Racial/Ethnic Differences in Trust in Health Care: HIV Conspiracy Beliefs and Vaccine Research Participation

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BACKGROUND: Prior research has documented a high prevalence of conspiracy beliefs about the origin of the human immunodeficiency virus (HIV) and the role of the government in the acquired immunodeficiency syndrome (AIDS) epidemic, particularly among racial and ethnic minorities in the United States. Whether such beliefs are a barrier to participation in HIV prevention research is not known.

OBJECTIVE: To understand the prevalence of HIV conspiracy beliefs and their relationship to willingness to participate in HIV vaccine research among three racial/ethnic groups.

DESIGN: Cross-sectional survey.

PARTICIPANTS: Six hundred and one community-recruited volunteers (33.0 % White, 32.5 % Mexican American, and 34.5 % African American).

MAIN MEASURES: We evaluated the level of agreement with six previously described HIV conspiracy beliefs, trust in medical research, and willingness to participate in HIV vaccine research. Multivariate models were used to compare these parameters among the three racial/ethnic groups while controlling for the potential confounding effects of socioeconomic status, access to health care, and other demographic factors.

RESULTS: African Americans, Mexican Americans, and whites had similar levels of distrust in medical research. African and Mexican Americans were more likely to endorse one or more of six HIV conspiracy beliefs than whites (59.0 % and 58.6 % versus 38.9 %, respectively, $P<0.001$), but were significantly more willing to participate in HIV vaccine research (ORs 1.58, CI 1.10–2.25 and 2.53, CI 1.75–3.66, respectively). Among respondents of all racial/ethnic groups, endorsing HIV conspiracy beliefs was not associated with willingness to participate in research.

CONCLUSIONS: HIV conspiracy beliefs, while common among all racial and ethnic groups in the United States, do not preclude willingness to participate in HIV prevention research.

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BACKGROUND

Substantial racial/ethnic disparities in human immunodeficiency virus (HIV) infection persist in the United States. In 2009, African Americans and Hispanic/Latino Americans comprised 13 % and 16 % of the general U.S. population, but accounted for 43 % and 19 % of people living with HIV/acquired immunodeficiency syndrome (AIDS), respectively.[1–3] Racial and ethnic disparities are even more pronounced among older Americans,[4] women,[5] and men who have sex with men (MSM).[6,7] In addition to having disproportionately high prevalence, recent analyses have also suggested that among individuals receiving HIV care, African American patients are less likely to be retained in care[8,9] and to achieve viral suppression in response to antiretroviral therapy.[10–12] Because they are disproportionately affected by the HIV epidemic, African Americans may derive greater benefit from participation in HIV research. Moreover, for clinical or prevention research to be appropriately representative of the at-risk population, investigators must recruit African American participants in relatively high proportions. However, African Americans have been traditionally underrepresented in HIV research.[13,14]

Greater distrust of health care and medical research among minority populations reflects the legacy of exploitation of minorities in research exemplified by the Tuskegee Syphilis Study,[15,16] and has been commonly cited as a barrier to participation in research by racial and ethnic minorities.[17–21] Research findings support this hypothesis. In a study at a single university-based HIV clinic, patients with greater trust in their physician were more likely to be willing to volunteer for HIV clinical trials.[22] Similarly, a survey conducted in the early years following the introduction of highly active antiretroviral therapy (HAART) found distrust in scientists and research institutions

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was associated with decreased willingness to participate in AIDS clinical trials.[23] In that study, nearly one third of respondents considered AIDS researchers ethically comparable to the Tuskegee Syphilis scientists.

Conspiracy theories related to HIV have been described since early in the epidemic[24,25] and provide a specific, yet complex example of institutional distrust in health care that may also influence individuals' willingness to participate in HIV related research.[26–28] These beliefs include genocidal theories that the HIV virus was manufactured and intentionally released by the government to harm minority groups, and that the government is intentionally withholding treatment or even cures for HIV from the public.[25] Prior research has shown that a sizeable proportion of Americans surveyed endorse one or more conspiracy beliefs, but it is unclear whether endorsing these beliefs influences individuals' behavior. A survey of the general population found that conspiracy beliefs were correlated with negative attitudes about condoms and less frequent condom use.[27] Among HIV-infected patients in clinical settings, these beliefs are common,[29,30] but not consistently associated with HIV-related health behaviors such as medication adherence and engagement in care.[30] One study of HIV-infected African American men found that while genocidal conspiracy beliefs were not associated with antiretroviral adherence, patients endorsing treatment-related conspiracy beliefs were significantly less likely to have optimal adherence over 1 month of follow-up.[29] In the same sample, HIV-infected men who endorsed genocidal conspiracy beliefs were also more likely to report unprotected sex.[31]

Previous studies have not addressed the degree to which HIV conspiracy beliefs may influence willingness to participate in HIV prevention research in general, and HIV vaccine research in particular. More than 30 years into the HIV/AIDS epidemic, an effective HIV vaccine remains an elusive public health goal. Despite important discoveries about the effectiveness of prevention interventions, such as male circumcision[32,33] and the use of antiretroviral drugs such as microbicides,[34] prophylactic therapy for HIV-uninfected individuals,[35,36] or life-long suppressive therapy for infected individuals,[37] an effective vaccine able to confer long-term immunity is still considered a necessity if we are to eventually end the global AIDS pandemic.[38] Our objectives with this research were to investigate (1) whether trust in research and HIV conspiracy beliefs differed by racial/ethnic group among community-recruited individuals in a large metropolitan area in the Midwest, and (2) whether trust in research and HIV conspiracy beliefs were associated with willingness to participate in HIV vaccine trials.

METHODS

Study Population and Survey Development

The study was designed to validate a measure of institutional trust in health care in diverse populations and to investigate relationships among trust, race/ethnicity, HIV conspiracy beliefs and willingness to participate in HIV vaccine research. We conducted a cross-sectional, computer-adapted survey among a convenience sample of adults shopping at selected supermarkets in 12 socioeconomically diverse neighborhoods in Chicago, IL. A table with two laptop computers placed behind privacy screens (similar to a voting booth) was placed at the entrance of participating stores. The computers used a touch screen technology, and if a participant could not read, they could use headsets to listen to all survey items and instructions for responding. A bilingual, bicultural research coordinator staffed the table and invited shoppers to participate before or after shopping as they entered the store. In gratitude for their time, participants received a $25 gift card to the grocery store where they participated. Participants were purposively selected to achieve a target study sample of 600 adults with equal proportions self-identifying as African American, Mexican American and white. To be eligible, individuals were required to be fluent in English or Spanish, 18 years of age or older, and to have no cognitive impairment that would preclude giving informed consent (Table 1). This study received Institutional Review Board approval from the Cook County Bureau of Health Services, and informed consent was obtained prior to the administration of the survey.

The questionnaire consisted of 235 items and evaluated numerous domains: demographics including socioeconomic status, health care access and utilization, perceived discrimination and general attitudes and beliefs related to health care and medical research. Trust in research was evaluated using a four-item scale validated by Hall et al.,[39] which is reproduced in Table 2. HIV conspiracy belief questions were informed by previous research,[25–28,40] and were assessed with a five-point Likert scale ranging from "strongly disagree" to "strongly agree" (Table 3). The main dependent variable of interest was captured with the question, "How willing would you be to join a study of a vaccine to prevent HIV infection if the study began tomorrow?" The range of possible responses consisted of a four-point Likert scale including "not willing," "probably not willing," "probably willing," and "very willing."

Statistical Analysis

Survey responses were compared using chi-squared tests for categorical variables and one-way analysis of variance (ANOVA) for continuous variables to test for independence across the three racial/ethnic groups. Exploratory analyses compared the distribution of responses to trust-related questions as ordinal variables. We then dichotomized the main trust-related questions by combining "agree" and "strongly agree" versus all other responses, to allow for simplified presentation of results according to racial/ethnic group. As in previous research,[39] numeric responses to the four trust in research items (i.e. 1="strongly disagree" . . . 5="strongly agree) were added to generate a composite score ranging from 4–20, with higher

Table 1. Description of Sample, Trust Level and Willingness to Participate in Research*†

	African American (*n*=208)	Mexican American (*n*=195)	White (*n*=198)
Sociodemographic characteristics			
Age (median, IQR)	44 (32–51)	34 (25–45)	43 (28–55)
Female	117 (57.9)	125 (64.4)	104 (53.1)
Married	50 (24.6)	116 (60.4)	85 (43.6)
Unemployed	81 (40.3)	34 (17.5)	51 (26.3)
Education			
Less than high school	25 (12.8)	37 (19.5)	13 (6.7)
High school diploma	139 (70.9)	104 (54.7)	103 (52.8)
At least some college	32 (16.3)	49 (25.8)	79 (40.5)
Annual household income			
Less than $16,000	117 (59.7)	72 (41.4)	55 (30.1)
$16,000 – $34,999	49 (25.0)	44 (25.3)	47 (25.7)
$35,000 – $74,999	24 (12.2)	40 (23.0)	50 (27.3)
Greater than $75,000	6 (3.1)	18 (10.3)	31 (16.9)
Health insurance			
Private Insurance/Military	71 (40.6)	87 (45.8)	109 (56.5)
Medicare/Medicaid	77 (44.0)	47 (24.7)	41 (21.2)
No insurance	27 (15.4)	56 (29.5)	43 (22 %)
Trust in research			
Composite trust in medical researcher score (mean±SD)‡	12.6±2.8	12.8±2.6	12.8±3.0
Endorsed at least one HIV conspiracy belief §	108 (59.0)	106 (58.6)	75 (38.9)
Composite HIV conspiracy belief score §	16.0±4.7	16.0±4.7	14.7±4.8
Willingness to participate in research			
Ever agreed to participate in a research study in the past?	70 (34.3)	81 (42.6)	51 (26.4)
Willing join a study of a vaccine to prevent HIV infection if the study began tomorrow?	116 (58.9)	95 (49.7)	74 (38.3)

* *Numbers in parentheses indicate percentage unless otherwise indicated*
† *p value from tests of independence between covariate and racial/ethnic group are all < 0.001, unless otherwise indicated*
‡ *P= 0.757, range 4–20, previously validated by Hall et al.*[32]
§ *P= 0.029, range 6–30, based on results from six HIV conspiracy items, Cronbach's alpha= 0.81*

scores indicating a greater level of trust. The negatively worded item was reverse-scored such that "strongly disagree" corresponded to a numeric value of 5. Similarly, Likert scale responses to the HIV conspiracy belief items were used to generate a composite score with a range of 6–30, with higher scores corresponding to greater agreement with the six HIV conspiracy statements. Cronbach's alpha coefficient was calculated for the six HIV conspiracy items to evaluate scale reliability. For preliminary, descriptive analyzes, we dichotomized the main outcome into willing to participate ("probably willing" and "very willing") and unwilling to participate ("probably not willing" and "not willing").

To identify other factors associated with willingness to participate in research, bivariate ordinal logistic regression models were created using the original four-level dependent variable and each covariate of interest. A multivariate model was developed to identify independent predictors of willingness to participate. Variables found to have significant bivariate associations with the outcome were included in multivariate model, and adjusted odds ratios with corresponding 95 % confidence intervals were calculated to estimate the degree of association between each of these factors and willingness to participate. To ensure the data included in the final model did not violate the proportional odds assumption for ordinal regression, we performed the Brant Test of Parallel Regression Assumption. Statistical analyses were conducted using Stata Statistical Software: Release 11 (StataCorp LP, College Station, TX).

Table 2. Trust in Research Questions

	Percent responding "agree" or "strongly agree"			
	African American (*n*=203)	Mexican American (191)	White (*n*=197)	*P*
Doctors who do medical research care only about what is best for each patient	81 (40.3)	90 (47.9)	68 (35.1)	0.04
Doctors tell their patients everything they need to know about being in a research study	81 (41.3)	86 (45.0)	84 (44.0)	0.75
Medical researchers treat people like "guinea pigs"	60 (29.7)	55 (28.8)	48 (24.4)	0.45
I completely trust doctors who do medical research	64 (31.5)	66 (35.1)	60 (30.6)	0.61

Table 3. HIV Conspiracy Belief Questions

	Percent responding "agree" or "strongly agree"			
	African American (n=201)	Mexican American (n=190)	White (n=196)	P
The government is lying about AIDS	37 (18.6)	37 (19.6)	29 (14.8)	0.43
AIDS is part of a government plot	27 (13.5)	21 (11.2)	22 (11.3)	0.74
I believe doctors and scientists when they say that you can't get AIDS through social contact	81 (40.5)	75 (38.5)	119 (61.0)	< 0.001
The government is using AIDS to experiment	42 (20.9)	31 (16.4)	20 (10.3)	0.02
The government is not telling us the whole story about how AIDS is spread	65 (32.3)	41 (21.8)	38 (19.4)	0.006
The government is using AIDS as a way of killing off minority groups	27 (13.4)	25 (13.4)	16 (8.2)	0.18

RESULTS

A third of shoppers invited to participate refused, leaving a final sample of 601 respondents: 33.0 % described themselves as white, 32.5 % as Mexican American, and 34.5 % as African American. There was no refusal pattern by race/ethnicity or gender. Demographic differences across racial/ethnic groups are shown in Table 1. Compared to whites and African Americans, Mexican American participants were younger, more likely to be married and less likely to be unemployed. African Americans in the sample were significantly less likely to have attended college and were more likely to be unemployed or to have an annual household income less than $16,000.

Overall, there was no significant difference in the composite trust in research scores across the three racial/ethnic groups (Table 1). For one of the four trust in research questions ("Doctors who do medical research care only about what is best for each patient"), Mexican American participants were more likely to agree or strongly (47.9 %) agree than African Americans (40.3 %) and whites (35.1 %; Table 2).

The composite score generated by the HIV conspiracy items was normally distributed, with an overall mean of 15.5 and standard deviation of 4.7. Cronbach's alpha was 0.80. Unlike the responses to the trust in research items, significant racial/ethnic differences were observed in responses to the HIV conspiracy questions. African American and Mexican American participants were more likely to agree or strongly agree with one or more of the six HIV conspiracy statements (59.0 % and 58.6 %, respectively) than white participants (38.9 %; Table 1). Of the individual HIV conspiracy items, the greatest disparities were observed for the statement "I believe doctors and scientists when they say that you can't get AIDS through social contact," with which only 40.9 % of African Americans agreed, compared to 47 % of Mexican American and 61 % of whites (Table 3). The groups similarly differed in their responses to the statement "The government is not telling us the whole story about how AIDS is spread," with African Americans (32.3 %) being more likely to agree than whites or Mexican American (19.4 % and 21.8 %, respectively). There were comparatively few respondents overall who endorsed the genocidal conspiracy item "The government is using AIDS as a way of killing off minority groups" (Table 3).

Regarding the main outcome of interest, African Americans were significantly more likely to express willingness to participate in an HIV vaccine study (58.9 % "probably willing" or "very willing") than Mexican American (49.7 %) and whites (38.3 %; Table 1). African Americans were also more likely to have volunteered for any research study in the past than whites (34.3 % vs. 26.4 %), but were less likely to have been a previous research participant than Mexican American participants (42.6 %; Table 1).

Several socioeconomic factors were significantly associated with willingness to participate in research in unadjusted ordinal logistic regression analysis (Table 4). African Americans and

Table 4. Predictors of Willingness to Participate in HIV Vaccine Research

	Unadjusted OR (95 % CI)	Adjusted OR* (95 % CI)
Racial/ethnic group		
White	1.00 (ref)	1.00 (ref)
Mexican American	1.58 (1.10–2.25)	1.18 (0.80–1.74)
African American	2.53 (1.75–3.66)	2.54 (1.67–3.87)
Age (per 5 years)	0.90 (0.85–0.95)	0.89 (0.84–0.94)
Female	0.83 (0.62–1.12)	
Married	1.19 (1.01–1.40)	
Unemployed	1.40 (1.00–1.95)	
Education		
Less than high school	1.00 (ref)	
High school diploma	1.22 (0.78–190)	
At least some college	0.76 (0.46–1.23)	
Annual household income		
Less than $16,000	1.00 (ref)	
$16,000–$34,999	0.65 (0.44–0.95)	
$35,000–$74,999	0.54 (0.36–0.82)	
Greater than $75,000	0.46 (0.27–0.80)	
Health Insurance		
Private Insurance/Military	1.00 (ref)	1.00 (ref)
Medicare/Medicaid	2.09 (1.46–3.00)	1.86 (1.23–2.74)
No insurance	2.52 (1.71–3.74)	2.35 (1.55–3.57)
Previous research participant	1.8 (1.38–2.58)	1.64 (1.15–2.35)
Composite trust in research score (per five units)	1.92 (1.45–2.53)	2.09 (1.55–2.82)
Composite HIV conspiracy belief score	1.00 (0.97–1.04)	

* *Adjusted odds ratios are presented for covariates noted to have statistically significant associations with willingness to participate in research in a multivariate ordinal logistic regression model with a four-level outcome*

Mexican Americans were over 2.5 times and 1.5 times more willing to participate in research than whites, respectively. Respondents were also more likely to report willingness to participate in research if they were younger, unemployed, earned less than $16,000 per year, and did not have private health insurance. Individuals with previous experience as a research volunteer had nearly twice the odds of being willing to participate in a future HIV vaccine study. Trust in research was significantly associated with greater willingness to participate (OR 1.92, 95 % CI 1.45–2.53 for every five-unit increase in composite trust score), but the composite level of agreement with HIV conspiracy beliefs had no such association (OR 1.00, 95 % CI 0.97–1.04). Adjustment for age, insurance status, previous research participation and overall trust in research did not attenuate the strong association between African American status and willingness to participate in research. In the multivariate model, the difference between Mexican American and white classification was no longer statistically significant. Similarly, marital status, low income and unemployment were not significant predictors of willingness to participate in the adjusted model. None of the individual HIV conspiracy items were associated with willingness to participate in research, nor did their inclusion in the final multivariate models change the magnitude or significance of any of the associations we detected (data not shown).

DISCUSSION

In this cross-sectional study of 601 community-recruited individuals in the Chicago metropolitan area, we observed that all racial/ethnic groups held HIV conspiracy beliefs to some degree, but a greater percentage of African Americans and Mexican Americans endorsed them than non-Hispanic whites. Endorsing such beliefs, however, did not appear to influence respondents' willingness to participate in an HIV vaccine study. In fact, African and Mexican Americans were more likely than whites to report willingness to participate in HIV research, even after adjusting for income, health insurance and previous participation in research.

Despite advances in the effectiveness and availability of medical therapy for HIV, we have not yet observed substantial decreases in HIV transmission on a national or global level.[41] HIV vaccine research involving volunteer human subjects will therefore be necessary for the foreseeable future, and participation of racial and ethnic minority groups who are most heavily affected by HIV/AIDS will be essential for the success of these efforts. Our findings suggest that while misinformation about HIV research and treatment continues to circulate, it may be a less significant barrier to minority recruitment into HIV research studies than has been feared. Similar to previous studies, we found that trust in medical research is associated with increased willingness to participate in research. Unlike prior research on this topic, we did not observe higher levels of distrust among racial and ethnic minorities. Rather, in this specific case of HIV vaccine research, racial/ethnic minorities appear more willing than whites to volunteer for a research study.

Several potential explanations could account for these findings. Individuals' perception of the balance between risk of HIV and potential benefit of research participation may be a more important determinant of willingness to participate than institutional trust in health care or belief in conspiracy theories. African and Mexican Americans who acknowledge that their racial/ethnic groups are at greater risk for HIV infection may feel stronger motivation to pursue a potentially beneficial HIV vaccine trial, despite suspicions that the government is withholding information or even has nefarious intentions regarding HIV. Alternatively, given that the more commonly endorsed conspiracy statements in our study involved beliefs about HIV transmission, minorities may be paradoxically more likely to volunteer for a vaccine trial because uncertainty about the facts related to HIV transmission causes a greater level of perceived risk. It is possible that the HIV conspiracy beliefs used in this study may be poorly reflective of institutional trust in health care. Rather than being a manifestation of institutional trust, agreement with the conspiracy statements may reflect idiosyncratic, culturally-specific sentiments that are commonly acknowledged, but do not influence behaviors in the same way as more internalized health-related beliefs.

Our results support previous suggestions that the underrepresentation of minorities in medical research may reflect inadequate or inappropriately targeted recruitment efforts on the part of researchers, rather than low levels of willingness to participate on the part of minorities. A study conducted at an academic HIV clinic found that just over half of African American patients had ever been asked to participate in a study, and that 86 % of those invited agreed to participate.[42] In this study, trust in the medical profession was not associated with willingness to participate in research. Another survey of HIV-infected patients in Chicago found that 40 % had participated in research in the past, but only 29 % had ever been asked by their physician to consider joining a study.[43] Reviewing data across 20 studies that reported consent rates by race or ethnicity, Wendler et al. reported that minorities were less likely to be recruited, but were equally likely to provide consent when asked to participate in health research studies.[44] This line of evidence seems to indicate that disparities in access to research studies, rather than disparate attitudes and beliefs, underlie the underrepresentation of minorities in research.

Several methodological issues may limit the generalizability of our findings. The data were collected from a convenience sample of Chicago residents shopping at selected supermarkets, which may not be representative of the target populations likely to be recruited for HIV vaccine trials. Individuals who refused to participate in the survey may also be more reluctant to participate in HIV vaccine research, causing our data to overestimate the overall level of willingness to participate in research. We did not assess individuals' level of behavioral risk for HIV infection, which would influence whether they

would be eligible for HIV vaccine studies and may shape attitudes and beliefs about HIV/AIDS. Assessing HIV conspiracy beliefs using a structured questionnaire could potentially over-estimate the importance of these beliefs. The very fact that the conspiracy statements were mentioned explicitly in a research questionnaire may lead to a perception of their legitimacy among some respondents. It may therefore be informative to interpret our results in the context of other studies that evaluate similar issues using complementary methods, such as qualitative interviews or focus groups.[45, 46]

These limitations notwithstanding, our study provides evidence that the medical profession and HIV research community are still failing to effectively communicate essential knowledge about HIV/AIDS, allowing the persistence of misperceptions and conspiracy beliefs about the government's role in HIV research and treatment. It is unique among related previous studies in directly comparing the attitudes and beliefs of white and African American individuals with Mexican Americans, who comprise the largest single Hispanic ethnic group in Chicago, rather than using a heterogeneous and culturally diverse category, such as Hispanic or Latino. In so doing, it confirms and builds upon previous reports indicating high levels of HIV conspiracy beliefs among Latinos.[28] Future research should continue to seek to understand the roots of these beliefs among all racial/ethnic groups, as well as explanations for their persistence into the 21st century, a time when scientific knowledge and the technological capacity to facilitate mass communication of health information have achieved unprecedented levels of sophistication.

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