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Titolo tesi: The effect of caregiver burden in spinal cord injuries

ABSTRACT

Background. Spinal cord injury is among the most disabling conditions, not only for the impaired person but for their family who, as the most likely caregivers, are subject to a high perceived burden. Most caregivers continue to live with the SCI individual following acute rehabilitation, and the complexity and level of intimacy involved means they are often reluctant to leave this responsibility to third persons. The SCI individual's high dependency level entails significant daily physical effort for caregivers, often resulting over time in a poor lifestyle and declining bodily and mental health. Although the concept of caregiver burden is widely used to refer to the demands of the role, this is poorly studied in the context of SCI because of a lack of dedicated measurement instruments.

Objective. There were three general research objectives: (1) to explore the experience of SCI individuals' caregivers and their needs during the final phase of hospitalization and at six months from discharge; (2) to assess the psychometric properties of the CBI- SCI, including its construct and reliability; and (3) to assess the SCI caregivers' perceived burden and its impact on their psychological and physical health.

Methods. Three different designs were used in this doctoral research. The first study employed a qualitative phenomenological narrative approach based on semi-structured interviews with 11 SCI caregivers. The second study used descriptive statistics and exploratory factor analysis to assess the psychometric properties of the CBI-SCI based on a sample of 176 caregivers. In the third study, a descriptive cross-sectional design, a set of instruments were administered to 55 SCI caregivers. Bivariate analysis was performed to identify any correlations between caregiver burden, quality of life (QOL) and psychological distress.

Results. In the first study, five main themes emerged, encompassing caregivers' implicit and explicit needs. All of these themes highlighted a need for adequate inclusion in the rehabilitation process, adequate multidisciplinary involvement and improved communication with healthcare professionals. The second study confirmed the five-factor structure of the CBI-SCI, showing excellent internal consistency (Cronbach's $\alpha = 0.91$) and congruent correlation coefficients for all instruments administered to test concurrent validity. The third study showed that SCI individuals' informal caregivers experience a significant level of perceived burden ($p < 0.01$), which is directly related to an increased need for psychological support ($r = 0.63$) and a decline in social functioning ($r = -0.68$), with mental ($r = -0.64$) and physical role limitations ($r = -0.55$).

Conclusion. This research confirms the effects of caregiver burden on SCI caregivers, including a significant impact on the existing coping interaction between caregivers and care recipient following discharge from the rehabilitation centre. The CBI-SCI was validated and can be used in clinical and research settings to identify caregivers at risk and to design follow-up programs. The use of this instrument on a small sample in Italy confirmed the hypothesised correlation between caregiver burden, increased need for psychological support and decreased QOL among SCI caregivers. Further research is needed, based on a longitudinal approach and larger sample sizes or dyadic studies of the interdependence of SCI caregiver and individual.