

# Knowing it When You See it: The Need for Continuing Innovation in Research on Healthcare Discrimination

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Healthcare discrimination is pervasive, yet difficult to identify. Research in the behavioral sciences shows that unconscious bias is pervasive among physicians,<sup>1,2</sup> and social and system scientists have demonstrated the impact of discrimination on care and outcomes in particular organizations and across healthcare systems.<sup>3,4</sup> At analytical levels in between the unconscious and organizational, however, it is difficult to pinpoint the actual behaviors by healthcare professionals that constitute discrimination or create its effects. Providers may not realize that they discriminate against certain patient groups, or social desirability bias may make healthcare professionals reluctant to acknowledge when their own behavior may constitute discrimination. In either case, when it comes to discrimination, healthcare providers resemble the residents of Garrison Keillor's fictional town of Lake Wobegon, where everyone is "above average."

In this context, defining and measuring discrimination constitutes a knotty challenge for health services researchers. Unconscious bias is not necessarily associated with disparities, and it does not predict discriminatory behavior.<sup>5</sup> The pervasiveness of unconscious bias thus raises questions about how to define and measure discrimination, rather than providing a pathway for doing so. In social and system sciences, discrimination is typically defined as unexplained variance in care or outcomes by demographic characteristics that persist after controlling for correlates of such differences. But this inferential strategy suffers from the potential for tautological reasoning. Multivariable models typically find racial or ethnic differences in outcomes after controlling for other sources of difference, e.g., clinical status and age, education, and income. But unexplained variance associated with race/ethnicity may reflect differences in preferences, challenges in cross-cultural communication, or the impact of social determinants of health. Attributing such differences to discriminatory interactions may be too simplistic and is rarely justified.<sup>6</sup> Neither individual psychology nor system performance provides a straightforward approach for examining

discrimination in practice, so what other research strategies can be used to identify its presence and impact?

In this issue of *JGIM*, Rogers et al. demonstrate one way to cut through this Gordian knot.<sup>7</sup> Using longitudinal data, they examine the association between perceived discrimination (at baseline) and the presence of new or worsened disabilities (at 2–5-year follow-up). The authors find that patients who perceived discrimination in the healthcare setting also had higher rates of developing new disabilities at follow-up. But, their study should be recognized as much for its approach as for its findings. The authors attempt to measure discrimination directly, and furthermore, to link measured discrimination to health outcomes. The investigators found this to be specifically associated with the experience of discrimination in the health care setting, but not in other more generalized settings. Perceived reasons for discrimination included age, gender and race—with race being particularly relevant for African American respondents. As opposed to framing the question as one about provider bias or system performance, the investigators focus on the negative potential impact of perceived discrimination, moving away from the more traditional approach of trying to determine whether discrimination truly occurred or not. By testing the link between the patient perception of discrimination and subsequent disability, the investigators are validating the clinical relevance of the subjective experience.

The study does not offer the definitive word on the issue, as the authors note a number of limitations. As an observational study with neither randomization nor fully adequate controls, the study's causal findings must be viewed with caution. They rely on secondary analysis of data collected for other purposes, and the primary measure of discrimination is self-reported at multiple levels of interaction (doctor, hospital, health care system). These factors make it difficult to pinpoint where discriminatory interactions may be occurring, and limits the study's ability to guide the targeting or design of potential interventions. Despite these limitations, the findings are striking and the work suggests the possibility that perceived discrimination, whether it is driven by system level or physician level factors, can have measurable, costly, and negative impacts on long-term health outcomes.

In the discussion, the authors provide a potential explanation for how perceived discrimination is translated into physical disability, and it is worth exploring this issue further. The

authors suggest that patients who experience discrimination may have worse outcomes if they are discouraged from seeking care. But in their study, patients who report high rates of perceived discrimination are also high utilizers of the health care system. If lack of access links perceived discrimination to poor outcomes, this link is not straightforward. Perhaps patients who perceive discrimination receive more services than average, but nevertheless receive fewer than they need. Risk adjustment or other measurement strategies could address this possibility, but additional mechanisms of how discrimination comes to be embodied in poorer outcomes should also be considered.

Translational studies suggest the possibility that perceived discrimination and the consequences thereof, including social isolation, may directly and negatively impact health.<sup>8</sup> Deranged cortisol metabolism has been linked to prolonged responses to stress<sup>9</sup> and is known to correlate with the development of diabetes, obesity and other diseases associated with metabolic syndrome.<sup>10</sup> Additional studies have shown the spontaneous development of mammary tumors in experimental animals subjected to social isolation.<sup>11</sup> Thus, understanding the pathways between discrimination and measurable health outcomes mandates simultaneous consideration of biological, psychological, and social mechanisms. This mandate is not new. In 1967, Michael Marmot's Whitehall Study began collecting prospective data that would eventually show compelling correlations between social contextual factors (grade levels of civil servant employment) and mortality.<sup>12</sup> Social epidemiologist Nancy Krieger has followed this line of investigation, looking for correlations between racial discrimination and cardiovascular disease.<sup>13</sup> Similar to Rogers' investigative team, both Marmot and Krieger found complex relationships between social discrimination and health. Therefore, continuing studies of discrimination should focus on modeling and understanding this complexity, bearing in mind the possibility that discrimination may constitute a fundamental, social cause of disease with effects that impact multiple levels of social life simultaneously.<sup>14</sup>

While Rogers et al. have not definitively answered the call to link social discrimination with biological, physical and mental health, taken at face value, their work raises an important cautionary point. Discrimination, when visited on consumers in the US health care system, can be harmful to long-term health outcomes. But at this point, the work is best considered exploratory, leaving us to question *how* bias and discrimination are translated into detrimental impacts on health and healthcare. Nonetheless, the results confront us with the reality that physicians, hospitals, and health care systems are embedded in an American society that favors youthfulness over advanced age; men over women; and whites over other racial/ethnic groups. It would be

arrogant to assume that physicians are immune to the bias and discriminatory behaviors that exist in US education, judiciary, and financial systems. Until society at large achieves the broader goals of social equity, the work of Rogers and colleagues should serve as a call for researchers, policy makers, physicians, and health system leaders to remain vigilant.

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