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Research Article

Caregiver Burden and Coping Strategies in Caregivers of Persons with Spinal Cord Injury

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Abstract

Background: A substantial number of patients with spinal cord injury (SCI) need support and care for their daily activities, and this is usually provided by a family member. This responsibility may have several physical and emotional consequences. The aim of the present study was to assess the caregiver burden and the coping strategies used by caregivers of patients with SCI.
Methods: A cross-sectional study on 50 primary caregivers of persons with SCI was conducted. The caregiver burden was assessed using Caregiver Burden Inventory (CBI) and Brief Coping Orientation to Problems Experienced (COPE) was used to assess the coping strategies used by the caregivers.
Results: The majority of caregivers (82%) were under 50 years of age and were women (66%). 12% of participants faced severe burden and 32% faced moderate to severe burden. Coping strategies involved avoidant, problem-focused, and emotion-focused strategies. Avoidant strategies were associated with moderate to severe burden. Active coping strategies were significantly associated with little or no burden. Greater use of positive coping strategies was related with less amount of caregiver burden. The caregivers with highest burden were found to engage in self-distraction, denial, and behavioral disengagement. The utilization of problem-focused coping strategies, emotional support, and religious practices was most prevalent in caregivers where there was minimal or no burden.
Conclusion: The study highlights that coping style plays a significant role in determining caregiver burden, with avoidant coping strategies being associated with higher burden, while active and positive coping strategies were associated with reduced burden. These findings emphasize the importance of promoting adaptive coping mechanisms and providing psychosocial support interventions to reduce caregiver burden and improve caregiver well-being.

Keywords: Caregiver Burden; Coping Strategies; Spinal Cord Injuries

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Background

Spinal cord injury (SCI) is a life-altering condition. After injury, a person faces challenges in relation to their physical, psychological, and social functioning. Their life gets affected, immediately altering their daily life, independence, and role within their family and society. A substantial proportion of persons with SCI need support in these areas for the rest of their life (1). Their need ranges from assistance with basic daily activities such as bowel and bladder management and dressing to instrumental activities of daily living, including managing household finances, shopping, or transportation. Rehabilitation often occurs at home with care provided by the family members. Family caregivers operate as an integral component of the health care delivery system that usually has to be given for an indefinite period (2).

One individual in a family frequently assumes most or all of the responsibilities of caring for a person with a disability, and this responsibility may have several physical and emotional consequences. For instance, the challenges that accompany a family caregiving role may result in a caregiver's inability to balance responsibilities at home and in the workplace. In addition, there is a tendency for caregivers to neglect their own health, which may lead to the person with SCI being unable to have the necessary care and support they require to function as independently as possible and participate in society because of the diminished capacity of their family support system.

This psychological pressure and additional burdens are particularly substantial on the immediate family caregivers. Moreover, family caregivers may also have to deal with possible negative psychological consequences of SCI like depression and aggressive behavior by the person with SCI. Caregivers have to adapt to the new circumstances, modify pre-injury lifestyle, and get a dual role as partner and caregiver, often without sufficient preparation (2). Financial burden arising in addition to any income forgone by the patient also has a significant effect on the entire family unit. Lifetime costs of managing SCI and related secondary conditions are staggering and pose a significant burden on individuals with SCI, their families, and society.

Burden refers to the impact that care provided in physical, psychological, social, and financial terms causes on the life of a caregiver of a sick individual unable to perform activities of daily living (ADL). It is a highly individualized experience. The extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, or spiritual functioning is vast (3). Care burden is a term frequently used for caregivers who provide informal care, that is, they do not have an educational background in the health field and are not paid for providing such care.

The burden of the caregiver is a multidimensional concept, which can be classified in two categories of objective and subjective burdens (4). The objective burdens are the outward consequences such as downturn of financial resources or disruption in family life and the activities related to provide care for people with SCI, which are obviously visible to the others. The subjective burdens are the psychological consequences such as emotional stress or depression reported by caregiver based on personal appraisals of care-giving experience.

Few researchers have analyzed the caregiver burden and coping strategies among caregivers of patients with SCI in the past (5-7). Identification of coping styles helps us to identify the need of education and planned interventions so that strategies can be formulated for well-being of caregivers. The present study was, therefore, aimed to identify the caregiver burden and the coping styles used by the caregivers of persons with SCI.

Methods

This study was conducted in a tertiary care medical center after getting Institutional Review Board (IRB) permission (BREC/Th/20/Ortho 01 dated 01/04/2021). A sample size of 42 caregivers was calculated for this purpose, but it was decided to enroll a minimum of 50 caregivers for this study. All the patients registered with spine clinic/outpatient department (OPD)/indoor in last one year were contacted. The primary caregivers of these patients were contacted, and consent for participation was taken after explaining about the purpose of the study. After the consent for participation, they were invited for a personal interview and an informed consent was obtained. To maintain the uniformity of the group, it was necessary to include the primary family caregivers. The family caregiver used in this study signified a family member, linked by blood or partnership who was responsible for caring for the SCI survivor at home.

The demographic information was recorded. The caregiver burden was assessed using Caregiver Burden Inventory (CBI), and Brief Coping Orientation to Problems Experienced (COPE) was used to assess the coping strategies used by the caregivers.

Statistical Analysis: Data collected were compiled on a Microsoft Excel worksheet and subjected to statistical analysis using SPSS software (version 25.0, IBM Corporation, Armonk, NY, USA). Descriptive statistics like frequency and percentage of categorical data and mean and standard deviation (SD) of numerical data in each time interval were depicted.

Descriptive statistics were used to describe study population, provided support, burden, mental health, and life satisfaction of the caregivers of individuals with SCI. Shapiro-Wilk test was used for distribution of data. The caregiver burden and its association with the different variables for physical, emotional, social, and overall burden were calculated. Parametric tests (t-test) and non-parametric tests (Kruskal-Wallis test and Wilcoxon-Mann-Whitney U test) were used to make group comparisons whereas Pearson's correlation coefficient and Spearman’s correlation coefficient were used to explore the correlation between the two variables.

Keeping alpha error at 5%, beta error at 20%, and power at 80%, $P < 0.05$ was considered statistically significant.

Results

The results show that the majority of caregivers (82%) were under 50 years of age and were women (66%). Table 1 shows the demographic characteristics of the participants.

Table 1. Demographics of caregivers

Variables	Categories	n (%)	95% CI
Age (year)	50	41 (82.0)	68.1-91.0
	> 50	9 (18.0)	9.0-31.9
Gender	Men	17 (34.0)	21.6-48.9
	Women	33 (66.0)	51.1-78.4
Employment	Yes	27 (54.0)	39.5-67.9
	No	23 (46.0)	32.1-60.5
Relation with patient	Father	6 (12.0)	5.0-25.0
	Mother	15 (30.0)	18.3-44.8
	Brother	3 (6.0)	1.6-17.5
	Wife	18 (36.0)	23.3-50.9
	Son	8 (16.0)	7.6-29.7

CI: Confidence interval

Table 2 shows the caregiver burden categories. 12% of participants faced severe burden and 32% faced moderate to severe burden.

Table 2. Burden in caregivers

Caregiver burden	n (%)	95% CI
Little/no burden	12 (24.0)	13.5-38.5
Mild to moderate	16 (32.0)	19.9-46.8
Moderate to severe	16 (32.0)	19.9-46.8
Severe	6 (12.0)	5.0-25.0

CI: Confidence interval

Table 3 shows various coping strategies used by the participants.

Table 3. Coping strategies

Brief-COPE		Mean ± SD	Median (IQR)	Range
Avoidant	Self-distraction	1.77 ± 0.58	2.00 (1.50-2.00)	1-3
	Substance abuse	1.44 ± 0.66	1.00 (1.00-2.00)	1-3
	Denial	1.45 ± 0.51	1.50 (1.00-2.00)	1-3
	Behavioral disengagement	1.99 ± 0.79	2.00 (1.12-2.88)	1-3.5
Problem-focused	Active coping	2.45 ± 0.67	2.25 (2.00-3.00)	1-4
	Use of informational support	2.16 ± 0.58	2.00 (2.00-2.50)	1-3.5
	Positive reframing	2.50 ± 0.55	2.50 (2.00-3.00)	1-3.5
	Planning	2.50 ± 0.51	2.50 (2.00-3.00)	1.5-3
Emotion-focused	Emotional support	2.40 ± 0.51	2.50 (2.00-2.50)	1.5-3.5
	Venting	1.64 ± 0.56	1.50 (1.00-2.00)	1-3
	Humor	1.16 ± 0.29	1.00 (1.00-1.38)	1-2
	Acceptance	2.70 ± 0.45	3.00 (2.50-3.00)	1.5-3.5
	Self-blame	2.38 ± 0.64	2.50 (2.00-3.00)	1-3
	Religion	2.53 ± 0.57	2.50 (2.00-3.00)	1-3.5

COPE: Coping Orientation to Problems Experienced; IQR: Interquartile range; SD: Standard deviation

Table 4 shows association of coping strategy with level of burden using Kruskal-Wallis test.

Discussion

The present study involved the caregivers of patients with SCI having neurological impairment. The primary caregiver is usually one individual who takes the most of the responsibility of caregiving (8). The demographic characteristics of caregivers show that most of the caregivers were less than 50 years of age, the majority were women, and life partners were most common caregivers. Previous studies have also shown that spouses are the most common caregivers (9).

Coping strategies are defined as an action, a series of actions, or a thought process used in meeting a stressful situation or in modifying one’s reaction to such a situation (10). The coping strategies were divided into three subscales namely problem-focused coping, emotion-focused coping, and avoidant coping.

Avoidant coping involves cognitive and behavioral efforts oriented towards denying, minimizing, or otherwise avoiding dealing directly with stressful demands.

Table 4. Association of caregiver burden with coping strategies

Coping strategy	Caregiver burden [Median (IQR)]				Kruskal-Wallis test	
	Little/no burden	Mild to moderate	Moderate to severe	Severe	χ^2	P-value
Avoidant: Self-distraction	1.50 (1.00-1.50)	1.75 (1.00-2.00)	2.00 (2.00-2.50)	1.75 (1.12-2.38)	16.296	0.001
Avoidant: Substance use	1.00 (1.00-1.00)	1.00 (1.00-1.25)	2.00 (1.00-2.50)	1.00 (1.00-1.75)	6.996	0.072
Avoidant: Denial	1.00 (1.00-1.00)	1.00 (1.00-1.50)	2.00 (1.50-2.00)	2.00 (1.25-2.00)	16.959	0.001
Avoidant: Behavioral disengagement	1.00 (1.00-1.12)	1.50 (1.50-2.00)	3.00 (2.38-3.00)	3.00 (2.62-3.00)	29.957	< 0.001
Problem-focused: Active coping	3.00 (3.00-3.12)	3.00 (2.00-3.00)	2.00 (2.00-2.00)	1.75 (1.50-2.00)	19.569	< 0.001
Problem-focused: Use of informational support	3.00 (2.50-3.00)	2.00 (2.00-2.50)	2.00 (2.00-2.00)	1.75 (1.50-2.00)	20.121	< 0.001
Problem-focused: Positive reframing	3.00 (2.88-3.00)	2.50 (2.50-3.00)	2.00 (2.00-2.50)	1.75 (1.50-2.00)	18.925	< 0.001
Problem-focused: Planning	3.00 (3.00-3.00)	2.75 (2.38-3.00)	2.00 (2.00-2.62)	2.00 (1.62-2.00)	19.693	< 0.001
Emotion-focused: Emotional support	3.00 (2.50-3.50)	2.50 (2.00-2.50)	2.00 (2.00-2.50)	2.00 (2.00-2.00)	22.227	< 0.001
Emotion-focused: Venting	1.00 (1.00-1.12)	1.50 (1.50-2.00)	2.00 (1.50-2.00)	1.50 (1.12-1.88)	12.210	0.007
Emotion-focused: Humor	1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.50 (1.00-1.50)	1.00 (1.00-1.38)	18.753	< 0.001
Emotion-focused: Acceptance	3.00 (3.00-3.00)	3.00 (2.88-3.00)	2.50 (2.38-2.62)	3.00 (2.25-3.00)	10.433	0.015
Emotion-focused: Self-blame	2.00 (1.50-2.50)	2.00 (1.88-2.50)	3.00 (2.50-3.00)	3.00 (3.00-3.00)	15.988	0.001
Emotion-focused: Religion	3.00 (2.88-3.00)	3.00 (2.38-3.00)	2.25 (2.00-2.50)	2.25 (2.00-2.50)	13.858	0.003

IQR: Interquartile range

Four components, namely self-distraction, substance use, denial, and behavioral disengagement, are components of this strategy. The results of the present study showed that the caregivers of patients with SCI used self-distraction [median score: 2 (1.5-2.0)] and behavioral disengagement [median score: 2 (1.12-2.88)].

Avoidance coping is largely ineffective as it does not address the root cause of stress. Behavioral disengagement reflects the tendency to reduce the efforts in stressful situation. It is the act of withdrawing from unpleasant situation. This might affect overall health and can lead to depression and reduced quality of life (QOL) (11).

Similarly, self-distraction is also a passive coping strategy. In this approach, person copes without confronting the situation. There was a strong association of these two coping strategies with moderate to severe burden measured by CBI.

The second coping style is problem-focused coping which includes active coping, use of informational support, positive reframing, and planning. It is a positive approach which uses all active efforts to manage stressful situation. It was seen that all the four methods of problem-focused coping were used by the caregivers, i.e., active coping [median score: 2.25 (2-3)], use of informational support [median score: 2 (2.0-2.5)], positive reframing [median score: 2.50 (2-3)], and planning [median score: 2.50 (2-3)]. All four coping strategies were associated with little or no burden in CBI. There was a strong negative correlation between all four coping strategies and CBI score. Problem-focused coping had been shown to promote mental health, reduce depression, anxiety, and aggression, and provide sense of control (12).

The third coping style used by the caregivers is emotion-focused coping. It includes emotional support, venting, humor, acceptance, self-blame, and religion. Emotional support [median score: 2.50 (2.0-2.5)], acceptance [median score: 3 (2.5-3.0)], self-blame [median score: 2.50 (2-3)], and religion [median score: 2.50 (2-3)] were used by the caregivers in the present study. Emotional support (rho = -0.7, $P \leq 0.001$), acceptance (rho = -0.37, P = 0.009), and religion (rho = -0.54, $P \leq 0.001$) were associated with little or no burden. Self-blame was associated with severe burden (rho = 0.55, $P \leq 0.001$). Emotion-focused coping involves regulating one's feelings and emotional response to problem instead of addressing the problem. It had been seen that emotion-focused coping was the most commonly used strategy among caregivers of patients with Alzheimer's disease (AD) (13). The use of emotion-focused coping associated with religion and spirituality may help reduce symptoms of depression and anxiety. In India, religious institutions have a major role in socializing, counseling, and providing emotional support. The use of proper coping strategies may help to reduce the caregiver burden.

In the present study, active coping and emotional support were associated with low burden, and avoidant coping was associated with high burden. Caregiver coping has two functions: to change the problems that raised the irritability, and to adjust the emotional reaction caused by it (14). These results of the present study illustrate that coping style is an important factor in determining the care burden of a caregiver; these also indicate that an active coping style can reduce the burden (Figure 1). However, 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, the broader the source of available knowledge and the easier the acquisition of active coping styles to deal with the problems. The effects of caregiving could possibly be explained by the way caregivers themselves cope with it. Greater use of coping strategies is related with higher QOL and self-reported health (15).

Chan studied the sources of stress and pattern of coping in spouses of persons with SCI among Hongkong Chinese. The results found that potential at-risk group was characterized by external locus of control, inadequate coping modes, and limited social support. He found that spouses of persons with SCI suffered the level of stress comparable to those of injured partner (5). Ma et al. found that negative coping strategy was most frequently used by caregivers compared to healthy adults, and was positively correlated with burden of care. Similar to the present study, they reported that a negative correlation was found between active coping style and care burden (7). Jeyathevan et al. explored the perceptions of individuals with SCI regarding the facilitators and barriers to undertaking and sustaining the caregiver role in the community. The facilitators identified were access to community support services, positive coping in relationship, social support, and mastery of caregiving role (16). Zanini et al. identified coping strategies used by family caregivers of persons with SCI. The main coping strategies identified were reppaisal, active acceptance, setting limits of caregiving role, and seeking support (17).

Health care workers should develop a detailed and practical rehabilitation plan with both patients with SCI 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.

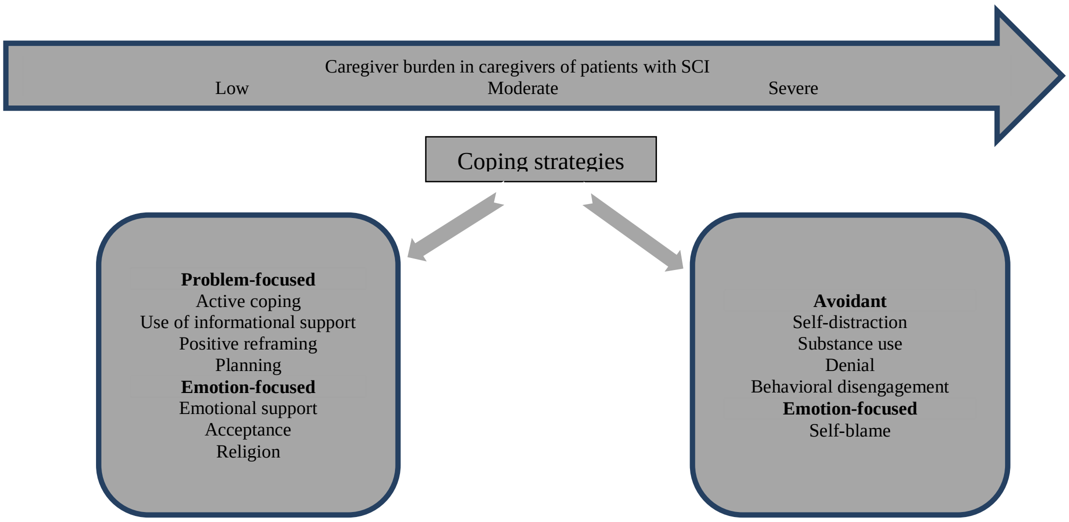

Figure 1. The association of coping strategies with the caregivers' burden
SCI: Spinal cord injury

Furthermore, caregivers should receive training on useful coping strategies and should be taught 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. Therefore, caregivers should be encouraged to take more active strategies through communication with friends and engaging in recreational activities (18, 19).

This study is the first of its kind in the local population as it examines the caregiver burden and the coping strategies used by caregivers of patients with SCI. Besides, this study has some limitations. The study's reliance on a single tertiary care setting may limit its generalisability to other healthcare facilities. Moreover, the sample size may not be large enough to fully represent the entire population.

Conclusion

The caregivers with highest burden were found to engage in self-distraction, denial, and behavioral disengagement. The utilization of problem-focused coping strategies, emotional support, and religious practices was most prevalent in the caregivers where there was minimal or no burden. Emotion-focused strategies such as venting, humor, and self-blame were found to be linked to a severe burden. The results of this study indicate that in order to reduce the burden on caregivers, healthcare professionals should encourage the implementation of training programs focused on effective coping strategies.

Conflict of Interest

The authors declare no conflict of interest in this study.

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