Reporting on Race and Racial Disparities: The Neglect of Racism as a Driver of Inequitable Care

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Background

- The volume of research on racial disparities has increased over the past two decades
- We hypothesize there is considerable variation in how race is contextualized, defined, and captured in the disparities literature, leading to its questionable validity and relevance as a covariate
- Recent guidelines for reporting have been suggested, but not yet applied

Aim

- This study reviews the current literature on racial disparities in breast cancer mortality, specifically evaluating the inclusion, justification, and discussion of race and ethnicity as a driver of disparities

Methods

- A rubric was developed to evaluate the reporting of race and/or ethnicity
- A systematic review (2010-2020) was performed to identify studies reporting on racial disparities in breast cancer surgery and mortality
- We evaluated these original articles based on key domains of race and/or ethnicity: justification for inclusion, formal definition, methodology used for classification, and type of racism contributing to disparity

Results

Table 1. Causes of disparities by race and/or ethnicity, as discussed by studies

Attributable cause of disparity	Number of studies*	Examples of causes of disparity (as discussed in manuscript text)
Access to care, Insurance status	34	Transportation, lack of healthcare access, concerns about cost sharing
Poorer quality of care	33	Lower guideline-concordant care, fragmented care, inappropriate primary surgical and radiation breast cancer treatment, failure to transition seamlessly through care, lack of physician referral, type of hospital performing breast surgery
Socioeconomic status	20	Employment status, lower SES, reside in lower SES neighborhoods
Cultural Factors, Mistrust	20	Folk beliefs, cultural beliefs and perceptions about treatment, patient-physician miscommunication
Other/unknown	20	Lower marital satisfaction, higher rate of surgical complications, more adverse side effects from radiation therapy, "fumbled handoffs," patient refusal of treatment, help-seeking behavior, toxic exposures
Cancer stage, Medical comorbidities	18	Treatment limiting comorbidities, more advanced stage at presentation, race/ethnicity impacts stage at diagnosis, poor nutrition, exercise, smoking
Genetics, Biological differences	17	Tumor characteristics, biologically different form of breast cancer
Care utilization patterns, Treatment delays	9	Underutilization of screening, ineffective organization structures contributing to underuse of cancer therapy, delay in radiation therapy
Health Literacy, Language barriers	5	Worry is associated with poorer understanding of information, language barriers
Racism	1	Perceived racism

*Total N > 50 because any single study could have attributed disparities to multiple causes

Table 2. Racism identified as cause of disparity.

	N (%)*	Examples of racism as discussed in the manuscript text
Not Mentioned	49 (98%)	
Direct use of the word "racism"		
Institutional	0	
Interpersonal/Personally Mediated	1 (2%)	"There may be other non-clinical factors influencing treatment and outcome… perceived racism or discrimination that vary by race/ethnicity and SES."[18]
Intrapersonal/Internalized	0	
Descriptive framing of racism	3 (6%)	"Provider biases or blatant discrimination may therefore potentially lead to disparities in surveillance mammography."[38] "… upstream factors, such as access to healthcare, routine screening, racial bias and socioeconomic status, contribute to the late-stage diagnosis and higher mortality experienced by Black patients with cancer."[39] "…with new advances, the benefits to control disease and death are often distributed according to resources of knowledge, money, power, prestige, and social connections."[40]

*Any single study could have identified racism as a cause of disparity

- Of the 50 studies assessed, none provided a formal definition for race and/or ethnicity
- A justification for the inclusion of race and/or ethnicity was provided in 72% of the studies
- While 80% of studies discussed at least one potential driver of observed racial disparities, only one study explicitly named racism as a driver

Conclusions

- Significant improvement in the reporting on racial disparities in surgical literature is warranted
- A more rigorous framework should be applied by both researchers and publishers when reporting on race and racism

Limitations

- Capturing qualitative data has inherent challenges of inconsistent intra-reader interpretability of language used
- While we attempted to clearly define variables in order to limit variations in interpretability, we cannot be certain that all variations were avoided
- This study was limited by a focus on breast cancer, potentially decreasing its generalizability
- Our assessment was performed using a new rubric that we developed, and the criteria has not been tested and validated by others