

What matters most for caregivers' health?

C Fekete, H Tough, J Siegrist, MWG Brinkhof. Swiss Paraplegic Research, Nottwil, Switzerland

Research highlights

- This study is among the first to analyse different dimensions of the caregiving experience with a comprehensive set of physical and mental health indicators in partners of persons with SCI.
- The study investigates negative aspects of caregiving in terms of burden as well as positive aspects of caregiving and their link to health.
- Objective burden was not associated to any health indicator.
- Subjective burden was associated with all health indicators.
- Partners who experienced positive aspects of caregiving reported better mental health.

Objective: To explore associations of objective caregiver burden, subjective caregiver burden and positive aspects of caregiving with self-reported health indicators in caregiving partners of persons with SCI.

Sampling frame: We used data from the *pro-WELL study*,¹ a nested study within the community survey of the *Swiss Spinal Cord Injury Cohort Study (SwiSCI)*.² This sampling frame included a representative adult population of 1922 persons with TSCI or NTSCI living in Switzerland. 676 were eligible for pro-WELL and 133 persons with SCI and their partners participated at baseline (response rate 19.7%).

Design: Pro-WELL is a longitudinal community survey with three measurement waves (baseline; month 6, month 12). The main objective is to investigate associations of availability and quality of social relationships and productive activities with well-being in persons with SCI and their caregiving partners.

Participants: Data from N=118 caregiving partners who completed the baseline assessment (05/2015-01/2016) were used.

Measures: Caregiving experience: Objective caregiver burden was measured by the daily hrs of caregiving and amount of ADL and IADL support provided. Subjective caregiver burden was measured with the Zarit Burden Interview (ZBI) short form including 12 items on personal feelings of strain. Positive aspects of caregiving were assessed by 2 items on deeper sense and satisfaction from the caregiver role. **Health indicators:** General health, role limitations due to physical and mental health, pain intensity, mental health, and vitality were assessed by SF-36 items. Three items assessed the frequency of different types of sleep problems.

Statistical analyses: Logistic (binary outcomes) and tobit regressions (continuous outcomes) were applied. The three types of sleep problems were considered as repeated measures within the individual and analyzed using a mixed-model logistic regression with patient ID as random intercept.

Results:

The study sample included N=118 caregiving partners of persons with SCI. Baseline characteristics of participants are displayed in **Tab 1-3**.

Tab 1. Sociodemographics & lesion type of care-receiver

Female gender, n (%)	86 (72.9)
Age in years, mean (SD)	50.7 (10.0)
Having paid work, n (%)	81 (68.6)
Lesion level of care-receiver, n (%)	
Paraplegia, incomplete	36 (31.0)
Paraplegia, complete	45 (38.8)
Tetraplegia, incomplete	22 (19.0)
Tetraplegia, complete	13 (11.2)

Tab 2. Health indicators

Good or very good health, n (%)	82 (70.7)
No role limitations due to mental health, n (%)	87 (77.0)
No role limitations due to physical health, n (%)	67 (58.3)
No sleep problems, n (%)	50 (43.9)
No or mild pain intensity, n (%)	81 (71.1)
Mental health, mean (SD), 0-100	59.1 (18.1)
Vitality, mean (SD), 0-100	73.9 (15.6)

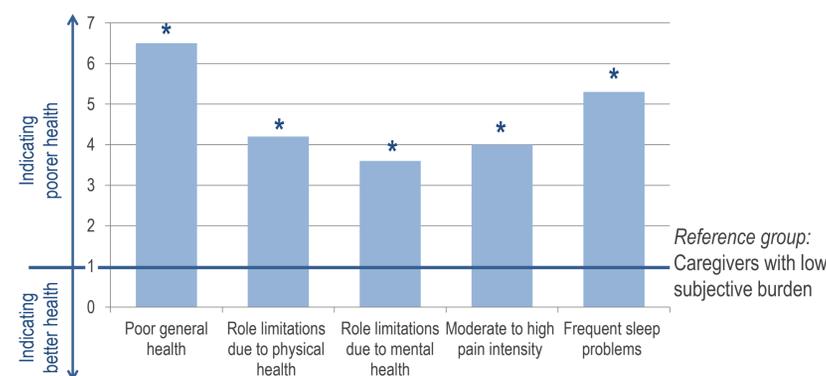
Tab 3. Caregiving parameters

Objective caregiver burden	
Daily hours of caregiving, mean (SD)	2.0 (3.5)
Amount of ADL support, 0-12, mean (SD)	2.4 (3.0)
Amount of IADL support, 0-10, mean (SD)	4.1 (2.7)
Subjective caregiver burden, 0-48, mean (SD)	7.4 (7.2)
Positive aspects of caregiving, n (%)	40 (39.6)

Objective caregiver burden was not associated to any health indicator.

Subjective caregiver burden was associated to all self-reported health indicators. High subjective burden was associated with poorer general health (OR 6.5, 95% CI 2.0-21.5), more role limitations due to physical health (OR 4.2, 95% CI 1.4-12.8), more role limitations due to mental health (OR 3.6, 95% CI 1.1-11.7), higher pain intensity (OR 4.0, 95% CI 1.4-11.5), more frequent sleep problems (OR 5.3, 95% CI 1.6-18.4) (**Fig 1**), poorer mental health (coeff -17.9, 95% CI -24.5- -11.2), and lower vitality (coeff -20.3, 95% CI -28.4- -12.1) (**Fig 2**).

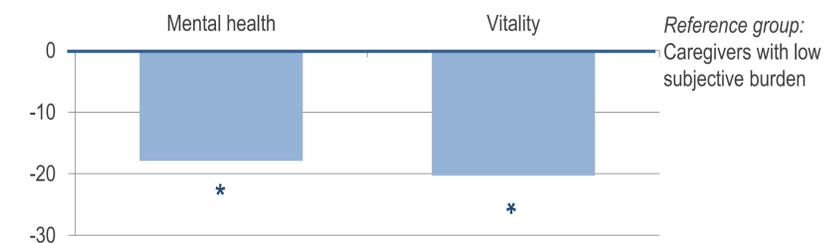
Fig 1. Odds Ratios for poor self-reported health in caregivers with high subjective burden



* $p < 0.05$

Adjusted for age, gender, lesion type care-receiver, time since caregiving, hrs of paid work, financial strain

Fig. 2 Coefficients for caregivers with high subjective burden



* $p < 0.05$

Adjusted for age, gender, lesion type care-receiver, time since caregiving, hrs of paid work, financial strain

Positive aspects of caregiving were positively related to mental health (coeff 6.5, 95% CI 0.2-12.8).

Strength:

- Use of a comprehensive set of health indicators, including physical and mental health.
- Associations were tested using state-of-the-art multivariable statistical methods, taking into account relevant confounders.
- The pro-WELL study was nested in a large cohort study, showing good representation of the source population of care-receivers in terms of sociodemographics and type of lesion.
- Sensitivity analyses using bootstrap techniques revealed good robustness of findings

Limitations:

- Causality regarding the caregiving experience and health cannot be inferred given the cross-sectional nature of data.
- Relatively small sample with low response rate.
- The Zarit Burden Interview provides an overall assessment of subjective caregiver burden, however, it may impose limitations on the interpretation for interventions as it provides limited evidence on tangible sources of strain.

Conclusions: We conclude that caregivers' physical and mental health may be strengthened by enhancing psychological and psychosocial resources to reduce the subjective strain resulting from the caregiver role. Furthermore, strengthening the feeling that the care for their partner has positive aspects may enhance mental health of caregiving partners.

¹ More information on the *SwiSCI* survey: Brinkhof M, Fekete C, Chamberlain JD, Post M, Gemperli A. Swiss national community survey on functioning after spinal cord injury: Protocol, characteristics of participants and determinants of non-response. *J Rehabil Med* 2016;48(2):120-130.

² More information on the *pro-WELL* study: Fekete C, Brinkhof M, Tough H, Siegrist J. Cohort profile: Longitudinal study of social participation and well-being among persons with spinal cord injury and their partners (pro-WELL). *BMJ Open* 2017;7:e011597.

This study is currently under review with *BMJ Open*. For more information: christine.fekete@paraplegie.ch