Community-Based Participatory Research: From Bench to Trench

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Defining Disparity

• Health disparity represents an unequal distribution of disease across a population of interest

• In the United States, disparity is often characterized along racial/ethnic lines

• Black-White differences in disease burden persist for most, if not all, conditions, despite repeated inquiry and intervention
Example: Infant Mortality


* Per 1,000 live births.
† American Indian/Alaska Native.
§ Hispanic mothers might be of any race.

Example: Cervical Cancer Incidence

Rates by Race and Ethnicity, US, 1975-2004
Race vs. Racism

- Framing health disparity in terms of racial/ethnic differences is problematic, especially in a multicultural context like the US

- Race is a socio-political, not biological, construct

- However, racism that ensues from, and may differentially affect, persons classified as one race/ethnicity or another, is associated with:
  - Reduced economic and educational opportunities
  - Increased exposure to unsafe environments
  - Limited access to the formal healthcare system

Example: Cervical Cancer Stage at Diagnosis

Stage by % at Least High School Education

Lowest 20%, % at least HS Education
- Stage I: 42.6%
- Stage II: 13.1%
- Stage III: 26.2%
- Stage IV: 11.1%

Remaining 80%, % at least HS Education
- Stage I: 60.2%
- Stage II: 18.0%
- Stage III: 17.4%
- Stage IV: 11.3%

Source: SEER, 9 Registry

Heterogeneity in US Black Population

Women Age 18+ Who Have Had a Pap Smear Within the Past 3 Years (FLORIDA)

Haitians: 44%
Blacks: 83%
Whites: 84%

Etiology of Health Disparity

• Health disparity likely ensues from the interplay of many determinants operating across multiple levels of influence

• Such determinants include:
  ❖ Genetic factors
  ❖ Health behaviors
  ❖ Socio-cultural norms about health and disease prevention
  ❖ Access and utilization of healthcare
  ❖ Environmental risk conditions
Determinants of Disparity

Multilevel Framework for Epidemiology

Role of Community-Based Research

• Community-based research is essential for assessing determinants of disparity, as well as, identifying solutions for change.

• Such research is consistent with the goals of translational science, which aim to integrate laboratory discovery into clinical practice.

• For maximal impact, new discoveries must transcend the academic context and be incorporated into community care.
Significance of Bench to Trench

1. From a public health, or population-based, perspective, disease burden is inherently a function of collective, not individual risk.

2. In the United States, the lag between scientific discovery and program delivery is, in itself, a determinant of health disparity.

This lag is often exaggerated for underserved communities who shoulder the greatest burden of disease incidence, morbidity and mortality.

Community Barriers to Research

• Underserved communities are often skeptical about research and distrustful of “outsiders”

• Historically, researchers have not consistently represented community interests

• This disconnect poses multiple challenges to the research process

• Community members become further sensitized against research, and more disenfranchised from the formal healthcare system
Introduction to Community-Based Participatory Research

• Community barriers to research render traditional research methods ineffective

• Researchers must identify innovative methodologies to circumvent such barriers and to support subsequent intervention

• Community-Based Participatory Research (CBPR) represents one such methodology

• CBPR is increasingly popular in public health, given the persistence of health disparities
Overview of CBPR

- CBPR is a population-based approach for understanding variability in health outcomes

- CBPR invites community participation at all points along research continuum

- CBPR helps circumvent barriers to research prevalent within underserved communities, and ensures that research findings are culturally-relevant and amenable to intervention

Back Story on my Work in Little Haiti

- In examining the geographic distribution of cervical cancer in South Florida, I identified an area characterized by excess disease incidence and mortality.
- The area is Little Haiti, the most significant enclave of Haitian settlement in the US.

Source: University of Miami Sylvester Comprehensive Cancer Center, Disparities and Community Outreach Core, Cervical Cancer Late Stage Diagnosis, 2010.
Overview of Miami’s Haitian Population

• Haitians are the fastest growing minority group in South Florida

• The majority reside in Little Haiti, which is located in northeast Miami-Dade County

• Generally, residents of Little Haiti are:
  - Recent immigrants
  - Poor and undereducated
  - Limited literacy in English and Spanish
  - Disenfranchised from the formal healthcare system
Little Haiti, Miami, Florida
Barriers to Research in Little Haiti

- General distrust of “outsiders”
- Predominance of mono-lingual Kreyol speakers
- Dissonance between Haitian and Western Medicine’s conceptualization of health and prevention
- Skepticism about research, especially health-related research

Patnè en Aksyon

• To circumvent such barriers, academic investigators from the University of Miami and community leaders from Little Haiti created a campus-community partnership known as Patnè en Aksyon.

• The partnership’s primary goal is to attenuate cancer disparities in the South Florida Haitian community.

• Patnè en Aksyon aims to accomplish this goal through community-based participatory research (CBPR) and intervention.
Establishing Partnership

• Patnè en Aksyon was created through the collective efforts of University investigators and directors of Haitian Community-Based Organizations who had worked together previously

• The CBO Directors first enumerated a list of other community leaders

• They then approached those individuals to solicit their participation in the partnership

Partnership Formalized

- Interested persons were invited to an inaugural meeting
- In collaboration with academic investigators, community members decided upon group’s name (Patnè en Aksyon), mission, and scientific focus
- Currently, the partnership supports a number of ongoing research initiatives
- All such initiatives are translational in orientation

Lessons Learned

• In ethnic enclaves such as Little Haiti, **WHO** you know may be more important than **WHAT** you know as an academic

• Meaningful progress towards change necessitates
  - Understanding how social networks conceptualize disease etiology and prevention
  - Mobilizing social networks
Little Haiti Rapid Assessment Survey Data

<table>
<thead>
<tr>
<th>Generally, where do you get information about health?</th>
<th>(n= 944) Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family / Friends</td>
<td>23.7</td>
</tr>
<tr>
<td>Church</td>
<td>8.0</td>
</tr>
<tr>
<td>Health Care Provider</td>
<td>52.2</td>
</tr>
<tr>
<td>TV</td>
<td>4.4</td>
</tr>
<tr>
<td>Radio</td>
<td>8.0</td>
</tr>
<tr>
<td>Other</td>
<td>3.6</td>
</tr>
<tr>
<td>Books/Magazines</td>
<td>28.1</td>
</tr>
<tr>
<td>Other medical professional</td>
<td>15.6</td>
</tr>
<tr>
<td>Ougan/Mambo</td>
<td>9.3</td>
</tr>
<tr>
<td>Internet</td>
<td>3.1</td>
</tr>
<tr>
<td>No where</td>
<td>43.7</td>
</tr>
</tbody>
</table>

Sources of Health Information

- Botanica *dokte fey* and other ethnomedical providers often serve as Haitian women’s primary source of health information

- Effective cancer communication must integrate these individuals into outreach efforts

- Radio also remains an important channel for communication and is essential for disseminating study findings and health information

- More traditional strategies for health promotion (and similarly participant recruitment) do not resonate with the socio-cultural context of Little Haiti and, perhaps, other, similar ethnic enclaves throughout the US
Community Health Workers (CHWs)

- Early on, community leaders advocated for integrating Community Health Workers (CHWs) into partnership research efforts.

- CHWs are indigenous to Little Haiti, speak English and Haitian Kreyol fluently, and are considered “natural helpers” by their peers.

- Perhaps most importantly, CHWs innately know how to address sensitive topics, such as cervical cancer.

- They also have large social networks and the ability to mobilize such networks around cancer prevention and control.
• They are formally employed by a social service organization in the area, and were trained to participate in research using a standardized training manual

• The CHWs recruit women and collect study data in most partnership research efforts
Outsider-Insider Paradox

• CBPR necessitates that academic investigators immerse themselves in the community

• By doing so, they ideally gain an emic, or insider’s, perspective of community dynamics and existing challenges to health promotion

• Without such insight, research and intervention efforts may prove futile

• It is essential to understand how to appropriately frame health messages and to identify the channels necessary for such messages to reach their intended audience
Example 1: Cervical Self-Sampler

- A cervical self-sampler provides an alternative to the traditional clinician-performed speculum exam.

- It is self-administered, relatively easy to use and comfortable.

- In clinical trials, self-sampling has been shown to have similar efficacy to Pap smear screening for detecting cervical abnormalities.
Dissemination to Little Haiti

- As part of ongoing CBPR initiative, community members played an integral role in deciding how to best distribute the sampler to age-eligible women.

- Community leaders advocated for using Community Health Workers (CHWs), who were lay women indigenous to Little Haiti.

- The CHWs were formally employed by a social service organization in the area, and were trained to participate in research using a standardized training manual.

- The CHWs recruited women from their personal social networks, as well as, those of the CBOs active in Patnè en Aksyon.
The majority of women found the self-sampler easy to use, and would recommend it to their friends and family.

Among women with a history of Pap smear screening, most preferred the self-sampler to the speculum exam.

In fact, acceptability was so widespread among study respondents that there was no variability to model for more detailed analyses.
## Acceptability of Self-Sampling

Acceptability of self-sampling device among ethnically Haitian Women living in Little Haiti, Miami, Florida

<table>
<thead>
<tr>
<th>Question</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you find the self-sampler easy to use?</td>
<td>95.1</td>
</tr>
<tr>
<td>Did you feel comfortable using the self-sampler at home?</td>
<td>97.6</td>
</tr>
<tr>
<td>Would you recommend using the self-sampler to your female family members and friends?</td>
<td>98.4</td>
</tr>
<tr>
<td>Did you experience any pain or discomfort using the self-sampler?</td>
<td>40.8</td>
</tr>
</tbody>
</table>

**Among women with history of Pap smear screening:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you prefer the Self-Sampler method over the Pap smear?</td>
<td>86.8</td>
</tr>
</tbody>
</table>

Age-Specific Prevalence of HPV

Figure 2. Age-specific prevalence of cervical human papillomavirus (HPV) DNA by LR, HR, and HR Types 16 and 18. Vertical bars indicated 95% confidence intervals of overall HPV prevalence. ■ HPV 16 and/or 18 (including co-infection), □ all other HR-HPV, □ LR-HPV only.

### HR-HPV Type Distribution by Cytology

<table>
<thead>
<tr>
<th>HR HPV Type</th>
<th>No. of infections n (%)</th>
<th>Abnormal † ( n =11)</th>
<th>Normal ( n =27)</th>
</tr>
</thead>
<tbody>
<tr>
<td>16</td>
<td>2 (5.2)</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>18</td>
<td>2 (5.2)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>31</td>
<td>1 (2.6)</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>33</td>
<td>2 (5.2)</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>35</td>
<td>3 (7.9)</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>45</td>
<td>2 (5.2)</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>52</td>
<td>3 (7.9)</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>53</td>
<td>4 (10.5)</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>66</td>
<td>1 (2.6)</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>68</td>
<td>3 (7.9)</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>82</td>
<td>3 (7.9)</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>83</td>
<td>3 (7.9)</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>84</td>
<td>1 (2.6)</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Unknown</td>
<td>2 (5.2)</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>HR Co-infections*</td>
<td>6 (15.8)</td>
<td>2</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Differential cytology</th>
<th>ASC-US</th>
<th>LSIL</th>
<th>HSIL</th>
</tr>
</thead>
<tbody>
<tr>
<td>results among HR-HPV positive women</td>
<td>7</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Differential cytology</th>
<th>ASC-US</th>
<th>LSIL</th>
<th>HSIL</th>
</tr>
</thead>
<tbody>
<tr>
<td>results among HR-HPV positive women</td>
<td>64%</td>
<td>18%</td>
<td>18%</td>
</tr>
</tbody>
</table>

† HPV = human papillomavirus, HR = high risk (oncogenic HPV type), LR = low risk (non-oncogenic HPV type).
* Co-infections by types 16 & 84, 52 & 53, 62 & 66, 62 & 68, (n=1 for each listed) and CP6108 & 82 (n=2)
††Total abnormal cases in the sample were: ASC-US =15, HSIL=2, LSIL =4.
Next Steps

• Center Grant (NCI 1U54CA153705-0) that employs RCT design to further establish efficacy of self-sampling

• Team Science (Bankhead-Coley 2BT02) to extend work to colorectal cancer

• Enhance existing community infrastructure to support further interdisciplinary inquiry
Significance of Trench to Bench

- Discourse surrounding translational research is often top-down in orientation.
- It is often assumed, if not expected, that scientific ideas will be disseminated from an academic to community context.
- However, the reverse does happen in CBPR.
- Grassroots science is essential to making real inroads in attenuating health disparities.
Twalet Deba / Lavamen

- There is a common cultural practice among Haitian women known as twalet deba.

- Simply put, twalet deba is a feminine hygiene practice to ensure cleanliness and tightening/drying of the vagina.

- Twalet deba involves the use of herbs, leaves, and commercial products that include, among other ingredients, boric acid and potassium permanganate.

- This practice may also involve monthly use of antibiotics.

Participant observation in local *botanicas* and a series of key informant interviews informed our understanding of the phenomenon.

Undoubtedly, community trust enabled women to comfortably disclose detailed information about this intimate practice.

Women and botanica owners/*dokte fey* described what products were used, how they were prepared, and the frequency of use.
<table>
<thead>
<tr>
<th>Product Inventory</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Asowosi</strong></td>
</tr>
<tr>
<td><strong>Camomille</strong></td>
</tr>
<tr>
<td><strong>Maskreti</strong></td>
</tr>
<tr>
<td><strong>Pwa kongo</strong></td>
</tr>
<tr>
<td><strong>Ti bonm</strong></td>
</tr>
<tr>
<td><strong>Verveine</strong></td>
</tr>
<tr>
<td><strong>Dlo sitwon</strong></td>
</tr>
<tr>
<td><strong>Savon</strong></td>
</tr>
<tr>
<td><strong>Savon bleu</strong></td>
</tr>
<tr>
<td><strong>Pèmeganat</strong></td>
</tr>
<tr>
<td><strong>Alum</strong></td>
</tr>
<tr>
<td><strong>Borasol</strong></td>
</tr>
</tbody>
</table>
Product Inventory

Dettol

Duvinal

Hygisol

Ogynol

Protectyl

Lemisol

Intimiss

Secret de Femme

Higisol

Massengill douche

Massengill wash
### Association Between Feminine Hygiene Products and Risk of HR-HPV Infection

<table>
<thead>
<tr>
<th>HR-HPV</th>
<th>Total n (%)</th>
<th>+ (n) (%)</th>
<th>- (n) (%)</th>
<th>OR (95% CI)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of product used</strong>&lt;sup&gt;¥&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Soap</td>
<td>327 (76.8)</td>
<td>41 (75.9)</td>
<td>286 (76.9)</td>
<td>0.9 (0.4-1.9)</td>
<td>0.84</td>
</tr>
<tr>
<td>Water with Lime</td>
<td>110 (25.8)</td>
<td>20 (37.0)</td>
<td>90 (24.2)</td>
<td>1.8 (0.9-3.6)</td>
<td>0.08</td>
</tr>
<tr>
<td>Alum</td>
<td>24 (5.6)</td>
<td>5 (9.3)</td>
<td>19 (5.1)</td>
<td>1.6 (0.5-5.3)</td>
<td>0.41</td>
</tr>
<tr>
<td>Condy's Crystals</td>
<td>214 (50.2)</td>
<td>28 (51.9)</td>
<td>186 (50.0)</td>
<td>1.0 (0.6-1.9)</td>
<td>0.91</td>
</tr>
<tr>
<td>Borasol®</td>
<td>28 (6.6)</td>
<td>3 (5.6)</td>
<td>25 (6.7)</td>
<td>0.5 (0.1-1.9)</td>
<td>0.28</td>
</tr>
<tr>
<td>Hygisol / Lemisol® / Ogynol®</td>
<td>28 (6.6)</td>
<td>3 (5.6)</td>
<td>25 (6.7)</td>
<td>0.8 (0.2-2.8)</td>
<td>0.64</td>
</tr>
<tr>
<td>Yellow Balsam</td>
<td>73 (17.1)</td>
<td>14 (25.9)</td>
<td>59 (15.9)</td>
<td>1.7 (0.8-3.5)</td>
<td>0.18</td>
</tr>
<tr>
<td>Castor oil</td>
<td>228 (53.5)</td>
<td>29 (53.7)</td>
<td>199 (53.5)</td>
<td>0.4 (0.2-1.1)</td>
<td>0.07</td>
</tr>
<tr>
<td><strong>Pwa Kongo</strong></td>
<td><strong>189 (44.4)</strong></td>
<td><strong>31 (57.4)</strong></td>
<td><strong>158 (42.5)</strong></td>
<td><strong>3.1 (1.2-7.7)</strong></td>
<td><strong>0.02</strong></td>
</tr>
<tr>
<td>Chamomille oil</td>
<td>14 (3.2)</td>
<td>3 (5.6)</td>
<td>11 (3.0)</td>
<td>1.7 (0.4-7.0)</td>
<td>0.50</td>
</tr>
<tr>
<td>Balsam pear</td>
<td>37 (8.7)</td>
<td>4 (7.4)</td>
<td>33 (8.9)</td>
<td>0.6 (0.2-1.9)</td>
<td>0.35</td>
</tr>
<tr>
<td><strong>Total number of products (n=53, 426)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Each additional product reported used</td>
<td></td>
<td></td>
<td></td>
<td>1.1 (1.0-1.3)</td>
<td>0.11</td>
</tr>
</tbody>
</table>

<sup>¥</sup> Adjusted for all other products.
Laboratory Findings

- Such products generally induce apoptosis of cervical Endothelial cell lines

- However, Pwa Congo enables unregulated cell growth, including cells infected with HR-HPV

- Currently conducting micro-array analyses to further understand impact on E6/E7 proteins and cellular function, more broadly
Next Steps

- Center Grant (NCI 1U54CA153705-0) that employs RCT design to further establish efficacy of self-sampling

- Team Science (Bankhead-Coley 2BT02) to extend work to colorectal cancer

- **Enhance existing community infrastructure to support further interdisciplinary inquiry**
Concluding Comments

• Ultimately, research discovery belongs in the public domain

• By shifting the focus from high risk individuals to communities, we create opportunity for more individuals to be healthy

• Such opportunity is essential for reducing the unequal burden of disease among low income, underserved population groups in the US
Acknowledgements

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- The CHWs who recruited participants and collected data
- The members of the Patnè en Aksyon Community Advisory Board for their vision
- My academic colleagues and collaborators
- My students