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Liberating Data:

Accessing Native Hawaiian and Other Pacific Islander Data from National Data Sets

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Summary

Using data from the National Center for Health Statistics, an assessment was performed on the quality of death reporting in accordance with standards, a working definition was developed, death counts and rates for several racial categories were analyzed, and data was modeled for use in data structures optimized for analysis and reporting with simple client tools. Most states were still not compliant with the 1997 Office of Management and Budget racial categories by 2005. Comparing the mortality experience of NHOPI to whites revealed many differences. Mortality was higher in NHOPI males and occurred at younger ages for both males and females. The place of death differed between NHOPI and whites, while place of injury (where applicable) was similar. Causes also varied after the top two causes of death.

Introduction

Native Hawaiians and Other Pacific Islanders (NHOPIs) experience severe health, social, economic, and service access inequities compared to the majority of Americans (Hirokawa et al., 2004; Ingram et al., 2003; Ponce et al., 2009). A variety of independent, nonprofit, culturally linked, community-based organizations work to address disparities faced by NHOPIs. Challenges facing these organizations include decentralized communities, funding shortages, and especially, limited data for monitoring the population's health and the impact of services. Available data on NHOPIs are neither current nor comprehensive. Many NHOPI data sets derive from research studies or focus on a limited geographic area such as the state of Hawai'i (home to approximately half of the NHOPI total population). The majority of federal publications, reports,

and manuscripts do not disaggregate NHOPI from Asians, despite Directive Fifteen issued by the Office of Management and Budget (OMB) in 1997, which states that the former statistical classification of Asian American and Pacific Islander was to be separated into two distinct categories of “Asian Americans” and “Native Hawaiians and Other Pacific Islanders” (Spoehr, 2006).

Limited population data results in the inability to advocate, influence policy, and secure resources for intervention. Challenging federal and state agencies to follow the OMB-revised directive is an effort in itself. However, even when NHOPI data are available, subanalyses are limited by sample size. Additionally, institutional barriers prevent data access, analysis, and reporting. Establishment of the Native Hawaiian Epidemiology Center (NH EpiCenter) and the Pacific Islander Epidemiology Center (PI EpiCenter) have improved the governance, credibility, and expertise needed to report on NHOPI. The NH EpiCenter is a subdivision of Papa Ola Lokahi in Honolulu, which is identified in federal law, Section 11705 of 42 U.S.C. 122, as the lead organization to consult with the Secretary of the U.S. Department of Health and Human Services in regard to Native Hawaiian health and wellness. The PI EpiCenter was established in 2010 within the TOA Institute, whose mission is to help improve the lives of Pacific Islander people through policy analysis, education, research, and programs. The NH EpiCenter and the PI EpiCenter work separately and in collaboration to improve the quality and availability of data on Native Hawaiians and Other Pacific Islanders across the United States.

Analysis

Traditional epidemiologic approaches enhanced through the application of business intelligence methods and technologies can significantly improve the accessibility, ease of analysis/reporting, and use of large health-relevant data sets. Using data from the National Center for Health Statistics, the NH Epicenter and the PI EpiCenter assessed the quality of death reporting in accordance with OMB standards, developed a working definition for NHOPI, analyzed death counts and rates for several racial categories, and modeled the data for use in data structures optimized for analysis and reporting (online analytic processing, or OLAP) with simple client tools (Microsoft Excel pivot tables and interactive Web-based dashboards). As a result, mortality data can be rapidly analyzed by

users with limited epidemiologic skills. Death counts and rates can be cross-tabulated, sorted, filtered, and charted along any combination of relevant dimensions, including racial category, age, sex, location, and cause of death. Customized visualizations also allow users to drill down into the data.

Analysis included national mortality data for the years 2003 through 2005. In 2003, only four states reported a full year of OMB-compliant mortality data with an additional three states reporting multiple race data on their death certificates (Hoyert et al., 2006). By 2005, seventeen states reported a full year of OMB-compliant mortality data and five additional states reported multiple race data (Hoyer et al., 2006; Kung, et al., 2008; Miniño, et al., 2007). It is unclear as to why the majority of states are incompliant with the OMB guidelines. No official justification has been publicly reported.

Working Definition of Native Hawaiians and Other Pacific Islanders

The five reported aggregations of “Hawaiian (includes Part-Hawaiian),” “Samoan,” “Guamanian,” “Other Asian or Pacific Islander,” and “combined other Asian or Pacific Islander” were used as a working definition (WD) of NHOPI for the purpose of analyzing mortality data. This definition would include certain smaller Asian groups not otherwise specified. The Asians in this definition excluded Asian Indian, Chinese, Filipino, Japanese, Korean, and Vietnamese, which have their own categories. The WD explicitly included Hawaiians, Samoans, and Guamanians.

The validity of the WD was assessed by comparing results to 2005 vital statistics reported by Hawaii (State of Hawaii, 2008). The WD showed a slightly higher percentage of deaths (21%) occurring among NHOPIs compared to that reported in the 2005 Hawaii statistics (17%). This is expected because the WD is slightly broader than a true NHOPI definition. The WD provides an interim method to analyze NHOPI mortality data until the 1997 standard is fully adopted.

Limitations

Limitations for the WD are the inclusion of “other Asians,” as described in the preceding text, and that the race category in death records does not differentiate between Native Hawaiians and part-Native Hawaiians. These limitations are sources of bias because the health of Native Hawaiians is markedly different from both

Asians and part-Native Hawaiians (Braun, Look, and Tsark, 1995). Another limitation is that racial assignment in mortality microdata is partly real data and partly imputed data. When full information was not available, the race variable was imputed based on a model derived from an analysis of the 2000 census (Parker et al., 2004).

The preliminary review of the 2003 through 2005 mortality data utilized simple counts and proportions to quantify the relative magnitude of NHOPI deaths by various descriptive categories. Comparisons were made between the NHOPI WD population and the non-Hispanic white U.S. population, traditionally the healthiest. Only the states of Hawai'i and California, which had the highest numbers of NHOPI deaths, were examined.

Findings

Between 2003 and 2005, 12,398 deaths of NHOPIs occurred in residents of Hawai'i and California: 6,440 or 0.9 percent of all deaths in California, and 5,958 or 21.5 percent of all deaths in Hawai'i. Males represented 55 percent of NHOPI deaths compared to 50 percent of white deaths. The age distribution of deaths in NHOPIs varied between states. Californian NHOPIs died at younger ages than NHOPI residents of Hawai'i. The difference in age distribution was more pronounced comparing NHOPIs to whites, with the former consistently dying at younger ages.

A higher proportion of NHOPI deaths, compared to the white population, occurred in hospital inpatient (46% vs. 36%) and outpatient (13% vs. 7%) settings. Similar proportions of deaths occurred in the home (24% vs. 29%). A lower proportion of NHOPI deaths occurred in long-term care settings (7% vs. 21%), which was consistent with the younger ages at death. When injuries were related to the deaths, the distribution of the place of injury was similar among NHOPI and whites. In both groups, the most frequently recorded place of injury (more than 40%) was at the home.

The five most common causes of death among NHOPI residents of California and Hawai'i, representing more than 80 percent of all deaths, were diseases of the circulatory system (36%), cancers (24%), injury and external causes (10%), diseases of the respiratory system (7%), and endocrine, nutritional, and metabolic diseases (5%). For whites, the top two most common causes of death, diseases of the circulatory system (38%) and cancers (23%), were similar. This is followed by diseases of the respiratory system (10%),

injury and external causes (7%), and diseases of the nervous system (5%).

Conclusion

Although racial reporting of deaths in accordance with the OMB standard improved, most states were still not compliant by 2005. Until compliance is achieved, it will remain difficult to analyze health data specific to NHOPIs.

Mortality analysis was accomplished by using a WD of NHOPI. Comparing the mortality experience of NHOPIs in Hawai'i and California to whites in those states revealed many differences. Mortality was higher in NHOPI males and occurred at younger ages for both males and females. The place of death differed between NHOPIs and whites, while the place of injury (where applicable) was similar. Causes also varied after the top two causes of death.

These results can be used as the starting point for NHOPI health policy decisions, such as prioritizing programs and services for the population or allocating resources. The WD of NHOPI is based on race categories from the bridged race re-coding algorithm. Validation of the working definition found that the NHOPI category included many smaller Asian groups and may not include all NHOPIs, due to underreporting or racial misclassification. Compliance with the OMB standard will address many of these concerns and will greatly assist in the assessment of NHOPI health issues.

Information technology has a role in improving accessibility to data for small populations who bear the largest health disparities in the United States. Data is essential for policy decisions, program planning, evaluation, and health surveillance. A partnership among federal agencies, community organizations, scientists, and information technologists can result in successful liberation of health data. The NH EpiCenter and the PI EpiCenter play a key role in assuring NHOPI data is available to all partners with a vested interest to serve this population. More work is needed to bring to light and address the alarming disparities experienced by this population.

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