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Why an Alternative Algorithm for Identification of Hispanic Subgroups Is Useful

In the Winter issue of the *Journal of Registry Management (JRM)*, our article, "HOIA: an Alternative Hispanic Origin Identification Algorithm for Cancer Registries,"[1] proposed an alternative algorithm for identification of Hispanic subgroup: HOIA (Hispanic Origin Identification Algorithm). The algorithm uses cancer registry records, death certificates, and the Hispanic surname list to accurately identify Hispanic ethnicity and subgroup, and is largely based on the NAACCR Hispanic Identification Algorithm (NHIA) developed by the North American Association of Central Cancer Registries (NAACCR) for use by central cancer registries nationwide.[2]

HOIA was not to designed to replace NHIA, but rather to serve as a practical instrument to allow the study of cancer in Hispanic subgroups in states like Florida with diverse Hispanic populations. Unlike NHIA, which takes into account the net data from all data fields regardless of their apparent accuracy, HOIA corrects for miscodes common in the Florida database in the NAACCR data item 190 "Hispanic Origin," eg, misclassification of unknown Hispanics as Mexican or inclusion of Brazilians and Portugese as Hispanics.

In addition, some state registries consolidate the demographic data of cancer registry records with the available death certificates prior to running NHIA, whereas in others that consolidation does not take place. This can result in significant state-by-state fluctuations in the completeness of the Hispanic cancer data, and the subsequent rates may be inappropriate for comparison across states. HOIA uses a stepwise approach to incorporate the information present in death certificates (birthplace and recorded Hispanic subgroup) with the same information from cancer registry records. Since publication of our article, HOIA has been validated against an independent cancer population of South Florida with satisfactory results.[3]

As we noted, NHIA v2.1 had not been released when the paper was submitted and thus the Winter issue of *JRM* took NHIA v2 into account, not NHIA v2.1.[2,4] Specifically, NHIA v2 did not use birthplace to assign a specific subgroup to Hispanic subjects. NHIA v2.1 and HOIA are now the same in this respect.

This letter compares HOIA using the same Florida data with the more recent NHIA v2.1 released in July 2008, to update the analysis performed in the Winter issue article. All algorithms were run separately. In each case, indirect identification of Hispanic ethnicity based on surname was restricted to counties with more than 5% of Hispanic population.

As shown in Table 1, HOIA identifies a larger number of individuals of Hispanic ethnicity, 30,238 vs. 29,687 identified by NHIA. In Florida, HOIA identifies a specific Hispanic subgroup for a larger proportion of cases than either NHIA v2 or NHIA v2.1. NHIA v2.1 increased the specific Hispanic subgroup from 46% to 52% in comparison to NHIA v2. In comparison, HOIA allocated a specific Hispanic subgroup in 68% of the cases in the same population.

Substantial decreases in absolute numbers occurred for Group 6 (Hispanic unspecified) and Group 7 (Hispanic by

Table 1. Hispanic Ethnicity/Origin in the Florida Cancer Population, 1999–2001, Based on Cancer Registry Data Alone, and Using Each Algorithm Separately (NHIA v2, NHIA v2.1 and HOIA)

DI 190 description	*DI* 190 code*	*Initial data (n=301,994)*	*NHIA v2 (n=301,994)*	*NHIA v2.1 (n=301,994)*	*HOIA (n=301,994)*
non-Hispanic	0	271,928	272,307	272,307	271,756
Mexican	1	1,416	1,441	1,470	1,085
Puerto Rican	2	1,355	1,446	1,643	2,809
Cuban	3	7,147	7,364	8,528	11,953
South and Central American	4	2,513	2,777	3,156	3,736
Spaniard or other	5	466	480	541	449
Hispanic unspecified	6	13,374	13,374	11,423	7,717
Hispanic surname only	7	1,401	2,757	2,757	2,063
Dominican	8	11	48	169	426
Unknown	9	2,383	--	--	--
Proportion of specific Hispanic subgroup	$\frac{1+2+3+4+5+8}{1 \text{ to } 9}$	43%	46%	52%	68%

*Data item

surname only) between NHIA and HOIA. Decreases were also seen for Group 1 (Mexicans) for reasons explained in the article and Group 5 (Spaniards and other specified Hispanics), as some specified Hispanics belonged to either Group 4 (South and Central Americans) or Group 8 (Dominicans). On the contrary, Group 2 (Puerto Rican), Group 3 (Cuban), Group 4 (South and Central American), and Group 8 (Dominican) saw substantial increases in numbers.

While HOIA was formally designed to improve the specificity of the Hispanic subgroup information, the algorithm also appears to improve the completeness of general ethnicity assignment (Hispanic versus non-Hispanic) for Florida over NHIA. HOIA may be appropriate for use in other states looking to improve the overall validity and completeness of data item 190.

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Letter to the Editor

Why We Need to Create Standardized Medicaid Administrative Data Linked with Cancer Registry Databases

I read with interest the two articles[1,2] published in the Winter 2008 issue of the *Journal of Registry Management* that report analysis based on linking cancer registry data with administrative or medical claims data. Both these articles limit their analysis to those aged 65 years and older, the age group that appears to be the focus of the majority of the research using similar linked databases. There have been a limited number of studies[3–5] using linked databases for those younger than 65 years, but these studies reflect a very small pool of evidence compared to the over 300 scientific articles that have been produced using the linked Surveillance, Epidemiology and End Results (SEER)-Medicare database alone for the elderly age groups.[6]

Overall, about 45% of all cancers are diagnosed among those younger than 65 years and this age group has a higher incidence of certain types of cancers, including breast and skin cancer.[7] The incidence rates therefore do not justify the skewed focus on the elderly in the analysis performed using linked cancer registry/administrative databases. There are several potential explanations for this. First, the health insurance coverage for the population younger than 65 years is fragmented; many are covered by private health plans sponsored by employers, others are enrolled in Medicaid, and a large number are uninsured. Second, individual state programs and private health plans often do not have large enough cohorts of cancer patients and therefore studies need to pool data from multiple sources to perform the required analysis. Third, no standardized linked dataset such as the SEER-Medicare database is available for the younger population.

Therefore, one approach to increase research on the non-elderly cancer patients is by making standardized linked databases more readily available. Creating a database that contains several state Medicaid administrative datasets linked with cancer registry databases would be one potential solution that can be implemented as a first step. Medicaid administrative data for all states are available in a standardized format from the Centers for Medicaid and Medicare Services (CMS) and historic data beginning with the year 1999 can be obtained. Thus, the Medicaid data from the various states can be easily combined together to increase the sample size available for analysis. Obtaining Medicaid claims linked with cancer registry from individual states is a cumbersome, time consuming, and expensive process when undertaken on a project-by-project basis (based on my experience of working with linked databases from 7 states). It would be far more efficient if linked, de-identified databases were produced for multiple states and made available through a single application process for researchers to analyze.

The Centers for Disease Control and Prevention (CDC), in collaboration with CMS, should consider supporting such an effort as it would substantially increase the utility of the cancer registry data collected through the programs funded by the National Program of Cancer Registries. Medicaid is the nation’s single largest source of health insurance for low-income individuals and provides coverage for more than 50 million non-elderly adults and children.[8] The linked cancer registry/Medicaid database will provide a unique population-based source of information for epidemiological and health services research, and quality improvement initiatives for the population younger than 65 years. Specifically, this linked database will provide a rich source of information on the cancer experience of the low-income pediatric, adolescent, and non-elderly adult populations. In addition, 1 in 5 non-elderly blacks, Latinos, and American Indian/Alaskan Natives are covered by Medicaid[9] and analysis of the Medicaid data can help identify measures to eliminate health disparities. Among the limitations of this linked database are the lack of complete information for managed care enrollees, short or disrupted enrollment periods, and potential differences in state Medicaid policies that can impact quality of care received and confound the assessments performed. In addition, the cancer care of the Medicaid population may differ from the non-elderly population with other types of health coverage.

Establishing a standardized linked dataset using state Medicaid administrative data and cancer registry databases will address one of the key recommendations of the Institute of Medicine’s report on Enhancing Data Systems to Improve the Quality of Cancer Care[10] by expanding support for cancer research using existing data systems. Cancer assessments based on the elderly are not always generalizable to the younger population and establishing data sources dedicated to non-elderly cohorts will facilitate future cancer studies with direct relevance to those younger than 65 years.

Sincerely,

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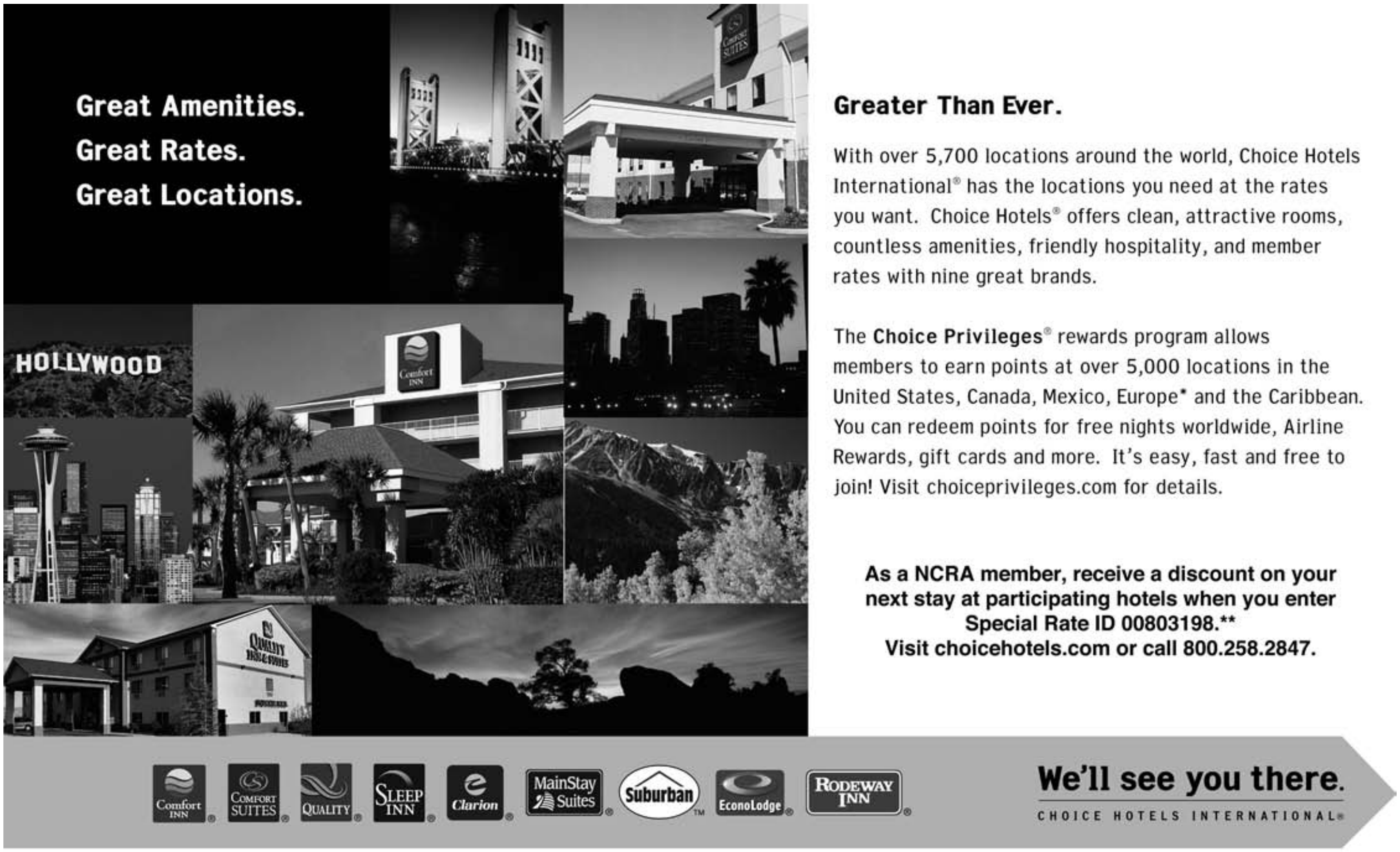

Original Article

Misclassification of American Indian Race in State Cancer Data among Non-federally Recognized Indians in North Carolina

Bonnie C. Yankaskas, PhD[a]; Karen L. Knight, MS[b];
Anthony Fleg, MPH[a]; Chandrika Rao, PhD[b]

Abstract: Background. Equitable distribution of health care resources relies on accurate morbidity and mortality data, classified by race. Accurate classification is a problem, particularly for non-federally recognized American Indians (AI) receiving care outside of the Indian Health Service. Methods. We identified counties in North Carolina that had the majority of AIs belonging to the 7 state-recognized, non-federally recognized tribes. We collaborated with the tribe in each county and compared the incident cases of cancer in the North Carolina Central Cancer Registry (NCCCR) to the tribal rolls. Data were analyzed to calculate what percent of names on both lists were not correctly identified as AI in the NCCCR. We corrected the NCCCR classification and calculated the percentage misclassified, then recalculated the cancer incidence rates for 4 major cancers (prostate, female breast, lung, and colorectal). We compared the recalculated rate to the original rate. Results. There were 626 AIs on the tribal rolls; 112 (17.9%) were not identified as AI on the NCCCR list. Comparing 1996–2000 age-adjusted cancer incidence rates before and after reclassification, the increase in rates were prostate 41%, female breast 18%, lung 10%, and 11% for colorectal cancers. There was less than a 2% increase in cancer rates for the combined 4 sites for Blacks and Whites, before and after reclassification, and 19% for AIs. Conclusions. The study estimated 18% misclassification of non-federally recognized AIs in cancer registration in North Carolina, and determined an underestimation of cancer rates in the population. The underestimation of cancer burden among AIs in North Carolina may affect resources allocated for prevention, screening, and treatment programs, as well as funding for research.

Key words: *American Indians, cancer, health statistics, morbidity, mortality, race misclassification*

Introduction

Equitable distribution of health care resources relies on accurate morbidity and mortality data for all races and ethnic subgroups of the population. Demographic information that uses indirect sources of racial or ethnic identification, such as a death certificate or a medical record if the patient is not directly asked for his or her race, may be prone to higher errors than a classification based on information collected directly from the individual. Many studies have shown that for American Indians and Alaska Natives (AI/AN), in particular, there is a large and varying amount of misclassification on death certificates and other disease surveillance systems. Several studies compared death certificates to Census data, Indian Health Service (IHS) data, or tribal registries to assess accuracy of mortality statistics.[1–4] A few compared death certificates to disease-specific registries where race and ethnicity was acquired directly from the patient to assess accuracy of incidence statistics.[5–10] Some studies used national data,[1, 4] while others used state or regional (mainly northwest) data.[2,3,5–9] One study compared Veterans Affairs self-reported race to an administrative database.[11] All these studies found varying rates of misclassification of American Indians (AIs) as non-American Indian, with misclassification rates varying from a low of 9% to a high of 90%–96%. Misclassification increased as the percent blood quantum (a measurement of AI ancestry) decreased.[2,6] This pervasive misclassification of AIs may substantially underestimate the mortality and morbidity rates of disease for AIs in the United States.

Cancer is the second leading cause of death among AIs and the leading cause among Alaska Natives (ANs).[4,12] The Centers for Disease Control and Prevention and the IHS analyzed death certificates to measure cancer rates for AI/ANs for 1990–2001, finding mortality rate ratios of 0.85 for women and 0.79 for men when compared to the US population. However, as reported in the 2008 supplement to the *Annual Report to the Nation on the Status of Cancer*, there is variability in AI cancer rates by type of cancer, gender, and region.[13]

The published studies above mostly relied on IHS data to estimate misclassification rates of national mortality and incidence data. These data are based on AIs covered by the IHS, which cannot necessarily be generalized to regions such as the southeastern United States, where the majority of AIs are not federally recognized, and not served by the IHS. North Carolina has the largest population of state-recognized and non-federally recognized Indians in the United States.[14]

"Misclassification of American Indian Race in State Cancer Data among Non-federally Recognized Indians in North Carolina"

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The objective of this study was to evaluate the accuracy of classification of AIs in North Carolina's Central Cancer Registry (NCCCR), and to estimate the effect on reported cancer incidence in North Carolina, where the majority of American Indians are not associated with federally-recognized tribes.

Methodology

The objective of the study was to estimate misclassification rates of race in the NCCCR for AIs in North Carolina. We matched cancer cases from the NCCCR to tribal rolls for 7 non-federally recognized Indian tribes in North Carolina: Coharie, Haliwa-Saponi, Lumbee, Meherrin, Occaneechi Band of Saponi Nation, Sappony, and Waccamaw-Siouan. To test if AIs listed with the NCCCR are correctly classified as AI, all persons appearing on both the NCCCR list and the tribal roll were reviewed to see if the racial identification on the NCCCR list was AI. This project was developed through a partnership between the NCCCR, the Carolina Mammography Registry (CMR), and the North Carolina Commission of Indian Affairs (NCCIA), with assistance from health outreach coordinators and tribal enrollment officers who were critical to the collection of data.

IRB Approval

Approval was obtained from the North Carolina Division of Public Health Institutional Review Board (IRB) as well as the UNC School of Medicine IRB. All tribes and NCCCR personnel were trained on Health Insurance Portability and Accountability Act (HIPAA) rules and rules of confidentiality.

Identification of Study Group

There are 7 state-recognized tribes in North Carolina that are not federally recognized and thus do not use the IHS.[15] An AI research assistant met with each tribe to explain the project and request that they partner with us. A person was identified at each tribe to work on the project. The first task was to identify the county or counties where the majority of their members resided. Because the linkage was manual, we limited the study to these counties. The NCCCR then produced a list of all persons with cancer of all types, who resided in the identified counties. We provided this list to the tribes for them to match to their tribal rolls. The frequency distribution of the tribal populations by county is presented in Table 1.

Table 1. North Carolina Tribes with Counties and Percent AIs

Tribe	*Counties Included*	*% of North Carolina AIs*
Lumbee	Robeson, Scotland, Hoke	54.2%
Haliwa-Saponi	Halifax, Warren, Nash	3.2%
Waccamaw-Siouan	Columbus, Bladen	2.4%
Coharie	Harnett, Sampson	1.9%
Occaneechi Band of Sapony Nation	Alamance, Orange	0.9%
Meherrin	Hertford	0.8%
Sappony	Person	0.2%

Data Collection

The linkage of the NCCCR names to the tribal rolls was performed by a member of the tribe, at the tribe location. The research assistant met with each tribe separately to train them for the research. A training video was created and presented to each tribe, using a representative of the NCCIA and the NCCCR as trainers. Once a tribal staff member was identified to work on the research, they completed HIPAA training through the University of North Carolina and signed a confidentiality agreement, to be kept on file at the NCCCR.

The list generated by the NCCCR included cases diagnosed between 1996 and 2002, as well as death records to mask which individuals had cancer. The list included last name, first name, middle name, gender, date of birth, and the last four digits of the patient's Social Security number. The last known address was included for verification of matches. The list did not include the race classification. All names on the NCCCR list were searched for in the tribal roll. If a name on the NCCCR list was found in the tribal listing, the name was highlighted on the NCCCR list. All tribal rolls were produced as paper lists, some from computerized listings and some from paper records. Because most tribal rolls were paper-based, the research assistant manually matched the two paper lists. Once the matching process was completed, the list was sent to the NCCCR.

Analysis

Matching results were evaluated based on the percentage of AIs identified through the matching process who were not previously identified as AI in the NCCCR database. Prior to the project, we calculated incidence rates age adjusted to the 2000 US Census for female breast, prostate, lung, and colorectal cancers diagnosed during the period 1996 through 2000 in the chosen counties for AIs. These tumor sites were chosen because the burden among these 4 sites is the highest for all racial groups combined, and provide stable incidence rates due to the large number of cases. The years 1996–2000 were chosen because data from the 2000 diagnosis year was the most current diagnosis year available at the time of the study. After completion of the project, these rates were recalculated to demonstrate the impact of correcting race on incidence rates.

To compare relative change among racial groups and to validate the impact of the matching project on incidence rates for AIs, we also recalculated rates for White and Black populations in the counties where the study was conducted, and calculated 95% confidence intervals for comparison.[16] Because the NCCCR database is changing continually, it is possible that increases in rates before and after the project could be due to new cases reported from previous years.

Results

The 7 participating tribes identified the counties with the majority of their population. There were 99,941 AIs in North Carolina in the 2000 census. The number of persons on the rolls included in this study was 63,562, representing 63.6% of all AIs in the tribes.[15] (Table 1) When the tribal rolls were matched to the NCCCR list of cancer cases, there were 626 AIs on the tribal rolls who were on the

Table 2. AI Misclassification of Race, by Tribe

Tribe	*Counties*	*N on Tribal Roll*	*N Subset on CCR List*	*% Misclassified*	*(95% CI)*
Lumbee	Robeson, Scotland, Hoke	554	468	15.5	(12.5, 18.5)
Waccamaw-Siouan	Columbus, Bladen	23	13	43.5	(23.2, 63.8)
Coharie	Harnett, Sampson	16	14	12.5	(0, 28.7)
Meherrin	Hertford	2	0	100.0	*
Haliwa-Saponi	Halifax, Warren, Nash	20	17	15.0	(0, 30.6)
Sappony	Person	2	1	50.0	(29.5, 70.5)
Occaneechi	Alamance, Orange	9	1	88.9	(68.9, 100.)
Total		626	514	17.9	(14.9, 20.9)

NCCCR list of cancer cases. Of these 626, 112 (17.9%) were not identified as AI on the NCCCR list. The results by tribe are shown in Table 2.

By cancer site, the cancer incidence rates for 1996–2000 increased after correction of race: cancer incidence in AIs rose 41% for prostate, 18% for female breast, 10% for lung, and 11% for colorectal cancer (Table 3). For all cancers combined, the increase in rate per 100,000 was significant at the 95% confidence level, and was much smaller for Whites and Blacks: 19% increase (285.8 to 340.2) for AIs compared to 2% (435.9 to 442.9) for Whites, and 2% (440.3 to 447.2) for Blacks. The small increase in rates for Whites and Blacks, indicates a small influence of increased reporting since the original rate calculations.

There were a sizable number of persons on the NCCCR list identified as AI who were not listed on tribal rolls. This is explained by several factors: 1) the tribal rolls are incomplete; 2) there are AIs living in NC who are members of tribes other than the 7 state-only recognized tribes, such as the North Carolina Eastern Band Cherokee; and 3) there are members of these tribes who belong to the American Indian Associations in urban areas, and are not listed on the tribal roll.

Discussion

This study verified and quantified misclassification of non-federally recognized AIs in cancer registration in North Carolina. Cancer rates among AIs underestimate cancer incidence rates in the non-federally recognized, non-IHS, AIs. We found that 17.9% of AIs listed on tribal rolls were not classified as such in the NCCCR. Rates of 4 selected cancers, compared before and after correcting the data for misclassification, resulted in a 10%–42% increase in the incidence rates of specific cancers.

There is published evidence that AIs are particularly susceptible to misclassification in medical data. A study of AIDS patients presented findings from health department AIDS case reports and self report identifying underclassification of AI on the death certificate 57% and 46% of the time, respectively. These were the highest misclassification rates of all races studied. In comparison, the misclassification ranged between 2% and 4% in Whites and Blacks.[5] In Washington State, death certificates revealed that 1 in 7 (14.7%) of AIs were classified as another race, with those with less than 25% blood quantum being misclassified 43.6% of the time. This is an alarming rate of misclassification for those with lower blood quantum, a group most analogous to AIs of North Carolina's state-recognized tribes.[2] In a study among Veterans Affairs patients seen nationally for root canal or tooth extraction, the misclassification of race when comparing self-report from the patient to the administrative database was highest for AIs. The number of AIs was small, but only 10 of 724 (1.4%) were correctly classified.[11] This seemingly systematic misclassification of AIs results in their misrepresentation and undercounting in national and regional health statistics. We

Table 3. Comparison of Cancer Incidence Rates before and after Correction of Misclassification

	*1996–2000 Before Correction Cancer Incidence Rates per 100,000**						*1996–2000 After Correction Cancer Incidence Rates per 100,000**					
	Whites		**Blacks**		**American Indians**		**Whites**		**Blacks**		**American Indians**	
Cancer site	**Cases**	**Rate**	**Cases**	**Rate**	**Cases**	**Rate**	**Cases**	**Rate**	**Cases**	**Rate**	**Cases**	**Rate**
Colon/Rectum	1,496	51.6	583	53.7	46	20.5	1,492	51.4	584	53.9	50	22.7
Lung/Bronchus	2,164	73.1	684	62.4	113	52.5	2,191	74.1	682	62.3	124	57.6
Female Breast	2,327	148.5	827	129.6	118	91.5	2,291	146.0	830	129.9	139	107.6
Prostate	1,651	131.4	907	210.6	120	131.2	1,658	132.8	957	222.7	161	185.0
All Cancers	12,707	435.9	4,858	440.3	635	285.8	12,908	442.9	4,930	447.4	752	340.2**

*Counties of Alamance, Bladen, Columbus, Halifax, Harnett, Hertford, Hoke, Nash, Orange, Person, Robeson, Sampson, Scotland and Warren

**Cancer incidence rates are significantly different from rates prior to correction for misclassification are lacking an accurate picture of the disease burden in AIs, particularly those not served by the IHS.

In the annual report to the nation, prepared by collaboration between the American Cancer Society, the Centers for Disease Control and Prevention, the North American Association of Central Cancer Registries, and the National Cancer Institute, there is a special comprehensive compilation of cancer information for AI/ANS. These data are compiled from the IHS Contract Health Service Area counties. This is done to overcome the problem of the small number of AI/AN population as a proportion of national data, and to lessen misclassification of AI identity. In the most recent report, which covered the years 1999–2004, wide variation in cancer incidence among AI/ANs was found by geographic region.[13] In these same geographic regions, this variation did not occur among non-Hispanic whites (NHW). For all cancers, male and female, overall cancer incidence was higher in the Northern and Southern Plains and among ANs. ANs have rates of lung, colon, and breast cancer that are at least 5 times higher than those of Southwestern Indians, and rates of stomach, kidney, uterine cervix, and liver cancer that are similar in the two regions, yet higher than NHW. Previous death certificate studies had different results, most likely due to misclassification of AIs. AIs are more likely to be accurately identified as AI/AN in the Service Contract areas.

Misclassification for AIs served by the IHS has been documented for both mortality records and for cancer incidence. In North Carolina, the results of a linkage between mortality records and the IHS showed 17% of AIs were misclassified as another race.[17] Similarly, results from a linkage of North Carolina 1995–2005 cancer incidence records and the IHS showed 21% misclassification. It is possible that in cancer data, compared to mortality or other diseases, misclassification might be a larger problem, as the cancer diagnosis that is reported to the NCCCR is the result of a surgical or radiological visit, and not a primary care visit for the patient. The physician may not know the patient, and may not ask for race.

Lower rates may result in less attention to screening and cancer education in AIs related to cancer. Support for prevention activities for cancer in AI populations may have low priority as a result of underestimated cancer rates. We did a brief search of the literature, searching for cancer incidence in AI/ANs and for African Americans or Black; we limited the search to the last 10 years and articles in English. There were 10 times the number of articles relating to African Americans (2,746) compared to AIs (247). We hypothesize that the perception that rates are low in this population has led to a vacuum in research in cancer in AIs.

The results are important in that they indicate the need for better reporting and recording of racial identity by the health care system. AIs should be encouraged to actively request that their race be put in their medical record and visit notes, to self-identify and correct documentation when receiving medical services. They should not assume that their provider knows that they are AIs, or if they do, that it will be recorded correctly in the record. The personnel in medical facilities could be more proactive in asking the patient for their race, and AI patients need to be encouraged. We recommend that in communities where AIs reside in appreciable numbers, that primary care practices and emergency room staff be encouraged to always request racial or ethnic identity information from the patient, and make sure it is accurately recorded in the medical record. Family members of AIs may want to request death certificates of deceased family members and check the racial identification on the record. While it is not expeditious to manually compare all deaths from cancer registries to tribal rolls, and the actual numbers of cases may be small, some have suggested regular linking the two sources of information should be considered.[9]

There are a few limitations to consider when interpreting our results. Though we included all non-federally recognized tribes in the process, we matched for counties where there was a large contingent of AIs for any one tribe, and not all the AIs in the state. It is possible, though unlikely, that the tribal members living away from the majority of members are more likely to be accurately identified in the NCCCR. This would make our results an overestimate of the problem. It is possible that there was human error in the matching process, such that the representative said a name matched their tribal rolls when indeed it did not, or that the representative said a name did not match their tribal rolls when it did. The presence of such error is unknown, making it impossible to estimate the effect on our results. If electronic tribal rolls including Social Security number and date of birth fields had been available, a computerized linkage could have increased the number of accurate matches, minimized the chance for human error, and provided a mechanism for efficiently matching with all counties on an ongoing basis.

There were names identified as AI on the NCCCR list that were not on the tribal rolls. Thus, the population identifying as AI, but not currently registered with a tribe, is not included in our misclassification rates. These include mostly AIs residing in North Carolina who are members of out-of-state tribes, are Eastern Band Cherokee, or belong to tribes not recognized by the state.

Another limitation to this study is that incidence rates for other races could be inflated by those classified as AIs who are not. As the AI population is very small, any misclassification in this direction should not have a noticeable effect.

Our study is the first to match tribal rolls to cancer registry data in a population that is, for the most part, not served by the IHS. Our results document that there is misclassification of AIs in cancer registration in North Carolina for non-federally recognized Indians. Race is determined at the point of medical services, therefore the solution lies in correctly identifying race at the point of care, usually at intake at a medical facility. For AIs to receive the benefit of research, care, and education about cancer, we must document cancer incidence and mortality correctly in this population. As AIs in the southeast, in particular, are mostly state recognized, are not federally recognized, and receive care outside the IHS, the issue of misclassification is particularly important and more difficult to address through linkages with paper tribal rolls. Indeed, the actual cancer experience in this population is not accurately reflected in the existing morbidity and mortality statistics.

Moreover, because misclassification leads to falsely low reported rates of cancer, it follows that screening, detection, and treatment may also be underfunded, and inadequately addressed. Addressing misclassification will result in more accurate accounting of morbidity and mortality rates for AIs. As a result, cancer research and awareness will receive the attention it deserves in the AI population.

Attributions

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Breast and Prostate Cancer Patient's Reliability of Treatment Reporting

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Abstract: Purpose. To compare patient reported cancer treatments with data obtained by trained abstractors in the Metropolitan Detroit Cancer Surveillance System (MDCSS) to assess the reliability of patient interviews as a source for cancer treatments. Methods. Patients (n=492 breast patients and n=291 prostate patients) were identified from the MDCSS and interviewed approximately 6 months after initial diagnosis for receipt of cancer treatment. Kappa statistics compared agreement between patient's report of their treatments and the MDCSS. Results. Breast cancer patients had moderate levels of agreement regarding receipt of chemotherapy and radiation and excellent agreement for surgery. In contrast, prostate cancer patients and registry reports achieved excellent concordance for radiation therapy, very good agreement for surgery, and moderate levels of agreement for hormone therapy. Sensitivity of chemotherapy, surgery, and radiation reporting exceeded 90% for both patient cohorts. Overall, patients reported more treatment than was recorded in MDCSS. Conclusion. Patients can be reliable data sources for medical information pertaining to cancer therapies, although recall may vary by treatment type and time since treatment. Protocols involving patient interviews may wish to consider these encounters as timely, reliable data source options.

Key words: *neoplasms, patient, registries, therapeutics*

Introduction

Researchers seek valid, timely sources of data for documenting medical treatment. Sources include administrative databases (eg, claims/encounter data), medical records, and patient reports. Researchers investigating specific conditions may have additional sources available in the form of surveillance systems. The Surveillance, Epidemiology, and End Results (SEER) registry is a cancer surveillance system that contains information about cancer incidence and first cancer-directed treatment. No source has been established as the gold standard for documenting cancer-directed therapy. Comparisons between Medicare claims data and SEER data suggest SEER underreports therapies other than surgery.[1–3] In this study, we compare patient reported breast and prostate cancer treatments to the treatments reported in the Metropolitan Detroit Cancer Surveillance System (MDCSS), a SEER participating registry.

Registry and SEER data are based on medical record audits that are held to high standards of completeness.[4] Abstractors undergo rigorous training and regularly abstract records to monitor proficiency and accuracy. At the time of this study, the SEER abstraction process primarily relied on inpatient hospital records to document treatment provided as the first course of therapy and occurring within the first 4 months following diagnosis. The data collection period has since been extended to 12 months. The MDCSS also abstracts data from selected radiation oncology outpatient facilities and private, non-hospital pathology laboratories. Data collected are limited to the first course of therapy. The potential for incomplete data remains high because treatments are increasingly provided in outpatient physician offices or other ambulatory settings not targeted for medical record abstraction.

Patient reported information offers benefits relative to other sources of health care information despite concerns over accuracy and recall. Patient reports may be obtained more timely than administrative or registry data. Furthermore, patients may provide more complete information than surveillance systems that rely on hospital-based data sources. Finally, patients can recount information related to complementary medicine that might be omitted from other sources.

Self-reported treatment validity varies depending on the nature and severity of events as well as occurrence of invasive procedures.[5–11] Patients may report routine or non-emergent services with less accuracy than inpatient stays or emergent health care data. Patient reports of invasive procedures tend to strongly agree with claims data.[6] Cotterchio and colleagues (1999) demonstrated substantial agreement between patients and physicians regarding antidepressant medication use and medication identification.[8] Similarly, Boudreau et al (2004) validated accuracy of use of antihypertensives and statins by older women with pharmacy records.[7]

A cancer diagnosis is a noteworthy medical event requiring generally invasive treatments with potentially serious side effects. Treatments include surgery, radiation, chemotherapy, or hormones. Patients receive considerable cancer-specific education to assist them in deciding a course of treatment and how to manage side effects.[13–15] Consequently, one would expect patients to report therapies with some degree of accuracy. Maunsell and colleagues (2005) documented very high agreements between patient report and medical record documentation for breast cancer treatments in a cohort of French-speaking, Canadian women. This group documented kappa values ≥0.89 as far out as 3 years post-diagnosis.[9] Similarly, men with prostate cancer were reported by Clegg et

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"Breast and Prostate Cancer Patient's Reliability of Treatment Reporting"

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al (2001) to have excellent agreement for invasive procedures such as prostatectomy and radiation when compared to medical records.[10] Our study expands on this line of inquiry by comparing patient reported treatment to SEER records.

Methods

Data

The sample was initially drawn for the purposes of studying labor market outcomes of breast and prostate cancer survivors. Participants were selected from the MDCSS because of data quality and the ability to identify patients within 6 months of initial diagnosis.

We interviewed 492 women with breast cancer and 291 men with prostate cancer diagnosed between June 2001 and April 2002. Patients were less than 65 years of age. Participants answered treatment questions during telephone interviews approximately 6 months following diagnosis. Due to the emphasis on labor market participation in the original study, nearly 90% of the sample was employed prior to diagnosis. The methodology used to recruit and enroll subjects is described elsewhere.[16] The participation rate was 83% and 76% of eligible women and men, respectively. Registry treatment data were obtained at 12 and 24 months following diagnosis. The study was reviewed and approved by the Institutional Review Boards at Michigan State and Wayne State Universities. Written informed consent was obtained from the study participants.

Variables

The primary outcome was concordance of registry-reported cancer treatments with patient-reported treatments. Interviewers asked participants if they had undergone surgery for their diagnosis. If so, additional questions on number, type(s) and date(s) of surgery were asked. Patients reported whether radiation or chemotherapy started, was planned, not planned, or unknown. Prostate cancer patients were asked about hormone or endocrine therapy. Women were not asked about oral hormone therapy (eg, tamoxifen). Treatment data were focused on chemotherapy and radiation as first-line therapy for breast cancer.

Analysis

We described treatments documented by patients at the 6-month interview and the registry. Overall agreement levels were reported using kappa statistics (1–5, 7, 9, 16). We also computed sensitivity and specificity with respective 95% confidence intervals using registry data as the gold standard. Statistics were calculated twice. The first set excluded participants who had treatment "planned" since delivery of the treatment could not be verified. The second included those with "planned" treatment in the treatment groups (results not shown). Including patients with "planned" treatments did not alter agreement levels for treatment categories. The number of men (n=5) reporting chemotherapy was too small to statistically analyze and were excluded from analyses. STATA (version 9.2) was used to analyze the data.

Results

Table 1 contains descriptive statistics for the participants. The majority of diagnoses occurred in early stages (*in situ* or local). The average age of the women and men were 50 (SD=7.6) and 56 (SD=5.9), respectively. Approximately three-quarters of both the breast and prostate cancer patients were white and had some college education. More than half of both patient groups were married. Forty percent of women and over half of men were from households earning $75,000 or more. As expected, sample characteristics more closely reflect an employed population instead of a random sample of adult cancer patients.

Table 1. Cancer Subjects Descriptive Statistics at Baseline Interviews

	Breast subjects (N=492)	*Prostate subjects (N=291)*
Mean age (SD)	49.9 (7.6)	55.7 (5.9)
Mean months between treatment and interview (SD)	5.4 (1.3)	3.4 (1.9)
Cancer Stage		
In situ	130 (26.4)	0
Local	206 (41.9)	230 (79.0)
Regional	142 (28.9)	58 (19.9)
Distant	12 (2.4)	1 (0.3)
Unknown	2 (0.4)	2 (0.7)
Race/ethnicity		
White, Hispanic, non-black	392 (79.7)	218 (74.9)
African-American, non-Hispanic	100 (20.3)	73 (25.1)
Marital status		
Married	313 (63.6)	236 (81.1)
Divorced, separated or widowed	135 (27.4)	37 (12.7)
Never married	44 (8.9)	18 (6.2)
Education		
No high school diploma	22 (4.5)	18 (6.2)
High school diploma	111 (22.6)	51 (17.5)
Some college	130 (26.4)	72 (24.7)
College degree	229 (46.5)	150 (51.6)
Employed	442 (89.8)	264 (90.7)
Household income		
≤$20,000	31 (6.6)	9 (3.2)
≥$20,000 and <$75,000	238 (50.4)	105 (37.2)
≥$75,000	203 (43.0)	168 (59.6)
Self-report cancer treatment		
Chemotherapy	279 (56.7)	4 (1.4)
Radiation	179 (36.4)	54 (18.6)
Prostate Surgery	n/a	203 (69.8)
Breast Surgery		n/a
Biopsy/lumpectomy	262 (53.2)	
Mastectomy	213 (43.3)	
Hormone therapy	n/a	40 (13.8)
SEER cancer treatment		
Chemotherapy	147 (29.9)	1 (0.3)
Radiation	160 (32.5)	54 (18.6)
Prostate Surgery	n/a	203 (69.8)
Breast Surgery		n/a
Biopsy/lumpectomy	290 (58.9)	
Mastectomy	184 (37.4)	
Hormone therapy	n/a	24 (8.2)

Over 90% of participants received treatment by the 6-month interview. The overall percent of women reporting chemotherapy was significantly greater than recorded in the registry, 57% vs. 30%, respectively (p<0.01). No statistically significant differences were noted between overall breast cancer patient reports and registry reports in the percentage reporting radiation (36% vs. 32% respectively) or surgery (96% vs. 96%). When breast surgery was defined as biopsy/lumpectomy vs. mastectomy, there were no statistically significant differences noted among the total percentage of patients reporting each type of procedure, 53% and 43%, respectively and 59% and 37% per registry report.

The percent of men reporting hormone therapy was statistically significantly greater than that recorded in the registry, 14% vs. 8%, respectively (p<0.05). No differences between patient and registry reports were noted for radiation or surgery among men with prostate cancer. Table 1 reports the overall proportion of subjects receiving each treatment documented by patient report and registry without regard to agreement between the sources.

Table 2 reports agreement between patient reports and the registry by treatment and cancer site with adjustment for agreement expected by chance alone. Level of agreement between self-reported treatment and registry-reported treatment was moderate for breast cancer patients for chemotherapy (kappa=0.51) and radiation (kappa=0.58) treatments. Women discriminated between biopsy/lumpectomy and mastectomy with excellent accuracy (kappa=0.81). Prostate cancer patients had varying kappa levels for each therapy. Moderate (kappa=0.51) agreement was noted for hormone therapy, substantial agreement (kappa=0.74) was documented for surgery, and excellent (kappa=0.84) agreement was observed for radiation.

Sensitivity values exceeded 90% for the breast cancer treatment reporting. Specificity estimates were lower and ranged from 60% for surgery and chemotherapy to 71% for radiation. Sensitivity estimates for radiation and surgery reporting by the prostate cohort exceeded 90%. The sensitivity for hormone therapy was 74%. Specificity for radiation and hormone therapy exceeded 90% while specificity for surgery was 82%.

Table 2. Agreement of Patient Reported and SEER Reported Cancer Treatments at 6 Months

	Breast subjects (N=492)	***Prostate subjects (N=291)***
Chemotherapy		
% Agreement	74.0	n/a
Expected Agreement	47.3	n/a
Kappa statistic	0.51	n/a
Sensitivity (95% CI)	96.6 (94.7–98.4)	n/a
Specificity (95% CI)	60.7 (55.8–65.5)	n/a
Radiation		
% Agreement	79.1	95.4
Expected Agreement	49.6	70.9
Kappa statistic	0.58	0.84
Sensitivity (95% CI)	94.0 (91.5–96.5)	95.2 (92.6–97.8)
Specificity (95% CI)	71.3 (66.5–76.1)	95.4 (92.9–98.0)
Surgery		
% Agreement	90.0	89.0
Expected Agreement	47.8	57.8
Kappa statistic	0.81	0.74
Sensitivity (95% CI)	97.7 (95.9–99.5)	92.1 (89.0–95.2)
Specificity (95% CI)	60.0 (54.2–65.8)	81.8 (77.4–86.2)
Hormone		
% Agreement	n/a	90.5
Expected Agreement	n/a	80.8
Kappa statistic	n/a	0.51
Sensitivity (95% CI)	n/a	73.9 (68.8–79.0)
Specificity (95% CI)	n/a	92.0 (88.8–95.1)
kappa reference:	below 0.0 (poor)	
	0.00 (no agreement beyond that which would be expected due to chance)	
	0.01–0.20 (slight)	
	0.21–0.40 (fair)	
	0.41–0.60 (moderate)	
	0.61–0.80 (substantial)	
	0.81–1.00 (excellent)	

Discussion

Discussion

Generally, patient report of treatment exceeded treatment documented by the registry for breast cancer patients. Sensitivity between patient and registry report was over 95%. Specificity between patient and registry was not as promising at only 61%. Some women reported receiving chemotherapy that was clarified at subsequent interviews to be oral tamoxifen treatment. These treatments are not classified by SEER medical record abstraction as chemotherapy but rather hormone therapy. Similar results were observed for radiation treatment. Meanwhile, agreement regarding occurrence and type of surgical intervention for breast cancer treatment was excellent with high sensitivity and moderate specificity. The kappa value observed for surgical treatment support published findings suggesting that the reliability of patient report is enhanced by procedure invasiveness.[7]

Prostate cancer patients' reports of hormone therapy exceeded that documented by the registry while the overall proportions of men reporting surgery or radiation therapy were nearly identical to estimates obtained from the registry. Excellent agreement per kappa value for radiation therapy was accompanied by sensitivity and specificity values exceeding 90%. This lends confidence to men's ability to accurately report radiation treatment. A substantial level of agreement per kappa value was documented for surgery with high sensitivity accompanied by less robust specificity. Finally, discrepancy in agreement level for hormone therapy may reflect the administration of this treatment in the outpatient setting. The kappa value was only moderate with lower sensitivity. Specificity of hormone treatment reporting exceeded 90% with a sensitivity estimate of 74%.

Conclusion

Findings from our study indicate that breast and prostate cancer patients report cancer treatments with a high degree of accuracy and patient interviews may be a substitute for or superior to other sources of data—particularly for those therapies that occur in outpatient settings. If a research study is constrained in budget and availability of medical records, patient interviews may be a reliable source of treatment information. Completed registry and claims/encounter data are often not available for months or years following diagnosis of a serious disease such as cancer. Registries may be incomplete sources of the full course of cancer therapy for several reasons. At the time of this study they captured the first course treatment initiated within four months of diagnosis. This was extended to a 12-month window during 2004. Registry data may also be deficient because patients seek treatment outside of the registry targeted health care facilities. Furthermore, administrative records provided by insurers may be incomplete when patients have multiple sources of payment for medical treatment or when specific components of care are not covered by medical insurance. Medical record audits are time consuming, expensive and require abstraction at several provider locations in order to document complete accounts of health care. Even with sufficient resources to perform abstraction, information contained within medical records may be incomplete due to provider recall or documentation deficiencies.[4]

This study has 3 limitations. First, characteristics of treating facilities and providers were not available. Characteristics of patient cohort, scope of patient education, and intensity of counseling may vary by facility and health care provider.[17] Second, our sample reflects an employed population that may limit the generalizability of our findings. Because of the employment requirement, our sample is likely to be younger, better educated, and to have higher incomes than the general population of cancer patients. Therefore, patients may be better able to correctly recall treatment relative to a random sample of cancer patients. Finally, we were unable to compare patient and registry treatment data against medical record audits or health care claims data.

Further investigation is necessary to compare patient report of treatments to health care claims or medical record information to determine which data source, registry or patient-reported data, is more accurate. The most comprehensive source is likely a combination of data sources despite the relative ease in acquiring patient reported treatment and registry data. Our results suggest that employed individuals are able to provide reliable information on cancer treatments received for breast or prostate cancer.

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Original Article

Cohort Follow-up: the 21st Century Procedures

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Abstract: The basic logic of designing an occupational cohort study has changed little since William R. Gaffey outlined the issues of follow-up, measurement of exposure, and analysis of data. However, many new avenues of tracking workers for epidemiological studies have been developed since Gaffey wrote his paper in 1973. Many disease registries also perform follow-up of subjects for vital status determination, so the procedures used with this process are common to the two applications. This article speaks to cohort construction for this occupational research as well as describes the 2007 methods for vital status follow-up. Rises in concern about work-related disease risks and the scientific resources for performing these studies coincided with the computer revolution. Government and private sources of data on vital status have changed in several ways over the 35 years since Gaffey's seminal paper. Some systems make the process of follow-up more rapid and productive, and some barriers have been imposed as societal concerns for privacy have risen. We describe the process of linking 5 sources of data to compile a roster of 6,820 workers employed at the Paducah Gaseous Diffusion Plant from 1953 to 2003. The record linkage processes achieved a final death cohort of 1,672 deaths—the ascertainment of these deaths (by time period) was 1,379 (1979–2003) and 293 (1953–1978); follow-up then was 100% for this cohort.

Key words: *cohort study, epidemiology, follow-up*

Introduction

The basic logic of designing an occupational study has changed little since 1973, when William R. Gaffey outlined the issues of cohort follow-up, measurement of exposure, and analysis of data.[1] Secular increases in societal commitment to occupational health studies and the scientific resources for those studies of work-related risk factors occurred proximal to the computer revolution (1970's). For cohort studies with long follow-up periods, today's vital statistics data are found in various digital formats, depending on the decade in which the data were collected and for what purpose. This diversity of format over time poses challenges for linking records that can be analyzed with modern statistical analysis software.

Many government and private sources of data on vital status have changed in ways that prompt us to revisit Gaffey's seminal paper. The creation of the National Death Index (NDI) is a boon to vital status follow-up. Proprietary agencies likewise now sell vital status information on persons when "authority to access the data is present" and one has key identifying data items. In the new century, the implementation of the Health Insurance Portability and Accountability Act (HIPAA) reflects increasing concerns for individual privacy and often raises a barrier with health-related research. Nonetheless, several sources for vital status information are available for follow-up in cohort applications.

Schall et al conducted a study comparing multiple vital status tracing services. They compared Pension Benefits Information (PBI), the Social Security Administration (SSA), and the Health Care Financing Administration (Medicare) for their utility with obtaining vital status on cohort members. The NDI was used to confirm the US state where death occurred and to obtain a death certificate number (for deaths after 1979). Schall concluded that PBI was the most comprehensive service for obtaining vital status information, especially for younger subjects and those with an earlier date of death (prior to 1979). However, all data services were deemed to have made a valuable contribution to the identification of deceased cohort subjects and all should be considered for use to achieve optimal mortality follow-up.[8]

In this paper we describe the process of linking 5 sources of data to compile a roster of workers employed at the Paducah Gaseous Diffusion Plant (PGDP) from 1953 (when the plant opened) to 2003 (the concluding date of follow-up for this cohort mortality study). The use of government and private sources for information to determine an individual's vital status and cause of death are described. These enhancements and the complications arising from modern digitized data processes are discussed in terms of the seminal framework for cohort follow-up that Gaffey provided in 1973.

"Cohort Follow-up: the 21st Century Procedures"

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The PGDP was opened in 1952 and is located in Western Kentucky, about 10 miles west of the City of Paducah. The primary function of the plant has been to produce enriched uranium for use by commercial reactors or as feed material for other plants that further enrich the uranium. The Department of Energy (DOE) is the federal agency with oversight for the PGDP. Until 1992, the Oak Ridge Operations office of the DOE was responsible for the overall operation of treatment systems for underground contamination and treatment systems, and for the operation of the facility and environmental management, compliance, and restoration. An independent company, United States Energy Corporation (USEC) managed the plant from 1992–1998. Bechtel Jacobs Corporation (BJC) has been the management and integrating contractor for the DOE site remediation activities since April 1998.[2]

With the opening of the federal government's nuclear weapons and energy complexes for study by outside epidemiologists (1986), extensive record systems have become available for the dozens of facilities where an estimated 600,000 workers were employed during the Cold War era. Still today, "national security" concerns arise to impede researcher access to needed information on nuclear weapons facilities. We found multiple data resources at the PGDP that were useful in this cohort study, such as employment rosters and exposure measurements.

Methods/Data

Our procedures for establishing the PGDP worker cohort were conventional, that is to say they involved visits to the plant and discussion with current and former administrators and employees. In epidemiologic studies the construction of a cohort represents a group of subjects who are followed over time to assess their health outcomes, in this case their date and cause of death. Occupational cohorts have occasionally been converted into ongoing cohort studies or what one may define as a worker registry.

The data sources used with for this study were personnel files from BJC, USEC, the Paper and Allied Chemical Workers Union* (PACE), and Oak Ridge Associated University (ORAU). Then a fifth source of personnel history was found with the USEC personnel archive; these were payroll records that we referred to as "yellow cards." The yellow cards represent a paper archive, maintained by USEC, which was found to be the most comprehensive of the various resources for worker-record linkage. The rationale for this designation as "most comprehensive" was: (1) it was the largest of the various data sources (numerically) and (2), the composition of the yellow card file was expressly for providing benefits to the workers at PGDP. The yellow cards were manually keyed to permit automated record linkage; this was the principal cost associated with constructing the "automated" yellow card file. Table 1 illustrates the time-period-of-hire for each data source and the number of personnel files obtained from the data source.

Table 1. The Paducah Gaseous Diffusion Plant Study Data Sources, the Numbers of Records Contained, the Time Period Represented

Data Source	*Number of records*	*Hire year period*
USEC (file location)	6,922	1951–1993
PACE	3,170	1951–1988
ORAU	2,347	1993–1988
USEC Personnel Records	6,804	1953–1998
BJC	401	1998–present

Data file linkage posed a challenge with the PGDP work force as each of the 5 information systems was designed and developed independently, though each shared a few standard elements, such as social security number. Other common elements vary between the specific information source, but additional examples include: date of birth, place of birth, race, gender, place of death, and year of death. The personnel files were entered into a Microsoft® Excel® database. SAS v9 (Cary, NC) was used to create the worker file.[3]

A last hurdle was the realization of a subtle error with the exclusion/inclusion criteria set when determining the worker cohort. The study's initial definitions excluded 42 workers who started work at PGDP prior to 1952 during its construction period. But, then these 42 persons continued to work after the beginning of the study date (1952, when the plant went into production). These workers were subsequently added to the worker file.

Cohort Follow-up

Many people perform follow-up of "at-risk" individuals. Cancer registrars were initially created for that exact purpose—for monitoring follow-up care for surgical patients to detect recurrences. In clinical trials, the treatment subjects are followed to determine the effect of the treatment(s) on the clinical course of the patients. This paper looks at the 2007 methods for performing individual follow-up for vital status.

Three of the five worker databases did not agree well with one another, perhaps owing to the differing time periods covered, or their use, eg, union membership. Again, the yellow card file contained information for every worker who was listed in any of the other 4 sources. The 5 information files also had differing information as to the cohort members who were deceased.

In our efforts to reconcile which cohort members were deceased, the worker roster was sent to the following organizations: PBI, SSA, and the Vital Statistics Departments of the states of Kentucky (KY) and Tennessee (TN). ORAU provided a copy of their personnel file that contained among other things, death information.

PBI was the first follow-up vital status resource that cohort data was sent to; their charge is low compared to others services. PBI and LexisNexis® (a credit bureau) offered to verify that a person was still living at the time of the analysis. Simple application processes were involved with employing each of these services, and there were nominal costs per record [less than $5/case in 2005]. PBI has developed an extensive database from independent government, private sources, as well as their own proprietary sources.

The PBI Social Security files are updated monthly to provide the most up-to-date information.[7] PBI uses death information from several sources: SSA, Civil Service Commission, Railroad Retirement Board, Department of Defense, and the State of California.[8] With LexisNexis, the vital status assignment is based on financial records such as credit usage.

Next we turned to the Vital Statistics Departments of the states of KY and TN for death record searches. We surmised from our fact-finding with PGDP workers that most of the plants workers had resided in one or the other of these two states. Neither state agency charged us for this record linkage service. The completion of requests for the record linkage, including Internal Review Board certification and federal funding for the study, were moderately time consuming.

As of 1994, due to the enactment of section 311 of the Social Security Independence and Program Improvements Act, SSA has the legal authority to release vital status data except for death data obtained from a state under the auspices of section 205(r) of the Social Security Act. SSA is also allowed to release "presumption of living" data based on reports of earnings obtained from the Internal Revenue Service. This authority was granted due to a companion change in the Internal Revenue Code (26 U.S.C. § 6103).[12]

Perhaps expectedly, the SSA application process was arduous. SSA and PBI included the state of death in their report. For those workers who died in states other than KY or TN prior to 1979, the state of death was contacted to obtain a copy of the death certificate. This involved contacting 20 states, prioritized by number of PGDP deaths reported from each state, and preparing complicated application materials, as with KY and TN. All states charged for copies of the death certificates, some small amounts ($5/record) and others more ($35/record).

For PGDP workers who died from 1979 and afterwards, NDI would provide the cause and underlying cause of death. The NDI is available to investigators in medical and health search solely for statistical purposes. It is a central computerized index of death record information, established by the National Center for Health Statistics (effective 1979) as a resource to help investigators with mortality ascertainment activities.[9,10] Information submitted to NCHS is used to conduct annual updates 10–12 months after the end of the calendar year.[11]

We used a hierarchical probability-of-intercept process whereby the PBI, ORUA, KY, and TN death information was compared to the SSA database to eliminate duplicate entries.[4] All SSA-identified deaths and those with an unknown death status were sent to the NDI. There is a substantive charge, per record, for NDI linkages, and their paperwork requirements are substantive. NDI is clearly an authoritative source but relies on death certificate data from states. This means that it is generally several months to nearly two years 'behind' the current time. The extensive amount of information provided to this study from NDI required that the returned file be run against the National Institute for Occupational Safety and Health (NIOSH) death match algorithm.[5] The step was needed to verify that the "death" reported for an individual was in fact, that of the person who had worked at PGDP.

Results

The data file linkage produced a worker file of 6,820 workers during the time period of 1953–2003. PBI, SSA, KY, and TN produced a total of 4,048 reported deaths. After de-duplication there were 1,423 unique records of death for PGDP workers. No information was available in any database for 588 workers. So a roster of 1,423 dead and the 588 unknowns was sent to NDI for confirmation of death, death information on the 588, and cause of death and underlying cause of death for those who died from 1979 and forward. These reviews produced a final tally of deaths to PGDP cohort members of 1,672. Unique identification was summed to 1,379 deaths from NDI for the period 1979–2003 and 293 deaths during 1953–1978. A total of 20 states were contacted for cause-of-death information prior to 1979, for 90 "known to be deceased workers" and 12 workers with unknown vital status. At the time of this publication, cause-of-death information has been received on 71 of these workers, as well as one worker's death whose vital status had been unknown.[6]

Follow-up of individuals for research purposes generally aims to accomplish 90% ascertainment as the "conventional" level of sufficient identification. In this study we achieved 97.8% follow-up. Table 2 shows the number of deaths obtained from each data source.

Table 2. The Paducah Gaseous Diffusion Plant Study Cohort Follow-up Sources and Numbers of Deaths Ascertained

Data Source	Number of Dead Identified
PBI	1,617
SSA	1,427
Kentucky Vital Records	825
Tennessee Vital Records	179
ORAU	1,072

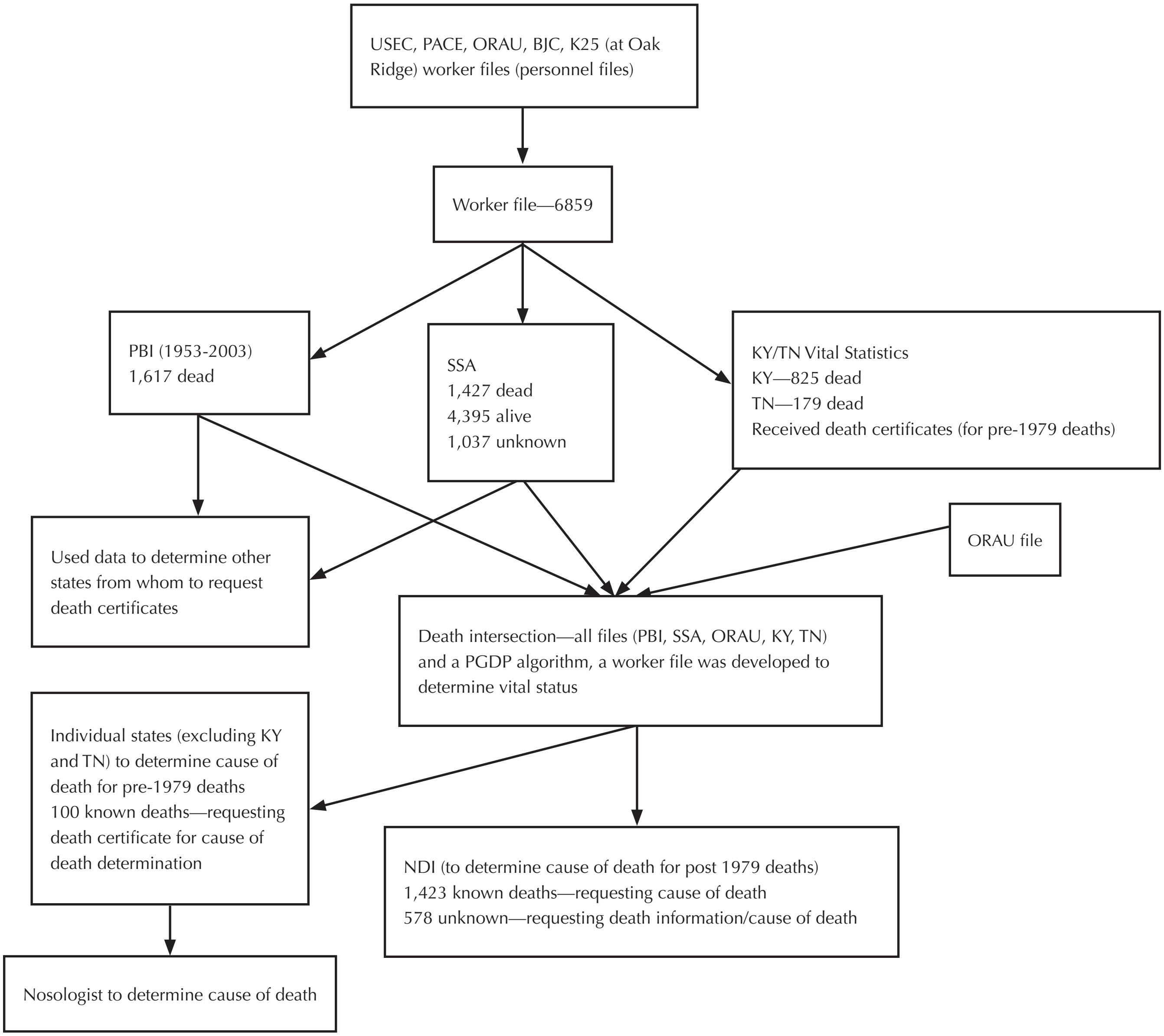
Discussion

This cohort follow-up experience was highly rewarding. New avenues of tracking cohort members have been developed since Gaffey wrote his paper in 1973. Computers alone have provided many new opportunities such as using LexisNexis to provide death date, birth date, and race information. Companies such as PBI have been able to provide epidemiologists with information for only the past 25 years. We found that convenient and cost-effective resources are available for obtaining vital status of study subjects, and respective cause of death information. We recommend that persons performing follow-up of individuals consider these resources for their applications.

Foreseen and unforeseen obstacles created problems in trying to complete this project in a timely manner. The first problem was with the cohort composition, due to the lack of data consistency in the 5 date sources—some lacked SS#, birth dates, and race. Next was the completion of bureaucratic paperwork required in obtaining information from federal, state, and private agencies. Finally, was the timeliness of states in returning requested death certificates.

By way of completeness, we comment that Gaffey discussed the calculation of a Standard Mortality Ratio (SMR). He stated that it is essential that SMRs be calculated for as detailed a cause breakdown as possible.[1] The SMR is the ratio of the number of observed deaths to the number of expected deaths based on some standard mortality rate.[13] Calculation of the SMRs for the PGDP studies also used an automated process. Specifically, we employed the Life Table Analysis System (LTAS) developed by NIOSH during the 1970s and updated in 2005. LTAS was created to analyze cohorts defined by occupational exposures. The program compares the observed rate for the cohort with comparison rates for several referent populations.[14] Stratified by age, race, sex, calendar time, duration of exposure (or cumulative exposure), and time of employment, LTAS calculates person-years at risk for the cohort under study.[15] The complexity of aligning Cause of Death coding schemes with the time-period of death is great.

Figure 1. A schematic protocol for occupation cohort follow-up, as applied by the Paducah Gaseous Diffusion Plant Workers Study



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This study has Institutional Research Board (IRB) approval (#438.02) from the University of Kentucky, Lexington. The IRB request states that the purpose of the study is to address the concerns about potential health effects of Paducah Gaseous Diffusion Plant workers from current and past exposures.

*PACE Union has merged with the United Steelworkers of America.

EPI Review

Data Directions

Faith G. Davis, PhD

Public health researchers draw data from many resources including surveillance systems, national surveys, medical records, and personal and surrogate interviews. The value of any study result is dependent on the quality of information included in the analysis. Quality has many dimensions: validity (does the data accurately reflect what you are trying to measure?) and reliability (can the data be replicated?) are of primary concern. These concepts have been expanded for both quantitative and qualitative research methods.[1,2] Unfortunately, there is often little actual information on these quality indicators for specific research efforts.

There is a body of literature related to the validity of disease codes on death certificates or other surveillance systems and studies which have validated self-reported family history of various medical conditions or individual medical conditions with those family or personal conditions reported in medical records or other data sources. Validation and reliability studies are often conducted to inform study design decisions but may not be considered of enough general scientific value to publish. Given the constraints of research dollars and the ever-changing community research environment, it seems that much more work like this is needed to minimize data collection efforts and to assist in understanding the robustness of research results.

In this issue, Oberst et al[3] have conducted a reliability study which has implications for cancer researchers beyond the bounds of their own research efforts. Study protocols that include self-report medical information have routinely been considered lacking unless an effort to validate that data is incorporated into the study. Validating medical record information is a monumental task in a health care system where patients see multiple doctors in multiple institutions and change health insurance plans with jobs and other life events. These authors utilized a primarily employed, under age 65 sample of approximately 500 women with breast cancer and 300 men with prostate cancer and compared their self-report data on cancer treatment to that available in a Surveillance, Epidemiology and End Results (SEER) Program registry. The agreement between self-report and SEER records was quite good. For prostate cancer the agreement on hormone and radiation therapy was about 90%. For breast cancer the agreement for chemotherapy and radiation therapy was more modest at over 70%. These are intriguing results considering that SEER data are limited to initial therapy. These data suggest that the labor-intensive efforts to validate treatment data in an employed population may not be necessary—that self-report cancer treatment information may in fact be quite reliable.

While these results need to be repeated in groups that may be more reflective of the general population (older, unemployed), in conditions which affect both genders so that gender differences can be assessed, and for other types of medical data, they are an important stimulus to public health researchers. As we establish data elements for which self-report data are shown to be valid and reliable, we will be able to streamline our protocols accordingly and better interpret self-report data that is available.

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Follow-Up Rates and Migration Habits

Michele A. Webb, CTR

If it were lawful to implant GPS tracking devices into cancer patients at the time of diagnosis, registrars would likely be lurking the hallways of hospitals nationwide with implant devices in hand! The challenge of keeping the lost to follow-up rates within compliance, or at least manageable, is a common problem. The cancer registrar can minimize the number of lost patients by collecting valuable data when the case is first accessioned. By taking a bit of time to study moving and relocation trends you can target specific data items that are commonly used in Internet and public record sources.

On September 4, 2008 the US Census Bureau published a press release summarizing migration habits in the United States.[1] Here is a quick overview:

- In the years 2006 and 2007, approximately 38.7 million people moved, or relocated, in the United States. Within this group, 25.2 million people moved to another residence in their same county of residence, 7.4 million moved to a different county of the same state, 4.9 million moved to a different state, and 1.2 million moved outside the United States. According to a USA Today report,[2] one in 26 Americans today has cancer, indicating that approximately 14.8 million cancer patients moved during the 2006 to 2007 calendar years.
- Migration habits are also studied by region. Individuals in the west had the highest moving rate (15%), followed by the South (14%), the Midwest (13%), and the Northeast (9%).
- The migration rates within different ethnic groups is also interesting with blacks having the highest moving rate (17%), Hispanics (16%), Asians (15%), and non-Hispanic whites (12%).
- Individuals between the ages of 20 to 24 and 25 to 29 have the highest moving rates (27% and 26%, respectively).
- People who are separated or who were married with absent spouses are the most likely to move. Widows are least likely to move. Individuals who have never married are more than twice as likely to move as people who are married with their spouse present.
- The trend for individuals who rent versus own their own home is also significant. Renters (about 29%) are more likely to move as compared to approximately one in 15 people who own their homes (7%).
- Individuals who are 16 years of age and older and are unemployed (23%) are more likely to move than those who are employed (14%) or those who are not in the labor force, such as disabled, retirees, etc. (10%).

The press release and other special reports published by the US Census Bureau describe each of these statistics and groups in more detail. If you are interested in reading more, you can access this information at the Web link below.[3]

So, what does this mean for cancer registrars? Simply put, the statistics provide a generic profile, or roadmap, for the patient types that will likely move or relocate over time. The registrar can minimize this effort by collecting some additional data items that are typically found in the cancer registry database. Additionally, the registrar can use the same statistics, combined with the data collected, to review the "lost" cases and identify potential sources for current addresses and death information. The concept of collecting data items that are not required for Commission on Cancer or State reporting may be debatable. However, having spent the last 5 years searching for lost patients as an independent consultant, I have come to understand the importance and value of this additional information. Based on your geographic region or the ethnic mix of patients at your facility, you may find different trends or data to collect that will be of benefit to your registry's needs.

Let's look at some common data items that can be used to search for lost patients in most Internet and public-record sources of information:

- Full legal name and alias name(s)
- Maiden name
- Marital status
- Name of spouse (or parent's name, for minor children)
- Place of birth (city and state)
- Occupation
- Employment status and employer
- Race
- Current street, city, state, and county of residence (include street addresses in addition to post office boxes)
- Names and addresses of next of kin and other patient-provided contact(s)

In summary, registrars are encouraged to study the unique qualities of their own community and region to determine which data items will be most helpful to their follow-up activities. By sharing your own practices with other registrars you may find additional sources of information that may be helpful for finding lost patients.

The best advice is to not get discouraged and to be proactive in your approach to managing your follow-up caseload. By collecting data items at the time the case is first accessioned, the registrar may save many hours of future searching.

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The Inquiry and Response System: I&R 4 U

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The Inquiry and Response (I&R) System is a valuable resource available to all cancer care professionals. It is a repository of thousands of questions and answers related to data and cancer program standards maintained by the American College of Surgeons Commission on Cancer (ACoS CoC) and the American Joint Committee on Cancer (AJCC).

The I&R Team is composed of technical staff members of cancer programs who meet weekly to review the questions submitted and determine consensus answers. At this point a decision is made to either post the question and answer on the Web for the public to view, or to retain it in the in house database for reference purposes. The technical staff includes certified tumor registrars (CTRs) who also have access to a team of physician and expert curators who provide additional input and support.

When submitting a question, the user is required to use the "Search Database" feature to seek an answer to their question. If after reviewing the results no answer is found, the question is submitted at this point using the "Submit a Question" feature that will appear at the end of the search results. More information about searching for answers or submitting questions to the I&R System can be found at: **http://web.facs.org/coc/FMPro?-db=ajccweb.fp5&-format=iandrintro.htm&-view**.

Statistically speaking, the I&R Team has answered more than 15,000 questions over the past 5 years. With a technical team of 5 to 6 people at any given time, that means each team member may answer 500 to 600 questions every year.

The most common question categories in 2008 were related to FORDS, followed by Multiple Primary/Histology, Cancer Program Standards, Collaborative Stage, AJCC, ICD-0, NCDB, and others. The average turnaround time from submission to response is 9 days.

The team enjoys the challenge of answering questions, particularly those that require us to go beyond the I&R database or manual searches. Our resources include *FORDS*, the *AJCC Staging Manual*, *Cancer Program Standards 2004* (revised), and SEER. These manuals, and the additional resources referenced, are valuable tools that require constant use as educational tools or resources for appropriate procedures.

In 2008, through a survey performed by the AJCC, we recognized the need to make some improvements to the I&R System to enhance the benefit to the cancer registry community. Following are some of the initiatives we have planned for 2009.

First, hire external contractor(s) to conduct a quality control review of the content of the database; remove older data; and maintain the years 2007, 2008, and forward. The quality control project will consist of removing duplicate questions, correcting incomplete questions or answers, and modifying erroneous information that may be related to updates or changes.

Once the quality control project is completed, we will implement a more interactive I&R System. We plan to enlist the expertise of the CTR community and allow others to partner with us to respond to submitted questions. Questions submitted to the I&R System will be viewable by the public every day, allowing them to be reviewed and answered by the user community. Initially, we will leave new questions online for 3 days, to allow for an external response to include an answer and source. The I&R Team will monitor the quality of the answers and comment as needed. Our hope is that we can eventually provide a more interactive system with bulletin board-like features for real time input and assistance from the registry community. Please watch for this new online feature in the spring.

As we continue to make improvements to the I&R System, we remind our users to take the following steps when submitting a question:

- Always search I&R prior to submitting a question
- If you cannot find your answer, check your manuals or other resources
- If you still cannot find your answer, include with your question what you think the answer may be
- Always include your sources for search
- Read your question back to yourself and see if it clear, concise, and contains all the necessary information to assist the I&R Team
- Be patient and do not submit a duplicate question; wait for us to answer

If we can work together in the CTR community to support each other, we can continue to have such fine resources as the I&R System. We look forward to making more improvements to the system and trust you will support our efforts.

For further follow-up on this article please contact Debbie Etheridge, CTR, Cancer Program Specialist, at ***detheridge@facs.org*** *or at (312) 202-5291.*

CORRECT ANSWERS FOR WINTER 2008

Journal of Registry Management Continuing Education Quiz

Linking the Ohio Cancer Incidence Surveillance System with Medicare, Medicaid, and Clinical Data from Home Health Care and Long Term Care Assessment Instruments: Paving the Way for New Research Endeavors in Geriatric Oncology

(correct answers in ***bold****)*

1. According to Surveillance, Epidemiology, and End Results (SEER) data:
   a) the number of elders in the United States will triple by 2030
   b) between 1998 and 2002, 56% of cancer deaths occurred in patients 65 years of age or older
   c) between 1998 and 2002, 71% of cancer deaths occurred in patients 65 years of age or older
   d) none of the above

2. The Comprehensive Geriatric Assessment (CGA):
   a) incorporates principles of geriatrics in the practice of oncology
   b) measures comorbidities, functional limitations, and geriatric syndromes
   c) is gaining recognition in clinical practice
   d) all of the above

3. According to Table 2: *Comparison of Cases by Matching Status with Medicare and Medicaid Files,* female breast cancer patients 85 years of age or older were more likely to be matched successfully with Medicare than those aged 65 through 69.
   a) true
   b) false

4. According to Figure 3: *Patients diagnosed with cancer in 2001 and receiving nursing home care (NHC)—distribution by timing of initiation of NHC relative to cancer diagnosis,* the proportion of patients initiating NHC a year or more prior to cancer diagnosis was highest in patients with which type of cancer:
   a) prostate
   b) breast
   c) colorectal
   d) kidney

5. Data elements needed for improved risk adjustment techniques include:
   a) comorbid conditions
   b) measures of functional limitations
   c) measures of geriatric syndromes
   d) all of the above

6. In this study, the patient population was limited to those patients receiving home health care (HHC) or long term care (LTC).
   a) true
   b) false

7. According to Figure 2: *Patients diagnosed with cancer in 2001 and receiving home health care (HHC)—distribution by timing of initiation of HHC relative to cancer diagnosis,* patients with the following cancer are least likely to initiate HHC within one to 6 months following cancer diagnosis:
   a) breast
   b) prostate
   c) colorectal
   d) kidney

8. Logistical issues involved with the development of CALD included:
   a) budgetary constraints
   b) data use agreements and Institutional Review Boards were not required
   c) an accepted & disseminated standard data linking strategy is used across the research community
   d) all of the above

9. As indicated by the findings in Table 1: *Number of Incident Cases Reported in the OCISS before and after Unduplication, Percent Matched with Medicare and Medicaid Files, and Percent Patients Deceased by December 31, 2005,* the highest match rate with Medicaid files for 1999, occurred in:
   a) female breast cases
   b) prostate cases
   c) kidney cases
   d) colorectal cases

10. Limitations of this study include:
   a) CALD is specific to Ohio
   b) patients for whom measures of functional status and geriatric syndromes are available do not constitute the majority
   c) both a and b
   d) none of the above

Journal of Registry Management Continuing Education Quiz—SPRING 2009

MISCLASSIFICATION OF AMERICAN INDIAN RACE IN STATE CANCER DATA AMONG NON-FEDERALLY RECOGNIZED INDIANS IN NORTH CAROLINA

Quiz Instructions: The multiple choice or true/false quiz below is provided as an alternative method of earning CE credit hours. Refer to the article for the ONE best answer to each question. The questions are based solely on the content of the article. Answer the questions and send the original quiz answer sheet and fee to the NCRA Executive Office before the processing date listed on the answer sheet. Quizzes may not be retaken nor can NCRA staff respond to questions regarding answers. Allow 4–6 weeks for processing following the submission deadline to receive return notification of your completion of the CE process. The CE hour will be dated when it is submitted for grading; that date will determine the CE cycle year.

After reading this article and taking the quiz, the participants will be able to:

- Explain how accurate classification by race contributes to equitable distribution of healthcare resources
- List the types of programs that may be affected by underestimation of cancer burden
- Discuss the rationale for choosing female breast, prostate, lung, and colorectal cancers for this analysis

1. Racial or ethnic identification gleaned from which of the following sources is least prone to error:
   a) death certificates
   b) medical records
   c) direct collection from the individual
   d) disease surveillance systems

2. Misclassification increased as the percent blood quantum (a measurement of American Indian ancestry) decreased.
   a) true
   b) false

3. Cancer is the second leading cause of death among American Indians and the leading cause among Alaska Natives.
   a) true
   b) false

4. In North Carolina, the majority of American Indians are:
   a) covered by the Indian Health Service
   b) not associated with federally-recognized tribes
   c) the smallest population of state-recognized and non-federally recognized Indians in the United States
   d) none of the above

5. Female breast, prostate, lung, and colorectal cancers were chosen for this analysis because:
   a) they provide stable incidence rates due to the small number of cases
   b) they provide unstable incidence rates due to the large number of cases
   c) the burden among these 4 sites is the lowest for all racial groups combined
   d) the burden among these 4 sites is the highest for all racial groups combined

6. After correction of race, cancer incidence rates for 1996–2000:
   a) increased 19% for American Indians
   b) were much greater for whites and blacks
   c) reflected higher increase for female breast than for prostate in American Indians
   d) decreased after correction of race

7. American Indians were listed on tribal roles but not classified as such in the NCCCR at a rate of:
   a) 10%
   b) 17.9%
   c) 42%
   d) 95%

8. According to Table 2: *American Indian Misclassification of Race, by Tribe*, the:
   a) Occaneechi Tribe had 468 names on their tribal role
   b) Meherrin Tribe residing in Person County were included in this analysis
   c) Coharie Tribe had a 12.5% misclassification rate
   d) Waccamaw-Siouan Tribe had 17 names on the CCR subset

9. Limitations that should be considered when interpreting the results of this analysis include:
   a) human error in the matching process
   b) the results may overestimate the problem
   c) not all American Indians in the state were represented
   d) all of the above

10. Falsely low reported rates of cancer can lead to:
    a) underfunding of screening, detection, and treatment programs
    b) inaccurate accounting of morbidity and mortality rates for American Indians
    c) both a and b
    d) neither a nor b

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6 ☐A ☐B ☐C ☐D
7 ☐A ☐B ☐C ☐D
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