CANCER HEALTH DISPARITIES

DEBORAH ERWIN, PHD
ELISA MARIE RODRIGUEZ, PHD, MS
OBJECTIVES

• Increase understanding of meaning and complexity of cancer disparities

• Increase understanding of efforts to study and eliminate these disparities
DISPARITIES

Differences in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions that exist among specific population groups in the U.S.
## DEMOGRAPHICS OF WNY

<table>
<thead>
<tr>
<th>Area</th>
<th>Population</th>
<th>Percentage Non-White/Minority</th>
<th>Percentage African American</th>
<th>Percentage Hispanic</th>
</tr>
</thead>
<tbody>
<tr>
<td>8-county area of WNY</td>
<td>1.5 million</td>
<td>18%</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>Erie County</td>
<td>919,040</td>
<td>22%</td>
<td>13%</td>
<td>4%</td>
</tr>
<tr>
<td>Buffalo</td>
<td>261,310</td>
<td>50%</td>
<td>39%</td>
<td></td>
</tr>
</tbody>
</table>
Although population of Buffalo and Erie County may have small amount of pop decline...

• 23% increase in minority populations 2000-2010
  • Hispanic 36% increase
  • Asian 30% increase
  • Native American 9% increase
  • African American 6% increase
  • Mixed 19,819
DEMOGRAPHICS OF WNY

• 8-county area  12.4% below poverty
• Erie County     13% below poverty
• Niagara Falls  16% below poverty
• Buffalo        27% below poverty
MEASURES FOR ASSESSING DISPARITIES & PATIENT DIVERSITY

- Race/ethnicity (often used as a proxy for everything else)
- Age
- Geographic location
- Insurance status
- Income (not available in EMR)
- Education (not available in EMR)
- Cultural context (country of birth, life experiences, religion, lifestyle... )
OVERVIEW OF DISPARITIES IN CANCER

• Blacks/African Americans more likely *to be diagnosed with cancer
• Age-adjusted total cancer mortality is higher in Blacks/African Americans*
• Blacks/African Americans less likely* to be diagnosed with early stage cancer
• Blacks/African Americans less likely to survive five years or longer*
• Disparities in most screening rates (exception – Pap)

* As compared to Whites
BREAST CANCER INCIDENCE RATES* BY RACE AND AGE

Rate per 100,000 female population

Age at diagnosis

Source: SEER 1996–2001* OLD DATA
Note: Graphs may not begin at age 20 due to sample size limitations.
BREAST CANCER INCIDENCE RATES BY RACE/ETHNICITY 1975-2010

BREAST CANCER STATISTICS, 2013
INCIDENCE BY AGE, RACE/ETHNICITY
AND ESTROGEN STATUS

Years 2000 to 2010

CA: A Cancer Journal for Clinicians
Volume 64, Issue 1, pages 52-62, 1 OCT 2013 DOI: 10.3322/caac.21203
Years
1975 to 2010
THE CHALLENGES OF ELIMINATING DISPARITIES

• Socioeconomic Status (SES) & Poverty

• Race/Ethnicity

• Social Context of SES, Color/Race & Health

• Biology & Behavior...?
CHALLENGES – SOCIOECONOMIC STATUS (SES) & POVERTY

• Chicken v. Egg
  • Poverty $\rightarrow$ health disparities
  • Poor health leads to higher med $ & reduction of work $\rightarrow$ poverty
• Proportional poverty
• Wealth...
CHALLENGES – RACE

• Race is frequently used

1. “...uncritically as a proxy for unspecified genetic, sociocultural, or behavioral risk factors.” (Gravlee, Non, Mulligan 2009)

2. “...studies that do test specific genetic or sociocultural hypotheses seldom test competing explanations” (Gravlee, Non, Mulligan 2009)
CHALLENGES – RACE

• Social justice issues
  • Social prejudice & racism (e.g., religion, new immigrants, minorities)

• Race & Health 1933-1999 (Levine et al Pub Health Rep 2001)
CHALLENGES – SOCIAL CONTEXT OF SES & RACE

- Racial residential segregation & health
  - Higher cost for housing, food, insurance, etc
  - Poorer quality grocery items → poorer nutrition
  - Targeted for tobacco and alcohol products
- Discrimination & Medical Mistrust
- Must move beyond biomedical model (focus on disease and individual risk behaviors)
  - Pathways for how we “embody” SES & Race
  - “How Race Becomes Biology…” (Gravlee 2009)
MULTIPLE FACTORS ➔ DISPARITIES
“UNNATURAL CAUSES”

• Is Inequality Making Us Sick?
  • [http://www.youtube.com/watch?v=diMVgcb8Qzk](http://www.youtube.com/watch?v=diMVgcb8Qzk)
HEALTH DISPARITIES: LOOKING AT MULTIPLE FACTORS

- Genetics
- Health Behaviors
- Social Determinants
HOW CAN RESEARCH HELP TO ELIMINATE HEALTH DISPARITIES?

• Community-Based Participatory Research
  
  • Collaborative approach that involves a research partnership with community members, groups and/or institutions
  
  • Action-oriented
  
  • Goal is to address issues recognized by the community (relevant to the community)
RESEARCH EXAMPLE
Roswell Park Cancer Institute
Office of Cancer Health Disparities Research

Research to understand, prevent, and cure cancer

Don’t be left out...
MOBILE RESEARCH UNIT
STUDY GOAL AND OBJECTIVE

• R03 Pilot Study, E. Rodriguez (PI)

• **Goal:** Test community-based approach to educate and recruit participants to biospecimen donation

• **Objective:** Examine the complexity of biospecimen donation participation process across community programs
SUMMARY: PROGRAM LEVEL DATA

- N=370 participants reached
  - Education n=264 participants
  - Open Events n=106 participants
- 24 programs delivered in English and Spanish
  - 14 Education Programs
    - 10 in English
    - 4 in Spanish
  - 10 Open Events
    - 7 in English
    - 3 in Spanish
COMMUNITY OUTCOMES
SELECTED CHARACTERISTICS OF PARTICIPANTS WITHOUT A CANCER DIAGNOSIS IN A COMMUNITY-BASED BIOSPECIMEN DONATION STUDY, BY RECRUITMENT METHOD (N=311)*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Education Program</th>
<th>Open Event</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n) (%)</td>
<td>(n) (%)</td>
</tr>
<tr>
<td><strong>Language of Program</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>146 (63)</td>
<td>40 (50)</td>
</tr>
<tr>
<td>Spanish</td>
<td>85 (37)</td>
<td>40 (50)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>176 (76)</td>
<td>69 (86)</td>
</tr>
<tr>
<td>Male</td>
<td>54 (23)</td>
<td>11 (14)</td>
</tr>
<tr>
<td>Not reported</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Age (in years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-39</td>
<td>27 (12)</td>
<td>17 (21)</td>
</tr>
<tr>
<td>40-59</td>
<td>70 (30)</td>
<td>50 (63)</td>
</tr>
<tr>
<td>60+</td>
<td>130 (56)</td>
<td>9 (11)</td>
</tr>
<tr>
<td>Not reported</td>
<td>4</td>
<td>4 (5)</td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>139 (60)</td>
<td>39 (49)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>92 (40)</td>
<td>41 (51)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school or less</td>
<td>112 (48)</td>
<td>34 (43)</td>
</tr>
<tr>
<td>Some college or higher</td>
<td>111 (48)</td>
<td>30 (38)</td>
</tr>
<tr>
<td>Not reported</td>
<td>8</td>
<td>16 (19)</td>
</tr>
<tr>
<td><strong>Biospecimen Donation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>83 (36)</td>
<td>44 (55)</td>
</tr>
<tr>
<td>No</td>
<td>148 (64)</td>
<td>36 (45)</td>
</tr>
</tbody>
</table>

*p-values*

* Manuscript under review.
## COMPARISON OF BIOSPECIMEN DONATION RATES BY PARTICIPANT LEVEL OF EDUCATION (N=223)*

<table>
<thead>
<tr>
<th>Level of Education</th>
<th>Biospecimen Donation</th>
<th>High School or Less</th>
<th>Some College or higher</th>
<th>Total</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>n</td>
<td>n (%)</td>
<td>n</td>
<td>(%)</td>
</tr>
<tr>
<td>Yes</td>
<td>31</td>
<td>50</td>
<td>(28)</td>
<td>(45)</td>
<td>81 (36)</td>
</tr>
<tr>
<td>No</td>
<td>81</td>
<td>61</td>
<td>(72)</td>
<td>(55)</td>
<td>142 (64)</td>
</tr>
</tbody>
</table>

* Manuscript under review
PROGRAMMATIC IMPLICATIONS

• Community-Based Approach-Capacity and Transparency

• Significant community ties were established prior to the implementation of both program formats

• Both efforts require trained staff
IMPACT ON CANCER HEALTH DISPARITIES

- Creation of an education program
- Increased participation from racial/ethnic minority community
- Built on existing community research partnerships to develop an innovative research area
DISPARITIES INTERVENTIONS & RESEARCH

HOW TO REDUCE DISPARITIES
BREAST CANCER & AFRICAN AMERICAN/BLACK WOMEN

• Incidence of aggressive breast cancer is higher among black women than white women, and black females have higher mortality and lower five-year relative survival

• Breast cancer in black women is less likely to be diagnosed in the local stage compared with white women

• Five-year relative survival rates are approximately ten percentage points lower for black women than for white women in each age group
THE WITNESS PROJECT®

• Culturally competent
• Community-based
• Breast and cervical cancer education
• Meet the needs of African American women
• Created in 1991

In church, people witness to save souls.
At the Witness Project, they witness to save lives.
THE WITNESS PROJECT®

• Culturally competent…
  • Survivors (credible messengers)
  • Telling their stories (meaningful messages
    – Narrative communication)
  • Within a spiritual context (credible and
    meaningful environment)
THE WITNESS PROJECT®

• Increase breast self-examination (BSE)
• Increase mammograms
• Increase clinical breast exams
• Increase Pap tests
• Decrease disparities in cancer morbidity and mortality in African American women

BREAST & CERVICAL CANCER DISPARITIES FOR LATINAS

- Use of Mammography
  - Latinas*  59.6%
  - NL Whites 68.1%

- Use of Pap tests
  - Latinas*  74.6%
  - NL Whites 81.4%

*Latinas – aggregated as a single racial/ethnic group
• Use of Mammography
  • Mexicans 59.4%
  • Cubans 68.4%
  • Puerto Ricans 72.5%
  • “Other” 68.5%
  • NL White 68.1%

ESPERANZA Y VIDA (HOPE & LIFE)

- Community-based intervention
- Cancer survivor role model
- Navigation to screening services
- Goal: Investigate effectiveness of Esperanza y Vida for increasing breast and cervical cancer screening compared to control (diabetes)
Methods

• Randomized Interventions
  • Cancer v. Diabetes

• Program sites (churches, homes, community org’s)
  • Arkansas (AR) (Mexico)
  • New York City (NYC) (Diverse)
  • Buffalo (WNY) (Puerto Rico)

• Audience Response System (ARS) data collection

• 2- month follow-up (educational program alone)

• 8-month telephone follow-up (with navigation)

• Focus on newer immigrants, Spanish-speaking, lower income
RESULTS

• Cancer knowledge did not enhance screening

Influential factors for Mammography & Pap:

• Outreach to women in the community & how to access the system (navigation)

• Navigators → cultural brokers (cognitive & sociopolitical factors)

• NY sites/Puerto Rican women most likely to be screened (higher bl screening)

• Negative impact of sociopolitical conservatism in the South

• Prior screening experiences

DISPARITIES & LUNG CANCER
LUNG CANCER

• Lung cancer incidence
  • African American men  112 per 100,000
  • White men  82 per 100,000

• Lung cancer incidence in WNY
  • African American men  97.4 per 100,000
  • White men  75.4 per 100,000

• Lung cancer mortality rate WNY
  • African Americans  80.8 per 100,000
  • Whites  58.0 per 100,000
LUNG CANCER

- High Risk Lung Cancer Clinic at RPCI
  - Spiral CT scan
  - Bronchoscopy
  - Removal of lesions
  - Tissue samples, surveys, etc \(\rightarrow\) Stacy Scott Lung Ca Registry

- Stacy Scott Registry
  - >400 patients
  - Only 4\% were African American

Initiated a pilot to address these disparities
LUNG CANCER - RESULTS

- Fire Fighter Recruitment
  - N=332
- Community Recruitment
  - N=164
Total N=496

- 19.2% African American
- 16.3% Native American
- 50% Males ages 40-59
- 21.2% High school graduates
- 127/496 (25.6%) former smokers
- 61/496 (12.3%) current smokers
DISCOVERING METHODS TO RECRUIT AFRICAN AMERICAN WOMEN INTO RESEARCH (H. OCHS-BALCOM, PI)
DISCOVERING METHODS TO RECRUIT AFRICAN AMERICAN WOMEN INTO RESEARCH - BACKGROUND

- BRCA1/2 genetic discoveries- 20 years ago
- Research with over 329 women from 23 extended families who volunteered genetic specimens
- 96% of BRCA mutation carriers are white

Why have we not explored inherited genetic links for breast cancer in women of color....?

African American and Black women in the U.S.

- higher incidence of pre-menopausal breast cancer
- higher breast cancer mortality rates than white women
THE BALANCING ACT OF GENETIC RESEARCH & “PERSONALIZED MEDICINE”

Exploitation

Inclusion
THE RESEARCH QUESTION

• An African American woman in Buffalo, NY (Veronica) asked me, “Why? What is the gene that is affecting MY family?”

From right: Evelyn, Veronica and Mary
GOAL & AIMS

Genome-wide linkage analysis: "Search for novel breast cancer susceptibility genes in pedigrees of African ancestry" ("Jewels in Our Genes")

- Recruit at least 125 relative pairs (i.e., families) with at least two women with breast cancer from each family,
- Older unaffected women from the family
- Total of at least 250 cases and 86 unaffected relatives
- N= 336 African American women

JEWELS IN OUR GENES -- METHODS

1. Partnership with National Witness Project (outreach & screening for breast & cervical ca)
2. Letters to black women who had participated in other epidemiological studies on breast ca
3. Face-to-Face, National conferences & Meetings (e.g., Sisters Network; Komen races)
4. Susan Love/Avon/Army of Women (AOW) website (e-blasts)
   • Telephone follow-up ..... For all of the above...
2009-2012

- Total of 342 African American women
- Affected by breast cancer (n=248) and
- Unaffected (n=94) siblings from
- 127 families completed biological donations and surveys

### RESULTS: WOMEN RESPONDING TO RECRUITMENT BY APPROACH

<table>
<thead>
<tr>
<th>Outcome</th>
<th>National Witness Project*</th>
<th>Letters to participants in other epidemiology studies</th>
<th>Avon/Army of Women Internet E-blasts</th>
<th>Face-to-Face National Conferences**</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>All women who responded or were contacted (&quot;total pool&quot;)</td>
<td>118</td>
<td>220</td>
<td>272</td>
<td>61</td>
<td>671</td>
</tr>
<tr>
<td>Determined to be ineligible</td>
<td>3</td>
<td>81</td>
<td>65</td>
<td>4</td>
<td>153(23%)</td>
</tr>
<tr>
<td>Refusals</td>
<td>4</td>
<td>15</td>
<td>9</td>
<td>2</td>
<td>30 (5%)</td>
</tr>
<tr>
<td>Outstanding</td>
<td>5</td>
<td>8</td>
<td>17</td>
<td>6</td>
<td>36 (5%)</td>
</tr>
<tr>
<td>Unable to contact or unresolved at close of study</td>
<td>11</td>
<td>34</td>
<td>65</td>
<td>0</td>
<td>110(16%)</td>
</tr>
<tr>
<td>Complete - affected - unaffected</td>
<td>70</td>
<td>57</td>
<td>87</td>
<td>34</td>
<td>248</td>
</tr>
<tr>
<td>Total recruited</td>
<td>95</td>
<td>82</td>
<td>116</td>
<td>49</td>
<td>342</td>
</tr>
<tr>
<td>% Yield</td>
<td>81%</td>
<td>37%</td>
<td>43%</td>
<td>80%</td>
<td>51%</td>
</tr>
</tbody>
</table>

TRIPLE-NEGATIVE BREAST CANCER (TNBC) IN AFRICAN AMERICAN WOMEN (C. AMBROSONE, PI)

• Parity-- formerly considered a risk reduction factor—actually increases risk of TNBC in African American women

• These breast cancer risks can be totally ameliorated in African American women if they breastfeed

• Breastfeeding rates in the U.S. are socially patterned
  • 59% of African American (AA) infants
  • 75% of white infants

SUMMARY …

• Importance of cultural tailoring and approach

• Sensitivity to variations in communities – importance of LOCAL culture

• Messaging and communication is sensitive to minor racial/ethnic/gender/age/geographic variations

• Importance of direct education & communication for low literacy, language challenged sub-groups
• Appropriate methods are time & labor intensive

• Medical mistrust, compliance issues, resistance to participation are based on experience(s)

• Inequities are a systems problem not a patient problem – Don’t blame the victim!
ACKNOWLEDGEMENTS – WITNESS PROJECT

- The National Witness Project Steering Committee
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Nikia Clark
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Linda Smith, NP
Databank and BioRepository (DBBR) Staff

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Cancer Control Advisory Board (C-CAB)
Esperanza y Vida (EyV)

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QUESTIONS?