Improving American Indian and Alaska Native Injury Statistics: Using Record Linkage to Correct Racial Misclassification in a State Trauma Registry

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Introduction

There are about 200,000 American Indians and Alaska Natives (AI/AN) in Washington State, or 3% of the population. This includes members of the 29 federally-recognized tribes with reservation lands in the state, as well as AI/AN from tribes outside the state. The urban AI/AN population continues to grow, and today nearly 70% of Washington AI/AN live in or near cities.¹

AI/AN in Washington state are at high risk for injuries, and are more likely than the general population to die as a result of a traumatic injury.² Based on Washington State death certificate data, corrected for misclassified AI/AN race, unintentional injury is the leading cause of death for AI/AN aged 1-54 years in Washington State.³ AI/AN suicide rates are 1.7 times higher than the general population while homicide rates are 3.7 times higher.² In 2011, AI/AN hospitalization rates for injuries were 1.8 times higher than the non-Hispanic white population in Washington State.⁴ However, death certificate and hospital discharge data provide an incomplete picture of injuries. Trauma registry data can supplement these sources by providing information on injury cases, severity, quality of care, and outcomes for those who survive their injuries long enough to be seen in a hospital.⁵

Misclassification of AI/AN patients as White, Black, or Other Races on hospital intake forms and medical records has been well documented.^{6,7,8} Since most state trauma registries draw their race information from these sources, it is likely that AI/AN race is also misclassified in trauma registries. Racial misclassification of AI/AN underestimates the true injury morbidity and mortality burden for this population,^{7,8,10} and limits the utility of trauma registry data for understanding and responding to injuries as a public health priority in this population.¹¹

One method to address racial misclassification is record linkage with lists of known AI/AN individuals, also known as tribal registries. Improving Data and Enhancing Access -Northwest (IDEA-NW), a project of the Northwest Tribal Epidemiology Center within the Northwest Portland Area Indian Health Board (NPAIHB), maintains the Northwest Tribal Registry (NTR), an enumeration of the AI/AN population in Idaho, Oregon and Washington. The NTR was founded in 1999 in response to numerous requests from NPAIHB member tribes for tribe-specific health data. At the time, more Northwest tribes were taking over management of their health care systems. As a result, the Portland Area Indian Health Service (PAIHS) area office downsized and became less able to provide health surveillance data at the community level. In addition, it was becoming clear that racial misclassification in public health data hindered the ability to produce accurate AI/AN health information. To address this issue, the NTR was created with seed money from the IHS and a grant from the National Cancer Institute. Through data sharing agreements with the PAIHS and resolutions from all 43 NPAIHB member tribes, the NTR was established using the PAIHS area patient file as the primary data source. Because the IHS patient file only captures about 57% of the AI/AN population in the Northwest,⁶ the NTR has been augmented with individual tribal enrollment data, tribal clinic registration data, and Urban Indian Health Organization patient data. These additional data were obtained through data sharing agreements with participating tribes and clinics, and inclusion has changed over the years. At the time of this linkage, the NTR contained the PAIHS patient file, the Seattle Indian Health Board patient registration data, and clinic registration data from one additional tribe.

Using probabilistic linkage, we matched the NTR with the Washington Trauma Registry (WTR), a statewide trauma registry which collects data from 77 trauma-designated hospitals in Washington. This includes one Level I trauma center, and four which provide pediatric and rehabilitation care. There are no IHS hospitals in the PAIHS region of Idaho, Oregon and Washington, and Veterans Administration hospitals do not report to the WTR.

The goal of this study was to evaluate the completeness and accuracy of race information within the WTR, examine factors associated with racial misclassification, and determine the extent to which AI/AN injury rates, patterns, and outcomes in Washington differed after correcting misclassified records.

Methods

Using the probabilistic linkage software Link Plus (version 2.0; Atlanta, GA), we matched the NTR to the WTR. The WTR includes data from all trauma patients who are discharged with an ICD-9-CM diagnosis of 800-904, 910-959, 994.1, 994.7, 994.8; and meet one or more of the following criteria: activated the Trauma Resuscitation Team, dead on arrival or died in facility, transferred into or out of the facility by EMS, transported by air from the scene, pediatric trauma patients (ages 0-14), or adults with length-of-stay in the reporting facility of more than 48 hours.¹² The WTR does not represent the entire population of trauma cases in the state, as the registry excludes injury patients who do not meet the eligibility criteria or who present to a hospital that does not report to the WTR. For the present study, we obtained all WTR trauma cases occurring between 2005 and 2009, the most current complete 5-year data period available as of the time of the linkage (N=111,701 records).

The NTR includes all AI/AN in Idaho, Oregon and Washington who have enrolled at an Indian Health Service (IHS) or Tribal health care facility from 1986-2012. We obtain the complete registry list from the PAIHS, and then restrict the data set to AI/AN registrants using several fields for which "Indian Status" can be assessed (Indian blood quantum, tribe of enrollment/affiliation, and classification (an RPMS-specific designation)). All non-AI/AN records and records for which race could not be determined are removed. Additionally, we include a subset of records from earlier versions of the NTR for facilities that had previously reported registration data to the PAIHS but no longer do so. Through a data sharing agreement

with the Seattle Indian Health Board (SIHB), we expanded the NTR to include their urban clinic patient registration data annually since 2008. Established in 1970, the SIHB is a nonprofit, multi-service community health center that targets urban AI/AN in the Puget Sound region of Washington. The patient registry used for this analysis included all patients who accessed care at one of SIHB's clinics and self-identified as AI/AN between 2007 and 2010. By augmenting the NTR with the SIHB patient records, we estimate that the NTR captures about 81% of Washington's AI/AN population.13 The NTR does not represent AI/AN who have not accessed IHS, Tribal or SIHB health care facilities, members of tribal groups that are not federally recognized, and others who self-identify as AI/AN but do not meet IHS eligibility criteria. The NTR likely underrepresents medically underserved AI/AN who have not used I/T/U facilities due to access barriers, and AI/AN who do not use I/T/U facilities because they have private insurance through an employer or spouse.

Date of birth, name and Social Security number were used to match records between the two datasets. Probabilistic linkage methods allow for accurate matching of individuals across data sources, even when they contain missing information or differ slightly. Four members of the study team, including staff from SIHB and the WTR, conducted clerical review of uncertain pairs and assigned match status by consensus. Trauma cases that matched a record in the NTR were reported to the state registry staff in order to improve the quality of race information within the WTR.

Pre-linkage AI/AN records were defined as those with any mention of AI/AN race or a Tribe name in the original WTR dataset; post-linkage AI/AN records included both pre-linkage AI/AN records as well as any records that had a match in the NTR. Records that matched with the NTR but were not originally coded as AI/AN in the trauma registry were considered misclassified.

Intent and mechanism of injury were coded according to the ICD9-CM external cause-of-injury matrix.¹⁴ Cases were selected using the ICD-9-CM codes 800.0-959.9 (excluding 908-909, 910-924, and 930-939), per the National Trauma Databank data standards. Injury severity score (ISS) was calculated in the Collector Database (Dicorp©, Forest Hill, MD). The ISS is used to score patients with injuries to multiple parts of the body, and ranges from 1 (minor injury) to 75 (unsurvivable injury).¹⁵ Death was defined as dead on arrival (DOA), death in emergency department, or death in hospital.

We compared the proportion of AI/AN cases pre- and postlinkage using binomial z test of proportions, and calculated crude rates (per 1,000 population). Rate denominators were calculated using the National Center for Health Statistics (NCHS) bridged-race population estimates.¹⁶ We used multivariable logistic regression to identify characteristics associated with misclassification. The threshold for statistical significance was set at p<0.05 for all statistical tests. All statistical analyses were conducted using SAS software (version 9.4; SAS Institute Inc., Cary, NC). The study was approved by the Institutional Review Boards of the Portland Area Indian Health Service and Washington State Department of Health.

Calculation of population-based rates using trauma registry cases is problematic due to limited inclusion criterial2. Patients who are treated in health care facilities that do not report to the WTR, or who die without medical attention, are not represented in the registry. It is not known to what extent the WTR captures AI/AN injuries in the state, and how that representativeness may differ from other populations. Therefore, we have not calculated population-based rates for comparison with other published data or with other populations. Comparison of pre- and post-linkage AI/AN rates is presented here as a measure of the impact of misclassification only.

Results

The WTR contained 111,701 records of injuries occurring between 2005 and 2009. Prior to linkage, the WTR contained 1,777 AI/AN records. Linkage with the NTR identified 2,251 matches between the two datasets, of which 1,262 (56.1%) were misclassified as a race other than AI/AN in the state dataset. Most of these were coded as white (64.7%) or were missing race information (29.2%). Correcting the race coding of these cases increased the total number of AI/AN records in the WTR from 1,777 (1.6% of WTR records) to 3,039 (2.7% of WTR records – see Figure 1). Linkage increased ascertainment of AI/AN trauma cases by 71.0% and revealed a misclassification prevalence of 41.5%.

Prior to linkage, the crude AI/AN injury rate was 2.6 per

Figure 1. Data linkage between the Northwest Tribal Registry and Washington Trauma Registry.





rates, Washington, 2005-2009.

1,000 population per year. After linkage, correction of misclassified cases increased the AI/AN injury rate to 4.4 per 1,000 (Figure 2). The rate ratio of 1.7 (95% confidence interval (CI) 1.6-1.8) demonstrated a statistically significant increase in the estimated AI/AN injury rate following linkage.

Table 1 compares the pre vs. postlinkage number of AI/AN cases for selected injury characteristics. Linkage significantly increased the proportion of AI/AN injuries in all categories, with the greatest relative changes seen for homicides, firearm injuries, penetrating injuries, and injuries caused by being struck by or against a person or object. Prior to linkage, 4.1% of all homicide victims in the registry were AI/AN patients. After the linkage, this increased to 6.7% (p<0.001), a relative increase of 2.6 percentage points (by comparison, AI/AN comprise approximately 2.9% the state population of in Washington).17 Firearm injuries increased from 2.3% of the registry to 4.0% after adding misclassified AI/AN cases, and the proportion of penetrating injuries that were AI/AN increased from 2.8% to 4.4%. Although the risk of death among AI/AN patients in the WTR was very similar to that seen among white patients, linkage did impact the

Figure 2. Effect of linkage on crude AI/AN trauma injury proportion of all deaths that were AI/AN. Using the pre-linkage race coding, 1.7% of all deaths were AI/AN. After linkage this proportion increased to 2.4% of all deaths (p=0.003).

> Odds ratios for factors associated with misclassification of AI/AN in the WTR are shown in Table 2. Transportation by helicopter (OR=1.96, 95% CI 1.30-2.96) and other methods (OR=1.36, 95% CI 1.12-1.65) was associated with higher odds of misclassification, compared with those transported by ground ambulance. AI/AN injured in metropolitan counties were more likely to be misclassified than those injured in rural counties (OR=1.24, 95% CI 1.01-1.54). AI/AN injured in regions that did not include a large tribe were more likely to be misclassified than those in a region with a large tribe (OR=2.30, 95% CI 1.86-2.84). There was a lower likelihood of misclassification for AI/AN treated at a Level I trauma center. AI/AN who were transferred to another facility for care, and AI/AN with suicide/self-harm related injuries. The model was also adjusted for age, sex, ICU admission, injury severity score, death, and mechanism of injury; however, none of these factors were significantly related to misclassification.

Discussion

Trauma registry data are an important tool in tribal public health surveillance, providing comprehensive information about the causes, circumstances, and outcomes of AI/AN injuries.

Table 1. Change in AI/AN cases following linkage, Washington Trauma Registry Cases, 2005-2009.

	Total cases in WTR	AI/AN cases pre-linkage	AI/AN cases post-linkage	Percent Change	
		N	N		
Penetrating Injuries	7,981	226	353	56.2%***	
Death	3,271	54	77	42.6%**	
Firearms injuries	2,501	57	99	73.7%***	
Motor Vehicle Crash Injuries	24,550	552	856	55.1%***	
Struck By/Against Injuries	6,674	172	280	62.8%***	
Head & Neck Injuries	36,806	691	1,146	65.8%***	
Suicides	1,630	45	58	28.9%*	
Homicides	7,047	290	474	63.4%***	
Injuries in which no safety equipment was used	58,478	1,110	1,803	62.4%***	
Severe ISS cases	23,333	431	704	63.3%***	
Cases admitted to ICU	20,118	400	661	65.3%***	
Comparison by binomial z test of proportions ICU = intensive care unit; ISS = Injury Severity Score * p<0.05, ** p<0.01, ***p<0.001					

However, for these data to be useful to AI/AN researchers and health professionals, errors in race coding must be corrected to allow for complete and accurate identification of AI/AN cases.

Record linkage with AI/AN registries provides a straightforward and relatively inexpensive means of addressing racial misclassification in trauma registries. Our linkage between the Washington Trauma Registry and the Northwest Tribal Registry demonstrated that nearly half of the AI/AN cases in the WTR were misclassified. Without correcting this misclassification, the registry data vastly underestimate AI/AN injury rates and the magnitude of disparities experienced by the AI/AN population in Washington.

Our analysis of characteristics associated with misclassification found that AI/AN injured in urban areas and in regions not including a large tribes were more likely to be misclassified, a finding that has been demonstrated in several previous studies.^{18,19,20,21} This may be due to the fact that there are no IHS or Tribal health facilities nearby, no obvious geographic boundaries, and the proportion of AI/AN in the population is small. Medical staff working in urban hospitals and clinics may be less attuned to the AI/AN population and more inclined to harbor stereotypes and misconceptions about where AI/AN live, their appearance, and so on.1 Those who were treated at lower level trauma centers and who were not transferred were more likely to be misclassified. This may imply a need for more comprehensive race data collection training at smaller facilities. Finally, AI/AN with unintentional injuries were more likely to be misclassified than those with suiciderelated injuries. This could be related to the presence of surrogate reporters (i.e., family members) who accompany suicide patients to the trauma center, or indicate a difference in trauma centers' data collection practices for suicide/self-harm trauma cases.

Conclusion

Linkage of the Washington Trauma Registry with the Northwest Tribal Registry enhanced the ascertainment of AI/AN injury cases, and produced more accurate estimates of injury morbidity and mortality for this population. Through the work of Tribal Epidemiology Centers and other AI/AN research organizations, tribal registries can be established and expanded to better represent this population. While no registry will ever capture the entire AI/AN population, augmenting IHS patient records with urban Indian health facility and tribal clinic registration lists will greatly increase the effectiveness of this work.

The IDEA-NW project has established successful partnerships to conduct record linkages with injury surveillance systems in Idaho, Oregon, and Washington. We also work closely with NPAIHB's Injury Prevention Program (IPP) to disseminate linkage-corrected injury data to NPAIHB's 43 member tribes. Northwest tribes can use these data to plan and implement injury prevention programs that meet the needs of their communities. The IPP has used linkage-corrected data to Table 2. Factors associated with AI/AN misclassificationwithin the Washington Trauma Registry, 2005-2009.

	Odds Ratio	95% Confidence			
	ouus natio	Interval			
Intent*					
Unintentional	1.0 (reference)				
Suicide/self-harm	0.37	(0.19, 0.74)			
Homicide/assault	0.88	(0.70, 1.09)			
Other/unspecified	0.71	(0.31, 1.62)			
Transportation Mode**					
Ground Ambulance	1.0 (reference)				
Helicopter Ambulance	1.96	(1.30, 2.96)			
Other	1.36	(1.12, 1.65)			
Transfer Status**					
Transferred	1.0 (reference)				
Direct	1.45	(1.11, 1.89)			
County of Injury*					
Urban	1.0 (reference)				
Rural	1.24	(1.01, 1.54)			
Region of Injury***					
Includes large tribe	1.0 (reference)				
Does not include large tribe	2.30	(1.86, 2.84)			
Trauma Center Level**					
Level I		(
Level II	2.08	(1.49, 2.89)			
Level III	1.17	(0.90, 1.52)			
Levels IV-V/no designation	1.24	(0.91 ,1.69)			
Calculated by multivariable logistic regression					
Adjusted for age, sex, ICU admission, injury severity score, death,					
and mechanism of injury					
* p<0.05, ** p<0.01, ***p<0.001					

prioritize the training, resources, and technical assistance they provide to Northwest tribes in the areas of motor vehicle safely, prevention of elder falls, helmet use, home and fire safety, and drowning prevention. This confirms the importance of continuing efforts to provide linkage-corrected injury data for use in the planning, implementation and evaluation of injury prevention programs in AI/AN communities.

References

- 1. Urban Indian Health Commission. Invisible Tribes: Urban Indians and Their Health in a Changing World. Seattle, WA: Urban Indian Health Commission, 2007.
- 2. Dankovchik J, Hoopes MJ, Kakuska E. Northwest American Indian And Alaska Native Mortality. Portland, Oregon: Northwest Portland Area Indian Health Board 2012.
- Hoopes M, Dankovchik J. Leading Causes of Death by Age Group American Indians/Alaska Natives, Washington, 2005-2009 Northwest Tribal EpiCenter2012 [cited 2013 April 10th]. Retrieved from: http://www.npaihb.org/images/epicenter_docs/

NW-Idea/2012/COD%20tables_WA_0509_new.pdf

- Improving Data and Enhancing Access Northwest. Linkage-corrected Comprehensive Hospital Abstract Reporting System (CHARS) data - 2011 records (unpublished). 2014.
- 5. Pollock DA. Trauma registries and public health surveillance of injuries. Proceedings of the International Collaborative Effort on Injury Statistics Bethesda, MD: National Center for Health Statistics, Centers for Disease Control; 1995. p. 11-1-6.
- Hoopes MJ, Taualii M, Weiser TM, Brucker R, Becker TM. Including self-reported race to improve cancer surveillance data for American Indians and Alaska Natives in Washington state. Journal of Registry Management. 2010;37(2):43-8.
- Sugarman JR, Soderberg R, Gordon JE, Rivara FP. Racial misclassification of American Indians: its effect on injury rates in Oregon, 1989 through 1990. American Journal of Public Health. 1993;83(5):681-4.
- Sugarman JR, Holliday M, Ross A, Castorina J, Hui Y. Improving American Indian cancer data in the Washington State Cancer Registry using linkages with the Indian Health Service and Tribal records. Cancer. 1996;78(7 Suppl):1564-8.
- Boehmer U, Kressin NR, Berlowitz DR, Christiansen CL, Kazis LE, Jones JA. Self-reported vs administrative race/ethnicity data and study results. American Journal of Public Health. 2002;92(9):1471-2.
- Puukka E, Stehr-Green P, Becker TM. Measuring the health status gap for American Indians/Alaska Natives: getting closer to the truth. American Journal of Public Health. 2005;95(5):838-43.
- Hicks KR, Morones R, Wallace D, Bill NM. Public health practice and the IHS Injury Prevenion Program: Guiding principles. *The IHS Primary Care Provider*. 2007;32(9):274-80.
- Washington State Department of Health. Washington State Trauma Registry Inclusion Criteria 2010 [cited 2013 August 12th]. Retrieved from: http://www. doh.wa.gov/Portals/1/Documents/Pubs/530113.pdf.

- Hoopes MJ. Northwest Tribal Registry, 9th Version (NTR9) Data Assessment. Portland, OR: Northwest Tribal Epidemiology Center: Northwest Portland Area Indian Health Board, 2012.
- Center for Disease Control and Prevention. Tools for classifying ICD Codes 2011 [cited 2012 August 23rd]. Retrieved from: http://www.cdc.gov/nchs/injury/ injury_tools.htm.
- 15. Baker SP, O'Neill B, Haddon W, Long WB. The Injury Severity Score: A method for describing patients with multiple injuries and evaluating emergency care. The Journal of Trauma. 1974;14(8):187-96.
- 16. National Center for Health Statistics. Bridged-race intercensal estimates of the resident population of the United States for July 1, 2000-July 1, 2009, by year, county, single-year of age (0, 1, 2, ..., 85 years and over), bridged race, Hispanic origin, and sex. October 26, 2012. Retrieved from www.cdc/nchs/nvss/bridged_ race.htm.
- 17. US Census Bureau. American FactFinder: Total Population by Race. 2012.
- Grossman DC, Krieger JW, Sugarman JR, Forquera RA. Health status of urban American Indians and Alaska Natives: A population-based study. JAMA. 1994;271(11):845-50.
- Bertolli J, Lee L, Sullivan P. AI/AN Race/Ethnicity Data Validation Workgroup. Racial misclassification of American Indians/Alaska Natives in the HIV/AIDS reporting systems of five states and one urban health jurisdiction, U.S., 1984-2002. Public Health Reports. 2007;122:382-92.
- Thoroughman, Frederickson D, Cameron HD, Shelby LK, Cheek JE. Racial misclassification of American Indians in Oklahoma state surveillance data for sexually transmitted diseases. American Journal of Epidemiology. 2002;155(12):1137-41.
- Harwell TS, Miller SH, Lemons DL, Helgerson SD, Gohdes D. Cancer incidence in Montana: rates for American Indians exceed those for whites. American Journal of Preventive Medicine. 2006;30(6):493-7.

