Mistrust, Empowerment, and Structural Change: Lessons We Should Be Learning From COVID-19

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See also Landers and Bowleg, p. 341.

Within the COVID-19 pandemic, public mistrust has been cast in the pivotal role of antagonist. From lack of acceptance of preventive measures, to online misinformation and disinformation, to low vaccination rates, "the epidemic of mistrust" has been characterized as a thwarter of public health mitigation efforts. However, among Black/African American individuals in the United States who remain twice as likely to die[1] yet significantly less likely to be vaccinated against COVID-19[2] versus White Americans, mistrust is not the primary etiology of racial and ethnic inequities. Instead, mistrust is a manifestation of the pervasive pathologies of structural racism and White supremacy.[3] Historical awareness of and contemporary exposure to structural racism—the system of hierarchy, privilege, and power that largely benefits White individuals—has resulted in mistrust as a rational, adaptive response to an adversarial environment. Furthermore, White supremacy, the belief that White people are superior to people of other racial backgrounds, sustains structural racism and, thus, is a fundamental driver of mistrust among people of color.[4,5]

A specific form of mistrust, medical mistrust, centers on the belief that health care providers, the health care system, the pharmaceutical industry, academic institutions, or the government as a steward of public health are acting against one's best interest or well-being.[6] As a multidimensional belief system, medical mistrust likely exists on a spectrum from skepticism, to active suspicion, to belief in conspiracy theories or secret plots concerning perpetrators, motivations, and modi operandi that are not necessarily apocryphal.[7] Typically, medical mistrust has been viewed through a deficit lens. This is unsurprising; negative characterizations of health beliefs espoused by people of color that diverge from those expressed by the dominant culture are a normative feature of race-based science. This is particularly true regarding mistrust beliefs. Individuals who express medical or research mistrust are frequently characterized as irrational, less well-educated, or possessing lower literacy.[8] Among Black/African American individuals, medical mistrust has been associated with suboptimal health behaviors, such as nonadherence to antiretroviral therapy among people living with HIV, poor engagement in care, and decreased uptake of preventive behaviors, including vaccines.[8,9] Unfortunately, a surfeit of attention within public discourse on combating the negative impacts of medical mistrust, particularly in regards to COVID-19 vaccine "hesitancy," has obscured the need to correct deficiencies and disparities in health care perpetuated by structural racism, White supremacy, and inequitable power structures in the United States.

Specific historical and recent events have oftentimes been cited as the root cause of medical mistrust. As such, medical mistrust has been framed as a reaction to instances of medical, research, or public health malfeasance. For example, the Tuskegee Syphilis Study, during which Black men were enrolled without informed consent and observed for 40 years with no offer of treatment, is frequently cited as the exemplar of this unethical behavior.[10,11] Another frequently cited example is compulsory and coercive sterilization dating back to the early 20th century, which disproportionately impacted Black/African American, Indigenous, and Latinx women.[12] Most recently, in 2020, unnecessary gynecological procedures were performed on women of color, many of whom were non–English speaking, held at Immigration and Customs Enforcement detention centers in the United States. Following an investigation, the Department of Homeland Security closed the facilities where the procedures were performed.[13]

These specific events are important to note. However, understood within a psychological and sociopolitical context, medical mistrust is an adaptive response to chronic, not episodic, inequity experienced by Black, Latinx,

Indigenous, and some Asian American Pacific Islander communities. As an adaptive response to repeated exposures, medical mistrust can be protective and potentially promote resilience to discrimination and maltreatment experienced directly or indirectly within one's social network, family, or community.[14] Given the persistence of COVID-19 inequities, a critical analysis of medical mistrust as an adaptive response that may promote individual-level resilience, community-level empowerment, and structural change is warranted.

UNDERSTANDING MISTRUST

Psychological literature, which is often deficient in racial diversity of both authorship and research participants, has contributed to pathologized views of mistrust.[15] A substantial portion of this research has focused on the more extreme end of the mistrust spectrum, exploring "conspiracy beliefs" as a reflection of individuals' psychological disposition. This research suggests that individuals who express "conspiracy beliefs" have low self-esteem, are paranoid, or are delusional.[7,16] Individual-level perspectives such as these delegitimize rational belief systems and ignore the origins of mistrust among people of color.

Other research has contributed to a broader understanding of medical mistrust as a protective coping mechanism. An epistemic rationale for belief in conspiracy theories posits that they arise in the face of persistent threat. In such instances, conspiracy theories provide causal explanation and render order in the place of uncertainty and injustice.[8] For example, racial and ethnic disparities in HIV incidence and mortality have been a persistent feature of the epidemic in the United States since its inception 40 years ago. In response, HIV-related conspiracy theories, such as HIV is a man-made virus or AIDS was created by the US government to control the Black population, have developed as common beliefs within the Black/African American community.[17]

Within health care settings, medical mistrust can develop as a response to inequitable or hostile situations. In a study to determine psychosocial factors associated with medical mistrust among Black/African American men, the author found that perceived racism in health care was the strongest correlate of mistrust and often resulted in lack of follow-up.[18] Thus, when faced with antagonistic circumstances such as racism, individuals may develop mistrust and disengage from care to minimize psychological harm and restore a sense of control. As a protective response, medical mistrust may also manifest as caution or self-preservation in light of adverse exposures both within and external to the health care system.[19] From a sociopolitical perspective, the interplay among physical, social, and political environments may contribute to stronger mistrust beliefs among individuals living in neighborhoods with higher concentrations of social vulnerability.[8,20] Medical mistrust may also be a learned attitudinal response that is transmitted among members of the same group or community with shared identity and cultural experience.[14]

INTERVENTIONS TO ADDRESS MEDICAL MISTRUST

Following the approval of COVID-19 vaccines, there has been intense interest in "vaccine hesitancy," a manifestation of medical mistrust, particularly among Black individuals.[9] Interventions to increase vaccine confidence include trusted messenger programs in which health care providers or community leaders communicate evidence-based data, debunk myths, and attempt to build trust in COVID-19 vaccines. While these programs may increase vaccine uptake, it is unlikely that short-term educational programming will have a sustainable impact on broader medical mistrust beliefs. Building trust in systems of care will necessitate structural change, authentic collaboration, and investment in community engagement.[21]

Interventions to mitigate medical mistrust at the patient and health care provider level have also been developed. However, to date, these interventions have been limited in scope, given how the concept has been oversimplified and undercontextualized. At the patient level, a few effective interventions using motivational interviewing and cognitive behavioral therapy have been implemented to increase awareness of the effects of medical mistrust on health outcomes.[8] Of note, the goal of these interventions is not to reduce medical mistrust among participants. Instead, these interventions acknowledge mistrust as a rational response to racism and a protective survival mechanism as well as raise awareness about the effects of mistrust on health. A handful of health care provider-level interventions that aim to increase cultural competency and empathy for patients have also been developed. These interventions have generally not shown effects on increasing patient trust. In addition, interventions at the health care provider level to improve patient-centered communication and shared decision-making have been suggested.[8] However, multilevel

interventions that include structural components to abolish racist policies and practices are necessary to improve the trustworthiness of the health care system and related entities.[8]

RESILIENCE, EMPOWERMENT, AND STRUCTURAL CHANGE

Resilience has been characterized as a "dynamic process encompassing positive adaptation within the context of significant adversity."[22(p543)] Within public health, resilience frameworks have often been applied to disaster preparedness to assess the ability of communities to recover and survive after an emergency. From a psychological perspective, resilience also involves growth and evolution. Melding the public health and psychological perspectives, community resilience is the ability to withstand acute or chronic threats, to adapt, to survive, and to utilize the experience to catalyze change.[23]

Thus, as a protective response that has the potential to promote resilience, mistrust may be an important or even necessary trait to catalyze community-level change.

Empowerment (e.g., self-reliance and self-sufficiency) is an essential component of community resilience. In addition, empowerment can also be conceptualized as an outcome. As a community adapts to and survives serious threat (such as pervasive racism), the change that occurs often necessitates a shift in power from external entities to the community itself. The shift usually requires advocacy, policy change, alteration of governance structure, and redistribution of resources. This process defines community empowerment.

Yet, can the adaptive, protective response of mistrust that promotes resilience also lead to individual-level and community empowerment? There are several HIV-related examples that suggest that it might. On the individual level, research determining barriers to uptake of key HIV-related interventions (e.g., preexposure prophylaxis [PrEP] and HIV testing) provide evidence of the positive association between HIV-specific medical mistrust (also known as HIV conspiracy beliefs) and intervention use. For example, higher HIV-specific mistrust was positively associated with willingness to use PrEP among Black women in the National Survey on HIV in the Black Community.[17] Similarly, medical mistrust among racially and ethnically diverse individuals has been positively associated with greater HIV testing likelihood.[8] Because mistrust may be an act of self-preservation against racist threats, engaging in self-protection behaviors, such as taking PrEP to prevent HIV infection, is a rational response if one believes that systems exist in opposition to one's own self-interest. Therefore, PrEP use and HIV testing may be acts of self-empowerment.

While similar evidence does not yet exist for COVID-19, similarities between the COVID-19 pandemic and the HIV epidemic within Black communities suggest that mistrust may contribute to the uptake of protective measures (e.g., greater testing or increased use of preventive measures such as masking).[24]

On the community level, the COVID-19 pandemic has incited a groundswell of activism and empowerment. Coalitions comprising Black, Latinx, and Indigenous community members have arisen to provide services, education, and psychological support, and to advocate equitable access to testing, therapeutics, and vaccines. These efforts have been spurred by centuries of structural racism, marginalization, and rational mistrust that current systems of power will fill critical needs equitably. Newly developed racially and ethnically defined coalitions like the Black Boston COVID Coalition (BBCC) and the Latino Coalition Against COVID-19 have formed to build upon existing community resilience and ensure that their communities' needs are met. In addition, existing Indigenous and Asian American Pacific Islander organizations, such as the National Urban Indian Family Coalition and National Council of Asian Pacific Americans, have shifted focus to COVID-19 and social determinants of health, such as poverty and food insecurity.

Structural change is defined by a dramatic shift in the way a system operates. Bolstered by simultaneous social movements, these empowered community coalitions have advocated structural change in the form of post–COVID-19 business recovery, workforce diversity, immigration reform, universal access to health care, and fundamental shifts in resource distribution to achieve and sustain equity. For example, the BBCC has demanded that pandemic efforts not only stem the tide of COVID-19 but also leave "Black residents and Black businesses in a better place post-pandemic than we were before and during."[25] Through BBCC's advocacy efforts, Black- and Latinx-owned businesses have been contracted to expand COVID-19 vaccination access within diverse communities. After the pandemic, newly formed community coalitions should be strengthened and directly funded to address health inequities beyond COVID-19. Similarly, advocacy organizations that arose during the early HIV era have expanded their scope to include

related infections, such as hepatitis C, as well as social justice issues (e.g., homophobia, transphobia, transactional sex work). Advocacy coalitions should also formally be engaged in partnerships with COVID-19 research networks to ensure that questions relevant to most-impacted communities are addressed and to mitigate medical and research mistrust.

CONCLUSION

Combating medical mistrust has been a central focus of efforts to address inequities, including those associated with both HIV and COVID-19. It is time to reconceptualize mistrust as a rational, adaptive response to structural racism. Leveraging this adaptive response and promoting resilience and empowerment require that we acknowledge the root cause of mistrust and support the development of community-led solutions that confront systemic inequity. Ultimately, empowerment realized at the community level will be an essential driver of structural change and lead to a more equitable future. AJPH

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CONFLICTS OF INTEREST

The authors report no conflicts of interest.

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