Determining Practices for Reporting Hmong Cancer Cases in Wisconsin
Special Supplement: *Cancer Incidence Data for Hmong*

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INTRODUCTION

Wisconsin is home to the third largest Hmong population in the United States, following California and Minnesota, and the Hmong population in Wisconsin increased by 106% between 1990 and 2000 to 33,791. In Wisconsin, Hmong are the largest Asian group, comprising approximately 38% of the Asian population.[1] The 2000 Census data show that nationally 35% of Hmong report being linguistically isolated and 38% of Hmong live below the poverty level.[2] Over two thirds of the Hmong population in Wisconsin are under 24 years of age, and 57% are under 18 years of age.[3]

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. Since 1994, WCRS has participated in the National Program of Cancer Registries, funded by the Centers for Disease Control and Prevention (CDC). WCRS is required to collect from facilities and report to CDC detailed race categories including Hmong and other Asian groups. 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 in comparison to the minimum Office of Management and Budget (OMB) categories 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.[4-5]

METHODS

The WCRS, Wisconsin Comprehensive Cancer Control Program (WCCCP) and Wisconsin United Coalition of Mutual Assistance Associations (WUCMAA) combined resources to conduct a survey of facilities that serve Hmong cancer patients. The first design phase included identifying medical facilities that provide cancer diagnoses and/or treatment to Hmong patients for the sample selection, and drafting questions regarding health services to Hmong, and quantification of cancer incidence and facility reporting practices. The second implementation phase consisted of conducting the survey of the medical facilities identified in the sample, and performing 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 selected to reach facilities (hospitals, clinics and physician offices) serving Hmong patients newly diagnosed or treated for cancer. According to the 2000 Census, 94% of the Hmong population reside in 12 Wisconsin counties.[1] To capture all facilities WCRS asked WUCMAA to compile a list of facilities where Hmong receive health care within those 12 counties (Milwaukee, Marathon, Brown, Sheboygan, Outagamie, LaCrosse, Dane, Winnebago, Eau Claire, Manitowoc, Portage and Wood).

The questionnaire was designed to collect information about special services for Hmong patients, practices for the collection of race and ethnicity data and training needs to improve reporting of detailed race categories.

A mail survey was conducted of 75 medical facilities in 12 Wisconsin counties with the majority of Hmong residents. Two telephone follow-ups to non-respondents were conducted. For the purpose

Summary

Objectives – The Wisconsin Cancer Reporting System (WCRS) collects data on cancer diagnoses in the state of Wisconsin. 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, WCCP and WUCMAA conducted a mail survey of facilities in 12 Wisconsin counties where Hmong populations reside.

Findings – The survey found that less than 30% of facilities collected Hmong ethnicity 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 data requirements and a pamphlet for Hmong patients was developed to explain the importance of self identification.

Implications – 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.

Special Supplement – WCRS summarized distributions of preliminary cancer incidence data for Hmong compared with whites and found dramatic differences.

of this project, 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.

RESULTS

The final response rate was 72% (54 facilities), and 66% (36) of 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, 58% 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 seven facilities collected Hmong as a distinct category. Most facilities reported Hmong patients with cancer to WCRS only as Asian, not otherwise specified.

Data collection procedures. The 27 facilities reporting race and ethnicity data were asked how they collect this information. 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.

TABLE 1. Wisconsin Cancer Reporting System (WCRS) Required Race Categories	
White	Chamorran
African American	Guamanian, NOS*
American Indian, Aleutian, Alaskan Native or Eskimo (includes all indigenous populations of the Western hemisphere)	Polynesian, NOS*
Chinese	Tahitian
Japanese	Samoan
Filipino	Tongan
Hawaiian	Melanesian, NOS*
Korean	Fiji Islander
Asian Indian, Pakistani	New Guinean
Vietnamese	No further race documented
Laotian	Other Asian, including Asian, NOS* and Oriental, NOS*
Hmong	Pacific Islander, NOS*
Kampuchean	Other
Thai	Unknown
Minimum Office of Management and Budget (OMB) Race Categories	
White	
African American	
American Indian/Alaska Native	
Asian	
Native Hawaiian or Other Pacific Islander	
Unavailable	

*Not Otherwise Specified

DISCUSSION

Strengths and weaknesses. 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 to help understand prevalent data collection practices. The primary limitation of the survey was that it may have resulted in under counting the number of Hmong patients, due to the lack of standardized data collection. However, due to the unique needs of many Hmong patients, the majority of facilities provide special services and therefore have general knowledge of Hmong patient admissions and treatments.

Survey products. 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 (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 three products. First, thank you letters were mailed to responding facility administrators with an announcement of a training webcast. Second, a 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 *HRET Disparities Toolkit for Collecting Race, Ethnicity and Primary Language*

Information from Patients, as a comprehensive resource.[6] Finally, 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

National data collection practices. 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 five categories.[7] 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.[8-10] Previous studies have reported deficiencies in Medicare data to measure racial and ethnic disparities in health care.[11]

To help standardize national cancer incidence data, CDC now requires that state cancer registries make revisions to reported data to help address under-reporting and misclassification of race and ethnicity: Hispanic and Asian algorithms, and the linkage of registry cases to Indian Health Service registrations are both implemented to help identify minority populations.[12-14]

PROGRAM IMPLICATIONS

The facility survey, resultant webcast for facilities and the Hmong educational patient pamphlet attempted to address systemic difficulties: lack of national or state regulations for race and ethnicity data collection; non-standardized facility collection of data; and reluctance to self-identify from refugee populations. Although hospitals, clinics, health centers, physician practices, health plans, and local, state, and federal agencies can all 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 the 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.

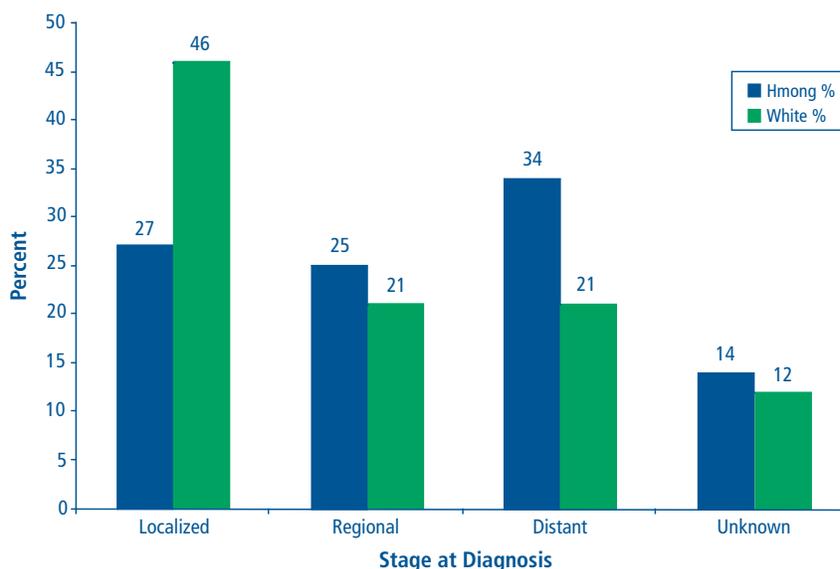## SPECIAL SUPPLEMENT: CANCER INCIDENCE DATA FOR HMONG

WCRS summarized the distributions of preliminary cancer incidence data for Hmong compared to whites in Wisconsin. Preliminary data do not represent the totality of Hmong cancer in Wisconsin, but show distributions of all Hmong cases collected in the state cancer registry as of January 2009 for diagnosis years 1995-2007. Cases were either directly reported as Hmong by facilities or classified as Hmong by the NAACCR Asian Pacific Islander Identification Algorithm, that re-classified "Asian, Not Otherwise Specified" to more detailed categories, based on Hmong surnames and places of birth.

Overall, Hmong cancers are diagnosed at later stages than white cancers (Figure 1). Between 1995 and 2007, only 27% of cancers diagnosed in Wisconsin's Hmong were detected at the early local stage, compared to 46% for whites. In Hmong patients, cancers also tend to be diagnosed in younger ages; 34% of Hmong cancer patients were under age 40 compared to 5% of the white cancer patients.

The Hmong community had low proportions of lung, breast and prostate cancers, but higher proportions of other cancers such as nasopharyngeal cancers, stomach and liver cancers (Figure 2). Similar to patterns reported from California and Minnesota cancer registries, these cancers are associated with chronic infections. Nasopharyngeal cancer is associated with several risk factors, including consumption of salted fish and infection with Epstein Barr virus. Liver cancer is associated with chronic hepatitis B virus and stomach cancer may be associated with bacterial H pylori and consumption of highly salted, smoked or pickled foods. Increased access to Western medicine, including hepatitis B immunization, antibiotics for bacterial infections and Pap screening, suggests that current rates of cancer could decrease within a generation.[15,16-17]

FIGURE 1. Stage at Cancer Diagnosis, Hmong and White, Wisconsin, 1995-2007

Source: Wisconsin Cancer Reporting System, Office of Health Informatics, Division of Public Health, Department of Health Services

FIGURE 2. Distribution of Major Cancer Sites for Hmong and Whites, Wisconsin, 1995-2007

Source: Wisconsin Cancer Reporting System, Office of Health Informatics, Division of Public Health, Department of Health Services

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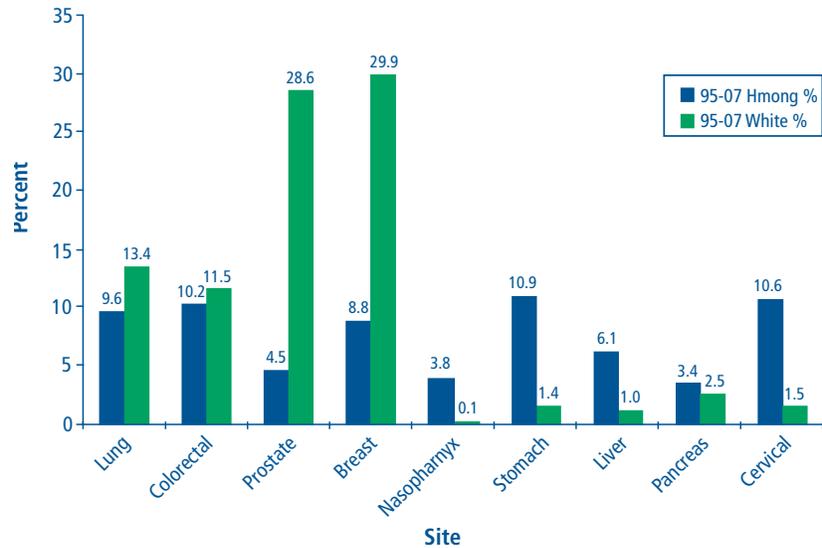
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