CBPR as Translation: The Case of Little Haiti

Erin Kobetz, PhD, MPH
Associate Director, Disparities and Community Outreach
Sylvester Comprehensive Cancer Center
University of Miami Miller School of Medicine
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.
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.
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.

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.
From a public health, or population-based, perspective, disease burden is inherently a function of collective, not individual risk.
• 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.
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
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.
LESSON LEARNED #2 (T0)

• 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
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.
SUCCESS LARGE RESEARCH PROJECT

- RCT of 600 women who have not been adequately screened for cervical cancer

- Primary Outcome: Self-reported cervical cancer screening at 6 months

- Secondary Outcomes: cervical cancer knowledge, access to care, time to follow-up and further testing among women having abnormal screens.

- Subgroup analyses: site and race/ethnic group
ITT Analysis N=600

- Outreach Only
- CHW Navigation
- CHW and HPV Sampling
The utility of self sampling is limited, in part, by the assays for detecting HPV. Such assays are expensive and require laboratory infrastructure, which is not universally available. Moreover, loss to follow up among HPV positive women remains a challenge to effective disease control.
Figure. Assay methodology. The cervical swab is transferred to a reaction tube containing the ligation and extension reagents as well as the reporter probe. This solution is incubated in the hand, and then the test strip is inserted into the reaction tube. Target and reporter probes are wicked up the test strip via capillary action for detection of amplified target and/or unhybridized reporter probe at the sites of immobilized capture probe and chitosan.
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LESSON LEARNED #3: INTERDISCIPLINARY MATTERS
LESSON LEARNED #4: TWALET DEBA

- 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.

• Be a good listener and practice humility
• Be transparent about your interests and have ongoing, open dialogue about the expectations of collaboration
• Be tenacious; change is a slow and sometimes painful process
• Don’t ever forget that you are an outsider
• Always remember that you know less than you think you do
• Stay focused on the BIG picture, and building capacity for sustainable change
CONCLUDING COMMENTS

• CBPR provides an effective platform for conducting science throughout the translational continuum to application

• This methodology is “team” oriented and requires the interplay of diverse perspectives and disciplines to achieve progress

• Even borrowing specific ideals from this approach can improve research focus and enhance impact
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