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**Patterns of change and stability in caregiver burden and life satisfaction from 1 to 2 years after severe traumatic brain injury: A Norwegian longitudinal study**

## **Abstract**

**OBJECTIVE:** To assess burden and life satisfaction in family members of patients with severe traumatic brain injury (sTBI) at 1 and 2 years post-injury, examine if change in burden can be predicted by family member and patient demographics, patient's functional status, family members social network or level of burden at 1 year.

**METHODS:** Prospective national multicenter study. Self-report from family members, patient data collected from a national cohort study on patients with sTBI. 80 family members participated.

**MAIN OUTCOME MEASURE:** The Caregiver Burden Scale (CBS), life satisfaction.

**RESULTS:** Total burden increased between years 1 and 2 post-injury ( $P=0.04$ ). Thirty percent of the family members reported an increased burden, 55% were stable, and 15% had a decrease in burden between the two follow-up times. Logistic regression analyses revealed that experiencing loneliness was an independent predictor of increased burden from 1 to 2 years post-injury ( $OR=4.35$ ,  $P<0.05$ ). Life Satisfaction was lower at the 2 year follow-up than at 1 year ( $p=0.03$ ).

**CONCLUSIONS:** The results demonstrate a need for long-term follow-up of patients and family members that focuses on professional support to relieve burden and risk of loneliness or social isolation. This group may benefit from additional follow-up interventions tailored to their needs.

*Keywords:* caregiver burden, life satisfaction, traumatic brain injury, social network

## **1. Introduction**

Severe traumatic brain injury (TBI) is one of the most common causes of death and disability in young adults and is therefore a major public health challenge (Sundstrom et al., 2005). TBI is considered as a “silent epidemic” given that society is mostly unaware of the magnitude and socioeconomic consequences of the injury (Roozenbeek et al., 2013). Family members serve a critical function as an extension of the health care system, but they lack the formal training and support to care for persons with severe TBI (Ramkumar & Elliott, 2010). Caregiver burden is defined as the social, psychological, physical, economic or emotional experienced by caregivers (George & Gwyther, 1986), which can accumulate over a long period of time (Kasuya et al., 2000). The concept of life satisfaction is described as a conscious cognitive judgment that compares one’s personal life circumstances with a set of self-imposed standards of needs or wants (Diener et al., 2003; Fugl-Meyer et al., 2002). In the present study, life satisfaction was considered as the caregiver’s view of satisfaction with his or her life.

In the past decades, studies on the impact of severe TBI on family members has highlighted a high level of caregiver burden, diminished life satisfaction, unmet family needs, adaptation to new roles, anxiety, depression, social isolation, emotional difficulties and challenges with family functioning (Bayen et al., 2013; Braine, 2011; Doser & Norup, 2016; Douglas & Spellacy, 1996; Gillen et al., 1998; Godwin & Kreutzer, 2013; Kolakowsky-Hayner et al., 2001; L. A. Livingston et al., 2010b; Manskow et al., 2015; McKinlay et al., 1981; Norup et al., 2010; Norup et al., 2012; Oddy et al., 1978). When the caregiver or close family member experiences lower burden, less anxiety and a good health, this has a positive impact on the person with severe TBI (O’Neill & Carter, 1998). Given the close relationship between the health and well being of the injured person and his/her family members, it is important to identify interventions that can improve the situation for both parties (Verhaeghe et al., 2005).

Several longitudinal studies have investigated caregiver burden or strain, with inconsistent findings: A New Zealand study of 52 caregivers of patients with severe TBI 6 and 12 months post-injury found no change in burden over time (Marsh et al., 2002), whereas increased strain in caregivers was found at 5 years as compared to 1 year post-injury (Brooks et al., 1986). The French Paris-TBI study reported a decrease in caregiver burden from 1 to 4 years post-injury (Bayen et al., 2014; Bayen et al., 2013). Among 57 caregivers of patients with severe TBI, the perceived level of burden was high at the 3-, 6- and 12-months follow-up times, with a slight increase between 6 and 12 months (M. G. Livingston et al., 1985). Meanwhile, another study of 69 caregivers reported a decrease in perceived burden during the first year post injury (Sander et al., 1997).

There is strong evidence to suggest that burden is correlated with patient's neurobehavioral problems (Bayen et al., 2014; Bayen et al., 2013; Kreutzer et al., 1994) and level of functioning (Boycott et al., 2013; Brooks et al., 1986; Kreutzer et al., 2009; Manskow et al., 2015). Social network is a broad concept that includes all social resources available to an individual, including interpersonal ties, health resources, and professional support, and the concept can also be defined more narrow as the individuals' social network (A. G. Anke et al., 1997; Gottlieb & Bergen, 2010). A poor social network has been previously shown to predict caregiver burden; caregivers with a high burden 1 year post-injury were more lonely and met with friends and family less frequently (Manskow et al., 2015). Although one study found no relationship between caregiver burden and lack of a social network (Knight et al., 1998), others have demonstrated that a lack of perceived social support was related to a higher caregiver burden (Hanks et al., 2007; Kreutzer et al., 2009).

Few studies have investigated life satisfaction measured at different time points in family members of patients with TBI. One study found diminished life satisfaction in this group several years after as compared to before injury (Kolakowsky-Hayner et al., 2001).

Another longitudinal study in the US found no changes in life satisfaction scores between 1 and 2 years post-injury (L. A. Livingston et al., 2010a), which was consistent with the findings of a cross-sectional study (Kreutzer et al., 2009). One investigation of caregiver burden and life satisfaction in caregivers of patients with stroke reported that a lower life satisfaction was associated with higher burden (Bergstrom et al., 2011).

The present study is the first to analyze simultaneous changes in caregiver burden and life satisfaction over time in a population of family members of patients with severe TBI. A unique aspect of our study is the regression analysis of the predictors of change in burden from 1 to 2 years post-injury. We hypothesized that (1) the level of burden is stable from 1 to 2 years post-injury; (2) the level of burden is associated with family members satisfaction with life; and (3) an eventual change in burden can be predicted by the functional impact of severe TBI and family members' social networks.

## **2. Methods**

### *2.1 Design*

This prospective, population-based, multicenter cohort study covered all regions of Norway. The study population included adult family members or acquaintances of patients ( $\geq 16$  years old) with severe TBI who were injured between January 2009 and December 2011. All patients were admitted to one of the four trauma referral centers in Norway. Inclusion criteria for participation in the study were as follows: closest family member or acquaintance of a patient included in the national multicenter study of severe TBI (i.e., unselected Glasgow Coma Scale (GCS) score of  $\leq 8$  during the first 24 hours post-injury) (Andelic et al., 2012); listed as the patient's closest family member or acquaintance either by the patient and/or in the patient's medical records; and age  $\geq 18$  years.

## *2.2 Data collection*

The regional project coordinator at each trauma center identified a close family member or acquaintance of the patient with severe TBI. Written informed consent was required from the patient and all participating family members. A family member consented on behalf of the patient if he/she was unable to give consent due to cognitive impairment. Family members were then contacted by telephone and informed about the study by the coordinator at the University Hospital of North Norway (responsible for the database). The questionnaires and informed consent forms were sent out by mail, and data were collected at 12 and 24 months post-injury. All participants had the possibility of withdrawing from the study at any time. The study protocol was approved by the Committee for Medical Research Ethics for Southeast Norway (no. 2009/702). Patient data were collected through the national multicenter patient study (Andelic et al., 2012).

## *2.3 Participants*

We designated the closest family member or acquaintance as the family member in this study. A total of 171 family members were identified and contacted for possible participation in the present study (Figure 1). A total of 119 family members completed the questionnaire in year 1 post-injury, and 80 participated in both years 1 and 2, giving response rates of 70% and 47%, respectively (Figure 1).

(Insert Figure 1 here)

Characteristics of non-participating family members were not available. Patient characteristics did not differ between those participants and non-participants, except that the proportion of male patients was higher in the former. Descriptive data for the family members and the patient-related variables are presented in Table 1; these did not differ between participants at 1 year and those at both 1 and 2 years post-injury. Around 75 % of family members were female, and nearly half were married to/cohabiting with the patient. Only those who responded at both 1 and 2 years (n=80) were included in further analysis.

(Insert Table 1 here)

#### *2.4 Family member measures at the 1- and 2-year follow-up*

Information was obtained from family members with a structured self-report questionnaire. Family members burden was assessed with the Caregiver Burden Scale (CBS), a generic 22-item scale developed to measure different dimensions of a caregiver's subjective burden (Elmståhl et al., 1996), that was previously used to evaluate burden in caregivers of patients with stroke and dementia as well as severe TBI (Andren & Elmstahl, 2005; Dahlrup et al., 2011; Manskow et al., 2015). The CBS contained five subscales representing different dimensions: general strain (eight items), isolation (three items), disappointment (five items), emotional involvement (three items) and environment (three items). The construct validity and internal consistency of the scale have been previously described, yielding Cronbach's alpha coefficients of 0.70 to 0.87 for all subscales except for environment (0.53) (Elmståhl et al., 1996). Test-retest reliability was also acceptable, with kappa values ranging from 0.89-



1.00 for all subscales except environment (0.69) (Elmståhl et al., 1996). The items were scored from 1 to 4 (1, not at all; 2, seldom; 3, sometimes; and 4, often) for a total score ranging from 22-88 with a high score indicating a high burden. Since subscales consisted of different numbers of questions, an index score was calculated based on the sum score of each subscale divided by the total number of items. Index scores of 1.0-1.99 indicated a low burden, 2.0-2.99 a moderate burden, and 3.0-3.99 a high burden (Bergstrom et al., 2011; Elmståhl et al., 1996).

Life satisfaction was measured according to a single global item: “Overall, how satisfied are you with your life right now?” The item was rated on a 5-point ordinal scale as follows: 1 (very dissatisfied), 2 (dissatisfied), 3 (neither satisfied nor dissatisfied), 4 (satisfied) or 5 (very satisfied). The validity of this item has been previously demonstrated in caregivers of patients with TBI (Kolakowsky-Hayner et al., 2001). Based on the previous results, two questions related to the family member’s personal social network were included in the analysis (Manskow et al., 2015). One questions addressed social network quantity; i.e., “How often do you meet friends and relatives with whom you do not live, for example, visiting each other’s homes, going out together, talking on the phone?” (once a week; less than once a week but at least once a month; or less than once a month). The other question assessed quality of their social network by focusing on social support: “Do you ever feel lonely?” (never or rarely; sometimes; or often) (A. G. Anke et al., 1997).

### *2.5 Patient outcome measures at baseline and 1-year follow-up*

Acute injury severity was assessed with the widely used and previously validated Abbreviated Injury Severity scale (AIS) (AAAM.org., 2008). The AIS head score was used in the present study to evaluate the severity of the brain injury with a higher score indicating a more severe

injury. The Glasgow Coma Scale (GCS) was used to assess the patient's level of consciousness in the acute phase of the TBI, and the lowest GCS score within the first 24 hours was recorded (Teasdale & Jennett, 1974). Patients were scored on the Glasgow Outcome Scale Extended (GOSE) based on a structured interview, and the score was used to evaluate the patient's functional level at the 1-year follow-up (Wilson et al., 1998). The GOSE categorizes patient status into one of eight categories: 1, dead ; 2, vegetative state; 3, lower severe disability; 4, upper severe disability; 5, low to moderate disability, 6, upper to moderate disability; 7, low to good recovery; and 8, upper good recovery.

## *2.6 Statistical analysis*

SPSS for Windows version 23.0 was used for statistical analyses. Descriptive data are presented as mean and standard deviation (SD) or as proportions of subjects. Cross-tabulations with  $\chi^2$ -tests were applied to nominal data. Assumptions of a normal distribution were visually inspected and tested with a skewness test statistic. Non-parametric statistical analyses were carried out when the data were not normally distributed. The Emotional Involvement and Environment subscales of the CBS were skewed in a positive direction. The independent samples t-tests was used to compare the means between two or more groups. The paired sample t-tests or Wilcoxon signed-rank test was used as parametric and non-parametric tests, respectively, to compare CBS scores at the 1- and 2-year follow-ups. When there were one (or two) missing data point(s) on the CBS, the data were replaced with the caregiver's mean value on each subscale. Participants with more than two missing data points on the CBS scale were excluded.

We determined the number of participants in each group with stable, improved, or worsened CBS sum scores between 1 and 2 years. Initially, a distribution-based method was used to calculate the standard error of measurement (SEM, based on Cronbach's alpha and the

observed variance statistic), which indicated the smallest change in raw score reflecting a true change and not measurement error. A difference of at least one SEM has been used to represent the minimal clinically important difference (Copay et al., 2007). However, we chose a stricter definition and required two SEM which in practice represented one-half the SD of the CBS total score to represent the minimal clinically important difference (Norman et al., 2003). The total CBS score at 1 and 2 years was evaluated for each participant and differences of at least two SEM were noted.

A  $\chi^2$  -test was performed to investigate the longitudinal change in caregiver burden between 1 and 2 years, with participants dichotomized into two groups at 1 year post-injury: (1) low burden and (2) moderate-to-high burden. A binary logistic regression analysis with backward stepwise regression was carried out to identify predictors of worsened caregiver burden from 1 to 2 years post-injury. Co-linearity was verified and only variables with correlation coefficients  $<0.7$  were entered together in the regression analyses. The CBS dependent variable was coded as 0 (stable/improved) or 1 (worsened).

The independent variables entered were age, gender, education, and GOSE score for patients and gender, relation to patient, education, time spent with patient, and frequency of meeting friends/family and loneliness measured at 1 year post-injury for caregivers. Initial univariate analyses were carried out to evaluate the association between each independent and the dependent variable. Multivariate logistic regression analysis was then applied to all variables with the Enter method and backward removal of insignificant variables; results are presented as adjusted odds ratios. Model fit was evaluated by applying the Hosmer and Lemeshow test, and the amount of explained variance in the outcome was assessed using Nagelkerke's  $R^2$ . The level of significance was set at  $P < 0.05$ .

### **3. Results**

#### *3.1 Caregiver burden and life satisfaction from 1 to 2 years post-injury*

At 1 year post-injury 12.5 %, 37.5% and 50% of caregivers experienced high, moderate, and low burden, respectively. The mean total CBS sum score (Table 2) showed an increase in burden at 2 years as compared to 1 year post-injury ( $P < 0.05$ , paired t-test), contrary to our hypothesis that there is no change in CBS score between these time points. Further analyses to identify subscales with significant changes showed increases in disappointment, emotional involvement, and environment subscales (Table 2). A proportion of 30% of the caregivers reported an increased burden, 55% a stable burden and 15% a decrease in burden from 1 to 2 years post-injury.

(Insert Table 2 here)

Life satisfaction scores decreased over time from a mean score of 3.7 (SD =0.85) at 1 year to 3.5 (SD= 0.96) at 2 years post-injury ( $P < 0.05$ , Wilcoxon signed rank test). The proportion of caregivers who reported being “very satisfied” decreased from 20% to 13%, with a comparable increase in individuals who reported being dissatisfied with life as a whole during this time frame (Figure 2).

(Insert Figure 2 here)

The correlations between total CBS and life satisfaction scores were strongly negative at both 1 and 2 years post-injury (Spearman's correlation = -0.79 and -0.79, respectively;  $P < 0.001$  for both).

### *3.2 Longitudinal individual changes in caregiver burden scores*

The CBS sum score at 1 year post-injury had a Cronbach's alpha value of 0.96. The formula for SEM yielded a change of 0.15 points corresponding to one SEM. Hence a change of 0.30 points or more (two SEM) defined the minimal clinically important difference between 1 and 2 years post-injury. Using two SEM, individual changes in total CBS scores from 1 to 2 years post-injury were trichotomized into better, same and worse (Table 3). Longitudinal changes in CBS score were statistically significant for participants reporting a low degree of burden at the 1-year follow-up as well as those reporting an initially moderate/high degree of burden ( $P < 0.05$ ). A larger degree of change was observed in the moderate/high-burden group according to reported P-values. By inspecting the cell numbers describing the change, 53% (10/19) and 82% (14 /17) of those that changed did so in a negative direction in the low- and moderate/high-burden groups, respectively.

(Insert Table 3 here)

### *3.3 Predictors of increased caregiver burden from 1 to 2 years post-injury*

Predictors of worsened CBS from 1 to 2 years post-injury were analyzed (Table 4). In univariate analyses, P-values  $< 0.1$  were observed for a low GOSE score (2-5), male

caregivers, and feeling lonely often. Since the association between worsened total CBS and low GOSE scores was marginally significant ( $P=0.067$ ), it was not examined further. The final model retained gender ( $P=0.11$ ) and loneliness ( $P=0.04$ ), explaining 12% (Nagelkerke's  $R^2$ ) of the variance in increased burden and correctly classifying 72.5% of the cases. The Hosmer and Lemeshow test indicated a good model fit ( $\chi^2=0.54$ , degrees of freedom=1,  $P=0.46$ ). The feeling of loneliness at 1 year post-injury was the only statistically significant predictor of an increase in caregiver burden from 1 to 2 years post-injury in this model.

(Insert Table 4 here)

#### **4. Discussion**

The present study found a significant increase in caregiver burden and a decrease in life satisfaction at 2 years as compared to 1 year post-injury, contrary to our hypotheses. The level of caregiver burden remained stable in approximately half of the participants. As predicted, we observed a strong correlation between burden and life satisfaction. A significant predictor of the increase in caregiver burden was the feeling of loneliness at 1 year post-injury, partly supporting our third hypothesis regarding social network as a predictor of increase in burden.

##### *4.1 Caregiver burden*

Although around half of the participants reported stable values from 1 to 2 years post-injury, the finding that 30% of the participants reported clinically significant increases in burden is relevant to health care service providers. In addition, burden increased more frequently among

caregivers with a moderate-to-high as compared to a low burden at the 1-year follow-up. One study found no significant change in caregiver burden between 6 and 12 months post-injury (Marsh et al., 2002), whereas the Paris-TBI study found a decrease in burden at 4 as compared to 1 year (Bayen et al., 2014; Bayen et al., 2013). However, the latter investigators did not compare the same population at the two time points; this along with the longer time span post-injury and differences in analytical approaches could explain the discrepancy between their results and ours. The results of our study are robust, since burden increased both in terms of mean CBS scores and when measured as minimal clinically important changes. A recent study from Denmark assessed caregiver burden with the CBS 3-6 years after severe TBI and reported burden scores within each subscale of the CBS that were similar to those in the present study, although the Danish study assessed only one time point (Doser & Norup, 2016).

There are several possible explanations for the findings that caregiver burden increased over time. At 1 year post-injury, family members may still hope for an improvement in the patient's condition and may not be fully aware of the long-term consequences of the injury. At 2 years post-injury, the family members may also be receiving less help from the community healthcare system. Family members of a person with TBI pass through six stages of reaction from the pleasure of the patient returning home and optimism about the future, to anxiety when energy and optimism decline between 9-24 months after injury and further (Lezak, 1986). This last stage is often followed by anxiety, depression, mourning, and emotional disengagement. Psychological intervention in addition to professional support in care may help families negotiate these stages and help them to understand the nature and long-term effects of the injury (Lezak, 1986).

#### *4.2 Correlation between caregiver burden and life satisfaction*

We observed a strong negative correlation between caregiver burden and life satisfaction. These findings are in accordance with a Swedish cross-sectional study that investigated burden and life satisfaction in caregivers of patients with stroke (Bergstrom et al., 2011). This is the first study to investigate caregiver burden and life satisfaction simultaneously after severe TBI. Only two Swedish studies have previously investigated this relationship in caregivers of patients with dementia, who reported moderate burden and good life satisfaction at the same time (Andren & Elmstahl, 2005); and caregivers of patients with stroke, who reported lower life satisfaction and higher burden (Bergstrom et al., 2011). Both studies used the same CBS as in the present study, although life satisfaction was measured with the Caregiver Assessment of Satisfaction Index and the Li-Sat 11, respectively.

The increased burden and decreased life satisfaction of caregivers must be addressed by community health care (family doctors, district nurses, teachers, etc.) as well as specialized health care services. For patients, multidisciplinary rehabilitation programs that have integrated or separate programs for family members should always be considered (Becker et al., 2014). Programs for family members focusing on education and coping strategies and providing information about available services and social rights (Ramkumar & Elliott, 2010). In previous studies such interventions have shown to reduce the burden of family members of patients with TBI (Holland & Shigaki, 1998; Perlesz & O'Loughlan, 1998).

#### *4.3 Life satisfaction*

The results presented here are in accordance with a study that reported a small but non-significant decrease in life satisfaction in caregivers of patients with TBI between 1 and 2 years post-injury, using the more extensive Satisfaction With Life Scale (L. A. Livingston et al., 2010a) as compared to the single item in the present study. Although the use of the single



item has been confirmed as valid by others (Kolakowsky-Hayner et al., 2001), and by the high negative correlation to the CBS score. Our findings also indicate that the single item showed good sensitivity to change. Another group used the same life satisfaction item to compare an assessment at least 4 years after injury with reported pre-injury satisfaction in 57 caregivers of patients with TBI, and found a long term decrease in life satisfaction; 87% of the caregivers were satisfied or very satisfied with life pre-injury, but this proportion decreases to 59% several years post injury (Kolakowsky-Hayner et al., 2001), which is higher than the proportion of family members that were satisfied 2 years post-injury in our study.

#### *4.4 Predictors of increased caregiver burden*

Feeling lonely was an independent predictor of increased caregiver burden from 1 to 2 years post-injury. Loneliness is the psychological aspect of social isolation and is referred to as perceived subjective isolation (Cacioppo et al., 2014), and has been described as low perceived social support and an important indicator of social network quality (A. G. Anke et al., 1997). In a recent study, loneliness was independently associated with a higher caregiver burden 1 year after severe TBI (Manskow et al., 2015). However, feeling lonely does not necessarily mean that the person is socially isolated (Nicholson, 2012). Loneliness has been reported as the most difficult aspect of social adjustment in caregivers of TBI survivors (Oddy et al., 1985). A qualitative study on caregivers of people with acquired brain injury found loneliness to be a key contributor to their overwhelming sense of loss and burden (Braine, 2011).

We found that men frequently experienced a greater burden over time than women, although the gender difference was not statistically significant. However, in a clinical review of caregiver burden, gender was not found to be a risk factor for increased in burden over

time, and this issue should be explored in future studies (Adelman et al., 2014). The patient's level of functioning 1-year post-injury was not an independent predictor of increased burden from 1 to 2 years. However, a trend towards a positive association between low GOSE score at 1 year and increased burden was observed in the univariate analysis ( $P=0.067$ ), implying a risk of type 2-error. These results also suggest that other factors such as little or no support from health and/or social services, family, and friends are more important factors contributing to increased burden (Hanks et al., 2007; Manskow et al., 2015).

#### *4.5 Consideration of methodology and design*

There are no established values for minimal clinically important changes in CBS score at the individual level. To evaluate changes in CBS, we used a difference of 0.30 points between the two time points as the minimum clinically important change. This corresponds to 10% of the range of the scale (1.0-4.0), a percentage that has previously been found to indicate a minimal clinically important change in other measures (Fayers et al., 2007). There is no consensus on what constitutes a minimal clinically important difference in the literature (Copay et al., 2007), and a SEM of one has been used (Norman et al., 2003). However, we selected a value of 0.3 that was twice the SEM and close to the alternative distribution-based method using half of the SD (Copay et al., 2007). The Life Satisfaction item used in the present study was uni-dimensional and only assessed overall satisfaction with life, whereas the Life Satisfaction Index (Neugarten et al., 1961), and the Life Satisfaction checklist (Fugl-Meyer et al., 2002) are multidimensional. Assessment of life satisfaction based on a single item is comparable to the use of a single measure of patients' health status and quality of life, which have been shown to be extremely useful indicators of patients well-being (Fayers & Sprangers, 2002). The one-item questionnaire was selected in accordance with previous studies (A. Anke et al.,

2015; Fujita & Diener, 2005; Kolakowsky-Hayner et al., 2001) and its validity was supported by our analyses.

## **5. Strengths and limitations of the study**

A strength of this study was the national prospective multicenter design in addition to the use of established and validated methods and assessment of two points. It is recommended that caregiver burden be assessed by prospective, longitudinal studies with similar follow-up times post-injury and the same level of TBI severity to assess burden over time (Ramkumar & Elliott, 2010; Thompson, 2009). The participation rate for those who responded at both follow-up times was 47%. Although we lacked information on the non-consenting family members, patients in non-participating and participating families did not differ significantly. However, we cannot exclude the possibility of selection bias, that is, non-participants may have experienced a higher or lower burden than participants. Although the number of participating family members was higher than in most previous longitudinal studies, the relatively small number of participants resulted in low statistical power.

A limitation of this study is the one-item question regarding loneliness and social support. However, the association between social support and burden is supported by several studies that have employed more elaborate measures (Hanks et al., 2007; Kreutzer et al., 2009). Another limitation is the lack of available neuropsychological data that could provide more information about patients cognitive functioning. We are aware that other factors not measured in this study are known to impact the burden and life satisfaction experienced by family members, including coping style, resilience and mental health status (Ponsford & Schonberger, 2010; Simpson & Jones, 2013). Therefore, our results may not be generalizable to (all) other countries or cultures due to differences in support systems after patient discharge

and the custom of family involvement\_ (Norup et al., 2015). Finally, the age of family members was not measured in this study; however, given that this has not been linked to caregiver burden we do not expect this omission to undermine our results.

## **6. Conclusion**

An increase in caregiver burden was associated with a decrease in life satisfaction over time, which has significant clinical implications. Family members play a fundamental role in the long-term care and rehabilitation of patients with severe TBI. The consequences of caregiving must be recognized and met with targeted action if family members are expected to effectively fulfill this role while participating in society and maintaining their quality of life. Our findings demonstrate a need for long-term follow-up of patients and family members that focuses on professional support to alleviate caregiver burden and risk of loneliness or social isolation. Identifying family members with a moderate-to-high burden is critical for developing appropriate interventions.

### *Declaration of interest*

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**Table 1. Caregiver and patient characteristics at baseline, 1 and 2 years follow-up. Presented as number of cases and (%) or as mean and SD.**

	Baseline	1 year (n=119)	2 years (n=80)
<b><i>Caregiver characteristics</i></b>			
Female		92 (77.3)	59 (73.8)
Married/cohabitant <sup>1</sup> (n=115/77)		95 (82.6)	66 (85.7)
<b><i>Relationship to patient</i></b>			
Spouse/cohabitant		52 (43.7)	38 (47.5)
Parent		51 (42.9)	28 (35.0)
Other		16 (13.4)	14 (17.5)
<b><i>Education (n=118/79)</i></b>			
Low ( $\leq 13$ y)		76 (64.4)	48 (60.8)
High ( $> 13$ y)		42 (35.6)	31 (39.2)
<b><i>Living with the patient</i></b>			
Yes		71 (60.2)	49 (61.3)
No		47 (39.8)	31 (38.8)
<b><i>Time spent with patient (n=117/78)</i></b>			
24 h/d		36 (30.8)	27 (31.8)
2-10 h/d		46 (39.3)	35 (41.2)
1-2 t/week or less		35 (29.9)	23 (27.1)
Working/education (n=117/79)		85 (72.6)	51 (64.6)
<b><i>Feeling loneliness</i></b>			
Never or rarely		59 (49.6)	30 (37.5)
Sometimes		46 (38.7)	39 (48.8)
Often		14 (11.8)	11 (13.8)
<b><i>Meeting friends/family (n=118/78)</i></b>			
Once a week or more		93 (78.8)	50 (64.1)
Less than once a week		16 (13.6)	22 (28.2)
Less than monthly		9 (7.6)	6 (7.7)
<b><i>Patient characteristics</i></b>			
Age (years), mean (SD)	39.4 (19.19)		
Male	107 (84.9)		
Married/cohabitant	57 (45.2)		
<b><i>Education</i></b>			
Low ( $\leq 13$ y)	79 (76.3)		
High ( $> 13$ y)	35 (30.7)		
AIS Head, mean (SD)	4.26 (0.90)		
GCS admission <sup>2</sup> , mean (SD)	5.35 (1.91)		
GOSE 12 months, mean (SD)		5.94 (1.66)	
GOSE <sup>3</sup> 12 months, score 2-5		39 (33.1)	
GOSE 12 months, score 6-8		79 (66.9)	

Abbreviations: AIS, Abbreviated Injury Scale; GCS, Glasgow Coma Scale; GOSE, Glasgow Outcome Scale Extended.

<sup>1</sup>Cohabitant status means if the caregivers are married or cohabitant in general and includes caregivers married to the patient and those married to others; <sup>2</sup>GCS admission means the lowest GCS score within the first 24 hours post injury; <sup>3</sup>GOSE score 2-5 indicates poor recovery; 6-8 indicate a good recovery.

**Table 2. Mean (SD) Caregiver Burden Scale score total and for the five subscales at both follow-up times (n=80).**

Mean (SD)	1 year	2 years	P-value
CBS total	2.08 (0.74)	2.17 (0.85)	0.04
General Strain	2.30 (0.85)	2.35 (0.97)	0.40
Isolation	2.15 (0.81)	2.09 (0.96)	0.28
Disappointment	2.14 (0.83)	2.25 (0.95)	0.04
Emotional Involvement	1.87 (0.77)	2.00 (0.91)	0.05
Environment	1.64 (0.73)	1.80 (0.77)	0.02

**Table 3. Longitudinal change in total CBS score from 1 to 2 years post injury.**

CBS-level at 1 year follow-up	Minimal clinical important change from 1 to 2 years follow-up <sup>a</sup>			P-value
	Improved (N)	Stable (N)	Worsened (N)	
Low burden (n=40)	9	21	10	0.036
Moderate and high burden (n=40)	3	23	14	0.001
All caregivers (n=80)	12	44	24	

<sup>a</sup> Minimal important clinical change  $\geq 0.3$  is presented separately for caregivers who had low (1.0-1.99) and moderate/high scores (2.0-4.0) at 1 year post injury.

**Table 4. Predictor analysis of worsened caregiver burden (versus stable/improved) from 1 to 2 years post-injury in relation to demographic variables, patient functioning and caregiver social network variables.**

	<b>Unadjusted OR</b>	<b>Univariate 95 % CI</b>	<b>P</b>	<b>Multivariate OR</b>	<b>95 % CI</b>	<b>P</b>
<i>Patient variables<sup>a</sup></i>						
Age	1.01	0.98-1.03	.553			
Gender, male	1.17	0.28-4.83	.832			
Education, low	0.63	0-23-1.72	.372			
GOSE (2-5)	2.50	0.94-6.64	.067			
<i>Caregiver variables<sup>a</sup></i>						
Gender, male	2.46	0.85-7.06	.096	2.46	0.83-7.34	0.11
Relation to patient, married <sup>b</sup>	1.36	0.52-3.56	.526			
Education, low	2.02	0.72-5.66	.179			
Time spent with patient	0.93	0.34-2.59	.894			
Loneliness, often	4.33	1.10-17.12	.036	4.35	1.07-17.66	0.04
Frequency meeting friends	1.35	0.40-4.54	.633			

<sup>a</sup> Variables entered as: Age (continuous), Gender (male/female); Education (low 7-12 years/high >12 years); GOSE (score 2-5/ score 6-8); Relation to patient (married or cohabitant/not married); Time spent with patients (24h a day/2-10h a day or less); Loneliness (Often/ sometimes or never); Frequency meeting friends (< 1 time per week/> 1 time per week).

<sup>b</sup> Cohabitant status means married/cohabiting in general and includes both caregivers married to the patient and married to others

**Figure 1. Flowchart participating family members.**

**Figure 2. Proportion (%) of scores on the Life Satisfaction item at 1 and 2 years post injury.**



