

CANCER HEALTH DISPARITIES

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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

- 8-county area of WNY 1.5 million
 - 18% non-white/minority
 - 10% African American
- Erie County 919,040
 - 22% non-white/minority
 - 13% African American
 - 4% Hispanic
- Buffalo 261,310
 - 50% non-white/minority
 - 39% African American
 - Hispanic, Mixed race/ethnicity

DEMOGRAPHICS OF WNY

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...)

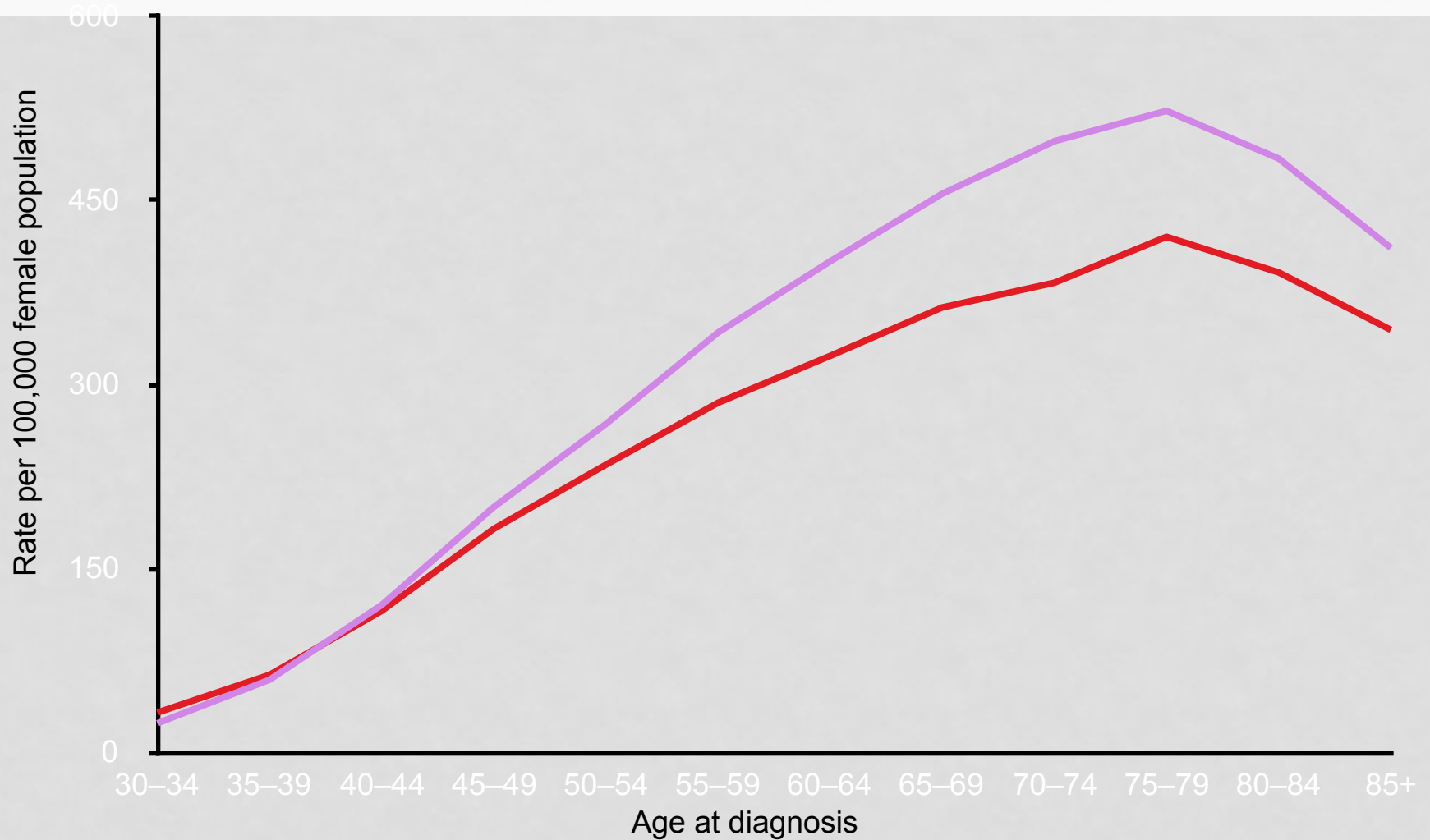
OVERVIEW OF DISPARITIES IN CANCER

- 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

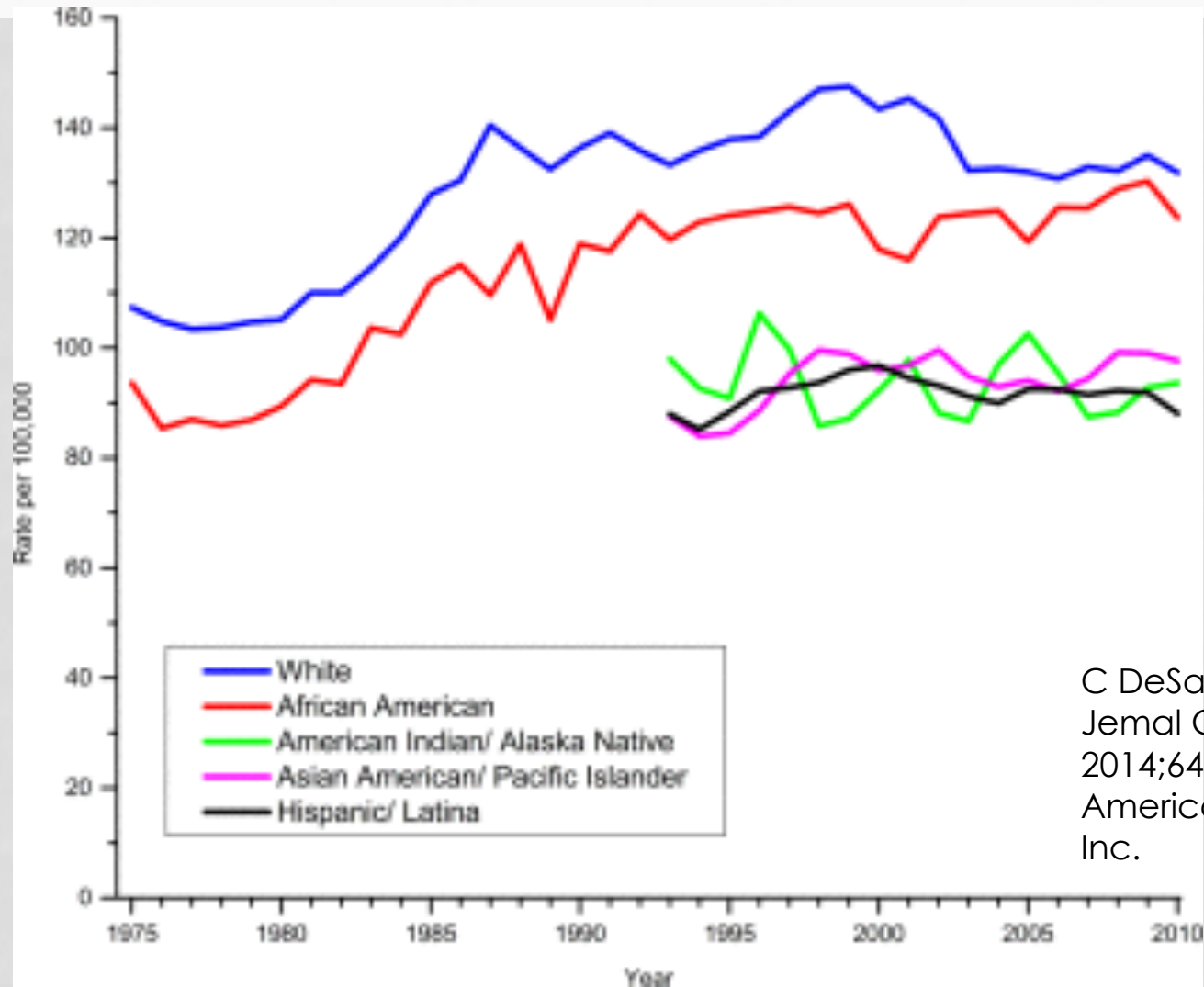
— Black — White



Source: SEER 1996–2001* OLD DATA

Note: Graphs may not begin at age 20 due to sample size limitations.

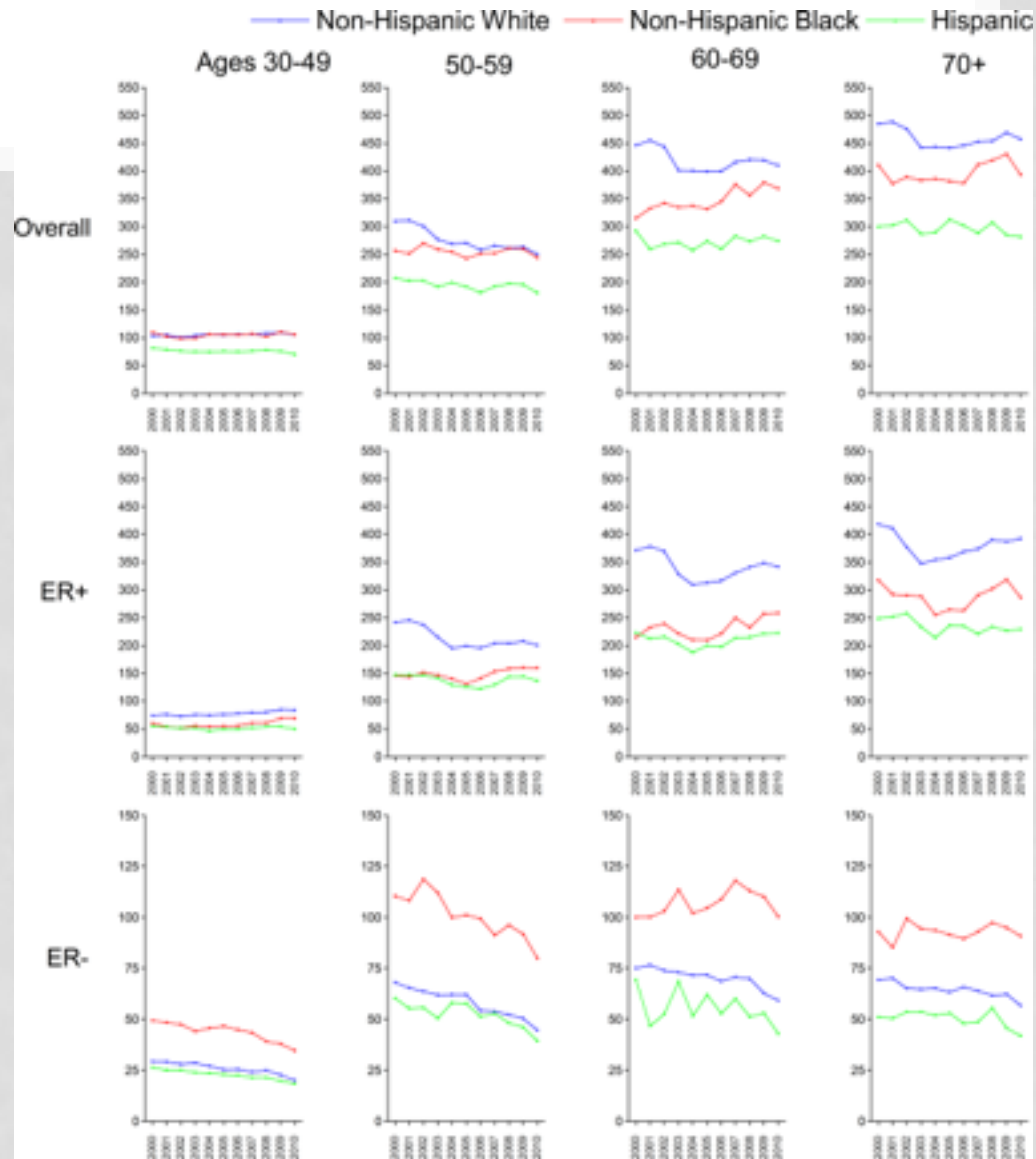
BREAST CANCER INCIDENCE RATES BY RACE/ETHNICITY 1975-2010



C DeSantis, J Ma, L Bryan, A Jemal CA Cancer J Clin 2014;64:52-62. © 2013 American Cancer Society, Inc.

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

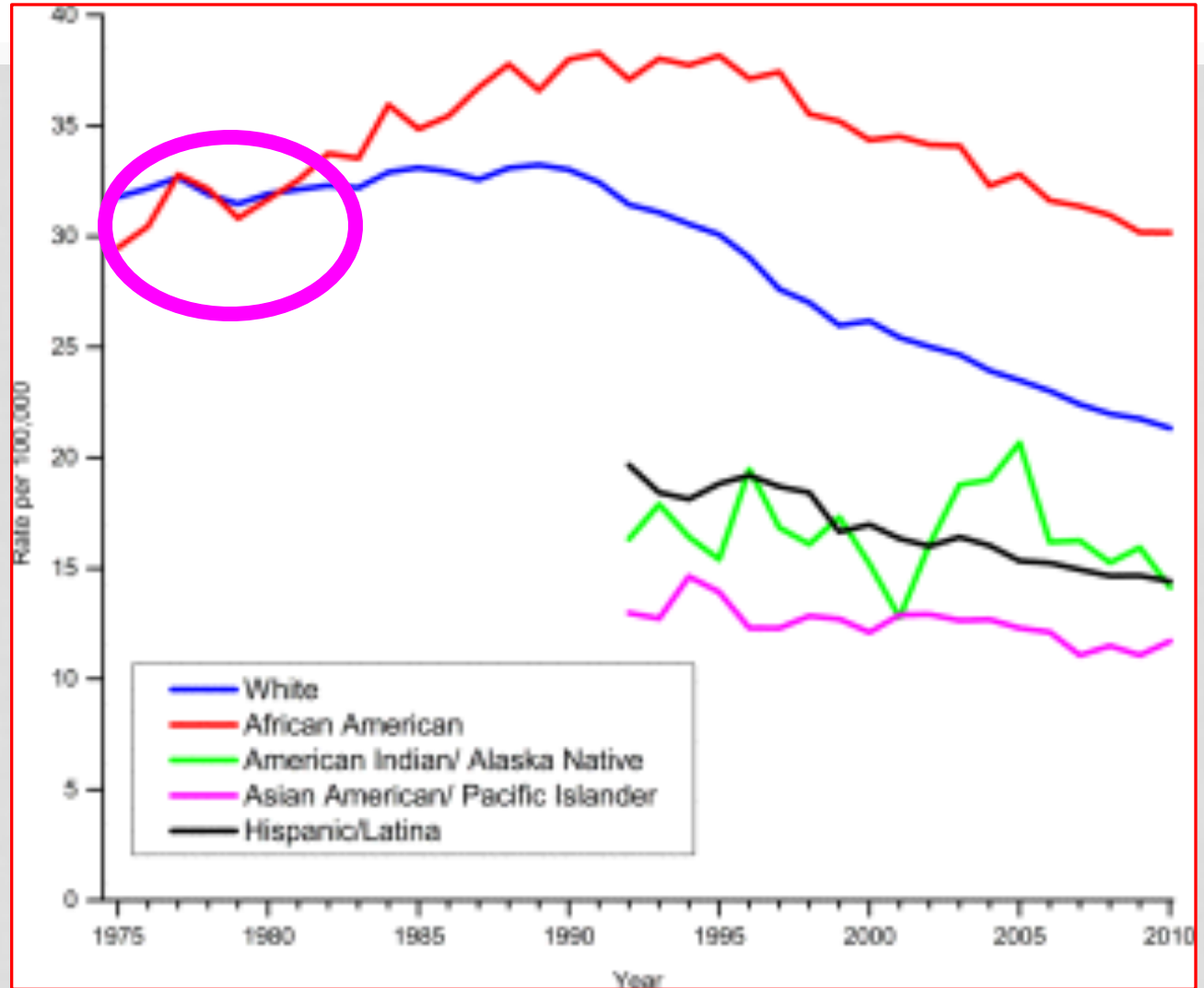
**Years 2000 to
2010**



BREAST CANCER STATISTICS, 2013

DEATH RATES BY RACE/ETHNICITY

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 → health disparities
 - Poor health leads to higher med \$ & reduction of work → 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>

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



Don't be left out...

Research to
**UNDERSTAND
PREVENT
AND CURE
CANCER**



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)*

<i>Characteristic</i>	Education Program		Open Event		p-values
	<i>n</i> (231)	(%)	<i>n</i> (80)	(%)	
<i>Language of Program</i>					
<i>English</i>	146	(63)	40	(50)	.038
<i>Spanish</i>	85	(37)	40	(50)	
<i>Gender</i>					
<i>Female</i>	176	(76)	69	(86)	.066
<i>Male</i>	54	(23)	11	(14)	
<i>Not reported</i>	1	-	-	-	
<i>Age (in years)</i>					
<i>18-39</i>	27	(12)	17	(21)	.000
<i>40-59</i>	70	(30)	50	(63)	
<i>60+</i>	130	(56)	9	(11)	
<i>Not reported</i>	4	(2)	4	(5)	
<i>Race/Ethnicity</i>					
<i>African American</i>	139	(60)	39	(49)	.075
<i>Hispanic</i>	92	(40)	41	(51)	
<i>Education</i>					
<i>High school or less</i>	112	(48)	34	(43)	.682
<i>Some college or higher</i>	111	(48)	30	(38)	
<i>Not reported</i>	8	(4)	16	(19)	
<i>Biospecimen Donation</i>					
<i>Yes</i>	83	(36)	44	(55)	.003
<i>No</i>	148	(64)	36	(45)	

* Manuscript under review.

COMPARISON OF BIOSPECIMEN DONATION RATES BY PARTICIPANT LEVEL OF EDUCATION (N=223)*

Biospecimen Donation	Level of Education						p-value
	High School or Less		Some College or higher		Total		
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	
<i>Yes</i>	31	(28)	50	(45)	81	(36)	.007
<i>No</i>	81	(72)	61	(55)	142	(64)	

* 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

Erwin, DO: *The Witness Project: Narratives that Shape the Cancer Experience for African-American Women*. In *Confronting Cancer: Metaphors Advocacy, and Anthropology*. J. McMullin, D. Weiner, eds. Pp. 125-146. Santa Fe: School for Advanced Research Seminar Series. 2009.

Erwin DO, Johnson VA, Feliciano-Libid L, Zamora D, Jandorf L. Incorporating Cultural Constructs and Demographic Diversity in the Research and Development of a Latina Breast and Cervical Cancer Education Program. *Journal of Cancer Education*, 2005; 20:39-44.



BREAST & CERVICAL CANCER IN LATINAS



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

BREAST & CERVICAL CANCER DISPARITIES FOR LATINAS

- 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)



ESPERANZA Y VIDA (HOPE & LIFE)

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 b1 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 → 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”



Inclusion

Exploitation

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...

JEWELS IN OUR GENES --RESULTS

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

Outcome	National Witness Project*	Letters to participants in other epidemiology studies	Avon/Army of Women Internet E-blasts	Face-to-Face National Conferences**	Total
All women who responded or were contacted ("total pool")	118	220	272	61	671
Determined to be ineligible	3	81	65	4	153(23%)
Refusals	4	15	9	2	30 (5%)
Outstanding	5	8	17	6	36 (5%)
Unable to contact or unresolved at close of study	11	34	65	0	110(16%)
Complete					
-affected	70	57	87	34	248
-unaffected	25	25	29	15	94
Total recruited	95	82	116	49	342
% Yield	81%	37%	43%	80%	51%

*Includes recruitment by sites and from site visits

**Face-to-Face & National Meetings other than National Witness Project, but staffed by Witness Project. Ochs-Balcom HM, et al., ...Erwin DO. J Community Genet. 2015 Jan;6(1):39-45.

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

Palmer, J. R., et al (2011).. *Cancer Epidemiology Biomarkers & Prevention*, 20(9), 1883-1891.

Palmer, J. R., et al.. . . Ambrosone, C. B. (2014). *Journal of the National Cancer Institute*, 106(10), 10.1093/jnci/dju237. Print 2014 Oct. doi:10.1093/jnci/dju237 [doi]

SUMMARY ...

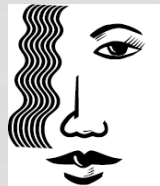
- Importance of cultural tailoring and approach
- Sensitivity to variations in communities – importance of LOCAL culture
- Messaging and communication is sensitive to minor racial/ethnic/gender/age/geographic variations
- Importance of direct education & communication for low literacy, language challenged sub-groups

...SUMMARY

- 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

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Community Partners:

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Men Allied for the Need to Understand Prostate Cancer (MAN UP)

Cancer Control Advisory Board (C-CAB)

Esperanza y Vida (EyV)

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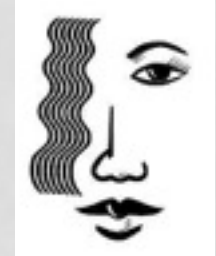
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QUESTIONS?