Healthcare distrust among hospitalised black patients during the COVID-19 pandemic

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ABSTRACT

Study purpose Distrust of the healthcare system is longstanding in the black community. This may especially threaten the health of the population when a highly contagious infection strikes. This study aims to compare COVID-19-related perspectives and behaviours between hospitalised black patients who trust versus distrust doctors and healthcare systems.

Study design Cross-sectional study at a tertiary care academic hospital in Baltimore, Maryland. Hospitalised adult black patients without a history of COVID-19 infection were surveyed between November 2020 and March 2021 using an instrument that assessed COVID-19-related matters. Analyses compared those who trusted versus mistrusted doctors and healthcare systems.

Results 37 distrusting hospitalised black patients were compared with 103 black patients who trusted doctors and healthcare systems. Groups had similar sociodemographics (all p>0.05). Distrustful patients were less likely to think that they were at high risk of contracting COVID-19 (54.0% vs 75.7%; p=0.05), less likely to believe that people with underlying medical conditions were at higher risk of dying from the virus (86.4% vs 98.0%; p=0.01) and less likely to be willing to accept COVID-19 vaccination (when available) (51.3% vs 77.6%; p<0.01) compared with those who were trusting.

Conclusion Healthcare distrustful hospitalised black patients were doubtful of COVID-19 risk and hesitant about vaccination. Hospitalisations are concentrated exposures to the people and processes within healthcare systems; at these times, seizing the opportunity to establish meaningful relationships with patients may serve to gain their trust.

INTRODUCTION

As of 1 July 2021, COVID-19 has resulted in more than 34 million infections and 620 000 deaths in the USA.[1] Multiple studies have shown that minorities have higher COVID-19-related morbidity and mortality compared with white people.[2 3] Early COVID-19 US data in 2020 showed death rates for predominantly black counties to be sixfold higher than that in principally white counties.[2] More recent evidence has suggested that black patients' death rate from COVID-19 has been double that of white patients.[3]

Healthcare disparities may be attributable to systemic inequalities such as historical oppression, structural racism, segregation and environmental racism.[4 5] These factors contribute to overcrowded low-income black communities where many are at increased risks of chronic diseases, low health literacy and lack of medical insurance.[4 5] These social determinants may also be at the root of historical ethical misconduct within research and medical practice such as Dr Sims' use of slave women for gynaecological experimentation,[6] the Tuskegee Syphilis study denial of curative treatment in order to document the natural history of the disease[6 7] and use of Henrietta Lacks' cervical cancer cells without her consent.[8] Together, such conditions and contexts, persisting in contemporary times largely through systemic racism, perpetuate healthcare disparities and contribute to a culture of ongoing mistrust of the biomedical system for many within black communities.[6 7] This is verified by empirical evidence confirming that black people have higher levels of medical distrust than do white people.[9 10]

Lack of trust in medical institutions is dangerous, and may even be deadly, as it decreases adherence with science-based medical recommendations, engagement with healthcare professionals and utilisation of healthcare resources.[10–12] Vaccine hesitancy may be a prototypical example as it is largely influenced by one's confidence in the competency and impartiality of biomedical research, health services and healthcare professionals.[13] COVID-19 vaccine hesitancy is much higher in black people compared with white people.[14 15] During the pandemic, we examined the extent to which hospitalised black patients were concerned about COVID-19 by studying their perceptions, knowledge and practices—and we compared those who trusted versus distrusted healthcare. We hypothesised that among hospitalised black patients, those who distrusted would be less concerned with their own susceptibility to COVID-19, practice less safeguards to reduce risk of contracting the virus and would be less receptive to receiving COVID-19 vaccination.

METHODS

Participants and setting

This study enrolled hospitalised black patients ≥18 years old without a previous or current infection of COVID-19 who were English speaking. All patients in this study specifically identified themselves as black. Patients with dementia or altered mental status, identified during the screening process and on review of provider documentation, were excluded. Additionally, if during the interview process, the patient appeared confused or did not

answer questions appropriately, they were excluded from the study. We also excluded patients who were hard of hearing or deaf, unable to verbally express themselves and those who could not understand the purpose of the study. Participants were identified among those admitted to the general medicine wards at a tertiary care university-affiliated hospital in Baltimore between 10 November 2020 and 10 March 2021. Study participants who were readmitted during the study period were not approached again to enter the study.

A total of 520 admitted patients were identified as potential subjects to be approached during the study period. Ninety-two patients either had a past or current COVID-19 infection, 109 had altered mental status or dementia and 10 had communication barriers. The remaining 309 patients were eligible for participation. Among them, 70 were discharged before being approached, and 99 refused to participate; this yield 140 patients for the final study cohort. Patients discharged from the hospital and those who declined to participate in the study were of a similar age and gender composition as the participants (both p>0.05).

Survey instrument and data collection

The survey was developed and prepared by hospitalist clinicians and researchers who cared for patients with COVID-19 and those who have expertise in clinical research. The survey was informed by our prior inpatient research,[16] [17] a review of the literature, meetings with larger teams at 'research in progress sessions' across two distinct divisions, and lengthy discussions with 10+ hospitalised patients with and without COVID-19 infections during the pandemic. These steps served to confer content validity evidence to the instrument. The survey was first piloted on in early November 2020 with eight patients who met eligibility criteria. These patients explained how they were interpreting each question, thereby rendering response process validity evidence to the instrument. The survey was further modified based on respondent feedback, and data collection began using Qualtrics online software in mid-November 2020.

During the data collection period, the research team reviewed patients admitted to the general medicine floor (Monday through Friday) to identify patient eligibility for this study. Eligible patients were either surveyed in person at the bedside or over the phone by study team members. Unavailable patients at the initial attempt at enrolment were revisited the next hospital day.

Measures

The primary outcome measures assessed were perceived risks and mortality associated with COVID-19, personal cautionary practices related to viral transmission and receptivity to vaccination. Likert scale response options (Strongly Disagree, Disagree, Neutral, Agree and Strongly Agree) were used to assess perspectives. Select statements that were explored include the following: 'I know a lot about COVID-19', 'People who have other medical conditions are at higher risk of getting COVID-19 than others', 'I, myself, am at high risk of getting COVID-19', 'People who have other medical conditions are at higher risk of dying from COVID-19, if they get it, than others', 'I know what I need to do to protect myself from getting COVID-19', 'I always wear a face mask when out in public around other people', 'I wash my hands much more now than before the COVID-19 pandemic' and 'I have been tested for COVID-19 prior to this current hospitalisation'. Other areas of inquiry were also explored such as: 'When a vaccine for COVID-19 becomes available, I will get vaccinated' and 'My people and community do NOT trust doctors and our healthcare system'.

Our study characterised *trust* using Gupta *et al*'s definition: 'Trust is the relational quality that enables and empowers individuals to rely on others in the face of vulnerability'.[18] Assessment of patients' own trust or distrust was determined by asking participants' level of agreement with a single unambiguous statement: 'I do NOT trust doctors and our healthcare system'.

Patient demographics were collected including age, sex, education, employment status and estimated median income based on zip code. Diagnoses precipitating the hospitalisation were also recorded, as were several comorbidities believed to be associated worse clinical outcomes in the setting of COVID-19 infection.

Statistical analyses

The primary analysis of the data examined survey responses comparing those patients who indicated personal 'trust' versus 'mistrust' in doctors and the healthcare system (named below and in tables as 'trusting' and 'distrustful'). Patient responses on the Likert scales were dichotomised—'Strongly Agree' and 'Agree' responses compared with all other options. Fisher's exact tests and t-tests for categorical and continuous variables, respectively, were used. We used Stata V.15.0 statistical software (Stata Corp, College Station, Texas, USA), and the p values for this study were two sided and type I error significance level at ≤0.05.

RESULTS

Table 1 shows patient demographics data for the trusting (n=103) and distrustful (n=37) groups. The two groups had similar sociodemographic characteristics.

Table 2 compares survey item responses between the groups. The distrustful patients were less likely to believe that they were at high risk of getting COVID-19 (57.1% vs 75.7%; p=0.05), less likely to believe that people with underlying medical conditions were at higher risk of dying from the virus (86.4% vs 98.0%; p=0.01), believed their community did not trust doctors or the healthcare system (78.3% vs 33.0%; p<0.01) and stated that they would be less likely to accept COVID-19 vaccination (51.3% vs 77.6%; p<0.01) compared with the trusting patients.

DISCUSSION

Our US-based study found that among hospitalised black patients, those who reported distrusting doctors or healthcare systems did not believe they were at high risk of contracting the virus, did not think those with underlying health conditions were at risk of being more sick with COVID-19 than those without comorbidities and were more hesitant about vaccination. These findings are worrisome because compared with white patients, black patients have much higher morbidity and mortality from COVID-19 infection.[2] [3] Historical and contemporary health inequity between black and white patients in the USA may have contributed to the distrust. Those with less trust have views that may jeopardise their potential to maintain health and avoid illness. This study highlights the need for health professionals to forge trusting relationships with patients, which may significantly impact understanding, engagement and behaviours.

Prior studies have sought to evaluate the awareness and attitudes related to COVID-19 symptoms and prevention strategies.[19–22] Furthermore, those studies only surveyed patients outside the hospital (by phone or online).[19–22] Our sample (hospitalised patients) and the resulting data are different; we collected perspectives related to COVID-19 in an acute inpatient environment—while these individuals are relying on medical care for their recovery, if not survival. In multivariate analyses of two separate studies, Wolf *et al* and Bailey *et al* showed that black

Table 1 Demographic data comparing 140 hospitalised African American patients who were classified as being trusting versus distrustful to doctors and the healthcare system

Characteristics	Trusting N=103	Distrustful N=37	P value§
Age in years, mean±SE	57.4±1.3	55.1±2.7	0.41
Female, n (%)	59 (57.2)	17 (45.9)	0.25
Body Mass Index (kg/m^2), mean±SE	32.2±0.8	29.2±1.2	0.06
Completed high school/General Educational Development, n (%)	83 (80.5)	30 (81.0)	1.0
Employment status, n (%)			0.4
Unemployed	8 (7.7)	7 (18.9)	
Employed	36 (34.9)	13 (35.1)	
Disability	29 (28.1)	9 (24.3)	
Retired	29 (28.1)	8 (21.6)	
Median income based on zip code (in US$), n (%)			0.46
1–32 667	28 (27.1)	10 (27.0)	
32 667–44 025	31 (30.0)	8 (21.6)	
44 025–49 444	21 (20.3)	6 (16.2)	
49 444–90 365	23 (22.3)	13 (35.1)	
Top reasons for admission, n (%)			
Cardiac*	23 (22.3)	10 (28.5)	0.49
Gastrointestinal†	22 (21.3)	4 (11.4)	0.22
Syncope/fall	15 (14.5)	5 (14.2)	1.0
Pulmonary‡	14 (13.5)	6 (17.1)	0.58
Cellulitis	7 (6.7)	1 (2.8)	0.67
Renal	5 (4.8)	2 (5.7)	1.0
Comorbidities, n (%)			
Hypertension	78 (75.7)	25 (71.4)	0.65
Dyslipidaemia	36 (34.9)	13 (37.1)	0.84
Obesity	56 (54.3)	12 (34.2)	0.05
Asthma	25 (24.2)	10 (29.4)	0.65
Type II diabetes mellitus	29 (28.1)	6 (17.1)	0.26
Congestive heart failure	29 (28.1)	5 (14.2)	0.11
Coronary artery disease	26 (25.2)	6 (17.1)	0.3
Chronic kidney disease (all stages)	31 (30.0)	5 (14.2)	0.07
Chronic obstructive pulmonary disease	20 (19.4)	4 (11.4)	0.43
Cirrhosis	3 (2.9)	3 (8.5)	0.17
Cancer (active)	7 (6.7)	2 (5.8)	1.0
Opiates/opioids D	21 (20.3)	8 (22.8)	0.81
Tobacco use	57 (55.3)	19 (54.2)	1.0

*Cardiac: diagnoses included chest pain, myocardial infarction, heart failure, poorly controlled hypertension (hypertensive urgency/emergency).
†Gastrointestinal diagnoses included colitis, gastroenteritis, gastrointestinal bleed, acute pancreatitis, abdominal pain.
‡Pulmonary: diagnoses included asthma exacerbation, chronic obstructive pulmonary disease exacerbation, pulmonary embolism, pneumonia.
§Fisher's exact tests were used to assess categorical variables; t-tests were used for the analysis of continuous variables.

Table 2 Comparisons of the survey responses of the 140 hospitalised African American patients who were classified as being trusting versus distrustful to doctors and the healthcare system

Survey item	Trusting N=103	Distrustful N=37	P value
I know a lot about COVID-19, n (%)	66 (64.0)	20 (54.0)	0.28
COVID-19 is easily transmitted from person to person, n (%)	92 (89.3)	32 (86.4)	0.64
People who have other medical conditions are at higher risk of getting COVID-19 than others, n (%)	97 (94.1)	32 (86.4)	0.13
People who have other medical conditions are at higher risk of dying from COVID-19, if they get it, than others, n (%)	101 (98.0)	32 (86.4)	0.01
I know what I need to do to protect myself from getting COVID-19, n (%)	99 (96.1)	35 (94.5)	0.69
I always wear a face mask when out in public around other people, n (%)	100 (97.0)	36 (97.2)	0.94
I wash my hands much more NOW than before the COVID-19 pandemic, n (%)	94 (91.2)	35 (94.5)	0.52
When I am out, I am careful to try to stay at least 6 ft away from other people, n (%)	101 (98.0)	35 (94.5)	0.28
I have been tested for COVID-19 prior to this current hospitalisation, n (%)	72 (69.9)	22 (59.4)	0.24
I, myself, am at high risk of getting COVID-19, n (%)	78 (75.7)	20 (57.1)	0.05
When a vaccine for COVID-19 becomes available, I will get vaccinated, n (%)	80 (77.6)	19 (51.3)	<0.01
My people and community do NOT trust doctors and our healthcare system, n (%)	34 (33.0)	29 (78.3)	<0.01

Fisher's exact tests were used for the analysis of the categorical variables.

vaccine hesitancy. Here, Bogart *et al* found that medical mistrust was high and associated with greater vaccine hesitancy.[23]

Curiously, study participants who distrusted medical systems had less understanding that people who have underlying medical conditions are at higher risk of dying from COVID-19. This suggests that distrustful patients either underestimate virulence of infectious pathogens or they are unaware of the impact pre-existing comorbidities have on clinical outcomes. Research by Wolf *et al* similarly found many patients with underlying comorbidities misjudged their own likelihood of contracting COVID-19.[19] These impressions may be influenced by the belief in conspiracies or falsehoods, such as myths of black immunity.[24 25] Such misinformation can potentially lead to risky behaviours and doubts about susceptibility.[24 25] Underestimation of the threat posed by COVID-19 undermines the indispensable value of vaccination. It is critical to acknowledge the justifiable vaccine hesitancy due to legitimate fears within black community based on historical medical transgressions and misconduct. Understanding the concerns and misinformation within the black community may help hospital-based clinicians to resolutely address concerns and dispel misrepresentations. Some hospitals are intimately involved and supportive of their surrounding communities; when trust has already been established, further counselling and education is much easier.

Several limitations of this study should be considered. First, we only surveyed hospitalised black patients admitted to the general

participants, those who were poor and those with low health literacy were less likely to believe that they would get infected with COVID-19.[19 20] Further, work by O'Conor *et al* determined that within this same demographic, there was less appreciation of the need to socially distance to reduce the risk of contracting COVID-19.[21] With regard to vaccinations, we found that receptivity to the COVID-19 vaccine among black patients is linked to trust, which is similar to other studies.[15 23] For example, a survey of black patients with HIV evaluated COVID-19 mistrust and

medical wards at a single hospital. Second, the participation/enrolment rate was good, but not great, because some refused and others were discharged prior to being approached. With refusals, there may be some non-response bias and thus we were unable to determine their trust/distrust level in healthcare.[26] It would be expected that a proportion of hospitalised patients prefer not to be bothered when they are acutely ill. Because participants and those who did not participate were similar in terms of age and gender, we suspect that those who opted out were fairly similar to our study group. Because all informants were assured that all data would be kept confidential and reported only in aggregate, we have no reason to suspect that any responses are disingenuous. Third, asking about future behaviours, like intention to take a vaccine, may be imprecise. Fourth, while most questions focused on knowledge and behaviours that are more objective, part of the inquiry explored attitudinal variables. Although some may not place much conviction in such responses, this is one of the only viable ways to characterise informants' feelings and perspectives. Lastly, categorising subjects into trusting versus distrustful groups is not simple. We ensured in pilot testing that subjects understood the intended definition of trust and felt that the discerning question was clear and unambiguous. Using a more extensive and validated 'trust scale' may be wise to consider in future research. However, after reviewing them, we are confident that there would be a high correlation with the single item used in this study.[27–30]

CONCLUSIONS

Hospitalised black patients who distrusted doctors and healthcare systems were less likely to think that they were at high risk of getting infected with COVID-19, less likely to believe that people with underlying medical conditions were at increased risk of dying from the virus and more hesitant about COVID-19 vaccination. Encouragingly, they admitted to observing similar safeguards to reduce risks of viral transmission. Our findings highlight the advantages that are associated with earning patient trust; when providers and healthcare systems earn the trust of patients and communities, engagement and clinical outcomes may be positively influenced.

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Main messages

► Hospitalised black patients who distrusted the medical system were less likely to believe they were at high risk of getting COVID-19, less likely to believe that people with underlying medical conditions were at higher risk of dying from the virus and were more hesitant about COVID-19 vaccination.

Current research questions

► Can interventions that enhance patient trust result in changed beliefs and behaviours associated with the pandemic—or other emergent healthcare adversities?
► What are the best practices for earning patient trust when meeting them in acute care settings—such as a hospital inpatient unit?

What is already known on the subject

► There are great disparities in COVID-19 outcomes between black and white communities.
► Medical mistrust continues to be pervasive within black communities.
► Medical mistrust is linked to poor clinical outcomes and vaccine hesitancy.

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