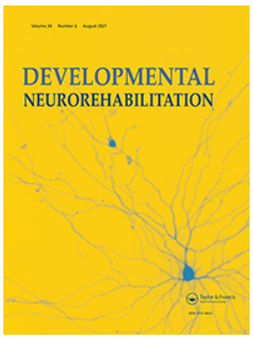

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Understanding the Five-Year Outcomes of Abusive Head Trauma in Children: A Retrospective Cohort Study

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ABSTRACT

Understanding the long-term medical and developmental outcomes for children who survive abusive head trauma (AHT) is important to ensure necessary supports and services are available. This study examined the retrospective global and specific medical and developmental outcomes of 55 children with AHT who were treated at The Children's Hospital at Westmead. Global outcomes were assessed using the Kings Outcome Scale of Childhood Head Injury (KOSCHI). Five years post-injury, one child had died and two had made a complete recovery. Forty-five children (81.8%) had a moderate or severe disability, an increase from 64.5% at acute discharge. At follow-up, the main impairments were behavioral problems (53%), vision impairment (44%), fine motor difficulties (26%), gross motor problems (26%), communication problems (24%) and 16% had seizures. A Spearman's Rank correlation revealed that only 41% of variance in KOSCHI scores five years post-injury could be accounted for KOSCHI scores at the time of acute discharge ($rs(55) = 0.638$, $p < .001$), and many children's presentation was worse at follow-up. Therefore, all children presenting with AHT need long term follow up regardless of early indications of good recovery.

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Abusive head trauma; shaken baby syndrome; global outcome tool; pediatric brain injury; five-year outcomes

Introduction

Abusive head trauma (AHT), shaken baby syndrome, non-accidental brain injury (NABI) and inflicted head trauma are all terms used to describe physical child abuse that results in brain injury.[1,2] AHT is a leading cause of infant head injury and death, particularly in those aged two years and under.[3–5] The incidence of AHT worldwide varies from 14 to 40.5 per 100,000 children in their first two years of life,[1,2,4,6,7] with mortality rates between 13% and 36%.[8] Determining that a head injury is non-accidental is difficult. In 2011, key criteria for assessing the likelihood that a brain injury was sustained through abusive mechanisms were proposed including an inconsistent, absent or incompatible report of how the injury was sustained, multifocal subdural hemorrhages and profuse retinal hemorrhages.[6,9]

Understanding the outcomes for children who sustain AHT is crucial to planning for their long-term needs. Studies have indicated generally a poor prognosis when considering both global and more specific medical and developmental outcomes.[10–12] The most prevalent-specific impairments reported approximately eight-years post injury include motor, visual, communication, and behavioral impairments and ongoing epilepsy.[1]

At a global outcomes level, there is variability in estimates of those with limited residual impairment, or a good outcome depending on the length of time post injury and the participants included. For example, 42% of 85 children who sustained an AHT and were treated by the rehabilitation team at the Children's Hospital Westmead (CHW) were deemed to have a good outcome two-years post-injury, while 34% had a moderate disability and 24% a severe disability.[13] A similarly high rate of good outcomes was found by Karandikar et al,[14] in their study of outcomes of children with AHT who sustained subdural hemorrhages at a mean post-injury time of 22 months. However, they had 5% of participants in a vegetative state, and 25% died. A Swiss study of 47 children five-years post injury established 29% had a good recovery, 31% a moderate disability and 22% a severe disability, while 8 children died.[15] A further study of 47 children who had received treatment in an intensive care unit (ICU) found only 15% experienced a good outcome at a median of eight-years post-injury, while 40% sustained a severe disability or were in a minimally responsive state.[1] However, it is unclear if the findings of worse outcomes could be attributable to children having sustained more severe injuries and hence requiring ICU treatment or having subdural hemorrhages. Further, the studies of shorter follow-up periods may inflate the proportion of children with good outcomes due to the "sign-free period," which refers to the long periods of time prior to signs of impairment secondary to AHT becoming apparent, particularly when the head injury is sustained at a very young age.[16] Indeed, there are few studies that detail outcomes five or more years post-injury and those that do have small sample sizes and large rates of children lost to follow up.[17] Understanding these longer-term outcomes is essential to

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Abbreviations **AHT**: Abusive head trauma; **CHW**: Children's Hospital at Westmead; **KOSCHI**: King's Outcome Scale of Childhood Head Injury; **ICU**: Intensive Care Unit; **CPU**: Child Protection Unit

planning for the rehabilitation services and support needs of children.

This study extends the work of Badger et al,[13] examining both global and specific medical outcomes at five years post-injury and includes all children who received follow-up care from the rehabilitation team, rather than focusing on only those who had the most severe injuries and spent time in an ICU. It also examines how outcomes change over time.

Methods

Sample

This study included children who presented to the Children's Hospital at Westmead with AHT prior to their fourth birthday between 2000 and 2015.

The Children's Hospital at Westmead (CHW) is one of the three pediatric trauma centers in New South Wales, Australia.[18] Children with AHT seen at regional hospitals in the state are referred to one of these three centers for care. At CHW all traumatic brain injury admissions are seen by the inpatient rehabilitation multidisciplinary team for initial assessment and consultation as soon after the brain injury as possible. Follow-up for review and additional interventions occurs in the rehabilitation outpatient brain injury follow-up clinics at 3, 6, 12, and 18 months after discharge and then at 3 and 5 years of age for multidisciplinary reviews. Additional reviews are planned as needed.

All children in the study were assessed by the Child Protection Unit (CPU) and considered to have an abusive head trauma. They were reviewed by the CHW rehabilitation team at four to six years post the initial injury. Only children with outcomes data at discharge from hospital *and* four to six years post-injury were included. Exclusion criteria were a previous head injury or a preexisting condition impacting neurological functioning (cerebral vascular accident or genetic condition with known neurological impacts).

Ethics approval was granted by the Sydney Children's Hospitals Network Human Research Ethics Committee (LNR/16/SCHN/236) and The University of Notre Dame Australia Human Research Ethics Committee (017163S).

Study Design and Procedure

Databases in the Rehabilitation Department, Child Protection Unit (CPU) and the hospital medical records were examined to identify participants. Medical records were examined by experienced clinicians including a Senior Pediatric Rehabilitation Specialist (fourth author) and head of the CPU at CHW to confirm a diagnosis of AHT.

Data pertaining to outcomes was extracted from each child's medical records at hospital discharge and their rehabilitation appointment closest to five years post-injury (range 4–6 years post-injury; see Appendix A) by the first author and recorded in an Excel spreadsheet.

The Kings Outcome Scale of Childhood Head Injury (KOSCHI;[19] was used to examine global outcomes). The first author, who was trained in the retrospective allocation of KOSCHI scores, used the qualitative medical data (see Table 1 for list of data reviewed) to allocate a KOSCHI score to each participant at hospital discharge and five-year follow up. This method of retrospective allocation of KOSCHI scores has been established as valid and reliable.[20] The Head of the Rehabilitation Department and Senior Pediatric Rehabilitation Specialist (fourth author) verified scores. Discrepancies were resolved through discussion and further consultation with other clinician authors.

Table 1. *Data reviewed for determining KOSCHI score*

Neurological examination
Epilepsy/medication
Vision/hearing/smell
Other medical (orthopaedic/maxillary-facial/bone health)
Return to school/Special needs education status/input
Behaviour/social reintegration
Mood/Personality changes
Communication (speech and language)
Sleep issues
Self-help skills
Headaches/dizziness/tinnitus
Psychosocial situation (parental job change/rehousing needs)
Scarring/deformity
Brain scan/EEG changes
Change in handedness

Adapted from (Crouchman et al., 2001)

Table 2. *KOSCHI category definitions*

Score	Description	Definition
1	Death	Patient did not survive injury
2	Vegetative	Breathing spontaneously, no communication or ability to respond to commands
3	Severe Disability	a) Some purposeful movement or ability to follow commands, very dependent, can communicate b) High level of dependency, but can assist with own care, fully conscious but can have post-traumatic amnesia
4	Moderate Disability	a) Mostly independent but requires supervision or help, has overt neurological problem (blind, deaf) b) Age appropriately independent but with residual learning/behaviour problems or neurological sequalae
5	Good Recovery	a) Head injury resulted in new condition that does not affect well-being or functioning b) Complete recovery with no detectable sequalae

Adapted from (Crouchman et al., 2001)

Materials

The Kings Outcome Scale of Childhood Head Injury (KOSCHI) is a five category tool, designed specifically to assess the degree of disability in *children* who have experienced a traumatic brain injury.[19] The five classification levels range from death (1), to a good outcome which may include mild disability or no functional sequalae (5; see Table 2). For those with a severe or moderate disability or good outcome (categories 3–5), there are more refined considerations of the extent of any impairment, with level B being a less severe impact than level A.

Data Analysis

Descriptive statistics (median, mean, range, standard deviation) as appropriate were calculated for each continuous

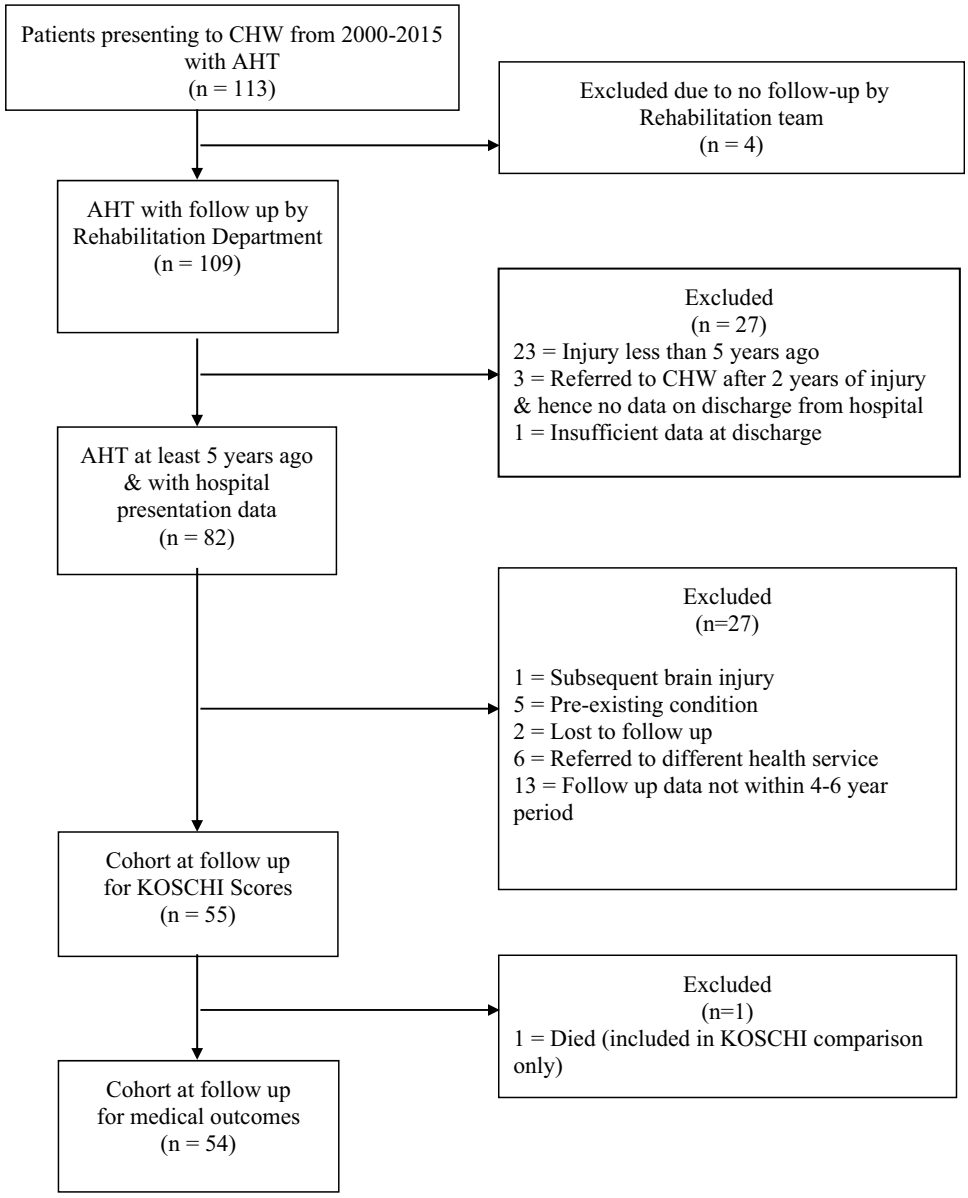

Figure 1. Participants included in the study

variable (e.g. age of injury, KOSCHI scores), with the percentage of children falling into each category calculated for outcomes assessed categorically. The change in KOSCHI from hospital discharge to follow up five-years post-injury was evaluated using the Spearman Rank correlation using the Statistical Package for Social Science (SPSS) version 25.

Results

One hundred and nine (109) children were identified as having presented to CHW with AHT between the years of 2000 and 2015. Of these, 55 met inclusion criteria including having medical record data available from their initial presentation to hospital and between four and six years post-injury (see Figure 1). One participant died post discharge; they were included in the data when comparing KOSCHI scores from discharge to follow-up, however, were excluded from the descriptive statistics of specific medical outcomes at five-years post-injury.

Participant demographics are presented in Table 3. Fifty-six percent (56%) of participants were male. The median age at presentation to CHW was 4.2 months and length of hospital stay was 18 days. Twenty-three (23; 42%) children spent time in the ICU for a median of eight days.

Global Outcomes

The overall level of disability at discharge from hospital and follow-up measured using the KOSCHI is presented in Figure 2. Participants at discharge from hospital were most commonly allocated a KOSCHI score of 5A (good recovery) (19) or 4B (moderate disability) (19). This contrasts with global outcome KOSCHI scores at five-years post-injury where the majority of participants were categorized as having a moderate disability (36; 4A = 23, 4B = 13). The number of participants with a good recovery decreased by nine participants five-years post-injury, with only two children making a complete recovery. The majority

Table 3. *Participant demographics*

Characteristic	Patients (N = 55 unless otherwise specified)
Sex (female:male)	24:31 (43.64%:56.36%)
Age at presentation [months - median (range)]	4.2 months (0.6-32.3)
Participants with time in ICU [n (%)]	23/55 (41.82%)
Median time in ICU [n=21[a]; days - median (range)]	8 days (2 -30 days)
Length of stay in hospital [n=53[b]; days - median (range)]	18 (1-159)
Time between first presentation and follow up [n=54[c]; years - median (range)]	4.96 years (4.02-6.50)
Age at follow up [n= 54[b]; years - median (range)]	5.60 years (4.42-7.67)

Note: Sample size is 55 unless otherwise specified, insufficient information was available for some participants. [a]n = 21 instead of 23 as there was no information on length of stay in ICU for 2 participants. [b]there were no dates of discharge from hospital for 2 participants. [c]one child died post hospital discharge.

Table 4. Change in KOSCHI scores over five-years (n=54)

	KOSCHI score five-years post-injury						
	Severe disability		Moderate disability		Good outcome		
KOSCHI score at hospital discharge	3A	3B	4A	4B	5A	5B	Total
Severe disability							
3A	4		1				5
3B		1		1			2
Moderate disability							
4A		3	2	4			9
4B			7	10	2		19
Good outcome							
5A			3	8	6	2	19
5B							
Total	4	4	13	23	8	2	54

Note: n = 54; 1 participant who was in a vegetative state (KOSCHI score 2) at discharge died during the five-year follow-up period (KOSCHI score 1).

of change in scores from hospital discharge to five-year post-injury occurred in the 19 children who were deemed to have a good outcome at discharge, with 58% (n = 11) presenting with a moderate disability five-years post-injury (see Table 4).

Overall, 42% (n = 23) of children had the same KOSCHI score at five-years post-injury as at discharge from hospital. Of the participants with changes in KOSCHI scores (n = 32), the majority moved one level over the five-years (e.g. 4B to 4A), with 15% improving by one level and 35% declining one level (see Figure 2).

Of the 32 children who had a change in KOSCHI score over the five-year follow-up period, there was a change in overall assessment of severity of disability (e.g. from good outcome to moderate disability, moderate disability to severe disability, or from moderate disability to good outcome) in 19 children (59.4%), with the majority of these having an increase in the severity of disability (n = 15, 79%).

Spearman's rank correlation revealed a significant moderate correlation between KOSCHI scores at discharge from hospital and five-years post-injury ($r_s(55) = 0.638$, $p < .001$). KOSCHI scores at discharge from hospital accounted for 40.7% of the variation in scores at five-years post-injury.

Specific Medical Outcomes at Five-Years Post-Injury

Participants presenting with a good outcome at five-years post-injury (KOSCHI score 5) had none of the medical or developmental impairments reviewed (n = 10, 18%). As noted, one child died between discharge and follow-up. The specific medical and developmental outcomes at five-years post-injury for the 44 children (80%) with moderate and severe disabilities (KOSCHI levels 3 or 4) are presented in Table 5. Behavioral problems (n = 29, 53%) and visual impairments (n = 24, 44%) were the most common problems at five-years post-injury; the majority of whom had a moderate disability. Functional (fine and gross motor skills) and communication impairments were most prevalent in those with a severe disability.

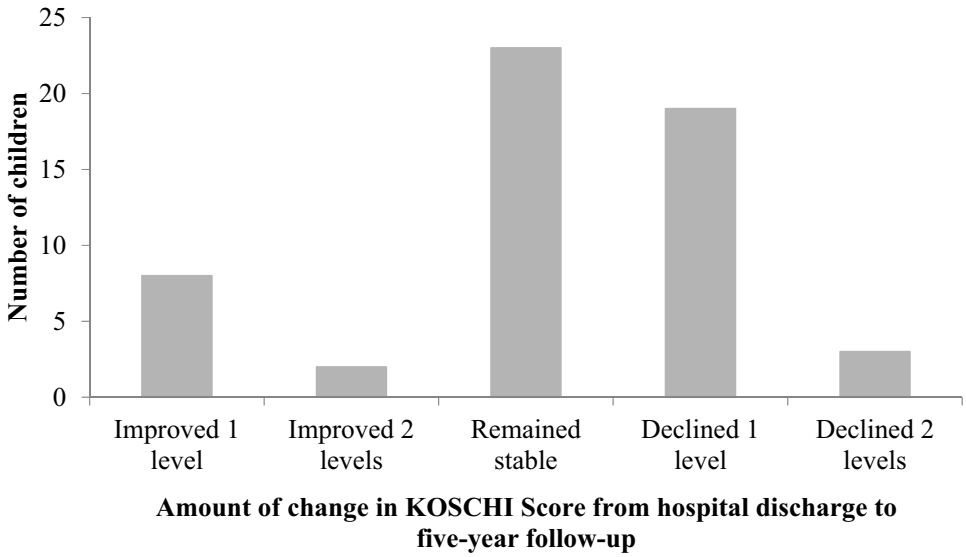

Figure 2. Change in KOSCHI scores from hospital discharge to five-year follow-up

Table 5. *Number of participants (%) with medical outcomes relative to global outcomes measured through KOSCHI*

	KOSCHI Score					
	4B 23	4A 13	3B 4	3A 4	Total (n=44[a])	Total (n=55[b])
Gastrostomy	0	0	0	1 (25%)	1 (2.27%)	1 (1.82%)
Seizures	1 (4.35%)	3 (23.08%)	2 (50%)	3 (75%)	9 (20%)	9 (16.36%)
Bone health Problems	0	1 (7.69%)	3 (75%)	3 (75%)	7 (15.91%)	7 (12.73%)
Vision Problems	5 (21.74%)	12 (92.31%)	3 (75%)	4 (100%)	24 (54.55%)	24 (43.64%)
Hearing problems	3 (13.04%)	1 (7.69%)	0	0	4 (9.09%)	4 (7.27%)
Behavioural problems	14 (60.87%)	10 (76.92%)	3 (75%)	2 (50%)	29 (65.91%)	29 (52.72%)
Sleep Problems	4 (17.39%)	2 (15.38%)	0	1 (25%)	7(15.91%)	7 (12.73%)
Gross motor function impairment	3 (13.04%)	3 (23.08%)	4 (100%)	4 (100%)	14 (31.81%)	14 (25.45%)
Fine motor function impairment	3 (26.09%)	4 (30.77%)	4 (100%)	3 (75%)	14 (31.81%)	14 (25.45%)
Communication impairment	5 (21.74%)	4 (30.77%)	0	4 (100%)	13 (29.55%)	13 (23.64%)

Notes: [a] *n = 44 represents the total number of participants with a moderate or severe disability (KOSCHI score 3 or 4).* [b] *n = 55 is the total number of participants in the study*

Discussion

This retrospective study aimed to understand the medical and global outcomes of 55 children five years after sustaining AHT and how these changed from initial discharge from hospital. At five-years post-injury, eight participants (14.55%) had a good outcome, 81% had a moderate or severe disability, and one child died. Although most participants had a moderate or severe disability at both time points, 58% of the sample demonstrated variation in their level of disability over time, with the majority presenting with an increase in the level of disability. In particular, the study highlighted that those children deemed to have a good outcome or less severe disability at discharge were more likely to have been assessed as having a have a worse outcome five years later. Indeed, the majority of children with a good outcome at hospital discharge had a moderate disability at follow-up. This is consistent with our finding that KOSCHI scores at discharge from hospital accounted for only 41% of the variance in scores five-years post-injury. This indicates the changing nature of the disability of children who have sustained AHT that may be due to a range of factors such as developmental stage at time of injury, not being able to determine outcome until a child has reached particular ages and the role of treatment, family and other environmental factors. It also indicates the need for monitoring of rehabilitation needs regardless of presentation at discharge from hospital.

The proportion of children with moderate to severe disabilities post-injury is similar to that reported by Lind et al,[1] whose study examined outcomes eight years post-injury. This differs from studies with a shorter follow-up period[13–15] where rates of good outcomes were much higher. Our study indicates that these differences are due to the changing nature of the extent of the disability, with more children actually having a poorer outcome at longer periods post-injury. This is consistent with the "sign free" period which indicates that the full impact of AHT cannot be known until children reach the age where certain developmental milestones are expected and lacking.[8,16]

There are also differences across studies in the proportion of children in a vegetative state or who died. These are most likely due to the differences in the samples, with some studies not including children whose initial brain injury was less severe.[1,14] Our study therefore builds the understanding of the outcomes across all who sustain an AHT.

While global outcome measures provide an indication of the level severity of outcome, they do not identify specific rehabilitation needs. The most prevalent specific medical and developmental problems of children in this study at five years post-injury were behavioral, vision, gross and fine motor function and communication impairments, and seizures. This is consistent with other literature.[1,8,14,17] As our sample included all children with AHT, it contributes to an understanding of the rates of these difficulties across all levels of severity of AHT.

Limitations

This study is the largest known to compare global outcome measures at two time points. In addition, there was no sample bias with all participants who received follow up from the Rehabilitation Department included in the study, not just children with the most severe presentation as has occurred in other studies. Whilst there are clear strengths of our study, there are also several limitations inherent in this retrospective study.

As with many studies, a large number of children were excluded due to not having follow-up. It is recognized that whilst long term follow up is necessary in this population, these participants are often very difficult to follow up, due to many psychosocial factors that coexist with children who sustain AHT.[8] Children who are lost to follow up are complex in many ways, including their living situation. Future studies may try to locate follow up data from other services that children attend. The results presented in this study were also only for children without preexisting or additional post-injury neurological or genetic conditions and thus the long-term impact on AHT for these children is unknown. However, these excluded children are a cohort whose rehabilitation needs are likely to be more complex.

As with all retrospective medical file reviews, there were no preset specifications around the data collected. Thus, there were variations in data recorded through individual clinician reports, and non-standardized assessment processes. However,

clinical reports were documented by senior clinicians using the most current evidence regarding AHT and developmental milestones. Prospective studies that specify assessment processes are required for more reliable data.

The limitations of global outcome measures are also noted, including that they were not designed specifically for use in infants, and that it is difficult to apply assessment of functions that are not expected to have been developed due to the child's age. However, they have been used in previous research into AHT.[1,15] Although there are some challenges with allocating KOSCHI scores retrospectively, this method has been established as valid and reliable.[20]

There are a range of factors that were not taken into consideration in this study including socioeconomic status, parental care post injury and the amount intervention the child received from any services. Outcomes were also only determined by clinical staff. Future studies may consider how additional factors influence outcomes, and how outcomes are defined by children and their carers. Despite the limitations discussed in this paper, it is able to demonstrate the five-year outcomes of children who have sustained brain injuries using global outcome measures and specific medical outcomes.

Conclusion and Future Recommendations

This study highlights the changing nature of medical and developmental outcomes of children who have sustained AHT. It informs the range of rehabilitation services and supports that children who sustain AHT require over the long term. It also indicates that regardless of presenting with a positive outcome at discharge from hospital, ongoing monitoring and review of rehabilitation needs is required at least until five-years post-injury. Further research is required to understand the trajectory of outcomes as the child continues to develop into adolescence and early adulthood to inform of ongoing rehabilitation service needs.

Disclosure Of Interest

The authors report no conflict of interest.

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Appendix A

Data extracted from medical files

Data Collected	Details
Patient demographics	Age Gender
Dates	Of presentation Suspected AHT occurred Length of hospital stay Follow up appointments
ICU	If they had time in the intensive care unit How long for
Respiratory	ETT Aspiration pneumonia Tracheostomy Breathing difficulties
Gastrointestinal	Modified barium swallow (MBS) Gastrostomy
Seizures	If they had an EEG result
Bone problems	As per radiology
Vision problems	Retinal hemorrhages Level of impairment as per ophthalmology
Hearing problems	Based on audiology reports
Behavioral problems	
Pain problems	
Sleep disturbances	
Medications	Including Colecalciferol, Ferroliquid, Ritalin (Methylphenidate), anti-epileptic durgs (Carbemazepine, Phenytoin, Phenobarbitone, Levetiracetam), Botiulum toxin, Melatonin and multivitamins),
Continence concerns	
Gross motor function concerns	
Fine motor function concerns	
Communication concerns	

Notes: Medical variables were documented based on medical records as yes, no or not recorded (NR)