

CHAPTER 2

LITERATURE REVIEW

According to the study on “the experiences of families with stroke survivors in Chiang Mai province”, literature begins with an overview of stroke followed by the families with stroke survivors. The overview of stroke included stroke’s situation, stroke survivors, and impacts of stroke. In addition, families with stroke survivors offer a review of the literature related to the concept of the Thai family and the experiences of families with stroke survivors and other chronically ill persons.

Overview of Stroke

The Stroke’s Situation

Stroke has defined by The World Health Organization (WHO) as “rapidly developing signs of focal (or global) disturbance of cerebral function, leading to death or lasting longer than 24 hours, with no apparent cause than vascular”. Stroke occurs when a blood clot blocks a blood vessel or artery, or when a blood vessel breaks, interrupting blood flow to an area of the brain. Oxygen supply to a localized area in the brain is interrupted which leads to the destruction of neural tissue and consequent brain damage. These cells usually die within minutes to a few hours after the evident started (Hock, 1999).

Worldwide, stroke is the second leading cause of death and is the leading cause of disability among adults in the U.S. Every 45 seconds, approximately one person has a stroke (The university hospital, 2006). In the U.S., strokes attack about 730,000 individuals annually, of which, approximately 500,000 are first-ever strokes and 200,000 are recurrent (Broderick, 2004). In Thailand, strokes are one of the major health problems and the third

leading cause of death (Thailand Ministry of Public Health, 2004). In addition, it is a major cause of long-term disability from neurological origins among adults (Mingkuan, Pothiban, & Pramoach, 2000). The number and rate of a stroke among Thais each year increased due to the aging of the population and the increase in other risk factors such as high blood pressure, high blood cholesterol, tobacco use, physical inactivity (Thailand Ministry of Public Health, 2004).

Types of stroke. Strokes currently are classified as either hemorrhagic or ischemic. Ischemic stroke refers to strokes caused by thrombosis or an embolism and accounts for 80% of all strokes. It can further be divided into two main types: thrombotic and embolic. An embolic stroke is caused by a clot within an artery, but in this case the clot (or emboli) was formed somewhere other than in the brain itself. Emboli may arise from the heart, the extracranial arteries or, rarely, right-sided circulation (paradoxical emboli). The sources of cardiogenic emboli include valvular thrombi (such as mitral stenosis, endocarditis, and prosthetic valves); mural thrombi (such as myocardial infarction, atrial fibrillation, and dilated cardiomyopathy); and atrial myxomas. This naturally restricts the flow of blood to the brain and results in almost immediate physical and neurological deficits. A thrombotic stroke occurs when diseased or damaged cerebral arteries become blocked by the formation of a blood clot within the brain. This type of event is responsible for almost 50% of all strokes. Cerebral thrombosis can also be divided into an additional two categories that correlate to the location of the blockage within the brain: large-vessel thrombosis and small-vessel thrombosis. Large-vessel thrombosis is the term used when the blockage is in one of the brain's larger blood-supplying arteries such as the carotid or middle cerebral. Arterial stenosis, atherosclerosis, and platelet adherence cause the formation of blood clots that either embolize or occlude the artery. Small-vessel thrombosis involves one (or more) of the brain's smaller, yet deeper penetrating arteries. This latter type of stroke is also called a lacunar stroke. Lacunar infarcts account for 13-20% of all cerebral infarctions and usually involve the small terminal vasculature of the subcortical cerebrum and brainstem. Lacunar infarcts commonly occur in patients with small vessel

disease, such as diabetes and hypertension. The most common lacunar syndromes include pure motor, pure sensory, and ataxic hemiparetic strokes but do not lead to impairments in cognition, memory, speech, or level of consciousness.

Hemorrhagic stroke occurs when an intracranial blood vessel ruptures, leaking blood into brain tissue, ventricles, or subarachnoid space (Miller & Elmore, 2005). The most common cause of an intracerebral hemorrhage is high blood pressure (hypertension). Many people with intracranial hemorrhage are not aware that they have high blood pressure, or that it needs to be treated because hypertension itself often causes no symptoms. Subarachnoid hemorrhage occurs when a blood vessel just outside the brain ruptures. The area of the skull surrounding the brain (the subarachnoid space) rapidly fills with blood. Subarachnoid hemorrhage is most often caused by abnormalities of the arteries at the base of the brain, called cerebral aneurysms. These are small areas of rounded or irregular swellings in the arteries. Where the swelling is most severe, the blood vessel wall becomes weak and prone to rupture. A patient with subarachnoid hemorrhage may have a sudden, intense headache, neck pain, and nausea or vomiting. The sudden buildup of pressure outside the brain may also cause rapid loss of consciousness or death.

Although each of the stroke processes involves a different type of vessel damage, the usual endpoint is death to the brain tissue and the effects vary. The specific abilities that will be lost or affected by any subtypes of stroke depend on the extent of the brain damage and most importantly where in the brain the stroke occurred.

The brain is an incredibly complex organ. It is divided into four primary parts, each having a responsibility for a particular function. Thus, each stroke affects a brain differently. The first part, the right hemisphere of the brain, controls the movement of the left side of the body and also controls analytical and perceptual tasks. A stroke in this part often causes paralysis in the left side of the body, which is known as left hemiplegia. Survivors of right-hemisphere strokes may also have problems with their spatial and perceptual abilities such as misjudging distances or being unable to guide their hands to pick up an object, button a shirt or tie their shoes. Moreover, the survivor often has

judgment difficulties that show up in their behavioral styles, may also experience left-sided neglect, and some will experience problems with short-term memory. Secondly, because the left hemisphere of the brain controls the movement of the right side of the body, speech and language abilities, a left-hemisphere stroke often causes paralysis of the right side of the body, which is known as right hemiplegia. Left-hemisphere stroke may develop aphasia- a catch-all term used to describe a wide range of speech and language problems, which affects the ability to talk, listen, read and write. Furthermore, left-hemisphere stroke patients may develop memory problems similar to those of right-hemisphere stroke survivors. By contrast, patients with a left-hemisphere stroke often develop a slow and cautious behavioral style.

Thirdly, the cerebellum controls many reflexes and much of balance and coordination. A stroke that takes place in this area can cause abnormal reflexes of the head and torso, coordination and balance problems, dizziness, nausea and vomiting. Finally, strokes that occur in the brain stem are especially devastating because it is the area of the brain that controls all of involuntary, “life-support” functions. The brain stem also controls abilities such as eye movements, hearing, speech and swallowing. Since impulses generated in the brain's hemispheres must travel through the brain stem on their way to the arms and legs, patients with a brain stem stroke usually develops paralysis in one or both sides of the body.

In summary, a stroke is a sudden loss of brain function caused by a blockage or rupture of a blood vessel to the brain. Stroke can affect different people in different ways depending on the type of stroke, the area of the brain affected and the extent of the brain injury. Consequently, stroke becomes a leading cause of long-term disability for patients who survive from a stroke.

Stroke Survivors

In the U.S., strokes attack about 730,000 individuals annually, resulting in approximately three million stroke survivors (Broderick, 2004). The literature on survival following strokes indicates strongly that a stroke is associated with a high risk of death, particularly in the first few weeks after the attack and also throughout the first year of a stroke (Bronnum-Hansen, Davidsen, & Thorvaldsen, 2001). Hankey et al. (2000) showed that one-year survivors of first-ever strokes continue to die over the next 4 years at a rate of approximately 10% per year. Many research findings lead to the conclusions that there are several factors influencing survival after a stroke.

Factors Influencing Survival After a Stroke

Survival after a stroke is varied by many factors. The clinical conditions and personal characteristics of stroke survivors, as well as health care settings where the stroke survivors are treated in the acute phase influence stroke survival.

Clinical conditions or neurological deficits of a stroke. Several research findings documented that types of stroke are associated with stroke survival. Improvement in survival and trends in long-term survival after strokes were most marked among patients with ischemic stroke (Bronnum-Hansen et al. 2001; Marini et al. 2001). Moreover, severity at the onset of a stroke can predict survival in survivors. Peltonen, Stegmayr, and Asplund (1998) showed that there was no improvement in survival among patients with the most severe deficits at onset. Hankey, Jamrozik, Broadhurst, Forbes, and Anderson. (2002) also indicated that moderate and severe hemiparesis were important predictors of death or disability within five years. In addition, Wang et al. (2000) illustrated that stroke patient with both cognitive and mobility impairments had a 2 to 3 fold greater risk of mortality than those with only a single disability.

Some coexisting physiological and psychological health problems of stroke survivors influence their survival. Hankey et al. (2000) documented that health problems such as urinary incontinence, and previous transient ischemic attack among 30-day survivors could predict death over five years. Survival after strokes also related to the psychological status of the stroke patients. Morris et al. (1993) presented that depression was strongly associated with 10-year mortality. Moreover, Lewis, Dennis, O' Rourke, & Sharpe (2001) revealed that patients who were fatalistic and felt helpless or hopeless did not survive as long as other patients who had a fighting spirit.

Personal Characteristics of stroke patients. Besides clinical conditions, personal characteristics of stroke patients such as age, gender, and socioeconomic status also influences survival after a stroke. Although strokes are often considered a disease of the elderly, 25% of strokes occur in persons younger than 65 years (Stroke Center, 2001). However, one of the most important predictors of death or disability at five years is advanced age (Hankey et al., 2002; Staaf, Lindgren, & Norrving, 2001). Bonita, Solomon, and Broad (1997) presented that the median duration of survival was less than 2 years for 75 year old. Moreover, long-term stroke survival in patients with less than 45 years of age was better than in those more than 45 years (Marini et al., 2001). Besides, studies reported that a stroke affects men and women differently. They were noted that female stroke survivors lived longer than male stroke survivors (Hannerz, Licentiate, & Nielsen, 2001; Sacco, 1997; Staaf et al., 2001). By contrast, Wang et al. (2000) and Bonita et al. (1997) showed different findings that women experienced a higher mortality rate than men. Different from other reports, Shahar et al. (1995) found that there is no evidence of two-year survival difference between men and women stroke patients.

Literature suggested that socioeconomic status of stroke patients is related to survival. Patients with lower socioeconomic status might have result in reduced access to care for a variety of medical services, including physician visits, cancer screening, and invasive cardiac procedures (Katz, Hofer, & Manning, 1996). A research performed by

Kapral et al. (2002) illustrated that stroke patients in the low income were less likely than those in the high income to receive physiotherapy, occupational therapy, speech-language therapy, and also to have access to hospitals with neurologists and such imaging modalities such as CT and MRI. Furthermore, one-year mortality was also higher in the lowest than the highest income quintile. Specifically, for every \$10,000 increase in median neighborhood income, there was a 5% decrease in 1-year mortality after stroke.

Care Settings. Research findings demonstrated that health care settings in the acute phase of stroke significantly influences survival. In a quasi-randomized controlled study by Running and Guldvog (1998), it was showed that one-year survival rate among patients treated in the stroke unit was 70.6% and in the general medical wards 64.6%, and 18-month survival rates were 65.1% and 58.0%, respectively. Likewise, a prospective cohort study by Glader et al. (2001) indicated that among stroke patients treated in general wards had a significantly increased risk of dying within two years after stroke and also were often less dependent in ADL functions as compared with patients in the stroke unit. Additional data indicated that the quality of hospital management may have an important effect on stroke mortality such as improved supportive and rehabilitative care of stroke patients (Shahar et al., 1995) and greater use of computed tomography, which dramatically improved the diagnosis of a stroke and its classification into subtypes (Broderick et al., 1989).

In conclusion, existing literatures demonstrated that stroke survival and impairments were influenced by many factors. These factors included the clinical conditions or neurological deficits of strokes, characteristics of stroke patients, and also places of care. However, many women and men surviving a stroke encounter life alterations that they have to live with for a long-time.

Long-Term Impacts of a Stroke to the Survivors

A stroke affects on the body, mind, and feelings of stroke survivors. Some of the effects of stroke is weakness (hemiparesis) or paralysis (hemiplegia) on one side of the body, which is on the side of the body opposite the side of the injured brain. A stroke can cause problems with balance or coordination that can make it hard for the person to sit, stand, or walk. Stroke survivor may also have problems using language (aphasia and dysarthria). A survivor with aphasia may have trouble understanding speech or writing, or the person may understand but may not be able to think of the words to speak or write. Moreover, stroke survivors are unaware of or ignore things on one side of the body (bodily neglect or inattention), such as pain, numbness, or odd sensations. An affected person with a stroke may have problems with memory, thinking, attention, or learning (cognitive problems). In addition, a stroke can make swallowing difficult (dysphagia), and there may be problems with bowel or bladder control. A stroke can also affect emotions of the survivor. They can present sudden unprovoked bursts of emotion, such as laughing, crying, anger, or depression.

Currently, more than 4 million people in the United States have survived strokes and are living with the after-effects (Wallace et al., 2002). Of the survivors, only 10 percent recover almost completely while 65 percent experience minor to severe impairments and require long-term care (The university hospital, 2006). As a consequence, these effects cause the survivor to depend on other persons and are in high risk of other complications. In addition, a stroke can also affect socioeconomic status of the survivor and families.

Dependency on activities of daily living. Disability is the major functional consequence of impairments from a stroke. It compels a stroke survivor be a long-term dependent person because of inability to self-care, to perform activities of daily living (ADLs), or to work (Kauffman & Myers, 1997). Some evidences revealed that after one year, 37% of the survivors were dependent (Appelros, Nydevik, & Viitanen, 2003) which

also extended to six years after survival (Murray et al., 1993). Carod-Artal et al.'s study (2000) showed that 52% of survivors at one-year were independent in their ADL. Of these, thirty-two percent of patients were dependent when bathing, and 7% were completely dependent for personal hygiene.

Some studies documented that the level of dependence was contingent on the stroke survivor's age and sex. A two-year follow-up study by Grimby, Andra, Daving, and Wright (1998) indicated a significantly higher overall level of dependence for male stroke survivors than for female stroke survivors. Moreover, stroke patients aged more than 55 years had a slightly higher level of dependence than those below that age. Likewise, a research project by Murray et al. (1993) reported that mean scores of dependent in all basic activities of daily living were lower for women. In addition, Appelros, Nydevik, & Viitanen, (2003) evidenced that dependency after a year post-stroke was associated with age.

Risk of complications and other health problems. Persons with long-term strokes are likely to be at high risk for health problems or complications, which were frequently related to patient dependency and duration after a stroke (Langhorne et al., 2000). Due to weakened bones, loss of feeling and/or mobility in an arm, leg, or one side of the body, risk of falling is increased in stroke survivors. Carod-Artal, Egido, González, and Varela de Seijas (2000) demonstrated that one year after a stroke, 40% of the survivors had falls at home, in the bathroom, or in the street. Dennis, Lo, and McDowall (2002) estimated that the proportions sustaining any hip fracture within two years were 4% and 1.1%, respectively, 1.4 times the rate of hip fracture in the general population. By 10 years, 10.6% had had fractures.

Fecal incontinence is a common complication after a stroke, affecting 11% at 1 year, and 15% at 3 years (Harari, Coshall, Rudd, & Wolf, 2003). This study also indicated that stroke patients are susceptible to constipation for both physiological and clinical reasons. Common clinical risk factors for constipation include impaired mobility, dehydration, poly pharmaceutical effects, dietary factors and difficult toilet access.

Depression is a common long-term consequence. Many stroke survivors experienced long-term depression and social isolation (Moris, Robinson, Andrzejewski, Samuels, & Price, 1993; Murray et al., 1993; Tuomilehto et al., 1995). The estimates of the incidence of poststroke depression range from 20% to 65% (Bruckbauer, 1991; Pohjasvaara et al., 1998). Astrom, Adolfsson, and Asplund (1993) indicated that the prevalence of major depression at three years was 29%. Long-term stroke leads a survivor to have psychological, emotional and behavioral changes, which depend not only on the brain injury but also the uniqueness of every individual such as perception of the stroke (Lewis et al., 2001), life experiences, and the person's strengths and weaknesses (Farzan, 1991). Moreover, stroke survivors deal with alterations in role function, fear of recurring or worsening symptoms secondary to the stroke, and perceived decreases in health status, all of which can bring on depression after stroke (Mol, 1997). In turn, depression after a stroke can affect the ability to work, diminish social activities, and delay the process of rehabilitation (Carod-Artal et al., 2000). In addition to depression, other post-stroke psychological disorders that have been presented include mania, bipolar disorder, anxiety, apathy, pathological crying (Robinson, 1997) and psychosomatic symptoms (Tuomilehto et al., 1995).

Fatigue, often manifesting as both physical and mental lack of energy, is also a common symptom in many chronic diseases, including long-term stroke. Many stroke patients suffer from fatigue after a stroke. It often interferes with the rehabilitation process and impairs the patient's ability to regain functions lost because of the stroke. In a study of Glader, Stegmayr, and Asplund (2002), of the 3,667 stroke patients who did not always feel depressed after two years, 366 (10.0%) always felt tired and another 1,070 (29.2%) often felt tire. Patients who always felt tired were older at the time of the stroke onset than the rest of the patients. Additionally, fatigue, two years after the stroke was more common among patients who were single before the stroke, lived in an institution, were dependent on others for primary ADL functions before the stroke, or experienced a recurrent stroke.

Because a stroke is a chronic condition, they may be taken for more than one medication for over a period of time. A negative combination of medications can counteract each other or produce undesirable side effects. Interactions between medications may cause confusion, memory loss, insomnia, nervousness and hallucinations or can contribute to depression (Stroke Center, 2001). Use of anticholinergic medications such as antipsychotics, tricyclic antidepressants, oxybutynin, or antiemetics can significantly increase the risk of fecal incontinence in stroke survivors by reducing contractility of the smooth muscle of the gut (Harari et al., 2003).

In addition, several other health problems may occur among long-term stroke survivors. Over half of the survivors had at least one other important disease in addition to a stroke. Tuomilehto et al. (1995) presented that about one fifth of all men and one tenth of all women who were 14-year stroke survivors had myocardial infarction. Diabetes mellitus is the another harmful complication, which significantly associates with a failure to exhibit improvement among 3-year stroke survivors (Desmond, Moroney, Sano, & Stern, 1996), and also was independent risk factors for recurrent strokes (Staaf et al., 2001). As a result, stroke survivors with coexisting health problems are at high risk of slow improvement and shorten long-time survival (Tatemichi et al., 1994). Furthermore, Hardie, Hankey, Jamrozik, Broadhurst, and Anderson (2003) and Engstad, Viitanen, and Arnesen (2003) reported that long-term stroke survivors had significant risk of death compared with stroke-free population.

Socioeconomic impacts. Social life and economical status of stroke survivors are also affected as a consequence of a stroke. Jiménez-Muro, de Pedro-Cuesta, Almazán, and Widén-Holmqvist (2000) found that social activities decreased 6 months after a stroke. Due to the lack of opportunity or inclination to visit friends or travel to social events, and a lack of appropriate facilities which are able to accommodate disabled people, often long-term stroke survivors were unable to carry on significant work, family, and community activities as they did before a stroke occurred. (Anderson, 1992).

In addition, most stroke survivors were employed before a stroke occurred and made income for their families. After survival, loss of employment among long-term stroke survivors was reported, which means a reduction in income and economic difficulties (McKevitt, Luse, & Wolfe, 2002). Tuomilehto et al. (1995) analyzed the socio-economic situation of the long-term stroke survivors and found that over 40% of men and over 30% of women had a sickness pension because of a stroke. Therefore, long-term stroke can also increase the financial burden to the survivors, their families, and health care system because of lost productivity and long-term health care expenses.

In summary, a stroke directly affects the entire body and life of the stroke patients including dependency of activities of daily living, risk of complications and other health problems, limits social activities, and economic burdens. Consequently, most long-term stroke survivors reported an overall reduced quality of life a few years after the stroke occurred (Becker, 1993; Niemi, Laakasonen, Kotila, & Waltimo, 1988; Tengs et al., 2001). Significantly, these survivors are required to take care for long periods of time, particularly from families.

Families Caring for Stroke Survivors

Most stroke survivors require long-term care, particularly from their family, in order to sustain their life and well-being throughout their remaining lifespan. To gain better understanding about the family with stroke survivors, this section attempts to present the concept of family in generally and specifically the Thai family providing long-term care for the stroke survivor.

The Concept of Family

Defining the family. The definition of family varies and has changed extensively. Shapiro (1983) defined the term family as “a network of interpersonal

relationships characterized by a continuous interchange between members and by reciprocal causal effects.” In addition, the family is viewed as an organic unit, a dynamic system in which every part is simultaneously organizing and being organized by other parts. Clemens Stone, McGuire, and Eigsti (2002) also identified a family in its broadest sense as “a group of two or more persons related by blood, marriage, adoption, or emotional commitment who have a permanent relationship and who work together to meet life goals and needs” (p. 175). Consistent with the latter one, Friedman (2003) explained that the family is “a system of members who decided to reside together with the primary objective of supporting each other.” The individuals may be blood, relative, or non-kin who are emotionally bonded through common characteristics and/or complementary talents.

The definition of family can be described as a combination of family structures and roles. Chesla (1994) identified a family as “a natural social system, with properties all its own, one that has evolved a set of rules, is replete with assigned and ascribed roles for its members, has an organized power structure, has developed intricate overt and covert forms of communication and has elaborated ways of negotiating and problem solving that permit various tasks to be performed effectively” (p. 3).

The family can be defined based on different perspectives. In accordance with social scientists, family is viewed as a social system that interacts with other social systems within society. This point of view focuses on the analysis of family between collateral systems such as school, work, or health care worlds and the transactions between the family and its subsystems (husband-wife dyad, sibling cliques, and personality systems of individual family member). The family in this approach is seen as open to outside influences and transactions. The interactionist, the other perspective, views the family as a unity of interacting personalities within which individual family members occupy a position or positions, such as husband-father, wife-mother, and daughter-sister. A cluster of roles such as provider, homemaker, companion, and sex partner are assigned to each of these positions. And a set of social norms or behavioral role expectations are perceived for each of these roles by the individual fulfilling them. This approach viewed the family as

being relatively closed to outside systems. However, Clemen-Stone et al. (2002) argued that the interactional framework emphasizes analysis of the internal aspects of family functioning but neglects the family's relationships with other social system.

Based upon the conceptual model of nursing, the term of family has also been defined in a variety way. According to King (1983), the family is “a social system that is seen as a group of interacting individual. As a social system, the family influences individuals as they grow, develop, and move from dependence in childhood to interdependence in adulthood”. Neuman (1983) explained that family is “a group of two or more persons who create and maintain a common culture; its most central goal is one of continence. The family system can be viewed as individual family members harmonious in their relationship-a cluster of related meanings and values that govern the family and keep it viable in a constantly changing environment. The family system is also exposed to stressors that affect its stability, that is relative wellness state”. For the theory of self-care, Orem viewed the family as a basic conditioning factor. She explained that the system of family living, the physical and social environment of the family, and the family's culture (are) basic conditioning factors for all family members. The role of family members is as dependent-care agents, that is, providers of care for other family members who are not capable of self-care agency.

In Rogers' view, the family refers to a range of configurations, which may be variously labeled as nuclear family, extended family, one-parent family, blended family, single person family, homosexual family, and others. Family members may or may not live in the same household. They may or may not be related by blood or by law. Moreover, Roy (1999) views the family as an adaptive system that, like the individual, has inputs, internal control and feedback processes, and out put. The inputs for the family as an adaptive system include the entire complex of stimuli that affect the family as a group, both internal to each person and those coming from the external environment. More specifically, inputs include needs of individual family member, as well as changes within members, among members, and in the environment. Internal processes relevant to the family are

support, nurturance, and socialization. Feedback mechanisms include transactional patterns and member control. Output of the family as an adaptive system focuses on behavioral goals, including survival, continuity, and growth.

However, “family” has been diversely defined, it reflects some attributes of the concept of family. Shapiro (1983) presented some characteristics of a family system as an open system, which has continuous interchange with the external social and physical environment. The family system confronted with continuous internal and external demands for change, may be able to respond with growth, flexibility and structure evolution. The family is complex, with an intricate organizational structure, and self-regulating, in the sense of containing homeostatic mechanisms to restore balance and equilibrium. Stuart (1991) analyzed the concept of family and also revealed the attributes of this concept. These are (1) family is a social unit that is self-defined by its members and is not a constant; (2) the members may or may not be related by birth, adoption, or marriage and may or may not live under one roof. There must be commitment and attachment among members and carry out the relevant functions of caregiving and socialization among its members.

Due to some events such as divorce, stepfamilies and a growing number of women and mothers in the workforce, the composition of households in both western and Asian countries has shifted dramatically. These events tend to alter traditional family patterns in many countries. For these reasons, family types and compositions have been shown in a variety way.

Types, structure, and functions of the family. Family structures have been categorized as traditional family structures and non-traditional family structures (Clemen-Stone et al., 2002). Traditional family structures present a variety of patterns: nuclear family, reconstituted nuclear family, dyadic nuclear family, single-parent family, single adult, three-generation family, and kin network. A nuclear family is a legally married couple with children in a common household with one or both partners gainfully employed. A reconstituted nuclear family refers to a blend or stepfamily household with children with

one or both partners gainfully employed. A dyadic nuclear family is a childless, legally married couple with one or both partners gainfully employed; this family may never have had children. A one-parent or single family is a consequence of divorce, abandonment, separation, or death. A single adult is a person living alone, usually with a career, who may or may not desire to marry. An extended family with three or more generations living in a common household is called a three-generation family. Finally, a kin network is a nuclear household or unmarried members living in close geographic proximity and operating within a reciprocal system of exchange of goods and services.

Non-traditional family structures include binuclear family, unmarried single family, unmarried couple family with children, heterosexual cohabiting family, commune family, and lesbian/gay family. A binuclear family is an operating and joint custody family system in which the child is part of two nuclear households. An unmarried single family is a one-parent family where marriage is not desired or possible, while an unmarried couple family with children usually refers to a common-law marriage. A heterosexual cohabiting family is an unmarried couple living together. A commune family is household of more than one monogamous couples with children, sharing common facilities and resources; socialization of children is a group activity. Last, a lesbian/gay family is a male or female couple living together with or without children.

Samukkarn (1996) also identified four types of family and their structures in relation to sociological and anthropological perspective. They are nuclear/elementary family, extended or joint family, composite or compound family, and essential family. A nuclear or elementary family is composed of father, mother, and their child (children). In some societies, such as Thai, other relatives may be added in this type. The nuclear family can easily establish as well as disintegrate. However, this family is fundamental to other types of family. The extended or joint family is a family that comprises at least two families. The important characteristic of the extended family is power in making decisions, which is bestowed on the oldest relatives. As a result, this family is life long living and members of the family can be increased. The composite or compound family has been

emerged in the society that allows men or women to have more than one spouse and live under the same roof. Because this family does not consist of at least two nuclear or elementary families, the composite or compound family can more easily disintegrate than the extended family. The last type, the essential family is an incomplete family, which is lacking a father who is the head of the family. Therefore, a mother takes the responsibility to be the head of the family.

Even though family structure has shifted to various forms and traditional family structures have declined, the family is still being the basic social unit in every society and also has many basic functions. In the U.S., the nuclear family is widely accepted as the typical American family form and has been universal in human groups through time. Today, it is not a universal or even stable form in the society. Married couples with or without children are still the most frequent family forms as separate households (Gilliss, Highley, Robert, & Martinson, 1989). Married children are normally expected to set up a home on their own and leave the family home. It appears that there is a hierarchy of obligation, where spouses are the primary source of support for married people and children are the next major support for aging parents (Gillen & Burk Hardt, 1998). The family performs functions for society and its individual family members. Similarly, the society also performs functions for the family.

Friedman, Bowen and Jones (2005) has identified that a family functions in several dimensions. These are the affective function, the socialization and social placement function, the reproductive function, the economic function, and the health care function, which entails obtaining physical necessities such as food, shelter, and clothing and health care for all family members (p. 102). In addition, Grotevant and Carson (1987) also identified that family functioning is a complex concept constituted by affective, structural, control, cognitive, and external relationship dimensions.

In sum, a concept of family has been defined based on different point of views. Family also has been identified as many types and having different functions. Inevitably, family in different cultures have their characteristics which are often different from families

in other cultures. Thai families present their own characteristics specifically for Thai culture.

The Thai Family

The oldest, smallest and, without a doubt, one of the most important units in Thai society is the family. Family is valued as the center of education, finance and administration in their most basic forms. Traditionally, the Thai family is an extended one, with several generations living under one roof, or at least under several roofs within the same compound. It is a kin group consisting of those who are related mainly, but not exclusively, through blood ties. Family members mostly share many aspects of day-to-day activities. The father is regarded as the head of the household to whom the wife and children show due respect (Samukkarn, 1996). Within the family, men work outside the home, while cleaning, cooking, and child rearing are done by women. The elderly reportedly have a very high status. Young Thai people respect and support the elders who serve as the cornerstones of the family (Kespichayawattana, 1999).

In Thailand, families often function within the culture of extended family constructs, even if they are outwardly nuclear families (Kespichayawattana, 1999). Thai people tend to have close family relationships, respect for seniority and they help each other follow from one generation to the next generation. As a result, hierarchy is significant in Thai society (Phengjard, 2001). The hierarchical structure defines sets of duties and responsibilities and indicates appropriate behavior. Moreover, within Thai families “we” or “us” rather than “I” or “me” is the fundamental basis for familial relations. A child growing up in such circumstances has a long list of elders: “fathers”, “uncles”, “mothers”, “brothers” and “sisters” in addition to its natural parents; a complex mesh of kinship ties.

Additionally, Thailand is primarily Buddhist. Buddhism plays a very significant role in Thai family life, which motivates individuals as well as the family to perform, perceive, and transmit traditions from one generation to another (Kespitchayawatana, 1999;

Sethabouppa, 2002). Buddhism is not centered on a god or gods but it is based on a system and a set of principles in which a person should exist. Among the principles, there is the belief of rebirth from one life to another, where the actions taken (either good or bad) in one life can transfer to the next. These actions believed by Buddhists, result in or unhealthy rebirth. So, regarding the teachings of Buddhism, disability is the outcome of the bad actions rather than good actions, which a person made in his/her previous life.

Furthermore, Thais are very tolerant of anything and anyone and believe each of us will get our just reward (good or bad) in the next life. Thai Buddhists have been taught a sense of awareness and gratitude towards someone who has done something that has benefit to us and doing something in return for these benefits (Kespichayawattana, 1999). Buddhist principle has become a traditional Thai cultural ideology of “parent repayment” in other words, in the Thai context it is called “kathanyu katawethi”, in which children are expected to repay their parents for having born and raised them (Sasat, 1998). Furthermore, religion strengthens family ties and ability to endure existential sufferings. A strong sense of family responsibility and thoughtful consideration were significant factors which led to the families' reticence in seeking help from outside their families or kin circles (Subgranon, 1999).

Over the last three decades, Thailand has become a newly industrialized country. Communications technology is rapidly becoming available and affordable in most area of the country, even in rural villages (Songwathana, 1998). The effects of urbanization on families and their living situations are likely to have affected how families live with chronically ill family members. One is the breakdown of the extended family system as a result of the change from a kin-based to a cash-based economy. Caffery (1991) points out that contributing factors have caused the breakdown of the Thai extended family. Younger family members migrate to urban areas in search of jobs; women also became involved in the job market; and birthrate decreases resulting in fewer children becoming caregivers to their parents. Furthermore, norms and values are changed, which emphasize individualism and competition rather than the interdependency characteristics of extended families; and

finally, the increased education of the young decreases the value of elders as cultural experts. Consequently, there is likely to be a reduction in kinship networks that might provide care for a growing number of dependent family members and a reduction in informal networks outside the family to offer support.

Although recently, a majority of Thai family structures are nuclear in structure, it has also been demonstrated that one child stays with the parents in the stem family when the parents become old. One of the prime responsibilities placed on children is that of taking care of parents in their old age, a prominent feature of the Thai concept of family (Siriboon, 1992). There is no feeling of being inconvenienced by this duty of caring for aged parents; on the contrary, their acquired wisdom gives them an honoured place in the household, and their counsel is actively sought in teaching their grandchildren and great-grandchildren to be responsible adults with the same traditional values. Therefore, in Thailand, it is likely uncommon for Thai families to place elderly parents or ill members into institutions such as nursing homes or residential homes. In addition, the care for frail family members is assumed to be a family responsibility that is usually shared among family members according to their age and disabilities.

In conclusion, an introduction to the family deals with the definitions, types, structures, and functions of family. In addition to these details, the family in Thai culture is also addressed. The family can be defined in this study as an open system composed of at least two persons who are related to each other either biological, emotionally, or legally and may or may not live in the same household. It is believed that family as a whole and cannot be comprehended by examining its individual parts in isolation from each other. Of course, this study was conducted as a “family research” in order to gain understanding of the whole experiences through multiple family members.

Families Providing Long-Term Care for Stroke Survivors

Family caregivers play a critical role in the stroke survivor's life, particularly as lengths of stay in hospitals and rehabilitation settings continue to decrease. Burman (2001) indicated that four out of every five American families must deal with a stroke at some point. Care for stroke survivors require lengthy, expensive, labor-intensive effort of the whole family. Hence, stroke becomes a family disease.

Family has been placed in research. As of these studies, there are "family related research" and "family research". The existing research are the focal concern in family related research (Uphold & Strickland, 1993). Feetham (1991) (as cited in Whall & Fawcett, 1991) presented a criterion specific to family-related research that the research examines the responses of individual family members and/or examines concepts related to families or family members. Family research, in contrast, refers to research that focuses on the family unit as a whole. Individual family members are not considered explicitly. Moreover, Adtedt-Kurki (2001) stated that the family is seen as the unit of analysis, data collection involves at least two family members in order to provide a broader perspective on the phenomena from the family. On the other hand, if the family is seen as a context of the individual, or when the basic focus is on individual well-being, one family member may be the most appropriate source for data collection.

Much of existing literature in both Western and Thailand have attempted to identify experiences of a stroke by a family member, particularly the primary caregiver, who were primarily spouses or daughters, and/or by the stroke survivors. In addition, these studies have predominantly been focused on investigating negative experiences of acute or one year post-stroke. The main findings of the literature review showed the results consistently found that they reported a decline in overall health and physical burdens (King et al., 2001; Periard & Ames, 1993; Robinson-Smith & Mahoney, 1995), depression (King et al., 2001; Robinson-Smith & Mahoney, 1995; Wright, Hickey, Buckwalter, Hendrix, & Kelechi, 1999), strain, perceived stress (Anderson et al., 1995; Bugge, Alexander, & Hagen,

1999; Dennis, O' Rourke, Lewis, Sharpe, & Warlow, 1998; Duncan & Lai, 2001; Fraser, 1999) and problems derived from improving home care (Chaungsawadisak, 1998; Davis & Grant, 1994).

Moreover, studies were also conducted to investigate coping abilities and management of stroke carers within one year post-stroke. For instance, Davis and Grant (1994) used a qualitative design to explore the management strategies of family caregivers by interviewing eight caregivers 14 weeks post-stroke. Four main management strategies were used to cope, including situational vigilance, creating solutions to functional loss, constructing the reality of recovery, and giving meaning to the experience. The other qualitative study by Pierce and Wilkinson (1999) reported coping strategies commonly used by primary caregivers as living for the moment and hoping for the future, evading conflicts, self-development, and self-contemplation. Additionally, to explain the process of caregiving among Thai caregivers of elderly stroke relatives, which is called "Maintaining caregiving at home", Subgranon (1999) conducted a research by using a grounded theory approach with 20 primary caregivers living in Chachoengsao Province. Its process composed of seven aspects which helped caregivers provide care for their relatives: (a) as an integral part of life; (b) an unavoidable task; (c) giving with love, sympathy, and attachment; (d) family and kinship support; (e) community support; (f) managing treatment; (g) managing problems and difficulties. However, the data provided a picture of Thai family structure living in Chachoengsao Province that came from family caregivers of elderly people. No attention was paid on other family members. Furthermore, many interventions were conducted in the term of supporting the primary family caregivers for example, providing information and psychological support in order to reduce primary family caregiver's depression and to increase problem-solving skills (Grant, 1999), improve knowledge in caring for the stroke survivors (Rodgers et al., 1999), and minimize the primary family caregiver burden (Julamate, 1997).

Regarding research on long-term stroke survivors, these studies have been little explored. The findings from a few studies, which focused on long-term stroke survivors

and their families, were mainly presented as impacts of long-term strokes to the family caregivers. Anderson, Linto, and Stewart-Wynne (1995) conducted a study, which aimed to identify factors in stroke patients associated with emotional distress in caregivers one year after stroke. The results reported that almost all caregivers of 241 patients who survived to one year after stroke and were living outside of an institution reported adverse effects on their emotional health, social activities, and leisure time. More than half reported adverse effects on family relationships and forty-six caregivers (55%) showed evidence of emotional distress. The other study of Greveson, Gray, French, and James (1991) which assessed long-term outcome from in 229 patients with acute stroke; revealed that 71% were independent or only mildly disabled and 76% were living at home. Institutionalized patients were significantly older, less often married, and had more cognitive impairment than those at home. Thirty percent of 44 informal carers showed marked strain and had more problems with emotional reactions, sleep and social isolation than expected.

Only the one study of Van den Heuvel, de Witteb, Stewartc, Schurea, Sandermanc, and Meyboom de Jonga (2002) has been found regarding the intervention for long-term stroke caregivers. In this study, the researchers conducted an intervention for informal caregivers of stroke survivors 6 months to three years based on the stress-coping theory of Lazarus and Folkman. Two intervention designs were developed: a group support program and individual home visits, in order to increase caregivers' active coping and knowledge, reduce caregivers' strain and improve well-being and social support. The participants included 49 in the home visit program, and 38 in the control group. Multiple step-wise regression analysis was used to determine the effects of the interventions. The findings showed that the interventions contributed to a small to medium increase in confidence in knowledge and the use of an active coping strategy while the amount of social support remained stable. Younger female caregivers benefited the most from the interventions. They showed greater gains in confidence in knowledge about patient-care and the amount of social support received compared with other caregivers.

Literature revealed that many researchers have paid attention to primary caregivers of stroke survivors within one year post-stroke. Moreover, most research titled “family” examined individual family member but did not examine family context. It can be remarked that there was no research on experiences of the entire family caring for long-term stroke survivor. Even though, there has been a few family studies, which data were collected from multiple persons in the family or those who were conceptualized from a family level of analysis, plenty of the research has been found in the area of other chronic-illness families and/or chronically ill children (child). Specifically for studies on families with an ill adult, there were only four studies. Junda (2002) integrated three theoretical approaches (family system theory, family stress theory, and family belief system theory) to explore experiences of families with women who had breast cancer by using ethnographic methodology. Eleven Thai women who were breast cancer patients at Ramathibodi Hospital and 17 adult family members living with the patients were studied. The study found that breast cancer had an impact on both the patient and the family unit, which generated six themes: 1) getting to know breast cancer up-close, 2) family’s reactions to it, 3) family’s life changes, 4) doing what’s best for us/our health, 5) outsiders’ support, and 6) interaction and communication.

The other instance was conducted by Katz and Lowenstein (2002). They explored family adaptation and coping strategies to chronic illness from four persons in each family. Five core categories emerged, which were (a) the advent of the illness and daily friction resulting from burdens; (b) perceptions of the illness-definition of the main problems and difficulties; (c) family resources-household arrangements, community support and use of formal support systems; (d) modes of reactions-caregiving tasks and feelings about caregiving; and (e) familial adaptation of caregivers-intergenerational family relations, patterns of communication and interaction regarding division of labor.

Moreover, a qualitative study of Smith and Soliday (2001) reported the effects of parents' chronic kidney disease on the entire family. Financial problems due to the invasive nature of the treatment for this disease became a major effect. The family system was also

affected because family members were less able to spend time together, spouses feel unable to fulfill gender-specific family roles, and because of the stress and financial burden associated with illness demands. Thus, family functioning was reportedly changed because of the implications of having a parent with kidney disease.

Johnson (1994) used a phenomenological approach to describe the experience of one family composed of seven family members, with a traumatic brain injury patient. Three themes captured the essence of the experience as helplessness and need to hope, need to be informed and involved, and impact of incubation. The parents acknowledged the deepened sense of closeness the family experienced throughout this ordeal. There was also a sense of personal pride and accomplishment expressed in having been able to enter into this experience and not back away from some of the more difficult aspects of it. The mother believed that prayer and spirituality played a major role in her son's recovery. Siblings' perspective was evident by a heightened awareness of the importance of family and friends and a sudden conscious awareness of their own mortality. The brother expressed the feeling that "life is short, you don't live forever, appreciate life and do everything that you can". The victim's unique perspective was captured by the themes: going home, concern for others, and piecing it together.

In conclusion, much research on stroke and family has been undertaken to explore the experiences of families through individual family members, who were mostly family caregivers, and also in the period of the first year after the stroke. Even though, to my knowledge, four family research studies have been conducted and most of the researchers have studied in Western societies regarding families with other chronic illnesses. Therefore, it is difficult to present the experiences of families with long-term stroke survivors from the prior research. In addition, the current focus of nursing care is to provide care for whole families. So, it is suggested that research should be paid attention to family research, particularly to families with long-term stroke, which is becoming a health issue.

Theoretical Framework

In this study, a family is viewed as a unit and open system. It is a system or where in the wholeness is composed of a set of elements, which means individual family members. The whole family interacts among themselves and with the environment, and also has a unique character. A change in one part of the family system would likely promote change in other parts and the system as a whole, or in other word, an improvement in one of the dimensions would likely lead to improvement in others. In the situation of a family providing long-term care for a stroke survivor at home, although a family member becomes chronically ill caused by long-term stroke, the whole family unit is affected and requires successful coping skills to maintain balance and routine of the family.

Because the family is an open system, family continuously interacts with the environment within and around the family and also exchanges energy and resources with other systems in attempting to achieve a dynamic state of equilibrium and survived. The environment in which a family system exists greatly influences how the system is able to function. Consequently, there are multiple factors within and around the family that influence the ways in which a family interacts with long-term stroke event. Particularly in Thailand, families caring for the survivor are also influenced by, for example, Thai culture, social structure, and the Buddhist religion. These factors shape the experiences of the family regarding how it perceives the situation, behaves and manages.