



Brain Injury Reporting in Alaska

Background of brain injury data collection for Alaska

Serious physical injuries or shocks to the body from violence or accidents that result in hospitalization rather than a brief visit to a clinic, doctor or emergency department are reported to the Alaska Trauma Registry (ATR). This data on trauma-related injuries has been collected from the 24 acute care hospitals¹ in Alaska since 1991, and de-identified information can be released to authorized agencies for analysis and reporting.

Using data from the ATR, brain injuries are reported in terms of the initial injury, with rates of death (mortality) or rates of survived injury (morbidity), and their causes. These rates are particularly helpful to the public in formulating policies based on proven life-saving measures like the use of seatbelts and helmets. Mortality and morbidity are also used to compare which groups (by age, race, gender, rural/urban, etc.) more frequently sustain traumatic brain injuries (TBIs). ATR is the single most cited source of brain injury reporting in Alaska, and is the source used by the Alaska Native Tribal Health Consortium (ANTHC), although they also use their own tribal hospital data, the Division of Public Health Alaska Scorecard Key Issues Impacting Alaska Mental Health Trust Beneficiaries (traumatic brain injury), and the Alaska Brain Injury Network (ABIN).

The purpose of most reports is to focus on identifying risk factors (risky behaviors and at-risk groups) and preventing or reducing the frequency of occurrence of TBI. ABIN also focuses on providing services to individuals with brain injuries and their families, and the Division of Senior and Disabilities Services (SDS), through the Traumatic or Acquired Brain Injury (TABI) Program and Registry, focuses on the initial injury and the subsequent recovery (length of any hospitalization and the prescribed rehabilitation), as well as the consequences (related conditions/comorbidities, financial and social costs) of injuries to the brain. This important information allows SDS to provide needed services and potential service funding (Medicaid, grants) to the people of Alaska.

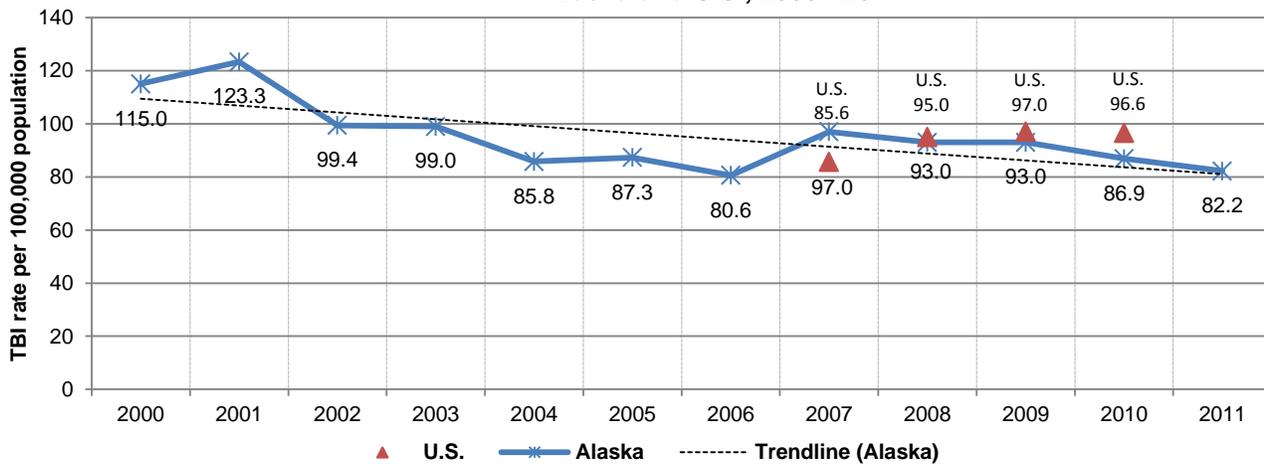
But all brain injuries do not result in hospitalization and the current primary source of information only includes traumatic injuries that require hospitalization.

What is missed in brain injury data collection in Alaska?

Using the most frequently cited Alaskan data source, Chart I includes Alaskan (blue) TBI from ATR data for the years 2000 through 2011, as published in the Alaska Scorecard². ATR data are collected at the point of admission and are limited to injuries a) that require hospital admission and b) where admission occurs within 30 days of the injury. It does not include patients that were treated in emergency departments and released. It also excludes patients that exhibit late-developing symptoms that may occur with mild TBIs. The trend line (dashed) shows the overall decline in ATR reported TBI hospitalizations for the 12 year period in Alaska.

The United States (US) data (red) in Chart I are related but not directly comparable to the Alaskan data due to a different data source. The US rate is based on the National Hospital Discharge Survey (NHDS) which statistically samples hospital discharges from non-fatal brain injuries rather than using all identified brain injuries from trauma registry reports, but it is a close approximation. The NHDS is published by the National Center for Health Statistics³ which selects (samples) inpatient medical records and looks at (abstracts) information from non-institutional and nonfederal short-stay (average of less than 30 days) general hospitals and children’s hospitals in all 50 states. The NHDS hospital sample is updated every three years, and 2011 data were not available at the time of this report.

Chart I - Non-Fatal Traumatic Brain Injury Requiring Hospitalization, Alaska and U.S., 2000 - 2011



Data Sources:

Alaska – AK DHSS, DPH, Emergency Programs, Alaska Trauma Program as reported in the DHSS Alaska Scorecard Key Issues Impacting Alaska Mental Health Trust Beneficiaries. (December, 2013).

U.S. (2007-2010) – Centers for Disease Control and Prevention, National Center for Health Statistics. Health Indicators Warehouse. Available at: <http://www.healthindicators.gov>

The brain injury registry in Alaska was created to include non-traumatic (acquired) brain injuries and traumatic brain injuries (TBI) that do not lead to immediate hospitalization. Concussions (a common and often mild TBI frequently occurring from falls and sports-related injuries) may not develop symptoms for weeks or months after the injury, and the symptoms may not be recognized or connected to the injury⁴.

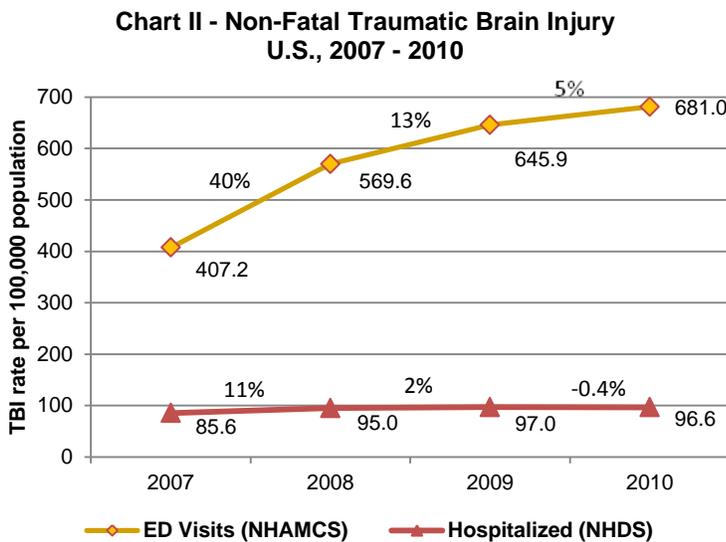
Both the Alaska and the U.S. data in Chart I are missing traumatic brain injuries that did not result in hospitalization and any non-traumatic acquired brain injuries, such as strokes or tumors.

Looking deeper at what is missing

The Centers for Disease Control and Prevention (CDC) recently increased the total number of TBI related hospitalizations, emergency department visits and deaths (due to any cause) to about 2.5 million⁵ in the U.S., either alone or combined with other injuries. The number published by CDC in 2013 was 1.7 million. The 2013 published total came from a report⁶ covering data for the years 2002-2006, which combined emergency department visits (National Hospital Ambulatory Medical Care Survey, or NHAMCS; 80.7%), hospitalizations (NHDS; 16.3%), and deaths (National Vital Statistics, or NVSS; 3.0%) to arrive at the overall U.S. incidence.

These numbers are important since they reveal that only 16% of the frequently cited U.S. estimated total comes from hospitalizations and, assuming the Alaskan and U.S. incidence totals occur in the same proportion, reporting the trauma registry hospitalization rate (ATR data) for Alaska may only recognize 16% of the traumatic brain injury total in Alaska, and does not include any non-traumatic brain injuries.

Recently the CDC Health Indicators Warehouse provided separate national hospital discharge and emergency department data for traumatic brain injuries. These results are presented in Chart II.



The National Hospital Ambulatory Medical Care Survey (NHAMCS)⁷ contains data (yellow) on the number of hospital emergency and outpatient department visits (ED) that did not lead to hospitalization.

The National Hospital Discharge Survey (NHDS) contains data (red) on the number of hospitalizations, as previously shown in Chart I.

Data Source:

Centers for Disease Control and Prevention, National Center for Health Statistics. Health Indicators Warehouse. Available at : <http://www.healthindicators.gov>

While theoretically, the SDS TABI Program and Registry could obtain the data, the cost to access that data is prohibitive. Direct analysis of the NHAMCS restricted use data necessary to accomplish state level analyses beyond the summary data in this chart requires a proposal and a set-up fee of \$750 per day.

Another state data set, the Alaska Hospital Discharge Database (HDD) has gathered inpatient data since 2001, and outpatient and ED data since 2007.⁸ The eleven participating hospitals in 2010 represented approximately 75% of discharges statewide. With only some hospitals reporting, the HDD is not sufficient for supporting complete statewide analysis of data for population health purposes at this time, although it can provide indicators for those areas of the state that do report. (See references 1 and 7 for a list of ATR and HDD reporting hospitals.)

Answering the questions

Questions about brain injuries typically revolve around three general areas: 1) the injury, and who, what, when, where and how it occurred, 2) the availability of, access to, and cost of rehabilitation services, and 3) recovery outcomes and effects on the injured person and his/her family. Reports on brain injuries can also be classified by the final goal of the report or reporting agency, whether that is prevention, funding for services, identifying more about a group of people, or a combination of goals. Accurate and complete knowledge of the source(s) of data used in a report is necessary before using report conclusions to make generalizations and, since brain injury data is very limited in Alaska, this means that available answers about Alaskan brain injuries may be limited until the Alaskan reporting system is improved.

Alaska has an expanded definition of brain injury when compared to other states (both traumatic and non-traumatic), no limits on level of severity to report (mild, moderate, or severe), and no age exclusions. When combined with the problem of very restricted data capable of capturing sufficient information to respond to the questions, answers must be built from unrelated sources and carefully examined to arrive at reliable and usable conclusions.

Future Brain Injury Bulletins will look at details of the first area of questions, the injury itself and who, what, where, when, and how Alaskans sustain brain injuries. For example, recent reports conclude that the Alaska Native/American Indian (AN/AI) population has “one of the highest rates of TBI in the U.S.,”⁹ with 2.3 times the risk of TBI as non-Native Alaskans and a mean (average) cost of hospitalization for TBI at \$11,000 more than for other injury cases.

Other Bulletins will examine the differences between the hospitalization rates (which seem to be stable or declining) and the number of emergency department visits with a brain injury diagnosis (which may be increasing). These differences could be due to hospital intake policy changes, increased medical knowledge about care-at-home benefits, or other causes not due to changes in the actual rate of TBI. Later issues will investigate the services and outcomes of brain injury in Alaska.

In 2005, a CDC panel of experts recommended that development of “state-based data systems that can help people with TBI get needed information and services should be a top priority.”¹⁰

This is our goal.

Future Questions?

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References and Details – Brain Injury Bulletin, March, 24, 2014

1 Twenty-four acute care hospitals report to ATR (a) through Institutional ATR Abstractors: AK Native Medical Center, AK Regional, Fairbanks Memorial, Ketchikan General, Providence Alaska Medical Center; and (b) through a Multi-Institution ATR Contractor: Bartlett Regional, Bassett Army, Central Peninsula, Cordova, Elmendorf AFB, Kakanak (Dillingham), Maniilaq (Kotzebue), Mat-Su Regional, Mt Edgecumbe SEARCH, Norton Sound Regional, Petersburg General, Providence Kodiak, Providence Seward, Providence Valdez, Samuel Simmons Memorial, Sitka General, South Peninsula, Wrangell, Yukon-Kuskokwim Delta Regional

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- 2 Alaska Department of Health and Social Services, Division of Public Health (DPH), Health Planning and Systems Development. *Alaska Scorecard, December 2013*. Available at: <http://dhss.alaska.gov/dph/HealthPlanning/Pages/scorecard/default.aspx>. Original data from DPH, Section of Emergency Programs, ATR.
 - 3 Centers for Disease Control and Prevention, National Center for Health Statistics. Health Indicators Warehouse. Available at: <http://www.healthindicators.gov/>
NHDS – Hospitalizations for nonfatal traumatic brain injuries (ICD-9-CM codes 800.0-801.9, 803.0-804.9, 850.0-854.1, 950.1-950.3, 995.55, 959.01 in any of the seven diagnostic fields) among the injury hospital discharge subset (principal diagnosis of ICD-9-CM 800-909.2, 909.4, 909.9-994.9, 995.50-995.59, 995.80-995.85). The TBI definition is based on the Barell Matrix. TBI types 1, 2, and 3 are included. The increased use of 959.01 was accompanied by a corresponding drop in the use of 854. Thus, to avoid underestimating TBI's, cases coded as 959.01 were also included. Those who died in the hospital were excluded.
 - 4 Centers for Disease Control and Prevention, Injury Prevention & Control: Traumatic Brain Injury, Concussion & Mild TBI, What are the Signs and Symptoms of Concussion? Available at: http://www.cdc.gov/concussion/signs_symptoms.html
 - 5 IBID, Traumatic Brain Injury in the United States: Fact Sheet. Available at: http://www.cdc.gov/traumaticbraininjury/get_the_facts.html
 - 6 Faul M, Xu L, Wald MM, Coronado VG. *Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations, and Deaths 2002-2006*. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control, 2010.
 - 7 Centers for Disease Control and Prevention, National Center for Health Statistics. Health Indicators Warehouse. Available at: <http://www.healthindicators.gov/>
NHAMCS – Initial emergency department visits for nonfatal traumatic brain injuries (ICD-9-CM codes 800.0-801.9, 803.0-804.9, 850.0-854.1, 950.1-950.3, 995.55, 959.01 in any of the three diagnostic fields) among the injury ED subset (first listed ICD-9-CM 800-909.2, 909.4, 909.9-994.9, 995.50-995.59, 995.80-995.85, E800-E869, E880-E929, E950-E999) that were not admitted to the hospital or transferred to another facility. The TBI definition is based on the Barell Matrix. TBI types 1, 2, and 3 are included. The increased use of 959.01 was accompanied by a corresponding drop in the use of 854. Thus, to avoid underestimating TBIs, cases coded as 959.01 were also included. Those who died, were admitted to the same or transferred to another hospital, or who have an unknown disposition were excluded.
 - 8 Alaska's Hospital Discharge Database. Multiple personal discussions and correspondence with Alice Rarig, Planner IV, Health Planning & Systems Development, Division of Public Health, Alaska Department of Health and Social Services, (2012-2013).
Only 11 of the 24 hospitals that report to the ATR also report to the HDD. In 2010, these were (for both inpatient and outpatient data), AK Regional, Fairbanks Memorial, Providence Alaska Medical Center, Bartlett Regional, Central Peninsula, Providence Seward, Providence Valdez, South Peninsula, and (for inpatient data only) AK Native Medical Center, Ketchikan General, and Providence Kodiak. Discharge data for Alaskan patients in Washington hospitals are also included in HDD.
The 13 Alaskan hospitals reporting to ATR but not to HDD include: Bassett Army, Elmendorf AFB, Cordova, Kakanak (Dillingham), Maniilaq (Kotzebue), Mat-Su Regional, Mt Edgecumbe SEARCH, Norton Sound Regional, Petersburg General, Samuel Simmons Memorial, Sitka General, Wrangell, and Yukon-Kuskokwim Delta Regional. Other long-term or non-acute Alaskan hospitals do not report to either the ATR or HDD: St Elias Long-Term Acute Care, North Star Hospitals, and Alaska Psychiatric Institute.
 - 9 Whose Head Hurts in Alaska? TBI Trends and Disparities, 1992-2011. Poster presentation at North American Brain Injury Society 11th Annual Conference by Hillary Strayer, Alaska Native Tribal Health Consortium and Jill Hodges, Alaska Brain Injury Network, Inc. (September, 2013).
 - 10 Langlois JA, Rutland-Brown W. *Traumatic Brain Injury in the United States: The Future of Registries and Data Systems*. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2005.