

CHAPTER 1

INTRODUCTION

This chapter presents several topics including background and significance of the research problem, objectives of the study, research questions, scope of the study, significance of the study, and definition of terms.

Background and Significance of Research Problem

Stroke is the leading cause of death and also a common cause of disability in many countries. The incidence of stroke increases every year. In Thailand, the rate of in-patient stroke from hospitals under the Ministry of Public Health has increased from 105.8/100,000 in 2000 to 151.5/100,000 in 2003 (Bureau of Policy and Strategy, 2000). Most stroke victims are elderly (Ministry of Public Health, 2004). Although stroke is primarily a disease of older individuals (age over 60), the incidence has increased in persons younger than 60 years. According to statistical report from the Department of Medical Services, Ministry of Public Health, Thailand, it was found that 91.9% of the patients who suffered a stroke in 2004 were over age 45 (Ministry of Public Health, 2004). The reason for this change is that the lifestyle and personal habits of people in developing country, including Thailand, have changed. There are many risk factors that cause stroke in younger people such as stress, high cholesterol diet, sedentary life style, and cigarette smoking.

Almost one in four men and one in five women currently aged 45, can expect to suffer a stroke if they live to their 85th year (Ebrahim, 1998; Wolfe, 2000). A study on stroke in the Thai elderly between 1994 - 1996 found that the prevalence of stroke among elderly in Northern Thailand was 0.6% (Viriyavejakul et al., 1998). In addition, according to the study of Sangsuwan, Sa-nguanmitra, and Navacharoen (1996) in medical wards of Maharaj Nakorn Chiang Mai during a one-year period, there were 188 patients with an age range of 45-64 years who suffered strokes from intracerebral hemorrhage and cerebral infarction. That study found that the percentage of cerebral infarction was 60.7 and that of intracerebral hemorrhage was 39.4. The mortality rate during a one-year period for cerebral infarction (both cardiac and non-cardiac related) and intracerebral hemorrhage was 20.6% and 25.7%, respectively.

Stroke mortality rates in Asian countries have declined since the mid-1960, leaving more individuals to live with their residual impairments and disabilities. These impairments pose significant problems for survivors' well-being (Clarke, Marshall, Black, & Colantonio, 2002). The incidence of stroke survivors with incomplete recovery has been estimated at 460/100,000 (Bonita, Solomon, & Broad, 1997). Of acute stroke survivors 10% are not disabled, 40% have mild disability, 40% have moderate/severe disability and 10% require long term care (Finn & Horgen, 2000). Another study suggested that two-thirds of the survivors would be permanently disabled; one half of those permanently disabled individuals were severely impaired (Doolittle, 1988).

In the recovery phase, most stroke survivors still have neurological sequelae.

The Agency for Health Care Policy and Research Clinical Practice Guideline

(AHCPR) no.16, Post-Stroke Rehabilitation states that among long-term (> 6 months) survivors, 48% have hemiparesis, 22% cannot walk, 24-53% report complete or partial dependence in activities of daily living (ADL), 12-18% are aphasic, and 32% are clinically depressed (Sacco et al., 1997). The impact of these stroke sequelae on the individual may have a dramatic effect on the individual's quality of life, which is an important health care outcome.

Quality of life (QOL) is defined differently in literature. However, most researchers do agree that it is a complex, multidimensional concept. Most studies viewed QOL in similar domains. World Health Organization (WHO) viewed QOL in four domains including physical health, psychological health, social relationship, and environment (WHOQOLgroup, 1998). Similarly, Duncan (1998) defined QOL as an outcome of stroke consistent with the health-related QOL of stroke as defined by the WHO. Lau and Mckenna (2001) proposed QOL in five domains of well-being including physical, functional, social, economic, and spiritual and philosophical.

QOL has been viewed generally, or specifically related to the health problem or disease. Many researchers stated that health related QOL is more specific to the people who are ill. Regarding stroke, Duncan (1998) identified stroke-related QOL as an outcome of the stroke and that impacts impairment, disability, and handicap. Since stroke has a great impact on survivors, it normally compromises QOL or well-being of the victim. Studies about QOL of stroke survivors were conducted mostly in the western countries. Many studies reported a decrease in QOL after stroke (Ahlsio, Britton, Murray, & Theorell, 1984; Astrom, Asplund, & Astrom, 1992; Clarke et al., 2002; Kim, Warren, Madill, & Hadley, 1999; Nakara, 1999; Niemi, Laaksonen, Kotila, & Waltimo, 1988). However, two studies found overall QOL was good, but

the domains of health and functioning were compromised (Jaracz & Kozubski, 2003; King, 1996).

In Thailand, Mingkuan (1997) studied stress and coping of elderly stroke survivors at early and late rehabilitation phases and found that stroke survivors had moderate stress at both phases. This study confirmed that the psychological domain of QOL may be affected by stroke. As other chronic illnesses, the goal of care for stroke survivors is enhancing QOL of the survivors, so they can live happy with the illness. The proper intervention needs to be implemented. The intervention should aim at increased QOL, reducing factors that negatively affect QOL, while increasing those that positively affect QOL.

Bay (2001) reviewed 39 studies that focus on QOL of stroke survivors during the recovery process. She found that independence in activities of daily living (ADL), increased functional ability, social support, and health care resources were positively associated with stroke survivors' QOL, but depression was negatively associated. From those findings, it was suggested that to enhance QOL of stroke survivors, nurses must encourage independence in ADL, manage depression, and foster the relationship between family members and the survivors.

Since physical disability is the most important problem of stroke survivors, improving functional ability is one among many nursing activities to enhance QOL of stroke survivors. Clarke, Marshall, Black and Colantonio (2002) reported that elderly living with stroke in the community experienced more restrictions in ADL and reported a lower sense of well-being than elderly living without the effects of stroke.

Depression management is another activity that nurses can implement to assist the survivors to improve QOL. As reported in many studies, among many

psychological reactions found in stroke survivors, depression is the most common (Sathirapanya, Silpasuwan, Phanthumchinda, & Poomriew, 2002). Depression reflects decreased psychological well-being. It also affected QOL of stroke survivors by decreasing their ability to perform ADL (Ahlsio et al., 1984).

Furthermore, it has been reported that perceived social support is one of many predicting factors of QOL after stroke (King, 1996). Family members are another resource that can help the stroke survivors improving their QOL. After going back to the community, stroke survivors have to cope with irreversible changes in their lifestyle. Families are important in helping them adjust to these changes.

According to the study by Dewey and colleagues, among 3-month stroke survivors, 74% required assistance with ADL and received informal care from family or friends (Dewey et al., 2002).

In the literature there are some studies conducted to investigate the proposed intervention in chronic illnesses such as heart disease, lung disease, arthritis, cancer, and spinal cord injury (Fisher & Watters, 2005; Lorig et al., 1999; Lucke, Lucke, & Martinez, 2004; Michalsen et al., 2005; Scott, Setter-Kline, & Britton, 2004; Wyatt, Donze, & Beckrow, 2004). The strategies used in those studies were education,

behavioral modification and cognitive intervention. Many studies used educational programs as an intervention (Evans, Matlock, Bishop, Stranahan, & Pederson, 1988;

Fisher & Watters, 2005; Folden, 1993; Johnson & Pearson, 2000; Kareen, Desrosiers, Gauthier, & Carbonneau, 2002; Larson et al., 2005; Lorig et al., 1999).

Regarding stroke, many studies investigated effects of interventions on QOL and related factors. Some studies were conducted by nurses while others were conducted by other health care professionals. Moreover, some interventions focused

on caregivers (Evans et al., 1988; Kalra et al., 2004; Larson et al., 2005; Mant, Carter, Wade, & Winner, 2000; Sathirapanya et al., 2002), while others considered only psychological domains (Michalsen et al., 2005). Some used meeting with rehabilitation programs (Zohar, Zoly, & Heidi, 2004), while others used a telephone intervention (Grant, Elliott, Weaver, Bartolucci, & Giger, 2002; Lucke et al., 2004). The previous studies of interventions for enhancing QOL above demonstrated that health education is still necessary for increasing QOL of stroke survivors (Johnson & Pearson, 2000; Kareen et al., 2002). Education can be done individually and/or in a group, and can be hospital-based, home-based, or community-based.

In Thailand, family is the traditional social institution for the care of the elderly. A nationally representative survey conducted in Thailand in 1986 showed that 77% of the population, aged 60 and older, live with one of their children (Knodel & Debavalya, 1992). The family ties and support from adult children to aged parents are still strong and very prevalent (Jittapunkul, Chayovan, & Kespichayawattana, 2002). In addition, the National Long-Term Plan for the Elderly in Thailand, 1996-2001 also emphasized the informal care provided by the family (Jittapunkul et al., 2002). It is very important to have the family involved in care for the ill elderly.

In Thailand, only one study of an intervention for stroke survivors conducted by physicians was found. That study investigated the effectiveness of an empowerment program intervention, using group process for patients and biofeedback training and skill training for caregivers, in enhancing QOL of ischemic stroke patients in the hospital. It was found that QOL measured by WHOQOL scale in the intervention group began to increase in 4th week, reached a peak level in 12th week, then it decreased again in 24th week (Sathirapanya et al., 2002). Since the

intervention effect lasted only 12 weeks, it is, therefore, necessary to find an intervention that can sustain QOL after 12 weeks, and can holistically enhance all aspects of QOL.

Considering the impact of stroke on the survivors, the significance of health education for enhancing QOL, and the need to have family members' support in care, the investigator believes that a home-based nursing intervention program may help to increase QOL of stroke survivors in communities. This educational program that provides care to both patient and family caregiver at home using teaching, skill training, supporting and counseling methods will improve functional ability, prevent or reduce post-stroke depression in the survivors, and foster a positive relationship between survivors and their family caregivers, which will result in an increase of the survivors' QOL. So far, there is no report of such a nursing intervention program in Thailand.

Therefore, this study aims to test the effectiveness of a proposed home-based nursing intervention program for enhancing QOL of stroke survivors. The study results will provide nurses the information necessary for planning appropriate nursing care to the people living with stroke.

Objectives of the study

The objectives of this study are:

1. To describe the difference in functional ability of stroke survivors between those receiving and not receiving a home-based nursing intervention program.

2. To describe the difference in post-stroke depression in stroke survivors between those receiving and not receiving a home-based nursing intervention program.

3. To describe the difference in perceived social support from family of stroke survivors between those receiving and not receiving a home-based nursing intervention program.

4. To describe the difference in QOL of stroke survivors between those receiving and not receiving a home-based nursing intervention program.

Research Questions

1. Do stroke survivors who receive a home-based nursing intervention program report better functional ability than those who do not receive the intervention?

2. Do stroke survivors who receive a home-based nursing intervention program have lower depression than those who do not receive the intervention?

3. Do stroke survivors who receive a home-based nursing intervention program report higher perceived social support from family than those who do not receive the intervention?

4. Do stroke survivors who receive a home-based nursing intervention program report a higher quality of life than those who do not receive the intervention?

Scope of the Study

This study was conducted in the stroke survivors who were discharged from a hospital within one year of their stroke. The stroke survivors were recruited from several hospitals in Chiang Mai province namely, Maharaj Nakorn Chiang Mai Hospital, Neurological Hospital, Nakorping Hospital, and McKane Rehabilitation Center between May 2004 and June 2005.

Definition of Terms

Quality of life is defined as subjective perceptions of the level of impact of stroke on individual health and life that cover eight domains including strength, hand function, mobility, activities of daily living, emotion, memory, communication, and social participation. The Stroke Impact Scale (SIS) developed by Duncan et al. (1999) was used to measure quality of life of stroke survivors.

Functional ability is defined as the ability to perform basic activities of daily living, including feeding, moving from chair to bed and return, grooming, transferring to and from a toilet, bathing, walking on level surface, going up and down stairs, dressing, and continence of bowels and bladder. The Barthel Activity of Daily Living Index (BAI) (Jitapunkul, Kamolratanakul & Ebrahim, 1994) was used to measure functional ability of stroke survivors.

Depression is defined as a disorder that presents with depressed mood, loss of interest or pleasure, feeling of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration (World Health Organization, 2005). This was

measured by Thai Geriatric Depression Scale – short form (TGDS-SF) (Jang, Small, & Haley, 2001; Yesavage, 1988).

Family social support is defined as perceived needs for support, information, and feedback fulfilled by family members including parents, siblings, spouses, children and close relatives of the stroke survivor. This was measured by the Modified Perceived Social Support from Family (MPSS-Fa) Scale, which was modified from Procidano and Heller's Perceived Social Support from Family (PSS-Fa) by Xiaoying (Xiaoying, 1999).

A Home-based Nursing Intervention Program is defined as deliberative cognitive, physical, or verbal activities that the investigator performed with individuals and their families at their home. These activities were directed toward accomplishing particular therapeutic objectives relative to individuals' health and well-being (Grobe, 1996). This program is an educational program which includes teaching, skill training, supporting and counseling methods.

Stroke survivors are persons, aged 45 and over, with a diagnosis of stroke who have been discharged from hospital within one year of their stroke.

Family caregivers are family members of stroke survivors providing care for the survivor during the post discharge recovery phase at home.