

COVID-19 Related Medical Mistrust, Health Impacts, and Potential Vaccine Hesitancy Among Black Americans Living With HIV

Laura M. Bogart, PhD,^a Bisola O. Ojikutu, MD, MPH,^{b,c,d} Keshav Tyagi, MPH,^e David J. Klein, MS,^a Matt G. Mutchler, PhD,^{e,f} Lu Dong, PhD,^a Sean J. Lawrence, BA,^e Damone R. Thomas,^e and Sarah Kellman, MS^e

Background: Medical mistrust, a result of systemic racism, is prevalent among Black Americans and may play a role in COVID-19 inequities. In a convenience sample of HIV-positive Black Americans, we examined associations of COVID-19-related medical mistrust with COVID-19 vaccine and COVID-19 treatment hesitancy and negative impacts of COVID-19 on antiretroviral therapy (ART) adherence.

Methods: Participants were 101 HIV-positive Black Americans (age: M = 50.3 years; SD = 11.5; 86% cisgender men; 77% sexual minority) enrolled in a randomized controlled trial of a community-based ART adherence intervention in Los Angeles County, CA. From May to July 2020, participants completed telephone interviews on negative COVID-19 impacts, general COVID-19 mistrust (eg, about the government withholding information), COVID-19 vaccine and treatment hesitancy, and trust in COVID-19 information sources. Adherence was monitored electronically with the Medication Event Monitoring System.

Results: Nearly all participants (97%) endorsed at least one general COVID-19 mistrust belief, and more than half endorsed at least one COVID-19 vaccine or treatment hesitancy belief. Social service and health care providers were the most trusted sources. Greater COVID-19 mistrust was related to greater vaccine and treatment hesitancy [b (SE) = 0.85 (0.14), $P < 0.0001$ and b (SE) = 0.88 (0.14), $P < 0.0001$, respectively]. Participants experiencing more negative

COVID-19 impacts showed lower ART adherence, assessed among a subset of 49 participants [b (SE) = -5.19 (2.08), $P = 0.02$].

Discussion: To prevent widening health inequities, health care providers should engage with communities to tailor strategies to overcome mistrust and deliver evidence-based information, to encourage COVID-19 vaccine and treatment uptake.

Key Words: adherence, Black/African American, COVID-19, HIV/AIDS

(*J Acquir Immune Defic Syndr* 2021;86:200–207)

INTRODUCTION

Nationally, Black Americans are more likely to be diagnosed, to be hospitalized, and to die from COVID-19.^{1–5} The death rate from COVID-19 has been reported to be 2–3 times higher among Black versus White individuals.^{4,6} Black individuals comprise 13.4% the US population, yet account for more than 24% of COVID-19 deaths.^{4,7} Inequities affecting Black Americans are believed to stem from systemic racism, which has led to higher levels of social risk factors such as unstable housing and homelessness, poverty, and lower-wage, higher-risk employment, which in turn are associated with a greater prevalence of underlying health conditions, such as hypertension, diabetes, and obesity (which are risk factors for severe COVID-19 disease and death).^{8–10}

Medical mistrust, defined as “distrust of health care providers, the health care system, medical treatments, and the government as a steward of public health,”^{11,12} is a response to current and historical systemic racism in health care and society as a whole and may play a role in COVID-19 inequities. Medical mistrust is particularly prevalent among Black Americans, compared with other races/ethnicities.^{13,14} The 2016 National Survey on HIV in the Black Community found that 18% of Black individuals agreed that the government usually tells the truth about major health issues.¹⁵ Medical mistrust has been associated with suboptimal health behaviors among Black individuals with HIV and other conditions, such as medication nonadherence and low health care engagement, as well as poor self-reported health, lower quality of life, and decreased uptake of screening and preventative behaviors^{16–21} and vaccines.²² Medical mistrust is a key mediator of the association between discrimination

Received for publication July 29, 2020; accepted October 28, 2020.

From the ^aRAND Corporation; ^bDivision of Infectious Diseases, Brigham and Women’s Hospital, Boston, MA; ^cInfectious Disease Division, Massachusetts General Hospital, Boston, MA; ^dDivision of Global Health Equity, Harvard Medical School, Boston, MA; ^eCommunity-Based Research, APLA Health & Wellness; and ^fDepartment of Health Science, California State University, Dominguez Hills.

Supported by the National Institute of Nursing Research, the National Institutes of Health Office of The Director, and the National Institute on Minority Health and Health Disparities (R01NR017334, R01MD014722), and supported by the Center for HIV Identification, Prevention, and Treatment Services, funded by the National Institute of Mental Health (P30MH058107) and the Harvard Center for AIDS Research, funded by the National Institute of Allergy and Infectious Diseases (P30 AI060354).

The authors have no conflicts of interest to disclose.

Correspondence to: Laura M. Bogart, PhD, RAND Corporation, 1776 Main Street, P.O. Box 2138, Santa Monica, CA 90407-2138 (e-mail: lbogart@rand.org).

Copyright © 2020 Wolters Kluwer Health, Inc. All rights reserved.

and worse health outcomes and behaviors among Black Americans.^{23,24}

Mistrust has been conceptualized as a form of coping that fulfills epistemic (desire to understand), existential (desire to control), and social (desire to maintain a positive view of self or one's in-group) motivations under a state of threat or uncertainty—such as COVID-19—and in the face of continued threat, such as widespread discrimination.^{25–27} Thus, high levels of medical mistrust among Black Americans may arise from history, knowledge, and continuous and repeated discrimination and harmful experiences toward their racial/ethnic group by the health care system and government, which in turn may affect health behaviors because it motivates distrust of governmental and public health information and avoidance of health care, as a self-protective coping strategy.²⁴

During the COVID-19 pandemic, medical mistrust specific to COVID-19 has been prevalent worldwide and in the United States, particularly among Black Americans. Such mistrust has taken the form of what has been called “conspiracy beliefs,” which are explanations of “the origin, treatment, and transmission of infection by reference to the actions of powerful people who attempt to conceal their role.”^{26,28} (Note that, under this definition, conspiracy beliefs are not necessarily false, harmful, unjustified, or irrational.) For example, the media has reported that Black individuals do not trust the health care system's or government's responses to COVID-19.^{29,30} In a national poll conducted in March 2020, 34% of Black individuals versus 26% of Whites believed that COVID-19 was created in a laboratory.³¹

Little is known how general medical mistrust related to COVID-19 might impact COVID-19-related behaviors, including vaccine and treatment hesitancy, in the United States. In an online survey in England, higher endorsement of COVID-19 conspiracy beliefs was associated with less willingness to accept a future vaccine and less adherence to health-protective (eg, social distancing) behaviors.³² Other surveys across several countries have similarly found that greater mistrust is associated with lower engagement in COVID-19 protective behaviors.^{33–36} A national US survey of a mostly White sample found that belief in COVID-19 conspiracies was associated with lower vaccine intentions.³⁷

In this study, in a convenience sample of Black Americans living with HIV, we examined levels of general COVID-19 mistrust related to COVID-19 and assessed associations between general COVID-19 mistrust and COVID-19 treatment and future vaccine hesitancy, hypothesizing that greater mistrust would be associated with greater hesitancy. We also hypothesized that negative COVID-19-related impacts would be associated with lower antiretroviral therapy (ART) adherence. Like COVID-19—and due to the same structural inequities—HIV disproportionately affects Black Americans.³⁸ Although limited data regarding HIV and COVID-19 co-infection are available,^{39–42} people living with HIV may be particularly vulnerable due to overlapping comorbidities (eg, cardiovascular disease, hypertension, diabetes, and advanced age).^{43,44} Moreover, health care system disruptions due to COVID-19 may affect access to health care and medications, and disruptions to employment, living

situations, and other social determinants of health may affect adherence and general health. It is critical to understand attitudes toward and the impact of COVID-19 in this especially vulnerable population; such data can serve as a basis for the development of interventions and policies to prevent the widening of both COVID-19 and HIV inequities in Black communities.

METHODS

Participants

Participants were recruited from the participant pool of a parent study that is a randomized controlled trial of a community-based motivational interviewing intervention to improve ART adherence among Black Americans living with HIV (NCT03331978). Participants in the parent study were recruited through a community-based HIV service organization in Los Angeles County, CA, using flyers and outreach to staff and clients of relevant community organizations; referrals from providers; online and print advertisements, radio shows, and online promotions; and in-person outreach onsite (at the community partner organization), at community events, and on the street (eg, near health care facilities).

Of the 136 active participants in the parent study, 103 participants were reached during the time frame (May–July, 2020), and 101 participants completed the 15–20 minutes COVID-19 telephone interview; 33 participants could not be contacted after multiple attempts and 2 participants declined. At the end of the interview, participants were offered resources for COVID-19 testing and any unmet social service and medical needs. Participants received a \$10 gift card incentive.

Measures

Sociodemographic and Health Characteristics

Items assessed age, gender identity, sexual orientation, education level, housing situation, employment situation, income level, incarceration history, and years since HIV diagnosis. Participants were asked if they had been tested for COVID-19; if they had experienced any symptoms of COVID-19 since February 2020; and if anyone in their household had been diagnosed with COVID-19.

COVID-19 Impacts

Twelve items assessed negative social and economic impacts of COVID-19 (eg, job loss and homelessness) and 3 items assessed negative health care impacts (eg, could not get HIV medications). Some items were adapted from the Epidemic–Pandemic Impacts Inventory.⁴⁵ Social/economic impacts and health care impacts were summed into one negative COVID-19 impact score.

General COVID-19 Mistrust

We developed 10 items to assess general COVID-19 mistrust, based on items used in previous research,^{46–48} that asked about mistrust in public health information advanced by the government and health care providers, as well as

conspiracy beliefs about the origins of COVID-19 and withholding of a cure (Table 1). The response set was 1 = strongly disagree, 2 = slightly disagree, 3 = neither disagree nor agree or unsure, 4 = slightly agree, and 5 = strongly agree. The scale had good internal consistency ($\alpha = 0.86$) and was significantly associated with validated scales assessing HIV-related mistrust (ie, HIV conspiracy beliefs; $r = 0.50$)^{17,46} and general medical mistrust ($r = 0.42$)¹² from the parent study survey, showing good concurrent validity.

COVID-19 Vaccine and Treatment Hesitancy

Three items, developed for this study, assessed COVID-19 vaccine hesitancy (ie, “If a vaccine were available to prevent COVID-19, I would not want to get it”; “...I would not trust it”; and “...I am worried that it could be harmful”; $\alpha = 0.90$) on the scale 1 = strongly disagree, 2 = slightly disagree, 3 = neither disagree nor agree or unsure, 4 = slightly agree, and 5 = strongly agree. Parallel items assessed COVID-19 treatment hesitancy ($\alpha = 0.91$). Item responses were averaged.

Trust in COVID-19 Information Sources

Participants were asked the extent to which they trusted 11 different COVID-19 information sources (eg, health care providers and federal government) on the scale 1 = strongly distrust, 2 = slightly distrust, 3 = not sure, 4 = slightly trust, and 5 = strongly trust. Items were averaged ($\alpha = 0.90$).

ART Adherence

ART adherence was assessed with the Medication Event Monitoring System (MEMS). A MEMS cap with an electronic chip that recorded the date and time of each bottle opening was used to monitor daily ART adherence throughout the parent study; for the present subsample, we use the past 1-month MEMS measurement that was closest in time to the COVID-19 survey. Study staff instructed participants on how to dispense the medication with the most complex dosing schedule, or the base medication of the regimen if all medications had the same schedule, into a bottle.⁴⁹ When adherence data were downloaded, participants completed a brief survey to assess instances in which the cap was not used as intended (eg, how often the bottle was opened without removing a dose). Data were adjusted using these responses.^{50,51} We derived continuous adherence (ie, percentage of total scheduled doses taken) and dichotomous adherence (>80% of doses taken vs. \leq 80% of doses taken), as a benchmark of “good” adherence (ie, likely to result in a suppressed HIV viral load).⁵²

Statistical Analysis

Descriptive statistics (means, SDs, and frequencies) were calculated for all study variables. Multivariate linear and logistic regression analyses were conducted predicting continuous and dichotomous ART adherence, respectively, with negative COVID-19 impacts. Multiple linear regression analyses were conducted predicting COVID-19 treatment and vaccine hesitancy with general COVID-19 mistrust. Covariates for multivariate models included sociodemographic characteristics that were associated with the outcomes at an alpha level of 0.05 in

TABLE 1. Sociodemographic and Health Characteristics and COVID-19 Impacts

	M (SD) or % (n)
Sociodemographic Characteristics	
Age	50.3 (11.5)
Male (cisgender)	87% (88)
Gay, bisexual, or other nonheterosexual identity	77% (78)
Education level: less than high school	13% (13)
Stable housing, past year	50% (50)
Employed (full-time or part-time)	14% (14)
Annual income level: less than \$10,000	41% (40)
Ever incarcerated (as an adult)	52% (53)
Health-related Characteristics	
Years since HIV diagnosis	19.8 (10.1)
Average % of ART doses taken (past month continuous)	73.7 (24.4)
>80% of ART doses taken (past month, dichotomous)	53% (26)
Tested for COVID-19	
No, but do not think I have it	68% (69)
No, but I may have it	1% (1)
Yes, tested positive	1% (1)
Yes, tested negative	30% (30)
Any COVID-19 symptoms	8% (8)
Anyone in household diagnosed with COVID-19	4% (3)
Negative Social/Economic Impacts	
Reduced your work hours	33% (17)
Could not pay important bills, rent or utilities	29% (29)
Had difficulty getting places due to less access to public transportation	25% (25)
Lost your job or closed your business	19% (11)
Could not get enough food to eat	19% (19)
Had to spend a lot more time taking care of a family member	14% (14)
Had to move or relocate	12% (12)
Lost housing	5% (5)
Became homeless	8% (7)
Increase in conflict with a partner or spouse	8% (8)
Had a child at home who could not go to school	7% (7)
Family or friends had to move into your home	4% (4)
Experienced at least one negative social/economic impact	58% (59)
No. of negative social/economic impacts, M (SD)	1.7 (1.9)
Negative Health Impacts	
Canceled a medical appointment or avoided getting medical care	18% (18)
Could not get HIV medications	6% (6)
Could not get necessary non-HIV medications	6% (6)
Experienced at least one negative health consequence	22% (22)
No. of negative health consequences, M (SD)	0.3 (0.6)

Note: Sample size range = 84–101 except for n = 58 and 52 for the work-related items, respectively, which were not applicable for those not working prepandemic and for ART adherence, which was limited to the subsample of n = 49 with available data.

bivariate analyses (age for adherence and education for COVID-19 treatment and vaccine hesitancy). In addition, we controlled for the intervention group in all models. The adherence models were conducted with the subset of 49 participants whose MEMS

data were available from the parent study during the COVID-19 pandemic (ie, whose data for the past month were downloaded after April 1, 2020).

RESULTS

Participant Description

Participant sociodemographic characteristics are shown in Table 1. Overall (of the 101 participants in the sample), participants were close to 50 years age on average, and many were of lower socioeconomic status, with only 14% employed and 41% with less than \$10,000 annual household income. Most (80%) were cisgender men (16% were cisgender women, 3% were transgender women, and 1% identified as queer/gender nonconforming). The majority (77%) were gay or bisexual (89% of men and 0% of women). Half were unstably housed (eg, homeless or temporary housing) in the past year, and more than half had ever been incarcerated. Participants had been diagnosed with HIV about 20 years before the survey. Slightly over half had good levels of adherence (defined as >80% of doses taken; of the 49 participants with available adherence data). Less than a third (31%) had been tested for COVID-19, and only one participant was found to be positive; 8 said that they had experienced COVID-19 symptoms, and of those 8, 6 were tested (5 tested negative and 1 tested positive) and 2 were not tested (and did not think they were infected).

Levels of Negative COVID-19 Impacts

Participants experienced significant disruptions from the pandemic (Table 1). The most common negative consequence was decreased work hours (33%), followed by not being able to pay important bills, rent or utilities (29%), and having difficulty getting places due to less access to public transportation (25%). Almost a fourth reported that the pandemic had affected their health care for HIV or other conditions. Overall, 64% ($n = 65$) experienced at least 1 negative COVID-19 consequence [$M (SD) = 2.0 (2.0)$].

To determine the possible effects of COVID-19 impacts on HIV outcomes, multivariate regressions were conducted predicting ART adherence with the negative COVID-19 impact score, controlling for age and intervention condition. Results indicated that participants who experienced more negative impacts from the pandemic showed lower ART adherence, both continuously [$b (SE) = -5.19 (2.08), P = 0.02$] and dichotomously [$OR (95\% CI) = 0.59 (0.39-0.89), P = 0.01$].

Levels of General COVID-19 Mistrust and Vaccine and Treatment Hesitancy

The sample showed high levels of general COVID-19 mistrust and high levels of hesitancy related to treatment and a future vaccine (Table 2). Nearly all (97%) endorsed at least one mistrust belief. The most prevalent general mistrust beliefs (endorsed by about half or more than half) concerned withholding information or a lack of honesty by the government. More than half of participants showed hesitancy regarding a COVID-

19 future vaccine or treatment across the items, with about a third saying they would not get vaccinated or treated.

The sample showed greater trust in health care providers than the government. Three-quarters felt that health care providers have patients' best interests in mind, and only a fifth said that Black people cannot trust health care providers (Table 2). Moreover, service providers or health professionals were the most trusted, followed by local public health officials or agencies and local (eg, Los Angeles or CA) government officials (Table 3). The least trusted source was the federal government, including the US President, followed by social media.

Pearson correlations indicated that participants with less than a high school education showed higher levels of general COVID-19 mistrust ($r = 0.27, P = 0.007$), vaccine hesitancy ($r = 0.20, P = 0.04$), and treatment hesitancy ($r = 0.23, P = 0.02$). No other sociodemographic characteristics were significantly related to these variables.

Associations of General COVID-19 Mistrust With Vaccine and Treatment Hesitancy

Greater general COVID-19 mistrust was significantly associated with greater vaccine hesitancy [$b (SE) = 0.85 (0.14), P < 0.0001$] and treatment hesitancy [$b (SE) = 0.88 (0.14), P < 0.0001$] in multivariate models controlling for education level and intervention condition. Follow-up sensitivity analyses predicting the single items measuring willingness to get COVID-19 treatment, or to get a future vaccine, yielded similar results. Greater general COVID-19 mistrust was associated with lower willingness to get a future vaccine [$b (SE) = 0.81 (0.17), P < 0.0001$] or to get treatment [$b (SE) = 0.97 (0.16), P < 0.0001$].

DISCUSSION

This study suggests that medical mistrust around COVID-19 is high and may be a barrier to the uptake of COVID-19 treatment and future vaccination among Black Americans living with HIV. Mistrust was widespread across the sample, most of whom were sexual minority individuals, and did not significantly vary by most sociodemographic characteristics—although those with less than a high school education showed higher mistrust. Moreover, those who had higher levels of medical mistrust around the COVID-19 government response, as well as around COVID-19 origins and treatment, were less willing to obtain treatment or a future vaccine.

Mistrust, which originates in systemic racism, is a rational coping response to centuries of oppression, starting with slavery, and includes historical and ongoing police brutality, high incarceration rates, poverty, and racial residential segregation of Black people.²⁴ Mistrust may be further increasing due to the US sociopolitical climate in 2020, in which members of the federal administration used divisive rhetoric (eg, in support of racist movements) at a time when there was a call for action and widespread Black Lives Matter protests to stop police brutality.⁵³⁻⁵⁵ Any interventions to address medical mistrust at the local level must acknowledge and address these societal-level reasons

TABLE 2. General COVID-19-Related Medical Mistrust and Vaccine and Treatment Hesitancy

	% (n) Endorsed (Strongly/ Slightly Agree)
General COVID-19-related medical mistrust	
A lot of information about COVID-19 is being held back by the government	62% (63)
The government cannot be trusted to tell the truth about COVID-19	60% (61)
The government is hiding information about COVID-19	58% (59)
Black people should be suspicious of information from the government about COVID-19	51% (51)
When it comes to COVID-19, the government is lying to us	50% (50)
COVID-19 is manmade	50% (50)
There is a cure for COVID-19, but it is being withheld from Black people	30% (30)
When it comes to COVID-19, Black people cannot trust health care providers	20% (20)
When it comes to COVID-19, doctors have the best interests of patients in mind*	74% (75)
When it comes to COVID-19, Black people will receive the same medical care from health care providers as people from other groups*	50% (50)
Endorsed any mistrust belief	97% (98)
No. of mistrust beliefs endorsed, M (SD)	4.4 (2.5)
Vaccine hesitancy beliefs	
If a vaccine was available to prevent COVID-19, I am worried that it could be harmful	51% (52)
If a vaccine was available to prevent COVID-19, I would not trust it	34% (34)
If a vaccine was available to prevent COVID-19, I would not want to get it	32% (32)
Endorsed any vaccine hesitancy belief	54% (55)
No. of vaccine beliefs endorsed, M (SD), range	1.2 (1.3)
Treatment hesitancy beliefs	
If there were a treatment for COVID-19, I am worried that it could be harmful	50% (50)
If there were a treatment for COVID-19, I would not trust it	35% (35)
If there were a treatment for COVID-19, I would not want to take it	32% (32)
Endorsed any treatment hesitancy belief	51% (52)
No. of treatment beliefs endorsed, M (SD), range	1.2 (1.3)

*Item reversed for evaluating the number of beliefs endorsed.

for mistrust. In tandem with grassroots organizing in communities, strong and consistent leadership voices, from the top down, are needed to counteract and address racism at the national level as a starting point to addressing mistrust.

TABLE 3. Trust in Sources of Information About COVID-19

Information Source Type	Trust M (SD)
Service providers or health professionals	4.3 (1.1)
Announcements or news conferences by local public health officials or agencies	4.0 (1.2)
Announcements or news conferences by local government officials (like the mayor of LA or governor of CA)	3.9 (1.3)
TV or radio	3.8 (1.3)
People I know, such as friends, family, neighbors, or coworkers	3.7 (1.2)
News websites or apps	3.6 (1.2)
Church leaders, newsletters, or announcements	3.5 (1.5)
Newspapers	3.5 (1.3)
My employer	3.4 (1.5)
Social media (such as Facebook or Twitter)	3.1 (1.4)
Briefings from the federal government, including the President of the United States	2.6 (1.5)

The sample size for “my employer” was 32 as most participants were not working; sample sizes ranged from 85 to 101 for all other items; Scale = 1, strongly distrust to 5, strongly trust.

A theme running through our results was that health care and social service providers are more trusted than other sources of information about the pandemic. Participants were less likely to believe that health care providers would be dishonest and were more likely to trust information from providers than from other sources, especially elected officials. These results are consistent with a US survey (with a primarily White sample) finding that doctors were the most trusted sources for COVID-19 information.³⁷ Our findings suggest that provider-led interventions to address COVID-19 mistrust would be well received. For example, health care providers could be trained on structural competency and learn how to use motivational interviewing skills⁵⁶ to acknowledge the roots of mistrust in systemic racism and address mistrust in a nonconfrontational nonjudgmental way, following previous intervention research.⁵¹

The President and federal government were the least trusted sources, consistent with the administration’s pandemic response, including disinformation conveyed by federal officials,^{57–59} such as assurances that sufficient testing was available at a time when many individuals were unable to get tested.⁶⁰ When individuals see the pandemic surging in their own communities, whereas testing is restricted, the disconnect between the US administration’s statements and local realities can breed further mistrust. Conversely, in countries such as New Zealand, where there was a strong national response to COVID-19, trust in politicians, law enforcement, and science actually increased pre-pandemic to post-pandemic.⁶¹

Our data also suggest that the pandemic is adversely affecting health outcomes of people living with HIV. A substantial percentage of participants reported experiencing high negative social, financial, and health care consequences as a result of the pandemic. Although participants were generally adherent to ART, those who experienced more health care disruptions exhibited greater nonadherence. Some

participants were unable to get medications or attend medical appointments; others experienced severe consequences, such as housing instability, lower income, and food insecurity, which have been associated with nonadherence in previous research.^{62–64} Given the high proportion of sexual minority individuals in our sample, our results on negative impacts and nonadherence complement findings from research demonstrating significant declines in mental health and adverse economic impacts, among sexual minority men during the pandemic.^{65,66} These results also are consistent with research showing that life chaos is a correlate of ART nonadherence, and life chaos may mediate the association between poverty and nonadherence.⁶³

Taken as a whole, among a population that already experiences severe stressors from systemic racism, including living in neighborhoods affected by poverty, our results demonstrate that COVID-19 has pushed vulnerable people with HIV to even greater disadvantage. COVID-19 inequities contribute to the cycle of inequalities in health and health care access and consequent mistrust: Inequities in COVID-19 impacts can exacerbate mistrust—and, in turn, lead to suboptimal health care behaviors. Thus, antiracist policies that aim to decrease COVID-19 inequities, with tailored interventions for Black communities, may simultaneously improve COVID-19 outcomes and reduce mistrust. Authentic community engagement that establishes equal partnerships with stakeholders up front—and shifts power to communities, to identify and determine community-defined solutions—are needed to address mistrust and access inequities, and ensure that COVID-19 services are responsive to community needs.

In this study, responses on the COVID-19 mistrust scale were associated with responses on general medical mistrust and HIV-related mistrust scales. This indicates the validity of our COVID-19 mistrust measure in tapping into an overall mistrust construct. These findings additionally suggest parallels between mistrust around COVID-19 and mistrust around HIV: both types of mistrust arose, in part, after perceived initial harmful or neglectful government responses to these infectious diseases. Accordingly, the types of conspiracy beliefs that have arisen in response to both conditions have been similar, with the manifestation of high endorsement of “malicious intent” theories (eg, around governmental intentional harm to communities of color).⁶⁷

Limitations of the study include the convenience sample, the low number of women and younger adults in the sample, the lack of concurrent viral suppression data (due to not being able to conduct venipuncture with parent study participants during the pandemic), and the relatively low sample size for the electronically monitored adherence data (due to restricted in-person data collection during the pandemic). Studies on medical mistrust related to COVID-19 using nationally representative samples of Black Americans are needed, to inform interventions and policy solutions at the individual and structural levels that can address mistrust and reduce COVID-19 inequities. Furthermore, research is needed that includes multiple racial/ethnic groups living with HIV, to compare levels of mistrust and vaccine hesitancy across groups. Because of

disinformation advanced by US political figures about the pandemic, mistrust may be heightened across groups. Accordingly, a national survey conducted in October 2020, several months after this study was conducted, suggests that, in the general population, a substantial proportion (34%) said that they would definitely or probably not get a free and safe COVID-19 vaccine; this percentage was much higher among Black Americans (49%) than among Whites (33%).⁶⁸

Our study is the first to report COVID-19 mistrust among Black Americans living with HIV, most of whom were sexual minority individuals, and to demonstrate the negative impact of COVID-19 on ART adherence. Our results suggest avenues for delivering public health messages around COVID-19 to which individuals may be more receptive, such as through their health care providers or community-based, nonpolitical entities. COVID-19 inequities may widen unless public health officials engage with communities to determine tailored approaches, including effective strategies, sources, and messaging, to deliver evidence-based information and overcome mistrust around COVID-19. In this time of heightened mistrust, only interventions that are developed by and in partnership with communities, following community-based participatory research principles,⁶⁹ can increase the percentage of individuals tested and lay the groundwork for treatment and vaccine uptake. Importantly, local community empowerment is needed, combined with both national leadership and antiracist policies, to bring awareness and action to overcome the root causes of mistrust in systemic racism.

REFERENCES

- Centers for Disease Control and Prevention. *CDC COVID Tracker*. 2020. Available at: <https://www.cdc.gov/covid-data-tracker/index.html#demographics>. Accessed June 26, 2020.
- Centers for Disease Control and Prevention. *COVID-19 in Racial and Ethnic Minority Groups*. COVID-NET. 2020. Available at: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/racial-ethnic-minorities.html>. Accessed July 10, 2020.
- Price-Haywood EG, Burton J, Fort D, et al. Hospitalization and mortality among Black patients and white patients with COVID-19. *N Eng J Med*. 2020;382:2534–2543.
- Centers for Disease Control and Prevention. *Weekly Updates by Select Demographic and Geographic Characteristics: Provisional Death Counts for Coronavirus Disease 2019 (COVID-19) 2020*. Available at: https://www.cdc.gov/nchs/nvss/vsrr/covid_weekly/index.htm. Accessed July 10, 2020.
- Stokes EK, Zambrano LD, Anderson KN, et al. Coronavirus disease 2019 case surveillance—United States, January 22–May 30, 2020. *MMWR*. 2020;69:759–765.
- Chicago City Department of Public Health. Chicago, IL: Latest data. 2020. Available at: <https://www.chicago.gov/city/en/sites/covid-19/home/latest-data/2020-05-17.html>. Accessed July 10, 2020.
- United States Census Bureau. *QuickFacts United States*. 2020. Available at: <https://www.census.gov/quickfacts/fact/table/US/PST045219>. Accessed July 10, 2020.
- Abrams EM, Szefer SJ. COVID-19 and the impact of social determinants of health. *Lancet Respir Med*. 2020;8:659–661.
- Shiau S, Krause KD, Valera P, et al. The burden of COVID-19 in people living with HIV: a syndemic perspective. *AIDS Behav*. 2020;1–6.
- Jordan RE, Adab P, Cheng K. COVID-19: risk factors for severe disease and death. *BMJ* 2020;368:m1198.

11. Jaiswal J, Halkitis PN. Towards a more inclusive and dynamic understanding of medical mistrust informed by science. *Behav Med.* 2019;45:79–85.
12. LaVeist TA, Isaac LA, Williams KP. Mistrust of health care organizations is associated with underutilization of health services. *Health Serv Res.* 2009;44:2093–2105.
13. Hoyt MA, Rubin LR, Nemeroff CJ, et al. HIV/AIDS-related institutional mistrust among multiethnic men who have sex with men: effects on HIV testing and risk behaviors. *Health Psychol.* 2012;31:269–277.
14. Ross MW, Essien EJ, Torres I. Conspiracy beliefs about the origin of HIV/AIDS in four racial/ethnic groups. *J Acquir Immune Defic Syndr.* 2006;41:342–344.
15. Bogart LM, Ransome Y, Allen W, et al. HIV-related medical mistrust, HIV testing, and HIV risk in the National Survey on HIV in the Black community. *Behav Med.* 2019;45:134–142.
16. Abel WM, Efrid JT. The association between trust in health care providers and medication adherence among Black women with hypertension. *Front Public Health* 2013;1:66.
17. Bogart LM, Wagner G, Galvan FH, et al. Conspiracy beliefs about HIV are related to antiretroviral treatment nonadherence among African American men with HIV. *J Acquir Immune Defic Syndr.* 2010;53:648–655.
18. Armstrong K, Rose A, Peters N, et al. Distrust of the health care system and self-reported health in the United States. *J Gen Int Med.* 2006;21:292–297.
19. Kinlock BL, Parker LJ, Bowie JV, et al. High levels of medical mistrust are associated with low quality of life among Black and white men with prostate cancer. *Cancer Contr* 2017;24:72–77.
20. Kimball D, Rivera D, Gonzales M, et al. Medical mistrust and the PrEP cascade among Latino sexual minority men. *AIDS Behav.* 2020;24:3456–3561.
21. Ford CL, Wallace SP, Newman PA, et al. Belief in AIDS-related conspiracy theories and mistrust in the government: relationship with HIV testing among at-risk older adults. *Gerontol.* 2013;53:973–984.
22. Jamison AM, Quinn SC, Freimuth VS. “You don’t trust a government vaccine”: narratives of institutional trust and influenza vaccination among African American and white adults. *Soc Sci Med.* 2019;221:87–94.
23. Eaton LA, Driffin DD, Kegler C, et al. The role of stigma and medical mistrust in the routine health care engagement of Black men who have sex with men. *Am J Public Health.* 2015;105:e75–e82.
24. Bogart LM, Takada S, Cunningham WE. Medical mistrust, discrimination, and the domestic HIV epidemic. In: Ojikutu BO, Stone VE, eds. *HIV/AIDS in US Communities of Color.* New York, NY: Springer; 2020:207–231.
25. Douglas KM, Sutton RM, Cichocka A. The psychology of conspiracy theories. *Curr Dir Psychol Sci.* 2017;26:538–542.
26. Douglas KM, Uscinski JE, Sutton RM, et al. Understanding conspiracy theories. *Polit Psychol.* 2019;40:3–35.
27. van Prooijen JW, Acker M. The influence of control on belief in conspiracy theories: conceptual and applied extensions. *Appl Cogn Psychol.* 2015;29:753–761.
28. Sunstein CR, Vermeule A. Conspiracy theories: causes and cures. *J Polit Philos.* 2009;17:202–227.
29. Morrison A JR. *Amid Coronavirus Pandemic, Black Mistrust of Medicine Looms.* ABC News. 2020. Available at: <https://abcnews.go.com/US/wireStory/amid-coronavirus-pandemic-black-mistrust-medicine-looms-69983726>. Accessed April 5, 2020.
30. *Latino Decisions. Poll of Latinos Finds Nearly 70% Feel President Ignored Early Signs of Coronavirus Spread.* 2020. Available at: <https://abcnews.go.com/US/wireStory/amid-coronavirus-pandemic-black-mistrust-medicine-looms-69983726>. Accessed April 24, 2020.
31. Schaeffer K. *Nearly Three-In-Ten Americans Believe COVID-19 Was Made in a Lab.* 2020. Available at: <https://www.pewresearch.org/fact-tank/2020/04/08/nearly-three-in-ten-americans-believe-covid-19-was-made-in-a-lab/>. Accessed July 01, 2020.
32. Freeman D, Waite F, Rosebrock L, et al. Coronavirus conspiracy beliefs, mistrust, and compliance with government guidelines in England. *Psychol Med.* 2020;50.
33. Allington D, Duffy B, Wessely S, et al. Health-protective behaviour, social media usage and conspiracy belief during the COVID-19 public health emergency. *Psychol Med.* 2020;50.
34. Plohl N, Musil B. Modeling compliance with COVID-19 prevention guidelines: the critical role of trust in science. *Psychol Health Med.* 2020;25:1–12.
35. Imhoff R, Lamberty P. A bioweapon or a hoax? The link between distinct conspiracy beliefs about the Coronavirus disease (COVID-19) outbreak and pandemic behavior. *Soc Psychol Pers Sci.* 2020;11:1110–1118.
36. Swami V, Barron D. *Analytic Thinking, Rejection of Coronavirus (COVID-19) Conspiracy Theories, and Compliance with Mandated Social-Distancing: Direct and Indirect Relationships in a Nationally Representative Sample of Adults in the United Kingdom.* 2020. Available at: <https://osf.io/8ft72d/>. Accessed July 24, 2020.
37. Earnshaw VA, Eaton LA, Kalichman SC, et al. COVID-19 conspiracy beliefs, health behaviors, and policy support. *Transl Behav Med.* 2020;10:850–856.
38. Centers for Disease Control and Prevention. *HIV and African Americans.* 2020. Available at: <https://www.cdc.gov/hiv/group/racialetnic/africanamericans/index.html>. Accessed July 02, 2020.
39. Meyerowitz EA, Kim AY, Ard KL, et al. Disproportionate burden of COVID-19 among racial minorities and those in congregate settings among a large cohort of people with HIV. *AIDS.* 2020;34:1781–1787.
40. Blanco JL, Ambrosioni J, Garcia F, et al. COVID-19 in patients with HIV: clinical case series. *Lancet HIV.* 2020;7:e314–e316.
41. Karmen-Tuohy S, Carlucci PM, Zacharioudakis IM, et al. Outcomes among HIV-positive patients hospitalized with COVID-19. *J Acquir Immune Defic Syndr.* 2020;85:6–10.
42. Gervasoni C, Meraviglia P, Riva A, et al. Clinical features and outcomes of HIV patients with coronavirus disease 2019. *Clin Infect Dis.* 2020; ciae579;71:2276–2278.
43. Triant VA, Lee H, Hadigan C, et al. Increased acute myocardial infarction rates and cardiovascular risk factors among patients with human immunodeficiency virus disease. *J Clin Endocrinol Metab.* 2007;92:2506–2512.
44. Centers for Disease Control and Prevention. *HIV and Older Americans.* 2019. Available at: <https://www.cdc.gov/hiv/group/age/olderamericans/index.html>. Accessed July 22, 2020.
45. Grasso DJ, Briggs-Gowan MJ, Carter AS, et al. *A Person-Centered Approach to Profiling COVID-Related Experiences in the United States: Preliminary Findings from the Epidemic-Pandemic Impacts Inventory.* EPII. Farmington, CT: University of Connecticut School of Medicine; 2020.
46. Bogart LM, Thorburn S. Are HIV/AIDS conspiracy beliefs a barrier to HIV prevention among African Americans?. *J Acquir Immune Defic Syndr.* 2005;38:213–218.
47. Eaton LA, Kalichman SC, Price D, et al. Stigma and conspiracy beliefs related to pre-exposure prophylaxis (PrEP) and interest in using PrEP among Black and white men and transgender women who have sex with men. *AIDS Behav.* 2017;21:1236–1246.
48. LaVeist TA, Nickerson KJ, Bowie JV. Attitudes about racism, medical mistrust, and satisfaction with care among African American and white cardiac patients. *Med Care Res Rev.* 2000;57(1_suppl):146–161.
49. Amsten JH, Demas PA, Farzadegan H, et al. Antiretroviral therapy adherence and viral suppression in HIV-infected drug users: comparison of self-report and electronic monitoring. *Clin Infect Dis.* 2001;33:1417–1423.
50. Bangsberg DR, Hecht FM, Charlebois ED, et al. Adherence to protease inhibitors, HIV-1 viral load, and development of drug resistance in an indigent population. *AIDS.* 2000;14:357–366.
51. Bogart LM, Mutchler MG, McDavitt B, et al. A randomized controlled trial of Rise, a community-based culturally congruent adherence intervention for Black Americans living with HIV. *Ann Behav Med.* 2017;51:868–878.
52. Byrd KK, Hou JG, Hazen R, et al. Antiretroviral adherence level necessary for HIV viral suppression using real-world data. *J Acquir Immune Defic Syndr.* 2019;82:245–251.
53. Shear M *Trump Retweets Racist Video Showing Supporter Yelling white Power.* New York Times. 2020 Available at: <https://www.nytimes.com/2020/06/28/us/politics/trump-white-power-video-racism.html?searchResultPosition=3>. Accessed July 10, 2020.
54. Baker P, Cooper H. *Trump Rejects Renaming Military Bases Named after Confederate Generals.* New York Times. 2020. Available at: <https://www.nytimes.com/2020/06/10/us/politics/trump-rejects-renaming-military-bases.html?searchResultPosition=9>. Accessed July 11, 2020.

55. CBS News. *When the Looting Starts, the Shooting Starts: Trump Tweet Flagged by Twitter for glorifying Violence*. 2020. Available at: <https://www.cbsnews.com/news/trump-minneapolis-protesters-thugs-flagged-twitter/>. Accessed July 08, 2020.
56. Miller W, Rollnick S. *Motivational Interviewing: Preparing People for Change*. New York, NY: Guilford Press; 2002:58.
57. Mazzetti M, Barnes JE, Wong E, et al. *Trump Officials Are Said to Press Spies to Link Virus and Wuhan Labs*. New York Times. 2020. Available at: <https://www.nytimes.com/2020/04/30/us/politics/trump-administration-intelligence-coronavirus-china.html?action=click&module=Spotlight&pgtype=Homepage>. Accessed July 8, 2020.
58. Thomas K. *FDA Revokes Emergency Approval of Malaria Drugs Promoted by Trump*. New York Times. 2020. Available at: <https://www.nytimes.com/2020/06/15/health/fda-hydroxychloroquine-malaria.html>. Accessed July 02, 2020.
59. McDonald J. *Trump Falsely Says COVID-19 Surge only Due to Testing, Misleads on Deaths*. 2020. Available at: <https://www.factcheck.org/2020/06/trump-falsely-says-covid-19-surge-only-due-to-testing-misleads-on-deaths/>. Accessed July 9, 2020.
60. Weiland N, Rogers K, Cochrane C. *Any American Can Now Be Tested for the Coronavirus, Pence Says*. 2020. Available at: <https://www.nytimes.com/2020/03/03/us/politics/trump-us-coronavirus.html?searchResultPosition=1>. Accessed July 1, 2020.
61. Sibley CG, Greaves LM, Satherley N, et al. Effects of the COVID-19 pandemic and nationwide lockdown on trust, attitudes toward government, and well-being. *Am Psychol*. 2020;75:618–630.
62. Harris RA, Xue X, Selwyn PA. Housing stability and medication adherence among HIV-positive individuals in antiretroviral therapy: a meta-analysis of observational studies in the United States. *J Acquir Immune Defic Syndr*. 2017;74:309–317.
63. Kalichman SC, Kalichman MO. HIV-related stress and life chaos mediate the association between poverty and medication adherence among people living with HIV/AIDS. *J Clin Psychol Med Settings*. 2016; 23:420–430.
64. Young S, Wheeler AC, McCoy SI, et al. A review of the role of food insecurity in adherence to care and treatment among adult and pediatric populations living with HIV and AIDS. *AIDS Behav*. 2014;18:505–515.
65. Sanchez TH, Zlotorzynska M, Rai M, et al. Characterizing the Impact of COVID-19 on men who have sex with men across the United States in April, 2020. *AIDS Behav*. 2020:1–9.
66. Linnemayr S, Barreras JL, Izenberg M, et al. Longitudinal assessment of changes in mental and sexual health outcomes due to COVID-19 among Latinx sexual minority men and transgender women. *J Acquir Immune Defic Syndr*. 2020;85:e90–e92.
67. Parsons S, Simmons W, Shinhoster F, et al. A test of the grapevine: an empirical examination of conspiracy theories among African Americans. *Sociol Spectr*. 1999;19:201–222.
68. Hamel L, Lopes L, Muñana C, et al. *Key Findings from the KFF/Undeclared Survey on Race and Health October 2020*. Available at: <http://files.kff.org/attachment/Report-Race-Health-and-COVID-19-The-Views-and-Experiences-of-Black-Americans.pdf>. Accessed October 22, 2020.
69. Desai MU, Bellamy C, Guy K, et al. If you want to know about the book, ask the author: enhancing community engagement through participatory research in clinical mental health settings. *Behav Med*. 2019;45:177–187.