

Gregorio Sorrentino ^a, Eléonore Bayen ^{a,b}, Hugo Câmara-Costa ^{a,b,c},
Leila Francillette ^{b,c}, Hanna Toure ^c, Anne Laurent-Vannier ^c,
Philippe Meyer ^{d,e}, Georges Dellatolas ^a, & Mathilde Chevignard ^{a,b,c}

^a Sorbonne Université, GRC 24 Handicap Moteur et Cognitif et Réadaptation (HaMCRE), Paris, France; ^b Sorbonne Université, INSERM, CNRS, Laboratoire d'Imagerie Biomédicale, LIB, Paris; ^c Rehabilitation Department for Children with Acquired Neurological Injury, Saint Maurice Hospitals, Saint Maurice, France; ^d Paediatric Anesthesiology Department, Necker Enfants Malades University Hospital, Paris, France; ^e Faculty of Medicine, Paris Descartes University, Paris, France.

INTRODUCTION

- Severe childhood traumatic brain injury (TBI) increases the risk of multiple disabilities over time with an enduring negative impact on family functioning and caregivers' well-being.
- Most studies have focused on informal caregivers' burden within the first-year post-injury, but the long-term impact of TBI on family functioning and informal caregivers' burden has been overlooked.

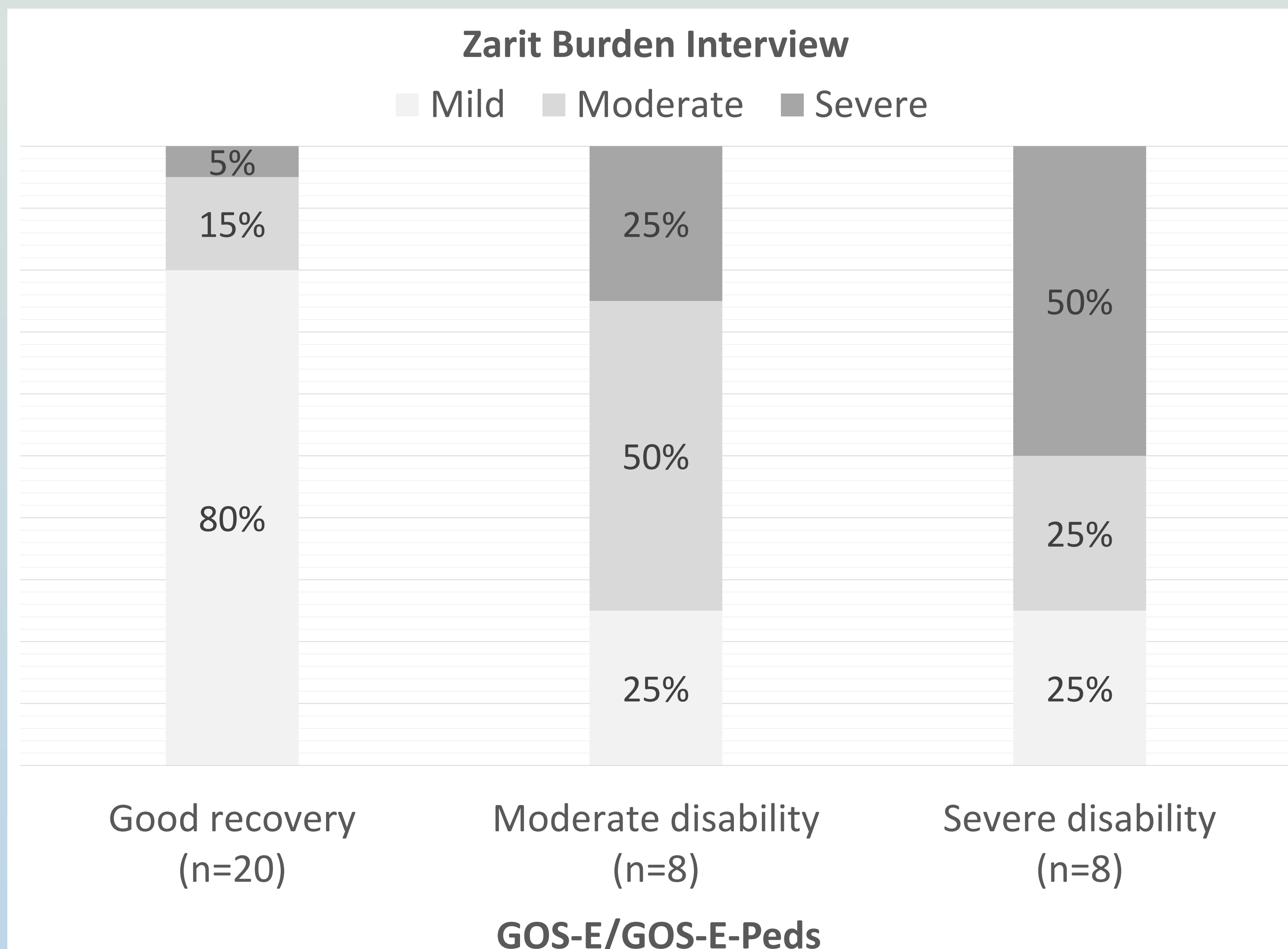
Aims:

- To evaluate the subjective level of burden reported by the Primary Family Caregiver (PFC) 7-years after severe pediatric TBI in the TGE prospective longitudinal study;
- To examine the relationship of reported burden with:
 - Sociodemographic characteristics of the patient and the PFC;
 - Injury-related factors (e.g. age at injury; indices of injury severity);
 - Family-related factors (family functioning, parental mental health, level of care and needs);
 - Concurrent outcomes 7-years post-injury (overall disability, intellectual ability, education/professional status, executive functioning, behavior, participation, quality of life and fatigue).

RESULTS

Subjective burden and overall disability 7-years post severe TBI

Percentages of mild, moderate and severe burden (n = 36) according to the GOS-E (r=0.56, p<0.001)



METHODS

Population

- Children (0 - 15 years) consecutively admitted in a single trauma center for severe non-inflicted TBI (GCS score ≤ 8 and/or Injury Severity Score (ISS) >16) over a 3-year period

Assessments 7-years post-injury

- Main outcome**
 - Subjective burden reported by the PFC:** Zarit Burden Inventory (ZBI) (Zarit, Reever & Bach-Peterson, 1980)
- Concurrent outcomes**
 - Physical and Mental Health of the PFC (self-report):** Short-Form Health Survey (SF-12) (Ware J, Kosinski M, Keller, 1996)
 - Family functioning according to the PFC:** Family Assessment Device (FAD) (Speranza et al., 2012)
 - Care and needs scales according to the PFC:** (Pediatric)-Care and Needs (P-CANS/CANS) (Soo et al., 2012, Tate, 2004)
 - Overall level of disability:** GOS-Extended (Wilson et al., 1998) and its Pediatric version (Beers et al., 2012)
 - Full-Scale Intellectual Quotient (FSIQ):** WISC-IV (Wechsler, 2005) or WAIS-IV (Wechsler, 2008)
 - Executive functions:** Pediatric (Gioia et al., 2014) and adult (Roth et al., 2015) Behavioral Rating of Executive Functions (BRIEF)
 - Behavior:** Achenbach's Behavior Checklist (Achenbach & Rescorla, 2001, 2003)
 - Participation:** Child and Adolescent Scale of Participation (CASP) (Bedell, 2004, 2009)
 - Health-related Quality of Life:** Pediatric Quality of Life Inventory (PedsQL) (Varni et al., 1999, Varni & Limbers, 2009)
 - Fatigue:** PedsQL Multidimensional Fatigue Scale (MFS) (Varni et al., 2002; Varni & Limbers, 2008)

Subjective burden reported by the PFC 7-years post severe TBI

Rank order of the 22-items' mean values from the Zarit Burden Interview

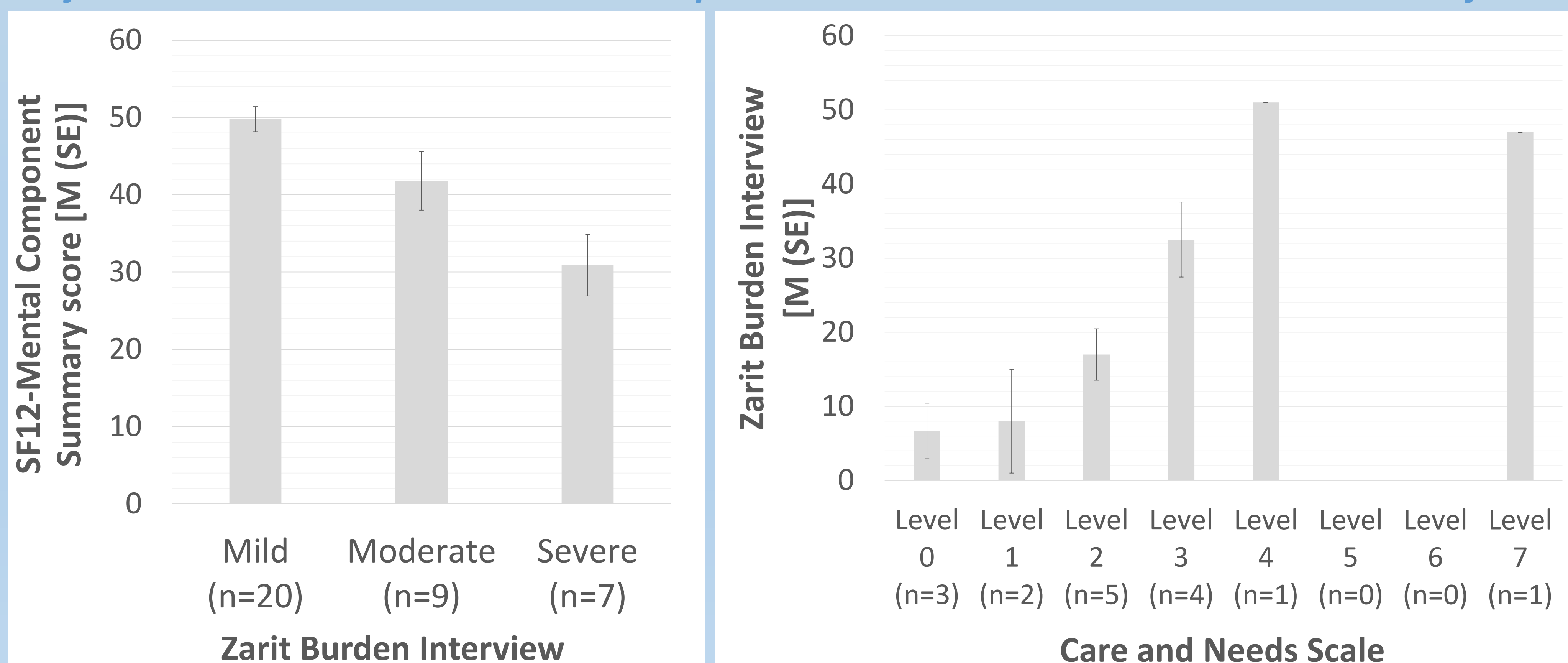
Item	Zarit Burden Interview (n=36)	Mean	SD	Min	Max
7.	I am afraid of what the future holds for the person I care for.	2.44	1.56	0	4
8.	I feel he/she is dependent upon me.	1.69	1.77	0	4
3.	I feel stressed between caring for him/her and trying to meet other responsibilities for my family or work.	1.47	1.58	0	4
1.	I feel that the person I care for asks for more help than he/she needs.	1.42	1.40	0	4
21.	I feel I could do a better job in caring for him/her.	1.39	1.34	0	4
20.	I feel I should be doing more for him/her.	1.17	1.38	0	4
2.	Because of the time I spend with him/her, I do not have enough time for myself.	1.14	1.55	0	4
12.	I feel that my social life has suffered because I am caring for this person.	1.11	1.43	0	4
17.	I feel that I have lost control of my own life since this person's illness.	1.06	1.41	0	4
22.	Overall, how burdened do you feel in caring for this person?	1.03	1.44	0	4
14.	I feel that this person expects me to take care of him/her as if I was the only one he/she could depend on.	1.00	1.31	0	4
4.	I feel embarrassed over his/her behavior.	0.94	1.26	0	4
10.	I feel that my health has suffered because of my involvement with the person I care for.	0.94	1.41	0	4
15.	I feel that I do not have enough money to support this person in addition to the rest of our expenses.	0.86	1.17	0	4
11.	I feel that I do not have as much privacy as I would like because of the person I care for.	0.61	1.25	0	4
16.	I feel that I will be unable to take care of him/her much longer.	0.56	1.03	0	3
9.	I feel strained when I am around the person I care for.	0.53	0.81	0	3
6.	I feel that he/she currently affects my relationship with other family members or friends in a negative way.	0.50	0.74	0	2
5.	I feel angry when I am around the person I care for.	0.43	1.04	0	4
19.	I feel uncertain about what to do about the person I care for.	0.42	1.02	0	4
13.	I feel uncomfortable about having friends over because of him/her.	0.25	0.60	0	2
18.	I wish I could leave the care of this person to someone else.	0.22	0.59	0	2
	Averaged total score	0.96	0.79	0	2.45
	Total score	21.14	17.30	0	54

Each item from the Zarit Burden Interview is scored in a 5-point scale (0=Never; 1=Rarely; 2=Sometimes; 3=Quite frequently; 4=Nearly always).

Factors associated with subjective burden 7-years post severe TBI

REGRESSION ANALYSIS	Zarit Burden Interview			
	R ²	β	S (β)	p
Step 1	0.69			
Overall disability (GOS-E / GOS-E-Peds)		3.94	2.16	0.09
Parental mental health (SF12-MCS)		-0.47	0.34	0.19
Executive functioning (BRIEF)		0.28	0.42	0.52
Behavior (C/ABCL)		0.07	0.62	0.91
Participation (CASP)		0.009	0.31	0.97
Health-related Quality of Life (PedsQL)		-0.12	0.25	0.65
Fatigue (MFS)		-0.04	0.26	0.87
Final step (backwards selection)	0.62			
Overall disability (GOS-E / GOS-E-Peds)		5.14	1.74	0.008
Executive functioning (BRIEF)		0.55	0.18	0.006

Subjective burden associated with lower parental mental health and increased levels of care



Conclusion

Almost half of the PFCs reported mild to moderate burden (25%) or moderate to severe burden (19%) 7-years after their child's severe TBI. Perceived burden was linked to poorer mental health and higher levels of care and needs reported by caregivers, as well as with all the questionnaires completed by the PFC assessing difficulties in executive functioning, behavior, participation, quality of life, and fatigue. Overall disability (GOS-E) and caregiver-reported everyday life executive functioning explained 62% of the variance of the perceived burden. The association of perceived burden with poorer mental health merits a reflection on assessing the need for psychological support to PFCs over time, in order to provide adequate support, preserve mental health and reduce burden in the long term.