Screening & Early Detection in Low-Resource Settings

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UAB MEDICINE

Knowledge that will change your world

Disclaimer

Funding

✓National Cancer Institute
- ✓ R01CA111799 (Scarinci)
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✓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

Application of Behavior Change Principles at the Population Level

- ✓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

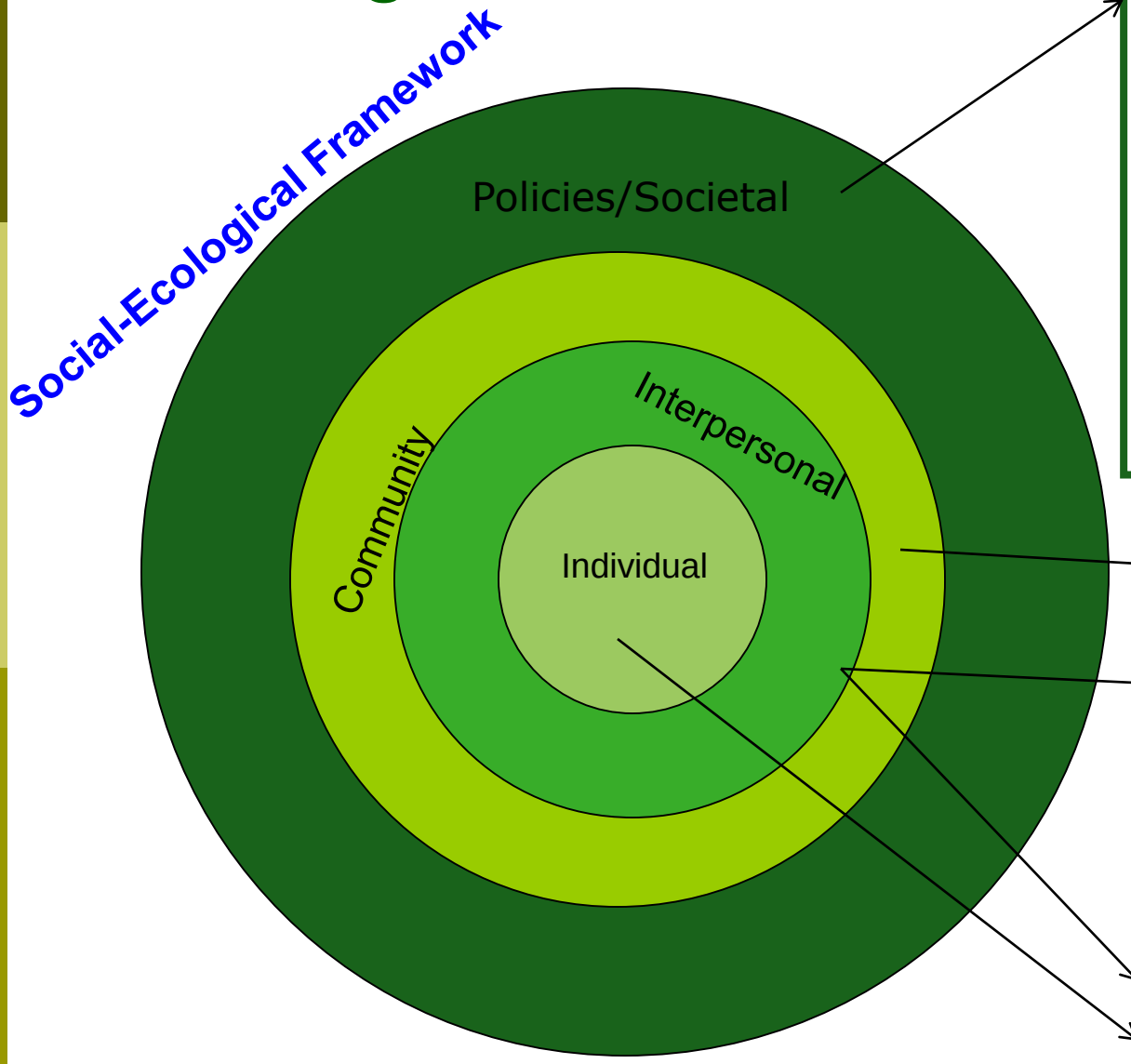
- ✓Grew up in a multicultural environment in South Brazil
- ✓Spent half of my life in a “rich state” in a low- middle income country and the other half in a “poor state” in a high-income country

The Discovery-Delivery Disconnect

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

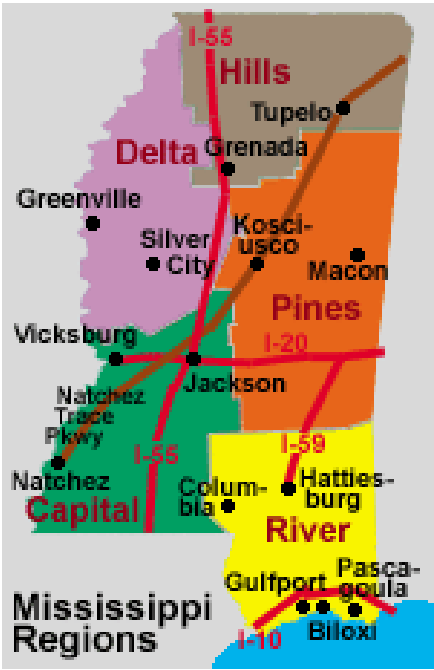
	Level of Available Resources			
	Basic	**Limited**	**Enhanced**	**Maximal**
Public Education & Awareness	Development of **culturally sensitive, linguistically appropriate** local education programs for target populations to teach value of early detection, breast cancer risk factors and breast health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

BO, Yip CH, Smith RA, et al. Cancer 2008;113(8 suppl):2221-43

Cervical Cancer Mortality (per 100,000)

	All Women	Whites	African Americans
United States *	4.1	2.0	4.2
Mississippi **	3.4	2.4	5.6
Mississippi Non-Delta **	3.0	2.4	4.6
Mississippi Delta **	3.4	2.7	8.6

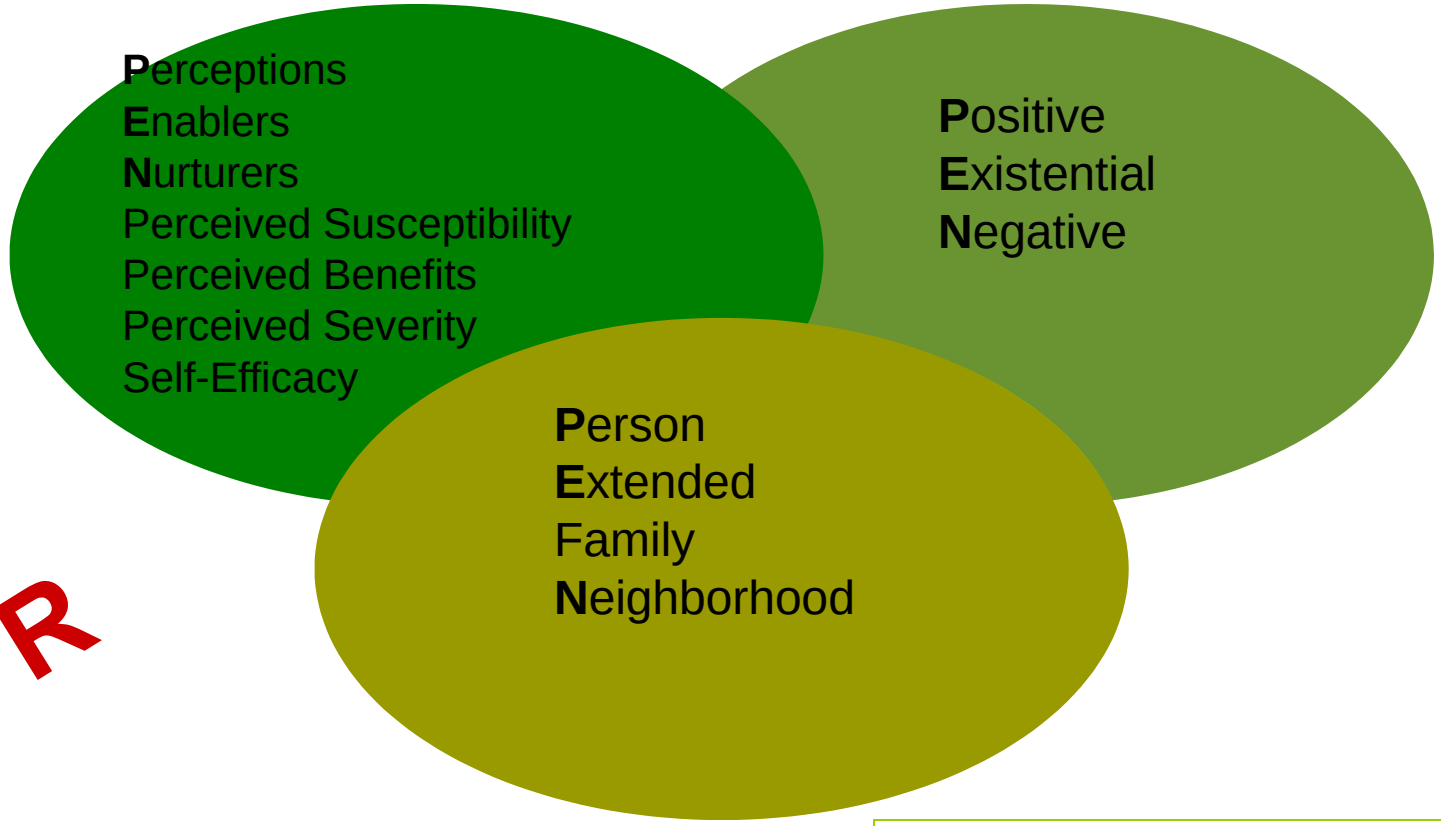
*Siegel et al., 2015 (data for 2007-2011)
** Mississippi Cancer Registry, 2015 (data for 2008-2012)



Theoretical Framework
PEN-3 & Health Belief Model

Educational Diagnosis of Health Behavior

Cultural Appropriateness of Health Behavior



CBPR

Airhihenbuwa, 1992; Rosenstock, 1999

Health Education

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)

Theoretical Constructs	Latina immigrants in Alabama
Perceptions	(+) Knowledge on the importance of screening (+) Motivated to be healthy to take care of others (-) Limited knowledge of the connection between cervical cancer and HPV (-) Stoic attitude toward health and illness
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
Nurturers	(+) Strong alliance to other Latinas and strong desire to help each other (-) Opposition from spouses in getting screened if provider is male
Perceived Susceptibility	(-) Not at risk for CC b/c they do not have the perceived risk factors (e.g., lack of hygiene) & preventive care is not a priority
Perceived Severity	(+) CC perceived as a deadly disease
Perceived Barriers	(-) Structural – lack of health insurance, do not know where to go, transportation (-) Intrapersonal – embarrassment, procrastination, lack of motivation, competing priorities, fear of results, test being uncomfortable
Perceived Benefits	(+) Belief that screening can detect cancer early (-) <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
Self-Efficacy	(-) Intrapersonal barriers $\longrightarrow$ low self-efficacy

Cervical Cancer Screening (Scarinci et al, 2012; 2013)

Theoretical Constructs	Latina Immigrants in Alabama	African American Women in the Mississippi Delta & rural & urban Alabama
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, uncomf	(-) 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 (-) 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
Self-Efficacy	(-) Intrapersonal barriers → low self-efficacy	(-) Intrapersonal barriers → low self-efficacy

Cervical Cancer Screening (Scarinci et al, 2012)

Theoretical Constructs	Latina Immigrants in Alabama	Brazilian Women in a Southern Town (Maringá)
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 – cancer, 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 systems	(+) Trust in some community-based organizations, community health workers
Nurturers	(+) Strong alliance to other Latinas (-) Opposition from spouses	(+) Strong alliance to other women (+) 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	(-) Not at risk for CC b/c they do not have the perceived risk factors & preventive care is not a priority
Perc. Severity	(+) CC perceived as a deadly disease	(+) CC perceived as a deadly disease
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Self-Efficacy	(-) Intrapersonal barriers → low self-efficacy	(-) Intrapersonal barriers → low self-efficacy

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

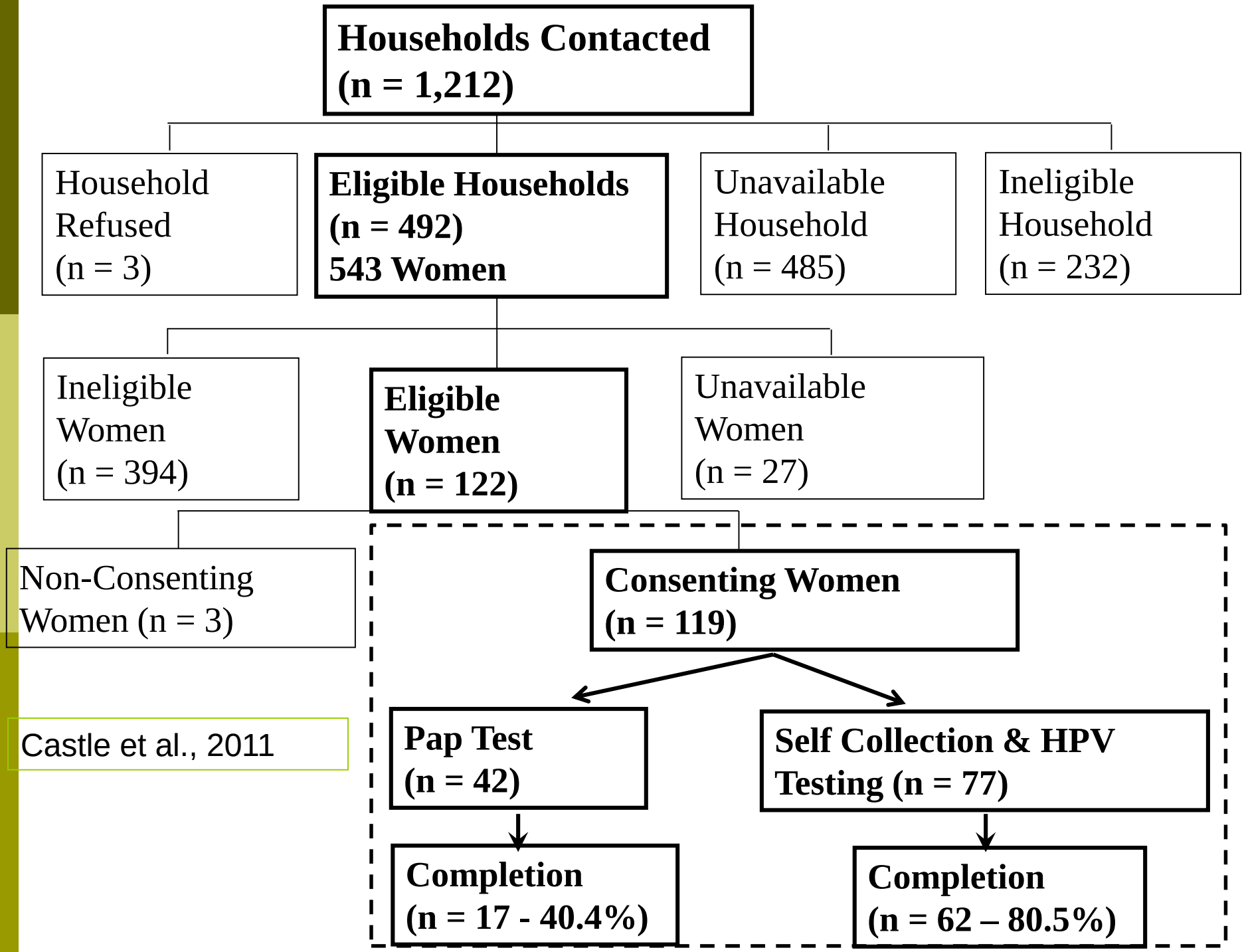
Strecher & Rosenstock, 1997

Concept	Definition	Strategies
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
- Unscreened 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)
Self Collection & HPV
Testing (n = 77)
Completion
(n = 17 - 40.4%)
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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