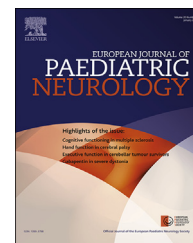




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Original article

Health-related quality of life in children and youth with acquired brain injury: Two years after injury



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ABSTRACT

Objective: To determine health-related quality of life (HRQoL) in children and youth with acquired brain injury (ABI) two years post-injury and explore associated factors.

Design: Cross-sectional.

Subjects: Children and youth ($n = 72$; aged 6–22 years) with mild to severe ABI (87% mild).

Methods: The primary outcome measures self-reported and parent-reported HRQoL were assessed with the Paediatric Quality of Life Inventory (PedsQL) and compared with age-appropriate reference values of the Dutch population. Spearman correlation coefficients (R_s) were used to explore relationships between HRQoL and sociodemographic and ABI characteristics, severity of impairments and presence of post-injury problems.

Results: Children and youth with ABI and the reference population had similar self-reported HRQoL. However, as reported by parents, children with ABI aged 6–7 years and youth aged 13–18 years had poorer HRQoL regarding psychosocial health. Children's post-injury cognitive, behavioural and social problems were moderately associated with poorer HRQoL, especially psychosocial health ($R_s \geq 0.40$). Severity nor type of injury were associated with children's HRQoL.

Conclusion: Two years post-injury, in children and youth with mild to severe ABI, reported HRQoL is similar to that in the general population, whereas parents reported less favourable outcomes. Post-injury cognitive, behavioural and social problems require ongoing attention during long-term follow-up.

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1. Introduction

Acquired brain injury (ABI) refers to any post-neonatal damage to the brain, due to an external cause (traumatic brain injury, TBI) or an internal cause (non-traumatic brain injury, NTBI) such as a brain tumour, stroke or infections such as meningitis or encephalitis.¹ In the Netherlands, the estimated yearly incidence rates in children and youth are 585/100.000 and 190/100.000, respectively for TBI and NTBI, with about 15% of ABI classified as moderate or severe.^{2,3} The consequences of NTBI are often similar to those of TBI.⁴

In children and youth, ABI may have a considerable impact on their functioning^{5–7} and health-related quality of life (HRQoL).^{8–11} However, results may vary between different samples and follow-up periods after injury. Studies including mild brain injuries and early assessment time points have found good HRQoL.¹² On the long-term, Anderson et al. (2010) suggested good HRQoL in adult survivors of mild and moderate TBI, and reduced HRQoL for survivors of severe TBI.¹³

In children and youth with ABI, several sociodemographic, physical and psychological factors have been identified as potentially affecting HRQoL, including: greater severity of ABI,^{12–16} younger age at onset,¹³ lower level of education,^{13,16} lower socioeconomic status (SES) of the parents,^{14,17} family situation (single parent family)¹⁷ and psychosocial problems.¹³ In addition, pre-injury functioning of the child,¹⁴ like poorer behavioural or academic functioning¹⁴ or pre-existing psychosocial problems^{14,17} are assumed to be important for the perceived HRQoL after brain injury.

Long-term consequences of childhood ABI (≥ 1 year post-injury), particularly for children with mild injury, have received limited attention and remain poorly understood.^{5,8} Clinical perceptions of long-term outcome may be negatively skewed, with only those children with severe and persisting problems presenting for healthcare services on the long term. Thus, there is little evidence to confirm whether long-term consequences reflect permanent deficits, or whether survivors have had the opportunity to 'catch up' with their peers. Parents and professionals working with children with ABI face the problem of adequately predicting outcome, and setting appropriate priorities for intervention and follow-up.^{16,18} Data on the long-term outcome of ABI regarding perceived HRQoL, using child-reported and parent-reported measures, may add to their knowledge.

Therefore, we performed a long-term follow-up study, two years after brain injury, in a heterogeneous sample of children and youth with ABI, taking into consideration age (6–22 years), type and severity of brain injury (mild, moderate and severe ABI).

The aim of the present study was to 1) investigate their HRQoL as compared with age-appropriate reference values of the Dutch population, and 2) determine associations between HRQoL and sociodemographic, injury-related and family-related characteristics, levels of physical functioning, and cognitive, behavioural or socioemotional problems.

Based on the literature and from clinical experience, we expected a poorer HRQoL for children with a more severe ABI, more severe neurologic impairments, younger age at onset, pre-injury or post-injury cognitive, behavioural or

socioemotional problems, and for children from families with a lower SES.

2. Materials and methods

2.1. Design and setting

This study was part of a larger cross-sectional two-year follow-up study on outcome of ABI in children and youth aged 6–22 years living in the south-western part of the Netherlands.^{2,3} A stratified sample was drawn from a multi-centre incidence cohort of 1892 patients with a diagnosis of ABI, year of onset 2008 or 2009, from large tertiary care hospitals in Rotterdam (Erasmus University Medical Centre, including Sophia Children's Hospital) and The Hague (Haga Hospital, including the Juliana Children's Hospital and Medical Centre Haaglanden).^{2,19} The sample was stratified for year of onset (2008; 2009), type of injury (TBI; NTBI), severity of injury (mild; moderate; severe) and age at onset (4–12 years; 13–20 years). Data collection took place in 2010 and 2011. Severity of TBI was based on the Glasgow Coma Scale (GCS) at time of presentation in the emergency room (mild GCS 13–15, moderate GCS 9–12, severe GCS < 9)²; severity of NTBI was classified using the modified paediatric Ranking Scale (mRS), assessed at discharge from the hospital (mild mRS 0–1, moderate mRS 2–3, severe mRS 4–5).^{2,20} Patients were first selected by age and subsequently a search in the patient files was performed using diagnosis codes and search terms related to ABI. Diagnosis codes are derived from the International Statistical Classification of Diseases and Related Health Problems (ICD-codes). The computer-based search strategy included the following terms: minor head injury, traumatic brain injury, concussion, skull/brain trauma, neurological trauma, epilepsy, brain tumour, stroke, infections (meningitis/encephalitis), post anoxia and otherwise (non-traumatic diagnosis).² Participants were excluded if they were diagnosed with trauma capitis (minor head injury without brain symptoms).

The two-year follow-up study was approved by the Medical Ethical Committee (METC) of the Erasmus University Medical Centre Rotterdam (METC-2009-440). All parents and patients, as required by law from 18 years, gave written informed consent to participate.

2.2. Participants

A representative, cross-sectional sample of children with ABI, two years after injury. Inclusion criteria for the follow-up study were: ability to understand and complete questionnaires in Dutch. Additional inclusion criteria for the study section on HRQoL were: completed self-reported and parent-reported PedsQL. For the study section on HRQoL we excluded six children aged ≥ 8 years who had an intellectual disability, since they were not capable to self-report on their HRQoL. In addition, two individuals were excluded since the study was considered to be too burdensome, e.g. due to the physical, mental or emotional effort, or in case of severe pre-injury comorbidity.

As an indicator of intellectual disability we used a severe cognitive deficit on the Paediatric Stroke Outcome Measure

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