The Journal of Health Design

EDITORIAL

Mistrust in health care as a potential motivator for vaccine uptake: A patient perspective

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To Cite: Montgomery C. Mistrust in health care as a potential for vaccine uptake: A patient perspective. JHD. 2021;6(2):401–404. https://doi.org/10.21853/JHD.2021.136

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SUMMARY

The prevalence of conversations about trust in health care seems to have increased since the onset of the COVID-19 global pandemic. Frequently, the discussion focuses on vaccine hesitancy among people of colour in the US and historical reasons for their mistrust in the healthcare system. The premise has been that increasing trust in health care will increase the likelihood that African Americans will take the COVID-19 vaccine. Conversely, focusing on the anxieties and realities caused by persistent disparate outcomes might offer an honest and transparent way to promote vaccine uptake, while acknowledging the systemic issues that erode trust.

Key Words

Trust; health disparities; COVID-19; vaccine; vaccine hesitancy

INTRODUCTION

The prevalence and prominence of conversations about trust in health care seem to have increased since the onset of the COVID-19 global pandemic. Frequently, the discussion is focused on vaccine hesitancy among people of colour in the US and the historical reasons for their mistrust in the healthcare system, including the Tuskegee Experiments on African American men with syphilis.[1] Early studies indicated African Americans might be more resistant to taking a COVID-19 vaccine because of this mistrust in health care.[2-4] As many experts have reflected, Tuskegee is an exemplar of the reasons for mistrust in health care among African Americans, but it's only the tip of the iceberg. The idea is that increasing trust in health care will increase the likelihood that African Americans will take the COVID-19 vaccine.

Researchers have found that doubts about vaccines, pharmaceutical companies, federal regulatory agencies, and the government all contributed to African Americans' vaccine hesitancy related to the influenza vaccine.[4] Specifically related to COVID-19 vaccine uptake, African Americans showed significantly lower levels of trust in the vaccine than Caucasian Americans.[2-3] Lack of trust in the vaccine among African Americans is often related to bigger issues of mistrust in government and the institutions that serve us.[5]

The racial and ethnic disparities in COVID-19 testing, outcomes, and vaccine uptake in the US are not alarming, considering that healthcare disparities are pervasive and persistent. From cancer to heart disease to health outcomes in general, African

Americans experience the worst of health care in the US.[6–8] The knowledge I have about these disparities colours every healthcare encounter I have, raising significant doubts about whether the care I am receiving is free of bias.

I have been reflecting on my own trust in health care as a patient advocate, care partner, and patient-family advisor, and I have come to a jarring realisation—I don't trust health care. Many of my experiences as a patient advocate and partner have eroded my trust in health care, not just with specific individuals who have demonstrated interpersonal racism but also with the systems responsible for delivering equitable outcomes.

As a patient, I have seen bias, discrimination, and lack of cultural competence at play in my own healthcare encounters. I've had practitioners ignore my concerns and throw microaggressions around carelessly. As a patient-family advisor, I have witnessed healthcare providers and leaders show resistance to diversity and equity. I have sat in rooms where the health and safety of marginalised communities would not have been part of the conversation if I had not brought it forward. I have often been the only person in the room advocating for the advancement of equity when policies are being made. These experiences have shown me that my presence is necessary in these spaces because without my voice, entire communities would have continued to be underserved. These current issues are far more relevant to my mistrust in health care than the Tuskegee Experiments. That's why I elected to be vaccinated against COVID-19.

Research shows that the fatality rate for COVID-19 is disproportionately higher for African Americans. Risk factors like high blood pressure, obesity, and diabetes—all more common among African Americans—result in higher rates of hospitalisation and death from COVID-19.[9] During the height of COVID-19 hospitalisations, there was concern about healthcare professionals rationing resources and making these resource decisions based on a patient's likelihood of survival. This is when my anxieties grew. Focusing on the anxieties and realities caused by persistent disparate outcomes might offer an honest and transparent way to promote vaccine uptake, while acknowledging the systemic issues that erode trust.

I sit at the intersection of multiple identities that influence my treatment in health care. As an overweight, middle-aged African American woman with chronic asthma and high blood pressure, I recognise that healthcare professionals might not deem my life worthy of saving if I were hospitalised with COVID-19. My voice might not be heard and my concerns might be minimised if I need to seek life-saving care. My family might not be effectively engaged in my care plan if I am hospitalised. My survival depends on the cultural competence of the providers—on how they see me and whether they see me. All of these uncertainties weighed heavily in my decision about the COVID-19 vaccine.

Given what we know about how bias influences practice, I chose the vaccine—not because my trust in health care is high, but because it is not. In short, my concerns about how I might be treated in the healthcare system led me to protect myself with vaccination so I can hopefully avoid contact with the healthcare system due to illness. I have received my COVID-19 vaccinations, but I will continue to take precautions against infection with COVID-19. Lowering my likelihood of a healthcare encounter seems to be the best way to ensure my own survival, given my personal risk factors and identity characteristics. As we grapple with how to increase the use of the vaccine among vaccine-hesitant populations, focusing on mistrust might have just as much value as focusing on building trust, which can be a long and uncertain road, especially as disparate outcomes and bias persist. It was much more practical for me to take my chances with a new vaccine than with an old system that has never delivered equitable outcomes for patients like me.

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ACKNOWLEDGEMENTS

No acknowledgement

PEER REVIEW

Not commissioned. Externally peer reviewed.

CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

FUNDING

None

ETHICS COMMITTEE APPROVAL

None