

Endometrial cancer disparities: a race-conscious critique of the literature

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Introduction

Endometrial cancer (EC) is the most common gynecologic cancer in the United States, affecting 1 in 37 women, with an increasing incidence each year.^{1,2} Racial disparities are pronounced. Black women with EC have an overall 55% higher 5-year mortality risk than white women, but the reasons for this are poorly understood.² The purpose of this article was to conduct a critical review of the EC disparities literature not merely to requantify known disparities, but to understand factors shaping the production of knowledge about the disparities.

Two important characteristics of traditional medical research are a focus on the biological conception of disease and a focus on individual factors, such as race, hypothesized to promote or reduce disease.^{3,4} However, in many areas of medicine, social factors such as racism have been shown to matter at least as much as the biological or other individual factors.⁵ These social factors have the greatest degree of influence when a given disease is treatable.^{6,7} Race is a social construct, with deep roots in the

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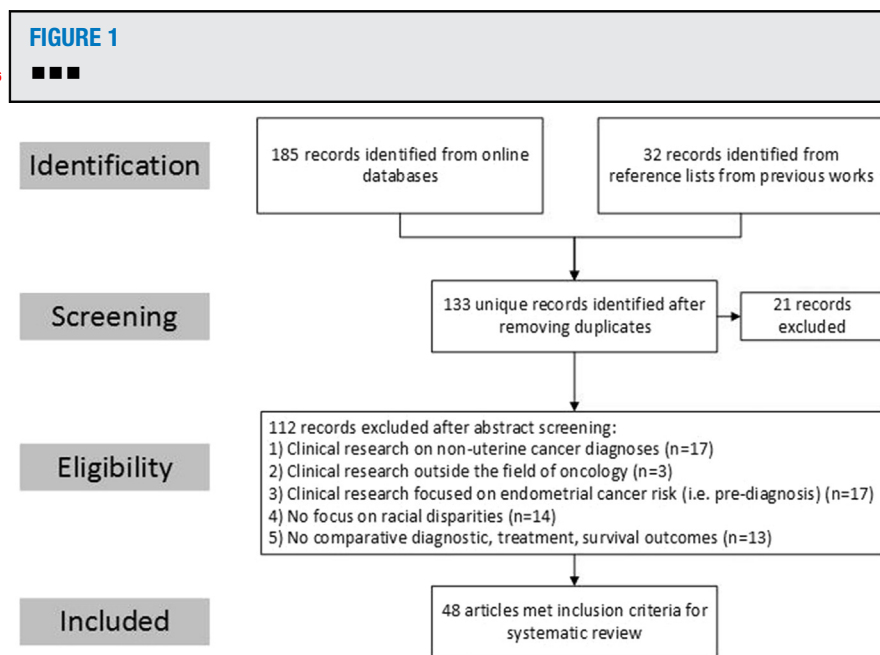
Racial disparities in endometrial cancer are stark and have increased over the past decade. While the disparities are well documented, intervention work to address the mortality gap is nonexistent. This review critiques how race has been conceptualized to explain the causes of endometrial cancer disparities, assesses gaps in knowledge production, and proposes new research priorities. Using public health critical race praxis, a research approach for examining racial disparities and knowledge production processes, we reviewed the endometrial cancer disparities literature from 1995 through 2016. Using systematic search methods, 133 unique records were identified and 48 studies critiqued. We found that a narrow definition of race as a purely biological construct is common throughout the literature. This appears to result in an underemphasis on the role of modifiable, nonbiological contributors to racial disparities and a lack of follow-up work to address these contributors. Key knowledge gaps identified were the role of health care systems in early diagnosis, a lack of intervention studies to address persistent treatment inequity by race, and the near absence of qualitative work to understand the perspectives of black women diagnosed with endometrial cancer. We conclude with an iterative demonstration of the public health critical race praxis and suggest new routes of inquiry to broaden the scope of research priorities to understand and improve the outcomes of black women with endometrial cancer.

Key words: African Americans, endometrial cancer, public health critical race praxis, race, racial disparities, racism

field of medicine.⁸ Originally, non-whites, including blacks, were conceptualized to have innate physical and behavioral pathology that defined and made them distinctly different from white races.⁸ We now know that race operates as a *rough proxy* for a range of underlying causal factors (socioeconomic status, cultural elements, and genes), and as an *indicator* of risk for mechanisms tied to the social stratification of people in a race-conscious society.⁹ This social stratification based on race/ethnicity (ie, racism) connotes the unequal allocation of opportunity and resources; it is associated with many poor health outcomes.¹⁰ To understand the health implications of these dimensions of race and racism requires reframing race as fundamentally a social construct, not a biological one. This means race is meaningful primarily because of differences in the sociopolitical treatment of people based on their group assignment.¹¹ While a rapidly expanding literature has shifted from

examining the contribution of “race” as a cause of disease toward examining the contribution of racism (ie, social inequality differentially affecting people based on race), how much the evidence on racial disparities in EC survival reflects this knowledge is not known.

Using the 4-stage research process and 10 central principles of public health critical race praxis (PHCRP),¹² we evaluate the extent to which the accumulated knowledge on EC disparities relies upon biological vs social constructions of race. Our critique was guided by 2 overarching questions: What is the primary definition of race being employed?; and, to what extent does the literature assess the role of racism (social stratification by racial classification) in disparate outcomes? Our results are presented in 3 parts: (1) a summary of the common themes identified in the literature review; (2) a critique of how race and racism have been conceptualized and the influence of this on knowledge production; and



PRIMSA screening process flow chart.

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(3) the use of the PHCRP to identify novel research questions.

The PHCRP

PHCRP is a biomedical research approach that grew out of critical race theory (CRT), which has its origin in legal studies.¹³ CRT has been adopted by fields such as education and ethnic studies as an approach to investigate, understand, and eliminate various inequities. It emphasizes the omnipresence of racism in society, including in health care settings, and the centrality of racism in the daily lives of people of color. According to PHCRP, scientific knowledge, including the knowledge on health disparities, is based primarily on Eurocentric paradigms that can work against the full achievement of equity in myriad ways. For instance, racial biases can inform the nature of research questions and a priori assumptions driving research. Key features of CRT for addressing such challenges include the use of counter-narratives and “voice,” which decenter whiteness as the frame through which to understand members of other groups.¹³⁻¹⁵ Another central theme is the concept of “intersectionality,” which recognizes how racism,

sexism, classism, and other forms of oppression or privilege co-occur simultaneously.^{13,16,17}

The PHCRP is a methodology that applies CRT to public health endeavors in equity research. It involves “a semi-structured process for conducting research that remains attentive to issues of both racial equity and methodologic rigor.”^{12,18} A schematic of the PHCRP process is shown in Figure 1. As originally conceptualized, the schematic functions as a 4-stage roadmap, indicating the kinds of questions on which to focus at each stage of the research process.¹² The 4 phases are: (1) contemporary patterns of racial relations, (2) knowledge production, (3) conceptualization and measurement, and (4) action. Here, the original schematic has been adopted to help clarify how research approaches used to examine EC disparities can influence understandings about the causes of the disparities. The 10 principles are: (1) race consciousness, (2) primacy of racialization, (3) race as a social construct, (4) ordinariness of racism, (5) structural determinism, (6) social construction of knowledge, (7) critical approaches, (8) intersectionality, (9) disciplinary self-critique, and (10)

voice. A flexible methodology, PHCRP has been used to explore police killings as a public health issue,¹⁹ substance abuse,²⁰ HIV prevention-related outcomes such as uptake of available HIV testing,^{12,21} psychological distress,²² and self-rated health.²³ For instance, Abdulrahim et al sought to understand if racial forms of discrimination are associated with psychological distress among >1000 Arabs, a group generally classified as white in the United States. The authors reported that even though all participants shared a similar culture, those with darker skin shade reported experiencing higher levels of discrimination, but the distress was greater for those of lighter skin shade who identified more closely with whites. The PHCRP reflects the perspectives of marginalized groups and encourages the development of evidence-based interventions that are based on these perspectives.

Our critique of the literature (Part II of this article) is based on the principles of the *Social Construction of Knowledge*^{Q5} and *Disciplinary Self-Critique*. Social construction of knowledge posits that culture and power shape knowledge production, by establishing the norms by which data are generated, the perspectives informing research questions, and the types of information deemed important.¹² Based on this principle, for each EC study, we considered how 3 norms influenced the design and interpretation of the work: a biological definition of race, whiteness as “normal,” and the belief in “colorblind” health care environments. We then considered what alternative hypotheses arise when removing these norms. The second principle we focused on, disciplinary self-critique, helps a discipline “shine a light on itself from within to understand how its norms may inadvertently buttress disparities either within the discipline or in society at-large.”¹⁸ Based on this, we assessed citation patterns to identify the studies with the most weight in the literature, and considered how the dominant themes identified in EC disparities research may influence future studies. For the generation of novel research questions (Part III of this article), we engaged PHCRP’s remaining

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