Data Issues in Studying Small Populations
Challenges, Opportunities, and a Case Study

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% limited English proficient range from 52% among Burmese and Vietnamese to 18% among Japanese.

Tremendous heterogeneity & hidden socioeconomic disparities

From “A Community of Contrasts. Asian Americans, Native Hawaiians and Pacific Islanders in California.”
Asian American Center for Advancing Justice. 2013.
The number of poor AAs increased 50% between 2007 and 2011.
Case Study:
Breast cancer in Asian American women
## Breast cancer incidence rates*, California, 1988-2004

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Rate (95% CI)</th>
</tr>
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<tbody>
<tr>
<td>N-H White</td>
<td>146.1 (145.5-146.7)</td>
</tr>
<tr>
<td>Asian **</td>
<td>82.7 (81.6-83.8)</td>
</tr>
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* Rates, per 100,000, adjusted to the US 2000 standard  
** Asian = Chinese + Japanese + Filipina + Korean + Vietnamese + South Asian
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<td>Asian **</td>
<td>82.7 (81.6-83.8)</td>
</tr>
<tr>
<td>Chinese</td>
<td>73.5 (71.6-75.4)</td>
</tr>
<tr>
<td>Japanese</td>
<td>102.5 (99.3-105.9)</td>
</tr>
<tr>
<td>Filipina</td>
<td>100.4 (98.1-102.8)</td>
</tr>
<tr>
<td>Korean</td>
<td>46.3 (43.8-49.0)</td>
</tr>
<tr>
<td>South Asian</td>
<td>77.0 (72.1-82.1)</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>59.9 (56.7-63.1)</td>
</tr>
</tbody>
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* Rates, per 100,000, adjusted to the US 2000 standard

** Asian = Chinese + Japanese + Filipina + Korean + Vietnamese + South Asian

From: Gomez et al. Am J Public Health 2010
Breast cancer incidence rates*, California, 1988-2004

<table>
<thead>
<tr>
<th>Race/ethnicity</th>
<th>Combined (US+foreign born)</th>
<th>US-born</th>
<th>Foreign-born</th>
<th>Rate ratio (95% CI) (US/foreign)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N-H White</td>
<td>146.1</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Asian***</td>
<td>82.7</td>
<td>120.6</td>
<td>76.3</td>
<td>1.6 (1.5-1.6)</td>
</tr>
<tr>
<td>Chinese</td>
<td>73.5</td>
<td>122.1</td>
<td>66.3</td>
<td>1.8 (1.7-2.0)</td>
</tr>
<tr>
<td>Japanese</td>
<td>102.5</td>
<td>106.1</td>
<td>103.1</td>
<td>1.0 (1.0-1.1)</td>
</tr>
<tr>
<td>Filipina</td>
<td>100.4</td>
<td>129.5</td>
<td>98.2</td>
<td>1.3 (1.2-1.4)</td>
</tr>
</tbody>
</table>

* Rates, per 100,000, adjusted to the US 2000 standard
** Asian = Chinese + Japanese + Filipina + Korean + Vietnamese + South Asian
From: Gomez et al. Am J Public Health 2010

Breast cancer in Asian Americans in California, 1988–2013: increasing incidence trends and recent data on breast cancer subtypes

Scarlett Lin Gomez, Julie Von Behren, Meg McKinley, Christina A. Clarke, SalmaShariff-Marco, Iona Cheng, Peggy Reynolds, et al.

Breast Cancer Research and Treatment
ISSN 0167-6806

Breast Cancer Res Treat
DOI 10.1007/s10549-017-4229-1

Springer
Incidence rates over time of invasive breast cancer among Asian American ethnic groups and non-Hispanic Whites, California, 1988-2013

Gomez et al. BCRT 2017
Higher incidence of breast cancer in young Asian American women?

- 3 studies showed higher incidence rates in young Asian American women (~age <50) relative to non-Hispanic White women*
  - More pronounced in US-born Asian American women (Gomez et al. AJPH 2010)
- Recent international analysis shows trend may be due to cohort (Sung et al. JNCI 2015) or period (Wang et al. Int J Env Res Pub Health 2015) effects of increasing breast cancer rates among Asian populations worldwide, not age-specific effect
  - due to changing risk factors

Breast cancer incidence rates* by age, California, 1988-2004

<table>
<thead>
<tr>
<th>Race/ethnicity</th>
<th>&lt;44 yrs</th>
<th>45-54 yrs</th>
<th>≥55 yrs</th>
</tr>
</thead>
<tbody>
<tr>
<td>N-H White</td>
<td>27.1</td>
<td>240.7</td>
<td>449.2</td>
</tr>
<tr>
<td>US-born</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>39.8</td>
<td>276.9</td>
<td>275.6</td>
</tr>
<tr>
<td>Japanese</td>
<td>23.9</td>
<td>205.8</td>
<td>294.2</td>
</tr>
<tr>
<td>Filipina</td>
<td>43.1</td>
<td>334.3</td>
<td>263.8</td>
</tr>
<tr>
<td>Foreign-born</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>18.9</td>
<td>161.2</td>
<td>167.9</td>
</tr>
<tr>
<td>Japanese</td>
<td>24.8</td>
<td>196.0</td>
<td>283.6</td>
</tr>
<tr>
<td>Filipina</td>
<td>25.9</td>
<td>215.1</td>
<td>245.0</td>
</tr>
</tbody>
</table>

Rates, per 100,000, adjusted to the US 2000 standard
From: Gomez et al. Am J Public Health 2010
Higher incidence of breast cancer in young Asian American women (cont)?

*Gomez et al. BCRT 2017*
Disparities within ethnic groups

• More HER2Neu+ tumors?
  • Higher proportional prevalence of HER2Neu+ tumors (Telli et al. BCRT 2010)
  • Compared to non-Hispanic white women, Filipinas and older Vietnamese women had higher incidence rates of some HER2+ subtypes (Gomez et al., BCRT 2017)

• Increasing rates of distant stage disease among Filipinas (2.1% per year) (Gomez et al., BCRT 2017)
Conclusions

Disaggregated data by ethnicity, nativity, and age shows that:

→ Vastly differing patterns in incidence, mortality, and incidence and mortality trends across sub-populations.

→ Burden of breast cancer is not low among Asians!
“I was diagnosed with breast cancer 5 years ago. When the doctor told me that I had breast cancer I was in shock because I thought this is a white women/old people disease. Later, I was even more surprised to find out that many of the Asian women I knew had breast cancer, but nobody talked about it.”

(personal communication from a breast cancer survivor in NYC, 2010)
“When Margaret Abe-Koga was diagnosed with breast cancer in 2015, she was as surprised as anyone. After all, no one ever had breast cancer in her Japanese-American family, she doesn’t have the genetic marker, and she’d been led to believe that Asian-Americans weren’t – as Abe-Koga put it – “a high-propensity group” for the disease.

[The results from the study] stunned Abe-Koga, 46, … For generations, she said, Asian-Americans have been under the wrong impression that breast cancer “is not prevalent in our community” so “it’s not something that people think about.” ”

Tracy Seipel (Mercury News), Chicago Tribune, April 27, 2017
Cancer research in Asian Americans, Native Hawaiians, Pacific Islanders: Challenges & opportunities

Scarlett Lin Gomez, Anne-Michelle Noone, Daphne Y. Lichtensztajn, Steve Scoppa, James T. Gibson, Lihua Liu, Cyllene Morris, Sandy Kwong, Kari Fish, Lynne R. Wilkens, Marc T. Goodman, Dennis Deapen, Barry A. Miller

Manuscript received September 19, 2012; revised April 17, 2013; accepted April 18, 2013.

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Journal of the National Cancer Institute 2013
Cancer incidence trends by Asian American group, females, SEER 13, 1990-2008

Asian Indian & Pakistani

Breast (3.0*)

CRC (0.7*)

CRC† (1.6)

Lung† (1.2)

Uterus† (3.0*)

Stomach (−1.5*)

Chinese

Breast (1.2*)

Lung (−0.3)

Uterus (3.0*)

Filipina

Breast (1.3*)

CRC (1.0)

Thyroid (2.5*)

Japanese

Breast

CRC

Lung

Uterus (1.1*)

Stomach (−3.7*)
Cancer incidence trends by Asian American group, females, SEER 13, 1990-2008

Kampuchean

Korean

Laotian

Vietnamese

Age-adjusted incidence rate

Year

Breast (4.7*)

CRC (2.8*)

Lung (2.1*)

Stomach (0.3)

Breast (3.2*)

CRC (5.9*)

Lung (−0.8)

Liver (2.2)

Breast (1.2*)

CRC (1.1)

Lung (−0.9)

Liver (−7.3*)

Liver (−8.5*)

Cervix (−2.3)

Cervix (−0.2)

Liver (5.3)

Liver (−0.9)

Liver (20.3)

Cervix (−3.0)

Cervix (4.4)
• NCI portfolio review showed virtually no studies of cancer etiology focused on this population (Nguyen, Srinivasan, et al., CEBP 2014)
• Lack of representation in current NCI-funded Cancer Epidemiology Cohorts and other cohorts
  • Multiethnic Cohort (MEC) includes only Japanese Americans and Native Hawaiians (with sufficient numbers for ethnic-specific analyses)
  • Many cohorts in Asia, but none in the U.S.
Challenges

- Small numbers in many ethnic groups
  - How granular can we go?
- Ethnicity information (often) not captured in health surveys, registries, hospital data
- Lack of standardization in data collection
- Other relevant data not captured, e.g., nativity, immigration factors, language, SES
Size + heterogeneity = Opportunities for accelerating cancer discoveries

- Heterogeneity (risk factors, disease risk) within population provides potential opportunities for identifying novel risk factors
- Research into what determines favorable prognosis despite poor prognosis tumor biology
- Potential of migrant studies, longitudinal studies, intergenerational studies
“My 1991 diagnosis was only obtained after I sought a second opinion, following a surgical oncologist's "refusal" to biopsy a very prominent and palpable breast lump. The reasons he refused to perform the biopsy was because I was "too young to have breast cancer", had "no family history of cancer", and "besides, Asian women don't get breast cancer". I believe the latter statement was made because of his familiarity with NCI SEER race/ethnic cancer data for "API" populations, which -- as you are well aware -- were then and continue to be reported in the aggregate. I have that surgeon to thank for turning me into a fierce cancer advocate” (personal communication from Susan Shinagawa, cancer survivor)
Thank you!

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