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Original Article

The investigation of care burden and coping style in caregivers of spinal cord injury patients

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ABSTRACT

Purpose: The level of care burden experienced by caregivers of patients with spinal cord injury and their coping style were evaluated in order to identify ways to improve their capacity to respond and reduce the care burden.

Methods: A convenience sampling method was used to select 150 spinal cord injury patients who were discharged from the Second and the Third Affiliated Hospital of Nanchang University and their primary caregivers. The Chinese version of the Zarit Caregiver Burden Interview and the Simplified Coping Style Questionnaire were distributed to assess caregiver burden and coping strategies.

Results: The care burden score of the caregivers of patients with spinal cord injury was 52.91 ± 11.56 points. Eighty-eight percent of caregivers reported moderate or severe care burden levels. The largest proportion of caregivers were female spouses, who were less likely to use an active coping strategy. A negative coping strategy was more frequently used by caregivers compared to healthy adults, and was positively correlated with burden of care. In contrast, a negative correlation was found between the care burden and an active coping style.

Conclusion: Primary caregivers of spinal cord injury patients report a heavy burden of care. As active coping strategies are more beneficial, medical care providers should encourage caregivers to make more use of these coping styles to promote physical and mental health for themselves, their patients and their family, as well as to improve the quality of care provided.

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1. Introduction

The development of transport and construction in China has led to an increase in the incidence of spinal cord injury (SCI). The estimated number of patients with spinal cord injuries worldwide is over three million, with more than one million in China, and 120,000 new cases every year [1]. Spinal cord injury is a relatively common serious disabling condition [2] that can cause permanent disability and leave individuals incapable of caring for themselves. Rehabilitation often occurs at home, with caregiving provided by the spouse. The psychological pressure and additional burdens are particularly substantial on the immediate family caregivers.

Previous studies have shown the coping strategies implemented by caregivers can affect their care burden [3,4]. Moreover, the burden felt by caregivers may seriously impact their own health as well as the quality of care they provide to their patients. The aim of this study was to evaluate the burden level on caregivers of patients with SCI and their coping strategies. The findings from this study will help provide a basis to identify effective coping methods that alleviate their burden to ultimately promote the common health of patients and their caregivers.

2. Subjects and methods

2.1. Subjects

A convenience sampling method was applied for the selection of caregivers of SCI patients discharged between January 2011 and November 2012 from the Second and Third Affiliated Hospitals of Nanchang University. Criteria used to identify SCI patients included: >18 years-old, diagnosed by computed tomography or magnetic resonance imaging as cervical, thoracic or lumbar SCI patients with paraplegia or quadriplegia, no history of mental illness, consent to participate in this study. Criteria for caregivers included: SCI patient family members who provided primary care (if more than one family member, the patient designated which was the primary caregiver), >18 years-old, provided care \geq seven days per week, able to understand the contents of the questionnaire and communicate with investigators in Mandarin without any barrier, consent to participate in this study. One hundred fifty-two of the 154 distributed questionnaires were recovered, yielding a 98.70% recovery rate. Of these, 150 were valid questionnaires, with an effective rate of 97.40%.

2.2. Questionnaire

2.2.1. General information

All data was collected from questionnaire responses. General information was collected from spinal cord injury patients, such as gender, age, medical expenses and sources of payment, etc., in addition to disease-related information, including which spinal segment was injured, admission time, clinical diagnosis, cause and severity of injury, treatment and complications. General information was also collected from

the caregivers, including basic conditions, personal health information and care information.

2.2.2. Zarit Caregiver Burden Interview (ZBI)

The Chinese version of the ZBI, developed by Lie Wang [5], assesses two dimensions of burden to caregivers (role and personal burden) in a survey comprised of 22 questions, and has been used for assessing the burden of caring for patients with stroke, hemodialysis, and chronic diseases such as Alzheimer's disease. Questions are scored on a 5-point scale ranging from 0 (never) to 4 points (always), and summed for a maximum total of 88 points with a higher score indicative of greater burden. The overall Cronbach's coefficient of internal consistency is 0.88, with a test-retest reliability of 0.87. The two dimensions within this assessment are internally consistent and show high content and construct validity.

2.2.3. Simplified coping style questionnaire

The first 12 questions of this questionnaire evaluate active coping response characteristics, and the remaining eight emphasize the negative coping characteristics. Questions are scored using a self-rated scale, ranging from a score of 0 (never) to 3 (often used). The overall Cronbach's coefficient for this questionnaire is 0.90, with a positive response subscale coefficient of 0.89 and a negative coping subscale of 0.78. The test-retest correlation coefficient for this questionnaire is 0.89. Factor analysis results show that, consistent with the theoretical conception, this questionnaire shows good validity for evaluation two factors, "active" and "negative" coping [6].

2.3. Statistical analysis

SPSS 17.0 statistical software (SPSS Inc., Chicago, IL, USA) was used for analyses of data frequency, mean, standard deviation, and percentage values. *T* and analysis of variance (ANOVA) tests were used to evaluate differences in gender, age, SCI, payment of medical expenses, education level, family role, and presence of religious beliefs of caregivers. Pearson's correlational analysis was used to assess the association between SCI caregiver burden and coping style. Data are expressed as mean \pm standard deviation, with a *p* value of 0.05 considered as statistically significant.

3. Results

3.1. Overall results

This study included a total of 150 cases of SCI. The majority of the patients were male (115/150, 76.7%) with an overall average patient age of 43.23 ± 11.92 years. The causes of SCI included: 65 cases from traffic accidents (43.3%), 52 cases of injury from falls (34.7%), 15 cases due to falls (10%), heavy injured in 10 cases (6.7%), and 8 cases of SCI injury due to other causes (5.3%). Most of the injuries were to the cervical spinal cord (102/150, 68%), 26 cases were injuries to the thoracic spinal cord (17.3), 18 cases involved the lumbar spinal cord (12.0%), and four cases involved injury to two or more segments (2.7%). Incomplete paralysis occurred in 93 of the 150 cases (62%), and total paralysis occurred in 57 cases (38%). One

hundred three patients were medically insured (68.7%), and 47 patients did not have health insurance (31.3%).

The majority of caregivers were females (120/150, 80%) with 88.7% (133/150) obtaining an education at or below the junior high school level. Consistent with the fact that most patients were males, 78.0% of caregivers were female spouses (117/150). Only 16 caregivers reported that they were associated with an organized religion (10.7%), with the majority (134/150, 89.3%) indicating no religion. Ten percent of the caregivers themselves were suffering from chronic diseases. The mean number of days of care provided was 50.17 ± 8.00 , and 90% of caregivers were satisfied with the care they provided, with 80% reporting that their own health had worsened since becoming a primary caregiver. All caregivers acknowledged the need to know how to take care of their patients, and hoped to communicate with a nurse about this. The sources of knowledge for the majority of caregivers were limited to doctors, nurses and TV.

3.2. SCI patient caregiver burden

Results from the ZBI-based evaluation of the 150 caregivers show that the average score of care burden for caregivers of patients with SCI was 52.91 ± 11.56 points. Moderate to severe burdens were reported by 88% of caregivers, with only 11.3% reporting mild burden levels. Table 1 shows the questions and average scores for the top five entries concerning role and personal burdens of the caregivers.

Evaluation of the impact of various factors impacting the two dimensions of caregiver burden found that male caregivers reported a greater personal burden than females (Table 2). Although caregiver age did not affect burden level, the

burden was significantly higher to those caring for patients with complete SCI compared to those caring for patients with incomplete SCI ($p < 0.05$). Furthermore, the burden was significantly higher to caregivers of patients with no medical insurance ($p < 0.05$).

3.3. Coping of SCI patient caregivers

3.3.1. Comparison of coping between SCI patient caregivers and healthy adults

There were significant differences between SCI patient caregivers and healthy adults on active and negative coping strategies ($p < 0.01$) (Table 3). Caregivers used more negative and less active coping methods than healthy adults.

3.3.2. Univariate analysis of impact of caregiver coping style

Univariate analysis indicated that male caregivers and those with higher education levels used active coping significantly more often than female caregivers or those with a limited education ($p < 0.01$) (Table 4). Caregivers that were the spouse of the SCI patient were also more likely to use negative coping strategies ($p < 0.01$). However, report of religious affiliation did not affect implementation of either an active or negative coping style.

3.3.3. Relationship between care burden and coping style of SCI patient caregivers

A correlational analysis revealed that the role and overall total caregiver burdens were negatively associated with an active coping strategy, and positively correlated with a negative coping strategy ($p < 0.01$) (Table 5). Personal burden was only positively correlated with a negative coping style.

Table 1 – Spinal cord injury patient caregiver burden (top five questions from each of two categories; $n = 150$).

Item	Score (mean \pm SD)
Role burden	
5. "Do you believe that the patient is troubled while you are there?"	2.55 \pm 1.46
8. "Do you think the patient depends on you?"	3.24 \pm 1.05
9. "When a patient is by your side, do you feel nervous?"	2.49 \pm 1.16
14. "Do you think you are the only person the patient depends on?"	3.45 \pm 1.05
17. "Do you think that providing care has made living according to your own life impossible?"	3.31 \pm 1.12
Personal burden	
2. "Do you think you have enough time to provide caregiving?"	2.83 \pm 1.19
3. "Do you feel pressure to do housework and jobs in addition to caregiving?"	2.75 \pm 1.25
11. "Do you think caregiving takes away time from your own private affairs?"	2.47 \pm 1.41
12. "Do you think caregiving has affected your social life?"	3.02 \pm 1.20
13. "Does having the patient at home prevent you from having friends visit?"	2.45 \pm 1.14

4. Discussion

4.1. Care burden of SCI patient caregiver

This study found that essentially all of the individuals serving as primary caregivers to patients with SCI feel some level of burden of care, with a large majority reporting that this burden is moderate to severe. These results differ from many domestic caregivers findings, as studies by Peng [7] and Li et al. [8] show that caregivers of stroke patients report mild to moderate burden levels. This discrepancy may be related to the fact that the majority of the SCI patients in this study were young men. However, the male to female ratio in this study was similar to the 4:1 ratio reported in a Beijing SCI epidemiological analysis [9]. As most of the SCI patients were the household providers, their injury resulted in severing of the family's main economic lifeline. Combined with high medical costs, the economic burden on the caregiver becomes particularly heavy, and consequently, may create a heavier burden.

The caregiver's burden is mainly a reflection of their patient's dependence. The work, life, and social activities of a caregiver are inevitably affected at various degrees, which contribute to the heavy burden of life, psychological, and social responsibilities. In this study, almost all of the caregivers agreed that becoming a caregiver has made it impossible to live according to their own life, and three quarters of them

Table 2 – Univariate analysis of spinal cord injury caregiver burden (n = 150).

Item	Role burden score (mean ± SD)	F/t	Personal burden score (mean ± SD)	F/t
Gender		1.228		2.261*
Male	27.10 ± 7.88		15.7 ± 3.95	
Female	25.43 ± 6.36		13.8 ± 4.16	
Age (years)		1.558		2.545
≤35	25.83 ± 7.59		15.3 ± 4.75	
35–50	24.81 ± 6.47		13.6 ± 3.98	
≥50	27.21 ± 5.70		13.8 ± 3.51	
Spinal cord injury		–4.115*		–2.414**
Complete	28.49 ± 5.16		15.2 ± 3.61	
Incomplete	24.09 ± 6.70		13.6 ± 4.38	
Medical Insurance		–1.90		–3.746**
Yes	25.14 ± 7.17		13.5 ± 4.41	
No	27.13 ± 5.33		15.8 ± 3.06	

Abbreviations: SD, standard deviation; F/t indicates values obtained by analysis of variance or Student's t-test. *P < 0.05; **P < 0.01.

claimed that they could spend more time caring for their patients, which is consistent with a study on caregivers of paraplegic patients by Lu [10]. As patients with SCI are often paralyzed and bedridden, they require a caregiver to take care of their washing, eating, toilet and other basic living activities in addition to assisting in the treatment, rehabilitation training, monitoring of the disease, and so on. Moreover, as the majority of the caregivers were the wives of the patients, they also had a further responsibility of the care and education of their children.

Despite the gender imbalance in this study, male caregivers reported a heavier personal burden. This suggests that in clinical care, more attention should be placed on the feelings of male caregivers. Female caregivers who cope well should be invited to share their own experiences and feelings with other caregivers. In addition, this study found that caregiver burden was higher when caring for patients with complete SCI. Thus, health care knowledge with comprehensive and detailed guidance should be provided to caregivers of these patients, and other family members should help provide additional financial and emotional support.

Importantly, this study found that almost all of the caregivers that were evaluated suffered from health problems as a result of the care of their patients. Furthermore, the probability of acquiring an illness only increases with the duration of the care needed, which in the case of SCI can be quite prolonged. This study abroad and consistent [11]. But in the survey, 10% of caregivers own had chronic diseases. These results suggest that most caregivers do not want to let anyone else take care of the patient, and alone bear the burden. However, these silent and loyal contributions from caregivers are a strong source of support for patients with SCI, and may provide them with encouragement and determination that

aids their recovery [12]. With this in mind, caregivers as well as patients deserve care and support from the community, and thus nurses should communicate with them regularly, so as to provide assistance and alleviate their burdens.

4.2. Comparison between SCI patient caregivers and healthy adults

The “stress-assessment-response” theory proposed by Lazarus and Folkman states that an individual is constantly changing their cognitions and behavioral efforts to adapt to the specific requirements of both internal and external environments [13]. Moreover, the consequences of a response will always affects one's values, attitudes, social adaptability and the development of physical and mental health. Studies by George et al. [14] and Boter et al. [15], among others, have shown that differential responses to the same pressure conditions will result in the differential changes in the body's immune function.

Compared to healthy controls, caregivers were less likely to utilize active coping strategies. This may be a result of the long duration of primary care provided by the caregivers. In addition, a large percentage of SCI patients included in this study were completely paralyzed, which requires a high level of care, and can lead to upper respiratory tract infections, pressure sores, muscle atrophy and other serious complications from being bedridden for a long time. Thus, the difficulty associated with caring for these patients may cause caregivers to cease active coping responses over time.

4.3. Correlation between care burden coping response

The analyses in this study indicated that males were more likely to use active coping strategies than females, which is consistent with previous research [16]. Furthermore, caregivers with a limited education and spouse-caregivers were less likely to cope using active strategies. However, the majority of caregivers in this study were female spouses, thus the overall responding capacity of caregivers of SCI patients was poor.

This study also shows that SCI patient caregiver burden was negatively correlated with an active coping style, which is

Table 3 – Spinal cord injury patient caregiver and healthy adult coping styles.

Item	Healthy adults (n = 1305)	Caregivers (n = 150)	t
Active coping	30.26 ± 8.74	25.41 ± 4.03	11.875**
Negative coping	21.25 ± 7.14	21.99 ± 2.33	2.697**

**P < 0.01.

Table 4 – Univariate analysis of spinal cord injury patient caregiver coping style (n = 150).

Item	Active coping score (mean ± SD)	F/t	Negative coping score (mean ± SD)	F/t
Gender		3.548**		–0.886
Male	27.53 ± 4.71		21.87 ± 1.22	
Female	24.76 ± 3.59		22.14 ± 1.58	
Education		–5.331**		1.964
Secondary and below	24.74 ± 3.67		22.17 ± 1.32	
High school and above	29.76 ± 3.51		21.41 ± 2.58	
Family roles		–2.493*		8.297**
Spouse	24.99 ± 3.74		22.68 ± 1.54	
Non-spousal	26.97 ± 4.76		19.47 ± 2.99	
Religion		–0.863		–0.643
Yes	26.13 ± 3.84		22.25 ± 1.00	
No	25.22 ± 3.40		22.07 ± 1.57	

Abbreviations: SD, standard deviation; F/t indicates values obtained by analysis of variance or Student's t-test. *P < 0.05; **P < 0.01.

consistent with findings by Lu in 2009 [10]. According to Folkman and Lazarus, caregiver coping has two functions: to change the problems that raised the irritability, and to adjust the emotional reaction caused by it [13]. Active coping can be sub-divided into problem coping and emotional coping. The aim of problem coping is to change the situation, such as by seeking and applying problem-solving information. Once this approach fails, individuals are more likely to engage in an emotional coping strategy, such as a re-evaluation of stressors and threats. However, this way is closer to a negative coping style, and cannot reduce the pressure load, but may increase the individual's burden level.

The negative coping behaviors were also highly correlated to caregiver burdens, which is consistent with results from Li et al. [8]. While these results illustrate that coping style is an important factor in determining the care burden of a caregiver, they also indicate that an active coping style can reduce the burden. However, most SCI caregivers took a passive coping style to relieve their burden, such as waiting, escapism, and fantasizing that tomorrow will be better, because they felt that there was no alternative recourse. In contrast, only a small number of caregivers achieved liberation through active strategies, such as work or some other activity. This may be a result of the lower level of education, as the higher the education level one has, the broader the source of available knowledge and the easier it is to acquire active coping styles to deal with the problems.

Health care workers should develop a detailed and practical rehabilitation plan with both SCI patients and caregivers, so that caregivers are aware of the long-term treatment and care needs of their patients. Cognizance of cultural differences is also necessary to expand caregivers' sources of knowledge and allow for maximal effort to recover patients' daily living

capabilities. Furthermore, caregivers should receive training on useful coping strategies and teach them that negative strategies often do not help, but rather add to, the overall burden. Previous studies demonstrate that active intervention for caregivers can reduce their burden of care and consequently improve the quality of care they provide as well as their own health [17,18]. Therefore, caregivers should be encouraged to take more active strategies through communication with friends and engaging in recreational activities.

5. Conclusion

In summary, caregivers of SCI patients generally experience moderate to severe levels of burden of care. Most caregivers take a more passive coping method, which correlates with a heavier burden. Conversely, active coping strategies correlate with lighter burdens. Caregivers should be provided with emotional support and specific assistance through psychological comfort, social support, effective rehabilitation guidance, and detailed relevant health education, so as to relieve their care burden. Moreover, a positive environment for treatment and extended care should be established to limit the development of negative coping behaviors, so as to improve the health of patients as well as the entire family.

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Conflicts of interest statement

We declare no potential conflicts of interest with respect to the research and/or publication of this article.

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Table 5 – Correlational analysis of spinal cord injury patient caregiver burden and coping style (n = 150).

	Total care burden	Role burden	Personal burden
Active coping	–0.418**	–0.442**	–0.071
Negative coping	0.613**	0.520**	0.228**

**P < 0.01.

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