# A Causal Model of Well-Being Among Caregivers of People with Spinal Cord Injury

Dalin Rattanasuk, Pikul Nantachaipan, Khanokporn Sucamvang, Wanchai Moongtui

**Abstract:** The act of caregiving for people with spinal cord injury at home can result in decreased caregiver well-being which directly affects their quality of caregiving. The purpose of this cross-sectional descriptive study was to develop and evaluate a causal model which illustrates the relationship among the rewards of caregiving, social support, caregiving hours, functional ability of people with spinal cord injury, caregiving burden, and the well-being of caregivers. This study used comprehensive empirical evidence from a literature review as the conceptual framework. A sample of **205** caregivers of people with spinal cord injury was recruited via five hospitals in Thailand where such people received treatment. Instruments used for data collection included the Demographic Questionnaire, the World Health Organization-Five Well-being Index, the Rewards of Caregiving Scale, the Social Support Questionnaire, the Barthel Index, and the Caregiving Burden Scale. Data were analyzed via path analysis using the Maximum Likelihood technique in the LISREL program.

Results revealed that caregiving hours did not significantly affect the well-being of caregivers. The rewards of caregiving, social support and caregiving burden had a direct effect on well-being of caregivers. The rewards of caregiving, social support and functional ability of people with spinal cord injury had an indirect effect on well-being of caregivers through caregiving burden. These four predictors in the Model of Well-Being among Caregivers of People with Spinal Cord Injury explained 31% of total variance in the well-being of caregivers. These findings can guide nurses and health care providers to develop appropriate interventions to promote the well-being of Thai caregivers.

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**Keywords:** caregiver well-being; caregivers; spinal cord injury; causal model

### Introduction

Spinal cord injury (SCI) affects people physically, psychologically, economically and socially. Physical problems include loss of motor and sensory function, bowel and bladder control, thermoregulation, and complications such as spasticity, pain, joint contracture, pressure ulcer, and urinary tract infection. Psychological problems include feelings of grieving and loss, negative self-concept and self-image, hopelessness, low

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Wanchai Moongtui, RN, DSN. Associate Professor, Faculty of Nursing, Chiang Mai University 110 Intawaroros Road, Muang District, Chiang Mai, Thailand 50200 self-esteem, and anger at self and others. In addition, physical disabilities cause patients loss of career and economic problems. Moreover, people with SCI are confined to wheelchair which is causing a decrease in social interaction and leading to social problems. As a result, people with SCI cannot live alone and need long-term care from caregivers. Caregivers, however, should receive care too, the same as people with SCI, because they have to provide life-long support to those they care for. Caregivers have to use many of their own resources, and so they may then suffer negative physical, psychological, social and economic impacts which in turn results in their decreased well-being.

Well-being refers to an individual's perception regarding the whole current life situations that the person is facing. A sense of well-being results from a number of factors, including one's personality, and the emotions and stressors of each situation, and includes individual assessment which can be changed over time. Persons who have decreased well-being may not be interested in their own health, exhibit negative health behaviors and a lack of enthusiasm to develop their potential, do not have the ability to adapt themselves, to cope with problems, have negative relationships with others,<sup>5</sup> and possibly depression.<sup>6</sup> The caregiving situation affects not only the caregivers in terms of decreased well-being, but also affects people with SCI as well. Caregivers with low levels of well-being are likely to behave aggressively, neglect the care of people with SCI or withdraw from their caregiving role. As a result, a decreased sense of wellbeing may adversely affect the caregiving quality and eventually have a negative effect on the people with SCI. Thus, the well-being of caregivers is important to explore. Nurses who provide health care services should develop effective nursing interventions to promote the well-being of caregivers. In order to gain a richer understanding and develop those appropriate interventions, the factors that influence well-being of caregivers should be identified.

Previous research in Thailand on caregivers' well-being has included the level of caregivers' wellbeing<sup>8</sup> and the factors related to this.<sup>9</sup> has been only one predictive study carried out on the factors associated with well-being among caregivers of patients with stroke.<sup>10</sup> Little is known about the magnitude of those effects and how various factors work together to affect the well-being of caregivers. There has been previous research in Western countries about the casual factors that affect the well-being of caregivers who provide care to patients with dementia<sup>11</sup> and elders who are disabled.<sup>12</sup> However, these study results can explain only some elements of the factors related to the well-being of caregiver of people with SCI because of the differences between the differing impacts of illness pathology on patient ability, differing caregiving activities, and the differences in the nature of the illness or disablement. Moreover, these studies were carried out in Western contexts, which are different from the Thai context in terms of the traditions, customs, cultures, norms and lifestyles. Therefore, we believe that appropriate interventions and a model to promote well-being of Thai caregivers of people with SCI have not been designed and are necessary to expand nursing knowledge.

#### Literature Review

Caregivers may care for people with SCI for short to long periods, sometimes over many years. Their caregiving tasks include: personal hygiene, dealing with complications or their prevention, helping them express their feelings, encouraging self-care activities to createfeelings of value and confidence, promoting relaxation to release stress, and providing economic support. These activities may affect caregivers' well-being.<sup>8</sup>

Well-being of caregivers in this study is defined as a persons' 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 (good spirits, relaxation), vitality (being active and waking up fresh and rested), and general interests (being interested in things). <sup>6</sup> Based on a comprehensive literature review about factors affecting caregivers' well-being in both western and eastern countries, the findings show that there are several factors that affect both caregivers and those in their care. For this study, the researcher selected only certain factors that have a strong relationship with caregivers' well-being and which can be managed for nursing interventions to promote their well-being. These factors were rewards of caregiving, social support, caregiving hours, the functional ability of the people with SCI, and caregiving burden.

Rewards of caregiving are the positive feelings of the caregiving role originating from experiences while providing caregiving. <sup>13</sup> The rewards of caregiving stimulate caregivers' positive attitude towards their caregiving situations and confirm their further caregiving activities. It can be said that, although providing caregiving may cause 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 while providing caregiving activities. Caregivers who perceive high rewards from their care have a low level of caregiving burden <sup>14</sup> and a high level of well-being. <sup>15</sup>

Social support refers to caregivers' perception about support provision from people who provide psychological resources, share tasks, and relieve emotional burden with the caregivers as well as providing material supplies, skills, and cognitive guidance to improve their caregiving situation management. Caregivers with sufficient social supports will perceive fewer problems because their stressful situations, emotional conditions and other problems can be mitigated by those supports over a shorter period. Further, receiving essential equipment for caregiving activities can reduce the amount of

caregiving activities required and save time. Social support can release caregivers' feelings of loneliness because they do not face the problems alone. All these feelings influence caregiver feelings as a high level of social support perception creates a low level of caregiving burden<sup>17</sup> and a high level of well-being.<sup>18</sup>

Caregiving hours is the time that caregivers spend daily for caregiving of people with SCI at home. Giving care for many hours per day can affect caregivers' ability to deal with existing care tasks and may cause a caregiving burden. Also, the more time spent on their caregiving, the less time spent for themselves which may cause tension and boredom. This not only affects their relaxing time with family members and other persons in society, but also caregiver feelings of well-being. Spending a lot of time for caregiving each day is likely to increase the caregiving burden<sup>19</sup> and reduce a sense of well-being.<sup>20</sup>

Functional ability refers to the ability of people with SCI to carry out their daily activities.<sup>21</sup> People who suffer from injury at a high level of the spinal cord often experience severe impairment of the physical organs which heightens their demand to depend on caregivers. These demands certainly affect caregivers' time available, energy, emotion and ability to take care of people with SCI. Their burden is further increased by the need for complicated care requiring particular skills. Finally, the caregivers might lose their confidence in giving care. To deal with these circumstances, several resources need to be accessed by the caregivers to encourage their well-being. People with SCI with low functional ability to do their daily activities will place a heavy burden on the caregivers<sup>22</sup> and create a low sense of well-being.<sup>9</sup>

Caregiving burden is the caregivers' perception on the time they spend and the difficulties they face when carrying out caregiving activities for people with SCI.<sup>23</sup> Some care activities provided to people with SCI at home are complex. Caregivers with insufficient knowledge and ability may be faced with time-consuming

care, requiring large amount of effort, and thus perceived as a caregiving burden. This burden brings about changes and difficulties in life which reduce their well-being. Caregivers who perceive a heavy burden will have a low sense of well-being. <sup>24</sup> Moreover, the caregiving burden is a factor which is transmitting the influence of rewards of caregiving, <sup>25</sup> social support, <sup>26</sup> caregiving hours, <sup>11</sup> and patients' functional ability <sup>26</sup> into the well-being of caregivers.

To gain more understanding of factors affecting SCI caregivers' well-being, this study examined a causal relationship among rewards of caregiving, social support, caregiving hours, functional ability of people with SCI, caregiving burden, as they relate to the well-being of caregivers.

#### **Theoretical Framework**

The hypothesized model (see Figure 1) was developed based upon comprehensive empirical

evidence from a literature review which indicated the relationship between well-being and significant predictors variables; rewards of caregiving, social support, caregiving hours, functional ability of people with SCI, and caregiving burden. The following hypotheses were posed:

- 1) rewards of caregiving, social support, and functional ability of people with SCI have a positive direct effect on well-being of caregivers;
- 2) caregiving hours and caregiving burden have a negative direct effect on well-being of caregivers;
- 3) rewards of caregiving, social support, caregiving hours, and functional ability of people with SCI have an indirect effect on well-being of caregivers, as mediated by caregiving burden;
- 4) caregiving hours have a positive direct effect on the caregiving burden; and,
- 5) rewards of caregiving, social support, and functional ability of people with SCI have negative direct effects on the caregiving burden.

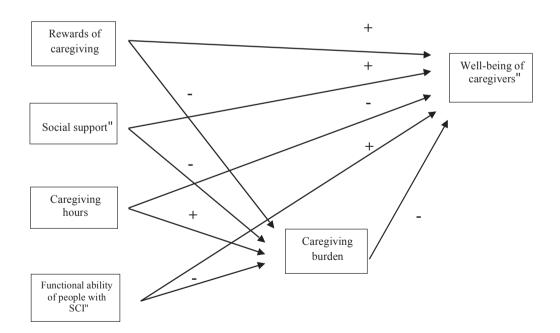


Figure 1 Hypothesized model for predicting well-being among caregivers of people with SCI.

#### Methods

**Design:** A cross-sectional, descriptive correlational design was used to examine the hypothesized model (see Figure 1).

Study population and sample: The target population was caregivers of people with SCI and so a purposive sampling method was used.Based on Kline, 27 the sample size of the path model with 20 parameters should have a minimum sample size of 200 cases. The hypothesized model in this study contained 20 free parameters, therefore, the minimum sample size in this study was set at 200 subjects. In summary, a sample of 205 caregivers of people with SCI was recruited for this study from information obtained inwards and out-patient departments(OPD) of the five tertiary care hospitals in Thailand. Inclusion criteria for caregivers were: aged 18-60 years old; legally or biologically related to the person with SCI who diagnosed by physicians with SCI at or above the fifth thoracic segment and being their primary caregiver at home; having provided care for at least three weeks<sup>28</sup> without payment; able to understand and communicate using the Thai language; and willing to participate in this study.

Ethical Considerations: This study was approved by the Research Ethics Review Committee of the Faculty of Nursing, Chiang Mai University and the research ethics committee of each of the five hospitals used as study sites. All eligible subjects were informed about the purpose, procedures, benefits of the study, and their rights. They were also informed that no invasive procedure was employed, were assured of the confidentially of their information and identity, the voluntary nature of their participation and the ability to withdraw from the study at any time without repercussions. All participants who agreed to participate signed a consent form before data collection began.

**Data collection:** All participants took approximately 45-60 minutes to complete the

questionnaires at their home. In case of those who were in-patients in hospital, the first researcher asked for permission to send the questionnaires to the caregivers by post three weeks after the patients with SCI had been discharged from hospital. In the case of out-patients in OPD, the questionnaires were given at OPD. All participants received a stamped, addressed envelope so they could return the questionnaires to the first researcher by mail. All questionnaires were returned with a response rate of 100% and were returned within two weeks. The completed questionnaires were assigned a code number for identification purposes.

Instruments: Six instruments were used to collect data. These included the: researcher-developed Demographic Data Form (DDF); World Health Organization-Five Well-being Index (WHO-5); Rewards of Caregiving Scale (RCS); Social Support Questionnaire (SSQ); Barthel Index (BI); and Caregiving Burden Scale (CBS). The DDF requested information regarding: age, gender, educational background, religion, marital status, occupational status after taking on the caregiver role, family income, income adequacy, relationship with the person with SCI, provision of care for other family members, health problems, duration of caregiving, caregiving hours per day, and caregiving assistant.

The WHO-5<sup>6</sup> is a 5-item, six-point Likert scale instrument, translated into Thai by Saipanish et al.<sup>31</sup> and was used for assessing the well-being of caregivers over the past two weeks. The WHO-5 measured three aspects of well-being including: a positive mood, vitality, and general interests. Examples of the items were: "You have felt cheerful and in good spirits"; "You have felt active and vigorous"; and "Your daily life has been filled with things that interest you." Each item is rated on scale of 0 (not present) to 5 (constantly present). A total score is obtained by summing across all items, with a possible score range of 0-25. A higher score means greater well-being. Cronbach's alpha coefficient of the WHO-5 in this study was 0.86.

The RCS<sup>13</sup> was used for assessing caregivers' positive feeling of providing care to people with SCI. Gasemgitvatana<sup>32</sup> translated, modified, and reduced the original RCS to 15 items in the Thai cultural context. This modified Thai version was divided into four categories 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). Examples of the items were: "Does caring for him or her help you feel like you are doing something important?" and "Does caring for him or her help you feel good about vourself?" The questionnaire applies a five-point Likert Scale for the responses, which range from (not at all) to 4 (a great deal). A total score is obtained by summing across all items, with possible scores ranging from 0-60 and a higher score reflects the perceived higher rewards gained from caregiving. Cronbach's alpha coefficient of the modified RCS in this study was 0.98.

The SSQ<sup>29</sup> was used for assessing caregivers' perception of support provision from people. Pipatananond<sup>33</sup> modified the original SSQ to fit the caregiver phenomena. The modified SSQ has three dimensions of social support: one item of information support, four items of emotional support and two of tangible support. The questions seeking information about the amount of support from five sources: families including a spouse, parents and children; siblings and relatives; friends, co-workers and neighbors; other providers in the community, such as traditional doctors, priests, police and others; and health care providers. Questions for each source of social support have seven items, and each source has the same questions. Examples of the items were: "How much did your spouse, parents, and children give you information, suggestion, and guidance during you giving care for people with an illness?" and "How much have your spouse, parents, and children helped you in your activities of daily caregiving during you giving care for people with an illness?" Each item was scored on a five-point Likert scale ranging from 0 (not receiving at all) to 4 (receiving a great deal). A total score from all sources of social support is obtained by summing across all items, with a possible score range of 0-140.A higher score means caregivers perceive a higher level of social support. The Cronbach's alpha coefficient of the modified SSQ in this study was 0.88.

The BI<sup>30</sup> was used for assessing functional ability of people with SCI who could live independently in their own homes for a 24-48 hour period as perceived by caregivers. Jitapunkulet al. 21 translated and modified the original BI for use in the Thai cultural context. The questionnaire contains ten items that measure feeding, grooming, transfer, toilet use, mobility, dressing, going up and down stairs, bathing, and bowel and bladder control. However, the score for each activity is not equal, but depends on the importance of each activity to the relevant person's lives. For example, possible responses to bowel control are 0="incontinent" to 2="continent," while the possible responses to mobility are 0="immobile" to 3= "independent, but may use an aid, such as a cane." A total score is obtained by summing across all items, with possible score ranging from 0-20. Higher scores suggested a higher level of independence with activities daily living. Cronbach's alpha coefficient of the modified BI in this studywas 0.89.

The CBS<sup>23</sup> is a 15-item instrument, translated into Thai by Gasemgitvatana<sup>29</sup> and used for assessing caregiving burden in three activity areas. It contains three items of direct care, four items of interpersonal care, and eight items of instrumental care. Examples of items are: "Taking care of treatment and nursing care such as making people with an illness take medicine, dressing wounds, suction, catheterization, or enemas" and "Taking care of medical and family expenses." Each question is scored on a five-point Likert scale and requires two kinds of answer: the demands and the

difficulty of caregiving. Caregiving demands measures caregivers' perception about their time spent on caregiving across various activities. Scores range from 1 (no time demand) to 5 (a great deal of time demand). Caregiving difficulty measures the complexity and effort required for each caregiving activity according to a caregiver's feelings. Scores range from 1 (easy activity) to 5 (hard activity). A total score is obtained by the square root of demand multiplied by difficulty. Then the scores of all items are added together, with possible score range of 15-75. A higher score indicates a higher level of caregiving burden. The Cronbach's alpha coefficient of the Thai version of CBS in this study was 0.85 for Demands of Caregiving subscale, 0.92 for Difficulty of Caregiving subscale, and for the whole CBS, 0.92.

Data Analysis: Descriptive statistics were used to delineate the participants' characteristics and variables. Statistical assumptions regarding normality, multicollinearity, homoscidasticity and linearity testing of the data in this study did not violate the criteria for path analysis. The Linear Structural Relationship (LISREL) 8.52 Program using Maximum Likelihood (ML) procedures was used to test the hypothesized model.

#### Results

Participant characteristics: A total of 205 caregivers of people with SCI participated in this study. Most caregivers were females (n = 171, 83.41%) with an average age of 43.93 years; completed elementary school (n = 122, 59.51%); Buddhists (n = 198, 96.59%); married (n = 175, 85.37%); employees (n = 68, 33.17%); and sufficient income without saving (n = 84, 40.98%). Monthly incomes ranged from 0-40,000 baht (mode = 3,000 baht). Among caregivers: 44.88% (n = 92) were spouses; 46.83% (n = 96) also looked after other family members; 20.49% (n = 42) had health problem; and 58.54% (n = 120) had a secondary

caregiver to support their caregiving. The caregiving duration ranged from 3 weeks-20.50 years (mean = 3.44 years) and time spent on caregiving activities each day ranged from 1 to 24 hours (mean = 14.88 hours per day).

Descriptions of variables: The analysis results for the study variables are presented in Table 1. The majority of caregivers reported the functional ability of people with SCI as being at the total dependency level (n=87, 42.44%), followed by mild dependency (n=65, 31.71%), severe dependency (n=30, 14.63%), and moderate dependency (n=23, 11.22%), respectively.

Model testing results: All the fit indices showed the hypothesized model did not fit the actual data. Thus, model modification was done until it fit the data well. The process was performed by eliminating non-significant paths, which were the paths from caregiving hours to caregiving burden, caregiving hours to caregivers' well-being, and functional ability of people with SCI to well-being of caregivers. After deletion, all fit indices for goodness-of-fit testing showed the final model adequately fit with the sample data and all path coefficients was significant. In the final modified model (see Figure 2), 31% of the variance in well-being of caregivers was accounted for by rewards of caregiving, social support, functional ability of people with SCI, and caregiving burden. Caregiving hours did not significantly affect wellbeing of caregivers. Rewards of caregiving had the largest direct effect, followed by caregiving burden, while social support had the smallest direct effect on well-being of caregivers. Caregiving burden was found to be a mediator between well-being of caregivers and the other predictors. Moreover, the results revealed that the fourth hypothesis was not supported and the remaining four hypotheses were partially supported. The results of the direct, indirect, and total effect of well-being among caregivers of people with SCI are presented in Table 2.

**Table 1** Results of analysis of study variables (n = 205)

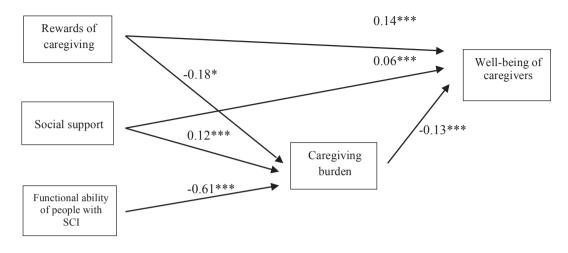
Variables	Possible	Actual	Mean	SD	Meaning of
	Range	Range			Mean score
Well-being	0 - 25	1 - 23	12.17	4.45	Moderate
Rewards of caregiving	0 - 60	13- 60	44.86	8.41	Moderate
Social support	0 - 140	6 - 138	72.92	21.40	Moderate
Family support	0 - 28	0 - 28	19.94	5.64	High
Health care providers support	0 - 28	0 - 28	17.16	6.15	Moderate
Relatives support	0 - 28	0 - 28	15.85	6.39	Moderate
Friends support	0 - 28	0 - 28	11.48	6.15	Moderate
Providers in the community support	0 - 28	0 - 26	8.49	5.77	Low
Caregiving hours	0 - 24	1 - 24	15.07	6.58	Moderate
Functional ability of people with SCI	0 - 20	0 - 20	7.53	6.02	Low
Caregiving burden	15 - 75	18 - 67	43.19	10.57	Moderate

**Table 2** Direct, indirect and total effects in the final model (n=205)

	Outcome Variables							
Predictor Variables	Caregiving burden			Well-being of caregivers				
	DE	IE	TE	DE	IE	TE		
Rewards of caregiving	-0.18*	-	-0.18*	0.14***	0.02*	0.16***		
Social support	0.12***	-	0.12***	0.06***	-0.02**	0.05**		
Functional ability	-0.60***	-	-0.60***	0.05	0.08**	0.13*		
Caregiving burden	-	-	-	-0.13***	-	-0.13***		
	$R^2 = 0.18$			$R^2 = 0.31$				

<sup>\*</sup>p<.05, \*\*p< 0.01, \*\*\*p< 0.001

Note: DE = Direct effect, IE = Indirect effect, TE = Total effect



\*p < .05, \*\*p < 0.01, \*\*\*p < 0.001 Chi-square = 0.88, df = 2, p-value = 0.64, RMSEA = 0.00

Figure 2 Final modified model of predicting well-being among caregivers of people with SCI.

#### Discussion

The results revealed that the rewards of caregiving had a positive direct and an indirect effect on well-being through caregiving burden, were congruent with prior research. <sup>15,25,34</sup> Caregivers in this study perceived a moderate level of rewards, and thus experienced positive feelings, from caregiving. They received compliments from others that created positive feelings of doing a good thing and were proud that those in their care had physical recovery as a result of their efforts. Also, they felt that they were important for those with SCI. This all helped establish positive self-esteem and feelings of being a caregiver. Caregivers who provide care with love and commitment, with reciprocity would have positive caregiving feelings because being a caregiver is one way to pay back the beloved person and giving care creates a positive relationship between the caregivers and people with SCI. 35,36 Moreover, in the Thai context, the spiritual reward is one an important factor that influences well-being of caregivers. Most of the

participants were Buddhists, and they believed in making merit and karma. They believed that taking care of people with SCI will accumulate merit for a good return in the future. All of the positive feelings of caregiving (rewards) motivate the caregivers to continue caregiving for people with SCI. Although they were faced with burdens, the rewards of caregiving enhance their well-being.

Consistent with prior research, 9,18,20,26 social support had a positive direct effect on well-being and a negative indirect effect on well-being through caregiving burden. Caregivers in this study perceived that the most support came from family members. Most participants were married and were aged around 44 years old on average and at this age, they had support from their children. In Thai culture, children have the responsibility to support their parents who were caregivers and make them feel better. Also, family support allows caregivers more time to undertake their own life activities. 9,35,36 Caregivers perceived that support from health care providers was at a moderate level. All five of the research settings had provided

holistic care programs for patients and their caregivers, and four hospitals had home visiting. This support can help caregivers gain more confidence to care and decrease the caregivers' stress. Caregivers also received support from their relatives and neighbors. All participants lived in the rural area in Thailand. In rural society, the relatives and neighbors pay attention to one another, and they respect and regard one another as their own family members. This support creates a positive feeling that they have someone else to give some help. All of these social supports can assist the caregivers to manage their caregiver burdens and contribute to a high level of well-being.

This study's finding is contrary to the previous research results where caregiving hours had a significant effect on well-being. 11, 20 However, the finding is consistent with findings from previous research, 10, 37, 38 in that caregiving hours was not a significant predictor of caregivers' well-being. Moreover, in this study, all caregivers had a close relationship with people with SCI as spouses, parents, children, siblings, or relatives. This relationship createdfeelings of generosity and good wishes in the caregivers which did not affect their well-being although they provided care for an average of 14.88 hours a day. In addition, the caregivers continue caregiving for an average of 3.44 years, which is a long time taken for the caregiver role. This may help caregivers to accept their responsibilities and successfully integrate this role into their daily lives. Also, they could manage their caregiving as a system and have time for themselves. 35 Most of caregivers had a secondary caregiver to support their own caregiving and this could help reduce the amount of care activities. Moreover, in this study 17.57% of participants had no job and 41.95% of them were agriculturalists and merchants. These situations did not seem to affect the role of being a caregiver. For example those sales people who had a shop in their home could do both duties at the same time, whereas

the farmers and labourers could only provide caregiving after work. Caregiving hours had no effect on well-being of caregivers.

Functional ability had a positive indirect effect on well-being through the caregiving burden. It was similar to prior research. 20 People who had a high level of the pathology of SCI were severely impaired and highly dependent on caregivers for a living. In such cases caregivers have to take all responsibilities in caring people with SCI in relation to physical, psychological, social, and financial demands. The caregiving tasks might exceed a caregiver's capacity to perform tasks, therefore a feeling of burden occurs. Moreover, our caregivers still had to do their own life activities such as their jobs or by being a housewife (44.4%). Female caregivers felt that they had to do all of their many duties based on Thai cultural expectation. If they ignore their caregiving duty, they would get blamed as guilty persons.<sup>36</sup> Living with many duties for a long time can create tiredness and feelings of burden. Thus, the caregivers taking people with SCI with a high dependency in daily life activities have a high level of caregiving burden and a low level of well-being.

Our results revealing that caregiving burden had a negative direct effect on well-being of caregivers was similar to prior research studies. 24,37,39 Of all our participants, 46.83% had to look after other family members during their caregiver role, and 41.46% of caregivers did not have a caregiving assistant. As a consequence of many duties, they had a difficult time to manage these responsibilities. Long-term care can cause tiredness, muscle pain, and lack of relaxation. 35,36 Some caregivers (20.49%) had their own health problems that might limit their physical performance, cause difficulties in giving care and lead to feelings of being exhausted and overloaded, and the reoccurrence of a health problem. Nearly 10% of participants had to leave their job and become a full time caregiver. Almost 40% held debts which developed a financial

burden situation. In addition, caregivers who were adults and had social participation were unable to join social activities and could not contribute to their own society because of their responsibilities.<sup>35,36</sup> These situations helped to add to their feelings of burden and contribute to low level of well-being.

#### Limitations

In this study, caregiving hours were collected by estimation and caregivers' memory recall that may have introduced measurement error and could have affected the validity of the predictions, thus the caregiving hours variable may not be totally correct. In addition, the sample of this study included caregivers who were both new and long term caregivers. The well-being of caregivers changed across time and this effects the duration and experience of caregiving. Since a cross-sectional methodology was used, the results of this study cannot be used to design nursing interventions to meet caregivers' specific needs at different points of time.

#### Conclusion and Recommendations

The findings provide foundation knowledge base for developing nursing interventions to promote caregivers' well-being in Thailand, addressing the elements identified in this study as important factors. Intervention programs should be designed in cooperation with nurses, other health care providers, caregivers, and family members. To promote caregivers' well-being and decrease caregiving burden, health care providers should promote the functional ability of people with SCI. Additionally, interventions can be planned in term of enhancing the rewards of caregiving and caregivers' perceptions of social support. Future studies should use other instruments to assess caregiving hours (for example, a diary for recording caregiving activity in hours,

interviews the other family members and people with SCI). Moreover, future studies need to consider to use of a longitudinal design to obtain data on the model comparison since the first day admission until the return to their community to make a clear understanding of the changing pattern of the entire caregiver's wellbeing trajectory.

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#### A Causal Model of Well-Being Among Caregivers of People with Spinal Cord Injury

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# แบบจำลองเชิงสาเหตุของความผาสุกของผู้ดูแลผู้ที่บาดเจ็บไขสันหลัง

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บทคัดย่อ: การดูแลผู้ป่วยบาดเจ็บไขสันหลังที่บ้านส่งผลให้ความผาสุกของผู้ดูแลลดลง ซึ่งมีต่อ คุณภาพการให้การดูแลแก่ผู้ป่วยในทางลบได้การศึกษาภาคตัดขวางเชิงบรรยายในครั้งนี้มีวัตถุประสงค์ เพื่อพัฒนาและทดสอบแบบจำลองเชิงสาเหตุระหว่าง รางวัลจากการดูแล การสนับสนุนทางสังคม จำนวนชั่วโมงที่ให้การดูแล ความสามารถในการทำกิจวัตรประจำวันของผู้ที่บาดเจ็บไขสันหลังและ ภาระการดูแล ต่อความผาสุกของผู้ดูแล โดยใช้การประมวลความรู้จากหลักฐานเชิงประจักษ์ของ วรรณกรรมงานวิจัยในอดีตเป็นกรอบแนวคิดในการศึกษา กลุ่มตัวอย่างในการศึกษาครั้งนี้ประกอบด้วย ผู้ดูแลและผู้ที่บาดเจ็บไขสันหลังจำนวน 205 รายที่เคยเข้ารับการรักษาในโรงพยาบาล 5 แห่งใน ประเทศไทยแบบสอบถามที่ใช้เก็บรวบรวมข้อมูลได้แก่ แบบสอบถามข้อมูลส่วนบุคคลของผู้ดูแลและ ผู้ที่บาดเจ็บไขสันหลัง ดรรชนีชี้วัดความผาสุกขององค์การอนามัยโลก แบบสอบถามรางวัลจากการ ดูแล แบบสอบถามการสนับสนุนทางสังคม แบบสอบถามความสามารถในการประกอบกิจวัตรประจำวัน ของผู้ที่บาดเจ็บไขสันหลัง และแบบสอบถามภาระในการดูแล ทดสอบรูปแบบสมมติฐานด้วยโปรแกรม ลิสเรลโดยวิธีความน่าจะเป็นสูงสุด

ผลการศึกษาพบว่าจำนวนชั่วโมงที่ให้การดูแลไม่สามารถทำนายความผาสุกของผู้ดูแลได้อย่าง มีนัยสำคัญทางสถิติ พบว่ารางวัลจากการดูแล การสนับสนุนทางสังคม และ ภาระการดูแลมีอิทธิพล โดยตรงต่อความผาสุกของผู้ดูแลรางวัลจากการดูแล การสนับสนุนทางสังคม และความสามารถใน การทำกิจวัตรประจำวันของผู้ที่บาดเจ็บไขสันหลังมีอิทธิพลโดยอ้อมต่อความผาสุกของผู้ดูแล ผ่านภาระการดูแล ปัจจัยทั้งสี่ร่วมกันทำนายความแปรปรวนในความผาสุกของผู้ดูแลได้ร้อยละ 31 ผลการศึกษาครั้งนี้ช่วยให้พยาบาลและบุคลากรทางสุขภาพนำไปพัฒนากิจกรรมพยาบาลที่เหมาะสม ในการส่งเสริมความผาสุกของผู้ดูแลไทยต่อไป

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คำสำคัญ: ความผาสุกของผู้ดูแล/ ผู้ดูแล/บาดเจ็บไขสันหลัง/แบบจำลองเชิงสาเหตุ

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