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Whose Responsibility Is It to Dismantle Medical Mistrust? Future Directions for Researchers and Health Care Providers

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Abstract

Medical mistrust persists and appears to be growing. The public health literature on medical mistrust has largely focused on mistrust among Black and African American populations due to legacies of abuse and mistreatment, such as the infamous Tuskegee Syphilis Study. However, research is now emerging that explores mistrust among various populations and in varying contexts, and the literature now largely emphasizes the role of ongoing, present-day social and economic inequalities in shaping and sustaining mistrust, particularly among populations who experience staggering health disparities. This special issue showcased nine articles exploring medical mistrust among diverse populations, exploring a wide array of topics and spanning myriad methodologies. In addition to a rigorous systematic review of the literature, this issue covers several critical subareas of the health disparities literature, including preventative health screenings among Black men, discrimination and cultural factors among rural Latinx communities, health care satisfaction among Latina immigrant women, the complex relationship between HIV testing and “conspiracy beliefs” among Black populations, pre-exposure prophylaxis use among transgender women, the impacts of mass incarceration on HIV care, eHealth interventions to address chronic diseases among sexual minority men of color, and participatory research to engage underserved populations as coresearchers. The purpose of this article is to provide a brief summary of the nine manuscripts in this special issue and to outline some recommendations and future directions for research on medical mistrust.

Keywords

health disparities; health care providers; HIV; medical mistrust; research

Medical mistrust: A survey of the literature

Historical trauma, particularly the Tuskegee Syphilis Study, is thought to be the primary underlying driver of medical mistrust among people of color, particularly Black and African

American people. Indeed, many of the foundational studies on medical mistrust have examined its effects on health care utilization,¹ health behaviors, health outcomes, and participation in biomedical research.² Despite the extensive literature on medical mistrust, there is not a clear consensus on what medical mistrust precisely entails, the breadth and depth of its influence, and the relationships between various underlying mechanisms.

The systematic review by Benkert et al. offers insights into many of these questions by delving into the qualitative and quantitative literature on medical mistrust and health-related behaviors and outcomes. The authors included qualitative studies in order to more fully contextualize the phenomenon. The authors systematically analyzed 124 articles concerning behavioral responses and health outcomes related to medical mistrust ($n = 36$ qualitative articles, $n = 88$ quantitative articles). Of importance, they emphasize that trust and medical mistrust are distinct concepts and are not merely the opposite of one another. In this sense, mistrust is not simply the absence of trust, as mistrust signifies the suspicion that there is an element of ill will at play. Overall, the authors problematize the frequent conflation of trust and mistrust, especially interpersonal trust. Related, they found that studies often did not define what kind of mistrust they were measuring (interpersonal, systemic, etc.). Moreover, most studies focused on Black people (and to a lesser extent, Native American people and sexual minority people) and Benkert et al. call for more research among more populations in order to better understand how mistrust manifests among various groups of people and in various contexts.

In the analysis of the qualitative articles, the authors found that medical mistrust was often not the main objective, thus warranting further research that specifically focuses on mistrust. They recommend that future work on medical mistrust should include more qualitative and mixed methods approaches and should consider an intersectional framework for understanding mistrust among other underserved populations. Their analysis of the quantitative literature also revealed several important observations. They also argue that we must clarify other antecedents and consequences of medical mistrust to untangle pathways that sustain and perpetuate health disparities. This has been difficult in part due to a lack of consensus around the definition of what constitutes medical mistrust. Specifically, they found that the association between medical mistrust and various sociodemographic variables was clear (e.g., race and ethnicity, income and educational levels) but that the extant literature largely lacks research that would examine the relationship between medical mistrust and “constructs” related to the experiences of vulnerable groups, such as racism. Additionally, they found a need for research that replicates the use of similar measures among both similar and different populations. They also called for more research that involves complex modeling, longitudinal designs, and mediator/moderator analyses. In doing so, we can refine our understanding of how mistrust operates in various contexts and among different populations.

The relationship between preventative health care and mistrust

Substantial literature documents the relationship between medical mistrust and preventative health behaviors. Mistrust is associated with lower health care utilization^{1,3,4} and lower health care satisfaction⁵ and is thought to negatively affect myriad preventative health

practices,^{1,5-13} particularly among people of color. These include colorectal cancer screening,^{14,15} mammography behaviors,¹⁶ and HPV vaccinations.¹³ Powell and colleagues build on previous research on mistrust among Black men¹⁷ and examine the associations among medical mistrust, perceived racism in health care, everyday racism, and preventative screening delays. They note that most research on medical mistrust does not attempt to account for other factors that may work in conjunction with mistrust to contribute to Black men's screening delays. Thus, centering the experience of racism, the authors conducted a cross sectional analysis of 610 African American men, of whom the majority were recruited from barbershops in four regions of the United States, with the intention of meeting people where they are.

Multiple regression analyses and tests for mediation revealed that African American men with higher levels of medical mistrust were more likely to delay blood pressure screening. Men with more frequent everyday racism exposure were more likely to delay routine checkups and blood pressure screenings, and higher levels of perceived racism in health care were associated with an increased likelihood of delaying cholesterol screening. Medical mistrust did not mediate the relationship between everyday racism and screening delays; these findings suggest that medical mistrust is indeed complex and is tangled up with other facets of a structurally unequal society. The authors note that "trust is theoretically history-based, cumulative, and thicken and thins as individuals transact with individuals and systems." In this sense, medical mistrust is not "just an attitudinal barrier but rather one catalyzed by proximal, lived experiences." The authors posit that medical mistrust "interacts with everyday racism" and that it may in fact be "modifiable," which suggests that active strategies can help dismantle it. However, the findings also suggest that medical mistrust alone may not be the most salient factor affecting underutilization of health care among African American men. They recommend patient-centered medicine as an evidence-based strategy that could help offset these concerns, but they note that Black people are less likely to have patient-centered interactions with health care providers. In addition to calling for a broader response to structural racism, they recommend implementing provider interventions across the medical education continuum.

Medical mistrust among Latinx people

As Benkert et al. noted in their review of the literature, there is an urgent need for mistrust research among diverse populations. Given the growing Latinx population in the United States, research is needed that examines the various contexts in which Latinx people may experience health-related mistrust. Recent studies have illuminated the deleterious impacts of institutionalized racism on Latinx people's health.¹⁸⁻²⁰ López-Cevallos et al. and Oakley et al. have previously examined mistrust among Latinx populations, finding that mistrust was associated with lower satisfaction with care.^{21,22} This special issue includes two articles that focus exclusively on Latinx populations, a population that has largely been understudied in relation to medical mistrust. First, Oakley and colleagues delve into the relationship among medical mistrust, cultural factors (acculturation, machismo and familismo), and a structural determinant (everyday perceived discrimination). The sample comprised 499 Latinx people living in rural Oregon, the majority of whom were Mexican. The authors ultimately found that acculturation and machismo were positively associated with medical

mistrust, while familismo was negatively associated. Machismo was only associated with medical mistrust among women. The authors theorized that women may be more likely to comply with their male partners' advice over men they encounter in the health care system. Notably, discrimination was the "most relevant factor" associated with medical mistrust. The authors theorize that it may be that in newer immigrant communities, discrimination may be more prominent, thus resulting in decreased trust in health care providers. In this sense, a stronger ethnic identity (which includes machismo) would serve as a protective mechanism. Importantly, the authors contextualize their findings in the current climate around immigration, i.e., racist policies, acts of violence against immigrant people, and hateful rhetoric endorsed by the Trump administration.²³ If people do not feel safe accessing care due to discrimination, racism, and/or concern over immigration status, this will also negatively affect health care utilization and health outcomes for this population. The authors recommend building a pipeline of diverse health care providers in order to begin dismantling this mistrust and building trust among Latinx people.

In a recent systematic review, Williamson and Bigman examined how medical mistrust has been measured in the literature.²⁴ Among the 185 analyzed articles, they found that nearly a quarter used a single item or a few items to assess mistrust. The most commonly used validated scales were the Medical Mistrust Index (MMI),¹⁰ the Group-Based Medical Mistrust Scale (GBMSS),²⁷ and the Health Care System Distrust Scale.²⁵ These scales assessed varying aspects of mistrust and its different objects (e.g., systemic level, interpersonal/individual-level). They found that these scales, while frequently used, were not consistently operationalizing mistrust in the same way. Moreover, they also noted that mistrust measures often focused on African Americans.²⁶ Indeed, Shelton and colleagues validated the GBMSS²⁷ among urban Black men,²⁸ thus demonstrating the scale's utility in examining mistrust among this population. Valera et al. validated the GBMSS among formerly incarcerated Black and Latino men,²⁶ and in this special issue, Sutton moves the field forward by validating the MMI scale among a sample of 168 Latina immigrants from various regions in Latin America, offering some insight into the relationship between mistrust and health care satisfaction. To assess construct validity, the authors examined the relationship between the MMI and three related items (racism, discrimination, and trust in doctors). Criterion validity was assessed by examining whether medical mistrust was associated with health care satisfaction, an important aspect of health care delivery. 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 the competence of the health care provider. They found that trust in health care provider competency was a "more robust determinant of women's [health care] satisfaction," as "competence" and "suspicion" explained 40% of MMI variance. This illuminating the need for untangling related but distinct dimensions of trust and mistrust. These results also support the reliability and validity of the MMI scale in Latina immigrants and move forward our understanding of the nuances of scales measuring medical mistrust.

Mistrust along the HIV prevention and care continua and among diverse populations

HIV continues to be a pressing issue in the United States and worldwide, particularly among people of color and sexual and gender minority people.²⁹ Medical mistrust features prominently in the literature on HIV testing, HIV prevention (including pre-exposure prophylaxis [PrEP]), and engagement in outpatient HIV care. This focus on mistrust reflects epidemiological patterns that have seen HIV disproportionately affect socially and economically marginalized populations, such as communities of color and sexual minority people. Studies have documented mistrust in relation to HIV testing and HIV risk behaviors,^{30–36} in addition to exploring “conspiracy beliefs” and denialism around HIV as an illness.^{37–41}

Three articles in this special issue reflect the broader literature’s focus on the relationship between medical mistrust and HIV-related behaviors and health outcomes. The articles in this set contribute to this subfield by disentangling the seemingly counterintuitive relationship between “conspiracy beliefs” and HIV testing among Black populations, expanding our understanding of mistrust among diverse populations, and linking mistrust to structural inequality in the prison system. First, Bogart and colleagues have provided an analysis of the nuanced relationship between these kinds of beliefs and HIV testing. Using data from The National Survey on HIV in the Black Community as well as from an adapted HIV “conspiracy belief” scale, the authors analyzed a nationally representative sample of 868 Black people aged 18 to 50. Using generalized structural equation modeling, the authors found that endorsing HIV-related “conspiracy beliefs” and HIV risk behaviors were both associated with higher likelihood of HIV testing. The association between HIV “conspiracy beliefs” and HIV testing was significantly mediated by individual-level HIV risk, but not by area-level socioeconomic position, which the authors used as an ecological determinant of HIV prevalence. Reflecting epidemiological patterns, the communities with higher access to HIV testing access are also the same populations that have experienced ongoing systemic discrimination. Overall, Bogart et al. found that mistrust persists among Black communities, although some “conspiracy beliefs” have proved more enduring than others. Given the persistence of this type of mistrust, they recommend that future research examine mistrust in the context of PrEP and HIV treatment as prevention.

Recently, PrEP uptake has been explored in the context of medical mistrust, particularly among sexual minority men^{42,43} (and to a lesser extent, transgender people). These studies have largely found that mistrust may play a role in decision making around PrEP use.^{8, 44–46} D’Avanzo et al. answer Bogart and colleagues’ call for research that addresses mistrust in the context of PrEP. The authors provide an analysis of how trans women, a heterogeneous population often grouped in with men who have sex with men, may experience mistrust in the context of considering PrEP. PrEP uptake among trans women is low and medical mistrust may play a role, as trans women often experience pervasive social and economic inequalities both within and beyond the health care system. This may especially be the case for trans women of color, for whom racism and discrimination may be a daily reality. Using a novel survey, the authors compared a pilot sample of 78 trans women and examine PrEP

acceptability in the context of mistrust. The women were clustered into two groups: one that is majority Black with lower educational attainment, the other majority White with higher educational attainment. Using a cluster analytic approach, analyses revealed that the clusters did not differ in terms of intent/knowledge around PrEP. However, there was a difference in regard to which cluster was more likely to have heard about PrEP from a doctor. Overall, cluster 1 indicated a greater comfort within health care settings and more positive experiences with doctors, while cluster 2 reported increased anticipation of negative health care experience and expressed more concern about health care discrimination and mistrust based on gender identity. Thus, greater concern was reported among the group comprising primarily White women, whereas women with more “structural vulnerabilities” appeared to have more positive health care experiences and thus reported less concern. The authors theorize that this difference, perhaps unexpected, can likely be attributed to the types of facilities that each cluster is most likely to access. Women of color were likely to have heard PrEP messaging in trans-competent settings, as women in this group were more likely to receive care from community-based organizations that provide trans-competent care. Interestingly, cluster 2 perceived themselves to have low HIV risk, but the authors note that a lack of trans-competent health care offering affirming care affects their risk perception. These findings suggest that a greater effort to provide trans-affirming care outside of community-based settings would help assuage the mistrust of White trans women as well.

The potential impacts of medical mistrust on engagement in outpatient HIV medical care have been widely explored. Some studies have found that medical mistrust may negatively affect engagement,^{47–51} while others have found that the influence of mistrust is less clear.^{52,53} The literature also suggests that medical mistrust is a factor in the relationships among HIV medication beliefs, HIV medication adherence, and/or serostatus disclosure to partners.^{7,9,49,54} However, there is little known about the relationship between medical mistrust and mass incarceration and the impacts on engagement in HIV care. Kutnick and colleagues use a mixed methods approach informed by critical race theory to explore the relationship between the experience of receiving an HIV diagnosis in prison and engagement in HIV medical care post-release. Drawing upon a qualitative sample of 28 Black and Latinx individuals who received an HIV diagnosis while incarcerated, the authors describe how lack of autonomy, substandard medical care, and poor social support while incarcerated contribute to mistrust and exacerbate people’s vulnerability to reincarceration and substance use. These experiences ultimately affect their ability to engage in outpatient HIV care in the long term. The qualitative data provided a rich account of how people felt powerless, coerced, confused, distressed, and isolated during their HIV diagnosis and how these experiences engendered long-lasting feelings of mistrust, stigma, and denial. In this sense, their diagnosis experience while incarcerated was a “lens through which health behaviors and health care choices were made long after release.”

Concrete approaches for moving forward

The final two articles by Ramos et al. and Desai et al. provide us with concrete strategies and recommendations to not only foster trust among research populations but also actively dismantle mistrust. First, Ramos and colleagues share an innovative framework using eHealth strategies to reach sexual minority men of color living with chronic health

conditions. eHealth interventions, such as virtual environments and avatar-led videos, are nontraditional approaches that can enable people to maintain anonymity and receive social support and avoid stigma, discrimination, and lower health care utilization. This may be especially relevant for those who do not identify as LGBTQ, as eHealth interventions can be a useful approach for reaching hard-to-reach populations, especially since smartphones are common. The authors detail two examples of using eHealth interventions: (1) a virtual environment to help people manage their diabetes and receive support and (2) an avatar-led eHealth video to increase PrEP and post-exposure prophylaxis (PEP) knowledge. These types of interventions could be applied to a wide variety of health conditions and would provide opportunities for researchers and, more broadly, the health care system to begin generating trust among underserved communities. The authors also call for researchers and clinicians to take active steps to dismantle mistrust and build trust, such as using community workers, working with faith-based organizations, hiring health care staff who reflects the population, and respecting people's time and effort by providing participant compensation. Moreover, throughout the research process, it is important to ensure privacy and confidentiality during data collection and to disseminate findings in an accessible and meaningful way.

Finally, Desai and colleagues describe a two-year initiative to meaningfully engage underrepresented community members as co-researchers using participatory research. Noting the power imbalances in the mental health care system as well as in research, the history of mistreatment and abuse in mental health settings, the neglect of participants' daily lives (transit, childcare, financial barriers, etc.), as well as differing cultural/medical understandings of what mental illness is, the team developed and implemented an innovative training program for researchers, patients, and other stakeholders focused on mental health and addiction. The authors provide a detailed report on the initiative their group created in order to bring together researchers, people with lived experiences, and stakeholders. They are explicit in their message that we cannot put the "onus on the public to simply overcome barriers through better psycho-education." The authors note that "trust is often implicitly assumed" but participatory research explicitly requires building genuine relationships where trust is cultivated over time by eliciting and valuing input from the "many experts in the room." The authors recommend directly addressing the "incongruence" between how investigators and community members view research, including the relevance and potential risk. This could include facilitating opportunities for communities with lived experiences to be heard, acknowledging power dynamics, competently and sensitively addressing historical and ongoing injustices, incorporating trauma-informed approaches, having open and honest dialogs about risk, and obtaining federal certificates of confidentiality. In doing so, researchers and clinicians can demonstrate that they respect people's time and autonomy, thus making research more patient- and participant-centered (and ultimately "more impactful and ecologically valid").

Future directions for research and clinical practice

The articles included in this special issue are diverse in terms of population, focus, and methodology, but they all share the notion that medical mistrust is created, perpetuated, and/or sustained by structural inequalities. This collection of articles speaks to several key

issues that can help us move forward with actively working to address mistrust and begin building genuine trust among researchers, the medical establishment, and the various populations with whom we work and serve. These points can serve as future directions for research on medical mistrust and for working alongside communities facing health disparities:

Ongoing social and economic exclusion, in the form of racism, discrimination, and stigma, powerfully shape medical mistrust.

Importantly, the articles in this special issue emphasize the role of both historical and ongoing racism and social and economic exclusion, not solely traumatic historical events. Thus, conceptualizing and assessing mistrust requires a dynamic understanding of how structural inequality continues to drive both medical mistrust and health inequalities more broadly.⁴⁰ For example, in the case of HIV-related “conspiracy beliefs,” it may be tempting to put the onus on the population to stop feeling mistrustful by employing interventions to debunk these notions. However, honing in on the structural determinants of mistrust enables us to “be mindful of the root causes of it. If not, [interventions] risk blaming the victim, attempting to ‘correct’ these beliefs without considering fully why they might appear credible in the first place.”⁵⁵

Definitions of mistrust must be articulated in order to refine its measurement.

When examining mistrust, we must be clear about what we are and are not measuring. Benkert and colleagues reviewed the state of the literature on mistrust and found that mistrust is rarely defined and is often conflated with interpersonal trust. The lack of a consensus on what medical mistrust entails makes it difficult to compare across populations and contexts and to develop novel and consistent ways to measure the phenomenon. Moreover, medical mistrust may entail mistrust of providers, the health care system more broadly, the pharmaceutical industry, and/or the government, among other entities. Being deliberate when defining the parameters of what we mean by mistrust will enable us to both refine and expand our understanding of the phenomenon.

Mistrust needs to be studied among diverse populations.

As noted by Benkert and colleagues, much of the literature on medical mistrust has been conducted primarily among Black and African American populations. In order to fully grasp how health-related mistrust affects people’s health behaviors and outcomes, it is necessary to understand how mistrust manifests in different contexts and among different populations. The articles in this special issue addressed mistrust among Black people, Latinx people, trans women, sexual minority men, people living with chronic illness, and people living with mental illness. An intersectional approach can help reveal the ways in which multiple, intersecting social structures create the environments in which people make decisions about their health.

More diverse and advanced methodologies are needed.

This collection of articles employed various methodologies to examine mistrust, including cross-sectional analyses, cluster analyses, qualitative and mixed methods approaches, and

structural equation modeling. Many of the articles called for the use of more advanced methodology to better understand how mistrust affects people's health, such as the need for mediation analyses that can unpack complex relationships, as well as longitudinal designs that can examine mistrust over time. Additionally, more qualitative and mixed methods approaches would also help us to contextualize this complex and persistent phenomenon.

Finally, and most importantly, the onus is on the scientific community to better understand the nature of these beliefs and experiences, and to respond accordingly.

The diversity of the articles in this special issue illuminated the need for novel approaches to address mistrust. The authors offer a range of suggestions that can be implemented in the research process, as well as outlined approaches that can be undertaken by clinicians in health care settings. These include eHealth interventions, rigorous community-based participatory research, trauma-informed approaches, provider interventions across the medical education continuum, patient-centered medicine, building a pipeline of diverse providers, and proactive strategies to ensure patients' and participants' privacy and dignity. These approaches go far beyond outdated frameworks of cultural competency and instead address structural competency and humility, where the onus is not on the patient (or participant), but rather on the system.⁷ Indeed, Ramos et al. note that "trust and trustworthiness are not established because of the ability to 'relate' in stereotyped language, vocal tone, or popular culture. Rather, it is built on authenticity, respectful interaction, clear, honest, thorough interactions, and consistent provision of the power of choice." These recommendations underscore the opportunity for researchers and medical practitioners to help dismantle mistrust by acknowledging the role we have played in maintaining damaging power dynamics and perpetuating mistrust.

Ultimately, it is imperative that the scientists working hand in hand with medical and other health practitioners work to dismantle racism and other forms of social and economic exclusion in order to decrease mistrust and begin engendering trust. We need to cultivate environments and relationships that do not require people to use medical mistrust as a coping mechanism against stigma and discrimination. This necessitates making research both meaningful and safe for participant populations and directing programs of research that are truly with and for the people whom we study; we also must educate and provide hands-on experiences to future students in public health and other health-related fields that will enable them to enact research that is truly community-engaged and that represents the voice of those whose lives we are seeking to improve. In doing so, we can equip populations with knowledge, behavioral skills, and social empowerment to enhance the well-being of individuals and communities.

This special issue is part of a growing literature on medical mistrust among diverse populations. This collection of articles showcases the complexity of the phenomenon, offers concrete suggestions to refine how we study it, and identifies the areas for future research moving forward. They also provide important data and concrete strategies on how researchers and health care providers can take an active approach in simultaneously advancing our science as well as dismantling mistrust and building trust and collaboration with participant and patient populations. In doing so, we are better equipped to develop

interventions and policies that meaningfully address structural inequality and highlight the need for meaningful and safe collaboration among researchers, the health care system, and communities.

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