



Published in final edited form as:

J Pediatr Surg. 2021 December ; 56(12): 2318–2325. doi:10.1016/j.jpedsurg.2021.02.019.

Long-term Impact of Abusive Head Trauma in Young Children: Outcomes at 5 and 11 Years Old

Jordan E Jackson, MD^{1,*}, Alana L Beres, MD, MPH¹, Christina M Theodorou, MD¹, Beatrice Ugiliweneza, PhD², Maxwell Boakye, MD², Miriam Nuño, PhD^{1,3}

¹Department of Surgery, Division of Pediatric Surgery, University of California, Davis Medical Center, Sacramento, CA.

²Department of Neurosurgery, University of Louisville, Louisville, KY.

³Department of Public Health Sciences, Division of Biostatistics, University of California Davis, Sacramento, CA.

Abstract

Background: Abusive head trauma (AHT) is a leading cause of morbidity and mortality among young children. We aimed to evaluate the long-term impact of AHT.

Methods: Using administrative claims from 2000–2018, children <3 years old with documented AHT who had follow-up through ages 5 and 11 years were identified. The primary outcome was incidence of neurodevelopmental disability and the secondary outcome was the effect of age at time of AHT on long-term outcomes.

Results: 1,165 children were identified with follow-up through age 5; 358 also had follow-up through age 11. The incidence of neurodevelopmental disability was 68.0% (792/1165) at 5 years of age and 81.6% (292/358) at 11 years of age. The incidence of disability significantly increased for the 358 children followed from 5 to 11 years old (+14.3 percentage points, $p < 0.0001$). Children <1 year old at the time of AHT were more likely to develop disabilities when compared to 2 year olds.

Conclusions: AHT is associated with significant long-term disability by age 5 and the incidence increased by age 11 years. There is an association between age at time of AHT and long-term outcomes. Efforts to improve comprehensive follow-up as children continue to age is important.

Keywords

child abuse; abusive head trauma; disability; long-term outcomes

1. INTRODUCTION

Abusive head trauma (AHT) involves injury to brain or skull, and can be inflicted by a variety of mechanisms, including vigorous shaking of the child. In the United States, AHT

*Corresponding Author: Jordan E Jackson, MD, Department of Surgery, University of California-Davis, 2335 Stockton Blvd, Room 5107, Sacramento, CA 95817, USA, Telephone: 510-289-4004, Fax: 916-734-5633, jorjack@ucdavis.edu.

is a leading cause of physical child abuse deaths in children less than 5 years of age and accounts for about one-third of all child maltreatment deaths[1]. Incidence of AHT is estimated to occur in 3–4 per 10,000 infants a year and between 5–35% of infants or children who are AHT victims die from their AHT[2–5].

Many victims of AHT suffer long-term consequences including visual impairment, developmental delays, and physical disabilities. It has been reported that as high as 72% of AHT victims have some degree of lasting neurological impairment, such as seizure disorders, intellectual disabilities, and learning disabilities[6–8]. Children who experienced AHT prior to age two were found to carry long-term health consequences by the age of five years, which included communication deficits and developmental delays in 11% and 47% of children, respectively[8]. While it is known that there are significant sequelae for children who are victims of AHT, the majority of research has focused on strategies and resources to prevent AHT. There is less research regarding the long-term adverse outcomes after AHT, especially for children beyond age five.

The aim of this study was to evaluate a large cohort of children who were victims of AHT before 3 years of age and to determine the long-term outcomes associated with AHT at age 5 and 11 years of age. We hypothesized that the long-term adverse consequences of AHT will continue to manifest beyond 5 years of age and that by age 11, most children will have developed a major disability.

2. METHODS

2.1 Data Source

The IBM MarketScan Research Database was used to identify children < 3 years old who were diagnosed with AHT. The IBM MarketScan Research Database contains both longitudinal and cross-sectional data and reflects the full continuum of care including inpatient, outpatient, and emergency department data[9]. The database includes nearly 100 health insurance plans contracted through employers, and data are available for more than 500 million claims for employees, retirees, and their dependents. Approximately six million Medicaid enrollees with neurological or neurosurgical conditions from multiple states are represented from 2000–2018 with more than 400,235 children < 3 years old with neurological or neurosurgical conditions represented in the 18-year study period. All 50 states in the U.S. are captured in the database. The presence of this longitudinal data allows review of the following: follow-up visits, which contain diagnostic codes (*International Classification of Diseases, Ninth and Tenth Revisions, Clinical Modification* [ICD-9-CM and ICD-10-CM]), procedure codes (Current Procedural Terminology 4th Edition [CPT-4]), and other variables. Data for this study received a designation of expedited review by the University of Louisville Internal Review Board (IRB# 10.0559) and the University of California, Davis Internal Review Board (IRB# 1582638).

2.2 Selection and Inclusion Criteria

The Centers for Disease Control and Prevention (CDC) defines AHT as an injury to the skull or intracranial contents of an infant or young child (<5 years of age) due to inflicted

blunt impact and/or violent shaking[10]. A precise definition of the codes utilized to identify patients with AHT can be found in Supplementary Table 1. Briefly, we utilized the recommended and operational case narrow definition for AHT as defined by the CDC which includes any of the head injury codes and the presence of an external cause of injury/abuse code. We included skull fracture as a specific sequela to provide further detail on the injuries that these children experience.

The inpatient files of the IBM MarketScan Research Database were queried to capture the records of children < 3 years old who were insured by Medicaid and diagnosed with AHT between January 1, 2000 and December 31, 2018. Two cohorts were presented in this study. The first cohort includes children with continuous enrollment data from the time of AHT diagnosis through to age 5. A second cohort includes children with continuous enrollment data through to age 11. Follow-up data were obtained from the IBM MarketScan Research Database from the time of AHT diagnoses through December 31, 2018. By including only those children with continuous enrollment data we ensured that any health-related services, hospital visits, diagnoses and procedures were captured, including documentation of the long-term consequences associated with AHT. We excluded children who were diagnosed with AHT during the study period but were lost to follow up prior to reaching the age of 5 years and therefore unable to be assessed for long-term outcomes.

Children insured by Medicaid were included in this study as children insured by Medicaid have a disproportionally higher risk of long-term disability and constitute over 90% of children with AHT captured in MarketScan[8]. With this in mind, we elected to only evaluate Medicaid insured children to remove any possible confounding bias related to insurance status and outcomes. The exclusion criteria by insurance status did not impact our study size given that an overwhelming majority of AHT cases were covered by Medicaid (>90%).

2.3 Primary and Secondary Outcome Measures

For the cohort of children with follow-up to age 5 years and the sub-cohort of those with follow-up to 11 years, we evaluated the incidence of all long-term outcomes. We documented the development of the following primary outcomes: behavioral disorders, communication deficits, developmental delays, epilepsy, learning disorders, motor deficits, and visual impairment. These were identified by ICD-9-CM and ICD-10-CM codes which can be found in Supplementary Table 2. A planned subgroup analysis was conducted to document the long-term outcomes of children who had uninterrupted follow-up through age 11 with a comparison of their long-term burden at both 5-years and 11-years. We also investigated the differences in the incidence of long-term outcomes based on the child's age at the time of AHT injury. Long-term outcomes were evaluated at each year of age from 1 to 11 years old and visualized on an incidence plot.

2.4 ICD-9-CM/ICD-10-CM-Based Injury Severity Score (ICISS)

As the MarketScan database does not report the Injury Severity Score (ISS), injury severity was calculated using the ICD-based Injury Severity Score (ICISS) algorithm[8, 11]. ICISS is calculated based on the product of survival risk ratios (SRRs) that correspond to each

incurred injury. The SSR is a point estimate of survival associated with each injury based on International Classification of Diseases (ICD-9-CM, ICD-10-CM codes). SRRs were developed using ICD-9-CM codes[12]. A crosswalk table was used to find ICD-10-CM equivalences[13]. ICSS ranges from 0–1 and a lower ICSS corresponds to more severe injuries while higher scores indicate less severe cases. For example, in a case of AHT with the presence of cerebral contusion (derived SRR=0.82) and fracture of the skull base (derived SRR=0.92), the ICSS would be the product of 0.82 and 0.92, giving an ICSS of 0.75. Children that experience more severe injuries such as retinal hemorrhage will have a much lower ICSS given that SRRs associated with the more severe injuries are much lower than those described for the aforementioned less severe injuries. ICSS is validated in pediatric trauma patients[14].

2.5 Associated Injuries with AHT

A detailed list of injuries previously described in children with AHT was captured for this study based on ICD-9-CM and ICD-10-CM diagnostic codes (Supplementary Table 3). Fractures were categorized according to location of injury: skull, trunk or spine, upper extremity, and lower extremity. Intracranial injuries such as epidural hemorrhage, subdural hemorrhage, subarachnoid hemorrhage, cerebral edema, contusion, and concussion were evaluated. Retinal hemorrhage was also recorded. These injuries were included to be able to calculate and adjust for ICSS for children as a way of determining the overall severity of abuse.

2.6 Statistical Analysis

Continuous variables are reported as the mean and standard deviation (SD) or median and interquartile range (IQR). Categorical variables are reported as frequencies and percentages. Changes in long-term outcomes between follow-up periods (5 and 11 years) were presented as percentage points. The bootstrap procedure (unrestricted random sampling), resampling patients 1000 times, was used to obtain 95% confidence intervals (CI) for changes in percent points. McNemar's test for correlated proportions was used to assess percentage point estimate differences between outcomes at 5 years old and 11 years old. Incidence rates for long-term outcomes were calculated based on age of diagnosis of the outcome. Multivariate logistic regression models were used to evaluate the effect of age at time of AHT on adverse long-term outcomes with odds ratios (OR) and 95% confidence intervals (CI) reported. All tests were 2-sided and used significance level of $p=0.05$. All analyses were conducted in SAS software, version 9.4 (SAS Institute, Cary, NC, USA).

3. RESULTS

A total of 3,240 children with Medicaid insurance were diagnosed with abusive head trauma (AHT) prior to the age of three during the study period. Among these children, 2,075 (60.0%) did not have continuous data through five years of age and therefore were excluded. The remaining 1,165 children were followed up to the age of 5 years at minimum and 358 of these children had follow-up through 11 years of age. In the 5-year-old cohort, most children were diagnosed with AHT at 1 year old (44.3%) or less than 1 year old (42.6%). The majority of this cohort were male (60.9%) and white (50.6%). The median ICSS was 0.68

[IQR 0.60–0.77], which correlates with modest severity injuries. Demographic information and associated injuries are shown in Table 1.

3.1 Long-Term Adverse Outcomes

The overall rate of long-term disability diagnosed in children that were followed up to age 5 was 68.0% (792/1165) and 81.6% (292/358) among those that were followed up to 11 years of age (Table 2). Developmental delays (45.8%), learning disorders (40.9%), and epilepsy (34.2%) were the most commonly reported long-term adverse outcomes at 5 years old. At 11 years old, developmental delays (55.0%), learning disorders (53.1%), and behavioral disorders (46.4%) were the most commonly reported. The incidence rate of any long-term adverse outcome increased with each year of age (Figure 1, Supplementary Table 4).

3.2 Long-Term Adverse Outcomes Between 5 and 11 years

We performed a subgroup analysis of those children who were followed through 11 years old. We aimed to determine if there was a change in the incidence of long-term disabilities in this cohort of children as they aged from 5 to 11 years old. To determine if the cohort with follow-up through 5 years old ($n=807$) was similar to the cohort with follow-up through 11 years old ($n=385$), we compared rates of adverse outcomes between the two cohorts at the 5 year old timepoint. At 5 years of age, there were no significant differences in the rate of developing any long-term adverse outcome between the 358 children with follow up through 11 years old and the 807 children in the cohort with evaluation up to 5 years old only (Table 2). Of note, there was a statistically significant difference between children with follow up through 11 years and children with follow up through 5 years for learning disorders ($p=0.042$), however the effect size calculation was 0.13 which correlates with a trivial difference between the two groups. This suggests that findings from analysis of long-term outcomes of the 358 children followed to 11 years of age would be applicable to the overall cohort of children with abusive head trauma. In this subgroup analysis, the overall rate of long-term disability increased 14.3 from 67.3% at 5 years to 81.6% at 11 years (95% CI 11.6–17.1). There was an increase in the rate of every individual long-term adverse outcome from 5 to 11 years of age, with the greatest rate of increase seen in behavioral disorders (24.3% at 5 years vs. 46.4% at 11 years, 95% CI 19.1–25.1, Table 3). The rate of visual impairment increased by 12.5 percentage points (95% CI 9.9–15.1), learning disorders increased by 7.8 percentage points (95% CI 5.7–9.8), and developmental delay increased by 7.0 percentage points (95% CI 4.7–8.9). Figure 2 represents the rate of incremental increase for each long-term adverse outcome as the children aged from 5 to 11 years.

3.3 Long-Term Adverse Outcomes by Age of AHT

We investigated the association between the age at the time of AHT injury with the presence of any of the primary outcomes with multivariable analysis to adjust for sex and ICISS in the overall cohort of 1,165 children (Table 4). Children who experienced AHT during infancy (<1 year) had an increased risk of developing any long-term disability by age 5 when compared to children 2 years of age at time of AHT (OR 1.51, 95% CI: 1.01–2.25). When evaluating specific disabilities, compared to children who experienced AHT at age 2, infants <1 year were significantly more likely to develop developmental delays (OR 1.68,

95% CI 1.15–2.46), epilepsy (OR 1.97, 95% CI 1.31–2.97), learning disorders (OR 1.92, 95% CI 1.29–2.85), and visual impairment (OR 2.15, 95% CI 1.31–3.54). When comparing children injured at 1 year old to those who were 2 years old, children injured at 1 year old were significantly more likely to develop learning disorders (OR 1.54, 95% CI 1.04–2.29) and visual impairment (OR 1.65, 95% CI 1.00–2.72).

We further assessed the effect of the age at time of AHT by evaluating for a rate of increase in long-term adverse outcomes for the subgroup of children who had follow-up at both 5 and at least 11 years of age. The overall rate of long-term disability significantly increased from age 5 to age 11 years in all three of the age groups: by 11.0 percentage points (95% CI 7.0–14.6) for children with AHT occurring when <1 year old, by 17.3 percentage points (95% CI 12.9–21.8) for those who were 1 year old when AHT occurred, and by 14.9 percentage points (95% CI 6.7–22.6) for those who were 2 years old when AHT occurred (Figure 3, Supplementary Table 5). More specifically, all but three individual long-term disabilities increased from age 5 to age 11 years, the three that did not reach statistical significance were: epilepsy for children <1 year old at the time of AHT, epilepsy for children 1 year old at the time of AHT, and communication deficits for children 2 years old at the time of AHT. On further analysis of long-term adverse outcome rate increases, the rate of behavioral disorders increased by the highest percentage points for all three ages at the time of AHT (<1 year old: 20.0 percentage point increase (95% CI 15.5–24.2), 1 year old: 22.4 percentage point increase (95% CI 17.5–27.0), 2 years old: 27.6 percentage point increase (95% CI 20.0–36.4)). The diagnosis of learning disorders also increased for all three age groups, but of note increased by the largest increment for those diagnosed with AHT at 2 years old (12.8 percentage point increase, 95% CI 6.1–19.4) compared to those who were <1 year old (5.8 percentage point increase, 95% CI 3.0–8.5) and those who were 1 year old (8.3 percentage point increase, 95% CI 4.7–11.3). The rate of increase for the diagnosis of visual impairment was highest for children with AHT at 1 year old (17.3 percentage points, 95% CI 12.7–21.9) compared to those <1 year old (9.7 percentage points, 95% CI 6.1–12.9) and those who were 2 years old (6.4 percentage points, 95% CI 2.9–10.3). We evaluated the presence of retinal hemorrhage to describe if the differences we observed regarding visual impairment were driven by the presence and age at time of retinal hemorrhage. However, the presence of retinal hemorrhage diagnosis was similar at all ages (40.9% for <1-year-olds, 41.5% for 1-year-olds, 42.5% for 2-year-olds). For epilepsy, children with AHT at 2 years old were the only age group that had a significant increase between ages 5 and 11 (8.5 percentage point increase, 95% CI 3.0–13.3).

4. DISCUSSION

In this cohort of 1,165 children covered by Medicaid who were diagnosed with abusive head trauma prior to three years of age, an alarmingly high rate of long-term disability was found by 5 years of age (68%), increasing up to 81.6% by 11 years of age. Behavioral disorders, developmental delays, epilepsy, and learning disorders were the most commonly diagnosed long-term disabilities at both follow-up intervals. When evaluated by age at time of AHT diagnosis, younger children (<2 years old) were more likely to have developmental delays, learning disorders, and visual impairment by the age of 5 when compared to those injured at 2 years old. Furthermore, among a sub-cohort of 358 children with follow-up through age

11, we found clinically relevant increases in the long-term burden of disabilities as they aged from 5 to 11 years old.

Overall, this study is the largest cohort evaluation of long-term outcomes of children with AHT, investigating 1,165 children up to the age of 5 years and a subset of 358 children up to the age of 11 years, using healthcare provider claims data. Our rates of long-term adverse outcomes at 5 years of age are similar to those found in other studies with varying cohort sizes and lengths of follow-up. Of note, the proportion of children developing any of the studied adverse outcomes was higher in the 11-year-old cohort when compared to other studies with shorter duration of follow-up, as there are minimal other studies with follow-up beyond 5 years and none with as large of a cohort. In our study, the most commonly identified long-term disability in the 11-year-old cohort was developmental delay (55.0%), which was present in 45.8% of 5-year-olds compared to a range of 22–92% in the literature[8, 15–18]. Similarly, learning disorders in the literature were reported at rates of 40–62%, similar to our findings of 40.9% at 5 years of age and 53.1% at 11 years of age[8, 15, 19–21]. Behavioral disorders were reported in 46.4% of 11-year-olds and 25.9% of 5-year-olds, compared to 29–61% in other studies[8, 15, 16, 20, 22]. For comparison, the CDC states that overall about 1 in 6 (17%) children aged 3–17 years are diagnosed with a developmental disability, which is reported by parents[23]. Additionally, intellectual disability prevalence is estimated to be from 8.7–36.8 per 1,000 children in the general pediatric population[24, 25]. Lastly, the estimated prevalence for visual impairment among all preschool aged children (36–72 months) was estimated to be 1.5%[26]. While these prevalence rates reflect the general population, they may include children captured by our current cohort. Nevertheless, it is helpful to consider these estimates as reference for the prevalence rates reported for children with AHT. The rate of long-term disability after AHT is high at 5 years of age and our data showed that this incidence increased further as these children aged, with rates of every single long-term adverse outcome significantly increasing as children aged from 5 to 11 years. The greatest long-term burden associated with AHT was observed for behavioral disorders and visual impairment suggesting that these long-term outcomes may not be identified until a child is in school or old enough to develop symptoms prompting work-up. We also evaluated the cumulative incidence rate for these long-term adverse outcomes for each year through 11 years of age, and found that for every long-term adverse outcome there was consistent incremental yearly increase in incidence as children aged.

While there have been numerous studies documenting that certain clinical characteristics, such as low Glasgow Coma Scale (GCS) score[16, 27], impaired consciousness[18, 22], and early post-traumatic seizures[6] are associated with worse long-term outcomes, the effect of age at the time of AHT has not been fully evaluated. Age less than 6 months at the time of AHT has been associated with poor prognosis and higher mortality in some studies[28–30], however is not consistently reported. This is particularly troubling as the highest frequency of AHT cases are noted in infants less than 1 year old[31]. In order to evaluate the effect of age at time of AHT on long-term adverse outcomes we performed two analyses. Initially, with multivariate analysis of the overall 5-year-old cohort, we found that infants <2 year of age at time of AHT were more likely to be diagnosed with developmental delays, epilepsy, learning disorders, and visual impairments. This suggests that the age at

the time of AHT has a critical impact on long-term outcomes, with younger children being at highest risk for adverse developmental sequelae. Anderson, et al found that children sustaining an early brain insult before age 2 years had worse global and cognitive deficits when compared to children of older age, suggesting a linear association between age at the time of brain insult and outcomes[32]. For children who have sustained a severe traumatic brain injury, it has been shown that younger age (3–7 years) at the time of injury is associated with minimal recovery, compared to better outcomes for older children (8–12 years). Furthermore, infants (<2 years) with moderate traumatic brain injuries had worse outcomes when compared to older children with similar severity of injury[33]. All of these findings suggest that very young children may be more susceptible or vulnerable to the effects of an acquired brain injury, likely secondary to a multitude of reasons. Our data regarding children after AHT also suggests that children <2 years of age have increased rates of long-term adverse outcomes, which is also likely multifactorial, including that the infant brain is more likely susceptible to shaking due to poor head control and the relative size of the head in comparison to the body[34, 35].

We then evaluated a subgroup of children who had follow-up at both 5 and 11 years old and when we analyzed the effect of age on long-term adverse outcomes by categorizing these children by age at time of AHT, we found that age at time of diagnosis additionally impacted the rate of increase in adverse outcomes between 5 and 11 years of age. For example, in this subgroup analysis, for those children who experienced AHT at 2 years of age, 62.5% of the long-term adverse outcomes studied displayed a greater magnitude of increase in diagnosis between age 5 and 11 when compared to younger children. More specifically, for disabilities such as epilepsy and learning disorders, if AHT occurred before 2 years old, most of the children were diagnosed with these long-term adverse outcomes by the time they reached 5 years of age, and the rate of increase in diagnosis from 5 to 11 years was small. However, if AHT occurred at 2 years of age, the rate of increase as they aged from 5 to 11 years was higher, suggesting that children injured at slightly older ages may be diagnosed with epilepsy or learning disorders later than children injured at younger ages. Furthermore, because the AHT occurred at 2 years of age, they only had a 3-year interval between AHT injury and follow-up at age 5, suggesting that it may take longer than three years post-injury to diagnose these disorders. Interestingly, for visual impairment the rate of increase between ages 5 and 11 years old was highest for children injured at age one. We found that the rate of retinal hemorrhage was relatively consistent regardless of age at time of AHT, therefore retinal hemorrhage at time of injury likely does not explain this increase in visual impairment for those 1-year-olds and further studies are warranted to understand this observed difference. Anderson in an evaluation of the trajectories of brain development, found that synapses and receptors within the brain are rearranged during two phases of life: immediately before birth and peri-adolescence[36]. During this peri-adolescent period, neuronal rearrangement occurs which represents a sensitive and critical period of brain development which could signify a potential cause for the increase in incidence of neurodevelopmental disorders throughout this period of aging from 5 to 11 years. In addition, the onset of attention deficit hyperactivity disorder (ADHD) and Tourette's syndrome both also occur during this period, around 7 years of age[36]. In line with these findings, our data suggests that the age at which AHT occurs does impact the

incidence and timing of long-term adverse outcomes. This further emphasizes that providers and caregivers of children exposed to AHT must continue to be diligent in evaluating for long-term disabilities throughout their entire childhood and not just the initial years after AHT by a multidisciplinary team to be able to identify any and all long-term sequelae and provide appropriate resources. Long-term monitoring of children with AHT is critical as the long-term consequences associated with injuries will continue to arise throughout their life; further studies are warranted to determine if this rate of long-term adverse outcomes continues to increase after age 11 years.

Our study has several limitations. Our data is administrative claims data from a large database which is collected for non-research purposes, and therefore may be limited by the accuracy of specific coding. As previously mentioned, we excluded children who were not insured by Medicaid which does limit our evaluations slightly in that we are not able to report on those children who were privately insured. This was done intentionally, however, in order to remove the confounding factor of insurance status. The cohort of children with private insurance was very small, and the included cohort of Medicaid-insured children was large enough for adequately powered analyses. This study is also limited by the fact that we cannot comment on if children who have a diagnosis of one of these disabilities have overcome it, as the diagnoses cannot be removed from their database claim. However, we have evaluated the presence of new diagnoses being added to their claims in order to determine if there is an increase in the incidence of positive reporting. We are unable to account for a child overcoming a given diagnosis, but our objective in this study was to evaluate this rate of additional or new diagnoses being added and therefore the risk of children developing these disabilities after experiencing AHT. The study is also potentially limited by the fact that in identifying an increase in long-term disability over time as children age from 5 to 11 years of age, we suggested that there was a lack of statistical difference between two cohorts. These two cohorts included those who had follow up at 5 years and those who had follow up at 11 years of age. The lack of statistical difference between outcomes in the two cohorts, however does not necessarily signify that the cohort of children with follow-up to 11 years of age is the same as there are many reasons why this could not be possible. One potential reason is that in this study 60.0% of children with documented AHT were excluded due to lack of complete follow-up from the time of documented AHT to the time they turned 5 years of age. Therefore, we are missing a significant proportion of children in our evaluation, which unfortunately is not avoidable with this type of database research. This does however potentially introduce selection bias which selects out children for a potential host of reasons, including but not limited to them no longer requiring follow-up due to clinical improvement, no further disability identified on follow-up, or death. These limitations can be addressed with prospective studies, which may allow for improved rates of long-term follow-up.

5. CONCLUSIONS

Young children who experience abusive head trauma develop significant long-term disabilities throughout childhood, which increase in incidence up to age 11 years. Almost all children with AHT developed at least one long-term disability by age 11. Age at time of AHT may also predispose a child to adverse long-term neurodevelopmental outcomes,

but full assessment to determine the extent of the effect of AHT and therefore long-term disability may not be possible until the child is fully developed. Overall, extended long-term follow-up is necessary for these children as all neurodevelopmental deficits may not be apparent until later in development. Services should be available for children to both diagnose and treat these long-term disabilities associated with AHT throughout a child's development including into adolescence and beyond. Providers must work with these children and their caregivers to improve their access to long-term care, rehabilitation services, and comprehensive follow-up.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Funding Source:

The project described was supported by the National Center for Advancing Translational Sciences, National Institutes of Health, through grant number UL1 TR001860 for author CT. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

Abbreviations

AHT	Abusive head trauma
COBRA	Consolidated Omnibus Budget Reconciliation Act
ICD	International Classification of Diseases
CM	Clinical Modification
CPT	Current Procedural Terminology
IRB	Internal Review Board
CDC	Centers for Disease Control and Prevention
ICISS	ICD-Based Injury Severity Score
ISS	Injury Severity Score
SRR	survival risk ratios
SD	standard deviation
IQR	interquartile range
CI	confidence interval
OR	odds ratio
GCS	Glasgow Coma Scale

REFERENCES

- [1]. National Center for Injury Prevention and Control DoVP. Preventing Abusive Head Trauma in Children.; 2020.
- [2]. Shaahinfar A, Whitelaw KD, Mansour KM. Update on abusive head trauma. *Curr Opin Pediatr* 2015;27(3):308–14. [PubMed: 25768258]
- [3]. StatPearls. 2020.
- [4]. Peterson C, Xu L, Florence C, Parks SE. Annual Cost of U.S. Hospital Visits for Pediatric Abusive Head Trauma. *Child Maltreat* 2015;20(3):162–9. [PubMed: 25911437]
- [5]. Frasier LD, Kelly P, Al-Eissa M, Otterman GJ. International issues in abusive head trauma. *Pediatr Radiol* 2014;44 Suppl 4:S647–53. [PubMed: 25501737]
- [6]. Barlow KM, Spowart JJ, Minns RA. Early posttraumatic seizures in non-accidental head injury: relation to outcome. *Dev Med Child Neurol* 2000;42(9):591–4. [PubMed: 11034451]
- [7]. Fanconi M, Lips U. Shaken baby syndrome in Switzerland: results of a prospective follow-up study, 2002–2007. *Eur J Pediatr* 2010;169(8):1023–8. [PubMed: 20213304]
- [8]. Nuño M, Ugiliweneza B, Zepeda V, Anderson JE, Coulter K, Magana JN, et al. Long-term impact of abusive head trauma in young children. *Child Abuse Negl* 2018;85:39–46. [PubMed: 30144952]
- [9]. Health IW. White paper: IBM MarketScan research databases for health services researchers, <https://www.ibm.com/downloads/cas/6KNYVVQ2>. [accessed Accessed October 26, 2020].
- [10]. Parks SE AJ, Hill HA, Karch DL. Pediatric Abusive Head Trauma: Recommended Definitions for Public Health Surveillance and Research. Atlanta, GA: Centers for Disease Control and Prevention; 2012.
- [11]. Osler T, Rutledge R, Deis J, Bedrick E. ICISS: an international classification of disease-9 based injury severity score. *J Trauma* 1996;41(3):380–6; discussion 6–8. [PubMed: 8810953]
- [12]. Meredith JW, Kilgo PD, Osler T. A fresh set of survival risk ratios derived from incidents in the National Trauma Data Bank from which the ICISS may be calculated. *J Trauma* 2003;55(5):924–32. [PubMed: 14608167]
- [13]. CMS' ICD-9-CM to and from ICD-10-CM and ICD-10-PCS Crosswalk or General Equivalence Mappings. Cambridge, MA: National Bureau of Economic Research; 2020.
- [14]. Tepas JJ, Leaphart CL, Celso BG, Tuten JD, Pieper P, Ramenofsky ML. Risk stratification simplified: the worst injury predicts mortality for the injured children. *J Trauma* 2008;65(6):1258–61; discussion 61–3. [PubMed: 19077610]
- [15]. Fischer H, Allasio D. Permanently damaged: long-term follow-up of shaken babies. *Clin Pediatr (Phila)* 1994;33(11):696–8. [PubMed: 7859433]
- [16]. Rhine T, Wade SL, Makoroff KL, Cassidy A, Michaud LJ. Clinical predictors of outcome following inflicted traumatic brain injury in children. *J Trauma Acute Care Surg* 2012;73(4 Suppl 3):S248–53. [PubMed: 23026962]
- [17]. Bonnier C, Nassogne MC, Saint-Martin C, Mesples B, Kadhim H, Sébire G. Neuroimaging of intraparenchymal lesions predicts outcome in shaken baby syndrome. *Pediatrics* 2003;112(4):808–14. [PubMed: 14523171]
- [18]. Ilves P, Lintrop M, Talvik I, Sisko A, Talvik T. Predictive value of clinical and radiological findings in inflicted traumatic brain injury. *Acta Paediatr* 2010;99(9):1329–36. [PubMed: 20377537]
- [19]. Barlow KM, Minns RA. Annual incidence of shaken impact syndrome in young children. *Lancet* 2000;356(9241):1571–2. [PubMed: 11075773]
- [20]. Lind K, Toure H, Brugel D, Meyer P, Laurent-Vannier A, Chevignard M. Extended follow-up of neurological, cognitive, behavioral and academic outcomes after severe abusive head trauma. *Child Abuse Negl* 2016;51:358–67. [PubMed: 26299396]
- [21]. Vinchon M, Defoort-Dhellemmes S, Nzeyimana C, Vallée L, Dhellemmes P. Infantile traumatic subdural hematomas: outcome after five years. *Pediatr Neurosurg* 2003;39(3):122–8. [PubMed: 12876390]

- [22]. Vinchon M, Defoort-Dhellemmes S, Desurmont M, Dhellemmes P. Accidental and nonaccidental head injuries in infants: a prospective study. *J Neurosurg* 2005;102(4 Suppl):380–4. [PubMed: 15926388]
- [23]. Zablotsky B, Black LI, Maenner MJ, Schieve LA, Danielson ML, Bitsko RH, et al. Prevalence and Trends of Developmental Disabilities among Children in the United States: 2009–2017. *Pediatrics* 2019;144(4).
- [24]. Boyle CA, Yeargin-Allsopp M, Doernberg NS, Holmgreen P, Murphy CC, Schendel DE. Prevalence of selected developmental disabilities in children 3–10 years of age: the Metropolitan Atlanta Developmental Disabilities Surveillance Program, 1991. *MMWR CDC Surveill Summ* 1996;45(2):1–14.
- [25]. Camp BW, Broman SH, Nichols PL, Leff M. Maternal and neonatal risk factors for mental retardation: defining the ‘at-risk’ child. *Early Hum Dev* 1998;50(2):159–73. [PubMed: 9483389]
- [26]. Varma R, Tarczy-Hornoch K, Jiang X. Visual Impairment in Preschool Children in the United States: Demographic and Geographic Variations From 2015 to 2060. *JAMA Ophthalmol* 2017;135(6):610–6. [PubMed: 28472231]
- [27]. Keenan HT, Runyan DK, Marshall SW, Nocera MA, Merten DF. A population-based comparison of clinical and outcome characteristics of young children with serious inflicted and noninflicted traumatic brain injury. *Pediatrics* 2004;114(3):633–9. [PubMed: 15342832]
- [28]. Duhaime AC, Christian C, Moss E, Seidl T. Long-term outcome in infants with the shaking-impact syndrome. *Pediatr Neurosurg* 1996;24(6):292–8. [PubMed: 8988494]
- [29]. Talvik I, Männamaa M, Jüri P, Leito K, Pöder H, Hämarik M, et al. Outcome of infants with inflicted traumatic brain injury (shaken baby syndrome) in Estonia. *Acta Paediatr* 2007;96(8):1164–8. [PubMed: 17578492]
- [30]. Shein SL, Bell MJ, Kochanek PM, Tyler-Kabara EC, Wisniewski SR, Feldman K, et al. Risk factors for mortality in children with abusive head trauma. *J Pediatr* 2012;161(4):716–22.e1. [PubMed: 22578583]
- [31]. Nuño M, Pelissier L, Varshneya K, Adamo MA, Drazin D. Outcomes and factors associated with infant abusive head trauma in the US. *J Neurosurg Pediatr* 2015;16(5):515–22. [PubMed: 26230462]
- [32]. Anderson V, Spencer-Smith M, Leventer R, Coleman L, Anderson P, Williams J, et al. Childhood brain insult: can age at insult help us predict outcome? *Brain* 2009;132(Pt 1):45–56. [PubMed: 19168454]
- [33]. Anderson V, Catroppa C, Morse S, Haritou F, Rosenfeld J. Functional plasticity or vulnerability after early brain injury? *Pediatrics* 2005;116(6):1374–82. [PubMed: 16322161]
- [34]. Jayawant S, Parr J. Outcome following subdural haemorrhages in infancy. *Arch Dis Child* 2007;92(4):343–7. [PubMed: 17376941]
- [35]. Ashton R Practitioner review: beyond shaken baby syndrome: what influences the outcomes for infants following traumatic brain injury? *J Child Psychol Psychiatry* 2010;51(9):967–80. [PubMed: 20524940]
- [36]. Andersen SL. Trajectories of brain development: point of vulnerability or window of opportunity? *Neurosci Biobehav Rev* 2003;27(1–2):3–18. [PubMed: 12732219]

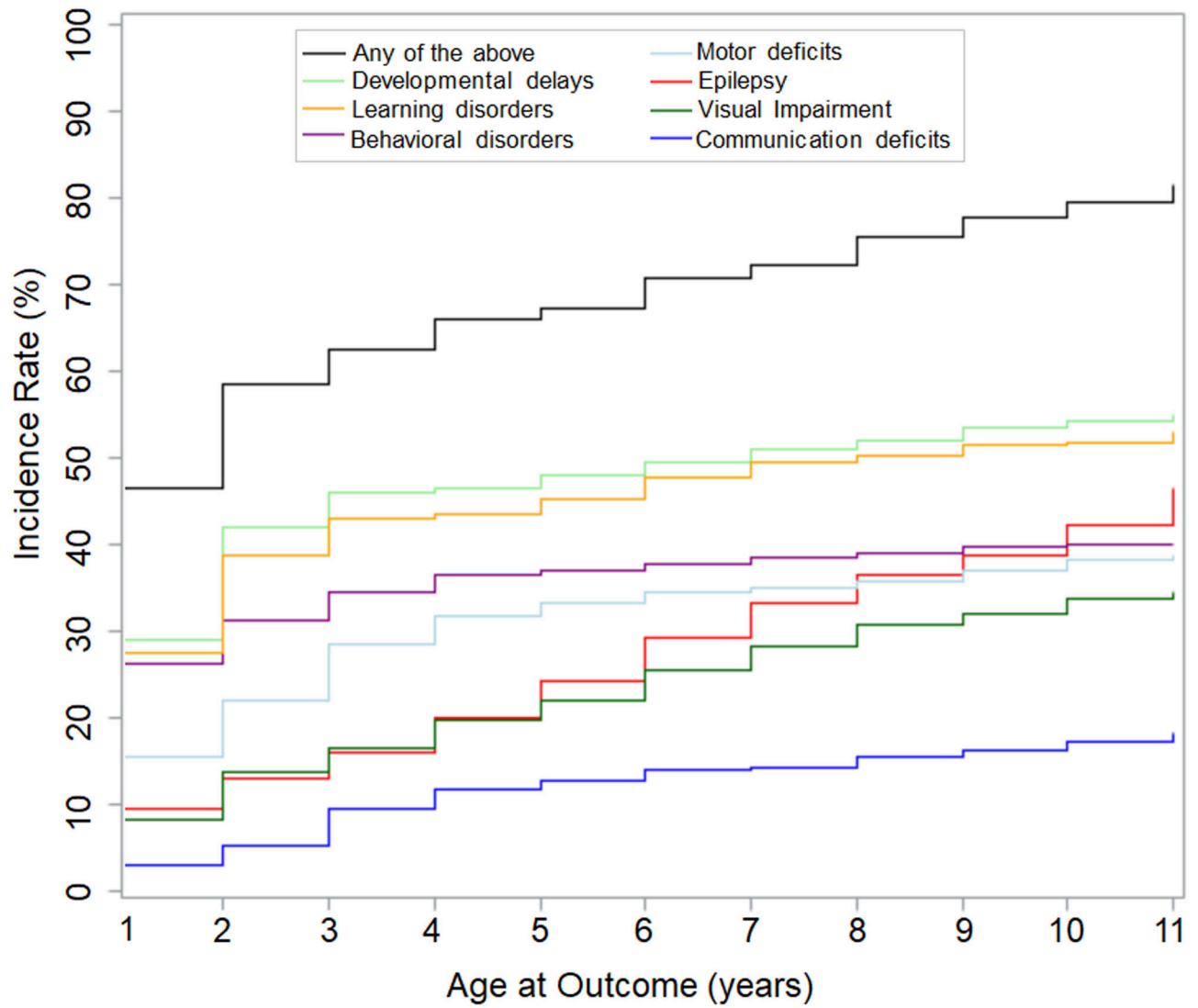


Figure 1.
Incidence rate of adverse outcome by age at outcome diagnosis.

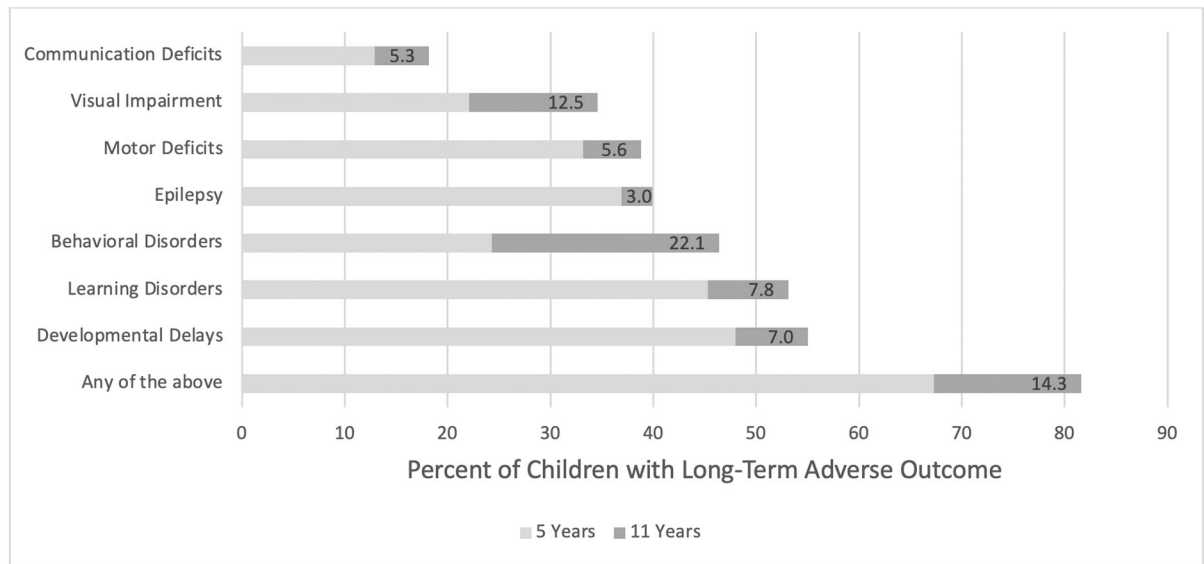


Figure 2.

Percentage point increase of long-term adverse outcomes at 5 years old and 11 years old.

As children aged from 5 to 11 years old there was an increase in the incidence of each long-term outcome. The percentage point increase for each of the long-term outcomes is represented in the dark grey bar of each long-term outcome with behavioral disorders having the highest rate of increase.

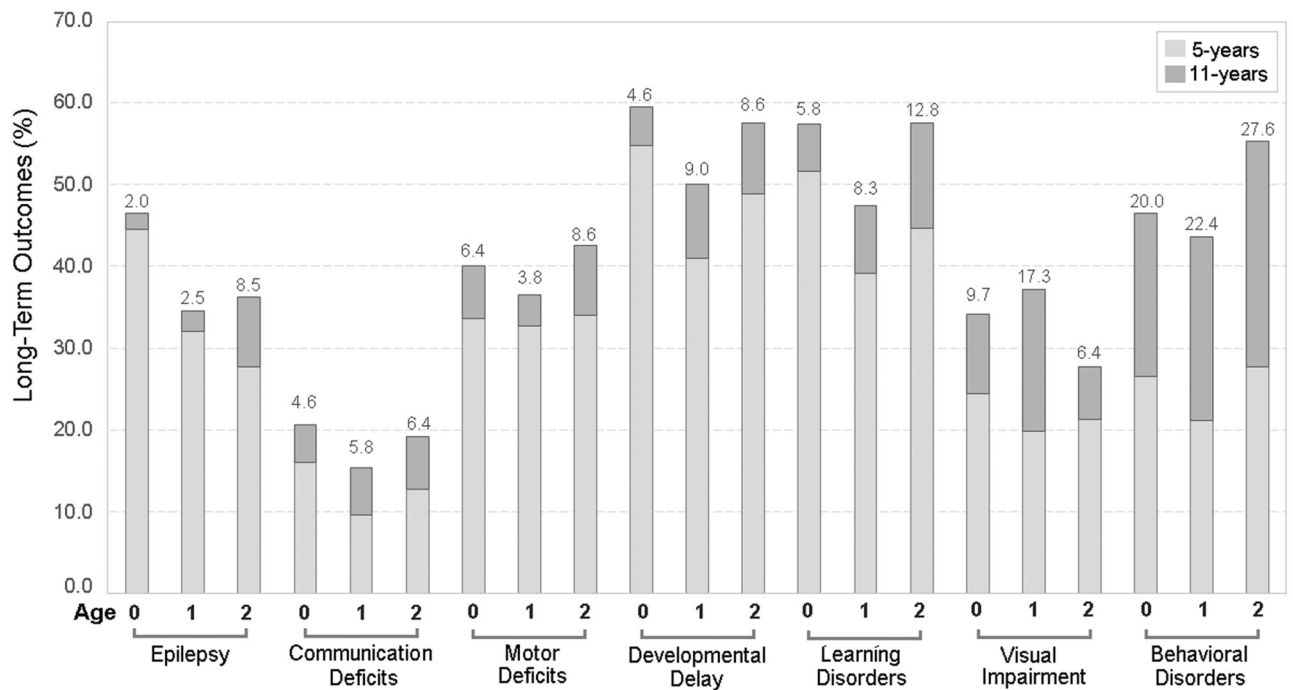


Figure 3.

Percentage point increase of long-term adverse outcomes at 5 years old and 11 years old stratified by age at time of AHT.

As children aged from 5 to 11 years there was an increase in the diagnosis of all long-term adverse outcomes. For each long-term adverse outcome, the rate at 5 years old is shown (light grey bars), as well as the percentage point increase from 5 to 11 years old (dark grey bars), shown by age at time of AHT injury (0, 1, and 2 years old).

Table 1.

Demographic characteristics of cohort.

Variables	Children with at least 5-year follow-up N=1,165	Children with only 5-year follow-up n=807	Children with 5-year and 11-year follow-up	p-value
Age in years, N (%)				
0	496 (42.6)	341 (42.3)	155 (43.3)	0.9404
1	516 (44.3)	360 (44.6)	156 (43.6)	
2	153 (13.1)	106 (13.1)	47 (13.1)	
Male sex, N (%)	710 (60.9)	503 (62.3)	207 (57.8)	0.1456
Race, N (%) *				
White	590 (50.6)	409 (50.7)	181 (50.6)	0.3163
Black	387 (33.2)	260 (32.2)	127 (35.5)	
Other	188 (16.1)	138 (17.1)	50 (14.0)	
Injury Severity Score, ICSS				
mean (SD)	0.68 (0.14)	0.69 (0.13)	0.67 (0.14)	
median (IQR)	0.68 [0.60–0.77]	0.69 [0.61–0.77]	0.66 [0.60–0.76]	0.0213 *
Associated injuries, N (%)				
Fractures				
skull	471 (40.4)	322 (39.9)	149 (41.6)	0.5812
trunk or spine	164 (14.1)	122 (15.1)	42 (11.7)	0.1252
upper extremity	112 (9.6)	79 (9.8)	33 (9.2)	0.7601
lower extremity	132 (11.3)	103 (12.8)	29 (8.1)	0.0205 **
any of the above	627 (53.8)	434 (53.8)	193 (53.9)	0.9669
Intracranial Injuries				
epidural hemorrhage	52 (4.5)	39 (4.8)	13 (3.6)	0.3596
subdural hemorrhage	730 (62.7)	508 (63)	222 (62.0)	0.7601
subarachnoid hemorrhage	199 (17.1)	130 (16.1)	69 (19.3)	0.1854
cerebral edema	123 (10.6)	101 (12.5)	22 (6.2)	0.0011 ***
cerebral contusion	73 (6.3)	48 (6.0)	25 (7.0)	0.5011
cerebral concussion	34 (2.9)	27 (3.4)	7 (1.96)	0.1933
any of the above	929 (79.4)	634 (78.6)	295 (82.4)	0.1325
Retinal hemorrhage	482 (41.4)	303 (37.6)	179 (50.0)	<0.0001 ****

Other race included Asian, Native American, Pacific Islander, other, or undocumented. Abbreviations: ICSS: ICD-9-Based Injury Severity Score; SD: standard deviation; IQR: interquartile range. P value comparing the children with only 5-year follow-up and the children with both 5-year and 11-year follow-up.

* Effect size of 0.46, which correlates with a small difference.

** Effect size of 0.15, which correlates with a trivial difference.

*** Effect size of 0.22, which correlates with a small difference.

**** Effect size of 0.25, correlates with a small difference.

Table 2.

Long-term outcomes

Outcome, N (%)	Children with at least 5-year follow-up N=1,165	Children with only 5-year follow-up n=807	Children with 5-year and 11-year follow-up N=358	p-value
Behavioral Disorders	302 (25.9)	215 (26.6)	87 (24.3)	0.4004
Communication Deficits	158 (13.6)	112 (13.9)	46 (12.9)	0.6359
Developmental Delays	533 (45.8)	361 (44.7)	172 (48.0)	0.2953
Epilepsy	398 (34.2)	266 (33.0)	132 (36.9)	0.1942
Learning Disorders	476 (40.9)	314 (38.9)	162 (45.3)	0.0422 *
Motor Deficits	388 (33.3)	269 (33.3)	119 (33.2)	0.9752
Visual Impairment	262 (22.5)	183 (22.7)	79 (22.1)	0.8182
Any of the above	792 (68.0)	551 (68.3)	241 (67.3)	0.7461

P value is comparing children with only 5-year follow-up and children with 5-year and 11-year follow-up.

* For learning disorders, even though the difference is statistically significant, it has an effect size of 0.13, which correlates with a trivial difference.

Table 3.

Long-term outcomes for 358 children that were evaluated at both 5 and 11 years old.

Outcome, N (%)	5-year-old cohort N=358	11-year-old cohort N=358	Percentage Point Change* (95% CI)	p-value**
Behavioral Disorders	87 (24.3)	166 (46.4)	22.1 (19.1–25.1)	<0.0001
Communication Deficits	46 (12.9)	65 (18.2)	5.3 (3.5–7.0)	<0.0001
Developmental Delays	172 (48.0)	197 (55.0)	7.0 (4.7–8.9)	<0.0001
Epilepsy	132 (36.9)	143 (39.9)	3.0 (1.7–4.4)	0.0026
Learning Disorders	162 (45.3)	190 (53.1)	7.8 (5.7–9.8)	<0.0001
Motor Deficits	119 (33.2)	139 (38.8)	5.6 (4.0–7.3)	<0.0001
Visual Impairment	79 (22.1)	124 (34.6)	12.5 (9.9–15.1)	<0.0001
Any of the above	241 (67.3)	292 (81.6)	14.3 (11.6–17.1)	<0.0001

* Difference in long-term outcomes at 5 and 11 years old.

** McNemar's test for correlated proportions. Abbreviations: CI: confidence interval.

Table 4.

Adjusted Odd Ratio (OR) and 95% confidence intervals (CI) for long-term adverse outcomes at 5 years old (N=1,165).

Adverse Outcome *	Age (Ref: 2 years old at time of AHT)	
	<1 year old at time of AHT N=496	1 year old at time of AHT N=516
Behavioral Disorders	0.97 (0.64–1.46)	0.82 (0.54–1.25)
Communication Deficits	0.82 (0.49–1.37)	0.84 (0.51–1.41)
Developmental Delays	1.68 (1.15–2.46) **	1.29 (0.89–1.88)
Epilepsy	1.97 (1.31–2.97) **	1.20 (0.80–1.81)
Learning Disorders	1.92 (1.29–2.85) **	1.54 (1.04–2.29) **
Motor Deficits	1.14 (0.77–1.70)	1.12 (0.76–1.67)
Visual Impairment	2.15 (1.31–3.54) **	1.65 (1.001–2.72) **
Any of the above	1.51 (1.01–2.25) **	1.10 (0.74–1.63)

* Models adjusted for ICISS and sex.

** Statistically significant at $p < 0.05$.