CHAPTER 1

INTRODUCTION

Background and Significance of Research Problem

Stroke is a major cause of death in many countries. It is the third leading cause of death in the United States. There are approximately 500,000 cases of stroke each year; of these, 15,000 are fatal (American Heart Association, 1991 cited in Hickey, 1997). Stroke is common in the American aged 65 years and older, and women account for 40% of the new cases (American Heart Association, 1988 cited in Hickey, 1997). At the moment, there are over 3 million persons with stroke alive in the United States (American Heart Association, 1992 cited in Hickey, 1997). In China, stroke was the second most common cause of death in urban residents and the third leading cause of death in rural residents (WHO, 1994 cited in He, Klag, Wu & Whelton, 1995). In 1986, the People Republic of China (PRC) National Stroke Study reported that the overall annual aged-standardized incidence and death rates in the general population of PRC were 115.6 and 81.88 per 100,000 persons, respectively. In Hunan, which is a province in the southern part of China, the incidence and death rates from stroke were much higher, being 141.15 and

86.20 per 100,000 persons, respectively. High prevalence of alcohol consumption and high density of population in Hunan province might be the relating factors (He, et al, 1995). At Division of Neurology, Xiangya Hospital, there were 203 stroke cases from November, 1997 to February, 1998, and estimatedly 80% of discharged stroke patients and their caregivers came to the Outpatient Department of Xiangya Hospital (Xiangya Hospital Statistics, 1997, 1998).

Stroke or cerebrovascular accident (CVA) occurs when a cerebral blood vessel is occluded by a thrombosis or embolus, or when cerebrovascular hemorrhage occurs. Both mechanisms result in ischemia of the brain tissue normally perfused by the occluded or damaged vessel (Clipps, Clanin & Clampbell, 1992). Once the patients have stroke, they can not be completely cured. The disease will result in many consequences which affect not only the patient himself but also the family members and relatives. Effects on each individual patient may be physical, psychological, social, and economical. Physical deficits that occur with stroke depend on the area of the damaged brain as well as the side of the brain. The most common focal signs and symptoms include contralateral paralysis or hemiplegia, contralateral sensory loss, dysphasia or aphasia, spatial-perceptual problems and contralateral homonymous hemianopsia (Black & Matassarin-Jocobs,1993). Hemiplegia, either left or right side will decrease physical activities and capabilities to perform activity of daily living (ADL). It has been reported that the activities that the stroke patient needs help most often were bathing, climbing stair, dressing and feeding (Wilkinson, et al, 1997).

Because of the dependence, feeling of loss of control, and brain emotional controlling dysfunction, most of patients have psychological problems such as depression, anxiety, agitation, oversensitivity, tearful, personality disorder, and irritability (Willcock, 1986). These psychological problems will in turn decrease the patient ability to take care of him/herself resulting in a high dependence on caregiver. It was found that changes in patient's mood and personality are often related to serious effects on the lives of the caregivers (Coughlan & Humphey, 1982 cited in Anderson, 1992). Besides, the loss of the patients as an active social partner and demands of the patients which reduce the time and energy available for social activities and disrupture of their leisure time may be important causes of problems and distress for stroke patient caregivers (Anderson, 1992). Furthermore, when the patients are hospitalized, a lot of diagnostic procedures and treatments are performed which cost a lot of money. In China, the cost of stroke care ranges from 480 to 3500 US dollars during hospitalization period (Xiangya Hospital Cost

Statistics, 1997). Those who work for the government can get total or partial reimbursement, but for those who had retired from work and did not have enough income, the payment will be on themselves or be the responsibility of his family members which certainly, put them into financial pressure.

In China, normally, the stroke patient will be hospitalized for 20 days and will be discharged after that. A few patients whose payment can be reimbursed or those who are quite rich will be admitted to sanatorium or aging hospital for further treatment and rehabilitation ranging from 10 days to 6 months. The stroke patients who are discharged from hospital usually have one or more physical and psychological problems. These patients, therefore, have some limitation in taking care of themselves, even in ADL activities. Furthermore, most patients cannot earn enough money for their living while needing more living expenses. These patients have always been taken care of by their spouse, child, daughter in law or grandchild. These caregivers, therefore, have to take all responsibilities in helping the patient meet the physical, psychological and socioeconomic demands. Dealing with the patient physical and psychological problems for a long time may ultimately lead the caregivers to unacceptably high level of pressure or burden. Besides, as previously mentioned, the caregivers have also been facing high financial strain for a long time.

Therefore, stroke patient caregivers in China might be facing burdensome events similar to those in other countries.

Burden is the feeling of load or pressure imposed on the person. Montgomery, Gonyea and Hooyman (1985) viewed burden objectively and subjectively. Objective burden is defined as the extent of disruptures or changes in various aspects of the caregiver's life and household because of caregiving. It is related to the task or activities with which the caregiver is involved. Subjective burden is defined as the respondent attitudes toward or emotional reactions to the caregiving. Because of disease consequences on patient, the stroke caregivers seem to have a lot of objective burden and experience some subjective burden. In Anderson Greenwish Stroke Study (1992), the caregivers reported the effects of stroke on their lives including social activity restriction (42%), leisure activities limitation (36%), financial restriction (26%) and problems for other family members (27%). A longitudinal community-based 3-year follow-up study of 35 consecutive primary stroke patients and their caregivers in Sweden, using New Caregiver Burden Scale, showed that most stroke patient caregivers felt exhausted, strain and overload in a long-term caregiving for the patients (Elmostahl, Malmberg, Annerstedt, 1996). Besides, caregiver's time was spent on taking care of the patients, some caregivers isolated themselves from social activities and felt frustration, resentment, impatience and distress (Anderson, Linto & Stewart-Wynne, 1995). The burden, even objective or subjective, negatively or directly affects the caregivers. Their physical, psychological, and social well-being will be decreased. Furthermore, caregiver's burden will indirectly affect the patients. The quality of patient care will be decreased because the caregiver is not in a well condition. Thus, to understand and to reduce the caregiver burden are necessary and should be emphasized among nurses.

According to Bull (1990) and Stuckey, Neundorfer and Smyth (1996), there are many factors predicting caregivers' burden among which social support is a very important one. According to Weinert and Brandt (1987), social support was defined as relational provisions from others 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. Social support through social attachments with family and friends has been shown not only to directly affect psychological adjustment but also to provide a buffer that helps to moderate the detrimental effects of life stress on person health and well-being. (Lynch, 1998).

Since the caregivers always reported exhaustion, strain, overload, and financial constrains in a long-term caregiving for the stroke patients, they need a relieve for each particular problem. Normally, caregivers need a tangible assistance with ADL and household responsibility as well as financial assistance to reduce the detrimental effect of burden. Furthermore, since the caregivers also experience isolation, frustration and distress, it is obvious that they need an emotional support as well. By giving them time off, the caregivers can participate in some recreational activities that they enjoy and the burden will be reduced. The findings from studies of social support to caregiver conducted in the United States suggested that the caregiver burden might be relieved by provision of respite care, use of personal aides services (Montgomery et al, 1985), use of spiritual support and extended family (Pratt, Wright, Schmall & Cleland, 1987). Caregivers who had lower social support were high risk to psychological distress (Baillie, Norbeck, & Barnes, 1988). Therefore, various interventions based on social support concept had been developed to reduce caregiver's burden which included a visit by a specialist outreach nurse, long-term counseling, and support group participation (Foster & Young,1996; Fried & Mccoll, 1992; Mittelman,1995). To conclude, social support is beneficial for the caregivers.

As previously stated, burden is a major problem for the stroke patient caregivers which will negatively related to social support. Therefore, nurse who takes care of the patients and their caregivers should reduce the caregivers' burden by enhancing their social support. Nursing care plan for these particular people should be based on the information about social support. In China, even though stroke patients are increasing in number and the caregivers are facing with more burdensome events similar to those in other countries, the information about burden and social support is not available. Therefore, this study was be conducted to describe the level of social support and stroke caregiver burden and to ascertain the relationship between these two variables. The result of the study will be available as database for nurse to provide necessary supports for stroke caregiver which hopefully will decrease the caregiver burden.

Objectives of the study

1. To describe the level of social support of stroke patient caregivers.
2. To describe the level of burden of stroke patient caregivers.
3. To ascertain the relationship between social support and burden of stroke patient caregivers.

Research Questions

1. What was the social support level of stroke patient caregivers?

2. What was the burden level of stroke patient caregivers?
3. Is there any relationship between social support and burden of stroke patient caregivers?

Hypothesis

There was a negative relationship between social support and burden of stroke patient caregivers.

Scope of Study

This study was conducted among 50 primary caregivers of stroke patients who attended Outpatient Department in Xiangya Hospital of Hunan Medical University, Changsha, China, during the period of November 1998 to January 1999.

Definition of terms

Stroke patient Caregiver the person who is accepted by patients or other caregivers as the one who takes care of the stroke patient most of the time, who may be either the patient spouse or adult child or adult grandchild or daughter in law.

Burden personal reaction to caregiving and effects of caregiving to stroke including objective and subjective aspects. Objective burden is defined as the extent of disruptures or changes in various aspects of the caregiver life and household. Subjective burden is as the respondent attitudes toward or emotional reactions to the caregiving experience (Montgomery, Gonyea & Hooyman, 1985) operationally measured by the Burden Scale developed by Montgomery, Gonyea and Hooyman (1985).

Social support The perceived relational provisions from othersby caregivers for attachment/ intimacy, social integration, opportunity for nurturance, reassurance of worth as an individual and in role accomplishments, and the availability of informational, emotional and material help (Weinert & Brandt, 1987) measured by Personal Resource Questionnaire-85 (PRQ-85) Part 2 developed by Weinert and Brandt (1987) and revised by Yan (1997).