Partnership for Cancer Health Disparities Research

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Associate Director, Cancer Health Disparities & Community Engagement
UCI Chao Family Comprehensive Cancer Center

ICTS CHRE
July 26, 2019
By the end of this lecture, you will:

1. Increase your understanding of cancer health disparities and community-based participatory research (CBPR)
2. Describe strategies that promote cancer health behaviors in community-based settings
3. Identify five strategies to cultural targeting/tailoring of health interventions
4. Explore the strengths and limitations of CBPR
Cancer health disparities are adverse differences between certain populations groups, such as incidence (new cases), prevalence (existing cases), morbidity (cancer-related health complications), mortality (deaths), survivorship and quality of life after cancer treatment, burden of cancer or related health conditions, screening rates, and stage at diagnosis.

These population groups may be characterized by race, ethnicity, disability, gender and sexual identity, geographic location, income, education, and other characteristics.

National Cancer Institute, Center for Cancer Health Disparities, https://www.cancer.gov/about-nci/organization/crchd/about-health-disparities/definitions
**WHAT ARE CANCER HEALTH DISPARITIES?**

Cancer health disparities are defined by the National Cancer Institute as adverse differences in cancer measures such as number of new cases, number of deaths, cancer-related health complications, survivorship and quality of life after cancer treatment, burden of cancer or related health conditions, screening rates, and stage at diagnosis that exist among certain segments of the population (1), including:

<table>
<thead>
<tr>
<th>Segment</th>
</tr>
</thead>
<tbody>
<tr>
<td>racial and ethnic minority groups;</td>
</tr>
<tr>
<td>individuals who lack or have limited health insurance coverage;</td>
</tr>
<tr>
<td>residents in certain geographic locations, including rural areas;</td>
</tr>
<tr>
<td>members of the lesbian, gay, bisexual, and transgender community;</td>
</tr>
<tr>
<td>individuals with disabilities;</td>
</tr>
<tr>
<td>individuals of different ancestry;</td>
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<tr>
<td>individuals of low socioeconomic status;</td>
</tr>
<tr>
<td>immigrants;</td>
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<tr>
<td>refugees or asylum seekers;</td>
</tr>
<tr>
<td>adolescents and young adults; and</td>
</tr>
<tr>
<td>the elderly.</td>
</tr>
</tbody>
</table>

Adapted from (1)

American Association for Cancer Research (AACR) Cancer Progress Report 2018
Figure 2. Trends in Age-adjusted Cancer Death Rates* by Site, Females, US, 1930-2015

*Age adjusted to the 2000 US standard population. †Uterus refers to uterine cervix and uterine corpus combined. ‡The mortality rate for liver cancer is increasing.

Note: Due to changes in ICD coding, numerator information has changed over time. Rates for cancers of the liver, lung and bronchus, colon and rectum, and uterus are affected by these coding changes.


©2018, American Cancer Society, Inc., Surveillance Research

Figure 5b. Trends in Female Breast Cancer Death Rates* by Race and Ethnicity, US, 1975-2010

*Rates are age adjusted to the 2000 US standard population.

Source: National Center for Health Statistics, Centers for Disease Control and Prevention, as provided by the Surveillance, Epidemiology, and End Results Program, National Cancer Institute. Rates for American Indians/Alaska Natives are based on data from the Contract Health Service Delivery Area (CHSDA) counties. For Hispanics, mortality rates do not include data from Connecticut, Maine, Maryland, Minnesota, New Hampshire, New York, North Dakota, Oklahoma, Vermont, and the District of Columbia.

American Cancer Society, Surveillance and Health Services Research, 2013
FIGURE 8. Trends in Female Breast Cancer Mortality Rates by Race/Ethnicity, United States.
Rates are per 100,000 females and are age adjusted to the 2000 US standard population. Data are not shown for American Indians/Alaska Natives because of unstable rates, reflecting small numbers of deaths. API, Asian/Pacific Islander. Source: National Center for Health Statistics, Centers for Disease Control and Prevention, 2017.
WHY DO CANCER HEALTH DISPARITIES EXIST?
WHY DO CANCER HEALTH DISPARITIES EXIST?

Complex and interrelated factors contribute to U.S. cancer health disparities. The factors may include, but are not limited to, differences and/or inequalities in:

- access to and use of health care;
- genetics;
- physical and mental health;
- treatments received;
- social and economic status;
- cultural beliefs;
- exposure to environmental cancer risk factors;
- clinical trial participation;
- health literacy; and
- lifestyle, including weight, diet, and physical activity.

Adapted from (18)

American Association for Cancer Research (AACR) Cancer Progress Report 2018
Breast Cancer Mortality in California

Breast Cancer Mortality in California

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Rate (per 100,000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Af Am</td>
<td>35.5</td>
</tr>
<tr>
<td>White</td>
<td>28.8</td>
</tr>
<tr>
<td>Hispanic</td>
<td>16.1</td>
</tr>
<tr>
<td>Asian Pacific Isl</td>
<td>14.4</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>7.8</td>
</tr>
<tr>
<td>Korean</td>
<td>8.2</td>
</tr>
<tr>
<td>Chinese</td>
<td>14.3</td>
</tr>
<tr>
<td>Samoan</td>
<td>28.6</td>
</tr>
<tr>
<td>Native HI</td>
<td>34.6</td>
</tr>
</tbody>
</table>

Denotes Healthy People 2010 Target (22.3 per 100,000)

* Unreliable rate, Relative Standard Error (RSE) greater than 23 percent.


Cancer Facts & Figures (American Cancer Society, 2019)

*Per 100,000, age-adjusted to the 2000 US standard population. †Data based on Indian Health Service Contract Health Service Delivery Area counties. ‡Persons of Hispanic origin may be of any race.

Sources: National Center for Health Statistics, Centers for Disease Control and Prevention, 2018.
Families are extended with many social connections (e.g., Hawaiian *ohana*, Samoan *aiga*) (Palafox & Warren, 1980)

Health is defined holistically, including balance between physical, mental, and spiritual (e.g., Hawaiian *lokahi*) (Wong et al., 2004)

Traditional diets are rich in low-fat, high-complex carbohydrate plant and fish-based foods (Blaisdell, 1996)

Traditional livelihoods are very physically active, including fishing and agriculture, and the importance of dance
THERE ARE OVER 221,458 PACIFIC ISLANDERS IN CALIFORNIA

<table>
<thead>
<tr>
<th></th>
<th>2000 California Population*</th>
<th>% &lt; HS deg</th>
<th>&lt; 100% FPL**</th>
<th>&lt; 200% FPL</th>
<th>% Pub Assist</th>
<th>% LEP ***</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Alone</td>
<td>Inclusive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Native Hawaiian</td>
<td>20,571</td>
<td>60,048</td>
<td>14%</td>
<td>11%</td>
<td>27%</td>
<td>5%</td>
</tr>
<tr>
<td>Samoan</td>
<td>37,498</td>
<td>49,804</td>
<td>22%</td>
<td>20%</td>
<td>45%</td>
<td>12%</td>
</tr>
<tr>
<td>Chamorro/Guamanian</td>
<td>20,918</td>
<td>33,849</td>
<td>20%</td>
<td>10%</td>
<td>29%</td>
<td>6%</td>
</tr>
<tr>
<td>Tongan</td>
<td>12,111</td>
<td>15,252</td>
<td>40%</td>
<td>18%</td>
<td>44%</td>
<td>10%</td>
</tr>
<tr>
<td>NH Whites</td>
<td>15,816,790</td>
<td>16,538,491</td>
<td>10%</td>
<td>8%</td>
<td>20%</td>
<td>3%</td>
</tr>
</tbody>
</table>

* US Census 2000
** Federal Poverty Line
*** Limited English Proficient
PACIFIC ISLANDERS AND CERVICAL CANCER

- Cervical cancer is the 4th most common cause of cancer mortality among Pacific Islanders
- Age-adjusted incidence rates:
  - Samoans – 15.1/100,000
  - Native Hawaiians – 12.3/100,000
  - Whites – 9.3/100,000
- 60% of cervical cancers among Samoans and Native Hawaiians were found at more advanced (regional/distant) stages
- Pap testing is the most important cervical cancer prevention, but Pacific Islanders have low rates (46-71%) of Pap testing compared to HP2020 goal of 93%
PACIFIC ISLANDER CANCER RISK IN SOUTHERN CALIFORNIA (2001)

California Health Interview Survey, 2001
COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR)

- Collaborative approach to research
- Close partnerships between academic researchers and members of underserved communities
- Partners contribute expertise, share decision making and ownership of the research endeavor
- The aim is to increase knowledge and understanding of a given phenomenon leading to the development and testing of interventions to improve the health and quality of life of communities

SUPPORTING OUR WOMEN (SOW) STUDY: PARTNERSHIPS

NIH grant number 5R01CA149324-05

Community Leaders & Members

Guam Communications Network
Orange County Asian and Pacific Islander Community Alliance
Pacific Islander Health Partnership
Samoan National Nurses Association
Tongan Community Service Center/SSG

Multiple PIs: Lola Sablan-Santos & Sora Tanjasiri

Academic Researchers

California State University, Fullerton

SOW
SUPPORTING OUR WOMEN STUDY: PARTNERSHIP

Guam Communications Network
Lola Sablan-Santos  Lou Quitugua
Perci Flores        Pete Flores

Samoan National Nurses Association
Dorothy Vaivao      Genesis Lutu
Marina Tupua        Peni Taito

Caroline Pele*

Tongan Community Service Center / SSG
Vanessa Tuione-May  Isi Vunileva
Elenoa Vaikona

Orange County Asian & Pacific Islander Community Alliance
Mary Anne Foo
Jason Lacsamana

California State University, Fullerton
Sora Park Tanjasiri  Michele Mouttapa
Jie Weiss           Ciara Paige
Ualani Ho`opai
Jasmine DeGuzman Lacsamana

Community Advisory Board members
Lolini Vaimaona     Albert Van Meter
Tamara Tavai       Sione Holakeituai
Nuuausala Gafa     Tina Holakeituai
Peka Petaia        Katalina Fehoko
Nerisa Laufil Time  Laulile Fehoko
Christina Dorame    Akanesi Fehoko
Viola Johnson      Setaleki Fehoko
Paau Manuatu (Tuisoso)
Semisi Uhi          Joe Vaivao
Faleiva Seti Pauliasi Taufa
SUPPORTING OUR WOMEN STUDY: STUDY DESIGN

- Longitudinal randomized community trial with intervention vs. wait-list controls to increase Pap testing among Pacific Islander women in Southern California.
- Targeted married Chamorro, Samoan and Tongan women age 21-65 years old.
- Included their husbands.
- Used CBPR in all aspects of the study design, implementation and evaluation.
Five strategies for targeting of health promotion programs:

- **Peripheral** – gives the appearance of cultural appropriateness to increase appeal (e.g., use of colors, images, fonts, pictures of group members, etc)
- **Evidential** – incorporates evidence of impact on a group to enhance perceived relevance (e.g., mortality data for that specific group)
- **Linguistic** – use of the dominant language to increase accessibility of the program (e.g., no Tongan word for cervix)
- **Constituent involving** – draw on the experience of group members by including them in the planning and decision making of the program (e.g., CBPR)
- **Sociocultural** – places the health-related topic within the context of the broader social and/or cultural values of the group (e.g., collectivism)

**SUPPORTING OUR WOMEN STUDY:**

**INTERVENTION**

- **WOMEN:** Get Pap tests to stay healthy for your family
- **MEN:** Encourage your spouse to get Pap tests because you love her

**Materials**
- Brochure
- PowerPoint
- Video
  - [http://youtu.be/0fX4M2OMKF8](http://youtu.be/0fX4M2OMKF8)
- Booster/reminder & magnet calendar

WHAT CULTURAL TARGETING STRATEGIES WERE USED?

• Peripheral?
• Evidential?
• Linguistic?
• Constituent-involving?
• Sociocultural?
SUPPORTING OUR WOMEN STUDY: METHODS

Figure 1: CONSORT Flow Diagram

- **Questionnaires:** Completed prior to receiving the intervention (Pre-test), immediately after completing the intervention (Post-test1), and 6 months after completing the intervention (Post-test2).

- **Measures:** Included demographics, Pap knowledge, attitudes, beliefs, behaviors, social support, and social desirability.

- **GLM mixed models** with repeated measures were computed to determine intervention vs. comparison group changes.
Table 1. Baseline Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Women (n=591)</th>
<th>Men (n-416)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (in years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21-39</td>
<td>122 (20.8)</td>
<td>81 (20.0)</td>
</tr>
<tr>
<td>30-39</td>
<td>120 (20.4)</td>
<td>90 (22.3)</td>
</tr>
<tr>
<td>40-49</td>
<td>163 (27.7)</td>
<td>96 (23.8)</td>
</tr>
<tr>
<td>50+</td>
<td>182 (31.0)</td>
<td>137 (33.9)</td>
</tr>
<tr>
<td>Employed</td>
<td>312 (58.3)</td>
<td>267 (65.9)</td>
</tr>
<tr>
<td>Has health insurance</td>
<td><strong>461 (78.8)</strong></td>
<td>298 (72.9)</td>
</tr>
<tr>
<td>Language at home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PI only</td>
<td>30 ( 5.2)</td>
<td>27 ( 6.6)</td>
</tr>
<tr>
<td>More PI</td>
<td>53 ( 9.2)</td>
<td>44 (10.7)</td>
</tr>
<tr>
<td>PI/English</td>
<td>250 (43.2)</td>
<td>157 (38.2)</td>
</tr>
<tr>
<td>More English</td>
<td>128 (22.1)</td>
<td>80 (19.5)</td>
</tr>
<tr>
<td>English only</td>
<td>118 (20.4)</td>
<td>103 (25.1)</td>
</tr>
<tr>
<td>Pap compliant</td>
<td>311 (53.2)</td>
<td>94 (32.0)</td>
</tr>
<tr>
<td>Pap intention</td>
<td>144 (52.7)</td>
<td>297 (74.4)</td>
</tr>
</tbody>
</table>

- Insurance status was significantly higher among intervention women compared to control women.
- There were no other statistically significant differences between intervention and control women and men.
## SUPPORTING OUR WOMEN STUDY: 6-MONTH OUTCOMES

<table>
<thead>
<tr>
<th></th>
<th>Intervention</th>
<th>Comparison</th>
<th>Fixed Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre-test</td>
<td>Follow-up</td>
<td>Pre-test</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>n</td>
<td>n</td>
</tr>
<tr>
<td>Women's knowledge</td>
<td>135</td>
<td>135</td>
<td>218</td>
</tr>
<tr>
<td></td>
<td>5.08</td>
<td>6.39</td>
<td>5.28</td>
</tr>
<tr>
<td></td>
<td>2.56</td>
<td>2.53</td>
<td>3.04</td>
</tr>
<tr>
<td></td>
<td>.640</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women's fatalistic</td>
<td>129</td>
<td>129</td>
<td>211</td>
</tr>
<tr>
<td></td>
<td>1.08</td>
<td>0.71</td>
<td>1.19</td>
</tr>
<tr>
<td></td>
<td>1.08</td>
<td>1.10</td>
<td>1.28</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women's perceived</td>
<td>135</td>
<td>135</td>
<td>225</td>
</tr>
<tr>
<td>social support</td>
<td>50.21</td>
<td>50.61</td>
<td>52.29</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men's knowledge</td>
<td>103</td>
<td>103</td>
<td>99</td>
</tr>
<tr>
<td></td>
<td>3.17</td>
<td>5.77</td>
<td>3.84</td>
</tr>
<tr>
<td></td>
<td>2.69</td>
<td>2.59</td>
<td>2.79</td>
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</table>

- Regardless of group, women increased their knowledge and decreased fatalistic attitudes about cervical cancer, and men increased their knowledge
**SUPPORTING OUR WOMEN STUDY: 6-MONTH OUTCOMES**

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Comparison</th>
<th>Fixed Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Intervention vs. Comparison Group</td>
</tr>
<tr>
<td>n (%)</td>
<td>n (%)</td>
<td>B (SE)</td>
</tr>
<tr>
<td>---</td>
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</tr>
<tr>
<td>Only women not compliant with Pap tests at pre-test</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scheduled Pap test</td>
<td>41 (55.4)</td>
<td>43 (40.2)</td>
</tr>
<tr>
<td>Received Pap tests</td>
<td>38 (51.4)</td>
<td>37 (34.9)</td>
</tr>
<tr>
<td>Man talked to woman about Pap test(^1)</td>
<td>38 (73.1)</td>
<td>45 (53.6)</td>
</tr>
<tr>
<td>Man encouraged woman to get Pap test(^1)</td>
<td>35 (71.4)</td>
<td>43 (52.4)</td>
</tr>
</tbody>
</table>

\(^1\)Analyses were adjusted for men’s report at pre-test that they had, at least once, recommended to their wife/female partner to have a Pap test.

- Women in the intervention group were more likely to have scheduled and to have received a Pap test compared to women in the comparison group.

Tanjasiri SP et al. *Cancer Epidemiology, Biomarkers, & Prevention*, 2019.
WHAT DO YOU THINK WERE THE STRENGTHS & LIMITATIONS

Positive outcomes

- High community engagement
- Wide dissemination to wait-list controls
- Strength of cultural targeting

Relied on self-reported Pap test behavior

- Retention: overall 25% loss to follow-up
- Recruitment took time and multiple meetings
- Uncertain generalizability
SUPPORTING OUR WOMEN STUDY: LESSONS LEARNED

- Importance of working with church and clan leaders to show respect regardless of denomination or clan ties
  - Ability to be flexible to accommodate schedules
  - Neutrality of community organizations and study staff
- Providing food at all recruitment and education activities as show of appreciation to organizations and individuals
- Emphasis on helping women and men overcome their reluctance to talk about the taboo subject of cervical cancer
  - Adding humor to all presentations
- Importance of wider dissemination: toolkit available at http://wincart.fullerton.edu
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Perci Flores Pete Flores

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Nerisa Laufili Time Laulile Fehoko
Christina Dorame Akanesi Fehoko
Viola Johnson Setaleki Fehoko
Paua Manuatu (Tuisoso)
Semisi Uhi Joe Vaivao
Faleiva Seti Pauliasi Taufa
COMMUNITY-UNIVERSITY CANCER CBPR JOURNEY

In Hmong woman dies in Long Beach from breast cancer (BC) (1995)

Community and researchers meet and decide to promote BC education in the Hmong community

OCAPICA, FiGH, UPAC, Stonesoup and UCLA get together to plan CBPR project

OCAPICA, CSUF and UCLA receive CDC REACH 2010 grant to build larger coalition with seven Asian and Pacific Islander communities (1999-2005)

OCAPICA, CSUF and UCLA get together to plan CBPR project

OCAPICA and UCLA receive CA BCRP grants to develop and test BC materials and education (1999-2002)

OCAPICA, CSUF, and UCLA receive CDC CEED grant to disseminate best practices across the U.S. (2005-2010)

OCAPICA and CSUF receive NIH WINCART grant to promote education, research and training for Pacific Islanders (2005-2016)

OCAPICA, CSUF and UCLA receive CDC REACH 2010 grant to build larger coalition with seven Asian and Pacific Islander communities (1999-2005)

RWJ ACCT

CDC REACH 2010

OMH Men’s Health

TCE PI Health

Komen

SOW Pap
Thank you & Questions

Sora Park Tanjasiri, DrPH, MPH
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