

## CHAPTER 1

### INTRODUCTION

#### **Background of the Study**

Stroke, or cerebrovascular accident is the second most common cause of death worldwide, accounting for more than 4.6 million deaths, of which two-thirds are in developing countries (World Health Organization, 1997), where stroke is still a major health problem. In ASEAN countries stroke is the four leading causes of death (Venketasubramanian, 1998); according to the Seamic Health Statistics (1999), strokes in Brunei, Malaysia and Singapore were the third or forth leading causes of death.

The most common risk factors of stroke in Indonesia are hypertension, heart disease, cigarette smoking, and diabetes mellitus (Misbach, 2001). Other risk factors include a previous history of stroke, obesity, an inactive life style, and hyperlipidemia (LeMone & Burke, 2000). Aging is also a major risk factor, and most stroke patients are more than 60 years old (Department of Health West Java Province, 2000). The increasing number of elderly stroke victims is also related to the increasing life expectancy of Indonesian people. In 1999, the life expectancy was 64.2 years old, which had increased to 65.6 years by the year 2,000, and is projected to reach 68.23 years old by the year 2005 (Department of Health West Java Province, 2000). Thus considering the risk factors noted above, in combination with the increasing number of elderly people due to increasing life expectancy. Thus, the number of stroke victims expects to be increase.

Stroke is a disease that usually carries long term consequences, in terms of long term physical disability, psychological, social, and spiritual effects (Sandin, Cifu, & Noll, 1994; Buscherhof, 1998; King, Carlson, Shade, Bares, Roth, & Heinemann, 2001). Physically, the stroke can lead to neurological symptoms or deficits (LeMone & Burke, 2000). A study conducted by Misbach, (2001) identified stroke in Indonesia and found that the most frequent stroke symptom was motor disability. Stroke disturbs the centers for thought, recollection, reasoning, feeling, communication, language, movement, cognition and memory (both short and long term), and character (Reeves, Roux, & Lochart, 1999; Gibbon, 1994). The common physical problems associated with stroke are loss of consciousness or drowsiness, hemiplegia, difficulty with balance and mobility, dysphagia, incontinence of urine, and sexual dysfunction (Kimura, Murata, Shimoda, & Roninson, 2001). These deficits and difficulties lead to various problems in most stroke survivors, such as bed sores, immobility, and limitations in performing activities of daily living (Dobkin, 1999).

The physical problems of the stroke patients usually influence their psychological dimension as well. Gibbon (1994) studied rehabilitation after strokes and found that the stroke survivors had disturbances relating to perceptual problems, a tendency to depression, and emotional instability. In addition, Fuh, Liu, Wang, Liu, and Wang (1997) studied post-stroke depression among the elderly in a rural Chinese community and found that a depressed mood was common after strokes, and inability to perform simple daily activities was strongly linked to a higher likelihood of depression in stroke survivors. In another study, Hayee, Akhtar, Haque, and Rabbani (2001) studied depression after stroke in 297 stroke patients and found that depression was common among stroke survivors at the third month, and the rate did not decrease

at a 1-year follow-up. Also, stroke-related physical and social disturbances could lead to depression and poor emotional relations within five years (Kivela, 1994). These findings show that the psychological state of stroke patients is often disrupted following their stroke.

The impact of the stroke can also have a negative impact on the social activities of stroke survivors. A study conducted by Clarke (1999) revealed that disability and depressive symptoms restricted the life activities of stroke survivors in the first year following their stroke. Dowswell, Lawler, Young, Forster, and Hearn (2000) conducted a study to investigate recovery from strokes, and they found a deterioration in the social lives of a majority of the respondents.

The spirituality of the stroke survivor also often changes, which is related to the other changes of their physical, psychological, and social life. These changes vary depending on the individual's theology, religious traditions, or philosophical understanding of the meaning or purpose of life (O'Brien, 1999). Some stroke survivors perceived that after their stroke they had negative changes in spiritual integrity, relating to their feelings of hopelessness, depression, dependency on others, and powerlessness (Hafsteinsdottir & Grypdonck, 1997). Many other stroke survivors, however, view the stroke as a part of their life, and become encouraged to reexamine their spiritual life, promoting spiritual growth and development (Robinson & Smith, 2002).

Stroke survivors often encounter problems following the stroke such as physical, psychological, social and spiritual problems in their daily lives and these problems lead the stroke survivors to develop their own coping mechanisms. If they have a positive coping mechanism to solve the new problem, they can survive the

stroke, but if they do not have the right internal resources to deal with the aftermath of the stroke, recovery can be more difficult. A good health care system can contribute positively to this process (Mitchell & Moore, 2004).

As health care providers, nurses require an understanding of the varieties of lived experiences, which arise from persons telling their descriptions of experience life events (Munhall, 1994). In order to build nursing care plans to assist stroke survivors solve their problems, the lived experience must be explored and revealed, especially in the community. Nowadays, most stroke patients prefer to live in their own home with their family rather than stay at a hospital. Thus, knowledge and understanding about the lives of the stroke survivors becomes important to help them adapt to their disability, prepare them for discharge planning, and continue their rehabilitation programs. In order to describe the lived experience of stroke survivors, phenomenological study is useful to gain a deep understanding of being a stroke survivor. The method investigates subjective phenomena in the belief that essential truths about reality are grounded in lived experience (Spiegelberg, 1965 cited in Streubert & Carpenter, 1995).

There have been many previous studies about strokes patients. Most of them were from western countries and using a quantitative approach. Mostly investigated the physical aspects of strokes (i.e. Wagenaar et al. 1990; Salter et al. 1991). Several focused on the lived experiences of patients using a qualitative approach. For example, one ethnographic study demonstrated a recovery path for stroke victims (Doolittle, 1992). A study conducted by Folden (1994) built on the understanding of the lived experience of stroke patients, and suggested that many stroke patients faced difficulty in returning to their pre-stroke life. A study undertaken by Haggstrom,

Axelsson, and Norberg (1994) attempted to elicit both the experience and future expectations of people living with stroke. Burton (2000) studied about living with the aftermath of a stroke and found that recovery from strokes involved adaptation in the physical, social and emotional aspects of an individual's life.

However, there have been few studies on the lived experience of stroke survivors at home, especially in an Indonesian setting. Many studies related to patient with stroke have been done in Thailand (i.e. Meuntip, 1994; Kenchaiwong, 1995; Jullamate, 1997; Hirunchunha, 1998; Chantawatchai, 1999; Kasriwong, 2001). Most of them focused on factors related to the stroke patients, and their families and/or caregivers. Few focused on adaptation in stroke patients. One study was undertaken by Kasriwong (2001), examined adaptation in stroke patients using a qualitative method based on Roy adaptation model (1964) and found that most of the patients had effective adaptive behaviors such as maintain good health, nutritional pattern, routine activity, regular exercise, a normal sleep pattern, effective sensitivity and role performance, and stable giving and receiving. Her study, however, focused only on the adaptation process and did not include the whole lived experience of the stroke survivors. Moreover, there are differences among western cultures, Thai culture, and Indonesian culture in terms of custom or tradition, and culture influences an individual's experience (Andrews & Boyle, 1995).

In the Indonesian culture, most people are Muslim. Muslim beliefs and culture influence their behavior and coping patterns. These beliefs, for instance, when someone gets sick, she or he will link the disease with God. According to Lev (1992), prayer is one specific strategy that can improve coping, and reduce stress. In the Muslim tradition, when a family member suffers a disease, all of family members

have a responsibility to take care of the patient. Muslim stroke survivors preferred to live with their family members within their beliefs. The Muslim religion influences to the stroke victim, in contributing to their acceptance of their role as a caregiver of a sick person, such an activity being seen as a good deed. Also, seeking available health services to assist in healing the disease is obligatory. In this way, different cultures and religions will influence the different points of view about the meaning and experience related to the disease. Moreover, the health care management systems in developing countries are different from those in developed countries, and affect a patient's adaptation and recovery after having a stroke.

To add more information to the matters discussed above, in an Indonesian setting, the study on the lived experience of stroke survivors was conducted in Bandung, Indonesia, to gain insight and understanding of what the experience is like for Muslim stroke victims, within their culture and religion. Such understanding will help nurses to manage the nursing care system and services that are appropriate for stroke patients in a holistic way, dealing with not only the physical aftermath of the stroke, but also being attentive to the psychological, social, and spiritual dimensions. Such information will also be useful in discharge planning, helping to adequately prepare the stroke patients for their return back to their home.

### **Research Objectives**

The objectives of the study were:

- 1) To describe meanings of being a stroke survivor.
- 2) To describe feelings of being a stroke survivor.
- 3) To describe impacts of the stroke on the stroke survivor's life.

- 4) To describe needs of a stroke survivor

### **Research Questions**

- 1) What does being a stroke survivor mean to the stroke survivor?
- 2) What are the feelings of being a stroke survivor?
- 3) What are the impacts of the stroke on the stroke survivor's live?
- 4) What are the needs of a stroke survivor?

### **Definition of Terms**

“Lived experience” refers to the past experiences that can be recalled by the stroke survivors. These experiences involve meanings of being a stroke survivor, feelings of being a stroke survivor, impacts of stroke on the stroke survivor's live, and needs of the stroke survivor.

“Stroke survivors” are stroke patients who have survived from a first stroke, and have returned home from the hospital. They have been in the recovery phase from the stroke at least three months.

### **Significance of the Study**

The study explored the experience and the meaning of being a stroke survivor during the recovery phase at home with the stroke survivor's family members. The researcher expects that the findings of the study will be beneficial: (1) for stroke survivors and their families, the findings can gain a better understanding about lived experiences in order to help the stroke survivors face their limitation/disability and/or psychosocial problems; (2) for nursing education, the research findings will be a source of knowledge, specifically help nurses and students have a better

understanding of stroke survivors in West Java province of Indonesia; (3) for general nursing practice, the findings can be used as a reference for nurses to develop better discharge planning for stroke patients; and (4) for nursing research, the research findings will be useful for baseline data for further research related to stroke survivors, especially for studies concerned with factors related to recovery after stroke.

### **Conceptual Framework**

Hermeneutic phenomenology was used in this study to explore the lived experiences of stroke survivors at their homes in Bandung, Indonesia. Hermeneutic phenomenology is a special kind of phenomenological study, designed to unveil otherwise concealed meaning in the studied phenomena (Spiegelberg, 1975, cited in Streubert & Carpenter, 1995). Hermeneutics uses the lived experiences of people as a tool for better understanding the social, cultural, political, and historical context in which those experiences occur (Polit, Beck, & Hungler, 2001).

The scope of the study included exploring the lived experience of stroke survivors at home regarding their experiences after the stroke in relation to their lives before the stroke. The lived experiences of stroke survivors related mainly to their meanings, feelings, impacts, and needs after they returned home to stay with their families. The concept of stroke was reviewed in order to gain understanding about stroke survivors. Several topics related to stroke patients in the context of the Indonesian situation were reviewed, such as management and rehabilitation of stroke victims, in order to guide the interview questions and to be sure the researcher was able to look at the stroke patient as a whole person.