

SHAKE UP MISSOURI:  
DOCUMENTING FATAL ABUSIVE HEAD TRAUMA INCIDENCE IN MISSOURI

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the Faculty of the Graduate School  
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Master of Science

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by  
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The undersigned, appointed by the dean of the Graduate School, have examined the thesis entitled

SHAKE UP MISSOURI:

DOCUMENTING FATAL ABUSIVE HEAD TRAUMA INCIDENCE IN MISSOURI

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and hereby certify that, in their opinion, it is worthy of acceptance.

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## DEDICATIONS

This work is dedicated to my husband, Ben, and our families. Ben, without your love, guidance, patience, and unfading support of my education I would not have been able to complete this work. Your love and companionship have made the rough times bearable and the good times sweeter. To our families – thank you for your continued, faithful support of my academic endeavors and perpetual confidence in my work. Your love, faith, guidance, and strong support of higher education have shaped me into who I am.

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## LIST OF ABBREVIATIONS

AAP	American Academy of Pediatrics
AHT	Abusive head trauma
CDC	Centers for Disease Control and Prevention
ICD	International Classification of Disease
ICD-9	International Classification of Disease, 9th Edition
ICD-10-CM	International Classification of Disease, 10th Edition, Clinical Modification
MCFRP	Missouri Child Fatality Review Program
MDHSS	Missouri Department of Health and Senior Services
MICA	Missouri Information for Community Assessment



## CHAPTER I

### INTRODUCTION AND LITERATURE REVIEW

Abusive head trauma (AHT), commonly referred to as “shaken baby syndrome,” is a serious form of child abuse that results in head injury in infants and children. AHT is the leading cause of abuse-related death in infants and children (American Academy of Pediatrics, Committee on Child Abuse and Neglect, 2001; Case et al., 2001; Keenan et al., 2003) and is also the leading cause of serious non-fatal head injury among infants in the United States (Parks, Annest, Hill, & Karch, 2012a). Reported mortality rates associated with AHT vary, but it is estimated that approximately 15-35% of AHT cases result in death (Shein et al., 2012, Keenan et al., 2003; Kesler et al., 2008).

Previous estimates of AHT incidence and monitoring of temporal trends have been limited by the lack of a consistent definition of AHT (Parks et al., 2012a). Inconsistent methods of tracking AHT incidence, as well as variations in definitions of AHT used by researchers and public health agencies result in inaccurate estimates of incidence, morbidity, and mortality associated with AHT (Parks et al., 2012a). Data available from the Missouri Child Fatality Review Program (MCFRP) Annual Reports indicated that from 2000–2009 a total of 114 children, including 55 infants, died due to AHT (MCFRP, 2014).

Yearly AHT totals ranged from 4-21 children (MCFRP, 2014). Although Missouri has one of the most comprehensive Child Fatality Review Programs in the nation, the number of AHT deaths documented by the Child Fatality Review Program may be an underestimate due to challenges related to identifying AHT in rural areas.

In an effort to provide a standardized approach to monitoring AHT incidence and trends in a population, the Centers for Disease Control and Prevention (CDC) published definitions of AHT that can be applied to hospital discharge and death record data to estimate the incidence of AHT in children under the age of 5 years (Parks et al., 2012a). The CDC definition utilizes International Classification of Disease (ICD) codes to identify deaths at two levels of certainty (Parks et al., 2012a). These definitions have been used to generate estimates of AHT incidence using national data (Parks, Kegler, Annett, & Mercy, 2012b; Parks, Sugerman, Xu, & Coronado, 2012c) but only a few states (Alaska, California, and North Carolina) have utilized standardized methods to determine AHT incidence (Parrish, Baldwin-Johnson, Volz, & Goldsmith, 2013; Shanahan, et al., 2013; Wirtz & Trent, 2008). To date, Missouri has not used the CDC definitions to evaluate AHT incidence or mortality. In late 2004 Missouri implemented Statute 191.748 to educate mothers about the dangers of AHT in infancy. Statute 191.748 mandates that a video about the dangers of shaking an infant be offered to every mother who gives birth in a Missouri obstetrical ward. Following considerable success of an AHT intervention in New York that provided a multifaceted approach to AHT prevention (Dias et al., 2005), many states enacted more rigorous standards, including individualized teaching by nurses and parental contracting, for AHT education (Diaz et al., 2005). Missouri requirements for AHT education lag behind many states (National

Conference of State Legislatures, 2012). Missouri has implemented laws that mandate only a portion of the interventions associated with significant AHT reduction.

Importantly, since implementation of Missouri statute 191.748, no effort has been made to evaluate the law's impact on AHT mortality rates.

The purpose of this study is to apply the standardized definitions of AHT developed by the CDC to Missouri death record data to document mortality, describe demographic characteristics of victims of fatal AHT in Missouri, and evaluate the effectiveness of Missouri Statute 191.748.

## CHAPTER II

### METHODS

This study utilized a secondary analysis of Missouri death record data to determine the statewide incidence of AHT during a 10-year period from 2000 to 2009. An ecologic design was utilized to assess AHT mortality rates, victim demographics, and the effect of Missouri's AHT prevention legislation on incidence of fatal AHT by comparing fatal AHT rates for the 5-year periods before and after Missouri statute 191.748 went into effect. Statewide rates of fatal AHT were calculated for each year, 5-year, and 10-year period under study.

#### **Population**

The study population consisted of all Missouri children (0-4 years) who died from January 1, 2000-December 31, 2009. From this population, children aged 0-4 years who sustained a fatal abusive head injury were identified using the CDC recommended definition. Groups were defined as deaths related to AHT and other deaths.

#### **Data Source**

Missouri death record data were used to carry out this study. The Missouri Department of Health and Senior Services (MDHSS) cooperates with other states in the exchange of non-resident deaths, so that the death of Missouri residents are included in death record data, even if the death occurred in a different state. Following review and

approval by the MDHSS and University of Missouri-Columbia Health Sciences IRB, a de-identified dataset of all deaths of Missouri children less than 5-years-old for the years 2000-2009 was obtained. The dataset included the sex, race, date of birth, year of death, age at death (for infants, in months), first significant cause of death, first significant condition, second significant condition, multiple causes of death, and date of injury.

### **Case Definition**

Pediatric AHT is defined conceptually as an injury to the skull or intracranial contents of an infant or young child due to inflicted blunt impact and or violent shaking, not caused by neglectful supervision or gunshot/stab/penetrating trauma (Parks et al., 2012a). In order to assist with public health surveillance, the CDC provided broad and narrow operational case definitions of fatal AHT based on ICD-10 and External Cause of Injury codes, and recommended the broad definition for population-level surveillance due to its enhanced sensitivity. AHT is identified by definite or probable degrees of certainty (Parks et al., 2012a). AHT fatalities were identified by applying the CDC definitions of definite or presumptive and probable AHT, listed in Table 1, to death certificate data from the state of Missouri. In order to be counted as a death due to AHT, the record was required to contain a qualifying ICD-10 diagnosis code and an external cause of injury code (E-code), which characterizes the mechanism of injury. All E-codes in the definite/presumptive category denote abuse or assault. Parks et al. (2012b) found that 90% of AHT deaths in their study met the definition for presumptive AHT.

Due to the small number of deaths identified in each category and previous findings that indicate that the majority of deaths occur in the presumptive category, this study reports only a combined number of all AHT deaths (definite/presumptive and probable) and uses this combined number in rate calculations.

**Table 1.** CDC Developed Definition of Fatal AHT in Children Under 5 Years of Age, using ICD-10-CM Codes.

AHT category	Clinical diagnosis code	Injury or abuse code
Definite or Presumptive	S02, S02.0-S02.1, S02.7-S02.9, S04.0, S06.0-S06.9, S07.1, S07.8-S07.9, S09.7-S09.8, T90.2, T90.5, T90.8-T90.9	Y00, Y01, Y04, Y07.0-Y07.3, Y07.8-Y07.9, Y08, Y09, Y87.1, T74.1, T74.8-T74.9
Probable	All those above	Y29, Y30, Y33, Y34, Y87.2

*Note.* AHT deaths must have both a clinical diagnosis and injury/abuse code.

In the first year under consideration, 2000, data were coded using ICD-9 codes and then categorized by type of death. All subsequent years (2001-2009) were coded using ICD-10 codes. Because of the variability in coding structure utilized by the State of Missouri, the CDC definition could not be applied completely to data from the year 2000. A modified definition, utilizing qualifying ICD-9 codes from the CDC non-fatal AHT definition, along with the presence the cause of death classification of “head injury” was utilized to identify AHT deaths in this single year.

### **Data Analysis**

To allow for assessment of temporal trends in AHT mortality, yearly, 5-year, and 10-year rates of AHT were calculated for the period from 2000-2009. Mortality related to AHT is known to occur more frequently in infants (Parks et al., 2012a; Parks et al., 2012b); because of this, calculating a rate for all children aged 0-4 years would have diluted the true infant mortality rate. Additionally, the most appropriate calculations for infant and child mortality utilize different denominators (Infants: births; Children:

population). To portray the most accurate picture of AHT mortality in Missouri, yearly AHT mortality rates for infants (0-11 months), Children aged (1-4 years), and all children under age 5 in Missouri were calculated. For infant mortality, the denominator utilized was all live births and is reported as the number of deaths related to AHT per 100,000 births. For children (1-4 years) the denominator was the population estimate of the number of children aged 1-4 years (obtained from MDHSS Missouri Information for Community Assessment (MICA) population estimates), and is reported as the number of deaths related to AHT per 100,000 children (1-4 years). A rate of total AHT (for all infants and children 0-4 years) was also calculated, using a population estimate as the denominator (obtained from MDHSS MICA population estimates), and is reported as deaths related to AHT per 100,000 children (aged 0-4 years). Due to the small number of deaths identified each year, the calculated yearly mortality rates were unstable. To deal with this instability, we calculated aggregate rates (5- and 10-year averages) for each age group of interest.

Statute 191.748 went into effect in late August of 2004. Following enactment of this statute, hospital compliance with offering videos to new mothers was assumed to be low due to the difficulty of standardizing practices across the state, especially in rural locations. To simplify the analysis in this project, and account for the period of transition in late 2004, the time before enactment of the law was evaluated as 2000-2004, and period after enactment as 2005-2009.

Infant mortality due to AHT is frequently reported by month of age (Parks et al., 2012b; MCFRP, 2014). In order to evaluate infant mortality due to AHT, incidence by month was analyzed to identify the pattern of AHT mortality in infants, by month of age, for the 10-years under evaluation.

Demographic characteristics (age, race, and sex) of the victims of fatal AHT (age 0-4 years) were analyzed using descriptive statistics. Characteristics are reported for infant and child victims of AHT and were compared to all other children (0-4 years) who died during the same time period using t-tests and chi-square analyses. For the category of race, we have reported only "white" and "all other" due to the small number of deaths in each non-white race category.

The evaluation of rates of AHT mortality in infants before and after implementation of Missouri statute 191.748 was conducted using Poisson regression analyses to evaluate the changes in AHT rates over time. Poisson regression is a multivariate regression procedure that is commonly used to model events that occur with relative infrequency, and as such is well suited for evaluating the rate of a rare event in a given population over time (Kleinbaum, Kupper, & Muller, 1988).



## CHAPTER III

### RESULTS

#### Rates of AHT

Application of the CDC definition of fatal AHT to MDHSS death record data identified a total of 46 AHT deaths over the 10-year period, with the largest number of deaths for any of the age group occurring in infants (n= 25). Figure 1 displays the distribution of AHT related fatalities for Missouri children by year of age for the years 2000-2009.

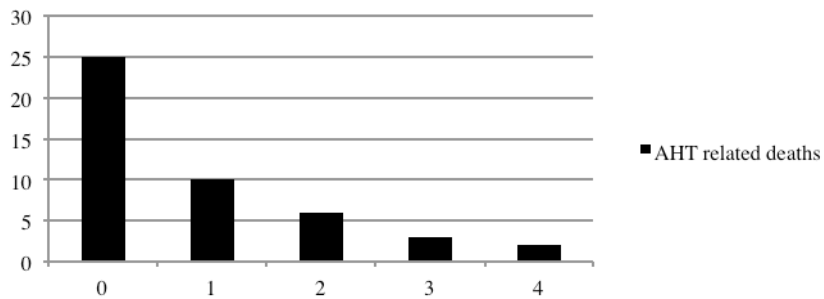


Figure 1. AHT Related Deaths in Missouri by Year of Age, 2000-2009.

Table 2 shows the distribution of AHT deaths by year and age group. Further analysis of Missouri data revealed 5-year average AHT incidence rates of 1.40 (2000-2004) and 1.04 (2005-2009) per 100,000 children (0-4 years), and 10-year average incidence of 1.22 deaths per 100,000 children (0-4 years). Infants in Missouri displayed a greater rate of fatal AHT at all reported time points than older children (1-4 years), with 5-year rates of

3.93 (2000-2004) and 2.49 (2005-2009) per 100,000 infants, and a 10-year rate of 3.19 deaths per 100,000 infants. Table 3 provides annual, 5-year, and 10-year rates for each age group from 2000-2009.

**Table 2.** Number of AHT Related Deaths by Year of Age, 2000-2009.

Age	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	Total
Infants (0-11 mo)	7	2	0	4	2	2	2	2	0	4	25
Children (1-4 yr)	2	2	2	4	1	1	2	2	2	3	21
Children (0-4 yr)	9	4	2	8	3	3	4	4	2	7	46

**Table 3.** Rates of AHT per 100,000 Persons, by Age Group.

Time Period	0-11 months	1-4 years	0-4 years
2000	9.17	0.68	2.43
2001	2.66	0.68	1.08
2002	0	0.67	0.54
2003	5.20	1.35	2.15
2004	2.57	0.34	0.8
<b>5-Year Rate (2000-2004)</b>	<b>3.93</b>	<b>0.74</b>	<b>1.40</b>
2005	2.55	0.33	0.79
2006	2.50	0.67	1.05
2007	2.44	0.66	1.04
2008	0	0.65	0.51
2009	5.07	0.97	1.80
<b>5-Year Rate (2005-2009)</b>	<b>2.49</b>	<b>0.66</b>	<b>1.04</b>
<b>10-Year Rate</b>	<b>3.19</b>	<b>0.70</b>	<b>1.22</b>

Fatal AHT in infants appeared to peak in early infancy, with four AHT-related fatalities reported in Missouri for infants who were 2- and 4-months old at the time of their death. Rates declined in the later months of infancy, with two or fewer AHT deaths identified in any time period after 4-months of age. Figure 2 shows the distribution of AHT related deaths by age in months for Missouri infants from 2000-2009.

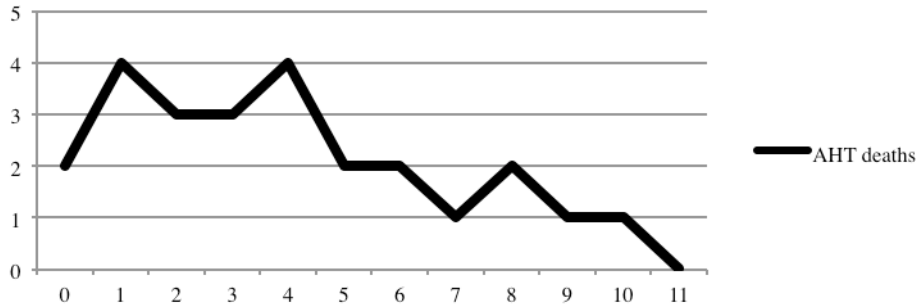


Figure 2. Number of Missouri Infant Deaths Related to AHT by Month of Age, 2000-2009.

### Demographic Characteristics

The demographic characteristics of deaths related to AHT and all other deaths are presented in Table 4. Victims of AHT in Missouri were predominantly male (67.4%), and white (67.4%), however the difference between males and females was not statistically significant (table 4). The population of children who died from other causes were also predominantly male (55.8%), and white (68.1%). Infants who died of AHT were significantly older than other infants who died in Missouri ( $t = 6.022$ ; CI 1.84 - 3.63). There was no significant difference between the mean age of children (1-4 years) who died from AHT and those who died from all other causes ( $t = -1.07$ ; CI 0.213 – 0.723). There was no significant difference between the race or sex of AHT victims and all other children who died.

Table 4. Demographic Characteristics, by Sample (2000-2009)

Characteristic	AHT Deaths (n=46) N(%)		Other Deaths (n=6632) N(%)		p Value
	M	SD	M	SD	
Sex					
Male	31(67.4)		3699(55.8)		0.115*
Female	15(32.6)		2928(44.1)		
Missing	-		5(0.1)		
Race					
White	31(67.4)		4515(68.1)		0.921*
All Other	15(32.6)		2117(31.9)		
Age					
Infant (0-11 mos)	3.96	2.85	1.22	2.27	<0.000t
Child (1-4 yrs)	1.86	1.01	2.11	1.08	

Note. \* denotes Chi-Square analysis. t denotes t-test of differences in means between groups.

### **Comparison of AHT Deaths Before and After Enactment of Statute 191.748**

Results of the Poisson regression indicated that there was no statistically significant difference between the rates of death due to abusive head trauma in time periods under consideration. Infants born in the years prior to implementation of Statute 191.748 (2000-2004) were not more likely to be the victim of fatal AHT compared to infants born after the implementation of the statute (2005-2009) (OR 1.6; 95% CI 0.72-3.56), after controlling for race and sex.

## CHAPTER IV

### DISCUSSION

This is the first study to apply the CDC definition of fatal AHT to death record data in the state of Missouri. We found 10-year mortality rates for infants, children (1-4 years), and all children (0-4 years) to be 3.19, 0.70, and 1.22 per 100,000 children, respectively. Parks et al. (2012b) previously reported infant AHT related mortality rates of 2.14 per 100,000 children when applying the CDC definition to national fatality data. Parks et al. (2012b) also reported an overall AHT fatality rate of 0.76 per 100,000 children (0-4 years). Our study, which utilized the same ICD code-based definition, reported slightly higher rates of AHT mortality in Missouri children.

It is important to note that the CDC definition of fatal AHT identified significantly fewer deaths (n= 46) related to AHT in Missouri children (0-4 years) than the MCFRP reported (n=114) for the same time period. The low numbers of AHT deaths determined by application of the CDC definition of AHT to Missouri death record data may be related to hesitancy of medical coders to utilize codes indicative of AHT (Parrish et al., 2013), disinclination of physicians to diagnose AHT, or routine use of codes not identified in the CDC definition. For example, we found that adding a single ICD-10-CM code for unspecified injury to the head (S09.9) to the CDC definition resulted in identification of an additional 137 deaths. A total of 162 death records (2.4% of all

deaths) contained the S09.9 code, and 25 of those deaths were identified as AHT by the original CDC definition. Addition of S09.9 to the CDC definition resulted in identification of a total of 46 infant and 116 child deaths related to AHT. Yearly totals with the amended definition ranged from 12-21 deaths. The number of deaths identified by adding the additional code, S09.9, more closely mirrored the number of AHT fatalities reported by the MCFRP during the same study period.

Reported rates of fatal AHT are commonly higher in children under 1 year of age (Agran et al., 2003), and typically peak in the early months of infancy when normal, age-related crying may contribute to caregiver frustration (Barr, Trent, & Cross, 2006; Fujiwara, et al., 2008). Our study found that 54% of fatal AHT occurred in infants, which is consistent with the 57% of AHT reported by of Parks et al. (2012) in their application of the CDC AHT definition to national mortality data. Our study also reported a peak in fatal AHT in young infants, with 56% of deaths occurring during the first 4 months of life, and 72% of deaths occurring during the first 6 months. This finding is similar to other studies on abusive head trauma that have reported the greatest incidence of AHT in the early months of infancy (Dias et al., 2005; Fujiwara et al., 2012; Kesler, et al., 2008; Parks et al., 2012b; Parrish et al., 2013). The higher rates of AHT mortality found in early infancy underscore the importance of early and effective parental education about age-based crying in infants.

Our findings indicate that, on average, infants who die from AHT related mortality are more than 2 months older than infants who die of other causes. This difference is not supported by other reports in the literature, which may be due to elimination of early infantile deaths from analysis.

It is likely that our study found these infants to be significantly older due to the influence of the large number (n= 3865) of neonatal (<1 month of age) deaths that occurred in our study population.

In this study, males accounted for a greater proportion of deaths related to AHT than females. Parks et al. (2012b) also reported that males accounted for a substantially higher percentage of AHT deaths with 58% of their identified deaths being of the male sex. Reports of male predominance in AHT are found consistently throughout both fatal and non-fatal AHT reports (Keenan et al., 2003; Kesler et al., 2008; Parks et al., 2012b; Parks et al., 2012c). The finding that male infants are injured by AHT more frequently than their female counterparts may be related to gender-related parental expectations, and should be considered when designing parental educational interventions.

### **Limitations**

This study contains limitations. A major limitation of this study is that it was conducted using data from only one state, as well as a single data source. In another study of abusive head trauma that utilized multiple sources and data linkage, death records only identified 60% of AHT deaths (Parrish et al., 2013), indicating that death record data alone may not be an adequate source for evaluating AHT in a population.

Another major limitation of the study is that it evaluates only the most severe form of AHT, fatalities. It is likely that the population estimates of the incidence of fatal AHT grossly underestimate the true incidence of AHT (including non-fatal AHT) in the population. Analysis of non-fatal AHT in Missouri children is also needed to determine the true incidence of AHT in Missouri.

Due to the ecological nature of this study, it is impossible to know whether infants who were shaken following the enactment of the law under study had mothers or caregivers who viewed or were offered the opportunity to view the mandated video about the dangers of shaking an infant. Because the study identifies AHT at the population level, there is no way to identify persons who received the intervention, and those who did not. Thus, it is difficult to confirm whether the law was successful, or if other programs and events impacted the number of deaths related to AHT.

Another limitation of this study relates to differences in the way Missouri deaths were coded during the period of study. That is, the deviation from the CDC definition of fatal AHT used in to identify AHT in year 2000 data may have impacted the analysis. It should be noted that the modified definition of AHT utilized in year 2000 data resulted in the highest number of deaths for any year under study (n=9). The deviation in definition may have led to identification of a larger or smaller number of AHT deaths than actually occurred during the year 2000.

We chose to evaluate the period of time prior to and after the enactment of Statute 191.748 as year 2000-2004 and 2005-2009, respectively, even though the statute was truly enacted in late 2004. This decision has the potential to allow a death due to AHT to be counted in the period before the law, even though the law was in effect.

Finally, our study utilized population estimates from the state of Missouri, rather than true counts of the number of children aged 0-4 years of age. This estimate may be higher or lower than the actual population of Missouri children, and has the potential to bias the results. This practice is widely accepted in epidemiological studies, and is unlikely to have a significant impact on the study results.



## CHAPTER V

### CONCLUSIONS

This is the first study to evaluate AHT deaths in Missouri utilizing the standardized CDC definition. Rates of fatal AHT among Missouri children were found to approximate the rates observed in data from a study utilizing national death record data. White males experienced the greatest number of AHT deaths in the Missouri population. There was not a statistically significant difference in the rate of AHT deaths following the enactment of statute 191.748, which may indicate that the law was not effective in preventing AHT deaths. The findings regarding statute 191.748 must be interpreted with caution given the small number of infant deaths related to AHT identified in the analysis. Due to the ecological nature of the study it is not possible to determine if rate of AHT deaths failed to change significantly because of the failure of the intervention or other, unmeasured factors. Because the law enacted in Missouri has failed to significantly impact the rate of infant deaths, the citizens of Missouri should call for more targeted and effective AHT education for parents and caregivers.

The continued incidence of AHT deaths among Missouri's children is disturbing, as is the difference in number of AHT deaths reported by the MCFRP program compared to this application of the CDC definition. These findings should prompt further investigation and intervention. Further study about the use of state-level death record

data as a single source for evaluating AHT mortality in children is needed. The small number of deaths identified by this study should also prompt further study of the CDC AHT definition in small populations. Additionally, investigation about when and how the ICD-10-CM code S09.9 is utilized in practice to code for AHT should be pursued.

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