

Introduction to Special Issue by Guest Editor, Merle Kataoka-Yahiro^a

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“Health Inequities of Asian-American, Native Hawaiian, and Pacific Islander Family Caregivers: Disaggregate vs. Aggregate Data & Findings”

The estimated number of Asian Americans (AA), Native Hawaiians (NH), and Pacific Islanders (PI) in the United States is 23.0 million (7.5%); AA (7.0%) and NH and PI (0.5%), respectively (U.S. Census Bureau, 2016a). AA are persons with ancestry from Asian countries and islands in the Pacific Rim Basin, and the largest AA populations are Chinese (4.8 million), Asian Indian (4.1 million), Filipino (3.9 million), Vietnamese (2.0 million), Korean (1.8 million), and Japanese (1.4 million) (U.S. Bureau of Census, 2016b). NH and PI are referred to as a person having origins in any of the original peoples of Hawai'i, Guam, Samoa, or other Pacific Islands (Hixson, Hepler, & Kim, 2012). NH and PIs include Native Hawaiians, Guamanians, Micronesians, Polynesians, and Samoans. The uninsured, lowest education, English as a second language, and foreign-born Asian Americans, Native Hawaiians, and Pacific Islanders (AANHPI) sub-groups in one or more of these categories should be recognized. These AANHPI include Pakistani, Cambodian, Bangladeshi, Micronesian, Samoan, Hmong, Taiwanese, Laotian, Indonesian, and Thai. Disaggregating AA, NH, and PI sub-groups is critical to avoid overlooking inequities and health disparity issues, which otherwise would be overlooked by analyzing and reporting aggregate data (National Council of Asian Pacific Islander Physicians, 2015).

Approximately 43.5 million Americans provided unpaid care to an adult or child in the last 12 months (National Alliance for Caregiving & AARP Public Policy Institute, 2015a) with family caregivers contributing an estimated \$522 billion of total expenditures for formal services provided by paid providers (Mehrotra, 2014). It is expected that between 2013 and 2030, there will be a 123% increase of older adults aged 65 years and older from racial/ethnic groups compared to only a 50% increase among the non-Hispanic, white group (U.S. Census Bureau, 2016c). In 2014, 42% of AA and PI were providing care for elders versus 22% of the general population (AARP Executive Summary Report, 2014). There is

a limited number of U.S. studies on palliative and end-of-life care with AANHPI family caregivers and, in particular, NH and PI family caregiver studies are sparse. Empirical work done in nursing homes with AANHPI family caregivers has either been aggregated, reported in small percentages, or there is no reporting of race/ethnicity. There is also a paucity of AANHPI studies in the area of mental health, and few studies disaggregate into subgroups. Sentell et al. (2013) explicates the need to disaggregate AANHPI groups to provide granular insights into mental health needs, access, and utilization.

There is limited research on AA, NH, and PI grandparents caring for their grandchildren in the United States. For example, NH and PIs grandparents caring and living with their grandchildren in comparison to other race/ethnic groups are the highest (9.9%); however, research is sparse among this group (U.S. Census Bureau, 2015d). Finally, Mayeno, Kaholokua, Liu, Asato, and Tseng (2011) resonate the need to disaggregate within both NH and PI and AA sub-groups in efforts to understand and address health issues, needs, and increase the visibility for health inequities that impact these individual communities. They further report that there is a growing body of evidence that health inequities exist among AA, NH, and PI children and youth and reporting disaggregate data and findings are needed to further expose health inequities, which would otherwise be concealed and not reported.

This special issue addresses the health inequities of AA, NH, and PI family caregivers by providing diverse and discrete elements of family caregiving based on six empirical studies on Asian,

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AA, NH, and PI family caregivers and their loved ones. The methodologies are varied ranging from population-based, feasibility, mixed method, and qualitative research approaches. The article “Hospice utilization of Medicare beneficiaries in Hawai’i compared to other states,” is a secondary data analysis study using the 2014 Medicare Hospice Utilization and Payment Public Use File to compare Hawai’i beneficiaries to other states. This national database aggregated all Asians into one category and NH and PI into “other race.” The Medicare data set included only a limited number of factors related to hospice use, and data was aggregated at the state level, which limited the ability to examine subgroup differences. The findings raise further questions about access and the need to better understand factors affecting hospice use among a diverse population.

The article “These classes have been my happy place: A feasibility study of a self-care program in Native Hawaiian custodial grandparents,” provides an attempt to move the science in health disparities research to more complex research designs. This includes testing self-care interventions and culturally competent innovations with NH custodial grandparents caring for their grandchildren.

The article “The applicability of the decisional conflict scale in nursing home placement decision among Chinese family caregivers: A mixed methods approach,” was conducted in Taiwan, but the findings can be cross-culturally useful to Taiwanese who live in the United States. This was a mixed methods study using a triangulation design of both qualitative and quantitative methods to address the same research questions thus providing a more complete and deeper description of nursing home placement decisional conflict among Chinese family caregivers.

The article “Sibling caregivers of individuals diagnosed with Schizophrenia,” was a descriptive phenomenological study conducted in Korea. Though the authors conducted the study in Korea, similar findings were found in the existing literature. The authors emphasize the need to compare and contrast differences in sibling caregivers’ experience among different cultural groups.

The article “Mālama nā makua i nā keiki me ka hānō: Native Hawaiian parents caring for their children with asthma,” is a descriptive qualitative approach using directed content analysis in the context of “uncertainty.” Culturally contextual influences resonated differences in approaching uncertainty among NH parents, which provided culturally rich findings to address in future studies.

The final article, “Beliefs in advance care planning among Chinese Americans: Similarities and differences between the younger and older generations,” is a qualitative study utilizing the Theory of Planned Behavior. The researchers identified barriers and facilitators based on beliefs of behavioral, nor-

mative, and control which provided culturally competent strategies to promote advance care planning for Chinese Americans.

The six articles in this special issue provided examples of how and why it is important to incorporate sub-group race/ethnicity in efforts to move the science forward. The articles point to the urgent need to conduct more research focusing on AA, NH, and PI. The inclusion of a greater representation of subgroups within larger groups is an important factor to include. Disaggregated or granular data is critical to obtain as aggregated data conceals disparities in these populations. It is not only important to study subgroups of AA and PIs to see trends that are sometimes hidden when using aggregate data and, at the same time, it is important to look at data as a ‘whole’ to evaluate similarities, differences, and patterns of disparities among all racial/ethnic groups. Researchers may be motivated after reading this special issue to pursue future large-scale prospective quantitative or mix method studies in efforts to make comparisons across and within groups. In conclusion, the articles in this special issue were selected based upon a grounded foundation in ethical conduct and culturally sound interventions and approaches.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest concerning the research, authorship, or publication of this article.

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