

CHAPTER 7

CONCLUSION AND RECOMMENDATIONS

Data derived from the study findings including context of families in long-term caring for stroke survivors, family life changes from having a permanently disabled family member, and family management in providing long-term care for stroke survivors are summarized in this chapter. Furthermore, recommendations for healthcare professional and further studies are also presented.

Conclusion

This family research entitled “The experiences of families with stroke survivors in Chiang Mai province” was aimed at exploring the real-life situations of Thai families in Chiang Mai after having to provide long-term care for stroke survivors at home for more than one, including their experiences and management of their family life.

This research was conducted based on family system perspectives and recognized the family as a unit. The ethnographic approach was employed to achieve the goal of the study. Fourteen families participated in this research. Data were collected by the researcher using multiple collecting methods including participant observation, informal interview, and field notes until saturation of data. The completion of all information was examined by using the triangulation method and analyzed by using Spradley's method of analysis. The studying findings were then categorized into three parts; 1. family contexts in caring for stroke survivors, 2. the experiences of families caring for stroke survivors, and 3. family management in providing long-term care for stroke survivors.

As for the family context in caring for stroke survivors, it was found that most of the participating families resided in Muang District. As regards the family's demographic

characteristics, most of the families were characterized as a nuclear or single family, which was composed of three to five persons living together in the same household. On the other hand, when it came to extended families, they had many generations of family members living together under the same roof, with the number of family members ranging from five to ten persons. The family size varied from three to ten family members on average. In addition, every family was Buddhist. Participating family members were mostly female. They were between 19 and 83 years old. The highest level of education of family members was mainly Bachelor's degree or lower. Most of them worked as private business owners, merchants, or employees, if they were not agriculturists. Their average incomes from their occupations ranged from 100-700 baht per day to 6,000-300,000 baht per month. With regard to caregivers, all primary caregivers were females who were 39-67 years of age, and most of them were the wife or daughter of the stroke survivors. Regarding the stroke survivors' characteristics, most of them were males ranging in age from 36 to 92 years, they had cerebrovascular infraction, and the survival period varied from two to nine years. The level of dependency also varied, as six were complete dependents, six were partial dependents, and two could help themselves.

The experiences of families providing long-term care for stroke survivors emerged as family life changes as a result of having a permanently disabled family member and dealing with new family management necessary in providing care for stroke survivors. Changes in family life due to having a permanently disabled family member were divided into two parts: encountering having a disabled family member and handling changes in family life. Encountering having a disabled family member was a family experience after facing unexpected stroke attack, followed by psychological changes of stroke survivors, and finally, acceptance of having a disabled member in the family. Changes in family life included increased family expenses from providing long-term care for stroke survivors at home, decreased family income, decreased family social activities, altered family roles and functions, increased family responsibility of being family caregivers, and increased family cohesion.

Family management in providing long-term care for a stroke survivor at home demonstrated that families adjusted the home environment, learned to live with caring for stroke survivors at home, and took care of the family's health. They adjusted the home environment and made it an appropriate setting for a long-term care of their stroke survivors by modifying the bedroom and toilet and equipping it with medical appliances necessary for stroke survivors. Regarding learning to live with caring for stroke survivors at home, the family adjusted their ways of living, managing stressful situations in the family, dealing with family finances, and re-organizing family roles and functions. Finally, the family took care of the family's health by providing care for stroke survivors' health through learning to take care of stroke survivors at home, care for the survivor's daily activities, and take care of the stroke condition. In addition to the health of stroke survivors, the family also turned to pay more attention to primary caregivers' health, as they had realize the importance of taking care of oneself.

Data derived from this study highlighted the fact that long-term care of stroke survivors at home became a long journey for every family, which required ongoing learning and taking time to adjust to changes that had occurred in the family. It is worth noting here that the research findings were consistent with the family system perspectives, which explain the fact that family is a system composed of sub-systems such as spouse, father-mother and offspring system, relative system, and cousins system. The members of the family have interrelationship roles and functions, which can maintain or loose family's stability. As a result, providing long-term care for a disabled family member affects not only the survivors, but also their whole family. The data also reflected specific characteristics of the Thai family system, which is influenced by internal and external environments of the family, such as Buddhist principles.

Recommendations

The researcher realized that the small purposive family sample did not invite generalization. However, the deep and rich details of the participating families' life experiences that had emerged, shedding light on the experiences of families providing long-term care for stroke survivors at home. Significant suggestions and recommendations are then proposed as follows:

Implications for Nursing Practice and Making Healthcare Policies

Data derived from this study can be applied in nursing practice as follows:

1. Providing continuum of home healthcare services

The findings confirmed the fact that despite the changes in population demographics and dramatic alterations in family structure, size, and functions, families became a primary and effective health resource in caring for a stroke survivor who remained dependent for a long period of time. Most families also appeared to recognize the need to receive continuum of home healthcare. Long-term home care services, in which the family is in partnership with healthcare providers and which is composed of a multidisciplinary team, are needed, be it promotional, preventive, curative, or rehabilitative healthcare.

2. Arranging family nurses

The research results pointed out the importance and the necessity of having family nurses in the Thai healthcare system. Family nurses could be beneficial to all family members by giving continuous and holistic healthcare services to all members in the family whether they stay at home with them or not, promoting and empowering family management of caring tasks and life changes as a result of caring for a stroke survivor. Furthermore, family nurse services should minimize and prevent family health problems

and also reduce the gap between healthcare providers as perceived by the participating families.

3. Developing models or interventions aimed to strengthen family life with caregiving for long-term stroke survivors at home

Nursing interventions to assist families to maintain and improve their family relationships and facilitate their role changes are needed for families caring for long-term stroke survivors at home. For example, creating self-care groups and family support groups are recommended. In addition, particularly for primary caregivers who have to live with stress caused by their long-term caregiver role, additional interventions to reduce the primary caregiver's burden including caregiver education, skill training, and encouragement of other families to participate in caregiving are also helpful. It may be important in boosting morale and preventing conflicts in the whole family.

4. Developing projects or programs for financial support for the families

Not only does the family have to face with permanent lack of family income used to come from the stroke survivors, but the family also has to deal with increasing family expenses due to long-term care of the survivors. Moreover, higher social expenses in the current situation increase the pressure for families caring for long-term disabled persons. These programs should begin with low income families which need more help, and it should be made suitable for each family, which has its own characteristics such as conditions and abilities of stroke survivors and family members, family environment, and available resources in the community. In addition, the programs should provide the survivors and family members, particularly primary caregivers, with a chance to work at home with flexible timeframes.

5. Modifying healthcare coverage or health insurance

In this study, most families became responsible for caring expenses because of the lack of a health insurance or social security for disabled persons. Healthcare coverage such as the 30 baht for all campaign some families had did not cover necessary expenses incurred from caring for long-term stroke survivors. Therefore, national health

policy makers should reconsider this policy. In particular, the core expenses which are specific for each chronic disease such as stroke should be taken into account as a way to reduce family burden. In addition, healthcare policies should provide social and community environments that make it possible for stroke survivors and their family to take part in outdoor activities.

Implications for Nursing Education

The findings yield support to the nursing curriculum as follows:

1. Nursing educators can apply the findings in the teaching, which is concentrated on the entire family providing long-term care for stroke survivors at home including family life changes as a result of having a permanent disabled family member and family management in providing care for stroke survivors. This teaching should take socio-cultural and economic issues influencing Thai family experiences into account as well.
2. The research findings can provide nursing knowledge that helps families dealing with a long-term care of stroke survivors at home.
3. Nursing educators can create nurses' roles in helping and promoting families caring for long-term stroke survivors at home by utilizing the findings of this study.

Recommendations for Future Research

Research findings support the following recommendations for future research studies:

1. The information from this qualitative research study could be used as an important database for further development of experimental research on models of care for families providing long-term care for stroke survivors at home, such as interventions to support the caregiving families, constructing temporary care resources in the community, etc.

2. Models to enhance the family's abilities in providing long-term care for long-term stroke survivors at home as well as the family's self-care efficacy should be further investigated.

3. Some unclear issues that have emerged in this study should be explored in detail such as the roles and the use of alternative treatments in caring for stroke survivors at home, the behaviors in seeking for external support resources for the families, accessibility to health care services among families caring for long-term stroke survivors, and the attitudes of families receiving health care coverage.

4. The findings showed that the families applied and created some equipment and caring methods to accommodate their home caregiving situations. Therefore, studies on innovation in caring for stroke survivors at home, into which the Thai local wisdom is integrated, should be carried out.

5. Research on health policies appropriate for long-term stroke survivors and their families should be conducted.

6. This study should be replicated to examine the experiences of families caring for long-term stroke survivors at home from various ethnic, cultural, and kinship groups.

7. As the data in this study were collected from only family members, not from the stroke survivors, the experiences of being long-term stroke survivors have become an interesting topic for further studies. The qualitative research design should be employed as it is the most suitable method when thick and rich descriptions of the long-term stroke survivors are needed to shed more light on the issue.

8. Studies should also be conducted to explore the quality of life of the families caring for long-term stroke survivors at home in the Thai Culture.

9. Longitudinal studies on family experiences, from the initial stage to the end of life of stroke survivors in the Thai culture should be carried out.