Screening & Early Detection in Low-Resource Settings

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IOM Workshop on Cancer Control in Low Resource Areas
October 27, 2015
Disclaimer

Funding

✓ National Cancer Institute
  ✓ R01CA111799 (Scarinci)
  ✓ R25CA106870 (Scarinci)
  ✓ P30 CA013148 – Research Supplement (Scarinci)
  ✓ U01CA114619 (Partridge)
  ✓ NCI Intramural Research (Castle)

✓ National Center for Minority Health and Health Disparities
  ✓ R24MD002747 (Scarinci)
  ✓ P60MD000502 (Fouad; Scarinci – Research Project)

✓ Centers for Disease Prevention and Control
  ✓ REACH 2010 (Fouad)
  ✓ Special Interest Supplement (SIP 05-05 - 2005) – Holt

✓ Susan G. Komen for the Cure (Scarinci)
“My Lens” or “Biases”

PROFESSIONAL
✓ Behavioral Scientist
✓ Master’s in Public Health
✓ Trained and built a career in the Paulo Freire philosophical approach – Empowerment Model
✓ My experience in screening is limited to three cancers: cervical, breast, and colorectal cancer

PERSONAL
✓ Grew up in a multicultural environment in South Brazil
✓ Spent half of my life in a “rich state” in a low-middle income country and the other half in a “poor state” in a high-income country
This *discovery to delivery* “disconnect” is a key determinant of the unequal burden of cancer.

*Voices of a Broken System: Real People, Real Problems*  
President’s Cancer Panel, Harold Freeman, March 2002
Why such “Disconnect” in Cancer Screening? Through my lens…

- Guidelines have been based on the “science” without taking into account availability of resources
- Lack of clear definition and/or understanding of sub-populations experiencing high burden of disease
- Behavioral scientists have not been involved in the development of screening technologies & basic/epidemiology scientists are not involved in the delivery
- Few studies validating theoretical models of behavior change among populations experiencing high disease burden
- “Culturally-Relevant” programs/interventions are broadly defined with multiple challenges in dissemination and replication
- Limited (or none) involvement of the target audience in the development of interventions
The Breast Health Global Initiative Guidelines for International Breast Health and Cancer Control – Early Detection

<table>
<thead>
<tr>
<th>Level of Available Resources</th>
<th>Basic</th>
<th>Limited</th>
<th>Enhanced</th>
<th>Maximal</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Public Education &amp; Awareness</strong></td>
<td>Development of <em>culturally sensitive, linguistically appropriate</em> local education programs for target populations to teach value of early detection, breast cancer risk factors and breast health awareness</td>
<td>Culturally &amp; linguistically appropriate targeted outreach/education encouraging CBE for age groups at higher risk administered at district/provincial level using healthcare providers in the field</td>
<td>Regional awareness programs regarding breast health linked to general health and women’s health programs</td>
<td>National awareness campaigns regarding breast health using media</td>
</tr>
</tbody>
</table>

| **Detection Methods** | Clinical history & CBE | - Diagnostic breast US +/- diagnostic mammography in women with positive CBE  
- Mammographic screening of target group | - Mammographic screening every 2 years in women ages 50-69  
- Consider mammographic screening every 12-18 months in women ages 40-49 | - Consider annual mammographic screening in women 40 & older  
- Other imaging technologies as appropriate for high risk groups |

| **Evaluation Goal** | Breast health awareness regarding value of early detection in improving breast cancer outcome | Downsizing of symptomatic disease | Downsizing and/or downstaging of asymptomatic disease in women in higher yield target groups | Downsizing and/or downstaging of asymptomatic disease in all risk groups |

### Cervical Cancer Mortality (per 100,000)

<table>
<thead>
<tr>
<th></th>
<th>All Women</th>
<th>Whites</th>
<th>African Americans</th>
</tr>
</thead>
<tbody>
<tr>
<td>United States *</td>
<td>4.1</td>
<td>2.0</td>
<td>4.2</td>
</tr>
<tr>
<td>Mississippi **</td>
<td>3.4</td>
<td>2.4</td>
<td>5.6</td>
</tr>
<tr>
<td>Mississippi Non-Delta **</td>
<td>3.0</td>
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<td>Mississippi Delta **</td>
<td>3.4</td>
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*Siegel et al., 2015 (data for 2007-2011)  
** Mississippi Cancer Registry, 2015 (data for 2008-2012)
Theoretical Framework
PEN-3 & Health Belief Model

Educational Diagnosis of Health Behavior
- Perceptions
- Enablers
- Nurturers
- Perceived Susceptibility
- Perceived Benefits
- Perceived Severity
- Self-Efficacy

Cultural Appropriateness of Health Behavior
- Positive
- Existential
- Negative

Person
- Extended
- Family
- Neighborhood

Health Education

CBPR

Airhihenbuwa, 1992; Rosenstock, 1999
Building Blocks…

- Engagement of all stakeholders
  - Policy makers → individuals

- Qualitative assessments
  - Social construction of health, cancer, and screening

- Quantitative assessments
  - Confirmation of qualitative findings

- Feedback to the community regarding the findings & their input - intervention development

- Development, implementation, an evaluation of interventions – research, education, and outreach

Scarinci et al., 2003; Holt et al., 2010; Drewry et al, 2010; Fouad et al., 2010; Wynn et al., 2011; Castle et al, 2011; Scarinci et al., 2012; White et al., 2012; Garcés-Palacio & Scarinci, 2012; Holt et al., 2012; Scarinci et al., 2013; Williams et al., 2015
# Cervical Cancer Screening

*(Scarinci et al, 2012)*

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<th>Theoretical Constructs</th>
<th>Latina immigrants in Alabama</th>
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<td><strong>Perceptions</strong></td>
<td>(+) Knowledge on the importance of screening</td>
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<td></td>
<td>(+) Motivated to be healthy to take care of others</td>
</tr>
<tr>
<td></td>
<td>(-) Limited knowledge of the connection between cervical cancer and HPV</td>
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<td>(-) Stoic attitude toward health and illness</td>
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<td><strong>Enablers</strong></td>
<td>(+) Trust in some community-based organizations, community health advisors</td>
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<td>(-) Lack of health insurance, lack of knowledge on where to go for screening, differences in health care between US and their home countries</td>
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<td><strong>Nurturers</strong></td>
<td>(+) Strong alliance to other Latinas and strong desire to help each other</td>
</tr>
<tr>
<td></td>
<td>(-) Opposition from spouses in getting screened if provider is male</td>
</tr>
<tr>
<td><strong>Perceived Susceptibility</strong></td>
<td>(-) Not at risk for CC b/c they do not have the perceived risk factors (e.g., lack of hygiene) &amp; preventive care is not a priority</td>
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<td>(+) CC perceived as a deadly disease</td>
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<td><strong>Perceived Barriers</strong></td>
<td>(-) Structural – lack of health insurance, do not know where to go, transportation</td>
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<td><strong>Perceived Benefits</strong></td>
<td>(+) Belief that screening can detect cancer early</td>
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<td>(-) &lt;20% believe that if CC is detected early the chances of survival are excellent or good; lack of understanding that screening can detect changes BEFORE cancer</td>
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### Cervical Cancer Screening (Scarinci et al, 2012; 2013)

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<th>Theoretical Constructs</th>
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<th>African American Women in the Mississippi Delta &amp; rural &amp; urban Alabama</th>
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| **Perceptions**         | (+) Knowledge on the importance of screening  
(+/-) Motivated to be healthy to take care of others  
(-) Limited knowledge - connection b/e CC & HPV  
(-) Misconceptions on risk factors  
(-) Stoic attitude toward health and illness & fatalism | (+) Knowledge on the importance of screening  
(+/-) Motivated to be healthy to take care of others  
(-) Limited knowledge - connection b/e CC & HPV  
(-) Misconceptions on risk factors  
(-) Stoic attitude toward health & illness/fatalism |
| **Enablers**            | (+) Trust in some community-based organizations, community health advisors  
(-) Lack of health insurance, lack of knowledge on where to go for screening, differences in health care between US and their home countries | (+) Trust in some community-based organizations, community health advisors  
(-) Lack of health insurance |
| **Nurturers**           | (+) Strong alliance to other Latinas  
(-) Opposition from spouses | (+) It does not matter what others think |
| **Perceived Susceptibility** | (-) Not at risk for CC b/c they do not have the perceived risk factors & preventive care is not a priority | (+/-) Fatalism & others perceived being susceptible |
| **Perc. Severity**      | (+) CC perceived as a deadly disease | (+) CC perceived as a deadly disease |
| **Perceived Barriers**  | (-) Structural – no health insurance, DK where to go, transportation  
(-) Intrapersonal– embarrassment, procrastination, lack of motivation, competing priorities, fear of results, uncomfortable | (-) Structural – no health insurance, transportation  
(-) Intrapersonal – embarrassment, procrastination, lack of motivation, competing priorities, fear of results, uncomfortable |
| **Perceived Benefits**  | (+) Belief that screening can detect cancer early  
(-) Few believe that if CC is detected early the chances of survival are excellent/good; lack of understanding that screening can detect changes BEFORE cancer | (+) Belief that screening can detect cancer early  
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# Cervical Cancer Screening (Scarinci et al, 2012)

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Intervention Development – one Example

Funded by the National Cancer Institute
Division of Cancer Epidemiology and Genetics
U01 CA114619 - Deep South Network for Cancer Control
Background

- To compare cytology vs. self-sampling for HPV testing
  - Pap test
  - Clinician-collected sampling for HPV testing
  - Self-collected sampling for HPV testing at home
- Three groups of women: Pap, colposcopy and unscreened
Women’s Health Project

✓ Engaged the existing Community Health Advisors, Health Officer, and other leadership in the community
✓ Focus groups with women coming to the public clinics for their Pap test and women from the community who have not been screened for the past three years
✓ One discussion group on the usability of the device
✓ Talks in the community about cervical cancer
✓ Radio programs, newspapers, etc.

Litton et al., 2013; Scarinci et al., 2013
## Health Belief Model/Recruitment

Strecher & Rosenstock, 1997

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<th>Concept</th>
<th>Definition</th>
<th>Strategies</th>
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| Perceived Susceptibility | “One's opinion of chances of getting a condition”             | Understand potential participants’ relevance of the trial to their personal lives and their perceived susceptibility to the disease  
Personalize the outreach message to heighten their awareness & potential susceptibility |
| Perceived Severity   | “One's opinion of how serious a condition and its consequences are”     | Understand potential participants’ perception of the disease severity and consequences  
Incorporate the findings in the outreach messages – adding personal relevance |
| Perceived Benefits   | “One's belief in the efficacy of the advised action to reduce risk or seriousness of impact” | Explore potential participants’ perceived benefits in participating in the program  
Reinforce the benefits in recruitment messages |
| Perceived Barriers   | “One's opinion of the tangible and psychological costs of the advised action” | Explore potential participants’ barriers in participating in the program  
Incentives, assistance – structural barriers  
Education, reassurance – emotional barriers |
| Cues to Action       | “Strategies to activate ‘readiness’ “                                    | Make it easier for participants to come – be available, reminders, etc |
| Self-Efficacy        | Confidence in one's ability to take action                               | Assure that potential participants’ are confident they can do it – clear instructions, reinforcement |
• The technology was acceptable & adopted
• Women correctly self-collected sampling for HPV testing
• Unscrened women returned for follow-up if HPV testing was abnormal
Feasibility Study to test the approach in the real world (Castle et al., 2011)

- Door-to-door approach – canvassing two entire towns in the Mississippi Delta (Sunflower County)
- Community Health Worker model
- Unscreened women between 26 and 65 – had been screened for cervical cancer within the past three years
- Women were given a choice of Pap test or self-sampling for HPV testing
- Primary Outcomes: choice and compliance with choice
Households Contacted (n = 1,212)

- Household Refused (n = 3)
  - Eligible Households (n = 492)
    - 543 Women
  - Unavailable Household (n = 485)
  - Ineligible Household (n = 232)
- Ineligible Women (n = 394)
- Eligible Women (n = 122)
- Unavailable Women (n = 27)
  
Non-Consenting Women (n = 3)

Consenting Women (n = 119)

- Pap Test (n = 42)
  - Completion (n = 17 - 40.4%)
- Self Collection & HPV Testing (n = 77)
  - Completion (n = 62 – 80.5%)

Castle et al., 2011
Community Health Worker Model as a Promising Strategy for Low-Resource Settings

- “Natural helpers” from within the targeted community
- Different terminology
  - Community health advisors, promotores de salud, lay health educators, lay health advisors
- Strengths – ability to implement disease prevention and/or management in a culturally relevant manner, social support, link between the community and health care system/social services
Challenges with the CHW Model

- Roles and responsibilities
- Qualifications/necessary skills
- Volunteers vs. paid staff
- Training
- Adherence to protocol
- Allegiance – who do they work for?
Lessons Learned

✓ Before we create expectations we must understand the infrastructure, political will, opposition forces & allies, and hidden agendas
  ✓ Low-resource settings within high income countries
  ✓ Low-resource settings w/in low- & middle-income countries
✓ We are influenced (and influence others) by our own cultural background & experiences
✓ Research, outreach or education in low-resource settings must consider sustainability, engagement, and social change
✓ Future work is needed on “cultural adaptations” – more similarities than differences
  ✓ Are they part of the “house structure” or “window dressing”? 
✓ Behavior change occurs at all levels
✓ Sometimes “low or high resources” are in the eyes of the beholder
Thank You

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