

'Participate?!': Challenges for children and young adults with acquired brain injury and their parents

Summary of the first results of a research project

'Participate?!' is a large, Dutch rehabilitation multi-center follow-up study on participation, family impact, fatigue and quality of life using a consensus-based set of patient/parent-reported outcome measures (PROMs). The aim of 'Participate?!' is to better describe and understand the target group's requests for help in order to better match the treatment program. Patients (8-25y) and parents (of patients 4-25 y old) completed a set of digital questionnaires prior to the first appointment (T0) as part of routine care. In order to follow the development over time, they completed the same questionnaires again 12 and 24 months after referral.

Outcomes at referral (T0): 223 patients (4 up to 25 years old) and 245 parents (n=245) in 10 participating outpatient rehabilitation clinics¹ were included.

Participation²: 88% of the patients and 73% of the parents reported 'restricted or very restricted patient participation'. These restrictions can be classified as 'somewhat limited' to 'very limited'. A majority of the patients with a late referral to rehabilitation after ABI onset (> 6 months) and those with mild TBI reported 'very limited' participation. Overall, patients consistently reported more severe participation restrictions than parents, and young adults (18-25 y) more than children (<18y). For both patient-reported and parent-reported CASP outcomes, and in all (age) groups (< 18 years/> 18 years/total), the lowest scores were found in the domain 'community participation' which includes participation related to e.g., social play/leisure activities with friends, events, sports, doing groceries, communicating with others in the neighborhood.

Participation was found to be highly correlated with patients functions and activities (Child and Adolescent Factors Inventory, CAFI), environmental factors (Child and Adolescent Scale of Environment, CASE) and quality of life (Pediatric Quality of Life Inventory™ Generic Core Scales, PedsQL GCS-4.0).

Family impact³: parents reported a substantial impact on their families, especially on the 'worrying' scale of the PedsQL Family Impact Measure (FIM). The reported family impact among families/patients referred to a rehabilitation center is consistently higher than was found in a Dutch hospital based cohort. Furthermore, higher family impact was found to be related to type of ABI (nTBI), time between onset and referral to rehabilitation (> 6 months after onset), and the presence of premorbid learning/behavioural/health-related problems.

¹Heliomare, De Hoogstraat, Vogellanden, Revalidatie Friesland, Reade, Revant, Libra Revalidatie & Audiologie, Klimmendaal, Merem and Basalt. De Hersenstichting and Handicap.nl financially supported the project.

²using the Child and Adolescent Scale of Participation (CASP) parent and youth version, yielding a total and 4 domain scores: home & community living activities; home participation; community participation; school/work participation. Scores were categorized (full/somewhat-limited/limited/very-limited participation. **Int. J. Environ. Res. Public Health** 2021, **18** (4):1625. Doi:10.3390/ijerph18041625.

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³ Using the Pediatric Quality of Life Inventory™ Family Impact Module (PedsQL™ FIM), a parent report yielding a total score and 4 scale scores: parental Quality of Life, family functioning, worrying and communication.

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Fatigue⁴: a substantial part of the patients and (their) parents reported fatigue (general fatigue, cognitive fatigue and sleep/rest fatigue) in daily life. Compared to Dutch norm data from healthy peers they either scored in the 'moderately fatigued' (score $>+1SD$) and 'severely fatigued' (score $>+2SD$). Patients reported more fatigue than their parents on the total score and all scale scores, especially regarding cognitive fatigue.

Implications for clinical practice and research:

Participation, family impact, fatigue and quality of life are major topics patients and parents report problems on at referral to rehabilitation. These topics should be measured and monitored to enable tailor-made rehabilitation programs for children and young adults with ABI and their families. Improving participation in valued home, school, work, and community activities should be an important aim in rehabilitation. Impact of pediatric ABI on family functioning and other aspects of the child's environment (peers, school/work, leisure time) are strongly related to participation and should be addressed in comprehensive, family-centered rehabilitation programmes.

To measure the above mentioned major topics, 4 outcome measures are recommended: CASP, PedsQL FIM & Fatigue & HR QoL. By measuring and using both patients' and parents' perspectives, a broader view on overall functioning is attained, providing health care professionals the opportunity to consider these perspectives, and the possible differences, when collaborating on rehabilitation goals. Classification of scores (Participation, Fatigue, QoL) and comparing data with healthy peers looks promising for the evaluation of clinical practice as well as for future research.

⁴Using the PedsQL™ Multidimensional–Fatigue–Scale (MFS) questionnaire, both self- and parent-reported, resulting in a total scale score and 3 subscale scores: general fatigue, cognitive fatigue and sleep/rest fatigue.
To be submitted summer 2021.