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Race and class in big data

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Social determinants of health are well-established drivers of health outcomes across a range of pulmonary diseases, from asthma (1) to COPD (2) to sarcoidosis (3,4). Developing interventions to address health disparities in pulmonary disease has been complicated by the wide-reaching and varied effects of structural racism and classism (5). In this issue of *Sarcoidosis, Vasculitis, and Diffuse Lung Diseases*, Cherabuddi and colleagues (6) present data on the effect of a range of socio-economic factors impacting access to care in sarcoidosis. This work investigates a range of potential drivers of disparity, providing valuable information regarding potential interventional targets.

Health research has historically focused on individual factors (genetics, exposures, knowledge, adherence to medication, and lifestyle recommendations). In recent years, there has been an increasing focus on understanding how social determinants of health - including racism - drive observed health outcomes. While much has been published on the impact of racism in the social sciences, the terminology can be unfamiliar to clinicians and health researchers (7). A granular understanding of the multifaceted effects of racism is especially important when interpreting large datasets.

A fundamental theoretical framework of the multi-effects of racism on health outcomes was described by Dr. Camara Jones in 2000 (8). This influential work described three primary levels of racism: institutional, personally mediated, and internalized racism. While no one model can fully describe the multifaceted effects of racism, this three-level framework serves as an excellent structure to understand the terminology surrounding racism. In addition to these three-levels, the concept of "structural racism" has emerged as a fourth level of racism.

Institutional racism was defined as unequal access to resources and power, be that housing, employment, medical care, or clean air (8). The complex nature of institutional racism means that no single variable can capture the whole, dynamic range of its effects. Additionally, untangling these effects frequently requires an understanding of local history. In a recent asthma needs assessment of Omaha, Nebraska, the authors presented a detailed history of the residents of North Omaha, beginning with the indigenous peoples displaced, influx of immigrants and Black workers to meatpacking plants, and subsequent redlining and highway development (9). This detailed accounting of local history greatly enlightens the subsequent analysis, and highlights institutional factors at play: housing, exposure to pollution, employment, and working conditions. Even this detailed analysis could not capture all facts of institutional racism likely experienced by the study population, including aggressive policing and mass incarceration. To date, few studies have investigated the effect of mass incarceration on health outcomes (10).

Structural racism is a term which can lead to significant confusion. Some authors use the term interchangeably with "institutional racism" (11). Other authors use "institutional racism" to describe individual racist policies or practices within institutions (e.g,

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discriminatory hiring practices) and "structural racism" for the totality of impact that all mutually supportive racist policies and practices have on a society (e,g, housing, incarceration, employment, education) (7). Still other authors use "structural racism" to refer to policies and practices at the state or national level and "institutional racism" to describe racist polices within organizations such as schools or companies (12). As scholarship on the impacts of structural and institutional racism progresses, it will be important for authors to define their use of these terms. It will likewise be important for analyses of large data sets to be cognizant of which facets of institutional/structural racism their data capture (e.g., redlining, access to health care), and which facets are unrepresented in the data (e.g., mass incarceration.)

Personally mediated racism, also commonly referred to as "interpersonal racism," is defined as differential assumptions or actions toward individuals based on their race (8). This differential treatment can be intentional or unintentional [i.e., unconscious (13) or implicit (14) bias]. Implicit bias is most routinely assessed using the Implicit Association Test (IAT) (15), a computerized test that measures the ability of an individual to match social concepts (race, age, gender) to attributes (good, bad, dangerous). There is a reinforcing effect of structural and institutional racism on implicit bias. For example, "colorblind" merit-based hiring led to the impression that minoritized groups are less competitive candidates for leadership when in fact they had fewer opportunities (16). This approach reinforces structural and institutional racism through lack of inclusion of minoritized individuals in hiring pools. In healthcare, it has been well documented that physicians have implicit bias against Black individuals (13, 14), that Black patients experience interpersonal racism when accessing medical care (17–19), and that these experiences are associated with worse health outcomes (20, 21). Alternatively, it has been observed that Black patients have reduced mortality in areas with increased Black physician representation (22). Taken together, it remains true that personally mediated racism continues to play a role in shaping patient health.

Internalized racism is the concept that exposure to a lifetime of structural, institutional, and interpersonal racism can lead a member of a minoritized community to accept the negative assumptions of their own abilities and worth (8). For example, the psychologist Claude Steele's work focused on the

Level of Racism	**Description**
Structural Racism	Multiple definitions • Synonymous with institutional racism, related to differential access to resources and power based on racial identity (8). • Totality of all policies within a culture that reinforce racial discrimination (7). • Laws or policies at a national or societal level that restrict access to resources/power (12).
Institutional (Systemic) Racism	Multiple definitions • Synonymous with structural racism, related to differential access to resources and power based on racial identity (8). • Separate racist policies within or between institutions (ex. differential hiring policies and unequal access to housing would be two separate examples of institutional racism that are part of overarching structural racism (7). • Explicit and implicit rules or norms within an organization resulting in discriminatory practices (12).
Interpersonal Racism (8, 12)	Two categories • Explicit Bias: racial slurs, harassment, and advocating for the superiority of a racial group. • Implicit Bias: unconscious stereotyping, microaggressions, and lack of trust or confidence in the abilities of minoritized groups.
Internalized Racism (8, 12)	• Minoritized individuals believing that they, or members of the group to which they belong, have inferior abilities or worth due to prolonged exposure to external discriminatory culture.

concept of stereotype threat as "the experience of anxiety of stress in a situation where a person has the potential to confirm a negative stereotype about his or her social group" (23). In his research on women's math performance, Steele and his colleagues found that when women were asked to note their gender prior to taking a math test, they were more likely to underperform on the test compared to women were not asked to indicate their gender (24), further reinforcing the stereotype of women having lower math ability than men.Internalized racism similarly serves to reinforce interpersonal, institutional, and structural expectations. While limited work has been published regarding the effect of internalized racism on health outcomes, it seems likely that the large body of work on self-efficacy (25), or self-advocacy (26) may be in part related to this concept. It is critical to note that in this view of racism, internalized racism is the result of external pressure from an unjust system and not a personal failing of the individual.

A final key concept to be considered in analysis of the effect of race on outcomes in large datasets is "intersectionality". The term was first coined by Kimberle Crenshaw in 1989 (27) and refers to the non-additive ways in which the various social groups to which a person belongs can impact how they are treated by society. In this seminal work, Crenshaw described employment practices at General Motors (GM) in the 1960s and 1970s. Prior to the Civil Rights Act of 1964, no Black women were employed at GM despite their hiring of Black individuals (men in factories) and women (White individuals in consumer-facing roles). In the six years following the passage of the Civil Rights Act, GM did hire Black women, but a "seniority-based" layoff in 1970 resulted in all of them being dismissed. The resultant lawsuit was unsuccessful as it could not demonstrate either isolated racial or gender discrimination. In other words, intersectional identities increased employment vulnerability. This case is also a vivid example of how using a single variable to describe a patient's "risk" for discrimination in law and in big data is insufficient.

It is important to be aware of what is being measured when "race" is included as a variable. Race is a social construct with loose association to genetic ancestry (28, 29), but with close association to the multileveled concept of racism. Use of race in datasets will require historically informed methodology, such as considering area deprivation, but also historical redlining. It will also require researchers to specify what levels of racism are measured, and which go unmeasured, in their work. While variables related to structural and institutional racism are readily available in this work by Cherabuddi and colleagues, captured by insurance status and area deprivation, data on interpersonal or internalized racism are frequently unavailable. In this work by Cherabuddi and colleagues, it is unclear if lack of portal access is due to internet access (structural racism), concerns that the medical team would not respond to portal messages due to patients' race/class (interpersonal racism), or belief of minoritized and under-resourced individuals that they are not "worth the time"(internalized racism), or some combination of all three issues (intersectionality). Understanding these complex interactions may frequently be impossible within the confines of "Big Data" and may necessitate a more patient centered approach (e.g., qualitative interviews, Community Engaged methodology). Finally, it is crucial to recognize that the persistence of disparate outcomes between White persons and people from minoritized racial and ethnic groups despite correction for a limited number of available co-variates should not be reflexively attributed to biologic differences.

So how do we apply this knowledge to "big data?" While the wide-reaching effects of racism on health outcomes are incompletely understood, they have been definitively proven (7, 10). The focus of research, therefore, must shift from identifying disparities, to understanding root causes with the purpose of intervening. The disparities exposed in the present study are not surprising, but they do provide important clues on where future interventions could be focused. The authors identified access to patient portal resources, and ability to attend follow up visits as potential intervention targets to improve equity of care. Development of community-engaged interventions offer the possibility for the individuals who are impacted by health disparities to provide vital input on how the multilayered effects of racism can be combated to improve clinical outcomes.30 Such research can shift the focus from a "deficit based" view to a "strength based" methodology, where the strengths of a community are identified, valued, and brought to bear on combating injustice and improving health (31). Untangling the impact of race and class on health outcomes

is challenging, but offers the potential of historically-aware and patient-informed interventions with the greatest likelihood of successfully promoting equity.

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