ADDRESSING CANCER DISPARITY AMONG HAITIANS IN MIAMI:
LESSONS LEARNED AND FUTURE CHALLENGES

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PERSONAL DISCLOSURES

- I no longer identify as a cancer epidemiologist

- In working with communities to address disparity, I have learned a lot and begun to consider myself a participatory action researcher...

- More than anything, I have learned that my academic training was largely inadequate, and that progress towards change necessitates community engagement
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.
LITTLE HAITI, MIAMI, FLORIDA
OVERVIEW OF LITTLE HAITI

- 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
- Emergent challenges since the January 12, 2010 earthquake in Haiti pose additional constraints to health promotion
In the United States, Black women experience an increased risk of developing and dying from cervical cancer.

In Miami, Florida, cervical cancer incidence and mortality is highest among Haitian American women.

Between 2000-2004, the incidence for disease was estimated to be 38/100,000 for Little Haiti, the predominately Haitian area in Miami.

Annual cervical cancer incidence for US as whole is approximately 9/100,000.
HETEROGENEITY IN US BLACK POPULATION

- Cancer surveillance data groups persons of similar phenotype into one category for research purposes

- This practice masks existing variability in known determinants of disease risk

- Increasing multiculturalism in the United States necessitates attention to such determinants, including ancestry and patterns of migration

COMMUNITY BARRIERS TO RESEARCH

- 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
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.

INTRODUCTION TO 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

SIGNIFICANCE OF COMMUNITY INPUT

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

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CBPR OPERATIONALIZED IN LITTLE HAITI

- Patnè en Aksyon members defined roles for academic and community partners based on this feedback.

- Community partners are generally responsible for defining the focus and scope of research, identifying culturally-appropriate study design and data collection strategies, and disseminating findings.

- Academic partners, in turn, write the majority of grant applications and protocols for Institutional Review Board (IRB) approval.

- All funded grants include a significant role for CHWs, who are formally employed by a large community-based organization located in the heart of Little Haiti.

- This organization serves as the community’s home and the director as a co-Principal Investigator on all research efforts.
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.

ROLE OF CHWS IN PATNÈ EN AKSYON

- 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.
CERVICAL CANCER

• CHWs approached nearly 1,000 Haitian women in various community venues across Little Haiti, including laundromats, flea markets, and churches

• Women who were eligible and interested completed a Rapid Assessment Survey (RAS)

• RAS are brief, in person interviews ideal for data collection in communities with limited literacy or cultural taboos related to revealing health information over the phone

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

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

In two separate research projects, we attempted to integrate new technology into data collection efforts. Both attempts failed and required us to modify study design midstream. Post-hoc examination of what accounts for such failure provides important insight for future research and intervention.
Community fears of deportation challenged the acceptability of collecting data via electronic media.

This finding has important implications for cancer communication.

Emergent strategies for health education, particularly those which are computer-based, may aggravate community sensitivities and further stigmatize research.
CHWs recruited women from a randomly generated list of women who had participated in a previous Patnè en Aksyon research initiative.

For women who were interested and eligible, the CHWs scheduled an in-person interview at a mutually-agreeable time and location.

Interviews were conducted in Haitian Kreyol and typically lasted one hour.

CHWs interviewed a total of 15 women, ages 41-60, before reaching data saturation.

The majority of Little Haiti residents are mono-lingual Kreyol speakers.

However, simply translating educational materials and/or research instruments into Kreyol is not effective for reaching this population sub-group.

The orthography for Kreyol was only developed in recent years, such that many older Haitians do not read or write in this language.

As a result, health information must be visually based, and pictorially convey the intended message.
FLIPCHART IMAGES
Haitian perceptions of disease etiology are pluralistic in orientation, blending biomedical and lay interpretations of illness causation.

For example, cervical cancer is perceived by many Haitian women to be a *maladi mou* or so-called “sent sickness” that is supernatural in origin.

From this perspective, Pap smear screening offers little to no benefit for disease prevention.
Dissonance between Haitian and biomedical interpretations of disease prevention are further complicated by concerns about modesty and vaginal tone.

In Little Haiti, many women believe that a Pap smear can introduce gaz into the vagina and potentially induce illness.

There is also a common concern that Pap screening may change vaginal tone, such that it is not as sere, or tight, as preferred by male partners.
The POI/NIH self-sampler tests for HPV, the primary risk factor for cervical cancer.

This device is low cost, easy to use, and can be used in the privacy of a woman’s home.

Self-sampling circumvents access and socio-cultural barriers to screening, prevalent in Little Haiti.
## 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><strong>95.1</strong></td>
</tr>
<tr>
<td>Did you feel comfortable using the self-sampler at home?</td>
<td><strong>97.6</strong></td>
</tr>
<tr>
<td>Would you recommend using the self-sampler to your female family members and friends?</td>
<td><strong>98.4</strong></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: (n = 189)

<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><strong>86.8</strong></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>7</th>
<th>64%</th>
</tr>
</thead>
<tbody>
<tr>
<td>results among HR-HPV positive women</td>
<td>LSIL</td>
<td>2</td>
<td>18%</td>
</tr>
<tr>
<td></td>
<td>HSIL</td>
<td>2</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.
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.

ETHNOGRAPHIC METHODS

- 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.

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Asowosi  Camomille  Maskreti  Pwa kongo  Ti bonm
Verveine  Dlo sitwon  Savon  Savon bleu
Pèmeganat  Alum  Borasol
PRODUCT INVENTORY

Dettol
Duvinal
Hygisol
Ogynol
Protectyl

Lemisol
Intimiss
Secret de Femme
Higisol
Massengill douche
Massengill wash
**LESSON #4: IT’S NOT WHAT YOU SAY, IT’S WHO SAYS IT**

### Little Haiti Rapid Assessment Survey Data

<table>
<thead>
<tr>
<th>Source of Information</th>
<th>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>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>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>

*(n= 944)*

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
<table>
<thead>
<tr>
<th>Type of product used</th>
<th>Total</th>
<th>+</th>
<th>-</th>
<th>OR (95% CI)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</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>Pwa Kongo</td>
<td>189 (44.4)</td>
<td>31 (57.4)</td>
<td>158 (42.5)</td>
<td>3.1 (1.2-7.7)</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>
</tbody>
</table>

**Total number of products** (n=53, 426)

Each additional product reported used  

1.1 (1.0-1.3) 0.11

*Adjusted for all other products.*
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
In Florida, Blacks have a higher incidence and mortality from colorectal cancer (CRC) than non-Hispanic Whites (NHWs)
- 19.5/100,000 Blacks vs. 14.6 in NHWs

In addition, Hispanics have a higher age-adjusted incidence of CRC than NHWs
- 56/100,000 in Hispanics vs. 49 in NHWs

Some minority communities in Miami-Dade are at especially high risk
- Little Haiti and Hialeah
APPROACH

- Three pronged strategy /Projects
  - Improved identification of at risk communities
  - Improved screening approaches using newer tech
  - Explore the molecular mechanisms that may underlie some of the racial and ethnic differences
Excess diagnosis of late-stage colorectal cancer in Hialeah and Little Haiti

Disparity largely reflects lack of access to, and underutilization of, routine screening

Colonoscopy, the gold standard for colorectal cancer prevention, remains a challenge for racial/ethnic minorities and recent immigrants

Project aims to circumvent barriers by increasing availability of Fecal Immunochemical Testing (FIT), a stool-based test that can be performed in the privacy of one’s home
OVERVIEW OF PROJECT

- Grounded in Community-based Participatory Research (CBPR) methodology
- Aims to test the feasibility and acceptability of FIT in our communities of interest
- Integrates Community Health Workers (CHWs) into study design and implementation
- Identifies high-risk individuals and navigates them to timely and appropriate follow-up
PROGRESS TO DATE

- Implementation delayed due to many factors, most of which were out of our immediate control
- Recruitment started in earnest approximately one month ago
- Since then, we have made tremendous progress towards our enrollment goals (n=150/year)
- In Little Haiti alone, we have screened 90 people for potential eligibility
- Of those 48 were eligible and interested in participating
- Thus far, 26 have completed FIT
- One participant was FIT positive; 23 were negative; two results are still pending
BRINGING IT ALL TOGETHER...

- CBPR process offers important insight into community needs and assets for health promotion

- Without such insight, efforts to attenuate cancer disparity may have limited positive impact

- Community participation is essential for ensuring that cancer prevention and control initiatives are effective, sustainable, and lead to meaningful social change
THE GOAL: COMMUNITY COMPETENCE

- The promise of social change can only be realized by designing community competent interventions.

- Community competence recognizes that history, culture, politics, ethnic identity, and linguistics shape the lived experiences and health of residents.

- Community competent praxis enables better understanding of how to structure health messages, identify the appropriate channels for their dissemination, and make meaningful progress towards eliminating disparity.
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