Racial Misclassification of American Indians and Alaska Natives by Indian Health Service Contract Health Service Delivery Area

Melissa A. Jim, MPH, Elizabeth Arias, PhD, Dean S. Seneca, MPH, MCURP, Megan J. Hoopes, MPH, Cheyenne C. Jim, MS, Norman J. Johnson, PhD, and Charles L. Wiggins, PhD

Objectives. We evaluated the racial misclassification of American Indians and Alaska Natives (AI/ANs) in cancer incidence and all-cause mortality data by Indian Health Service (IHS) Contract Health Service Delivery Area (CHSDA).

Methods. We evaluated data from 3 sources: IHS-National Vital Statistics System (NVSS), IHS-National Program of Cancer Registries (NPCR)/Surveillance, Epidemiology and End Results (SEER) program, and National Longitudinal Mortality Study (NLMS). We calculated, within each data source, the sensitivity and classification ratios by sex, IHS region, and urban–rural classification by CHSDA county.

Results. Sensitivity was significantly greater in CHSDA counties (IHS-NVSS: 83.6%; IHS-NPCR/SEER: 77.6%; NLMS: 68.8%) than non-CHSDA counties (IHS-NVSS: 54.8%; IHS-NPCR/SEER: 39.0%; NLMS: 28.3%). Classification ratios indicated less misclassification in CHSDA counties (IHS-NVSS: 1.20%; IHS-NPCR/SEER: 1.29%; NLMS: 1.18%) than non-CHSDA counties (IHS-NVSS: 1.82%; IHS-NPCR/SEER: 2.56%; NLMS: 1.81%). Race misclassification was less in rural counties and in regions with the greatest concentrations of AI/AN persons (Alaska, Southwest, and Northern Plains).

Conclusions. Limiting presentation and analysis to CHSDA counties helped mitigate the effects of race misclassification of AI/AN persons, although a portion of the population was excluded. (*Am J Public Health.* 2014;104:S295–S302. doi: 10.2105/AJPH.2014.301933)

Accurate determinations of disease and mortality are a critical first step toward addressing disease burden and health disparities. American Indian/Alaska Native (AI/AN) populations experience some of the greatest health disparities in the country compared with other racial and ethnic groups.[1–3] Health and mortality status assessments for AI/AN populations are often hindered by a lack of complete and accurate data on race and ethnicity in surveillance and vital statistics systems. AI/AN populations are more likely to be misclassified as another race than other racial groups in cancer registries, resulting in underestimates of cancer incidence.[4–10] Similarly, misclassification of AI/AN race is a common problem on death certificates,[11–18] on which ascertainment of race is usually provided by a funeral director. As a result, mortality estimates for the AI/AN population in the United States have been significantly underestimated.[13]

A study of racial/ethnic misclassification on US death certificates, which compared self-identified race from the US Census Bureau's Current Population Survey (CPS) to the race recorded on death certificates for a sample of decedents in the National Longitudinal Mortality Study (NLMS) database, found markedly higher race misclassification of AI/AN persons (30%) compared with persons of other races that varied substantially by degree of geographic co-ethnic concentration.[13] For example, AI/AN decedents who died in counties with high concentrations of AI/AN populations were significantly more likely to be classified correctly on death certificates than those who died outside of these counties.[13] Similarly, a study comparing the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) Program with NLMS found that SEER data considerably underreported AI/AN persons.[19] A project matching Indian Health Service (IHS) patient registration records with the National Death Index (NDI) records of persons who died from 1986 to 1988 showed that the percentage of inconsistent classifications of AI/AN race varied from 1.2% in the Navajo IHS Area to 30.4% in the California IHS Area.[20]

The IHS provides primary health care to approximately 2.2 million enrolled members of federally recognized tribes, a number equivalent to approximately 64% of the United States estimated 3.4 million AI/AN population.[21,22] Health care services for AI/AN individuals are provided in more than 670 IHS and tribal health care facilities, mostly in rural and isolated areas.[23] Eligible AI/AN persons can receive health care at any IHS facility, but complex rules govern and restrict the delivery of contract health services for specialty medical care that is not available at IHS facilities.[24] One eligibility requirement for contract health services is residence within the Contract Health Service Delivery Area (CHSDA) of the tribe in which the patient is enrolled. The geographic composition of the CHSDAs follows county boundaries and is established for each federally recognized tribe by the IHS.[25] Details of the IHS regions (Northern Plains, Alaska, Southern Plains, Pacific Coast, East, and Southwest) and CHSDA areas are provided elsewhere[26] and shown in Figure A (available as a supplement to the online version of this article at http://www.ajph.org).

Record linkages with IHS patient enrollment data are 1 method for addressing misclassification of AI/AN race in central cancer registries and in vital statistics mortality data; such linkages have been found to be both timely and cost effective.[8,26–29] An additional method to reduce the impact of race misclassification that

has been used in cancer and mortality reporting is that of restricting analysis to CHSDA counties.[26,28,30–32] The proportion of AI/AN persons in the total population is higher in CHSDA counties than in non-CHSDA counties, and previous studies have shown lower levels of racial misclassification for AI/AN persons in CHSDA counties.[13,33] The rationale for this approach is that there is likely to be more awareness of AI/AN race in theses counties.[13]

Our objective was to evaluate racial misclassification in both cancer registry incidence and all-cause mortality databases and to present evidence for using CHSDAs in future reports to address race misclassification of AI/AN individuals. To investigate this, we used data from the IHS linkages with mortality and cancer registries, with confirmation from an IHS-independent linkage in the form of the NLMS.

METHODS

Detailed methods describing the mortality data are explained elsewhere in this supplement.[34] Detailed methods describing incidence data are available in a previous publication.[26]

IHS–National Vital Statistics System Mortality Files

The IHS patient registration database was linked to the NDI to identify IHS AI/AN decedents.[34] Following this linkage, IHS AI/AN records for persons identified as deceased, by matching with the NDI, were then linked to 1990 to 2009 annual National Vital Statistics System (NVSS) mortality files, and the linked records were flagged to identify AI/AN ancestry. The final numbers of decedents classified as being of AI/AN race in the amended NVSS mortality files included those that were already classified as such in the original NVSS mortality file and those we identified as AI/AN decedents through the linkage with IHS. The amended NVSS mortality files provided the ability to evaluate the racial classification on the death certificate by comparing IHS race classification to race classification on the death certificates of linked records.

Indian Health Service. For a person to receive services they had to prove that they were eligible. IHS has a classification (beneficiary) code that can be used to identify an individual as AI/AN. We restricted the IHS patient registration file to only those individuals that IHS classified as AI/AN.

Death records. The NDI is a central electronic repository maintained within the NCHS of death record information on file in individual state vital statistics offices.[35] The NDI is a file of national death record information (beginning with 1979 deaths) containing personal identifiers that is compiled from electronic files submitted by individual state vital statistics offices.

National Vital Statistics System annual mortality files. The NVSS is the product of a voluntary contractual agreement between individual vital statistics registration areas and the Centers for Disease Control and Prevention (CDC) National Center for Health Statistics (NCHS) to collect US birth and death information. Death certificate data are compiled by each state and sent to the NCHS, where the data are assessed and edited for consistency. The NCHS makes this information available to the research community as part of the NVSS, and includes underlying and multiple cause of death fields, state of residence, age, sex, race, and ethnicity.[36] The NVSS covers more than 99% of all deaths occurring annually in the 50 states, the District of Columbia, New York City (a separate area from that of New York State), and the US territories.[13] Because some states have adopted the 2003 Standard Death Certificate, requiring the collection of multiple races, but others continue to use the 1989 Standard Death Certificate, which requires race categories to be in single race, the NCHS uses the same algorithm to bridge multiple race responses on death certificates to single race, which the Census Bureau uses to attain uniformity and comparability until all states adopt the 2003 standard.[37]

Cancer Data

We used data from state and regional population-based cancer registries in the United States that collect information on newly diagnosed primary cancers. These registries participate in the CDC's National Program of Cancer Registries (NPCR) or the NCI's SEER program.[38–40] Incident cancer cases diagnosed from 1999 to 2002 from 43 population-based state cancer registries that provided clinical and demographic characteristic data were included in this analysis (AK, AZ, AR, CT, DE, GA, HI, ID, IA, IN, KY, LA, ME, MD, MA, MI, MS, MO, MT, NE, NV, NM, NY, NC, ND, OH, OK, OR, PA, RI, SC, SD, TN, TX, UT, VT, VA, WA, WV, WI, WY).[26] We used data from 1999 to 2002 because the first IHS linkage covered those years and provided the best estimates of racial misclassification in the cancer registries. Some cancer registries updated race in response to the IHS linkages, thereby affecting calculations of sensitivity and classification ratios for more recent years.

To examine the patterns of misclassification of AI/AN cases as non-AI/AN persons, all records from the NPCR and SEER population-based registries were linked with the IHS patient registration database. Files were prepared by the registries and sent to the IHS Division of Epidemiology and Disease Prevention in Albuquerque, New Mexico for linkage. Link Plus 2.0 (CDC, Atlanta, GA),[41] a probabilistic linkage software program, was used to link the central cancer registry data with IHS using key patient identifiers.[26]

National Longitudinal Mortality Study

The NLMS is made up of a series of CPS Annual Social and Economic Supplements and a sample of the 1980 decennial census combined with NVSS death certificate information to identify mortality status and cause of death. The CPS is a multistage, stratified probability sample of the US noninstitutionalized civilian population with an approximate 95% response rate.[42]

Currently, the NLMS includes 30 files covering years 1973 and 1978 to 2002, for a total of approximately 2.7 million records. Through a linkage with the NCHS NDI for 1979 to 2002, more than 341 000 of these records were identified as deaths. We evaluated the degree of racial misclassification on death certificates from 1990 to 2002 for the AI/AN population using the NLMS by comparing race as reported on the CPS to race as reported on death certificates for the sample of NLMS decedents who self-identified or were identified as AI/AN by a household member on the CPS.

Population Estimates

We used county-level population estimates produced by the US Census Bureau as

denominators in the rate calculations. To manage multiple race data collected since 2000, a technique of bridging race categories into single-race annual population estimates was developed by the NCHS in collaboration with the Census Bureau.[43]

The NCI made further refinements regarding race and county geographic codes and adjustments for population shifts because of Hurricanes Katrina and Rita in 2005, and provided public access to these estimates at the SEER website for calculation of incidence and death rates.[44]

Statistical Analyses

We evaluated race classification on death certificates for AI/AN decedents and in cancer registries for AI/AN cases by calculating 2 statistical measures (Table A, available as a supplement to the online version of this article at http://www.ajph.org). First, record-level agreement between the IHS patient registration or CPS databases and the death certificates or cancer registry records for individual decedents was estimated through a measure of sensitivity. Sensitivity is the percentage of individuals who were truly AI/AN as classified by IHS or self-identified in the CPS who were correctly classified as such on the death certificate or in cancer registry records. Second, a measure of the net difference in assignment of AI/AN race between 2 distinct data collection systems was ascertained through the estimation of "classification ratios."[13] Classification ratios were the ratios of the total number of AI/AN persons in the IHS or CPS to the total number of AI/AN persons on the death certificate or in cancer registry records. These 2 measures of racial misclassification were estimated for CHSDA and non-CHSDA counties, and by IHS region.[34] We restricted the analyses to only those decedents or cases that linked to IHS in the IHS-dependent linkages and to only those decedents that linked to CPS in the IHS-independent NLMS linkage.

The calculation of sensitivity and classification ratios for each of the comparisons is described in Table A. The χ^2 statistic was used to determine whether differences between CHSDAs and non-CHSDAs were statistically significant.[45]

All-Cause Death Rates

The amended NVSS mortality files were combined with corresponding annual bridged race intercensal population data files to create an analytical file in SEER*Stat version 8.0.4 (NCI, Bethesda, MD; AI/AN-US Mortality Database [AMD]). All-cause death rates, expressed per 100 000 population, were directly age adjusted, using SEER*Stat software,[46] to the 2000 US standard population and using 11 age groups (less than 1, 1–4, 5–14, 15–24, 25–34, 35–44, 45–54, 55–64, 65–74, 75–84, and 85 years and older) in accordance with a 1998 US Department of Health and Human Services recommendation.[47,48] These data are different from, and therefore, were not comparable with, published death rates adjusted using a different standard population.

During preliminary analyses, it was discovered that the updated bridged intercensal populations estimates significantly overestimated AI/AN persons of Hispanic origin.[49] Therefore, to avoid underestimating all-cause mortality in AI/AN populations, rate analyses were limited to non-Hispanic AI/AN persons. Non-Hispanic White was chosen as the most homogeneous referent group. For conciseness, the term "non-Hispanic" is henceforth omitted when discussing both groups.

Using the age-adjusted, all-cause death rates, standardized rate ratios (RRs) were calculated for AI/AN populations using White rates for comparison. Ninety-five percent confidence intervals (CI) for age-adjusted rates and standardized RRs were calculated based on methods described by Tiwari et al. using SEER*Stat 8.0.4 and were presented as rounded to 2 decimal places.[50]

RESULTS

Table 1 shows counts of death, estimates of sensitivity and classification ratios by sex, IHS region, urban–rural classification, and CHSDA county status. The IHS linkage with the NDI yielded a total of 187 537 IHS decedents for 1990–2009. Of the 187 537 decedents, 151 880 were identified as an AI/AN person on the death certificate, and the remaining 35 657 were misclassified as another race (data not shown). Misclassification results varied considerably by IHS region: the lowest percentages of

TABLE 1—Sensitivity and Classification Ratios for Death Certificates That Linked to IHS: IHS-NVSS Mortality Files, United States, 1990–2009

Group	No. AI/AN CHSDA Deaths		No. AI/AN Non-CHSDA Deaths		Sensitivity[a]		Classification Ratio[b]	
	IHS	DC	IHS	DC	CHSDA	Non-CHSDA	CHSDA	Non-CHSDA
Male and Female[c]	170 743	142 675	16 794	9205	83.6	54.8	1.2	1.82
Male	94 538	79 690	9035	5050	84.3	55.9	1.19	1.79
Female	76 205	62 985	7759	4155	82.7	53.6	1.21	1.87
Northern Plains[c]	33 804	31 053	4960	3678	91.9	74.2	1.09	1.35
Alaska[d]	13 782	12 888	NA	NA	93.5	NA	1.07	NA
Southern Plains[c]	42 615	27 834	3223	1237	65.3	38.4	1.53	2.61
Southwest[c]	51 910	48 953	1373	992	94.3	72.3	1.06	1.38
Pacific Coast[c]	23 292	17 505	3454	1828	75.2	52.9	1.33	1.89
East[c]	5340	4442	3784	1470	83.2	38.8	1.2	2.57
Urban[c]	65 551	51 001	12 658	7008	77.8	55.4	1.29	1.81
Rural[c]	105 092	91 577	4136	2197	87.1	53.1	1.15	1.88

Note. AI/AN = American Indian and Alaska Native; CHSDA = Contract Health Service Delivery Area; DC = death certificate; IHS = Indian Health Service; NA = not applicable; NVSS = National Vital Statistics System. Data from 50 states and the District of Columbia. Analyses include AI/AN persons of Hispanic origin and are limited to decedents who linked to IHS.
Source. IHS-NVSS Mortality Files.

[a]Percentage of IHS decedents also coded as AI/AN on the death certificate of all IHS decedents.

[b]Ratio of the total number of decedents classified as AI/AN in IHS to the total number of decedents classified as AI/AN on the death certificate.

[c]Chi-square test indicates statistically significant differences between the number of AI/AN deaths in CHSDA and non-CHSDA counties, $P < .01$.

[d]All counties are CHSDA counties.

misclassified decedents were observed in the Southwest (6.3%) and Alaska (6.5%), whereas the highest percentages of misclassified decedents were observed in the East (35.2%) and the Southern Plains (36.6%; data not shown). The majority of IHS decedents were residents of CHSDA counties (170 743 vs 16 794 in non-CHSDA counties) and rural counties (109 228 vs 78 209 in urban counties).

Record-level agreement or sensitivity was 83.6% for decedents in CHSDA counties and 54.8% in non-CHSDA counties. Sensitivity varied by region and county type. Among CHSDA counties, sensitivity ranged from 65.3% in the Southern Plains to 94.3% in the Southwest. In non-CHSDA counties, sensitivity ranged from 38.4% in the Southern Plains to 74.2% in the Northern Plains. In urban areas, sensitivity was 77.8% in CHSDA counties and 55.4% in non-CHSDA counties. Rural CHSDA counties had a sensitivity of 87.1% compared with 53.1% in rural non-CHSDA counties. Sensitivity was higher in rural CHSDA counties than urban CHSDA counties.

All-Cause Death Rates

The effects of race misclassification were explored by examining age-adjusted, all-cause death rates and death rate ratios for AI/AN compared with White persons before and after the IHS linkage in CHSDA counties only (Table 2). The number of decedents identified as an AI/AN person on the death certificate increased

TABLE 2—Death Rates for All Causes by IHS Region and Sex for American Indians/Alaska Natives Compared With Whites: CHSDA Counties, United States, 1990–2009

	Prelink					Postlink					AI/AN Differences		
IHS Region/Sex	AI/AN Count	AI/AN Rate	White Count	White Rate	AI/AN:White RR (95% CI)	AI/AN Count	AI/AN Rate	White Count	White Rate	AI/AN:White RR (95% CI)	Count	Rate	RR
Northern Plains													
Male and female	21 522	1337.3	788 175	772.5	1.73* (1.70, 1.76)	23 331	1461.8	786 392	770.6	1.90* (1.87, 1.93)	1809	124.5	0.17
Male	11 782	1604.6	387 075	929.5	1.73* (1.69, 1.77)	12 709	1748.8	386 164	927.4	1.89* (1.84, 1.93)	927	144.2	0.16
Female	9740	1133.0	401 100	650.9	1.74* (1.70, 1.78)	10 622	1243.4	400 228	649.2	1.92* (1.88, 1.96)	882	110.4	0.17
Alaska													
Male and female	8042	1142.4	24 162	752.5	1.52* (1.48, 1.56)	8616	1218.6	23 621	738.2	1.65* (1.61, 1.70)	574	76.2	0.13
Male	4435	1333.9	13 912	873.9	1.53* (1.47, 1.59)	4771	1431.6	13 600	856.8	1.67* (1.61, 1.74)	336	97.7	0.14
Female	3607	982.1	10 250	639.2	1.54* (1.48, 1.60)	3845	1041.2	10 021	627.3	1.66* (1.60, 1.73)	238	59.1	0.12
Southern Plains													
Male and female	21 802	931.8	367 010	951.0	0.98* (0.97, 0.99)	30 421	1313.1	358 711	928.7	1.41* (1.40, 1.43)	8619	381.3	0.43
Male	11 600	1127.6	179 964	1127.9	1.00 (0.98, 1.02)	15 946	1568.7	175 778	1102.2	1.42* (1.40, 1.45)	4346	441.1	0.42
Female	10 202	781.8	187 046	810.2	0.97* (0.95, 0.98)	14 475	1116.3	182 933	790.9	1.41* (1.39, 1.44)	4273	334.5	0.45
Southwest													
Male and female	31 488	960.9	671 400	791.9	1.21* (1.20, 1.23)	33 325	1017.8	669 622	789.7	1.29* (1.27, 1.30)	1837	56.9	0.08
Male	17 826	1183.4	348 602	928.9	1.27* (1.25, 1.30)	18 836	1251.4	347 628	926.2	1.35* (1.33, 1.37)	1010	68	0.08
Female	13 662	780.3	322 798	672.2	1.16* (1.14, 1.18)	14 489	828.1	321 994	670.4	1.24* (1.21, 1.26)	827	47.8	0.07
Pacific													
Male and female	17 088	889.2	1 462 986	798.0	1.11* (1.10, 1.13)	20 779	1091.5	1 459 406	796.0	1.37* (1.35, 1.39)	3691	202.3	0.26
Male	9011	1016.3	723 661	936.0	1.09* (1.06, 1.11)	10 875	1238.3	721 856	933.7	1.33* (1.30, 1.36)	1864	222	0.24
Female	8077	785.7	739 325	685.6	1.15* (1.12, 1.17)	9904	971.1	737 550	683.8	1.42* (1.39, 1.45)	1827	185.4	0.27
East													
Male and female	5610	753.4	1 559 827	796.0	0.95* (0.92, 0.97)	6172	828.7	1 559 313	795.7	1.04* (1.01, 1.07)	562	75.3	0.10
Male	2937	854.7	750 874	958.0	0.89* (0.86, 0.93)	3231	939.1	750 611	957.7	0.98 (0.94, 1.02)	294	84.4	0.09
Female	2673	668.1	808 953	671.3	1.00 (0.96, 1.04)	2941	735.4	808 702	671.0	1.10* (1.06, 1.14)	268	67.3	0.10
Total													
Male and female	105 552	994.0	4 873 560	801.7	1.24* (1.23, 1.25)	122 644	1165.9	4 857 065	798.8	1.46* (1.45, 1.47)	17 092	171.9	0.22
Male	57 591	1186.9	2 404 088	952.0	1.25* (1.23, 1.26)	66 368	1381.8	2 395 637	948.8	1.46* (1.44, 1.47)	8777	194.9	0.21
Female	47 961	839.0	2 469 472	681.1	1.23* (1.22, 1.24)	56 276	991.5	2 461 428	678.6	1.46* (1.45, 1.47)	8315	152.5	0.23

Note. AI/AN = American Indian and Alaska Native; CHSDA = Contract Health Service Delivery Area; CI = confidence interval; IHS = Indian Health Service; RR = rate ratio. Analysis includes only persons of non-Hispanic origin. States and years of data excluded because Hispanic origin was not collected on the death certificate: LA: 1990; NH: 1990–1992; OK: 1990–1996. Rates are per 100 000 persons and are age-adjusted to the 2000 US standard population (11 age groups - Census P25-1130). RRs are calculated in SEER*Stat before rounding of rates and may not equal RRs calculated from rates presented in table. Percent regional coverage of AI/AN persons in CHSDA counties to AI/AN persons in all counties: Northern Plains = 64.8%; Alaska = 100%; Southern Plains = 76.3%; Southwest = 91.3%; Pacific Coast = 71.3%; East = 18.2%; total US = 64.2%.

Source. AI/AN Mortality Database (AMD 1990-2009). Data are based on linked Indian Health Service-National Vital Statistics System mortality files.

*$P < .05$.

from 105 552 before the linkage to 122 644 after the linkage, for a misclassification prevalence of 14%.

The US estimated age-adjusted, all-cause death rate for AI/AN persons rose from 994 per 100 000 (prelink) to 1166 per 100 000 (postlink). Relative to the rate among Whites, this represented an increase in RRs from 1.24 to 1.46. Age-adjusted, all-cause death rates varied by region, with RRs relative to White increasing as little as 8% in the Southwest and 9% in the East to as high as 43% in the Southern Plains (Figure B, available as a supplement to the online version of this article at http://www.ajph.org).

Cancer Cases in NPCR-SEER Data

The IHS linkage with the NPCR and SEER central cancer registries yielded a total of 12 553 matches for males and females in diagnosis years 1999 to 2002. Table 3 shows misclassification measures, sensitivity, and classification ratios by sex, IHS region, urban–rural classification, and CHSDA county status. The percent of cases that linked to IHS and were correctly identified by cancer registries was 77.6% in CHSDA counties and 39.0% in non-CHSDA counties. Sensitivity measures by IHS region in CHSDA counties ranged from 52.8% in the East to 99.4% in Alaska, and in non-CHSDA counties, sensitivity varied from 13.9% in the Southern Plains to 71.4% in Northern Plains. In CHSDA counties, the sensitivity measure in urban areas was 72.9%, and in rural areas, it was 80.8%, whereas in non-CHSDA counties, the sensitivity in urban areas was 41.6%, and in rural areas, it was 52.1%.

The classification ratios also reflected significantly better agreement between IHS and cancer registry incidence data in CHSDA counties than non-CHSDA counties. The classification ratios for males and females in non-CHSDA counties was 2.6, meaning that the IHS linkage identified an additional 156% of AI/AN cases compared with the cancer registries alone, whereas in CHSDA counties only an additional 29% were identified. Classification ratios varied greatly by IHS region and county type. In CHSDA counties, the ratios ranged from 1.01 in Alaska to 1.90 in the East; in non-CHSDA counties, they ranged from 1.40 in the Northern Plains to 7.22 in the Southern Plains. Similarly, classification ratios were higher in urban than in rural counties, particularly in non-CHSDA areas.

TABLE 3—Sensitivity and Classification Ratios for Cases That Linked to IHS: NPCR-SEER Data, United States, 1990–2009

	No. AI/AN CHSDA Cases		No. AI/AN Non-CHSDA Cases		Sensitivity[a]		Classification Ratio[b]	
Group	IHS	Registry	IHS	Registry	CHSDA	Non-CHSDA	CHSDA	Non-CHSDA
Male and Female[c]	11 351	8811	1202	469	77.6	39.0	1.29	2.56
Male	5233	4046	512	204	77.3	39.8	1.29	2.51
Female	6118	4765	690	265	77.9	38.4	1.28	2.6
Northern Plains[c]	2387	2106	416	297	88.2	71.4	1.13	1.4
Alaska[d]	1260	1253	NA	NA	99.4	NA	1.01	NA
Southern Plains[c]	3817	2144	296	41	56.2	13.9	1.78	7.22
Southwest[c]	2314	2062	57	36	89.1	63.2	1.12	1.58
Pacific Coast[c]	1228	1064	70	40	86.6	57.1	1.15	1.75
East[c]	345	182	363	55	52.8	15.2	1.9	6.6
Urban[c]	4593	3349	526	219	72.9	41.6	1.37	2.4
Rural[c]	6758	5462	292	152	80.8	52.1	1.24	1.92

Note. AI/AN = American Indian and Alaska Native; CHSDA = Contract Health Service Delivery Areas; IHS = Indian Health Service; NA = not applicable; NPCR = National Program of Cancer Registries; SEER = Surveillance, Epidemiology and End Results. Analysis includes AI/AN persons of Hispanic origin. Registries used: (43 states) AK,[z] AZ[z], AR, CT,[z] DE, GA, HI, ID[z], IA,[z] IN,[z] KY, LA,[z] ME,[z] MD, MA,[z] MI,[z] MS,[z] MO, MT,[z] NE[z], NV,[z] NH, NJ, NM,[z] NY,[z] NC,[z] ND,[z] OH, OK,[z] OR,[z] PA,[z] RI,[z] SC,[z] SD,[z] TN, TX,[z] UT,[z] VT, VA, WA,[z] WV, WI,[z] WY,[z] ([z]indicate states with at least 1 county designated as CHSDA). Analyses limited to cases who linked to IHS.

Source. Cancer registries in the Centers for Disease Control and Prevention's NPCR or the National Cancer Institute's SEER.

[a]Percentage of IHS cases also coded as an AI/AN person in the cancer registry of all IHS cases.

[b]Ratio of the total number of cases classified as an AI/AN person in IHS to the total number of cases classified as an AI/AN person in the cancer registry.

[c]Indicates statisticially significant differences ($P < .01$) between the number of AI/AN cases in CHSDA and non-CHSDA.

[d]All counties are CHSDA counties.

National Longitudinal Mortality Study

Table 4 presents sensitivity measures and classification ratios by sex, IHS region, urban–rural classification, and CHSDA county status for the sample of NLMS decedents who self-identified as an AI/AN person on the CPS and died between 1990 and 2002. These findings also supported the hypothesis that AI/AN decedents were significantly more likely to be correctly classified on the death certificate in areas of greatest concentration of AI/AN persons. Nationally, AI/AN decedents were significantly more likely to be correctly classified on death certificates in CHSDA than in non-CHSDA counties. Sensitivity was 68.8% in CHSDA counties and 28.3% in non-CHSDA counties. Classification ratios were 1.18 in CHSDA counties and 1.81 in non-CHSDA counties. Classification varied by IHS region, with the highest levels of misclassification in the East (CHSDA = 3.34 vs non-CHSDA = 1.90) and the lowest in Alaska (CHSDA = 0.96) and the Northern Plains (CHSDA = 1.00 vs non-CHSDA = 1.20). In almost all instances, classification was best in CHSDA counties, with an exception in the East, which was likely because of the very small sample size. Similarly, racial classification was found to be better in rural CHSDA counties (1.08) versus urban CHSDA counties (1.36).

DISCUSSION

Our evaluation of racial misclassification in national cancer incidence and all-cause mortality data added to the evidence that racial misclassification is a widespread problem for the AI/AN population.[11–18] Racial misclassification resulted in significant underestimations of all-cause death rates and cancer incidence among AI/AN populations.

We described racial misclassification of AI/AN persons in 2 IHS-related linkages and 1 IHS-independent linkage. In the IHS-related linkages, we observed less misclassification in CHSDA counties than in non-CHSDA counties as predicted, because a large majority of IHS

TABLE 4—Sensitivity and Classification Ratios: National Longitudinal Mortality Study, United States, 1990–2002

Group	No. AI/AN CHSDA Deaths		No. AI/AN Non-CHSDA Deaths		Sensitivity[a]		Classification Ratio[b]	
	CPS	DC	CPS	DC	CHSDA	Non-CHSDA	CHSDA	Non-CHSDA
Male and female	1073	996	479	333	68.8	28.3	1.18	1.81
Male	571	516	238	163	69.7	30.2	1.20	1.77
Female	502	480	241	170	67.8	26.8	1.16	1.84
Northern Plains	370	373	116	99	85.5	38.6	1.00	1.20
Alaska[c]	208	217	NA	NA	95.3	NA	0.96	NA
Southern Plains	97	75	74	53	42.6	29.9	1.51	2.00
Southwest	212	189	31	31	79.9	2.8	1.14	1.18
Pacific Coast	160	132	45	21	64.9	10.7	1.16	3.34
East	26	10	181	98	12.3	28.9	3.34	1.90
Urban	321	274	252	157	49.5	23.2	1.36	1.86
Rural	752	722	227	176	81.4	36.9	1.08	1.74

Note. AI/AN = American Indian and Alaska Native; CHSDA = Contract Health Service Delivery Area; CPS = Current Population Survey; DC = death certificate; NA = not applicable. Includes AI/AN of Hispanic origin. Analyses are based on weighted data and are limited to decedents who linked to CPS.

[a]Percentage of CPS AI/AN decedents also coded as AI/AN on the death certificate of all CPS AI/AN decedents.

[b]Ratio of the total number of decedents classified as AI/AN on the CPS to the total number of decedents classified as AI/AN on the death certificate.

[c]All counties are CHSDA counties.

registrants resided in IHS CHSDA counties. Self-reported race was often thought to be the "gold standard," but the AI/AN sample size in the IHS-independent NLMS was very small and did not allow regional analyses. However, its inclusion confirmed that our results were applicable to other data sets. Again, it confirmed that there was less misclassification of AI/AN persons in CHSDA counties than non-CHSDA counties.

Estimates of aggregate-level agreement between the 2 data systems, classification ratios, further supported our hypothesis that racial classification on death certificates was better in areas with high co-ethnic concentration. In other words, there was significantly better agreement between IHS and death certificate race classification in areas with the greatest concentrations of AI/AN populations: CHSDA counties versus non-CHSDA counties, rural counties versus urban counties, and in Alaska and the Northern Plains versus other regions.

We found that racial misclassification was lowest in Alaska, followed by the Southwest and the Northern Plains consistently across all 3 data sets. These were the regions with the highest percentage of the AI/AN population in CHSDA counties.[34] In the IHS-NVSS mortality files, racial misclassification was highest in the Southern Plains and Pacific Coast, whereas in the NPCR-SEER and NLMS data sets, racial misclassification was highest in the Southern Plains and the East. The percentage of the AI/AN population in CHSDA counties varied in these 3 regions, with an estimated 76.3% of the AI/AN population residing in CHSDA counties in the Southern Plains, 71.3% in the Pacific Coast, and 18.2% in the East. In the Southeast, the majority of AIs were not members of federally recognized tribes and were not served by IHS.[51] The 2010 Census found that the geographic distribution of the multiple-race AI/AN population differed from the AI/AN-alone population. The percent distribution of multiple-race AI/ANs who lived in the Northeast (13%) was nearly twice as high as the percent distribution of the AI/AN-alone population.[52]

Several other factors might influence the differential misclassification observed in these regions. These included the availability and types of health services (e.g., some regions had no hospitals or specialty facilities operated by IHS, and certain regions had more health facilities that were operated by tribes by contract or compact instead of directly by IHS), thus making their patient data less likely to be included in the IHS registration database. In regions that did not have a large IHS presence, such as the East, it was reasonable to assume that our estimates were still inaccurate, and misclassification of AI/ANs was even higher than we found. It was also found that as percent blood quantum (degree of AI/AN ancestry) decreased, misclassification increased, suggesting that health care personnel might be completing race information largely based on appearance.[15,53–55] Regional data for percent blood quantum is currently not available; therefore, multiple-race AI/AN persons were used as a proxy. Multiple-race AI/AN persons were less likely to live in AI/AN areas (i.e., federal reservation or off-reservation trust land, Oklahoma tribal statistical area, state reservation, or federal- or state-designated American Indian statistical area).[56] In addition, the proportion of AI/AN persons residing in urban areas is continually increasing.[57] This in turn diminished the likelihood that these individuals would be seen at IHS and included in the IHS registration database; thus, multiple-race AI/AN persons could still be misclassified as non-AI/AN persons. Some ongoing efforts are attempting to address these issues by including tribal enrollment and urban clinic populations in linkages with state surveillance data.[51,58,59]

Using record level data from the IHS-NVSS mortality files, we found that the effects of misclassification varied considerably by urban–rural classification, CHSDA county status, IHS region, and in some cases, sex. It was possible that other subpopulations (e.g., age groups) were also differentially affected by racial misclassification, further complicating the reporting of health statistics for this population.

Limitations

There were several limitations to consider when interpreting the results presented in this article. First, the linkage with the IHS patient registration database improved the race classification for many AI/AN decedents, but the issues were not completely resolved because AI/AN persons who were not members of federally recognized tribes were not eligible for IHS services and not represented in the IHS registration database. Additionally, some decedents might have been eligible for, but

never used IHS services, and therefore, were not included in the IHS registration database. Second, the findings from CHSDA counties highlighted did not represent all AI/AN populations in the United States or in individual IHS regions. Third, race reported in the IHS patient registration database and in the CPS was used as the standard for comparison with the classification from the death certificate and cancer registries. IHS patient registration and CPS race classification were not without error; however, it was assumed that the information provided by an IHS registrant or survey respondent about racial identity was more valid than proxy reporting by a funeral director or medical record. Fourth, the individuals self-reporting AI/AN race in the CPS might not have been enrolled in a tribe or otherwise eligible for IHS services; thus, they likely represented a different population from the AI/AN persons captured in the IHS linkages. Fifth, self-report allowed individuals to identify their race differently at different times or in different settings; this limitation would apply to the population estimates collected by the Census and upon which all population health statistics are based. Finally, although the exclusion of Hispanic AI/AN persons from the rates presented in Table 2 reduced the overall AI/AN deaths by less than 5%, it might disproportionately affect some states.

Conclusions

The availability of accurate mortality and cancer data are essential for planning, implementation, and evaluation of public health strategies and programs to address the magnitude of health disparities in this population. The high rate of misclassification of AI/AN persons has resulted in significant underestimates of cancer incidence and mortality estimates in this population.[4–18] The IHS-dependent and IHS-independent linkages that we analyzed indicated that racial misclassification of AI/AN individuals varied by region and was less likely in areas where AI/AN persons were a higher percentage of the population. Therefore, limiting analysis to CHSDA counties is crucial to improving the key health indicators (mortality and cancer incidence) and to improving the overall health status of AI/AN persons. ■

About the Authors

Melissa A. Jim is with the Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Albuquerque, NM. Elizabeth Arias is with the Division of Vital Statistics, National Center for Health Statistics, Centers for Disease Control and Prevention, Hyattsville, MD. Dean S. Seneca is with the Division of Public Health Capacity Development, Office for State, Tribal, Local and Territorial Support, Centers for Disease Control and Prevention, Atlanta, GA. Megan J. Hoopes is with the Northwest Tribal Epidemiology Center, Northwest Portland Area Indian Health Board, Portland, OR. Cheyenne C. Jim is with Immunization Services Division, National Center for Immunization and Respiratory Diseases, Centers for Disease Control and Prevention, Albuquerque, NM. Norman J. Johnson is with the National Longitudinal Mortality Study Branch, US Census Bureau, Suitland, MD. Charles L. Wiggins is with the New Mexico Tumor Registry, University of New Mexico Cancer Center, Albuquerque.

Correspondence should be sent to Melissa A. Jim, MPH, CDC Division of Cancer Prevention and Control, 1720 Louisiana Blvd NE, Suite 208, Albuquerque, NM 87110 (e-mail: melissa.jim@ihs.gov or mjim@cdc.gov). Reprints can be ordered at http://www.ajph.org by clicking the "Reprints" link.

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Contributors

M. A. Jim conceptualized the study, completed the analyses, and led the writing. E. Arias assisted with the analyses and writing. D. S. Seneca assisted with the writing. M. J. Hoopes assisted with the writing. C. J. Jim assisted with the linkages and the writing. N. J. Johnson assisted with the analyses. C. L. Wiggins assisted in planning the analyses and writing. All authors helped to conceptualize ideas, interpret findings, and review drafts of the article.

Human Participant Protection

Centers for Disease Control and Prevention and Indian Health Service determined this project to constitute public health practice and not research; therefore, no formal institutional review board approvals were required.

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