

Disability-Adjusted Life-Year Burden of Abusive Head Trauma at Ages 0–4

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KEY WORDS

child abuse, DALY, Health Utilities Index, maltreatment, shaken baby syndrome, traumatic brain injury

ABBREVIATIONS

AHT—abusive head trauma

DALY—disability-adjusted life-year

HCUP—Healthcare Cost and Utilization Project

HUI-2—Health Utilities Index, Mark 2

NCSBS—National Center on Shaken Baby Syndrome

SMR—standardized mortality ratio

Dr Miller initiated the study, secured external funding, led study design and interpretation of results, conducted data analysis, and drafted and edited the manuscript; Mr Steinbeigle initiated the study, secured external funding, assisted with study design and interpretation of results, negotiated access to contact lists, fielded the survey, and edited the manuscript; Mr Wicks assisted with study design and interpretation of results, negotiated access to caregiver contact lists, fielded the survey, and edited the manuscript; Dr Lawrence assisted with study design and interpretation of results, conducted data analysis, and edited the manuscript; Ms Barr initiated the study, secured external funding, negotiated access to pediatrician contact lists, assisted with study design and interpretation of results, and edited the manuscript; and Dr Barr initiated the study, secured external funding, assisted with study design and interpretation of results, and edited the manuscript. All authors approved the final manuscript as submitted.

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(Continued on last page)



WHAT'S KNOWN ON THIS SUBJECT: Children who suffer abusive head trauma (AHT) have lasting health and development problems. AHT can reduce life expectancy dramatically. AHT's contribution to the burden of disease has been estimated only as part of a broad category of intentional injury.



WHAT THIS STUDY ADDS: The DALY burden of a severe AHT case averages 80% of the burden of death, with most survivors dying before age 21 years. Even mild AHT is extremely serious, with lasting sequelae that exceed the DALY burden of a severe burn.

abstract



OBJECTIVE: We estimated the disability-adjusted life-year (DALY) burden of abusive head trauma (AHT) at ages 0 to 4 years in the United States.

METHODS: DALYs are computed by summing years of productive life that survivors lost to disability plus life-years lost to premature death. Surveying a convenience sample of 170 caregivers and pediatricians yielded health-related disability over time according to severity of AHT (measured with the Health Utilities Index, Mark 2). Incidence estimates for 2009 came from Vital Statistics for Mortality, Healthcare Cost and Utilization Program Kids' Inpatient Database for hospitalized survivors, and published ratios of 0.894 case treated and released and 0.340 case not diagnosed/treated while in the acute phase per survivor admitted. Survival probability over time after discharge came from published sources.

RESULTS: An estimated 4824 AHT cases in 2009 included 334 fatalities within 30 days. DALYs per surviving child averaged 0.555 annually for severe AHT (95% confidence interval: 0.512–0.598) and 0.155 (95% confidence interval: 0.120–0.190) for other cases. Including life-years lost to premature mortality, estimated lifetime burden averaged 4.7 DALYs for mild AHT, 5.4 for moderate AHT, 24.1 for severe AHT, and 29.8 for deaths. On average, DALY loss per 30-day survivor included 7.6 years of lost life expectancy and 5.7 years lived with disability. Estimated burden of AHT incidents in 2009 was 69 925 DALYs or 0.017 DALYs per US live birth.

CONCLUSIONS: AHT is extremely serious, often resulting in severe physical damage or death. The annual DALY burden several years after mild AHT exceeds the DALY burden of a severe burn. *Pediatrics* 2014;134:e1545–e1550

Shaking and abusing infants and toddlers causes thousands of abusive head trauma (AHT) cases annually in US children aged <5 years.^{1,2} Most injuries are inflicted before the child turns 1 year of age.³ Many victims die or are impaired for life.¹ AHT incidents typically are debilitating, and they often result in vision loss, brain damage, and reduced life span.^{4,5}

Pediatricians have myriad responsibilities regarding AHT. They play critical roles in preventive counseling, case identification, case reporting to child protective services, acute care, and planning and delivery of long-term treatment. They must be prepared to counsel grief-stricken caregivers about the management and prognosis of injuries that tend to be life-shattering. A clear grasp of the burden that AHT imposes will help to inform planning and communication.

Disability-adjusted life-years (DALYs) are widely accepted as the standard global measure of burden of disease.^{6,7} They are computed by summing life-years lost to premature death plus years of productive life survivors lost to disability (ie, the portion of quality of life lost during those years). The DALY or health-related quality of life loss to AHT or for child maltreatment more broadly has not been fully quantified.⁸

The goal of the present article was to quantify the burden of AHT by providing DALY estimates for the United States. Its disability estimates are survey based.

METHODS

Computing DALYs requires knowing the incidence (ie, the number of cases of AHT that occurred in 2009), the immediate mortality, the effect on survival over time for those who survive beyond acute care, and the disability burden over time for survivors. We estimated the survival and disability impacts according to incident severity.

Incidence

In 2008, expert panels developed case definitions based on diagnosis codes and external cause codes that can be used to identify probable AHT cases in mortality files and hospital discharge files.^{1,2} We used those rules to estimate AHT deaths from 2009 Vital Statistics mortality data and hospital admissions from the 2009 Healthcare Cost and Utilization Project (HCUP) Kids' Inpatient Database. Truven MarketScan private insurance and Medicaid data indicated that per case admitted, 0.894 case was treated and released and 0.340 case was not treated at hospitals within 2 days after initial diagnosis (which suggests they were not diagnosed during the acute phase).⁹ Multiplying those ratios by the admission count yielded estimated cases seen only in these nonadmitted settings. We chose MarketScan over HCUP Nationwide Emergency Department Sample data² as a source for the emergency department ratio because the HCUP sample includes data from states that do not code injury causes for patients who are treated and released, which means that the HCUP sample data undercount emergency department cases.

Survival and Mortality

We estimated that 5% of severe AHT victims would die in the first 6 months after hospital discharge. This estimate mirrors the traumatic brain injury mortality rate in Colorado during 1998 to 2003.¹⁰ It exceeds 6-month traumatic brain injury mortality rates in other developed countries.^{11,12} A standardized mortality ratio (SMR) is the ratio of the death rate among a group of people, in this case AHT victims, to the death rate among the US population (from a life table). For those surviving 6 months, Strauss et al¹⁵ estimate that traumatic brain injury mortality for severely injured children is 5% per year for the first 8 years (an SMR from ages 1–8 years averaging 44.7 times the normal

rate from the 2009 US life table¹³) and 4% per year thereafter (an SMR of 21.0 times the norm from ages 9–45 years). For children, they estimate lifelong standardized mortality rates of 1.7 times the norm after moderate brain injury and 1.06 times the norm after mild brain injury.

Health-Related Quality of Life Lost

We collected survey reports on functional capacity loss due to AHT. Survivors of AHT are too rare to find through a survey of the general population. We instead surveyed caregivers of AHT victims and pediatricians. All protocols and instruments were approved by Pacific Institute for Research and Evaluation's institutional review board.

Survey recruitment channels to caregivers of victims included: (1) a National Center on Shaken Baby Syndrome (NCSBS) announcement and survey link sent to the 363 members of a Shaken Baby Support Group Yahoo Listserv, the 304 members of a closed (ie, invitation-only) Facebook caregiver support group, and the 254 members of a closed survivor support group; and (2) 79 e-mail invitations sent by the NCSBS to others assisted by or attending biennial conferences organized by the NCSBS, with a hard copy option available on request (no one requested hard copy). Membership in the 3 support groups included some unavoidable overlap.

The NCSBS and a collaborating pediatrician invited (again by e-mail) the 524 members of the Section on Child Abuse and Neglect of the American Academy of Pediatrics to complete de-identified surveys about their patients.

All surveys were completed anonymously by using the online SurveyMonkey tool. They did not identify the child, the caregiver, or the pediatrician. We requested that respondents not complete multiple surveys about the same child. To further reduce the chance of analyzing 2 surveys about the same child, we asked

respondents how certain they were that no one else had completed a survey about this child. No one said a duplicate report existed. A few respondents stated they were unsure. In those instances, we searched for another survey about a child of the same age and gender who was abused at roughly the same point in time. We found no matches, and we therefore included those surveys in the analysis.

Survey Content

AHT varies in severity depending on long-term health effects. Because the survey came from a convenience sample, we expected its severity distribution to differ from the AHT population. To cope with that bias, we collaborated with an informal advisory group of child abuse pediatricians to design 11 severity assessment questions and a rudimentary classification algorithm (Supplemental Information) for use in the survey. The severity questions covered vision loss, use of shunts and medical assistive devices, number of different antiepileptic medications currently taken, and use of selected other medications. To compute overall burden, we reweighted the survey data to better reflect national AHT severity.

The survey was brief, requiring just 5 to 7 minutes to complete. It included the severity assessment; a few demographic characteristics (victim's gender, age at abuse, current age); whether the child spent at least 10 days in the ICU; whether the child entered foster care or was adopted; and respondent rating of the child by using the Health Utilities Index, Mark 2 (HUI-2)^{14,15} without the optional fertility question. HUI-2 assesses 6 aspects of functioning: ambulation, cognitive, sensory, emotion, self-care, and pain. We chose it because it was initially designed to provide functional assessments to guide decision-making about neonatal intensive care. Hence, it is an appropriate tool for caregivers

and pediatricians to use in assessing infants and children with AHT. Based on pilot testing, we supplemented the HUI-2 responses by adding a "child is too young to judge" response category for ambulation and cognitive learning ability and a "child cannot communicate well enough to judge" response category for pain. A HUI-2 score of 1.0 represents perfect health and a score of 0.0 is assigned to death, with scores <0.0 possible. For example, therefore, a patient with a HUI-2 utility score of 0.75 has 75% of the quality of life of someone in perfect health, which equates to a 0.25 DALY level (1.0–0.75) or 25% disability.

Data Analysis

Functional losses were scored by using the HUI-2 utility scoring algorithm.¹⁵ When the respondent said the child was too young to judge an aspect of his or her functional ability, we assumed the child would have the mean functional level of children with known functionality and the same AHT severity.

The surveys yielded a snapshot of victim disability across severity levels and time periods since injury. To assess how disability varied over time since injury and severity, we used linear regression with child gender, years postinjury, severity, and in some models whether the case was reported by the pediatrician versus caregiver as explanators.

The disability estimates came from a convenience sample that may have overemphasized severe cases. To correct for this possibility, we weighted survey estimates of disability according to severity into an overall average based on the severity distribution in the national incidence data. We estimated 80% of live inpatient discharges for AHT (44% of all nonfatal AHT) were severe because 78% to 84% of hospitalized AHT patients have multiple and typically bilateral retinal hemorrhages, often

in conjunction with other devastating injuries.⁴ We distributed the remaining cases between mild and moderate in proportion to the mild versus moderate severity distribution in the survey. This method provided estimates of 30% mild and 26% moderate AHT cases.

Following the Panel on Cost-Effectiveness in Health and Medicine guidelines,¹⁶ future losses of quality of life and of life-years were discounted to present value at a 3% annual discount rate. This procedure also matches older Global Burden of Disease practices, although the 2010 Global Burden estimates are undiscounted and consequently much larger.¹⁷

At the age when abused children suffered their AHT, their average life expectancy would have been 77.97 years if they had not been abused, which becomes 29.85 present value years when a 3% annual discount rate is applied (computed by using the 2009 US life table¹³ and the age and gender distributions of AHT deaths¹). AHT victims either will lose those life-years or will live them burdened by disability. Using the SMR-adjusted life tables, for each AHT severity, we computed the expected remaining life span after the AHT. Those life-years will be burdened by disability, with the remaining life-years lost. For example, with the SMR-adjusted life table for a severe case, the present value of life expectancy drops to 12.98 years. As shown in the following discussion, we estimated that severe AHT imposes a disability burden of 0.555 DALY per year of life. That means DALYs for a severe AHT case total 24.08 years ($[29.85 - 12.98]$ years of life lost + 12.98×0.555 DALYs while alive).

RESULTS

Table 1 summarizes selected characteristics of the 170 AHT victims described by survey respondents. Severity was mild in 27 cases (15.9%), moderate in 23 (13.5%), and severe in 120 (70.6%). Across

TABLE 1 Selected Characteristics of Children Described in the AHT Survey

Characteristic	Number	Percent
Total cases	170	100
Reported by caregiver	108	64
Reported by provider	62	36
Male	93	57
Age at injury, y		
0	135	83
1	18	11
2	5	3
3–5	5	3
Mild injury	27	15.9
Moderate injury	23	13.5
Severe injury	120	70.6
ICU stay ≥10 d	119	70
Child entered foster care	68	41
Child adopted	25	16
Partially blind or blind due to shaking	96	57
Blind	30	18
Eye surgery but no blindness	8	5
Feeding tube	39	23
Assistive eating device: Yes	18	14
Assistive eating device: Too young to know	14	11
Brain shunt	29	17

Note: Number of responses used in computing percentages varies by item.

all cases, AHT left 57% blind or partially blind, and another 5% requiring eye surgery. Of severe cases, 86% involved vision loss or corrective eye surgery (result not tabulated).

The survey yielded utility scores and age data for 107 children rated by caregivers and 57 rated by pediatricians (with 6 additional cases missing data on years since injury). In regression analyses, mean HUI-2 utility scores did not differ substantively or significantly between mild and moderate cases ($P = .58-.89$) across models controlling for years since AHT, gender, or whether the case was contributed by a pediatrician versus a caregiver (results not tabulated). Therefore, the final analysis pooled those 2 groups.

Table 2 shows mean HUI-2 utility score according to time since AHT occurrence and AHT severity. Overall means were 0.800 for mild/moderate cases (95% confidence interval: 0.757–0.843) and 0.400 for severe cases (95% confidence interval: 0.366–0.436). Although scores fluctuated around the means by severity, the 95% confidence intervals show they clustered tightly. Regression

(results not tabulated) showed scores did not vary systematically with years between AHT occurrence and survey completion.

Among severe cases, mean scores for cases rated by pediatricians were 0.10 lower than for cases rated by caregivers ($P = .03-.04$) across an array of models controlling for years since AHT and gender (results not tabulated). For mild and moderate cases, however, scores for children rated by pediatricians were slightly, but insignificantly, higher (0.05; $P = .23$).

DALYs for nonfatal cases are the difference between the population norms and measured HUI-2 quality of life scores. Norms for HUI-2 were 0.96 (ie, 96% of perfect health) at age 8 years and 0.95 at age 13 years.^{18,19} Assuming a 0.955 norm, the mean annual burden would be 0.555 DALY per year (0.955 norm–0.400 mean for severe AHT cases from Table 2) for severe AHT (95% confidence interval: 0.512–0.598). For mild to moderate cases, mean annual burden would be 0.155 DALY (0.955–0.800 [95% confidence interval: 0.120–0.180]). Including life-years lost to

premature mortality, the present value of estimated mean lifetime loss per case was 4.7 DALYs for minor AHT, 5.4 for moderate AHT, 24.1 for severe AHT, and 29.8 for deaths (Table 3). DALY burden for a severe AHT case averages 80% of the burden of death. On average, DALY loss per 30-day survivor includes 7.6 years of lost life expectancy and 5.7 years lived with disability.

Death certificate data undercount child maltreatment mortality.¹ For 2009, HCUP Kids' Inpatient Database estimated 261 AHT deaths as hospital inpatients (257 definite, 4 probable; based on 173 unweighted cases). Vital Statistics mortality data put the 2009 death count at 187 including 114 hospital inpatients and 73 at other locations. Consequently, an approximate lower bound death count was 334 (261 + 73). Another 4490 children survived at least 30 days after AHT detection in 2009.

In total, the estimated US burden of AHT in 2009 was 69 925 DALYs. With 4 000 000 live births in the United States in 2009, the AHT burden was 0.017 DALY per live birth.

DISCUSSION

AHT is debilitating. One in 14 cases is fatal before hospital discharge. More than one-half of severely injured survivors will die before age 21 years. Our estimates suggest that disability burden for the 44% of survivors who are severely injured is a 55.5% (0.555) reduction in their health-related quality of life. Even those who have mild injuries have an estimated 15.5% reduction in quality of life.

The present study's main limitation is its unavoidable reliance on a convenience sample to determine DALY loss over time by AHT severity level. Survey respondents reported that 62% of AHT survivors suffered vision loss, including 85% of those who spent at least 10 days in ICUs. If anything, this finding is lower than the 78% to 84% of 504 patients

TABLE 2 Cases in the Survey and HUI-2 Score According to Years Since Injury and Injury Severity

Years Since Injury	Mild/Moderate		Severe	
	Cases	HUI-2 Score	Cases	HUI-2 Score
0	10	0.807	12	0.341
1	8	0.821	15	0.400
2	7	0.772	8	0.332
3	1	0.914	13	0.589
4	3	0.906	7	0.272
5	5	0.852	6	0.345
6	4	0.771	6	0.518
7	1	0.808	4	0.356
8	0		5	0.363
9	2	0.52	3	0.339
10	1	0.806	5	0.469
11	1	0.808	5	0.341
12	3	0.816	7	0.401
13	1	0.845	6	0.359
14–22	1	0.808	12	0.422
32–36	1	0.612	1	0.292
Total	49	0.800	115	0.400

Note: 6 cases lacked data on years since injury. The norm for DALY level in this age group is 0.955.

TABLE 3 DALYs per Case and for All US Cases of AHT in 2009 According to Severity

Variable	Mild	Moderate	Severe	Nonfatal	Fatal	All
DALYs per case	4.7	5.4	24.1	13.3	29.8	14.5
Years of life expectancy lost	0.1	0.9	16.9	7.6	29.8	9.1
Years of disability	4.6	4.5	7.2	5.7	0	5.3
Burden relative to a fatality, %	15.8	18.1	80.1	44.7	100.0	48.6
Cases in 2009	1365	1163	1962	4490	334	4824
Total DALYs due to 2009 cases	6422	6282	47 249	59 953	9972	69 925

with retinal injury reported in studies of serial AHT hospitalizations.⁴ Comparing demographic characteristics of the survey and victim populations, survey respondents reported on a population that was 57.4% male. Consistent with that, nationally, 58.6% of AHT cases treated in the emergency department (including those subsequently admitted to the hospital) were male,² as were 57.7% of AHT fatalities¹ and 60% of AHT cases treated as inpatients.³ The survey, however,

reported on victims who were younger than the average victim when injured. Among survey cases, 83% were <1 year old when abused, compared with 77% of all inpatients³ and 60% of all emergency department patients.²

The DALY metric allows comparison of the burden for AHT versus other injuries. Even a mild AHT case has lasting sequelae that exceed the DALY burden of a severe burn.²⁰ The annual DALY burden of 0.155 several years after a mild to moderate AHT is 2 to 4 times the

annual burden of 0.038 to 0.042 DALY in adulthood from the average child maltreatment case.²¹ Thus, even mild AHT is extremely serious.

AHT is a debilitating illness in terms of injury severity, devastating clinical findings, and the trauma of the experience for young children and their families. A previous study documented that AHT results in substantial medical care costs.⁹ The DALY burden estimated here reveals significant losses in quality of life and life expectancy measured according to standard procedures used for other conditions. These findings reinforce the significant challenge AHT cases pose for society and underline the potential benefits of effective prevention efforts. Thus, our findings strengthen the policy case for aggressive preventive intervention and for recognizing that perpetrators have committed a serious crime.

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