Traumatic Brain Injury Summary Report

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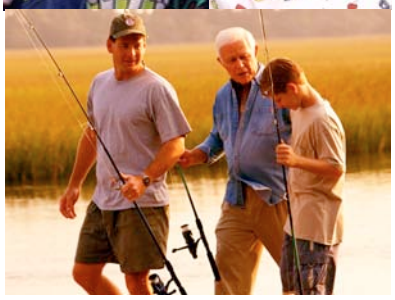

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Traumatic Brain Injury Summary Report

Background

United States. Traumatic brain injuries (TBIs) are a leading cause of death and disability in the U.S.[1] Approximately 1.5 million people sustain a TBI each year, resulting in 50,000 deaths, over one million emergency department visits, 235,000 hospitalizations, and 80,000-90,000 permanent severe neurological disabilities.[2-5] Brain injuries are complex and only rarely are consequences limited to a single deficit. Many survivors with serious injuries experience a constellation of symptoms and impairments, such as physical, emotional, cognitive, and behavioral problems that may require months or years of rehabilitation.[1] Although 75% of TBIs are considered mild, about 15% of these persons continue to experience negative consequences 12 months later.[4,6] Costs were estimated at $56.3 billion in 1995.[7]

Oklahoma. From 1992-2003, a total of 39,967 Oklahoma residents suffered a TBI that was fatal or serious enough to require hospitalization. The highest rate of TBI was among persons 75 years and older, followed by persons 15-24 years of age. Males were nearly two times more likely to be injured than females. Motor vehicle crashes and falls were the most common causes of TBI, accounting for 31% of injuries each, followed by gunshot wounds (11%) and assaults (8%). Falls increased steadily from 1997-2003 and were the leading cause of TBI from 1999-2003. Ninety-six percent of firearm injuries were known to be intentional; 77% of these injuries were self-inflicted. In 1992-2000, more than half of TBIs were of moderate severity (Abbreviated Injury Scale score of 2). Among survivors, the causes associated with the most severe TBIs were firearm and motorcycle-related incidents. Among survivors in 1998-2000 with a known outcome, 80% had a good recovery based on Glasgow Outcome Scale score, 11% had a moderate disability, 9% had a severe disability, and 1% were discharged in a persistent vegetative state.

The 2004 TBI Data Report was submitted to the National Center for Injury Prevention and Control (NCIPC) in October 2006.

TBI Data Collection in Oklahoma

Authority. The Injury Prevention Service (IPS) has had the authority to collect and maintain TBI surveillance data since TBIs were mandated a reportable condition in April 1991 by the Oklahoma Board of Health and the Oklahoma legislature (HJR 1040) (Appendix 1).

History of TBI Data Collection. Statewide surveillance for hospitalized and fatal TBIs has been conducted in Oklahoma since 1992 using standard morbidity and mortality codes from the NCIPC. Because a complete, consistent hospital discharge database was not available in Oklahoma until January 2005 (2002 data), TBI surveillance data were collected directly from medical records for 1992-2003. A contact person was designated at each hospital medical records department to work with IPS staff to generate a list of TBI patients based on the TBI discharge codes and to make medical records available for review. Data elements were collected

through medical record reviews by trained IPS staff at all 116 acute care hospitals (including federal facilities) in the state. From 1992-1998, approximately 100 variables, including most of the current basic and extended data elements, were collected on all hospitalized cases. From 1999-2000, a 50% random sample of hospital medical records was selected and abstracted for both the basic and extended variables. For the remaining 50% of medical records, only the basic variables were abstracted. From 2001-2003, due to reduced funding, only basic variables were collected on all TBI cases. A list of medical records that were not available during each hospital site visit was maintained and records were requested until they became available. TBI deaths were identified from the Office of the Chief Medical Examiner from 1992-1999 and from Vital Statistics beginning in 2000.

TBI Surveillance Methodology for 2004

TBI Case Definition. Data were collected on men and women of all ages and racial and ethnic groups among Oklahoma's 3.5 million residents. The TBI mortality case definition codes in the *Central Nervous System Injury Surveillance Data Submission Standards—2002*[8] (referred to as *Standards* in the rest of the summary report) were used (Appendix 2). Fatal TBI cases were identified in the Vital Statistics database by searching all 20 multiple cause of death code fields for a code indicating a TBI. Oklahomans who died out of state were included. For nonfatal injuries, the TBI morbidity case definition codes in the *Standards* were used. Hospitalized TBI cases were identified in the HDD by searching the principal diagnosis and all 15 other diagnosis codes for a code indicating a TBI. TBI cases were limited to Oklahoma residents who died or were discharged from acute care during 2004. Persons injured more than 12 months before the date of discharge or death were excluded.

Data Contributors. The Oklahoma State Department of Health (OSDH) Vital Records Division maintains death certificates on all deaths that occur in the state. Death certificates are coded to multiple causes by the National Center for Health Statistics. A real-time electronic Vital Statistics file, which includes all deaths in Oklahoma and deaths of Oklahoma residents that occurred outside of the state, is made available to the IPS through the OSDH intranet and can be accessed daily. A final centralized statewide electronic database of deaths for the year, including multiple cause coding and personal identifiers such as name, date of birth, and date of death is obtained by the IPS annually.

Data for the centralized statewide electronic hospital discharge database (HDD) are collected and maintained by the Health Care Information Division of the OSDH. The HDD includes all state licensed general and specialized hospitals; federal government facilities are excluded. Discharge data records are submitted for persons discharged within a calendar year from all hospital beds. A separate record is submitted for each discharge, including information on the patient, provider, service, diagnosis and treatment, payer, and charges/bill type. A comprehensive data quality program is run on the database, including checks to ensure that all

required fields are completed, ages are appropriate (0-115 years), date fields have the correct year of discharge and proper date sequences, there are not duplicate records, E codes are present for injury-related discharges, etc. Letters regarding missing and inappropriate data are sent to hospitals to obtain updated information and/or clarification. The IPS receives a finalized HDD each year. Personal identifiers, including name, date of birth, last four digits of the social security number, and medical record number are obtained by the IPS for reportable injuries, including TBIs.

Data Elements. The IPS collected data for all TBI cases from the HDD on all available basic variables as described in the *Standards*. In addition, all available extended variables were obtained during medical record reviews for the 1200 sampled cases; these variables were updated in the TBI database. All TBI data elements were sent to the NCIPC in October 2006 using required variable names, formats, lengths, and values.

Data Linkage and Sampling Methodology. Deaths in the 2004 centralized electronic HDD and Vital Statistics database were linked using the probabilistic linking software SAS LinkPro. The databases were linked using soundex (a phonetic transliteration) of the last name and first name, last four digits of the social security number, date of birth, sex, and age. Cases were first linked using strict criteria; the criteria was loosened with each subsequent run of unlinked cases until either no further linkable pairs were identified or a large percentage of spurious links occurred. The final weights for the linked pairs were sorted and the lower weight cases manually examined to verify that they were the same record. In addition, all unlinked cases were manually examined to determine if any matches were missed.

For persons with multiple hospitalizations for the same event, back-to-back stays were combined and the definitive care hospital was documented. Patients transferred from one hospital to another were identified using the source of admission and personal identifiers. Protocols were established to determine if non-consecutive stays were for the same injury (deleted second stay from the database) or for a second injury (included second stay in the database). Persons in the Vital Statistics database were also compared to patients in the HDD using personal identifiers to identify and combine duplicates.

As specified in the *Standards*, a representative sample of at least 1000 TBI cases (preadmission deaths not included) needed to be successfully abstracted using a stratified sampling approach. An initial sample of 1200 cases was selected to allow for false positive cases and missing records. Hospitalized cases were divided into strata based on hospital size (<100 beds and ≥100 beds). The proportion of cases in each of the hospital strata was calculated and the sample followed the same proportions. The sample was formed by selecting the predetermined number of cases in each strata from a randomized, stratified database of TBI cases. The procedures to link the databases and obtain a sample of cases are detailed in Appendix 3. Appendix 4 is the SAS program used to link the TBI records and select the sample.

Extended Medical Records Surveillance. The IPS abstracted all basic and extended variables for all 1200 sampled cases. Data were recorded on-site at hospitals on an abstraction form (Appendix 5) from large and medium size hospitals. Data were obtained by telephone from a medical records employee for small hospitals that had only one or two randomly selected cases. The IPS determined and documented if the case met the NCIPC's clinical case definition for a TBI as defined in the *Standards*. Quality assurance measures included double-checking forms for missing or inconsistent information and periodic blind reviews on approximately 5% of records to assess inter-rater reliability. In addition, "TBI Surveillance Notes" with definitions for most variables and notes about unusual/confusing issues was prepared and readily available on all site visits (Appendix 6). A list of sampled records was maintained and missing records were re-requested until they were received. Information on the basic and extended variables from the abstraction forms was entered under security into an Access 2000 file and was combined with a database of non-sampled cases. Abstraction forms were kept in locked cabinets in a locked room. As outlined in the *Standards*, TBI cases found to be false positives during abstraction were included in the data set submitted to the NCIPC; false positive cases were flagged by the "abstract" variable.

Usefulness of the Data

The need for standardized TBI data is well documented.[1,6,9] In Oklahoma, TBI data are needed for describing the problem and demand for services and for funding treatment, prevention, and research. Standardized data on TBI allow the identification of high-risk populations and risk factors and the development of targeted prevention programs and evaluations. Data also enable policymakers and the public to put various health conditions in perspective. It is also important to frame the costs of treating injuries versus expenditures for prevention.

In May 2005, IPS staff collaborated with a local emergency department physician to publish an article, All-Terrain Vehicle-related Central Nervous System Injuries in Oklahoma, in the *Journal of the Oklahoma State Medical Association*. The article described the magnitude and epidemiology of all-terrain vehicle (ATV) injuries in Oklahoma from 1992-2002 (Appendix 7). Almost 400 persons were hospitalized or died during this time period (average 3.5 deaths and 32 non-fatal hospitalizations per year). Forty-five percent of deaths occurred among persons under 16 years of age. The number of cases tripled during the 11-year time period. As a result of the article, ATV safety legislation was introduced to require helmets for children under 18 years of age and to ban passengers for drivers under 14 years of age. Although the legislation did not pass in the spring of 2006, it will be reintroduced in 2007 since the number of deaths is continuing to climb. From January 1 to September 30, 2006, 20 ATV-related deaths occurred in Oklahoma.

Strengths of the Data

TBI data were collected statewide for fatal and hospitalized cases in a standardized manner established by the NCIPC. Fatal cases were obtained from the Vital Statistics database and

hospitalized cases were obtained from the HDD. Although Oklahoma hospital discharge data have been collected since 1997, the data have only been collected in a standardized manner from all acute care hospitals in the state (except federal facilities) since 2001. The completeness of TBI reporting in the HDD was assessed by obtaining a list of all persons (including name, other personal identifiers, and date of discharge) discharged with a TBI code from all hospital medical records departments in the state (including eight federal facilities that reported a total of 85 cases); the hospital lists were cross-checked with the HDD. Using both databases, a total of 4148 cases were identified. The hospital discharge database included 3946 (95%) cases and the lists from medical records departments included 3900 (94%) cases. At least one E code was present for 91% of cases in the hospital discharge database and 90% of cases obtained from medical records departments.

Limitations of the Data

The Oklahoma TBI surveillance system excluded persons with less severe TBIs who were treated in an emergency department and released home and persons treated in a physician's office.

TBI data for hospitalized cases were obtained from the hospital discharge database. The HDD did not obtain data from federal hospitals (military and Native American facilities) nor did it include Oklahoma residents who were hospitalized out of state. In order to estimate these deficits, the IPS contacted federal hospitals to determine the number of TBI cases in these facilities and contacted injury prevention personnel in bordering states to obtain the number of Oklahomans hospitalized in these states. These numbers are reported in the data summary.

Persons with two consecutive hospital stays were likely transferred from one facility to another for additional care for the same injury and the two stays were combined. If there was a gap between stays, it was difficult to determine if the person was readmitted for the same injury or suffered a second injury. Standardized methods were used to classify cases as one injury or two separate injuries (described in Appendix 3); however, all cases may not have been corrected classified.

A few variables not directly available in the HDD were calculated or inferred. The date of injury was not included in the HDD, but as stated in the *Standards*, the date of admission was assigned for this variable. The state of injury was assumed to be Oklahoma and the county of injury was assumed to be the same as the county of residence unless information from medical records reviews indicated otherwise. Based on medical record reviews in 2002, 99.7% of TBI cases occurred in Oklahoma and 90% occurred in the patient's county of residence.

Causes of death and coding of death certificates may not have been accurate for all cases of TBI. IPS staff worked with an Epidemic Intelligence Service officer and determined the sensitivity of 2002 Vital Statistics data for fatal TBI was 78%. Results of the study were published in *Public Health Reports* (Appendix 8). Vital Statistics surveillance was significantly more likely to miss deaths among persons 65 years and older, from traffic crashes,

and from falls. This discrepancy resulted in firearms rather than traffic crashes being listed as the leading cause of death when unadjusted for the missed records.

The TBI database was evaluated prior to being sent to the NCIPC to ensure complete and quality data. All cases were reviewed to verify that they had a TBI code, were discharged or died in the surveillance year, were residents of Oklahoma, and were not duplicate records. Date fields were checked for improper sequences and conflicts. Frequencies were run on all variables to ensure completeness of the data and to verify that they were in the proper format required by the NCIPC. Checks were made to ensure that false positive cases were included and identified in the database and that all available ICD-9-CM, ICD-10, and E codes were submitted in the proper position. The crude death and hospitalization incidence rates were calculated and compared to previous years. Predictive value positive was calculated based on medical records reviews to determine the probability that persons with a TBI code actually experienced a TBI. A marker for sensitivity was also calculated based on cases of hospitalized TBI deaths.

Lessons Learned

Background Work

- Establish a primary and secondary contact person at all medical records departments in the state.
  - The medical records director may not be the best contact person due to a busy schedule.
  - Create a list of all hospitals including the official name of the medical records department, the address, and the contact persons' name, phone number, fax number, and e-mail address.
- Maintain a file folder for each hospital with copies of all correspondence and notes on all telephone calls.
  - Keep a map/directions to each out-of-town hospital in the folder.
  - Keep race codes/other specific hospital information in the folder.
- Send a preliminary letter to medical records primary contact persons to explain the TBI surveillance process before making any telephone calls to set up hospital visits/telephone reviews.
- Consider having an injury prevention office support staff worker schedule hospital visits/telephone reviews and send confirmation letters.
  - Provide the support staff worker with abstractors' schedules of dates available for reviews.
  - The confirmation letter should include the date of the visit, the approximate time of arrival, the number of abstractors coming, and a list of cases to be reviewed.

Training

- Conduct refresher training for all abstractors to enhance their knowledge of TBI and TBI data collection before beginning a new surveillance year.
  - Go over every variable on the forms; spend extra time on new questions and challenging questions (e.g., Glasgow Outcome Scale).
  - Invite a neurosurgeon to give a general presentation on TBIs, including medical treatment, CT scans, etc.

- Conduct training on information to document to allow assignment of E codes and Abbreviated Injury Scale scores.

Preparing for Site Visits/Telephone Reviews

- Obtain the HDD, select the sample, and review medical records as soon as possible.
  - If data collection is delayed, medical records may have to be requested from off-site storage.
- Design a TBI data collection form and have all abstractors and data entry personnel review the form.
  - Allow ample white space between questions on the TBI form to help prevent missed questions, make data entry easier, etc.
  - Include unknown/not applicable choices so that every question requires an answer.
- Prepare "TBI Surveillance Notes" with definitions for variables and notes about unusual/confusing issues; continually update the Notes as additional issues arise.
  - Bring the "TBI Surveillance Notes" on all site visits.
- Create a "surveillance bag" with TBI forms, a list of cities and their county, extra pencils/leads, sticky notepads, a medical dictionary, and a state map.
- Find travel routes to visit more than one small to medium size hospital in a day, if possible.
  - Work longer hours some days to finish as many hospitals/medical records as is feasible.

Collecting Data from Hospitals

- Call each hospital the day before the site visit to remind them of the medical records review.
- Fill out all known information ahead of time on the TBI forms for hospitals that have medical records on computer; verify the information while at the hospital.
  - A clerical person with good attention to detail can fill out known information ahead of time.
- Keep multi-volume medical records together by turning them sideways in the stack of medical records.
- Have abstractors share tips with each other at individual hospitals on where difficult to find information is located in the medical record.
- Before leaving each hospital, review all TBI forms for missing data and cross-check TBI forms with the hospital list to verify that all requested medical records were obtained.
  - Request and review missing medical records before leaving the hospital.
- For hospitals with one or two randomly selected cases, conduct medical record reviews by telephone.
  - Fax a TBI form to the medical records department before calling—they will usually look for information ahead of time and medical record reviews may take only about 10 minutes.
  - Fill out known information (name, medical record number, admit and discharge dates, etc.) before calling and confirm the information on the call.

- Prompt medical records personnel on where to look for hard to find items (e.g., Glasgow Coma Score—on pink emergency medical services run report).

After the Visit/Telephone Review

- Send a thank you letter promptly after conducting medical records reviews.
  - Hospital personnel appreciate being thanked.
  - Document that all TBI surveillance is complete for the year or include a list of missing medical records on the letter to keep track of what has been done and what is still needed.
- Give completed forms to the data entry specialist the day after each site visit.
- Have an experienced person assess and assign correct E codes and record Abbreviated Injury Scale scores.

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