

Burden of Caregivers of Traumatic Spinal Cord Injury in a Tertiary Care Centre in South India -A Descriptive Cross-sectional Study

Povara Îngrijitorilor Persoanelor cu Leziuni Traumatische ale Măduvei Spinării într-un Centru de Îngrijire Terțiară din Sudul Indiei - Un Studiu Transversal Descriptiv

Sankavi Santosh KUMAR¹, Santosh Kumar KAMALAKANNAN²

Abstract

Background: Spinal cord injuries (SCI) carry significant morbidity and are associated with significant loss of productive years in the life of a victim. It results in significant burden to the families, caregivers, health care system and the community as a whole. Rehabilitation of these patients requires expertise and the results are not entirely satisfactory even in the best of the centres. Burden faced by the caregivers is often neglected. This study was done to determine the burden faced by the caregivers of traumatic spinal cord injury and to correlate their burden with their quality of life using different scales such as Caregivers Burden Inventory for Spinal Cord Injury (CBI-SCI), Burden Assessment Score (BAS), and Adult Carer Quality of Life Index (AC-QoL). *Materials and methods:* A descriptive cross-sectional observational study was carried out on 40 primary caregivers of SCI patients. The inclusion criteria were primary caregivers of SCI patients aged between 20 to 55 years of age. Caregivers with major psychiatric illness and comorbidities were excluded. Information about socio-demographic characteristics were collected. Demographic data was represented with mean and standard deviation. Pearson's correlation of coefficients was used to assess the caregiver's burden. *Results:* The results of Pearson correlation of coefficients demonstrated there exist a strong negative correlation between burden of the caregiver and his quality of life. This is demonstrated by R^2 values of -0.858 and -0.718 for BAS and CBI-SCI respectively which is very unlikely to occur by chance. *Conclusion:* This study shows that caregiver burden is an important factor to be considered as a part of every rehabilitation effort for traumatic SCI patients. Assessment of burden would guide medical professionals to prevent burnout of caregivers and help them to provide long-term care for their patients.

Keywords: traumatic spinal cord injury; caregiver burden; Burden Assessment Score (BAS), Caregivers Burden Inventory for Spinal Cord Injury (CBI-SCI), Adult Carer Quality of Life Index (AC-QoL)

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¹ Government Rehabilitation Home, Mallavadi; Tamilnadu Medical Services

² Corresponding author; Department of Neonatology, Saveetha Medical College and Hospital, Thandalam, Chennai, India; drsantoshmddm@gmail.com

Rezumat

Introducere: Traumatismele vertebra-medulare (TVM) au o morbiditate semnificativă și sunt asociate cu pierderea unui număr semnificativ de ani de productivitate în viața unei victime. Cauzează o povară semnificativă pentru familii, îngrijitori, sistemul de sănătate și pentru comunitatea în ansamblu. Reabilitarea acestor pacienți necesită expertiză și rezultatele nu sunt pe deplin satisfăcătoare chiar și în cele mai bune centre. Povara cu care se confruntă îngrijitorii este adesea neglijată. Acest studiu a fost realizat pentru a determina sarcina cu care se confruntă îngrijitorii persoanelor cu leziuni traumatice ale măduvei spinării și pentru a corela sarcina lor cu calitatea vieții lor, utilizând diferite scale, cum ar fi inventarul sarcinii pentru îngrijitori (CBI), scorul de evaluare a sarcinii (BAS) și calitatea îngrijitorilor pentru adulți. Indicele vieții (AC-QoL). *Materiale și metode:* Am efectuat un studiu observațional descriptiv, transversal, pe 40 de îngrijitori primari ai pacienților cu TVM. Criteriile de includere au fost îngrijitorii primari ai pacienților cu TVM cu vârsta cuprinsă între 20 și 55 de ani. Au fost excluși îngrijitorii cu boli psihiatrice majore și comorbidități. Au fost colectate informații despre caracteristicile socio-demografice. Sarcina îngrijitorului a fost documentată utilizând Scara de evaluare a sarcinii (BAS) și Inventarul de sarcină a îngrijitorilor (CBI) și calitatea vieții acestora a fost evaluată prin Indicele calității vieții pentru îngrijitorii adulților (AC-QoL). Datele demografice au fost reprezentate prin medie și abatere standard. Corelația coeficienților lui Pearson a fost utilizată pentru a evalua sarcina îngrijitorului. *Rezultate:* Rezultatele corelației Pearson a coeficienților au demonstrat că există o corelație negativă puternică între sarcina îngrijitorului și calitatea vieții acestuia. Acest lucru este demonstrat de valorile R^2 de -0,858 și -0,718 pentru BAS și respectiv CBI-SCI, ceea ce este foarte puțin probabil să apară întâmplător. *Concluzie:* Acest studiu arată că sarcina îngrijitorului este un factor important care trebuie luat în considerare ca parte a oricărui efort de reabilitare pentru pacienții cu TVM. Evaluarea poverii ar ghida profesioniștii medicali pentru a preveni epuizarea îngrijitorilor și îi poate ajuta să ofere îngrijire pe termen lung pacienților lor.

Cuvinte cheie: traumatism vertebra-medular; povara îngrijitorilor; Scala de evaluare a sarcinii (BAS); Inventarul de sarcină a îngrijitorilor (CBI); Indicele calității vieții pentru îngrijitorii adulților (AC-QoL)

Introduction

Spinal cord injury (SCI) is associated with significant functional disability. SCI has both short term and long term impact the life of the victims and also on their family and caregivers [1]. Almost all the domains of the life namely physical, psychological, social, financial, emotional are significantly affected leading to multiple medical, social and vocational complications. This causes burden and suffering not only to the patients but also to their families, caregivers, to the health care system and to the community as a whole. The human and financial costs and implications of SCI are enormous [1, 2]. Despite the devastating physical, social and emotional consequences of SCI, a comprehensive

rehabilitation program can often enable these individuals to function independently, comfortably, and productively.

Caregiver burden refers to the physical, psychological, social and financial impact of caring for another person who is ill, disabled or otherwise functionally impaired [3]. Caregivers can be a member of the family or can be a person hired to care of the victim [4]. But generally, the term is used in reference to informal caregivers i.e., person acting in an unpaid, non-professional capacity such as family members. To a great extent now, family members are responsible for a wide range of services provided formally by traditional health care providers.

There are few studies which have attempted to assess the burden of caregivers of victims of spinal cord injury from India. With the available limited information about the impact of care giving post SCI injury very little efforts have been taken by the health care system and government organisations to help these caregivers emotionally and financially [5, 6].

This study was done to focus on the burden faced by the caregivers of the SCI. During initial phase of the rehabilitation, the major focus is on the patient. Caregivers are often the forgotten half of the rehabilitation process. It is well known fact that caregivers bear substantial amount of burden on them which needs to be addressed. Further it is a well understood that the well-being of the caregiver is likely and directly tied to the well-being of individuals with spinal cord injury.

Results from assessment of caregiver burden would provide evidence that can be utilised in the development of beneficial services and programs for the caregivers. With respect to SCI victims this may identify adequate resources and prevent institutionalisation and abandonment.

Materials and Methods

Type of study: Descriptive cross sectional

Place of study: Government Institute of Rehabilitation medicine, Madras Medical College Chennai.

Duration of the study: August 2017 to January 2018

Objectives of the study:

1. To assess the burden in caregivers of traumatic spinal cord injured patients.
2. To correlate caregiver burden with patient's disability, handicap status and quality of life.

A descriptive cross-sectional study was conducted on caregivers of individuals with Spinal Cord Injury (SCI), admitted in the Government Institute of Rehabilitation medicine, Chennai. Data was collected in Microsoft excel 2010 Statistical analysis was done using the IBM SPSS statistics for Windows version 23. To describe the descriptive statistics frequency analysis and percentage analysis was done for categorial variables and mean and SD was used for continuous variables. Pearson's Correlation of Coefficients was obtained to demonstrate the degree of correlation.

Inclusion Criteria

1. Primary caregivers of SCI patients
2. Aged between 20 to 55 years.

Exclusion Criteria

1. Caregivers with major psychiatric illness
2. Caregivers with Co-morbid physical or cognitive problems.

Those who met the above criteria were contacted and the nature of the study was explained. Informed consent was taken from the caregiver. Information about socio-demographic characteristics of the caregivers-age, gender, occupation, education and relationship with the patient were collected.

A total of 40 caregivers were interviewed during the study period.

Scales used:

1. Burden assessment scale (BAS) [7]
2. Caregivers burden inventory –Spinal cord injury (CBI-SCI) [8]
3. Adult Carer Quality of Life Index (AC-QoL)

Burden assessment scale

Initially developed by the Schizophrenia centre for research foundation (SCARF) to assess the burden of caregivers of schizophrenia patients, but has been modified by the WHO and used to assess caregiver's burden in other situations also. It consists of a total of 40 questions in total covering various domains of their burden. Each question has a score between 0 to 3.

Caregivers burden inventory –Spinal cord injury (CBI-SCI)

The Caregiver Burden Inventory comprises 24 closed questions divided into five dimensions: time-dependence, developmental, physical, social and emotional burden. There are five items in each dimension except for physical burden, which has four items dedicated to. Each item is given a score between 0 (not at all descriptive) and 4 (very descriptive), where higher scores indicate greater caregiver burden; there are no cut-off points for classifying burden. Therefore, total scores for factors one, two, four and five can range from zero to 20. An equivalent score for physical burden can be obtained by multiplying the sum of items in this dimension by 1.25

Adult Carer Quality of Life Index (AC-QoL)

The Adult Carer Quality of Life Questionnaire (AC-QoL) is a 40-item instrument that measures the overall quality of life for adult carers, and subscale scores for eight domains of quality of life:

1. Support for caring: This subscale measures the extent of support carers perceive that they receive encompassing emotional, practical and professional support.

2. Caring choice: This subscale measures the extent to which carers feel that they have control over their own life, and are able to choose ventures outside caring, such as social activities.
3. Caring stress: This subscale measures the mental and physical stress from caring, such as exhaustion and depression.
4. Money matters: This subscale measures how carers feel about their financial situation.
5. Personal growth: This subscale measures how much the carer feels they have grown and developed, and the positive experience of the carers' circumstances.
6. Sense of value: This subscale measures the extent to which the carer feels they are valued and respected, and the positive relationship between the carer and the person they are caring for.
7. Ability to care: This subscale measures the extent to which the carer is able to provide care for the person they care for, how they cope with the caring role, and how they feel about their competency to care.
8. Carer satisfaction: This subscale measures the extent to which the carer is satisfied with their life and role as a carer, and how they feel about being a carer.

Results

A total of 40 primary caregivers of spinal cord injury patients were studied. Majority of the caregivers were females mostly the spouse and in the age group 20 to 40 years, which is the most productive age group. Majority of the caregivers are females and mostly the spouse. There is a good positive correlation between the two burden assessment scores used in the study namely CBI-SCI and BAS with a R2 value of 0.985. There exists a strong negative correlation between burden of the caregiver and his quality of life. This is demonstrated by R2 values of -0.858 and -0.718 for BAS and CBI-SCI respectively.

Table 1. Demographic characteristics of the Caregivers

Variable	Number (n)	Percentage (%)	Mean±SD
Age in yrs			(33.44±8.59)
Up to 20	2	5.0	
21-30	8	20.0	
31-40	18	45.0	
41-50	8	20.0	
51-60	4	10.0	
Gender			
Male	11	27.5	
Female	29	72.5	
Relation to patient			
Father	4	10.0	
Mother	7	17.5	
Wife	19	37.5	
Husband	2	5.0	
Brother	2	5.0	
Sister	1	2.5	
Son	2	5.0	
Daughter	1	2.5	
Cousin/Nephew	1	2.5	
Uncle/Aunt	1	2.5	

Table 2. Caregivers burden assessed using the various scores

Parameter	NUMBER (n=40) (Mean ±SD)	95%CI	P value (Two tailed Hypothesis)
BAS scores	55.25±25.8	55.25 ±7.995 (±14.47%)	< .00001
CBI SCI scores	46.62±22.6	46.6154 ±7.09 (±15.21%)	< .00001
ACQOL Scores	61±27.31	61 ±8.463 (±13.87%)	< .00001

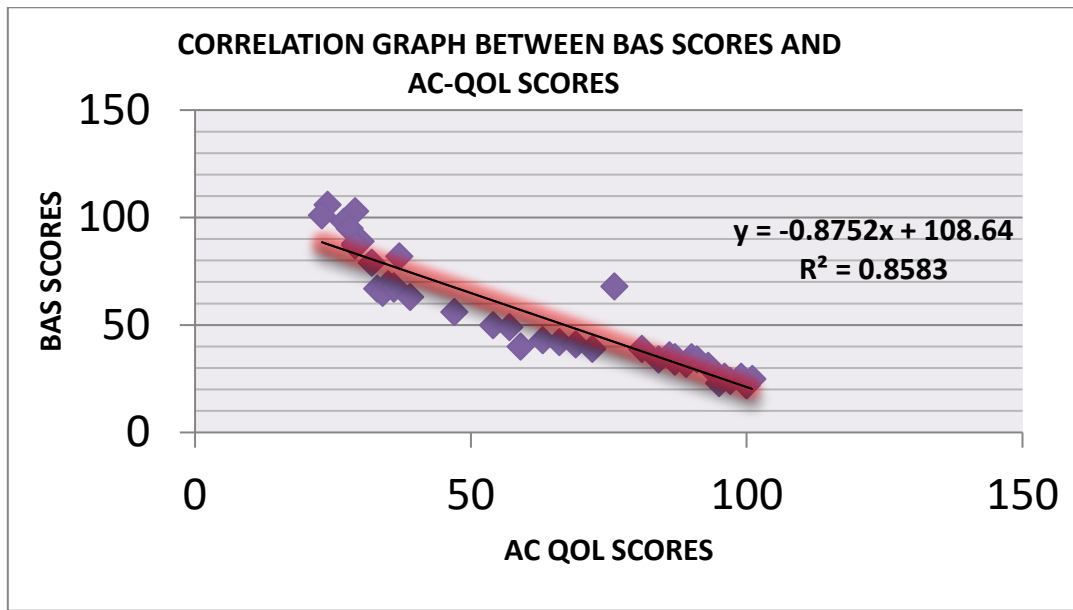


Figure 1. Correlation between BAS score and AC-QOL Scores

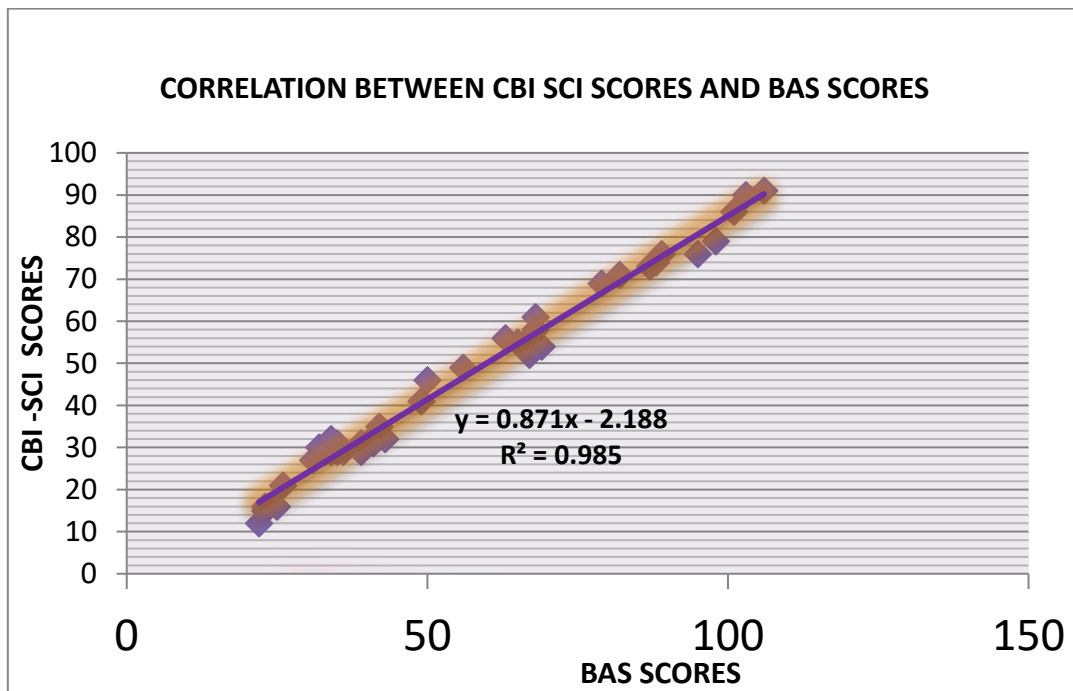


Figure 2. Correlation between BAS score and CBI SCI

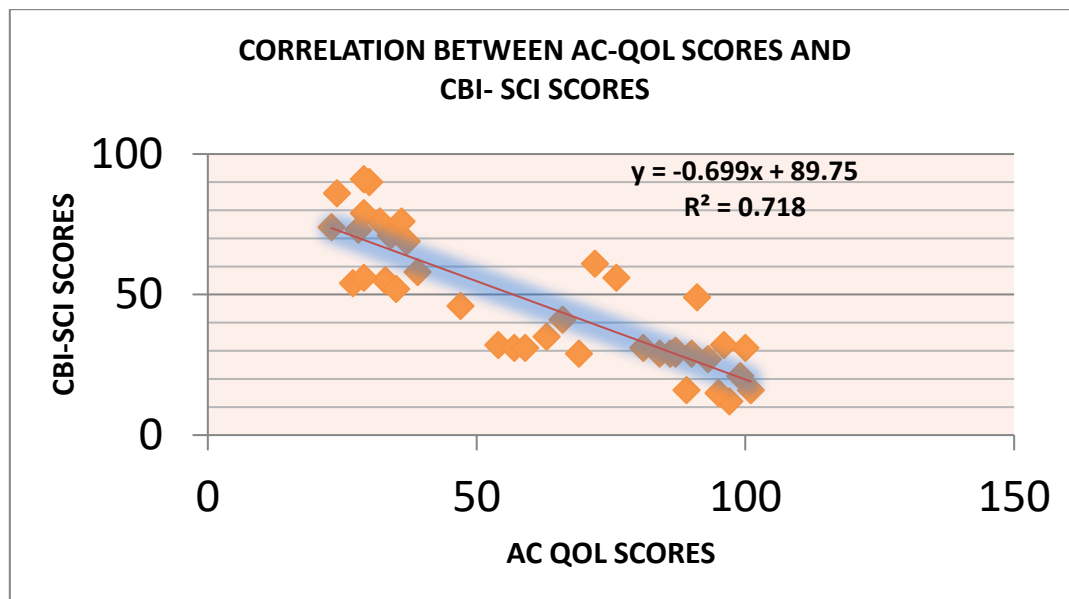


Figure 3. Correlation between AC-QOL Scores and CBI-SCI scores

Discussion

Post spinal cord injury the injured person requires assistance to carry out his activities of daily life. This can range from help in carrying out bathing, dressing to doing one's bowel and bladder activities or providing transportation. The health and well-being of the SCI caregiver is very important, as this can affect the well-being of the individuals with SCI.

The assessment of caregiver's burden is defined as the extent to which Caregivers perceived their emotional/physical health, social life and financial status to have changed as a result of caring for a person with SCI. This will help clinicians to investigate the factors affecting the level of stress and design appropriate intervention strategies to further improve the outcomes of SCI patients.

The caregiver burden was assessed using Caregiver burden inventory (CBI-SCI), the most commonly used and well validated questionnaire. Apart from this another common questionnaire that was used was the burden assessment scale (BAS). The quality of life of the caregiver was assessed by adult carer quality of life index (AC-QoL). In our study, forty caregivers of SCI patients were assessed for caregiver burden and the scores showed significant negative correlation with patient's quality of life.

Similar results were obtained by Timothy Elliot et al. in their study where they found that caregivers experience high levels of distress and burden impact the patient's QOL. Primary caregivers of people with SCI showed significantly lower QOL than people who were not caregivers.

In another study by Marcel Post et al. it was reported that burden is higher with older and female caregivers and caregivers of persons with more disability experience heavy burden. The study population in our study also showed a predominance of female caregivers but we did not analyse the burden with respect to the gender and age distribution.

Marcel Post et al. report that burden is higher with older and female caregivers and caregivers of persons with more disability experience heavy burden. [10]

The outcome of patients SCI is significantly dependent on the adequate social support and caregiver's attitude towards the patients. Susan Mockus found that younger the patient, higher the level of burden perceived by caregiver [11].

Faison et al reported that caregivers experiencing high levels of burden negatively impact patient's QOL [12]. The caregiver burden shows significant correlation with patients' disability in the current study.

Chan et al reported that partners of persons with SCI perceived more distress than patient's themselves [13].

Conclusion

The results show the need for the assessment of caregiver's burden which needs to be incorporated in the comprehensive rehabilitation program of SCI patients. Better care of caregivers will ensure their continued participation in the welfare of traumatic SCI patients. Steps need to be taken to plan for community-based support to the care givers in form of self-support groups. Financial support and aid from governmental and non-governmental organisations will play a significant role in the overall rehabilitation of the SCI victims.

References

- [1] Elliot, T.R.; Shewchuk, R.M. (1998). Recognizing the family caregiver: Integral and formal members of the rehabilitation process. *Journal of Vocational Rehabilitation*;10(2):123-7.
- [2] Naveen, S.R. (2016). Quality of life in traumatic spinal cord injured. *J Evid Based Med Healthc*;3(5):176-83.
- [3] Goldberg, D.P.; Williams, P. (1988). *A User's guide to the general health questionnaire*. Windsor, Berks: NFER-Nelson.
- [4] Jette, A.M. (1994). Physical disablement concepts of physical therapy research and practice. *Phys Ther*;74(5):380-6.
- [5] Ditunno, J.F.; Young, W.; Donovan, W.H. et al. (1994). The international standard booklet for neurological and functional classification of spinal cord injury. *Paraplegia*;32(2):70-80.
- [6] Dodds, T.A.; Martin, D.P.; Stolov, W.C. et al. (1993). A validation of the functional independence measurement and its performance among rehabilitation in patients. *Arch Phys Med Rehabil*;74(5):531-6.
- [7] Chakraborty. S.; Bhatia, T.; Anderson, C.; Nimgaonkar, V.L.; Deshpande, S.N. (2014). Caregiver's burden, coping, and psycho-education in indian households with single-and multiple-affected members with schizophrenia. *International Journal of Mental Health*. Apr 1;43(1):30-49.
- [8] Conti, A.; Clari, M.; Nolan, M.; Wallace, E.; Tommasini, M.; Mozzone, S.; Campagna, S. (2019). The Relationship Between Psychological and Physical Secondary Conditions and Family Caregiver Burden in Spinal Cord Injury: A Correlational Study. *Topics in Spinal Cord Injury Rehabilitation*. 25. 271-280. 10.1310/sci2504-271.

- [9] Joseph, S.; Becker, S.; Elwick, H.; Silburn, R. (2012). Adult carers quality of life questionnaire (AC-QoL): Development of an evidence-based tool. *Mental Health Review Journal*. 17. 10.1108/13619321211270380.
- [10] Post, M.W.; Bloemen, J.; de Witte, L.P. (2005). Burden of support for partners of persons with spinal cord injuries. *Spinal Cord*;43(5):311-9.
- [11] Parks, S.M.; Novielli, K.D. (2000). A practical guide to caring for caregivers. *American Family Physician*; 62(12): 2613-2620.
- [12] Faison, K.J.; Faria, S.H.; Fran, D. (1999). Caregivers of chronic ill elderly: perceived burden. *Journal of Community Health Nursing*;16(4):243-53.
- [13] Chan, R.C.; Lee, P.W.; Lieh-Mak, F. (2000). Coping with spinal cord injury: personal and marital adjustment in the Hong Kong Chinese setting. *Spinal Cord*;38(11):687-96.