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, survivorship and burden of cancer and related adverse health conditions that exist among specific population groups in the U.S.

DEMOGRAPHICS OF WNY-POP.

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

1.5 million

919,040

261,310

DEMOGRAPHICS OF WNY- POP. INCREASE

Although population of Buffalo and Erie County may have small amount of pop decline...

- 23% increase in minority populations 2000-2010
- Hispanic
- Asian
- Native American
- African American
- Mixed

36% increase 30% increase 9% increase 6% increase 19,819

DEMOGRAPHICS OF WNY-POVERTY

- 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)

BREAST CANCER INCIDENCE RATES BY RACE/ETHNICITY 1975-2010



BREAST CANCER STATISTICS, 2013

DEATH RATES BY RACE/ETHNICITY

Years 1975 to 2010



http://onlinelibrary.wiley.com/doi/10.3322/caac.21203/full#caac21203-fig-0004

THE CHALLENGES OF ELIMINATING DISPARITIES

- Socioeconomic Status (SES) & Poverty
- Race/Ethnicity
- Social Context of SES, Color/Race & Health
- Behavior
- Biology

CHALLENGES – SOCIOECONOMIC STATUS (SES) & POVERTY

Chicken v. Egg

- Poverty \rightarrow 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 \rightarrow 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)

STRATEGIES TO REDUCE AND ELIMINATE CANCER DISPARITIES

- Multiple and often interrelated factors contribute to disparities
- Strategies to reduce disparities need to address multiple causal factors and may also require multilevel approaches

EXAMPLES OF STRATEGIES

- Community-Based Participatory Research
 - Collaborative approach that involves a <u>research partnership</u> with community members, groups and/or institutions
 - Action-oriented, lay-health advisor models (e.g., community health worker/CHW)
 - Goal is to address issues recognized by the community (relevant to the community) and increase capacity

EXAMPLES OF STRATEGIES RELATED TO THE SOCIAL ENVIRONMENT

- Access to Health Services- environment
 - Increasing access to care (e.g., early detection/screening)
 - Health insurance coverage of preventive services, minimize cost to patient
 - Make the process user friendly and convenient
- Health Care Providers- environment
 - Cultural sensitivity and community competence
 - Patient and health-care provider communication
 - Referrals from health-care providers
- Health Policy- environment
 - Policy can affect the greatest # of people
 - Policies that focus on social determinants can have a major impact on the social conditions that contribute to disparities
 - Achieve Health Equity (e.g., quality care-relevant to everyone; regulations on health status reporting; and research that supports comparative effectiveness; adoption of evidence-based practices and practice-based evidence)

EXAMPLES OF STRATEGIES RELATED TO THE INDIVIDUAL AND ENVIRONMENT

- Knowledge and Awareness- individual
 - Community-based education and outreach efforts
 - Culturally appropriate-language and belief systems
 - Targeting and tailoring messages-literacy and communication issue
- Clinical Trials Participation- individual and environment
 - Generalizability to the population
 - Underrepresentation of racial and ethnic minority groups in clinical trials
 - Barriers: distrust related to past abuses in research; access to research participation; knowledge and awareness; cost; lack of insurance; eligibility criteria; cultural barriers; low literacy; practical obstacles

COMMUNITY-ENGAGED RESEARCH EXAMPLE



MOBILE RESEARCH UNIT



STUDY GOAL AND OBJECTIVE

- R03 Pilot Study
- **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

HOY Y MAÑANA STUDY RESULTS

- N=370 participants reached
 - Education n=264 participants
 - Open Events n=106 participants
- Participants with some college or higher were more willing to donate as compared to participants with high school or less and this was shown to be significant in actual donation of a sample
- We did compare willingness prior to donation and again those with more education were also more willing to donate.

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

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
 - The more children, the more the risk increased
- 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]

NOVEL INTERVENTION TO INCREASE LACTATION BY AFRICAN AMERICAN WOMEN (NIH/NCI R21)

- Pilot Study n=280 African American women in WIC
- Randomized to social media intervention (Texts, Facebook, polls, Pre-post birth surveys)
 - Intervention Arm: Messages on Breast Feeding Benefits plus Breast Ca Risk Reduction by Breast Feeding
 - Control Arm: Messages focused on Breast Feeding Benefits
 alone
- Outcomes:
 - Affective Association (Feeling) changes
 - Cost- Benefit & Knowledge (Cognitive)
 - Intent & Breast Feeding behaviors
 - Impact on Family (mothers, sisters, partners)

COLORECTAL CANCER (CRC) SCREENING STUDY

- African American disparities in CRC screening, incidence & mortality
- RCT N=2453 African Americans in Buffalo & NYC
 - N= 1841 Baseline (\geq 50 y.o, consented)
 - <u>Intervention:</u> Education program with narrative communication video
 - <u>Control:</u> Education program with didactic video
 - 48.5% <u><</u>H.S.
 - 56.6% <u><</u>\$19,999 (9.6% <u>></u>\$50K)
- Preliminary Data
 - Higher levels of education & income were associated with higher CRC screening (Baseline only)
 - Narrative Communication most effective for lower SES & positively impact negative feelings about colonoscopy

Clinician and Parent Perspectives on Educational Needs for Increasing Adolescent HPV Vaccination



100 ASS THE REY TO MARCER DREWENDED

Widman, C.A., Rodriguez, E. M., Saad-Harfouche, F., Twarozek, A. M., Erwin, D. O., & Mahoney, M. C. (2016). Clinician and Parent Perspectives on Educational Needs for Increasing Adolescent HPV Vaccination. *Journal of Cancer Education*, 1-8. PMID: 27640203. NIHMS817544

BACKGROUND

- Human Papilloma Virus (HPV) is a significant public health challenge despite availability of vaccine
 - More than 120 types identified
- HPV is ubiquitous
- The International Agency for Research on Cancer (IARC) lists oncogenic strains as carcinogenic
- Three HPV vaccines available 2 in the US
- Rates of vaccine remain low

Cancers Caused by HPV, U.S.

	Average number of cancers per year probably caused by HPV			Percentage
Cancer site	Male	Female	Both Sexes	per year
Anus	1,400	2,600	4,000	91%
Cervix	0	10,400	10,400	91%
Oropharynx	7,200	1,800	9,000	72%
Penis	700	0	700	63%
Vagina	0	600	600	75%
Vulva	0	2,200	2,200	69%
TOTAL	9,300	17,600	26,900	

CDC, United States Cancer Statistics (USCS), 2006-2010

EXPLORATORY AIM:

 To explore barriers, opportunities, resources and potential collaborations focused on the issues of HPV vaccination.

METHODS

- Complete an environmental scan on HPV vaccine uptake
- Mixed methods study
 - Interviewer administered semi-structured interview with clinicians (n=52)
 - Self-administered survey completed by parents (n=54)
 - Clinician interviews conducted on the phone
 - Parent surveys completed in person pre-education session
- Data collection took place between January and April 2015

CLINICIAN RESULTS

- Dominant themes on educational needs around HPV vaccination:
- 1. Cancer prevention
- 2. HPV vaccine efficacy, benefits, and safety
- 3. Provider-patient communication
 - HPV vaccine efficacy, benefits, and safety topics were discussed
 - Acknowledge importance of clinician recommendation
 - Include males in recommendations



- Completion of HPV vaccine is more important than completion of Tdap
- Completion of HPV vaccine is more important than completion of MCV4

PARENT RESULTS

- Dominant themes on educational needs around HPV vaccination:
- 1. Lack of knowledge is primary barrier to HPV uptake
 - Specifically, HPV-related disease, HPV vaccines, HPV vaccine safety, sexual concerns, and misinformation encountered on social media
 - Cited cancer prevention as key message to use; remove sexual connotations
 - Open to receiving this education through children's schools

NEXT STEPS...

- The research team is currently working on a practice-based intervention with pediatric practices throughout WNY to help improve HPV vaccination rates
- Health care provider/patient observational component has been completed-qualitative data analysis in process
- Currently finalizing the intervention for testing in pediatric offices with low HPV vaccination rates

DISPARITIES & LUNG CANCER





LUNG CANCER

- Lung cancer incidence
 - African American men
 - White men

112 per 100,000 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 SCREENING GUIDELINES

THIS WAS NOT LISTED IN THE OVERVIEW ARTICLE!

- Smoking history (<u>></u>20 Pack Years)
- Prior aerodigestive cancer history (e.g., lung, mouth, throat)
- Asbestos-related lung disease
- COPD (e.g., emphysema, chronic bronchitis)
- Additional consideration of family history of aerodigestive cancers and environmental tobacco smoke (ETS) exposure

LUNG CANCER SCREENING AT RPCI

- 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 EDUCATION - 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

METHODS TO RECRUIT AFRICAN AMERICAN WOMEN INTO RESEARCH (H. OCHS-BALCOM, PI)



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

Ochs-Balcom HM, Rodriguez E, Erwin DO. Journal of Community Genetics. 2011; 2(4):223-231

JEWELS IN OUR GENES -- RESULTS

• Through partnership with the National Witness Project, using registry resources & having raceconcordant staff for follow-up...

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

Ochs-Balcom HM, et al., ... Erwin DO. J Community Genet. 2015 Jan;6(1):39-45.

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!

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