Title

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CLINICAL COMMENTARY

A Legacy of Mistrust: African Americans and the US Healthcare System

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Early in the COVID-19 viral infection pandemic, an erroneous claim widely circulated that people of African descent were immune to the COVID-19 infection. Furthermore, a conspiracy theory that COVID-19 was a virus created by the federal government was widely circulated on social media platforms. Some theorists pointed to a low presence of COVID-19 infection in Africa. Others referred to the disease being most prevalent, at the time, in predominantly white communities, such as the Seattle area and New Rochelle, New York.[1] Many African Americans possess an abiding distrust of the medical community.[2,3] This lack of confidence along with erroneous information may have led to a false sense of security and inadvertently placed a large number of African Americans at risk.

Unfortunately, as more recent data show, black Americans are dying of COVID-19 infection at disproportionately high rates. In Milwaukee County, for example, nearly three quarters of COVID deaths were black, with blacks representing only about a quarter of the county's population. Additional data from New Orleans, Detroit, Chicago and New York show similar racial imbalances.

Although challenges including increased incidence of chronic health conditions, lack of health insurance, substandard housing — challenges caused and exacerbated by racism- are a main factor contributing to the racial imbalance of COVID-19 infection and complication rate, another factor to consider is the high level of distrust within black communities of the healthcare system.[3]

Throughout my career I can recount multiple examples of black patients who preferred to work with me, an African American physician. In one example, a middle aged black male patient refused to see my colleagues while I was on maternity leave because I was the only doctor he “trusted”. On our first meeting, the patient explained his lack of prior routine preventative care was due to his inability to find a doctor that “looked like him” and understood him culturally. Thus, despite needing crucial medical care for his diabetes during my absence, the patient did not receive medical care for several months. His distrust of the medical system superseded his need for treatment.

In another example a black female patient with fibromyalgia once commented that her chronic condition only improved after working with African American health care providers. In the patient’s opinion, receiving unbiased, patient-centered care was essential to the improvement of her condition. Throughout previous years she received treatment for her chronic pain from multiple physicians but regularly walked away with the experience of feeling ignored and unheard.

Similar patient sentiments, like the ones expressed above, are not uncommon. In a 2009 study in Pittsburgh, Pennsylvania, patients of black parents were twice as likely as white parents to distrust medical research. Although level of education was also a predictor of distrust, being black remained a predictor of distrust despite controlling for education.[4]

Trust facilitates care-seeking behavior and promotes patient honesty and adherence. Distrust inhibits care-seeking behavior, compromises medical care, and may lead to patient non-adherence.[5] To further complicate the issue, research shows African American patients are more at risk to receive lower quality health services, including for cancer, HIV, prenatal care, and preventative care.[6,7]

In order to understand this distrust of the U.S. healthcare system, there must be exploration of its historical roots. A portion of that medical mistrust likely developed as a result of historical treatment of African-Americans within the US medical system.[5]

The US medical institution has a long legacy of discriminating and exploiting black Americans, the haunting remembrance of which remains ingrained in the collective consciousness of the community. Historically, the medical establishment used African bodies, without consent, for its own advancement and supported medical theories, technologies, and institutions to strengthen systems of injustice.[5]

In the 19th century 90 percent of American blacks resided in the South and an overwhelming majority were slaves. Physicians used slaves as subjects of abusive, involuntary medical experimentation for both developing cures and profit. Slaves no longer deemed as profitable in the fields were sold outright for medical experimentation. The slaves were not provided informed consent. There were no regulations to protect slaves’ rights or health. In time, African Americans associated “western” medicine with punishment, loss of control over their most intimate bodily functions, and degrading public displays. The experimentation of slaves was justified by the theory blacks were inhumane. Early medical journals during slavery and post-Civil War commented on black inferiority. Countless examples demonstrated black bodies as a form of demonstration to teach and experiment within the western medical infrastructure.[8]

Another example contributing to the development of medical distrust was the Tuskegee Syphilis study. Conducted during the years 1932-1972, the infamous clinical study conducted at the historically black college, Tuskegee Institute in Alabama by the US Public Health Service studied the natural progression of untreated syphilis in poor, rural black men. To do this study the black participants were lied to by health officials and provided sham treatments.

Investigators enrolled a total of 600 impoverished, African-American sharecroppers; 399 who had previously contracted syphilis before the study began, and 201 without the disease. For participating in the study, the men were given free medical care, meals, and free burial insurance. However, the men were never told they had syphilis, nor were they ever treated for it; they were told they were being treated for "bad blood," a local term used to describe several illnesses, including syphilis, anemia and fatigue.

The 40-year study was controversial for reasons related to ethical standards; researchers knowingly failed to treat patients appropriately after the 1940s validation of penicillin as an effective cure for the disease syphilis.

The Tuskegee study is an iconic symbol of racialized medical abuse within the African-American community and its legacy still reverberates among many within the black community today. It remains a tremendous challenge to recruit African-Americans into clinical trials and the distrust has helped compromise many public efforts geared towards addressing healthcare issues within the black community.[5,9]

How do we begin to change the climate of medical distrust within black communities? The medical community must directly confront its marked past which bred the suspicion, distrust, and cynicism embedded in black collective memory.

One solution is to increase minority inclusion within healthcare institutions and research. The medical workforce should reflect the culture and ethnic diversity as the populations it treats. One way to achieve this goal is creating high school and college pipelines programs for under-represented minorities to encourage increased entry into careers in healthcare.

A recent study found that care for black patients is improved when they see black physicians. The study randomly assigned 1300 African-American patients to black or non-black primary care physicians. Those who saw black doctors received 34 percent more preventative services. One reason, reported by the study, was due to improved trust and communication.[10] To further support this theory, a systematic review found that racially matched pairs of patients and doctors resulted in improved communication.[11] Several studies have shown that many non-white patients prefer health care practitioners who share their racial identity and their overall medical care is improved. Patients in these studies cited improved communication, respectful treatment, and increased availability as reasons for seeing providers of same racial identity.[11,12]

But it is unlikely that all black patients can see black doctors even if they desired to. Although African Americans make up 13 percent of the US population, only 4% of current practicing physicians are black.[6] Therefore it is important we focus on training all physicians on skills of cultural competency, recognizing implicit bias, and practicing patient centeredness and how to effectively implement these skills in order to engage in higher quality communication with racially discordant patients.[5,11]

Lastly, removal of socioeconomic barriers and improvement of access to the healthcare system is a critical key in ensuring equal access to quality medical care. Increased expansion of Medicaid eligibility will enable lower income Americans to have health insurance. Stronger incentives to medical providers who accept Medicaid insurance would increase the healthcare provider pool.

Addressing the general mistrust of healthcare from black Americans head on is essential to moving forward in wake of the COVID-19 pandemic and addressing the large impact of COVID-19 in black communities. As of now there is no clear strategy on how government and public health officials plan to “reopen the country,” yet it is likely this will include voluntary restrictions on our civil liberties we previously held dear. These opt in strategies intrinsically rely on trust in their design and their designer. It is important that those who shape these reopening policies receive input from leaders within African American communities to avoid fanning the flames of medical mistrust and conspiracy. Furthermore, it is imperative that black communities have equitable access to COVID-19 testing and future treatments/vaccines. Black communities need ready access to health care providers who can provide testing and treatment for COVID-19. Lastly, the medical providers must have substantial training on cultural competence and implicit bias in order to help guide African American communities during this global pandemic.

REFERENCES

1. **Breslow J**. Why misinformation and distrust are making COVID-19 more dangerous for black America. Available at: https://www.npr.org/sections/coronavirus-live-updates/2020/04/10/832039813/why-misinformation-and-distrust-is-making-covid-19-more-dangerous-for-black-amer. Accessed 4/20/20.
2. **Williams JC**. Black Americans don’t trust our healthcare system – here’s why. Available at: https://thehill.com/blogs/pundits-blog/healthcare/347780-black-americans-dont-have-trust-in-our-healthcare-system. Accessed 4/20/20.
3. **Armstrong K, Ravenell KL, McMurphy S, Putt M**. Racial/ethnic differences in physician distrust in the United States. *Am J Public Health*. 2007 Jul;97(7):1283-9. Epub

2007 May 30. PubMed PMID: 17538069; PubMed Central PMCID: PMC1913079.

4. **Rajakumar K, Thomas SB, Musa D, Almario D, Garza MA**. Racial differences in parents' distrust of medicine and research. *Arch Pediatr Adolesc Med*. 2009 Feb;163(2):108-14. doi: 10.1001/archpediatrics.2008.521. PubMed PMID: 19188641; PubMed Central PMCID: PMC2842910.
5. **Jacobs EA, Rolle I, Ferrans CE, Whitaker EE, Warnecke RB**. Understanding African Americans' views of the trustworthiness of physicians. *J Gen Intern Med*. 2006 Jun;21(6):642-7. PubMed PMID: 16808750; PubMed Central PMCID: PMC1924632.
6. **Frakt A**. Race and Medicine: The Harm That Comes From Mistrust. Available at: https://www.nytimes.com/2020/01/13/upshot/race-and-medicine-the-harm-that-comes-from-mistrust.html. Accessed 4/20/20.
7. **Powell W, Richmond J, Mohottige D, Yen I, Joslyn A, Corbie-Smith G**. Medical Mistrust, Racism, and Delays in Preventive Health Screening Among African-American Men. *Behav Med*. 2019 Apr-Jun;45(2):102-117. doi: 10.1080/08964289.2019.1585327. PubMed PMID: 31343960.
8. **Washington HA**. Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to Present. Harlem Moon, New York, 2006.
9. **Scharff DP, Mathews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D**. More than Tuskegee: understanding mistrust about research participation. *J Health Care Poor Underserved*. 2010 Aug;21(3):879-97. doi: 10.1353/hpu.0.0323. PubMed PMID: 20693733; PubMed Central PMCID: PMC4354806.
10. **Alsan M, Garrick O, Graziani G**. Does diversity matter for health? Experimental evidence from Oakland. *American Economic Review*. 2019 Dec;109(12):4071-4111.
11. **Shen MJ, Peterson EB, Costas-Muñiz R, Hernandez MH, Jewell ST, Matsoukas K, Bylund CL**. The Effects of Race and Racial Concordance on Patient-Physician Communication: A Systematic Review of the Literature. *J Racial Ethn Health Disparities*. 2018 Feb;5(1):117-140. doi: 10.1007/s40615-017-0350-4. Epub 2017 Mar 8. PubMed PMID: 28275996; PubMed Central PMCID: PMC5591056.
12. **Boulware LE, Cooper LA, Ratner LE, LaVeist TA, Powe NR**. Race and trust in the health care system. *Public Health Rep*. 2003 Jul-Aug;118(4):358-65. PubMed PMID: 12815085; PubMed Central PMCID: PMC1497554.