

Medical Mistrust: What It Is, Its Roots & How to Address It

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Learning Objectives

- Define medical mistrust
- Characterize the relationship between medical mistrust and select HIV and COVID-19 outcomes
- Be familiar with provider- and institutional-level approaches to addressing medical mistrust

Presentation Roadmap

- Medical Mistrust: HIV & COVID-19
- Origins of Medical Mistrust in the Black community: A Snapshot (Content Warning)
- Approaches to Addressing Medical Mistrust



Presentation Roadmap

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- Origins of Medical Mistrust in the Black community: A Snapshot (Content Warning)
- Potential Approaches to Addressing Medical Mistrust



Case Vignette

- You see one of your clients and they tell you that they've been having fever, cough and difficulty breathing for the past few days
- You're worried that your patient may have COVID-19 and you tell them you think they need to go to the ED nearby, but they say:

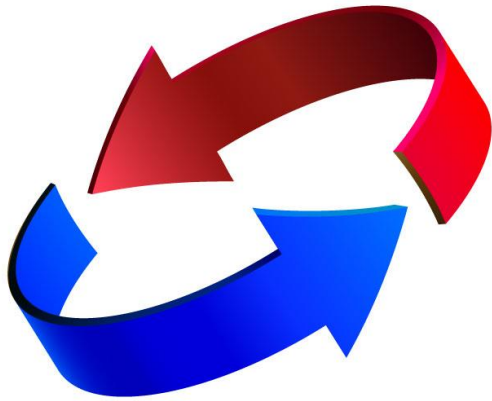
"I don't trust that hospital to take care of me. The staff there haven't treated me well in the past. I'd rather go home until I really need help."

What is Medical Mistrust?



Medical mistrust is not just a lack of trust in health care providers & organizations to genuinely care for patients' interests. but also the belief that the health care system is acting/will act with ill intent towards a certain individual or group.

What causes Medical Mistrust?



- “A phenomenon created by and existing within a system that creates, sustains and reinforces **racism, classism, homophobia and transphobia**, and **stigma**” (also known as **inequality-driven mistrust**)¹
- Considered “an active response to direct or vicarious (e.g., intergenerational or social network narratives) marginalization”²

Nota Bene: Conspiracy Beliefs vs. Counternarratives



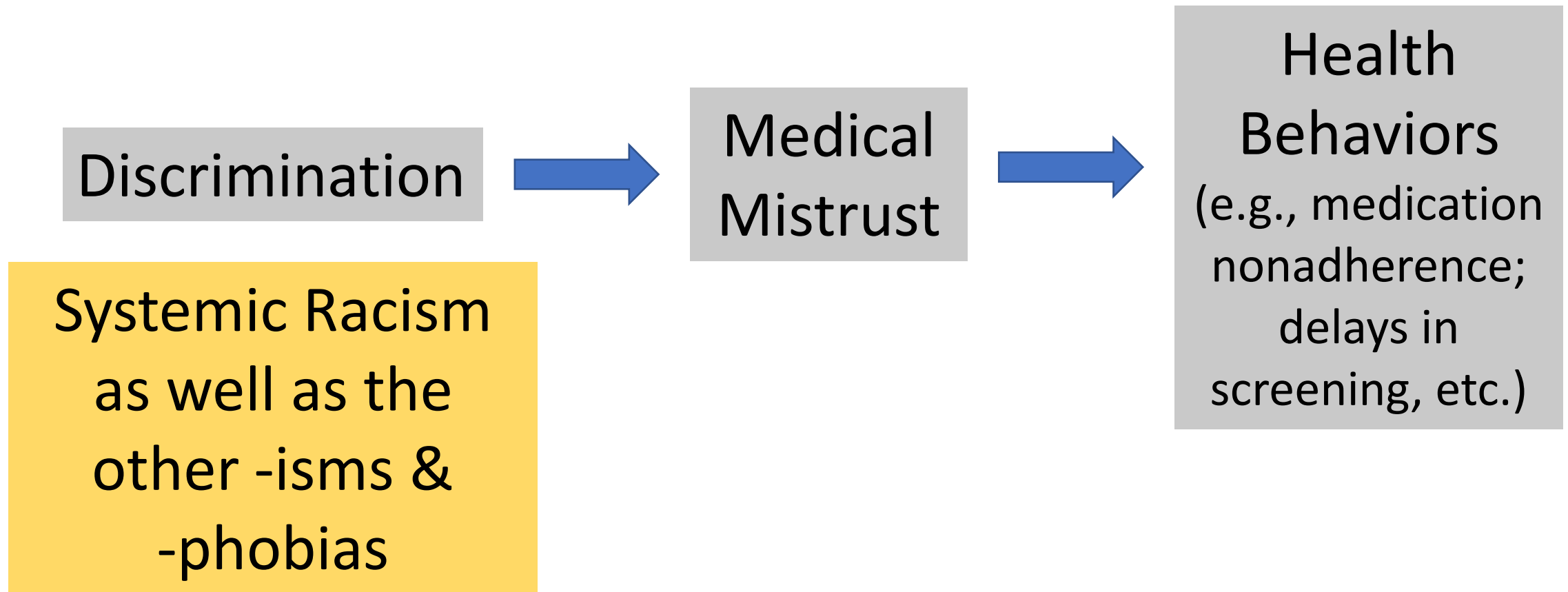
- “Conspiracy beliefs” can be true and not necessarily false, harmful or unjustified
- **Counternarratives** - narratives that arise from the vantage point of those who have been historically marginalized; beliefs that differ from the beliefs of dominant culture

Medical Mistrust as a Coping Mechanism



- An appropriate survival mechanism that allows people to protect themselves or prepare counter measures
- A form of resilience and a way for people from marginalized groups to empower themselves

The Relationship between Discrimination, Medical Mistrust & Health Behaviors



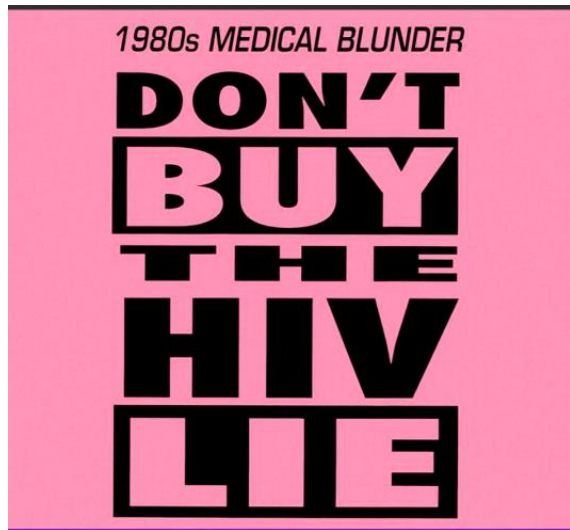
Medical Mistrust Impacts Health Behaviors

- Lower health care utilization including preventive health practices¹⁻⁵
- Lower adherence to medical treatment⁶⁻⁹
- Poorer quality patient-provider relationships^{10,11}
- Higher likelihood of engaging in behaviors that place people at risk¹²
- Lower rates of involvement in biomedical research^{13,14}

¹Eaton et al. AJPH. 2015; ²Brenick et al. LGBT Health. 2017.; ³LaVeist et al. Health Serv Res. 2009; ⁴Arnett et al. J Urban Health. 2016; ⁵Powell et al. Behav Med. 2019; ⁶Dale et al. J Health Psych. 2016.; ⁷Kalichman et al. Behav Med. 2016; ⁸Bogart et al. Soc Sci Med 2016; ⁹Bickell et al. J Clin Oncol. 2009; ¹⁰Tekeste et al. AIDS Behav. 2019; ¹¹Benkert et al. J Nurs Scholarsh. 2009; ¹²Bogart et al. AIDS Behav. 2011; ¹³George et al. AJPH. 2014; ¹⁴Smirnoff et al. AJOB Empir Bioeth. 2018



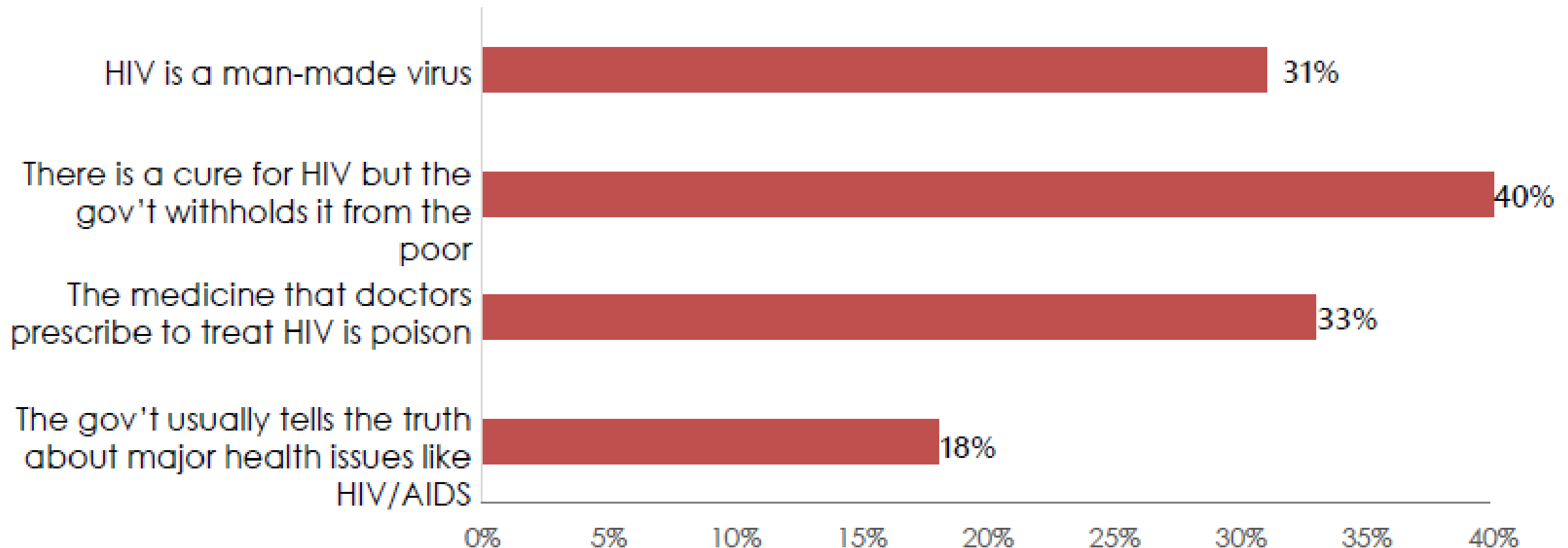
Medical Mistrust & HIV



- “Conspiracy-related” beliefs
 - The idea that the government created HIV as a form of genocide against Black people and other marginalized groups
- Treatment-related beliefs
 - The idea that HIV treatment (antiretrovirals) is used to experiment on or kill those who take it or that a cure is available, but is being withheld by the government and/or pharmaceutical company for profit

HIV-related mistrust remain common among many Black Americans

2016 National Survey of HIV in the Black Community (n = 868)



Medical Mistrust is Negatively Associated with Many HIV-related Outcomes

- Lower uptake of HIV testing
- Lower uptake of condoms
- Less comfort talking to providers about PrEP
- Lower PrEP awareness and uptake

- Lower likelihood to believe HIV treatment is effective
- Lower antiretroviral adherence
- Less likelihood of viral suppression
- Engagement in HIV care?

Mistrust and Engagement in HIV care

- Qualitative study focused on people who were not engaged in HIV care
- 27 participants, 78% Black
- Found HIV-related beliefs are common, but may not necessarily be a barrier to care. Participants in various stages of engagement insisted that these beliefs did not play a central role in how they managed their health

“I mean, I do, but I don't. I think they experiment with a lot of stuff and things happen, and the stuff just starts forming. I can't be thinking about all that. I got other stuff to think about...”

Medical mistrust: COVID-19 origins & vaccines

Study: Nearly a third of Americans believe a conspiracy theory about the origins of the coronavirus

A new Pew study finds 30 percent of Americans believe scientists created Covid-19. That isn't what happened.

By Aja Romano | @ajaromano | Apr 12, 2020, 9:30am EDT



HEALTH

'Tuskegee always looms in our minds': Some fear black Americans, hardest hit by coronavirus, may not get vaccine

Jayne O'Donnell USA TODAY

Published 7:00 a.m. ET Apr. 19, 2020 | Updated 10:09 a.m. ET Apr. 20, 2020

Nearly one-third of Americans believe a coronavirus vaccine exists and is being withheld, survey finds

Joey Garrison USA TODAY

Published 5:00 a.m. ET Apr. 24, 2020 | Updated 11:05 a.m. ET May 12, 2020

<https://www.vox.com/covid-19-coronavirus-us-response-trump/2020/4/12/21217646/pew-study-coronavirus-origins-conspiracy-theory-media>

<https://www.usatoday.com/story/news/politics/2020/04/24/coronavirus-one-third-us-believe-vaccine-exists-is-being-withheld/3004841001/>

<https://www.usatoday.com/story/news/health/2020/04/19/coronavirus-vaccine-black-americans-prevention/5146777002/>

Medical mistrust: COVID-19 origins & vaccines



Dr. Oni #BraylaStone Blackstock ✓
@DrOniBee

Just passed by an older Black man who said "It's manmade. They already have a vaccine for it."

Holding space for counternarratives based on historical & current truths & that there are aspects of [#COVID19](#) pandemic that are "manmade" such as the racial/ethnic inequities we see.

5:44 PM · May 2, 2020 · [Twitter for iPhone](#)



Sylvia K. Alston ✓
@SylviaKAlston

Folks, I've polled black people & as I suspected- they will not be taking the vaccine for [#COVID](#) once it becomes available.

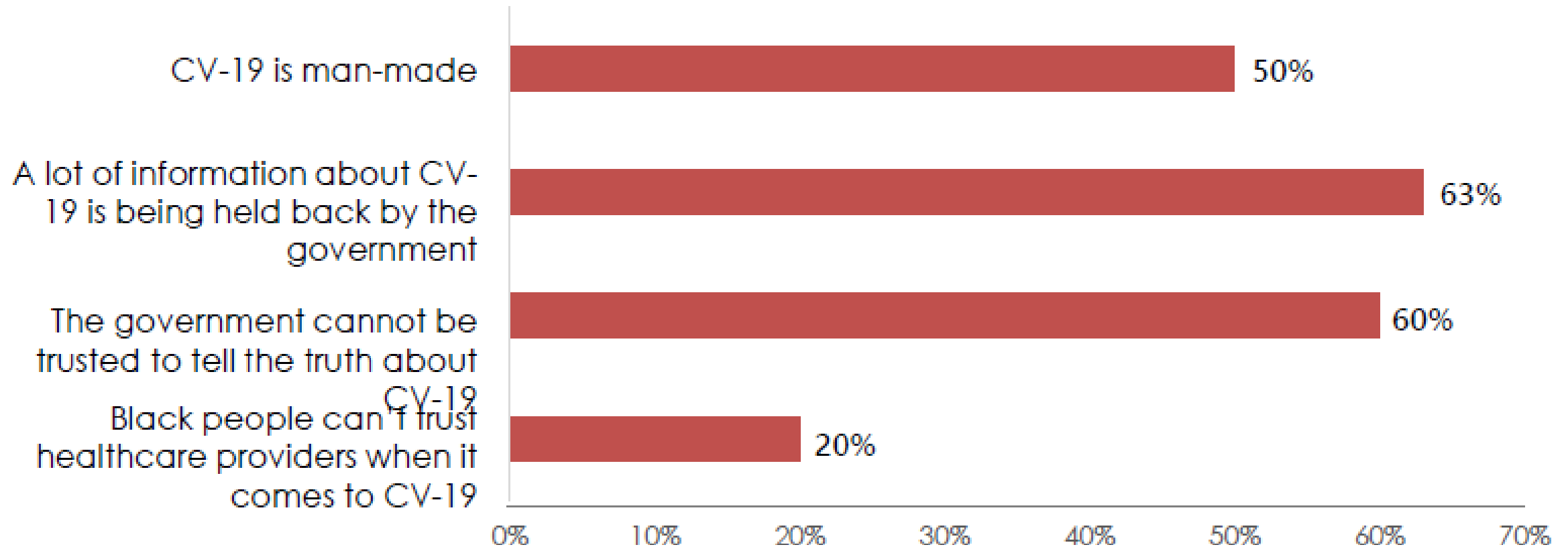
When asked for their reasoning, they mentioned Henrietta Lacks, The Tuskegee experiment, Monday, Tuesday in the US.

Just thought I'd inform, yeah nah.

4:29 PM · May 18, 2020 · [Twitter for iPhone](#)

COVID-19 mistrust may be common

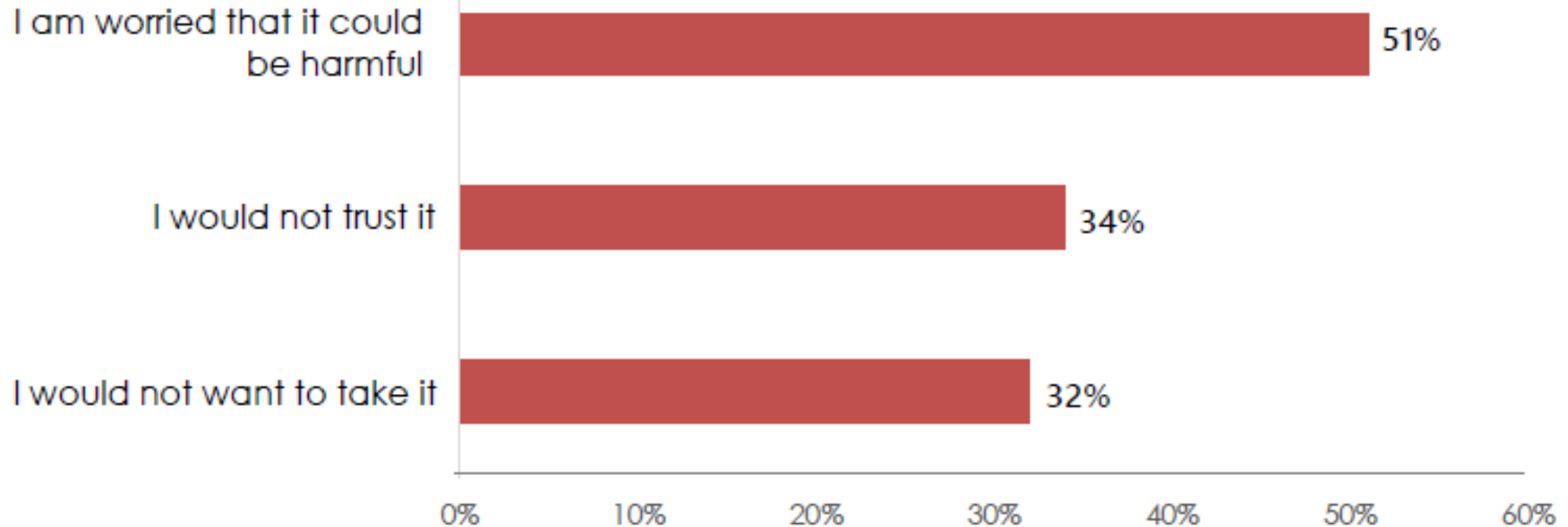
HIV-positive Black Adults in Los Angeles County, CA (convenience sample)



Note: 97% agreed with at least one mistrust belief (of 10 items)

COVID-19 vaccine hesitancy/mistrust may be high

If there were a COVID-19 vaccine...



101 HIV-positive Black Adults

COVID-19 Beliefs among Black People Living with HIV

- Nearly all (97%) endorsed at least one general COVID-19 mistrust belief
- Over half endorsed at least one COVID-19 vaccine or treatment hesitancy belief
- **Social service and healthcare providers were the most trusted sources**
- Greater COVID-19 mistrust was associated w/ greater vaccine and treatment hesitancy
- Participants experiencing more negative COVID-19 impacts showed lower ART adherence.

Vaccine hesitancy

Vaccine contemplation

Vaccine vigilance

Valid & Justifiable concerns

Vaccine ambivalence

Vaccine skepticism

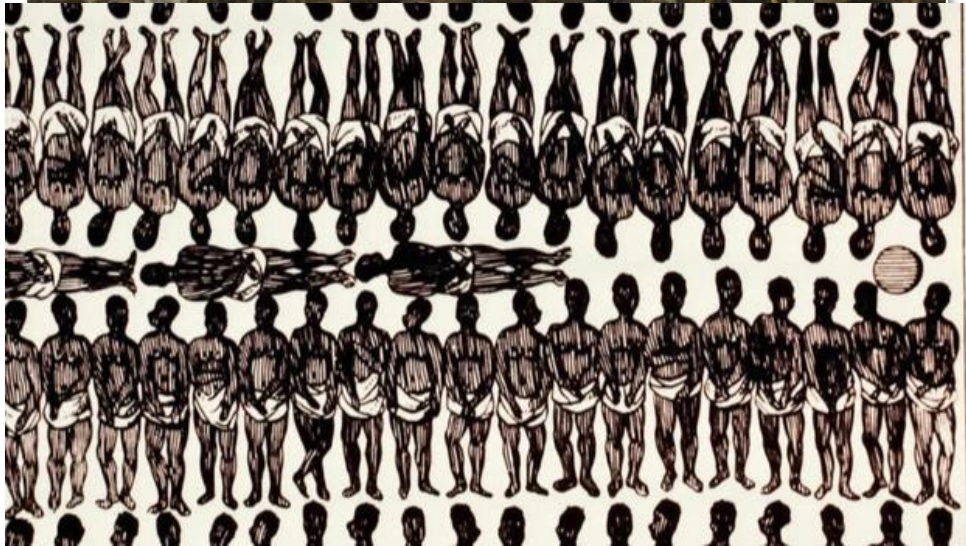
Vaccine deliberation

Presentation Roadmap

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“Medical practice” during the Transatlantic Slave Trade



- “Medically managed enterprise”
- Doctors inspected enslaved people before they were forcibly taken to slave ships; hired to ensure the “cargo” remained alive and healthy (enough) during transport
- Compensated with money as well as with enslaved people
- Passage of the Dolben Act (aka the Slave Carrying Bill) in 1788 mandated all English slave ships to have a doctor on board

“Medical practice” during the Transatlantic Slave Trade

“The more you preserve of them for the Plantations the more Profit you will have, and also the greater Reputation and Wages [you will get for] another voyage.

Besides it's a Case of Conscience to be careful of them as the White Men. For although they are Heathens yet have they have a rational Soul as well as us, and God knows whether it may not be more tolerable for them in the latter Day than for many who profess themselves Christians.”

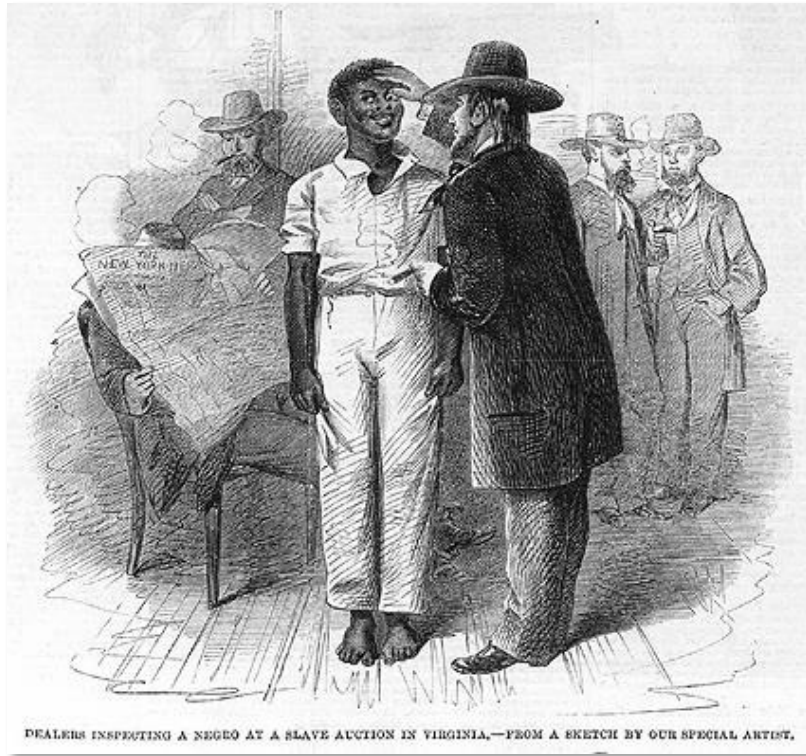


The birth of “race”



- Evolved in the 18th century driven, in part, by an increased awareness about animal subspecies as a result of animal breeding
- Occurred as the slave trade was growing
- People of African descent categorized as *Homo sapiens afer* (“ruled by caprice”)
- Associated with innate inferiority – creating a “hierarchy of humanity”
- Reified by what Europeans said where physical and mental defects of Black people (e.g., cranium size [phrenology], drapetomania, Hebetude (“laziness”), **different manifestations of syphilis**)

“Medical practice” during slavery: A medical partnership between doctor & slaveowner



- Played a key role in establishing “soundness” at the auction block
- If an enslaved person became ill or died, it was considered a significant financial loss for the owner
- Because enslaved people were often hospitalized at their owner’s expense, owners did what they could do to avoid professional medical care

The care of enslaved persons

NEGRO HOSPITAL,
NOS. 4 AND 6 WILSON-STREET.
J. J. CHISOLM, M. D., Surgeon. D. J. CAIN, M. D., Physician.

THE attention of owners of sick negroes is called to the great advantage of treating all diseases, particularly those of a chronic character, in such an institution.

Negroes suffering from medical or surgical diseases, will be received at all hours.

The usual charges for medical and surgical attendance. Only necessary visits will be charged. No contagious diseases will be received.

For further particulars, address
Dr. J. J. CHISOLM, 46 Havell-st., or
Dr. D. J. CAIN, 30 Wentworth-street.

September 13 850W

Charleston Mercury, Jan. 17, 1857



- First attended to by other enslaved people who used traditional methods passed down over generations
- Enslaved people often wanted to avoid often harsh “treatments” from their owners
- Then a physician was called; if not able to help, then was admitted to poorly resourced “slave hospitals”
- **Black midwives:** Most plantations designated women who attended births of both enslaved women and slaveowners' wives alike as well as caring for their babies and children.

Medical experimentation on enslaved people: the Case of Dr. J. Marion Sims



- “Father of modern gynecology”; founded the New York Women’s Hospital
- Owned enslaved people and did experiments on them without their consent or anesthesia
- Surgical experimentation on babies to learn about “newborn” tetanus
- Purchased 11 Black women to develop and refine repair of vesicovaginal fistula

Abuse to Black bodies after death by the medical establishment



- Frenzied need for bodies to practice anatomy and various procedures
- This made Black and poor White people wary about going to hospitals – that they would be unnecessarily experimented or allowed to die so they could be practiced upon
- “Grave robbing” and worry about the “night doctors” emerged
- Bodies often shipped to medical schools in the North as well - schools advertised that they had “dissecting material”

- Content warning for the next four slides: Images from the documentary ““Until The Well Runs Dry: Medicine & the Exploitation of Black Bodies” by Shawn Utsey, PhD demonstrating examples of the ways in which Black people’s bodies were used in anatomy classes at Medical College of Virginia



Screenshot from “Until The Well Runs Dry: Medicine & the Exploitation of Black Bodies” directed by Shawn Utsey Ph.D.

<https://vimeo.com/28188054>



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Segregated Hospitals: Separate and Unequal Care



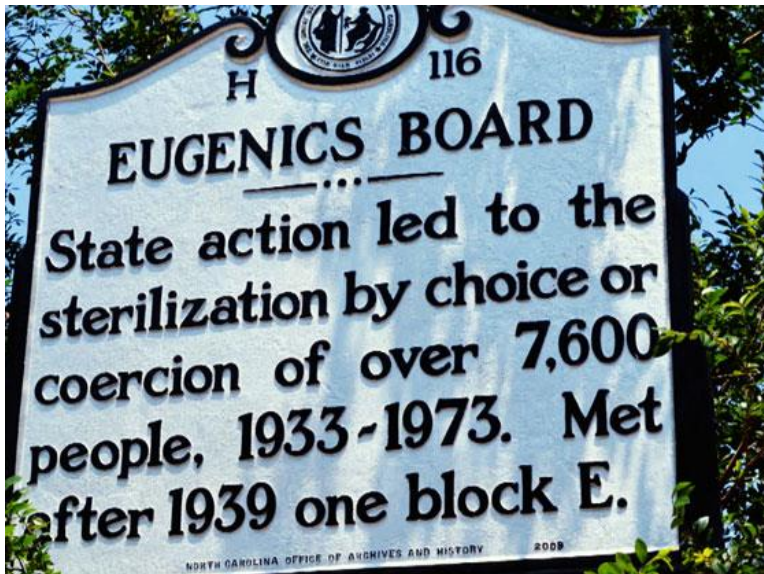
- Up until the 1960s, hospitals were rigidly segregated by race
- In the South, as per Jim Crow laws, few healthcare facilities where Black people could go
- Long waits and often relegated to basements and hallways of White hospitals
- Receiving care could be contingent on “consenting” to being experimented

A Legacy of Medical Experimentation Without Informed Consent



- 1932-1972: The U.S. Public Health Service Syphilis Study at Tuskegee
- 1940s: Untreated syphilis on Guatemalan prison inmates and psychiatric patients
- 1951: Henrietta Lacks's cervical cancer cells taken without her consent becoming 1st immortalized cell line
- 1955: "The Pill" studies in Puerto Rico
- 1974: The National Research Act established Institutional Review Boards

Eugenics & Government-sanctioned programs



- Throughout most of the 20th century, compulsory surgical sterilizations of communities considered “unfit” to reproduce – disproportionately Black women – were legal
- North Carolina **Eugenics** Commission sterilized 8,000 mentally disabled persons through the 1930s, 5,000 were Black
- South Poverty Law Center estimates 100K to 150K women using federal funds, ½ were Black
- However, many sterilizations happened outside of the law at the discretion of physicians (“Mississippi appendenctomy”)
- Governmental public assistance programs also linked sterilizations to welfare benefits

Eugenics & Government-sanctioned programs

More migrant women say they didn't OK surgery in forced hysterectomy allegations

AP By Nomaan Merchant and Kate Brumback

Sunday, September 20, 2020 7:50PM



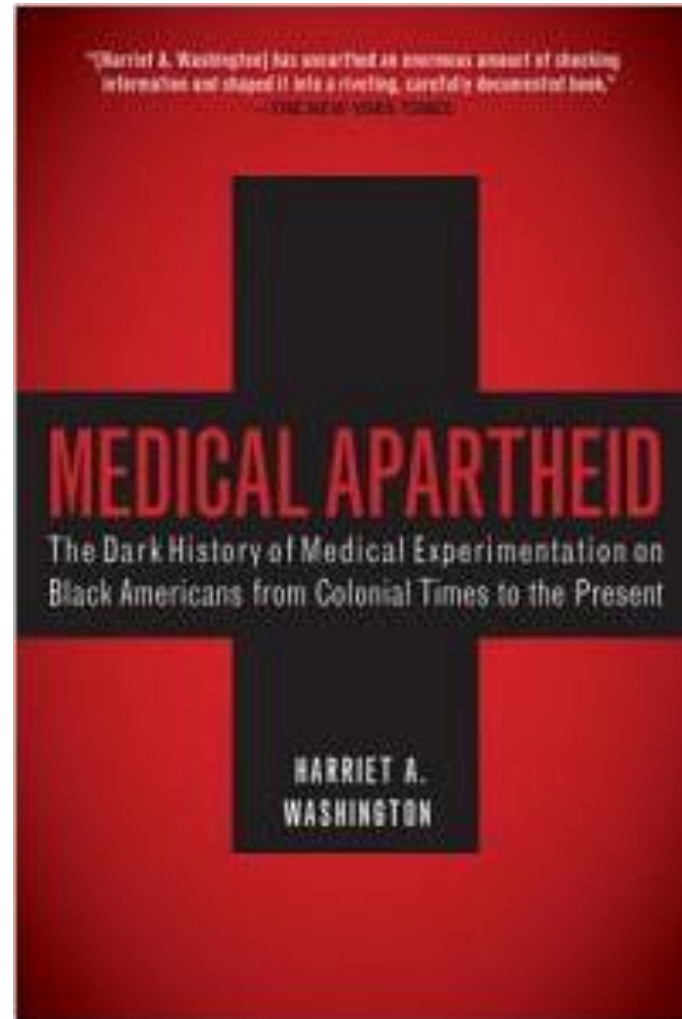
AP

Dawn Wooten, left, a nurse at Irwin County Detention Center in Ocilla, Georgia, listens to protesters at the immigration jail. (AP Photo/Jeff Amy)

Shocking ICE Abuse of Women Includes Forced Sterilization



A Must Read: Medical Apartheid by Harriet Washington



“Implicit Bias” & Health Care Professionals

- Systematic review by Hall et al. of studies looking of health care professionals (HCPs) examining the association between implicit bias and health care outcomes (n=15)
- Found low to moderate levels of racial/ethnic bias among HCPs
 - Scores similar to those in the general population
 - Levels of implicit bias against Black, Latinx and dark-skinned individuals relatively similar across groups



“Implicit Bias” & Health Care Professionals

- Results showed trends towards “implicit bias” being significantly and negatively associated with:
 - **Patient-provider interactions** (e.g. dominant communication style)
 - **Treatment decisions** (e.g., Black patients less likely to be provided appropriate pain treatment)
 - **Treatment adherence** (Black patients of pro-White bias providers less likely to fill scripts)
 - **Patient health outcomes** (Black patients reporting worse psychosocial and physical outcomes)



Health Care Inequities: Pain Treatment as an Example

- Compared to White people, Black people are less likely to receive pain treatment¹⁻¹⁰
- If Black people do receive pain treatment, the amount/quantity is lower than that received by White people
 - A study found that Black patients were significantly less likely than White patients to receive analgesics for extremity fractures in the emergency room (57% vs. 74%), despite having similar self-reports of pain.⁶
 - In a study of appendicitis among children, Black patients received opioid analgesia significantly less frequently than white patients (12.2% vs 33.9%)¹⁰



¹Anderson et al. J Pain. 2009; ²Bonham et al. J Law Med Ethics. 2001; ³Cintron et al. J Palliat Med. 2006; ⁴Cleeland et al. Ann Intern Med. 1997; ⁵Freeman et al. NEJM. 2000; ⁶Todd et al. Ann Emerg Med. 2000; ⁷Green et al. Pain Med. 2003; ⁸Shavers et al. J Health Care Poor Underserved. 2010; ⁹Smedley et al. National Academies Press. 2013; ¹⁰Goyal et al. JAMA Pediatr. 2015

Health Care Inequities: Pain Treatment as an Example

- Study of false beliefs in “biological differences” between Black and White people
 - “Blacks age more slowly than whites”; “Blacks’ nerve endings are less sensitive than whites”; “Blacks’ blood coagulates more quickly than whites”; “Whites have larger brains than blacks”
- 14-58% of White people in the study endorsed false beliefs about Black people
 - Including 58% of white people who believed that “Blacks’ skin is thicker than Whites”
 - False beliefs were associated with lower ratings for pain in Black people (vs White people) and inappropriate pain treatment recommendations

Presentation Roadmap

- Medical Mistrust: HIV & COVID-19
- Origins of Medical Mistrust in the Black community: A Snapshot (Content Warning)
- **Potential Approaches to Addressing Medical Mistrust**



How do we intervene on medical mistrust?



- No evidence-based provider interventions that address medical mistrust
- A few have studied interventions to improve trust in individual providers, but not the healthcare system
 - ❑ Training on cultural competency, empathy, and patient-centered communication
 - ❑ Most not effective; none tested for HIV

How do we intervene on medical mistrust?

- A few patient-level interventions focus on improving trust in HIV-related information and decreasing HIV-related mistrust
 - ❑ Community-based peer navigation, for peers to serve as a bridge to healthcare
 - ❑ Community-based peer counseling interventions that use motivational interviewing or cognitive behavior therapy strategies to acknowledge, validate, and discuss mistrust as a justified response to discrimination

Patient/Client-Centered Care: Recognizing Potential Signs of Mistrust

- Lack of engagement in healthcare interaction
 - ❑ Doesn't ask questions or make eye contact, seems uncomfortable, doesn't verbally agree to recommended behavior
- Lack of healthcare engagement
 - ❑ Non-adherence, missed visits
- Direct statements
 - ❑ Says they don't like taking medication, or don't like or trust the medication

Patient/Client-Centered Care: Motivational Interviewing



- Make eye contact, have an open figure
- Express empathy through reflective listening
- Be non-judgmental
- Avoid argument and direct confrontation
- Adjust to client/patient resistance rather than opposing it directly
- Support self-efficacy and optimism

Patient/Client-Centered Care: Motivational Interviewing

- Ask open-ended questions about patient's beliefs
- **Validate** patient's concerns/mistrust
 - ☐ Acknowledge historical and current realities that may have led to mistrust including person's own experiences
 - ☐ Communicates that patients'/clients' thoughts, behaviors, or emotions are well-grounded, justifiable, relevant, and meaningful
 - ☐ Ask for permission to share information after validating

Patient/Client-Centered Care: Validating Mistrust

“Given the mistreatment that Black Americans have faced, it makes sense to believe that providers aren’t looking out for your best interests.

There are so many past and current examples of discrimination in the US, especially in healthcare settings.

So it is understandable to be cautious about healthcare providers, and wonder if the medications really work.”

Patient/Client-Centered Care: Validating Mistrust



“We are trying to improve our relationships with patients. If there is anything that I do or say, or that someone at the clinic does or says that makes you feel uncomfortable, would you mind letting me know?”

Whatever you tell me will not affect your treatment or healthcare. I can keep it confidential and convey your concerns anonymously to my supervisors, if you prefer.”

Patient/Client-Centered Care

“I don’t want to assume anything about your identities. How do you identify racially, ethnically, culturally?”

Many of my clients/patients experience racism while receiving health services. Are there any experiences you would like to share with me?

What have your experiences with the health care system been like?

Have you had any experiences that caused you to lose trust?

Patient/Client-Centered Care: Asking for Permission after Validating

“So it sounds like you don’t trust HIV treatment. Would it be alright if I shared some information with you about the treatment, and you can tell me what you think?

... I understand there are many common beliefs around HIV. A lot of them are understandable responses to discrimination and mistreatment experienced by Black Americans in healthcare and society in general. At the same time, these beliefs can impede people from getting effective treatment and staying healthy. And I have personally seen many patients dramatically improve from the medications—in fact, I had a patient recently who did not initially trust the medications but decided to give them a try—and is now undetectable.”

Patient/Client-Centered Care: Open-ended Questions

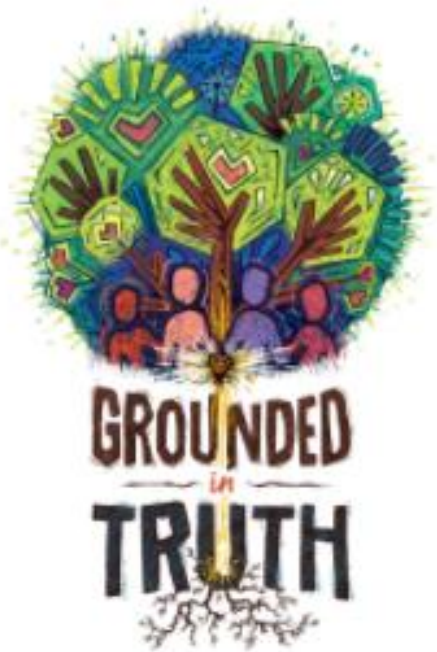


- “What might it take for you to take this treatment [vaccine]?”
 - ☐ Encourage patients to discuss the reasons why they may be motivated to engage in the behavior (e.g., it is consistent with their goal to remain healthy)
 - ☐ Explore pros and cons
 - ☐ Reflect their reasons back to them



Institutional
Trustworthiness

Building Institutional Trustworthiness



- Truth & Reconciliation
 - Facilitate critical reflection, courageous dialogue, and accurate documentation about institutional actions, policies and practices that have demonstrated untrustworthiness
 - Admit untrustworthy actions towards Black, Latinx, Indigenous and other people of color
 - Acknowledge publicly that institutional distrust is justifiable
 - Provide tangible reparations for harms committed

Building Institutional Trustworthiness



- Community-centered public health practice
 - Meaningfully engaging those communities that are the most burdened
 - Funding to support community engagement with credible and trusted FBOs and CBOs
- Staff that reflects the patient population particularly in leadership positions
 - Increasing underrepresented group representation among health care providers
- Using community health workers or peer navigators
- Funding to grassroots organizations led by and serving Black, Indigenous and Latinx communities

Building Institutional Trustworthiness



- **Longitudinal** anti-racism training for public health & health care professionals and organizational leadership
 - ❑ Include education about **historical and present-day factors** contributing to medical mistrust and how mistrust impacts interactions with patients incl. engagement in care and adherence to treatment, and ultimately health outcomes

Building Institutional Trustworthiness

- Institutional commitment to and work towards becoming a fully inclusive anti-racist organization
 - Training in anti-racism and structural competency for all staff especially leadership
 - Racial equity tools so that equity is centered during all decision-making opportunities that influence outcomes



THANK YOU! Questions?



<https://healthjustice.co>
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