CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

This final chapter describes the conclusions and the recommendations of this research study.

Conclusions

A cross-sectional descriptive correlation study was used to examine the causal relationships among the selected variables and to predict the influencing factors of the caregiving burden and the well-being of caregivers. The conceptual framework was based on the empirical evidence from the literature review. The participations were 205 spinal cord injury patients and their caregivers who were recruited from five hospitals in three provinces of Thailand during March 2011 to April, 2012. The self-administered questionnaires used for the data collection consisted of the Demographic Questionnaire, the World Health Organization - Five Well-being Index, the Rewards of Caregiving Scale, the Social Support Questionnaire, the Barthel Index, and Caregiving Burden Scale. The reliability of each instrument was tested with 10 primary caregivers who took care of spinal cord injury patients. The characteristics of the 10 primary caregivers were similar to the participants in this study and all of questionnaires were acceptable.

For research findings, the LISREL 8.52 was employed to test and modify the model. The selected multiple fit indexes were used to assess the model fit. The final modified model proved to have a good fit with the data. The chi-square and the degrees of freedom ratio (.88/2 = .44), p-value (.64), RMSEA (.00), GFI (1), and CFI (1) were at the acceptable levels.

The results reveal that the research hypotheses were partially supported. The causal relationship indicated the rewards of caregiving had a significant negative direct effect on caregiving burden and a positive direct effect on well-being of caregivers, as well as a significant positive indirect effect on well-being of caregivers through the caregiving burden. Furthermore, the caregiving burden presented a mediating effect in this model.

Social support had a significant positive direct effect on the caregiving burden and the well-being of caregivers, as well as there was a significant negative indirect effect on well-being of caregivers through caregiving burden. As this result, the caregiving burden presented a mediating effect through the relationship between social support and the well-being of caregivers.

The functional ability of persons with spinal cord injury had a significant negative direct effect on the caregiving burden, whereas a positive direct effect of functional ability on the well-being of caregivers was non-significant. Moreover, functional ability had a significant positive indirect effect on the well-being of caregivers through the caregiving burden. The caregiving burden presented a mediating effect in this model.

The caregiving burden had a significant negative direct effect on the well-being of caregivers. Finally, among the independent variables in the model, caregiving hours did not have a significant effect on both the caregiving burden and the well-being of caregivers.

In conclusion, the path analysis results suggest that the level of reward of caregiving and social support had a positive direct effect on caregivers' well-being. In contrast, their caregiving burden had a negative direct effect on their well-being. The inspection of the beta weights suggest that the reward of caregiving ($\beta = .14$, $p < .001$) was the most important predictor of well-being followed by the caregiving burden ($\beta = -.13$, $p < .001$). The least significant predictor was social support ($\beta = .06$, $p < .001$). In addition, reward of caregiving ($\beta = .02$, $p < .05$), social support ($\beta = -.02$, $p < .01$), and functional ability of the patient ($\beta = .08$, $p < .01$) had an indirect effect on well-being through caregiving burden. These variables explained 31% of the variance of the well-being score.

Implications

The findings of this study indicate the following contributions for nursing science, implications for nursing practice, policy recommendation, and implications for nursing education.

Contributions to Nursing Science

Since little is known regarding the determinants of well-being among Thai caregivers of persons with spinal cord injury, this study proposed a causal model which explained 31% of the variance of the caregivers' well-being. The results of this study increase the nursing knowledge. It not only explains the important roles of the rewards of caregiving, social support, functional ability of persons with spinal cord injury, and caregiving burden on caregivers' well-being, but also contributes to the knowledge of nursing. It can be used as a guideline in nursing interventions to promote well-being among Thai caregivers of persons with spinal cord injury.

Implications for Nursing Practice

The research results demonstrate those caregivers who take care of spinal cord injury patients perceived high levels of rewards of caregiving, social support, patients' functional ability and the high level of well-being whereas their caregiving burden perceptions were low. These results could be developed for effective nursing interventions based on the variables in this study with other health care providers to encourage the well-being of caregivers.

Rewards of caregiving had both a direct and an indirect effect on the well-being of caregivers. To enhance the positive perception of caregiving, nursing intervention should be developed to assist and inspire the caregivers who take care of spinal cord injury persons. It could be done by identifying the positive aspects of caregiving that occurred through their caregiving experiences. Also, the nurses should support those caregivers to discover self-empowered strategies and supplement the caregiving experiences to promote a meaningful life. Furthermore, giving a compliment as they are able to perform and solve the problems of the caregiving activities properly will create in their mind a feeling of being a good caregiver and promote their perceptions of rewards of caregiving.

In addition, social support had both a direct and indirect effect on the well-being of caregivers. The nurses should promote the perception of social support by providing and planning the activities for the caregivers on the first day of the patient's admission. The social support promotion activities should be done by a team of health care providers such as nurses, doctors, physical therapists, occupational therapists and social workers. The information provided should include how the persons' abilities were affected due to the spinal cord injuries, treatment guidelines, complications, the support resources, stress management, homecare training and a spinal cord injury caregiving manual. Also, let them release their frustration. Before the patients are discharged, the nurses, the caregivers and the family members should make a plan of caregiving together. The caregiving responsibility and house work should be shared between the caregivers and other family members and those activities should be integrated into their life styles. The health care providers should visit them at home continuously for a nursing evaluation and give regular telephone follow-up after hospitalization. All of these supports contribute to a high level of social support perception of caregivers.

This investigation shows that functional ability of spinal cord injury patients had no direct effect on the caregivers' well-being. However, it had an indirect effect on the caregivers' well-being through the caregiving burden. Therefore, encouragement to do the daily life activities of the persons with spinal cord injury will decrease the level of their dependence and burden perception, this then can enhance the well-being of caregivers. Intervention can be planned in terms of their daily life activities. Recovery involves physical therapy, occupational therapy, orthosis and accommodation environmental adjustment.

The analysis of caregiving burden demonstrates that there was a direct effect on the well-being of caregivers. Nurses should give information of their pathology and the treatment plan. Also, caregivers should be taught how to provide care. Giving efficient support resources including information to release their stress while giving care at home are necessary. Before the spinal cord injury patients are discharged, it is important to ensure that the caregivers receive sufficient information and understand how to access all professional and non-professional health care services, home health care nurses, and health care volunteers. Telephone call services are beneficial for both spinal cord injury patients and the caregivers, particularly in the transition period during the first month after being discharged. Sufficient and clear information could contribute to the caregiver’s confidence and motivate them to provide appropriate home care continuously and that can eliminate their caregiving burden perception.

Policy Recommendation

Health care policy should involve the transfer system and the caregivers of spinal cord injury patient network. First, a patient transfer system should be to the nearest health care service center for both the patients and their caregivers based on a holistic view. Moreover, providing health care service or home care service for the chronic illness and temporarily disabled persons will decrease the burden of caregivers and encourage the well-being of caregivers. They will have more time for themselves, spend some time away from their caregiving burden and join social activities. Secondly, the caregiver network should include the healthcare centers and the local team of health care providers. The caregivers can share their caregiving experiences and support each other by community, public, and private support. These policies can contribute the high level of well-being of caregivers.

Implications for Nursing Education

The current study's findings provide knowledge about the factors affecting the well-being of caregivers of persons with spinal cord injury. These findings can be applied for nursing education and nursing practice to look after the patients with chronic illness, limited self-care and spinal cord injury. Particularly, these findings are an efficient nursing guideline for the nurses and student nurses to care for the patients who are disabled and demand care from others at home. Not only the patients' but also the caregiver's well-being are considered which encourages registered nurses and student nurses provide holistic care.

Limitations of the Study

There are some limitations in this study as presented below.

1. Caregiving hours were collected by estimation and caregivers' memory recall of the past. It was not the actual hours that they were giving care as it happened. Therefore, that may have introduced measurement error which could have affected the validity of the predictions. The finding that caregiving hours was not a significant direct or indirect effect on well-being of caregivers thus may not be totally correct.

2. The sample of this study included caregivers who were both new to caregiving and long term caregivers. Well-being of caregivers changes across time and depends on the duration and experience of caregiving. A cross-sectional design was carried out to determine relationships of variables, in which all variables were measured at the same point of time. The results of this study cannot be used to design

nursing interventions to meet the caregivers of spinal cord injury patient's specific needs at different points of time.

3. The new caregivers informed that the patients, who had been admitted at Maharaj Nakorn Chiang Mai Hospital and Lampang Hospital, had a follow up appointment one month after of discharge. However, this study collected the data three weeks after discharge. This situation impacts caregivers' perception of burden because lack of caregiving experience covering the whole caregiving activities.

Recommendations for Further Studies

Based on the findings and the limitations of this study, there are some recommendations for further studies.

Firstly, to collect the data of caregiving hours, future studies should use other instruments such as a diary for recording the time of each caregiving activity, and interviews of the other family members and persons with spinal cord injury. Moreover, the questionnaires of caregiving hours should be separated from the demographic data for collection because it is an important factor.

Secondly, longitudinal studies should be carried out to determine any relationships of variables across time. It is necessary to design a proper nursing interventions to maintain or improve well-being for caregivers throughout the entire caregiving trajectory. The nursing interventions should be designed to meet the caregivers' specific needs of spinal cord injury patients at that time. The well-being of caregivers experience at one point in time may not reflect the experience of well-being over time. A model comparison over time would further permit a more in-depth understanding of the well-being of the caregivers. The further studies should follow the progress of caregivers' well-being over time from the first day of the admission until the return to their community to make a clear understanding of the changing pattern of the entire caregiver's well-being experiences.

Thirdly, further studies should collect the data with caregivers who have caregiving experiences for the whole care activities.

Fourthly, this research results explain the specific predictors of caregivers' well-being to provide potential targets for the appropriate intervention design. Future research studies need to build on these findings by testing those predictors to measure the actual perception of well-being change. Therefore, nurses should conduct an experimental study for both developing and testing effective interventions to promote the perception of caregivers' well-being based on the significant factors that are indentified in this study.

Finally, the findings indicate the four predictors significantly account for 31% of variance in well-being of caregivers. This means that there will be other variables in this phenomenon that influence the well-being of caregivers. Therefore, further model-testing studies should clarify the role of other potential variables that directly and/or indirectly affect the well-being of caregivers. For instance, sense of coherence, self-efficacy, self-esteem, personal mastery, caregiver-patient relationship, religion, coping, depression, caregiving stress, anxiety, the demographic characteristics and the socioeconomic status of caregivers are predictors that should be added to the model in order to increase the power of prediction.

In summary, the results of this research generated relevant knowledge for nurses and the policy planners. It is the researcher’s desire to apply the knowledge from this research investigation. Also, nurses, other health care providers, and policy planners can apply this knowledge for designing and developing effective intervention programs and relevant policies for the caregivers. The nurses could influence the policy planners to emphasize services to bolster the reward of caregiving, enhance the social support, as well as promote the functional ability of spinal injury patients. The most important point to consider is that care for the persons with spinal cord injury at home should not be left to caregivers alone. Instead, they should be assisted by other family members and healthcare providers as well as others in the community.