

Caregiver's Burden in Rehabilitation of Patients with Neurological Deficits following Traumatic Spinal Cord Injury

¹Vinu V Gopal, ²PT Baburaj, ³PK Balakrishnan

ABSTRACT

Introduction: Traumatic spinal cord injury (SCI) is an emerging public health problem reaching epidemic proportions. Reduced functional capacity after SCI not only affects the quality of life (QOL) of the patient, but also creates an added social, financial, and psychological burden on the family. Caregiver is responsible for providing the patient with physical, emotional, and functional support. Therefore, the increasing burden on the caregiver worsens all the domains constituting the QOL of the patient. Thus, the understanding of caregiver burden in terms of demographic profile of caregivers, severity of SCI, cost of care, mode of treatment adopted, and employment and education of the caregiver is important in the rehabilitation of patients with SCI.

Materials and methods: A cross-sectional analytical questionnaire survey was performed with 50 SCI patients and their primary caregivers at a tertiary care institution between June and September 2016. The caregiver burden was assessed using the Zarit burden interview scale, and its relation with severity of injury and type of treatment was analyzed using nonparametric statistics. The demographic variables influencing caregiver burden were also studied.

Results: About 38% of patients had complete SCI. About 34% of caregivers of patients were their own spouse. The mean age of caregiver was 42.9 ± 1.2 years. The majority (44%) of caregivers had moderate burden. Completeness of SCI significantly influenced caregiver burden ($p = 0.02$). Type of treatment adopted did not influence the caregiver burden ($p = 0.52$). Employment status and education of caregiver were found to be significantly associated with caregiver burden ($p = 0.001$ and $p = 0.046$ respectively).

Conclusion: Caregivers had significant burden of care in terms of severity of SCI. Age, employment status, education, and marital status affect caregiving burden. We hope the results of the study will guide experimental research in this field, motivating the health care professionals in providing early psychological intervention leading to positive belief and

attitude change in society. The study will encourage society in focusing on community-based rehabilitation, which can potentially reduce the overall burden.

Keywords: Burden, Caregiver, Spinal cord injury, Traumatic.

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INTRODUCTION

Traumatic spinal cord injury (SCI) is an important emerging public health problem reaching epidemic proportions.¹ The global incidence of traumatic SCI varies widely from 30/million in industrialized countries to fewer than 10/million in developing countries. The prevalence of SCI is 365/million population.¹ In India, the incidence and prevalence of SCI are 15/million and 236/million respectively.² Reduced functional capacity after SCI not only affects the quality of life (QOL) of the patient, but also creates an added social, financial, and psychological burden on the family. The cost of care for SCI is also very high.³ The bulk of this occurs in the first year after injury wherein hospitalization expenses account for the major expenditure. Costs also depend on the level of injury; higher the level, longer the hospitalization, and greater is the cost. Indirect costs also are very high due to loss of future wages and productivity. Younger the age of injury, higher is the indirect costs. The caregiver is responsible for providing the patient with physical, emotional, and functional support. Increasing burden on the caregiver negatively impacts the domains constituting the QOL of the patient. Thus, the understanding of caregiver burden in terms of demographic profile of caregivers, severity of SCI, cost of care, mode of treatment adopted, and employment and education of the caregiver is important in the rehabilitation of patients with SCI. Considering these facts, it is appropriate to analyze a study that would throw light on all these facts. There are no baseline data or research in Kerala dealing with caregiver profiles and their burden.

^{1,2}Associate Professor, ³Professor and Head

^{1,3}Department of Neurosurgery, Government Medical College Kottayam, Kerala, India

²Inter University Centre for Disability Studies, School of Behavioural Sciences, Mahatma Gandhi University, Kottayam Kerala, India

Corresponding Author: Vinu V Gopal, Associate Professor Department of Neurosurgery, Government Medical College Kottayam, Kerala, India, Phone: +919656769340, e-mail: vinoogopa@gmail.com

MATERIALS AND METHODS

The research design adopted was a cross-sectional analytical questionnaire survey. After obtaining ethical clearance from the institutional review board of the Government Medical College, Kottayam, India, 50 patients and their caregivers were selected as per inclusion criteria from the neurosurgery outpatient clinic, wards, and intensive care unit between June 2016 and September 2016. Patients with SCI due to causes other than trauma were excluded from the study. A purposive sampling technique was adopted. Caregiver burden was assessed by Zarit⁴ burden interview score (reliability, r = 0.81, construct validity, r = 0.91). A 20- to 25-minute interview was conducted by the investigator, and the patients and caregivers were asked to fill in the Zarit burden interview. Demographic variables were also assessed by a clinical proforma. Caregiver burden of those with (1) complete/incomplete injury and (2) surgical/conservative management was assessed. Mann–Whitney *U* test was used for nonparametric data on two groups and Kruskal–Wallis test for three groups. Categorical variables, such as education and employment status influencing caregiver burden were also assessed. Fischer exact test was done for categorical variables. Pearson product moment correlation (*r*) was done to assess relationship among continuous variables like total cost of care and duration of care. Findings were considered significant, if *p* < 0.05. Statistics were done using Statistical Package for the Social Sciences software version 16 (Chicago Inc.).

RESULTS

Out of the 50 SCI patients, 38% had complete SCI, whereas 54% had incomplete injury and 6% had no neurological deficits (Graph 1). About 50% of the patients adopted surgical management (Graph 2). The mean age of the caregiver was 42.9 ± 12.5 years. The majority of caregivers were in the age group of 40 to 60 years. The minimum age was 20 years and the maximum age was 62 years (Table 1). All the caregivers were literate and the majority (64%; *n* = 32) had completed high school. About 58% (*n* = 29) of caregivers were employed. The majority (34%; *n* = 17) were spouse caregivers. Cost of care was >Rs. 50,000 in 19 (38%) patients (Table 1). About 44 % of the study population had moderate burden as per Zarit burden interview (Table 2). Distribution of burden score showed a skewed distribution (Graph 3). So, we adopted nonparametric statistics like Mann–Whitney test for two groups and Kruskal–Wallis for three groups. The burden score was significantly high in patients with complete SCI (Kruskal–Wallis, *p* = 0.029) (Graph 4 and Table 3). No statistically significant differences were found in burden score according to treatment strategy adopted (Mann–Whitney, *p* = 0.52) (Table 3). Employment status

Table 1: Demographic profile of caregivers of SCI patients

Variable	Frequency (<i>n</i> = 50)	Percentage
Age of caregiver (years)		
20–30	10	20
31–40	14	28
41–50	08	16
51–60	10	20
60–70	08	16
Gender		
Male	18	36
Female	32	64
Education of caregiver		
Primary	14	28
High school	16	32
College graduate	16	32
Postgraduate	04	08
Occupation of caregiver		
Unemployed	21	42
Employed	29	58
Cost of care (Rupees)		
0–19,999	11	22
20,000–49,999	20	40
50,000–79,999	16	32
>80,000	03	06
Caregiver relation		
Spouse	17	34
Parents	11	22
Children	14	28
Mother	5	10
Other relative	3	6

Table 2: Distribution of caregiver burden scores according to severity

Caregiver burden	Frequency	Percent
0–20 (little/no)	16	32
21–40 (mild to moderate)	22	44
41–60 (moderate to severe)	5	10
61–88 (severe)	7	14
Total	50	100

Table 3: Influence of completeness SCI and mode of treatment on caregiver burden score

Variable	Burden score				Test, <i>p</i> -value
	Mean	Standard deviation	Median	Interquartile range	
Type of injury					
Complete	38.8	45.7	32	38.2	Kruskal–Wallis test, <i>p</i> = 0.029
Incomplete	29.3	35.9	22.6	28.6	
Normal	23.3	40.8	5.9	0	
Treatment					
Conservative	32.6	40.5	24.7	32.3	Mann–Whitney <i>U</i> test, <i>p</i> = 0.521
Surgical	32.5	38.1	26.9	32	

Table 4: Association of employment status and caregiver burden

Employment	Caregiver burden					Total
	Little/No	Mild to moderate	Moderate to severe	Severe		
Fulltime	N 2	4	2	2	10	
	% 20	40	20	20	100	
Part-time	N 6	5	1	5	17	
	% 35.3	29.4	5.9	29.4	100	
Retired	N 0	0	2	0	2	
	% 0	0	100	0	100	
Not employed	N 8	11	0	0	19	
	% 42.1	57.9	0	0	100	
No change	N 0	2	0	0	2	
	% 0	100	0	0	100	
Total	N 16	22	5	7	50	
	% 32	44	10	14	100	

$\chi^2 = 32.341$; df = 12; p = 0.001; Fischer exact p = 0.007

Table 5: Association of education status and caregiver burden

Education of caregiver	Caregiver burden					Total
	Little/No	Mild to moderate	Moderate to severe	Severe		
Primary	N 5	6	0	3	14	
	% 35.7	42.9	0	21.4	100	
High school	N 6	6	0	4	16	
	% 37.5	37.5	0	25	100	
College graduate	N 5	8	3	0	16	
	% 31.3	50	18.8		100	
Postgraduate	N 0	2	2	0	4	
	% 0	50	50	0	100	
Total	N 16	22	5	7	50	
	% 32	44	10	14	100	

$\chi^2 = 17.176$; df = 9; p = 0.046; Fischer exact p = 0.048

Table 6: Correlation between cost of care and duration of care with caregiver burden

Correlation between burden score and other parameters	Pearson (r)	p-value
Cost of care	0.076	0.602
Duration of care	0.108	0.043

(Table 4) and education of caregiver (Table 5) were found to be significantly associated with caregiver burden (Fischer exact p = 0.003 and p = 0.048 respectively). There was no significant correlation between cost of care and caregiver burden (Pearson correlation, r = 0.076, p = 0.602) (Table 6). Duration of care had a positive correlation with burden (Pearson correlation, r = 0.108, p = 0.043) (Table 6).

DISCUSSION

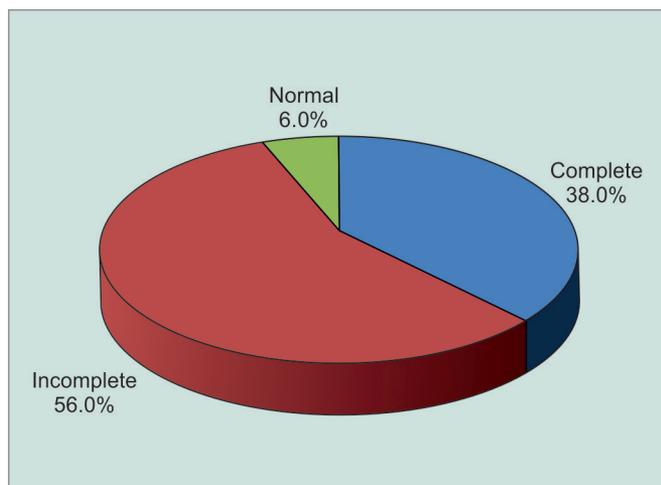
In this cross-sectional analytical survey, we studied the demographic profiles of caregivers, their burden in caring for SCI patients, and the factors influencing the same.

Age of Caregivers

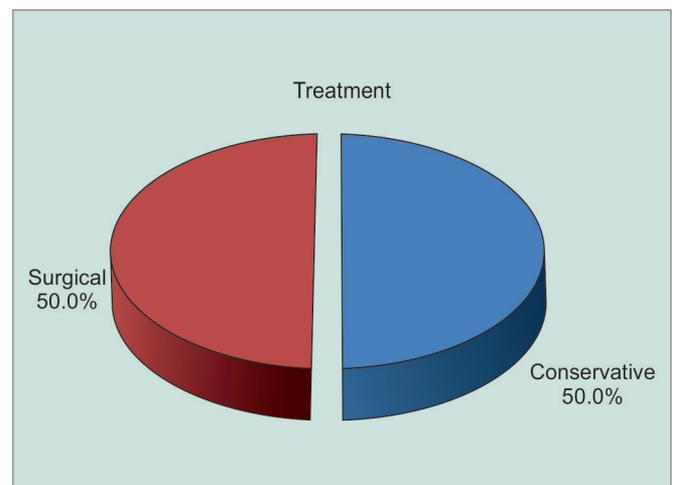
We found that the majority of caregivers were their own spouses, who were in the 4th to 6th decade of their lives. This finding was in concordance with the study by Riedijk et al,⁵ where the majority of caregivers were in their middle ages, and age was an independent predictor of burden. They proposed that caregivers in their middle ages experience physical vulnerability caused by aging being a greater burden. Our study needs to further address such problems of middle-aged caregivers and the psychological, vocational, and financial burdens faced by them.

Caregiver Relationship

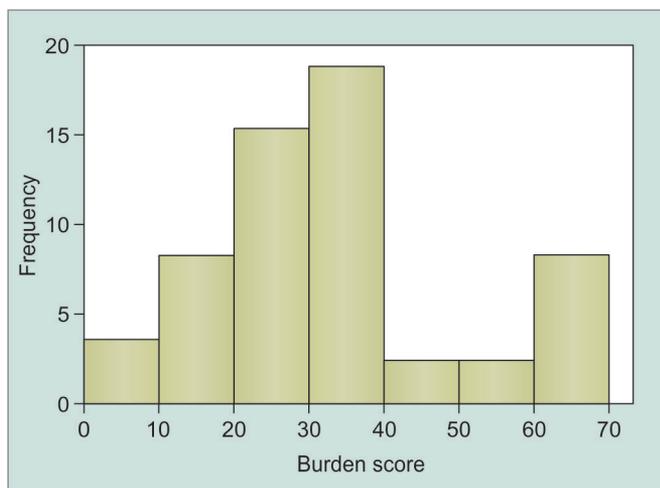
As per our study, the majority of caregivers were their spouses and were females. Spouse caregivers reported more depressive symptoms and increased caregiver burden.⁶ Female caregivers get trapped in their social role, and are relatively more exposed to aggressive behavior



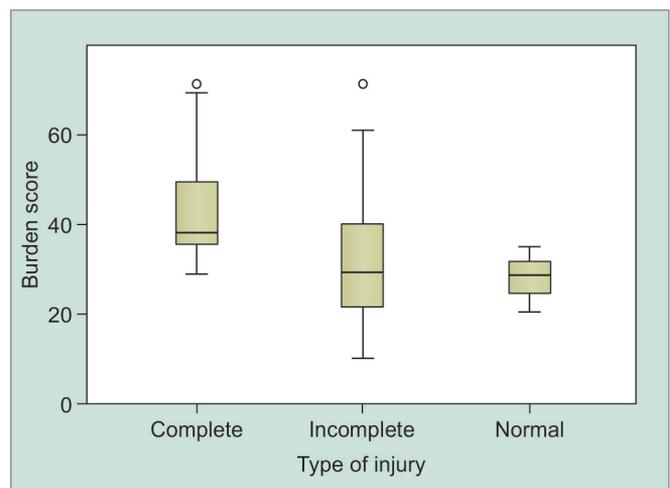
Graph 1: Classification of SCI according to severity



Graph 2: Mode of treatment adopted for SCI patients



Graph 3 Histogram showing skewed distribution of caregiver burden score



Graph 4: Box plot showing the relation of completeness of SCI and caregiver burden

of their male counterparts. Our society still imposes a caring role for women in terms of family responsibility. Our study had a limitation, as it addressed only the caregiver demographic profile in a small population. A large sample study addressing the above issue needs to be initiated for precise information.

Caregiver Education

As per our study, all the caregivers were literate. Baumgarten et al⁷ specified the importance of education. Caregivers who understand and realize the evolution of disease searched for information and assistance to cope with changes and eventually had lesser burden. Available support programs and practical guidance can reduce burden. On the contrary, it was also proposed that even less-educated people had reduced burden in terms of providing support in contrast to nuclear families of higher economically forward sections of society.⁷ The less-educated tend to see life positively, as they are unaware of future complications and had less future expectations. Psychoeducational interventions (counseling) and awareness regarding respite care services, where patient care is temporarily undertaken by official services, give caregivers enough rest and reduce their burden. These issues need to be studied further in an interventional study.

Caregiver Employment

As per our study, two-thirds of the caregivers were employed. Studies by Lidal et al⁸ stated that caregivers needed flexibility in their employment situation in order to successfully maintain employment as well as provide care. As per the study, many of the family caregivers felt that there were times when the two responsibilities came into conflict. Participants stopped working as a result

of taking over the role of caregiver. Some reduced their working hours or changed to a more accommodating job. Some started their own business, so they could work from home. The benefit of creating peer support groups for caregivers has been a useful addition to the rehabilitation process. Helping caregivers anticipate problem areas, such as potential conflicts between work and caregiver responsibility can aid in reducing the burden. Further research in this area needs to be done for precise information.

Cost of Care

According to this study, cost of care was high and varied according to the treatment modality adopted. Several other studies support our finding.³ The high costs accounted for the financial burden on the family. The annual cost of caring for an SCI patient is a huge economic burden on the health care system and family. The annual SCI costs were estimated to be 9.7 billion.³ These high expenses add on to the caregivers' burden. However, this study showed that there was no correlation between the cost of care and burden of caregivers. This might be due to the fact that cost of care in a government hospital is fully taken up by financial assistance from the government through various schemes like Rashtriya Swasthya Bhima Jojana.

Mode of Treatment

As per our study, there was no difference in caregiver burden, whether the patient had undergone surgical treatment or conservative management. Early surgical or medical treatments can reduce the burden of caregivers as per Dumont et al.⁹ Psychological and pharmacological interventions reduce the symptoms and improve the QOL, resulting in decreased burden and improved

well-being of the caregiver. Early surgical treatment will help in early mobilization of the patient, subsequently reducing the cost and burden of caring of such patients. The discordant finding may be due to the small sample size in our study.

Duration of Caregiving

In this study, there was a positive correlation between duration of care and burden. This might be due to significant coping mechanisms adopted by the caregivers in adjusting to the stressful event. As duration of care increases, they can plan their activities in a better way with ample social and emotional support.

Severity of Injury

Our study showed that complete SCI increased the caregiver's burden. This finding is in concordance with other studies. Kraus et al¹⁰ observed higher burden with severe SCI due to the fact that functional disability of the patient and the dependency arising from it increase the burden on the caregiver.

LIMITATIONS

The major limitation of the study was that it was conducted only on a limited number of patients in a single institution. Results would have been better if a larger sample had been studied. The study might have been more valid and meaningful if the burden of caregivers was studied among early and late post-SCI patients. Assessment was done with a one-time questionnaire alone. Sample was nonhomogeneous, and gender inequality needs to be addressed. A larger interventional study on matched samples may be conducted, so that the question of whether counseling and peer support group help in reducing burden can be answered. This would provide useful information and help addressing the problem of caregiver burden and provide recommendations for solving the issues faced by them. The results can also guide authorities in drafting health care policies relevant to this field.

Regardless of the above limitations, the study will be an eye opener for health authorities in Kerala where there are no baseline data addressing the issues of caregiver burden. We hope that though done on a small sample population that attended a tertiary care center, this study will guide future experimental research, which would be relevant in health care policy making in Kerala as well as throughout India.

CONCLUSION

Caregivers of SCI patients had significant burden of care. Severe SCI increases caregiver burden. Mode of treatment

adopted (surgical/conservative) and total cost of care did not influence the caregiver burden, as patients in government hospitals were benefited by existing insurance schemes. Age, employment status, education, and marital status affect the burden in caregiving. The result of the study will definitely motivate health care professionals in providing early psychological interventions in the form of counseling, and will eventually lead to positive beliefs and attitudinal changes among society and family members. The study results will also motivate community-based rehabilitation measures to be undertaken in the form of support groups, which, in turn, will reduce the economic and psychological burden of caregivers of SCI patients.

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