Conspiracy Beliefs about HIV Infection Are Common But Not Associated with Delayed Diagnosis or Adherence to Care

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Abstract

We sought to determine the prevalence of HIV conspiracy beliefs in patients with HIV and how those beliefs correlate with access and adherence to HIV care and health outcomes. From March to December 2005, 113 patients at four public facilities in Houston, Texas, diagnosed with HIV for 3 years or less, participated in a cross-sectional survey. Conspiracy beliefs were assessed with five items that dealt with HIV origin, cure, and vaccine. Medical records were reviewed for CD4 cell counts, HAART use, and appointment dates. Statistical analyses (including analysis of variance [ANOVA], χ^2 testing, and regression) determined the predictors of conspiracy beliefs and correlated them with outcomes. Sixty-three percent of the participants endorsed 1 or more conspiracy beliefs. African American patients more often held HIV conspiracy beliefs than white and other/mixed race patients (73%, 52%, 47%; $p = 0.045$). Persons holding 1 or more conspiracy beliefs had higher CD4 cell counts at diagnosis (254 cells/mm³ versus 92, $p = 0.03$); and similar rates of highly active antiretroviral therapy (HAART) use (73% versus 71%), 100% adherence to HAART by self-report (53% versus 45%), mean adherence by pharmacy refill (83% versus 87%), and gaps in care greater than 120 days (49% versus 53%), compared to subjects who did not hold any conspiracy beliefs (all $p > 0.40$). Since recruitment focused on patients in care, patients with extreme conspiracy beliefs may be underrepresented. Despite this, more than 50% of the study population endorsed 1 or more conspiracy belief. However, these beliefs did not negatively impact access or adherence to HIV care. Efforts to improve adherence to HIV care may not need to focus on eliminating conspiracy beliefs.

Introduction

HIV INFECTS 1.1 MILLION PEOPLE in the United States, more than half of whom are African American or Hispanic. Beliefs that HIV was released on purpose by a government or other organization to eliminate undesirable segments of the population, such as racial and ethnic groups, injection drug users, and men who have sex with men (MSM), have been documented, as have beliefs that a cure for the infection is being withheld. For example, approximately 20% of a convenience sample of the general population believed HIV was created to kill minority populations. This conspiracy belief existed among all ethnic groups sampled.¹ Over half of the MSM respondents in a study conducted by the

U.S. Centers for Disease Control and Prevention believed that a cure for HIV was being withheld.² Similarly, Cunningham et al.³ found that almost half a sample of 102 women in the Bronx believed a cure for HIV was being withheld, and 30% believed HIV was created in a laboratory. Interestingly, these beliefs were not more common in women with HIV infection compared to women who did not have HIV infection.

Adverse consequences of holding conspiracy beliefs have not been well documented. Bogart and Thorburn found that men who held HIV conspiracy beliefs were nearly 40% less likely to use condoms consistently, thus increasing their risk of contracting HIV.⁴ Altice et al.⁵ studied mistrust in medical institutions, including beliefs in the intentional release of HIV

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and the withholding of cures for HIV, in prisoners in 1996. Mistrust in medical institutions was associated with less use of antiretroviral therapy. In a cohort of HIV positive subjects recruited during 2001, Whetten et al.⁶ found that 16% of their respondents believed that AIDS was created by the government to control the black population. A related belief that “a lot of information about AIDS is being withheld” was also common, and these two beliefs were combined to indicate distrust in the government. Distrust in the government was, in turn, associated with more emergency department visits and worse mental and physical health. In a study of nearly 1000 HIV-infected patients from 10 urban sites in the United States, patients who mistrusted the health care system in general were less likely to be in HIV care, although the study did not assess conspiracy beliefs in particular.⁷

Two facets of conspiracy beliefs about HIV infection warrant further investigation. First, more data are needed on the prevalence of conspiracy beliefs among persons with HIV infection. Others studies have measured general trust in physicians and the health care system in HIV positive cohorts. This study examines conspiracy beliefs specifically because persons with HIV infection might be more likely to hold conspiracy beliefs since they could be perceived as the victims of the conspiracies. Second, the impact of conspiracy beliefs on patterns of health care utilization or health outcomes should be determined. Regardless of whether conspiracy beliefs are more common in persons with HIV infection, the beliefs might impact the patient–physician relationship, the level of trust in the health care system, and belief in medications. All of these intermediaries might in turn affect health care utilization and health outcomes, and, therefore, reducing or eliminating conspiracy beliefs might be a goal of interventions to improve health care utilization in this population.

We sought to identify the prevalence of conspiracy beliefs, and the correlates of having such beliefs, in a group of underinsured or uninsured low-income patients recently diagnosed with HIV infection in publicly funded facilities in Houston, Texas. Furthermore, we wanted to determine if conspiracy beliefs were associated with delayed diagnosis of HIV infection (indicated by a low CD4 cell count at diagnosis), lower rates of highly active antiretroviral therapy (HAART) utilization and adherence to HAART, worse retention in care, and lower quality of life and overall health status.

Materials and Methods

From March 2005 to December 2005, a convenience sample of participants was recruited from four publicly funded

facilities for HIV-infected persons in Houston, Texas: the Thomas Street Health Center, the Northwest Health Center, the Michael E. DeBakey VA Medical Center, and the Ben Taub General Hospital. Patients were referred to the study by physicians, nurses, pharmacists, or social workers or they were directly recruited while awaiting services at the outpatient clinics. Patients diagnosed with HIV infection for 3 years or less were eligible for the study. Patients were excluded if they were less than 18 years old, blind, too sick to participate, unable to communicate in English or Spanish, evacuees from New Orleans, Louisiana (because their medical records would be unavailable), or had a neurocognitive deficit that would preclude them from reliably completing the study’s survey. Over 90% of eligible patients invited to participate agreed and completed the study’s interview.

Participants completed an interviewer-administered survey about their attitudes and beliefs about HIV disease and care. Potential participants were not informed that part of the survey would be about conspiracy beliefs. Conspiracy beliefs were assessed by asking participants to indicate their level of agreement with statements about the origin of HIV/AIDS in the population, the withholding of a cure for HIV/AIDS, and the withholding of a vaccine to prevent HIV infection (Table 1). A conspiracy score was then created to investigate intensity of belief; this score was defined as the sum of responses to the five conspiracy items, with higher scores indicating greater levels of agreement with HIV conspiracy beliefs. The five conspiracy items functioned well as a scale, with a standardized Cronbach α of 0.90 (raw score = 0.91). A dichotomous variable was also created to represent the holding of any conspiracy belief (i.e., any level of agreement with any of the statements) versus holding no conspiracy beliefs (i.e., no level of agreement with any of the statements, or, in other words, some level of disagreement with all the statements). Potential predictors of conspiracy beliefs were evaluated and included demographic characteristics, education, employment status, income, insurance, homelessness, and HIV risk factor.

Outcomes were CD4 cell count at diagnosis and current CD4 cell count (within 90 days of the interview), utilization of and adherence to HAART, retention in care, quality of life, and overall health status. CD4 cell count at diagnosis and current CD4 cell count were ascertained from medical record review. Low CD4 cell count at diagnosis was considered a surrogate of late testing for HIV infection. Receipt of HAART was assessed for patients with a nadir CD4 cell count of 350 or less who had been diagnosed more than 6 months before their survey date. Adherence to HAART was assessed (1) with a visual analogue scale for all participants on HAART, and (2) using pharmacy refill data for all participants who

TABLE 1. STATEMENTS USED TO ASSESS CONSPIRACY BELIEFS

HIV was released on purpose by the government.
The government has a cure for HIV but will not release it.
The government has a vaccine to prevent HIV infection but will not release it.
The drug companies have a cure for HIV but will not release it.
The drug companies have a vaccine to prevent HIV infection but will not release it.

All responses were made using a 6-point Likert scale: Strongly agree (6), Agree (5), Somewhat Agree (4), Somewhat Disagree (3), Disagree (2), Strongly Disagree (1). Higher scale scores indicate higher levels of conspiracy belief.

used the pharmacy at the Thomas Street Health Center.⁸ Retention in care was assessed by whether patients who had at least 180 days between their first outpatient clinic visit and their survey date had ever gone more than 120 days without a primary care visit. Quality of life and overall health status were each measured using a self-administered visual analogue scale (1 = worst possible quality of life or health status; 10 = best possible quality of life or health status).⁹

Univariate statistical analyses for the dichotomized conspiracy variable were carried out with χ^2 testing for categorical outcomes and, for continuous data, either Student's *t* test (for parametric data) or the Kruskal-Wallis test (for non-parametric data). Univariate statistical analyses for the continuous conspiracy score was accomplished with Student's *t* test and ANOVA. A multivariable logistic regression was performed to determine factors associated with holding at least one conspiracy belief (i.e., the dichotomized conspiracy vari-

able was the dependent variable). Multivariable regression analyses for each of the outcomes were carried out adjusting for the factors associated with having conspiracy beliefs in univariate analyses. Separate analyses were conducted for each outcome, and using both the dichotomized conspiracy variable and the continuous conspiracy score as independent variables. All reported *p* values were two-sided and used a statistical significance level of $p < 0.05$. All data were analyzed with SAS 9.1 (SAS Institute, Cary, NC). The study was approved by the Institutional Review Board for Baylor College of Medicine and Affiliated Hospitals. All participants provided written informed consent.

Results

The study enrolled 149 patients. Twenty patients were excluded (17 were diagnosed more than 3 years before enroll-

TABLE 2. PARTICIPANT CHARACTERISTICS AND CHARACTERISTICS ASSOCIATED WITH CONSPIRACY BELIEFS AMONG ONE HUNDRED THIRTEEN PATIENTS WITH HIV INFECTION IN HOUSTON, TEXAS

Characteristic	All participants % (n)	Participants with any conspiracy belief % (n)	Participants with no conspiracy beliefs % (n)	<i>p</i> value	Conspiracy score ^a	<i>p</i> value
All patients	113	63 (71)	37 (42)			
Age				0.79		0.99
18–29	24 (27)	59 (16)	41 (11)		16.0	
30–39	28 (32)	59 (19)	41 (13)		15.6	
40–49	35 (39)	64 (25)	36 (14)		15.7	
≥50	13 (15)	73 (11)	27 (4)		16.1	
Gender				0.42		0.29
Female	39 (44)	66 (29)	34 (15)		15.0	
Male	61 (69)	61 (42)	39 (27)		16.4	
Race				0.05		0.00
Black	53 (60)	73 (44)	27 (16)		17.7	
Other or multiple race	15 (18)	47 (8)	53 (9)		13.5	
White	32 (36)	52 (19)	47 (17)		13.9	
Ethnicity				0.28		0.28
Hispanic	27 (31)	55 (17)	45 (14)		14.8	
Not Hispanic	73 (82)	65 (54)	34 (28)		16.3	
Sexual orientation				0.29		0.88
Gay/lesbian	22 (25)	64 (16)	36 (9)		15.8	
Heterosexual	69 (78)	65 (51)	35 (27)		14.9	
Other	9 (10)	40 (4)	60 (6)		16.0	
Education				0.57		0.95
Never finished high school	29 (33)	64 (21)	36 (12)		15.8	
High school diploma or GED	41 (46)	67 (31)	33 (15)		16.1	
Any college	30 (34)	56 (19)	44 (15)		15.6	
HIV risk factor				0.68		0.54
Men who have sex with men	32 (36)	67 (24)	33 (12)		16.8	
Any injection drug use	13 (15)	67 (10)	33 (5)		15.9	
Heterosexual intercourse	55 (62)	60 (37)	40 (28)		15.3	
Time since HIV diagnosis				0.04		0.24
< 6 months	26 (30)	50 (15)	50 (15)		14.2	
6–24 months	50 (56)	61 (34)	39 (22)		16.2	
> 24–36 months	24 (27)	81 (22)	19 (5)		16.9	
Diagnosis location				0.39		0.13
Inpatient	38 (43)	58 (25)	42 (18)		15.1	
Jail or prison	13 (15)	53 (8)	47 (7)		13.6	
Other	49 (55)	69 (38)	31 (17)		17.0	

^aConspiracy score: Higher scores indicate more belief in HIV conspiracy theories (range, 5–30).

ment; 3 were not patients at one of the participating sites), 2 did not complete the interview, 8 did not complete the section on conspiracy beliefs, and 1 withdrew consent. In addition, initial CD4 cell counts were not available for 5 patients, leaving 113 participants in the final data analysis. Participant characteristics are presented in Table 2. Most patients (63%) were between the ages of 30 and 49 years, 39% were women, 53% identified themselves as black, 32% as white, 15% as another race or more than one race, and 27% identified themselves as Hispanic. While 22% of the men and women self-identified as gay or lesbian, 32% of the male subjects were men who reported sex with men as a risk for HIV infection. Thirteen percent of the study population reported injection drug use. Twenty-nine percent never completed high school, and 30% had some college education.

Seventy-one participants (63%) endorsed at least one conspiracy belief; most of these participants, however, endorsed more than one belief: 8 (7%) endorsed only one belief, while 13 (12%) endorsed 2 beliefs, 6 (5%) endorsed 3 beliefs, 28 (25%) endorsed 4 beliefs and 16 (14%) endorsed all 5 beliefs. Approximately half of the white and the other/multiple race participants endorsed at least one conspiracy belief, while 73% of black participants did, resulting in a marginally significant difference in the race distribution between those who did and did not endorse a conspiracy belief ($p = 0.045$). This finding was similar when examining conspiracy beliefs as a continuous variable. The mean conspiracy score for black participants (17.7) was found to be significantly higher than scores for white (13.9) and for other/multiple race participants (13.5), indicating a stronger belief in HIV conspiracies among black participants ($p < 0.0001$). The prevalence of

conspiracy beliefs also increased with time since HIV diagnosis. Twenty-six percent of participants diagnosed less than 6 months before their survey date endorsed at least one conspiracy belief, while 81% of participants diagnosed 2–3 years before their survey date endorsed such beliefs ($p = 0.04$). Results involving race and time since HIV diagnosis were confirmed in a multivariate model (Table 3). Participants diagnosed 2–3 years before their survey date were nearly five times more likely to hold at least one conspiracy belief than were patients diagnosed <6 months before their survey date (adjusted odds ratio [AOR] = 4.77; 95% confidence interval [CI] 1.30–17.49); although not statistically significant, black participants were almost three times more likely to hold at least one conspiracy belief than were white participants (AOR = 2.74; 95% CI 0.92–8.24).

We assessed the association of conspiracy beliefs with delayed HIV diagnosis, poorer retention in care, and poorer current health. Persons holding at least one conspiracy belief had higher current CD4 cell counts and higher CD4 cell counts at diagnosis (median CD4 cell count at diagnosis of 254 in participants with at least one conspiracy belief compared to 91.5 in participants with no conspiracy beliefs, $p = 0.03$; median current CD4 cell count of 326 in participants with at least one conspiracy beliefs compared to 170 in participants with no conspiracy beliefs, $p = 0.04$). As shown in Table 4, there were no differences in receipt of HAART, adherence to HAART, retention in care, or current health and current quality of life according to whether or not subjects held conspiracy beliefs, or the intensity of the conspiracy beliefs, as indicated by the conspiracy beliefs score. In multivariate analyses adjusting for race and time since HIV diag-

TABLE 3. MULTIPLE LOGISTIC REGRESSION OF FACTORS ASSOCIATED WITH HOLDING AT LEAST 1 CONSPIRACY BELIEF AMONG ONE HUNDRED THIRTEEN PATIENTS WITH HIV INFECTION IN HOUSTON, TEXAS

Predictor	Adjusted odds ratio (AOR)	95% CI	p value
Race			
Black	2.74	0.92–8.24	0.07
Other or multiple race	0.70	0.19–2.39	0.59
White	Referent		
Ethnicity			
Hispanic	1.08	0.33–3.40	0.89
Not Hispanic	Referent		
Age			
≥50	2.05	0.43–9.33	0.36
40–49	1.07	0.32–3.55	0.91
30–39	1.15	0.34–3.90	0.82
18–29	Referent		
Gender			
Female	0.85	0.32–2.22	0.73
Male	Referent		
Education			
Any college	0.57	0.19–1.71	0.32
High school diploma or GED	1.08	0.37–3.17	0.89
Never finished high school	Referent		
Months since diagnosis			
> 24 to 36 months	4.77	1.30–17.5	0.02
> 12 to 24 months	2.08	0.67–6.37	0.20
6 to 12 months	1.30	0.38–4.48	0.68
< 6 months	Referent		

CI, confidence interval.

TABLE 4. THE ASSOCIATION OF OUTCOMES AND THE PRESENCE OF CONSPIRACY BELIEFS AMONG PATIENTS WITH HIV INFECTION IN HOUSTON, TEXAS

Outcome	Outcome result by presence or absence of conspiracy beliefs		
	Participants with any conspiracy belief	Participants with no conspiracy beliefs	p value
CD4 cell count at HIV diagnosis, median (25th, 75th, percentile, cells/mm ³) (n = 113)	254 (87, 537)	91.5 (12, 408)	0.03
Current CD4 cell count, median (25th, 75th, percentile, cells/mm ³) (n = 101)	326 (167, 484)	170 (60, 412)	0.04
Never received HAART, % (n = 65) ^a	18	24	0.59
Not currently on HAART, % (n = 65) ^a	27	29	0.91
<100% adherence to HAART by self-report, % (n = 54)	47	55	0.57
Mean adherence to HAART by pharmacy refill data, % (n = 38)	83	87	0.48
Gap in care > 120 days, % (n = 60) ^b	49	53	0.77
Current health, mean (SD) (n = 111)	6.8 (2.1)	6.3 (2.1)	0.21
Quality of life, mean (SD) (n = 112)	7.1 (2.3)	6.5 (1.9)	0.21
Mean (SD) conspiracy score by presence or absence of outcome			
CD4 cell count at HIV diagnosis, < 200 cells/mm ³ (n = 113)	14.9 (6.9)	16.7 (6.0)	0.14
Current CD4 cell count, < 200 cells/mm ³ (n = 101)	14.6 (6.6)	16.5 (6.3)	0.15
Never received HAART (n = 65) ^a	16.2 (7.1)	16.7 (6.6)	0.78
Not currently on HAART (n = 65) ^a	16.1 (6.8)	16.8 (6.7)	0.71
<100% adherence to HAART by self-report, (n = 54)	16.4 (6.9)	15.9 (7.0)	0.78
<80% adherence to HAART by pharmacy refill data (n = 38)	18.8 (6.8)	15.4 (7.2)	0.18
Gap in care > 120 days (n = 60) ^b	16.9 (7.0)	17.1 (6.8)	0.91
Current health ≤ 5 (n = 111)	16.4 (6.8)	15.5 (6.4)	0.50
Quality of life ≤ 5 (n = 112)	16.6 (6.6)	15.5 (6.5)	0.43

^aAmong patients with a nadir CD4 count ≤ 350 and diagnosed at least 6 months before the survey.

^bAmong patients surveyed at least 180 days after their first clinic visit.

HAART, highly active antiretroviral therapy; SD, standard deviation.

nosis, there were no significant associations between conspiracy beliefs and any of the outcomes, whether using the dichotomized conspiracy variable or the continuous conspiracy score as the independent variable (all *p* values > 0.13; data not shown).

Discussion

In this study of 113 persons in care for HIV in publicly-funded facilities in Houston, Texas, 63% had at least one conspiracy belief related to the origin of HIV, the lack of a cure for HIV infection, or the lack of a vaccine to prevent it. These beliefs were most common in black participants but were not uncommon in participants of other racial and ethnic backgrounds; the prevalence of holding these beliefs was similar to that observed in other studies of HIV-infected patients in the southern United States.⁶ We hypothesized that persons with HIV infection who harbor conspiracy beliefs might be less engaged in care and less healthy as a result. However, we could not document any adverse patterns of health care utilization or health outcomes associated with holding these

beliefs. Compared to persons without conspiracy beliefs, persons with conspiracy beliefs had higher CD4 cell counts at diagnosis of HIV infection and higher current CD4 cell counts, but similar use of HAART and adherence to HAART, similar retention in medical care, and similar overall health and quality of life.

Whetten et al.⁶ studied HIV-infected patients in the Deep South of the United States and correlated lack of trust in care providers and the government with health care utilization and outcomes. They found that lack of trust in the health care provider was associated with greater self-reported use of emergency department services, fewer clinic visits, less use of antiretroviral therapy, and worse mental and physical health. Similar to the present study, Whetten et al.⁶ found that distrust of the government was not associated with self-reported outpatient HIV clinic utilization, use of HAART, CD4 cell count, or HIV viral load, although it was associated with more emergency department use. The present study, based on a broader definition of conspiracy beliefs and with additional health care utilization measures, did not find evidence of an association of conspiracy beliefs with adverse

patterns of health care utilization. These results suggest that conspiracy beliefs may not be associated with adverse patterns of health care utilization. In contrast, Whetten et al.⁶ and others³ have found important associations between trust in care providers and health care utilization. Trust in care providers may not be closely correlated with trust in the government and conspiracy beliefs and may more directly influence health-related behaviors. Empiric data to test that hypothesis are needed.

Our findings reinforce the notion that minority populations in the United States are still distrustful of the government and the pharmaceutical industry. Black race has long been associated with conspiracy beliefs about HIV disease and care.^{1,6,10,11} The differences in conspiracy beliefs by race are often attributed to the history of misuse and mistreatment of minority patients by the government and not necessarily by their physicians.^{4,12} Indeed, other studies have shown that trust in and relationship with the actual health care provider is related to whether patients remain in care and are adherent to care.^{13,14} Results from the present study lead us to believe that patients are able to distinguish their beliefs about the origins and treatment of HIV from their own need for health care. This is a reassuring finding since conspiracy beliefs are so common, even among the educated. Health care professionals should make a greater effort to build trusting relationships with HIV positive patients in order to help patients remain in and benefit from care.

Educational level was not a predictor of belief in HIV conspiracies (Table 3). However, the prevalence of holding conspiracy beliefs increased with length of time since diagnosis of HIV infection. It may be that interactions with other HIV-infected patients over time results in the spreading of conspiracy beliefs, perhaps reinforced by medication side effects, perceived discrimination by the health care system, or experiences of HIV-related stigma. We could not test these hypotheses, and the observation that beliefs increase over time needs confirmation in a longitudinal study.

This study has certain limitations. The sample studied was a convenience sample, selected from persons using publicly funded health care facilities. These facilities, however, provide care to approximately 40% of the persons in care for HIV infection in Houston. Furthermore, nearly 50% of persons in care for HIV infection in the United States are either uninsured or on Medicaid, so the results are likely relevant to a large segment of the population with HIV infection. The sample size did not allow stratification by recruitment site. The data are cross-sectional, and recruitment focused on persons in care so that those with the most extreme beliefs may not have been captured in the study. The relationship between conspiracy beliefs and access and adherence might differ in patients who did not participate in the study. Prospective studies are needed to assess change in beliefs over time and to establish a temporal relation between having the beliefs and exhibiting less desirable patterns of health care utilization and outcomes. Unfortunately, there were no resources for computer-assisted survey administration, and low literacy rates forced us to rely on an interviewer-administered survey. If the interviewer-administered format introduced bias, it would have most likely resulted in underreporting of conspiracy beliefs. Results might therefore be biased toward the null. Finally, many of the outcomes could only be studied in a subset of the participants, and

sample size limits our power. Nonetheless, we did not find evidence suggestive of adverse health care utilization or health outcomes for any of the six outcomes we studied.

In this study of 113 persons in care for HIV in publicly funded facilities in Houston, Texas, conspiracy beliefs about the origin of HIV and the lack of a cure or preventive vaccine for HIV infection were quite common but were not associated with adverse patterns of health care utilization or health outcomes. Efforts to improve adherence to care, including adherence to HAART and retention in care, may not need to focus in depth on combating these common beliefs. These observations await confirmation in prospective cohort studies, currently underway, with attention to how conspiracy beliefs change and affect health care utilization over time.

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