

CHAPTER 2

LITERATURE REVIEW AND THERETICAL FRAMEWORK

Literature review and related research

In this section, the review of literature included the following categories:

1. Overview of a stroke
2. Effects of a stroke on the self-care ability of stroke survivors
 - 2.1 Orem's Self-care Theory
 - 2.2 Self-care ability of stroke survivors
3. Family social support of stroke survivors
4. The relationship between the family social support and self-care ability

Overview of a stroke

A stroke or cerebrovascular disease designates any abnormality of the brain resulting from a pathological process of blood vessels that supply the brain. It is an abrupt or rapid clinical syndrome of neurologic deficit. Many factors will place a person at risk for a stroke (Sacco et al., 1997). Age, gender, race/ethnicity, hereditary, and geographic location have been identified as non-modifiable

risk markers of strokes. Potentially modifiable risk factors include cardiovascular disease, cigarette smoking, transient ischemic attacks, diabetes mellitus, heavy alcohol consumption, and use of oral contraceptives. Hypertension is one of the important modifiable risk factors. It has been suggested that the efficacy of antihypertensive treatment is a major reason for the acceleration in the decline of stroke mortality (He et al., 1995).

The term stroke is used to describe an event that can be caused by a number of different pathological processes. Pathological processes means any lesion or altered permeability of the blood vessel wall, occlusion of the lumen by thrombus viscosity or other changes in the quality of blood (Adams & Victor, 1993). If blood flow through the cerebral vessels is interrupted, the brain is unable to receive an adequate blood supply through collateral or shunting of blood via other pathways. The brain must receive a constant blood flow for normal functioning, as it is unable to store oxygen or glucose and or remove metabolic waste. Deprived of its blood, the brain can be damaged within a few minutes. In the event of stroke, ischemia occurs in the brain tissue, leading to brain dysfunction (Adams & Victor, 1993).

Generally, a stroke is divided in two main types. They are ischemic stroke and hemorrhagic stroke. Over 80% of strokes are ischemic, the remainder are hemorrhagic

(Mower, 1997). Ischemic strokes result from a decreased blood flow to the brain secondary to partial or complete occlusion of an artery. The most common subtypes of ischemic strokes are thrombotic and embolic. A thrombotic stroke is commonly associated with the development of atherosclerosis of the blood vessel wall. Thrombus formation extends along the interior of the artery, gradually occluding the lumen of the artery, so the thrombotic stroke tends to have a slow onset. An embolic stroke is caused by an embolus or a group of emboli that break off from one area of the body and travel to the cerebral arteries via the carotid artery. The usual sources of the emboli are as follows: mural thrombosis in the left atrium or ventricle, septic emboli from bacterial endocarditis, or atrial fibrillation. Emboli tend to become lodged in the smaller cerebral blood vessels at their point of bifurcation or where the lumen narrows. As the emboli occlude the vessel, and ischemia develops, the client experiences signs and symptoms of a stroke. Embolic strokes are characterized by the sudden development and the rapid occurrence of focal neurologic deficits (Adams & Victor, 1993).

The second classification of stroke is hemorrhagic stroke. Two subtypes are intracerebral hemorrhage and subarachnoid hemorrhage (SAH). The most common cause of hemorrhagic stroke is hypertension. The exact mechanisms

involved are unknown, it is hypothesized that elevated systolic and diastolic pressures cause changes in the atrial wall that leave it prone to rupture (Adams & Victor, 1993). An intracerebral hemorrhage occurs when the vessel ruptures into the brain tissue itself. SAH is caused by cerebral aneurysm and arteriovenous malformation, both are thin-walled, dilated vessels. The vessels may eventually rupture, causing bleeding into subarachnoid space.

The stroke syndromes depend on the anatomic site of the brain, the rate of onset, the size of the lesion, and the presence of collateral circulation. The neurologic deficit reflects both the location and size of the infarction or hemorrhage. The middle cerebral artery distribution is the most common site for cerebral infarction, leading to typically contralateral hemiplegia, somatosensory deficits and homonymous hemianopia (Hickey, 1997). The most visible sign of stroke is hemiplegia or paralysis on one side of the body. A person with hemiplegia, either left or right, often shows abnormal muscle tone to some degree, affecting the limbs and the trunk. Abnormalities of muscle tone, combined with motor weakness and joint stiffness, will influence mobility (Galarneau, 1993) and the activities of daily life (ADLs) (Duncan, 1994). In addition to hemiplegia, the survivors may have one or more of the following difficulties: loss of feeling in or loss of awareness of the face, difficulty in

seeing out of one side of each eye (visual field cuts), difficulty in understanding what is said and in speaking to others (dysphasia), difficulty in coughing or swallowing (dysphagia), and incontinence of bowel or bladder, etc. Some of these deficits are associated with each other, due to the site or nature of the neurological lesion. So the stroke survivors with right hemiplegia are more likely to suffer from speech and language deficits, whereas the stroke survivors with left hemiplegia more often have spatial and perceptual deficits (Hayn, 1997).

Once a stroke has occurred, the major management of the acute stroke is to institute appropriate basic cardiopulmonary life-saving measures, prevent possible further neurological deterioration and ensure rapid specific medical or surgical therapy. Treatments of stroke by thrombolytic and neuroprotective agents have been developed with positive result by saving neurons and reducing the size of the lesion (Jørgensen, Nakayama, Raaschou, & Olsen, 1997). There is a narrow 3-hour therapeutic window for use of thrombolytics. When given early enough after the onset of symptoms, tissue plasminogen activator (t-PA) may limit neurologic deficits in ischemic stroke (Jørgensen et al, 1997). Although these treatments may decrease the severity of stroke, the damage to the brain tissue often remains irreversible. Prevention or treatment of general medical complications is of the utmost importance and early

initiation of rehabilitation is recommended as soon (D'Alton & Norris, 1987).

Strokes are the leading cause of chronic disability (Chipps, Clanin, & Campbell, 1992). Commonly, the main cause of physical disability after stroke is hemiplegia (Anderson, 1992). Since the sequel of a stroke depends on the extent and the location of the ischemia, the degree of physical disability varies greatly. Garrad and Bennet (1971, cited in Anderson, 1992) described disability as limitation of performance in one or more activities which are generally accepted as essential basic components of daily living. Based on the Barthel Disability Score, five ranges of disability have been coded: 0-4 as very severe, 5-9 as severe, 10-14 as moderate, 15-19 as mild, and 20 as normal (cited in Anderson, 1992). Patients with moderate or mild disability have been discussed as "good prospects" for survival (Anderson, 1992). This kind of stroke survivor should be motivated to perform activities to prevent various complications by themselves.

Cognitive problems that impair social interaction, problem-solving, and memory are deficits commonly experienced by stroke survivors (National Stroke Association, 1994, cited in Grant, 1996). To function as a fully functioning person, the quality and quantity of cognition must be intact. Intact cognitive function reflects the highly integrated functions of many parts of

the cerebral hemispheres, cortex, and subcortical structures known as the reticular activating system (RAS). The most crucial components of cognitive functions involved in carrying out daily living activities are as follows: orientation, memory, attention, judgment/reasoning, problem-solving, intellectual functioning skills, organization, initiation, sequence, and motivation. Altered cognitive function occurs when the RAS is disrupted, leading to various neurobehavioral deficits such as; disorientation or confusion, apathy, lack of initiation, decreased attention, impaired judgment, poor problem-solving skills, impulsivity, emotional lability, and lack of insight (Gatens & Hebert, 1996). The Mini Mental State Examination (MMSE) is popularly used to measure the cognitive status and a score of more than 20 in the MMSE is considered cognitively intact (Folstein, 1975).

Beside physical consequences, stroke survivors will also face psychological problems. They are related to changes in self-perception because of the alteration in physical appearance, impairment of bodily functions, and loss of autonomy. Anxiety and depression are common emotional reactions following strokes, manifesting with a difficulty in concentrating, insomnia, and loss of appetite (O'Rourke, Machale, Signorin, & Dennis, 1998). It was suggested that as many as 60% of patients experienced significant depression after strokes (Robinson, Starr,

Lipsev, Rao, & Price 1984). The location of the lesion and degree of functional loss are factors that influence post-stroke depression (Bruckbauer, 1991). Dysphasia, memory deficits, and behavioral changes in grooming habits, personality, and actions often result in misunderstanding and difficulty in communicating with others. Ineffective communication can give a feeling of loneliness, stressful relationships with others, and social isolation, separating the stroke survivors from pre-stroke recreational and social activities (Goodstein, 1983; Kelly & Winograd, 1985). Stroke survivors often lose the ability to work, gain money, and thus become economically dependent. Without other's financial help they can hardly support their daily living and can not improvement their functional ability.

Stroke survivors are at risk of developing a wide range of complications secondary to their stroke. Davenport, Dennis, Wellwood and Warlow (1996) observed complications after acute strokes in 613 inpatient stroke survivors. Fifty-nine percent of the subjects (n=360) were recorded with complications. The most common individual complications were falls (22%), skin breaks (18%), and urinary tract (16%) or chest (12%) infections. These complications are important because they may cause death or delay successful rehabilitation (Dromerick & Reding, 1994).

In summary, a stroke is an infarction of the brain, causing disruption of brain functions due to ischemia or

hemorrhage. Physical and psychosocial consequences of a stroke leave the stroke survivors in a state of chronic disability, which increase their therapeutic self-care demands to regain mobility and functional ability, control over risk factors, and overcome feelings of loss of control. In order to maintain life, health, and wellbeing the stroke survivors should actively participate in self-care to regain independence and function at a maximum level, and to prevent various complications and recurrent stroke attacks.

Effects of strokes on the self-care ability of stroke survivors

Orem's self-care theory

Orem (1991, 1995) has developed the concept of self-care agency (S-CA) along with the concepts of self-care and self-care deficits within a self-care deficit theory of nursing. The theory explains "the relationship between the action capabilities of individuals and their demands for self-care" (Orem, 1991, p.73). The term self-care is defined as "the daily practice of deliberate, patterned, sequential, and purposeful activities that individuals continuously and voluntarily perform on their own behalf to maintain life, health and wellbeing" (Orem, 1995, p. 104). Whether self-care is performed or not depends on the individual's ability, called self-care ability (S-CA), to perform the necessary actions to meet the demands of what

must be done. The demands, known as therapeutic self-care demands (TS-CD), dictate what self-care must be done, as well as the specifications of S-CA. Basic conditioning factors affect an individual's abilities to engage in self-care and the kind and amount of self-care required (Orem, 1995). There are ten basic conditioning factors: age, gender, developmental state, state of health sociocultural orientation, health care system factors, family system factors, environment factors, and resource availability and adequacy. If S-CA is adequate to meet TS-CD, then no self-care deficit exists. Alternatively, if S-CA is not adequate to meet the TS-CD, then a self-care deficit exists, and outside assistance may be needed. In order to evaluate S-CA, it is need to understand the S-CA structure in its relationship to self-care phases of action.

S-CA, the capability to engage in self-care, is expressed as a set of human abilities for deliberate action. It is actualized through an interactive process of the three-part S-CA construct and self-care operations, the outcome being self-care behavior. The first part of the construct is foundational capability and disposition (Orem, 1995). These provide the basis and establish the boundaries for available action; they are developmental in nature, include age and gender, and vary with the state of (Orem, 1995). Other factors affecting foundational capabilities and dispositions include the individual's aptitude for

education, knowledge of relevant events and conditions, and prior ability. All of these would aid in observing and correlating events in a manner leading to possible solutions. Capabilities are dependent on lifelong learning experiences and values and are related to culture and resource availability (Orem, 1991). Overall, in health or illness, the adult's usual learned pattern of response to internal and external stimuli affects decisions and related actions of self-care. Examples of foundational capabilities and dispositions are the ability to learn, to reason, and to make decisions.

Capabilities provide the basis for and continually interact with the second part of the S-CA construct, power components. These are known as human conditions, and they are the particular way that foundational capabilities are used to perform self-care. Some power components are the ability to reason within a self-care framework, motivation, ability to make decisions about care of self and to operate on these decisions, a repertoire of cognitive and perceptual skills adapted to the performance of self-care operations (Orem, 1995). Power components depend upon foundational capabilities. For example, being able to reason is necessary before one can reason within a self-care framework. The degree to which each power component is present and the relationships among and between the components dictate how well the individual can perform the

action phases of the operations of self-care. In other words, the time-specific values of each of the ten components affect the ability of S-CA (Orem, 1995).

The third part of the construct is the capability of the self-care agent to perform the two action phases of self-care operations in order to accomplish self-care (Orem, 1995). Self-care is accomplished through two action phases. Phase I is called estimative and transitional operations. It is mainly intellectual and investigative. It includes judgments, and must culminate with decisions about which actions must be performed to attain a specific self-care purpose (Orem, 1991). Orem (1991) states that one of the first steps for practicing self-care is answering "Can I do it?" (p.161). In order to engage in estimative operations it is necessary to acquire and use empirical knowledge about the self and external environment. Based on that initial knowledge, individuals judge whether and how "What exists" can be changed. Transitional operations require that individuals know what results can occur as a result of a judgement. This is an affirming judgment about what ideally should be done, and it requires use of reason and consideration of personal values. Finally, "What will be done" is decided. It is important to note that "What will be done" is not always what the individual knows is the ideal course of action. The second action phase may follow the first action phase ending with a decision (Orem, 1995).

Phase II is called productive operations. It is mainly self-preparatory and productive and includes all subsequent regulatory process related to actually carrying out the self-care behavior (Orem, 1991). Regulation occurs, as one's behavior is self-monitored for changing condition, effects, and adequacy of the operations performed. Based on the monitoring, the individual determines whether to continue or stop the operation, or whether reentry into phase I is necessary. As such, there is movement within and between both operations.

Self-care ability is the concept most frequently operationalized by instruments. Kearney and Fleischer (1979) developed the Exercise of Self-care Agency (ESCA) scale based on their own conceptual analysis. They identified five dimensions of "exercise of self-care agency": (1) attitude of responsibility for self, (2) motivation to care for self, (3) application of knowledge for self-care, (4) value of health priorities, and (5) high self-esteem. The Denyes Self-care Agency Instrument (DSAI) was developed by Denyes (1981) based on a strength and limitation analysis of self-care agency. Based on the combination of ten power components and productive operations of self-care, Evers (1986) viewed self-care agency as the power of an individual to engage in operations that are essential to self-care and developed the Appraisal of Self-care Agency (ASA) scale. Knowledge, decision making

and productive operations are three parts of this scale. It consists of 24-items to be rated using a five-point Likert-type scale. The ASA scale is popularly used in nursing research to measure one's power to perform the productive operation of self-care. Decramer, Gosselink, Troosters, Verschueren, and Evers (1997) used the ASA scale in their research of COPD patients. Ward-Griffin and Bramwell (1990) used the ASA scale to investigate the congruence of elderly clients and nurse perceptions of the clients' self-care agency.

Concisely stated, self-care is produced through the interaction of the three components of the self-care ability construct (foundational capabilities and dispositions, power components, and capability for action), both self-care operations. In this study, self-care ability is defined as an individual's abilities and characteristics that are essential for the performance of self-care activities regarding knowledge, decision-making, and productive operations.

Self-care ability of stroke survivors

After a stroke attack, the stroke survivors will be affected by various physical and psychosocial consequences. All these increase therapeutic self-care demands such as regaining mobility and functional ability, and control over risk factors, whereas the capabilities for the stroke

survivors to perform necessary actions to meet these demands are decreased. Self-care is action-oriented and focuses on problem solving. Individuals who practice self-care may engage in self-observation, recognize and label symptoms and judge their severity, assess and choose treatment options, and evaluate the effectiveness of self-care.

Based on the assessments of stroke survivors' long-term learning needs, Johnson, Pearson and McDivitt (1997) found that stroke survivors and their families, need and desire to learn more about the life-altering aspects of living with the aftermath of a stroke. So knowledge gives power to stroke survivors to develop self-care strategies for living with their stroke-related disabilities.

Self-care ability influences the client's potential to manage the resources required for self-care (Orem, 1985). A stroke is a crisis for the individual and the family. The sudden change in health status and functional ability requires many decisions to be made regarding long-term care. The rapid onset of a stroke leaves much uncertainty regarding the future, as well as fear of a relapse. Individuals experience loss of control. Physical and social immobility facilitates dependency and helplessness. McDermott (1993) identified that helplessness was inversely related to self-care ability.

Psychosocial changes may reduce stroke survivors' attention, motivation, and abilities to judge and make

decision regarding self-care. They often cause problems with personal and social relationship that can lead to increasing isolation for the stroke survivors and their family (Anderson, Linto & Stewart-Wynne, 1995). These deficits reduce the patient ability to cope with physical impairment and may interfere with rehabilitation progression (Censori et al., 1996).

In summary, stroke survivors have to face many problems resulting from disability and psychological consequences, which could affect their self-care ability. Physical disabilities reduce their physical energy to perform self-care behavior. Lack of relevant knowledge of control and prevention of recurrent strokes and various complications influence their ability to judge themselves and the environmental factors. Therefore, they may need support, information and feedback which could be fulfilled by their social network when they take care of themselves.

Family social support of stroke survivors

Network refers to the web of identified social relationships that surround an individual and the characteristics of those linkages. Social support can be considered as an interactive process in which emotional, instrumental, or financial aid is obtained from one's social network. One approach to defining social support proceeds from the consideration of the source, functions, and

characteristics of relationships.

Cobb (1976) defined social support as "information that leads a person to believe that he/she is cared for and loved, esteemed and valued, and a member of a network of mutual obligations" (p. 300). It emphasizes the emotional impact of support on the supported person. Besides emotional support, Caplan (1974, cited in Wilcox & Vernberg, 1985) conceived that social support as a construction with two other dimensions--informational and tangible. Emotional support refers to providing love, care, and concern. Informational support refers to extending information and guidance relevant to a stressful situation. Tangible support includes acting to assist an individual in daily functioning. House (1984, cited in Israel, Hogue & Gorton, 1984) defined the content of four broad types of support: emotional support (affect, esteem, concern), appraisal support (feedback, affirmation), informational support (suggestion, advice, information) and instrumental support (aid in labor, money, time).

Social support may protect the individual during a crisis from a wide variety of pathological states, reduce the amount of medication required, accelerate recovery, and facilitate compliance with prescribed medical regimens (Cobb, 1976). Bruhn and Philips (1984) identified four mechanisms of social support. They are (1) to fulfill the need to belong, (2) to modify the effects of negative

stress, (3) to strengthen or restore hope or morale, and (4) to provide and to receive social support enhances a person's ability to use these skills in new situations.

Social support most commonly refers to helpful functions performed for an individual by significant others such as family members, friends, co-workers, relatives, and neighbors. Family, as the basic unit of society (Friedman, 1986), is regarded as one part of the social network (Cooley, 1995; Danielson, Hamel-Bissel, & Winstead-Fry, 1993). The concept of family social support is considered as social support from the family and is usually discussed within the context of social support. Brillhart (1988) identified four aspects of family social support as physical care, economic support, emotional support, and social support which includes communication, response, and a sense of belonging. According to Procidano and Heller (1983), social support is the perceived need for support, information, and feedback. They developed the Perceived Social Support from Family scale (PSS-Fa) to measure the extent to which an individual believes his/her needs for support, information and feedback are fulfilled by the family (Procidano & Heller, 1983).

The family is the primary source of social support. Elderly persons often rely heavily on the family to fulfill social support needs (Connidis & Davies, 1992). In most cases, spouses were far more likely to be the primary

caregivers, with children predominately as secondary caregivers (Cantor, 1991). In China, 70% of the elderly live with their adult children (Jia, 1997). The notion of allegiance to parents and the emphasis on filial piety is a common value shared among Asian cultures (Pleanbangyang, 1998). Traditionally, most of Chinese consider family as their greatest source of social support, especially when they get ill.

The majority of stroke survivors reside at home with family members. Because of the close relationship, families are in a unique position to be able to adapt the principles of social support to caring for a stroke survivor. When facing with chronic disability, families often coalesce (Reiss, Gonzalez & Kramer, 1986), and influence the attitudes and behavior of the disabled people (Evans et al., 1992). The availability of emotional, informational, and instrumental support from family members enhances the stroke survivor's ability to cope with the chronic phase of recovery (Evans et al., 1992).

Glass and Maddox (1992) examined the impact of types of social support on changes in the functional status of 44 stroke survivors followed for 6 months after their first stroke. All three types of support (emotional, instrumental and informational) were significantly related to the recovery of functional capacity. The stroke survivors, who reported high levels of emotional support

from their family, showed dramatic improvement despite having the lowest baseline functional status. Instrumental support is most closely related to positive outcome when provided in moderate amounts. Unlike the other two types, the effect of informational support is mediated by disease severity.

In summary, family is the primary source of social support for the stroke survivors. In this study, family social support means an individual's perceived needs for support, information and feedback fulfilled by the family.

The relationship between family social support and self-care ability

Knowledge, decision-making and productive operations of self-care are important components of self-care ability for a person to perform as self-care behavior. Emotional support from the family may enhance the motivation to perform self-care behavior. The family can provide information to build the knowledge and skills needed for the performance of self-care. Therefore, how the family provides support to the patient may influence the patient's ability to perform self-care. According to Orem (1995), the family system can condition the nature of therapeutic self-care demands, practice of self-care behavior and the development of self-care ability.

Emotional support is the most important dimension

(Hill, 1991; Lakey & Cassady, 1990). Offering emotional support includes providing comfort, sharing emotional burdens through sympathy or empathy, providing encouragement, and expressing concern. The family of the stroke survivor believes that the disabled member is able to learn, grow, and succeed and therefore provides opportunities for these accomplishments. This type of support sustains self-esteem by meeting the patient's need for attention and affection, and reinforcing the patient's feeling of self-worth. With the feelings of being loved, valued, and self-esteem, the stroke survivors seldom feel helpless and have more motivation to participate in self-care activities. McDermott (1993) considers helplessness as an interacting variable, which may influence the self-care agent in a manner that can negatively influence self-care ability.

Information and feedback provided by family members can be considered as the knowledge essential for the chronic patient to judge and decide what to do in self-care. Morisky and colleagues (1985) evaluated the effects of a family health education for long-term control of high blood pressure in 400 hypertension patients. After being interviewed, counseled, and provided with a booklet for the purpose of education, and being involved in home management, the family members could assist the patient with medical compliance, keeping appointments, as well as diet and weight

control.

In conclusion, few research studies had been done to examine the relationship between family social support and self-care ability. How the relationship between family social support and self-care ability is among stroke survivors needs to be investigated.

Summary

A stroke can result in increased self-care demands and decreased self-care ability. Self-care ability is the complex acquired ability to meet one's continuing requirement for care that regulates life process, maintains or promotes integrity of human structure, and functioning and human development, and promotes well-being (Orem, 1995). Knowledge, decision-making and productive operations are three important components of self-care ability. Family is an important source of social support for stroke survivors. Family social support is helpful to improve self-care ability by enhancing the motivation and building the knowledge and skills needed for self-care.

Conceptual framework

The conceptual framework for this study is derived from Orem's (1995) Self-care Theory of Nursing.

Stroke survivors affected with physical and psychological consequences of strokes may decrease their

abilities to perform self-care due to the physical disabilities. Self-care ability is defined as an individual's capabilities and characteristics essential for the performance of self-care activities regarding knowledge about post-stroke self-care, decision-making and productive operations of self-care in order to stabilize his/her structural, functional, developmental status, health and well-being. Family social support is operationally defined as the stroke survivor's perceived needs for support, information, and feedback fulfilled by family members. In order to improve self-care ability, especially productive operations the family system is one of the basic conditioning factors that should be considered as an important factor. Support provided by family members may increase the knowledge of stroke survivors, promote decision-making, and enhance productive operation.