

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.

Mathilde Chevignard, Hugo Câmara-Costa, Éléonore Bayen, Hanna Toure Pellen, Philippe Meyer, Georges Dellatolas

▶ To cite this version:

Mathilde Chevignard, Hugo Câmara-Costa, Éléonore Bayen, Hanna Toure Pellen, Philippe Meyer, et al.. 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. 2022 Joint Conference Abstracts Brain Injury, 2022, New York (NY), France. pp.E502-E608, 10.1097/HTR.000000000000000845 . inserm-03970792

HAL Id: inserm-03970792 https://inserm.hal.science/inserm-03970792

Submitted on 15 Mar 2023

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers. L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

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

Mathilde Chevignard^{1-3,5}; Hugo Câmara-Costa^{2,3}; Eleonore Bayen²⁻⁴; Hanna Toure Pellen⁵; Philippe Meyer⁶; Georges Dellatolas³

- ¹ Saint Maurice Hospitals, Saint Maurice, France;
- ² Sorbonne Université, CNRS, INSERM, Laboratoire d'Imagerie Biomédicale, LIB, Paris, France;
- ³ Sorbonne Université, GRC 24, Handicap Moteur Cognitif et Réadaptation HaMCRe, Paris, France;
- ⁴ Department of Physical Rehabilitation Medicine, Pitié-Salpêtrière Hospital (AP-HP), Paris, France;
- ⁵ Rehabilitation Department for Children With Acquired Brain Injury, and Outreach Team for Children and Adolescents With Acquired Brain Injury, Saint Maurice Hospitals, Saint Maurice, France;
- ⁶ Assistance Publique des Hôpitaux de Paris (APHP). Centre Université de Paris, Paris, France

Introduction

Childhood traumatic brain injury (TBI) is a major public health concern. Severe TBI often leads to significant physical, cognitive, and behavioral impairments, which have long-standing impact on the child's functioning, participation, education, and quality of life. The Care and Needs Scale (CANS) and the Pediatric Care and Needs Scales (PCANS) were developed for adults (>15 years) and children (5-15 years) to assess the type and amount of assistance needed. The purpose of this study was (1) to study the utility of the CANS and the PCANS to assess the level of care and needs in children and young adults who experienced severe childhood TBI compared with a matched control group, and (2) to specify the factors (sociodemographic, injury-related, and concurrent outcome measures) associated with parental report of high levels of care and needs.

Methods

From the 65 children (0-15 years) consecutively admitted to the Parisian regional TBI reference intensive care unit following severe TBI and included in this prospective longitudinal study, 39 patients (age at injury: M = 7.5 years, SD = 4.6; age at assessment: M = 15.3, SD = 4.4; initial Glasgow Coma Scale score: M = 5.7, SD = 1.7; length of coma: M = 6.7, SD = 4.9 days) were followed 7 years postinjury and compared with a control group matched for age, sex, and parental education level (n = 34). We used the CANS and the PCANS, completed by the caregivers during a semi structured interview, to assess the primary outcome. 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.

Results

We used the CANS in 18 participants with TBI and 18 controls aged 16 years or older, and the PCANS with 21 TBI participants and 15 controls aged younger than 16 years. In the control group, the level of care and needs was very homogeneous for the CANS, whereas PCANS scores were extremely variable. The level of care and needs was higher in the TBI group than in the control group, the difference being significant with the CANS only. We defined 2 TBI subgroups, a subgroup of high-level needs (n = 19), including participants with scores higher than all the controls, and a low-level needs subgroup, including the remaining participants (n = 20). High level of dependency was significantly associated with initial TBI severity (higher length of coma), receipt of special education, higher levels of behavioral problems, executive function deficits, fatigue, and lower levels of participation. Caregivers' burden was strongly associated with the CANS.

Discussion and Conclusion

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