

The effect of the burden of caregiving for people with spinal cord injury (SCI): a cross-sectional study

Patrizia Maitan¹, Simona Frigerio¹, Alessio Conti^{1,2}, Marco Clari¹, Ercole Vellone² and Rosaria Alvaro²

¹Azienda Ospedaliero-Universitaria Città della Salute e della Scienza di Torino, Turin, Italy

²Dipartimento di Biomedicina e Prevenzione, Università degli Studi di Roma Tor Vergata, Rome, Italy

Abstract

Aim. To assess the caregiver burden (CB) of caregivers for people with Spinal Cord Injury (SCI) and to examine the psychological impact of the burden of caregiving.

Materials and methods. Cross-sectional study. A set of structured questionnaires was administered to 55 family caregivers of individuals with SCI. The Modified Barthel Index was used to evaluate the independence of care recipients. The Caregiver Burden Inventory was modified and used to assess the CB. The Family Strain Questionnaire – Short Form was administered to measure the psychological impact of CB. The Short Form 36 was used to assess the health status of the participants.

Results. CB affects mainly the domains related to time management, the physical condition of caregivers and their sense of personal failure. An increased level of CB and the dependency level of SCI survivors is significantly correlated ($p < 0.01$) with an increase in the need of psychological support and a decrease in perceived health and quality of life.

Conclusions. Caregiving for people with SCI implies the occurrence of CB. The contribution of caregivers should be recognised and supported with tailored relief interventions.

Key words

- spinal cord injuries
- caregiver
- burden
- quality of life

INTRODUCTION

Spinal cord injuries (SCI) are some of the most complex and disabling diseases, implying severe outcomes for many facets of existence for people affected by SCI and their carers [1]. It is uncertain how many individuals in the world are currently living with SCI, but international data suggests that 250 000 to 500 000 people worldwide sustain a spinal cord injury annually. Most of these cases are traumatic SCI, the leading causes of which are road traffic injuries and falls, due to the lack of roads and work safety programs, especially in developing countries, or violence [2, 3]. At the same time, recent studies show an increase in the age of SCI onset and a gradual increase in the proportion of non-traumatic SCI cases, partly attributable to the world's ageing population in developed countries [4]. The direct and indirect costs of SCI might exceed from 2 to 20 times those related to other disabling neurological diseases, such as dementia or sclerosis [5]. Direct costs may include hospital expenses for acute care and rehabilitation, while indirect costs are linked to lost productivity due to premature death or disability, social

isolation or stress [4]. Certainly the injury level and its severity have a significant influence on costs. Direct costs are higher during the first year after SCI onset [6], while during the following years indirect costs become higher [7, 8].

Based on the level of injury, people with SCI could have a high level of dependency; thus, caregivers are essential for their care [9]. The assistance given by the caregivers is necessary to maintain the disease-related health status and the well-being of SCI individuals, as well as to preserve their status as living in the community. This may produce severe psychological distress in both parties and create a significant burden on caregivers who are not ready to take on the role of caregiving [10]. Family caregivers who willingly accept the position of caregiving may also experience obvious levels of distress and burden when they realise they have little support once they have taken over the role [11, 12].

Caregiver burden (CB) is a common term used to describe the weight or load carried by caregivers due to their adoption of the caregiver role [13]. Even though

CB is a phenomenon that is broadly recognised, there is no International Classification of Diseases, Ninth Revision (ICD-9) or ICD-10 code which defines it. Zarit *et al.* proposed a useful definition of this phenomenon as “The extent to which caregivers recognise that caregiving has hurt their emotional, social, financial, physical, and spiritual functioning” [14]. This definition helps us to understand the multidimensional experience that affects many aspects of caregivers’ lives and that CB is perceived in a different way for every one of them [15]. The burden condition prompts a significant discomfort for caregivers, who are subjected to high-stress levels, leading to anxiety and, in the most critical cases, to authentic traumas with repercussions for the person they care for [16]. Many daily aspects may influence the onset of burden in caregivers; for example, the need for assistance with the activities of daily living and social isolation. Moreover, caregivers could experience financial deprivation because of the care recipient’s cost of illness and the necessity of reducing hours or leaving work to take care of their loved one. Despite this, other aspects can be emotionally rewarding, such as confirming family ties with the person in need of attention and saving family resources [17].

Even though CB is a well-recognised concern among caregivers of people with SCI, there are few studies which specifically address its evaluation. The majority of studies conducted on SCI are mainly focused on the assessment of caregivers’ quality of life (QOL), their mental and physical health, and the impact of respite programs for this population [1, 10, 18]. In the culture of Southern Europe, family caregivers have a central role in the recovery of individuals with SCI; it is uncommon for people with SCI, after rehabilitation, to be discharged into low-complexity facilities such as nursing homes or clinics. The majority is discharged to their homes where family members give the main support [18]. This may produce severe stress at a psychological level which, combined with the effect of the economic crisis which struck Mediterranean Countries from 2008 and the decreased support given by national health systems, could create a profound burden on families that were not prepared to take on the role of caregiving [19, 20].

To our knowledge, limited studies have been conducted in Italy to assess CB; these are limited to the field of dementia [21], paediatrics [22], or neurorehabilitation [23, 24]. Therefore, the purpose of this study is to assess the CB of caregivers of people with SCI and to examine the impact of the burden on the psychological and health status of the family caregivers.

MATERIALS AND METHODS

Study design

This study uses a cross-sectional design. The data were gathered from family caregivers of persons with SCI discharged from the Spinal Cord Injuries Unit (SCU), Città della Salute e della Scienza Hospital in Turin, Italy. The data collection was performed between January and April 2016.

Participants: A convenience sample of family caregivers of individuals with SCI was recruited. The definition

of family caregiver used in this study is a family member, linked by blood or partnership, who is responsible for caring for the SCI survivor at home. Inclusion criteria were: i) to be a family caregiver of an individual with any SCI; ii) to have been discharged at least six months ago; iii) to understand the Italian language, and iv) to be aged 18 or older. Formal caregivers or individuals with cognitive disorders were excluded from the study.

Ethical consideration

The study design was submitted to the Head Office of Città della Salute e della Scienza Hospital of Turin, Orthopaedic Traumatological Centre, and received approval for its fulfilment. The Città della Salute e della Scienza di Torino, Mauriziano Hospital, ASL TO 1 Research Ethics Committee, Turin, Italy, gave the Ethics approval (Resolution n° 1002/2016 - #CS/1040). Participants signed informed written consent before the questionnaires were administered. All data obtained from them were confidentially treated and anonymity was maintained during the research process.

Data collection

Participation was voluntary, and caregivers who met the inclusion criteria and provided the written informed consent were asked to complete a set of structured questionnaires. A presentation letter informed them of the study aim and researchers were available to answer any questions of the participants. Participants were recruited during control visits at the SCU outpatient’s clinic. The complete toolset, which required a collection time of about 15 minutes, was fulfilled in a separate area to avoid the risk that the presence of care recipients might alter the responses of their caregivers.

Instruments

The data described below were collected.

Sociodemographic information of caregivers and SCI survivors

Socio-demographic information was gathered using a questionnaire expressly designed for this study to describe the characteristics of caregivers. This information included age, gender, relationship to the SCI survivor, cohabitation, marital status, level of education, working status, and economic and housing status. The same variables were gathered from SCI survivors; also, the clinical details of the SCI related to the level of injury, aetiology and time since injury were collected.

Functional independence of individuals with SCI

The standard of dependency of care recipients was assessed using the Modified Barthel Index (MBI) [25]. This mono-dimensional questionnaire consists of 10 items about the person’s daily functioning. MBI scores range from 0 to 100; i.e., from total dependence (0) to independence (100) in Activity of Daily Living (ADL). Kucukdeveci *et al.* [26] reported excellent internal consistency (Cronbach’s $\alpha = 0.88$) and criterion validity ($r = 0.76$) with the American Spinal Injury Association (ASIA) motor scores in a SCI population. In this study, the questionnaire was completed by the caregivers.

Caregiver burden

Caregiver burden was assessed using a modified version of the Caregiver Burden Inventory (CBI). CBI is a multi-dimensional scale developed by Novak and Guest in 1989 [27] to evaluate the impact of the burden on different aspects of a caregiver's life. CBI is a multiple choice questionnaire with five burden dimensions: time-dependent burden (T/dep-B), evaluating stress caused by limitation of individual's personal time; developmental burden (Dev-B), referring to the sense of failing regarding one's hopes and intentions; physical burden (Phys-B), relating to physical strain and bodily disorders; social burden (Soc-B), caused by struggling to fulfil the roles related to the caregiver's job or family; and emotional burden (Emot-B) referring to any humiliation or shaming feeling caused by the patient.

All dimensions except Phys-B contain five items, with a scoring system ranging from 0 (strongly disagree) to 4 (strongly agree) and a total score ranging from 0 to 20 for each group. Since Phys-B consists of four items, it was multiplied by a correction factor of 1.25 in order to be compared with the other groups. Thus, the total score of CBI was calculated starting from a minimum of 0, indicating no burden, to a maximum of 100, indicating the maximum attainable burden level.

This self-reported questionnaire has revealed interesting characteristics and it has already been used in different caregiver populations [28], including in the field of SCI [29, 30]. In our study, a modified version of CBI, called CBI-SCI, was used to make a more proper assessment for SCI. Three items were changed as they were specific to dementia and behavioural disorders, but not appropriate for our target population which is not affected by cognitive impairments and, consequently, does not have behaviours causing embarrassment for caregivers. Specifically, the original Item-3, "I have to watch my care receiver constantly", was changed to "I have to maintain a high level of attention"; the original Item-20, "I feel ashamed of my care receiver", was modified to "I feel embarrassed about my care receiver's condition"; the original Item-23, "I feel uncomfortable when I have friends over", was changed to "I feel uncomfortable when I have friends over or when we go out". The process changing these items was performed by two nurses (PM, AC) with experience in SCI and a third nurse (MC) who is an expert in psychometrics and the development and validation of assessment tools.

With regard to the psychometric properties of the new questionnaire, the CBI-SCI scored a 0.83 Content Validity Index/Ave, which was obtained by involving a panel of five healthcare professionals and five caregivers who are experts in the SCI field for at least five years; the items that compose it reached the 0.78 cut-off value for everyone, showing their validity [31]. The face validity of the scale obtained a value of 9.43 out of 10 after a preliminary test completed with 12 caregivers.

Regarding the CBI-SCI reliability, we found that both the scale and its dimensions proved to be very reliable with an overall Cronbach's $\alpha = 0.89$ and value of each dimension which overcame the $\alpha = 0.70$ determined cut-off [32].

Psychological health of caregivers

The Family Strain Questionnaire - Short Form (FSQ-SF) was used to determine the psychological impact of caregiving. This self-administered assessment tool was developed from the original scale by Vidotto et al. in 2010 [33] to assess the caregiver strain and the associated potential risks of emotional and psychophysical disorders. The FSQ-SF is a mono-dimensional instrument composed of 30 dichotomic questions ordered by severity and grouped in increasing psychological risk areas: Ok (ranging from 0 to 6), indicating positive coping expressed by caregiver; Recommended (ranging from 7 to 12), showing the need to direct caregivers to seek counsel; Strongly Recommended (ranging from 13 to 20), indicating a great need to direct caregivers to seek psychological assessment and support; Urgent (ranging from 21 to 30), indicating a crucial need to introduce caregivers to a psychologist and/or a psychiatrist. The highest score attainable is 30, which implies that the more severe the level of strain felt by the caregiver, the higher the risk of psychological issues. In their study, Vidotto et al. [33] reported satisfactory psychometric properties of this assessment tool in caregivers of people with dementia; this is the first time that this instrument has been administered to a SCI population.

Health status of caregivers

The Short Form 36 (SF-36) was used to assess the general health status of caregivers. This self-administered evaluation instrument was introduced in 1992 and designed to be utilised for all health conditions and determine fundamental human values which define health concepts relevant to a person's functional status and well-being. It consists of 36 questions which are distributed on a Likert scale covering eight domains: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems, and mental health. Every domain is assessed differently and its value shows an increase or a decrease from the mean expected value in the general population. In general, each domain is directly represented on a 0–100 scale; the lower the score, the more the impairment in the specific domain. The SF-36 reported very reasonable levels of validity and reliability (Cronbach's $\alpha = 0.82$) [34]: for this reason, it is the most extensively used health survey. It has been widely adopted to discriminate, evaluate and anticipate outcomes in different health conditions, including SCI [35].

DATA ANALYSIS

Statistical analysis of all data collected was carried out using the IBM SPSS® program (Version 22) for Windows.

Descriptive statistics were used to analyse the socio-demographic characteristics of the sample. Means and standard deviations were used to define continuous variables, and frequency distribution was gathered from categorical data.

A t-test was used to observe differences in continuous variables, while a chi-square test was used for qualitative variables. Differences between gender, age, edu-

cational level and the relationship of participants were compared with CB status. Furthermore, SCI survivors' functional independence, level and aetiology of injury, and months of assistance were assessed to observe differences when compared with the results of CBI-SCI.

To assess the relationship between the CB and the level of independence of care recipients, the correlation between the results of the CBI-SCI and those that were obtained with the MBI was calculated using bivariate analysis. In the same way, the CBI-SCI results were correlated through a bivariate analysis to the FSQ-SF and the eight subscales of SF-36 scorings, in order to assess the relationship with CB and the psychological impact of caregiving and the health status of participants. Furthermore, to deepen the relationship between CB and the other variables collected, the results of the five dimensions of CBI-SCI were correlated to the other administered instruments. The Pearson's *r* coefficient was determined: a value of ± 0.30 was considered to be a weak correlation, a value of ± 0.50 was considered a moderate correlation and a value of ± 0.70 was considered a strong correlation [36].

All tests were two-tailed and a *p*-value < 0.05 was considered significant.

RESULTS

Of the 61 family caregivers of people with SCI eligible for the study, 55 agreed to participate. *Table 1* presents the socio-demographic characteristics of caregivers and related care recipients.

Most of the participants consist of partners ($n = 31$; 56%) or parents ($n = 20$; 36.4%) of the person affected by SCI, and almost all are living with them ($n = 50$; 90.9%). One caregiver out of five has a child in the family ($n = 12$; 21.8%). In most cases, family caregivers in the sample have been assisting their relatives for more than three years (83.6%), and only four (7.3%) have assumed the role of assistant for less than one year. More than two thirds ($n = 36$; 65.5%) of the sample reported

a worsening in their economic level in the last year, while a third of participants ($n = 18$; 32.7%) benefited from the support of a family assistant and about half ($n = 24$; 43.6%) used the home care services provided by the Italian National Health System in response to health complications of their assisted person. Almost all the participants ($n = 52$; 94.5%) did not have a hospital readmission for their assisted person in the last year. Most of the sample lived in apartments ($n = 38$; 69.1%), despite half of the sample living outside of urban areas ($n = 27$; 49.1%).

The SCI survivors assisted by participants are in most cases quadriplegics ($n = 30$; 54.5%) and almost all suffered a spinal cord injury more than three years ago ($n = 48$; 87.3%). The most frequent cause of SCI in the sample is traumatic ($n = 44$; 80.0%); road accidents are the most represented type of injury ($n = 21$; 38.2%), followed by work accidents ($n = 8$; 14.5%). People assisted by participant family caregivers suffered several complications including: urological ($n = 52$; 94.5%), pressure ulcers ($n = 25$; 45.5%), spasticity ($n = 21$; 38.2%), chronic pain ($n = 13$; 23.6%), respiratory ($n = 12$; 21.8%), psychological ($n = 10$; 18.2%) and nutritional ($n = 6$; 10.9%) issues.

Table 2 presents the results of the assessment tools administered to the sample. Dependence level determined in SCI survivors assisted by study participants appears to be more than moderate in 69.1% ($n = 38$) of individuals. The level of burden perceived by family caregivers in the sample has a mean of 43.40 ($SD = 17.55$), and the dimensions more affected by CB are the Time-Dependent Burden ($m = 14.18$; $SD = 5.16$) and the Physical Burden ($m = 10.87$; $SD = 5.39$). The General Health ($m = 52.95$; $SD = 20.84$) and Vitality ($m = 43.18$; $SD = 21.35$) perception of participants obtained the lowest results in the SF-36 subscales. They indicate problems with work and activities of daily living dependent on physical health or show a state of fatigue or physical strain. Despite this, only a quarter of par-

Table 1
General characteristics

| Sample characteristics | | Caregivers | | Care recipients | |
|------------------------|---------------------|---------------|------|-----------------|------|
| | | n = 55 | % | n = 55 | % |
| Gender | Male | 7 | 12.7 | 46 | 83.6 |
| | Female | 48 | 87.3 | 9 | 16.4 |
| Age | Mean (SD) | 58.55 (13.18) | | 52.38 (16.19) | |
| Marital Status | Married/Partner | 40 | 72.7 | 27 | 49.1 |
| | Not Married | 10 | 18.2 | 27 | 49.1 |
| | Widowed | 5 | 9.1 | 1 | 1.8 |
| Education | Primary School | 8 | 14.5 | 12 | 21.8 |
| | Middle School | 20 | 36.4 | 17 | 30.9 |
| | High School | 24 | 43.6 | 25 | 45.5 |
| | University | 3 | 5.5 | 1 | 1.8 |
| Employment | Employee | 15 | 27.3 | 3 | 5.5 |
| | Unemployed | 6 | 10.9 | 5 | 9.1 |
| | Withdrawn from work | 8 | 14.5 | 4 | 7.3 |
| | Retiree | 20 | 36.4 | 39 | 70.9 |
| | Other | 6 | 10.9 | 4 | 7.3 |

Table 2
Scores of administered instruments

| Assessment Tool | | |
|-------------------------------------|----------|-----------|
| Modified Barthel Index (MBI) | n | % |
| Total | 18 | 32.7 |
| Severe | 20 | 36.4 |
| Moderate | 12 | 21.8 |
| Mild | 3 | 5.5 |
| Minimum | 2 | 3.6 |
| CBI-SCI | M | SD |
| CBI - SCI Total | 43.40 | 17.55 |
| CBI - T/Dep-B | 14.18 | 5.16 |
| CBI - Dev-B | 9.76 | 5.87 |
| CBI - Phys-B | 10.87 | 5.39 |
| CBI - Soc-B | 5.04 | 4.38 |
| CBI - Emot-B | 2.84 | 3.55 |
| SF-36 | M | SD |
| Physical Functioning | 71.64 | 24.79 |
| Role Limitations / Phys | 50.45 | 37.72 |
| Bodily Pain | 53.67 | 28.02 |
| General Health | 52.95 | 20.84 |
| Vitality | 43.18 | 21.35 |
| Social Functioning | 62.05 | 26.99 |
| Role Limitations / Emot | 63.44 | 40.79 |
| Mental Health | 58.04 | 21.66 |
| FSQ - SF | n | % |
| OK | 13 | 23.26 |
| Recommended | 21 | 38.2 |
| Strongly Recommended | 18 | 32.7 |
| Urgent | 3 | 5.5 |

CBI-SCI Caregiver Burden Inventory - Spinal Cord Injuries; T/Dep-B Time-Dependent Burden; Dev-B Developmental Burden; Phys-B Physical Burden; Soc-B Social Burden; Emot-B Emotional Burden; FSQ-SF Family Strain Questionnaire - Short Form; M: mean; SD: standard deviation.

ticipants (n = 13; 23.6%) exhibit that they do not need psychological support.

Among the recruited family caregivers, statistically significant differences were observed between the results of CBI-SCI and gender ($p = 0.027$), and functional independence of individuals with SCI ($p = 0.000$) assisted by participants. No statistically significant differences were observed between CB perceived by participants and their age ($p = 0.332$), educational level ($p = 0.347$) and relationship with SCI survivors ($p = 0.898$). In the same way, CBI-SCI results in the sample did not show significant difference with the injury level ($p = 0.140$), the aetiology of injury ($p = 0.430$) and the months of assistance ($p = 0.416$).

Results of the bivariate analysis are reported in Table 3 and underline the statistically significant correlation ($p < 0.01$) between CBI-SCI and its dimensions with the psychological, social and health status. In particular, the highest inversely proportional correlations were

between CBI-SCI and SF-36's Social Functioning ($r = -0.687$; $p = 0.000$) and Mental Health ($r = -0.647$; $p = 0.000$) subscales. This indicates many issues in participation in social activities due to physical or emotional issues, and constant feelings of depression and nervousness. Furthermore, there is a moderately positive correlation ($r = 0.630$; $p = 0.000$) between CBI-SCI and FSQ-SF, showing an increase in need of psychological support when a rise in CB is perceived. The correlation between the CBI-SCI and the MBI is weak and inversely proportional ($r = -0.427$; $p = 0.001$), indicating that increased burden relates to a greater dependency level. Caregiver burden also affects the physical health of participants; in fact, the SF-36's Role-Physical Limitation subscale, which highlights issues in performing work and daily activities due to physical health, is the only one that showed a statistically significant correlation ($p < 0.05$) in all CBI-SCI dimensions.

DISCUSSION

The results of this study show that family caregivers have a level of perceived burden which is directly related to the increased need for psychological support, and deprivation in their social condition, mental and physical health.

The results are similar to those obtained in studies performed in Asia and Oceania on smaller samples of family caregivers of people with SCI [29, 30]; nevertheless, given the different socio-cultural context and the collection variables, it is difficult to make a more significant comparison between these populations. The domain which received the highest result is the time-dependent burden; the time reduction is caused by the need to assist a person with SCI in their daily activities and is strictly related to the social role, which is significantly decreased for participants. As already observed in other studies [30, 37], most of our participants left their jobs to assist the SCI survivors; such a decision results in a reduction in income and, consequently, the impossibility of recruiting a formal caregiver to provide paid assistance.

Given the high numbers of assistance hours spent by caregivers, the financial constraints deriving from this condition are predictors of developing burden, which necessarily leads to social isolation [38, 39]. Other factors that were identified as leading to social isolation were that most of the participants are unable to choose alternative solutions because they live with the assisted person, they have a middle to low educational level, and their relatives have a high dependency level [1, 9, 38]. Loneliness and a lack of spontaneity affect life outside of caregiving and the social life of family caregivers [40], and this is relevant when one considers that the majority of participants have assisted their relatives for more than three years; poorer QoL is associated with a longer duration of caregiving [37].

The family caregivers in the sample are exposed to a physical burden. Furthermore, the results obtained from the sample confirm that CB leads to tiredness and a reduction in the perceived stability of well-being, as already stated in international literature [13, 41]. Due to the often physical nature of daily activities performed

by caregivers, assisting a SCI survivor is frequently linked to pain and poor physical health [1], which are associated with adverse outcomes such as the occurrence of depression [39]. This seems to be the feedback from the sample, where the physical burden perceived is associated with the social and the emotional burden; this is important because it highlights how physical health directly influences other dimensions.

As previously found in other studies assessing CB in SCI [29, 30], the emotional burden domain showed the lower score. This result disagrees with the frequently strongly recommended need for psychological support, as highlighted in the FSQ-SF questionnaire in this sample. As emphasised in previous studies, this is probably because the adaptation process may become emotionally rewarding for carers, since it affirms familiar bonds and results in the saving of resources [15]. In previous studies, it has been shown that psychological disorders in caregivers of people with SCI commonly first appear six weeks after returning home from rehabilitation units; this is followed by a decrease in psychological disorders at sixth months and a progressive increase during the following two years [18]. It is interesting to note that, although they had been in the caregiving role for several years, participants showed a continuing need for psychological support, even if readjustment is normally expected at this point. This is fundamental, as depression and poor mental well-being were identified as predictors of burden, rather than family and social support given to caregivers or care recipients' level of independence, which affect only their physical health [39].

In line with what is underlined in the literature, the sample consists predominantly of women [42] and, arguably, this could be the reason for the differences in burden found between male and female participants. Even though the age of our sample is higher when compared with studies performed on caregivers for people with SCI in other countries [18, 25, 32-34], this difference might reflect the ageing process that has occurred in the general population, especially in industrialised countries [4]. It is also essential to highlight the significant presence in our sample of people with non-traumatic SCI; this is interesting in the light of the progressive changes in this aetiology which might constitute a problem for developing countries in future decades [43].

The people with SCI who are assisted by our participants are predominantly affected by quadriplegia, which gives rise to close or high dependency levels; this result makes it difficult to compare this study with other studies regarding CB in SCI, where the SCI population included was mainly composed of individuals with paraplegia [29, 30, 41, 44, 45]. Although the level of independence was not a predictor of burden, it is interesting to note that in the sample it is related to an increase in the level of time-dependent burden.

In Italy, people with SCI receive a public disability pension. The amount depends on the level and causes of disability; for example, it would be different if the SCI occurred in a car accident during work activity, rather than during a leisure activity. If the individual has taken out private insurance, the broker will com-

Table 3
Correlation between CBI-SCI, sub-dimensions and administered assessment tools

| Assessment Tool | Total CBI-SCI | | T/Dep-B | | Dev-B | | Phys-B | | Soc-B | | Emot-B | |
|---|---------------|---------|-------------|---------|-------------|---------|-------------|---------|-------------|---------|-------------|---------|
| | Pearson's R | P value | Pearson's R | P value | Pearson's R | P value | Pearson's R | P value | Pearson's R | P value | Pearson's R | P value |
| Modified Barthel Index (MBI) | -0.427 | 0.001 | -0.686 | 0.000 | -0.186 | 0.174 | -0.254 | 0.061 | -0.163 | 0.235 | -0.126 | 0.359 |
| Family Strain Questionnaire Short Form - FSQ SF | 0.630 | 0.000 | 0.236 | 0.082 | 0.594 | 0.000 | 0.522 | 0.000 | 0.436 | 0.001 | 0.402 | 0.002 |
| SF 36 - Physical Functioning | -0.414 | 0.002 | -0.185 | 0.175 | -0.212 | 0.120 | -0.355 | 0.008 | -0.323 | 0.016 | -0.337 | 0.012 |
| SF 36 - Role Limitations / Phys | -0.553 | 0.000 | -0.412 | 0.002 | -0.300 | 0.026 | -0.479 | 0.000 | -0.386 | 0.004 | -0.334 | 0.013 |
| SF 36 - Bodily Pain | -0.521 | 0.000 | -0.332 | 0.013 | -0.333 | 0.013 | -0.597 | 0.000 | -0.160 | 0.242 | -0.347 | 0.010 |
| SF 36 - General Health | -0.564 | 0.000 | -0.254 | 0.062 | -0.425 | 0.001 | -0.656 | 0.000 | -0.262 | 0.054 | -0.295 | 0.029 |
| SF 36 - Vitality | -0.550 | 0.000 | -0.131 | 0.339 | -0.644 | 0.000 | -0.500 | 0.000 | -0.227 | 0.096 | -0.299 | 0.026 |
| SF 36 - Social Functioning | -0.687 | 0.000 | -0.353 | 0.008 | -0.592 | 0.000 | -0.588 | 0.000 | -0.399 | 0.003 | -0.387 | 0.004 |
| SF 36 - Role Limitations / Emot | -0.514 | 0.000 | -0.385 | 0.004 | -0.370 | 0.005 | -0.398 | 0.003 | -0.355 | 0.008 | -0.268 | 0.048 |
| SF 36 - Mental Health | -0.647 | 0.000 | -0.248 | 0.068 | -0.657 | 0.000 | -0.451 | 0.001 | -0.360 | 0.007 | -0.486 | 0.000 |

Legend: CBI-SCI Caregiver Burden Inventory - Spinal Cord Injuries; T/Dep-B Time-Dependent Burden; Dev-B Developmental Burden; Phys-B Physical Burden; Soc-B Social Burden; Emot-B Emotional Burden.

pute the damage and the amount of the award. A social security service benefit is provided for disabled people to cover part of the cost of assistance in everyday life activities, but specific benefits for caregivers of people with SCI are not provided. This inadequate economic support from the national health services may be co-responsible for CB onset, as stated by Adelman [13].

Although CB is a well-recognised issue among family caregivers of individuals with SCI, there are no specific instruments designed for its evaluation and the assessment of the perceived strain is usually performed through questionnaires designed for several different constructs. Indeed, the burden is often considered as an individual phenomenon, characterised by subjectivity; for this reason, the research approach most often used to describe it has been undoubtedly qualitative [46]. This contrasts with quantitative methods, which are criticised because they do not consider some variables, especially in cultures influenced by emotional intimacy and close support networks among family members. The need to have a specific assessment tool capable of measuring the level of burden in caregivers of people with SCI, perhaps combined with a qualitative approach, would be an essential tool for healthcare professionals, allowing them to make a more profound and richer picture of the phenomenon and promptly react to the different problems which characterise it.

The continuous assessment of the level of burden in caregivers of SCI survivors can allow healthcare professionals and social workers, who are involved in the rehabilitation process and the discharge of these patients to their homes, to plan strategies which will help to preserve the quality of life of family caregivers. Due to the importance of social support in protecting against feelings of depression, which are predictors of burden, targeted interventions which include family caregivers and their assisted people are fundamental for helping social integration, decreasing feelings of isolation and regaining a sense of identity. Furthermore, a greater understanding of the effects of the burden is needed in order to identify the key elements needed in the construction of educational programmes aimed at reducing the perceived strain of family caregivers and improve their confidence in managing the situation. If caregivers are more capable of gaining a sense of control over their condition, this might decrease secondary complications which affect them and SCI survivors, thereby reducing these significant issues for public health.

This study has some limitations. The non-probabilistic convenience sampling, in addition to the limited number of participants, reduced the generalisability of results. Furthermore, the level of dependency may

be found to differ as study sample included a greater number of caregivers of people with quadriplegia, usually related with a higher dependency level. In this study functional independence of individuals with SCI was measured through MBI even if the Spinal Cord Independence Measure (SCIM) demonstrated better sensitivity than MBI in this population [47]. Nevertheless, as in this study the primary aim was to assess the level of burden perceived by caregivers rather than the dependency of their relatives, MBI was selected as a simpler and shorter tool that could be fulfilled more easily by participants. Therefore, results obtained are generalisable with caution about the general population of caregivers of people with SCI, as derived from a sample inserted in a particular geographic, regional and national level relating to the Italian National Health Service. This is due to the limited prevalence of people with SCI and their various distributions on a regional scale. Considering the low incidence and prevalence ratio of SCI, future development of our study in several Spinal Cord Rehabilitation Units in different European regions would be the best next step for an in-depth examination of the data.

CONCLUSION

Caregiver burden is a relevant issue that very often is inadequately considered in SCI rehabilitation units, where the focus is usually on the caregivers' acquisition of specific knowledge and practical skills. It is essential to pay attention to families, because the most significant experiences of health and illness are acquired in the family context, influencing future reactions of members to their life experiences. The family is a fundamental component of an individuals' well-being, and the promotion, maintenance and recovery of households are an unavoidable necessity to the survival of society.

Acknowledgements

We wish to thank the caregivers and the staff at the Spinal Cord Injuries Unit, AOU Città della Salute e della Scienza Hospital of Turin for dedicating their time to this study.

Conflict of interest statement

There are no potential conflicts of interest or any financial or personal relationships with other people or organizations that could inappropriately bias conduct and findings of this study.

Received on 17 February 2018.

Accepted on 7 May 2018.

REFERENCES

1. Blanes L, Carmagnani MIS, Ferreira LM. Health-related quality of life of primary caregivers of persons with paraplegia. *Spinal Cord*. 2007;45(6):399-403.
2. Surkin J, Gilbert BJ, Harkey HL, Sniezek J, Currier M. Spinal cord injury in Mississippi. Findings and evaluation, 1992-1994. *Spine*. 2000;25(6):716-21.
3. Lenehan B, Street J, Kwon BK, Noonan V, Zhang H, Fisher CG, et al. The epidemiology of traumatic spinal cord injury in British Columbia, Canada. *Spine*. 2012;37(4):321-9.
4. World Health Organization – International perspectives on spinal cord injury. WHO. Available from: www.who.org.

- int/disabilities/policies/spinal_cord_injury/en/.
5. Economics A. The economic cost of spinal cord injury and traumatic brain injury in Australia. Rep Access Econ Vic Neurotrauma Initiat Canberra Access Econ. 2009;31.
 6. DeVivo M, Chen Y, Mennemeyer S, Deutsch A. Costs of care following spinal cord injury. *Top Spinal Cord Inj Rehabil.* 2011;16(4):1-9.
 7. Haeusler J-MC, Tobler B, Arnet B, Huesler J, Zimmermann H. Pilot study on the comprehensive economic costs of major trauma. Consequential costs are well in excess of medical costs. *J Trauma.* 2006;61(3):723-31.
 8. Munce SEP, Wodchis WP, Guilcher SJT, Couris CM, Verrier M, Fung K, et al. Direct costs of adult traumatic spinal cord injury in Ontario. *Spinal Cord.* 2013;51(1):64-9.
 9. Samsa GP, Hoening H, Branch LG. Relationship between self-reported disability and caregiver hours. *Am J Phys Med Rehabil.* 2001;80(9):674-84.
 10. Raj JT, Manigandan C, Jacob KS. Leisure satisfaction and psychiatric morbidity among informal carers of people with spinal cord injury. *Spinal Cord.* 2006;44(11):676-9.
 11. de Azevedo GR, Santos VLC de G. (Handicapped) caregiver: the social representations of family members about the caregiving process. *Rev Lat Am Enfermagem.* 2006;14(5):770-80.
 12. Elliott TR, Berry JW, Richards JS, Shewchuk RM. Resilience in the initial year of caregiving for a family member with a traumatic spinal cord injury. *J Consult Clin Psychol.* 2014;82(6):1072-86.
 13. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. *JAMA.* 2014;311(10):1052-60.
 14. Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: A longitudinal study. *The Gerontologist.* 1986;26(3):260-6.
 15. Gillick MR. The critical role of caregivers in achieving patient-centered care. *JAMA.* 2013;310(6):575-6.
 16. Glzman JM. Quality of life of caregivers. *Neuropsychol Rev.* 2004;14(4):183-96.
 17. Tarlow BJ, Wisniewski SR, Belle SH, Rubert M, Ory MG, Gallagher-Thompson D. Positive aspects of caregiving. Contributions of the REACH Project to the development of new measures for Alzheimer's caregiving. *Res Aging.* 2004;26(4):429-53.
 18. Middleton JW, Simpson GK, De Wolf A, Quirk R, Descallar J, Cameron ID. Psychological distress, quality of life, and burden in caregivers during community reintegration after spinal cord injury. *Arch Phys Med Rehabil.* 2014;95(7):1312-9.
 19. Cervero-Liceras F, McKee M, Legido-Quigley H. The effects of the financial crisis and austerity measures on the Spanish health care system. A qualitative analysis of health professionals' perceptions in the region of Valencia. *Health Policy.* 2015;119(1):100-6.
 20. Karanikolos M, Mladovsky P, Cylus J, Thomson S, Basu S, Stuckler D, et al. Financial crisis, austerity, and health in Europe. *The Lancet.* 2013;381(9874):1323-31.
 21. Marvardi M, Mattioli P, Spazzafumo L, Mastriforti R, Rinaldi P, Polidori MC, et al. The Caregiver Burden Inventory in evaluating the burden of caregivers of elderly demented patients: results from a multicenter study. *Ageing Clin Exp Res.* 2005;17(1):46-53.
 22. Molteni S, Carbon M, Lops J, Soto EC, Cervesi C, Sheridan EM, et al. Correlates of subjective caregiver strain in caregivers of youth evaluated in a pediatric psychiatric emergency room. *J Child Adolesc Psychopharmacol.* 2016;27(5):451-61.
 23. Calugi S, Taricco M, Rucci P, Fugazzaro S, Stuart M, Dallolio L, et al. Effectiveness of adaptive physical activity combined with therapeutic patient education in stroke survivors at twelve months: a non-randomized parallel group study. *Eur J Phys Rehabil Med.* 2016;52(1):72-80.
 24. Moroni L, Colangelo M, Galli M, Bertolotti G. [A 'I would like to give him my life': results of a psychological support intervention to caregivers of patients undergoing neuromotor rehabilitation]. In Italian. *G Ital Med Lav Ergon.* 2007;29(3 Suppl B):B5-17.
 25. Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index. A reliability study. *Int Disabil Stud.* 1988;10(2):61-3.
 26. Kucukdeveci AA, Yavuzer G, Tennant A, Suldur N, Sonel B, Arasil T. Adaptation of the modified Barthel Index for use in physical medicine and rehabilitation in Turkey. *Scand J Rehabil Med.* 2000;32(2):87-92.
 27. Novak M, Guest C. Application of a multidimensional caregiver burden inventory. *The Gerontologist.* 1989;29(6):798-803.
 28. Greco A, Pancani L, Sala M, Annoni AM, Steca P, Paturzo M, et al. Psychometric characteristics of the caregiver burden inventory in caregivers of adults with heart failure. *Eur J Cardiovasc Nurs.* 2017;1474515117693890.
 29. Gajraj-Singh P. Psychological impact and the burden of caregiving for persons with spinal cord injury (SCI) living in the community in Fiji. *Spinal Cord.* 2011;49(8):928-34.
 30. Chan RC. Stress and coping in spouses of persons with spinal cord injuries. *Clin Rehabil.* 2000;14(2):137-44.
 31. Polit DF, Beck CT, Owen SV. Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Res Nurs Health.* 2007 Aug 1;30(4):459-67.
 32. DeVon HA, Block ME, Moyle-Wright P, Ernst DM, Hayden SJ, Lazzara DJ, et al. A psychometric toolbox for testing validity and reliability. *J Nurs Scholarsh.* 2007;39(2):155-64.
 33. Vidotto G, Ferrario SR, Bond TG, Zotti AM. Family Strain Questionnaire – Short Form for nurses and general practitioners. *J Clin Nurs.* 2010;19(1-2):275-83.
 34. Brazier JE, Harper R, Jones NM, O'Cathain A, Thomas KJ, Usherwood T, et al. Validating the SF-36 health survey questionnaire: new outcome measure for primary care. *BMJ.* 1992;305(6846):160-4.
 35. Nogueira PC, Rabeh SAN, Caliri MHL, Dantas RAS. Health-related quality of life among caregivers of individuals with spinal cord injury. *J Neurosci Nurs.* 2016 Feb;48(1):28.
 36. Altman D, Machin D, Bryant T, Gardner M. *Statistics with Confidence. Confidence Intervals and Statistical Guidelines.* John Wiley & Sons; 2013. 283 p.
 37. Ebrahimzadeh MH, Shojaei B-S, Golhasani-Keshtan F, Soltani-Moghaddas SH, Fattahi AS, Mazlumi SM. Quality of life and the related factors in spouses of veterans with chronic spinal cord injury. *Health Qual Life Outcomes.* 2013 Mar 18;11:48.
 38. Rodakowski J, Skidmore ER, Anderson SJ, Begley A, Jensen MP, Buhule OD, et al. Additive effect of age on disability for individuals with spinal cord injuries. *Arch Phys Med Rehabil.* 2014;95(6):1076-82.
 39. Secinti E, Yavuz HM, Selcuk B. Feelings of burden among family caregivers of people with spinal cord injury in Turkey. *Spinal Cord.* 2017;55(8):782-7.
 40. Dickson A, O'Brien G, Ward R, Flowers P, Allan D, O'Carroll R. Adjustment and coping in spousal caregivers following a traumatic spinal cord injury. An interpretative phenomenological analysis. *J Health Psychol.* 2012;17(2):247-57.
 41. Nogueira PC, Rabeh SAN, Caliri MHL, Dantas RAS,

- Haas VJ. Burden of care and its impact on health-related quality of life of caregivers of individuals with spinal cord injury. *Rev Lat Am Enfermagem*. 2012;20(6):1048-56.
42. Lynch J, Cahalan R. The impact of spinal cord injury on the quality of life of primary family caregivers: a literature review. *Spinal Cord*. 2017;55(11):964-78.
43. New PW, Farry A, Baxter D, Noonan VK. Prevalence of non-traumatic spinal cord injury in Victoria, Australia. *Spinal Cord*. 2013;51(2):99-102.
44. Post MWM, Bloemen J, de Witte LP. Burden of support for partners of persons with spinal cord injuries. *Spinal Cord*. 2005;43(5):311-9.
45. Simpson G, Jones K. How important is resilience among family members supporting relatives with traumatic brain injury or spinal cord injury? *Clin Rehabil*. 2013;27(4):367-77.
46. Bastawrous M. Caregiver burden – A critical discussion. *Int J Nurs Stud*. 2013;50(3):431-41.
47. Bonavita J, Torre M, China S, Bressi F, Bonatti E, Capirossi R, et al. Validation of the Italian version of the Spinal Cord Independence Measure (SCIM III) Self-Report. *Spinal Cord*. 2016;54(7):553-60.