CHAPTER 2

LITERATURE REVIEW

This chapter presents an integrative review of the empirical literature that describes the concepts in the hypothesized model and the interrelationships among them. The literature review covers the overview of spinal cord injury, caregiving, well-being of caregivers, as well as factors affecting the well-being of caregivers of persons with spinal cord injury patients. The overview of the relevant factors consists of rewards of caregiving, social support, caregiving hours, spinal cord injury patients' functional ability, and caregiving burden.

Overview of Spinal Cord Injury

Definition of Spinal Cord Injury

Spinal cord injury means the damage within the spinal canal at the spinal cord and nerve root which is divided into two types as follows (Sisto, Druin, & Sliwinski, 2009):

1. Tetraplegia (or quadriplegia) is the impairment or loss of motor and/or sensory function in the cervical segments, due to damage of neutral elements within the spinal cord. Tetraplegia is identified as the injury at the first thoracic segment (T_1) or above. It does not include brachial plexus lesions or injury to the peripheral nerves

outside the neural canal. Tetraplegia causes functional impairments of the arms, trunk, legs and pelvic organs.

2. Paraplegia is motor and/or sensory functions impairment in the thoracic, lumbar, or sacral (with the exception of cervical) segments of the spinal cord secondary to damage of neural elements within the spinal canal. Paraplegia occurs at the second thoracic segment (T_2) or below. Paraplegia also refers to cauda equina and conus medullaris injuries, but not lumbosacral plexus lesions or peripheral nerves outside the neural canal. With paraplegia, neurologic function in the upper extremities is spared, but depending on the injury level impairment might involve the trunk, legs, and/or pelvic organs.

Classification and Neurologic Recovery in Spinal Cord Injury Patient

There are two types of cord injury as follows: 1) Incomplete injury is with some sensation preservation and/or motor functions below the neurological injury level that include the lowest sacral segments (S_4 and S_5). The patients can perceive some sensory perceptions and control some parts of muscles under the injury area and there could also be some spinal cord recovery. However, the physical function may not be as full as the previous condition. 2) Complete injury is the sensory and motor function absence in the lowest sacral segments. The patients have lost muscle control, sensory perception and all reflexes at the injury level and lower. There is little chance for spinal cord recovery. The paralytic condition effects appear from the injury level and down to the lower (Kirshblum & Donovan, 2002).

Moreover, the international standards for neurological and functional classification of persons with spinal cord injury based on American Spinal Injury Association (ASIA) impairment scale is a standard method to help determine the course of recovery, effect of interventions in the treatment, and regeneration of spinal cord injury. They are divided into five grades as below (American Spinal Injury Association [ASIA], 2002):

A = Complete. No motor or sensory function is preserved in the sacral segments S4-S5.

B = Incomplete. Sensory but not motor function is preserved below the neurological level and includes the sacral segments S_4-S_5.

C = Incomplete. Motor function is preserved below the neurological level, and more than half of key muscles below the neurological level have a muscle grade less than 3/5 strength.

D = Incomplete. Motor function is preserved below the neurological level, and at least half of key muscles below the neurological level have a muscle grade greater than or equal to 3/5 strength.

E = Normal. Motor and sensory functions are normal.

The neurologic function recovery in the patients with spinal cord injury is an important factor of caregiving and the well-being of caregivers. It encourages and increases the patients’ daily life activities and decreases the caregiving burden. The neurological recovery of spinal cord injury patient after treatment occurs from six months to two years after injury. It mostly occurs within the first year after the injury (Somers, 2001). The neurologic recovery depends on the type of spinal cord damage as an incomplete cord injury recovery is faster than a complete cord injury. Kovintha

(1993) studied 383 spinal cord injury patients at the Maharaj Nakorn Chiang Mai and found the average admission days and rehabilitation periods were 82 days. At admission, 42% of the patients with the early diagnosis of an incomplete tetraplegia had neurological recovery when they were discharged (improvement of ASIA's classification at least one grade) and 8% reached to the normal recovery level (ASIA grade E). However, 49% of the patients with an early diagnosis of an incomplete paraplegia had neurological recovery when they were discharged and 6% reached to the normal recovery level (ASIA grade E).

Study of neurological recovery system with the complete cord injury patients have been conducted by Waters, Adkins, Yakura, and Sie (1993) who explained the motor nerve recovery from complete tetraplegia. The arm muscle strengths increased rapidly and maintained for the first six months. The results presented 97% of the complete tetraplegia patients had the muscle strength levels between 1/5 and 2/5 after one month of injury, then the muscle strength reached to level of 3/5 after one year while 96% of the complete paraplegia patients still had complete paraplegia after two years. Only 4% of paraplegia patients recovered to the stage of incomplete cord injury after 4 months (Waters, Yakura, Adkins, & Sie, 1992). In a Thai study, Kovintha (1993) found 25% of the complete tetraplegia patients had neurological recovery (improvement of ASIA's classification at least one grade). Only 5% of complete paraplegia had improvement of ASIA's classification at least one grade. None of complete cord injury patients recovered to the normal state (ASIA grade E).

It can be seen that some incomplete cord injury patients have a chance of neurological recovery which could decrease the burdens of caregivers. In contrast, the patients with complete cord injury have a small recovery chance which means the caregiver’s burden might last a long time. However, most spinal cord injury patients are not able to return to normal function. They have to live with spinal cord injury conditions for their entire lives and rely on the caregivers for a long time.

Caregiving Demands of Persons With Spinal Cord Injury

Persons with spinal cord injury must have self-care response for their illness conditions to maintain the body structures, functions, and promote rehabilitation. Their illness conditions affect their body movement and daily life activities. Therefore, they demand to be cared for based on the following:

Physical care demands. Patients require physical care to meet their life demands and maintain the normal structures and body functions. The physical care demands of spinal cord injury patients are as follows:

Demand of sufficient breathing. The effects of breathing depend on the level of spinal cord injury. The higher level, the greater the effect on breathing; an injury level at C_1-C_3 affects self-breathing and a ventilator is required. An injury level at C_4-C_8 affects self-breathing but diaphragms can still function. However, the abdominal and intercostal muscles parts of breathing become weakened. Therefore, the chest cannot expand effectively which produces ineffective breathing and coughing. The sputum excretion and gas exchange decrease and cause complications such as pneumonia or atelectasis, especially in patients who were heavy smokers, when their bodies stay in one posture for a long time (Zejdlik, 1992). The first cause of death of spinal cord injury patients is respiratory disease, particularly pneumonia (DeVivo, Black, & Stover, 1993).

Demand of sufficient and appropriate water consumption. An appropriate amount of water consumption daily is important. The effects of insufficient water consumption include hypotension, weight loss, dried skin and lack of elasticity, and oliguria. In contrast, consuming too much water causes water overload, edema and high blood pressure (Puttadechakhum & Leelahakul, 2002).

Demand of sufficient and appropriate food. Nutrients of five main food groups strengthen the body, increase immunity, and reduce the risk of diseases. The five main food groups consist of carbohydrates, fats, proteins, vitamins and minerals (Noonin, 2000).

Demand of normal urinary elimination pattern. The brain cannot control urinary elimination of the bladder and cannot receive the feeling of being impelled to urinate in spinal cord injury persons. The bladder dysfunction and neurogenic sphincter produce a large post-voiding residual urine and urinary incontinence. Retaining the indwelling catheter or intermittent catheterization is needed, which requires continuous care.

Demand of complication prevention. Physical malfunction or dysfunction may cause complications which can appear gradually with spinal cord injury patients. The neglect of the complications can cause death. The complications which may occur are as follows:

Joint contracture. Patients with motor paralysis are not able to move their joints actively because the brain function loses the control of muscle movement and produces joint contracture.

Pressure ulcer. It is a common complication of spinal cord injury patients. The sensory impairments and motor movement affect the skin condition because of the automatic nervous system dysfunction cause decrease producing sweat. The skin becomes dry and lacks elasticity. Pressure ulcer also occurs from blood circulation system dysfunction and lowers blood pressure. In addition, patients frequently suffer from pressure ulcers as the profuse sweat skin is neglected (Somers, 2001).

Urinary tract infection. It is the most common complication of spinal cord injury, particular the tetraplegic (49%) and a common cause of hospital readmission (Noreau, Proulx, Gangnon, Drolet, & Laramee, 2000). Spinal cord injury causes neurological dysfunction and lack of urinary bladder elasticity that produces a large post-voiding residual urine. The urinary tract infection occurs because high intravesical pressure causes vesicoureteral reflux to the bladder (Pajaree, 2000), as well as retaining the indwelling catheter or intermittent catheterization (Koopanthavee, 1998).

Constipation. Difficult defecation or excretion less than three times a week is called constipation. Spinal cord injury affects the function of the bowel movement system and a normal defecation.

Postural hypotension. After paralysis, muscle tone and contraction ability is reduced and there is a loss of regular blood flow return through the heart. Also, sympathetic automatic nervous system at the spinal cord T_2 -T_6 level loses the vessel function control within the abdomen, body, and legs. As a result, the effect of those three parts of body involved the position changing from lying down to sitting up. The internal abdominal organs and muscles vessels are unable to contract causing abdomen, trunk and legs congestion. Consequently, insufficient blood supply to the brain occurs and causes vertigo, dizziness, pallor, and fainting (Zejdlik, 1992).

Thermoregulation dysfunction. Losing body temperature control is a result of sympathetic automatic nervous system damage. Human body temperature change depends on the environment conditions. A high body temperature condition could cause hyperthermia as the body heat could not be released by sweating. On the other hand, the low body temperature could cause hypothermia and the paralytic muscle discontraction affects the body heat production (Kovintha, 1990).

Autonomic dysreflexia. Person with spinal cord injury above the T6 lesion can experience autonomic dysreflexia as a result of a disconnection between the brain and the sympathetic neurons in the thoracolumbar spine. It is characterized by a sudden increase in blood pressure, bradycardia, a pounding headache, and flushing and profuse sweating above the level of the lesions in response to noxious stimuli below the level of injury. Common origins of the noxious stimulus include bladder or rectal distension, urinary tract infection, and bowel impaction. Other causes include pressure ulcers, ingrown toenails, spasticity, gastric ulcers, and restricting clothing. Untreated autonomic dysreflexia can lead to intracerebral hemorrhage and death (Somers, 2001).

Pain. It can occur during the acute phase after injury or as a chronic problem in the month and years that follow. This pain can result from a variety of neurologic (example: nerve root impingement, central neuropathic pain), orthopedic (example: heterotopic ossification, chronic overuse injuries), or even medical (example: deep vein thrombosis, visceral disorders) causes (Somers, 2001).

Psychological care demands. The change from a healthy person into a disabled person affects the psychological condition. They need psychological support as follows:

Grief and loss. The psychological reactions when the patients acknowledge their disability and loss of movement are grief and loss. It can be as critical and life changing as a self-perception of dying and losing their loved ones (Fraley, 1992). Kubler-Ross (1973) claimed that grief and loss are divided into five phases. Phase 1 is the denial and isolation. The patients do not accept the truth and reject it. Phase 2 is the anger with the involvement of oneself, which marks the underlying problem. Phase 3 is the bargain for emotional support such as God or a holy deity depending on their religion. Phase 4 is depression. When they become dependent persons, the experience of grief and depression occur. And finally Phase 5 is acceptance. This phase usually takes time for the adjustment. Patients have calmed down but the feelings of grief and disappointment still remain. These feelings might repeatedly occur depend on individual perception of situation.

Engel's theory (1964) explained the phase of grief and loss as the acceptable of disability that consists of four phases. Phase 1 is shock and disbelief of the occurrence. Phase 2 is the development of awareness. Phase 3 is characterized by restitution, and phase 4 is the resolution. Finally, the patients adjust to accept the assistance and cooperate with the treatment.

The changes of self-concept and body image disturbance. Self-concept is the attitude or feelings of self-ability. Body image is the subjectivity of persons towards their appearance, characteristics and body proportion, the effectiveness of body organ function and abilities. Also, it is important for the people's subjectivity of themselves. The changes of self-concept and body image might cause depression. Patients feel useless and unhappy as well as have a loss of self-pride.

Anxiety. It is an emotional expression of unhappiness from an unknown pathological disease, medical treatment and disease prognosis, including the daily living concerns and life dependence. As a result, they have to rely on a caregiver. Anxiety can cause patients to lose self-control, get stressed, have a lack of consciousness and self-confidence, and have communication problems.

Economic care demands. Patients are unable to work to earn money because of their physical disabilities. Moreover, their chronic illness impacts their ability to work because they spend most of time for the health recovery and medical treatment. The effects on this situation are lack of income and health care expenses. Hence, they need to rely on someone else on financial issues due to the expenses of medical treatment, health recovery and life.

Social care demands. Immobility causes problems with patients' social roles. They have to be in a wheel chair to meet other people which is an interaction obstacle. In the long run, those patients might isolate themselves causing social withdrawal (Koopanthavee, 1998). Patients should join activities with disability persons who have a similar condition. This will build the relationships with the others. They can exchange data with each other. As it is a social gathering, acceptance among them is built up. Finally, the patients feel that they are a person with self-esteem. Thus, the social isolation disappears.

After the spinal cord is injured, patients become dependent and need physical, mental, economical and social support. The important persons who give them care at home are caregivers.

Caregiving

Nowadays, patients with spinal cord injuries are treated at hospital during the critical period and have early recovery at home which has the benefit of reducing the number of inpatients and health care cost as well as enhancing the family relationship. As a result, there are more patients who need caregiving support from caregivers at home.

Concept of Caregiving

Scholars offer several caregiving definitions from their own perspectives. Grieco and Kowalski (1987) described caregiving as the range of responsibilities and tasks that are carried out by caregivers who provide care of emotional support, physical assistance, treatment regimen, household chores that include observing and calling for assistance. Bull (1990) stated that caregiving is the performance of instrumental tasks or provision of hands-on care. Pearlin, Mullan, Semple, and Skaff (1990) indicated that caregiving consists of the activities and the care-providing experiences for disabled relatives or friends. Pepin (1992) explained that caregiving is an activity or a set of tasks that the family caregivers provide to an impaired elderly or a chronically ill person at home.

Swanson, Jensen, Specht, Johnson, and Maas (1997) reviewed 63 articles of nursing and health-related literature on family caregiving and clarified the concept of caregiving as: 1) a task which emphasizes providing care regarding personal daily living activities such as personal health care, shopping, transportation, financial management, meal preparation, and household; 2) a transition which extends the caregiving perspectives beyond the immediate tasks by providing care of incorporation, performance, activities delegation and management as well as transferring to an institution; 3) caregiving is a role. Caregiving is viewed as a simple extension of the roles customarily enacted by family members and/or others; and 4) caregiving is a process. Caregiving is a process that occurs over time or a series of change. Swanson et al. (1997) claimed that a sense of responsibility of health care, filial obligation, social support adequacy, a history of the relationship between caregivers and care recipients, and a role acceptance are caregiving antecedents.

Bowers (1987) conducted grounded theory research to determine significant caregiving aspects with 27 parents and 33 of their offspring and summarized caregiving concept as: 1) the anticipation of behaviors or decisions based on patients' possible needs to participation; 2) the prevention of complications, and physical and mental deterioration; 3) an active and direct involvement in supervision of caregivers such as care arrangement, check up and set up care; 4) instrumental caregiving which includes hands-on caregiving to maintain physical integrity and health status; and 5) protection, to prevent unrecognized consequences. Based on Bowers' finding, only the fourth concept includes hands-on caregiving behaviors or tasks. The other four concepts are not observable behaviors but are processes crucial to intergenerational caregiving and to understanding of the experience of intergenerational caregiving.

Based on the above, caregiving can be referred to the assisting of care operations by a caregiver who provides care for physically and psychologically disabled persons to meet their demands of living due to a self-care limitation. After the spinal cord injury patients are discharged from hospital, they will be supported by caregivers at home who assist their living and surviving under the illness conditions.

Caregiving Activities for Persons With Spinal Cord Injury

The effects on spinal cord injury patients' immobility cause their self-care limitation. The caregivers' supports are important roles for the patients' daily activities and their medical treatment cooperation after passing the critical period with a stable condition. The caregiving tasks of caregivers that can perform in the hospital until patients rehabilitation at home include the following:

Physical care. Serving and providing physical care for daily activities and preventing complications are the main caregivers' duties. However, patients should be encouraged to do their daily life activities as much as they can along with caregivers' assistance when needed. Self-confidence, value and worth develop when patients are able to do activities by themselves. The caregiving activities that can be provided are as follows:

Breathing effective care. Encouraging an effective cough and training assistive cough techniques are necessary by placing the patients in a lying down position and put their hands below the diaphragm around the xiphoid and push it up while the patient exhales to increase the pressure in abdomen and chest (Satayawiwat & Chuesuwan, 2008). In addition, respiratory infection signs such as chest pain during inhale-exhale respirations and green or yellow mucous should be observed.

Water consumption. Patients with an indwelling catheterization need water 2,500-3,000 cc. per day and urination excretion should not less than 2,000 cc. a day. Patients with an intermittent catheterization need water 2,000-2,500 cc. per day and urination excretion should not less than 1,500 cc a day (Nesathurai, 2000).

Food consumption. A moderate calorie intake is important because patients should not to be overweight or underweight. The important food nutrition includes protein, vitamins and fiber. Each day, 80-100 grams of protein must be consumed to maintain flexible skin and prevent pressure ulcers. Vitamin C, 2-3 g/day, is needed to produce skin collagen and induce the urine acid because an acidic urine condition is an inappropriate environment for bacteria development; therefore it reduces a chance of infection and prevents gallstones due to dissolved calcium (Zejdlik, 1992). Fiber, found in vegetables, fruit and brown rice prevents constipation.

Regular urination. Patients with indwelling catheterization need to be observed for a tube obstruction or leak, lower abdominal expansion and oliguria. Patients with intermittent catheterization should release urine at least 4-6 times a day (Nesathurai, 2000). A normal urine condition is clear and released at approximately 1500-2000 cc a day. The overall liquid intake and output should be recorded every eight hours to check the water balance and signs of dehydration.

Personal hygiene. Since the spinal cord injury patients cannot do all daily activities by themselves, their personal hygiene needs to be taken care of by the caregivers.

Complications prevention. Complications that can be prevented are as follows:

Joint contracture. All joints such as wrists, elbows, shoulders, hips, knees, ankles, fingers and toes have to be exercised gently and slowly twice a day. It takes ten rounds for each exercise (Kovintha, 1990).

Pressure ulcer. Caregivers provide weight shifting, turning in bed at least every 2 hours, and the use of a preventive device to help the patient avoid skin break down. In the case of sitting on a wheel chair, the chair should be the correct size, type, and configuration for the individual. The caregivers should supply material support for sitting on the wheel chair and weight shift in upright every 15 to 30 minutes to allow adequate oxygen replenishment to muscles. Observing and caring for skin irritation, specifically, in the sacrum, coccyx, and joints areas, exercising the joints to stimulate blood circulation as well as encouraging proper food consuming are the important responsibilities of caregivers (Singhakhumfu, Chaisri, & Phuvaparothai, 2006).

Urinary tract infection prevention. Patients with an intermittent catheter have the risk of the urinary tract infection. Therefore, caregiving training of urine catheterization with a sterile technique is essential. The genital area should be dry. The indwelling catheter has to be changed every four weeks (Nesathurai, 2000). Also, infection and obstruction should be continuously observed.

Constipation prevention. A high-fiber diet, high fluid intake and physical activities produce normal feces. The patients should practice regular stool excretion that should be about half an hour after meal or ingestion of a hot liquid because the colon contraction occurs after meals. However, when there is constipation, manual evacuation is necessary, and followed by an enema (Kovintha, 1990). A laxative suppository can be used for serious constipation (Satayawiwat & Chuesuwan, 2008). The patient needs to be cleaned and observed for abdominal distension and flatulence after excretion.

Postural hypotension prevention. Reducing the vein congestion on the legs and abdominal organs can prevent postural hypotension by wrapping an elastic bandage from the foot to the thigh or the abdominal binder around abdomen for sitting position. When changing position, caregivers should observe the symptoms of low blood pressure such as dizziness, blurry vision, headache, and palpitation. Resting with the head down and elevating legs or leaning the back down for 15 to 20 minutes are positions to increase blood circulation (Zejdlik, 1992).

Body temperature. A change of body temperature depends on the environment temperature. In hot weather, the body should be kept cool by wearing light clothes and arranging a ventilated area away from the heat, as well as drinking 8 to 10 glasses of fluid per day. In cold weather, the patients should be kept in a warm environment by wearing extra protective clothes, drinking warm water frequently and cleaning the body with a warm bath (Koopanthavee, 1998).

Autonomic dysreflexia. When patients exhibit signs and symptoms of autonomic dysreflexia, she or he should be positioned with her or his head and torso elevated and the lower extremities lowered. This positioning may lower the blood pressure and promote cerebral venous return. The underlying source of the noxious sensation causing the dysreflexia should be investigated and eliminated as quickly as possible. Clothing and other devices that may be constricting should be loosened. Since bladder distention is the most common stimulus for autonomic crisis, draining the bladder may stop the crisis. A rectal examination can then be performed, and fecal impaction removed if present. If first aid treatment as mentioned above are not successful, caregivers should consult a physician promptly (Somers, 2001).

Psychological care. Physiological changes can cause mental and emotional problems. The following are psychological care needs (Koopanthavee, 1998).

Feelings of loss and grief prevention. Emotional expression such as crying or the feeling of anger are the patients’ reaction that caregivers should accept and pay attention to because they are a way to release their feeling of loss.

Negative self-concept and body image prevention. As mentioned above, the patients should be allowed to release their feelings and concerns. A caregiver should be a good listener without commenting. In addition, observing signs of depression and encouraging them to do their self-care activities create feelings of value, pride and confidence, especially with compliments.

Anxiety prevention. A comfortable sleeping position and massaging should be arranged for patients' relaxation. For example, meditation, praying, listening to the radio, watching television and reading their favorite books can be applied for relaxing to prevent anxiety.

Financial supports. The financial and economical concerns are significant stressors for patients. Support for the patients' expenses such as the cost of medicines, medical procedures, rehabilitation, physical devices and accommodation can reduce the stress.

Interaction supports with others. Although the patients' physical limitation is a barrier to social interaction, their needs of joining family and community activities should not be neglected. They might get the others' suggestion or assistance. Social participation influences creates a personal value and social acceptance. Social acceptance can make them feel proud and it is also motivation for them to take care of themselves. Caregivers can be a coordinator between the patients and the health care providers or the health government organization so that patients receive proper services.

The Effects of Caregiving for Spinal Cord Injury Patients

There are several caregiving tasks for spinal cord injury patients. These caregiving experiences can create both negative and positive consequences with caregivers:

The negative effects of caregiving. The caregiving situation creates negative aspects with caregivers as follows:

Physiological health. Physiological health problems are as follows: 1) Back pain. Pain from moving the patient is a common effect that most caregivers experience. Backache can also be psychosomatic, a caregiving stressor. It is a warning sign for needing a rest (Sasat, 2006). 2) Fatigue. Working long hours causes fatigue and affects caregivers' health and emotion directly. As a consequence, the complication of caregivers' health and their emotion affect their caregiving (Sasat, 2006). 3) Health problems increase. Because the caregiving tasks are full time work, the caregivers do not have enough time for themselves. They miss their own scheduled activities such as doctor's appointments, and taking medication or meals. They may also get insufficient rest. Hence, their own sickness might be aggravated and create more health problems (Schofield, 1998).

Psychological health. Stress and mental health problems are as follows: 1) Burden. The burden is the caregivers' perception of caregiving for a chronically ill person (Hunt, 2003). Caregivers perceive that they have caregiving responsibilities and feel difficulties in doing them (Morris & Edwards, 2006). The feeling of burden can be greater or lesser depending on several factors such as the severity of patients' pathology, the caregivers' personal characteristics and their responsibilities, and a period of time of caregiving (Wittaya-Sooporn, 1996). 2) Role stress. The role stress of caregivers involves role ambiguity, conflict and overload. First, role ambiguity is the uncertainty feeling of giving care due to lack of the caregiving knowledge. Second, role conflict appears when the caregivers perceive that they could not act appropriately in their family, job and society as the expectations and desires from family, job and society are different. Third, role overload occurs when the caregivers need their time and energy due to burden management failure. Not only caregiving but also earning money and looking after their family are their duties as well. Therefore, it can be difficult to set proper time for those duties effectively which can cause the role stress (Gasemgitvatana, 1993). 3) Burnout. It is an exhaustion of both physiology and psychology due to long hours of caregiving (Morris & Edwards, 2006). Similarly, Weitzenkamp, Gerhart, Charlifue, Whiteneck, and Savic (1997) explained that being a caregiver of a spouse with spinal cord injury has physiological and psychological effects which create upset feelings and burnout. 4) Hassles. It is the feeling of being annoyed, which is not a drastic situation. It appears when faced with difficult and complicated events. The accumulation of those events increases the feeling of being hassled and affects the mentality such as a chronic stress and their well-being (Hunt, 2003). 5) Guilt. Feelings of guilt occur after anger because of inability to respond the patients' needs (Sasat, 2006). In addition, when they face difficult caregiving events, they may wish that the patients would die. However, this feeling could not be expressed as it would be unacceptable in society. As a result, guilt causes caregivers' stress and suffering (Luengamornlert, 1994).

Social problems. Social problems are as follows: 1) Impact on work. Lifestyle of caregivers has to be adjusted for suitable caregiving. For instance, their work pattern may change from working full-time to part-time. Work condition changes as leaving the job earlier or being absent. Spending time for caregiving affects the power and a quality of work because of exhaustion and stress so there is less progress in their work situation (Schofield, 1998). Similarly, Maneewan et al. (1994) found 45% of caregivers who care for chronically ill patients could not work as usual. 2) Impact on family. The responsibilities of caregiving and taking care of their family should be managed effectively. Ineffective caregiving management can lead to a family problem such as less time for family activity and family neglect (Schofield, 1998). Also, the rejection of family responsibilities such as caregiving and family expenses occur. Maneewan et al. (1994) found the caregivers did not have enough time for their children and they argue with their spouses which were important family problems. 3) Isolation. The caregivers have to take care of patients 24 hours a day because they could not leave the patient alone. They have no time to socialize with their family and friends, therefore they feel isolated and alone in society (Luengamornlert, 1994; Sasat, 2006). This relates with a study on caregiving activities, caregivers' needs and the effects on elder orthopedics patients by Yothayai (2004), which found that 59% of caregivers had fewer social activities. 4) Change of lifestyles. Changes of the lifestyle of caregivers include missing meals, having unrest, lacking exercise, or being unable to do favorite activities (Chinsuwan, 2006).

Financial problems. Financial problems are as follows: 1) Decreased income. Income is reduced because they may have become a full time caregiver instead of working or cannot do overtime in their job. It is not only losing their income but also their savings. Yothayai's study (2004) showed that caregivers experience financial burden (59%), job resignation (18 %) and decreased incomes

(33%). 2) Expenses increase. The caregiving expenses involve medication, transportation and accommodation adjustment costs for the comfort and safety of patients (Morris & Edwards, 2006). 3) Debts: the patients with spinal cord injury need to be cared for in the long term which requires a lot of money to pay for medical treatment and increases in their expenses. Many caregivers have small incomes and some have to resign from their full time job to be a caregiver which requires them to save the money for these circumstances. Some might sell their properties, borrow money from their relatives or someone else. (Morris & Edwards, 2006; Schofield, 1998)

The positive effects of caregiving. Despite a high level of negative effects, caregivers also experience positive psychological states during caregiving. Having a positive feeling about caregiving enables the caregivers to cope better with stressful situations. The caregiving situation creates a positive feeling with caregivers as follows (Hunt, 2003):

Caregiver esteem. Caregiver esteem is the confidence or satisfaction caregivers feel as a direct result of caregiving. Caregivers feel that their patients get better because of their care and feel proud of themselves.

The feeling of repayment. Some caregivers might feel exhausted and upset with giving care and they need a rest. However, they still maintain their caregiving because of their feeling of paying back to a person’s favor or the loved one.

Gaining a sense of fulfillment for meeting an obligation. Caregivers feel proud of themselves as they can perform their roles of being a wife/husband or daughter/son.

Feeling needed. Caregivers feel as a value person, being needed by patients and praised by the family and the other people.

Enhancing relationship. Caregiving enhances the relationship between the caregivers and patients.

Learning new skills. Caregiving establishes a good life experience of gaining the knowledge of caregiving and learning to manage emotions, particularly their caregiving abilities.

Finding or making meaning through caregiving. The meaning of caregiving as the positive beliefs one holds about one's self and one's caregiving experience. When caregivers have a meaningful framework by which to face life adversity, they are more willing to accept the adversity and see it as a life challenge.

Because of the pathological conditions of spinal cord injury patients, they become a dependent person who needs to be cared for most of the time. Therefore, the caregivers spend a long time or their entire life giving care. In addition, there are many caregiving tasks such as excretion, personal hygiene, complication prevention and patients' mental, emotional, social and economical supports. These activities affect the caregivers' life and their well-being.

Well-Being of Caregiver

Well-being is a desire for all humans. It is a major goal of health care. It has been a variable in the study of health care service measurement. According to the literature review, well-being is a common variable on nursing outcome measurements in patients with cancer, cognitive impairment, dependence, chronic illnesses, and caregivers as well.

Perspectives in Well-Being

Scholars define well-being as a self-perception towards one's personal existence which expresses pleasure, life satisfaction, happiness, one's purpose and achievements to maintain personal development (Orem, Taylor, & Renpenning, 2001). Dirksen and Erickson (2002) described well-being as perception of a person on life satisfaction. Also, Anderson, Keith, Novak, and Elliot (2002) stated that well-being is an individual determination to receive good things and be satisfied in life due to his/her attitude or thought. According to the definition above, well-being refers to individuals' perception of their personal existence and/or situations, and the positive feelings of satisfaction and happiness.

Other scholars offer slightly different definitions of well-being which are multidimensional. The WHO (1998) describes well-being as an individual life perception that relates to his/her responsible abilities. It is a subjective dimension with a positive mood (good spirits, relaxation), vitality (being active and waking up fresh and rested), and general interests (being interested in things). Well-being is a state of successful performance throughout life course integrating physical, cognitive, and social-emotional functions. It is a subjective dimension of satisfaction which relates to an individual's potential success (Bornstein, Davidson, Keyes, & Moore, 2003). Well-being is the whole image of an individual's physical, mental, social and environmental status. Each aspect interacts with the others and has different levels of importance and affects the others individually (Kiefer, 2008).

Dupuy (1984) describes well-being as a positive or negative feeling of personal experiences. Higher positive feeling indicates better well-being. He considered well-being as a reflection of psychological conditions individually in six aspects as follows:

Anxiety. A result of dangerous situation evaluation. The danger evaluation differences depend on a personal decision-making process. The responses stimulate the automatic nervous system and present as tension, temper, and fear.

Depression. A mournful, depressed, sorrow, discouraged, hopeless, pessimistic, self-blaming and feeling-useless mental state.

General health. A relation between physiology and mentality is presented as an illness, a physical abnormality, and pain that affects directly to psychology or the illness concerns.

Positive well-being. A happiness and satisfaction of life for example, life achievement, a good family and family support, etc.

Self-control. An ability to control one's behavior, thoughts, emotions, and feelings help to manage some problems effectively which reduces stress and problem concerns. Generally, the more the self-control there is, the more positive the feelings are.

Vitality. A feeling of power, freshness, spirit, and encouragement which encourages a person to do activities without exhaustion.

Ryff (1989) explained well-being occurs with persons who accomplish over their life spans. The conceptualization of well-being covers six different dimensions:

Self-acceptance. A positive self-recognition attitude with a good feeling about the past are a personal self-concept. In contrast, a person without self-acceptance is unsatisfied and disappointed at his/her past and the desire in life is different from the others.

A positive relationship with others. The characteristic of a warm person presents positive relationships with others and can be trusted. The other characteristics include an interest of the others' welfare, an understanding of others' feelings, understanding giving and receiving the relationships with others. The opposite personalities would not receive trust or creditability.

Autonomy. Independent people are able to determine their own lives. They have a self-confidence which can handle social pressures. Those pressures cannot interfere with their thoughts of what they want to do under their self-control. The people who lack autonomy focus on the expectations and judgments of others only. Their important decision-making depends on someone else's decision and their actions are controlled by social pressures.

Environmental mastery. Effective environmental or surrounding management can be done by using available opportunities. Persons with the power of environmental management can master an appropriate context to their needs and benefit, whereas persons who lack power to manage their environment commonly experience difficulty of managing situations.

Purpose in life. Personal purpose in life is the way and meaning of living. It establishes personal values of the past and present living. Lack of life purpose present no meaning of living, life direction and attitudes or beliefs.

Personal growth. Personal growth development is a feeling of growing up individually that allows a person to gain new experiences and potential behavior improvement along with self-understanding. Without personal growth, an interest in life and desire of attitudes and behaviors are undeveloped.

Wang and Shieh (2001) summarized the concept of well-being as attributions of 1) a multidimensionality aspect compose of physical, mental, social and spiritual dimensions; 2) a dynamic continuum with time that ranges from negative through neutral to positive views imparting a sense of well-being; 3) cognitive and/or affective perceptions of everyday life experiences as a value by an individual and; 4) appraisal from internal essentially subjective feelings that cannot observed. To sum up, well-being is the personal cognitive and/or affective perceptions of daily life experiences with a dynamic continuum and multidimensional nature of physical, psychological, social, and spiritual dimensions. Antecedent of well-being are life experience and self-appraisal. Consequence of well-being is the result of a positive quality of life and health status.

Further, Zaff et al. (2003) concluded the meaning of well-being is a whole aspect which combines the dimensions of physical, social, and emotional aspects including cognition. Each aspect affects the others. The details of each dimension as follows:

Physical well-being. Physical health and safety is the first dimension of well-being. The important factors of physical well-being include good nutrition, health care, physical exercise, security and safety, avoidance of drug addiction and safe sexual behavior. Therefore, maintaining positive health, health behavior promotion, life security and potential of making-decision produce well-being in physiology.

Social and emotional well-being. Adaptation in different situations, stress management, effectiveness of reactions and positive feelings establish social and emotional well-being. Intellectual and emotional development, optimistic self-concepts and self-esteem, understanding of other's feelings, and sympathy a person's social and emotional life.

Cognitive well-being. Thoughts, perceptions, recognition, imagination, inference, and reason for receiving or utilizing knowledge. Communication involves the exchange of thoughts, needs and emotions. These are necessary for social relationship development and maintenance. Cognition is an adjustment basis of persons' concepts of health care, in order to participate in positive activities, and receive benefits from society and the environment.

A comparison of well-being with quality of life shows that well-being is only a subjective feeling assessment and interpreted into psychological or emotional factors. Quality of life is viewed as a whole image in objective and subjective assessments (Haas, 1999; Meeberg, 1993). However quality of life and well-being are related to each other such as well-being contributes quality of life and quality of life affects individuals' well-being (Wang & Shieh, 2001). Orem et al. (2001) stated that well-being is different from health but related to health. Persons with sufficient well-being are likely to have an optimal self-care and a positive health status. Similar, Antonovsky (1991) differentiated the meaning between health and well-being as health components are some kinds of an individual's well-being which make the boundary of health narrower than that of well-being.

From the literature review, the majority of scholars' well-being concepts relate with a positive feeling. Only Dupuy (1984) claimed that well-being is a personal feeling including both positive and negative sides. In summary, well-being refers to the individual assessment to the whole current life situations that person is facing. Well-being occurrence is a result of personalities, emotions, and stressors performance in each situation includes individual assessment or opinions which can be changed by time. The well-being levels depend on individual perception that is considered for all physical, mental and social aspects. Therefore, well-being assessment has to cover those three aspects in ones' self evaluation as it is a subjective perception. Persons with well-being can be described as a healthy person, with health attention, positive health behavior, positive self-attitudes, goal of life, a potential development, independence of decision-making, coping with stress and adaptation, good relationships with others and environment management to serve his/her needs.

For this study, the researcher applies a definition of caregivers' well-being as an individual's life perception that relates to the ability to take care of their own responsibilities. It is a subjective dimension as a positive view represents a person with a positive mood, vitality, and general interests (WHO, 1998). This definition is the best suitable meaning towards the objective of gaining insights into the caregivers' well-being related to their caregiving experiences in home care.

Measurement of Well-Being

Currently, the well-being concept is being applied for several research measurements in the health care fields. According to the literature review, well-being can be concluded to be a perception within an individual mind. Thus, the measurement of well-being assessment is an individual evaluation as a self-report as follows:

The General Well-Being Schedule. The General Well-Being Schedule developed by Dupuy (1984) was used to assess well-being and people distressed in community. It is divided into two parts as 18 self-report items that consists of 14 questions (seven positive and seven negative questions) in the first section. Those questions cover 6 aspects: anxiety (4 items), depression (3 items), general health (2 items), positive well-being (3 items), self-control (3 items) and vitality (3 items). The respondents assess these aspects during the past month. The answers are clarified as a rating scale (0-5 scores), with six levels. The first part total scores are between 0-70. The second part consists of 4 questions with two positive and two negative questions. Each question ranges from 0 to 10 points. The second part total scores are between 0-40. The scores calculation involves reversing the negative items scores first and then calculating the overall scores. The total score is between 0-110. A high score presents high well-being. Well-being levels are designated as 0-60 severe distress; 61-72 moderate distress, and 73-110 positive well-being.

Nakayama, Toyoda, Ohno, Yoshiike, and Futagami (2000) tested the general well-being validity among a sample of 1,224 middle-aged Japanese by employing exploratory factor analysis with orthogonal (varimax) rotation. The researcher found 53% of the total variance with three factors, i.e. depression, health concerns, and life satisfaction and emotion stability. The results of a correlation coefficient were -.76 with the General Health Questionnaire; -.67 with the state anxiety scale and -.66 for the trait anxiety scale of the State-Trait Anxiety Inventory; -.59 with the Center for Epidemiologic Studies Depression scale, and -.55 with Zung's Self-Rating Depression Scale. The instrumental internal consistency reliability was tested and found Cronbach's alpha coefficient of .90. The stability reliability of the instrument was tested by the test-retest method and the Pearson's correlation coefficient of the instrument was found to be .81.

Hanucharoenkul, Intarasombut, and Putvattana (1989) translated this English instrument into Thai and tested the instrument reliability among 30 nurses of the Nursing Department of Ramathibodi Hospital and found a Cronbach's alpha coefficient of .92 and among 230 nursing instructors of the Faculty of Nursing from Chiang Mai University, the Faculty of Medicine, Ramathibodi Hospital, and Mahidol University, with a Cronbach's alpha coefficient of .91. Kasemsuk (2002) examined the Thai version of the instrument with 2 caregivers' groups of delayed development children at the Northern Child Development Center. One group of children lived at the center and the other received day-care treatment, with 10 caregivers per group yielding a Cronbach's alpha coefficients of .80 and .83 respectively. Chaoum (1993) applied this instrument with 20 family caregivers of dependent elderly people with a Cronbach's alpha coefficient of .90. Furthermore, Daonophakao (2004) applied this instrument with 30 caregivers of stroke patients and found a Cronbach's alpha coefficient of .81.

Cantril Self-anchoring Ladders Scale. Cantril Self-anchoring Ladders Scale developed by Kilpatrick and Cantril (1960) was used for measuring well-being levels in specific situations. The score is 1-10, with a higher score indicating higher well-being. This scale has only one item. In order to further evaluate the instrument's reliability, Klin-ual (2001) subjected it to a test-retest reliability (Peason's Product Moment Correlation) with 15 elderly persons during a period of one week and found a reliability coefficient equal to .83. Previously, Pangjai (1999) also tested the instrument with 15 elderly persons for a two-week period and found a reliability coefficient equal to .95. Moreover, Kingnetr (1996) tested it with patients who suffered from leukemia and received chemotherapy over one week and found a reliability coefficient of the instrument equal to .86.

Four Single Item Indicators of Well-Being. Four Single Item Indicators of Well-Being was created by Andrew and Crandall (1976) for general life satisfaction assessment in the general population and patients. This instrument tests the past and present situations and includes people's expectation of the future which composed of four scales:

The Delighted-Terrible Scale. A rating scale of 1 to 7 to measure feelings about life from delight to commiseration.

The Faces Scale. A score value from 1 to 7 based on seven cartoon faces. Each faces have stable eyes with changes of the mouth. The mouth in each picture expresses differently, from a happy smiling face to an unsatisfied frowning face. The respondents are asked which face expression is the best to represent their feelings of life.

Ladder Scale instrument. A picture of nine step-ladders where the top-step stands for feeling of the best that life could be and the bottom step for feeling of the worst that life that could be.

The Circles Scale instrument. It is composed of nine circles. Each circle contains eight channels and each channel has the symbols as + and –. The first circle contains all minus and the ninth circle only plus symbols. The plus symbols indicate good things and minus symbols indicate bad things. The respondents are asked which circle stands for their feelings of life.

Testing the reliability scale, Andrew and Crandall (1976) applied a test-retest reliability method with 222 adults and found a reliability coefficient equal to

.70. Suwan (1994) translated this instrument to Thai. However, according to the literature review, the Thai version instrument has not been applied to any studies in Thailand yet.

The World Health Organization-Five Well-Being Index. The World Health Organization-Five Well-Being Index, WHO-5 is a self-report measurement. It consists of five well-being index items that were developed from the World Health Organization-Ten Well-being Index (Beach, Gudex, & Johansen, 1996). It assesses well-being in the past two weeks. WHO-5 questions investigate positive mood (good spirits, relaxation), vitality (being active and waking up fresh and rested), and general interests (being interested in things). The scores on a six-point Likert scale ranging from 0 (not present) to 5 (constantly present). Total scores range between 0-25 where higher scores indicate better well-being. Less than 13 points indicate poor well-being.

De Wit, Pouwer, Gemke, Waal, and Snoek (2007) tested the reliability of WHO-5 with 91 type 1 diabetic teenagers and found a Cronbach's alpha coefficient was .82 and found confirmatory factor analysis for one-factor structure. The one-factor explained 62.5% of the variance. Moreover, Awata et al. (2007) also assessed the reliability with 129 diabetic patients and obtained a Cronbach's alpha coefficient equal to .89 and found confirmatory factor analysis for one factor. The one-factor explained 70.8% of the variance.

The English version of the WHO-5 Well-being Index was translated into Thai by Saipanish et al. (2009), including forward-translation, synthesis of the translation, backward-translation, cross-cultural adaptation and pilot testing. The Thai version of WHO-5 Well-being Index (WHO-5-T) consists of the same five well-being index items as the original English version. WHO-5-T was tested for reliability and validity among 274 patients with chronic illness in the outpatient clinic of the Department of Family Medicine, Ramathibodi Hospital. The Cronbach's alpha coefficient reported was .87. A factor analysis showed only one factor, which explained 66.8% of the variance, by considering eigenvalues more than 1.0. Using Pearson's correlation coefficient to determine the convergent validity, the total score of the WHO-5-T and the Hamilton Rating Scale for Depression (HAM-D), which scored in opposite directions, were negatively correlated (-.54, $p < .001$).

For this study, the assessment of well-being of caregivers of spinal cord injury patients was based on the World Health Organization-Five Well-Being Index Thai version by Saipanish et al. (2009). This instrument was selected because the questions relate with the definition of well-being caregivers with spinal cord injury patients in this study. Also, psychometric properties of the measurement in Thailand showed high reliability.

Factors Influencing Well-Being of Caregivers

To promote caregivers' well-being, it is necessary for nursing consideration to understand which factors influence caregivers' well-being in order to develop effective nursing intervention. The related factors are divided into two aspects as follows:

Patient factors.

The illness severity. The different levels of spinal cord injury pathology affect the patients' self-care ability differently (Nesathurai, 2000; Pajaree, 2000). Caregiving of upper spinal cord injury is more difficult and complicated than the lower injury. The dependent patients with a high level spinal cord injury need more help and support from caregivers. The caregivers have to put in more effort for long term care. Working long hours with a complicated task, especially for caregiving with a high level of spinal cord injury patient, might discourage caregiving and well-being.

Psychological changes. The effect of spinal cord injury is that it changes the patient from a healthy person to a dependent person. It affects the ability to work. The patient becomes unemployed and loses social roles that can cause adverse psychological conditions (Koopanthavee, 1998). The acceptance and living adjustment required with the illness are important factors influencing emotions. Persons who are unable to accept and adjust their living with illness might appear moody for no apparent reason, do not try to do their self-care activities and require help most of the time. These behaviors of patients create conflicts between the patients and the caregivers. This conflict situation cause stress to caregivers and decrease their well-being.

Caregivers factors.

Age. One of factors that differentiate spiritual maturity, perception and ability to perform behavior is age. Older caregivers have a lot of life experience and information support. Therefore, their burden of family and society are less than younger ones (Morris & Edwards, 2006; Phuvaravutphanich, 1994). However, a poor health condition of older caregivers affects the caregiving as they might not be able to serve care for a long time.

Gender. Gender differences affect the beliefs, attitudes and values. Female caregivers may be brought up to be a housekeeper and a caregiver. Society also tends to expect females to be a caregiver more than males (Morris & Edwards, 2006).

Hence, females' acceptance and adjustment to take the roles of caregivers is possibly easier than males.

Educational level. Intellectual development and logic are the result of education. Persons with a higher educational degree are usually more able to realize and understand the events; use logic to solve problems; and have positive attitudes of caregiving. Moreover, caregivers with higher education are able to acquire more knowledge and understanding of the illness condition as well as request some assistance from existing information resources (Chaoum, 1993).

Knowledge. Knowledge and understanding of patients' physical and psychological aspects are important for the caregiver. Those knowledge and skills enhance caregivers to serve care effectively with confidence and spend less time, which are positive results towards the well-being of caregivers (Chaoum, 1993; Chappell & Reid, 2002).

Health conditions. Caregiving is a continuing and time consuming task that might cause caregivers' health problems. Their daily routine changes such as delayed meals or less food consumption, poor appetite, lack of exercise, insufficient rest, insomnia, serious tension, etc that can affect their well-being (Decker, Schultz & Wood, 1989).

Economic conditions. Income is a influencing factor as it is a basic need of life. The persons with high income have more beneficial sources to support their caregiving (Jaroonsit, 2011).

Coping with stress. An effort of thoughts and actions in dealing with situations that affect one's welfare is called coping with stress. Caregivers have to use beneficial sources to support their efforts. If they can manage their stress appropriately, then their well-being can be established (Rammohan, Rao & Subbakrishna, 2002).

Sense of coherence. It is a strong feeling of belief that whatever happens in the internal or external environment, those events can be solved as the expectation. It encourages environmental adjustment and establishes one's well-being (Hanucharoenkul, Intarasombut, and Putvattana, 1989). Furthermore, the problems are viewed as challenging, meaningful, hopeful and understandable. These problems can be solved by eliciting and applying the knowledge from existing beneficial sources to manage or deal with the tension appropriately (Antonovsky, 1991).

Rewards of caregiving. Caregivers' well-being derives from a positive feeling from being a caregiver that is composed of a positive obligation and the duties of being husband/wife or children/grandchildren and making merit (Sasat, 2006). It establishes the relationship between patients and caregivers (Yothayai, 2004). Also, the caregivers obtain valuable experiences, a social network and caregiving skills. Providing caregiving causes problems to caregivers in various aspects, the rewards can act as buffers to relieve the negative feelings and reduce the burden as well as support their feelings of well-being.

Burdensome feeling. Caregiving is a time consuming and difficult task for caregivers that create tiredness, muscle pain, and lack of relaxation. The caregivers might feel exhausted and overloaded and thus perceived as a caregiving burden. This burden brings about changes and difficulties in life which reduce their well-being (Chaoum, 1993; Chappell & Reid, 2002).

Patients and caregivers relationships. A good relationship between caregivers and patients establishes understanding and sympathy for caregiving. Caregivers are willing to take care of the patients without any expectations or returns (Sasat, 2006). Thus, caregivers who care patients with positive relationship will perceive well-being. In contrast, a poor relationship can be a stressor and has an influence on the unwillingness and decrease well-being of caregivers.

Social support. A useful resource of caregivers is social support. It may decrease the stress and emotional problems and help manage various problems.

Caregiving hours. Providing care takes several hours per day, and may cause exhaustion, discouragement, stress and diminished well-being.

Based on the literature review of those factors affecting caregivers' well-being, the findings show that there are several factors affect their well-being, including factors related with patients and caregivers. For this study, the researcher selected only certain factors by choosing the variables that have a strong relationship with caregivers' well-being and which can be managed for nursing interventions to promote well-being of caregivers. The selected factors include rewards of caregiving, social support, caregiving hours, a patient's functional status, and caregiving burden. According to the literature review, there are no comprehensive and clear theories or concepts which explains caregivers' well-being phenomenon. However, the researcher developed a conceptual frame work based on an extensive literature review. Hence, these related factors are hypothesized in this study. The details about the concepts and the relationships between the factors selected in the hypothesized model are as follows:

Rewards of Caregiving

Previous studies mostly focused on undesired effects such as stress, strain, burdens, depression and health risks. However, some research studies show positive consequences or benefits of caregiving. The review below covers the rewards of caregiving perspectives and assessment and explains the relation of rewards on caregiving, burden and well-being.

Perspectives in Rewards of Caregiving

Caregivers feel good and positive from taking care of patients despite possible negative qualities of caregiving conditions. Those positive feelings generated during the caregiving process are called ‘rewards of caregiving’. Some studies use words like uplifts, gains, caregiving satisfaction, positive aspects of caregiving, and gratification. Kramer (1997) defined ‘gains’ as the extent to which a caregiving role enhances and enriches an individuals’ life space. The study of Shirai, Koerner and Kenyon (2009) stated that the caregivers feeling gains are the positive feelings that occur as a result of providing care.

Additionally, Kinny and Stephens (1989) conducted an ‘uplifts’ study of caregiving to a family member who had dementia. They defined uplifts as the events that make caregivers feel good, joyful, glad or satisfied. Motenko (1989) clarified ‘gratification’ as a caregiver’s experience of warmth, comfort, and pleasure during caregiving. Lawton, Kleban, Moss, Rovine, and Glicksman (1989) identified ‘caregiving satisfaction’ as a positive aspect from caregiving. Caregiving satisfaction is defined as what one does or feels as a caregiver is a source of personal satisfaction. Pearlin et al.

(1990) asserted the positive outcomes of caregiving can be represented by the caregivers' inner growth, self-confidence or appreciation for their abilities because of caregiving challenges. Similarly, Farran, Kaeane-Hagerty, Salloway, Kupferer, and Wiken (1991) identified valuing 'positive aspects of the caregiving experience' as a positive consequence of caregiving. Positive value aspects have two dimensions of relations and caregiving. The relational aspects are family values and social relationships, love, memories and accomplishment with others. The caregiving aspects consist of being appreciated, having positive caregiving responses, and confidence value.

Other scholars defined the 'rewards of caregiving'. For instance, Thibaut and Kelley (1959) defined rewards as the pleasures, satisfactions, and gratifications of providing care. Nye (1978) expanded this list to include status, relationships, interaction, and feelings which provide gratification. Samartkit (2008) stated that caregivers' positive feelings that they perceive and experience from caregiving for their family member are called rewards of caregiving.

Moreover, Hinrichsen, Hernanden, and Pollack (1992) studied the rewards of caregiving with 150 spouses and adult child caregivers of older adults with major depressive disorder. The results are reported as three dimensions of caregiving rewards: 1) A caregiver's relationship with patient has improved or been enhanced since patient became ill. There is greater appreciation to see the patients' condition improvement because of their assistance. 2) Caregiver's satisfaction over having fulfilled an obligation to the patient. They are satisfied with gaining strength from helping others 3) The relationships between caregiver and other family members and health care providers.

Archbold et al. (1995) stated that rewards of caregiving create positive feelings which support the caregivers' feelings. Their lives become more meaningful and proud. Archbold et al. (1995) divided the rewards of caregiving into five aspects: 1) Rewards of meaning for oneself means the extent to which the caregiver has a sense of personal accomplishment and finds life more meaningful because of caregiving. 2) Rewards of learning means gaining beneficial learning that occurs for the caregiver because he or she fulfills the caregiving role with better understanding of health conditions, sickness and provision of care for patients. 3) Financial rewards refer to occasional material gains in the form of objects or money from other relatives exclusive of paid employment. 4) Rewards from spiritual fulfillment means the caregiver's feeling of fulfillment from the spiritual philosophy of religion, which includes accumulating good deeds or meritorious acts which could enable them to get good things in return. 5) Rewards from being there for patient means the caregivers' perception of caregiving as a good opportunity to assist, support, and love the patient.

Picot, Youngblut, and Zeller (1997) defined a similar perceived rewards definition as positive subjective feelings or objective changes with both internal and external caregivers' lives that are as a result of their caregiving. Picot, Debanne, Namazi, and Wykle (1997) divided perceived caregiver rewards into two domains as: 1) external rewards as verbal or nonverbal communication with God, health care professionals, and care receiver regarding the quality of the caregiver's caregiving; and 2) internal rewards encompassing the caregiver's personal feelings of achievement and growth, such as stabilizing or improving the patient's health status, obtaining skills and knowledge.

Yamamoto-Mitani et al. (2001) divided a positive care appraisal into four domains: 1) Relationship satisfaction is a positive appraisal obtained from the relationship attachment with the patient. 2) Role confidence is a caregiver's perception of caregiving and being the best person for the patient. 3) Consequential gain is a perception of reward incurred as a result of the caregiving experience such as insight into human life, personal growth, or new meaning in the caregiver's life. 4) A normative fulfillment means caregivers have a good feeling of caregiving because they consider it to be virtuous.

Based on all of the above review, the rewards of caregiving have meanings close to uplifts, satisfaction, positive aspects of caregiving, personal gains of providing care, as well as gratifications from caregiving. The meaning of rewards of caregiving in this study is based on Archbold et al. (1995) as it is the caregivers' positive feelings resulting from caregiving experiences.

Measurement of Rewards of Caregiving

According to the literature review, the reward of caregiving concept is the perception within caregivers' mind. Thus, it has to be measured by an individual assessment as a self-report. The self-assessment measurements are as follows:

The Rewards of Caregiving Scale. It was developed by Archbold et al. (1995) to evaluate caregivers' positive feelings of caregiving. There are 27 items divided into five rewards aspects of: meaning for oneself, caregiver learning, finance, spirit, and being with a care receiver. This questionnaire is a five-point Likert Scale. Each item is scored ranging from 0 (not at all) to 4 (a great deal). The total scores are 0 to 108. A high score indicates high rewards of caregiving.

The internal consistency reliability testing in this instrument has been done by Archbold et al. (1995) and Eldredge et al. (2006). The study by Archbold et al. (1995) indicated a high internal consistency (Cronbach's alpha coefficient .77 to .94). The other study by Eldredge et al. (2006) found the internal consistency reliability among caregivers of people recovering from autologous blood replacement and marrow transplantation with a Cronbach's alpha coefficient equal to .85.

The internal consistency reliability testing in this instrument in the Thai version was conducted by Gasemgitvatana (2002, personal communication, March 8, 2010) who translated the original 27-item Rewards of Caregiving Scale into Thai and modified it to fit Thai culture, using factors analysis with 310 caregivers of stroke patients. The new version of the Rewards of Caregiving consists of 15 items and is divided into four aspects as: rewards of meaning for oneself (4 items), rewards of family-strengthening (2 items), rewards from spiritual fulfillment (4 items), and rewards of self-gratification (5 items). Cronbach's Alpha for the Thai new version questionnaire was .88. Another study presented a Cronbach alpha coefficient of .93 in both groups of 30 and 290 caregivers of traumatic brain injured patients (Samartkit, 2008).

The Positive Appraisal of Care (PAC) Scale. The Positive Appraisal of Care Scale was developed by Yamamoto-Mitani et al. (2001). The PAC items identify caregiving experience appraisals in the previous two weeks. It is a self-administered questionnaire that consists of 21 items of four domains as: satisfaction relationship (5 items), role confidence (5 items), consequential gain (6 items), and normative fulfillment (5 items). There is a four-point scale from 0 (not at all applicable) to 3 (very much applicable). The possible range score is 0-100, with higher scores indicating more positive appraisal. This instrument has been examined with the caregivers of elderly patients (Yamamoto-Mitani et al., 2003). The report of Cronbach alpha coefficients were satisfaction relationship aspects (.84), role confidence (.83) consequential gain (.84), normative fulfillment (.74), and for the overall instrument (.92). However, there is no Thai version for this instrument.

The Picot Caregiver Rewards Scale (PCRS). The Picot Caregiver Rewards Scale (PCRS) developed by Picot, Youngblut, et al. (1997) with 24 items divided into two domains of 13 internal and 11 external rewards items. Respondents are asked to rate their caregiving feelings on a five-point Likert Scale from 0 (not at all) to 4 (a great deal). The possible range of total scores on perceived rewards is 0-96. The higher the score the higher the caregiver's perceived rewards. The internal consistency reliability test was examined among 83 African-American female caregivers of elderly with dementia patients yielding a Cronbach alpha coefficient of .86 (Picot, Debanne, et al., 1997). However, there is no Thai version in this instrument.

For this study, the researcher applied the Rewards of Caregiving Scale that was translated and improved by Gasemgitvatana (2002, personal communication, March 8, 2010). This instrument is based on Archbold et al. (1995) which relates to the rewards of caregiving definition of this study. Moreover, the psychometric properties have been tested and an instrument reliability of more than .80 was found (Burns & Grove, 2005).

Relationship Between Rewards of Caregiving and Caregiving Burden

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 while providing caregiving activities. According to the literature review, there are few research studies of rewards of caregiving and caregiving burden. Therefore, it is of interest to study the positive feelings of being a caregiver including uplifts of caregiving, caregiving satisfaction, positive aspects of caregiving, as well as personal gains and gratifications from caregiving and caregiving burden.

Pinquart and Sorensen (2003) conducted a meta-analysis on 228 studies of caregivers of the patients suffering from dementia, cancer, Parkinson’s disease, and older adults with physical and mental impairments. There were 24 studies of the caregiving uplifts and caregiving burden. The findings showed a negative relationship between caregiving uplifts and the caregiving burden (correlation coefficient -.19 to -.13). This is similar to Lawton et al. (1991)’s study on well-being of 285 spouse caregivers and 224 adult child caregivers with Alzheimer’s disease patients who found caregiving satisfaction and caregiving burden have a negative relationship ($r = -.33$, $p < .05$), and caregiving satisfaction directly influences the caregiving burden ($\beta = .27$, $p < .05$).

Son, Wykle, and Zauszniewski (2003) studied caregiving satisfaction among 117 adult child caregivers of older adults with dementia. The outcome presented a negative relationship between caregiving satisfaction and caregiving burden ($r = -.32$, $p < .01$). Also, Talkington-Boyer and Snyder (1994) studied the impact on 110 family caregivers of Alzheimer's disease patients. The result showed the relationship between caregiving satisfaction and the caregiving burden was negative ($r = -.17$, $p < .05$). In addition, Cohen et al. (2002) conducted research on the positive aspects of caregiving among 289 caregivers of elderly people and found caregiving positive aspects were in a negative relationship with the burden ($p < .001$).

Briefly, those studies results are similar as the rewards of caregiving have a negative relationship with the caregiving burden. The caregivers with a high perception of caregiving rewards have a low level of caregiving burden perception. However, the rewards and burden of caregiving are mostly found in correlation research studies. The evidence about the causal relationship was not clear. Studies on the relationship between reward and caregiving burden have not been found in any Thai research study. Therefore, it is interesting to study this topic in the Thai context.

Relationship Between Rewards of Caregiving and Well-Being of Caregivers

Caregiving is a source of positive affect to caregivers such as feeling more useful, feeling needed, increased self-knowledge, elevated self-esteem, heightened self-efficacy, and improvement in the caregiver-patient relationship as well as a sense of greater purpose and adding meaning to one's life (Hunt, 2003). These positive feelings induced caregivers to generate feelings of well-being while providing caregiving activities. According to the literature review, there are few research studies of rewards of caregiving and well-being of caregivers. Therefore, it is of interest to study the positive feelings of being a caregiver including uplifts of caregiving,

caregiving satisfaction, positive aspects of caregiving, as well as a personal gains and gratifications from caregiving and well-being of caregivers.

Pinquart and Sorensen (2004) determined caregivers' well-being with dementia patients or chronic disease by conducting meta-analysis of 60 studies. There were nine studies which revealed a positive relationship between uplifts of caregiving and their well-being. The correlation coefficient was between .20-.29. Similarly, Lawton et al. (1991) tested the well-being of 285 spouse caregivers with Alzheimer's patients caregiving and found a positive relationship between caregiving satisfaction and well-being ($r = .32$, $p < .05$) and the satisfaction had direct influence on well-being ($\beta = .45$, $p < .05$). Elsewhere, Martire, Stephens, and Atienza (1997) studied 118 female caregivers providing care for ill or disabled parents or parents-in-law and found caregiving satisfaction had a positive relationship with well-being ($r = .32$, $p < .01$) and a negative relationship with depression ($r = -.20$, $p < .05$). Moreover, Cameron et al. (2006) examined 109 informal caregivers of survivors of acute respiratory distress syndrome and discovered that well-being was associated with personal gains from providing care. In Cameron et al.'s study, personal gain was based on the definition by Pearlin et al. (1990) and found personal gains, mastery, and social support could explain 43% of the variance of caregivers' well-being, much like Motenko (1989) who studied caregiving gratifications and the well-being of 50 female caregivers who provided care for dementia husbands at home. The well-being concept of Dupuy (1984) was applied for this study and showed a positive relationship between the caregiving gratification and the well-being ($r = .43$, $p < .05$).

To summarize, the rewards of caregiving have a positive relationship with well-being ($r = .20$-$.43$, $p < .05$) and also predicts the well-being of caregivers ($\beta = .45$,

$p < .05$). However, there is no evidence of an empirical study of the relationships between the rewards of caregiving and caregivers' well-being in Thailand. Certainly, the Thai caregiving contexts differ significantly from those in the Western countries. Therefore, it is informative to investigate the relationship between the rewards of caregiving and the caregivers' well-being to gain a more specifically Thai insight.

Social Support

Humans exist in a complex network because everyone relies on each other to serve their psychosocial and physical needs. Social support has an important role to assist and solve problems or difficulties in lives and adjust oneself in different situations as well. Therefore, social support is a significant factor for health professionals, especially nurses. The perspectives in social support, assessment as well as the relationships that relate to the burden and well-being of caregivers are reviewed below.

Perspectives in Social Support

Scholars offer various definitions of social support. Weiss (1974) proposed five types of social support provisions as 1) a relationship of attachment with a parent, spouse and relatives that makes a person feel loved and cared for; 2) social integration as a person has an opportunity to participate in social activities and able to share information, feelings, and care with others; 3) nurturance means a person has a chance to take care of and bring up his/her children in a comfortable life and feel desired by others; 4) reassurance of worth, i.e. the feelings of an being accepted, honored and valued from their families and the society; and 5) receiving instruction from health providers when critical assistance is needed.

Cobb (1976) reviewed the studies of social support from 1960-1970 and claimed that the totality of what persons receive to establish their beliefs of care, love, attention, value, honor, and social belonging are social support. There are three types of social support as 1) emotional support such as love and care; 2) being valued and accepted by people in the society, and 3) social participation as a person perceives help from social network when needed. Cobb (1976) focused on only emotional support and social network. Both Wiss (1974) and Cobb (1976) omitted material support and services.

Caplan (1974) explained social support as a continuing nature mediated by an enduring set of relationships with one or more significant others or groups that provide special assistance in dealing with particular long-term burdens or privation. Social supports are likely to mobilize persons' psychological resources and emotional burdens mastery by sharing the tasks, providing extra material supplies, tools, skills, and instruction to aid in the improvement of the situation. Caplan (1974) included material support in the reciprocity characteristics of social support conceptualization.

Kaplan, Cassel, and Gore (1977) defined social support as satisfaction towards the social base of a person and environment, which encourages communication and interaction with others. Brandt and Weinert (1981) revised Weiss's social support concept in a comprehensive fashion as composed of five dimensions: 1) provision for attachment/intimacy; 2) social integration (being an integral part of a group); 3) opportunity for nurturant behavior; 4) reassurance of worth as an individual and in role accomplishment, and 5) availability of informational, emotional, and material assistance.

Schaefer et al. (1981) divided social support into three types: 1) emotional support such as a feelings of attachment, reliability and trust; 2) informational support such as advice and behavior or action feedback information, and 3) tangible support such as materials, money, services or other things. Jacobson (1986) divided social support into 1) emotional support which includes behaviors that enhance emotion relief, respect, love and care; 2) cognitive support which includes information, knowledge, or advice, and 3) material support which includes services or materials.

Thoits (1982) stated that social support consisted of emotional, social, material, and informational provisions from society to assist persons to cope with stress. However, these definitions of social support focus on only the care receiver. Next, House (1985) identified the social support concept as 1) emotional support which includes affection, trust, concern, listening and compliments; 2) appraisal support which includes behavior affirmation or feedback information to compare with other people in their society; 3) informational support which includes directions, information, advice and suggestions for understanding and adjustment of the changes, and 4) instrumental support which includes aid, money, labor, service, time, and environmental modification.

Langford, Bowsher, Moloney, and Lillis (1997) analyzed the concept of social support by reviewing approximately 85 articles and found that critical attributions of social support involves emotional, instrumental, informational, and appraisal support. Within the attribute of social support, the support exchange or reciprocity must be presented continuously. Social networks, social embeddedness, and social climates were identified as antecedents of social support. Social support consequences were subsumed under the general rubric of positive health status or behaviors. For instance, personal competence increases in times of stress, health behavior maintenance, effective of coping behaviors, perception of control, sense of stability, self-worth recognition, positive effect, psychological well-being, whereas anxiety and depression decrease personal competence.

Finfgeld-Connett (2005) clarified the concept of social support by meta-synthesis of strategies from 44 qualitative studies and three linguistics analyses. The report presented that critical attributions of social support involved interpersonal process, dynamics, and advocacy. Social support antecedents such as a perceived need, a social network and climate were social support exchange conductions. Finfgeld-Connett (2005) indicated social support consequences occurred in a broad category of mental health improvement and, in large part, pertained to increased personal competence. This definition clarified an interpersonal process promoter characterized by reciprocal information exchange and specific context. Moreover, McDowell (2006) mentioned that support from groups of reliable and credible people enhance the personal value of receiver.

Although social support is intended to be helpful, it can sometimes result in negative consequences for recipients, including poorer emotional and physical well-being (Bolger, Zuckerman, & Kessler, 2000). Four possibilities have been suggested as explanations. First, high levels of support which are more than the recipient needs may harm the recipient's self-worth including perceived incompetence, independence, and lacking in autonomy. The recipient feels that the provider thinks he or she cannot handle the problem alone. Second, the support received might be unwanted, ineffective, inappropriate, or incongruent with the specific needs of the recipients. Third, the recipients perceived that effective support is invisible support, goes unnoticed or is not interpreted as helpful support. Fourth, the recipients feel indebtedness, over benefit, and inequity in received support (Bolger & Amarel, 2007; Scholz, Kliegel, Luszczynska, & Knoll, 2012).

There are various social support terminologies, all those definitions refer a positive interaction or helpful behavior for a person who needs support. The three common types are emotional, tangible, and informational supports. In this study, social support is conceptualized as caregivers' perception of resource availability and adequacy of informational, emotional, and tangible supports (Schaefer et al., 1981).

Measurement of Social Support

According to the literature review, social support and its dimension are identified by scholars in different ways. Thus, the social support instruments are varied. However, the scholars conclude that social support is a subjective perception that has to be assessed by self-report only. These measurements are as follows:

The Personal Resource Questionnaire (PRQ). The Personal Resource Questionnaire (PRQ) was developed by Brandt and Weinert (1981) that associates with Weiss' social support concept (1974) in order to assess the social support perception. There are two parts to the questionnaire: personal beneficial resources and person with society reaction. The personal beneficial resources are evaluated by the interviewees' identification of 10 life situations in the last six months that they needed resources to support. If the interviewees have experiences from any situations, they then specify the satisfaction level of help that they received.

The person with society reaction assessment has 25 items divided into five aspects as 1) the indication that one was valued (worth), 2) one belongs to a group (social integration), 3) the provision for attachment (intimacy), 4) the opportunity for nurturance (nurturance), and 5) the availability of information, and subjective and material helps (assistance/guidance). There are seven levels of rating scale from 1 (strongly disagree) to 7 (strongly agree). The total score range is 25-175 and a high score indicates a high level of social support.

The internal consistency reliability was investigated by Weinert (1987) with 132 middle adults and found the Cronbach's alpha coefficients of self-worth (.78), social integration (.66), intimacy (.73), and the entire questionnaire (.89).

Hongtrakul (1989) translated this instrument into the Thai language and tested reliability with 100 hypertension patients and found a Cronbach's alpha coefficient of .90. Gasemgitvatana (1993) modified this same instrument and tested it with 104 wife-caregivers of chronic ill patients. The Cronbach's alpha coefficients for self-worth, social integration, intimacy, nurturance, and assistance were .73, .67, .74, .82, and .83, respectively. The coefficient for the whole questionnaire was .91.

Social Support Questionnaire. Pipatananond (2001) modified the Social Support Questionnaire that had been converted from two original instrument versions into Thai by Hanucharoenkul (1988). Hanucharoenkul (1988) modified the Social Support Questionnaire from the Social Support Questionnaire (Schaefer et al., 1981) and the Norbeck Social Support Questionnaire (Norbeck, Lindsey, & Carrieri, 1981). This social support questionnaire measures support a person receives from other people. Pipatananond (2001) altered this questionnaire to be appropriate for the situations of caregivers with illness patients rather than self-care. There are three aspects of social support evaluation which include information (1 item), emotion (4 items) and tangible (2 items). The quantity of help from five resources are asked as 1) families (spouse, parents, and children; 2) siblings and relatives; 3) friends, co-workers, and neighbors; 4) other providers in community such as traditional doctors, priests, police, and others; and 5) health care providers. The rating scale has five levels starting from 0 (never giving help) to level 4 (give most help). Each social support resource consists of the same seven questions. The total score from all sources of social support is obtained by summing across all items, with a possible total score range from 0 and 140. Higher scores present higher social support.

Pipatananond (2001) tested the content validity of her Social Support Questionnaire Thai version that was confirmed by six experts. Pipatananond obtained a content validity index of one. Construct validity was tested with 566 schizophrenic patients and results were analyzed by factor analysis. The tests showed only one factor could explain the variance at 81.6% in social support among caregivers. Reliability testing of questionnaire items was examined with 30 caregivers of schizophrenia patients with the Cronbach's alpha coefficient of emotional dimension (.93), tangible (.88), and total questionnaire items (.98), except information test report. Moreover, testing with 566 schizophrenia patients found the Cronbach's alpha coefficient in the domain of emotion (.94), tangibles (.91) and total questionnaire items (.96). This test also had no information test report. The correlation coefficient obtained by Pearson's Product of Moment correlation between the supports of information and emotion (.88), information and tangibles (.78), and tangible and emotion (.86).

Santati (2005) tested the reliability of the Social Support Questionnaire that was modified by Pipatananond (2001) among 30 parent caregivers of pre-school asthmatic children and found the Cronbach's alpha coefficient of the total questionnaire of .95.

Inventory of Social Support Behaviors (ISSB). Inventory of Social Support Behaviors (ISSB) was developed by Barrera, Sandler, and Ramsay (1981) to evaluate the social support of the general population in the preceding month. There are four aspects, namely emotional support, tangible support, guidance, and society. There are 40 statements with four answer choices of one or two times, once a week, several times a week, and almost every day. The total score is between 40 and 160. A high total score refers to a high level of social support.

Furthermore, Barrera et al. (1981) investigated the internal consistency reliability and found the Cronbach's alpha coefficient at .93. A test-retest correlation coefficient was .88. Nirattharadorn (2005) back translated the instrument into Thai and modified the original 40 question items to 35 items. The modified ISSB was used to assess three aspects of social support namely, guidance (13 items), emotional support (15 items), and tangible support (7 items). The score was divided into five levels as 1 (never received) to 5 (received every day). The total score is between 35 and 175. A higher score refers to higher social support. Nirattharadorn (2005) tested reliability of the modified ISSB with Thai adolescent mothers and found a Cronbach's alpha coefficient of the instrument equal to .94.

The Social Support Questionnaire. The Social Support Questionnaire was developed by Toljamo and Hentinen (2001) to measure social support based on the concept of House (1985) by assessing five support aspects of emotion (4 items), instrument (2 items), information (3 items), peer (2 items), and finance (1 item). The rating scale is from 1 (strongly disagree) to 5 (strongly agree). There are 13 questions and the total score is between 13-65 points. A high total score refers to a high social support level. The reliability of back translation to Thai language version by Methakanjanasak (2005) was examined on 10 hemodialysis patients and the Cronbach's alpha coefficient for the questionnaire was .87.

The Social Support Questionnaire based on Pipatananond (2001) is applied for this study because it was tested in the Thai context of caregiving that included the aspects of information, emotional and tangible supports (Schaefer et al., 1981) which are concordant with the definition of social support of this study.

Relationship Between Social Support and Caregiving Burden

The caregivers who get 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.

Edwards and Scheetz (2002) carried out a study of burden predictors with 41 caregivers of patients with Parkinson's disease and found a negative relationship between the perceived social support and caregiving burden (r = -.56, p < .001). It also found patients' activities of daily living levels and perceived social support could predict the caregiver burden at 44.3%. Bull (1990) studied the factors influencing family caregiver burdens with 47 family members caring for physically ill persons. This study covered both subjective and objective burdens. The result presented the size of the social network was inversely related to burdens ($r = -.26$, $p < .05$) and also the functional abilities of caregivers and recipients, and size of the social network could together predict the caregiver burden at 50%.

Chiou, Chang, Chen, and Wang (2009) investigated the caregiver burden predictors. The samples were 301 family caregivers of older persons. The results explained that high levels of social support and satisfaction with family function were associated with a lower levels of caregiving burden ($r = -.22$, $r = -.33$, $p < .001$ respectively) and also that social support and satisfaction with family function could together predict the caregiving burden at 14% as well. Moreover, Dyck, Short. and Vitaliano (1999) studied the burden predictors with 70 caregivers of schizophrenia patients and found that tangible social support had a negative relationship with caregiving burden ($r = -.30$, $p < .05$). The more severe the patients' negative symptoms, the greater levels of anger control, self-blame coping, and tangible social support increased, which together could predict the caregiving burden at 24%.

Somnuek, Pantusena, and Limchaiarunrueng (1999) examined the relationship between caregiving burden and social support need with 50 Thai caregivers of stroke patients living at home. This study is based on House's (1985) four social support aspects. The result showed the association between caregiving burden and overall social support ($r = .44$, $p < .001$), instrumental support ($r = .41$, $p < .01$), information support ($r = .35$, $p < .01$) and emotional support ($r = .29$, $p < .01$). Sukkheo (2000) studied the social support and burden among 120 caregivers of schizophrenic patients based on the social support concept of Cobb (1976) and Schaefer et al. (1981). It was found that caregiving burden had a negative relationship with overall of social support, instrumental, emotional and social supports (r = -.38, r = -.41, r = -.27, r = -.28, p < .01 respectively).

In addition, Kenchaiwong (1996) determined the relationship between social support and burden among 50 caregivers of stroke patients. This study investigated both subjective and objective burdens according to Montgomery, Gonyea, and Hooyman (1985) and five dimensions of social support, according to Brandt and Weinert (1981). The reports of a relationship between social support and caregiving burden was negative, especially objective burden (r = -.43, p < .001) because of the problems and needs of the participants about tangible support such as labor, equipment, advice, knowledge and money. Significant findings were that only social support in assistance and guidance aspects had a negative relationship with caregiving burden and were predictors in both subjective and objective burdens (r = -.68, r = -.47, p < .001 respectively), where both aspects predicted subjective burdens (47%) and objective burdens (22%).

In summary, the relationship between social support and caregiving burden is negative (r = -.22 to -.68, p < .05). Social support is a predictor of caregiving burden. Receiving sufficient social support would likely decrease perceived caregiving burden.

Relationship Between Social Support and Well-Being of Caregivers

Social support from family, relatives, friends, and others in the community can help the caregivers assuage feelings of loneliness, as they are aware that they do not face problems alone. Social support from health care providers, such as knowledge about caregiving to patients at home and the resources caregivers can ask for, make the caregivers understand the situation of caregiving at home better and feel self-confident in caregiving. All these feelings will affect the well-being of caregivers.

Webb et al. (1998) studied social support and the well-being of caregivers with caregivers of 59 schizophrenia patients and 25 bipolar disorder patients based the concepts of Dupuy (1984). It covered sources of social support from family, friends, and others. The results revealed satisfaction with social support had a positive relationship with the well-being of caregivers ($r = .26$, $p < .05$). Rammohan et al. (2002) found similar results on well-being of 60 caregivers providing care for relatives with schizophrenia. Social support had a positive relationship with the well-being of caregivers ($r = .26$, $p < .05$).

Love, Street, Harris, and Lowe (2005) also studied the well-being of caregivers and social support of caregiving. Their participants were 75 primary caregivers with motor-neuron disease patients and found caregivers' perception of social support networks positively relates with well-being. The social support networks perception could predict well-being at 39% and stress on relationships which as a subscale of a caregiver network scale best predicts the well-being of caregivers. In the other words, when the caregivers had a stressed family relationships and with other people, the well-being of caregivers would decrease ($\beta = -.37$, $p < .05$). In addition, Chappell and

Reid (2002) studied well-being among 243 caregivers who took care of Alzheimer's disease, dementia, or other patients with serious memory loss problems. The reports revealed a positive relationship between the social support perception and well-being (r = .34, p < .001), and that the social support perception directly affected well-being of the caregivers (β = .19, p < .01).

In Thailand, Daonophakao (2004) investigated the influencing factors of well-being among 100 caregivers of stroke patients. This study applied the social support and well-being concepts based on Brandt and Weinert (1981) and Dupuy (1984). The results revealed a positive relationship between social support and well-being (r = .43, p < .05). Stepwise multiple regressions show a sense of coherence and social support contributed to 54% of well-being.

In summary, all studies have similar results of a positive relationship between social support and well-being of caregivers (r = .26-.43, p < .05) and also social support could predict their well-being (β = .19-.34, p < .05). Caregivers who receive sufficient social support would perceive greater well-being in their lives. However, these studies applied different concepts of social support and well-being, thus these outcomes cannot be certain conclusions and need further study.

Caregiving Hours

Caregivers spend a lot of time, day after day to perform care activities for the patients. Their caregiving tasks might be too difficult for their abilities. As a result, they may not have sufficient potential for existing tasks and they have to put a lot of effort and energy for giving care. In addition, caregivers often don't have enough time for themselves, and that affects their emotions such as feeling bored, having recreation and interactions with others decrease, and feeling isolated from family and society. When caregivers hold these feelings for a long time the perception of well-being may decrease. Caregiving tasks are time consuming for caregivers. Caregiving hours refers to the number of hours that caregivers spend providing care each day. The review below covers the topic of caregiving hours relates to caregiving burden and caregivers' well-being.

Relationship Between Caregiving Hours and Caregiving Burden

If caregivers endure long caregiving hours, this affects their ability to assess themselves, as they have insufficient ability to deal with existing care tasks, and need to use effort and energy beyond their capabilities. The caregivers then feel that caregiving is so onerous that the care tasks are a burden. Studies of the relationship between caregiving hours and burden have been done by Pinquart and Sorensen (2003), Chappell and Reid (2002), and Puymbroeck, Hinojosa, and Rittman (2008).

Pinquart and Sorensen (2003) determined the association of stressors and caregiving burden by conducting a meta-analysis in 228 research studies. The stressors in this study were care receiver's impairment (physical impairments and cognitive impairments) and level of caregivers' involvement (the number of caregiving hours, the number of caregiving tasks, and duration of caregiving). The participants were caregivers of dementia, cancer, and Parkinson's disease patients, and older adults with physical and mental impairments. The results revealed 31 studies related to caregiving hours and burden. There was a positive relationship with the caregiving burden (correlation coefficients ranged .20 - .24) and caregiving hours per week had a direct influence on well-being ($p < .001$).

Chappell and Reid (2002) studied the burden of 243 caregivers of Alzheimer's disease or dementia patients and others with serious memory loss illnesses. They found that caregiving hours during the previous week had a positive relationship with caregiving burden ($r = .16$, $p < .05$) and also it had a direct influence on the caregiving burden ($\beta = .30$, $p < .001$). Furthermore, Van Puymbroeck, Hinojosa, and Rittman (2008) studied the influencing factors of the burden of 87 caregivers with stroke patients and found that the caregiving hours was an average of nine hours a day. There was a positive relationship between the caregiving hours spent per day and caregiving burden ($r = .22$, $p < .05$) and it was direct influence on caregiving burden ($\beta = .17$, $p < .01$).

In summary, it could be assumed that caregiving hours have a positive relationship with caregiving burden ($r = .16\text{-}.24$, $p < .05$). Also, caregiving hours could predict the caregiving burden ($\beta = .17\text{-}.30$, $p < .01$). The more time spent on caregiving, the more the caregiving burden. Based on above, there are few studies on the relationship between caregiving hours and caregiving burden, thus further studies are needed to explore this.

Relationship Between Caregiving Hours and Well-Being of Caregivers

If caregivers have to use most of their time taking care of the patients, they lose their private lives, causing tension and boredom. Relaxing activities happen less and interaction with family members and other persons in society are also reduced; the caregivers also experience a reduction in feelings of well-being. Some researchers explored the relationships between caregiving hours and well-being of caregivers.

The study of well-being by Chappell and Reid (2002) and; White-Means and Thornton (1996) revealed the same result as there was a negative relationship between informal care hours and well-being and direct negative effect on well-being. Chappell and Reid (2002) studied well-being among 243 caregivers of dementia or serious memory problem patients and found the mean of providing care was 26.1 hours of informal care per week. There was a negative relationship between informal care hours and a direct negative effect on well-being of the caregiver ($r = -.14$, $p < .05$, $\beta = .24$, $p < .01$, respectively). White-Means and Thornton (1996) studied well-being among 111 caregivers of indigent black older persons and found the similar results. The mean of informal care hours was 7.5 hours per day and negatively related to well-being ($p < .05$).

Harris (2009) determined well-being among 822 White and African American caregivers providing care for the elderly, ill, or disabled family members by developing a structural model of caregivers' well-being. The research design was a cross-sectional descriptive design. The variables were race, hours of care per week, formal and informal coping uses, manageability, and well-being of caregivers. The AMOS structural modeling program was used for data analysis and found the hours of care per week had a direct effect on well-being of caregivers ($\beta = -.36$, $p < .001$).

In summary, caregiving hours clearly present a negative relationship with the well-being of caregivers. Spending less hours of care improved well-being perception. However, no one has conducted a causal relationships study in Thailand. As a result, it is informative to study the causal relationships between caregiving hours and well-being of caregivers in a Thai context.

The Functional Ability of Persons With Spinal Cord Injury

The functional ability of persons with spinal cord injury strongly determines the well-being of caregivers. Patients with a high level of injury and low functional ability need more caregiving support because of their disability consequences. The tasks of caregiving are complicated and difficult; therefore; caregivers require knowledge, skills, effort, and energy for providing care. The review below covers the perspectives of functional ability and functional ability assessment, and includes an explanation of how functional ability relates to caregiving burden and caregivers' well-being.

Perspectives in Functional Ability

Functional ability is defined as the maximum potential activities performance that a person is able to do to meet the basic needs and, fulfill usual roles, and maintain their health and well-being (Leidy, 1994). Functional ability means the actual or potential capacity of an individual to perform activities and tasks to live as independently as one can normally expect (Lueckenotte, 1996). Functional ability means the ability to perform the activities done regularly in daily life (Jitapunkul, 1999). Another scholar describes functional ability as a capacity to perform given functions or activities (Knight, 2000). In this study, the functional ability of a person with spinal cord injury refers to the actual capacity of a person with spinal card injury to independently perform the activities of daily life (Jitapunkul, 1999).

Spinal cord injury affects patients by paralyzing some organs or several parts of the body. It may affect their ability to do any activities of daily life whether totally or with difficulty. The activities of daily life are divided into two levels (Jitapunkul, 1999), which are:

1. The basic activities of daily living (BADL) are activities which can be done using basic skills of the body for achievement including the necessary activities of living independently within households or residences such as the ability to wear clothes, eat, use the bathroom and bathe, dressing, etc.

2. The instrumental activities of daily living (IADL) are activities which need higher skills for management or solving problems with more complex environments. In other words, it refers to the activities that are needed to be done independently in the community such as shopping and transportation services.

The assessment of functional ability of persons with spinal cord injury in this study focuses on BADL and measures the physical ability performance of the basic activities of life within their accommodation. Their functional abilities depend on the pathology of the injury to the spinal cord. The ability to perform daily routines activities after recovery is as given below (Pajaree, 2000):

1. Patients with pathology of level C_1-C_3 need constant respirator support because of diaphragm muscles dysfunction. Patients with pathology level C_4 can

breathe after passing through a critical period. However, they cannot move the muscles of their limbs or trunk. As a result, they need a caregiver to lift them up and put them down into bed. Daily activities such as eating, bathing, dressing, and cleaning after urination and defecation also require assistance.

2. Patients with pathology of level C_5 can move some parts of the body such as deltoids and biceps and can push against their weight. Special equipment can assist them to do some daily activities, such as eating and brushing teeth. However, changing their positions or moving, showering/bathing, dressing, urination and defecation need a caregiver's help.

3. Patients with pathology of level C_6 can move their shoulders with a full range of motion but cannot tilt their wrists completely. They cannot hold objects strongly, because of hand ligaments impairment. The elbows can be bent but cannot be stretched. Some patients are able to sit up by pulling a rope that is hooked into the end of bed. Most of patients are able to sit on a wheelchair using a plank and moving backwards and forwards on the chair to lessen the sitting pressure. Also, they can do a self-care such as eating, cleaning their face, brushing teeth, dressing and using special equipment for daily activities. However, they still rely on a caregiver to do some activities such as showering/bathing, voiding, and defecating.

4. Patients with a pathology level of C_7-C_8 can move their bodies from bed to a wheelchair because of adequate strength of the triceps. They can also move backwards and forwards to lessen the pressure of sitting position, as well as move their wheelchairs and clean themselves after urination and defecation. However, their caregiving activities such as showering/bathing, changing clothes, and changing

positions from sitting on the floor to wheelchairs require help because their arms do not have full function.

5. Patients with pathology levels of T_1-T_5 can do most things by themselves, except wearing pants. They can move their wheelchairs and insert intermittent catheters and suppositories.

6. Patients with pathology levels of T_6-T_{11} can control their upper body muscles. Therefore, they can do daily activities, sit, and wear pants. Some patients are able to use knee-ankle-foot orthoses and crutches for walking and standing.

7. Patients with pathology of level T_{12}- L_1 can walk in their home by using knee-ankle-foot orthoses and crutches or walkers.

8. Patients with pathology of level L_4-S_5 can walk for long distance by using ankle-foot orthoses and crutches or canes.

According to the pathology levels of spinal cord injuries above, there are various activities that patients cannot perform. High levels of pathology present more disabilities and require a lot of continuous care at home after discharge, while the patients with low levels of pathology need less assistance. Hence, caregivers who provide care for patients with high levels of pathology work harder than the patients with low levels of pathology. This study focuses on caregivers with spinal cord injury persons who have an injury at T_5 level or above because the spinal cord injury persons at the T_6 level or below are able to do their daily activities without caregivers.

Measurement of Functional Ability

The functional ability assessment measures the ability of disabled persons to do their self-care activities and also refers to the caregiving demand for the activities of daily life. The instruments are as follows:

The Barthel Index. The Barthel Index was developed by Mahoney and Barthel (1958), and consists of 10 activities: 1) feeding, 2) moving from wheelchair to bed and returning, 3) doing personal toilet, 4) getting on and off the toilet, 5) bathing , 6) walking on a level surface or propelling a wheelchair, 7) ascending and descending stairs, 8) dressing, 9) controlling bowels, and 10) controlling bladder. This instrument has 10 items and a total score is from 0-100. The overall scores demonstrate the amount of time and assistance that a patient needs. An overall high shows greater ability of patients to mostly do these 10 activities independently.

Oveisgharan et al. (2006) tested the internal consistency reliability of the Barthel Index with 459 stroke patients and found a Cronbach’s alpha coefficient was .93. As another measure of reliability, test-retest reliability with 58 stroke patients by the same interviewer on 2 consecutive days was .99 ($p < .001$).

Jitapunkul et al. (1994) translated and modified questions of the Barthel Index suitable for the Thai context. The Modified Barthel Index assesses the ability to do the activities of living independently within the house during the last 24-48 hours, including 10 activities: feeding, grooming, transferring, using the toilet, moving, dressing, walking up and down stairs, bathing, continence of bowel and bladder. Score for each activity is different as it depends on the importance in daily life. The total score is from 0 to 20. A high score refers to high abilities to do daily activities.

Jitapunkul et al. (1994) clarified the level of patients' functional abilities by dependent level scores ranges as 0-4 = total; 5-8 = severe; 9-11 = moderately severe, and more than 12 = mildly severe.

Jitapunkul et al. (1994) tested the construct validity of the Modified Barthel Index with 703 elderly patients who lived in the Klongtoey Slum by exploratory factor analysis with orthogonal (varimax) rotation. The numbers of factors were considered from the Eigen value of more than 1.0 and the factor loading more than .50. They found that all 10 questions were divided into four factors as the basic self-care ADLs, extended (or instrumental) ADLs, mobility ADLs, and bladder/bowel control.

Kenchaiwong (1996) tested the reliability of the Modified Barthel Index that Jitapunkul et al. (1994) translated and modified by applying for 10 stroke patients and found a Cronbach's alpha coefficient of .89. Also, Jatupornpipat (2000) tested this questionnaire with 15 stroke patients and obtained a Cronbach's alpha coefficient of .86. In addition, Khampolsiri (2006) tested the reliability of the Modified Barthel Index with 10 stroke patients and found a Cronbach's alpha coefficient of .86.

The functional Independence Measure (FIM). The functional Independence Measure was developed by Hamilton, Granger, Sherwin, Zielezny, and Tashman (1987). This instrument has 18 items including six aspects as self-care (6 items), sphincter management (2 items), mobility (3 items), locomotion (2 items), communication (2 items), and social cognition (3 items). A rating scale of seven levels from level 1 (cannot do daily activities by themselves) to level 7 (can do daily activities by themselves without any help). A score value is between 18 and 126. The low score refers to the ability to do only a few daily activities and depends on caregivers and equipment. The Thai Rehabilitation Medicine Association (Aksaranugraha, 1996) translated this instrument into Thai and it was tested by Srirat (2003) to determine the reliability with 10 paraplegia patients by the test-retest method within two weeks and found the coefficient of stability equal to .92.

The PULSES Profile. The PULSES Profile was developed by Moskowitz and McCann (1957) to assess the patients' physical activities ability by observation. It consists of six components: physical condition (P), upper limb function (U), lower limb function (L), sensory status (S), excretory function (E), and mental and subjective status (S). Each component has four score levels. The total score of the instrument is between 6 and 24. A low score infers a greater need for patients to rely on others.

Granger, Albrecht, and Hamilton (1979) modified The PULSES Profile and tested the modified instrument reliability by the test-retest method and found the coefficient of stability equal to .87. Marshall, Heisel, and Grinnell (1999) tested the reliability of the Modified PULSES Profile with 197 stroke patients and found a Cronbach's alpha coefficient was .74 and .78 for admission and discharge score, respectively. This instrument was translated into Thai by Suwan (1994), but no Thai research studies have utilized this instrument.

The Index of ADL. The Index of ADL was developed by Katz (1976). It assesses the patients' abilities in six activities: bathing, dressing, using the toilet, transferring from bed to chair, continence, and feeding. The assessment was carried out by observation and questioning for the last two weeks. The meaning of self-dependence levels and other-dependence are set as follows:

A = Self-independent for doing all six activities

B = Self-dependent for doing all activities except one

C = Self-dependent for doing all activities except bathing and one other activity

D = Self-dependent for doing all activities except bathing, dressing and one other activity

E = Self-dependent for doing all activities except bathing, dressing, using the toilet and one other activity

F = Self-dependent for all activities except bathing, dressing, using the toilet, transferring from bed to chair and one other activity

G = Self-dependent for doing all six activities

Other = Other-dependent for doing two activities excluding C, D, E, or F

Brorsson and Asberg (1984) used this instrument with 100 patients. The report showed that 32 patients who were assessed as independent performing of daily living activities were still alive and living in their own accommodation for a year after discharge from the hospital. Only eight patients had passed away. On the other hand, 23 from 42 patients who were assessed to be other-dependent passed away one year after discharge. Only eight patients were still alive and living in their own homes. The rest of them were living in institutions. Moreover, Brorsson and Asberg (1984) also found the patients who are assessed as independent in daily living activities have a shorter length of hospital stay and are discharged to their homes more often than the dependent patients. This instrument could predict the continuous results in both short and long terms. It was translated to Thai by Suwan (1994), but it has not been applied for research study in Thailand.

For this study, the researcher applied the Modified Barthel Index that was translated and modified by Jitapunkul et al. (1994) to assess functional ability of persons with spinal cord injury. The details of questions are relevant with the definition of the functional ability of persons with spinal cord injury of this study. Moreover, the psychometric properties have an acceptable reliability higher than .80 (Burns & Grove, 2005).

Relationship Between Functional Ability of Patients and Caregiving Burden

The ability to do daily activities of patients is a factor indicating the burden 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. The caregivers have to use time, energy and ability to take care of patients, and the caregivers face difficulties in terms of providing care to these patients. In these circumstances, the caregivers will perceive that caregiving takes much time and presents many difficulties and these make the caregivers perceive they have burdens.

Son et al. (2003) studied the predictors of burden among adult child caregivers of older adults with dementia and found the physical dependency in activities of daily living (ADL) and instrument activities of daily living (IADL) had a positive relationship with the caregiving burden ($r = .41$, $p < .01$). It was also found the physical dependency in ADLs and IADLs, memory and behavioral problems, cognitive impairments, and caregivers' perceived health could together predict the caregiving burden at 42%. Moreover, Lawton et al. (1991) studied the caregivers of Alzheimer patients among 632 persons. It was found that the severity of disabled person's symptoms directly influenced caregiving burden ($\beta = .22$, $p < .05$).

Bull (1990) studied the influence factors of caregiving burden. The samples were family members caring for a physically ill person. There were two groups of data collection. The first group of 55 people was collected after two weeks and the second group of 47 people was collected two months after hospital discharge. It was found that the patients' functional ability had a negative relationship with the caregiving burden after two weeks ($r = -.49$, $p < .05$), and two months ($r = -.59$, $p < .05$) of hospital discharged. It was also found the patients' functional ability could predict the caregiving burden after two months of discharge with a statistical significance ($\beta = -.57$, $p < .01$). This was in accordance with a study of Edwards and Scheetz (2002) who studied the predictors of burden in 41 caregivers who were married to or cohabitating with individuals with Parkinson's disease. It was found that the amount of assistance needed with daily life activities had a positive relationship with the caregiving burden ($r = .62$, $p < .001$) and also the patients' activities of daily life and family support perception could together predict caregiving burden at 44.3%.

In Thailand, Kenchaiwong (1996) studied the relationship between patients' dependency and burden in 50 caregivers of stroke patients. The assessment of dependent patients' basal activities of daily life was the Barthel Activity of Daily Living Index and the instrumental activity of daily living was the Chula Activity of Daily Living Index. The reports showed the basic activities of daily living had a negative relationship with the objective burden ($r = -.62$, $p < .001$) and subjective burden ($r = -.47$, $p < .001$). It was also found that the instrumental activities of daily living had a negative relationship with the objective burden ($r = -.40$, $p < .01$) and subjective burden ($r = -.34$, $p < .01$). In addition, Somnuek et al. (1999) studied the relationship between the functional ability of stroke patients and the caregiving burden. The samples were 50 caregivers at home who took care of stroke patients. The level of functional ability was examined by employing the Barthel Activity of Daily Living Index and found the functional ability of stroke patients had a negative relationship with caregiving burden ($r = -.33$, $p < .05$).

In summary, those studies result are similar in that the functional ability of a patient has a negative relationship with the caregiving burden. In addition, the functional ability of a patient could predict the caregiving burden. In the other words, for patients who have less ability to function in the daily living activities, the caregivers would have a greater caregiving burden.

Relationship Between Functional Ability of Patients and Well-Being of Caregivers

A patient's ability to perform daily activities is one of the factors that affect the well-being of caregivers. If caregivers have to give complicated care and require particular skills, it may cause the caregivers feel stress and a lack of confidence in terms of giving care. Caregivers have to use many resources to help their patients which can affect the well-being of the caregivers themselves.

Testing the relationships between the functional ability of a patient and the well-being of the caregiver has been done by Pinquart and Sorensen (2004) who studied the associations of caregiver stressors and caregiver well-being by conducting a meta-analysis of 60 studies providing care for dementia or elderly people with chronic diseases. The 18 research studies of caregivers with physical impairment patients found that care receivers physical impairments had a negative relationship with their well-being with a correlation coefficient ranging was between -.12 and -.06.

Moreover, care receivers' physical impairments positively related to caregivers' depression with a correlation coefficient ranging between .12 and .16. Similarly, Early et al. (2002) studied child functional ability and caregivers' well-being of 164 family caregivers of children with emotional disorders and found that child functional ability had a positive relationship with the well-being of caregivers ($r = .46$, $p < .05$), and functional ability directly influences the well-being of caregivers ($\beta = .21$, $p < .05$). In addition, Lawton et al. (1991) studied well-being among 632 caregivers of Alzheimer patients and learned that the amount of help given by a caregiver negatively related to caregivers' well-being ($r = -.17$, $p < .05$).

As one can see from the above studies, the functional ability of patient has a positive relationship with the well-being of their caregivers. If patients could perform more of their daily activities, their caregivers would perceive improved well-being. However, most of the research studies aim to study the correlations only. Therefore, the present study aims to determine causal relationships because no one has yet conducted the study of the causal relationships between functional ability of patients and the well-being of caregivers in the Thai context.

Caregiving Burden

The responsibilities of caregiving to meet the disabled people's needs take time and effort that might cause burden. The review provides perspectives in caregiving burdens, caregiving burden assessment, caregiving burden as a mediator variable and explaining how the relationship of caregiving burden relates to caregivers' well-being.

Perspectives in Caregiving Burden

Hoening and Hamilton (1966) were the first authors to dichotomise burden into objective and subjective dimensions. Objective burden refers to caregiving activities involving negative experiences and subjective burden refers to the feelings or emotions that are generated during providing care. Zarit, Reever, and Bach-Peterson (1980) explained that an uncomfortable feeling of caregivers as the result of caregiving is called caregiving burden. The uncomfortable feeling can be measured by evaluating physiological and psychological health, economic status, and social life. In this definition, they consider only the subjective burden. Poulshock and Deimling (1984) defined caregiving burden as a caregivers' subjective perception of providing care for a disabled patient. The perceptions of caregiver measurement could be tested by the difficulties, effort or negative feelings of caregiving.

Platt (1985) described objective burden as the problems and difficulties of the life of caregivers and their families that can be observed and verified. The feeling of subjective burden is a personal's view on their caregiving. Montgomery et al. (1985) divided caregiving burden into two dimensions; objective and subjective. Objective burden is the extent of difficulties or changes in the daily lives of caregivers and their families. Subjective burden is considered as the attitudes or emotional reactions of caregivers towards the caregiving experience. Zarit, Todd, and Zarit (1986) defined caregiving burden as the extent that caregivers recognize the caregiving effect on their physiological, economic and social states. To summarize, caregiving burden is the impact on caregivers caused by giving care.

Bull (1990) defined objective burden as the time consumed for caregivers' activities to meet care receiver's demands. The feelings, attitudes, and emotions of caregivers towards caregiving are the subjective burden. Similarly, caregiving burden was identified as demand and difficulty (Carely, Oberst, McCubbin, & Hughes, 1991; Oberst, 1991; Oberst, Thomas, Gass, & Ward, 1989). Demand refers to the extent to which a treatment plan or other activities for patient caring requires time and energy. Difficulty refers to the difficulty and the bother of caregiving activities imposed on caregivers. These components of burden indicate that the meaning of caring demand is as same as the objective burden, and the meaning of caring difficulty is as same as subjective burden. Braithwaite (1996) defined caregiving burden as the caregivers' problems that are the results of patients' needs and their caregiving abilities imbalance.

Chou (2000) analyzed the concept of caregiving burden as critical attributes of burden including subjective perception, multidimensional phenomena, dynamic change, and overload. Antecedents of caregiving burden were the characteristics and demands of caregivers due to caregiving involvement. The consequences of the burden generated problems for the patient, caregiver, family, and health care system. Based on concept analysis, caregiving burden is an individual subjective perception of overload in one or more perspectives of the physical, psychological, social, and financial effects arising from the caregiving process. In addition, Hunt (2003) stated that caregiving burden meant the caregivers' feelings of concerns or hassles of providing care for chronic patients.

Thus, according to the literature review, it can be concluded that caregiving burden means the feelings of responsibilities of the caregivers towards caregiving to their patient. Burden is an estimation of the situation of caregivers about the time consuming and difficulty of caregiving activities, which depends on personal cognition and thought. It appears that scholars clarify caregiving burden as objective and subjective. The various definitions of caregiving burden are similar. Generally, objective burden includes activities and time for providing care, while caregivers' attitudes, feelings and emotions towards caregiving are subjective burden. In this study, the caregiving burden is measured as the time spent and emotional difficulties arising while providing care (Oberst, 1991) in both of objective and subjective burdens.

Measurement of Caregiving Burden

The concept of caregiving burden mentioned above explains caregiving burden as the perception of the caregivers' mind. Thus, the caregiving burden assessment must not be measured in terms of objective approach with equipment or by observation from other persons. This can be done as self-report only. Moreover, most of the existing measurements evaluate caregiving burden from the caregivers' reaction to their caregiving tasks. A number of researchers have developed measurements for caregiving burden as follows:

The Caregiving Burden Scale (CBS). The Caregiving Burden Scale (CBS) was developed by Oberst (1991) to assess the burden of family members caregiving for chronic illness at home. This Caregiving Burden Scale was modified from the Caregiving Load Scale (Oberst et al., 1989) to evaluate caregivers' time quantity and energy care expended in activities operations. It included 10 questions, with Carey et al. (1991) adding another four to make 14 items in total. In the same year, Oberst (1991) added one item for 15 items in total. The CBS questions covered three aspects of care activities: direct care (3 items), interpersonal care (4 items), and instrumental care (8 items). The respondents answered all 15 items twice as follows:

1. The assessment of demand of care to evaluate the feelings of caregivers with time spent caregiving. Scores range from 1 (activity which takes the least time for caring) to 5 (activity which takes the most time for caring).

2. The assessment of difficulty of care to evaluate the caregivers' feelings of difficulty degree to do activities in each item. Score ranges from 1 (activity is not difficult) to 5 (activity is most difficult).

The result of caregiving burden level of each item was calculated as the square root of demand multiplied by difficulty. Then the scores of all 15 items were added together for a total score between 15 and 75. Low scores indicate low caregiving burden. Oberst (1991) tested the construct validity of the CBS by exploring factor analysis in 240 family members of patients with cancer. The number of those factors considered was from factors loading was more than .49. Those 15 questions were divided into three factors: direct care, interpersonal care, and instrumental care. The three factors together explained the variance at 57%. The Cronbach's alpha coefficients of the demand of care part for direct care, interpersonal care, instrumental care, and overall questionnaire were .78, .71, .83, and .88, respectively. The Cronbach's alpha coefficients of the difficulty of care part for direct care, interpersonal care, instrumental care, and overall questionnaire were .83, .71, .81, and .91, respectively.

Gasemgitvatana (1993) translated this scale into Thai and examined content validity with four nurse experts in chronic care. Some questions were modified to fit in the Thai context. However, only the care demand subscale was considered. This instrument was tested with 104 wife-caregivers of chronic ill patients. The Cronbach's alpha coefficient of direct care, interpersonal care, instrumental care and whole instrument were .69, .72, .71, and .77. Test-retest method was also carried out at four-week intervals, the correlation coefficient was .68.

Cheewapoonphon (1998) also tested the reliability of this questionnaire with 20 family caregivers of advanced cancer patients. Cronbach's alpha coefficient of overall questionnaires was .83. Moreover, there was an additional test with 200 participants and found the Cronbach's alpha coefficient of overall questionnaires .78. Also, the instrument reliability was tested by Chaoum (1993) with 2 sample groups. The first group consisted of 20 caregivers of dependent elderly and yielded Cronbach's alpha coefficients for care demand and the care difficulty of .87 and .89, respectively. The second group was made up of 100 caregivers and had Cronbach's alpha coefficients for the care demands and the care difficulty of .86 and .90, respectively. In addition, Tosuksri (1997) examined this instrument reliability with 100 caregivers of congestive heart failure patients and obtained Cronbach's alpha coefficients of care demands of .87 and care difficulty of .90.

The Subjective and Objective Burden Scale. The Subjective and Objective Burden Scale of caregivers (CSOB) was developed by Montgomery et al. (1985) based on their caregiving burden concept. The purpose is to assess burden of the elderly disability caregivers. There are two parts:

The Objective Burden. The Objective Burden is the perception of the changes of caregivers’ life experiences that involve personal life, work, social participation, interpersonal relationships, and health. It consisted of nine questions.

The Subjective Burden. The Subjective Burden which concerns the caregivers’ feeling of the changes in the subjective responses and attitudes from their care experiences. This part consisted of thirteen questions.

This rating scale had five answer selections, ranging from 0 (never) to 4 (regularly). The total score of objective burden ranges 0 to 24 and subjective burden ranges 0 to 32. The total score of each part was considered separately. Low total score of any part of burden represented caregivers had low burden of that part.

Kenchaiwong (1996) translated this instrument into Thai, and tested its content validity with five experts. The interrator agreement coefficient was .77 and the content validity index was .76. Also, the reliability was tested with 10 caregivers of stroke patients and found the Cronbach alpha coefficients of the objective burden of .83 and the subjective burden of .76.

The Zarit Burden Interview (ZBI). The Zarit Burden Interview (ZBI) was developed by Zarit et al. (1980) to measure the degree to which caregivers perceive their responsibilities as having an adverse effect on caregiver’s health, personal and social life, finances, emotional well-being, and the relationship between the caregiver and patient. There were 22 question items that consisted of the subjective response of caregivers to elderly dementia patients. The question items were divided into 5 levels, ranging from 0 (never) to 4 (regularly). The total scores assessment was between 0 and 88. High scores referred to caregivers perceiving a high burden.

Arai et al. (1997) assessed stability of this measurement by applying the two-week test-retest reliability with 29 caregivers of elderly persons. The findings were a Pearson's correlation coefficient (.76) and a Cronbach's alpha coefficient of internal consistency with 66 caregivers of elderly persons (.93). The result showed the subjective burden measurement only. Ko, Yip, Liu, and Huang (2008) tested the construct validity of the ZBI by exploring factor analysis of 181 caregivers of patients with dementia. Factor analysis found five factors which accounted for 60% of the total item variance. For the reliability analysis, Cronbach's alpha coefficient was .89. The stability of this measurement was assessed by applying the two-week test-retest reliability with 36 caregivers of patients with dementia. The intraclass correlation coefficient was .88.

The English version of ZBI was translated into Thai by Toonsiri, Sunsren, and Lawang (2011), using a blind back translation method. The Thai version of ZBI consists of 22 items which is the same as the original English version. The ZBI Thai version was tested for validity among 501 caregivers of chronic illness patient by employing exploratory factor analysis with orthogonal (varimax) rotation. The researcher found 60.01% of the total variance with four factors, i.e. personal strain, privacy conflict, guilt, and uncertain attitude. The internal consistency reliability was tested and found Cronbach's alpha coefficient was .92.

The Caregivers Burden Scale. The Caregivers Burden Scale (CB scale) was developed by Elmstahl, Malmberg, and Annderstedt (1996) to measure the perceived burden in family caregivers of stroke and dementia patients. There were 22 items and divided into five domains as the items of: 8 general strain, 3 isolation, 5 disappointment, 3 emotional involvement , and 3 environment. The score was a four-point Likert Scale and score ranges from 1 (no burden) to 4 (greater burden). The total score was 22 to 88. High scores indicated high caregiver burden.

Elmstahl et al. (1996) tested the internal consistency reliability of the instrument with 35 caregivers of patients three years after stroke and found Cronbach's alpha coefficients of general strain (.87), isolation (.76), disappointment (.70), emotional involvement (.70), environment (.53) and all of instruments (0.89). Akinci and Pinar (2012) tested the reliability of the CB scale with 161 family caregivers who provide care for haemodialysis patients and found Cronbach's alpha coefficients of general strain (.83), isolation (.74), disappointment (.69), emotional involvement (.61), environment (.63) and all of the 22 items (.91). Factor analysis found five underlying factors similar to original Scale's five-factor solution. According to the literature review, there is no Thai version of the instrument.

For this study, the researcher applied the Caregiver Burden Scale, Thai version by Gasemgitvatana (1993). Several studies in Thailand have tested the psychometric properties of the instrument and found that reliability was at an acceptable level, higher than .80 (Burns & Grove, 2005). Moreover, the CBS was designed based on caregiving burden concept of Oberst (1991) which was in accordance with the definition of caregiving burden of this study.

Relationship Between Caregiving Burden and Well-Being of Caregivers

Giving care to the patients with limitations of self-care, caregivers have to accept the additional roles by being caregivers. Moreover, some activities of caregiving to persons with spinal cord injury at home are complicated. If the caregivers have insufficient knowledge and abilities to respond to the demands of patients, this may cause the caregivers 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. Based on the literature review, there is no particular research study of the relationship between well-being and caregivers' burden on providing care for spinal cord injury patients. However, the study of relationships between caregiving burden and their well-being for other illnesses patients are described below.

Chappell and Reid (2002) studied the well-being of 243 caregivers of Alzheimer's disease or dementia patients and other serious memory loss illnesses and conducted a cross-sectional descriptive study to examine causal relationships by employing a path analysis. It focused on the patients' cognitive status, patients' physical function, patients' behavioral problems, caregiving hours during the previous week, perceived social support, frequency of taking breaks, hours of formal service, self-esteem, and burden as predictor variables. The result showed negative relationships between caregiving burden and their well-being (r = -.29, $p < .001$) and caregiving burden influence directed to the well-being of caregivers (β = -.15, $p < .05$). Also, well-being could be predicted from perceived social support, hours of caregiving during the previous week, self-esteem, and burden of caregivers at 38%.

Lawton et al. (1991) conducted a study of the well-being of 244 adult child caregivers of Alzheimer's disease patients and used a cross-sectional descriptive study to examine the causal relationships. The LISREL program was employed for data analysis and used impaired person symptoms, caregiver health, amount of caregiving activities, informal caregiving assistance to caregiver, caregiving satisfaction, caregiving burden, and depression as predictor variables. The finding was that caregiving burden had a negative relation with the well-being of caregivers ($r = -.36$, $p < .05$) and a positive relation with depression ($r = .63$, $p < .05$).

Rammohan et al. (2002) conducted research on the well-being of 60 caregivers of schizophrenia patients in both objective and subjective burden. The result was similar to other studies that caregiving burden had a negative relation with the well-being of caregivers ($r = -.56$, $p < .01$). Coping strategies of denial and problem solving, strength of religious beliefs, and perceived burden accounted for 62% of the variance in well-being among caregivers. Webb et al. (1998) studied burden and well-being with 84 caregivers of severely mentally ill patients and found results were not different as caregiving burden had a negative relation with the well-being of caregivers ($r = -.43$, $p < .001$).

In Thailand, there is only one study on the well-being of caregivers that was conducted by Chaoum (1993) to examine caregiving burden based on Oberst’s concept (1991) and well-being based on Dupuy’s (1984) concept with 100 family caregivers who cared for dependent elderly people. The results showed that well-being of caregivers had a negative relation with the amount of time caregiving ($r = -.22$, $p < .05$), the difficulties of caregiving ($r = -.45$, $p < .001$), and overall burden ($r = -.40$, $p < .001$). The researcher also found well-being of caregivers had a negative relation with medical expenses ($r = -.31$, $p < .01$) and a caregiver’s burden was a significant predictor and accounted for 16% of variance in well-being as well.

All these studies describe an undeniably negative relation with caregiving burden which always remains an important factor for predicting the well-being of caregivers. Thus, it can be summarized that as the burdens of caregivers' duties decrease, their well-being increases.

Caregiving Burden as a Mediator Variable

Research documents illustrate the caregiving burden operation as mediator variables between the rewards of caregiving, social support, caregiving hours, the functional ability of patients and the well-being of caregivers.

The result studies of the rewards of caregiving and functional ability of patients presented an indirect effect on the well-being of caregivers through caregiving burden, as shown by Lawton et al. (1991) who studied the well-being of 244 adult child caregivers of elderly parents with Alzheimer's disease. A structural model of caregiving was developed for a cross-sectional descriptive study. The variables were stressors (severity of the disable person's symptoms and amount of caregiving assistances), resources (personal resources and social resources), secondary appraisal (caregiving satisfaction and caregiving burden), and well-being. Data was analyzed by the AMOS structural modeling program and found caregiving satisfaction and amount of caregiving assistances had indirect effects with well-being through caregiving burden. In other words, the caregivers who perceived the rewards of caregiving had a low burden and caregiving for the patients who were able to do activities in daily life themselves created less burden. These affected the well-being of caregiver.

A study of social support and functional ability of the patient presented an indirect effect on well-being of caregivers through caregiving burden by Harwood et al.

(2000). The predictors of well-being were examined with 114 caregivers of Alzheimer's disease by using a structural equation analysis. The hypothesized model of variables included objective stressors (patient behavioral disturbances, level of functional impairment, and level of cognitive impairment), caregiver resources (self-reported physical health and perceived emotional support), caregiver ethnicity (white non-Hispanic and Hispanic American), cognitive appraisal (subjective caregiving burden), and outcome (well-being). The AMOS structural modeling program was used for data analysis and found social support and functional impairment had an indirect effect on well-being through burden which implied that if the caregivers received enough social support they would be likely to perceive low caregiving burden and this support would affect caregivers' feeling of well-being in life. Moreover, the result revealed the levels of functional impairment of patient had an indirect effect on well-being through burden. Giving care for patients who have high ability of daily living results in caregivers having a low burden which enhances their well-being in life.

Another study found the caregiving hours had an indirect effect on the well-being of caregivers through caregiving burden. Chappell and Reid (2002) examined well-being in 243 caregivers of dementia and nondementia patients using path analysis. This was a study of cross-sectional descriptive study. The variables consisted of 1) primary stressors (patient cognitive status, physical function, and behavioral problem), 2) primary appraisal (hours of caregiving during the previous week), 3) mediators (perceived social support, frequency of getting a break, and hours of formal service use), 4) secondary appraisal (burden), and 5) outcome (well-being). The study found that informal hours of care had an indirect effect with well-being through burden.

Moreover, Yates, Tennstedt, and Chang (1999) conducted a cross-sectional descriptive study of well-being in 204 informal caregivers of disabled elders using path analysis. The variables consisted of 1) primary stressors (cognitive impairments, functional disability, and problem behaviors), 2) primary appraisal (time spent on care), 3) mediators or resources (formal services, quality of relationship, emotional support, and mastery) 4) secondary appraisal (caregiver overload), and 5) outcome (well-being). The study found that time spent on care per week provided had an indirect effect on well-being through caregiving burden. Two of the studies presented relevant results. Caregivers who had the least number of caregiving hours of patients each day had the lowest feeling of caregiving burden. This affected the well-being of the caregivers.

In conclusion, it can be hypothesized that caregiving burden may be a mediating variable between the rewards of caregiving, social support, caregiving hours, and functional ability of patient and the well-being of caregivers. However, the indirect relationship of these variables with the well-being of caregivers through caregiving burden has not been clearly concluded, because there are few studies and none have yet been done in Thailand. Thus, in order to explain the indirect connection between all of exogeneous variables and the well-being of Thai caregivers, this relationship needs to be explored.

According to the literature review, studies of well-being of caregivers in Thailand have been conducted mainly in exploring relationships. These studies purpose only the relationship between well-being and factors related with unclear predictor variables and the outcome results. A causal relationships study is knowledge expansion for the prediction and the explanation of causes and the outcome variables effects. Thus, this study purpose is to construct a prospective research design, incorporating related variables to the well-being of caregivers such as rewards of caregiving, social support, caregiving hours, functional ability of patients, and caregiving burden. The research findings should explain the causal relationship between these variables and the well-being of caregivers more clearly. Hence, the research findings can be used as information for the explanation and the well-being of caregiver predictors with spinal cord injury persons in the Thai context. Moreover, the findings should be guidelines for further research to develop the effective nursing interventions to promote the well-being of Thai caregivers with spinal cord injury patients in the future.

Conceptual Framework of the Study

The conceptual framework of this study is based on empirical evidence from the literature review. The influential factors chosen are clearly affecting the direct and indirect effects of caregivers' well-being. The researcher developed a hypothesized model with four exogenous variables, including rewards of caregiving, social support, caregiving hours, and functional ability of persons with spinal cord injury; and two endogenous variables, including a mediator variable – caregiving burden and an outcome variable, that is, well-being of caregivers. In this study, well-being of the caregiver is the individual's perception of their position in life, in relation to their ability to take care of each responsibility. It is a subjective dimension in the sense that a positive view represents caregivers with a positive mood, vitality and general interests (WHO, 1998).

Rewards of caregiving in this study are the positive feelings about the role of caregiving originating from experiences while providing care for the patients (Archbold et al., 1995). Positive feelings gained from caregiving can be a buffer to relieve negative feelings from caregiving, and reduce burdens and help the caregivers have well-being. Rewards of caregiving may directly, negatively influence caregiving burden, as well as directly, positively and indirectly influence well-being of caregivers through caregiving burden.

Social support in this study is support that people provide to caregivers for mobilizing psychological resources and mastering emotional burden, sharing tasks. Additionally they provide caregivers with material supplies, skills, and cognitive guidance in order to improve their handling of the caregiving situation (Caplan, 1974). Getting various types of help from people can reduce the amount of caregiving and reduce the time of caregiving activity, which makes caregivers perceive the difficulties as decreasing and relieving their burden. Social support helps caregivers feel less lonely and in that they do not face problems alone which results in caregivers experiencing more well-being. Social support may directly, negatively influence the caregiving burden and may directly, positively, and indirectly influence well-being of caregivers through caregiving burden.

Caregiving hours in this study means time in hours that the caregivers use each day to care for persons with spinal cord injury at home. If caregivers have to use most of their time in giving care to patient, this will cause the caregivers to use more effort and energy. The caregivers then feel that caregiving is a burden. Moreover, if caregivers have to use most of their time to take care of the patients, it will cause tension and boredom with caregiving. These will decrease the caregivers’ perceived well-being. Caregiving hours may directly, positively influence caregiving burden, as well as may directly, negatively and indirectly influence well-being of caregivers through caregiving burden.

Functional ability in this study means ability of persons with spinal cord injury to carry out their daily activities (Jitapunkul et al., 1994). Patients who have a lot of impairment of the physical organs and need to depend on caregivers to do the activities of daily life, making caregivers use time, energy, and ability to take care of patients. Caregivers will perceive that they have burden. Moreover, if caregivers need to give care to patients with complicated activities and requiring particular skills, it may cause the caregivers to feel stress and lack of confidence. These negative feelings will affect the well-being of caregivers. Functional ability of patients to do daily activities may directly, negatively influence caregiving burden, and may directly, positively and indirectly influence well-being of caregivers through caregiving burden.

Caregiving burden in this study is the perception caregivers have of the time used and the difficulties faced when caring for persons with spinal cord injury (Oberst, 1991). Caregiving to persons with spinal cord injury at home may cause the caregivers to perceive that giving care is time consuming and difficult. This causes caregivers to use too many resources, and brings about changes and difficulties in life which reduces well-being of caregivers. Caregiving burden may directly, negatively influence the well-being of caregivers. Moreover, caregiving burden is the mediator variable with the function of transmitting the influence of rewards of caregiving, social support, caregiving hours, and functional ability of patients, into well-being of caregivers. Rewards of caregiving, social support, caregiving hours and functional ability of patients, may indirectly influence well-being of caregiver through caregiving burden. The proposed relationship between the variables that will be tested is depicted in the hypothesized model presented in the following figure:

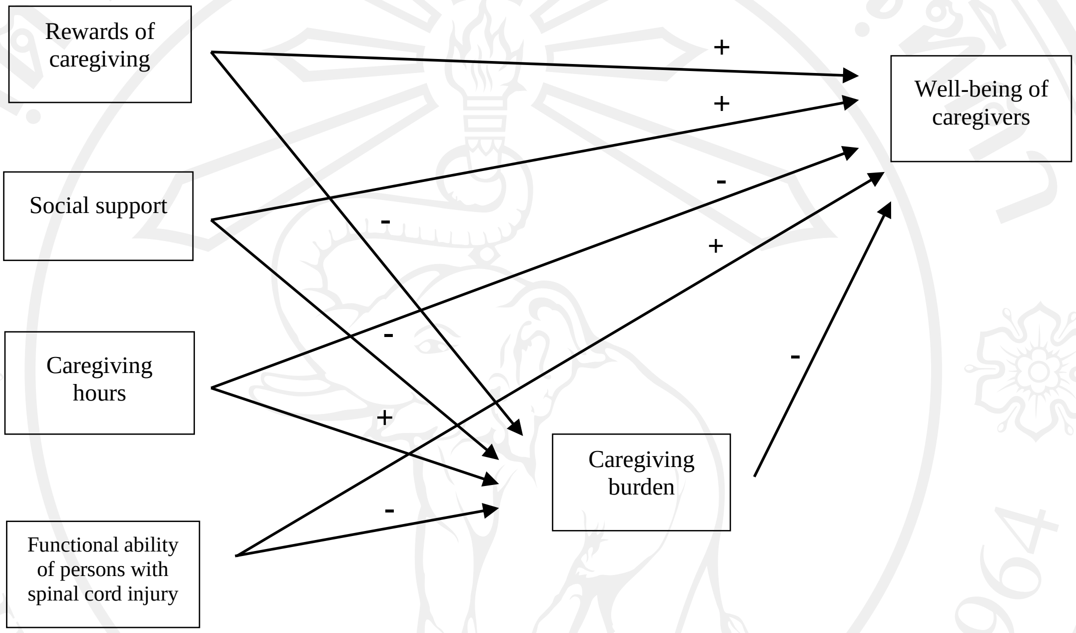

Figure 1. The hypothesized model predicting well-being of caregivers of persons with spinal cord injury

This hypothesized model explains the positive feeling of care caregiving that encourages the caregivers to continue giving care with positive attitudes. Also, their duties of giving care cause the burden. However, sufficient social support can decrease their burden of caregiving to manage the problems. As a result, they have less burden of caregiving and a positive feeling of giving care appears. Social supports for the caregivers such as consultation, caring of their feelings, listening to their problems for releasing the stress. Moreover, they feel they do not face the difficult caregiving situations alone. These feelings create the power to continue giving care positively and improve their well-being as well.

Caregivers’ life style is strongly affected by having to look after patients who have less ability of doing their daily life activities and rely on the caregivers very much. Those caregivers dedicate their life and spend their time for caring so long which impact on their ability to manage those duties. Because they have to put a lot of effort for caregiving activities burden occurs. Furthermore, the feeling of caregiving burden of those who care for the person with low ability of daily life activities and who thus consume s lot of time for giving care influence the caregivers’ personal life activities. They have less relaxation and time for their own family members and community activities and thus face social isolation. In case of caring for patients with complications, caregivers put much more effort of caregiving skills and abilities for these cargiving activities. The effect of this event builds anxiety, stress and uncertain of giving care. All of these situations take a lot of energy, resources and support to take care of the patients that cause their life complexion and changes. When those feelings appear with no solution, a negative effect on the caregivers’ well-being occurs. The consequences of less caregivers’ well-being are lack of health care, negative attitudes, undeveloped caregiving, dependence other on thoughts and decision, unable to adapt or face with difficult situations. Ultimately, the patients with spinal cord injury get the negative effect of these consequences.