Evaluation of African-American and White Racial Classification in a Surveillance, Epidemiology, and End Results Cancer Registry

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Objectives: This study evaluated the validity of registry-reported race for individuals who participated in research studies conducted since 1980 through the Metropolitan Detroit Cancer Surveillance System (MDCSS), a Surveillance, Epidemiology, and End Results (SEER) Program registry.

Methods: 5329 individuals who self-identified as African American or White and were classified in the MDCSS registry as African American or White were included. Self-identified and registry-reported race were compared, and associations between demographics and racial misclassification were examined.

Results: Most self-identified African Americans and Whites were correctly classified (sensitivity=98.5%, specificity=99.7%). Males were two times more likely to be misclassified than females [odds ratio (OR)=2.13, 95% confidence interval (CI): 1.06–4.29]. Individuals diagnosed with cancer after 1990 were two times more likely to be misclassified than those diagnosed before 1990 (OR= 2.17, 95% CI: 1.07–4.42). African Americans were four times more likely to be misclassified than Whites (OR=4.39, 95% CI: 2.24–8.60).

Conclusions: Misclassification in the MDCSS registry of African Americans as Whites, and vice versa, is relatively low. Additional studies should evaluate misclassification of African Americans and Whites as other races and/or ethnicities in the SEER registry. (*Ethn Dis.* 2005;15:713–719)

Key Words: African Americans, Epidemiology, SEER Program

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INTRODUCTION

Racial classification has traditionally been used as a risk indicator for health outcomes, as a marker of unmeasured biological differences, and as a proxy for unmeasured social factors affecting health.[1] Racial patterns in morbidity and mortality are important for both program planning and resource allocation. In cancer epidemiology, race is integral to studies of incidence, morbidity, mortality, survival, and treatment; racial variability in these parameters has led to investigations of the etiologic roles of genetic, cultural, socioeconomic, and environmental factors.

The Metropolitan Detroit Cancer Surveillance System (MDCSS) is a population-based cancer registry established in the 1950s and a founding member of the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program since 1973. The large proportion of African Americans in the MDCSS tri-county coverage area (25% as of the 2000 US Census[2]) and of African-American cases currently in the registry has facilitated the calculation of race-specific cancer statistics over time. Racial patterns in data collected through SEER have led to an increased awareness of the need for aggressive efforts at early detection and treatment among African Americans.

Among all SEER sites, African Americans had higher incidence rates and mortality rates for all cancers combined than persons of any other racial and ethnic group between 1996–2000.[3] In light of the importance of high-quality registry data in efforts to measure and reduce racial disparities in the burden of cancer, little is known about the extent

> *Among all SEER sites, African Americans had higher incidence rates and mortality rates for all cancers combined than persons of any other racial and ethnic group between 1996–2000.[3]*

of African-American misclassification in the SEER registry or its potential for distorting race-specific cancer statistics. For the calculation of many cancer statistics, counts of cases are used in the numerator, and counts of the source population are used in the denominator. Minority groups are particularly vulnerable to undercoverage in population enumeration, which has implications for the validity of the denominators of a variety of health statistics.[4,5] The MDCSS obtains racial classification of cancer cases (used in the numerator of race-specific statistics) from medical records or death certificates, which are often based on subjective assessments by hospital personnel or funeral directors. Because incongruence between the numerator and denominator may result in misleading estimates of race-specific cancer statistics, we felt evaluating the level of racial misclassification in this registry was important.

Two other SEER sites have investigated misclassification of racial/ethnic groups other than African American, reporting that Hispanics,[6,7] Vietnamese,[8] and Native Americans[9] are often

Table 1. Cross-classification of study subjects classified as African American or White in the Metropolitan Detroit Cancer Surveillance System registry and self-identified as African American or White in research studies (N=5329)*

Group	Self-Identified African American (*n*=1637)	Self-Identified White (*n*=3692)
Registry classified African American (*n*=1625)	Correctly classified African American 1612	Incorrectly classified 13
Registry classified White (*n*=3704)	Incorrectly classified 25	Correctly classified White 3679

* Kappa statistic for agreement = 0.9833.

misclassified (34%–40%). To date, no published studies have evaluated misclassification of African-American race in the SEER registry, but evidence for this form of misclassification exists in other data sources; misclassification of African Americans as White was estimated to be >5% in the population-based National Health Interview Survey.[10] To evaluate the level of agreement between registry-reported and self-identified racial status of African Americans and Whites in the MDCSS registry, we compared registry-reported race with self-identified race obtained from 5329 individuals who participated in research studies conducted through the MDCSS and explored associations of demographic characteristics with racial misclassification.

METHODS

The MDCSS collects data on all newly diagnosed cancer cases in the tri-county (Wayne, Oakland, and Macomb) metropolitan Detroit area. Cancer cases are ascertained from records of hospitals, clinics, pathology laboratories, and radiation facilities. The registry relies primarily on hospital admission data and medical charts to ascertain racial information. If racial information is not included in the medical record, the SEER program uses racial data from death certificates. In both medical charts and death certificates, race information is often based on observation by medical or funeral personnel, rather than patient self-report.

Cases from ten completed research studies conducted since 1980 through the MDCSS registry were eligible for inclusion. Each research study protocol and consent form was approved by the Wayne State University Human Investigation Committee, and all subjects provided informed consent prior to the interview. Self-identified race, as well as other demographic information (including marital status, educational attainment, and income level), was obtained by in-person or telephone interviews according to individual research study protocols. Cancer cases were linked to the MDCSS database by using unique registry identifiers to ascertain current registry data on racial classification (registry-reported race) and year of cancer diagnosis. Using self-identified race as the "gold standard," we assessed the validity of registry-reported race and explored associations of demographic characteristics with racial misclassification in cancer cases who were classified by the registry and who self-identified as being African-American or White. Misclassification was defined as discordance between self-identified and registry-reported race.

STATISTICS

The kappa statistic was calculated to evaluate the agreement between registry-reported and self-identified race. Distributional differences by classification status for categorical variables were made by using two-tailed chi-squared tests. *P* values <.05 were considered statistically significant. Diagnosis year

was dichotomized by using the mean of the distribution of year of cancer diagnosis (1990) into two categories (prior to 1990, during or after 1990). Logistic regression analyses were conducted to explore the associations of demographic characteristics with misclassification and to estimate odds ratios (OR) and 95% confidence intervals (CI). Characteristics determined to be statistically significant in the crude (unadjusted) analyses were included in a multivariable regression model (adjusted). Data analyses were performed with SAS version 8.2.[11]

RESULTS

Of the 5533 individuals eligible for the study, seven (0.1%) were excluded because self-identified race was unknown and 54 (1.0%) were excluded because of missing values for registry-reported race. Ten individuals (0.2%) for whom self-identified and registry-reported gender did not match were excluded. Individuals who were classified as races other than African American or White, by either the registry (*n*=30, 0.5%) or self-identification (*n*=103, 1.9%), were excluded, resulting in a final sample size of 5329 individuals.

Most self-identified African Americans were classified correctly as African American by the registry (1612/1637), yielding a sensitivity of 98.5% (Table 1). Most self-identified Whites were classified correctly as White by the registry (3679/3692), yielding a specificity of 99.7%. A high proportion of individu-

Table 2. Distribution of sociodemographic characteristics by classification status among subjects classified as African American or White in the MDCSS registry and self-identified as African American or White in research studies (*N*=5329)

Characteristic	African American by Registry and Self-Identification (*n*=1612)		White by Registry but Self-Identified African American (*n*=25)		African American by Registry but Self-Identified White (*n*=13)		White by Registry and Self-Identification (*n*=3679)	
	n	%	*n*	%	*n*	%	*n*	%
Gender*								
Male	833	51.7	18	72.0	5	38.5	1384	37.6
Female	779	48.3	7	28.0	8	61.5	2295	62.4
Marital status*								
Married	934	57.9	14	56.0	9	69.2	2504	68.1
Single/divorced/separated	599	37.2	9	36.0	2	15.4	792	21.5
Other/refused	3	0.2	0	0	0	0	2	0.1
Not asked†	76	4.7	2	8.0	2	15.4	381	10.4
Education*								
HS grad/GED or less	1058	65.6	18	72.0	6	46.2	1957	53.2
Some college or more	544	33.8	7	28.0	7	53.9	1715	46.6
Refused	10	0.6	0	0	0	0	7	0.2
Income*								
<$35,000	998	61.9	19	76.0	5	38.5	1722	46.8
$35,000–$75,000	306	19.0	4	16.0	4	30.8	1060	28.8
>$75,000	38	2.4	0	0	0	0	181	4.9
Other/refused	14	0.9	0	0	0	0	36	1.0
Not asked‡	256	15.9	2	8.0	4	30.8	680	18.5
Year of cancer diagnosis*								
Prior to 1990	666	41.3	8	32.0	3	23.1	1863	50.6
During or after 1990	920	57.1	16	64.0	9	69.2	1724	46.9
Data not available§	26	1.6	1	4.0	1	7.7	92	2.5

* Chi-square *P* value <.0001.
† Marital status was not ascertained in two research studies (461 individuals).
‡ Income was not ascertained in three research studies (942 individuals).
§ Because Metropolitan Detroit Cancer Surveillance System (MDCSS) identifiers were removed from these cases, we were unable to link back to the MDCSS database to obtain year of diagnosis (120 individuals).

als classified as African American by the registry self-identified as African American in our research studies (1612/1625, or 99.2%). Similarly, 99.3% of individuals classified as White by the registry self-identified as White in these research studies. Excellent agreement (kappa statistic=0.983) was observed between registry-reported and self-identified race.

Demographic characteristics of individuals correctly and incorrectly classified by the registry are presented in Table 2. As compared to African Americans who were correctly classified by the registry (column 1), a greater proportion of African-American individuals whose race was missed by the registry (column 2) were male, had completed up to a high school education, had annual incomes <$35,000, and were diagnosed with cancer during or after 1990. Significant distributional differences were seen by classification status for all sociodemographic characteristics examined (*P*<.0001).

A greater proportion of males were misclassified as compared to females, more African Americans were misclassified than Whites, and more subjects diagnosed during or after 1990 were misclassified than those diagnosed prior to 1990 (Table 3). Unadjusted logistic regression analyses yielded similar results (Table 3). Males were twice as likely to be misclassified as compared to females (OR=2.13, 95% CI 1.06–4.29). Self-identified African Americans were more than four times as likely to be misclassified as compared to self-identified Whites (OR=4.39, 95% CI 2.24–8.60). Individuals who were

diagnosed with cancer during or after 1990 were twice as likely to be misclassified as compared to those diagnosed prior to 1990 (OR=2.17, 95% CI 1.07–4.42). No significant associations were seen between misclassification and marital status, education, or income level.

When the three statistically significant predictors of misclassification (gender, race, and year of cancer diagnosis) were included in a multivariable regression model, only race remained significantly associated with misclassification (Table 3). Self-identified African Americans were four times as likely to be misclassified as compared to self-identified Whites, after adjusting for gender and year of cancer diagnosis (OR=4.0, 95% CI 1.98–8.07). Gender and year of cancer diagnosis were

Table 3. Odds ratios for misclassification among subjects classified as African American or White in the MDCSS registry and self-identified as African American or White in research studies (*N*=5329)

Characteristic	Correctly Classified (*n*=5291)		Misclassified (*n*=38)		Unadjusted Odds Ratio for Misclassification*		Adjusted Odds Ratio for Misclassification†	
	n	%	*N*	%	OR‡	95% CI‡	OR‡	95% CI‡
Gender§								
Female (*n*=3089)	3074	99.5	15	0.5	1.0		1.0	
Male (*n*=2240)	2217	98.9	23	1.0	2.13	1.06–4.29‖	1.73	0.88–3.42
Race (self-identified)§								
White (*n*=3692)	3679	99.7	13	0.4	1.0		1.0	
African American (*n*=1637)	1612	98.5	25	1.5	4.39	2.24–8.60‖	4.0	1.98–8.07‖
Year of cancer diagnosis§¶								
Prior to 1990 (*n*=2540)	2529	99.6	11	0.4	1.0		1.0	
During or after 1990 (*n*=2669)	2644	99.1	25	0.9	2.17	1.07–4.42‖	1.86	0.89–3.72
Data not available (*n*=120)	118	98.3	2	1.7				
Marital status¶								
Married (*n*=3461)	3438	99.3	23	0.7	1.0			
Single/divorced/separated (*n*=1402)	1391	99.2	11	0.8	1.18	0.56–2.43		
Other/refused (*n*=5)	5	100	0	0				
Not asked (*n*=461)	457	99.1	4	0.9				
Education¶								
HS grad/GED or less (*n*=3039)	3015	99.2	24	0.8	1.0			
Some college or more (*n*=2273)	2259	99.4	14	0.6	0.78	0.40–1.51		
Refused (*n*=17)	17	100	0	0				
Income¶								
<$35,000 (*n*=2744)	2720	99.1	24	0.9	1.0			
$35,000–$75,000 (*n*=1374)	1366	99.4	8	0.6	0.66	0.30–1.48		
>$75,000 (*n*=219)	219	100	0	0	—#	—#		
Refused (*n*=50)	50	100	0	0				
Not asked (*n*=942)	936	99.4	6	0.6				

* Unadjusted odds ratios were generated by a logistic regression model including each individual characteristic of interest only.

† Adjusted odds ratios were generated by a multivariable logistic regression model that included categorical variables for characteristics determined to be statistically significant in the unadjusted analyses (gender, self-identified race, and year of cancer diagnosis).

‡ OR=odds ratio; CI=confidence interval.

§ Chi-square *P* value <.05.

‖ *P* value <.05 from logistic regression.

¶ Logistic regression model does not include ''Data not available,'' ''Other/refused,'' or ''Not asked'' categories.

Logistic regression model failed to converge because no racial misclassifications were found in this category.

no longer significantly associated with misclassification in the multivariable regression model.

DISCUSSION

Because inaccuracies in racial data reported in cancer registries may lead to biased estimates of race-specific cancer statistics, we evaluated the representativeness of African-American and White racial classification in the MDCSS registry to determine whether information recorded in the registry truly reflects self-identified race. In this study, we identified only 38 of the 5329 individuals under study

(0.7%) who were misclassified as either African-American or White in the MDCSS registry, based on self-reported information. In addition, we found significant unadjusted associations between misclassification and gender, race, and year of diagnosis, with race remaining significantly associated with misclassification after adjustment for the other two characteristics in the model. In the MDCSS registry, discordance between registry-reported and self-identified race is mostly likely to occur because the information recorded in the registry often reflects subjective observations by healthcare personnel rather than patients' report.

The high sensitivity detected in this study (98.5%) for African-American racial classification indicates that agreement between registry-reported and self-identified race may be higher for African Americans than for racial/ethnic groups that have been evaluated at other SEER registry sites. In the San Francisco-Oakland cancer registry, 34% of persons of Hispanic ethnicity were misclassified as White, non-Hispanic[6]; a separate study of the same registry identified several factors associated with Hispanic misclassification, including Spanish-language knowledge, sex, education, income, and insurance type.[7] Another study in that registry reported that 74% of those classified as Viet-

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namese agreed with that classification in a telephone interview, and that misclassification was significantly associated with age, sex, year of immigration, education, and language use.[8] The misclassification of Native-American race and the extent to which misclassification may contribute to the low cancer incidence among this subgroup was evaluated in the Seattle-Puget Sound cancer registry by comparing registry-reported race with information from the Indian Health Service medical services registry. In this study, a strong association was observed between blood quantum level and racial misclassification, whereby full-blooded Native Americans were least likely to be misclassified.[9]

The reliability of racial classification recorded in medical records has been shown to vary across racial groups,[12] and the reliability of ethnic classification is presumed to vary as well.[7] Because the current study analyzed data pooled from several research studies conducted through the MDCSS since 1980, which may have had differing definitions and methods for collection of patient ethnicity, we did not assess the level of agreement between self-identified and registry-reported ethnicity. Nevertheless, measures to correct inaccuracies in certain racial or ethnic classifications have been implemented in the SEER registry and in other health and population surveillance systems. For example,

when self-identified Hispanic ethnicity is not available, ethnic classification may be determined by matching names in the registry to the list of Spanish surnames compiled from the 1980 Census[13] or by using Spanish parentage, Spanish mother tongue, and Spanish or Mexican heritage[7]; using a composite of several of these methods has been shown to provide the most sensitive classification of Hispanic ethnicity.[6] Suggestions for how to reduce racial misclassification among Native Americans include linking cancer registry data with the Indian Health Service (IHS) patient registration records and/or tribal enrollment records and providing race-specific training for healthcare personnel on how to ask about racial identification.[9,14] Use of such techniques may not result in 100% sensitivity of racial and/or ethnic classification but is an important component in reducing bias in cancer statistics.

Identifying corrective racial classification measures for African Americans has not been straightforward. In the MDCSS registry, attempts have been made to validate data on Hispanic ethnicity by using surnames and language use; however, at present, no systematic algorithm is in place to identify and resolve inconsistencies in racial classification for African Americans or to verify their racial classification at the time of data collection. However, we plan to share the results from the current study with MDCSS data abstractors to encourage the verification of race while in the field by checking multiple sources in the medical chart, if available, especially for African Americans and males.

Several approaches for adjusting cancer rates for biases associated with misclassification have been suggested. Stewart et al[15] estimated the extent of misclassification in two ethnic groups and used a method that combined logistic regression parameter estimates to adjust cancer incidence rates for misclassification. Sugarman et al[16] sup-

plemented Washington State Cancer Registry (WSCR) data with IHS and tribal membership data to estimate cancer incidence among Native Americans; the authors reported that the estimated prelinkage cancer incidence rate would be 43.6% lower than rates calculated after the addition of persons listed as Native American on the IHS or tribal rolls but not in the WSCR. Partin et al[17] compared cancer incidence rates among Native Americans in Minnesota before and after linking registry racial data with information on IHS membership, which revealed incidence rates of lung and cervical cancer that were higher than previously assumed.

The collection of race and ethnicity information has long been a component of public health surveillance efforts to identify, monitor, and reduce racial and ethnic disparities in health status. In recent years, however, a movement toward creating a more ''colorblind'' government has called into question the collection of racial/ethnic data that enable these fundamental public health activities. For example, a controversial voter initiative on the October 2003 California ballot (Proposition 54: Racial Privacy Initiative) called for the removal of all references to race and ethnicity from state government forms. While the initiative exempts ''otherwise lawful classification of medical research subjects and patients,''[18] critics have argued that the narrow definitions used by the initiative would exclude most epidemiologic research as well as other population-based research that is used for calculating many health-related statistics. Although the proposition was not passed, it has brought about an increased awareness of the lack of consensus regarding the collection of racial and/or ethnic data. In our study, the higher levels of misclassification among those diagnosed with cancer during or after 1990 may, in part, reflect changing attitudes toward the inclusion of racial/ethnic information in medical records.

Racial information recorded in medical records in the past decade may have been less likely to have been attained from the patient and more likely to have been based on subjective assessment of observers and, therefore, more prone to misclassification.

A limitation of this study is that we were unable to evaluate misclassification of other racial/ethnic groups in the MDCSS registrybecause of small numbers and were limited to examining misclassification of African Americans as Whites and Whites as African Americans. However, we did examine the distribution of self-identified race for the 103 individuals we excluded from our sample because they self-identified as races other than African American or White. Among the 32 excluded individuals classified as African American by the registry, 5 (15.6%) self-identified as Native American, 21 (65.6%) self-identified as ''other'' race, and 6 (18.8%) specified ''unknown'' for their race. Among the 71 excluded individuals classified as White by the registry, 12 (16.9%) self-identified as Native American, 4 (5.6%) self-identified as Asian/Pacific Islander, 18 (25.4%) specified ''other'' race, and 37 (52.1%) specified ''unknown'' for their race. Nearly two thirds of the 103 excluded individuals (n=66, or 64.1%) were diagnosed during or after 1990, and the remaining 37 (35.9%) were diagnosed prior to 1990, which may suggest an evolving pattern of racial and/or ethnic self-identification over time.

While the MDCSS catchment area is made up of ≈25% African Americans,[2] the proportion of registry-reported African Americans in this study was 1625/5329 (30.5%) because African Americans were oversampled in some of the research studies used for these analyses. The positive predictive value (99.2%) determined in this study must be interpreted in the context of the relatively high prevalence of African Americans in the MDCSS registry catchment area.

Although no studies of misclassification of African-American race have been conducted in the SEER registries, some evidence for this form of misclassification does exist. A study conducted in 1980 that compared self-identified race with interviewer-observed race among respondents to the National Health Interview Survey found that 5.8% of self-identified Blacks were classified as White by the interviewer, and that 32.3% of self-identified Asians/Pacific Islanders and 70% of self-identified Alaskan Natives/Native Americans were classified as Black or White.[10] While observer bias may account for some of the discrepancy, other factors, including changing preferences of racial self-identification, definitional issues for persons of mixed racial identity, inconsistencies between data collection systems in racial categorization, and heterogeneity within racial and ethnic populations, add to the methodologic difficulties in accurately classifying race. In light of the integral role of racial and ethnic classification in health disparities research, we must ensure that available data represent as accurately as possible the populations under study. Additional studies of racial and ethnic classification provide an important quality control measure for optimizing the utility of cancer registry data and have implications for the validity of epidemiologic studies that use these data.

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