

**STROKE CAREGIVING NETWORKS IN BANGKOK:
PATTERNS OF SOCIAL EXCHANGE BEHAVIOR**

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Somnuk Sakunhongsophon

STROKE CAREGIVING NETWORKS IN BANGKOK: PATTERNS OF SOCIAL EXCHANGE BEHAVIOR.**SOMNUK SAKUNHONGSOPHON 4637616 NRNS/D****Ph.D. (NURSING)****THESIS ADVISORY COMMITTEE: YUPAPIN SIROPO-NGAM, D.S.N., TONI TRIPP-REIMER, Ph.D., FAAN, TIRAPORN JUNDA, Ph.D.****ABSTRACT**

The aim of this study was to describe and explore the variety of social exchange behaviors within stroke caregiving networks in Bangkok. The social network concept was used to describe the people and relationships in stroke caregiving networks. Social exchange theory was used to explore patterns of social exchange behavior among 18 stroke caregiving networks. Elderly stroke patients and their associated caregiving networks were selected from Ramathibodi Hospital, the Neurological Institute Hospital, and community health centers. The 42 participants consisted of 22 primary caregivers (19 women, 3 men), and 20 caregiving network members (19 women, 1 man) who had participated in caregiving for between 4 months and 20 years. Ethnographic methodology was utilized and data were collected through observation at homes, hospitals, and communities. The data consisted of 44 formal interviews and a number of informal interviews, field notes, geographical mapping, photographs, household assessments, and network recording and analysis. Data was collected from January to September 2008. The context analysis was designed to look for consistency among items, units, patterns, and structures following the method outlined by Lecompte and Schensul. The Nvivo software program was used to capture the patterns of behavior.

The study found three major patterns of social exchange behavior. The first pattern was sharing care in which functions of care are divided among primary caregiver and caregiving network members. The second was dual care in which functions of care shift between two primary caregivers and caregiving network members. The third was supplementary care in which the primary caregiver performs the caregiving alone or with just occasional support from the network. Factors associated with social exchange behaviors were satisfaction, size, duration, time, finances, communication, and relationships. These factors mobilize the “wheel of caregiving”, a model constructed by the study to capture caregiving exchange in its particular Thai context. The network-exchange configurations of caregiving characteristics were identified in terms of difference in size of, and homogeneity of networks, and of degree of connection, frequency of interaction, directionality, gender and status of primary caregivers and network members. The “wheel of caregiving model” was developed in terms of six themes: 1) “No one else can do it”, 2) “Don’t know what to do”, 3) “Let’s try it”, 4) “Relying on each other”, 5) “Whatever happens, happens”, and 6) “When the time comes, there will be a way”.

This study investigated stroke caregiving networks in Bangkok and their caregiving exchanged behaviors. The implication of the “wheel of caregiving” model and the patterns of social exchange behavior are discussed to understand caregiving behaviors in stroke care. Given this new understanding, instruments of adequate caregiving that are sensitive within the context of Thai culture and intervention programs that are appropriate to Thai elderly stroke patients will be able to be developed.

KEY WORDS: CAREGIVING NETWORK/ STROKE PATIENT/ SOCIAL EXCHANGE**454 pages**

เครือข่ายผู้ดูแลผู้ป่วยอัมพาตจากหลอดเลือดสมองในกรุงเทพฯ: รูปแบบการช่วยเหลือทางสังคม
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จิราภรณ์ จันดา, Ph.D.

บทคัดย่อ

การศึกษานี้มีวัตถุประสงค์เพื่ออธิบายรูปแบบการช่วยเหลือทางสังคมของเครือข่ายผู้ดูแลผู้ป่วยอัมพาตจากหลอดเลือดสมองในกรุงเทพฯ แนวคิดเครือข่ายทางสังคมนำมาช่วยในการศึกษาเครือข่ายความสัมพันธ์ระหว่างกัน และทฤษฎีการแลกเปลี่ยนทางสังคมนำมาช่วยในการศึกษาการแลกเปลี่ยนความช่วยเหลือในเครือข่ายผู้ดูแลผู้ป่วยอัมพาตจากหลอดเลือดสมองจำนวน 18 เครือข่าย ผู้ป่วยอัมพาตสูงอายุเป็นผู้ป่วยจากโรงพยาบาลรามธิบดี สถาบันประสาทวิทยาและศูนย์สุขภาพชุมชน ผู้ให้ข้อมูลสำคัญจำนวน 42 คนคือผู้ดูแลหลักจำนวน 22 คนเป็นหญิง 19 คนชาย 3 คน และสมาชิกเครือข่ายจำนวน 20คนเป็นหญิง 19 คนชาย 1 คน การศึกษานี้เป็นการวิจัยเชิงชาติพันธุ์วรรณา (Ethnographic study) เก็บข้อมูลโดยการสังเกตที่บ้าน โรงพยาบาล และชุมชน การสัมภาษณ์แบบเจาะลึก 44 ครั้งและการพูดคุย การบันทึกเทป การเก็บข้อมูลภาคสนาม การทำแผนผังความสัมพันธ์เครือข่าย การถ่ายรูป การประเมินสิ่งแวดล้อมในบ้าน การบันทึกและวิเคราะห์เครือข่ายระหว่างเดือนมกราคมถึงเดือนกันยายน 2551 การวิเคราะห์บริบทของข้อมูลตามขั้นตอนของ Lecompete และ Schensul โดยใช้ Nvivo software program

ผลการศึกษารูปแบบการช่วยเหลือทางสังคมในเครือข่ายผู้ดูแลผู้ป่วยอัมพาตจากหลอดเลือดสมองในบริบทกรุงเทพฯเป็น 3 รูปแบบคือ การแบ่งกันดูแล (Sharing care) การร่วมกันดูแล (Dual care) และการสนับสนุนการดูแล (Supplementary care) ปัจจัยที่เกี่ยวข้องประกอบด้วย ความพึงพอใจ ขนาดเครือข่าย ระยะเวลาที่อยู่ในชุมชน เวลาที่ใช้ในการดูแล การเงิน การสื่อสาร และสัมพันธภาพ แนวคิดเครือข่ายและทฤษฎีการแลกเปลี่ยนทางสังคมช่วยอธิบายความแตกต่างการช่วยเหลือทางสังคมของเครือข่ายในเรื่องขนาดเครือข่าย ความเหมือนคล้ายคลึงกัน ระดับความสัมพันธ์ ความถี่ในการติดต่อ ทิศทางการติดต่อ เพศ และสถานภาพสมรส ซึ่งการศึกษานี้พบว่ารูปแบบวงล้อการดูแล (Wheel of caregiving model) นำมาอธิบาย จาก 6 ขั้นตอนคือ ไม่มีใครทำตรงนี้ได้, ไม่รู้จะร้องเพลงอะไร, ผู้ได้ต้องผู้ไปก่อน, ต่างคนต่างอาศัยกัน, อะไรจะเกิดมันต้องเกิด, ถึงตอนนั้นก็มีทางไปได้

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CHAPTER I

INTRODUCTION

Background and significance of the study

The cases of elder care and chronic illness are increasing both in number and complexity worldwide. In the United States, advances of knowledge and technology in health care have raised the survival rate of elderly people with chronic ailment (National Center of Health Statistics, 2007). About 75% of elderly (age 65 and over) have at least one chronic disease and about 50% have at least two chronic diseases (US. Department of Health and Human Services, 2002). In Thailand, 10.7% of the population are aged 60 years and older (National Statistical Organization Survey, 2007), which is expected to rise to 15.3% by the year 2020 (Jitapunkul & Chayovan, 2001). Recently, the Health Research Institute (2006) indicated that 5% of Thai elders had at least seven chronic diseases. As the percentage of elderly people with chronic disease increases, the difficult situation of aged dependency will be elevated and needs to be addressed. These concerns have focused on attaining a full understanding of the problems of chronic health conditions in elders and how to deal with them.

One of the major diseases of older adults is stroke. Stroke is the first leading cause of disease burden in Thai female, and the forth cause burden of disease in Thai male (International Health Policy program, 2006). Living with the consequences of disease, stroke survivors suffer from physical impairments, for example cognitive impairment, loss of motor function, and language difficulty (Greenberg, Treger & Ring, 2004). They also have many problems associated with loss of feeling in the body, emotional difficulties, impaired sexuality, and social interaction (Murray & Harrison, 2004). About 14% of them die within six months after discharge from hospital (Bravata, Brass, Concato, Scinto & Meechan, 2003). Throughout the rest of their lives, half the stroke survivors need assistance for daily living and one fourth of them need total care (Miller & Woo, 1999). For solving these

problems and needs of patients, stroke caregiving needs to address in terms of both formal and informal care.

As a review of the literature on stroke caregiving demonstrates, research results show that there have been developing both formal and informal care for stroke survivors. Formal care refers to care from health care professionals and volunteers from organizations that provide care at home, in the community or in institutions (Day, 2006). Numerous countries have developed stroke units (Candelise, Gattioni, Bersana, Micieli, Sterzi, & Morabito, 2007; Sulter, Elting, Langedijk, Maurits & Keyser, 2003), stroke teams (Webb, Fayad, Wilbur, Thomas & Brass, 1995), stroke care programs (Mant, Carter, Wade & Winner, 2000), and clinical practice guidelines (Duncan, Zorowitz, Bates, Choi, Glasberg, Graham, et al., 2005). In Thailand, the national clinical practice guidelines for ischemic stroke and hemorrhagic stroke were developed in 2001, and 2004, respectively (Samsen, 2008). Stroke fast tracking and a modified stroke unit have been set up in a medical school (Dharmasaroja, 2008). The objectives of stroke care to decrease mortality, dependence, and institutionalization. Most formal care provides care in the hospital while little formal care is done in home settings.

With health care reform worldwide, health policy is changing from a concept of a welfare state to self-reliance. To reduce cost and service provisions, patients are being discharged as soon as possible (Jenkins, 2005). More than 20% of stroke survivors stay in rehabilitation hospitals (Burman, 2001), while 80% of them are discharged to the community (Anderson, Linto & Stewart, 1995). Consequently, formal care has extended outside the hospital in a short period. Relatives can be motivated and prepared to participate in caring as informal caregivers (Kawkun, 1990; Suwanno, 2003). Thus, informal care needs to be developed in ensuring continuous quality stroke care from hospital to home-based care.

Informal care is unpaid care offered by family, friends, neighbors, a volunteer of temples or churches. Relatives or unpaid non-relative caregivers provide care at home with help in activities of daily living, and giving instrumental support daily living (Langa, Fendrick, Flaherty, Martinez, Kabeto, & Saint, 2002), and giving assistance to the ailing patients in their homes (Sirapo-nagm, 2003). The informal care consists of primary caregiver and the caregiving networks. To clarify, primary caregiver refers to a person who is regularly and continually in charge of a patient is

cared (Horowitz, 1985), while caregiving networks refer to the sources of support for the primary caregiver to maintain the caregiving roles (Fudge, Neufed & Harrison, 1997).

Originally, a network means the linking of the individual to a large social system (Pearlin, Aneshensel, Mullan, & Whitlatch, 1996). A network is a structure of relationship, while social support is a function of relationship (Ryan & Austin, 1989). Research on caregiving networks has focused on attributes of network structure such as network size, homogeneity, degree of connection, duration, frequency of contact, directionality, and composition of networks (Boonchalaksi, 2000; Coward, Culter & Mullens, 1990; Dickenson, Green, Hayes, Gilheany & Whittaker, 2002; Dwyer, 1988; Hirdes & Strain, 1995; Zimmer & Kwong, 2003). The studies in the stroke caregiving literature show the effects of networks on the outcome of care in terms of negative and positive results. Three studies found that families were the ordinary sources of support to stroke caregivers only at the beginning process but did not provide any more regular support (Anantato, 2006; Hatthakit, 1999; Hirunchunha, 1998). The stroke patient's family members had interdependent relationships and little support within their wider social networks. Additionally, the stroke patients had to be re-admitted into hospital many times, and caregivers suffered from quarrels with their relative networks because of financial problems and the poor condition of the patients. In contrast, Obe-om and her colleagues (2006) reported the positive results that the stroke family had closer relationship and family responsibility was increased by sharing the costs and experiences in both modern medicine and traditional medicine, and changing family's food pattern to use more non-fatty and non salty food. To meet the adequacy of caregiving, we need greater understanding of how it works.

The caregiving concept emerged as both a process and outcome (Hunts, 2003; Swanson, Jensen, Specht, Johnson, Mass & Saylor, 1997). From a lot of information has been provided to increase the understanding the components of caregiving as a process including roles, tasks, processes, and transitions (Swanson et al., 1997). A distinctive concept of caregiving described caregiving as an outcome consisting of negative or positive experiences. The neutral experience is the co-occurrence of both negative and positive outcomes (Hunt, 2003). Robertson and her colleagues (2007) identified four patterns of both positive and negative caregiving

experiences: Well adjusted (i.e. high positive affect, low negative effect); ambiguous (i.e. low on both positive and negative affect); intense (i.e. high on both positive and negative affect); and distressed (i.e. high negative affect, low positive affect).

In the past four decade, caregiving research has been studied, based on the stress/coping paradigm. Evidence studies focused on caregivers but little is known about caregiving networks. Most empirical research provides much understanding of problems and needs of caregivers and impacts on the health and well being (Bäckström & Sundin, 2009; Mak, Mackenzie & Lui, 2007; Pierce, Steiner, Hicks & Holzaepfel, 2006; Sansee, Limtragool, & Tamdee, 2008; Van Puymbroeck & Rittman, 2009). For stroke caregiving, psychological distress of stroke caregivers was reported between 37-54% in the first year of caregiving and the distress were 2.5 times more than that for non caregivers (Simon, Kumar & Kendrick, 2009). The stroke caregiver perceived stress, depression, and burden (Anderson, Linto & Stewart-Wynne, 1995; Berg, Psych, Palomaki, Lönnqvist, Lehtihalmes & Kaste, 2005; Bocchi, 2004; Han & Haley, 1999; Kotila, Numminen, Walimore & Kaste, 1998; Wyller, 2003). Around 40% of stroke caregiver reported physical health problems (Meesuk, 2005; Prawtaku, 2006; Sit, Wong, Clinton, Li & Fong, 2004). Some caregivers had burden from financial cost (Hickenbottom, Fendrick, Kutcher, Kabeto, Katz & Langa, 2002; Moongkhetklang, 1999), others suffered from social isolation (Ekwall, Sivberg & Hallberg, 2005; Larson, Franzen, Billing, Murray & Wredling, 2003).

In Thailand, caregiving research shows different results from the Western studies. Many of the Thai studies indicated that stroke caregivers had fewer emotional problems and more positive experiences. Thai caregivers reported mild stress and burden (Jullamate & Thanatwanich, 2001; Sirapo-ngam, Puttawattana & Wongjunlonsin, 2002), mild role strain (Natechang, 2002; Matayamool, 2003; Meesuk, 2005), and mild or no emotional exhaustion and depersonalization (Navarat, 2002; Saewun, 1994). In contrast, several studies have revealed life satisfaction and good quality relationships between Thai patients and caregivers (Kenchaiwong, 1996; Thipsamniag, 2000). Stroke caregivers presented family hardiness and good levels of well being (Niyomthai, Putwattana, & Panpakdee, 2003), received rewards from caregiving in terms of gaining experiences, food and money (Kopachon, 2002;

Songwattanayut, 2002). Few studies found that caregiving outcomes exist both negative and positive experiences (Chinsuwan, Chirawatkul & Nualnetr, 2007). These results demonstrate different experiences of stroke caregiving between Western and Thai cultures. This points out that culture is one of the significant factors in caregiving.

Further advances in caregiving research have been made in the past two decades. Stroke caregiving has been investigated through qualitative studies and the caregiving concept has expanded from physical and psychosocial aspects to the cultural aspects. Research results show that universally cultures expect caregiving to be a woman's role (Songwattanayut, 2002; Vatcharapichat, 2000; Wuest, 1993), and home is considered the best place for stroke recovery (Obe-om, et al., 2006; Ricauda, Bo, Mlaschi, et al., 2004). Caregivers with different cultural backgrounds vary in perceptions and reactions to caregiving in different ways. Cultural diversity clarifies how caregivers vary in social networks, social supports, negative effects, coping, cultural effects, and help seeking behaviors (Ayalong, 2004; Dilworth-Anderson, William & Gibson, 2002; Erickson, Hessler, sundh & Steen, 1999; Pinquart & Sörensen, 2005; Valle, Yamada & Barrio, 2004).

In the context of Thai social values, caregiving research has indicated that stroke caregivers have adopted the ideas from culture, religion, and traditional ways of life to cope with caregiving role (Srinim, 2001; Subgranon & Lund, 2000). Thai caregivers have developed a variety of managing processes such as the use of a combination of modern medicine, traditional medicine, and alternative therapies in stroke care (Hatthakit, 1999; Komjakraphan, 2001; Obe-om et al., 2006; Subgranon & Lund, 2000), and receiving supports from family and community (Hatthakit, 1999; Hirunchunha, 1998; Subgranon & Lund, 2000). Stroke caregiving research provides more understanding of what caregivers do but little is known about how caregiving network members exchange their behaviors. To broaden the caregiving concept, there is a need to realize who serves in the caregiving networks, the type and adequacy of the content of exchanges, and how these networks vary.

In Thailand, no study has been conducted on social exchange behaviors in stroke caregiving networks. Though, these studies provide understanding about the caregiving in the stroke family, but there is limited study in caregiving network members, particularly in major urban areas. Most studies have focused only on a

caregiver or between a patient and a caregiver in rural area or in large provinces in rural areas (provincial cities) (Hatthakit, 1999; Obe-om et al., 2006; Srinim, 2003; Subgranon & Lund, 2000). This study plans to explore caregiving exchange between caregivers and caregiving network members in urban area particularly in Bangkok.

Bangkok, the capital city of Thailand, is the center of modernization. Similar to a large city, there is difference from provincial cities in rural areas in terms of cost of daily living and working conditions. Under the high cost of living arrangement in Bangkok, the Thai family has changed a family structure from an extended to a nuclear family. There has been a decrease in family size to smaller than other provinces and an increase in childless marriage (National Statistic Organization Survey, 2007). Women are increasing to participate in the workforce. When elderly relatives have chronic disease, such as stroke, women are to be the predominant family caregivers in caregiving networks (Boonchalaksi, 2000; Kespichyawattana, 1999; Sasat, 1998). Women's roles are served in both work and the family.

With regard to a strong Buddhist-based family caregiving system, Thai adult children respect for the elderly, and took care of elderly parent. It is based on the concepts of "*katanyu katawethi*" in which children provide care as the "parent repayment" (Kespichayawattana, 1999). A growing number of caregiving network studies show that there are changes in adult child caregiving networks in term of familial, social, and cultural contexts; caregivers' abilities and resources; and care burden (Szinovacz & Davey, 2007). In modern society of Bangkok, this cultural value is involved with the changing traditional family arrangements. Therefore, understanding caregiving networks is necessary so that nurse can identify patient and caregivers at risk of poor support and develops intervention strategies to help patients and caregivers mobilize their resources in caregiving networks.

The literature mentioned above demonstrate that there is limited information as to how stroke caregiving networks exchange their caregiving. To accomplish the knowledge gaps, this study explores patterns of social exchange behaviors that reflects on how family and their caregiving networks influence stroke caregiving. Moreover, this study helps expand caregiving knowledge from the primary caregiver's experience to the experience of caregiving network members. Informal and formal cares are an integrated rather than separated system. To describe the individuals

and relationship in caregiving network, the social network concept is used. Social exchange theory is used to investigate the patterns of social exchange behaviors in stroke caregiving networks.

Purpose of the study

The objective of this study is to explore and describe the variety of stroke caregiving networks. The contribution of the care network of stroke caregivers, the nature and adequacy of the exchange within the caregiving network, and the variation of network exchange are the areas that are clarified in this study.

Research questions

The research questions are:

1. Who contributes to the care networks of stroke caregivers?
2. What is the nature and adequacy of the exchange within care networks?
3. How do network-exchange configurations of caregiving characteristics vary by stroke caregivers?

Definition of terms

The preliminary definitions are provided for the theses as follow:

Primary caregiver refers to a family caregiver who provides majority of care for elderly stroke patient at home for at least two months.

Elderly stroke patient refers to elderly people who were aged 60 or older. They got stroke disease and were evaluated by Barthel Index Score of 20 or lower.

Caregiving network is the structure of relationships in caregiving. In this study, caregiving network refers to both informal and formal caregiving members relating to stroke caregiving in terms of size, relationship, degree of connection, directionality, frequency of contact, homogeneity, and sociodemographic features.

Social exchange behaviors refer to the exchange processes of individuals to meet their goals both items and services among caregiving network members in the present, in the past and in the future.

Conceptual Framework

The social network concept (Carpentier & Ducharme, 2003; Laireiter & Baumann, 1992; Mitchell, 1969; Moren-Cross & Lin, 2006; Sokolovsky, 1986) and social exchange theory (Gergen, Greenberg & Willis, 1980; Molm, 1997) has been selected as the conceptual framework of this study.

The social network concept has been developed in social science over the last fifty years. The early work of anthropologists and sociologists, Bott (1957), and Barnes (1954) investigated the relationships of people in many social structures. They used the social network concept as a basic concept to describe human behaviors in terms of size, homogeneity, degree of connection, duration, frequency of contact, directionality and sociodemographic character. By utilizing network analysis, the network members are identified in the following diagrams to understand the individuals and relationships with the caregivers in their caregiving networks. However, the social network concept is only a framework to collect data for further analysis. Other theories have been used to analyze the relationship of network members, such as interaction theory (Adam, 1967), system theory (Schulberg & Baker, 1970), attachment theory (Cicirelli, 1993), and social exchange theory (Hirdes & Strain, 1995). From the previous study, Subgranon and Lund (2000) found the concept of “bun-khun” in a Thai stroke caregiving study. They clarified that this concept is related to reciprocity, indebtedness, and obligation. These concepts are close to equity theory, theory of indebtedness, and resource theory underpinning social exchange theory. Consequently, in this study, social exchange theory has been chosen to analyze the mechanism of behavior in Thai stroke caregiving networks.

In addition, social exchange theory is a social science theory that can be used to explore caregiving behaviors in terms of exchange relations. Social exchange theory has been transferred from its origins in economics to applications in anthropology, sociology, and psychology. Social exchange theory expands from understanding people’s behaviors to an analysis of the motivation of exchange behaviors. Sociologists and psychologists utilize reciprocity and altruism to explain attitudes and motivations to care (Homans, 1961; Emerson, 1979; Molm, 1997), whereas anthropologists have developed three theories: equity theory, theory of indebtedness, and resource theory (Gergen Greenberg & Willis, 1980). Based on these

three underlying theories, social exchange theory is used to provide an understanding of the motivation of caregiving in this study.

Using this conceptual framework, shown as Figure 1, stroke caregiving networks have been investigated in terms of their relationships to stroke caregivers and stroke patients. The attributes of degree of connection, directionality, duration, frequency of contact, homogeneity, size, and sociodemographic features have been focused on. Patterns of social exchange behavior have been explored in terms of physical care, psychological care, socio-cultural care, financial care and spiritual care. The social network concept and the social exchange theory guide the interviews and observation of family caregivers, caregiving network members, and the mechanisms of exchange interaction in stroke caregiving.

In conclusion, the social network concept is used to describe all members in stroke caregiving network and social exchange theory is used to explore behaviors under the specific events of stroke caregiving.

Social exchange behaviors

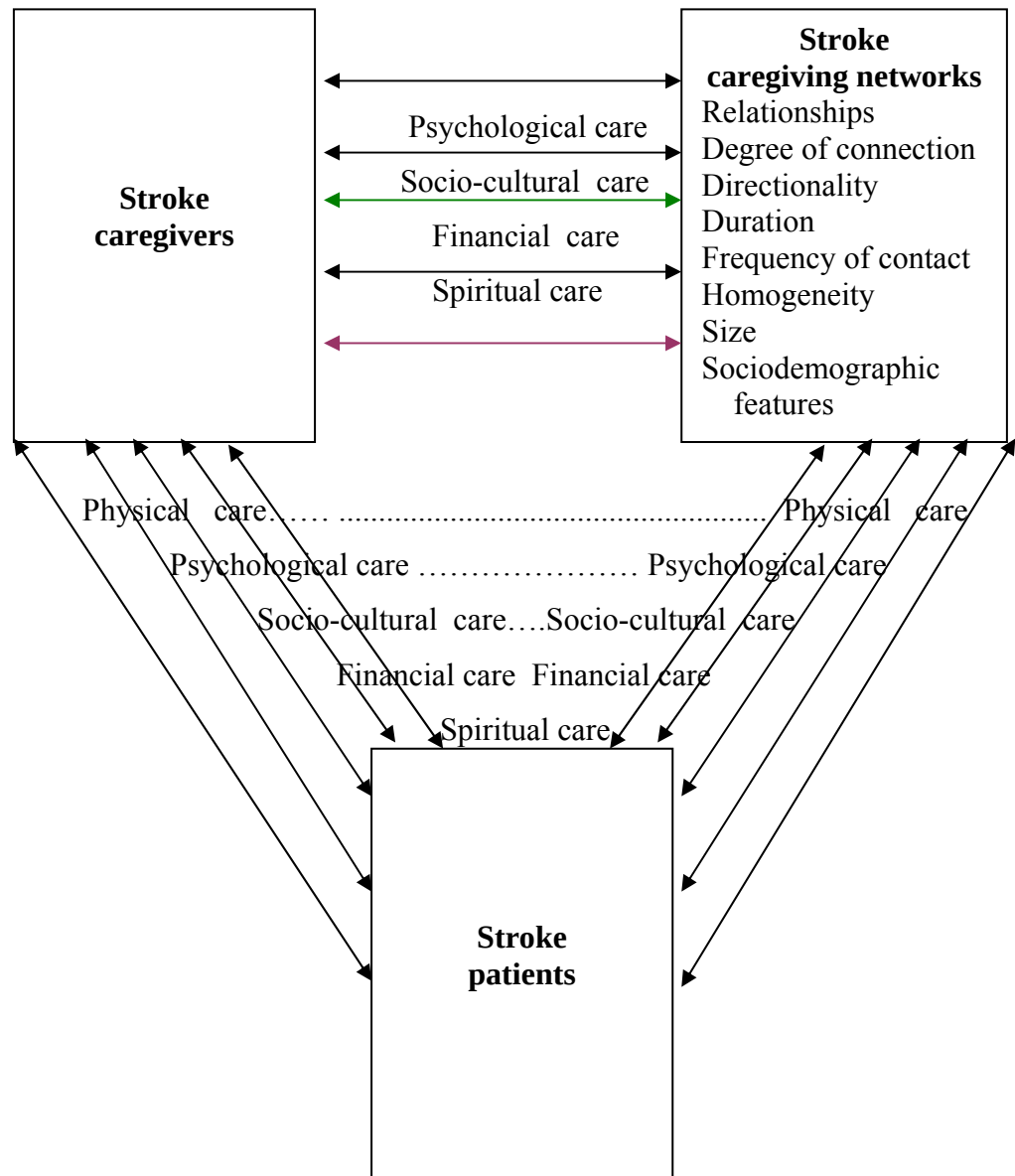


Figure 1 Conceptual framework of stroke caregiving networks

CHAPTER II

LITERATURE REVIEW

In this chapter, the empirical evidence and theoretical perspectives relating to caregiving are presented. The review of the literature of qualitative and quantitative studies on family caregiving for elderly people with stroke focuses on caregiving attributes and outcomes of care in caregiving in the first part of the chapter. The second part describes social perspectives and theoretically based studies of the social network concept and social exchange theory. Then more specifically, care is reviewed from a cultural perspective with particularly attention to Thai caregiving. The final section reviews social exchange behavior of elder caregiving networks and relevant research on social exchange and stroke caregiving research.

Caregiving overview

Caregiving is rapidly escalating as there are increasing numbers of elderly. Worldwide demographic transitions are evident due to the advance of knowledge and improvements in treatment technology. In Western countries, the burdens of financing and service provision have produced a shift from institutional care to outpatient and home health care. Care at home usually requires families to provide care for their disabled and frail elderly members. Over the past four decades, numerous studies have focused on the nature of caregiving (Grad & Sainsbury, 1963; Sirapo-ngam, 2003; Yodpet, 2005; Zarit, Reever & Bach-Peterson, 1980) and its impact on health and well being of the caregivers (Cantor, 1983; Christakis & Allison, 2006; George & Gwyther, 1986; Wright, Hickey, Buckwalter, Hendrix & Kelechi, 1997). These studies on caregiving emanate from multiple disciplines including gerontology, nursing studies, women's studies, family studies, and public health policy and services.

Literature from the field of nursing studies has analyzed caregiving as both a process and outcome of care (Hunt, 2003; Swanson, Jensen, Specht, Johnson, Maas, & Saylor, 1997). Swanson and her colleagues (1997) noted that caregiving is a

complex and multidimensional concept. They conducted a concept analysis of caregiving role performance as a task, a transition, a role, and a process. These attributes relate to behaviors within the process of care including both direct and indirect caregiving. Direct caregiving is providing assistance with activities of daily living, housekeeping, transportation and provision of social and emotional support, whereas indirect caregiving is more complex than direct caregiving encompassing decision making, supervision, and evaluation of care management. Focusing on antecedents, skills, attitudes, beliefs, and values of the caregivers affect the role performances for direct caregiving, while feelings of attachment, adequate income, good physical and emotional health, self-confidence, and a solid marriage in spousal caregivers also promote positive caregiving for indirect caregiving. The list of antecedents of caregiving affecting direct and indirect caregiving may include ability of the caregiver to provide support and the possession of the social skills to receive support by mobilizing needed resources (Given, 1997). In brief, these are the conceptual categories of what the caregiving is.

In another view, Hunt (2003) reviewed how caregiving is experienced. She approached her analysis much differently than Swanson and her colleague. She clarified that caregiving is not only objective experience, as Swanson's team maintains, but also subjective experience, and must be thought of in this way to complete the picture of outcomes of care. She organized this concept into negative, neutral, and positive experiences. Her review of literature identified caregiver burden, hassles of caregiving, caregiver strain, and caregiver stress as negative concepts of caregiving. When the paradigm shifts from problems and needs of care to the positive aspects, the outcomes of caregiving have been shown to increase caregiver self-esteem, uplifts from caregiving, caregiver satisfaction, meaning through caregiving, and skills from the caregiving experiences. Caregivers evaluate caregiving situations as positive, neutral, and negative feelings. This view reflects how caregiving works.

From the general perspective, caregiving encompasses both a state and a process as a multidimensional concept. The attributes of this concept vary according to what caregiving is in terms of task, transition, role, and process. With such a wide range of outcome experiences, caregiving may be not only a positive or negative outcome but also described in a neutral sense. Stroke caregiving is reviewed on tasks

of caregiving, caregiving transitions, roles of caregiving, caregiving processes, and outcomes of caregiving.

1. Tasks of caregiving

The main objective of stroke care is rehabilitation that helps individuals with a disability return to optimal effectiveness in daily living. Numerous tasks of caregiving serve to promote physical, emotional, and social care in stroke recovery. Much of the research has focused on problems and needs of stroke caregivers in acute care, rehabilitation and long-term care (Bakas, Austin, Okonkwo, Lewis & Chadwick, 2002; Chuansawadsak, 2001; Kenchaiwong, 1996; Lui, 1999; O'Connell, Baker & Prosser, 2003; Pierce, Finn & Steiner, 2004; Pierce, Steiner, Hicks & Holzaefel, 2006; Zwygart-Stauffacher, Lindquist & Savik, 2000). Few studies have investigated what caregivers do for their family members with stroke (Bakas, Austin, Jessup, William & Oberst, 2004; Tirapaiwong, 1997; Thipsamniag, 2000; Tuangsin, 2001), and little is known about the quality of caregiving of stroke caregivers (Chuchuaiy, 2004; Ngamkham & Viboonwatthanakitt, 2007; Suwano, 2003). Tasks of stroke caregivers are reviewed for the caregiving supports they provided, caregiver's capabilities in the tasks of stroke caregiving, and how they complete their tasks.

Studies of what caregivers do generally provide a picture of continuing stroke care from hospital to the home setting. Stroke care is presented in terms of task performance and appraisal of the difficulty of caregiving demands (Wallhagen, 1992). Stroke caregiving demands consist of direct care, interpersonal care, and instrumental care (Thipsamniag, 2000). Direct care is mainly associated with activities of daily living such as feeding, grooming, and dressing. The appraisal of difficulty is described by the concept of doing double duty which means activities for the caregiver and the repetition of those activities for the patient. Some of the tasks are repetitive, such as taking the patients to the washroom several times a day (Coombs, 2007). Specific tasks of stroke caregiving are rehabilitation tasks that need special skills in providing medications and observing side effects, assessing abnormal breathing, managing pressure sores, managing diarrhea, preventing upper respiratory tract infection, promoting exercise, toileting, removing secretions, and checking on urinary retention. Skill in these tasks need to be developed by self learning from self awareness, past experiences, observation, trial and error practices, and information seeking and by

formal learning from nurses and health care personnel (Suwanno, 2003). Furthermore, interpersonal care refers to emotional support, contact with health care providers, managing behavior problems, monitoring health status, and additional aids (Thipsamniag, 2000). Lastly, there are tasks of stroke caregiving for assisting in activities or in instrumental care such as financial support, providing transportation. Public transportation is not always available for patients with impairments. Some caregivers do not drive before and needed supports from others (Coombs, 2007). Therefore, among the tasks of stroke caregiving are providing support and receiving support.

Focusing on providing support, the tasks of stroke caregiving can be investigated in two dimensions: the amount of time consumed and the difficulty of tasks. Some stroke caregivers spend from 12-18 hours a day caring and the range of time spent caregiving is from 2 to 24 hours a day (Thipsamniag, 2000; Prawtaku, 2006; Sangboon, 2002). Research clarifies the difficulty caregiving that the greatest time and effort of stroke caregivers is in the area of providing transportation, followed by emotional support, contacting with health care providers, and dealing with patients' behavior problems (Tirapaiwong, 1997; Tuangsin, 2001). Other findings are reveal that stroke caregivers spent the most time giving emotional support, followed by providing transportation, managing finances, and performing household tasks such as cleaning (Bakas et al., 2004; Thipsamniag, 2000).

With regard to receiving support, there have been reports of family support, kinship and community support, supports from local social work departments, and respite care to stroke caregiver (Kerr & Smith, 2001; Peri, 1995). Vatcharapichat (2000) clarified that stroke caregivers received support from closed networks in their families, while some caregivers received emotional support from visiting neighbors. They shared their distressed feelings with their mothers or closest daughters. However, this support is not enough and the researcher has reported conflict between their caregiver roles and the personal well being of caregivers (Vatcharapichat, 2000). In addition, there have been studies of the relationship between receiving support and caregiver well being. Anderson Linto and Stewart-Wynne (1995) reported that all stroke caregivers had adverse effects on emotional health, social activities, and leisure time. Thirty-five percent of stroke caregivers had adverse effects on family

relationships including tension, misunderstandings, or feelings of neglect among family members because of the physical and emotional needs of the patients. Fifty-five percent of caregivers reported receiving help from other family members and forty-two percent of caregivers received support from community services, but there were still adverse effects on caregivers. The high level of emotional distress among stroke caregivers reflects their unmet needs. Bakas and her colleagues (2002) have further described how stroke caregivers dealt not only with the stroke survivors' problems but also with their own. They also found that some stroke caregivers had difficulty asking families and friends to help them, while others complained about their worsening physical health and the lack of concern from health professionals. Where higher amount of time were consumed in caregiving this could predict negative outcome of caregivers in social functioning, subjective well being and physical health (Anderson et al., 1995; Bakas et al., 2004).

Above all, stroke caregiving is not limited to only direct care for activities of daily living and specific caregiving, but also includes indirect care for instrumental activities of daily living and interpersonal care such as providing emotional support. However, little is known about how caregivers meet to their needs (receiving support). For more understanding, the nature of the stroke caregiving transition is clarified next.

2. Caregiving transitions

Transitions or turning points relate to the assumption that new roles and new relationships are normative. Schumacher, Jone and Meleis (1999) state that transition is a passage between two stable periods of time. Individuals will move from one life phase, situation, or status to another. The transition from order to chaos occurs when a system is pushed beyond its capability to deal with stress. To move toward chaos or to stabilize a new behavior, a person moves through an integration of the new change.

For individual and family transitions, changes occur in identities, roles, relationships, abilities, patterns of behaviors (Schumacher & Meleis, 1994), and lifestyle (Periard & Ames, 1993). Lifestyle is manifested in both social and individual identities in terms of leisure activities, personal care, and community activities. Moreover, stroke caregiving involves disruption in relationships within their

caregiving networks (Ewall et al., 2005). In contrast, some caregivers become closer with their networks due to working together for stroke patients, but the conflicts can become greater (Anantato, 2005; Anderson, et al., 1995). For understanding the patterns of care behaviors, an ongoing process from hospital to community is described.

Fraser (1999) identified the experiences of a new stroke caregiver in hospital in the transitional process. The process starts with changing relationships, becoming a caregiver then stepping back, enduring emotional turbulence, taking one day at a time, and struggling to hang onto hope. This study confirms that the transition process of the caregiver is a non-linear process in which a new stroke caregiver attempts to deal with problems and develops her capabilities to be a caregiver in a short period.

Studying the one-year period post stroke, in Thailand, Hirunchunha (1998) described the transitional process as having four stages: inability to adjust/think, a transition period, seeking/ modifying caring techniques, and settling into a normal lifestyle. Similarly, Burman (2001) supported this transitional process. She explored the trajectory management strategies of American stroke caregivers. She revealed five themes stemming from the belief that stroke caregivers had “no idea” about what the recovery of their loved ones would be like. They constructed a positive recovery, reconstituted family, maintained family routines, created a safety net, and redoubled self-reliance. These two studies provide a picture of transitions over a long-term period that show how stroke caregivers develop themselves and the nature of their transitions to maintain caregiving at home.

Moreover, caregiving transitions include not only moving from noncaregiving to caregiving experiences, but also moving from caregiving to noncaregiving experiences. In a three-year prospective study, Seltzer and Li (2000) reported three types of stroke and coronary artery caregiving transitions: entry, institutionalization, and bereavement. Some caregivers were still keeping the caregiving role, whereas, others ended the caregiving role by two transitions of caregiving. Institutional placement of the relatives and bereavement of caregivers has been found as process to end caregiving. Approximately one fourth (25.8%) of caregivers of persons with stroke and coronary artery disease were still providing care

5 years later, while others had moved from the caregiving roles because of their own death, their spouses' deaths, or the placement of the patient in a long-term care facility (Burton et al., 2003).

Stroke caregiving transitions are multidimensional experiences and are described as both forward and backward transitions. Caregiving transitional processes are presented and compared in table 2.1. Focusing on the transitional process from this table, the stroke caregiver has a personal transition from an unexpected role to a caregiving role with multidimensional experiences. Caregiving transitions in short term (Fraser, 1999), and long-term periods (Burman, 2001; Hirunchunha, 1998) are different in their beginnings and endings. Various studies provide evidence of turning points or events in dealing with transitions. The final critical points are stabilization in new routines, skills, lifestyles, and related self care activities (Meleis, Sawyer, Im, Hilfinger Messias & Schmacher, 2000).

Table 2.1 Comparison on caregiving transitional processes

Caregiving transitional process	Hirunchunha (1998)	Fraser (1999)	Burman (2001)
Inability to adapt/no idea	●		●
Remaining positive			●
Becoming a caregiver	●		
Change in relationships		●	●
Enduring emotional turbulence		●	
Time for self		●	
Seeking /modifying technique	●	●	●
Normalization	●		●

The outcomes of transition are a healthy transition or an ineffective role transition. Therefore, understanding transition provides more understanding of stroke caregiving.

3. Roles of caregiving

Schumacher (1994) pointed out that the term “role” stems from two schools of thought: structural functionalism and symbolic interaction. According to the

structural functionalism, roles are associated with positions in a social system. Roles are defined as behaviors, feelings, and expectations by selves and others following to their social positions. In contrast, from symbolic interaction, roles are defined as patterns of behaviors emerging from interaction. Roles are adjusted and defined by individuals as fluid. Therefore, integrating two perspectives, the caregiving role is viewed as a pattern of behaviors shaped by both individual and social norms. As the literature reviews on stroke caregiving role demonstrate, research has shown that role is not only one dimensional but there is multiple roles, such as woman's roles, marital roles, adult children's roles, working roles, and intergenerational roles.

3.1 Woman's role: Numerous studies have shown that stroke caregiving is a woman's role. Sixty to eighty two percent of stroke caregivers are women (Jullamate & Thanatwanich, 2001; Navarat, 2002; Srithares, 2003; Matayamool, 2003; White et al., 2003). Based on gender theory, the nature of caregiving is the woman's role because of two main reasons (Walker, Pratt & Eddy, 1995). The first reason is that social norm that expects a working role for a man and a household role for a woman. The second reason is an ideological factor that presumes that caregiving behaviors are the care activities of daily living such as cleaning, dressing and instrumental activities of daily living such as preparing food. These care activities are the household behaviors for a woman, while home maintenance chores, financial, and managerial assistance are behaviors for a man.

In contrast, Campbell and Martin-Mathews (2003) studied male involvement in caregiving, based on three concepts. The first concept is a commitment to care. There is less expectation of caregiving for male caregivers, but sons do feel filial obligations to become involved in caregiving. The second concept is legitimate excuses. Legitimate excuses means an inability to provide support such as not being available, lacking skills for the tasks, and geographic distance. The last concept is caring by default because no other individuals are available to provide care. This study showed that geographic proximity and sibling network compositions could predict men's involvement. Male caregivers live closer to elder relatives providing more care than those farther away. Men without siblings were more involved in care than men with brothers or sisters. In Thailand, Chaiyawut (2004) found that Thai men became stroke caregivers because of love and relationship (44.6%), followed by duty and

responsibility (39.1%), and there being no one else available (16.3%). The most frequent responsibilities of male caregivers are taking the patients to see the doctor, giving a bath, dressing, transferring, and so on. Moreover, based on restrictions of time and energy for caring, the number of children in the household has no significant effect for men becoming caregivers, whereas a woman having two or more children has a significantly lower rate of becoming a caregiver (Henz, 2006).

3.2 Marital role: Being a spouse and in particular a wife are valuable resources in stroke caregiving. Spouse caregivers feel obligated to care for stroke survivors at home, providing emotional support or assisting the person in activities of daily living (Larson, Franzén-Dahlin, Billing, Murray & Wredling, 2005). Research studies indicate that spouse caregivers can develop a realistic expectation of a stroke patient's abilities during the rehabilitation period and being married was a predictor of improved neurological functioning of stroke patients (Chantawatachai, 1999). Moreover, stroke patients with spouses complete rehabilitation more than those without spouses (Baker, 1993). Spouse caregivers are at risk of a high level of burden because of their own personal lives, heavy responsibility, constantly worry, and by the fact that stroke survivors rely only on their care (Coombs, 2007; Scholte op Reimer, Haan, Pijnenborg, Limburg & van den Bos, 1998; Morimoto, Schreiner & Asano, 2003). As a result of caregiving role, some spouse caregivers reported that they had adequate income for family expenses but they had no savings (Niyomthai, 2002; Srithares, 2004). Others had inadequate incomes with debts (Matayamool, 2003). Some spouse caregivers have problematic health conditions prior to being involved in a caregiver role (Meesuk, 2005; Navarat, 2002; Srithares, 2004). In a comparison of health problems of stroke caregivers, Prawtaku (2006) found that spouses have developed health problems at 50%, whereas children and sibling are at 30.8% and 34.6% respectively. Compared to non-caregiver, spouse caregivers had generally worse health at 5-year follow up (Burton, Zdaniuk, Schulz, Jackson & Hirsch, 2003).

3.3 Adult children role: Most Thai stroke caregivers are adult children in middle age (Chaum, 1993; Hiranchunha, 1998; Kenchaiwong, 1996; Kopachon, 2002; Natechang, 2002; Sangboon, 2002). Only few Thai stroke caregivers are spouses (Matayamool, 2003; Navarat, 2002; Srithares, 2004). Thai Adult children are supposed to take the main responsibility for taking care of their parents in any

situation (Gasemgitvatana, 1994). Research results showed that adult children spent a lot of times with their parents with stroke, the mean times were 12-18 hours a day and range of times were from 3-24 hours (Sangboon, 2002; Saengratsanee, 2004). As a result, some adult children caregivers had financial problems because they reduced the time of working for caregiving (Chuangawadisak, 1998) but others did not worry about expenses for the patients because of supporting for medical expense from the government (Songwattanayut, 2002; Saengratsamee, 2004). In contrast with Western studies, Fraser (1999) revealed the experience of daughters facing difficulty in their new roles. The caregivers felt that the stroke caregiver role impacted on their close relationship. They needed to get a break from their roles by taking one day a time. These results show the same problem on with difficult time but different outcomes.

3.4 Working role: Caregiving duty leads to caregiver life style change. Stroke caregivers attempt to balance between roles, commitments of caregivers, and activities other than caregiving, such as job responsibilities (Hirunchunha, 1998; Pierce, Steiner, Hicks & Holzaefel, 2006). Some stroke caregivers have to change their jobs (Srinim, 2001), maintain partial working status (Natechang, 2002), or quit their jobs (Kopachon, 2002; Perkdetch, 2002, Saengratsamee, 2004). Saengratsamee (2004) reported that 27.3% of Thai daughters quit their jobs to be stroke caregivers because they felt they could take care of patients effectively because of their responsibility/duty and love/bonding. Moreover, Henz (2006) found that there is a higher level of unemployed persons as stroke caregivers because they have more time or more family support than others. Female caregivers quit their jobs more than male because females generally have lower income jobs or only part time jobs. She suggested that increasing caregiver's job flexibility alone could not keep informal caregivers in employment.

In maintaining jobs, there are negative and positive aspects. Hirunchunha (1998) has addressed caregiver's role strain from lack of resources. She found that a patient can wake up many times at night and the caregiver has to wake up with him/her. As a result, the caregiver does not get enough sleep and feels tired because he has to work full-time outside the home. She concluded that combining work and caregiving roles brings about the conflict among caregiver's work, family, and personal role. In addition, Bouvol and Ford-Gilboe (2004) found that spouses'

employment status, number of supports, and functional independence of stroke patients predicted 40.6% and 46.3% of the variance in quality of life of patients and spouse caregivers. Employed spouse caregivers may be less available to their partner and decrease quality of life for both partners. On the other hand, complementary role have positive aspects such as a sense of accomplishment from handling the demands of each role, enhancing interpersonal relationships with co-workers as well as the care recipients, and opportunities to compensate for limitation experienced in each of the separate roles (Scharlach, 1994).

3.5 Intergenerational role: The caregiving role is shifting from self care of caregivers to collaboratively collaborative role. Intergenerational transfer means the distribution of economic, emotional and human resources from one generation to the next within an extended family structure, integrating both inter-household and intra-household exchanges (Hermalin, 2000). Numerous studies have shown that stroke family caregivers have at least one person to assist in caregiving (Chuangawadisak, 1998; Chumbler, 2004; Niyomthai, 2002; Peterson, 2002; Saengratsamee, 2004). Research results show that caregiving assistants are not only secondary family caregivers, but also paid caregivers and volunteer caregivers (Perkdetch, 2002; Sangboon, 2002; Songwattanayut, 2002). Bowers (1987) clarified intergenerational caregiving as an overlapping of care. She described five types of caregiving characteristics: anticipatory care (sharing opinions together), preventive care (active monitoring to prevent complication), supervisory care (checking up to evaluate care), instrumental care (working to maintain the patient's physical integrity and health status), and protective care (representing a reversal of roles for protection). Role reversal describes how roles change the child becomes "like a parent" and the patient "like a child". Moreover, intergenerational relationships have been investigated in Asian Americans and it has been found that adult children feel more obligated to their parents depending on financial and structural factors. Adult children's financial status and the elderly parents' needs for assistance were significantly associated with the frequency of adult children's support for their elderly parent (Ishii-Kuntz, 1997). Focusing on Thai intergenerational support, Pattaravanich (2001) found that adult children in central region were of less support to their parents than in the northeastern region. She gave two reasons why adult children increase support to their own children

and reduce their obligation to their parents. Firstly, adult children in the north and northeast remain in the parental household to take care their parents. Secondly, adult children in the central region encourage their children to pursue higher education and pay attention to their children rather than giving support to their parents. However, in regard to intergenerational role of stroke caregivers, it has been found that most stroke assistants were siblings at 55.5% (Kophachon, 2002; Navarut, 2002; Sangboon, 2002; Saengratsamee, 2004) and stroke caregiving is not only one person's responsibility; the whole family is involved in caregiving.

There has been a new type of home-care helpers. These helpers are both formal and informal caregivers. Porter and her colleagues (2004) identified four new types of home-care helpers: regular helper, on-call helper, can-will doers and mainstays. A regular helper is a helper coming at a specific time to do a certain task such as cleaning the house. An on-call helper is a helper with a new problem or in an emergency, or providing transportation on an irregular basis. A can-will doer is a helper for tasks that are too difficult for the caregiver to manage alone. A mainstay is a helper for not necessarily frequent and multiple responsibilities such as handling business affair and shopping. These helpers vary from providing willing, available, flexible to consistent help and social exchanges vary from none to cash, goods, non-monetary to monetary paybacks and public funds. The people involved as home-care helpers are kin, neighbors, friends, volunteers, hired helpers, health care providers, employees of government, agencies and business. Therefore, the pattern of caregiving has been changed overtime.

In brief, the roles of caregivers in stroke caregiving are not limited only to those of family caregivers but also expanded to the whole caregiving network. Little is known about patterns of care behavior in stroke caregiving networks. Studying the stroke caregiving process could provide deep understanding of caregivers' abilities in terms of coping and managing process.

4. Caregiving processes

In the literature of stroke caregiving, family caregivers deal with severe and long-term disability (National Stroke Association, 2005). Caregiving processes are cognitive and managing process. The cognitive processes are identified as the coping

strategies of family caregivers to deal with many problems over time. Coping strategies are adapting to change (Davis & Grant, 1994; Obe-om et al, 2006; O'Connell & Baker, 1994), giving positive meaning (Davis & Grant, 2004; O'Connell & Baker, 1994), motivating from love or sense of duty (Pierce, 2001; Subgranon & Lund, 2000), making comparison with others who are worse off, and using humor (O'Connell & Baker, 1994). Managing processes consist of the behavioral management in acute and rehabilitation care (Davis & Grant, 1994; Kerr & Smith, 2001; Srinim, 2001), and long- term care (Hirunchunha, 1998; Obe-om, 2006; Subgranon & Lund, 2000). The managing process is the process of constructing (Davis & Grant, 1994), time for recover (Srinim, 2001; O'Connell & Baker, 2004), promoting health behaviors (Srinim, 2001), changing the employment status (O'Connell & Baker, 2004), using family, friend, professional and community supports (Kerr & Smith, 2001; O'Connell & Baker, 2004; Peri, 1995), integration of all treatment modalities, promotion of caregiver's health, and modification of lifestyle (Srinim, 2001), and maintaining a balance between care-receiver needs and their own needs (Peri, 1995). In the short period, stroke caregivers focus on developing their capabilities to fulfill these needs.

With long-term care in rural areas, the stroke caregiving process is considered in regard to how to maintain caregiving at home. Research results indicated that stroke caregivers have developed their knowledge and skills, attitude, beliefs, empowerment, environment and resources to fulfill their objectives. Hirunchunha (1998) clarified how to develop stroke caregivers' capabilities and several resources have been used as "a care model". . This model consists of the process of preparing caregivers, developing caregivers' caring and self-management abilities, self-reliance on their caring abilities and adjusting to their roles, maintaining quality of care and adjusting their lifestyle. In addition, Subgranon and Lund (2000) described "maintaining caregiving at home" of stroke caregiving process in terms of seven contextual situations: caregiving as an integral part of life, caregiving as an unavoidable task, caregiving with love, sympathy, and attachment, family and kinship support; community support, managing treatment; and managing problems and difficulties. This study expands caregiving process into explanation of its cultural diversity. Obe-om and her colleagues (2006) found that family caregivers managed

long term care by adapting the home environment as a long term care setting, learning how to live with caring for stroke patients at home, and taking care of the family's health. The increasing family responsibility as being family caregivers related to increase family cohesiveness as well. This study confirmed that the caregiving process involves not only caregivers and their families but also internal and external environments of family caregiving. This study provides more understanding of the Thai family caregiving system culture.

In Western country, Coombs (2007) conducted a phenomenological study to understand the experiences of spouse caregivers for stroke survivors in semiurban and rural areas. The average length of the caregiving experience was 3.4 years. She explained how spouse caregivers experience a profound sense of loss, adjust to a new relationship with a spouse, take on new responsibilities, feel the demands of caregiving, have to depend on support of others, and maintain hope and optimism. She clarified the loss experiences of spousal caregivers as a loss of sharing in marital relationship, a loss of leisure time in their interests, and a loss of freedom to leave their homes. This study reflects the provision of support of stroke caregivers during the caregiving process. But they also received support, such as transportation support from their friends, psychological support from their families, and continuing caregiving from their faith and trust in God. Pierce (2001) conducted a descriptive ethnographic study at urban community in Northwestern Ohio. Stability in which the family's role in the caregiving process is described. Multiple complex processes were expressed by four themes: emotional burden, evasion of conflict, motivation from love and sense of duty between caregivers, care recipient, and their families, and filial value. This study provides different results on the caregiving process and confirms the differences in helping behavior between rural and urban area (Amato, 1993). Therefore, the caregiving process in urban area needs more study.

In summary, stroke caregiving processes require ongoing interrelationship roles and functions, which maintain a family's stability. Table 2.2 shows that using the cognitive and managing process. The process expands from a transitional process to long-term care relating to individual, family, friend, professional, and community supports. Stroke caregiving processes are compared in terms of acute and long-term care, and rural and urban area.

Table 2.2 Comparison on stroke caregiving processes.

Process	Early week		Acute & long-term		Rural area	Rural in big province (province)				Urban area
	Peri	Srinim	Davi & Grant	Kerr & Smith	Hirun chunha	Subg & Lund	O'Con & Baker	Obe- om	Coomb	Pierce
	1995	2001	1994	2001	1998	2000	2004	2006	2007	2001
Coping process										
Sense of loss									●	
Adapt to change		●					●	●	●	
Take new responsibility		●							●	
Motivation						●				●
Giving meaning			●	●			●			
Humor							●			
Burden							●		●	●
Conflict										●
Hope									●	
Beliefs					●	●				
Unavoidable task						●				
Managing process										
Construct reality			●							
Comparison							●			
Time for self							●			
Modification	●	●	●	●						
Balancing needs		●								
Employment change							●			
Management	●			●	●	●	●	●		
Support	●			●	●	●	●	●	●	●

The stroke caregiving process has expanded from the individual to the family, but there are few studies on the urban caregiving process which provide the configuration processes of caregiving. The outcome of caregiving is clarified to complete the picture of caregiving.

Outcomes of stroke caregiving

Stroke caregiving brings about negative, positive, and neutral outcomes. With regard to negative outcomes, stroke caregiving has been studied the caregiving demand and task difficulty as a caregiving burden and role strain (Chaiyawut, 2004; Matayamool, 2003; Prawtaku, 2006; Srithares, 2003; Songwattanayut, 2002). On the other hand, positive outcome of caregiving has been studied is used the term interchangeable with reward, gain, benefits, satisfaction, gratification, uplifts, and making meaning (Lawton, Rajagopal, Brody & Kleban, 1992; Montenko, 1989).

1. Negative outcomes

In the acute and rehabilitation phase, stroke caregivers spend time and energy on tasks of caregiving that disrupt their regular routines for personal time and that causes employment changes (Bakas et al., 2002; Chuansawadsak, 2001; Thipsamniag, 2006; Tooth et al., 2005). In long term care, stroke caregivers have decreased physical, psychological and social health (Chinsuwan, Chirawatkul & Nualnetr, 2007; Srithares, 2003). They have a feeling of burden (Bocchi, 2004; Chumbler, Rittman, Van Puymbroeck, Vogel, & Qin, 2004; Kotila, Numminen, Waltimor & Kaste, 1998; Wyller, 2003, Visser-Meily, Post, Riphagen & Lindeman, 2004), depression (Dennis, O'Rourke, Lewis, Sharpe, Warlow, 1998; Kotila, Numminen, Waltimor & Kaste, 1998; Han & Haley, 1999; Ski & O'Connell, 2007), hassles of caregiving (Anantato, 2005), caregiver stress (Anderson, Linto & Stewart-Wynne, 1995), strain (Blake, Lincoln & Clake, 2003; Bugge, Alexander & Hagen, 1999; Natechang, 2002; Matayamool, 2003; Meesuk, 2005; Perkdetch, 2002; Songwattanayut, 2002; Srithares, 2003), and low self esteem (Teel, Duncan & Lai, 2001).

1.1 Caregiving burden The burden of care relates to the balance between the needs of care and the resources they have. Numerous studies have shown that stroke caregivers have a feeling of being over burdened (Bocchi, 2004; Chumbler, Rittman, van Puymbroeck, et al., 2004; Kotila, Numminen, Visser-Meily, Post, Riphagen & Lindeman, 2004; Waltimor & Kaste, 1998; Wyller, 2003,). In addition, other problems are burdens of care from financial cost (Hickenbottom, Fendrick, Kutcher, Kabeto, Katz & Langa, 2002), and social isolation (Ekwall, Sivberg

& Hallberg, 2005, Larson, Franzen, Billing, Murray & Wredling, 2003; Miller & Montgomery, 1990).

The relationships between caregiving burden and social support have been shown to be significantly negative ($r = -.365$, $p < .01$). Social support was significantly negatively associated with subjective burden ($r = -.421$, $p < .01$) but not with objective burden (Qingping, 1999). Objective burden refers to actual demands and disruptions of the caregiving role, while subjective burden is defined as the distress experiences associating with these demands (Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003). In addition, Van Puymbroeck and Rittman (2005) found that caregiver burden was predicted by the caregiver's relationship to the stroke survivor at 1 month ($\beta = -.37$, $p < .0002$) at 6 months ($\beta = -.42$, $p < .001$), and the coping ability of the stroke caregiver at 1 month ($\beta = -.45$, $p < .0001$) at 6 months ($\beta = .47$, $p < .0001$). They identified a sense of coherence as a new factor in caregiver literature and as related to the ability of caregiver to mobilize their resources. Caregiver who mobilizes resource effectively has lower level of burden and fewer symptoms of depression.

In contrast, Thai caregiving studies have revealed different results from Western studies. Stroke caregivers had a mild burden (Taungsin, 2002; Tirapaiwong, 1997). Another study, Saewun (1994) found that the level of burnout of stroke caregiver is zero to mild emotional exhaustion and depersonalization. Focusing on the relationship, caregiving burden and social support were similarly significantly negatively related. Social support was significantly negatively associated with the objective burden ($r = -.4339$, $p < .001$), but not with the subjective burden of the caregiver (Kenchaiwong, 1996). Caregiving self efficacy was negatively related to caregiving burden ($r = .266$, $p < .006$), whereas support from nurse was not significantly associated with caregiving burden ($r = .035$, $p = .072$). Caregiving efficacy directly affected caregiving burden ($\beta = -.11$) (Taungsin, 2002). The results show that caregiving burden was predicted by patient-caregiver relationship at 13% (Tirapaiwong, 1997); social support and gender at 15.8%, gender and age at 13.7%, and age at 5.83% (Saewun, 1994). Therefore, good patient-caregiver relationships and caregiving self efficacy should promote for reducing burden in stroke caregiver.

1.2 Depression Much of Stroke caregiving research has shown that caregivers develop levels of depression at both acute stroke phase and chronic stroke phase (Han & Haley, 1999). The prevalence of stroke caregiver's depression ranges from 34% to 52% varied by the instruments, such as Center for Epidemiologic Studies Depression Scale (CES-D), Beck's Depression Inventory (BDI), the General Health Questionnaire (GHQ), the Hamilton Depression Rating Scale (HDR), the Wakefield Assessment of Depression Inventory (Han & Haley, 1999), and Zung self-Rating Depression Scale (Ski & O'Connell, 2007). Cameron and colleagues (2000) confirmed that 44.7% of stroke caregivers are at risk of depression. Some of them are likely to remain depressed from six months to two years when giving long-term care (Dennis, O'Rourke, Lewis, Sharpe, Warlow, 1998; Kotila, Numminen, Waltimor & Kaste, 1998). Caregiver depression is significantly associated with stroke survivor functional status at 1 month ($\beta = -.73$, $p < .0001$) at 6 months ($\beta = -.76$, $p < .0001$). Therefore, resulting from depression, stroke caregivers are at risk of coronary heart disease and increased mortality (Christakis & Allison, 2006; Lee et al., 2003).

1.3 Caregiver stress Relating to coping mechanisms, Lazarus and Folkman (1984) identified stressed persons as constantly appraising their transactions with their environment. Transactions are seen as a threat, challenge, and as harmful, requiring emotion-focused coping to control distress or problem-focused coping to solve the problem. Stroke caregivers have reported high levels of emotional distress (Anderson, Linto & Stewart-Wynne, 1995), and increasing anxiety and stress (Wilkinson, Wolfe, Warburton, Rudd, Howard, Ross-Russel, et al., 1997). However, in Thailand, family caregivers have reported mild stress from providing care, and mild to moderate stress from dealing with behavior problems of the patients. Stroke caregivers used a combination of coping strategies. The most common coping styles of stroke caregivers is confrontive, followed by palliative, and emotive styles (Jullamate & Thanatwanich, 2001; Sirapo-ngam, Puttawattana & Wongjunlonsin, 2002; Wongjunlonsin, 1999). The active coping strategies (such as confronting) are related to a positive effect on strain and depression in stroke caregivers, whereas the passive coping strategies (such as non confronting) are associated with a negative effect (van de Heuvel et al., 2001).

1.4 Hassles of caregiving The hassles of caregiving are defined as threatening or annoying or troublesome feelings relating to assistance with care in daily living. Anantato (2005) investigated the experience and management of stroke caregivers. The researcher found that bad conditions of stroke patients related to their having involuntary caregivers or having unsupported caregivers. The caregivers had negative responses when stroke patients got sick. They suffered from quarrels with their relatives over many issues such as who would pay and why the patients got worse. They worried about financial problems. They were in conflict with their family members because of their abilities to take care of their family. Finally, they were tired and got sick from the long hours of care.

1.5 Role strain Caregivers generally have experiences of role strain because of limited financial and physical resources (Mui, 1992). Bugge, Alexander and Hagen (1999) reported that 37% of stroke caregivers were experiencing strain at six months after stroke. Blake, Lincoln and Clake (2003) reported that 34% of stroke caregivers were at a high level of role strain at three months and 35% of caregivers have strain up to six months. Strain is predicted by caregiver mood. In contrast, Thai stroke family caregivers reported low levels of role strain (Kopachon, 2002; Natechang, 2002; Matayamool, 2003; Meesuk, 2005; Perkdetch, 2002; Songwattanayut, 2002; Srithares, 2003).

Focusing on relationship with other factors, evidence studies show that caregiver's role strain had positive relationships with strain from direct care ($r = .519$, $p < .001$), lack of resource ($r = .714$, $p < .001$) (Matayamool, 2003), strain from worry ($r = .33$, $p < .01$), and level of dependency ($r = .31$, $p < .01$) (Srithares, 2004). Caregiver role strain had negative relationships with economic status ($r = -.196$, $p < .05$), self-transcendence ($r = -.216$, $p < .01$), predictability ($r = -.242$, $p < .01$) (Matayamool, 2003), and mutuality ($r = -.18$, $p < .05$) (Srithares, 2004). Caregiver role strain had a non significant relationship with perceived level of dependency (Kopachon, 2002; Matayamool, 2003; Meesuk, 2005; Natechang, 2002; Perkdetch, 2002; Songwattanayut, 2002; Srithares, 2003), and no or a low level of perceived emotional exhaustion and depersonalization (Navarat, 2002; Saewun, 1994). Role strain is predicted by level of dependency at 9%, and by mutuality at 6% (Srithares, 2004), by direct care at 4% (Sangboon, 2002), and by worry from caring at 6-11% (Sangboon,

2002; Srithares, 2004), Worry from caring was the predictor that influenced the health status of caregiver ($R = .624$, $p < .001$) (Natechang, 2002). As a result, stroke caregiver with high perceived self-efficacy, high satisfaction with social support and frequent use of the coping strategy of confronting have less role strain and higher mental well-being (Van de heuvel et al., 2001).

1.6 Low self esteem Stroke caregiver functioning is not static. The caregiver reaction assessments investigated caregiver's responses to the caregiving environment over time. Teel, Duncan, and Lai (2001) conducted a longitudinal study at 1, 3, and 6 months after stroke. They found that stroke caregivers reported more difficult in the caregiving role and had more negative effects compared with caregivers of person with cancer. They identified that stroke caregivers had lower self esteem than cancer caregivers. This finding needs further study.

Numerous studies have indicated that 71-100% of stroke caregivers have some problematic health conditions after being involved in a caregiver role (Meesuk, 2005; Natechang, 2002; Prawtaku, 2006; Sritares, 2004; Sit, Wong, Clinton, Li, & Fong, 2004). Spouses have the highest level of health problems rather than siblings and children. These health problems are hypertension, diabetes mellitus and heart disease (Prawtaku, 2006), and minor illness are muscle pain in shoulders, back, arms, neck, wrists, and knees. They often have headache, anxiety, fatigue, low appetite, insomnia and weight loss (Natechang, 2002; Sangboon, 2002). Health related quality of life and quality of life of stroke caregivers are impact at two years after a family member's stroke (White, Poissant, Côté-LeBlanc & Wood-Dauphinee, 2006). Role strain and communication problems could co-predict caregiver's health status by 28.7%. Role strain was negatively associated with caregiver's health status ($r = -.483$, $p < .05$) and could predict caregivers' health status by 23.3%, while communication problems could predict caregivers' health status by 5.4% (Meesuk, 2005). Other problems are ineffective role and role conflicts, stroke caregivers have ineffective roles because of inadequate knowledge and skills in caring for patients (Chuangawadsak, 1998; Srinim, 2001), and financial problems (Anantato, 2005; Chuangawadsak, 1998; Kenchaiwong, 1996; Srinim, 2001). Role conflict refers to incompatibilities of role expectation. Stroke caregivers have role conflicts among

family members because of inability to take care of stroke patients and their own families (Anantato, 2005).

2. Positive outcomes

Stroke caregivers have positive outcomes in terms of caregiver satisfaction (Kenchaiwaong, 1996, Thipsamniag, 2000), caregiving good well-being (Niyomthai, Putwatana & Panpakee, 2003), rewards of caregiving from finding or making meaning (Ayers, 2000), and from gaining in care experiences (Kopachon, 2002).

2.1 Caregiving satisfaction is described as a positive outcome of caregiving. Stroke caregivers reported a high level of life satisfaction with self, roles, and interdependence relationships. Thipsamniag (2000) reported overall mean scores of time spent in stroke caregiving were at moderate level, while overall mean scores of patient-caregiver relationship, and life satisfaction were at high level. She has analyzed these relationships and has reported that life satisfaction of caregiver is not associated with caregiving demands of stroke patients but positively correlated with the patient-caregiver relationships ($r = .605$, $p < .05$). She reported that stroke caregivers had the most satisfaction on feeling themselves important to the patients, whereas the least satisfaction derived from feeling burdensome for asking another's assistance. Chuchuyay (2004) echoed this result, saying that the highest capabilities of stroke caregivers were physical skill and satisfaction to take care of stroke patients, whereas the lowest capabilities were judgment and decision.

2.2 Caregiving well being The relationship among caregiving duration, family life events, family hardiness, and well being of stroke caregivers (Niyomthai, Putwatana & Panpakdee, 2003). Based on the Family Resiliency Model of Family Stress, Adjustment, and Adaptation developed by Mc Cubbin and Mc.Cubbin, they clarified family life events as the accumulation of family life changes. Any change makes demands for readjustment both in intensity and length of time to maintain homeostasis. They found that stroke caregivers had good well being, family hardiness at the moderate level, and family life events at a low level. Family life events and family hardiness explained 31% of variance in family caregivers' well being.

2.3 Reward of caregiving is the positive feeling that encourages caregivers to recognize the important of life and to be proud to be a caregiver. The reward of caregiving results from finding or making meaning and gaining in the caregiving experience.

2.3.1 Reward of caregiving from finding or making meaning Finding meaning through caregiving is the highest reward of caregiving (Sangboon, 2002). Ayers (2000) studied finding meaning of caregiving and classified the caregiving experience in terms of the process of expectation (as the predictor of events), explanation (as the reason for past, present, and future events), and strategies (as the action plans for fulfillment of chosen expectation). For example, a patient needs a shower. Caregiving is expected to help him. The caregiver explains this event as normal. The action is good provision of care. She explains the rewards of care resulting from love between caregiver and recipient. Therefore, love/bonding is a reason to become a stroke caregiver (Perkdetch, 2002; Pierce, 2001; Sangboon, 2002).

2.3.2 Reward of caregiving from gaining in the caregiving experience Gain in caregiving stems from the concept of caregiver gain. Krammer (1997) identified the relationship between caregiver resources and gain. Gain is the concept which is both event-specific and role-specific. Event-specific gain refers to responses to specific caregiving tasks, while role-specific gain refers to general appraisal of the caregiving role. Strain and gain are opposites on a continuum. Moreover, caregivers assess gained experiences in terms of received rewards from caregiving (Kopachon, 2002; Sangboon, 2002). Around forty to fifty percent of stroke caregivers received rewards during caregiving from their siblings, relatives, and neighbors in terms of food, and money (Perkdetch, 2002; Songwattanayut, 2002).

3. Neutral outcome

Few studies have found dual outcomes of caregiving. Sangboon (2002) found that stroke caregivers reported a high level of strain from worry and rewards of caregiving. In a qualitative study, Chinsuwan, Chirawatkul and Nualnetr (2007) explored perception of stroke caregivers. They found a broad spectrum from negative outcome such as the feeling of “a life of uncomfortable feelings, tolerance and embarrassments”, to positive outcome such as having “a newly empowered life with

freedom”. They described negative feelings including: a life filled with hardships, a feeling that they will always be looking after the sick, a sense of being slighted and/or neglected, a lack of fulfillment, and personal ill health. In contrast, they described positive feelings such as feeling life is better, taking pride in their works, feeling empowered, and bonding with the patient. These results show negative and positive emotional component in psychological well being. Negative and positive emotional outcomes have different antecedents, for example religious belief, kinship, kindness of others. Negative results are related to health and internal attributes, such as feeling of hardships and strain from worry. In turn, positive outcomes are associated with the external events, such as rewards of care and good patient-caregiver relationships.

The reasons or motivation of stroke caregiving are presented as antecedent of caregiving. The reasons are caregiving with love (Perkdetch, 2002; Pierce, 2001; Sangboon, 2002; Subgranon & Lund, 2000), sympathy and attachment (Subgranon & Lund, 2000), sense of duty (Pierce, 2001; Sangboon, 2002; Perkdetch, 2002), gratefulness (Perkdetch, 2002), satisfaction associated with the patient-caregiver relationships (Kenchaiwong, 1996; Thipsamniag, 2000), paying back (Sangboon, 2002; Perkdetch, 2002), and living in the same house (Perkdetch, 2002). The negative reasons are no one else available to assume the caregiving role (Perkdetch, 2002; Sangboon, 2002; Songwattanayut, 2002), no family responsibility (Sangboon, 2002; Perkdetch, 2002), no money to hire other caregiver, and unemployment (Perkdetch, 2002).

In brief, the caregiving concept reflects to antecedent, attributes and outcome in the stroke caregiving phenomenon. Antecedents of stroke caregiving have been revealed the reasons for caregiving but the social skill to mobilize resource needs more study. Attributes of stroke caregiving have been clarified in terms of task, role, transition, and process. Tasks of stroke caregiving expand from activities of daily living and instrumental activities of daily living to complex and difficult tasks. The role of caregiving is not a one-dimension but a multidimensional experience. Stroke caregiving transitions include forward and backward transition. Stroke caregiving processes have been described in the short period and long-term period. Finally, outcome of stroke caregiving has been classified in terms of negative, positive, and neutral outcomes of caregiving and not only typically focused on the patient and/

family caregivers. But also the family and social aspects are significant areas of concern. Therefore, social perspective and patterns of care need more understanding.

Social perspective

Caregiving is a family affair and cannot be completed by only one person. Caregiving involves many persons and activities. These processes focus only on the caregiver's mechanism, but not those of person in the caregiving networks. Social networks provide understanding of the structure and composition of persons in caregiving, while social exchanges explain more of the human behaviors in caregiving. The theoretical perspectives and related research will be reviewed in this section. Even though there has been little study specially aimed at caregiving networks in the context of stroke caregivers and their social exchange behaviors, there is an extensive literature on caregiving networks and social exchanges in the phenomena of elder care and care for chronically ill patients.

Social network concept

Social networks refer to the web of social relationships linking members (or actors or nodes) by one or more specific types of relations in terms of persons, objects, and events. (Mitchell, 1969; Moren-Cross & Lin, 2006; Seeman, Abert, Lusignolo & Bergman, 2001). Social networks emerged from the early work of anthropologists and sociologists as a methodological strategy to study families, communities and complex situations. Barnes (1954, 1984) applied social networks to analyze social relations in Norwegian fishing communities. Bott (1957) investigated married couples and social networks. These works represent anchor points for social networks.

Social network concepts have been analyzed for their attributes by many schools of thought. These attributes are network, linkage, and member attributes.

1. Network attributes (Carpentier & Ducharme, 2003; Laireiter & Baumann, 1992; Mitchell, 1969; Moren-Cross & Lin, 2006; Sokolovsky, 1986). Network attributes refer to characteristics of individuals in the network as follows:

1.1 Size Size is the total number of active network members.

Boonchalaksi (2000) has identified family size and elder care. She evaluated network size based on number of siblings of children and family members. Stoller and Pucliesi

(1991) defined size of the network as the number of helpers, other than spouse. Moreover, Bennett and his colleagues (2006) identified the size of network as the numbers of individuals including relatives and other close friends with whom the patients could discuss private matters or could call on in emergencies and whom the patient see at least once per month.

1.2 Density The members are interconnections with others in terms of volume and type of relationships. Lemieux-Charles and her colleagues (2005) investigated density of caregiving network in terms of type and numbers of individuals and organizations belonging to the networks. Type of network members consisted of care providers, programs and agencies (outpatient and ambulatory geriatric medicine, outpatient and community geriatric psychiatry, home health care, long term care), other organizations (educational facilities, planning, research, advocacy bodies), and individuals (family physician, consumers, and caregivers). Forrester-Jones and her colleagues (2004) explained network density as calculated by using the formula:

$$D = \Sigma N / P (P-1)$$

D means density and range from 0 to 1.00

P is the total number of members of social network

N is the number of contacts known by each member of it summed across all members.

1.3 Spatial distribution Spatial is used to describe things in terms of size, area, and position. “Birds of a feather flock together” refers to persons tending to befriend those like themselves (Wong, Pattison & Robins, 2006). Network members are distributed spatially in relation to ego. Rapael (1965) identified that the forms of political organization varies with spatial distribution of members and the size of membership of a network. Spatial distribution is used to evaluate social interaction. She divided two categories of spatial distribution spatially concentrated members (one to five), and spatially dispersed members (ten or more).

1.4 Homogeneity The network member attributes (e.g., age, class, and ethnicity) are selected for similarity. Kalmijn and Vermunt (2007) studied the homogeneity of social networks by age and marital status. They classified age groups and marital status differences, such as single, married; married and divorced; divorced and widowed and so on.

1.5 Degree of connection This is the average number of relations each person has with others in the same network. Degree of connection is measured by density and reachability. Reachability means the maximum number of ties it takes to connect any two nodes. Wongcharoenkul (1997) found that elderly people received information from both their close networks and outside their close networks. Relatives, friends, neighbors, leadership, and monks are all connection. The elders directly give them the news but their close networks provide more understanding of the information by reading it and explaining it to them. Therefore, degree of connection in close elder network is stronger than outside the network.

1.6 Number of social clusters Numbers of segments of a network have high-density interaction. Ray & Street (2005) investigated social support networks for caregivers. They identified number of social clusters in network including intimate friends, old friends, and general friends. Intimate friends were those people who caregivers shared deep feelings with. Old friends were important in networks but caregivers did not share the deeper levels of engagement. General friends were in sporting clubs, interest groups, and religious or cultural affiliations.

1.7 Dispersion Dispersion assesses an individual's ability or propensity to make contact with another; It is often measured in terms of geographic distance. A long distance between persons and social networks loosen the ties of connections. Konrad and colleagues (2002) assessed distance between parent and adult children such as child living in the same household, living in the same neighborhoods, living in the same urban community, living in a different community but less than two hours travel time away, and living further away.

2. Linkage attributes (Carpentier & Ducharme, 2003; Laireiter & Baumann, 1992; Mitchell, 1969; Moren-Cross & Lin, 2006; Sokolovsky, 1986). These attributes refer to relationships among ties within the network.

2.1 Duration The person who has close relationship over a long duration will receive more support. Wongcharoenkul (1997) assess duration by the number of years that the two people have known and related to each other.

2.2 Frequency of interaction Social networks have greater frequency of contact with close relatives and family than with those outside the family. Wongcharoenkul (1997) assessed frequency of interaction by the number of

interconnections between elderly and social networks. Dickinson and colleagues (2002) evaluated frequency of daily contact of the study group. A mean of contact in study group is 16 contacts within the previous month, whereas the comparison group is 29 contacts per month.

2.3 Directionality The direction is the transactional flow, such as instrumentally (from ego to another); reciprocally (between ego and another); and dependently (from another to ego). Pattaravanich (2001) studied intergenerational support and found that directionality of Thai adult children support is downward to their children rather than upward to their parents.

2.4 Magnitude The level of exchange within the context of a given content is clarified. Hermalin (2000) identified the magnitude as an amount of money or value of goods and amount of time exchange.

2.5 Activity field The institutional sector of society is occupied by a link (household, extended kin sector, co-worker). Wonganutrohd (2001) investigated community networks that were formed on the basis of diverse relationships by sharing of activities and interests via ceremony, belief, culture and occupation. The institutional sectors are local schools, temples and social groups.

2.6 Bases of link The circumstances vary as to whom joins a network with concept, such as fictive kin, job interaction, ritual procedure, playing a role. Jordan-March and Harden (2005) classified of caregivers outside the household. Fictive kin or chosen kin are defined as a family-type relationships relating to social linkage brought about through religious rituals or close friendship and non blood relations or marriage. Fictive kin is a resource of caregiving for older adult in Western countries. Similarly, Prakogpol and colleagues (2007) have identified *kalyanamitta* is a word from Buddhism that means good friends or good teachers. There are seven characteristics of *kalyanamitta* including being lovable, respectable, adorable, a counselor, a patient listener, able to deliver insightful discourses, and never leading to a useless end. People who are *kalyanamitta*, help each other as a resource of caregiving support.

2.7 Temporal fluctuation This linkage consists of short-term variations (diurnal, monthly, seasonal in contact). Lohapontakul (1996) studied network of a radio station (jor sor 100) that linked urban people through mobile phone

for reporting traffic conditions in Bangkok. Members exchange their information and feel free to contact others with a fair relationship. They link together in a variety of ways.

2.8 Content The resources flow in the dyadic transaction.

Girdwichai (2001) studied support network in the migration of Thai people. He found that the past experience of immigrants who had received support before meant they were likely to help news, immigrants most often through financial support.

2.9 Intensity This describes how intensely individuals are linked to others. Intensity reflects on the strength of relationships or diversity of connections. Girdwichai (2001) reported that the mean number of immigrants is 1.4 person accompanied with a close network and sub network. Different population affects the relationship of the persons and those who support them.

2.10 Uniplex-multiplex This classifies the diversity of linkage. Some have single status (uniplex), others have multiple status or multiple roles (multiplex). The single transaction links to networks member is uniplex, whereas multiplex involve multiple content. With regard to multiplex, Satusean (2000) classified communication networks flows among their networks via individual and group meeting through flipchart, booklets, follow up and advice.

3. Member attributes (Moren-Cross & Lin, 2006; Sokolovsky, 1986). These attributes refer to sociodemographic characteristics, such as sex, age, occupation, ethnicity, and residential location.

In summary, many attributes in social networks stem from a variety of schools of thought. The similarity and difference of these attributes are compared in the table 2.3.

Table 2.3 Comparison of characteristics of attributes in social networks.

Attributes	Mitchell 1969	Sokolovsky 1986	Laireiter & Baumann 1992	Carpentier & Ducharme 2003	Moren- Cross & Lin 2006
Network:					
Size	•	•	•	•	•
Density	•	•	•	•	•
Spatial distribution	•	•	•		
Homogeneity		•		•	
Degree of connection		•		•	
No. of social clusters		•	•		
Dispersion		•		•	
Linkage:					
Duration	•	•	•		•
Frequency of contact	•	•	•	•	•
Directionality	•	•		•	•
Magnitude		•			•
Activity field		•			
Basis of link		•			
Temporal fluctuation		•			
Content	•	•		•	
Intensity	•	•			•
Uniplex-Multiplex		•	•	•	•
Member:					
Sociodemographic features	•				•

In this study, network attributes only focus on size, and degree of connection. Linkage attributes concentrate on frequency of contact, and directionality. Member attributes focus on relationship. As a result, network analysis is developed as a tool to identify structures, interactions, and members in social networks.

Network analysis

Network analysis or structural analysis is a way to study social structure by emphasizing relations among others (Knoke & Kuklinski, 1982; Wellman, 1983). Network analysis has been developed from several different disciplines. Cook and Whitmeyer (1992) concluded that there are three sources for network analysis: empirical work in anthropology, the practice of sociometry, and more abstract mathematical models and theory such as biased net theory, and graph theory.

According to Wasserman and Faust (1994), network analysis views social relationships in term of nodes and ties. Nodes are the individual actors within the networks, and ties are the relationships between the nodes. These concepts are displayed in a social network diagram. Nodes are the points and ties are the lines. Social networks are classified in three types of diagrams. These diagrams show respectively centrality or centralization relationship, cohesive subgroup relationship, and position relationship and are presented in the following diagrams.

1. Centrality and prestige mode: Centrality is defined non directional relations, whereas prestige is defined by the distinction between ties sent and tie received (Wasserman & Faust, 1994).

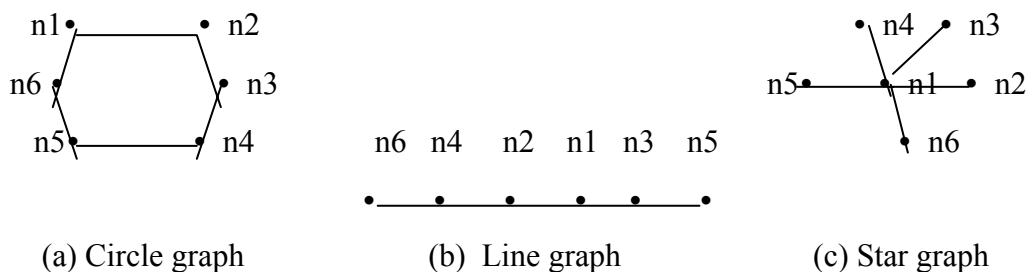
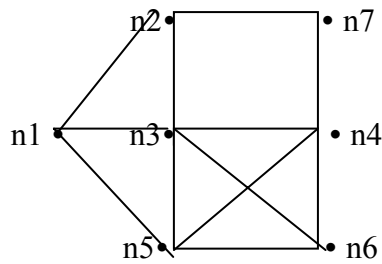


Diagram 1 Centrality and prestige model (resource from: Wasserman & Faust, 1994)

This diagram shows a relationship expanding from one to another. All nodes in the circle are interchangeable and should be equally central. One node in the star completely outranks the other, while the other five themselves are interchangeable. In the line graph, the nodes' centrality decreases from n1 to n2 to n3 and so on.

2. Cohesive subgroups relationship refers to subset of actors among whom there are relatively strong, direct, intense, frequent, or positive ties. Clique is a graph that completes a subgroup of at least three nodes.



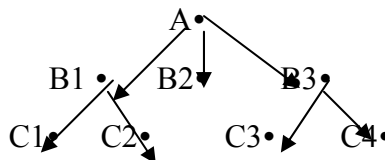
A graph and its cliques

Cliques: (1, 2, 3), (1, 3, 5), (3, 4, 5, 6)

Diagram 2 Cohesive group relationship (resource from: Wasserman & Faust, 1994).

This diagram shows the relationships among a big group. As a result, there are three levels in cohesive subgroup the individual actor, subset of actors, and the whole group.

3. Position relationship: Social position identifies actors who are similar in their ties with others. In social network, it is unlikely that any actors will be exactly equivalent. Equivalence means the formal mathematical conditions under which we will consider actors in a network to possess equivalence. Structural equivalence is a mathematical property of subsets of actors in a network. Two actors are in structurally equivalent if they have identical ties to and from all others in the networks.

**Diagram 3** Position relationship (resource from: Wasserman & Faust, 1994)

This diagram shows the social networks emerging from the most powerful member of the society.

The network's shape can determine the usefulness of social networks. Smaller and tighter networks are less useful than lots of loose connections (weak ties). A group of individuals with connections to a variety of networks should have access to a wide range of information more than can be accessed simply by the many connections within a single network. Network analysis identifies not only how structural properties affect behavior beyond the effects of normative prescriptions, personal attributes, and dyadic relationships, but also how the pattern of ties in a network affects the access of people and institutions to these resources, such as information, wealth, and power. These

relationships consist of two basic aspects: the content of relationships and the level of relationships (Knoke & Kukilinski, 1982).

1. The content of relationships

Network analysis investigates the contents of relationship by types of relations. Common types of relational content are transaction relations, communication relations, authority/power relations, and kinship relations.

Transaction relations refer to transfer of material resources. Relations include exchange of gifts, borrowing or lending items, and sales or purchases. Social support ties are an example of transactions.

Communication relations refer to patterned flows of information, where ties represent messages transmitted or information received.

Authority or power relations consist of ties that represent the authority of one actor over others, especially in a management setting.

Kinship relations have been studied by using network methods. Ties can be based on marriage or descent relationships.

3. The level of relationships

Network analysis is used to investigate from the simplest level of the egocentric network to the highest level of the complete network. In a large population and focusing on a particular problem, the egocentric network is appropriated to this study. In the small population, the whole network can be used to assess all of people in the study (Wonganutrohd, 2001).

As the literature review on social networks, the terms of social networks (Holtzman, Rebok, Saczynski, Kouzis, Doyle & Eaton, 2004; McGrath, 1986; Tennstedt, 1984), elder care networks (Kelley, 2002), helping networks (Coward, Cultler & Mullens, 1990), kinship networks (Holroyd & Mackenzie, 1995), and caregiving networks (Dwyer & Miller, 1990; Dwyer, 1988; Loretta, 2002; Moore, 1991; Sydelle, 1987) are used interchangeably. However, these terms indicate different unit of analyses with social support networks (Kelley, 2002). Social support is the main function of relationships, whereas social networks are the structure of relationships (Ryan & Austin, 1989). Social support focuses on interactional and interpersonal exchanges between selected network members, while social networks

pay attention outwardly to surrounding contexts and complex attachments (Pearlin, Aneshensel, Mullan & Whitlatch, 1996). The perspective of support in social networks involve attachment, social interaction, nurturance, reassurance of worth, reliable alliance with bloodline kin, and availability of support, such as affection, affirmation and aid over the course of life (Kelley, 2005).

In caregiving networks, social support is different from those in other stressful situation. Pearlin and his colleagues (1996) identified that dimensions of social support in caregiving networks have two sides of supports: providing support and receiving support. The former focuses on caregiver acting as donors; the other focuses on caregivers as the recipient of supports from others. Moreover, caregiving support consists of both social support and care support. Social support has also been studied in caregiving researches in terms of tangible, informational, problem solving, ego-enhancing, and emotional support (Pearlin, Aneshensel, Mullan & Whitlatch, 1996). Kelley (2005) classified behaviors for the provision of care support as involving three types of care. Firstly, care support is activities of daily living (ADLs; e.g., dressing, using the toilet, moving about the house, bathing, and transferring). Secondly, care support is an instrumental ADLs (IADLs; e.g., shopping, meal preparation, light and heavy housework, using the telephone, and laundry). Lastly, advanced ADLs (AADLs, are yard work, medication, taking care of money, and looking after long-term personal finances.

Network attributes related to caregiving

In this study, network attributes focus on size, degree of connection, homogeneity, duration, frequency of contact, directionality, and sociodemographic features, such as age, marital status, gender, and residential location.

Size: Size of caregiving networks is associated with the care recipient's age, gender, and marital status (Barrett & Lynch, 1999; Hibbard, Neufeld & Harrison, 1996; Stoller & Pugliese, 1991), whereas severity of patients is not relevant to network size (Teresi & Blum, 1994). The younger men and men of higher socioeconomic status have larger social networks than other men (Hibbard, Neufeld & Harrison, 1996). Marital status affects network size significantly and the married have smaller network than those who are not married because of decreasing social

relationships with others (Barrett & Lynch, 1999; Stoller & Pugliese, 1991). In female caregiving networks, the factors of age, years of caregiving and socioeconomic status of women caregivers are not significantly associated with the size of their social networks (Hibbard, Neufeld & Harrison, 1996).

Degree of connection: Degree of connection refers to the intensity of connection in caregiving networks. Cicirelli (1993) explained the process of the motivation to form a network as moving between attachment and obligation. Attachment appears to directly affect caregiving behavior, whereas obligation involves the family caregiver's adherence to internalized standards of proper filial behavior. At the present, many adult children hold traditional beliefs of obligations about support for parents in old age in larger social networks. However, future generations of elders will have fewer children. Therefore, informal care may need to become mobilized for resources outside the family, such as neighborhood community resources (Cornman, Lynch, Goldman, Weinstein & Lin, 2004).

Homogeneity: Network typology has been used as a practical tool or mechanism to identify the problems and predict the outcome of care (Wenger & Tucker, 2002). Wenger (1989), Litwin (2001), Fiori and her colleagues (2006) developed and modified five social networks types, based on closeness of ties, homogeneity, and the level of interaction between them. These types are family, friend, neighbor, diverse, and restricted (this type refers to a non-family network or a non-friend network). They confirmed that quality of support varied by network type. Individuals in a diverse or a friend-focused network perceived more love and care than those in a family-focused or restricted network. They explained that family is generally obligatory, whereas friendships are optional relation.

Duration: Elderly caregivers had limited density and reciprocity in caregiving networks after they had been in a long term care facility for six months (Bear, 1990). Cohen and his colleagues (1994) pointed out that caregiving networks were associated with the severity of a patient's illness rather than duration of caregiving. With increased illness severity, the informal network provides more material support to the caregiver by providing advice, intimacy, and friendship. In addition, formal networks provide more affective support to the caregiver.

Frequency of interaction In interaction theory, the frequency of interaction between friends and kinship are differentiated. Adams (1967) explained that consensus tends to be modal in friendship, and positive concern in kinship. Consensus refers to sharing common values, interests, and attitudes. In another aspect, positive concern is considered as a synonym for affection, liking, and attraction. Positive concern is mutual aid and a desire for contact that express a willingness to help if the need should arise. Individual may be frequent interaction without liking. A friendship network is suited to provide services that require an intermediate time commitment, whereas kinship ties are adapted to fulfill needs demanding a more long-term commitment (Barrett & Lynch, 1999).

Directionality: Transaction flow in network is reflected in directionality. Hirdes and Strain (1995) identified the balance exchange in instrumental support with network members outside the household. The researchers confirmed that the relationship with age and exchange is U-shaped curvilinear. The young and the old tend to receive more than they provide to others.

Age: Dwyer (1988) suggested that models of caregiving networks should include three stratified groups for elders with functional limitation. Household income has a significant impact on setting the caregiving networks when the care receiver is at aged 65 to 74 and primary caregivers care for two functionally limited older adults. Paid helper may provide care for specific functional impairments, particularly for those aged 75 to 84. Furthermore, Ray and Street (2005) found that people in older age groups identified more diverse but consistent support system, whereas people in younger groups reported more fluctuations in the strength of relationships.

Marital status: Unmarried women may maintain relationships with family members, including their children; in contrast, single men tend to rely on their friends. Children tend to provide assistance to widowed parents whereas other relatives, such as siblings more often help those who have never married (Barrett & Lynch, 1999). Based on social regression theory, Barrett and Lynch (1999) explained that married persons had smaller network sizes than the unmarried because marriage increases exchanges within the marital relationship and causes withdrawal from other

social ties. They further explained that the divorced/separated had the smallest networks compared with the widowed and never married.

Gender: In caregiving networks, Tennstedt (1984) indicated that primary caregivers were usually spouses for male recipients and offspring for female recipients. Male recipients reported higher level of care with more contact although they were less impaired than females. Although secondary caregivers were available for patients in families, the majority of care was provided by primary caregivers. Men have higher rates of assistance from informal sources, whereas women have formal care (Stoller & Cutler, 1992).

Residential location: Coward, Cutler and Mullens (1990) compared elder residence and four types of helpers: no assistance, informal help, formal help and mixed help. The researchers found no evidence of a significant association between residence and network composition. In contrast, Dwyer and Miller (1990) showed there are significant residential differences in characteristics of caregiving networks, but variation in primary caregiver stress and burden. In Thai families, Boonchalaksi (2000) found that small family size provides more supports and greater possibility of the family sharing the same household with their elderly parents compared to large family size.

Caregiving network outcomes

Caregiving network outcomes relate to genders, sizes and ties of caregiving networks. Focusing on the relationship of genders and outcome of caregiving, female caregivers had more conflict in their social networks than males (Hibbard, Neufeld, & Harrison, 1996). Fudge, Neufeld and Harrison (1997) explained the experiences of caregivers' satisfaction or conflict relating to the characteristic of their social networks. Female caregivers reported high satisfaction with diverse social support and a high degree of conflict related to kinship social network.

Relating to the relationship of size and caregiving outcome, the caregiving network has a direct effect on psychological distress (Cohen, Teresi, & Blum, 1994). Caregivers in larger networks reported feelings of loneliness less than noncaregivers (Ekwall, Sivberg & Hallberg, 2005). Interestingly, extended family members and non-family caregivers reported that they provided fewer hours of care than family

caregivers but they perceived the highest feeling of burden (Thiedecall, Finch, Huck & Kane, 1999). Members of a family network who provide only a little caregiving or non-caregivers had experience of depression symptoms rather than caregivers (Amirkhnyan & Wolf, 2003). Caregiver with a high level of resources reported a high level of caregiving competence, whereas caregiver with a lower level of resources had a high level of burden (Greenberger & Litwin, 2003).

With regard to relationships, weakness of relationships in caregiving network was significantly associated with caregiver burden, such as constraints in social activities, negative effects on family life, and a feeling of loss (Magliano et al., 2006). Low level of social interactions and few social ties was associated with mortality risk and was slightly higher for women than men (Orth-Gomér & Johnson, 1987).

In another view of caregiving networks outcome, relating to the care recipients, the caregiving networks research provides understanding of the relationship between care recipient health and their networks. The average length of hospital stay was directly associated with the proximity of the primary informal caregiver. Increasing the distance between the elder and the caregiver from 0-15 minutes to 30-60 minutes resulted in a predicted increase in the average length of stay of 6.5 day (Skinner, 1991). The interaction in larger social network prevents cognitive decline of patients at follow up 12 years later relating to interpersonal activity and emotional support to cognitive function (Holtzman, Rebok, Saczynski, Kouzis, Doyle & Eaton, 2004). Furthermore, the relationship between a regression of functional status of the care receiver and stability of type or of caregiving networks becoming smaller can predict institutionalization. The elders who had no care or formal care only were at a greater risk of becoming nursing home residents (Chao, 1997). Moreover, elders with serious health problems have poor outcomes related to their lower levels of social support to access formal and informal networks (Cleak & Howe, 2003).

In brief, social network analysis defines a person's social environment and their relationships. This can be shown by means of diagrams (Dekker, 2003). In addition, McGrath (1986) has used social network analysis to study the social bonds of terminally ill persons. Bear (1990) has examined the characteristics and patterns of interpersonal ties and their effects on behavior. Kossinet and Watts (2006) explained

that the networks as a whole tend to be stable, but the individual level (properties of interaction) is unstable. Moreover, Cohen and Sokolovsky (1979) used network analysis to provide quantitative and qualitative data for therapeutic interventions and agency planning decisions. However, as the literature review in caregiving networks, shows social network analysis should not have to and cannot explain human behavior precisely (Mitchell, 1969). Many theories have been utilized to explain the detailed information of behaviors. Two of these theories are interaction theory (Adams, 1967), system theory (Schulberg & Baker, 1970), and social exchange theory (Hirdes & Strain, 1995).

Cook and Whitmeyer (1992) explained that social exchange theory and network analysis are based on similar concepts of both action and structure. Conversely, they are differentiated by the nature of the ties that make up the networks. Network analysis has been used less theoretically and more empirically than has social exchange. Network analysis refers to the evidenced observation that sees the pattern of interaction of many actors who are linked in networks. Social exchange theory consists of exchange relations of value items and motivation by interests or rewards/punishments from individual level to groups, organizations or the nations of networks and much more. Therefore, for a better understanding of the motivation of caregiving, this study utilizes social exchange theory to clarify patterns of social exchange behaviors and utilizes network analysis to identify persons and relationships in caregiving networks.

Social exchange theory

Social exchanges, then borrows concept from economic exchanges for understanding people's behaviors. Anthropologist, sociologist, and psychologist also are more interested in complex social exchange in terms of various motivations than economists, who consider only self-interest (Uehara, 1990).

Social exchange theory was developed in the early works of economics. The general characteristics of social life, such as goods, services, companionship, information, and status serve a similar function to money in economic exchange. The history of social exchange has been developed by two approaches. The structural

approach is most common in anthropology, whereas the motivational approach is developed by sociology and social psychology (Befu, 1980).

Based on motivational approach, sociologists and social psychologists have developed social exchange theory to explain how interactions in social life are limited by norms and roles (Molm, 1997). The motivational approach focuses on individual strategies of exchange. Much research reveals attitudes and motivations toward caregiving based on mechanism of social exchanges: reciprocity and altruism (Tennstedt, 1984; Fudge, Neufeld & Harrison, 1997; Jordan-Mersh & Harden, 2005).

Reciprocity is an individual exchange mechanism to motivate for caregiving networks. Hamilton and Sandelowski (2003) explained that individuals engage in reciprocal relationship when the proportion or numbers of network members giving and receiving support are equal. They identified reciprocal mutual aids as a strategy. Network members pool their resources as a support bank or social fund. Individuals deposit and withdraw resources in the extended family as they do with money in a banking system.

Altruism is classified as a specific type of reciprocal interaction among two or more individuals (Jaffe, 2002). In nature, Wilson (2005) explained kin selection as the key to altruism. Under the rules of natural selection as defined by Charles Darwin, Wilson argues that altruistic behavior is an individual interest serving the interests of a larger group beyond its own offspring: siblings of the queen bee, for example protect her and form a colony. Kin selection theory describes all interactions throughout a group of relatives and non-relatives by their interests. As a social exchange mechanism, reciprocity is considered the balance of both caregiver and care receiver, whereas altruism is the imbalance of relationship.

On the other hand, based on the structural approach, anthropologists expand social exchange theory from two mechanisms in sociology to three theories in order to understand the social or cultural rules as adaptive strategies of human aggregates (Befu, 1980; Uehara, 1990). The structural approach is considered in light of the rules of exchange and a cultural frame of reference. Individual strategy is ignored or a few are mentioned as variables. This approach focuses on social exchange as a cultural system, as a system of norms and values. Three theoretical frameworks

are equity theory, theory of indebtedness, or resource theory (Gergen, Greenberg & Willis 1980).

1. Equity theory

Walster, Walster and Berschied (1978) described equity theory as relating to issues of fairness. Individuals who discover they are in an inequitable relationship will attempt to eliminate their distress by restoring equity. The individuals will release their distress by two mechanisms through “actual equity” or “psychological equity”. Actual equity refers to alteration of one’s own behaviors and/or those of others person, involving in the exchange. Psychological equity is to change own perceptions of the situation.

Social exchanges based on equity theory have been applied in areas of caregiving (Ingersoll-Dayton, Neal, Ha & Hammer, 2003; Wright & Aquilino, 1998; Ybema, Kuijer, Hugedoorn & Buunk, 2002). Ingersoll-Dayton and her colleagues (2003) studied the caregiving process of siblings providing parental care. They found two thirds of siblings were inequitable relationships, whereas one third were in equitable. situations. They confirmed that siblings used a variety of behavioral strategies to forge actual equity and/or used cognitive strategies to forge psychological equity. The actual equity strategies are visiting, emotional support, and financial help, whereas psychological equity is achieved by sharing of care. These strategies are influenced by gender, employment status, proximity, other family responsibilities, and personality of siblings. In addition, Wright and Aquilino (1998) identified the significance of emotional support within spousal caregiving relationships. Based on the equity assumption, when wife caregivers reciprocate in helping their husbands, they experience both giving and receiving support as a balance in exchange relationships. These wives reported lower levels of burden and higher levels of marital happiness. In contrast, Ybema and her colleagues (2002) examined to the correlation between caregiver burnout, marital quality and perception of inequity. They reported that higher perceptions of inequity are strongly associated with higher rates of emotional exhaustion and depersonalization, and lower feeling of personal accomplishment.

2. Theory of indebtedness

Greenberg (1980) identified the fact that people feel that they should help and not injure those who have helped them. The recipients can reduce their feeling of indebtedness by reciprocating the benefit, and/or they can cognitively restructure the situation by enlarging their past and future time perspective. In repaying a past debt, a recipient reevaluates his or her beliefs about the locus of causality of the donor's action and the donor's motives for providing benefit. Focused on increasing their contribution in the future, the recipient convinces himself or herself to anticipate opportunities for reciprocity. This cognition is not only to reduce the magnitude of indebtedness but also to decrease some of his or her discomfort and tension.

While theories of indebtedness and inequity have the same antecedents, they have different consequences (Gergen, Greenberg & Willis, 1980). Both can be viewed as forms of what an individual receives from another and what he/she ought to repay in the normative sense. In contrast, these two theories differ in four important areas. Firstly, equity motivation results from the imbalance between the outcomes and inputs of caregiver and care recipient, whereas indebtedness motivation recognizes the disparity and the reason for motivation helping the recipient. Secondly, indebtedness associates two parties: a caregiver and a care recipient, whereas inequity often involves a third party who has power for allocation of rewards between two individuals. Thirdly, not all activities of reducing inequity are appropriate for reducing indebtedness. Inequity tends to balance by increasing caregiver's inputs or decreasing his/her outcomes. Conversely, indebtedness works by increasing caregiver's outcomes and/ or helping care recipient to reduce caregiver's inputs. Lastly, inequity implies a third party, whereas indebtedness implies only two.

3. Resource theory

A resource refers to anything transacted in an interpersonal situation. Tornblom and Foa (1993) used resource theory to understand the cognitive organization of inter personal relationships. This theory builds on the economic model and learning theory. There are two principles, underling resource theory: gain and loss come from economics and reward or punishment from learning reinforcement theory. The resource theory classifies reward and punishment into six classes: love, status,

information, money, goods, and service. People are more likely to choose the same resource in exchange for a given resource.

Resource categories are separated into two dimensions: particularism versus universalism and concreteness versus symbolism. Particularism refers to give a resource for the particular people or general people in social exchange. In another dimension, concreteness refers to interpersonal behavior from object to symbol performance that are the form or type of expression characteristics. Berg, Piner & Frank (1993) expanded two dimensions to five dimensions of exchange between close and causal relationships. Firstly, a close relationship is more interdependent. Secondly, highly particularistic resources, such as love, are exchanged between people who have a close relationship. Thirdly, close relationships are expected to exchange different kinds of benefits rather than those in a casual relationship. A fourth in casual relationships, the exchange is based on the norm of reciprocity or a contribution rule. The people give the benefits to others because they have benefited from them in the past or will in the future. Lastly, people with close relationship are expected to self-disclose to the other this is not expected in causal relationships.

In brief, using these theoretical perspectives, social exchange scientists describe the mechanism of giving and taking. Balanced and imbalance relationships are explained by equity theory. In contrast, as for the disproportion between giving and taking, resource theory is considered to have positive and negative outcome/resources, whereas theory of indebtedness expresses deals with receiving or inputs in the past.

The three theories provide assumptions behind social exchange theory. The scope of the assumptions of social exchange theory covers actors, resources, structure of exchange, and process of exchange (Molm, 1997).

Actors: Actors behave in ways that increase outcomes they positively value and decrease outcomes they negatively value.

Resources: Every class of valued outcomes obeys a principle of satiation (in psychological terms) or diminishing marginal utility (in economic terms). While economic exchange focuses on the exchange of goods or services for money, social exchange is wide ranging.

Structure of exchange: Exchange relations develop within structures of mutual dependence. Structure of exchange describes the patterns of relations among actors. There are direct exchange, indirect exchange, and productive exchange (Molm, 1997).

1. Direct exchange: Each actor's outcomes depend directly on the other actor's behaviors. The transaction between two actors is defined as same as the reciprocal exchange (Lawer, Thye & Yoon, 2000)

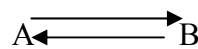


Diagram 4: Direct exchange (resource from Molm, 1997)

2. Indirect exchange: In three-actor exchange, the indirect reciprocity involves only one additional actor. The form of exchange is defined as generalized exchange in which A gives B who gives to C who gives to A. (Lawer, Thye & Yoon, 2000)

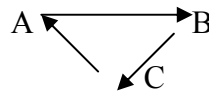


Diagram 5: Indirect exchange (resource from Molm, 1997)

3. Productive exchange: Most actors in the relations must contribute in order for either to obtain benefits. This exchange relates to mutual interdependencies that collaborate to individual actors. Lawer and his colleague (2000) explain four properties of productive exchange: Involving two or more individuals, joining together for outcomes, occurring in the context of significant problem and exchanging from person-to-group.

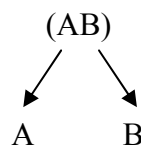


Diagram 6: Productive exchange (resource from Molm, 1997)

Process of exchange

Exchange transactions: Benefits obtained from other actors are contingent on benefits given in exchange.

Exchange relations: Actors engage in recurring, interdependent exchanges with specific partners over time.

Social exchange theory consists of four propositions (Molm & Cook, 1995).

1. People depend on one another for the things they value,
2. People behave in ways that increase the outcomes they value and decrease outcomes they do not value,
3. People engage in organizing mutually contingent exchanges with specific partners over time,
4. All outcomes obey a principle of satiation-that is, diminishing marginal utility or, conversely, increasing marginal costs.

Three significant concepts of social exchange theory are norms of reciprocity, the rule and strategy of exchange, and a cultural frame of reference.

1. Norms of reciprocity

Norm of reciprocity serves as starting mechanism to be motivated to initiate interaction. Reciprocity refers to the normative obligation of recipients to assist persons who have provided help to them (Gouldner, 1980). Balance is a central concept in reciprocity. Helping exchange within particular relationships is always giving support in one hand and receiving support on the other hand. However, norms of reciprocity in families differ from economic exchanges in that they need not involve equal, direct, or coexisting transactions (Horwitz, Reinhard & Howell-White, 1996). Each culture has a set of normative values. The concept of fairness is prevalent in American culture, whereas the concepts of “*katanyu katawethi*” and “*Boon-kun*” are prevalent in Thai culture (Kespichayawattana, 1999; Sasat, 1998).

2. Rule of exchange

The rule of exchange refers to specific cultural roles governing particular manner of giving and receiving. Schreck (1994) identified the role of the local church in strengthening social networks of the elderly. Volunteerism is seen as a

form of exchange through three factors: costs and rewards, perceived distribution of resources, and social distance. The volunteers provide a variety of services to older people in their own homes. The degree of closeness and the frequency of interaction were both significantly associated with the frequency of receiving support from church members (Taylor, Lincoln & Chatters, 2005). In family caregiving, the daughters received aid from mothers in turn for help they give while mothers who reported giving advice and money had better health (Walker, Pratt & Oppy, 1992). There are a variety of children and adults' activities to assist elders both with services and commodities while elders provide different motivational mechanisms: historical, current, and future reciprocity for children and adults in their care networks (Kelley, 2005). Moreover, Kelley (2005) identified the gender differences in elder care. Men were less involved in actual activities than women. She noted a reason that this was partly based on the poverty in a village, the men migrated to urban areas for work.

In Thai society, family caregivers look after their elderly relatives in all aspects, such as helping with activities of daily living, medical care etc (Papangkorn, 2003) while the non co-resident children are the sources of economic, gifts of food and useful items, and frequent visitation to their parents (Knodel & Chayovan, 1997). In turn, most of elders provide a crucial role as supporters both for their own families and communities. They take care of their grandchildren, cooking, cleaning, looking after the house, financial support, and joining social and religious activities (Yodpet, 2005).

3. Cultural frame of reference

Cultural frame of reference sets the background from which the norm, rules, and strategies operate. Relating to practicing of reciprocity in African American communities, Nwoga (2000) developed program "take-a-village (TAV)" to construct a health promotion model based on exchange system. The kinship network is both the support network and a critical part of Afrocentrism philosophy. The rules of this network of kin and friends include giving, temporary child exchange or child keeping, shared parenting, and the maintenance of a stable number of people who share reciprocal obligations. Others are to do with family support during illness.

In conclusion, the mechanisms of social exchange provide understanding the dynamic process in caregiving network. Based on three theories, norms of reciprocity, the social or cultural rules and cultural frame of reference provide better understanding why the people exchange in caregiving network. A variety of forms of exchanges demonstrate how members in caregiving networks operate both in family care and non-family caregiving. The caregiving networks and social exchanges are guides in this study. Caregiving networks are the structures through which care is organized and delivered, while social exchange is one way to conceptualize the reasons for care. Instead of only looking at the typical characteristics (age, gender, and socioeconomic status) as involving individuals, it may be fruitful to think of those actors as members of caregiving networks. The characteristics of the linkages and nature of what is to be exchanged are highlighted. Particularly, the cultural backgrounds, affecting caregiving are clarified.

Cultural perspective

During caregiving process, many decisions based on cultural background of caregiver (Purnell & Paulanka, 1998) are made. These cultural backgrounds encompass both cultural universals and cultural diversity.

Cultural universals are the common features across all societies. They exist as basic values and social processes in terms of perceiving, evaluating, feeling, and acting (Cuff & Payne, 1981 cited in Tabane, 2004). All cultures have recognizable expectations for patterns of caregiving. Some of these include the idea that caregiving is the women's role. Shaibu and Wallhagen (2002) show that the care of the elders and disabled is generally considered women's work and includes tasks that may be taboo for men, for example bathing, dressing, and toileting. Moreover, Walker, Pratt and Oppy (1992) have demonstrated social and ideological structures that contribute to the idea that caregiving is women's work. Focusing on social structure, women take on unpaid care responsibilities or accept lower payment than men under the limitation of available formal care. The ideological underpinning differentiates paid work as the dominant role for men and natural caregiving as the dominant role for women.

In another view of cultural background on caregiving, cultural diversity refers to the different values, norms, and behavior that vary from culture to culture (Popenoe et al., 1998). Much of the literature deals with ethnic difference in minority groups. Dilworth-Anderson, Williams and Gibson (2002) reviewed caregiving experiences and found that outcomes varied across racial and ethnic groups. There are four domains of social support, negative effects, coping, and cultural effects. This study had a limited understanding of caregiving among diverse groups because of its nontheoretical approach. Pinquart and Sörensen (2005) used a meta-analysis to investigate ethnocultural differences in care between ethnic minority caregivers and white caregivers. The results show that ethnic minority caregivers had lower socioeconomic status, were younger, were less likely to be a spouse, more likely to receive informal support, and they had stronger filial obligation beliefs to provide care than White caregivers. The Asian-American caregivers used less formal support than others, that Hispanic and Asian-American caregivers had higher levels of depression than Whites and that lowest burden and depression was found in African-American caregivers. All groups reported worse physical health than Whites. The ethnic difference is confirmed.

In contrast, Ayalong (2004) found commonality across different ethnic groups. The researcher used four theories to explain caregiving experiences across three ethnic groups of African-American, Caucasian American and Latino caregivers. The researcher indicated four major themes that characterized the caregiver experiences. There are caregiving dissonance, the role of culture, familial conflicts, and formal service use. With regard to caregiving dissonance, caregivers reported both cognitive and emotional dissonance. Dissonance is a lack of agreement between the contradictory experiences. This study showed that caregivers had both satisfaction and burden. These contradictory experiences need to be recognized together rather than separately and resolved to alleviate symptoms of anxiety, depression, and burden of caregivers. The second theme is the role of culture. The researcher has described traditional informal care was the mechanism for socialization of family members into caregiving. Family caregivers were concerned on changing of caregiving in the next generation because of assimilation to the majority culture. The third theme is familial conflict. This conflict varied with the level of familial involvement. Interestingly, there

is also conflict between caregiver and care recipient. The last theme is formal service use. All caregivers in this study attempted to keep caregiving in the family system for many reasons. These reasons were dissatisfaction with the quality of formal care, the view of caregiving as a personal responsibility, lack of visibility of formal services, lack of culturally sensitive services, lack of financial resources, and the wish to keep patients in natural environment. By focusing on similarities across three ethnic groups, this study supports the idea of caregiving as a part of cultural system. For more understanding of cultural care, the definition of culture needs to be clarified.

In an attempt to define culture, Tripp-Reimer (1984) identified the culture as a three-tiered pyramid made up of values, beliefs and patterns of behavior. Values positioned at the base of that pyramid play a central role in a culturally diverse family and shape the ideas and behaviors. Values do not exist in isolation in the same way as symbols. They relate to one another to form a unified pattern and come in pairs by positive and negative values (Tabane, 2004). In the literature of caregiving research, values of autonomy versus interdependence, and individualistic versus collectivist have been consistently identified. Going beyond basic values between individualistic vs. collectivist, Wallhagen and Yamamoto-Mitani (2006) compared the value placed on caregiving by daughters in the U.S. and daughters-in-law in Japan. The researchers found that in the U.S., the source of value for caregiving comes from a personal perspective about what is happening to caregivers. Caregiving generates a diversion in their life as an unexpected caregiver. On the other hand, societal expectation is the source of value for the caregiver in Japan. Caregiving responsibility is a recognized as cultural norm for daughters-in-law or unmarried daughters. Caregiving in the U.S. emphasizes individualism, separateness of persons, and controllable worlds that involve reason. Caregiving in Japan by comparison is premised in a collectivist/interdependent world where intuition and connection are central values of the society. Therefore, this study confirmed the different culture in caregiving relating to collectivist vs. individualistic value.

The second-tier of pyramid, beliefs are the state or habit of mind in which trust or confidence is felt in person or things. Beliefs are the blueprints from which persons develop their identities within families, professionals, and communities (Wright, Watson & Bell, 1996). The distinction between values and beliefs are family

values as a whole unit while beliefs are particular to the individual within the family does the caregiving tasks. Filial piety is a prominent belief about caregiving (Dilworth-Anderson & Burton, 1994). Filial piety operates to foster respect and obligation. Filial piety refers to an expectation that the young will respect the old. Chow (2004) classified filial piety into three levels at which children should practice respect. The first level starts with taking care of their parents' basic physical needs, followed by the objectives of making their parents' happy and ultimately proud. Within this belief structure, Asian elders expect support from their children, especially their married oldest son's family (Sheu, 1997). Beliefs about filial piety form the basis of traditional Asian caregiving ideology (Albert, 1992; Pinquart & Sorensen, 2005), especially in Chinese (Sheu, 1997; Reese, 2003), Japanese (Asai & Kameoka, 2005), Korean (Kim & Theis, 2000; Yu, 2002), and Thai families (Caffrey, 1992; Kespichayawattana, 1999). Another aspect of filial piety, obligation relates to commitment to caregiving (Campbell & Martin-Matthews, 2003). Chao and Roth (2000) studied the experiences of Taiwanese women caring for their parents-in-law. For these women "Just doing" emerged as the core theory explaining, how these women accept the caregiving role. They recognized that their duties relate to the beliefs of obligation, repayment, women's role and humanity. They have much more experience with trials, and responding to the caregiving situation as a routine. Expectation to maintain this normative structure is influenced by religion, philosophy, and reflects how the caregiver interprets her caregiving role and her ability to ask for help or resources for difficult process of care.

Patterns of behaviors, the top level of the cultural "pyramid", refer to the communication, religion, family patterns, recreation, and dietary habits. Patterns of behaviors in caregiving among minority groups have been extensively studied (Braun, Takamura, & Mougeot, 1996; Daker-White, Beattie, Gilliard & Mean, 2002; Yeo & Gallagher-Thompson, 1996). The knowledge of different ethnic and minority groups provide important insights into variations in how these groups take care of family members (Dilworth-Anderson & Burton, 1994). However, some concepts, developed and defined by the dominant American culture are not appropriately applied to eastern culture. Braun and her colleague (1996) explored the perceptions of dementia among Vietnamese refugee caregivers and help seeking behaviors within that context. They

found that the symptoms of dementia were considered as a natural part of aging. Hierarchical family and community structures were seen as more important than individuals. Older adults are highly respected by everyone, followed by men, women, and then children. If the elder's behavior needs modifying, the children do not use reason or threat, but must use *nói ngọt* or 'sweet talk'. These patterns are shaped by their cultural values and beliefs systems.

Specially, in Thai culture, the interdependence and the interactive relationships of people is a significant characteristic in an agricultural work pattern. Thai people usually participate with their family and others in the community. Temple is the center for a number of activities of Thai people (Fox, 2005). In addition, hierarchical positions are established in Thai society. Evidence in the past, is supplied by the concept of the power of the land, in Thai language "*sak-di-na*" which provides the picture of inferior and superior relationships between the peasant and the landlord (Pongpaichit & Baker, 1996). In the community, the villagers should respect and follow their leader. In the family, adult children should respect and support their elderly parents. Therefore, interdependent relationships between across and hierarchical groups are viewed as a Thai value.

"Do the best and the best things will return to you:" reflects the beliefs in Thai culture: It is modeled upon a Buddhist principle. Ninety five percent of Thai people are Buddhist, whereas 5% are Muslim, Christian, and Hindu (Knodel & Chayovan, 1997). According to religious belief, the concept of "*karma*" is a belief in cause and effect. An action in this life will have an impact on the next life. Thai people adopt this idea as a traditional ideology of caregiving. Many people's position on caregiving is that helping each other together is insurance for happiness in the future. In terms of elder care, adult Thai children believe in the behavior of taking care of their parents and grandparents to gain merit (*boon*, in phonetic Thai). Whereas, were they to refuse to provide caregiving, this would bring demerit (*bab*). Correspondingly, belief in a strong sense of moral obligation, coincides with parent repayment. The complementary concepts of "*katanyu katawethi*" and "*boon-kun*" are firmly embedded in Thai society. These concepts are founded in diverse reciprocal action. *Katanyu* refers to the sense of awareness or gratitude towards parents, and *Katawethi* is the obligatory actions of giving back by caring about and supporting parents. *Katanyu*

katawethi focuses specifically on the parent-child relationship. *Boon-kun* is the obligation of repayment of debt across many realms of life (Kespichayawattana, 1999; Knodel & Chayovan, 1997). In brief, caregiving is a way to repay their past deeds, to make merit, and to show gratitude to their elderly relatives (Subgranon & Lund, 2000).

As for patterns of behaviors in Thai culture, adult children will show respect to elders in their families and community in different ways. Ingersoll-Dayton and Saengtienchai (1997) classified forms of respect into five categories: gestures and manners, tokens, customs and rituals, advice, and obedience. The researchers described the traditional forms by which young people deal with Thai elders by naming them as if they were family members. For example, if at the elder is at the age of their grandmother, young people will call them grandmother. Focusing on customs and rituals during Thai New Year, adult children perform a variety of rituals by bringing elders food, presents, and ritually pouring water over their hands to receive lucky from them. Thai people will consult the elderly for advice on matter such as auspicious dates for weddings, house constructions, festival dates and solving problems. If the problem is small, older people are consulted. When there are larger problems, the village headman is consulted. For very serious problems, they would turn to the police (Ingersoll-Dayton & Saengtienchai, 1997).

The cultural perspective serves as the context of caregiving that clarifies our understanding about the motivations for caregiving. Researchers should go beyond ethnocentric and value laden perspectives to the perspective of humans as products of their own values and assumptions. Another perspective on caregiving is the social perspective, particularly the cultural backgrounds and social conditions that affect caregiving (Aranda & Knight, 1997; Connell & Gibson, 1997; Janevic & Connell, 2001; Pinquart & Sorensen, 2005).

Caregiving in Thai society

The cultural background of the Thai family motivates and provides caregiving by the characteristics of living arrangement, roles and responsibility. Relating to living arrangement, evidence from a survey of elderly in Thailand by National Statistical Office (2005) show that 92.9 % of Thai elders live with their spouse, their children, or with other relatives and only 7.1% of them live alone. In a variety of form of living arrangement, the majority of Thai people still live in rural area. Adult children tend to live in separate dwellings, but nearby for daily contact in rural areas (Sung, 2000). Elderly parents live together until one of them dies then there is initiated a move for co-residence (Knodel & Chayovan, 1997). A contrary situation in urban areas with the high price of land and house and problems of the social environment, adult children and elderly are more likely to share the same household (Chaoum, 1994). Urban elderly are mainly supported by their pension and saving, whereas rural elderly rely on their own work or their spouse's work (Knodel & Chayovan, 1997). Similarly, Fox (2005) confirmed that older people, especially in rural areas, subsisted on money and goods provided by their families and their own labor because there have no welfare safety net to support those without employment.

Focusing on caregiving role and responsibility, Caffrey (1992) has studied role and responsibility of caregivers of the elderly in the Northeast of Thailand. Patterns of care behaviors are obtaining medical care, buying medicine from the hospital, or local pharmacy, administrating the medicine to the elderly, providing personal care, special care, and psychological care by staying up with them at night or sleeping nearby, and arranging spiritual care. "*sutra khwan luang*" means a ceremony for calling to the spirit of the person who is ill. In addition, Kespichayawattana (1999) classified role and responsibility of adult children who take care of their elderly parents into three caregiving dimensions: physical, psychological, and spiritual caregiving. Focusing on physical caregiving, there were five caregiving activities, such as maintaining parents' daily activities, nursing care activities, environmental modifications to promote parental function, obtaining assistance, and seeking alternative methods of treatment. Psychological caregiving was described as talking with parents, being there, and using humor. Spiritual caregiving related to religious belief, such as merit-making for parents and praying for the better condition of their

parents. In turn, she reported that caregivers felt upset and socially isolated when they did not receive help from persons who are expected to help in caregiving for elders.

Above all, these caregiving studies in Thai society portray the patterns of caregiving behaviors in terms of their relations to traditional values and religious belief. Most Thai elders live with their relatives and expect to receive care. The well being of Thai elder has been studied the social relations in terms of harmony, acceptance, interdependence, respect, and enjoyment (Ingersoll-Dayton, Saengtienchai, Kespichayawattana & Aungsuroch, 2001) and showed in table 2.4

Table 2.4 Relationships between social relations and elderly well-being

Characteristics of social relations	Elderly well-being				
	Harmony	Acceptance	Inter dependence	Respect	Enjoy ment
1. Giving money			●	●	
2. Giving materials			●	●	●
3. Taking care of illness			●		●
4. Cleaning house		●	●		●
5. Caring for children			●	●	●
6. Providing education.	●	●	●		
7. Visiting			●	●	●
8. Asking about health			●		●
9. Sharing advice	●	●	●	●	

Ingersoll-Dayton and colleagues (2001) showed the importance of social relatedness as the fundament of Thai elderly well being. Based on a collective view the self in terms of a sense of belonging to a web of social relationships, the researchers found that Thai elders want harmonious relationships among individuals in their social networks. Elders want interactions among their children to be peaceful and happy. These findings expand harmonious relationships from only two individuals to concern among individuals.

However, demographic transition has resulted from the growing of the aging population and from fertility decline. The Thai family has become smaller in size because of successful family planning (Jitapunkul & Bunnag, 1999). Family structure has shifted from a compound family to a single family and household size has decreased from an average of 4.1 in 1990 to 3.6 persons per household in 2000 (National Statistics Organization, 2003). Furthermore, family function has been rapid changed in Thai society. Women have gained access get higher education and often work outside the home (Choowattanapakorn, 1999).

During the last two decade, there have been significant developments in the social and economic in Thailand. The rapid expansion of industry makes the shift of labor force from rural to urban area (Jitapunkul & Bunnag, 1999). Younger people migrate to big city to seek work and support finance to their families (Fox, 2005). Seventy seven percent of Thai elderly in 2002 reported receiving income and material support from children and about 3-5 % of elderly received source of income from a government welfare allowance (Knodel et al., 2005). Assistance from other relatives is rare in Thailand.

Moreover, social change involves to urbanization and cultural adaptation. Fox (2005) conducted ethnographic research in rural Mae Hai village, Chiang Mai province. The researcher reported that modernization was less significant than obligation and reciprocity that emerges from Buddhism and other cultural systems. Two studies of social change in urban areas provide linkages in this area, Pramuanratkan (1979) explored community living in urban areas such as Bangkok and suburb areas. The researcher found that there had been changes and losses of the village way of life. The forms of community are created by people who link and interact with each other through daily consumption needs, not through ethnic origin or background. Some of them are local residents, and others commute as migrants. Not only does change of members and linkages in social networks occur but also the culture of people in urban areas is transformed. Nathalang (1999) studied social transition in central Thailand. The researcher described and analyzed three communities in Rangsit, district of Pathumthani province north of Bangkok. The researcher found that identifying someone as having the same ethnic identity is less significant. However, the Muslim community still maintained a culture of community.

The dynamics of the people who commute or migrate are focused on earning and job opportunities. An urban way of life influences an individualist way of life rather than promoting people's interaction.

Consequently, the changing of Thai family structure, economic and social change has influenced support systems. Particularly in urban area, the family is confronted by fewer family supports (Hermalin, 2000). As a result, family caregivers have a conflict between the obligation to care for their parents and the hardships of life. It is culturally unacceptable for Thai people to let their parents move into an institution for the elderly. Choowattanapakorn (1999) identified three reasons why Thai caregivers refuse to institutionalize elder relatives in nursing home. Firstly, Thai caregivers believe that it is responsibility of children to take care of their parents, even if they are poor. Secondly, they feel residential aged care is only for those elderly people who have no relatives. Lastly, elderly Thais express conflicting feelings about institutional aged care because they are happier to live together with the companionship and understanding of their children. However, about 3 percents of men aged 60 and over live in temple, 98% of whom are monks. Only about 0.2 percent of elderly women live in temples as nuns (Knodel & Chayovan, 1997). To assure adequate care for the elderly, Thai policy supports an informal care system in order to keep the elders at home as much as possible by decreasing tax on adult children who take care of their elder relatives (Jitapunkul & Bunnag, 1998). In addition, formal care has been developed by a combination of government, and non government organization, and people who volunteer as caregivers to take care of vulnerable elderly people in the community (Matichol Weekly, 2007).

Evidence from the World Health Organization shows that many countries will be greatly affected by the number of dependent people worldwide requiring daily assistance from another person in providing healthcare and support from human and financial resources (Hardwood et al., 2004). Recently, caregiving for chronic illness patients has become a significant issue because most patients return to the community with complex technology, such as tracheostomy tube, feeding tube, and foley's catheter (Maneewan, Sudchinda, Chulaitassanee & Prsanatikom, 1995). Thai family members deal with complicated disease, complex cares and limitation of resources. Sirapo-ngam (2003) using a systematic review of 80 family caregiving studies for

family member with chronic illness in Thailand concludes that most family caregivers are adult children (92.5%). The researcher pointed to the role and responsibility of family caregiver for patients with chronic illness who is faced with many difficult problems in direct care, emotional and psychological support, mediating with formal organizations which provide services and social welfare, and providing financial and material support.

Above all, caregiving in Thai society has been developing both through advances of supportive care and through the need to overcome the limitations of caregivers. Because of the complicated condition of elder care receivers, Jitapunkul, Kamolratanakul, Chandrapraset and Bunnag (1994) studied the prevalence of disabilities in Klong Toey slum in Bangkok. They reported that forty three per cent of the elderly were dependent in activities of daily living. One point six percents were moderately severely or severely disabled and needed special care. One-third of the problems of this population were caused by stroke. The epidemiology of stroke in the elderly in Thailand was investigated from 1994 to 1996. Viriyavejakul and his colleague (1998) conducted a longitudinal study from four regions. Three thousand and thirty six Thai elderly people received physical and neurological examination by neurologist. The researchers indicated that the nationwide prevalence rate of elderly stroke is 1.12 % and the central region has the highest prevalence rate of 1.99%. Hypertension is the main risk factor followed by diabetes mellitus, smoking, alcohol consumption, hyperlipidemia, and heart disease. Moreover, the prevalence of dementia in Thai stroke survivors is 33.02% (Poungvarin, Prayoonwiwat, Devahastin and Viriyavejakul, 1995). Therefore, most caregivers provide caregiving for both stroke and other complicated diseases. Sasat (1998) found that family caregivers were still willing to continue to provide care despite difficulties in caring because of a strong filial obligation based on the Buddhist belief in reciprocity, but the effect of the caring relationship and the quality of care need further study. Caregiving for the elderly with severe chronic illness needs to be explored in terms of its patterns and relationships.

Stroke care is represented in the caregiving for chronically ill and disabled people in the community. The patterns of care are shaped on the basis of cultural and religious background, the role of the caregiver in the caregiving process, living arrangement in urban area, and traditional belief about stroke care. Therefore, studying

stroke caregiving in urban area will provide fruitful understanding of the family caregiving system.

Caregiving networks and social exchange

In the literature review on Thai social network, much of the research has been in the area of anthropology (Lohapoontakul, 1996; Wattanasin, 1993; Wongcharoenkul, 1997), demography (Boonchalaksi, 2000; Gridwichai, 2001), nursing (Sasat, 1998), public Health (Satusen, 2000; Wongwattanadilok, 1997), and social work (Na Phuket, 2000). Social exchange has also been studied by population studies (Damri, 2003). Few studies have focused on elder care networks and social exchange (Kelley, 2005). Little is known about stroke caregiving networks (Hatthakit, 1999; Obe-om et al., 2006; Pierce, 2004) and there is only one study on the patterns of social exchange behaviors in stroke caregiving networks (Thompson, 2002). These studies are identified as followed:

Focusing on elder care network, Kelley (2005) has studied exchange behavior between minor children and adult children with community-dwelling frail elders in a semi-rural village in St.Lucia in the Caribbean. Care exchanges are identified as care activities and benefit. An elder care activity is the care provided by a caregiver to an elder on at least one occasion while caregiver benefit is what an elder gives to the caregiver for elder care on at least one occasion. She found 188 care network members over a one week period including: family, neighbors, and friends. Network members were adult children (76%) and minor children (24%). Elder care activities were 355 activities. The most frequent of which were visit, help with food, errands, laundry, money, supplies, water, protection, house cleaning, and checking up on. Caregiver benefits were 280 benefits namely food, visits, money, prayers, housing, birth/life, clothing/supplies, and good deeds in the past. Of social exchanges, 73% were for current commodities, 15% were for repayment in the past, and 12% were for possible future benefits. There were differences in reciprocal exchange for elder care and motivational mechanisms for minor children and adult children in their care networks. This study provides a picture of patterns of social exchange behavior in elder care networks.

With regard to stroke caregiving network, Hatthakit (1999) explored and described the lay care (self care) of stroke patients and family caregivers in Songkla province. This study provides understanding of two sides of caregiving and care receiving, caregiver burden and satisfaction, using both Western and traditional medicine. She developed a family-oriented self care model for a well family, and for a family with sick members. The researcher identified three patterns of individual-family interaction: individual-focused, family-focused and resource-focused. These patterns of interactions shift over time. However, the researcher found family members are interdependent and less dependent on their wider social networks. In addition, Obe-om and her colleagues (2006) conducted an ethnographic study in Chiang Mai province. They found that family cost for providing care is increased, when income is decreased. In addition, family responsibility increased as being family caregivers increased family cohesiveness as well. Two studies provide patterns of interaction behaviors within stroke caregiving members. Moreover, Pierce (2004) revealed that at the beginning, family caregiver of stroke patients shared problematic and positive outcomes of caring with each other and the nurse. They pulled their family together and helped one another to provide care for the care recipient.

Based on social exchange theory, Thompson (2002) identified caregiving styles and the sources of caregivers' attitudes. She classified three models of care in stroke caregiving including involvement, resentment, and patient source model. The involvement model identifies the situation in which overprotective behaviors result from being overly intrusive and involved. This model describes situation in which the patient is seen as infantile a person to whom baby talk can be used. Another model is resentment model that refers to over-controlling caregiving style and the caregiver expressing frustration toward the patient. The last model is the patient source. This model came from the attitudes and dependence behaviors of care recipients. They found strong support for the resentment model and no support for the involvement model. They identified that sources of the resentment are the exchange relationship and unequal status between caregiver and patient roles. Based on exchange theory, partners' satisfaction with their relationship is influenced by their perceptions of the balance of resource given and received in the relationship. The caregivers judge that their relationships are inequitable. Caregivers, who have no skills, adopt an over-

controlling style by restricting the autonomy of patients. Another source of resentment is patient dependence. This study provides an understanding of the mechanism of attitudes and behaviors of stroke caregivers on caregiving.

Summary

Caregiving knowledge is developing due to a dramatic increase in the proportion of elders with chronic illness worldwide. Stroke is one of the predominant diseases of elderly people. Stroke caregiving research has shown the negative, positive, and neutral outcomes of caregiving. The research results are different in Western and Eastern culture. In Thailand, much of the research has focused on being a caregiver, and typically focuses on the patients and /family caregivers. To expand caregiving knowledge, cultural and social perspectives need to be considered in terms of stroke caregiving networks. There is a lack of caregiving studies on caregiving networks. The patterns of social exchange behaviors have been investigated in stroke caregiving network members largely through stroke caregivers. In particular, this study explores patterns of social exchange behaviors. Social network concept is used for understanding networks, linkages, and member attributes. Network analysis is used as a tool for describing persons and relationships in stroke caregiving networks. Social exchange theory is used to explain the motivation of care and social exchange behaviors in the events of caregiving.

CHAPTER III

METHODOLOGY

The exploratory descriptive ethnographic study is used to investigate stroke caregiving networks in Bangkok. This study aims to describe networks of care for caregivers of stroke patients and explore the patterns of social exchange behaviors in stroke caregiving networks. The methodology of ethnography is chosen as a mean to achieve this aim and as an appropriate tool for research questions. In this chapter the discussion starts from the reasons for selecting the method for this study. Further, discussion is done on the value of ethnography for the development of nursing science. Finally, an overview of the research design based on the ethnographic method describes the setting, participants, instrument, data collection, data analysis, ethical considerations involved in the data collection, and issues of rigor.

Ethnography

Ethnography means “portrait of a people” (Burn & Grove, 2005). For describing and discovering the knowledge of a group of people who have lived in it, ethnography presents particular patterns of a culture of people (Emerson, 1983; Fetterman, 1989; Leininger, 1985). Ethnography can be obtained by observing what is happening, participating in activities, and asking the “natives” about what is seen and what is being done (interviewing), and examining the existing documents (Roper & Shapira, 2000). An ethnographic approach combining qualitative and quantitative data, namely triangulating data, provides rich and complementary data sets to complete a picture of people rather than the isolated data that a single method only provides.

Historically, the ethnographic tradition is known as both a research process and product (Lecompte & Schensul, 1999; Morse & Field, 1995). By utilizing ethnography as a research process “naturalistic method”, the researcher is an instrument of data collection and analysis (Creswall, 1998). Ethnographers are persons who work through long-term involvement, and interact with people in the research site.

At present, contemporary ethnography focuses only on a particular aspect or dimension of culture because most researchers can not spend years in a single site (Lecompte & Schensul, 1999). Besides, society today is no longer isolated resulting from the influence of globalization. The revolution of contemporary ethnography is considered to be problem oriented, referring to specific issues or problems in cultural and social context (Lecompte & Schensul, 1999). Additionally, contemporary ethnography utilizes reflexive processes throughout every stage of conducting study to make it more credible because ethnographers cannot isolate themselves from social world of the people. In turn, ethnographers become a part of a social world (Hammersley & Atkinson, 1995). Therefore, the evolution of ethnography serves to narrow and focus on problem oriented rather than the scope of area concerns.

As a product of research, ethnography is a “descriptive analysis of the values, beliefs, and patterns of a culture” (Tripp-Reimer, Enslein, Rakel, Onega & Sorofman, 1998). The product is a story about a group of people and their historical materials, cultural artifacts, diaries, poetry, video, pictures, documents, and patterned use to paint a picture of people going about daily lives during a period of time (Lecompte & Schensul, 1999; Magan, 2001). The ending result of ethnography is a thick description of the nature of a phenomenon (Magan, 2001). It was explained that thick description is deep, dense, detailed account of data, which enables someone interested in making a transfer to more conclude the result (Lincoln & Guba, 1985).

While qualitative study can produce and is guided by theory, ethnography is guided by generated theory, namely formative theory. Theory serves as a map to organize observations and interviews into units, patterns, and structures early in the research. Conversely, ethnography does not test the formative theory to determine whether it is right or wrong. Similar to grounded theory, data emerging from observed results are constantly compared against the expected results derived from the formative theory. Theory helps the researcher determine what to consider and what to leave out of observation (Schensul, Schensul & Lecompte, 1999). In this thesis, social network concepts and social exchange theory were used to guide interviews and observations of the people and their exchange behaviors in stroke caregiving networks.

Recently, a variety of studies involved in approaching social networks in ethnographic research have been reported (Giradwichai, 2001; Kelley, 2002; Rempel,

Neufeld & Eastlick Kushner, 2009; Ray & Street, 2005; Suphunnakul, 2007; Wattanasin, 1993; Wonganutrohd, 2001; Wongcharoenkul, 2000). Three levels of approaches to social networks are ethnographic network mapping, ego-centered or personal network research, and full relational social networks (Schensul, Lecompte, Trotter II, Cromley & Singer, 1999). The method of ethnographic network mapping is used to obtain lists of groups by name and identify individuals who are members of these groups. Network Typologies are created as useful tools for understanding the cultural variations within group networks. For example, Wonganutrohd (2001) created community network maps to form three layers of relations: the community, among active citizens, and among core members of the group.

Personal or ego-centered networks form one of the main cultural conditions that reflect values and beliefs through the people with association or avoidance. Ego-centered networks focus on size and composition of individual characteristics and normally use either questionnaires or interviews to obtain the influencing behaviors with which they link. For example, Gridwichai (2001) studied the social network of migrants. This study focused on the migrants who associated with two networks: a close network and a distant network. A close network related by blood relationship while a distant network associated with degree of connection, frequency of contacts, duration of relations.

Full relational social networks describe both actual and potential connections between all of the members of the network. Carpiano (2008) studied actual or potential neighborhood resources, access to resources and health of female caregivers. The results showed that social capital forms were directly associated with positive and negative health outcome. In neighborhood level, neighborhood attachment significantly moderate relationship between social capital and health.

The social networks deal with human problems by searching the subgroup within the network and commonly use diagrams, charts, tables, data matrices, cluster diagrams, and verbal descriptions to classify common or unusual social roles and positions in the network (Schensul, et al., 1999). This study explored the patterns of social exchanges in stroke caregiving networks. By utilizing ego-centered networks, the patient is the center of caregiving networks. The caregiving network is defined as a set of linkages among a group of people with the aim of providing and receiving

care. The social exchange behaviors include the observed and reported behavioral component of caregiving which is every activity done between members of caregiving network, patients, and primary caregivers in stroke caregiving networks. The concept of social networks is used to identify caregiving network structure and composition, while social exchange theory is used to describe the linkage relationship.

There are two main reasons why the ethnographic network approach has been chosen for this study. Firstly, stroke caregiving network research employs both qualitative and quantitative studies because the complex experiences of stroke caregiving need to be understood in terms of the caregiving behaviors, network size, frequency of contact, duration etc. Both data sets can provide the triangulation that appears to be crosscheck validity (Schensul, Schensul & LeCompte, 1999). The advantage of ethnographic research is the way it depicts the patterns of behaviors of persons within a particular culture (Roper & Shapira, 2000). This study captures human behaviors, belief, and values for a holistic perspective through summaries of interview and ongoing observation of exchange behaviors in stroke caregiving.

Another reason for this selection is that little information is known about stroke caregiving networks and social exchange behaviors. A review of the literature on caregiving indicates that Thai stroke caregiving are interdependent (Hatthakit, 1999; Obe-om et al., 2006), and the ethnographic approach could present a detailed view of this topic. This study is designed to explore persons in caregiving networks and describes the behaviors exchanged in caregiving. Ethnographic methodology is used to investigate exchange behaviors by following stroke patients and caregivers in clinic, home, and community settings. Following the people is the technique used in multi-sited ethnography (Marcus, 1998). The current thesis study uses participant observation, interviewing, and others in these settings.

In particular, exploratory descriptive study is the simplicity and flexibility design that fit to this study. The use of these methods provides more understanding, a meaningful theory and knowledge in nursing.

Ethnography and Nursing science development

Ethnography was established as a research method in the early work of British anthropologists. This technique has been applied as a qualitative methodology in education, history, psychology and sociology. Nursing has adopted the method to guide nurses in expanding from only human responses and human experiences to social, cultural, and political contexts. Leininger and Tripp-Reimer, both of whom are nurses and anthropologists, created several concepts, such as the transcultural nursing concept and health grid concept to extend nursing knowledge by creating awareness of the cultural differences of patients and their families. During the last two decades, ethnography has been studied in various aspects of Thai nursing in clinical settings (Ketsumpun, 1993; Pichitpornchai, 2000), home settings (Obe-om, Fongkeaw, Panya & Senaratana, 2006), both clinical and home settings (Hatthagit, 1999; Junda, 2002; Pradikul-Asdormwised, 2000), and community settings (Boonyaprapa, 1992; Changtong, 2002; Prompat, 2003). These studies explored the meanings and interpretations of people in a culture of nursing practices. To develop nursing knowledge from the ethnographic method, the philosophical assumptions that have been discussed are the ontological issue, the epistemological issue, the axiological issue, and the methodological issue.

The philosophy underpinning ethnography is the naturalistic paradigm. The ontology of the naturalistic paradigm is based on relativism, whereas the positivist paradigm is based on realism (Lincoln & Guba, 1985). For relativism, the view of truth is based on multiple realities and is characterized by the assumptions that reality is complex, holistic, and context dependent (Monti & Tingen, 2002). This current study is consistent with the assumptions that caregiving networks are not individual entities existing in a space but caregiving networks are social entities including individuals, families, organizations, and communities. Multiple realities stem from the perceived view of individuals and caregiving network members in patterns of social exchange behaviors. The context of this study is the cultural background of Thai stroke caregiving.

Using epistemological analysis, researchers with this worldview believe that knower and known are interactive, inseparable in mutuality and transformation as the nature of human processes. From the perspective of purely empirical or positivist

science, knower and known are separated and aware of confounding factors. In the naturalistic paradigm, the ethnographer is an instrument which interacts with significant participants in specific cultures. This study interacts with stroke caregiving networks of Thai culture.

The axiology of the naturalistic paradigm is value-laden. This current study recognizes that ethnographic research is value-laden and biases will be presented by using reflexivity. It is known that reflexivity allows researchers to become aware of their roles, to identify biases and their potential influences on the data and the distinction between science and common sense, between activities and knowledge (Hammersley & Atkinson, 1995). The reflexivity provides the logic of inquiry and holistic views of both the views of caregiving networks (emic view) and the interpretative views of caregiving networks (etic view). The change together or opened discussion of values is in a way with feedback and feed forward making the distinction between cause and effect meaningless, gossip and tacit knowledge.

The methodology of naturalistic inquiry is the inductive method to increase understanding and knowledge of lived reality (Monti & Tingen, 2002). Ethnographers utilize several informant sources for data on the topic context, process, and content, which helps obtain more accurate and complete records. This is known as triangulation. Triangulation means using mixed philosophical approaches to study the same phenomena (Tripp-Reimer, 1985). Wolcott (1994) described an ethnographic approach using three different modes including enumeration to document frequency data (census data), participant observation to describe incidents, and informant interviewing to learn institutionalized norms and statuses. This current study utilizes social network concept and social exchange theory as the conceptual framework, the center of interviewing, observation, and field notes. Census data are collected from geographical mapping photography, household assessments, network recording and analysis for confirmation of findings and ensuring rigor in data collection procedures.

In brief, ethnography has evolved in nursing science development. For increasing nursing knowledge, this current study moves beyond the level of the individual and family to the social context where people are living and interacting within a network, and extends the relationships from physical and psychosocial aspects to cultural and social aspects. This study provides basic knowledge for more

understanding patterns of social exchange behavior in stroke caregiving networks in the urban area in Thailand. In nursing practice, the knowledge of ongoing actual behaviors and interactions has implications for quality of care. Nurses can use this information to identify patients who cannot receive any help due to lack of potential caregiving networks and those who have risks of poor health outcomes. On the other hand, nurses are able to evaluate caregivers who cannot provide effective caregiving to the patients. Finally, in health policy, caregiving networks could shape health care services to integrate both formal and informal care rather than to separate these systems. If the health care system does not develop in its caregiving network settings, and if it is not sensitive to Thai culture, how could people get real quality of care.

Research Design

This study design was guided by the social network concept and the social exchange theory to explore and describe the patterns of social exchange behaviors within stroke caregiving networks in Bangkok. An overview of the research design based on the ethnographic method describes settings, participants, instruments, data collection, ethical considerations involved in the data collection, data analysis, and issues of rigor.

Settings

The study has been conducted in Bangkok. This city is selected as the study site because there is a large number of working people or poor income people here. According to the Thai census (2007), 6.8 million people live in this city. As the largest city, the capital city, and the most developed city in Thailand, home health care provisions are provided under Ministry of Public Health, Ministry of Education, and Health Centers of Metropolitan Bangkok.

Several clinics, stroke patients' homes, and community based settings were selected. The clinic-based settings were the out patient clinics in the medical division of the Faculty of Medicine, Ramathibodi Hospital and the Neurological Institute where the stroke patients came for follow up. To study social exchange behavior in clinic based setting, observation of the stroke patients and their members in caregiving networks was followed. However, there were some stroke patients who stopped going

to the hospital because of bedridden or high body weight to move from their homes. Then, home visiting for these group were conducted by health personnel.

The home based settings were the stroke patients' homes in Bangkok. Home is considered to be the place where caregiving network members have ongoing activities involving the patients and caregivers. A weekly home visits was performed until trust is established. For example, the participants remembered the researcher's name or nickname or had some activities together, such as joining Songkarn festival, birth day's party or going shopping with caregiving network members. The researcher observed and talked about social exchange behaviors within caregiving networks with their network members.

Community based settings were the places where caregiving networks are most evident. The researcher asked for a permission to observe activities of the caregivers relating to others in several places. These places were convenient for the caregivers and their caregiving networks, such as mosque, school, and massage parlor of Bangkok Metropolitan in the community and so on. To deeply understand the context of caregiving, the history and cultural background of Bangkok were clarified.

Bangkok

Bangkok is located in the central region of Thailand. Bangkok Metropolis, the capital city, was founded in 1782 by King Rama I. The name of Bangkok was made up of two words, namely; "*bang*" and "*kok*". While "*bang*" was defined as a "village" or "district" located on the river bank. "*kok*" came from the name of "*makok*" the olive tree which were abundantly found in the area. Therefore, Bangkok means the "village of olives" (Chadchaidee, 1998). Presently, most Thai people conveniently use only the first two words of the formal name "*Krung Thep*" rather than Bangkok Metropolis.

Bangkok occupies a total area of 1,568 square kilometers that is divided by *Chao Phraya* River in the middle. The city was divided into three areas: inner, middle, and outer area, with a total of 50 districts (*khets*). In inner area, there are 21 districts, while the middle area consists of 18 districts and the outer area has 11 districts. In the past, Bangkok citizen earned their living in agriculture, plantation, and livestock farming. At present, living styles of people in the middle and inner areas of Bangkok

have been changed to adapt more commercial and industrial society. A small number of people are still living in the farmland as farmers in some outer areas. The environment transformation reflects a change in Bangkok people's culture and habits.

The congestion population is found in Bangkok. According to the National Statistical Office (2007), 6.8 million people were registered to live in Bangkok. In fact, more people from other part of the country and other countries migrate to Bangkok each year for working, studying, and so on. As a result, about 10 million people are living in Bangkok which bring a lot of social problems, such as accident, health service utilization etc. For solving these problems, many innovative networks have emerged with the advance of technology. Some networks are voluntary while others are combined both formal and informal networks.

Many voluntary networks have been set up to provide free services for the population in Bangkok, such as radio communication network, emergency medical service network, elder clubs, exercise groups, and community health volunteers. The communication network, namely "*Jor sor 100*", "*Sor wor por 91*" in Thai language, consist of volunteers connecting through radio station FM.100 MHz., or AM.91 MHz. using telephones. These volunteers provide the traffic picture in Bangkok for twenty-four hours. In addition, they also exchange information of the individuals in crisis, who urgently needed support such as care car accident, birth delivery and so forth. For combined networks, emergency medical service networks which consist of several volunteers are working with non-government organizations, such as *Po-tek-teng* and *Rum-kar-tun-yu* to help people in emergencies. These networks work to cooperation fully with formal health system to provide services on carrying dead people or individuals with illness to the hospital. At the present time, several people in Bangkok participate in various health clubs. Bangkok Metropolitan Health center collaborates with elder clubs and many exercise groups to promote strength and encourage good health to people in the community. Community health volunteers take part in various activities of Bangkok Metropolitan Health center, such as checking blood pressure, and monitoring body weight. These types of networks in Bangkok reflect as part of the patterns of behavior of Thai people utilizing many health services.

Thailand health service system has been categorized into five levels: family level, primary health care level, primary care level, secondary care level, and tertiary care level (Wibulpolprasert, 2008). In general, people look after themselves by keeping balance between self care and seeking help at family level. The primary health care level is the community participation. The community health volunteers who provide care the people in their communities; have been developed care abilities by training from health personnel. The primary care level provides care by health personnel and general practitioners in primary care units (PCU) or health centers, or outpatient departments of public and private hospital. The objective of primary care is to balance of optimization of health and coverage of people. The secondary care level refers to the basic care provided in community hospital while tertiary care level will take care of patients who need complex care and specialist. There have developed in terms of health service resources, and health care financing.

People in Bangkok use health service resources both western and traditional medicine. With regard to Western medicine, there are 41 government hospitals, 103 private hospitals, and 9 metropolis hospitals providing both general and special care in Bangkok (Bangkok Metropolis Report, 2006). Bangkok has 65 metropolitan health centers to provide primary care services in fifty districts. On the other hand, traditional medicine, namely alternative health care has been used to complement western medicine or used as a complete alternative health care system. Alternative health care methods for stroke patients are Thai traditional massage, foot massage, herbal therapy, acupuncture, food supplement, worship or using magic (Komjakraphan, 2001).

In the financial system, Public Health Protection Schemes cover all Thai people into three patterns (Sakunpanit, 2006). The first pattern covers 11% of people by Public Employee Schemes where the largest group is the Civil Servant Medical Employee Benefit Schemes (CSBBS). The second pattern is 15% of people in Social Security Schemes (SSS), and the last is 74% of people in Universal Coverage of health care schemes (UNC). Under the Universal Coverage of health care scheme since 2002, Thai people are allowed to choose their health services. Primary care units are established to provide primary care for the people with contracts. The people will be

transferred to a higher-level of health care delivery when they have complex conditions and need specialist.

As mentioned above, the setting of Bangkok as the research location is useful for investigation patterns of behaviors in Thai culture. This study will fulfill the picture of networks in the micro level of family and Thai society by focusing on patterns of social exchange behaviors in stroke caregiving networks in Bangkok.

Participants

Prior to the fieldwork process, the research protocol was submitted to and approved by the Institutional Review Board (IRB) of the settings. In order to obtain access to key persons, the researcher connected to Ramathibodi Hospital, the Neurological Institute, and community health centers and described the purposes of this thesis. With the help of the nurses, and health volunteers from the three sites as the gatekeepers, the researchers contacted the caregivers who took care of stroke patients in their homes. The informed consent was signed after the researcher explained the purposes and procedures of data collection to the participants. To meet the objectives of the research, this study used convenience sampling, snowball sampling, and theoretical sampling to meet the objectives of research.

Convenience sampling was established by access to the participants directly. The lists of stroke patients who were evaluated by Barthel Index Score that was equal or lower than a half and have ever received home health care services from three health care settings in Bangkok are reviewed. Ramathibodi Hospital represents patients from university hospitals and the Neurological Institute represents those from hospital of Ministry of Health. Community health centers represent patients using health services from health volunteers who took care by Bangkok Metropolitan center or Ramathibodi Hospital. The three different service areas were selected to establish a variety of patterns of caregiving networks. The ethnographer needs to use the big net approach to ensure a wide-angle view of event before the focus narrows to specific portions of the population (Fitterman, 1989). Stroke caregivers who were the participants need to meet the following criteria:

1. Having taken care of their elderly stroke patients who were aged 60 or older at least two months,
2. Living with their patients in same household or household area in Bangkok,
3. Being able to communicate in Thai with the researcher,
4. Being not paid caregivers from agency,
5. Willing to co-operate in this study.

Stroke Patients and family caregivers who have paid were excluded from the study because they had different supports and social exchange behaviors. Snowball sampling was used to identify the stroke caregiving networks. Theoretical sampling was utilized during ongoing analysis. This strategy provided the significant persons with essential information to deep understanding of the meaning and social exchange behavior of members in stroke caregiving networks variation.

There was no absolute method of identifying a suitable sample size. In previous studies of elder care network and stroke care experience, there have been ten to fourteen participants (Hatthakit, 1999; Kelley, 2002). Morse (1991) had explained two methods for evaluation of the participants. Firstly, the test of appropriateness is a strategy to evaluate informants during the process of data collection. When the researcher finds new information, the new criteria would utilize that information for another informant selection. Secondly, the test of adequacy is a strategy to evaluate saturation of data. This study found that 18 caregiving networks provided experiences of social exchange behaviors and had no new information of exchange behaviors. This study was evaluated saturate data after the themes and categories were repeated.

Instrument

In ethnography, a researcher is an instrument. This concept of human-as-instrument has been applied in data processing and confirms the result with respondents in the field. During data collection and analysis process, the researcher needs to develop characteristics that ensure sensitive responses to all personal and environment cues in the fieldwork. Further characteristics are adaptation to multiple situations and taking a holistic view. In this current study, the triangulation had been

used to confirm the validity between the data from interviewing and observation, from caregiver and caregiving network members.

For a researcher of this study, personal and professional backgrounds are presented in the worldview and characteristics to conduct this research. I am single, fifty-two- year old. I was born in Bangkok and grew up in a Thai-Chinese family. My parent are similar in terms of their ethnicity. Both of them had father who came from China and got married with the mother who were Thai women. My father and his younger brother were sent to China for studying. After finishing school, both of them went back home to Thailand with their Chinese culture. When my grandfather died, his body was returned back to China for the funeral. The history of my grandfather made me understand how he attempted to keep his Chinese culture alive within Thai culture. My worldview has blended Thai-Chinese cultures because of socialization.

Another aspect of my worldview stems from my religious beliefs. I studied at a Catholic school in Bangkok, namely St Joan of Arc., where a church was centered in the school and the students had to attend a religious class before regular class every morning. Catholic students studied in the church while other students studied their own religion in the classroom. However, I was exposed to many ceremonies of Christian people, such as Baptis, Christmas, and so forth. When I studied in secondary school at Satrivittaya, the students there also had to practice meditation every morning before studying. My past experiences provided me to understand about the religious and beliefs of Thai people in Bangkok.

I finished bachelor degree in nursing from the Ramathibodi School of Nursing at Mahidol University. I worked in the Pediatric ward for eleven years, before joining in the Ambulatory Nursing Division for ten years. My area of interest had been changed to elder care and care for chronic illness patients. I returned to study for a master's degree in Public Health Nursing, majoring in gerontological nursing at Mahidol University. I interested in family caregivers especially for the elderly with chronic illnesses since they were important members of the family. Therefore, I realized that health problems are matters of holistic care. Quality of life of the patient results from the quality of care of the caregiver and the quality of caregiver stems from their caregiving networks.

The most important idea came from my individual experience of stroke caregiving. My father got sick with diabetes mellitus at thirty-seven years old. He had complication with heart disease and stroke at fifty years old and seventy years old respectively. He had right hemiplegia and had partial self care in eating, walking and talking. I was the eldest daughter and had two younger brothers and younger sisters. My youngest brother played a vital role in taking care of him because my mother and I worked outside. Another important reason was gender. My father did not allow his daughters to clean his body but only my mother or my young brother. I played a role in preparing medication and took care of him at the hospital.

Besides, I participated with Neurological Institute to develop clinical practice guidelines for stroke patients from hospital to the home care setting. Also, my colleagues and I set up stroke care workshops for nurses to improve quality of stroke care. Nowadays, I am a nursing instructor in community health nursing and expect to continue improving stroke care. From my personal and professional backgrounds, I have gained many experiences on stroke caregiving behaviors both from my family and other families in Thai society that have made me sensitive and understand how to approach this phenomenon.

Mantzoukas (2004) pointed out that in qualitative study, the researcher is the central figure, the interpreter, the writer, the creator, and the constructor. The researcher needs more experience and skills before conducting a qualitative study. Theoretical sensitivity is an important concept in evaluating a researcher's skill and readiness to attempt a qualitative inquiry.

Theoretical sensitivity develops from a variety of sources, such as professional literature, professional experiences, and personal experiences. The more the ability to be sensitive to the data and to make appropriate decisions in the field the researchers have, the heavier the creditability of the qualitative research report for the readers. Morse (2005) identified qualitative inquiry as being more than a collection of technical strategies but as a way of thinking. To develop these characteristics, she demonstrated patterns or models of learning as follows:

1. Learning from textbooks. These students learn qualitative research despite lack of a course or mentor. They read and memorize qualitative text in a way that is only superficial for insight and acquiring.

2. Peer group support. The students form a support group, meeting on a regular basis to figure out things and assist each other with analysis. However, there are problems in methods and various modes of conceptualization.

3. Learning through formal instruction. This model consists of course, such as a workshop. The first level course should introduce a variety of methods. It is limited by focusing on particular method.

4. Learning by doing. These students are thrown into the field with or without a background of learning by instruction. Some students are confused in decision making, while others need to evaluate correct decisions.

5. Learning from a mentor. This is an ideal model of learning. Experienced researchers can demonstrate how to do qualitative research. Mentors are sounding boards should an ethical dilemma emerge or if the student becomes mired in analysis with no clear direction.

As being a researcher is being a human research instrument, I have designed myself to studying the ethnographic method not only by gaining experiences in ethnographic exercises, but also by training with an expert nursing- scientist, namely Professor Dr. Toni Tripp-Reimer. Dr. Tripp-Reimer is Professor in the College of Nursing at the University of Iowa. She is a current Director of the Iowa Veterans Affairs Nursing Consortium (focusing on elder acute confusion assessment and management) and Director of NINR funded Gerontological Nursing Interventions Research Center. Besides, a nursing scientist and anthropologist, she is currently studying health behavior interventions for the ethnic elderly.

During ethnographic exercises and the training process with Professor Dr. Tripp-Reimer, I utilize based on four concepts about exposure, experience, expertise, and embedding (Farkas, Farkas, Jette, Tennstedt, Haley & Quinn, 2003).

Exposure strategy is the knowledge distribution method that focuses on the goal of increased knowledge. I have learnt how to develop human research protection, how to develop projects, and how to critique qualitative articles. In addition, I have learnt from journal articles, lectures, and meetings from dinners and gerontological conference. By using both active and passive methods, I have learnt how to explore, decide, and confirm the information rather than just reading it.

Experience strategy is the knowledge utilization method that focuses on the goal of increased positive attitude. This method helps to encourage young researchers to develop new studies. Dr. Tripp-Reimer provided new knowledge by demonstration and discussion. I have observed and spoken with her on the emotional factors that make her continue on doing qualitative research. She is a role model.

Expertise strategy is the knowledge utilization method that focuses on the increased competence. Training or capacity building is a key process leading to precise performance and predictable outcomes. Dr. Tripp-Reimer supervised me by giving feed back on my project and analysis of data. She provided journal articles and suggestions on qualitative problems. It can be said that she is an encyclopedia for all questions as same as her book, namely “The Encyclopedia of Nursing Research”.

Embedding strategy is the complex knowledge utilization method whose goal is to increase the use of knowledge. This aspect focuses on support, such as peer groups, and funding. Dr. Tripp-Reimer provided group members including a research staff, doctoral students, and a visiting scholar. I have learnt to breakthrough the language barrier with Japanese visiting scholar. She attempted to translate data from English to Japanese language before analysis. Dr. Tripp-Reimer demonstrated how to use computer program to translate language and discussed about the language barrier together. Moreover, she demonstrated how to use the software for qualitative data analysis, namely NVivo program for coding and sorting data. My mentor, a researcher from hospital, a doctoral student, a visiting scholar, and I have analyzed to determine the points of thematic agreement and divergence together. She taught pragmatics: what coding was good, what coding was far from data.

As explained above, I am confident that I have gained a lot of knowledge and many experiences to develop theoretical sensitivity for this study. My personal and professional background including training experiences have increased my credibility as an instrument of data collection.

Data collection

Ethnographic research is research conducted in the field, namely fieldwork. The objective of fieldwork is to go outside in a natural setting and capture

people's activities. The basic types of data in ethnography are information obtained from saying, doing, and leaving behind (LeCompte & Schensul, 1999). In this study, the methods of data collection were conducted by interviews, participant observation, field notes, geographical mapping, household assessments and network recording and analysis.

Interview

To perform the interview, nurses and health volunteers from the three research sites acted as the gatekeepers and helped introduce the researcher to the participants. Some gatekeepers provided the directions of stroke patient's houses by traveling or walking survey with them. The information that have to inform the participants including of researcher name, a status of doctoral student, and the objectives of the study to understand social exchange behaviors among caregiving networks. I accessed to each stroke patient and the caregiver who has taken care of the patient for a long time. Each primary caregiver was invited be a participant to this study after the risks and benefit of this study were explained to ensure that the participants felt free to withdraw at any time. The participants were asked to sign consent forms or giving their verbal permission on tape recorder to confirm their willingness to be the participants in this research.

On the first interview, I began with grand tour questions to collect demographic information. Formal and informal interviews have been applied in open ended interview format. By using the social network concept and social exchange theory. I developed semi-structured interviews to explore persons involved in stroke caregiving networks and their relationships to the patients and caregivers. The social exchange behaviors have been confirmed by formal interviews with the key participants. Confidentiality has been explained and a permission to tape records was asked before starting an interview. The in-depth interview helps explored in the caregiver's life with a focus on the area of care support and social support in stroke caregiving networks. Storytelling and memories of care were recorded by tape. For informal interviews, audiotape recorder did not used. These recorded interviews were the conversations between the researchers and the participants which was further noted in them in the field notebook as soon as possible. The interviewees were individuals

involved in caregiving networks and social exchange behaviors. These behaviors have been confirmed by participant observation.

Participant observation

In fieldwork, participant observation is defined as a device for collecting data and a set of behaviors (Junker, 1960; Gold, 1969), or as a process of observation after presenting in a social condition (Schwartz & Schwartz, 1955). Besides, participant observation was used as an “umbrella of activity” by the ethnographer (Roper & Shapira, 2000). Three aspects of participant observation was clarified (Pearsall, 1965). The first aspect is as a role, such as reciprocal role. The second aspect is as a body of techniques for getting the information. The third aspect is as a methodology to obtain maximum knowledge and understanding of human behaviors in their context.

The first aspect of preliminary period is a time of trying on the roles. I introduced myself to the participants, presented my role and tried to achieve a rapport with the participants at the clinical setting many times. When the stroke patients discharged from the hospitals, I arranged an appointment to go to their homes.

Also, in its second aspect, participant observation is an ideal method of fieldwork for exploring the caregiving activities of daily living and worldviews of people within a culture (Malinowski, 1992). The setting for this study is the home, clinics and community settings. I functioned as an active participant observer in order to observe the patterns of caregiving networks at homes, and within the local community on numerous occasions. Magan (2001) identified the degree of participant observation from non-participant to complete participant as follows:

1. A complete observer or non-participant is a role as only an observer without interacting in day-to-day activities.
2. The observer as participant is primarily a role in observation but the observer is involved in the activities as a secondary role.
3. The participant as observer is a full participant involving herself in daily activities but taking time to record observations.

4. The complete participant is a member of the group in the setting and does not clarify the environment as the researcher. However, this role rarely exists because of ethical violations.

Focusing on the method of observation, photos, letters, papers and other cultural artifacts were collected as non-participant observer. Being an active participant, the researcher joined various family activities, such as following to the hospital in taxi, or ambulance car, participating in Birth day party of the stroke patient, or giving respect to the stroke patient in Songkarn festival along with the patient's family members. As active participant is involved in activities to experience and learn the culture (Kelley, 2002). The observations have been conducted in clinics, homes, or communities in order to cover all activities occurred in caregiving networks. Based in social exchange theory, the field notes have been developed to include the episodes of caregiving, the identification of the giver and the receiver, and the relationships among caregiving networks members. Each participant has been observed in clinics, homes, and communities. Data from observation were recorded by taking notes, diagram, and pictures in a small booklet during active fieldwork and by filling up the notes routinely.

Field notes

Field notes are the processes that the researcher uses in the initial stages of qualitative fieldwork. It consists of inscription, description, and transcription (LeCompte & Schensul, 1999). Inscription refers to some prior lists of questions, traits, or hypotheses. It occurs during conversation between researchers and informants. Data was observed and recorded when I entered the field. Description refers to writing down jottings, diaries, logs, and field notes to produce thick descriptions or narratives of events, conversations, activities, interpretation and explanation. This process took place in a other place far from the field of observation and interaction with the participants. Transcription produced in field note is a formal process. These processes are writing down the verbatim answer of the participants during interviewing, taking dictation, recording stories, legends etc., and keeping records during specific periods of observation (LeCompte & Schensul, 1999). In this study, field notes were used to record data after the interviews and participant observation on every visit. These

records were very useful to examine the accuracy of the data and outline new questions for further interviewing. The new questions sometimes came from the field. For example, the meaning of primary caregiver, and the adequacy of caregiving are emerged during data collection because there was confusion between two caregivers who helped together in providing care or the adequacy of caregiving from the perspective of participants.

Geographical Mapping, Photography and Household Assessment

Geographical mapping of stroke caregiving network members has been carried out because the location of residence was a variable of stroke care. Geographic proximity of the caregiver was one of the characteristics of caregiving networks. The participants showed how long time that the caregiving network members walked or traveled to their houses to understand the frequency of contacts and degree of connections within the caregiving networks.

Photography is a piece of equipment used to record behaviors in caregiving networks. The benefit of taking photography is to recall and provide more information on activities in caregiving networks. A number of photos have been used to represent the social exchange activities in several situations. For example, the activities of stroke patient and their caregiving network members in the past had been shown for more understanding of relationship and the degree of connection within caregiving networks.

Household assessments were the description of the types of home, location, and resources available for stroke caregiving that was recorded in fieldwork. The instruments and household changing reflected to the social exchange behaviors among caregiving network members to the participants.

Network recording and analysis

Network analysis is a tool which views social relationship in term of nodes and ties (Hill & Dumber, 1992). Nodes were the individual actors within the networks, and ties are the relationships between the nodes. These concepts were displayed in a social network diagram. Nodes were illustrated in points and ties were illustrated in lines. The usefulness of social network was able to determine by the network's shape.

The method of identifying the caregiving network started from a particular individual (actor) whose behavior the researcher wish to study. By taking the stroke patient and family caregiver as the center and examining the people related to them, the researcher could draw the lines connecting the patient and caregivers with other related people. These connections reflected the relationship characteristics of the patient, caregiver and other people in caregiving networks.

Network analysis was used to identify three behaviors. First, network analysis determined the structure of the stroke caregiving network. Second, network analysis is a key to understand the processes of how people make connections with the patient and the caregivers. Third, social network analysis is the way to understand the contents, the specific purposes and functions of each of the caregiving network configurations.

In general ethnographic research usually uses about 30-50 interviews and/or observation is about 100 to 200 units of observations (Sandelowski, 1995). In this study, the researcher collected data in open-ended interview questions and recorded on tape from 36-40 interviews by two or three formal interviews for primary caregivers and some caregiving network members within 18 caregiving networks. Moreover, there were informal interviews during observation. Data analysis was conducted simultaneously until theoretical saturation was achieved.

Data analysis

Context analysis was performed in order to determine the constancy in patterns and variables in diverse caregiving system. Inductive analysis was focused on descriptions of the difference. During data collection, every piece of data including exchange behaviors, network recordings, geographic mapping, photography, and household assessments were analyzed, and interviewing data were conducted in the areas that emerged from inductive work of stroke caregiving. Lecompte and Schensul (1999) identified a technique of data preparation for analysis as management in many types of files. In this study, several files were created as follow:

1. Document files

Document file consisted of document data files and field note files. Data files were collected from interviewing, observation, network recordings and analysis, geographic mapping, photography, and household assessments.

2. Field note files

Field note file were collected from data collection procedure, problems and problem solving record during research procedure.

3. Background files

Background files were collected from general data, demographic data, mapping and environments.

4. Text files

Text files were the rich text from the study. Names and descriptions of paragraphs were categorized in many levels. An Nvivo software data management program was utilized these data to free nodes, trees, cases, and sets. From table 3.1 Context analysis proceeds from the bottom up by building up from items and variables (units) to factors (patterns), domains (structures), and paradigms as followed:

Units (variable level) were range from simple to complex attributes.

Patterns (factor level) were relationships among variables measured or assessed as either qualitative or quantitative data.

Structures (domain level) were relationships among patterns

Table 3.1 Linking theoretical and operational levels in ethnographic research

	Structure	Pattern	Unit	Fact
Domain	Relationships of patterns			
Factor		Relationships of modes of behaviors		
Variable			Modes of behaviors	
Item				Frequency of social exchange behaviors

Source: Developed from Lecompte & Schensul (1999)

As part of the figure 2 context analysis process, the context chart develops and maps in graphic form the interrelationships among the roles and groups that make up the context of individual behavior (Mile & Huberman, 1994). This current study uses the context chart to identify the process of analysis.

Context chart

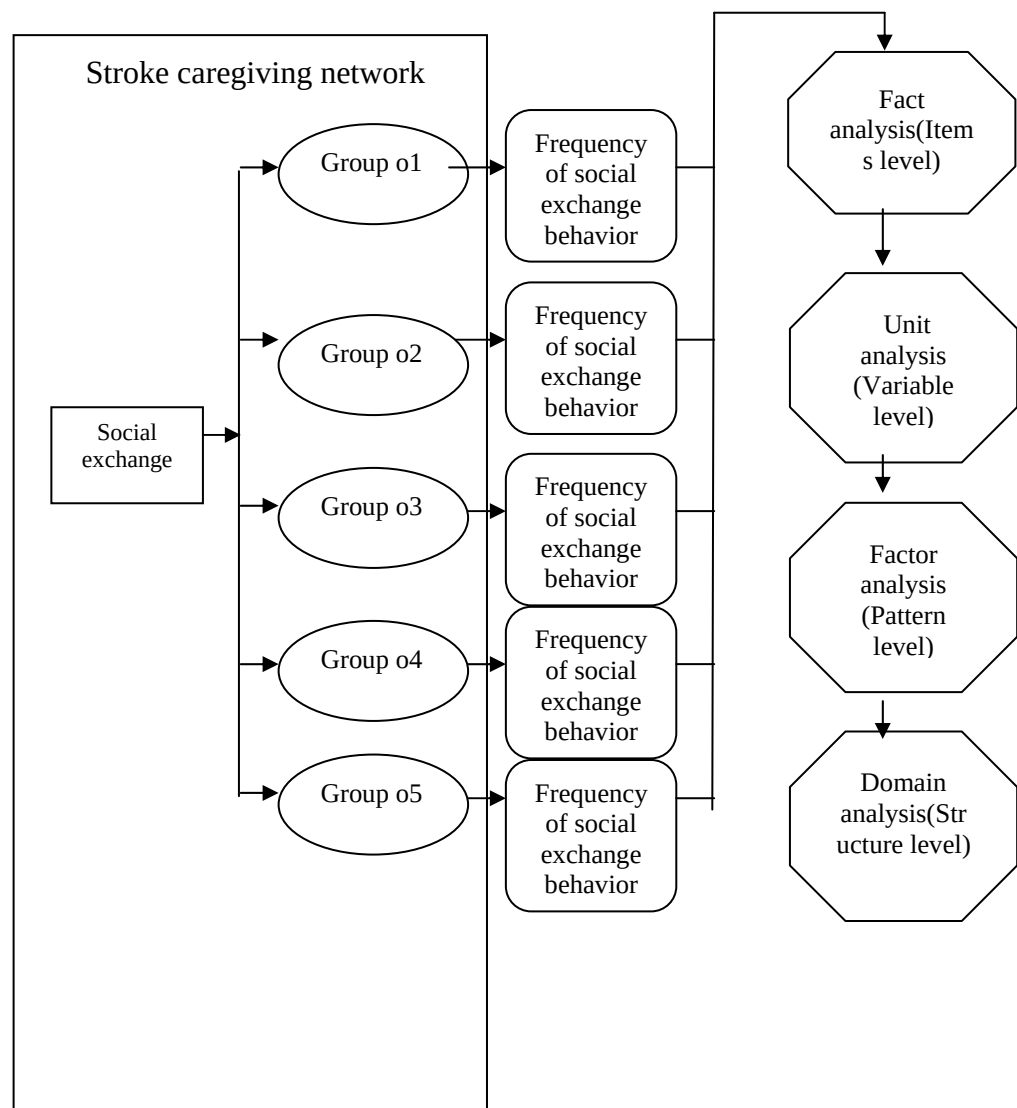


Figure 2 Context analysis chart

This analysis concentrated on comparison of frequency of social exchange behaviors of stroke patients, their families, and community members in caregiving networks to caregivers. The networks were analyzed in the terms of size, homogeneity, degree of connection, duration, frequency of contact, directionality, and sociodemographic character of members. Every piece of data is evaluated by fieldwork note taking. As a result, data might be modified if the false data was dropped or the useful data were more penetrating.

Trustworthiness

In qualitative study, rigor is required to prevent errors of either a constant or intermittent nature. A study attains rigorous by establishing trustworthiness (Sandelowski, 1986) which includes these criteria: credibility, applicability, consistency, and neutrality (Lincoln & Guba, 1985).

Credibility

Trust value and credibility underpin the internal validity of naturalistic research. This is determined for both the validity of data and the analysis of data. According to the reported of Tripp-Reimer (1984), six criteria were applied to increase the credibility of ethnographic research: time, place, circumstance, language, intimacy, and consensus (Tripp-Reimer, 1984). In addition, Lincoln and Guba (1985) identified strategies to establish credibility as follow:

1. Activities increasing the probability those credible findings have been produced. Three activities are prolonged engagement, persistent observations, and triangulation. Prolonged engagement provides the opportunity to build trust. Persistent observation adds the dimension of salience. Prolonged engagement provides scope, while persistent observation provides depth. Denzin (1978 cited in Fielding & Fielding 1986) has clarified four different modes of triangulation by different data (sources), methods, investigators, and theory. These types take the form of comparison to confirm validity. In this study used interviewing, picture and field notes to confirm observations. For example, the socio-cultural care in Songkarn festival was interviewed and confirmed by observation and photograph in Songkarn day.

2. Member checking. This is both informal and formal checking continuously with members of the stakeholder group. Member checking is returning to participants to check out the interpretations. This method provides additional information, to assess intentionally, to account for errors of fact and challenge what are perceived to be wrong interpretations, to summarize and to assess the overall adequacy. For example, this study confirmed transcribed interviews by interviewing the same question with caregiving network members two times for the meaning of some words, such as the definition of a primary caregiver, and sparking emotion.

Applicability or Fittingness

In quantitative study, external validity or generalize ability refers to the distribution of findings to populations. In contrast, applicability is the fittingness and transferability of the findings to other contexts. It was suggested that the findings from qualitative study are generalized by ensuring that theory is comprehensive, complete, saturated, and covers the negative case (Morse, 1999). This current study detailed the patterns of social exchange behaviors in stroke caregiving networks in terms of sharing care, dual care, and supplementary care that the findings can justify applicability in other context of caregiving.

Consistency or Dependability

In quantitative study, reliability refers to consistency, stability, and dependability (Sandelowski, 1986). However, in qualitative research, consistency mean findings are reliable when another researcher can clearly follow the decision trail used by the researchers. Triangulation is used for consistency. This current study was evaluated by filed notes and reflexive sessions with participants during data collection. For example, the meaning of primary caregiver was emerged in data collection and was consistency among primary caregivers and caregiving network members in several stroke caregiving networks.

Neutrality or confirmability

The standard of neutrality represents the importance of freedom from bias (Morse & Field, 1995). To prevent bias, the researcher used multiple strategies to confirm the findings, such as participant observation, and interviews. During the network study, the researcher used multiple sources of data to cross-validation exchange patterns. For example, I gain more understanding of the financial support to disabled people by interviewing the participants, health volunteers, and the office personals of the Ministry of Social Development and Human Security.

Human Subject Protection

In conducting the study, a research proposal, interview guide, and informed consent have been reviewed and approved by Human Research Review Committee of Faculty of Medicine Ramathibodi Hospital, and Neurological institute. The committee's judgment was based on the ethic principle, justice, beneficence, and respect for persons which was fundamental to research (National Commission for the Protection of Human Subjects of Biomedical and Behavioral research, 1979). This study utilized three essential principles including guidelines for obtaining informed consent, risk and benefits assessment, and respect for privacy and confidentiality.

The relationship between researcher and participants depended on accurate information, trust, and respect. Convenience samples were invited to participate in this study. The researcher explained the objective, research procedure, benefits and risks further to patients and their caregivers, and the length of time for interviews and participant observation at clinics, homes, and community settings. Upon informed about their right and confidentiality, the participants agreed to participate the study using both verbally in the tape records or signing the consent. The participants were informed to have rights to withdraw from the study at any time without pre-justice. To assure that the data was protected for confidentiality purposes, the name of each participant was not appear in any paper or tape record. All paper and tapes have been kept in a safety locker at the researcher's house and would be destroyed after next five years. All participants received a little token of appreciation from the researcher.

CHAPTER IV

RESEARCH FINDINGS

The aim of this chapter is to present the findings of the research questions. The first question was who contributes to the care network of stroke caregiver. These findings provided a picture of stroke caregiving in Bangkok to enable people to set up their own networks. The second question asked about what is the nature and adequacy of the exchange within caregiving networks. These results describe features of the patterns of social exchange behaviors and how who perform to fulfill their needs for adequacy. The last findings answer the question as to how the network–exchange configurations of caregiving characteristics vary in stroke caregivers. The results provide variation of social exchange behaviors relating to different characteristics of stroke caregivers in terms of gender, goals of care, caregiving roles, and caregiving styles. These findings are categorized into five sections as follows:

The first section described the characteristics of the caregivers, caregiving network members, and the stroke patients. In this section, a picture of 18 caregiving networks is drawn. In each network, the composition of relationships is presented in terms of size, type of relationship, degree of connection, directionality, frequency of contact, duration, homogeneity, and exchange behaviors within stroke caregiving.

The second section explored the nature and adequacy of social exchange behaviors of stroke caregiving network in which behaviors are shaped by Thai culture. This exploration reviews how caregivers in Bangkok set up caregiving network as a **“wheel of caregiving” model**. The wheel of caregiving model explains the nature, perspectives, and adequacy of social exchange behavior in stroke caregiving into six themes:

Theme 1 “No one else can do it”(*mi-me-krai-thum-trong-nee-dai*)
(ไม่มีใครทำตรงนี้ได้),

Theme 2 “Don’t know what to do”(*mi-ru-ja-rong-pleng-ari-rai*)
(ไม่รู้จะร้องเพลงอะไร),

Theme 3 “Let’s try it” (*su-dai-tong-su-pai-kon*) (ผู้ได้ต้องผู้ไปก่อน),

Theme 4 “Relying on each other” (*tang-kon-tang-are-sai-gun*)

(ต่างคนต่างอาศัยกัน),

Theme 5 “Whatever’s happen, happens” (*ari-rai-ja-kert-mun-tong-kert*)

(อะไรจะเกิดมันต้องเกิด),

Theme 6 “When the time comes, there will be a way” (*teong-ton-nun-*

kho-me-tang-pai-dai) (ถึงตอนนั้นก็มีทางไปได้)

The third section describes the variations of stroke caregiving. This section presents the differences among caregiving through the use of four categories: gender, goals of care, roles of care, and caregiving styles.

The fourth section explores the patterns of social exchange behaviors of stroke caregiving network between primary caregiver and caregiving network members in Bangkok. A wheel of caregiving model based on Thai culture, explains the social exchange behaviors consisting of three patterns: sharing care, separating care, and supplementary care. These patterns are important exchange behaviors between caregiving networks to maintain stroke care in Bangkok.

The fifth section identified the factors influencing social exchange behaviors to achieve physical, psychological, social, spiritual, cultural, financial, and emergency care. These factors include network size, information, relationship, financial support, and management. These conditioning factors are conceptualized as the mechanism to maintain the wheel of caregiving model.

The first Section

In this section, 18 stroke caregiving networks are portrayed through the self-identified characteristics of participants; firstly primary caregivers, then stroke caregiving network members, and finally the characteristics of stroke patients.

4.1 Characteristics of the participants

The participants of this study were individuals who defined themselves as the primary caregiver and/or caregiving network members. From a total 18 caregiving networks, there were 22 participants who declared that they were primary caregivers, and 20 caregiving network members.

4.1.1 Characteristics of primary caregiver

Among 18 caregiving networks, 14 networks had only one primary caregiver, and 4 networks had two primary caregivers. As shown in table 4.1,

all 22 primary caregivers, 19 women and 3 men, were family members with differing relationships to the stroke patient. Half of the caregivers were daughters where four were the youngest daughters, two were the eldest daughters, and five were other daughters. Apart from daughter, six of them were wives, two were sons, one was a daughter-in-law, one was a niece, and one was the youngest brother of the patient. Majority of them were middle aged while six caregivers were old aged. Age ranged from 28 to 75 years old with an average of 52 years. Four caregivers were young adult while six of them were older adult. Half of the caregivers were married. Six caregivers were single while five of them were widowed.

Most caregivers were Buddhists and only three caregivers were Muslim. The duration of care ranged from 4 months to 20 years. More than half of the caregivers had taken care of stroke patient for one to five years. The median was four years. Interestingly, four caregivers provided care instead of the former caregivers because they had died. More than half of them had at least one underlying disease while eight caregivers had no disease. Focusing on their diseases, four caregivers had bone disease, two of them had heart disease and two caregivers had allergy disease. Diabetes mellitus, diabetes mellitus with hypertension, hypertension, migraine, and breast mass were reported in one case each. More than one-third caregivers had primary education. Six of them had secondary school education while four of them had no formal education but able to read and write. Two caregivers had higher education in vocational school and one caregiver had completed a Bachelor degree.

Due to the changes in the available time for work after taking care of stroke patients, almost half of the primary caregivers did not work while twelve of them continued working and taking care of patients at the same time. Relating to employment of caregivers, only two caregivers worked in outside companies, while ten of them worked at home with their own businesses, such as hair salons, grocery stores, selling food, selling lottery tickets, seam stressing and laundry service. More than half of the caregivers had no income while nine of them had income ranging from 1,000 baht per month to 10,000 baht per month with an average of 4,000 baht. However, most caregivers had enough income to sustain their lives while only five of them did not have enough income to cover their expenses. The summary is shown in table 4.1.

Table 4.1 Demographic characteristics of the caregivers (N=22)

Characteristic		Number
Gender		
	Female	19
	Male	3
Relationship to patients		
	Daughter	11
	Wife	6
	Son	2
	Daughter-in-law	1
	Younger brother	1
	Niece	1
Age (years): Youngest 28 years, oldest 75 years (mean = 52 years $\pm$ 12.6 years)		
	21-40	4
	41-60	12
	61-80	6
Marital status		
	Married	11
	Single	6
	Widowed	5
Religion		
	Buddhist	19
	Muslim	3
Duration of care: Shortest 0.4 months, longest 20 years (median = 4 years)		
	<1	2
	1 - 5	12
	6 – 10	7
	>10	1
Underlying disease		
	Yes	14
	No	8
Level of highest education		
	No formal education but able to read and write	4
	Primary school	8
	Secondary school	6
	Vocational school	3
	Bachelor degree	1
Current occupation		
	Working and taking care of patient	12
	Not working	10
Income		
	None	13
	1,000-10,000 baht/month	9
Economic status		
	Enough income	17
	Not enough income	5

4.1.2 Characteristics of the stroke caregiving network members

The caregiving network members consisted of people from both inside the family and outside the family. Within the family, there were stroke patients, siblings, and cousins. Members from outside the family included a housekeeper, a friend, health volunteers, a primary care nurse, home health care nurses, neighbors, ambulance center personnel, officers of the National Council on Social Welfare of Thailand, and officers from the Ministry of Social Security and Human Development. Twenty caregiving network members, 19 women and one man, were approached to participate in in-depth interviews. More than half of the caregiving network members interviewed were daughters. Of these, six were the youngest daughter, two were the eldest daughters and five were other daughters. Besides daughter, two of them were nieces, two were health volunteers, one was a primary care nurse, one was a friend, and one was a neighbor. The network members ranged in age from 28 to 60 years old with an average of 41.6 years. Half of the network members were single, while nine of them were married and only one member was widowed. Most of the members were Buddhist but four of them were Muslim. Nearly one-third of the members had finished secondary school. Another one-third had higher education in Bachelor degree and Master's degree, while four of the members had primary school education. Only one member had not attended in school. More than half of the network members lived in the same household as did the stroke caregivers and patients, while six members lived in another houses about 5-10 minutes walk to these houses. There were four members who lived about 30-120 minutes away. The summary is depicted in table 4.2.

Table 4.2 Demographic characteristics of the caregiving network members (N=20)

Characteristic	Number
Gender	
Female	19
Male	1
Relationship to patients	
Daughter of patients	13
Niece of patients	2
Health volunteer	1
Primary care nurse	1
Friend	1
Neighbor	1
Age (years): Youngest 28 years, oldest 60 years (mean = 41.6 years $\pm$ 10 years)	
21-30	5
31-40	5
41-50	5
51-60	5
Marital status	
Single	10
Married	9
Widowed	1
Religion	
Buddhist	16
Muslim	4
Level of highest education	
No formal education but able to read and write	1
Primary school	4
Secondary school	6
Vocational school	5
Bachelor degree	2
Duration of traveling to the patient's homes (minutes)	
None	11
1 - 10	6
>10	4

4.2 Characteristics of the stroke patients

From the 18 stroke caregiving networks, three groups of six patients were recruited to represent each hospital and communities participating in this study. More than half of their accommodations were living in the inner Bangkok. There were five patients who lived in the middle areas while two patients lived in the outer areas of Bangkok. The stroke patients, chosen met the criteria for this study with the age 60 years or older and by Barthel Index Score 20 points or lower (Total score = 40). Stroke patients consisted of 9 women and 9 men. Two-thirds of the patients were in the young-old adult category (age 60-79) and one-thirds of patients were in the old-old adult category (age 80-99). Their age ranged from 65 to 92 years with an average of 74.6 years. Having to meet the Barthel Index Score (BI) of 20 points or lower, seven of the patients had a score of zero. These patients were bedridden and needed total care. Six patients had score lower than ten (BI =1-10) which meant they could perform mild activities of daily living. Five patients had score higher than ten (BI =11-20) so that they could perform some activities by themselves.

Most of the patients were Buddhist and three patients were Muslim. More than half of patients were married while six were widowed, and one was divorced. Focusing on family children in the family, two-thirds of the stroke patients had less than five children, while one-third of them had more than five children. The number of children ranged from one to eleven with an average of five children. Focusing on educational level, nearly half of the patients had not received any formal education, while six had finished primary school and three had finished secondary school. Only one patient had completed a Bachelor degree. Before their illness, more than half of the patients did not work outside the home: seven patients were housewives and three patients had retired from their own businesses, a state enterprise, and a company. Nearly half of them had worked at home or outside. Five of them had their own businesses in respectively: a grocery store, car repairs, selling lottery tickets, selling food, and seam stressing, one of them had worked in a sport newspaper company as an editor and one had worked in the temple as an undertaker. One patient had worked as a taxi driver. After they suffered stroke, all of them retired from their work.

The duration of illness ranged from 4 months to 20 years. The median was 4.5 years. Two patients had suffered stroke less than one year while one patient had suffered it for twenty years. Nearly half of patients had suffered stroke more than one to five years and seven patients had suffered stroke more than five to ten years. Focusing on types of payment, half of the patients were reimbursed for health care cost, while eight of them had Universal Coverage of National Health Insurance. Only one patient paid out of her own pocket because her family did not take her to the hospital.

Nearly half of the patients lived in their own houses while eight of them stayed in their children's houses. Only two patients lived in rented houses with their family members. Relating to numbers of people in the household, two-thirds of patients had less than five persons in the household, while one-third of them had more than five persons in one house. Two-thirds had no income, while one-third had income from 300 baht to 15,000 baht per month. However, two-thirds said they had enough income to cover living cost while one-third said they did not have enough. The summary is shown in table 4.3.

Table 4.3 Demographic characteristics of stroke patients (N=18)

Characteristic	Number
Setting	
Ramathibodi Hospital	6
Neurological Institute	6
Community health center	6
Areas of residence	
Inner part of Bangkok	11
Middle part of Bangkok	5
Outer part of Bangkok	2
Gender	
Female	9
Male	9
Age (years): Youngest 66 years, oldest 92 years (mean= 74.6 years $\pm$ 8.23 years)	
60-79	13
80-99	5
Barthel Index Score Lowest score = 0, highest score = 20	
0	7
1-10	5
11-20	6
Marital status	
Married	10
Single	7
Widowed	1
Religion	
Buddhist	19
Muslim	3
Number of children: Lowest 1 child, highest 12 children (mean = 5 $\pm$ 3.14)	
1 - 5	12
6 – 10	4
>10	2

Table 4.3 Demographic characteristics of stroke patients (N=18) (cont.)

Characteristic	Number
Level of highest education	
No formal education but able to read and write	8
Primary school	6
Secondary school	3
Bachelor degree	1
Working condition before illness	
No working	10
Working	8
Duration of care: Shortest 4 moths, longest 20 years (median = 4.5 years)	
<1	2
1 - 5	8
6 – 10	7
>10	1
Type of payment	
National Health Insurance	9
Government Welfare	8
Out of pocket	1
Living condition	
Own house	8
Children's house	8
Rental house	2
Number of persons in the household: Lowest 3 persons, highest 7 persons (mean = 5 ± 1.5)	
1 - 5	12
6 - 10	6
Income	
Enough income (2,000 –15,000 baht/month)	12
Not enough income (0-300 baht/month)	6

The stroke caregiving networks

Each stroke caregiving networks is displayed in terms of the structure of relationships and caregiving exchange behaviors.

Caregiving network 1 (Mrs. Ant)

Mrs. Ant, a 76 year old stroke patient, was widowed twice and had had nine children in all. She had one daughter with her first husband, who then died. After her husband died, she got married and had eight children with the second husband. Previously, Mrs. Ant had lived in a rental house with her husband near her eldest daughter's house. Each unit of the rental house consisted of one small room and one toilet. These rental houses were partitioned by a wooden wall on the first floor with high stairs about four feet above the ground. Under the ground floor, sewage had dampened the soil with spilled garbage. This area was lined with pieces of wood for walking. In front of the house, there was a big jar for collecting water. This area was the place for cleaning the dishes, doing laundry or taking a bath (see picture1). The family members brought the bench and desk to gather under the tree for talking and cooking. In the rainy season, plastic cloth was used to protect them from the rain



Picture 1: In front of the house



Picture 2: Temple is the center of community

After the second husband had been dead for a few years, Mrs. Ant moved to live with her eldest daughter's family in the same room. The eldest daughter, namely, Mrs. Bee, was 58 years, was living with her husband and two nephews. Mrs. Bee had three daughters and one son who had left to set up their own families. Only one daughter's family lived close to her house. Her daughter (Mrs. Ant's niece) regularly asked Mrs. Bee to cook food for her family and gave 2,000 baht to support Mrs. Bee and 300 baht to Mrs. Ant every month.

Mrs. Bee's family lived in the Wat Cheon Wai community. This community consisted of a temple, two schools, and a community health center. The temple is the center of this community where people come to join in many activities together throughout the year, such as Songkarn festival (see picture 2). Mrs. Bee joined in the community activities, such as preparing food for people at funeral care or the ceremony of ordination into the monkhood. During the Songkarn festival, the Thai New Year, family members came to Mrs. Bee's house to give respect to Mrs. Ant by pouring water on her hand and Mrs. Ant gave the good words to them (See 3)



Picture 3: Pouring water on Songkarn festival



Picture 4: community health center

The community health center is a building that located close to the temple. In this building, there are many rooms for community services. For example, the activity room is the room for community people doing handmade flower arrangements together, whereas the first aid room is where medication and medical equipment are kept (picture 5). Community health volunteers are the personnel who provide care to the people in the community such as giving general medications, and connecting to the poor or disabled in the community with the social welfare services of the Bangkok Metropolitan Authority (See picture 6). In addition, there is a community charity to provide funeral care for the members. Mrs. Bee paid 600 baht to be a member and paid 20 baht each time there was a death in the community. If she passes away, the community group would provide funeral care for her.



Picture 5: Equipments



Picture 6: Community health volunteer

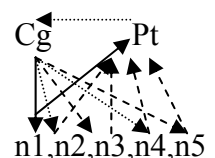
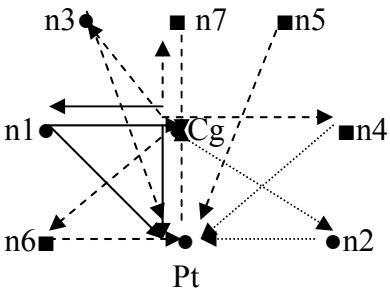
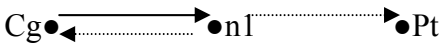
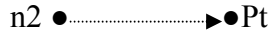
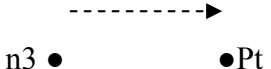
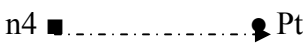
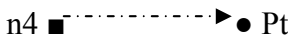
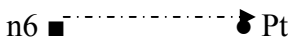
Mrs. Ant had a stroke ten years ago (Barthel Index Score =18 from total score = 40). Her family took her to stay in her second daughter's house on Lumlooka road because of better environment. Mrs. Ant did not want to stay there and protested to all about her care by refusing to eat and sleep. Thus, Mrs. Bee received external force from her siblings to play a role as a primary caregiver because of none of Mrs. Ant's children wanted to take this responsibility and Mrs. Ant did not want to live with them. Then, Mr. Ant's children took her back to Mrs. Bee's rented room but she could not walk to the toilet in the room. Therefore, her children took Mrs. Ant to stay in the kitchen that was newly built close to this room. Mrs. Ant felt more comfortable for urinating or defecating in the bedpan rather doing in the room with Mrs. Bee's family. In the morning, Mrs. Bee woke up to cook food for her family and her daughter's family. She prepared a bowl of water for Mrs. Ant to clean herself and gave her glass of chocolate milk with her medication. After Mrs. Ant finished drinking the milk, voiding, and cleaning herself, Mrs. Bee helped her with cleaning the glass, dish and bedpan. Mrs. Bee completed her housekeeping work and laundry before going to the market. After she got back, she had lunch with her family. In the afternoon, Mrs. Bee usually had activities with her neighbors, such as talking, cooking food at the ground floor, while Mrs. Ant took a nap in the kitchen. Mrs. Bee cooked and had dinner in the evening before providing a bowl of water for cleaning to Mrs. Ant. On Sunday, the youngest daughter of Mrs. Ant came to Mrs. Bee's house to help give a bath to Mrs. Ant on the floor in front of their house while Mrs. Bee's husband occasionally helped in carrying Mrs. Ant from the upstairs.

Time	Activities
5.30-7.00	Prepare breakfast for the patient and family
8.00	Give a glass of chocolate milk and medication to patient and clean the patient's bedpan
9-10.00	Clean the dishes and do laundry before going to the market
11-12.00	Have lunch with the patient and family
13-16.00	Talk with the neighbor and have activities together, such as cooking food
17-18.00	Cook food and have dinner with the patient and family
20.00	Clean of the patient by the eldest daughter

Caregiving network: Structure and relationship

This caregiving network consists of both family members and non family members. It is obvious that the eldest daughter of the patient plays the role of primary caregiver. The family members are the eldest daughter's husband, niece, patient, and the youngest daughter while the non family network members are health volunteers, home health care nurses, the temple, and social welfare staff.

The star graph below shows the relationships in the caregiving network that are focused on both the caregiver and the patient. The caregiver provided information to the network members and the patient received support from the network members. Cliques reflected subsets of actors that consisted of five groups of member who carried out caregiving together. Additionally, there were two types of exchange behaviors: direct, and indirect exchange. The direct exchange is presented the relationship between the caregiver and the patient's niece, also between the caregiver and the patient. The indirect exchange is presented the relationship among five groups associated with the caregivers, the patients, and the network members (the patient's niece, the caregiver's husband, the youngest daughter, health volunteers, and the temple). The degree of connection is presented by the frequency of support in the relationship of the caregiving network members. The diagram showed that there was a regular support from the youngest daughter weekly, niece and home health care nurse monthly, and health volunteer yearly, while there are occasional support from the husband, niece, the patient, and temple.

Relationship	Structure
Star graph, Cliques (n1, Cg, Pt), (n2,Cg,Pt), (n3,Cg,Pt), (n4,C,Pt), (n6,Cg,Pt) Direct exchange n1 $\longleftrightarrow$ Cg Pt $\longleftrightarrow$ Cg n7 $\longleftrightarrow$ Cg Indirect exchange 	Eldest daughter (Cg), Niece (n1), Youngest daughter (n2), Eldest daughter's husband (n3), Health volunteer (n4), Home health care nurse (n5), Temple (n6) neighbor (n7)  ● n1, ● n2, ● n3 Family member ■ n4, ■ n5, ■ n6 ■ n7 Non family member ————→ regularly - - - - -> weekly, monthly, yearly - - - - -> Occasionally — / —> stop caregiving
Degree of connection	Niece gave 2,000 baht monthly to the caregiver and gave 300 baht per month to the patient while the caregiver cooked food to her daily. 
	The youngest daughter provided a bath for the patient weekly. 
	The eldest daughter's husband carried the patient occasionally. 
	Health volunteer connected to social welfare to have information sent yearly. 
	Home health care nurse provided home visit and checked up blood pressure to patient monthly. 
	Temple provided hand made wheel chair to caregiver. 

On the aspect of exchange behaviors, the caregiving network members exchanged caregiving in physical, psychological and financial care. On the subject of physical exchange, Mrs. Ant and Mrs. Bee had direct exchanges of caregiving with each other. Mrs. Ant could not walk but could move a little. She could eat by herself. Mrs. Bee helped her mother with cooking food while Mrs. Ant provided the information to remind her for losing things. When Mrs. Ant voided in the bedpan and cleaned herself, Mrs. Bee helped her with cleaning the bedpan.

However, the primary caregiver (Mrs. Bee) faced difficulty in the caregiving task of bathing. Via indirect exchange, she talked with her husband and her youngest daughter about her limitation. As a result, her husband helped her with lifting Mrs. Ant to take a bath occasionally. The youngest daughter of Mrs. Ant came from her house at Bangsue 30 minutes-away to help Mrs. Bee with giving a bath for their mother every Sunday. Through bringing Mrs. Ant to follow up at the hospital, Mrs. Bee knew about the hand-made wheel chair at the temple. She asked the monk at the temple to give a hand made wheel chair for her to transfer her mother from her house to the road. Moreover, a home health care nurse came from the Metropolitan health center to provide home visiting and to check blood pressure for Mrs. Ant monthly. Mrs. Bee was also able to go to the health center to collect the medication instead of her mother having to go.

On financial exchange, Mrs. Bee's daughter asked her to cook food for her family. She had direct exchange with Mrs. Bee by providing 2000 baht monthly. In addition, she had indirect exchange with Mrs. Ant by giving 300 baht monthly when her mother informed her about the lack of financial support for Mrs. Ant from the other children. Moreover, Mrs Bee had indirect exchange with the health volunteer by sending information about the disability of Mrs. Ant to the health volunteer and he helped her by connecting to social welfare yearly. As a result, Mrs. Ant received 500 baht monthly from the government for one year.

Based on Thai social value of cultural exchange, Mrs. Bee believed in “*boon*” (goodness) and “*karma*” (badness). For the goodness, Mrs. Bee believed in the direct exchange of merit making. She helped her neighbors and expected that they could help her in the future. When she took care of her mother, her children would provide care for her later. She also believed that she received improvements in her life

through thing such as receiving food and materials from others as the result of her taking care of her mother.

“*Karma*” or “badness” emerged through the communication problems which occurred because Mrs. Bee and her nephew could not understand about Mrs. Ant’s speaking. When Mrs. Ant quarreled with them, Mrs. Bee got stressful and loudly yelled at her. When she calmed down, she thought about her bad words to her mother. She felt so guilty and took flowers to ask for forgiveness from her mother as the direct exchange.

Focusing on spiritual indirect exchange, when Mrs. Bee told Mrs. Ant about merit making activities, such as sharing in the construction of a Buddha image or in funeral care, Mrs. Ant donated her money or shared in the merit making with Mrs. Bee by speaking with delighted approval in the same way as Christian do through saying “Amen” or “Hallelujah”

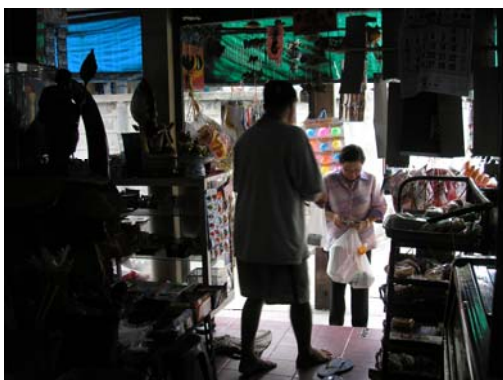
Directionality Direct exchange	• The caregiver provided care to the patient by cooking food, cleaning the bedpan, washing clothes while the patient gave information to remind the caregiver about losing stuff. • The caregiver cooked food to her daughter’s family while her daughter gave her 2000 baht per month. • The caregiver helped her neighbor with cooking, while she expected that the neighbors would provide care for her in the future. • The caregiver took flowers to ask her mother forgiveness for her bad word while her mother gave a word to comfort her.
Indirect exchange	• The caregiver talked the eldest daughter’s husband, and the youngest daughter of the patient about her limitation in giving a bath to the patient, so they helped her with lifting the patient to take a bath. • The caregiver gave information about the patient’s financial status to her niece and the health volunteer so they then provided financial support to the patient.

Indirect exchange	• The caregiver gave information to the monk at the temple about her limitation in transferring the patient, so the temple gave a hand-made wheel chair to patient. • The caregiver provided care to the patient and expected that her children would take care of her in the future. • The home health care nurse visited and checked blood pressure for the patient monthly while caregiver went to the health center to collect medication instead of the patient having to go. • The caregiver helped her neighbors in community activities and hoped that she would receive help from them in the future.							
Duration	Ten years of stroke caregiving							
Frequency of contact	Health volunteer yearly Niece, Home health care nurse.....monthly The youngest daughter weekly Caregiver's husband, temple, neighbor...occasionally							
Size	Eight persons							
Sociodemographic	Cg	n1	n2	n3	n4	n5	n6	n7
Sex (F = Female; M= Male)	F	F	F	M	M	F		
Age (year)	58	30	38	66	40	-	-	-
Religion(B=Buddhist)	B	B	B	B	B	-	-	-
Occupation H = Housewife B = Business E = Employee G = Government	H	B	E	E	E	G		
Residential location S = Same house	S	5 mins	30 mins	S	5 mins	30 mins		

Caregiving network 2 (Mrs. Bell)

This caregiving network was the only one network that consisted of family members alone. In Wat Cheon Wai community, Mrs. Bell, was a 72 year old stroke patient. She was widowed because her husband had died of stroke disease many years before. She has three children and is living with the eldest daughter and the second son. The youngest son is working and living in Rayong province nearby. Mrs. Bell has her own grocery store to sell various items in the local community, such as food, drinks, disserts and so on. Her eldest daughter works as a seamstress at the Thai army dressmaking department and her second son works with Mrs. Bell in the grocery store.

Mrs. Bell's house had two storeys. On the ground floor, she partitioned the front part of the house into a grocery shop (see picture 7), and living room while there was a kitchen in the back. Her younger sister's house was near Mrs. Bell's house just a few minutes walk away. Mrs. Bell's younger sister lived with her daughter, her son in law, and two nieces. Mrs. Bell's family and her younger sister's family had close relationship and always joined in many activities together, such as going to the seaside, and relying on each other.



Picture 7: Grocery shop



Picture 8: Stroke caregiving family

In the past, these two families had experience in providing care for the elderly in the community. Mrs. Bell, her eldest daughter, and her niece had helped together with taking care of an older lady who was their landlord. All of them provided care to this elderly person by bathing her, cooking and feeding her. As a result, the landlord allowed Mrs. Bell's family to live in her land without paying the ground rent. In addition, she allowed Mrs. Bell to collect the rental fees for her every month.

Mrs. Bell had stroke six years ago. She could not walk at all but she was able to sit down and chew the food, fed to her by others. (Barthel Index Score = 4, total score = 40). Her second son (namely Mr. Bo) played a role as a primary caregiver to provide care for her during the daytime and took care of her grocery store. Her eldest daughter worked outside and provided care to her mother during the nighttime and on weekend.

Every morning, while the eldest daughter gave a bath to Mrs. Bell before going out to work, Mr. Bo went to the market to buy food and other things and then came back home to open the grocery store. While selling his goods, he fed food and gave medication to Mrs. Bell before he had breakfast. When Mrs. Bell took a nap, he went to clean the dishes. Mr. Bo was single and felt awkward in cleaning his mother's body. Similarly, Mrs. Bell felt too embarrassed to allow her son to do that. To confirm this behavior, Mrs. Bell shied away from taking a photograph of kissing with her children.

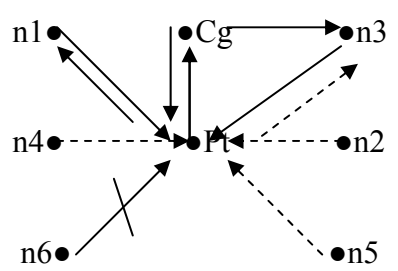
A schedule of a week by the caregiver

Time	Activities
6.00	Bringing food and goods to sell by caregiver while the eldest daughter bathe the patient
8.00	Opening the grocery store by caregiver while the eldest daughter goes out to work
8.30	Feeding and giving medication to the patient by caregiver having his own breakfast afterwards.
9-11.00	Allowing the patient to take a nap and caregiver going to clean the dishes
12.00	Changing the wet diaper and cleaning the patient by her niece
13.00	Feeding and giving medication to the patient, then caregiver having lunch
14-16.00	Watching television with caregiver in the relaxing time
17.00	Cooking special food for the patient by the eldest daughter
18.00	Bathing of the patient by the eldest daughter
19.00	Feeding and giving medication to the patient and having dinner together
21.00	Closing the grocery store
22.00	Bringing the patient to sleep in the bedroom by the eldest daughter

As a result, every noon, Mrs. Bell's niece came to help her with changing her wet diaper and provided cleaning for her body. In the past, the younger sister-in-law of Mrs. Bell's niece had played this role but she stopped providing care because of working out. After Mrs. Bell's niece had completed her job, Mr. Bo fed the lunch and gave medication to his mother then had his own lunch. During the relaxing time, Mr. Bo and Mrs. Bell watched television together. In the evening, Mrs. Bell's eldest daughter came back home. She cooked some special food for her mother. She provided a bath for her before she fed dinner and gave medication to her. Her family had dinner together and closed the grocery store. During the nighttime, Mrs. Bell and her eldest daughter slept together in the same bedroom.

Caregiving network: Structure and relationship

This stroke caregiving network consists only of family members. The first son (second child) played a role as a primary caregiver. The family network members were the eldest daughter, the youngest son, niece, niece's daughter, niece's younger brother-in-law, niece's younger sister-in-law. As shown in the figure, the star graph shows the main center of the patient while the clique graph presents the subset group of activities for indirect exchange between the primary caregiver, Mrs. Bell, and her niece. The degree of connection reflects the frequency of daily support in the relationship from the primary caregiver, the eldest daughter, and niece while the occasional support comes from the youngest son, niece's daughter, niece's younger brother-in-law and of niece's younger sister-in-law (who eventually had stopped giving support).

Relationship	Structure
Star graph, Clique (Cg,n3,Pt) Exchange Direct exchange n2 $\longleftrightarrow$ Cg Pt $\longleftrightarrow$ Cg Pt $\longleftrightarrow$ n3 Indirect exchange n2 $\rightarrow$ Pt Cg $\rightarrow$ Pt	Son (Cg), eldest daughter (n1), youngest son (n2), niece(n3), niece's daughter (n4), niece's young brother-in-law (n5) niece's young sister-in-law (n6)  ●n1, ● n2, ● n3, ● n4, ● n5, ● n6 Family member $\longrightarrow$ regularly $\cdots\cdots\longrightarrow$ weekly, monthly, yearly $\cdots\cdots\longrightarrow$ Occasionally $\longrightarrow$ / $\longrightarrow$ stop caregiving
Degree of connection	The son took care of the patient in the daytime Cg ● $\longrightarrow$ ● Pt
	The eldest daughter took care of the patient during the nights and on the weekends n1 ● $\longrightarrow$ ● Pt
	The youngest son gave some money to the patient occasionally n2 ● $\cdots\cdots\longrightarrow$ ● Pt
	The niece cleaned the patient at noon daily n3 ● $\longrightarrow$ ● Pt
	The patient listened to her niece to reduce her stress Pt ● $\cdots\cdots\longrightarrow$ ● n3
	The niece's daughter fed and gave water to the patient occasionally n4 ● $\cdots\cdots\longrightarrow$ ● Pt
	The niece's younger brother-in-law took the patient to the seaside by car occasionally n5 ● $\cdots\cdots\longrightarrow$ ● Pt
	The niece's younger sister-in-law had provided perineum care to the patient in the past, but now she stopped caregiving n6 ● $\longrightarrow$ / $\longrightarrow$ ● Pt

Relating to the exchange behaviors, the caregiving network members exchanged caregiving in physical, psychological, socio-cultural, and spiritual care. Focusing on physical exchange, Mr. Bo had direct exchange with Mrs. Bell. She faced difficulty moving by herself and taking care of her grocery store. Mrs. Bell gave this store to Mr. Bo while he took care of the store and provided care to her during daytime. At the beginning, Mr. Bo changed the environment, such as changing the toilet to make it more comfortable to sit on, installing a rail for walking in the house, and acquiring a machine for shoulder exercise. However, Mr. Bo felt conflict in his caregiving between the need for rehabilitation and the possibility of an accident. He was afraid when Mrs. Bell tried to walk a little to the toilet and fell down and cut herself. Consequently, Mr. Bo did not allow Mrs. Bell to go to the toilet except by using diaper. He reduced the goal of care from rehabilitation to long life caregiving for her.

The direct exchange was not only physical and physical exchange but also psychological exchange. The eldest daughter of Mrs. Bell provided care to Mrs. Bell by cooking, giving a bath, sleeping in the same bedroom during the night and taking care of her while selling goods in the grocery store on the weekend. She perceived that Mrs. Bell was her mother whom she had to do the best for by returning caregiving back to her. In contrast, there was an indirect exchange between the eldest daughter, the caregiver, and the patient. Sometime Mrs. Bell's eldest daughter was angry because Mr. Bo denied his help to her by taking a rest in his room or going out with his friend. She coped with her problem by stopping talking about the problem. If her emotion erupted, her younger brother did not provide care to her mother, she would feel terrible because she was working in a government department and could not take care of her mother during the daytime.

For the indirect exchange between Mrs. Bell, her niece, and niece's children, Mrs. Bell's niece recognized that her caregiving to Mrs. Bell was a role model for her children to gain an idea of taking care of the elderly in the future. In addition, when she was so stressful by her mother's behavior, she could express her problem to Mrs. Bell by talking about her mother. Mrs. Bell then provided support by making jokes and saying to hit her younger sister for this bad behavior.

In the area of socio-cultural exchange, Mrs. Bell's caregiving network members shared information on caregiving activities. The eldest daughter shared her experience of helping disabled people together. She felt proud of the admiration that people felt for her because of her activities such as taking the patient out to eat in a restaurant or traveling to the sea with her family. On the other hand, Mrs. Bell's family felt conflicts about taking her out because of Mrs. Bell's worsening condition. She got sick after coming back home from an excursion and the information got back to network members.

In Thai culture, there are gender differences in caregiving. A Thai single person would be ashamed to care special area of opposite gender. Mr. Bo was single and had limitations in cleaning his mother's body. The indirect exchange emerged from sending information from Mr. Bo to Mrs. Bell's niece. When the patient's niece knew his problem, she came to provide changing of Mrs. Bell's wet diaper and cleaning for her body. In addition, based on believing in "*boon*" (goodness) and "*karma*" (badness), Mrs. Bell's niece believed that she provided care to Mrs. Bell as merit making.

For the indirect exchange of doing the goodness, Mrs. Bell's niece found that when she had serious problems in her business or with her children, she received help for herself and her family from an invisible hand (the hand of God). Similarly, the eldest daughter believed that Mrs. Bell had suffered stroke but it was not so severe because of help from her "*old boon*" in the past.

Directionality Direct exchange	• The caregiver took care of the patient in the daytime and her grocery store while she gave her store to him • The eldest daughter provided care to her mother in the nighttime and on weekend while she received the benefits of a close relationship with her mother • The niece cleaned the patient every noon while the patient listened to her and made her feel relaxed.
Indirect exchange	• The family members shared information to take the patient out while they felt proud of the admiration they received from people.

Indirect exchange	- The niece provided care to the patient while she found that she received help from an invisible hand (the hand of God) for her serious problems. - The eldest daughter believed that Mrs. Bell had had a stroke but it was not so severe because her doing goodness had helped her take it from a severe to a small problem.						
Duration	Six years of stroke caregiving						
Frequency of contact	Caregiver, the eldest daughter, niece.....daily Niece's daughter, niece's young brother-in-law....occasionally Youngest son						
Homogeneity	The eldest daughter had had an experience in taking care of the elderly in the community and of her father who had had stroke.						
size	Seven persons						
Sociodemographic	Cg	1	2	3	4	5	6
Sex (F =Female M = Male)	M	F	M	F	F	M	F
Age (year)	44	45	42	42	12	40	39
Religion (B= Buddhist)	B	B	B	B	B	B	B
Occupation G = Government E = Employee B = Business S = Student	B	G	E	E	S	E	E
Residential location S = Same house	S	S	Rayong province	5 mins	5 mins	5 mins	5 mins

♣ Second son (Cg), eldest daughter (n1), youngest son (n2), niece (n3), niece's daughter (n4), niece's young brother-in-law (n5) niece's young sister-in-law (n6)

Caregiving network 3 (Mr. Cat)

This small caregiving network consisted of family members, the spouse, a friend, and a home health care nurse. The stroke patient, namely Mr. Cat, was 65 year old and had three children. Mr. Cat lived with his wife, his second daughter and his youngest son while the eldest son lived with his own family close to Mr. Cat's house in Yim Pra Yoon community. This community has a main street in the central area. Along the road are business premises, a condominium, small houses, and town houses. There is a community center and some health volunteers, who work with Metropolitan health center. Mr. Cat's house is a townhouse, which is planned to be re-developed as a new community center in this community by the Metropolitan health center.



Picture 9: Housing along the road



Picture10: Playing together

Mr. Cat and his wife both worked in a sport newspaper. He was an editor while his wife was a reporter. Both of them were also writers of many famous novels in the past. However, they had different way of life. Mr. Cat loved gambling and spoiled himself to play rummy with his friends while his wife liked to go out to eat in the hotels or restaurants relating to her entertainment work. Mr. Cat got diabetes mellitus and had poor control of blood sugar. He first suffered stroke for three years ago and could walk a little at the beginning. He had heart disease and renal disease that made it necessary that he be readmitted to hospital. His health condition was rapidly deteriorating. He could only sit down to eat and he moved a little by himself but he could not stand up or walk to anywhere. (Barthel Index Score =16, total score = 40). His wife, (Mrs. Can) played a role as a primary caregiver to take care of Mr. Cat, her family, and her job. In the morning, she cleaned the patient and did the laundry. After

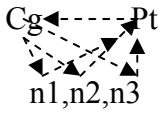
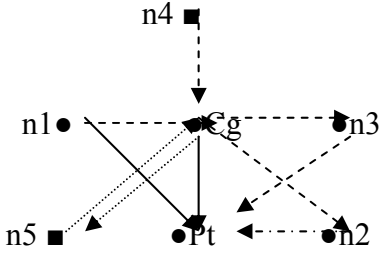
she provided an insulin injection and bought some cooked food to the patient, she went out for working only twice a week. During this time, she asked her daughter to stay with the patient. When she did not go out for work, she had breakfast and watched television with the patient. In the evening, she gave him a bath and an insulin injection before they had dinner together. All family members joined activities by watching television, going shopping, and eating together in the restaurants. All children were working and provided help to their parents occasionally.

A schedule of a week of caregiver

Time	Activities
9.00	Cleaned the patient and took a laundry
10.00	Provided insulin injection 10 units to the patient
10.30	Bought some cooked food and prepared medication to the patient before went outside to work twice a week
11.00	Had a breakfast and medication by the patient
12-14.00	Watched television together and had some snack together
15-17.00	Went in the front of the house by wheel chair for sight seeing
18.00	Provided taking a bath to the patient
19.00	Provided insulin injection 6 units to the patient
20.00	Bought cooked foods and had a dinner together
21.00	Provided medication to the patient
22-5.00	Watched television or slept in the bed alternation

Caregiving network: Structure and relationship

This caregiving network of stroke caregiver consisted of the family members and non- family members. The family members were the patient, his wife, the eldest son, second daughter and the youngest son while the non-family members were the wife's friend, and a Metropolitan health nurse. As shown in the figure, the star graph represents the relationship of the caregiving network focusing on both the caregiver and a patient. The clique graph shows the subset of actors that describes three groups of network members joining activities together. Focusing on the directionality, there are three direct exchanges and three indirect exchanges.

Relationship Star graph Line graph (Cg, n1, Pt), (Cg, n2, Pt), (Cg, n3, Pt). Exchange Direct exchange Cg → Pt Cg → n5 Indirect exchange exchange 	Structure Wife (Cg), the youngest son (n1), the second daughter (n2), the eldest son (n3), wife's friend (n4), metropolitan health nurse (n5)  ● n1, ● n2, ● n3 Family member ■ n4 ■ n5 Non-family member —→ regularly —→ weekly, monthly, yearly - - - - -→ Occasionally /→ stop caregiving
Degree of connection	The caregiver provided care to the patient, such as bathing him, doing laundry, buying food, taking him to the hospital, and taking care of all daily expenses. Cg ● —→ ● Pt The youngest son took care of patient by driving to him the hospital The youngest son gave some money to the caregiver and drove him to a department store or restaurant monthly. Cg ● ← n1 ● → ● Pt The second daughter provided care for the patient occasionally. n2 ● - - - - - → ● Pt The eldest son provided cleaning and participated in the patient's rehabilitation occasionally. n3 ● - - - - - → ● Pt The wife's friend provided psychological support to the caregiver occasionally. n4 ● → ● Cg Metropolitan health nurse will take care of the caregiver in the future. n5 ● → ● Cg

This caregiving network had exchanged caregiving in physical, psychological, socio-cultural, and financial care. In physical exchange, there was direct exchange between Mr. Cat and Mrs. Can. Mrs. Can perceived that she was indebted to her husband for looking after three children instead of her doing it in the past. When the three children were young and had voiding or vomiting, she faced difficulty providing care for them. Mr. Cat helped her with cleaning the three children. When Mr. Cat had a stroke, she wanted to give back to him by taking care of him. For indirect exchange, when Mrs. Can got sick, she asked her eldest son to help her with giving a bath to Mr. Cat. If Mrs. Can went out to work, she asked her daughter to give an insulin injection to Mr. Cat. When Mrs. Can took Mr. Cat to follow up at the hospital, she told her youngest son to drive the car for Mr. Cat.

For psychological exchange, when Mrs. Can stayed at home, she took her husband by wheel chair for sightseeing in front of the house. They talked and played together (see picture 13). In addition, Mrs. Can could express her stress to her friend while her friend listened and provided support for her.

Relating to socio-cultural exchange, there was a direct exchange between Mrs. Can, and the Metropolitan health nurse. Mrs. Can became a health volunteer and allowed her house to be developed as the new community center. She expected that the Metropolitan health nurse would take care of her in the future.

For the financial indirect exchange, Mrs. Can felt conflict in providing financial support for alternative treatment for her husband. Mr. Cat knew from a taxi driver about the alternative of massage. He transferred this information to Mrs. Can and asked her to take him to the massage in Saraburi province. She hoped to gain freedom in her way of life if her husband could recover and take care of himself. She felt conflict because Mr. Cat was not concerned about the high cost of care since Mrs. Can was a main person, who bore all expense in the family. Her youngest son gave 1000 baht to Mrs. Can monthly.

In the area of spiritual belief, Mrs. Can believed in the supernatural and respected the cult of monarch. When she faced difficulty problem, she asked the supernatural, figure of King Rama V help her solve the problem

Directionality Direct exchange	- The caregiver took care of the patient because he used to look after their three children in the past. - The caregiver allowed her house as a community center and expected that Metropolitan health nurse would take care of her in the future. - The caregiver took the patient by wheel chair for sight seeing and she talked and had fun with the patient for relaxation.					
Indirect exchange	- The caregiver asked her youngest son, and he drove the patient to follow up at the hospital monthly. - The caregiver told the daughter when she went out and the daughter took care of the patient occasionally - The caregiver asked the eldest son to help her and he provided cleaning and participated in the rehabilitation of the patient occasionally.					
Duration	Three years of stroke caregiving					
Frequency of contact	Caregiver.....daily The youngest son monthly The second daughter, the eldest son.....occasionally The wife's friend, Metropolitan health nurse					
Homogeneity	-					
size	Six persons					
Sociodemographic	Cg	1	2	3	4	5
Sex (F =Female, M = Male)	F	M	F	M	F	F
Age (year)	60	26	31	35	-	-
Religion (B =Buddhist)	B	B	B	B	-	-
Occupation E = Employee G = Government	E	E	E	E	-	G
Residential location S = Same house	S	S	S	5 mins	5 mins	20 mins

Caregiving network 4 (Mrs. Dang)

In Yam Pra Yoon Pattana community, there is a caregiving network has exchanged their caregiving activities more than ten years. The network has changed both members and caregiving processes to fit their ways of lives. To understand the behavior in everyday situations, the portrait of the caregiving network displayed here.

Mrs. Dang, a stroke patient, was 74 year old. She was widowed and had five children. She lived with her family consisting of five family members: the second daughter, the third son, the third son's wife, a niece, and the fourth daughter while the eldest son, the youngest son, and her husband had passed away many years ago. Previously, she was a housewife and took care of her children, while her husband was a soldier. He bought a townhouse with his pension when he retired. Every morning, she offered food to the monks and talked with her neighbors while her husband took their niece to school.

Mrs. Dang had her first stroke for ten years ago. She was able to sit in a wheelchair and eat by herself. During that time, her husband and her third son (namely Mr. Drum) provided care to her at home. When Mrs. Dang went to follow up at the hospital, the fourth daughter (namely, Ms. Dee) and her boy friend would drive her to the hospital. When Mrs. Dang got recurrent stroke, all family members waited for Ms. Dee to take her to the hospital. Ms. Dee felt so sad wondering why family members did not promptly respond in taking Mrs. Dang to the hospital. At this time, Mrs. Dang was bedridden and unable to eat any food by herself. Her family member had to feed her via a feeding tube with commercial diet four time a day (Barthel Index Score = 0, total score = 40). After Mrs. Dang's husband got intestinal cancer and had been dead for three years, Mr. Drum could not take care of Mrs. Dang just by himself. As a result, Ms. Dee quit her job to take care of her mother as a primary caregiver instead of her father.

The second daughter (namely Ms. Do) was a teacher in a private school. Ms. Do worried about the cost of living and taking care of her mother because she was the only one who worked outside the house. She discussed her financial concerns with her siblings. With her saving, she opened a small grocery store in front of her house to sell some food, drinks, and desserts. She asked Ms. Dee and Mr. Drum to look after the store. Mr. Drum sold the goods while Ms. Dee went shopping and bought the items

to fill the store. The income of this grocery store was separated and distributed to three persons: Mrs. Dang, Ms. Dee, and Mr. Drum. Interestingly, Mr. Drum's wife was a hairdresser and had her small shop at the left side in this grocery store.

Every morning, Ms. Dee fed the diet to her mother while Ms. Do went to work outside. After Ms. Dee opened the store and had breakfast, she and her niece helped each other to clean Mrs. Dang. Ms. Dee usually turned a television on to stimulate Mrs. Dang, while she did laundry and cleaned the house. Around noon, she fed the diet to Mrs. Dang and had lunch. When she had leisure time, she talked with Mrs. Dang or fed orange juice to her. In the evening, she went to the market and cooked food. She fed the diet to Mrs. Dang again and had dinner with Ms. Do while Mr. Drum had a dinner with his family. After relaxing, Ms. Dee and Ms. Do bathed her mother and fed the fourth diet to her at 12 p.m.

A schedule of a week by caregiver

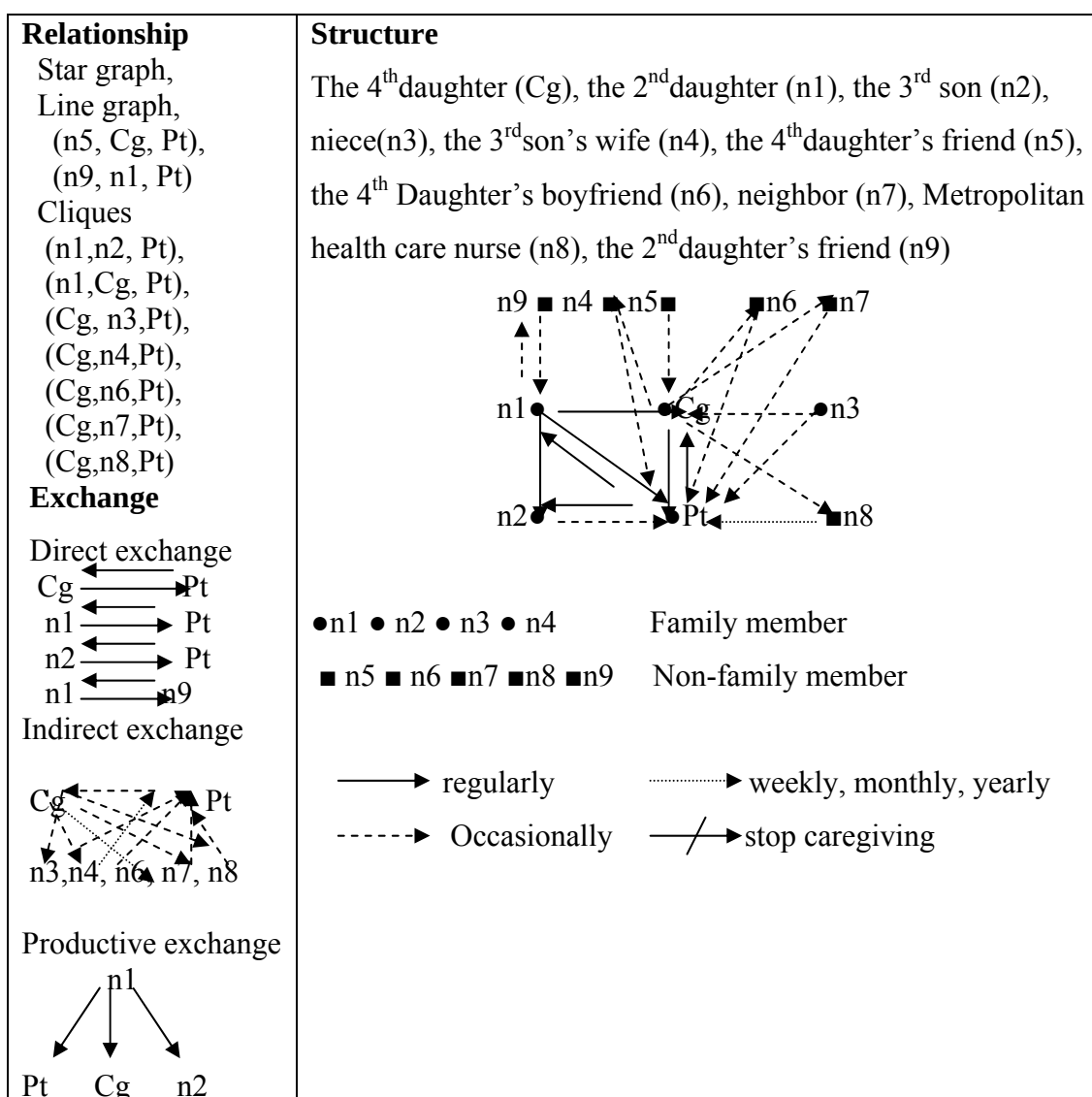
Time	Activities
6.00	Prepare and feed commercial diet to the patient
7.00	Open the store and had breakfast
8.00	Bathe the patient with the help of her niece
9.00	Turn the television or radio on to stimulate the patient
10-11.00	Do laundry and cleaned the house
12.00	Feed commercial diet to the patient and have lunch
13-16.00	Feed orange juice and talk with the patient
17.00	Go to the market and cooked food
18.00	Feed commercial diet to the patient
19.00	Have dinner with her sister while her brother has dinner with his family
20.00	Bathe the patient with the help of her sister
24.00	Feed commercial diet to patient

Caregiving network: Structure and relationship

This stroke caregiving network consists of both family members and non-family members. Of the family member, there were the second daughter, the fourth

daughter, the third son and his wife, and a niece. The non- family members were consisted of Ms. Dee' s boy friend, Ms. Dee 's friends, her neighbors, and the Metropolitan health care nurse.

In the figure below, the star graph presents the relationships of the caregiving network members. Most relationships focused on the patient while there were some relationships among the caregivers. The line graph showed the linear relationship from the fourth daughter's friend to the caregiver and the patient, or the daughter's friend to the second daughter and the patient. The clique graph clearly describes the subset of actors. There were 10 groups of members that exchanged caregiving together. For the exchange behaviors, there were four direct exchanges, five indirect exchanges and one productive exchange.



Degree of connection	The caregiver took care of the patient in the daytime. Cg●—————▶●Pt
	The 2 nd daughter took care of patient in the nighttime and on weekends. n1 ●—————▶●Pt
	The 2 nd daughter provided financial support to caregiver and the 3 rd son monthly. n2 ●◀-----n1 ●-----▶●Cg
	The 3 rd son provided care to the patient occasionally. n2 ●-----▶●Pt
	The niece provided care to the patient occasionally. n3 ●-----▶●Pt
	The 3 rd son's wife provided haircut to the patient occasionally. n4 ●-----▶●Pt
	The 4 th daughter's friend called to support caregiver occasionally. n5 ■-----▶●Cg
	The 4 th daughter's boy friend took patient to follow up by driving occasionally. n6 ■-----▶●Pt
	The neighbors visited the patient occasionally. n7■-----▶●Pt
	The Metropolitan health care nurse visited the patient to check blood pressure and changed feeding tube for the patient monthly. n8■-----▶●Pt
	The 2 nd daughter exchanged information with her friend occasionally. n9■-----▶■n1

The caregiving network members exchanged the caregiving in physical, psychological, socio-cultural, and spiritual aspects. Relating to physical exchange, there were direct exchanges between the patient and her three children. Ms. Dee took care of Mrs. Dang during the daytime, such as feeding diet, changing the diaper and changing the patient's position while Ms. Do took care of the patient during the night and over weekends. When Ms. Dee had to go out, Mr. Drum was able to provide care

instead of her. The niece also shared caregiving with Ms. Dee and Ms. Do when they helped together with taking a bath for Mrs. Dang. All family members were very capable in taking care of Mrs. Dang.



Picture 11: Altering care among caregiving network

All of the family members explained that they provided care to Mrs. Dang as an exchange that they were giving back to her. Based on Thai culture, Ms. Dee gave the reason for providing care to Mrs. Dang: it was because she was her mother and had looked after her when she was young. When Mrs. Dang got stroke, she had to provide long life caregiving to her. Similarly, Ms. Do said she wanted to provide the best care to Mrs. Dang by her returning care back to her mother. All the children wanted to pay back through “*boon khun*” their mother. These caregiving behaviors were direct exchange consisting of physical and psychological exchange.

The indirect exchanges did occur when the caregiver (Ms. Dee) sent information to her boyfriend, Mr. Drum’s wife and the Metropolitan health nurse. When Ms. Dee’s boyfriend received the information, he provided care for Ms. Dee and her mother by driving her to follow up at the hospital occasionally. Later, Ms. Dee sent information to Mr. Drum’s wife and she provided a haircut to Mrs. Dang occasionally. Also, Ms. Dee sent information to the Metropolitan health nurse. She came to visit Mrs. Dang to check blood pressure and change feeding tube to her monthly.

For direct exchange in psychological care, based on homogeneity, Ms. Do had a direct information exchange of caregiving with her friend whose mother had also suffered stroke. Ms. Do compared the caregiving between her family and her friend’s family caregiving to a self-help group. In addition, there was productive exchange among Ms. Dee, Mr. Drum, and Ms. Do. Ms. Do was a buffer against the conflicts

between Ms. Dee and Mr. Drum. She provided support to both of them. To reduce the complexity of care that might make it a stressful job. Ms. Dee initiated the plan to buy cans of commercial diet weekly instead of Mr. Drum going to buy the blenderized diet from the hospital everyday. To get Mrs. Dang's medication, they changed from taking Mrs. Dang to the hospital monthly to buying the same medication from the drug store. When there had an argument, Ms. Dee managed her stress by stop talking with Mr. Drum to discontinue the problem and going out for relaxation by shopping or calling on with her friend. For indirect exchange in socio-cultural care, the neighbors received the information about Mrs. Dang and came to visit her. Ms. Dee talked with her neighbors instead of her mother.

Focusing on productive exchange in financial care, Ms. Do set up the grocery store to bring money income to the family. She gave this money to support the patient's expense such as medical cost, commercial diets, and diapers. After she had taken care of Mrs. Dang's expenses, she divided the income with Ms. Dee and Mr. Drum. Ms. Do said it was not a salary but it was more like giving and taking.

In indirect exchange in spiritual care, which was based on the personal belief in "*karma*", Ms. Dee believed that Mrs. Dang earned demerit in her previous life and this made her suffer to stroke for ten years. For increasing merit to Mrs. Dang, Ms. Dee offered foods to the monks on Mrs. Dang's birthday and Ms. Do donated some money in the name of Ms. Dang.

Directionality Direct exchange	• The caregiver took care of the patient during the daytime to return grateful thank to her mother. • The second daughter provided care to the patient during the night and over weekend to pay back to her mother. • The second daughter exchanged information with her friend whose mother had also suffered stroke. • The niece helped caregiver and the second daughter for returning back of looking after her in the past.
Indirect exchange	• The caregiver sent information to her boy friend and he took the patient to the hospital for follow up. • The caregiver sent information to the Metropolitan

	health care nurse and the nurse came to check the blood pressure of the patient and change the feeding tube. • The caregiver sent information to the third son's wife and she provided a haircut to the patient. • The neighbors heard about the patient and came to visit her and the caregiver talked with them. • The caregiver and the second daughter made merit to increase the goodness of the patient by charity to the monks and other.									
Productive exchange	• The second daughter set up the grocery store for increased financial support to caregiver and the third son while both of them provided care to the patient. • The second daughter provided support to Ms. Dee and Mr. Drum for reducing conflict between them.									
Duration	Ten years of stroke caregiving									
Frequency of contact	The caregiver, the 2nd daughter, niece.....daily The home health care nurse.....monthly The 3rd son, the 3rd son's wife, neighbors.....occasionally The caregiver's friend and boy friend									
Homogeneity	The 2 nd daughter exchanged information of caregiving experience to take care of stroke patient with her friend.									
size	Ten persons									
Sociodemographic	Cg	1	2	3	4	5	6	7	8	9
Sex (F =Female, M = Male)	F	F	M	F	F	F	M	F	F	F
Age (year)	43	51	45	17	40					
Religion (B =Buddhist)	B	B	B	B	B					
Occupation S =Student E = Employee M = Merchant	M	E	M	S	E					
Residential location S = Same house	S	S	S	S	S					

Caregiving network 5 (Mr. Egg)

This caregiving network was a network that had two primary caregivers, who provided care to stroke patient (namely Mr. Egg). Mr. Egg was 65 years old and his family consisted of his wife, two sons, eldest son's wife, and his youngest brother. In the past about twenty years ago, Mr. Egg had worked as a mechanic in a car-company. To increase financial status, he and his youngest brother went abroad to Saudi Arabia for work while his wife and his youngest son went with her cousin to work in Denmark. After Mr. Egg came back home, he had his own garage for repairing cars. His youngest brother (namely, Mr. Ed) worked as a security guard in a television station and stayed in Mr. Egg's house. However, his wife and the youngest son were still working and living in Denmark but came back home to visit their family every year. His eldest son lived with Mr. Egg in Bangkok and worked in the water supply department of the government. He got married and his wife was a hairdresser who had her own salon close to Mr. Egg's house in Suan Geon community.



Picture 12: Main street in the community



Picture 13: Primary care nurse

Suan Geon community is located in the inner Bangkok. There is a main street in the middle of the community. Along the road are many small houses and shops, made of wood (see picture 12). This community consists of local residents and temporary residents. The local residents own rental houses for the temporary renter to stay in while working in Bangkok. Given the heavy traffic in Bangkok, most people in this community earned a living by making floral garlands and selling them at the intersection. Under the Universal Coverage of healthcare scheme, the local residents had the contract with Ramathibodi hospital to take care of their health. The Ramathibodi hospital set up a primary care unit (PCU) in the community to provide health service by a primary care nurse (see picture 13).

Two years before, Mr. Egg had a broken leg and was looked after by his daughter in law (the eldest son's wife namely, Mrs. Eng) for a few months. Although Mrs. Eng provided care to him over a short period, she said she felt too stressed to clean his body when he had diarrhea. She had never been a caregiver before. When Mr. Egg had had stroke for one year, he was bedridden with tracheostomy and feeding tube. (Barthel Index Score = 0, total = 40). His wife came back home to start the caregiving management. She asked her daughter in law to close her hairdressing salon and the youngest brother of the patient to quit his job so that they could help each other to take care of Mr. Egg. She set up a new room equipped with necessary apparatus for Mr. Egg. When the wheel of caregiving was ongoing, she went back to Denmark. She and her youngest son came to visit their family yearly. Then the patient's youngest brother and daughter in law were the primary caregivers.

Every morning, two primary caregivers participated in stroke caregiving while the eldest son went out to work. Mrs. Eng prepared many instruments, such as forceps and a bowl for dressing by boiling. After she provided suction and dressing tracheostomy tube, she and Mr. Ed helped together to clean Mr. Egg's body. She fed the medication to Mr. Egg before feeding and had breakfast herself while Mr. Ed went out to buy the blenderized diet from the hospital every morning. It took five minutes for him to ride a motorcycle from the house to the Ramathibodi hospital. Mr. Ed went back home to feed blenderized diet for Mr. Egg and then had his own breakfast. He turned on the television to stimulate Mr. Egg while Mrs. Eng did the laundry, cleaned the house and went out for socialization by talking or playing badminton with the neighbors. In leisure time, Mr. Ed took a nap on the floor close to Mr. Egg. At noon, Mr. Ed or Mrs. Eng fed blenderized diet to Mr. Egg and had their own lunch. In the evening, Mrs. Eng provided suction and dressing of the tracheostomy tube again before she and Mr. Ed cleaned Mr. Egg together. After Mrs. Eng fed blenderized diet to Mr. Egg, she cooked food for the family and they had dinner together. She or Mr. Ed fed the last diet to Mr. Egg at 8 p.m.

A schedule of a week by caregivers

Time	Activities
5.00	Prepare the instruments by boiling for sterilization
6.00	Provide suction and dressing tracheostomy
7.00	Clean the patient by the eldest son 's wife & young brother of patient
8.00	Go to hospital to buy blenderized diet by younger brother of patient
9.00	Feed blenderized diet and had breakfast
10-11.00	Do the laundry and cleaned the house by helping together
12.00	Feed blenderized diet to the patient and had lunch
13-14.00	go out while younger brother takes a nap close to the patient
15-16.00	Provide suction, dressing tracheostomy, and cleaning the patient
17-18.00	Feed diet to the patient and prepared foods for the family
19.00	Have dinner with the family
20.00	Feed blenderized diet

♣ On weekend, the eldest son's wife and her husband go shopping to buy food, and materials to the patient or visit their cousins in another province.

Caregiving network: Structure and relationship

This stroke caregiving network consists of both family members and non-family members. Mrs. Eng (the eldest son's wife) and Mr. Ed (the youngest brother) were the two primary caregivers. They participated in caregiving for Mr. Egg. If Mrs. Eng was busy, Mr. Ed switched to provide care for Mr. Egg. Mrs. Eng said if she had no any help from Mr. Ed, she could not have provided care to Mr. Egg. The non-family members included a primary care nurse, a home health care nurse, and three neighbors (namely neighbor A, neighbor B, neighbor nurse C).

As shown in the figure, the star graph presents the relationship focusing on both patient and caregiver while the clique graph refers to the subset of actors in 8 groups among the caregivers, the patient's wife, the patient's youngest son and neighbors. The exchange relationship is described into three types: direct exchange, indirect exchange and productive exchange.

Relationship Star graph, Line graph, Cliques (n2,Cg1, Pt), (n3,Cg1, Pt), (n2, Cg2,Pt), (n3, Cg2,Pt), (Cg1,n5,Pt), (Cg1,n6,Pt), (Cg1,n7,Pt), (Cg1,n8,Pt) Exchange Direct exchange Indirect exchange Productive exchange	Structure The eldest son's wife (Cg1), the youngest brother (Cg2), the eldest son (n1), wife(n2), the youngest son (n3), primary care nurse (n4), home health care nurse (n5), neighbor A (n6) neighbor (n7), neighbor nurse (n8) ● n1 ● n2 ● n3 Family member ■ n4 ■ n5 ■ n6 ■ n7 ■ n8 Outside family member ————→ regularly → weekly, monthly, yearly - - - - → Occasionally — / — stop caregiving
Degree of connection	The eldest son's wife took care of the patient daily The youngest brother provided to the patient daily The eldest son bought some food and materials weekly Wife provided financial support to the eldest son's wife and the youngest brother monthly and visited the patient yearly

Degree of connection	The youngest son gave financial support to the eldest son's wife and the patient's youngest brother monthly and visited the patient yearly <pre> Cg1 ◀-----●n3-----▶Cg2 ▼●Pt </pre>
	The primary care nurse provided information to public ambulance center for emergency care occasionally <pre> n4 ●-----▶Pt </pre>
	The home health care nurse provided home visit to the patient occasionally <pre> n5 ■-----▶Pt </pre>
	Neighbor A. donated the old bed for the patient <pre> n6 ■-----▶Pt </pre>
	Neighbor B. visited the patient occasionally <pre> n7 ■-----▶Pt </pre>
	Neighbor C. inserted feeding tube to the patient occasionally <pre> n8 ■-----▶Pt </pre>

This caregiving was exchanged in physical, psychological, socio-cultural, and spiritual aspects. On the physical exchange, both of the caregivers participated in cleaning the patient, doing laundry, cleaning the house, and following up at the hospital. They alternated in doing the tasks of diet feeding and staying with the patient while they completely separated care in suction and dressing, and buying diet.



Picture 14: Providing suction to patient

Based on personal belief and relationship, Mrs. Eng wanted to pay back for her indebtedness to the patient in their previous life. In addition, Mrs. Eng had had a good relationship with Mr. Egg because he was very kind and sweet-talking to her in the past. Mr. Ed said he had a very close relationship with Mr. Egg because both of them went abroad to work together. When Mr. Ed was young, Mr. Egg looked after him and provided him with financial support. Mr. Ed sacrificed himself to do everything for Mr. Egg and wanted to provide care to Mr. Egg as a way of making merit.

On the indirect exchange in physical care, Mrs. Eng sent information of the patient to a home health care nurse of Ramathibodi hospital and a nurse provided home visits to Mr. Egg monthly. Based on homogeneity, a neighbor A, who had experienced a family member dying of stroke, had an old bed used by the patient. Mrs. Eng asked neighbor A for it, and the neighbor donated this bed to Mr. Egg. In another exchange, when the feeding tube of patient was pulled off, a neighbor C who was a nurse helped the caregivers with the insertion of a new nasogastric tube to the patient occasionally. In addition, when Mr. Egg had complication with fever, a primary care nurse helped the caregiver by transferring information of the patient through calling the public emergency health center for free ambulance car occasionally.

Focusing on the indirect exchange in socio-cultural care, A neighbor B received information from the caregiver and went to visit the patient. A neighbor B sat only outside the patient's room because she was afraid to bring infection to the patient. On weekends, Mrs. Eng and her husband went shopping to buy some food and materials such as diapers for the patient.

Relating to the productive exchange in financial support, Mr. Egg's wife and the youngest son provided money to cover the patient's expenses, and those of Mrs. Eng, and Mr. Ed monthly. They asked Mrs. Eng to close her hairdressing salon and provided financial support to the parents of Mrs. Eng instead of to her directly. They asked Mr. Ed to quit his job and they provided income support to him.

On the direct exchange in spiritual care, Mrs. Egg's wife asked Ms. Eng to donate some money to make merit on behalf of the patient. However, Mrs. Eng said that she would keep ongoing to provide lifelong care to Mr. Egg until he had passed away. This was to terminate her indebtedness to him. However, Mr. Ed thought that he

Duration	One years of stroke caregiving									
Frequency of contact	The eldest son's wife, the youngest brother.....daily Wife, the youngest son.....yearly Primary care nurse, home health care nurse occasionally Neighbor A, neighbor B, neighbor C									
Homogeneity	Neighbor A, who had a stroke patient in the family. When the patient passed away, she donated an old bed to Mr. Egg									
size	Ten persons									
Sociodemographic	Cg1	Cg2	n1	n2	n3	n4	n5	n6	n7	n8
Sex (F =Female M = Male)	F	M	F	M	M	F	F	F	F	F
Age (year)	35	55	60	38	40					
Religion B=Buddhist	B	B	B	B	B					
Occupation H= House wife G = Government E = Employee	H	E	G	E	E	G	G			
Residential location S = Same house D = Denmark	S	S	S	D	D	10 mi ns	10 mi ns			

The eldest son's wife (Cg1), the youngest brother (Cg2), the eldest son (n1), wife(n2), the youngest son (n3), primary care nurse (n4), home health care nurse (n5), neighbor A (n6) neighbor (n7), neighbor nurse (n8)

Caregiving network 6 (Mrs. Fly)

This caregiving network exchanged caregiving for the oldest stroke patient in this study with 92 years, namely Mrs. Fly. Mrs. Fly was widowed and had eight children. She was living with the youngest daughter's family that consisted of the youngest daughter, the youngest daughter's husband (Mrs. Fly's son in law), her son (Mrs. Fly's grandson), and the daughter of the eldest daughter (Mrs. Fly's niece), and a nephew of the eldest daughter (Mrs. Fly's great grandson). This family lived in a third floor of flat in Din Dang community for more than twenty years. This community was in the inner area of Bangkok and consisted of many rental flats, business premises, a public stadium, a public library, a market, schools, and the Metropolitan health center (see picture 15, 16).



Picture 15: Flat in Din Dang community



Picture 16: Public library

Mrs. Fly's husband died when the youngest daughter was only three year old. Mrs. Fly and her youngest daughter (namely Mrs. Fan) lived together and both of them had looked after her niece (namely Ms. Fang) since she was young. Mrs. Fly provided financial support to her niece for study while Mrs. Fan looked after her and used to taking her to the school in the past. At this time, Mrs. Fan and Ms Fang took care of a nephew (Mrs. Fly's great grandson), who was a son of Ms. Fang's sister. Ms. Fang's sister was divorced and let her son to live with Ms. Fang in this rental flat for study.

Mrs. Fly's room was separated into three areas. The first area was a living room with a television, computer, and Mrs. Fly's bed. A bedroom was in the second area which was separated from the living room by the wooden wall. The third area was a kitchen and bathroom. Mrs. Fly gave the ownership of this room to Mrs. Fan. Mrs.

Fly did not want to go anywhere because of her motion sickness. She loved watching television at home while Mrs. Fan hired her neighbor to do laundry. Her husband was a teacher who often went to other province as a supervisor of the school. Her son was studying in the vocational school. When her niece (Ms. Fang) graduated with a Bachelor's degree, she worked in a financial company. Ms. Fang's nephew went to school.

Mrs. Fly had had Diabetes Mellitus for ten years and had had stroke for two years. At first, Mrs. Fly was able to sit down and eat by her self. She was easily moody and shouting. She did not co-operate in her care, such as eating food, and taking a bath. Mrs. Fan took a long time to open Mrs. Fly's mouth for feeding. In addition, it was difficult to carry her by wheel chair in a small room for taking a bath. The previous year, Mrs. Fly had recurrent stroke and was readmitted to the hospital. She was bedridden and unable to eat by herself. She retained nasogastric tube to be fed blenderized diet. She could not void by herself and retained Foley's catheter (Barthel Index Score=0, total =40). Mrs. Fly's family moved her to stay in the eldest daughter's house at Lumlooka's Road and Mrs. Fan came to provide care as a primary caregiver in this house everyday. Mrs. Fly refused to stay in this house by opening her eyes all the time. When Mrs. Fan told her to bring her back to the Din Dang flat, she showed that she agreed with this idea by closing her eyelids. Consequently, Mrs. Fly went back to stay in her room while Mrs. Fan took care of her and did her own job in laundry service. Her niece (Ms. Fang) was another caregiver who alternated care with Mrs. Fan in the evening and on weekends.

Every morning, Mrs. Fan took urine out of the urine bag, she started preparing blenderized diet. To dress the buttock wound of Mrs. Fly, she prepared sterilized utensils, such as forceps, and a bowl for boiling the instruments, After she provided cleaning and dressing of the wound to the patient, she provided insulin injection before feeding her the diet. When she made the blenderized diet and fed it to the patient, she had her own breakfast before doing laundry and cleaning the house. Around noon, she fed the diet to Mrs. Fly and finished her lunch. In the evening, she provided cleaning, dressing the wound and feeding diet to the patient. Mrs. Fan or Ms. Fang cooked food and had dinner with family members. They changed the patient's position and provided the last feeding to the patient at 8 p.m.

A schedule of a week by caregiver

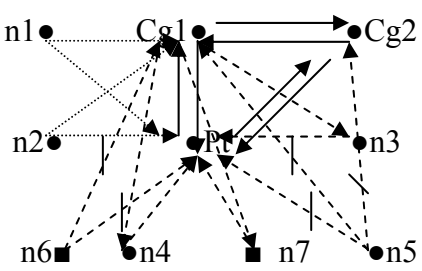
Time	Activities
5.00	Take the urine out off urine bag
5.30	Prepare sterilized utensils by boiling
6.00	Clean the patient and dress the wound.
7.00	Prepare blenderized diet
7.30	Provide insulin injection before feeding diet
8.00	Feed blenderized diet and have breakfast
9.00	Do laundry and cleaned the house
10-11.00	Take a nap, watch television or go out to talk with neighbors
12.00	Feed blenderized diet to the patient and have own lunch
13-14.00	Take a rest, watch television or go out to talk with neighbors
15-16.00	Provide suction, dress the wound, and clean the patient
17-18.00	Feed diet to the patient and cook food for the family by niece
19.00	Have dinner with family members
20.00	Feed blenderized diet and change position of patient by two caregivers

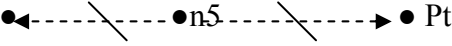
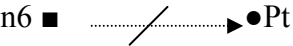
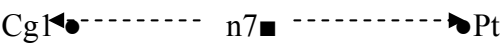
♣ On weekend, niece switched caregiver to provide care for the patient.

Both of them helped each other with changing the patient's nasogastric tube and Foley's catheter of patient monthly.

Caregiving network: Structure and relationship

This stroke caregiving network consisted of both inside and non-family members. The family members consisted of the youngest daughter (Mrs. Fan) and niece (Ms. Fang), who were both primary caregivers, Mrs. Fan's husband and son, the eldest daughter and the second son of Mrs. Fly. The non-family members consisted of a home health care nurse, and the neighbors. As shown in the figure, the star graph presents the relationships of the caregiving network focusing on the patient rather than the caregiver. The cliques described the subset of actors in nine groups of members that exchanged caregiving. There were three direct exchanges, four indirect exchanges and two productive exchanges

Relationship Star graph, Cliques (Cg1,Cg2, Pt), (n2,Cg 1, Pt), (n3, Cg1, Pt) (n4,Cg1,Pt), (n5,Cg1,Pt), (n6,Cg, Pt), (n7,Cg1,Pt) Exchange Direct exchange Cg1 ↔ Cg2 Cg1 ↔ Pt Cg2 ↔ Pt Indirect exchange Cg1 - - - - - Pt n4,n6,n7,n8 Productive exchange n2,n3 Cg 1 Pt n5 Cg1 Cg2	Structure The youngest daughter (Cg 1), niece (Cg 2), the eldest daughter(n1), the 2nd. son (n2), the youngest daughter's husband (n3), the youngest daughter's son (n4), niece's sister (n5), home health care nurse (n6), neighbor (n7)  ● n1 ● n2 ● n3 ● n4 ● n5 Family member ■ n6 ■ n7 Outside family member ————→ regularly → weekly, monthly, yearly - - - - -→ Occasionally ———/→ stop caregiving
Degree of connection	The youngest daughter took care of the patient daily Cg1 ● —————→ ● Pt
	Niece provided care to the patient in the evening and on weekends. Cg2 ● —————→ ● Pt
	The eldest daughter and the second son provided financial support to the caregiver and the patient monthly n1 ●→ ● Cg1→ ● n2 n1 ●→ ● Pt→ ● n2
	The youngest daughter's husband, or her son lifted the patient occasionally n3 ● - - - - -→ ● Pt ← - - - - -● n4

Degree of connection	The niece's sister used to provide care to the patient and provided coaching support to both caregivers, then she stopped care 
	The home health care nurse used to provide home visits to patient, then she stopped providing care 
	The neighbor lifted the patient occasionally, and provided mental support to caregiver occasionally 

This caregiving network exchanged the caregiving in physical, psychological, socio-cultural, and spiritual aspects. Relating to the direct exchange in providing physical care, Mrs. Fan provided the patient with suction, dressing the pressure sore, insulin injection, cleaning the patient, doing laundry, and cleaning the house. She said that it was her duty to do the best she could for her mother since her mother returned back by giving her the ownership of the flat.

Ms. Fang alternated to provide feeding diet and staying with the patient in the evening and on weekends. She wanted to pay back to Mrs. Fly because Mrs. Fly had looked after her since she was young. In addition, she felt guilty for her behavior to Mrs. Fly because she did not obey and often disrupted her in the past. She also wanted to support Mrs. Fan by helping her to take care of Mrs. Fly.

For sharing the caregiving in the follow up at the hospital, Ms. Fang took a leave from her work and went to the hospital with Mrs. Fly in the morning for a blood test. They used a round trip service from hospital ambulance by booking in advance and payment a fee of 1200 baht. While waiting to follow up in the stretcher at out patient department of medicine in Ramathibodi hospital, Mrs. Fly pulled off her feeding tube. Mrs. Fan completed her work at home and came to the hospital at noon with blenderized diet of the patient and inserted the new nasogastric tube to feed the diet. After Mrs. Fly had been fed, the doctor checked her up and prescribed medication for her. Ms. Fang discussed with the doctor about the health condition of the patient and went to the drug department while Mrs. Fan stayed and waited with the patient.

When medications and instruments were completed, all of them returned back home by hospital ambulance (see picture 17, 18).



Picture 17: Carrying to upper stairs



Picture 18: Turning position together

It is seen that, there were four indirect exchanges in physical care. Mrs. Fan sent information to her family members (her husband and son) and non-family members (neighbor and home health care nurse of Ramathibodi hospital). She told her husband, her son and neighbor about her difficulties in caregiving in lifting the patient. They knew of these problems and provided help to the patient by lifting her occasionally. Mrs. Fan informed the home health care nurse about her problem because Mrs. Fly often pulled off her feeding tube. She said she could not find anyone to provide smooth changing of the feeding tube. As a result, the home health care nurse allowed her to develop her skill in changing the feeding tube, changing Foley's catheter, and providing insulin injection by coaching her.

In addition, there was a productive exchange in physical care among Mrs. Fan, Ms. Fang, and niece's sister. The niece's sister had an experience in taking care of her husband's mother who suffered stroke. She received the information about Mrs. Fly from her younger sister (Ms. Fang). She came from England to visit Mrs. Fly and stayed with her for a short period. She supervised Mrs. Fan and Ms. Fang to take care of Mrs. Fly. Both of them said they felt more confident with the coaching of the niece's sister.

For the exchange in psychological care, Mrs. Fan hired her neighbor to do laundry. When she had heavily stress, her neighbor was a resource to express her problem. She also had stressful situation with her husband and her niece rather than with the patient. Her husband was a teacher and wanted to watch only documentary programs on T.V. Mrs. Fan thought that it was her T.V. so why could she not watch

her favorite movie. Moreover, she was annoyed with her niece when Mrs. Fang complained to her nephew about his studying.

Focusing on the financial care, another productive exchange was also presented in this caregiving network. The eldest daughter and the second son of the patient provided financial support to Mrs. Fan monthly and they also came to visit their mother monthly. The patient's second son worked in Thai Navy and could reimburse the medical cost for Mrs. Fly.

Based on personal belief in spiritual care, there was an indirect exchange among Mrs. Fan, the monk, and the indebtedness of Mrs. Fly in the previous life. Mrs. Fan offered food to the monks as a merit making. She believed that was the way to pay back those to whom, Mrs. Fly was indebted (*jau karm nai vien*) from her previous life

Directionality Direct exchange	• The youngest daughter took care of the patient because it was her duty while her mother gave this flat to her. • The niece provided care to the patient while the patient used to look after her before.
Indirect exchange	• The youngest daughter talked her husband and her son about her difficulties while both of them helped her with lifting the patient occasionally. • The youngest daughter told her neighbor about her problem and the neighbor provided help to her with lifting the patient and listening her problems occasionally. • The youngest daughter offered foods to the monk as making merit to ask for forgiveness from the person to whom her mother was indebted in the previous life. • The youngest daughter complained of her concerns to the home health care nurse and the nurse taught her how to insert feeding tube, Foley's catheter, and provided insulin injection to the patient.
Productive exchange	• The niece's sister provided coaching to the caregiver and niece for taking care of patient at the beginning

Productive exchange	The eldest daughter and the second son of the patient supported money to the youngest daughter and the patient and visited both of them monthly.								
Duration	Two years of stroke caregiving								
Frequency of contact	The youngest daughter, niece.....daily The eldest daughter, the 2 nd .son.....monthly Home health care nurse, neighbor..... occasionally niece's sister, caregiver's husband & son								
Homogeneity	- The niece's sister had once taken care of her husband's mother when she had had stroke. She came back to Thailand and stayed with the patient's family as a mentor. - The second son whose his wife's mother had had stroke, provided information about nursing home to the youngest daughter.								
size	Nine persons								
Sociodemographic	Cg1	Cg2	n1	n2	n3	n4	n5	n6	7
Sex (F =Female M = Male)	F	F	F	M	M	M	F	F	F
Age (year)	50	30	60	58	52	22	35		
Religion (B = Buddhist)	B	B	B	B	B	B	B		
Occupation H= House wife G = Government E = Employee	E	E	H	G	G	S	H	G	
Residential location S = Same house E = England	S	S	2hrs.	1 hr.	S	S	E	1 hr.	5 mins

Caregiving network 7 (Mrs. Gold)

This caregiving network had exchanged the longest caregiving for twenty years. Mrs. Gold, a Muslim stroke patient was 66 years old. She had four children and was living with her family at Lat Prao 102 in Suloaw Donsakare community. This community located in the middle Bangkok that consisted of a big department store, a private hospital, restaurants, condominium and many business buildings. Similarly to other in Bangkok, Suloaw Donsakare community had a main street in the middle and along the road were many small houses, shops, buildings, a community health center, a mosque and an Islamic school. There was a motorcycle-taxi service that served the people to go anyplace in the community and nearby (see picture 19, 20).



Picture 19: Mosque



Picture 20: Community health center

Most people in the community are Muslim who participate in community activities, such as reading the Koran. Every Friday, they come to the mosque and clean their bodies in five areas: head, face, mouth, hands, and elbows before they worship Allah's kindness. The children learn how to do and pray every evening



Picture 21: The patient's family



Picture 22: Peritoneal dialysis

Mrs. Gold stayed with her husband, the youngest daughter and the second son's family. The second son's family consisted of his wife and twin daughters. Mrs. Gold had diabetes mellitus and first had had stroke for twenty year ago when her children were young. She could move and eat food by herself. Her youngest daughter worked in a factory and took care of her during the night and on weekends. In the daytime, the second son's wife, who worked as a seamstress, prepared lunch for Mrs. Gold. When the eldest daughter's husband died with a gun shot wound, the eldest daughter and her daughter returned to build a new house sharing a partie-wall with Mrs. Gold's house. The eldest daughter (namely, Mrs. Green) brought Mrs. Gold to stay with her in this house and took care of her mother in the daytime as a primary caregiver during work as a seamstress at home. The youngest daughter (namely Ms. Gaew) moved to live with Mrs. Green and shared caregiving for her mother in the night and on weekends.

Mrs. Green's house had only one room and was separated into three areas. The first area was a living room for the patient at the right of the room. The second area was a working area in the middle room and the third area was a bedroom in the left of the room. Mrs. Gold's health was deteriorating and had had renal failure for one year. She needed much more caregiving on insulin injection every morning, hemax injection (epoetin alfa) every month, and hemo-dialysis three times a week. (Barthel Index Score=20, total =40).

Every morning, Ms. Gaew cleaned Mrs. Gold's body and helped her to worship of Allah's kindness. After she provided the insulin injection to Mrs. Gold, all family members took her by wheelchair to have breakfast at the shop in front of the Islamic school. After they went back home, Ms. Gaew went to work and her niece went to school. Mrs. Gold made worship to Allah five times a day on waking up, in the morning, at noon, in the evening, and at nighttime. Mrs. Green took Mrs. Gold to the hospital for hemodialysis at the hospital three times a week. If both of them did not go to the hospital, Mrs. Green did her sewing work and Mrs. Gold watched television or listened to the religious teaching from the radio. When Ms. Gaew came back home in the evening, she took care of her mother by cleaning her and then they had dinner together. At night, Mrs. Gold made the last time of worship before sleeping.

A schedule of a week by caregivers

Time	Activities
6.00	Clean the body and help the patient worship of Allah by the youngest daughter
7.00	Provide insulin injection and take the patient by wheelchair to have a breakfast at the shop in front of the school
8.00	Give medication by the eldest daughter
9.00	Clean the body and help patient worship in the second time
10-12.00	Take the patient to hospital three times a week for hemo-dialysis by the eldest daughter or stay at home to watch T.V or listen to the radio
13.00	Clean and help patient worship in the third time
15-16.00	Take a nap or watch T.V.
17-18.00	Clean and help the patient worship by the youngest daughter
19.00	Have dinner together
20.00	Clean and help patient worship by the youngest daughter

♣ On weekend, the youngest daughter altered with the caregiver to provide care for the patient. Now, she has quit her job to take care of patient with the eldest daughter and there has been a change of dialysis from hemo-dialysis to peritoneal dialysis four times a day

Caregiving network: Structure and relationship

This stroke caregiving network consists of both inside and non-family members. Of the family members, the eldest daughter was the primary caregiver to provide care in the daytime, while the youngest daughter took care of patient in the night and over weekends. As shown in the figure, the star graph demonstrates the relationships of the caregiving network focusing on patient and primary caregiver. The cliques describe a group of members that exchanges caregiving behaviors. There were six direct exchanges, and ten indirect exchanges.

Relationship Star graph, Cliques (Cg,n1,Pt), (Cg,n2,Pt), (Cg,n4,Pt), (Cg,n5,Pt), (Cg,n6,Pt), (Cg,n9,Pt), (Cg,n10,Pt), (Cg,n11,Pt) Exchange Direct exchange Cg ↔ Pt n1 ↔ Pt Cg ↔ n1 n3 ↔ Pt n7 ↔ Pt n8 ↔ Pt Indirect exchange Cg ↔ Pt n2 ↔ n3 n3 ↔ n6 n6 ↔ n1 n1 ↔ n10 n10 ↔ n11	Structure The eldest daughter (Cg), the youngest daughter (n1), niece (n2), patient's husband (n3), the 2nd. son (n4), the 2nd.son's wife (n5), the 3rd.son (n6), husband's sister (n7), parent of the patient (n8), home health care nurse (n9), neighbor (n10), boss (n11) ●n1 ●n2 ●n3 ●n4 ●n5 ●n6 ●n7 ●n8 Family member ■n9 ■n10 ■n11 Non- family member -----> regularly ———/——> weekly, monthly, yearly Occasionally stop caregiving
Degree of connection	The eldest daughter took care of the patient daily Cg ● —————> ●Pt The youngest daughter provided to the patient in the evening and on weekends. n1 ● —————> ●Pt The patient's husband talked and visited patient daily n3 ● -----> ●Pt The second son lifted and helped the patient by driving to hospital occasionally n4 ● -----> ●Pt The second son's wife prepared food for lunch to the patient, now she has stopped care n5 ● ———/——> ●Pt Niece took care of patient occasionally n2 ● -----> ●Pt

Degree of connection	The third son visited patient weekly and gave money support to caregiver monthly Cg ● ● n6 ► ● Pt
	The husband's sister visited patient occasionally n7 ● ► ● Pt
	The home health care nurse provided home visit to patient, now she has stopped providing care n8 ■ / ► ● Pt
	The neighbor (nurse) provided mentor support to caregiver occasionally n9 ■ ► ● Pt
	The caregiver's boss came to receive work back by own self monthly n10 ■ ► ● Pt

This caregiving network exchanged caregiving in physical, psychological, socio- cultural, and spiritual aspects. For physical exchange, Mrs. Green (the eldest daughter) provided insulin injection, cleaning of the patient, cooking food, doing laundry, taking the patient for hemodialysis and cleaning the house. Mrs. Green said her mother looked after her and she could take care of her mother. Similarly, Ms. Gaew (the youngest daughter) shared caregiving by cleaning and staying with her mother in the night and over weekends. Ms. Gaew said this was her mother. Now, she quit her job and had her own a small coffee shop in front of her house. She exchanged caregiving with Mrs Green by separating the role of care. There was a change from hemo-dialysis to peritoneal dialysis because of a tube problem. Ms. Gaew took peritoneal dialysis four times a day to her mother (see picture 26).

In addition, there were six indirect exchanges in physical care. Firstly, the primary caregiver told the second son of the patient to help her with lifting the patient in emergency care or following up at the hospital. Secondly, the youngest daughter asked the second son's wife to provide food to the patient at noon. Thirdly, primary caregiver told the third son of the patient about the appointment of the patient with the doctor. When he had time, he came to visit the patient and took her to the hospital by driving. Fourthly, the primary caregiver told her daughter (Mrs. Gold's niece) to help

her with taking care of patient, such as cleaning the buttock of the patient, combing the hair of the patient, and bathing the patient. Fifthly, Mrs. Green sent information to home health care nurses and they provided home visiting. Now, they have stopped providing care at home. Lastly, Mrs. Green consulted her neighbor who was a nurse, on how to provide hemax injection to the patient.

For psychological care, there were both direct and indirect exchanges. In direct exchanges, Mrs. Green had some health problem with migraine. The patient showed her concern about Mrs. Green's condition by asking. In addition, a nine year old niece provided mental support to the primary caregiver by giving her a glass of water when she was tired from caregiving. In addition, Mrs. Green's boss had her mother who had stroke in the past. She understood this situation and provided support to Mrs. Green by coming to receive the complete clothes and providing the new clothes to Mrs. Green.

Focusing on socio-cultural care, both direct and indirect exchanges have been emerged in caregiving. Relating to three direct exchanges in social care, Firstly, Mrs. Gold went to visit her parents regularly. When she had stroke, her family members often took her to visit her parents. Secondly, the second son drove his car to take his mother and the family travelling. He came to visit Mrs. Gold and had lunch with her that made her eat much more. Lastly, Mrs. Gold and her husband's sister had a close relationship because they bought the food at the school together in the past. Her husband's sister often came to visit and gave a dessert to Mrs. Gold. For indirect exchange, niece talked with the primary caregiver to take the patient by wheel chair in the school meeting. They came to see the children's activities in the school together.

Relating to indirect exchange in financial care, the third son of the patient knew about the financial burden of the caregiver. He gave some money to support the caregiver monthly. In addition, he reimbursed the medical cost for the patient. Based on religious belief in spiritual care, there was an indirect exchange among the caregiver, the youngest daughter and the patient. The youngest daughter alternated with the caregiver by cleaning the patient before she made a worship of Allah's kindness regularly. In addition, the caregiver and the youngest daughter receive the religious teaching and information from Muslim older adult that the heaven was under mother's feet. When they took care of their mother, they would receive happiness.

Directionality Direct exchange	• The caregiver took care of the patient because she was her mother. The patient provided mental support to primary caregiver when she got sick from migraine. • The youngest daughter took care of the patient because her mother had looked after her. • The third son provided care to the patient because the patient had ever looked after him before. • The husband's sister visited the patient regularly because both of them had a close relationship. • The patient went to visit her parents regularly with her family members because they had close relationship. • The niece (caregiver's daughter) provided mental support to the caregiver while the caregiver looked after her.
Indirect exchange	• The caregiver asked the second son about her difficulty caregiving. The second son helped her with lifting the patient occasionally. • The youngest daughter asked the second son's wife to take care of patient in the daytime. She helped the patient with providing food to her at noon. • The caregiver sent information to home health care nurses and they came to home visit the patient and the caregiver. • The caregiver consulted her neighbor who was a nurse about her problem in providing hemax injection. The neighbor provided coaching to her occasionally. • The caregiver's boss understood the situation of the caregiver and provided support by receiving complete clothes and bringing new clothes to the primary caregiver. • The niece talked with the caregiver to take the patient to participate in school meeting.

Indirect exchange	- The third son knew about the financial burden of the caregiver and provided financial support to the primary caregiver monthly. - The caregiver and the youngest daughter received information from older Muslim adults and from the religious belief that talking care of their mother would make them happy.											
Duration	Twenty years of stroke caregiving											
Frequency of contact	The youngest daughter, niece.....daily The third son, the sister of patient's husband, boss....monthly The home health care nurses, the second son and his wife , the patient's husband, the patient's parents, neighbor....occasionally											
Homogeneity	The caregiver's boss had her mother with stroke. She supported the caregiver by receiving complete clothes and gave new clothes to the caregiver by own self.											
size	Eleven persons											
Sociodemographic	Cg	n1	n2	n3	n4	n5	n6	n7	n8	n9	n10	n11
Sex (F =Female M = Male)	F	F	F	M	M	M	F	F	M/ F	F	F	F
Age (year)	44	37	9	66	41	40	39	68	87/ 84			
Status W= widowed S = Single M = Married	W	S	S	M	M	M	M	M	M			
Education 1 st . = primary school 2 nd =secondary school B= Bachelor degree M= Master's degree	1 st .	2 nd .	1 st .	1 st .	B	M	1 st .	1 st .				

Sociodemographic	Cg	n1	n2	n3	n4	n5	n6	n7	n8	n9	n10	n11
Religion (I= Islamic)	I	I	I	I	I	I	I	I	I			
Occupation G = Government E = Employee S = Student M= Merchant	E	E	S	E	G	G	E	M				
Health problem M= Migraine DM= Diabetes Mellitus	M				D M	D M						
Residential location S = Same house	S	S	S	S.	S	2 hrs	S	1 hr.				

The eldest daughter (Cg), the youngest daughter (n1), niece (n2), patient's husband (n3), the 2nd. son (n4), the 2nd.son's wife (n5), the 3rd.son (n6), husband's sister (n7), parent of the patient (n8), home health care nurse (n9), neighbor (n10), boss (n11)

Caregiving network 8 (Mrs. Honey)

This caregiving network took care of Mrs. Honey, a Muslim stroke patient, who was 65 years. She was a housewife and took care of eight children while her husband was a barber. Based on Islamic social value, she let her husband have a second wife and stayed in the same rental house on a different floor. She lived in the first floor while her husband and the second wife lived on the second floor. The second wife had her own shop to sell food in front of these rental houses. These small rental houses in Petchaburi Soi 7 had only one room and the occupants shared a bathroom.

Petchaburi Soi 7 is a Muslim community in inner Bangkok. Similar to other community in Bangkok, there is a main street in the middle of community and motorcycle taxi in front of the community. About half the people are permanent local residents while another half are temporary residents. The local residents own the rental houses or apartments for temporary renter to live in for work or study. In addition, there is a mosque and Muslims put their birds' cages in front of their houses and mosque in the morning. A mosque was a center of Muslim activities and funeral care. Every Friday, Muslims go to pray and made worship of Allah kindness together at noon (see picture, 23). The Muslims worship five times a day. Many people came to participate in ceremony, such as Islamic food market vendors.



Picture 23: Mosque



Picture 24: Community health center

Most local residents have a contract with Ramathibodi hospital to take care of their health based on the Universal Coverage of health care scheme (UC). There is a community health center where health volunteers provide primary care, such as checking blood pressure, and blood sugar, and dressing simple wound (see picture 24).

Mrs. Honey suffered a stroke for nine years ago. She was morbid obese with body weight of more than 100 kilograms (see picture 25). She could move a little and cook food by herself with materials prepared by her family members (Barthel Index Score=20, total =40). Her eldest son was her primary caregiver and worked as a painter. He provided care to the patient for about eight years before he died with lung disease. Her youngest daughter played this role instead of him for one year because Mrs. Honey's daughter in law who stayed with her did not take a caregiver role. The youngest daughter lived with her second husband and her children. She had the eldest daughter with the first husband and a second son with the second husband.



Picture 25: Patient and niece



Picture 26: Looking after the nephew

Every morning, the youngest daughter (namely Mrs. Ho) came from her rental room that was close to Mrs. Honey's room to take care of her by doing things, such as preparing water and materials for cleaning, preparing food, and washing clothes. Mrs. Honey could brush her teeth and clean her mouth by herself before she made worship of Allah's kindness five times a day. After Mrs. Ho completed caregiving for Mrs. Honey, she went out to work with her sister selling food. Mrs. Honey took care of a nephew (Mrs. Ho's son) by rocking the cradle (see picture 26). Sometimes, Mrs. Honey wanted to cook her special food. Mrs. Ho or others helped her with preparing materials and kept the children from interfering with her. Mrs. Honey was able to cook food, clean her body, and change her diaper after she voided using only one hand. On weekends, Mrs. Ho and the other daughters helped each other to take Mrs. Honey for taking a bath or hair dressing.

A schedule of a week by caregivers

Time	Activities
5.00	Clean the body by caregiver and brush the teeth by the patient
6.00	help the patient make a worship of Allah
7.00	Provide a glass of hot tea and pa-tong-koh (fried dessert)
8.00	Clean the body and help patient worship for the second time
9.00	Provide food by caregiver and take medication by patient
10-11.00	Watch television and looked after the nephew by the patient
12.00	Clean the body and help patient worship for the third time
13.00	Provide food and wash the clothes
14-16.00	Watch television and look after the nephew by the patient
17.00	Clean the body and help the patient worship for the forth time
18.00	Have dinner together
19-20.00	Watched television and sleep in the bed
21.00	Clean the body and help patient worship for the last time

♣ On weekend, primary caregiver and other daughter bathed for the patient.

Caregiving network: Structure and relationship

This stroke caregiving network consisted of a large numbers of people with both family and non-family members. Of the family, the youngest daughter was the primary caregiver to provide care for the patient while the second son came to help the caregiver on weekends. The sixth daughter, the seventh daughter, and the husband provided care occasionally. The non-family members consisted of family physicians, health volunteers, and community people.

In the figure, the star graph demonstrates the occasionally relationships of caregiving networks focusing on the patient. The cliques describe the group of members in the caregiving network that exchanged caregiving. There were two direct exchanges, and five indirect exchanges.

Relationship Star graph, Line graph (n4,Cg,Pt) Cliques (Cg,n5,Pt), (Cg,n6,Pt), (Cg,n7,Pt), (Cg,n10,Pt) (Cg,n11,Pt) Exchange Direct exchange Cg $\longleftrightarrow$ Pt n3 $\longleftrightarrow$ Pt Indirect exchange Cg $\longleftrightarrow$ Pt n5,n6,n7,n10,n11	Structure The youngest daughter (Cg), the 7th. daughter (n1), the 6th.daughter (n2), patient's husband (n3), the second wife (n4), the 3rd.son (n5), nephew (n6), the 2nd.daughter (n7), the eldest son (n8), family physician (n9), health volunteer (n10), community (n11) ●n1 ● n2 ● n3 ●n4 ●n5 ● n6 ●n7 ●n8 Family member ■n9 ■n10 ■n11 Outside family member ————→ regularly → weekly, monthly, yearly -----→ occasionally ———/→ stop caregiving
Degree of connection	The youngest daughter took care of the patient daily Cg ● —————→ ●Pt The seventh daughter provided care to the patient occasionally n1 ● -----→ ●Pt The sixth daughter took care of patient occasionally and she provided money to the father for regular hemodialysis. n3 ● n2 ● -----→ ●Pt The patient's husband visited and talked with the patient occasionally n3 ● -----→ Pt The second wife gave some food to the primary caregiver and transferred it to the patient n4 ● —————→ Cg ● —————→ ●Pt

Degree of connection	The third son went to the hospital to receive medication monthly n5●.....▶● Pt
	The patient looked after her nephew daily Pt●————▶● n6
	The eldest son took care of patient in the past, now he passed away n7●———/——▶● Pt
	The family physician provided home visit to patient monthly n8■.....▶● Pt
	The family physician provided home visit to patient monthly n8■.....▶● Pt
	The health volunteer connected to social welfare to support patient yearly n9■.....▶● Pt
	The community allowed patient to use wheelchair occasionally n10■-----▶● Pt

This caregiving network exchanged caregiving in physical, psychological, social and spiritual care. For direct exchange in providing physical care, Mrs. Ho (the youngest daughter) cleaned the patient, washed the clothes, and bathed Mrs. Honey while Mrs. Honey looked after her nephew in the daytime by rocking the cradle. Mrs. Ho said her mother had looked after her, her eldest daughter and her second son. There were four indirect exchanges in physical care. Firstly, the caregiver sent information to the family physician for checking up the patient at home monthly. Secondly, the caregiver told the third son of the patient to collect medication from the hospital after the family physician came to visit. Thirdly, the caregiver asked the second daughter of the patient to help with bathing and hair dressing for the patient weekly. Fourthly, the second wife of her father knew about Mrs. Honey's condition and allowed the caregiver to bring food from her shop to the patient daily. In psychological care, there was a direct exchange between patient and her husband. Her husband came to visit and talked with her regularly. Sometime he gave some money to the patient while Mrs. Honey was concerned about her husband's disease.

Focusing on socio-cultural care, the caregiver faced difficulties in taking the patient anywhere because of her morbid obesity. When the eldest son who was the former caregiver passed away, the family members borrowed a wheel chair from the community to take her to the mosque for her eldest son's funeral care. For indirect exchange in financial care, the health volunteer knew about the financial problem of the patient. She connected with social welfare to provide financial support to the patient yearly.

Because of on religious belief about spiritual care, there was an indirect exchange between the caregiver and the patient. The caregiver cleaned Mrs. Honey before she made a worship of Allah's kindness five times a day regularly. In addition, the caregiver and others had received the religious teaching that the heaven was under the mother's feet. When they took care of their mother, they would receive happiness in the future.

Directionality Direct exchange	• The caregiver took care of the patient because she was her mother and had ever taken care of her during her post partum. • The husband of patient came to visit and talked with the patient regularly while she was concerned about his renal failure disease.
Indirect exchange	• The caregiver asked the third son to collect medication from the hospital instead of her doing it monthly. • The caregiver told to the second daughter to help her with lifting the patient for taking a bath weekly. • The caregiver received information from Islamic religious belief that talking care of their mother made them happy. • The caregiver borrowed a wheelchair from a community to take the patient to the mosque for her eldest son's funeral care. • The health volunteer knew about financial problem of the patient and family members. She connected to social

	welfare to provide financial support yearly.											
Duration	Nine years of stroke caregiving											
Frequency of contact	The caregiver, husband of patient, and the second wife.....daily The third son, family physician.....monthly The second daughter.....weekly The health volunteer.....yearly The sixth daughter, the seventh daughter..... occasionally a community											
Homogeneity	-											
size	Eleven persons											
Sociodermographic	Cg	n1	n2	n3	n4	n5	n6	n7	n8	n9	n10	n11
Sex (F =Female M = Male)	F	F	F	M	F	M	M	F	M	M	F	
Age (year) m=month	28	30	32	66	50	34	4m	36	die			
Status M = Married	M	M	M	M	M	M	M	M				
Education 1 st . = primary school	1 st .	1 st .										
Religion (I= Islamic)	I	I	I	I	I	I	I	I	I			
Occupation H= House wife E= Employee M= Merchant N = None	H	E	M	E	M	E	N	E				
Health problem R= Renal failure	-	-	R	-								
Residential location	1 min	2 hrs	2 hrs	1 min	1 min	2 hrs	1 min	2 hrs				

Caregiving network 9 (Mr. Ink)

This small caregiving network exchanged caregiving for four years. Mr. Ink, the stroke patient, 69 years old, was living with his family in an outer area of Bangkok. This community is located behind Turakitbundit University and there is an irrigation canal for tap water in front of the community. Most people live in one floor houses behind the business premises (see picture 27).



Picture 27: Housing



Picture 28: Patient and his dog

Mr Ink had retired from a transportation company and worked as a community leader while his wife had a small food shop. They had three children. The eldest son was a policeman and had died from car accident many years before. His wife remarried and allowed her daughter to live with Mr. Ink's family. Mr. Ink's family consisted of five family members including his wife (namely Mrs. Im), the second son, the youngest daughter, and a niece. The second son worked as a makeup artist while the youngest daughter worked as a manager of a club in the nighttime from 4 p.m. to 5 a.m. and his niece was studying in the university at Nakorn Prathom province.

Four years ago, Mr. Ink suffered stroke and was bedridden (Barthel Index Score = 0, total score =40). He could not breathe by himself and had a tracheostomy tube. He could not eat and needed feeding of a blenderized diet four times a day. His second son was the primary caregiver to clean the patient, provide suction, and insert feeding tube by himself while Mrs. Im cooked food, made the blenderized diet, and alternated in providing suction, and feeding diet to the patient. When the patient pulled off the feeding tube, Mrs. Im called her son and he hurried back home to insert a new feeding tube.

The wind of change blew last year. His son needed to work at Samui island in Surat Thani province. Mrs. Im became the primary caregiver instead of her son for one year. Mrs. Im was 66 year old and stayed with the patient all the time while her children went to work and her niece went to study. Every morning she woke up at four o'clock and started boiling materials to prepare for dressing and feeding, such as a bowl, forceps and a variety of food to make the blenderized diet. After the materials were sterilized, Mrs. Im provided suction and dressing the tracheostomy tube. She cleaned Mr. Ink's body before she went out to buy the food by riding the bicycle to the market nearby. When she came back home, she blended a variety of boiled food to make the blenderized diet and cooked food for her family and her two dogs. She fed diet to Mr. Ink via a nasogastric tube. After she did laundry, she had a breakfast. She fed the blenderized diet at noon and cleaned the house. In the relaxing time, she read a newspaper, talked with the neighbors or took a nap. She provided suction and dressed the tracheostomy tube in the evening while her youngest daughter went out to work and came back home in the morning. After Mrs. Im fed the diet to Mr. Ink, she had her dinner by herself. In the night, she did meditation or walked outside for relaxation.

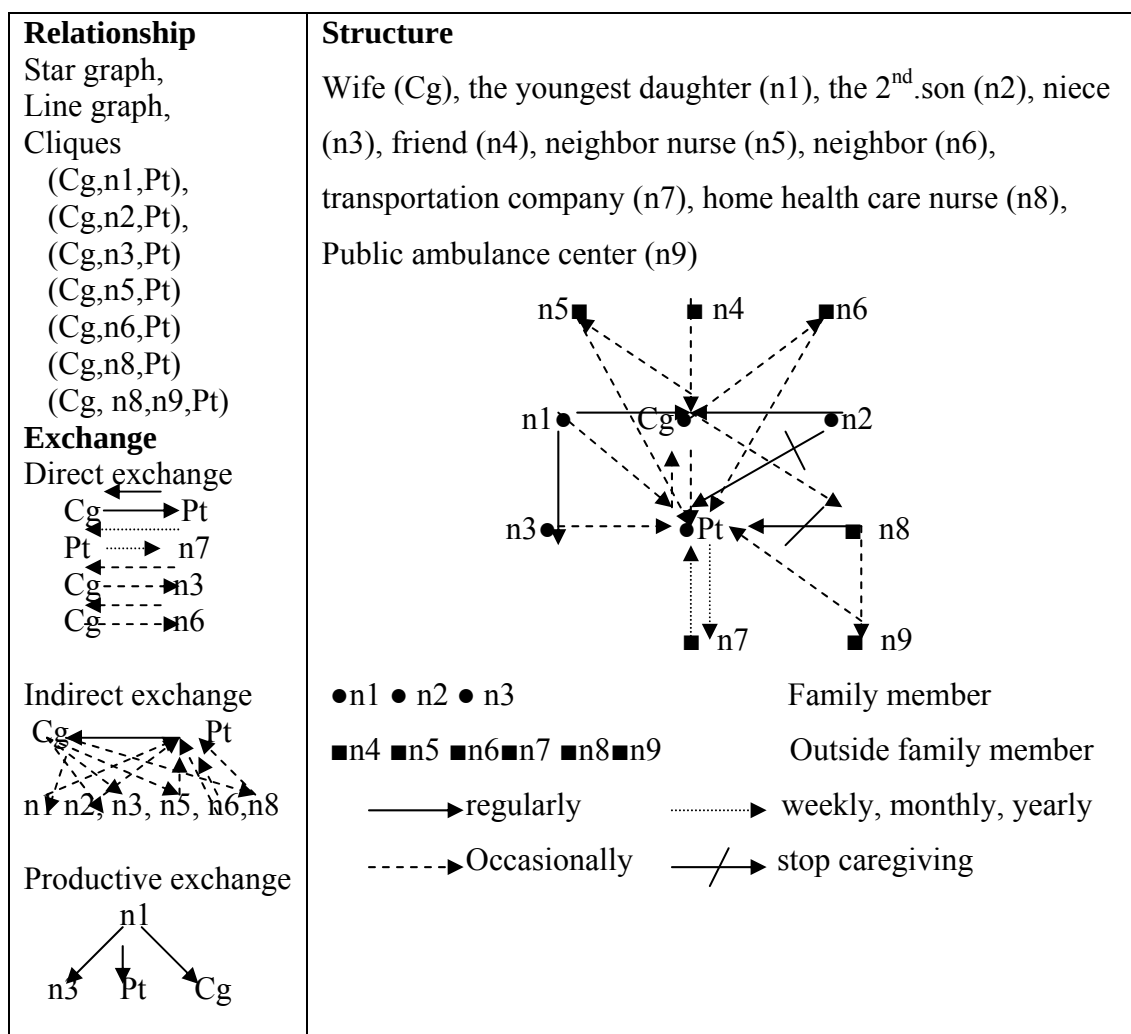
A schedule of a week by caregiver

Time	Activities
4.00	Boil some foods to make blenderized diet and the materials for dressing
5.00	Provide suction and dress tracheostomy tube
6.00	Go to the market to buy some food by riding the bicycle
7.00	Blend variety of foods and prepare food for family members and dogs
8.00	Feed blenderized diet to the patient
9-11.00	Take a laundry and have breakfast for own self
12.00	Feed blenderized diet to the patient
13-16.00	Clean the house and read the newspaper or took a nap
17.00	Provide suction and dressing tracheostomy tube
18.00	Feed blenderized diet to the patient
19-20.00	Clean the house or take a nap
21.00	Feed blenderized diet to the patient and have dinner for herself
22-5.00	Take meditation or walk outside for relaxation

Caregiving network: Structure and relationship

This stroke caregiving network consists of both inside and non-family members. Of the family members, the wife was the primary caregiver to provide care while the youngest daughter, the second son, the youngest daughter, and a niece took care of patient occasionally. The non-family members consisted of friends, neighbors and a neighbor nurse, transportation company, and the public ambulance center.

In the figure, the star graph demonstrates the relationships of the caregiving network members focusing on the patient rather than the caregiver. In line graph shows the linear relationship from a friend to the caregiver transferring to the patient. Another line begins with the caregiver, goes to the second son, and transfers to a public ambulance center. The cliques describe the group of members in the caregiving networks that exchanged caregiving behaviors. There were five direct exchanges, nine indirect exchanges, and one productive exchange



Degree of connection	
The wife had taken care of the patient all the time.	Cg ● —————> ●Pt
The youngest daughter took care of the patient occasionally and provided financial support monthly.	Cg ● <----- n1 ● -----> ●Pt n3 ●
The second son took care of patient in the past and provided financial support to the caregiver monthly.	Cg ● <----- ●n2 -----> /-----> ● Pt
The niece took care of patient occasionally.	n3 ● -----> ●Pt
The patient's friend provided food to patient occasionally.	n4 ■ -----> ● Pt
The neighbor (nurse) provided materials support to the caregiver occasionally and helped the caregiver with insertion of the feeding tube.	Cg ● <----- ■ n5 -----> ●Pt
The neighbor visited and helped patient with lifting the patient occasionally.	n6 ■ -----> ●Pt
The transportation company provided funeral care for the patient in the future while the caregiver sent money instead of the patient monthly.	Cg ● ----- ■ n7 <-----> ●Pt
Home health care nurse provided home visit to patient, now she stopped providing care.	n8 ■ -----> /-----> ●Pt

This caregiving network exchanged caregiving in physical, psychological, socio-cultural, and spiritual care. For direct exchange in physical care, Mrs. Im provided feeding of the blenderized diet, cleaning of the patient, cooking food, doing laundry, and cleaning the house. Mrs. Im said her husband and she were *ku-vein-ku-karma* that had done some bad things in the previous life. She took care of him a way of discharging her indebtedness.

Moreover, there were six indirect exchanges in physical care from the caregiver sending information to her family members (the second son, the youngest daughter, and niece), and non-family members (neighbors, a neighbor nurse and a home health care nurse of Ramathibodi hospital). Firstly, the caregiver called the second son after the patient pulled off the feeding tube. He came back home to insert the new feeding tube and went back to work later. Secondly, the caregiver told the youngest daughter about the appointment of the patient with the doctor. She carried the patient to follow up at the hospital by taxi. Thirdly, the caregiver told her niece to provide care instead of her occasionally. Fourthly, the caregiver asked her neighbor to lift the patient when he came back from the hospital. Fifthly, the caregiver asked the neighbor (nurse) to insert the new feeding tube when her husband pulled off it and her children were not at home. Lastly, the caregiver sent information to the home health care nurse of Ramathibodi hospital. The nurse provided support to the patient and family members by home visiting for a short period. Now, the home health care nurse stopped providing care at home.



Picture 29: Primary caregiver



Picture 30: Lifting the patient

In psychological care, there were two direct exchanges. Mrs. Im was so stressful to her youngest daughter's behavior because she worked at night and did not do anything only giving financial support. The second son often called and provided emotional support to Mrs. Im by making her laugh while talking with him. In addition, Mrs. Im often went to talk with the neighbor and they laughed together. Moreover, Mrs. Im coped with her situation by doing meditation, or taking a walk to relax at night.

Focusing on direct exchange in socio-cultural care, the stroke patient had been a leader of community in the past. He and his wife often participated in community activities such as cooking food for children on Children's Day, and Songkarn festival. At this time, their neighbors came to visit the patient and the caregiver. They gave some mangoes to the caregiver during research observation.

On direct exchange in financial care, the second son knew about the financial burden of the caregiver. He gave some money monthly to support the caregiver. Another indirect exchange occurred because the patient had lent his friend money in the past. Mrs. Im said his friend bought some bananas to the patient for making the blenderized diet as payment of this debt.

In emergency care, there was an indirect exchange when the caregiver called her son at Samui Island about the worsened condition of the patient. He connected to public ambulance center by phone and sent information about the patient's condition. As a result, the ambulance center allowed an ambulance car to transfer the patient to receive treatment at the hospital.

Because of religious belief about spiritual care, there was a direct and indirect exchange. In direct exchange, the caregiver believed that she had done a bad thing to the patient in the previous life. As a result, she took care of the patient to discharge her indebtedness. For indirect exchange, the second son believed that the patient had his own indebtedness to someone in the previous life. He could not get well because his indebtedness had not been discharged. His son made prayer books to donate to making merit as a substitute for his father paying off the debt.

Directionality Direct exchange	• The caregiver took care of the patient and she believed that she was indebted to the patient for actions in the previous life. • The caregiver received emotional support from her second son • The caregiver and the patient participated in community activities. Both of them had a good relationship with the neighbors and neighbors came to visit and gave some fruit to them. • The caregiver came to talk with the neighbor and she made them laugh together when talking.

Directionality Indirect exchange	• The caregiver called the second son and he came back to insert the new nasogastric tube for the patient. • The caregivers called the second son and he connected to the public ambulance center to provide information. The ambulance center allowed an ambulance care to transfer the patient to the hospital. • The caregiver told the youngest daughter about the appointment of the patient with the doctor and she took the patient to follow up at the hospital. • The caregiver told her niece to take care of patient instead of her occasionally while she looked after her niece before. • The caregiver asked her neighbor to lift the patient, when the patient went back from the hospital. The neighbor came to lift the patient from the taxi as her resource. • The caregiver asked her neighbor nurse to insert the new feeding tube when her children were not at home. • The caregiver sent information to the home health care nurse and she came to the house to provide support to the patient and caregiver at the beginning of the illness. • The caregiver sent some money to the transportation company instead of patient doing it and ensuring that the patient would receive funeral care from this membership. • The second son made prayer book and donated them to the people as a way of making a merit as a substitute for the patient discharging his indebtedness acquired in the previous life. • The patient's friend gave some fruit to the primary caregiver as same as a substitute for returning money received from the patient in the past.

Productive exchange	The youngest daughter provided 200 baht per day to support the caregiver. She and the second son went half and half for the patient's expenses, and supported the niece's study expenses.									
Duration	four years of stroke caregiving									
Frequency of contact	The youngest daughter.....monthly Transportation Company.....yearly The second son, niece, neighbor nurse, ...occasionally a home health care nurse, a friend of the patient, neighbors, the public ambulance center									
Homogeneity	-									
size	Ten persons									
Sociodemographic	Cg	n1	n2	n3	n4	n5	n6	n7	n8	n9
Sex (F =Female, M =Male)	F	F	M	F	M	F	F			
Age (year)	66	33	35	19						
Status S = Single M = Married	M	S	S	S						
Education U = university 2 nd =secondary school V vocational education	2 nd .	V	2 nd .	U						
Religion B =Buddhist	B	B	B	B						
Occupation S = student H= House wife E = Employee	H	E	E	S						
Health problem G= Gall stone	G									
Residential location S = Same house Su=Surat Thani province	S	S	Su	S	1 min	1 min	1 min			

Caregiving network 10 (Mr. Jim)

This caregiving network had the oldest primary caregiver with 75 years. The stroke patient (namely Mr. Jim) was 78 years old. His family consisted of his wife and four daughters. The eldest daughter and the youngest daughter had married and gone to live with their families in other areas in Bangkok. The third daughter had married but she was still living with her parents in this house. She worked in the Ministry of Labour and often went to stay in a resort she owned with her husband at Koh Chang in Surat Thani province. The second daughter, who was a nurse, single, she stayed in the hospital on working days and came to this house on weekends. This house was at Soi Charun Sanith Wong 77 in Duang Dee community. This community was in the inner Bangkok that consisted of a big department store, private and public hospitals, schools, temples, and business premises. The temple is the place of community activities, such as Songkarn festival and mobile market (see picture 31). The people used small mini buses, motorcycle taxi, and bicycle to travel along these small roads (see picture 32).



Picture 31: Mobile market in the temple



Picture 32: Minibus in the community

In the past, Mr. Jim and his wife (Mrs. Jun) lived in Ayutthaya province while four their daughters stayed in Bangkok for their education. Both of them worked as tailors and did religious activities together, such as praying before having food, participating in the ceremony of ordaining a new monk, or staying in the temple for praying and studying Buddhism on holy days. Mr. Jim did not drink and smoke and he went regularly to visit his sister and cousin. Moreover, Mr. Jim and Mrs. Jun had taken care of Mrs. Jun's mother for 30 years. Mr. Jim cooked food while Mrs. Jun cleaned her mother's body. Mrs. Jun's mother died when she was 97 years. After Mr. Jim and

Mrs. Jun got sick, they moved to stay with their children in Bangkok. The second daughter felt uncomfortable when they waited for her back home everyday.

When Mr. Jim suffered stroke, his behavior changed. In the Cambodian language, he cried “*bo-niang-nung-nung-bo-bo*”, which means “brother loved young brother and young brother loved brother”. His cousin said Mr. Jim had received external power (“*took-klong*” in Thai language). Mrs. Jun and her daughter consulted the expert who did meditation and made the merit water for Mr. Jim. After this ritual, Mr. Jim did not say it again. He was deteriorating. He spoke little and could not take care of himself (Barthel Index Score = 4, total = 40). His family modified many instruments to improve his health, such as making two rails to help his walking, changing the floor, getting a hospital bed and wheelchair, and so on (see picture 33, 34).



Picture 33: Two rails for walking



Picture 34: Changing the floor

Mr. Jim and his wife stayed together in the daytime while their two daughters went out to work. Therefore, Mrs. Jun was the primary caregiver for her husband. Mrs. Jun had had myocardial infarction for three years. She used lingual pills to release angina pain. She was very tired when she had many activities. After she received cardiac catheterization, she became well. She was so happy and thought that she was healthy resulting from her doing goodness (*are-ni-song* in Thai language). When she came back home, she gave her treasures to her four daughters by drawing prize in the same way as making merit. Now, she was healthy and did not use lingual pills.

Every morning, Mrs. Jun cleaned the patient's body and gave him medication before breakfast. She took care of herself by having a glass of chocolate milk. After she prayed, she fed her husband. In the relaxing time, she listened to the

radio or took a nap. She turned the position of her husband and changed his wet clothes. The youngest daughter's husband, who was a policeman, rode the motorcycle to this house every noon. He took the patient to take a bath before he went back to the police station to work in the afternoon. Her neighbor allowed her housekeeper to buy the food from the market instead of Mrs. Jun. Mrs. Jun said her neighbor was so nice and she felt appreciated of the variety of foods that her neighbor bought for them. She said her neighbor helped her family because her second daughter had helped take care of her neighbor's mother by inserting the new nasogastric tube seven year ago. To buy the food, her second daughter went to the market on weekends, or Mrs. Jun went to the shop close her house on the Buddhist holy days. In the evening, the third daughter came back from work. She brought the patient to take a bath and fed him instead of the primary caregiver. Mrs. Jun and her daughter watched television and talked together before bedtime.

A schedule of a week by primary caregiver

Time	Activities
6.00	Clean the patient and give medication before breakfast
7.00	Have a glass of chocolate milk
8.00	Pray before breakfast for the patient and herself
9-11.00	Listen to the radio with the patient and change his wet clothes
12.00	Take a bath by the youngest daughter's husband at noon
13.00	Buy some food from the market by neighbor daily or by the second daughter on weekends, and by the caregiver on the Buddhist holy days
14-17.00	Listen to the radio with the patient, change his position and wet clothes, and clean the house
18.00	Clean the patient and feed the food to the patient by the third daughter
19-22.00	Have dinner with her daughter and talk together before sleeping

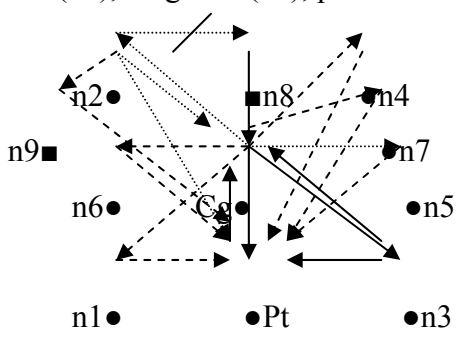
♣ On weekend, the second daughter provided care to the patient

The eldest daughter and her husband alternated in playing this role when the primary caregiver went to another province.

Caregiving network: Structure and relationship

This caregiving network mainly consisted of inside family and only a few of non-family members. Of the family members, there were the wife, four daughters, the eldest daughter's husband, the youngest daughter's husband, and a nephew. The non-family members were a neighbor and a public ambulance center.

In the figure, the star graph demonstrates the relationship focusing on both patient and primary caregiver while the clique graph refers to the subset of actors. There were three direct exchanges, nine indirect exchanges, and one productive exchange.

Relationship Star graph, Cliques (n1,Cg, Pt), (n2,Cg, Pt), (n3,Cg,Pt), (n4,Cg,Pt), (n5,Cg,Pt), (n6,Cg,Pt), (n7,Cg,Pt), (n2,n8,Cg), (Cg,n2,n9,Pt) Exchange Direct exchange Cg → Pt Cg → n2 Cg → n3 Indirect exchange Cg → Pt n1n2n3n5n6n7n8 Productive exchange n4 n6 n7	Structure Wife (Cg), eldest daughter (n1), the 2nd.daughter (n2), the 3rd.daughter (n3), the youngest daughter (n4), the eldest daughter's husband (n5) the youngest daughter's husband (n6), nephew (n7), neighbor (n8), public ambulance center (n9)  ●n1 ● n2 ● n3● n4 ● n5● n6● n7 Family member ■n8 ■n9 Outside family member -----regularly —/— weekly, monthly, yearly Occasionally stop caregiving
Degree of connection	Wife took care of the patient daily. Cg ● —————→ ●Pt The third daughter provided to the patient each evening. n3 ● —————→ ●Pt The second daughter alternated in providing care to the patient on weekend. n2 ●→ ●Pt

	The eldest daughter and her husband took care of patient occasionally. n1 ●----->● Pt <-----● n5
	The youngest daughter allowed her husband and nephew to take care of patient occasionally. n6 ●----->● Pt <-----● n7
	The neighbor helped the primary caregiver with buying food daily. n8 ■----->● Pt
	The public ambulance center allowed ambulance car for transferring patient to the hospital.. n9 ■----->● Pt

This caregiving was exchanged between caregivers and caregiving network members in physical, psychological, socio-cultural, and spiritual care. For direct exchange in physical care, the primary caregivers cleaned the patient, fed the patient, did laundry, cleaned the house, and followed up at the hospital. Of the relationships between the primary caregiver and the patient, Mrs. Jun said her husband was a very nice man. He had a sweet-talking way with her and they did not quarrel. This relationship made her want to provide care to him. In addition, her four daughters could alternate with her in providing care. All of them had good relationships with their mother and Mrs. Jun also gave all her treasures to them by drawing prizes.

For indirect exchange in physical care, the caregiver sent information about the patient to the four daughters, the eldest daughter's husband, the youngest daughter's husband, and the nephew. They provided care to the patient in many situations. Firstly, the eldest daughter and her husband provided care to the patient when the primary caregiver went to Ayutthaya province. Secondly, the second daughter took care of patient instead of her mother on weekends. Thirdly, the third daughter provided care to the patient in the evening and took him to follow up at the hospital. For productive exchange in physical care, the youngest daughter allowed her husband and nephew to bathe the patient at noon.

In addition, there was indirect exchange in emergency care. When Mr. Jim was convulsing, Mrs. Jun called the second daughter. Her daughter connected to a public ambulance center and sent this information. As a result, they provided an ambulance car to transfer the patient for treatment at the hospital.

Relating to direct exchange in psychological care, Mrs. Jun received moral support from her neighbor. She expressed her emotion about the doctor to her neighbor. The second daughter said Mrs. Jun was sincere and honest. She provided great help to others. As a result, the neighbor loved supporting her.

For indirect exchange in socio-cultural care, Mrs. Jun went to the funeral care of her cousin. In Thai culture, there is a process of pouring water on the hand of the corpse before the body is placed in the coffin. Mrs. Jun saw the dead body's legs and asked her cousin why he did not let his dead body's legs down. He told her that these legs were stiff and could not be let down. As a result, Mrs. Jun allowed someone to provide massage for Mr. Jim regularly to prevent joint stiffness. In addition, Mrs. Jun expected that the children should respect and provide care to their elderly parents. She had a poem about the children taking care of older adults to provide this information to the people. Consequently, she hoped that her children would provide care and cook food for them but the second daughter said she could not do that. She did not want to cook food but she bought it for her parents. Moreover, Mrs. Jun went back home to Ayutthaya province many times by herself to participate in Songkarn festival and so on. Mrs. Jun was sorry but she understood that their children did not go to Ayutthaya province with her. Their children had to take care of the patient instead of her doing it.

For indirect exchange in financial care, the second daughter was the main person to buy some necessities, such as diapers, and food. The third daughter provided financial support by reimbursement of the medical cost while the primary caregiver gave her all treasures to her four children.

For direct exchange in spiritual care, Mrs. Jun allowed Mr. Jim to offer food to the monks on his birthday. She believed that the result of the good things (*are-ni-song* in Thai language) came from doing good in the past. She thought that she had recovered well from myocardial infarction for 6-7 years because of the goodness

(*boon*). Mrs. Jun prepared for the dead of the patient and herself by preparing their pictures for their funeral care (see picture 35, 36).



Picture 35: Preparing picture



Picture 36: Preparing picture

Directionality Direct exchange	• The caregiver took care of the patient because he was so nice and had spoken only sweetly with her in the past. • Their four daughters took care of the patient and the primary caregiver because both of them had looked after them. • The caregiver expressed her emotions and received moral support from her neighbor. Her second daughter said the caregiver was sincere and honest to the neighbor and that this made the neighbor love to help her. • The caregiver regularly made merit in the temple and helped other. She believed that she had recovered well from the myocardial infarction because of her goodness in the past.
Indirect exchange	• The caregiver called the second daughter about the worsened condition of the patient and her daughter connected to the public ambulance center to give them this information. The public ambulance center let a free ambulance car transfer the patient to receive treatment at the hospital. • The caregiver told her second daughter to take care of the patient on weekends.

Indirect exchange	• The caregiver told her third daughter to take care of the patient to following up at the hospital and in the evening. • The caregiver told her eldest daughter and her husband to take care of the patient instead of her when she went away. • The caregiver knew about joint stiffness from her cousin and she prevented third form happening to her husband by arranging regular massage. • The caregiver wrote poem about elder care for other to read and hoped that her children would provide care for her. • The second daughter went to buy materials and food for the patient and the caregiver.
Productive exchange	The caregiver told the youngest daughter about her limitation in bathing the patient and her daughter let her husband and nephew come to help her with giving the patient a bath.
Duration	Three years of stroke caregiving
Frequency of contact	Wife, the youngest daughter, neighbor.....daily the youngest daughter's husband & nephew The second daughter.....weekly The eldest daughter & her husband..... occasionally the public ambulance center
Homogeneity	• The caregiver knew about joint stiffness from the cousin and allowed someone to massage her husband regularly. • Her second daughter changed the neighbor's feeding tube monthly for seven years. Now, the neighbor helped the caregiver with buying the variety of food from the market
size	Ten persons

Sociodemographic	Cg	n1	n2	n3	n4	n5	n6	n7	n8	n9
Sex (F =Female M = Male)	F	F	F	F	F	M	M	M	F	
Age (year)	75	55	51	48	46	55	53	18		
Status M = Married S = Single	M	M	S	M	M	M	M	S		
Education 1 st . = primary school B = Bachelor degree M= Master degree U = University	1 st .	B	M	B	B	M	B	U		
Religion B = Buddhist	B	B	B	B	B	B	B	B		
Health problem H = Heart disease Ht = Hypertension DM = Diabetes Mellitus G = Gout	H	Ht	-	-	-	-	DM G Ht	-		
Occupation H= House wife G = Government E = Employee S = Student	H	G	E	G	E	G	G	S		
Residential location S = Same house	S	1 hr	S	S	½ hr	1 hr	½ hr	½ hr		

Wife (Cg), eldest daughter (n1), the 2nd.daughter (n2), the 3rd.daughter (n3), the youngest daughter (n4), the eldest daughter's husband (n5) the youngest daughter's husband (n6), nephew (n7), neighbor (n8), public ambulance center (n9)

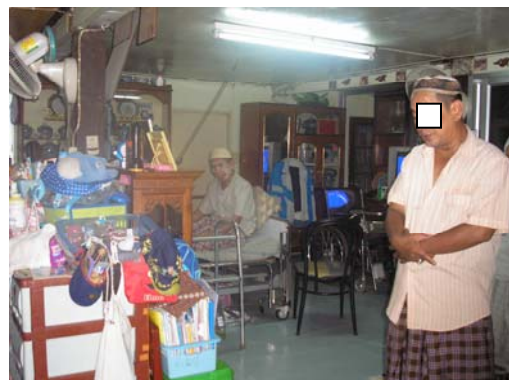
Caregiving network 11 (Mr. Kai)

The caregiving network was also Muslim network in Soi Sulaw Petchaburi 7 community. Mr. Kai was 74 years and had twelve children. He rented the land to build his a single story house in this community for fifty years. In front of his house, his third daughter had her small tailor shop and the second daughter worked as a seamstress of this shop. Mr. Kai was living with his wife, the eldest son's family, the second daughter, and the sixth daughter in this house. Some children lived in the same community, such as the third daughter's family and the fourth son's family. Other children lived in another community but most of them usually came to this house everyday. For example, the third daughter came to open her shop at in front of Mr. Kai's house every morning after she took her five children to school. The fourth son came to have dinner with his parents. The ninth daughter stayed with her father on working days because her office was close to her father's house. She brought two young children to stay with her in this house and went back home at Bang Bua Thong on weekends.

Previously, Mr. Kai was an imam who taught Muslim people in the mosque on every Friday. After Mr. Kai retired from the State Railway of Thailand, he was very moody and had hypertension. His wife quit her job selling foods because of her disease. She had Diabetes Mellitus and one leg was amputated. Mr. Kai had suffered stroke five years before and could not walk by himself. He also had problems of speaking, eating and voiding. As a result, he had a gastrostomy tube for feeding the blenderized diet four times a day and a cystostomy tube for urination. He communicated with his children by his hand signals and this made him moody from the misunderstanding. (Barthel Index Score=4, total =40) (see picture 41). His second daughter was the main person to be a primary caregiver.

In the morning, the second daughter (namely Ms. Kan) took urine out of the urine bag and provided medication before feeding. She cooked food for her family and prepared the ninth daughter's children to go to the school. She fed some milk via gastrostomy tube to Mr. Kai. The sixth daughter helped her with preparing the blenderized diet before she went to work in a government organization. Ms. Kan divided the diet into four bags and fed the diet to Mr. Kai at 8 a.m. She cleaned her mother's body and both of them had breakfast together. The eldest son lifted Mr. Kai

to take a bath in the bathroom and helped him make a worship of Allah's kindness before he went to work as a minibus driver. To relax, Mr. Kai watched television or took a nap or received massage from an elderly neighbor while Ms. Kan sewed the clothes. At noon, the eldest son came back home to clean the patient's body in five areas and make a worship (*la-march* in Arabic) before Ms. Kan fed the blenderized diet to the patient (see picture 38).



Picture 37: Patient in his bed Picture 38: Making worship of Allah's kindness

In the evening, the fourth son called Ms. Kan to ask about what kinds of food and materials she would like and he bought them back to the house. After Ms. Kan completed her work, she started cooking for her family. In the rush hour, she asked her nephews (the third daughter's sons) that passed by to help her with feeding the blenderized diet to Mr. Kai. Sometimes the nephew (the ninth daughter's son) went back to school and played with Mr. Kai and this made him laugh. In addition, the ninth daughter and her husband made the bed for Mr. Kai and took the laundry. Then the eldest son cleaned and helped Mr. Kai to make worship again. The nephews or the youngest son that passed by provided the last blenderized diet at 8 p.m. The third daughter provided dressing for the gastrostomy and cystostomy at 9 p.m. After that Ms. Kan and her family had dinner, she started boiling some food and vegetables to prepare for making blenderized diet the following morning.

A schedule of a week by caregiver

Time	Activities
6.00	Take urine out of urine bag and cook food for the family member
7.00	Give a pill before feeding the patient and prepare the 9 th .daughter's children for school
7.30	Feed milk via gastrostomy tube
8.00	Prepare blenderized diet by the sixth daughter before going to work
8.30	Divide diet into four bags and clean her mother before having breakfast
9.00	Bathe and help the patient worship Allah by the eldest son
10.00	Feed blenderized diet to the patient by the second daughter
10-11.00	Watch television or take a nap or received massage from an elderly neighbor while the second daughter sewed the clothes and listened to the radio
12.00	Clean the body and help patient worship by the eldest son
12.30	Feed blenderized diet by the eldest son or the second daughter
13.00	Call by the fourth son about buying food and materials from the market
14-15.00	Watch television while the second daughter sews the clothes
16.00	Cook food and ask the nephew that passed by to feed diet to the patient
17.00	Clean the body and help the patient worship by the eldest son
18.00	The ninth daughter and her husband made the bed and did the laundry
20.00	Feed blenderized diet by the youngest son or the nephew that passed by
21.00	Clean the body and help the patient worship for the last time
21.30	Provide dressing the gastrostomy and cystostomy by the third daughter
22-23.00	Boil some food and vegetables to prepare blenderized diet for the next day

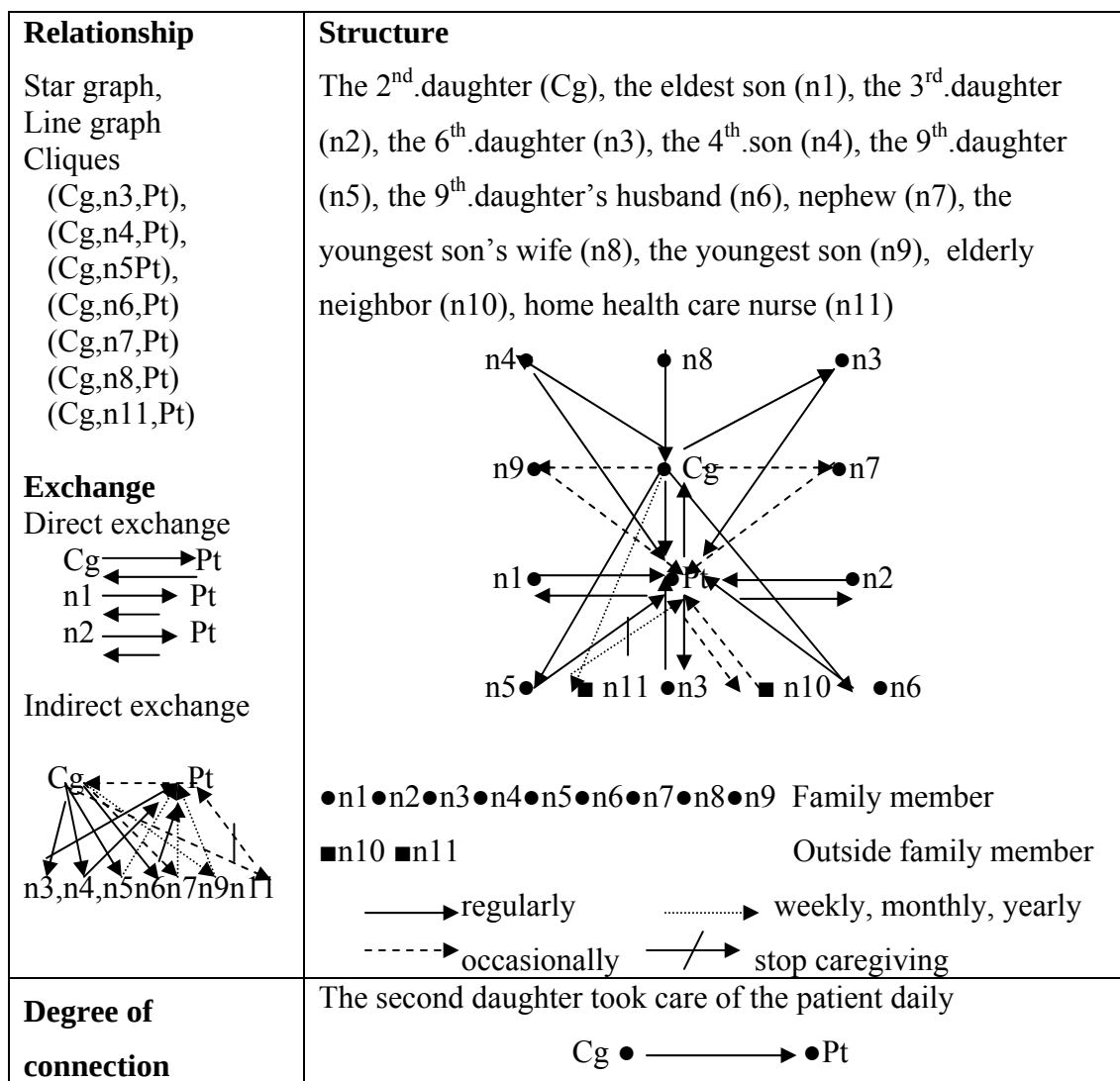
♣ The youngest son's wife came to help the primary caregiver cook food occasionally. The 6th.daughter provided care to the patient on evening and on weekend

Caregiving network: Structure and relationship

This stroke caregiving network consisted of a large numbers of family members. The second daughter was the primary caregiver who stayed with the patient all the time. The caregiving network members separated functions of care, such as

making of the blenderized diet by the sixth daughter, bathing and helping the patient worship by the eldest son, buying the food and materials by the fourth son, making the bed and doing the laundry by the ninth daughter and her husband, and dressing the gastrostomy tube and cystostomy tube by the third daughter. The youngest son's wife came to help Me. Kan cook food and the youngest son fed the last blenderized diet occasionally. The non-family members were the home health care nurse and the elderly neighbor.

In the figure, the star graph demonstrates the regular relationships of caregiving network members to the patient. Cliques describe the group of members in the caregiving network that exchanged caregiving behaviors regularly. There were two direct exchanges, and eleven indirect exchanges.



Degree of connection	The eldest son bathed the patient and helped his worship daily. n1 ●————→●Pt
	The third daughter dressed the gastrostomy and cystostomy for the patient daily. 2 ●————→●Pt
	The sixth daughter prepared blenderized diet for the patient daily. n3 ●————→●Pt
	The fourth son bought food and materials to the patient daily and gave some money to caregiver occasionally. Cg ●-----n4●————→●Pt
	The ninth daughter made a bed and took the laundry daily. n5 ●————→●Pt
	The ninth daughter's husband made a bed daily. n6 ●————→●Pt
	The nephew made patient laugh occasionally n7●-----→●Pt
	The youngest son's wife helped primary caregiver with cooking food occasionally -----n8-●-----→●Pt
	The youngest son and the nephew that passed fed blenderized diet to the patient occasionally n9 ●-----→●Pt
	An elderly neighbor provided massage to the patient occasionally. n10■-----→●Pt
	Home health care nurse provided home visiting monthly, now she stopped providing care n11■-----/-----→●Pt

This caregiving network exchanged caregiving in physical, psychological, social, and spiritual care. For indirect exchange in physical care, the primary caregiver sent the information to her family members consisting of the eldest son, the fourth son, the sixth daughter, the ninth daughter, and her husband, the youngest son's wife, the youngest son, and the nephew that passed by. For the non-family members, the

primary caregiver had indirect exchange with a home health care nurse of Ramathibodi Hospital, and an elderly neighbor.

Firstly, Ms. Kan asked the eldest son to bathe and help the patient make a worship of Allah's kindness five times a day. Secondly, Ms. Kan called the fourth son to buy food and materials when he went back home in the evening. Thirdly, Ms. Kan told the sixth daughter to make blenderized diet before she went to work. The sixth daughter took care of patient in the evenings and on weekends. Fourth, Ms. Kan told the ninth daughter and her husband to make the bed and do the laundry. Fifth, Ms. Kan told the youngest son's wife to help her with cooking in the evening. Sixth, Ms. Kan told the youngest son or the nephew that passed by to help her with feeding the blenderized diet when she was busy. Seventh, Ms. Kan sent information to home health care nurse and the nurse used to come to provide home visits to the patient. Now, she has stopped providing care. Lastly, the direct exchange between Mr. Kai and the elderly neighbor, Mr. Kai allowed the elderly neighbor to provide massage and he gave some money to the elder.

In psychological care, there were two indirect exchanges between Mr. Kai and the nephew and primary caregiver. The nephew played with Mr. Kai and Mr. Kai laughed with him while the primary caregiver looked after the nephew. Moreover, the nephew's parents (the 9th.daughter and her husband) took Ms. Kan for relaxation in their home at Bang Bua Thong or in the department store on weekend.

For direct exchange in financial care, Mr. Kai gave 1, 000 baht per month to support Ms. Kan while Ms. Kan took care of him all the time. Based on religious belief in spiritual care, there was an indirect exchange between the patient and primary caregiver, and the patient and the third daughter. Ms. Kan provided feeding the patient, and staying with him all the time. Ms. Kan said elderly people told her that she would receive the heaven totally. Similarly, the third daughter provided dressing pf the gastrostomy and cystostomy daily. She said that Allah did not give directly to her but Allah provided indirectly to her as through the invisible hand.

Directionality Direct exchange	• The caregiver took care of the patient all the time and the patient gave money 1, 000 baht to her monthly.

	• The patient allowed the elderly neighbor to provide massage to him while he gave some money to her.
Indirect exchange	• The caregiver asked the eldest son to bathe the patient and helped him worship daily. • The caregiver told the sixth daughter to help her with making the blenderized diet daily and took care of the patient in the evenings and on weekends. • The third daughter dressed the gastrostomy and cystostomy daily. • The caregiver asked the youngest son's wife to help her with cooking occasionally. • The caregiver asked the youngest son or the nephew that passed by to feed blenderized diet for the patient occasionally. • The caregiver received information from the elders about the Islamic religious belief that she would receive the heaven totally because she took care of her father. • The third daughter believed that Allah helped her through the invisible hand when she took care of the patient. • The nephew played with the patient and made him laugh while the caregiver looked after him. • The caregiver called the fourth son to buy foods and materials from the market. • The ninth daughter and her husband made the bed and did the laundry daily. • The caregiver looked after the ninth daughter's children and the ninth daughter and her husband took the caregiver for relaxation in their house and at a department store on weekends.
Duration	Nine years of stroke caregiving
Frequency of	The caregiver, the eldest son, the third daughter.....daily

contact	the fourth son, the sixth daughter, the ninth daughter and husband the elderly neighbor, The home health care nurse.....monthly The youngest son and his wife, the nephew, .. the nephews that passed by..... occasionally											
Homogeneity	-											
size	Twelve persons											
Sociodemographic	Cg	n1	n2	n3	n4	n5	n6	n7	n8	n9	n10	n11
Sex (F =Female,M = Male)	F	M	F	F	M	F	M	M	F	M	F	F
Age (year)	51	52	50	46	48	40	41	8	36	35	45	65
Status M = Married S = Single	S	M	M	S	M	M	M	S	M	M	M	M
Education 1 st . = primary school 2 nd = secondary school V = Vocational school B = Bachelor degree	1 st .	V	1 st .	B	B	B	B	1 st .	V	V	B	1 st .
Religion I = Islamic B = Buddhist	I	I	I	I	I	I	I	I	I	I	B	I
Occupation S= Student G= Government St = State Enterprise E= Employee M= Merchant	E	E	M	St	St	G	G	S	E	E	G	E
Health problem B= Breast mass G= Gall stone P= Peptic Ulcer HT = Hypertension	B, G	HT	P	B	HT	-	-	-	-	-	-	-
Residential location	S	S	5 min	S	5 min	S	S	S	5 min	5 min	30 min	5 min

Caregiving network 12 (Mr. Loy)

This caregiving network exchanged caregiving within a broken family. The stroke patient, namely Mr. Loy, had divorced his wife, namely Mrs. Lin and got married with the second wife, when the youngest daughter was only seven years. Mrs. Lin looked after her six children and went out to sell the food. She had no one to take care of her children. As a result, she kept her children in the house by locking the door. Some of the children did not study in the school while the other children had only a basic education. For example, the second daughter had no education and could only sign her name. She was employed as a hair model for hairdressing student and received little money. She learnt how to do hairdressing by observation. When she grew up, she was a hairdresser and had her own salon.

In 1992, Mrs. Lin moved her family from Nakorn Sawan province to Klong Tai community in Bangkok. When Mrs. Lin had much more money, she had a small business of rental houses and allowed the fourth son to take care of these houses. She built her new house in Morawan 1 community and lived with her youngest daughter's family (namely, Mrs. Lulu) while the second daughter (namely Mrs. Lala) lived in her hairdressing salon next to Mrs. Lin's house in the same community (see picture 39).



Picture 39: Housing along the road



Picture 40: Housing along the river

This community is located at Soi On Nut 49 in the middle area of Bangkok. Similar to other communities, there were business premises, factories, a school in front of the community, and small house along the main road of community. On the other side of the community, there was a temple, a mosque, and many houses located along the canal. The Buddhist went to the temple while Muslim came to the mosque at the opposite side of the canal (see picture 40).

Mrs. Lin's family was still connected to Mr. Loy's family. Some of the children went to visit their father regularly. When Mr. Loy was an older adult, the children asked Mrs. Lin to let him live in the rental house to take care of him. However, the fourth son was opposed to this idea but he needed to be acceded to his mother's opinion. As a result, Mr. Loy stayed in one of the rental houses.

When Mr. Loy was 79 years and had a stroke (Barthel Index Score=0, total score = 40), Mrs. Lala and Mrs. Lulu were concerned about Mr. Loy's condition and worried about the fourth son's wife being able to provide caregiving. They asked Mrs. Lin to bring Mr. Loy back with them. They separated an area of Mrs. Lala's hair salon for Mr. Loy. Mrs. Lulu came from her house that was opposite to her sister's hair salon for Mr. Loy. Mrs. Lala said it was better for their father to take care by both of them instead of the fourth son's wife. They took care of Mr. Loy for six years as the primary caregivers. Whoever had a time, they switched to provide care for their father. It was not a timetable.



Picture 41: Caregiver's shop



Picture 42: Two primary caregivers

Every morning, Mrs. Lulu walked to her sister's house. She provided cleaning and feeding with a cereal diet to Mr. Loy. When Mrs. Lala had no customers, she switched to provide feeding to him. After Mr. Loy had already been fed the diet, her daughters provided dressed a pressure sore and did laundry. In relaxing time, his daughters turned on radio and changed his diaper. At noon, Mrs. Lala or Lulu switched to feed the cereal diet and changed his position. In the evening, Mrs. Lulu cleaned his body, changed his wet cloth, and kept him warm by dressing him in a hat and socking. Sometimes, the youngest daughter of Mrs. Lala, who was eleven years, fed the last diet at 9 p.m. When the patient needed cleaning, Mrs. Lala and Mrs. Lulu helped together

with lifting the patient to give him a bath, and washing his hair. Mrs. Lulu's husband and son helped with lifting and driving to take the patient to the hospital monthly.

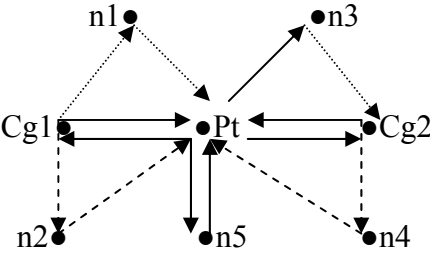
A schedule of a week by caregivers

Time	Activities
7.00	Fed cereal diet via feeding tube
8.00	Cleaned patient, provided dressing pressure sore, and took a laundry
9-11.00	Listened to the radio
12.00	Fed cereal diet via feeding
14-16.00	Listened to the radio
17.00	Fed cereal diet via feeding
18.00	Clean the patient, change the wet clothes, kept warm by wearing hat and socking
20.00	Fed cereal diet and changed position of patient

♣ The 2nd daughter and the youngest daughter alternated to provide care for the patient.

Caregiving network: Structure and relationship

This stroke caregiving network consisted only family members. The second daughter and the youngest daughter were two primary caregivers. In addition, the eldest daughter, niece, the youngest daughter's husband and son provided care to the patient. In the figure, the star graph demonstrates the relationships of the caregiving network focusing on the patient rather than the caregivers. The cliques describe the subset of actors in the groups of members that exchanged caregiving. There were three direct exchanges, and six indirect exchanges.

Relationship Star graph, Cliques (n1,Cg1, Pt), (n2,Cg1, Pt), (n3,Cg2,Pt), (n4,Cg2,Pt), Exchange Direct exchange Cg1 → Pt Cg2 → Pt n5 → Pt Cg1 ↔ Cg2 Indirect exchange Cg1 ↔ Pt n1 ↔ n2 n2 ↔ n3 n3 ↔ n4 n4 ↔ n5	Structure The 2nd.daughter (Cg1), the youngest daughter (Cg2), niece (n1), the eldest daughter(n2), the youngest daughter's husband (n3), the youngest daughter's son (n4), the patient's wife (n5)  ●n1 ● n2 ● n3 ●n4 ●n5 Family member → regularly weekly, monthly, yearly ----- Occasionally / stop caregiving
Degree of connection	The second daughter provided feeding, housing, buying cereal for the patient daily and she gave some money to support the youngest daughter occasionally. Cg 2 ● ----- Cg1 ● → ●Pt The youngest daughter cleaned the patient, provided feeding to the patient daily. Cg ● → ●Pt Niece provided feeding to the patient each night. n1 ● → ●Pt The eldest daughter provided care to patient occasionally. n2 ● ----- ● Pt The youngest daughter's husband, or son lifted the patient occasionally. n4 ● ----- ●Pt ----- ●n5 The patient's wife allowed the patient to live in her house. n6 ● → ●Pt

This caregiving network exchanged caregiving in physical, psychological, socio-cultural, and spiritual care. For direct exchange in physical care, Mrs. Lala provided feeding diet, bought the cereal diet, and provided housing to take care of her father because of her obligation to him. Mrs. Lulu provided feeding, cleaning, and

taking him to follow up at the hospital because her father had been responsible for her conception and thus, ultimately, birth and life. When he got sick and needed help, she could provide care. In addition, she believed that her mother suffered from her broken family because she had done something to Mr. Loy in the previous life. Therefore, her mother received the result in this life.

In addition, there were four indirect exchanges in physical care from the caregivers sending information to the family members. Firstly, Mrs. Lala told the niece and she helped Mrs. Lala with feeding cereal diet to the stroke patient. Secondly, Mrs. Lulu told her husband and her son about her difficulty lifting the patient. They provided care to Mr. Loy by lifting occasionally. Thirdly, Mr. Lulu asked her husband to help her with driving to the hospital. Lastly, Mrs. Lala asked the eldest daughter about her broken bone problem. Mrs. Lala had fallen down and was unable to provide care for Mr. Loy. When Mrs. Lulu took Mrs. Lin to follow up at the hospital, the eldest daughter came from her house to take care of Mr. Loy instead of Mrs. Lala.

For indirect exchange in psychological care, Mrs. Lala studied about detoxication. She sent this information to Mrs. Lulu. When Mrs. Lulu was so stressful, she used detoxication by pure coffee to reduce the stressful of life. She said she worried about negative feeling to Mr. Loy. She stopped this idea that was making her stressed. She was concerned about thinking bad thought and that it would make her provide bad caregiving. Moreover, Mrs. Lulu said she had started practicing in meditation since 1993 when her father disappeared and that had made her get better.

In direct exchange in financial care, Mrs. Lala gave money to support Mrs. Lulu and Mr. Loy regularly while Mrs. Lala helped her with taking care of Mr. Loy and Mrs. Lin. In addition, Mr. Loy had a small pocket in his shirt to collect the money when his children came to visit him.

Based on personal belief in spiritual care, there was an indirect exchange. Mrs. Lala allowed the monk to come inside Mr. Loy's room and Mr. Loy offered the food to the monk by own self. She believed that making merit was to pay back for Mr. Loy's indebtedness in the previous life.

Directionality Direct exchange	- Caregiver 1 took care of the patient because it was her obligation to her father. - Caregiver 2 provided care to the patient because the patient was her natural father. - The patient's wife allowed the patient to live in her renting house while her daughter believed that her mother was paying for bad things done to the patient in her previous life. - Caregiver 1 gave financial support to the caregiver 2 while caregiver 2 helped her with taking care their parents.
Indirect exchange	- Caregiver 1 told the niece to provide feeding cereal diet for the patient each night. - Caregiver 2 asked her husband and her son to lift the patient occasionally. - Caregiver 2 told her husband to help her with driving to the hospital monthly. - Caregiver 1 asked the eldest daughter of the patient to help her in providing care when she had broken a bone and caregiver 2 went to the hospital with their mother. - Caregiver 1 sent information about detoxification to caregiver 2 and she used it to reduce stress in her life. - Caregiver 2 helped the patient with offering the food to the monk to make merit. The patient made merit to pay off his debts from the previous life.
Duration	Six years of stroke caregiving
Frequency of contact	The second daughter, the youngest daughter, niece.....daily The youngest daughter's husband and son..... ..occasionally the eldest daughter, the patient's wife

Homogeneity	-						
size	Nine persons						
Sociodemographic	Cg1	Cg2	n1	n2	n3	n4	n5
Sex (F =Female M = Male)	F	F	F	F	M	M	F
Age (year)	55	43	11	60	43	14	77
Status M = Married D = Divorced S = Single W = Widowed	W	M	S	S	M	S	D
Education N = no education (only sign her name) 1 st . = Primary school 2 nd . = Secondary school	N	2 nd ..	1 st .	2 nd ,	2 nd .	1 st .	N
Religion (B = Buddhist)	B	B	B	B	B	B	B
Health problem B = Broken bone	B	-	-	-	-	-	-
Occupation H = Housewife E = Employee B = Business Ha = Hairdresser S = Student	Ha	H	S	E	E	S	B
Residential location S = Same house	S	1 min	S	1hr.	1 min	1 min	1 min

Caregiving network 13 (Mrs. Mei)

This caregiving network was a small network that exchanged caregiving only within the family of the stroke patient, namely Mrs. Mei. She had six children but two of them had died many years ago. The youngest daughter (namely Ms. May) had the problem with bone disease when she studied in the primary school. As a result of this disease, she could not walk by herself but was able to move a little on the floor. When Mrs. Mei went gambling, she carried her daughter so they could go together. Mrs. Mei's husband had died ten years before from Cholera. She and Ms. May moved from Nakorn Rachasema province to Bangkok and lived with her eldest daughter's family in an outer area of Bangkok at Don Maung district while her two daughters were still living in Nakorn Rachasema province.

The eldest daughter's family had four family members, including her second husband, her niece, her niece's husband and great grandson. The eldest daughter's house was a business building with three floors (see picture 43). On the ground floor, there was a living room, a kitchen and a bathroom. The eldest daughter's husband stayed here because he had terminal cancer. Mrs. Mei and Ms. May lived together in the second floor that consisted of the middle room for the Buddha image (see picture 44), the bedroom, the bathroom, and a space in the back for sun-drying clothes. The niece's family lived on the third floor.



Picture 43: Business building



Picture 44: Sleeping close the Buddha image

The eldest daughter had her own shop to sell cooked food in the morning while the niece was a merchant and the youngest daughter (Ms. May) prepared materials such as meat, chicken, and vegetables for cooking. Mrs. Mei also sold the cooked food by walking around the community with her dog.

When Mrs. Mei was 80 years old, she had a stroke. She could not eat by herself and needed feeding of a blenderized diet via gastrostomy tube six times a day. (Barthel index Score =4, total score =40). At the beginning, the family made a decision to allow a niece of daughter in Nakorn Rachasema province to take care of the patient. She provided care for a few days and escaped to go back home. The eldest daughter and her family members came to ask her niece to return but she did not come back. Two daughters of Mrs. Mei did not come to visit her and said they had no money, so there could be no visiting. As a result, the youngest daughter (Ms. May) provided care as a primary caregiver because there was no one else in her caregiving network to do it.



Picture 45: Carrying a small bowl Picture 46: The eldest and youngest daughter

Ms. May could not walk anywhere but she moved a little to carry a small bowl for cleaning her mother (see picture 45). She said she was heart-broken and could not accept these conditions. Sometime she was so stressed because her mother always called her all the time. Because of the loud voice of Mrs. Mei, Ms. May felt *kreng jai* (fearfulness) to other persons, such as her sister's husband who had liver cancer and slept downstairs, and neighbors who walked in front of the house and asked about what was happening.

Similarly, her niece (namely, Mrs. Mo) was ashamed when she took Ms. May by wheelchair to learn how to make the blenderized diet. The dietitian asked Mrs. Mo about any person in her house who was responsible for preparing the diet and she did not know how to answer the question. When Mrs. Mo took Mrs. Mei to follow up at the hospital, she could not provide any feeding to Mrs. Mei because of her fear. As a result, May needed to be fed by double feeding before going to hospital. Mrs. Mo also

said if her mother passed away before her grandmother and Ms. May, it would be difficult to her and her husband to provide care to both of them in the future.

Every morning, Ms. May woke up and fed the blenderized diet to her mother. She had breakfast before she washed the clothes. After she started cleaning the patient and provided dressing of the gastrostomy tube, she fed the blenderized diet at noon. In her relaxation, she watched television or took a nap. In the evening, Ms. May provided cleaning and changing of the wet clothes before she went to help her sister with preparing the chicken, meat, and vegetable in the shop. After she went back home, she started preparing the blenderized diet and divided it into 6 bottles. She fed the blenderized diet to her mother and had dinner with her sister's family at 10 p.m. She cleaned the floor and took a bath before she fed the last diet at 12 p.m.

A schedule of a week by caregiver

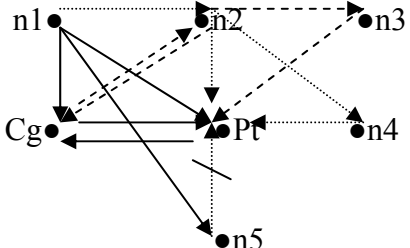
Time	Activities
7.00	Feed diet via gastrostomy tube
8.00	Have breakfast and wash the clothes
9.00	Clean patient and provided dress gastrostomy tube
10-12.00	Feed diet via gastrostomy tube and have lunch
14.00	Feed diet via gastrostomy tube
15-16.00	Watch the television or take a nap
17-18.00	Feed diet via gastrostomy after cleaning the patient and changing the wet clothes
19.00	Go to the shop to prepare chicken, meat, and vegetable in cooking
20-21.00	Prepare blenderized diet, divide into 6 bottles, and feed diet
22.00	Have dinner with her sister's family
23.00	Clean the floor and take a bath
24.00	Feed blenderized diet via gastrostomy tube

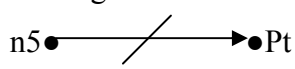
♣ The niece and her husband took the patient to follow up at the hospital monthly

Caregiving network: Structure and relationship

This stroke caregiving network consists of only family members including the eldest daughter, a nephew, a niece, and a niece's husband while the youngest daughter as the primary caregiver.

In the figure, the star graph demonstrates the relationships of the caregiving network focusing on the patient rather than the caregivers. Cliques describe the subset of actors in the groups of members that exchanged caregiving. There were two direct exchanges, three indirect exchanges, and one productive exchange.

Relationship	Structure
Star graph, Cliques (n2,Cg, Pt), (n1,n2, Pt), (n1,n3, Pt), (n1,n4, Pt), (n2,n5, Pt) Exchange Direct exchange Cg $\longleftrightarrow$ Pt Cg $\dashrightarrow$ n2 Indirect exchange n1 $\longleftrightarrow$ Pt Cg, n2, n4, n5 Productive exchange n1 Cg n2 n5 Pt	The youngest daughter (Cg), the eldest daughter(n1), a niece (n2)the niece's husband (n3), the great grandson (n4), a nephew (n5)  ●n1 ● n2 ● n3 ●n4 ●n5 Family member $\longrightarrow$ regularly $\cdots\cdots\cdots\longrightarrow$ weekly, monthly, yearly $\dashrightarrow$ Occasionally $\diagup$ stop caregiving
Degree of connection	The youngest daughter cleaned the patient, and provided feeding to the patient daily. Cg ● $\longrightarrow$ Pt The eldest daughter provided financial support to the patient and caregiver monthly. Cg ● $\cdots\cdots\cdots$ n1 ● $\cdots\cdots\cdots$ Pt The niece took the patient to the hospital monthly. n2 ● $\cdots\cdots\cdots$ Pt The niece's husband provided support the patient occasionally and and great grand son played with her occasionally. n3 ● $\dashrightarrow$ Pt $\dashleftarrow$ n4

Degree of connection	The nephew provided financial support to the patient in the past, now he stopped providing care 

This caregiving network exchanged caregiving in physical, psychological, and financial care. For direct exchange in physical care, Mrs. May provided feeding diet, cleaning, and staying with her mother because of her obligation. Ms. May said that each person of her family had an obligation and an own job. In addition, there was an indirect exchange in physical care from the eldest daughter to her family members. The eldest daughter told both niece and a niece's husband to carry the patient for following up the hospital. Mrs. Mo would book a hospital ambulance for roundtrip transportation of the patient. For indirect exchange in psychological care, Mrs. Mo brought her son to play with Mrs. Mei that made her smile. Ms. May and Mrs. Mo were close relationship. When Ms. May was so stressful, Mrs. Mo would carry her to side seeing for relaxation by motorcycle.

Focusing on financial care, there was both indirect and productive exchange. For indirect exchange, the eldest daughter looked after a nephew because her younger sister's died. When she told her nephew about Mrs. Mei, he came to visit Mrs. Mei and gave money 3000 bahts per month to Mrs. Mei. In the productive exchange, the eldest daughter provided financial support to Mrs. Mei, Ms. May, and Mrs. Mo monthly.

Directionality Direct exchange	• The caregiver took care of the patient because it was her obligation to her mother. • The caregiver and her niece had a good relationship. When the caregiver was very stressed, niece would take her sightseeing by motorcycle for relaxation.
Indirect exchange	• The eldest daughter told the niece to take the patient for follow up at the hospital monthly. • The niece asked her husband to go to the hospital with the patient occasionally.

Indirect exchange	The eldest daughter told the nephew about the patient and the nephew came to visit and had given financial support to her monthly in the past. But he later stopped providing support.					
Productive exchange	The eldest daughter provided financial support to the patient, the primary caregiver, the niece monthly.					
Duration	Two years of stroke caregiving					
Frequency of contact	The youngest daughter, niece.....daily The niece's husband and son.... occasionally the nephew.....monthly					
Homogeneity	-					
size	Six persons					
Sociodemographic	Cg	n1	n2	n3	n4	n5
Sex (F =Female, M = Male)	F	F	F	M	M	M
Age (year)	38	54	32	32	1	26
Status M = Married S = Single	S	M	M	M	S	S
Education N = No education 1 st . = Primary school 2 nd . = Secondary school V = Vocational school	1 st .	1 st .	V	V	N	2 nd .
Religion (B = Buddhist)	B	B	B	B	B	B
Health problem B = Bone disease	B	-	-	-	-	-
Occupation E = Employee C= Children	E	E	E	E	C	E
Residential location S = Same house	S	S	S	S	S	20 mins

The youngest daughter (Cg), niece (n1), the eldest daughter (n2), the niece's husband (n3), the great grandson (n4), nephew (n5)

Caregiving network 14 (Mrs. Nu)

This was a Thai-Chinese family who took care of the stroke patient (namely Mrs. Nu). Mrs. Nu, 85 years old, was widowed. She had seven children but one daughter had died many years before. She lived with her youngest daughter who was single and worked in the National Bank. Her youngest daughter's townhouse was in the middle of Bangkok on the main road in Soi Prachacheon 24 community (see picture 47).



Picture 47: Housing



Picture 48: Lifting together

Mrs. Nu was born in China and came to Thailand with her husband for 60 years previously. In the past, her family had lived in the Daungkae community and she sold several things by walking around the community. She believed in an external devilish power that made her afraid to send her children away for their studies. As the result, her daughters did not do any formal study except for the boy and the youngest daughter. The third daughter (Mrs. Nid) said Mrs. Nu was concerned about the safety of her children when they went to school. Apart from the youngest daughter, the other children asked their parents to let the youngest daughter study in the school opposite to their house.

After Mrs. Nu's husband passed away, she moved to live with her youngest daughter and often went to traveling to many places. Both of them went together to make merit or Mrs. Nu went by only one as a tourist. They had a close relationship. When Mrs. Nu suffered stroke with worsening condition, the youngest daughter prayed to the Buddha that she might devote her years to her mother. According to the Doctrine, one can transfer one's own age to another and she believed in this. For six years in the past, Mrs. Nu had been a stroke patient but she could talk and eat. Mrs. Nid moved from her house to take care of her as the primary caregiver.

She stayed with the patient all the time. Consequently, the eldest daughter and the second son supported her with some money monthly.

Mrs. Nu had recurrent stroke with severe conditions. She could not breathe and needed a tracheostomy tube and feeding tube. She was bedridden with Barthel Index score = 0 (total score = 40). Her family allowed the fourth daughter (Mrs. Nong) to participate in taking care of Mrs. Nu. Mrs. Nid said her young sister played a role in washing the clothes and helping her to lift the patient together (see picture 48).

Mrs. Nu stayed at the living room in front of the house. This townhouse had two floors and was close to the main street of Soi prachacheon 24. Her family prepared several pieces of equipments, such as a hospital bed, a suction machine, forceps, a pole and so on. There was a television opposite the patient's bed and a big bench for caregiver. On the right of patient's bed, there were two plastic boxes for collecting the patient's materials, such as suction tubes, gloves, and sterile cotton.

Every morning, Mrs. Nid prepared the blenderized diet in four bottles and then she cooked food. She brought the monk inside the house and she helped the patient make merit by offering the food to the monk at the patient's bed. She provided suction via tracheostomy tube and fed blenderized diet. Mrs. Nong washed the clothes of the patient. After both of them turned the patient's position, they had breakfast. At noon, Mrs. Nid started cleaning the patient, dressing the tracheostomy, evacuating the feces, and feeding the blenderized diet. In relaxation time, Mrs. Nid and Mrs. Nong watched television together, took a nap or sewed clothes. They turned the patient again and fed her the blenderized diet. In the evening, Mrs. Nid cleaned the patient and fed the last blenderized diet before both of them helped in changing the patient's position.

Mrs. Nid changed the nasogastric tube and retained new Foley's catheter monthly by herself. When Mrs. Nu went to follow up at the hospital, three daughters came together to take care of the patient. The youngest daughter said she was a supervisor to check if any problems happened while the others provided care. However, many caregivers had many different ideas. Mrs. Nid told about good relationship among the siblings in the past before. As time passed, each person became emotionally upset and they quarreled with each other.

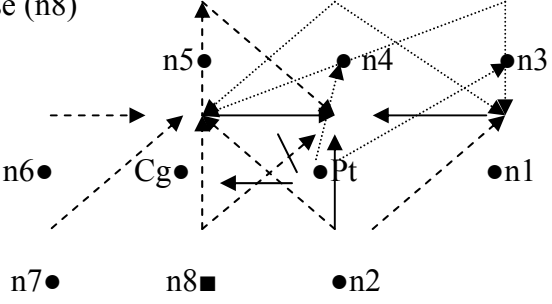
A schedule of a week by primary caregiver

Time	Activities
5.00	Prepare blenderized diet and cook food
6.00	Help patient offer the food to the monk
7.00	Suction, feed blenderized diet and change patient's position
8.00	Have breakfast and wash the clothes by the fourth daughter
9.00	Clean and evacuate the feces of patient, and dress the tracheostomy
10.00	Feed blenderized diet via feeding tube
11-12.00	Watch television or sew the clothes
13.00	Have a lunch and change the patient's position
14.00	Watch television, sew the clothes, or take a nap
15.00	Feed blenderized diet via feeding tube
18.00	Clean the patient and turn the patient together
19.00	Feed blenderized diet via feeding tube
20.00	Have dinner and turn the patient together

Caregiving network: Structure and relationship

This caregiving network mainly consisted of family members. The primary caregivers were the third daughter (Mrs. Nid) while the family caregiving network members consisted of the eldest daughter, the second son, the youngest daughter, the fourth daughter, a niece, a nephew, and a cousin who was a neurologist. The non-family member was a home health care nurse.

In the figure, the star graph demonstrates the relationship focusing on both patient and primary caregiver while the clique graph refers to the subset of actors. There was one direct exchange, six indirect exchanges, and one productive exchange.

Relationship Star graph, Cliques (n2,Cg,Pt), (n3,Cg,Pt), (n4,Cg,Pt), (n5,Cg,Pt), (n8,Cg,Pt), Exchange Direct exchange Cg ↔ Pt Indirect exchange Cg ↔ Pt n2n3n4n5n8 Productive exchange n2n3n4 Cg → n1	Structure The 3rd.daughter (Cg 1), the 4th.daughter (n1), the youngest daughter (n2), the eldest daughter (n3) the 2nd.son (n4), a niece (n5), a nephew (n6), a cousin (n7), home health care nurse (n8)  ●n1 ●n2 ●n3 ●n4 ●n5 ●n6 ●n6 Family member ■n8 → Non-family member ----- regularly / weekly, monthly, yearly Occasionally stop caregiving
Degree of connection	The third daughter took care of the patient daily. Cg1 ● → ●Pt The fourth daughter participated in providing care for the patient daily. n1 ● → ●Pt The youngest daughter provided suggestion to the primary caregivers occasionally. Cg ← ●n2 → ●Cg2 The eldest daughter and the second son provided financial support to caregivers monthly. n3 ● → ●Cg ← ●n4 n3 ● → ●n1 ← ●n4 The niece helped the caregiver with insertion feeding tube occasionally n5 ● ----- ●Pt The nephew provided suggestion to the caregiver with decision making about the tracheostomy tube occasionally. n6 ● ----- ●Cg ● ----- ●Pt

Degree of connection	The cousin provided suggestion to the caregiver with decision making about tracheostomy tube occasionally n7 ●-----↻g ●-----▶Pt
	The home health care nurse used to provide care to the patient , but later she stopped doing this n8■...../.....▶Pt

This caregiving was exchanged between the caregiver and the caregiving network members in physical, financial and spiritual aspects. For direct exchange in physical care, primary caregiver helped the patient with preparing the blenderized diet, feeding the patient, providing suction, dressing the tracheostomy tube, and changing the nasogastric tube and Foley's catheter. Mrs. Nid said her mother had disliked her when she was born. Her parent often quarreled together and projected the idea that they were unlucky.

For indirect exchange in physical care, the caregiver sent information about patient to a niece, a nephew, and the home health care nurse. Firstly, the caregiver asked her daughter to insert a new feeding tube when the patient had pulled it off. Secondary, the primary caregiver consulted nephew who was a doctor and he gave suggestion to the patient's children for decision making about the tracheostomy. Similarly, the caregiver consulted a cousin who was a neurologist and she provided suggestions to the patient's children for making a decision about the tracheostomy.

Focusing on productive exchange in financial care, the eldest daughter and the second son provided money 8, 000 baht to the patient. Six thousand baht of this was given to Mrs. Nid each month. Mrs. Nid said she gave some money to Mrs. Nong and bought some materials to Mrs. Nu. Moreover, the youngest daughter provided suggestion to her two sisters and reminded them about caregiving activities.

For indirect exchange in spiritual care, based on the doctrine of Buddhism, the youngest daughter prayed to the Buddha and donated two years of her aged for extending her mother's aged. Similarly, Mrs. Nid said she also made merit to the Buddha Image and donated her aged to her mother.

Directionality Direct exchange	• The caregiver took care of the patient because she was her mother.
Indirect exchange	• The caregiver asked the niece to insert the feeding tube when the patient pulled it out. • The caregiver consulted the nephew about the tracheostomy and he gave information to her to help her decision. • The caregiver consulted the cousin about the tracheostomy and she gave information to her to help in her decision. • The caregiver gave information to the home health care nurse and she provided home visiting to the patient and family. • The youngest daughter prayed to the Buddha to donate two years of her life to extend the life of her mother. • The caregiver gave her years to increase the years of her mother's life.
Productive exchange	• The eldest daughter and the second son provided financial support to the patient, the caregiver, the fourth daughter • The youngest daughter gave information to her two sisters and reminded them about caregiving activities.
Duration	Six years of stroke caregiving
Frequency of contact	The fourth daughter, the youngest daughter.....daily The eldest daughter, the second son.....monthly A niece, a nephew, a cousin, a home health care nurse occasionally
Homogeneity	During admission at the Sirinthorn center (a rehabilitation center), the third daughter had talked with other caregivers about stroke caregiving and they shared their experiences together.

size	Nine persons								
Sociodemographic	Cg	n1	n2	n3	n4	n5	n6	n7	n8
Sex (F =Female M = Male)	F	F	F	F	M	F	M	F	F
Age (year)	63	60	50	67	65	30	30	58	40
Status S = Single M= Married W= Widowed	W	W	S	M	M	S	S	M	M
Education N = No formal Education B = Bachelor degree	N	N	B	N	N	B	B	B	B
Religion (B = Buddhist)	B	B	B	B	B	B	B	B	B
Health problem DM = Diabetes Mellitus	DM								
Occupation H= House wife G = Government E = Employee	E	E	G	H	G	E	G	G	G
Residential location S = Same house	S	S	S	1hr.	1hr.	20 min s	2hrs	1hr.	30 min s

The 3rd.daughter (Cg 1), the 4th.daughter (n1), the youngest daughter (n2), the eldest daughter (n3) the 2nd.son (n4), a niece (n5), a nephew (n6), a cousin (n7), a home health care nurse (n8)

Caregiving network 15 (Mr. Oat)

The caregiving network exchanged caregiving to the stroke patient, namely Mr. Oat. He was 65 years and retired from the Ministry of Defense and worked as an undertaker. His family had worked in the temple to provide funeral care from generation to generation. He had three sons. His two sons and a daughter in law worked with him in the temple while his wife was employed by the neighbors to look after their children at home. Mr. Oat and his wife (Mrs. Oil) enjoyed taking care of other children as much as they did of their own children.



Picture 49: Housing environment



Picture 50: Caregiving network members

Mr. Oat lived in Soi Somthawin community. This community is behind the business premises in congestive congested area. His house was only a one story wooden house. In front of the house, there was a sidewalk for walking along the railway road that passed the community (see picture 49). Most people stayed in small houses and there were many trees and bushes that made it easy for the thieves to steal money from the people.

Although, they lived in a poor unsafe environment, they had good relationship with their neighbors. When Mr. Oat and his wife went out, they allowed their neighbor to take care of their house. In return, when the neighbor went out to pick up her child from school, she asked Mr. Oat and his wife to look after her baby.

Four year previously, Mrs. Oat had had stroke when he was working in the temple. He could not walk by himself. He needed help from someone to lift him for cleaning, dressing, taking a bath, and going to the hospital (Barthel Index score was 20 and total score was 40). The second son was the main person to take care of him while his wife cooked food and looked after their nephew (see picture 53).

The wind of change came when the second son died with lung disease. Mrs. Oil took care of her husband because there was no one else in the family to do it. Her eldest son and the eldest son's wife went out to work in the temple while the youngest son and his wife lived in another house close to Mr. Oat's house. On Monday morning, the youngest son took his son to his parent's house. He let his son stay with his parents on the working day and took him back on Friday evening.

Mrs. Oil had a closed friend when she was young. Both of them worked in the same weaving factory 20 years before. Her friend often came to visit her and her family while Mrs. Oil's family regularly visited her in Nakorn Prathom province. At this time, Mr. Oat and his wife could not go to anywhere but her friend still visited and provided help to them. She helped with carrying Mr. Oat to take a bath, cooking food and cleaning the house. Mr. Oat talked about travelling. He said he could not go to anywhere because he had no car and had no idea how to do that.

A schedule of a week by caregiver

Time	Activities
5.00	Wake up and carry to the bathroom for taking a bath
6.00	Have a cup of coffee by the patient
7.00	Take care of the nephew before going to the market and cooking food
8-9.00	Provide food to the nephew, dog, and patient while the eldest son's wife did laundry
10-12.00	Listen to the radio and take care of the nephew by the patient
13-14.00	Provide soft diet, such as pumpkin soup to the patient
15-17.00	Listen to the radio or watch the television
18.00	Clean the nephew and the patient
19.00	Have dinner with his family

♣ The eldest son carried the patient to take a bath on weekend and riding the motorcycle to follow up at the hospital monthly

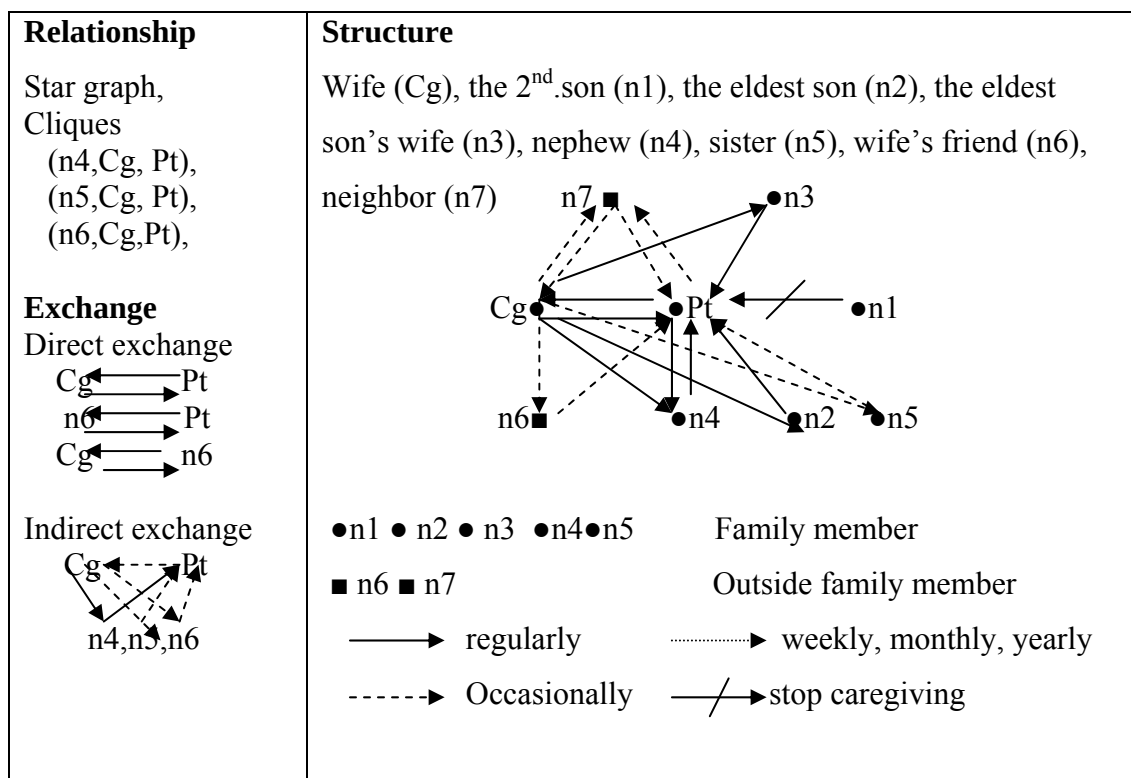
In the morning, Mr. Oat woke up and went to the bathroom with his eldest son. After Mr. Oat took a bath and had a cup of coffee, his eldest son went to the temple to work and the eldest son's wife did laundry. Mrs. Oil took care of the nephew

before she went to the market and cooked food while Mr. Oat listened to the radio and looked after the nephew in the cradle. Mrs. Oil provided food to the nephew, the dog and soft diet such as pumpkin soup to the patient. In relaxation period, Mr. Oat watched television or listened to the radio. In the evening, Mrs. Oil cleaned the nephew and the patient. When the eldest son's family went back home, they had dinner together.

Caregiving network: Structure and relationship

This stroke caregiving network consists of family members and outside family. The patient's wife was the primary caregivers while the caregiving network members consisted of the eldest son, the eldest son's wife, the nephew, the 2nd.son, the patient's sister, the wife's friend, and the neighbor.

According to figure, star graph presented the relationships of caregiving network focusing on patient rather than caregivers. Cliques presented the groups of members that exchanged caregiving together. There were four direct exchanges, and three indirect exchanges.



Degree of connection	The wife took care of patient and nephew daily n 4 ● ←———— Cg ● →————▶ Pt
	The 2 nd .son provided care to patient, now he passed away n1 ● ————/————▶ Pt
	The eldest son took care of patient daily n2● —————▶ Pt
	The eldest 's son provided care to patient occasionally n3 ● - - - - -▶ Pt
	The nephew played and made humor with the patient and his wife daily Cg ◀———— n4 ● —————▶ Pt
	The patient's sisters came to visit the patient occasionally n5 ● - - - - -▶ Pt
	The wife's friend took care of patient and helped caregiver with cooking occasionally Cg ◀- - - - -n6■ - - - - -▶ Pt
	The neighbor asked the patient and caregiver to take care of her son while she gave information about herbs to the patient occasionally Cg ● - - - - -n7■ ◀- - - - -▶ Pt

The caregiving network members exchanged caregiving in physical, psychological, social and financial aspects. For direct exchange in physical care, Mrs. Oil provided cleaning of the body, food, and medication to the patient while the patient provided financial support to her. In addition, the wife's friend came from Nakorn Prathom province to visit Mrs. Oil's family regularly. Because of their good relationship for 20 years before, the wife's friend lifted the patient to take a bath and helped the caregiver with cooking and cleaning the house. Furthermore, the neighbor provided help to Mr. Oat and Mrs. Oil in return for Mr. Oil taking care of her son when she went to school to pick up her other son. She also provided information about herbs to reduce the abdominal symptom of the patient. In addition, there were two indirect exchanges in physical care. Firstly, Mrs. Oil told the eldest son to take the patient for follow up at the hospital. He also lifted the patient to take a bath on

weekends. Secondly, Mrs. Oil asked her daughter in law to help her with the laundry every morning before she went to the temple.

For direct exchange in psychological care, Mrs. Oat and Mrs. Oil looked after their nephew while he played with both of them and made them happy. However, Mrs. Oil said Mr. Oat was easily moody. Both of them talked together.

Focusing on the indirect exchange in social care, the wife's friend was a regular visitor to Mr. Oat's family. In addition, the stroke patient's sisters came to visit him when they knew about his condition.

Directionality Direct exchange	• The caregiver took care of the patient while the patient provided financial support to her. • The caregiver and the patient looked after the nephew while he played with them and made them feel not so lonely. • The caregiver had a good relationship with her friend and she lifted the patient to take a bath and helped the caregiver with cooking food and cleaning the house. • The caregiver and patient looked after the neighbor's son while she gave information about herbs to patient.
Indirect exchange	• The eldest son knew about the patient and took him to follow up at the hospital and gave him a bath on weekends. • The eldest son's wife helped the primary caregiver with taking a laundry every morning. • The patient's sisters knew about the patient's condition and they came to visit the patient.
Duration	Four years of stroke caregiving
Frequency of contact	The wife, eldest son's wife, nephew.....daily The eldest son.....weekly, monthly The sisters, wife's friend, neighbor.....occasionally
Homogeneity	A neighbor who had had stroke. She had a daughter to take care of her and she got well. Mrs. Oil believed that the

	daughter would provide better care than son but she had no daughter.							
size	eight persons							
Sociodemographic	Cg	n1	n2	n3	n4	n5	n6	n7
Sex (F =Female M = Male)	F	M	M	F	M	F	F	F
Age (year)	59	33	36	32	9 mos	53	67,69	30
Status M = Married S = Single	M	M	M	M	S	M	M	M
Education N = no education (only sign her name) 1 st . = Primary school 2 nd . = Secondary school	N	2 nd	2 nd	2 nd	N	1 st	-	2 nd .
Religion (B = Buddhist)	B	B	B	B	B	B	B	B
Health problem H = Hypertension D = Dead	H	D	-	-	-	-	-	-
Occupation H = Housewife E = Employee N = No occupation	H	-	E	E	N	H	H	H
Residential location S = Same house NP= Nakorn Prathom province	S	-	S	S	5 mins	NP	2 hrs	1 min

Wife (Cg), the 2nd.son (n1), the eldest son (n2), the eldest son's wife (n3), nephew (n4), sister (n5), wife's friend (n6), neighbor (n7)

Caregiving network 16 (Mr. Po)

This Thai Chinese family took care of the stroke patient, who had only one eye (namely Mr. Po). He was 77 years and lived with his family that consisted of his wife (namely Mrs. Porn) and one son (namely Mr. Pan) in a cheap flat in Din Dang community. This community is located in the middle of Bangkok and has business buildings, markets, schools, a stadium, a Metropolitan health center. Mr. Po and his family lived in the second floor of the flat (see picture 51). It had only one living room with a separated area for a bed, a table and a big television in the left side of the room and a kitchen in the back. There was a bathroom close to the kitchen.



Picture 51: Pavement in front of the room Picture 52: Caregiving network members

In the past, Mr. Po had an accident when he worked fixing cars. His left eye was blind and he used a prosthesis. The National Council on Social Welfare of Thailand provides low price lottery tickets to disabled people to sell. Mr. Po received the lottery tickets to earn income for his family while his wife was employed by her neighbors to do laundry. His son worked in the National Housing Authority. He was studying in the university in the evening and on weekends to increase his educational level and salary.

Mr. Po was the youngest son of five children. He had three sisters and one brother. Three days after he was born for three days, his mother passed away. His father allowed another Chinese wife to look after his children and had seven more children. Mrs. Porn said Mr. Po and the eldest daughter of his Chinese mother had breast feeding on each side. Mrs. Porn was only one daughter. When she was 5 years old, her father passed away. Her mother married to a widower who had eight children by a previous marriage. Her parents had three more daughters. Therefore, Mr. Po and

Mrs. Porn had many cousins. When anything happened, family members spend information among themselves.

For ten years, Mr. Po had stroke but he could move a little to the bathroom. He sat up on the bed and ate food by himself. (Barthel Index score = 20, total score =40). His wife was the main person to take care of him in the daytime, while his son provided care in the night (see picture 52). His wife quit her job at a laundry service and sold lottery tickets instead of her husband at the market on the ground floor of her flat.

Every morning, Mrs. Porn woke up at 4 a.m. and went to buy soymilk and food from the market. After she came back home, she provided cleaning for the patient and gave him a glass of soy milk. When she went to sell the lottery tickets at the market, her son went out to work. Mrs. Porn went back home to cook food and gave medication to the patient at 10 a.m. After they had breakfast, they watched television or took a nap. Mrs. Porn went to sell lottery tickets again in the evening while her son came back home. He bought some food and helped his father with taking a bath. When Mrs. Porn came back home, they had dinner together. If the patient could not void by himself, Mrs. Porn or Mr. Pam provided intermittent catheter to him (see picture 53).



Picture 53: Equipment for intermittent catheter Picture 54: Clothes for cleaning

Mrs. Porn had a good relationship with her neighbors. For example, a neighbor A, a seamstress, lived in the same floor and same flat. She provided pieces of cloth from her work to clean the buttock of the patient instead of paper (see picture 54). In addition, a neighbor D who was working with Metropolitan health, provided massage with herb to the patient (see picture 55, 56).



Picture 55: Community health massage Picture 56: Warming herb ball for massage

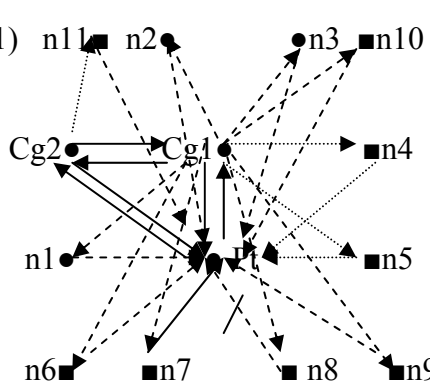
A schedule of a day by primary caregiver

Time	Activities
4.00	Buy soy milk and food
5.00	Provide a glass of soy milk to the patient
6 -9.00	Clean the patient and go to sell the lottery tickets at the market
10.00	Prepare food and medication for the patient and have breakfast
11-15.00	Watch the television or sleep
16.00	Buy the food by his son while his wife goes to sell lottery tickets
17.00	Help the patient with taking the bath by his son
19-22.00	Have dinner with his family

Caregiving network: Structure and relationship

This caregiving network consisted of both family members and non-family members. Of the family members, there was the wife, a son, a young brother, a young sister, and a nephew. The non-family members were the neighbors, the National Council on Social Welfare of Thailand, the public ambulance service, and the Metropolitan health nurse.

In the figure, the star graph demonstrates the relationship focusing on both patient and the caregiver while clique graph refers to the subset of actors. There were three direct exchanges, and eleven indirect exchanges.

Relationship Star graph, Cliques (n1,Cg1, Pt), (n2,Cg1, Pt), (n3,Cg1,Pt), (n4,Cg1,Pt), (n5,Cg1,Pt), (n6,Cg1,Pt), (n7,Cg1,Pt), (n8,Cg1,Pt), (n9, Cg1, Pt), (n10,Cg1,Pt), (n11, Cg2,Pt), (Cg1,Cg2,Pt) Exchange Direct exchange Cg1 ↔ Pt Cg2 ↔ Pt Cg1 ↔ Cg2 Indirect exchange Cg1 ↔ Pt n1 ↔ n2 ↔ n3 ↔ n4 ↔ n5 ↔ n6 ↔ n7 ↔ n8 ↔ n9 ↔ n10 ↔ n11	Structure: Wife (Cg1), son (Cg2), young brother (n1), young sister (n2), nephew (n3), neighbor A (n4), neighbor B (n5), neighbor C (n6), neighbor D (n7), the National Council on Social Welfare of Thailand. (n8), public ambulance (n9), metropolitan health nurse (n10), the National Housing Authority (n11)  ● n1 ● n2 ● n3 ● n4 Family member ■ n5 ■ n6 ■ n7 ■ n8 ■ n9 ■ n10 ■ n11 Outside family member ————→ regularly - - - - -> weekly, monthly, yearly> Occasionally /> stop caregiving
Degree of connection	The wife took care of the patient daily Cg1 ● —————> ● Pt
	The son provided care to the patient daily evening Cg2 ● —————> ● Pt
	The young brother connected to the private hospital and giving some money to the patient occasionally n1 ●> ● Pt
	The young sister provided suggestion and help to the caregiver occasionally n2 ●> ● Pt
	The nephew provided suggestion and help to caregiver occasionally n3 ●> ● Pt
	The neighbor A gave some pieces of clothes to the patient monthly n4 ■> ● Pt
	The neighbor B lifted the patient from his room to the taxi monthly n5 ■> ● Pt
Degree of connection	

	The neighbor C donated the wheel chair to the patient occasionally n6 ■ ----- ●Pt
	The neighbor D provided massage to the patient in the past, now she stopped providing case. n7 ■ ——— / ———> ●Pt
	The National Council on Social Welfare of Thailand provided low price lottery to the patient twice a month n8 ■> ●Pt
	The public ambulance center allowed ambulance car for transferring patient to the hospital occasionally n9 ■ -----> ●Pt
	The Metropolitan health nurse provided home visiting to the patient in the past, now she stopped providing care n10 ■ ——— / ———> ●Pt
	The National Housing Authority provided some money to caregiver 2 for help the patient n11 ■ ——— / ———> ●Cg

This caregiving was exchanged between caregivers and caregiving network members in physical, psychological, and financial aspects. For direct exchange in physical care, the caregiver 1 provided cleaning, cooking of food, taking medication, taking a laundry, and taking the patient to follow up to the hospital while the patient took care of her. The caregiver 2 took care of the patient by preparing food, giving him a bath, cleaning, and taking him to the hospital while the patient had been his natural father and transferred the right to receive low price lottery tickets to him. Mr. Pam said he was my father that I had to provide caregiving .

With regard to indirect exchange in physical care, the caregiver1 sent information about the patient to his young brother, young sister, the nephew, and four neighbors. Firstly, the caregiver 1 called the younger sister of the patient about his worsening condition. His younger sister came to the hospital with the patient and his

wife to share for decision making and sending information to others in the family. Secondly, the younger sister called the younger brother to share information about Mr. Po. As a result, his younger brother contacted the private hospital and brought Mr. Po to be examined by a famous neurologist. The younger brother provided some financial support and bought a new television to Mr. Po. Thirdly, the caregiver 1 asked the nephew to bring Mr. Po for treatment. Her nephew provided information and helps to the patient.

Moreover, there was indirect exchange between non-family members. Fourthly, a neighbor A was a seamstress and asked the caregiver 1 about how she cleaned Mr. Po. When a neighbor A learnt that Mrs. Porn used pieces of paper to clean the patient, she gave some pieces of cloth from her work to clean Mr. Po and to reduce the cost of care. Fifth, Mrs. Porn asked a neighbor B to carry the patient with caregiver 2 from the room to the taxi when Mr. Po went to follow up at the hospital. Mrs. Porn gave some money to neighbor B's children in return for his help. Sixth, Mrs. Porn had employed neighbor C to do laundry in the past. He knew about Mr. Po's condition from Mrs. Porn. He had a wheelchair of his parents and gave it to Mr. Po. Seventh, Mrs. Porn knew that neighbor D provided massage with herbal herb in the community. She allowed a neighbor D to provide massage for Mr. Po three times but neighbor D did not receive any money from Mrs. Porn. Eighth, Mrs. Porn sent information about Mr. Po to Metropolitan health nurse and she went to provide home visiting to Mr. Po.

In addition, there was indirect exchange in emergency care. Mrs. Porn sent information about Mr. Po's condition to the public ambulance center. The center allowed an ambulance van to take the patient to the hospital. Focusing on direct exchange in psychological care, Mrs. Porn and Mr. Pam exchanged moral support together. Mr. Pam expressed his concern about the health of Mrs. Porn. He said "Mom please took care of your self". If Mom got sick, how he could not stay alone? Similarly, Mrs. Porn encouraged Mr. Pam to live simply. She said Mr. Pam were not naughty that made her satisfied. For indirect exchange in financial care, Mrs. Porn sent information to seek a reduction of 1, 000 baht each time from the National Council on Social Welfare. In addition, the National Housing Authority provided a gift to employee on New Year or Birthdays. When they knew about Mr. Pam's father, they changed from giving a gift to giving financial support Mr. Pam.

Directionality Direct exchange	- Caregiver 1 took care of the patient while he had taken care of her in the past. - Caregiver 2 provided care to the patient in the night because the patient was his father. - Caregiver 2 expressed his concern to caregiver 1 while she provided moral support to him.
Indirect exchange	- Caregiver1 called the younger sister of the patient about the condition of patient and she provided suggestion. - The younger brother knew about the patient's condition and he provided financial support to Mr. Po. - Caregiver1 asked the nephew to take the patient to the hospital. - Neighbor A asked about the cleaning of the patient and she gave pieces of cloth to Caregiver 1 for cleaning. - Caregiver 1 asked neighbor B to lift the patient while she provided some money to the children of a neighbor B. - Neighbor C knew about the condition of the patient and he gave his parent's wheelchair to the patient. - Neighbor D knew about condition of patient and provided massage to the patient. - Caregiver 1 obtained reimbursement of the medical costs from the National Council on Social Welfare of Thailand. - Caregiver 1 contacted to a public ambulance center to give them information. The public ambulance center let an ambulance van transfer the patient to the hospital. - Caregiver 1 contacted to the Metropolitan health center. A Metropolitan health nurse had provided home visiting to the patient in the past, but now she had stopped providing care - The National Housing Authority knew about the condition of the patient. They provided some financial support to caregiver 2 to help the patient.

Duration	Ten years of stroke caregiving												
Frequency of contact	Wife, son.....daily A neighbor A, a neighbor B.....weekly The young sister, a young brother, a nephew. occasionally A neighbor C, a neighbor D, a public ambulance center, A Metropolitan health nurse, the National Housing Authority, the National Council on Social Welfare of Thailand.												
Homogeneity	- The caregiver1 had previous experience of stroke. The sister of the patient had died many years before from stroke. - A neighbor A, who took care of her elderly parent, was a seamstress. She gave pieces of cloth to caregiver 1 monthly												
size	Thirteen persons												
Sociodemographic	Cg 1	Cg 2	n1	n2	n3	n4	n5	n6	n7	n8	n9	n 10	n 11
Sex	F	M	M	F	M	F	M	M	F	-	-	F	-
Age (year)	66	30	72	77	40				60				
Status M = Married S = SingleW=widow	M	S	M	M	M	M	M	M	W				
Education 1 st . = primary school B = Bachelor degree V=Vocational school	1 st .	V										B	
Religion B=Buddhist	B	B	B	B	B	B	B	B	B				
Health problem B = Bone disease	B												
Occupation H= House wife G = Government E = Employee M = Merchant	H	E	M	H	M	E	M	M					
Residential location	S	S	1 hr	1 hr	1 hr	1 mi	5 mi	5 mi	5 mi				

Caregiving network 17 (Mrs. Quartz)

A small caregiving network took care of the stroke patient, namely Mrs. Quartz. She was 84 years and came from Nakorn Sawan province after her husband had died many years ago. She lived with her youngest daughter's family in Tong Karu, a middle area of Bangkok (see picture 60). The youngest daughter, namely Mrs. Quick, lived with her husband and two sons in a two-story townhouse. In this area, there were many factories and new communities for the people who were employed in them. Like other persons in the community, Mrs. Quick and her husband had worked in the jewelry factory, separating precious stones. In addition, both of them sold clothes in the bazaar on weekends while Mrs. Quartz stayed alone in the townhouse during the daytime every day. Sometimes she came to her hometown in Nakorn Sawan province for practicing meditation and making merit in the temple.



Picture 57: Entrancing the community



Picture 58: Feeding via oral

Mrs. Quick talked about the terrible experience when Mrs. Quartz had had a stroke four months previously. When her family members went out to work and her children went to school, her mother experienced with hemiparesis and could not speak. Mrs. Quartz put an effort to move a little bit and hit the wall to call for help. When the neighbor came to her house, she threw her the key to open the door. The neighbor called Mrs. Quick to take Mrs. Quartz to the hospital. Mrs. Quartz could not sit down and eat food by herself. She needed a feeding tube to eat a blenderized diet four times a day (Barthel Index score = 10, total = 40). When Mrs. Quartz was discharged from the hospital, Mrs. Quick stopped working to take care of her mother for one month and she did not receive her salary. Mrs. Quick could not stay with her mother all the time because she needed to continue working. She consulted her siblings to help her with this situation. As a result, the third daughter came from Nakorn Sawan province to

play a role as a primary caregiver. The third daughter, namely Mrs. Quin, was widowed and had only one son, a soldier. She had experienced taking care of her husband who had had terminal cancer. She had financial problems in her work of selling foods and desserts. Therefore, Mrs. Quick provided some money to support her monthly.

Every morning, Mrs. Quin woke up to cook food for Mrs. Quick's family and fed a bottle of milk via a feeding tube to her mother. When Mrs. Quick's family went out, she started cleaning her mother. She made the blenderized diet two times a day because of mechanical problems with the refrigeration. After she completed feeding her mother at 10.00 a.m., she had her own breakfast. In her relaxation time, she watched television with her mother after she had washed the clothes. She fed her mother again at 2 p.m. and had her lunch. She cleaned the house while Mrs. Quartz watched television or took a nap. When Mrs. Quick and her husband came back home, they provided cleaning for the patient. Mrs. Quin started making the blenderized diet again to feed her mother at 6 p.m. All family members had dinner and watched television together. Mrs. Quick stopped feeding the fourth meal because she worried about her mother's body weight. She said she could not lift her mother and her sister had a back problem. In the nighttime, her husband took care of Mrs. Quartz while Mrs. Quin went to her bedroom.

On weekend, Mrs. Quick did a laundry for all family members. She and her husband provided a bath and hair shampoos to Mrs. Quartz before they went to the bazaar to selling clothes. When Mrs. Quartz went to follow up at the hospital, Mrs. Quick and her husband stopped working and helped each other to take her to the hospital. When Mrs. Quartz pulled out her feeding tube, both of them brought her to retain the new feeding tube at the private hospital. To prevent the pulling out of Mrs. Quartz's feeding tube, Mrs. Quick needed to use a small box to put Mrs. Quartz's hand inside. At this time, Mrs. Quin tried to feed the diet orally to her mother to take her off the nasogastric tube (see picture 58).

A schedule of a day by caregiver

Time	Activities
5.00	Wake up and cooked food
6.00	Feed milk via feeding tube to the patient while the youngest daughter's family goes outside for working and the children went to school
7.-8.00	Clean the patient
9.00	Make blenderized diet and boil equipment for feeding
10.00	Feed diet to the patient and have her own breakfast
11-13.00	Watch television with the patient after she wash the clothes
14.00	Feed diet to the patient before having lunch
15-16.00	Watch television with patient after cleaning the house
17.00	Clean the patient by the youngest daughter and her husband
17.30	Make blenderized diet and cook food
18.00	Feed diet via feeding tube to the patient and all members had a dinner
19-22.00	Watch television and talked together

♣ The youngest daughter does a laundry on weekend

The youngest daughter and her husband provided a bath with hair cleaning to the patient on weekend and each other to take the patient to follow up at the hospital monthly

Caregiving network: Structure and relationship

This small stroke caregiving network consisted of both family members and non-family members. The third daughter was the primary caregivers while the caregiving network members were the youngest daughter, the youngest daughter's husband, the nephew, the fifth son, the neighbor and a Metropolitan health care nurse.

In the figure, the star graph demonstrates the relationships of the caregiving network focusing on the patient rather than caregivers. Cliques describe the groups of members that exchanged caregiving together. There were three direct exchanges, seven indirect exchanges and one productive exchange.

Relationship Star graph, Cliques (n1,n2,Pt), (n1,n3,Pt), (n1,n4,Pt), (n1,n5,Pt), (n1,n6,Pt). Exchange Direct exchange Cg → Pt n1 → Pt Cg → n1 Indirect exchange Cg → Pt n2,n3,n4,n5,n6 Productive exchange n1 → Pt Cg → Pt	Structure The 3rd.daughter (Cg), the youngest daughter (n1), the youngest daughter's husband (n2), nephew (n3), 5th.son (n4), neighbor (n5), Metropolitan health care nurse (n6) ● n1 ● n2 ● n3 ● n4 Family member ■ n5 ■ n6 Outside family member → regularly weekly, monthly, yearly ----- Occasionally —/— stop caregiving
Degree of connection	The third daughter took care of patient in the daytime daily Cg ● → ● Pt
	The youngest daughter took care to patient in the evening, on weekend and carried her to the hospital monthly and provided financial support to primary caregiver monthly Cg ● ← n1 ● → ● Pt
	The youngest daughter's husband took care of patient daily in the evening and in the nighttime n2 ● → ● Pt
	The nephew played and made humor with the patient occasionally n3 ● ----- ● Pt
	The fourth son provided financial support by reimbursement cost of care monthly n4 ● → ● Pt
	The neighbor came to visit the patient occasionally n5 ■ ----- → ● Pt
	The Metropolitan health care nurse provided home visiting to patient occasionally n6 ■ ----- → ● Pt

The caregiving network members exchanged caregiving in physical, psychological, financial, social and spiritual aspects. For direct exchange in physical care, Mrs. Quin provided cleaning of the body, food, and medication to the patient while the patient had given birth to her. In addition, the youngest daughter took care of her mother in the evening and on weekend while her mother provided care to her as her child. There were two indirect exchanges in physical care from family members. Firstly, Mrs. Quick told her husband to clean Mrs. Quartz every evening. Both of them took the patient to take a bath on weekends and to follow up at the hospital monthly. Secondly, Mrs. Quick sent information to the Metropolitan health center and home a health care nurse came to provide home visiting to the patient.

For indirect exchange in psychological care, Mrs. Quick allowed her sons to play with the patient, and this made her smile. Moreover, there was a direct exchange between primary caregiver and her youngest sister. Mrs. Quin had her own financial problems and needed to keep working. Mrs. Quick helped her with financial support. On the other hand, Mrs. Quick had financial problems because her friend did not return some money. She was so stressed but she paid the money back instead of her friend. She did not want to talk with her husband but she expressed her emotional problem with her sister. She received oral support from Mrs. Quin.

With regard to indirect exchange in financial care, Mrs. Quick consulted her brother and he helped her with reimbursing the cost of care and provided monetary support to the patient. There was a productive exchange. Mrs. Quick gave some monetary support to her sister and her mother.

For indirect exchange in social care, Mrs. Quick talked about her mother's condition to her neighbor, who came to visit Mrs. Quartz. In addition, there were two indirect exchanges in spiritual care. When the patient was discharged from the hospital, she needed to go to make merit in Nakorn Sawan province. Mrs. Quick told her sister and brother to take her to Nakorn Sawan province. On New Year, Mrs. Quin did not go to make merit. Therefore, Mrs. Quick went to the temple to make merit instead of her sister.

Directionality Direct exchange	• The caregiver took care of the patient while the patient had given birth and provided birth care to her in the past. • The youngest daughter provided care to the patient while the patient gave birth to her and looked after her in the past. • The caregiver told her financial problem to her youngest sister and she provided monetary support to her. When the youngest sister expressed her emotional problem to the caregiver, she provided moral support to her.
Indirect exchange	• The youngest daughter asked her husband to help her with cleaning the patient, taking a bath, and taking her to follow up at the hospital. • The youngest daughter allowed her son to play with the patient and this made her smile. • The fifth son knew about the patient from the youngest daughter and he reimbursed the medical cost and gave some money to the patient. • The youngest daughter told her neighbor about the condition of the patient and the neighbor came to visit the patient.
Indirect exchange	• The youngest daughter sent information to the Metropolitan health center and a home health care nurse provided home visiting to the patient. • The youngest daughter knew about spiritual needs of the patient and sent information to others in her family. They helped her with taking the patient to make merit. • The youngest daughter knew about spiritual needs of the caregiver. She went to make merit in the temple and at the national pillar instead of the caregiver.

Productive exchange	The youngest daughter provided monetary support to the patient and the caregiver.						
Duration	Four months of stroke caregiving						
Frequency of contact	The third daughter, the youngest daughter.....daily The youngest daughter's husband, The fifth son..... monthly A nephew, a neighbor, a home health care nurse occasionally						
Homogeneity	The youngest daughter's friend provided suggestion about private caregiver from agency but the youngest daughter had no money to support the high cost of caregiver.						
size	Seven persons						
Sociodemographic	Cg	n1	n2	n3	n4	n5	n6
Sex (F =Female,M = Male)	F	F	M	M	M	F	F
Age (year)	61	43	43	10	56	-	-
Status M = Married S = Single, W= Widowed	W	M	M	S	M	-	-
Education 1 st . = Primary school 2 nd . = Secondary school B = Bachelor degree	1 st .	2 nd .	2 nd .	1 st .	2 nd .	-	B
Religion (B = Buddhist)	B	B	B	B	B	-	B
Health problem A = Allergy	A	-	-	-	-	-	-
Occupation M = Merchant E = Employee G = Government S = Student	M	E	E	S	G	-	G
Residential location S = Same house	S	S	S	S	1hr	5 mins	1hr.

Caregiving network 18 (Mr. Roy)

Mrs. Ree a 66 year-old woman who was the primary caregiver for her 72-year-old husband, namely Mr. Roy. They had four children: three sons and one daughter. The eldest and the second son got married and separated to set up their families while the third son and the youngest daughter lived with them in the same household. In the past, Mrs. Ree worked at the central office of a chain of alcohol sales outlets and her own branch while Mr. Roy had his own work in electronic repairs.

Many years ago, he had retired from working and had the time to join with two senior clubs five days a week. In addition, he was a community volunteer who received training to protect the community as local police volunteer. Moreover, he enrolled to study Thai traditional medicine to take care himself because he had been with diabetes mellitus. Mrs. Ree said her husband did not follow up to the hospital but he used many herbs to treat his disease. The second son talked about the bad experience of Mr. Roy that made his father not go to private hospital. In the past four months, Mrs. Ree had had heart disease. She retired from her business and allowed other to rent her building. Mr. Roy and his family moved from the old house that was the business building in Klongsarn to live in Bangkrae, a middle area of Bangkok.

After Mr. Roy and his family moved to a new two-story house, he felt lonely and saw the album of old pictures many times. He could not go to join with senior clubs by his motorcycle because of the long distance. In addition, his children had no time to take care of him by driving him there. After only two months in the new house, Mrs. Ree found him lying down on the floor. She was frightened and called her children back. They faced difficulty contacting with a public ambulance center. Therefore, they transferred Mr. Roy to go to Prasat Neurological Institute hospital by their car.

Mr. Roy had had a stroke could not breathe by himself. He had a tracheostomy and feeding tube inserted before he was discharged from the hospital. Mrs. Ree played a role as a primary caregiver because there was nobody else in the house. Mrs. Ree was prepared through discharge planning from the nurse on how to take care of her husband from the nurse. However, she was very stressed and could not take care of him alone. As a result, her children took Mr. Roy to stay in the private nursing home. They went to visit him many times and found that Mr. Roy had a fever.

Mr. Roy was readmitted to Prasat Neurological Institute hospital after he had stayed in the private nursing home for only one month.

During caregiving in the hospital, a former employee called Mrs. Ree to request that she be allowed to work with her. She said she had stopped her business but she needed someone else to help her take care of her husband. The employee, namely Mrs. Rung, agreed with this idea and came to stay with her in the same house as a housekeeper. Mr. Roy was discharged from the hospital without tracheostomy tube and went back home with a feeding tube. He could look around but he did not say anything. He could not eat or move by himself (Barthel Index score was zero).

Mr. Roy stayed on his bed in the living room. There was a television in front of his bed while his family members watched television or talked together in this room. His bed was close to the bathroom and the kitchen. All family members and the housekeeper had their bedrooms on the second floor while the third son stayed with Mr. Roy in the living room in the nighttime.

Every morning, the third son woke up to clean Mr. Roy's body, remove secretions, and provide mouth care. He took the patient outside to in front of his house by wheelchair and fed him a bottle of milk via feeding tube before the third son and the youngest daughter, namely Ms. Rose, went outside to work. After Mrs. Ree had breakfast, she and Mrs. Rung helped each other in giving a bath to the patient. She fed the blenderized diet to Mr. Roy while Mrs. Rung provided massage to him. In relaxation times, Mrs. Ree watched television and Mr. Roy took a nap while Mrs. Rung did the laundry. After Mrs. Ree had lunch, she provided feeding of the diet again to Mr. Roy. Mrs. Ree and Mrs. Rung helped each other with changing the position of Mr. Roy (see picture 60).



Picture 59: Housing



Picture 60: Turning position

In the evening, Ms. Rose went to supermarket for buying the food. She went back home for making blenderized diet while the third son provided suction with bubble pump and cleaned to the patient. After Ms. Rose completed her blenderized diet and divided into four bottles. She fed blenderized diet to her father before all of them had dinner together. The third son fed the last diet to Mr. Roy before Mrs. Rung cleaned his body again. They helped together with turning position, and checking the safety of the patient before they went to sleep.

A schedule of a day by caregiver

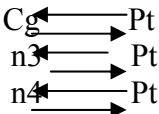
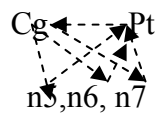
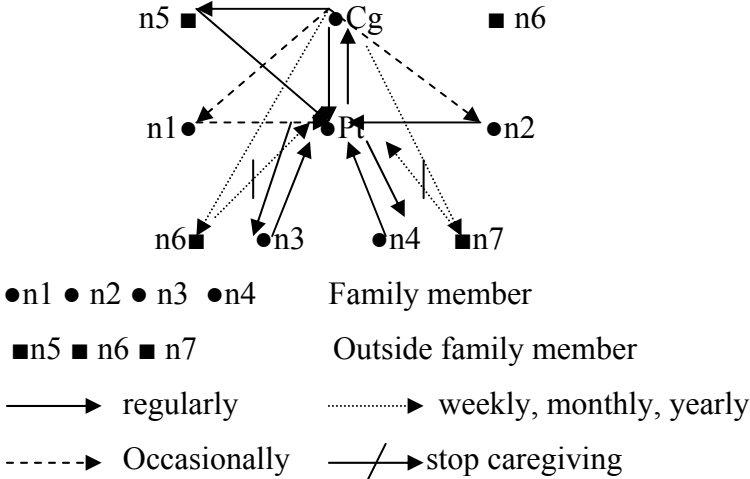
Time	Activities
6.00	Cleaned the body, suction, and mouth care the patient by the 3 rd .son
7.00	Carried the patient by wheelchair to go in front of the house by the 3 rd .son
8.00	Fed a bottle of milk via feeding tube by the 3 rd .son or caregiver
9.00	Had a breakfast before providing a bath by caregiver and housekeeper
10-12.00	Fed diet by caregiver and provided massage by housekeeper
13.00	Had a lunch of caregiver and did a laundry by housekeeper
14.00	Fed blenderized diet via feeding tube by caregiver
15-17.00	Turned position of the patient by caregiver and housekeeper
18.00	Fed blenderized diet via feeding tube and had dinner
19.00	Cleaned the body and suction by the 3 rd .son while the youngest daughter made blenderized diet and divided into four bottles
20-21.00	Watched television together
22.00	Fed blenderized diet via feeding tube by the 3 rd .son
23.00	Cleaned the body of the patient by housekeeper
24.00	Turned position and checked safety of the patient by 3 rd .son

Caregiving network: Structure and relationship

The stroke caregiving network consists of both family members and outside family members. The patient's wife was the primary caregivers while the caregiving network members consisted of the first son, the second son, the third son,

the youngest daughter, a housekeeper, a home health care nurse, and a physical therapist student.

As shown in the figure, star graph demonstrated the relationships of caregiving network focusing on patient rather than caregivers. Cliques described the groups of members that exchanged caregiving together. There were three direct exchanges, and five indirect exchanges.

Relationship Star graph, Cliques (Cg,n1,Pt), (Cg,n2,Pt), (Cg,n3,Pt), (Cg,n4,Pt) Exchange Direct exchange  Indirect exchange 	Structure Wife (Cg), the 1st.son (n1), the 2nd.son (n2), the 3rd.son (n3), the youngest daughter (n4), housekeeper (n5), Metropolitan health nurse (n6), physical therapist student (n7)  ●n1 ● n2 ● n3 ●n4 Family member ■n5 ■ n6 ■ n7 Outside family member ————→ regularly → weekly, monthly, yearly -----→ Occasionally —/—→ stop caregiving
Degree of connection	The wife took care of patient daily Cg ● —————→ ●Pt The eldest son provided financial support to caregiver monthly and reimbursed medical cost for patient monthly Cg ● n1 ●→ ●Pt The second son carried the patient to follow up monthly n2 ●→ ●Pt The third son provided care to patient daily n3 ●/.....→ ● Pt The youngest daughter made blenderized diet and fed diet to the patient daily n4 ● —————→ ●Pt

	The housekeeper took care of patient with the caregiver daily n5 ■ —————▶ ● Pt
	The Metropolitan health care nurse provided home visiting to the patient monthly, now she stopped providing care n6 ■ —————▶● Pt
	The physical therapist student provided home visiting to the patient for 6 month, now he stopped providing care n7 ■ ————/————▶● Pt

The caregiving network members exchanged caregiving in physical, psychological, social and financial care. For direct exchange in physical care, Mrs. Ree took care of Mr. Roy all the day while he had ever provided care to her in the past. In addition, the third son provided cleaning Mr. Roy's body, suction, mouth care, feeding diet, and stayed with him in the night while the patient had given birth to him. The youngest daughter made blenderized diet, and fed diet to the patient while the patient had given birth to her.

Moreover, there were seven indirect exchanges in physical care from caregiving network members. Firstly, Mrs. Ree called the second son to carry the patient for following up at the hospital. Secondly, Mrs. Ree allowed Mrs. Rung, a housekeeper, to employ for taking care of the patient with her and she provided monetary support to her. Thirdly, Mrs. Ree sent information to the Metropolitan health center. A Metropolitan health nurse provided home visiting to Mr. Roy. Lastly, Mrs. Ree allowed the physical therapist student came to her house for case study while the physical therapist student provided visiting to the patient for 6 months.

For direct exchange in psychological care, Ms. Ree was so stressful to take care of patient by only one else. Her children helped her with carrying the patient to stay in private nursing home. In addition, Ms. Rose provided mental support to Mrs. Ree by positive thinking that the patient was better than other. He could receive blenderized diet well and had no any diarrhea.

With regard to indirect exchange in financial care, Mrs. Ree told the eldest son about Mr. Roy's condition. He provided financial support to her and reimbursed medical cost to the patient

Directionality Direct exchange	• The caregiver took care of the patient while the patient provided care to her in the past. • The third son took care of patient in the night and provided cleaning, suction, and feeding to the patient while the patient had given birth and provided birth care to him. • The youngest daughter bought the food and provided mental support to primary caregiver. She made blenderized diet and fed diet to the patient while both of them had given birth to her.
Indirect exchange	• The eldest son provided financial support to the caregiver and the patient. • The second son took the patient to follow up at the hospital • The housekeeper took care of patient while the caregiver provided monetary support to her. • The caregiver sent the information of the patient to the Metropolitan health center and a metropolitan health nurse provided home visiting to the patient. • The physical therapist student visited the patient while the caregiver allowed the patient to be his case study.
Frequency of contact	Wife, the third son, the youngest daughter, housekeeper.....daily The eldest son, the second son.....monthly The Metropolitan health nurse, ...occasionally The physical therapist student
Homogeneity	• The brother of patient got stroke for 7 years but he could walk and ate by own self. The patient did not do anything and did not say when he had stool or urine.

Homogeneity	The caregiver observed and gained an experience from the relatives of stroke patients who provided care in the hospital.							
Duration	Four months of stroke caregiving							
size	Eight persons							
Sociodemographic	Cg	n1	n2	n3	n4	n5	n6	n7
Sex (F =Female M = Male)	F	M	M	M	F	F	F	M
Age (year)	65	39	37	35	30	38	-	18
Status (M = Married S = Single)	M	M	M	S	S	M	-	S
Education 1 st . = Primary school 2 nd . = Secondary school U = University student B = Bachelor degree	2 nd .	B	B	B	B	1 st	B	U
Religion (B = Buddhist)	B	B	B	B	B	B	B	B
Health problem H = Heart disease	H	-	-	-	-	-	-	-
Occupation H = Housewife E = Employee G = Government S = Student	H	G	E	E	E	E	G	S
Resident Location S = Same house KK = KonKan province	S	KK	1hr	S	S	S	30 mins	1 hr

Wife (Cg), the 1st.son (n1), the 2nd.son (n2), the 3rd.son (n3), the youngest daughter (n4), housekeeper (n5), Metropolitan health nurse (n6), physical therapist student (n7)

The second section

In this section, the stroke caregiving networks were set up as a wheel of caregiving model. This model explained the nature of stroke caregiving that was a dynamic process of social exchange behaviors within the caregiving network. These behaviors were captured in terms of their structure/theme from the perspectives of caregivers and caregiving network members. The behaviors are seen as maintaining a wheel of caregiving. Six themes emerged to explain the nature of how caregiving sphere was set up and how the stroke caregiving process was maintained. The perceptions and experiences of participants are explored under the first theme captioned as “no one else can do it” (*mi-me-krai-thum-trong-nee-dai*). The second theme presents the initial feelings that participants faced as “don’t know what to do” (*mi-ru-ja-rong-pleng-ari-rai*). The third theme describes how the participants dealt with the problems, caregiving roles under the heading “let’s try it” (*su-dai-tong-su-pai-kon*). The fourth theme reviews the exchange behaviors of stroke caregiving networks under the heading “relying on each other” (*tang-kon-tang-are-sai-gun*). The fifth theme, describes the outcome of caregiving as “whatever happens, happens” (*ari-rai-ja-kert-mun-tong-kert*). The last theme is “when the time comes, there will be a way” (*teong-ton-nun-kho-me-tang-pai-dai*) that relates to the dynamic process of caregiving.

Table 4.1 A summary of themes

Themes/Structures	Patterns	Categories
1. No one else can do it. <i>(mi-me-krai-thum-trong-nee-dai)</i> ไม่มีใครทำตรงนี้ได้	• Motivation to be caregiver • Empathic feelings of valuing • Beliefs	• External motivation -Family’s decision -Patient’s decision -Economic decision • Internal motivation -From role and responsibility -From love and attachment -From feeling of guilt -From the relationships • Mixed motivations • To patient • To caregiver • In the previous life • In the present life • In the future life

Themes/Structures	Patterns	Categories
2. Don't know what to do (<i>mi-ru-ja-rong-pleng-ari-rai</i>) ไม่รู้จะร้องเพลงอะไร	- Being afraid - Facing difficulty - Being tired - Coming to accept (<i>tham-jai</i>) ทำใจ	- Being afraid of the new responsibility - Being afraid of giving poor care - Being afraid of medical procedures - Own health -From own disease -From disability - Emotional strain -Frustration -Cannot bear the demands -Feeling disappointment - Life change -Daily life change -Social life change -Working life change - Economic burden -Supporting all expense -Having no income - Care discontinuities from culture -Being shy in gender care -Having hierarchical issues - Physical tiredness -Not receiving regular help from others -Having multiple roles - Emotional tiredness -Being erupted of emotion -Becoming tolerant to emotion - Healing process -Positive thinking -Having past experience -Comparing with other -Consulting to other -Connecting to supernatural power by sensation (<i>Ti-pung- tang-jai</i>) ที่พึ่งทางใจ - Relaxing process -Changing attention -Keeping humor

Themes/Structures	Patterns	Categories
3. Let's try it (<i>su-dai-tong-su-pai-kon</i>) ผู้ได้ต้องผู้ไปก่อน	- Preparing to be caregiver - Building caregiving knowledge - Experiencing trial & errors of care - Trying alternative care - Seeking help	- Developing care skills -By coaching -By doing more -By evaluation - From health care professionals - From family member - From relative and friend - From own self - Caregiving flexibility - Caregiving errors - Using folk remedies to solve the cause of disease - Using herbs as a supplementary drug - Using traditional massage as a supplement - Complex care - Co-operative care - Supporting care
4. Relying on each other (<i>tang-kon-tang-are-sai-kun</i>) ต่างคนต่างอาศัยกัน	- Wanting to help (<i>num-jai</i>) (น้ำใจ) - Encouragement (<i>kum-lung-jai</i>) (กำลังใจ) - Exchanging caregiving	- Doing the best - Devotion -Direct devotion -Indirect devotion - From one's own self - From patient - From family member - From spiritual support - Balanced exchange - Imbalanced exchange -Control -Negotiation

Themes/Structures	Patterns	Categories
5. Whatever happens, happens (<i>ari-rai-ja-kert-mun-tong-kert</i>) อะไรจะเกิดมันต้องเกิด	• Positive outcome • Negative outcome • Neutral outcome	• Gaining knowledge, experience, love • Being aware of own health • Closer relationship • Being proud of caregiving • Having better life • Working • Income • Feeling of boredom • Stress • Seeing as it is (<i>Suth-ja-thum</i>) • Normalizing
6. When the time comes, there will be a way (<i>teong-ton-nun-kho-me-tang-pai-dai</i>) ถึงตอนนั้นก็必有ทางไปได้	• Planing for uncertain future • Finding new ways of care	• Preparing for patient's dying • Preparing for caregiver's dying • Preparing for family change • Finding a new primary caregiver/assistance • Finding a new way to deal with patient's deteriorating • Learning to modify care

Theme 1: No one else can do it (*mi-me-krai-thum-trong-nee-dai*)

The theme of “no one else can do it” shows how the stroke caregiving networks were set up. . The caregiving networks started from choosing a main person to be the primary caregiver by motivations, participating to be the web of networks by emphatic feelings of valuing the patient and caregiver and maintaining of networks based on their belief. The meaning of the theme “no one else can do it” was described the process of selection and decision to involve in caregiving network as there being no one among the network members suitable to do caregiving except the primary caregiver and the caregiving network members.

1. Motivation

Motivation is generally defined as something (external or internal to a person) that urges a person to act in a certain way. In a caregiving dimension, the motivation focused on choosing the primary caregiver. Any motivations that were predominated by external to the caregiver were considered as external motivations, whereas other motivations that originated internally from the caregiver’s thoughts were considered as internal motivations. The motivations that were predominated by both external and internal sources were categorized as mixed motivations. Under this theme, the individuals were motivated by predominant external factors, internal factors, and mixed factors. External motivation was related to three decisions, the family’s decision, the patient’s decision, and economic decision while internal motivation was related to the caregiver’s decision about his/her responsibility, and endurance. Mixed motivation integrated both external and internal motivation.

1.1 External motivation

In caregiving dimensions, the external motivation was related to three decisions comprising the family’s decision, the patient’s decision, and economic decision. The result reveals that the family’s decision was the predominant external motivation followed by the patient decision and economic decision. Six participants had external motivation from family’s decision while two participants were motivated by the patient’s decision. One participant presented the external drive from economic.

1.1.1 Family's decision

Family decision refers to the predominant motivation from the family in their search for someone who was suitable as a primary caregiver. On the definition of a primary caregiver, some participants said that a primary caregiver was the main person who stayed all the time with a stroke patient. A few participants defined a primary caregiver as one who provided all the direct care to the patient. Based on their understanding, families considered that a caregiver should be the one who could stay all the time with the patient and provide the majority of care to the patient. There were some other thoughts related to social and cultural expectation, such as gender and marital status which influence family's decisions.

With regard to family decision, four wives and one adult child, stayed with the patient all the time, were motivated to be the primary caregiver. Three wives provided direct care to patient because their adult children were out working. One wife took care of patient in stead of her son who passed away. These five participants who participated in this study indicated that there was no other person as suitable to be as the primary caregiver whom they chose. Even though some caregivers were elderly or disability and had their own health problems, family members still chose them because there was no choice. For example, Ms. May, a disabled person, had to do this role because there was no other person available in her family. Her sister had to take care of her husband with liver cancer and she worked outside the house, while her niece looked after her baby. The family asked a niece to take care of the stroke patient but she could not do that. Ms. May, the youngest daughter, was the only one left who could be a primary caregiver, although she was a disability person who could not walk.

“Although I was sick, I had to do that because of nobody else being available. Someone had to look after her baby and someone had some health problems. Other worked outside and came back around 10.00-11.00 p.m.”

“ป่วยก็ต้องทำ เพราะไม่รู้ใครจะทำ ข้างล่างก็ไม่มีใครว่าง ใช้นั่นก็ต้องดูลูก ตัวมันก็ไม่ถ้อยสบายคนนั้นก็ไม่ได้ว่าง นี่จะออกไปกว่าจะได้เข้าก็สี่ห้าทุ่ม”.

(Case # 13 pp. 225)

1.1.2 Patient's decision

Patient's decision refers to the needs of patient which motivate family member to be his/her caregiver. Two patients demonstrated

their needs to live in their own house rather than a daughter's house by refusing to eat and sleep. As a result, their families took them back to their own houses although these houses were small and poor environment for caregiving. For example, Mrs. Bee shared her story of external motivation from the patient's decision as follow:

“When my mother came back from hospital to my younger sister's house, she refused to eat anything. My younger sister called me to visit her and told me that she refused to eat. She was on strike. She wanted to go back home. She did not eat rice for ten days. She had no urination and feces. How could she survive? We sent her to the hospital again. After she had been admitted for 15 days, she asked me to bring her back home. She was also afraid of seeing someone die in the hospital. She cried and did not want to stay there. As a result, we had to take her back home.”

“แกกลับมาแกไม่ยอมกินข้าวกินปลา น้องสาวโทรมาบอกเจ้ มาดูแม่หน่อยซิ แกไม่ยอมกินข้าว แกประท้วง แกจะกลับมานี้ 10 วันแกไม่ยอมกินข้าว แกไม่ซื้อไม่เย็บ แกอยู่ได้อย่างไร ต้องส่งโรงพยาบาลอีก สรุปแล้วพออยู่ได้ 15 วัน แกรับจะกลับบ้าน แกกลัวด้วยข้างเตียงเดียวคนนี้ตายแกร้องไห้ แกไม่ยอมอยู่ จนต้องรับกลับมาอยู่นี้ แกอยู่นอนไม่ได้ แกประท้วง”

(Case # 01 pp. 18)

1.1.3 Economic decision

Economic decision refers to the financial motivation that influenced decision-making. The caregiving networks compared the cost between the private caregiver and family caregiver. A participant shared her story.

“(My friend) suggested that I hire a paid caregiver but I did not. It was very expensive. I said truthfully that it was expensive at 10,000 baht per month. She (the paid caregiver) came to stay with us. Her salary was 8,500 baht per month. On weekend, we had to pay for her food at 100 baht a day. My salary is not enough to pay for that.”

“เค้าแนะนำให้จ้างศูนย์ ของเราไม่จ้าง มันแพง พูดตรงๆ มันแพง เป็นหมื่นเค้าต้องมากินอยู่กับเราเงินเดือนแปดพันห้า เสร้าอาทิตย์ต้องให้ค่าข้าวอีก 100 เงินเดือนเราทำไหวเอง”

(Case #17 pp. 340)

1.2 Internal motivation

In caregiving dimension, the internal motivation is internally originated from a caregiver's thought that she/he is able to care for the patient and volunteer, to be a main person for caregiving. Ten participants made a decision to play this role relating to the caregiver's role and responsibility, love and attachment, feeling of guilt, and caregiver's endurance (*jum-jai*). Seven participants said their motivation came from their own role and responsibility, five participants were motivated from love and

attachment, while another two participants had the motivation from their guilty feelings.

1.2.1 From role and responsibility

Caregiver's role and responsibility are the commitment of caregiver to take care of patient. The participants described what made them recognize this responsibility. Five participants considered that the caregiver roles were the obligation for the adult children and were also appropriated to female role. Based on Thai social value, the adult children have the duty to respect and provide care to their parents. Mrs. Jun expected to her adult children's role as shown in her poem:

Being the dead wood, but hoping to be, a shelter,
 Being an elder, but hoping someone, a caregiver,
 Just like a supporter of children linked together,
 Being an auspicious person and staying for warmth.
 Not forgetting the helper during your difficulty,
 No matter rich or poor, having father and mother,
 Standing by the old whatever sickness or sadness,
 Hot or cool, you will blow and bless your elderly.
 Not talking painfully, being heartless,
 Bringing them to accrue merit, through generosity,
 Taking care with goodness and gentleness,
 Giving some rice as taking it before,
 Not allowing them to leave, but to be proud to be there,
 Respecting them is the heart's goal.

ถึงเป็นไม้ใกล้ฝั่งก็ยังหวังเป็นร่มใจ
 จะแก่เฒ่าสักปานใดก็ยังหวังได้พึ่งพิง
 ที่พึ่งทางใจลูกสิ่งพันผูกลูกชายหญิง
 อบอุ่นยามแอบอิงถือเป็นสิ่งมีมงคล
 อย่าลืมพระคุณที่เกื้อหนุนยามขัดสน
 จะรวยหรือยากจนปกใจล้นพ่อแม่มี
 ยามป่วยขอให้ลูกเฝ้ายามเศร้าลูกอย่าหนี
 ยามร้อนจะพัดวีหนาวเหลือที่จะห่อให้
 ไม่ว่าให้เข้าใจจะพาไปทำบุญทาน
 จะเลี้ยงท่านอย่างดีถ้อยวจีจะอ่อนหวาน
 หาข้าวตักใส่จานเหมือนอย่างท่านเลี้ยงเรามา
 จะไม่ให้ท่านไปไหนให้ภูมิใจว่ามีค่า
 พ่อแม่แก่ชราควรบูชาเป็นหลักชัย

(Case #10 pp.142-148)

The participants demonstrated their obligations to accept the caregiver role. For example, Mrs. Green shared her intention to adopt a caregiver role because she was the eldest daughter, while Mrs. Ho was a caregiver because of no one else to do it in the family. In addition, the participants talked about the caregiver role as suitable for adult children, especially woman.

“I was the eldest daughter. I thought that being the eldest daughter I should take direct responsibility for care of my mom. I usually did only the household work, so I had time and could take care of my Mom. Others younger sisters had to work and others had to take care of their own families. I thought it was better if I held this responsibility.”

“เราคิดว่าเราคนโต เราคิดว่าเราควรจะได้รับภาระตรงดูแลแม่ และน้อง ๆ เขาก็ไม่ได้ทำอะไร เราทำงานบ้านอยู่แล้วเราก็ดูแลได้ เพราะคนอื่นเค้ามีงานกันอยู่เค้าก็ทำงานของเค้าไป และเค้ามีครอบครัวกันหมดด้วย เราจะให้เค้าดูแลก็ไม่ได้ เราคิดว่าตรงนี้ดีกว่าเราทำเองดีกว่า”.

(Case # 7 pp. 66)

“Each of them had their own families. They were responsible for their own, there was no volunteer. If no one volunteered to do this, my Mom would not have any caregiver to take care of her. She had a daughter-in-law, but she rarely provided care to my Mom.”

“แต่แต่ละคนเค้าก็มีครอบครัวกันทั้งนั้น ตัวใครตัวมันไม่มีใครช่วยหรอก ถ้าไม่มีเราก็ไม่มีใครดูแล มีลูกสะใภ้เค้าก็ไม่ค่อยดูแล นาน ๆ ที”

(Case # 8 pp.250)

“The man is not like the woman in term of taking care or concern”.

“คืออย่างว่าผู้ชายไม่เหมือนผู้หญิงเนอะ การดูแลหรือการเอาใจใส่”.

(Case # 12 pp. 103)

1.2.2 From love and attachment

Going beyond the obligation to adult children's role, the participants described the unconditional love between the patient and primary caregivers. Five participants described the motivation that made them provide caregiving. The participants expressed themselves in these terms: She/he is my mother/father, and it is a blood relation. For example, Mrs. Lulu talked about her commitment to provide care although her father did not look after her when she was young.

“We had never left our parents. When they had some problems, we were at their sides to help them. When they had a difficult time, we went to visit and stay with them. It was the blood relation, so we never leaved them.”

“เราไม่เคยทิ้งพ่อแม่ เวลาแกมีเรื่องอะไร เอ้า..ออกหน้าอย่างนี้ ถ้าเรารู้ว่าแกมีอะไร เอ้าไปเราไม่ทิ้งแก มีแต่แกจะทิ้งเรา แกมีเรื่องอะไรเราก็จะไปเยี่ยมแก มันสายเลือนคนนะ คือเราไม่ทอดทิ้งแก” (Case #12, pp. 401)

On the other hand, one participant described her internal motivation from the perceptions of suffering to play a caregiver role. Mrs. Can had suffered from her husband's behavior in the past. He loved gambling. He was not concerned about his family and his own disease. When he had stroke, Mrs. Can got all of the burdens particularly the cost of care.

“I did not accept him because of his previous behavior. He was not caring for himself. He was not concerned for his family....He was happy while his family members were having a hard time. We were happy because I worked hard and had more money saved. He was distressed and took it out on me. Indeed, I was a receiver of all misery. He had happiness in my suffering. I suffered both from him and myself”.

“ยอมรับว่าช่วงที่เค้าดี ๆ เค้าไม่ใส่ใจตัวเอง เค้าไม่ห่วงครอบครัว.... ตอนที่ตัวเองมีความสุข ลูกเมียลำบาก แต่ในขณะเดียวกันลูกเมียสบายแล้ว พี่หาเงินเก่งเข้า เค้ามีความสุข เค้าเอาความสุขมาให้พี่ สรุปแล้วเราเป็นผู้รับทั้งนั้น มีความสุขบนความสุขของพี่ คือทั้งขึ้นทั้งล่อง” (Case #03 pp. 31)

1.2.3 From feeling of guilt

Another internal motivation was motivated from the feeling of guilt. Guilt is the feeling of self-awareness of bad thing in the past and it can produce a decision to do things differently. A participant shared her responsibility because she felt guilty for her behavior with the patient in the past.

“When she (stroke patient) was healthy in the past, I did not obey her and quarreled with her (crying sound and red eyes). When she was in critical condition, I regretted what I had done to her. I wanted to make it up by taking the best care for her (start crying)”.

“คือตะกอนที่เค้าดี ๆ เราก็ไม่ค่อยเชื่อฟังเค้าบ้าง ไปเถียงเค้าบ้างอะไรอย่างนี้ (เสียงเครือลงตาแดงขึ้น) พอเจ็บหนักก็เลยมาคิดได้ อยากแก้ตัวด้วย ก็พยายามดูแลเค้าให้ดีที่สุด (นิ่ง แล้วร้องไห้ออกมา) (Case # 6 pp.220)

1.2.4 From the relationships

Some participants felt conflict to be the primary caregivers. They presented their internal motivations from the relationship and the perceptions of suffering that care would bring. There were two sides of relationship

question in motivating participants to take on the role of caregiver. There were good or bad relationship to motivate for caregiving. Focusing on good relationship, Mrs. Eng shared her story about good relationship with her father-in-law in the past. She took a caregiver role although she did not provide care before.

“Sometime I thought about caregiving because I had never provided care to my father before. He passed away. However, I was willing to do that because my husband was so nice. He gave me many things that I wanted. Particularly, my father-in-law (the stroke patient) was also nice to me and he had sweet-talking with me all the time. He was a very good man”.

“บางครั้งฉันก็คิดเหมือนกันแหละ อะไรพ่อเรายังไม่เคยทำ แต่พ่อเราก็เสียไปแล้ว แต่เราก็เต็มใจเพราะว่าเราอยู่กับแฟน เขาก็ดีกับเราทุกอย่าง อยากได้อะไรเขาก็ให้ กับพ่อเขาก็รักเราดีเรียกลูกทุกคำเลย เขาก็ดีมาก”

(Case #05 pp. 44)

On the other hand, Mrs. Im shared her experience of a poor relationship between the patient and her in the past. She said the patient gave his pension to his cousin instead of his family. When the patient had stroke, Mrs. Im’s son took care of him. Her son went to work in other province. As the result, Mrs. Im had no choice but to play this role. She said she did it with resentment.

“Empty. He (the stroke patient) had already dispensed money to others. I was speaking truthfully. I provided care for him with resentment. Everyday, I did it with resentment. When he had money, he dispensed it to other. His cousin who received his money, did not provide any care or any help to him for four years”.

“หมด แจกเค้าหมด พูดเรื่องจริง ทำไปอย่างนี้ ถึงบอกตอนนี้นำไปด้วยความแค้น ทุกวันนี้ทำด้วยความแค้น มีเงินแจกเค้าหมด ทุกวันนี้พี่น้องที่แจกเค้าไป ไม่เคยมาดู 4 ปีแล้ว”

(Case # 9 pp. 120)

1.3 Mixed motivation

The mixed motivation is predominant from both external and internal motivations. The primary caregiver is motivated to play this role by more than one motive. Four participants described mixed motivations from both economic and caregiver decisions. Ms. Do and Ms Dee shared their experiences to use mixed motivation. With regard to economic decision, Ms. Do, a caregiving network member compared the ability of family member to make much more money between working outside than in providing care to the patient at home. As a result, family member, who earned much more money than the other, was still working while the family member, who worked a low-paying job, was deemed to be suitable to be a primary caregiver.

“In general, most people know that this disease cost much more money. The person earning money supported them. Someone, who made more money, should keep going on. Other who did not work, had to play a caregiver role instead”.

“ส่วนมากเค้าจะเป็นอย่างนี้ ถ้าเป็นโรคอย่างนี้ต้องใช้เงินเยอะ คนเค้าก็ต้องไปทำมาหาเงิน
คนหาเงินก็หาไป คนที่ไม่ได้หาเงินก็ต้องดูแล” (Case # 4 pp. 365)

For caregiver decision, Ms. Dee, a primary caregiver made a decision to quit her job because of her own problem. She evaluated the cost of care was reducing after her father died. Therefore, she played a caregiver role based on her need.

“Before my father passed away, the cost of care was high because both parent got sick at the same period. At this time the cost of care was reduced. I could retire from my job and had little money...I had a problem in my work. Every working place had a problem. I was also boring to people. People were jealous. When I had many more problems, I quit my job and the cost was reduced”.

“ก่อนคุณพ่อเสียชีวิตค่าใช้จ่ายเยอะเหมือนกันเพราะป่วยพร้อมกันสองคน ตอนนั้นค่าใช้จ่ายลดลง
ก็เลยออกมาดูได้ เราก็กหารายได้นิด ๆ หน่อย ๆ.....แต่ก็มีปัญหาที่ทำงาน ก็มีปัญหากุหลาบที่ละ
พี เรามั่นก็เบื่อกับ เบื่อคน เบื่อคนจู้จี้จรรยาอะไรอย่างเงี บางทีเรามีปัญหามาก ๆ เลย
ลาออก แล้วค่าใช้จ่ายก็ลดน้อยลงแล้ว” (Case # 4 pp. 38)

2. Empathic feelings of valuing

Empathy is to feel and understand what individuals feel and mean (DeVito, 1994). To empathize with individuals, there is likely to do in the same situation of a person.. Thai society consists of homogeneity of its people based on the collectivistic culture (Kespichayawattana, cited in Triandis, 1995). Thai people are praised and recognize one who helps each other in the community, such as participating in community activities, taking care of their elderly parents etc. In contrast, people reject the individuals who did not follow Thai social value. In caregiving situation, people recognize the individuals who follow Thai social value as a good man/woman. The goodness is the “*boon*” or “*ba-ra-me*” to increase help from others. The caregiving network members have emphatic feelings of valuing the patient and caregiver as the center of caregiving networks because of his/her goodness. The participants echoed that no one else can do that (except to do for the patients or the caregivers) because they respect and recognize he/she helps each other in the community (Case # 1, 9, 10), and he/she provided good care to the elderly parents (Case # 2, 11, 16). The caregiving network members described if he/she was another person, they would not provide help.

2.1 To patient

In caregiving network, patient has been described as the center of caregiving network because of his/her goodness. For example, Mrs. Im talked about her husband that he was a good leader of the community and elder club. He had many activities to serve the people in the community. When he had stroke, the neighbors have empathic feelings of valuing to willing help him as follow:

“(Neighbors) provide all help. They concerned and said that if uncle got poor conditions, please let them know. When the Po-tek-tung (charity organization) ambulance came here, the road was full of people. That day, he (the patient) got stroke and the road was crowded. Many people recognized (him).... He took a leader of both community and the elderly club in the past before....When someone had passed away, he walked around to receive donations for funeral care. This made him have a long life. It was his “*boon*”.

“(เพื่อนบ้าน)ให้ทุกอย่าง เลี้ยงส่งสาร...ป้าถ้าลุงเป็นอะไรบอกนะ แล้ววันนั้นรถปอ-เต็ก-ตึง มาคนเต็มไปหมด วันที่เป็นคนเต็มถนน คนนับหน้าถือตา....เค้าเป็นประธานชุมชนและ ประธานชมรมผู้สูงอายุ....เมื่อก่อนบ้านใครตายลุงก็ไปเรียไรได้เงินเป็นหมื่น ถึงยังไม่ตาย ใจ บุญของเค้า”.

(Case # 9 pp.297)

2.2 To caregiver

Some caregiving network members described that a caregiver was the center of caregiving network because of her/his goodness. The caregiver is the good man/woman who usually helps others in the community (Case # 1, 10) or the good children to take care of elderly parents (Case # 2, 11, 16). For example, Mrs. Jun did good thing to others in the community. In addition, Mrs. Porn talked about why neighbor helped her husband because of goodness of her son.

My mother is a person who provides extremely help to others. She has much *ba-ra-me*. I could not do as much as her because I selected some doing. She has many friends because she is sincerely, and honesty. She does not impose on anyone. Therefore, many people love her”.

“แม่พี่เป็นคนทีใครมีอะไรเค้าช่วยเต็มที่ใจคะ เค้าบารมีเยอะ เรายังไม่ได้ทำเค้าเพราะเรายัง มานั่งเลือกงาน เค้าจะมีตรงนั้นเยอะ ญาติมิตรเยอะ ความทีเค้าจริงใจเค้าซื่อ ไม่เอาเปรียบ ใครอะไรอย่างนี้ คนก็จะชอบกันเยอะ”

(Case # 10 pp. 412)

“We knew her family for 6 years. Lifting up and down on 1 a.m. or 2a.m., we always called her. She said my son was a good boy. If he was another, she would not help. She thought that if a bad son did not take care of his parents, why did she help him?”

“รู้จักกันตั้งแต่เค้ามาอยู่ตรงนี้ 6 ปี ยกขึ้นยกลง (ผู้ป่วย) ดีหนึ่งดีสองไปเรียกเค้าตลอด เค้าบอกว่าเห็น ลูกชายเป็นเด็กดี ถ้าเป็นคนอื่นเค้าไม่มาช่วยหรอก เค้าก็ถือว่าถ้าลูกเกรไม่เอา พ่อเอาแม่ เค้าจะมาช่วยทำไม”.

(Case # 16 pp. 490)

3. Beliefs

Beliefs are defined as the cognitive traits and conviction individuals have (DeVito, 1994). Relating to religious belief, ten participants believed that “whatever you do you must receive”. The meaning is that when a person does good (*boon*) or bad (*bab*) thing, these actions (*karma*) would return to the person. This belief provided a sense of awareness for the person not to do the bad thing. The participants demonstrated their beliefs in being the caregiver or network members as being based on three categories: in the previous life, in the present life, and in the future life.

3.1 In the previous life

Thai Buddhists believed that there was a previous life. A person will reborn after they die. If they did the bad things in the previous life, they will receive the outcome in the present life. For example, Mrs. Im believed that she did a bad thing to the patient in the previous life. As a result, she needed to be a primary caregiver to pay back to the patient in the present life.

“That was the bad *karma* between both of us in the previous life. I did not know what bad thing I had done in the past. We (the patient and caregiver) were as suffering as a couple (*ku wain ku karma*). When I was angry, I scolded him”.

“เป็นวิบากกรรมของเราสองคนทำมาแต่ชาติปางก่อน ชาติก่อนไม่รู้เราทำอะไรมา.....คล้ายๆ ลูกคู่กรรมกันมา บางทีโมโหด่ามันบ้างเหมือนกัน”

(Case # 09 pp. 351)

3.2 In the present life

The belief in the present life reflected to the result the results of past experience. During the caregiving process, the participants expected and evaluated caregiving as doing good or bad thing. Mrs. Best believed that caregiving was one of the good things by which she could be a role model to her children.

“That was the direct experience for my children to learn how their mother, aunt, and uncle behaved. Their psychological perspective will be considerate towards the elderly”.

“ก็ปลูกฝังให้ลูกมันเห็นด้วย แม่ ป้า ลุง มันทำอย่างนี้นะ จิตใจเค้าจะได้ใกล้ชิดคนแก่”

(Case #02, pp.55)

Moreover, Thai people believe that caregiving is an act that makes merit because we do good thing to our parents. In the Buddhist religion, merit making refers to good activities, made through thought, word, or deed. In caregiving situation, sometimes we do both good and bad. Our intention is to do good but sometime conflict occurs and produces strong feelings in both patient and caregiver. Mrs. Nid said she had done bad things, such as scolding the patient during caregiving process.

“Someone said that caregiving’s like making merit. But I think it is not. When she had been bad tempered for a long time, I would react to her. I scold her. I say truthfully I was not a good daughter. When my mother hit me, I hit her back. Why did I do that? Mom, I am sorry I did wrong to you. When I died, even the hell will not allow me inside.”

“บางครั้งใคร ๆ ก็ว่าทำบุญเหมือนไม่ใช่ ตายมุนรกเค้ายังไม่ให้อยู่เลย เอ็ดเค้ามั่ง อะไร เค้ามั่ง อารมณ์เค้าไม่ดีขึ้น ๆ เค้าเราก็ตอบมั่ง พูดตรง ๆ เค้าก็ไม่ใช่เป็นลูกที่ดีนักเมื่อก่อนนี้ เวลาอาบมาโมโหตีเรา เราก็ตีกลับ พูดตรง ๆ อู๊ยยเราทำอย่างนี้ทำไม แม่ขอโทษนะมันทำไปแล้ว คิดว่านี่ทำไม่ถูกนะ”.

(Case #14 pp. 231)

3.3 In the future life

The belief in the future life refers to expectations of the future or the next life. Mrs. Lala believed that doing the best in the present life would bring about a good outcome in the future.

“At this time there was nothing but I thought that was happening”.

“ตอนนี้มันยังแค่คิดว่าต้องมี”

(Case #12 pp. 237)

Not only does this doctrine apply in Buddhist, but also in Islamic religion, Mrs. Green believes that caregiving would make her happy in the future.

“Based on Islamic religion, if we provide caregiving to our parents, we would receive much more heaven. Heaven is under the mother’s feet”.

“ทางอิสลามเค้าบอกว่า ถ้าเราได้ดูแลพ่อแม่ เราจะได้สวรรค์มาก เพราะสวรรค์อยู่ใต้ฝ่าเท้ามารดา”.

(Case #7 pp. 231)

On the other hand, Mrs. Cat said she could not go anywhere because she was concerned about providing caregiving for her husband such as giving him his insulin injections, providing cooked food and so on. She hoped that she would get her freedom when the patient got well.

“If he recovers, I would not stay with him. He could go anywhere. If he wanted to come back home, he could come. If he wanted to go, he could go. I would be free to go anywhere whenever I liked much and I would not be of any concern to him”.

“คือถ้าเค้าดี เราจะได้ไม่ต้องมาอยู่กับเค้าแบบนี้ เค้าจะไปไหนก็ไป ของเค้าอยากมาบ้านก็มา อยากไปก็ไป อยากกินก็กินไม่อยากจะกินก็ไป แต่เราเป็นอิสระ หัวหกกันชีวิตของเราไม่ต้องห่วงทางนี้แล้ว” (Case #03 pp. 72)

In conclusion, stroke caregiving network was started by setting up the main person to be a primary caregiver with three main reasons while the people participated in caregiving network relating to their focused, and their belief in caregiving. How did the caregiving network maintain the wheel of caregiving? Most caregivers and caregiving network members, who were participants, explained their problems and needs during the process of caregiving.

Theme 2: Don't know what to do (*mi-ru-ja-rong-pleng-ari-rai*)

This theme “don't know what to do” portrays the picture of caregiving role transition that suddenly happened after the decision to be a primary caregiver. The current needs of caregivers and their coping strategies have been described within caregiving network. Four caregiving networks have two primary caregivers while fourteen caregiving networks have a primary caregiver for one network. The stroke caregiving is different from general chronic conditions of the elderly that involves progressive deterioration such as dementia. Caregiving duties for elderly with dementia are increasingly associated with cognitive and functional decline overtime. In contrast, stroke caregiving is suddenly required in contrast to other diseases because caregiving is a new situation in the family. In the wheel of caregiving, a primary caregiver is the main person to handle caregiving wheel while caregiving network members involve in social exchange behaviors to move the wheel smoothly. To start caregiving process, the participants may at first be afraid to provide care, they face difficulty, and are tired and, then they come to accept this situation.

1. Being afraid

Being afraid is the feeling of fear of being the primary caregiver. Three participants presented their fear in three categories: Being afraid of the new

responsibility, being afraid of giving poor care, and being afraid of medical procedures.

1.1 Being afraid of the new responsibility

Being afraid of the new responsibility refers to the attitudes and feelings to new caregiver's role. The participants shared their perceptions of fear. Although the caregivers had been prepared by health professionals before the patients were discharged from the hospital, the participant felt so stressed and had no confidence to provide care. For example, Ms. May shared her story on this situation, was stressed and fearful similar to her niece.

“I sat down and thought whether I could provide care to her or not. I thought to myself and cried....I always sat down with sadness for a week. My niece was also sad. At that time, her son was not born. I was only stressed, sad, and fearful. Fearful was the most. I was afraid that I was not able to take care of her. When she cried, I wanted to kill my mother in that time. Thinking about her dying and I died. I thought to kill her and kill myself. It stopped doing bad thing (*wain and karma*). I used to think like this because I had no idea how to provide care. She cried and cried. I had no idea how to respond. I did not know where she had pain.”

“นั่งคิดอยู่คนเดียวจะทำให้เค้าได้หรือเปล่า นั่งคิดอยู่คนเดียวก็ร้องไห้.....ตอนนั้นคิดมาก นั่งหน้าเศร้าตลอด เศร้าเป็นอาทิตย์... หลานก็เศร้าไปด้วยคอนันลูกของหลานยังไม่เกิด มีแต่ความเครียด ความเศร้า ความกลัว ความกลัวเป็นหนึ่ง กลัวจะทำให้เค้าไม่ได้ ตอนเค้าร้อง ตอนนั้นความคิดอยากฆ่าแม่ตัวเองให้ตาย ความคิดเค้าตายเราก็ตาย คิดอย่างนั้นฆ่าเค้าตายเราก็ตายซะ มันจะได้หมดเวรหมดกรรม เคยคิดอย่างนี้เพราะเราทำไม่เป็น เค้าร้อง ร้องทำไม่ถูก เค้าเจ็บตรงไหนปวดตรงไหนเราไม่รู้เรื่อง” (Case # 13 pp. 341)

1.2 Being afraid of giving poor care

Being afraid of giving poor care refers to being of providing care alone in the future. Most stroke caregivers have had training to provide care in the hospital. In fact, some primary caregivers were fearful and insecure about providing care alone at home. For example, Ms. Ree was afraid to provide the poor care and worried that her husband would have to be readmitted to the hospital. Mrs. Ree shared her experience to this situation and consulted her children.

“It was a difficult time, when we went back home. We could not provide care. I was not worrying about other things. At the beginning, I was afraid that if I provided care for him that was not good enough, he would be infected”

“หนักใจ...กลับไปบ้านคือเราทำไม่ค่อยได้ ไม่ได้หนักใจเรื่องอื่นเท่าไร แรก ๆ ก็กลัวทำไม่ดีเดี๋ยวเค้าคิดเชื่อ”
(Case # 18 pp.165)

1.3 Being afraid of medical procedures

Being afraid of medical procedure refers to the caregiver's fear of the complexity of care with many instruments. Stroke care consisted of caregiving for stroke and its underlying diseases such as hypertension, diabetes mellitus, heart disease and so on. Stroke caregiver faced not only providing care for the disability of stroke but also taking care of these chronic diseases. The participants provided insulin injections, tube feeding, airway suction, tracheostomy care, changing naso-gastric tube, inserting intermittent catheter, and retaining new urinary catheter. All participants were trained to do those procedures before the stroke patients were discharged to their homes. However, the caregivers talked about their fear to provide care to the stroke patients with these medical procedures at home. Two participants shared their experiences to the medical procedures.

“She (primary caregiver) told me about her injection and had bleeding. She was scared. I was scared too (loud voice). I got bleeding too. How did I do? Pressed it. The physician ordered to press it. You should much more. At the beginning, I accepted that I was afraid. I discussed with the physician to refuse injections for a long time”.

“เค้าเล่าให้ฟังว่าฉีดแล้วเลือดมันออก เค้าก็กลัว ภูก็เป็น (เสียงดังขึ้น) เลือดก็ออกเหมือนกันแหละ ทำไงได้กดเข้าไปซิ หมอสั่งให้กดเข้าไปก็กดเข้าไป แรก ๆ ก็กลัว ๆ เมื่อก่อนก็กลัวยอมรับ เที่ยงกับหมอตั้งนานไม่ฉีดไม่ได้หรอก”.

(Case #7, pp. 585)

2. Facing difficulty

Facing difficulty refers to the caregivers' perceptions and caregiving network members' thoughts to caregiving that usually come from the patients' disabilities and demands of care from the disease. There are many kinds of tasks that caregivers and caregiving network members do, such as the direct care, special care, indirect care on instrumental activities of daily living, and interpersonal care in providing emotional support. Difficult tasks of stroke care are contingent on the low competency of caregivers and caregiving network members to meet caregiving needs of stroke patients. Moreover, the physical, psychological, and socio-cultural changing

of the participants have been presented as the difficulty resulting from their own health, emotional strain, life change, economic burden, and cultural sensitivity on care.

2.1 Own health

Own health refers to the health conditions of primary caregivers. Some stroke caregivers also faced their own diseases, and disability.

2.1.1 From own disease

Fourteen caregivers had their own chronic diseases, such as diabetes mellitus, heart disease, hypertension, bone disease, and migraine. Some participants got sickness. They faced with difficult tasks when they provided care to the stroke patient.

“Sometime I was sick and I planed to do tube feeding for the patient at 8 a.m. I went to the health center for booking queue. The health center was nearby my house. I was in a hurry to receive medication because I had to go back home on time for feeding.

“บางทีป่วย จะให้สาขางให้อาหารตอนแปดโมง เอบัตรไปขึ้นที่ศูนย์ ศูนย์อยู่ตรงนี้ เวลาเราป่วยเอามาให้หน่อย แห่ออาหารอยู่” (Case # 9 pp. 29)

2.1.2 From disability

A participant had bone disease and could not walk when she was young. She told about her difficulty from her disability to provide care.

“The health personnel of the hospital suggested that I use a bed. But if there was a patient’s bed, I could not do anything. I could not walk. If I used a wheelchair, I could not take anything. As I was on the floor, I could move a little. For example, when I made blenderized diet, I cut the vegetable in the bathroom. I boiled it in the electric pan at this corner before I blended all together”.

“ที่โรงพยาบาลก็อยากให้มีเตียง แต่ถ้ามีเตียงทำอะไรไม่ได้เลย เพราะเราเองเดินไม่ได้ ให้เรานั่งรถเข็นก็ทำอะไรไม่ได้ อย่างนี้ยังพอกระเียบไปได้บ้าง อย่างเวลาปั่นอาหารเราก็หันผักที่ห้องน้ำ แล้วเอามาต้มที่กะทะไฟฟ้าตรงนี้แล้วค่อยปั่น”.

(Case # 13 pp. 45)

2.2. Emotional strain

Emotional strain refers to the psychological problems that happen during caregiver role. The participants made an effort to deal with difficulty and had emotion strain because of frustration, cannot bear the demands, and feeling disappointment.

2.2.1 Frustration

Frustration is the feeling of being upset or angry because of being unable to do anything about the problem. During the caregiving process, three participants talked about their frustration because they could not meet their goals of care. To solve the problems, the participants tried to put more energy and creativity into the difficulty they faced. The participants presented their frustration because they were unable to deal with the difficulties from poor co-operation and communication of the patient. For example, Mrs. Can felt upset and angry with poor compliance of her husband and her daughter echoed to the patient's behaviors

He did not co-operate with me. If he participated with caregiving, why I was so angry....Why did a family member ignore the patient if the patient had good compliance with the family? Whoever did not want her husband got well?

“เค้าไม่ร่วมมือกับเราไง ถ้าร่วมมือจะอาจจะดีอย่างนี้ม๊ย....ทำไมญาติผู้ป่วยเค้าถึงไม่เอาผู้ป่วย ถ้าหากผู้ป่วยร่วมมือกับญาติผู้ป่วย ใครจะไม่อยากให้สามีตัวเองหาย?”.

(Case # 3 pp.46)

“My father was so stubborn. For example, when my mother gave a medication to him, he said he did not take it at this time. My mother was so angry and stressed because of his poor co-operation... Sometimes his urine box fell down and made the floor dirty. My mother had to clean it up. When he had a bowel movement, he did not hurry to tell us but he excreted all dirty feces. Again, my mother had to clean it up and it made her angry and she scolded him but he did not say anything”

“พ่อดื้อมากอย่างเวลาให้ทานยา ก็บอกว่ายังไม่อยากทาน แม่ก็จะโมโหและเครียดมากที่พ่อไม่ร่วมมือ...บางครั้งกระบอกคอมฟอร์ดใส่ปัสสาวะหกเลอะไปหมด แม่ต้องมาทำความสะอาด บางครั้งถ่ายอุจจาระก็ไม่รีบบอก แต่ถ่ายออกมาเลอะไปหมด แม่ต้องทำความสะอาด ทำให้แม่โกรธก็จะว่าพ่อ พ่อก็ไม่ได้เถียงอะไร”

(Memo case # 3)

The frustration occurred and continued overtime between the primary caregiver and patient and this led to caregivers' withdrawal from caregiving. Mrs. Im clarified her feeling of withdrawal from taking care of her husband.

“My son lived by himself in Koh Samui. My niece stayed in Nakorn Prathom. It was difficult for me to care for him without any help from others. It was easy to talk withdrawal. In the nighttime, I could not sleep...for five years ago. Sometimes, when I started eating rice, I could hear the secretion sound (fod...fod) and bubble happened. I was sealing talking truthfully and that made me withdraw.

“ลูกชายอยู่เกาะสมุย อยู่ตัวเค้าคนเดียว หลานอยู่นครปฐมนี่มันลำบาก....ลำบาก ถึงบอกว่า
ถอดใจ...ถอดใจเลย พุดกันง่าย ๆ เลขนะ ถอดใจเลย กลางคืนก็ไม่ได้นอน บางทีข้าวเข้า
ปากปุ๊บ ฟืด..ฟืด เมื่อกี้เป็นโป่ง นี่พูดเรื่องจริง ถึงบอกถอดใจใจ”

(Case # 9 pp. 445)

2.2.2 Cannot bear the demands

Caregiving demand refers to the expectations placed on the stroke caregivers to care for the patients. The consequence of caregiving demand that was overloaded presented as emotional strain. The participants could not provide care to serve all the patients' needs or caregiving network members. Ms. May and Mrs. Nid talked about their emotional strain to these situations.

“Sometime I was so stressed because she always called me all the time. I did it but she cursed me. Just only did it. Sometimes she pushed the pillow off, but she said she fell down from the pillow. For example, she told me that her mouth was dirty from the food but there was nothing.”

“บางทีก็เครียดเพราะแกร้องเรียกตลอดเลย ทำให้แล้วก็ขี้ขลาดก็บอกว่าทำได้เท่านี้แหละ
บางทีแกก็ดันหมอนออกแล้วเรียกบอกตกหมอน อย่างเมื่อกี้แกบอกเลอะ ๆ อาหารหกเลอะ
แกทั้ง ๆ ที่ไม่มีอะไร”

(Case # 13 pp. 22)

2.2.3 Feeling disappointment (Noy-jai)

Feeling disappointment refers to hoping for but not receiving of understanding from others. In general, when the primary caregivers played a caregiving role, they needed others understanding of their difficult tasks. In contrast, the participants presented the feeling of disappointment in the patient or their caregiving network members. For example, Mrs. Ant kept her feeling from younger sisters who did not come to visit her but went to visit their husbands' families.

“Sometimes I was angry (with my younger sister). I did not speak and cry. I was angry with her why did she not come. She lived close to my house but she could go far away to visit her husband's parents”.

“บางทีโมโหมันไม่ด่าไม่ว่ามัน บางทีโมโหมันน้ำตามันก็ไหล บางทีโมโหมันน้อยใจ อยู่แค่นี้มันมาไม่ได้ บางทีพ่อพี่แม่พี่มันไปได้”.

(Case # 1 pp. 127)

2.3 Life change

Life change refers to the changing of caregiver's life after the participant adopted the caregiver role. All participants talked about life changes in three categories: Daily life change, social life change, and working life change.

2.3.1 Daily life change

Daily life change refers to experience of change in activities of daily living. Based on the schedule of caregiving, the participants provided the picture of caregiving from the morning to the nighttime. Some participants faced difficult tasks due to change in daily living, while other participants perceived these as normal.

“In the morning, I brought her to take a bath and went back to sleep here before I prepared my self to go out to work....I went back home at 5 p.m. If I saw her routine food, I would cook the new food for her...On weekends, I took care of her and this shop by myself....For the past six years, there was not any difficult in caregiving for me and I did it as a part of my activities of daily living”.

“เช้าก็เอาแกไปอาบน้ำ เสร็จแล้วเอามาอนตรงนี้ แล้วเราจึงอาบน้ำแต่งตัวไปทำงาน... กลับมาประมาณ 5 โมงเย็น บางทีเห็นแกกินจำเจก็เปลี่ยนทำให้แก..... ถ้าเป็นเสาร์อาทิตย์ก็รับหมศขายของด้วยดูแลด้วย.....ดูแลมา 6 ปีไม่มี (อะไรยากลำบาก) ก็ทำเป็น กิจวัตรประจำวัน”

(Case # 2 pp.176, 240)

2.3.2 Social life change

Social life change refers to experience of change in social activities. When going out, the caregivers were concerned about their patients and their difficult tasks because no one else could do it. Eleven participants described their social life changes. They changed their behaviors to not going anywhere, but if they had to go out, they would do it within a limited time. If they needed to go somewhere else, they could not stay overnight and there would be someone who could take care of patient, while they were away.

“We could go anywhere in the daytime. We did not stay out because we worried about his father. We just only went to his mother’s house in Prajinburi province”.

“ก็ไปได้กลางวันแต่ไม่เคยค้างที่ไหน เพราะเค้าเป็นห่วงพ่อ มีไปปราจีนไปบ้านแม่เค้า”.

(Case #5 pp.27)

Moreover, not only caregivers but also caregiving network members changed their social life. Mrs. Bee’s shared her story.

“For more than ten years in the past, I did not go to anywhere after my mother got stroke. At time, I went to travel because of my friend’s group. If I stayed home, I did not want to go any place. I did not go travelling anywhere. Sometime, my friend said I was stingy and wanted to stay at home for selling. I did not think about

travelling but I often thought to help my younger sister and younger brother. If I had time, they would relax from caregiving”.

“เป็นสิบปีแล้วที่พี่ไม่ได้ไปเที่ยวไหนนะ ตั้งแต่คุณแม่ไม่สบาย นาน ๆ ครั้งเพราะเค้าไปกัน เราอยู่ในกลุ่มนั้นเราก็ต้องไปด้วย แต่ถ้าอยู่เฉย ๆ แล้วฉันอยากไปโน้นฉันอยากไปนี่ไม่เคยคิด ไม่เคยคิดว่าอยากไปเที่ยว บางทีเพื่อนเค้ายังบอกว่ามันงก คิดแต่จะอยู่บ้านขายของ คือเราไม่ได้นึกถึงว่าเราอยากจะไปเที่ยว เราคิดว่าเราหยุดเราอยากช่วยน้องเรา น้องเราจะได้พักผ่อนบ้าง”

(Case # 3 pp. 321)

2.3.3 Working life change

Working life change refers to experience of change in working. Some primary caregivers had their own jobs. In taking care of the stroke patient, they faced difficulty and could not perform their duties. Six participants decreased their time for working while five participants quit their jobs.

“If he did not recover, everything was my responsibility. When he got better, he would go where he wanted. I could go early for working. I could earn much more than usual rate when I wrote the novel. At that time, I hurried to go out and hurried to come back quickly”.

“ถ้าเค้าไม่หายทุกอย่างอยู่ที่พี่หมด ภาระอยู่ที่เรา.. ให้เค้าหายจะไปไหนก็ไป พี่สามารถทำงานแต่เช้า เค้าสามารถจ้างพี่อัตรามากขึ้น ในกรณีเขียนหนังสือส่งเค้า นี่พี่ต้องรีบตลาดาเหลือกและตลาดาเหลือกกลับ”.

(Case # 3 pp. 49)

2.4 Economic burden

Economic burden refers to the financial problems when primary caregivers provide care for patient. The caregivers faced difficulty if they did not take care of the patient and family member needs. Eleven participants experienced helplessness or resentment when they had financial burden because of bearing all expenses in caregiving or having no income.

2.4.1 Supporting all expenses

Supporting all expenses refers to the responsibility to provide financial support. The cost of caregiving comprised not only medical costs but also the cost of daily living, transportation and so on. Five participants were the main persons to take care of stroke patient and provided financial support for all expenses in their families. For example, Mrs. Can presented her resentment on the financial burden when she paid for the high cost of traditional Thai massage to meet

the need of the patient. Although Mrs. Can had enough money to provide support, she felt financial burden because of her support for all expenses.

“He requested a Thai massage. I called a person to provide him with Thai massage. The taxi driver gave information to him and he wanted to go there. My children told me about the high cost. I said I wanted to support him. We paid three thousand baht each time. Three times were nine thousand baht. We paid ten thousand baht per period.... I took responsibility for all expenses of my family”.

“อยากนวดไทยเรียกหมอนวด แท็กซี่เค้ามาบอกเอง แล้วยกเค้าออกไป ลูกบอกแม่ เสียขายเงิน เลยบอกช่างเถอะ ก็อยากสู้ ไปแต่ละครั้งสามพัน สามครั้งเก้าพัน...ไปแต่ละครั้งเสียเงินเป็นหมื่น ๆ นะ ในบ้านทุกอย่างที่รับผิดชอบค่าใช้จ่าย”

(Case #3 pp. 29, 43)

2.4.2 Having no income

Having no income refers to the responsibility for providing care but not being able to support the cost of care. The participants talked about their financial burden because lack of income. They faced difficulty from the poor co-operation of patients. When the patient pulled off the feeding tube, the participant had to buy a new one for feeding. They had to ask for financial support from others because they were unemployed. Ms. May shared her experience.

“I was stressed because I had no income. I was an unemployed worker that made me stressed. I depended on other although she was my sister. I had to think about it because I did not have any work. Pulling off feeding tube with no reason made me more stressed. I was not happy, and not laughing. All the time, I felt suffering, fear, and such sadness”

“เราเครียดเพราะเราหาไม่ได้ เราเป็นคนหาเราเครียดเพราะเราหาไม่ได้ เราต้องอาศัยเค้า ถึงจะเป็นพี่ที่จริงเราก็ต้องคิดเราหาไม่ได้ ดึงโดยใช่เหตุเราหาไม่ได้ เราก็เลยเครียดไปอีก เราไม่เคยมีความสุขเลยตอนนั้น หัวเราะก็ไม่มี มีแต่ความทุกข์ตลอด ความกลัวความเศร้า ... คิดตลอดของเรา คิดโง่โง่คิดโง่โง่” (Case # 13 pp. 364)

Moreover, the participants presented their financial burden because they provided financial support not only for the cost of medical care of the patient but also the cost of living of the family members. Mrs. Im shared the financial burden of her niece's education and her food because she did not have enough money to provide support.

“The cost of medical care, 3000 baht, was divided each other (between her daughter and her son). It was that I did not know what to do.... There were the tuition fees for my niece and the cost of

food... Sometime, I cried, I was stressed. I did not have enough money for expense. I was stressed and he looked into my eyes”.

“อย่างค่าหมอ 3000 บาท หารกันไปคนละพัน มันต้องเป็นแบบนี้แหละ ไม่รู้จะร้องเพลงอะไรเลย.....ไหนหลานจะเรียนไหนค่าเทอม ไหนค่ากับข้าวอีก บางทีเราต้องให้ เราเครียดนะ เงินทองก็มีไม่พอใช้จ่าย เราเครียดนะเค้าก็มองตาเรา”

(Case #9 pp.42, 65, 224)

In contrast, some caregivers accepted to their caregiver roles and their decreased work income. Two participants said that they had less income but lived simply. Ms. Kan said that was enough for her.

“I am a seamstress, sewing fine work. When my father got sick, I had no time. I stopped working because this was a fine work. If I had no time, it was better to quit this job. Never mind, because I was a single.....He (my father) gave me 1000 baht per month (laughing). I thought I did not go anywhere and it was enough for me.”

“เป็นช่างปัก ปักชุดอะไร ๆ พอพ่อมาเจ็บตรงนี้ ไม่มีเวลาเลยตรงนี้เลยทิ้งไปไม่เอา เพราะถ้ารับงาน งานตรงนี้เป็นงานละเอียดนะ ถ้าไม่มีเวลาจริง ๆ อย่าทำเลย ช่างมันเราตัวคนเดียว.....เค้าแบ่งให้ไว้พนนึง (หัวเราะ) พี่ถือว่าไม่เที่ยวไม่อะไร พอใช้”.

(Case # 11 pp.51)

2.5 Care discontinuities from culture

Care discontinuities means caregiving that is broken, not smooth relating to cultural issues (gender, hierarchy) that could lead to discontinuity. Based on Thai social value, there are differences in gender and hierarchy in society. On gender role and expectation of participants, they believed that the primary caregiver should be the woman's role. From the hierarchical view, the children should respect and take care of elderly parents. The care discontinuities from culture had two categories: being shy in gender care and having hierarchical care.

2.5.1 Being shy in gender care

Being shy in gender care refers to the sensitive feelings of caregiver when he/she provides care for a patient of a different gender. This study found gender sensitivity as a personal preference. The participants' shyness in gender care consisted of being shy of patients, being shy of primary caregivers, and being shy of caregiving network members. Focusing on being shy of patients, the participants described that the patients did not want caregiving from a person of other gender because the patients were shy.

“Yes. She (the patient) was shy. Washing the body with soap, cleaning, and powdering.....I thought that nephew was a boy. Grandmother was timid. Just only sat down”.

“ค่ะยังอายอยู่ ตอนเช็ดตัวทำความสะอาด เอาแป้งโรย...เราก็คิดหลานเป็นผู้ชาย ขายก็อายเลยให้นั่งห่าง ๆ”.

(Case # 17 pp. 237)

Moreover, most Thai caregivers were female and faced difficult tasks from being shy to provide care for male patients. This situation was the same for the male caregivers who cared for women patients. For example, Ms. Bo talked about her younger brother who was a primary caregiver to his mother. He could not provide care in special areas for his mother and asked his cousin to change the diaper every noon.

“He was generally doing it. He was a man. He could not do that and could not change it (diaper). He’s a single. He had never done it before, he dare not to do it.....”.

“เค้าก็จะทำทั่ว ๆ ไปเค้าเป็นผู้ชาย ทำไม่ได้เปลี่ยนไม่ได้ เค้าไม่มีครอบครัว เค้าไม่เคยทำ ไม่กล้า.....”

(Case # 3 pp.3, 209)

2.5.2 Having hierarchical care

Having hierarchical care refers to providing care to persons with different status. Thai society has been developed from hierarchical status and relationship. Children should respect their parents while young people should respect senior people. For example, Ms. Lala blamed her brother about his bad words with her father although her father used to neglect his children in the past.

“My brother had conflict with father. He said he (father) had never looked after us. Why did he come back (to live) with us? My brother should not say that. We are his children. Whatever he may be and may be he never takes care of us but he is still our father. We should not talk like that”.

“พี่ชาย...เค้าเคยมีปากเสียงกับพ่อ พูดในลักษณะไม่เคยเลี้ยงลูก ทำไมมาอะไรกับลูก เค้าไม่ควร ไม่ควรพูด เราเป็นพ่อลูกกัน ถึงเค้าจะเป็นยังไง ถึงเค้าจะไม่เคยเลี้ยง เค้าเป็นพ่อเรา ไม่ควรพูด”.

(Case #12 pp.341)

This study illustrated that the participants faced difficulty when they violated to this norm. The participants presented two concerns with their caregiving: concern with religious beliefs and concern with images in society With regard to concern with religious belief, the children should respect their parents. They believe that their parents are as the monk in their houses and that most of their children should

respect in three ways: in behavior, words, and thought. For example, when the patient quarreled with her nephew, Mrs. Bee was angry with her mother and spoke loudly to her mother. Mrs. Bee said she would fall into the hell because of not speaking well with her mother. She was so sorry and brought a garland to ask her mother for forgiveness of her mistake.

“Sometime she (the patient) quarreled with the nephew. I asked her why she quarreled with him. She said “Her..Her”. I said mom made me fall into hell because I could not tolerate it and got angry with her.....On Mother’s Day, I bought a garland of flowers to respect her. Mom, please do not think about my behavior. Please forgive me. She said Err..Err”.

“บางทีแก (ผู้ป่วย) ทะเลาะกับหลาน แม่จะบู๊กับมันทำไม ร้อง เอ้อ เอ้อ แม่จะทำให้หนูตกนรก เวลาโมโหขึ้นมาเราก็คอดไม่ได้ พอถึงวันแม่อะไรอย่างนี้ ก็ซื้อพวงมาลัยมาไหว้แก แม่อย่าถือหนูนะ แม่ยกโทษให้หนูนะ แกก็เอ้อ...เอ้อ” (Case # 1 pp.16)

In addition, relating to Thai social values, Thai people are concerned about their image when it is different from others. Ms. May’s niece talked about the loud voice of the patient that made her shy when the neighbor asked her about what was happening in her family.

“My grandmother cried loudly. The neighbors, who were walking past, heard her voice. They asked about my grandmother. They thought that I did something to her. I said there was nothing”.

“ยายร้องเสียงดังมากจนชาวบ้านเดินไปมาได้ยิน ช้างบ้านเค้าก็ถามว่ายายเป็นอะไร เค้าคงคิดว่าเราทำอะไร ก็บอกเค้าว่าไม่มีอะไรหรอก”. (Case # 13 pp. 140)

3. Being tired

Being tired refers to the perception of exhaustion or weariness from caregiving demands. In taking care of stroke patients, the caregivers dealt with the physical impairments such as dysphasia, incontinence, constipation, and so on. Some patients were on a feeding tube, tracheostomy tube, Foley’s catheter, gastrostomy tube, cystostomy tube, and Hickman’s port for hemodialysis. Caregiving activities spanned a broad range from providing care for physical symptoms to psychological symptoms. Ten participants presented both physical tiredness and emotional tiredness.

3.1. Physical tiredness

Physical tiredness refers to the fatigue, exhaustion, and weariness of caregiver during caregiving. Twelve participants had taken care of their

patients from one to five years, while seven participants had provided care from six to ten years. Interestingly, seven patients had Barthel Index score as Zero which means they needed total dependent care. Eight participants presented with their physical tiredness to not receiving regular help from others and also having their multiple roles.

3.1.1 Not receiving regular help from others

Not receiving regular help from others refers to physical tiredness that came from doing care alone. Five participants presented that they mostly provided caregiving alone and received occasional support from caregiving network members. Mrs. Im shared her experience of taking care of her husband, and Ms. May talked about her tiredness in providing care for her mother.

“Oh don’t ask me. I am speaking the truth when I say that I am tired. Why am I so tired? Very, very tired! I am running alone. I am in a hurry to clean the tracheostomy tube, suction, and dressing...Others have lunch while I have my breakfast. I am dying. Tired. Very tired.”
 “I truly say I am tired. When my daughter went back home, she did nothing. She just slept. It was that. She thought that she provided financial support and so she did nothing”.

“ไอ้โฮ...อย่าถามป้าเลย อันนี้บอกตรง ๆ บางทีเหนื่อย ทำไมเหนื่อยจังเลย....เหนื่อยจริง ๆ เราคนเดียววิ่งไปวิ่งมา วิ่งมาวิ่งไป มาล้างท่อเจาะคอ ล้างสายยาง มีแผลท่อเจาะคอทำแผลอีก บางคนเค้ากินข้าวเที่ยง เราเพิ่งกินข้าวเช้า ชั้บบอกตายแล้ว อย่างนี้ตายแน่นอน เหนื่อย...เราเหนื่อยมากเลย” “นี่พูดเรื่องจริง เราเหนื่อย อย่างเค้านกลับมา อย่างลูกสาวกลับมาเค้าไม่ทำอะไรเลยเค้าจะนอนอย่างเดียว มันเป็นอย่างนั้นเค้าถือว่าเค้าหาแล้วเค้าไม่ทำอะไรแล้ว”.

(Case # 9 pp. 19, 454)

3.1.2 Having multiple roles

Having multiple roles refer to physical tiredness that came from many roles. The participants played the role not only a primary caregiver or caregiving network member but also the roles of wife/husband, daughter/son, mother/father and so on. Three participants presented their tiredness as coming from their multiple roles.

“In the morning, (I provide care to) the child, the older adult, and the dog. Everybody goes out. I must do it by myself. This (dog) follows me because he is hungry and cries (geui geui). He does not eat until my nephew has already eaten. When my nephew is asleep, I will take a bath that makes me comfortable. Then, I prepare food”.

“นี่ก็ด้วยเข้าขึ้นมาทั้งเด็ก, คนแก่ (ผู้ป่วย)แล้วก็หมา เค้าไปกันหมดก็ต้องทำคนเดียว ไอ้ฉันเดินตามหิวข้าว เจียว...เจียว ไอ้ฉัน (สุนัข)ไม่ได้กินให้หลานกินก่อน พอหลานหลับอาบน้ำอาบทำให้ใจเย็นก่อน แล้วค่อยหาให้กิน”. (Case # 15 pp.127)

3.2 Emotional tiredness

Emotional tiredness refers to the conditions of feeling overwhelmed or emotionally exhausted. Six participants presented as both physically and emotionally tiredness. Four participants felt erupted of emotion when they were exposed to the mood swings of the stroke patients and the emotions of caregiving network members, while two participants said they were able to tolerate these situations. The participants presented their emotional tiredness in two subcategories: being erupted of emotion, and becoming tolerant to emotion.

3.2.1 Being erupted of emotion

Being erupted of emotion refers to the emotional tiredness from angry feelings of caregiving. The participants talked about their tolerance to emotions of the patient during caregiving. They described their feeling of eruption with anger to the patient or caregiving network members. For example, Mrs. Nid presented the emotions within caregiving network members.

“At the beginning, we had good relationship. When the time went on, we each had emotions. She (my younger sister) acted to me with emotion and I reacted emotionally back to her”.. Sometime I shouted at her. I was violent and loud”

“ที่แรกก็ดี นานแล้วต่างคนต่างมีอารมณ์ เค้าก็ใช้อารมณ์กับเรา เราใช้อารมณ์กับเค้า.... บางทีฉันจะตะโกนเรียก ชื่นเป็นคน คุ้ยๆ เสียงดังด้วย”

(Case # 14 pp. 220)

3.2.2 Becoming tolerant to emotion

Becoming tolerant to emotion refers to emotional tiredness that presented as tolerance of caregivers with the emotions of patient and caregiving network members. The participants developed their abilities in becoming tolerant to bad emotions. For example, Ms May shared her experience to her mother's emotion.

“In the past, she did not do much scolding. When she got sick, she cursed too much and often called.”. “I am tired, but I must tolerate”.

“แกไม่ค่อยด่าเท่านี้ พอป่วยแกด่ามากขึ้น ร้องบ่อยมาก” “เราเหนื่อยแต่ไหนเราก็ทนนะ”

(Case # 13 pp. 105, 158)

4. Coming to accept (*tham-jai*)

Coming to accept or *tham jai* is the coping process to recognize of stroke caregiving and caregiver role. Stroke caregiving is a stressful experience for the caregiving network. Ms. May expressed her stress when her mother had stroke.

“I was frightened by her twisted mouth. I was so sorry and cried all night. I sat and lay down to look after her. We lived together. I could not accept it. We had two people but I had just only one. I could not accept it for myself and could not accept for her. Why did she change to this?.....Why did she get this (disease)? It broke my heart and did not accept it. I did not think that she got this (disease) before”.

“ตกใจ ปากเค้าเบี้ยว เสียใจ ร้องไห้ไม่ได้นอนทั้งคืน นั่งเฝ้านอนเฝ้าเค้า เคยอยู่กันสองคน ร้องไห้รับไม่ได้ เคยอยู่กันสองคนมาเหลือเราคนเดียว รับตัวเองก็ไม่ได้รับเค้าก็ไม่ได้ ทำไม่ต้องมาเป็นอย่างนี้...ทำไมต้องเป็นอย่างนี้ ใจสลายรับไม่ได้เลยไม่คิดว่าจะเป็นอย่างนี้”

(Case # 13 pp. 341)

The participants described the various styles to deal with this situation. They presented their behaviors to accept the role or *tham-jai* by the healing process and the relaxing process.

4.1 Healing process

Healing process refers to the coping process of the primary caregiver and caregiving network members to the stroke caregiving. Fourteen participants clarified their processes, such as positive thinking, having a past experience, comparing with other, consulting with other, and having a sense of connection to supernatural power (*ti-pung-tang-jai*)

4.1.1 Positive thinking

Positive thinking refers to a good attitude for caregiving. Two participants talked about their positive thinking to stroke care. Mrs. Porn said her husband was lucky because he did not pass away.

“If he (stroke patient) fell down in this area, he would end up (silence)...He was very lucky (long voice). He fell down and I could not help him by my hand . I woke up my son. Your father fell over mom!”

“ถ้าอีหล่นไปตรงนี้ก็จบเลย....(เงิบ) ยังบอกว่าอีโชคดีมาก อีหล่นลงมาเราเอามือรับไว้ไม่อยู่แล้วไง เรียกอีนี้ตื่น ตื่นเร็ว เต็มมึงลงมาใส่แม่แล้ว”.

(Case # 16 pp.353)

4.1.2 Having past experience

Having past experience refers to the caregiving experience of other people before. Four participants talked about their past experiences of taking care of elderly people with stroke or chronic disease. The participants recognized stroke caregiving as a normal life. For example, Mrs. Bell's niece and the eldest daughter had an experience to take care of her elderly neighbor with stroke.

“I loved to take care of the elder. Mrs. Best and I did it together. We provided care to the elderly stroke woman, who was our landlord. We lifted her to take a bath when we were young. My mother cooked food and we ate together. We carried her to go anywhere because of her poor visual field..... My mother was a role model of caregiving”.
 “เป็นคนชอบทำให้คนแก่อยู่แล้ว...เมื่อก่อนยายเจ้าของที่ป่วยเป็นอัมพฤกษ์ สองคนกับ (ชื่อลูกพี่ลูกน้อง) หามกันคนละข้างเอามาอาบน้ำ...เพราะแม่เค้าดี ๆ จะทำอาหารส่งกัน เมื่อก่อนทำกับข้าวก็เรียกแกมากินข้าวมัน ตามองไม่เห็นก็จูงกันไป เหมือนแม่เป็นตัวอย่าง”

(Case # 2 pp.211)

4.1.3 Comparing with other

Comparing with other refers to the coping process by comparison between two things/persons. Two participants presented their healing process by comparing with others, this can help them accept stroke caregiving role. For example, Mrs. Ree compared by asking other caregiver.

“I must *tham jai*. The doctor told me to make *tham jai*. The patient has a higher rate of readmission in the hospital. I must *tham jai* that is normal. I am luckier than other.....I have ever asked others who came to visit their patients in this (hospital). We talked together about how to take care, how to prepare the diet. Some patients were more severe than mine and others were better than mine”
 “ต้องทำใจให้ได้ หมอบอกแล้วว่าต้องทำใจให้ได้ คนไข้ต้องเข้า ๆ ออก ๆ โรงพยาบาลมีสูง เราทำใจว่าเป็นธรรมดา เรายังโชคดีกว่าคนอื่น....ก็ถามไถ่คนแถว ๆ นี้ ที่เค้ามาเยี่ยมกันก็ไปคุยกัน ดูแลยังไง ทำอาหารยังไง บางคนก็หนักกว่าเรา บางคนก็เบากว่าเรา”

(Case # 18 pp. 168)

4.1.4 Consulting others

Consulting others refers to the coping process by expression of problems and needs. Two participants consulted other for healing themselves. For example, Ms. Bo and Ms. Do consulted the doctor and tried to accept this caregiving while Mrs. Ree consulted her adult children about her fear of providing caregiving and her children helping her to bring patient to stay in the nursing home for ten days.

“I had no idea what to do and I dared not to do. I consulted my children on how to do that. As a result, we brought him to admit in the Golden Year (nursing home) for ten days. At the Golden Year, there were personnel and nurses to suction the secretion and so on”.

“เราทำไม่ได้เลย ทำไม่เป็น เราก็ก้าวไม่กล้าทำ ก็ปรึกษาลูกจะทำยังไง ก็เอาไปดูแลที่
โกสเด้นเยียร์ได้สิบกว่าวัน เขามีพนักงานมีพยาบาลให้เค้าช่วยดูแลผลให้ทำอะไรให้”

(Case # 18 pp. 40)

4.1.5 Having a sense of connection to supernatural power

Some Thai people believed in the supernatural powers. They described these invisible powers that could influence their lives. If they believe and respect to supernatural power that will make them peaceful lives and protect them from danger. The supernatural powers come from the unseen things that Thai people have faith in respected persons who have passed away, such as famous monks, members of the royal family. But also, the supernatural powers result from ghosts who could give bad things to the people. Three participants described a sense of connection to supernatural power (*ti-pung-tang-jai*) that made them tolerate and accept to caregiving situation. For example, Mrs. Cat believed in the power of the royal family.

“When he (the stroke patient) got sick, I prayed and told to the picture of King Rama V. that I could not tolerate to this condition”.

“อย่างเวลาเค้าป่วย ลูกรับไม่ไหว พี่บอกเสด็จพ่อรัชกาลที่ 5 บอกพี่รับไม่ไหวแล้ว”

(Case # 3 pp. 318)

On the other hand, three participants believed that stroke disease resulted from external cause. They thought that the stroke disease resulted from the supernatural power.

“Two years ago, when he had stroke, he cried *bo-niang-nung-nung-nung-bo-bo* at home and in hospital. My cousin evaluated that he took *klong* (receiving some power). He could not get well by this treatment. A woman, who provided massage to him, came from Buriram province. She told that was the Cambodian language. She translated the meanings of these words about brothers loved young brothers, young brothers love brothers”.

“เมื่อสองปีก่อนที่เค้าเป็นใหม่ ๆ อยู่ ๆ ก็ร้อง โบ-เนียง-นัง-นัง-นัง-โบ-โบ พูดยที่บ้านและที่
โรงพยาบาล ญาติที่เค้ามาบอกว่าลูกถูกของ มารักษาอย่างนี้ไม่หายหรอก พอฉันมีหมอนวด
เค้ามาจากจังหวัดบุรีรัมย์ เค้าบอกว่าเป็นภาษาเขมร เค้าแปลว่าพี่รักน้อง น้องรักพี่”

(Case #10 pp.178)

4.2 Relaxing process

Relaxing process refers to the process of coping with stressful situations. There were eleven participants who indicated the relaxing process that helped them accept to stroke caregiving and caregiver roles. The participants used various methods of changing attention, and making humor for adaptation.

4.2.1. Changing attention.

Most participants showed how they switched their attentions from caregiving. Seven participants changed the attention by going out, working more, reading a book; doing meditation; and using detoxication. For example,. Mrs. Im shared her experiences by reading newspapers and doing meditation.

“Everyone could go to anywhere but I could not do that because of taking care..... I was only doing meditation and praying.....(I love) reading the newspaper because I cannot follow the programs on TV shows. If I watch drama movie, I need to do it regularly and on time. When the patient is coughing, I needed to wake up to see him. It was not continuing that made me moody. I like to read news from the newspaper. I have time to read at noon”.

“เค้าไปเที่ยวที่ไหนเราก็ไม่ได้ไปมัวแต่อยู่.....นั่งสมาธิเอาสวดมนต์เอา..อ่านหนังสือพิมพ์ เพราะถ้าเราไปดูหนังมันไม่ติดต่อ คล้าย ๆ อย่างเราติดละครถ้าเราดูต้องติดต่อกัน พอคนไข้ไอก็ต้องลุกไปดู มันก็ไม่ติดต่อเดี๋ยวอารมณ์เสีย แต่หนังสือพิมพ์ชอบอ่านข่าว บางทีกว่าจะได้อ่านก็เกือบเที่ยง”

(Case # 9 pp.148, 155, 314)

4.2.2 Keeping humor

In Thai society, people love talking and making humor by symbol wordings with others in the society. Three participants talked about using humor within family and laughing with neighbors. Mrs. Quick and Mrs. Porn shared her humor with their patients.

“When he voided into the urine box, I (teased him by saying as in the Chinese movie) respecting you one tumbler (laughing). I will tease him by saying, “Respect one tumbler”

“บางทีนั่งอยู่ (เค้า) จี๋ใส่กระบอก เอ้า...การวะลื้อ 1 จอก ชื่นลื้อเค้าแล้วการวะ 1 จอก (หัวเราะ)

(Case # 16 pp. 554)

In summary, this theme illustrated the picture of beginning the process of stroke caregiving and caregiver role. The current needs of the participants were clarified through the situations of being afraid, facing difficulty, being tired, and coming to accept these situations.

Theme 3: Let's try it (*su-dai-tong-su-pai-kon*)

This theme reflects on the coping mechanism of the participants in dealing with their problems. "Let's try it" was described as the process of becoming familiar with standard care by developing caregiving abilities in terms of preparing a person to be a caregiver. In addition, the participants expanded their abilities through learning new knowledge to modify caregiving as the building caregiving knowledge. Moreover, the participants shared their experiences in errors and trying alternative care. When the participants faced their limitations, they learned how to seek help. This theme provided the picture of how caregiver and caregiving network members tried to do caregiving

1 Preparing to be a caregiver

Primary caregiver received discharge planning from the nurse of Ramathibodi Hospital and Neurological Institute Hospital before the stroke patient was discharged from the hospital. The participants developed their abilities in terms of both skills and knowledge to provide care for the patient.

1.1 Developing care skills

Developing care skills refers to the increasing of caregiving abilities for skillful care. Two participants showed how to change naso-gastric tube, and Foley's catheter by themselves while three participants provided suction via tracheostomy tube, and oxygen. Nine participants fed diet and seven participants prepared the blenderized diet daily by themselves. Five participants kept on dressing and cleaning tracheostomy and gastrostomy tube, while one participant provided intermittent catheter. On the developing skill process, seven participants received training by being coaching, while three participants tried to care by trial and error. Two participants talked about their skills having developed by much more doing and two participants presented their evaluations.

1.1.1 By coaching

The participants learned about caregiving by coaching. Four participants received coaching by a home care nurses and two participants learned from neighbor nurse while one participant had a family member as her coach. Mrs. Fang shared her story that she had her sister and home health care nurse to provide coaching her at the beginning of caregiving, while Mrs. Green shared

her experience in dealing with difficult caregiving tasks and was coached in giving injections for her mother by coaching by her neighbor (a nurse).

“At that time, there was my sister. She had ever provided care to her mother-in-law, who got the disease the same as my grandmother. She lived in a foreign country. When my grandmother was sick, she arrived in Bangkok.....She stayed with us and taught us how to care. She made us more confident to care”.

“ตอนนั้นมีพี่อีกคนนึง เคยเลี้ยงแม่แฟนเค้าเป็นลักษณะขาย เค้าอยู่เมืองนอก พอขายอาการไม่ดีเค้าเลยบินกลับมา....เหมือนเป็นพี่เลี้ยงให้เราคนนึง ทำให้เรามั่นใจขึ้น โหนทำให้ดูซิ”.

(Case # 6 pp. 304)

“When she needed to be injected with hemax (Epoetin alfa), I could not do that. There was a nurse who had her own business by giving nursing aid at home. She rented the office of my aunt. I asked her to teach me so that I could develop care abilities”.

“พอมาลิควิทยาทำอะไรไม่ได้ พอศิริตรงนี้เค้ามาสอนให้ เค้าเป็นพยาบาลส่ง nursery ตามศูนย์ดูแลผู้ป่วย เค้ามาดูแล พอดีเค้ามาเช่าห้องอาอยู่ เลยไปขอร้องให้เค้ามาสอนให้ก็ทำได้”

(Case #7 pp. 209)

1.1.2 By doing more

Two participants talked about their developing caregiving skills by doing/ practicing more. They presented their skilful caregiving in taking a short period of time, providing smart care, and becoming familiar with caregiving. Ms. Do and Ms. Dee shared their experiences of developing their skills for providing care in a shorter time.

At the beginning, it was difficult because I had never done before. I took a long time-one hour to complete caregiving I was not familiar with it enough to do by myself. I had to change her position. When I moved her, she slid her body down. I pulled her up... At this time, I took care for a short time half an hour to complete the care by myself”.

“ใหม่ ๆ ก็ลำบากเหมือนกันเพราะยังไม่เคย กว่าจะเสร็จมันช้า...มันช้ามากเลย ยังไม่คุ้นเคย ไม่ถนัดคนเดียวด้วย ต้องพลิกตัวเค้า พลิกไปพลิกมาตัวเค้าก็คอยแต่จะไหลลง ต้องคอยดึง ๆ ไว้...แต่ตอนนี้เร็วขึ้น อาบคนเดียวก็แค่ครึ่งชั่วโมง”

(Case # 4 pp.340, 346)

1.1.3 By evaluation

Two participants presented their skilful experiences that had been developed by evaluation of the outcome or the patients' conditions. For example, Mrs. Porn observed her husband's urine to provide intermittent catheter.

“The doctor of the hospital taught (me). If his bladder had bleeding urine, we would provide intermittent catheter. They prepared all the instruments.....If there was bleeding, I would provide intermittent catheter. If he does not get well, we must go the hospital”.

“หมอที่โรงพยาบาลสอนอีก พอกระเพาะปัสสาวะเป็นเลือดสวนเลย แก้วให้ (เครื่องมือ) มาเสร็จ ถ้าไม่จำเป็นถ้าไม่มีเลือดเราก็จะไม่สวน มีเลือดปัสสาวะ ๗ ติดมาเราสวนให้แล้วก็หาย ไม่ต้องไปโรงพยาบาล”.

(Case # 16 pp. 632)

2. Building caregiving knowledge

Building caregiving knowledge refers to the caregiving knowledge that has been developing in the home and in the community setting. All participants presented the learning process through which they developed from many strategies. Four participants developed their knowledge from health personnel, and two participants learned from family member, while one participant learned how to deal with caregiving from her relatives and a friend, and two participants created new strategies from their own ideas to provide caregiving that fitted their schedule and their life.

2.1 From health personnel

The participants clarified the knowledge gained through their shared experiences in informal learning at home from health personnel to provide effective caregiving. For example, Mrs. Green presented how she monitored the hypoglycemia of her mother because she gained this experience from a nurse (her neighbor).

“I had provided insulin injection of 20 units. She was fatigued but I still give her the same dose. The physician suggested that we use an instrument for blood sugar checking. That day, her blood sugar was at 50 (mg%). It was very lucky that a nurse, who was my neighbor, came here to provide an injection for Hemet. She touched my mother and found her body was cool. She checked her blood sugar and found that it was only 50 (mg%). She gave a little sweet drink to my mother until she got well. As a result, I was afraid to inject her and I had to check her blood sugar before injection”.

“เมื่อก่อนฉีดอยู่ 20 ทีนี้คุณแม่เค้าเพลียลงเราก็ฉีดอยู่เหมือนเดิม คุณหมอแนะนำให้ลองซื้อเครื่องวัดมาดูเราก็ซื้อมา วันนั้นฉีดไปน้ำตาลลงเหลือ 50 เอง ดิฉันมีพยาบาลตรงนี้จะให้เค้ามาดูฉีดเพิ่มเลือดนะ เค้าก็มาดูจับตัวคุณแม่ทำไมตัวเย็นจังเลย เค้าก็เลยเจาะดูตอนนั้นเหลือ 50 ก็คอยให้น้ำตาลจนดีขึ้น ทีนี้เลยไม่กล้าฉีดอะไรสุ่ม เลยต้อง Check ก่อน”

(Case # 7 pp.201)

2.2 From family members

Some participant shared their experiences of learning knowledge from family members. For example, Mrs. Kaew shared her experience of dealing with the communication problems of the stroke patient. She used her children's backboard so that the patient could write instead of speak.

“Sometimes, family members did not understand what he said and they were angry. They allowed me to ask him what he wanted. Sometimes I did not understand his words and changed to writing. I used a blackboard because of seeing it from my children's report. Goodness. I gained knowledge from my children”.

“บางทีคนในบ้านฟังพ่อไม่เข้าใจ นื่อง ๆ เล่าจะโมโห เล่าก็ให้เรามาถามว่าจะเอาอะไร บางทีเราก็อ่านไม่รู้เรื่องเอาเขียน ชื่อเพิ่มชื่อบอร์ดจากลูกเล่าทำรายงาน เออดีไว้ ได้ ความรู้หลาย ๆ อย่างจากลูก”.

(Case # 11 pp. 438)

2.3 From relative and friend

Two participants shared their experiences of developing knowledge from their relatives and friends who had the family members with stroke. Mrs. Jun shared her experience of her relative that had stiffness of the knee joint.

“If I did not massage him, his extremities would be twisted. I knew someone whose son worked in the National Bank. He had stiffness of the knee joint. When he passed away, his leg could not be extended because of stiffness.”.

“ถ้าเราไม่นวดไวนะ แขนขาบิด มีอยู่คนบ้านเดียวกันลูกทำงานแบงค์ชาตินะ เป็นมานาน เานี้จะตั้งขึ้นมาพอเสียแล้วยึดไม่ออก .ติดอย่างนี้เลยนะ..เราจะไปอาบน้ำศพเอาขาลงไม่ได้”

(Case # 10 pp. 166)

2.4 From own self

Some participants described new knowledge emerging during caregiving process by themselves. For example, Ms. Rose talked about how she developed her knowledge of communication. She provided the meaning of the stroke patient's crying and how to evaluate her father's consciousness.

“Sometime he cried. Crying might mean he was calling to us because he used to call my brother's name while staying with him in the past. When my brother asked him, he did not say anything. In my opinion, his crying needed to be heard and understood...”.

“บางทีเล่าร้อง ร้องเพราะอาจจะอยากเรียกเราก็ได้ เพราะเมื่อก่อนตอนที่พี่ชายนอนเฝ้า เล่าจะเรียกชื่อพี่ชาย พอพี่ถามเล่าก็ไม่ได้พูดอะไร เลยคิดว่าการที่เล่าร้องเพราะเล่าต้องการเรียก”.

(Case # 18 pp. 351, 395)

3. Experiencing trial and errors

During the caregiving process, the participants provided care following to the standard of care. Some participants shared their experiences of flexible caregiving and six participants talked about their mistakes in caregiving.

3.1 Caregiving flexibility

The participants arranged their caregiving process to appropriate with daily living. Some participants changed their tasks in the short periods while others were still kept ongoing their changing as a routine care. For example, Mrs. Cat changed the time of her caregiving to provide insulin for her husband while Mrs. Nid talked about the reason why she inserted naso-gastric tube for her mother instead of taking her to the hospital.

“I changed the time (to provide insulin injection). He (the patient) had breakfast at 11 a.m. I changed to provide injection at 11 a.m. and the next injection was postponed in the nighttime. When I discussed with the doctor, he changed the pill (of hypertensive drugs) from two tabs two times a day to four tabs a day?”

“พี่ชื้อนเวลา แทนที่เราจะกินเช้า เค้กกิน 11 โมงเราก็ฉีด 11 โมง กลางคืนก็ฉีดดึกหน่อย พอบอกหมอ หมอก็ปรับยาให้มั่ง.... 4 เม็ดเช้า เค้กไม่ทานหรอกค่ะ ไม่เป็นไรหมอบปรับให้ใหม่เป็นเช้า 2 เม็ดเย็น 2 เม็ด” (Case # 3, pp. 437)

3.2 Caregiving errors

Some participants talked about why they could not provide care and shared their experiences of mistakes in caregiving. Six participants described their errors in medication and nutrition.

3.2.1 Medical errors

Medical errors refer to mistakes in caregiving relating to providing medical caregiving, such as preparing medication, and following up at the hospital. Three participants shared their experiences on missing medication. For example, Mrs. Gaew talked about her error. Her mother should have had every eight hours to prevent convulsion. She forgot to give it to her and this made her convulsion.

“At that time, she was convulsing for an hour from missing her medication. She had anti-convulsion drugs every eight hours. I ironed the shirt while my sister sewed the cloths. I forgot to give her a pill. I planned to give it to her and my mother watched the

television. At 6 p.m., my sister asked me if I had given the medication to mom. No! Each of us forgot it and we hurried to give it to her at 6 p.m.”

“ตอนนั้นเป็นชั่วโมงเอาไม่ลง สงสัยจะขาดยาละ เพราะมียากันชักกินทุก 8 ชั่วโมง เรา ริดผ้าที่สาวก็เช็ดผ้า เราลืมไปเลย กะว่าเดี๋ยวจะให้ลืมไป แม่ก็นั่งดูหนัง จน 6 โมง มองหน้ากันถามบะให้ยากันชักแม่หรือยัง ลืมวะ ต่างคนต่างลืมก็รีบให้ตอน 6 โมง”

(Case # 7 pp. 403)

3.2.2 Nutritional error

Nutritional error refers to the changing of nutrition supports in terms of volume and composition. Some participants reduced volume of diet in order to prevent patient's weight gain because she could not lift the patient up. Moreover, a participant had a limitation to provide feeding diet while they were at the out patient department. As a result, the patient had not been fed when they went to hospital for follow up.

“In fact, I would feed the last meal at 10 p.m. but I did not feed. It was enough to my mother because I was afraid of her over weight and I could not lift her”

“จริง ๆ สักทุ่มเค้าต้องมีให้อีกมื้อหนึ่งแต่เราไม่ให้แล้ว พอแล้วแม่เราเรากลัวเรายกไม่ได้ไหว”

(Case # 17, pp51)

4. Trying alternative care

In Thailand, alternative medicine has been developed to provide treatment for the people from time to time. Thai people use alternative medicine to deal with their physical, psychological, financial and spiritual needs. Nine participants described their trying out alternative cares by using herbs, traditional medication, traditional massage, rituals, acupuncture, and an external power. The participants shared their experiences of how they used alternative care in three categories: using folk remedies to solve the cause of the disease, using herbs as a major drug, and using traditional massage to supplement.

4.1 Using folk remedies to solve the cause of disease

Two participants identified using alternative care to deal with the spiritual problem. They believed that the cause of stroke came from external power. For example, Mrs. Jun shared her story of the stroke patient saying that stroke could not be cured by western medicine.

“When he had just got newly stroke, he cried “*Bo-niang-nung-nung-nung-bo-bo*” at home and in hospital. My cousin evaluated that he had taken *klong* (external power). He could not get well by this

treatment....I asked my daughter to go there (to meet with the expert). He was not a doctor. He did meditation and made merit water. After this ritual, the patient did not say it again”.

“ก่อนที่เค้าเป็นใหม่ ๆ อยู่ ๆ ก็ร้องโวยวายเนือง ๆ โวย ๆ ๆ พุดที่บ้านและที่โรงพยาบาล ญาติที่เค้ามาบอกลุงของ มารักษาอย่างนี้ไม่หายหรอก.....ให้ลูกพาไป... เค้าไม่ใช่หมอ เค้าทำพิธีให้เป็นน้ำเสก หลังจากนั้นหายไม่พุดอีกเลย”

(Case # 10 pp.184)

4.2 Using herbs as a supplementary drug

Some participants talked about using alternative care to solve the physical impairments and financial problems. In the past, Thai people paid for health care service from their own pockets if they did not work with the government or for a company. In 2001, the government implemented health insurance coverage to cover all Thai people. However, health insurance had limitation for some treatments, such as hemodialysis. As a result, three participants tried using herbs as a supplementary drug to improve the health condition of stroke patients. For example, Mr. Oat shared his experience on how to use herbs, Ms. Dee used herbs at the beginning of the disease, and Mrs. Can used herbs to restore his renal condition.

“I have constipation. I tried to use *ra-dom-pon* (Thai medicine), but it was not better. My neighbor suggested taking *bai-kaew*. He opened the bag and showed his medication. When I have bad symptom because of constipation, I will take four pills. It is better”

“ผู้ป่วยมีปัญหาท้องผูก ลองใช้ยาระดมพลแต่ไม่ดีขึ้น เพื่อนบ้านจึงซื้อยาระบายคราใบแก้ว มาให้ลองทาน (เปิดกระเป๋าทดลองให้ดู) ถ้าหากถ่ายไม่ออกจะทานประมาณ 4 เม็ด ระบายท้องได้ดี”

(Case # 15 memo)

In contrast, two participants talked about her rejection of herbs or traditional medications. Mrs. Ree did not want to use herbs although her husband had been using them before. She was afraid of a harmful outcome.

“Someone suggested me to bring the patient to some place for alternative treatment but I didn't. I took him to be treated at this hospital Why take a risk? I just said thank you for the information. Just listening!”

“มีคนมาแนะนำเราไปหาตรงโน้นตรงนี้ซิ เราเอามารักษาตรงนี้เรื่องอะไรเราจะเอาเค้าไปเสี่ยง เราไม่เอาคนไข้ไปทดลองยาหรอก.....ขอบคุณมากที่ให้ข้อมูล รับฟังเฉย ๆ”.

(Case # 18 pp. 176)

4.3 Using traditional massage as a supplement

The participants described using alternative care to meet the physical and psychological needs of stroke patients. Thai traditional massage has been popular among Thai people for relaxation. When people got sick, they needed traditional massage from a skillful person. Six participants demonstrated the use of traditional massage to improve physical impairments and prevent complications, such as edema, stiffness of joints. For example, Ms. Karn used traditional massage to her father's need.

“We are also using traditional massage and compression because there are no prohibited foods such as alcohol or pork. There is an older woman who earns her living by providing massage. I allowed her to provide massage for my father. Although it is expensive, the father has his pension.”

“ก็มีนวดประคบเหมือนกันเพราะไม่มีของที่เป็นต้องห้าม เหล้าหรืออาหารที่เป็นหมู ทุกวันนี้มีหมอนวดหาเงินเลี้ยงหลาน บางทีถามว่านวดมั๊ยก็เค้าจะหาเงินเราเห็นก็สงสาร นวดกันนวด.....ถึงจะแพงแต่พ่อเค้าก็มีเงินบำนาญเอาเงินของเค้า ใช้ไปเถอะ ไม่ต้องเอามาไว้ให้ลูกหรอก ลูก ๆ มีเงินเดือนกินกันแล้ว”.

(Case # 11 pp.171, 179)

5. Seeking help

When the participants tried providing caregiving, some had limitation in developing their abilities for care. Five participants talked about helping each other through dividing the task between two primary caregivers while seven participants divided care within caregiving network members, and there were six participants who needed help from others to overcome their limitations. The participants shared their strategies in complex care, co-operative care, and supporting care.

5.1 Complex care

Complex care refers to the caregiving abilities that the participants could not provide care by themselves. Four participants received help from health personnel monthly. For example, Mrs. Ree received help from home health care nurse to change new feeding tube for the patient at home.

“The home health care nurse of health center No. 40 provided a change of feeding tube every month. Prasat Hospital gave the referral letter with us and we brought it to the health center. The home health care nurse would come to provide a home visit and the hospital would follow up by calling the health center again”.

“เจ้าหน้าที่พยาบาลที่ศูนย์ 40 เข้ามาดูแลเปลี่ยนสายยางให้อาหารทุกเดือน ทางโรงพยาบาล
ประสาท เข้าเอาจดหมายให้เราไปขึ้นที่ศูนย์ แล้วทางศูนย์เค้าจะมาช่วยดูแลโดยทาง
โรงพยาบาลจะโทรศัพท์ติดตามมาที่ศูนย์อีกที”. (Case # 18 pp. 433)

5.2 Co-operative care

Co-operative care refers to caregiving abilities in which the participants could not provide care alone but they needed help in caregiving. The participants talked about co-operative care among family members, neighbors, health personnel, and personnel of the ambulance center. Seven participants received help for lifting the patients to take a bath, while six participants needed help with continuing treatment of the patients by going to the hospital or receiving treatment at home.

5.2.1 Co-operative care with lifting

In general, Thai people need to take a bath everyday. When the patients had stroke, the primary caregivers could not lift them for taking a bath daily. Four participants presented that they received help with lifting for taking a bath daily, weekly or monthly while three participants received help occasionally.

“Taking a bath was her big problem....The forth daughter’s husband was a policeman. He went to help her in taking a bath for him everyday in the past”

“อาบน้ำเป็นเรื่องใหญ่สำหรับเค้า คนที่ 4 ที่มีแฟนเป็นตำรวจ เมื่อก่อนเค้าจะมาช่วยอาบน้ำให้ลูกเค้าทุกวัน” (Case # 10 pp. 61)

5.2.2 Co-operative care to go to treatment

Another aspect of co-operative care was to take the patient to the hospital. Ten participants usually received help from family to take the patients while two participants obtained regular help from neighbors and two participants commonly used a hospital ambulance for transferring the patients to follow up.

“The second son was the one whom I called about following up for his father. He would drive to take him to the hospital”.

“มีลูกชายคนที่สอง โทรเรียกเค้าบอกพ่อจะไปโรงพยาบาล เค้าจะขับรถพาพ่อไปโรงพยาบาล”. (Case # 18 pp. 107)

Three participants stopped going to follow up at the hospital, however there were health personnel to provide home visit. For example, Mrs. Honey received checking up regularly from a physician and medical student because of her body weight being more than 100 kilograms. Moreover, Ms. Dee shared her experience of why she did not take her mother to follow up at the hospital.

“Mostly, we received medication from the physician who went to provide physical exam to my mom at home. My brother was driving to refill medication at Ramathibodi hospital”.

“ส่วนมากจะรับยาหมอที่เค้ามารวดที่บ้าน ส่วนใหญ่พี่ชายจะขับรถไปรับยาที่รามา”.

(Case # 8 pp. 62)

“No follow up. We bought medication by ourselves because we could not take her for follow up at the hospital...We brought her for follow up for a few years, but now we don't. It was terrible to get there. We lifted her from the car to the wheel chair and waited for an hour, but her symptoms did not improve. Whenever we went to the hospital, the doctor prescribed the same drugs. If we went there, we could reimburse the medical cost. To reduce the problem, we bought the same medication over the counter instead”.

“ไม่ได้รักษา ซื้อมาทานเองเพราะเอาไปไม่ไหว...ในปีสองปีแรกก็พาไปตอนเย็นหมอเค้านัด ทุกๆที อุ้มขึ้นรถไปนั่งรอเซ็นที่โรงพยาบาล แล้วนั่งรอเป็นชั่วโมง อาการก็ไม่ดีขึ้น ไปที่ไรหมอเค้าก็ให้ยามาปกติ ถ้าเราไปหาหมอเราเบิกค่ายาได้ แต่นี้คือปัญหาเลยซื้อมาเอง”.

(Case # 4 pp. 15)

5.2.4 Co-operative care in emergency condition

In Bangkok, the emergency medical care system (EMS) was set up to provide free emergency services for the patient. The first emergency center of the Ministry of Public Health, namely the Narenthorn Center, consisted of public and private hospitals as networks to provide basic life support and advanced life support. Nowadays, Bangkok Metropolitan has set up the Aerawan Center to provide mainly emergency service in Bangkok. The patients get free emergency services for transferring to the first hospital but they must pay for the cost of transportation to the second hospital or they have no acute problem. Four participants talked about their management in an emergency. For example, Mrs. Jun talked about help from her daughter who is a nurse to contact the public ambulance center.

“He had a convulsion at home. My mother called me and I told her to call Narenthorn Center because she stayed alone at home. If both of them went by taxi, the driver could not lift him. From my workplace

to home, it took more than half an hour. Therefore, I called Narenthorn Center to pick her up with no payment.”

“เค้าเกิดอาการชักที่บ้าน พอติเค้า(มารดา)โทรมาบอก จ๊นแม่ขอนแก่นเลย เรียกแท็กซี่เค้า อยู่คนเดียวไง แท็กซี่ก็ไม่ว่างจะหิ้วยังไง เราก็อยู่ตรงนั้นกว่าจะไปถึงครึ่งชั่วโมงกว่า แม่เรียก นเรนทรเลย แต่แม่พี่ไม่ได้เรียก พี่เรียกแทน บอกแม่เดี่ยวรถไปนะไม่มีค่าตอบแทนนะ”.

(Case # 10 pp. 569)

5.3 Supporting care

Supporting care refers to the caregiving abilities in support for disabled stroke patient and primary caregiver. Some participants presented their success in seeking help but others talked about their failure. The participants identified seeking help in supporting care: materials, money, and persons.

5.3.1 Materials

During the caregiving process, the participants needed some material support to provide care, such as a wheel chair, the patient's bed, and medical equipment. Some participants could pay for those materials by themselves, but some participants could not. Two participants talked about seeking materials support from neighbors and temples.

“The first time, we discussed about the bed. There was a nearby house, where her father passed away. She allowed us to borrow and use her father's bed.”

“ก็คุยกันอันดับแรกเรื่องที่พักก่อนพยาบาลก็มาแนะนำให้ แต่นี้พอดีข้างบ้านพ่อเค้าเสีย ไป เค้าเลยให้ยืมตอนแรกจะซื้อแล้วอยู่ใกล้ๆ บ้านเนี่ย บอกว่าเอาเตียงมัยไม่ได้ใช้”

(Case # 5 pp.90)

“There was a hand-made wheelchair that my younger sister in law got from the temple. It was made of plastic and could not flex. It was difficult to put into the car. If the patient went outside, I had to borrow from others. I could not borrow a wheelchair from the community health center because there was nothing available”.

“รถแบบทางวัดเค้าต่อ พิงอยู่ตรงนั้น น้องสะกั้เค้าไปขอมาให้ เป็นโต๊ะพลาสติก หุบไม่ได้อะไรไม่ได้ เ็นอย่างเดียว ถ้าไปไหนมันก็ลำบากเอาขึ้นรถไม่ได้ ถ้าจะเอาไปไหนก็ต้องไปยืมรถเค้า เคยไปยืมที่ชุมชนแล้วมันไม่มี”.

(Case # 1 pp.167)

5.3.2 Money

The participants talked about the money support for disabled patients. The Ministry of Social Development and Human Security provides social welfare for eight categories. These categories are poor children and family, HIV and AIDs patients, children affecting by HIV and AIDs, registration of disabled

people, employment of disabled people, wheel chair and three wheeled motorcycle for disabled people, loans for disabled people, and financial support per month. However, some disabled people could access 500 baht per month in financial support while other did not receive it.

“I gave information to the Welfare by myself. She (home health care nurse) came to visit. The doctor came to visit and sent this information to register as a disabled person. I brought this document to the social welfare office and have earned money since then.”

“ไปแจ้งเอง เค้ามาคู หมอมาคูแล้วส่งเรื่องไปเป็นผู้พิการทำเรื่องเบิก ให้เราถือเรื่องไปที่สำนักงานที่สะพานขาว ได้มา 2 ปีแล้ว”. (Case # 16 pp. 36)

5.3.3 Persons

The participants shared their experiences to seek someone for help the primary caregiver. For example, Mrs. Jun talked about how she needed a helper for caregiving while Mrs. Ree described her housekeeper who was an old employee in her shop and wanted to help her with taking care of the patient.

“Someone suggested finding a person for help me. They perceived that I had heart disease and knee’s problems. At this time, *su-dai-tong-su-pai-kon-* (let’s try it) but there is a success to seek a person (to help me) later”.

“เค้าแนะนำให้หาคนมาช่วย เค้าเห็นฉันเป็นโรคหัวใจด้วย เป็นขาเป็นเข่าทุกอย่าง ตอนนี้อยู่ได้ต้องสู้ไปก่อน แต่ซักวันนึงก็ต้องหามาได้”.

(Case # 10, pp.175)

In summary, this theme provides the picture of developing caregiving. The participants changed their abilities to take caregiver roles and were exposed with many experiences during the caregiving process. Some participants developed caregiving abilities to provide care whereas others could not and need help. When the nature of many needs occur, caregiving networks stabilize and continue their caregiving processes by offering of social exchange behaviors.

Theme 4: Relying on each other (*tang-kon-tang-are-sai-gun*)

This theme provides the significant picture of caregiving activities among stroke caregiving network members. “Relying on each other” reflects to Thai culture in giving someone a hand. Thai people in agriculture contexts in the past have helped each other. “Relying on each other” is focused on wanting to help (*num-jai*), encouragement (*kum-lung-jai*), encouragement and an exchanging caregiving.

1. Wanting to help (*num-jai*)

Based on the Buddhist doctrine, Thai people believe in the next life. They thought that the people, who were born in the previous life, would be their cousins. They call each other brother, sister, aunt, uncle, grandmother, grandfather and so on. Because of this belief, most participants presented their empathy and wanted to help each other or “*num jai*” among caregiving network members. “*num jai*” refers to the willingness to help each other is presented as doing the best, and devotion oneself to others.

1.1 Doing the best

Doing the best refers to the commitment of the primary caregiver or caregiving network members to provide care for the stroke patient. The stroke patients are not only Thai people but also they are family members. Six participants presented their commitments to provide caregiving by doing it from the heart, doing the best as much as they can, and not deserting their patients.

“Caregiving is done from the heart. If they did not love enough to care, they could not do that. My younger sister told that she could not care although she had ever lived with my aunt before. Could not do that meant could not do that. We could not force her”.

“ของอย่างนี้ต้องทำด้วยใจรัก ถ้าใจไม่รักทำไม่ได้ อย่างน้องสาวแท้ ๆ เคยอยู่กับป้ามาตั้งหลายปี แก้ออกทำไม่ได้ ทำไม่ได้ก็คือทำไม่ได้ เราจะไปบังคับเค้าไม่ได้”.

(Case # 2 pp.67)

“Do what I can. Do the best as much as I can”.

“ทำเท่าที่ทำได้ ทำให้ดีเท่าที่เราทำให้ได้”.

(Case # 12 pp.351)

1.2 Devotion

Devoting refers to the objectives of helping each other. Based on religious belief, Thai people believe in the value of giving, namely “*boon*”(goodness). Thai people collect “*boon*” as same as the money in the bank. They devote their money, things, and energy not only by themselves as direct devotion but also by giving to someone as “*boon*” and transferring “*boon*” to others as indirect devotion.

1.2.1 Direct devotion

Direct devotion refers to direct experience for providing help, money, food and so on. The participants did direct devotion to the patients by helping them to make “*boon*” or make “*boon*” in the patient’s name. The

participants shared their experiences to prepare the context that patients could offer food, money to the monk by themselves. Three participants invited monks to go inside their houses to receive food from the patients at their beds, while three Muslim patients could make worship to Allah (*la-marche*) by themselves with help from the participants. These activities were the direct devotion experiences to the patients. In addition, seven participants brought the names of the patients to donate some money to the temple.

“Doing it everyday. When it is a time, I clean her body before *la-marche*. She sits down to make *la-marche* everyday and she has never stopped doing it. Moreover, she listens to religious teaching. She listens to teaching everyday..”.

“ทำทุกวัน พอถึงเวลาเราก็ให้อาบน้ำละหมาดให้ นั่งทำทุกวัน ทำตลอดไม่ขาด...มีนั่งฟังบรรยายแม่ก็นั่งฟังของเค้าทุกวัน.....” (Case # 7 pp.83)

“When I made merit, I allowed my mother to share it with me. Sometimes she donated her money to help the people in community together with me”.

“เราจะไปทำบุญหรือใส่บาตร ให้แจกมั่งอะไรมั่ง บางทีบอกแล้วว่าทำบุญนะ แกก็จะให้ตั้งไปช่วยงานเค้า”. (Case # 1 pp.71)

1.2.2 Indirect devotion

Indirect devotion behavior is giving something from the participant to someone and transferring it to the patient. In caregiving dimension, the participants donate their money, and things as making “*boon*” to people. They believed that this “*boon*” could transfer to the patient. For example, Mrs. Ing talked about her children made the praying book for donation to people as transferring “*boon*” to the patient.

“Two children made merit for him. He made the praying book that made the sharp idea and had much more Boon. His son made a hundred praying books. He made them for his father”

“ลูกสองคนเค้าทำพอเห็นพ่อเค้าป่วย เค้าก็สร้างหนังสือสวดมนต์ สร้างหนังสือ ปิณญาแหลมปิณญาคมได้บุญมามาก ลูกชายเค้าทำอุทิศให้ ทำหลายร้อยเล่มแล้วไปแจกเป็นทานหมด” (Case # 9 pp. 205)

In addition, some participants talked about transferring their remaining aged to the patient. According to a tale in Buddhist legend, Phra Pom (similar to the God) built the human and allowed him to enjoy the world. The human had a lifespan

of 30 years and did not do any work. Phra Pom built the buffalo to work instead of the human for 30 years but the buffalo wanted to live only 10 years. The human requested to transfer the remaining 20 years from the buffalo to the human so that the human would survive for 50 year. When the human had much more treasures, Phra Pom built the dog to protect them for 30 years. Similarly, the dog wanted a lifespan of only 10 years and the human asked to have the remaining years transferred from the dog to make 70 years. Phra Pom built the monkey to make enjoyable to the human for 30 years but the monkey needed only 10 years. As a result, the human obtained a lifespan that increased from 70 to 90 years. Therefore, the human enjoyed their life in the first 30 years, working as hard as the buffalo from 30-50 years, stayed at home like the dog from 50-70 years and had fun like the monkey from 70-90 years. Correspondingly, the participants (Mrs. Nid and her youngest sister) wished to transfer their remaining years of life to the patient.

“If I knew that my mother would have the tracheostomy tube and not able to speak, I would not have allowed her to have the incision. Seeing her made me feel pitiful and suffering (crying with red eye). I did not know whether the children were selfish or not. My youngest sister prayed to the Buddha to reduce her ages by two years and transfer it to my mother. By the way, I was also praying to the Buddha to decrease my ages in order to increase my mother’s age”.

“ถ้ารู้ว่าเจาะแล้วอาม่าจะไม่มีเสียงจะไม่ให้เจาะ เห็นแล้วสงสารมันทรมาน (ร้องไห้ตาแดง รื้อ ๆ) ไม่รู้ว่าลูก ๆ เห็นแก่ตัวเกินไปหรือเปล่า น้องสาวก็ไปไหว้พระลดอายุเค้าสองปีให้อาม่า ขึ้นก็มาไหว้พระลดอายุชั้นให้อาม่า”.

(Case # 14 pp.495)

Going beyond the money, efforts or material goods, “*num jai*” (empathy and wanting to help) has been described in terms of doing the best and devotion to the receiver. The function of “*num jai*” depends on provider that perceives of different value. Some participant felt good to do that while others felt upset because of having no “*num jai*”. For example, Mr. Bo’s sister talked about providing some money as “*num jai*” for Mr. Bo when he helped her take care of mother and the shop. In contrast, Mrs. Cat talked about her devotion to help her husband but he did not agree with her caregiving. It was likely that he did not keep her “*num jai*” that Mrs. Cat made an effort to take care of him.

“In the past, he did not work. I gave him some money as “*num jai*”. I bought all things by myself. Specially, the cost of diaper was 1000 bahts per month”.

“เมื่อก่อนเค้าไม่ทำงานก็ให้เงินเค้าบ้าง ก็ให้ไม่มากเป็นน้ำใจเท่านั้น แต่ของเงินในบ้านซื้อหมด ทุกอย่างคนเดียว เฉพาะ pampers เดือนนึงเป็นพัน”.

(Case # 2 pp.182)

“I was empty. How’s it true? I worried to his condition but he did not concern about that. Why did I worry him? Why did I do that? (The patient) did not keep “*num jai* (between both of us). That was he did not love himself and why I still love him”.

“ความรู้สึกเราหมดเลย จริงมั๊ยคะ เราห่วงเค้าแต่เค้าไม่รักตัวเอง ห่วงเค้าทำไม ทำไปทำไป(เค้า)ไม่รักขนาน้ำใจกัน ก็เค้าไม่รักตัวเองแล้วเราจะรักเค้ายังงี้”

(Case # 3, pp. 16)

2. Encouragement (*kum-lung-jai*)

Encouragement refers to a type of support for psychological well being. Encouragement is the factor that mobilizes to the concept of “whatever happens, happen” In this study, encouragement consisted of three categories: from themselves, patients, family members, and supernatural power.

2.1 From one’s own self

The participant explained the encouragement “*kum-lung-jai*” that could be developed by oneself. For example, Ms. Rose shared her experience on how she built up her encouragement “*kum-lung-jai*” by positive thinking.

“Seeing everything is *kum-lung-jai* (encouragement). I need *kum-lung-jai*. My father also needs *kum-lung-jai*. Everyone needs *kum-lung-jai*. I can build *kumlungjai* by positive seeing. At least, we have taken care of him. We are luckier than others who faced sudden changes and their children have no chance to care for them. Now everything can happen. He is still living with us and we must give *kum-lung-jai* for him, so he is luckier than others. (He) gets sick but we have enough money to take care of him. Moreover, he is an older adult who is not the main worker in the family. Other are poor and family leader. When he got sick, he had more suffering”.

“มองทุกอย่างเป็นกำลังใจ เราต้องการกำลังใจ พ่อก็ต้องการกำลังใจ เราสามารถสร้างกำลังใจได้โดยมองด้านบวก อย่างน้อยเราก็ได้ดูแลเค้า เรายังโชคดีกว่าคนอื่นที่เป็นอะไรโดยกระทันหันโดยลูก ๆ ไม่มีโอกาสได้ดูแล สมัยนี้อะไรก็เกิดขึ้นได้ เค้ายังอยู่กับเราและเราต้องให้กำลังใจเค้าว่ายังโชคดีกว่าอีกหลายคน ที่เจ็บป่วยแต่เรายังมีฐานะที่พอจะดูแลเค้าได้และเค้าก็แก่แล้ว ไม่ต้องเป็นหลักในการทำมาหากิน คนอื่นที่เค้ายากจนเป็นหัวหน้าครอบครัว แล้วมาเจ็บป่วยยังลำบากกว่า”.

(Case # 18 pp. 355)

2.2 From the patient

Three participants perceived that the patient was the key person to encourage (*kumlungjai*) them. Mrs. Green, Ms. Fang and Mrs. Nid presented their similar encouragement (*kumlungjai*) coming from the patients.

“(Violating her mother’s hand) that was ok... She was a reason that I could not say anything. Sometimes I touched her hands and pressed them together. It could transfer from heart to heart. When she went to take hemodialysis, I would sit down beside her. She knew that I was there. We did not need words”.

“(เขย่ามือมารดา) แค่นี้พอแล้ว เค้านั้นแหละ มันบอกไม่ถูกนะ บางทีจับมือกันมีบีบมือกันไปบีบมือกันมา มันถ่ายทอดถึงกัน เวลาไปฟอกไต เราก็ไปนั่งข้าง ๆ เคื่ารู้ว่าเราอยู่ด้วย ไม่ต้องมีคำพูดอะไร”.

(Case # 7 pp.253)

2.3 From family members

The participants shared their experiences of exchanging encouragement among family members. Some participants could receive their encouragement from family members while other participants talked about not receiving any encouragement from their family members.

“(Kum-lung-jai) also came from my younger sister. We hug each other. When she was depressed, I would encourage her. When I felt sad, she spoke to give me strength”.

“จากน้องสาวด้วย ก็จะปลอบกันสองพี่น้อง บางทีเค้าท้อเราก็จะปลอบ บางทีเราท้อเค้าจะพูดให้เราเข้มแข็งขึ้น”.

(Case # 7 pp. 260)

“(Silence with looking at her husband) sound of crying...Focusing on *kum-lung-jai* (encouragement), It let me know that *kum-lung-jai* (encouragement) was truly like this. Sometimes I was too depressed to continue my life. (I understood) how someone could commit suicide by falling from building. The *kum-lung-jai* (encouragement) that others talked about was real”.

“(เงียบพร้อมกับมองไปทางสามี) เสียงครี้อ เรื่องกำลังใจรู้เลยว่าที่เค้าว่ากำลังใจเป็นจริงอย่างนี้เอง บางทีเลขท้อแท้อยากตาย ที่เค้าโคตรดีกลายเป็นแบบนี้เอง กำลังใจมันมีจริงอย่างที่เค้าว่า”

(Case # 6 pp.478)

2.4 From spiritual support

Three participants talked about their encouragement from their spiritual beliefs when they faced difficulty. For example, Mrs. Im shared her experience.

“I start practicing (meditation) by own self.....At first, I could take it only five minutes. Sometimes I could sit down for an hour.... Helping....This (meditation) could help me so much....In the past, I prayed on Chi-na bun chon. These made me clam. I wish I was healthy to do that. It was truly. The miracle happened”

“ก็ฉันเอง ทำเอง ตอนแรกนั่งได้ห้านาที บางทีทำได้เยอะ เมื่อคืนทำได้เป็นชั่วโมง
...ช่วยได้มากเลยคุณ สมาธิช่วยได้มาก..มาก..ก่อนนั้นป้าสวดมนต์ สวดคาถาจีนนะบ๊วย .
...มันสงบก็ได้ตรงนี้แหละช่วย ขอให้สุขภาพร่างกายเราแข็งแรงอย่าได้เป็นอะไร ก็คือเรื่อง
จริง ปาฏิหาริย์มีจริงนะคุณ (Case # 9, pp. 159)

3. Exchanging caregiving

In the dynamic process of caregiving, the participants made an effort to balance the exchange of providing and receiving caregiving between caregiver and caregiving network members. All participants shared their experiences of receiving caregiving and how they provided caregiving. Exchange caregiving encompasses balanced exchange and imbalanced exchange.

3.1 Balanced exchange.

Balanced exchange refers to the objective of exchange should be equal between providing and receiving care. For example, Mrs. Ho provided care to her mother and her mother helped her with taking care of her son. Moreover, Mrs. Jun's eldest daughter who is a nurse changed feeding tube her neighbor's mother for many years. When Mr. Jim (her father) got stroke, the neighbor helped Mrs. Jun to buy the food from the market instead of her everyday.

“I provided cleaning her body (the patient) everyday.....When my son was sleeping, I went to sell the food outside. I tied the rope with the cradle and asked her (the patient) to move my son's cradle. She could help me”

“เช็ดตัวเช็ดให้ทุกวัน.....ถ้าลูกหลับก็ออกมาช่วยเค้าขายของ เค้าเช็ดลูกเปลี่ยนให้เค้าช่วย
โกวให้หน่อย ก็ช่วยได้”. (Case # 8 pp. 278)

“The neighbor's housekeeper bought food by herself. She managed what kinds of food and bought it without orders. She prepared the fruits and desserts alternatively that made me satisfy. *Tang-kon-tang-arsai-kun* (relying on each other). Her neighbor's mother got stroke for seven years. My daughter provided changing her feeding tube every fifteen days. Her mother did not go to the hospital. We rely on each other”.

“เด็กบ้านนี้เค้าซื้อให้ เค้าจะจัดมาเลยวันไหนซื้ออะไรไม่ต้องจด เค้าจะจัดผลไม้ของหวาน เปลี่ยนมาให้ถูกใจ ต่างคนต่างอาศัยกัน แม่เค้าก็เป็นอัมพาตมา 7 ปี ลูกสาวเนี่ย ทุก 15 วัน จะไปเปลี่ยนสายยาง แม่เค้าก็ไม่ต้องไปรพ. เค้าอาศัยเรา เราก็คืออาศัยเค้า”

(Case # 10 pp. 54)

3.2 Imbalanced exchange

During exchanging caregiving, the participants set up the schedule of caregiving to control balanced caregiving. On the other hand, the participants talked about their experiences of imbalanced exchange and negotiated to keep balanced caregiving.

3.2.1 Control

The caregiving networks identified individuals to exchange caregiving by setting schedule of care. Some participants took care of the patients all the time as a primary caregiver while others provided caregiving regularly in daily, weekly, monthly, and yearly as the secondary caregivers. All of them are the caregiving networks and were prepared individuals to fit their abilities for exchanging caregiving. The caregiving networks agreed with their members to follow the schedules of caregiving as a control of imbalanced caregiving. For example, Mr. Bo talked about his responsibility to provide caregiving at the daytime while his sister exchanged to take care of the patient in the nighttime. Mrs. Gaew described her time to take care of her mother in the nighttime. When she went back home lately, there was a problem with her sister who provided care in the daytime.

“In the morning, I bought some food enough for eating for a day, and also bought goods for my shop. I had to be in a hurry back home before my sister went outside for working. My sister’s responsible for taking a bath for the patient every morning before she went to work and did it again after she went back from work. I was the only one who stayed with the patient during daytime. We routinely did it”.
 “เช้าก็ซื้อขนมไว้ก่อนเลย เช้าถึงเย็น ขนมน้ำและซื้อของเข้าร้านด้วย รับประทานอาหารก่อนที่สาวไป พอที่สาวไปแล้วต้องอยู่แทนแล้ว....ทำกันโดยอัตโนมัติ ตอนเช้าหน้าที่ผมละ.... ที่สาวเป็นคนอาบน้ำให้ก่อนไปทำงานและกลับมาอาบน้ำตอนเย็น”.

(Case # 2 pp. 7, 91, 98, memo)

3.2.2 Negotiations

Negotiation refers to the process of making a new agreement with others in which individuals or networks meet their objectives

(Johnson, 1993). Three participants described their experiences on negotiations between the time and caregiving. The participants set the new rule from their agreements to solve imbalanced caregiving. The process of negotiation started from the perception of imbalanced caregiving and searched to the new strategy for keeping balance of care among caregiving networks. When the participant agreed with these new ideas, they changed some caregiving to meet their objectives. For example, Mrs. Gaew shared her experience in changing time schedule to balance caregiving with her brother. In addition, Ms. Do talked about the new strategy by opening the store to increase financial support for caregiving network members after she evaluated that she was only one to provide financial support for caregiving.

“Today, my father had doctor’s appointment for two clinics, one in the morning and another in the afternoon. I worked at my shop while my brother took my father to follow up in the morning, and in the afternoon I took turn to take care of him. I asked my husband to close my shop in stead of me in the afternoon. My husband felt moody when he knew that my brother ordered me to buy a bottle of water for him. I negotiated to extend 5-10 minutes lately.”

“วันนี้พ่อมาตรวจ พี่ต้องขายปลาตุ๋นฟูที่องค์การเภสัชกรรมในตอนเช้า พี่ขายพาพ่อมาตรวจเช้า(และพี่ต้องพาตรวจบ่าย) พี่บอกแฟนให้มาช่วยเก็บของในตอนบ่าย แฟนพี่หงุดหงิดมากที่พี่ขายบอกให้พี่ซื้อน้ำดื่มที่องค์การเภสัชมาให้ด้วย พี่เลยบอกว่าถ้าอย่างนั้นต้องเข้าไปอีก5-10 นาที” (Case # 11 memo)

“My younger brother had no salary. My younger sister also had no salary. In the past, we did not buy anything; I played a role as the main responsible person and had a little money. When I opened this shop, we divided it to support my mother’s expenses in terms of commercial diet and medication cost. Opening this shop was to provide for mother. After we cut off this money, we gave the rest to both my younger brother and younger sister. It was not a wage. It seemed to be giving and taking.”

“น้องชายก็ไม่มีเงินเดือนน้องสาวก็ไม่มีเงินเดือน ตะกอนไม่ได้ขายของ พี่ก็เป็นคนรับภาระคนเดียว เงินก็มีบ้าง พอเปิดร้านขายของ สมมติเดือนนี้มีกำไรหมื่นนี้ เราหักเป็นค่าใช้จ่ายคุณแม่เลย อันนั้นนะค่านม ค่ายา ที่เหลือแบ่งกัน....ทำแล้วคุณแม่ได้ตรงนี้ที่เหลือแบ่งกันไม่ได้คิดเป็นค่าจ้างค่าจ้าง คิดว่าแบ่งกันใช้”. (Case # 4 pp. 135)

In summary, caregiving network members presented their empathy and wanting to help other by doing the best and devoting. The exchanging caregiving were balanced exchange and unbalanced exchange. The process of “relying on each other” portrayed what caregiving network did in the context of caregiving and the outcomes of caregiving were clarified in the next theme.

Theme 5: Whatever happens, happens (*are-rai-ja-kert-mun-tong-kert*)

This theme illustrates the outcome of exchanged caregiving. The participants presented that they accept the results as “whatever happens, happens”. There were positive outcomes, negative outcomes and neutral outcomes.

1. Positive outcome

Positive outcome refers to the experiences that are predominated from positive experiences. After the participants provided stroke caregiving, they presented their positive experiences on gaining, close relationship, being proud of caregiving, being aware of their own health, and having a better life.

1.1 Gaining

Gaining refers to the increasing of outcomes. Five participants presented their gaining of knowledge, experience, and love from caregiving.

“I gained the knowledge of caregiving for my mother by taking care of my grandparent. I could check their blood pressure and blood sugar. I could do that for them. It was very useful to gain the knowledge”.

“ก็เป็นประโยชน์ เอาความรู้จากการดูแลแม่ก็ไปดูแลยายกับตา ว่าความดันเค้าขึ้นมัยน้ำตาลได้เท่าไร ไปดูให้ได้ประโยชน์นะ”.

(Case # 7 pp.344)

1.2 Being awareness of one's own health

Some participants described the positive concern to their health status after they provided caregiving. For example, Mrs. Ree presented her fear of this disease and talked about her new-found awareness of food.

“Now, I am careful with food. In the past, he loved eating a high fat diet. He liked to eat the pig's head and allowed the children to buy it. I did not take it. The fried egg intake was decreasing. The high fat diet was not taken. Fear”

“ก็ตอนนี้ก็ต้องระวังในเรื่องอาหารการกิน เมื่อก่อนเค้าชอบกินมัน ๆ ชอบหัวหมู ให้เด็กไปซื้อ ชั่นไม่เอาเลย ไข่เจียวน้อยลงไปเยอะ ของมัน ๆ จะไม่เอาเลย กลัว”.

(Case # 18 pp. 220)

1.3 Close relationship

The participants presented their positive relations between the participants and patients. Five participants described their psychological attachment during the caregiving process. For example, Ms.Jun's daughter described her closer relation with the patient than in the past before.

“When he was healthy, I did not get close to him by touching his cheek, pinching the cheek, and bothering him. I am in the older generation that does not hug together. When he got sick, we became closer and playfully teased each other. In the past, I did not touch his body. When I cleaned his body, I teased him and pinched his cheek. I feel that my father and I are closer together”.

“ถ้าพ่อเค้าดี ๆ อยู่เราคงจะไม่ไปใกล้ซัดแตะแถมแถม ดึงแถม แหย่เหยอะไอย่างนี้ เรารุ่นเก่าจะไม่ไปกอดคลุกคลี...พอพ่อป่วย...แหย่เหยอะไอย่างนี้ เมื่อก่อนเราจะไม่ค่อยสัมผัสใจ สัมผัสเนื้อตัวเวลาเช็ดตัวแหย่ ไปดึงแถมอะไอย่างนี้ มันรู้สึกพ่อกับเราใกล้กันมากขึ้น”.

(Case # 10 pp. 645)

1.4 Being proud of caregiving

Some participants described the positive outcome of psychological well being. Three participants presented a feeling of pride in themselves because of their caregiving, and the feeling that other were proud of them. For example, Ms. Nid felt about herself to be a primary caregiver.

“I feel proud that I can do that. She (nurse) allows me to learn how to care. (I developed my self) from unskilled to skillful experiences”.

“เรารู้สึกภูมิใจที่เราทำได้ เค้า (พยาบาล) พาไปเรียน จากที่ไม่เป็นก็ต้องเป็น”.

(Case # 14 pp. 183)

1.5 Having a better life

Two participants talked about the positive outcomes that happened in their life. They described the invisible hand that helped them when they faced difficult problems. For example, Mrs. Kaew had many problems when her husband retired from his job. She had five children and took care of her father who got stroke. She believed that she had a better life from her caregiving.

“While waiting for the doctor, I went to have some food while my father lay (on the stretcher). What could I do while my husband was not working? I had to do it all by myself and my children needed to study. There was increasing expense. I tried to sell (goat) milk. I asked a merchant how to sell it in the cafeteria. She told me to contact the cafeteria club. I was lucky. I found this help. He (Allah) did not directly provide it to me but he indirectly gave me it through an invisible hand”.

“ระหว่างที่รอหมอก็เดินมาหาอะไกรกินให้พ่อนอนคอย จะทำยังไงนี้แฟนก็ไม่ได้ทำงาน แล้วเราก็คนเดียว ลูกก็ต้องเรียนมันต้องมีรายจ่ายเพิ่ม ลองมาขายนมดูซิ ไปถามแม่ค้าว่าเค้าติดต่อยังไง ก็ให้มาติดต่อสโมสร เราก็โชคดี ถึงบอกเจอแบบนี้ เค้าไม่ได้ให้เราตรง ๆ พระเจ้าให้เราอ้อม ๆ เหมือนกับมือที่มองไม่เห็น”.

(Case # 11 pp. 587)

2. Negative outcome

Negative outcome refers to the experiences that are predominated by negative experiences. Seven participants presented their negative outcome after they provided caregiving. The negative outcomes were reduced work, reduced income, no money no visits, feeling bored and stressed from many people and many ideas.

2.1 Working

The participants described the negative outcome in working. Six participants reduced their working time, while three participants were still working and provided caregiving. Mrs. Bo shared her experience of going work lately.

“I was often working lately because I was afraid that she would fell off from the bed. At the beginning, she often stood up. I waited for my younger brother to come back from the market before I went to work”

“เมื่อก่อนโฮ...สาขเรื้อยเลย เพราะว่าเรากลัวแตกเตียงไง เป็นใหม่ ๆ แยกคอยแต่จะดูก็ต้องรอให้น้องชายกลับจากตลาดมาก่อนแล้วค่อยไป”.

(Case # 2 pp. 166)

2.2 Income

Some participants presented the negative outcomes about income. Two participants talked about their negative experiences relating to reduce income from caregiving.

“She (the youngest daughter) reduced her income because she worked doing laundry. She stopped working”..

“น้ำเค็ดลด เพราะเค้าทำงานซักผ้าต้องงดไปเลย”.

(Case # 6 pp.602)

2.3 Feeling of boredom

The participant described the negative experience in taking a caregiver role. The participant felt bored because she stayed with the patient.

“I want to go back to work because I am bored living with this situation. ...I want to go back to selling because I just got some person to rent my shop that it is not much money”.

“อยากกลับไปทำงานเพราะอยู่อย่างนี้ก็เบื่อ อยากกลับไปค้าขายเพราะว่าให้เค้าเช่าร้านอยู่ไปเก็บค่าเช่าเป็นรายได้ไม่มาก”

(Case # 18 pp. 436)

2.4 Stress

Stress refers to the negative outcome of participant. Some participants expressed their negative experiences from many persons and many ideas.

“Stress...I don’t know how to say it. In the past, my mother and I stayed together, just the two of us. We had nobody else and no problems. When someone visited me, she said I was in a good mood. Now there are many persons. Just stress. It is not peaceful that I cannot tolerate it. Being serious and tense”.

“เครียด มันบอกไม่ถูก ก่อนนั้นฉันอยู่กับอาม่าสองคนไม่มีอะไร คนที่เค้ามาเยี่ยมยังบอก
ว่าฉันอารมณ์ดี.....แต่เดี๋ยวนี้มันอยู่กันหลายคน มีแต่เครียด คือมันไม่สงบอยู่ไม่ได้เลย ..
มีแต่เครียด ๆ ตึง ๆ ไปหมด” (Case # 14 pp.417)

3. Neutral outcome

The neutral outcome refers to the outcome that is predominated by both positive and negative experiences. Two participants talked about the neutral outcome in terms of seeing it as it is (*suth-ja-thum*) and normalizing.

3.1 Seeing as it is (*suth-ja-thum*)

Seeing as it is refers to understanding the meaning of life in that it consists of suffering and happiness. A participant talked about her opinion about caregiving. She felt both guilty and happy feeling to provide caregiving.

“I have more understanding in *sutchatum* (seeing as it is). I have much more understanding of my life. I had a thought that I did not provide any good care to her in the past before. I feel comfortable to take care of her by myself”.

“หนูเข้าใจเรื่องสังขารมากขึ้น....ได้เข้าใจชีวิตมากขึ้น....มาคิดได้.....เรารู้ดูแลเค้าไม่ผิดนะ
สมัยก่อน สบายใจที่ได้ดูแลเค้าเอง”.

(Case # 6 pp.423)

3.2 Normalizing

Normalizing refers to the meaning of caregiving as part of normal life. Two participants adopted caregiving in daily life and saw it as normal. They did not perceive it as a positive or negative outcome.

“Nothing. It is a normal, as I feel familiar with doing it. Really, I did not think that it was terrible. At first, I thought that I could not do that by my self. But ongoing caregiving, was not any burden”.

“ไม่มีอะไร ธรรมดาเหมือนอยู่กันจนชินแล้ว ...จริง ๆ ไม่คิดว่ามันลำบากอะไร ตอนแรก
คิดว่าเราจะทำไม่ได้ คิดว่าตัวเองทำไม่ได้ แต่ทำไป ๆ ก็ไม่เป็นภาระอะไรเลย”.

(Case # 6 pp. 439)

In summary, this theme presented the picture of outcomes of care during stroke caregiving. However, the wheel of caregiving is still moving through caregiving process as “when the time comes, there will be a way”.

Theme 6: When the time comes, there will be a way (*teong-ton-kho-me-tang-pai-dai*)

The last theme described the dynamic process of caregiving. The participants talked about the planning of caregiving when there had been changes in caregivers, patients, or families. In addition, this theme provided the picture of finding the new solutions to the same problems to continue caregiving.

1. Planning for uncertain future

The participants developed caregiving management as a dynamic process of caregiving in the future. Four participants talked about their planning and preparation for the patient's dying, the caregiver's dying, and family changes

1.1 Preparing for the patient's dying

The participants described planning of caregiving management for the dying of patient in the future. Two participants showed how they prepared for the patients' dying. One participant prepared the funeral care of the patient, such as pictures while the other prepared the patient to think about Buddha. Based on religious belief, Thai people believe that the people had a last thought before they passed away and that thought was to carry them to the good way. For example, Mrs. Lala often talked about Buddha to her father.

“I do not know. I do not curse. I do not know when he will pass away. I have talked to him about whether he is thinking of (Buddha). He says yes. I often talk to him of thinking as sleeping, thinking as waking”.

“เราไม่รู้นะ ไม่ได้แช่ง ไม่รู้ว่าแกจะไปตอนไหนหรืออะไรตอนไหน เคยบอกแกว่าพ่อนึกได้มัย ได้ หลับก็นึกตื่นก็นึกนะ” (Case # 12 pp. 219)

1.2 Preparing for the caregiver's dying

The participants presented their planning for the dying in the future. Two participants talked of caregiving management for the patient and herself if they passed away before the patient. Mrs. Kaew presented her planning to the next caregiver.

“I put it all (in this bag). When he (the patient) go to hospital, they can take it. This is preparing. Whatever there is to be done, needs to be prepare. I do not prolong life. I do not know what time I pass away”.

“ใส่ไว้ใน(กระเป๋า)นี้ให้เค้าไป เวลาไปหยิบเอาเลย นี่ต้องเพื่อ เพื่อไว้ ทำอะไรต้องเพื่อ คนเราไม่มีชีวิตอยู่ตลอด เราไปวันไหนเราก็ไม่รู้”.

(Case # 11 pp. 575)

1.3 Preparing for family change

Some participants planned of caregiving in the future for changes in the caregiving network. Three participants shared their opinions when there were changes of family members, and housing circumstance.

1.3.1 Caregiving network members

A participant talked about her planning in the future for providing caregiving to her grandmother and her aunt if her mother passed away before both of them. She felt a burden for her family to continue providing care.

“At the present, my stepfather has passed away. I worry about my mother’s health. If she gets worse and passes away, my husband and I cannot provide care to my grandmother and my aunt. It is a burden to both of us. I must take care only of my family”.

“ตอนนี้พ่อเลี้ยงเสียชีวิตแล้ว (หลานสาว)รู้สึกกังวลว่าถ้าแม่เป็นอะไรไปก่อน ตัวเองกับสามี คงไม่สามารถแบกภาระดูแลยายกับนี้ได้ คงต้องดูแลเฉพาะครอบครัวตัวเองเหมือนกัน”.

(Case # 13 memo)

1.3.2 Home

Three participants presented of planning to relocate in other areas in Bangkok or other province. For example, Mrs. Jun was worried about her youngest daughter planning to live in another province.

“She (the youngest daughter) plans to relocate at Trat province. She works at the Ministry of Labor. The town hall and her house are being close. At noon, she can see her father by walking.... My daughter wanted both of us staying with her. She talked about the good environment. Wherever it is, it is not a home, if you are not staying with the family. All members have known each other together along this Soi (alley)”.

“เห็นเค้า (ลูกสาวคนเล็ก)ว่าจะย้ายไปที่ตราด เค้าทำงานกระทรวงแรงงานใน ศาลากลางกับ บ้านที่ซื้อไว้มันใกล้ ตอนกลางวันเดินจากศาลากลางมาดูแลพ่อได้ แต่เค้าอยากให้เราไป เค้า บอกว่าอากาศมันดี มันอยู่ที่ไหนไม่เหมือนอยู่กับญาติพี่น้อง ตลอดชอยรู้จักกันหมด”.

(Case # 10 pp. 119)

2. Finding new ways of care

The participants find new strategies to solve the problem of caregiving. The participants identified the ways of care by finding a new primary caregiver or assistant and learning to modify care.

2.1 Finding a new primary caregiver or assistant

The participants described the strategy to solve the problem because of caregiver leaving. During the stroke caregiving process, three primary caregivers passed away before the stroke patients while two primary caregivers went to work in other provinces. The participants found new primary caregivers.

“In the future, if my mother passes away before my father, there is a person who will need to make sacrifices. I think that duty is mine because I am single.....Mostly, my younger sister and I are mainly the supporters because she has no children. We have talked together before. She says that she will retire. I say I will quit my job too. When that is the time, there is a way”

“มองไปในอนาคต เกิดแม่เป็นอะไรไปก่อนพ่อ ก็ต้องมีคนใดคนหนึ่งเสียสละ พี่ก็นึกในใจ พี่นั้นแหละเพราะพี่เป็นคนโสด.....ส่วนใหญ่น้องพี่คนที่แฟนเค้าอยู่ติดกับพี่ support กัน มากหน่อยเพราะเค้าไม่มีลูก เคยคุยกัน เค้าบอกชั้นจะลาออก พี่ก็บอกว่าชั้นก็ลาออกได้ ถ้าไปถึงตอนนั้นก็มีการไปได้”.

(Case # 10 pp. 679)

2.2 Finding new ways to deal with the patient's deterioration

The participants talked about the strategy to deal with deterioration of stroke patient. The participants find out the way of caregiving to deal with this situation by praying, accepting to change, and discussing it together.

“We hoped that he would pass away by himself. If we ignored him, it would be like killing him. It would be a sin of the mind. At that time, my daughter asked me to pray *Cheena-bun-chorn* for him. By the way, praying was carrying him when he passed away”

“อยากให้เค้าตายเอง ถ้าปล่อยเหมือนว่าเราฆ่าเค้า ก็เหมือนบาปทางใจอะไรอย่างเงี้ย วันนั้น ลูกสาวบอกสวดชินนะบัญชรให้เค้าหน่อย สวดนำทางเวลาเค้าไป”.

(Case # 9 pp. 187)

2.3 Learning to modify care

The participants described their finding new ways of cares which were faster and easier, and of adjusting task to fit the schedule and life

2.3.1 Finding faster and easier ways to care

The participants described their strategies to have feeding diet and cleaning the patients.

“I went to learn how to prepare blenderized diet. When I transferred my knowledge to my daughter, she helped me to prepare diet.”

“มาที่นี่มาเรียนทำอาหาร พอเรียนเสร็จแล้วไปบอกลูกสาว ลูกสาวเค้าก็ช่วยทำ”

(Case # 18 pp. 51, 409)

“I went to receive the blenderized diet at the hospital everyday. (The nutritionist) had already taught us but we had no times. (His family) had much more money to order the diet. That was more convenient and I went to get it every morning”.

“ไปเอาอาหารที่โรงพยาบาลทุกวัน (นักกำหนดอาหาร) สอน ๆ แต่ไม่มีเวลาไป แต่เค้ามีเงินมั่งใจก็สั่งเค้า สะดวกกว่า ผมก็ไปเอาทุกเช้า”.

(Case # 5 pp. 183)

“At the first time, we bought the bottled blenderized diet everyday at Bangpo hospital. There was a suggestion about this commercial diet. It was too simple and we did not go every day”.

“อาหารตอนแรกไปซื้อที่โรงพยาบาลบางโพมาเป็นขวด ๆ ไปซื้อทุกวันเลย ไป ๆ มา ๆ มีคนเค้าแนะนำก็ซื้อแบบนี้ (กระป๋องอาหารสำเร็จรูป) สะดวกดีไม่ต้องไปทุกวัน”.

(Case # 4 pp.190)

Moreover, two participants talked about modifying the cleaning of the patients. Mr. Boy shared his experience of using diapers instead of voiding training because he was afraid of an accident while Mrs. Porn said her neighbor gave her a piece of cloth from seamstress's working to clean the patient instead of toilet paper.

“Tissue was wasteful. She took care of her father but he was dead. She said she would bring some clothes to me.....Please let her know, if it was empty. Cleaned it and threw it away”.

“ทิ้งขุไปล้างตายเลย ข้างห้องเค้าดูแลพ่อเค้าแต่พ่อเค้าตายไปแล้วละ เค้าบอกเดี๋ยวหนูเอาเศษผ้ามาให้... หมดแล้วบอกนะเจ้ เช็ดแล้วทิ้งเลย”. (Case # 16 pp. 544)

2.3.2 Adjusting task to fit the schedule and life

The participants modified some caregiving because these cares did not fit the schedule and life, such as food, and medication. For example, Mrs. Porn shared their experiences of noncompliance with medication that was not appropriated to their meals.

“The doctor ordered three times but I gave (medication) for two times a day. At 10 a.m., he eats rice and takes medication. At 4 p.m., he eats rice and takes a pill”

“เค้าให้กิน 3 อ้วเหลือ 2 มื้อ.... ก็สับโมงกินข้าวแล้วให้ยา สับโมงกินข้าวแล้วให้ยาเท่านั้นแหละ”

(Case # 16 pp.588)

In conclusion, this theme provides the dynamic process of caregiving to adapt to the caregiving situation. The participants described their planning for an uncertain future and finding a new way of care that reflected to “when the time comes, there will be a way”.

The third section

This section described the network-exchange configurations of caregiving characteristics varying in stroke caregivers and caregiving network members to meet the objective of adequacy of caregiving. Based on social network concepts and social exchange theory, the participants described the difference of networks by three attributes: network attributes (e.g., size, homogeneity, and degree of connection,), linkage attributes (e.g. frequency of contact), and member attributes (e.g., gender, status).

1. Network attributes

Network attributes refer to the characteristics of individuals in the network that is different in terms of size difference of main caregivers, uniqueness of network, and degree of connection.

1.1 Size difference of main caregivers

The size difference of main caregivers refers to the different numbers of individuals who are the primary caregivers. The characteristics of the primary caregiver illustrate the picture of the potential for adequacy of caregiving. The size difference of caregivers is as follow:

1.1.1 Individualists

Most of participants described that there is a main person for providing caregiving all the time as primary caregiver. The participants talked about the caregiving exchange between the primary caregiver, secondary caregiver and other caregiving network members. Secondary caregiver had a specific role to provide regular care, such as making blenderized diet, doing laundry, driving to the hospital, and so on. However, some primary caregivers described that they had limitation of members of caregiving networks who played a secondary caregiver to provide regular care. As a result, they need to take responsibilities to all caregiving.

The significant characteristic is the separated caregiving and there is only one main person to take care of patient. This main person is the primary caregiver or secondary caregiver or caregiving network members. For example, Mr. Bo was the primary caregiver but he did not go to the hospital with Mrs. Bell. Mr. Bo's sister took care of Mrs. Bell instead of him by going to the hospital with Mrs. Bell by own self.

“We traveled by taxi together. When we went to hospital, there was a wheelchair. Sometimes her body (the patient’s body) slightly dropped (from the wheelchair) but she did not fell down. I ran quickly in time to prevent accident. I hurried by running from down stair in stead of using elevator”.

“นั่งแท็กซี่ไปกัน พอไปถึงก็มีรถเข็น บางทีแกก็นั่งไหลลงมาแต่พอดีไม่หล่น วิ่งทัน ก็ต้องรีบอย่างเดียว กระโดดเลื่อนก็วิ่งขึ้นไปเลย”

(Case # 2, pp. 224)

1.1.2 Collectivists

In contrast, some participants hold predominantly collectivism value to have many persons joined together in the same caregiving. Four caregiving networks have two main caregivers for taking care of patients (case # 5, 6, 12, 16). Two primary caregivers helped together at the same time to provide care or switched together in the time that they were not available. However, three caregiving networks have a team or clique (at least three members) joined together to the same caregiving, such as going to hospital (Case # 7, 14, 18). For example, Mrs. Fang talked about caregiving exchange between Mrs. Fan and her to take care of Mrs. Fly when she followed up at the hospital.

“I would check the documents and instruments. If it was not complete, I would errand to the physician office for new medications and instruments following to my record of lacking. I paid a role to connect with others while the youngest daughter of the patient would be here with the patient. For example, she went to lab for booking blood testing with the patient while I went to pay money for this testing. I had to pay money as the same day as blood testing. We would switch to have a lunch. When she went to eat, I would be here. When she came back, I would go there”.

“หนูไปเดินเรื่องเกี่ยวกับเอกสารได้ ไปโน่นไปนี่ได้ของครบหรือเปล่า ถ้าไม่ครบหนูจะวิ่งกลับไปหาหมออีกที บอกอาจารย์ว่านี่นะคะ หนูก็จะมีโพยของหนูด้วย คอยติดต่อให้ น้ำเค้าจะอยู่เป๊ายาย เราก็จะวิ่งทำโน่นทำนี่ อย่าไปเจาะเลือดแยกกันละ น้ำเค้าจะไปกับรถเข็นเราถือบิลวิ่งไปเสียเงินเพราะเดี๋ยวนี้เสียเงินวันเจาะเลือด แล้วมามหาน้ำเอาบัตรคิวไปเจาะเลือด อย่าที่ขงก็จะผลัดกันไปกินข้าว น้ำไปหนูจะเฝ้า น้ำมาหนูจะไปกิน”

(Case # 6, pp. 406)

1.2 Uniqueness of network

Uniqueness of network refers to the identity network. Uniqueness is the characteristic of network development resulting from goal of caregiving and composition of network.

1.2.1 Goal of caregiving

The goal of caregiving has been set up in caregiving network to guide of caregiving. In general, caregiving networks have a common perception to provide adequacy of caregiving. The caregiving networks set their objectives from their perspectives relating to beliefs and values. It was evident that the goals of caregiving are the same ideas with medical perspective but some networks were different from medical perspective, such as rehabilitation versus accident, bedridden versus moody, and hopelessness versus life long caregiving.

Rehabilitation versus accident

The caregiving network set up the goal to improve stroke patient conditions by changing home environment and searched some materials to use in rehabilitation. Home environment refers to the context of caregiving at home. All participants have a space for the patient in the living room while three participants have renovated the house such as rail, pavement, a new special room for only the patient (case # 5, 7, 12). In addition, materials are the instruments that have been used in caregiving, such as suction machine, oxygen tank, wheel chair, special bed for preventing pressure sore, or changing position and so on. These materials came from donating by family members or neighbors, buying by one self, modifying chair to move the patient from upstairs, and bubble syringe similar to bubble syringe of the hospital (Case # 2, 3, 4, 5, 6, 7, 9, 10, 11, 12, 14, 18).

In contrast, some participants aim to prevent accidents rather than rehabilitation. They were afraid of accident and did not want the patient to walk anywhere by own self. For example, Mr. Bo talked about how he prevented accident by using diaper.

“I changed a toilet. I made a rail for her but she did not use it. There was a walker but she could not tolerate to walk. I made the shoulder exercise machine but she did not use it. I had a wheel chair.....

...At first, she wanted to go to the toilet. She was shy. I told her about diaper that she used it. Didn't go anywhere and slept down”.

“ก็มีเปลี่ยนเป็นชักโครก ผมว่าจะทำราวให้แกเดินแรก ๆ ก็เดินไม่ได้ walker ก็เดินไม่ไหว เคยทำที่ออกกำลังกายแต่ไม่ได้ใช้ก็เอาออกไป มีรถเข็น....ตอนแรกแกจะเข้าห้องน้ำ อาย เออ ก็บอกว่ามี pampers อยู่ ไม่ต้องไปไหนนอนซม ดีแล้วลูก..... ”

(Case # 2 pp. 152)

Bed ridden versus moody

Seven stroke patients had Barthel Index scores of zero. For physician's perspective, the stroke patient with zero score was bedridden that was in the worst condition. If the patient was worst conditions, the process of stress was emerging in caregiving network members. Some participants felt so stresses and set their goals for intensive care. For example, Mrs. Nid said when her mother was bedridden, caregiving network members were isolated and did not join community activities. All of them had more emotions to each other. These experiences provide better understanding the process of stress starting after bedridden of the patient.

“In the past, she had a voice during speaking. She could nip when she was angry, stressful, and expressive. Now, she does not express. The past is better than now. She had an expression. Now, she seems to be drowsy. It is not drowsy but she is deterioration”.

“เมื่อก่อนแกพูดมีเสียงได้ แกจะหิกลได้เหมือนกับมีอาการเกรี้ยวกราด เครียด แสดงออก แต่เดี๋ยวนี้ไม่แสดงออก เมื่อก่อนต้องดึกว่าซี มีการแสดงออก เดี่ยวนี้เหมือนแกซึม จะว่า ซึมก็ไม่ใช่แกเสื่อม”.

“If someone stayed here, I could asleep. If there was nobody here, I would turn on television and kept an eye to her as much as I could tolerate”.

“ถ้าไม่มีคนอยู่ชั้นไม่กล้าจะนอน พอมีคนอยู่ชั้นพยายามจะนอน พยายามจะนอน ถ้าไม่มีคนอยู่ชั้นจะเปิดโทรทัศน์ จ้องแต่ตรงนั้นพยายามจะจ้องเลย จนชั้นไม่ไหวจริง ๆ”.

(Case # 14 pp.224)

In contrast, some participants compared the conditions of bedridden stroke patients were better than the patient with moody emotion because they faced difficulty to manage patient with moody emotion. When the patient was bed ridden, the participants could set the time schedule for the patient and for themselves. For example, Ms. Fang shared her opinion of stressful experience when her grandmother was moody. After she was bedridden and did not speak, caregiving network felt better to provide caregiving. These experiences made much more understanding the process of stress emerging before bedridden.

“Her bedridden status was better than newly condition that she was easily moody and shouting. We lifted her into wheelchair for taking a bath..... We were so tired for lifting. She complained too much. We were very tired.... In that time, it was lightly (loudly) more lightly than in the past before. Focusing on emotion, I was upset when she complained too much and lifting her...She was moody and shouting by bad word. Everyone was upset”.

“เค้านอนอย่างนี้ดีกว่าตอนที่เค้าดิ ๆ เค้าจะหงุดหงิดง่าย ช่วงที่เค้าลุกนั่ง...ต้องยกเค้านั่งรถเข็นไปอาบน้ำ... ตอนนั้นมันเหนื่อยมากก็ต้องยก แล้วเค้าจะบ่นอะไรอย่างนี้ ตอนนั้นเหนื่อยมาก..ก ตอนนี้อย่าว่าเบา เบากว่าเยอะเลย อารมณ์เราด้วย อารมณ์เสียเพราะเจอขายบ่นแล้วต้องยกอะไรอย่างนี้ เค้าจะหงุดหงิดโวยวาย ค่าอะไรอย่างนี้ คนในบ้านเริ่มจิตตก”.

(Case # 6 pp.320)

“In the past, when she (the patient) took some medication, she did not chew. When we gave much more food, she stopped opening her mouth. ...It was difficult and we had no idea how to deal with her. We were so stressed when she said she did not eat or doing against to us as a child. At this time, it was a time schedule to manage caregiving for her and ourselves”.

“แต่ก่อนกินข้าวกินยาอะไรเค้าจะไม่กินไม่เคี้ยว พอเราเริ่มป้อนแรก ๆ ก็กินหลัง ๆ ไม่กินไม่อ้าปาก เราไม่รู้จะทำยังไง เราก็หงุดหงิด เค้าไม่กิน ชื่นไม่กิน คือ ก็มีโมโหบ้าง ก็เหมือนเด็กเลย ตอนนี้เป็นเวลาแล้วเราจะบริหารเค้าได้แล้ว เราจะจัดการเค้าได้ ก็ไม่ทำอะไรแล้วเราจะรู้ตัวแล้ว เรายังจะแบ่งอะไรได้ถูกต้อง”

(Case # 6 pp.332)

Hopelessness versus life long caregiving

The physician viewed the patient with bedridden was hopelessness and did not plan for aggressive treatment. Some caregiving networks stopped going to the hospital but they still provided life long caregiving by reducing the complex care. For example, Ms. Dee shared her experience of her caregiving to her mother. Her caregiving network members did not take the patient to follow up but they bought the same medications by themselves. They allowed the home health care nurse to check up the patient's condition at home.

“Stopping going to the hospital but we bought the same medication by ourselves. (We could not take her to hospital) because of exhaustion...We had a wheelchair but we did not take her to sit down. This time, she could not perceive or sat down. As a result, we let her sleep in the bed for a long time...Ten years were a long time. Someone could eat food but she retained feeding tube for ten years. We had no hope because we had already discussed with the doctor. We only hoped that she would be here with me although she was bedridden”.

“ไม่ได้รักษา ซื่อๆทานเอง เพราะเอาแก่ไปไม่ไหว....เดิมมีรถเข็น เคี้ยวนี้ไม่ค่อยได้นั่ง..... ตอนนี้อย่าค่อยรับรู้ นั่งทรงตัวไม่ได้.... เลขต้องปล่อยให้อนอนอย่างนี้ ปล่อยมานานแล้วสิบปีนี่เยอะนะพี่ บางคนกินได้อะไรได้นอนให้สาขอย่างเดียวสิบปีมานี้ กับคุณยายก็ไม่หวังอะไรมากเพราะว่าคุยกับหมอ... เราก็หวังว่าเค้าจะอยู่กับเรานาน ๆ ถึงเป็นอย่างนี้ละ”

(Case # 4 pp. 58, 69)

In contrast, other caregiving network's perspective viewed that the bedridden condition reflected to the needs of patient and the caregiving network members should provide life long caregiving. For example, Ms. Fang shared her opinion about her grandmother (92 years). When she (the patient) was worse condition, the caregiving network would take her to the hospital for receiving treatment. They could not stop their caregiving although the physician had ever discussed with the caregiving members about goal of care. In caregiving dimension, the participants could not ignore to worse condition. That meant that they made decision of dead time for the patient (Case # 6), and it was sin to the family (Case # 9). Five caregiving networks kept on life long caregiving although the patients were hopelessness.

“If she slept and passed away, I could not provide any help. If she was breathing, I had to carry her to hospital. I could not ignore by not doing anything... In my opinion, If she wanted to pass away, she could die by natural. I could not make a decision instead of her. If she could not tolerate to this condition, that was her decision”

“กรณีที่หลับไปเองก็คงช่วยไม่ได้ แต่ถ้ายังมีหายใจอยู่ก็ต้องพาไป จะมาปล่อยทิ้งไว้ให้เห็น ๆ ได้ไง จะมานั่งดูตายได้ไง..ในความรู้สึกของหนูนะ ถ้าเค้าอยากไปเค้าคงไปเอง ไม่ใช่เราไปตัดสินใจแทนเค้า ถ้าเค้าไม่ไหวเค้าจะไปก็เป็นเรื่องของเค้า”.

(Case # 6 pp. 464, 475)

Above all, the hopelessness has been guided the caregiving network to exchange caregiving or not. Some participants continue to provide care as the same caregiving before. Relating to their belief, they could not stop caregiving because they were afraid of sin or made him/her die. In contrast, other participants thought that there was no hope to improve the patient's condition. They reduced the complex care that made them exhausted but they still kept on live long caregiving. These results provide more understanding the mechanism of uniqueness of network which has their own perspective relating to their beliefs and value.

1.2.2 Composition of network

The composition of network reflects to the uniqueness of stakeholders participating in caregiving exchange. In Bangkok, people consist of local residences and temporary residences. In inner area of Bangkok, people are local residences and participate in many activities. When a patient had stroke, there are caregiving exchange between family members and the outside family members. In

contrast of outer areas of Bangkok, people move from others to set the new community. The participants exchanged caregiving within their family members, others could exchange caregiving. The composition of network is different between family members and mixed caregiving members.

Family member network

This characteristic of network comprised of family members. The participants talked about the adequacy of caregiving and did not want any help from outside family. For example, Mr. Bo's sister and Ms. May talked about caregiving within their families.

“That was no need help from the neighbors because we had many relatives”

“ไม่ถึงจำเป็นต้องให้เพื่อนบ้านมาช่วย เพราะพี่น้องเราเยอะ”

(Case # 2 pp. 74)

“I thought that it was enough to living. (Finding help from neighbor is) noting. Mostly, we relied on each other”

“คิดว่าพออยู่ได้ไม่ลำบาก..(การไปขอความช่วยเหลือจากเพื่อนบ้าน) ไม่มี ส่วนใหญ่ช่วยกันเอง”

(Case # 13 pp. 94)

Mixed caregiving members network

Some participants had small size of family members and limitation for caregiving. They seek help from non-family members with whom they have known before. For example, Mrs. Im was well known in her community because her husband was the former leader of the community and both of them had participated in many community activities. When the patient had stroke, the neighbors provided help in many caregiving, such as lifting the patient from the taxi, giving some fruits for making the blenderized diet, providing some materials, such as cotton bud for dressing tracheostomy tube, and talking with caregiver for relaxation.

“The people knew (about our activities). On the Children's day, they asked me about participating in cooking many kinds of food. Both of us (patient and caregiver) were not tired. We did it more than 27 years. The people helped all. They were empathy and told that if the patient changed her conditions, please let them know”.

“คนชอยนี้เค้ารู้ทั้งนั้นวันเด็กที ข่ายครัวเลี้ยงเด็กมัย ๑๑ บางทีแกงเจียวหวานหม้อใหญ่

ข้าวต้ม สองหม้อใหญ่ สองคนผิวเมียไม่เคยเหน็ดเหนื่อย ทำมาแล้ว 27 ปี.....

(เพื่อนบ้าน) ให้ทุกอย่าง เค้าสงสาร ป้า..ถ้าลุงเป็นอะไรนอกนะ ”

(Case # 9 pp. 317)

1.3 Difference in degree of connection

Difference in degree of connection refers to the dissimilarity of connection in caregiving network. The degree of connection reflects to strength of caregiving between provider and receiver. This characteristic serves as psychosocial mechanism with intensity of network-exchange behaviors. The degree of connection is different between strong and loose connection.

1.3.1 Strong connection (*pook-pun*)

Strong connection (*pook-pun*) reflects to the intensity of connection. Five caregiving networks described the strong connection to involve social exchange behaviors. The participants illustrated the strong connection (*pook-pun*) came from the patient. For example, Mrs. Bell's daughter talked about the strong connection among caregiving network members.

“*pook-pun* (strong connection). She (the patient) is her aunt and two families are “*pook-pun*” (strong connection)”.

“ความผูกพัน เพราะเค้าเป็นน้ำ เพราะสองครอบครัวผูกพันกัน

“We were *pook-pun* (strong connection) and I did not want to go anywhere because of *pook-pun* between both of us. When she (the patient) got sick, we were stronger connection”.

“เราก็ผูกพัน ไม่ไปไหนเลย ก็ผูกพันกันอยู่แล้วพอขี้นป่วยก็ยิ่งผูกพันกัน”

(Case # 2 pp.233)

1.3.2 Loose connection

Loose connection refers to lower degree of connection among caregiving network members. Some participants provided care with loose connection with the patient. For example, Mrs. Lala shared her opinion why she had loose connection with her father who ignored her since she was seven year old.

“I have no feeling because he (the patient) gave birth to me. What a matter. I did not have any ideas. He got sick and no one else could do it. I could do that. No matter”

“ไม่รู้สึกละยังไงก็เค้าให้เราเกิดมา ก็แค่นั้นเอง ไม่ได้คิดอะไรมาก เค้าไม่สบายไม่มีคนดูก็ช่วยกันดูก็แค่นั้น...”

(Case # 12 pp. 196)

2. Linkage attribute

Relating to linkage attribute, the difference in frequency of contact is the interaction between provider and receiver by daily, weekly, monthly, yearly contact. The participants presented the adequacy of caregiving from regular contact. In

contrast, the participants described inadequacy of caregiving from occasional contact, and no contact.

2.1 Regular contact

The participants described regular contact on daily, weekly, monthly, and yearly. Daily contact implied to exchange caregiving in daily living activities, such as bed bathing, cooking food, making worship of Allah and so on while the weekly contact was to exchange caregiving for going shopping, restaurant or shops. The monthly contact was to exchange caregiving consisting of money support, following up to the hospital and yearly contact related to Social Welfare organization, joining to Songkarn festival. For example, Mrs. Fan shared her experience of regular contact from her sister and brother.

“My eldest sister and eldest brother came regularly to visit us. They gave money to me monthly but I paid the cost of an ambulance service for transferring to hospital. I paid 1200 bahts for a roundtrip”.

“พี่สาวคนโตแบพี่ชายคนโตมาเยี่ยมประจำ เขาก็มาให้ทุกเดือน แต่ค่ารถเวลาเอาไปโรงพยาบาล ป้าเป็นคนออกเอง ไปตามรถโรงพยาบาลมาครั้งละ 1,200 บาท”

(Case # 6 pp.38)

2.2 Occasional contact

Four caregiving networks talked about their occasional contact. They presented their needs and inadequacy of caregiving in daily support to the patients. For example, Ms. Bell’s daughter talked about her younger brother who stayed in other province and went back home occasionally. He also provided financial support.

“A younger brother came back home occasionally and provided some money support”

“น้องชายอีกคนนาน ๆ ที่เขาก็กี่ให้”

(Case # 2, pp.274)

2.3 No contact

One participant described that some children did not want to contact with their mother because they had no money.

“We went to the houses of two daughters of my grandmother. Both of them postponed visiting to their mother because they had no money. My mother said that my grandmother waited for them but they did not go to visit her for three years (memo).

“เราไปหาลูกสาวอีกสองคนของยาย เค้าจะพักผ่อนไม่ยอมมา อ้างว่าไม่มีเงิน แม่บอกว่า ยายเค้ารออยู่อยากให้เราดูกัน แต่ไม่เคยมาเยี่ยมเลยตลอด 3 ปี”

(Case # 13 pp., memo)

3. Member attributes

Member attributes refer to socio-demographic characteristics. In cultural expectations, there are different caregiving in gender and status.

3.1 Gender difference

In Thai social values, individuals believed that the caregiver role should be a woman better than a man. Some participants expected that male caregivers could provide lifting the patient, driving to go to the hospital but they could not provide cleaning for the patient. They expected that caregiver was a woman role. When this norm is violated, the adequacy of caregiving needs to be concerned. The participants talked about uncertainty of good caregiving. For example, Mrs. Oil compared the adequacy of caregiving between female and male caregiver.

“The neighbor, who got stroke disease, has a daughter to take care of her. She gets well. Her daughter provides good care, but I have no any daughter”.

“ก็มีบ้านนั้นไง เค้ามีลูกสาวคอยดูแลช่วยเหลือ ตอนนี่ดีขึ้นเยอะ....บ้านเราไม่มีลูกสาว”.

(Case # 15 pp.102)

3.2 Status difference

In Thai society, the adult children should respect and took care of their parents. The adult children should be the primary caregiver rather than the spouse. In this study, five participants were wives of the stroke patients while twelve participants were daughters. The participants talked about their “*kreng-jai*” (concerns) to their parents, and to others.

3.2.1 Concern (*kreng-jai*) to higher status

The participants thought that the parent is higher status than children. For example, Ms. Do said she could not assign to her father for cleaning her mother.

“No..no. We did not assign him (our father) to provide caregiving. There are many children here why we asked our father to do that”.

“ไม่...ไม่ จะไม่ยากให้เค้าทำ แหมมีลูก ๆ แล้วจะไปใช้ให้คุณพ่อเค้าทำอะไรอย่างงี้”.

(Case # 4 pp. 285)

3.2.2 Concerns (*kreng-jai*) to other

In general, Thai people did not ask some help from non-family members when they were obligation to their roles. The people thought that was the children's roles to take care of their parents. If they could not do that or allowed others to provide care instead of them, they felt *kreng-jai*. Two caregiving networks shared their experiences of *kreng-jai* when they depend on other. For example, Mrs. Lulu talked about the daughter-in-law of the patient and thought that was her role to take of her father rather than the daughter-in-law. In addition, Mr. Bo's sister shared her opinion to allow the niece of the patient to provide care every noon.

“(He) stayed with her brother for a week. It was said that a man does not provide care as same as women. Moreover, I felt *kreng-jai* to my sister-in-law. It was different and she had no time (for taking care of him)”.

“รู้สึกว่าจะอยู่ได้อาทิตย์กว่า ๆ มั้ง คืออย่างว่าผู้ชายไม่เหมือนผู้หญิงนะ การดูแลหรือการเอาใจใส่ แล้วเราก็เกรงใจพี่สะใภ้เค้าด้วย มันไม่เหมือนกันเค้ามีการะ”

(Case # 12 pp. 103)

In conclusion, the variations of network-exchange caregiving clarified the nature of caregiving configuration and implied to adequacy of caregiving. The adequacy of caregiving was described to the regular contact rather than occasional or no contact. The size difference of main caregivers portrayed the adequacy of caregiving in collectivists rather than individualists. Moreover, the goal of care relating to network perspective provided understanding the process of stress and how the caregiving are inadequate. The composition of caregiving gave the reasons why some participants accepted to their caregiving, other seek help to fulfill caregiving. The strong connection provide adequacy of caregiving more than loose connection. Lastly, the difference of gender and status relating to cultural expectation illustrated that the participants accepted their limitations and inadequacy of care when norms are violated.

The fourth section

This section explores the patterns of social exchange behaviors of stroke caregiving networks in Bangkok. The proposed model has been developed as a “wheel of caregiving model” to describe the social exchange behaviors. The proposed model has linked 6 concepts (themes) from “no one else can do it”, “don’t know what to do”, “let’s try it” to social exchange behaviors with the concept of “relying on each other”. The concept of “relying on each other” identifies the exchange caregiving behaviors in physical, psychological, socio-cultural, spiritual, financial, and emergency care. After the exchange of caregiving, the concept “whatever happens, happen” emerges as the outcome of caregiving. However, the caregiving is not only the outcome but also the process. The last concept “when the time comes, there will be a way” portrays an ongoing process of caregiving to move in continuity of care.

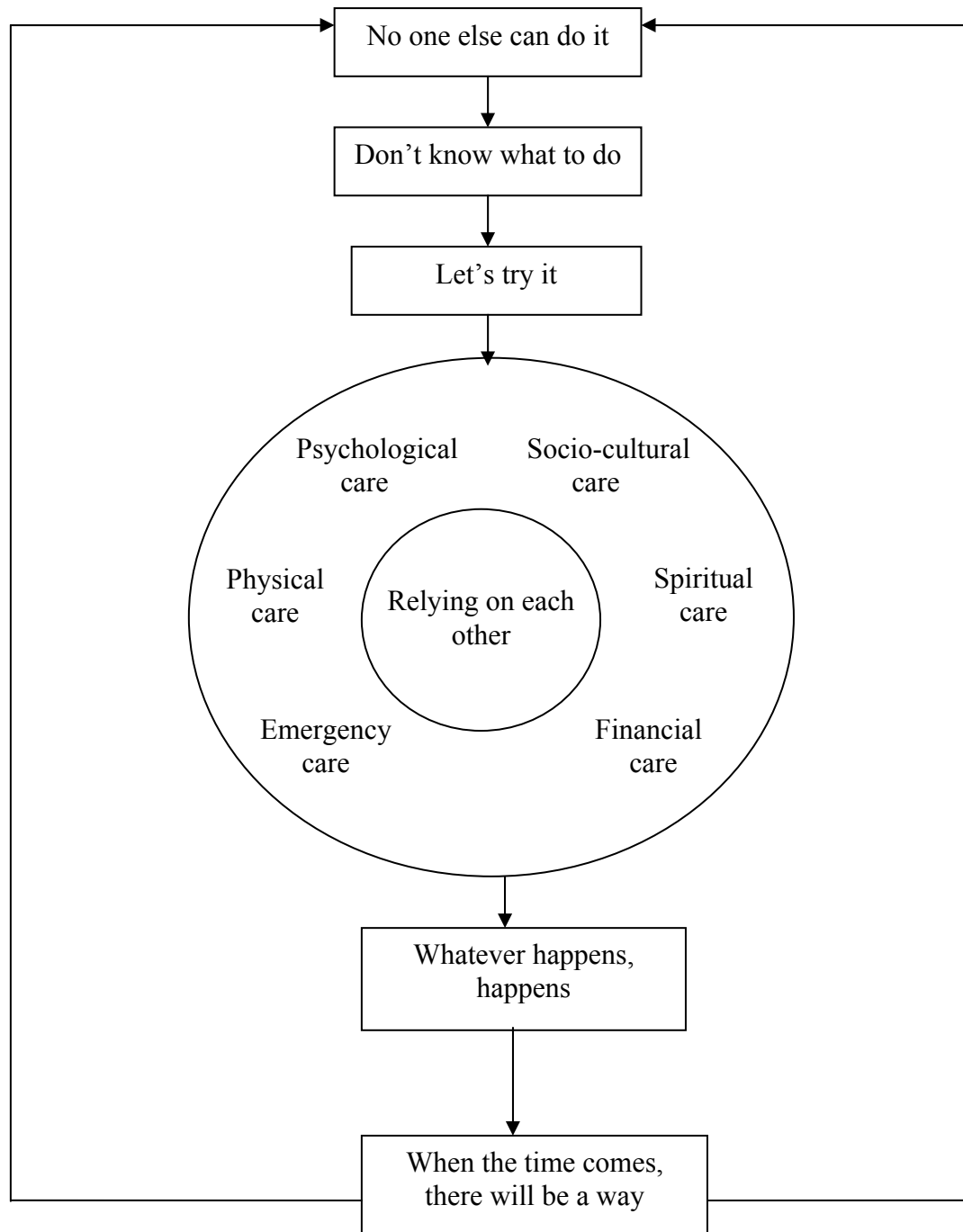


Figure 3: Wheel of caregiving model

As presented in figure 3, the “wheel of caregiving model” illustrates the relationships among the six concepts. Under the first concept “no one else can do it”, the decision making to motivate someone suitable to be a primary caregiver and caregiving network members are found. This concept describes three subcategories: motivation, emphatic feelings of valuing, and beliefs that stroke caregiving networks use to select the main person for playing a caregiver role and caregiving members. This study provides understanding of how caregiving networks are set up and the meaning of the primary caregiver. The primary caregiver is defined as a main person who stays with the patient all the time, or during the daytime and provides direct care or does everything for the patients. Moreover, this study found that there can be one or two primary caregivers, who meet this definition. Focusing on motivation, the participants are motivated by external motivation from family, patient, and economic decision to play a caregiver role. When the participants could not do some care tasks, caregiving network members allowed another person to provide care to meet the responsibilities of caregiving. The emphatic feeling of valuing is predominated members to participate in caregiving networks focusing on patient or caregiver. If those people are not patient or caregiver, the caregiving network members do not want to participate in caregiving networks. Moreover, beliefs are guided individuals to provide caregiving in terms of belief in the previous life, the present life, and the future life. Relating to beliefs of whatever you do, you receive, the participants have had the objectives to provide caregiving for result of the previous life, or receiving in the present life, or in the future life.

The second concept “don’t know what to do” is presented as the chaotic situation whereby stroke caregivers and caregiving network members deal with being afraid, facing difficulty, being tired, and eventually coming to acceptance (*tham-jai*). The participants portrayed their experiences of fearfulness to accept caregiver roles. The participants presented the different kinds of problems that made caregiving difficult from their own health worries, emotional strains, life changes, economic burdens, and cultural to care discontinuities. The participants faced physical and emotional tiredness during the caregiving process. They used a healing process to adapt to the new situation and a relaxation process in coming to accept these roles.

The third concept “let’s try it” shows the process of development of stroke caregivers in preparing to be caregivers, building caregiving knowledge, experiencing trial and errors of care, trying alternative care, and seeking help. The participants were prepared to be caregivers and developed caring skills through coaching from home health care personnels, nurses, and family members. In addition, the participants showed how they developed their skills by doing more and evaluation. The participants build caregiving knowledge from health personnel, family, neighbor and friend, and own self. The participants provided care while experiencing trial and errors of care. Some participants tried to use alternative care while others did not. They sought help for complex care, co-operative care, and supporting care.

The fourth concept “relying on each other” describes the balanced exchange of caregiving. As depicted in the figure 3 with the circular structure, stroke caregiving involves exchanges in physical, psychological, emergency, socio-cultural, spiritual, and financial care. For caregiving exchanges, the participants had wanting to help (*num-jai*) by their commitments to do the best and give devotion to their tasks. The participants received encouragement (*kum-lung-jai*) from one’s own self, patient, family members, and supernatural power. The participants exchanged caregiving in two subcategories: balanced exchange and imbalanced exchange. Focusing on balanced exchange, there is two sides of caregiving between providing and receiving care. In contrast, imbalanced exchange is caregiving abilities in which caregiving networks try to keep ongoing care by control or negotiation.

The fifth concept “whatever happens, happen” is the outcome of caregiving exchange. The arrows indicate the relationships between the caregiving exchange in “relying on each other” as the center of “wheel of caregivingz” that results to the outcomes of caregiving exchange in “whatever happens, happen” in three dimensions: positive outcomes, negative outcomes, and neutral outcomes. If the wheel of caregiving was balanced exchange, the process of caregiving would be smoothly ongoing. The outcomes of caregiving tend to positive experiences in terms of gaining, being aware of one’s own health, closer relationship, being proud of caregiving, and having a better life. In contrast, if the wheel of caregiving was imbalanced exchange, the process of caregiving would be obstruction or irregular moving or stopped moving. The outcomes of caregiving risk to negative experiences in terms of reduced work,

reduced income, feeling of boredom, and stress. However, there is the transition between balanced and imbalanced exchange to the adequacy of caregiving. As a result, the neutral outcomes are predominated of both positive and negative experiences in terms of seeing it as it is (*suth-ja-thum*), and normalizing.

The sixth concept “when the time comes, there will be a way” reflects the dynamic process of stroke caregiving. There was planning for an uncertain future when there were changes in the patient, caregiver, and family. The participants prepared for the patient’s dying, for the caregiver’s dying, and for family changes. Moreover, the participants planned to find new ways of caregiving in terms of finding a new primary caregiver or assistant, finding a new way to deal with a patient’s deterioration, and learning to modify caregiving. The arrows show the return of relationships between the planning of caregiving in “when the time comes, there will be a way” to the beginning of “no one else can do it”. Three participants shared their experiences when the former caregivers passed away. Two participants presented the change of primary caregivers because of moving out to stay in other provinces.

In summary, the wheel of caregiving model depicts the stroke caregiving networks in Bangkok, how the caregiving networks were set up and the difficulty they had during caregiving. Moreover, this model explores the social exchange behaviors to maintain caregiving by relying on each other. The outcomes are the consequences of exchanging behaviors and the dynamic of caregiving process is explained by “when the time comes, there will be a way. In this study, the patterns of social exchange behaviors are explored in the next section.

Contextual factors

The contextual factors that influenced caregiving exchange consisted of structural factors, informational factors, social factor, economic factors, and psychological factors.

1. Structural factors: size

Size is defined as the total number of active network members. Several studies have defined size as measured by individuals, who are family and non-family members (Bennett et al., 2006; Boonchalaksi, 200; Stoller & Pucliesi, 1991). In this study, size is the number of members who participate in stroke caregiving in terms of exchange caregiving. The network consists of family members and members who are outside the family. The members outside family are not only friends, and neighbors but also organizations that provide support. These various members constitute the network of stroke caregiving. Size has been divided into three sizes as follow:

1.1 Small size

Small size refers to caregiving networks consisting of four to five family members. This network needs help from outside family. In this study, eight caregiving networks consisted of four to five members from family members and two to eight members from non-family members (Case # 1, 3, 4, 5, 9, 16, 17, 18). The non-family members are housekeeper, friends, neighbors, health volunteers, primary care nurse, home health care nurse, public ambulance center, and the National Council on Social Welfare of Thailand. Some participants talked about the numbers of members in caregiving network size are enough for caregiving while others received help from non-family members. For example, Mrs. Im shared her experience when her husband had convulsion and her children did not stay with her during that time. The non-family members, who lived outside, participated in emergency care. Her neighbor contacted to a public ambulance center for transferring the patient to the hospital.

“At nighttime, I asked my neighbor to call taxi whenever my husband was convulsion. That day, his tracheostomy tube was pulled out and could not find out a taxi. The public van of *Poh tek tung* foundation came here but did not take him (from lacking of instruments). The patient could not do (breathe) by own self. As a result, the public ambulance center called the networks (consisting of public and private ambulances). The private ambulance came to carry him. My son phoned where you are. I said I was in ambulance

van. He asked about the cost of care. Free service and (the personnel) provided good caregiving”.

“กลางคืนบอกข้างบ้านไว้เลย ถ้าซักอะไรให้ไปตาม taxi วันนั้นจับที่คอหลุดเรียก Taxi ไม่ได้ก็เรียกรถปอเด็กดิ่งมาก็ไปไม่ได้ ช่วยเหลือตนเองไม่ได้ไปไม่ได้ ก็เรียกรถ...(เอกชน) ลูกชายโทรมาแม่อยู่ไหน บอกอยู่บนรพพยาบาล ลูกถามเสียดั่งค์หรือเปล่าแม่ ไม่เสียหรือรอกเค้าทำดีดี”.

(Case # 9 pp. 239)

1.2 Medium size

Medium size refers to caregiving networks consisting of six to seven family members. In this study, three caregiving networks exchanged caregiving within their family (Case # 2, 12, 13). They perceived of adequacy of caregiving and they did not want help from outside family networks. On the other hand, two caregiving networks received some help. Each of caregiving network had two non-family members (Case # 6, 15).

“That was not any need from the neighbors because we had many relatives”.

“ไม่ถึงจำเป็นต้องให้เพื่อนบ้านมาช่วย เพราะพี่น้องเราเยอะ”. (Case # 2 pp. 74)

“I thought that was enough to simply living. (Finding help from neighbors) There is nothing. Mostly, we help each other”.

“คิดว่าพออยู่ได้ไม่ลำบาก...(การไปขอความช่วยเหลือจากเพื่อนบ้าน) ไม่มี ส่วนใหญ่ช่วยกันเอง”.

(Case # 13 pp. 94)

“When she came here, she provided cleaning me”

“ถ้าเค้ามาก็ช่วยอาบน้ำให้”

(Case # 15 pp. 25)

Large size

Large size refers to caregiving network consisting of eight to ten family members and one to three non-family members. This study found five large caregiving networks exchanged caregiving within and outside family members. The participants talked about inadequacy of caregiving exchange in their family networks and receiving help from outside family members, such as neighbors, boss, health volunteers, home health care nurses, physicians, and public ambulance center.

“This was a (neighbor) nurse who came here (to help me) when I provided injection”.

“มีพยาบาลตรงนี้จะให้เค้ามาดูแล”

(Case # 7 pp. 202)

“Mostly, we would receive the prescription from the physician, who came to check up (my mother) at home”

“ส่วนมากจะรับยาหมอที่เค้ามาตรวจที่บ้าน”

(Case # 8 pp. 61)

In conclusion, the structural factor (size) provides understanding the picture of exchanged behaviors. The small size of network sought resources from outside to fulfill their needs while the large size had a few members from non-family member. The medium size of network exchanged caregiving within their families or needed a few members (equal two members). (See table 4.5)

Table 4.5 Comparison size of network among small size, medium size, and large size

Case	Small size		Medium size		Large size	
	Number	Number	Number	Number	Number	Number
	Family	Non-family	Family	Non-family	Family	Non-family
1	4	4				
2			6	0		
3	4	2				
4	5	5				
5	5	5				
6			7	2		
7					9	3
8					9	3
9	4	6				
10					8	2
11					10	2
12			7	0		
13			6	0		
14					8	1
15			6	2		
16	5	8				
17	5	2				
18	5	3				

2. Informational factor: communication

Information refers to news, message, data, or knowledge that is shared between primary caregivers and caregiving network members. Information about the major needs and concerns of stroke caregiver has been analyzed in several studies (Bakas et al., 2002; Piece, Fin & Steiner, 2004). Stroke caregivers perceive unmet needs in tangible support because they have no information on what support is available (Sit et al., 2004). Communication is the informational factor that stimulated caregiving network members to participate in caregiving. This study showed that caregivers communicate to caregiving networks for caregiving exchange. Communication is defined as the informational factor to mobilize caregiving exchange between caregiver and caregiving network members. It includes direct, indirect, and stop communication.

2.1 Direct communication

Direct communication refers to the act of sending and receiving information between the caregiver and caregiving network members. The participants talked about directly communication between the participants and caregiving network members (Case # 5, 8, 9, 10, 13, 14, 17, 18). For example, Mrs. Porn talked about her information on the patient with caregiving network members. As a result, she received caregiving support from her relatives, neighbors, the National Council on Social Welfare of Thailand, and the National Housing Authority.

My neighbor asked me what I used for cleaning. I told her I took a tissue. *Tai...lew* (oh!) . Tissues are wasteful. She used to take care of her father but he had died (by using a piece of cloths from her sewing instead of tissue). She said she would bring some cloths to me”.

“เพื่อนบ้านเค้าถามเงิเอาอะไรเช็ดตาแป๊ะ ฉันบอกทิชชูชื เปลืองตาเลย ข้างห้องเค้าดูพ่อ
เค้าแต่พ่อเค้าตายไปแล้ว เค้าบอกเดี๋ยวนูเอาเศษผ้ามาให้”.

(Case # 16 pp. 544)

2.2 Indirect communication

Indirect communication refers to the act that information is transferred indirectly from caregiver to caregiving network members and to others in the family. Some participants did not talk directly of her idea with other network members. The objectives were to send information, opinions, idea to others but did not want the receiving back from them (Case # 1, 3, 7, 14). For example, Mrs. Nid talked

about her idea to manage the obstruction of nasogastric tube that was different strategy from her younger sister. She did not talk directly to her younger sister but she talked with the third person and made the loudly voice for younger sister's listening.

“If I did it, I would not do like that. I would crush this tube feeding as much as I could. If I put some water into tube feeding, she would be full”.

“ถ้าเป็นฉัน ฉันจะไม่ทำอย่างนี้ ฉันจะขี้ ๆ สายจนสุดความสามารถ เพราะใส่น้ำลงไป เดี่ยวอาม่าจะอึดไป”.

(Case # 14 pp.323)

2.3 Stop communication (or silence communication)

Stop communication refers to the act that information is not transfer among caregiving network members. The objectives of stop communication were stopping the problems, and keeping their relationships (Case # 2, 4, 6, 11, 12, 15). For example, Ms. Dee shared her story of stopping communication with her brother.

“I separated our living and eating. They (the brother and his wife) lived in front of the house. I did not join with them. If there was much more problem, it was better to stop communication. The more I spoke, the bigger problems we had. If there was some tasks, my sister would do it instead of me”

“ต่างคนต่างอยู่ ครัวก็แยกกัน เล้าก็อยู่ข้างหน้า เราก็ไม่ค่อยไปยุ่งกับเค้า มีปัญหาเราก็ไม่พูดดีกว่าพูดแล้วเรื่องมากเราก็ไม่พูด มีอะไรให้พี่สาวเค้าเป็นนั่นแทน

(Case # 4, pp.49)

3. Social factor: Time and duration

Time is a social factor that influences the caregiving activities in terms of time available and duration in the community. In this study, the participants shared their experiences to participate in caregiving relating time that they were fine and time schedule. The duration of living in the community is another social factor that influences the people to participate in caregiving including short and long duration.

3.1 Time

Time consumption is of interested in caregiving studies that focus on time and difficult tasks done by stroke caregivers. Range of time was between 2- 24 hours with an average of 12 –18 hours (Bakas et al., 2004; Chuangsawadsak, 1998; Sangboon, 2002; Srithares, 2003). Time available is defined as the rationale to exchange caregiving by regular time, or irregular times that members were available.

3.1.1 Regular time

Regular time refers to the time that has been divided and set up for caregiving from individuals. The participants talked about their multiple roles to take care herself/himself, children/spouse, work, and the patients. They provided regular time with a schedule to help the caregiver taking care for patients and left a window of time open for them. For example, Ms. Fang shared her experience to help her aunt with taking care of her grandmother.

“When we turned his position and had already fed blenderized diet, we had two or three hours for going shopping. We could manage time to go outside and get back home”.

“คือเราจะพลิกตัวแล้ว อาหารยาย feed แล้ว เราก็จะรู้ว่าสองสามชั่วโมงนี้เราว่าง ไปห้างไปซื้อของได้ จัดเวลาได้ อย่างให้อาหารช่วงบ่าย เราว่างแล้ว กลับมาได้ช่วงเย็น รู้เวลา”.

(Case # 6 pp.383)

3.1.2 Irregular time

Irregular time refers to the time that caregiving members were fine to provide caregiving. Other caregiving network members provided the time to help the primary caregiver when they were available. They alternated their schedules to provide caregiving among caregiving network members, if there was no one else to help the patients and primary caregivers. For example, Mrs. Lala talked about her time available to help her younger sister with taking care of her father.

“Whoever has time has to take care. It is not a timetable. If I have time, I will take care. If she has a time, she will do it”.

“คือใครว่างก็ไปดูไม่ได้เป็นเวลา เราว่างเราก็ทำแล้วว่างแล้วก็ทำ”.

(Case # 12 pp. 120)

3.2 Duration

Duration refers to the time that the patient's family live in the community. The duration of time in the community effects to people who come to participate in the caregiving network. There are long and short duration in the community.

3.2.1 Long duration

Some families are the local residences and live in an old community from generation to generation. The old community is located in the inner and middle area of Bangkok. The temple is the center of community activities. Most of them knew and have community activities together, such as Songkarn festival,

the ceremony of ordination into the monkhood, and funerals etc. The participants stay long duration in the community (Case # 1, 2, 5, 6, 7, 8, 9, 10, 11, 15, 16). There is a variety of caregiving exchange with non-family members in terms of physical, psychological, socio-cultural, emergency care.

“When he (the patient) got sick, many neighbors gave some food because of good relations.....When I (caregiver) admitted in the hospital, I would give the key for her (neighbor). She came inside (by opening the lock) to ask my husband about what kind of food he wanted. When he told her about the fish, she would buy it for him. She helped me because my son went to work out. She came from Northeast province. We knew together for six years. Sometimes, I called her family at 1a.m. for lifting my husband to taxi”.

“ตอนที่ไมเคิลนั้นเามาคนนี้อามา ตั้งแต่ ๑ ก็เสวนากันอยู่ ขึ้นไม่อยู่ไปรพ.ก็ให้ญาติเฝ้าไว้ เค้าก็มาถามแล้วอากงจะกินอะไร บอกปลาตุ๋นเค้าก็ซื้อปลาตุ๋นมาให้อาข้าวมามาให้เพราะลูกเค้าไปทำงาน เค้าก็บอกว่าคนอีสานนะรู้จักกันตั้งแต่เค้ามาอยู่ตรงนี้ 6 ปี ยกขึ้นรถลงดีหนึ่งดีสองไปเรียกเค้ามาตลอด” (Case # 16 pp. 490)

3.2.2 Short duration

In contrast, other families live in the new community which has been set up from the expansion of Bangkok. The people migrate from other areas or provinces. They have short duration in the community and they do not participate in community activities (Case # 3, 4, 12, 13, 14, 17, 18).

“I had not joined (with community activities). If there is a ceremony, my sister donated some money on behalf of my mother. In the past, I had only one day on weekends. I did not stay at home and did not participate in activities”

“ถ้าตัวเองไม่เคยไป ถ้ามีอะไรส่วนใหญ่พี่สาวเอาชื่อแม่เอาเงินไปทำบุญ มีเลี้ยงพระ ก็ช่วยใส่ซองทำบุญเมื่อก่อนทำงานหยุดวันอาทิตย์วันเดียว ก็ไม่ค่อยได้อยู่บ้านไม่ได้ไปรวมอะไร” (Case # 4, pp.94)

4. Economic factor: Finances

Finances in terms of both amount and adequacy are an important factor in stroke caregiving. Several studies have focused on the amount of money, and adequacy of financial support (Chuangswadsak, 1998; Niyomthai et al., 2003; Sangboon, 2002; Srithares, 2003; Songwatthayut, 2002). Some caregivers did not work and had to rely

on others, such as the patient, sibling etc. The caregivers described regular support, and occasional support.

4.1 Regular support

Regular support refers to money given every month from some caregiving network members to support caregiver. For example, Ms. Kan talked about her money support from the patient while Mrs. Nid received support from his brother.

“The eldest brother provides 8,000 baht per month to my mother. This money was transferred to me 6,000 baht”.

“พี่ชายคนโตเค้าให้อาม่าเดือนละ 8,000 ก็เลยแบ่งมาให้ฉัน 6,000”

(Case # 14 pp.485)

4.2 Occasional support

Occasional support refers to financial support from caregiving network members occasionally. For example, Mrs. Lala talked about the management of finances by polling money together occasionally.

“There is a money pocket in his shirt. If the children come to visit him, they put their money in the bag of father’s shirt pocket..... Helping is from our siblings. Every little helps from these and those children. Sometimes my sister came here and gave 1000 baht to me but she did not come every month. When she gives money, I will collect it”.

“ที่เสื้อมีกระเป๋าตังค์เสียบไว้ในกระเป๋าเสื้อหน้าอกด้านซ้าย.....ก็ช่วย ๆ กัน พี่ ๆ น้อง ๆ คนนี้นิด คนนี้หน่อย.....บางทีพี่สาวเค้ามา เค้าก็ให้ไว้เดือนนึงพันนึง แต่ไม่ใช่ทุกเดือน”.

(Case # 12 pp. 113)

5. Psychological factor: relationships, satisfaction.

5.1 Relationships

Relationship is a significant factor that has been studied in several stroke studies (Song wathanayut, 2002; Tirapaiwong, 1998). In this study, the relationship is the factor related to caregiving exchange. When the participants exchange caregiving, the relationships among caregiving networks are in terms of close and conflict relationship.

5.1.1 Close relationship

Close relationship results from balancing caregiving. The participants described their satisfaction and strong connection (*pook-pun*) was more than in the past. For example, Ms. Dee described her satisfaction to help the youngest daughter to take care of their mother.

“I did not go anywhere since my mother had stroke. When my friends went together, I occasionally joined with them. In general, I did not want to travelling. My friend said I was stingy and stayed at home. I thought that I did not want to go out because I wanted to help my younger sister. She would be free from doing caregiving”.

“เพราะเป็นสิบปีแล้วที่พี่ไม่เคยไปเที่ยวไหนนะ ตั้งแต่คุณแม่ไม่สบาย นาน ๆ ครั้งเพราะเค้าไปกันเราอยู่ในกลุ่มนั้นเราต้องไปด้วย แต่ถ้าอยู่เฉย ๆ แล้วฉันอยากไปโน่นฉันอยากไปนี่ ไม่เคยคิดอยากไปเที่ยวไหนอยากไปเที่ยวนี้ไม่เคยคิด ไม่เคยนึกว่าจะไปเที่ยว บางทีเพื่อนเค้ายังบอกว่ามันงก คิดแต่จะอยู่บ้านขายของ คือเราไม่ได้นึกถึงว่าเราอยากจะไปเที่ยว เรานึกว่าเราหุคเราอยากช่วยน้องเรา น้องเราจะได้พักผ่อนบ้าง เรานึกอย่างงี้”

(Case # 4, pp.321)

5.1.2 Conflict relationship

Conflict relationship results from unbalancing caregiving. The participants talked about their disappointment and anger with each other. For example, Mrs. Nid shared her experience of conflict of relationship among caregiving networks. She and her younger sister had different idea to solve the problem of caregiving. She shared her experiences.

“If I provided caregiving, I would not do like that. I would crush this tube feeding as much as I could. If I put some water into tube feeding, she would be full.....At the beginning, we are good (relationship). When the time goes on, we each have emotions. She (her younger sister) takes me with emotion. I would take emotionally back to her”.

“ถ้าเป็นฉัน ฉันจะไม่ทำอย่างนี้ ฉันจะขี้ ๆ สายจนสุดความสามารถ เพราะใส่ น้ำลงไปเดี๋ยวอาม่าจะอิมไป ทำได้ ๆ ถ้าฉันตายก่อนอาม่าแล้วทำยังไง
ที่แรกก็ดี นานแล้วต่างคนต่างมีอารมณ์ เค้าก็ใช้อารมณ์กับเรา เราใช้อารมณ์กับเค้า”

(Case # 14, pp. 220, 323)

5.2 Satisfactions

The satisfactions refer to affective system of the caregiving networks for exchanging caregiving. In this study, the participants described their willingness (*tem-jai*) to participate in caregiving while others talked about their endurance (*jum-jai*) to do it.

5.2.1 Willingness (*tem-jai*)

In the context of “no one else can do it”, the participants were motivation to be caregiver. Regard to religious belief, Thai people believed that caregiving was to merit-making (*tam-boon*). Based on the rule of practice

in the Buddhist doctrine of making merit, there were two subcategories: merit-making for publicity and for good will (*met-ta*) (Buddhadāsa Bhikkhu, 1993).

For publicity

The merit-making for publicity aims to exchange for paradise or heaven in order to rebirth in beautiful or rich man/woman. Some participants described their objectives to receive the heaven or good thing in the future (Case # 1, 7, 11), and happiness (*sabai-jai*) (Case # 17). For example, Mrs. Bee talked about her objective to provide caregiving and the result of caregiving in the present. She hoped that she would receive the outcome of caregiving from her children in the future.

“I had no idea. It was common sense to take care of her because there was no one else. Someone said she had no time, others went to work out..... The result came urgently. When I had no anything to eat, others provided it to me. Really...Someone went to other province and brought a gift back to me....I hoped that I took care of my mother and my children would provide care to me in the future”.

“ไม่รู้สิก็ยังงั้น มันธรรมดา ต้องดูแลเพราะไม่มีใครดู ไม่มีใครเค้าเอา บางคนเค้าบอกว่าไม่มีเวลาดูมั่งไปทำงานมั่ง.....เวลารกรรมมันทันตานะ....อย่างเมื่อก่อนไม่มีกิน พุงกางๆ ทำอะไรก็ดี ดีขึ้นเรื่อย ๆ เราคิดว่าเราทำอะไรให้แก ลูกเค้าจะทำให้เราเมื่อก่อนเราเจ็บเราไข้”

(Case # 1, pp.81, 115, 123)

For good will (*met-ta*)

Another objective of making merit is a good will (*met-ta*). The value of practicing good will is not relating to self interest but it is the behavior to do for other person. In this study, the participants described their objectives of love (Case # 10, 16), bonding (*pook-pun*) (case # 2, 6), bloodline (Case # 12), and pity (*song-san*) (Case # 4, 8, 14, 18),

“Yes, I felt pity. I took him back home and thought that he would be happy when he saw his family”.

“ค่ะ สงสารเค้า ให้กลับมาอยู่บ้านให้เค้ามีความสุขอบอุ่นได้เห็นหน้าลูกหน้าเมีย”

(Case # 18, pp. 242)

5.2.2 Endurance (*jum-jai*)

Some participants described to their endurance (*jum-jai*) to be the caregiver. They had no choice because of no one else to do that. They illustrated the problems of caregiving network relating to dying of former

caregiver (Case # 15), moving from Bangkok of former caregiver (Case # 9, 13), and having no person available (Case # 3, 5).

“Empty. He had already dispensed money to other. I was truly speaking. I provided caregiving with resentment. Everyday I did it by resentment. When he had money, he dispensed to other. Today, his cousin who received this money, did not provide any help to him for 4 years ago..... If my son stayed here, he did everything. At this time, he went to work at Koh Samui for five months ago. If he lived here, he would provide help.....”

“หมดแจกเขาหมด พูดเรื่องจริง ทำไปอย่างนี้ถึงบอกตอนนี้ทำด้วยความแค้นทุกวันนี้ทำด้วยความแค้น มีเงินแจกเค้าหมด ทุกวันนี้พี่น้องที่แจกเค้าไป ไม่เคยมาดู 4 ปีแล้ว ถ้าลูกชาย เค้าอยู่เค้าทำให้เสร็จสรรพ ลูกชายเขาไปทำที่เกาะสมุยได้ 4-5 เดือน แล้ว ถ้าเค้าอยู่เค้าช่วย”

(Case # 9, pp.129)

In summary, “the wheel of caregiving” is process of caregiving which mobilize by many factors: size, satisfaction, time, duration, finances, communication, and relationships. “The wheel of caregiving” is smoothly ongoing, when there are appropriate members for caregiving network with willingness (*tem-jai*), regular time to care, long duration in the community, regular financial support, direct communication, and close relationship. On the other hand, “the wheel of caregiving” is discontinuing when the caregiving network members are not enough members to exchange caregiving with endurance (*jum-jai*), irregular time to care, short duration in the community, occasional financial support, indirect or stop communication, and conflict relationship.

The fifth section

This section explores the patterns of social exchange behaviors in the context of stroke caregiving in Bangkok. From the wheel of caregiving model, patterns of social exchange behaviors are the center to move caregiving. Three patterns of social exchange behaviors are sharing care, dual care and supplementary care.

Pattern 1: Sharing care

Sharing care refers to the pattern of network exchange that separated caregiving roles and responsibilities among caregiving network members. There were regular supports from subgroups / individuals of networks. They separated caregiving, in terms of making blenderized diet, doing the laundry, cleaning the patient and etc.

Eight caregiving networks used sharing care as the pattern of social exchange behaviors (Case # 2, 4, 7, 8, 11, 14, 17, 18). The significant characteristic is the subgroups or individuals who had competency appropriate to their roles. The interaction relationships were supervisor and working bees. Some supervisors were not primary caregivers, such as two youngest daughters (Case # 14, 17), two other adult daughters (Case # 4, 11), one eldest daughter (Case # 2), and one patient (Case # 8). Others were primary caregivers, such as one wife of the patient Case # 18), and one eldest daughter (Case # 7). Three supervisors provided suggestion without caregiving or with some caregiving (Case # 8, 14, 18), while five caregiving networks provided suggestion with participation in caregiving (Case # 2, 4, 7, 11, 17).

Mostly, this pattern consisted of four large size (Case # 7, 8, 11, 14), while three caregiving networks were small size (Case # 4, 17, 18) and one of them was medium size (Case # 2). All caregiving networks were willing to be a caregiver and caregiving network members. Focusing on exchanging caregiving, the participants shared their times, finances, and information. Five caregiving networks balanced their time with schedule (Case # 2, 4, 8, 17, 18), while three of them negotiated and provided times that they were available (Case # 7, 11, 14). Four caregiving networks had regular financial support (Case # 4, 14, 17, 18), while others had occasional support (Case # 2, 7, 8, 11). Five caregiving networks shared direct communication (Case # 4, 7, 11, 17, 18), while three of them shared indirect communication (Case # 2,

8, 14). Four caregiving networks had close relationships (Case # 4, 11, 17, 18), while others had conflict relationships (Case # 2, 7, 8, 14), as shown in table 4.6.

Table 4.6 Pattern of social exchange behaviors in sharing care (8 networks)

No one else can do it		Relying on each other				Whatever' s happens, happens
Satisfaction	Size	Time	Duration	Finances	Communication	
Willingness (8 nets)	Small size (3 nets)	Regular time (6 nets)	Long duration (4 nets)	Regular support (8 nets)	Direct communication (4 nets)	-Close relationship (4 nets)
	Medium size (1 net)	Irregular time (2 nets)	Short duration (4 nets)		Indirect communication (1 net)	-Conflict relationship (4 nets)
	Large size (4 nets)				Stop communication (3 nets)	

*Nets mean Networks

The conditional factors

The social exchange behaviors consisted of factors that influenced sharing care, as follows:

1. Satisfaction factor

This pattern emerges from sharing care among caregiving network. “no one else can do it” is considered as a factor associated with social exchange behaviors through satisfactions. Eight caregiving networks exchanged caregiving by willingness of caregivers.

“She is my mother. She looked after me. When she is changing, I should provide long live caregiving”.

“เค้าเป็นแม่เรา เค้ายังเลี้ยงเรามาได้ พอเค้ามาเป็นอย่างนี้เราก็คงต้องดูแลเค้าให้ถึงที่สุด”.

(Case # 4, pp. 110)

2. Size factor

A pattern was found in the large size of caregiving networks where separated functions of care existed within the caregiving networks. The participants

delegated functions of care, such as providing a bath, making blenderized diet, and helping the patient worship Allah, taking the patient to the hospital and so on. In contrast, the small size of caregiving network had a limitation of primary caregiver and allowed other caregiving network members to provide some special care instead of primary caregiver.

“He could not do that because he had to take care of his shop. My younger sister in law could help him”.

“ทำไม่ได้เพราะเค้าต้องดูแลร้าน ก็จะมีน้องสะใภ้มาช่วยดูให้ได้”

(Case # 2 pp.22)

In this pattern, eight caregiving networks divided their roles as the supervisor and working bees. They played as a supervisor to make decisions while the caregiving network members took the role of working bees. Of those who took the supervisor role, most of them were not the primary caregiver but they were one of the caregiving network members. For example Mrs. Nid shared her experience in caregiving role while the youngest daughter talked about her supervisor role to recommend about caregiving..

“I provide caregiving while my younger sister cleans the room and washes the cloths”

“เราทำหน้าที่ดูแล ส่วนน้องสาวทำความสะอาดห้อง, ซักผ้าให้คนไข้”.

“Sometimes I remind her about the medication she gives. Mostly, Just more recommending. I will remind her and ask her of did you do this or did you do that”

“บางครั้งก็กำชับเค้าว่าให้ยาหรือยัง ส่วนมากกำชับมากกว่า คอยเตือน ๆ กันไงทำนี่หรือยัง ทำโน่นหรือยัง”

(Case # 14 pp. 385, memo)

3. Time factor

This pattern exchanged caregiving between providers and receivers in time, finances, and communication. Focusing on regular time, five caregiving networks shared regular time according to a timetable (Case # 2, 4, 8, 17, 18). The primary caregiver provided caregiving in the daytime of weekdays while caregiving network members took care of patient in the nighttime and on the weekends.

“If he (my third son) was not asleep, he came to see his father at 1 a.m. or 2 a.m. They divided their jobs. Someone made blenderized diet. They did not negotiate together”.

“ถ้าเค้าไม่หลับตีหนึ่งตีสองเค้าก็ลงมาดู เค้าจะแบ่งหน้าที่กัน คนหนึ่งทำอาหารไม่ค่อยเที่ยงกัน”.

(Case # 18 pp. 302, 305)

On the other hand, three caregiving networks could not provide care by regular times. They wanted to take care of patient at the time they were fine (Case # 7, 11, 14). One member shared her experience of separating time to provide care.

“When I came back, she (the caregiver) did not help with anything. She stopped doing the job (caregiving) at 5 p.m. You inherited this job at 5 p.m. If I went for a long time, there was a reaction (from the caregiver). I could not go back home late. It was time up”.

“พอกลับมา (เค้า) จะไม่แตะแล้วห้าโมงเย็นคือหมดเวลาทำงานของเค้า มารับช่วง (การดูแล) ก็รับไป ถ้าไปไหนยาวไหนก็มีปฏิกิริยา กลับบ้านเย็นยังไม่ได้...หมดเวลา”.

(Case # 7 pp. 426, 435)

4. Duration factor

Four caregiving networks live in the community for a long duration (Case # 2, 7, 8, 11). Relating to a long time in the community, the participants knew many people in their communities. They described their experiences to exchange caregiving among their neighbors in many situations, such as coaching for injection, inserting a new feeding tube and etc.

“When she (the patient) needed hematide injection at home, I could not do that. There was a nurse who had her own business by sending nurse aid at home. She rent the office of my aunt. I asked her to teach me and I could develop care abilities”

“พอมานิด ฮีเมท ทำไม่ได้พอดีตรงนี้เค้ามาสอนให้เค้าเป็นพยาบาลส่ง nursery ตามบ้าน ศูนย์ดูแลผู้ป่วยเค้ามาดูแลพอดีเค้ามาเช่าห้องอาศัยก็เลยไปขอเรื่องให้เค้ามาสอนให้ ก็ทำได้”

(Case # 7, pp.208)

In contrast, four caregiving networks live in the outer area of Bangkok for short duration because of moving from another province (Case # 13, 17), or other areas of Bangkok (Case # 4, 18). They did not know the people in their communities and had exchanged caregiving in their families. For example, Mrs. Ree waited for her children back home in emergency care because her family moved in the new houses for four months and did not know other neighbors.

“I was frightened because I stayed alone. My children went out to work and I lived alone. This housekeeper did not come here. I did not know how to pull him up and he had urination. I was frightened and called my children. For two hours, they would come back”.

“คือเราก็ตกใจเพราะเราอยู่คนเดียวลูก ๆ เค้าไปทำงานกันหมด อยู่คนเดียวพอดีเด็กคนนี้ก็ยังไม่มา จะทำยังไงถึงคนเดียวก็ตั้งไม้ขึ้นแล้วเค้าก็ออกมา ก็ตกใจเรียกลูก ลูก ๆ กว่าจะมา ตั้ง 2 ชม”

(Case # 18, pp. 15)

5. Finances factor

Six caregiving networks shared their financial support monthly to the primary caregivers (Case # 7, 8, 11, 14, 17, 18). Two caregivers presented regular support but it was not enough for caregiving expenses (Case # 7, 8). On the other hand, two caregivers received financial support from their grocery stores (Case # 2, 4). For example, Mrs. Green received regular support from her younger brother but it was not enough for caregiving.

“I had my reserved money and wage from sewing cloths. My young brother gave 1,000 baht per month...The cost of caregiving was about 3,000-4,000 baht per months. It was not enough for all expense”

“เก็บเงินส่วนตัวของตัวเองไว้ ก็เอาออกมาใช้จ่ายและงานจากที่เย็บที่ทำ และน้องชายเค้าให้แม่เดือนละพัน (ค่าใช้จ่ายในการดูแล) เดือนนึงประมาณ 3,000-4,000 นะคะ ก็ไม่พอหรอกค่ะ”

(Case # 7, pp.116, 291)

6. Communication factor

Four caregiving networks exchanged direct communication among the caregiving networks. The information has been shared together (Case # 8, 11, 17,18).

“Consulting together. How much food does mom eat? How are we doing? We are considered it together”.

“ปรึกษากันตลอด แม่กินได้มั้ย ทำยังไงปรึกษากัน”.(Case # 17 pp. 351)

On the other hand, two caregiving networks did not directly share information or knowledge together. They used indirect communication to others. For example, Mrs. Nid talked with the researcher through her youner sister (Case # 14).

“(The younger sister took a break from tube feeding). She uses the syringe to push the water into blenderized diet.....If I (Mrs. Nid) do it, I would not do it like this. I will crush this tube feeding as much as I can. If I put some water into the tube feeding, she (the patient) will be full”.

“(น้องสาวมาถอดสาย feeding tube) แล้วใส่น้ำลงไปในไซริงค์แล้วดันอาหารที่ติดอยู่ถ้าเป็นชั้น ชั้นจะไม่ทำอย่างนี้ชั้นจะขี้จนสุดความสามารถเพราะใส่น้ำลงไปเดี๋ยวอาาจะอิม”

(Case # 14 pp. 323)

Finally, three caregiving network members stop communication. They described their reasons because they need to stop the problems (Case # 2, 4, 7).

“We separated our living and eating. They (the brother and his family) lived in front of house. We did not join with them. If there were many problems, I said nothing. The more I spoke, the bigger problems I had”

“ต่างคนต่างอยู่คร่ำก็แยกกัน เค้า (พี่ชายและพี่สะใภ้) ก็อยู่ข้างหน้า (ส่วนด้านหลังของบ้าน) เราก็ไม่ค่อยไปยุ่งกับเค้า มีปัญหามากเราก็ไม่พูดดีกว่าพูดแล้วเรื่องมากเราก็ไม่พูด”
(Case # 4 pp.49)

7. Relationship factor

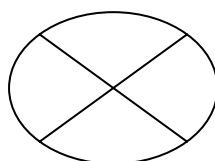
This pattern mainly consisted of adult children taking care of their parents while only one caregiving network had an intergenerational relationship between spouses and adult children. Four caregiving networks presented close relationship (Case # 4, 11, 17, 18). For example:

“I shared the idea with my younger sister. We loved together. Two women were closer than men”
“คิดกันสองคนกับน้องสาว เราสองคนรักกันเน้อ เราเป็นผู้หญิงสองคนก็ต้องใกล้ชิดมากกว่าผู้ชายเค้า”.
(Case # 4 pp.390)

On the other hand, four caregiving networks had conflict relationships within caregiving networks (Case # 2, 7, 8, 14).

‘If they (the younger and youngest sister) are not satisfied (to caregiving), let them take care (of patient) by themselves. Sometimes I cannot provide care to please them. I did not accept them. I truly said that if you are indeed skillful, you should take care by yourself. I am very bored’
“ไม่พอใจให้มาดูแล บางครั้งทำไม่ถูกใจเราก็ไม่ยอม พูดตรง ๆ มึงเก่งจริงก็มาดูแลซิ กูก็เบื่อแล้ว”
(Case # 14 pp. 237)

Eight caregiving networks used this pattern of “sharing care” to exchange caregiving by separating functions and roles of caregiving as a piece of pie. This picture “piece of pie” represents to separating functions and roles of caregiving.



The factors influenced the exchanging caregiving consisting of satisfaction, size, times, finances, duration, communication factors and relationship factors. These factors mobilize the wheel of caregiving as shown in the figure 4. The mechanism of the wheel of caregiving model started from the willingness, and exchanged in time duration, finances, and communication. The outcomes have close and conflict relationships and the pathway of sharing care has been presented in figure 5.

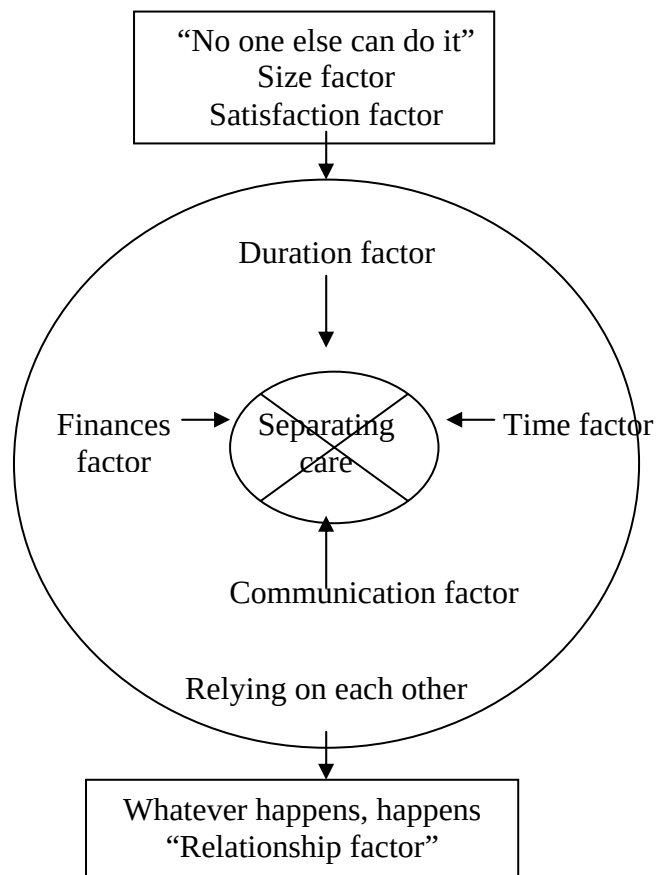


Figure 4: Pattern of "sharing care"

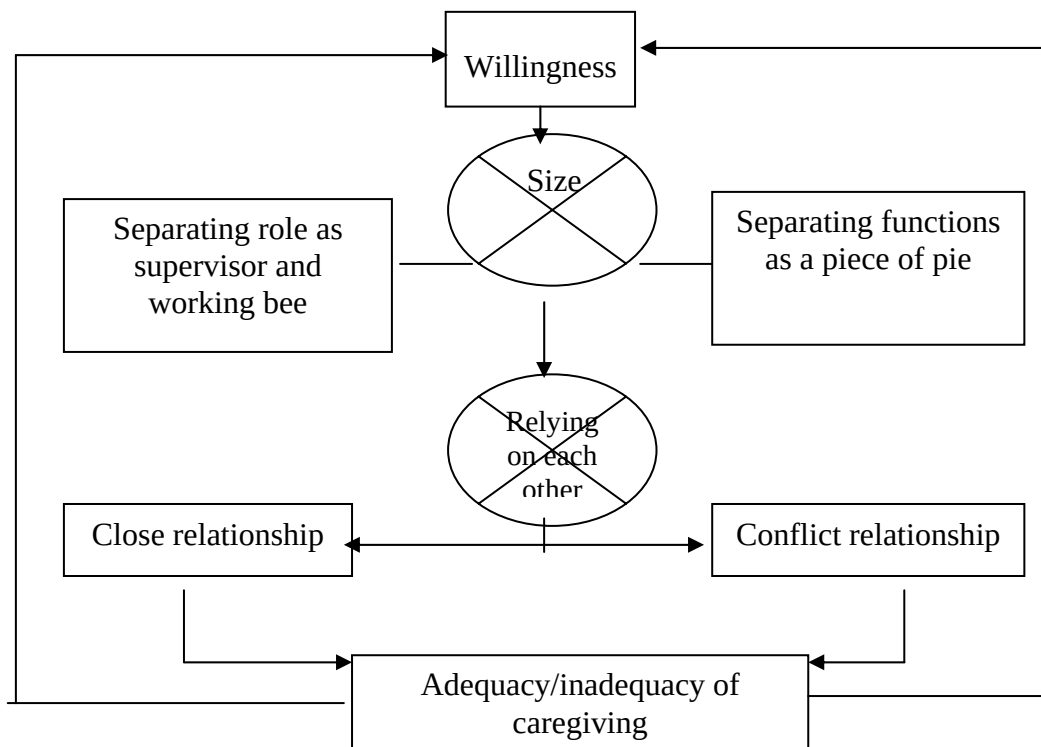


Figure 5: Pathway in the pattern of "sharing care"

In sharing pattern of social exchange behaviors, the caregiving network exchanged caregiving in physical, psychological, socio-cultural, financial, and emergency care. Six caregiving networks perceived of adequacy of caregiving. In contrast, two caregiving networks perceived inadequacy of caregiving.

Adequacy of caregiving refers to the objective of caregiving that is completed caregiving. The caregiving networks balanced caregiving or imbalanced caregiving by control and negotiation to meet their objectives. Six caregiving networks perceived adequacy of caregiving and demonstrated time management, enough caregiving members, positive outcome, and sustaining relationship. For example, Mrs. Quick talked about adequacy of caregiving by time management while Mrs. Bo' sister described her coping to sustain relationship for keeping their objectives as follows:

“That is O.K. In the nighttime, my mother had no caring need. In the daytime, my sister provided caregiving by herself and there was no serious problem”.

“ได้นะ กลางคืนแม่เค้าไม่มีอะไร กลางวันพี่สาวเค้าดูแลคนไข้ บางทีก็ไม่ต้องมาอะไรมาก”

(Case # 17 pp. 206)

“(I) would not speak. If there was a problem and he did not work, I would be in trouble. It was my duty. If he did not provide care, I would take care instead of him. I was also working outside and was terrible”.

“ไม่พูดเดี๋ยวมีเรื่องงานการไม่ทำเดี๋ยวเราลำบาก...มันเป็นหน้าที่มึงเค้าไม่ทำเราก็ต้องทำแทน เราทำงานอยู่ด้วยเราก็ลำบาก”.

(Case # 2 pp.313)

Inadequacy of caregiving refers to the objective of caregiving that it is not fulfill the caregiving needs. Two caregiving networks described the inadequacy of caregiving in coping to this situation and unsatisfying to caregiving (Case # 7, 14).

“I don't know whether it was enough or not. We each lived together. If she did not help me, I would take care of her whether it was adequate or not. She was my mother and she did not have another person. Whoever did not take care of her, I did not care”.

“ไม่รู้เหมือนกัน จะให้พี่คิดว่าพอมั๊ย อยู่กันสองคน ถ้าเราไม่ช่วยเราเราก็ต้องดูแล พอไม่พอนี้แม่นะไม่ใช่คนอื่น ใครไม่ดูแลเค้า”.

(Case # 7 pp. 682)

If they are not satisfied (with my caregiving), please come to provide care by themselves. I truly said if you were the expert, you had to provide care by yourself. I was also bored (pp. 237).

“ไม่พอใจให้มาดูแล บางครั้งทำไม่ถูกใจเราก็ไม่ยอม พูดตรง ๆ.. เก่งจริงก็มาดูแลเองซิ ูกก็เบื่อแล้ว”

(Case #14, pp. 237)

The caregiving network study in sharing care (Case # 11)

This caregiving network was an Islamic network in the inner area of Bangkok. Mr. Kai, a 74 year-old stroke patient lived with his wife and had twelve children. The eldest son, the second daughter, and the sixth daughter stayed with both of them. Three adult children lived with their families near Mr. Kai's house while other adult children often came to his house and had dinner together in the evening.

The caregiving network member described her willingness to help the patient because of her obligation.

“They (the children) see everything that I make. They ask why are you doing it? I do it with my obligation”.

“ลูกเห็นเราทำทุกอย่าง แม่แต่ลูกยังถามทำไมต้องเป็นมะ เราก็ทำหน้าที่ของเราไป”

Focusing on the size of caregiving, Ms. Karn who was the second daughter provided care to Mr. Kai as a primary caregiver. This caregiving network was a large size and consisted of eleven members including nine members from the family and two members from outside.

“It was enough (to provide care). The main people were Mrs. Kaew, my younger sister, Mr. Korn and I. Another person was my youngest brother. If there was some problem, I needed to call him”.

“พอ.....ผู้หญิงหลัก ๆ ก็ตนเอง (พี่น้องสาว 2 คน) ผู้ชายมีลุงเป็นหลักคนเดียว ส่วนน้องชายคนเล็กถ้าจำเป็นก็ต้องเรียก”.

This caregiving network divided their roles as supervisor and worker bees. Mrs. Kaew, the third daughter, played as a leader to suggest things to other members. She had taken care of her father since she was younger and had not got married. .

“I paid attention to the (gastrostomy) tube and checked how edema it was. They did not know, but I just did it by myself. If they gave the diet and found the tube obstructed, they would ask me. I would pump it with pressure and water. If it did not flow, I would take the syringe to push it. There are two types of syringe. The glass syringe is mine and I do not allow other to use it”.

“เราจะคอยดูว่าสายบวมมั้ย พวกที่เค้าให้อาหารเค้าไม่รู้หรอก ทุกคนเค้าให้อาหารแต่เราไม่มีหน้าที่ให้อาหารหรอกแต่จะคอยตรวจดู เค้าไม่รู้เราทำอะไรหรอกรู้คนเดียว เวลาให้อาหารไม่ลงเค้าจะมามอก ตัวเองจะบีบ ๆ แล้วเอาน้ำใส่ลงไป ถ้าไม่ลงก็เอาไซริงค์คั่นลงไปเป็นไซริงค์แก้ว มีไซริงค์ 2 อย่าง ไซริงค์แก้วนี่จะไม่ให้พวกเค้ามาใช้นอกจากตัวเรา”.

The caregiving network shared care by regular support according to a timetable. The eldest son provided a bath and helped the patient do his daily prayers and the sixth daughter prepared blenderized diet every morning. Mrs. Karn stayed with him and took care of Mr. Kan all day. She gave the tube feeding diet to him four times a day. Mrs. Kaew, the third daughter came to provide wound dressing for gastrostomy and cystostomy to Mr. Kan daily and took him to follow up at the hospital monthly. The fourth son bought food and materials to the patient daily and gave some money to the primary caregiver occasionally. The ninth daughter stayed at home on working day and returned to her home on weekends. She and her husband made the bed and did the laundry for Mr. Kan daily. The youngest son and his wife came to with cooking food and feeding diet in the evening occasionally. A neighbor often provided massage to Mr. Kan and a home health care nurse provided home visits to him occasionally.

“My eldest brother (provided taking a bath everyday)...(my younger sister) helped with making blenderized diet...For cooking, the fourth younger brother was working at the railway organization at Makasun and there was a market. He would phone to ask what kinds of food I wanted”.

“พี่คนโต...แล้ว(เขื่อน้องสาว)เค้าช่วยปั่นให้..กับข้าว น้องชายคนที่สี่เค้าทำงานรถไฟอยู่ มักกะสัน และมีตลาดที่นั่น เค้าจะโทรมาถามว่าเอาอะไรมั่ง”.

For exchange caregiving, this caregiving network exchanged their time, finances, duration, and communication. Focusing on time, there was negotiation of time among caregiving network members.

“Sometimes I wanted to delegate caregiving of my parent to others. The more siblings we have, the more negotiating we get”.

“บางครั้งให้คนอื่นแบ่งเบาเรื่องพ่อหรือแม่บ้าง พี่ ๆ น้อง ๆ ก็ยุ่งกันไม่ค่อยให้ความช่วยเหลือ”.

With regard to finances, the caregiving networks had direct exchange between the patient and primary caregiver.

“The pocket is under his pillow. He keeps it by himself. When it is the time, my younger brother will withdraw money for him. He gives me 1000 baht. I do not go anywhere and it is enough for me”

“กระเป๋าดังค้อยู่ใต้หมอนเค้า เค้าเก็บของเค้าเอง ถึงเวลาที่ให้น้องสาวไปเบิกมาใส่ไว้ เค้าแบ่งไว้ให้ใช้พูนึง พี่ถือว่าไม่เที่ยวไม่อะไร พอใช้”.

This stroke family lived in this community for a long duration. The stroke patient was an imam who taught Muslim people in the mosque every Friday. Many people knew him and his family members. However, the caregiving network members are family member rather than non-family members.

“I have no idea to employ other person. We have many children”
 “แต่เรื่องจะไปจ้างใครก็ไม่แน่ ลูกหลานมีตั้งเยอะแยะ”

Communication has been direct exchange between the caregiving network members and the primary caregiver. The primary caregiver had directly communicated with caregiving network member.

“Sometimes he (the patient) needed to change wet diaper. (I told) my younger sister, who got married, came to change it. She was not shy and changed it by turning off electricity.
 “บางทีใส่ pampers ก็อึดอัด เค้าแต่งงานเค้ามาใส่ให้ เค้าก็ไม่เงิน เค้าก็ดับไฟมืด ๆ เวลาใส่ให้”

Relating to relationship, there were conflict relationships between the patient, primary caregiver, and caregiving network members.

“My brother had a duty to lift my father to take a bath every morning. He hurried to provide care and did not allow the patient to have self care....He often brought the same shirt to my father and this made him have a fungus at his head and back. My brother felt unsatisfied and my mother was also dissatisfied....”.
 “พี่ชายมีหน้าที่อุ้มพ่ออาบน้ำทุกเช้า เค้าก็จะรีบ ๆ ทำให้เสร็จ อะอะก็จะอุ้มพ่อ ลากพ่อไม่ปล่อยให้เค้าหัดทำเอง พี่ชอบเอาเสื้อผ้าเก่ามาให้พ่อใส่ซ้ำ เรายกบอกทำให้พ่อบมีปัญหาเชื้อราที่ศีรษะและที่หลัง พี่ชายก็ไม่พอใจ มารดาก็ไม่พอใจ....”.

In conclusion, this caregiving network used “sharing care” to exchange caregiving. This network divided functions of caregiving and their roles. There was regular support according to a timetable. Although, there were some conflict relationships, this caregiving network perceived adequacy of caregiving because there were enough caregiving network members and caregiving network members could negotiate and relying on each other.

“If we could not do that, please come to take care of patient instead of me. That was enough for caregiving”.
 “แต่ใครว่างมาแทนกันหน่อย....คิดว่าพอนะ”

Pattern 2: Dual care

The dual care refers to the pattern of social exchange behaviors in which has two primary caregivers, who take care of patient as the buddies. The caregiving network did not divide caregiving but provided dual care together. When a caregiver had limitation, another caregiver shifted to take care to complete the caregiving.

Four caregiving networks had dual care pattern of social exchange behaviors. Both caregivers developed their competency in the same level of caregiving, such as suction via tracheostomy tube and feeding diet (Case # 5), feeding diet (Case # 6, 12), and intermittent catheter (Case # 16). However, there was a caregiving network in which both of them had a difficult level of caregiving in providing insulin injection and making blenderized diet (Case # 6). Two caregiving networks were willing to participate in caregiving while two of them were endurance and accepted to be the primary caregivers. There were two small size networks, and two medium size networks. Relating to “relying on each other”, caregiving networks exchanged their time, finances, and information. All networks had regular support and direct information. Three caregiving networks exchanged caregiving with time schedule while only one caregiving network had negotiation. As a result, two caregiving networks had close relationship while two caregiving networks had conflict relationship as shown in table 4.7.

Table 4.7 Pattern of social exchange behaviors in dual care (4 networks)

No one else can do it		Relying on each other				Whatever 's happen, happen
Satisfaction	Size	Time	Duration	Finances	Communication	
Willingness (2 nets)	Small size (2 nets)	Regular time (4 nets)	Long duration (3 nets)	Regular support (4 nets)	Direct & Indirect communication (2 nets)	Close relationship (2 nets) Conflict relationship (2 nets)
Endurance (2 nets)	Medium size (2 nets)		Short duration (1 net)		Stop communication (2 nets)	

* Net means Network

The conditional factors

The pattern of dual care illustrates social exchange behaviors of caregiving network influenced by the factors, as follows:

1. Satisfaction factor

Two caregiving networks were willing (*tem-jai*) to take care of patients by their internal motivations (Case # 12, 16). They presented their willingness to be the primary caregivers from own self. For example, Mrs. LuLu shared her story as follow:

“When he had a problem, we would go to visit him. It is the blood relation that we never leave him. In the past, he lived with his second wife in *Klong Tai*. I went to see how he lived. When he was fine, I did not worry. Mostly, we all do not neglect our parent. Although he has not provided anything since I was born, I still take care of him”

“แกมีเรื่องอะไร..เราก้ไปเยี่ยมแกมันสายเลือดคนนะนะ คือเราไม่ทิ้งแก สมัยแกไปมีเมีย น้อยอยู่คลองเตย เราก้ไปดูว่าแกอยู่ยังงัย พอแกสบายแล้วเราก้ไม่ได้ห่วงไม่ได้อะไร พวกพี่น้องโดยมากจะไม่ทิ้งพ่อแม่ ทั้ง ๆ ที่แกไม่ได้เลี้ยงดู ไม่ส่งเสียตั้งแต่เรากเกิดมา ไม่มีใคร ที่ช่วยเหลือกันตลอดกับพ่อ”. (Case # 12, pp.401)

The existing evidence shows that two primary caregivers were endurance (*jum-jai*) to accept this role (Case # 5, 6). They described their endurance from the family decision and patient decision. For example, Mrs. Eng talked about her opinion to be a primary caregiver as follow:

“Sometimes, I thought why I take care of him (the patient). I did not take care of my father but he had passed away”.

“เป็นบางครั้ง มันท้คิดเหมือนกันและ อะไรพ่อเราข้งไม่เคยทำ แต่พ่อเราก้เสียไปแล้ว”.

(Case # 5 pp.44)

2. Size factor

Of four caregiving networks, there were two small size (Case # 5, 16), and two medium size (Case # 6, 12). In this pattern, there were two primary caregivers. The primary caregivers did not divide the role of caregiving but they took turns to provide care as buddies.

“He helped me with everything. I could not do that without him because the patient was very heavy. He was spasm when we lifted him. We needed both of us to do that. I could not lift him by myself alone”.

“แกช่วยทุกอย่าง เพราะถ้าไม่มีอาก้ทำไม่ได้เหมือนกัน เพราะเอาแรงแกไม่ไหว เวลา ยกแกเกร็งขึ้นมาเอาแกไม่ไหวละต้องสองคน คนเดียวไม่ไหว”. (Case # 5 pp. 72)

Focusing on function of care, both of them helped each other in caregiving, such as taking a bath, going to follow up at the hospital, retaining feeding tube or Foley's catheter, and so on. In two caregiving networks, they both stayed with the patient all the time. On the other hand, in two caregiving networks one of them went out to work. A primary caregiver provided caregiving during daytime while another primary caregiver took care of the patient during nighttime and on weekends.

“The doctor asked who took care of him. I answered that it was me. When my son got back home, he took care of him instead of me”.

“หมอถามใครดูแลอากง บอกฉันเองดูแล ลูกกลับมาเค้าก็ดูแลแทน”

(Case # 16 pp157)

3. Time factor

In this pattern, four caregiving networks received regular support. There was exchange caregiving in time, duration, finances, communication, and relationship. The caregiving networks provided regular time with schedule. When a primary caregiver had limitation for caregiving, another primary caregiver took turns to do that.

“(While going to follow up), I played a role to connect with others while my aunt stayed with the patient. For example, when she (my aunt) went to the lab for booking the patient, I paid money for the cost of blood testing and went back with the receipt to take the patient for blood testing. We took turns to have a lunch. When she went to eat, I would be there. When she came back, I would go to eat”.

“(เวลาไปโรงพยาบาล) จะคอยติดต่อให้ น้าเค้าจะอยู่เฝ้ายาย เรายังจะวิ่งโน่นทำนี่ อย่างไปเจาะเลือดก็แยกกันละ น้าเค้าจะไปกับรถเข็น เรายังวิ่งไปเสียเงิน แล้วมาหาน้ำอาบัตริทิวไปเจาะเลือด อย่างเที่ยงก็จะผลัดกันไปทานข้าว น้าไปหนูจะเฝ้า น้ามาหนูก็ไปกิน”.

(Case # 6 pp. 406)

4. Duration factor

With regard to duration, three caregiving networks lived long duration in the community (Case # 5, 6, 16). They live in the inner area of Bangkok. The participants talked about caregiving exchange from non-family members in community when they needed help.

“She (the neighbor) came from the northeastern region. We knew her family for six years. Lifting up and down on 1 a.m. or 2a.m., we always called her (to receive help from her husband)”.

“เค้าก็บอกว่าคนอีสานนะ รู้จักกันตั้งแต่เค้ามาอยู่ตรงนี้ 6 ปี ยกขึ้นยกลงตีหนึ่งตีสองไปเรียกเค้ามาตลอด”

(Case # 16, pp. 490)

There is one caregiving network live in the outer area of Bangkok. The patient moved in her daughter's house. The caregiving network members are only family and rely on each other.

“We (primary caregiver) had not asked for help. Mostly, we relied on each other among siblings”

“(ไปขอความช่วยเหลือจากเพื่อนบ้าน) ไม่เคยเลยนะ ส่วนมากพี่น้องช่วยกัน”

(Case # 12, pp. 425)

5. Finances factor

Focusing on finances, four caregiving networks had regular financial support monthly from a member to the primary caregiver. However, it was not enough for living. Three primary caregivers were still working (Case # 6, 12, 16).

“My eldest sister and eldest brother came to visit every month. They gave money to me every month but I paid the cost of ambulance service for transferring to hospital. I paid 1,200 baht per time. Six hundreds baht for going and six hundreds baht for returning back. They had a portable stretcher to carry her. For medicine/drug, we could be reimbursed”.

“พี่สาวคนโตกับพี่ชายคนโตเค้ามาเยี่ยมประจำ เค้าก็มาให้ทุกเดือน แต่ค่ารถเวลาไปโรงพยาบาลเป็นคนออกเอง ไปตามรถโรงพยาบาลมาครั้งละ 1,200 บาท ไป 600 กลับ 600 เค้าก็เอาเปลมารับ ส่วนค่ายาก็เบิกเอา”. (Case # 6 pp. 38)

6. Communication factor

With regard to communication, three caregiving networks had both direct and indirect communication between the primary caregiver and caregiving network members (Case #5, 16). For example, Mrs. Porn talked about indirect communication in caregiving network.

“He (the younger brother of the patient) called me. He knew about his brother (the patient) got sick. He knew only one and spread to all

“เค้า (น้องชาย) โทรมา เค้ารู้หมดแล้วนี่ว่าเค้า (ผู้ป่วย) ไม่สบาย เค้ารู้คนเดียวก็สื่อถึงกันหมดแล้ว”

(Case # 16, pp.427, 635)

In contrast, one caregiving network did not exchange caregiving through communication together (Case #6, 12). For example, Mrs. Fan had problem with her husband. They stop talking together to prevent the problems.

“Silence (looking at her husband and crying). Walking out in a short period. I was very tired and felt quickly heart rate”.

“ผู้ดูแลเงียบ.(นานประมาณ 5 นาทีตาแดงๆ มองหน้าสามี น้ำตาไหลออกมา)ก็เดินออกไปข้างนอกสักพัก นี่ช่วงนี้เหนื่อยมากรู้สึกหัวใจเต้นแรงมาก”. (Case # 6 pp. 49)

7. Relationship factor

Three caregiving networks consisted of intergenerational relationships to take care of their patients while in one caregiving network, the members were adult children. The intergenerational roles were wife and son, aunt and niece, younger brother and daughter in law. Two caregiving networks presented close relationship. For example, Mrs. Lulu described her close relationship with the patient although he did not look after his children in the past.

“He (my father) was close to me when he got sick. Focusing on close relationship, he was close to my sister. When he was healthy, my sister took him to the hospital”.

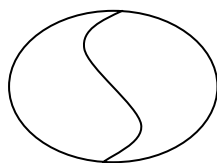
“เพิ่งจะมาสนิทกันตอนไม่สบาย พุดถึงสนิทนะ สนิทกับพี่สาวมาก ตอนที่เค้าดี ๆ พี่สาวเป็นคนพาไป (โรงพยาบาล)”. (Case # 12 pp.179)

Two caregiving networks presented conflict relationships within the caregiving network (Case # 5, 6). For example, Mrs. Eng talked about her conflict to be a primary caregiver but she accepted this role from the good relationships in the past.

“Sometimes, I thought why I take care of him (the patient). I did not take care of my father but he had passed away. However, I was *tem-jai* (willing) to do that because my husband was so nice. He provided many things that I wanted. Particularly, my father was so nice by sweet-talking with me all the times. He was a good man”.

“เป็นบางครั้งก็คิดเหมือนกันแหละ อะไรพ่อเราเรายังไม่เคยทำ....แต่เราก็เต็มใจเพราะว่าอยู่กับแฟนเค้าก็ดีกว่าเราทุกอย่าง อยากได้อะไรเค้าก็ให้ กับพ่อเค้าก็รักเราดี เรียกลูกทุกคำเลย เค้าดีมาก”. (Case # 5 pp. 81)

With regard to “the wheel of caregiving model”, the pattern of dual care was represented by the picture as the shift of water.



These factors influenced the exchanging caregiving including satisfaction, size, time, duration, finances, communication and relationship factors. In the wheel of caregiving model, the pattern of dual care used these factors to mobilize the wheel of caregiving as shown in figure 6. The pathway of dual care is shown in figure 7

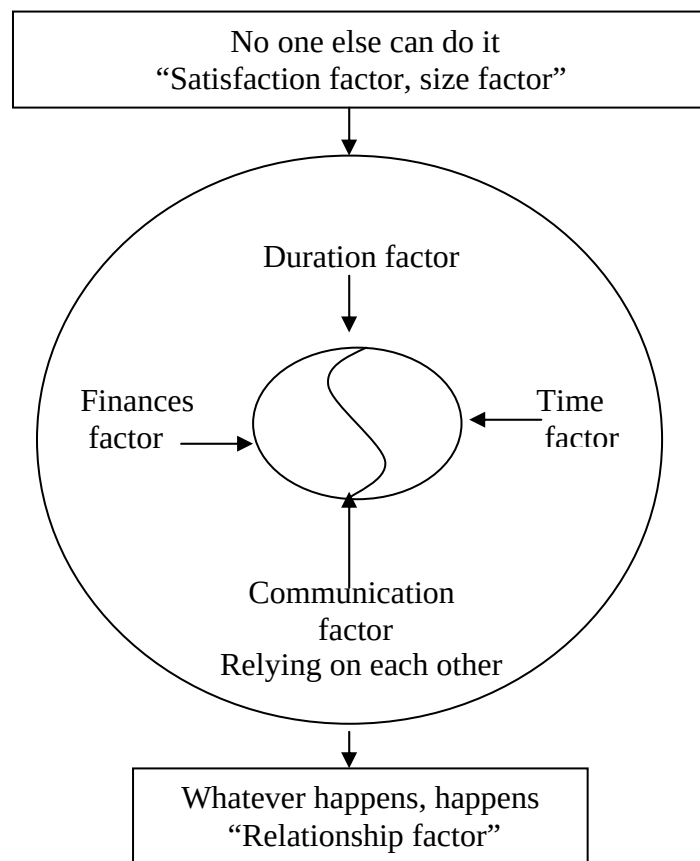


Figure 6: Pattern of "dual care"

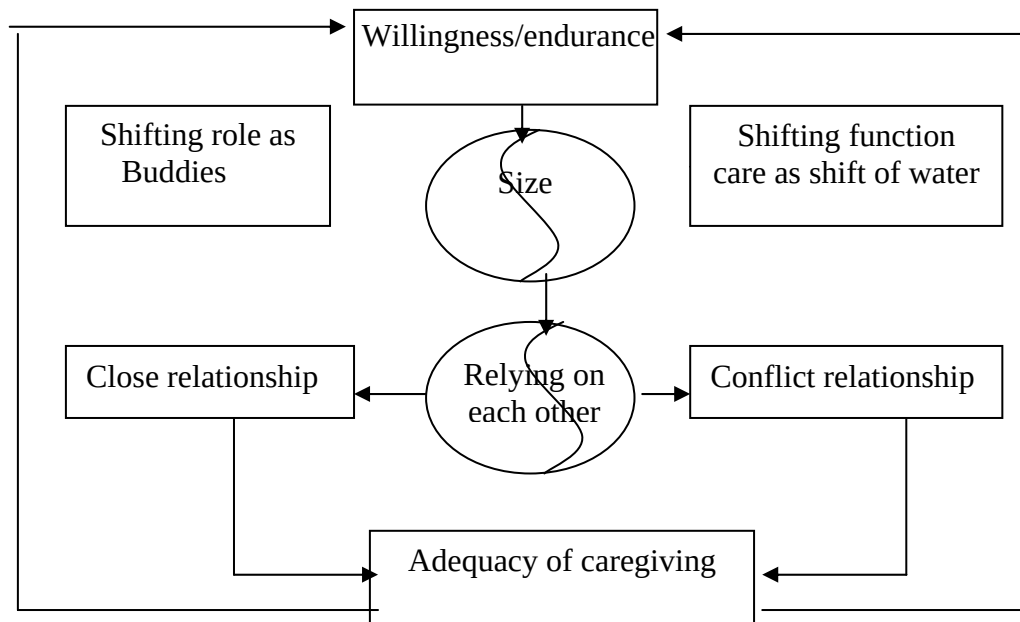


Figure 7: Pathway in pattern of "dual care"

In the dual pattern, the caregiving network exchanged caregiving in physical, psychological, socio-cultural, financial, and emergency aspects. The final process of the wheel of caregiving is to balance caregiving. Only one caregiving network balanced caregiving with close relationship while three caregiving networks had conflict relationships. All caregiving networks perceived of adequacy of caregiving although one of them did not fulfill all caregiving tasks (Case # 6).

Adequacy of caregiving refers to the objective of caregiving which is met by balancing and Imbalanced caregiving. Four caregiving networks perceived of adequacy of caregiving in terms of reducing the objective of caregiving, being not any severe conditions providing the same caregiving, and having a caregiver with the patient all the times as follow:

“He can (do it) because he learns how to provide care together”.

“ได้หมด เพราะเค้าก็เรียนมาด้วยกัน (Case # 5, pp. 29)

“That is enough. If someone goes anywhere, a person takes turn to care. Enough for caregiving”.

“พอ (ตอบพร้อมกันสองคน) ถ้าเกิดจะไปไหนก็ผลัดกันแต่พอทำได้นะ”

(Case # 6 pp. 363)

The caregiving network study of dual care (Caregiving network # 5)

In the inner area of Bangkok, this caregiving network has been set up to take care of Mr. Egg, 74 year-old stroke patient. He had two sons and lived with the eldest son, eldest son's wife, and his youngest brother while his wife had gone abroad to live with his youngest son in Denmark. When Mr. Egg had stroke and was bedridden, his wife arrived in Bangkok to make a decision for caregiving. She allowed Mrs. Eng, her daughter-in-law and Mr. Ed, Mr. Egg's youngest brother to quit their jobs while she and the youngest son provided financial support every month.

Relating to “no one else can do it”, Mr. Egg's youngest brother talked about his opinion from family decision to let him take care of patient. Mrs. Eng shared her opinion to “no one else to do that” and her belief of previous life. At first, both primary caregivers were endurance but they could accept these roles.

. “What else could I do because he had no other person to take care of him” “ทำไงได้เพราะเค้าไม่มีใคร”

“I suspected that I had done bad things to him in the previous life. I had to pay back in the present life”.

“ก็คิดว่าสงสัยชาติที่แล้วเคยเป็นเวอร์เป็นกรรมเค้ามา ชาตินี้จึงมาเจอแบบนี้”

Focusing on the size, this caregiving network was a large size consisting of ten members. Five caregiving members came from family while the rest of members were from outside the family. Two primary caregivers took turns caregiving together in the role of buddies. The daughter in law and the youngest brother of the patient helped together with taking a bath, providing suction via tracheostomy, doing laundry and going to the hospital.

“We mainly took care together (and could not identify who was primary caregiver) yes. In the past, I did it by myself alone. When I went anywhere, I had to prepare another caregiver to take care of him”.

“ส่วนมากก็ดูกันสองคน (จะบอกว่าใครเป็นหลักไม่ได้) ไข่ เมื่อก่อนหนูคนเดียวทำทุกอย่างหมด ตอนหลังเพื่อเราไปไหนมาไหน”.

For “relying on each other”, this caregiving network exchanged their time, duration, finances, and communication. Focusing on time, two caregivers did not separate their functions of caregiving but both of them blended and took turns caregiving.

“We did not talk about your job or my job. For example, she took the clothes to laundry and went to take a bath. When the laundry machine stopped working, I would take the sun-dried clothes...We did not separate care, we helped each other whenever we were available”.

“ไม่มีคุยว่าใครทำหน้าที่นั้นหน้าที่นี้ สมมติว่าคุณ.....เอาผ้าไปซักแล้วอาบน้ำอยู่ พอเครื่องซักผ้าหยุดผมก็เอาไปตาก ไม่แบ่ง ใครทำก็ทำไปอะไรขาดอะไรสกปรกก็ล้างใครว่างก็ทำ”.

Relating to duration, this network had long duration in the community. There were caregiving supports from the neighbors from their relation in the community.

“There was a neighbor nurse who stayed here. If the feeding tube was pulled out, she came to help us”

“มีคนในนี้เค้าเป็นพยาบาล เค้าอยู่ใกล้ ๆ ตรงนี้ ถ้าสาขอะไรหลุดเค้ามาช่วย”

Regarding financial factors, there was productive exchange of finances between the patient, the patient’s wife and primary caregiver.

“My income was decreasing. The patient’s wife gave some money to me. My husband gave it too. I did not send money back to my mother because they sent it instead to me. They solved all of my problems”.

“ลดลง แต่แม่เค้าก็ให้มั่ง แพนเค้าก็ให้ เวลาส่งไปให้แม่ที่บ้านเราก็ไม่ต้องส่ง เค้าก็จัดการให้หมด ไม่มีปัญหาอะไร”.

Relating to whatever's happen, happens, there was conflict relationship between the patient, primary caregiver and caregiving network members.

“Sometimes I thought about caregiving because I had never taken care of my father before. However, I was willing to do that because my husband was so nice. He provided many things that I wanted. Particularly, my father in law (the patient) was also nice by sweet-talking with me all the times. He was a good man”.

“เป็นบางครั้งก็คิดเหมือนกันแหละ อะไรพ่อเราเรายังไม่เคยทำ....แต่เราก็เต็มใจเพราะว่าอยู่กับแพนเค้าก็ดีกว่าเราทุกอย่าง อยากได้อะไรเค้าก็ให้ กับพ่อเค้าก็รักเราดี เรียกลูกทุกคำเลย เค้าดีมาก”.

In summary, this caregiving network used “dual care” to exchange caregiving. This network blended functions of caregiving and took the buddy role to help each other with caregiving. This caregiving network perceived adequacy of caregiving because both of them could provide care instead of another caregiver.

“He could (do it all). We learnt how to provide care together”.

“ได้หมด เพราะเค้าก็เรียนมาด้วยกัน

Pattern 3: Supplementary care

Supplementary care refers to the pattern of network exchange in which primary caregiver was mainly taking the functions of care and a caregiver role by herself/himself alone. All primary caregivers presented occasional support from caregiving network members and needed help.

Six caregiving networks were described the supplementary pattern of social exchange behaviors. Four caregiving networks were willing to provide caregiving with internal motivation while two caregiving networks were endurance and had external motivation from family decision. The majority of this pattern was small size (3 networks). Two caregiving networks were medium size, and one large size. For “relying on each other”, caregiving networks exchanged the time, finances, and information. Most caregiving network members provided regular support and they did in the times that they were available. There was equal between direct and indirect information. Only one caregiving network had close relationship while five caregiving networks had conflict relationship. The result was shown in table 4.8.

**Table 4.8 Pattern of social exchange behaviors in supplementary care
(6 networks)**

No one else can do it		Relying on each other				Whatever' s happen, happen
Satisfaction	Size	Time	Duration	Finances	Communication	
Endurance (6 nets)	Small size (3 nets)	Regular time (5 nets)	Long duration (4 nets)	- Regular support (4 nets)	-Direct communication (3 nets)	-Close relationship (1nets)
	Mediu m size (2 nets)	Irregular time (1 net)	Short duration (2 nets)	Occasio nal support (2 net)	-Indirect communication (2 nets)	-Conflict relationship (5 nets)
	Large size (1 (net)				Stop communication (3 nets)	

*Nets mean Networks

The conditional factors

The social exchange behaviors of supplementary pattern influenced by four factors as follows:

1. Satisfaction factor

In the supplementary pattern, all primary caregivers described their endurance (*jum-jai*) from external motivation. Three primary caregivers presented the change of former caregivers because of death (Case # 15) and relocating to another province (Case # 9, 13) while two caregivers had no one else qualify (Case # 10), and the need of patient (Case # 1). Only one primary caregiver talked about her needs of freedom if the patient got better (Case # 3).

“If he got well, I did not stay with him (all the time). He would go anywhere he wanted. If he wanted to go back home, he could come in. If he wanted to eat, he could do that. But I had freedom to go anywhere and did not worry about his condition. This was my goal”.

“คือถ้าเค้าดี เราจะได้ไม่ต้องมาอยู่กับเค้าอย่างนี้ เค้าจะไปไหนก็ไป ของเค้าอยากกลับบ้านก็

มา อยากกินก็กิน ไม่อยากกินก็ไป แต่เราเป็นอิสระหัวทกกันชีวิตของเรา ไม่ต้องห่วงทาง
นี้ คือต้องการเท่านั้นแหละ” (Case # 3, pp. 72)

2. Size factor

This pattern was mainly found in small size caregiving network. There was one medium size and one large size. In four caregiving networks, the wife played the role of caregiver (Case # 3, 9, 10, 15), while two primary caregivers were adult children (Case #1,13). Three wives took role as a leader (Case # 3, 9, 10) while one patient was the leader of caregiving network (Case # 15) and two eldest daughters played the role as a leader of caregiving networks (Case # 1, 13).

“Yes. It is our obligation. Each person of our family has their own responsibility. The person downstairs takes care of the patient and takes a role to make income. If there was nobody downstairs, all of us would starve. She was the leader of our family. My sister”.

“ถือว่าเป็นหน้าที่ ในครอบครัวของเราก็มีหน้าที่แต่ละอย่างที่ต้องทำ ส่วนข้างล่าง (พี่สาว) ก็มีหน้าที่ทั้งดูแลคนป่วย (สามี) และหาเงินเข้าบ้าน ถ้าไม่มีข้างล่างก็อดทั้งบ้าน ถือว่าเป็นหัวหน้าครอบครัวคนเดียว”.

(Case # 13 pp. 293)

The primary caregiver took responsibility to provide caregiving by himself/herself alone. As a result, some primary caregivers needed to develop skills and knowledge to provide caregiving.

“I was not skillful but I needed to be skilled. The nurse taught me..... My daughter didn't do it...Let me go to learn because I had no one. I needed to learn so that I could do it”

“ไม่เก่งก็ต้องเก่ง หมอเค้าสอน ลูกไม่เคยทำเลย ไหน ๆ ก็ไหน ๆ แล้ว ไม่มีใครทำก็ต้องทำ”.

(Case # 9 pp. 48)

3. Time factor

In this pattern, there were caregiving exchanges between provider and receiver in time, finances, and communication. With regard to time, all caregiving networks received occasional support. There was supplementary care from caregiving network members at the time when they were available. For example: Mrs. Jun's daughter shared her story of time that she was available to help her mother.

“Everyone will provide help at the time when we are available... Sometimes my mother and father expect the children to take care of them...I argue to wake up late on weekend. I do not to wake up at the same time as when I go out to work. She has her timetable. She thinks that I should wake up early”.

“คือเราทุกคนจะให้แต่ให้ในช่วงเวลาที่สะดวก...บางทีเค้าคาดหวังลูกนี้ทั้งพ่อด้วย เค้าคาดหวังว่าปรนนิบัติพ่อแม่ เสร็จอาทิตย์ขอสายได้มัยไม่ใช่ต้องตีห้าเหมือนเวลาทำงานนะ แม่...เพราะของเค้าต้องมีเวลาปะ ๆ เค้าคาดหวังว่าตื่นแต่เช้า”.

(Case # 10 pp. 328, 364)

4. Duration

Four caregiving networks lived a long duration in the community while two caregiving networks had short duration. Some primary caregiver said when the patient needed emergency care, her neighbor provided help to her in the nighttime..

“In the nighttime, I asked my neighbor beside my house to find out taxi if my husband had convulsion. I had an experience to go to the hospital with him. Then, I called to my daughter..... When she finished her work, she would follow to us”

“กลางคืนบอกข้างบ้านไว้เลยถ้าชักอะไรให้เค้าไปตาม taxi เดียวไปกับคนไข้ เคยมีเหตุการณ์มาแล้ว โทรบอกส้ม.....เค้าเลิกงานเค้าตามไป” (Case # 9 pp. 240)

5. Finances factor

Focusing on finances, four caregiving networks received regular support (Case #1, 3, 9, 13). Two caregiving networks said it was not enough for caregiving. As a result, one primary caregiver was still working.

“Her niece gave 300 baht per month to her while her children did not give anything”.

“ลูกสาวเค้าให้เดือนละ 300 บาท เค้าจะให้ยายทุกเดือน ลูกซะอีกไม่เคยมีใครมาให้”.

(Case # 1 pp.74)

6. Communication factor

Relating to communication, three primary caregivers talked about their needs directly to caregiving network members (Case # 9, 10, 13), while two caregivers used indirect communication to seek help for their limitations, such as lifting patient to take a bath, taking patients to follow up at the hospital (Case # 1, 3).

In the past, I lifted her to take a bath by myself. She saw that I could not lift my mother. She provided a bath every Sunday”.

“เมื่อก่อนนี้อาเบเอง เค้าเห็นเรายกไม่ค่อยไหว เค้าก็มาช่วยมาอาบน้ำให้เอง เดียวนี้วันอาทิตย์ เค้าหยุด เค้าก็ลงมา”.

(Case # 1 pp.96)

7. Relationship factor

This pattern mainly consisted of spouses in relationships taking care of their husbands while two in caregiving networks it was the adult children. Five caregiving networks presented conflict relationships (Case #1, 3, 9, 13, 15) while one

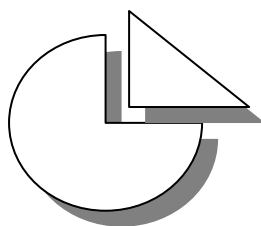
caregiving networks presented the close relationships within the caregiving network (Case # 10).

“I must take care of her because there is no-one else to care. There are no other people to do it. Someone said she had no time. Another said she went to work. My younger sister is not insufficient as me but she cannot stay with her. O.K. No problem. Yes, I can. She is also my mom. If she gets worse, I will not tell anyone”.

“ต้องดูแลเพราะไม่มีใครเค้าดู ไม่มีใครเค้าเอา บางคนเค้าบอกว่าไม่มีเวลาดูมั่ง ไปทำงานมั่ง อย่างน้องสาวเค้าไม่อดทนต่ออย่างเรา แกก็อยู่กับเค้าไม่ได้ เอ้า ไม่เป็นไรดูได้ แม่ดูเหมือนกัน ถ้าแม่เป็นอะไรไป ลูกจะไม่บอกมันซักคน”.

(Case # 1 pp.81)

Six caregiving networks fitted the “supplementary care” pattern. This picture refers to supplementary functions of caregiving as fulfill by doing alone or alternated care



The factors influenced the exchanging caregiving, including satisfaction, size, time, duration, finances, communication, and relationship factor. The factors are mobilized the supplementary care pattern as shown in figure 7. The pathway of sharing care is presented in figure 8

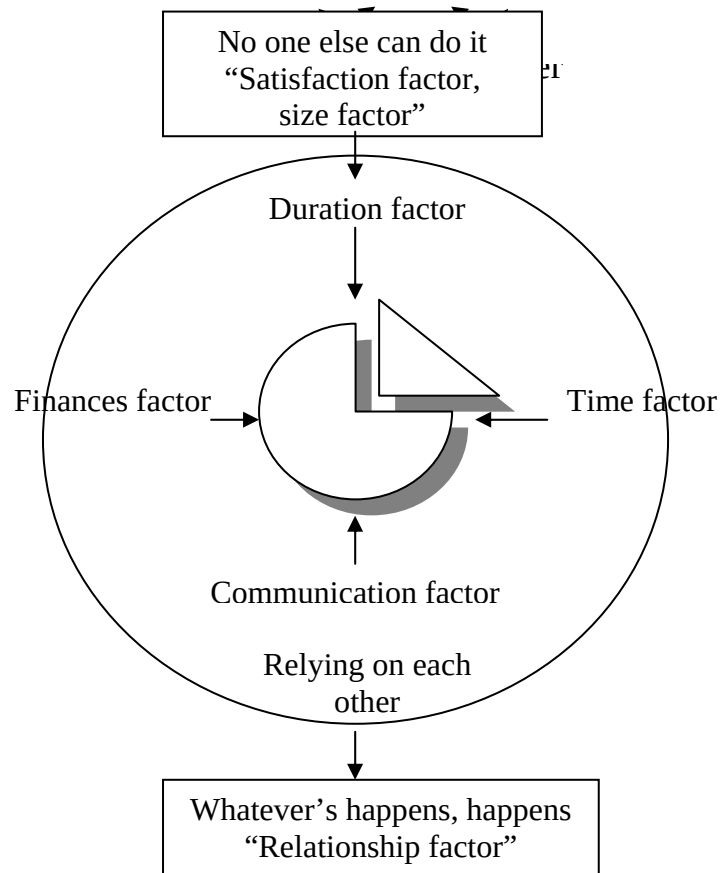


Figure 8: Pattern of “supplementary care”

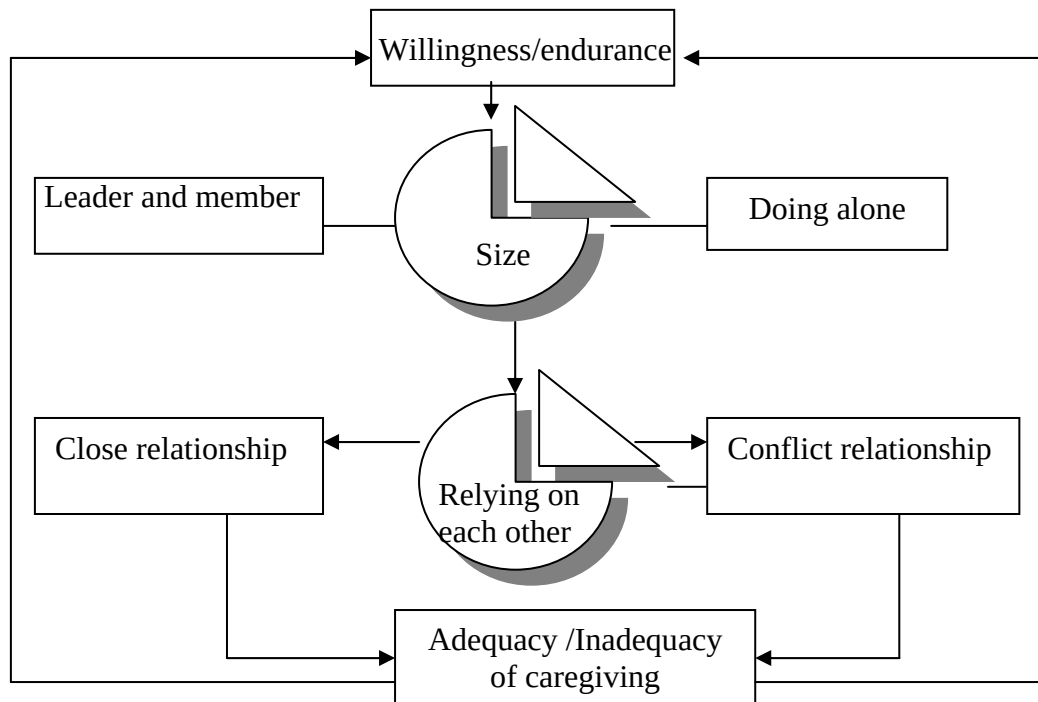


Figure 9: Pathway in pattern of “supplementary care”

The supplementary pattern has presented the limitation of social exchange behaviors. The caregiving networks exchanged caregiving in physical, psychological, socio-cultural, financial, and emergency care. They were exchanged of caregiving in time, finances, and information. One caregiving network had close relationship while five caregiving networks had conflict relationships. Four caregiving networks perceived of adequacy of caregiving while three caregiving networks perceived inadequacy of caregiving.

Adequacy of caregiving is the objective of caregiving which is completed by balancing and unbalancing caregiving. Four caregiving networks negotiated by the time that they were available (Case # 1, 3, 10, 15), while two caregiving networks did so by his/herself alone (Case # 9,13). Three caregiving networks perceived of adequacy of caregiving (Case # 1, 3, 13, 10) and presented helping in the difficulties of caregiving, and sustaining caregiving as follow:

“I will take care of her until she dies. If she is dead, I think it stops taking *vain* and *karm* (bad doing) between my mother and I.... I think to take care of her until the end. Keeping on caregiving to the end of life”

“ทำจนกว่าเค้าจะไป ถ้าเค้าไปก็ถือว่าหมดเวรหมดกรรมกับเค้าและเรา เราก็คิดอย่างนี้ ก็ดูจนกว่าจะถึงที่สุดแหละ ดูจนถึงที่สุด”. (Case # 13 pp. 288)

Inadequacy of caregiving is the objective of caregiving, which is not met. Three caregiving networks described the inadequacy of caregiving (Case # 9, 15) in terms of having no daughter, doing it by his / herself alone and withdrawal of caregiving.

“My son lived by himself in Koh Samui. My niece stayed in Nakorn Prathom. That was difficult for me to care for him without any help from others. Easily talking that was withdrawal. In the nighttime, I could not sleep...for five years ago. Sometimes, when I started eating rice, I can hear the secretion sound (fod..fod) and bubble happened. I was truly talking that made me withdraw.

“ลูกชายก็อยู่เกาะสมุย อยู่ตัวเค้าคนเดียว หลานอยู่นครปฐมนี่มันลำบากลำบาก ถึงบอกว่าถอดใจถอดใจเลย พุดกันง่าย ๆ เลขนะ ถอดใจเลย กลางคืนก็ไม่ได้นอนบางทีข้าวเข้าปากปุ๊ป ฟอด.. ฟอด เมื่อกี้เป็นโป่ง นี่พูดเรื่องจริง ถึงบอกถอดใจใจ”

(Case # 9, pp.445)

The caregiving network study of supplementary care (Caregiving network # 10)

This caregiving network was in the central area of Bangkok. Mr. Jim, a 78 year-old stroke patient lived with his wife. They had four daughters. They stayed with the second daughter and the third daughter while the eldest daughter and the youngest daughter had married. The third daughter got married and stayed with her parents on office days and went to her resort in Koh Chang to stay with her husband on weekends. The second daughter was single and was an executive nurse in a private hospital. She stayed in the hospital during weekdays and went back home on weekends. All children often came to join together on weekends and holidays.

Mrs. Jun, 75 year-old, was the oldest caregiver in this study. She had had myocardial infarction for three years. She used sublingual pill to release angina pain when she was tired and had a lot of activities. After she received cardiac catheter, she got well and thought that she got healthy because of good deeds in the past. When she went back home, she gave her treasures to her four daughters and did not use any sublingual pill. With regard to “no one else can do it”, when the patient got stroke, she played the role as primary caregiver. At the beginning, the third daughter hired a paid caregiver to help Mrs. Jun but there were many problems.

“The first reason is that she is miser. She is concerned about the high cost. The second reason is that the private caregiver is not clean. (He smokes). The third reason is that my house has not had any servant before. Many things were left around the house. My younger sister did not say anything before he came here. I could not go out. I was so stressed.....I had no diamond or gold, but my watch and money were kept carefully. The closet was opened the lock before. It needed to be locked. Lastly, when my mother did not stay at home, I had already fed the food to my father. I had a time to go outside for two hours because my father had no pressure sore. I could go to fitness or everywhere. When he came here, I could not go anywhere. Moreover, I needed to prepare food for him and clean the dishes...It was difficult to go out and plan all day”.

“อันที่หนึ่งลึก ๆ เค้าก็เหนียว เค้าไม่ยอมให้ลูกเสียดั่งค์ อันที่สองไปได้คนที่ไม่ชอบเค้าไม่ค่อยสะอาดเท่าไร (สับบุหรี่)อีกอย่างหนึ่งที่บ้านเราไม่เคยมีคนใช้ข้าวของเราวางระเกะระกะอยู่ ๆ ส่งมาเลย พี่ก็เครียด วันนั้นพี่ออกจากบ้านไม่ได้เลย....จริง ๆ ข้าวของเพชรทองเราไม่มี แต่สตางค์เราก็วางตู้ไม่เคยต้องใส่กุญแจ ทำยสุดท้ายแม่พี่ไม่อยู่พอพี่ป้อนข้าวเสร็จพี่เว็บสองชั่วโมงได้เพราะพ่อพี่ไม่มี bed sore พี่เว็บไป fitness ได้พอคนนี้มาพี่ไปไหนไม่ได้ หน้าที่พี่ต้องหาข้าวให้เค้ากิน ล้างจานให้อีกต่างหาก ...มีหน้าเค้าจะกินอะไร ต้องมาพะวง...ต้องวางแผนทั้งวัน ปกติถ้าเราอยู่คนเดียวจะไปซื้ออะไรเราก็ปิดบ้าน”.

Focusing on the size of caregiving, this network was a large size and consisted of nine members with seven family members and two members from outside the family members. Mrs. Jun talked about the adequacy of caregiving members.

“I am tired. My eldest daughter has much more work. Two nieces are studying and she needs taking care of. There is a nephew of the youngest daughter who came to help with bathing during his school break. My third daughter is so skillful. The fourth daughter’s husband has no skill but is better than the eldest daughter’s husband”.

“เหนื่อยเหมือนกันแหละ แต่คนที่อยู่เทคนิค (ลูกสาวคนโต) เข้ามาระยะ ลูกสาวสองคน กำลังเรียนต้องคอยรับส่ง มีหลานชายลูกของลูกสาวคนเล็กเข้ามาช่วย ช่วงปิดเทอมเค้าก็มาช่วยอาบน้ำ มาช่วยยก...แต่ลูกสาวคนที่สามเค้าเก่ง เค้าเอาพ็อคลิ่งไปอาบน้ำได้ คนนี้คนเดียวเก่ง ลูกเขยที่เป็นตำรวจยังละเทะแต่ลูกเขยคนใหญ่ยังไม่ได้เรื่อง”.

For exchange caregiving, there were exchanges of time, finances, duration, and communication. Focusing on time, there was the time available among caregiving network members to alternate care instead of caregiver.

“Everyone will provide help at the time when we are available... My mom wanted to go to make merit on the holy day. I had to make a schedule for every one otherwise I would have to do it by myself alone”

“คือเราทุกคนจะให้แต่ให้ในช่วงเวลาที่สะดวก.....แม่พี่เค้าจะขอวันพระใหญ่ พี่เค้าจะไปทำบุญ ที่นั่นพี่เค้าเตรียมแล้วลือคจัดเวร เพราะไม่งั้นจะตกพี่คนเดียวเพราะพี่คนเดียว

With regard to duration, the primary caregiver knew many neighbors.

“My mother provides extremely help to other. She has much more virtue. I do not care as much as her because I have selected some doing. She has many cousins and friends because she is sincerely, and honesty. She does not impose on anyone. Therefore, many people love her”

“เพราะแม่พี่เป็นคนที่มีอะไรเค้าช่วยเหลือที่ใจกะ เค้ามีบารมีเยอะ เรายังไม่ได้ทำเท่าเค้า เพราะเรายังมานั่งเลิอกงาน เค้าจะมีตรงนั้นเยอะ ญาติมิตรเยอะ ความที่เค้าจริงใจเค้าซื่อ ไม่เอาเปรียบใครอะไรอย่างนี้ คนก็จะชอบกันเยอะ”

Relating to finances, this caregiving network had regular support to the primary caregiver from the caregiver network members.

“I was the one who provided support. I loved shopping. I would buy everything for them. When it was a time, I would buy for them. But the time, I needed it”.

“พี่จะเป็นฝ่ายสนับสนุนในเรื่องของค่าใช้จ่าย แล้วไม่ต้องมาค้ำนิงหрок พี่ชอบ shopping พี่จะซื้อทุกอย่างที่มีอยู่ ก็จะซื้อทุกอย่างไปให้ พอถึงเดือนก็จะมีไปหมด แต่เวลานี้ขอ”.

For communication factors, there was direct communication among caregiving members. There was *tang-kon-tang-arsai-kun* (depending on each other). The neighbor knew about the difficulty of the primary caregiver. She (neighbor) provided help to her with buying some food because the primary caregiver's daughter had helped her mother by replacing the feeding tube to her mother in the past.

The neighbor's house maker bought it by herself. She managed what kinds of food and bought it without orders. She prepared the fruits and desserts alternatively that made me satisfied. *Tang-kon-tang-arsai-kun* (depending on each other). Her mother had had stroke for seven years. My daughter provided changing her feeding tube every fifteen days. Her mother did not go to the hospital. We depend on each other".

“เด็กบ้านนี้เค้าซื้อให้ เค้าจะจัดมาเลยวันไหนซื้ออะไร ไม่ต้องจด เค้าจะจัดผลไม้ของหวาน เปลี่ยนมาถูกใจ ต่างคนต่างอาศัยกัน แม่เค้าเป็นอัมพาตมา 7 ปี ลูกสาวเนี่ยทุก 15 วันจะไป เปลี่ยนสายยาง แม่เค้าไม่ต้องไปโรงพยาบาล เค้าอาศัยเรา เราอาศัยเค้า”

Relating to relationship, there was a close relationship between the patient, primary caregiver, and caregiving network members.

“When he was healthy, I was not close to him by touching his cheek, pinching his cheek, and teasing him. I am one of the older generation that does not hug together. When he got sick, we became closer”

“ถ้าพ่อเค้าดี ๆ อยู่เราคงไม่ไปใกล้ชิดแตะแถมดั่งแถมเหย เรารุ่นเก่าจะไม่กอดคลูกคลี พ่อป่วยมันรู้สึกกว่าพ่อกับเราใกล้ชิดกันมากขึ้น”. (Case # 10 pp. 645)

In conclusion, this caregiving network used “supplementary care” to exchange caregiving. This network took the functions of caregiving by receiving support from caregiving network members when the time was available. The caregiving network exchanged caregiving of time, finances, and information factors to mobilize the wheel of caregiving. This caregiving network perceived adequacy of caregiving from enough caregiving network members and good relationships to help each other.

“In my opinion, my father is getting better. I worry about my mother. she is going from bad to worse. Yet, she has still fixed her ideas and does everything by herself. I am concerned about how to release her from this job”.

“พี่ว่าพ่อพี่ดีขึ้น แต่พี่นะห่วงแม่พี่ เค้านับวันถอยกำลังลงไป ถ้าเค้ายัง fixed idea ต้องดูแลเอง ต้องทำเองหมดทุกอย่าง”.

“I was tired”

“เหนื่อยเหมือนกันแหละ”

CHAPTER V

DISCUSSION

This ethnographic study has described and explored the patterns of social exchange behavior of stroke caregiving network in Bangkok. In this chapter, the research findings are discussed in terms of the demographic characteristics of the participants and the patterns of social exchange behaviors of stroke caregiving networks. In addition, a discussion of the wheel of caregiving model is undertaken. Lastly, there are discussions of theoretical issues and methodological issues.

Demographic characteristics of the participants

The family caregivers

The forty-two participants in this study came from 18 caregiving networks. There were 22 primary caregivers and 20 caregiving networks members. Focusing on primary caregivers, all of them were family members. The majority of primary caregivers were female (83.6%) and there were three male primary caregivers (13.6%) who took care of nine male and nine female stroke patients. The participants generally believed that caregiver role was appropriate to women. This result is congruent with other stroke caregiving studies that have also found that women are perceived as appropriate for the caregiver role (Bakas et al., 2004; Im-ote, 2007, Subgranon & Lund, 2000; Tang & Cheng, 2002). Similarly, world wide elderly care studies have also found that 75-84% of those playing the role of primary caregiver (Family Caregiver Alliance, 2009; Mak, Mackenzie & Lui, 2007; National Alliance of Caregiving and the Center of Productive Aging, 2008). This result is also congruent with a meta-analysis of 229 studies which found that the informal caregiver were mostly woman (Pinquart & Sörensen, 2006).

According to gender theory, the caregiver is perceived as the woman's role because of social norms and ideological behaviors. For the social norms, a woman is expected to take care of household work while the man is expected to be in the

workforce earning the family income. Relating to ideological factors, caregiving behaviors consist of care activities, such as cleaning, preparing food, and etc. These are perceived as a part of woman's role while the home maintenance chores, and finances are the man's role (Walker, Pratt & Eddy, 1995). Based on gender theory, Matthews and Rosner (1988) developed five types of helping patterns for help given by adult children to elderly parents. These five types were routine help, back up help, circumscribed help, sporadic help, and dissociation. This study found that caregiving network members provided caregiving relating to the gender as follow:

1. Routine help refers to regular support that is appropriate to daughters.

In this study, primary caregivers, mostly daughters of stroke patient, provided routine care, such as feeding, giving medication, giving a bath, and staying with the patient all the time.

2. Backup help refers to predictable support. Daughter mainly offered this help. This study showed that other daughters helped patients worship Allah, and they bought food and materials, prepared feeding diet, and provided dressing of cystostomy tube, and gastrostomy tube etc. (Case # 2, 4, 6, 7, 8, 11, 14, 17, 18).

3. Circumscribed help refers to predictable support. Son mainly provided this as financial support. (Case #2, 6, 7, 14) However, this help was not limit to male; daughters also gave monetary support (Case # 8, 12, 13, 17).

4. Sporadic help refers to occasional support that was common from sons. This study showed that sons and sons-in-law helped patients with driving to follow up at the hospital (Case #.3, 7, 12,15, 17, 18), and driving to the seaside (Case # 2).

5. Dissociation refers to changing of help when a caregiver could not provide specific cares, such as giving a bath, or cleaning specific area (Case # 2, 11).

In this study, three male caregivers played the caregiver role although some caregivers had limitation in providing some specific cares, such as giving a bath. or female hygiene cleaning. The family incorporated other caregiving network members to perform this care. Based on the principle of substitution, when care provider and care receiver are of a different gender, there is a "strong sense of gender boundaries" (Campbell & Martin-Mathew, 2003). As a result, a female caregiving member provided care instead of the male caregiver because of the reluctance of males to perform cross gender care (Case # 2).

In this study, all stroke patients had been married and most of them had children. Seven patients were widowed, and one was divorced. Consequently, about two-thirds of primary caregivers were adult children (72.7%) while one-third of them were wives (27.2%). This result was consistent not only with Thai stroke caregiving studies (Natechang, 2002; Perkdetch, 2002; Sangboon, 2002; Songwattanyut, 2002; Subgranon & Lund, 2000), but also with a systematic review of 80 family caregiving studies for patients with chronic illness in Thailand (Sirapo-ngam, 2003) in which most of the family caregivers were adult children. In contrast, only a few Thai caregivers and some Western caregiver studies for elderly stroke patients have found that most caregivers were spouses (Anderson et al., 1995; Bakas et al., 2004; Meesuk, 2004; Niyomthai et al., 2003; White, Poissant, Côté-LeBlanc & Wood-Dauphinee, 2006). Moreover, using data from the 2007 survey of the older people in Thailand, on the patterns of family support to Thai elderly people, the highest level of living arrangement reported was of older adults who were living with three generations: grandparents, mother/father, and children in the same household (Sunthorntada, 2009). In the intergenerational context, there is a transmission of cultural value to the adult children to encourage the adoption of caregiver roles for taking care of older adults in the family (Piercy & Chapman, 2001). Similarly, in the context of Thai family and society, the children learn how to take care of elderly people from their family actions (Wannasiri, 1998). Various studies show the same result that adult children were the main primary caregivers in Thai caregiving (Chaum, 1998; Hirunchunha, 1998; Kenchaiwong, 1996; Kopachon, 2002; Natechang, 2002; Sangboon, 2002).

These adult children caregivers were identified as youngest daughters (22.7%), the eldest daughters (9%), and other daughters (22.7%). The numbers of the youngest daughters reported was lower than an elderly care study in Northeast Thailand which slightly over 25% were youngest daughter (Caffrey, 1992). Even though two youngest daughters were living with the patients, they could not be the caregivers. They could not leave their jobs in a jewelry factory and in the National Bank and they asked other daughters to play a caregiver role instead of them (Case # 14, 17). As a result, the numbers of the youngest daughter providing care as the primary caregiver in Bangkok was smaller than the numbers of the youngest daughters playing that role in Northeast Thailand. In accordance with Thai social value, daughters bring

their husbands into their houses when they get married. The youngest daughters stay with the elderly parents and take care of their parents until they pass away (Caffrey, 1992; Sasat, 1998). This study also found that five of the youngest daughter played the primary caregivers role because they had stayed with the patients before. In contrast under traditional Korean, Japan, and Chinese cultural norms, the first daughter-in-law is the main person to provide caregiving for elderly parent-in-laws (Kim, 2001; Yamamoto & Wallhagen, 1997; Zimmer & Kwong, 2003). The traditions of filial piety and living arrangement reflect the different characteristics of the daughter who came to take care of her husband's family rather than her own family. For example, an evidence-based study indicated that elderly Koreans, having only one daughter, were liable to move into nursing home when they could not provide care for themselves (Shin, 2008). Although Thai adult children provide the same caregiving as adult children in Asian countries, but there is a difference of culture in that the daughter and not the daughter-in-law is usually the primary caregiver of the elderly.

In this study, the adult children's age ranged from 28 to 75 years with an average age of 52 years. The mean age of caregivers was close to the mean age of primary caregivers in some other stroke caregiving studies in which it was between 50 years and 54 years (Natechang, 2002; Sritares, 2004). In the book *"Women over 50: Caregiving Issues"*, women over the age of 50 mostly played the caregiver role (Ackerman & Banks, 2007). Other studies had a lower mean age of the caregiver at between 42 years and 48 years (Chaiyawut, 2004; Niyomthai et al., 2003; Perkdetch, 2002; Kopachon, 2002; Sangboon, 2001). In this study, eleven caregivers were married. Relating to the concept of "woman-in-the-middle" (Brody, 2006) and the "the sandwich generation" (Abaya, 1999), the middle-aged women provides care to their parents and children as norm (Stull, Bowman & Smerglia, 1994). These results were showing adult children of middle age take caregiver roles are congruent with results on Thai culture.

Most of the caregivers were Buddhists and only three caregivers were Muslim. Given the Buddhist belief of reciprocity, the primary motivation came from a strong sense of parent repayment or "*Katanyu Katavedi*" (sense of gratitude and action to pay back), these caregivers believed that they provide caregiving to repay their elderly parents for caring for them in the past as children (Caffrey, 1992;

Kespichayawattana, 1999; Sasat, 1998). In addition, Thai people believe in “*karmic Buddhism*” in which “*karma*” or “action” of individuals done in the past or in the present life, may manifest itself immediately or a long time into the future or in the next life (Sasat, 1998). When individuals provide care for their parents, their children will provide care for them in the future. When a person has not taken care of elderly parents in the past life, a person’s karma may appear, in the present life, obliging them to a care for their parents to discharge their own karmic, indebtedness. In this study, some caregiver believed that they provided care to the patients because of indebtedness to them in the past or in the previous life (Srinim, 2002; Subgranon & Lund, 2000) (Case # 3, 5, 8, 13). But in contrast, they also believed that the patients had done some bad thing in the past life and their parents had stroke because of their own indebtedness (Case # 4, 6) or “*karma*” in both cases (Case #9). Similarly, Muslim caregivers believed that heaven is under the mother’s feet and the caregiving is a kinship role (Case # 7, 8, 11). Therefore, stroke caregivers believed that caregiving is making a virtue and they did not want anything in return from the patients.

The duration of caregiving was between one and five years with an average of four years. Relating to the wear and tear model of caregiving, Bookwala (2009) illustrated that the increasing of caregiving demands destroys the caregiver’s resources and health conditions. This present study found that four former caregivers passed away and 14 caregivers had at least one underlying disease. Although eight caregivers had no health problem, they were also concerned about their future health. The caregivers were at risk of poor health when the stroke patients declined their functional status (Nelson et al., 2008).

Moreover, most caregivers had low education and four of them had no formal education. This result is congruent with previous studies on stroke caregiving in which around 43-70 % of stroke caregivers had low education (Niyomthai et al., 2003; Sit et al., 2004; Songwatthanayut, 2003; Sritares, 2002). In addition, this characteristic corresponded to work: ten caregivers did not work while more than half of the caregivers worked at home and outside the home. This result is similar to other studies of stroke caregivers in Bangkok in which 27-42% of stroke caregivers quit their jobs to take care of the patients (Sangboon, 2002; Saengratsamee, 2004). Similarly, 30-36% of Western stroke caregivers decreased their working hours or quit their jobs to take care

of the patient (Ko, Aycock & Clark, 2007; Scharlach, 1994; Van Puymbroeck & Rittman, 2005). Evidence from studies in rural areas has shown that 41-62% of stroke caregivers had to take early retirement from their work to provide caregiving (Perkdetch, 2002; Songwattanayut, 2002). In another study, all stroke caregivers had stopped working (Hirunchunha, 1998). These results reflect the fact that stroke caregiver in Bangkok need to keep their jobs more than caregivers outside Bangkok. This study extends the understanding of the fact that a caregiver with low education who does not earn much money, can stop working more easily than other members.

Most caregivers had no income while nine of them had income from 1,000 to 10,000 baht per month with an average of 4,000 baht. However, 17 caregivers had enough income for living expenses (77.2 %) while only five of them did not have enough expenses (22.8%). This result is consistent with a finding that two-thirds caregivers for elderly stroke patients had sufficient income (Subgranon & Lund, 2000) but this number was higher than in other studies (Chaiyawut, 2004; Navarat, 2002) in which only 42-58 % of stroke caregivers had adequate income for family expenses. On the other hand, some studies have shown that stroke caregivers and caregiver for older adults had financial problems (Niyomthai et al., 2003; Srinim, 2001, Yodpet, 2003).

Above all, the decision making process relating to selecting the primary caregiver in this study allowed one of the caregiving network members to adopt this role in one of the five following patterns:

1. A decision made by the judgment of the primary caregiver from his or her perspective as a member of the caregiving team that he or she was a person who could stay with the patient all the time and who could be the main person to provide direct care to the patient. The objective was to have a person staying with the patient all the time. This study found that adult children, who had stayed with the patients before, were the first in line to be primary caregiver (Case # 2, 7, 11). Some adult children had not lived with the patient before because their parents were divorced. When the patient had stroke, they moved the patient to their houses in order to have someone staying with the patient (Case # 12).

2. A request made by the patient to live in the same house. When he/she had stroke, caregiving network members took him/her to stay in the other house where there was a good environment. The patient rejected living there and showed that he/she

wanted to go back home by resistance to caregiving. As a result, these caregiving network members took him/her back home and the adult children needed adopt this role resulting from the external motivation of stroke patient (Case #1, 6).

3. A decision made by family and economic forces when the role was assigned to a primary caregiver who still wanted to keep on working and refused to take the caregiver's role. The family members turn to motivate other children to take this role. This decision came from the mixed motivation factor of the family decision and internal motivation factor of the primary caregiver decision. For example, there were two families in which some children had moved in to live and provide care to the stroke patients while the other children provided financial supports (Case # 14, 17). In another family, even though the adult children moved in to stay with patient, they still kept working. The children allowed a housekeeper to assist in some caregiving activities with the primary caregiver instead of them doing it themselves during the daytime (Case # 18). Moreover, in one family, a wife could not take care of her stroke husband because she was working abroad. Therefore, other family members had to cover this role by quitting their jobs to take care of their patient (Case # 5).

4. A request made by a former caregiver. There was mixed motivation from external motivation relating to the former caregiver having passed away, and having gone to another province and internal motivation from other adult children (Case # 4, 8, 13).

5. A last-resort decision made when there was no adult children available to take on the role (Case # 3, 9, 10, 15, 16). Therefore, five wives of stroke patients needed to play this role because of internal motivation.

This process is congruent with four cultural rules: the family first rule, the generation and gender rule, the exemption rule and relational concepts (Jacobson, 1987). The family first rule refers to support that ranges from family, friends, and formal services. The generation and gender rule refers to the provision of support within the family by which the elderly requests help first from the children, preferably, daughters; then siblings, preferably sisters; and grand children, preferably grand daughters. The exemption rule refers to family members or friends who have their own resources, such as time, money, energy etc., which are equal to or greater than demands of the elderly. Lastly, relational concepts refer to modifications from the weighting between the self

and social relationships. This study started from the decision to select the family member, particularly daughters to be primary caregiver in conformity with to family rule; then the stroke patient decision is congruent the generation and gender rule. The decisions involving family and financial supports are congruent with the to exemption rule. The last-resort choice of the spouse as caregiver is consistent with relational concept.

In conclusion, the family caregivers were mainly women aged over 50 years. Most of them were adult daughters; particularly the youngest daughters and they had enough income for living. The selection of a primary caregiver consisted of five processes that started from the definition of the primary caregiver. The primary caregiver was the major person, who stayed with the stroke patient all the time and provided direct care to the patient. The second process was the patient's decision to stay in her/his home. The third process was the family decision and economic forces. The fourth process was the changing of primary caregiver when the former caregiver could not provide care. The last process was when the decision was made by wife of stroke patient when there were no children available.

The stroke caregiving network members

These caregiving network members comprised family members and non-family members. The family members were stroke patients, siblings, and cousins. The non-family members were housekeepers, friends, health volunteers, primary care nurses, home health care nurses, neighbors, ambulance center personnel, officers of the National Council on Social Welfare of Thailand, officers of the Ministry of Social Security and Human Development, and officers of the Housing Authority Organization. The caregiving network members are different from the secondary caregivers. The secondary caregivers are the people who provide indirect care and could not take care of the patient regularly (Dilworth- Anderson, Williams & Cooper, 1999; Horowitz, 1985), or play a supplementary care (Gaugler, Mendiondo, Smith & Schmitt, 2003). In this study, the caregiving network members consist of secondary caregivers and others. They provide both regular and occasional caregiving. The regular care is the daily, weekly, monthly, and yearly caregiving, such as preparing blenderized diet, giving a bath, doing laundry, giving financial support, connecting to

social welfare and etc. while occasional caregiving is the irregular care, such as lifting the patient, donating a bed and etc. The definition of caregiving network members is different characteristics and the wide range of care provided from the secondary caregiver.

Twenty caregiving network members were approached for this study, 19 women and one man. Focusing on the composition of these caregiving network members, most of them were daughters of stroke patients. Previous stroke caregiver studies have reported that 66-82% of stroke caregivers had helpers in caregiving (Perkdetch, 2002; Sangboon, 2002; Songwatthanayut, 2003). Importantly, 17% of the helpers of stroke caregivers were sister/younger sister, 27%-29% of them were daughters/sons, 13-42% of them were parents, and 1-7% of them were spouses (Perkdetch, 2002; Sangboon, 2002; Songwatthanayut, 2003). From these studies, it emerges consistently that the helpers of stroke caregivers are mainly adult children. According to Lubben's social network model (2000), there are two types of structural networks consisting of kinship networks (spouse, children, siblings, and relatives) and friendship networks (friends and intimate friends). Similarly, several studies have indicated that Thai elderly people received support not only from family members but also from friends and neighbors (Damsangsawat, 2000; Wongcharoenkul, 2000). In this study, the caregiving network goes beyond kinship and friendship networks to organizational networks. For example, a participant shared the information about his parent's sickness with his manager in the Housing Authority Organization and he received monetary support 1000 baht from his workplace for one year (Case # 16). Relating to the Act on older person: 2003, there was a benefit to support caregiving at home. The children, who took care of their elderly parents, could reduce their tax by 30,000 baht per year (Country Report Thailand, 2007). For the elderly people, there was monetary support of 500 baht (14 US\$) for individuals who were 60 years-old and over from the government (Country Report Thailand, 2007).

The caregiving network members ranged in age from 28 to 60 years with an average of 41.6 years. This result indicates that the age of caregiving network members was generally younger than primary caregivers. Half of them were single, while nearly half of them were married. The age of caregiving network members is explained by the social disorganization theory which states that friendship networks

link individuals with similar in age and interests while kin networks link different generation (Amanto, 1993). This study found that only one primary caregiver had a link with a close friend (Case # 15). Most of the caregivers linked to kin networks and caregiving members were usually relatives and younger than primary caregivers.

The caregiving network members were a significant resource for primary caregivers to maintain their caregiving. The network sizes ranged from 4 to 11 persons with an average of 7 persons. This average of network size is similar to the 7 persons in an average network, in a study Alzheimer's disease caregiving (Bennett, Schneider, Tang, Arnold & Wilson, 2008). In contrast, this result was different from other studies in which caregiving networks had an average of 3 to 5 members (Tennstedt et al., 1989). In this study, a small network is classified as a network of 4-5 members, while the medium size network was 6-7 members and a large size was 8-11 members. The network size of this study was higher number than the family size in elder care studies where lesser than 3 members was small size, 4-6 members was medium size, and more than 7 members was large size (Boonchalaksi, 2000; Sasat, 1998). Using data from the National Statistic Survey, the elder care studies defined the family size from only family members in household while this stroke caregiving network study defined network size from total numbers of members of caregiving networks who provided exchanging including both those in household and those from outside the family.

Most caregiving members were Buddhist and four of them were Muslim. Gans (2007) investigated the role of religiosity in the degree of filial obligation and actual support to their aging parents. Using multinomial regression analyses, the researcher demonstrated that non-religious adult children had no commitments and did not involve in elder care (Gans, 2007). In addition, it is noted that religious beliefs shaped patterns of behaviors in helping each other (Krause, Ingersoll-Dayton & Liang, 1999). Relating to religious belief, Krause and colleagues classified helping behaviors in three dimensions. Firstly, the degree of individuals helping each other varied with religious commitment. Secondly, the activities of providing support have been found in a variety of religious setting. Lastly, the experience of helping others return to health, increases self-esteem, strengthens network ties, and improves immune functions. Similarly, in this study, based on the Buddhist belief "whatever you do you must receive", these caregiving network members became involved in helping others

and these things will return for them. When caregiving networks members provide help each other, they will get the good thing in the future (Case # 9, 10). They wanted to be as a role model for children so that the children would eventually take care of them later (Case # 1, 2).

Similarly, Muslim caregiving members also believed that when they provided help to their relatives, Allah would help them through his “invisible hands” (Case # 8, 11). Adam Smith developed the “invisible hands” theory in 1776 as the mechanism whereby God manages the universe to ensure human happiness. This theory has been used in the market-based economy to ensure the maximization of human economic well-being. The exchange has shown that if you give me what I want and you will get what you want (Joyce, 2001). Unlike the economic exchange that involve a fixed and particular transaction, the caregiving exchanges are not just only balanced in the same time but there are continuing exchange from the present to build support in the future (Horowitz, Reinhard, Howell-White, 1996). Therefore, when these people provided caregiving to another person, they believed that they would receive other things in return as if they would be receiving the good thing from the God. The beliefs of Buddhism and Islamic religion are congruent with the resource theory in terms of particularism/ universalism and concreteness/symbolism (Tronblom & Foa, 1993). The caregiving network members provided help focusing on the patient and the caregiver and they believed that the good things happen as invisible hands in the present (Case # 11) or in the future (Case # 1, 2, 7, 8, 12).

In this study, caregiving network members mostly had higher education than primary caregivers. One-third of them had graduated with a Bachelor degree and/ or a Master’s degree. This result confirmed that caregiving network members who had higher education and made more monetary income, were still working and provided caregiving support to the caregiver in terms of tangible, psychological, and financial support. Caffrey (1992) described the changes from direct care by kin-based support to providing money in cash-based support. Similarly, evidence from a Chinese study has echoed that the children decrease the instrumental supports but increase financial support because of greater flexibility and pooling of resource from many children from living away from the family home (Zimmer & Kwong, 2003). This study indicated the reasons why caregiving members could not provide direct caregiving but the

caregiving network members provided productive caregiving. For example, some caregiving members went outside the home or abroad for work and they sent financial support back to stroke patients and primary caregivers (Case # 5, 9, 10, 14, 17, 18).

Most caregiving network members lived in the same household with stroke caregivers and patients while six members stayed close to patients' houses within 5-10 minutes walk; four members lived 30-120 minutes from the patient's house. For this result is congruent with another study of living arrangements of elderly parents and adult children: there was at least one adult child living with or living close to the parent (Knodel & Chayovan, 2008). This characteristic is similar to the model of the neo-extended family in which young adult children contribute to a new type of extended family by exchange of support with their parents living nearby (Chen, 2006). In Bangkok, extended families in the same household have changed to expanded nuclear families living close to the parent houses because of economic factors. The children continue to exchange caregiving when elderly parent had have stroke. This study found both similar and different living arrangements where the elderly parents moved into married adult children's homes when they need caregiving (Brody, Litvin, Hoffman & Kleban, 1995) (Case # 7, 12). In contrast, widowed adult children moved into their elderly parents' house to provide caregiving (Case # 14, 17).

In conclusion, caregiving network members were the persons who participated in stroke caregiving. Most of them were younger than the primary caregivers and were family members rather than non family members. Most of them had higher education than primary caregivers and were still working. As a result, these caregiving network members could provide support to patients and primary caregivers. Caregiving network members, who lived in the same household, could provide direct care with the primary caregiver while other members, who lived at a distance, participated in caregiving by providing some money to support the patients and the primary caregivers.

Characteristics of the stroke patients

The stroke patients consisted of nine women and nine men. Two-thirds of patients were the young-old adult (age 60-79). The age ranged from 65 to 92 years with an average of 74.6 years. These elderly stroke patients were older than the

patients in the previous studies, For example, Niyomthai and her colleague (2003) found that the patients' average age in their study was 64.92 years. Based on the inclusion criteria for elderly stroke patients in this study, the stroke patients should be those with a Barthel Index (BI) score of 20 or lower. This study found that seven patients had a zero score. These patients were bedridden and needed total care while most stroke patients had mild activities of daily living or could perform some activities by themselves. This result was congruent with other elderly stroke studies in which one-third of patients were dependent in all activities of daily living (Subgranon & Lund, 2000) or 29-30% of stroke patient were severely or moderately disabled (Wilkinson et al., 1997).

All elderly stroke patients had been married and two-thirds of them lived with their children because their spouse had passed away or they had separated. One-third of them lived with their spouse and adult children. These results are congruent with other studies in which there are at least one or two children staying with the elderly parents (Caffrey, 1992; Knodel & Saengtienchai, 1999). It was found that the people 60 years and older living at least one adult child is 70.5% in Thailand (Survey of older persons in Thailand, 2007) 58% in Japan, 17% in the United State, and 15% in Germany (Carbinet, 2001). However, the boomerang household was the common living arrangement in Japan by returning to live with their children when the elderly parents were poor health and widowed (Takagi, Silverstein & Crimmins, 2007).

Focusing on family size in the household of this study, two-thirds of stroke patients had less than five family members, while one-third of them had more than five persons in the one house. The family size of elderly stroke patients was an average of 5 persons (S.D. = 3.14). This result is congruent to family size of other stroke studies which have shown an average of 5.14 persons (S.D. =1.78) (Jullamate & Thanatwanich, 2001). In contrast, the family size in this study was different to family size in elder care studies in which the average between 2 persons (Boonchalaxsi, 2000) and 3.3 persons (The National Statistic Institute, 2007). Many elderly caregiving studies use the family size to clarify support network to older adults (Boonchalaksi, 2000; Sasat, 1998). Transitions of social support to support network and caregiving networks have been classified through the use of a wheel of support network (Keating et al., 2000). The characteristics of support network consist of size and composition

with linkage by social bonds and frequency of contacts. The transition of support network to caregiving network is influenced by the same factors but there are differences in type and intensity of caregiving in everyday life. When support networks provide caregiving, these networks become caregiving networks that are smaller in size than support networks. For example, the mean number of members of the perceived support network was 8 persons while mean number in the actual support network was only 2 persons (Sit et al., 2004). It was clear why stroke caregiving network received less support given their wider support networks (Hathakit, 1999).

The duration of illness ranged from 4 months to 20 years. The median was 4.5 years. The duration of caregiving is a wide range from the beginning of stroke and long term care for more than 20 years. The diversity of durations in caregiving provides a variety of patterns of caregiving support exchange across the life course (Merz, Schengel & Schulze, 2009). Focusing on types of payment, half of patients could be reimbursed for health care cost, while eight of them had Universal Coverage of National Health Insurance (UC). Only one patient paid out of her own pocket because her family did not take the patient to follow up at the hospital and wanted her to buy medication on her own account. This result is similar to other stroke caregiving studies which have found that 54-63% of cases the source of payments for medical expenses was the government. 23-35% of patients received support by the UC while 5-10% of patients paid by them and 4-6% of patients received support from the government and paid some on their own account (Perkdetch, 2002; Songwattayanut, 2002).

Focusing on the educational level, most stroke patients had lower education and only one patient had completed Bachelor degree. Before diagnosis with stroke, all patients were older adults who had retired from their works or were not working prior to stroke. After they got stroke, none of them worked. Two-thirds of patients had no income and one-thirds of them had income ranging from 300 baht to 15,000 baht per month. However, two-third of them said they had enough income for living while one-third of them had not enough income for living. These results were similar to the Thai National Statistic Institute (2007) which found that 52.3 % of Thai older adult received support from their children.

In summary, most of the stroke patients were the young old (60-79 years) but they were in moderated and in severe conditions in that they were bed ridden or could perform only mild activities of daily living. Most of them were parents who lived with their adult children.. They had low education and they had already retired from work.

Patterns of social exchange behaviors

This study described the social exchange behaviors of stroke caregiving networks into three patterns: sharing care, dual care, and supplementary care.

1. Sharing care

Sharing care refers to a pattern in which a primary caregiver and caregiving network members plan for roles and functions of caregiving together so that it is a “piece of pie”. There is a time schedule to take care of the patient. Based on individual difference, caregiving is negotiated to split the tasks in such a way that make sense given siblings’ responsibilities and which is suitable to individual activities (Willyard, Miller, Shoemaker & Addison, 2009). This pattern divides the roles and functions of care relating to their caregiving abilities. Some care activities are limited to primary caregiver but other member can make it available instead of primary caregiver in order to fulfill the needs of the stroke patient.

This pattern was found in eight of the caregiving networks (Case # 2, 4, 7, 8, 11, 14, 17, 18) with four large, three small, and one medium sized network. In general, the network size reflects the numbers of caregiving network members. A large size of the network provided more types of tasks and high volume supports than a small size. Many of the caregiving studies have found a small family provided more support to elderly parents than large families (Boonchalaksi, 2000; Zimmer & Kwong, 2003). This present study discovered that a pattern of sharing care was found in both large and small sized networks.

In addition, relating to the composition of caregiving network, this pattern mainly consisted of only children: this was true in seven caregiving networks while only one caregiving network comprised of intergenerational parent-children roles among mother, children and housekeeper. Relating to the task specific model, Litwak

(1995) classified the expectations of caregiving relating to tasks and relationships, such as spouses being expected to give emotional and physical support. The children are expected to provide some emotional and instrumental support while siblings and friends provide companionship. In this study, the significant characteristics of the sharing care were not considered in relation to the expected roles. The caregiving networks were focused on the functions of care that fitted to the abilities of caregiving members and sharing care.

Focusing on “no one else can do it”, the satisfaction is to do the caregiving as the primary caregiver or caregiving network members. The participants described their willingness from the motivations to be the caregivers, and emphatic response aside to be the caregiving network members. The motivations of caregiving in this study were internal motivation (Case # 4, 7, 8, 11) and mixed (Case # 2,14,18) rather than a motivation from external (Case # 17). These motivations are similar to the motivations of family caregivers in long-term care (Kolmer, Telling, Gelissen et al., 2008). Kolmer and colleagues identified their motivational theories as being derived from the work of three philosopher and anthropologists, namely Buber, Levinas and Ricoeur, and family therapist, Boszormenyi-Nagy. The philosopher Buber thought that individuals provide care for each other based on the mutual and reciprocal relations necessary for a meaningful life. Boszormenyi-Nagy thought that a person provides care for other in the family because of loyalty (a feeling of obligation). This loyalty is developed from blood relations or a mutual relationship in the past. In Levinas’ view, individuals provide care for each other because of responsibility and altruism (a feeling of responsibility for dependent other), while philosopher Ricoeur thought that individuals provide care for each other because of reciprocity and morality (self-directed motive). This pattern is similar to Levinas in terms of responsibility (Case # 2, 14, 17, 18) and altruism (Case # 4, 7, 8, 11) because the primary caregivers wanted to provide help and did not need anything from the patients.

Besides, religious belief influences people to participate in helping network (Krause, Ingersoll-Dayton & Liang, 1999). Based on the beliefs from the Buddhist concept of “*boon*”, giving and wanting return will receive “*boon*” lower than giving and need nothing. The giving and need nothing is called “*metta*” (good will) as the great merit (Buddahad asa Bhikkhu, 1993). It was similar to two types of norms in

terms of norm of reciprocity and norm of solidarity (George, 1986 cited in Caffrey, 1992). In the norm of reciprocity, the members provide and receive equally while the norm of solidarity is giving without considering to a return. In addition, the members of caregiving network realized to offer help for the patients and caregivers. Toennies (cited in Dale et al., 2006) identified the behaviors of a person including two types as follow:

1. Natural will refers to a simple characteristic of a person that is the behavior of children as “doing it for their needs” or the adults as “that is the right thing to do” In this study, the participants were willing to help because of the right thing to do for their father/mother (Case # 4, 7, 11, 14) and her aunt (Case # 2).

2. Rational will refers to sophisticate characteristic of a person that the people make a decision to the outcome. In this study, the participants described that it is suitable to do because of no one else (Case # 8, 17, 18).

The participants showed that they shared the caregiving in terms of sharing their roles and responsibilities. The roles of caregiving are categorized into five types: anticipatory caregiving (sharing opinions), preventive caregiving (active monitoring to prevent complication), supervisory caregiving (checking up to evaluate care), instrumental caregiving (working to maintain the patient’s physical integrity and health status), and protective caregiving (working to protect against any possible future threat to the patient’s physical integrity, and health status) (Bower, 1987). Additionally, the cohesive subgroup model of network was established in this pattern. The participants set up small groups in cleaning the patient, preparing blenderized diet, following up to the hospital etc. For the position model, the network expanded to the lower part, the caregiving network members separated the role of caregiving as the supervisor and working bees. The supervisor took the role in making decisions, or giving suggestion to the members for caregiving while the members took caregiving tasks as the working roles. The people, playing supervisor role, were stroke patient, primary caregiver, or caregiving network member while working bees were primary caregiver or caregiving network members.

The significant characteristics of the pattern “sharing care” are not only size and composition but also relying on each other. Primary caregivers and caregiving network members exchange caregiving in time, duration, finances, and

communication. This pattern described the balance of caregiving in time with schedule of caregiving. Time schedule is the controlling process that is used in caregiving management. On the other hand, when caregiving could not follow to time schedule, the negotiation has been emerged among the members of the caregiving network to balance the caregiving. Negotiating is the interactional process among the caregiver and the members of the caregiving networks. Schumacher (1994) shared her experience from her study that two types of interactional process consisted of defining the parameters of self-care and caregiving and micro-interactions (adjusting a course of actions). In this present study, interactional process has been emerged to balance caregiving. For the defining balance caregiving, there is sharing care by time schedule to control the steadiness of the process. For micro-interaction, when the balance of caregiving was broken, the caregiving networks negotiated to extend other times for returning back to adjust the imbalance caregiving.

Besides, when inequity in caregiving happened among the sibling caregivers for their elderly parents, the conflict relationship also happens. Based on equity theory, two strategies are approached to balance inequities in their sibling relationships by requesting behavior changes and making cognitive changes (Ingersoll-Dayton, Neal, Ha & Hammer, 2003). In this present study, there is a time schedule to provide care for elderly stroke patients. When the caregiving member came back home late, the primary have reactions to her. The caregiving member recognized the distress inequitable and changed her behaviors. She stayed in department store longer to make actual equity. By using cognitive strategies, she bought and bought many things varying her emotions to shape psychological equity. As a result, some strategies did not reduce the distress and made the sibling feel angry (George, 1986). For example, a caregiving network member felt anger to her sister who was the primary caregiver. She also felt angry with the patient when the patient asked her for caregiving (Case # 7).

Focusing on duration factor, there are equal between long period (Case # 2, 7, 8, 11) and short period in the community (Case # 4, 14, 17, 18). People tend to participate in social network when they are residentially stability (Amato, 1990). Three of the caregiving networks who live in the community for a long time, had two or three non-family members participating in their networks (Case 7, 8, 11) while one network did not contain a non-family members (Case # 2). In contrast, the short living period,

one caregiving network had only one non-family member while three of the caregiving networks consisted of five non-family members involved the caregiving. Interestingly, the non-family members were formal caregivers, such as home health care nurses etc who provided home care service for both short and long resident period in the communities.

With regard to finances, one or two members of six caregiving networks took responsibilities to regularly provide financial support. Interestingly, only one patient provided financial support to the caregiver (Case # 11). There were two caregiving networks which had their own grocery stores to support all expenses of caregiving (Case # 2, 4). The financial system in sharing care is similar to two sided altruism and illustrate (Laitner, 1997). The adult children or elderly parent with economic problems expected to get financial support from other family members. On the contrary, using the National Survey of Families and Households, the majority of the American people have a low providing financial assistance, time help, and advice to other family members. It was found that 11% of American adult children were highly supports to their elderly parent (Hogan, Eggebeen & Clogg, 1993).

In caregiving context, the caregiving network members transfer news, knowledge, and information from one to others. In this study, the participants talked about direct communication in sharing care (Case # 7, 11, 17, 18) while one participant used the indirect communication with her younger sister about management of feeding tube (Case # 14). When the participants had some problems, they used silence communication to stop the problems (Case # 2, 4, 8). In Thai language, “*mai-pen-rai*” is translated as “it is not a problem” that reflects to the tolerance and compromising nature of Thai people. The interpersonal conflicts are not face in confrontation when the people want to keep their relationships (Vongvipanond, 2004).

Focusing on “whatever happens, happens”, the relationship factor is close relationship and conflict relationship. This pattern mainly consisted of kinship networks and risks of high conflict which were greater than other diverse networks. The diverse groups could provide more various supports from homogeneous groups as kinship networks (Fudge, Neufeld & Harrison, 1997). Conflict between family relations, particularly siblings, to provide caregiving for elderly parent is a normal situation (Lowenstien, 2007; Suitor & Pillemer, 2002). Semple (1992) classified the

conflict of family relatives into three types: disagreements on the types and levels of care, disagreement on the caregiver's perceptions and family members' preference to provide caregiving, and disagreements concerning the family's attitude to caregiver performance. These conflicts have been found in disagreements over family treatment of the patient (Case # 14) and the family's attitude to caregiver role performance (Case # 2, 7, 11). In this present study, half of caregiving networks had conflict relationships while the remainder had close relationships.

Overall, sharing care together is close to the constellation pattern of caregiving in which stroke caregiving activities are shared among biological kin and fictive kin (Lingler, Sherwood, Cringhton, Song & Beth Happ, 2008). Moreover, the pattern of sharing care fits the pattern of collaborative care in which there is a mutual involvement in caregiving through task specialization and task supplementation (Schumacher, 1994). Task specialization focused on desires, interests, and culturally sensitive role that fit to be the family relatives while task supplementation concerned the abilities of the person with disease and the difference between patient and caregiver. Interestingly, the pattern of sharing care was close to the pattern of reinforcement teamwork model of a stroke caregiving study in Bangkok (Anantato, 2005). The reinforcement teamwork model consisted of a caregiver and a few members who divided care appropriate to cater to their limitations

In summary, the sharing care pattern separates functions and roles of caregiving. The functions of care are related to the interests and needs of caregiving members while the roles of care are divided into those played by the supervisor and worker bees. There are culturally sensitive cross gender tasks that are appropriate only to certain caregiving member. In addition, some caregiving members negotiated the care that needed balancing of the caregiving process.

2. Dual care

Dual care refers to the pattern in which two caregivers provide caregiving to the patient at the same time as "buddies". They take turns caregiving among themselves, and with other caregiving network members. The primary caregivers do not set a timetable but there are fluctuations over time in the amount of caregiving they perform. Caregiving is balanced in a fluid way.

This pattern has been demonstrated in four caregiving networks (Case # 5, 6, 12, 16), including two small size and two medium size. With regard to the composition of networks, this pattern was found in three networks of intergenerational relationships (Case # 5, 6, 16), and one kinship network (Case # 12). Intergenerational relationships refer to the connection of two or more generations, such as the oldest, middle, and youngest generation (Mills & Wilmoth, 2002). In this pattern, two primary caregivers came from two generations, such as parent-child (Case # 16), aunt-niece (Case # 6), young brother-daughter-in-law (Case # 5), and a kinship network. Roles of care are equal and rely on each other. This pattern is similar to sandwiched couples but it is different. This dual care pattern has two primary caregivers to take care of one patient. In contrast, the dual-earner couples provide caregiving to elderly parent and children (Cullen, Hammer, Neal & Sinclair, 2009).

Focusing on the concept of “no one else can do it”, this dual care pattern indicated that caregiving networks are equally between willingness (Case # 12, 16) and endurance (Case # 5, 6) of satisfaction factor. In the view of the philosopher Boszormenyi-Nagy, people provide care to each other because of loyalty from their blood relations while Levinas viewed that people take care of each other because there are calls for responsibilities (Kolmer et al., 2008). In this study, the participants are motivated from her/his bonding (Case # 12, 16) while others came from the decision of patient and family (Case # 5, 6). Evidence from one study indicated that ongoing intergenerational exchange was motivated by obligation, and family loyalty (Carruth, 1996). In this study, three of caregiving networks were intergenerational relationships. Accordingly, two participants described their willingness from the natural will to provide care for their father (Case # 12, 16), for brother (Case # 5.2), or for grandmother (Case # 6.2). In contrast, two participants talked about their endurance to be a caregiver from the rational will because of no one else to do it (Case # 5.1, 12.1).

Regarding to caregiving network members, the dual pattern shows that there were three caregiving network living long duration in the community (Case # 5, 6, 16) while only one network lived short period (Case # 12). The duration is congruent with the participating in caregiving network and regular supports to the patient and caregiver. In the extreme case of long duration, the caregiver talked about her need for household management when she was admitted in the hospital because of

her bone disease and her son went out to work during daytime. The caregiver gave the key to her neighbor. Her neighbor came to ask her husband (the patient) about the kind of food by opening the lock of her room and brought the food to him everyday (Case # 16).

For the concept of “relying on each other” concept, the dual pattern is mobilized by time, finances, and communication factors. For the time factor, two primary caregivers helped each other in the same time or alternated care in the daytime and nighttime as complementary (Dale, Smith, Norlin & Chess, 2006). The complementary care is the actions of one member of the group fitting together with the actions of another member. For example, two primary caregivers participated in cleaning the patient, doing laundry, cleaning the house, and following up at the hospital while they alternated care in doing the tasks of staying with the patient.

With regard to finance factor, this dual pattern consists of financial caregiving in terms of productive exchange from wife and youngest son of the patient to two primary caregivers (Case # 5), from eldest daughter and second son to primary caregiver and patient (Case # 6), from one primary caregiver to another primary caregiver (Case # 12), and shared financial care between two caregivers (Case # 16). The financial caregiving is similar to exchange theory that caregiver and caregiving network members exchange caregiving by providing care to patient and receiving financial support from each other.

In this dual pattern, the participants communicated and gained information on stroke caregiving. Relating to access the internet on web based information; one stroke caregiving network pulled family together and helped each other to take care of patient (Pierce et al., 2006). In this study, there was direct communication transferring among caregiving network members. When they came to visit the stroke patients and they pooled their money to provide monetary support to the primary caregivers. Also, the non-kin network members pooled caregiving members together to lift the patient (Case # 6, 12, 16), or to contact emergency medical services (Case # 5, 6, 16). Conversely, some participants described to stop communication when they wanted to keep their relationships (Case # 6, 12).

Focusing on “whatever’s happens, happens”, the relationship factor consists of close and conflict relationship. There were three intergenerational networks and a kinship network. A diverse network can provide various supports to primary caregiver. However, there were two diverse networks that presented conflict relationships (Case # 5, 6). Conflict is a situation in which difficult issues have not been resolved over time (Lowenstien, 2007). One primary caregiver presented her conflict in taking care of patient even though he was a nice man (Case # 5). Another caregiver mentioned about conflicts with her niece and her husband (Case # 6). The caregivers did not talk about their conflicts with their family members but they expressed their feelings to the neighbors. The result is similar to a study of married daughters in caregiving network; friends were identified as the most important source of emotional support while siblings were the source of instrumental support and interpersonal stress (Suitor & Pillemer, 1996).

This dual care pattern from this study is similar to the shifting pattern of self-care and caregiving between caregiver and patient (Schumacher, 1994). However, this present study found a difference in shifting care because in this pattern turns were taken between two primary caregivers. This present pattern was also similar to both the tug-team model (defined model by Ananatato, 2005), and social reinforce model of a stroke caregiving study in Bangkok (Anantato, 2005). The tug-team model includes many generations merging their care. In this study, three of the caregiving networks were intergenerational networks that consisted of different generations, who participated in caregiving as the buddies. In the social reinforce model, there are the non-family network members to participate in stroke care (Anantato, 2005). Similarly, this present study found that stroke caregiving networks allowed the neighbors and other organizations to participate in stroke caregiving.

In conclusion, the dual care pattern has two primary caregivers. Both of them combine functions of care to provide care together. Four caregiving networks presented this dual pattern. This pattern was found in two small size and two medium size networks. The reason of caregiving came from both willingness and endurance. The outcomes are both close and conflict relationships.

3. Supplementary care

Supplementary care refers to a pattern in which a primary caregiver takes care of the patient but at the same time a caregiver also needs help from caregiving network members. The caregiving network members provided caregiving whenever they were available.

This pattern was found in six caregiving networks (Case # 1, 3, 9, 10, 13, 15). These networks mostly had small size and had only one primary caregiver to take care of stroke patient all the time. The majority of the caregivers were wives (Case # 3, 9, 10, 15), while the other two networks were the eldest daughter and the youngest daughter (Case #1, 13). Most of the spousal caregivers were the key person who made decisions as the leader of the family. This characteristic is similar to Thai social values that the elderly parents should be heads of the family. If they consciously deteriorated, they transferred their responsibilities to caregivers (Caffrey, 1992).

Focusing on satisfaction factor, the participants described their endurance (Case # 1, 3, 9, 13, 15) rather than willingness (Case # 10). The eldest daughter was motivated to be a caregiver by patient decision (Case # 1) while the youngest daughter was motivated by family decision (Case # 13). Both motivations were mixed motivations from external motivation (family and patient decision). In contrast, four caregivers who were wives, presented their internal motivations to accept caregiver role because there were no children available to take it on (Case # 3, 9, 10, 15). As a result, the participants expressed their endurance relating to rational will. They talked about the feeling of no one else to do that (Case # 1, 13, 15), letting try it to do (Case # 10), suffering (Case # 3), and withdrawal of care (Case # 9).

In many elder care studies, informal caregivers have been spouses. When a spousal caregiver is unable to provide care, the adult children are the next-in-line to take care of their elderly parents (Stuifbergen, Van Delden & Dykstra, 2008). In contrast, this study indicated that spousal caregivers were the last person to provide care when there were no children available. Focusing on four wives caregiving networks, two wives took care of the elderly stroke patient because her son passed away (Case # 15) and another caregiving network had a son who went to work in other province (Case # 9). Focusing on spousal caregiver, one caregiving network paid for a formal caregiver from an agency to provide caregiving but they faced many problems,

such as the smoking habit of the male formal caregiver, paying much more money, having no security for valuables, and having no privacy for themselves. As a result, the stroke patient's wife played this role in stead of formal caregiver because all four children needed to work (Case # 10). The last case of spousal caregiver was the reporter and writer of a novel (Case # 3). She managed her time to provide care because the patient did not need caregiving all the time. He could sit down and have food by himself whether there was someone in the house with him or not. Intergenerational ambivalence, having two opposing feelings at the same time in later life, ambivalence is rooted in behaviors, cognition, and emotions that are shaped by social structures or located within these structures (Lowenstein, 2007). This study found that spousal caregiver presented both love and hate to the patient depending on the nature of caregiving process (Case # 3, 9).

In the context of relying on each other, this supplementary care pattern described exchange caregiving by mobilizing time, finances, and communication to maintain caregiving. Focusing on time factor, the caregiving network members exchanged caregiving at the time that they were available. It was reported that, primary caregivers who suffered from lacking of supports from the family caregiving network, negotiated exchanges for continuing caregiving (Becker, Beyene, Newsom & Mayen, 2003). The new caregiving network members were linked to neighbors and organizations (Case # 1,9,10). When caregiver needed support, they sent asked for help. However, it was found that older wives who were caregivers, taking care of dependent elderly husband, faced the feelings of constraint and resentment because of poor compliance with caregiving by the patients (Fitting, Rabins, Lucas & Eastham, 1986) (Case #3,9). As a result, the primary caregivers encouraged themselves by practicing meditation, talking with neighbors, and talking with supernatural powers (Case # 3, 9,10).

For whatever's happens, happens, this pattern indicated that the primary caregiver prepared for the death of her husband and herself (Case # 10). Evidence has shown that Thai elderly people are considered a proper funeral important although this is a high cost of care (Caffrey, 1992). It was not surprised that most caregiving networks had conflict relationships (Case # 1, 3, 9) and only one caregiving network had close relationship (Case # 10).

Above all, the supplementary care is not a substitution care or the pattern of an intergenerational family care chain. When primary caregivers could not provide care, they assign other family members to take care of patients instead of them (Lingler, et al., 2008). In this pattern, there was only one caregiving network in which caregiving member came to provide care instead of the primary caregiver when she went to other province; most stroke caregivers had no one to provide care instead of them. As a result, sometime the stroke patient did not receive important caregiving, such as insulin injection (Case # 3), and feeding blenderized diet during follow up at the hospital (Case # 13). These results are similar to the study of caregiving to elderly in Surathani province in that the safety issue was not considered from caregiver (Laubunjong et al., 2008).

The supplementary care is the pattern of caregiving in which caregiving network members provided some caregiving tasks in stead of primary caregiver, such as providing a bath, lifting the patient to sit down, buying some food from the market. Mostly, family members or friends provided occasional support to caregivers but they needed regular support. In contrast with Western stroke caregiving in which, spousal caregivers needed occasional support from others for an hours or two because it is difficult to provide caregiving without assistance from others (Comb, 2007). Additionally, the caregiving triangle involves caregiver, the care recipient, and significant persons, such as neighbors, and health personnel. There is conflict relationship because the caregiver does not want be disturbed from others and desires to do it alone. Caregiver can be too shy to ask for help from others and dissatisfied with receiving help from others (Wilson, 1989). This supplement pattern was close to the pattern of employment model (Anatato, 2005). In this model, the caregivers needed to work outside and left the patient alone because there was no one else This present study also found that when caregiver went to work and the family members could not provide care in stead of her, the patient stayed alone in the house (Case # 3).

In summary, the patterns of social exchange behaviors created more understanding in caregiving exchanges of stroke caregiver and caregiving network members. There are dividing roles and functions of care appropriate to individuals (sharing care pattern), providing caregiving together as buddies (dual care pattern), and doing it alone with occasionally support (supplementary care pattern). These patterns

are classified to maintain stroke caregiving with the factors of satisfaction, size, time, duration, finances, communication, and relationship. The dynamic of the wheel of caregiving is ongoing to balance caregiving. The overall of patterns of social exchange behavior is summarized in table 5.1.

Table 5.1 Summary of patterns of social exchange behaviors

Factors	Sharing care	Dual care	Supplementary care
Size	Large > Small > Medium size	Small = Medium size	Small > Medium > Large size
Composition	Kinship > Intergenerational network	Intergenerational > Kinship network	Spousal > Kinship network
Satisfaction	Willingness	Willingness = Endurance	Endurance
Motivation	Internal > Mixed motivation	Internal = External motivation	External > Mixed motivation
Time	Time with schedule Regular > Irregular	Fluctuation over time	Time that they were available
Duration in community	Long = Short duration	Long > Short duration	Long > Short duration
Finances	Regular support	Regular support	Regular > Occasional support
Communication	Direct > Stop > Indirect communication	Direct = Stop communication	(Direct = Stop communication) > Indirect communication
Outcome relationship	Conflict = Close relationship	Close > Conflict relationship	Conflict > Close relationship
Interaction Relationships	Supervisor and members	Buddies	Leader and members
Function	Task specific care	Reciprocal care	Alternated care

The “wheel of caregiving” model

The “wheel of caregiving model” describes the stroke caregiving process from the initiation of the network under various conceptual headings. The correlations among these headings are identified. The model describes the concepts and their relationships. Six concepts emerged: “no one else can do it”, “don’t know what to do”, “let’s try it”, “relying on each other”, “whatever happens, happens”, and “when the time comes, there will be a way”.

1. No one else can do it

The first concept “no one else can do it” is defined as the situation in which there is no one to adopt the caregiver role (except the primary caregiver) and caregiving network members. The process of adopting caregiver role is a complex phenomenon (Yodpet, 2005) and has been explored by Schultz (1989 cited in Sirapongam, 2003) clarified four factors that encouraged someone help each other as follow:

1.1 Bystander effect refers to the situational factor, in which there are many people but only a few people provide help. This effect strongly supports the idea that the size of network is inversely related to the likelihood of helping behavior (Levine & Crownther, 2008). Several previous stroke caregiving studies have found that there was a smaller support within wider stroke network (Hatthakit, 1999), and smaller support was provided at the beginning of the illness (Hirunchunha, 1998). In this study, “no one else can do it” reflects the fact that there were no other caregiving network members available to play a caregiver role (except the primary caregiver). This result is consistent with findings of stroke caregiving studies in Bangkok that 33 % - 44% of stroke caregivers reported the reason that they became caregivers was “no one else can do it” (Perkdetch, 2002; Sangboon, 2002; Songwatthayut, 2002). Similarly, under half of caregivers for elder care were not willing to assist with elder care (Gardner, Tripp-Reimer, Simpson, 2007).

1.2 Characteristics of care recipient refers to the personal factors. Findings from elder care studies showed that level of caregiving varied with the functional status of the older adult (Caffrey, 1992; Laubunjong, Phlainoi, Graisurapong & Kongsuriyanavin, 2008). In this study, the patient had moderate to severely impaired functional status and needed caregiving.

In addition, the caregiving network members described their empathic feelings of valuing to participate in caregiving. Relating to the mechanisms of social network, there were selection and structural mechanism. The structural mechanism refers to the size in caregiving network, the available of members and geographical proximity while the selection mechanism is attitudes and relatively strong connection to members (Bruycker, 2008). In this study, caregiving network members described the characteristic of primary caregiver was a good person or a person who provided help to others in the past. As a result, the selection mechanism is explained why non-family members provide care to patient or primary caregivers (Case # 9, 16). On the other hand, some caregiving networks talked about the adequacy of family (Case #2, 4). The structural mechanism has been used to explain why family members participate in caregiving network.

1.3 Homogenous factor refers to personal factor by which the similarity and difference among individuals can be classified through an analysis of the factors of household and family. It was reported that living arrangement is a significant factor in reflecting the level of support of older adults in many countries (Caffrey, 1992; Knodel, Chayowan & Siriboon, 1992; Raymond, Coward, Stephen, Cutler, Russel & Miller, 1990; Dwyer & Miller, 1990; Zimmer & Kwong, 2003). The result of this present study showed that most caregivers lived with the stroke patients in the same household. There were two primary caregivers moved into the houses of the youngest daughter of the stroke patient because the youngest daughters needed to continue working.

1.4 Motive of helping is the most significant factors to make a decision for helping another. There are two types of motive of helping.

1.4.1 Egoistic motivation (self- serving motive) refers to motive by one's own self, such as anticipation of rewards, social appreciation, and anticipation of punishment, such as social blame, and guilt feeling. In this study, stroke caregiver wanted to repay to the patients because of what they had received in the past or in a previous life (Case # 3, 5, 9) and because of their guilt feelings (Case # 6). This motivation is correspond to several elderly stroke caregiving studies (Srinim, 2002; Subgranon & Lund, 2000) that have found that stroke caregivers provided care

to the patients to repay elderly parents for cares in the past or to resolve their indebtedness from a previous life.

1.4.2 Altruistic motivation (empathy motive)

refers to motivation that serves other needs. This motivation consists of is where benefit to other is the main objective while the caregiving is considered on the basis of kinship, similarity, past relationship or a combination of these. In this present study, altruistically motivated stroke caregiver did not expect a return. They were considered the needs of the stroke patients rather than the benefits of caregiving that might flow to them from the stroke patients (Case # 1, 2, 4, 14, 17).

In the concept “no one can do it”, motivation is a significant factor which can be classified into external, internal, and mixed motivation. The external motivators were the family, the patient, and economic factor that were outside the control of primary caregiver while internal motivation focused on caregiver decision and the motivators were the caregiver’s responsibility, and the caregiver’s endurance. In addition, this study expanded into mixed motivation which is a combination both external and internal motivation.

Fifteen caregivers were motivated by internal motivation while two caregivers presented external motivation and five caregivers resulted from mixed motivation. These results were consistent with previous studies on Thai stroke caregiving where the internal motivation was the most significant motivator to adopt the caregiver role. The results showed that 40% of the caregivers felt gratefulness, 27%-30% of the caregivers presented their love; 48 - 61% of the caregivers came from their roles, and 4% wanted to repay their parents. The external motivation was because 5% of the caregivers were unemployed, and 3% of the caregivers reported that they had no money to hire other caregiver (Perkdetch, 2002; Sangboon, 2003; Songwatthayayut, 2002; Srithares, 2003). This study expanded the mixed motivation that comprises both external and internal motivation, such as economic decision (external motivation) and their roles (internal motivation).

It was been found that the most significant factor is a good relationship between parents and children while filial obligation is much weaker (Stuifbergen & Van Delden & Dykstra, 2008). In Thai social value, “*katanyu katavedi*” is the sign of good persons. Thai society expects that the children should take care of their parents

and blame the persons who do not provide care (Kespichayawattana, 1999). In this present study, the empathic feelings of valuing was predominated the caregiving network members to participate in stroke caregiving. The participants described the reasons of caregiving network members to provide help because the primary caregiver is the good boy/girl and respect to his/her parent (Case # 2, 16). Another reason was the helping in social activities of the patient in the past (Case # 9). As a result, the caregiving network members would willingly (*tem-jai*) help the patients and primary caregivers or endurance (*jum-jai*) to participate in caregiving.

2. Don't know what to do

The concept “don't know what to do” is defined as the process whereby a family member is transformed into a caregiver. On the setting up of the stroke caregiving network, there are many chaotic experience of stroke caregiver in the transformation process (Hirunchunha, 1998). This present study also found that stroke caregiver started from being afraid, facing difficult task and emotion, being tired, and becoming to accept. All of these processes are similar to stroke caregiving transitions in that they are multidimensional experiences including forward and backward transitions (Burman, 2001; Fraser, 1999, Hirunchunha, 1998). These transitional processes are congruent with inability to care/no idea and becoming a caregiver (Burman, 2001; Hirunchunha, 1998). This present study expanded to clarify the cultural sensitive to care that happened for cross gender over patient and caregiver. The concept “don't know what to do” provided the picture of stressful experiences on the setting up caregiving network by caregivers. This concept is both the state and the transforming process that focuses on difficult tasks and emotional issues before moving to behavioral issues.

3. Let's try it

The concept “let's try it” is defined as a developing process based on caregiving exchange between primary caregiver and caregiving network members. This concept focused on behavioral issues in that caregivers and caregiving network members exchange caregiving in many different situations. This concept identified the developing processes as moving from preparing to be a caregiver, building caregiving

knowledge, experiencing trial and errors of care, trying to alternative care, and seeking help. It was clear that the process of developing abilities of caregiver required many resources to fulfill caregiving demands which is similar to “promoting care at home” (Hirunchunha, 1998). The strategies for promoting care and let’s try it was similar building trust and confidence, promoting self-reflective skill, mutual participation, seeking support groups, empowerment, incorporating traditional and non traditional caring etc. Therefore, the concept “let’s try it” reflected to caregiving experiences that focused on behavioral issues.

4. Relying on each other

The concept “relying on each other” is defined as caregiving activities, which are receiving and providing caregiving to keep the balanced exchange. This significant concept provides the feature of caregiving exchange which was based on Thai culture. The concept of “relying on each other” reflects a collectivistic culture in which is defined by patterns of behaviors of devoting oneself to the group and placing a high value on intragroup harmony and connection (Phillips & Crist, 2009). Relying on each other came from the agricultural society in the past in where Thai farmers helped each other by pooling the labor force working on each farm. After a burden in their own farms had been completed, they would help out at other farms called *lounk klak* (Thai language). The interdependence and interactive relationships shaped their behavior to participate in family and community.

This concept had three dimensions on wanting to help (*num jai*), encouragement (*kum-lung-jai*) and exchanging caregiving. The wanting to help (*num-jai*) is the pattern of behavior which enables service in stroke caregiving by doing the best and devoting oneself to the task. These behaviors are altruistic which means that the focus is not on individual interests but on serving the larger group (Wilson, 2005), and boosting the family to act as the “corporate unit” by pooling the resources for caregiving (Zimmer & Kwong, 2003). In this present study, the participants described caregiving as “doing it from the heart, doing the best I can”. These objectives are matching with “making the best of it” which is the caregiver meaning (Noonan, Tennstedt & Rebelsky, 1996). The caregiver meaning consist of two dimensions: cognitive and emotional dimension. The cognitive dimension explains to caregiver’s

belief for keeping this role and emotional dimension is satisfaction to the reward outcome. The concept of caregiver meaning are gratification and satisfaction with caregiver role, a sense of family responsibility/reciprocity, the friendship and company which caregiving gave, and a commitment to doing what needs to be done. This caregiver meaning is strongly explained why caregiver kept ongoing this role.

With regard to encouragement (*kum-lung-jai*), the pattern of behavior is to return of wanting to help. Relating to collectivistic culture, the people focus on the group harmony and group glory. They need to be accepted from the social responding (Lalwani, Shrum & Chiu, 2009). In this study, the participants described their needs of encouragement which was expected to receive from one own self, from patient, from family members, and from spiritual support. When they gave “*num-jai*” to patient or caregiver, they wanted “*kum-lung-jai*” from them. These behaviors were closed to reciprocity which was an exchange mechanism in which receiving and providing are equal (Hamilton & Sandelowski, 2003).

The exchanging caregiving are physical care, psychological care, social care, cultural care, financial care, spiritual care, and emergency care. The participants keep balanced exchange based on social exchange theory. Three theories underpinning social exchange theory were equity theory, indebtedness theory, and resource theory. In equity theory, the participants kept the balance caregiving relating to fairness and equity issues (Walster & Berschied, 1978). In this study, when a caregiver or two caregivers provided caregiving the patient, there is sharing care among caregiving network members or dual care between two caregivers. In addition, there are direct exchange between caregiver and patient. When the caregiver took care of patient, the patient provided love (Case # 2, 7), house (Case # 6), and money support to the caregiver (Case # 11). Relating to indebtedness theory, Greenberg (1980) classified the patterns of behavior in which people help each other because of repaying a past debt. In this present study, the patient used to take care of the primary caregiver when he (caregiver) went to work in Bangkok. Since both of them had closer relationship. When the patient got stroke, the primary caregiver wanted to provide care to him (Case # 5). With regard to resource theory, the people exchange of resources in terms of esteem and respect, friendship, love, goods, services, and information (Foa et al., 1993). In this study, caregiving network member exchange resources with her

neighbor by helping her neighbor to retain new feeding tube monthly for seven years. When her father got stroke disease, the neighbor provided support to her mother by buying some food from the market everyday instead of the caregiver (Case # 10).

5. Whatever happens, happens

This concept is defined as the perception experience of caregiver and caregiving network members in caregiving exchange. The outcome of caregiving was identified into three categories: positive outcome, negative outcome, and neutral outcome. Positive outcome refers to perception of good experiences. This present study found the positive outcomes were gaining, being awareness of own health, closer relationship, being proud of caregiving, having a better life. In contrast, negative outcome refers to perception of bad experiences. This study showed the negative outcomes were reducing working, reducing income, boring feeling, stress. The neutral outcome refers to perception of normal that consists of good and bad. This present study demonstrated the neutral outcome were being a normal, and seeing as it is (*sutchatum* in Thai language). This conception was not totally closed to broaden-and-build theory. Fredrickson's (2001) clarified the positive outcome increases while negative outcome decreases due to the resources on the problem. The positive outcome expanded or broadened the field. Therefore, caregiving for older adult was both the positive and negative experiences (Robertson, Zarit, Duncan, Rovine & Femia, 2007), both the costs and rewards (Raschick & Ingersoll-Dayton, 2004), both the good days and bad days (Koerner & Kenyon, 2007), two-sided to caregiving story (Pierce, Steiner, Govoni, Thompson & Friedeman, 2007). This concept was correspond to Buddhist doctrine which could be found in three are three categories: Happiness, suffering, and not perceived to happiness or not perceived to suffering (*U-beg-kha* in Thai language) are the part of life.

6. When the time comes, there will be a way

This concept is defined as the perception of the dynamic process of caregiving. This study found two categories: planning for uncertainty in the future and seeking a new way of care. Focusing on planning for uncertainty in the future, there were preparing for patient's dying and preparing for caregiver's dying. Based on

Buddhist belief, Thai people believed that the most certainly thing is uncertainty. We should prepare for today with free from worry. Thai elderly people will prepare for funeral care (Caffrey, 1992). This present study also found that primary caregiver prepared her and her husband's funeral by talking with her children and prepared the photographs for funeral care. Relating to finding a new way of care, there were seeking a new primary caregiver or assistant, finding a new way to deal with patient's deteriorating, and learning to modify care.

These six concepts reflect to the dynamic process of caregiving that there will be change during caregiving process. Several studies in stroke caregiving focused only the end of caregiving by returning to normalization (Burman, 2001; Hirunchunha, 1998), In contrast, a stroke caregiving study was correspond to this study. There is ongoing process of caregiving from system maintenance, coherence, and turned to problem in system maintenance versus. change or turned to success in individuation and system maintenance (Pierce et al., 2007).

In qualitative study, Knafl and Breitmayer (1991) explained how to approach and confirm the themes through multiple triangulations. The qualitative study was confirmed by using five types of triangulation in terms of investigator, data sources, methods, unit of analysis, and theory (Knafl & Breitmayer, 1991). Focusing on investigator triangulation, this study consisted of a dissertation team member whose diverse perspectives on elderly, cancer and caregivers. The different areas of expert could help the contribution to the interview guide both the caregiver and caregiving network members. Relating to data resource, this study obtained data from caregivers, patients, and caregiving network members to maximize the range of data. The triangulation of data sources provided better understanding of the social network and social exchange behaviors being investigated. With regard to methods, this study used several strategies, such as participant observation, in-depth-interview, field notes, geographical mapping, photography, household assessment, network recording and analysis to collect the different caregiving dimensions. For triangulation of unit analysis, the researcher applied Nvivo software data management program to utilize these data from items and variables (units) to factors (patterns) and domains (structures).

The theoretical triangulation is either theory testing or theory generating studies. This study used the existing models of “Care Model” and “Maintaining caregiving at home” Findings from the “wheel of caregiving” model suggest the process of stroke caregiving. This model consists of six concepts: no one can do it, don’t know what to do, let’s try it, relying on each other, whatever happens, happens, and when the time comes, there is a way. These concepts are similar to the “Care Model” for caregivers of stroke patients at home (Hirunchunha, 1998). Hirunchunha developed a caregiver transformation process consisting of four stages: Inability to adjust/think, a transition period, seeking/modifying care technique, and settle into a normal lifestyle. Similarly, the “wheel of caregiving model” is congruent with “Maintaining caregiving at home”. Subgranon and Lund (2000) classified the elements of caregiving as involving transition, tasks, roles, processes, and outcomes of the caregiving concept. These models of stroke caregiving are compared and shown in table 5.1

Table 5.1 Comparison of stroke caregiving among the “wheel of caregiving”, “care model” and “maintaining caregiving at home” models.

Wheel of caregiving model	Care model	Maintaining caregiving at home
No one else can do it	In abilities to adjust/think	Caregiving as unavoidable task
Don’t know what to do	Transition period	Managing problems and difficulty
Let’s try it	Seeking /modifying care techniques	Managing treatment
Relying on each other		-Family and kinship support -Community support
Whatever happens, happens	Normal lifestyle	-Caregiving as an integral part of life -Managing with love, sympathy, and attachment
When the time comes, there will be a way		

In summary, this present study further expands more than Hirunchunha (1998), Subgranon and Lund (2000) on the planning for the future in terms of “when the time comes, there will be a way” because there is a new cycle to move caregiving process along as in the wheel of caregiving model. This model can be used to describe the phenomenon of caregiving in terms of both process and outcome. In addition, this model can explore the patterns of social exchange behaviors during caregiving in three patterns: Sharing care, dual care, and supplementary care.

Theoretical Issue

This present study used network analysis concepts and social exchange theory as guideline. These theories have been used in sociology and anthropology. Based on this concept and theory, questions have been developed to assess size, and compositions of caregiving networks and caregiving behaviors. This topic-oriented ethnography is guided by these theories which narrow the focus in many aspects (Spradley, 1980). In the context of caregiving in Bangkok, this present study found many problems and needs to set up the caregivers and caregiving networks to take care of stroke patients. The social network concept was very useful to identify who were the caregiving network members in the family, non-family and organization. The hidden power of social network could be demonstrated how to develop effective collaboration (Cross & Parker, 2004). In this present study, the inner working of caregiving has been shown rather than only supports. Network analysis was used to portray the connectivity of caregiving network members and the invisible caregiving have shown their directions on the diagrams in terms of lines and arrows, central people, peripheral people, and subgroups.

Social exchange theory was an important tool for the observation and selective observation. This theory has provided more understanding of the picture of caregiving in terms of both providing and receiving care. However, there are limitations and sensitivities to Thai culture in some aspects. Social exchange theory is derived from economy theory and extends to sociology and anthropology. Based on the assumption of social exchange theory, people help each other because of the benefit. When giving and receiving from caregiving were asked, some caregivers

avoided answering directly. Under Thai social values, individuals learn how to provide help to others and do not expect anything in return. It is highly sensitive in Thai culture about providing care with attention to outcomes and benefits. Thai people turn to words on receiving such as, *num-jai* (wanting to help) rather than money.

Methodological Issue

This study used the ethnographic method to describe and explore patterns of social exchange behaviors of stroke caregiving network in the context of Bangkok. The methodology consisted of many methods listed as follows:

1. Collecting data

The validity is the significant issue in collecting data of quantitative study. This issue relates to social desirability that is a systematic error (Adam, Matthews, Ebbeling, Moore, Cunningham, Fulton & Hebert, 2005; Johnson & Fendrich, 2002). Social desirability is the tendency of individuals to answer or present themselves in cultural norms. In this present qualitative study, this issue is concerned during social interaction. For the freedom from bias (neutrality), the data were collected by many strategies, such as interviewing with the participants and observations their activities. For example, in Muslim's family, the stroke patient presented her friendly when the community health volunteer came with the researcher. When I came alone, I feel about the loneliness of the patient. I interviewed the primary caregiver and caregiving network members about their caregiving in different places. They presented their activities relating to cultural norms that the heaven is under mother's feets but they did not talk about the psychological caregiving. I interviewed the community health volunteer. She talked about the hidden issue of violence in these family members.

2. Context analysis

Context analysis has various definitions relating to dimensions. In social support dimension, there are situational, temporal, and personal context of support (Jacobson, 1987). The context of this current study is the cultural context of stroke caregiving network in Bangkok. The context analysis pays attention to cultural assumptions and expectations of primary caregiver and caregiving system. There is "cultural rules" to make a decision of caregiver". For increasing credibility of

ethnography by six criteria (Tripp-Reimer, 1984), this present study used time, place, circumstance, language, intimacy, and consensus. The participants presented about the youngest daughter would stay with their parents as the last person before they got married. It is the reason of time for the youngest daughter to be the caregiver. In Thai value, the daughter, who is a single or gets married are still living with their parents in the parent's houses or building a house in the same wall rather than going to live outside. Relating to hierarchical status in circumstance, the youngest daughter respects the eldest daughter/son and the reason to accept this role rather than negotiate to other siblings. In Thai wordings, the daughter would provide care better than the son. Thai parents were close to the youngest daughter/son. The consensus of 18 caregiving networks demonstrated that the youngest daughter was the mainly person to be the primary caregiver (22.7%) while the eldest daughter was reported 9%. There are other daughters (22.7%) but it could not point out that was the third, the fourth...and so on. As a result, the youngest daughter was the first in line to be the primary caregiver.

In addition, the question and answer had been emerged in the social situation from insider perspective (Spradley, 1980). From the outside the cultural view of professional, the primary caregiver is the unpaid care who provides direct caregiving. In this present study, the question of the primary caregiver in Bangkok is clarified by caregivers and caregiving network members. The consistency meaning of primary caregiver is individuals who stay with the patients all the time and provide direct care to them. Although there have no cost of caregivers, this study has clarified the hidden cost of caregiving in terms of living arrangement of caregivers, transportation to carry the patient with bedridden in Bangkok.

3. Writing

The writing is the most difficult part because of changing themes. When I changed to other themes and categories, I had to revise all the content accordingly the writing. It was very terrible and hard work to write all pages again and again. I encouraged myself to keep going to do the revision of my writing. The language is the big problem because I did not have a deep understanding the meaning of the English language. My major advisor, co-advisor, editor were the important people to help.

Strengths and limitations

This qualitative study provides more understanding of caregiving in Thai culture. Based on social value and belief, the patterns of social exchange behaviors were observed and interviewed to probe for understanding. In this section, the current study has been critiqued in terms of strengths and limitations.

Strengths

The meaning of the primary caregiver emerged during data collection and the details of financial support for the primary caregiver role are presented. These aspects have not been revealed in other previous studies before.

Secondly, the strength of this study was the participants who consist of stroke patient, primary caregiver, and caregiving network members. Much caregiving research has been studied separating between patients and caregivers. By collecting data from different people, the data triangulation has been used to confirm validity of research content.

Thirdly, there are two approaches to caregiving network including exchange theory and network analysis. Network analysis is used to define persons and relationships. Social exchange theory is used to understand the mechanism of caregiving by three theories: equity theory, theory of indebtedness, and resource theory.

Limitations

There is, however, a limitation on our ability to generalize from the findings of this qualitative study was limited. The objectives of this study were to describe the people and relationships in caregiving networks and to explore patterns of social exchange behaviors.

Another limitation of this study is in the area of validation because the researcher could not observe caregiving exchange activities all the time in the participant's house. Some patients were bedridden and one patient did not follow up at the hospital (Case # 4). The observation of caregiving is limited in hospital and in community..

Finally, the language has been translated from Thai to English. There are some changes of data to ensure understanding but the meanings have been kept to reflect caregiving behaviors.

CHAPTER VI

CONCLUSION

This chapter included two sections. The first section is the summary of the study. The second section consists of the implications in nursing education, nursing practice, and nursing research and recommendation.

Summary of the study

This exploratory descriptive ethnography aimed to describe stroke caregiving network in Bangkok and explored the patterns of social exchange behaviors. Social network concept and social exchange theory were used to guide this study. The study was conducted in Bangkok for ten-month period. Eighteen elderly stroke patients, who were over 60 year-old and Barthel Index score were equal or lower than a half of total score, were recruited from Ramathibodi hospital, Neurological Institute hospital, and community health center. Eighteen stroke caregiving networks included 22 primary caregivers (19 women, 3 men), and 20 caregiving network members (19 women, one man), who took care stroke patients more than 2 months were the participants. A date, time were arranged by telephone contact or direct contact with community health volunteers and consent form for interviewing and photography were performed respectively.

Data were collected through participant observation at homes, hospitals, and communities; 44 formal interviews and informal interviews; field notes; geographic mapping, photograph, household assessments, network recording and analysis. The contextual analysis is to look for consistency from items, units, patterns, and structures (Lecompte & Schensul, 1999). Nvivo software program was used to capture the patterns.

The findings indicated three patterns of social exchange behaviors in Bangkok. The first pattern was “sharing care” that roles and functions of care were divided within caregiving network members. The second pattern was “dual care” that

functions of care were shifted within caregiving networks. The third pattern was “supplementary care” that primary caregiver was doing alone or was supplemented by caregiving network member occasionally. Factors related to social exchange behaviors were satisfaction, size, time, duration, finances, communication, and relationship.

The “wheel of caregiving” model was developed and six themes were emerged as follow: 1) No one else can do it, 2) Don’t know what to do, 3) Let’s try it, 4) Relying on each other, 5) Whatever’s happens, happens, 6) When the time comes, there will be a way. Based on social network concept and social exchange theory, the network-exchange configurations of caregiving characteristics were identified the difference on size, homogeneity, frequency of contact, directionality, gender, and status.

Implications and Recommendations

Implications for nursing education and practice

From this study, the meaning of primary caregiver in the perspective of caregiver has been changed from the old meaning that caregiver is an unpaid care to the new meaning that is an unpaid and paid care. Nursing education needs developing the body of knowledge in caregiving to fit the new meaning. The primary caregiver is the person who stays with the patient all the time and provides direct care to patient. The primary caregiver may or may not the leader of family or caregiving network who makes the decision to the patients. There is only one or two primary caregivers based on patterns of social exchange behaviors. The definition of primary caregiver provides clear understanding who is the main person in caregiving context.

The patterns of social exchange behavior provide the picture of caregiving exchange in the “wheel of caregiving” model. This model could describe the caregiving movement along the caregiving process, the problems and needs in caregiving, the patterns of social exchange behavior, the outcome happening, and the dynamics of caregiving to ongoing the wheel of caregiving. The nature of caregiving has been explored to better understanding the structure of caregiving network and the mechanism of caregiving exchanges. The intervention of support program would develop to sensitive of beliefs and values of Thai culture. Using the “wheel of

caregiving” model could strengthen and meaningful nursing service from nursing knowledge.

Implications for policy

The long-term care needs to be developed in Thailand. Relating to increase of elderly people, caregiving for older adult with chronic illness should prepare to control the problems not only health conditions but also resources available. The result of this study provides understanding the natural caregiving networks. The patterns of social exchange behavior described the strengths and limitation to adequacy of caregiving. The conditional factors are classified in terms of human resources (size and compositions), time, duration, communication, and financial system

Relating to human resources, there are limitations of support to difficult tasks of caregiving, such as transportation for stroke patients who could not walk by themselves or providing taking a bath and so on. The difficult tasks make much more burden for caregiver that needs more services to support informal caregiver, such as preparing blenderized diet, giving a bathe, taking to follow up at the hospital and etc.

With regard to time available and duration in the community, some caregiving networks have limitation of resources to exchange caregiving. The non-family members need to provide supplementary care by using communication system. The effective communication strategies needs to be developed for ongoing the wheel of caregiving.

Focusing on financial system, in general, the caregiver is unpaid informal care but there are hidden cost of caregiving in terms of living arrangement, transportation and etc. In urban area as Bangkok, it is not enough to provide care and did not receive any financial support. The hidden cost of elderly and stroke care need to be recognized because community care is better and cheaper than institutional care (Fast, Williamson & Keating, 1999). When the caregivers are burn out and could not keep on caregiving, the stroke patient was readmitted in the hospital with high cost of care. Thai government provides financial support for family caregiver to take care of HIV and AIDs. Other caregiving for chronic patients like stroke patient need similar supports.

Recommendations for future research

The growing of body of knowledge in caregiving has been continued development in stress and coping of caregiver. This study provides many areas that need to further study.

The “wheel of caregiving” model has been developed from qualitative study. This model and concepts have been emerged in stroke caregiving network in Bangkok and need further developments to fit in the other contexts, such as rural areas or cross cultural situations. Some new variables were wanting to help (*num-jai*), encouragement (*kum-lung-jai*), caregiver’s enduring (*jum-jai*) that need much more understanding.

Findings from patterns of social exchange behaviors are three patterns that were different and congruent with other patterns of stroke caregiving (Anantato, 2005; Lingler et al., 2008). The patterns of social exchange behaviors provide more understanding the nature of informal caregiver and caregiving network members that maintain caregiving at home for the longer than 20 years. Caregiving knowledge needs further developing program that more sensitive to Thai caregivers.

Most of the caregiving studies focus on the social support, the study of caregiving network is limitations. To more understand both side of support, the research of structure of relationship (social network) need much more understanding as same as the study of function of relationship (social support).

Moreover, the study of male caregiver had limitations. Gender difference of social network of male and female need more understanding to find out the variable that sensitive to gender care.

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APPENDICES

APPENDICES

ประกอบด้วย

1. APPENDIX A ประกอบด้วย

- เอกสารประกอบ ๔ เอกสารชี้แจง/คำแนะนำแก่ผู้เข้าร่วมการวิจัย
(Participant Information Sheet)
- เอกสารประกอบ ๕ ก หนังสือยินยอมโดยได้รับการบอกกล่าวและเต็มใจ
(Informed Consent Form)
- หนังสือแสดงความยินยอมให้ถ่ายภาพและบันทึกเสียง
(Informed Consent Form for photograph and tape record)

2. APPENDIX B ประกอบด้วย

- การบันทึกช่วยจำ ในการลงรหัสกลุ่ม
- ข้อมูลทั่วไปผู้ป่วย
- ข้อมูลทั่วไปผู้ดูแล
- ข้อมูลทั่วไปเครือข่ายผู้ดูแล

3. APPENDIX C

- แนวคำถามปลายเปิดผู้ดูแล
- แนวคำถามปลายเปิดเครือข่ายผู้ดูแล

4. APPENDIX D ประกอบด้วย

Documentary proof of ethic clearance committee on human right
related to research involving human subjects

- Neurological Institute
- Faculty of Medicine, Ramathibodi Hospital, Mahidol
University.

APPENDIX A

เอกสารประกอบ ๔



เอกสารชี้แจงข้อมูล/คำแนะนำแก่ผู้เข้าร่วมการวิจัย (Participant Information Sheet)

- ชื่อโครงการ** เครื่องช่วยผู้ดูแลผู้ป่วยอัมพาตจากหลอดเลือดสมองในกรุงเทพ: รูปแบบการช่วยเหลือทางสังคม
- ชื่อผู้วิจัย** สมนึก สกุนหงส์โสภณ
- สถานที่วิจัย** แผนกผู้ป่วยนอกอายุรกรรมโรงพยาบาลรามารับดี, สถาบันประสาทวิทยา, ศูนย์สาธารณสุขกรุงเทพมหานคร, บ้านของผู้ป่วยและผู้ดูแล

บุคคลและวิธีการติดต่อเมื่อมีเหตุฉุกเฉินหรือความผิดปกติที่เกี่ยวข้องกับการวิจัย

ถ้าหากคุณมีข้อสงสัยเกี่ยวกับการศึกษาครั้งนี้กรุณาติดต่อที่ นางสาวสมนึก สกุนหงส์โสภณ ภาควิชาพยาบาลศาสตร์ คณะแพทยศาสตร์โรงพยาบาลรามารับดี ถนนพระรามหก เขตราชเทวี กรุงเทพฯ 10400 เบอร์โทรศัพท์ 081-4851015

ผู้สนับสนุนการวิจัย มหาวิทยาลัยมหิดลและสภาพยาบาล

ความเป็นมาของโครงการและวัตถุประสงค์

การวิจัยครั้งนี้มีจุดประสงค์คือ เพื่อทำความเข้าใจอย่างลึกซึ้งโดยละเอียดเกี่ยวกับรูปแบบการช่วยเหลือทางสังคม ในเครื่องช่วยผู้ดูแลผู้ป่วยอัมพาตจากหลอดเลือดสมองในกรุงเทพ ผู้วิจัยหวังว่าการเพิ่มพูนความรู้ความเข้าใจจะนำไปสู่การพัฒนาเครื่องช่วยการดูแล ผู้ป่วยอัมพาตจากหลอดเลือดสมองในอนาคต ผู้ดูแลที่ได้รับเชิญให้เข้าร่วมการศึกษานี้ เพราะเป็นผู้ที่ให้การดูแลผู้ป่วยอัมพาตจากหลอดเลือดสมองที่บ้าน (โดยมิใช่เป็นเจ้าหน้าที่ดูแลจากศูนย์เอกชน) โดยให้การดูแลมาแล้วอย่างน้อยสองเดือนและพักอาศัยอยู่ในกรุงเทพ

รายละเอียดที่จะปฏิบัติต่อผู้ร่วมวิจัย

ถ้าหากผู้ดูแลยินดีเข้าร่วมกับการศึกษานี้ ผู้วิจัยจะขอเข้าไปสังเกตกิจกรรม การช่วยเหลือในการดูแลระหว่างกันในการช่วยการดูแลที่บ้าน และสถานที่ที่ผู้ดูแลอนุญาตเป็นต้นว่า

แผนผู้ป่วยนอกอายุรกรรม, สถานพยาบาลศูนย์สาธารณสุข ฯลฯ หลังจากนั้นจะมีการขอสัมภาษณ์เกี่ยวกับการสนับสนุนช่วยเหลือที่ท่านได้รับและข้อมูลเกี่ยวกับลักษณะ เครือข่ายการดูแลผู้ป่วยอัมพาต เช่น จำนวนบุคคล, ความสัมพันธ์กันภายในเครือข่าย, ระยะเวลาที่รู้จักกัน, ความถี่ในการติดต่อให้ความช่วยเหลือกัน ฯลฯ ตลอดจนข้อมูลในเรื่องของอายุ, การศึกษา, อาชีพ ฯลฯ การสนทนาแต่ละครั้งจะใช้เวลาประมาณ 45 ถึง 60 นาที ประมาณ 2 ถึง 4 ครั้งและขออนุญาตบันทึกเสียงการสนทนา สำหรับการสังเกตการณ์ประมาณ 3 ถึง 4 ครั้งและอาจมีการถ่ายรูปถ้าอนุญาต เพราะภาพถ่ายสามารถบอกเล่ารายละเอียดของการสนับสนุนการดูแล

ประโยชน์ของงานวิจัยและผลข้างเคียงที่จะเกิดแก่ผู้เข้าร่วมการวิจัย

ผู้ดูแลผู้ป่วยอัมพาตจากหลอดเลือดสมองอาจไม่ได้รับประโยชน์โดยตรง ในการร่วมการศึกษาครั้งนี้ ประโยชน์ที่เกิดขึ้นจากการค้นพบในการศึกษาจะถูกนำไปพัฒนาแนวทางในการช่วยเหลือญาติที่ให้การดูแลผู้ป่วย, ผู้ป่วยหรือเครือข่ายการดูแลผู้ป่วยต่อไป

การศึกษานี้จะไม่เกิดอันตรายหรือความเสียหายใด ๆ ต่อผู้ดูแล หรือไม่ทำให้เกิดความลำบากใจในการพูดคุยเกี่ยวกับประสบการณ์ในการช่วยเหลือการดูแล, การสังเกตหรือการถ่ายภาพ ถ้าหากผู้ดูแลรู้สึกไม่สบายใจในการตอบคำถามในการสัมภาษณ์ หรือการสังเกตการณ์ใด ๆ ตลอดจนการถ่ายภาพ สามารถยุติการตอบคำถามหรือไม่ให้มีการสังเกตการณ์หรือถ่ายภาพใด ๆ ได้ตลอดเวลา การปฏิเสธหรือถอนตัวจากการศึกษานี้ จะไม่กระทบต่อการดูแล ผู้ป่วยในปัจจุบันหรือในอนาคต

การเก็บข้อมูลเป็นความลับ

ข้อมูลและเอกสารทุกอย่างในการศึกษานี้จะถูกเก็บอย่างเป็นความลับ ไม่มีการระบุชื่อในการเขียนหรือบันทึกเรื่องราวในการศึกษานี้ ข้อมูลทั้งหมดจะนำมาใส่เป็นรหัสเพื่อใช้ในการเผยแพร่ต่อสาธารณะ ข้อมูลทั้งหมดจะถูกเก็บไว้ในสถานที่ปลอดภัย และถูกทำลายภายในห้าปี

เอกสารประกอบ ๕ก



หนังสือยินยอมโดยได้รับการบอกกล่าวและเต็มใจ
(Informed Consent Form)

ชื่อโครงการ เครื่องข่ายผู้ดูแลผู้ป่วยอัมพาตจากหลอดเลือดสมองในกรุงเทพ: รูปแบบการช่วยเหลือทางสังคม

ชื่อผู้วิจัย สมนึก สกุนหงส์โสภณ

*ชื่อผู้เข้าร่วมการวิจัย.....

เป็นผู้ดูแลผู้ป่วยชื่อ.....เลขที่เวชระเบียน.....

คำยินยอมของผู้เข้าร่วมการวิจัย

ข้าพเจ้า นาย/นาง/นางสาว.....ได้ทราบรายละเอียดของโครงการวิจัยตลอดจนประโยชน์ และข้อเสี่ยงที่จะเกิดขึ้นต่อข้าพเจ้าจากผู้วิจัยแล้วอย่างชัดเจน ไม่มีสิ่งใดปิดบังซ่อนเร้นและยินยอมให้ทำการวิจัยในโครงการที่มีข้อข้างต้น และข้าพเจ้ารู้ว่าถ้ามีปัญหาหรือข้อสงสัยเกิดขึ้นข้าพเจ้าสามารถสอบถามผู้วิจัยได้ และข้าพเจ้าสามารถไม่เข้าร่วมโครงการวิจัยนี้เมื่อใดก็ได้ โดยไม่มีผลกระทบต่อการรักษาของผู้ป่วยที่พึงได้รับ นอกจากนี้ผู้วิจัยจะเก็บข้อมูลเฉพาะเกี่ยวกับตัวข้าพเจ้าเป็นความลับและจะเปิดเผยได้เฉพาะในรูปที่เป็นสรุปผลการวิจัย การเปิดเผยข้อมูลเกี่ยวกับตัวข้าพเจ้าต่อหน่วยงานต่าง ๆ ที่เกี่ยวข้อง กระทำได้เฉพาะกรณีจำเป็นด้วยเหตุผลทางวิชาการเท่านั้น

ลงชื่อ.....(ผู้เข้าร่วมการวิจัย)

.....(พยาน)

.....(พยาน)

วันที่.....

คำอธิบายของผู้วิจัย

ข้าพเจ้าได้อธิบายรายละเอียดของโครงการ ตลอดจนประโยชน์ของการวิจัยรวมทั้งข้อเสี่ยงที่อาจเกิดขึ้นแก่ผู้เข้าร่วมการวิจัยทราบแล้วอย่างชัดเจนโดยไม่มีสิ่งใดปิดบังซ่อนเร้น

ลงชื่อ.....(ผู้วิจัย)

วันที่.....

หมายเหตุ: กรณีผู้เข้าร่วมการวิจัยไม่สามารถอ่านหนังสือได้ ให้ผู้วิจัยอ่านข้อความในหนังสือยินยอมฯ นี้ให้แก่ผู้เข้าร่วมการวิจัยฟังจนเข้าใจดีแล้ว และให้ผู้เข้าร่วมการวิจัยลงนามหรือพิมพ์ลายนิ้วหัวแม่มือรับทราบในการให้ความยินยอมดังกล่าวข้างต้นไว้ด้วย

* ผู้เข้าร่วมการวิจัย หมายถึง ผู้ยินยอมตนให้ทำวิจัย



คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี
หนังสือแสดงความยินยอมให้ถ่ายภาพและบันทึกเสียงผู้ป่วย
(Informed Consent Form for photograph and tape record)

วันที่.....เดือน.....พ.ศ.....

ข้าพเจ้า นาย/นาง/นางสาว.....นามสกุล.....อายุ.....ปี
อยู่บ้านเลขที่.....ตรอก/ซอย.....ถนน.....ตำบล/แขวง.....
อำเภอ/เขต.....จังหวัด.....รหัสไปรษณีย์.....ในฐานะ ☐ ผู้ป่วย
☐ ผู้มีอำนาจกระทำการแทนผู้ป่วยในฐานะ.....ของผู้ป่วยชื่อ.....
เวชระเบียนเลขที่.....ของแสดงความยินยอมให้บุคลากร
ในสังกัดคณะแพทยศาสตร์โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล ถ่ายภาพและบันทึกเสียง
โดยนำภาพและเสียงที่เกี่ยวกับการรักษาพยาบาลของผู้ป่วยที่เกิดขึ้นระหว่างวันที่.....เดือน.....
พ.ศ.....ถึงวันที่.....เดือน.....พ.ศ.....ณ.....ไปใช้ในการ
เรียนการสอนทางการแพทย์ ตีพิมพ์ หรือเผยแพร่โดยวิธีอื่นใด เพื่อประโยชน์ในทางวิชาการหรือ
เพื่อประโยชน์ในทางการแพทย์เท่านั้น

ทั้งนี้ บุคลากรในสังกัดคณะแพทยศาสตร์โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล
จะไม่เปิดเผยชื่อ นามสกุล และที่อยู่ของข้าพเจ้าในการเรียนการสอนทางการแพทย์ รายงานทาง
วิชาการหรือในการเผยแพร่โดยวิธีอื่นใด ดังกล่าวข้างต้น

ลงชื่อ.....(ผู้ให้ความยินยอม)
(.....)

ลงชื่อ.....(พยาน)
(.....)

APPENDIX B

การบันทึกช่วยจำ (Researcher's memorandum)

รหัสกลุ่ม เป็นรหัส 4 ตัว □□□□

- ☐ ลำดับแรก หมายถึง รหัสผู้ป่วยที่..... เริ่มจาก 1,2,3.....
- ☐ ลำดับสอง หมายถึง รหัสครอบครัวผู้ป่วยที่.....เริ่มจาก 1,2,3.....
- ☐ ลำดับสาม หมายถึง รหัสผู้ดูแลหลักคนที่ 1 ผู้ดูแลรองคนที่ 2, 3.....
- ☐ ลำดับสี่ หมายถึง รหัสเครือข่ายคนที่.....เริ่มจาก 1,2,3.....

ส่วนของผู้ป่วย

รหัสผู้ป่วย.....รหัสโรงพยาบาล.....

ชื่อ-นามสกุลผู้ป่วย.....

เบอร์โทรศัพท์.....

ที่อยู่.....

แผนที่บ้าน

ข้อมูลทั่วไปผู้ป่วย

รหัสของผู้ป่วย □□□□

คำชี้แจง กรุณาตอบแบบสอบถามเกี่ยวกับตัวท่าน โดยทำเครื่องหมาย □ หรือเติมคำลงในช่องว่าง
หน้าข้อความที่ตรงกับตัวท่าน (กรณีผู้ป่วยไม่สามารถตอบได้ ผู้ดูแลเป็นผู้กระทำแทน)

- 1.เพศ () ชาย () หญิง
- 2.อายุ (นับจากวันเกิดครั้งล่าสุด) ปี.....เดือน.....
- 3.สถานภาพสมรส () โสด () คู่ () ม่าย () หย่า () แยก
4. ศาสนา () พุทธ () คริสต์ () อิสลาม () อื่น
- 5.อาชีพก่อนเจ็บป่วย () รับจ้าง () ค้าขาย () แม่บ้าน () เกษตรกร
() อื่น ๆ โปรดระบุ.....
- 6.อาชีพหลังเจ็บป่วย () รับจ้าง () ค้าขาย () แม่บ้าน () เกษตรกร
() อื่น ๆ โปรดระบุ.....
- 7.การศึกษา () ไม่ได้เรียน () ประถมศึกษา () มัธยมศึกษา
() ประกาศนียบัตร () ปริญญาตรี () อื่น ๆ โปรดระบุ.....
- 8.รายได้ต่อเดือน บาท () เพียงพอ () ไม่เพียงพอ
- 9.ค่ารักษาพยาบาล () บัตรประกันสังคม () เบิกได้ () ชำระค่ารักษาเอง
() อื่น ๆ โปรดระบุ.....
- 10.ระยะเวลาที่เป็นอัมพาต.....ปี
- 11.บ้านที่พักอยู่ในปัจจุบัน () ผู้ป่วยเป็นเจ้าของ () บ้านเช่า () บ้านของผู้ดูแล
() อาศัยอยู่กับผู้อื่น ระบุเจ้าของ.....
- 12.จำนวนบุตร () ไม่มี () มี จำนวน.....คน
- 13.จำนวนสมาชิกในครัวเรือน จำนวน.....คน โปรดระบุ

Family tree

ข้อมูลทั่วไปของผู้ดูแล

รหัสของผู้ดูแล □□□□

คำชี้แจง กรุณาตอบแบบสอบถามเกี่ยวกับตัวท่าน โดยทำเครื่องหมาย □ หรือเติมคำลงในช่องว่าง
หน้าข้อความที่ตรงกับตัวท่าน

1. เพศ () ชาย () หญิง
2. อายุ (นับจากวันเกิดครั้งสุดท้าย) ปี.....เดือน.....
3. สถานภาพสมรส () โสด () คู่ () ม้าย () หย่า () แยก
4. ศาสนา () พุทธ () คริสต์ () อิสลาม () อื่น
5. อาชีพเดิม () รับจ้าง () ค้าขาย () แม่บ้าน () เกษตรกร
() อื่น ๆ โปรดระบุ.....
6. อาชีพปัจจุบัน () รับจ้าง () ค้าขาย () แม่บ้าน () เกษตรกร
() อื่น ๆ โปรดระบุ.....
7. การศึกษา () ไม่ได้เรียน () ประถมศึกษา () มัธยมศึกษา
() ประกาศนียบัตร ()ปริญญาตรี () อื่น ๆ โปรดระบุ.....
8. รายได้ต่อเดือน บาท () เพียงพอ () ไม่เพียงพอ
9. โรคประจำตัว () ไม่มี () มี โปรดระบุ.....
10. ระยะเวลาที่ดูแลผู้ป่วย.....ปี
11. ความสัมพันธ์กับผู้ป่วย () คู่สมรส () บุตร/ธิดา () หลาน () เพื่อน
() อื่น ๆ โปรดระบุ.....
12. มีผู้ดูแลอื่นช่วยเหลือการดูแล () ไม่มี () มี จำนวน.....คน

Household Assessments

ข้อมูลทั่วไปเครือข่ายผู้ดูแล

รหัสเครือข่ายของผู้ดูแล

- 1.เพศ () ชาย () หญิง
- 2.อายุ (นับจากวันเกิดครั้งสุดท้าย) ปี.....เดือน.....
- 3.สถานภาพสมรส () โสด () คู่ () ม้าย () หย่า () แยก
4. ศาสนา () พุทธ () คริสต์ () อิสลาม () อื่น
- 5.อาชีพปัจจุบัน () รับจ้าง () ค้าขาย () แม่บ้าน () เกษตรกร
() อื่น ๆ โปรดระบุ.....
- 6.การศึกษา () ไม่ได้เรียน () ประถมศึกษา () มัธยมศึกษา
() ประกาศนียบัตร ()ปริญญาตรี () อื่น ๆ โปรดระบุ.....
- 7 () ไม่มี () มี โปรดระบุ.....
- 10.ระยะเวลาที่รู้จักกับผู้ดูแล.....ปี
- 11 ความสัมพันธ์กับผู้ป่วย () คู่สมรส () บุตร/ธิดา () หลาน () เพื่อน
() อื่น ๆ โปรดระบุ.....
- 12 ลักษณะการพักอาศัย () อยู่บ้านเดียวกับผู้ดูแล () พักอาศัยคนละบ้าน
- 13 ระยะห่างระหว่างที่พักอาศัยกับบ้านผู้ป่วย กม.
ใช้เวลาเดินทาง.....ชั่วโมง.....นาที

Network Assessment

APPENDIX C

แนวคำถามปลายเปิดผู้ดูแล (Interview guideline)

เครือข่ายผู้ดูแลผู้ป่วยอัมพาตจากหลอดเลือดสมองในกรุงเทพ:

รูปแบบการช่วยเหลือทางสังคม

รหัสของผู้ดูแล □□□□

คำถามทั่วไปผู้ดูแล

1. กรุณาเล่าให้ฟังเกี่ยวกับตัวคุณ เป็นคนกรุงเทพฯ โดยกำเนิดหรือไม่.....ย้ายมาจากที่จังหวัดใดมาบ้าง....และมาอยู่ที่นี่ได้อย่างไร?
2. ก่อนที่จะเข้ามารับหน้าที่ดูแลคุณ....คุณต้องรับผิดชอบอย่างไรในครอบครัวบ้าง?
3. กรุณาเล่าความเป็นมาของการที่คุณมาเป็นผู้ดูแลได้อย่างไร....ตั้งแต่เมื่อไร และอะไรเป็นสาเหตุที่คุณเข้ามารับหน้าที่นี้?
4. งานที่ทำอยู่ก่อนหน้านี้นี้อย่างไร....งานในปัจจุบันยังคงเดิมหรือเปลี่ยนไปอย่างไร?

คำถามเฉพาะ

จุดประสงค์ที่ 1 เพื่อบอกเล่าประสบการณ์ในชีวิตประจำวันของผู้ดูแล (ประเด็นเกี่ยวกับภาระงาน, บทบาทหน้าที่, กระบวนการเปลี่ยนผ่าน, กระบวนการการดูแล)

1. กรุณาเล่าให้ฟังว่าในแต่ละวัน คุณมีกิจวัตรอะไรที่ต้องทำเป็นประจำให้ผู้ป่วย? (เจาะประเด็น การดูแลด้านร่างกาย, จิตใจ, สังคม, ประเพณีวัฒนธรรม ฯลฯ)
2. กรุณาเล่าให้ฟังเกี่ยวกับการพยาบาล หรือการดูแลพิเศษที่คุณทำให้ผู้ป่วย? (เจาะประเด็นความยากลำบากในการดูแล)
3. คุณได้รับการฝึกหัดหรือมีประสบการณ์อะไรที่ช่วยพัฒนาความสามารถในการดูแล?(เจาะประเด็นกระบวนการเปลี่ยนผ่านการเป็นผู้ดูแล)
4. ชีวิตคุณเป็นอย่างไรบ้างในการมาเป็นผู้ดูแลเช่นนี้ (เจาะประเด็นการเผชิญปัญหาและกระบวนการจัดการดูแล)
5. คุณรู้สึกอย่างไร....คุณคิดอย่างไรต่อสิ่งที่คุณทำอยู่นี้ (เจาะประเด็นผลลัพธ์ด้านบวก,ลบ, ทั้งบวกและลบ)

จุดประสงค์ที่ 2 เพื่อบอกเล่าเกี่ยวกับสมาชิกในเครือข่ายการดูแลผู้ป่วยอัมพาต (ประเด็น เรื่องขนาด และองค์ประกอบทางสังคมมิติของเครือข่าย, ความแน่นหนาของความสัมพันธ์, การให้ความสำคัญ, ระยะทางการติดต่อสัมพันธ์, ความถี่ในการติดต่อสัมพันธ์, ความคล้ายคลึงกันของสมาชิกเครือข่าย)

1. กรุณาเล่าถึงผู้ที่เข้ามาช่วยเหลือคุณในการดูแลผู้ป่วยมีใครกันบ้าง? (เจาะประเด็นขนาดเครือข่ายความสัมพันธ์ คือ จำนวนคนที่เข้ามาช่วยปกติ/ฉุกเฉิน)
2. กรุณาให้รายละเอียดของผู้ที่เข้ามาช่วยเหลือคุณ สิ่งที่เขาช่วยเหลือมีอะไรบ้าง (เจาะประเด็น ด้านความถี่, ปริมาณและคุณภาพของการช่วยเหลือที่ได้รับ)

3. คุณรู้จักสนิทสนมกับบุคคลเหล่านี้อย่างไรคะ ? (เจาะประเด็น ความแน่นหนาของสัมพันธภาพ)
4. คุณมีการติดต่อระหว่างกันมากน้อยเพียงใดคะ? (เจาะประเด็น จำนวนครั้ง ระยะเวลา)
5. คุณพอจะเล่าความเหมือนหรือแตกต่างระหว่างคุณและผู้เข้ามาช่วยเหลือหรือรับความช่วยเหลือจากคุณเป็นอย่างไรบ้าง (เจาะประเด็น อายุ เพศ ฯลฯ)
6. คุณพอจะทราบไหมคะอะไรเป็นสาเหตุที่ทำให้คนเหล่านั้นเข้ามาช่วยคุณ? (เจาะประเด็น เหตุผลของการแลกเปลี่ยนการช่วยเหลือ เช่น บุญคุณ)

ชุดประสค์ที่ 3 เพื่อบอกเล่าประเพณีวัฒนธรรมของสมาชิกในเครือข่ายการดูแล (ประเด็น เรื่อง ค่านิยม,ความเชื่อ, ประเพณีปฏิบัติ)

1. กรุณابอกเล่าถึงความสัมพันธ์ในครอบครัวเป็นอย่างไร? สัมพันธภาพระหว่างคุณกับผู้ป่วย คุณกับญาติพี่น้อง (เจาะประเด็นค่านิยมในครอบครัว เช่น การเป็นตัวของตัวเอง ต่างคนต่างอยู่หรือช่วยเหลือเกื้อกูล)
2. คุณมีความเชื่อเกี่ยวกับอะไรบ้าง และความเชื่อเฉพาะที่ครอบครัวให้ความสำคัญ? (เจาะประเด็น ความเชื่อทางศาสนา, ความเชื่อทางพิธีกรรม)
3. ความเชื่อทางศาสนาที่คุณและครอบครัวยึดถือปฏิบัติอย่างสม่ำเสมออะไรบ้าง? (เจาะประเด็น การเข้าวัด, การทำบุญ, การฝึกสมาธิ)
4. ความเชื่อทางประเพณีวัฒนธรรมท้องถิ่นที่คุณและครอบครัวปฏิบัติอย่างสม่ำเสมอมีอะไรบ้าง? (เจาะประเด็น การทำพิธีสะเดาะเคราะห์)
5. คุณได้มีโอกาสเข้าร่วมกิจกรรมในชุมชนอะไรบ้าง? (เจาะประเด็น ระยะเวลา และการให้ความสำคัญ)

ชุดประสค์ที่ 4 เพื่อทำความเข้าใจอย่างลึกซึ้งโดยละเอียดถึงพฤติกรรมการรับและให้การช่วยเหลือของสมาชิกในเครือข่ายการดูแลแก่ผู้ดูแล (ประเด็น การช่วยเหลือด้านต่าง ๆ เช่น ข้อมูล, ค่าใช้จ่าย, การเดินทาง อื่น ๆ)

1. กรุณาเล่าประสบการณ์สำคัญ ๆ ในการดูแลผู้ป่วยที่คุณคิดว่าเป็นอุปสรรคหรือสนับสนุนในการดูแลมีอะไรบ้าง? (เจาะประเด็น การดูแลด้านร่างกาย, จิตใจ อื่น ๆ)
2. คุณกรุณาเล่าถึงลักษณะการช่วยเหลือระหว่างกันเวลาที่เหตุการณ์ฉุกเฉิน? (เจาะประเด็น ชนิดของการช่วยเหลือ)
3. คุณมีความเห็นต่อการช่วยเหลือที่ได้รับเพียงพอหรือไม่อย่างไร? (เจาะประเด็น ความสมดุลของการรับและให้การช่วยเหลือ)
4. คุณต้องการได้รับการสนับสนุนในด้านใดอีกบ้าง ? (เจาะประเด็นปริมาณและคุณภาพ, ความยากลำบากในการขอความช่วยเหลือ)
5. กรุณابอกเล่ารายละเอียดถึงกิจกรรมอะไรบ้างที่ช่วยเหลือซึ่งกันและกันในการดูแลผู้ป่วย (เจาะประเด็น กิจกรรมที่เกิดขึ้น)

แนวคำถามปลายเปิดเครือข่ายผู้ดูแล
เครือข่ายผู้ดูแลผู้ป่วยอัมพาตจากหลอดเลือดสมองในกรุงเทพ:
รูปแบบการช่วยเหลือทางสังคม

รหัสของเครือข่ายผู้ดูแล

คำถามทั่วไปเครือข่ายผู้ดูแล

1. กรุณาเล่าให้ฟังเกี่ยวกับตัวคุณ เป็นคนที่ไหน....และมารู้จักกับครอบครัวนี้ได้อย่างไร?
2. ก่อนที่จะเข้ามาช่วยเหลือดูแล.....คุณเคยช่วยเหลืออะไรในครอบครัวนี้บ้าง?
3. กรุณาเล่าความเป็นมาของการที่คุณมาช่วยเหลือผู้ดูแลได้อย่างไร....ตั้งแต่เมื่อไร และอะไรเป็นสาเหตุที่คุณเข้ามาช่วย?
4. คุณทำงานอะไรอยู่ในขณะนี้....การเข้ามาช่วยเหลือมีผลต่องานประจำหรือไม่อย่างไร?

คำถามเฉพาะ

จุดประสงค์ที่ 1 เพื่อบอกเล่าประสบการณ์ในการเข้ามาช่วยผู้ดูแล (ประเด็นเกี่ยวกับการะงาน, บทบาทหน้าที่, กระบวนการเปลี่ยนผ่าน, กระบวนการการดูแล)

1. กรุณาเล่าให้ฟังว่าในแต่ละวัน คุณมีกิจกรรมอะไรที่ต้องช่วยเหลือเป็นประจำให้ผู้ดูแล? (เจาะประเด็น ด้านร่างกาย, จิตใจ, สังคม, ประเพณีวัฒนธรรม ฯลฯ)
2. กรุณาเล่าให้ฟังเกี่ยวกับกิจกรรมพิเศษที่คุณทำให้ผู้ดูแล?
(เจาะประเด็นความยากลำบากในการดูแล)
3. คุณได้รับประสบการณ์อะไรบ้างที่เข้ามาช่วยผู้ดูแล?
(เจาะประเด็นกระบวนการเปลี่ยนผ่าน)
4. ชีวิตคุณเป็นอย่างไรบ้างในการมาเป็นผู้ช่วยผู้ดูแลเช่นนี้
(เจาะประเด็นการเผชิญปัญหาและกระบวนการจัดการดูแล)
5. คุณรู้สึกอย่างไร....คุณคิดอย่างไรต่อสิ่งที่คุณทำอยู่นี้
(เจาะประเด็นผลลัพธ์ด้านบวก,ลบ, ทั้งบวกและลบ)

จุดประสงค์ที่ 2 เพื่อบอกเล่าเกี่ยวกับสมาชิกในเครือข่ายการดูแลผู้ป่วยอัมพาต (ประเด็น เรื่องขนาด และองค์ประกอบทางสังคมมิติของเครือข่าย, ความแน่นอนของความสัมพันธ์, การให้ความสำคัญ, ระยะทางการติดต่อสัมพันธ์, ความถี่ในการติดต่อสัมพันธ์, ความคล้ายคลึงกันของสมาชิกเครือข่าย)

1. กรุณาเล่าถึงผู้ที่เข้ามาช่วยคุณ.....มีใครกันบ้าง? (เจาะประเด็นขนาดเครือข่าย ความสัมพันธ์ คือ จำนวนคนที่เข้ามาช่วยปกติ/ฉุกเฉิน)
2. กรุณาให้รายละเอียดของการเข้ามาช่วยเหลือผู้ดูแล ได้ช่วยเหลืออะไรไปแล้วบ้าง และสิ่งที่ยังทำอยู่ (เจาะประเด็น ด้านความถี่, ปริมาณและคุณภาพของการช่วยเหลือที่ได้รับ)
3. คุณรู้จักสนิทสนมกับผู้ดูแลได้อย่างไร ? (เจาะประเด็น ความแน่นอนของความสัมพันธ์ภาพ)
4. คุณเข้ามาช่วยเหลือผู้ดูแลสม่ำเสมอมากน้อยเพียงใด? (เจาะประเด็น จำนวน ครั้ง,ระยะเวลา)

5. คุณพอจะเล่าความเหมือนหรือแตกต่างระหว่างคุณและผู้ดูแลเป็นอย่างไรบ้าง (เจาะประเด็น อายุ, เพศ ฯลฯ)
6. คุณพอจะเล่าเหตุผลที่ทำให้คุณยังคงเข้ามาช่วยผู้ดูแลต่อไป และนานแค่ไหน? (เจาะประเด็นเหตุผลของการแลกเปลี่ยนการช่วยเหลือ เช่น บุญคุณ)

จุดประสงค์ที่ 3 เพื่อบอกเล่าประเพณีวัฒนธรรมของสมาชิกในเครือข่ายการดูแล (ประเด็น เรื่อง ค่านิยม, ความเชื่อ, ประเพณีปฏิบัติ)

1. กรุณาบอกเล่าถึงความสัมพันธ์กับผู้ดูแลหรือครอบครัวเป็นอย่างไร? (เจาะประเด็นค่านิยมในเครือข่าย เช่น ต่างคนต่างอยู่หรือช่วยเหลือเกื้อกูล)
2. คุณมีความเชื่อเกี่ยวกับอะไรบ้าง และความเชื่อเฉพาะที่คุณให้ความสำคัญ? (เจาะประเด็น ความเชื่อทางศาสนา, ความเชื่อทางพิธีกรรม)
3. ความเชื่อทางศาสนาที่คุณยึดถือปฏิบัติอย่างสม่ำเสมอมีอะไรบ้าง? (เจาะประเด็น การเข้าวัด, การทำบุญ, การฝึกสมาธิ)
4. ความเชื่อทางประเพณีวัฒนธรรมท้องถิ่นที่คุณปฏิบัติอย่างสม่ำเสมอมีอะไรบ้าง? (เจาะประเด็น การทำพิธีหรือ สะเดาะเคราะห์)
5. คุณได้มีโอกาสเข้าร่วมกิจกรรมในชุมชนอะไรบ้าง? (เจาะประเด็น ระยะเวลา และการให้ความสำคัญ)

จุดประสงค์ที่ 4 เพื่อทำความเข้าใจอย่างลึกซึ้งโดยละเอียดถึงพฤติกรรมการรับและให้การช่วยเหลือของสมาชิกในเครือข่ายการดูแลแก่ผู้ดูแล (ประเด็น การช่วยเหลือด้านต่าง ๆ เช่น ข้อมูล, ค่าใช้จ่าย, การเดินทาง อื่น ๆ)

1. กรุณาเล่าประสบการณ์สำคัญในการช่วยเหลือผู้ดูแล ที่คุณคิดว่าเกิดผลลัพธ์ตามแผนหรือผลตรงข้ามมีอะไรบ้าง? (เจาะประเด็น การดูแลด้านต่าง ๆ)
2. คุณกรุณาเล่าถึงลักษณะการช่วยเหลือระหว่างกันเวลาที่มิเหตุการณ์ฉุกเฉิน? (เจาะประเด็น ชนิดของการช่วยเหลือ)
3. คุณมีความเห็นต่อการช่วยเหลือที่ให้เพียงพอหรือไม่อย่างไร? (เจาะประเด็น ความสมดุลของการรับและให้การช่วยเหลือ)
4. คุณต้องการสนับสนุนในด้านใดอีกบ้าง? (เจาะประเด็น ปริมาณและคุณภาพ, ความยากลำบากในการขอความช่วยเหลือ)
5. กรุณาบอกยกตัวอย่างกิจกรรมอะไรบ้างที่ช่วยเหลือผู้ดูแล (เจาะประเด็น กิจกรรมที่เกิดขึ้น)

APPENDIX D



เอกสาร เลขที่ 003/2551

คณะกรรมการวิจัยสถาบันประสาทวิทยา

สถาบันประสาทวิทยา กรมการแพทย์ กระทรวงสาธารณสุข

โครงการวิจัย	เครือข่ายผู้ดูแลผู้ป่วยอัมพาตจากหลอดเลือดสมองในกรุงเทพ : รูปแบบการช่วยเหลือทางสังคม (เลขที่โครงการ 51010)
ผู้วิจัยหลัก	นางสาวสมนึก สกุดหงส์โสภณ ภาควิชาพยาบาลศาสตร์ คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล
สถานที่ดำเนินการวิจัย	สถาบันประสาทวิทยา
เอกสารที่พิจารณา	1.แบบเสนอโครงการวิจัย 2.หนังสือแสดงความยินยอมให้ถ่ายภาพและบันทึกเสียงผู้ป่วย 3.เอกสารชี้แจงข้อมูล/คำแนะนำแก่ผู้เข้าร่วมการวิจัย (Participant Information sheet)
วันที่พิจารณาอนุมัติ	26 ธันวาคม 2550

คณะกรรมการวิจัยสถาบันประสาทวิทยา ได้พิจารณาโครงการฉบับภาษาไทยและ/หรือฉบับภาษาอังกฤษแล้ว
คณะกรรมการฯ พิจารณาอนุมัติในแจ้งจริยธรรมและให้ดำเนินการวิจัยข้างต้นภายในสถาบันประสาทวิทยาได้ ทั้งนี้โดย
ยึดตามเอกสารฉบับภาษาไทยเป็นหลัก


(นายสุชาติ หาญไชยพิบูลย์กุล)

ประธานคณะกรรมการ


(นางสาวพิมพ์ชนก พุดขาว)

คณะกรรมการและเลขานุการ



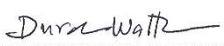
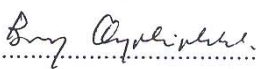
คณะแพทยศาสตร์ โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล
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**Documentary Proof of Ethical Clearance Committee on Human Rights
Related to Researches Involving Human Subjects
Faculty of Medicine, Ramathibodi Hospital, Mahidol University**

MURA2007/499

Title of Project	Stroke Caregiving Networks in Bangkok: Patterns of Social Exchange Behavior
Protocol Number	ID 11-50-31
Principal Investigator	Miss. Somnuk Sakunhongsoophon
Official Address	Department of Nursing Faculty of Medicine, Ramathibodi Hospital Mahidol University

The aforementioned project has been reviewed and approved by Committee on Human Rights Related to Researches Involving Human Subjects, based on the Declaration of Helsinki.

Signature of Secretary Committee on Human Rights Related to Researches Involving Human Subjects	 Assoc. Prof. Duangrudee Wattanasirichaigoon, M.D.
Signature of Chairman Committee on Human Rights Related to Researches Involving Human Subjects	 Prof. Boonsong Ongphiphadhanakul, M.D.
Date of Approval	December 20, 2007

BIOGRAPHY

NAME	Miss Somnuk Sakunhongsophon
DATE OF BIRTH	15 March 1958
PLACE OF BIRTH	Bangkok, Thailand
INSTITUTIONS ATTENDED	Mahidol University, 1980 Bachelor of Nursing (Nursing & Midwifery), Mahidol University, 1997 Master of Science (Public Health Nursing) Mahidol University, 2010 Doctor of Philosophy (Nursing)
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