Racial Disparities in Rheumatology Through the Lens of Critical Race Theory

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KEYWORDS

• Race • Disparities • Giant cell arteritis • Osteoarthritis • Gout

KEY POINTS

- Race is a social construct, and there is considerable ancestral heterogeneity within racial groups.
- Critical race theory asserts that racism remains pervasive in society. The authors propose applying this theory to better understand and address racial/ethnic disparities in rheumatic diseases using the public health critical race praxis.
- Contrary to traditional teaching, giant cell arteritis is not rare in non-White populations, which often have considerable White ancestry.
- Lower rates of knee arthroplasties among Black patients cannot be fully attributed to patient preference; physicians must appropriately educate and build trust with patients and examine their own biases.
- HLA-B*5801 allele frequency and allopurinol-associated severe cutaneous adverse reactions remain elevated among Black patients but few rheumatologists order testing; thus, this population may benefit from genetic screening.

INTRODUCTION

The term race has historically been defined as a distinct group of people with similar physical characteristics and ancestry.[1] However, the work of late 20th century

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geneticists has confirmed that race is not a biologic construct based on genetics, but rather a social construct invented by those who would classify themselves as White in order to subjugate members of other races.[1] Indeed, geneticists and paleontologists have demonstrated that all human beings have ancestral origin in Africa,[2] and that there is more ancestral diversity within racial groups than between racial groups.[3] White race is often considered to be an exclusive group of pure European origin, and individuals who have a White parent and a non-White parent are typically assigned to the non-White group because of this concept of hypodescent.[4] Historically within the United States, the dominant narrative was that lighter skin color and ancestral European origin (also known as White race) was superior to darker skin color and ancestral origin in Africa, Asia, or the Americas.[5] This notion of White supremacy suggested that members of the White race were physically, intellectually, and morally superior to darker-skinned people. In the United States, this narrative of White supremacy was used to justify the genocide and theft of property from American Indians, the brutal enslavement and subsequent multifaceted oppression of Black Americans, and the discrimination against and marginalization of Asian American and Hispanic American communities. Consequences of this White supremacist ideology reverberate to this day, with ongoing massive inequality between the races in regards to wealth accrual, employment opportunities, incarceration rates, health care access and outcomes, and many other measures.[6] This enforced racial hierarchy, which has historically been perpetuated by the US government in order to uplift members of the White race, is also known as racism.[7]

In order to better study and combat the nuanced ways racism operates in the post-civil rights era, critical race theory (CRT) was formulated by a group of non-White legal scholars in 1989,[8] with foundations in the work of Derrick Bell.[9,10] According to CRT, racism is pervasive in modern US society, and is often covert. In regards to medicine and public health, CRT asserts that racism itself is a social determinant of health, and that racial bias has been incorporated into medical knowledge in ways that reinforce White supremacy. CRT has been applied to the field of health equity research using the public health critical race praxis (PHCRP),[11] which provides guidance for biomedical researchers (**Fig. 1**). The PHCRP framework considers all research to be informed by a priori biases; therefore, it calls for critical examination of a priori assumptions related to racial issues. In addition, it considers the complex ways in which membership in multiple oppressed groups may affect individuals synergistically (a concept known as intersectionality), the need for the perspectives of marginalized groups to drive the research process, and the need to take action based on the research outcome in order to advance racial health equity.

This article applies the PHCRP version of CRT to race-related topics in rheumatology. Many rheumatic diseases are associated with known racial and ethnic disparities,[12,13] which are defined by the Institute of Medicine as "differences in the quality of care received by minorities and non-minorities who have equal access to care… when there are no differences between these groups in their preferences and needs for treatment."[14] Specifically, the article explores three common misconceptions among rheumatologists through the lens of CRT:

Giant cell arteritis is rare in non-White populations.
Black patients are less likely to undergo knee replacement surgery because of patient preference.
HLA-B*5801 screening should only be performed for patients of Asian descent.

Accordingly, this article will explore how racism, racial bias, and lack of understanding of ancestral heterogeneity within racial groups perpetuate these common rheumatologic myths.

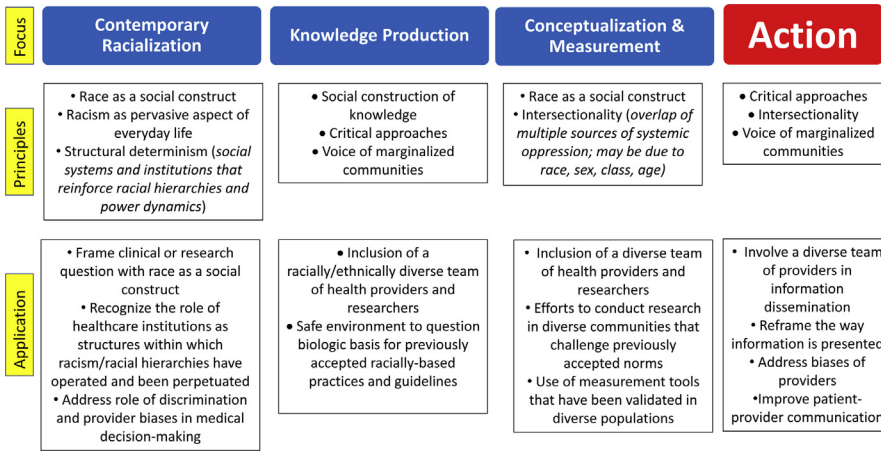

Fig. 1. Public health critical race praxis. (*Data from* Ford CL, Airhihenbuwa CO. The public health critical race methodology: praxis for antiracism research. Soc Sci Med 2010;71:1390-8; and Ford CL, Airhihenbuwa CO. Critical race theory, race equity, and public health: toward antiracism praxis. Am J Public Health 2010;100 Suppl 1:S30-5.)

CONTENT

Myth 1: Giant Cell Arteritis is Rare in Non-White Populations

Giant cell arteritis (GCA), the most common type of systemic vasculitis, may lead to adverse outcomes such as blindness and stroke if not diagnosed and treated promptly.[15] The incidence of GCA was initially studied in predominantly White populations of northern European ancestry who were at increased risk for this disease,[16] and historically GCA was believed to be exceedingly rare in non-White populations. For example, GCA has been found to be two- to fivefold more common in northern European versus southern European countries.[17] Compared with White Americans, the risk of GCA has historically been reported to be 20 times lower in Asian Americans, five to seven times lower in Black Americans, and lower in Hispanic-Americans and people of Arabic descent.[17] However, more recent studies have found that GCA is not as rare among non-White populations in the United States as was previously thought. A 2019 study from the Johns Hopkins Wilmer Eye Institute found that among 92 patients over the age of 50 with biopsy-proven GCA treated between 2007 and 2017, 15% self-identified as Black.[18] In that study, there was no significant difference in the incidence rate of biopsy-proven GCA between White and Black patients (incidence rate ratio 1.2; 95% confidence interval [CI] 0.6–2.4; P=.66). Similarly, a study of 32 patients with biopsy-proven GCA treated at the University of Miami between 1996 and 2002 found that 41% of these patients self-identified as Hispanic.[19] As these studies have demonstrated, GCA is not rare in non-White populations, and rheumatologists must maintain a high level of vigilance in order to detect and treat all patients with GCA in a timely manner, regardless of their race or ethnicity.

This controversy regarding race and GCA emphasizes an important concept, the ancestral heterogeneity within racial groups in the US. For example, Americans who self-identify as Black have 24% genome-wide European ancestry on average.[20] The European ancestry among Black American descendants of slaves is attributable to widespread rape of Black women by White men during slavery[21] and consensual inter-racial relationships since the mid-20th century. Additionally, Hispanic Americans frequently have mixed European, Native American, and/or African ancestry; the

average amount of genome-wide European ancestry among Hispanic Americans is 65%.[20] It is important for physicians, including rheumatologists, to understand this ancestral heterogeneity in order to avoid making incorrect assumptions regarding disease risk based on a patient's assumed or self-reported race. Indeed, this sort of diagnostic triage based on race may lead to missed diagnoses, untreated disease, and avoidable adverse outcomes that contribute further to racial inequities.

Myth 2: Black Patients Are Less Likely to Undergo Knee Replacement Surgery Due to Patient Preference

Osteoarthritis (OA) is the most common type of arthritis globally, with over 80% of cases involving the knee.[22] The only curative treatment for knee OA is knee replacement surgery, or knee arthroplasty. Several studies have demonstrated that in the United States, Black patients have lower rates of knee arthroplasty than White patients.[23–29] US nationwide studies have also shown that economic factors do not explain the lower odds of knee arthroplasty in Black men.[24,30] Other studies have reported that Black patients are less willing to undergo joint replacement surgery because of lack of understanding of the procedure, concerns about procedure efficacy, increased perception of operative risk, and concerns about postoperative pain and debilitation.[31–35] Additional studies have reported that when Black patients are given a hypothetical scenario between medical versus surgical treatment of knee OA, they are less likely to choose surgery (odds ratio [OR] 0.63, 95% CI 0.42–0.93),[36] and that racial differences in patient preference for total joint replacement may fully explain known racial disparities in joint replacement rates.[37]

However, attributing this racial disparity in knee arthroplasty rates to patient preference ignores both the responsibility of physicians to fully educate all patients about the risks and benefits of knee arthroplasty using nontechnical language that is tailored to an individual patient's health literacy, as well as the ways that provider characteristics (eg, implicit bias) may contribute. Studies have found that videos that educate Black patients about knee arthroplasty can improve expectations about the postoperative course[38] and that increased knowledge about knee arthroplasty among minorities can mitigate racial disparities in receipt of this procedure.[39] Additionally, mistrust of physicians may influence Black patients' decisions regarding knee arthroplasty. It is the physician's responsibility to build rapport with patients of color, particularly given the history of mistreatment of communities of color by the US medical establishment, which has engendered this mistrust. Black patients have been found to have worse outcomes than White patients after joint replacement surgery,[40] possibly related to delayed care/more advanced disease at presentation or poorer quality of care; it is therefore conceivable that Black patients know individuals within their social networks who have had poor outcomes after joint replacement, which may discourage receipt of surgery. Lastly, physicians have an obligation to be aware of their own racial biases, which may affect how patients are counseled about knee arthroplasty. For example, a 2014 study presented 543 primary care physicians (PCPs) with a hypothetical scenario describing either a Black or White patient with severe OA refractory to medical treatment, and found that PCPs had significant implicit and explicit racial bias that led them to label White patients as more medically cooperative, which could conceivably affect referral patterns for knee arthroplasty.[41] In summary, patient preference regarding knee arthroplasty can only be determined after physicians have educated patients about the risks and benefits of the surgery using appropriate language, established a trusting relationship with patients, and accounted for the racial and other biases they bring to the clinical encounter.

*Myth 3: HLA-B*5801 Screening Should Only Be Performed for Patients of Asian Descent*

Gout is an episodic arthritis that affects greater than 3% of the US population,[42] and the first-line treatment is the urate-lowering drug allopurinol. The most feared complications of allopurinol are severe cutaneous adverse reaction (SCARs), which may be fatal in up to 25% of cases.[43] The risk of allopurinol-associated SCARs in the general population is low at 0.1% to 0.4%; however, risk increases by greater than 500-fold in individuals who possess the HLA-B*5801 allele.[43] The 2012 American College of Rheumatology (ACR) guidelines for the management of gout recommend screening for the HLA-B*5801 allele prior to initiation of allopurinol in several populations of East Asian descent (Koreans with $\geq$ stage III chronic kidney disease, Han Chinese, and Thai).[44] This recommendation is based on literature revealing that HLA-B*5801 allele frequency is increased in these populations (6%–12%), along with greater than 300-fold increased risk of SCARs in these populations when exposed to allopurinol.[45–47]

However, the frequency of the HLA-B*5801 allele is also higher in Black patients (4%–6%) compared with White and Hispanic patients (both 1%).[48] Additionally, a 2018 US Medicaid study found that both Black and Asian patients have a threefold higher risk of allopurinol-associated SCARs compared with White and Hispanic patients.[49] The 2020 American College of Rheumatology guidelines update the conditional recommendation for HLA-B*5801 testing and now include Black individuals with patients of Southeast Asian descent.[50] However, currently rheumatologists are not trained to routinely screen Black patients for HLA-B*5801 positivity prior to initiating allopurinol, even though the consequences of not screening may be life-threatening. It is also important to recognize the constraints of using race to classify patients, as patients' genetic makeup may not be reflected by their apparent or self-reported race.

SUMMARY

CRT provides rheumatologists with a framework to study racial disparities related to rheumatic diseases and clarify exactly how racism contributes to them. One needs to understand that racism and racial bias are deeply embedded in all aspects of society; rheumatologic patient care, education, and research are not excepted. This article draws on CRT in order to offer guidance regarding 3 problems in the area of rheumatic disease that warrant further attention. Rheumatologists are taught that GCA is rare in non-White populations, even though recent studies have disputed this dogma; this example highlights that non-White populations may actually have considerable amounts of White ancestry, and that physicians are potentially misdiagnosing non-White patients with GCA, which may lead to serious consequences such as preventable blindness. Physicians are taught that Black patients with advanced, medically refractory osteoarthritis choose not to have total knee arthroplasties; however, this assertion is based on incomplete data, which neither account for the responsibility physicians have to educate their patients and build trusting relationships with them, nor examine how phsycians' own racial biases may affect the way they care for and counsel patients. Physicians are taught that they should screen patients of Korean, Han Chinese, and Thai descent for HLA-B*5801 prior to initiation of allopurinol for treatment of gout, but have not been taught do so for Black patients even though they too have significantly elevated risk of carrying the HLA-B*5801 allele and suffering from allopurinol-associated SCARs. CRT teaches that one must continually examine the field's beliefs in regard to race-related topics so that one is promoting health equity for all and taking the best possible care of one's patients.

DISCLOSURE

The authors have nothing to disclose.

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