



# The Landmark Series: The Breast Cancer Burden of the Asian American Population and the Need for Disaggregated Data

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**ABSTRACT** The Asian American Pacific Islander (AAPI) population is a heterogeneous group of people from geographically and ethnically distinct regions of the world. Traditionally, these patients have been reported as one large aggregate in the breast cancer literature under the race category of “Asian.” A detailed examination of this group shows compelling evidence that breast cancer manifests differently among Asian ethnic subgroups, resulting in overlooked health disparities when these races are grouped together. The AAPI community is the fastest growing ethnic group in the United States, and their incidence of breast cancer is increasing at rates greater than among their non-Asian counterparts. When these patients are disaggregated by race, they show wide variations in breast cancer screening, presentation, treatment, and outcomes. This population often faces additional unique challenges in the health care system due to cultural, social, health literacy, and language barriers, which can contribute to further disparity. Our landmark series aims to showcase the breadth of the breast cancer burden in the AAPI population and highlight the need for disaggregated ethnic data.

## DEFINITIONS

Asian Americans (AsAm), the fastest growing population in the United States (U.S.), increasing by 81% from 2000 to 2019, are projected to pass 35 million by 2040.<sup>1</sup> Six origin groups comprise approximately 85% of the AsAm population. In descending order, they are the Chinese, Indian, Filipino, Vietnamese, Korean, and Japanese populations.<sup>2</sup> Frequently, AsAms are considered as one entity when racial/ethnic data in the breast cancer (BC) literature are reported. It has been common for Native Hawaiians or Other Pacific Islanders (NHOPI), defined as persons “having origins in any of the original people of Hawaii, Guam, Samoa, or other Pacific Islands,” to be grouped with AsAms creating an Asian American Pacific Islander (AAPI) category.<sup>1</sup> This encompassing definition may include persons from more than 50 countries and comprise more than 100 languages, thereby overlooking differences between races and cultures.<sup>3</sup>

## BREAST CANCER INCIDENCE

Historically, AAPI women have a relatively low incidence of BC when reported in aggregate compared with other racial/ethnic groups.<sup>4–7</sup> A recent update from the American Cancer Society (ACS) found that AAPI women had the second lowest incidence of BC, at 111.3 per 100,000 between 2015 and 2019. By comparison, non-Hispanic white (NHW) women had the highest rate, at 133.7 per 100,000, and Hispanic women had the lowest rate, at 99.2 per 100,000.<sup>8</sup> However, discrepancy in annual incidence rates between the different Asian ethnic groups has been consistently reported.<sup>9–12</sup> One such study found

the BC incidence per 100,000 ranged from 135.9 for Hawaiian women to 35 for Cambodian women, with the former just one point below the rates for NHW women.<sup>9</sup>

Additional disparities emerge when temporal trends of BC incidence are examined. Between 2015 and 2019, BC among AAPI women increased by 2.1% per year, which was the highest of any reported ethnic group, including NHW women, during this time.<sup>8</sup> The annual increase in incidence rates further varies between Asian ethnic subgroups. A 2017 study by Gomez et al.<sup>13</sup> that examined incidence trends between 1988 and 2013 found the largest increase in the Korean population, with an annual percentage change (APC) of 4.7% (95% confidence interval [CI], 3.8–5.7) between 1988 and 2006 compared with all the other Asian ethnic subgroups evaluated.

Southeast Asians, defined in this article as Cambodian, Laotian, Hmong, and Thai populations, also were found to have a large APC between 1988 and 2013, at 2.5% (95% CI, 0.8–4.2). This is in contrast to an APC of 1.1% among Chinese (95% CI, 0.7–1.5) and Filipinas (95% CI, 0.7–1.4), with no significant increase observed for Japanese women during this period. Another study by Tuan et al.<sup>14</sup> similarly found an increase in BC incidence rate between 1990 and 2014 among Chinese, South Asian (Asian Indians and Pakistani), Korean, Vietnamese, and Filipino women, with no such trends seen in NHW or Japanese women.

## BREAST CANCER SCREENING

Women in the AAPI population have among the lowest prevalence of up-to-date BC screening compared with other ethnic groups.<sup>4,15,16</sup> A 2018 report from the ACS found that only 55% of AAPI women older than 45 years were up to date on their mammography screening compared with 64% of NHW women.<sup>15</sup>

Studies have demonstrated that reporting statistics on AAPI women in aggregate can either completely mask or downplay screening disparities.<sup>17,18</sup> Chawla et al.<sup>19</sup> found that although mammography rates increased over time when AsAms were evaluated as one group, after disaggregation, this was observed only among Chinese, Japanese, and Vietnamese women during the 2001–2009 study period. In addition, they found a wide range of screening rates between these groups, with 93.8% of Japanese versus 63.3% of Korean women reporting recent mammograms. These differences persisted after the study controlled for other variables, including education and income level.

Other data have shown that a higher education level among certain Asian ethnic groups may be negatively associated with mammogram screening, indicating that the usual relationships between sociodemographic factors and

health care maintenance cannot be presumed in this population.<sup>20</sup> Similar to previous data, a 2019 study by Shon et al. found that immigrant Korean American women had the lowest rate of mammogram use compared with immigrant Chinese and Vietnamese women.<sup>20,21</sup> Multivariate analysis found that the number of recent doctor visits was associated with mammography use only among Chinese women.<sup>22</sup> These data suggest that access to care is not the only factor affecting adherence to BC screening in this population. Several studies have demonstrated that disparities in cancer screening between AAPI and NHW women are stable or even more pronounced when the analysis adjusts for socioeconomic status and health care access, which is unique to AAPI women in the United States.<sup>23–25</sup>

Several studies have sought to examine the complexity of cancer screening disparities in AAPIs. Kandula et al.<sup>26</sup> found that 33% of Vietnamese Americans reported income below the poverty line, and 30.7% completed less than a high school level education, demonstrating higher poverty rates and lower levels of education compared with other Asian ethnic groups. Intriguingly, Vietnamese women reported the second highest rate of screening mammography in the past 2 years, surpassed only by NHW women. Once the study adjusted for nativity, years of residence in the United States, and language used at home, Vietnamese women were significantly more likely to have undergone mammography screening in the past 2 years than NHW women. Similarly, a 2014 study by Thompson et al.<sup>17</sup> found that mammography completion rates were highest among Vietnamese and Japanese women compared with Asian Indian, Korean, Filipina, and Native Hawaiian and Pacific Islander (NHPI) women. When patient-provider level data were examined, Vietnamese patients were found to have the second highest percentage of non-English speakers ( $p < 0.001$ ) but the highest rate of language concordance with their physician among patients who did not speak English ( $p < 0.0001$ ). These provider level relationships likely play a crucial role in BC screening adherence among Asian subgroups.

## DIFFERENCES IN PRESENTATION AND DISEASE STAGE

According to recent data, AAPI women have the highest rate of BC diagnoses among women ages 40 to 49 compared with all other ethnic groups, including NHW women.<sup>8</sup> The diagnosis of BC in AsAm patients between the ages of 20 and 49 has been increasing in recent years compared with other races/ethnicities.<sup>27,28</sup> Once the races/ethnicities are divided into subgroups, significant differences are observed. A study by Chuang et al.<sup>29</sup> found that

the mean age at diagnosis among Korean women was 39.2 years. This was significantly younger than among Chinese, Filipino, and Japanese women, whose mean ages at diagnosis were respectively 51, 51, and 47 years ( $p < 0.0001$ ). Another study by Tuan et al.<sup>14</sup> found that 41% of Korean and Vietnamese patients were younger than 50 years at diagnosis, compared to 20% of Japanese patients and 19% of NHW women.

Although the median diagnosis of BC in the United States occurs in the sixth decade of life, the aforementioned data suggest that earlier BC cancer screening may be warranted among specific AAPI subgroups for earlier detection.<sup>30</sup> This is of particular importance because Asian women have been shown to have dense breast tissue compared with other ethnic groups, including NHW women.<sup>31–33</sup> Given the increased risk of BC among women with dense breasts, screening using additional imaging methods, such as ultrasound, also may be considered for this population.<sup>34–36</sup>

In addition to differences in age at diagnosis, research has shown disparities in disease stage at presentation for this population. Gomez et al.<sup>13</sup> found that in aggregate, AsAm women versus NHW women had consistently lower incidence rates for localized (60.6 vs. 91.4 per 100,000), regional (27.4 vs. 39.4 per 100,000), and distant (4.1 vs. 6.9 per 100,000) BC between 2009 and 2013. In this same study, the AsAm population was examined as seven distinct ethnic subgroups. For localized BC, the highest incidence rate was seen among Japanese women, at 78.7 per 100,000, and the lowest among the Southeast Asian group (Cambodian, Laotian, Hmong, and Thai women), at 32.5 per 100,000. For regional BC, the incidence rates among Filipina women approached those for NHW women, at 34.7 versus 39.4 per 100,000, respectively. Korean and Southeast Asian patients had the lowest incidences of regional disease, at 19.8 and 16.5 per 100,000, respectively. A similar trend was observed in cases of distant disease, with an incidence of 5.7 for Filipina and 6.9 for NHW women per 100,000. Southeast Asian and Chinese patients had the lowest rates of distant BC, at 2.8 and 3 per 100,000, respectively.

Other studies have found similar discrepancies in disease stage distribution. A 2015 study by Iqbal et al.<sup>37</sup> found that Japanese women were more likely to have a diagnosis of stage I BC (56.1% vs. 50.8%;  $p < 0.001$ ), whereas Asian Indian and Pakistani women were less likely to have a diagnosis of stage I BC compared with NHW women (40.4% vs. 50.8%;  $p < 0.001$ ).

## TUMOR BIOLOGY

Distinct patterns of BC molecular subtypes also vary among AAPI women. Acheampong et al.<sup>38</sup> found that between 2010 and 2016, the rate of luminal A breast cancers increased by 2.5% (95% CI, 0.6–4.5%) for AAPI women between the ages of 40 and 54 years. By comparison, NHW and black/African American (AA) women experienced annual increases in luminal A BC rates until 2014 and 2012, respectively, followed by stable or declining rates for this subtype.

When AAPI women are disaggregated, more differences are evident. In a 2014 study of 346 Asian women living in New York, Chinese and Japanese women had a significantly higher proportion of luminal A ( $p = 0.004$ ) BC and a lower proportion of human epidermal growth factor receptor 2 (HER2)/neu-like cancers ( $p = 0.001$ ) than Korean and Filipina women.<sup>29</sup> Similarly, Telli et al.<sup>39</sup> found that among Asian ethnic groups, Japanese women had the most favorable phenotypic distribution, with a relatively high frequency of hormone receptor-positive (HR+) disease and a lower frequency of HER2+ and triple-negative disease. In contrast to the 19% of Japanese (95% CI, 17–22%) and NHW (95% CI, 18–19%) women with HER2+ BC, Korean, Filipina, and Vietnamese women demonstrated greater frequencies of this molecular subtype, with respective rates of 36% (95% CI, 32–40%), 31% (95% CI, 29–32%), and 29% (95% CI, 26–33%). Several other studies also have demonstrated a greater frequency of HER2+ BC among certain Asian ethnic groups than among NHW, AA, and Hispanic women.<sup>37,40</sup> Furthermore, although triple-negative BC (TNBC) rates are relatively low among AAPIs as a combined group, patients with Indian continent ethnicity have been shown to have a higher frequency of TNBC than NHW women (odds ratio [OR], 1.25; 95% CI, 1.01–1.53).<sup>37,41</sup>

## DIFFERENCES IN TREATMENT

Once BC is diagnosed, disparities persist for AAPI women. In a large study using the National Cancer Database (NCDB) to analyze more than 299,827 patients from 2010 to 2011, AAPI women ( $n = 9508$ ) were found to have the lowest rates of breast-conserving surgery (BCS) among all the ethnic groups. These findings persisted after adjustment for demographic, geographic, and tumor characteristics (OR, 0.84 (95% CI, 0.80–0.88;  $p < 0.001$ )).<sup>42</sup> A 2006 study by Gelber et al.<sup>43</sup> examined treatment differences between Asian ethnic subgroups in Hawaii. Their results showed a statistically significant difference, with Japanese and Filipina patients undergoing less BCS than their white counterparts even after adjustment for patient

and breast tumor variables. Additionally, Filipina patients more often omitted radiation. Longer surgery-to-radiation intervals also have been reported for NHPI and South Asian (Indian and Pakistani) women than for NHW women.<sup>44</sup>

It has been postulated that AAPI persons may opt to undergo mastectomy rather than lumpectomy due to differences in breast size because BCS may lead to unacceptable cosmetic outcomes for women with smaller breasts.<sup>42</sup> This distinction also is perhaps due to differing cultural preferences or beliefs, which have been difficult to elucidate in studies. The social environment, including immigration, neighborhood, and hospital quality/proximity, also have been implicated as contributing factors to this mastectomy and radiation omission disparity.<sup>45</sup> Even after mastectomy, evidence indicates that AAPI patients are less likely to undergo any form of ipsilateral breast reconstruction.<sup>46–49</sup> Data from studies investigating the reasons for this using disaggregated groups are sparse.<sup>46</sup> More recent data have shown that BCS and radiation therapy provide some survival benefit over mastectomy for early-stage BC, putting this population at risk for disparate cancer care based on current trends in surgical management.<sup>50,51</sup> These findings provide a greater impetus for further investigation into the surgical treatment decisions among the disaggregated AAPI population.

## SURVIVAL

Racial disparities exist in the U.S. BC population, with the lowest 5-year relative survival rate for the AA population, followed by the American Indian/Alaska Native, Hispanic, and NHW population, and lastly the AAPI population.<sup>30</sup> Breast cancer mortality has been declining in recent years (2016–2020), by 1.0% to 1.4% in the AA, Hispanic, and NHW populations, while decreasing by 0.6% in the AAPI population.<sup>8</sup>

Mortality from BC has traditionally been low in absolute terms among the AAPIs when reported in aggregate. However, examination of subgroups shows a range of outcomes, dispelling our previous notion that AAPIs have better survival than their non-Asian counterparts.<sup>8,30,44</sup> A study by Medina et al.<sup>52</sup> used data from the California Department of Public Health to examine cancer mortality in Asian ethnic subgroups compared with the NHW population. They found that BC mortality varied between subgroups, ranging from 8.6 per 100,000 (95% CI, 7.5–10.0) among Vietnamese women to 28.8 per 100,000 (95% CI, 24.0–34.2) among NHOPI women, the latter of whom had higher BC mortality than NHW women.<sup>52</sup> This mortality gap also is evident when Native Hawaiians are compared with NHW women, as repeatedly demonstrated

using Hawaii's SEER registry as well as the NCDB.<sup>11,44,53</sup> Interestingly, the NCDB also showed that a South Asian (Asian Indian and Pakistani) cohort of women had improved overall survival and similar time to treatment compared with NHW women despite having higher rates of TNBC, a known prognosticator of poor survival.<sup>44,54</sup> These variations imply the existence of multiple unaccounted factors such as possible underreporting of survival statistics, barriers to access, social determinants of health, and cultural preferences that may contribute to these differences. Breast cancer survivorship research also is limited for the AAPI population because studies have shown underrepresentation in survivorship and longitudinal studies in this population.<sup>55</sup> Unfortunately, AAPI underrepresentation in cancer research studies is not a new concept because AAPI National Institutes of Health (NIH)-focused research represents only 0.17% of the research during 26 years.<sup>3</sup>

It is important to note that AAPI survival rates from the ACS may be overinflated due to unaccounted follow-up evaluation and underreporting in cancer registry data.<sup>8,56</sup> Pinheiro et al.<sup>56</sup> examined the SEER database cancer survival statistics and found that the “presumed alive” statistical method overestimated survival for Hispanics and Asians because they were more likely to have incomplete follow-up evaluation than non-Asians. They also found that “death ascertainment was not equal across racial-ethnic groups,” underscoring a likely masked disparity in cancer survival statistics and urging caution in interpretation of these data.

## SOCIAL DETERMINANTS OF HEALTH AND CULTURAL CONTEXT

Health care providers must consider the influence of both socioeconomic (income, health care access, insurance coverage) and cultural (health beliefs, modesty) factors when addressing BC care. In aggregate, AsAms have above average median household incomes and lower poverty rates compared with the overall U.S. population.<sup>2,57</sup> Once AsAms are disaggregated however, notable heterogeneity is observed among Asian American subgroups.

The mean income ranges from \$44,000 for Burmese Americans to \$119,000 for Indian Americans.<sup>57</sup> Similarly, education levels are high among Asian Americans in aggregate, with 51% older than 25 years holding a bachelor's degree (versus 30% of Americans). However, these data vary dramatically between subgroups, from 9% for Bhutanese to 72% for Indian Americans.<sup>57</sup> These socioeconomic differences play an important role in access to health care and insurance coverage.<sup>58</sup>

Discrepancies also are seen when studies examine rates of English proficiency, with certain ethnic groups having higher rates of English acquisition.<sup>2,19</sup> This is an important consideration because data have shown lower screening rates and poorer health outcomes when patient-physician language discordance exists.<sup>17,23,59</sup>

Although traditional socioeconomic factors are important to consider, cultural factors play an important role in how individuals perceive medical information and view their medical provider. A study by Jun<sup>23</sup> found significant variation between Asian ethnic subgroups when assessing their odds of seeking cancer information, with Korean patients being the most likely (OR, 3.72; 95% CI, 3.71–3.73) and Japanese being the least likely (OR, 0.72; 95% CI, 0.72–0.72) to do so. Unsurprisingly, Korean patients also were the most likely (OR, 2.81; 95% CI, 2.80–2.82) and Japanese patients least likely (OR, 0.58; 95% CI, 0.58–0.58) to report receiving BC screening information from their providers. The data are conflicting, but a 2015 study by Oh et al.<sup>60</sup> found that Korean American women obtain much of their cancer information from Korean media and the internet, often citing inaccessibility and cost as impediments for discussing these issues with their American doctors. This finding may at least partially explain why cancer information-seeking does not always translate into higher rates of screening in this population.

Research has demonstrated the importance of a culturally sensitive approach and consideration of social determinants of health when patients of Asian descent are treated to better understand disparities and provide optimal care.<sup>61–64</sup> Thus, having an understanding of specific cultural attitudes toward health care can be used to design targeted educational materials and facilitate community-specific outreach initiatives.<sup>65,66</sup>

## IMPLICATIONS AND FUTURE DIRECTIONS

A broad range of data are available for the heterogeneous AAPI BC population in nearly every aspect of BC care. It is clear that this rapidly growing ethnic population can no longer be regarded as one distinct grouping of persons given the current range of findings among the ethnic subgroups. The AAPI population has been perceived to have a low incidence of BC and high survival rates compared with other races, but studies show that the spectrum of incidence, treatment, and prognosis actually is disparate. This cancer disparity trend is not specific to the disaggregated Asian subgroups in BC care, but also is present in gastric, prostate, liver, cervical, and lung cancer care.<sup>56,67</sup> This misconception feeds into the “model minority myth,” wherein all AAPI persons are seen as socially and economically affluent, and thus as having

better access to health care and treatment. The danger associated with this stereotype is its potential to fuel and further under-recognition of BC disparities.<sup>67,68</sup> Additionally, anti-Asian hate and discrimination increased during the COVID-19 pandemic, likely exacerbating the Asian-American community’s health disparities.<sup>67</sup> Further research is warranted to prioritize accurate classification of ethnic subgroups within the AAPI population in order to address their disparities in a culturally sensitive context.

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