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HIV-Related Medical Mistrust, HIV Testing, and HIV Risk in the National Survey on HIV in the Black Community

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Abstract

Black Americans are greatly affected by HIV disparities and exhibit high levels of medical mistrust, including HIV conspiracy beliefs, a form of mistrust around HIV's origin and treatment. A 2002–2003 national survey of Black Americans found that 48% believed that “HIV is a manmade virus.” However, the extent to which such beliefs remain widespread is unknown. Moreover, HIV conspiracy beliefs have been associated with greater HIV risk, but have also been associated with a higher testing likelihood—and no research to date has attempted to explain these seemingly contradictory findings. We obtained updated data on prevalence and correlates of HIV conspiracy beliefs from the US National Survey on HIV in the Black Community, a nationally representative e-mail survey of 868 Black individuals aged 18–50 years (February–April 2016). Substantial percentages agreed that HIV is man-made (31%) and that the government is withholding a cure for HIV (40%). HIV conspiracy beliefs and HIV risk were both significantly associated with a higher HIV testing likelihood. The association between HIV conspiracy beliefs and HIV testing was significantly mediated by individual-level HIV risk (73% of total effect), but not by area-level socioeconomic position (an ecological determinant of higher HIV prevalence). Mistrust remains high among Black Americans, but the association of mistrust with prevention behaviors is complex. People who do not trust the public health system may also be at greater risk—and thus, more likely to get tested, potentially due to greater access to community-based testing venues that engage higher risk populations.

Keywords

African American/Black; HIV/AIDS; medical mistrust; survey methods

Introduction

Of all races/ethnicities in the United States, Black Americans are the most highly affected by HIV-related disparities. Although Black Americans comprise 14% of the US population, they accounted for 44% of all new HIV diagnoses in 2016.¹ Black Americans living with HIV show lower levels of adherence to antiretroviral treatment (ART) and viral suppression than do members of other racial/ethnic groups.²

Medical mistrust has been proposed to be a contributor to HIV-related disparities. Such mistrust has arisen in the context of current and historical racism in the United States.³ Structural discrimination, in terms of residential racial segregation at the neighborhood level, has created disparities in access to safe and affordable housing and to high-quality education and health care. Interpersonal discrimination based on negative stereotypes about Black Americans has persisted and can impact health.⁴ For example, specific to HIV, discrimination based on race/ethnicity has been associated with nonadherence to ART for HIV, and with having an unsuppressed viral load.^{5,6} Within medical care, a history of unethical medical experimentation and current events and recent experiences with discrimination and poor communication with providers have furthered suspicion and mistrust of the medical system.^{3,7} Accordingly, empirical research indicates that medical mistrust mediates the association between discrimination and HIV-related treatment adherence.⁸

Termed HIV-related medical mistrust or “HIV conspiracy beliefs,” mistrust around the origin and treatment of HIV is prevalent in Black communities.^{9–11} A national survey of Black Americans conducted in 2002–2003 found that 48% strongly or slightly believed that “HIV is a manmade virus” and 53% believed that “There is a cure for HIV but it is being withheld from the poor.”⁹ More recent data similarly indicate high levels of endorsement of HIV conspiracy beliefs in smaller convenience samples of the general public and of people living with HIV.^{12–16} A 2010–2012 study of a convenience sample of Black Americans living with HIV found that 63% endorsed any HIV conspiracy beliefs, with almost one-third agreeing that “There is a cure for AIDS, but it is being withheld from the poor.”¹³ However, the most recent national prevalence data were collected in 2002–2003, and thus it is unknown whether such beliefs remain widespread in Black American communities.

Belief in HIV conspiracies among Black Americans varies by some sociodemographic characteristics, tending to be higher among men and among people who have lower educational and income levels.¹⁷ HIV conspiracy beliefs have been associated with a host of HIV-related health behaviors and outcomes, including sexual risk (inconsistent condom use, multiple sexual partners), and (as noted above) nonadherence to ART.^{9,14,18} Qualitative data complement these quantitative results, suggesting that some HIV-positive Black Americans may not adhere to ART because of suspicions that HIV was created by the government and that ART leads to accelerated disease progression.¹⁹

The relationship between HIV conspiracy beliefs and HIV testing has been less clear. Some research has found that stronger belief in HIV conspiracies is associated with higher odds of testing, whereas other research has found that stronger belief in HIV conspiracies is

associated with lower odds.^{15,16,20–22} The two studies finding a negative association were conducted in South Africa^{20,21}; both assessed genocidal conspiracy beliefs (e.g., role of the government or West in creating HIV or withholding a cure), and one additionally assessed mistrust of HIV treatment. In South Africa, the government initially did not acknowledge the scope of the epidemic and the president publicly endorsed conspiracies about HIV and traditional medicines for treatment, leading to a general acceptance of such messages and a low prioritization of HIV prevention and treatment at the governmental policy level.²³ Although in recent years the government has initiated large-scale campaigns for HIV testing and treatment, given its history, South Africans who are suspicious of HIV's origins may be similarly suspicious of prevention strategies (e.g., testing) that are perceived to be based on mainstream (and not traditional) medicine.

The two studies finding a positive association between HIV conspiracy beliefs and HIV testing were conducted in the United States,^{15,16} and assessed conspiracy beliefs in terms of HIV as a form of genocide by the government. In the United States, despite government reluctance at the beginning of the epidemic to recognize the scope of the problem, there has since been a tradition of grassroots organization and community-based prevention campaigns about the severity of the epidemic and the need to get tested, with a particular focus on Black communities. Thus, although people who endorse conspiracies may question the origins of HIV, they may also believe (from community-based messaging) that HIV is a serious disease associated with known risk behaviors and that a reliable test exists—and that people who are at risk should be tested. Because belief in conspiracies is associated with higher HIV risk,⁹ and communities at greater risk have been targeted for HIV testing in the United States, we hypothesized in the present research that the positive association between HIV-related conspiracies and testing may be at least partially accounted for (i.e., mediated) by a third variable: HIV risk at the individual level (i.e., in terms of risk behaviors) and ecological level, in terms of area-level socioeconomic position (SEP) (because in the United States, HIV is mainly concentrated in lower socioeconomic status communities²⁴). We reasoned that Black Americans at high risk for HIV may be likely to endorse conspiracy beliefs but they also may have a high likelihood of HIV testing, because of greater access to testing in their communities.²⁵

In the present study, we analyzed data from the National Survey on HIV in the Black Community (NSHBC) to (1) obtain updated prevalence data on HIV conspiracy beliefs among Black Americans and (2) examine ecological (community-level), sociodemographic, and behavioral correlates of holding HIV conspiracy beliefs. We hypothesized that greater belief in conspiracies would be associated with a higher odds of HIV testing, consistent with prior US research. As shown in Figure 1, we also hypothesized that individual-level HIV risk (i.e., behaviors that biologically can increase HIV risk: recent condomless sex, multiple partners, and anal sex²⁶) would at least partially mediate the association between HIV conspiracy beliefs and HIV testing. As lower ecological-level socioeconomic status is associated with higher prevalence of HIV and increases individuals' risk for STIs in the United States,^{24,27} we similarly hypothesized that area-level SEP would also mediate the association between HIV conspiracy beliefs and HIV testing.

Methods

Procedure

Data for the present analysis were drawn from the NSHBC, a nationally representative e-mail survey of Black/African-American individuals aged 18–50 years in the United States that was conducted from February to April 2016, and analyzed throughout 2017. Participants were eligible if they identified as Black/African American and were between 18 and 50 years old. Participants were recruited from a probability-based Web panel (using GfK's KnowledgePanel) through both random-digit dialing and address-based sampling to ensure inclusion of households served by cell phones and without landline telephones, and households were provided with Internet access and hardware if needed (see <http://www.knowledgenet-works.com/ganp/index.html>). Written informed consent was obtained from participants prior to their participation, and ethical approval was obtained from Boston Children's Hospital (where the first author was employed when the study was initiated).

Of the entire national panel of more than 55,000 respondents, all 1,969 Black/African American participants were sampled. Of those 1,969 individuals, 46% (n = 896) consented to completing a brief sociodemographic survey confirming their race and age; 74 responded but did not provide consent, and 999 did not respond to the question about consent. Of the 896 who consented, 97% (n = 868) were eligible and completed the NSHBC, 15 were eligible but only partially completed the survey, 9 did not confirm their race and were screened out, and 4 refused to answer the screening questions.

Poststratification weighting, which incorporated sociodemographic benchmarks from the March 2016 supplement of the Current Population Survey, was used to ensure that estimates were representative of adults living in households in the United States in 2016.

Measures

Sociodemographic covariates—Potential covariates included continuous age, gender identity, marital status (married, unmarried, divorce/widowed/separated), employment status (coded as employed [as a paid employee or self-employed] or not working [on temporary layoff, looking for work, retired, disabled, or other]), education level (less than high school high school diploma or GED, college degree or higher), annual income (<\$25,000, \$25,000–\$49,000, \$50,000 or greater), and US region (Northeast, Midwest, South, West).

Predictor: HIV-related mistrust—HIV-related mistrust was assessed with an adapted HIV Conspiracy Beliefs scale (which was shortened from the original version due to the time constraints of the telephone survey).⁹ Participants indicated their agreement with each of four beliefs on the scale as 1 = strongly disagree, 2 slightly disagree, 3 = neutral, 4 = slightly agree, and 5 = strongly agree (see Table 2). To create the scale, we reverse-scored one positively worded item (indicative of trust) and then derived a mean score across items ($\alpha = 0.70$). To examine prevalence of HIV conspiracy beliefs (as compared to the 2002–2003 survey), we examined the percentage of participants who strongly or slightly agreed with each item, compared to the percentage who strongly or slightly disagreed or who selected “neutral.”

Generalized structural equation modeling (GSEM), which uses equation-wise deletion for missing values, was used to test the association between average HIV conspiracy beliefs and recent HIV testing, and the potential mediating associations of individual-level HIV risk and ecological-level SEP separately. The paths between conspiracy beliefs and anal sex and condom use were fitted using log-Poisson models because those outcomes also exceeded 20% prevalence. The path from conspiracy beliefs to multiple sexual partners (and from conspiracy beliefs to the ecological variables) was fitted using a logit-Bernoulli model, which produces an odds ratio. All paths to HIV testing were fitted with a log-Poisson model. Multivariable analysis was adjusted for gender and marital status, which were significantly

associated with HIV testing in bivariate models. We forced continuously coded age into the model as an additional covariate, given known age differences in HIV testing.³¹

We calculated the proportion of indirect to total effect (i.e., proportion mediated). We only assessed mediation for HIV risk variables that were significantly related to HIV testing.

The indirect effect was considered to be statistically significant if the confidence interval of the regression coefficient did not include zero.³² Statistical significance for the indirect effect was examined via the bias corrected standard errors from bootstrapping with 500 repetitions. All calculations for mediation analysis were done directly in STATA 14.0.^{33,34}

Results

Participant characteristics

About half of participants were male, and participants were about 33 years old on average (Table 1). Most participants (70%) were not married and were employed (70%), and the majority had finished college (56%); a quarter had low annual incomes (below \$25,000). On average, about one-fifth of residents in participants' neighborhoods lived in poverty, and more than one-tenth were unemployed. More than half of participants were drawn from the US South. About one-third did not use condoms at last sex, and more than one-third had anal sex in the last 3 months; 11% had multiple partners in the last 3 months. Only 28% had been tested for HIV in the last 12 months. Scores on the HIV conspiracy beliefs scale averaged on the midpoint [$M (SD) = 3.1 (0.8)$], and higher agreement with HIV conspiracy beliefs was associated with being single, not having graduated high school, having had anal sex in the past 3 months, and residing in an area of higher poverty.

Prevalence of HIV conspiracy beliefs

Table 2 shows the national prevalence of each HIV conspiracy belief item in the 2016 and 2002–2003 surveys. Substantial percentages of the sample continued to endorse conspiracy beliefs in the 2016 survey as compared to the 2002–2003 survey. However, a lower percentage endorsed the beliefs that HIV is man-made and the government is withholding a cure for HIV in the 2016 survey (31% and 40%, respectively) than in the 2002–2003 survey (48% and 53%, respectively), whereas a higher percentage (33%) in the 2016 survey (vs. 7% in the original survey) endorsed the belief that HIV treatment is poison. Moreover, 18% in the 2016 survey (vs. 37% in the original survey) endorsed the belief indicative of higher trust in the government around health issues including HIV. Thus, while some mistrust-related beliefs appear to have decreased over time, others, including general mistrust of the government around health care, increased.

Associations of HIV conspiracy beliefs with individual-level HIV risk and HIV testing

In bivariate regression analyses (not shown in tables), greater belief in HIV conspiracies and HIV risk (in the form of having had multiple partners and anal sex in the past 3 months) were significantly associated with a higher likelihood of HIV testing [prevalence ratio (PR) = 1.2, 95% confidence interval (CI) = 1.0–1.5, $p = 0.02$ for HIV conspiracy beliefs; PR = 1.6, 95% CI = 1.1–2.2, $p = 0.01$ for multiple partners; PR = 1.8, 95% CI = 1.4–2.4, $p <$

0.001 for recent anal sex]. Having had recent condomless sex was not significantly associated with HIV testing (PR = 1.1, 95% CI = 0.8–1.5, $p = 0.53$). In addition, participants were more likely to have been tested if they were widowed, divorced, or separated vs. married (PR = 1.8, 95% CI = 1.1–2.9, $p = 0.02$). Belief in HIV conspiracies was significantly associated with having had anal sex in the past 3 months (PR = 1.2, 95% CI = 1.1–1.4, $p = 0.01$), but was not significantly associated (PR with having had condomless sex (PR = 0.95, 95% CI = 0.87–1.03, $p = 0.23$) or multiple partners 1.30, 95% CI = 0.94–1.78, $p = 0.11$).

As shown in Table 3, in multivariable models controlling for sociodemographic characteristics but excluding the HIV risk behavior variables, the direct path between HIV conspiracy beliefs and recent HIV testing was statistically significant (adjusted prevalence ratio [APR] = 1.22, 95% CI = 1.02–1.45, $p = 0.03$). In the full mediation model using the causal inference framework (testing the indirect effect of conspiracy beliefs on HIV testing through HIV risk behavior), the association between HIV conspiracy beliefs and HIV testing was no longer significant (APR = 1.04, 95% CI = 0.87–1.24, $p = 0.62$). The indirect effect of anal sex on the association between HIV conspiracy beliefs and HIV testing was significant (APR = 1.13, 95% CI = 1.03–1.26, $p = 0.02$) and accounted for 73% of the total effect of HIV conspiracy beliefs on HIV testing. Thus, as depicted in Figure 1, a substantial amount of the positive association between HIV conspiracy beliefs on HIV testing was attenuated by the indirect contribution of greater HIV risk (i.e., having had recent anal sex).

Associations of HIV conspiracy beliefs with area-level SEP and HIV testing

Area-level SEP was not significant in the multivariate regression (Table 2) and was not a significant mediator of the association between HIV conspiracy beliefs and HIV testing (APR = 1.06, 95% CI = 0.93–1.21, $p = 0.40$; Table 3).

Discussion

The results of this nationally representative survey indicate that HIV-related mistrust remains substantial among Black Americans, more than 10 years after the original 2002–2003 national survey was conducted on this topic. Although some HIV conspiracy beliefs showed lower levels of endorsement than in the past, 30% to 40% of the sample endorsed “genocidal” conspiracy beliefs (that HIV is man-made and that the government is withholding a cure) and the treatment-related conspiracy belief (that HIV medications are poison) was endorsed at a relatively high rate (by more than one-third). Moreover, we found lower trust in the government around health issues than in the prior survey, with less than one-fifth believing that the government tells the truth about health issues such as HIV. Although the survey items were not identical across years, our results do suggest a continued deep suspicion of the government in its motives regarding the public health.

Consistent with prior research, HIV conspiracy beliefs were associated with a greater likelihood of both HIV risk⁹ and recent HIV testing^{16,35}; however, prior research has not examined all three constructs within the same analysis. Research has shown mixed findings regarding the association between HIV conspiracy beliefs and HIV testing, although the two studies finding a significant positive relationship were both conducted in the United States,

similar to the present study.^{20,21} Our results suggest that historical and cultural context play a role in how mistrust manifests and affects behavior. In the United States, who gets tested for HIV and who does not may largely be a result of structural factors related to HIV testing access, based on need: Communities at higher risk are targeted for both HIV testing and education about HIV risk factors²⁵—and such communities may also be likely to have high mistrust, given structural and other forms of racial discrimination (e.g., residential segregation and law enforcement practices such as stop-and-frisk³⁶). In short, people who do not trust the public health system may also be at greater risk for HIV—and thus may be more likely to get tested, due to high knowledge about risk from community campaigns, as well as access to trusted community-based testing venues.

Our study has several limitations. We used a cross-sectional, nonexperimental design, in which HIV testing and risk were assessed as past behaviors, whereas HIV conspiracies were measured as present beliefs; thus, we cannot draw causal inferences about the direction of associations. For example, it is possible that individuals at high risk for HIV had greater mistrust because they were tested for HIV and experienced mistreatment from health care providers during the testing visit. In addition, we conceptualized having recent anal sex and multiple partners as HIV risk factors, but we did not assess whether condoms were used for anal sex or for each partner, which would have decreased HIV risk, and we did not assess partners' HIV serostatus, which would have allowed for a more rigorous assessment of risk behavior. We also did not specifically target recruitment around high-risk individuals and thus any effects of high-risk sexual behavior could have been underestimated. Due to limited data on HIV prevalence and incidence in the communities from which participants were drawn (i.e., HIV prevalence data were only available for 169 participants, or less than one-quarter of the sample), we could not directly test the hypothesis that ecological-level HIV risk (e.g., HIV prevalence) accounted for the association between HIV conspiracy beliefs and HIV testing. We also did not have data on HIV-related programs and services, including HIV testing, in these communities. Instead, we used area-level SEP as a proxy for HIV risk; because this index captures factors that are social determinants of HIV risk (e.g., poverty) rather than being a measure of risk itself, we potentially introduced measurement error into the analysis. Moreover, as preexposure prophylaxis (PrEP) becomes more widely available in Black communities, future investigations will need to assess mistrust and risk behaviors in the context of PrEP. For example, research has suggested that misconceptions and mistrust around PrEP may impede PrEP use.^{37–39} People who have misconceptions around PrEP as well as other biomedical prevention options (such as treatment as prevention) may also show higher mistrust and have higher risk.

Conclusions

Our results demonstrate that HIV-related medical mistrust (in the form of HIV conspiracy beliefs) continues to be high among Black Americans. Moreover, given that greater mistrust is associated with higher HIV risk, contextual factors need to be considered to further understand the seemingly paradoxical positive association between HIV-related mistrust and HIV testing. Future research with more precise measures of HIV risk could further examine potential mediators of the association between HIV conspiracy beliefs and HIV-related prevention behaviors. In order to design effective HIV prevention campaigns that address

disparities, such misconceptions need to be addressed, and the mechanisms behind these associations must be more fully understood.

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Figure 1.

Proposed model showing individual-level HIV risk and area-level socioeconomic position (SEP) mediating the association between HIV-related mistrust and HIV testing.

Table 1.
 Characteristics of Participants in the National Survey on HIV in the Black Community (February–April, 2016)

Participant Characteristic	Weighted Percent (unweighted n) or Weighted Mean (Unweighted SD)	Bivariate Association With HIV Conspiracy Beliefs B (SE), p-value
<i>Socio-Demographic Characteristics</i>		
<i>Gender</i>		
Male	45.40% (346)	Ref
Female	54.60% (522)	-.08 (.07)
Age	33.63 (9.07)	-.01 (.00)
<i>Marital Status</i>		
Married	29.65% (243)	Ref
Unmarried	61.70% (539)	.20 (.06) ***
Widowed, Divorced, Separated	8.65% (86)	.13 (.11)
Employed	71.32% (618)	-.00 (.08)
<i>Education Level</i>		
<High School	11.36% (62)	.26 (.10) **
High School or GED	32.75% (179)	.08 (.08)
Some college or higher	55.89% (627)	Ref
<i>Annual Income</i>		
<\$25,000	25.32% (322)	Ref
\$25,000–\$49,000	26.96% (211)	.08 (.08)
\$50,000 and above	47.72% (335)	-.09 (.07)
<i>U.S. Region</i>		
Northeast	18.15% (152)	-.08 (.10)
Midwest	17.15% (175)	.02 (.08)
South	54.13% (439)	Ref
West	10.57% (102)	-.14 (.14)
Area-Level Socioeconomic Position (SEP) ^a	.41 (.05)	.05 (.03) ⁺
<i>Individual-Level HIV Risk Behavior</i>		
Condomless Sex, last intercourse	32.50% (234)	.10 (.08)
Multiple Partners, last 3 mos.	10.93% (85)	.18 (.11)
Anal Sex, last 3 mos.	36.09% (318)	.18 (.07) **

Participant Characteristic	Weighted Percent (unweighted n) or Weighted Mean (Unweighted SD)	Bivariate Association With HIV	Conspiracy Beliefs B (SE), p-value
HIV Testing, last 12 mos.	27.67% (253)	—	—
HIV Conspiracy Belief Scale, range = 1 – 5	3.08 (.79)	—	—

[†] $p < .10$,
^{*} $p < .05$,
^{**} $p < .01$,
^{***} $p < .001$

^a Area-level SEP is a factor score comprised of % US population with less than a high school diploma, % unemployed, % below the federal poverty level, and median income (rescaled to match the direction of the other variables). All variables are from the American Community Survey (ACS) 2017 5-year estimates.

Table 2.

Prevalence of HIV Conspiracy Beliefs in the 2002–2003 vs. 2016 National Surveys of Black Americans

HIV Conspiracy Belief Item	Percentage Endorsed ^a		
	2016 NSHBC (weighted)	2016 NSHBC (unweighted)	2002–2003 National Survey (unweighted)
HIV is a man-made virus	31.35%	30.55%	48.20%
There is a cure for HIV but the government is withholding it from the poor	39.77%	38.30%	53.40%
The medicine that doctors prescribe to treat HIV is poison	32.72%	34.77%	6.80%
The government usually tells the truth about major health issues, like HIV/AIDS ^b	17.85%	19.15%	37.00%

Note: NSHBC = the National Survey of HIV in the Black Community^aEndorsement was calculated as the percentage who agreed strongly or agreed in the 2016 survey and who agreed strongly or slightly in the 2002–2003 survey^bIn 2002–2003 survey: “The government is telling the truth about AIDS”*Note:* Unweighted percentages are presented for comparability across the surveys (since only unweighted percentages were available for the 2002–2003 survey).

Table 3.
Associations of HIV Testing with HIV Conspiracy Beliefs and Potential HIV Risk Mediators

	Multivariable Generalized Structural Equation Models Predicting HIV Testing (past 12 months) Adjusted		
	Basic Model	Model with Individual-Level HIV Risk Mediators	Model with Area-Level Socioeconomic Position Mediators
HIV-Related Mistrust	1. (1.02, 1.45) *	1.04 (0.88, 1.24)	1.21 (1.01, 1.44) *
Socio-demographic Characteristics			
Age	1.00 (.98, 1.02)	1.00 (1.00, 1.02)	1.00 (.99, 1.01)
Female	1.29 (.96, 1.74) +	1.35 (1.00, 1.83) *	1.27 (.94, 1.70)
Unmarried	1.58 (1.10, 2.30) *	1.80 (1.24, 2.61) **	1.56 (1.07, 2.28) *
Widowed, Divorced, Separated	1.78 (1.08, 2.94) *	1.66 (1.00, 2.76) *	1.73 (1.05, 2.84) *
Individual-Level HIV Risk Variables			
Condomless Sex (last intercourse)	—	.94 (.70, 1.25)	—
Multiple Partners (last 3 months)	—	1.31 (.90, 1.90)	—
Anal sex (last 3 months)	—	1.71 (1.27, 2.28) ***	—
Area-Level Socioeconomic Position			1.06 (.93, 1.21)

* $p < .05$,

**

$p < .01$,

$p < .001$

^a Adjusted Prevalence Ratio, estimated because the outcome was over 20%