

Medical Mistrust and Distrust: Past and Present

Speakers:

Michelle Ogle, MD, FAAP, AAHIVS

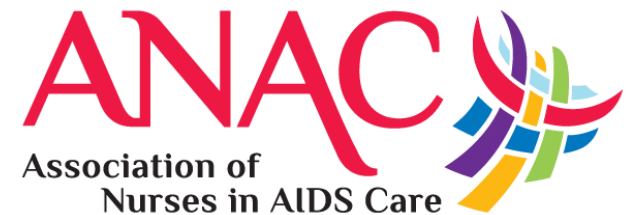
Deborah Wafer, PA, RNP

Panelists:

Sheldon D. Fields, PhD, RN, FNP-BC, AACRN, FAANP, FAAN

Doris Browne, MD, MPH

Ace Robinson, MHL, MPH



Continuing Nursing Education

Upon full participation in this webinar & completion of an evaluation, participants will be awarded 1.0 contact hours.



The Association of Nurses in AIDS Care (ANAC) is accredited as a provider of nursing continuing professional development by the American Nurses Credentialing Center's Commission on Accreditation.



Agenda

- Introductions
- Presentation
- Panelist discussion
- Q&A

Disclosure

The speakers have no potential conflicts of interest to disclose.

Objectives

- Explain the difference between mistrust and distrust
- Summarize the history of medical mistrust and distrust in the healthcare system
- Identify how systemic healthcare racism contributes to poor clinical outcomes in communities of color
- Discuss interventions to address barriers to research participation in communities of color

Introductions



Michelle Ogle, MD,
FAAP, AAHIVS



Deborah Wafer,
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Medical Mistrust and Distrust: Past and Present

Michelle Collins-Ogle, MD, FAAP, AAHIVS
Division of Pediatric Infectious Diseases
Pediatric and Adolescent HIV
Children's Hospital at Montefiore
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Achieving Health Equity in the Black Community is an Uphill Battle

“Of all the forms of inequality, injustice in health is the most shocking and inhuman”

Martin Luther King, Jr., March 25, 1966

Mistrust vs. Distrust

- **Distrust**

-Lack of trust or confidence. A “feeling” that someone or something is not being honest. Also framed as a “suspicion” and often leads to the feeling that one can not be trusted.

- **Mistrust**

-A valid response to a betrayal or having been betrayed. This sense of betrayal within the health care system leads to anxiety, anger, of self-doubt.

- These words are used interchangeably and often referencing the same experiences.

Racism is Deeply Rooted in the U.S.



Hatred of 'the other' is deeply embedded in U.S. history.



400 Plus Years of Institutional and Structural Racism

even if remove income, insurance, coverage, and education, BIPOC still have worst outcomes – race is an independent factor that affects our health – implicit bias affects outcomes

The Somber History of Medical Mistrust

- From the beginning of slavery, white physicians played a key role in the abuse and mistreatment of Black bodies. Slaves were medically neglected and abused because they were not legally human. Slave owners decided when and if healthcare was given.
- Medical care was rendered to save the life of slave owner's property after their homemade remedies failed.
- When slaves were ill, they were accused of faking, feigning or being lazy. Physicians were used to reinforce the slave owner's diagnoses or decide whether slaves were actually ill. Many southern physician's profitability and support of slavery put them in a position to render medical decisions based on their shared economic success.

The Concept of Teaching Hospitals and The Charity Ward

- The concept of teaching hospitals: Evolved in the nineteenth century, medical students were expected to experience specialized teaching. Blacks and poor whites were thought to be excellent teaching subjects because they didn't have the financial resources to obtain medical treatment.
- Historically, black folks weren't anxious to be hospitalized so how were medical and nursing students going to continue to learn and gain knowledge experimenting on black bodies after the abolition of slavery?
- To address this dilemma, hospitals established a "Charity Ward" to house experimental subjects which included blacks (enslaved and free) and poor whites.
- Having access to black bodies, was used as a marketing tool to attract students to medical schools and teaching programs throughout the south. This unlimited access to black bodies became very lucrative, providing limitless access for surgeries, observing physical progression of infections and response to various experimental treatments.

It's About More Than Tuskegee

- The Tuskegee and Guatemala Syphilis Studies

1932 U.S. Public Health Service In collaboration with the [Tuskegee](#) Institute in Alabama called “Tuskegee Study of Untreated Syphilis in the Negro Male.” In Guatemala, the U.S. government paid for similar research to be conducted on vulnerable people such as people with mental illness and prisoners.

- Women of Color Mass Sterilization and the “Mississippi Appendectomy”

1930s – 1970s North Carolina Eugenic Commission sterilized thousands of Black women and women in Puerto Rico eventually earned the dubious distinction of having the highest sterilization rate in the world. What’s more, some Puerto Rican women died after medical researchers tested early forms of the birth control pill on them. Native American women reported being sterilized at Indian Health Service hospitals after going in for routine medical procedures such as appendectomies.

**** And this Mass Sterilization on women of color as well as adolescent females continues to date.**

It Ain't Just About Tuskegee: 30 Years of HIV in the African American Community

- 1981 – CDC reports first known cases of AIDS (26 cases, 1 African American)
- 1984 – CDC reports 50% of pediatric AIDS cases are among African Americans
- 1988-1991 – For the first time, the number of new infections among African Americans exceeds the number of infections in whites and remains that way; the Magic of Earvin Johnson
- 1995 – NEJM Publishes Dr. Ira Chasnoff's research on "Crack Babies"

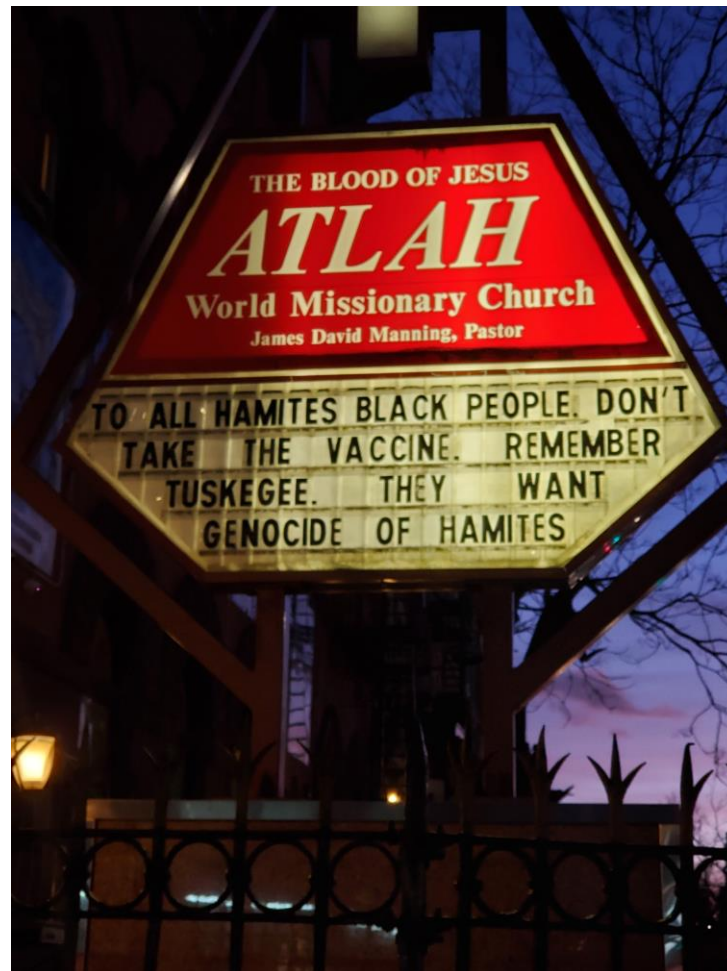
*Centers for Disease Control

30 Years of HIV in the African American Community

- 2000 – HIV cases among Black and Latino men who have sex with men exceed those among their white counterparts
- 2001 – First Annual National Black HIV/AIDS Awareness Day
- 2008 – The Black AIDS Institute reports that if Black America were its own country it would rank 16th in the world in terms of number of people with HIV—ahead of Ethiopia, Botswana and Haiti
- Today – African Americans, have the highest rates of HIV infection in the nation. Although just 13% of the U.S. population, blacks account for nearly 50% of those living and dying with HIV / AIDS. Among African Americans, gay and bisexual men are the most affected, followed by heterosexual women.

* Center for Disease Control

No, Many Black People Are Not Over It!

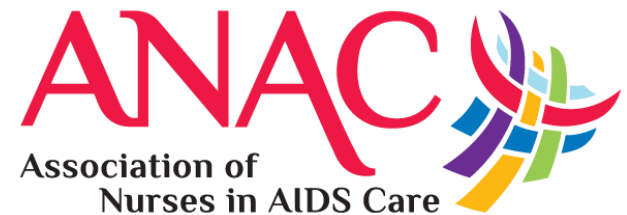


Say Her Name!

- Dr. Susan Moore in her own words. She embodies how systemic racism in the healthcare system continues to kill us.
<https://youtu.be/XpLBhAcTpTw>

Medical Mistrust and Distrust

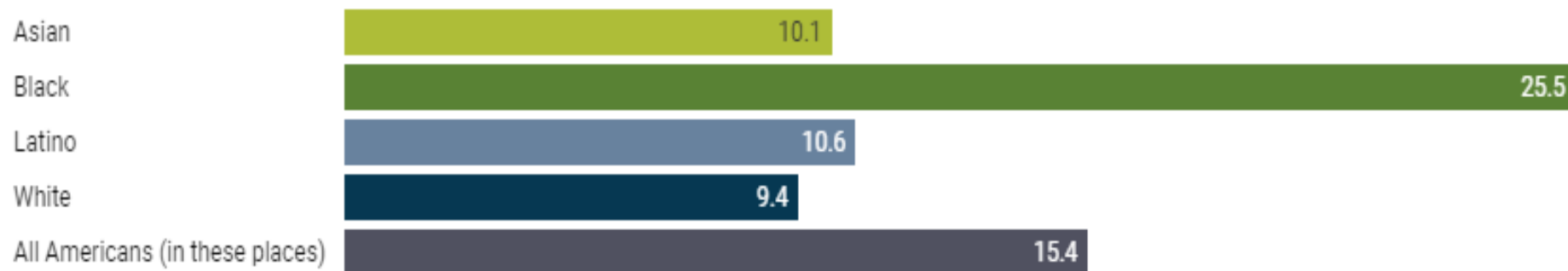
**Deborah Wafer PA, RNP
HIV Prevention Medical Scientist
Gilead Sciences
ANAC Chair of Diversity and
Inclusion Committee**



Rate of COVID-19 Deaths by Race

Rate of COVID-19 deaths reported by race/ethnicity through April 23, 2020

For all U.S. states with available data and Washington, D.C. Mortality rate per 100,000 residents of each group.

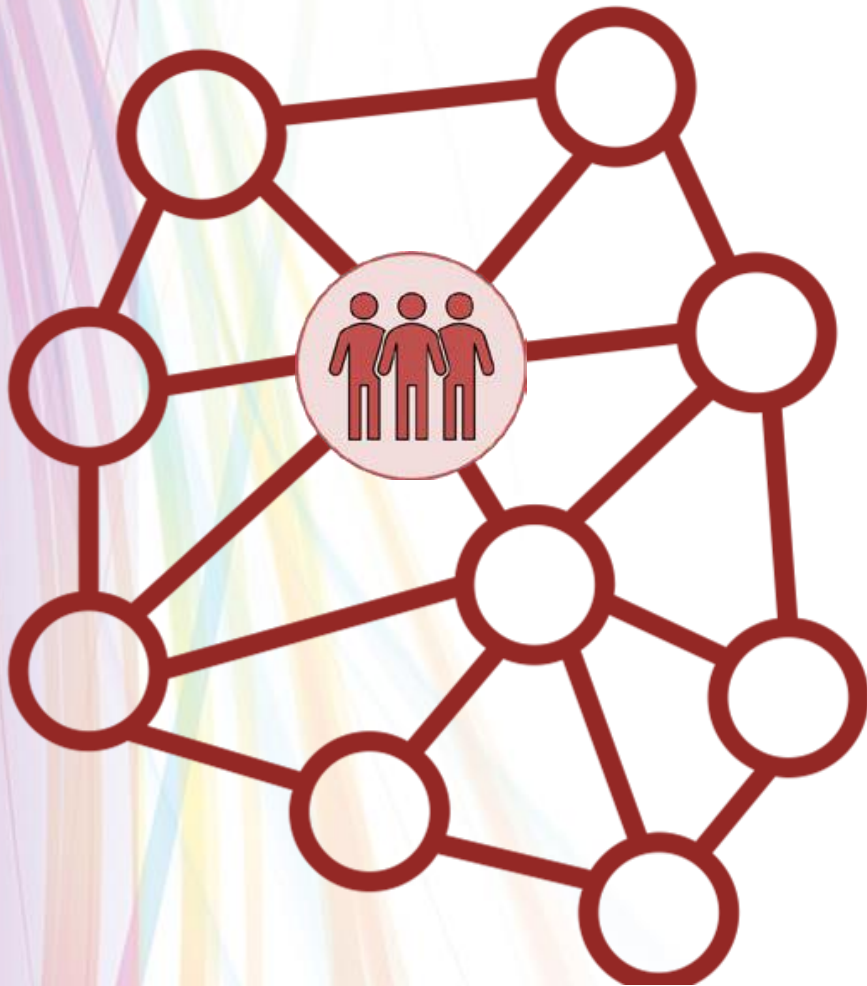


Mistrust can be a form of resilience



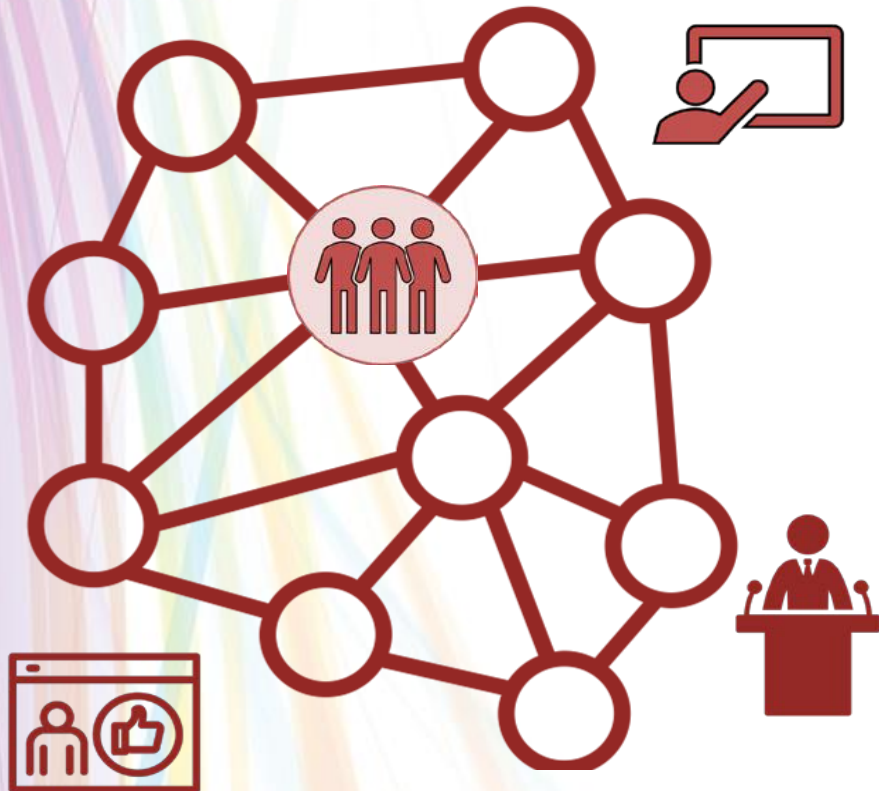
- Mistrust is not necessarily harmful
 - Can empower individuals for change when channeled effectively
- Protective/adaptive survival mechanism in face of oppression
- Healthy, functional coping mechanism

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)
 - A few interventions have been tested to improve trust in individual providers (not overall)
 - 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

Develop provider trainings

- 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 Providers

Harness the positive effects of mistrust

- Catalyze healthcare consumers
 - Find out about local organizations' care quality
- Encourage healthcare organizations to engage community stakeholders at the beginning
- Advisory boards
 - Review patient data and policies for disparities
- Civic engagement
 - Show up in community
- Reciprocity

Medical Mistrust

- Lack of confidence in the medical system and intentions and work of medical professionals.¹
- Black Americans are more likely than White Americans to have medical mistrust.^{2,3}

1 Ball, Lawson, & Alim, 2013

2 Doescher, Saver, & Franks, 2000

3 Halbert, Armstrong, Gandy, & Shaker, 2006

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Additional References

- [HIV Specialist - September 2020 \(nxtbook.com\)](#)
- [Why White HIV Leadership Needs to Give Reins to Black Leaders](#)

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<https://www.classmarker.com/online-test/start/?quiz=qbj60256b157a23d>

You will be asked to create a login. This is a temporary account that will allow you to return to the evaluation if you do not finish it. This is not the same login as your ANAC account.

Additional Questions?

Email Hina at hina@anacnet.org or Kara at kara@anacnet.org

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