The Usefulness of Health Care Databases in Wisconsin for Identifying Hmong Patients with Cancer

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ABSTRACT

Objectives: The Wisconsin Cancer Reporting System (WCRS) collects data on cancer diagnoses in the state of Wisconsin. California and Minnesota cancer registries have reported that Hmong have higher rates of certain cancers than the general population. WCRS collaborated with the Wisconsin Comprehensive Cancer Control Program (WCCCP) and Wisconsin United Coalition of Mutual Assistance Associations (WUCMAA) to investigate the reporting of cancer cases in the Hmong population by medical facilities.

Methods: WCRS, WCCCP, and WUCMAA conducted a mail survey of facilities in 12 Wisconsin counties where Hmong populations reside.

Results: The survey found that <30% of facilities collected Hmong as a demographic category or identified cancer patients as Hmong; most facilities reported Hmong patients only as Asian. A training webcast was developed for facilities to reinforce WCRS reporting requirements and to elucidate the Hmong culture. A pamphlet for Hmong patients was developed to explain the importance of self identification for more racially representative cancer data in Wisconsin.

INTRODUCTION

Wisconsin is home to the third largest Hmong population in the United States, following California and Minnesota. The Hmong population in Wisconsin increased by 106% between 1990 and 2000, to a total of 33,791. Hmong comprise approximately 38% of the Asian population and are the largest Asian group in Wisconsin.[1] The 2000 US Census data show that 34.8% of Hmong report being linguistically isolated compared to 4.1% of the general population, and 38% of Hmong live below the poverty level compared to 12% of the US population.[2] Over two-thirds of the Hmong population in Wisconsin are under 24 years of age, and 57.1% are under 18 years of age.[3] The South East Asian Hmong traditionally were an agrarian people in isolated villages with no formal education, and resettlement in the United States presented many challenges for them.[4]

The studies of cancer incidence in the Hmong population in California revealed elevated age-adjusted incidence rates for hepatic, gastric, cervical, and nasopharyngeal cancers, as well as leukemia and non-Hodgkin's lymphoma.[5,6] California and Minnesota studies also showed that Hmong experienced a later stage and higher grade of disease at diagnosis compared to the rest of the population.[6,7] Other racial disparities in larger Wisconsin populations have been documented,[8,9] but accurate data are necessary to meet the health needs of the Hmong community and to support current cancer prevention and control initiatives.

The Wisconsin Cancer Reporting System (WCRS) is the population-based state cancer registry in the Division of Public Health that collects data on all newly diagnosed cancer cases for Wisconsin residents. Newly diagnosed cancer cases are reported to WCRS by Wisconsin hospitals, clinics and physician offices, cooperating out-of-state cancer registries, and selected Minnesota hospitals. Funded by the Centers for Disease Control and Prevention (CDC), WCRS has participated in the National Program of Cancer Registries since 1994. WCRS is required to collect from facilities and report to CDC detailed race categories including Hmong and other Asian groups. WCRS collaborated with the Wisconsin Comprehensive Cancer Control Program (WCCCP)[10] and the Wisconsin United Coalition of Mutual Assistance Associations

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(WUCMAA) to improve surveillance of cancer in the Hmong population.

Table 1 shows the race categories and codes required by WCRS and most state cancer registries in the National Program of Cancer Registries since 1995. It then compares them to the minimum Office of Management and Budget (OMB) categories, still collected by many health care facilities. WCRS reports cancer cases among Wisconsin residents to CDC and other federal agencies for virtually all major national publications.[11,12] The collaborative survey asked the following questions: Where are Wisconsin's Hmong receiving cancer care, what services are provided, and what are the processes for collecting data on ethnicity and race and, in particular, Hmong patients with cancer?

METHODS

The 3 statewide organizations combined resources to approach a long-standing scarcity of cancer data for the Hmong population. WUCMAA provided cultural- and community-based knowledge of Hmong health care practices. WCCCP offered a network to make appropriate contacts for partnerships and additional staff as needed to conduct the survey. WCRS designed the survey, developed the data collection instruments, and created training and educational resources, many of which were promoted directly to facilities. The design phase identified medical facilities that provide cancer diagnoses and/or treatment to Hmong patients for the sample selection and drafted questions regarding health services to Hmong, quantification of cancer incidence, and facility reporting practices. The implementation phase consisted of conducting the survey of the medical facilities indentified in the sample, and follow-up techniques to obtain maximum response rate. Data consisting of small numbers were compiled in descriptive statistics of frequencies and cross tabulations.

The survey sample was developed to reach facilities (hospitals, clinics, and physician offices) serving Hmong patients newly diagnosed or treated for cancer. According to the 2000 Census, roughly 94% of Hmong in Wisconsin could be found in 12 Wisconsin counties.[1] To capture all facilities, WCRS asked WUCMAA to compile a list of facilities from the 14 regional office rosters where Hmong receive health care within those 12 counties (Milwaukee, Marathon, Brown, Sheboygan, Outagamie, La Crosse, Dane, Winnebago, Eau Claire, Manitowoc, Portage, and Wood). Seventy-five facilities were identified as having any potential for past or current experience with Hmong cancer patients.

The survey questionnaire included a screening question to eliminate those facilities that did not diagnose or treat cancer patients. The questionnaire was designed to collect information in several integrated areas: special services for Hmong patients; cancer screening, diagnostic, or treatment services provided; cancer case referral patterns for Hmong patients; practices for the reporting of race and ethnicity to the state; current staff resources; and training needs to improve reporting of detailed race categories.

A survey was mailed to 75 medical facilities in the 12 Wisconsin counties. The cover letters, self administered questionnaires, and postage-paid return envelopes were mailed to facility administrators. The cover letters assured facilities of confidentiality and offered training resources based on results of the survey. Two survey follow-ups to non-respondents were conducted. One month after the first mailing, a second reminder cover letter, replacement questionnaire and postage-paid return envelope were mailed. Approximately 6 weeks after the initial mailing, a third and final telephone follow-up was conducted.

For the purpose of this analysis, data were calculated in frequencies and cross-tabulations to provide descriptive statistics. The relatively small number of facilities serving Hmong patients and scarcity of Hmong cancer cases did not support higher-level analytical techniques.

Table 1. Wisconsin Cancer Reporting System Required Race Codes

Code	Race	Code	Race
01	White	21	Chamorran
02	African American	22	Guamanian, NOS
03	American Indian, Aleutian, Alaskan Native or Eskimo (includes all indigenous populations of the Western hemisphere)	25	Polynesian, NOS
		26	Tahitian
		27	Samoan
		28	Tongan
		30	Melanesian, NOS
04	Chinese	31	Fiji Islander
05	Japanese	32	New Guinean
06	Filipino	88	No further race documented
07	Hawaiian		
08	Korean	96	Other Asian, including Asian, NOS and Oriental, NOS
09	Asian Indian, Pakistani		
10	Vietnamese		
11	Laotian		
12	**Hmong**	97	Pacific Islander, NOS
13	Kampuchean	98	Other
14	Thai	99	Unknown

Minimum Office of Management and Budget Race Categories

White
African American
American Indian/Alaska Native
Asian
Native Hawaiian or Other Pacific Islander
Unavailable

NOS = not otherwise specified

For purposes of improvements in cancer surveillance, the collaborators were most interested in the extent of reporting compliance, the distribution of Hmong patients throughout the state, and the special services available.

RESULTS

The final response rate of 72% (54 facilities), higher than average for mail surveys,[13] was largely attributable to the follow-up measures and to primary contact with facility administrators. Sixty-six percent (36) of responding facilities reported diagnosing or treating cancer patients. In response to the question, "Has your facility ever provided health care services to Hmong patients?", 86% (31) of those cancer facilities reported serving Hmong patients in general.

Facility Services for Hmong Patients
Those 31 facilities with Hmong patients were asked about special services. The largest proportion of facilities, 87%, reported providing Hmong language interpreters, followed by 61% that reported case management services. Fifty-eight percent reported providing culturally sensitive medical information to Hmong patients, and 54% reported providing general educational information about cancer. Just over half reported providing transportation services.

Cancer Data Collection for Race and Ethnicity
The majority of facilities (27) reported collecting race and ethnicity cancer data. However, of those collecting race/ethnicity data, only 7 facilities collected Hmong as a distinct category. Most facilities reported Hmong patients with cancer to WCRS only as Asian, not otherwise specified.

Method of Collecting Race Classifications
The 27 facilities reporting race and ethnicity data were asked how they collect this information from patients. Sixty-three percent of facilities reported that admission staff asked patients; 12% reported that patients completed a form (wrote race or checked box); 5% reported admission staff completed the information based on observation; and almost 20% did not answer or reported that it varied by circumstance.

DISCUSSION

The major strengths of the survey were the broad collaborative sponsorship, including WUCMAA, and a commitment to provide resources to address facility needs. Also, the relatively high response rate provided an adequate number of facilities serving Hmong patients to help understand prevalent data collection practices. The primary limitation of the survey, due to the lack of standardized collection of race data, was that it may have resulted in undercounting the number of Hmong patients. However, due to the unique needs of many older generation Hmong, the majority of facilities provide special services and therefore have general knowledge of Hmong patient admissions and treatments. Therefore, we are confident that this investigation captured the majority of targeted cancer care facilities.

One major finding of our survey of Wisconsin cancer care facilities was that although the majority of facilities reported minimum OMB race categories to WCRS, the detailed categories (such as Hmong) required by WCRS were not even collected at most facilities. There was also a general lack of standardized practices and procedures for collecting data on race and ethnicity. To address the problems identified in the survey, collaborators responded with 3 products: (1) thank you letters were mailed to responding facility administrators with an announcement of a training webcast. (2) Training webcast was broadcast to help facilities understand Hmong culture and special needs of Hmong patients, and to emphasize the requirement of reporting Hmong cases to the state cancer registry. The webcast recommended the *Health Research and Educational Trust Disparities Toolkit for Collecting Race, Ethnicity and Primary Language Information from Patients* as a comprehensive resource.[14] The webcast expressed the rationale for detailed data collection standards to address racial disparities. Webcast speakers included a Hmong health educator, a Hmong physician, and a Certified Tumor Registrar. (3) In partnership with the WUCMAA, a bilingual pamphlet was developed for Hmong patients to explain the importance of self-identification and the need for accurate data to better serve Hmong patients. The pamphlet is available at: https://dhs.wisconsin.gov/wcrs/pubs.htm. *(Accessed Aug 3, 2010.)*

Although we investigated race/ethnicity data collection from the context of cancer registry requirements, the lack of standardization has implications for other national data programs. Like Wisconsin, most states have growing diversity in their populations, although the difficulties in race/ethnicity data collection persist. There is no current uniform national policy for collecting these data at health care facilities. Some of the largest medical surveys collect only the OMB minimum 5 categories. The National Hospital Discharge Survey, the National Ambulatory Medical Care Survey, and the National Health and Nutrition Examination

Survey collect the minimum OMB categories.[15] Our results of an underreporting of race and the variability in data collection practices are similar to those found in a California survey and the National Hospital Discharge Survey.[16-18] Previous studies have reported deficiencies in Medicare data to measure racial and ethnic disparities in health care.[19]

To help address the current lack of national uniformity, there is growing support for national standardization of detailed data collection, as emphasized in the recent report from the Institute of Medicine *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*, available at the American Hospital Association's Web site (http://www.ahanews.com). This report recommends the collection of fine-grained categories, beyond the 5 minimum OMB categories. The report also states that opportunities should be afforded for individuals who want to self-identify their race and ethnicity, that locally relevant categories of detailed race and ethnicity should be chosen, and that these new standards should be used by federally funded health care programs and in electronic health record systems. The Health Research and Educational Trust also recommends that, when possible, organizations should collect detailed data on race and ethnicity.[14]

Although national organizations may strongly recommend more detailed race and ethnicity data, and CDC requires the detailed data from all state registries in the National Program of Cancer Registries, many states—including Wisconsin—have neither statutory enforcement nor penalties for noncompliance. Also, evidence indicates current misclassification is in the direction of misclassifying minority non-white races as white. To help standardize national cancer incidence data, CDC now requires at least 3 remedial data revisions for state cancer registries to help address widespread underreporting and misclassification of race and ethnicity: Hispanic algorithm, Asian algorithm, and the linkage of registry cases to Indian Health Service enrollment records.[20-22] Adding to the challenge of accurate measurement, the 2000 and 2010 US Census forms did not provide the Hmong category, but rather "Other Asian" with an option of writing in one's race.[23,24] There is reason to believe that Wisconsin Hmong were undercounted in the 2000 Census,[2] and there is no definitive count of the Hmong population.

The facility survey, resultant training webcast, and educational patient pamphlet were provided to address the systemic difficulties: lack of national or state regulations for race and ethnicity data collection, nonstandard-

ized facility collection of detailed race data, and reluctance of minority populations to self-identify. To bring measurable progress to troubling disparities in cancer detection and treatment, continuing promotion, education, and monitoring are necessary. Although hospitals, clinics, health centers, physician practices, health plans, and local, state, and federal agencies all can play key roles by incorporating race and ethnicity data into existing data collection practices, each faces opportunities and challenges in attempting to achieve this objective. The survey helped us to better understand these opportunities and challenges in the context of current facility practices. In the future, more detailed and systematic collection of race and ethnicity data across all facilities in Wisconsin should greatly benefit mandates for eliminating health disparities in public health programs.

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