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Towards a More Inclusive and Dynamic Understanding of Medical Mistrust Informed by Science

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ABSTRACT

Mistrust of medical advances and the medical professions continues to persist, and is perhaps increasing. The popular press has documented the growing number of parents globally whose concerns around childhood vaccination, albeit based on faulty scientific information, has led to the anti-vax movement which has already resulted in outbreaks of measles in various parts of the U.S. In recent years, the AIDS Healthcare Foundation has increased speculation and mistrust with regard to the denialism of the effectiveness of pre-exposure prophylaxis (PrEP) to avert HIV infections, again based on misinformation. However, in other cases, medical mistrust reflects the very real historical and ongoing injustices experienced by socially and economically marginalized groups. Whether the genesis of the mistrust is based on fact or fallacy, the results may be similar. There are myriad negative consequences associated with medical mistrust, including lower utilization of healthcare and poorer management of health conditions. Mistrust is thought to provide a partial explanation for staggering health disparities, particularly among Black and African American people, and much of the public health and medical literature cites the infamous Tuskegee Study as a main catalyst for this persistent health-related mistrust among people of color and other groups who experience social and economic vulnerability. While mistrust is often referred to as a phenomenon existing within an individual or community, we must rethink this conceptualization and instead locate mistrust as a phenomenon created by and existing within a system that creates, sustains and reinforces racism, classism, homophobia and transphobia, and stigma. The purpose of this article is to briefly address the state of the medical mistrust literature, and to provide a summary of the articles included in this special issue on medical mistrust. Although the scholarship in this issue addresses diverse methodologies, outcomes and populations, they share a message: social inequality drives mistrust.

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In recent times there has been an increased awareness of the mistrust that populations hold toward medical advances, medical approaches, and the medical professions. The popular press has documented the growing number of parents globally whose concerns around childhood vaccination, albeit based on faulty scientific information, has led to the anti-vax movement,¹ which has already resulted in outbreaks of measles in various parts of the United States.² In recent years, the AIDS Healthcare Foundation has increased speculation and mistrust with regard to the denialism of the effectiveness of Pre-exposure Prophylaxis (PrEP) to avert HIV infections, again based on

misinformation.³ However, in other cases, medical mistrust reflects the very real historical and ongoing injustices experienced by socially and economically marginalized groups. Unfortunately, whether the genesis of the mistrust is based on actual fact or fallacy, the results may be similar. There are myriad negative health consequences associated with medical mistrust, including lower utilization of health care,^{4,5} and poorer management of health conditions including HIV, cancers, and diabetes.^{6–13} Medical mistrust is also associated with lower levels of involvement in biomedical research,^{14–16} which hampers our efforts to advance knowledge.

The majority of the medical mistrust literature explores the phenomenon among people of color, particularly Black and African American people,¹⁷ and to a lesser degree, sexual minority people,^{7,18} as these populations tend to disproportionately experience these poor outcomes (as has been recently noted in a report on the health of boys and men¹⁹). Medical mistrust is thought to provide a partial explanation for these staggering health disparities,^{4,20,21} and much of the public health and medical literature cites the infamous Tuskegee study as a main catalyst for this persistent health-related mistrust among racial and ethnic minority people.^{22,23}

Between 1932 and 1972, the US Public Health Service conducted the now infamous Tuskegee Syphilis Study, in which socially and economically marginalized Black men were subjected to syphilis experiments, even after the creation of penicillin, which was withheld to assess the long-term effects of syphilis on the body.²⁴ In 2019, 47 years after the end of this experiment, its legacy continues to loom over both medicine and public health. In public health, popular culture and media, this study is frequently cited as the key contributor to medical mistrust among racial and ethnic minority people.^{23,25,26} If we are to better understand how medical mistrust manifests among various populations and how to best address its deleterious effects, we must consider sources of mistrust beyond the Tuskegee study. Importantly, medical, public health, and research-related abuse of vulnerable people occurred long before the beginning of the Tuskegee Study in 1932 and continue to occur since its culmination in 1972.

The enduring focus on the Tuskegee Study has in some ways obscured both historical and recent examples of research misconduct, which often includes instances of racism in research and medicine (ranging from unethical practices in pharmaceutical trials to coercive sterilization of Native American and Puerto Rican women).^{27–30} Indeed, there is a wealth of literature suggesting that Tuskegee alone is an insufficient explanation for medical mistrust among people of color.^{31–33} Thus, while mistrust is often referred to as a phenomenon existing within an individual or community (largely low-income racial and ethnic minority people), we must rethink this conceptualization, and instead locate mistrust as a phenomenon created by and existing within a system that creates, sustains and reinforces racism, classism, homophobia and transphobia, and stigma.^{34–36}

So what exactly does medical mistrust entail? Although medical mistrust is extensively cited in the

extant literature as having an influence on a wide range of health behaviors and outcomes, it is infrequently defined or specifically conceptualized. Overall, the science to date suggests that mistrust is not merely the opposite of trust but is more than negative simply the absence of trust; mistrust often refers to the belief that the entity that is the object of mistrust is acting against one's best interest or well-being.^{37,38} However, the Benkert and associates' systematic review (included in this special issue) note that it is common for researchers to informally define medical mistrust as the lack of trust. Indeed, much of the literature on medical mistrust pertains to interpersonal trust between physicians and patients, although some studies explore mistrust toward health care systems, hospitals, health insurers and/or the pharmaceutical industry.^{39,40} Two key scales measuring mistrust, Medical Mistrust Index (MMI)³¹ and the Group-Based Medical Mistrust Scale (GBMSS),⁴¹ are commonly used in the literature. MMI includes items that assess mistrust at the interpersonal level (e.g., health-care providers) as well as system-level (e.g., hospitals, healthcare system), whereas GBMSS focuses on mistrust as experienced by a social group (e.g., racial/ethnic group). This special issue also aims to contribute to advancing our knowledge around how to utilize these scales among diverse populations.

A particularly substantial subset of the medical mistrust research revolves around "conspiracy beliefs." Broadly, a conspiracy theory, by definition, is a set of beliefs or ideas that feature a "proposed plot by powerful people working together in secret to accomplish some (usually sinister) goal."^{42,43} Conspiracy theories typically highlight perceived or actual power differentials between higher and lower-status groups, and are not by definition false, as many proven conspiracies have come to light over the years. These traits contribute to their durable nature, and provide a partial explanation for why these kinds of beliefs persist over time.⁴³ HIV-related "conspiracy beliefs" in particular are widely explored in the literature, although recent literature has also explored such beliefs surrounding Ebola, Zika virus, and vaccinations.^{44–46} HIV-related "conspiracy beliefs" center around the notion that the US federal government has been involved in creating and/or maintaining HIV/AIDS as a form of genocide against African Americans and/or other marginalized populations, such as other racial and ethnic minority groups, and possibly sexual minority men and people who use drugs.^{47,48} These ideas also refer to beliefs that ART is used to experiment upon, and/or kill those who take

it, or that a cure is available but is being secretly withheld by the government and/or pharmaceutical companies and who profit from the sales of ART medication. These ideas are captured in Bogart's HIV conspiracy belief scale,^{47,48} and have also been qualitatively documented as well.^{35,36,49} HIV-related "conspiracy beliefs" are associated with a variety of health practices and outcomes, including those related to HIV testing,^{50,51} birth control and condom use,^{47,48} HIV vaccines,^{52,53} and participation in HIV-related clinical research^{54,55} as they expose fears about reproductive rights violations and genocide.³⁵ The literature largely considers medical mistrust and "conspiracy beliefs" to be a barrier to healthier behaviors and outcomes,^{48,56,57} although some research has complicated this narrative,^{36,50,58} suggesting more research is needed to untangle the various mechanisms underlying medical mistrust.

Medical mistrust, and conspiracy beliefs in particular, have been conceptualized as a "cultural barrier," insinuating that such mistrust is a characteristic of populations of color in the United States. This framing is problematic and likely racist in that it situates the onus to overcome medical mistrust on the population experiencing structural, social, political, and economic exclusion and marginalization, rather than the institutions and entities that have created environments that engender mistrust and sustain institutionalized inequalities. The same can be said of sexual minority men on whom the onus was placed to change their own behaviors with regard to HIV/AIDS (i.e., wear a condom every time) rather than recognizing the role that social and structural factors play in fueling this ongoing health challenge.⁵⁹ Finally, in our own scientific space, it is also too common that researchers and clinicians impose their will, research and clinical programs on populations without necessarily understanding the group's particular needs or desires. In this sense, researchers' prioritization of their own agenda can also fuel mistrust.

Researchers should root this work on the following underlying question: What do these medical mistrust beliefs mean for the individuals, communities, and populations that endorse them? Waters (1997) suggests that "conspiracy beliefs" among African Americans may seek to explain ethnic inequality and tremendous uncertainty in interethnic relations, and may represent manifestations of the various ways in which society is shaped by rigid, interlocking structures of racism, sexism, and classism.⁶⁰ Similarly, Mackenzie posits that "conspiracy beliefs" should be viewed as "counter-narratives" that "create a rhetorical

space for challenges to power through the articulation of oppositional ideas about dominant scientific knowledge," ultimately seeking to discredit or resist a dominant biomedical discourse.³⁵ Heller (2015) also argued that HIV-related conspiracy beliefs are not ignorance, but a result of historical and ongoing experiences that engender distrust, which become a source for ongoing anxieties associated with the HIV epidemic, drug use, and African-American people's place in American society.⁴⁹ Recent work by Jaiswal and colleagues (2018) supports these interpretations, finding that medical mistrust and "conspiracy beliefs" reveal the intersectional nature of racism and classism experienced by Black and Latinx people.³⁶

Despite these understandings, there is still much to untangle and learn about medical mistrust, and significant work remains to be undertaken. Medical mistrust- encompassing notions of system-level mistrust, interpersonal (e.g., health care provider), and "conspiracy beliefs," continues to play an important role in trying to understand and ultimately ameliorate health disparities. An intersectional approach to social injustice is at the heart of understanding how medical mistrust manifests and how it may affect people and communities. Thus, this special issue of Behavioral Medicine seeks to further our understanding of this multifaceted phenomenon by providing a diverse collection of manuscripts that address the complexities that surround medical mistrust. These articles span an array of topics related to medical mistrust, from preventative health care to psychometrics to potential strategies for meaningfully addressing medical mistrust. Although they cover a diverse set of topics, they share a message: social inequality drives mistrust.

The opening article, a systematic review by Benkert and colleagues, approaches medical mistrust as a social determinant of health. Importantly, they are careful to distinguish medical mistrust and interpersonal trust, noting that medical mistrust is "not part of a continuum range from low trust to high trust," as medical mistrust is not the same thing as the absence of trust. Benkert and colleagues conceptualize medical mistrust as a protective response against the pervasive, interlocking structural inequalities that result in restricted access to resources, including housing, educational opportunities, employment, and healthcare, in addition to daily experiences of racism, stigma and discrimination. This review provides a foundation for jumping into the next empirical studies on the role of medical mistrust in shaping people's health-related behaviors. First, Powell and colleagues examine the relationship between medical mistrust, racism and

delays in preventative health screenings among African American men. Specifically, they examine the associations between medical mistrust, perceived racism in healthcare, everyday racism, and the screening delays. The authors define medical mistrust as “lack of trust in or suspicion of medical organizations,” and note that it stems not only from the legacy of Tuskegee Study, but also “deeper legacies.” Taking a structural viewpoint, they emphasize that racism operates at both the interpersonal and structural levels, and that we must dismantle racism inside and outside of health care system.

Moving forward, Oakley and colleagues examine the association between cultural and structural factors and perceived medical mistrust using a modified GBMSS among Latinx people in rural Oregon. The authors note that both cultural and structural influences likely shape how people experience mistrust. Like Powell and colleagues, the authors examine how discrimination is related to medical mistrust. The authors delve into acculturation, machismo and familismo (cultural) and everyday perceived discrimination (structural) to explore medical mistrust among this understudied population. Sutton and coauthors also recognize the need for further study of medical mistrust among Latinx communities, and contribute an article examining the psychometric properties of the MMI scale and its associations with healthcare satisfaction in Latina immigrants. As noted by Oakley above, medical mistrust among this population is understudied, and medical mistrust measures have previously not been validated among this group. The authors note that most studies of Latinas have used the GBMSS, but that there are other dimensions of satisfaction with care that should be examined, such as trust in competence of healthcare provider.

The next set of articles explores the relationship between medical mistrust and HIV-related behaviors and outcomes. Building on a robust body of work on this topic, Bogart and colleagues explore the unclear relationship between “conspiracy beliefs” and HIV testing among Black people. Emphasizing the importance of considering both historical and ongoing racism and structural inequality, the authors use generalized structural equation modeling to understand how individual risk behaviors and socioeconomic status may or may not mediate the relationship between “conspiracy beliefs” and HIV testing. They also provide an update on how HIV-related “conspiracy beliefs” among this population has changed over the years. Continuing with the theme of HIV prevention, D’Avanzo and associates explore medical mistrust

among trans women, a population that is most often grouped together with men who have sex with men, may think about pre-exposure prophylaxis (PrEP). The authors note that trans women have unique sexual health needs and face distinct barriers, including disproportionately higher HIV incidence than cisgender women, as well as pervasive social and economic exclusion (stigma, discrimination, homelessness, lower healthcare access, sex work, etc.). Using a cluster analytic approach, the authors compare two groups of women, one that is majority Black, the other majority white with income differentials. Their findings demonstrate the innate complexity of medical mistrust, and are perhaps unexpected, but nonetheless extremely valuable in moving forward and endeavoring to provide high quality, trans affirming care (including recommendations on how to best tailor messaging). Moving from HIV testing to HIV prevention, the next article now moves to the impacts of medical mistrust on engagement in outpatient HIV care. Kutnick and colleagues use a mixed methods, ecological approach informed by critical race theory to examine the relationship between incarceration experiences and engagement in HIV medical care post-release among Black and Latinx people. The authors examine how lack of autonomy, substandard medical care, and poor social support while incarcerated contribute to medical mistrust and exacerbate people’s vulnerability to re-incarceration and substance use, and ultimately affects their ability to remain engaged in outpatient HIV care.

The final two articles offer concrete strategies on how to begin overcoming mistrust by acknowledging past and ongoing trauma, actively dismantling mistrust, and working to build trust and collaboration among communities that have experienced both historical and ongoing social and economic exclusion. First, Ramos and colleagues present an innovative framework using eHealth strategies to reach sexual minority men (SMM) of color and address chronic conditions such as diabetes and HIV. eHealth interventions, such as virtual environments and avatar-led videos, are nontraditional approaches that can help combat stigma, discrimination and lower healthcare utilization by enabling SMM of color to maintain anonymity and receive social support (both of which may be particularly important for those who do not identify as LGBTQ). Like the previous authors showcased in this special issue, Ramos et al. also emphasize the role of both historical and ongoing forms of systemic racism and discrimination. The authors note that “all too often, trust is expected before trustworthiness can

be established.” In order to begin building trust, researchers and clinicians must actively work to reduce mistrust among participant and patient populations. Ramos and colleagues provide strategies to begin this critical work, as does the final article in this special issue. Desai and colleagues provide an excellent report on how to meaningfully engage underrepresented community members as co-researchers using participatory research. The authors describe a two-year initiative to improve both the quality and quantity of participatory research in their psychiatry department via an innovative training program for researchers, patients, and other stakeholders. Noting the serious power imbalances in research, particularly in the mental health field, the authors address mistrust toward mental health systems, as well as mistrust toward mental health research. Desai and coauthors call on us to dissolve classic distinction between “science” and “community,” and they provide concrete suggestions on how to do so.

Looking ahead, it is becoming increasingly clear that medical mistrust must be addressed at multiple levels of society, including government, policy, and health care systems, among others. Often framed as a direct consequence of slavery and the Tuskegee Syphilis Study, we must endeavor to broaden our understanding of medical mistrust, and shift our emphasis to its ongoing, rather than solely historical, nature. This requires a shift in perspective—rather than viewing medical mistrust as a cultural or population characteristic, medical mistrust is a phenomenon that can be meaningfully addressed by researchers and clinicians.

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