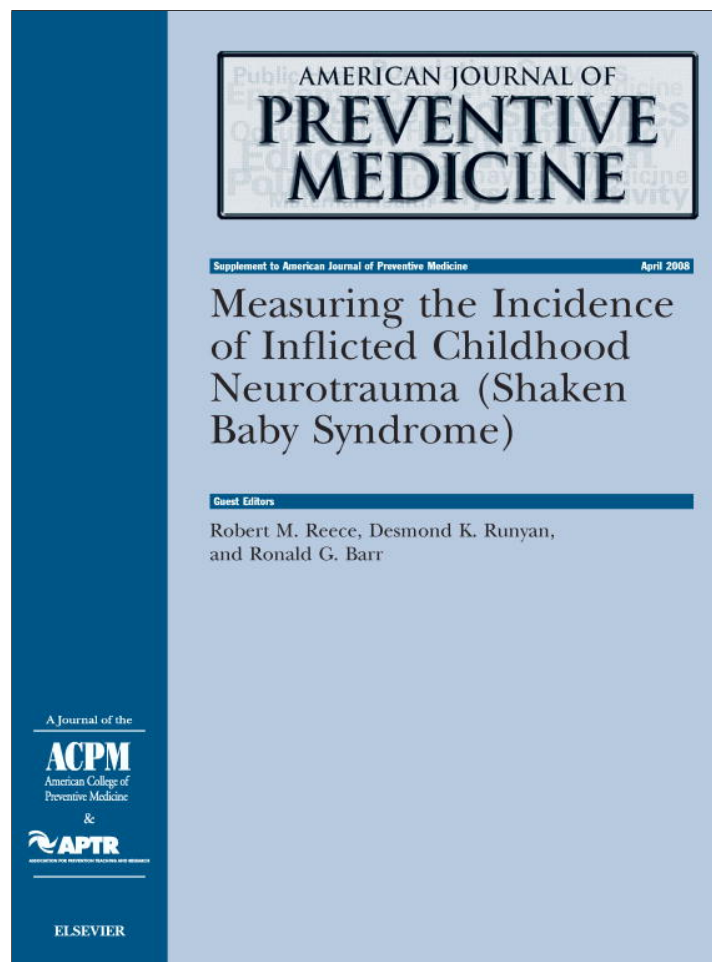


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# Using Hospital Discharge Data to Track Inflicted Traumatic Brain Injury

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**Background:** Inflicted traumatic brain injury (inflicted TBI) in infants has been the subject of recent preventive interventions, yet the burden of this problem is poorly defined. This article estimates the national incidence of hospitalizations due to inflicted TBI in infants aged <1 year using hospital discharge databases (HDDs) over 3 years, compares findings to previous infant inflicted TBI studies, and assesses differences in case composition and coding over time.

**Methods:** The Kids' Inpatient Databases (KIDs) for 1997, 2000, and 2003 were used to estimate the incidence of inflicted TBI hospitalizations in infants. Cases were identified by the presence of ICD-9-CM codes indicating both TBI and abuse. Incidence estimates were generated by dividing the weighted number of inflicted TBI cases identified by the year-specific infant population. Changes over time were evaluated using Cochran–Armitage and ANOVA statistical tests.

**Results:** The 1997, 2000, and 2003 KIDs yielded infant inflicted TBI incidence estimates of 27.5 (95% CI=20.8–34.0), 27.5 (95% CI=22.6–32.3), and 32.2 (95% CI=26.9–37.4) cases per 100,000 infants per year, respectively. KIDs estimates were within the range of previous inflicted TBI incidence studies that used active surveillance. Over time, the proportion of cases covered by Medicaid increased ( $p<0.0001$ ).

**Conclusions:** The KIDs can be used to generate incidence estimates of infant inflicted TBI hospitalizations that are consistent with previously published active surveillance estimates. HDDs can be used to assess the scope of infant inflicted TBI as well as trends in case composition and coding practices. Such assessments may be useful for the evaluation of prevention programs.

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## Introduction

Inflicted traumatic brain injury (inflicted TBI) in infant populations is both devastating and preventable, yet its burden has been defined by incidence estimates generated in relatively small geographic areas. Infant inflicted TBI, commonly the result of shaken impact syndrome, is among the most serious forms of child abuse, with such consequences as death and significant neurologic impairment for survivors.<sup>1,2</sup> In 2005, the first major evaluation of a program to prevent infant inflicted TBI was published, demonstrating that a hospital-based program to educate new parents significantly reduced abusive head injuries among an intervention group versus a comparison group.<sup>3</sup> Localized surveillance and evaluation are important in de-

termining the efficacy of particular interventions, but they are also resource-intensive. No population-based surveillance has been established for consistently and feasibly monitoring the incidence of inflicted TBI nationally. In this study, nationally representative hospital discharge databases (HDDs) were used to examine the incidence of infant inflicted TBI in the U.S.

Determining valid and efficient ways to monitor the incidence of infant inflicted TBI in large populations is important for several reasons. First, no national estimates of inflicted TBI exist in the U.S., making ongoing surveillance of national trends impossible. Researchers have made population-based incidence estimates of infant inflicted TBI in various regions of the United Kingdom<sup>4,5</sup> and in one U.S. state<sup>6</sup>; there also are two similar population-based studies of inflicted subdural hematomas,<sup>7,8</sup> a subpopulation of inflicted TBI. Measuring national trends, however, is important in understanding the impact of widespread intervention campaigns designed to prevent shaken impact syndrome in infants ([www.dontshake.com](http://www.dontshake.com)).<sup>9</sup> Second, previously published studies have relied on active surveillance techniques, which are resource-intensive and relegate

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estimates to small geographically-determined populations. While such studies are likely to produce reasonably valid estimates of the incidence, the time and expense of using active surveillance prohibits such studies in larger populations. Third, infant inflicted TBI is a rare enough occurrence that precise estimates, particularly when stratified by potentially important demographic characteristics, are difficult to generate for relatively small populations. Finally, easily replicated passive surveillance methods (using HDDs) can be used to set realistic prevention objectives such as those used by the U.S. Public Health Service's Healthy People prevention planning activities ([www.healthypeople.gov](http://www.healthypeople.gov)).

In previously published studies<sup>4-6</sup> of the incidence of inflicted TBI, researchers identified cases using both active and passive (or retrospective) surveillance techniques. Active surveillance means that an investigator identifies cases as they occur through frequent and ongoing contact with a group of professionals likely to encounter inflicted TBI cases (e.g., clinicians, medical examiners, or social workers). With passive surveillance, investigators identify cases after they occur by retrospectively examining records (e.g., hospital discharge, medical examiner, or Child Protective Services [CPS] records). Investigators may use a combination of active and passive surveillance techniques by frequently reviewing records, flagging probable cases, and then following up with relevant professionals to confirm the identification. Although active surveillance is the preferable surveillance technique, it is often not feasible due to resource and personnel limitations. In the case of infant inflicted TBI surveillance, passive monitoring of large infant populations is possible from hospital discharge data, yet incidence estimates from this type of monitoring have not been published.

Statewide discharge databases from hospitals are routinely compiled by state health departments, with diagnoses identified using ICD-9-CM codes.<sup>10</sup> Infant inflicted TBI may be identified using a combination of ICD-9-CM diagnosis codes and a subset of these codes called external cause-of-injury codes (E-codes). Therefore, the objectives of this study were: (1) to examine whether large HDDs could be used to develop national incidence estimates for infant inflicted TBI with reasonable confidence intervals; (2) to compare estimates to those generated by active surveillance in smaller, population-based studies; and (3) to assess differences in infant inflicted TBI case composition and coding over time. Incidence estimates were generated from 3 different years (1997, 2000, and 2003) using multistate hospital discharge data compiled and weighted (to be nationally representative) by the same federal agency. In the absence of a gold standard for the incidence of inflicted TBI, these incidence estimates were compared with smaller, population-based studies that used active surveillance. The major hypothesis was that passive surveillance with HDDs would produce systematic underestimates of

infant inflicted TBI, since infants who die prior to admission would not be identified in a discharge database, but that these databases would identify the majority of cases that could be identified by active surveillance.

## Methods

The Kids' Inpatient Databases (KIDs) for 1997, 2000, and 2003 were used to estimate the year-specific incidence of inflicted TBI hospitalizations in infants aged <1 year; inflicted TBI was identified using ICD-9-CM discharge diagnosis codes, including E-codes. The 1997, 2000, and 2003 KIDs are part of the Healthcare Cost and Utilization Project (HCUP) by the Agency for Healthcare Research and Quality (AHRQ).<sup>11</sup> The KIDs were created to allow investigators access to a broad range of illness and injury information on children (including rare conditions) by collecting a large percentage of non-birth-related discharge information from most hospitals in multiple states.

The KIDs include data from 22 states for 1997, 27 states for 2000, and 36 states for 2003. Each database contains a randomly selected 80% sample of all non-birth-related pediatric discharges from all hospitals in the states surveyed in a given year (excluding veterans and psychiatric hospitals). The KIDs surveyed 2521 hospitals in 1997, 2784 hospitals in 2000, and 3438 hospitals in 2003. In 1997, rehabilitation hospitals were also included in the data-collection effort; in 2000 and 2003, however, rehabilitation hospitals were excluded. Throughout this paper, the term "infant" means a child aged between birth and 12 months.

The KIDs contain basic demographic and payment information for inpatient pediatric discharges, as well as 15 fields for ICD-9-CM diagnosis codes. In 1997 and 2000, E-codes were included in the 15 diagnosis fields; in 2003, there were 15 diagnosis fields, with four separate fields for E-codes only. On discharge, coders follow standard guidelines and assign diagnosis codes and E-codes based on information in the patient's chart<sup>12</sup>; billing and reimbursement are often based on this coding. An ICD-9-CM diagnosis code describes the clinical presentation of a disease or injury, while an E-code describes the cause of injury. Codes are stored in hospital databases and compiled into larger databases by individual states.

The case definition for traumatic brain injury (TBI) was based on the Centers for Disease Control and Prevention (CDC)'s TBI case definition published in the 1995 Guidelines for Surveillance of Central Nervous System Injury<sup>13</sup> and the definitions used in the smaller population-based studies that utilized ICD-9-CM codes. The case definition used in this article was slightly more conservative than the CDC definition for TBI because cases coded as skull fractures with no mention of intracranial injury were excluded. This exclusion was consistent with the only population-based study conducted in one U.S. state.<sup>6</sup> Table 1 lists the codes associated with the various types of TBI.

Child abuse was identified by the presence of an ICD-9-CM diagnosis code for abuse or an E-code denoting assault or abuse (Table 2). To be included in the numerator of the incidence estimate, an infant must have had at least one TBI code and at least one abuse or assault code in any of the discharge diagnosis

**Table 1.** Criteria used to identify traumatic brain injury in infants using ICD-9-CM diagnosis codes

Code	Description
800.1–800.4; 800.6–800.9	Fracture of vault of skull with intracranial injury <sup>a</sup>
801.1–801.4; 801.6–801.9	Fracture of base of skull with intracranial injury
803.1–803.4; 803.6–803.9	Other and unqualified skull fracture with intracranial injury
804.1–804.4; 804.6–804.9	Multiple fractures involving skull or face with other bones with intracranial injury
850.0–850.9	Concussion
851.0–851.9	Cerebral laceration and contusion
852.0, 852.1, 852.4, 852.5	Subarachnoid or extradural hemorrhage, following injury
852.2, 852.3	Subdural hemorrhage, following injury
853.0–853.1	Other and unspecified intracranial hemorrhage, following injury
854.0–854.1	Intracranial injury of other and unspecified nature

<sup>a</sup>Intracranial injury is defined as: cerebral laceration and contusion; subarachnoid, subdural, or extradural hemorrhage; other unspecified intracranial hemorrhage; or intracranial injury of other and unspecified nature.

or E-code fields. The numerator for each year was then adjusted by a weight variable from the data set so that the numerator would be representative of the U.S. population.<sup>11</sup> The denominator for each estimate was the number of infants aged 0 in December of the year-specific census from the U.S. Census Bureau<sup>14</sup> (3.76 million, 3.97 million, and 4.06 million in 1997, 2000, and 2003, respectively).

The incidence of infant inflicted TBI for each year was calculated by dividing the weighted numerator by the denominator. For each year, the confidence intervals were estimated using the following equation:

$$95\% \text{ CI} = \frac{iTBI \pm 1.96 * \sqrt{\text{var}}}{\text{Infant Population}} * 100,000$$

In the equation above, inflicted TBI represents the weighted number of inflicted TBI cases for a given year. The variance was estimated using the Taylor series approximation (SAS, version 9.1.3.), which accounted for the sampling scheme used to select cases for the KIDs, as well as the uncertainty introduced by generating a weighted estimate.

The methodologic details of three previously published, population-based estimates of infant inflicted TBI were examined. Active surveillance was defined as direct and regular contact with pediatric care providers and passive surveillance as the use of hospital discharge codes or response to an existing surveillance system not specifically designed to identify inflicted TBI cases. Additionally, information was collected on the time period, location, and other confirmatory information used to identify inflicted TBI cases, such as medical examiner data, follow-up with social services, and review of clinical records.

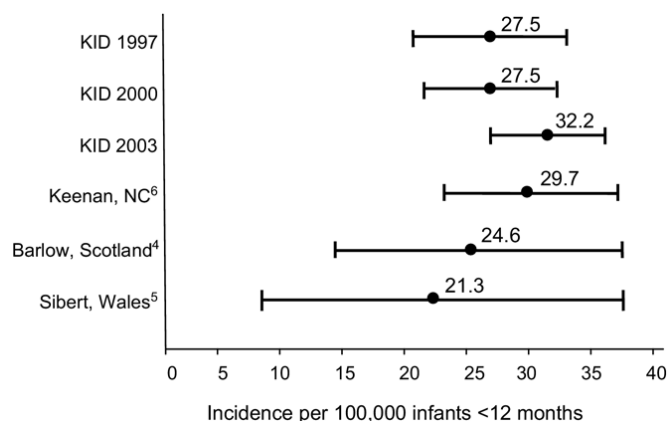
To examine differences in the case characteristics and coding practices over time, only infant inflicted TBI cases

were examined from the 3 years. To test the statistical significance of differences over time, Cochran–Armitage Trend Tests<sup>15</sup> were used for categorical variables (gender, insurance coverage, clinical diagnosis category, and abuse coding category), and an ANOVA was used for age.

The study was considered exempt from human subjects review by the institutional review board of Yale University School of Medicine.

## Results

Figure 1 shows estimates for the incidence of inflicted TBI hospitalizations for infants from the 3 years of the KIDs and three previously published population-based studies.<sup>4–6</sup> The KIDs estimates for infant inflicted TBI hospitalizations per 100,000 were 27.5 (95% CI=20.8–34.0) in 1997; 27.5 (95% CI=22.6–32.3) in 2000; and 32.2 (95% CI=26.9–37.4) in 2003. The incidence estimates generated from these three databases yielded rates within the range of those generated by three previous studies, which relied on a number of additional surveillance techniques.<sup>4–6</sup> As seen in Figure 1, the inflicted TBI estimates for the 1997, 2000, and 2003 KIDs were within Keenan’s incidence estimate for the state of North Carolina of 29.7 per 100,000 infants per



**Figure 1.** Incidence of inflicted traumatic brain injury in infants per 100,000 per year and 95% confidence intervals. KID, Kids’ Inpatient Databases.

**Table 2.** Criteria used to identify intentional injury (child abuse or assault) using ICD-9-CM

ICD-9 code/ E-code	Description
995.5	Child maltreatment syndrome
E960–E966	Assault: unarmed or with weapon/instrument
E967	Child and adult abuse
E968	Assault by other and unspecified means
E969	Late effects of injury purposely inflicted by other person

**Table 3.** Methodologic techniques used in population-based studies

Study	Keenan <sup>6</sup>	Barlow <sup>4</sup>	Sibert <sup>5</sup>
<b>Time period</b>	2000–2001	1998–1999	1996–1998
<b>Location</b>	N. Carolina	Scotland	Wales
<b>Infant inflicted TBI cases (per 100,000/year)</b>	29.7	24.6	21.3
<b>Active surveillance</b>			
Direct and regular contact with pediatric care centers	X	X	
Regular calls to relevant pediatric care providers	X	X	
<b>Passive surveillance</b>			
ICD codes used to identify cases	X	X	
Reporting cards sent after existing surveillance system identified case			X
<b>Confirmatory information</b>			
Death/medical examiner data	X	X	
Confirmation of findings with social services	X		X

year for 2000 and 2001.<sup>6</sup> When excluding cases identified only through a medical examiner, Keenan's estimate decreased to 26.4 (95% CI=19.9–33.0) (H. Keenan, University of Utah, personal communication, 2006).

Table 3 shows the methodologic details of the three regional, population-based studies.<sup>4–6</sup> One study was conducted in North Carolina,<sup>6</sup> and two in the United Kingdom.<sup>4–5</sup> Two of the studies used active surveillance,<sup>4,6</sup> two included information from the medical examiner's office,<sup>4,6</sup> and two were able to access information from child-protective services.<sup>5,6</sup>

Table 4 shows differences over time in the demographics and coding for inflicted TBI cases identified in the 3 years of the KIDs. While there were no significant changes in gender or age, there was a significant increase in the percentage of inflicted TBI cases receiving Medicaid, from 54% in 1997 to 67% in 2000 and 69% in 2003 (*p* for trend <0.0001). The majority of inflicted TBI injury codes were for subdural hemorrhage (between 59% and 61% of cases), and this pattern was stable over time. When coding of abuse was examined over time, there was a significant increase in

the percentage of cases coded as abusive with both ICD-9-CM and E-codes as opposed to **either** an ICD-9-CM or an E-code (*p* for trend <0.0001). The significance of this difference was driven by the increase from 55% in 1997 to 69% in 2000.

### Discussion

The results show that hospital discharge data can be used to generate useful incidence estimates and confidence intervals for hospitalization due to inflicted TBI in infants across broad cross-sections of the U.S., and that these estimates fall within the range of previously published ones. While prior estimates were generated using multiple surveillance techniques in smaller geographic regions, the results from this study suggest that using only hospital discharge data to monitor incidence trends and case composition of infant inflicted TBI is feasible and accurate on a large scale. The fact that more cases in the later periods had both a diagnosis code and an injury code suggests that coding practices may be improving over time. Such improvements in the

**Table 4.** Comparison of demographics and abuse coding of inflicted TBI cases for 1997, 2000, and 2003

	1997 Weighted % or mean (SD) (N=1033)	2000 Weighted % or mean (SD) (N=1090)	2003 Weighted % or mean (SD) (N=1306)	<i>p</i>
<b>Demographics</b>				
Male	65.6	60.1	63.8	0.4519
Public insurance (Medicaid)	54.1	66.8	69.3	<0.0001
Age (in months)	4.4 (4.6)	4.0 (4.2)	3.9 (3.6)	0.1022
<b>Injury codes<sup>a</sup></b>				
Subdural hemorrhage	59.1	59.1	60.7	0.4211
Fractures with intracranial injuries	27.3	31.1	29.6	0.2654
Other inflicted TBI	13.1	9.1	7.9	<0.0001
Cerebral laceration and contusion	6.6	4.5	6.2	0.7426
<b>Abuse codes</b>				
ICD-9 only	23.3	16.2	12.9	<0.0001
E-code only	21.4	14.6	19.4	0.3005
Both ICD-9 and E-code	55.3	69.2	67.8	<0.0001

<sup>a</sup>Cases could have more than one code for TBI so the percentages add to more than 100% for each year of the KID. Inflicted TBI, inflicted traumatic brain injury.

completeness of discharge coding enhance the validity of incidence estimates generated from discharge databases.

The only other U.S. study of inflicted TBI incidence—conducted by Keenan in North Carolina<sup>6</sup>—yielded an infant inflicted TBI incidence within the range of those generated by the KIDs. It is important to keep in mind that Keenan used data from the medical examiner and, therefore, identified cases of children who died before being admitted to a hospital. Such cases would not appear in an HDD. After excluding cases identified by the medical examiner only, Keenan recalculated the incidence in the North Carolina study and found an incidence of 26.4 per 100,000 infants, slightly lower than but still within range of estimates generated by the KIDs.

The quality of discharge coding can be linked to several points of influence. Discharge codes are based on information in hospital medical records and are assigned by coders, trained in the application of ICD-9-CM codes. Discharge codes offer a standardized classification of conditions and procedures for billing and other purposes. Doctors represent an important point of influence as their notes in medical records represent the evidence used by the hospital coders to assign discharge codes. Educating doctors about how their notes may be interpreted on discharge records is important if discharge databases are to produce valid estimates of clinical conditions. In addition, ensuring that all coders are trained properly and consistently across hospitals and states will increase the accuracy and utility of discharge data for population monitoring.

States also play a role in mandating the use of various codes by hospitals for compilation of a statewide discharge database. Currently, there is variation in how states regulate hospital discharge coding. For example, in 2004, 26 states mandated that hospitals assign E-codes for patients with injuries, 16 states routinely collected E-codes although it was not mandated, three states had statewide discharge databases but did not collect E-codes routinely, and five states did not have a statewide HDD at all.<sup>16</sup> The validity of estimates derived from HDDs in this study is potentially compromised by incompleteness although states without statewide databases were not included in the KIDs.

Reliance on ICD-9-CM diagnosis and injury codes for abuse may lead to underestimation of abuse cases. A study published in 1995 found that E-codes were not good markers of abuse.<sup>17</sup> There is reason, however, to believe that the validity of E-coding has increased over time, with state legislation mandating its use and with increased coder familiarity with E-codes. Still, coders must rely primarily on doctors' notes to ascribe a code, and doctors may not definitively document abuse or assault or identify the perpetrator due to legal and social complications. Such omissions from a patient's record may result in the underestimation of the true

incidence of infant inflicted TBI. In addition, HDDs systematically underestimate the overall number of cases of inflicted TBI since no pre-hospital deaths are included, and some cases may be missed due to transfers and referral patterns.

Conversely, it is possible that using hospital discharge data may overestimate infant inflicted TBI if children are admitted twice to the hospital for the same abusive injury. Although it was possible to establish the independent case status for most infant inflicted TBI hospitalizations in the KIDs, the data sets contain no individual identifiers, making it impossible to be certain that each hospitalization represents a different child. Therefore, the incidence estimates from the KIDs must be interpreted with these caveats in mind.

Another limitation is the absence of a population-based comparison data set obtained by active case surveillance for inflicted TBI in the states covered by the KIDs. Such a data set could be used as a gold standard and would allow the calculation of sensitivity, specificity, and positive predictive value for the KIDs as a surveillance system. Without a gold standard, however, the best comparisons are smaller population-based studies. These smaller studies are limited both by size and generalizability. The population in North Carolina may be different from the combined population of KIDs states in meaningful ways that confound accurate comparison. For this reason, the comparisons with population-based studies are viewed not as exact measures; rather, these comparisons should be viewed as approximate benchmarks to assess whether ICD-9 codes are able to generate estimates in the proximity of population-based studies. More specific studies are needed to assess the validity of the KIDs as a surveillance system for inflicted TBI.

Despite suboptimal comparison data sets, the estimates derived from the KIDs proved to be consistent with the few existing incidence studies. The KIDs also have advantages over other national discharge data sets, such as the National Hospital Discharge Survey (NHDS), which was used by the CDC in their 2006 report on TBI.<sup>18</sup> The NHDS is nationally representative, but is not as well equipped as the KIDs to examine less common conditions in a specific population subset. Because the NHDS samples a smaller overall number of pediatric discharges than the KIDs, it is difficult to generate reliable estimates for rare conditions in narrow age strata.

There are several implications for the use of HDDs for monitoring infant inflicted TBI on a population scale. State policymakers may find the examination of their own HDDs useful in monitoring and appropriately targeting prevention programs. Further, the finding that the number of inflicted TBI cases covered by Medicaid significantly increased over time suggests that the coupling of preventive programs with services typi-

cally reimbursed by Medicaid may be a strategy for funding prevention programs.

## Conclusion

Despite the inherent limitations of using hospital discharge data, it is important to find ways to monitor child abuse by using and improving the quality of HDDs, which until now have been underutilized. Although the occurrence of inflicted TBI is rare on a population scale, it may be the result of more common and preventable behaviors. For example, in a recently published study, researchers anonymously interviewed mothers in North and South Carolina about shaking very young children as a form of discipline, among other parenting practices. Researchers found that for every child sustaining a serious injury as a result of shaking, an estimated 150 children were shaken but went undetected, suggesting that early inflicted TBI prevention and education programs potentially can reduce a common but dangerous behavior.<sup>19</sup> Without tangible evidence of program efficacy and reproducibility, however, it is unlikely that these interventions will be supported. Accurate and feasible measurements of the incidence of inflicted TBI and trends over time are critical components in the formation and design of interventions. The use of HDDs, given continued improvement in discharge coding practices, may be a useful method for monitoring the incidence of this devastating problem.

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