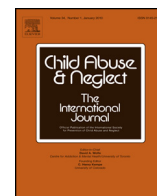




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## Child Abuse & Neglect



### Research article

# Extended follow-up of neurological, cognitive, behavioral and academic outcomes after severe abusive head trauma

Katia Lind<sup>a,b,c</sup>, Hanna Toure<sup>a,d</sup>, Dominique Brugel<sup>a,d</sup>, Philippe Meyer<sup>c,e</sup>,  
Anne Laurent-Vannier<sup>a,d</sup>, Mathilde Chevignard<sup>a,f,\*</sup>

<sup>a</sup> Rehabilitation Department for Children with Acquired Neurological Injury – Saint Maurice Hospitals, 14 rue du Val d'Osne, 94410 Saint Maurice, France

<sup>b</sup> General Pediatric Department, Hôpital Necker-Enfants-Malades, 149 rue de Sèvres, F-75015 Paris, France

<sup>c</sup> Paris Descartes University, 12 rue de l'Ecole de Médecine, F-75006 Paris, France

<sup>d</sup> Outreach Team for Children and Adolescents with Acquired Brain Injury – Saint Maurice Hospitals, 14 rue du Val d'Osne, 94410 Saint Maurice, France

<sup>e</sup> Pediatric Neurosurgery Department, Hôpital Necker-Enfants-Malades, 149 rue de Sèvres, F-75015 Paris, France

<sup>f</sup> Sorbonne Universités, UPMC Univ Paris 06, CNRS, INSERM, Laboratoire d'Imagerie Biomédicale (LIB), 75013 Paris, France

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### ABSTRACT

Studies about long-term outcome following abusive head trauma (AHT) are scarce. The aims of this study were to report long-term neurological, cognitive, behavioral and academic outcomes, ongoing treatments and/or rehabilitation, several years after AHT diagnosis, and factors associated with outcome. In this retrospective study, all patients admitted to a single rehabilitation unit following AHT between 1996 and 2005, with subsequent follow-up exceeding 3 years, were included. Medical files were reviewed and a medical interview was performed with parents on the phone when possible. The primary outcome measure was the Glasgow Outcome Scale (GOS). Forty-seven children (out of 66) met the inclusion criteria (mean age at injury 5.7 months; SD = 3.2). After a median length of follow-up of 8 years (range 3.7–12), only seven children (15%) had “good outcome” (normal life – GOS I) and 19 children (40%) presented with severe neurological impairment (GOS III and IV). Children sustained epilepsy (38%), motor deficits (45%), visual deficit (45%), sleep disorders (17%), language abnormalities (49%), attention deficits (79%) and behavioral disorders (53%). Most children (83%) had ongoing rehabilitation. Only 30% followed a normal curriculum, whereas 30% required special education services. Children with better overall outcome (GOS I and II) had significantly higher educated mothers than those with worse outcomes (GOS III and IV): graduation from high school 59% and 21% respectively ( $p = 0.006$ ). This study highlights the high rate of severe sequelae and health care needs several years post-AHT, and emphasizes the need for extended follow-up of medical, cognitive and academic outcomes.

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### Introduction

Abusive head trauma (AHT), also labeled various ways in the literature, such as *shaken baby syndrome*, *shaken impact syndrome*, *whiplash-shaking injury*, *inflicted head trauma*, *non-accidental head injury*, is an inflicted brain injury defined by an acute brain injury (often associated with subdural or subarachnoid hemorrhage) where no history or no compatible history

\* Corresponding author.

with the clinical presentation is reported. Diagnostic criteria have recently been published (Laurent-Vannier et al., 2011). AHT occurs most often under 2 years of age, at the average age of 6.2 months (Makaroff & Putnam, 2003), with a male:female ratio of around 3:2 (Fanconi & Lips, 2010; Talvik et al., 2006). The annual incidence rate is estimated at 14 to 40/100,000 infants (Fanconi & Lips, 2010; Niederkrotenthaler, Xu, Parks, & Sugarman, 2013; Talvik et al., 2006) and is certainly underestimated (Chadwick, Chin, Salerno, Landsverk, & Kitchen, 1991; Williams, 1991). Mortality rates range from 11% to 36%, with a median of 20–25% (Barlow, Thomson, Johnson, & Minns, 2005; Chevignard & Lind, 2014). Initial clinical severity, brain lesions on imaging findings and outcome are more severe than following accidental traumatic brain injury (TBI; e.g., injury following clearly accidental mechanisms, such as road traffic accidents or witnessed falls) occurring at the same age (Chevignard & Lind, 2014; Ewing-Cobbs, Prasad, Kramer, & Landry, 1999; Hymel, Makoroff, Laskey, Conaway, & Blackman, 2007; Niederkrotenthaler et al., 2013).

Studies reporting outcomes following AHT with follow-up exceeding 5 years, when children have reached school age, are scarce (Chevignard & Lind, 2014). Furthermore, of the available studies, samples are small and attrition rates are high (48–57%). Overall, the studies report high rates of visual, neurological (motor deficits, post-traumatic epilepsy, etc.), cognitive, behavioral and sleep impairments, and special education needs, with only 8–36% of children achieving a “good outcome” (see Table 1). As environmental demands increase and the child’s abilities are expected to develop (Barlow et al., 2005), a delayed presentation of sequelae is very frequent in infants whom are thought to have recovered after the acute phase. This can result in an apparent *sign-free interval* in some children with deficits emerging a few years later, leading to severe consequences on independence for daily life activities and academic achievement (Barlow et al., 2005; Bonnier, Nassogne, & Evrard, 1995; Duhaime, Christian, Moss, & Seidl, 1996; Karandikar, Coles, Jayawant, & Kemp, 2004).

Factors predicting a worse outcome include: (1) demographic and environmental factors (such as family instability, low parental socio-economic status, younger age at injury); (2) initial clinical and radiological markers of injury severity (initial severe presentation, such as lower Glasgow Coma Scale (GCS) scores, presence, depth and duration of impaired consciousness, necessity for cardio-pulmonary resuscitation or intubation, raised intra-cranial pressure, occurrence of seizures at any time, presence and extent of retinal and vitreous hemorrhages; extent and severity of brain lesions on initial or delayed imaging); and (3) post-injury factors (cranial growth deceleration, persistent adverse environmental influences, uncontrolled seizures) (Chevignard & Lind, 2014).

The aims of this study were to assess the long-term neurological, cognitive, behavioral and academic outcomes; assess the amount of treatments and rehabilitation still needed several years after AHT; and identify the factors that influence these outcomes.

## Methods

### Study Design and Procedure

The study sample for this retrospective study consisted of all infants who had been consecutively admitted to one single rehabilitation unit, dedicated to children with acquired brain injury in the Paris area (France), following a diagnosis of AHT (initially treated and diagnosed at the same regional pediatric neurosurgical unit), between January 1996 and December 2005.

For this study, the inclusion criteria was a diagnosis of AHT that had led to referral to the rehabilitation department, with subsequent follow-up by the treating clinician after the hospital phase for at least 3 years (so that the children were all at least of pre-school age at the time of the study). The diagnosis of AHT was based on (Committee on Child Abuse and Neglect, 2001): (1) the presence of an intracranial hemorrhage, including subdural hemorrhages, with a history that was inconsistent with the observed injuries and/or that changed over time; (2) with or without associated retinal hemorrhages or bones fractures; (3) exclusion of any hematological or genetic condition capable of causing spontaneous intracranial hemorrhages. Referral and admission to the rehabilitation unit usually occur when, after the acute phase, the infants are medically stable, but require specialized medical care and rehabilitation following their brain injury (Chevignard, Toure, Brugel, Poirier, & Laurent-Vannier, 2010), for hemi- or quadriplegia, truncal hypotonia, swallowing difficulties, etc. Those whose injuries are not sufficiently severe to require inpatient rehabilitation care can receive outpatient follow-up in clinics, with care (when needed) organized in the community (those children were *not* included in the study). On the other hand, a few children with very severe brain injury and neurological impairment are sometimes discharged directly from the neurosurgery department to a specialized long-term medical unit, and would not be included here either.

The study was approved by the local Research Ethics Committee. The study sample was identified using the department’s admission records. Parents were contacted by mail, and asked if they wished to participate in the study. If they agreed, a telephone medical interview was performed. If the families could not be reached by phone, follow-up data was collected from the medical files. In the context of their routine medical follow-up in the department, when needed (e.g., in order to determine rehabilitation goals, to implement school adaptations or to organize orientation towards special education), and when appropriate (e.g., patients able to perform cognitive testing), a number of patients had undergone comprehensive neuropsychological assessment at some point.

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