma, it causes family members to practice religious ceremonies continuously, such as going to temples, making merits, offering foods to the monks and behaving in accordance with the teachings of Buddhism. This is so that those merits would result in the relief of any sufferings that they are now facing. Also, they expect that their merits should lead themselves to happiness. "I don't expect anything. It depends on my merits and karma. It's like old merits and a new karma because this disease is so called a disease of fate and karma. He has done a lot of karmas. So, I have to think that I now return his karma and should stay with him. I make merits and give foods to the monks every day." (Wife, 50 years)

This is consistent with the study of Ekaphon Duangsri which reported that karma is something undesired by every human. It is believed to be real and humans certainly get the results of their actions, which they cannot resist. The goal in a human life today is to be free from the cycles of karma and have a good life (Duangsri, 2018)

Having gratitude is another teaching in Buddhism. It is a unique social and cultural identity of a Thai family which has been taught to practice it for a long time. With virtues, caregivers of stroke survivors have a sense of their duties and responsibilities. It is one of the reasons why caregivers take care and treat their parents and benefactors so well.

"When I work, she takes care of me. She washes my clothes, prepares my meals and gives me medications for illnesses. So, when she is in this condition, I have then to take care of her." (Husband, 60 years) "I need to take care of him. He is my father. No matter how he is, I have to care of him." (Son, 34 years)

Gratitude means knowledge and acceptance of merits. Also, it is an attempt to act in return with graciousness, such as taking care of one's parents, being obedient to adults, supporting, helping, praising, honoring and caring for people, animals, things, and the natural environments to remain in good condition. Gratitude is an important fundamental virtue that fosters good family relationships and a source of responsibility for taking care of parents in their old age or illnesses (Thãvaro, Phrakrukosolattakit, & Phrakhrukositwattananukul, 2019)

From the above mentioned, virtue, love and gratitude are the key attributes of caregivers for stroke survivors. It is a good conscience that manifests itself as a belief according to Buddhist teachings, the law of karma and gratitude to parents and benefactors. It is believed that the practice of good caring and being nice to parents or benefactors should result in better blessings for oneself and the family.

(2) Experiences in Caring - The experiences gained by caregivers and family members of stroke survivors, both now and in the past, are learnt

through a reflection on experiences related to stroke and caring which comes from observation, self-learning and memory as lessons of life. Each caregiver has different experiences, including those that caregivers used to contact or have a stroke themselves before caring for a family member.

"In the past, I had this disease. My arm had an atrophy, but I exercised until I recovered. I had a hemorrhagic stroke and received a surgery to remove the blood clot. It took many years for me to recover. I was in the hospital for a month. I tried to exercise. I cycled and played petanque in the evening. I ate non-oily foods. I had high blood pressure. I always took medicine and went to see the doctor per my appointments." (Husband, 60 years)

Caregivers had experiences to take care of their close relatives or others before becoming caregivers for family members who suffered from a stroke. Caregivers may be transferred or learnt from experiences, such as being a public health volunteers or having been trained as caregivers before.

"When asked whether or not I have a knowledge, I don't have it. I've received training about first aid. However, for the care as I am doing today, I have never done it before. Perhaps, it may be because I used to take care of my grandmother. When Grandma was sick, she was bedridden. At that time, I sought some advice from doctors and nurses. So, I had a little knowledge." (Older sister, 41 years)

"Before taking care of my aunt and my uncle, I used to be a volunteer. So, I gained my knowledge from experiences while being a volunteer." (Husband, 60 years)

From the experiences of caregivers for family members who have a stroke, it is like an empirical learning to review the knowledge of caring, as well as reflect, analyze, come up and conclude overall ideas. Caregivers are able to bring knowledge and experiences to be applied in their own daily activities, stroke survivors and family members.

(3) Good Health and Self-Care – Caregivers have to provide care in responding to the needs of stroke survivors. In the meantime, caregivers also receive a direct effect on their own physical and mental health caused by the needs for self-care (Caro et al., 2017; Lu et al., 2019) According to the personal information of caregivers who care for family members with a stroke, half of the caregivers are at the mature age of 60 years and over and usually found with the degeneration of health conditions, leading to their lower ability to perform activities (Chiaranai, Chularee, & Srithongluang, 2018) In particular, they are often noted with chronic diseases, including a stroke as well.

"I also had a stroke. I have it just about two or three years after her. I first fell at the escalator of BTS. I could not stand up. The security guard helped me. When I got home, my hands were shaking. I had to lean on the wall while washing the dishes. My mouth was palsy. I received the MRI and stayed in the hospital for 3-4 days. I still have to take the medications today." (Husband, 68 years)

"Before, he could cook. But now, he could not do it. He is weak. I sometimes cannot do the cooking, but mostly a simple omelet with rice. I walk to buy foods. I hurt my legs very much. When I feel lots of pains, I go get a massage at the health center." (Wife and Sister, 78 years)

Approximately 41% of the caregivers are at the elderly age (40-59 years old), with a starting experience of health problems and underlying diseases. Nevertheless, they have to be responsible for caregiving to family members with a stroke and their own healthcare at the same time. This results in a lower ability to perform daily activities and their own healthcare management, including a reduced social interaction.

"Now, I hurt my back very much. I have back pains. The doctor said that I need to get a surgery for my herniation. But, I can't receive the surgery because there is no one taking care of him. If I get a surgery, I need time for a rehabilitation. In particular, no one earns a living. So, I have to tolerate the pain. If I cannot tolerate the pain, I go to see the doctor. If it is severe, the doctor gives me an injection and prescribes the medicine. I would want him to be cured first, then I should get a surgery. Just take turns to take care each other. But, I don't know when he will be cured. He hopes that he will be cured. Sometimes, I have got a back pain. So, I complain. The back pain is very severe. I cannot sleep sometimes and massage myself. The doctor teaches me to lie on the side when I feel pain. Then, I put a pillow underneath the side of the leg that I feel pain press it again and again until I feel better." (Wife, 50 years) This is in accordance with the study of Whitehead (2017) and Camila et al., (2017) which reported that fatigue and a feeling of burden from caring for people with illness can affect the health status and quality of life of caregivers and family members (Byun & Evans, 2015; Caro et al., 2017; Whitehead, 2017) Being responsible for people with a stroke can change the time or eating behavior and daily activities, in line with an inadequate rest due to a fatigue from the caring burden, stress and boredom from the caregiving (Misawa et al., 2018) Their own chronic diseases and that of family members cause caregivers to realize and oversee the importance of selfcare management in the future (Sundin, Pusa, Jonsson, Saveman, & Östlund, 2018) According to a study, caregivers modify, change and manage their own health. They adjust their health behaviors with daily life.

"Before, I used to drink and smoke. I have tried to stop drinking and nourished my body because I have damaged my body a lot. I just maintain my body to be better. I eat fruits and vegetables more. I used to hate fruits and eat only bread and fast food." (Older Sister, 41 years)

"We must stand it. I do not hope for anyone to help. I must live and be strong. I used to care for nothing. Today, I eat fruits and vegetables. I must be physically strong. In the evening, I prepare the foods for him. Then, I go out for exercising and walking around the Fang Temple. In the past, I didn't hurt the hips, so I went running at the Ministry. Now, there are many people with illnesses. No one will take care of us. We must take care of ourselves. The mind is good, but I must be strong. I will not be stuck. It is not right to sit and cry for nothing. I must be strong then." (Daughter and Wife, 54 years)

The activities that caregivers modify are driven by their motivation and desire to improve their own health or maintain good health both physically and mentally. Managing their own health care is to perceive and respond according to the needs of caregivers themselves, in both normal health and illnesses, to prevent the deterioration of health or maintain a good health of caregivers for family members with a stroke. According to Ryan's Integrated Theory of Health Behavior Change, a good health is the result of continuous self-management behavior that affects the health of caregivers (Ryan, 2009) Important factors affecting the changes of selfcare behaviors involve knowledge and awareness of the ability to modify one's health behaviors. The management of one's own health care is thus extremely essential. If caregivers are in good health, it will reflect the quality of life of stroke survivors, including the health of all family members.

(4) Good Management of Emotions - Factors affecting the mental health of caregivers for stroke survivors include family members' desire, stressors, and caregivers' coping strategies.

The desire of family members is what caregivers and family members expect in the uncertainty of future life (Byun & Evans, 2015). "It is OK to be able to walk. I don't want him to be bedridden." (Daughter, 51 years) This seems to be the desire for people they care for to get better and continue to live even if the disease cannot be cured. Some caregivers wish for stroke survivors to be able to resume their daily activities, or even walk and help themselves again although they can't return to be normal. "It is impossible to be normal and the same. Just wish him to be able to feed himself, walk and talk with understanding. This is OK." (Daughter, 57 years) However, there are still some people who expect stroke survivors to recover from the disease and disabilities, so they can return to have a normal life as previously planned. "I want him to recover and have a sum of money. If he can recover, I want to take him home. I have a house in Nakhon Sawan province." (Wife, 50 years). Caregivers also wish to gain their own independence. The responsibilities and the role of caregivers do not allow them to have more personal time and to do their activities outside the house for as long as they desire.

"I feel that it is impossible to go anywhere. If so, I have very little time to go. I have to feed him during lunch time. I help him take a shower. The problem is that I don't have a lot of personal time. It's not convenient. Before, I don't have to worry. I can go wherever I desire and do whatever makes me happy." (Wife, 58 years)

Like Qi Lu's study, it was found that caregivers received a significant impact on their personal life in caring for stroke survivors (Lu et al., 2019). In addition, caregivers also desire for family members to be happy physically and mentally, with a good physical and mental health.

"Everyone has got a sickness. Having lots of money, we are sick anyway. Many people have lots of money, but not very much happy. Some people have no money, but they have a happy family. I think that family happiness is good for health and a good mind. Money comes later. We have enough to eat. It is our sufficiency." (Wife, 68 years)

Stressors make caregivers feel that caring for stroke survivors affects their mental health or significantly causes negative feelings among the caregiver and other family members (Byun & Evans, 2015; Misawa et al., 2018), including stresses and anxieties. "*I feel pity for him. I can't go anywhere. When turning back and seeing him, he is like this. How can he live and eat?*" (*Daughter and wife, 54 years*) Also, it leads to the family's conflict. "*I take care of his diet alone. But, others don't help us. I don't know what to do.*" (*Daughter, 33 years*). These pressures negatively affect a person's duty (Rice, 2000), causing caregivers to feel depressed, angry, frustrated, saddened and discouraged. Then, caregivers express their aggressive behaviors and make inappropriate decisions.

"At first, he didn't want to walk. At that time, I got annoyed and admitted that I scolded him. I complained about him a lot. Because I sometimes felt so tired. Why didn't he help me? Now, I take care of my mother alone. Is it like I do not have time for myself? I have to take care of him at all times. But, I sometimes feel why it is only me take care of him? If I feel bored, I think too much. It comes quickly when I am bored." (Daughter, 51 years)

Coping strategies are the ways that caregivers of stroke survivors use to deal with their own negative moods and problems which occur during the caring of their family members (Misawa et al., 2018), such as stress, anger, suffering and conflicts with family members. "At first, I was stressed. Then, I started to realize why I would feel stressed. After going outside the house, I should leave the problems there." (Daughter, 52 years) This is to enable themselves to continue their caregiving for family members (Byun & Evans, 2015) Some caregivers use the avoiding method in dealing with problems or try to get out of the situations.

"I can't speak. I am sick, aren't I? I asked myself why he is very much frustrated to me. I explain but he doesn't understand. I speak too slowly and he doesn't understand. So, I don't speak. I feel tired (laughing)." (Daughter, 46 years).

Some people solve problems by escaping from the situations, such as walking away, talking to others or using silence to reduce the severity of their moods or avoiding the quarrels. "When he is frustrated, I go away. Otherwise, we *quarrel very much. That is it.*" (*Wife, 57 years*) Some families think that the arguing or quarreling between members is normal for every family. "It is normal to have a quarrel in the family. But, at my house, we walk away after quarreling. On the next day, we talk as usual." (*Daughter, 51 years*) After quarreling, members often turn to talk about their needs to fill and adjust their understanding among themselves (Benzein, Olin, & Persson, 2015) Partly, caregivers try to perceive the problems and think of the reasons. Then, they accept what happens. They try to live with the realities at present. "I feel discouraged, but think that the he is more discouraged and feel worse than me. He still can live. If he can live, I must live." (Wife, 50 years). Some people find other activities to replace those feelings, such as listening to the radio or listening to music.

"When feeling depressed, I turn on the music so loud (laughing). I work while listening. I turn on the music so loud because no one is around. When I turn the music on, he likes to listen to it. Sometimes, I turn on the music for him." (Wife, 58 years)

In addition, the caregivers who are the elderly often have a faith and want to perform religious activities, such as going to the temple, making merits, giving alms and praying. *"Before going to bed, I pray to bless the family to be fine and healthy. On his birthday, I take him to give alms to the monks."* (*Wife, 64 years*) Caregivers apply the teachings of the Buddha to deal with their stresses and control their emotions. They let everything go, relax the mind, do the meditation or pray, and listen to Dharma.

"I don't feel stressed. I and my wife talk to each other, listen to Dharma, relax the mind, and pray. I tell her not think too much and accept the reality. Don't think. Don't be stressed. If stressed, it is bad for the mental health." (Husband, 60 years)

Like a study on the experience of a Greek family on patients with critical conditions by Sofia Koukouli *et al.*, it was found that the family members could adjust to the problems and be optimistic. They have a family support to each other. They have a faith and believe in the religion and the spirituality (Koukouli et al., 2018).

(5) Freedom in dealing with problems and obstacles – This includes the freedom to manage problems and obstacles that affect the quality of care of caregivers for stroke family members, such as the willingness and readiness of care.

According to the study, the most often found problem was that caregivers had no prior experience in caring for family members with a stroke. "I have never had an experience in caring for a person with illness. This is my first experience and it is to care for my husband. When going to the hospital, I care for him during the day and the night. I take care of him today by myself, thinking how to give a care. When going for a physical therapy, I observe and remember it to do for him at home" (Wife, 68 years) Caregivers are then forced to learn and practice the additional care skills by themselves. As a result, they are worried and lack the confidence to assist stroke survivors. "In my life, I have never taken care of anyone. At first, I had to adjust a lot. In the past, I was awkward and not dare to clean the urine and feces. Besides, I am a male. I have never done these things." (Husband, 60 years) Caregivers often feel that caring interferes with their daily life, causing them to neglect their self-care or not to have time for taking care of themselves.

"To tell the truth, I have had no time to go out since he was sick. I work in the morning. I cook the foods for him to sell. After work, I make the foods for him to eat, take him for a shower, give him the medicine and prepare the vegetables for cooking to sell at four or five o'clock in the morning. I rarely have time to take care of myself. I have no time to eat. In a day, I only eat lunch. If very tired, I rarely eat dinner. I never eat breakfast. I rarely have time to take care of myself. There is no time to relieve my stress." (Wife, 50 years).

This problem directly affects both physical and mental health. In addition, the feelings of anxiety, fear and a heavy difficulty in the responsibilities and activities of caring. This leads to a feeling that caregiving for stroke survivors is a burden (Sundin et al., 2018)

In addition, the lifestyle of caregivers in the way of quasiurban and urban society is one of the major obstacles affecting the families in caring for stroke survivors. This study collected the data of families in a semi-urban context at Mueang District, Nonthaburi province, with cultural diversities and dense populations. The lifestyle of people living in the semi-urban areas is usually not much different from that of urban communities. There are high struggles and competitions. Most of the population have to leave for work very early in the morning or they have to live near their offices. This is because they have to struggle to earn money for payment of their expenditures for their survival and that of their families. "Money is a very important factor for each family. In the past, people in the country can share with one another. But nowadays, this can't be shared." (Wife, 58 years) So, the family structure has been changed and this results in less time spent for doing activities together within the family. "Before, we could do activities together. Right now, we don't have a lot of free time. He doesn't tell in advance that he would come. He comes to stay for a moment and goes back. He just comes to bring something for me." (Wife and sister, 78 years) In the meantime, the relationships with neighbors or people around is also less intimate. "Don't expect others to come and help us. Wherever we go, we have to hire a caregiver." (Daughter, 56 years) This causes caregivers who care for family members with a stroke and live in the context of quasi-urban communities to feel that they are unable to rely on family members, neighbors or other people.

"If I and my grandfather are busy, there is no one to help take care of him. If we go out, we can't ask people next door to take care of him for us. Around the house, there are brothers and sisters. My aunt's house is next door. He can't walk properly. If we leave the house not for long, she can come to watch him for us. If we leave the house for long, she can watch him for us." (Daughter, 46 years).

The same is true in a study by Mirgissa Kaba *et al.* (2020) which found that urban residents value a competitive living. They often lack love, respect and a positive attitude towards healthcare providers. Community-defined values deprive urban residents of a common understanding on health care issues and service problems, including limited spending capacity that leads to a lack of awareness on their own health care (Kaba, Taye, Getachew, & Gizaw, 2020)

### 4.1.2.2 Family Functions and relationship

Families of stroke survivors have to face critical situations that alter the lifestyles of their family members. The family structure, as well as the roles and duties of family members, together with the illness of family members can have an effect in many ways to the family (Byun & Evans, 2015) In some families, caregivers are not solely responsible for caring for stroke survivors. Others may be involved in relieving their responsibilities. In some cases with complications to stroke survivors, additional activities may be required. Additionally, the family member' relationships and their abilities to manage problems demonstrate family functions. From the study, there are 5 factors related to the caring of stroke survivors that family members need to pay attention to: 1) Family structure, 2) Roles and duties of caring members, 3) More special activities, 4) Family Relationships between members and 5) Management of family problems

(1) Family Structure - The structure of the family caring for a stroke survivor demonstrates the family's role in taking care of members who have a stroke. The family members are closely related and bonded to help each other. Nonetheless, this study showed that the number of family members is not significantly associated with the reduction of burdens of caregivers. For the family living in a semiurban community, members of working age have to work outside the home. "There are seven people in the family. The younger sister will help with money because she is not good at taking care of him. Most of the caring will be done by older sisters and my mother. Grandchildren will do housework. We relieve the burdens of one another." (Older sister, 41 years). Some families have to take care of each other and provide additional care for their grandchildren. "There are three of us, including me, him and nephew aged 12 years. He calls me and him as father and mother all the time" (Wife, 50 years). In some families, single children are responsible for taking care of their parents in their old age. "I am not married. If I am married, I can't live like this. Today, there are three members in the family. I am the middle one. I have an older sister and a younger brother. They have moved to another place." (Daughter, 46 years) Some families do not have children, but they have to take care of their father and mother with a stroke. "Grandpa has only me. My younger sister died long time ago. So, I'm tired. But, I do not work all day. It's a duty. He has got only me. I have to do it." (Daughter, 57 years) Most caregivers are unable to deny their responsibilities for caring of family members with a stroke.

(2) Roles and Duties of Caring Members - Caregivers realize about the important role of families in caring for stroke survivors. Both caregivers and family members must have basic knowledge of stroke and skills to provide an effective care that fully meets the needs of for family members with a stroke. "*Before, I had no experience. When he was sick, I received training from the nurses who taught me at the hospital. They taught me how to give a therapy to patients and a caring for this type of patient.*" (*Wife, 50 years*) Mostly, they learn about caregiving while stroke survivors are hospitalized. After returning home, the knowledge can be gained from the advice or memories of other people. "*The one taking care of him for us decides what to do*. *When going to the physical therapist, I watch him and remember to do it at home.*" (*Wife, 68 years*). Some people have skills from the observation of caregiving by themselves and practice on their own in daily life. "At first, she had a problem with excretion. After that, I made her eat bananas, it was then easier for her to excrete. When drinking water, the water would flow out of the mouth. So, I must feed her with a syringe, while watching to avoid the spilling. I slowly fed her, or she would choke." (*Husband, 60 years*) This is consistent with a previous study by M.Amalia Pesantes *et al.* which reported that caregivers were not trained on the post-caring after stroke survivors were discharged and only a few of them received a psychological support (Pesantes et al., 2017)

For the role of helping with daily activities, the family must provide caring, so that stroke survivors can fully perform their daily activities. Each day, caregivers need to have various activities in assisting and caring for stroke survivors, especially the basic activities such as eating, bathing, cleaning, moving, excreting, etc.

"She can eat by herself. I bathe her. I put her on a chair and pour the water for her. She can take a shower by herself, but she doesn't want to do. She wants me to do it for her. She can dress herself. I help her to go to the bathroom. She can excrete and clean by herself without any help. She can get out of bed on her own. She uses a chair to help her move with her feet pushing. She uses the commode pot when excreting or goes to the bathroom. When finishing with the commode potty, she stands up and I insert the potty for her to wash. I pour the water and she washes by herself." (Husband, 68 years)

The needs for assistance are different, depending on the stroke survivors' dependency. Sometimes, caregivers need help to relieve their burdens of caring from other family members in case of caregiving to stroke survivors with a high dependency, such as bedridden or no cooperation with caregivers. "At night, I have to take care of my mother. Sometimes, my mother coughs and I have to come to see her. If I don't get up, the phlegm will stick to my mother's throat. If my sister is there, she will get up and come to take care herself. I can sleep a bit." (Daughter, 46 years) Caregivers have another role of drug management, both routine medications and supplements provided by family members for stroke survivors to maintain their healthy body.

Caregivers also play a role in preventing various complications to stroke survivors by doing intensive physical therapy to reduce the chance of permanent disabilities. They have to provide a close caring to prevent accidents, reducing complications and recurrence of a stroke. "She is very disobedient. I just take care of the symptoms. We provide supplementary foods. I want her to get better. I have to observe the symptoms and all food intake. I try to make her take medicine without missing any medications. I always take her to see the doctor, without missing any appointments." (Daughter, 50 years) So, families should support, promote and encourage stroke survivors and caregivers, which becomes an important and necessary family role to increase both physical and mental encouragement to stroke survivors (Koukouli et al., 2018) Caregivers believe that the mutual encouragement of family members should help stroke survivors towards a faster recovery. "I talk to her every day to cheer up. I see her improvement from the symptoms little by little. Relatives are nice. They call to ask for her symptoms every day. Neighbors always ask about her with nice greetings and encouragement." (Husband, 60 years)

The study also revealed that the lifestyles of good family members to care for their love ones who suffer with a stroke require a sacrifice of their personal time and supports to each other. In particular, the elderly caregivers would emphasize on spending time together for various activities with children and family members. "A happy family must be together. No matter how difficult it is, stay together." (Wife, 60 years) Another important thing is the gratitude as a unique culture in Thai families, which has been upheld and practiced for a long time. Thai society values and appreciates the gratitude and it is nice to find a way to give it back to one another. "What makes me take care of her is that I think like this way. When I work, she takes care of me. She washes my clothes and prepare my foods. When I am sick, she gives me a medicine. So, when she is sick, I need to take care of her." (Husband, 60 years). Gratitude comes from two words, "grateful" and "appreciative." Grateful means the perception and acceptance of the gratefulness of persons, animals, things, natures, and environments towards us both directly and indirectly. Appreciative is defined as the attempts to return, pay back, assist, honor, and maintain for the niceness. This includes taking care of parents when they are sick or older, paying special favors to benefactors, giving the best love and care for one's spouse, and showing good behaviors towards each other with kindness, generosity, and respect to one another, with graciousness as an expression of gratitude (Loem & Payago, 2019; Phra Tamsinghaburajan (Luang Po Jaran Tittammo), (n.d.); Phrateprattanasutee, 2014)

(3) More Special Activities - When stroke survivors have complications, their caregivers and family members need to acquire more knowledge and skills, such as a pressure ulcer care, post-infection care of various systems or chronic diseases. Caregivers are not only responsible for the daily activities of stroke survivors, but they also need to do more special activities. "*I still have such a headache*. *I have to take a dialysis course. I want someone to help me because I need to do the dialysis for the whole life.*" (*Grandson, 57 years*) From the study, special activities that require the increasing responsibilities each day can directly affect caregivers both physically and mentally.

"I have never told or talked to my children. They need to know by themselves. Why do parents have to tell them? It's on their conscience. Parents can endure and tolerate. If they want anything, they can get all. Have they ever given? Never ... So, I feel upset. Why do I want from them? They should know their duties as children. One candy that my children give to me, it is meaningful (crying). If they go anywhere and come back with souvenirs, it is meaningful." (Daughter and wife, 54 years) "

"When I take care of a patient, I don't want him to suffer. But, I sometimes cannot stand it, Sometimes, I feel tired and bored. I have to be back and do the same. It has to be in this state, sometimes I can't do it." (Grandson, 57 years)

Families need to provide assistance and alleviate the caring burdens of caregivers. Besides, there are some families that caregivers are responsible for caring of more than one member. "*Grandpa has been sick for more than 2 years, sleeping on a regular futon and feeling weak on the right side. He can raise his arms but he cannot walk. He can normally eat, no choking. He can do it all by himself. He can hold urine and poop normally. Grandma is his older sister. She is 82 years old. She has been sick for about 8 years. Her right side is weak. Grandma can't walk and can't move. If she moves, it hurts. Grandma has to prepare foods for grandpa and feed him.*  He couldn't eat by himself. He uses Pampers and grandma then cleans him. Grandma takes care of both of them all the time." (Wife and sister, 78 years) Thus, caregivers need more help.

(4) Family Relationships Between Members - It is an important factor affecting the quality of care for stroke survivors and the health condition of caregivers. Many families have relationship problems and conflicts after a stroke. It is a challenge for families to maintain strong relationships between caregivers and other members (McCarthy, Lyons, Schellinger, Stapleton, & Bakas, 2020) From the study, caregivers viewed that the relationship between family members must consist of good ties and nice communications.

Good relationships lead to understanding, sympathy and mutual assistance of family members. "*Relationship and compassion make us take care of each other. I want him to be better and help himself as much as I can do for him.*" (*Wife, 60 years*) Family relationships are one of the driving forces for family members to provide understanding and willingness in caring of stroke survivors towards more effective care. Like a study by Michael J. McCarthy *et al.*, there are challenges of relationships between stroke survivors and their family caregivers. The findings highlighted various issues that should be considered in fostering strong family relationships to meet the needs of members (M. J. McCarthy et al., 2020).

Beautiful communication is good between family members. It is an art of building good relationships among family members who have a stroke. "My husband is close to his child. They love each other very much. They hug and kiss." (Daughter and wife, 54 years) Beautiful communication consists of words and gestures, such as eye contacts, smiling faces, hugs, talking and listening. It is a support to show mutual encouragement and care between the members. A study by Benzein *et al.* found that the communication between family members can fulfill members' needs. Health workers should support the standard of care for all families (Benzein et al., 2015) Having a good relationship is warm and creates a feeling of trust among family members and encourages them to learn new things towards a proper care. Using appropriate communication methods also enhances the caregivers and families to feel accomplished in providing care for stroke survivors. It can also develop a good selfcare ability of their own.

Moreover, secondary caregivers are also necessary in helping the primary caregivers. Secondary caregivers are individuals help managing whose family prepared to replace the primary caregivers so that the primary caregivers can have more time to rest or do their own activities. In addition, the relatives (kinships) are also important in supporting and helping caregivers.

"My sister comes back to see my father. She would ask how my father is. Sometimes, we have problems that we can't handle, namely my father likes to eat oily foods. I told my sister to talk to my father, instead of me." (Daughter, 33 years)

(5) Management of Family Problems – Caring for stroke survivors exposes families to many unexpected changes that families need to manage stroke caregiving at home (Michael J. McCarthy & Bauer, 2015) The study found that post-stroke management is very important to families. In particular, the managing of family members' roles, leisure time of caregivers, and conflicts among members is crucial to maintain the ability to perform duties of the family in caring for members who suffer with a stroke and enhance good relationships among members. Managing of family members' roles must be agreed upon in the family to have caregivers for members with a stroke. Household responsibilities should also be shared among each member. "After my husband is sick, I have to become the head of the family. I have to do everything." (Daughter and wife, 54 years) Some family members have a little change on their roles. In many families, caregivers must act as the caregivers and the head of the family at the same time.

Managing of leisure time is important for families so that caregivers can have time to rest or relieve their stress to reduce fatigue and burdens. A study by Lena Olai *et al.* reported that the length of care for stroke, functional ability of stroke survivors, and family relationships can result in caregiving burdens (Olai, Borgquist, & Svärdsudd, 2015). To build good relationships, family members should do various activities together by going out, dining, or helping to alleviate burdens. Thus, they should take turns for caregivers to have more time to rest and take care for themselves. "*On special holidays, we make something to eat together. On Sundays, my*  daughter has a day-off. So, we cook. For me, children will take me to the temple and make merits, but not staying overnight." (Wife, 58 years)

Conflict management is the duty of members to work together to promote relationships, affection, and harmony in the family. Conflicts are one of the bad family relationships that cause both physical and mental health conditions among stroke survivors and caregivers. Conflicts affect the emotional, psychosocial, and behavioral expressions of family members.

"He does not behave properly. He is disobedient. He does not refrain from salty, oily, sweet foods. What the doctor forbids, he wants to eat. The disease was caused by his stubbornness. He refuses to listen. I come to take care. I feel annoyed and bored. I say it without thinking. I do my duty that I promise to his sister. I must live there. He can't find anyone to help him. They send him to the nursing care, but not accepted. We can't do anything. So, we must live together. Others expect nothing. They don't pay attentions. To say frankly, they ask why he has not died yet." (Grandson, 57 years)

The conflicts that arise are often caused by self-centered habits, misunderstanding between members and not talking to each other or telling their own feelings and needs. They often exhibit as inappropriate behaviors, such as arguing, neglecting, not paying attentions to each other, not caring for members with a stroke and pushing the burdens of caring to others in the family. Conflicts are therefore major obstacles to the quality of care that caregivers are responsible for members who suffer from a stroke. Caregivers may be in a gloomy mood, irritated, angry or tired of caring. This can cause conflicts or misunderstandings between family members. Most caregivers tend to manage by adopting a conflict resolution approach, controlling their own emotions, and avoiding confrontations while being in a gloomy mood.

"I calm myself. I don't think of anything. I do not take any burdens. I do not accept any problems. Sometimes, when being together, I get annoyed, so I walk out for a while and come back." (Husband, 60 years)

# 4.1.2.3 Resource Support

Support is one of the key areas needed by the families caring for members with a stroke. It includes a support from either family members or external sources. From the study, it was found that families of members with a stroke need supportive factors and assistance for caring. A support is divided into three main areas:1) Financial support, 2) Health service support and 3) Environment support

(1) Financial Support - It is important for families with caregiving to stroke survivors who live in semi-urban communities. Due to the high costs of living expenses in every family, such as housing, foods and burdens in caring for stroke survivors, the family may have insufficient income. "In the past, I was in a private company. I got about twenty thousand baht per month. There are too many expenses, not enough payment. My father's costs of medicine can't be reimbursed. The costs are ten thousand baht per month. They are very high." (Daughter, 56 years). This is consistent with a study by Rajsic et al. which revealed that the economic burdens of the families increase with post-stroke treatment and care (Rajsic et al., 2018) This results in a financial poverty in the families. Some families have debts from their borrowings from others. Therefore, they struggle to earn adequate income to cover their living and medical expenses.

"Most of the income comes from me. I am only one who works. The average monthly income is only ten thousand baht. I do my best, but not quite enough. In the whole family, I am the only one who can find a job. In the morning, I cook for him to sell in front of the factory. The income is not enough with the expenditures. I have to borrow others to spend month after month. This month's income pays off old debts and I borrow again. If I don't do this, I won't be able to support my family." (Wife, 50 years)

Some caregivers have to quit their full-time jobs to take care of people with a stroke, causing the family to lose income that used to come from work and a lack of income from caregivers. "*I am not working right now*. When she was sick, *I left the job to take care of her. So, the income is from two children. She has a Pracharat welfare card for two hundred baht a month and a handicap card for the disabled, with a total of one thousand baht. But, I have got nothing.*" (*Husband, 60 years*) This includes financial liquidity problems in the family, causing caregivers who need a financial support from family members to spend for the caring and daily life.

In addition to support from family members, the government is also the one who helps support and alleviate some of the burdens for the family. The state welfare can help the families that care for stroke survivors to earn more income and reduce the burdens of healthcare expenses (Boukeaw & Teungfung, 2016) "*I*  receive the welfare from a gold card for senior citizen and a handicap card. The income is from my children and the allowances for the disabled and the elderly." (Wife, 68 years) The state welfare includes the allowances given to the elderly aged 60 years and over, while the handicap allowances are for stroke survivors with the disabilities from 6 months or more, as well as the state welfare cards for low-income families. Also, there is a free medical care for the elderly and the disabled. "Grandma gets s seven hundred baht from the elderly allowances and three hundred baht from the welfare cards to buy the necessary things." (Daughter, 51 years)

Living in a semi-urban society requires families of stroke survivors to adjust so that they have enough money to spend. "Money is very important. At least in one month, we have money to buy foods. Month after month is better. Don't be in the needy. If we are in need, we will mentally suffer. Money is the number one factor and a priority for each family." (Wife, 58 years) The sufficiency for spending is something that families of stroke survivors living in the urban society should take it seriously. Not being extravagant, with economical spending and no incurring debts, will strengthen the family both physically and mentally. It also helps to reduce conflicts within the family. "A healthy family must have enough money, so no troubles and no quarrels. If there is not enough money to spend, we argue. Having money makes life easy, so you can do whatever you want." (Wife, 76 years)

(2) Health Service Support - It is something that the families of stroke survivors pay attentions. The provision of health support that meets the family needs can help a greater access to their rights of healthcare for the health of everyone in the family. A review of research by Dominika M. Pindus et. al showed that caregivers and stroke survivors do not have full access to the primary care and community health services, in terms of the post-follow-up for hospital care, appointments, communication, and information (Pindus et al., 2018) In this study, caregivers demonstrated two areas of health support needs: Health insurances and Healthcare services.

Health insurances means the rights to access the basic medical service and public health insurance system through health promotion, disease prevention, treatment and rehabilitation. This is part of building the stability for life and the well-being of family. Health insurance is based on the basic needs of a family care for stroke survivors, namely the rights for medical treatment and the rights of disabled persons, in which some families still lack knowledge and do not have access to those rights.

"Now, I have been informed that he will be removed from the social security program. Then, I use the thirty-baht card for health coverage. When going to claim for the rights, the doctor said that he doesn't know how long to use the rights. If the government changes a new policy, I need to go back the original rights in the area of Nakhon Sawan province. He didn't transfer his name. There has never been a copy of the house registration here. This house belongs to the boss. So, if he lives and tomorrow he has to see the doctor at the hospital. If he wants to exercise his rights at this hospital, he needs to move his name into the house registration of Nonthaburi province. In fact, he can register as a disabled person. But, private hospitals can't do that for him. He must request his medical history to submit for the rights to be a disabled person at a governmental hospital instead." (Wife, 50 years)

The migration to work in urban communities with a request to change from the social security rights to the universal health insurance coverage has caused many families to face some difficulties in exercising these rights of medical care. At present, there are 3 major systems for the use of medical treatment rights from the government for Thai people, namely the Civil Servant Medical Benefit Scheme, Social Security Scheme and the Universal Coverage Scheme (Pachanee & Wibulpolprasert, 2006; Tangcharoensathien et al., 2010)

It is beneficial to help families for an access to better health services. Most families receive their services from the primary care units (Pachanee & Wibulpolprasert, 2006), which are upgraded to employ nurses in providing health information to people in the areas, such as knowledge to strengthen the health of oneself and family members, as well as knowledge and skills in caring for stroke survivors, prevention of complications, continuation of physical and mental rehabilitations. This includes the provision of comprehensive health services or Active health services, which helps support and encourage families to be more prepared to care for stroke survivors (Pindus et al., 2018) In the contrary, health services that cannot meet the needs of families can lead to more difficulties to access health services. "I don't take him to see the doctor right now. Every time I go, I can't find the cause. The x-ray doesn't do anything. I don't know why we have to go. He had an xray before, and later he came for check-up and he had a seizure. They didn't do anything. After that, we didn't go. Now, I would like to take him for a physical therapy to exercise his shin and his legs. His right leg and hand have become atrophied. He used to see the doctor at the Sirindhorn Center. But, they said it's been a long time of 18 years, so he could only maintain the conditions. Then, he made some appointments. They just did the talk to him for his leisure. So, I didn't take him to go there again." (Daughter and wife, 54 years)

Like a study of Tetiana Stepurko et al. on "Health Service User Satisfaction on Quality and Access to Healthcare Services in Six Countries in Central and Eastern Europe," as well as "The Access Satisfaction Study and Quality of Healthcare Services for Community-based Spinal Cord Injuries" by Elias Ronca et al., it indicated that the services that meet health care-related needs could affect the level of satisfaction on the service access (Ronca et al., 2020; Stepurko, Pavlova, & Groot, 2016).

(3) Environment Support – The environment support is the support in the community both physical and mental support. These supports are places, facilities, or devices such as public park, rehabilitation centers, wheelchairs, canes, walkers and other equipment prepared by the families for rehabilitation. The environmental support plays an important role in helping and supporting families in taking care of the daily life of members who have illnesses, including the continuous rehabilitation of stroke survivors. It also gives caregivers more time to take care of themselves and relieve their stress and burdens in caring for stroke survivors.

"We have an exercise bike with a pulley for pulling arms to exercise. He is diligent to do it. He wakes up early in the morning and ties his arms to the pulley for exercising. He walks and exercises under the flat. Since moving here, he hasn't done anything, just sitting, eating, and then sleeping. He said he is better and does nothing." (Daughter and wife, 54 years)

Stroke survivors do not often cooperate in doing their activities. Therefore, it is the family's duty to encourage them to use devices for their continuous rehabilitation. The visit, conversation, and encouragement from long distant relatives can greatly reduce the stress from caring for stroke survivors. Besides, supporters of expenses and necessities can be like indirect enhancement in caring of stroke survivors. This is because caregivers cannot bear all the responsibilities for themselves.

"My younger sister is the one who buys all the things for the house, such as foods and other necessities. If I want something, then I will ask her. Before, no one gave me any supports. So, I had to sell the stuffs. When I stop selling, my sister helps and the need for support is met." (Daughter, 51 years)

Despite not being caregivers, the supporters are rather important persons to provide support and assistance in other matters, such as household expenses, foods or essential supplies and so on. Emotional support is pleasantly a sign of friendships and relationships between caregivers and family members, friends, relatives, or others in society. "Good health is not just about eating, living and talking. If there is an understanding and encouragement to each other in the family, everyone is cheer-up." (Daughter, 33 years) This can help caregivers feel encouraged and have an energy to sustain a life. Also, it reduces stresses and anxieties in providing care for stroke survivors.

From the analysis of data, factors related to caregivers who care for stroke survivors that will promote healthy family are shown in Figure 4.1. All of the 3 factors could drive caregivers to change their behavioral and caring methods to achieve the goals. The researcher conducted further research to develop a care model using a participatory action research process by presenting the methodology in the Phase 2 of research study.



**Figure 4.1 Factors related Caregivers on Caring** 

## 4.1.3 Healthy Family in the Context of Stroke Caregivers

The researcher studied the characteristics of healthy families from Curran's Theory of Family psychology (1983). It was found that the characteristic of healthy families was: the family that combines morality with a family workload, so it can continue to serve family members towards a time to talk and listen to each other. This should be demonstrated by accepting, honoring and trusting each other. There is a balance of interaction between members by sharing responsibilities, having free time with each other, training members to learn the responsibilities according to religious principles, listening to problems and finding ways to help each other (Curran, 1983). Meanwhile, the theory of Family psychology focuses on the relationships and diverse contexts in the family, which influence the functioning of family members as well as the interactions between individuals and environments based on the system theory with the view of family as a whole (Thoburn & Sexton, 2016). In the Phase 1 study, caregivers of stroke survivors targeted the happiness in life and the ability to perform daily activities according to their thoughts and intentions. Therefore, it was analyzed into the definitions of a healthy family as "happiness" which arises from the mind, such as seeing family members healthy both physically and mentally, having no debts, being in a warm and understanding family and experiencing a good relationship between members and people in society.

"A healthy family in my opinion is having good physical health. I want my family members to be healthy, with no worry about diseases of our grandchildren. If someone has a disease, they have to think about how to get rid of it. A healthy family makes our mind happy. We do not have to worry." (Wife, 58 years).

"Everyone has got a sickness. Despite having overflowing money, we are still sick anyway. There are many people who have money but no happiness in the family. Others have no money, but their families are happy. I think that family happiness is a good health and a good mind. Money comes later. Just need to have enough money to pay for food." (Wife, 68 years)

"A healthy family is not just about eating, living, and talking. If people in the family understand and support each other, it is an encouragement. For the food, we can make changes little by little." (Daughter, 33 years).

"I think that a healthy family needs warmth. There must be understanding. There must be no disease. I only think 50/50 to maintain. But for how long will it last? I don't know, but we have to do it well every day." (Older sister, 41 years)

"A healthy family must have a caring mainly about foods. There must be a recommended tasting of sour, sweet and salty. I have never recommended to refrain, but to reduce. Everyone is strong, but there will be some stresses. I recommend going to the temple, learn Dharma, and have no stressful conversation. Let things go. Talk with fun. Today, family members must have a good heart, no stress, and be happy. The mind is primary and food is secondary." (Friend, 62 years)

In addition, many families have embraced the teachings of religion in doing good, performing religious activities, making mental refinement, reinforcing positive energy, thinking well, and doing right. Meanwhile, there is an implementation of the Sufficiency Economy Philosophy in life, with natural living, moderate eating and being happy with what we are today despite having to take care of family members with illnesses.

"My wife and I will talk to each other, listen to the Dharma, relax and pray. I tell her not to think too much. Accept reality. Don't think. Don't get stressed. If stressed, your mental health becomes bad." (Husband, 60 years)

"A healthy family doesn't have to think too much. Stay at ease. No trouble is enough. Wherever you want to go, then go. Buy anything you want to eat. No pain, no fever." (Wife, 68 years)

"I don't expect anything. Every day I live happily without thinking too much. She is not stressed. She has enough to eat. Just the family having enough to eat and not needy is sufficient." (Husband, 68 years)

"A healthy family must have happiness in the family. Even if you have a disease, you can be happy. It's in our heart. If our heart does not think much, the family and children come together. They come to see you. Don't leave them alone. You will be happy. An old man doesn't expect much, only hopes for his grandchildren to come and visit." (Daughter, 51 years)

From the results of content analysis in Phase 1, the results could be summarized into three main concepts: 1) Caregiver characteristics, 2) Family functions and relationship, and 3) Assisting support. The researcher applied the results of this study to set the goals of family healthcare for members of the groups who voluntarily participated in the participative action research in Phase 2. The aims were to encourage the participants to think about an appropriate caregiving based on the context, analyze problems, and work together towards an action plan for healthy family members according to the goals.

In conclusion, the meaning of the healthy family in this study consists of four components including 1) Happiness that comes from within the mind considering the reflection of the family caregivers, family members, and stroke survivors, 2) Physical health of caregivers, family members, and also, the health recovery of stroke survivors, 3) Financial balancing that the caregivers experienced, receiving from other members and the community, and 4) Family bonding from good relationship and reciprocity of family members.

## 4.2 Phase 2: Family-Based Caring Model Development Process Outcome

The process of developing a family-based care model for stroke survivors to foster healthy families at this stage was continued from Phase 1, starting with the study process between October 2020 and January 2021 in the context of a semi-urban community, Mueang District, Nonthaburi Province, using a participatory action research process. The study volunteers were 14 family caregivers for stroke members, who were divided into two groups: Wednesday group and Sunday group, based on the community areas and the convenience to come for participation in group activities of research volunteers. During the research, the researcher presented the data and concepts obtained from data collection in the first phase of the study for the participants to brainstorm by setting goals and developing an action plan to reach the goals of caregiving set by the participants.

#### 4.2.1 Characteristics of Research Participants and Their Families

The sample groups who participated in the participative action research were caregivers of stroke survivors through interviews or group discussions in the Phase 1 study as volunteers in the action research cycle. The sample groups, living in the semiurban community areas of Bang Khen Sub-district Health Promotion Hospital, Muang Nonthaburi District, Nonthaburi Province, were divided for data presentation into 2 groups: Wednesday group and Sunday group according to the community areas and the convenience for participation in activities as the volunteers in this research.

Participants consisted of 14 family caregivers who cared for stroke survivors. There were 13 females and 1 male, aged between 30 to 76, average age 58 years. They provided care for stroke survivors, 2 females and 12 males, aged 56–87 years, mean age 70 years. The duration of stroke ranged from 1 month to 204 months, or 17 years, mean duration 5 years. The family lived together with 3–10 people, with average 5 people. Each family lived in the community for at least 20 years. Activities that family members often did together includes talking, eating, traveling, staying, and going to make merit on important days/occasions. There was only one family that did not share activities. Most of the conflicts in the family came from the dissatisfaction with family members, impulsiveness, different opinions and views. The general information of families participating in the research for data on family activities and conflicts is shown in Table 4.3 and Table 4.4.

General Information	Lowest	Highest	Average
Age of caregiver	30	76	58
Age of stroke survivors	56	87	70
Duration of stroke (months)	1	204	61
Number of family member (persons)	3	10	5
Period of stay in the community (years)	20	40	29

 Table 4.3 General Information of Each Family Group (N=14)

## Table 4.4 Data on Family Activities and Conflicts

Торіс	N=14	
Daily activities	Talking (4) Eating (3) No activity (7)	
Activities on important	Traveling (4) Making merits (3) Eating (6)	
occasions	No activity (3)	
Activities on important	Making merits (3) Staying with all members (3)	
days	Eating (8) No activity (1)	
Conflicts	Displeasing talk (6) Impatient, Annoyed, Scolding (5)	
	Misunderstanding/Disagreement (6) Money (1)	
	Caregiving (1) Disobedient (1) Scolding (2)	

## 4.2.2 Developing a Family-Based Caring Model

At the second phase of the study, 14 participants who had done deep interviews and group conversations continued participating in the study for 16 weeks voluntarily. The activity is having group meetings every week. The researcher divided the participants into two groups. One group would have a meeting on Wednesday, and another would have meeting on Sunday. In the meeting, the participants help each other to design activities and create strategies to take care of stroke survivors to reach the goal of healthy family or "happiness" as the researcher concluded in the first phase of the study. Then, the participants try using the strategies with their families and observe the results. After try using the strategies with their family, there are group conversations for them to discuss the problems that occur while providing care for stroke survivors and adjust the way to provide care suitable for each family. Finally, all participants share the results and the changes in their families in the last week of the program.

#### 4.2.2.1 Cycle 1: Week 1-4

The activity started with introducing themselves and having general talks with other members in the group. As all participants are from the same neighborhoods, some of them have known each other before and it is easier for them to make friends. The activity helps the participants to know each other more. After that, the researcher presented information about the study to the participants and gave them a chance to ask questions. The researcher also presented the data from the first phase of this study and the definition of healthy family in cases of families that have to take care of stroke survivors so that they can set the goal for taking care of stroke sufferers. After the presentation, the participants discussed with each other and finally concluded that the aim of caring is providing care with happiness.

From the group conversation in the first circle, members from the two groups exchanged their experiences and activities that can help them to be happy while taking care of stroke survivors. Also, they got information and guidelines for taking care of stroke survivors from the researcher. Consequently, the activity of the study was successful and reached the goal they set at first. In the first cycle, the researcher concluded and divided the results into three concepts: (1) Setting goals for caring for stroke survivors (2) Barriers and problems in caring for stroke survivors, and (3) Caregivers' adaptation. (1) Setting Goals for Caring Stroke Survivors: The members in each group shared their experiences of taking care of stroke survivors and set the goal of taking care of stroke survivors together which they can adjust to their own families including providing care with happiness, having knowledge, more understanding of patients' symptoms, and patients doing daily routine activities themselves and getting good food, medication, and supplements. Also, patients should get proper rehabilitation.

1) Providing care with happiness: From the group conversations, it was found that the participants would like to provide care for stroke survivors with happiness even though they sometimes face problems while providing care. As well as stroke survivors, they still need happiness from inside their minds. The participants said that if they need a good quality of care, the caregivers need to be happy first. They said:

> "If we were happy, we might be able to do everything better." (G2\_912) "I don't mind working hard as long as I'm happy." (G2\_911)

> "Before making the patient happy, we have to be happy first." (G1\_902)

"The goal of making the patient happy is we have to be happy too."  $(G1_913)$ 

2) More understand about disease and symptoms: The participants would like to get educated from the healthcare providers so that they will better understand about the disease and symptoms of stroke. They think that having proper knowledge will help them to make a good plan for taking care of stroke survivors and improve the quality of care. The participants shared that most problems occurring while taking care of stroke survivors are about symptoms, daily activities, food and supplements, and mental support. Therefore, having nurses or specialists who know how to look after stroke survivors well to provide health education will be very useful as they can use the knowledge from health professionals with the care plan. They explained:

"I don't know how to help him change position, walk, or help him to move from the bed. That's why I have to keep asking." (G2\_912)

"I want doctors to teach us more, I also want them to understand the patient more"  $(G1_901)$ 

"If I have more knowledge, I think I can provide care better. Now, I have a smattering of knowledge. I'm not sure if what I do is right." (G1\_903)

3) Stroke survivors can do daily routine activities themselves: Daily routine activities including eating, moving, elimination, sleeping, and socializing are the most important things in providing care for stroke survivors. Thus, the family would like them to be able to completely do daily routine activities themselves. However, in real life, the caregiver is the one who does that for them because stroke survivors cannot do the activities themselves and they sometimes do not cooperate to do. Some families managed to use equipment such as wheelchairs to help in doing activities while some families assigned responsibilities to each family member and help each other to provide care for stroke sufferers. They stated:

"I would like to get a new wheelchair. The old one is broken. He cannot walk, and always uses the wheelchair. I want only this." (G1\_901)

"I do bed bath, feeding, and changing position but not wound dressing. My sister will do dressings after she gets home in the afternoon" (G2\_910)

"First thing I do when I wake up is making sure that he got fed and his body is clean, then I do other things for myself later" (G1\_901)

"I'm the one who does the bed bath and gets food for him. I do everything to make sure that he gets all he needs."  $(G1_906)$ 

4) Stroke survivors get good food, medication, and supplements: The family members want stroke survivors to get good food with nutrients and get medications and supplements as doctors order. They would like to promote health for stroke survivors so that stroke survivors will be healthier. Besides this, stroke survivors also want to recover from the sickness. As a result, they tried to find the best medications or herbs which they believe will benefit their body and improve their health. However, they sometimes order those medications or herbs from untrustworthy advertisements, or from others telling them their personal beliefs. Some supplements and medicines are not included in doctors' suggestions and might have bad effects on patients' health. The participants explained:

"I will take care of him until the end of his life. I will go travel with him and find good nutrients food for him."  $(G1_906)$ 

"These people would like to fully recover from sickness. Same as my dad? He likes watching TV programs which have people with the same health issue and see what kind of medicine they take then ask people at home to order it for him. However, we don't support this. You know why? Because just only the medicines from the hospital are enough to be toxic to kidneys. I don't think those supplements from the TV ads will be good for health, but rather make health worse." (G2\_912)

"Sometimes the patient listens to others and believes them that it's good. Recently, he's been drinking Java tea. I think it's fine because I know it's herb. But if it's some unknown capsule medicine, I won't support that." (G2\_912)

5) Stroke survivors can live independently: In this case, the caregivers expected the stroke survivors to be able to look after themselves more. The main goal of taking care of stroke survivors is to make them healthier and rely on others less than before. The caregivers would like them to be able to do basic routine activities such as eating, doing indoor activities, standing or walking to toilet, having a shower, and cleaning after elimination. If the stroke survivors could do those activities themselves, it will help the caregivers save time and not be too tried from their caregiving. The caregivers will have more time for themselves, can go to work or even enjoy social activities. They said:

"I want him to be able to look after himself so that I will have time to do other things." (G2\_914)

"I want him to at least have a shower himself/herself so that he/she does not have to call me all the time." (G2\_912)

"I want him to be able to do something himself so that I will have time left for myself." (G1\_906)

6) Stroke survivors continue receiving rehabilitation: Stroke survivors need to do rehabilitation continuously to reduce the chance of permanent disability and complications such as muscle atrophy, weakness, ankylosis, delirium, which can finally lead to being bed ridden. Encouraging patients to do exercise will help them to improve their health. From the group conversations, the family would like the stroke survivors to do more activities and not sleep too much. They stated:

"I want him to do more exercise. I sleep all day and night. Sleep after eating, sleep after going to the toilet, even when watching TV. I don't want him to sleep that much." (G1\_906)

"He's lazy, always sleeps. He said he would like to be able to walk again but is too lazy to move, not even moving his legs and arms." (G2\_914)

## (2) Barriers and Problems in Caring for Stroke Survivors:

After the members shared their needs with the goal of taking care of stroke sufferers, they shared problems they had faced while taking care of stroke survivors as follows: the lack of knowledge about caring and disease, feeling that patients do not do self-care properly, bad relationship within the family, disagreeing between members in the family, not getting any support from family, caregivers' health issue, and socioeconomic problems.

1) Lack of knowledge in caring for stroke sufferers: The participants reflected that the caregiver and family still have a lack of knowledge which led to lots of questions about symptoms and behaviors of stroke survivors which showed that they do not understand the disease properly. For example, speaking or perceptions which do not match reality, patients moving slower than before, patients having behavioral changes and unstable emotions. They said:

"I don't understand why the patient with stroke is always frustrated and aggressive."  $(G1_905)$ 

"He always goes out and get lots of leaves outside to eat, eat lots of things outside. I told him not to, but he never listens to me. So stubborn." (G2\_911)

"I think his brain is worse than his body. He/She can walk and do self-care but seems like he/she doesn't understand anything I say, never listens to me." (G2\_912)

"Last week, he didn't eat anything for a day until I had to ask the doctor what I should do." (G2\_911)

"Why are people with stroke so stubborn and get annoyed easily. I can't say anything because he will get annoyed." (G2\_912)

From symptoms and behaviors of stroke survivors, it causes the caregivers to provide care following what they believe by listening to others. For instance, if the patient has a headache, the caregiver will take them to do acupuncture. In case of elderly patients, the caregivers will not do rehabilitation because they believe that elderly patients are fragile, and rehabilitation might cause bone fracture. The misunderstanding of disease and symptoms will cause the caregivers to become frustrated and tired. This might affect the patient's feelings. The patient sometimes feels guilty and feels like they are the cause of the caregiver's burden, especially in long-term care. The participants mentioned:

"I don't know much about this brain disease stuff. I just do whatever others told me to do."  $(G2_{911})$ 

"Having stroke need to do lots of exercise and rehabilitation but my sister said he's old already. She asked why I have to hurt him, what if his arms or legs were broken."  $(G1_902)$ 

"We did all kinds of treatment including physical therapy and acupuncture, but he still has pain." (G2\_911)

"He still cannot walk properly but he/she has good memory." (G2\_912)

"How long will he be like this? Why do other patients not have symptoms like him?" (G2\_911)

"To be honest, I want him to die now. It's more than 10 years already that I have been taking care of him. I look after him very well. Why is his condition still not better?" (G1\_901)

"I would like to ask him to suicide with me so that it will end now. He/She has been treated for months but his condition is not any better. I don't know what to do now. It's very stressful." (G2\_911)

2) There is no health system for rehabilitation or physical therapy at home: From caregivers' experiences, they feel like the patients do not try to do self-care. The caregivers noticed that they do not try to move their bodies or do activities that they can do themselves. The patients always ask for help such as doing daily routine activities and doing indoor activities as there is no rehabilitation service at home. They explained:

"He can do by himself with some help, but he doesn't want to do. Just keeps calling and waiting for others to help. How can I have time to rest?" ( $G1_905$ )

"He does not really try to walk. He wants me to be with him all the time. He always use the wheelchair rather than try walking himself." (G1\_901)

*"He keeps calling me all night. Whether eating or peeing, he calls for help every time."* (G2\_907)

3) Bad relationship and conflicts within the family: The participants shared experiences about having conflicts between family members. These conflicts cause them to show bad behavior to each other such as speaking impolitely to

each other, not wanting to do activities together, arguing or even ignoring the family member who had stroke. They said:

"As I said, we have tried to make him recover as much as we can, but some people disagree. When someone always tries to stop, I can't do much. Just my best." (G1\_902)

"The patient always watches TV. I don't want him to watch that much, but TVs are everywhere in the house. He/She turns it on all the time until the son-in-law said he will get a new one and put it in the toilet." (G1\_903)

"All my children go to work. They have money but never give it to their parents. On holidays, they always go to travel with their kids, never come to visit dad. I told them once 'Listen to me, when I die you will understand me. Now, you don't have to look after your dad. But when I'm not here anymore you will know it.' I can't say much, or it will hurt their feelings." (G1\_901)

"I just pull his/her body a bit, then he/she said it's too hard. When I speak a bit louder, he thinks I'm yelling at him." (G1\_905)

4) The family does not cooperate or give support: Due to the conflicts within the family, family members do not communicate with each other properly. This causes other family members who have no responsibility in taking care of patients to not understand the pathophysiology of the disease or the situation that the main caregiver has to face. Other family members do not know how difficult it is for the caregiver, who needs to spend much time, energy, and money. All of these can affect the mental and physical health of both caregivers and patients. When the caregiver is stressed, it affects the rehabilitation of the patients, causing the patient to be more dependent. The participants explained:

"I want to provide the best care, but other family members do not cooperate with me. It makes me feel like I'm not myself. When I would like to do something for the patient such as exercise, they always stop me. They said I'm gonna make his bone break. My sister always blames me and doesn't let me do anything. So, my grandpa just lies down on the bed until he cannot even get up now." (G1\_902)

"My sister does not cooperate with me. She does not allow him to do exercise, said he's old. Just let him sit on the wheelchair until he cannot walk now." (G1\_902)

5) Providing care for the stroke patient alone: The data from each family showed that even though there are more than two family members, only one member provides care for the stroke patient. The reason is that other family members do not cooperate when the participants try to use the strategies when caring for patients. Thus, the participants have to provide care alone without any support from the family and this makes them feel very stressed and tired. They mentioned:

"He/She keeps calling me all night, either would like to go to toilet or hungry. Calls me all the time." (G2\_907)

"My sister can help me only on the weekend. Seems like she helps but doesn't. She just plays on her phone and doesn't care about dad. Doesn't even talk with him."  $(G1_913)$ 

6) The caregivers have underlying diseases: The participants' personal data indicated that they have underlying diseases. Most of them are elderly with non-communicable diseases such as diabetes, hypertension, dyslipidemia, asthma, and one of them had a stroke. Taking care of stroke survivors makes them have less time to look after themselves and increases the chance of having complications. Plus, it can affect the quality of care for stroke sufferers. They said:

"I also have underlying diseases, hypertension and dyslipidemia. I cannot do everything quickly. He sometimes complains about this." (G2\_914)

"I can't go out for long. I eat via PEG because my esophagus was cut already. No one knows about this. I sometimes chew the food to taste it before feeding myself via PEG. This is the reason why I cannot do work like others. It's because the way I eat is different." (G2\_911)

"I have asthma. I sometimes have symptoms when I'm tired. Plus, I also have to look after my kid. He keeps calling me all night. I don't have time to sleep at all."  $(G2_907)$ 

7) Families have socioeconomic issues due to the high cost of taking care of stroke survivors: As known that caring for stroke survivors costs much, each family has to spend money on medications and transportation when going to follow-up visits with the doctor and doing the rehabilitation. Moreover, the family gets less income because stroke survivors cannot do work as before and, in some families, the caregivers need to quit their jobs to look after the patient. From the group study, it found that participants' families are living in urban areas where the cost of living is quite high. After the family is responsible for taking care of stroke survivors who can rarely do self-care themselves, the caregiver needs to spend all their time taking care of stroke survivors until they do not have time to go out for work and get paid. This results in socioeconomic problems and causes them to have more debt. Some families have to work harder or get extra jobs and some families need to ask for help from outside sources such as temples or neighbors. Here are some of the words they said:

"I have lots of things to do. Apart from taking care of him, I have to look after my nieces and nephews. I have to prepare food for them, do housework, and others. I'm tired but have no choice. He has been sick for years. He said he wants to get better but doesn't even try to move his body." (G2\_914)

"We need money to live. We need to work. I don't have time to look after him 24/7." (G2\_911)

"Recently, it's very difficult to earn money. There are lots of things we need to spend money on, but I still have a debt to pay. It's very difficult to earn even just 1 Baht." (G2\_911)

"I don't have much money. I am sometimes a temporary employee, but it's still not enough. I usually go to the temple to eat free food or wait for others to give food for me." (G2\_907)

(3) Caregivers' Adaptation: The caregiver and family need to cooperate and discuss the care plan, make good relationships, and provide care with love and understanding. They sometimes use Dharma with care. Furthermore, they have to take care of themselves. All of these will help the caregivers reach the goal of caring for stroke survivors as the following details.

1) Adjusting strategies for taking care of stroke sufferers: The participants help each other to create the plan for caring for stroke survivors which is suitable for individuals. For instance, changing daily activity support equipment to use cane or walker with wheels instead of a wheelchair so that stroke survivors will have more physical activities and strengthen their legs and arms muscles. The participants said that if the family has more chance to talk with each other or get support from others, it will assist them to understand the situation and symptoms of stroke survivors more. The family members who are not responsible for taking care of stroke survivors will have a chance to help and listen to the main caregiver. The caregiver adjusts and accepts some activities that stroke survivors do if there is no bad effect on the patient, as per the following statements.

"If he does not cooperate, I need to change the plan. He wants me to be with him all the time. I have to change from a wheelchair to a walker with wheels. Then I can just support him. It needs to be like this. If he can walk, he should. Don't let him sit on the wheelchair too much." (G1\_901)

"After the group meeting, I told everyone that it's good. I gained lots of knowledge and experience when others shared how to deal with some symptoms. They listened but do not follow what I told them to do. If others go to visit him and help me to talk with them, they might understand me more." ( $G2_912$ )

2) Relationship within the family: Making a good relationship within the family and taking care of each other with love and understanding is the way that the participants shared is the best method to reduce conflicts between family members. The family members need to control their emotions and be reasonable. They have to respect and speak politely with each other. Also, it would be good if they have a chance to do activities together. They said:

"I want my family to be united, with more communication with each other or going to hang out together to make a good relationship between family members." (G1\_913)

"Have you ever had a general talk with her? Maybe you can try talking about general topics with her such as 'you look so fresh this morning' 'you look so good' so that she can feel that you did not ignore her and help her feel better."  $(G2_908)$ 

3) Making merit follows their religious belief: The participants found that their families and themselves believe in Buddhism. So, they use Dharma as a spiritual anchor of their lives. They make merit and go to meditation retreats. They believe that making merit will help to accumulate merit for patients so that they can use those merits in their life after death as believed in Buddhism.

"My dad is 83 years old already. I would like to take him out to make merit with other family members so that he can use those merits in his life after death." (G1\_913) 4) Changing behaviors: Apart from adjusting the way to provide care for stroke sufferers, the caregivers also adjust the way to look after themselves both physically and mentally. For example, they try to control their emotions and be more reasonable. Besides this, they changed their eating behavior by reducing eating sweets. They said:

"I want him to control his emotions." (G1\_905)

"I want her to be more reasonable and be able to control her feelings. I'm a hot-headed person. When she is frustrated, I'm frustrated too." (G2\_909)

"I have tried to adapt myself. Try not to argue. But sometimes it's really hard." (G2\_909)

They further stated about their eating behavior:

"I can reduce eating fatty food, but sweets... I like eating sweets, especially before going to bed." (G2\_909)

From observations and participating in group activities in the first cycle, all participants can make the goal and plan for caring for stroke survivors. They had planned physical care for stroke survivors, specifically for each family. The significance of this cycle is participants in each group had a chance to discuss and set the goal of the activity. Plus, they also had a chance to share their opinions and create strategies for taking care of stroke survivors, encouraging them to do daily activities and rehabilitation to make them healthier. The caregivers can use the knowledge and strategies from group activities with their own family, and make the collaboration between family members to take care of stroke survivors at home. They helped each other to solve the problems such as doing physical therapy, socioeconomic issues, exercising, eating behavior, and avoiding conflicts in the family. Furthermore, from the activities in each week, it showed that the participants had adjusted the way they look after stroke survivors at home including adjusting care plans, building good relationships in the family, using Dharma in caring, and changing self-care behavior. This cycle is called **Strategic design and collaborating**.

In the next cycle, the researcher and team plan to encourage the participants to participate in the activities more, and follow-up and adjust the care plan so that the family will have more role in taking care of patient, both mentally and physically.

#### 4.2.2.2 Cycle 2: Week 5-8

In cycle 2, the participants better understand the process of planning and creating strategies. They can share their opinions and comments other members' plans for caring for stroke survivors. The researcher observed and felt that the participants got used to each other and became closer after doing group activities. In the first week of cycle 2, the participants started to have more talk with each other. They brought food and shared it with members of the group. While having meals, the participants also had general talks and shared their experiences and problems that they had faced in the past week. They invited other members to visit their house. The researcher found that they were concerned about others. They gave advice and suggested the activities they thought might benefit other members in the group. In this cycle, the participants helped other members in the group to adjust the strategies and practice for taking care of stroke survivors, which leads to good rehabilitation and good health of stroke survivors and making the family happy with the care, which is the aim. The researcher concluded the results from this cycle into three concepts as follows: (1) Sharing experiences in caring, (2) Cooperate in caring, and (3) Mental health support.

The participants shared their experiences in providing care for stroke survivors with other members in the group. These experiences come from problems that occurred within the family while taking care of stroke survivors. They dealt with the problems using strategies which were suitable for their own families. The experiences which the participants shared in the group are constipation problems, encouraging patients to do activities, muscle pain relief, finding benefit resources, adaptation, and successful outcome from the practice, as per the following details:

1) Constipation problems: The caregivers found that stroke survivors usually have constipation. One participant shared in the group that the doctor suggested drinking Castor oil. After the participant gave Castor oil to the patient to drink, the constipation problem was better. Apart from drinking Castor oil, another participant shared about using ivy gourd leaves to help with constipation problems. The participants used ivy gourd leave as the main ingredient for cooking food. As the participants said: "He also has constipation. So, the doctor suggested drinking Castor oil. Would you like to try with him maybe it will help him feel better? Next time we have a group activity, I'll bring it for you. The doctor gave me lots." (G1\_902)

"The patient at home needs to eat ivy gourd leaves. I sometimes make it as soup or stir-fried with eggs for him. He doesn't like eating other veggies. Now, his constipation problem is much better."  $(G1_905)$ 

2) Encouraging patients to do activities: Stroke survivors often do not do activities themselves. They prefer to rely on caregivers and family members. This results in the delay in physical rehabilitation and might cause permanent disability and being more dependent later. Therefore, the caregivers have to create strategies to help stroke survivors do more activities themselves. In case of patients who can move their hands, the caregivers might encourage them to do activities themselves with some help from the caregivers such as encouraging patients to do sponge bath themselves and the caregivers are just there to assist, letting the patients eat by themselves instead of feeding them, encouraging the patients to change position themselves without any support from the caregivers, extending the activity time period during day time and forcing them to walk or do more exercise so that they will not sleep during day time. All these activities will help to improve patients' condition and health. Further than that, it might help patients to be able to look after themselves again. Consequently, the caregiver will have more time for themselves to rest and relax as the patient can look after themselves, and help in reducing responsibilities in providing care, as the participants stated:

"The patient at home was forced to do exercise. I'm a strict person. He's afraid of me because I'm very strict with him. I told him if he couldn't walk just go to live other places. I have to force him to walk. Now, he can even run. He goes running 2 km a day." (G1\_903)

"We need to let the patient take care of themselves. Are their hands good? If yes, then let them do sponge bath themselves. We just help to prepare things for them. We have to practice or their hands will have stiff joints. Like my mom, I forced her to do sponge bath herself and she can do it. You should practice him as well so that he can do himself and reduce your work overload." (G2\_908) "Can he sit? Can we adjust the bed for him so that he can sit and eat himself? My aunt said he can't sit but I saw he's able to sit on the wheelchair so I think he can. So, I told my aunt to change his position to sit." (G2\_912)

3) Muscle pain relief: The participants talked about how they managed with patients' muscle pain on both weakened and non-weakened sides. The pain causes the patient to stay still and not move, resulting in joint adhesion and permanent disability. Thus, the caregivers use traditional medicine knowledge they know about taking care of stroke survivors. For example, putting the pain area in water from washing rice, doing massage, pulling fingers to make muscle and joints at fingers relax, putting burned-cape lily leaves on the pain area as they believe that it is a traditional herb helping in relieving pain. They stated:

"I use water from washing rice and do massage at his fingers. It helps to prevent joint adhesion. I do this for him every day. We also can do with his feet." (G1\_902)

"When he first has a symptom, I put cape lily leaves on bricks then burn it and put on the pain area. I sometimes told him to step on it. Do like this twice a day. It really helps to relax muscles." (G1\_903)

4) Finding benefit resources: The participants shared their benefit resources, which can help support them while providing care for stroke survivors, with others in the group. If they would like to get a hospital bed or assistive devices, they can contact the health promoting hospital so that they do not need to buy a new one. When they do not use that medical equipment anymore, they can give it back to the hospital to give to others who need it. In addition, the participants also stated about how to do rehabilitation for stroke survivors and help the patient continue doing rehabilitation until they can look after themselves again. Mostly, stroke patients in the first stage will receive rehabilitation at Sirindhorn center and then continue rehabilitation at home. The participants supported others' statements and shared their own experiences in rehabilitation for stroke survivors to strengthen leg muscles until they can walk by themselves, which is the same method with members in the group. For instance, help the patients to stand up and raise their legs up and down. As the example from the participants: "We're lucky we got donated a hospital bed when he's sick. You can try asking the health promoting hospital. You can borrow the hospital bed. Maybe it will help him to be more comfortable. If your sister complains, you just tell her that every single bed at the hospital has someone died on the bed before." (G1\_913)

"Sirindhorn center taught me how to do rehabilitation as auntie Pha said. First, help the patient to stand up, then tell the patient to raise the leg up and down to strengthen leg muscles. I added weight to counterbalance as well. I told him to do like this every day. I think it's better than taking medicine from nowhere. Now, he doesn't have to void on the bed. He can go to the toilet himself." (G2\_912)

5) Adaptation: The participants shared in the group conversation that they have to deal with many problems while providing care for stroke survivors. Most of the problems are about emotions of both caregivers and patients, which result in conflicts and arguments with family later. After doing the activity in cycle 2, the participants used experiences from other members in the group with their own family. One participant shared how to manage with conflicts within family. This participant tried to ignore some small issues and not argue with others in family. This strategy helps to make a better relationship within the family, as the participant stated:

"The patient used to be very self-centered. When a sick person gets angry, a healthy person like me gets angry too. After listening to others when we had meeting, I told my mom that if dad would like to say something, just let him. Do not argue. He also adapted himself. Now, they do not argue anymore. They speak politely to each other." (G2\_912)

6) Successful outcome from the practice: The success of the second cycle is that each family was provided a home-visit from other members and the researcher who is in the role of a health professional. The activities done while home visiting were observing the environment that might affect patient's health and care plan, providing care for stroke survivors, and building a good relationship within family. The observation had been done at the same time with counselling and health promotion, specifically for the environment in each family. Besides this, building a good relationship had been done by providing knowledge about how to take care of stroke survivors to other family members to make them more understand patient and be more participated in caring. The participants also used knowledge from the group activity in

caring for stroke survivors. They shared successful results from using the caring strategies. This successful result can be seen from stroke survivors as they started to do exercise and activities themselves and be more independent. These also can be seen from the family members as they participate more in caring, making a safe environment to support caring by adding handrails in the house. As the participants mentioned:

"After that day, he does exercise lots. Lifts his arms, walking, he said he likes it. We gave him good advice." (G1\_901)

"My sister listens to me. After going to visit that day, she often comes to visit dad and help me look after him and talk to him more."  $(G1_902)$ 

"She gives me freedom and does not interrupt my care plan. I think it's because others came to visit that day."  $(G1_902)$ 

"He started doing exercise himself since the day the doctor came to visit at home. Now, he can get up and sit. He has a strong motivation and would like to be able to walk again." ( $G2_{914}$ )

"Since that day we went to visit, I told my child. Now my child will make a handrail in the house so that it will help him to walk easier. My child will renovate the house and build a new room for him." (G1\_901)

"Since the doctor came to visit on that day, he walks very often. Walks all day. He sometimes feels pain and not better after taking medicine but he still tolerates the pain." (G2\_911)

"Uncle Wichian is better. He can move his butt now. My sister let me help him to strengthen his muscle. She's sometimes worried but doesn't complain as before." (G1\_902)

"He said 'I will be able to walk within the next few months.' He tries to get up himself many times a day. Sit and eat by himself." (G2\_914)

(2) Cooperate in Caring: Group conversation helps the participants to improve their knowledge and experiences as well as make them have confidence to provide care for stroke survivors. In addition, the activity helps them to be more assertive as they become closer and help each other to create strategies for caring for stroke survivors. For instance, caring assessment, adjusting the environment, rehabilitation technique, stress management, and building the relationship within family, as per the following details:

1) Assess the factors which might affect both stroke patients and caregivers: After the participants joined the health education program provided by the researcher and participated in the group activity every week, the participants can assess their own care plan and think about factors which might affect the caring and quality of life such as complexity that might have because of the sickness and improper care which might affect patients' and caregivers' health. Plus, the participants can give advice to others. One participant suggested another participant in the group use the bed which is still in good condition, as the one with dents has a chance for water to get stuck in it and can cause bedsores later. Moreover, the participant can assess a risk to have pneumonia in patient who does not wear shirt properly as well as assess and adjust the environment to support and improve caregivers' quality of life. They said:

*"This bed has dents. The urine can get stuck in those dents when he urinate. It might cause pressure sores later." (G1\_913)* 

"Is the bed height too low? If you made it higher, it would help with your back pain. Now, you have to bend your back forward to pull him up." (G1\_902)

"Is he cold? I see him take off his shirt all the time. Be careful. He could get pneumonia easily because of the cold weather." (G2\_912)

2) Adjusting environment to support and improve patients' and caregivers' health: The members in the group activity can suggest others to adjust the environment at home to support the care and improve family members' health. There is one participant who mentioned about increasing airflow in the house to reduce the musty smell and humidity in the bedroom by opening windows, tidying up, and removing unneeded stuff from the room. Another two participants suggested the members who have to look after dependent patients install the supportive equipment in the house such as handrail or pulley to help with the rehabilitation. Moreover, adjusting the environment can help with reducing the risk of accident and physical burden of the caregivers. They said:

"The airflow in his room is not good. You can open the windows during the day time so that it will help him to feel better. This room has a musty smell. Maybe you can move some stuff out."  $(G1_904)$ 

"I think the bathroom is fitted with the body. If you add the handrail on both sides, it would help to support him to walk himself so that you won't have to carry him to the bathroom and don't have to be worried that he will fall down as well. Also, what if both of you fall down? Having handrails would be very useful for both of you."  $(G1_902)$ 

"He can raise arms and legs himself. If you installed the pulley up there, maybe he could do exercise himself too, which will help to strengthen his muscles." (G2\_908)

3) Rehabilitation technique for stroke survivors: The participants suggested strategies for rehabilitation they used with stroke survivors to other members and these strategies help with strengthening leg muscles. The technique which the caregivers used is letting the patients try standing bedside and start walking back and forth when they feel confident until the muscles are strong. Another participant also shared an easy activity that the patients can do themselves with the members in the group so that the caregivers will have more personal time. They stated:

"Auntie Lee, you can try letting him stand bedside. Just stand, not walk. Then give him a walker to support him. If he feels confident to walk, you can let him try walking forward and backward first. Make sure he feels confident before start walking. I did like that with my dad too." (G2\_912)

"He still does not have dementia. I think he can do something himself. We need to practice him to do activity himself. If we do everything for him, he will get used to it. And if we do like this, we won't have any time to do other things." (G2\_908)

4) Stress management: The caregivers often have to face lots of problems which cause them to be tired and worried, also have stress from other factors. In the group activity, the participants can feel others' feelings, especially the one who has to look after a person living with stroke alone. So, they suggested to ask for help from other family members so that the main caregivers will have time for themselves to rest and deal with the stress such as having relatives come to visit on holidays. The participant mentioned:

"If it is like this, you need to let others to help so you can rest and not be so stressful. For example, having children or grandchildren come to visit. He would be very happy seeing lots of people come to visit him." (G1\_904)

5) Building relationship within family: If the relationship between family members is good, they will love and support each other including help

in providing care for stroke person and other issues in family. From the group activity in this cycle, it found that the problem in providing care for stroke survivors that participants mentioned the most is the conflicts between family members. This problem is the barrier to achieve the goal of caring. As a result, the participants suggested each other the way to solve this problem such as adaptation, as one participant stated:

"My uncle and I have to talk and meet in the middle and adjust if something is too much or too less. If we can make balance and meet each other in the middle, it would be great. Try it." ( $G2_912$ )

(3) Mental health support: While doing the group activity, the participants showed empathy to each other. They gave others positive energy, encouraged and supported other members with good speech, especially mental health support, to make them relaxed and less worried. Moreover, they adjust the ideas for taking care of stroke survivors from members in the group with their own families including providing help and support, showing empathy, and building self-confidence for the patient, as per the following details:

1) Resourcefulness: The participants gave heed to each other. While having group conversation, the participants observed other members' gestures and words they said which made them notice which participants were having problems or were worried. They gave others a chance to talk about the problems and encouraged those who were facing difficulties to accept the problems, move on and continue providing care to the patients.

"That day he still looks good. He's friendly and very lovely. Don't be hopeless, Auntie Yai. Let us visit him at home first." (G1\_902)

"How about you, Noi? I deeply understand you. I'm here to support you. Keep going." (G1\_913)

2) Empathetic responding: While doing group activity, the researcher saw that some participants have empathy to other members in the group. They can feel others' feelings and understand the situation that others have to deal with. They supported each other and gave each other positive energy. For instance, giving comfort to make others calm down, being optimistic, being more reasonable, having the presence of mind, living in the present, not blaming others, and not caring about

others too much. The participants shared and discussed the strategies to help the caregiver in providing effective care. They said:

"Ja, you have to be calm. Just do your best. I'm sure others will finally understand you why you have to do like that with your grandpa." (G1\_903)

"I understand how you feel but you have to let it go. Don't care about others' issue and what they said. Like my family. Don't care other people's business. It's their business, not ours. Also do not blame others, just be us." (G2\_908)

"Your dad looks so much better, especially when he has friends to talk to. He seems happy and very friendly. I think it's normal he sometimes gets annoyed with people in family." (G1\_906)

3) Encouraging: This is the way the participants use to strengthen patients' willpower, hope, and energy to do activity themselves, as well as being more independent. After visiting a member's house, other members in the group praise and encourage the stroke person who gained muscle strength from fixing shoes, which was his job before he had stroke. They also made the patient be more confident and able to get back to work again. This helped the patient to be less dependent as well. The participant stated:

"He did well. He recovered very fast. I asked if he would like to do a parttime job as he used to be a cobbler. I will find the shoes for him to fix so that he will earn money and do hand exercise. Kill two birds with one stone." (G1\_913)

From group activity in the second cycle, the distinctive point of this cycle is that the participants set a goal for providing care for stroke survivors. The activity helped to promote good health to the caregivers and adjust the environment to support caring and lead to effective rehabilitation. Plus, the strategies helped the family to provide care with happiness. The participants can adapt using experiences and ideas from the group activity including the way to solve the problems occurred while providing care for stroke survivors, giving support and promoting self-confidence to the patient to reduce the burden from caring stroke survivors. This cycle is called **Supporting and fulfilling care potential.** 

Next cycle, the researcher and the participants will promote cooperation within the family and follow up the care after they adjust the strategies for providing care for stroke survivors. Also, the researcher will strengthen mental health for the participants and give the family and patient a chance to participate in the activity to achieve the goal they set.

# 4.2.2.3 Cycle 3: Week 9-12

In this cycle, the participants can share their opinions towards others' care plans more. The activity in each week made them become closer until they were not afraid to share their feelings and brave enough to tell personal problems to other members in the group. They also help each other to solve problems. The researcher observed while the participants were having a conversation and found that they started talking about a general topic, which shows how they worried about others' issues. They shared how the situation at home changed after the healthcare provider visited them. They suggested enhancing mental health by doing meditation retreats to manage with problems that might affect both their mental and physical health, be able to control their emotions, and be ready to deal with any situation. From the activity in the third cycle, the participants from both groups adjust the care strategies and practice the Dharma, which leads to caring with happiness. The activity gave stroke survivors and families a chance to cooperate in the caring process to achieve this cycle's goal that the participants set. The researcher concluded the results of this cycle into three concepts: (1) Thinking of good things and providing care with love, (2) Improving mental health, and (3) Promoting physical health, as per the following details:

(1) Thinking of Good Things and Providing Care with Love: After reviewing all activities the participants have done in the previous weeks, they agreed that their thoughts and feelings are the barriers in providing care for stroke survivors. It can be said that tiredness from caring, high expectation, and disappointments cause frustrated feelings and lead to expressing bad behavior to other people. Thus, the participants suggested changing thinking concepts by practicing emotional control and having a presence of mind. These will help them to provide care with happiness. Therefore, they changed the care plan from the first two cycles. The new plans resulted in better physical and mental health. They became more optimistic, reflected on themselves while providing care, and were kind to others, as per the following details:

1) Contemplation: The participants shared their experiences which different from what happened in other family. Most of them thought it is difficult

to make life happier as they have burden and have many responsibilities being caregivers. Moreover, stroke survivors have behavioral and emotional change. The caregiver needs to accept and carry those feelings with them. At the beginning, the participants tried to change their behavior to avoid arguing with stroke survivors and family members. They thought about the previous situation such as actions or bad speech they did in the past, problems resulting from negative thoughts and mind including greed, anger, and fascination or actions in the past which affect the present life. They tried to find the problems and the way to solve those problems. Here are the examples of statements of two participants reflecting about buying lottery tickets because of greed.

"I tried to control myself. I tried to break up with them (greed, anger, fascination). I would like to know what I should do?" (G2\_909)

"I can't stop buying lottery, but I try to buy less than before." (G2\_908)

"I'm good at being greedy. I also know fascination. It means being credulous."  $(G2_909)$ 

2) Being grateful: The caregivers have to face lots of struggles while providing care for stroke survivors. They also have burdens, feel tired and bored. At the same time, they thought that taking care of stroke survivor is the way to show how grateful they are. When they think about being grateful to their parents, they changed their minds and continued taking care of stroke survivors. They think about the responsibilities and how valuable to take care of parents with a pure mind instead. After the group activity, the participants suggested to change opinions to think about being grateful, even though there are some difficulties that cause them to have burdens. Everything that happened while providing care will be a good chance for them to learn from experience and achieve the goal later. A participant stated that although the stroke survivor was stubborn and did not cooperate with caring, the stroke survivor would be healthier as long as they can eat food. Therefore, being stubborn does not matter.

"He's getting better. Still being stubborn when it's time for him to eat. But it's ok as long as he can eat because his condition worsens if he can't eat."  $(G1_913)$ 

Moreover, the participants believed that being grateful to parents will cause the caregivers to be happier. The participants said:

"I will continue doing good thing unconditionally." (G1\_903)

"I don't care whether my siblings would like to help or not. I don't want anything from them. I can look after my parents. I'm happy to." (G1\_913)

3) Being kind: The participants mentioned about the way to practice themselves to be a kind person. Being king is one of the things which is important in the participants' perspective. This started from love and desire to make stroke survivors be happy physically and mentally. This means proving care with a pure heart and doing their best. The methods the participants talked about are taking stroke survivors out with family, taking care of them when they are sick, and not ignoreing the stroke survivors.

"We have been through many things together. We have to look after each other. It's not like because he's being like this, then I'll leave him. I'll take care of him." (G1\_903)

"These past three weeks, I took him outside and met his friends and relatives. He was very talkative. He even walked himself and did lots of exercises." (G1\_913)

"He has been kind to me. He supported tuition fees for my children and has been looking after me for ten years. I can do nothing but being grateful for him." (G1\_902)

(2) Improving Mental Health: In this cycle, the researcher invited an outsource person, a specialist in psychology, to be a moderator. The moderator gave advice to the participants about mental health, said that mental health is the most important thing the caregivers need to be concerned about. Having strong mental health will make the caregiver to be happy and provide care effectively. The moderator taught the participants how to understand their own minds and how to make themselves happy. The moderator created activities including meditation retreats to strengthen mental health, be able to control feelings, and know how to let something go.

1) Having mindfulness and controlling negative feelings: The participants talked about stress, worries, and their unstable feelings, which are the main factors in providing care for stroke survivors. After the participants joined the meditation retreats activity, the participants can use mindfulness to control their feelings and change their behavior to make it suitable for taking care of stroke survivors. They tried to understand the stroke survivors' symptoms and negative feelings which might be because of the stroke. Thus, when the stroke survivors were frustrated, the caregivers will not bother them at the time. They said:

"I try to control my feelings and reflect myself. I'll try to care about others. I pray every morning to make me have a presence of mind." (G2\_909)

"I don't blame him. If he doesn't have good mood, I'll let him stay alone. Give him some time and he will feel better himself." (G2\_911)

2) Understand the real situation: The result of continue doing meditation retreats is that the participants can control their emotions better and have a presence of mind. Furthermore, the participants used the present reality technique or removing negative thoughts and feelings away. It made them to be more relaxed and happier.

"I think I'm a better person now. I know how to let something go. Do not keep things in my mind. I feel much better." (G2\_909)

3) Praying: All participants believe in Buddhism and use Dharma as the spiritual anchor. They believe that meditation retreats such as praying and making merit will help them to have a better life both physically and mentally. Especially for practicing Dharma, the participants pray every morning to make them have a presence of mind and be more concentrated. The participants pray in the morning or before going to bed everyday depending on the time they are available. From the exchanging experiences, the participants who pray regularly said that praying helps them to be more concentrated, have a presence of mind, and they can sleep better.

"It's good. Praying makes me be more concentrated and not overthink." (G2\_912)

"I have to concentrate on praying, or I will forget the mantra" (G2\_908)

"I cannot pray when I am distracted. I can pray in the morning. I can pray only when I feel comfortable."  $(G2_909)$ 

"I pray every morning to make me have the presence of mind." (G2\_909) "Whenever I feel frustrated, worried, or confused, I'll pull myself back to Dharma. When I started praying, I suddenly feel happy and comfortable." (G1\_913) "It makes me sleep better. I have never prayed before until I joined this group activity. I usually have difficulty in sleeping, not sure if it's because I'm getting older."  $(G1_902)$ 

4) Encouraging: In the activity each week, the participants supported each other's feelings by asking questions and showing how they were concerned about other members in the group. Also, they encouraged other members in the group to make them be more confident. For example, giving compliments about the gesture of the members which is looking fresher and happier.

"Noi, you look much better. Since you joined the group, your face looks so much happier." (G1\_906)

"This week grandma came to sit outside. Does it mean she is not angry at you anymore?" ( $G2_{912}$ )

"You used to have a worried face. Now you look happy. Have a smiley face. The situation at home is going well, right?" (G2\_908)

"You're so great. You are the first one who got here today. Also, participate more in the group activity."  $(G2_910)$ 

"Did you sleep well last night? He didn't call you at night, right? You look so fresh today." (G2\_912)

(3) **Promoting Physical Health** by doing exercise at least 30 minutes a day for at least 3 days a week during free time each day. Each family has a different style of doing exercise depending on their family context. For example, the limitation is that the stroke survivor gets tired easily. So, they chose to do an arm swing for 20 minutes instead of walking. Another participant shared the experience of doing exercise with the stroke survivors to improve their own health at the same time.

"I do arm swing for 20 minutes every morning. I cannot walk for long. I get tired easily." (G2\_914)

"There is a playground in front of our house. When I take him out for exercise, I'll do it too. So that we will be healthy together. He's sick and I'm not that healthy. So, I have to take care of myself as well." (G2\_911)

The significance of this cycle is that the participants helped each other to make the goal of care and create activities that assist in promoting mental and physical health. They created positive energy, changed their perspectives, and thought about the kindness that stroke survivors had for them in the past. They did meditation retreats to help them to be more reasonable, be able to control feelings, and use wisdom to solve problems. Having good mental and physical health cause the caregiver to have the energy to take care of stroke survivors effectively and continuously, and also achieve the goal of caring. The researcher named this cycle **"Balancing the body and mind for creating positive energy"** 

The next cycle is the last cycle of the study. The next cycle will be the cycle for summarizing the strategies participants have been using to provide care for stroke survivors. The activity will promote cooperation within the family and adjust the care depending on each family context. The activity will still focus on enhancing both physical and mental health to eliminate negative obstacles and build positive factors under the atmosphere of caring for each other, being realistic, optimistic, kind, and grateful, leading to well-being.

#### 4.2.2.4 Cycle 4: Week 13-16

The fourth cycle is the last cycle for this study. The participants shared their experience by presenting the situation and the results. After the participants joined the first three cycles, of which the first cycle is strategic design and collaborating, the second cycle is supporting and fulfilling care potential, and the third one is balancing the body and mind for creating positive energy, the participants had been using the strategies with their families to provide care for stroke survivors, promoting their own health, and changing the environment inside the house to support stroke survivors' rehabilitation. Moreover, the activity helps with mental health enhancement and adaptation which assist in self-control and preparing for the problems that might occur in the future. Besides this, group activity also gave the participants positive energy as the members in the group supported each other. They made other members face reality and be optimistic. Talking with other members helped them to reflex on themselves and be more kind with their own family members and community. From the group conversations in the fourth cycle, the members from two groups adjusted the strategies and provided the care with happiness, which is the aim of caring. To fulfill the perfection of the care, the participants added more strategies which are (1) Facing reality and (2) Life balancing, as per the following details.

(1) Facing Reality: From the previous group activities, the participants shared their experiences in providing care for stroke survivors in the group activities. It found that the problems were different due to each family context. However, the problems and barriers were quite similar at the same. The most similar problems found while providing care were about mental health such as stress, anxiety, and expectation. So, the participants need to adapt themselves to the situations and face the reality that they cannot avoid. From the group activity, the participants have learned and exchanged experiences together. They did meditation retreats to make their minds stronger and deal with the problems until they can provide care for stroke survivors with happiness. Facing reality helped in resolving problems and improving themselves to achieve the goal they set. To face reality, two factors are needed.

1) Understanding the situation and problems: This means the participants know the situation within the family and understand the symptoms and disease effects on stroke survivors mentally and physically. For instance, the sickness causes the stroke survivors to be more dependent and have difficulties in doing activities including speaking, communication, thinking process, and making decisions. All of these cause the caregivers and family to have a burden from stress and responsibilities, and also have conflicts within the family. The group activity helped the participants to understand the disease and symptoms, understand stroke survivors, and tiredness of the caregiver. In addition, the positive atmosphere in the group helped the participants to support each other, be kind, be optimistic, and be able to adapt themselves to the hard situations they have to face. They helped each other to find the way to solve problems, as per the following statements:

"The patient at home has changed a lot. I understand him more as well. I'm not sure if he understands me but I don't care. (laugh)" (G2\_912)

"It's much better. I'm happy and got lots of knowledge. I forgive him as I understand that it's because of the sickness." (G2\_911)

"We need to understand that he's like this. He gets annoyed easily. The best thing we can do is stay quiet."  $(G1_913)$ 

"I tried to make my sister understand grandpa's condition that he needs rehabilitation. If we do not do anything, he will get worst and has ankylosis." (G1\_902)

"After I got home, I told my son what we need to do with dad. My son told me straight away that he's gonna make the handrail so that he can do exercise and support him to stand up himself."  $(G1_901)$ 

"I understand that my daughter needs to work hard. She has to take care of me and my wife. So, I try to help her by not being a burden to her." (G2\_909)

2) Reality acceptance: This means accepting and facing the facts in life, including suffering, sadness, disappointment, tiredness, and difficulties in providing care. Besides this, accepting the reality assists the caregiver and stroke survivors to understand the disease which affects effective rehabilitation. The stroke survivors will cooperate with the caregivers to do the rehabilitation if they understand what they need to do. If they get along together, they both will be happy living their lives. After the conversation group and previous activities, the participants can perceive and understand situations and problems more. They adjusted themselves and had a presence of mind. They learned how to deal with the pressure by using strategies, consulting others. They asked the stroke survivors about symptoms and desires, promoted health, and built good relationships within the family. Everything they did resulted in happiness in the family. They became happier and be more relaxed, and also achieved the goal they set before starting the activity.

"The world has changed. Really. We have to accept it so that we will feel better." (G2\_908)

"The best way is to let it go. The more we speak, the worse situation is. We have to let it go and do not argue with him."  $(G1_913)$ 

"What goes around comes around. I can just walk away. If I stay there, something bad will happen." (G1\_903)

"We think in the opposite way. What should we do? Of course, we need to accept it, so we won't be stressed."  $(G1_905)$ 

"I'm so happy that my family is being like this. Do not have any arguments. At first, we couldn't accept this. But now, we have talked and that made us feel better. If we couldn't accept the fact, we won't be happy like this." (G2\_909)

"When he feels pain, he won't say anything. I told him that it's because of his sickness that he needs to accept. The pain won't be gone. If you feel pain, then take medicine or I can do massage for you. Now, he can help me lots. Get this and that for me even if he is sometimes confused and gives wrong change (laughs)" (G2\_911)

(2) Life Balancing in physical, mental, social, and environment to help caregiver and family in providing effective care for stroke survivors: After doing group activities, the participants tried to change their thoughts, actions, environment in the house, and actions they show to each other. They would like to make the stroke survivors feel comfortable mentally and physically. Although many things have changed, the stroke survivors were still provided effective care. These changes can be called life balancing. There are two factors for making life balanced, making balance within the family and adjusting the care plan to make the stroke survivor happy, as per the following details:

1) Making balance within the family physically, mentally socially, and environmentally: After the group activity, the participants can provide better care for the stroke survivors with happiness. They shared the strategies to make life balance with others in the group. One of the strategies is talking to family members about their needs, suggestions, and help in providing care for stroke survivors. Also, talking about the situation and problems so that they can find a way to solve problems together. Talking to each other will help the family in getting ready to provide care as well as supporting the main caregiver not to have burdens from providing care.

"I tried to open my mind and meet them in the middle to see how much I can accept and how much my children can accept. We have to be open-minded." (G2\_908)

"My dad can look after himself well. It helps my mum lots. It's not much different for me as I haven't helped lots since at first. But for my mom, it does. She's less tired and less grumpy than before." (G2\_912)

"I told him 'You cannot do nothing. I'm old already and if you do nothing for yourselves, who will? If you would like to recover you have to do exercise and try walking.' After that, he did as I said until he could almost walk like normal. I'll get angry if he does not do exercise." (G1\_903)

2) Adjusting the care plan by providing beloved stuff for stroke survivors to make them happy: As the example of one participant, the participant said that the stroke survivor's hobby is collecting Buddha amulets. So, the participant moved the amulets to the stroke survivor's room so that the stroke survivor can see them and be happy. Another participant invited relatives to the house to visit the stroke survivor which made the stroke survivor to talk more and do more activities. This helped the stroke survivor to recover mentally and physically. Plus, another participant encouraged the stroke survivor to do work the stroke survivor did before to enhance the stroke survivor's self-esteem and confidence. They stated:

"I moved all his Buddha amulet to his room so that when he see his collection, he will be happy. He was so happy when he saw them yesterday. Ha had a very big smile. I asked if he likes it and he said 'Yes yes yes of course! I have been collecting them for all my life.' I'm happy if he's happy." (G1\_913)

"Grandpa is very happy when he sees his children's and grandchildren's faces. He smiles and laughs a lot. I walk past his house every day. I can see that he's happy." (G1\_902)

"He used to be a cobbler. I tried to make him do hand exercise, so I brought old shoes for him to fix. Now, he does it as his job and earn money from fixing shoes. I'm so proud of him." (G1\_903)

In cycle 4, the participants joined the group meeting once a week and did as same as in the cycle 1, 2 and 3. Stroke survivors and families still cooperate with the activity and the stroke survivors still need to do practice and exercise continuously to promote their health. The activities in this cycle continued follow-up, observation, adjusting the plan, cooperation of the family members in providing care, promoting both physical and mental health, facing reality and life balancing. In the last week of the activity, the participants discussed and summarized the results of all previous weeks. The results showed that they can manage all problems by adjusting care plans and environments in the house, and using supportive equipment, depending on each family context. The researcher named this cycle **Self-improvement for happiness**, following the aim of this cycle.

After the participants did all activities in each cycle, they can adapt using strategies getting from the activities with stroke survivors to help in rehabilitation and improving the environment. They had changed their behavior to enhance their physical and mental health. They did meditation retreats to make them a kind person, grateful, have a presence of mind, and solve problems reasonably. Plus, they changed the environment inside the house to make it support both the caregiver and the patient's rehabilitation.

Participatory action research (PAR) was used for doing group activity in cycles 1, 2, 3, and 4 by starting with planning, doing and observation, and reflection. The researcher analyzed the process of group activity, exchanging ideas, sharing problems and barriers, and sharing the successful outcomes, following group and individual goals. Furthermore, the interaction between participants in the group resulted in changes in each cycle: **cycle 1** Strategic Design and collaborating, **cycle 2** Supporting and fulfilling care competency, **cycle 3** Balancing the body and mind for creating positive energy, and **cycle 4** Self-improvement for happiness. These cycles can be analyzed as a strategy to enhance healthy families for the families of stroke survivors to develop care strategies for them in the future.

#### 4.2.3 Family-Based Caring Model: FBCM

There are many factors related to enhancing a healthy family for the family of stroke survivors. Those factors directly affect achieving the goal of care. The caregivers need to choose the right strategies which support both physical and mental health. The researcher has analyzed a family-based caring model for stroke survivors to enhance healthy families as shown in figure 4.2.



Figure 4.2 FBCM for Stroke Survivors to Enhance Healthy Family

The development of caring for stroke survivors concluded that there are three main factors that affect caring, which are caregiver characteristics, family function, and assisting support. Caregiver characteristics is the special characteristics of a caregiver which help in responding to the patient's needs as the patient has limitation in thinking and doing activities themselves. Therefore, the caregiver needs to be kind, provide care with love, have proper knowledge and experience in caring, have good stress management and freedom to manage problems occurring while providing care.

Next is the family function that the family has to face while providing care for stroke survivors. Taking care of stroke survivors makes the role and responsibility of the family members change. Other family members need to help and support the main caregiver, and help them to be able to do daily activities themselves as well as rehabilitation. Therefore, a good relationship among family members is needed to motivate and support the stroke survivor and caregiver, resulting in a better quality of care.

The last one is assisting support from both family and outsourced supporters. This includes financial support such as medical expenses and living expenses, and health support such as health insurance and healthcare services. The support will help the family of stroke survivors to access the basic medical insurance system. In addition, it will be easier for the family to get health promotion, disease prevention, treatment and rehabilitation, resulting in better quality of life. The assisting support will help the caregiver to have time for themselves to relax as well.

After analyzing these three factors with the practice, the caregiver and the community care commander have a role in developing proper strategies for taking care of stroke survivors. The community care commander in this context means the researcher who is a community nurse. The community care commander has an essential role in supporting caring achievement by providing health education about stroke symptoms, treatment, rehabilitation, exercise, medication, proper eating behavior, and giving guideline to every participant in the group. The community care commander will cooperate in assessing the situation or problems, then encourage family members and stroke survivors to use their potential to look after themselves. Also, the nurse will be a health counselor and give a chance to both family members and stroke survivors to share their experiences and opinions, give compliments and support others, as well as show their capability to take care of stroke survivors depending on each family context. The community care commander has to cooperate in doing activities to improve the quality of care and make convenient for stroke survivors and families so that they can achieve the goal of care.

Furthermore, community resourcefulness will help to find benefit resources for the family of people living with stroke to support care including support from healthcare workers, volunteers, or organizations, which can help both in an emergency situation and in the long-term. Also, community resourcefulness will help to provide medical equipment support such as bed, cane, wheelchair, or other assisting equipment for care and rehabilitation.

For the caregivers, they are the main person in propelling the care model to enhance a healthy family and achieve the goal. As the caregiver is the one who directly gets affected by caring for the stroke survivor, the caregivers have to be patient, kind, and work hard. Moreover, they need to learn to have proper knowledge and skill so that they can achieve the goal of care. The caregiver needs to get support from the community care commander and community resourcefulness. The support will help the caregiver to have more knowledge and skills for providing care for people living with stroke. This will also make convenient in developing a strategy to provide care for stroke survivors, which is called "Caring Achievement." The developed strategy will help caregivers and families to be healthy as the aim of care. Caring achievement has details as follows:

**1. Setting goals in caring to motivate group activities** between stroke survivors and family members by encouraging them, giving them a chance to reflect themselves and do activities they like together.

**2. Exchanging the experiences of difficulties and obstacles** that occurred while providing care to make them have more knowledge and understand the symptoms and disease more. Exchanging the experiences will help in making care plans following their own family context.

**3. Proposing adaptation methods.** The caregiver and family members shared the problems in providing care for stroke survivors, personal health issues, conflicts, and other problems within the family. Then, they suggest ways to solve problems and make a proper plan for their family context.

**4. Supporting and fulfilling care competency** for the caregiver and family members. Family, nurse, and community need to cooperate with each other to

give support to the caregiver so that the caregiver can provide care for stroke survivors effectively.

**5.** Balancing the mind to create positive energy This method is the way to strengthen the physical and mental health of the patient, caregiver, and family so that they can provide care with happiness. The family members need to have self-care by eating food with nutrients, doing exercise at least three times a week continuously, controlling emotions, doing meditation retreats, being concentrated, and being optimistic. All of these will help the caregiver to achieve the goal of care.

6. Self-improvement for happiness. The caregiver, stroke survivor, and family need to assess the outcome of care and assess their own feelings. The caregivers need to understand their roles and responsibilities in providing care for people living with stroke. They also need to improve knowledge and skills, relationships within the family, trustworthiness, and encourage family members to cooperate in caring. The caregivers need to provide care with kindness. For stroke survivors, they need to accept and understand their ability to do activities. The stroke survivor needs to cooperate with the caregiver to do activities. Furthermore, family members have to understand the caregiver, give the caregiver authority to provide care for the patient and support the stroke survivor and caregiver depending on each family context.

A community care commander is the main key to supporting caring achievement and helping the family to provide care for the stroke survivor. The support from the community care commander will help the family to achieve the goal of care which is a healthy family including (1) Happiness from the deep of their mind, which can be assessed by the family's and patient's reflections (2) Physical health of the caregiver and family members and stroke survivor's rehabilitation (3) Financial Balancing in family members' perspective as they receive help and support from family members and community (4) Family Bonding from a good relationship within the family, as per the following details:

Happiness in this context means the mental health of the caregiver, stroke survivor, and family. This can be assessed from the satisfaction of the result that they reflected after doing activities together such as reality acceptance, forgiveness, and being reasonable. These will help to enhance better relationships within the family. The family members will help and support each other, and also be kind to each other. Consequently, it will result in a feeling of happiness and better quality of care, as the caregivers stated.

"I moved all his Buddha amulet to his room so that when he see his collection, he will be happy. He was so happy when he saw them yesterday. Ha had a very big smile. I asked if he likes it and he said 'Yes yes yes of course! I have been collecting them for all my life'. I'm happy if he's happy." (G1\_913)

"It's much better. I'm happy and got lots of knowledge. I forgive him as I understand that it's because of the sickness." (G2\_912)

"Although it took time to help my grandpa back to be able to stand himself again, I understand his condition more. I will try to help him do rehabilitation and does not have more stiff joints. My sister also is more open-minded. Still only have a problem with my brother. He's a bit crackpot. I need to tell him when I'm gonna do something."  $(G1_902)$ 

"I take care of him very well. Since he got sick until now. I have been taking care of my dad until he can walk himself. I don't care what others say. I don't care if they will help me or not. I'm happy to do it. I believe in what goes around comes around. I can look after my dad." (G1\_913)

"His happiness is seeing his children and grandchildren. He was happy when he saw them. He looks fresh, smiles and laughs. I walk past his house every day and see that he's happy." (G1\_906)

*"From all I have done, it makes me happy and feel so comfortable."* (G1\_913)

Physical health in this context means the physical health of the caregivers, family members, and stroke survivors after changing behaviors such as exercise, diet control, and having enough rest. It also can be assessed from the cooperation of the stroke survivor in doing rehabilitation until they can be able to do activities themselves again. Here are some statements from the caregivers.

"My dad can look after himself well. It helps my mum lots. It's not much different for me as I haven't helped lots since at first. But for my mom, it does. She's less tired and less grumpy than before." (G2\_912) "The patient at home is getting better. He speaks more and keeps getting better. I have been taking care of him since he was bedridden until he can walk and do activities himself."  $(G1_913)$ 

"I also do exercise. I do exercise with the patient. When I take the patient out for a walk, I also walk with him. I sometimes use exercise equipment and ride a bike there too." (G2\_911)

"I do arm swing for 15 minutes every morning in the kitchen while waiting for food to reheat so that I don't waste time waiting there doing nothing." (G2\_914)

"He's getting better. Still being stubborn when it's time for him to eat. But it's ok as long as he can eat because his condition worsens if he can't eat." (G1\_913)

For the financial balancing, it can be assessed from the caregivers' and family members' feelings if they feel like they can afford the personal living expense and medical expenses, and rehabilitation for stroke survivors. They can get support from other family members or community organizations nearby. Here are some statements from the participants:

"Now I have my siblings to support (expense). My mom and siblings are helping, so I have to do my best." (G1\_913)

"I had lots of debt before but now the situation is better. I opened noodle restaurant. I'll treat you someday. There are many customers every day. Always sold out. I plan to have a day-off. The business is going well. I get profits and have some left for saving." (G2\_911)

"There are canes, wheelchairs, and stretchers at the health promoting hospital. We can borrow from there. People who don't use them anymore donate to the hospital. We don't have to spend money." ( $G2_{908}$ )

Family bonding in this context means a good relationship within the family. It can be assessed from the gestures and behaviors they express to others as well as how they helped and supported others in providing care for stroke survivors. The family members had discussed about the problems and the way to solve those problems. They assigned shifts to help each other to look after the patient and did activities together. In addition, the relatives of the stroke survivor came to visit regularly. All of these make good relationships within the family and bring happiness and peace to the family. The participants stated:

"I'm happy that my family is being like this. Do not have any arguments. At first, we couldn't accept this. But now, we have talked and that made us feel better. If we couldn't accept the fact, we won't be happy like this." (G2\_909)

"You can come and see. He's so nice. Never be aggressive and do not get annoyed with me."  $(G1_905)$ 

"You used to look stressed all the time. Now, you have smiley face. Does it mean the situation at home is better?"  $(G2_912)$ 

"Did you sleep well last night? He didn't call you at night, right? You look so fresh today." (G2\_908)

"I have been looking after my dad until I do not have time for my boyfriend. My boyfriend told my mom 'I love her lots. I feel pity for her. I can't leave her alone." I started crying when I heard that." (G1\_913)

"The day before, nephews and nieces came to visit. He looked so happy and smile all the time. He even could eat and speak more."  $(G1_913)$ 

Caring Achievement resulted in a healthy family, including happiness, physical health, financial balancing, and family bonding. The result of the assessment was sent back to the caregiver. Then, the caregiver checked if it achieved the goal. The issues which did not achieve the goal were considered again. After consideration, the caregiver made new care plans for stroke survivors following their family context. This process happened like a cycle while the caregiver and family provided care for the stroke survivor.

After analyzing the developing process to enhance healthy family for the family of stroke survivors, the proper strategies emerged from the process as follows: setting the goal of care together to motivate them to do group activity, exchanging experiences and barriers in caring, proposing adaptation methods depending on each family context, supporting and fulfilling care competency to help the caregiver and family achieve the goal of care, life balancing and creating positive energy to enhance physical and mental health, and making themselves happy. The developed strategy will help the family of the stroke survivor to achieve the goal of care, be happy while providing care for stroke sufferers, and also have a good relationship within the family through their reflective thinking and experiences getting from caring stroke survivors. The strategy will push to the bigger goal, from the goal for individuals to the family. However, to achieve the goal, support from the community care commander and community resourcefulness are needed.

#### 4.3 Discussion

This study is a qualitative study that aims to develop the Family-Based Caring Model (FBCM) for stroke survivors to enhance healthy families in urban society. There are two phases in this study. The first phase is analyzing experiences and needs in caring of the caregivers and finding the meaning of being healthy in a stroke family's context. The second phase is developing FBCM through Participatory Action Research (PAR). The study process started with planning, practice and observation, and reflective practice. The researcher analyzed the practice process from the group activities in which the participants had exchanged experiences, shared the ways to solve problems, shared their success, and had interactions with others. Analyzing the practice process helped to analyze the Family-Based Caring Model for stroke survivors to enhance healthy families and achieve the goals of the study. The researcher collected the data and analyzed the data by using the computer software called ATLAS.ti 8.0, which can show the data systematically and support qualitative data analysis. In this study, the researcher analyzed the qualitative data to interpret the information got from observation and group activities (Creswell & Poth, 2018; Miles et al., 2014) by coding, grouping, and concluding in concept follows five steps of data analysis by Miles, Huberman including 1) Managing and organizing the data for analysis, 2) Reading and re-reading, 3) Describing and classifying codes into themes, 4) Assessing the interpretation to understand and be able to explain the situation happened in the withincase and cross-case analysis, 5) Representing and visualizing the data with mapping or diagram. From the data analysis, the results can be described following the aim of the study as follows:

# 4.3.1 To Synthesize Family Life Experiences and Needs for Caring

In the first phase of the study, the researcher interviewed 40 caregivers and did a focus group with two groups of caregivers to reflect how important the caregivers are in providing care for stroke survivors, who have lots of limitations such as thinking, memory, and behavior changes, and sometimes need help in doing daily life activities. In addition, the knowledge, health, and beliefs of the caregivers are factors helping the caregivers to respond to stroke survivors' needs which are different in each family context (Duthie, Roy, & Niven, 2015; Sornarkas, Deoisres, & Wacharasin, 2015). Thus, the caregivers need to use lots of energy, be patient, sacrifice their own time, and respond to stroke survivors' needs to help the stroke survivors in doing daily activities. In this interview, the caregivers reflected their experiences in providing care for stroke survivors. For instance, they have to prepare healthy food and make sure that the stroke survivors get enough nutrients. The caregivers also need to provide care at night such as suction, changing position, and hygiene care to support good sleep. More than that, the caregivers do medication management and take the patient to the hospital to continue following up with the doctor or whenever there is something wrong with caring or symptoms. The caregivers need to help the stroke survivors to do daily activities and continue doing rehabilitation so that the stroke survivors can back to live normal life as soon as possible and reduce a chance of disability and complications. The study written by Qi Lu (2019) also described the caregiver's experience that it is like living on the edge. The caregivers have responsibilities for everything under the stroke survivor's authority. This made them feel like they are prisoners who were sentenced to jail for a long time (Lu et al., 2019). Not only providing care for stroke survivor, but the caregiver also has to take care of others family members, do housework, and help with financial support other than the medical expense of the stroke survivor.

In addition, the caregivers reflected on problems happened in daily life while providing care for stroke survivors. The problems cause burden to the caregivers and make them sometimes have bad behaviors. This related to the Caregiver burden and coping strategies in caregivers of older patients with stroke study. The study found that the caregivers who have high responsibilities use negative strategies to face the problems more (Kazemi et al., 2021), and resulted in conflicts within family. The same as the study of Qi Lu, the study found that stroke survivor care affects the caregiver's personal life (Lu et al., 2019). The caregivers also reflected on what they would like for helping in taking care of stroke survivors. They would like the family to listen and talk to each other, and they would like to be free in making decisions and problem management. Whitehead (2017) and Camila et al. (2017) stated that the burden from taking care of patients can affect the health and quality of life of the caregivers (Byun & Evans, 2015; Caro et al., 2017; Whitehead, 2017; Hekmatpou, Baghban, & Dehkordi, 2019). Therefore, the caregivers need to be healthy and able to deal with bad emotions and stress. They need to have self-care and get proper information from doctors and nurses to provide care for stroke survivors. Continuing to receive care and rehabilitation services from the healthcare providers are also needed. When they go to the hospital, they would like the healthcare providers to give them some advice about caring for stroke survivors as well. From the study about satisfaction of people who received healthcare services, it indicated that the satisfaction level is related to a decision to receive services of the clients (Ronca et al., 2020; Stepurko, Pavlova, & Groot, 2016). Furthermore, the caregiver reflected that they need support to provide care for the stroke survivor, both support from the family and outside sources, including financial support, health, and environmental factors. However, the government has been providing financial support for the stroke survivors' families. Receiving government service is one of the supports that will help the family of stroke survivor to have higher income (Boukeaw & Teungfung, 2016) and accessing to healthcare services in primary care units will help to reduce medical expenses (Pachanee & Wibulpolprasert, 2006) or receiving active health services will help in preparing the family to be ready to take care of stroke survivors (Pindus et al., 2018).

The caregivers have the responsibility of doing chores in the house along with providing care for the stroke survivor. There are many obstacles while providing care and those obstacles cause them to have lots of feelings in both positive and negative sides (Byun & Evans, 2015; Misawa et al., 2018). The positive feelings are such as love, gratefulness, kindness, and caring for each other. These are basic religious beliefs in Buddhism that the caregiver and family have been using as an anchor of mind, and basic morals which will result in a good relationship within the family and responsibilities to provide care for parents when they get older or sick (Thãvaro, Phrakrukosolattakit, & Phrakhrukositwattananukul, 2019). If the family members understand each other and cooperate in caring as well as having healthcare workers to provide support, the quality of care and quality of life of both caregiver and stroke survivor will be better. Understanding each other will also result in a better interaction between family members as they will be more reasonable and accept reality. The same as the study of Sofia Koukouli and friends about a Greek family in providing care to a critical patient, it illustrated that the family can get through the situation by being optimistic, getting family support, and having religion and spirituality as an anchor of the mind (Koukouli, Lambraki, Sigala, Alevizaki, & Stavropoulou, 2018).

# 4.3.2 To Identify Family Functions for Reaching a Healthy Family While Caring for Stroke Survivors

The information from interviewing the caregivers in the first phase reflected the role of family in providing care for stroke survivors. Caring for stroke survivors causes changes in the family member's life, starting from family function until the role of family members in taking care of stroke survivors and other family members (Byun & Evans, 2015). This is the reason why the family have to do lots of activities other than daily routine activities, affecting the relationship between family members and problem management.

The study in semi-urban community reflected that the number of family members does not have any effect on the family function in responsibilities for taking care of the stroke survivor or help to reduce the caregiver's burden. Most families of the caregiver who participated in this study are single families. Although some are extended families, because of the recession and high-cost living in semi-urban community, there are more people of working age who need to go work outside. Similarly, Rajsic et al. (2018) illustrated that a family's economic burden is worst due to medical expenses and long-term care. Some families have lots of debt from borrowing money, so they need to work more to get balance between income and living expenses (Rajsic et al., 2018), causing the elders and stroke survivors to live alone at home. The interviews also reflected on how important the family are in providing care for the stroke survivor. Both caregiver and family members need to have basic knowledge and skills of how to take care of the stroke survivor in order to provide effective care and completely respond to the patient's needs, especially assisting in doing basic daily activities such as eating, cleaning, moving, and elimination. The caregivers believed that supporting each other will help the patient to recover faster. So, the family members need to support and encourage each other to enhance the physical and mental health of both the caregiver and stroke survivor (Koukouli et al., 2018). The family can help to reduce the caregiver's burden by assigning the role and responsibilities of each family member and managing time for relaxation. Lena Olai et al. (2015) illustrated that long-term care, ability to take care of the stroke survivor, and

relationship within the family can cause caregiver burden (Olai, Borgquist, & Svärdsudd, 2015).

Furthermore, conflicts within family are the main cause of physical and mental issues. The conflicts affect emotions, psychosocial, and behaviors the family members express to each other (Widmer, Girardin, & Ludwig, 2018). Consequently, conflict management is the responsibility that the family members have to do together to enhance a better relationship and harmony within family. Having good relationship within family is like a driving force to make family members provide care for stroke survivor with understandings. Similarly, the study of Michael J. McCarthy et al. (2020), which studied about the challenges in relationship between stroke survivor and caregiver, also focused on strengthening the relationship within the family to respond to the needs of family members.

The caregiver reflected on the meaning of heathy family that it is happiness, which means the family members have good health both physically and mentally, have no debt, stay in family that understand each other, have good relationship, and be able to do activities freely. They used the Dharma to lead their lives, especially the religious doctrine about doing good things and think positively. Moreover, the family members also used sufficiency economy philosophy with living their live by living with nature, be modest and be happy with the present. Curran (1983) said that the characteristics of a healthy family is the family which blend the morals with their responsibilities. For the meaning of a healthy family in this study, the caregiver cares about family members more than only focusing on caring for the stroke survivor, which is related to family psychology. The family psychology focuses on the interactions and diversity of roles in the family which affect the responsibilities of family members, including the interaction between people and the environment. It is based on the system theory which looks at the overview of the whole family (Thoburn & Sexton, 2016).

# 4.3.3 To Motivate Self-Directed Learning to Cope with Family Stress

In the first phase of the study, the researcher analyzed and identified the meaning of health family, which means "happiness" from inside their mind. The happiness come from behavior change, responsibility, self-care, as well as using Dharma in their daily life. The happiness also happened because of doing good things, doing religious activities, being optimistic, following sufficiency economy theory, and being happy with present. Caregiver and family of the stroke survivors have identified the meaning of this by assessing from responsibilities, values, and experiences of the caregivers of stroke survivors. The expected outcome of healthy family is that the family can deal with problems, change behavior, keep function of the family, and family members can do self-care. The family has set the meaning of healthy family or happiness from caregivers' opinions such as family members have good physical and mental health, have good atmosphere in the house, family members care and understand each other, have good relationship within family. The healthy family can be happened by starting from caring and rehabilitation for stroke survivors, and caregiver's and family members' self-care. This study aims to enhance family's health physically, mentally, and spiritually. The families have used care strategies with many positive factors to support rehabilitation for the stroke survivor under the warm atmosphere in family. They did activities which help to strengthen their physical and mental health. They also be kind and be grateful to others. They use wisdom to solve problems which might affect their health reasonably. Besides this, they adjusted the environment in the house to make it more convenient for the stroke survivor to do rehabilitation. In the study written by Sararin Pitthayapong, the study applied giving information pattern, motivation, and improve the skills in creating program for caring patients into the study. Things applied into the study help the family to improve their caring skills and gain self-efficacy in caring for the stroke survivor. As a result, the stroke survivors continue receiving care properly and have a lower chance of complications, causing them to recover faster (Pitthayapong, 2017).

#### **4.3.4** To Design the Caring Behaviors by the Families

In phase 2 of the study, the caregiver had developed care strategy for caring stroke survivor called Caring Achievement. This strategy is suitable for family context and will directly make happy family as the goal of care. Caring achievement includes:

(1) Setting goals in caring to motivate group activities: The family members discussed, made plans, and goal of care together. Setting goal of care will help the family to know problems and barriers and make a good relationship within family. Further than that, it will help to guide the family in providing care and achieve the goal in the end. The previous systematic review and meta-analysis about the effect of goal setting on rehabilitation outcomes in older rehabilitation patients indicated that 8 out of 14 studies used the instruments to set the goal and mentioned about positive results of setting goal in rehabilitation for elders (Smit et al., 2019). Besides this, a study, Effect of Goal Setting for Motivation, Self-Efficacy, and Performance in Elementary Mathematics, found that the students are more successful if they set a goal of the study. However, setting a goal in the study does not affect the encouragement or perception of self-efficacy of the students (Sides and Cuevas, 2020). Another study, Brothers and sisters sharing in the care of a parent with dementia, illustrated that the goal of care of the family is responding to the needs of patient who are their parents. The study also found that cooperating in caring can affect the relationship within the family. It has been reported that the relationships between siblings are better (Kokorelias, 2022).

(2) Exchanging the experiences of difficulties and obstacles: After setting the goal of care, the caregivers have a chance to share their experiences so that the family members know their needs and problems they have to face. Then, the family made care plan together in order to make to meet the family's needs. From the study, it reflected that if the caregivers have a chance to talk and share their experiences and needs, the family members seem to understand the situation and help in providing care for the stroke survivor more. Further than that, it will help to reduce conflicts and caregiver's burden. The result of this study is also similar to the previous study of Ahmad et al. about family experience of caregivers in Dementia care-sharing. In that study, it found that if the caregivers share the problem or consult with other family members, it will help them not to feel lonely and not to be too tired from their responsibilities in caring (Ahmad, van den Broeke, Saharso, & Tonkens, 2022).

(3) Proposing adaptation methods for caring and solving the problems: After the participants exchanged their experiences in caring stroke survivors, they discussed the best way to solve problems and adjusted caring strategies in order to achieve the goal of care. The participants offered the new strategies to provide care for the stroke survivor such as changing environment in house, using assistive devices, finding benefit resources, changing lifestyle and behavior. Similar to the study written by Dharma, Damhudi, Yardes, & Haeriyanto, the study used Royd's adaptation model as the base of the health promoting program for the caregivers to improve skills and quality of life of the stroke survivors in the experimental group effectively. Royd's adaptation theory stated that a person can face complex problems and respond to positive situation by using strategies to face with those problems, showing that a person can make balance to achieve goal in life (Dharma, Damhudi, Yardes, & Haeriyanto, 2018).

(4) Supporting and fulfilling care competency: The family members helped each other in providing care for the stroke survivor. They also encourage and make others to feel confident to take care of stroke survivor and achieve the goal of care smoothly. The cooperation between family members will help the main caregiver to have self-confident and be able to improve their knowledge and skills for self-care as well (Perngmark, Waebuesa, & Holroyd, 2022). A Meta-analytic Study of Predictors for Informal Caregiver Burden in Patients with Stroke mentioned that changing lifestyle and using proper assistive equipment for the stroke survivor will help to reduce burden and responsibilities of the caregiver (Zhu, & Jiang, 2018).

(5) Balancing the mind to create positive energy: This can strengthen physical health by doing exercise and eating healthy food, and enhancing mental health by praying, doing meditation retreats, and making merits as their beliefs. Meditation retreats and praying will help them to be happy, relaxed, concentrate, have a presence of mind, be able to control emotions, and solve the problem reasonably. In addition, trying to think positively and replace negative emotions by the positive ones, by talking positively and looking at the advantages the family has, will make the brain to remember good things, cause the caregiver and family to get through the barriers (Wacharasin, 2017; Thammarongpreechachai, 2021).

(6) Self-improvement for happiness: The happiness means satisfaction, success, fulfillment. It does not mean only external factors or materials. In Buddhist terms, happiness from objects or materials is unstable happiness. Another kind of happiness which is stable and can be created from internal factors is called intellectual happiness. This kind of happiness comes from the understanding of nature and situation as its reality and do not expect the results. These will help them not to suffer from disappointment (Thammarongpreechachai, 2021). Therefore, the family members can make themselves have true happiness from caring by understanding the role and their self-efficacy in providing care for the stroke survivor. Also, they can

improve their skills, be kind, accept both positive and negative sides in life, as well as understand the limitation in life (Thammarongpreechachai, 2021). It is related to the doctrine in Buddhism called four sublime states of mind. The four sublime states of mind are the doctrine to make people in society interact with others with kindness and do no malice. The practice is included with four things: loving-kindness, compassion, sympathetic joy, and equanimity (Bodharamik, 2018; Phra Maha Kasem Panya Waro, 2017). Besides this, family members cooperated in doing activities and give value to the activities they did together, understand and support each other as their own family context. The results of these are that the family members love each other, are harmonious, and have good interactions between family members (Wacharasin, 2017).

The developed strategy from the study or Caring Achievement is related to the study of Qi Lu and friends which presented the aspect of good support from family and friends, healthcare provider, community, and caregivers who have the same experiences. It will help the caregiver to find the turning point which will make the care to be more meaningful, reduce stress and burden, and lead to a better quality of care (Lu, Martensson, Zhao, and Johansson, 2019).

# 4.3.5 To Enhance a Healthy Family Based on the Individual by Themselves

The development of A family-based caring model for stroke survivors to enhance healthy family in this study come from the desire to strengthen health for the families of stroke survivors. The figure 4.2 explained that caregivers who participated in this study are the ones who directly got affected from caring. They are the key persons in propelling the care strategy called caring achievement by getting support from the community care commander and community resources to enhance a healthy family, which will directly affect the caregiver, as per the following details.

There are three factors affect the care for stroke survivors and affect the caregiver on how to provide care and respond to the needs of stroke survivors who have different limitations in each family context. These factors are Caregiver Characteristics, Family Function, and Assisting Support.

For this study, the caregivers need to understand themselves, have morals, provide care with love and kindness, have proper knowledge and experience, be healthy, be able to control emotions, have freedom, and be able to deal with problems and make decision themselves.

From the analysis of family function of the stroke survivors' family, it indicated that family structure as well as the role of family members have been changed because the family members were forced to change their functions (Gawulayo, Erasmus, and Rhoda, 2021). Therefore, the family members need to have no conflicts and cooperate in caring for stroke survivors, as well as help the stroke survivors to do rehabilitation continuously. They also need to have responsibility and try to have selfdevelopment which will result in the better quality of care and be successful as planned. Gawulayo, Erasmus, and Rhoda studied about the role of the family in providing care for the stroke survivor and found that if the family has positive experiences in caring, they can improve the family structure to support the stroke survivor's new life (Gawulayo, Erasmus, and Rhoda, 2021).

Getting support from the family members and outsource including financial support for medical and living expense of the stroke survivors related to the previous study, Economic burden of stroke. The study stated that caring for stroke survivors affects family economy. The family needs to spend lots of money on rehabilitation and long-term care (Persson, Ferraz-Nunes, and Karlberg, 2012; Persson et al., 2017: Movahed, Barghazan, and Rezapour, 2021). Hence, health support, both health insurances and healthcare services will help the family to access medical services and Basic Medical Insurance System. The support will make the family easier to access treatment and rehabilitation, which will make the family members have better health and build stability in life. Experiences of Thai Buddhist family caregivers, study by Wiseso et al., mentioned that understanding the experiences of the caregivers and improving healthcare services will help to improve the quality of life of both patient and family (Wiseso, Fongkaew, Pinyokham, and Speirs, 2017). Moreover, the support from environmental factors will help the caregivers to have time for themselves, be more relaxed, and reduce the feeling of burden. The study about positive experience of family caregivers for stroke also found that supporting family both physically and mentally is the main factor in reducing the feeling of burden of the caregivers and help in keeping the family function, especially the relationship between the caregiver and stroke survivor (Bunlikitkul, 2012).

The factors mentioned before will help the caregiver to be more patient, provide care for the stroke survivor with kindness and love, and try hard to provide care continuously. The caregiver has learned and improved practical skills, and also improves the performance in providing care for the stroke survivor. This is similar to the study about family's adaptation to the role of care written by Elizabeth (2022). The study found that family members need to adjust themselves to provide physical, psychosocial, and spiritual care for the stroke survivor. The family members also need to do activities by using knowledge and expertise to help the stroke survivor to be able to do activity as they cannot do it independently (Elizabeth, 2022).

The Community Care Commander will help to support the caregiver in developing the proper strategy for caring for the stroke survivor (Caring Achievement). The Community Care Commander means the researcher who is a community nurse. The community nurse will have an essential role as chief commander to support caregivers and family and make them provide care with confidence. The roles of the community care commander in this context includes providing information about caring for stroke survivors, following up, assessing care and family, coordinator, organizing activities and support the family following each family context. Information, advice and care received from the community care commander will be under the nursing standards, which will help the family to understand the disease more and reduce the gap of knowledge (Darley, Coughlan, and Furlong, 2021). Guo and Liu also suggested that the nurses should assess the family status of stroke survivors' families. The nurses should continuously provide care and information about strokes as well as provide emotional support to reduce the caregiver's burden and enhance the ability to deal with emergency situations (Guo and Liu, 2015). The information the community care commander should provide are included with information about signs and symptoms of stroke, caring, exercise and rehabilitation, how to prevent complications, proper food and medications, and how to do self-care for caregivers. The nurses also should give the family a guideline to help the family understand about stroke more and have proper skills to provide care for the stroke survivor. Similarly, Silva et al. (2016) also suggested the nurses or healthcare teams provide strengthen health education and encourage proactivity to family members in order to make the family be able to

continuously provide care for patient by themselves effectively (da Silva, da Silva Carvalho Vila, Martins Ribeiro, and Vandenberghe, 2016).

The Community Care Commander will participate in the process of assessment, planning, solving problems, and enhancing self-development for the family and stroke survivor. Further than that, the community care commander will motivate the patients to use their potential to take care of themselves by letting the patients and families to share their opinions and experiences. The community care commander will also guide the family and stroke survivor to find themselves and show their potential in providing care for stroke survivors. In addition, the community care commander will also be a counsellor for the family and stroke survivor. According to Coyne et al. (2017), it is illustrated that the nurses need to be close to the family to find the strengths and resources the family has, as well as providing support and information specifically for each family context to make a better outcome (Coyne, Dieperink, Østergaard, and Creedy, 2017). The Community Care Commanders need to cooperate in doing activities to improve the ability and potential of the family and caregiver. Also, they need to be coordinators to contact the related organizations in order to make it convenient for the family and support them until they can achieve the goal of care. Elizabeth (2022) stated that nurses have a role to assess how the family can cope with caring and help the family members by providing materials important in providing care for the stroke survivor such as gloves, cotton, as well as emotional support. The nurses need to give information as the family require and give some advice to ensure that the family can provide care for the stroke survivor continuously (Elizabeth, 2022), as well as getting proper support from the community.

Community Resourcefulness will help in supporting benefit resources for caring for the stroke survivor for the family such as adjusting environment, finding assistive equipment, or making it convenient to do activities. The purpose of the support is to promote the stroke survivors to have self-management and to make the caregivers provide care objectively. This is related to the study of Ugargol et al., which found that environment management is significantly related to health, disability, along with the care plan (Ugargol, Hutter, James, and Bailey, 2016). Therefore, supporting from healthcare providers, volunteers, neighbors, and organizations in long-term care are essential. Plus, supporting medical equipment such as hospital bed, cane, wheelchair, fitness equipment, or assistive equipment for rehabilitation, will help to motivate the stroke survivors to do self-care and rehabilitation and help the family to provide care more effectively (Demain, et al., 2013).

Therefore, after the caregiver gets support from the Community Care Commander and Community Resourcefulness, the support will help the caregiver to have more knowledge and skills in providing care for the stroke survivor and help to develop the care strategy (da Silva, et al., 2016), called Caring Achievement, which is suitable for each family context. Consequently, the family will achieve the goal of care, which is a healthy family including (1) Happiness from inside, which can be assessed from family's reflection (2) Physical health of the family members and rehabilitation of the stroke survivor (3) Financial Balancing assessed from family members' feelings of receiving support from other family members and community and (4) Family Bonding from the good relationship within the family.

After the family follows the caring achievement that they developed, it results in heathy family including happiness from inside their minds. Each family members' action can affect others, especially for communication and responsibilities both in family and society (Wright, and Leahey, 2013). Their actions can help the family to manage with the situations happily while providing care for the stroke survivor (Bunlikitkul, 2012). In this study, happiness can be assessed from satisfaction that the family members reflected after doing activities together, including knowing how to move on, understanding their own thoughts, living with reality, and accepting the imperfection. These will help to reduce suffer and effects from the problems (Thammarongpreechachai, 2021) such as perception of sickness, limitations, and disabilities, accepting their own self-efficacy, forgiving others and being reasonable. For example, exercise will help to manage their health problems and strengthen physical health. Doing rehabilitation continuously will help the stroke survivor to recover faster and reduce the risk of joint stiffness. Letting the stroke survivors to do activities themselves will help with rehabilitation and increase their self-confidence to socialize. The previous study, the healing process of moving on of Carole A. Robinson, also found that a family living well should start with the fight of resisting the illness. Then, the family needs to accept the situation, try to understand the symptoms and disease, share the experiences, and find helpful resources in family and community in

order to get through problems and live with sickness happily (Robinson, 2017). For this study, the result of caring enhanced a better relationship within family. The family members become more helpful to each other, treat others with love and kindness. Finally, it will lead to a good quality of care, happiness, and peace of mind.

It is known that providing care for stroke survivors affects the physical health of the caregivers such as abdominal pain, high blood pressure, fatigue, body pain, and insomnia (Zhang and Lee, 2017). Therefore, physical health in this context means physical health of the caregiver and family members which come from the behavior change, including doing exercise, eating healthy food, and having enough rest. From the Integrated Theory of Health Behavior Change by Ryan, it is believed that the caregiver can be healthy if they have proper behavior management (Ryan, 2009). Moreover, physical health can be assessed from the cooperation from the stroke survivors to do rehabilitation continuously until they can do activities themselves. According to the previous review literature, it showed that encouraging stroke survivors to do daily activities themselves will help them to recover and be able to get back to living normally faster (Church, Smith, Broom, and Sage, 2022).

For the rehabilitation and caring for the stroke survivor in the long term, the family have to spend lots of money (Persson, Ferraz-Nunes, and Karlberg, 2012; Persson et al., 2017: Movahed, Barghazan, and Rezapour, 2021). Therefore, financial balancing in this context can be assessed from the caregiver's and family's perspective of capability for financial liquidity. This included personal living expenses and medical expenses for the stroke survivor. They might get support from other family members and from the community. When the caregiver gets support from other family members, it shows how good the relationships within the family are.

Good relationship within the family or family bonding is the communication between family members, which show how they care about others and how they support each other to provide care for the stroke survivor. The family members will be able to talk and share their feelings or their thoughts if they have good relationship with others. Also, family members who listen to other's problems will help in supporting one another by using the words showing that they understand, have empathy, and are ready to support. The cooperation of the family members is important and is a positive factor to support the family to achieve the goal of care and help with stroke survivor's physical and mental health (Bunlikitkul, 2012). Robinson (2017) stated that the families, with whom the caregivers can share the emotional or spiritual experience in taking care of stroke survivor, will help the caregiver not to feel lonely. In contrast, if the caregiver cannot share their uncomfortable feelings, it will cause the caregiver to have a burden and result in ineffective care (Robinson, 2017). Similarly, Guo and Liu said that good communication among family members will help the family to adjust or create a strategy for solving problems they have to face (Guo and Liu, 2015). In this study, the family members shared problems and barriers in providing care. They assigned shifts for family members to take care of the stroke survivor which allowed them more time to do activities together. Plus, other cousins or relatives also managed time to frequently come to visit the patient. All of these cause a happy family and good relationship within the family. This is similar to the previous study about family members' role of care adaptation written by Elizabeth (2022). The study said that if there is good relationship among family members, they will help and support each other physically, mentally, and spiritually. Good relationships will allow to the family to cope with caring properly (Elizabeth, 2022).

The result of caring achievement is the healthy family including happiness, physical health, financial balancing, and family bonding. These results will help the caregiver in their ability for self-adjustment, and understanding themselves and family members (Khomkham, Rattanathanya, and Krainuwat, 2015). The caregivers need encouragement and support from the family members, community, nurses, and multidisciplinary team (Sirisom, Thaniwattananon, and Jittanoon, 2017; Martinsen, Kirkevold, and Sveen, 2015). If the caregiver assessed the strategy and sees that it is not as good as they plan, the strategy will be edited again so that it can help to solve the problems and be suitable for the family context. The same as Zhang and Lee (2017) who stated that the positive meaning in caring will happen if the family find the turning point that will change the care plan and change from impossible to possible. The family need to reset the goal of care together and make it suitable for their family context. It will be like a cycle that happens all the time while the caregiver and family provide care for the stroke survivor.

# CHAPTER 5 CONCLUSIONS AND RECOMMENDATIONS

The aim of this study was to develop a model of care for families with stroke survivors towards a healthy family. A participatory action research process was used under the environment of semi-urban community in Nonthaburi Province where its demographic characteristics and contexts covered problem issues and research objectives. This research proposed to study realistic situations in caring for stroke survivors and defining a healthy family and strategies to foster healthy families of caregivers. This led to a synthesis of a model for healthy family care of stroke survivors which could be practically applied to families caring for stroke survivors. Sample groups were caregivers responsible for caring for stroke survivors in the family. A specific sample selection method was utilized and willingness to cooperate in data collection was obtained. It was divided into in-depth interviews of 40 participants and group discussions of 14 participants in Phase 1 and Phase 2. The sample groups of 14 participants who passed those interviews and group discussions voluntarily participated in action research cycles for a period of 16 weeks.

In Phase 1, the total sample groups consisted of 54 caregivers of stroke survivors. Those caregivers were divided into 11 men (20.4%) and 43 women (79.6%), aged 25–84 years ( $\bar{x} = 57.31$ , S.D. = 12.83). Almost half of them were still at work (42.6 percent). The age of stroke survivors for caregiving was between 37–89 years ( $\bar{x} = 68.13$ , S.D. = 11.43), including 39 males (72.2%) and 15 females (27.8%). Most of them had a stroke for at least 2 years. Also, half of those stroke survivors were recovered and able to help themselves (51.8%).

In Phase 2, volunteers willing to participate in the action research cycles were 14 families, including 13 females and 1 male, from families with caring for stroke survivors. They were divided into 2 groups according to days of group activities: Wednesday group and Sunday group. The Wednesday group comprised all female caregivers, aged between 35 and 76, mean age 58.57, with caregiving to all male stroke survivors, aged 69–87, mean age 75.57, and mean duration of stroke 4 years. The Sunday group composed of 6 females and 1 male caregivers, aged 30–68, mean age

56.71, with caregiving 2 females and 5 males of stroke survivors, aged between 56 and 78, mean age 68.86, and mean duration of stroke 6 years. There were total members of 3–10 persons in both groups who lived together in the community for at least 20 years. Group activities among family members included talking, eating, travelling to other provinces, and going to make merits. Most of family conflicts came from dissatisfaction of speech, frustration, and different views or opinions.

Data collection was performed by the researcher with participants' rights protection from January 2020 to February 2021, using open-ended interview forms verified by 5 experts, tape-recorded discussions, field notes, and observation of participative group action research. Content-based data were analyzed using "ATLAST ti.8" program with types of data categorization.

### **5.1 Conclusions**

The results of this research study could be summarized as follows.

# 5.1.1 Results of Phase 1

**5.1.1.1 Family Situations in Caring for Stroke Survivors** were concluded as 3 essential factors, including:

(1) Caregiver characteristics – It comprised 1) Virtuous love and gratitude, 2) Experiences in caring, 3) Good health and self-care, 4) Good management of emotions, and 5) Freedom in dealing with problems and obstacles.

(2) Family functions and relationship – There were five main factors: 1) Family structure, 2) Roles and duties of caring members, 3) More special activities, 4) Family relationships between members, and 5) Management of family problems.

(3) Assisting support – It composed of 1) Financial support, 2) Health service support, and 3) Environment support.

**5.1.1.2 Healthy Family in the Context of Stroke Caregivers -** In this study, caregivers defined a healthy family as "happiness" that occurs within the caregiver's mind which adapts to change for family coping, caring behaviors, maintaining functions, and self-care. Happiness incorporates the principles of religious teachings in doing good things, performing religious activities, clearing the mind,

having positive energy, thinking well, doing right. Also, using sufficiency is a basic key of life through a natural living, eating in moderation, and being happy today.

#### 5.1.2 Results of Phase 2

**5.1.2.1 Developing a Family-Based Caring Model** included actions during the 4 participatory action research cycles:

Cycle 1: Strategic Design and collaborating – It composed of three concepts: 1) Setting goals for caring for stroke survivors, 2) Barriers and problems in caring for stroke survivors, and 3) Caregivers' adaptation.

Cycle 2: Supporting and fulfilling care potential – There were three concepts: 1) Sharing experiences in caring, 2) Cooperate in Caring, and 3) Mental health support.

Cycle 3: Balancing the body and mind for creating positive energy – It comprised of 1) Thinking of good things and providing care with love, 2) Improving mental health, and 3) Promoting physical health

Cycle 4: Self-improvement for happiness – It were 1) Facing reality and 2) Life balancing.

**5.1.2.2 Family-Based Caring Model: FBCM** – This was performed by using a participatory action research process for caring for stroke survivors over a period of 16 weeks. Caregivers improved and changed how they provided family care, indicated as a caring achievement under the assistance of the community care commanders and the community resourcefulness for a healthy family comprised of happiness, physical health, financial balancing, and family bonding.

# **5.2 Recommendations**

From the development of FBCM for stroke survivors, using a participative action research process to promote a healthy family, the results showed that a process of self-help group and supporting system enabled successful caring of family members with a stroke. This study recommended for the implementation of FBCM in community health services, nursing care, research, and policy planning as follows:

#### **5.2.1 Community Health Services**

(1) There should be a development of community service system. The goal was to provide families with a potential to care for stroke survivors and adjust their ways of life to be happy by encouraging and supporting family members towards more participation in caring for stroke survivors.

(2) It was recommended to have a system to clearly support self-help group activities in the community. The goal was to help, consult, point out or give advice in various issues. During group activities, family caregivers could exchange information and experiences in caring for stroke survivors. Meanwhile, it enhanced the improvement of caring quality and more potential of family care for stroke survivors. In addition, caregivers and families were mentally encouraged to reduce their stresses from caregiving.

#### 5.2.2 Nursing Care

(1) Nursing personnel could apply the FBCM as a guideline to help promote and encourage families with stroke survivors in the community towards a better health.

(2) Nursing personnel working in the community should increase knowledge for caring of stroke survivors in all aspects, such as use of herbal medicines, Thai traditional medicine, and mental healthcare. Also, there should be a development of process for knowledge and nursing skills in adjusting home and community environments with greatest benefits, such as use of home equipment for caring for stroke survivors. In the meantime, this could provide accurate information and advice for people in the community to have knowledge and appropriate adjustment according to the contexts of each family.

# 5.2.3 Research

(1) This family care model was developed for families caring for stroke survivors who lived in semi-urban communities. It was recommended to expand the study in other areas with similar characteristics and continuous follow-up.

(2) There should be further studies to develop a model of family care with involvement of the community, personnel, and other related persons in caring for stroke survivors.

### 5.2.4 Policy

(1) The information of the study interrelated to the needs of the families' illness situations that was an essential part for the local policy in developing practical policies and programs to recognize the importance of providing home-based assistance and more facilities to enhance family strength as the primary care unit.

(2) Policies should be developed this model to support for local service systems to help families and healthcare professionals to participate in care. They will involve and integrate both local and professional knowledge in the development of service systems to comply with their problems and needs for caring for stroke survivors.

# **5.3 Suggestions**

The suggestions for utilization of FBCM for enhancing a healthy family in the stroke families in semi-urban area, Nonthaburi Province, Thailand. There must be understanding and acceptance of contexts of each family that are different. Healthcare providers such as community nurses should make available active services for assisting and approaching family members to participate in the group activities. FBCM can be applied to other families that are caring for chronic patients such as families of diabetes, hypertension and demented people.

## **5.4 Research Limitations**

This study was a qualitative study using a participatory action research process. A specific study was performed on caregivers of stroke survivors in semi-urban communities. The results could not be referred to as general diseases or other situations. The researcher suggests that it can be applied to samples that are similar to this study such as studies in the stroke families that lived in semi-urban areas in other provinces. Moreover, studying in a semi-urban community had limited participation time and place for some groups of people that have high privacy which made access quite tricky, and furthermore it took a long time for the researcher to establish trust.

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#### **Conference Session**

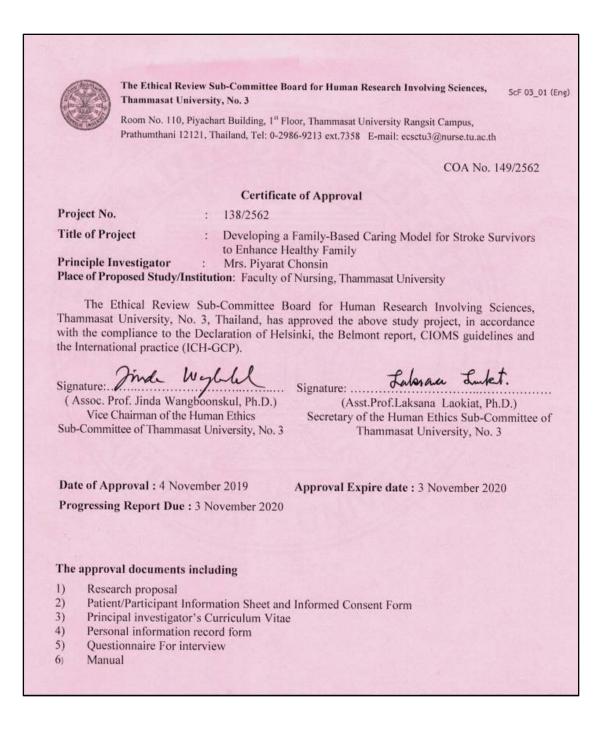
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## APPENDICES

#### **APPENDIX** A

# THE INSTITUTIONAL REVIEW BOARD OF THE UNIVERSITY ETHICS





The Ethical Review Sub-Committee Board for Human Research Involving Sciences, ScF 03\_01 (Eng) Thammasat University, No. 3

Room No. 110, Piyachart Building, 1st Floor, Thammasat University Rangsit Campus. Prathumthani 12121, Thailand, Tel: 0-2986-9213 ext.7358 E-mail: ecsctu3@staff.tu.ac.th

COA No. 149/2562

#### Certificate of Approval

 Project No.
 : 138/2562

 Title of Project
 : Developing a Family-Based Caring Model for Stroke Survivors to Enhance Healthy Family

 Principle Investigator
 : Mrs. Piyarat Chonsin

 Place of Property
 : Stroke Survivors

Place of Proposed Study/Institution: Faculty of Nursing, Thammasat University

The Ethical Review Sub-Committee Board for Human Research Involving Sciences, Thammasat University, No. 3, Thailand, has approved the above study project, in accordance with the compliance to the Declaration of Helsinki, the Belmont report, CIOMS guidelines and the International practice (ICH-GCP).

Wyle Signature: (Assoc. Prof. Jinda Wangboonskul, Ph.D.)

(Assoc.476). Jinda Wangboorskul, Ph.D.) Chairman of the Human Ethics Sub-Committee of Thammasat University, No. 3

Signature: Jakoan Luntet.

(Assoc.Prof.Laksana Laokiat, Ph.D.) Secretary of the Human Ethics Sub-Committee of Thammasat University, No. 3

Date of Approval : 4 November 2020

Progressing Report Due : 3 November 2021

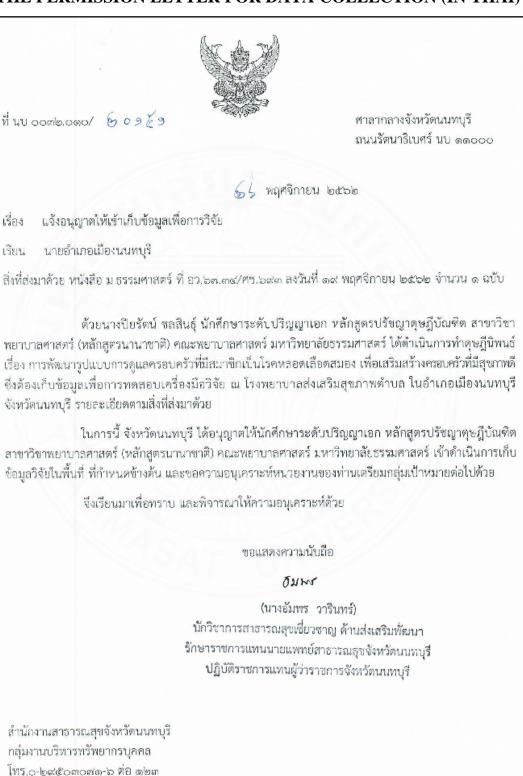
Approval Expire date : 3 November 2021

#### The approval documents including

- 1) Research proposal
- 2) Patient/Participant Information Sheet and Informed Consent Form
- 3) Principal investigator's Curriculum Vitae
- 4) Personal information record form
- 5) Questionnaire For interview
- 6) Manual

#### **APPENDIX B**

#### THE PERMISSION LETTER FOR DATA COLLECTION (IN THAI)



โทรสาร 0-๒๕๘๙๙๑๒๑

### **APPENDIX C**

### **INFORMED CONSENT FORM (IN THAI)**

หนังสือแสดงความยินยอมเข้าร่วมการวิจัยของอาสาสมัครวิจัย

# (ระยะที่ 1 สัมภาษณ์ผู้ดูแล)

### Informed Consent Form

ทำที่			
วันท <u>ี่</u>	เดือน	พ.ศ	

เพื่อเสริมสร้างครอบครัวที่มีสุขภาพดี

- ชื่อผู้วิจัย นาง ปิยรัตน์ ชลสินธุ์
- **ที่อยู่ที่ติดต่อ** คณะพยาบาลศาสตร์ มหาวิทยาลัยธรรมศาสตร์ อาคารปิยชาติ 99 หมู่ 18 ถนนพหลโยธิน ต.คลองหนึ่ง อ.คลองหลวง จ.ปทุมธานี 12120
- **โทรศัพท์** 092-852-6156

ข้าพเจ้า **ได้รับทราบ**รายละเอียดเกี่ยวกับที่มาและวัตถุประสงค์ในการทำวิจัย รายละเอียดขั้นตอนต่างๆ ที่จะต้องปฏิบัติหรือได้รับการปฏิบัติ ความเสี่ยง/อันตราย และ ประโยชน์ซึ่งจะเกิดขึ้นจากการวิจัยเรื่องนี้ โดยได้อ่านรายละเอียดในเอกสารชี้แจง อาสาสมัครวิจัยโดยตลอด และ**ได้รับคำอธิบาย**จากผู้วิจัย**จนเข้าใจเป็นอย่างดี**แล้ว

ข้าพเจ้าจึง**สมัครใจ**เข้าร่วมในโครงการวิจัยนี้ ตามที่ระบุไว้ในเอกสารชี้แจง อาสาสมัครวิจัยโดยข้าพเจ้ายินยอมสละเวลา ตอบแบบสอบถามข้อมูลส่วนบุคคล จำนวน 3 หัวข้อใหญ่ หรือ 33 ข้อย่อย หนึ่งครั้ง และให้สัมภาษณ์ ตอบข้อซักถามพร้อมบันทึกเสียง ซึ่งใช้เวลาทั้งสิ้นประมาณ 90-120 นาที เมื่อเสร็จสิ้นการวิจัยแล้ว แบบสอบถามและ ข้อมูลการบันทึกเสียงที่เกี่ยวข้องกับการวิจัยจะถูกทำลายภายในระยะเวลา 2 ปีหลังเสร็จ สิ้นงานวิจัย

ข้าพเจ้ามีสิทธิ**ถอนตัว**ออกจากการวิจัยเมื่อใดก็ได้ตามความประสงค์ **โดยไม่ต้องแจ้ง** เหตุผล ซึ่งการถอนตัวออกจากการวิจัยนั้น จะไม่มีผลกระทบในทางใดๆ ต่อข้าพเจ้าทั้งสิ้น ข้าพเจ้าได้รับคำรับรองว่า ผู้วิจัยจะปฏิบัติต่อข้าพเจ้าตามข้อมูลที่ระบุไว้ในเอกสาร ชี้แจงอาสาสมัครวิจัยและข้อมูลใดๆ ที่เกี่ยวข้องกับข้าพเจ้า ผู้วิจัยจะ**เก็บรักษาเป็นความลับ** โดยจะนำเสนอข้อมูลการวิจัยเป็นภาพรวมเท่านั้น ไม่มีข้อมูลใดในการรายงานที่จะนำไปสู่ การระบุตัวข้าพเจ้า

หากข้าพเจ้าไม่ได้รับการปฏิบัติตรงตามที่ได้ระบุไว้ในเอกสารชี้แจงอาสาสมัคร วิจัย ข้าพเจ้าสามารถร้องเรียนได้ที่: คณะอนุกรรมการจริยธรรมการวิจัยในคน มหาวิทยาลัยธรรมศาสตร์ ชุดที่ 3 ห้อง 110 ชั้น 1 อาคารปิยชาติ มหาวิทยาลัยธรรมศาสตร์ ศูนย์รังสิต โทรศัพท์ 02-986-9213 ต่อ 7358

ข้าพเจ้าได้ลงลายมือชื่อไว้เป็นสำคัญต่อหน้าพยาน ทั้งนี้ข้าพเจ้าได้รับสำเนาเอกสาร ข้อมูลสำหรับอาสาสมัครวิจัย และสำเนาหนังสือแสดงความยินยอมเข้าร่วมการวิจัยของ อาสาสมัครวิจัยไว้แล้ว

ลงชื่อ	ลงชื่อ
() ผู้วิจัยหลัก วันที่///	() อาสาสมัครวิจัย วันที่///
ลงชื่อ	ลงชื่อ
() พยาน	() พยาน
วันที่///	วันที่///

# หนังสือแสดงความยินยอมเข้าร่วมการวิจัยของอาสาสมัครวิจัย (ระยะที่ 1 การสนทนากลุ่ม)

## Informed Consent Form

ทำที่			•
วันที่	เดือน	พ.ศ.	

**เลขที่** อาสาสมัครวิจัย\_\_\_\_\_

ข้าพเจ้า ซึ่งได้ลงนามท้ายหนังสือนี้ ขอแสดงความยินยอมเข้าร่วมโครงการวิจัย เรื่อง การพัฒนารูปแบบการดูแลครอบครัวที่มีสมาชิกเป็นโรคหลอดเลือดสมอง

เพื่อเสริมสร้างครอบครัวที่มีสุขภาพดี

ชื่อผู้วิจัย นาง ปิยรัตน์ ชลสินธุ์

**ที่อยู่ที่ติดต่อ** คณะพยาบาลศาสตร์ มหาวิทยาลัยธรรมศาสตร์ อาคารปิยชาติ 99 หมู่ 18 ถนนพหลโยธิน ต.คลองหนึ่ง อ.คลองหลวง จ.ปทุมธานี 12120

## **โทรศัพท์** 092-852-6156

ข้าพเจ้า **ได้รับทราบ**รายละเอียดเกี่ยวกับที่มาและวัตถุประสงค์ในการทำวิจัย รายละเอียดขั้นตอนต่างๆ ที่จะต้องปฏิบัติหรือได้รับการปฏิบัติ ความเสี่ยง/อันตราย และ ประโยชน์ซึ่งจะเกิดขึ้นจากการวิจัยเรื่องนี้ โดยได้อ่านรายละเอียดในเอกสารชี้แจง อาสาสมัครวิจัยโดยตลอด และ**ได้รับคำอธิบาย**จากผู้วิจัย**จนเข้าใจเป็นอย่างดี**แล้ว

ข้าพเจ้าจึง**สมัครใจ**เข้าร่วมในโครงการวิจัยนี้ ตามที่ระบุไว้ในเอกสารชี้แจง อาสาสมัครวิจัย โดยข้าพเจ้ายินยอมสละเวลาในการร่วมสนทนากลุ่ม หนึ่งครั้ง เพื่อพูดคุย แลกเปลี่ยนความคิดเห็นและประสบการณ์ในประเด็นที่นักวิจัยนำเสนอ พร้อมบันทึกเป็น ภาพ และเสียง โดยใช้เวลา 60-90 นาที หลังจากนั้นตอบแบบสอบถามข้อมูลส่วนบุคคล จำนวน 3 หัวข้อใหญ่ หรือ 33 ข้อย่อย เป็นเวลา 30 นาที รวมระยะเวลาที่ใช้ทั้งหมด ประมาณ 90-120 นาที เมื่อเสร็จสิ้นการวิจัยแล้ว แบบสอบถาม ข้อมูลการบันทึกภาคสนาม ทั้งภาพและเสียงที่เกี่ยวข้องกับการวิจัยจะถูกทำลายภายในระยะเวลา 2 ปีหลังเสร็จสิ้น งานวิจัย

ข้าพเจ้ามีสิทธิ**ถอนตัว**ออกจากการวิจัยเมื่อใดก็ได้ตามความประสงค์ **โดยไม่ต้องแจ้ง** เหตุผล ซึ่งการถอนตัวออกจากการวิจัยนั้น จะไม่มีผลกระทบในทางใดๆ ต่อข้าพเจ้าทั้งสิ้น ข้าพเจ้าได้รับคำรับรองว่า ผู้วิจัยจะปฏิบัติต่อข้าพเจ้าตามข้อมูลที่ระบุไว้ในเอกสาร ชี้แจงอาสาสมัครวิจัยและข้อมูลใดๆ ที่เกี่ยวข้องกับข้าพเจ้า ผู้วิจัยจะ**เก็บรักษาเป็นความลับ** โดยจะนำเสนอข้อมูลการวิจัยเป็นภาพรวมเท่านั้น ไม่มีข้อมูลใดในการรายงานที่จะนำไปสู่ การระบุตัวข้าพเจ้า

หากข้าพเจ้าไม่ได้รับการปฏิบัติตรงตามที่ได้ระบุไว้ในเอกสารชี้แจงอาสาสมัคร วิจัย ข้าพเจ้าสามารถร้องเรียนได้ที่: คณะอนุกรรมการจริยธรรมการวิจัยในคน มหาวิทยาลัยธรรมศาสตร์ ชุดที่ 3 ห้อง 110 ชั้น 1 อาคารปิยชาติ มหาวิทยาลัยธรรมศาสตร์ ศูนย์รังสิต โทรศัพท์ 02-986-9213 ต่อ 7358

ข้าพเจ้าได้ลงลายมือชื่อไว้เป็นสำคัญต่อหน้าพยาน ทั้งนี้ข้าพเจ้าได้รับสำเนาเอกสาร ข้อมูลสำหรับอาสาสมัครวิจัย และสำเนาหนังสือแสดงความยินยอมเข้าร่วมการวิจัยของ อาสาสมัครวิจัยไว้แล้ว



# หนังสือแสดงความยินยอมเข้าร่วมการวิจัยของอาสาสมัครวิจัย (ระยะที่ 2 การวิจัยเชิงปฏิบัติการแบบมีส่วนร่วม)

Informed Consent Form

ทำที่			
วันที่	เดือน	พ.ศ.	

ข้าพเจ้า **ได้รับทราบ**รายละเอียดเกี่ยวกับที่มาและวัตถุประสงค์ในการทำวิจัย รายละเอียดขั้นตอนต่างๆ ที่จะต้องปฏิบัติหรือได้รับการปฏิบัติ ความเสี่ยง/อันตราย และ ประโยชน์ซึ่งจะเกิดขึ้นจากการวิจัยเรื่องนี้ โดยได้อ่านรายละเอียดในเอกสารชี้แจง อาสาสมัครวิจัยโดยตลอด และ**ได้รับคำอธิบาย**จากผู้วิจัย**จนเข้าใจเป็นอย่างดี**แล้ว

ข้าพเจ้าจึง**สมัครใจ**เข้าร่วมในโครงการวิจัยนี้ ตามที่ระบุไว้ในเอกสารชี้แจง อาสาสมัครวิจัยโดยข้าพเจ้ายินยอมสละเวลา ตอบแบบสอบถามข้อมูลของครอบครัวหนึ่ง ครั้ง รวมถึงการเข้าร่วมในกระบวนการวิจัยครั้งนี้เป็นระยะเวลาทั้งสิ้น 4 เดือน โดย ส่ง ผู้ดูแลผู้เป็นโรคหลอดเลือดสมอง เข้าร่วมอภิปรายกลุ่มครอบครัว 4 ครั้งต่อเดือน ซึ่งใช้ เวลาประมาณ 90-120 นาทีต่อครั้ง เพื่อร่วมกันออกแบบกิจกรรมให้กับสมาชิกใน ครอบครัวเพื่อเสริมสร้างครอบครัวที่มีสุขภาพดี พร้อมทั้งยินดีให้นักวิจัยเยี่ยมบ้าน สังเกตการณ์กิจกรรมในครอบครัวเมื่อนักวิจัยร้องขอ โดยนักวิจัยจะช่วยอำนวยความ สะดวก สนับสนุน และกระตุ้นให้สมาชิกในครอบครัวพูดคุยเกี่ยวกับความคืบหน้าของ กิจกรรมการดูแลผู้เป็นโรคหลอดเลือดสมองในสภาพแวดล้อมที่บ้าน รวมถึงอนุญาตให้ ผู้วิจัยทำการบันทึกข้อมูลโดยการจดเป็นตัวหนังสือ ถ่ายภาพ และบันทึกเสียง เมื่อเสร็จสิ้น

Ref. code: 25655914320022LPH

การวิจัยแล้ว แบบสอบถาม ข้อมูลการบันทึกภาคสนามทั้งตัวหนังสือ ภาพและเสียงที่ เกี่ยวข้องกับการวิจัยจะถูกทำลายภายในระยะเวลา 2 ปีหลังเสร็จสิ้นงานวิจัย

ข้าพเจ้ามีสิทธิ**ถอนตัว**ออกจากการวิจัยเมื่อใดก็ได้ตามความประสงค์ **โดยไม่ต้องแจ้ง** เหตุผล ซึ่งการถอนตัวออกจากการวิจัยนั้น จะไม่มีผลกระทบในทางใดๆ ต่อข้าพเจ้าทั้งสิ้น

ข้าพเจ้าได้รับคำรับรองว่า ผู้วิจัยจะปฏิบัติต่อข้าพเจ้าตามข้อมูลที่ระบุไว้ในเอกสาร ชี้แจงอาสาสมัครวิจัยและข้อมูลใดๆ ที่เกี่ยวข้องกับข้าพเจ้า ผู้วิจัยจะ**เก็บรักษาเป็นความลับ** โดยจะนำเสนอข้อมูลการวิจัยเป็นภาพรวมเท่านั้น ไม่มีข้อมูลใดในการรายงานที่จะนำไปสู่ การระบุตัวข้าพเจ้า

หากข้าพเจ้าไม่ได้รับการปฏิบัติตรงตามที่ได้ระบุไว้ในเอกสารชี้แจงอาสาสมัคร วิจัย ข้าพเจ้าสามารถร้องเรียนได้ที่: คณะอนุกรรมการจริยธรรมการวิจัยในคน มหาวิทยาลัยธรรมศาสตร์ ชุดที่ 3 ห้อง 110 ชั้น 1 อาคารปิยชาติ มหาวิทยาลัยธรรมศาสตร์ ศูนย์รังสิต โทรศัพท์ 02-986-9213 ต่อ 7358

ข้าพเจ้าได้ลงลายมือชื่อไว้เป็นสำคัญต่อหน้าพยาน ทั้งนี้ข้าพเจ้าได้รับสำเนาเอกสาร ข้อมูลสำหรับอาสาสมัครวิจัย และสำเนาหนังสือแสดงความยินยอมเข้าร่วมการวิจัยของ อาสาสมัครวิจัยไว้แล้ว

ลงชื่อ	ลงชื่อ
()	()
ผู้วิจัยหลัก	อาสาสมัครวิจัย
วันที่///	วันที่////
ลงชื่อ	ลงชื่อ
()	()
พยาน	พยาน
วันที่//	วันที่///

#### **APPENDIX D**

# PARTICIPANT INFORMATION SHEET (IN THAI) เอกสารให้ข้อมูลสำหรับอาสาสมัครวิจัย (Participant Information Sheet)

**โครงการวิจัยเรื่อง** การพัฒนารูปแบบการดูแลครอบครัวที่มีสมาชิกเป็นโรคหลอดเลือดสมอง เพื่อเสริมสร้างครอบครัวที่มีสุขภาพดี

> (Developing a Family-Based Caring Model for Stroke Survivors to Enhance Healthy Family)

ชื่อผู้วิจัย นาง ปิยรัตน์ ชลสินธุ์

ตำแหน่ง นักศึกษาปริญญาเอก คณะพยาบาลศาสตร์ มหาวิทยาลัยธรรมศาสตร์ สถานที่ติดต่อผู้วิจัย

(ที่ทำงาน) คณะพยาบาลศาสตร์ มหาวิทยาลัยธรรมศาสตร์ อาคารปิยชาติ 99 หมู่ 18 ถนนพหลโยธิน ต.คลองหนึ่ง อ.คลองหลวง จ.ปทุมธานี รหัสไปรษณีย์ 12120

(ที่บ้าน) 848/271 คอนโดยูดีไลท์ 3 ถนนประชาชื่น แขวงวงศ์สว่าง เขตบางซื่อ กรุงเทพมหานคร รหัสไปรษณีย์ 10800

โทรศัพท์ (ที่ทำงาน) 66-2-986 9213 ต่อ 7316-8 โทรศัพท์มือถือ 092-852-6156

E-mail: piyarat022@nurse.tu.ac.th

อาจารย์ที่ปรึกษาวิทยานิพนธ์ รองศาสตราจารย์ ดร. ธีรนุช ห้านิรัติศัย

(ที่ทำงาน) คณะพยาบาลศาสตร์ มหาวิทยาลัยธรรมศาสตร์ อาคารปิยชาติ 99 หมู่ 18 ถนนพหลโยธิน ต.คลองหนึ่ง อ.คลองหลวง จ.ปทุมธานี รหัสไปรษณีย์ 12120 โทรศัพท์ (ที่ทำงาน) 66-2-986 9213 ต่อ 7316-8 โทรศัพท์มือถือ 089-046-0088

E-mail: harnirat@gmail.com

### เรียน อาสาสมัครวิจัยทุกท่าน

ท่านเป็นผู้ที่ได้รับเชิญจากผู้วิจัยให้เข้าร่วมเป็นอาสาสมัครในการวิจัยครั้งนี้ ก่อนที่ท่านจะ ตัดสินใจตกลงเข้าร่วมการวิจัย ขอเรียนให้ท่านทราบถึงเหตุผล และรายละเอียดของการศึกษาวิจัยใน ครั้งนี้ กรุณาใช้เวลาในการอ่านข้อมูลต่อไปนี้อย่างละเอียดรอบคอบ และสามารถสอบถามข้อมูล เพิ่มเติมหรือข้อมูลที่ไม่ชัดเจนได้ตลอดเวลา

การวิจัยครั้งนี้ต้องการทราบถึงวิธีการพัฒนารูปแบบการดูแลครอบครัวเพื่อเสริมสร้างครอบครัว ที่มีสุขภาพดี สำหรับครอบครัวที่มีสมาชิกเป็นโรคหลอดเลือดสมอง โดยทำความเข้าใจสถานการณ์การ ดูแล สำรวจปัญหาและการปรับตัวที่อาจส่งผลกระทบต่อสมาชิกในครอบครัวเมื่อต้องให้การดูแลสมาชิก ที่บ้าน วิธีการวิจัยเน้นการมีส่วนร่วมของสมาชิกในครอบครัว ค้นหาความหมายและปรับเปลี่ยนวิธีการใช้ ชีวิตที่จะทำให้ครอบครัวเป็นครอบครัวที่มีสุขภาพดี เพื่อเพิ่มความสามารถในการดูแลตนเอง และร่วมกัน ค้นหาวิธีการดูแลสมาชิกในครอบครัวที่เจ็บป่วยได้อย่างมีประสิทธิภาพ ลดความรู้สึกการเป็นภาระของ ผู้ดูแล ลดความวิตกกังวลต่าง ๆ ของสมาชิกในครอบครัว และส่งเสริมให้ครอบครัวมีคุณภาพชีวิตที่ดีขึ้น

วัตถุประสงค์หลักในการศึกษาวิจัยครั้งนี้ เพื่อพัฒนารูปแบบการดูแลผู้เป็นโรคหลอดเลือด สมองโดยครอบครัว สำหรับเสริมสร้างครอบครัวที่มีสุขภาพดี โดยมีวัตถุประสงค์ 5 ประการ คือ

 อธิบายประสบการณ์ชีวิตครอบครัวและความต้องการของครอบครัวในการดูแลผู้เป็นโรค หลอดเลือดสมอง

2. อธิบายถึงหน้าที่ของครอบครัวในระหว่างการดูแลผู้เป็นโรคหลอดเลือดสมอง

3. ออกแบบการดูแลผู้เป็นโรคหลอดเลือดสมองโดยครอบครัว

4. ระบุความหมายของครอบครัวที่มีสุขภาพดีสำหรับครอบครัวของผู้เป็นโรคหลอดเลือดสมอง

5. ครอบครัวออกแบบรูปแบบการดูแลของตนเองในการเสริมสร้างครอบครัวที่มีสุขภาพดี

การศึกษาวิจัยครั้งนี้แบ่งออกเป็น 2 ระยะ ซึ่งอาสาสมัครวิจัยต้องมีอายุไม่ต่ำกว่า 18 ปี และมี คุณสมบัติ ดังนี้

ระยะที่ 1 อาสาสมัครวิจัยที่เข้ารับการสัมภาษณ์รายบุคคล จำนวน 40 คน และอาสาสมัครวิจัยที่เข้า ร่วมสนทนากลุ่ม จำนวน 20 คน ซึ่งแบ่งออกเป็น 2 กลุ่ม กลุ่มละ 10 คน ต้องเป็นสมาชิกในครอบครัว ที่รับผิดชอบดูแลสมาชิกที่เป็นโรคหลอดเลือดสมอง อาศัยอยู่ร่วมกันโดยปราศจากการจ้าง มี ความสัมพันธ์กับสมาชิกที่เป็นโรคหลอดเลือดสมองในฐานะ คู่สมรส บุตร บิดามารดา หรือเพื่อน และ รับผิดชอบในการดูแลสมาชิกที่เป็นโรคหลอดเลือดสมองที่บ้าน อย่างน้อย 4 ชั่วโมงต่อวัน

*ระยะที่ 2* อาสาสมัครวิจัยที่เข้าร่วมการวิจัยเชิงปฏิบัติการแบบมีส่วนร่วม ต้องมาจากครอบครัวที่มี สมาชิกเป็นโรคหลอดเลือดสมอง จำนวน 20 ครอบครัว ซึ่งประกอบด้วย สมาชิกในครอบครัวตั้งแต่ สองคนขึ้นไป ผู้เป็นโรคหลอดเลือดสมอง เป็นผู้ที่อยู่ในระยะเรื้อรัง โดยไม่มีภาวะแทรกซ้อน สามารถ เข้าใจและสื่อสารได้ สมาชิกในครอบครัวมีความสัมพันธ์กันในฐานะคู่สมรส บุตร บิดามารดา หรือ เพื่อน พักอาศัยอยู่ร่วมกับผู้เป็นโรคหลอดเลือดสมอง หรืออาศัยอยู่ในครัวเรือนอื่นขึ้นอยู่กับ สถานการณ์ แต่ต้องมีการติดต่อกับครอบครัวของผู้เป็นโรคหลอดเลือดสมองอย่างน้อย 4 ครั้งต่อ สัปดาห์ และผู้เป็นโรคหลอดเลือดสมองและสมาชิกในครอบครัวยินดีที่จะดูแลตัวเองและตกลงที่จะ ทำงานร่วมกัน และอาสาสมัครจะได้รับการยกเว้นการเข้าร่วมวิจัยเมื่อผู้เป็นโรคหลอดเลือดสมองนอน โรงพยาบาลหรือเสียชีวิต กระบวนการการวิจัยที่อาสาสมัครวิจัยจะได้รับจากผู้วิจัย ภายหลังตกลงเข้าร่วมการ ศึกษาวิจัย มีดังต่อไปนี้

ระยะที่ 1 - อาสาสมัครวิจัยที่สมัครใจเข้าร่วมการสัมภาษณ์ ตอบแบบสอบถามข้อมูลส่วนบุคคล จำนวน 3 หัวข้อใหญ่ หรือ 33 ข้อย่อย หนึ่งครั้ง ผู้วิจัยขออนุญาตสัมภาษณ์ที่บ้านของท่าน โดยผู้วิจัย จะนัดหมายล่วงหน้าก่อนเข้าทำการสัมภาษณ์ ซึ่งใช้เวลาทั้งสิ้นประมาณ 90-120 นาทีต่อครั้ง การ สัมภาษณ์อาจจะมากกว่าหนึ่งครั้งขึ้นอยู่กับความสะดวกของท่าน ในระหว่างการสัมภาษณ์ผู้วิจัยขอ อนุญาตบันทึกเสียง และจดบันทึกการสนทนาเพื่อความถูกต้องของเนื้อหา

- อาสาสมัครวิจัยที่สมัครใจเข้าร่วมการสนทนากลุ่ม หนึ่งครั้ง พร้อมตอบแบบสอบถาม ข้อมูลส่วนบุคคลภายหลังเสร็จการสนทนากลุ่ม จำนวน 3 หัวข้อใหญ่ หรือ 33 ข้อย่อย นัดหมาย สถานที่ในการใช้สนทนากลุ่มตามที่กลุ่มสะดวก เช่น ศาลาประชาคมของชุมชน หรือโรงพยาบาล ส่งเสริมสุขภาพตำบล เป็นต้น ผู้วิจัยขออนุญาตนำเสนอหัวข้อการสนทนากลุ่มและสังเกตการณ์ขณะ ดำเนินการสนทนากลุ่ม ซึ่งใช้เวลาทั้งสิ้นประมาณ 90-120 นาที ผู้วิจัยขออนุญาตบันทึกเสียง และจด บันทึกการสนทนาเพื่อความถูกต้องของเนื้อหาในระหว่างทำการสนทนากลุ่ม

ระยะที่ 2 อาสาสมัครวิจัยที่สมัครใจเข้าร่วมการวิจัยเชิงปฏิบัติการแบบมีส่วนร่วม ตอบแบบสอบถาม ข้อมูลของครอบครัวหนึ่งครั้ง รวมถึงผู้วิจัยขึ้แจงรายละเอียดและวิธีการเข้าร่วมในกระบวนการวิจัยครั้งนี้ ซึ่งใช้ระยะเวลาทั้งสิ้น 4 เดือน โดยผู้ดูแลผู้เป็นโรคหลอดเลือดสมองเข้าร่วมอภิปรายกลุ่มครอบครัว 4 ครั้งต่อเดือน ซึ่งใช้เวลาประมาณ 90-120 นาทีต่อครั้ง และร่วมกันออกแบบกิจกรรมให้กับสมาชิกในแต่ ละครอบครัว ซึ่งสมาชิกจะนำรูปแบบการดูแลที่ได้ไปปรับใช้ในครอบครัวของตนเองเพื่อเสริมสร้าง ครอบครัวที่มีสุขภาพดี หากอาสาสมัครวิจัยไม่สามารถเข้าร่วมอภิปรายกลุ่มครอบครัวได้ตาม กำหนดการ อาจส่งตัวแทนสมาชิกที่มีส่วนร่วมในการดูแลผู้เป็นโรคหลอดเลือดสมองในครอบครัวได้ตาม กำหนดการ อาจส่งตัวแทนสมาชิกที่มีส่วนร่วมในการดูแลผู้เป็นโรคหลอดเลือดสมองในครอบครัวได้ตาม ร่วมอภิปรายกลุ่มครอบครัวแทน หรือนัดหมายกับผู้วิจัยเพื่อให้ข้อมูลที่ได้จากการอภิปรายกลุ่มครอบครัว แต่ละครั้งผู้วิจัยขออนุญาตในการเข้าร่วมสังเกตการณ์ และบันทึกข้อมูล ทั้งนี้ ผู้วิจัยจะขออนุญาต เยี่ยมบ้านสังเกตการณ์กิจกรรมในบางครอบครัว โดยนักวิจัยจะช่วยอำนวยความสะดวก สนับสนุน และ กระตุ้นให้สมาชิกในครอบครัวพูดคุยเกี่ยวกับความคืบหน้าของกิจกรรมการดูแลผู้เป็นโรคหลอดเลือด สมองในสภาพแวดล้อมที่บ้าน รวมถึงผู้วิจัยขออนุญาตทำการบันทึกข้อมูลโดยการจดเป็นตัวหนังสือ ภาพถ่าย และบันทึกเสียงเพื่อความถูกต้องของข้อมูล

ในการเข้าร่วมเป็นอาสาสมัครวิจัยครั้งนี้ เป็นการให้ข้อมูลโดย**สมัครใจ** และท่านสามารถ **ปฏิเสธ**ที่จะเข้าร่วมหรือ**ถอนตัว**จากการวิจัยได้ทุกขณะ โดยไม่ต้องให้เหตุผลและไม่สูญเสียประโยชน์ที่ พึงได้รับ และไม่มีผลกระทบต่อการดูแลรักษาพยาบาลแต่อย่างใด ระหว่างการสัมภาษณ์ หรือทำ กิจกรรม ท่านมีอิสระในการให้สัมภาษณ์ และสามารถปฏิเสธการตอบในข้อคำถามที่ท่านรู้สึกไม่สบาย

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ใจได้ ผู้วิจัยจะใช้รหัสแทนชื่อและนามสกุลจริงของท่านลงในแบบบันทึกข้อมูล โดยแบบบันทึกการ สนทนา ภาพถ่าย และการเสียงการสัมภาษณ์ จะถูกทำลายภายในระยะเวลา 2 ปีหลังเสร็จสิ้นการ วิจัย จะไม่มีการเผยแพร่ภาพถ่ายที่มีรูปของท่านแก่สาธารณะ หากผู้วิจัยมีความจำเป็นต้องแสดง ภาพถ่ายที่มีรูปของท่านจะแจ้งท่านทุกครั้ง ผู้วิจัยจะระมัดระวังไม่ให้เห็นภาพหน้าทั้งหมดของท่าน และจะใช้แสดงเพื่อประโยชน์ทางวิชาการเท่านั้น หากท่านมีข้อสงสัยให้สอบถามเพิ่มเติมได้โดย สามารถติดต่อผู้วิจัยได้ตลอดเวลา และหากผู้วิจัยมีข้อมูลเพิ่มเติมที่เป็นประโยชน์หรือโทษเกี่ยวกับการ วิจัย ผู้วิจัยจะแจ้งให้ท่านทราบอย่างรวดเร็ว**เพื่อให้ท่านทบทวนว่ายังสมัครใจจะอยู่ในงานวิจัยต่อไป** หรือไม่

การเข้าร่วมโครงการวิจัยของอาสาสมัครครั้งนี้ ท่านจะได้รับความรู้ในการดูแลตนเองและ สมาชิกที่ป่วย รวมถึงสมาชิกคนอื่นๆ ในครอบครัวของท่าน โดยการนำความรู้ที่ได้ไปปรับเปลี่ยน บทบาทใหม่เพื่อเผชิญกับการเปลี่ยนแปลงที่เกิดขึ้นในการดำรงชีวิตประจำวัน การปรับตัวเพื่อให้อยู่ ร่วมกับสมาชิกที่เจ็บป่วยได้อย่างมีความสุข เพื่อสร้างครอบครัวที่มีสุขภาพดี ทั้งนี้ การเข้าร่วม โครงการวิจัยอาจส่งกระทบโดยตรงต่อความไม่สบายกายจิตใจ อารมณ์และความรู้สึกของท่าน หรือ สมาชิกในครอบครัวของท่าน ซึ่งผู้วิจัยมีการจัดการความเสี่ยงทางสุขภาพระหว่างดำเนินการวิจัย ในช่วงการสัมภาษณ์ หรือทำกิจกรรมกลุ่ม หากอาสาสมัครวิจัยมีปัญหาสุขภาพใดๆ เกิดขึ้น ผู้วิจัยจะ หยุดกิจกรรมทันที และติดต่อ ประสานงาน ส่งต่อ เพื่อเข้ารับบริการดูสุขภาพตามสิทธิการรักษาของ อาสาสมัครวิจัย

ผู้วิจัยขอรับรองว่าข้อมูลการวิจัยที่ได้รับจากท่านจะถูก**เก็บเป็นความลับ** ไม่มีการะบุชื่อหรือ ข้อมูลส่วนตัวของท่าน ซึ่งจะไม่ทำให้เกิดความเสียหายและผลกระทบแก่ท่านแต่ประการใด จะ นำเสนอเพียงผลการวิจัยในภาพรวมเท่านั้น ข้อมูลใดที่สามารถระบุถึงตัวท่านได้จะไม่ปรากฏใน รายงานการวิจัย ทั้งนี้ท่านที่ได้รับการสัมภาษณ์ และท่านที่เข้าร่วมการสนทนากลุ่ม ของการวิจัยใน *ระยะที่ 1* จะได้รับของที่ระลึกเป็นกระเป๋าผ้า ลูกบอลบีบบริหารมือ และคู่มือสุขภาพประจำบ้านเรื่อง การดูแลผู้ป่วยโรคหลอดเลือดสมองฉบับครอบครัว เพื่อตอบแทนการเป็นอาสาสมัครวิจัย และสำหรับ ท่านที่เข้าร่วมการสนทนากลุ่ม ของการวิจัยใน*ระยะที่ 1* รวมถึงท่านที่เข้าร่วมการวิจัยเชิงปฏิบัติการ แบบมีส่วนร่วม ใน*ระยะที่ 2* ผู้วิจัยได้จัดเตรียมอาหารว่าง หรืออาหารกลางวัน สำหรับท่านในวันและ เวลาที่มีการทำกลุ่มสนทนา รวมถึงผู้วิจัยจะเป็นผู้รับผิดชอบเรื่องยานพาหนะและค่าใช้จ่ายในการ เดินทางครั้งละ 200 บาท อาสาสมัครไม่ต้องเสียค่าใช้จ่ายในการวิจัยเพิ่มเติม

หากท่านไม่ได้รับการปฏิบัติตามข้อมูลดังกล่าวสามารถร้องเรียนได้ที่ : คณะอนุกรรมการ จริยธรรมการวิจัยในคน มหาวิทยาลัยธรรมศาสตร์ ชุดที่ 3 ห้อง 110 ชั้น 1 อาคารปิยชาติ มหาวิทยาลัยธรรมศาสตร์ ศูนย์รังสิต โทรศัพท์ 02-986-9213 ต่อ 7358

### **APPENDIX E**

## **DEMOGRAPHIC DATA (IN THAI)**

# แบบสอบถามข้อมูลทั่วไปของผู้เข้าร่วมวิจัยในระยะที่ 1

# 1. ข้อมูลส่วนบุคคลของผู้ดูแล

1.1 เพศ	🗌 ชาย	□หญิง
1.2 อายุปี		
1.3 สถานภาพสมรส		
่ □โสด	สมรส	่ □หม้าย/หย่า/แยกกันอยู่
1.4 สถานภาพในคระ	อบครัว	
ทั่วหน้าครอบครัว		🗖 สมาชิกในครอบครัว
1.5 การศึกษา		
ประถมศึกษาหรือ	ต่ำกว่า	มัธยมศึกษาตอนต้น
🗖 มัธยมศึกษาตอนเ	ปลาย	🗖 ปริญญาตรีหรือสูงกว่า
1.6 การประกอบอาจ์	ช้พในปัจจุบัน	
่่ ่ ่ ่ ่ ่ ่		□ไม่ได้ทำงาน
1.7 จำนวนสมาชิกใน	เครอบครัว	คน
1.8 รายได้ของครอบ	ครัวต่อเดือนประมาณ	บาท
1.9 ที่มาของรายได้เจ	วพาะผู้ดูแลในปัจจุบัน	
1.10 ความเพียงพอ	ของรายได้	
🗖 เพียงพอเหลือเก็บ		🗖 เพียงพอแต่ไม่เหลือเก็บ
อขัดสนบ้าง		ไม่เพียงพอ
1.11 สิทธิการรักษา	พยาบาลหลัก	
🗖 ข้าราชการ/รัฐวิส	าหกิจ	🗖 ประกันสังคม
🗖 ประกันสุขภาพถ้ว	านหน้า	่ □อื่นๆ
1.12 ระยะเวลาของ	การเป็นผู้ดูแลผู้เป็นโรคหล	าอดเลือดสมองบีเดือน
1.13 เคยมีประสบก	ารณ์ในการดูแลผู้ป่วยมาก่	อนหรือไม่
🗖 เคย ระบุระยะเว	ลาในการดูแลปี	□ไม่เคย
1.14 ความสัมพันธ์ก่	<b>้</b> บผู้เป็นโรคหลอดเลือดสม	อง
1.15 ต้องรับผิดชอบ	เดูแลบุคคลอื่นนอกเหนือจ	ากผู้เป็นโรคหลอดเลือดสมองหรือไม่

2.	[ 1 	<ul> <li>□ต้องดูแลบุคคลอื่า</li> <li>มิใครบ้างโปรดระ</li> <li>บุคคลนั้นป่วยเป็า</li> <li>.16 ขณะนี้ท่านรู้สี</li> </ul>	ู่ ใปู	อดสมองจำนวนคน
	Ū	1 เพศ	ชาย	□หญิง
		2 อายุโ		
	- //_	่⊒โสด		่ ☐หม้าย/หย่า/แยกกันอยู่
	2	4 สถานภาพในคร	อบครัวก่อนที่จะเป็นโรคห	ů
		ไห้วหน้าครอบครัว	3	🗖 สมาชิกในครอบครัว
	2	5 การศึกษา		
		<b>_</b> ประถมศึกษาหรื	อต่ำกว่า	🛙 มัธยมศึกษาตอนต้น
	۵	]มัธยมศึกษาตอน	ปลาย	🗖 ปริญญาตรีหรือสูงกว่า
	2	.6 การประกอบอา	ชีพก่อนที่จะเป็นโรคหลอด	เลือดสมอง
	C	]ทำงาน		่ []ไม่ได้ทำงาน
	2	.7 จำนวนปีที่เป็นโ	รคหลอดเลือดสมอง	เดือน
	2	.8 ภายหลังจากเป็ง	นโรคหลอดเลือดสมอง ท่า	นคิดว่าผู้ป่วยต้องการความช่วยเหลือใน
	Ø	้านใดมากที่สุด เพร	าะเหตุใด	
3.	ประเร	มินความสามารถใเ	นการดำเนินชีวิตประจำวั	นของผู้เป็นโรคหลอดเลือดสมอง
	3	.1 รับประทานอาห	กรที่เตรียมสำรับไว้ให้เรียง	บร้อยต่อหน้า
	[	🛛 ไม่สามารถตักอา	าหารเข้าปากได้เอง ต้องมีค	านป้อน
	[	🗋 ตักอาหารเองได้	แต่ต้องมีคนช่วย เช่น ใช้ช้า	อนตักไว้ให้หรือตัดชิ้นเล็กๆไว้ล่วงหน้า
	[	🗋 ตักอาหารรับประ	ะทานได้เอง	
	3	.2 การอาบน้ำ		
	C	ไม่สามารถทำเอ	งได้	
	۵	🛛 อาบน้ำเองได้		

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3.3 ล้างหน้า หวีผม แปรงฟัน โกนหนวด เมื่อเตรียมอุปกรณ์ไว้ให้

🔲 ต้องให้ความช่วยเหลือ

🛛 ทำเองได้

3.4 การสวมใส่เสื้อผ้าที่เตรียมไว้ให้

🔲 ต้องมีคนสวมใส่ให้ ทำเองไม่ได้หรือทำได้น้อย

🔲 ต้องให้ความช่วยเหลือบ้าง เช่น การติดกระดุม รูดซิบ

🔲 ใส่เสื้อผ้าได้เอง ไม่ต้องการความช่วยเหลือ

3.5 การใช้ห้องน้ำ

🗖 ช่วยเหลือตัวเองไม่ได้

🔲 ทำความสะอาดตัวเองได้ภายหลังจากขับถ่าย แต่ต้องการความช่วยเหลือในบางสิ่ง

🛛 ช่วยเหลือตัวเองได้ดี ไม่ต้องให้ความช่วยเหลือ

3.6 ลุกนั่งจากที่นอน หรือจากเตียงไปยังเก้าอี้

🔲 ไม่สามารถนั่งได้ (นั่งแล้วจะล้มเสมอ)

🔲 ต้องให้ความช่วยเหลืออย่างมากจึงจะนั่งได้ เช่น ใช้คนพยุงหรือดันขึ้นมา

🔲 ให้ความช่วยเหลือบ้าง เช่น ช่วยพยุงเล็กน้อย หรือต้องมีคนดูแลเพื่อความปลอดภัย

🔲 ทำได้เอง ไม่ต้องให้ความช่วยเหลือ

3.7 การเคลื่อนที่ภายในห้องหรือบ้าน

🔲 ต้องให้ความช่วยเหลือในการเคลื่อนย้าย

🔲 นั่งรถเข็น

🔲 เดินหรือเคลื่อนที่โดยมีคนช่วยพยุง

🔲 เดินหรือเคลื่อนที่ได้เองอย่างอิสระ รวมถึงการใช้อุปกรณ์ช่วยเหลือ เช่น ไม้เท้า

3.8 การขึ้น-ลงบันได

🗖 ต้องให้ความช่วยเหลือ

🔲 ขึ้น-ลงได้เอง

3.9 การควบคุมการถ่ายอุจจาระ

🗖 กลั้นไม่ได้ หรือต้องสวนอุจจาระอยู่เสมอ

🛛 กลั้นไม่ได้บางครั้ง

🔲 ควบคุมการขับถ่ายได้เป็นปกติ

3.10 การกลั้นปัสสาวะ

🛛 กลั้นไม่ได้ ต้องสวนหรือใส่สายสวนปัสสาวะ

🔲 กลั้นไม่ได้บางครั้ง

🛛 กลั้นได้ปกติ

# แบบสอบถามข้อมูลทั่วไปของครอบครัวที่เข้าร่วมวิจัยในระยะที่ 2

รหัสครอบครัว: \_\_\_\_\_

# ข้อมูลของสมาชิกในครอบครัว:

รหัส สมาชิก	สถานะใน ครอบครัว /บทบาท	เพศ	อายุ	สถานภาพ สมรส	ศาสนา	การศึกษา	อาชีพ	ระยะเวลา ในการ ดูแลผู้ป่วย
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-	ระยะเวลาที่ครอบครัวอาศัยอยู่ในพื้นที่
-	กิจกรรมที่สมาชิกในครอบครัวปฏิบัติร่วมกันเป็นประจำในชีวิตประจำวัน
	ความบ่อยของกิจกรรมที่ได้ทำร่วมกัน
-	กิจกรรมที่สมาชิกในครอบครัวทำร่วมกันในโอกาสสำคัญ
	ความบ่อยของกิจกรรมที่ได้ทำร่วมกัน
-	กิจกรรมที่สมาชิกในครอบครัวทำร่วมกันในวันสำคัญต่างๆ
	ความบ่อยของกิจกรรมที่ได้ทำร่วมกัน
-	สมาชิกในครอบครัวมักทะเลาะเบาะแว้ง ขัดแย้ง หรือขัดใจกันในเรื่องใด
-	

#### APPENDIX F

### **INTERVIEW GUIDE (IN THAI)**

### คำถามในการสัมภาษณ์และสนทนากลุ่ม ระยะที่ 1

#### 1. โครงสร้างทั่วไปของครอบครัวที่มีสมาชิกเป็นโรคหลอดเลือดสมอง

- สมาชิกในครอบครัวประกอบด้วยใครบ้าง
- ในครอบครัวผู้ที่มีส่วนร่วมในการดูแลสมาชิกที่เป็นโรคหลอดเลือดสมองมีใครบ้าง
- สัมพันธภาพระหว่างสมาชิกในครอบครัวที่เป็นโรคหลอดเลือดสมองและสมาชิกคนอื่น ๆ ในครอบครัว
   ของท่านเป็นอย่างไรบ้าง เช่น ความสนิทสนม ความใกล้ชิด หรือความขัดแย้ง

#### 2. ปัจจัยที่เกี่ยวข้องกับครอบครัว

- กิจกรรมที่คุณและสมาชิกคนอื่นๆ ในครอบครัวทำร่วมกันเป็นประจำในชีวิตประจำวัน โอกาสสำคัญ หรือในวันสำคัญต่างๆ เป็นอย่างไรบ้าง
- คุณได้รับความรู้ในการดูแลผู้เป็นโรคหลอดเลือดสมองอย่างไร
- คุณดูแลสมาชิกคนอื่นๆ ในครอบครัวก่อนเกิดโรคหลอดเลือดสมองอย่างไร และปัจจุบันการดูแล แตกต่างหรือไม่อย่างไร
- ในส่วนของตัวคุณเอง เรื่องการดูแลตัวเองมีการปรับเปลี่ยนอย่างไร
- คุณพูดคุยกับคนอื่นๆ ในครอบครัวเรื่องการดูแลซึ่งกันและกันอย่างไร
- คุณมีความรู้สึกอย่างไรในการดูแลสมาชิกที่ป่วย และจัดการกับความรู้สึกนั้นอย่างไร ด้วยวิธีการใด
- เมื่อเกิดภาวะวิกฤติในครอบครัว คุณจัดการกับสถานการณ์นั้นอย่างไร
- อะไรคือสิ่งที่ช่วยหรือสนับสนุนให้คุณดูแลสมาชิกในครอบครัวที่เป็นโรคหลอดเลือดสมอง
- การเจ็บป่วยที่เกิดขึ้นกับครอบครัว คุณมีความเชื่ออย่างไร มีสิ่งยึดเหนี่ยวจิตใจหรือไม่อย่างไร
- 3. เป้าหมายสูงสุดของการดูแลสมาชิกในครอบครัวที่เป็นโรคหลอดเลือดสมอง
- จากที่ดูแลผู้เป็นโรคหลอดเลือดสมองมาอยากเห็นภาพ หรือคาดการณ์ว่าเขาต้องเป็นอย่างไร
- คุณคิดว่าสมาชิกคนอื่นๆ ในครอบครัวมีความคาดหวังอย่างไร
- ในภาพรวมคุณมีความคาดหวังให้ครอบครัวของคุณเป็นอย่างไร
- 4. วางแผนเพื่อให้ชีวิตครอบครัวมีสุขภาพดี
- ครอบครัวที่มีสุขภาพดีในความคิดของคุณเป็นอย่างไร
- ปัจจุบันคุณคิดว่าครอบครัวของคุณสุขภาพเป็นอย่างไร
- ทำอย่างไรครอบครัวครอบครัวของคุณจะมีสุขภาพดีอย่างที่คุณคาดหวัง

หมายเหตุ: คำถามมีการเปลี่ยนแปลงได้ตามข้อมูลที่ปรากฏและเมื่อต้องการเจาะลึกในประเด็นนั้นๆ

# APPENDIX G PARTICIPATORY ACTION RESEARCH GUIDELINE (IN THAI) แนวทางการวิจัยเชิงปฏิบัติการแบบมีส่วนร่วมในระยะที่ 2

#### แผนการวิจัยเชิงปฏิบัติการแบบมีส่วนร่วม:

- ผู้วิจัยคัดเลือกครอบครัวที่มีสมาชิกเป็นโรคหลอดเลือดสมองในระยะเรื้อรัง โดยวิธีสุ่มตัวอย่าง แบบเฉพาะเจาะจง และแบบบอกต่อ จำนวน 20 ครอบครัว ที่มีคุณสมบัติตรงตามเกณฑ์และตกลงที่จะ เข้าร่วมในกระบวนการวิจัยเชิงปฏิบัติการ จากรายชื่อของผู้เป็นโรคหลอดเลือดสมองในพื้นที่ให้บริการ ของโรงพยาบาลส่งเสริมสุขภาพตำบล ในชุมชนกึ่งเมืองของประเทศไทย พร้อมทั้งแนบเอกสารชี้แจง ข้อมูลเกี่ยวกับโครงการวิจัยและเอกสารแสดงความยินยอมเข้าร่วมวิจัย รวมถึงให้สมาชิกในครอบครัวลง นามรับทราบ และอนุญาตให้ผู้วิจัยบันทึกข้อมูลขณะทำการศึกษาวิจัย

 - แต่ละครอบครัวจะได้รับเชิญให้เข้าร่วมในการอภิปรายกลุ่มครอบครัว โดยจะแบ่งออกเป็น 2 กลุ่ม กลุ่มละ 10 ครอบครัว เพื่อใช้ข้อมูลในการตรวจสอบแบบสามเส้า

 กระบวนการในการวิจัยเชิงปฏิบัติการแบบมีส่วนร่วมจะดำเนินการในระยะเรื้อรังของโรค หลอดเลือดสมอง ในบรรยากาศสภาพแวดล้อมที่บ้าน

- การอภิปรายกลุ่มครอบครัวจะดำเนินการที่ห้องประชุมของโรงพยาบาลส่งเสริมสุขภาพตำบล
 4 ครั้งต่อเดือน หรือในสถานที่ และเวลาที่สมาชิกกลุ่มสะดวก

 ผู้วิจัยเป็นผู้แนะนำหัวข้อสำหรับการอภิปราย และสนับสนุนกลุ่มในฐานะผู้อำนวยความ สะดวกและเป็นผู้ช่วยเมื่อครอบครัวร้องขอ

สมาชิกในแต่ละครอบครัวที่เข้าร่วมในกระบวนการวิจัย จะดำเนินการเพื่อจัดการกับอุปสรรค
 ของตนเอง กำหนดเป้าหมายและผลลัพธ์ รวมถึงออกแบบกิจกรรมของตนเอง

กระบวนการ ในการวิจัยเชิงปฏิบัติการแบบมีส่วนร่วมมี 4 วงรอบ แต่ละวงรอบจะใช้รูปแบบ
 วิธีการวิจัยเชิงปฏิบัติการประกอบด้วย 4 ขั้นตอน คือ การวางแผน การลงมือปฏิบัติ การสังเกต และการ
 สะท้อนกลับ

## เกณฑ์สำหรับเลือกครอบครัวของผู้เป็นโรคหลอดเลือดสมองในกระบวนการวิจัยเชิงปฏิบัติการ แบบมีส่วนร่วม:

 ครอบครัวไทยที่มีสมาชิกเป็นโรคหลอดเลือดสมอง ซึ่งประกอบด้วยสมาชิกตั้งแต่สองคนขึ้น ไป อายุอย่างน้อย 18 ปี  สมาชิกในครอบครัวของผู้เป็นโรคหลอดเลือดสมอง กำหนดความสัมพันธ์ภายในครอบครัว ในฐานะคู่สมรส บุตร บิดามารดา พี่ น้อง หรือเพื่อน

 พักอาศัยอยู่ร่วมกับผู้เป็นโรคหลอดเลือดสมอง หรืออาศัยอยู่ในครัวเรือนอื่นขึ้นอยู่กับ สถานการณ์ แต่ต้องมีการติดต่อกับครอบครัวของผู้เป็นโรคหลอดเลือดสมองอย่างน้อย 4 ครั้งต่อสัปดาห์

 4. ผู้เป็นโรคหลอดเลือดสมองและสมาชิกในครอบครัวยินดีที่จะดูแลตัวเองและตกลงที่จะ ทำงานร่วมกัน

#### กระบวนการวิจัยเชิงปฏิบัติการแบบมีส่วนร่วม:

1. ขั้นตอนของกระบวนการวิจัยในแต่ละวงรอบ:

ขั้นตอนของการวางแผน คือการประชุมสนทนากลุ่มครอบครัวโดยจัดให้มีตัวแทนของ
 ครอบครัวประมาณ 10 ครอบครัวต่อกลุ่ม ซึ่งแต่ละกลุ่มจะร่วมมือกันประเมินความต้องการ ความคิด
 ความเชื่อ และความคาดหวังในการดูแลของแต่ละครอบครัว รวมถึงปัจจัยที่นำพาครอบครัวไปสู่
 ครอบครัวที่มีสุขภาพดี และร่วมกันออกแบบกลยุทธ์สำหรับการดูแลผู้รอดชีวิตจากโรคหลอดเลือดสมอง
 และจะกำหนดเป้าหมายร่วมกันเพื่อบรรลุเป้าหมายครอบครัวที่ตั้งไว้

ขั้นตอนของการปฏิบัติและการสังเกต แต่ละครอบครัวจะนำกลยุทธ์ที่ได้จากการอภิปรายกลุ่ม
 ครอบครัวไปปฏิบัติ และสังเกตการณ์กิจกรรมในครอบครัวของพวกเขา นักวิจัยจะช่วยอำนวยความ
 สะดวก สนับสนุน และกระตุ้นให้สมาชิกในครอบครัวพูดคุยเกี่ยวกับความคืบหน้าของกิจกรรมการดูแลผู้
 เป็นโรคหลอดเลือดสมองในสภาพแวดล้อมที่บ้านเมื่อครอบครัวร้องขอ

 ขั้นตอนการสะท้อนกลับ จะเป็นการอภิปรายกลุ่มครอบครัว ซึ่งแต่ละกลุ่มจะร่วมมือกัน ประเมินประเมินผลและสรุปกลยุทธ์ที่ได้นำไปปฏิบัติมาวางแผนปรับกลยุทธ์ใหม่ที่จะนำไปปฏิบัติในรอบ ถัดไป

- 2. ระยะเวลาที่ใช้ในแต่ละขั้นตอน:
  - ขั้นตอนการวางแผน สัปดาห์ที่ 1
  - ขั้นตอนของการปฏิบัติและการสังเกต สัปดาห์ที่ 2-3
  - ขั้นตอนการสะท้อนกลับ สัปดาห์ที่ 4

วงรอบ	กระบวนการ
วงรอบที่ 1	ขั้นตอนการวางแผน 1:
ได้ปัจจัยสู่ความสำเร็จสำหรับปรับ	การนำรูปแบบจำลองของการดูแลครอบครัวผู้เป็นโรคหลอดเลือดสมอง
ชีวิตครอบครัวให้มีสุขภาพดี	(Pre-FBCM) ไปใช้เพื่อสร้างครอบครัวที่มีสุขภาพดี:
0 9511 90 0119 9251992 091 1921	> ตรวจสอบปัจจัยที่นำไปสู่ความสำเร็จในการปรับชีวิตครอบครัวให้มี สุขภาพดี
	<ul> <li>รางกลยุทธ์ในการสื่อสารกับสมาชิกในครอบครัวเกี่ยวกับการดูแลผู้เป็น</li> <li>โรคหลอดเลือดสมอง</li> </ul>
	<ul> <li>&gt; ค้นหาความสามารถหรือทรัพยากรเพื่อเพิ่มประสิทธิภาพในการดูแลผู้</li> <li>เป็นโรคหลอดเลือดสมอง</li> </ul>
	> สำรวจความเชื่อและวัฒนธรรมที่เพิ่มความแข็งแกร่งให้กับครอบครัว ของผู้เป็นโรคหลอดเลือดสมอง
	<ul> <li>ตั้งเป้าหมายสูงสุดสำหรับชีวิตครอบครัวที่มีสุขภาพดีของครอบครัวผู้</li> <li>เป็นโรคหลอดเลือดสมอง</li> </ul>
R	> พัฒนากลยุทธ์ในการดูแลผู้เป็นโรคหลอดเลือดสมองซึ่งประกอบด้วย
	การระดมทรัพยากรของครอบครัวเพิ่มความแข็งแกร่งของครอบครัว
	เสริมสร้างความสามารถในการดูแลครอบครัว วิธีการดูแล และรูปแบบ
	การเผชิญปัญหาเชิงบวกเพื่อสร้างสมดุลในชีวิตครอบครัว
	ขั้นตอนของการปฏิบัติและการสังเกต 1:
	> ดำเนินการดูแลตามกลยุทธ์ที่ได้วางแผนไว้ และสังเกตกิจกรรมของพวก
	เขาโดยผู้ดูแล ซึ่งในแต่ละครอบครัว ผู้ดูแลจะมีการปรับกิจกรรมไปพร้อม กับสมาชิกคนอื่น ๆ
	ขั้นตอนการสะท้อนกลับ 1:
	> ประเมินการใช้กลยุทธ์รวมถึงชี้แจงอุปสรรค ความสำเร็จตามเป้าหมาย
	และข้อเสนอแนะของการกำหนดวิธีในการปรับชีวิตครอบครัวให้เป็น
	ครอบครัวมีสุขภาพดี
วงรอบที่ 2	ขั้นตอนการวางแผน 2:
เข้าใจและได้กลยุทธ์เพื่อปรับชีวิต	> นำข้อเสนอแนะที่ได้จากวงรอบที่ 1 มาปรับเปลี่ยนกลยุทธ์และวิธีการสู่
ครอบครัวให้มีสุขภาพดี	ความสำเร็จใหม่ เพื่อให้บรรลุเป้าหมาย "ครอบครัวที่มีสุขภาพดี"
	ขั้นตอนของการปฏิบัติและการสังเกต 2:
	> ดำเนินการดูแลตามแนวปฏิบัติที่ปรับเปลี่ยนใหม่ตามขั้นตอนการ
	วางแผน 2 ทดสอบความเป็นไปได้ดำเนินการในวิธีการใหม่และสังเกตโดย

วงรอบ	กระบวนการ
	ผู้ดูแลในแต่ละครอบครัว พร้อมเลือกวิธีการที่เหมาะสมกับครอบครัวของ ตนเอง <i>ขั้นตอนการสะท้อนกลับ 2:</i> > ประเมินปัญหา และอุปสรรค พูดคุยถึงความรู้สึกและข้อเสนอแนะ เกี่ยวกับการแก้ไข และความเป็นไปได้ในการเลือกใช้กลยุทธ์เพื่อให้บรรลุ เป้าหมาย "ครอบครัวที่มีสุขภาพดี"
<b>วงรอบที่ 3</b> ได้รูปแบบการดูแลครอบครัวเพื่อ สร้างครอบครัวที่มีสุขภาพดี	<ul> <li>ขั้นตอนการวางแผน 3:</li> <li>&gt; นำข้อเสนอแนะที่ได้จากขั้นตอนการสะท้อนกลับ 2 มาปรับเปลี่ยน รูปแบบกลยุทธ์ที่เหมาะสมสำหรับครอบครัวของผู้เป็นโรคหลอดเลือด สมองใหม่ เพื่อให้บรรลุเป้าหมาย "ครอบครัวที่มีสุขภาพดี"</li> <li>ขั้นตอนของการปฏิบัติและการสังเกต 3:</li> <li>&gt; นำกลยุทธ์การดูแลตามแนวปฏิบัติที่ปรับเปลี่ยนใหม่ตามขั้นตอนการ วางแผน 3 มาใช้และทำการสังเกตปัจจัยความสำเร็จของการดูแล การ ปรับบทบาทผู้ดูแล สมาชิกและผู้เป็นโรคหลอดเลือดสมองให้เหมาะสม ขั้นตอนการสะท้อนกลับ 3:</li> <li>&gt; สรุปและประเมินความสำเร็จในการเปลี่ยนแปลงของสมาชิกในครอบครัว ของผู้เป็นโรคหลอดเลือดสมอง</li> </ul>
<b>วงรอบที่ 4</b> ยืนยันรูปแบบการดูแลครอบครัว เพื่อสร้างครอบครัวที่มีสุขภาพดี	<ul> <li>ขั้นตอนการวางแผน 4:</li> <li>สรุปรูปแบบของการดูแลครอบครัวผู้เป็นโรคหลอดเลือดสมอง (FBCM)</li> <li>ออกมาเป็นรูปแบบที่ชัดเจน เพื่อให้บรรลุเป้าหมายของการสร้างครอบครัวที่</li> <li>มีสุขภาพดี</li> <li>ขั้นตอนของการปฏิบัติและการสังเกต 4:</li> <li>การนำรูปแบบสรุปการดูแลครอบครัวผู้เป็นโรคหลอดเลือดสมอง (FBCM)</li> <li>มาใช้ และทำการสังเกตโดยผู้ดูแลในแต่ละครอบครัว</li> <li>ขั้นตอนการสะท้อนกลับ 4:</li> <li>ประเมินผลการนำรูปแบบการดูแลครอบครัวผู้เป็นโรคหลอดเลือดสมอง</li> <li>(FBCM) ซึ่งสามารถสร้างครอบครัวที่มีสุขภาพดีที่เหมาะสมกับแต่ละ</li> <li>ครอบครัว และรายงานผลเป็นรูปแบบการดูแลที่สมบูรณ์</li> </ul>

#### BIOGRAPHY

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