CHAPTER 2

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

Literature Review

The literature review for this study included:

1. Stroke and effects on patients and caregivers
2. Burden
3. Social support
4. Relationship between social support and burden of stroke patient caregivers.

Stroke and effect on patients and caregivers

Stroke

Stroke is defined as the abrupt or ictal onset of focal or global neurological symptoms caused by ischemic or hemorrhage within or around the brain resulting from disease of cerebral blood vessels (Sacco, 1995). Stroke includes cerebral infarction (ischemic stroke), and intracerebral hemorrhage and subarachnoid hemorrhage (hemorrhagic stroke). The classification of stroke is based on the underlying problem created within the cerebral artery or blood supply to the brain. In the brain, plugging by atherosclerosis or a clot create a narrow lumen preventing adequate flow of blood to cerebral tissue. Alternatively, rupture resulting from a weakened vessel cause leakage of blood into the brain or subarachnoid space (Hickey, 1997). Signs and symptoms may occur isolatedly or in various combination. A left stroke damages the brain left hemisphere leaving patient with many deficits, such as weakness or paralysis or hemiplegia on his right side. The patient with a left stroke will typically have speech and language deficits, and may also have difficulty in listening, understanding, gesturing, reading or writing, and possibly aphasia, perform tasks slowly and cautiously, and many have distress and depression in related to disability. A right stroke damages the brain right hemisphere, creating paralysis or hemiplegia on his left side. Furthermore, patient with right stroke will have spatial-perceptual deficit. These patients may be impulsive, neglect the left side of the body, denying the illness, and typically have memory deficits in performance and difficulty in learning and may also have agnosia-inability to recognize visual, tactile or audible stimuli (Mower, 1997).

Impact of stroke on patients

After discharge from the hospital, a few survivors will make completely functional recovery and return to the usual employment. Most of them, however, will be left with residual disability of vary degrees. The disability following stroke is usually in sufficient degree to seriously interfere with the patient ability to carry out the essential daily personal activity of self-care, such as getting out of bed, bathing, drinking, elimination, and locomotion (Brandstater & Basmajian, 1987). Wilkinson and associates (1997) examined 106 follow-up stroke survivors in London and found that 29% of stroke survivors were severely or moderately disabled, and 37% were mildly disabled. They also found that the activities that patient need help most were bathing, climbing stairs, dressing, and feeding.

Patient's social situations may alter dramatically as a result of stroke. They may lose jobs, and suffer from financial restrictions, lose prestige and power, experience sexual problems, withdraw and isolation (Brandstater & Basmajian, 1987). Anderson (1992) noted that not only stroke patients' physical disability but also some psychological aspects such as depression, fear, poor self-image or low morale, poor advice and lack of social support can contribute to social problems.

The physical impairment, social life changes or possible mental process disturbance can cause great psychological disturbance. The patient may demonstrate insomnia, agitation, irritability, apathy, oversensitivity, and depression. They may be tearful, and seem to be dependent on external support and excessively demanding

(Willcock, 1986). Gainotli (1972 cited in Willcock,1986) found anxiety reactions, tears, vocative utterances, depression or sharp announcements, and refusal to continue to task in hand, as symptoms occurring with left side lesions. With right side lesions, the patient may show anosognosia, indifference, a tendency to joke, and expressions of hate towards affected body parts. Wilkinson and associates (1997) found that 23% of stroke patients reported depression, 13% had borderline depression, and 19% experienced clinical anxiety. Another study conducted by O'Rourke, Machale, Signorini and Dennis (1998) examined 105 follow up stroke survivors in Scotland showed a similar result in which 27.5% of the patients had depression, and 7.5% had anxiety. Depression may cause secondary aggravation of residue effects of a stroke and may increase social problem. Brandstater and Basmajian (1987) reported that patient may become irritable and anxious, or may appear to be neurotic so that the patient become excessively dependent.

In conclusion, the sudden nature of stroke in which functions can be impaired is an extremely stressing event, resulting in considerably physical, psychological and social problems to the patient. Coping with these problems, and relating them to previous self-concepts, must be devastating. The stroke patients become powerless and unable to control their own lives, therefore, they will highly depend on the caregivers both on ADLs and psychosocial aspects.

Impact of stroke on caregivers

Because of the physical disability from stroke, the patients' ADL activities may be impaired. Patient's ADL demands may take caregiver's most of time, disrupture their own lives, spend most of their energy, refrain them from the recreational and social activities, giving up their work, and make them feel overload, strain and exhausted (Elmostahl, et al, 1996). The physical aspects of caregiving also may interfere with management of caregivers' own physical conditions, such as hypertension or cardiac disease. Anderson, et al (1995) studied 492 chief caregivers of follow-up stroke patients, the results showed the impact of caregiving on different aspects of caregivers' lives included emotion ill-health (in 79%), disrupture of social activities (79%), and leisure time (55%). Thirty five percent of caregivers reported adverse effects on family relationship for a variety of reasons including tension, misunderstandings, or feelings of neglect among family members because of the physical and emotional demands of patients. At the other times caregivers frustration and anger with respect to patients were placed on others.

Many caregivers felt anxious about leaving the patients unattended for the whole day because of fear that the patient might fall or experience another stroke. The caregivers may withdraw due to anxiety about their own vulnerability and if depressed, blame others (Reisberg & Ferris, 1982 cited in Brandstater & Brasmajian, 1987). The stroke patient's agitation, irritability, apathy, oversensitivity, which may place on caregivers, can directly affects caregivers' psychological responses. And as previously mentioned, depression causes patients excessively dependent on caregivers. Williams (1994) noted that the most stressful problems of stroke patients identified by caregivers were irritability, and dependency. Anderson (1995) study indicated that a variety of caregivers' adverse emotional reactions that related to stroke patients included anxiety (58%), depression (50%), fear (35%), frustration (32%), resentment (29%), impatience (25%) and guilt (10%).

Furthermore, the loss of patients as an active social partner and demands of patients which reduce the time and energy available for social activities may be important cause of problems and distress for the patients' caregivers. Among the spouses of younger stroke patients, the loss of companionship interfered with the enjoyment of life (Coughlan & Hunyphrey, 1982 cited in Anderson, 1992). Marital relationship can be greatly affected by stroke. Patients and spouses often separated (Brandster & Basmajian, 1987).

In summary, the impact of caregiving to stroke on caregivers is overwhelming, caregiving to stroke patients affects a variety of caregivers' lives in physical, psychological and social aspects.

Burden

Concept of burden

Burden was viewed as either objective or subjective or both. Beck (1960 cited in Platt, 1985) viewed burden objectively and defined burden as the presence of problems, difficulties, or adverse events which affect the life of psychiatric patient's significant other.

Poulshock and Deimling (1984) recognized burden as a subjective phenomenon. In Poulshock and Deimling's model, the concept of burden was used to refer to the subjective perceptions of caregivers in related to the degree of problems experienced in relation to elderly's special impairment. Further, these impairments should be differentiated in terms of the mental and physical capacities of the elder. Stuckey, Neundirfer and Smyth (1996) also defined burden in subjective aspect, as caregiver perceptions of impact of caregiving on the lives, physically, mentally, financially, and socially.

Hoeing and Hamiton (1965 cited in Loukissa, 1995) studied the experience of burden, distinguishing the concept objective and subjective burden. Objective burden referred to certain behaviors of mentally ill relatives which were assumed to be disruptive and family problems that occurred as a result of impaired relatives, while subjective burden referred to emotional reaction to caregiving. Similarly, Platt (1985) pointed out that objective burden involved disrupture to family/household life that is potentially verifiable and observable; as much, objective burden differed from subjective burden, which depends entirely on caregivers sharing their personal feeling. Montgomery, Gonyea and Hooyman (1985) also viewed burden objectively and subjectively. Objective burden is defined as the extent of disruptures or changes in various aspects of the caregiver life and household because of caregiving, whereas subjective burden is defined as the respondent attitudes toward or emotional reactions to the caregiving.

Caregiver burden is a multidimensional construct in current view. According to George and Gwyther, (1986 cited in Braithwaite, 1992), caregiver burden is the physical, psychological, or emotional, social, and/or financial problems that can be experienced by family members caring for impaired older adult.

A needs-based conceptualization of caregiver burden was presented by Braithwaite (1990) in which caregiver burden was defined as the caregiver perception of the extent to which the meeting of caregiving demands threatens satisfaction of the caregiver basic needs. The definition has three key elements. First, it specifies that carers are the informants on the degree to which caregiving threatens needs satisfaction. Second, it restricts the threat to the caregiving context. Third, it defines the target of the threat as basic needs.

Miller and Mcfall (1991) represented caregiver burden by two variables that summarize the personal and interpersonal dimensions of caregiving. Personal burden referred to the caregiver appraisal of limitations in personal actions and activities caused by providing care. Interpersonal burden reflected the caregiver perceptions of older person problematic behaviors.

Lim and associates (1996) also viewed caregiver burden as multidimensional, consisting of three parts: burden antecedents, burdens and burden consequences. Burden antecedents including cognitive impairment burden and physical impairment burden, which refer to the degree to which a caregiver believed the elderly was cognitively and physically incapacitated. Burdens include social functioning burden and disruptive behavior burden resulting from a caregiver's perception of the elderly's s cognitive incapability and physical impairment. Burden consequences consist of negative changes in elderly-caregiver-family relationship and social activity restriction.

In summary, even though, the concept of burden remains various and broad. The objective and subjective view of burden and multidimensional characteristics of caregiver burden seem to be well accepted among researchers. Most theorists referred concept of burden to the caregivers of physical or mental impaired elderly people. Stroke is one of the most common causes of disability, handicap and psychological impairment among elderly people (Anderson, et al, 1995; Gresham, et al, 1997). Therefore, the multidimensional burden concept is appropriate for guiding study of stroke patient caregiver burden.

Factors contributing to burden

Literature suggested that there were many factors influencing caregiver burden. According to Braithwaite (1990), the factors contributing to caregiving burden included (1)workload (task-oriented demands and socio-emotional demands of the carereceiver), (2)crisis of the decline (awareness of carereceiver degeneration, unpredictability, time constrains, caregiver-carereceiver relationship and choice restriction), (3)personal resources (caregiver personality, health and coping strategies), (4)and social and material resources.

Poulshock and Deimling (1984) conducted a study using data and findings from Benjamin Rose Institute survey of 614 families in which impaired elders resided with and provided care by family members. Burden was viewed as a subjective phenomenon. The results showed the elder cognitive incapacity and ADL impairment demonstrated the strongest association with their caregiver responding burden.

Bull (1990) studied 60 chronic debilitating patients and their primary caregivers in northeastern region of United States. Robinson's Strain Index (Robinson, 1983) which assesses subjective and objective burden was used this study. The result showed that the caregiver's physical health, functional ability, and size of social network as well as patient's physical health, functional ability, family per capita incomes and social support predicted burden of caregivers of chronic illness patients (Bull, 1990).

Dwyer and Miller (1990) studied a matched sample of 1388 noninstitutionized functionally limited elderly people and primary caregivers, measured the burden of primary caregiver by summing unweighted positive responses to nine problems experienced by the primary caregiver as a results of caregiving to the elderly people. The results showed that the number of elders' instrumental activities of daily living impairments and total hours of care was positively related to burden of primary caregiver in rural, small city as well as urban areas.

An ex-post facto study used data from control group:

randomized selected of 40 stroke survivors with known caregivers; and experimental group: a convenient sample of 40 stroke patient caregivers who participated in stroke club. Burden was defined as a highly personal, individualized subjective perception, it referred to perceive physical, emotional, social and financial problems by the caregivers. The researcher found advanced educational status, high income of caregivers and moderate physical disabilities of stroke patients were related to reduced feeling of caregiver burden (Printz-Feddersen, 1990).

Jones (1996) conducted a longitudinal, cohort, quasi-experimental study over 3-year period in 514 caregivers. Objective caregiver burden was comprised of those tasks required to care for the client, whereas subjective burden indicated the extent to which the caregiver "minds" performing these tasks. The results showed that objective burden related to caregiver behaviors (grooming, medication, housework, shopping, cooking, transportation, money management, child care, and time management) was more intense than objective burden related to client behaviors (embarrassment, excessive demands, keep up at night, violence, suicide, excessive drink, and drug abuse). The study also found that for burden as related to caregiver behaviors, objective burden is systemically higher than subjective burden. However, for burden related to client disrupture behavior, there are more equal intensity between objective burden and subjective burden.

In summary, the evidence from literature indicated that patients' cognitive incapacity, physical disability, ADL impairment, disrupture behaviors, social support, as well as caregivers' physical health, functional ability, caregiver behaviors, educational status, high income and social network can influence caregiver burden.

Measurement of burden

From the literature, there are three groups of authors who developed the instruments to measure burden based on the different views of caregiver burden concept.

The first group considered burden as objectively. Grad and Sainsbury (1963 cited in Platt, 1985) designed an interview schedule to estimate the burden on each family by rating the effect the patient had on the work, leisure, and health of family, on the children and on the family' relations with the neighbors. In addition, the amount and type of care that the family had to provide for the patient and their ability to provide it were assessed. Dwyer and Miller (1990) developed dichotomous questionnaire. This instrument was designed to measure disable elders' caregiver burden by summing unweighted positive response to problems experienced by the primary caregiver as a result of caring for the care receiver. The summing score (range 0-9) reflects the degree of burden experienced by the primary caregiver.

The second group viewed burden subjectively. Poulshock and Deimling (1985) developed Burden Scale including four subscales: ADL impairment burden, sociability, disrupture behavior and cognitive incapacity. The instrument used in family caring for elderly. Stuckey and associates (1996) developed Burden Scale which measures caregivers' perception of the impact of caregiver on the lives, physically, mentally, financially and socially. Scholte op Reimer and associates (1998) developed Sense of Competence Questionnaire (SCQ) to assess the caregivers' perceived burden from a wide range of possible problems related to caregiving. The SCQ used to measure the burden of caregiver of dementia patient, as well as stroke patients. Although these scales contribute to measure caregiver burden in physio-psycho-social and financial aspects, there are limited to one conceptual domain of burden-subjective phenomena.

The third group viewed burden both objectively and subjectively. A scale that differentiated objective burden from subjective burden was developed by Hoeing and Hamiton (1969 cited in Loukissa, 1995). Reliability and validity of this scale was not mentioned. Spitzer and associates (1971 cited in Loukissa, 1995) developed the Family Evaluation

Form, a standard interview for family members to describe the person behavior in the week prior to evaluation and its effects on the family. It consisted of 455 items grouped into 45 summary scales to assess objective and subjective burdens.

The Social Behavior Assessment Scale developed by Platt (1985) was used to measure psychiatric illness patients' symptomatic behavior and social role performance and to evaluate both subjective and objective burden of the family members. Adverse effects on others (objective burden) are assessed by rating 18 items, rated on 3-point scales. The information subjective burden was tested by using 4-point global scale.

Montgomery, Gonyea and Hooyman (1985) conducted a study with 80 people caring for, or assist for elderly relative, and developed the Burden Scale. Construct validity of the Burden Scale was tested by using Pearson's product moment correlations between objective and subjective burden. Zero-order correlation coefficients were computed for the two measures of burden and independent variables. The data showed that subjective and objective burden were correlated (r=.34). The two types of burden share only 12% of common variance. The findings supported that the factors contributing to subjective burden were different from those contributing to objective burden. Internal consistency was tested by Cronbach's alpha from which the coefficients obtained were .85 for objective burden and .86 for subjective burden. Robinson (1990) using this instrument conducted a study in a sample of thirty-one caregivers with an impaired elders suffered from dementia in USA, Chronbach's alpha for objective burden was .86 and for subjective burden was .77. Foxall (1996) studied 24 family caregivers of bone marrow transplant patients, using the Burden Scale to describe the burden of caregivers, the researcher also got an acceptable Cronbach's alpha (Objective Burden Subscale was .80, Subjective Burden Subscale was .92).

Biegel, Milligan, Putnam and Song (1994) developed a twenty-seven-item scale of overall caregiver burden to assess burden of lower social class family caregivers of person with chronic mental illness. The burden scale include four dimensions: family disruption, client dependency, stigma, and caregiver strain. The first dimension is very similar to previous measures of objective burden, while the remaining three dimensions can be said to components of subjective or emotional burden.

In conclusion, measurement of caregiver burden varies and is broad. Objective burden instrument measures the disrupture or changed of the caregiver lives, while subjective burden instrument measures feeling or perceived burden from a wide range of possible problems related to caregiving. However, the most widely used subjective burden scales have incorporated both feeling about giving care and about effects on the caregiver life (Braithwaite, 1992). In this study, the instrument for measuring caregiver burden will be the Burden Scale developed by Montgomery, Gonyea and Hooyman (1985) since it appears to be empirically as well as conceptual distinct indices of burden.

Burden of stroke patient caregivers

Providing care for spouse or relative stroke survivors has been accepted widely as an exhausting and harrowing experience, indeed a burden. Literature review indicated that there were some studies on burden of stroke patient caregivers.

According to Brandster and Basmajian (1987). Stroke is actually a family illness. The family members, especially caregivers often face many problems, including social isolation, limited of leisure activities time, financial strains, behavior problems, loss of sleep, giving up the jobs and health problem.

Anderson (1992) conducted the Greenwish Stroke Study among 75 stroke patient caregivers in USA. The findings showed that 35% of caregivers reported a little burden, 20% of caregivers reported moderate burden and 9% of caregivers reported a large burden nine months after the patients suffered stroke. The caregivers reported that the effects of stroke on their lives including social activity restriction (42%), leisure activities limitation (36%), financial restriction (26%) and caused problems for other family members (27%), many stroke patient caregivers felt exhausted, upset and distress.

Browning and Schwirian (1994) conducted a study among 102 elderly people caregivers. Caregiver burden was defined as caregiver physical and emotional health, social life, and financial status affected as a result of caregiving for the family member and was measured by 22-item Burden Interview developed by Zarit and associates (1980, 1983). The data suggested that in term of concept of caregiver burden, there were some difference according to diagnoses. Caregivers of patients with a diagnosis of stroke reported higher burden than did caregivers with other illness patients.

Anderson and associates (1995) studied a chief caregivers of follow-up one-year stroke survivors (N=492) in Australia, using the Hospital Anxiety and Depression Scale, 28-item General Heath Questionnaire and Social Behavior Assessment Schedule to measure caregiver burden. The findings showed that caregiver emotional ill-health (in 79%, including fear, frustration, resentment, impatient and guilt), disrupture of social activities (in 79%) and leisure time (in 55%) were the most affected by caregiving for stroke patients. They also found that the financial and work-related problems were most relevant among families in which the main wage-earner had experienced stroke or among some children who support disable parents.

In a longitudinal community-based 3-year follow-up study of 35 conservative primary stroke patients and their caregivers in Sweden, Elmostahl and associates (1996) based on Perlin and associates (1990) theoretical model in which burden was defined as an outcome variable including decreased feeling of well-being and increased health problems, developed and used New Caregiver Burden Scale. The findings showed the caregivers experienced exhausted, strain, disappointment and isolation. Spouse caregivers experienced the same total burden as children and other caregivers but a higher degree of disappointment and isolation.

In conclusion, the direct effects of stroke on caregivers as well as caregivers' perception of the responsibilities to the stroke survivors are overwhelming burden, resulting in detriments in physical and psychological, and social well-being.

Social support

Concept of social support

In recent years, the concept of social support has emerged as a major psychosocial variable in health-related research. However, there is no universal accepted definition or conceptualization of social support. The concept of social support was viewed from three aspects: network structure (number and composition of one interpersonal ties), support functions (emotional, appraisal, informational, and instrumental support), and the nature of support (satisfaction with support received, the direction or degree of reciprocity between network members, and whether network interaction is helpful or conflicting) (Vrabec, 1997).

Some theorists viewed social support mainly on functional assistance. Cobb (1976) defined social support as that piece of information which convinces people that others love them, care for them (emotional support), that others respect them and value them (esteem support) and that they are part of network of communication and mutual obligation (network support). House (1981 cited in Schabracq, et al, 1996) also viewed social support mainly on functional aspects and distinguished four kinds of support: instrumental support (helping persons directly by doing something); emotional support (give care, love, sympathy); informational support (giving information that can be used by the receiver for coping); and appraisal support (feed back about personal functioning directly at enhancing self-esteem).

Weiss (1974) identified six categories of relational provisions of social support including attachment, social integration, opportunity for nurturance behavior, reassurance of worth, a sense of reliable alliance and obtaining of guidance. Based on Weiss' (1974) model of relational functions, Weinert and Brandt (1987) defined social support mainly on support structure and functional assistance aspects as provision for attachment/intimacy, social integration, opportunity for nurturant behavior, reassurance of worth as an individual and in role accomplishments, the availability of informational, emotional and material help. Attachment or intimacy refers to the sharing of concerns, information and ideas in a social network. Opportunity for nurturance refers to take responsibility for well-being of another. Reassurance of worth related to an individual competence in a social role. The availability of informational, emotional and material help is the support during stressful situation when the individual seeks emotional support, informational and material help from a trustworthy and authoritative figure. Similarly, Lin (1986 cited in Desrosier, Catanzaro & Piller, 1992) emphasized social support on network structure and support function. Social support was defined as the perceived or actual instrumental and /or expressive provisions supplied by the community, social network, and confiding partners. In Lin's model of social support, the words social and support were examined as separate entities rather than one unified concept. Social relations are conceptualized in three layers. The outermost layer is that the individual relationships with large community in which is referred one sense of integration and belongs to the large social structure (e.g., one local community or neighborhood). The second are social networks, through which one has access other individuals (e.g., schools and churches); the third and innermost layer of social relations is that of one relationship with confiding partners, those closest to individual and most significantly related to one overall well-being. Support has two dimensions: instrumental and expressive. Instrumental support is the use of relationship as the means to achieve a goal. Expressive support is the form of exchanged interpersonal relationship.

Kahn (1979 cited in Norbeck, Lindsey and Carrieri, 1981) proposed social support mainly on functional assistance and nature of the support. Kahn included the characteristics of reciprocity in the conceptualization of social support. Social support was defined as interpersonal transactions that include one or more of following: the expression of positive affect of one person toward another; the affirmation or endorsement of another person behaviors or expressed views; and the giving of symbolic or material aid to another.

In summary, literature suggested that conceptualization of social support can be analyzed in term of dimension. The dimensions of social support include structural aspects of support network, functional types of assistance available or actual received, and the nature of support.

Factors contributing to social support

Research assessing the role of social support in moderating the negative effects of life stress indicates that the effectiveness of such support depends on many factors. These include the type and amount of support provided, as well as the context surrounding the support transaction and recipient's satisfaction with the support (Antonucci, 1985; Krause, 1987; Powell, 1990; Vaux, 1985; & Ward, 1985 cited in Lynch, 1998).

Findings indicate that the social and family relationships of women, when compared to those of men, tend to exhibit more closeness and intimacy, and that women place a high value on support reciprocity (Antonucci, 1994; Kessler & Mcleod, 1984, Schultz, 1991 cited in Lynch, 1998).

Lynch (1998)conducted a study among 1154 Caucasian people in American, using Positive Support Indices created by House and Kahn (1985 cited in Lynch 1998) to measure caregiver support systems. The results showed that men appeared to perceived spouse support as most positive, while women seem to perceive the support received from children as being the most positive. However, it was apparent that those with spouse, children, and friends/other relatives are important sources of support for both men and women.

In conclusion, literature indicated that gender, type and amount of support, support context as well as satisfaction with the support affecting recipient's social support

Importance of social support

The beneficial effects of social support on health are well documented. Social support has been associated with long life, psychological well-being, compliance with heath regimen, decreased mobility and recovery from serious physical illness and injury (Israel & Rounds, 1987 cited in Heaney, 1991).

Cobb (1976) stated that social support can protect people in crisis from a wide variety of transitions in life cycle from birth to death. It seems to be a buffer when individual encounters problems. Kaplan, Cassel and Gore (1977) also proposed that social support protect the individual from a variety of stressful stimuli. Similarly, Cohen and Wills (1985 Cited in Cohen, 1988) proposed that social support may have a protective function serving as stress-buffering or moderating role in health outcomes. Social support is important to individual well-being through out the life course both for its direct contribution and for its ability to moderate the effects of stress. The beneficial effects of social relationships derive from the content and quality of social relationship (Cohen & Wills 1985 Cited in Cohen, 1988). House, Landis and Umberson (1988) noted that a wide range of evidences from laboratory and field studies indicated that the presence of social relationships reduced the experience of stress, improved health or buffered the impact of stress on health.

The benefit of social support to caregivers was proposed by Braithwaite (1990), who stated that social support which mediated the burden-symptom relationship was regarded as responses which carer might use to coping with the difficulties, and was proved advantageous, buffering burden carer.

A variety of studies addressed the importance of social support to caregivers physically or psychologically. Some studies identified the importance of social support on physical well-being. Hardy and Riffle (1993) conducted an intervention study among 8 primary caregivers of dependent persons to assess how a support group was used to modify the problem of inadequate social support and social isolation of caregivers. The results showed that support group participation developed an increased awareness of their own needs, and the relationship of having the needs meet and the ability to function in the caregiver role. Attendance at the group created a social outlet that helped caregivers feel more socially integrated. The results also showed that sharing of feelings and the sense of affiliation with and support from others were felt to be most beneficial aspects of group participation.

Some authors noted that social support was an important factor in caregiver psychological adjustment. Fengler and Geodrish (1979 cited in Robinson, 1990) studied the benefits of social support to caregivers. The researcher reported that visit from children, relatives and friends became important social support for high-morale caregiving wives. Anderson, Reiss and Hogarty (1986 cited in Reinhard, 1994) also claimed that social support from professionals can reduce family members' sense of burden. In Baillie, Norbeck and Barnes (1988) study, caregivers who were caring for mentally impaired elders, had been proving care for an extended time, and had low social support were at high risk for psychological distress or depression.

Griven, Stommel, Collins, King and Given (1990) using data from 159 spouse caregiver of dependently elders found that lack of assistance, and lack of affective support contributing to predicting caregiver feeling of abandonment. Mittelman and associates (1995) conducted the comprehensive program including individual and family counseling, the continuous availability of ad hoc counseling, and support group participation for primary caregiver and family members of Alzheimer patients over the entire course of disease (n=206, 103 for treatment group and 103 for control group). The results indicated that enhancing long-term social support had a significance impact on depression in caregivers.

In conclusion, there are evidences that social support from differently social network has a beneficial effect on caregiver health, although the exact mechanism for this effect is not clear (Heaney, 1991). Literature suggested that social support was negative associated with caregiver burden, depression and distress. Social support can increase the caregiver morale, and enhance the function of caregiver role.

Measurement of social support

Since social support is a multidimensional construct, it has been measured differently from study to study based on the different views of social support. Norbeck Social Support Questionnaire (NSSQ) was developed by Norbeck, Lindsey and Carrie (1981, 1982) to measure multidimensional of social support based on Kahn' idea (Kahn, 1979 cited in Norbeck, Lindsey and Carrie 1981). The instrument has three aspects: total function, total network, and total loss. The NSSQ included items to measure the three supportive transaction components: affect, affirmation, and aid; to assess representative convoy or network properties which include number in network, duration of relationship, and frequency contact. Internal consistency was tested through intercorrelations among all items. The correlation between the two affect items was .97; between the two affirmation items was .96, and between the two aid items was .89. Robinson (1990) used NSSQ to measure social support of adult caregivers of impaired elders. The internal consistency Cronbach's alpha was .47, .93, .99 for affirmation, aid, and affect variables, respectively, for total function, .97.

The Personal Resource Questionnaire 85 (PRQ-85) measured multidimensional characteristics of social support (Weinert, 1987; Weinert & Brandt, 1987). PRQ-85 based on Weiss (1974) model of relation functions, is composed of five following dimensions: provision for attachment/intimacy, social integration, opportunity for nurturant behavior, reassurance of worth as an individual and in role accomplishments and the availability of informational, emotional, and material help. The PRQ-85 consists of two parts of measures of social support. Part I is an assessment of the number of interpersonal resources a person can count on across nine life situations and the person satisfaction with these resources. Part 2 of PRQ is 25-item 7-point likert scale that measures the person perceived level of social support. Scale score ranged from 25-175 with high score indicating high level of perceived social support. The PRQ-85 part 2 had high internal consistency reliability (Cronbach's alpha for total score .93, subscale ranged from .79 to .88). Using data from 100 adults, aged 30-37 years from a University of Washington alumni, construct validity was established by using Pearson's correlation between PRQ-85 part 2 measure and mental health measures, and between social support measure and personality measure. The results showed that social support variable was significantly related to the mental health measures and to the personality indicators ($p <.001$). PRQ-85 part 2 was also moderately associated with anxiety, depression, neuroticism, and extroversion personality. The test-retest coefficient were $r=.72$ ($p<.01$) (Weinert & Brandt, 1987). Kenchaiwong (1996) tested for the internal consistency of PRQ-85 part 2 from which the Cronbach's alpha coefficient obtained was .83.

Other instruments such as Health Support Index (Robbins & Slavin, 1988) was developed to assess existing social support for planned changes in health-related behaviors. Sarason Social Support Questionnaire (SSSQ) (Sarason, Sarason, Hacker & Basham, 1983 cited in Robinson, 1990) was designed according to Caplan's (1974) definition of an enduring of continuous or intermittent ties that play a significant part in maintaining physical and psychological health over time. The questionnaire was intended to measure the perceived amount of social support and satisfaction with social support available.

In conclusion, there are variety of instruments for measuring social support available and have been tested their validity and reliability. The selection of the instrument is based on the congruency between the variable the researcher want to measure and the dimensions of the instrument has been designed to measure. In this study, PRQ 85 part 2 will be used because it has a high internal consistency reliability and construct validity.

Social support of stroke patient caregivers

From the literature review, although there were various studies of social support in disabled or demented patient caregivers, little research on social support in stroke patient caregivers exists.

Printz-Feddersen (1990) conducted an ex-post facto study using data from control group: randomized selected of 40 stroke survivors with known caregivers and experimental group: a convenient sample of 40 caregivers with known stroke club. The results showed in primary service of stroke club involvement, the source of friendship was most helpful (50%). Providing emotional support was the second most beneficial (40%) and educational and informational benefits were the least important (10%).

Kenchaiwong (1996) studied social support among 50 caregivers of stroke patients, using personal Resource Questionnaire part 1 and part 2 developed by Brandt and Weinert (1985). The results showed that the major sources of support for stroke patient caregivers were relatives or family members, child or children, spouse or partner or significant others, parent and neighbor or coworker, respectively. The results also showed that stroke patient caregivers were moderately satisfied with the help received in most situations.

In conclusion, few studies suggested that social support from a variety of social network was beneficial to stroke patient caregivers.

Relationship between social support and burden of stroke patient caregivers.

As review, there were evidences to show that social support negatively related to burden or stress of patient caregivers. Reinhard (1994) conducted a study to examine the relationship between professional support and burden of mental illness caregivers (n = 94) in Newjersy. Caregiver burdens including objective burden and subjective burden were measured by 19-item Burden Assessment Scale devised in the study. Professional support was measured by seven Instrumental Support and four Affective Support items.

Hierarchical Multiple regression analysis demonstrated that professional support selectively reduced burden. Practical advice on managing disruptive behavior reduced objective burden ($p < .05$).

There were only few studies that addressed the relationship between social support and burden of stroke patient caregivers from the literature review. An ex-post facto study used data from control group: randomized selected of 40 stroke survivors with known caregivers; and experimental group: a convenient sample of 40 caregivers with known stroke club involvement. The findings showed that there was no significant different burden between caregivers who participated in stroke club (experimental) and those who did not (control group) (Printz-Feddersen, 1990). The limited degree of assistance from stroke club, the control group connection with the neurology clinic which provide similar support to that of a stroke club may be relating factors to the results.

Kenchaiwong (1996) conducted a study among 50 stroke patient caregivers using PRQ part 1 and part 2 developed by Brandt and Weinert (1985) to measure social support, and the Burden Scale developed by Montgomery, Gonyea and Hooyman (1985) to measure burden. The results showed that there was significant negative relationship between social support and caregivers' objective burden ($p < .001$). The finding also found statistically significant negative relationship between assistance/guidance type of social support and both caregiver objective and subjective burden (p <.001).

In summary, there were only few studies tested the relationship between social support and burden of stroke patient caregivers, and the negative relationship between the two variables was partially proved. Therefore, the relationship between social support and burden of stroke patient caregivers need to be investigated.

Conceptual Framework

This study was based on the concept of burden of Montgomery, Gonyea and Hooyman (1985) and the concept of social support of Weinert and Brandt (1987).

Stroke will result in patient dependency: physically, psychologically, and socially. The impact of stroke survivors' dependency for caregivers includes effects of caregiving to the caregivers' lives and caregiver perception of caregiving. The caregivers are often facing with problems in the areas of the health, pursuit of leisure time, loss of sleep, social isolation, financial restriction, psychological disturbance. According to Montgomery, Gonyea and Hooyman (1985), burden was viewed both objectively and subjectively. Objective burden was defined as the extent of disruptures or changes in various aspects of the caregiver life and household because of caregiving, whereas subjective burden is defined as the respondent attitudes toward or emotional reactions to the caregiving. Those who have burden need assistance from others so that burden will be reduced. According to Weinert and Brandt (1987), social support is beneficial to person. Perceived provision of social support includes attachment/intimacy, social integration, opportunity for nurturant behavior, reassurance of worth as an individual and in role accomplishments and the availability of informational, emotional, and material help. Social support, which serves as stress-buffering or moderate role in health outcome, is regarded as reciprocity responses which caregiver might use to cope with the difficulties and social network might provide social support to help the caregiver cope with the difficulties. Therefore, the more the social support, the possibly less the burden of caregivers as shown in Figure 1.

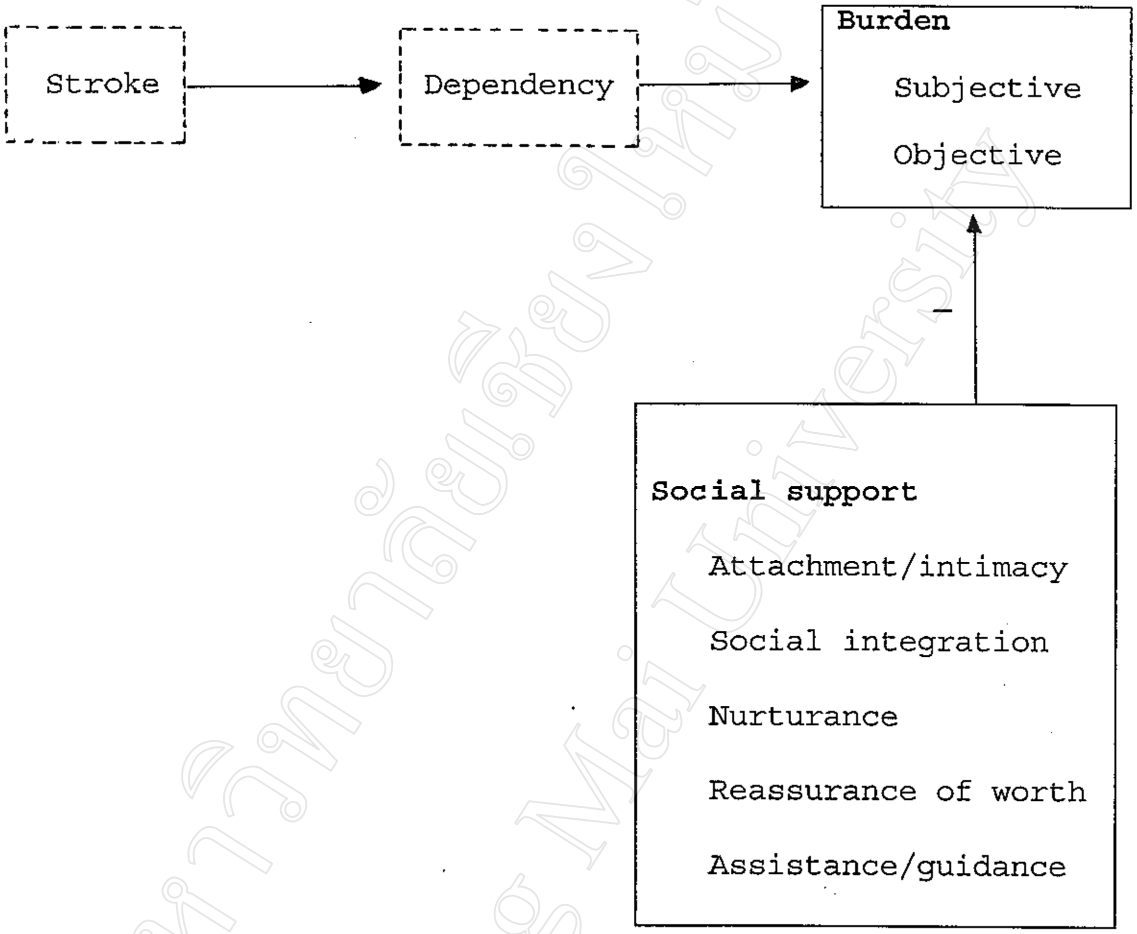

Figure 1 : Conceptual framework for the study