CHAPTER 1

INTRODUCTION

Background and significance of research problem

Strokes are a major cause of disability in many countries. Each year, strokes strikes approximately 550,000 people in the United States, claiming the life of about 150,000 of its victims and leaving more than 300,000 disabled (Mower, 1997). Since 1995, more than 3,000,000 people are currently stroke survivors in the United States, 25% of them are left with permanent mental and functional disabilities resulting in the need for assistance with the activities of daily life (ADLs) (Mower, 1997).

The incidence of strokes in the People's Republic of China (PRC) is among the highest in the world (Cheng et al., 1995; Stegmayr et al., 1997). The 1986 PRC National Stroke Study reported that the stroke incidence was 115.6 per 100,000 with a stroke mortality of 81.88 per 100,000 (He, Klag, Wu, & Whelton, 1995). Each year, more than 1,000,000 residents of the PRC die from strokes (WHO, 1994). Of individuals who survive strokes, 60-80% will be left with some form of disability (The 1986 PRC National Stroke Survey, cited in Su & Meng, 1994). Shanghai is the biggest city in China with a resident population of over 13 million

(The census of resident population in Shanghai, 1992, cited in Song, 1997). According to the 1986 PRC National Stroke Study, the stroke incidence of Shanghai is 144.85 per 100,000 and the mortality of strokes is 138.63 per 100,000 (He et al., 1995).

After a stroke attack, the stroke survivors will be affected with various physical and psychosocial consequences. Most of the stroke survivors have physical disabilities such as immobility and limitation to perform ADLs, which make them more dependent on others. It is estimated that 80% of stroke survivors have mild to moderate disability (American Heart Association, 1991, cited in Chipps, Clanin, & Campbell, 1992). If they don't do any exercises, practice some activities and perform ADLs to improve their functional ability, the stroke survivors with physical disabilities are at a high risk for various complications such as: skin breaks, urinary tract infections, and painful shoulders (Davenport, Dennis, Wellwood, & Warlow, 1996). The survivors are susceptible to recurrent strokes because of many risk factors such as hypertension, cardiac disease, cigarette smoking, and consumption of alcohol (Goldberg & Berger, 1988). The stroke survivors may also lose their work, recreational and social activities, which could make them financially dependent on their families and experience a feeling of loss of control, long-term depression and social isolation

(Goodstein, 1983; Kelly & Winograd, 1985; Miller, 1992; Neimi, Laaksonen, Kotila, & Waltimo, 1988). These physical and psychosocial consequences make the stroke survivors unable to meet their increased need to regain mobility and functional ability, control over risk factors, and overcome the feelings of loss of control. As a result, the stroke survivors who are affected by mild or moderate disabilities may need life-long self-care.

Orem (1995) defined self-care as "the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" (p. 104). Whether self-care is performed or not depends on the individual's capability, called self-care ability, to perform the necessary actions in order to meet the therapeutic self-care demand (Orem, 1995). Therapeutic self-care demand stands for the sum of the self-care measures required to meet the specific self-care actions of a person at a point in time. Self-care ability is the complex acquired ability to meet one's continuing requirement for care that regulates the life process, maintains the integrity of human structure and functioning, and promotes human development and wellbeing. According to Orem (1995), self-care ability is conceptualized as a hierarchal three-part structure. The first part refers to general abilities of the person that are not specific to engagement in self-care, which are called foundational

capabilities and dispositions. The second part refers to abilities that are generally enable one to engage in self-care operations and are referred to as the power components. The third part refers to abilities that relate directly to performing the operations of self-care. Evers (1986) viewed self-care ability as the power of an individual to engage in operations that are essential to self-care and proposed that knowledge, decision-making and productive-operations are three important components of self-care ability.

For stroke survivors, the physical and psychosocial consequences may increase their therapeutic self-care demands and decrease their self-care ability regarding knowledge, decision-making and productive-operations. They may need support, information and feedback provided by their social network when they perform self-care.

Family has been cited as one of the most important supportive resources for the patients with various chronic diseases such as cancer (Dodd & Dibble, 1993) and diabetes mellitus (Borrow, Avruskin, & Siller, 1985). With emotional support from the family, the patient may develop a feeling of control and be willing to initiate self-care. A supportive family will be active in searching for information and providing feedback for the patient regarding self-care. The information may be important for the patient to judge their conditions of oneself and environment, and decide what to do. According to Orem (1995), the

individual's ability to engage in self-care is influenced by basic conditioning factors. The family system is considered one of the basic conditioning factors that condition the development of self-care ability. Therefore, social support from the family could influence the self-care ability of stroke survivors in their long-term self-care.

In China, the reform of the health care delivery system is ongoing with changes of medical care. The family will need to pay at least 20-30% of the total medical expenses (Huashan Hospital Annual Record, 1997). Many insurance companies will not pay for expenditures associated with chronic illness or other disabilities. If a person needs long-term care within the home, the individual or the family usually pays for associated expenses. Traditionally, most Chinese consider family as their greatest source of support, especially when they get ill. Usually, stroke survivors are discharged from the hospital to return home with various types and different levels of disabilities. So they may need someone, especially a family member, to take care of them. Whether the support from the family is adequate or not can influence the self-care ability of stroke survivors.

After reviewing the literature, no study has been found in China on the relationship between the family social support and self-care ability, especially in stroke survivors. Because of the high rate of stroke survivors

with permanent disability, family social support and self-care ability are two important factors for stroke survivors in a life-long recovery. A study of family social support, self-care ability, and the relationship between family social support and the self-care ability of stroke survivors could provide knowledge in the area of nursing care for stroke survivors.

Objectives of the study

There were three objectives of the study:

1. To describe the self-care ability of stroke survivors.

2. To describe the family social support perceived by stroke survivors.

3. To determine the relationship between family social support and self-care ability among stroke survivors.

Hypothesis

There is a relationship between family social support the and self-care ability of stroke survivors.

Scope of the study

The study was aimed at investigating family social support and the self-care ability among stroke survivors. Data was obtained from the Outpatient Department of Neurology, Huashan Hospital and Zhongshan Hospital, Shanghai

Medical University, Shanghai, the People's Republic of China. The data collection was conducted during a four months period from November 1998 through February 1999.

Definition of terms

Family social support: Perceived needs for support, information, and feedback fulfilled by family members including parents, siblings, spouse, children and close relatives. This was measured by the Modified Perceived Social Support from Family (MPSS-Fa) Scale modified from the Perceived Social Support from Family (MPSS-Fa) Scale of Procidano and Heller (1983).

Self-care ability: An individual's capabilities and characteristics that are essential for performance of self-care activities, consisting of knowledge, decision-making, and productive operations of post-stroke self-care. This was measured by the Modified Appraisal of Stroke Self-care Ability (MASSA) Scale modified by the

investigator from the Appraisal of Self-care Agency (ASA) Scale of Evers (1986).

Stroke survivor: A person with mild or moderate physical disability measured by the Barthel Disability Score, who is cared for by his/her family members in the post-stroke period.