Challenges in Identifying Native Hawaiians and Pacific Islanders in Population-Based Cancer Registries in the U.S

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Abstract

Lack of disaggregated data for Native Hawaiians and Pacific Islanders (NHPIs) in the U.S. has resulted in severe gaps in understanding health disparities and unique health needs of NHPIs. Telephone interviews were conducted with 272 cancer patients identified by a population-based cancer registry. The self-reported NHPIs status was compared with that identified by the registry. Sensitivity, Specificity, Positive Predictive Value (PPV), and Negative Predictive Value (NPV) were calculated. Alternative NHPIs identification methods were explored. The registry had acceptable sensitivity (89%), specificity (96%) and NPV (99%), but low PPV (62%) in identifying NHPIs. Using additional information on surname and birthplace from the registry improved the identification of NHPIs, but either increased the false positive or decreased the counts of true NHPIs cases. Improved data collection methods and practices in identifying NHPIs in population-based cancer registries are needed and caution in interpreting cancer data for NHPIs is warranted.

Keywords

Native Hawaiians and Pacific Islanders; Cancer registry; Birthplace; Surnames

Background

Study of ethnic patterns of disease can provide crucial information on etiology and causal relationships. Such studies, however, rely on the reliable and accurate classification of ethnic information. With the increasing size and diversity of the ethnic populations in the U.S. comes the challenge of assuring the availability of accurate data on ethnic demographics and disease occurrence. Problems with either can introduce significant biases in disease rates. For instance, in Washington 14.7% of deaths among American Indians and Alaskan Natives were misclassified, leading to an underestimation of disease burden in these populations [1].

The health status of Native Hawaiians and Pacific Islanders (NHPIs) in the U.S. is largely understudied and as a result, NHPIs remain "invisible" [2, 3] in many health statistics. Due

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to their relatively small population numbers and disparate geographic locations, NHPIs have long been under-represented in public health domains [4]. As minorities, NHPIs are often aggregated with the much larger and also diverse groups of Asians in reports and presentations of health data. As disease incidence and mortality vary greatly by ethnic identity, lack of disaggregated data has resulted in severe gaps in our knowledge of the health needs of NHPIs.

The Pacific Islands contain 789 habitable islands and are divided into the three geographic areas: Polynesia, Melanesia, and Micronesia. The U.S. associated states and jurisdictions include Hawai'i, Guam, American Samoa, Commonwealth of the Northern Mariana Islands, Federated States of Micronesia, and Palau. NHPIs in the U.S. include many groups that differ in language and culture. Three groups—Native Hawaiians, Samoans, and Guamanians—together accounted for 74% of the NHPIs population [5]. In the 2000 census, 0.3%, or 874,414 people, of the U.S. population identified themselves as NHPIs, either exclusively or in combination with other groups [5]. More than half of the NHPIs population (56%) reported more than one race in 2000 census [5]. The majority of NHPIs lived in two states—Hawaii and California. In 2004, more single race NHPIs lived in California (30%) than in Hawaii (26%) [6].

NHPIs is one of the fast-growing population groups in the U.S. with unique socioeconomic characteristics. Compared with the non-Hispanic white population, NHPIs are younger, less educated, more likely to be in poverty, more likely to live in extended families, and less likely to be employed in management, professional, and high-pay occupations [6]. The change of lifestyle from an active farming- and fishing-based subsistence economy to a more sedentary one has resulted in high obesity rates among NHPIs [7–11]. It has been speculated that NHPIs may be genetically predisposed to store fat for times of scarcity [12]. These and other unique characteristics play important roles in the health status of NHPIs. The NHPIs were found to have generally worse cancer survival than non-Hispanic whites [13].

While many existing databases collect NHPI identifiers, no study to date has ever attempted to validate the quality of such data with self-reported information. Although population-based cancer registries in the U.S. strive to fill in the gaps by collecting 12 detailed NHPIs ethnic identities, the effort is reportedly plagued by misclassifications, especially in areas with low presence of NHPIs [14]. Key to the reduction of cancer health disparities among NHPIs in the U.S. is the development of a comprehensive cancer control agenda that identifies and addresses significant barriers while taking into account unique cultural and psychosocial features that influence health behaviors both across and within ethnic sub-groups.

Working with the NCI-funded consortium, *WINCART: Weaving an Islander Network for Cancer Awareness, Research and Training* whose aim is to increase cancer prevention activities among NHPIs in Los Angeles and throughout Southern California [15], we conducted a study in 2007 to evaluate the accuracy of the NHPIs identity in population-based cancer registry and to explore alternative methods for increasing the reliability and validity of identifying NHPIs in population-based cancer registry database. The purpose of this paper is to report on the findings from this study and the implications for studying the health of NHPIs.

Methods

The Los Angeles Cancer Surveillance Program (LACSP) is the population-based cancer registry for Los Angeles County, California. It identifies and obtains information on all

incident (newly diagnosed) cancer patients within the geographic boundaries of the County. The registry was organized in 1970 and it operates within the administrative structure of the University of Southern California (USC) Keck School of Medicine and the USC/Norris Comprehensive Cancer Center. The registry became essentially population-based by 1972 and complete incidence data for Los Angeles County are available from that year onward. It is part of the California Cancer Registry (CCR) and National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program. It is also a member of the North American Association of Central Cancer Registries (NAACCR). The LACSP follows the standard case-finding and data coding protocols of CCR and SEER and has been consecutively granted the highest awards by NAACCR for data quality. To date, the LACSP database contains over 1.3 million records and some 35,000 newly diagnosed cancer cases are added each year. Los Angeles County is the most populous County in the country with culturally and ethnically diverse populations of nearly 10 million. Over 40,000 NHPIs currently live in Los Angeles County.

In order to evaluate the accuracy of the LACSP's classification of NHPIs cases, we conducted telephone interviews with existing registry patients, selected from among those identified as NHPIs, and a selection of non-NHPIs cases. First, we requested three types of cancer patients diagnosed during 2000–2004 from the LACSP: (1) cases with reported race as NHPIs, (2) cases with unknown or unspecified race (i.e., race unknown or other race), and (3) cases who lived in three census tracts that had the highest proportion of NHPIs population in the county at the time of cancer diagnosis. Cases were limited to the years 2000–2004 because this was an interview-based study, where we sought to recruit recently diagnosed cancer incident cases to avoid survivorship bias. We used a 5-year span of incident cases in order to achieve a sufficiently large sample size. A total of 1,330 subjects meeting the three selection criteria were identified for the project. After excluding deceased cases (using information from LACSP annual follow-up methods, including linkage with the National Death Index) and cases without valid contact information, 955 (72%) subjects remained in the study sample with one or more telephone numbers resulted from a vigorous tracing and updating process using public records. Due to disconnected or wrong phone numbers, 721 (75%) out of the 955 patients were actually contacted by the study. The contacting of patients was preceded by notification letters to both the patients and their attending physicians introducing the study and explaining about the upcoming phone interview. The study protocol and survey instruments were reviewed and approved by the Institutional Review Board (IRB) of the University of Southern California. All study interviewers were previously experienced and trained specifically for this study. IRB-approved interview scripts and study questionnaires were used for each interview that was conducted with verbal consent from each participant.

Of the 721 contacted subjects, 234 (32%) refused to participate, 125 (17%) were unreachable after ten attempted calls at different times, 40 (6%) incomplete interviews, and 50 (7%) non-English speaking individuals, leaving a total of 272 (38%) completed surveys. Pearson chi-square test was used to compare the homogeneity in the distributions of demographic characteristics between the 721 contacted and the 272 participating subjects. As shown in Table 1, there were no statistically significant differences between the survey groups in terms of sex, race/ethnicity, socioeconomic status, and birthplace. Nonetheless, the age composition of the study participants was significantly younger than that of all the contacted subjects (Table 1).

We also created and tested a community-enhanced NHPIs surname list as an alternative method for increasing the reliability and effectiveness of identifying NHPIs in population-based cancer registries. We first requested the surnames of cases reported as NHPIs from the LACSP database with detailed subgroup identity. Then we worked with leaders from four

local NHPIs community-based organizations to review these surnames and added additional typical NHPIs-specific surnames and deleted atypical ones (if less than 50% of registry cases with the surname were recorded as NHPIs in the registry database). These four organizations are members of WINCART and were skilled and experienced in community-based research efforts to understand and address cancer health disparities for Pacific Islanders in Southern California. The resulting list included surnames for Native Hawaiians, Samoans, Tongans, Chamorros, and Fijians.

Using the self-reported NHPIs status as the gold standard, we evaluated the following methods for identifying NHPIs: (1) registry reported NHPIs race (i.e., existing cases in the registry that are already identified as having a NHPIs race compared to self-reported NHPIs status); (2) registry reported NHPIs birthplace (i.e., existing cases in the registry that are already identified as having a NHPIs birthplace); (3) registry reported NHPIs race plus NHPIs birthplace; (4) use of NHPIs surname list (i.e., use of the community-enhanced NHPIs surname list compared to self-reported NHPIs status); (5) use of NHPIs surname list plus registry reported NHPIs birthplace; and (6) use of NHPIs surname list plus registry reported NHPIs birthplace and registry reported NHPIs race. For each method, we calculated the following: Sensitivity (proportion of true positives identified by a method), Specificity (proportion of true negatives identified by a method), Positive Predictive Value (PPV) (the proportion of correctly identified positives by a method), and Negative Predictive Value (NPV) (the proportion of correctly identified negatives by a method).

Results

The three different registry-identified methods had similar outcomes in classifying NHPIs cases correctly. As shown in Table 2, among the 272 surveyed 16 out of 26 (62%) of registry-identified NHPIs were also self-reported NHPIs; conversely, 2 out of 18 (11%) self-identified NHPIs were misidentified by registry as non-NHPIs. Registry-identified race had acceptable sensitivity (89%), specificity (96%), and NPV (99%) but low PPV (62%) in classifying NHPIs. Thus, it appears that the LACSP identified most actual NHPIs cases correctly: LACSP misidentified 2 (11%) (1 multiracial, 1 born in Western Samoa). However, many others assigned NHPIs race by LACSP were not confirmed by self report (38%). Most of those falsely assigned NHPIs race/ethnicity by the LACSP were of Asian or Hispanic ethnicity, who the LACSP said were born in Hawaii and of Hawaiian ethnicity. The net result was the LACSP race assignment yields 44% more NHPIs cases than would occur on the basis of self-report.

The LACSP correctly located NHPIs birthplace for 88% of NHPIs cases, depending on accuracy of Hawaiian birthplace (assuming LACSP birthplace of Hawaii was correct if self-reported U.S.-born). Aside from the assumption about Hawaiian birthplace, LACSP slightly (10%) undercounted NHPIs-born cases. The LACSP birthplace appeared to be a slightly less accurate indicator of self-reported race than the LACSP's version of race (58% vs. 62%). Requiring both the LACSP race AND birthplace to be "NHPIs" resulted in the most accurate overall approach to finding NHPIs cases (68%). LACSP race and birthplace combined resulted in a less accurate count of NHPIs population than the LACSP race alone, but yielded a more accurate net count of NHPIs cases (6% gain). Taking either birthplace or race/ethnicity as being NHPIs from the LACSP resulted in the most complete assessment of NHPIs cases (95%), but obviously also resulted in the largest number of false positives (42%).

The alternative method of using a registry-generated, community-enhanced NHPIs surname list alone (Table 3) had much poorer outcome (61% sensitivity and 18% PPV) than using any registry item as shown in Table 2. But combining the use of surname list with registry

information improves the identification of NHPIs to be better than using registry items only. For instance, using both the surname list and registry birthplace information resulted in 82% of the identified NHPIs being true; adding registry race information brought the PPV to 100% eliminating any false positives. However, such improved accuracy was at the expense of the reduced proportion of true NHPIs being identified by the methods from 61% (surname only) to 50% (surname + LACSP birthplace) and 44% (surname + LACSP birthplace + LACSP race).

Discussion

As an integral part of public health monitoring system, population-based cancer registries represent an important resource for studying cancer disparities among racial/ethnic populations in the U.S. The quality of classifying race/ethnicity in the registry databases, especially for the small NHPIs group, is crucial to identifying and addressing racial/ethnic cancer disparities. Given its sizeable and growing NHPIs population, the LACSP offers unique opportunities for examining data quality for NHPIs. Using the patient self-reported NHPIs identity as the gold standard, we evaluated the registry's identification of NHPIs and tested some alternatives of identification methods. This method of self identification is not only a logical choice in the absence of a "true" gold standard for race/ethnicity, but it also most closely represents NHPIs identification from the Census, which is the source of populations for cancer incidence rates.

We found the LACSP classified NHPIs reasonably well, but with room for improvement. The registry-based and community-enhanced NHPIs surname list alone did not predict self-reported NHPIs race very well. Inference of ethnicity from surname is most common in the U.S. for Spanish surnames. The U.S. Census Bureau has produced and released Spanish Surname lists since the 1950 census [16]. The 1980 and 1990 census-based Spanish surname lists in particular have been widely used by researchers and programs for the identification of people of Hispanic/Spanish origin [17, 18]. Developing ethnic-specific NHPIs surname lists is more complicated than doing so for Spanish/Latino populations. The much smaller NHPIs population size, adoption of English names, and the lack of a national sample from which example surnames can be extracted all contribute to the difficulties. As a result, NHPIs surname lists developed by various organizations for a variety of purposes with different methods are of limited use and value. Combining registry race and birth-place information or adding these registry items to NHPIs surname list improves the accuracy but lowers the counts of identified true NHPIs cases. Previous studies have reported biases in reporting birthplace information among Asians and Hispanics in population-based cancer registry [19, 20]. Evaluation of bias in applying birthplace data for classifying NHPIs should be conducted with larger data sets.

To our knowledge, this was the first study of its kind to explore and evaluate methods of understanding and improving NHPIs classification in population-based cancer registries on the continental U.S. Our findings demonstrate the complexity of issues in classifying and identifying NHPIs. The low response rates in the LACSP survey prevented an accurate assessment of self-reported information, and undoubtedly biased our observations with unpredictable magnitude and direction of effect. Due to the small numbers, we were unable to evaluate the NHPIs identifications by subgroups. Instead we examined the identification of NHPIs versus non-NHPIs. Short of the self-reported gold standard, caution is advised in interpreting any evaluation results by using the registry-based information, as varying degrees of misclassification is possible. The high proportion of multiracial individuals among NHPIs could be a contributing factor in misclassifying NHPIs with a single race scheme, while the multiracial classification of people is still not yet widely practiced or used.

Moreover, the poor response rate highlights the difficulty in studying cancer in NHPIs populations. The methods that we used to identify, trace and contact individuals for this study are identical to those shown to be effective in the recent past for studies of other racial/ethnic groups [21, 22]. In consultation with our WINCART partners, we concluded that the main reason for the low response rates was either that a high proportion of NHPIs cancer cases came to Los Angeles for diagnosis and treatment and did not stay here after diagnosis (and hence were not able to be located for the study), or that members of the NHPIs population are less likely to agree to participate in research studies than other populations are. There is substantial evidence that recruitment and retention of NHPIs and other minority populations in clinical trials is substantially lower than for other populations [23–25], so this hypothesis has some rationale. Both of these possibilities further impinge upon our ability to accurately track cancer control efforts and outcomes in NHPIs populations in the U.S.

The findings from this study underscore the need to develop better methods to accurately classify NHPIs in health-related data sets, and a better understanding of the challenges in identification of NHPIs. The continuing problems of misclassification can result in misleading underestimates of cancer incidence and prevalence for NHPIs populations. As it has been already recognized, improving data quality for race/ethnicity is most effectively attempted at the reporting source of data, i.e., hospitals in the case of cancer reporting [26]. Education and awareness among health care staff of the importance of race/ethnicity are the keys to reporting from both patients and hospitals. Accurate assessment of racial/ethnic disparities in cancer incidence, as well as in other diseases, is necessary in order to provide valuable information regarding the risk exposures, disease etiology, and access to health care, which forms the basis for understanding the disease and developing targeted interventions and public health planning. We urge future research to build upon our methods and results to improve the correct classification by detailed race/ethnicity in population-based cancer registries and other health organizations.

Acknowledgments

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Table 1

Distributions of registry reported demographic characteristics of study subjects, Los Angeles County, California, 2000–2004

	Contacted		Participating	
	Cases	%	Cases	%
Total	721	100.0	272	100.0
Sex (*P* = 0.26)				
Female	329	45.6	135	49.6
Male	392	54.4	137	50.4
Age at diagnosis (in years) (*P* = 0.02)[a]				
21–59	311	43.1	140	51.5
60–95	410	56.9	132	48.5
Race/ethnicity (*P* = 0.59)				
White	132	18.3	63	23.2
Black	19	2.6	8	2.9
Asian	239	33.2	76	27.9
Hawaiian	14	1.9	11	4.0
Micronesian	1	0.1	0	0.0
Guamanian, NOS	2	0.3	1	0.4
Polynesian, NOS	2	0.3	0	0.0
Samoan	21	2.9	8	2.9
Tongan	10	1.4	2	0.7
Fiji Islander	3	0.4	1	0.4
Pacific Island, NOS	5	0.7	3	1.1
Other	22	3.1	10	3.7
Unknown	251	34.8	89	32.7
Socioeconomic status (*P* = 0.90)				
Highest	202	28.0	81	29.8
Mid-high	155	21.5	63	23.2
Middle	154	21.4	57	21.0
Mid-low	97	13.5	30	11.0
Lowest	57	7.9	19	7.0
Unknown	56	7.8	22	8.1
Birthplace (*P* = 0.33)				
Hawaii	25	3.5	15	5.5
Other U.S.	147	20.4	63	23.2
Outside U.S.	196	27.2	68	25.0
Unknown	353	49.0	126	46.3

[a] Indicates statistically significant differences between contacted and participating subjects

Table 2

Comparisons of registry (LACSP) information against self-reported NHPIs status by race and birthplace, Los Angeles County, California, 2000–2004

		Self-reported race			Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)
		NHPIs	Non-NHPIs	Total				
LACSP	NHPIs	16 (89%)	10 (4%)	26 (10%)	89	96	62	99
Race	Non-NHPIs	2 (11%)	244 (96%)	246 (90%)				
	Total	18 (100%)	254 (100%)	272 (100%)				

		Self-reported birthplace			Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)
		NHPIs	Non-NHPIs	Total				
LACSP	NHPIs	22 (88%)	2 (1%)	24 (9%)	88	99	92	99
Birthplace[a]	Non-NHPIs	3 (12%)	244 (99%)	247 (91%)				
	Total	25 (100%)	246 (100%)	271 (100%)				

		Self-reported race			Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)
		NHPIs	Non-NHPIs	Total				
LACSP	NHPIs	14 (78%)	10 (4%)	24 (9%)	78	96	58	98
Birthplace	Non-NHPIs	4 (22%)	244 (96%)	248 (91%)				
	Total	18 (100%)	254 (100%)	272 (100%)				

		Self-reported race			Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)
		NHPIs	Non-NHPIs	Total				
LACSP	NHPIs	13 (72%)	6 (2%)	19 (7%)	72	98	68	98
Race + Birthplace	Non-NHPIs	5 (28%)	248 (98%)	253 (93%)				
	Total	18 (100%)	254 (100%)	272 (100%)				

		Self-reported race or birthplace			Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)
		NHPIs	Non-NHPIs	Total				
LACSP	NHPIs	18 (95%)	13 (5%)	31 (11%)	95	95	58	100
Race or birthplace[a]	Non-NHPIs	1 (5%)	240 (95%)	241 (89%)				
	Total	19 (100%)	253 (100%)	272 (100%)				

[a] Assuming CSP birthplace of Hawaii was correct if self-reported U.S.-born

Table 3

Comparisons of alternative identification results against self-reported NHPIs race, Los Angeles County, California, 2000–2004

		Self-reported race			Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)
		NHPIs	**Non-NHPIs**	**Total**				
Survey used	NHPIs	11 (61%)	50 (20%)	61 (22%)	61	80	18	97
NHPIs surnames	Non-NHPIs	7 (39%)	204 (80%)	211 (78%)				
	Total	18 (100%)	254 (100%)	272 (100%)				
		Self-reported race			Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)
		NHPIs	**Non-NHPIs**	**Total**				
NHPIs surnames +	NHPIs	9 (50%)	2 (1%)	11 (4%)	50	99	82	97
LACSP birthplace	Non-NHPIs	9 (50%)	252 (99%)	261 (96%)				
	Total	18 (100%)	254 (100%)	272 (100%)				
		Self-reported race			Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)
		NHPIs	**Non-NHPIs**	**Total**				
NHPIs surnames +	NHPIs	8 (44%)	0 (0%)	8 (3%)	44	100	100	96
LACSP birthplace +	Non-NHPIs	10 (56%)	254 (100%)	264 (97%)				
LACSP race	Total	18 (100%)	254 (100%)	272 (100%)				