Medical Mistrust, Discrimination, and HIV in Black/African American Communities

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What is medical mistrust?

Distrust of

Healthcare systems

Providers

Treatments

Absence of trust that providers/organizations genuinely care for patients’ interests, are honest, practice confidentiality, and have competence to produce the best achievable results

African Americans show high levels of medical mistrust—which is thought to arise from historical and ongoing discrimination
What is HIV-specific medical mistrust (aka HIV conspiracy beliefs)?

• Specific form of medical mistrust around the origin, prevention, and treatment of HIV
  – e.g., HIV was created by the government, antiretroviral treatment (ART) is poison or ineffective, a cure is being withheld

• Effort to explain HIV by reference to the actions of powerful people who attempt to conceal their role
  – Not necessarily false, harmful, unjustified, or irrational
HIV conspiracy beliefs remain common among many African Americans

2016 National Survey of HIV in the African American Community

- HIV is a man-made virus: 31.4%
- There is a cure for HIV but the gov’t withholds it from the poor: 39.8%
- The medicine that doctors prescribe to treat HIV is poison: 32.7%
- The gov’t usually tells the truth about major health issues like HIV/AIDS: 17.9%
How does medical mistrust affect HIV outcomes?

Prevention Outcomes

- Inconsistent condom use
- Lower comfort discussing PrEP with providers
- Lower PrEP awareness
- Lower intention to adopt PrEP
- Lower uptake of PrEP

Treatment Outcomes

- Lower adherence to ART
- Detectable viral load
- Weaker beliefs about the effectiveness of ART (which in turn is related to nonadherence)
Why does mistrust affect HIV outcomes? A multilevel perspective

A. Structural Discrimination

B. Interpersonal Discrimination

C. Medical Mistrust
   - General
   - Conspiracy Beliefs

D. HIV Outcomes
   - Prevention
   - Care
   - Treatment

E. Individual level
   - Coping/motivation

F. Social level
   - Social network
   - Peer group

G. Structural level
   - Leadership
   - Community
Discrimination leads to mistrust

Mistrust stems from knowledge of current and historical injustices in healthcare and U.S. society in general.

- Experiencing discrimination is associated with higher mistrust
- Mistrust explains the association between discrimination and health behaviors (longer time since medical exam, nonadherence)
- Closer residence to Macon County, AL related to more mistrust, lower healthcare utilization, and greater mortality among Black men from before to after 1972

Photo: National Archives Atlanta, GA (U.S. government)
Mistrust can be a form of resilience

- Mistrust is not necessarily harmful
  - Can empower individuals for change when channeled effectively
- Protective/adaptive survival mechanism in face of oppression
- Healthy, functional coping mechanism
Mistrust can spread in social networks

- Reliance on social network members for healthcare advice
- Social network members understand the context of discrimination in healthcare and thus are more credible than healthcare providers
- HIV treatment nonadherence is related to hearing HIV conspiracy beliefs from similar network members
Mistrust can be reinforced at the structural level

- Formal leaders (elected officials, religious leaders) and informal popular opinion leaders (e.g., artists, musicians) may reinforce mistrust
- Online and in person (social media, music, sermons, etc.)
How can medical mistrust be addressed?

• No evidence-based interventions address medical mistrust

• A few interventions have been tested to improve trust in individual providers (not overall)
  – Training on cultural competency, empathy, and patient-centered communication
    • e.g., through intensive tailored patient case feedback
  – Most not effective; none tested for HIV

• A few patient-level interventions focus on improving trust in HIV-related information and decreasing HIV conspiracy beliefs
  – Community-based interventions (e.g., peer navigation) for peers to serve as a bridge to healthcare
  – Will be focus of another community forum
Recommendations for Providers

- Teach providers how to respond to mistrust in a sensitive manner while conveying accurate information
  - Motivational interviewing skills
    - Empathy, reflective listening
    - Non-judgmental, non-confrontational
    - Acknowledge historical and current context of discrimination as root cause of mistrust
Recommendations for Communities

- Catalyze individuals to be informed healthcare consumers
  - Find out about local organizations’ care quality

- Encourage healthcare organizations to engage community stakeholders on advisory boards
  - Review patient data and policies for disparities

- Civic engagement
  - Vote and encourage others to vote!
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