The Urgent Need for Cross-cutting Race-Conscious Approaches to Cancer Disparities Research

Kemi M. Doll, MD MSCR
Associate Professor, Department of Obstetrics and Gynecology
University of Washington
Fred Hutchinson Cancer Research Center
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Disparities in Cervical Cancer Mortality by Race/Ethnicity in the US

Mortality

Stage Distribution

SEER Reference

2
US Endometrial Cancer Statistics by Race/Ethnicity: Incidence

Data from: SEER cancer statistics review 1975-2018, Available at: seer.cancer.gov
US Endometrial Cancer Statistics by Race/Ethnicity: Mortality

Data from: SEER cancer statistics review 1975-2018, Available at: seer.cancer.gov
Racial disparities in cancer outcomes are the default outcome of our current biomedical research and healthcare delivery systems.

Fundamental Cause Theory
(Link & Phelan)

Differences in outcomes based on social position in a society arise in the context of the treatability of a given condition.


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**Phase 1: Natural Inequalities**
Limited knowledge about risk factors, or limited effective treatment.
Stable mortality rate.

**Phase 2: Increasing Inequalities**
Unequal diffusion of innovations, risk factor reduction, treatment strategies.
Decreasing mortality rate with *increasing* disparities.

**Phase 3: Reducing Inequalities**
Increased access to new knowledge and innovation.
Decreasing mortality rate with *decreasing* disparities.

**Phase 4: Reduced Mortality**
Widely available prevention and/or effective treatment.
Minimized or absent mortality with minimal or no disparity.

*Doll, KM. Investigating Black-White disparities in gynecologic oncology: Theories, conceptual models, and applications. Gynecologic Oncology. 2018 Apr;149(1):78-83*
Treatability increases because of federally funded biomedical research.

**Phase 1: Natural Inequalities**

- Limited knowledge about risk factors, or limited effective treatment.
- Stable mortality rate.

**Phase 2: Increasing Inequalities**

- Unequal diffusion of innovations, risk factor reduction, treatment strategies.
- Decreasing mortality rate with increasing disparities.

Example

**Endometrial Cancer**

NIH lead discovery of Innovations, Risk factors, and Treatments…

….WITHOUT an equity lens

Tolerance of predominantly White trial participants
Absence of equity science expertise
Narrow definitions of success
Disparities persist because of the disproportionate lack of federally funded equity research.

**Phase 2: Increasing Inequalities**
- Unequal diffusion of innovations, risk factor reduction, treatment strategies.
- Decreasing mortality rate with increasing disparities.

**Phase 3: Reducing Inequalities**
- Increased access to new knowledge and innovation.
- Decreasing mortality rate with decreasing disparities.

**Example** Cervical Cancer

**Underfunding**
- Exclusion of Black & URM Researchers
- Misaligned incentives
- Poor research design and execution

**Targeted, specific innovation** to adapt the status quo by disrupting key flexible resources (knowledge, money, prestige, power, and social connections).
Our Default Approach is Not Working

• Inappropriately low funding allocated
IC Total Budget and Percentage Women's Health Research Spending, FY2020

Inappropriately low allocation for ALL of women's cancer research incentivizes the de-prioritization of marginalized women’s cancer

Sources:
1. Women’s health spending data derived from NIH RCDC data system frozen file.
Our Default Approach is Not Working

• Inappropriately low funding allocation
• Systematic underfunding and exclusion of Black & Underrepresented Minoritized researchers
“The cluster with the lowest award rate (7.5%) is characterized by the words *ovary, fertility, and reproductive*...”

Currently, it makes more sense for Black and URM cancer researchers to **avoid** women’s health and disparities research than to engage in it.

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**SCIENTIFIC COMMUNITY**

**Topic choice contributes to the lower rate of NIH awards to African-American/black scientists**

Travis A. Hoppe¹,², Aviva Litovitz¹,², Kristine A. Willis³*, Rebecca A. Meseroll¹,², Matthew J. Perkins¹,², B. Ian Hutchins¹,², Alison F. Davis⁴, Michael S. Lauer⁵, Hannah A. Valantine⁴, James M. Anderson², George M. Santangelo¹,²†

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Fig. 1 Funding gap between AA/B and WH scientists at each stage of the R01 application and review process. Arrows on the left indicate the number of AA/B and WH R01 applicants in FY 2011–2015. The total number of applicants with a reported race/ethnicity is 45,998. Rocket charts depict the number of applications that were submitted, discussed, and funded per applicant. Comparative rates of discussion, funding of discussed applications, and overall funding rates are presented on the top right (**P < 0.01**).
Time to first R01 award according to URM status and gender among K awardees

Members of the group with the worst gynecologic cancer outcomes are currently the **LEAST likely to be supported** in an NIH-funded research award.

Source: https://nexus.od.nih.gov/all/2021/07/27/further-demographic-analyses-of-nih-r01-grant-outcomes-of-t32-postdoctoral-participants/
Our Default Approach is Not Working

- Inappropriately low funding allocation for women’s health
- Systematic underfunding and exclusion of Black & Underrepresented Minoritized researchers
- Systematic underfunding and exclusion of racism research
Racism operates at ALL levels across societal structures and environments.

There should be as many RFAs, study sections, and opportunities for funding as there are connections between upstream / downstream factors and the cancer care continuum.
How do we DISRUPT this process on behalf of improving the lives of all people with gynecologic cancers?

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A Race-Conscious Approach to Women’s Cancer Research
1. Embrace cross-cutting approaches that acknowledge the power and complexities of how racism influences health

- Early detection in the setting of social and physical environments?
- Clinical trial design in the setting of racist funding processes?
- Treatment environment as a mediator of treatment completion?
- Survivorship in the setting of the value of Black labor?
2. Align funding to incentivize the study of unjust creation, dissemination and delivery of cancer research knowledge

- Use disciplinary self-critique to disrupt the current pattern of *colorblind innovation* that creates and exacerbates ongoing inequities
3. Prioritize equity research grounded in theories and frameworks that undergird race, gender, and health.

- Example: Intersectional Frameworks for Research Participation – Andrea Gilmore-Bykovskyi PhD, RN

4. Prioritize equity research grounded in theories that undergird race, gender, and health.

• Example: Inclusion Science for Recruitment of Marginalized Populations into Clinical Trials – Jonathan Jackson PhD

Used with permission from Dr. Jackson
5. Embrace a goal of NIH-funded research as a tool to disrupt the default outcome of marginalized women as the secondary priority.

- Redefine innovation in cancer research to be equity-conscious
- Redefine high-risk, high-reward in cancer equity research
  - Community engagement, support, and co-leadership
- Fund Black Scientists\(^1\)
- White is not the default human\(^2\) – divest from the ‘control’ group fallacy
- Fund cancer equity research with more money – divest from the scarcity myth

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A Race-Conscious Approach to Women’s Cancer Research

1. Recognize that the default structure of cancer research creates and exacerbates cancer inequities for marginalized women.

2. Embrace cross-cutting approaches that acknowledge the power and complexities of how racism influences health.

3. Align funding to incentivize the study of the unjust creation, dissemination and delivery of cancer research knowledge.

4. Prioritize equity research grounded in theories on how race, gender, and health operate in our society.

5. Embrace a goal of NIH-funded research as a tool to disrupt the default outcome of marginalized women as the secondary priority.
Suggested RFA Solicitations for Gynecologic Cancer Equity

- Quantitative and Qualitative Evaluation of Bias and Exclusion in Biomedical Cancer Research
- Development of multi-level Approaches to Equitable Representation of Marginalized Populations in Cancer Clinical Trials
- Impact of structural and interpersonal racism on outcomes in the cancer care continuum
- Life course approaches to evaluate gynecologic cancer disparities among Black and Native women
- Interdisciplinary structural interventions to overcome expected inequity in clinical trial participation
Thank you!

Kemi M. Doll, MD MSCR