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Parental report of levels of care and needs 7-years after severe childhood traumatic brain injury: results of the Traumatisme Grave de l'Enfant (TGE) cohort study

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Running head: Care and needs 7-years after severe childhood TBI

Abstract

This study investigated parental reports of the level of care and needs 7-years following severe childhood traumatic brain injury (TBI), and the factors associated with this outcome.

From the 65 children (0-15 years) consecutively admitted to the Parisian regional TBI reference intensive care unit following severe TBI, included in this prospective longitudinal study, 39 patients [M(SD) age at injury=7.5 years (4.6) and assessment 15.3(4.4)] were followed 7-years post-injury and matched with a control group composed of typically developing participants ($n=34$) matched by age, sex and parental education level.

We used the Care and Need Scale (CANS) and its Pediatric version (PCANS) to assess the primary outcome 7-years post-injury. Concurrent measures included overall level of disability, and parent- and/or self-reported questionnaires assessing executive functioning, behavior, quality of life, fatigue, participation and caregivers' burden.

The level of care and needs was significantly higher in the TBI group than in the control group, the difference being significant with the CANS only. PCANS scores were extremely variable in the control group. High level of dependency was associated with initial TBI severity (higher coma duration and initial Injury Severity Score), higher levels of behavioral problems, executive function deficits, fatigue, and lower participation levels. Caregivers' burden was strongly associated with the CANS.

The CANS provides a simple and reliable measure of the support needed long-term after childhood TBI, in accordance with previous studies. The PCANS scores were not significantly different between the TBI and the control groups, which seems to illustrate the difficulty to assess accurately mild-to-moderate deficits of functional independence/adaptive behavior in children based exclusively on parental reports.

Keywords: severe traumatic brain injury, child, long-term outcome, supervision, care and needs

Parental report of levels of care and needs 7-years after severe childhood traumatic brain injury: results of the Traumatisme Grave de l'Enfant (TGE) cohort study

Traumatic brain injury (TBI) is a major public health concern and the main cause of childhood acquired brain injury (ABI) (Chevignard et al., 2020). The incidence of pediatric TBI varies from 47 to 280 per 100 000 children, and severe pediatric TBI, defined by an initial Glasgow Coma Scale (GCS) score of 8 or less, represents 3 to 7% of all childhood head injuries (Dewan et al., 2016). The physical, cognitive and behavioral consequences of severe pediatric TBI have a long-term impact on the child's functioning, participation, academic achievement and quality of life (Anderson et al., 2009; Câmara-Costa, Francillette, et al., 2020b; Ewing-Cobbs et al., 2006; Neumane et al., 2021).

In adults with ABI, independence is the main goal of rehabilitation. The burden on caregivers is strongly linked to the degree of dependence of the patient, and most often, parents and other family members become the main caregivers (Bayen et al., 2016). In typically developing children, the degree of independence reported by the parents depends on the child's age, individual non-pathological characteristics, and cultural, socio-demographic and family related factors. In brain-injured children, additional needs related to delayed autonomy acquisition due to chronic neurological impairments and/or to clinical care needs might emerge (Slomine, 2006).

Teams from Australia developed and validated the Care And Needs Scale (CANS) for adults with TBI (Soo et al., 2007; Soo, Tate, Aird, et al., 2010; Tate, 2004), and subsequently developed the Pediatric Care and Needs Scales (PCANS) for children with ABI, aged 5-7, 8-11, 12-14, and 15 years, respectively) (Soo et al., 2008; Soo, Tate, Anderson, et al., 2010). The development of these scales, to be completed by the caregivers during a semi-structured interview, followed the domains of activity and participation proposed by the International

Classification of Functioning, Disability and Health (ICF) (WHO, 2001) and its Youth version (WHO, 2007). Their aim is to assess accurately the type and amount of assistance needed, in order to improve intervention strategies.

The main purposes of the present study were twofold: (1) to investigate the level of care and needs assessed with the CANS and the PCANS in children and young adults who experienced childhood severe TBI 7-years post-injury in comparison with a matched control group; and (2) to specify the factors (socio-demographic, injury-related, and concurrent outcome measures) associated with parental reports of high levels of care and needs.

We formulated the following hypotheses: 1) the level of care and needs would be higher in the TBI group 7-years post-injury compared with the control group; 2) higher levels of care and needs 7-years after severe TBI would be associated with younger age at injury and higher TBI severity, typically associated with more severe and diffuse brain lesions. For this second hypothesis, we also estimated that increased levels of care and needs would be associated with a number of objective and questionnaire-based outcomes assessed concurrently (such as overall level of disability, lower intellectual ability, everyday life executive functioning deficits, behavioral problems), and with higher parent-reported burden, based on the comprehensive literature review of Chevignard and colleagues (2020).

Materials and Methods

Participants

TBI group

Children aged 0 to 15 years, consecutively admitted within 6 hours following severe accidental TBI to the pediatric neurosurgical reference intensive care unit (Necker-Enfants-Malades Hospital, Paris, France) between January 2005 and December 2008, whose parents provided informed written consent, were included in the study. Severe TBI was defined as a GCS score ≤ 8 , and/or an Injury Severity Score (ISS) >16 . Causes of TBI included motor

vehicle accidents and falls. Exclusion criteria were no vital signs at admission, non-accidental head injury (because of different pathophysiology of injury, lack of precise time of injury, secondary anoxic brain lesions due to increased delay to adequate care, and well-known more severe outcomes [Chevignard et al., 2020]), and previous history of diagnosed neurological, psychiatric or learning disorders (to avoid confounding factors explaining subsequent deficits).

Eighty-one children were included at the acute stage of TBI. Sixteen children died in the initial phase. Follow-up of the 65 survivors included medical and comprehensive neuropsychological assessments at 3-, 12-, 24-months, and 7-years post-injury (for more detailed description of the TGE cohort, see (Câmara-Costa, Francillette, et al., 2020a, 2020b; Câmara-Costa, Opatowski, et al., 2020; Câmara-Costa et al., 2021; Le Fur et al., 2020; Neumane et al., 2021; Viot et al., 2019). At 7-years post injury, 26 of the 65 survivors were lost to follow up or did not wish to participate, resulting in 39 participants (age 7-22 years) for the present study. These participants did not differ significantly from those lost to follow-up for any of the demographic and environmental variables, initial TBI severity scores, and outcome measures at 3-, 12- or 24-months post-injury (all $p > 0.05$, see Câmara-Costa, Francillette, et al., 2020a, 2020b; Câmara-Costa, Opatowski, et al., 2020; Câmara-Costa et al., 2021; Le Fur et al., 2020; Neumane et al., 2021).

Control group

For the 7-year follow-up phase of the study, we recruited a control group of typically developing participants from local schools or via general medical practices. We closely matched controls to patients according to age, sex and parental education level. Exclusion criteria were the same as for the TBI group, in addition to a history of TBI (these elements were collected from parents/participants interviews before inclusion in the study). At 7-years

post injury, the recruitment allowed the inclusion of 38 controls, from which 34 had available data on the CANS ($n=18$) or the PCANS ($n=16$).

Measures

Socio-demographic characteristics and pre-injury education

We collected data on the participant's age, sex, parental education level (*low*: neither of the parents had a secondary school diploma or *medium-high*: at least one of the parents had a secondary school diploma), family situation (child living with both biological parents or not), and pre-injury education status (*regular education* or *aided/delayed*).

Initial injury severity

We used the Glasgow Coma Scale (GCS) (Teasdale & Jennett, 1974), the Pediatric Trauma Score (PTS) (Tepas et al., 1987), and the Injury Severity Score (ISS) (Baker et al., 1974). We also recorded length of coma (in days).

Outcome measures collected 7-years post injury

Primary outcome measures:

(1) *Care and Needs Scales*: We used French translations (with the authors' permission) of the Care and Needs Scale (CANS) (Tate, 2004) for participants aged 16 years and above, and the Pediatric Care and Needs Scale (PCANS) for younger participants (Soo et al., 2008). The *Care and Needs Scale* is an 8-level categorical scale designed to measure the level of support needs for people who are 16 years of age and older with TBI. It was constructed in accordance with the domains from the activities/participation components of the ICF (WHO, 2001). The CANS comprises two inter-related sections. The first section corresponds to a 24-item Needs Checklist covering the type of care and support need. This ranges from very basic vital medical care needs (e.g., tracheotomy, feeding) to complex elaborated needs related to instrumental activities of daily living and participation in society. The checklist items are classified into a hierarchy of five groups

(A to E) representing decreasing levels of support needs. The second section comprehends eight support levels assessing the length of time that the subject can be left alone. These levels range from a minimum score of “0”: “can live in the community, totally independently; does not need contact” to a maximum score of “7”: “cannot be left alone; needs nursing care, assistance and/or surveillance 24 hours per day”. Previous research has indicated that the CANS provides a reliable and valid measure to assess support needs of people with traumatic brain injury (Soo et al., 2007; Soo, Tate, Aird, et al., 2010).

The *Pediatric Care and Need Scale* (PCANS) is a 97-item scale, plus 8 items assessing high level needs (*e.g.*, tracheotomy management, feeding), designed to provide a measure of the intensity and extent of physical assistance and supervision for children and adolescents aged 5 to 15 years with ABI. We used age-appropriate PCANS versions for the age groups of 5-7 years, 8-11 years, 12-14 years, and 15 years. In any given version, each item is classified into three categories: “Independence is not expected” (NE) (*e.g.*, shaving, preparing a hot meal and cooking, at 5 to 7 years); “Emerging skills” (EM) (*e.g.*, washing self in bath/shower, making own bed, at 5 to 7 years); or “Independence is expected” (IND) (*e.g.*, using cups, continence: keeping dry during day, at 5 to 7 years). In the 5-7 years version, 17 items are classified “independence expected”, 20 “independence not expected” and 60 “emerging skills”; whereas in the 15 years version, no item is classified “independence not expected”, 34 are “emerging skills”, and 63 “independence expected”. The 97 items cover 13 domains: high level needs (*e.g.* tracheotomy, feeding), personal hygiene, bathing/dressing, food preparation activities, shopping, home living, health-safety-medication use, money management, everyday devices, transport and outdoor surfaces, interpersonal relationships, leisure-recreation-play, and school. For each item (excluding items classified “independence not expected”) a three-level score is

used (“0” = none, “1” = some, and “2” = a lot) for the need for physical assistance on one hand (except for items of the domain interpersonal relationships), and for the need for supervision on the other. Three summary scores (range 0 “no supports” to 2 “a lot of supports”) are proposed for physical assistance, supervision and overall level of support (physical assistance + supervision). Previous works have validated this instrument for the assessment of support needs following childhood acquired brain injury (Soo et al., 2008), and presented normative data by year of age for a sample of 300 Australian children from different cultural backgrounds (Soo, Tate, Anderson, et al., 2010).

Secondary concurrent outcome measures:

- (2) *Overall level of disability* was measured using the adult and pediatric versions of the Glasgow Outcome Scale – Extended, GOS-E (Wilson et al., 1998) and GOS-E Pediatric version (Beers et al., 2012). The pediatric scale ranks overall levels of disability into eight categories: (from “1” = Upper Good Recovery to “8” = Death. The adult GOS-E scale uses the reverse rating (Death = 1; Upper Good Recovery = 8). The adult scores were reversed to allow combined analysis of disability level in the TBI group.
- (3) *Presence of motor deficits*, collected through neurological examination, was rated as the absence or presence motor deficit, and/or signs of cerebellar dysfunction.
- (4) *Ongoing education* was classified in two categories: *mainstream education* (patients enrolled in general education classrooms, independently from the presence of a support and/or repeat year), and *special education*.
- (5) *Intellectual ability* was measured using age-appropriate French versions of the Wechsler scales, namely the Wechsler Intelligence Scale for Children-IV (WISC-IV) (Wechsler, 2005) and the Wechsler Adult Intelligence Scale-IV (WAIS-IV) (Wechsler, 2008).
- (6) *Executive Functioning* was assessed using parent-reported versions of the French adaptation and standardization of the Behavior Rating Inventory of Executive Function

(BRIEF) for children/young people aged up to 17 years (Gioia et al., 2014), and self- and proxy-reported versions of the Adult-BRIEF questionnaire for participants aged 18 years or above (Roth et al., 2015). Mean (SD) BRIEF *T*-Scores are 50 (10), with higher scores indicate worse executive functioning.

- (7) *Behavior* was measured using age-appropriate versions of parent-report forms of the Child or Adult Behavior Checklist (CBCL, ABCL, ages 6 to 18 years) and/or self-report forms of the Youth or Adult Self Report Checklist (YSR, ASR, from 11 years) (Achenbach & Rescorla, 2001, 2003). Mean (SD) C/ABCL or Y/ASR *T*-Scores are 50 (10), with higher scores indicating worse behavior problems.
- (8) *Participation* was assessed using self- (from 11 years) and parent-reports of the Child and Adolescent scale of Participation (CASP) (Bedell, 2004, 2009). Higher scores indicate better participation.
- (9) *Health-related Quality of life* (HRQoL) was assessed using age-appropriate French-validated versions of self- and parent-reports of the Pediatric Quality of Life Inventory (PedsQL) for children (ages 2-18 years) (Varni, Seid, & Rode, 1999), and young adults (ages 18-25 years) (Varni & Limbers, 2009). Lower scores indicate worse HRQoL.
- (10) *Fatigue* was evaluated using the self- and parent-report forms of the Multidimensional Fatigue Scale (MFS) for children (ages 2-18 years) (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002) and young adults (ages 18-25 years) (Varni & Limbers, 2008). Lower scores indicate worse levels of fatigue.
- (11) *Family functioning* was assessed using the 12-item short form of the French version of the Family Assessment device (FAD) (Speranza et al., 2012). Higher scores indicate worse family functioning reported by the caregivers.
- (12) *Caregivers' burden* was measured using the Zarit Burden Inventory (ZBI) (Zarit et al., 1980), which assesses self-reported burden through 22 questions rated on a 5-point scale

each (from 0 = no burden to overburdened = 4). Clinical cut-off scores enable to grade burden severity as mild (total score range 0-20), mild to moderate (21-40), moderate to severe (41-60), and severe (61-88).

Procedure

The TGE study initiated in the Paris-5 University Hospital Necker-Enfants-Malades. Follow-up at the different phases of the study occurred in the Rehabilitation Department for Children with Acquired Neurological Injury at Saint Maurice Hospitals. The *Comité de Protection de Personnes d'Île-de-France VI* (CPP IDF-VI) ethics committee approved the present study. At the 7-year follow-up, patients/parents were contacted by mail and invited to participate in the study. If they agreed, assessment was organized after they had provided their informed written consent (and the children had provided oral consent). Patients underwent a comprehensive neuropsychological assessment and answered the self-report questionnaires with a neuropsychologist, while parents answered the parent-report questionnaires. The neuropsychologist also rated the GOS-E and GOS-E Peds, as well as the CANS and PCANS scores, during a semi-structured interview with parents. A 1-hour medical clinic also took place with a senior Physical Medicine and Rehabilitation consultant, who performed the comprehensive neurological examination, recorded ongoing treatments, rehabilitation and follow-up, type of ongoing education, and collected the caregiver questionnaires. For the purposes of the present study, we recorded in the neurological exam the presence (versus absence) of motor deficit/hemiparesis, and presence (versus absence) of signs of cerebellar dysfunction (ataxia and/or coordination disorders) (Viot et al., 2019; Neumane et al., 2021).

Data analysis

The statistical procedures included non-parametric (Wilcoxon) tests and chi-square or Fisher-exact tests to compare scores and proportions between the TBI and the control groups. The distribution of the CANS and PCANS scores in the control group allowed a division of the TBI group into two subgroups: a low-needs subgroup, with CANS/PCANS scores within

the range of the controls, and a high-needs group with scores outside the range of scores obtained by the control group.

We used Spearman correlations to examine the associations of the total PCANS and CANS scores with initial severity factors and the 7-years post-injury concurrent outcomes. The statistical significance level was set at 0.05 and we performed Benjamini-Hochberg procedures with a false discovery rate (FDR) set at 10% to control for multiple comparisons (Benjamini & Hochberg, 1995). For each Benjamini-Hochberg procedure, we included and ranked all the *p*-values observed in the non-parametric analyses.

Results

Description of the TBI group and comparisons with controls

Table 1 summarizes socio-demographic variables, initial TBI characteristics and markers of severity, as well as global outcomes 7-years post injury of the 39 participants. Seven-year post-injury, 54% presented “good recovery” and 21% “severe disability according to the GOS-E, 20% had motor deficits, and 23% were attending special education services. Mean FSIQ was about one standard deviation below expected value, with high variability (range 40-129). Means of questionnaire-based scores assessing executive function, behavior, quality of life, participation, fatigue, and family functioning were highly variable, and significantly different from those of the control group. The TBI group showed higher levels of executive deficits (especially in parental report), of behavioral difficulties (self- and parent-report), lower levels of participation (parental report), poorer quality of life (especially in self-report), and higher levels of fatigue (self-and parent-report).

Insert Table 1 around here

Correlations between questionnaires completed by the same informant

As seen in Table 2, correlations between executive function, behavior, quality of life, participation and fatigue, assessed with questionnaires completed by the same person (i.e. patient or parent), were generally significant and often strong: self-reports *Spearman Rho*

(absolute values) from 0.32 (behavior problems and participation) to 0.86 (executive functions and behavior problems); parent-reports from 0.53 (participation and quality of life) to 0.86 (executive functions and behavioral problems). Correlations between informants assessing the same domain ranged from 0.51 (executive function) to 0.69 (behavior).

Insert Table 2 around here

CANS and PCANS results: Care and Needs 7-years post-injury

CANS: We used this scale in 18 participants with TBI and 18 controls aged ≥ 16 years. Figure 1a shows that the dominant level (15/18) in the control groups was “1”, which corresponds to “can live alone, but needs intermittent, less than weekly, contact for occupational activities, interpersonal relationships, living skills or emotional support”. The remaining three participants of the control group obtained level “0”, which corresponds to “totally independent, does not need contact”. In the TBI group, 6 participants obtained level “0” or “1”, whereas the majority (11/18) obtained a level between “2” (“can be left alone for almost all week, needs contact”) and “4” (“can be left alone for part of the day and overnight, needs a person each day for up to 11 hours for assistance”). One participant fell within level “7” (“cannot be left alone, needs nursing care, assistance and/or surveillance 24 hours per day). We defined two TBI subgroups based on the scores in the control group: a group of low-level of needs, which included the six participants who obtained scores similar to the controls (*i.e.* “0 or “1”), and a group of high-level needs, which included the 12 participants obtaining scores higher than the controls (*i.e.* > 1).

PCANS: We used this scale with 21 TBI participants and 15 controls aged 15 years or less. Figure 1b shows the distribution of the total score in the TBI and the control groups. Seven participants in the TBI group obtained scores higher than the highest mean score observed in the control group (*i.e.* $M=0.40$). We defined two TBI subgroups, as for the *CANS*: a subgroup of high-level needs, which includes the seven participants with scores

higher than all the controls, and a low-level needs subgroup, which includes the remaining 14 TBI participants. The proportion of “high-needs” according to the CANS (66.6%) was significantly higher than the proportion of “high-needs” according to the PCANS (33.3%, $p=0.04$, Chi-square test).

Combining the results of the CANS and the PCANS, the “high-needs” subgroup had 19 participants (12+7), and the “low-needs” subgroup 20 participants (6+14). Among the 19 TBI participants of the “high-needs” subgroup, four (one assessed with the CANS and three assessed with the PCANS) obtained very high care-and-needs scores (Figure 1a and 1b). All four presented severe disability according to the GOSE, attended special education institutions, and three of them presented clinically significant motor deficits.

Insert Figure 1 around here

Table 3 shows the overall and the domain scores obtained with the PCANS in the TBI and in the control groups. Total scores of “physical assistance”, “supervision” and “overall” did not differ significantly between groups. Comparisons by domain showed two “physical assistance” scores (bathing/dressing and health safety and medication use $p = 0.02$) and three “supervision” scores (health and medication use, interpersonal relationships, and school, $p < 0.01$) clearly higher in the TBI than the control group. Inspection of the individual total scores of the PCANS in the control group showed very strong variability (from 0 to 57), without a clear age effect (see supplemental materials, Table s1).

As for the CANS, the total score was significantly higher in group of participants who underwent severe TBI compared to the control group ($p = 0.004$).

Table 3 around here

Correlations of the PCANS and CANS with injury severity and 7-years post-injury outcomes

As indicated in Table 4, the injury severity score and length of coma correlated significantly with the CANS total score, but moderately (albeit not significantly) with the

PCANS total score. On the contrary, overall disability 7-years post-injury was significantly correlated with the PCANS score, but not significantly with the CANS score.

The CANS evidenced significantly strong correlations (*Spearman Rho* > 0.80) with parental questionnaire-based measures pertaining to executive function, behavior problems, participation, and caregiver burden. The correlations were much lower and not significant (except parent-report of participation) with the PCANS.

Insert Table 4 around here

Discussion

This prospective longitudinal study shows that long-term outcome 7-years after severe childhood TBI is extremely variable: “good recovery” (GOS-E/GOS-E Peds) was observed in about half of the cases, but about one fifth of the group presented “severe disability”; full scale IQ varied from 40 to 129; most children attended mainstream schools, but about one fourth needed special education services; motor deficits were present in 26% of the cases. Presence of executive deficits, high levels of fatigue, poor quality of life and participation, according to self- and parent-reports, was also highly variable (these findings have been described in detail in previous reports (Câmara-Costa, Francillette, et al., 2020a, 2020b; Câmara-Costa, Opatowski, et al., 2020; Le Fur et al., 2020).

The present report focuses on the levels of care and needs 7-years post-injury, in comparison with a group of matched controls. One third of the 39 participants who sustained severe childhood TBI had reached adult age. Two thirds of the TBI group aged ≥ 16 years, and one third of the younger patients (<16 years) required significantly higher needs than the matched controls. Participants with high needs had sustained significantly more severe injury and presented a range of indicators of more severe disability (higher proportion of special education services, higher levels of cognitive and behavioral difficulties and fatigue and lower levels of participation). Further, the subjective burden reported by the parents correlated

strongly with the levels of care and needs, especially in the older participants. On the other hand, other important measures of outcome, such as overall disability (assessed by the GOS), intellectual ability and the presence of motor deficits, correlated poorly or moderately with the reported level of care and needs.

The present findings also highlight the difficulty to assess “pathological” levels of care and needs in children based exclusively on parental reports. Given the large variability of such parental reports in typically developing children, especially at younger ages, it becomes particularly challenging to determine which children might present clinically significant levels of care and needs, particularly following severe TBI, when compared to the levels that are normally expected according to their developmental age.

The CANS is a simple 8-level measure of the time the person (aged 16 years and older) can be left alone without assistance. This time is reduced (level “7” to “4”) in case of positive answers at “high needs” items (*e.g.* major mobility, communication, feeding or behavioral problems; tracheotomy), and high (level “4” to “1”) in case of need of assistance in more complex everyday activities only. Typical older adolescents and adults obtained scores of “0” or “1”, and it was easy to define atypical/abnormal “dependence” (or a high-needs group) based on scores higher than “1”. The difference between the TBI group and the control group was clearly significant. These results confirm the pertinence of using the CANS as an assessment measure of care and needs in adolescents and young adults, as reported in previous research pertaining to its reliability (Soo et al., 2007; Soo, Tate, Aird, et al., 2010).

The situation was different with the PCANS, which, given the way it was constructed to fit various age groups and developmental and individual variability, contains a list of activities requiring - or not - physical assistance and/or supervision. PCANS does not propose a clear hierarchy of needs, as does the CANS: “high needs” items have the same weight as the need for supervision for activities, such as bathing, shopping, money management, or getting

to school on time. The results obtained in the control group suggest that the amount of parent-reported supervision for such everyday activities might vary greatly in typically developing children. For example, in one case, a 7-year old was reported to be almost completely independent, but in another case, a 13-year-old was indicated to need a lot of physical assistance and supervision. This “normal” variability led the PCANS to detect only children presenting very high levels of needs of care and supervision in the TBI group: a few young participants in the TBI group clearly presented a pathological amount of care and needs. Accordingly, we found that caregivers’ subjective burden correlated strongly with the CANS, while the correlation with the PCANS was only moderate.

We explored factors associated with higher needs according to the CANS and the PCANS. Overall, higher needs were associated with significantly more severe injuries (higher Injury Severity Score and longer length of coma), which is coherent with the literature evidencing an association between injury severity and long-term functional outcome (Fay et al., 2009; Neumane et al., 2021). Age at injury was not associated with the level of care and needs. Younger age at injury has often been associated with worse outcomes (Keenan et al., 2019), attributed to the lack of expected gains over time resulting from the early brain injury, leading to an increasing gap between the patients’ performance and their peers’. This observation is not, however, constant (Le Fur et al., 2020; Resch et al., 2019). In addition, the differential ability of the CANS and PCANS scales to pick up needs, given their different construction, and the high reliance of the PCANS items responses on factors related to cultural and family functioning, might have contributed to compromise the effect of age-at-injury. However, the present findings may also suggest that participants who were older at injury have not achieved the expected gains in terms of autonomy and independence. This becomes more obvious and easily measurable when full (or almost full) independence is expected as patients reach adult age, and the needs for external help become more evident. To

answer the complex question of an effect of age at injury on the level of care and needs, this construct would need to be measured after all participants have reached 16 years of age, allowing the use of the CANS.

Our results partially support our hypothesis that many of the concurrent 7-year outcomes (ongoing education, executive functions, behavior, participation, fatigue) were significantly less favorable in case of high-needs. Correlations of intellectual ability and GOSE with CANS and PCANS scores were in the expected direction, although moderate and not always significant, suggesting the implication and interaction of numerous factors in the development of independence and related care needs. On the other hand, the very strong correlations between scales completed by the same informant, (e.g. between the CANS and many other parental reports) may suggest response bias. The totality of the items of almost all questionnaires used in the present study have a positive/negative character (e.g. the absence of “difficulties” is better than their presence). Some respondents may be influenced by an overall tendency to respond positively (“no problems”, “everything seems fine”) or negatively (“difficulties seem to be worse”), which would increase correlations between questionnaires.

It is noteworthy the lack of association between family factors (parental education, family functioning) and the level of care and needs 7-years post-injury, considering the existing evidence describing the family correlates associated with cognitive, behavioral and educational outcomes following severe TBI (Petranovich et al., 2020). We have previously observed in the TGE cohort that some cognitive outcomes were associated with parental education (e.g. executive functions at 3-, 12- and 24-months post-injury [Krasny-Pacini et al., 2017], but not at 7-years post-injury [Le Fur et al., 2020]), while others were not (e.g. memory was marginally associated at 3, 12- and 24-months [Viot et al., 2019], but not at 7-years [Câmara-Costa et al., 2021]). In addition, none of those cognitive outcomes were associated with family functioning (assessed with the short French version of the FAD),

although we did observe an association between behavioral outcomes (measured with the Achenbach checklist [C/ABCL or Y/ASR]) and family functioning (Tokpo et al., 2022). A plausible explanation for this lack of association is that in this specific group of children who had sustained severe TBI, the 7-year outcomes were collected when one third of the cohort had reached adult age. We hypothesize that, at this time point, other environmental factors might have come to play a more preponderant role on children's development, and contributed to hinder the effects of parental education and family functioning. Our measures aimed at assessing family background were probably not sufficient to capture additional important environmental factors influencing children's outcomes 7-years post-injury, such as parenting style, or the presence of interventions, rehabilitation, and school adaptations. Further, despite scientific evidence regarding the influence of parental education and family functioning on cognitive, behavioral and academic outcomes, (Petranovich et al., 2020), it is less clear how these factors could be associated with parental perceptions of their child's level of care and needs. Indeed, children who need assistance to get dressed, to do their homework, to cross a street or to go shopping, probably do so regardless of their parent's education and their family functioning. On the other hand, parents associate clearly their perception of their child's level of care and needs to their own sense of subjective burden (Aitken et al., 2009).

This study has a number of limitations, including a rate of 40% of participants lost to follow-up at the 7-year follow-up, which is common in longitudinal cohorts. However, the study sample was representative of the initial cohort. Further, the study did not allow recording and measuring the exact amount of rehabilitation received by each child, and the effect this could have on their needs several years down the track. We recorded the type of weekly rehabilitation sessions received at each time point (e.g., physiotherapy, occupational therapy, speech and language therapy, psychological support), as well as the other adaptations, such as school adaptations or receipt of special education, but it was not possible

to measure the goals, content, and exact amount of each type of intervention. Thus, it appeared that those patients who received the highest levels of rehabilitation were those who were the most in need of such interventions, because of their numerous impairments.

In conclusion, a large proportion of children and young adults still suffer a range of deficits and require elevated levels of care and needs, 7-years post-severe TBI. The present study was the first to use the French version of the CANS and PCANS in a TBI population followed prospectively 7-years post-injury. The present findings suggest that the CANS provides a simple and useful measure of functional independence, based on the time an adult patient (>16 years) can be left alone, which is strongly linked to caregiver's burden. The findings are less in favor of the usefulness of the PCANS, given the very high variability of parental reports of care and needs in typically developing participants.

The clinical implications of the present study are noteworthy. Obtaining information about the levels of required care and needs of patients who sustained significant childhood brain injury is important, as it relates to a number of concurrent outcomes, but not all of them, and it is strongly associated to parental reports of burden. Given the importance of family functioning and overall environment to improve outcomes following severe brain injury, those aspects are important to consider and to address during follow-up. It is however difficult to assess mild-to-moderate deficits of functional independence/adaptive behavior with the PCANS, given the importance of non-pathological factors influencing the levels of supervision parents provide to their children in the general population (as illustrated in our control group described in supplemental Table s1). It might be useful to avoid measures of child's independence relying strongly on the "need" for verbal prompts or "indirect supervision" in child's daily activities, and to systematically adopt a hierarchy among the "needs", as the CANS does. In all cases, parental reports should be complemented by other more "objective" measures of care and needs based in particular on clinical and neuropsychological data, as well as situational information, such as the need for special

education services and rehabilitation therapies. Because the amount of care and needs relates closely to functional independence and adaptive behavior, further studies should clarify the merits of the different instruments proposed for the assessment of these domains in children with ABI. Ultimately, these instruments should allow the development of tailored interventions targeting the domains demanding higher levels of care, needs and supervision following severe TBI.

Declaration of interest

The authors report there are no competing interests to declare.

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Table 1. Descriptive statistics and group comparisons of sociodemographic characteristics, pre- and post-injury education and 7-year injury outcomes between participants with severe traumatic brain injury and matched controls

	Severe TBI <i>n</i> = 39						Controls <i>n</i> = 34						<i>p</i> [†]		
	N	M	SD	Min	Max	<i>n</i>	%	N	M	SD	Min	Max		<i>n</i>	%
Sociodemographic characteristics															
Age at injury (years)	39	7.5	4.6	0.3	14.7			34	-	-	-	-	-	-	-
Time since injury (years)		7.8	0.8	5.9	9.3				-	-	-	-	-	-	-
Age at assessment (years)		15.4	4.4	7.4	22.7			15.2	4.6	7.2	22.5				.89
Sex, male						25	64						22	65	.96 ^{††}
Parental education level															
<i>Medium-high</i>						20	51						22	65	.25 ^{††}
Family situation															
<i>Recomposed or monoparental</i>						13	33						14	41	.49 ^{††}
Pre-injury education															
Assisted and/or Delayed						5	13						0	0	.03 ^{††} *
Injury severity															
Lowest initial GCS Score		5.7	1.7	3	8										
Pediatric Trauma Score		3.8	2.3	-1	9										
Injury Severity Score		27.9	9.9	4	50										
Length of coma (days)		6.7	4.9	1	22										
7-year post-injury outcomes															
Overall disability															
(GOSE/GOSE Peds)															
Good Recovery						21	54								
Moderate Disability						10	26								
Severe Disability						8	21								
Motor deficits															
Presence						10	26								
Ongoing education															
Mainstream						24	62						34	100	
Specialized						9	23						0	0	.0012 ^{††} *
No longer at school						6	15						0	0	
Intellectual ability (FSIQ)	37	86.2	17.8	40	129			34	97.9	14.5	63	124			.003 *
Executive function (BRIEF)															
GEC (Parent-report)	34	59.9	14.3	37	89			25	50.1	10.5	37	73			.005 *
GEC (Self-report)	12	61.3	10.7	46	79			11	51.9	10.5	40	69			.05 *
Behavior (C/ABCL, Y/ASR)															
Total problems (Parent-report)	33	59.3	10.4	39	78			29	50.4	8.6	25	69			.0006 *
Total problems (Self-report)	24	58.4	10.4	35	75			23	51.2	6.8	37	64			.007 *
Participation (CASP)															
Total score (Parent-report)	37	87.8	11.6	57.5	100			29	96.4	4.8	82.5	100			.0002 *
Total score (Self-report)	27	89.1	10.6	62.5	100			24	91.6	9.6	66.3	100			.39
Quality of life (PedsQL)															
Total score (Parent-report)	25	71.7	18.9	34.8	96			19	84.5	16.1	47.8	100			.0225 *
Total score (Self-report)	34	71.2	18.2	34.8	98.9			31	84.4	11.8	52.2	100			.0009 *
Fatigue (MFS)															
Total score (Parent-report)	25	67.8	20.3	31.9	100			19	87.8	11.6	58.3	100			.0002 *
Total score (Self-report)	34	61.1	18.8	27.8	94.4			31	77.8	15	41.7	97.2			.0002 *
Family functioning (FAD)	35	1.8	0.4	1	2.7			32	1.5	0.6	0	2.6			.04 *
Caregiver burden (ZBI)															
Mild (0 – 20)						20	56								
Mild to moderate (21 – 40)						9	25								
Moderate to severe (41 – 60)						7	19								

TBI: Traumatic Brain Injury; M: Mean; SD: Standard Deviation; Min: Minimum; Max: Maximum; GCS: Glasgow Coma Scale Score. GOSE/GOSE Peds: Glasgow Outcome Scale-Extended; Glasgow Outcome Scale-Extended, Pediatric version; FSIQ: Full Scale Intellectual Quotient; BRIEF: Behavior Rating Inventory of Executive Function; GEC: Global Executive Composite score; CASP: Child and Adolescent Scale of Participation; C/ABCL: Child/Adult Behavior Checklist; Y/ASR: Youth/Adult Self Report; PedsQL: Pediatric Quality of Life inventory; MFS: Multidimensional Fatigue Scale; FAD: Family Assessment Device; ZBI: Zarit Burden Interview. [†] Wilcoxon test; ^{††} Chi-square test. *Significant *p*-values after the Benjamini-Hochberg procedure for multiple comparisons.

Table 2. Spearman correlations between parent- and self-reported measures of executive function, behavior problems, participation, quality of life and fatigue

	<u>Parent-reports</u>														
	<u>Executive function</u>			<u>Behavior</u>			<u>Participation</u>			<u>Quality of life</u>			<u>Fatigue</u>		
	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>
Parent-reports															
Executive function	.	.	.	33	0.86	< 0.001	34	- 0.76	< 0.001	23	- 0.57	0.004	23	- 0.62	0.001
Behavior							33	- 0.79	< 0.001	22	- 0.58	0.004	22	- 0.55	0.008
Participation										25	0.53	0.007	25	0.63	0.001
Quality of life													25	0.83	< 0.001
	<u>Self-reports</u>														
	<u>Executive function</u>			<u>Behavior</u>			<u>Participation</u>			<u>Quality of life</u>			<u>Fatigue</u>		
	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>
Self-reports															
Executive function	.	.	.	12	0.86	0.001	12	- 0.65	0.021	12	- 0.76	0.004	12	- 0.69	0.011
Behavior							24	- 0.32	0.134	24	- 0.46	0.023	24	- 0.66	0.001
Participation										27	0.59	0.001	27	0.48	0.011
Quality of life													34	0.78	< 0.001
	<u>Parent-reports</u>														
	<u>Executive function</u>			<u>Behavior</u>			<u>Participation</u>			<u>Quality of life</u>			<u>Fatigue</u>		
	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>
Self-reports															
Executive function	11	0.51	0.112												
Behavior				23	0.69	0.001									
Participation							27	0.66	0.001						
Quality of life										21	0.56	0.009			
Fatigue													21	0.65	0.001

All *p*-values were significant after the Benjamini-Hochberg procedure for multiple comparisons.

Table 3. Group comparisons between participants with severe traumatic brain injury and controls according to the items of the Pediatric Care and Needs Scale and the score of the Care and Needs Scale

	Severe TBI					Controls					ES	p ^{††}
	N	M [†]	SD	Min	Max	N	M [†]	SD	Min	Max		
PCANS [Age at follow-up (years)]	21	11.8	2.4	7.4	16.3	16	10.9	2.1	7.2	15.4		0.28
Physical Assistance												
Personal hygiene		0.05	0.09	0	0.33	0	0	0	0	0	0.79	0.05
Bathing/dressing		0.25	0.47	0	1.43	0	0	0	0	0	0.75	0.02 *
Food preparation		0.34	0.42	0	1.57	0.15	0.17	0	0.63	0.59	0.20	
Shopping		0.78	0.74	0	2	0.48	0.65	0	2	0.43	0.26	
Home activities		0.33	0.68	0	2	0.17	0.37	0	1.17	0.29	0.51	
Health safety and medication use		0.27	0.41	0	1.2	0.01	0.05	0	0.20	0.89	0.02 *	
Money management		0.86	0.76	0	2	0.72	0.67	0	1.75	0.20	0.53	
Everyday devices		0.19	0.47	0	1.75	0.02	0.06	0	0.25	0.51	0.25	
Transport and outdoor surfaces		0.17	0.27	0	1	0.03	0.09	0	0.33	0.70	0.04	
Interpersonal relationship						Not scored						
Leisure recreation and play		0.29	0.40	0	1.50	0.15	0.12	0	0.25	0.47	0.68	
School		0.31	0.48	0	1.90	0.10	0.09	0	0.31	0.61	0.35	
Supervision												
Personal hygiene		0.18	0.34	0	1	0.03	0.13	0	0.50	0.58	0.15	
Bathing dressing		0.32	0.62	0	2	0.05	0.10	0	0.29	0.61	0.22	
Food preparation		0.35	0.34	0	1.13	0.21	0.16	0	0.63	0.53	0.45	
Shopping		0.92	0.71	0	2	0.60	0.60	0	2	0.49	0.23	
Home activities		0.64	0.71	0	2	0.45	0.46	0	1.33	0.32	0.52	
Health safety and medication use		0.37	0.34	0	1	0.07	0.14	0	0.50	1.15	0.002 *	
Money management		1.07	0.67	0	2	0.88	0.67	0	1.70	0.28	0.53	
Everyday devices		0.21	0.47	0	1.75	0.05	0.14	0	0.50	0.46	0.34	
Transport and outdoor surfaces		0.27	0.32	0	1	0.07	0.12	0	0.33	0.83	0.04	
Interpersonal relationship		0.32	0.42	0	1.67	0.02	0.08	0	0.31	0.99	0.001 *	
Leisure recreation and play		0.39	0.40	0	1.50	0.17	0.10	0	0.25	0.75	0.19	
School		0.52	0.57	0	1.90	0.13	0.09	0	0.33	0.96	0.01 *	
Overall scores												
Extent Physical Assistance		0.32	0.36	0	1.07	0.15	0.14	0	0.37	0.62	0.28	
Extent Supervision support need		0.43	0.37	0.05	1.22	0.21	0.14	0	0.45	0.79	0.09	
Overall level of support		0.37	0.36	0.04	1.45	0.18	0.14	0	0.40	0.70	0.19	
CANS [Age at follow-up (years)]	18	19.5	1.81	16.8	22.7	18	19	2.1	15.2	22.5		0.45
Total score		2.22	1.73	0	7	0.83	0.92	0	1	1.00	0.004 *	

TBI: Traumatic Brain Injury; M: Mean; SD: Standard Deviation; Min: Minimum; Max: Maximum; PCANS: Pediatric Care and Needs Scale; CANS: Care and Needs Scale; ES: Effect sizes (Cohen's *d*). [†] Mean score: possible range 0 -2 for the PCANS. ^{††} Wilcoxon test.

*Significant *p*-values after the Benjamini-Hochberg procedure for multiple comparisons.

Table 4. Correlations between the Pediatric Care and Needs Scale (PCANS) and the Care and Needs Scale (CANS) with injury severity and 7-years-post-injury outcomes

	PCANS			CANS		
	<i>n</i>	<i>r</i>	<i>p</i>	<i>n</i>	<i>r</i>	<i>p</i>
Injury severity						
<i>Age at injury</i>	21	-0.31	0.165	18	-0.16	0.519
<i>Lowest Glasgow Coma Scale score</i>	21	0.01	0.954	18	-0.30	0.221
<i>Pediatric Trauma Score</i>	21	-0.19	0.419	18	0.06	0.799
<i>Injury Severity Score</i>	21	0.41	0.068	18	0.66	0.003 *
<i>Length of coma</i>	21	0.39	0.077	18	0.57	0.013 *
7-years post-injury outcome						
<i>Overall disability (GOSE/GOSE Peds)</i>	21	0.57	0.007 *	18	0.37	0.133
<i>Intellectual ability (FSIQ)</i>	20	-0.36	0.116	17	-0.49	0.044
Executive function (BRIEF)						
<i>GEC (Parent-report)</i>	18	0.29	0.236	16	0.83	<0.0001 *
<i>GEC (Self-report)</i>	0	-	-	12	0.54	0.071
Behavior (C/ABCL, Y/ASR)						
<i>Total problems (Parent-report)</i>	17	0.25	0.342	16	0.89	<0.0001 *
<i>Total problems (Self-report)</i>	7	0.86	0.012 *	17	0.68	0.003 *
Participation (CASP)						
<i>Total score (Parent-report)</i>	20	-0.63	0.003 *	17	-0.88	<0.0001 *
<i>Total score (Self-report)</i>	10	-0.60	0.065	17	-0.44	0.079
Quality of life (PedsQL)						
<i>Total score (Parent-report)</i>	20	-0.16	0.501	5	-0.63	0.252
<i>Total score (Self-report)</i>	17	-0.55	0.021 *	17	-0.28	0.274
Fatigue (MFS)						
<i>Total score (Parent-report)</i>	20	-0.32	0.170	5	-0.63	0.252
<i>Total score (Self-report)</i>	17	-0.54	0.025 *	17	-0.33	0.189
Family functioning (FAD)						
<i>Total score (Parent-report)</i>	20	0.02	0.929	15	0.17	0.546
Caregiver burden (ZBI)	20	0.22	0.344	16	0.87	<0.0001 *

r; Spearman Rho; GOSE/GOSE Peds: Glasgow Outcome Scale-Extended; Glasgow Outcome Scale-Extended, Pediatric version; FSIQ: Full Scale Intellectual Quotient; BRIEF: Behavior Rating Inventory of Executive Function; GEC: Global Executive Composite score; CASP: Child and Adolescent Scale of Participation; C/ABCL: Child/Adult Behavior Checklist; Y/ASR: Youth/Adult Self Report; PedsQL: Pediatric Quality of Life inventory; MFS: Multidimensional Fatigue Scale; FAD: Family Assessment Device; ZBI: Zarit Burden Interview. *Significant *p*-values after the Benjamini-Hochberg procedure for multiple comparisons.

Figure 1A.

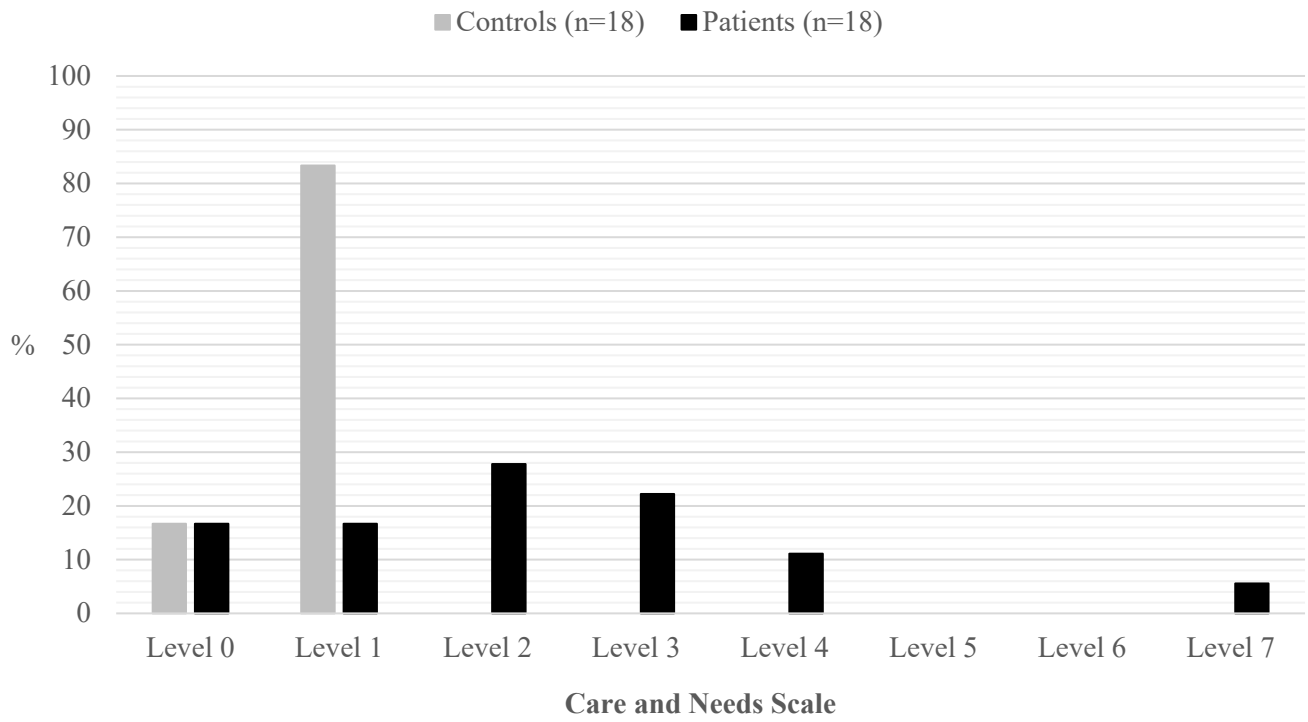


Figure 1B.

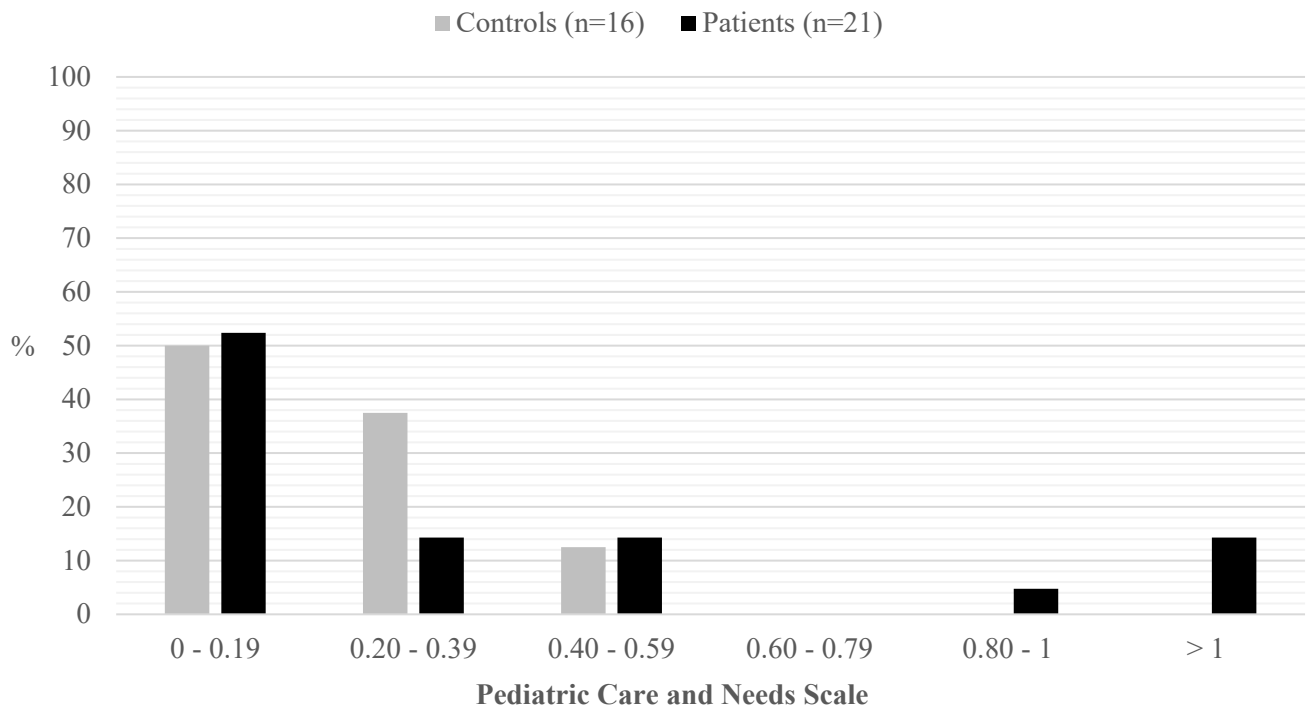


Figure captions

Figure 1A. Distribution of the overall level of needs assessed by the Care and Needs Scale (age ≥ 16 years) according to participants with severe Traumatic Brain Injury 7-years post-injury and controls. Higher scores indicate increased level of care and needs. Level 0 = Can live in the community, totally independently. Level 1 = Can live alone, but needs intermittent (*i.e.*, less than weekly) support. Level 2 = Can be left alone for almost all week. Level 3 = Can be left alone for a few days a week. Level 4 = Can be left alone for part of the day and overnight. Level 5 = Can be left alone for part of the day, but not overnight; Level 6 = Can be left alone for a few hours. Level 7 = Cannot be left alone. **1B.** Distribution of the mean scores of care and needs (“0” = independent, “1” = some support, and “2” = a lot of support) assessed by the Pediatric Care and Needs Scale (age < 16 years) in participants with severe TBI 7-years post-injury and in controls. Higher scores indicate increased level of care and needs.

Supplemental materials

Table s1. Pediatric Care and Needs Scale (PCANS) raw scores by domain for children included in the control group, according to the child's age

PCANS age form	Age (years)	Personal hygiene	Bathing/dressing	Food preparation	Shopping	Home	Health	Money	Devices	Transport	Interpersonal	Leisure	School	Total
A	7.17	0	0	1	0	0	0	0	0	0	0	0	0	1
B	8.25	0	1	7	16	10	0	9	1	2	0	4	0	50
	8.67	0	2	1	1	2	0	5	0	0	0	4	4	19
	9.25	3	2	4	5	15	1	12	3	0	0	4	8	57
	9.33	0	0	10	16	10	2	0	0	4	0	4	6	52
	10.17	0	0	4	4	3	0	10	0	0	0	4	4	29
	10.67	0	0	3	4	5	0	12	0	0	0	4	4	32
	11.17	0	0	4	6	0	0	12	0	0	0	4	4	30
	11.58	0	0	2	0	0	0	0	0	0	0	0	0	2
	11.58	0	0	2	4	4	0	12	0	0	0	4	4	30
	11.75	0	0	1	3	0	0	2	0	0	0	1	2	9
	11.75	0	0	3	3	0	0	2	0	0	4	1	2	15
C	12.33	0	0	1	4	0	4	13	0	2	0	1	4	29
	12.83	0	0	3	6	6	0	24	0	2	0	4	4	49
	13.67	0	0	0	1	4	2	12	0	1	0	2	2	24
D	15.42	0	0	0	0	0	0	0	0	0	0	0	0	0

Note. Comparison of the median score observed in the Pediatric Care and Needs Scale (PCANS) for children aged 11 years: present study median = 15 ($n=5$); Soo et al., 2010 study median = 49 ($n=30$).