CHAPTER 1

INTRODUCTION

Background and Significance of the Research Problem

Spinal cord injury is one of the major causes of disabilities and results in a limitation of self-care. According to 2010 US data, spinal cord injury was caused by motor vehicle accidents (41.3%), falls (27.3%), acts of violence or shooting injury (15.0%), sporting activities (7.9%), and others (8.5%). The incidence of such injuries is approximately 12,000 persons a year. Of approximately 262,000 people who survived spinal cord injury 55.2% had tetraplegia while 44.4% had paraplegia (National Spinal Cord Injury Statistical Center, 2010). In Thailand, the causes of spinal cord injury at three hospitals in Chiang Mai province during the period 2004 to 2005 were traffic accidents (53.3%), falling from a height (33.3%), gunshot injury (10.0%), and others (3.3%). The number of spinal cord injury patients with tetraplegia was 55.0% whereas paraplegia was 45.0% (Chinchai & Wittayanin, 2008).

Due to the pathology of spinal cord injury, patients' functional capability decreases. Patients need long term help from others after being discharged from hospital. As a result, caregivers are vital resources for the provision of care to home based spinal cord injury patients. From 2009 US statistical records, it was found that there were 65.7 million persons caregivers in total which accounted for 29% of the whole population. These caregivers need an average of 20.4 hours per week to take care of patients and the overall duration of providing care averages 4.6 years (Family Caregiver Alliance, 2009). However, there are no national statistics reports or surveys regarding the number of caregivers in Thailand. Most spinal cord injury patients at the sixth thoracic segment and below level can do all daily activities by themselves (Pajaree, 2000), thus it can be estimated that the number of caregivers of persons with spinal cord injury in Thailand is around 3 out of 4 of the number of spinal cord injury patients.

Spinal cord injury affects the patient physically, psychologically, economically and socially. Physical problems include loss of mobility, sensory loss, bowel and bladder incontinence, pain, an inefficiency of the respiratory system, thermoregulation dysfunction and spasticity, as well as complications such as joint contractions, pressure ulcers, urinary tract infections, constipation, autonomic dysreflexia, deep vein thrombosis, postural hypotension, atelectasis and pneumonia (Zeidlik, 1992). The psychological problems include serious grieving and feelings of loss, self-concept changes resulting in pessimism, and bad feelings regarding the image of one’s body. The patient is likely to feel discouraged, hopeless, lacking in pride, have low self-esteem, and be angry with him/herself. In addition, physical disabilities prevent a patient from working, resulting in a loss of career leading to decreased income and increased expenses from medical treatment. Consequently, patients often have economic problems. Moreover, patients are confined to bed or wheelchairs much of the time, causing a decrease in social interaction. As time passes, the patient often stays quietly at home and becomes withdrawn from society (Koopanthavee, 1998) leading to social problems.

Because of the patients’ problems as described above, they cannot live alone and require life-long care from caregivers. Caregivers must provide direct care to patients because of their limited physical capacity, including assisting patients to get sufficient air, water and food, helping with personal hygiene and rehabilitation, and preventing and taking care of complications. In terms of psychological care, caregivers provide the patient with an opportunity to express their frustrations and must accept behavior of patients such as crying, getting angry etc. Moreover, the caregivers provide financial support to the patients as well, such as helping with treatment expenses, medical equipment expenses, as well as expenses related to the environmental adjustment within the patient's home in order to facilitate them to move around. In terms of social care, the caregivers encourage patients to participate in social activities and interact with others. The caregivers have to mediate with others in order to help the patient gain the opportunity to receive appropriate and beneficial services. As mentioned above, caregivers have substantial responsibilities in terms of caregiving. These activities have many impacts on the caregivers.

Only a few studies have reported the consequences of being a caregiver of persons with spinal cord injury in particular. Therefore, the researcher reviewed the literature more broadly, considering those caregivers of chronic diseases patients. These patients also depend on caregivers, and caregivers of these patients may also experience hardship and troubles. It was found that the impacts of being a caregiver at home are physical, psychological, social and financial. The physical impacts of being a caregiver include backache and all over body pain from lifting and moving the patient (Lucke, Coccia, Goode, & Lucke, 2004). Caregivers' health deteriorates because they spend all their time with the patient and they have no time to take care of their own health even the time to attend doctor's appointment. Any of their own underlying diseases are more likely to relapse. The psychological impacts from being a caregiver include feeling a heavy burden and role stress (Gasemgitvatana, 1993). Caregivers often experience burnout because they lose physical and mental energy from caregiving activities over such a long period of time (Morris & Edwards, 2006). Moreover, the caregivers may even sometimes wish that the patient would die, and these feelings can make the caregivers feel miserable, guilty and depressed (Luengamornlert, 1994).

Being a caregiver can also have an impact on a person socially. Caregivers need to change their work schedule; some caregivers have to change from working full-time to working part-time. In addition, caregivers may have problems with other family members, because they often do not have time for their own family, making some members feel neglected and isolated (Maneewan, Sujinda, Jaraitassanee, & Nilnukkara, 1994). Moreover, since caregivers regularly take care of the patient almost 24 hours a day, they lose the ability to have their own private life and to interact and socialize with their friends in the community, which leads them to become isolated from society (Luengamornlert, 1994). Furthermore, providing care can have an impact on caregivers' finances. A caregiver's income may decrease because he or she is unable to work overtime, leave early from their work, and some caregivers have to resign from their job and take care of a patient full-time. Therefore, their income and savings decrease. They often have to spend their own money to take care of a patient, paying for transportation to the hospital and for creating an appropriate home and environment, which can lead to debt and additional financial problems (Morris & Edwards, 2006).

Actually, caregivers should receive no less care than the patients themselves. In other words, caregivers are actually hidden patients (Sasat, 2006), because they commonly have to provide life-long support to those they care for. Caregivers have to use many of their existing resources, and sometimes the difficulties faced are too much for their resource base, so they then suffer negative physical, psychological, social and economic impacts. These impacts result in the decreased well-being of the caregivers' lives. Well-being of a caregiver refers to an individual life perception that relates to his/her responsible abilities. It is a subjective dimension with a positive mood, vitality, and general interests (World Health Organization [WHO], 1998). The caregivers who have low levels of well-being will be those who are not interested in their own health and exhibit negative health behaviors, lack enthusiasm to develop their potential, do not have the ability to adapt themselves and to cope with problems, and have negative relationships with others (Ryff, 1989). Moreover, caregivers who lack a sense of well-being reveal possible depression and a reduced quality of life (WHO, 1998). The caregiving situation affects not only the caregivers in terms of decreased well-being, but also affects the patient as well. If the caregivers have a decreased sense of well-being, they are more likely to behave aggressively, neglect to take care of the patient, or withdraw from the caregiving role, which may adversely affect the quality of caregiving and eventually have a negative impact on the patient (Beach et al., 2005).

Based on the afore-mentioned issues, the well-being of caregivers is exceptionally interesting to explore, and nurses who provide health care services should develop an effective nursing intervention to promote the well-being of the caregivers, so they can look after the patient fully and effectively. In order to gain a richer understanding about the well-being of caregivers and to develop a proper intervention to promote their well-being, the influencing factors should be identified.

A literature review on factors related to the well-being of caregivers, found that rewards of caregiving is one of the factors that affect caregivers' well-being. Rewards of caregiving are positive feelings which have been developed during caregiving (Archbold et al., 1995). Rewards of caregiving affect the positive attitudes of caregivers towards their caregiving situations and will confirm further caregiving activities. It can be said that although providing care to the patient may cause problems to caregivers in various respects, rewards can act as buffers in helping to relieve the negative feelings induced and reduce the burden, helping the caregivers to generate feelings of well-being while providing caregiving activities. The caregivers who perceive high rewards from caregiving had a low level of caregiving burden (Cohen, Colantonio, & Vernich, 2002), and perceive a high level of well-being (Cameron, Herridge, Tansey, McAndrews, & Cheung, 2006).

Social support is another factor that relates to caregivers' well-being. Social support refers to support provisions which caregivers receive from people (Caplan, 1974). The caregivers who receive sufficient social support will perceive fewer problems because social support helps them cope with stressful situations and emotional conditions over a shorter period and helps the caregivers find alternative ways to manage their problems. The caregivers may get various types of help, such as the provision of equipment needed for providing care and bringing comfort to caregivers. Getting help in the form of labor can also help to reduce the amount of caregiving required and reduce the time spent on caregiving activities, further relieving their burden. Social support can also help the caregivers assuage feelings of loneliness, as they are aware that they do not face problems alone. All these feelings will affect the well-being of caregivers. Those caregivers who perceive a high level of social support will have a low caregiving burden (Bull, 1990) and perceive a high level of well-being (Chappell & Reid, 2002).

Caregiving hours is one of the significant factors which is associated with caregivers' well-being. If caregivers endure long caregiving hours, this will affect their ability to assess themselves, as they will have insufficient ability to deal with existing care tasks, and will need to use effort and energy beyond their capabilities. The caregivers will then feel that caregiving is so onerous that the care tasks are burdensome. Moreover, if caregivers have to use most of their time taking care of the patient, they lose their private lives, causing tension and boredom. Relaxing activities will happen less and interaction with family members and other persons in society will also be reduced; the caregivers will also experience a reduction in feelings of well-being. Those caregivers who have to spend a lot of time taking care of patients each day are likely to have a high caregiving burden (Chappell & Reid, 2002) and have a low sense of well-being (White-Means & Thornton, 1996).

Furthermore, a patient's ability to perform daily activities is one of the factors that affect the well-being of caregivers. Patients who suffer from injury at a high level of spinal cord often experience severe impairment of the physical organs which heightens their need to depend on caregivers (Pajaree, 2000). The caregivers have to use time, energy and ability to take care of patient, and the caregivers face difficulties in terms of providing care to these patients. In these circumstances, the caregivers will perceive a heavy burden. Moreover, caregivers who have to give complex levels of care in addition to needing particular skills may feel stress and a lack of confidence in terms of giving care. Caregivers have to use many resources to help their patient which can affect the well-being of the caregivers themselves. Those patients who have a low functional ability to do their daily activities had a heavy burden on the caregivers (Bull, 1990) and create in them a low sense of well-being (Early, Gregoire & McDonald, 2002).

Another factor affecting the well-being of caregivers is the caregiving burden which is the perception of caregivers about the time they spend and the difficulties they face when carrying out caregiving activities for the patient (Oberst, 1991). Some care activities provided to a patient at home are complex. If the caregivers have insufficient knowledge and ability, it may cause them to perceive that giving care is time consuming, difficult and requires a significant amount of effort. This causes caregivers to perceive their burden as using up too many resources, and that this burden brings about changes and difficulties in life which reduce their well-being. Caregivers who perceive a heavy burden had low sense of well-being (Chaoum, 1993). Moreover, caregiving burden is a factor which was transmitting the influence of rewards of caregiving (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991), social support (Harwood, Ownby, Burnett, Barker, & Duara, 2000), caregiving hours (Chappell & Reid, 2002), and functional ability of patient (Harwood et al., 2000) into well-being of caregiver.

Based on the literature regarding caregivers in Thailand, it was found that most of the prior studies have paid little attention to caregivers' well-being. Previous research about the well-being of caregivers has included the level of well-being of the caregivers (Kasemsuk, 2002), and factors related to their well-being (Chaoum, 1993), in which the research results were a correlation. There has been only one predictive study carried out about factors affecting the well-being of stroke patient caregivers (Daonophakao, 2004); however, that study did not focus on determining the direct and indirect effects of predictors of well-being of caregivers. Little is known about the magnitude of predictive factor effects and how these factors affect the well-being of caregivers, even though there has been some research done in Western countries about the causal factors affecting well-being of those providing care to dementia (Chappell & Reid, 2002) and Alzheimer's patients (Lawton et al., 1991). Because these researches studied caregivers of chronic illness patients, the study results could explain only some elements of the factors related to the well-being of those who care for spinal cord injury patients. However, the impacts of the illness pathology on patient's ability and caregiving activities are different. The outcome of these studies cannot be fully applied to the caregivers of persons with spinal cord injury. Moreover, these studies were carried out in the context of Western countries, which are different in terms of the traditions, customs, cultures, norms and lifestyles when compared to Thailand, and this means there are limitations when wishing to apply Western research in the Thai context. Hence, there should be studies carried out with regard to the caregivers of persons with spinal cord injury in Thailand.

As stated previously, it can be shown that the body of knowledge regarding factors influencing well-being of caregivers in Thailand is currently still limited, therefore the appropriate interventions to promote well-being of caregivers cannot be designed. Hence, developing a model for predicting well-being of Thai caregivers has a significant role in expanding well-being knowledge on Thai caregivers of persons with spinal cord injury. The findings of this study can address the identified gap in knowledge by enhancing the understanding of factors affecting well-being in caregivers and illuminating the magnitude of the influence each causal variable has and in which way it relates to well-being of caregivers. As a consequence of the situation described above, the researcher would like to examine the causal model of well-being of spinal cord injury persons' caregivers. The researcher developed the hypothesized model from the comprehensive literature review and used it as the basis of the conceptual framework. In the present study, the researcher investigated the degree to which the following variables: rewards of caregiving, social support, caregiving hours, functional ability of persons with spinal cord injury, and caregiving burden, predict the well-being of caregivers of persons with spinal cord injury.

Objective of the Study

The objective of this study is to test the causal model of well-being among caregivers of persons with spinal cord injury, which illustrates the causal relationship between rewards of caregiving, social support, caregiving hours, functional ability of persons with spinal cord injury, caregiving burden and well-being of caregivers of persons with spinal cord injury.

Research Hypotheses

The hypotheses derived from the hypothesized model are:

1. Rewards of caregiving, social support, and functional ability of persons with spinal cord injury have a positive direct effect on well-being of caregivers.
2. Caregiving hours and caregiving burden have a negative direct effect on well-being of caregivers.

3. Rewards of caregiving, social support, caregiving hours, and functional ability of persons with spinal cord injury have an indirect effect on well-being of caregivers, as mediated by caregiving burden.

4. Caregiving hours have a positive direct effect on caregiving burden.

5. Rewards of caregiving, social support, and functional ability of persons with spinal cord injury have negative direct effects on caregiving burden.

Definition of Terms

Well-being of caregivers. It refers to an individual's perception of their position in life in relation to their ability to take care of their own responsibilities. It is a subjective character in which a positive view represents a person with a positive mood, vitality, and general interests. It was measured by the World Health Organization - Five Well-being Index, developed by the World Health Organization (1998) and was translated into Thai by Saipanish, Lotrakul, and Sumrithe (2009).

Rewards of caregiving. It refers to the positive feeling of caregivers resulting from their experiences in providing care to the patient. It comprises four aspects including rewards of meaning for oneself, rewards of family-strengthening, rewards from spiritual fulfillment, and rewards of self-gratification. It was measured by the Rewards of Caregiving Scale, developed by Archbold et al. (1995) and modified by Gasemgitvatana (2002, personal communication, March 8, 2010).

Social support. It refers to the help as perceived by caregivers in which they are provided by others for mobilizing psychological resources, mastering emotional burdens, and sharing tasks. Additionally, they provide caregivers with material supplies, skills, and cognitive guidance in order to improve their handling of the caregiving situation. It was measured by the Social Support Questionnaire, developed by Schaefer, Coyne and Lazarus (1981) and modified by Pipatananond (2001).

Caregiving hours. It refers to the time in hours that the caregivers spent on caregiving activities each day with the spinal cord injury patient at home as reported by the caregivers. It was collected by the Demographic Questionnaire.

Functional ability. It refers to the physical ability of patient to perform activities of daily living as perceived by caregivers, including feeding, grooming, transfer, toilet use, mobility, dressing, using the stairs, bathing, bowels and bladder control. It was measured by the Chular Activities of Daily Living Index, developed by Mahoney and Barthel (1958) and modified by Jitapunkul, Kamolratanakul, and Ebrahim (1994).

Caregiving burden. It refers to perception of the caregivers about the amount of time spent (demand) and emotional difficulties (difficulty) encountered while providing care for patient. It was measured by the Caregiving Burden Scale, developed by Oberst (1991) and translated into Thai by Gasemgitvatana (1993).

Caregiver. It refers to person who takes care of a spinal cord injury patient at home and has been identified by the patient's family members as the primary caregiver who continuously provides most of the caregiving activities to the patient.

Persons with spinal cord injury. It refers to the men or women whom physician diagnosed as having an injury of the spinal cord and an impairment or loss of motor and/or sensory function of organs, which has resulted in a limitation in them carrying out daily activities, such that they need help from a caregiver.