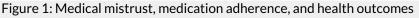# HIV & Medical Mistrust: A Summary

WHAT IS MEDICAL MISTRUST? HOW DOES IT AFFECT HIV PREVENTION AND TREATMENT?

Medical mistrust is a key contributor to racial/ethnic health and healthcare disparities in the U.S., including for HIV [1]. It is defined as mistrust in healthcare providers and systems, mistrust in providers' skills and competence, and mistrust in the assurance that people will receive equal care regardless of their race or ethnicity. Structural and interpersonal discrimination, including mistreatment in healthcare, can contribute to medical mistrust.

Medical mistrust has serious health consequences for people living with and at risk for HIV. For instance, medical mistrust can affect a patient's comfort level in discussing their sexual behaviors and pre-exposure prophylaxis (PrEP) with their providers, leading to decreased uptake of PrEP, which is a highly effective medication to prevent HIV acquisition [2].

Medical mistrust can also influence how patients think about medications, which in turn may impact their motivation to take them, leading to non-adherence and adverse health outcomes. **Figure 1** illustrates this general progression:

Figure 1: Medical mistrust, medication adherence, and health outcomes

Medical mistrust also can affect views about HIV. Mistrust about the origin, prevention, and treatment of HIV (also known as "HIV conspiracy beliefs") can take several forms: **Genocidal Beliefs** commonly attribute HIV disparities to malicious government actors (e.g., the CIA) who are intentionally withholding a cure and/or that created HIV in a government laboratory as a form of genocide against people of color. **Treatment-Related Beliefs** focus on medications related to HIV, such as that the medications are poisonous or ineffective, or that people who take antiretroviral therapy for HIV are serving as laboratory animals in experiments for the government. **See Figure 2 for a definition of a conspiracy belief.**

What is a conspiracy belief? A conspiracy belief is an effort to explain the causes of an event, practice, or circumstance as the actions of powerful people who attempt to conceal their role. It is not necessarily a false, harmful, unjustified, or irrational belief.

Figure 2: What is a conspiracy belief?

HIV conspiracy beliefs are not uncommon among Black Americans. Figure 3 illustrates results from a 2016 nationally representative email survey of Black individuals aged 18-50 in the U.S. [6].

31% agree "HIV is a man-made virus"

40% agree "There is a cure for HIV but the government is withholding it from the poor"

33% agree "The medicine that doctors prescribe to treat HIV is poison"

Figure 3: 2016 survey results from U.S. Black individuals aged 18-50

Medical mistrust has important implications for HIV prevention, testing, and treatment. Among racial/ethnic minority individuals, **HIV-related medical mistrust has been associated with lower awareness of [3] and lower intention to adopt PrEP [4], as well as lower antiretroviral therapy adherence among those living with HIV [5].**

Note: While research indicates robust associations between medical mistrust and health outcomes and behaviors related to HIV, most of this research is among Black Americans. More research is warranted involving Latinx and other minority racial/ethnic subgroups.

WHY IS MISTRUST ASSOCIATED WITH HIV OUTCOMES? A MULTILEVEL PERSPECTIVE

The chapter proposes a model to present the effects of mistrust on disparities in HIV prevention, care, and treatment.
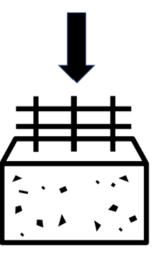
Imagine that forming medical mistrust is like mixing concrete. Concrete is a mixture of **solid elements** (rocks of various sizes plus cement) and **water.** Each component is not solid on its own, but when they interact, a hard matrix is formed that lends cement its solidity. **Once formed, it is difficult (but not impossible) to break.** Breaking hardened medical mistrust is possible with effort, just as the structure of concrete itself will yield to a strong enough drill.
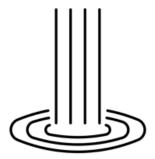
The authors' model for medical mistrust follows this formula. Discrimination, represented here by the solid components, are experienced on an interpersonal level (such as in interactions with healthcare providers) and/or structural level (systemic racism, healthcare systems, knowledge of historical injustices), and form the origin of mistrust. What sustains mistrust, or gives mistrust greater "durability" are a range of factors. Mistrust is **sustained as a coping mechanism against continued oppression**, in order to maintain a sense of control and meaning over one's life. Mistrust also can be **sustained through interpersonal relations**, such as seeking medical advice informally from one's social network rather than from one's healthcare providers. And finally, mistrust can be **sustained through messages** from elected officials and other community leaders as well as through media. **Figure 4** below illustrates the model:

Discrimination: Interpersonal and Structural

Sustaining Factors: 1) Mistrust as coping mechanism, 2) Messages from social network, 3) Messages from elected/community leaders

DURABLE MISTRUST

Individual-Level Interventions

Few individual-level interventions to improve trust in providers and healthcare systems have been subject to testing. Some individual-level interventions are currently being tested that empower individuals to leverage their innate resilience resources to improve their health in the face of discrimination, and to discuss concerns and process discrimination experiences with others like themselves [7,8]. **These individual interventions conceptualize mistrust as a form of resilience** in the face of centuries of oppression—a survival mechanism that helps individuals cope with discrimination and maintain a sense of meaning, control, and empowerment to make change in their communities. Thus, their larger aim is change at a community level.

Social Network-Level Interventions

One pilot study focusing on church congregant networks among Black and Latinx communities showed increased HIV testing. This pilot study aimed to decrease HIV stigma and HIV conspiracy beliefs and to increase HIV testing among congregants and social network members in participating Black and Latinx churches. Results indicated greater HIV testing among those in the intervention arm and reductions in stigma and medical mistrust (measured as HIV conspiracy beliefs) [9]. **The study was insufficiently powered** to examine reasons for reductions in medical mistrust in some churches and not others, and effects at the community- and social network-levels were not measured.

Healthcare provider interventions

A handful of studies have aimed to increase providers' cultural competency and empathy in order to increase patients' trust in providers. The results are unclear, with most of those that have been tested showing non-significant effects. It remains unknown the extent to which these interventions, which focus on increasing trust in a patient's own provider, generalize to decrease individuals' medical mistrust overall and whether such interventions would be effective for increasing adherence and engagement in care, especially for HIV. Future directions include testing interventions with non-clinical and clinical healthcare providers to examine whether training at the healthcare provider network-level can successfully address patient mistrust and improve patient outcomes.

Future Directions

Future interventions could focus on breaking the association between mistrust and less healthful behaviors and outcomes, and harnessing mistrust for positive effects. Any intervention to address medical mistrust—whether at the individual, social network, or healthcare provider level—**must first acknowledge the historical and current context of discrimination in the U.S. as the root cause of medical mistrust.** Because medical mistrust is rooted in awareness of and experiences with discrimination, structural-level interventions to address medical mistrust must also identify ways in which discrimination operates and how the effects of discrimination can be mitigated within the health context and beyond. **Systemic interventions to address medical mistrust leading to societal change have yet to be explored.**

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