

The Roots of Medical Mistrust

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Disease Intervention Specialist Summit Series

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Learning Objectives

- Define medical mistrust
- Understand the historical factors that have contributed to medical mistrust in the Black community
- Characterize the relationship between medical mistrust and select health outcomes
- Identify approaches to addressing medical mistrust with clients/patients

Presentation Roadmap

- Overview of Medical Mistrust
- Origins of Medical Mistrust in the Black community (Content Warning)
- Provider Bias
- Potential Approaches to Addressing Medical Mistrust



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Case Vignette

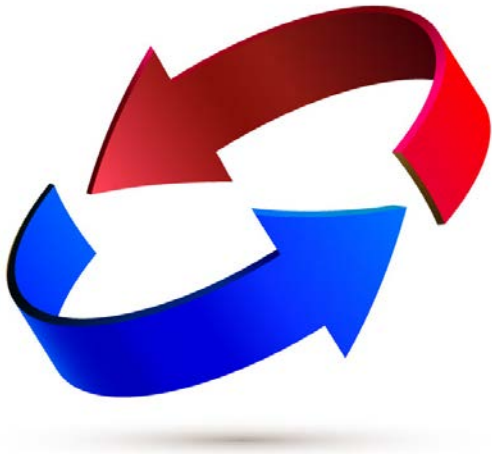
- You call a client to do partner notification
- However, you notice that the person doesn't sound well and they say they're having fever, cough, and difficulty breathing
- You're worried that they may have COVID-19 and you tell them you think they need to go to the ED near them, but they say:
- *"I 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 have to go."*

What is Medical mistrust?



Medical mistrust is not just a *lack of trust* in the medical system (i.e., hospitals, providers, treatments, etc.), *but the belief the medical system is acting/will act with ill intent towards a certain individual or group*

What is Medical Mistrust? (continued)



- Considered “an active response to direct or vicarious (e.g., intergenerational or social network stories) marginalization”¹
- “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)²
- Mistrust explains the association between discrimination and health behaviors

What is Medical Mistrust? (continued)



- Can be viewed as an appropriate survival mechanism that allows people to protect themselves or prepare counter measures
- Can be considered a form of resilience and a way for people from marginalized groups to empower themselves

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

Medical Mistrust and HIV

HIV Conspiracy Belief Item	2016 NSHBC (weighted)
HIV is a man-made virus	31.35%
There is a cure for HIV but the government is withholding it from the poor	39.77%
The medicine that doctors prescribe to treat HIV is poison	32.72%
The government usually tells the truth about major health issues, like HIV/AIDS	17.85%

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](#)

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

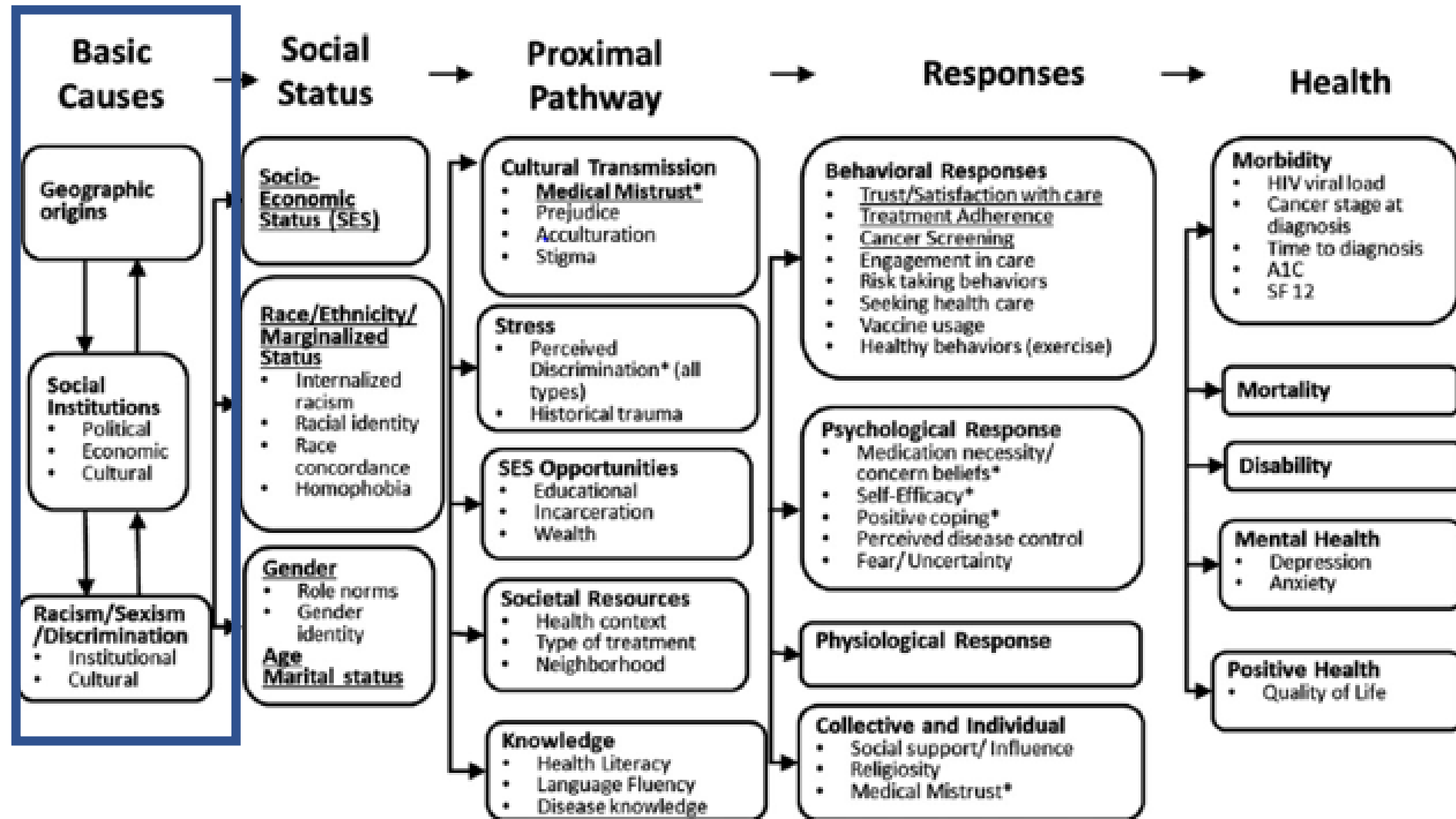
Published 5:00 a.m. ET Apr. 24, 2020 | Updated 11:05 a.m. ET May 12, 2020

<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/>

How might Medical Mistrust impact health?

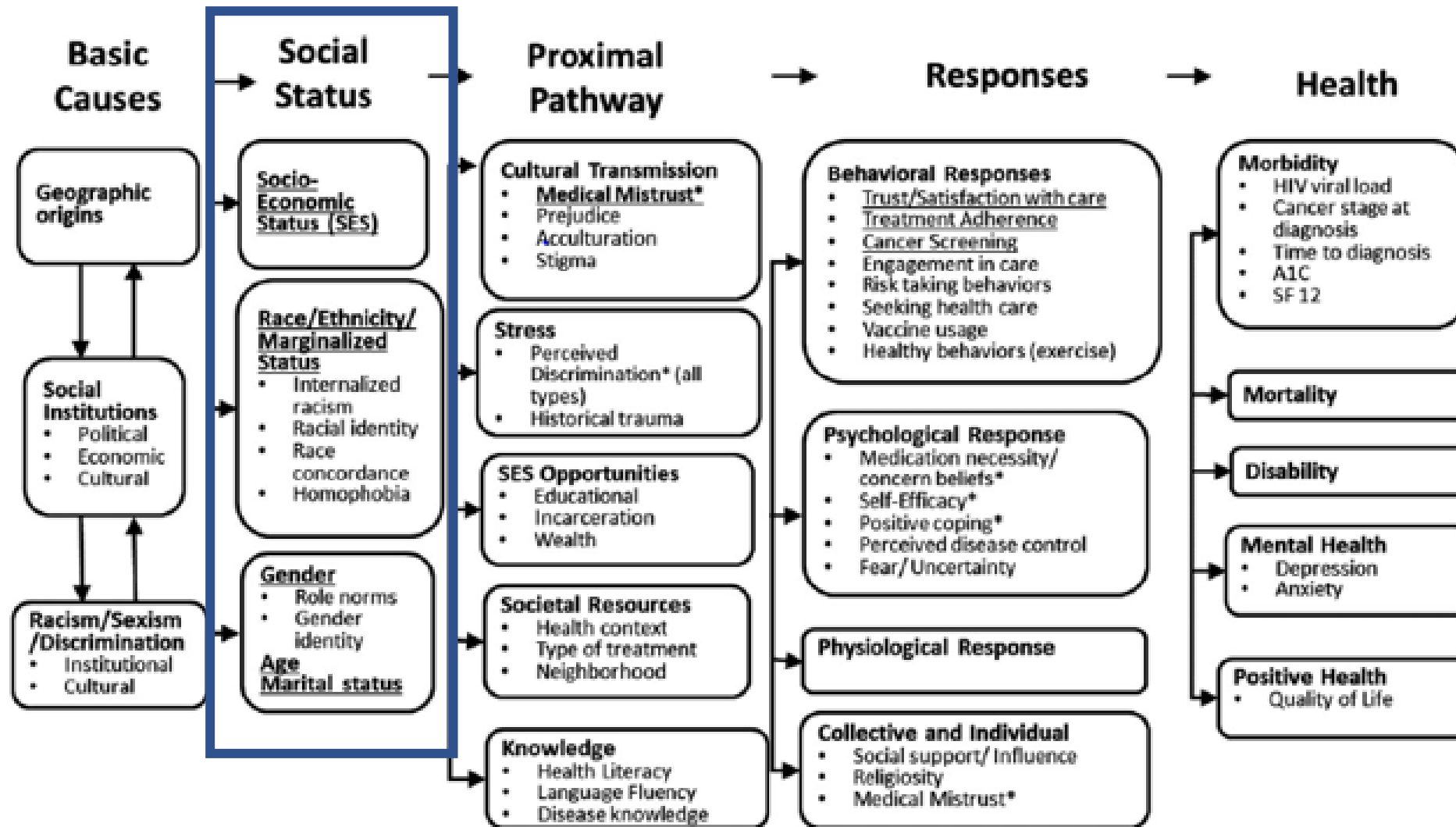


Racism and Health Framework for the study of medical mistrust and health.

Adapted from Williams and Mohammed, 2013.

Benkert et al. Behav Med. 2019

How might Medical Mistrust impact health?

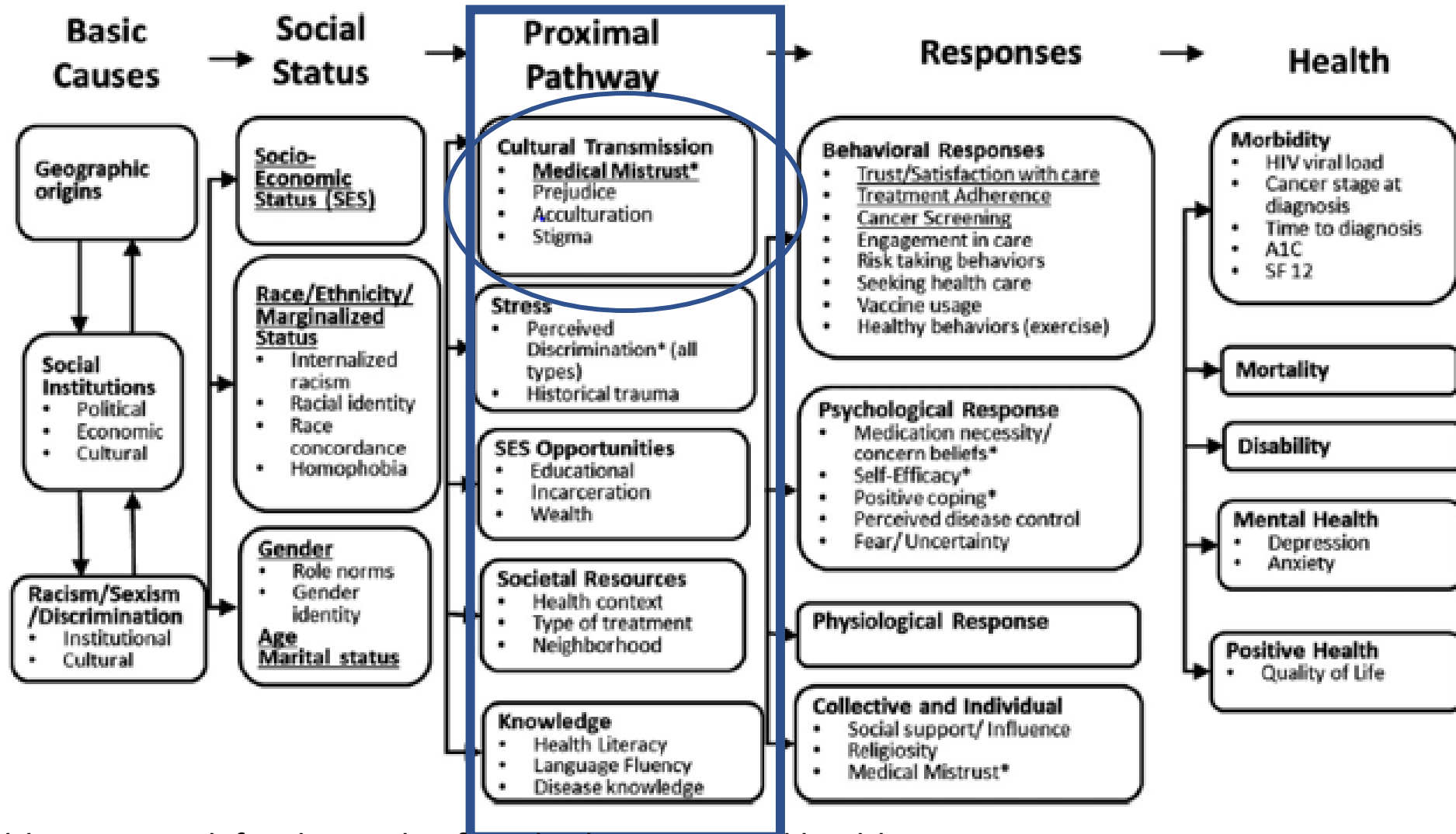


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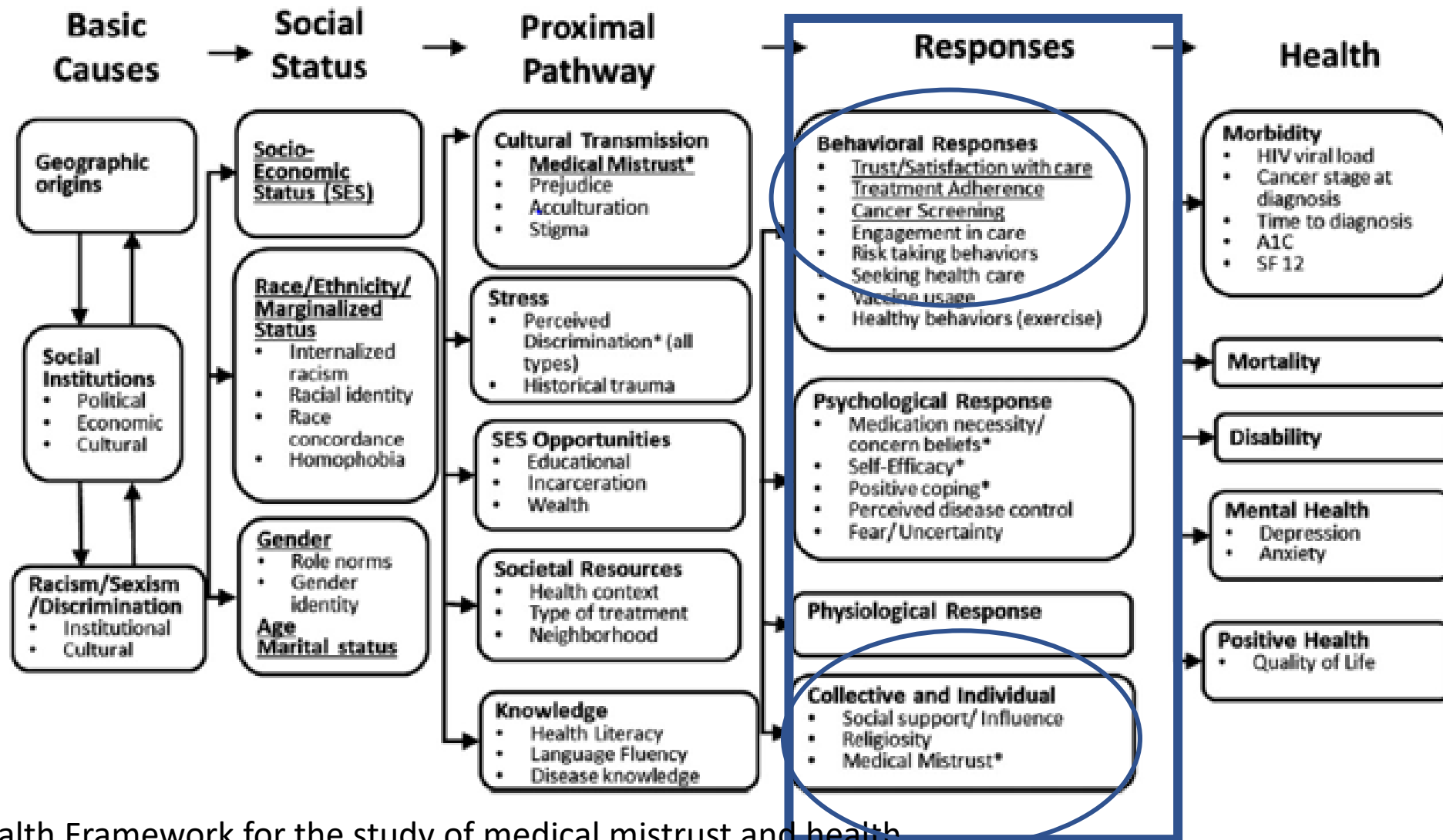


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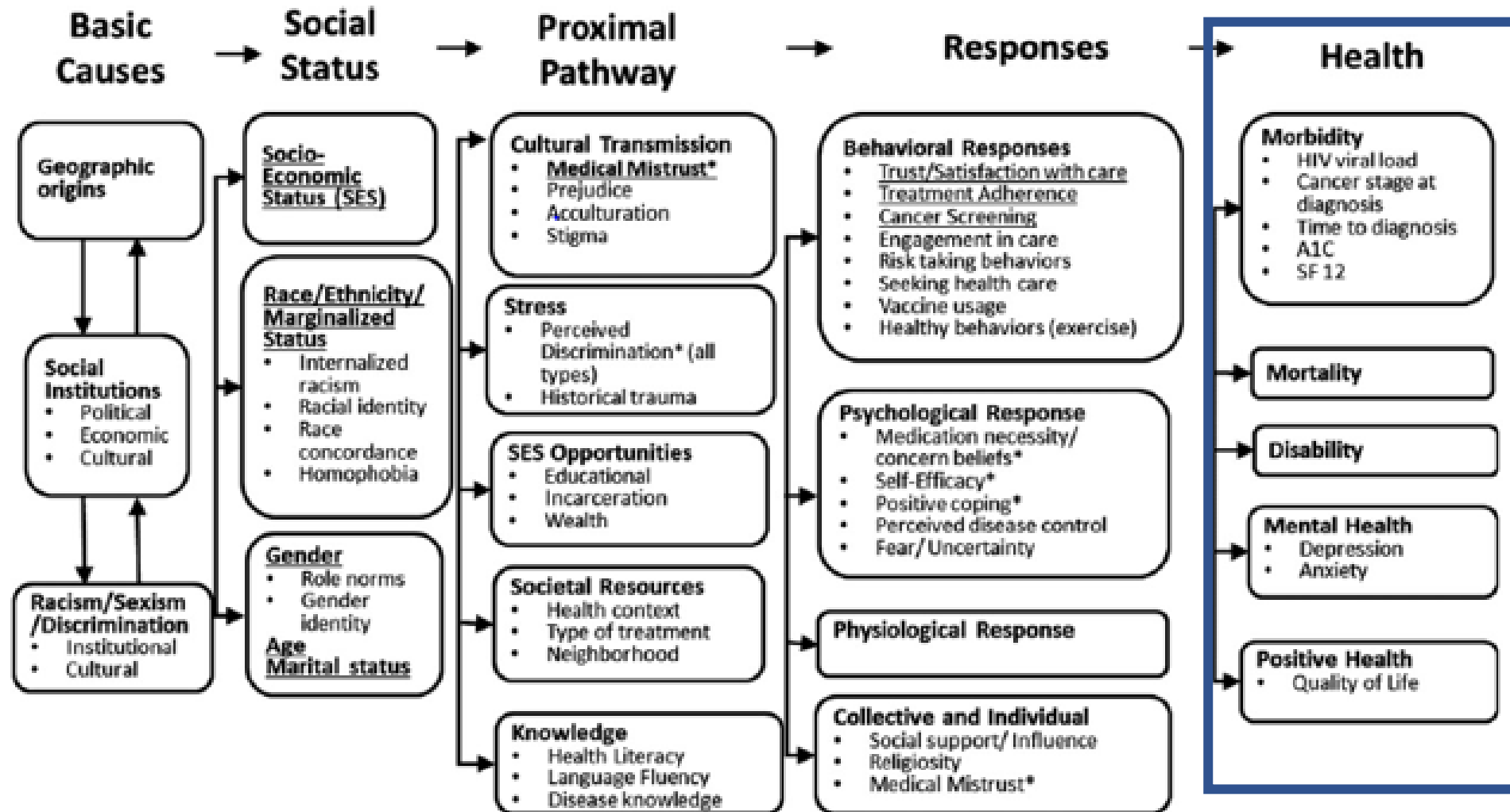


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Medical Mistrust & Health

- 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 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
- 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

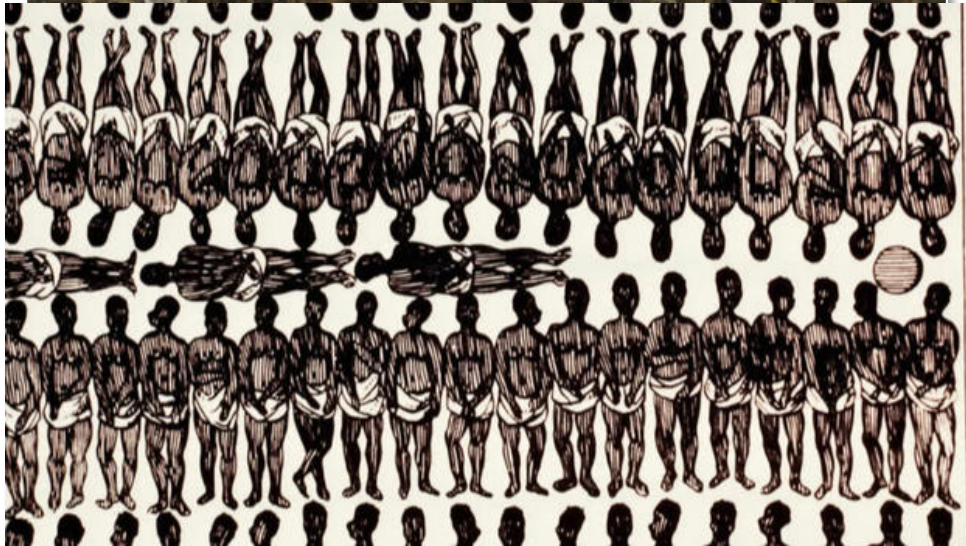
“I mean, I do, but I don't. I think they experiment with a lot of stuff and things happen, and the stuff just starts forming. I can't be thinking about all that. I got other stuff to think about...”

Presentation Roadmap

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- **Origins of Medical Mistrust in the Black community (Content Warning)**
- Provider Bias
- Potential Interventions to Address Medical Mistrust



“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 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 another voyage.

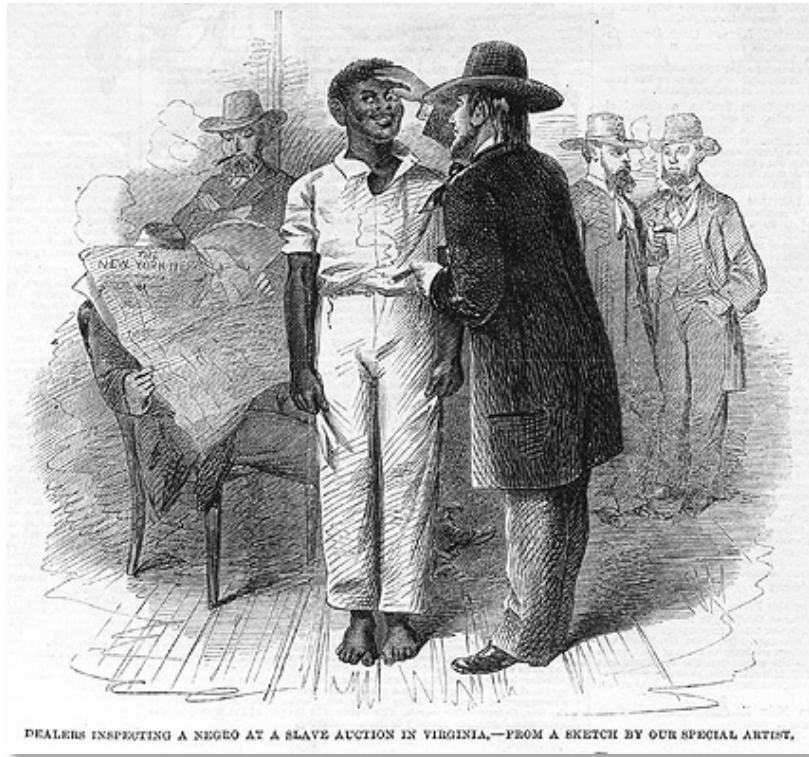
Besides it's a Case of Conscience to be careful of them as the White Men. For although they are Heathens yet have they have a rational Soul as well as us, and God knows whether it may not be more tolerable for them in the latter Day than for many who profess themselves Christians.”

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 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/mistresses 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 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
- Sometimes had to agree to being experimented on to receive care

Emergence of Black Hospitals: “The Black Hospital movement” (1865-1960s)



- Freedmen’s Hospital established in 1862 in Washington, DC – would later become Howard University Hospital
- Established by the Medical Division of the Freedmen’s Bureau
- At its peak, the Black Hospital movement had 90 new hospitals for Black people throughout the U.S.
- Represented “the move from exclusion to segregation in hospital care”

Hospital Desegregation Happened Quietly



- With the passage of the Medicare program, desegregation of hospitals was swift
- Hospitals could receive funding only if they integrated
- Johnson administration's Office of Equal Health Opportunity—five staff – and 1,000 employees from federal agencies and 10,000 Civil Rights organizers became inspectors on the ground who fanned out to hospitals to make sure they were in compliance with the law and thus eligible for federal funds.

<https://www.usnews.com/news/articles/2015/07/30/desegregation-the-hidden-legacy-of-medicare>

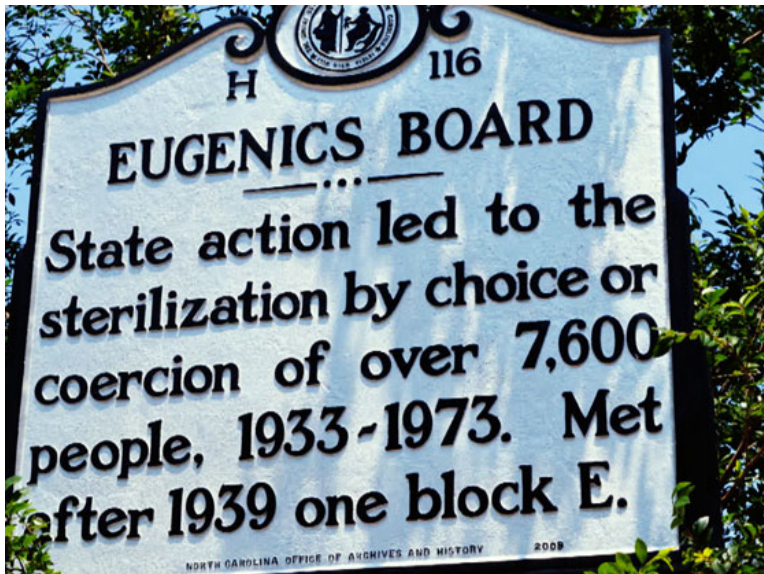
<https://khn.org/news/1965-the-year-that-brought-civil-rights-to-the-nations-hospitals/>

A legacy of Medical Experimentation Without Informed Consent



- 1932-1972: “Tuskegee Study of Untreated Syphilis in the Negro Male”
- 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

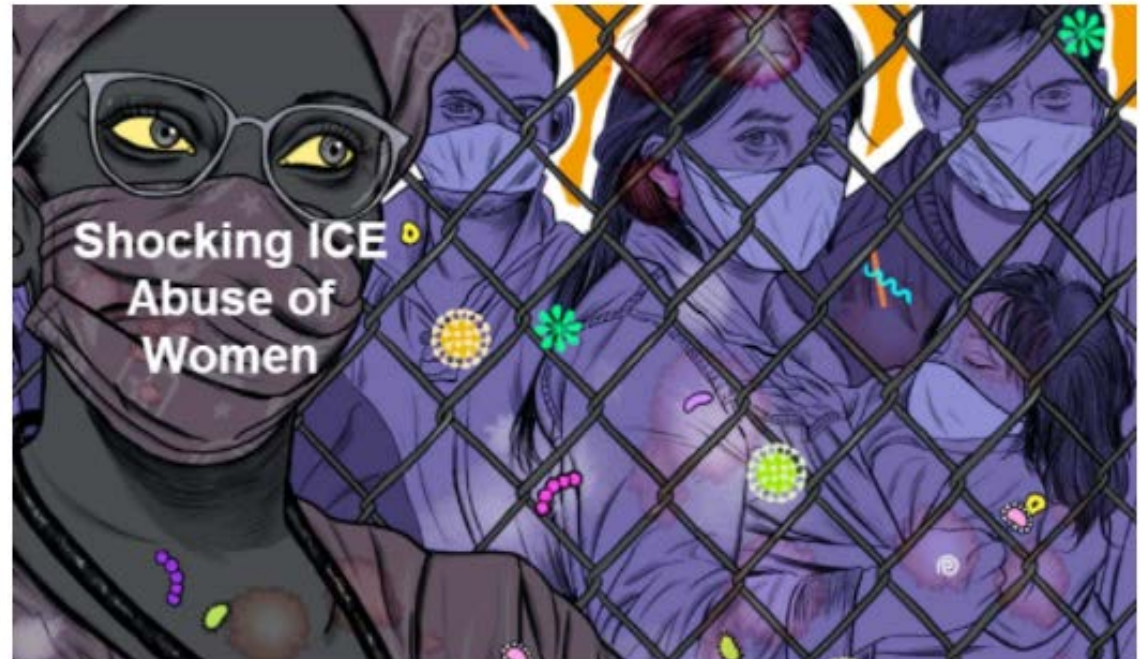
Sunday, September 20, 2020 7:50PM



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

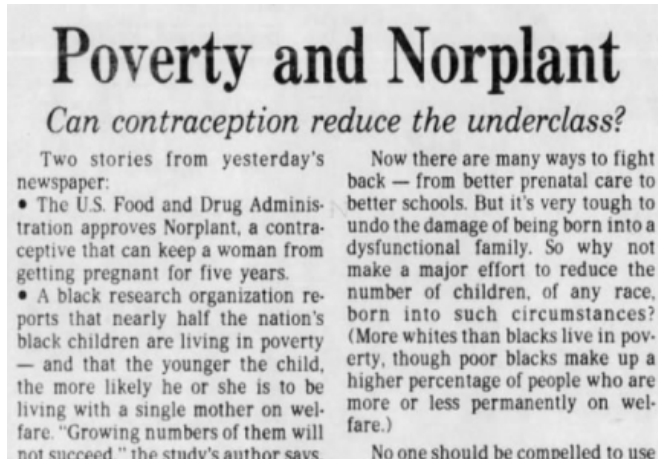


Reproductive coercion

- Margaret Sanger, founder of Planned Parenthood, moved from women's reproductive rights to eugenics
- Her American Birth Control League merged with another organization and developed up the "Negro Project" which set up birth control clinics in Black neighborhoods around the country
- The Pill as well as other contraceptive methods were made available to Black women w/ low-incomes for free or at low cost through government-sponsored Planned Parenthood clinics
- Raised community concerns about genocide in these clinics

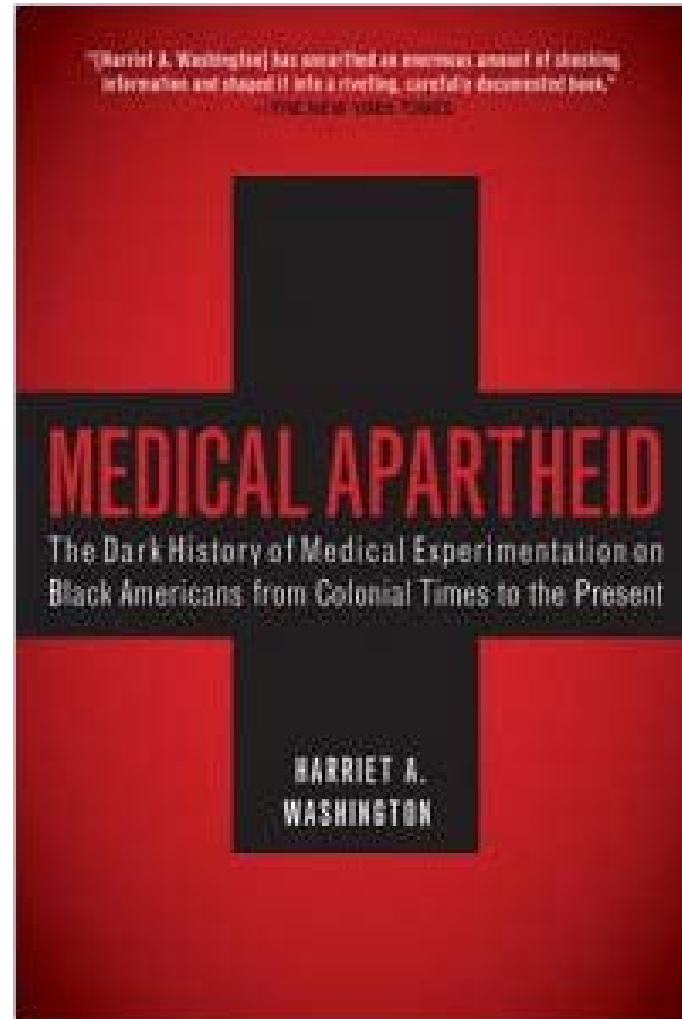


Reproductive coercion



- First new contraceptive on the market in 25 years made (1990)
- Many bills proposed to “incentivize” Norplant use for people on public assistance and even to mandating it for women on Medicaid who had an abortion (North Carolina)
- Lawmakers also made Norplant expensive to remove
- Medicaid only reimbursed providers if Norplant was in for five years
- Promoted throughout urban areas, groundswell of opposition by advocates and community groups
- Eventually discontinued 2002 after multiple class action lawsuits and concerns about its adverse side effects

A Must Read: Medical Apartheid by Harriet Washington



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- **Provider Bias**
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Provider Bias: The Role of “Implicit Bias”



- Implicit bias refers to attitudes or stereotypes that affect our understanding, actions, and decisions in an unconscious manner
- Thought to be activated involuntarily and without an individual’s awareness or intention control
- Considered different from explicit biases and are thought to form from very early ages influenced by early life experiences, media, etc.
- Concerns for impact on health outcomes

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 styles)
 - **Treatment decisions** (e.g., Black patients less likely to 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 outcomes)

Health Care Inequities: Pain Treatment

- 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

- 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)

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Potential Approaches to Addressing Mistrust



- Ask open-ended questions about patient's beliefs (e.g., those related to medication)
- Recognize signs of medical mistrust
- **Validate** patient's concerns/mistrust
 - Acknowledge historical and current realities that may have led to mistrust
 - Ask for permission to share information after validating

Potential Approaches to Addressing Mistrust



- Express empathy through reflective listening
- Avoid argument and direct confrontation
- Adjust to client/patient resistance rather than opposing it directly
- Support self-efficacy and optimism

Potential Approaches to Addressing Mistrust



- Patient-centered approach (continued)
 - Elicit from patient their priorities related to their health
 - Understand their competing priorities/concerns
 - Utilize shared decision-making
- Longitudinal anti-racism training for public health & health care professionals and institutional leadership
 - Include education about historical and current factors contributing to medical mistrust and how mistrust impacts health outcomes

Questions for first visit goal is to make the implicit, explicit:

1. "I don't want to assume anything about your identities. How do you identify racially, ethnically, culturally and what are your pronouns?"
2. "Many of my pts experience racism in their health care. Are there any experience you would like to share with me?"
3. "What have been your experiences with the healthcare system?"
4. "Have there been any experiences that caused you to lose trust in the healthcare system?"
5. "It is my job to get you. You shouldn't have to work to get me. If I miss something important or say something that doesn't feel right please know you can tell me immediately and I will thank you for it."
6. "Put up more visible cues for safe space: BLM, Flag, etc."
7. "acknowledging, honoring what pts are already doing – "wow, you're already doing so much"
8. "what's happened to you" vs. "what are you doing"
9. "Curiosity can feel like colonizing language: Not, "can you explain to me why...." instead "there is something I don't know that I really need to understand...."

Potential Systems-level Approaches to Addressing Mistrust

- Having staff that reflects the patient population
 - Increasing underrepresented group representation among health care providers
- Using community workers or peer navigators
- Working with faith-based organizations and other CBOs
- Commitment to and work towards becoming a fully inclusive anti-racist organization

Questions?



@DrOniBee