CHAPTER 1

INTRODUCTION

Statement and Significance of the Problem

Worldwide, stroke is the second leading cause of death and is the leading cause of disability among adults in the U.S. Every 45 seconds, approximately one person has a stroke (The university hospital, 2005). When it occurs, it can affect sensory, motor activity, memory, emotions, speech and ability to understand speech, behavioral and thinking patterns. However, medical technology for the treatment and nursing care of stroke patients has recently advanced. Thus, stroke patients now have an average life expectancy of 5 to 10 years following a stroke (Broderick et al., 1998). Most recovery occurs within six-months, but can extend to one year (Grant, 1996; National Stroke Association [NSA], 1992). As a result, neurological impairments such as these, can be permanent and progressive, which limit long-term survivors' ability for self-care, employment and social activities. (Becker, 1993; Tengs, Yu, & Luistro, 2001).

More than 4 million people in the United States have survived a stroke and are living with the after-effects (Wallace, Duncan, & Lai, 2002). Of the survivors, only 10% recover almost completely while 65 % experience minor to severe impairments and require long-term care (The university hospital, 2005). In Thailand, the number of stroke victims each year increased from 58,366 in 2000 to 84,804 in 2003. As expected, in Northern Thiland, the number also increased from 15,583 in 2000 to 24,595 in 2003 (Thailand Ministry of Public Health, 2004). Thus, continued care is vital as the number of stroke survivors continues to increase.

Four of five families will somehow be affected by stroke over the course of a lifetime. Care of a person with disabilities in the home becomes a greater responsibility of

the family due to the shorter length of stay in health care settings and the emphasis towards community care. Hence, families become quite significant when providing long-term care for stroke survivors at home. The family is an open system and functions as a unit. A change in an individual's capacity as a result of a stroke will effect the entire family in a variety of ways, based on who the stroke survivor is and their previous role in the family. Consequently, family dynamics may need to be altered (Dewey, 2002).

In the past decade, studies on stroke and primary caregivers, in both the west and Thailand, (For example, Anderson, Linto, & Stewart-Wynne, 1995; Bendz, 2000; Natechang, 2002; Sangboon, 2002; Thipsamniag, 2002) show that families caring for stroke survivors at home were affected in a variety of ways such as suffering the loss of a family member, feeling frightened, burden or overwhelmed by their responsibilities, and economic problems. However, these studies were conducted among the acute post-stroke patients and primary caregivers. As Astedt-Kurki (2001) noted that data collection from one family member are usually not enough to describe the entire family because one respondent gives his or her own point of view, which cannot fully represent the quality or reality of the family system. Family involvement becomes even more important when stroke survivors require long-term care. But, insufficient attention has been paid to what other family members have to say and how they provide long-term home care for stroke survivors.

Families rooted in different cultural and socioeconomic milieus also have differing interpretations of the meaning and significance of a particular illness (Shapiro, 1983). Studies on caring for stroke survivors in Thailand indicate that apart from negative experiences of family caregivers, family members cared for the survivor with love, gratefulness, compassion, and preferred caring at home, which was especially noted among Thai families (Natechang, 2002; Sangboon, 2002; Thipsamniag, 2000). Moreover, the data reflected that Buddhism, social norms and the socio-economic context play a significant role in Thai families and caregiving for ill family members (Kespitchayawatana, 1999; Sethabouppa, 2002). Nevertheless, Thailand is rapidly undergoing modernization and change in Thai society, such as industrialization, migration, and decreased fertility are

expected to affect Thai family structures as well as traditional family practices for chronically ill patients at home (Tussri, 2002, pp.12-13). These changes may inevitably affect families who continue to take full responsibility for family members with the long-term consequences of stroke.

Further, as stroke survivors increase, so too do their needs. The Northern region is high rate of patients with cerebrovascular disease, followed by the Central region (excluding Bangkok) (Thailand Ministry of Public Health, 2003). Chiang Mai Province is Thailand's second largest city. Although no epidemiological studies have been conducted for stroke patients in Chiang Mai, approximately 30 patients received follow-up care and 50 received rehabilitation at the neurological clinic of Maharaj Nakhon Chiang Mai Hospital (manually calculated from records by researcher between January and June, 2002). Thus, suggesting that stroke survivors live at home. Chiang Mai society represents a mixture of both modern and traditional Thai society. Its inhabitants are mostly Buddhists, and family is a value that is held high. Thus, family members who are ill, including long-term stroke survivors, are provided care. According to the researcher's pilot study (2001), long-term stroke survivors in Chiang Mai were cared for by family members at home. Family members were responsible for providing care even though they worked full-time and did not live with the stroke survivor. Even so, long-term care for a stroke survivor burdened the family, they regarded caregiving as an obligation, fulfillment of a social expectation, a sense of duty, and as the family's Karma. However, the findings were limited by sample size and also the primary caregivers. As a consequence, data were insufficient to explain the breadth of the entire family experience.

To facilitate understanding of family experiences in long-term care of a stroke survivor at home, an ethnographic approach is deemed as an appropriate method. This qualitative methodology aims to describe how people live their daily environment, and their beliefs and customs that influence their thoughts and behaviors (Muecke, 1994). Therefore, findings derived from this approach hope to gain better description of how families in Chiang Mai provide long-term care for stroke survivors. In addition, the result will also

provide essential information for health care providers and policy makers to develop health care services for families providing long-term care for stroke survivors at home.

Objectives of the Study

The aim of this study was:

1. to explore experiences of families with long-term stroke survivors in Chiang Mai.

2. to explore how families with long-term stroke survivors in Chiang Mai manage their family.

Research Questions

1. What were experiences of families with long-term stroke survivors in Chiang Mai?

2. How did families with long-term stroke survivors in Chiang Mai manage their family?

Significance of the Study (expected benefits)

The findings of this study expect to give health care providers a better understanding of how to care for families with a long-term stroke survivor. Further more, to encourage the development of health policy for families that care for long-term stroke survivors at home.

Definition of Terms

Terms were defined as follows:

Family: a self-identified group that is made up of at least two persons who may or may not be related by birth, adoption, or marriage, may or may not live under one roof, but share experiences in relation to providing care for long-term stroke survivor.

Stroke survivor: a person with a stroke for at least one year, has physical disabilities, and required care from family.

Scope of the Study

This study intended to better understand how families in Chiang Mai provide long-term care for stroke survivors at home.