

## CHAPTER 5

### CONCLUSIONS AND RECOMMENDATIONS

This final chapter is presented in two parts: summary of the study, and recommendations.

#### Summary of the Study

This hermeneutic phenomenological study was conducted to explore the lived experiences of stroke survivors in Bandung, Indonesia. Ten stroke survivors who met the selection criteria were enrolled in the study from the outpatient neurological clinic of Hasan Sadikin Hospital, Bandung. Data collection was done from November 2003 to April 2004 using in-depth interviews at the participants' homes. The instruments included a demographic data record form, interview guide, and the Barthel Index assessment. Descriptive analysis was applied to the demographic data while the van Manen method was used as a guide to analyze the ten transcribed interviews.

In this particular study there were more female stroke survivors than males. The average age was 55.76 years, most were married, with senior high school education. Their occupations before the stroke were housewife, teacher, laborer and retired. Following the stroke, most of them stayed at home. Most had family income between Rp 1,000,000-2,000,000 per month. The time since the stroke ranged from 3 months to 6 years. The majority of their caregivers were spouses and children.

The lived experiences of the stroke survivors at home were drawn and described, and four main themes emerged to describe the meaning of being a stroke survivor: being obedient to the doctor, regressing to childlike status, being under

supervision and assistance, and being tested from God (Allah). The experience of having to obey the doctor was the dominant perception of the aftermath of the stroke among these participants, and having to adhere to the medical treatment. The regression to childlike state of dependence was also strongly felt, as the participants perceived that as a stroke survivor they lacked the ability to perform many basic activities required in their daily living. The participants also perceived their post-stroke existence as one of constantly being under supervision and assistance, because they had to be supervised and assisted by someone almost all of the time..

Five main “feelings” themes emerged from the research - uncertainty about hope, being bound at home, dependence on someone, powerlessness, and low self-confidence. The uncertainty about hope was dichotomous, as there was some hope about their eventual recovery, but mixed with uncertainty about the future. The participants keenly felt the restrictions of being bound at home because they could not do the normal activities of daily living by themselves, and were unable to go anywhere freely. The theme of dependence on someone arose because the stroke survivors were dependent on someone to help them conduct many or all of the necessary activities of daily living. The feeling of powerlessness was due to the aftermath of stroke, that there were so many things they could not do for themselves due to their new disability. And the low self-confidence was the result of many factors, perhaps the most prevalent being their inability to even communicate clearly verbally.

The impacts of their strokes resolved into five main themes: being unable to be active, having to adjust to emotional changes, unable to undertake social tasks, failure to fulfill former responsibility, and being growth in spiritual life. The theme of

being unable to be active included the inability to perform common tasks of daily living, memory loss, and sexual dissatisfaction. Emotional changes mainly involved having to deal with pessimism concerning their new problems. Their inability to fulfill their responsibilities weighed heavily on them since their strokes. They all became more deeply involved with their religious practice as a coping method for dealing with the aftermath of the stroke, to help them find peace and acceptance.

The participants described four common themes in terms of the needs of a stroke survivor: informational need, understanding and attention need, joyful/leisure time need, and choices of therapy. The informational need spoke to the inadequacy of information about the rehabilitation, management, and prevention of recurrent stroke they felt they received from the hospitals where they were treated. They also needed understanding and attention from the health providers and the family members as well as they adapted to their changed lives and increased dependency, and they all felt they needed joy/leisure time to allow them to think about ways of enhancing their ability to deal with their new lives. Searching for alternative therapies to augment the hospital care was something they all were interested in.

## **Recommendations**

Based on the findings and discussions of this study, the following recommendations for health care system, nursing education and administration, and nursing research are offered for the following aspects:

### **Health Care System**

The findings of the lived experiences of stroke survivors can be used to help health providers to perform a better quality of care especially to understand how the

survivors construct their views, how they think, act and reflect on their life, and how they feel about the stroke. The recommendations for health care system consist of rehabilitation, prevention, and promotion as follows:

#### (1) Rehabilitation

The health providers should perform this rehabilitation holistically, addressing the physical, psychological, social and spiritual aspects of the patients' life. The doctors and/or nurses should emphasize prayer as good way to solve psychological and spiritual problem particularly for Muslim patients. The prayer also could increase a hope to maintain adherence during rehabilitation. Adequate information about medication, diet, exercise, and prevention a second stroke should be provided for the patients and family members. Attending nurses should prepare an appropriate and adequate discharge plan for stroke patients.

#### (2) Prevention

Community hospital as first prevention of care should perform health services for the stroke survivors proactive. Thus, those stroke survivors who had financial and transportation problems able to have available health services properly. This way the local nurses can help the stroke survivors in maintaining their health, while qualified medical doctors are available at the community hospital if needed.

#### (3) Promotion / home Care.

The involvement and support system from the family members is beneficial to enhance the stroke victim's recovery. The nurses and family members should involve the stroke survivors in the activities of daily living as much as possible. Nurses as well as family members should able to communicate with the stroke victim in order to ease the psychological and spiritual burdens they feel from being bound at home – religion

and/or spiritual practice can help the stroke survivors deal with the psychological and spiritual problems. Also regular exercise and alternative and complementary therapies can be used to help the stroke survivors maintain their health and to enhance recovery from the stroke. Nurses should also be trained to be able to act as counselors for stroke survivors who have sexual and social problems.

### **Nursing Education and Administration**

The findings of this study can be used to suggest recommendations for educators and administrators in nursing to emphasize the role of neurological nurses and for nursing students in the needs of stroke survivors, providing better understanding of the life, and to give a picture of the lived experiences of being a stroke survivor in order to help the patients to regain optimal health. Nurse educators should emphasize the importance of understanding the meaning of being a stroke survivor when caring for these patients. These findings also provide data for nursing administrators to better manage the care of stroke survivors to offer a better quality of life for the stroke survivors in the hospitals.

### **Nursing Research**

This study provides some basic information on the experience of stroke survivors at home. For nursing researchers the results of this study can be used as support evidence or guidelines for developing some programs to enhance and promote the health of stroke survivors, and to provide a new reference for others studying the experiences of stroke survivors. Several recommendations are suggested for further research as follows:

a) This study focused on the stroke survivor's experience. In order to have comprehensive experiences of stroke survivors and their environment, it should be useful to explore the caregiver's experiences of coping during taking care for the stroke patients.

b) There should be a study to explore religious or spiritual practices as coping mechanisms to reduce the psychological and spiritual problems among stroke survivors.

c) It would be useful to conduct a study using action research to develop a care system model to assist stroke survivors in their homes, in order to formulate a standard of care practice, especially in the Indonesian setting.