Pediatric Abusive Head Trauma in Virginia: A Protocol for Public Health Surveillance Using the Virginia Statewide Trauma Registry

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A Capstone Presented to the Graduate Faculty of the University of Virginia in Candidacy for the Degree of Doctor of Nursing Practice

School of Nursing

University of Virginia August, 2014 Degree will be conferred

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#### Abstract

Pediatric Abusive Head Trauma (AHT) incidence and related fatalities may be underestimated if public health surveillance methods exclude those children that have injury patterns consistent with AHT, but the mechanism of injury (E-code) is reported as a minor fall. Abusive head trauma is a severe form of child abuse and the primary cause of child maltreatment deaths in the United States. Recent efforts to portray an accurate incidence of AHT in Virginia indicated wide variability in the number of cases and likely understated the incidence. This Capstone project reports on a review of current AHT diagnostic literature, which was used to develop an AHT Surveillance Pilot Protocol for rigorous case capture of AHT in Virginia. A retrospective review of cases drawn from the Virginia Statewide Trauma Registry (VSTR) of children aged three and under, who sustained traumatic brain injury between 2008 and 2012 was completed, and non-fatal AHT and AHT mortality outcomes reported.

Using the Centers for Disease Control and Prevention (CDC) AHT algorithm broad definition, 78 Virginia children under age three were hospitalized for non-fatal AHT, between 2008 and 2012. Of those, 65 were categorized as definite or presumptive cases and 13 were categorized as probable AHT cases. The CDC algorithm indicated a non-fatal AHT rate of 5.14 per 100,000 children under age three. The AHT Surveillance Pilot Protocol identified an additional 158 cases that met diagnostic criteria for non-fatal definitive/presumptive or probable AHT, but reported an E-code that indicated the cause of injury was a minor fall. The AHT Surveillance Pilot Protocol and CDC algorithm combined results, showed a non-fatal AHT rate of 15.56 per 100,000 children under age three. The AHT fatality rate in Virginia children under age three, between 2008 and 2012, was 4.15 per 100,000 children, with 63 reported AHT deaths.

#### Section I Introduction and Research Question

The Centers for Disease Control Pediatric Abusive Head Trauma Recommended Definitions for Public Health Surveillance and Research defines pediatric abusive head trauma "as an injury to the skull or intracranial contents of an infant or young child (five and under) due to inflicted blunt trauma and/or violent shaking" (Centers for Disease Control and Prevention [CDC], 2012). Abusive head trauma (AHT) is the leading cause of child maltreatment fatality in the United States (U.S.), with the highest rates among children under age one (Klevens & Leeb, 2010). The estimated incidence rate of non-fatal AHT in the U.S. is 32.3 cases per 100,000 children under age one (CDC, 2012). The majority of pediatric AHT victims have significant neurologic and functional deficits, which can include blindness, seizures, mobility disorders, respiratory problems, feeding difficulties and other debilitating sequela (CDC, 2012; Keenan, Runyan, Marshall, Nocera, Merten, & Sinal, 2003). As many as 20 to 25% of AHT victims perish each year (CDC, 2012; Minns, Jones, & Mock, 2008).

The protection and safety of children, particularly those who are too young to protect themselves, is a core function of any society. There are numerous U.S. Federal legislative initiatives that address the protection of children from abuse, but there is no nationwide prevention program for abusive head trauma. Various states have initiated AHT prevention programs, but children who reside in states where there are no such programs, including Virginia, may be at higher risk for abusive head trauma. Recent legislative activity by the Virginia General Assembly suggests a growing awareness of AHT, but significant limitations in Virginia's incidence and mortality data have led to a lack of awareness of the scope of the problem (Joint Commission on Health Care, 2012). The CAPTA Reauthorization Act of 2010, among other directives, advised the U.S. Secretary of Health and Human Services to complete studies on Shaken Baby Syndrome (now known as Abusive Head Trauma), and report back to Congress (Child Welfare Information Gateway, 2012). The U.S. Government Accountability Office (GAO) reported to a Joint Congressional Hearing in July 2011, that a "lack of evidence and inconsistent interpretations," were contributing to the problem of identifying child maltreatment fatalities and listed shaken baby syndrome (SBS) as an example where this was evident (U.S. Government Accountability Office, 2011).

A substantial barrier to the accurate diagnosis and reporting of AHT incidence rates is the difficulty in differentiating between AHT and non-abusive head trauma (nAHT) because of the non-specific presenting symptoms these children display (Jenny, Hymel, Ritzen, Reinert & Hay, 1999). The expertise and experience level of clinicians, as well as social and legal concerns are also contributors to inconsistent identification of these cases (Wood, Hall, Schilling, Keren, Mitra, Rubin, 2010). Inappropriate documentation of AHT by clinicians can affect accurate coding by professional coders (Bjorn, Falk, Flodmark, Ygge, 2009). As a result, many health professionals believe the incidence of AHT is significantly higher than current data reflect.

Sound evidence-based diagnostic criteria are necessary to differentiate between AHT and nAHT (also called accidental head trauma). The evidence-based literature regarding diagnostic criteria for AHT has developed rapidly over the last five years and includes numerous systematic reviews as well as prospective and retrospective studies. Utilization of the most rigorous and current evidence-based AHT literature, as the basis for accurate diagnosis and for the development of an AHT Surveillance Pilot Protocol, is essential for correctly identifying the scope of the problem and addressing prevention. Richmond-Crum, Joyner, Fogerty, Ellis and

Saul (2013), suggested the *Public Health Model for Prevention*, originally developed by Dahlberg and Krug (2002), as a tool for reducing the incidence and fatalities of child maltreatment. The logical steps in this model begin with defining the problem and identifying risk and protective factors, leading to the development and testing of prevention strategies and finally, scaling those strategies to meet population needs (Richmond-Crum et al. 2013).

The cost of disease burden in part, drives public health prevention policy. In 2012, Preer, Sorrentino, Ryznar & Newton reported on the findings of a New Zealand study which calculated AHT hospital costs, long-term medical and rehabilitation care, educational costs and the cost of conducting criminal and civil litigation at a "high lifetime cost of \$44,117,853 U.S. dollars." In order to evaluate the cost of disease burden for AHT in Virginia, accurate incidence and fatality rates are essential.

A 2011 preliminary retrospective review by the author of suspected/definite AHT cases utilizing ICD-9-CM codes reflective of intracranial injury - treated at the University of Virginia (UVA) and documented in the Clinical Data Repository (CDR) between 2008 and 2010, identified 37 children who sustained intracranial injury, aged two and under. Of the 37 cases, four were confirmed AHT (ICD-9-CM Shaken Infant Syndrome code 995.55). Because code 995.55 is thought to be specific but not sensitive (CDC, 2012), this led to questions about a possible gap between confirmed cases of AHT and suspected AHT cases. The Virginia Department of Health (VDH) reported that for children aged two and under, who were treated at UVA during the same time period, only two cases were identified by code 995.55, indicating a gap between data generated for VDH by Virginia Health Information (VHI) and data taken directly from the UVA hospital discharge data. In 2011, statewide incidence data provided by VDH, which was generated from VHI data using code 995.55, for the period of 2008 through 2010, indicated there were 23 AHT cases. The Virginia Department of Social Services Child Protective Services division reported 50 cases for approximately the same time period, 16 of which perished (Joint Commission on Health Care, 2012). The death to case ratio indicated by CPS data is higher than that reported in the literature (32%), and may reflect an under estimated AHT incidence. The inconsistencies reported in statewide AHT data signified the need for further research (Centers for Disease Control, 2012; Minns et al. 2008).

Rigorous, evidence-based rates of AHT incidence and mortality, as well as accurate cost of disease burden, may increase the political will among members of the Virginia General Assembly to initiate prevention policy. Therefore, the research question guiding this Capstone Project is: What is the most rigorous method for calculating the AHT incidence and mortality rates in children under age three in Virginia?

#### **Section II Review of the Literature**

#### Literature Search Criteria

A literature search for the most rigorous evidence-based AHT diagnostic models was undertaken in order to incorporate these diagnostic practices in the AHT Surveillance Pilot Protocol (AHT SPP). The literature search methodology included the following inclusion criteria: any study that addressed AHT or SBS diagnostic models available in English, and current publication (2007 to 2013). PubMed, Ovid/Medline, CINAHL and Cochrane Systematic Reviews were searched using the key words, Shaken Baby Syndrome or Abusive Head Trauma and cohort studies, quasi-experimental studies and case control studies. The final review consisted of 38 articles: seven systematic reviews, four prospective (cohort) studies, 20 retrospective case reviews, three consensus statements, one literature review and three expert opinion articles. Three classic studies were referred to in a number of the current research articles and are discussed, but were not included in the review because of date parameters.

#### **Evidence Ranking**

All evidence was ranked by quality, with systematic reviews, prospective studies, and retrospective studies representing Level 1B. Evidence-based literature which was lower in the hierarchy of evidence, were considered Level 2, and conclusions based on published expert opinion or consensus statements were considered Level 3. All research articles included in this literature search were categorized in one of the above three levels. The study author(s), sample and setting, study design, the intervention, and where appropriate - the comparison intervention, study outcomes and study limitations, are provided in *Appendix A*. Although a randomized control trial is considered the gold standard in evidence-based medicine, observational studies provide the only ethical method for research on AHT (The Cochrane Library in Association with

the Campbell Library, 2010) and subsequently Level 1B represents the most rigorous evidence presented. Within Level 1B, Cochrane Systematic Reviews are the highest standard, followed by other systematic reviews, prospective and retrospective studies, consensus statements and expert opinions. Levels 2 and 3 evidence offer opportunities for future research in AHT diagnosis and public health surveillance.

#### Level One B

In 2003, Keenan et al. established the first U.S. population based prospective study of the incidence of AHT in children aged 2 years or younger. Minns, Jones and Mock (2008), utilized the guidelines of Keenan et al. for categorizing certainty and uncertainty in diagnosis to provide an incidence rate of AHT in Scotland. Minns et al. looked only at cases with a provisional diagnosis of suspected AHT, which subsequently excluded missed diagnosis cases. Duhaime's algorithm for determining inflicted injury in children with intracranial hemorrhage, developed in 1992, was reliant upon associated fractures and soft tissue injury, but did not address the presence of retinal hemorrhage as a diagnostic factor (Duhaime, Gennarelli, Thibault, Bruce, Margulies, & Wiser, 1987). Kelly and Farrant (2008) utilized Duhaime's algorithm in a prospective and retrospective study to establish the AHT rate in children under age two in New Zealand. A rate of 14.7 – 19.6 AHT cases per 100,000 children was reported, with higher levels among the Maori population (32.5 – 38.5/100,000).

In 2008, Fujiwara, Okuyama and Miyasaka reported that retinal hemorrhage, seizures prior to or upon admission, and a lack of injury history were predictive of AHT and provided additional guidance to the clinician in distinguishing between nAHT and AHT. Gill, Goldfeder, Armbrustmacher, Coleman, Mena and Hirsch showed that in autopsy results of New York City head injury deaths in children under age two, 84% were homicide. Curcoy, Trenchs, Morales, Serra and Pineda (2009) established that the chance of developing retinal hemorrhage following a seizure was low (under 0.05) and that seizures alone were unlikely to cause retinal hemorrhage in AHT (Curcoy et al. 2009). Adamsbaum, Grabar, Mejean and Rey-Salmon (2010) conducted a retrospective observational study that demonstrated there were no statistically significant differences between confessed cases of AHT and those without perpetrator confession, and 25% of cases present with a report of minor fall as the cause of injury.

Leventhal, Martin and Asnes (2010) utilized the 2006 Kids' Inpatient Database, to establish the incidence of traumatic brain injury and/or fractures in children younger than age three (35 months). In abused children under 35 months of age, Leventhal et al. reported that 29.9% had traumatic brain injuries (TBI) only, 28.3% had TBI and fractures and 41.8% had fractures only. The following mechanisms of injury were reported: fall, motor vehicle accident and "other." During the first two months of life, TBI was more likely to be caused by a fall than by abuse, yet from two to seven months of age, abuse was more common. During the first year of life, TBI with skull fracture - caused by a fall - was more commonly the cause of injury. For skull fracture only, nearly all injuries were attributed to falls. Falls were more common than abuse, even in very young children. Leventhal et al. did not address the height of fall relative to the pattern of injury (Leventhal et al. 2010).

Fortin and Stipanicic (2010) conducted an exhaustive literature review on AHT going back to 1975 and reported that in 70% to 97% of AHT cases, there was denial of a history of trauma or injury. In one cited study, which examined falls in children, Fortin and Stipanicic stated that it was implausible that deaths resulting from a fall of less than four feet had a fatality rate of 7%, yet the fatality rate for falls from five to nine feet produced a 0% death rate, and falls from 10 - 45 feet produced a 0.8% death rate. The authors reported that a short-distance fall of four feet or less does not cause injury in most cases. The authors indicated that the primary initial symptoms of AHT, such as decreased alertness, seizures, lethargy, respiratory distress, skin lesions of abuse, hypotonia, vomiting, apnea and irritability are non-specific and inconsistently reported in the literature (Fortin & Stipanicic, 2010).

Wood, Hall, Schilling, Keren, Mitra and Rubin (2010) documented that social and racial bias affect the diagnosis of abusive head trauma. Bhardwaj, Chowdhury, Jacobs, Moran, Martin and Coroneo (2010) showed that when intraocular hemorrhage was present after head injury, specificity for abuse was 94%, retinal folds or retinoschisis were correlated with AHT 100% of the time, and optic nerve sheath hemorrhage was associated with AHT 71% of the time. Curcoy, Trenchs, Morales and Serra (2010) established that an Apparent Life Threatening Event (ALTE) is unlikely to cause retinal hemorrhage.

Guenther, Power, Srivastava and Bonkowsky (2010) showed the odds that an infant with ALTE was diagnosed as AHT, were 27 times greater if certain physical examination findings were present and "149 times more likely to be diagnosed with abusive head injury if story discrepancy was reported." In addition, more AHT cases had evidence of a call to 911 and a history of vomiting or irritability. Goldstein, Leonhardt, Kmytyuk, Kim, Wang and Wainwright established in 2011 that early neuroimaging findings in suspected AHT cases might prove helpful in identifying children at risk of seizures.

Ibrahim, Wood, Margulies and Christian (2012) retrospectively looked at differences in fall types and the impact of age on head injuries in children under age four. Children with cause of injury (E-codes) indicative of child abuse were excluded from this study. Falls were categorized by low height (three feet or under), intermediate (three to ten feet) and high (over ten feet). Head injuries were reported as primary (bleeding) or secondary (hypoxia, edema). Ninetyfive children who were under age 48 months and had fallen from a height of three feet or less presented with primary intracranial injury, and five sustained secondary injury. This study showed that even though injury severity scores were similar between infants and toddlers, infants had more skull fractures than toddlers did, and of the children who presented with primary intracranial injury, 30% had no skull fracture, and 8% had no skull fracture or cranial soft tissue injury. The authors advised clinicians that they must evaluate fall type and age when assessing injuries (Ibrahim et al, 2011).

Three Cochrane Systematic Reviews were examined and were based on the Bhardwaj et al., Kemp, Jaspan, Griffiths, Stoodley, Mann, Tempest and Maguire (2011), and Piteau, Ward, Barrowman and Plint (2012) systematic reviews. These systematic reviews report the following AHT diagnostic criteria:

1) Neuroimaging: "Multiple Subdural hematomas or hemorrhages (SDH) over the convexity, inter-hemispheric hemorrhage, posterior fossa SDH, hypoxic ischemic injury and cerebral edema are all significantly associated with AHT and should be considered together with clinical findings when identifying the condition" (Kemp et al., 2011).

2) In children where intracranial injury and rib fracture or retinal hemorrhage accompany any one of the other features (rib fracture, retinal hemorrhage, long-bone fracture, seizures, head and/or neck bruising, apnea), the odds ratio for AHT is greater than 100, with a 95% confidence interval and 85% positive predictive value. Any combination of three or more of the six significant factors yields an odds ratio of greater than 100, with a positive predictive value for AHT of 85% (Kemp et al., 2011).

3) Subdural hemorrhage(s), cerebral ischemia, retinal hemorrhage, skull fracture(s) plus intracranial injury, metaphyseal fracture(s), long bone fracture(s), rib fracture(s), seizure(s) at

presentation or within 24 hours, apnea, and an inadequate history of injury are all individually significantly associated with AHT (Piteau et al., 2012).

The systematic review of Piteau et al. (2012) also identified diagnostic characteristics that are individually associated with AHT, in an effort to address the circular reasoning often noted in AHT diagnostic literature. Choudhary, Bradford, Dias, Moore & Boal (2012), compared the incidence of spinal canal subdural hemorrhage (SCSH) in AHT versus nAHT with thorocolumbar imaging and found that in 60% of AHT cases, SCSH was present. In 2012, Parks, Sugerman, Xu, and Coronado published a nationwide retrospective analysis of AHT cases from 2003 to 2008, utilizing the newly formulated *Centers for Disease Control Pediatric Abusive Head Trauma Recommended Definitions for Public Health Surveillance and Research*. They estimated a non-fatal incidence rate for hospitalized children under age one at 32.3 per 100,000 children (Parks et al. 2012).

In 2013, Selassie, Borg, Busch and Russell conducted the first U.S. retrospective cohort study examining all severity levels of AHT, including those treated and released from the emergency department. Selassie et al. utilized ICD-9-CM and E-codes to determine AHT incidence, and examined the average injury severity (AIS) scores to determine the likelihood of AHT fatality in South Carolina. Incidence ranged from 28.9/100,000 in infants to 4.1/100,000 in five year olds (Selassie et al. 2013). John, Kelly and Vincent (2013) established the possibility that the reported history of injury in structural head trauma is false in some cases, particularly in children less than six months of age with a history of minor fall, or no reported history of injury. Parrish, Baldwin-Johnson, Volz and Goldsmith (2013), utilized the CDC algorithm for AHT surveillance with minor modifications, to produce a rigorous evidence-based incidence of AHT in Alaska by utilizing multiple data sources. Parrish et al. (2013) included the Alaska Trauma

Registry, Hospital Discharge Data, Medicaid, Violent Death Reporting System and the Maternal Infant Mortality Review - Child Death Review, to develop their incidence rate of 34.4/100,000 in children less than age two.

Shanahan, Zolotor, Parrish and Barr (2013) utilized the CDC narrow and broad algorithms for calculating a ten-year (2000 to 2009) national average, regional and North Carolina incidence of AHT, using the KIDS National Database and North Carolina annual hospital discharge data. An average annual incidence rate of 33.4 (narrow) and 38.8 (broad) cases per 100,000 children under age one was determined. They noted large but statistically insignificant variation in AHT rates annually, with the Midwest reporting the highest incidence and the Northeast reporting the lowest. Reasons for the lower rates in the Northeast were unclear, but a number of AHT prevention programs are in place in this region. In North Carolina, the broad CDC algorithm detected 475 cases and reported a mean rate of 38.5 per 100,000 children under age one. The mean age of children diagnosed with AHT ranged from 3.4 to 5.2 months of age (Shanahan et al., 2013).

#### Level Two

Trenchs, Curcoy, Navarro and Pou (2007), performed an AHT retrospective review that indicated only 65% of cases of subdural hematoma have a full diagnostic workup for child abuse. Biron and Shelton examined the functional time limit between normal infant behaviors and when symptoms of head injury appear, and established that the period between assault and onset of symptoms was brief, particularly when symptoms were severe. Oral, Yagmur, Nashelsky, Turkmen and Kirby (2008) completed a retrospective case review of children under age four who were diagnosed with AHT and expired, to determine if a past history of abuse was missed by medical staff. Oral et al. determined that misreading of radiographic studies and clinician failure to consider abuse as a differential diagnosis, were the two leading causes of missed cases. In 2010, Margolin, Shrinivastav and Trobe completed a retrospective review of retinal hemorrhage prevalence in AHT cases where the perpetrator confessed, to determine the prevalence of retinal hemorrhage. Margolin et al. established that unilateral retinal hemorrhage, or fewer than five hemorrhages, does not exclude a diagnosis of abusive head trauma.

Ng, Watts, Lawson, Kemp and Maguire used RetCam imaging to evaluate and describe retinal hemorrhage and developed a valid reporting tool for assessment of retinal hemorrhage in suspected AHT cases. Curcoy, Trenchs, Morales, Serra and Pou (2012), reported on a prospective study which determined that no cases of retinal hemorrhage were found among 35 children aged two and under, who were admitted to the hospital with pertussis. Curcoy and others (2012) sought to disprove that paroxysmal coughing can cause retinal hemorrhage.

Hooft, Ronda, Schaeffer, Asnes and Leventhal (2013) examined the electronic child abuse registry maintained by the Yale-New Haven Children's Hospital from 2007 to 2010, to determine the accuracy of ICD-9-CM/E-codes for capturing child physical abuse. Hooft et al. reported that ICD-9-CM/E-codes have a high specificity (100%) for detecting child abuse, but a sensitivity of only 77%, indicating that using these codes to detect physical abuse - led to an underestimation of the occurrence. Code error or omission and errors in clinician documentation were the two most commonly cited issues. More specifically, Hooft et al. (2013) reported that the *ICD-9-CM Official Guidelines for Coding and Reporting* directs coders that "questionable, probable, or suspected" cases should be E-coded as "undetermined" cause. Because both diagnosis and E-codes can be utilized in coding abuse, the guidelines are less clear on how to properly use diagnostic codes for AHT (Hooft et al. 2013).

### Level Three

Runyan, Berger and Barr (2008), in their attempt to define a gold standard for diagnosing AHT, discussed the lack of a clear definition of AHT and suggested the ideal AHT incidence evaluation system necessitates measures to audit data and address coding manuals, as well as providing training for professional coders. Barnes (2011) provided an expert opinion based upon his perception of the absence of an evidence base for the definitive diagnosis of AHT and offered an exhaustive list of differential diagnoses to consider. Barnes' opinion differed significantly from other published literature and lacked evidence-based substantiation to support a number of his conclusions. Kemp (2011) used odds ratios and positive predictive value for features associated with AHT, and reported that persistent neurological impairment with a low impact fall was a clinical indicator of AHT. Herman, Mackaroff and Corneli (2011), discussed the diagnostic work up for AHT, suggesting specific lab studies to rule out differential diagnoses, and pointed out problems with adequate documentation in the medical record, as well as the legal reporting obligation of clinicians. Herman et al. also described the minimal likelihood of intracranial injury with minor falls.

In 2012, Parks, Annest, Hill and Karch published a set of guidelines for use with emergency department and hospital discharge data for public surveillance of AHT, on behalf of the CDC, entitled *The Centers for Disease Control Pediatric Abusive Head Trauma Recommended Definitions for Public Health Surveillance and Research*. The guidelines provided a uniform definition of AHT as well as an algorithm for surveillance.

# **Summary of Evidence**

Hierarchy of evidence organized the literature review and studies are in chronological order within each level, illustrating the changes in scientific evidence over time. The majority of

studies contained in this literature review were published subsequent to the development of the CDC algorithm for AHT surveillance, including four systematic reviews and all three Cochrane reviews. These more recent studies build upon the prior evidence-base by expanding and refining the clinical criteria on which AHT diagnosis is based and by reporting the outcome of various methods for determining AHT incidence. Multiple studies provided incidence rates utilizing the CDC algorithm; several of these studies modified guideline parameters. One recent study utilized multiple data sources to determine AHT incidence, and several studies point out the limitations in relying on cause of injury (E-codes) to capture AHT cases. Seven studies critically examined the biomechanics of minor falls and the low likelihood of intracranial hemorrhage resulting from such falls. The literature contained in Level 1B provided the strongest evidence-base for use in AHT diagnosis and surveillance and pointed to gaps in existing methodology used for determining incidence.

#### **Section III Methods**

The primary purpose of this project was to determine the number of children, three years of age and under, who were diagnosed with non-fatal AHT over a 5-year period, utilizing both the CDC algorithm, and a new AHT Surveillance Pilot Protocol, which incorporated current evidence-based diagnostic criteria to distinguish between AHT, indeterminate AHT and nAHT, when E-codes indicate a minor fall as the cause of head injury. The age parameters selected for this project were based upon multiple studies that calculated incidence rates in children aged three and under (35 months).

A secondary goal of the project was to identify AHT fatalities in children aged three and under that occurred during the same time period. All recorded fatalities in children under age three (35 months) for the five- year period of 2008 to 2012, were manually reviewed by The Virginia Office of the Chief Medical Examiner (OCME), using text (in lieu of codes) and the search terms "head trauma, injuries to the head and head injury" in the "manner of death" documentation. The OCME provided the fatality data to the Virginia Statewide Trauma Registry (VSTR) and results were linked using the Virginia Medical Examiner Data System (VMEDS). This methodology captured AHT cases that went directly to the medical examiner for autopsy, bypassing the hospital. The Virginia OCME utilizes national standards of the National Association of Medical Examiners (NAME) for categorizing the cause and manner of the death. Determination of manner of death contained in the Virginia death certificate is established by a forensic pathologist review of autopsy findings and the investigations by legal authorities and child protective services. The fatality data were derived using a more rigorous method than the application of ICD10 codes to a vital statistics dataset, in order to determine the most accurate AHT fatality rates.

The Centers for Disease Control Pediatric Abusive Head Trauma Recommended Definitions for Public Health Surveillance and Research relies upon ICD-9-CM diagnosis and external cause of injury code (E-codes) to differentiate AHT from nAHT, with one group of Ecodes utilized to determine definite/presumptive AHT and a second group of E-codes to define probable Abusive Head Trauma (*Appendix B, Table 1*). In definite/presumptive AHT, E-codes reflect maltreatment or assault; in probable AHT, E-codes indicate the cause of injury was undetermined. The CDC algorithm for non-fatal AHT surveillance excludes unintentional injuries that resulted from negligent supervision and subsequently, those intracranial injuries that have an E-code indicating an accidental fall as the cause of injury (CDC, 2012).

While E-codes provide cause of injury information that is important in identifying AHT, they are insufficient for detecting all AHT cases (Selassie et al. 2013). E-code use is voluntary at all nationwide hospitals and therefore not consistently reported; relying upon E-code criteria for AHT identification almost certainly misses cases. Only 65% of Virginia's published AHT cases (2004 to 2008) included assigned E-codes (Virginia Department of Health, 2010).

The Abusive Head Trauma Surveillance Pilot Protocol utilized head trauma diagnostic codes similar to the CDC generated broad ICD-9-CM diagnostic codes, and the same cause of injury E-codes that reflect AHT, except in cases where the E-code indicated a minor fall as the cause of injury. When E-codes reflected a minor fall (3 feet or less), the AHT SPP distinguished definite/presumptive, probable, indeterminate and nAHT by using current evidence-based diagnostic models (*Appendix B, Table 2*). The AHT SPP evidence-based diagnostic models include the following categories, established a priori (*Appendix B, Table 3*):

Definite/Presumptive AHT

1. Intracranial injury and rib fracture or retinal hemorrhage, plus any one of the other features (rib fracture, retinal hemorrhage, apnea, long-bone fractures, seizures, head and/or neck bruising); or intracranial injury plus any combination of three or more of the six significant factors.

2. Intracranial hemorrhage and intraocular hemorrhage, particularly extensive, bilateral and multi-layered.

3. Age <12 months, intracranial injury, skull fracture plus long bone fracture; or intracranial injury plus non-skull fracture.

4. All cases coded as 995.55 (no E-code needed).

Probable AHT

5. Age two to seven months and intracranial injury.

6. Primary intracranial injury and secondary intracranial injury (hypoxemia, ischemia, edema).

Indeterminate

7. Intracranial injury and less than two months of age - or intracranial injury and greater than eight months of age.

Non-Abusive Head Trauma (nAHT)

8. Isolated skull fracture, or any head injury case that does not conform to the diagnostic criteria for definite/presumptive, probable or indeterminate AHT.

9. Age < 12 months, intracranial injury and skull fracture

### **Research Design**

This Capstone project design is that of a retrospective case review of VSTR data, using a descriptive approach. The CDC algorithm diagnostic and mechanism of injury codes replicate those contained in the *Centers for Disease Control Pediatric Abusive Head Trauma Recommended Definitions for Public Health Surveillance and Research*. The AHT SPP used all CDC algorithm diagnostic codes, but augmented with ICD-9-CM codes that reflect current evidence-based diagnostic criteria, including retinal hemorrhage, afebrile seizures, certain types of fractures, head or neck bruising and apnea. The AHT SPP augmented the CDC algorithm's mechanism of injury codes with six ICD-9-CM E-codes indicative of minor fall (884.2, 884.3, 884.4, 884.5, 884.6, 884.8). The additional diagnostic and mechanism of injury codes contained in the AHT SPP were applied only when the E-code indicated a minor fall.

When this information was available in the VSTR dataset, birth trauma, coagulation defects, congenital anomalies, gunshot wounds, stab wounds, and penetrating injury cases were excluded from the CDC algorithm and the AHT SPP, except when there were additional codes indicating abuse, per CDC algorithm guidelines (CDC, 2012). The AHT SPP also excluded E-code E907 (late results of injury) as recommended by Selassie et al. (2013).

#### **Sample Description and Setting**

The sample included all Virginia children aged three and under, who sustained traumatic head injury from January 1, 2008 through December 31, 2012. The sample data were taken from VSTR and OCME data. For the years examined, the VSTR data fields contained up to 28 diagnostic codes and two E-codes. The dataset included patients who were admitted (or held for observation for up to 23 hours), as well as patients initially seen in the emergency department and subsequently admitted to the hospital. The VSTR does not require hospitals to report on

patients seen in the emergency department and discharged home. The VSTR dataset requires Ecodes be entered for all reported trauma cases and subsequently provided the best available data source for use with the CDC algorithm and the Abusive Head Trauma Surveillance Pilot Protocol.

#### **Outcome Measures**

The primary outcomes were evidence-based five- year AHT incidence and mortality rates for Virginia children under age three. The CDC algorithm and AHT SPP incidence rates and demographic characteristics were described. The 2010 population of Virginia children under age one, two and three, were drawn from the *KIDS COUNT Data Center* and used to establish the non-fatal AHT incidence and AHT mortality rates (KIDS COUNT, 2013). Head trauma cases identified in the AHT SPP "indeterminate" and "nAHT" categories were described.

### Procedures

Leading experts in the field of AHT research were consulted regarding SPP content. These experts included Sharyn Parks, PhD, CDC - lead author of the *Centers for Disease Control Pediatric Abusive Head Trauma Recommended Definitions for Public Health Surveillance and Research*; Julie Haarbauer –Krupa, PhD, Traumatic Brain Injury Team of The National Center for Injury Prevention and Control, CDC; John Leventhal, MD - Board Certified Child Abuse Pediatric Specialist, Yale-New Haven Children's Hospital Child Abuse Program; and Virginia Powell, PhD - Program Manager, Fatality Review and Surveillance, Office of the Chief Medical Examiner, Virginia Department of Health. Each expert provided comments regarding AHT SPP content and project design.

### **Protection of Human Subjects**

The University of Virginia (UVA) Institutional Review Board (IRB) granted study approval (*Appendix C*) and a copy of the approval letter was provided to the VSTR and the Virginia Office of the Chief Medical Examiner. *Application for Access to and Use of Data* was submitted to the Virginia OCME, and their research committee approved the study. Copies of the UVA IRB coded research agreement signed by VSTR and OCME representatives, the principal investigator and co-investigator, were provided to each participant.

All patient data gathered by VSTR staff were de-identified, all bad values and duplicate data were removed and the subsequent dataset was provided for review and analysis.

### **Data Management and Analysis**

Incidence data. Using SAS, Version 9.3, all diagnostic and E-codes for AHT from the CDC algorithm and AHT SPP, were applied to the VSTR trauma dataset and AHT cases were identified. In the event of multiple admissions, only the first admission that contained ICD-9-CM codes for head trauma was included. Analysis indicating the frequency distribution of demographic data resulting from the CDC algorithm and AHT SPP were completed.

**Mortality data.** The OCME AHT fatality cases were separated into two categories, accidental head trauma and homicidal head trauma. The Office of the Chief Medical Examiner provided the resulting data to the VSTR and secondary investigator.

#### **Section IV: Results**

The purpose of this project was to determine the most rigorous evidence-based method for calculating the abusive head trauma incidence and mortality rates in Virginia for children under age three. The outcomes from the CDR algorithm and AHT SPP were combined to provide AHT incidence and mortality rates.

### **Abusive Head Trauma**

The CDC algorithm indicated that from 2008 to 2012, 78 Virginia children sustained AHT, 65 were categorized as definite/presumptive, and 13 were categorized as probable AHT. Using the CDC broad definition of AHT, the CDC algorithm generated a rate of 5.14 per 100,000 in children under age three (*See Table 1*).

Table 1

Under Age Inree					
Surveillance	Definite	Probable	Total by	Indeterminate	nAHT
Method	Presumptive		Method		
	1				
CDC	65	13	78	0	37
A UT SDD	68	00	158	227	20
AIII SFF	08	90	138	231	30
Total Cases	133	103	236	237	67
	155	105	230	231	

CDC Surveillance and Abusive Head Trauma Surveillance Pilot Protocol Outcomes in Children Under Age Three

*Note:* Non-Abusive Head Trauma (nAHT). Abusive Head Trauma Surveillance Pilot Protocol (AHT SPP) results represent cases coded as minor fall, only.

The AHT SPP identified 158 AHT cases from 2008 through 2012, which met diagnostic criteria for non-fatal definitive/presumptive or probable abusive head trauma but had a reported E-code indicating a minor fall. Using the AHT SPP algorithm, an AHT incidence rate of 15.56 per 100,000 children under age three, and 41.9 per 100,000 children under age one, was estimated.

Of the non-fatal AHT cases identified, 47% were white, 26% were black and 22% were categorized as "other" racial origin. The non-fatal AHT average age was 6.3 months, gender rates were approximately equal (51% male) and the average length of hospital stay was 3.6 days. Most children who sustained non-fatal AHT were injured at home (82%), and of the children who met diagnostic criteria for AHT but were reportedly injured from a minor fall, 25% were coded as having fallen from bed, 16% from other furniture and 6.4% were coded as having fallen from a chair. Upon discharge, 23% of children were transferred to another acute care facility, 3.8% were discharged to a skilled nursing facility or inpatient rehab, and the remainder (71%) were discharged home. The primary source of insurance coverage was Medicaid (44%), followed by private insurance (26%), unknown or other payer (27%) and a small number (4%) were reportedly self-pay (See *Table 2*).

#### Table 2

Descriptive Category N=236	Outcomes	N (%)
Race	White	112(47)
	Black	62(26)
	Other	51(22)
Gender	Male	121(51)
Mean Age	6.3 Months	-
-	< age one	214(91)
Length of Hospital Stay	3.6 Days	-
Location Where Injury Occurred	Home	193(82)
Payer Source	Medicaid	103(44)
	Private	62(26)
	Unknown	42(15)
	Other	26(11)
	Self-Pay	10(04)
Discharge Disposition	Home	168(71)
	Acute care facility	54(22)
	Skilled nursing	4(02)
	Inpatient Rehab	5(02)
Minor Fall	From bed	58(25)
	From (other) furniture	37(16)

*Surveillance Pilot Protocol Non-Fatal Abusive Head Trauma Descriptive Characteristics* 

The most common diagnoses among children who sustained non-fatal AHT were skull fractures (98), subdural hemorrhage (55), femur fracture (37), other long bone fractures (27), one or more rib fractures (25) other unspecified injury to the head (24) subarachnoid hemorrhage (21) injury to internal organs (16) and other unspecified intracranial injury (12). Two cases were coded as shaken baby syndrome (See *Table 3*).

Table 3

Abusive Head Trauma Surveillance Pilot Protocol Non-Fatal Diagnoses in Children Under Age Three

Diagnosis N=236	Fractures	ICI	Internal
			Injury
Skull fracture	98		
Subdural hemorrhage		55	
Femur	37		
One or more ribs	25		
Unspecified injury to head		24	
Subarachnoid hemorrhage		21	
Humeral	18		
Injury to internal organs			16
Unspecified ICI		12	
Tibia and/or fibula	9		
Cerebral contusion		6	
Anoxic brain injury		2	
Shaken Baby Syndrome		2	
Total Non-fatal diagnoses	192	122	16
Note: Intracranial Injury (ICI)			

### **Indeterminate Abusive Head Trauma**

The most common mechanism of injury for indeterminate TBI cases was a fall from bed (54%), even among children less than 2 months of age. The majority of children identified in this category were eight months of age or older.

6.4

#### **Non-Abusive Head Trauma**

The AHT SPP captured 11 cases that sustained intracranial injury only and 19 that sustained intracranial injury and/or other fractures, but identified a mechanism of injury inconsistent with abusive head trauma.

### Fatalities

The AHT SPP identified 63 AHT fatalities in children under age three (2008 to 2012), indicating a five-year mortality rate of 4.15 per 100,000 children. When AHT SPP fatality data were linked to the VSTR, 44 (70%) cases had matching files. Fifteen (34%) of these linked cases were accidental/unintentional fatalities and 29 (66%) were homicide/intentional. Of the 112 cases, 43 were classified as accidental or unintentional, which included motor vehicle accidents, gunshot wounds, crush injuries, jumps and animal bites. Sixty- eight cases were classified as non-accidental or homicide. The AHT injuries varied in the exact language contained in the death certificate, but included "inflicted head trauma, abusive head trauma, blunt force injuries to the head, massive head injuries, non-accidental head injuries" (OCME, 2014). One traumatic head injury case was classified as undetermined. Eight percent of all fatalities were attributed to head trauma and seven percent were attributed to Abusive Head Trauma. Thirty three percent of AHT fatality cases "had in their initial investigatory report, that the injury may have been related to a fall" when the information appeared in V-MEDS narrative data (OCME, 2014).

Of the linked AHT fatality cases, the most commonly identified diagnoses were subdural hemorrhage (16) or other intracranial hemorrhage (15) and skull fractures (31). There were no retinal hemorrhage diagnostic codes reported, though injury to the optic nerve was indicated. Six children sustained spinal cord injury and one case was reported via ICD-9-CM code 995.55 (Shaken Baby Syndrome) (*Appendix B, Table 4*). E-codes identifying perpetrator demographic

information were most often non-specific and were omitted from two of the VSTR linked AHT fatality cases (*Appendix B, Table 5*).

The mean age of children who died from AHT was 9.1 months, and the mean length of hospital stay was 5.6 days. Most AHT fatalities were among children under age one (72%) and were predominantly female (64%). Fifty-two percent of victims were white, 32% were black and 18% were categorized as "other" or "unknown" racial origin. The majority of AHT fatalities (92%) were transported to the hospital for treatment via ambulance or helicopter. Medicaid was the primary payer source (60%) and Medicaid insurance is often used as a designated lower socio-economic indicator (Selassie et al. 2013). Most children who died from AHT-related injuries resided in a Primary Metropolitan Statistical Area (PMSA), followed by Metropolitan Statistical Areas (MSA). Twenty percent of children who sustained AHT fatalities, resided in rural areas (Executive Office of the President, 2013; US Census Bureau, 2014), (See *Table 4*).

Table 4.

Descriptive	ÁHT	N(%)	Accidental	N(%)
Category			Head Trauma	
All		63(56)		43(38)
Head Trauma				
Mean Age	9.1 Months (< age 3)	-	21.5 Months	-
Admission	5.5 Months ( $\leq$ age 1)			
Age by Category	< 1 year	18(72)	<1 Year	3(20)
	1-3 years	6(24)	< Age 2	(33)
			> Age 2	7(47)
Length of Hospital	5.6 Days	-	.5 Days	-
Stay				
Gender	Females	64	Male	53
Race	White	52	White	46
	Black	32	Black	33
Payer	Medicaid	60	Medicaid	40
	Unknown	16	Unknown	27
	Private	12	Other	20
Location of Injury	Home	88	Home	47
			Street/Hwy	33
Rural/Urban	PMSA/MSA	80	PMSA/MSA	80
	Rural	20	Rural	20

Fatalities: Abusive Head Trauma Versus Accidental Head Trauma in Virginia (2008 – 2012)

*Note:* Abusive Head Trauma (AHT)

#### **Section V: Discussion**

The Abusive Head Trauma Surveillance Pilot Protocol outcomes provide the first reported incidence of non-fatal AHT in Virginia, drawn from a statewide trauma dataset that included both emergency department and hospital admissions. The Virginia Department of Health published a non-fatal AHT incidence occurrence for a five-year period (2003 through 2007) in Virginia, of 98 cases. The VDH utilized ICD-9-CM code 995.55 (Shaken Baby Syndrome) to identify and calculate the incidence occurrence of non-fatal hospitalized AHT, and reported a five year crude rate of 15.9 per 100,000 in children less than age one (VDH, 2010). The U.S. incidence rate for non-fatal AHT during the same period was 32.3 per 100,000. Selassie et al. (2013) reported an incidence rate of 28.9 per 100,000 children under age one from 2000 through 2010. The AHT SPP non-fatal AHT rate for 2008 through 2012, was 41.9 per 100,000 children under age one (*Appendix, Table 6*).

The AHT fatality report published by VDH (2010) showed 26 fatalities over a five-year period (2003 to 2007), using code 995.55 to identify cases. A crude five-year death rate of one per 100,000 children under age four was reported, compared to the AHT SPP rate of 4.15 per 100,000 children under the age of three, from 2008 through 2012. The higher AHT fatality rates from 2008 through 2012 may be reflective of the different methods utilized to calculate AHT fatalities, or the different time frames being examined.

#### Weaknesses

A bias toward more severe (hospitalized) cases is likely since the VSTR does not require reporting for trauma cases that were seen in the ED and released - although 260 cases seen in the ED and discharged home - were included in the data. The use of billing codes (ICD-9-CM) to identify AHT, without reviewing supporting documentation in medical records was a potential weakness, but this was addressed by utilizing the VSTR in lieu of other data sources. The VSTR is not reliant upon ICD-9-CM codes assigned by hospital billing coders, rather, individual trauma coders assign the ICD-9-CM codes - irrespective of billing implications. This project relied on the accuracy of coding by trauma registrars who input data in to the VSTR; trauma hospitals automatically transfer their trauma data to the VSTR, non-trauma hospitals must do so manually.

The possibility of circular reasoning exists in this project. Circular reasoning involves using a statement to prove itself - A is true because B is true, and B is true because A is true. Piteau et al. (2012) discussed the risk of circularity in their AHT diagnostic research and addressed this issue by developing a comprehensive list of diagnoses individually associated with AHT cases. Each of the diagnostic clinical indicators contained in the AHT SPP outcomes were also included in the list of diagnoses individually associated with AHT by Piteau et al., with the exception of age.

The outcomes of this project were specific to Virginia, and because of differences in statewide trauma registry-coding practices, may have limited generalizability. However, the processes used for the AHT SPP development, provide a useful model for other states concerned about the accuracy of diagnostic data related to AHT cases in the vulnerable population of infants, aged three and under.

### **Strengths of the Design**

A strength of this project was the large sample size, which included all Virginia children aged three and under who were admitted through an emergency room and were subsequently hospitalized for traumatic head injury. The AHT SPP use of categories that measure non-fatal AHT diagnostic evidence (definite/presumptive, probable, indeterminate and nAHT), was also a strength. The use of OCME generated statewide fatality data to determine the fatality rate minimizes the possibility of AHT cases being mis-categorized. Linked VSTR and OCME fatality data allowed the identification of fatal AHT cases that were coded in the VSTR database as having resulted from a minor fall. Lastly, VSTR data were extracted from medical records by trained trauma specialists that may utilize the entire medical record to report diagnosis and mechanism of injury information; hospital billing coders are limited to certain portions of the medical record for assigning diagnostic and cause of injury codes.

#### **Implications for Practice**

The outcomes of this project may be useful for AHT prevention policy at the institutional or state level. The nursing implications arising from rigorous accounting of AHT incidence, mortality and demographic data, are myriad. Two widely known prevention programs with strong evidence-based outcomes are the *Period of PURPLE Crying* and *Portrait of Promise*; bedside nurses administer both programs to new mothers and family members/caregivers. By using the project outcomes to implement AHT prevention, especially where indicators show high risk, Virginia nurses have a unique opportunity to take the lead in effectively addressing prevention of this tragic form of child abuse.

In addition, the Capstone project illustrated the need for future nursing research regarding trauma coding practices, clinician AHT diagnostic and documentation practices, the cost of disease burden, protective factors and prevention strategies specific to Virginia. To date, there are no definitive clinical guidelines for diagnosing abusive head trauma. The evidence base used in formulation of this project, as well as outcomes reported by this work may provide information useful to the development of such guidelines.

# **Products of the Capstone**

The Capstone Project yielded a descriptive report of the non-fatal AHT incidence and mortality rates in Virginia. Descriptive demographic information pertinent to prevention policy, including age, gender, race, payer source, location of injury and other descriptive data were provided. The project yielded a manuscript suitable for publication, in the form of a research brief to *The American Journal of Public Health*; manuscript format requirements are included in *Appendix D*.

Section VI. Manuscript

Pediatric Abusive Head Trauma in Virginia: A Protocol

For Public Health Surveillance

Using the Virginia Statewide Trauma Registry

# ABSTRACT

**Objectives**: Abusive Head Trauma (AHT) incidence may be underestimated if surveillance methods exclude children with AHT injury patterns because a minor fall was recorded as the mechanism of injury. An AHT Surveillance Pilot Protocol (AHT SPP), which includes minor falls was developed and evaluated. **Methods:** A retrospective review of traumatic brain injury cases in children under age three, between 2008 and 2012 was completed, using the Virginia Statewide Trauma Registry (VSTR) and Virginia Office of the Chief Medical Examiner (OCME) datasets. Non-fatal and fatal AHT rates were calculated and descriptive characteristics identified. **Results:** The Centers for Disease Control and Prevention (CDC) AHT algorithm identified 78 non-fatal AHT cases and an estimated rate of 5.14 per 100,000 children. The AHT SPP identified an additional 158 non-fatal AHT cases and the combined results estimated a non-fatal AHT rate of 15.56 per 100,000 children. An AHT fatality rate of 4.15 per 100,000 children was reported, with 63 deaths. **Conclusions:** The AHT SPP, which includes minor falls, may provide a useful model for calculating more inclusive and accurate rates of non-fatal and fatal AHT.

Public Health Surveillance of Abusive Head Trauma in Virginia

Public health Surveillance Methods for Pediatric Abusive Head Trauma (AHT), that rely upon ICD-9-CM mechanism of injury coding for case identification, may underestimate AHT incidence and related fatalities. This is a concern particularly if they exclude cases with injury patterns that are consistent with AHT, but are coded as being caused by a minor fall. Pediatric Abusive Head Trauma is defined as "an injury to the skull or intracranial contents of an infant or young child (five and under) due to inflicted blunt trauma and/or violent shaking" (Centers for Disease Control and Prevention [CDC], 2012). The estimated incidence rate for non-fatal, hospitalized AHT in the U.S. was 32.3 cases per 100,000 children under age one, between 2003 and 2008 (Parks, Sugerman, Xu and Coronado, 2012). Abusive Head Trauma is the leading cause of child maltreatment fatality in the United States (U.S.), with the highest rates among children under age one (Klevens & Leeb, 2010). The majority of AHT victims have significant neurologic and functional deficits, and as many as 20 to 25% of these children die from their injuries (CDC, 2012; Keenan, Runyan, Marshall, Nocera, Merten and Sinal, 2003; Minns, Jones & Mock, 2008).

There are significant barriers to the accurate diagnosis, documentation and ICD-9-CM coding of AHT, which ultimately affect surveillance outcomes (Bjorn, Falk, Flodmark &Ygee, 2009). The non-specific symptoms a child with head injury may exhibit when presenting for treatment, and the difficulty differentiating between AHT and non-abusive head trauma (nAHT) are two such barriers (Jenny, Hymel, Ritzen, Reinert & Hay, 1999). The expertise and experience level of clinicians, as well as social and legal concerns can also impact accurate identification of these cases (Wood, Hall, Schilling, Keren, Mitra & Rubin, 2010). The lack of a universal AHT definition and methodology for surveillance prompted a 2008 meeting between

AHT medical experts and coding and surveillance specialists from the Centers for Disease Control and Prevention. The resulting surveillance algorithm, *Pediatric Abusive Head Trauma Recommended Definitions for Public Health Surveillance and Research*, relies upon accurate ICD-9-CM diagnosis and mechanism of injury E-codes to identify definite/presumptive and probable abusive head trauma (Parks, Annest, Hill & Karch, 2012). Head trauma cases reportedly caused by minor accidental falls are excluded from consideration as AHT in the CDC surveillance algorithm, though a minor fall is often the reported mechanism of injury in AHT cases (Adamsbaum, Grabar, Mejean and Rey-Salmon, 2010; Bjorn et al. 2009; CDC, 2012)

Subsequent to the formulation of the CDC algorithm, a number of systematic reviews (including Cochrane Systematic Reviews), and prospective and retrospective studies have been published that expand and refine the evidence base for diagnosing, identifying and tracking Abusive Head Trauma. A number of these studies reported the minimal likelihood that minor falls (less than three to four feet) cause intracranial injury or death (Fortin & Stipanicic, 2010; Herman, Mackaroff & Corneli, 2011; John, Kelly & Vincent, 2013; Kemp, 2011; Thompson, Bertocci & Pierce, 2013). The accuracy of ICD-9-CM coding for identifying child abuse was examined in a recent Yale-New Haven Children's Hospital study, which found these codes accurately reflected the physician's conclusions 76.7% of the time among child abuse pediatricians from one hospital. The most common reasons for mis-identifying cases were code error or omission and physician documentation inaccuracies (Hooft, Ronda, Schaeffer, Asnes & Leventhal, 2013). Selassie, Borg, Busch and Russell (2013) reported that E-codes were insufficient to identify all AHT cases in South Carolina. This body of evidence suggested the possibility that AHT may be underestimated when ICD-9-CM coding is used to identify child

abuse based on hospital discharge data, particularly when diagnostic indicators of AHT were present, but the cause of injury was coded as a minor fall.

Rigorous incidence and descriptive data are essential in understanding the scope and severity of AHT, so that effective targeted prevention and evaluation may occur (Richmond-Crum, Joyner, Fogerty, Ellis & Saul (2013). The *Public Health Model for Prevention* created by Dahlberg and Krug (2002), provides a framework for reducing child maltreatment incidence and fatalities. This model uses a systematic approach to prevention by first defining the problem and then identifying risk and protective factors through surveillance, leading to the development and testing of prevention strategies, and widespread use of the evidence-based strategy (Richmond-Crum et al. 2013). The outcomes of this project were the development of rigorous incidence and descriptive data necessary for evidence-based public health prevention of child maltreatment related to AHT in Virginia.

# **METHODOLOGY**

An AHT Surveillance Pilot Protocol (AHT SPP) was developed for retrospective review of Virginia children aged three and under, that were hospitalized with non-fatal traumatic brain injury (TBI) during a five-year period (2008 through 2012). The AHT SPP uses all CDC broad category ICD-9-CM suggested codes, but adds additional codes, which reflect current rigorous evidence-based AHT diagnostic criteria, for use in distinguishing AHT from accidental minor fall-related head trauma. These diagnostic criteria include retinal hemorrhage, afebrile seizures, certain types of fractures, head or neck bruising, apnea and certain age parameters. Six ICD-9-CM E-codes that indicate a minor fall-related mechanism of injury were included in the AHT SPP (See *Table 1, Abusive Head Trauma Surveillance Pilot Protocol Diagnostic Criteria for Minor Falls*).

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Table 1

Level of Evidence	Definite	Probable	Indeterminate	Non-
Diagnostic Criteria	Presumptive			AHT
Intracranial injury plus rib fracture or intracranial injury plus retinal hemorrhage, plus any one of the other features (rib fracture, retinal hemorrhage, apnea, long-bone fractures, seizures, head and/or neck bruising); or intracranial injury plus any combination of three or more of the six significant factors.	Х			
Intracranial hemorrhage plus intraocular hemorrhage, particularly extensive, bilateral and multi-layered.	Х			
Age <12 months plus intracranial injury plus skull fracture plus long bone fracture; or intracranial injury and non-skull fracture(s).	Х			
All cases coded as 995.55 (no E-code needed).	Х			
Age two to seven months and intracranial injury.		Х		
Primary intracranial injury and secondary intracranial injury (hypoxemia, ischemia, edema).		Х		
Intracranial injury plus age less than two months - or intracranial injury plus age greater than eight months.			Х	
Isolated skull fracture, or any head injury case that does not conform to the diagnostic criteria for definite/presumptive, probable or indeterminate AHT.				Х

Abusive Head Trauma Surveillance Pilot Protocol Diagnostic Criteria for Minor Falls

These additional diagnostic criteria were applied only where a minor fall E-code (E-884.2, 884.3, 884.4, 884.5, 884.6, 884.8) was noted as the cause of head trauma. All head trauma cases were categorized as either definite/presumptive AHT, probable AHT, indeterminate or Non-

Abusive Head Trauma. When no E-codes were present, or when diagnostic codes were missing, the case was excluded from consideration. Both the CDC algorithm and SPP exclude (where noted) AHT fatalities, birth trauma, coagulation defects, congenital anomalies, unintentional gunshot wounds, stab wounds, and penetrating injury - except when ICD-9-CM codes indicate abuse (CDC, 2012).

Virginia requires all hospitals that treat emergency patients to report trauma-related diagnosis and mechanism of injury (E-code) data to the Virginia Statewide Trauma Registry (VSTR) database, if the patient was admitted for care. E-codes are not otherwise mandatorily reported in Virginia hospital discharge datasets. As such, the VSTR represented the most rigorous database for use in applying the CDC algorithm and Surveillance Pilot Protocol.

The AHT SPP relied upon the Virginia Office of the Chief Medical Examiner (OCME) for AHT fatality data, in lieu of utilizing an ICD10 coding schema for case identification. Virginia OCME forensic pathologists utilize the standards of the National Association of Medical Examiners for categorizing the cause and manner of the death, which includes a review of autopsy findings and the investigations of legal authorities and child protective services (OCME, 2014). All fatalities for children under age three, from the Virginia Medical Examiner Data System (VMEDS), were manually reviewed by the OCME using words (in lieu of codes) to identify cases that included head trauma in the manner of death. The cases were then categorized as accidental/unintentional or homicidal/intentional or undetermined, based upon OCME designation.

# RESULTS

The purpose of this project was to determine the most rigorous evidence-based method for calculating AHT incidence and mortality rates in Virginia, for children under age three, and to identify descriptive characteristics for use in prevention planning. The CDC algorithm and the AHT SPP were separately administered and results described.

# **Abusive Head Trauma**

The CDC algorithm was run on the 856 Virginia children who sustained trauma between 2008 and 2012, and of those, 78 were determined to be non-fatal AHT, 65 were categorized as definite/presumptive and 13 were categorized as probable abusive head trauma. An incidence rate of 5.14 per 100,000 children under age three was reported. The incidence rate in children under age one was reported as 4.15 per 100,000 children.

The AHT SPP identified 158 additional AHT cases from 2008 through 2012, which met diagnostic criteria for non-fatal definitive/presumptive or probable AHT, and had a reported Ecode indicating a minor fall. The CDC algorithm and SPP combined results, provided a total incidence of 236 AHT cases. A non-fatal AHT incidence rate of 15.56 per 100,000 children under age three, and 41.9 per 100,000 children under age one, were estimated (See Table 2, Abusive Head Trauma Surveillance Pilot Protocol).

Table 2

mensive mene	11 dittinid Still Fel		110100011	1 + 11 Stitter (2000	2012)
Surveillance	Definite	Probable	Total by	Indeterminate	nAHT
Method	Presumptive		Method		
	_				
CDC	65	13	78	0	37
лит срр	68	90	158	237	30
AIII SII	00	)0	150	231	50
Combined	133	103	236	237	67
Results	155	105	230	231	07

*Abusive Head Trauma Surveillance Pilot Protocol in Virginia (2008 – 2012)* 

Note: Non-Abusive Head Trauma (nAHT). Abusive Head Trauma Surveillance Pilot Protocol (AHT SPP) results represent non-fatal AHT cases coded as minor fall only. Source: Virginia Statewide Trauma Registry Dataset

Of the non-fatal AHT cases identified, 47% were white, 26% were black and 22% were categorized as "other" racial origin. The non-fatal AHT mean age was 6.3 months, gender rates were approximately equal (51% male) and the average length of stay was 3.6 days. Most children who sustained non-fatal AHT were injured at home (82%), and of those children who met diagnostic criteria for AHT but were reportedly injured from a minor fall, 25% were coded as having fallen from bed, 15.7% from other furniture and 6.4% were coded as having fallen from a chair. Upon discharge, 23% of children were transferred to another acute care facility, 3.8% were discharged to a skilled nursing facility or inpatient rehab, and the remainder (71%) were discharged home. The primary source of insurance coverage was Medicaid (44%), followed by private insurance (26%), unknown or other payer (26.3%) and a small number (4.3%) were reportedly self-pay.

The most common diagnoses among children who sustained non-fatal AHT, were skull fractures (98), subdural hemorrhage (55), femur fracture (37), other long bone fractures (27), one or more rib fractures (25) other unspecified injury to the head (24) subarachnoid hemorrhage (21) injury to internal organs (16) and other unspecified intracranial injury (12). Two cases were coded as shaken baby syndrome (*See Table 3. Diagnosis Type: Fatal Abusive Head Trauma Versus Non-Fatal Abusive Head Trauma in Virginia (2008 - 2012)*.

#### **Indeterminate Abusive Head Trauma**

The most common mechanism of injury for indeterminate head trauma cases was a fall from bed (54%), even among children who were unable to roll over unassisted (less than 2 months of age). An indeterminate head trauma incidence rate of 8.44 per 100,000 children under age three was estimated. The majority of children identified in this category were eight months of age or older.

# Table 3

Diagnosis Type	Intracranial		Rib/Long Bone		Internal Organ							
					Fra	ctures	5					
Fatal versus Non-Fatal	Fata	1/%	nFat	al/%	Fata	al/%	nFa	tal/%	Fat	al/%	nFa	tal/%
Skull Fracture	20	.32	98	.42								
Subdural Hemorrhage	16	.25	55	.23								
Other Intracranial Hemorrhage	15	.24										
Unspecified Intracranial Injury			12	.05								
Unspecified Injury to head			24	.10								
Cerebral Contusion			6	.03								
Anoxic Brain Injury	3	.05	2	.01								
Injury to Internal Organs									10	.16	16	.07
Subarachnoid Hemorrhage	5	.08	21	.09								
One or More Rib Fractures					5	.08	25	.11				
Humeral Fracture							18	.08				
Tibia and/or Fibula Fracture					3	.05	9	.04				
Femur Fracture					3	.05	37	.16				
Total Diagnoses/	59	.94	218	.94	11	.17	89	.38	10	.16	16	.07
Percentage												

Diagnosis Type: Fatal Abusive Head Trauma Versus Non-Fatal Abusive Head Trauma in Virginia (2008 – 2012)

*Note*: Abusive Head Trauma (AHT) Fatalities: N=63; Non-Fatal AHT (nFatal): N=236. Shaken Baby Syndrome (SBS). Source: Office of the Chief Medical Examiner Virginia Statewide Trauma Registry

# **Non-Abusive Head Trauma**

The AHT SPP identified 11 children that sustained intracranial injury only, and 19

children that sustained intracranial injury and/or other fracture(s), but had a recorded mechanism

of injury not associated with Abusive Head Trauma.

# **Abusive Head Trauma Fatalities**

Of 112 head trauma related fatalities between 2008 and 1012, 43 were classified as accidental or unintentional, which included motor vehicle accidents, gunshot wounds, crush injuries, jumps and animal bites. Sixty- eight cases were classified as non-accidental or homicidal, which included gunshot fatalities. The AHT SPP identified 63 AHT fatalities in children under age three (2008 to 2012), for a five- year mortality rate of 4.15 per 100,000

children. When the AHT fatality cases were linked to the VSTR, 44 (70%) cases had matching files. Fifteen (34%) of these linked cases were accidental/unintentional fatalities and 29 (66%) were homicide/intentional fatalities.

The mean age of children who died from AHT was 9.1 months, and the mean length of hospital stay was 5.6 days. (See *Table 4, Fatalities: Abusive Head Trauma versus Accidental Head Trauma in Virginia (2008 - 2012)*. Most AHT fatalities were among children under age one (72%) and were predominantly female (64%). Fifty-two percent of victims were white, 32% were black and 18% were categorized as "other" or "unknown" racial origin. The majority of AHT fatalities were transported to the hospital for treatment via ambulance or helicopter (92%), Table 4

Descriptive	AHT	N(%)	Accidental	N(%)
Category			Head Trauma	
All Head Trauma		63(56)		43(38)
Mean Age	9.1 Months (< Age 3)	-	22 Months	-
On Admission	5.5 Months (< Age 1)			
Age by Category	< 1 year	18(72)	<1 Year	3(20)
	1-3 years	6(24)	< Age	(33)
			> Age 2	7(47)
Length of Hospital Stay	6 Days	-	.5 Days	-
Gender	Females	64	Male	53
Race	White	52	White	46
	Black	32	Black	33
Payer	Medicaid	60	Medicaid	40
	Unknown	16	Unknown	27
	Private	12	Other	20
Location of Injury	Home	88	Home	47
			Street/Hwy	33
Rural/Urban	PMSA/MSA	80	PMSA/MSA	80
	Rural	20	Rural	20

*Fatalities: Abusive Head Trauma Versus Accidental Head Trauma in Virginia (2008 – 2012)* 

*Note:* Abusive Head Trauma (AHT). All Head Trauma: excludes penetrating trauma. Source: Virginia Statewide Trauma Registry; Office of the Chief Medical Examiner

and the majority (60%) were insured by Medicaid, a designated socio-economic indicator (Selassie et al. 2013). Most children who died from their AHT- related injuries resided in Primary Metropolitan Statistical Areas (PMSA), followed by Metropolitan Statistical Areas (MSA). Twenty percent of children that sustained AHT fatalities, resided in rural areas (Executive Office of the President, 2013; US Census Bureau, 2014).

Of the linked AHT fatality cases, the most commonly reported diagnoses were skull fractures (31), subdural hemorrhage (16) or other intracranial hemorrhage (15). There were no retinal hemorrhage diagnostic codes reported, though injury to the optic nerve was indicated. Six children sustained spinal cord injury and one case reported ICD-9-CM code 995.55 (Shaken Baby Syndrome).

E-codes identifying perpetrator demographic information were most often non-specific and E-codes were omitted from two of the VSTR linked AHT fatality cases. Interestingly, Ecodes were assigned to all accidental head trauma fatality cases.

## DISCUSSION

The CDC algorithm and AHT SPP outcomes provide the first reported incidence of nonfatal AHT in Virginia, from a statewide trauma dataset that included both emergency department and hospital admissions, and produced the highest rates to date, 15.56 per 100,000 children under age three and 41.9 per 100,000 children under age one. The Virginia Department of Health (VDH) reported a non-fatal AHT incidence of 98 cases in children under age four, from 2003 through 2007, using ICD-9-CM code 995.55 (Shaken Baby Syndrome), and a five -year crude rate of 15.9 per 100,000 children under age one (VDH, 2010). Using the CDC algorithm, the U.S. incidence rate for non-fatal AHT in children under age one during the same five-year period was 32.3 per 100,000 children (Parks et al. 2012). Selassie et al. (2013) reported an incidence rate of 28.9 per 100,000 children under age one in South Carolina, over an eleven -year period from 2000 through 2010. It is unclear whether the higher estimated non-fatal AHT incidence rates among children under age one reflect an increase in incidence from 2008 through 2012, or are reflective of the different methodologies used for surveillance.

In 2010, an AHT fatality report published by VDH showed 26 deaths in children under age four, between 2003 and 2007, drawn from the Virginia Violent Death Reporting System (VDH, 2010). A crude five-year death rate of 1 per 100,000 children under age four was reported, compared to a rate of 4.15 per 100,000 children under the age of three, between 2008 and 2012 using the Abusive Head Trauma Surveillance Pilot Protocol. The AHT SPP fatality rates may reflect an increase in AHT deaths over the last five years, or the higher rates may be attributable to the use of different surveillance methodologies.

The use of OCME generated statewide fatality data allowed comparison of the characteristics of accidental versus AHT deaths, as well as comparison of non-fatal and fatal AHT characteristics. The mean age of children that died from accidental head trauma related injuries was 21.5 months, compared to a mean age of 9.1 months among AHT fatalities. The average length of hospital stay was 5.6 days in AHT fatalities and .53 days with accidental head trauma, and a higher percentage of children who died from AHT injuries had Medicaid insurance coverage (60%). Most of the children who died from AHT were injured at home (88%), whereas in accidental head trauma, 33% were injured in the street or highway and 46.6% were injured at home.

The AHT related fatalities varied in the exact language contained in the death certificate, but included "inflicted head trauma, abusive head trauma, blunt force injuries to the head, massive head injuries and non-accidental head injuries" (OCME, 2014). Non-fatal AHT cases reported a higher percentage of skull, rib and long bone fractures, and fewer injuries to internal organs, versus AHT fatalities. In addition, there were no spinal cord or eye injuries recorded in non-fatal AHT cases.

Less than one percent of traumatic head injury fatalities were classified as "undetermined" intent. The primary cause of head trauma related fatalities in children under age three, was Abusive Head Trauma. Thirty- three percent of AHT fatality cases "had in their initial investigatory report, that the injury may have been related to a fall", when noted in V-MEDS narrative data (OCME, 2014).

Data contained in the VSTR were extracted from the hospital medical record by trained trauma specialists that utilize the entire medical record to assign diagnosis and mechanism of injury codes, whereas hospital discharge coders collect data primarily for billing purposes and are limited to certain portions of the medical record for assigning codes. The VSTR database proved to be a robust source for head trauma and fracture related injury, as well as demographic data necessary for AHT surveillance and prevention, but was less robust in reporting traumatic injury to the eye, seizures, apnea, and bruising.

# LIMITATIONS

A bias toward more severe (hospitalized) cases is likely, since the VSTR does not require reporting for trauma cases that are seen in the ED and released, although 260 trauma cases seen in the ED and discharged home were included in the data. The use of billing codes (ICD-9-CM) to identify AHT, without reviewing supporting documentation in medical records is a potential weakness, but this was addressed by utilizing the VSTR database in lieu of other data sources. In Virginia, trauma hospitals automatically transfer their trauma data to the VSTR, but non-trauma hospitals must do so manually, which may have affected coding accuracy.

Because of the risk of circularity in AHT diagnostic research, Piteau et al. (2012) developed a comprehensive list of diagnoses individually associated with Abusive Head Trauma. Each of the diagnostic clinical indicators contained in the AHT SPP were also included in the list of diagnoses individually associated with AHT by Piteau et al., with the exception of age.

The outcomes of this project were specific to Virginia, and because of differences in statewide trauma registry coding practices, generalizability may be limited. However, the processes used for developing the AHT SPP, provide a useful model for other states concerned about the accuracy of AHT surveillance data in the vulnerable population of infants, ages 35 months and under.

# CONCLUSIONS

The Abusive Head Trauma Surveillance Pilot Protocol results indicate that when calculating the incidence of non-fatal AHT, careful scrutiny should be considered before excluding head trauma cases reportedly caused by a minor fall, and consideration should be given to the likelihood of coding errors and omissions. The outcomes of this project may prove helpful in guiding future research efforts, including clinician identification of AHT in the community, clinic and hospital setting; medical record documentation of traumatic and abusive head injury, alternative data sources for AHT surveillance, and improving trauma registry coding practices. To date, there are no definitive clinical guidelines for diagnosing Abusive Head Trauma. The evidence base used in formulation of this project, as well as outcomes reported by this work may be useful in the development of such guidelines.

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