Process of Overcoming Difficulties of Nuclear Family's Caregivers in Caring for Older Adult Stroke Survivors During Transition from Hospital to Home

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I hereby certify that this work has not been accepted in substance for any degree, and is not being currently submitted in candidature for any degree.

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ชื่อวิทยานิพนธ์: กระบวนการเอาชนะความยากลำบากของผู้ดูแลในครอบครัวเดี่ยว ในการดูแลผู้สูงอายุโรคหลอดเลือดสมองในช่วงเปลี่ยนผ่านจากโรงพยาบาลสู่บ้าน
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บทคัดย่อ

การศึกษาครั้งนี้ มีวัตถุประสงค์เพื่อค้นหากระบวนการในการเอาชนะความยากลำบากของผู้ดูแลครอบครัวเดี่ยวในการดูแลผู้สูงอายุโรคหลอดเลือดสมอง ในช่วงเปลี่ยนผ่านจากโรงพยาบาลสู่บ้าน รวมทั้งปัจจัยที่เกี่ยวข้อง โดยใช้ระเบียบวิธีการวิจัยเชิงคุณภาพแบบการสร้างทฤษฏีรากฐาน ทำการรวบรวมข้อมูลด้วยวิธีการสัมภาษณ์แบบเจาะลึก ร่วมกับการสังเกตแบบมีส่วนร่วม และการจดบันทึกเรื่องราว ผู้ให้ข้อมูลเป็นผู้ดูแลในครอบครัวเดี่ยวที่ให้การดูแลผู้สูงอายุโรคหลอดเลือดสมองอย่างน้อย 1 เดือนถึง 1 ปี จำนวน 26 ราย คัดเลือกกลุ่มตัวอย่างแบบเฉพาะเจาะจงตามคุณสมบัติที่กำหนด และคัดเลือกตามการชี้นำของแนวคิดที่ค้นพบ วิเคราะห์ข้อมูลโดยกระบวนการให้รหัสร่วมกับการเปรียบเทียบข้อมูล

ผลการศึกษาพบว่า กระบวนการในการเอาชนะความยากลำบากของผู้ดูแลผู้สูงอายุโรคหลอดเลือดสมองช่วงเปลี่ยนผ่านจากโรงพยาบาลสู่บ้าน เป็นกระบวนการต่อสู้เพื่อให้ได้มาซึ่งความรู้สึกถึงการควบคุมได้ แบ่งเป็น 3 ระยะ ระยะแรกเป็นระยะที่สูญเสียการควบคุม ซึ่งมีสาเหตุจากการพบกับความเปลี่ยนแปลงที่ไม่ได้คาดคิด และความไม่แน่นอนในเหตุการณ์ที่เกิดขึ้นต่อไปทำให้ผู้ดูแลเกิดความเครียดและความกดดัน จุดเปลี่ยนที่ทำให้ผู้ดูแลสามารถข้ามพ้นระยะนี้ไปได้ คือ การเข้าใจสถานการณ์ที่เกิดขึ้นตามความเป็นจริง ระยะที่สองเป็นระยะต่อสู้กับความไม่แน่นอน ประกอบด้วย 1) การเผชิญกับความยากลำบากในเรียนรู้บทบาทการเป็นผู้ดูแล 2) การไม่พร้อมสำหรับการดูแลที่บ้าน และ 3) การดิ้นรนในการคงไว้ซึ่งการดูแลที่บ้าน โดยใช้กระบวนการเผชิญกับปัญหาและการเรียนรู้จากการลองผิดลองถูก จนเกิดความชำนาญและมีความมั่นใจในการทำหน้าที่เป็นผู้ดูแล ซึ่งเป็นจุดเปลี่ยนให้ผู้ดูแลเข้าสู่ระยะที่สาม คือ คือระยะบรรลุการควบคุม

ปัจจัยสำคัญที่ช่วยให้ผู้ดูแลในครอบครัวเดี่ยวสามารถเผชิญปัญหา/ความยุ่งยากในการดูแลผู้สูงอายุโรคหลอดเลือดสมองในช่วงเปลี่ยนผ่านจากโรงพยาบาลสู่บ้าน ประกอบด้วย ความสามารถในการจัดการดูแลของผู้ดูแล แรงสนับสนุนจากเพื่อนผู้ดูแลด้วยกัน/เครือข่ายผู้ดูแลขณะอยู่โรงพยาบาล การวางแผนการจำหน่ายที่ดี และการได้รับความช่วยเหลือจากเครือข่ายทางสังคมในชุมชน

ผลการวิจัยชี้ให้เห็นว่า ผู้ดูแลต้องการความช่วยเหลือจากแหล่งสนับสนุนทั้งภายในและภายนอกครอบครัว ในการเอาชนะความยากลำบากในการดูแลผู้สูงอายุโรคหลอดเลือดสมองช่วงเปลี่ยนผ่านจากโรงพยาบาลสู่บ้าน ซึ่งแตกต่างกันไปตามระยะเวลา พยาบาลจึงควรทำการประเมินความต้องการการช่วยเหลือของผู้ดูแลในแต่ละระยะให้ครอบคลุม เพื่อการวางแผนให้การดูแลช่วยเหลือได้อย่างเหมาะสม

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ABSTRACT

This qualitative study used grounded theory methodology to explore the process of how nuclear family's caregivers overcome difficulties in caring for older adult stroke survivors during transition from acute care in hospital to home. Theoretical sampling procedures were employed to recruit a total of 26 family caregivers who provided care for older adult stroke survivors. Data were collected through semi-structured in-depth interviews, participating observations, and field notes. Constant comparative analysis was conducted through open, axial, and selective coding procedures.

The results of this study revealed that fighting to gain a sense of control was a core category for describing the process of overcoming difficulties of nuclear family's caregiver in caring for older adult stroke survivors during transition from hospital to home. It comprised of three stages: loss of control, striving to master uncertainty, and achieving sense of control. Loss of control was caused by caregivers experienced of unexpected change and uncertainty of future events. They move through this stage by attempting to understanding the changing situation. The second stage was striving to master uncertainty, which comprised of confronting difficulties in adopting caregiving role, unreadiness to provide care at home, and struggling to maintain care at home, by coping and learning process. This led the caregiver gained role mastery that trigger them move to the third stage, achieving sense of control. It acted as outcomes the process which the caregivers were being competent and felt confidence to managed the caregiving situation.

Key factors that helped nuclear family caregivers to overcome the difficulties in caring for older adult stroke survivors during transition from hospital to home comprised of; caregivers' ability in managing care, peer support, good discharge planning, available of supportive network in community.

The findings suggest that caregivers needed of supports from both within and outside the family to deal with the caregiving difficulty situations which were vary across care trajectory. Therefore, nurses should do a timely and comprehensive assessment of the support needed of the family caregivers, and the appropriate interventions need to be designed to provide support.

DEDICATION

I wish to dedicate this dissertation to my beloved parent, Arb Sirisom, who has been both mother and father to her eight children. For you, I am eternally grateful for your devotion to all your children. I am grateful for your providing me with the experience of being a stroke caregiver. You taught me how to find strength through the difficulties of caring for a stroke survivor. You gave me the invaluable experience of how to live in a new world after losing a beloved parent, how to continue the journey of life without you. I would like to apologize that I could not save your life. If there was any way that I offended or did wrong to you, please forgive me. I love you, Mom. You are my endless love. I hope your soul will be happy at peace in heaven.

I also dedicate this dissertation to all my teachers and to the stroke survivors and their families who contributed to my research, those who are still living and those who have passed away, for their very wonderful resource of life experiences and lessons.

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My deepest gratitude goes to all the research participants for their willingness to share their time and lived experiences openly with me. These valuable experiences may enable health professionals to improve their care of other stroke survivors and their families, and assist other family caregivers in similar situations. My sincere thanks are extended to the staff of the Home Health Care Center at Hat Yai Hospital and at the Continuing Care Unit of Songkhla Hospital, who helped me to recruit participants for this study.

Finally, my very eternal gratitude is given to my beloved family who have always supported and encouraged me throughout this journey in so many ways. My sincere thanks to my doctoral classmates at Prince of Songkla University for the support, friendship, knowledge and experience they shared with me throughout my study.

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CHAPTER 1

INTRODUCTION

Background and Significance of the Problem

Thailand is becoming an ageing society with a population of older adults aged ≥ 60 of 12.14% (Ministry of Public Health [MoPH, 2011). This is expected to increase to 15% of the total population by 2020 (United Nations Population Fund [UNFPA], 2011). At the same time, the occurrence of diseases has shifted from communicable to non-communicable, which are usually chronic, resulting in an increase in the numbers of disabled older adults due to chronic diseases, especially stroke. The incidence rate of stroke in this population increased from 795.56:100,000 in 2004 to 1,013.7: 100,000 in 2009 (MoPH, 2009). The Epidemiologic Stroke Study conducted in 2004 to 2006 indicated that the rise in stroke prevalence was associated with age, increasing from 1.10% in those aged 45 to 54 years to 3.14% in those aged 75 to 84 years (Hanchaiphiboolkul et al., 2011). The mortality rate dropped by 33.3% from 2004 to 2006 (MOPH, 2007) due to advances in medical treatment and technology (Shaughnessy et al, 2009). Approximately 70% of the Thai older adult stroke survivors are discharged to home with some functional impairment and rely on their family for caregiving (Julamate, Azeredo, Paul, & Subgranon, 2006).

The impact of a stroke is dramatic not only for the stroke survivors but the family members who have little time to adapt to the new circumstances (Lut, Young, Cox, Martz & Creasy, 2011). This impact is further complicated by the trend toward shorter lengths of hospital stay. Therefore, stroke survivors are discharged from the hospital to the home not only creating a sudden transition for stroke survivors but also for family members who have to quickly adapt to the caregiving role. The caregiving transitional process includes the time from when the patients are hospitalized and extends to the post-discharged period (Bull, 1992; Esche & Turner, 2005). The period of transition varies among caregivers ranging from 4 months (Grant, 2004) to 1 year post-discharge (Saban & Hogan, 2012; Pierce, Steiner, Govoni, Thompson, &

Friedemann, 2007). It depends on the degree of recovery and severity of stroke survivors (Hirunchunha, 1998).

When stroke survivors transition from hospital to home the family caregivers are faced with a lot of difficulties. Providing care for the older adult stroke survivors at home involves more than personal care but often includes management of medical devices such as feeding tubes and possibly even tracheostomy tubes requiring specialized knowledge and skills. Family caregivers also must assess and cope with acute and chronic changes in physical, behavioral and emotional effects from the stroke (Bakas, Austin, Jessup, Williams & Oberst, 2004; Grant, 2004; King & Semik, 2006). Because caregiving is time-consuming (Bakas, Austin, Okonkwo, Lewis & Chadwick, 2002), many family caregivers take on the responsibility of caregiving on top of their routine job and responsibilities. Family caregivers usually struggle with time management and balancing all of their responsibilities (Lund, 2005; Miller, Shoemaker, Willyard & Addison, 2008). In addition to all the physical and emotional caregiving responsibilities they must also manage new and complicated financial issues that arise following the stroke in a loved of one (Niyomathai, 2009; Obe-om, 2005). Family caregiving also entails coping and interacting with the healthcare system (Hartke & King, 2002).

There are several factors which influence the caregivers successful transition from hospital to home. These include the caregivers’ psychosocial factors, social support, and socio-cultural factors. Research reported that the caregivers’ psychosocial factors including self-management (Silva-Smith 2007), knowledge and care skills (King & Smik, 2006), positive coping styles, problem solving ability (Lui, Lee, Greenwood, & Ross, 2011; Qiu & Li, 2008), and attitude (Pierce et al. 2007) can have a positive influence in dealing with stroke caregiving problems. On the other hand, negative physical and mental health, and lack of knowledge and care skills showed a negative influence in caregiving outcomes (McCullagh et al. 2005, Ilse et al. 2008).

Social support includes service, assistance, education, information received from health professionals, family, and friends. Among these, supportive services from professionals were the most prominent factors reported as promoting caregiver outcomes. Several supportive care services including home health care services, respite care, counseling, support groups, help lines (King & Semik 2006), education and training (Smith, Gignac, Richardson, & Cameron, 2008) were identified as critical parts of social support by stroke caregivers. However, some of these care services, such as respite care, counseling, support groups, and help lines are not well implemented in Thailand.

Another important factor influencing caregiving transition was socio-cultural factors. This includes religious belief and social norms in caring for older adults. Previous studies indicated that religious faith helps the caregivers release the stress related to their caregiving situation (King & Smik. 2006, Greenwood, Mackenzie, Cloud, & Wilson, 2009a; Subgranon & Lund, 2000). Religious faith was also reported as a source of strength for family caregivers. They did religious practice such as praying and meditation to help them to organize their sentiments and to give them strength (King & Smik. 2006, Greenwood et al. 2009a). Similarly, a strong belief in *katanyu katavedi* and the norms of interdependence or giving assistance to each other have been reported as promoting factors helped for Thai families in providing care for their older relatives (Subgranon & Lund, 2000).

In the past, caring for Thai older adult stroke survivors was considered a filial obligation of adult children. This complex and difficult duty has been shared among extended family members that had more than two caregivers and presented a strong kin-ship support (Hattakit, 1999; Niyomthai, 2009; Obe-om, 2005). However, Thailand nowadays is rapidly undergoing industrialization and social change such as migration, the participation of women in the workforce, and a decrease in fertility. These changes significantly impact on family structure, family size and the living arrangements of older adults (Knodel & Chayovan, 2008). The modern Thai family has shifted from an extended family to a nuclear family with a limited number of family members available for caregiving and support for disabled older adults. The result of this is that taking care of disabled older adult stroke survivors within the family is becoming more difficult due to the limited number of children and the changing pattern of children working further away from home. These changes affect normative filial obligations. Care provided for disabled old adults by family members is starting to be replaced by paid caregivers (Knodel & Chayovan, 2011). The dependent older adults vulnerable to a lack of caregiving by their family members. Many caregivers are older persons who are taking care of themselves and their spousal stroke survivors (Prawtaku, 2006). Despite those transitions in Thai society the family is still expected to be the main provider of care for older adult stroke survivors at home.

The difficulties of taking care of older adult stroke survivors lead to emotional distress and other negative health outcomes for caregivers (Bakas, Austin, Jessup, Williams, & Oberst, 2004) that can consequently contribute to poor patient rehabilitation outcomes leading to the termination of the caregiving role and may shift the patients to institutional care. On the other hand, Thai health care policy for older persons has shifted from hospital-based care to home/community-based care which emphasizes enabling older adults to continue living in their own home or in the community (Kespichayawattana & Jitapunkul, 2009). However, the implementation of this policy is still in the pilot project and so the availability of community-based services to support families in providing care for older adults is still very limited (Nnodel & Chayovan, 2008). This situation indicates that support for informal caregiving for older adult stroke survivors in a nuclear family needs more specific healthcare services and nursing intervention.

Nevertheless, most of the previous researches on Thai family caregivers of stroke survivors was conducted only on the extended family (Hatthakit, 1999; Hirunchunha, 1998; Niyomthai, 2002) or mixed both extended and nuclear family (Obe-om, 2005). Additionally, the existing studies usually focused on the experiences of caregiving (Obe-om, 2005), caregivers health outcomes (Chaiyawut, 2004; Chansri, 2008; Natechang, 2002; Matayamool, 2003; Navarat, 2002), educational and support needs (Prawtaku, 2006), intervention to improve health outcomes of stroke survivors (Chalermwannapong, 2009; Khumpolsiri et al., 2006; Phongsai, 2009), and an intervention to improve health outcomes of caregivers (Opura, Griffiths, Pryor, & Mott, 2010, Intharuk, 2008). Studies focusing on how a nuclear family’s caregivers overcomes the difficulties in taking care of their older adult stroke survivors are very limited. In order to support nuclear family’s caregivers in successfully transitioning into their caregiving roles and maintaining continuity of care at home, it is important to understand the processes that undergo in order to overcome those difficulties during transitional periods of caregiving. Therefore, this study aims to explore the process of overcoming difficulties of nuclear family’s caregivers in caring for the older adult stroke survivors during transition from hospital to home.

Objectives of the Study

The purpose of this study was to generate a substantive model to describe the process of overcoming difficulties of nuclear families' caregivers in caring for an older adult stroke survivor during transition from hospital to home.

Research Questions of the Study

There were two main research questions used to draw out the process of overcoming difficulties of nuclear families' caregivers in caring for older adult family members who have survived a stroke during the transitional period from hospital to home. These were:

1. How do nuclear families' caregivers overcome difficulties in caring for an older adult stroke survivor during transition from hospital to home?
2. What are the conditions/contexts/factors associated with the process of overcoming the difficulties of nuclear families' caregivers in caring for an older adult stroke survivor during transition from hospital to home?

Theoretical Framework of the Study

The theoretical framework of the study was based on the philosophies of the transition theory and grounded theory.

Transition theory

The transition theory was partially used in this study with three aims; 1) to define the time frame of the transitional period for nuclear families' caregivers in caring for older adult stroke survivors 2) to define selection of participants in regard to this period, and 3) to guide the analysis of influencing factors in the process of overcoming difficulties during the transitional period. This theory is composed of four major domains including; the nature of transitions, transition conditions, patterns of response and therapeutic nursing (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). Two related domains: the nature of transitions; and transition conditions were utilized to frame this study.

1. *The Nature of transitions*

Three concepts contributing to the nature of transitions are; type, pattern, and property. Only the later, the properties of transition, is described here. The properties of transitions are composed of three salient characteristics. First, they are usually precipitated by a critical marker event or turning point that requires a new pattern of response. Second, transitions are processes that take a period of time starting from the initial change event until stability is again experienced. Third, they involve changes in identity, role, relationships, abilities, and patterns of behavior. The other two properties added in the last development of the theory are awareness and engagement (Meleis et al., 2000).

The transition process is composed of three phases that are; entry, passage, and exit. The entry is the beginning of the transition triggered by a disruptive event such as the onset or diagnosis of a stroke. The passage is a period in which new needs arise, old needs are not met in the previous familiar way, and old sets of expectations are no longer congruent with changing circumstances (Schumacker & Meleis, 1994). It is a period of disorganization when individuals and the family attempt to adjust and adapt to the transition. During this period they seek to regain control over the disruptive event. Thus, they seek new skills, new relationships, and new coping strategies (Click & Meleis, 1986; Meleis &Trangenstein, 1994), to reconstruct the sense of self. The exit phase is a consequence of the transitions occurring at the end of the transition process that may end with successful or unsuccessful outcomes.

2. *Transition conditions*

The transition conditions are personal, community, and social factors that influence the transition processes and transition outcomes. Personal factors include meanings of change that people have, cultural beliefs and attitudes, socioeconomic status, preparation and knowledge. The community condition concerns the available community resources to support the transition. Social factors consist of gender, social role or position, and cultural attitudes.

Grounded theory

A review of relevant literature reveals two key underpinning philosophies of grounded theory, symbolic interactionism and pragmatism. Three basic beliefs of symbolic interaction are; 1) human beings act toward things on the basis of meaning they define of those things, 2) the meanings of such things are derived from, or arise out of the social interaction that one has, 3) these meanings are handled in and modified through an interpretive process used by individuals in dealing with the things they encounter (Blumer, 1969; Lambert & Lambert, 2010). In addition symbolic interaction is a branch of interpretivism.

Symbolic interactionism views human behavior as an ongoing activity humans construct based upon their perceptions of situations encountered and interpreted through interactions with themselves and others. Through social interaction individuals learn the meanings and symbols essential to the expression of thought. This understanding in turn allows people to carry out actions and interactions. As people interpret their situations, they modify the meaning and symbols used in an action. Interaction with self and others allows one to understand the situation and to make choices (Lambert & Lambert, 2010).

Based on the symbolic interactionism, the researcher believes that caregivers in a nuclear family may face with the same problem in caring for older adult stroke survivors and may experience a common social psychosocial process to find resolutions. This study aims to explore how family caregivers give meaning to the difficulties which occur during the transitional period, and how they act or respond in their own feelings and with other family members, health professionals, and other persons in the community to overcome those difficulties. Therefore, symbolic interactionism will be applied in this study to frame the interpretation of nuclear family caregiver acts or interactions with others family members, patients, health personnel and the community. On the other hand, it will be used to guide the ontology, epistemology, and methodology applied through grounded theory in this study.

The ontology of grounded theory has been influenced by critical realists and relativists (Annells, 1997). The critical realists believe that reality exists but is an incomplete measure and therefore, the researcher and the researched are incapable of fully comprehending the situation and the difficulty in the construction of the phenomenon (Guba & Liclon, 1994). Thus, the researcher in this paradigm is believed to be independent from the researched. On the other hand, relativists believe that reality cannot be known but can be interpreted (Strauss & Corbin, 1990; 1998). The epistemology of grounded theory is modified objectivism and subjectivism.

Objectivism locates the researcher as a neutral observer outside of the area of inquiry. In contrast, subjectivism asserts that all knowledge starts with the private sensations, ideas, or sense data of the individual mind. Subjectivism places the researcher inside the inquiry and views the data as being socially constructed by which it is interpretive.

In addition, pragmatist perspectives emphasize human actions and problematic situation. Pragmatists believe that truth cannot be gained through deductive reasoning from an existing theory but rather must be developed inductively with constant empirical verification.

Definition of Terms

Process of overcoming difficulties

Process of overcoming difficulties refers to the step of actions/interactions of family caregivers responding to the encountered problems relating to care of older adult stroke survivors from their admittance to hospital until discharge and return home.

Transitional period

Transitional period refer to the time frame of hospitalization through to hospital discharge and including the time after returning home where family members care for the older adult stroke survivors for a period of no more than 1 year.

Nuclear family

Nuclear family is defined as the family form or structure which is composed of two generations of parents and children, or grandparents and their young grandchildren. It includes family composed of only a husband and wife, or composed of parents (father and mother, or single parent) and their unmarried children, or skip family. The family members are self-defined and may or may not be living in the same house.

Significance of the Study

With the trend towards an ageing society and an increase in stroke impairment in older adults, family caregivers are an important resource in the promotion of both successful health outcomes in the older adult stroke survivors’ life and a more cost-effective use of health and social service resources. However, family caregivers are usually faced with difficulties in caring for older adult stroke survivors, especially during hospitalization and the first few months after the stroke survivors return home. This results in emotional distress and other negative health outcomes for stroke caregivers that can consequently contribute to poor patient rehabilitation outcome, ending caregiving roles. Therefore, to support family caregivers in sustaining their caregiving roles and maintaining continuity of care at home, it is important to understand the social processes that they undergo to overcome those difficulties during in caring for older adult stroke survivors during transition from hospital to home .

The findings of this study will provide information about problems, related factors, and patterns of response to those problems throughout the pathway of transition from acute care in hospital to post-discharge in the home. Such results will guide nurses to explore and design specific interventions that cover all stages of transition and meet the needs of older adult stroke survivors and their caregivers. The results of this study will also direct the administrators of the health care system to develop strategies to integrate care pathways and strengthen the coordination between care settings. In addition, it will encourage policy makers, both at the local and national level, to develop a health policy to serve the nuclear family in providing long-term care at home.

CHAPTER 2

LITERATURE REVIEW

The review of literature presented in this chapter consists of stroke in the Thai older adult population, nuclear families and their roles in caring for older adults, the transitional process of the family caregiver in caring for a stroke survivor at home, difficulties in the caregiving transitional process, influencing factors of the caregiving transitional process, sense of control, and grounded theory.

Stroke in the Thai Older Adult Population

Thailand is now undergoing a demographic change with an ageing society. The Thai older adult population, defined as aged ≥ 60 has been continually increasing, and will reach 15% of the total population by 2020 (UNFPA, 2011). Therefore, undoubtedly a stroke is one of the most important health problems faced by elderly Thais, since its increasing prevalence is associated with age. The incidence rate of strokes in the elderly has been reported as increasing from 795.56:100,000 in 2004 to 1,013.7: 100,000 in 2009 (MOPH, 2009). A stroke is not only the leading cause of death in both Thai males and females (Rao et al., 2010), but is also the major cause of serious long-term disability (Poungvarin, 2001). Although the mortality rate tends to decrease due to medical advances and the technology now available in emergency and acute medical care departments (Shaughnessy et al., 2009), around 60% of stroke survivors are left with a certain degree of neurological impairment and functional disability which needs long-term rehabilitation and assistance from family members (Family Caregiver Alliance Nation Center on Caregiving, 2006 as cited in Lutz & Young, 2010). Family caregivers have to deal with the variety of stroke patients' difficulties including mobility, self-care, communication, cognitive impairment, depression, and personality changes (Han & Haley, 1999). Therefore, they usually experience stress and increased burden (Shyu, 2000) which results in a decline of physical and mental health and a reduced quality of life (McCullagh et al., 2005; Thomas & Greenop, 2008).

In conclusion, the onset of a stroke abruptly affects many aspects of the lives of both patients and their family due to stroke impairment residual. Therefore, a stroke is not only a major health problem among the ageing Thai population, but also has a heavy impact on family members assuming caregiving roles.

Thai Culture and Social Values Related to Family Caring for Older Adults

Thai culture and social values are considered as basic factors influencing on Thai families caring for older adults. It include gratefulness, seniority and respect, and interdependence

1. Gratefulness

Gratefulness is reflected as *katanyu katavedi* which plays a prominent role in families caring for their older relatives. *Katanyu* (a sense of gratitude) and *katavedi* (an obligatory action) are based on the *Bunkun* system (Kespichyawattana, 1999). *Bunkun* refers to a goodness that individuals have done as a benefit to others, for example, parents giving love and caring for their children, teachers giving knowledge to students, favors given to relatives, friends and others in a social network (Podhisita, 1985, as cited in Kespichyawattana, 1999). In the *Bunkun* system, goodness/favors that one receives are imposed as a moral obligation that must be repaid. Giving birth and nurturing children are considered a goodness of the parents (Mulder, 1994 as cited in Choowattanapakorn, 1999). Children, on the other hand must return favors by looking after their parents when they get old or suffer illness. The repayment of parents’ goodness is perceived as a characteristic of good people in Thai society.

2. Respectfulness of seniority

Seniority has long been a general social value among Thai people. The norm of respect for seniority is rooted in the hierarchical tradition of “Sakdina” system in which people occupy differently ranked social positions. The hierarchical structure defines a set of responsibilities and indicates appropriate behaviors of Thais for Thai people. Within the family, the father is assigned as a leader who works outside the home to earn the money for the family to live. The mother, on the other hand, is responsible for doing housework, raising children, and caring for family members (Richter & Podhisita, 1992). Children and the younger generation are taught to be obedient and strictly respect their parents and elders who are given high status (Choowattanapakorn, 1999). Therefore, in Thai society, children are expected to care for their older adult parents/relatives, and wives/husbands are expected to look after their spouse.

3. Interdependence

Thai lifestyle is based on interdependence rather than individualism. This view of interdependence is reflected as a “give-and-take” relationship. It entails a complex interplay of giving assistance, interdependence and dependence (Ingersoll-Dayton, Saengtienchai, Kespichayawattana & Aunguroch, 2001). It demonstrates the relationship between individuals, family, community and the wider social network. Within a family, every family member gives support and help to each others. The amount and type of support that family members give and receive at certain stages of family life varies with their role (Hatthakit, 1999). Generally, Thai older adults view themselves as giving to others, especially to their children in various forms such as giving money, or advice and teaching young children. Many older adults who are grandparents also help to raise their grandchildren. On the other hand, they want to be able to rely on the assistance of their children and younger family members when they become frail (Ingersoll-Dayton et al., 2001). Hatthakit (1999) reported that family practices in caring for stroke survivors in Thai society are based on personal and social interdependence demonstrated as a process of reciprocity which is associated with the *Bunkun* system.

Therefore, Thai cultural values, social norms, and traditions of gratefulness, respect for seniority, and interdependence can influence the nuclear family’s response to difficulties in caregiving for older adult stroke survivors during transition from hospital to home.

Thai Nuclear Families and Their Role in Caring for Older Adults

In order to gain an understanding of the care of older adult parents/ relatives within the Thai nuclear family context, it is necessary to explore the concept of family, the characteristics of the Thai family focusing on family structures, family functions and their relationships and the family role in caring for elderly dependents.

1. Concept of family

The concept of family is in constant evolution, and its' definition varies based on what it is focused on. For example, Allen and colleagues (2000: p. 1), defined a family as "two or more persons related by birth, marriage, adoption or choice. Families have emotional ties and enduring responsibilities, particularly in terms of one or more members' dependence on others for support and nurturance". Social scientists define the family as a group of people who are related to each other through kinship ties, especially blood ties, and who may or may not share the same residence (Limanonda, Podhisita, & Wongsith, 1991). They also view the family as the social system that interacts with other social systems within the society. Friedman, Bowden and Jones (2003) explained that the family is "a system of members who decided to reside together with the primary objective of supporting each other".

Although the family has been diversely defined, some common characteristics of the family concept exist. Stuart (1991 as cited in Denham, 2003, p.23) suggested that critical family attributes are; (1) family is a system or unit, (2) members may or may not be related or live together, (3) a family may or may not have children, 4) members have commitment and attachment to each other which implies present and future obligations, (5) a family has a function to care and socialize among its members. In addition, Shapiro (1983 as cited in Obe-om, 2005) stated that the characteristic of a family system is an open system, which has continuous interchange with the external social and physical environment. The family facing continuous internal and external demands for change, may be able to respond with growth, flexibility and structure evolution. The family is rooted in different cultural and socioeconomic backgrounds that have differing interpretations of the meaning and significance of particular situations. Therefore, the family in different cultures has characteristics which are often different from other cultures. Thai families present their own characteristics specifically for Thai culture.

Generally, family is classified based on its structure and is divided into two categories: nuclear family and extended family (Steptoe, Lundwall, & Cropley, 2000). The nuclear family is composed of no more than two generations of parents and children. It also includes a single parent and his/her children (UNESCO, 1992) and a married couple without children or childless family subtype. In some societies, such as Thai, other relatives may be added in this type (Limanonda et al, 1991). An extended family, which was typical of the Thai family's structure in the past, is composed of three or more generations living under the one household or several houses within the same area (Limanonda et al. 1991). It is composed of three subtypes: stem, lineal, and fully extended family (Lee, 1982).

2. Characteristics of the Thai family

Traditional Thai families are demonstrated as a kin group in which family members mostly share many aspects of day-to-day activities. As a result, Thai people tend to have a strong closeness in family relationships, and respect for seniority and they help each other follow from one generation to the (Richter & Podhisita, 1992). However, in the past two decades, Thailand has been rapidly undergoing industrialization and modernization due to a dramatic growth of the Thai economy. This change has been accompanied by an effective family planning program affecting the family structure which consequently affects family relationships and functions (Choowattanapakorn, 1999).Thai family size at present is smaller than the past, with a steady decline in the average family size from an average of 5.6 in1960 to 3.6 persons in 2000 (Jitapunkul & Bunnag, 1999). Furthermore, it is expected to reduce from 3.4 persons in 2004 to 3.09 persons in 2020 (MOPH, 2007). At the same time, modernization has provided women with equal access to education and they are more likely to be employed outside the home (Narknisorn & Kusakabe, 2013). This results in both young men and women migrating to work in big cities outside their communities, which contributes to a splitting up and breaking down of the family. As a consequence, the traditional extended family unit is being steadily replaced by the nuclear family, especially in urban areas (Limanonda, 1995). This change has also affected the living arrangements of the Thai elderly. Co-residing with their adult children has decreased (Knodel, Saengtienchai, & Sittitrai, 1995; Chayovan & Knodel, 2012), while living alone or only with a spouse has increased (Knodel & Chayovan, 2008). As a result, the two parent nuclear family has become the most predominant type of household in Thailand (Laminonda, 1995). The changing pattern in living arrangements combined with a decreasing family size has led to limited available support, especially for personal care physical support (Knodel & Chayovan, 2012).

Modernization has also affected family functions and relationships. As a result of higher education, women’s status and social positions in Thai society have changed. At present, familial authority in Thai society is shared between wives and husbands. Women’s roles have extended into earning money and social advocacy. On the other hand, men’s roles are now more involved with housework (Narknisorn & Kusakabe, 2013). Once the extended family is broken down and replaced by the nuclear family, it is likely to result in a reduction of the kinship ties and the support of each other in terms of interdependency is less common (Narknisorn & Kusakabe, 2013; Theerawanviwat, 2014).

3. Family Roles in Caring for Older Adults

Providing care for dependent family members like older adults is recognized as a basic family function (Denham, 2003: p.126). It is viewed as a part of a moral role which connects family background in a particular social context (Stuifbergen & Van Delden, 2011). In Thai culture, the family’s role in providing care for older adult members has been seen as a norm of filial obligations (Choowattanapakorn, 1999). It is a sense of duty and fulfillment of social expectation and in regards to Buddhist teachings, as Karma (Kespichayawattana, 1999). Family members, particularly adult children, are the main persons providing care to frail older persons or the elderly with chronic conditions. Even though the social and family structure changes, family members continue to take the major responsibilities of caregiving for stroke survivors (Choowattanapakorn, 1999). Therefore, eldercare is mostly kin-based or provided by family members (Rosenberg, Jullamate, & Azeredo, 2009).

The term “caring” has been defined as “attending physically, mentally, and emotionally to the needs of another and giving commitment to the nurturance, growth and healing of that other” (Davies, 1998 as cited in Schofielda, Tolsona, Arthurb, Daviesc, & Nolan, 2005). Caring for the older adults can be viewed as providing care and support for the needs of the older adults including physical, emotional, social, and spiritual needs. In accordance with those definitions, the family role in caring for the elderly can be viewed as basic care in normal daily living and/or caring for them in chronic illness. Family members are supposed to assist the older adults with daily activities, make sure that they stay in normal condition both physically and psychologically, and take them to the hospital when needed. Therefore, the family serves as the most important and primary source of care for the majority of older people (Miller et al., 2008), especially those who suffer disabilities and dependencies such as stroke that require assistance.

Family caring for the elderly who have disease or chronic conditions has been viewed as informal caregiving. However, evidence from the reviewed research conducted by Pepin (1992 as cited in Lee, 2005), suggested that caregiving was conceptualized mainly as an activity or a set of tasks while caring was conceptualized as commitment, respect and protection towards the cared for. Caring is also involved in emotions and feelings associated with care. Family roles in caring for older adult stroke survivors, therefore, not only include caregiving tasks but also involve psycho-emotional and spiritual supports (Jullamate, de Azeredo, Rosenberg, Pàul, & Subgranon, 2007) as well as a feeling of commitment to care. The caregiving tasks involve care for individuals in the activities of daily living (ADLs) such as bathing, feeding, and the instrumental activities of daily living (IADLs) such as shopping, transportation, and financial assistance (Miller et al., 2008; Silverstein, Gans, & Yang, 2006). It also includes doing household tasks and giving medical/nursing treatments to patients and assisting in rehabilitation (Bakas et al., 2004). In addition, Swanson and colleagues (1997) proposed that care-task performance of the family can be identified as direct and indirect care. Direct care involves personal care activities, and indirect care involves the organization and management of care.

In conclusion, the conceptual definition of family has been based on different point of views. Regarding the purpose of this study, the family is viewed as a system consisting of two or more persons who identify themselves as being a part of a family, and who have commitment and attachment to each other through the kinship ties and may or may not be living in the same house. One important function of the family is to provide care and support for their elderly members both in healthy ageing conditions and disease conditions. This responsibility is assumed to be shared among family members and viewed as role obligation, especially in Thai culture. The family role in caring for their elderly includes, providing caregiving tasks which includes both direct and indirect care, and providing financial, psychological, emotional and spiritual supports. However, the Thai family nowadays tends to be a nuclear family which may impact on the family role in caring for the elderly due to the small number of family members available to provide care and support.

Transitional Process of Family Caregivers in Caring for Stroke Survivors at Home

Concept of transition

1. *Definition*

According to Schumacher, Jones and Meleis (1999) transition is defined as a passage between two relatively stable periods of time in which the individuals move from one life phase, situation, or status to another. Transition occurs when an individual's current reality is disrupted, causing forced or chosen change that needs to construct a new reality. Thus, transition involves change and response to changes (Hilton, 2002; Kralik & van Loon, 2007; Kralik, Visenten & van Loon, 2005).

2. *Characteristics of transition*

The universal features of transitions are composed of three salient characteristics. First, they are usually precipitated by a critical marker event or turning point that requires a new pattern of response. Second, transitions are processes that take a period of time starting from the initial change event until stability is again experienced. Third, they involve change in identity, roles, relationships, abilities, and patterns of behavior (Click & Meleis, 1986).

Transition process consists of three phases: entry, passage, and exit. The entry is the onset or beginning of the transition which is triggered by a critical marker event. The passage is a period in which individuals demonstrate the response to change by trying to adjust and adapt to the transition. This results from the old needs not being met in the previous familiar way and new needs arise (Schumacher & Meleis, 1994). Thus, they seek new skills, new relationships, and new coping strategies to regain control of the disruptive event (Click & Meleis, 1986; Meleis & Trangenstein, 1994). The exit phase is the consequence occurring at the end of the transition process that may end with a successful or unsuccessful outcome.

3. *Caring for stroke patient at home and impact on family*

The sudden onset of a stroke causes unexpected changes in both the patient and their family's lives (Rittman, Boylstein, Hinojosa, Hinojosa, & Haun, 2007; Obe-om, 2005). This changed situation is the marker event that triggers family members to undergo transition due to the adoption of the caregiver role (Schumacher, 1995). Taking on the new role drives them to adopt new needs such as a new skill, a new practice and new lifestyle (Wu, 2009). As a result, family caregivers experience role change and also a loss of self and their normal life style (Bäckström & Sudin, 2010; Coombs, 2007). This is congruent with Hirunchunha (1998) who reported that in providing care for stroke survivors at home, the caregiver experienced a transformation process which consists of four stages including: the inability to adjust/think, a transition period, seeking/modifying caring techniques, and settling into a normal lifestyle.

4. *Caregiving transitional process*

As a process, based on Meleis's transition theory, the caregiving transitional process is described in aspects of; transition period, role change and care needs for the transition.

4.1 Transition period

Caregiving transitional processes are related to both the patients' phases of illness and the daily adjustments made by families in response to the patients' life changes, associated deficits, high physical and emotional needs, and symptoms (Waldrop, Kramer, Skretny, Milch & Fin, 2005 as cited in Blum & Sherman, 2010). The phases of illness of a stroke are often characterized by sudden onset, acute hospital care, followed by rehabilitation and a return to community living (Cameron, & Gignac, 2008). The period of the caregiving transitional process takes is the time from the stroke survivor's hospitalization and extends into post-discharge (Bull, 1992; Esche & Turner, 2005) when the caregiver gains a new sense of normality and feels confident in performing their caregiving roles. The period of time for adjustment to normal routine varies among caregivers. Some of them began to feel a new sense of normality within 4 months post-discharge (Grant, 2004), while others took 1year to settle into normality (Bäckström & Sudin, 2010; Obe-om, 2005; Pierce et al., 2007; Saban & Hogan, 2012). The difference in the transitional period among caregivers may depend on the severity of the stroke and the survivor’s level of dependency. This notion is supported with the findings of Hirunchunha (1998). She found that family caregivers who provided care for stroke survivors with paralysis could settle into normal life after about 4 months post-discharge, but those caregivers taking care of stroke survivors who were unconscious took about 12 months.

4.2 Role changes

Following the onset and the diagnosis of a stroke, the stroke survivor transits from being non-disabled to disabled (Cott, Wiles, & Devitt, 2007) resulting in their becoming a care recipient, while the family members are forced to take the role of caregiver (Green & King, 2009). A change in role can be especially challenging in the context of family function and spousal relationship (Thompson, 2008; Thompson & Ryan, 2009). Older women caregivers need to take authority and make decisions in all aspects by themselves, while male caregivers must take on unfamiliar household tasks such as cooking and cleaning, or helping in personal hygiene care for their spouse (Lund, 2005). Children who become caregivers for their parents may experience an even greater shift or complete role reversal, where the parent upon whom they have relied on for support their entire lives is suddenly no longer available to them and instead requires their support (Fraser, 1999).

4.3 Care need for transitions

Becoming a caregiver for an individual who has survived a stroke is a complex and difficult process (Brereton & Nolan, 2000) which needs support, especially in the early stage (Brereton & Nolan 2002, O’Connell & Baker 2004). Six domains of support care needs that have been reported by caregivers are informational, practical, physical, psychosocial, emotional and spiritual needs (Maclsaac, Herrison, & Godfrey, 2010). During hospitalization many family caregivers also need training from health care professionals to assist with the provision of physical care in the home, and to learn about the signs of potential problems that could signal new adverse health events. Family caregivers seek various resources to deal with their needs (Brereton & Nolan 2002). Prior to discharge, they seek out resources to learn caregiving and learn some care skills (Wu, 2009). They also seek practical information such as information about community services (Cameron & Gignac, 2008).

However, family caregivers often report that they are not supplied with the necessary training to enable a successful transition to the home environment (O’Connell, Baker, & Prosser, 2003; Smith et al., 2004; Wu, 2009). In particular, they are given limited advice to cope with the patients’ psychological and emotional problems (Mackenizien, Perry, Lockhart, Cottee, Cloud, & Mann, 2007). Additionally, with the trend towards a shorter hospital stay, the period of adjustment to changes during hospitalization through to discharge and return home is rather short (Lut et al., 2011). Although family caregivers often feel ready when their relatives are discharged, they are not ready to face and manage the complexity of the care skills and associated demands after discharge (Shyu, 2000). They are still not confident in their ability to perform care-tasks (King & Semik, 2006; Wu, 2009), especially in the first month after discharge (Grant, 2004). Thus, once at home, the family caregivers usually experience difficulty in managing care, and they describe an uncertainty about their caregiving abilities (Cameron, Tsoi, & Marsella, 2008; Wu, 2009).

In conclusion, the onset of a stroke in older adults is a changing event inducing the family members’ transition into a caregiving role. The caregiving transitional process of family members caring for older adult stroke survivors begins from the onset of the stroke when the patient is hospitalized and ends when caregivers feel confident in their caregiving role and have created a new normal routine. The duration of the transition period varies from 4 months to 1 year depending on the severity of the stroke.

Difficulties in Caregiving Transitional Process of Family Caregiver

Based on the review, the difficulties in the caregiving transitional process of family caregivers can be classified into 4 categorizes; (1) difficulty with learning care skills, (2) difficulty in caregiving tasks, (3) difficulty in balancing roles and time, and (4) financial difficulty

1. Difficulty with learning care skills

Before discharge, family caregivers are usually prepared with knowledge of basic skills in caregiving for stroke survivors at home. Care skills that they learn including bathing, changing diapers and clothes, risk prevention, and rehabilitation

(Intharuk, 2008). Some caregivers have to learn complex care skills such as NG feeding, tubing care and suction (Intharuk, 2008; Wu, 2009). At the beginning in hospital, new family caregivers described that they need to spend more time to complete those basic care skills, but they had a limited time to practice in the hospital. They also felt nervous and fearful when performing a complex care those skills (Wu, 2009).

2. Difficulty in caregiving tasks

Although family caregivers had learned essential care and felt ready for their relative to go home, they faced a variety of unexpected difficulties in performing caregiving in the home environment. The three most difficult caregiving tasks reported by family caregivers, especially during the first three months after discharge were 1) managing stroke survivors safety, 2) managing the activities of ADLs, and 3) managing behavioral and emotional problems (King & Semik, 2006; Obe-om, 2005; Smith et al., 2004; Wu, 2009). The difficulties in managing stroke survivors safety involve position change, lifting, transferring (Wu, 2009), and adjustments to the home environment (Hatthakit, 1999; Obe-om, 2005). It also involved monitoring for symptoms of secondary stroke (Bakas et al., 2004) and managing the stroke survivor's physical symptoms such as pain, breathing and sputum, swallowing (Wu, 2009), and skin problems (Grant, 2004). The tasks that were most often reported as being difficult when managing ADLs include elimination and Foley catheter care (Grant, 2004), diet preparation and NG feeding, transportation and bathing (Wu, 2009). Difficulties in managing behavior problems and emotional problems (i.e., mood swing, memory loss, confusion, fear of abandonment) involved providing emotional support (Bakas et al., 2004). This may be extremely difficult due to problems communicating with the patients.

3. Difficulty in balancing roles and time

Many family caregivers take on responsibilities in caregiving along with their other roles such as spouse, parent, and routine job (Hatthakit, 1999; Lund, 2005; Obe-om, 2005; Miller et al, 2008). They experienced problems with giving care and working in their jobs because they felt they could not perform both well enough (Obe-om, 2005). At the same time many family caregivers also have to fill the role previously performed by the stroke survivors. Additionally, providing care for stroke survivors, especially who are completely dependent, is perceived by caregivers as time-consuming (Bakas et al., 2004). Most Thai stroke survivors' caregivers spent more than 12 hours a day in their caregiving role (Chaiyawut, 2004; Prowtaku, 2006; Obe-om, 2005. Some caregivers mentioned they had not enough time to do caregiving tasks (Grant, 2004). These changing situations forced them to reduce their social activities (Hartke & King, 2002; Obe-om, 2005). As a result, family caregivers are usually affected by role strain.

4. Financial difficulty

Financial difficulty is one important issue frequently expressed by family caregivers. This is due to increased family expenses relating to the cost of long-term care for stroke survivors (Hatthakit, 1999, Hartke & King, 2002) along with decreased family income (Obe-om, 2005). Besides the cost of treatment, families had to pay a lot of money on preparing equipment (i.e, beds, airbeds, wheelchairs, suction machines, diapers) and the home environment (i.e., bed room, toilet) to facilitate caregiving of stroke survivors at home. Some family caregivers left their job to be a caregiver (Changsuwun, 2005) leading to a decline of family income. The financial difficulties tended to be more intense if the main source of family income used to come from the stroke survivor (Obe-om, 2005). Some families have insufficient income to pay for those things mentioned above (Changsuwun, 2005).

In conclusion, the difficulties in the caregiving transitional process of family caregivers when their relative transitions from hospital to home are composed of 4 categorizes: 1) difficulty with learning care skills, 2) difficulty in caregiving tasks, 3) difficulty in balancing roles and time, and 4) financial difficulty. All of those are related to the family assuming new caregiving roles and the change of care environment from hospital to the home setting.

Influencing Factors in Overcoming Difficulties in the Caregiving Transitional Process

The three main factors that contributed to successful caregiving transition were the caregivers' psychosocial factors, social support, and socio-cultural factors.

1. Caregivers' psychosocial factors

Three components of the caregivers' psychosocial factors that facilitated a successful caregiving transition were knowledge and care skills, problem-solving and coping ability, and positive attitude.

1.1 Knowledge and care skills

Because the caregiving transitional process is a role transition, inadequate preparation, insufficient care skills and knowledge often increase the family caregiver's sense of uncertainty (Schumacher & Meleis, 1994). Preparing the caregivers to provide family care was found to predict caregiver's role strain (Archbold et al., 1995) and decrease re-hospitalization of stroke patients (Kalra et al., 2004). Research has shown that most stroke caregivers immediately adopted the caregiving role (King & Semik 2006; Lut et al., 2011). They were uncertain about their ability to provide care and to cope with caregiving problems (King & Semik, 2006, Greenwood, Mackenzie, Wilson, & Cloud, 2009b), particularly during the first month of caregiving. They needed information and emotional support to help them feel confident in their role (King & Semik, 2006). Caregivers who received education and care skills training during the hospital stay showed significantly less strain and better quality of life than caregivers who received a normal care service (Oupra et al., 2010). Having relevant experience and skills helps the caregiver to cope with uncertainty in providing care at home (Greenwood et al., 2009b). Additionally, research reported that caregiver's with a sense of self-efficacy and mastery had significantly fewer depressive symptoms (Greenwood et al., 2008)

1.2 Problem-solving and coping ability

Good coping ability is essential for caregivers to manage stress as it enhances the well-being of both family caregivers and stroke survivors (Lui et al. 2011; Qiu & Li, 2008). Evidence from the literature review suggested that positive coping strategies such as self-control skills, planning (O'Connell & Baker, 2004), seeking sources of assistance (Pierce et al., 2007; Wu, 2009), and problem-oriented coping strategies (Yeung, Lui, Ross, & Murrells, 2007) showed a positive relationship with family well-being. In contrast, emotion-oriented coping strategies showed a negative relationship with family well-being (Chansri, 2008). Seeking information was an important strategy suggested by the caregivers in preparing for caregiving (King &

Semik, 2006) and dealing with uncertainty about their ability in the new role (Greenwood et al., 2009b). Seeking assistance and accepting support were helping strategies that caregivers identified in overcoming their feelings of being overwhelmed in caregiving (Pierce et al. 2007) and sustaining themselves particularly during the first 3 months after discharge (King & Semik, 2006). Focusing on the present or living day-by-day and the avoidance of thinking were strategies that caregivers used to manage uncertainty in their changing life (Silva-Smith, 2007; Greenwood et al., 2009b).

1.3 Positive attitude

Research has shown that a positive attitude and coping strategies fostered stroke caregivers in overcoming their caregiving difficulties and attaining normalization (King & Semik, 2006; Pierce et al. 2007; Silva-Smith, 2007; Greenwood et al., 2009a). Most caregivers suggested that being positive helped them to sustain themselves and their family during the adaption to their role (King & Semik, 2006). Keeping a positive outlook was a key strategy indentified by older caregivers in coping with difficult times while caregiving (Smith et al., 2008). Researchers also found that having hope and a sense of humor were useful for caregivers when dealing with uncertainty during the first 4 weeks of caregiving (Silva-Smith, 2007; Greenwood et al., 2009b).

2. Social Support

This factor is associated with the support available from healthcare professionals or healthcare providers, family, and friends. Among these, supportive service from professionals was the most prominent factor reported as promoting caregiver outcomes. Research indicates that provision of supportive care services or programs by healthcare providers were linked with positive caregiver outcomes which can promote caregiving transition (McCullagh et al., 2005; King & Semik, 2006; Mak et al., 2007; Smith et al., 2008; Oupra et al., 2010). Several supportive care services including educational/training programs, respite care, counseling, and support groups (King & Semik, 2006; Smith et al., 2008) were identified by caregivers as critical elements of social support. Educational and caregiving training programs could help the caregiver to reduce caregiver stress and enhance his/her quality of life (McCullagh et al., 2005; Oupra et al., 2010). The availability of care services and supportive care in the community such as home health care services, help lines and telephone supports were useful for the caregiver when coping with caregiving difficulties at home (King & Semik, 2006; Oupra et al., 2010).

In addition, a supportive social environment including accessible community resources (White et al., 2007), and assistance from other family members and friends (Pierce et al., 2007) were also reported as facilitators of a successful caregiving role. Additionally, coordination of care between care settings and between health care professionals and family were also identified by caregivers as being facilitators (White et al., 2007).

3. Socio-cultural factors

Two crucial domains of social factors which assist in overcoming difficulties during transition are religious belief and culture. Buddhist caregivers believe that providing care for older adult stroke survivors was a way to gain merit. Islamic caregivers believe that caregiving for their parents or spouses was a way to go to heaven. These beliefs help them to provide good care and maintain caregiving at home (Subgranon & Lund, 2000). Previous studies also indicated that religious faith helps the caregivers to release stress related to their caregiving situation (King & Semik, 2006; Greenwood et al., 2009a, Cecil et al., 2013). Some caregivers indicated that religious faith was a source of strength. They did religious practice such as praying and meditation to help them to organize their sentiments and to give them strength (King & Semik, 2006, Greenwood et al., 2009a). They also expressed gratitude for the situation being no worse than it was (Cecil et al., 2013). Similarly, the Thai cultural norms of interdependence or giving assistance to each other were reported as contextual conditions that help Thai caregivers to receive support from family, friends, and the community. As a result, the caregiver is able to continue their caregiving at home (Subgranon & Lund, 2000).

In conclusion, there are three main factors that affected caregivers in overcoming difficulties in caring for older adult stroke survivors during transition from hospital to home. These included the caregivers' psychosocial factors, social support, and socio-cultural factors.

Sense of control

Sense of control is a personal psychological resource indicative of psychological resilience which is essential in buffering the effects of negative events. It had been defined as a belief in one’s ability to master, control, or effectively changes one's own environment (Ross & Mirowsky, 1992). This factor is considered as the individual’s ability to affect his/her environment in the way he/she desires. Having a sense of control has been positively linked to recovery as it helps provide the necessary motivation to take action towards directing and participating in one’s own care plan in regard to mental health-(Koenig as cited in Fukui, Starnino, Nelson-becker, 2012). Gaining a sense of control over a life changing situation might be important for family caregivers continuing to provide care for their family members. Feelings of control are important for the maintenance of well-being (Brown, 2007). Many measures of this construct exist, including personal mastery, perceived control, helplessness, and locus of control (Ward, 2012).

Grounded Theory

To gain an understanding of grounded theory, its history and development, the philosophical perspective in terms of three scientific basic element paradigms: ontology, epistemology, and the methodology of grounded theory is described in this section.

Grounded theory is a qualitative research method that was first developed in 1960s by two sociologists, Barney Glaser and Anslem Strauss (1967). It differs from other qualitative research methods in that it is not only provides meaning, understanding and a description of the phenomenon under study, but is also theory-generating (Creswell, 2007: pp.63). Two types of theories can be produced by grounded theory; substantive and formal. The most common one is substantive theory which concentrates on specific social processes within the substantial area of psychosocial enquiry, for example client care, professional practice, or specific social behavior. In contrast, a formal theory is developed for the conceptual area of sociological enquiry, for instance deviant behavior and illness experiences. Therefore, it is broader and more general than substantive theory. Glaser and Strauss (1967: pp.34) asserted that substantive theory is usually induced / deduced??? from the data and formulated first and then this substantive theory is followed by formal theory. Both types of theory may be considered as middle-range theories (Glaser &Strauss, 1967: pp.32).

Over more than fifty years after the first introduction of *The Discovery of Grounded Theory* as a new method in qualitative inquiry, grounded theory has contentiously evolved. Currently, there are at least three different versions of the grounded theory method, including Glaser's classic method (Glaser & Strauss, 1967), Strausssian's method (Strauss & Corbin, 1990) and Chamaz's constructivist method (Chamaz, 2006). Glaser's classic method is emphasized in an inductive process in that the theories naturally emerge from ground data without forcing the idea of the researcher. This version was critiqued as a more open and less structured approach (McCann & Clark, 2003). Strausssian's mode highlights more fully structured coding, memoing and analysis which describe the procedures of open, axial and selected coding. It also recommends using the Paradigm Model (Strauss & Corbin 1990: pp. 99), in which a set of relationships are identified denoting causal conditions, phenomena, context, intervening conditions, action/interaction strategies and consequences (Annells, 1997).The last version is the constructivist approach which places value on the interpretation of phenomena in which the researchers and participants share experiences and relationships (Bryant & Chamaz, 2006).

In this study the researcher decided to employ Strauss and Corbin's approach because this version provides practical techniques and procedures for generating substantive theory. It provides useful tools for analyzing qualitative data in a flexible approach. This version provides a more structured approach for data collection and analysis which is useful for the novice researcher. Strauss and Corbin's version emphasizes the importance of identifying symbolic and interacting influences on describing the cultural scene and socially constructed world of family caregivers (McCann & Clark, 2003).

The foundations of grounded theory are embedded in symbolic interactionism concerned with the process by which people interact with each other within society. Interaction is symbolic because this process uses symbols, words, interpretations and language. Symbolic interactionism believes that human action and interaction are resulting from the meaning that an individual gives to artifacts and through verbal and non-verbal communications within the contexts of their lives (Spezial-Streubrt& Carpenter, 2007). The influence of symbolic interactionism can be seen in the ontological and epistemological focus of grounded theory (Fassinger, 2005)

Ontology

Ontology refers to the nature of social reality, that is, how people view the world, as a stable place (positivist view) or as a fluid place (interpretive view). The ontology of grounded theory is influenced by critical realists and relativists (Annells, 1997). Classic grounded theory method underpins the beliefs of critical realists. Supporters of critical realism believe that reality exists but only imperfectly which science can study and is independent of human thought on the topic and the social reality is real (Guba & Lincoln, 1994). Additionally, Straussian's grounded theory is based on relativism which is the idea that some elements or aspects of experience or culture are relative to, or dependent on, some element or aspect. Strauss and Corbin (1990), proposed that a reality cannot actually be known, but can always be interpreted.

Epistemology

Epistemology is the belief in the relationship between the researcher and the researched (participants), in particular how the knowledge of reality is gained. It refers to an underlying assumption about how it is possible to acquire knowledge about social reality and how the knowledge that exists can be made known (Denzin & Lincoln, 1994). The epistemology of grounded theory is modified objectivism and subjectivism. Objectivism states that human knowledge and values are objective which exist and are to be discovered by one's mind, and are not created by the thoughts one has. Objectivists locate the researcher as a neutral observer outside of the area of inquiry. Thus, the knowledge gained by this approach is discovered naturally without the research idea. In contrast, subjectivism asserts that all knowledge starts with the private sensations, ideas, or sense data of the individual's mind. As a result, one's expressions are subjective because they are dependent on the opinion of the person making the statement. Subjectivists place the researcher inside the inquiry and view data as being socially constructed by which the interpretive researcher draws on personal views and values (Bryant & Charmaz, 2007). Therefore, knowledge gained by the grounded theory approach relies upon meaning being constructed between the researcher and the participant. Classical grounded theorists accept the dualism of the subject and object. On the other hand, constructivists consider that there is mutuality between subjects and objects (Clarke, 2005; Mills, Bonner, & Francis, 2006).

The methodology of grounded theory

The methodology refers to the principles and ideas on which researchers base their procedure and methods (Holloway & Wheeler, 2010). The grounded theory method uses interpretive, inductive and deductive strategies to develop the substantive theory. Inductive analysis involves the generation of categories and themes from research data collected from the informant's perspective. Findings emerge through the researcher's interaction with the data. Therefore, theory "grounded" in data, generated by induction and verified deductively by the researcher in the process of reflexivity, is substantive theory (Glaser & Strauss, 1967). The specific elements and method of grounded theory include theoretical sensitivity, theoretical sampling, constant comparative data analysis, theoretical saturation, coding and categorizing data, and writing memos.

1. *Theoretical sensitivity*

Theoretical sensitivity is the ability of the researcher to have insight, to understand meaning and to capture the conceptual ideas to generate concepts from the data (Strauss & Corbin, 1998). It helps the researchers in the differentiation between significant and less important patterns in data (Holloway & Wheeler, 2010). Theoretical sensitivity can be seen as the researchers' manipulation in order to explain data in the way that best reflects reality. Glaser (1978) recommended that the first way of gaining theoretical sensitivity is by entering the field with as few predetermined ideas as possible. Additionally, Strauss and Corbin, (1998) proposed that theoretical sensitivity comes from several sources including literature, professional experience and personal experience. The researcher can build up and enhance theoretical sensitivity over time from reading (Holloway & Wheeler, 2010) and interacting with the data (Strauss & Corbin, 1998).

2. *Theoretical sampling*

Theoretical sampling refers to the sampling of events and incidents or happenings for the purpose of formulating the theory (Strauss & Corbin, 1998). It involves a process of data collection by which the researcher simultaneously collects, codes and analyzes the data in order to decide what data to collect and where to sample next according to the emerging codes and categories. At the beginning of the study, the researcher makes the initial sampling on the particular groups that will maximize the possibilities of obtaining data and provide direction for more data on questioning the topic being studied. Thus, the theoretical sampling involves purposeful selection in the initial stage (Coyne, 1997). When the initial data is collected and analyzed, the emerged concepts are used to direct further data collection until each category is saturated (Glaser, 1992). Theoretical sampling, therefore, takes place when the researcher collects new data to compare, fill out and extend theoretical categories (Bryant & Chamaz, 2007).The aim of theoretical sampling is to maximize opportunities to compare concepts to look for the variation in terms of properties and dimension (Strauss & Corbin, 1998). Therefore, negative cases or different things/different people are included in the sampling process (Bryant & Chamaz, 2007), and it also involves researcher sensitivity (Glaser & Strauss, 1967, Glaser, 1992). Nevertheless, the researcher should avoid using preconceived ideas during the theoretical sampling. It is important to the inductive-deductive process. The inductive process involves the theory emerging from data, whereas the deductive process involves the purposeful selection of samples to check out the emerging theory.

According to Strauss and Corbin (1990) the process of theoretical sampling is conducted as open sampling, relational sampling and variational sampling and discriminate sampling along with open coding, axial coding and selective coding. In open sampling systematic, purposeful, and flexible factors are utilized in the initial stage of data collection and open coding in order to discover variations in the event and happening (Strauss & Corbin 1990). Then, relational and variational sampling is employed during axial coding in order to gather data on theoretically relevant categories. Sampling at this phase consists of re-interviewing some of those who have already participated, to achieve clarification of the major categories. Finally, with discriminate sampling, the researcher chooses the sites, persons and documents that will maximize the opportunities for verifying the relationships between categories and for filling in poorly developed categories (Strauss & Corbin 1990) in order to achieve saturation.

3. Constant comparative method

The constant comparative method is the principal approach in data analysis which aims to develop a grounded theory (Hutchison, 1993). While coding and analyzing the data, the researcher looks for patterns, and compares incident (indicator) with incident, incident with category, and category with category or construct with construct. By this method the researcher can compare the similarities and the differences among the data. The data containing similar ideas or properties are grouped together to form a higher abstract concept (Hutchison, 1993). In addition, Glaser and Strauss (1967), described four stages in the process of the constant comparative method; 1) comparing incidents applicable to each category, 2) integrating categories and their properties, 3) delimiting the theory, 4) writing the theory.

4. Coding procedure

Coding is the process of analyzing and identifying patterns or events in the data to establish themes and concepts by transforming and naming it. According to Strauss and Corbin (1998), there are three steps or levels of coding: open coding, axial coding and selective coding.

4.1 Open coding

Open coding, also referred to as Level I or substantive coding, is the process of breaking down the data into smaller segments so it is word by word, line by line and comparing incidents in the data. It also involves labeling those segments (concepts), examining and comparing them and then grouping them under a more abstract concept (category). The focus should be on the constant comparison of incident to incident, not on the fracturing of data. There are two types of open coding: *in vivo* codes and sociological construct. *In* vivo codes refers to the word or phrase used by the participants, while sociological constructs are established from grounded data combined with the researchers' scholarly knowledge and expertise.

4.2 Axial coding

Axial coding is also known as theoretical or level II coding. The aim of this procedure is to systematically develop and relate categories. Strauss and Corbin, (1990), described axial coding as the process whereby the data is put back together by making connections between the categories. The categories are linked to subcategories along the line of their properties and dimensions through a coding paradigm involving conditions, contexts, actions/interactions or strategies, and consequences. The researcher looks at the phenomenon for the answers to questions such as why or how come, where, when, how, and with what in the phenomenon, and then relationships among categories are discovered.

4.3 Selective coding

Selective coding is the process of selecting the core category, systematically relating it to other categories, validating those relationships and filling in categories that ~~require~~ further refinement and development. Similarities and difference between the themes are noted, which lead to the formation of larger categories (Strass and Corbin, (1990). In this step the major categories or core categories are obtained.

5. Theoretical saturation

Saturation refers to the completeness of all levels of codes when no new properties and dimensions are emerging from continued coding and comparison (Hutchison, 1993). Therefore, theoretical saturation is achieved through constant comparison of incidents in the data which elicit properties and dimensions of each code (Holton, 2007). Theoretical saturation is considered when the researcher achieves these criteria: 1) no new relevant data emerges within the category, 2) the categories are well formulated, and 3) the relationships among the concepts and categories are verified (Strauss & Corbin, 1998). When all data fits into the established categories, interactional and organizational patterns are visible, behavioral variables are described, and behavior can be predicted. It indicates that, the researcher has reached a sense of closure, by repeatedly checking and asking questions of the data (Hutchison, 1993). Additionally, theoretical saturation is achieved by applying these three standards (Morse, 1995). First, select the sample attaining the similar conceptual ideas regarding the phenomenon being studied. Second, theoretical sampling enhances theoretical saturation quicker than other sampling procedures. Finally, the sample data fills all possible variations, and the researcher should pay attention to all hypotheses generating a theory.

6. *Memos*

Memos are notes that the researcher makes throughout the research in order to record and elucidate the theory as it is developed. Strauss and Corbin (1998) define memos as records of analysis, thoughts, interpretations, questions and directions for further data collection. They reflect the researchers' internal dialogue with the data at a point of time along the research process. Memoing allows the researchers to explore provisional hypotheses about codes, categories, and theoretical directions as they emerge. Thus, it is a tool to assist the researchers in capturing the abstract thinking for theory development. Strauss and Corbin (1998) recommended that memos be written as code notes, theoretical notes, and operational notes, reflecting the various activities undertaken during the research process.

Trustworthiness of the study

Trustworthiness in a qualitative study can be achieved by four standard criteria: credibility, transferability, dependability and confirmability (Lincon & Guba, 1985)

According to Glaser and Strauss (1967), credibility refers to the believability, fit, and applicability of the findings to the phenomenon under study. It is a term equal to internal validity used as a measure of rigor in quantitative research. A qualitative study is judged to be credible when "the description and interpretation of the experience is so accurate that it would immediately be recognized by the people having the experience" (Sandelowski, 1986). Thus, credibility is a criterion used to evaluate the truth value, the vivid and faithful descriptions or interpretations of the phenomenon under study. In grounded theory, credibility is achieved by the methodological techniques which include; 1) using the constant comparative method, where data is continuously validated by triangulation obtained from in-depth interviews, field observations and other documents; 2) theoretical sampling which is flexible to verify information from multiple sources and informants. Strauss and Corbin (1998) stated that the grounded theory method is an attempt to verify its resulting hypothesis through the comparison of incoming data. Therefore, credibility is established through verifying the data. There are several strategies to enhance credibility including; prolonged engagement, persistent observation, triangulation, peer debriefing and member checking (Holloway & Wheeler, 2010).

1. *Dependability*

Dependability or auditability or reproducibility refers to the ability to replicate the findings under similar conditions and rules for analysis (Hall & Callery, 2001). It can be achieved by using an audit trial which includes all decisions made by the researchers at each stage of data analysis (Beck, 1993). Since the grounded theory process depends on the interaction between the data and creative process of the researcher, reflexive notes throughout data collection are kept as records and cognitive trails of the researcher are immediately recorded in the form of memos. Therefore, the investigator should be clear about documents, researcher decisions and the choice and insight of the study, which enables the reader to know how methodological, analytical, and theoretical decisions have been made (Sandelowski, 1986). Dependability is demonstrated in the research report when the reader and the second researcher are able to clearly follow the proceeds of events in the study and understand their logic (Sandelowski, 1986).

2. *Transferability*

Transferability or fittingness is the criterion used to evaluate the applicability of the research findings, how well the working hypotheses or propositions fit into a context other than the one from which they were generated (Lincoln & Guba, 1985). Transferability can be illustrated by describing the research method and participant characteristics, contexts, and setting. Moreover, the researcher should provide enough thick description for the reader to access the potential transferability and appropriateness for their settings (Lincoln & Guba, 1985). A test of fittingness is passed when the findings can fit into a context outside the study situation and when the reader views the findings as meaningful and applicable in terms of their own context. Sandelowski (1986) suggested that a major threat to the transferability of the study is the tendency to make data look more patterned or regular or congruent than they are. To prevent this threat, the investigator must carefully collect, interpret and analyze the data. Additionally, the utilization of member-checking techniques for clarification and elaboration of the meaning from the informants and checking out their evolving interpretation of the data can improve the fittingness of the data and subsequently the research findings.

3. Confirmability

Confirmabity is the criterion of neutrality in qualitative research. It refers to the findings themselves and their freedom from the researcher’s bias (Sandelowski, 1986). Confirmability is achieved when auditability, truth-value and applicability are established (Linclon & Guba, 1985).

In addition, Glaser (1978) recommended four specific criteria to evaluate the emerging theory. These include: 1) fit – meaning the categories of the theory must fit the data; 2) work – the theory should have an explanatory power and be able to interpret what is taking place within the context; 3) relevance – the researcher allows the theory to emerge from the data without imposing preconceived ideas on the data; 4) modifiability – the theory should be adaptable to changing social circumstance.

Summary

This chapter describes the literature review related to the study of stroke in older adult, the nuclear family and their role in caring for the elderly, the transitional process of the family caregiver in caring for the stroke sufferer at home, influencing factors of the caregiving transitional process, difficulties in the caregiving transitional process, and grounded theory. A stroke is still the most important health problem among elderly Thais, and it impacts on the family members who are suddenly transitioned into the caregiving role. The caregiving transitional process is initiated from the onset of the stroke when the patient is admitted to hospital and extends to a few months after post-discharge. The family members usually face difficulties in their role transition, especially during the time the patient is hospitalized and extending to the first three months after the stroke survivors return home. There are several factors influencing the caregiving transitional process. One important factor challenging the current changes in Thai families is social support from the family, which is related to the number of family members within the family. However, previous research on families caring for elderly stroke sufferers in Thailand has usually been focused in the extended family, and research on the nuclear family is still limited. Therefore, this study focused on overcoming the difficulties in the transitional process of the nuclear families’ caregiver caring for older adult stroke survivors.

CHAPTER 3

METHODOLOGY

The focus of this chapter was to describe the research methodology used in this study. This includes research design, study setting and context, the participants, participant recruitment, data collection, research instruments, data analysis, theoretical sampling, memos, protection of human subject rights, and trustworthiness of the study.

Research Design

This study was designed to explore the meanings, relations, pattern and variation, among components of the process of overcoming difficulties for Thai nuclear families' caregivers faced with an unexpected caregiving situation following their older adult relatives' sudden attacked by stroke. This qualitative study employed grounded theory as a research method to generate the substantive model that explain the process nuclear families' caregivers undergo in overcoming difficulties when caring for older adult stroke survivors during their transition from hospital to home. Grounded theory is a research methodology based upon the principle of symbolic interactionism which places the individual in the center of the analysis

Grounded theory was chosen as most appropriate for this study for several reasons. Firstly, the grounded theory method can capture the social process when the goal is a framework or theory explaining human behavior in the context (Glaser & Strauss, 1967). Additionally, grounded theory is useful when the phenomenon has not been previously investigated or has limited information (Streubert & Carpenter, 2007) particularly for a study in the complex area of human behavior and society (Chenitz & Swanson, 1986). As little is known about the process of overcoming difficulties during the transitional period for the nuclear families' caregiver caring for an older adult family member who has survived a stroke, the grounded theory approach is well-suited to explicate the social and psychological process through which the Thai nuclear family live with their older adult stroke survivor.

Study Setting and Context

The study was conducted on nuclear families' caregivers of older adult stroke survivors who live in both rural and urban areas, of Songkhla province and were discharged from Songkhla hospital located in the southern region of Thailand. Emergency cases of stroke patients receive the first assessment at the emergency room and severe cases are admitted to the ICU, whereas less severe cases are admitted to the medical ward. There are four medical wards in Songkhla hospital; two wards for women and two for men. The standard of care provided to stroke patients during hospitalization follows a care map which is a multidisciplinary care plan for five days of hospitalization. This care map covers the medical treatment, nursing care rehabilitation and preparation of family caregivers. During this period, the patient's physical functions are assessed by utilizing the Barthel Index. According to the care map, the patient stays in the hospital for at least 5 days. However, if the patients or family caregivers feel a lack of confidence to go back home, the length of stay will be extended. After discharge, the patient is transferred to a chronic care center to manage continuing care. The patients are then referred to a PCU or a health care center close to their home to receive home health care services. After discharge, eligible persons can receive nursing home visits or health care volunteer home visits every month. However, not all stroke survivors can receive home care services.

Healthcare system context

The discharge planner is responsible for preparing family caregivers, including providing necessary education, recommendations for assistive care devices, and referral for home care service and long term care management centers. Home care service provides in home health service after discharge. The home care services include nurse visits two times each month.

Participants

The study participants were 16 primary caregivers and 11 secondary caregivers who provide care for older adult stoke parents/relatives. In initiating this study, the purposeful sampling technique was used to select participants. The criteria of the study includes: participants who were 1) aged 18 and older, 2) defined themselves as a caregiver of an older adult stroke survivor in a nuclear family, 3) provide care for survivors of a first stroke within a period of 1 - 12 months. After starting the first data collection and analysis, the participants were theoretically chosen based on the directed concepts which emerged from the data until theoretical saturation was reached.

Participant Recruitments

Recruitment procedure

1. The researcher primarily contacted RN case managers in medical wards and staff nurses in the Chronic Care Unit (CCU) of the hospital to introduce the research project and its objective.
2. The researcher explained the criteria of the participants that they needed to recruit into the study.
3. The researcher looked for the potential participants from the name list and medical records to gather the basic information about age and type of family and then consulted with nursing staff about which older adult stroke survivors have family members who met the inclusion criteria.
4. The researcher asked nursing staff at the CCU to introduce the researcher to the caregivers who met the inclusion criteria by phone, and then invited them to participate in the study.
5. After the participants agreed to participate in the study, the researcher called them directly to make an appointment for an interview and then asked permission to visit their homes.

Data Collection

The data collection started after the research proposal, research instrument and informed-consent form had been approved by the Institute of Research Board of the Faculty of Nursing, Prince of Songkla University along with permission from Songkhla hospital. Data collection was conducted using both the retrospective and perspective methods. The data were collected by in-depth interviews and observations. The interviews took place at the participants' homes. All interviews were tape-recoded and transcribed into Thai verbatim following each interview as soon as possible. Spontaneous observations of the caring activity and interaction between family members and older adult stroke survivors were made during the interview and the observed caregiving or family events was recorded in field notes and memos immediately following each interview. These memos and field notes were used as a part of the data. Only verbatim quotations presented in the writing were translated into English by the researcher and then these were edited by an English-speaking expert for grammatical accuracy.

Research Instruments

The instruments used for data collection in this study included: the researcher, a demographic form, interview guides and an observation record form.

The researcher

In grounded theory research, the researcher takes a major role in the process of data collection and analysis because the findings of the study are dependent on the interaction between the data and the creative process of the researcher. Therefore, it is important that the background or professional and personal experiences, as well as the self-preparation in the research area of the investigator, are revealed.

1. *Professional experience*

The researcher was a nurse in a community (district) hospital for nineteen years. After that, she moved to work as a nurse instructor at Boromarajonani College of Nursing, Songkhla for three years, before studying in Doctoral of Philosophy program While working in hospital, the researcher gained experience in caring for patients in the emergency care unit and in the inpatient unit (4 years for each) and in the primary care unit (1 year). During these periods, the researcher cared for stroke patients during the acute phase while hospitalized. The researcher also had an opportunity to provide home health care services and home visits for stroke patients and their families while working in the primary care unit. The researcher also teaches nursing students to care for stroke patients who were hospitalized in the medical ward of Songkhla hospital while she worked as a nurse instructor.

In regard to qualitative methodology, the researcher has taken a course in advanced qualitative research in nursing for one semester, as studied in the first year of the doctoral program. The course established some skill in data collection by doing observations and interviews, writing field notes, performing content analysis with identifying themes, coding, and categorizing. In addition, during a visit to the School of Nursing, Pennsylvania University, the researcher passed the Protection of Humans Subject Research Course in CITI (Collaborative Institutional Training Initiative) training. The researcher also has had an opportunity to participate in grounded theory research critique and in data analysis in grounded theory study.

2. *Personal experience*

The researcher has experience as a caregiver of the elderly who have suffered chronic illness which is dependent on activity on daily livings and requires long-term care and support. During this time, the researcher perceived and recognized the difficulties of providing care for the dependent elderly at home.

Demographic form

The demographic form (Appendix A) was designed to collect demographic data including age, religion, educational status, the number of members in the family, occupation before and after taking the role of caregiver, income and economic status, and the duration of care provided for their older adult relatives who has survived a stroke.

Interview guide

The interview guide (Appendix B) was used for conducting indepth-interviews about overcoming difficulties during the caregiving transitional process. It consisted of eleven questions including reactions to their older adult relatives having a stroke, response to becoming a family caregiver, the difficulties in the transition into the caregiving role, and overcoming difficulties in the transition.

Observation record form

The Observation record form (Appendix C) was used for field notes on the setting and context. These included health care services, informant action and the informant’s family action, interaction, relationships, and events during hospitalization, rehabilitation, discharge, and during home visits. These data were collected through non-participant observation by the researcher.

Data Analysis

Data analysis was the process of systematically arranging and scrutinizing transcription, field notes, and other artifacts. The constant comparative method of data analysis guided by Strauss and Corbin (1998) was used to generate a grounded theory to explain the process of overcoming difficulties in the transition of the nuclear family caring for older adult stroke survivors. Data collection and data analysis were performed simultaneously. Following each interview, the audiotape was transcribed verbatim by a trained transcriptionist or the researcher. Each transcript was formatted with a wide right margin to simplify manual coding. The researcher verified the accuracy of each transcription by listening to the audiotape while reading the transcript word-by-word. The constant comparative analysis proceeded along with three steps of coding procedure: open coding, axial coding and selective coding (Figure 1).

Open coding

Open coding is the first step of data analysis aimed at establishing the concept. In this step, each transcribed piece of data and the observation notes were broken down into small segments word-by-word, and line-by-line to find out the emerging keywords/short phrases which constitute the main idea of each sentence or line. These keywords or short phrases were highlighted and written in the margin of the transcript sheet. Following line-by-line coding, the researcher returned to the beginning of the transcript and proceeded with open coding which describes the action illustrated in the data. Each incident or action within the data was coded in every possible way to ensure the comprehensive exploration of each interview. The analytical tools which facilitate the process of open coding are questioning and constant comparative analysis. Concepts were examined by asking questions e.g. when does it occur?; why does it happen?; what are the effects of it occurring?; how does it affect different family caregivers and to what degree are they affected? The questions helped the researcher to conceptualize and link the categories to generate the theory.

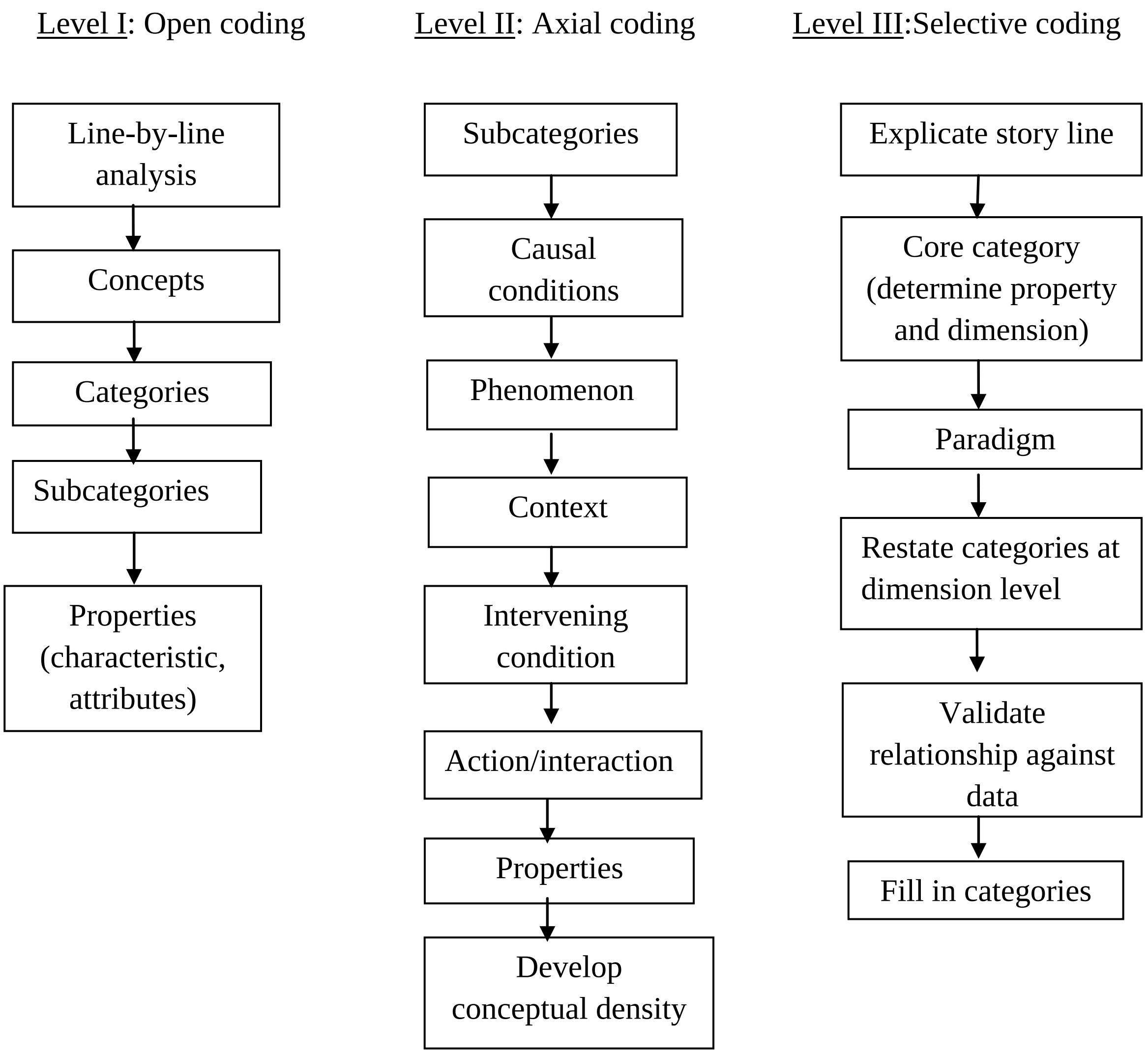

Figure 1: Diagrammatic representation of Strauss and Corbin's (1998) coding analysis of grounded theory.

Axial coding

Axial coding was done to relate the emerged concept and categories utilizing the paradigm model. This model is composed of five components: 1) the causal condition 2) its relationship to the key phenomenon, 3) the context of that relationship, 4) the action and interactions that impacted upon the phenomenon, and 4) consequences of the actions or the outcomes (Corbin & Strauss, 1990). The constant comparative method was employed in this process to examine similarities and differences among categories and identify causal relationships.

Selective coding

In this step, the attributes or characteristics of the categories were refined based on the properties and dimensions of identify concepts as the interview and analysis are carried out in parallel (Strauss & Corbin, 1998). This was done by asking constant questions: What are those factors which influence the process of overcoming difficulties in transition related to the core category?; How is the meaning of those core concepts defined among nuclear family caregivers?; Who was the caring agent in the family?; How do they do this? When they do that action?. In order to keep track of the emerging framework or theory, the researcher rechecked all the summaries of the interview scripts from the first interviews and other materials including field notes, coding, memos and diagrams that the researcher had generated over the multiple steps of data analysis with the purpose of identifying the key linkage or core category.

Theoretical sampling

Initially, purposive sampling was used to recruit the participants who met the inclusion criteria of this study and were able to provide detailed descriptions and reflections on their experiences. When the categories began to emerge during data analysis, the family caregivers who were seen to have expanded or specific experiences were sought, for example, those who had hired paid caregivers to help in caregiving tasks. The next situations and participants that presented different characteristics, such as different backgrounds (age, gender, employment, preparedness etc.), different support systems, and presented differences in the patient’s condition or level of dependency were chosen. Those participants recruited included both family caregivers who received and those who did not receive home care services. Sampling continued until saturation occurred and no new information was being obtained.

Memos

The memos were the written records of the reflective thinking of the researcher ~~on~~ in regards to the coding process of data analysis. As data was coded, speculations, insights, and ideas were written down in the form of a memo and used as analysis and as a part of the audit trial. These memos were dated in order to follow developing ideas chronologically. They were recorded and reviewed on a regular basis as theoretical notes, operational notes, and code notes. The theoretical notes during open coding were used to guide the researcher in developing the emerging themes. As common characteristics emerged, the researcher asked questions and looked for supporting data for the emerging themes. The operational notes were used as a reminder to the researcher to determine, to look for, and to give direction for the next interview and/or observation. These notes suggested further sampling or suggested categories or subcategories to focus on in the next interview. The code notes were done during axial coding to reflect the questions that were generated during the coding process such as "What is the relationship between the two concepts?" Incidentally, abstract thinking and theoretical development was derived from the data.

Protection of Human Subject Rights

The research proposal was submitted for review and approval to the Research and Ethics Committee at the Faculty of Nursing, Prince of Songkla University. Additionally, permission was sought from Songkhla Hospital before starting the study. Prior to starting data collection, each potential participant was informed about the purpose of the study and their rights as a participant via a telephone call. Each participant who met the criteria and was willing to participate in the study was informed about the full purpose of the study, a brief outline of the methods and the potential risks and benefits on the day of the first interview. Verbal permission to tape-record was obtained prior to starting the interviews. Because the nature of the interviews and some of the questions asked may have caused some discomfort, the researcher showed respect to the participants by stopping discussion of any such topic when this became obvious. In addition, to insure the confidentiality and anonymity of the participants and the data, after completing the study, the recordings were erased.

The participants' names were replaced with a numerically coded number. All of the written data, including notes and the code book used to keep count of the participants in the study, were shredded after the study was completed. Each of the study participants was specifically informed that they could withdraw from the study at any time without any punishment or impact on the benefits or services they received from any heath care providers.

Trustworthiness of the Study

To ensure the quality of this study included demonstration of rigor, trustworthiness was addressed in four scientific criteria: credibility, transferability, dependability, and confirmability as proposed by Lincoln and Guba (1985).

Credibility

The credibility of the study was established using four methods; prolonged engagement, triangulation, member checking, and peer debriefing. Firstly, prolonged engagement was used to build familiarity and trust. For this purpose, the researcher explained the study procedures and answered all questions prior to consent. The researcher made one to three visits to interview the participants in their home. Each interview took about an hour. Secondly, triangulation was carried out via multiple methods of data collection including in-depth interviews, observations and field notes. Thirdly, credibility was also established through a member checking procedure in which transcripts and interpretations were reviewed with participants who guarantee the authenticity of the data (Lincoln & Guba, 1985). The participants were asked if the main idea was disclosed during analysis of their first interview. A peer debriefing with the advisory committee and academics was done to enhance credibility of this study. Each committee member and academic independently read the findings and confirmed or questioned the categories and sub-categories. Additionally, since this study employed the grounded theory approach, the credibility of the study was accomplished through this process; for instance, by using constant comparative analysis where the data were continuously triangulated, theoretical sampling verified the information from various sources and participants.

Transferability

The transferability in this study refers to the theoretical applicability of the developed substantial theory to other groups of nuclear families caring for older adult stroke survivors. Sandelowski (1986) proposed that a test of transferability is passed when the findings are grounded in and reflect the phenomena being studied, and when the reader finds them meaningful in terms of their own or other familiar contexts. In order to ensure the transferability of the research findings, these following activities were undertaken:

1. The research methods, contexts, settings, and the participant's characteristics were clearly described.
2. Acquiring enough thick description was achieved by purposive sampling in the initial phase and then followed by theoretical sampling to fulfill the theoretical need. These detailed descriptions were demonstrated in the research report.
3. Coding was labeled in both Thai and English language.

Dependability

Dependability, auditability or reproducibility refers to the ability to replicate the findings under similar conditions and rules for analysis (Hall & Callery, 2001). In order to meet the criteria of dependability of the research findings in this study, all data from taped recordings, transcriptions, field notes, and memos, were conducted and kept as documents and/or a database to ensure accuracy and facilitate the audit trail. Detailed descriptions of the data provided enough information for the reader and the participants to judge the key elements, clusters, categories, and themes of the analysis.

Confirmability

Confirmabity is the criterion of neutrality or objectivity which refers to the findings themselves and their freedom from the researcher's bias (Sandelowski, 1986). It was achieved through the awareness of the researcher in regard to subjectivity by using the following strategies:

1. The participants were recruited based on theoretical sampling and member checking, in addition to the actual words or phrases used by the participants being quoted and incorporated in to the findings.
2. To avoid pre-empting the findings, the comprehensive review of literature was delayed until after the analysis had begun.

3. The researcher’s presuppositions relating to caring for stroke patients were set aside or bracketed, to be revisited after the interview data were analyzed.

Summary

In this chapter, the researcher has justified the utilization of the grounded theory method to explore the process of the nuclear family overcoming difficulties in transition. The participants were recruited from one regional hospital and one provincial hospital, in the southern region of Thailand. The data were collected through in-depth interviews, observations, and memo records. The participants were purposively selected in the initial phase, and then after the first data analysis theoretical sampling was utilized during data collection and analysis. Data were analyzed by using the constant comparative method through three steps of coding procedure: open, axial, and selective coding to formulate the concepts, categories, and substantive theory, respectively. The trustworthiness of this study was established based on the four criteria of credibility, transferability, dependability, and confirmability.

CHAPTER 4

FINDINGS AND DISCUSSION

The purpose of this study was to explore family caregiving difficulties and generate a substantive model explaining the process of overcoming the difficulties for caregivers in nuclear families when caring for older adult relatives who have survived a stroke during the transition period from hospital to home. It was conducted to answer two research questions using grounded theory methodology. First, how do in nuclear families overcome difficulties in caring for older adult stroke survivors during the transition from hospital to home? Second, what are the factors influencing the process of overcoming difficulties in caring for older adult stroke survivors during the transition from hospital to home? This chapter describes and discusses the backgrounds of the participants and the process of fighting to gain a sense of control, along with the influencing factors.

Findings

Characteristics of participants

The characteristics of the participants were classified into three categories: (1) demographic characteristics of the caregiver participants; (2) the stroke survivors' characteristics, and (3) an interpretation of caregiving for older adult stroke survivors.

1. Demographic characteristics of the participants

The caregiver participants consisted of 16 primary caregivers and 10 secondary caregivers who provided care for 16 older adult stroke survivors. Most of the participants were females (n = 17), Buddhist (n = 22), and had finished high school (n = 10). The mean age of the participants was 53.7 years ranging from 21 to 82 years. They were the patients' children (n = 16), spouse (n = 6) daughter in law (n = 1), sibling (n = 2), and grandchild (n = 1). Half of the participants lived with the older adult stroke survivors, the others were living nearby. One third of the participants' family had an insufficient economic status. A summary of the participants' demographics are presented in Table 1.

Table 1 *Demographic characteristics of the caregiver participants* (N=26)

Characteristics		Frequency
Age	Mean = 53.7, S.D. = 15.44, Min. = 21, Max. = 82	
	21 – 40 yrs.	4
	41 – 60 yrs.	15
	≥61yrs.	7
Gender		
	Male	9
	Female	17
Education level		
	Elementary school	8
	Secondary school	8
	High school	10
Religion		
	Buddhist	22
	Muslim	4
Relationship		
	Spouse	6
	Daughter	11
	Son	5
	Daughter in law	1
	Sibling	2
	Grandchild	1
Living in the same house		
	Yes	13
	No	13
Family economic status (n=16)		
	Insufficient	5
	Sufficient	7
	Some savings	4

Table 2 *Stroke survivors' characteristics*

	Characteristics	Frequency
Age	Mean = 77.88, S.D. = 8.02, Min. = 60, Max. = 92	
	60 – 70 yrs.	2
	71 – 80 yrs.	7
	81 – 90 yrs.	6
	90+ yrs.	1
Gender		
	Male	6
	Female	10
Type of stroke		
	Hemorrhagic	7
	Ischemic	9
Operation (Craniotomy/ Crenectomy)		
	Yes	5
	No	11
Weakness		
	None	1
	Left side	2
	Right side	9
	Both sides	4
Device		
	None	7
	Trachoestomy tube	5
	Nasogastric (NG) tube	9
	Foley catheter	1
Living area		
	Metropolitan	5
	Urban	6
	Rural	5

Table 3 *Interpretation of caregiving for older adult stroke survivors*

Themes	Representative quotes
Caregiving is an obligation (n=22)	My parents don’t have anyone else. They only have me. There is no doubting my of love. I don’t have to mention that I love my parents. But more than that, it is my duty to take care of them. Taking care is a duty, love is another thing." (F010a L29-31 P16) I think that it’s natural to take care of her. That’s how I made up my mind [*Plong jai dai*] to do it. She took care of me before, so I would care of her. (F005a L14-15 P8)
Caregiving is a stressor (n=2)	As a caregiver, it makes my life more difficult. I am more tired because I have to take care of my three children, and my mom can’t take care of herself. So there is no one to take care of my dad. (F009 L12-16 P11)
Caregiving is loss of one’s life (n=1)	I have no life for myself, and cannot think about myself. If I didn’t take care of him, I would be able to manage time for my life. But now I need to take care of my brother. I cannot imagine my life as it was before. I just have to give my life to him. It means that I don’t have time to do anything for myself. (F013 L20-27 P10)
Caregiving is late life care (n=1)	In my thoughts, we have been together for a long time. So during this time, late in our life, I need to take good care of him (her husband). (F003 L25-27 P9)

2. *Stroke survivors' characteristics*

The older adult stroke survivors consisted of ten females and six males, with an average age of 77.88 years (ranging from 60 – 92 years). Most of the stroke survivors had suffered an ischemic stroke (n = 9) and had weakness in one or both sides (n = 15). Nine of the stroke survivors were equipped with one or more tubes including NG tube, tracheostomy, and Foley's catheters. A summary of the stroke survivors' characteristics was presented in Table 2.

3. *Interpretation of caregiving for older adult stroke survivors*

The interpretation of caregiving for older adult stroke survivors varied in different caregivers and could be classified into four sub-categories: (1) caregiving is an obligation; (2) caregiving is a stressor; (3) caregiving is the loss of one's life; (4) and caregiving is responsibility in later life; as presented in Table 3.

Most participants viewed their caregiving for their older adult as an obligation. This characteristic was described by participants who were the children of stroke survivors as well as spousal caregivers.

The Process of overcoming difficulties: Fighting to gain a sense of control

The results of the study revealed that fighting to gain a sense of control was the basic social psychological process that caregivers in nuclear families used to overcome difficulties in taking care of older adult stroke survivors during the transition from hospital to home. The process is comprised of three stages namely; (1) loss of control, (2) striving to master uncertainty, and (3) achieving a sense of control. Two additional themes; understanding the changing situation, and gaining role mastery were identified as transitioning points between stage 1 and 2, and stage 2 and 3 respectively (Figure 2). The process was driven by the recovery trajectory of older adult stroke survivors which involved three periods; the hospital period, discharge period, and post discharge or home period. The details of each stage are described in the following.

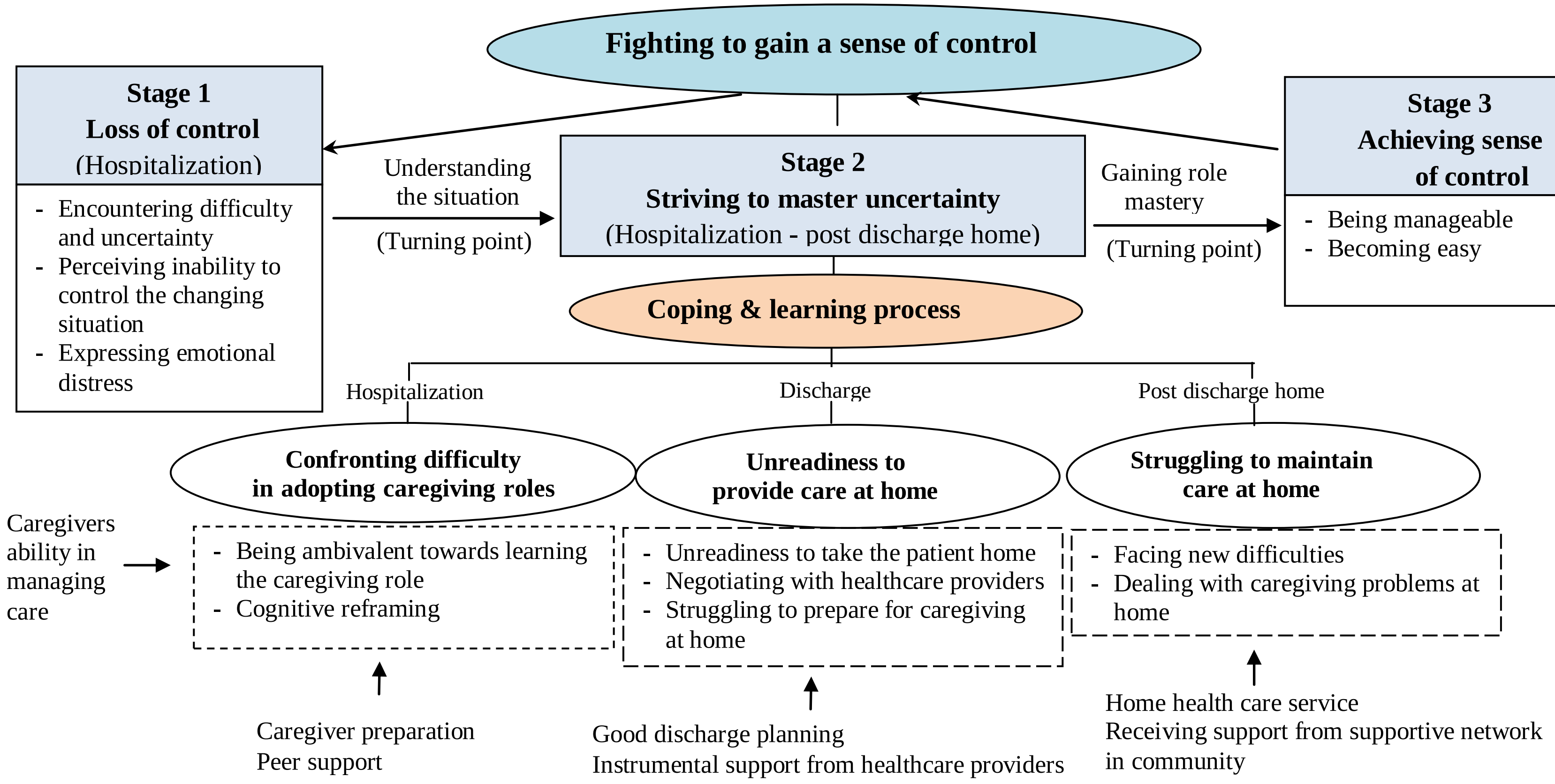

Figure 1: Process of overcoming difficulties: fighting to gain a sense of control, and its influencing factors

Stage 1: Loss of control

Loss of control was the initial stage of the process when the participants responded to the critical changes in their family life caused by their relatives' stroke. This stage began when the older adult family member suffered a stroke and was hospitalized. This initial process is comprised of three sub-categories; (1) encountering difficulty and uncertainty, (2) perceiving inability to control the changing situation, (3) expressing emotional distress, and (4) understanding the changing situation, as described below.

1. *Encountering difficulty and uncertainty*

Encountering difficulty and uncertainty was the participants' experiences of the problems and unpredictable changes in their family life due to the stroke suffered by the older adult family member. It included perceiving change and uncertainty about the older adults' illness condition, being concerned about the older adult adults' condition, and having difficulty in making decisions in choosing the treatment options.

1.1 Perceiving change and uncertainty

After the older adults were diagnosed with a stroke and admitted to the hospital, the participants perceived that their cognitive and physical functioning had changed which led to uncertainty about their family members' recovery and the possibility of that they could be disabled. Some participants also perceived that the older adults were in a critical condition which caused uncertainty in regards to the patient's survival. These perceptions were based on the information the participants received from health professionals and their own past attitudes about strokes. The participant's perceptions of the older adults' condition were reflected in the following quotations:

> At that time (the patient was hospitalized), I thought in my mind that she (his wife) might not be able to sit up. I was afraid that she might not survive... People said that if the blood vessel in the brain were obstructed, most victims didn't survive. I thought this myself. (F005a L1-2, L 6-7P3)
>
> The doctor told me that if she (her mom) had an operation, we, the relatives needed to accept (*Thum jai*) that she had a fifty-fifty chance. He didn't say she would survive or not survive. Fifty-fifty meant unsure. (F010a L22-23 P1)

1.2 Having difficulty in making decisions regarding treatment options

Some FCGs were asked to make decisions related to life-changing treatment for their older adult family members, such as brain surgery, and tracheostomy. They experienced difficulty in making such decisions. While FCGs wanted their older relatives to survive and recover, they were informed by a doctor that their family member was in a critical condition and needed intensive care and an operation which had a "fifty-fifty" chance of survival. They were also concerned that their decision might make their loved one suffer pain. As a result, they felt uneasy and uncomfortable in making a decision, as shown in the following statements:

> I wanted her to recover, but the doctor said that she had a fifty percent chance of surviving. I thought if she had an operation, she had a twenty percent chance of shock and a twenty percent chance of an increase in blood pressure. So, I rejected the operation. (F008b L26-27 P2)
>
> After she stayed in hospital for two weeks, the doctors told us that she (her mother) had to have a tracheostomy, otherwise she might get an infection because of the prolonged tubing. Initially, I rejected that and wished to take her home because she was too old and we (the family members) didn't want to make her suffer. And with her condition, we thought that she would not survive. But on that day, the nurses didn't take out the endotracheal tube. They said if we wished to take her home, we would have to take it out by ourselves. So, we had to let her stay in the hospital and let her have a tracheostomy. (F011a L19-21, L27-29P4)

1.3 Being concerned about the older adults' condition

The participants reported that they were concerned about their older adult family member's condition including the uncertainty of survival, the need for an operation and intensive care. Some participants were also concerned about the recovery of their older relative.

> Once my mother was hospitalized, I was uneasy. I saw she had tubing through her nose (nasogastric feeding tube), I felt very afraid. That tube made me feel that my mom had a severe condition, that her condition was not so good. (F005b L25-26, L29 P8)
>
> All of us (the patient's children) went to look after mom at the hospital, all day and night. Everyone was unable to work because we were concerned about our

> mom, We did not know whether our mom would survive or die, we were not sure if she would pass this crisis (on a ventilator). Then all of us came to look after her because we were concerned for our mother. (F006a L7-8 P2, L2-4 P7)

2. *Perceiving inability to control the changing situation*

This was the participants' response to changes in their lives due to taking care of the older adult family member who had suffered an acute stroke. Initially, the participants' perception of uncontrollability involved their concern for the older adults' survival. After the older adults had survived the stroke, this response was associated with the participants' feelings of incompetence in regard to providing care. This category is comprised of the caregivers' perception of the patient's need for care, the caregivers' perceived incompetence in providing care and their reliance on healthcare providers, and the difficulties in accessing help from healthcare staff.

2.1 Perceiving change of patient's need of care

Due to the alterations in the cognitive and physical functions of the older adult family member who had suffered a stroke, the participants perceived that the family member could not carry out personal care in daily living activities by his/herself and needed care provided by others.

> Before surgery, the doctors said he couldn't guarantee that my father would be able to walk or how it would be, but that he would need long term care. As I have seen in these patients (stroke) if they didn't pass away, they couldn't take care of themselves and only lay in bed. (F002 L26-29 P1)

> At the hospital, she was unconscious. She lay in the same position all the time, If she did not defecate, she remained in the same position. If I knew that she had defecated, I would change the diaper for her. But I was alone. I couldn't do it. (F010b L3-9 P3)

2.2 Being incompetent in providing care and relying on healthcare providers.

At the beginning when their loved ones were first admitted to hospital the participants had no idea how to care for them. As a result they relied on the nurses or nurse's assistants to help them perform care skills and provide care for their older adult stroke survivor. The following quotations of the participants describe how they perceived their incompetence and powerlessness in managing the changing caregiving situation.

> When the doctor told you that the patient has a stroke, what did you think about? How did you feel? (the interviewer)...I was just confused. had no idea. I hung on to the doctor. Whatever he’s going to do, let him do it. I have no idea. (F010a L24-25 P5)
>
> Once the doctor told me my mother had a stroke, I thought that any treatment that she was given meant she was surviving. Whatever the doctor told me to do, I did. The doctor would provide the treatment and I would go along with it. To save her life, I was okay with everything that was suggested by the doctor. (F010a L13-16 P4)

2.3 The difficulties in accessing help from healthcare staff

The participants had difficulty in receiving help from the nurses/nurse’s assistants, since often they did not receive help promptly as needed and sometimes they did not get any response from the nurses as they had expected. The participants reported that they did not want to wait for help and needed to manage the care by themselves, but they could not due to a lack of care skills and experience in providing care for the stroke survivors. Some quotations that reflected this component are given below:

> At that time, I didn’t know how to suction. I couldn’t do it. My father had secretions, so I asked the nurse to do the suction. She (the nurse) promised yea...I waited 5 minutes then 10 minutes but she didn’t come. When my father had a cough because of secretions, I asked the nurse for help again. She said that patients with tracheostomys were like this. My dad had a lot of productive coughing until nearly 4 a.m. the next day, it was like he had secretions in the throat. I decided to ask the nurse to suction my dad one more time. She nodded, but she didn’t come. (F002 L17-22 P3)
>
> My mom had many assistive devices while she was in the hospital. There were so many lines in her body. The problem was that every time my mom defecated, I couldn’t take care of her by myself. I needed some help from a nurse and that was a difficulty. I needed to wait until they (the nurses) were available. It was difficult relying on the nurses. (F010a L6-12P2/I1)

3. *Expressing emotional distress*

The unexpected changes in their family life, concerns over their older adults' survival and recovery, and perceptions of their inability to control the changing situation caused the participants to feel that they were faced with a crisis. This expressed itself as emotional distress including feeling frightened, fear of loss, and frustration.

3.1 Feeling frightened

Feeling frightened was of the participants sudden fear of what might happen to their loved one. Most participants were frightened after they had perceived that their older relatives had had a stroke and needed an operation. Participants who had never before thought about stroke were frightened when they were first informed that their older adult family member had had a stroke. Some participants were frightened after they knew that their loved one was in a critical condition, as shown in the following quotations:

> When the doctor told me that he (her husband) needed to have an operation, I was badly frightened. I didn't know what he would be like after the surgery. (F001L1-2 P2)

> I was very frightened. I thought she (her mom) had only fainted. I never thought it was a stroke, never thought about it. I didn't expect that she would be in a serious condition like that (stroke). (F010a L8-10 P1)

3.2 Fear of loss

Most participants identified that they experienced the fear of losing their loved one. This experience was prominently expressed by participants who were the children or spouse of the stroke patient, as shown in the following quotations:

> We were in fear of losing our mom, someone who could tolerate the situation, someone who didn't cry, but the others who couldn't tolerate it were crying. (F006a L25-26 P1)

> At that time (when the patient was hospitalized),…I was afraid that she (his wife) might not survive...The people usually said that if the blood vessel in the brain was obstructed, most victims didn't survive. (F005a L1-2, L 6-7 P3)

3.3 Frustration

Some participants experienced feelings of disappointment in the nursing care services. They perceived that the changing situation was beyond their control, and they needed help and support particularly from the health care professionals. However, these needs were often unmet and so the participants expressed frustration, as shown in the following quotation:

> Relatives of the patients are unsure whether some symptoms of the patients are abnormal or not. When the relatives say that there are abnormal symptoms, why don't you (the nurses) come to see? At least you could come to encourage us. When we are frustrated, we need you (a nurse) for a little help. You should tell us whether you're able to come or not. Come to advise us. I noticed that both patients and relatives are relieved when the nurse just shows up. Suffering and stress disappear or are reduced. We can control our fear. But if I am alone, I panic and seek help from many people because I see that the patient had a change in their condition. (F006b L14-30 P8)

Understanding the situation: turning point

During the period when older adult stroke survivors are under acute hospital care, the participants begin to understand their reality of the situation. They begin to recognize that what has happened to their family lives. They also began to realize that they need to plan what to do next. The participants were able to understand their changing situation by receiving information, comparing their situation to others, and accepting their older adults' condition.

1. Receiving information

Receiving information about their older adult's condition, medical treatment, and care plan prescribed by a physician or nurse helped participants to understand the reality of the situation.

> Before surgery, a doctor told me that he couldn't guarantee that the patient would be able to walk or how it would be after surgery, but that long term care was needed. As I've seen in these patients (stroke) if they didn't pass away, they couldn't do any self-care and were bed ridden. Then we all (the patient's

> children) discussed it; if it was going to be like that how would we take care of him, who would be the caregiver? (F002 L26-29 P1)
>
> With her condition, we thought that she would not survive. At that moment, we wanted to take her home, but a doctor told us that her symptoms could be treated. (F011a L18-9, L13-14 P5)

2. Comparing their situation to others

Some participants mentioned that they attempted to understand their situation by comparing it to others who faced a same or similar situation. This strategy helped the participants to view their circumstances more positively. This assisted them in dealing with their problem, as one participant stated:

> We needed to recognize that it (stroke) does not happen to us (her family) alone. Other people had more difficulties than us; at least we had some potential resources. (F002 L30-31 P5, L8-11 P8)

3. Accepting the reality of their older adult conditions

While some participants hoped their older adult relatives could survive and recover, some mentioned that they realized their loved relatives were old and so it was reasonable to have some illness due to physical deterioration. They thought that it would be difficult for their older relatives to recover and they needed long-term care. Accepting the reality of their older adult relatives' condition led them to start planning what to do next.

> Before surgery, a doctor said he couldn't guarantee that the patient would be able to walk or how it would be after surgery, but that long term care was needed. As I've seen in these patients (stroke) if they didn't pass away, they couldn't do any self-care and were bed ridden. Then we all (the patient's children) discussed it; if it was going to be like that how would we take care of him, who would be the caregiver?...Some people thought that it was karma, but I thought it is his disease. We need to accept it. (F002 L26-29 P1, L8-11 P8)
>
> I had to think it was because of his old age; the age, when the physical body and the internal organs start to deteriorate; because he (her father) was over eighty years old. I knew that it is because of his old age. I did not expect that he would be the same, but I took care of him. (F009b L16-17 P1, L2-4 P2)

Stage 2: Striving to master uncertainty

This stage took place when the participants felt their needs were unmet and this triggered them to learn to be caregivers and ended when they learned to care for their older adult stroke survivors at home. This stage is comprised of three sub-categories: (1) confronting difficulty in adopting caregiving roles; (2) feeling unprepared to provide care at home; (3) struggling to maintain care at home. Because the difficulties and uncertainties the participants experienced changed overtime during the period of transition from hospital to home, the findings of this stage were elaborated on based on three periods of transition care: the hospitalization period; the discharge period; post discharge, as follows.

Hospitalization period

Confronting difficulty in adopting caregiving roles

Confronting difficulty in adopting caregiving roles involved the participants attempting to deal with challenges or problems in learning to be caregivers. It is composed of two categories; (1) being ambivalent towards learning the caregiving role and (2) cognitive reframing ("I need to learn and I can do it").

1. *Being ambivalent towards learning the caregiving role*

Being ambivalent meant the mutual existence of two opposed and conflicting attitudinal and emotional reactions towards learning about the caregiving role. The phrase "being ambivalent" could be interpreted as "*Kla kla Klua klua"* as described by the caregivers. It is composed of two components: (1) desiring to learn care skills; and (2) being fearful of learning care skills.

1.1 Desiring to learn care skills

The feeling of incompetence and difficulties in accessing help from healthcare staff caused the participants to feel stressed and powerless to control the care situation. As a result, they wanted to learn care skills to be able to provide care by themselves for the older adult stroke survivors, as shown in the following quotation:

> At that time, I didn't know how to suction. I couldn't do it. My father had secretions, so I asked the nurse to do the suction. She (the nurse) promised yea...I waited 5 minutes then 10 minutes but she didn't come. When my father had a cough because of secretions, I asked the nurse for help again. She said that patients with tracheostomies were like this. My dad had a lot of productive

> coughing until nearly 4 a.m. the next day, it was like he had secretions in the throat. I decided to ask the nurse to suction my dad one more time. She nodded, but she didn't come. I was so mad and I told her (the nurse) I knew it would be like this. If you didn't want to do it (suction) you could teach me, teach me. I'll do it by myself. (F002 L17-24 P3)

1.2 *Being fearful of learning care skills: "I don't want to do it and I cannot do it."*

Being fearful of learning care skills involved the participants' feelings towards learning care skills. Most participants stressed that they were scared to perform care skills at the beginning, because caregiving was a new experience for them. Lack of experience, including a lack of knowledge in caregiving, caused the participants to have no confidence in practicing such skills. They were also afraid of making a mistake that might cause their loved one's condition to worsen or cause harm which could result in them being blamed by the nurses. This type of situation led the participants to feel stressed as expressed by their anxiety and nervousness when practicing care skills. These feelings were obvious when they practiced complex care skills such as nasogastric (NG) feeding, suction, and dressing a tracheostomy wound. This is reflected in the quotations below.

> The difficulty is my due to my concern about providing right or wrong care as a nurse or doctor does. If I make a mistake, I am concerned whether it will affect my mom or not. I am not used to taking care of her that way. I fear I will make a mistake. (F006b L11-15 P4)

> At the beginning, I was afraid that a nurse would blame me if I couldn't do something properly. For example, I was very nervous when I was wearing gloves. I was pretty slow because it was wet. (F012 L6-9 P8)

> My first time practicing, when I fed my dad, my hand was shaking. At that moment, my dad had a cough with a secretion, I panicked as I'd no idea what I should do...I was shaky. (F002 L20-22 P4)

The participants fear influenced their thinking/attitude to performing the caregiving role. As a result, in the beginning the participants identified unwanted feelings in regard to taking on the role and expressed this in negative ways such as "I cannot do it" further thoughts are presented in the following quotations.

> I was very afraid at the beginning. There were many lines, particularly the NG tube. I was afraid that it would dislocate. I can't even replace a tie at the neck. I'm fearful of doing that. I don't think I can do it." (F002 L5-8 P4)
>
> I'm afraid of making mistakes, I am very fearful. When I feed my mom, I'm afraid that I'll make her aspirate. They (the nurses) told me to draw out the stomach content for checking, I was so scared and didn't want to do it. I did not dare to look at it. I did not dare to draw it out because I was afraid that it may be hazardous to my mom. (F005a L25-28 P4)

2. *Cognitive reframing: "I need to learn and I can do it"*

Cognitive reframing was the participants' reaction in the sense of changing their conceptual viewpoint into a more positive meaning in regards to their experience of a difficult situation. This concept can be described by three sub-categories: (1) re-appraisal of the situation and realizing the problem; (2) change of thinking: I need to learn and I can do it"; and (3) trying to learn

2.1 Re-appraisal of the situation and realizing the problem.

Re-appraisal was the participants' cognitive reactions by which re-thinking and evaluating their past actions/reactions related to their new caregiving role. This reaction was driven by the caregiving situation and the stroke survivors needs. As some participants said:

> Initially, I thought I could not do it (care skills), absolutely, because there are so many things (devices). But later when I had a re-think, I thought I need to do this because there is no one else to do it, if I didn't do it. (F011a L27-31 P21)
>
> If I was afraid, who would do this (caregiving tasks), because my dad needed to go home, I had thought. How would I be able to do it if I don't learn. I had realized that if I could not do it, who would do it. (F002 L10-124 P4)

2.2 Change of thinking; "I need to learn and I can do it."

After they realized that their stroke surviving family member need continuing care at home, the participants thought that they must learn caregiving skills.

> At the beginning of practicing, I was not sure whether I could do it. But in my mind I knew that I needed to take care of him after he returned home because he had no one else. I thought I need to do it (practicing) and I can do it. (F001 L16-18 P3)

> I had thought if I cannot do this who would do this (caregiving tasks). Since I saw someone else able to do, I thought I must do it and I can do it. (F011a L1-4 P8)

2.3 Trying to learn

While the patient was hospitalized, the participants identified that they tried to learn the required skills from the nurses and other people with similar experiences by using strategies including; observation, interacting with others, and practicing.

2.3.1 Observation

Participants identified that they started to learn by observing the demonstration of caregiving practice. They also observed the practice of the nurses when providing care for other patients who had similar illness conditions as their older adult family member, as presented in the following quotations:

> In practicing of care, we need to observe a nurse and how she did it. Wiping pellets (faeces) wiping pee (urine), how they made it. (F006a L20-21 P2)

> Sometimes when they (nurses) provided care at another bed, I just always observed them, observed that how they suction. Then I could think over whether I was doing it right. (F011a L1-2 P10)

2.3.2 Interacting with others

Even though the participants received care skills teaching, most of them described that the nurse generally provided one or two times of teaching which lacked any assessment of their understanding. They could not remember all the aspects that they were taught. Therefore, they found out more information in learning to care through interacting with others. Some of the participants helped the others when they doing care, while others interacted by asking nurses and other people with similar experiences.

> We have to be considerate of other patients nearby. For example, when they are alone and need their diaper changed. I help them and I had learned how to do it. But if I don’t care or didn’t give any help to others, it would be difficult for me. (F002 L5-9 P3)

> I had to talk with nurses, I had to asked them how to do it. Another thing during hospitalization, there was not only my dad’s case, there were many people that have been like this before. I had to learn from them. (F002 L3-6 P3)

2.3.3 Practicing

Some participants stated that they tried to learn by being involved with the nursing care team in providing personal care for their older adult family member while he/she was admitted in the hospital, while others learnt by themselves through practicing care for their loved one. Some participants’ expressions of trying to learn by practicing are given below:

> I try to practice again and again. Then I can do it. (F011a L2P10)

> First time, I couldn’t do it (feeding). But I try to do. I try to do it and ask the people who are at the bedside whether I am doing it right? (F013 L18-21P7)

However, the level of learning in this period varied among the participants, and this depended on how long as well as the frequency that they observed and practiced the required caregiving tasks. Some who had more time to learn such tasks became familiar with the tasks and dared to practice. By comparing with nurses’ practice they gradually developed their practice and got some feeling of confidence. While the others who had a limited time of learning described still feeling un-confident and uncertain about their ability to provide care at home, as one participant said:

> They provide a single time of teaching and then the patient was discharged. I felt stressed I know that when she returns home, I can’t do it. I am not confident. I don’t dare do suction for my mom. I am afraid that I might put the suction tube too deep then it would be dangerous for her. (F010a L3-5 P24)

The other participants who had more time in learning stated:

> I observed the nurses' practice and compared this with my practice whether I do it like them. When I can do it like the nurse's, I think it's okay. Later, I do it like that again and become used to it. (F011a L15-17 P8)
>
> Over a long time, we have seen more about their (nurses) practice. Then we adjusted our practice, and we began to learn. (F006b L7-8 P5)

Discharge period

Unreadiness to provide care at home

Unreadiness in providing care at home was the participants' reaction to the caregiving transition from the hospital to the home setting. It took place when the illness condition of the older adult stroke survivors became stable and their discharge was planned. This composed of three sub-categories: (1) unreadiness to take the patient home; (2) negotiating with healthcare providers; and (3) struggling to prepare for caregiving at home. The details regarding the conceptual idea of being unwilling to go home is given below.

1. Unreadiness to take the patient home

Almost half of the families under the study expressed un-readiness in taking the patient home. The characteristics of this sub-category composed of perceiving the poor condition of the older adult stroke survivors, lack of resources, having no idea about caregiving at home, and not being confident to provide care at home. The details of each component are described below.

1.1 Perceiving the poor condition of the older adult stroke survivors

Participants' perception of the condition of their family members' illness was different from the physicians' perspectives. Although the physicians had considered that the stroke survivors' condition was well enough for discharge to continue care at home, some participants were unwilling to take the patient home because they perceived their loved one as still having a severe illness condition that needed professional care in the hospital. This perception was demonstrated in the following quotes.

> He had been admitted in the hospital for eight days, he had not got well when he was discharged. I don’t understand the doctors nowadays. We take the patient to the hospital to be cured, and hope to rely on them. But he (patient) still had not recovered, still had a lot of phlegm..I think he's going to stay until he gets a little bit better. But the doctor still needs to discharge him. Then, we have to take him back home. (F003L9-11P1, L3-4P2)

> They (nurses) said that you need to have (prepare for) oxygen at home. I felt it’s scary if we need to use oxygen at home. In my opinion, my mom should have continued in the hospital to let her get better before discharge. (F010aL21-22P5)

1.2 Lack of resources

Some participants indicated as not being ready to take their older adult stroke survivor home because of a lack of resources to provide care at home. This included caregiving equipment, money, and a caregiver. When the stroke survivors’ condition became stable, the participants were informed by a physician or nurse about a discharge plan. They also received information about what to prepare for caregiving at home from the nurses. However, the participants identified that the information generally provided was unclear or insufficient. The physician informed only the patient of the plan for discharge, however, a specific date for discharge was not indicated. The relatives of the stroke survivors were informed of the specific date of discharge on the day of discharge. As a result, some participants indicated they had not had enough time to prepare caregiving equipment. In addition, some participants stated that their older adult stroke survivor needed to use some expensive devices such as an oxygen tank, fowler bed with air mattress, and suction machine. But they did not have enough money to prepare all of those devices. As a result, they faced difficulty in preparing for caregiving at home and this caused emotional distress in the participants. Some exemplars of descriptions reflect this component as given below:

> She just told me about the equipment that I should prepare. But she didn’t tell me how to rent it or how to prepare a document for renting the equipment. She didn’t tell me in advance that the patient would be discharged in the next seven days. She told me just two or three days before. (F013L18-22P9)

> The nurse told me that I needed to buy a bed that costs about 40,000 baht, the suction that costs about 5,000 baht, and the oxygen tank that costs about 8,500 baht. The total price is about 100,000 baht. We earn a little money per day so we can't find that amount of money. (F008L29-30P5, L1-2P6)

Furthermore, some old aged participants who lived with their older adult stroke survivors alone, identified that they lacked a caregiver to help in caregiving at home, as one participant stated:

> Once the patient (his wife) got better, the doctor told me that she could be discharged home, no need to stay in the hospital because she'll be at risk to infection. At that moment I still couldn't find a care attendee (paid caregiver). I told him that I didn't have a caregiver, I can't find one. (F015L30-31P6)

1.3 Having no idea about caregiving at home

Having no idea about caregiving at home was one characteristic of the un-readiness to provide care at home as responded to by the participants. Although the primary caregivers received care skill teaching, they experienced uncertainty about their ability in taking care of older adult stroke survivors at home. They did not know about care at home for stroke patient, as one participant stated:

> I did not know about care at home, what and how to provide care at home. I have never come across a case before. (F010aL16P5)

1.4 Being unconfident in providing care at home

Being unconfident was the participants' responses to their new role related to performing care skills at home. Because the participants usually only received a single teaching of care skill practice during hospitalization, they also only had a short time to practice these new care skills. They needed time to practice and learn more on those care skills, particularly the complex ones such as suctioning, in the hospital to make them feel confident, as some participants stated:

> Doctor had ordered to discharge the patient, but I didn't feel confident in suctioning. Then, I asked a nurse to postpone the discharge date. I needed to learn more about suctioning to have confidence before discharge, when I was ready I would tell you (nurse). (F002 L3-6 P1/I2)

> Once she (her mom) returned home, we must do everything that is we must rely on ourselves, don't think to rely on anyone. We must be able to do everything by ourselves. I worried whether I could do it, whether I will complete it all (tasks), I had thought. (F011a L21-23 P11)

2. *Negotiating with healthcare providers*

Negotiating was the participants' trying to find a way to overcome their being un-ready to take the patient home by discussing the problem with health professionals and asking for care to be continued in hospital. After the participants knew that their loved one would be discharged while they felt un-ready to take the patient home, they tried to talk to the doctor or nurse about their un-readiness. They asked the doctor or nurse to allow the patient to stay in the hospital. Most of them were not successful in the negotiation, while only two participants had success in such negotiating. However, some participants were successful in getting some benefits from the negotiation. For example, some received partial support for caregiving equipment, and some could extend the time of discharge. Some participants' expressions reflected this sub-category as given below:

> They (health staff) asked me to sign out to take the patient home. I said that "doctor please allow him to continue in the hospital, he hasn't got better." He didn't listen to me, he still discharged the patient...It might be because he wanted to do a tracheostomy on the patient, but I refused for that to happen. (F015L5-6, L13-14P2)

> At that time, I asked the doctor could she (her mom) be discharged later because we didn't have enough money to buy the needed equipment for her. The doctor said "why you are delaying this, why didn't you prepare." I told him that there was no money, we have no money. Then he said he will talk to the nurse to consider providing some support for us." (F011aL8-12P13)

3. *Struggling to prepare for caregiving at home*

Struggling to prepare for caregiving at home required the participants' effort to overcome the trouble arising from the transition of care from the hospital to home. It was characterized by two components; (1) having difficulty in preparing care equipment, and (2) seeking needed resources and support

3.1 Having difficulty in preparing care equipment

After the participants were not successful in negotiating with the health care provider, they faced new stressful situations due to having difficulty in preparing the care environment at home. This was because they lacked money, were unfamiliar with care equipment, and did not know where to source the equipment.

> Another difficulty was buying things that we didn't know about, and never seen before. They (nurses) told me about buying an oxygen tank. But we didn't know which was the right tank. Because oxygen can come in both a tank and as a machine, but at that time we didn't know, we had never seen the oxygen machine before. The seller ask me which one you need, when we were going to buy it. We couldn't answer him. (F011a L19-26 P24)
>
> They (nurse) did not suggest where to find the device, we were struggling to ask. We had struggled to ask by ourselves. Some other patients' relatives and some nurses who were generous suggested borrowing the hospital's equipment. But when we tried to borrow, they didn't have such equipment. (F010a L10-14 P4/I1)

3.2 Seeking needed resources and support

Seeking resources and support was the participants' reaction to solve the difficulty in preparing care equipment at home. After they tried to negotiate with their health care provider and had realized that their older adult survivors needed to return home, they started to find the needed resources and support including any sources of those resources. They also sought out resource information from other people with similar experiences. Some families received help from the hospital which provided some equipment for borrowing. Some also received help from nurses in seeking a paid caregiver. Nevertheless, the hospital could not provide everything that the survivors needed to use at home. The families needed to look for some equipment from other sources. In other words, they needed to buy some equipment that led the participants to encounter new difficulties and stress due to lack of money.

> They (nurses) said the patient couldn't continue to stay in the hospital, because the doctor had signed the patient's discharge. I told them that I would get the patient out in the evening. Then I rushed to seek caregiving equipment in that morning… Fortunately I have a friend, who is a nurse at the hospital X to help

> me. And fortunately someone whose mom had died and was cremated on that day donated the bed (laughing). She called me to carry the bed. I got everything from that case. (F010aL8-12, L14-18 P6)

> I tried to contact the district hospital. A staff member recommended to me a suction machine that costs 3,500 Baht. I got some discount. The district hospital lent me an oxygen tank, and this bed belongs to our neighbor.(F008b L4-11 P6)

> I told the nurses that I didn't know anyone (caregiver), could you help me to find one. I need one who has caregiving experience and can be trusted. Then the nurses helped me in finding a paid caregiver. (F015 L11-12 P6)

Post discharge period (at home/community)

Struggling to maintain care at home

Struggling to maintain care at home was defined as a process through which the participants put effort in overcoming uncertainty encountered in their home environment. The sub-categories in this stage are: (1) facing new difficulties and (2) dealing with caregiving problems at home.

1. *Facing new difficulties*

After the older adult stroke survivors had been discharged from the hospital, all the participants experienced one or more new difficulties. They described experiences of difficulties when faced with unexpected symptoms of stroke survivors, facing emotional and behavioral changes, managing a paid caregiver, work overload, experiences of physical stress, a patient's un-cooperative state, and financial strain.

1.1 Facing unexpected stroke survivors' symptoms

Facing unexpected stroke survivors' symptoms was reported as one of the most difficult aspects by some participants in caring for their older adult stroke survivor at home, as one participant stated:

"The most troublesome aspect in providing care at home is that the unexpected symptoms occur without our understanding." (F013L26-28P11)

Two unexpected stroke survivors' symptoms reported by participants in this study were breathing difficulty and having a convulsion.

1.1.1 Breathing difficulty

Some participants experienced breathing difficulty and ineffective sputum removal of the older adult stroke survivor. The family caregivers indicated that breathing difficulties were the hardest caregiving problem to handle, particularly in the early period at home. This was due to the participants having insufficient information and skill in suctioning. These caused the unplanned re-hospitalization of two stroke survivors and another two has emergency room visits.

> On the day that she was discharged home, my mother had difficulty in breathing out at night...It’s probable she was obstructed with phlegm, and at that time I had never suctioned before. When I was suctioning, I couldn’t put down the suction tube, I didn’t know how to do it...I called a friend who works in hospital X. She told me to call the ambulance to take the patient to the hospital. (F010a L21-25 P7)
>
> Two days after he returned back home, he had a lot of phlegm. I was panicking then I called my daughter to take her father to the hospital. (F003L12-13 P1)
>
> Sometimes he is like in a coma condition but it is just for a while. He seems to stop breathing for a while and then he gets better. His breathing is unstable, sometimes it is slow, sometimes it is rapid, and then he has a dent chest when he breathes (accent on a long sound). Then for a while he is back to normal. (F002L11-23P6)

Another participant faced difficulty in sputum removal for her older adult stroke survivor family member because she lacked the appropriate care equipment to provide care at home, as one woman stated:

> It was the rainy season when he (her husband) had just been discharged from the hospital. He had a lot of phlegm. I suctioned him and then I had to do it again in less than 15 minutes. I needed to pull out an iron tube and clean it with hot water. I put in and pulled it out many times. I didn’t have a suction device like in the hospital. Using a rubber ball for suction couldn’t remove the phlegm effectively. That was the hardest time. I didn’t sleep, and it was most stressful. (F001 L15-20 P11)

1.1.2 Convulsion

Some participants described experiencing difficulty in taking care of their older adult stroke survivor when they had the incident of a convulsion. This situation caused the participants to experience stress and confusion, as one participant expressed:

> I am taking care alone, when I meet with an unexpected patient's symptom I am just confused. I don't know what it is? For example, one day he has a seizure. I'm not quite sure what happened to him. (F013L26-29 P9, L4-5P10)

1.2 Facing emotional and behavioral changes of the stroke survivors

In the early period after the older adult stroke survivors returned home, some participants experienced difficulty in managing emotional and behavioral problems of the older adult stroke survivors. They also struggled with the difficulty in managing care associated with such problems. These situations caused the participants to get stressed and feel overwhelmed, as some participants stated:

> Sometimes she couldn't sleep. She pulled out the lines in her body. I needed to hold her all the time. She moved a lot and tried to sit up. I restrained her to the bed. But she was able to pull her hand out of the bed and then pulled this (pointing to a feeding tube through the nose). I needed to keep my eyes on her very often (showing sneaking looks) since I was worried that she would pull it out. (F006a L11-18 P3/I1)
>
> I couldn't sleep at all when he was just discharged from the hospital. I walked around his bed. It seemed his brain didn't function. He didn't know who was who. When I did sputum suctioning for him, he wouldn't let me do it. I needed to restraint his hands. (F001 L12-14 P1)
>
> In the early period at home, I couldn't go anywhere. She (her mom) calls me every 10 minutes. I would just only eat a meal, and she would call me. While I was eating one dish, I had to run to see her four to five times. The matter was that she didn't dare to be alone. (F010 L17-21 P11)

1.3 Caregiving situation difficulties

1.3.1 Difficulty in managing feeding

Some participants described experiencing difficulty in managing feeding included maintaining the NG tube and diet preparation. Pulling out the NG tube by the stroke survivors was a situation that occurred more often due to a patient’s confusion and the participants felt pity in restraining the patient.

> The most difficult time is when he is unconscious. He was trying to pull out the feeding tube. Sometimes he does it twice a day. I have to call a nurse to put the feeding tube in again. After feeding, if I am not aware, he will pull out the feeding tube. He does it very fast. (F001 L7-12 P11)

Diet preparation was one problem frequently described by participants in feeding their older adult stroke survivor at home. Some participants were concerned about the cleanliness and nutrients of foods that might affect their loved one. The others who lived far from the city faced difficulty in buying some raw materials for a blended diet preparation, as some participants stated:

> Now, the difficulty is that we have no time in preparing a blenderized diet. We already bought all the needed equipment for that, but there is no time...Another matter is that in preparing it we need to use rice bran oil. That is quite hard to buy, we have to go to buy it in the city. (F007 L2-3, L23-24 P10)
>
> I was concerned. It seemed like if we do the diet and have germ contamination, or we prepare improperly cooked food, it is dangerous for mom. We had considered about that, so we decided to buy instants foods for her. (F008bL2-4P9)

1.3.2 Difficulty in managing oxygen supply

The participants, with older adult stroke survivors who needed oxygen therapy at home, described experiencing difficulty in managing the supply of oxygen. All indicated that changing a oxygen tank was the hardest activity in managing the supply of oxygen. This is because of the weight of the tank that makes it difficult to transport. Thus, some of the participants handled this problem by renting or buying an oxygen machine. Some participants’ expressions about this problem are given as follows:

> One oxygen tank can be used for only a few hours. The tank is big and heavy so it is hard to move. It is very difficult to bring the tank to refill with oxygen because it is big and heavy. It is hard to lift it by myself so I need many people

> to help me. However, they are busy at work so they are not able to give me a hand. (F012 L27-29 P13)
>
> If it as a tank, it must be filled the oxygen every two days. I'm elderly if I have to drive for that I would be dead, I cannot do it…Then my niece, who works at a nursery in one hospital, advised me to buy an oxygen machine. I have not had difficulty with the oxygen matter. (F015 L9-11, L16-19 P8)

1.3.3 Difficulty in moving the patient

The participants reported experiencing difficulty in lifting, transferring, and changing position, particularly when providing personal care activities such as bathing, and changing diapers. This difficulty was prominent for some participants who have taken on the responsibility for caregiving alone.

> The most difficult thing is lifting the father. Sometimes he moved from the mattress to the wooden floor. I need to raise him back. That is a hard problem…I had to find a way to move him back. Sometimes I have to pull him, I didn't know if that is right. (F009a L3-4, L7-8 P16)
>
> Daily I do either a shampoo or bed bath for her because it is hard to go outside. I take her outside the house when I shampoo her…The difficulty is holding her when going from inside to outside the house. I need 3-4 people to help me because the patient is big. (F007L5-7, L27-28 P9)
>
> After changing the patient's position, his body moved down. I wanted to move him up to the top. But I couldn't do it alone. I needed some help to lift him up. (F001L13-15 P14)

1.3.4 Patient's uncooperation

Some participants experienced difficulty in performing caregiving activities due to the survivor not cooperating. This is because the stroke survivors' emotions and behavior have become out of control and some of them having a pain issue. Therefore, they were uncooperative with care activities, as some participants reflected:

> My dad didn't cooperate with me when I did physical exercise for him. He is against my force. He doesn't let me do it. It is a problem. Sometimes he spits medicine out when I give it to him. It depends on his mood...Sometimes he refuses to eat. He closes his mouth when I feed him. He throws the medicine

> when I give it to him. These are problems even though it doesn't happen very often. (F009 L28-30P6, L6-8P7

> It seemed his brain didn't function. He didn't know who was who. When I do a sputum suction for him, he doesn't let me do it. I need to restraint his hands. (F001 L13-14 P1)

1.3.5 Managing co-morbid condition

Beside hypertension, three older adult stroke survivors had other co-morbid conditions that included asthma, heart disease, hyperthyroidism, and bladder stones. These conditions made some participants experience more difficulty in providing care for the older adult stroke survivor at home, as one participant stated:

> Another difficulty is he had asthma when he first returned home. A doctor prescribed a bronchodilator inhaler for him, but it is difficult for him to use. Because he's unable to keep it in his mouth. (F009a L17-19P16)

1.4 Difficulty in managing paid caregiver

The participant who hired someone to take the main role of caregiver for the older adult stroke survivor described experiencing difficulty in managing the paid caregiver. The difficulty was related to the participant's concern about the security and distrusting characteristics of paid caregivers, such as carelessness and un-cleanness. One aged participant expressed the problems in managing paid caregiver as follows:

> At first, I quite distrusted her (paid caregiver) because she's rough…she's careless, and an un-careful person. Sometimes she throws the garbage, but it doesn't fall into the trash…When she's washing the dishes, I'll hear a bang, and it isn't clean. (F015 L18-19, P1, 24-26 P3/I2)

> There are many problems. She (paid caregiver) talks on her phone all day. Sometimes her friends come into my house…The day before, she asked me to pay her wage ahead of schedule for 2000 baht. Okay I pay her. After that her boy friend came to get money from her. When night falls, I locked the front door and kept the key…Because I was concerned about the security. Perhaps she may arrange a guy to come in the house. (F015 L4-7, L11-13 P2/I2)

1.5 Work overload

The participants described experiencing work overload particularly when taking care alone or having multiple roles. Some stated that they had to do both care activities and household chores. They also described that they had to perform a lot of care activities from the early morning until late at night. They spent most of their time completing the tasks and had a little time to rest, particularly in the first two to four months after discharge. One participant stated:

> I wake up at 5 a.m. to prepare some food for my child and wash the dishes. In the morning I go to take care of my parents and cook for them before going to take my three children to school. Then I go back to feed my dad some food and medicine. I boil some water and give him a bath. I go back home and have breakfast around 9:30 a.m. Then I clean my house, wash some of my parents clothes and my children's…I do both houses. When I finish all the chores then I will have time to get a little rest in the afternoon. Around 3 pm. I start to cook dinner. After that I go to pick up my children from school. I go to provide some food for my parents. Then I go back home to take care of my children in terms of having dinner, doing homework and so on. (F009 L24-7 P11-12)

1.6 Physical stress

After about four months of providing home care, some of the participants identified they experienced physical stress. They reported that they were exhausted, tried and had less sleep. This is resulting from the constant provision of care, meeting physical demands and time constraints in the early period of the stroke survivor being at home. Some participants' expressions reflected physical stress as presented below:

> About two months, she (his mom) bawled her eyes out and she pulled out everything; the clothes, diapers, she pulled out everything. During that time she also didn't sleep for three or four nights. So, we could not sleep too. This made me suffer and feel very stressed. (F006 L6-8 P7)

> I'm so tired. I accepted that now I'm tired. If I go to sell goods at the local market I have to wake up at 3 a.m. to have a bath and change her diapers …and sometimes I didn't have any sleep at all in the day time. (F007 L19-20, L23 P19)

> About four to five months after my dad left the hospital, I felt exhausted. And at about eight months I'm extremely exhausted and started fainting. Everything is

> my burden…I must to do everything alone so sometimes I faint. (F009 L12-16 P11)

1.7 Financial strain

Some participants experienced financial difficulty associated with providing care for their older adult stroke survivor. They mentioned that they faced the high cost of care spent on caregiving equipment and supplies including diapers, instant blenderized diet, oxygen, suction tubes, gloves, and miscellaneous. While the family and their own income was decreased. As a result, they experienced financial strain that consequently caused stress, as some participants stated:

> The wage for a caregiver is 4,000 baht per month. It is pretty hard because I earn money from harvesting sugar palm fruit. But it is the money that I need to pay. I can't ask my son/daughter to quit his/her job. They earn more money than I do. And they give me some money. If they quit their job, I will not have money to spend for living…I can't spend money the same as when she (his wife) is not sick. When she was still well, I could work and earn some money. Since she has been ill, the majority of income is from my daughter. She takes care of all expenses alone. (F005a L13-18 P6, L2-6 P9)

> During this time, I am stressful. I couldn't pretend that I am alright. At some point, there is something that I have to think about like spending a lot of money without any income. So how can I live my life. (F001 L18-20 P17)

1.8 Difficulty in accessing care services

The participants identified three aspects of difficulty in accessing care services including rehabilitation therapy, follow up, and home care services. Many participants indicated that they needed further rehabilitation services. However, most of them could not access the service. The three causes of difficulty in accessing rehabilitation services identified by the participants were time constraint, transportation problems, and a lack of rehabilitation services in the community. They also identified needs of formal physical therapy for the stroke survivors at home, as some participants expressed:

> I want to take my mom to rehabilitation. But I can't do so because there are not enough people at home. I have to work and do the chores. If I take my mom for her physical therapy at the hospital, it will take one full day without doing

> anything at home. So I can’t do this...Another thing when we take her to the hospital, we have difficulty in transportation matters…Taking her to get rehabilitation we have to request an ambulance from the municipality, it’s difficult. (F010a L21-27 P17, L19-20 P18)

> Staff at the hospital told me that a physical therapist would visit us at home. But there was no one who came to see us. He called me once and asked me about the patient’s condition. I replied that his condition was the same; his left arm moved slightly. I expected that the staff should sometimes come and take care of the patient. He told me that he would come but he never showed up…What I would like to happen is that the authorities have to see and sometimes take care of the patient such as providing physical therapy, and giving some advice. That would be better. (F009 L29-31 P12, L1-3 P13, L3-4 P15)

Some participants described experiencing difficulty in obtaining care services related to follow up regimen. Some identified the difficulty involved with patient transportation. While others described the difficulty involved with the waiting time in receiving treatment, as some participants stated:

> We had the first doctor’s appointment at 1 p.m. Accidentally, on that day the patient’s nasogastric tube disengaged. So we needed to rush to the hospital earlier in the morning. We contacted a nurse. She sent us to the emergency room to get the first examination. But the nurses at the emergency room neglected that. The patient got a physical examination at 2 p.m., and it finished at 3 pm. (F008 L5-8 P28)

> I meet a lot of trouble, when I take the patient to see a doctor on appointment day…For example, not following the queue. Sometime the staff said the patient needs to have a blood examination first. Then I must wait about two hours for the results. Instead of spending half a day it becomes a full day, maybe four o'clock to pick up the drugs. The drug line was so long. (F009b L13-17 P4)

Some participants also indicated difficulty in accessing home health care services in the community. They expressed they needed someone who has knowledge to help when they face uncommon situations, as one participant said:

> Those who have knowledge didn’t come. I know nothing, there are not any health care staff to come forward to give suggestions. Because sometimes he had uncommon symptoms, I didn’t know. For example, the first month he had spasms, but at that time I didn’t know what it was..You should send a specialist

> at least once per two weeks to see us. You should assign the staff in each zone to be responsible for taking care of patients. (F013L6-11P25, L21-23P26)

2. *Dealing with caregiving problems at home*

Dealing with caregiving problems was the strategic process which participants used to solve the trouble situations related to caregiving for the older adult at home. The four main strategies participants used to deal with caregiving problems at home that emerged from the analyzed data are: (1) managing care at home, (2) adjusting lifestyles, managing stress, and learning to care at home, (3) managing stress, and (4) learning to provide care at home.

2.1 Managing care at home

Managing care was the participants' cognitive response to have control of the caregiving situation which ensured maintaining care for the older adult stroke survivors at home. The participants used some strategies including sharing the responsibility among family members, hiring someone to help in performing caregiving tasks, seeking and accepting support, and supervising paid caregivers.

2.1.1 Sharing responsibility among family members

There were a number of cases in this study where the older adult stroke survivors lived alone or with a spouse, and the adult children come to share the care for their parent. Some participants described sharing the responsibility of care by taking turns to be on duty. Not only performing caregiving tasks but also the money was shared among these participants. Some participants' expressions are given below:

> The first-half month after discharge, all her (his mom) children gathered here. Everyone was concerned about her, because during that time she has had to use oxygen…After that we shared the duty by arranging it as a shift. There are two persons taking on the duty in each shift, and we are on the duty for five days and then another couple takes a turn. (F006a L21-23 P3, L4-5 P4)

> Someone said that if hiring an outsider to take care of her, we have to pay ten thousand baht as a minimum. That is we have to share the cost of at least two thousand baht. Now we share the cost of care for mom at least five thousand per month per person, for food and the grandchild [who is hired to be the caregiver]. (F008b L2-8 P15)

2.1.2 Hiring someone to help in performing caregiving tasks

Some participants noted hiring someone to help in performing caregiving tasks was as a strategy that helped them to cope with limited numbers of caregivers and some caregiving situation difficulties. Some aged participants with children living far away from their parents or those who had no children, they could not handle all caregiving tasks by themselves, particularly when the illness condition of the stroke survivor was severe. Two aged spousal participants hired a paid caregiver to take the main role because they were unable to provide 24 hours of care. While another took the main role, but hired someone to help in specific jobs of caregiving such as changing position, giving a bed bath etc.

> At the beginning, I hired someone for giving care because there was no one else in the house. I hired her for two months….Since everyone had to work, no one can take care of the patient. I need to climb palm trees to earn some money for living. We decided to employ someone. And we share the fee for care. (F005 L7-9 P2, L5-7 P6)
>
> I hire someone to help the patient for a bed bath. He is a man so he can change the patient's postures and make up the bed…I will pay him extra money for helping in doing a bed bath twice a day. I pay him 50 baht a day. (F013L11-15P11)

2.1.3 Seeking and accepting support

Seeking and accepting support was another strategy that the participants used to handle the caregiving situation to be in the control. They received help and support by both asking and without asking other family members, friends, neighbors, as well as health professionals. The type of support they received was informational, emotional, instrumental, financial support, assistance in caregiving tasks, and assistance in housework.

> Sometimes when my nephew stops working, I asked him to help with a bed bath in the morning to help my father sit up, because his balance wasn't good and he needed someone to hold his body. (F002 L1-4P8)
>
> I cannot raise him because I had spinal surgery ten years ago. When I need to raise him (her husband), I call for my daughter who lives next door to help me

> to do that. (F003L15-16, L20-21P4)
>
> If she (paid caregiver) has to go somewhere for an hour or two hours, I asked a neighbor who has been a nurse and she has retired to take care of her (patient) for a while. She is very nice, she comes to see and is support for me. (F015L9-10 P9)
>
> We take care of her as the duties we have to do such as dressing wounds, feeding, cleaning the feces, wiping pee. That’s normal. But in the aspect of controlling her confusion symptom, we couldn’t. That is if mom had the symptom, we let it be. Finally, we had consulted a doctor. He gave us some pills for her then she is better. (F006b L16-20 P10)

2.1.4 Supervision for paid caregiver

Supervision was described by the participants as the way that they used to control the difficulties related to managing paid caregivers. The supervision involved not only care activities but also activities of normal daily living related to security, as one participant mentioned:

> She (paid caregiver) can do everything. But I also must supervision her... I stand nearby her to watch and to control her and told her “go softly”. I gently explain to her and request her to go softly. (F015L28-29 P1, L22-33 P3/I2)
>
> I locked the front gate. It is a precaution. I think it could be preventable. Sometimes late at night, I wake up to survey the area…I don’t want to be careless, just a lookout. (F015 L14-16 P2/I2)

2.2 Adjusting lifestyles

Adjusting lifestyles refers to the participants adjusting their way of living to fit in with caregiving demands. They used a variety of strategies to adjust their lifestyles including making plans, rearranging daily activities and time management.

2.2.1 Making a plan

Making plans or a schedule was a strategy that the participants used to organize their caregiving tasks and household chores. They also used this strategy to make sure that they could provide good care and complete all of the tasks each day, as some participants stated:

> I get up at 5 a.m. to do a quick bed bath for the patient. I touch him gently to wake him up. Then I give him an expectorant. I soak a (drug-coated stomach? Is there a word missing..is this a medicine?) since this drug is very difficult to dissolve. I need to soak it for about two hours and wait until it dissolves. So I can feed him easily. After that I do passive exercise for him by moving his body. And then I can give him a complete bed bath prior to giving some breakfast. (F013 L6-11P11)

> On the day of doctor's appointment, I would finish all chores in the morning. And in the afternoon, I went to the hospital. It took me half a day. I was at the hospital until 5 p.m. Then I went back home and did the chores until I was finished at around 10 p.m. (F010a L2-4P18)

2.2.2 Rearranging daily living activities

To maintain both the pre-existing work and caregiving tasks, some participants spoke about having to rearrange their daily living activities. Some of them changed their sleeping schedule by waking up early to perform care for their older adult stroke survivor before going to work in the morning. However, others needed to stop working due to the high demand of the caregiving role.

> We had to reschedule our work. Before this we go to the market fair at 1 pm., now we have to go at 2 pm. We have to complete care for mom first, and then we go out to sell goods. When it is close to the time of feeding or doing anything for her, we have to keep to it and come back. (F007 L2-4 P8)

> Now I am solving a problem by being there (her parents house) from early morning until noon. And I wait until I finish feeding my mom at lunch time. Then I go back home (her house) to take a shower. I used this way to resolve arguing with my dad. If I come back at 10:30 a.m. to take a shower and then go to see mom at noon, dad will scold me. (F010a L12-15 P12/I2)

2.2.3 Managing times

Some participants identified adjusting their lifestyles by managing time. For some participants, this strategy was an attempt to have control over the caregiving load and physical stress. As some of them reported that they had less time to spend for social activities, such as hanging out at night with friends, in order to spend the time in providing care for a parent. Some participants also decreased their work hours to fulfill their caregiving roles. The example quotations reflect how participants manage their time as given in the following:

> I have to control myself. I have to give up some activities that I have done before this, mostly the social ones. I have to slip away from meeting with my friend because I have to take care of mom and I have had sleepless nights. Once I come back to my house I needed to take a rest. (F006b L16-20 P11)
>
> We have decreased the amount of time for selling goods, because we have to take care of her (her mother in-law) at around 6 a.m., and 6 p.m. Now we stop selling in some markets that are far from here…We also left one morning market to take care of her. (F007 L18-19 P7)

2.2.4 Taking care of self

Taking care of one's self was a strategy that the participants used to focus on their own health by keeping a healthy lifestyle in order to maintain caregiving roles. Some identified looking after themselves by taking a rest. Likewise, another Muslim participant gave up fasting during Ramadan month to maintain normal health. Some participants' expressions that reflected this component are presented below:

> One neighbor said to me that tomorrow will be the fasting ritual (Teu Seil Od). Will you do the ritual? I replied that I mightn't because I am taking care of a patient. I am concerned that I will have weakness and fainting, if I don't eat while I have less sleep, and who will help me to take care of him. (F001 L5-8 P10)
>
> At the beginning, I went to sleep with my parents (speaks with a trembling voice). Leaving my children here (her house). But when I did that for several nights, I had a headache because I was tired all day and night. I gave up and changed to sleep at my home to be fully relaxed. (F009 L17-20 P18)

2.3 Managing stress

Managing stress was a coping strategy that the participants used to deal with the difficulties in providing care for their older adult stroke survivor at home.

2.3.1 Psycho-emotional strategies

Adapting the mind [Tum Jai Hai Yom Rub or Plong Jai]

Most participants mentioned adapting their mind was the significant strategy used to relieve their stress. They used a variety of approaches to adjust their mind including acceptance [Plong], endurance, and letting go. Some participants mentioned they had to be patient when they could not handle some caregiving problem, or when they felt the situation was beyond their control. They also had to let it go and make up their mind to accept the reality of the situation, as some participants stated below:

> I feels like..it's better if she had not (stroke). But once it happened I needed to accept it [Tum Jai Hai Yom Rub], and then do the best in taking care of her (his mom). (F008L8-9 P31)
>
> When my mom was anxious, we couldn't do anything. We couldn't talk with her. We were so stressed because we couldn't solve the problem at all. It seemed like easy to say, we couldn't hit her. We couldn't do anything. So, let her go, and then waiting for the right moment. (F006 L15-18 P14)
>
> Initially, I didn't trust her (paid caregiver) more because she was not careful. But now, I have to be resigned to this [Plong]. (F015 L18-19 P17)

Thinking positively

Some participants noted that they maintained an optimistic attitude while facing with stress caused by the stroke and caregiving situations. As one participant said:

> I have to accept and have positive thinking that it does not happen to us alone. Others they were worse than us, they have more difficulty than us. At least we still have enough to buy needed caregiving equipment. (F002 L23-25 P5)
>
> I never give up, because I think that taking care of my older brother is a good thing. That's it. I forget the rest. I don't think about anything else. (F013L1-3P11)

Taking time off

It was a reaction that participants used to give his/herself space from the situation that caused them to be stressed. Some families which have more than one or two caregivers took turns to do the job. Most participants mentioned accepting respite or taking a short period of time off from routine caregiving as a way to help them to feel relaxed and in control. Some described going away to give their eyes a break from the troubled situation. The examples of participants' expressions are presented as follows:

> When I faced a stressful event, I walked away from there to find the way to relax. (F015L1 P18/I2)
>
> There is manpower to replace when a person has stress, another one will replace the stressed one to let them relax for a while. If not, it can be very stressful. (F006a L26-27 P14/I2)

Talking with others

Talking with other people was one strategy that was usually used by several participants particularly in the female participants. Family, friends and neighbors were mentioned as being important people to talk to. This strategy gave the participants an opportunity to share their thoughts and feelings with such people. They received informational and emotional support and relief from stress. Some participants described how talking with others was important for them.

> When I get stressed, I talk to my relative, my sister. I can talk about everything with my youngest sister. Sometimes I called to talk with my friends. (F002 L26-27 P10)
>
> Because it seemed like his brain didn't know who he was. When I would do the tasks, for example doing sputum suction for him, he doesn't let me do it. I need to restraint his hands...He says someone will harm him. I don't know how to handle this. So I walk around his bed crying alone. But in the day time, there are neighbors coming to chitchat. I just feel a little bit relaxed. (F001 L6-11 P4)

Negotiating

Negotiating with the older adult stroke survivors and healthcare staff was a strategy that the participants used to deal with some difficult situations to get a sense of control. They negotiated with the older adult stroke survivors to get some time to themselves, to be able to perform some basic activities in their daily life or their own work, as one participant stated:

> I was frustrated at the beginning; my mom called me when I was washing some dishes.. I told her that she shouldn't call me if it was not so important. Sometimes she calls for nothing. I need to finish washing dishes. I explained to her that she should understand me that she couldn't call me often because I have to work alone and finish the work. F010a L4-8P13 / I1)

In this stage, the participants also negotiated with healthcare staff about the patients' rights and accessing care services. They also asked healthcare staff to get information about appropriate care services that they could receive, as one participant expressed:

> For the doctor, I needed to have some arguments…For example, my mom was left on the day that the tracheostomy tube slipped out. I knew that he had a lot of patients. But they might communicate with us why couldn't you?…I must talk to the nurse that 'the patient had taken the oxygen off from 3 p.m., and now it's already 7 p.m. (F008 L3-8, L11-13 P27)

2.3.2 Spiritual strategies

Some caregivers found strength in relying on their spiritual beliefs and practice to help them cope with their stressful situations. The participants identified religious practice and having faith in God as spiritual strategies that they used to relive distress and get the strength to care for the stroke survivors.

Asking help from God

Asking help from God was a strategy that some participants used when they were in the situation that they could not seek assistance from anyone. By using this strategy, it helps to relieve stress and make them feel better, as one participant expressed:

> Sometimes he sees people walking around in the room and I cannot see them as he sees them. I am scared. I don't know what he sees. But I don't see it that makes me scared. So I sit down and pray… I think what should I do? I follow a religion that I believe in asking for help. I ask God to protect me to be safe, and to help the patient to be better...I don't know anyone that I can consult. It's like Buddhists think about monks, and Muslims think about Allah. I pray for being safe and sound, and hope that no bad things happen. (F001 L29-31 P4, L1-6 P5)

Having faith on Gods or Religion

Some participants mentioned that placing one's faith and trust in God helped them feel better when they are confronted with difficulty over their ability to control the situation, as one participant stated:

> If I thought it over it may cause me a headache, then I have faith in Allah, if he allows us to be alive we are alive, if he would want us to be happy we would be happy. If it is what he would give us to be, it's okay. Then I could sleep, but before I go to sleep I pray to Allah for protection. (F001 L6-17 P12)

Religious practice

The participants also identified religious practice as a significant strategy that helped them to go through their difficult and uncertain times. Donations and praying were common ways of religious practice described by the participants in this study.

> Sometimes I kneel down and raise my hand and pray to Allah. I read the Al-Quran as I have been taught. I keep praying to Allah. I usually focus on it."(F001 L5-7 P19)

2.4 Learning to provide care at home

Learning to provide care at home was a strategic process that the participants used to master the difficulties in providing care at home. The way in which they learn how to provide care for the older adult stroke survivors at home included trial and error, seeking needed information, guidance and support, and the application of previous knowledge and skills

2.4.1 Trial and error

Trial and error could be referred to "*Long phid Long tuke*" in Thai words. In other words, it means learning from the mistake or learning by doing through his/her own way. It is composed of three components; (1) try by doing and observation, (2) application of previous knowledge and skills, and (3) seeking needed information, guidance and support.

Try by doing and observation

Most participants identified that they tried by giving care and observing what would happen. Doing and observation was often used before family caregivers tried other approaches, as some participants stated:

> When he was back home, he pulled out his nasogastric tube every other day... Until on the fourth day after discharge, at Songkran festival, it was a holiday so the community health center was closed. If I took him to the hospital, I would have to call for an ambulance and it's difficult to move him. I did not know what to do, hence I tried to feed the patient by mouth. I observed that he was able to chew. So there was no need to use the nasogastric tube. (F013 L26-30 P6)

> The first day that she (her mom) was discharged, my mother had difficulty in breathing out at night....It's probable she was obstructed with phlegm, and at that time I had never done suctioning. When I was suctioning, I couldn't put down the suction tube, I didn't know how to do it...After that when I faced that problem I asked my friend at hospital X to come to help me, to teach and supervise me while I suction. Later on, I did trial and error. It's like practicing a skill that it's okay. It might not be so good while it was happening, but it's gradually improved. (F010a L21-25, L28-29 P7, L3-6 P9)

Application of previous knowledge and skills

Some participants indicated that they try by applying their previous experience and knowledge in providing care for the older adult stroke survivor at home. Some described that such experience and knowledge helped them in learning to deal with some caregiving situations of difficulty, as one participant stated:

> A physician had prescribed him a bronchodilator inhaler. But my dad couldn't use it. When I pressed a puff of bronchodilator, he didn't inhale, he would open his mouth. Then I applied the children's face mask on him when I give the bronchodilator to him…I find my own way because there's no other way. I've used this method with my children, since those two children have asthma. (F009a L19-21, L24-27P16)

Seeking needed information, guidance and support

Some participants described that they learn through seeking needed information, guidance and support. Some of them used this approach when their prior method could not solve the problems that they faced. They need to know and understand more about the stroke survivors' conditions and the relevant skills required to provide care, and this compelled them to search for deeper understanding, as some participants expressed:

> The other day, I have learned via telephone from my friend who works at hospital X. I call her pretty often when I have a problem. I called her when I could not push down a suction tube. And she suggested to me how to do it. I called her when a feeding tube was a little bit dislocated. So she told me how to put it back. I have learned by myself via telephone. (F010a L18-24 P24/I2)
>
> Using a plastic bag is easy to be full of urine. I could not check it often so the urine overflowed onto the bed sheet. I had to change it often. My daughter in law suggested that I should buy a rubber tube and then connect it to a container. So I did it (wearing a plastic bag on a penis and connecting the bag with a rubber tube to a urine container that is put under the patient's bed). (F003 L23-27 P5)
>
> I steadily collected the necessary phone numbers during the events I faced. For me, I think if it's a big problem, I would contact others. So, I think by myself (Kid Ang)…I also learn from TV, radio and my life experience. (F013 L22-24, L29-30 P19)

2.4.2 Improving caregiving skills

Improving caregiving skills was a consequence of trial and error. The participants indicated that after they learn by trials and error for about two to four months they could improve their caregiving skills and became familiar with caregiving situations. Self-appraisal and adjusting caregiving practice were identified as the strategies they used to improve their caregiving skills, as shown in the following expressions:

> At the beginning, I was afraid of putting the suction tube in to deep; it might irritate some of the patient's organs. But later on, I noticed how to put the suction tube in; how deep should it be that it would not cause my mom's coughing. After that we had adjusted our practice by avoiding inserting the suction tube too deep. (F006b L9-11 P6)
>
> Later on, when she (her mom) had a lot of phlegm, I asked my friend from X hospital to help me. She stood beside me and watched me when I was doing the suctioning... I was not confident to suction. I was concerned about my mom's safety. So I asked my friend to come and help. And next time I can do it. It's

> learning by doing. I think it’s okay to take it as a trial and error. It helps me to improve my skills... At that time, I might not do it so good but it gradually improves. (F010a L28-29P7, L3-6, L20 P9)

Gaining role mastery: turning point

Gaining role mastery was a consequence of striving to master uncertainty and it also acted as a turning point which drove the participants to the next stage. After the participants struggled with their caregiving situation for several months, most of them mentioned that they had gained more experience and had learned about care. This led them to gain role mastery. Two characteristics of role mastery mentioned by the participants in this study were characterized as becoming competent and being confident in performing care.

1. Having knowledge and being skillful

The participants identified that gaining knowledge resulted from their caregiving experience. They also described their skills in providing care for the stroke survivor as gradually developing based on repeating caregiving practices. As time progressed they learned more and became familiar with the tasks. Some participants said when they started they felt bewildered by even small steps, but as they became more proficient it made them feel more confident in providing care at home. Some of the participants’ statements are presented as following:

> At the beginning, I was afraid of doing suction drainage tubing. If it was too deep, it could be dangerous. When I did it, I knew how deep it was. I noticed that it was not harmful to my mum. So I dared to do it. I learned how to do it gradually. (F006a L24-28P5/I1)
>
> We got better because we did it repeatedly; again and again and that made us more agile and confident to do it. As time passed we became more skillful. (F006c L22-23 P5/I2)
>
> Before this, I couldn’t do anything. Now, using an oxygen machine, turning it on and off, filling the water, checking the oxygen level is what it should be, and observing her (the stroke survivor) breathing. I could do it all; suctioning, changing diapers, I can do everything. (F011a L24-25 P20)

> I gained a lot of knowledge...It seemed like my mom's sickness taught me how to do another job. I have knowledge of this subject (caring), only I don't know about medicine and I cannot give injections. (F011a L13-16 P22)

2. *Being confident*

Once the participants gained more knowledge and skill in providing care for the older adult stroke survivor, they felt confident to perform and to continue their role. Some participants talked proudly about their ability to do caregiving tasks and their feeling of confidence:

> Now, I have confidence. I can do it all (care skills). If something happens (a problem) I don't feel scared; I can do everything they taught me…Now, supposing I was hired to work as a patient carer, I am sure I could do it, and it would be okay. (F011a L12-13 P16, L26-27 P20)
>
> I said to mom that now I could easily be a nurse (laughing). I have care skills and I can do everything. (F010a L7-9 P9)

Stage 3: Achieving Sense of Control

Achieving mastery was the final stage of fighting to gain a sense of control. This acts as a consequence (outcome) of the coping and learning process. This concept refers to the participants' subject definition of the caregiving situations they experienced after using their internal and external resources to deal with the stressful events. It can be described by two categories; being manageable and becoming easy.

1. *Being manageable*

After participants struggled with many difficulties and caregiving demands by using strategies as well as resources from both internal and external sources, they learned about care at home and thus adjusted the practice by themselves. They pointed out their caregiving situation was being manageable. They felt confidence to manage the caregiving situation. They also felt easy to deal with the caregiving problem, as some participants stated below:

> At present it's okay, like in providing of care or when anything happens, now it's easier than that at the beginning. At first it was dark when I faced a problem,

> a lot of questions arose about how I would do it. But now if I have any problem I work through it step by step. (F002L4-8P9)

> Initially, I muddled on, but as time progressed, it became familiar. Now I feel I don't want to take her to be treated in a hospital. Keeping care in the style we have is better than returning to the hospital. (F011aL26-29P11)

> At first, sometimes I dared to do, and sometimes I was afraid. But when I do it (caregiving tasks) several times, I have a deftness, and when I do it several days I have a skill. Before this when I took care of her (his mom) alone, I was anxious because we had never done this. But now it is not a problem. (F006cL4-6P6)

2. Becoming easy

Most participants reflected providing care for the older adult family member became easier when they had more required knowledge and skills as well as more understanding and caregiving experiences, as some participants stated below:

> At present it's okay, like in providing of care or when anything happens, now it's easier than that at the beginning. At first it was dark when I faced a problem, a lot of questions arose about how I would do it. But now if I have any problem I work through it step by step. (F002L4-8P9)

> Actually the activities we do today are not difficult, once we understand. But at that moment, the difficulty is my concern of providing right or wrong care as a nurse or doctor does. If I'm doing it wrong, I worry whether it would affect my mom. Now, I have more understanding and confidence, I feel it's not complicated. (F006bL10-14P4)

Factors influencing family caregivers' overcoming difficulties

Factors influencing family caregivers' overcoming difficulties are intervening conditions in mitigate or alter the causal condition (Figure 3). They can be described as facilitating factors and hindering factors

Facilitating factors

Facilitating factors are the factors or conditions that promote coping and the learning process of family caregivers in providing care for their older adult stroke survivors. It comprises of seven sub-categories: (1) personal resources of caregivers; (2) family resources; (3) social support; (4) accessibility of supportive services/resources in community; (5) supportive environment in teaching and learning care skills; (6) coordination between care settings; (7) Thai socio-cultural context.

1. Personal resources of caregivers

1.1 Positive attitude and interpretation of caregiving roles

Positive attitude and the meaning that participants give to their caregiving are powerful factors that facilitate the caregiver to master uncertainty and caregiving difficulty. Some participants defined the meaning of their caregiving as an obligatory role. They believed that taking care of their ill parents or spouse was a good chance for them to repay their parents' goodness. Some of them also believed that caring for their older adult stroke survivors was an end of life care. Similarly, some participants believed that caring for their family member gained merit. These ways of thought encourage them to provide good care, and help them to overcome the stressful situation. Some participants' views that reflect this factor are presented as follows:

> How long you spent time to move from the chaotic until you could deal with the problem step by step? (Interviewer)
> For me, I it was not too long. It may be depend on ones' characteristic, the ability to deal with a problem, consciousness, and thinking. In caring for older adult with stroke, we (caregivers) need to think positively, and then you can find out way for solution. (F002 L12-14P9)

> What could make us overcome the problem? This is exactly the abstract, it means we want to repay our parents, doing it the best as we can. We don't know how much, but we try our best. (F006b L25-28 P5)

1.2 Ability in managing care

There were some conditions described by participants that enhance their ability to manage care for their older adult stroke survivors and it related issues during transition from hospital to home. These included ability in planning, seeking helps, making connection with others, and negotiating with healthcare providers, and their experience. Some participants described that their experiences in taking care of ill persons with similar conditions or their children helped them to minimize or to deal some aspect of caregiving difficulties. Some exemplars quotation reflects to this theme are given below:

> I experienced taking care of my mother-in-law who had similar conditions to my mom. I can care for someone with a tracheostomy tube. Then we decided to let him (the physician) do tracheostomy for our mom. (F006a L1-3P2/I1)

> They (nurses) taught me only on the discharge day. But for a dressing wound, I had my own resourcefulness. I already know some…I have experience in taking care of my children like that. (F010a L20-21, L29 P10)

> The caregiver is very important, we have to take a look, observe, think, and deal with it. (F013 L8-9 P26)

2. *Family resources*

The three components of family resources were identified as facilitators by participants were family harmony, good economic status of the family, and available family supporters.

2.1 Family harmony

Participants mentioned family harmony as a critical factor help to cope with problems or difficult caregiving situations. It could be referred to as "*Kwam-Rug Kwam-Sa-Muk-Ke*" in Thai. Family harmony is characterized as love, family unity, family relationship, family communication, agreement on decision making, and helping family members. These characteristics helped the participants to easily access the needed support from the family, as some participant indicated:

> What helped me overcome difficulties in caring for father? Family relationship, it's as if we (siblings) usually phone to each other. My sister who lived in Phuket called to ask about dad's symptoms every day. I knew that she's concerned, it's as if we care for each other. (F002 L25-30 P10)

> Love and family unity...if we have anything that needed deciding in the family, everyone (siblings) would decide together with the same agreement and direction. We trust each other. (F006c L10-12 P13)

> Once we (siblings) had a problem, we would talk together... We could talk about everything among, we never quarrel. We always phone each other. If anyone has stress, we will talk to give support. (F008b L4-6 P23, L2-6 P29)

2.2 Good economic status

A good economic status was one of the most important factors helping caregiver participants. This was obviously when the stroke survivors needed more advanced equipment, or lacked a caregiver, or had their aged spouse as a primary caregiver. A family in a good financial position could afford to buy such equipment or hire a paid caregiver to undertake the caregiving tasks. Thus, the economic factor usually affected participants' caregiving during discharge and post-discharge time.

> The cost of caring for this type of patient is high. If you have no money it would be difficult. Because it's unavoidable, you must care. (F006aL14-15P8)
>
> The wage for a hired caregiver is 700 baht per day. It costs a total of 21,000 baht per month without overtime. Using her (his wife's) pension to pay for that...not a hardship matter. If it is any hassle, I must fight. (F015L21-25P9)

2.3 Available of family supporters

In some families, having a large number of family members was helpful for caregivers in sharing the responsibility of caregiving in terms of both performing caregiving tasks and paying for caregiving expenses. Therefore, more family members means more supporters were available. However, this is not really true for some participants who had a family conflict. Some participants' reflections on this factor are given below:

> During her (her mom) hospitalization, everyone (older adults' children) rotated to look after her every day. All five siblings would rotate daily. So, I didn't feel much discomfort. (F008 L30-31 P8, L1 P9)
>
> I went to the hospital every morning to look after her during the day time. In the night time, I hired a nurse to take care of her for two shifts, evening shift and night shift...Because there was nobody, we had three members in our family and my daughter is working in Bangkok...For myself, I'm aged 82 then I couldn't look after her all the day and night time. (F015 L22-29 P2)

3. Social support

Social support was reported as a facilitator by the participants throughout all periods of the caregiving transition from hospital to home. The types of support valued by participants included informational support, emotional support, instrumental support, and spiritual support. Those factors helped the participants to minimize distress and enhanced their feelings of being in control.

3.1 Informational support

The participants indicated receiving informational support, including guidance and advice from health care staff, friends, neighbors, and peers (other caregivers who had similar experiences) helped them to gain understating and to cope with caregiving problems. In the hospital period, receiving information about their older adult's condition, medical treatment, and care needed, including care-skills prescribed by a physician or nurse helped participants in understanding and accepting the situation. As they started to learn about care they also received some advice on practicing care-skills from peers. This support made them felt relieved from stress, as one participant stated:

> Doctors and nurses gave me some information that gave me a little encouragement... They told me that the patient did not have other diseases or complications. He only had a stroke. This made me feel relieved. (F001L22-30P3)

During the discharge period, the participants needed the necessary information about what should be expected for caregiving in the home environment, involving equipment support, and emergency contact. However, most of them indicated that the information they received from the discharge planner usually focused on only personal care, physical exercise, diet preparation, and care equipment. They also mentioned receiving inadequate information.

During the time at home, most participants received the necessary information from the home-care-nurse, local health care volunteers, friends, and neighbors:

> I have a friend who works at one hospital. She advised me to contact Mrs. S who is an owner of a medical equipment shop and provides the oxygen machine for rent. So I called her to rent the oxygen machine. Fortunately, it was available. (F012L4-9P15)

> I was informed by a village health volunteer that I should get an identity card for disabled people. But I needed to wait six months. On that day, the village

> health volunteer told me that I should inform the municipality in order to get welfare. (F007L5-8P17)

3.2 Emotional support

Emotional support means providing empathy by giving supportive words or visiting and being with the participants to enhance their feeling of comfort, encouragement, confidence, and reduced of fear and concern with their stressful situations. Family members are the significant persons providing this kind of support in all periods. During hospitalization and the home period, they were also supported by relatives, friends, neighbors, and health professionals. As some participants stated:

> She (a primary caregiver) complained to me that it was the first time and she was worried. I encouraged her that she could do it. Just trying to learn the suction technique is not too complicated. I asked her to keep on practicing little by little. And finally she was able to do it. (F011b L27-31 P7)
>
> They (neighbors) visited and asked about mom’s condition. It’s encouraging. Someone didn’t come, but they asked how she was doing, if she could sit up. It’s okay that the neighbors asked about her with deep concern. That made me feel comfort. (F008 L31 P10)

3.3 Instrumental support

Provision of instrumental support included, material, money, and assistance in caregiving tasks or chores and modification of the home environment; these were helpful for all participants in dealing with caregiving difficulties. The significant persons who provided instrumental support to the participants usually were their family members, both during the time the stroke survivors were hospitalized and at home. Their family members gave support by helping in doing caregiving tasks or chores, giving money and food. Their relatives also helped and gave things to the participants during this period. This support helped the participants to decrease their stress from the work-load and financial strain. It also helped some participants who have multiple roles to maintain their previous role. Some participants’ expressions relating to this are given below:

> Each morning, my son who lived at “Ta-Sa-Arnt” would come to give a bed bath to his father. The daughter who lived next to my home would help with cooking, feeding, cleaning the house, and washing both of my and her father’s clothes, she was responsible for all of these. The daughter who lived in Yala province was responsible for shopping for diapers, suction tube, drugs, and all care supplies used for her father. She would come once a month. The eldest son comes every weekend to carry his father to take a bath in the bathroom. (F003 L14-21 P8)

> My dad took care of her (her mom) at night, and I would replace him during the day time. Then, before I went to hospital I could do the chores in the morning. (F010a L19-20 P2)

> His nephew helped him. He contributed two thousand baht for him every month to buy a diapers and stuff. We are alive because of his help. (F001 L25-27 P3)

During the discharge period, some participants were provided needed care equipment by health care providers. This support facilitated the participants to overcome their un-readiness to give care at home caused, as one participant stated:

> The oxygen tank, hospital X lent us, and this bed belongs to the neighbor who lives nearby here (chuckles). Then we could take the patient back home. Actually, she (her mom) would still have to stay in the hospital. (F008 L10-15 P6)

Additionally, during the home period, the participants were also instrumentally supported by home-care nurses, local government organizations, health care officials in the community, and the community social network. As one participant stated:

> When the doctor discharged the patient from a hospital, I told the doctor that we didn’t have any place to live since our house was damaged by a storm. The house was being rebuilt. It was not finished yet because we didn’t have money to repair it. Finally, his friends donated some money to help him (patient), about ten thousand baht or so. They (neighbors) helped in buying wood. And then in the evening, the students and neighbors helped in repairing the house us for us. (F001 L4-12 P15)

3.4 Spiritual support

Spiritual support is help that relates to religious belief or natural superstition to promote psychological and spiritual well-being of both the participants and their older adult stroke survivors. The significant persons who provided this kind of support to the participants were their friends and neighbors, during both hospitalization and the home period. Some of them reminded the participant to have faith and trust in God, another did a spiritual ritual for the patient, as some participants stated:

> My neighbors also encouraged us. They went to visit him (patient) at hospital, and encouraged me. They told me don't think too much, and focus on Allah. Whatever will happen, let it be. It is in the hands of Allah. He will decide it. Just try to relax and be free from worries. (F00 1L22-26 P2)
>
> A few days before this, He (a patient's friend) came to do a spiritual ritual to better her fate. He volunteered to do that, because he loved the patient so much. His wife has been with her. (F015 L11-141 P4/I2)

4. Accessibility of supportive services/resources in community

Participants identified that the availability and accessibility of supportive services/resources, such as home health care service and social welfare policy in the community were important factors which helped them to deal with caregiving difficulties at home.

4.1 Home health care service

Many participants spoke of feelings of encouragement and benefits they received from home healthcare services that facilitated them in continuing to provide care at home. One participant described the value of drug dispensing by health-care staff at the local health care centre. Home visits, for training or advice, and the patient's physical check-up were viewed as important, as some participants stated:

> Health officials (health staff from the Primary Care Unit) visited us every month to take blood pressure and do a blood test. They said that if a feeding tube become dirty, we should not hesitate to call them. And they gave me the phone numbers. (F003 L27-30 P6)
>
> Nurse X, a home care nurse, came to visit a patient and tell me how to take care of the patient. She was kind and flattering. I felt encouraged, they didn't abandon us even when the patient was back home. (F001 L29-3 P6-7)
>
> In the matter about his medicine, nurse B who works at the local health care center managed that. She comes to check pretty often. She delivers it every two

> months. Nurse B does venipuncture, and takes blood pressure at home. It makes me feel encouraged. She is nice and very supportive. (F001 L19-23 P7)

4.2 Social welfare policy

The participants also talked about the importance of help that was available from the local social welfare. Many of them described the value of transportation to the hospital, and obtaining needed materials, such as diapers as facilitators for managing caregiving at home, as some participants stated:

> When I take a patient to hospital, I call an ambulance from a local government organization. A nurse gave me the phone number. I called them twice when the patient had a severe condition. They provided a good service. They prepared a stretcher to move the patient from home. (F003 L21-29 P11)

> Municipality X provides social welfare to newborn, sick people... Yesterday a staff-member told me that he will come to take a photo, and then the patient will get two free packs of diapers every month. (F007L18-19P16, L4P19)

5. Supportive environment for teaching and learning care skills

The participants identified the importance of a supportive environment for the teaching and learning of care skills, particularly during the hospitalization period. This including supportive manner of nurses or health care staff and flexible time for practice. They described the supportive manner of nurses that made them feel relaxed and encouraged them to learn care skills as reflected in the following expressions:

> It depends on nurses too. If they encourage me (hai kumlung jai) and say the supportive words to me, it will make me relax. So doing anything seems to be easier for me. But, if the nurse talks with me, like blaming me, it will discourage me. Like one nurse said, ‘It’s a trifle. Why you couldn't do it?’ Okay, that is a trifle to you, but it is very hard for someone else. (F002L19-24 P4)

> The nurses are very nice. They are friendly. They said that I could do it little by little. Everyone has to learn about it. (F001 L19-21 P3)

Some participants also identified the needs of time flexibility. This is because of a lack of experience. They described having to spend more time, while health care staff works with a time schedule in a hurried style. This made them feel pressure and discomfort, as one participant said:

> When I do care, it’s slowly. But nurses must work with time constraints. She must check each bed, each person there. Then she saw me, and I was unfinished. I felt discomfort when she looked at me like she didn’t understand me. She might have thought that I didn’t want to do it or I didn’t know how to. Meanwhile, the nurses were rushed. They set the time so that from six to eight everything would be finished because the doctors would come. That’s your time. You could finish three tasks within an hour. But for me, I could not finish even one task. (F006b L23-31P4, L1-2P5)

6. Coordination between care settings

The participants mentioned coordination between care settings was important for sharing information and that facilitated them, as some participants stated:

> Once a home-care-nurse came to visit, she suggested we consult the physician. She suggested that if the patient had symptoms like this (bawl and not sleep) we should consult the psychiatric department. She made a connection to that department for us. Then we took the patient there and could directly connect to health staff, only we told them we were guided by her (home care nurse). If she didn’t make a suggestion to us, we will still be in the dark. (F006L25-29P10)

> At that time, I asked the doctor if she (her mom) could be discharged later because we didn’t have enough money to buy the necessary equipment for her. A doctor asked, ‘Why did you delay? Why didn’t you prepare?’ I told him that there was no money, we have no money. Then he said he would talk to the nurse to consider providing some support for us. After that, the home-care-nurse come to visit us at ward. They told us that the home health care center has a bed and a suction machine to lend us. (F011a L8-12 P13)

7. Thai socio-cultural context

This section describes Thai socio-cultural context that influences coping and the learning process of family caregiver participants. It could be identified as the Thai social value of *katanyu katavedi* and *bunkun* system and interdependent relationships in Thai society, and religious belief.

7.1 Thai social value of the katanyu katavedi and *bunkun* system

In Thai culture, children take care of their parents, and wives/husband take care of their spouses and it is considered to be a moral obligation. This value influences the ways participants think, that taking of their older adult family members, particularly who are parents, gains merit. Due to their belief in this doctrine, they put effort into taking good care of their parents or spouses, as shown in the following expressions:

> My feeling, while I wiped my mom's urine and stool, hit me in my heart. I felt delight when I bathed my mom; I did it. We did it for our mom, more or less was not a matter. But we are willing to do for her. It's very touching to us. Briefly, we follow the Dhamma (following Buddha teaching); each person is grateful and shows gratitude to their parents. It's the last time that we can repay Mom's kindness. Only this time because there is no next time. (F006 L30-31 P15, L1-4 P16)

7.2 Interdependent relationships in Thai society

Interdependent relationships are prominent characteristics of social relationships between individuals, family, friends, community and the wider social network in Thai society. This interpersonal tie is helpful for the participants to access the needed support from different sources. However, the availability of support might vary among individuals depending on how they have been giving assistance to others, as one participant stated:

> He used to help a lot of people. But it's good that these people repay him as much as they could. He had helped a lot of his friends. So, he's alive today. (F001 L10, L29-30 P11)

7.3 Religious belief

Religious belief about the law of karma, merit and sin, and life after death influences the participants' thinking patterns that consequently effect their practice on caregiving and in coping with uncertainty. This belief was similar for both Buddhist and Muslim participants. Buddhist participants believed that good deeds (*bun*) or evil deeds (*bap*) are bound to bring about effects not only in the present life but also in future lives. Likewise, Muslim participants believed that good actions (merit) they have performed will enable them to go to heaven, while their bad actions (sin) will bring them to hell. These beliefs motivated them to give good care for their older adult stroke survivors, as one participant stated:

> According to my thoughts, I think that we have been together for a long time. So during this time, it's the end stage of life, right? We need to take good care of him (her husband). If he leaves this world, we will complete what we need to do. We will not spoil it. It is like making merit; if we take good care of him, we will receive the merit back… If he dies, we will help him to be ready. We will not let him miss anything as that is the way that we believe. (F003 L25-31 P9)

Religious belief also influences participants' perspective on illness. Buddhist participants believed that the illness of their older adult has resulted from their previous karma, while Muslims view an illness as the will of Allah. This belief helped them to accept a difficult situation and have less stress. Some expressions reflecting religious belief are given below:

> A doctor told me "you should not be stressful". I replied that I was not stressful. Being alive or dead was up to Allah. I did not have to think about anything. If Allah wants him to be alive, we will take care of him as much as we can. It was useless to worry. No one wants to be sick. But it is up to Allah. We all are destined by him. It is all about him. There is nothing that we worry about. (F003 L28-31 P7, L1-2 P8)

> I don't think anything, the matter of illness is based on Karma, it depends on her (patient) bun and karma. (F016 L2-4 P4)

> My neighbors have advised me to make merit (tum bun). So I usually buy something for the mosque every Friday. No matter what religion, Buddhism or Islam, we all have some person with previous deeds. I tell them that do not harm the patient… I will make merit for them. (F001 L14-17 P5)

Hindering factors

Hindering factors were the facts that obstructed the participants in successful transition and undertaking the caregiving roles. These factors included: (1) limiting capacity of caregivers to provide and mange care; (2) stroke survivors' conditions; (3)

lack of family support; (4) health provider barrier; and (5) hesitating *(kreng jai*) in asking for helps

1. Limiting capacity of caregivers to provide and mange care

There were some factors described by participants that have negative influenced their ability to provide and manage care during transition from hospital to home. These included old age, negative physical condition, and financial strain. One participant described he could not provide 24 hour care to his wife because he was old. Another older participant mentioned that her ability to provide physical care for her husband was limited by her previous back injury and physical condition, as showed in following expressions:

> I hired a nurse to take care of her for two shifts, evening shift and night shift...Because there is nobody, we had three members in our family and my daughter is working in Bangkok...For myself, I'm aged 82 then I couldn't look after her all the day and night time. (F015 L22-29 P2)
>
> I had knee pain and back pain. I've been got spine surgery to insert a steel splint more than ten years ago. But I don't feel the same. When I walk about 9 or 10 steps, I'll get backache…So, I couldn't raise him (her husband). Usually, my children will help to raise him. If he wrestled, I'll call my daughter at the next door to lift him. (F003 L14-17 P20-21 P4/I1)

In addition, participants who have low economic status experienced more difficulty in term of unreadiness to provide care at home. They could not afford to buy the needed care equipment for their older adult stroke survivors. Some participants also stated that they wanted to provide better care for their older adult stroke survivors at home, but they could not do as they desired due to financial strain. The effects of financial strain on caregiving situation were presented below:

> The nurse told us that we need to buy a bed that costs about 40,000 baht, the suction that costs about 5,000 baht, and the oxygen tank that costs about 8,500 baht. The total price is about 100,000 baht. We earn a little money per day so we can't find that amount of money. (F008 L29-2 P5-6)
>
> I wanted to take care of my brother better than this. But I couldn't because of finances. For example, now I have hired a person to do massage for him. She is a masseuse, she's not like a physical therapist in the hospital. Actually, I want to

> have a physical therapist come to my house. Then I could talk to him. So I can learn and take the knowledge from him…But their wages are high they often referred to 300-500 baht per visit. (F013 L20-26 P24)

2. *Stroke survivor's conditions*

The participants identified uncertainty and the severe condition of their older adult stroke survivors as a barrier to learning and caring. They described feelings of fear when their older adult stroke survivors had unstable symptoms. They also expressed hardship in performing care related to their older adult stroke survivors' condition as showed in following statement:

> My mom's symptoms made me afraid of doing it (caregiving). She had excessive secretion. I needed to do suction all the time. And that time she was in the hospital for over a month. But there was nothing to say that she was responding well or having a better condition. However recently, I observed that she has had positive reaction, such as oxygen saturation value and respiratory rate. Previously her symptoms were up and down, but recently they tend to be stable. (F006b L15-22 P6)
>
> At the hospital, my mom had many assist-devices. There were so many lines on her body. The problem is that every time my mom poops, I can't take care of her by myself…I needed some help from a nurse. That was a difficulty. (F010a L2-9 P2)

3. *Lack of family support*

Lacking family support was described as hindering factor in achieving a sense of control by participants in this study. Some participants expressed feeling frustrated, angry and helpless due to lacking support from their siblings. One participant described feelings of fear because there was a lack of supportive persons in the family. The participants spoke out of how the limitations of family support troubled them, see below:

> At the beginning, my older siblings came every week. But later on, they disappeared. I needed them to take turns in the duty, they did not cooperate because it troubled their work. I have to do everything. It is a burden to me alone. (F008 L1- 2 P6, L7-9 P6)

> My siblings never give support to me. I ask if I caused the problem. No, I did not cause the problem, why don't the people around me help me? I have no income, I do not work. They have many cars but when I take the patient to the hospital, I didn't have anyone to help me. I had to call for the car from the municipality. (F013 L10-15 P21)

Additionally, another two related factors were identified as a cause of a lack of family support; a limited number of family members and family conflict, as showed in the following expressions:

> During the time he (her husband) had his operation, I felt afraid because I was alone in the hospital. I had no relatives with me, no one was around. If something happens to him, I don't have anyone to consult or talk to. What I should do? I am afraid. (F001 L24-27 P1)

> My dad doesn't understand me. He wants me to take care of mom all the time. He thinks that it is my responsibility 100%. But I actually think that some of the time, my dad should replace me to take care of mom. I will give an example; I usually serve dinner for my mom at 5 p.m. but one day, she complained that she was hungry at 4 p.m. or so. I already cook some rice soup for her before I went out. I wish my dad could have fed her but he waited until I returned home and I did it. (F010a L6-11 P9/I2)

4. Health provider barriers

4.1 Ill preparation for the caregiver role

Most participants tended to be given little preparation for the hospital discharge of their older adult stroke survivor. They reported that the nurse generally taught two sessions and never assessed their understanding. They also had insufficient time to practice the required care skills which lead to the feeling of unconfident to provide care and this caused of participants' emotional stress. Some participants described their experienced of difficulties related to receive inadequate information, or poor communication from healthcare staff, as showed in the following statements:

> Relatives of the patients can observe some symptoms of patients whether it is abnormal or not. When the relatives say that there are abnormal symptoms, why don't you come to see? At least you come to encourage us. When we are frustrated, we need you (a nurse) for a little help. You should tell us whether you're able to come or not. Come to suggest to us. I noticed that both patients

> and relatives are recovered when the nurse just shows up. Suffering and stress disappear or are reduced. (F006b L14-17 P8)
>
> Once I took my mom to the emergency room. There was an injured patient from a car crash. I knew that his condition was more severe. But the nurse needed to communicate with me. She should say please wait a minute or tell me what was going on. The nurse should not let us wait without any hope. (F008 L21-25 P28)
>
> When they taught, they taught briefly because they needed to care for the other patients too. I had to see and remember it quickly because they had to go to take care of the others.
>
> This error is caused by my worry about my mom, and the staff provided insufficient understanding. Sometimes the staff thought that I understood but I didn't. You (the staff) teach me how to do those things, how to do this. You teach me how to do many things. But it is not easy to me. You understand, but I didn't understand. You have done that a thousand times but I have just done it for the first time. I feel uncertain that I might make a mistake that makes me feel unconfident. Because we never do that, and the staff don't give us enough information. (F006 L16-23 P4)

4.2 Lack of emergency contact persons

Some participants also identified lacking emergency contact persons was a barrier in maintaining caregiving for their older adult stroke survivor at home. They did not know whom to contact for post-discharge caregiving issues once home. They expressed this need if faced with an emergency. However, they could not contact any healthcare staff when they encountered that difficulty. This made some participants took their older stroke survivor back to hospital. Some participants' expressions are given below:

> You should give a contact phone number to the patients' relatives; they can contact you in case of emergency. You can be our first consultant and then we will have peace of mind that a nurse is with us. But what we do now is call for a car not a man. (F013 L24-28 P26)

5. Hesitating in asking for help

Even though the social relationships among Thais were prominently interdependent, the participants frequently described hesitation (*kreng jai*) when asking for help, particularly from government office and health care professionals. This characteristic of Thai culture obstructed them to access the available support, as some participants stated:

> At the beginning in hospital, I felt serious, I'm thought that I could not do anything (caregiving tasks), I felt hesitant (*kreng jai*) if I ask them (nurse) every time. (F011a L19-20 P7)
>
> Before this, when we took our mom to the hospital, we usually called for the ambulance from the local government organization A. But now we hire a car nearby our house. Because that organization was being out of our area (Tumbon), sometime we hesitated to ask for help from them. (F008 L9-11 P10/I1)

In summary, fighting to gain a sense of control was identified as a core process overcoming difficulties of nuclear family's caregivers who caring for older adult stroke survivors during transition from hospital to home. The process moved through three continual and some overlapping stages; loss of control, striving to master uncertainty, and achieving sense of control. The process demonstrated the difficulties and the ways that the participants used to overcome such difficulties in three different periods of care transition from hospital to home. Coping and learning process was a key strategy that the participants used to deal with those difficulties. They combined resources including personal, internal and external family support to cope with caregiving difficulties. The findings verified that coping behaviors were distinctive among different participants depending upon age, the interpretation of caregiving roles, attitude toward seeking support, and family relationships, and the available of resources within and outside the family. It also showed that despite the burden experienced in caregiving the participants showed sense of obligation to provide care their older adult stroke survivors.

Discussion

The findings of this study were compared to previous relevant studies and theories by focusing on the similarities and differences in three main topics: (1) characteristics of the participants; (2) process of fighting to gain a sense of control; and (3) factors influencing family caregivers' overcoming difficulties.

Characteristics of the caregiver participants

The characteristics of the participants were discussed in two aspects: (1) demographic characteristics of the participants; and (2) the interpretation of caregiving for older adult stroke survivors.

1. Demographic characteristics of the participants

Most of the participants in this study were adult children of older adult stroke survivors. This finding was similar to the previous studies in the Thai context (Hattakit, 1999; Niyomthai, 2009; Obe-om, 2005). However, it was different from studies in China and western countries. Lee (2005) found that most of the family caregivers of older adult stroke survivors in China were their spouses. There are two factors that could explain this difference.

This might result from the strong belief in *katanyu katavedi* and the *bunkun* system in Thai culture where adult children were expected to take care of their elderly parents (Choowattanapakorn, 1999). Even though most of the children participants lived separately and had their own family, they took care of their parents when they had a stroke.

Another aspect is the prominence of female caregivers in this study which confirmed the gendered nature of family caregivers in several studies in the past (Hattakit, 1999; Niyomthai, 2009; Ob-om, 2005) since most participants in this study were female. This might be because the family norm regarding elder care was more likely to be transmitted to daughters than to sons (Silverstein & Conoy, inpress as cited in Silverstein, Gans & Yang, 2006). However, it could be observed that the beliefs of specific genders on caregiving was depend on family tradition in development of a caregiving relationship between children and parents and a strong sense of filial gratitude.

2. Interpretation of caregiving for older adult stroke survivors

The interpretation of caregiving for older adult stroke survivors varied in different caregivers but could be classified into four categories; caregiving is an obligation, caregiving is a stressor, caregiving is loss of one’s life, and caregiving is late life care. However, most participants in this study gave the meaning of caregiving for an older adult as an obligation. This finding was consistent with previous studies

(Hattakit, 1999; Obe-om, 2005; Subgranon, 1999). Despite the burden of care, the majority of the participants expressed the view that providing care for older adult stroke survivors was a good opportunity to repay their relatives kindness. It would appear from the descriptions of the participants that this duty was fulfilled because of feelings of reciprocity for care given in the past, or love and attachment that arise from longstanding relationships with stroke survivors. This feeling of reciprocity or having a good longstanding relationship with their relative makes it easier to find positive aspects in their role (López, López-Arrieta, & Crespo, 2005).

Additionally, it seemed that this was not a reluctant duty, but was regarded as virtuous. This is because Thai society considers caring for family members, particularly elderly parents, as a moral obligation. (Choowattanapakorn, 1999; Kespichayawattana, 1999). Thai adult children are taught to care for their older relatives and this virtue is gained through religious training and parents' role modeling as a family rule (Julamate et al., 2006). Therefore, it could be assumed that this definition of caregiving is shaped by their religious beliefs and Thai socio-cultural values on *katanyu katavedi* and the *bunkun* system in caring for older parents/relatives.

Regarding meaning of caregiving as a stressor, this was characterized by the caregiver having a heavy workload, feeling overwhelmed and describing physical and emotional stress. This given meaning was evident in participants who had multiple roles and were lacking family support. Likewise, a previous study reported that Latino women caregivers viewed the caregiving for their husband stroke survivors as a stressor which was related to physical and emotional stress, but they also expressed a deep sense of spousal obligation (Arabit, 2008).

Caregiving is the loss of one’s life characterized by the caregiver having enormous changes in personal plans, missing personal time, losing their social life and income, and feeling overwhelmed. This given meaning was particularly evident in sibling caregivers who are single and had not intended to be caregivers. Similarly, the previous study found that female caregivers of stroke family member identified losing their normal life as it has been before (Saban & Hogan, 2012).

For the category of caregiving is late life care, this category of meaning of caregiving has not been in the stroke caregiving literature. This might be due to the participant being aware that their loved one is old. They also perceived that the survivor’s physical and cognitive function would not recover. It was described as the final time to take care of their loved ones. Despite the personal burden, this time could be an important opportunity for the participants to demonstrate their love for the older adult stroke survivor, and to pay back what they had previously received from their loved one. They also intended to provide care as good as possible to gain a sense that they had fulfilled their duties and responsibilities. These characteristics were similar to the findings of systematic reviews on experiences of relatives in end of life care (Andershed, 2006).

Process of overcoming difficulties: fighting to gain a sense of control

The journey of the participants through difficulties in caring for their older adult stroke survivors moved through three stages of fighting to gain a sense of control namely; loss of control, striving to master uncertainty, and achieving mastery/sense of control, as described in the previous section. The discussion on such process was described in each stage.

1. Loss of control stage

The study’s findings revealed that initially when the participants were faced with difficulties caused by the stroke event they went through the stage of loss of control, when they perceived that the event lie outside of their control. This stage is expressed as a time of high anxiety, shock, and disbelief for the family caregivers. This could be because of the sudden onset and unexpectedness of the stroke event which disrupts the life of stroke survivors and family caregivers (Greenwood & Mackenzie, 2010). This finding is congruent with some previous studies that explored stroke caregiving experiences which reported that the stroke event was a shock for the caregivers and other family members at the beginning of the situation (King & Semik, 2006; Lut et al., 2011; Obe-om, 2005).

1.1 Encountering difficulties and uncertainty

Difficulties and uncertainty have been reported as common experiences of family caregivers particularly when their family members were diagnosed with stroke and were in acute care. (Greenwood et al., 2009b; King & Semik, 2006; O’Connell et al., 2003). They began to be aware of what happened to them and wonder what would happen next (Lutz et al., 2011). The difficulty and uncertainty was focused on their concern for the older adult's survival. The participants in this study also faced difficulty in making decisions regarding treatment options. This might be due to the fact that the decisions were often life-changing and concerned the survival of their loved ones. The amount of time that the patient and caregiver had to face this crisis and make life-changing decisions was often very short.

1.2 Perceiving inability to control the changing situation

The study showed that the participants' perception of being unable to control the changing situation was linked to their recognition of their older adult survivors' need of care and their perception of inability to fulfill this care. This led them to feel powerless and to rely on healthcare professionals to fulfill the survivors' need. The reason for this might be that they lack knowledge about the disease and care skills for caring for the stroke persons. This lack of knowledge and skills could make them perceive themselves as lacking power to manage care and the changing situation since, an individuals' personal sense of power coincides with their control over resources and position of authority (Anderson, John, & Keltner, 2012). Therefore, in a hospital setting healthcare professionals may be considered as having more power than patients or their family caregivers, based on their professional expertise and the role that they fulfill in the hospital (Caswell, Pollock, Harwood, & Porock, 2015). The feelings of powerless and lack of control might be exacerbated by difficulty in accessing help from healthcare staff. This notion was supported by the participants' expression of frustration when faced with that difficulty.

1.3 Expressing emotional distress

The study's findings revealed that during this stage the family caregiver experienced a high degree of stress. A variety of negative emotional expressions were described by the participants included including being frightened, fear of loss, and frustration. These findings were in line with some previous studies (King & Semik, 2006; Lut et al., 2011; Smith, 2004) which found that during the period the stroke patients were hospitalized and under acute care, the family caregiver experienced stress, confusion, fear, and loss of control. This reaction was obviously expressed in the participants who perceived that their older adult relatives were in a critical condition and survival was uncertain. The response of the participants in this stage could be explained by the cognitive theory of stress and coping (Folkman, 1984), whereby people appraised the environmental situation that they encountered as a stressful event that exceeded their resources and threatened potential harm/loss of their well-being. This threatened appraisal is characterized by negative emotions. The study findings also pointed out unmet needs of the family caregivers to rely on and/or receive help from health professionals. This was one important source of disappointment of caregivers during this stage. This notion was congruent with King and Semik' research (2006), which found that lack of support from healthcare staff and uncaring staff were reported as distressing factors by the stroke caregiver during the hospitalization period.

Understanding their changing situation was found to be a turning point that helped participants to move through the stage of loss of control and drive them to attempt to deal with their difficulty and uncertainty in the second stage. There were some factors that could explain this finding. Firstly, it might be due to the fact that as time progressed the participants expressed their distress and then released their tension. At the same time they received more information about their older relatives' which may have enabled them to picture their future more clearly. In addition, the support they received from family members or relevant others could have helped them recognize some positive aspects of lives which in turn might increase their awareness of what was going on. This finding was similar to the concept of "coming to terms with their situation" described by older cancer patients and their families in regard to their experiences of transition to palliative care (Duggleby et al., 2010). However, the participants in this study gained understanding of their situation based on the information present, while participants in those studies used life review and reframing in order to come to terms with their situation.

2. *Striving to master uncertainty stage*

The findings showed that the participants' experiences of difficulty and uncertainty changed overtime. At the beginning of this stage the difficulty and uncertainty related to the feeling of uncertainty in their ability to practice care skills. During discharge, the uncertainty experienced focused on a lack of confidence to perform care at home. Once the older adult stroke survivors returned home, the uncertainty involved the combination of lacking confidence in their ability to provide care and unpredictable caregiving situations related to the stroke survivors' condition. These findings are similar to previous studies which found that the family caregivers experienced uncertainty about future events related to providing both short and long-term care (Greenwood et al., 2009b; O' Connell et al., 2004; White, Barrientos, & Dunn, 2014). The findings were also congruent with the characteristics of uncertainty in a family caregivers study by Penrod (2007). In this concept advancement study, uncertainty was described as an uneasy sensation or discomfort state which was dynamic and mediated by feelings of confidence and control. This discomfort state was described as a non-normative state that was harmful rather than growth producing.

Coping and learning processes emerged as a core strategy to master those difficulties and uncertainty in this stage. Lazarus and Folkman (1984: pp.141) define coping as thought and behavior that an individual used to manage specific external and/or internal demands that are appraised as stressful situations. Two main types of coping are proposed: problem-focused which are attempts to tackle the problem, and emotion-focused which are attempts to reduce the emotional distress caused by the problem. Lazarus and Folkman state that, in general, problem focused coping strategies are more likely to be used when the stressful situation is responsive to change, whereas emotion-focused coping is used more often to deal with situations beyond the individual's control. The participants in this study used both of those coping styles.

During hospitalization period

In most hospitals in Thailand, after the medical condition of the stroke patient stabilizes, the patient is generally moved from the intensive care unit to a step down or general ward. During this period, the family caregivers were required to take care of their relatives for 24 hours. They were also required to practice some care skills such as bathing and feeding. The participants in this study were confronted with difficulties in adopting the caregiving role. They desired to learn care skills, but at the same time felt fearful to do so, particularly when it involved some complex care skills, such as NG feeding and sputum suction. This was because they lacked experience in care and were unfamiliar with the care environment and/or the older adults' condition. They were also concerned about their older adults' safety. Interestingly, female caregivers tended to verbally express more fear than male caregivers. Although the participants desired to learn care skills, fear could induce anxiety and interrupt the learner's readiness to learn (Kitchie, 2003). The study's findings suggested that although the family caregivers desired to learn care skills, it does not mean they were always ready to learn.

The participants overcome the challenges in learning care skills by using a cognitive reframing strategy. With this strategy, individuals place their experiences of a situation in a different frame that fits the concrete "facts" and changes their negative thinking to more positive meaning (Robson & Tretman-Jordan, 2014). They realized that they would be a caregiver for their older adult when they returned home. The realization of this fact induced a change in the participants' thinking from "I cannot and do not want to do this" to "I need to learn and I can do this". Cognitive reframing has been found to play an important role in developing coping strategies in psycho-educational groups of caregivers for dementia sufferers (Lavoie et al., 2005). For the participants in this study, this positive reframing allowed them to learn care skills by observation, interacting with others, and doing or practicing care. The findings of this study were congruent with those of a previous study; that is, family caregivers experienced initial difficulty in learning care skills and their learning process started from "can't" to "can" by using watching and doing strategies (Wu, 2009). In this study, however, family caregivers expressed specific about strategies for cognitive reframing to overcome their fearful feelings.

The supportive manner of nurses in teaching and learning along with providing adequate time for learning and practicing care skills were important factors identified by participants as they influenced their ability to learn care skills during this period. Encouragement from close family members and friends also helped the participants move through those difficulties and assisted in learning care skills. In contrast, their concerns about be blamed by healthcare staff seemed to enhance their fear of practicing care skills. Furthermore, the participants described feeling hesitant to ask health staff for information regarding health care skills. But they preferred to ask for such information from other caregivers who had experience in taking care of patients with similar a condition. Seeking information from informal networking has been reported by caregivers when information from health professionals was absent (Brereton &

Nolan, 2002). This finding reflected insufficient health service preparation of family caregivers. It also shed light on the influences of hierarchical relationships on the learning process of caregivers in Thai culture. Since most relationships among Thais are linked to status or role, wealth, education, professional rank and age (Hallinger & Kantamara, 2000), the interpersonal interaction between family caregivers and health care professionals is more likely to be subordinate which might create a communication barrier.

The quality and quantity of interactions between family caregivers and health care professionals prior to discharge could affect the degree to which caregivers perceived they had the knowledge and skills to carry out their responsibilities (Zwygart-Stauffacher, Lindquist, & Savik, 2000). In addition, the hesitation in asking crucial questions from health care staff may cause misunderstanding of the requirements of the caregiving role (Camak, 2015).

During discharge period

Unreadiness to provide care or being uncertain about their ability to provide care at home emerged as a difficulty in this period. It was characterized by the participants expressing lack of readiness to take the patients home, negotiating with health care providers, and struggling to prepare for caregiving at home. The causal conditions of being uncertain about providing care at home were composed of; perceiving the poor health condition of their old adult stroke survivors, lacking resources, having no idea about caregiving at home, and lacking confidence in providing care at home. This might be because the participants usually expected that when the survivors were discharged, things would return to almost normal, as in their life before the stroke, with few or minimal changes. This belief has been supported by previous studies (Ellis-Hill et al., 2009; McKevitt, Redfern, Mold, & Wolfe, 2004) which reported that the view of recovery between health professionals and the stroke survivors and their families was different. While health professional measure recovery in terms of regaining function, for patients and their relatives recovery can mean return to pre-stroke life. Discharge was seen as difficult when individuals feel unsupported, or they felt uncertain about the recovery (Ellis-Hill et al., 2009).

Most participants did not have adequate time to learn care skills before the patients were discharged. Thus, the family caregiver felt doubtful about their ability to provide care at home. The degree to which the caregivers' capacity to provide care and the level of patient care required impacted on how well the stroke survivor and caregiver were able to make the transition home, as supported by previous research (Lut, 2004) while an imbalance between the caregivers ability and the patients' need of care could maximize the un-readiness for transition to home (Lut et al., 2011). However, this study's findings indicated that the family caregivers' capacity to provide care was usually not fully assessed prior to discharge. This argument was congruent with previous studies about discharge planning in Thailand which reported that one problem in the discharge process was lack of assessment of the knowledge, understanding, and needs of family caregivers (Panichakit, 2007; Promchan, 2009)

In addition, the discharge date was usually unknown until a day or two prior to discharge, or when the physician ordered the patient to be discharged (Silprakhom, 2003). As a result, caregivers do not have adequate time for preparing the home and the required supplies for care at home which leads them to feel overwhelmed and experience emotional distress. This finding was supported by previous studies on family caregivers' experiences (Hirunchunha, 1998; Lut et al., 2011; Plank, Mazzoni, & Cavada, 2012). Discharge created a new crisis for stroke's caregivers when they realized that they were not ready to manage the tasks and responsibilities of care to accommodate the needs of the survivors after discharge (Lut et al., 2011). Thus, the caregiver described emotional overload during this period (Plank et al., 2012).

The findings suggested that as the stroke survivors' condition improved and they were able to transfer from acute care in the hospital to home, the family caregivers were often not ready to move to the next level of care. The emergence of this theme might reflect ineffective discharge planning by health care providers. While family caregivers relied on health care providers, particularly nurses, for adequate preparation for discharge (Camak, 2015), the performance of discharge planning by nurses was mostly aimed at routine tasks based on their responsibilities such as planning to teach necessary things to patients and their family caregivers rather than thoughts of the future events of the patients and their family caregivers after discharge (Silprakhom, 2003). The family caregiver also described limited involvement in the discharge process (Panichakit, 2007). Although discharge planning has been used as a tool to facilitate the transition of care from hospital to home for several years in Thailand (Pichitpornchai, Street & Boonton, 1999), the studies continually reported numerous problems and barriers in the practice of discharge planning (Panichakit, 2007; Promchan, 2009; Silprakhom, 2003). These included nurse nursing staff workload, lack of coordination with multidisciplinary teams, lack of continuity and system in the activity of discharge planning, lack of cooperation from relatives/families, and lack of discharge planning form for specific diseases.

The factors identified by caregivers that helped to minimize un-readiness to providing care at home were financial resources and supportive networks including family, health care professionals, and community. This is consistent with a previous study which reported that the family caregivers who could afford to pay for the required equipment/assistance or who received assistance from those supportive networks were not as overwhelmed as if they were left to manage the transition home alone (Lut et al., 2011).

Post discharge period

Consistent with previous research (Cecil et al., 2013; Grant 2004; King & Semik, 2006; Lut et al, 2011; Niyomthai, 2009; Wu, 2009), providing care for older adult stroke survivors at home was described as a new difficult situation for all participants, particularly during the first one to five months. Two factors that could explain these experiences of difficulties included; family caregivers having insufficient of knowledge or skills and change of care environment. Existing researches have reported that the family caregivers were placed abruptly in unfamiliar roles (King & Semik, 2006; Obe-om, 2005; O’Connell et al., 2004). They felt that they had been thrown into a restricted situation without knowledge (Bäckström & Sudin, 2007). Some participants in this study mentioned that they had inadequate time to learn and practice the required care skills before the stroke survivors were discharged. As a consequence, they lacked confidence in their ability to provide care at home. This was congruent with the findings of another study which found that family caregivers were often underprepared to assume even the basic tasks to meet the patients’ needs on discharge.

They also did not have the time to learn strategies to deal with functional limitations that might persist after discharge (Lut et al., 2011). Plank and colleagues (2012) found that new family caregivers felt fear of the unknown which was often increased due to a perceived lack of information and preparation. Lack of information, particularly about dealing with psychological, emotional, and behavioral problems along with lack of local service information were identified by the stroke caregivers before and after discharge (Mackenizie et al., 2007) and led them to feel ill-prepared to take on the new role (Bauer et al., 2009). This might be because the family caregivers had insufficient knowledge and skills to deal with the difficulties of the early months at home.

Secondly, research has shown that the caregiving situation at home was different from the hospital environment. During hospitalization, the patient care schedule was organized and outlined by healthcare professionals. However, providing care at home meant self-reliance for the family caregivers, they needed to do everything by themselves without the health professional protection or support (Plank et al., 2012). This resulted in safety concerns for caregivers (Lut et al., 2011). Although the family caregivers had learned essential care skills and felt ready to go home, they also encountered difficulties which were different from what they had learnt to mange in the hospital (Wu, 2009). They realized that the skills they learned while the stroke survivors were in the hospital were not always useful in the home environment (Plank et al., 2012). They could not deal with their new situation in the early months after discharge (Chalermwannapong, 2009). Therefore, this period was reported as a time of crisis for the stroke survivors and their caregivers (Lut et al., 2011).

In this study, however, it was found that the difficulties varied among the participants depending upon stroke survivors' conditions, the caregiver's characteristics, and family resources. It was noted that work overload was associated with having multiple roles, family conflict, and lack of family support. This was consistent with a previous study (Bastawrous, Gignac, Kapral, & Cameron, 2015), which found the daughter as caregiver has caregiving responsibilities to their parents and to both their husband and children. This role overload often limited the female caregivers' ability to engage with their own families, which caused conflict with their spouses. This led to the family caregiver experiencing additional stress in those relationships (Bastawrous et al., 2015).

Lack of family support also impacted on the work overload of family caregivers, since lack of family support or having unsupportive siblings left the primary caregiver to take on the caregiving role alone. It appeared that female caregivers who had unsupportive siblings in the family of origin also faced conflict within their own family. The combination of having multiple roles and lacking family support caused the family caregiver to feel overwhelmed and burnout by the caregiving role. In an attempt to maintain her own well-being and relationship with her husband, one participant in this study could not overcome those difficulties and gave up some care activities for her father, a stroke survivor. These findings pointed to the need for community nurses to conduct assessment screening for caregiver burden to offer creative and appropriate assistance.

Regarding the difficulties in assessing care after discharge, the study's findings indicated that rehabilitative care is one of the most common services required for the stroke family caregivers who participated in this study. However, in Thailand, this type of service is unavailable in the community and is only available in the hospitals (Lorga, 2004). Thus, the difficulty in accessing this type of care results from the lack of services in the community. The existing hospital-based rehabilitative service requires travelling from home to the hospital which is unsupported and described as difficult by most families. These findings pointed to the need for health care providers to improve the standards of provision for supportive care services for older adult stroke survivors and their family caregivers.

The study found that the four main strategies used by the family caregivers to cope with caregiving difficulties at home included; managing care at home, adjusting lifestyles, managing stress, and learning to provide care at home. These findings were in line with other reviews of qualitative studies which examined how family caregivers coped with the difficulties of caring for stroke survivors at home (Ang, Chow & Poon, 2013; Greenwood et al., 2009a; Hesamzadeh, Dalvandi, Maddah, Khoshknab, & Ahmadi, 2015).

Managing care at home

For managing care at home, different strategies were employed by the participants and included; sharing responsibility among family members, hiring someone to help in performing caregiving tasks, seeking and accepting support, and taking care for self. Sharing responsibility for providing care for the stroke survivor among family members has been documented in Thai family caregiving (Chanprachone, 2007; Niyomthai, 2009; Obe-om, 2005). This reflects the characteristic of Thai families which focuses on the kin group and has strong family relationships which help each other (Richter & Podhisita, 1992). It was noticeable that when the participants talked about their families they referred to all of their siblings or all of the older adults' children including those who were not living in their parents' home.

Interestingly, the intensity of shared responsibility among family members seemed to be related to the family's background; who the stroke survivors were (the relationship between caregiver and care recipient) and the pattern of relationship within the family. A high degree of shared responsibility among family members could be noted when the older adult stroke survivors were parents, and/or the family members were in harmonized relationships. In contrast, a low degree of shared responsibility was presented when the older adult stroke survivors were not parents, or the family members were in conflict relationships. These findings were similar to some previous studies (Chanprachon, 2007; Niyomthai, 2009) which reported that co-responsibility in caring for stroke survivors took place in families with a high degree of hardiness (Niyomthai, 2010) or when family members have positive relationships rather than frustrated relationships (Chanprachon, 2007). One plausible explanation is that Thais have a strong sense of filial obligation. The caring for parents is valued as a merit which is influenced by religious teachings (Kespichaywattana, 1999). This suggested that despite the social and family structural changes that have made Thai families tend to be nuclear rather extended, the family norms and traditions regarding taking care of family members, particularly older adult parents, still exist.

Seeking and accepting support was a common and crucial strategy that the participants used to maintain care for their older adult stroke survivors at home. Because almost all of the care recipients in this study were impaired stroke survivors that needed highly demand of care. It could be said that it is not possible to maintain the requirements of family caregiving for stroke survivors without support. Therefore, they have to rely on support from family, friends and neighbors, as well as health professionals. This finding was similar to other studies (Coombs, 2007; Saban & Hogan, 2012) which reported that caregivers often sought out advice and guidance from healthcare providers to deal with the challenges in the first year of caregiving for their relatives who had survived stroke (Saban & Hogan, 2012). They also depended on help and support from family and friends to maintain care for their stroke survivors in the community (Coombs, 2007).

Adjusting lifestyles

Most of the older adult stroke survivors in this study were impaired and so required a high level of care (Bakas et al., 2004). The family caregivers had to adjust their lifestyles to fit with the caregiving roles as well as balance their everyday life by planning, rearranging daily activities and time management. Numerous researches on family caring for stroke survivors, both in Thai (Changsuwan, 2005; Obe-om, 2005) and Western contexts (Greenwood et al., 2009b; Silva-Smith, 2007; Smith et al., 2004), also reported similar findings. Modifying daily living routines and planning were reported as ways to reduce the level of uncertainty, restructure life and gain a greater sense of control for stroke caregivers (Greenwood et al., 2009b; Silva-Smith, 2007; Smith et al., 2004).

Managing stress

As mentioned above, providing care for older adult stroke survivors at home was described as a stressful event. The family caregivers had to manage the stress that occurred from caregiving. Based on Lazarus's stress and coping model (Folkman & Lazarus, 1984), for managing stress is an emotion-focused coping strategy which aims to reduce feelings of stress rather than to try to control the stressful situations (Folkman & Lazarus, 1984). This finding supported other studies that reported family caregivers predominantly used emotion-oriented coping strategies to adapt to daily problems and stresses (Arabit, 2008; Gholamzadeh, Aizan, Sharif, Hamidon, & Rahimah, 2015; Thomas & Greenop, 2008). The participants in this study used both psycho-emotional and spiritual strategies to deal with their stress. These psycho-emotional strategies included adapting the mind, thinking positively, temporarily withdrawing, talking with others, and negotiating. This is in line with previous studies (Ang et al., 2013; Greenwood et al., 2009b) and is also congruent with the support needs of stroke caregivers (Maclsaac et al., 2010). However, adapting the mind *[Tum Jai Hai Yom Rub or Plong Jai]* was a common psycho-emotional strategy for Thai caregivers of stroke survivors. In this sense, adapting the mind is much more than acceptance but included calming the mind by avoiding thinking about the situation and learning to let go. Regarding the spiritual strategies used by the family caregivers in this study, these were prominently related to religious beliefs, old age and female caregivers. This is congruent with previous study which reported that religiosity was a major way of coping for female caregivers (Gholamzadeh et al., 2015). Female participants also usually talked with others and followed religious practices, but male participants did not. This study also found that there were gender differences in coping styles for stress management.

Consistent with previous research, the importance of temporarily withdrawing or taking time out from the caregiving role was often mentioned as an influencing factor in maintaining caregiver well-being (O'Connell & Baker, 2004). However, the study showed that some participants did not have available family members to replace them. The findings indicated that supporting the family caregivers by allowing them to have short breaks from their caregiving roles would help them release stress and maintain well-being. This suggested the need for a respite care policy for family caregivers who have limited resources; such as a lack of family members or friends, no finances for informal respite care or were themselves old aged.

Most participants appeared to find it beneficial to express their thoughts and emotions with others. This has been supported in existing literature. Interaction with others also appeared to enable a break from the stresses of caregiving, by focusing on someone else rather than the stroke survivor and their needs. It has been suggested that emotional strategies provide for the processing and expressing of emotions, and in turn talking to others has been linked with decreased depression and hostility (Folkman & Moskowitz, 2004). This suggests that services such as counseling and help lines could be useful for family caregivers, particularly those who have a limited amount of support within the family.

Learning to provide care at home

Learning has been reported as a general coping strategy that stroke caregivers adopted to help them gain a better understanding about what they were undergoing (Ang et al., 2013; Greenwood et al., 2009a; Greenwood et al., 2009b; Karen et al., 2012; Niyomthai, 2009; Wu, 2009). The participants in this study learned to provide care as well as solve the problems related to care for their older adult stroke survivors at home by trial and error, seek needed information, guidance and support, and apply previous knowledge and skills. However, the strategies that they used and time they consume to learn of care at home were varies depending on the participants intervening conditions. These conditions were their personal resources, family resources, receiving support, and religious beliefs. These findings were consistent with a previous study (Cecil et al., 2009; Cecil et al., 2013; Lut et al., 2011; White et al., 2007, Wu, 2009), as discussed in the next section.

This study's finding revealed that gaining role mastery was a transitioning point that triggered the participant move to the stage of achieving sense of control. The finding showed that as the participants had more experience in providing care and dealing with caregiving problems, they increased their caregiving skills and gain more in self-confidence. This is in line with previous studies related to family caregiving (Mackenzie & Greenwood, 2012; Niyomthai, 2009; Obe-om, 2005; Wu, 2009). This theme is also congruent with Meleis's transition theory which proposed that mastery was one critical outcome indicator of successful transition (Meleis et al., 2000). Mastery played an important role in contributing to the family caregivers's ability to provide care for the stroke survivors at home (White et al., 2007).

3. Achieving sense of control stage

The findings showed that the participants attempted to deal with the variety of caregiving difficulties they encountered until finally gaining role mastery when they achieved a sense of control. They were then able to manage and keep the caregiving situation under control. They also felt at ease with their daily caregiving roles. This finding was similar to the experiences of close relatives of stroke survivors in another study which reported that after several months caregivers felt that they had begun to acquire new practical routines in their daily family lives, when things were familiar, expected and under control (Bäckström & Sudin, 2010). They felt proud of their ability to care for the stroke members and increased self-reliance (Burman, 2001). They also felt happy in being able to master the caregiving skills and their ability to survive despite uncertainty (Wu, 2009). Therefore, this serves as a motivator and resource for family caregivers to continue in the caregiving role. However, the findings indicated that this process seemed to be cyclical, since some participants stated that they felt panic again when they were faced with new difficulties.

Factors influencing family caregivers' overcoming difficulties

This study identified a number of factors that facilitated or inhibited participants in dealing with the difficulties and uncertainty of caregiving for older adult family members during transition from hospital to home. These included the participants' personal resources, family resources, social support, and the Thai socio-cultural context.

Personal resources of the caregivers

This study identified a number of factors that placed participants in a strong position and supported their caregiving roles and facilitated them in overcoming difficulties in providing care at home. These factors included good physical condition, positive belief/attitude, positive definition of caregiving, and having relevant experience and skills. These findings were similar to previous researches (Cecil et al., 2013; Greenwood et al., 2009; Lut et al., 2011). However, the findings in this study highlight the impact of the positive definition of caregiving on the stroke caregiving phenomenon. Andren and Elmstalh (2005) reported that the given meaning in the caregiving role influences the caregiver's motivation for taking on, coping with and sustaining the ongoing responsibility of caring for their family members. In this study, the participants who gave the meaning of caregiving/interpreted caregiving as an obligation, usually used positive coping strategies to deal with difficult situations and they tried to do the best in their roles. This was consistent with Epps's study (2014), which reported that family obligation correlated significantly with an increased positive appraisal of caregiving. In contrast, the participants who gave the meaning of their caregiving as a stressor seemed to give up in their roles when they felt tired and faced with stress. As a result they did not take good care of their older adult stroke survivors. It was noted that one older adult stroke survivor had a bed sore while another had poor hygiene with a bad smell, on the day of the interview.

Family resources

The findings indicate that family and kin network were powerful resources that helped Thai family caregivers to overcome those difficulties. It appeared that some of the participants who had good family resources; family harmony, and strong support from their family members or had a wider kin network, financial security which supported their caregiving roles were more able to deal with caregiving difficulties. This is consistent with previous studies conducted in both Thailand (Hattakit, 1999; Niyomthai, 2009; Obe-om, 2005) and other countries (Lut et al, 2011).

Research reported that mutual support, open communication, and family hardiness were found to be important family resources for dealing with care problems (Hesamzadeh et al, 2015; Niyomthai, 2009). In contrast, poor family functioning including lack of communication and ability to work together cooperation was associated with mal-adaptation and negative mental health outcomes for family caregivers (Epstein-Lubow, Beevers, Bishop, & Miller, 2009; King, Shade-Zeldow, Carlson, Feldman, & Philip, 2002). Similarly, this study showed that family harmony was a critical family resource that assisted family caregivers to deal with caregiving difficulties. However, family harmony is much more than mutual support and open communication for family members. It entailed love, understanding and cooperative decision making.

Receiving support

Consistent with previous researches, receiving support from family, friends, health professionals and the community were reported as helping factors for family caregivers to gain strength to deal with the everyday life of caregiving for stroke survivors (Ang et al., 2012; Coombs, 2007; Saban & Hogan, 2012). Lazarus and Folkman (1984) mentioned that social support is one significant source that may be accessible to caregivers as they appraise their conditions. Thus, social support acts as a coping resource for the family caregivers. This finding was also congruent with previous studies which reported that social support contributed to the family caregivers adjustment (Grant et al., 2006), and played an important role in buffering the caregivers’ stress (Ostward et al., 2009) and enhancing their quality of life (Oupra et al., 2010). Integrated social support, especially from health services had a strong positive impact on family adaptation to stroke (Hesamzadeh et al., 2015). In addition, perceived social support, especially perceived emotional support, diminished stress-induced psychological distress (Grant et al., 2006; Sit, Wong, Clinton, Li, & Fong, 2004). In turn, lack of support either from family or from external sources such as the community and health care professionals was reported as a stressor for the family caregivers (Gholamzadeh et al., 2015; King & Semik, 2006; Saban & Hogan, 2012).

The study findings highlighted the benefit of home health care services in assisting family caregivers to overcome caregiving difficulties at home. However, some participants could not assess these services. This indicated that the implementing of home health care services was different in each area. Some health care providers do not recognize the importance of such services in supporting family caregiving in the community. The study findings also reflect family caregivers’ need for support. They need to know that someone is available to assist, answer questions and provide guidance when needed. This was congruent with the study by Bakas and colleagues (2009) who reported that when caregivers perceived that someone is available to discuss issues and provide guidance during difficult times, it greatly reduces anxiety and loneliness.

Three factors involving health professionals were frequently mentioned by the family caregivers as barriers in dealing with difficulties in caring for older adult stroke survivors. These were; the limited time for teaching and learning care, inadequate information being provided, and poor communication of health care staff. This might be because the sharp increase in the number of patients combined with shortened hospital stays forced healthcare professionals to provide care in a hurried, abbreviated manner (Caswell et al., 2015). Furthermore, Thai government hospitals have a shortage of nursing manpower required to provide care for clients (Thailand Nursing and Midwifery Council [TNC], 2009). The nurse-to-patient staffing ratios in those settings were reported as an average of 1:10 (Nantsupawat, Srisupan, Kanavikktikul, Wichaikum, Aunsuroch, & Aiken, 2011), which is higher than the recommended ratio from the TNC which is 1:4-5 (TNC, 2005). Thus, nurses are pressed to provide care quickly. This argument is supported by a systematic review about staff-family relationships in caring for older persons which found that organizational factors including staff workloads, lack of sufficient staff, high levels of staff turnover, and other work pressures interfered with the amount and quality of time staff had to interact with relatives (Haesler, Buaer, & Nay, 2007).

Thai socio-cultural context: Kreng jai as a barrier to seeking help

Komin (1991) defined "*Kreng jai"* as feeling considerate for another person, not wanting to impose or cause another person trouble, or hurt his/her feelings (pp. 135). It is a Thai characteristic that is displayed by a person functions to maintain or improve the existing social atmosphere, interpersonal relationships, attitudes, and one's self-image (Komin, 1991: pp.136). This study showed that this Thai characteristic acts as a barrier in the coping and learning process of family caregivers. This finding was congruent with a study of the experiences of Thai families living with a person with AIDS, which reported that the family experienced suffering due to "*Kreng jai*" when negotiating with or questioning health professionals, particularly doctors and nurses (Nilmanat, 2001).

CHAPTER 5

CONCLUSION AND RECOMMENDATIONS

In this chapter, the study findings are concluded. Then the recommendations for nursing practice, nursing education, further research, and improving the healthcare policy are presented.

Conclusions of the study

The purpose of this study is to generate a substantive model to describe the process of the family caregivers overcoming difficulties in caring for an older adult stroke survivor during the transition to home. A qualitative grounded theory was conducted with 26 participants who provided care for the older adult stroke survivors in a nuclear family for 1 month to 1 year. The substantive model of "fighting to gain a sense of control" emerged in this study. The process started when the family caregivers were faced with an unexpected stroke event that occurred in an older adult family member and finished when the family caregiver had gained mastery in their caregiving experiences. The process is comprised of three stages: loss of control; striving to master uncertainty; and archiving sense of control.

Stage 1: Loss of control

This stage began when the participants perceived that their older adult member had suffered a stroke that might cause death and needed acute or intensive care in the hospital. Some participants were asked to make life-changing treatment decisions for the older adults members. This crisis situation caused the participants difficulty in making such decisions. They also felt powerless in providing and managing care for their older adult, and relied on health professionals. However, the family caregivers were not able to receive all the help and support they needed. As a result, they experienced emotional distress expressed as being frightened, the fear of lose, and frustration. Loss of control, therefore, involved the participants' feeling of being unable to control the caregiving situation as well as not having control over their own emotions. Receiving emotional and informational support were the factors that helped the participants move through this stage.

Stage 2: Striving to master uncertainty

This stage took place when the participants were required to learn to be a caregiver and ended when they gained role mastery in providing care for the older adult family member stroke survivors. The participants had to put in a high level of effort to overcome difficulties related to caring for their older adult stroke survivors, which changed overtime throughout the period of transition from hospital to home. It involved a time frame from the hospitalization period and included the discharge period to post discharge at home.

Hospitalization period

The participants confronted difficulty in learning to be a caregiver. This composed of being ambivalent towards learning the caregiving role and cognitive reframing. Being ambivalent was demonstrated as the participants' desire to learn caregiving skills, but at the same time they felt fearful of learning care skills ("I don't want to do it and I cannot do it"). Cognitive reframing was a strategy that the participants used to overcome this difficulty. This included a re-appraisal of the situation and a change of thinking ("I need to learn and I can do it"). After the participants had re-thought their situation, they realized that they had to learn care skills because they must provide care for the older adult survivors after discharge. This change of thought activated the participants to try to learn the required skills from the nurses and other people with similar experiences by observation, interacting with others, and practicing.

Factors that promoted the participants to overcome difficulties during this period included the emotional and informational support from family members, friends, and health professionals as well as a supportive environment in teaching and learning care skills. In contrast, the limited time in teaching and learning, the inadequate information provided by health care staff, the poor communication of health care staff, and hesitation *(kreng jai*) in asking for help or asking any questions were the hindering factors that inhibited the participants to deal with learning to be a caregiver.

Discharge period

At a time of patient discharge, the participants faced an un-readiness to provide care at home which composed of an unreadiness in taking the patient home, negotiating with healthcare providers, and struggling to prepare for caregiving at home. The participants' experience of unreadiness in taking the patient home was caused by their perception of the poor condition of the older adult stroke survivor, lack of resources, having no idea about caregiving at home, and not feeling confident to provide care at home. To deal with these difficulties, the participants negotiated with the healthcare providers to extend the hospitalization period for the patient. However, most of the participants were not successful with this interaction. Thus, they continued to struggle to prepare for caregiving at home due to a lack of money, being unfamiliar with the care equipment, and not knowing where to source the equipment needed. However, they could overcome these difficulties by seeking the needed resources and support. They also received instrumental support from the healthcare providers and social network in the community.

Post discharge period

Struggling to maintain care at home was an emerging theme in this period. It composed of facing new difficulties and dealing with caregiving problems at home. The participants faced a variety of difficulties in providing care for their older adult stroke survivors at home. These included meeting unexpected symptoms of stroke survivors, facing emotional and behavioral changes, managing a paid caregiver, work overload, experiences of physical stress, a patient's un-cooperative state, and financial strain. A number of strategies were used by the participants in dealing with caregiving problems at home and included; managing care at home, adjusting life styles, managing stress, and learning to provide care at home.

Many factors were identified by the participants as the facilitators to cope with difficulties in providing care at home. These were their personal resources (positive attitude and interpretation of caregiving roles, ability in managing care), family resources (family harmony, good economic status, available family supporters), social support, accessibility of supportive services/resources in the community (home healthcare service, social welfare policy), coordination between care settings, and the

Thai socio-cultural context (Thai social value of *katanyu katavedi* and *bunkun* system and interdependent relationships in Thai society, and religious beliefs about the law of karma, merit and sin, and life after death). In contrast, old age and poor physical status of a caregiver, health care staff providing inadequate information, family's low economic status or financial strain, lacking family support, lacking emergency contact persons, hesitating *(kreng jai*) in asking for help were identified as the hindering factors in providing care at home by the participants.

Stage 3: Achieving Sense of Control

Achieving sense of control was the consequential outcomes of the coping and learning process, which can be described by two categories; being manageable and becoming easy. After the participants struggled with their caregiving situation for several months, most of them mentioned that they had gained more experience and had learned about care. They also identified having gained knowledge and care skills from their caregiving experience. This made them feel confident in their ability to handle caregiving situations. They also felt their caregiving situations were manageable. Becoming easy was described when the participants had ease in performing caregiving tasks. They explained that they could work through step-by-step to solve any problem and could adjust their caregiving practice by themselves.

Recommendations of the Study

The study findings highlight the difficulty and the ways that the participants used to overcome such difficulties in the three different periods of care transition from hospital to home. This study also identified the factors affecting how the family caregivers coped when encountering difficulties. The findings also indicated support needs and gaps in care for the older adult stroke survivors and their caregivers as they transition from hospital to home, resulting in the following recommendations for nursing practice, nursing education, further research, and the health policy.

Nursing practice

The findings from this study can be applied in nursing practice as follows:

During hospital period

1. The study findings indicated family caregivers need of support particularly emotional and informational support. However, most of them pointed out their needs were unmet which was one important source of distress and disappointment of the caregivers during this stage. Therefore, it is important for health care staff, particular nurses, to develop a friendly relationship and provide emotional support to family caregivers during this period.
2. The study finding suggested that as the family caregivers desired to learn caregiving skills, it did not mean they were always ready to learn. Therefore, there is a need for nurses to improve teaching/training strategies to prepare a family caregiver. These strategies should be composed of; 1) comprehensive assessment of the family caregivers' readiness to learn including feelings of fear and concern related to learning and providing care, 2) cognitive reframing , 3) peer learning, 4) providing adequate time for practice
3. The nurse providing stroke education for the caregivers must be trained appropriately regarding strokes, the risk factors and pathophysiology, implications and effects of strokes, available community resources, and emotional needs of patients. Stroke education provided by a nurse should also include stress management skills and guidance in managing the physical, cognitive and behavioral changes of the stroke survivor.

During discharge period

Nurses should pay more attention to this and should undertake a thorough assessment to identify what makes the family caregiver feel un-ready to take the patient home. It is also suggested that the preparedness of the family caregiver should be comprehensively assessed before patient discharge, and the anticipated care problems encountered by the family caregivers after discharge should be addressed during hospitalization to ensure they can provide good care at home.

Post discharge at home

1. The findings showed that the home health care service was strongly emphasized as the helping factor by the family caregivers. The findings also reflected that this service was mainly carried out by nurses. Family caregivers recognize the need to receive a continuum of this service. At the same time they need to receive continue rehabilitative care at home. Therefore, providing home health care services should be continued and it should be composed of a multidisciplinary team.

2. The understanding of the process of overcoming difficulties including any related factors in caring for older adult stroke survivors during the transition from hospital to home could facilitate nurses or other health professionals to design nursing programs/ interventions to promote family caregivers in providing care for the sick family members.

Nursing education

The findings yield support and can be applied to nursing education as follows:

1. A nursing educator can apply the findings in teaching nursing students, which needs to be focused on the difficulties of a family in caring for older adult stroke survivors during the transition from hospital to home. This teaching should include the nurses’ role in assessing difficulties/readiness of the family and in promoting the family to provide care for family members who have had a stroke. It should also include socio-cultural, economic, and health care service aspects influencing Thai family caregiving.

2. The findings indicated the complexity of stroke care in the transition from acute to ambulatory and home, as it is transited from formal care provided by nurses to informal care provided by family caregivers. Therefore, developing a Care Transition Course is needed for the nursing curriculum in the future, and the findings from this study can be used as the database to do so.

Further research

1. A model to enhance the family caregivers’ ability in providing care for the older adult stroke survivors as well as caregiver competency should be investigated

2. The data derived from this study can be used as an important database for the further development of supportive interventions or experimental research on a specific model of care for family caregivers caring for the older adult stoke members in

each period of care trajectory. At the same time, the transitional care model in the Thai context should be investigated. This model should include supportive care in the acute care period, comprehensive discharge plan, and supportive services after discharge.

3. The findings verify that coping behaviors are distinctive among different participants depending upon their available resources. Thus, an individualized intervention should be investigated further. This intervention should also be linked to the family and cultural background of the caregivers.

4. This study disclosed the structure of the process of overcoming difficulties in caring for older adult stroke survivors during the transition from hospital to home, thus future research aimed to develop nursing knowledge by testing the interrelationship of this middle range theory should be conducted.

5. Some unclear issues that emerged in this study should be explored in detail such as a model of an effective discharge plan for stroke survivors and their family caregivers, the role of nurses in facilitating the family to supervise a paid caregiver.

Health policy

1. Findings suggested that family caregivers need multiple types of support in caring for the older adult stroke survivor and in dealing with the problems related to care. Thus, caregiver support policies need to be developed in order to help the caregivers reduce burdens as well as to promote them to continue their caregiving role. Based on study results, caregivers' support policies should focus on the following factors: emergency contact line or help line, financial support, material and equipment support, home-based rehabilitative care, rehabilitative ward, and respite care.

2. A policy to strengthen family solidarity is needed. Since strengthening family ties was recognized as a way to enhance family harmony which consequently helps in providing support for the family caregiver and the older adult stoke member. The Thai government has tried to promote family caregiving and filial obligation, and these efforts should be continued through the education system, mass media and both government and non-government agencies. The existing public policy aimed at strengthening and maintaining traditional and cultural values of respect and care for the older adult should be extended.

3. The findings also reflected several issues related to caring for the older adult stroke survivors and their family caregivers. Those issues are often linked to organizational factors and the shortage of nursing manpower. This suggested that a policy about increasing the number of nurses needs to be considered.

REFERENCES

Allen, K. R., Fine, M. A. & Demo, D. H. (2000). An overview of family diversity: controversies, questions and values. In D. H. Demo, K. R. Allen, & M.A. Fine (Eds.), *Handbook of family diversity* (pp. 273-281). Oxford: Oxford University Press.

Andershed, B. (2006). Relatives in end-of-life care-part 1: a systematic review of the literature the five last years, January 1999-February 2004. *Journal of Clinical Nursing, 15*(9), 1158-1169. doi:10.1111/j.1365-2702.2006.01473.x

Anderson, C., John, O. P., & Keltner, D. (2012). The personal sense of power. *Journal of Personality, 80*(2), 313-344. doi: 10.1111/j.1467-494.2011.00734.x

Andren, S. & Elmstalh, S. (2005). Family caregivers' subjective experiences of satisfaction in dementia care: aspects of burden, subjective health and sense of coherence. *Scandinavian Journal of Caring Sciences, 9*(4), 157-168.

Ang, J. Y. H., Leng, C. Y., & Poon, E. W. H. (2013). Literature review: coping strategies of family caregivers caring for stroke survivors. *Singapore Nursing Journal, 40*(2), 19-27.

Annells, M. (1997). Grounded theory method, part I: within the five moments of qualitative research. *Nursing Inquiry, 4*(2), 120-129.

Annells, M. (2006). Triangulation of qualitative approaches: hermeneutical phenomenology and grounded theory. *Journal of Advanced Nursing, 56*(1), 55-61.

Arabit, L. d. L. (2008). Coping strategies of Latino women caring for a spouse recovering from a stroke: a grounded theory. *The Journal of Theory Contruction & Testing, 12*(2), 42-49.

Archbold, P. G., Stewart, B. J., Miller, L. L., Harvath, T. A., Greenlick, M. R., Van BurenL, Kirschling, J. M.,…& Hagan, J. M. (1995). The PREP system of nursing interventions: a pilot test with families caring for older members. Preparedness (PR), enrichment (E) and predictability (P). *Research in Nursing & Health, 18*(1), 3-16.

Bäckström, B., & Sundin, K. (2010). The experience of being a middle-aged close relative of a person who has suffered a stroke – six months after discharge from a rehabilitation clinic. *Scandinavian Journal of Caring Sciences, 24*(1), 116-124.

Bakas, T., Austin, J. K., Okonkwo, K. F., Lewis, R. R., & Chadwick, L. (2002). Needs, concerns, strategies, and advice of stroke caregivers the first 6 months after discharge. *Journal of Neuroscience Nursing, 34*(5), 242-251.

Bakas, T., Austin, J. K., Jessup, S. L., Williams, L. S., & Oberst, M. T. (2004). Time and difficulty of tasks provided by family caregivers of stroke survivors. *The Journal of Neuroscience Nursing, 36*(2), 95-106.

Bakas, T., Farran, C. J., Austin, J. K., Given, B. A., Johnson, E. A., & Williams, L. S. (2009). Content validity and satisfaction with a stroke caregiver intervention program. *Journal of Nursing Scholarship, 41*(4), 368-375.

Barbic, S. P., Mayo, N. E., White, C. L., & Bartlett, S. J. (2014). Emotional vitality in family caregivers: content validation of a theoretical framework. *Quality of Life Research, 23*(10), 2865-2872.

Bastawrous, M., Gignac, M. A., Kapral, M. K., & Cameron, J. I. (2015). Adult daughters providing post-stroke care to a parent: a qualitative study of the impact that role overload has on lifestyle, participation and family relationships. *Clinical rehabilitation, 29*(6), 592-600.

Bauer, M., Fitzgerald, L., Haesler, E., & Manfrin, M. (2009). Hospital discharge planning for frail older people and their family. Are we delivering best practice? A review of the evidence. *Journal of Clinical Nursing, 18*(18), 2539-2546.

Beck, C. T. (1993). Qualitative research: the evaluation of its credibility, fittingness, and auditability. *Western Journal Of Nursing Research, 15*(2), 263-266.

Blum, K., & Sherman, D. W. (2010). Understanding the experience of caregivers: a focus on transitions. *Seminar in Oncology Nursing, 26*(4), 243-258. doi:10.1016/j.soncn.2010.08.005

Blumer, H. (1969). *Symbolic interacitionism: perspective and method*. Englewood Cliffs, NJ: Prentice Hall.

Brereton, L., & Nolan, M. (2000). You do know he’s had a stroke, don’t you? Preparation for family caregiving–the neglected dimension. *Journal of Clinical Nursing, 9*(4), 498-506.

Brereton, L. & Nolan, M. (2002). Seeking: a key activity for new family carers of stroke survivors. *Journal of Clinical Nursing, 11*(1), 21-23.

Brown, E. (2007). Care recipients’ psychological well-being: the role of sense of control and caregiver type. *Aging and Mental Health, 11*(4), 405-414.

Bryant, A. & Chamaz, K. (2007). *The SAGE handbook of grounded theory*. CA: SAGE Publications.

Bull, M. J. (1992). Managing the transition from hospital to home. *Qualitative Health Research, 2(1), 27-41.*

Burman, M. E. (2001). Family caregiver expectations and management of the stroke trajectory. *Rehabilitation Nursing, 26*(3), 94-99.

Caffrey, R. A. (1992). Caregiving to the elderly in Northeast Thailand. *Journal of Cross-Cultural Gerontology, 7*(2), 117-134.

Camak, D. J. (2015). Addressing the burden of stroke caregivers: a literature review. *Journal of Clinical Nursing, 24*(17-18), 2376-2382. doi:10.1111/jocn.12884

Cameron, J. I. & Gignac, M. A. M. (2008). ‘‘Timing It Right’’: a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient Education and Counseling, 70*, 305–314.

Cameron, J. I., Tsoi, C., & Marsella, A. (2008). Optimizing stroke systems of care by enhancing transition across care environments. *Stroke, 39*(9), 2637-2643.

Carlsson, G. E., M ller, A., & Blomstrand, C. (2009). Managing an everyday life of uncertainty: a qualitative study of coping in persons with mild stroke. *Disability & Rehabilitation, 31*(10), 773-782.

Caswell, G., Pollock, K., Harwood, R., & Porock, D. (2015). Communication between family carers and health staff about EOL for older people. *BMC Palliative Care, 14*(35), 1-14. doi:10.1186/s12904-015-0032-0

Cecil, R., Parahoo, K., Thompson, K., McCaughan, E., Power, M., & Campbell, Y. (2010). The hard work starts now: a glimpse into the lives of carers of community-dwelling stroke survivors. *Journal of Clinical Nursing, 20*(11-12), 1723-1730.

Cecil, R., Thompson, K., Parahoo, K., & McCaughan, E. (2013). Towards an understanding of the lives of families affected by stroke: a qualitative study of home carers. *Journal of Advance Nursing, 69*(8), 1761-1770. doi:10.1111/jan.12037

Chaiyawut, K. (2004). *The factors influencing roles strain among male caregivers of cerebrovascular disease patients*. (Unpublished master's thesis). Mahidol University, Thailand.

Chalermwannapong, S. (2009). *Effects of the transitional care program on functional ability and quality of life of stroke survivors.* (Unpublished doctoral dissertation). Chiang Mai University, Thailand.

Chamaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative*. Los Angeles: SAGE Publications.

Changsuwan, S. (2005). *Caregiving experiences among caregivers of stroke patients.* (Unpublished master's thesis). Chiang Mai University, Thailand.

Chanprachon, J. (2007). *Family attachment and the process of family management in caring for stroke patients.* (Unpublished master's thesis). Christian University of Thailand, Thailand.

Chansri, W. (2008). *Relationship of coping behaviors, social support, and family well-being of family with stroke patients.* (Unpublished master's thesis). Mahidol University. Thailand.

Chenitz, W. C., & Swanson, J. M. (1986). *From practice to grounded theory: qualitative research in nursing,* CA: Addison Wesley.

Choowattanapakorn, T. (1999). The social situation in Thailand: the impact on elderly people. *International Journal of Nursing Practice, 5*(2), 95-99.

Click, N., & Meleis, A. I. (1986). Transitions: a nursing concern. In P. L. Chinn (Eds.), *Nursing research methodology: issues and implementation* (pp. 237-257). Maryland: Aspen Publisher, Inc.

Clarke, A. E. (2005) *Situational analysis: grounded theory after the postmodern turn*. Thousand Oaks, CA: Sage Publications.

Coombs, U.E. (2007). Spousal caregiving for stroke survivors. *Journal of Neuroscience Nursing, 39*(2), 112–119.

Cott, C. A., Wiles, R., & Devitt, R. (2007). Continuity, transition and participation: Preparing clients for life in the community post-stroke. *Disability & Rehabilitation, 29*(20-21), 1566-1574. doi: 10.1080/09638280701618588

Coyne, I. T. (1997). Sampling in qualitative research: purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing, 26*(3), 623-630.

Creswell, J. W. (2007). *Qualitative inquiry & research design: choosing among five approachs* (2nd ed.). Thousand Oaks: USA. SAGE Publication.

Denham S. 2003. *Family health. A framework for nursing*. Philadelphia: F.A. Davis Company.

Denzin, N. K., & Lincoln, Y. S. (1994). *Handbook of qualitative research*. Thousand Oaks, CA: Sage Publications, Inc.

Duggleby, W. D., Penz, K. L., Goodridge, D. M., Wilson, D. M., Leipert, B. D., Berry, P. H., . . . Justice, C. J. (2010). The transition experience of rural older persons with advanced cancer and their families: a grounded theory study. *BMC Palliative Care, 9*(1), 1-9.

Ellis-Hill, C., Robison, J., Wiles, R., McPherson, K., Hyndman, D., & Ashburn, A. (2009). Going home to get on with life: patients and carers experiences of being discharged from hospital following a stroke. *Disability & Rehabilitation, 31*(2), 61-72. doi: 10.1080/09638280701775289

Epps, F. (2014). The relationship between family obligation and religiosity on caregiving. *Geriatric Nursing, 35*(2), 126-131.

Epstein-Lubow, G. P., Beevers, C. G., Bishop, D. S., & Miller, I. W. (2009). Family functioning is associated with depressive symptoms in caregivers of acute stroke survivors. *Archives of Physical Medicine and Rehabilitation, 90*(6), 947-955.

Esche, C. A. & Turner, E. K. (2005). Resiliency: a factor to consider in facilitating the transition from hospital to home in older adult. *Geriatric Nursing, 26(4), 218-222.*

Fassinger, R. E. (2005). Paradigms, praxis, problems, and promise: grounded theory in counseling psychology research. *Journal of Counseling Psychology, 52*(2), 156-166.

Folkman, S. (1984). Personal control and stress and coping process: a theoretical analysis. *Journal of Personality and Social Psychology, 46*(4), 839-852.

Folkman, S., & Moskowitz, J. T. (2004). Coping: pitfalls and promise. *Annual Review in Psychology, 55*, 745-774.

Fraser, C. (1999). The experience of transition for a daughter caregiver of a stroke survivor. *Journal of Neuroscience Nursing, 31*(1), 9-16.

Friedman, M. M., Bowden, V. R., & Jones, E. (2003). *Family Nursing: research, theory & practice*: Pearson.

Fukui, S., Starnino, V. R., & Nelson-Becker, H. B. (2012). Spiritual well-being of people with psychiatric disabilities: the role of religious attendance, social network size and sense of control. *Community Mental Health Journal, 48*(2), 202-211.

Gholamzadeh, S., Aizan, H. T., Sharif, F., Hamidon, B., & Rahimah, I. (2015). Exploration the supportive needs and coping behaviors of daughter and daughter in-law caregivers of stroke survivors, shiraz-iran: a qualitative content analysis. *International Journal of Community Based Nursing and Midwifery, 3*(3), 205-215.

Glaser, B. G. (1978). *Advances in the methodology of grounded theory: theoretical sensitivity*. Mill Valley, CA: The Sociology Press.

Glaser, B. G. (1992). *Emergence vs Forcing: Basics of grounded theory analysis*. Mill Volley: Sociology Press.

Glaser, B. G., & Strauss, A. (1967) *The discovery of grounded theory: strategies for qualitative Research*. NY: Aldine de Grutyer.

Grant, J. (2004). Problems and associated feelings by family caregivers of stroke survivors during the second and third month of caregiving. *Journal of Neuroscience Nursing, 36*(2), 107-110.

Grant, J. S., Elliott, T. R., Weaver, M., Glandon, G. L., Raper, J. L., & Giger, J. N. (2006). Social support, social problem-solving abilities, and adjustment of family caregivers of stroke survivors. *Archives of Physical Medicine and Rehabilitation, 87*(3), 343-350.

Green, T. L., & King, K. M. (2009). Experiences of male patients and wife-caregivers in the first year post-discharge following minor stroke: a descriptive qualitative study. *International Journal of Nursing Studies, 46*(9), 1194-1200.

Greenwood, N., Mackenzie, A., Cloud, G. C., & Wilson, N. (2008). Informal carers of stroke survivors - factors influencing carers: a systematic review of quantitative studies. *Disability and Rehabilitation, 30*(18), 1329-1349.

Greenwood, N., Mackenzie, A., Cloud, G., & Wilson, N. (2009a). Informal primary carers of stroke survivors living at home - challenges, satisfactions and coping: a systematic review of qualitative studies. *Disability & Rehabilitation, 31*(5), 337-351.

Greenwood, N., Mackenzie, A., Wilson, N., & Cloud, G. (2009b). Managing uncertainty in life after stroke: a qualitative study of the experiences of established and new informal carers in the first 3 months after discharge. *International Journal of Nursing Studies, 46*(8), 1122-1133.

Greenwood, N., & Mackenzie, A. (2010). Informal caring for stroke survivors: meta-ethnographic review of qualitative literature. *Maturitas, 66*(3), 268-276.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. *Handbook of qualitative research, 2*(163-194), 105.

Haesler, E., Bauer, M., & Nay, R. (2007). Staff–family relationships in the care of older person. *Research in Nursing and Health, 30*(4), 385-398. doi:10.1002/nur.20200

Hafsteinsdóttir, T. B., Vergunst, M., Lindeman, E., & Schuurmans, M. (2011). Educational needs of patients with a stroke and their caregivers: a systematic review of the literature. *Patient Education and Counseling, 85*(1), 14-25.

Hall, W. A., & Callery, P. (2001). Enhancing the rigor of grounded theory: incorporating reflexivity and relationality. *Qualitative Health Research, 11*(2), 257-272.

Hallinger, P., & Kantamara, P. (2000). Educational change in Thailand: opening a window onto leadership as a cultural process. *School Leadership & Management, 20*(2), 189-205.

Han, B., & Haley, W. E. (1999). Family caregiving for patients with stroke: review and analysis. *Stroke, 30*(7), 1478-1485.

Hanchaiphiboolkul, S., Poungvarin, N., Nidhinandana, S., Suwanwela, N. C., Puthkhao, P., Towanabut, S., . . . Samsen, M. (2011). Prevalence of stroke and stroke risk factors in Thailand: Thai Epidemiologic Stroke (TES) Study. *Journal of the Medical Association of Thailand, 94*(4), 427-436.

Hartke, R. J., & King, R. B. (2002). Analysis of problem types and difficulty among older stroke caregivers. *Topics in Stroke Rehabilitation, 9*(1), 16-33

Hattakit, U. (1999). *Family-oriented-self-care: An ethnographic study of stroke patients in Thailand.* (Unpublished doctoral dissertation). Curtin University of Technology, Australia.

Heath, H., & Cowley, S. (2004). Developing a grounded theory approach: a comparison of Glaser and Strauss. *International Journal of Nursing Studies, 41*(2), 141-150.

Hesamzadeh, A., Dalvandi, A., Maddah, S. B., Khoshknab, M. F., & Ahmadi, F. (2015). Family adaptation to stroke: a metasynthesis of qualitative research based on double abcx model. *Asian Nursing Research, inpress*, 1-8.

Hilton, E. L. (2002). The meaning of stroke in elderly woman: a phenomenological investigation. *Journal of Gerontological Nursing, 28*(7), 19-26.

Hirunchunha, S. (1998). *Development of a care model for the caregivers of stroke patients at home*. (Unpublished doctoral dissertation). Mahidol University, Bangkok, Thailand.

Holloway, I. & Wheeler, S. (2010). *Qualitative research in nursing and healthcare* (3rd ed.). WILEY-BLACKWELL: A Johnson Wiley & Sons, Ltd., Publication.

Holton, J. A. (2010). The coding process and its challenges. *The Grounded Theory Review, 9*(1), 21-40.

Hutchison, S. A. (1993). Grounded theory: the method. In P. L. Munball & C. O. Boyd (Eds.), *Nursing research: a qualitative perspective* (pp. 180–212). National League for Nursing Press: New York, Ingersoll-Dayton, B., Saengtienchai, C., Kespichyawattana, J., & Aungsuroach, Y. (2001). *Psychological Well-being Asian Style: The Perspective of Thai Elders*. Research Report. No. 01-474.

Intharuk, N. (2008). *The effect of a video modeling training on older person with stroke caregiver's anxiety.* (Unpublished master thesis). Chulalongkorn University, Thailand.

Jitapunkul, S. & Bunnag S. (1999). Ageing in Thailand. *Family Planning and Population*, 2, 6 (Fact sheet): Retrieved from http://advisor.anamai.moph.go.th/factsheet/Ageing.htm

Jullamate, P., Azeredo, Z. D., Paul, C. & Subgranon, R. (2006). Thai stroke patient caregivers: who they are and what they need. *Cerebrovascular Diseases*, *21* (1-2), 128–133.

Jullamate, P., de Azeredo, Z., Rosenberg, E., Pàul, C., & Subgranon, R. (2007). Informal stroke rehabilitation: what are the main reasons of Thai caregivers? *International Journal of Rehabilitation Research, 30*(4), 315-320.

Kalra, L., Evans, A., Perez, I., Melbourn, A., Patel, A., Knapp, M., & Donaldson, N. (2004). Training carers of stroke patients: randomised controlled trial. *British Medical Journal, 328*(7448), 1099-1113.

Kespichayawattana, J. (1999). *Katanyu katavedi and caregiving for frail elderly parents the perspectives of Thai families in metropolitan Bangkok, Thailand*: (Doctoral dissertation, Oregan University). Retrieved from http://digitalcommons.ohsu.edu/etd/1020

Kespichayawattana, J., & Jitapunkul, S. (2009). Health and health care system for older persons. *Ageing International, 33*(1-4), 28-49.

Khampolsiri, T., Pothiban, L., Sucamvang, K., Panuthai, S., Khampolsiri, T., Pothiban, L., . . . Panuthai, S. (2006). A home-based nursing intervention for enhancing quality of life of stroke survivors. *Chula Medical Journal, 50*(10), 707-725.

King, R. B., & Semik, P. E. (2006). Stroke caregiving: difficult times, resource use, and needs during the first 2 years. *Journal of Gerontological Nursing, 32*(4), 37-44.

King, R. B., Shade-Zeldow, Y., Carlson, C. E., Feldman, J. L., & Philip, M. (2002). Adaptation to stroke: a longitudinal study of depressive symptoms, physical health, and coping process. *Topics in Stroke Rehabilitation, 9*(1), 46-66.

Kitchie, S. (2003). Determinants of learning. In S. B. Bastable (Ed.) *Nurses as educator: principles of teaching and learning for nursing practice* (pp. 75-118). Boston: Jones and Bartlett.

Knodel, J. & Chayovan. (2008). Intergenerational relationships and family care and support for Thai elderly. *Ageing International, 33*(1-4), 15-27.

Knodel, J., & Chayovan, N. (2012). Intergenerational family care for and by older people in Thailand. *International Journal of Sociology and Social Policy, 32*(11-12), 682-694.

Knodel, J., Saengtienchai C., Sittitrai, W. (1995). The living arrangements of elderly in thailand: views of the populace. *Journal of Cross-Cultural Gerontology, 10* (1-2), 79-111.

Komin, S. (1991). *Psychology of the Thai people: values and behavioral pattern.* Bankok Research Center, National Instutuete of Development Administration (NIDA).

Kralik, D., Visentin, K., & van Loon, A. (2006). Transition: a literature review. *Journal of Advanced Nursing, 55*(3), 320-329.

Kralik, D., & van Loon, A. (2007). Understanding transition in chronic illness. *Australian Nursing Journal, 1*5(2), 29.

Lambert, V. A. & Lambert, C. E. (2010). Philosophical basis for grounded theory (editorial). *Pacific Rim International Journal of Nursing Research*, 14(4), 281-282.

Lavoie, J. P., Ducharme, F., Lévesque L., Hébert R., Vézina J., Gendron C.,…& Voyer, L. (2005). Understanding the outcomes of a psycho-educational group intervention for caregivers of persons with dementia living at home: a process evaluation. *Journal of Mental Health Aging, 9*(1): 25–34.

Lazarus, R. S., Folkman, S. (1984). *Stress Appraisal and Coping*. New York: Springer

Lee, G. R. (1982). *Family structure and interaction: a comparative analysis* [electronic vesion]. University of Minnesota Press, USA.

Lee, L. T. R. (2005). *Caring for stroke-impaired elderly family members: a study of family adaptation in a Chinese context*. (Doctoral Dissertation, The Hong Kong Polytechnic University). Retrieved from: https://scholar.google.co.th/scholar?q

Lincoln, Y. S. Guba, E. G. (1985). *Naturaliistic inquiry.* Beverlly Hills, CA: Sage.

Limanonda, B. (1995). Family in Thailand: Belief and realities. *Journal of Comparative Studies,* 26(1), 67-83.

Limanonda, B. (2009). *An empirical analysis on the stem family: a case study of Thailand.* The stem family in Eurasian perspective: revisiting house societies, 17th-20th centuries, 459.

Limanonda, B., Podhisita, C. & Wongsith, M. (1991). *Report on a Thai family and household survey*. Institute of Population Studies, Chulalongkorn University. Bankok, Thailand.

López, J., López-Arrieta, J., & Crespo, M. (2005). Factors associated with the positive impact of caring for elderly and dependent relatives. *Archives of Gerontology and Geriatrics, 41*(1), 81-94.

Lorga, T. (2004). *Authoritativeness of service coverage.* (Unpublished doctoral dissertation). La Trobe University, Australia.

Lui, M. H. L., Lee, D. T., Greenwood, N., & Ross, F. M. (2011). Informal stroke caregivers’ self-appraised problem-solving abilities as a predictor of well-being and perceived social support. *Journal of Clinical Nursing, 21*(1-2), 232-242.

Lund, M. (2005). Caregiver, take care. *Geriatric Nursing, 26*(3), 152-153.

Lutz, B. J. (2004). Determinants of discharge destination for stroke patients. *Rehabilitation Nursing, 29*(5), 154-163.

Lutz, B. J., & Young, M. E. (2010). Rethinking intervention strategies in stroke family caregiving. *Rehabilitation Nursing, 35*(4), 152-160.

Lut, B. J., Young, M. E., Cox, K. J., Martz, C., & Creasy, K. R. (2011). The crisis of stroke: experiences of patients and their family caregivers. *Topics in Stroke Rehabilitation, 18*(6), 786-797.

Mackenzie, A., Perry, L., Lockhart, E., Cottee, M., Cloud, G., & Mann, H. (2007). Family carers of stroke survivors: needs, knowledge, satisfaction and competence in caring. *Disability and Rehabilitation, 29*(2), 111-121.

Mackenzie, A., & Greenwood, N. (2012). Positive experiences of caregiving in stroke: a systematic review. *Disability and rehabilitation, 34*(17), 1413-1422.

Mak, A. K. M., Mackenzie, A., & Lui, M. H. L. (2007). Changing needs of Chinese family caregivers of stroke survivors. *Journal of Clinical Nursing, 16*(5), 971-979.

Maclsaac, L., Herrison, M. B., Godfrey, C. (2010). Supportive care needs of caregivers of individuals following stroke: a synopsis of research. *Canadian Journal of Neuroscience Nursing, 32*(1), 39-46.

Matayamool, C. (2003). *Factors affecting to role strain of caregivers in stroke patient.* (Unpublished master's thesis). Mahidol University, Bangkok, Thailand.

McCann, T., & Clark, E. (2003). Grounded theory in nursing research: part 3-application. *Nurse Researcher, 11*(2), 29-39.

McCullagh, E., Brigstocke, G., Donaldson, N., & Kalra, L. (2005). Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke, 36*(10), 2181-2186. doi:10.1161/01.str.0000181755.23914.53

McKevitt, C., Redfern, J., Mold, F., & Wolfe, C. (2004). Qualitative studies of stroke: a systematic review. *Stroke, 35*(6), 1499-1505. doi:10.1161/01.STR.0000127532.64840.36

Meleis, A. I., & Trangenstein, P. A. (1994). Facilitating transitions: redefinition of the nursing mission. *Nursing outlook, 42*(6), 255-259.

Meleis, A. I., Sawyer, L. M., Im, E., Messias, D. K. H., & Schumacher, K. (2000). Experiencing transitions: an emerging middle-range theory. *Advances in Nursing Science, 23*(1), 12-28.

Mills, J., Bonner, A., & Francis, K. (2006). Adopting a constructivist approach to grounded theory: implications for research design. *International Journal of Nursing Practice, 12*(1), 8-13.

Miller, K. I., Shoemaker, M. M., Willyard, J., & Addison, P. (2008). Providing care for elderly parents: a structurational approach to family caregiver identity. *Journal of Family Communication, 8*(1), 19-43.

Ministry of Public Health, (2007). Thai health profile 2005-2007.

Ministry of Public Health, (2009). Thai health profile 2007-2009.

Morse, J. M. (1995). The significance of saturation. *Qualitative Health Research, 5*(2), 147-149.

Nantsupawat, A., Srisuphan, W., Kunaviktikul, W., Wichaikhum, O. A., Aungsuroch, Y., & Aiken, L. H. (2011). Impact of nurse work environment and staffing on hospital nurse and quality of care in Thailand. *Journal of Nursing Scholarship, 43*(4), 426-432.

Narknisorn, B., & Kusakabe, K. (2013). Issues challenging future Thai elder care by women and family. *International Journal of Sociology and Social Policy, 33* (1-2), 21-32.

Natechang, S. (2002). *Influencing of caregiving role strain, worry from caring, and caregivers' factors on health status of caregivers of stroke patients.* (Unpublished master's thesis). Mahidol University, Thailand.

Navarat, W. (2002). *A study of influences of lack of resources, strain from direct care, and caregivers' factors on health status of family caregivers of patient with cerebrovascular disease.* (Unpublished master's thesis). Mahidol University, Thailand.

Nilmanat, K. (2001). *The experiences of Thai families living with a person with AIDS.* (Unpublished doctoral dissertation). La Trobe University, Australia.

Niyomathai, N. (2002). *Caregiving duration, family life event, family hardiness, and well-being of family caregivers of stroke survivors*. (Unpublished master's thesis). Mahidol University, Thailand.

Niyomthai, N. (2009.). *Family strength in caring for a stroke survivor at home.* (Unpublished doctoral dissertation). Chiang Mai University, Thailand.

Niyomathai, N., Tonmukayakul, O., Wonghongkul, T., Panya, P., & Chanprasit, C. (2010). Family strength in caring for a stroke survivor at home. *Pacific Rim International Journal of Nursing Research, 14*(1), 17-31.

Obe-om, T. (2005). *Experiences of families with stroke survivors in Chiang Mai Province*. (Unpublished doctoral dissertation). Chiang Mai University, Thailand.

O'Connell, B., & Baker, L. (2004). Managing as carers of stroke survivors: strategies from the field. *International Journal of Nursing Practice, 10*(3), 121-126.

O'Connell, B., Baker, L., & Prosser, A. (2003). The educational needs of caregivers of stroke survivors in acute and community settings. *Journal of Neuroscience Nursing, 35*(1), 21-28.

Ostwald, S. K., Bernal, M. P., Cron, S. G., & Godwin, K. M. (2009). Stress experienced by stroke survivors and spousal caregivers during the first year after discharge from inpatient rehabilitation. *Topics in Stroke Rehabilitation, 16*(2), 93-104. doi:10.1310/tsr1602-93

Oupra, R., Griffiths, R., Pryor, J., & Mott, S. (2010). Effectiveness of Supportive Educative Learning programme on the level of strain experienced by caregivers of stroke patients in Thailand. *Health and Social Care in the Community*, *18*(1), 10–20.

Panichakit, J. (2007). *A propose model of discharge planning for cerebrovasular disease patient: a case study of inpatient department, Srisangworn Hospital*. (Unpublished master’s thesis). Naresuan University, Thailand.

Pearlin, L. I., Morton, A. L, Elizabeth, G. M., & Joseph, T. M. (1981). The Stress Process. *Journal of Health and Social Behavior, 22*(4), 337–56.

Pierce, L., Steiner, V., Hicks, B. & Holzaepfel, A. L. (2006). Problems of new caregivers while caring for persons with stroke. *Rehabilitation Nursing, 31(4),* 166-172.

Pierce, L., Steiner, V., Govoni, A., Hicks, B., Thompson, T. & Friedemann, M. (2007). Two sides to the caregiving story. *Topics in Stroke Rehabilitation, 14(2),* 13-20.

Plank, A., Mazzoni, V., & Cavada, L. (2012). Becoming a caregiver: new family carers’ experience during the transition from hospital to home. *Journal of Clinical Nursing, 21(13-14),* 2072–2082.

Phongsai Nopphawan. (2009). Effect of transitional care on activities of daily living among stroke patients. (Unpublished master’s thesis). Chiang Mai University, Thailand.

Poungvarin, N. (2001). *Cerebrovascular accident.* Bangkok: Rernkaw Publishing.

Prawtaku, S. (2006). *A comparison of needs for helps and caregivers role strain among spouse, children and sibling's caregivers of patients with stroke* (Unpublished master’s thesis). Mahidol University, Thailand.

Promchan, P. (2009). *The development of discharge planning model for intracerebral hemorrhage patient undergone surgery by multidisciplinary team neurosurgical department Udornthani Hospital*. (Unpublished master’s thesis). Khon Kaen University, Thailand.

Qiu, I., & Li, S. (2008). Stroke: Coping strategies and depression among Chinese caregivers of survivors during hospitalization. *Journal of Clinical Nursing, 17*(12), 1563-1573. doi: 10.1111/j.1365-2702.2007.02156

Richter, K., & Podhisita, C. (1992). Thai family demography: a review and research prospects. *Warasan Prachakon Lae Sangkhom, 3*(1-2), 1-19.

Rittman, M., Boylstein, C., Hinojosa, R., Hinojosa, M. S., & Haun, J. (2007). Transition experiences of stroke survivors following discharge home. *Topics in Stroke Rehabilitation*, *14*(2), 21-31.

Robson, J. P., & Troutman-Jordan, M. (2014). A concept analysis of cognitive reframing. *Journal of Theory Construction & Testing*, *18*(2): 55-59.

Rosenberg, E., Jullamate, P., & Azeredo, Z. (2009). Informal caregiving: cross-cultural applicability of the person-environment model. *Health Sociology Review, 18*(4), 399-411.

Ross, C. E., & Mirowsky, J. (1992). Households, employment, and the sense of control. *Social Psychology Quarterly*, 217-235.

Schofield, I., Tolson, D., Arthur, D., Davies, S., & Nolan, M. (2005). An exploration of the caring attributes and perceptions of work place change among gerontological nursing staff in England, Scotland and China (Hong Kong). *International Journal of Nursing Studies*, *42*(2), 197-209.

Schumacher, K. L. (1995). Family caregiver role acquisition: Role-making through situated interaction. *Scholarly Inquiry for Nursing Practice, 9*(3), 211-226.

Schumacher, K. L., & Meleis, A. I. (1994). Transitions: a central concept in nursing. In A. L. Melies (Ed). *Transition theory: middle-range and situation-specific theories in nursing research and practice* (pp. 38-51). New York: Springer.

Schumacher, K. L., Jones, P.S., & Meleis, A. I. (1999). Helping elderly persons in transition: a framework for research and practice. In E. A. Swanson, & T. Tripp-Reimer (Eds.). *Life transitions in the older adult: issues for nurses and other health professionals* (pp.1–26). New York: Springer.

Schure, L. M., van den Heuvel, E. T. P., Stewart, R. E., Sanderman, R., de Witte, L. P., & Meyboom-de Jong, B. (2006). Beyond stroke: description and evaluation of an effective intervention to support family caregivers of stroke patients. *Patient Education and Counseling, 62*(1), 46-55. doi: 10.1016/j.pec.2005.05.015

Shaughnessy, M., Michael, K., Stein, J., Zorowitz, R., Harvey, R., Macko, R., & Winstein, C. (2009). Stroke in older adults. *Stroke Recovery & Rehabilitation* (pp. 653-663). New York, NY: Demos Medical Publishing.

Shyu. Y. I. (2000). The needs of family caregivers of frail elders during the transition from hospital to home: a Taiwanese sample. *Journal of Advanced Nursing, 32*(3), 619-625.

Silprakhom, P. (2003). *Study of knowledge, practice, problems, and barriers in discharge planning of professional nurses in Nopparatrajathanee Hospital*. (Unpublished master’s thesis). Mahidol University, Thailand.

Silva-Smith. A. L. (2007). Restructuring life: preparing for and beginning a new caregiving role. *Journal of Family Nursing, 13*(1), 99-116.

Silverstein, M., Gans, D., & Yang, F. M. (2006). Intergenerational support to aging parents the role of norms and needs. *Journal of Family Issues, 27*(8), 1068-1084.

Sit, J. W. H., Wong, T. K. S., Clinton, M., Li, L. S. W., & Fong, Y. (2004). Stroke care in the home: the impact of social support on the general health of family caregivers. *Journal of Clinical Nursing, 13*(7), 816-824.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8*(3), *27-37.*

Smith, L. N., Lawrence, M., Kerr, S. M., Langhorne, P., & Lees, K. R. (2004). Informal carers' experience of caring for stroke survivors. *Journal of Advanced Nursing, 46*(3), 235-244.

Smith, S. D., Gignac, M. A., Richardson, D., & Cameron, J. I. (2008). Differences in the experiences and support needs of family caregivers to stroke survivors: does age matter? *Topics in Stroke Rehabilitation, 15*(6), 593-601. doi:10.1310/tsr1506-593

Strauss, A. & Corbin, J. (1990). *Basic of qualitative research: techniques and procedures for developing grounded theory* (1st ed.). Newbury Park: SAGE Publications.

Strauss, A. & Corbin, J. (1998). *Basic of qualitative research: techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks: SAGE Publications.

Steptoe, A., Lundwall, K., & Cropley, M. (2000). Gender, family structure and cardiovascular activity during the working day and evening. *Social Science & Medicine, 50*(4), 531-539.

Streubert Speziale. H. J., & Carpenter, R. D. (2007). *Quaitative research in nursing: advancing the humanistic imperative* (4th ed.). Philadelphia: Lippincott Williams & Wilkins.

Stuifbergen, M. C., & Van Delden, J. J. (2011). Filial obligations to elderly parents: a duty to care? *Medicine, Health Care and Philosophy, 14*(1), 63-71.

Subgranon, R., & Lund, D. A. (2000). Maintaining caregiving at home: a culturally sensitive grounded theory of providing care in Thailand. *Journal of Transcultural Nursing, 11*(3), 166-173.

Thailand Nursing and Midwifery Council. (2005). *Standard of nursing and midwifery service in secondary and tertiary level*. Nontaburi, Thailand.

Theerawanviwat, D. (2014). Intergenerational transfers and family structure: evidence from Thailand. *Ageing International, 39*(4), 327-347.

Thomas, M., & Greenop, K. (2008). Caregiver experiences and perceptions of stroke. *Health SA Gesondheid, 13*(1), 29-40.

Thompson, H. S. (2008). A review of the psychosocial consequences of stroke and their impact on spousal relationships. *British Journal of Neuroscience Nursing, 4*(4), 177-184.

Thompson, H. S., & Ryan, A. (2009). The impact of stroke consequences on spousal relationships from the perspective of the person with stroke. *Journal of Clinical Nursing, 18*(12), 1803-1811. doi: 10.1111/j.1365-2702.2008.02694.x

UNESCO (1992). *The Changing Family in Asia.* RUSHSAP Series on monographs and occasional papers 35, principal regional office for Asia and the Pacific, Bangkok

United Nations Population Fund (UNFPA). (2011). *Impact of demographic change in Thailand*. Bangkok, UNFPA.

Ward, M. M. (2013). Sense of control and self-reported health in a population-based sample of older Americans: assessment of potential confounding by affect, personality, and social support. *International Journal of Behavioral Medicine, 20*(1), 140-147.

White, C. L., Barrientos, R., & Dunn, K. (2014). Dimensions of uncertainty after stroke: perspectives of the stroke survivor and family caregiver. *Journal of Neuroscince Nursing*, *46*(4), 233-240. doi:10.1097/JNN.0000000000000066

Wu, C. (2009). *Learning to be a family caregiver for severely debilitated stroke survivors during the first year in Taiwan* (Doctoral dissertation, University of Iowa). Retrived from http://ir.uiowa.edu/etd/451.

Yeung, S., Lui, M. H. L., Ross, F., & Murrells, T. (2007). Family carers in stroke care: examining the relationship between problem-solving, depression and general health. *Journal of Clinical Nursing*, *16*(2), 344-352.

Zwygart-Stauffacher, M., Lindquist, R., & Savik, K. (2000). Development of health care delivery systems that are sensitive to the needs of stroke survivors and their caregivers. *Nursing Administration Quarterly*, *24*(3), 33-42.

APPENDICES

Appendix A

Demographic form

รหัสผู้ให้ข้อมูล...

วันที่..

ชื่อ...

อายุ....................................... ปี เพศ..................................ศาสนา ....

ระดับการศึกษา...

สถานภาพในครอบครัว(บุตร/สามี/ภรรยา)..

จำนวนสมาชิกในครอบครัว.......................................คน

อาชีพก่อนเป็นผู้ดูแล..อาชีพปัจจุบัน..................................

รายได้ต่อเดือน..บาท

สถานภาพการเงิน ☐ เหลือเก็บ ☐ พอใช้ ☐ ไม่พอใช้

ความพิการและความสามารถในการทำกิจวัตรประจำวันของผู้ป่วย

....

....

....

....

....

Appendix A

Demographic form

Informant code…………………………………………………………………………..

Date of participant recruitment………………………………………………………..

Name…………………………………………………………………………………….

Age…………………………Gender……………………..Religion…………………….

Education level………………………………………………………………………….

Occupation

- Before take a role of caregiver……………………………………………………….
- After take a role of caregiver…………………………………………………………

Income……………………bath

Economic status:

☐ have saving money

☐ enough for daily spending

☐ not enough for daily spending

Stroke survivors' functional ability:

……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………

Appendix B

Interview guide (Thai version)

แนวคำถามสำหรับการสัมภาษณ์

1. กรุณาเล่าให้ดิฉันฟังหน่อยได้มั้ยคะ มีอะไรเกิดขึ้นกับคุณและครอบครัวบ้างตั้งแต่คุณ.....ป่วยเป็นโรคหลอดเลือดสมอง?
    - 1.1. คุณรู้สึกและคิดอย่างไรอย่างไรเมื่อแรกทราบว่าคุณ........ป่วยเป็นโรคหลอดเลือดสมองและต้องนอนโรงพยาบาล?
    - 1.2. คุณรู้สึกและคิดอย่างไรอย่างไรเมื่อทราบว่าหมอให้คุณ........ออกจากโรงพยาบาล?
    - 1.3. มีอะไรเกี่ยวกับผู้ป่วยและตัวคุณเองที่ได้เปลี่ยนไปจากเดิมบ้างตั้งแต่คุณ........ออกจากโรงพยาบาล? เปรียบเทียบสิ่งเคยทำ เคยเป็นกับสิ่งที่เป็นอยู่ในปัจจุบัน
2. กรุณาเล่าให้ดิฉันฟังหน่อยได้มั้ยคะว่าการทำหน้าที่เป็นผู้ดูแลของคุณเป็นอย่างไรบ้าง?
    - 2.1 คุณทำอะไรบ้างในการดูแลคุณ.......?
    - 2.2 ตั้งแต่คุณ....อยู่โรงพยาบาลจนกระทั่งกลับมาอยู่คุณประสบความอยากลำบากในการให้ดูแลอะไรบ้างหรือไม่? ความยุ่งยากนั้นคืออะไร?
    - 2.3 อะไรที่เป็นปัญหายุ่งยากมากที่สุด? เกิดขึ้นอย่างไร?
    - 2.4 กรุณาเล่ารายละเอียดเพิ่มเติมเกี่ยวกับเรื่องนี้ให้ดิฉันฟังหน่อยนะคะ?
3. คุณเอาชนะปัญหา/ความยุ่งยากในการดูแลคุณ.........เมื่ออยู่โรงพยาบาลและเมื่อเขา/เธอกลับมาอยู่บ้านได้อย่างไร?
    - 3.1. เวลาคุณประสบกับปัญหา/ความยุ่งยาก คุณทำอย่างไรในการจัดการกับปัญหา/ความยุ่งยากที่เกิดขึ้น? สามารถจัดการได้หรือไม่ได้?
    - 3.2. อะไรที่คุณคาดหวังว่าจะทำแต่คุณไม่สามารถทำได้? เพราะอะไร?
    - 3.3. กรุณาเล่าระเอียดเพิ่มเติมเกี่ยวกับเรื่องนี้นิดหนึ่งนะคะ?
4. อะไรบ้างที่ช่วยคุณในการเอาชนะปัญหา ความยุ่งยากที่เกิดขึ้น? (บุคคล กลุ่มบุคคล แหล่งประโยชน์ อื่น ๆ) สิ่งเหล่านี้ช่วยเหลือคุณอย่างไร?
5. อะไรบ้างที่เป็นอุปสรรคต่อคุณในการเอาชนะความยุ่งยากที่เกิดขึ้น? สิ่งเหล่านี้เป็นอุปสรรคต่อการจัดการกับความยุ่งยากอย่างไร?
6. คุณมีประสบการณ์อย่างอื่นที่เกี่ยวกับการให้ดูแลคุณ...ที่อยากจะเล่าให้ดิฉันฟังเพิ่มเติมอีกไหมคะ?

Appendix B

Interview guide

These interview guides are designed to probe overcoming difficulties during transition from hospital to home of nuclear family caring for older adult stroke survivors.

1. Tell me what have happen to you and your family since…….had stroke?
   - 1.1 How did you feel and think when you were first told that…….had stroke and had to admit in hospital?
   - 1.2 How did you feel or think when you were told that …….will be discharged to home?
   - 1.3 What has been changed of the patient's situation or yourself since …….discharge? Compare and contrast things to do/done? (feeling, thought, emotion, activities, relationship with others etc.)
2. Could you tell me about your caring roles?
   - 2.1 What did you do to caring for …….?
   - 2.2 Did you experience any difficulties in taking care for …….since he/she was admitted to return home? What were those?
   - 2.3 What is the most difficult task for you? Why?
   - 2.4 Please tell me in detail about this?
3. How did you overcome these problems/difficulties in taking care for…….when he/she was hospitalized, and when he/she was at home?
   - 3.1 When difficulties happen, what did you manage?
     Can or cannot? Why?
   - 3.2 What did you expect to do but you cannot do? Why?
   - 3.3 Please tell me more about this?
4. What are the things (person or group of persons, resource, etc.) that help you to overcome those difficulties? How do they help?

5. What are obstacles to you in overcoming those difficulties? How do they hinder the management of those difficulties?
6. Is there anything about your experience of providing care for…….that you would like to share more?

Appendix C

Observation record form

Informants code……………………………………………………………………..

Interview Date…………………Starting time………………Ending time……………

Pre-interview goal for interview……………………………………………………

Observed	Objective	Description/Field note
- Location & environment		
-people present		
-Non-verbal behavior (i.e. tone of voice, posture, facial expression, eye movement)		
-activities/action/ interaction		
-Researcher impression		

Appendix D (Thai version)

ใบยินยอมเข้าร่วมการวิจัย

เรื่อง “กระบวนการเอาชนะความยากลำบากของผู้ดูแลในครอบครัวเดี่ยวในการดูแลผู้สูงอายุโรคหลอดเลือดสมองในช่วงเปลี่ยนผ่านจากโรงพยาบาลสู่บ้าน”

คำชี้แจงและการพิทักษ์สิทธิ์ของผู้เข้าร่วมวิจัย

ดิฉัน นางสาวกฤตพร สิริสม เป็นนักศึกษาปริญญาเอก คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์ และกำลังทำวิทยานิพนธ์เพื่อศึกษากระบวนการเอาชนะปัญหาและความยุ่งยากลำบากของครอบครัวเดี่ยวในการดูแลผู้สูงอายุที่เป็นโรคหลอดเลือดสมองในช่วงเปลี่ยนผ่านจากโรงพยาบาลสู่บ้าน ซึ่งมีวัตถุประสงค์เพื่ออธิบายว่าครอบครัวเดี่ยวที่ให้การดูแลผู้สูงอายุที่เป็นโรคหลอดเลือดสมองมีกระบวนการเอาชนะความยากลำบากในช่วงเปลี่ยนผ่านของการดูแลจากโรงพยาบาลและเมื่อมาอยู่บ้านอย่างไร

ท่านเป็นผู้หนึ่งที่มีความสำคัญในการศึกษาครั้งนี้ ในฐานะที่คุณเป็นผู้มีประสบการณ์การดูแลผู้สูงอายุที่เป็นโรคหลอดเลือดสมอง ดิฉันเชื่อว่าคุณสามารถจะให้ข้อมูลที่มีคุณประยชน์ในการวิจัยครั้งนี้ ดิฉันจึงขอเชิญคุณเข้าร่วมวิจัยครั้งนี้ ซึ่งจะเก็บข้อมูลโดยการสัมภาษณ์ 2 ครั้ง แต่ละครั้งจะใช้เวลาประมาณ 1 ชั่วโมง ซึ่งดิฉันจะขออนุญาตมาสัมภาษณ์ที่บ้านของคุณ ในการสัมภาษณ์ดิฉันจะถามคำถามเกี่ยวกับความคิดความรู้สึกของคุณเกี่ยวกับการดูแลผู้สูงอายุที่เป็นโรคหลอดเลือดสมอง ปัญหา และการเอาชนะปัญหาที่ท่านประสบในช่วงเวลาตั้งแต่ผู้ป่วยอยู่โรงพยาบาลจนกระทั่งกลับมาอยู่ที่บ้าน ระหว่างการสัมภาษณ์คุณสามารถปฏิเสธการตอบคำถามใด ๆ ที่คุณไม่ต้องการตอบ และสามารถขอหยุดการสัมภาษณ์เมื่อคุณต้องการ การสัมภาษณ์จะดำเนินต่อไปเมื่อคุณต้องการ การสัมภาษณ์ครั้งที่สองหรือครั้งต่อไป ดิฉันจะสรุปข้อมูลและการแปลความหมายข้อมูลจากการพูดคุยครั้งก่อนให้คุณฟัง หากคุณไม่เห็นด้วยกับข้อมูลหรือการแปลความหมายข้อมูลนั้น คุณสามารถแก้ไขข้อมูลให้ถูกต้องและให้ข้อมูลแก่ดิฉันเพิ่มเติม ดิฉันอาจจะขอสอบถามคุณเพิ่มเติมในประเด็นคำถามที่ยังไม่ได้พูดคุยกัน หรือเพื่อเพิ่มความเข้าใจหรือความชัดเจนของข้อมูลที่พูดคุยกันครั้งก่อน และเพื่อความสมบูรณ์ของข้อมูลที่ท่านให้มา ดิฉันขออนุญาตใช้เครื่องบันทึกเสียงเพื่อบันทึกการพูดคุยสัมภาษณ์ ข้อมูลทั้งหมดที่ได้จากการสัมภาษณ์จะถือเป็นความลับ ไม่มีการเปิดเผยชื่อจริงของคุณในข้อมูล และข้อมูลจะถูกใช้ประโยชน์เพื่อการศึกษาและวิชาการเท่านั้น ในระหว่างการสัมภาษณ์

การเข้าร่วมวิจัยครั้งนี้เป็นไปโดยสมัครใจของคุณ คุณสามารถตัดสินเข้าร่วมหรือไม่เข้าร่วมก้อได้โดยไม่มีผลกระทบใด ๆ ต่อการรับบริการสุขภาพที่คุณได้รับ และถ้าคุณเห็นด้วยที่จะเข้าร่วมในการวิจัย คุณมีสิทธิ์ที่จะถอนตัวจากการวิจัยเมื่อไหร่ก้อได้ที่คุณต้องการโดยไม่มีผลกระทบใดต่อการรับบริการสุขภาพที่คุณได้รับเช่นกัน ในระหว่างการเข้าร่วมวิจัย หากมีข้อสงสัยประการใดเกี่ยวกับการวิจัยหรือการเข้าร่วมการวิจัย ดิฉันยินดีที่จะตอบข้อสงสัยของคุณตลอดเวลา โดยติดต่อได้ที่ 086-695-0297

Appendix D

Consent Form

Title: Process of overcoming difficulties of nuclear family's caregivers in caring for older adult stroke survivors during transition from hospital to home

Dear Participant

My name is Krittaporn Sirisom. I am a student in Doctor in Nursing Pragramme, Faculty of Nursing, Prince of Songkla University. I am conducting a research project entitled "Processes of overcoming difficulties during transition from hospital to home of nuclear family in caring for older adult stroke survivors". The purpose of this study is to explain how nuclear family overcoming difficulties in caring for older adult stroke survivors during transition from hospital to home.

The finding from this study will be used to guide and design nursing intervention to felicitate nuclear family to overcome difficulties in transition. Since you have experienced as caregiver proving care for older adult stroke survivors, I would like to invite you to participate in the study which collect data by interview. The interview will spend time around 1 hour at least two times. All data will be analyzed by keeping confidential and used only in academic reports without any personal identification. This is a voluntary; you can decide to participate or may not participate without any affect to care service that you receive. Also, if you agree to participate in the study, you are free to stop any interview and to withdraw from the study at any time without any affect to your care. If you have any question about the study or your participation in it, I greatly appreciate to give the answer to you. Would you agree to take a part in this study? If yes, please sign your name below this. Your signature on this form will indicate that you understand and are willing to participate in this study.

Name ……………………………………….

Signature ……………………………………….

Date ……………………………………….

Memo sheet

Direct quote (extract)	Key elements	Subcategories	Category	Interpretation (essence/theme)

Family Descriptions

Family 01: Gha and Sa

Background Information

Gha and Sa are a Thai Muslim family comprised of only two members: Sa a 92 year-old husband who is a stroke survivor, and Gha is a 60 year-old housewife who became a caregiver. Gha changed her religion from Budhhist to Muslim after she married Sa who had separated from first Muslim wife several years ago. They have no children. They live in the Songkhla metropolitan area, in a small row house which used to belong to Sa’s younger brother who has passed away. Sa used to work as a railway officer and he got early retirement with one reward; he never saved any money.

Characteristics of the stroke survivor

Prior to having a stroke he was healthy, he could go cycling to buy something to eat and could help his wife in selling Thai vermicelli (*khanom jean*). Last year, he had a hemorrhagic stroke while taking a nap in the late morning. He was unconscious after craniotomy operation and was discharged. He was discharged with a tracheostomy tube and nasopharyngeal feeding tube. Gha (the caregiver), said that at the early stage at home her husband still unconscious. However, became better after four months post-discharge.

The Caregiver

She experienced a lot of difficulty during the first three to four months after discharge and said that that was very stressful.

Family 02: Bow and Leang

Background Information

Family 02 is a Thai Buddhist family, namely, a 73 year-old husband and 73 year-old wife. They live in a housed owned by the primary caregiver, in the urban area of Songhkla. They have seven adult children, however, none of them live with their parents. The two sons are married and live with their family in another province. One daughter is married and lives with her family close to her parents’ house. Two daughters and one son are single and work and live in Phuket province. The other daughter is single and lives in her own house in the Songkhla metropolitan area. The living expense of the couple is supported mainly by their fourth child, Bow.

Characteristics of the stroke survivor

Kiang, the father, suffered a stroke while going to the restroom. He was diagnosed with a hemorrhagic stroke after he got a sudden headache and felt weak. He was semi-consciousness after his craniotomy operation and needed total assistance in ADL. He sleeps most of the day, but responds to pain and loud voices. He has a tracheostomy tube and nasogastric tube for feeding. He has a slight edema on his feet and arms, and an abrasion wound of 3 cm in diameter on his right leg. He also has a frequent cough with moderate secretion and requires suction and oxygen support.

The Caregiver

Bow, the 43 year old, unmarried daughter, takes responsibility as the primary caregiver and has done so for five months (the key informant). She is college-educated and has a vocational certificate. She used to work in the hospitality industry in Phuket province and also had her own evening restaurant. She sold the restaurant to her friend and resigned from work after her father's stroke. She said that taking care of her father is a first priority for her. In the beginning, early after discharge, her older sister took this role. However, because she is a nervous person and could not elaborate upon the details of her father symptoms over the phone, she thought that her sister was in-appropriate for this role. She decided to stop working and adopt the role of caregiver for her father. She takes all the responsibilities in caregiving: suction, feeding, bathing, position changing, and the housework. However, she needs help from her nephew when she changes the bed sheet in every morning because her mom cannot help her due to back pain.

Setting

The house is a one story, concrete house with a small free space around the house. It also has a space used as a living area in front of the house. There is a big wooden bed placed in this area. The stroke survivor's bed is a Fowler's bed placed in the living room, close to the front door. There is an oxygen tank with a collar mask placed in the left corner, and a suction machine placed on the right side of the stroke survivors' bed. The Buddha statue is placed on the shelf above the bed. It also has a table to place supplies, such as gloves, suction tubes, cotton, normal saline, alcohol, disinfectant, and blue pads.

Family 03: Da and Wa

Background Information

Family 03 is Thai Muslim family composed of a 79 year-old husband and a 72 year-old wife. Currently, the couple live in their own home located in one of the Muslim communities in a metropolitan area. They have six adult children: two sons and four daughters. All of them are married and live with their own families. Four of those live in the district of Songkhla. One daughter lives next door to her parents, and the other daughter is in Yala province. However, all of them share responsibility in taking care of their father and helping their mother.

Characteristics of the stroke survivor

Wa, a stroke survivor, had a sudden stroke attack during his sleep. He was diagnosed with ischemic stroke and admitted to the hospital for eight days. During hospitalization, he had a lot of sputum. In order to solve this problem, the doctor planned to do a tracheostomy intubation, but Da (the stroke survivor's wife) did not comply with the doctor. She believes that if people die, they should go in their complete body. Because the health staff did not recommend preparing a suction machine at home, at early after discharge, when Wa had sputum Da was unable to deal with the problem. As a result, Da told her children to bring their father back to the hospital. Wa was re-admitted in the hospital for three days. During this admission, Da and her daughter were taught to do suction. At the early of second discharge, Wa still had lots of sputum and required frequent suction. This made Da had less sleep and felt tired.

Currently, he is semi-consciousness with left hemiplegia, and has cataracts in both eyes. He also has a nasogastric tube for feeding and plastic bag as a container for urine due to his incontinence. The bag continuously drains the urine by connecting the bag with the tip of a small rubber tube ending in a small bucket placed below the patient's bed. The stroke survivor usually cries out without meaning and always places his right leg in a flexed position. Da said that she is old and has back pain, she cannot always care for this issue. However, she knows that there is the risk of stiffness of the knee joint. To prevent such a problem, she uses a piece of cloth to tie his leg to be extended along the side of the bed.

The Caregiver

Da, a primary caregiver, is housewife who has her own health problems like back pain. She looks after her husband, and comforts by position changing, urine checking, suction, fanning and cleaning when the survivor has sweats. She said that she takes responsibility of the caregiver because all her children have to work for their own family, they unavailable to take care of their father all day and all night. But she has free time, because she is not working now. However, all of her children share the responsibility in taking care of their father and helping their mom. Every morning, the second son takes responsibility for bed bathing and changing the bed sheets, and the third son takes the evening shift. The fourth daughter who lives next door stops her work to help her mom. She prepares the blended diet and feeds her father, washes her parents' cloths, and cleans her parents' house. However, she gets 7,000 baht per month payment for those jobs from her younger sister (the fifth daughter) who has a business and cannot help in any caring activity. Every Sunday, the oldest son carries his father to take a bath in the bathroom. The youngest daughter, who lives in Yala province, is the person providing financial care for her father.

Setting

The house is a one story, concrete house with a fence and a medium free space in front of the house. The stroke survivor's unit is set in one corner of the living room, located in front of the rest room. The unit is separated from the dining area and caregiver's bedroom by a plastic partition. The bed is a Fowler's bed placed close to the front window. There is a suction machine placed on the right side of the patient's bed. It also has a cabinet to place care supplies.

Family 04: Pan, Pen, and Prang

Background Information

Family 04 is a Thai Buddhist family whose members are the stroke survivor, who is a mother aged 84, and their oldest daughter who is 59 and widowed. They live in their own home in Sinhanakorn district. The mother, Prang, has five adult children:

included three daughters and two sons. The first three children (two daughters and 1one son) are married. The son lives with his family elsewhere, the second daughter lives nearby her mother’s house. The last two children are single. The youngest daughter works in Bangkok and one son, who is the fourth born, is a policeman and lives in different *Tumbon*, but in the same district.

Characteristics of the stroke survivor

Prang had a minor stroke, consequently she has a drooping mouth, a slur, choking, and a weakness on her left side. She was hospitalized for three days and treated with thrombolytic drug injections. The caregiver stated that her mom has well and progressed after receiving the injection. The stroke survivor now looks healthy, has no signs and symptoms of stroke, and can partake in daily living by herself under her daughter’s close observation. Sometimes she likes to walk outside the house to plant vegetables.

The Caregivers

Pan, the oldest daughter who lives with her mother is the primary caregiver. The secondary caregiver is the second daughter, Pen. Both of them finished primary school. During hospitalization, Pen takes the main responsibility in caring for her mom because Pan cannot leave her house. One month after discharge, when their mom still had slight weakness and needed some assistance to prevent a fall, they took shifts to take care of her. When Pan needs to work in the farm, she asks Pen to be in her home. Pen also takes responsibility in accompanying her mom to see the doctor for follow-ups. However, she is helped by her youngest brother who has a car to transport them to the hospital.

Setting

The family home is located in a rural area about 30 kilometers out of the city and 30 minutes away from the provincial hospital. It is a large, two story house: the first floor is concrete and the second floor is wood. The living room, kitchen and bath room are found on the first floor. The second floor is a bedroom. There is a big field with some fruit trees around the house and also a small backyard garden. In the day time, the stroke survivor stays on the bottom floor, but she still steps up to sleep on second floor, as per usual, at night. There is no medical equipment in the house.

Family 05: Dum, Sorn, and Dang

Background Information

Family 05 is a Thai Buddhist family comprised of a 74 year-old husband, and an 81 year-old wife and a 9 year-old grandchild. They live in their own house located in a rural village where there are kinsfolk in the same area. They have five adult children. Four of them are married and live with their own family elsewhere. The youngest daughter is divorced who leaves her 9 year-old son with her parents in order to work in Songkhla town. She visits her parents and her children once or twice a month.

Characteristics of the stroke survivor

Sorn is 81 years old who has had right side hemiplegia for four months. Her husband, Dum, said that her stroke symptoms began with ataxia and then a fall.. After that she could not speak, he thought his wife was attacked by *lom amapreng*. He gave her some folk medicine and massage for three days, but his wife was not better and became worse (indicated by no movement). He decided to call his children to bring their mother to the hospital. She was hospitalized for four days and was discharged with nasogastric tube feeding. About two months after discharge, the stroke survivor pulled out the nasogastric tube by herself. Currently, she is conscious, but has difficulty in speaking. A drooping mouth can be observed, but she can eat without choking. She can move herself a little, but still needs assistance in all activities of daily living because her left side is weak.

The Caregiver

The primary caregiver is her husband, Dum, who became the housekeeper since his wife had her stroke. Because their children live elsewhere and the youngest daughter needs to earn money to support her parents, they hired one female who lives in the same village to be a caregiver. Two months after discharge, the stroke survivor got better (they also did not have enough money to pay for the caregiver). Dum decided stop his work (*KheunTan*= ขึ้นตาลโนด) and take responsibility for caregiving.

Setting

The family home is a rural Thai style house. It is wood, one story with a ground space under the house. There are three rooms, a bed room, a kitchen, and an open space used as a living room. It also has porch with open space extended from the front side of house floor. The porch floor is about 40 centimeters below the house floor and is approximately two meters wide and four meters broad. This area is used as a living place for the stroke survivor. There are some personal belongings, including a cloth, bedding, bathing set, electric fan and television which are set on one side of this area. It also has a washing machine placed in one corner of the porch, and the bathing area is set near the machine and sleeping area. During the day, all family members use this area as resting place, but it is set up to be the sleeping area (picnic mattress, blanket, and mosquito net) for the stroke survivor at night.

Family 006: Ya, Yod, Young, and Lai

Background Information

This is a Thai Buddhist family composed of 82 years old mother, 63 years old sons, and 60 years daughter in law. Lai, the stroke survivor, was widowed and had ten adult children, seven sons and three daughters. Most of them were married, except the youngest son who works in Ranong province. Her children do the real estate (room for rent) as a family business (*Kong Zi*) in Songkhla city. Prior the stroke Lai lived with her ninth son in Ranod district where far from Songkhla city approximately 80 kilometers. Because her children concerned about their mother safety, they decided to move Lai to her oldest son's house which located nearby the provincial hospital. So, it is convenient to travel to the hospital if has any emergency situation with their mother. The family did not hire paid caregivers even though they could afford for this because they did not trust paid caregivers, and they thought that this is the good opportunity for them to repay their mother

The stroke survivor

Before the stroke, Lai had hypertension with regular control for several years. Lai was admitted in the provincial hospital for 2 months with hemorrhagic stroke. She was discharged with nasogatric feeding tube and tracheostomy with oxygen supply. After stroke she could not move her right side, while the life side could moderately movement. Three months after discharge, Lai needed oxygen support because she has a lot of phlegm. At the early month after discharge, she also had emotional problem. She usually cried and did not sleep that made her children stress and exhausted due to having less sleep. This condition was lasted when home health care nurse visited (about two months). She advic the family to take Lai to see a Psychiatrist. After, she received the prescription from the Psychiatrist. Her conditions is better, she could sleep and could breathing in the room air. But she still needs feeding via nasogatric tube and still on tracheostomy tube. Her children move her to the wheelchair and take her to the outside every morning before provide a morning bed bath.

The Caregivers

The first half of month early after discharge, all of Lai's children were gather together at Yai's house in order to take care of their mother. After that they made assignment as a shift. Each shift comprised of two persons and take time for 5 days. However, Ya (children 6) take the responsible as a primary caregiver because has experienced in caring for his mother in-law who had a similar condition with his mother. Ya is 51 years old, married, and had no children. He and his wife lived in their own house but the same village with his older brother. Ya come to look after his mother everyday even though it is not his shift because he did not trust his siblings to do dressing tracheotomy wound for his mother.

Setting

The family houses were two buildings with two floor town-house styles located in Songkhla City nearby the provincial hospital. One building as a living place of Yai and his wife, another one was used as a living place for Lai and caregivers. Lai stayed in the living room, on the first floor. There was a hospital bed with air mattress next to a front door. A suction machine and some caring stuff were organized and set on right sides of the bed. Next to Lai's bed, there was wooden bed for caregiver. A TV set was on the opposite side, so she could watch TV from her bed. The room environment was clean.

Family 007: Jaa, Cha, Juan and Juang

Background Information

Juan, 70 years old, has three children, two sons and one daughter. All is married. And they live one kilometer away from each other in the same village, except the oldest son who live in Phatthalung. Juan lives with her new husband, Juang. Her ex-husband passed away for many years. Jaa, her daughter in law, informed that Juan has had gallstones in renal pelvis, and hypertension. She used to have thyroid disease. She had some symptoms of stroke around at 3 am. It was too early so the husband of her did not want to disturb the children. He waited until 5 am. He went to his children's house, Cha and Jaa, to tell them about Juan's symptoms. But they already went out to sell things at a market. They came back home around at 1 pm.,and knew that their mother was sick. They found that she was very weak, and severe. So they were in hurry to take her to a provincial hospital. But they could not access the treatment easily when they arrived the hospital, because they did not have a referral document from a district hospital. So they decided to pay for the treatment.

The stroke survivor

The patient is alert, responsive to verbal stimuli, but she cannot speak, and move her right arm and leg. However, she is able to move her left side. She sleeps almost all the time. She cries when she has an abdominal pain from kidney stone. She has liquid diet via NG feeding 4 meals a day, and no nausea or vomiting. She has grade 1 bed sore (dark red skin and abrasion) size 4x6 cms. at a sacrum area. However her body is clean and no bad odor.

The caregivers

Jaa, the patient's daughter in law, serves as the primary caregiver. Cha, the patient's son, does not dare to provide feeding and NG tube care for his mother. But he can help Jaa to bathing, shampooing, and changing clothes for her. Jaa and Cha have been married for many years but they have had no children. Before the sick of Juan, his mother, Cha and Jaa live in a house, which is about one kilometer away from Juan's house. After the sick of his mother and need of care, he has built a row houses next to his mother's house. Cha and Jaa have a pick-up car that mainly used for selling some vegetables at markets. They need to adapt their job to take care of the mother. Juang takes care of Juan when Cha and Jaa go to work. But he cannot take care the patient much. He can sometimes only wipe the patient's face and eyes.

Setting

The patient's house locates in a rural area. It is an one-story concrete house. The bedroom is on the back. There is a space at corner used as a kitchen. The front room is an open space which used to be the residence of the patient. There is a low wooden couch and a picnic mattress used for the patient. Banana leaf is used as a bed sheet. Caregiver believes that it can cool down the patient's skin on the back. And it can prevent some bed sore. From the observation, the bed was not suitable for Jaa and Cha performing care activities. She had difficulty in changing her mother's position and difficulty to prepare patient's position for feeding. It also has a risk of bed falling. They once considered buying one hospital bed, but they could not afford for this. Then, Cha asked his friend who is a welder to build the patient bed for his mother, but it is not finished. There also is a small shelf near the patient's bed for placing her personal stuff such as instant milk powder, gloves, and medicine. A front door of the patient's room is a hinged door that can be opened to a space in front of the house. This area has a plumbing pipe and a sink that used for cleaning and washing stuff, bathing, and shampooing the patient.

Family 008: Fern, Toy, and Doung

Background Information

Doung, 73 years woman lives with her husband who is 74 years old. The couple has seven married children who live with their own families elsewhere. Two daughters, the youngest and the younger, live nearby the parents' house. The others live far away but in Songkhla province. During Doung was admitted in hospital, her children took turns taking care of her. After she was discharge they decided to hire their niece, Fern, to be a primary caregiver of their mother because they have to earn money for their own family. The reasons that they did not hire outsider caregiver were they could not afford for as well as trust to that kind of caregiver. All her children shared responsibility on taking care of their mother by sharing the money for caring expenditure. They also took turns on the caregiving duty on the weekend to allow Fern to have a short break from caregiving role. The oldest son who could not do this duty would pay additional money to Fern. Her two daughters, who live nearby, came to visit their mother everyday. Toy, the youngest daughter, would accompany with Fern to take her mother to see doctor on appointment schedule or when she has a problem. Because Fern could give caregiving information to health staff but could not make decision about her grandmother treatments.

The stroke survivor

Doung had hypertension and heart disease with regular control for more than 10 years. On April 2014, she got fainting during she help her sister in law’s dead ceremony. She was sent to the community hospital where she was remarked with stroke. Then she was referred to provincial hospital where she was admitted for one night. At that time her children was informed by the physician that her brain vessel was swollen. Approximately one month after that she fall down due to right side weakness during walking in the house. She was sent to the provincial hospital where she was diagnosed with hemorrhagic stroke. She was intubation and admitted into the semi-intensive care unit for one week and then was moved to the medical ward. After hospitalization in provincial hospital for 17 days, she was referred to the community hospital nearby her home despite discharged to home. Due to lacking of care equipment at home she was admitted in community hospital for 3 days. After all needed care equipments were prepared, she was discharged with a nasal gastric tube, tracheotomy, and Foley catheter placements. Currently, she was consciousness, had right side paralysis, and equipped with the same devices as she was discharge. Cachexia is presented. She received oxygen support 2-3 L/min via mask at the night time and when she had difficulty or rapid breathing. She could use her left hand to catch the bed rail to turn her body to the right side.

The caregivers

Fern, the primary caregiver, was 21 years old, married but did not have a child. She was Doung’s granddaughter. She has been with her grandmother when she was a child until she finished her secondary school (Grade 5). She was a housewife before caring for her grandmother. She took on this role because she was unemployed, has strong affection with her grandmother, paying back for grandmother’s rearing her, and helping the family. However, she got allowance of 7,000 baht per month for her caregiving role. After deciding to take on the role, she and her husband moved to live with her grandmother. She was replaced on her duty by the Doung’s children on Saturday and Sunday. Fern learned care skills, including bathing, changing diapers, NG feeding, wound care, sputum suction and range of motions when her grandmother was in the provincial hospital. But she did not confident in her practice while her grandmother was discharge from this hospital. She became confidence in doing those care skills when she has more time to practice in the community hospital. She also trains her aunt and uncle to do those care skills at home.

Setting

The family house is Thai rural house comprised of two buildings: the small building at the front; the big one was behind the small building. Both of them are one floor building. The bed room, kitchen, and bath room are in the big building. The small building has been used as a storage room. The family adapted this room to be a living place for Doung her after she was discharge. There are the hospital bed for the stroke survivor and the big wooden for a caregiver placed in the room.

Family 009: Jai, Ji, Jom and Chum

Background Information

Jom, aged 81 years, lives with his 78-year-old wife who has amnesia and hearing loss. They have four daughters; all is married. The eldest daughter lives nearby, about 400 meters away. The second daughter (Ji) opens a beauty salon and lives in the city of Hat Yai. The third daughter lives in Satun. And the youngest daughter has moved to live with her husband in Satun after marriage. She was pregnant and back to her parents' home when giving birth of her child. So she goes back and forth between her parents and her husband's home. She has three children.

There is no one to take care of her parents. So Jai needs to come back and look after them. She lives in a row house built next to the home of her parents. Her children have moved to study in Hat Yai. But her husband still lives in Satun and does a shrimp farming. He comes to visit his wife and children once in a while. There are three adjoining rooms in the row house. She uses two rooms for living with her children. The other room is for rent. The monthly rent costs 2000 baht.

Jom had stroke around at 5 pm. while Jai was cooking in a kitchen at her home that is not very far from his house (about 20 paces). She heard a vomiting of her father. So she ran to see him and found that he was lying face down, sweating, and vomiting sticky saliva. Then she called her siblings who live nearby in order to take their father to a hospital. However, their mother asked us not to take him to the hospital since she believed that he was just pass out. If we take him to the hospital, a doctor will give him an injection that might cause him die. So we decided to take care of him at home by ourselves such as feeding him some balsam and soft drink. But he still complained of having headache. That night, Jai was with her mother until 10 pm. And then she was back home to be with her children. Her siblings went back to their homes. Until in the morning on the day after, Jai went to see her father and found that he was lying down with convulsion and crooked mouth. She called her siblings immediately to come and take their father to the hospital. The father was diagnosed with Stroke.

Chum cannot assist in the care of Jom even she has a strong body. Since she is not able to cook and prepare some meal. She also depends on Jai. She sometimes has amnesia, walk out to a main road, and forget to have a meal. So Jai needs to remind her about that. Sometimes Jai cooks some rice porridge and put it to her father. Chum throw it away because she thinks that it is spoiled rice. Hence Jai decides to cook some rice/prepare food at her own house, and then bring it to her parents at the meal time.

The stroke survivor

Jom has never had physical examination before his current illness. A caregiver told that before his illness, he did a backyard garden and could help himself for daily activities. He was admitted in the hospital for 5 days. Admission in the hospital let us know that he has a heart attack and dyspnea. After discharge from the hospital, he still had left hemiplegia. He could move his left arm and leg slightly. But he rarely moves. He refuses to do muscle exercise when the caregiving encourages him to do so which causes stiffness of his left shoulder and elbow. He is able to have oral feeding with soft diet. But he often chokes when drinking water. He has urinary incontinence. The caregiver put on a diaper but he often pulls it out. So he urinates on his cloth that causes a musty smell urine.

The caregivers

While uncle Jom was admitted to the hospital, Jai could not go to see him because she needed to take care of the mother with amnesia. So the other three siblings took care of their father alternately. However, after Jom was discharged from the hospital, Jai was the only one who had to take care of him. She told that at the beginning, her siblings came to visit the father every week. But later on they did not come often as before. She said that neighbors visited him more often than his children did, except her second older sister who brings some meal to the parents every

Wednesday. Besides a daily routine care of her father such as a bed bath and feeding, she also does an housework of two houses like cooking, laundry, house cleaning, and giving a ride to her children to school. Sometimes she needs to help her husband’s business. These make her father a late meal/not on time. He needs to wait for her return. Jai’s husband has suggested her to talk to her siblings about taking care of the father. But she thinks that it is useless to do that. Because she ever asked her sister’s child, who lives nearby her house to take the mother to see a doctor, but she was denied. She has thought that her siblings are selfish. They only concern about their lives. So she gives up to ask for any help from them.

Ji (a secondary caregiver), the second older sister, serves a duty of taking the father for a doctor's appointment since she has a car. She has opened a beauty salon in the city of Hat Yai. She delivers some meal to the father every Wednesday since it is a day that she closes her salon. It takes two hours for the visit and then she goes back. Ji has considered that the illness of her father is a common thing. Because he is getting old. She takes care of her father as much as she can such as cooking. Whereas Jai wants to provide the best care for her father. However sometimes she feels tired since she takes those burden alone. So she is not able to provide a good care enough to her father.

Setting

The patient lives in a wood house located in the suburb of Hat Yai. It is about five kilometers away from the hospital and near the highway which is convenient to access. The house consists of two bedrooms and a hall that is a space area in front of the house and between two bedrooms. This area has been arranged for utensils and refrigerator. Another part of the house is arranged for the patient's bed. There are a picnic bed on a mat and a fan.

Family 010: Pun, Pu, and Bol

Background Information

Bol, aged 73 years old, lived with her husband, uncle Pun, aged 70 years old. They have two children; two sons and one daughter. All is married. And they live far away, except the daughter who lives next door. Although Pu (the daughter) is married and lives separately from her parents, she still cooks in a kitchen of her parent’s house and have meals with them. The oldest son has a family and works in Bangkok. He comes to visit his parents every 4-5 years. Bol has been admitted to hospital recently. He comes to visit her only one time. He has never shown up anymore. The youngest son passed away about two years ago. Before having stroke, she was a merchant and healthy. She has had the underlying diseases, hypertension and dyslipidemia, for 4 years. And she has a problem about drug discontinuation.

The stroke survivor

Stroke's symptoms of Bol showed when she went to buy some foods at a close market in the morning. She was dizzy, weak, and crooked mouth. Some witnesses called her daughter, and ambulance to bring her to the closest hospital which was a tertiary hospital. She was taken to the hospital within 30 minutes. She could respond to some questions with slurred speech. And she could not lift her left hand. She was admitted to the stroke unit. Later on she was inspected using CT scan. The result showed that she has had an ischemic stroke. Doctor ordered anti-coagulant injection for her. After staying one night in the stroke unit, the doctor informed that the ant-coagulant did not work effectively. She needed a brain surgery because she had a brain swelling, and semi-conscious state. Otherwise she would die. So her relatives decided to consent for the surgery to save the patient's life. After the surgery, Bol was in ICU for 2 weeks, and then was transferred to a general ward for 2 weeks. She was discharged with a tracheostomy tube and a NG feeding tube replacement. After being at home for one month, she pulled out the feeding tubes. Doctor agreed that the patient could have some milk per mouth. So he ordered oral feeding. The tracheostomy was re-inserted. But it was fell out again after 2 weeks. The doctor agreed that she could spit her phlegm by herself so he decided not to insert the tracheostomy tube again. According to a visiting, the patient was good conscious. She could drink some milk and had some rice porridge. She could respond with slurred speech. She could tell when she wanted to urinate and defecate. She was able to use her right hand to support to turn her body. She had muscular atrophy on her left leg, and a slight foot drop. The patients did not like to sit up. She cried and complained about her pain when a caregiver tried to let her sit up.

The caregivers

Pu, the primary caregiver, lives with her husband and two children. Her children are in elementary school. Her house has been built in the same area as her parents. It locates about 30 meters away on the front of her parents' house. She has her own business in relation to a real estate. Her husband is a home renovation contractor. While her mother was admitted to the hospital, she took a turn with her father to take care of the mother. Pun (a secondary caregiver) takes care of the patient at the night time until in the morning of the next day. Then he goes back home to take a shower, have breakfast, and come back to the hospital again in the late afternoon to take care of the patient. Pu takes care the patient only a short time during the day time when her father goes back home. She is busy with her job and her children. As a result, nurse does not have a chance to teach Pu about feeding and suction. Until the day of the patient's discharge, the nurse called Pu to teach her about how to do feeding, suction, and tracheostomy wound care. She was not confident to provide care at home. The first night at home, she did not suction the patient properly; she could not insert a suction line. So patient had a shortness of breath and gasp for breath. The patients must be taken to the emergency room. Later on Pu asked for help from her friend who was a nurse in a private hospital. She trained and supervised Pu to perform suctioning. And then Pu could do so. After the patient returned home, Pu provide all care activities such as bathing, changing bed sheet, suction, feeding and tracheostomy wound dressing. Her husband and father helped her some activities like bathing and changing bed sheet. The husband or father help patients take a bath linen. Besides those the patient care activities, Pu is responsible for housework such as cooking, washing clothes, cleaning both houses; her house and the patient's house. Pu said that the first 4-5 months, there must be someone to be with the patient all the time. Because the patient needed someone. So if Pu was busy, there would be asked her husband or father to be with the patient.

Setting

The patient's house is half-timbered building and pretty old. It locates in the outskirt of Hat Yai. There is an orchard behind the house. The patient has been placed in the hallway on the ground floor of the house which is a L-shaped and connected to the kitchen. The patient's bed is a hospital-style bed that can be adjusted and has a handrail on both sides. It is placed next to the front door and in front of the patient's bed. There is a chair placed near the wall where Pun uses to sit and look after his wife.

A television is turned on and put at the end of the patient’s bed. The patient’s personal stuff such as bed pan, a kidney-shaped bowl are placed nearby. And an oxygen tank is placed at the room’s corner; it is prepared just in case of emergency.

Family 011: Nok, Chon, and Won

Background Information

Aunt Won, 89 years old, widow, and Buddhist, has eight children. Her oldest son passed away. Five of her children are married. Two other sons are single and live with her; one raises some cow at home, the other one is a security guard who usually works at a night time. Most of her children live nearby, except her youngest son, Chon, who lives in other district, about 30 kilometers away from Hat Yai. However he works for a private company in the city of Hat Yai. So he has an opportunity to visit his mother,Won, almost every day. He is mainly responsible for the cost of caring of his mother since he has more income than other siblings.

The stroke survivor

Aunt Won has had hypertension for many years. She used to be able to help herself until she has stroke. She had some symptoms of stroke while going to bed. And she was alone at home. Her son was going out. When he was back home, he saw his mother was lying on the bed and collapsed. Her saliva was full in her mouth. But she is responsive to verbal stimuli and interactive. She was taken to the hospital quickly. The CT scan showed a brain haemorrhage. After one day of admission, her level of conscious was worse. So she was intubated with ET tube. Doctor let the patient’s sons and daughter make a decision of the brain surgery. They decided not to do so because the patient was old. After a two-week of admission in the hospital, doctor said that the patient required tracheostomy since long-term intubation could cause infection. The patient’s sons and daughters did not want that medical procedure. They wanted to bring their mother back home. But nurse said that if they took their mother back home, they needed to do extubation by themselves. Nurse would not do that. In addition, the doctor said that the patient’s condition was curable. So they finally agreed with doctor for undergoing tracheostomy. Since then, the patient had been in the hospital for 5 months.

The Caregivers

Nok (primary caregiver), the youngest daughter, is married and lives in different sub-district from her mother. She has one son who studies in vocational college. Prior to the sick of her mother, she used to be a massager in Phuket. But her husband and son have in Hat Yai. After her mother was admitted in the hospital, she needed to quit her job in Phuket in order to take care of her mother. Because the two single brothers who live with the mother cannot take care of her, for example, they cannot clean up after her urination. Nok takes care of her mother from Sunday to Friday. Chon, her younger brother, and his wife take care of the mother on Saturday. Chon is a secondary caregiver. If he is busy, he will hire his niece who is a village health volunteer and live nearby to take care of his mother. She is the one who help Nok for bathing the patient every day. Chon supports Nok by paying her 300 baht per day because Nok has quitted her job to take care of the mother. Moreover, Chon is a main supporter of the cost of care of the mother. The second sister pays 1500 baht a month. And the older brother, who lives with the mother pay 3000 baht per month.

Setting

The patient's house, a half-timbered house, locates on the outskirt of the Hat Yai municipality. The patient has been placed in the hallway on the ground floor of the house. The front door is a wide open and connected to a wide terrace that set as a living room for the rest of the family members. The back room has a connected door to the kitchen and bathroom. The patient's bed is an adjustable bed as used in a hospital, and with handrails on the side. There is a mosquito net attached with ceiling above the patient's bed. The oxygen tank and suction machine are placed on the left side and top of the patient's bed. There is a long table put opposite the patient's bed used for placing the patient's stuff such as ambu bag, gloves, and feeding kits. It is properly arranged. On the right side of the patient's bed, there is a wide space that can be opened and connected to another room. There is a large wooden couch in the room that the caregivers can use it. An environment of the house is clean.

Family 012: Porn, Non, and Jun

Background Information

Jun, a Buddhist father, was 82 years old, widowed and had five married children, two sons and three daughters. He lives with the oldest daughter (Porn) and the oldest son (Non) who are single. The second daughter is married and live with her own family in Songkla city. The youngest daughter is married. She lives with her own family and work in Bangkok. The youngest son is single and work in Satun province, he frequency visit his father on the weekend. He also helps Porn to take their father to see the doctor on the schedule appointment.

The stroke survivor

Before the stroke, Jun was healthy and did not has chronic diseases. He could walk with a staff, but needed self-care assistances due to aging. He usually spent most of the time for sleeping. His stroke initially presented with having eyes bulge during sleep in the day time, and un-respond to the question. He was sent to nearby hospital and was hospitalized for 40 days. During hospitalization he was diagnosed with enlarged prostate gland. He was discharge with nasogatric feeding tube and Foley catheter replacement. After stroke, he had right side paralyzed, left side weakened, a difficulty swallowing, and aphasia. Currently, he had slightly edema at his hands and legs. He received 4 time feeding with added 2 white eggs per meal. His urine was well flow and clear.

The caregivers

Porn is 58 year-old. She finished the primary level of educational school. Prior to take a role of caregiver, she was a merchant selling the fruit and desert. She stop her job to take care of her Jun, her father, after he had stroke. She naturally took this role because she lived with him. Another reason for Porn taking on the role was affection and role responsibility. Porn received help from Non, her younger brother in performing some care activities such as, lifting and changing Jun's position, bathing, and proving massage. Others sibling who could not provide direct care for their father would support the money for the care expense.

Setting

The family house is two-floor building. The front house faced a small macadamized road. A living room, kitchen and bathroom were in the first floor. The second floor was the bedroom. The patient room is in the first floor. This room has been the living before. There is a hospital bed with an electronic air mattress for Jun. There are suction machine and many care stuffs orderly kept in two cabinets and one small table. Everything was neat. From the patient room, there is an open space connecting to the kitchen which is behind. There is a terrace in front of a patient room which is connected with 2-section sliding doors.

Family 013: Ped and Wat

Background Information

Wat, a stroke survivor, is a 60 years old man and unmarried. He has one younger sister (Ped), and two older sisters who are married and live with their own families. His oldest sister lives in Satingpra. The second one lives in Songkhla city nearby their parent house. But his parents pass away for many years. Before stroke, he did a business in relation to a real estate and lived with his girl friend in Hat Yai. At the beginning, his partner took care for him with the money support of his siblings. Wat eldest sister view that his partner did not provide the good care for her brother, because she found that Wat was frequency left alone when she visit him. So, she took Wat to be care in her house without of his medicine, because she intended to bring him to treat with folk medicine. But Ped did not agree with her sister and volunteer to take Wat to see a doctor in order to get the medicine for him. After that, Ped was compulsory to be Wat’s caregiver, because her sister did not take Wat back to her home.

The stroke survivor

Before stroke, Wat had hypertension with irregular control. He developed the severe hemorrhagic stroke, and was admitted in nearby hospital. He had endotracheal tube with a ventilator treatment in medical ward for 40 days. During his period, his consciousness was in coma status. After that he wake up and his endotracheal tube was removed. About two week of hospitalization, the physician recommended performing a tracheostomy. But Ped refused because she thought the surgery would not help in improving Wat’s condition, but it might make the patient die due to pain. She also thought that tracheostomy might cause a problem to the patient and to the caregiving performance as she said “I realize that it become a problem for me because I had no knowledge…if he has a tracheostomy replacement it means I have to do more complicate care”. After 50 days hospitalization, he was discharged with NG tube. After discharge, Wat frequently pulled out his NG tube. Until the fourth time, it was a holiday and the Health Center Services was closed. Ped could not contact health staff to replace the tube. Ped considered to take Wat to the hospital, but it was difficult for her to do so. Then, she tried to feed Wat per mouth, and could eat. However, two month after that Wat developed seizure and had difficulty in swallowing, and he was replacement with NG tube. At present, he had both side paralysis, but his consciousness is intact. Ped told that he frequency developed a seizure. Muscle atrophy is presented at both legs and arms. His body is slightly rigid.

The Caregivers

Ped is 52 years old Chinese-Thai lady, and unmarried. Ped left her home to live in Hong Kong when she was 18 years. She came back to visited her siblings in Songkhla one or two time a year. Latest (February, 2014), when she came to visited her home during Chinese New Year, she became a compulsory caregiver for Wat. However, Ped continue to provide the good care for her brother because she thought that caring for him is a merit. During Wat was hospitalization, Ped went to the hospital to look after Wat during the day time everyday. But she hired her family employee to replace her during the night time. She also hired this employee to help her to perform morning bed bath for Wat because she could not change the bed sheet alone. Beside difficulty in performing bathing, Ped also indicated several difficulties and challenges at home, including, NG tube care, transportation, and monitoring the patient symptoms. However, Ped continue to provide the good care for Wat, because she believes that caring for her brother is a merit. Another reason that help Ped to overcome the caregiving difficulties was her parents. She thought that if her parents alive, they would have to take this responsibility. Thus, she does it for her parents. When she felt tried and stress she usually look to her parent pictures.

Setting

The family house is their parent house located in Songkhla city. The house is one floor concrete-townhouse styles. In front of the house, there is a cement wall as a fence which faced a small macadamized road. The fence door is narrow which is difficult to move the patient out. The house has a L-shaped big lobby: long side is living room, short side is used as living place for Wat. These two area were connected with an open space, and tt needed one-step up from living room to Wat's unit. There is a Chinese altar and their parents' picture in the living room. Wat's bed was a hospital bed with an electronic air-mattress on it. Ped prepared all bed supplies (bed linen, bed sheet, insulator) used for Wat as same as used in the hospital. There were a suction machine and many care stuffs orderly kept in two cabinets and one small table. Everything was neat. The indoor environment was very clean and tidy.

Family 014: Yee, and Mhead

Background Information

It is a Muslim family whose member is 83 years old wife (Yee), a stroke survivor, and 82 years old husband (Mhead). The couple had been married for 64 years and had eight married children, four sons and four daughters. All of them live with their own family elsewhere, except the youngest son live nearby his parents' house. However, he did not involve in taking care of his parents. Before stroke, Yee did not have any chronic diseases and could do all activities of daily living by herself. After she had stroke, her daughter (Zao, the seventh children) moved her parent to live with her family where is about 30 kilometers far from their house. But Mhead did not familiar and did not like to live with his daughter's family. Therefore, they came back to their own home after lived with their daughter about one month.

The stroke survivor

Yee's stroke symptom was initially developed with left side weakness needed need someone to support when she was walking. Her seventh children took her to the doctor at the community hospital. She expected that Yee would be admitted in hospital. But the physician told that she did not have nothing wrong and let Yee to go home. About one month after that, Yee tried to walk without support, and she fall down. She was sent to the provincial hospital where she was diagnosed with ischemic stroke. After hospitalization for 3 days, she was discharged to rehab at home. After this stroke, Yee had swallowing difficulty and left side was paralyzed. Early at home, she could eat soft-boiled rice. About two months post discharge, her swallowing was terrible. She could eat only liquid diet. The interviewer suggested her children to take the patient to the hospital. But Yee unwanted to placement NG tube and reject to go to hospital. Mhead and his children also believed that if the patient could not eat it mean that she/he nearly died. So, her/his relatives should prepare for that situation. This belief made them did not seeking for treatment for Yee.

The Caregivers

Mhead, took on the role because of the marriage and strong affection. In fact, he did not what happen to his wife, he known only his wife had weakness. He tried to provide care for his wife by himself. Although Zao tried to take responsibility in taking care of her parents by move them to her house, Mhead and Yee could live with their Zao' family. However, he received help from Zao and her children to do personal care (bathing, changing diapers and clothes) for Yee in the morning and evening of each day. After setting bedding and mosquito net for Yee, they went back to slept in their home, and left the couple to live alone in the time night time. Mhead do care activities by his own way, such as feeding, and wiping Yee's body and face when he felt her body was hot.

Setting

The family lived in a rural village. The family home is a wooden house, one story with ground space under the house. The house floor is about 2 meters high from the ground. There is a wooden stair step from the ground to the house floor which is difficult for daily living of the stroke survivor. Mhead, therefore, built the new floor (look like a big litter) between the house floor and ground floor to use as a living place for him and his wife. This floor is about 3 foots raised-up from the ground, and have only two side of the wall to prevent the wind. There are some foods and personal belonging including; a clothes, diapers, mosquito net, and bathing set are place on one corner of floor.

Family 015: Wi and Wun

Background Information

Wi, 72 years old and retired from being a civil servant, is a former director of secondary school. She lives with her husband, 82 years old, who retired from a state enterprise. Both of their hometowns are in Phatthalung. They have moved to Hat Yai long time ago. They only have one daughter who lives in Bangkok. They do not have many relatives who live nearby. When she was admitted to the hospital, her daughter came to visit her for one week. And her relatives from Phattalung came to visit her from time to time. Her husband is old so he cannot be with her at the hospital for 24 hours so he hired nurse to take care of her at the night time. He only went to see her during the day time. He has realized about the limitation of his family. He requested nurse to find a caregiver before discharge his wife from the hospital. His daughter helped him to order some necessary stuff used at home for caring the patient except the patient's bed. They needed to borrow it from the hospital. Wun said that his daughter has planned to move back and work closer to home. But it might take about one year. She comes to visit her mother every weekend or long holidays while she is waiting for moving,

. The stroke survivor

Wi has a past medical history of hyperthyroidism, hypertension, cardiac tamponade resulting from the toxic hyperthyroidism. She received the treatment from a clinic but she did not take medicine regularly. Wun told that normally he and his wife sleep in the same room but different bed. He usually sleeps before his wife. She likes to watch television and stays up late. The day that his wife got stroke was in the early morning. He went to do exercise as usual. Normally every time when he passes by his wife's bed, she asks him that what breakfast that he wants to have. But that day she did not do so. He was not wondering about her because he thought that she went to bed pretty late. When he was back home around at 6 am., he found out that his wife did not get up. He went to the bed room, turned on the light, and then he saw his wife was lying down with full of saliva in her mouth and vomiting. She opened her eyes but could not talk. He called a neighbor for help. She was sent to the hospital by an ambulance. At the hospital, doctor performed ET intubation and CT scan. The result showed that she had an ischemic stroke on her brain stem. She was on the ET tube for 20 days and then she received tracheostomy. During the hospitalization, she was alert but could not move her arms and legs. She had NG feeding. She was discharged from the hospital after 45 days of the admission. After returning home, she could move her legs and arms slightly. She used diaper for excretion and was on a low oxygen volume during the night time. She cries every time when people come to visit her and talk about her daughter.

The caregivers

Wun hires a paid caregiver to perform care activities for Won (21,000 baht per month). He uses her pension as a wage. The caregiver used to work with an agency. But now she works on her own. Nurse at the hospital helps her to get a customer. The caregiver was called to test her ability of the patient care one day prior to discharge of the patient. Wun told that the first week after discharge from the hospital, the nursing recruiters came to supervise the caregiver to take care of the patient at the house. Later on the caregiver takes care of the patient with supervision of Wun, and he helps some simple activities like preparing some diet and medicine for feeding. He said that the caregiver is more competent but he does not trust her much since is not neat and she uses her cell phone a lot. Sometimes she wants the wage in advance and asks a man to come and get money at the house. Since then Wun becomes worry about the security. He is afraid that the caregiver might let the man come to the house at the night time. Paid caregiver tried to offer Wun to take the patient to get rehabilitation at Bang Klam hospital. She told him that if Wi get such therapy, it would help her to recover faster. But Wun did not believe her, he want to search more information about that matter.

Setting

The house, a two story building, locates in the city of Hat Yai. It is connected with other building on the left side. There is a space on the right side which is surrounded by a fence. The front gate is opened for access into the house. The patient live in a one floor room with a balcony measuring about 6 x 8 meters extended from the back of the house. It has been renovated and equipped with air conditioner. Floor and walls have been covered with glazed tiles. Wall on top of the patient’s bed was converted to a cabinet built-in used to put things and equipments for patient care, such as suction tubes, gloves, and dressing sets. There is the Buddha image put up on the top of the patient’s bed. The patient’s bed is a Fowler bed. There is a trash bin with a cover near the bed, and a sink at the left side of the bed. There is an oxygen tank at the right side of the bed. The wooden bed is provided for the caregiver. The front door is a sliding door that can be opened widely for seeing outside and ventilation. A round table with chairs is placed in the corner used as a living room. There is a washing area. The house has been arranged properly.

Family 016: Nong, Nob and Aum

Background Information

Nong, a stroke survivor, is 72 year-old, Buddhist-Thai woman, and unmarried. She has one younger sister, one older sister, and one older brother. She lives with her brother who is single, and her older sister who is windowed. Her younger sister is married and live with her own family. However, she frequency visits her older sister and brother. Before stroke, she did a mini-grocery in her house. She did not has any chronic disease and could do all activities of daily living, household shores by herself. During hospitalization, the physician told her relatives that her condition could not cure, either she was in hospital or return back home her condition would be the same, could not recovery. But their friend who works at that hospital advice to bring Nong’s brain CT scan film to consult one Neurosurgerist at his private clinic. Then, they did as their friend suggested and the doctor told them that he could treat Nong’s condition to able to do some self-care activities. Therefore, after discharge they took Nong to the doctor at private clinic, and follow the prescription of that Neurosurgerist until now.

The stroke survivor

Nong initially presented of a stroke with dizziness, weakness at right side. She was sent to a nearby hospital and was hospitalized ischemic stroke for 4 days. At the discharge, her right side was weakened and needed some assistance for self-care. At present, she could eat soft-diet by mouth and could move with a walker.

The caregivers

Nob is 76 year-old, widowed. Her previous work was caring for a older adult woman who live alone in same village with her. After Nong had stroke, she stop that job to take care of Nong. Her caregiving activities mostly focused on prepare food, do the household shores that have been run by Nong, and help Nong in walking to bathroom/toilet. She received help from her youngest sister to take Nong to see the doctor on the appointment schedules. Her sister also supported the money for Nong's medication. Aum does not too much involve in the caregiving, but he helps the family by replaced Nong to run mini-grocery.

Setting

The family lived in a two-floor house: the first floor is concrete and the second floor is wood. The living room, kitchen and bathroom are found on the first floor. The second floor is a bedroom. But all of them (Nong, Nob, and Aum) move to sleep in the living room after Nong had stroke. In this floor, there is additional room in front of the house used as a mini-grocery. There is a door connect this room to the living room. The living room was separate into two areas; front side and back side, by a cabinet and wardrobe. In the front side, there are the two wooden beds and one long visitor's chair. This area are used as the living place in the day time and used as bedroom in the night time. The room has several windows which provided properly ventilation and bright for living. In the back side, there is stair to step up to the second floor. The kitchen and bathroom are next to the living room. The house environment is clean.

LISTS OF EXPERTS

1. Assoc. Prof. Dr.Siriorn Sindhu, Surgical Nursing Instructor, Faculty of Nursing, Mahidol University.
2. Assoc. Prof. Dr.Praneed Songwattana, Surgical Nursing Instructor and Director of Research Center for Caring and Healing System for People with Trauma, Emergency and Disaster (RC care TED), Faculty of Nursing, Prince of Songkla University.
3. Asst. Prof. Dr.Wipawee Kongin, Medical Nursing Instructor and Director of Research Center for Caring System of Thai Elderly, Faculty of Nursing, Prince of Songkla University.

VITAE

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Master of Science (Pathobiology)	Faculty of Science, Mahidol University, Thailand	2001
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Certificate in Nursing and Midwifery	Boromarajonani College of Nursing,Nakhonsrithumarat Thailand	1985

Scholarship Award during Enrolment

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Research and Publication

Sirisom, K., Wunnawilai, P., &Kawmahakan, O. (2009). Caring behaviors of nursing students during a practicum in the nursing care of persons with health problem I course, as perceived by themselves, instructors, and clients. *Journal of Boromarajanani College of Nursing Songkhla*, *5*(1), 9-17. (Thai manuscript)

Supepre, N., Wunnawilai, P., Junchareon, K., &Sirisom., K. (2009). *Needs of caring perceived by the relatives of critically ill patients admitted in Songkhla hospital* (in Thai). Reseach report. Boromarajonani College of Nursing, Songkhla, Thailand.

Junchareon, K., Sirisom, K., &Wunnawilai, P. (2009). *The capacity and preparedness of local governmentorganization to engage in producing community nurses by community to community* (in Thai). Research report.Boromarajonani College of Nursing, Songkhla, Thailand.

Sirisom, K., Wunnawilai, P., Ampansirirat, A., Chuencharoen, S., &Chitviboon, A. (2015). Effect of case studies combined with concept mapping technique on critical thinking of nursing students. *Journal of Nursing Science, 33* (Suppl 1), 18-26.

International Nursing Conference

1. Oral presentation in the International Conference on “Health and the Changing World”, during November 11-13, 2008, at Rama Gardens Hotel, Bangkok, Thailand.
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2. Oral presentation in the 1st Asian Congress in Nursing Education (ACiNE): “Transformative Nursing Education for Global Health”, during June 4-6, 2014, at Rama Gardens Hotel, Bangkok, Thailand.
   “Effect of case studies combined with concept mapping technique on critical thinking of nursing students”
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   “State of The Science for Promoting Family on Caregiving Following a Loved One’s Stroke”
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